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Caretakers of ASD Children: Challenges and
Recommendations

By

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Dedication

To my loving parents...

To my life partner...

To my beloved son...

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Caretakers of ASD Children: Challenges and Recommendations

Mira Al Shurafa

ABSTRACT

Autism has become one of the most widespread childhood disorders. It is a development disability that affects verbal and nonverbal communication and social interaction. This study was motivated by a pursuit to investigate the attitudes of Lebanese parents of autistic children when their child is diagnosed with autism. It aims at revealing parents' knowledge about early intervention and discovering the challenges and difficulties these parents face and what they recommend for the future. This study followed the qualitative study using statistics; quantitative data was collected from 19 participating parents who were surveyed in different early intervention centers in Lebanon. Qualitative data was collected using semi-structured interviews with three special educators in different centers for students with special needs as well as content analysis of three different booklets about Autism from the Ministry of Social Affairs. Findings indicate that parents face challenges with their autistic child such as behavioral and communication problems and lack of social skills. The results of this study are compatible with similar research conducted in the West. Having more awareness campaigns about autism and offering early intervention services in Lebanon are recommended. Further research on the topic is suggested.

Keywords: Autism Spectrum Disorder, ASD, Special Education, Parents' Attitudes, Early Intervention, Parents' challenges with ASD, Parents' knowledge about ASD, Caregivers, Special Needs Centers, Lebanon.

Table of Content

CHAPTER ONE	1
Introduction	1
1.1. Background of the Study.....	1
1.2. Rationale and Significance	3
1.3. Purpose of the Study	3
1.4. Research Questions.....	4
1.5. Operational Definitions of Variables	5
1.6 Thesis Division	6
1.7. Conclusion	7
CHAPTER TWO	8
Review of the Literature	8
2.1. Introduction.....	8
2.2. Autism Spectrum Disorder	8
2.3 Early Intervention	9
2.4. Individualized Service Plan (IFSP).....	10
2.5. Types of Treatments	11
2.6. Parents’ Attitude	13
2.7. Parents’ Reactions.....	13
2.8. Parenting Stress in Families with an ASD Child	17
2.9. Parents’ Challenges.....	17
2.10. ASD in Lebanon	18
CHAPTER THREE	20
Methodology	20
3.1. Research Design	20
3.2. Sample	20
3.3. Participants.....	21
3.4. Instruments.....	21
3.5. Data Analysis	30
3.6. Ethics in Education	31
CHAPTER FOUR	33

Results	33
4.1. Quantitative Results	33
4.2. Interview Results	41
4.3. Content Analysis Results	44
4.4. Conclusion	50
CHAPTER FIVE	52
Discussion	52
CHAPTER SIX	57
Conclusion	57
6.1. Limitations of the Study	57
6.2. Recommendations for Future Research	58
6.3. Recommendations for Future Practices	58
References	59
Appendix A	68
Appendix B	76
Appendix C	77
Appendix D	83
Appendix E	84
Appendix F	85
Appendix G	86
Appendix H	87

List of Tables

Table 1: Participants	23
Table 2: Research Questions and answers	26

List of Figures

Figure 1	33
Figure 2	34
Figure 3	34
Figure 4	34
Figure 5	35
Figure 6	35
Figure 7	36
Figure 8	36
Figure 9	37
Figure 10	38
Figure 11	38
Figure 12	39
Figure 13	39
Figure 14	41

CHAPTER ONE

Introduction

1.1. Background of the Study

Nowadays autism has become one of the most widespread childhood disorders. It is considered the second most common developmental disability, affecting (1 out of 166) 0.6 percent of the population in the USA (Hallahan, Kauffman & Pullen, 2009). Autism as defined by the Individuals with Disabilities Education Act (IDEA) “is a developmental disability affecting verbal and nonverbal communication and social interaction, generally evident before age 3 that affects a child’s performance” (Hallahan et al., 2009, p.425).

The period of early childhood is a phase of family life that is likely to cause stress for parents. This is mainly due to the many challenges families have to deal with, such as reconciliation of work, couple, family and childcare (Koeske & Koeske 1990; Williford, Calkins & Keane, 2007). This phase of child development can be very stressful for parents of children with developmental disabilities as autism spectrum disorders (ASD). Faerstein (1981) asserts that a child’s disability is a triadic experience, involving three-way interactions among the child who experiences the dysfunction, the family that is affected by it, and the external environment where the disability is manifested.

Parents deal with this diagnosis differently: there are parents who accept the diagnosis and start to adapt to the situation, and there are parents that may be inflexible; they resist and/or deny the reality. A considerable number of studies show that parents

of children with ASD report higher stress levels than parents of typical children or parents of children with other difficulties (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Blacher & McIntyre 2006; Bouma & Schweitzer 1990; Dumas, Wolf, Fisman & Culligan, 1991; Holroyd & McArthur 1976; Mugno, Ruta, D'Arrigo & Mazzone, 2007; Olsson & Hwang, 2001; Sanders & Morgan 1997; Wolf, Noh, Fisman & Speechley, 1989).

Many parents notice signs of autism as early as when their child is two years old. The earlier a child with autism begins treatment, the better the outcome of the child's verbal and non-verbal communication, behavior, and social interaction with others. When parents notice such signs as impaired social interactions, lack of communication skills, occurrence of repetitive behaviors, or have any concerns, they should directly communicate their concern to their primary care pediatrician. The latter is the one responsible to refer the child to a specialized center where the child should be diagnosed. If the child is diagnosed with a certain disability, the pediatrician and the specialized center are responsible to refer parents to an early intervention program. In fact, primary care pediatricians state that they are strongly advised to refer infants with developmental delays or disabilities to early intervention programs. (Shonkoff & Hauser-Cram, 1987).

There are three main characteristics associated to children with autism spectrum disorder, which are present by the age of three years. These characteristics are lack of social skills, participation in repetitive activities, and lack of verbal and non-verbal communication (Hallahan et al., 2009). Children with autism spectrum disorder have certain set of behaviors, but the severity of the behavior can differ in scales.

The American Psychiatric Association (2002) explains that children with autism spectrum disorder (ASD) have a major impairment in language and communication, social interaction, and restricted pattern of interest and repetitive behavior (Wong & Kwan, 2010). The early intervention program is used to reduce the impaired social interaction, impaired verbal and nonverbal communication, cognitive limitations, behavioral problems, and any physical limitations of the child with autism. The early intervention programs provide parents with effective ways of teaching their child and reducing the challenging behavior often associated with ASD. Early intervention programs teach parents how to manage challenging behavior to help in reduce parental stress and maternal depression (Birkin, Anderson, Seymour & Moore, 2008).

1.2. Rationale and Significance

There is an increase in the number of children diagnosed with ASD and other developmental disabilities in Lebanon. Parents in Lebanon do not have enough information and lack knowledge about these developmental disabilities. In Lebanon, there is very little information about children with disabilities and knowledge of what interventions are provided. Moreover, there is a lack of existing research addressing parents' awareness and knowledge about ASD and early intervention programs in Lebanon.

1.3. Purpose of the Study

The purpose of this study was to examine the attitudes of Lebanese parents of autistic children when their child was diagnosed with autism. This study also explored Lebanese parents of autistic children's knowledge about early intervention. Moreover,

this study attempted to discover what challenges and difficulties parents of autistic children go through, and what parents and special educators recommend for the future.

This study examined the emotional phase most parents pass through when they know their child is diagnosed with ASD. It studied parents' awareness and background knowledge about autism and early intervention programs used in Lebanon.

1.4. Research Questions

This study attempts to answer the following research questions:

1. What were the parents' reactions when their child was diagnosed with ASD?
2. What do parents of children with autism know about early intervention programs?
3. What are the challenges and recommendations from families who have an autistic child?

1.5. Operational Definitions of Variables

1.5.1 Autism Spectrum Disorder (ASD): Autism spectrum disorder (ASDs) consists of a group of developmental disabilities that are caused by a neurological disorder. ASD includes “several types of conditions with a wide range of symptoms, differences in when symptoms start, and different level of severity, from very mild to severe” (Lerner & Johns, 2011, p. 217). However, all kinds share the same symptoms, such as social problems, language impairment and communication, and repetitive behavior.

According to Lerner and Johns (2011), there are three types of autism spectrum disorder identified by the centers for disease control and prevention:

- a. Autistic disorder: also called classic autism. Children with classic autism have significant language delays that appear during the first 3 years of a child’s life. Moreover, children with classic autism will show social and communication problems and they engage in unusual behaviors and interests.
- b. Pervasive developmental disorder - Not Otherwise Specified (PDD- NOS): it’s also called atypical autism. Children with PDD-NOS have the same symptoms as classic autism but may not be as severe or extensive as classic autism.
- c. Asperger’s syndrome (AS): also called high functioning ASD. Children with AS do not have problems with language or intellectual disability. They show problems with social interaction, sensory integration and motor skills. Students with AS are usually getting high-level or age appropriate education.

1.5.2 Early intervention: It's a word used to define the programs used to treat the child's disability at a young age, typically aged from three years old until 6 years old. "Research demonstrates that early intervention is beneficial for children with disabilities, for their families, and for society" (Lerner & Johns, 2011, p. 229).

Early intervention services help children to increase their cognitive and social developmental skills. Moreover, it reduces the child's behavioral problems. Since autism can be detected at an early age, parents can begin early intervention as early as they know their child is showing autistic traits. Early intervention programs include speech therapy, occupational therapy and behavior modification programs. "Early intervention for the communication impairment in autism is important since social communication deficits in autism are a major stressor for parents, and since gains in communication skills are related to prevention and reduction of maladaptive behaviors" (Landa, 2007, p.18).

1.6 Thesis Division

This thesis includes six chapters. The first chapter serves as an introduction to the topic, rationale and significance, research questions, and operational definitions of variables used in this study. The second chapter includes a review of the literature, and chapter three displays the methodology adopted in this research study. It highlights the research design, participants, and data analysis. The results are presented in chapter four followed by chapter five which is the discussion of the results. The last chapter concludes the study, lists the limitations, and the recommendations for future research.

1.7. Conclusion

After introducing the topic, and the research questions in chapter one, an analysis of the literature review is presented in chapter two. Chapter two focuses on six sections: The definition of Autism Spectrum Disorder and the history of autism, early intervention and the importance of early intervention, what is an individualized family service plan, types of treatments, parents attitude and parents challenges.

CHAPTER TWO

Review of the Literature

2.1. Introduction

In this section, a comprehensive review of the literature is presented. A description on Autism Spectrum Disorder (ASD) and the history of the disorder is provided. In addition to a brief description of early intervention in autism and the importance of this program, the review also provides information on the research conducted on parents' emotional state, background knowledge about autism and knowledge about early intervention programs provided for autism children.

2.2. Autism Spectrum Disorder

The work in the field of autism began when the two physicians Leo Kenner and Hans Asperger started their research about autism independently. Both Kenner and Asperger used the word autistic to refer to the children they were observing (Hallahan et al., 2009).

Autism is a developmental disability affecting the child's verbal and nonverbal communication and social interaction. The symptoms of autism are generally evident before the child's third birthday, and these developmental disabilities affect a child's performance. Autism is a neurological disorder that is not curable (Hallahan et al., 2009).

Diagnosis of Autism is established by the American Psychiatric Association (2000), it focuses on communication skills, social interactions, and repetitive and stereotyped patterns of behaviour, and it is often diagnosed by a psychiatrist. Moreover,

when diagnosing a child with autism, the child should be observed in a room and clinicians should be provided a detailed history about the child (Hallahan et al., 2009). “The identification and diagnosis of autism occurs in multiple settings and is made by a variety of health and community professionals, including pediatricians, psychologists, medical specialists, psychiatrists, and school psychologists” (Heidgerken, Geffken, Modi, & Frakey, 2005, p. 323). Also, pediatricians are the ones responsible to identify autism at an early age. When the parents get concerned about their child’s behavior, they ask their pediatrician or physician for advice. “Pediatricians and family practitioners are typically one of the first medical professionals to whom parents will voice concerns regarding their child’s development” (Heidgerken et al., 2005, p. 323).

2.3 Early Intervention

Early interventions are services provided for children with emotional or behavioural disorders, which support the child and the family to help prevent the child from developing additional problems or disabilities (Hallahan et al., 2009). “Early intervention refers to a variety of educational, psychological, or therapeutic intervention provided for handicapped, at-risk, or disadvantaged pre-schoolers to prevent or ameliorate developmental delays or disabilities or to provide support in cases in which these disabilities exist” (White, Bush & Casto, 1985, p. 418). Findings suggest that early intervention programs are effective in both improving the children’s global development and limiting the risk of secondary complications (Golubovic, Markovic, & Perovic, 2015; Guralnick, 2005; Leite & Pereira, 2013). When children receive early intervention at an early age, they gain the necessary skills to enter school and succeed. Early intervention programs are usually delivered in a multidisciplinary, coordinated

and in a least restrictive environment. The least restrictive environment is when the child is separated from non-disabled children and from their home, family and community as little as possible. Children from birth to 5 years of age with emotional or behavioral disorders and their families are eligible for an early intervention program. “Many educators and social scientists believe that the earlier in life a disability is recognized and a program of education treatment is started, the better the outcome will be for the child” (Hallahan et al., 2009 p.69).

Federal laws in the United States of America require a variety of early intervention programs that need to be provided and available for all infants and toddlers who are identified as having difficulties. These early intervention programs provide special education instruction, physical therapy, speech and language therapy, and medical diagnostic services. Also, the law requires that each child should have an Individualized Family Service Plan (IFSP). An IFSP is a plan that is set by professionals to meet the child and his family need (Hallahan et al., 2009).

2.4. Individualized Service Plan (IFSP)

According to Heward (1996), most early intervention services are ordinarily prepared and delivered to enable children’s development within the six major domains or skill areas: cognitive, communication and language, motor skills, social and play skills, affective and emotional development, self-care and adaptive skills. The IFSP includes a statement of the child’s present level of developmental areas as physical (hearing, vision, and health status), cognitive, communication, psychosocial, and adaptive behavior. Also, it includes a statement about the family strengths, resources, concerns, and priorities related to the child’s development. The IFSP consist of, the

objectives and major outcomes expected to achieve with the child and the child's family, the frequency and the method of how is the early intervention service will be implemented, and when will the child start with the early intervention program and for how long. Also, the IFSP has a written consent form from the parents or the legal guardians, the name of the service coordinator that is responsible in implementing the early intervention program, and where will the services be provided (Hallahan et al., 2009).

Sandall, McLean, and Smith (2000) added that these programs are delivered by a team of 'interventionists', a group of professional (teachers, therapist, social workers...etc.), who are responsible for planning and delivering the child's individualized early intervention program.

2.5. Types of Treatments

Each child with autism is different, and each autism intervention plan should address the needs of the child. There are multiple developmental systems that are impaired in autism. They include aspects of perceptual, motor, cognitive, social and cross-modal processing systems (Landa, 2007). Most studies as cited in Landa (2007) have shown that early intervention improves the child learning, communication and social skills. (e.g., Rogers, Herbison, Lewis, 1986; Smith, Groen, & Wynn, 2000; Landa & Holman, 2005; Kasari, Freeman, & Paparella, 2006). In fact, there are a number of effective early intervention treatments that are provided for children with autism that helps the child and the child parents. According to Yildirim (2013), there is a growing body of evidence that developmental interventions can be effective in education of young children with ASDs (see for instance, Ingersoll, Dvortcsak, Whalen, & Sikora, 2005; Mahoney & Perales, 2003, 2005; Schertz & Odom, 2007; Wetherby & Woods,

2006). Early intervention includes occupational therapy (OT), physical therapy (PT), speech therapy (ST) and applied behavioral analysis (ABA).

Occupational therapy helps children develop their fine motor skill development and social interaction. Occupational therapy helps children master daily living skills as dressing, bathing, toileting and improve their fine motor skills (handling small objects, handwriting and oral-motor skills (see for instance Werner De Grace (2004), Whiteford, Townsend, & Hocking, 2000, and Wilcock, 1998). Physical therapy helps the child develop their gross motor skills as sitting, walking, running and jumping. Also, occupational and physical therapists are responsible of the sensory integration (SI) therapy. In fact, many children with autism have difficulties in processing sensory information as movement, touch, smell, sight and sound (Werner De Grace, 2004).

As for speech therapy, autistic children have difficulty using conversational speech or understanding the tones of language and nonverbal cues when talking with others (Whalen, Schreibman, & Ingersoll, 2006).

O. Ivar Lovaas (1927–2010) devoted nearly half a century to ground-breaking research and practice on autism (Smith & Eikeseth, 2011). His research aimed at improving the lives of children with autism and their families. It is in the 1960s that he pioneered applied behavior analytic (ABA) interventions to decrease severe challenging behaviors and establish communicative language. “Children with ASD especially the ones with severe levels of autism, display highly inappropriate behavior as hitting, biting, throwing tantrums or screaming” (Hallahan et al., 2009, p. 439). These children are highly recommended to go for an applied behavioral Analysis therapy (ABA). ABA is a “highly structured approach that focuses on teaching functional skills and

continuous assessment of progress; grounded in behavioral learning theory” (Hallahan et al., 2009, p. 442). ABA may help to decrease or eliminate these behaviors. A lot of research indicated that children with autism who received early intensive ABA achieved better outcomes than similar children who received little or no ABA (Smith & Eikeseth, 2011). “Early intensive behavioral interventions based on ABA have been shown to enhance IQ, communication, positive social behavior and adaptive behavior in some children with autism” (Cebula, 2012, p. 848).

2.6. Parents’ Attitude

This phase of child development can be especially stressful for families of children with developmental disabilities (DD) such as autism spectrum disorders (ASD), as the characteristics related to these disorders may complicate the overall challenges for families (Rivard, Terroux, Parent-Boursier & Mercier, 2014). Having a new baby can have a major effect on the parents and the siblings. “The effects on the family of the birth of a child with a disability can be even more profound” (Hallahan et al., 2009, p.119).

2.7. Parents’ Reactions

Parents of children with disabilities have many reactions when their child is diagnosed with special needs. “As a challenge to the family, autism must rank among the most stressful of childhood developmental disabilities. Problems with communication, emotional expression and antisocial behaviours, all combined to place tremendous stress on the families of children with autism” (Gray, 2006, p.970). Some parents go through a sequence of emotions while others may experience only one or several reactions. The parents’ typical stages of adjustment are shock, denial, anger,

shame, acceptance, and adjustment. Frey, Greenberg, and Fewell, (1989), Quine and Pahl (1991), Baxter, Cummins, and Yiolitis (2000), and Hassall, Rose and McDonald (2005) reported that despite these broad findings, parents of children with a disability vary a lot in the different levels of stress they experience. Furthermore, their stress levels are usually linked to many variables. Zand, Pierce, Bultas, McMillin, Gott and Wilmott (2015) in their research about the accuracy of mothers and fathers knowledge of child development and early intervention services stated that many researchers reported that parents who are better informed tend to recognize problems earlier and thus act effectively to address them. (Bornstein, Cote, Haynes, Hahn, & Park, 2010; Hickson & Clayton, 2002; Melamed, 2002).

2.7.1 Parental Shock

Parents may show shocking emotions as crying or depression; also, some parents may express their shock through physical outbursts, or inappropriate laughter occasionally. According to Heiman (2002, p.160), “the crisis engendered by the first intimation or diagnosis that something is wrong with their child is probably the parents’ most difficult and shocking experience.” Heiman (2002, p. 160) added that parents’ initial reactions tend to be negative similar to reactions related to bereavement.

2.7.2 Parental Denial

Parental denial and parental shock complete each other. Some parents may deny their child’s disability or try to avoid reality while other parents do not go through shock or denial in their child disability because they are the ones who felt there is something wrong with their child. Hallahan et al. (2009) explain that in general parents do not engage in denial, they are often the first to suspect a problem. “Families either

adapt flexibly and mobilize into effective action or freeze in various degrees of rigid, ineffective reactions, whereas others tend to resist or even deny the diagnosis itself” (Falik, 1995, p.336).

2.7.3 Parental Anger

Parents may demonstrate their anger externally in the form of anger. “Verbally attacking anyone who might be blamed for their unfortunate circumstance, including displacement of responsibility onto the original diagnostician or any supportive professionals, is common” (Healey, 1996). Parents at this stage start blaming anyone for their unlucky life and situation. “Parents question "Why?" They are angry that they were singled out by fate, and they seek someone to blame. Alternately they blame themselves, the doctor, their spouse, society and God” (Fortier & Wanlass, 1984, p. 20).

2.7.4 Parental Shame

In this stage parents accept and cope to the fact that their child has a disability. “This is a phase of putting things in place, of being reconciled to the fact that something has happened that deeply affects and will continue to affect the total family” (Fortier & Wanlass, 1984, p. 21).

While on the other hand, parents may feel shameful to have a child with disability they start showing an attempt to hide the child, especially from friends and relatives. “For a few parents, retreating, accompanied by an attempt to hide the child, especially from friends and persons during organized or routine social encounters may be the first sign that they have begun to accept the fact their child has a disability” (Healey, 1996).

2.7.5. Parental Acceptance

In this stage parents show acceptance for the child's condition and the disability, and they begin to accept to help their child. Healey (1996) added that in this stage, cognition, parents understand and appreciate their child. Moreover, they try to strengthen their skills in coping with life's trials in order to help their child, themselves, and others. "In the process of acceptance the family is capable of beginning to care for itself and for the disabled child according to a professional plan, to solve the conflict, and to accept the child despite the limitations" (Kandel & Merrick, 2007, p.1802).

2.7.6. Parental Adjustment

This is the last stage in parents' reaction to their child's disability. Parents accept their child's disability and start to put their life together by enjoying living, preparing a good future for their child, and discussing appropriate intervention with professionals for children. "At this stage the parents search for solutions to their problem and ways to help their child advance. They learn to appreciate their inner strength to deal with the affliction and consider alternative solutions" (Kandel & Merrick, 2007, p. 1802).

Families who starts adjusting and adapting to their child's disability find a proper balance in taking responsibilities towards their other children, spouses, personal needs and work. Coping and adjusting to their child's disability will help the parents seek resources, gather information, and cooperate with professionals. If parents of a child with autism or other disability is knowledgeable and has background knowledge about the different kinds of disabilities and early intervention services, parents will identify their child's disability, seek help and cope easily with the situation. "The more proficient and varied the family's resources before the birth of the disabled child – the

easier it will be to adapt and cope efficiently with the new situation” (Kandel & Merrick, 2007, p.1804).

2.8. Parenting Stress in Families with an ASD Child

A lot of studies and data demonstrated higher stress among families of children with ASD compared to families that has typically developing children or children with other developmental disabilities (Baker-Ericzen et al., 2005; Dumas et al., 1991).

“Existing studies of families of children with autism suggest that behavioral, social, and cognitive dimensions of the disorder are associated with stress in parents. It is true, that the more severe the child’s symptoms, the greater will be the degree of parental stress” (Bashir, Khurshid & Qadri, 2014, p. 43).

2.9. Parents’ Challenges

“A child with autism may be a severe stressor on the family for many reasons, including the ambiguity of diagnosis, the severity and duration of the disorder, and the child’s lack of adherence to social norms” (Altieri & Von Kluge, 2009, p. 142). At first, parents of autistic children may face a lot of challenges for many reasons as when the diagnosis is still unclear, the severity of the disorder, their child lack of social skills, parents do not have the right techniques that will help them cope with their child, and if the autistic child has siblings, parents will fall into the siblings’ adjustment phase.

“Parents have many questions and may experience intense confusion during the period before they receive an official diagnosis. Although the quest to help their child may alleviate some negative feelings, the stress increases when parents realise that there is no cure for autism” (Altieri & Von Kluge, 2009, p. 142).

Other than psychological challenges, parents may also face financial challenges when raising an autistic child. “Mothers also reported stress due to financial burdens, perceived stigmatization associated with ASD, and their own lack of knowledge about the etiology and treatment of ASD” (Obeid, Daou, De Nigris, Shane-Simpson, Brooks, & Gillespie-Lynch, 2015, p. 3521). Since an autistic child should go through many therapies as occupational therapy, speech therapy and behavioral therapy, parents will face heavy financial strains. “Financial hardships may be another important factor that influences parent wellbeing. In general, families with children with disabilities experience much higher expenditures than other families” (Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010, p. 140). Insurance companies in Lebanon and the Lebanese National Social Security Fund do not cover the costly evaluations and treatments needed for autistic children. Moreover, mothers of autistic children may leave their job in order to take care of their child and this may result in family struggles. Azar and Badr (2006) attributed the high levels of stress and depression observed among mothers of children with intellectual disabilities in Lebanon to stigma associated with disability and to financial burdens associated with caring for their children.

2.10. ASD in Lebanon

Lebanon is a small country in the Middle East that is multilingual and multicultural, that has limited support for people with Autism. “In Lebanon, no estimate for autism prevalence exists” (Chaaya, Saab, Maalouf, & Boustany, 2016, p.514). Moreover, Chaaya et al. (2016) states that in Lebanon and neighboring Arab countries (Syria, Jordan, Palestine), there are no estimates on the prevalence of autism. “ASD in Arab countries such as Lebanon has received relatively little attention from the research

community” (Obeid et. al., 2015, p. 3521) While on the other hand, “data collected at the American University of Beirut Medical Center (AUBMC) Special Kids Clinic indicate that the number of pediatric patients with ASD is increasing” (Chaaya et al., 2016, p. 515). Since the number of autistic children in clinics is increasing Chaaya et al. found it necessary to study the prevalence of ASD in Lebanon. The study done by Chaaya et al. in Nurseries in Lebanon “estimated a prevalence of ASD of 153 per 10,000 which is similar to the prevalence of 147 per 10,000 reported by the CDC (CDC 2014a)” (Chaaya et al., 2016, p.518).

Furthermore, parents of children with Autism lack the knowledge and information about Autism and Early intervention services since there is lack of awareness about Autism in Lebanon. Divan, Vajaratkar, Desai, Strik-Lievers, and Patel (2012); Grinker, Yeargin-Allsopp, and Boyle (2011), Mirza, Tareen, Davidson, and Rahman (2009), Obeid et al. (2015), explain that government-supported services for individuals with ASD and other developmental disabilities are rarely available in middle to low-income regions (p. 3522). That’s why Autism related services are rare in Lebanon. “Government-based, ASD-specific educational services are infrequently available in Arab countries and when available, they are often of low quality” (Obeid et al., 2015, p. 3521).

In conclusion, autism is a neurological disorder that affects a child’s communication and social skills. It is important that children with autism receive early intervention services at an early age. Children with autism get early intervention services and treatments according to the child’s ability and needs. Every parent react to their child’s disability differently and parents face different kind of challenges.

CHAPTER THREE

Methodology

This chapter describes the research design used to explore parents' reaction to their autistic child, parents' knowledge about autism and early intervention in Lebanon, and parents' challenges and recommendations. It reports on the sample, the instruments utilized to collect data, and finally the procedures followed to collect and analyze the data.

3.1. Research Design

This study is exploratory and qualitative in nature which fits my study purpose of exploring parents' knowledge and perceptions. According to Fraenkel, Wallen and Hyun, (2012), "In the exploratory design, results of the qualitative phase give direction to the quantitative method, and quantitative results are used to validate or extend the qualitative finds" (p.560). In other words, information derived from one instrument guide constructing items for the other one, and consequently the results are validated. Thus, this design is considered useful to explore attitudes of Lebanese parents of autistic children when their child was diagnosed with ASD, Lebanese parents of autistic children knowledge about early intervention in Lebanon, and the challenges parents go through and what they recommend.

3.2. Sample

Purposive sampling is appropriate to this study since it "serves the researcher's purpose and objectives of discovering, gaining insight, and understanding into a particular chosen phenomenon" (Burns, 2000, p. 465). It is purposive since

participants were chosen according to a criteria set by the researcher. The criteria was parents of children with autism aged between 2 to 4 years, enrolled in an early intervention program, and diagnosed or have features of Autism. According to Fraenkel et al. (2012) “purposive sampling is a nonrandom sample selected because prior knowledge suggests it is representative, or because those selected have the needed information.” In other words, my sample was chosen on purpose because they can provide rich information that is relevant to my study. In order to collect data, I emailed and visited different special needs centers that have early intervention services. I explained the purpose of my research, and submitted my IRB documents. The centers that accepted to participate in the research, they asked the parents if they would like to fill the survey. The parents that accepted to fill the survey signed the consent form and filled the survey with the help of an employee from the center.

3.3. Participants

First, in this study parents of children with features of autism aged 2-4 and not yet in kindergarten were administered in different early intervention centers. I gained access to these centers by visiting them personally, explained my purpose of the study, and submitted the IRB documents.

3.4. Instruments

The research aims to determine what parents’ attitude were when their child was diagnosed with autism, how they knew about early intervention, what challenges they are facing and their recommendations by filling a questionnaire. Also, an interview with the special educators in these centers was conducted to determine parents’ attitudes,

knowledge and reaction toward their child disability. Also, analysis of documents done by special needs centers and the Ministry of Social Affairs was done.

Therefore, in this study, three instruments were used for data collection: a survey for parents' of autistic children (see Appendix A), semi-structured interviews with special educators (see Appendix B), and an analysis of the documents prepared by special needs centers working with autistic children and the Lebanese Ministry of Social Affairs. These documents were chosen because they were the only available documents in Lebanon. There is a lack of resources on autism in the country.

3.4.1 Survey

A survey was developed based on the literature review, and the research questions. For example some items covered the parents' educational level, age, emotional state when their child was diagnosed with autism, previous knowledge about autism and early intervention, and who is their source of information about their child case. Also, a question if the parent found their child physician knowledgeable about their child disability or not, and to verify their answer. Also, there are two questions related to what age was the child diagnosed with autism, what kind of therapies the child attends, and for how many hours a week. Another two questions, which ask the parents about the challenges that parents are facing with their child, and what do they recommend for the future.

To ensure validity i.e. the survey measures what it is supposed to measure, it was translated from English to Arabic then back to English (See Appendix C). It was then distributed to parents of children with autism in special education centers in Beirut catering for students with ASD.

The advantage of this survey is that it provides quantitative data on the parents' reactions when their child was diagnosed with ASD, the parents' knowledge about the early intervention program, and the challenges parents' face with their child. The survey is an advantage because it describes and shows how parents' from different areas and backgrounds respond to the same question in order to get accurate results.

Nineteen Arabic version questionnaires were filled by parents in three early intervention centers across Lebanon: Two centers in Beirut and one in North Lebanon. In center 1, there are six children diagnosed with autism in the early intervention program, but only two parents accepted to fill the questionnaire. In center 2 six parents filled the questionnaires, and 11 questionnaires were filled by parents in center 3. As in center 4, there were no children with Autism in the early intervention program. Center 5, it is not allowed to interact with patients and their parents. (see table 1)

Table 1: Participants

<u>Early Intervention Centers</u>	<u>Participants</u>
Center 1	Two out of six accepted to fill the survey
Center 2	Six parents filled the survey
Center 3	Eleven parents filled the survey
Center 4	There were no children in the early intervention program
Center 5	It is not allowed to interact with patients and their parents

The surveys filled were for 15 boys (79%) and 4 girls (21%) diagnosed with autism. Children age ranged between 2 and 5 years old; 16% are 2 years old, 21% are 3 years old, 16% are 4 years old, and 47% children are 5 years old. 84% of the parents are from Beirut, 11% are from North Lebanon, and 5% from Northern Mount Lebanon.

2.4.2. Semi-Structured Interview

As for the interviews, three interviews were conducted with three special educators in three different early intervention centers.

According to Fraenkel et al. (2012) a semi-structured interview is a verbal and formal questionnaire that consists of a series of questions designed to elicit specific answers on the part of respondents. A semi-structured interview is used for the qualitative research. It helps get rich information because I could add questions and ask for examples and more explanations. Interviews were conducted with special educators in different early intervention centers in Lebanon, to investigate their views on how parents react to their child diagnosis, how knowledgeable parents living in Lebanon are about autism and early intervention, and what challenges do parents pass through. The questions were as follows (see Appendix B):

- 1) What are parents' emotional state/attitude when they know that their child has features of Autism or diagnosed with Autism?
- 2) Do some parents come to you convinced that their child has a disability or they all come with a denial state? Please explain.
- 3) Do parents living in Lebanon have background knowledge about developmental disabilities or Autism? Explain.

- 4) Do parents of children with developmental disabilities or Autism have background knowledge about the Early Intervention Program? Explain.
- 5) Who refers parents' of children with disabilities to your center for diagnosis?
- 6) Do you have an idea about the challenges parents face with their autistic child?
- 7) What plans do you recommend for the future, in order to raise more awareness in Lebanon about early intervention programs and Autism?

The interviews were conducted in the special needs centers, by taking an appointment from the special educators according to their availability. The interviews took half an hour each, and verbatim notes were taken by the researcher.

Interviews data were analyzed by first coding the ideas that were repeated frequently into categories. Then, the data was classified according to the identified categories and analyzed according to the research questions.

2.4.3. Documents

Documents published by researchers, centers that work with autistic children, and documents prepared by the Ministry of Social Affairs about Lebanese parents' of autistic children were analyzed. I obtained documents on the prevalence of autism in Lebanon, and parents' knowledge about autism and early intervention. The research paper that was analyzed is the only research paper done in Lebanon about the prevalence of autism, parents' knowledge about the signs of autism, titled "Prevalence of Autism Spectrum Disorder in Nurseries in Lebanon: A Cross Sectional Study. Also, booklets prepared by the Ministry of Social Affairs and North Autism Center (NAC) were analyzed, since they were published every year to raise awareness about Autism in

Lebanon. Those were the only documents chosen, since there were no other resources about Autism in Lebanon.

Table 2: Research Questions and answers

Research questions	Sample survey items	Sample interview items	Sample documents selected
<p>Research question</p> <p>1: What were the parents' reactions when their child was diagnosed with ASD?</p>	<p>What did you feel when you were told your child may have ASD?</p> <p>a. You were Shocked</p> <p>b. You lived in denial that this is not true</p> <p>c. You were angry and started blaming others</p>	<p>1) What are parents' emotional state/attitude when they know that their child has features of Autism or diagnosed with Autism?</p> <p>2) Do some parents come to you convinced that their child has a disability or they all come with a denial state? Please explain.</p>	

	<p>d. You felt ashamed and started hiding the truth from your relatives and people who are close to your family</p> <p>e. You accepted the truth and started seeking help from professionals</p> <p>f. You directly adjusted your life and time according to your child's needs</p>		
<p>Research question 2</p> <p>: What do parents of children with autism know about early intervention programs?</p>	<p>Who were your main source of information about your child's case?</p> <ol style="list-style-type: none"> 1. Pediatrician 2. Center of diagnosis 	<p>1) Do parents living in Lebanon have background knowledge about developmental</p>	<p>Article:</p> <p>Prevalence of Autism Spectrum Disorder in Nurseries in</p>

	<p>3. Special educators</p> <p>How did you know about the early intervention program?</p> <p>a. Relatives</p> <p>b. Friends</p> <p>c. Pediatrician</p> <p>d. From the place I diagnosed my child in</p> <p>Myself (Please specify From where did you know</p> <p>Did you directly accept to enroll your child in an early intervention program?</p>	<p>disabilities or Autism?</p> <p>Explain.</p> <p>2) Do parents of children with developmental disabilities or Autism have background knowledge about the Early Intervention Program?</p> <p>Explain.</p>	<p>Lebanon: A</p> <p>Cross Sectional</p> <p>Study.</p>
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	<p>a. Yes</p> <p>b. No (please specify why not)</p>		
<p>Research question 3</p> <p>: What are the challenges and recommendations from families who have an autistic child?</p>	<p>Are you facing challenges with your autistic child?</p> <p>a. Yes</p> <p>b. No</p> <p>If yes, please specify what are the challenges you already faced and facing. What are your recommendations for the future?</p>	<p>1) Do you have an idea about the challenges parents face with their autistic child?</p> <p>2) What plans do you recommend for the future, in order to raise more awareness in Lebanon about early intervention programs and Autism?</p>	<p>Article: Prevalence of Autism Spectrum Disorder in Nurseries in Lebanon: A Cross Sectional Study.</p> <p>The three booklets that are used to raise awareness.</p>

3.5. Data Analysis

Three instruments were used for data collection to triangulate and ensure validity and reliability: data from the questionnaire, interviews, and document analysis were analyzed separately, then, the convergence and divergence of the results were discussed. When quantitative and qualitative data are combined, results are triangulated making it possible to get more reliable information that is crosschecked from several instruments and respondents (Fraenkel & Wallen, 2008). The process of using and relating several sources of data is an effective strategy in ensuring that data is valid and reliable (Mertler, 2009). In the study, the survey and interview were piloted to ensure clarity and relevance. An expert in the field checked the items for me.

For the surveys, simple frequency counts were conducted. I summarized the results in order to draw some conclusions. First I reported the total size of the parents and the overall percentage of returns. Then, I calculated the percentage of the total number of parents' responses to each item and the percentage of parents who chose the alternative for each question.

The interviews were analyzed using coding. Strauss and Corbin (1998) define coding in qualitative studies "as the analytic process through which data are fractured, conceptualized and integrated to form theory" (Fraenkel et al., p.436, 2012). In coding, first the ideas that were repeated frequently I divided them into categories. Then, the data was classified according to the identified categories and analyzed according to the research questions. Four categories emerged from the interviews which were parents' emotional state, Lebanese parents' background knowledge about autism and early intervention services, the challenges parents' are passing through, and the special

educator's recommendations for the future. Under each category the common answers were written.

3.5.1 Content Analysis of documents

“Content Analysis is a technique that enables researchers to study human behavior in an indirect way, through an analysis of their communications.” (Fraenkel et al., 2012, p. 478). In my content analysis I had to summarize the documents since there is no enough documents to compare and contrast between them.

3.6. Ethics in Education

An informed consent section was included in the survey and in the interview (See Appendix D, E, F and G) Also, all participants were assured that the information will be confidential and will only be used for the purpose of the study. Moreover, the purpose of the study was clearly indicated to participants before answering the survey. All required permissions to carry out the study were attained prior to data collection through the IRB. (see Appendix H)

This study was exploratory and qualitative, and three instruments were used for data collection. A survey that is translated from English to Arabic then back to English was given for parents' of autistic children, a semi-structured interview with special educators, and analysis of documents done by special needs centers working with autistic children and the Ministry of Social Affairs. The surveys and interviews had an informed consent section to protect the privacy of participants. Interviews were done with three special educators, 19 surveys were filled by parents of autistic children and content analysis of three booklets given by the Ministry of Social Affairs. Then the data

was analyzed by summarizing the surveys to draw conclusions, coding the interviews and booklet analysis.

CHAPTER FOUR

Results

This section reports the results of parents' questionnaires and special educator's interviews. The primary focus of this section is to answer the research questions: What were the Lebanese parents' attitude when their child was diagnosed with ASD, Lebanese parents' knowledge about early intervention programs, and the challenges they are passing through and what they recommend.

4.1. Quantitative Results

Quantitative data were gathered using a survey conducted by me and analyzed using excel.

The surveys filled were for 15 boys (79%) and 4 girls (21%) diagnosed with autism (see figure 1). Children age ranged between 2 and 5 years old; 16% are 2 years old, 21% are 3 years old, 16% are 4 years old, and 47% children are 5 years old (see figure 2). 84% of the parents are from Beirut, 11% are from North Lebanon, and 5% from Northern Mount Lebanon. (see figure 3)

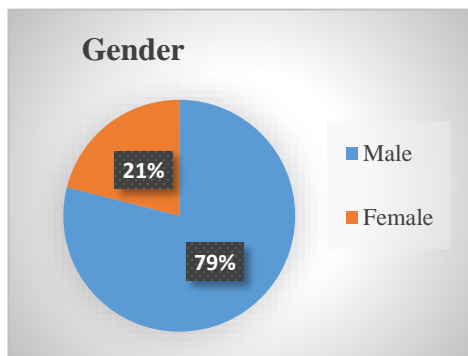


Figure 1

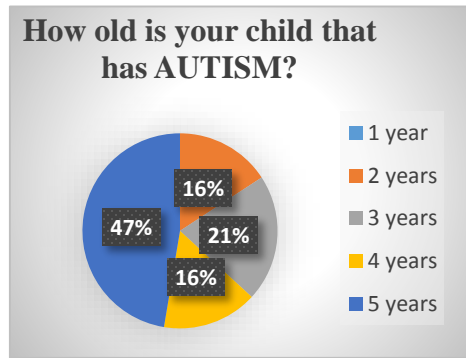


Figure 2

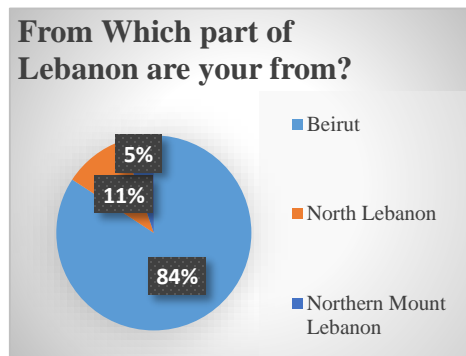


Figure 3

All parents who filled the questionnaires were the father or mother of the child who lived and studied in Lebanon all their lives. When parents were asked about their highest level of education, they replied as follows 69% of the parents have Bachelor degree, 26% have High School Diploma or equivalent, and 5% have a Master's degree.(see figure 4)

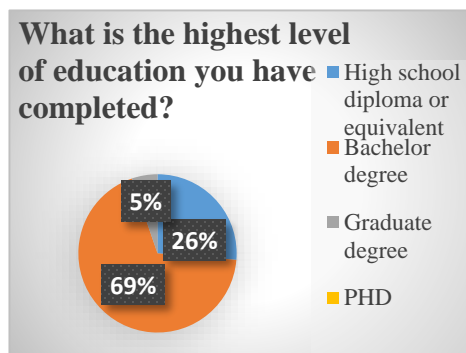


Figure 4

The age of the parents are as follows: 53% their age ranged 30 - 39, 26% are between 24 – 29 years, and 21% are between 40 – 49 years. (see figure 5) On the other hand, all the children who are diagnosed with autism have no siblings with autism, and only one child with autism has a sibling with another developmental disability.(see figure 6)

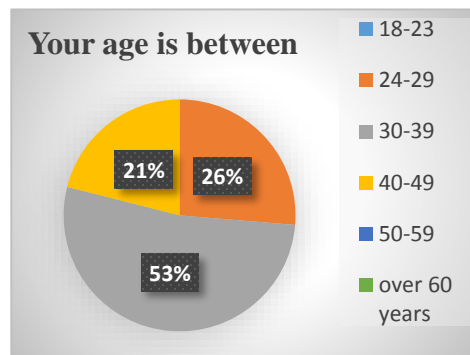


Figure 5

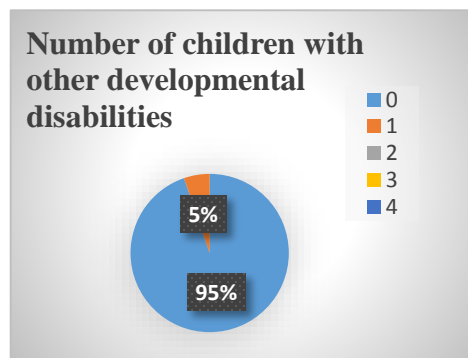


Figure 6

Parents were then asked to respond to the question regarding their feeling when they were told their child may have Autism. There are some parents who responded by choosing two answers which that they accepted their truth and started seeking help from professionals, and that they directly adjusted their life and time according to their child's need. 32 % of the parents accepted the truth and started seeking help from

professionals, and 29% directly adjusted their life and time according to their child's needs. On the other hand, 21% of the parents reported that they were shocked, 11% lived in a denial claiming that the diagnosis was not true, and 7% of the parents stated that they were angry and started blaming others.

In the following question, parents were asked who pinpointed to them that their child may have autism. 8.42% parents knew on their own, 7.37% parents knew from their child's pediatrician, and 4.21% had a relative pinpoint their child problem. (see figure 7) On the other hand, 69% of the parents knew their child had autism when their child was 2 years old, 26% knew when their child was 1 year old, and 5% knew when their child was 3 years old (see figure 8)

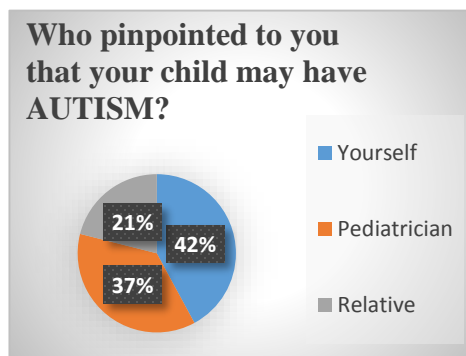


Figure 7

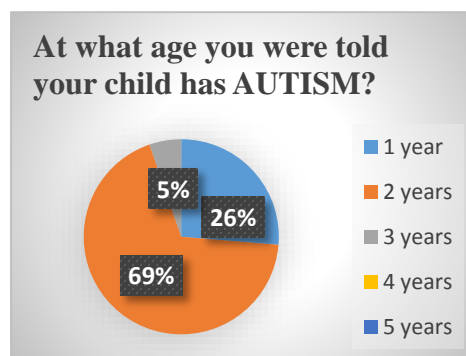


Figure 8

As for the question that claims if the child's physician is knowledgeable about autism, 55% answered that their pediatrician is not knowledgeable about autism, and 45% responded that their pediatrician is knowledgeable (see figure 9). According to the parents that claimed that their physician is not knowledgeable, most of the parents had the same answer that the pediatrician:

- Did not care about their child special case and did not discuss the issue with them.
- Did not figure out their child's special case even though they kept asking the physician if what their child going through was normal or not.
- Always explained that the speech delay, lack of social skills and behavioral problems do not result in a bad diagnosis and that the child needs time.
- Never gave them advice about their child special case, even when parents explain to their pediatrician that their child is diagnosed with autism.

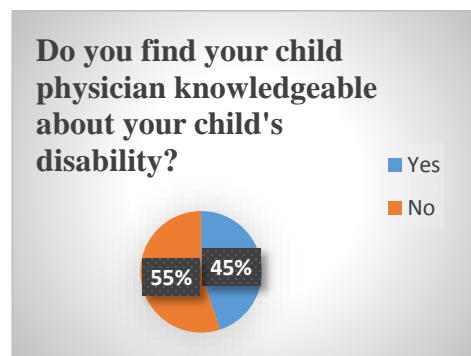


Figure 9

According to the survey, 58% of parents' main source of information about Autism is the center of diagnosis they take their child to, 16% from their child's pediatrician, another 16% from the internet and their friends, and 10% from special educators at their child's school or daycare. (see figure 10)

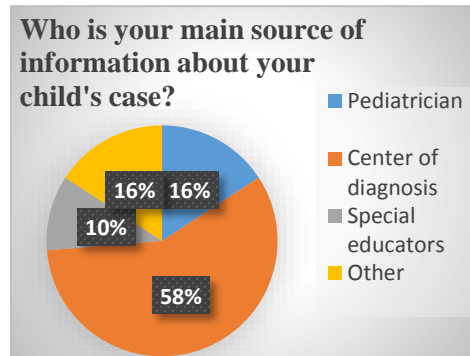


Figure 10

When participants were asked how they knew about the early intervention program 55% indicated that they knew from the center they diagnosed their child in, 15% from other sources as the internet and the school the child goes to, 10% knew about the early intervention before they had a child with autism, another 10% knew from their pediatrician, 5% knew from their friends, and another 5% knew from their relatives. (see figure 11) All participants accepted to enroll their autistic child in the early intervention program when they knew about it.

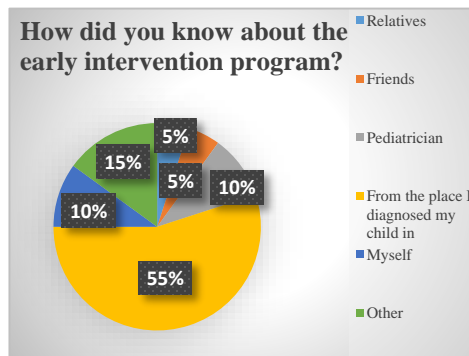


Figure 11

All participants know what programs their children are attending in the early intervention program. Seventeen (32%) are attending speech therapy, 13 (21%) are attending Sensory Integration (SI) therapy, 11 (21%) attending Applied Behavioral Analysis (ABA) therapy, 9(17%) attended occupational therapy (OT), 2(4%) are attending other programs, and 1 (2%) attended physical therapy. Most of the children attend more than one therapy (see figure 12)

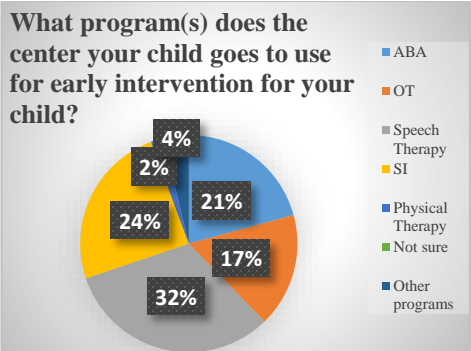


Figure 12

Most of the children 8(42%) attend therapies from 0-5 hours/week, 5(26%) attend from 6-10 hours/week, 2(11%) attend 21-25 hours/week, another 2(11%) attend 26 or more hours/week, 1(5%) attend between 11-15 hours/week, and 1(5%) attend 16-20 hours/week. (see figure 13)

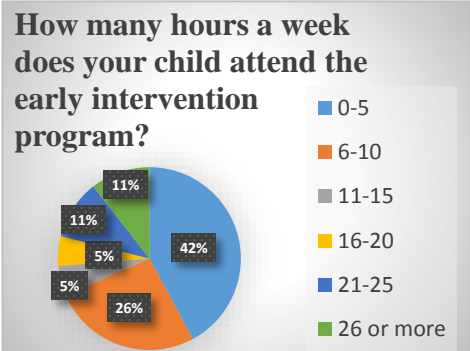


Figure 13

When parents were asked if they are facing any challenges with their autistic child, 13(68%) answered yes, and 6(32%) answered no (see figure 14). The parents who are facing challenges with their children reported their challenges as follows:

- Behavioral problems and tantrums in public.
- The parent lacks skills in dealing with his/her child at home and in public.
- The child is active at home and doesn't listen to directions, while he/she interacts well at the center.
- The child doesn't interact with his/her relatives.
- The child lacks social skills.
- Parents find difficulties in interacting with their child at home.
- The child needs time to adapt to new places.
- The child can't express his/her feelings since he/she has speech problems.
- Stubbornness.
- In Lebanon there are no special play areas for children with disabilities.
- The child cries for no reason
- There are no daycares that accept autistic children.
- Therapies cost a lot.

- Therapies need a lot of time and effort from parents.

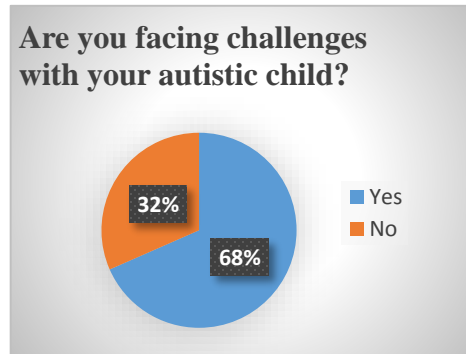


Figure 14

4.2. Interview Results

Data were gathered from interviewing three special educators from the early intervention programs based on availability and access. The main inquiry addressed in the interview was about parents' emotional state/ attitude when they know that their child is diagnosed with autism, if parents' have background knowledge about developmental disabilities or autism, and early intervention programs. Also, to know who refer parents' of children with disabilities to their centers for diagnosis, what the challenges parents face, and what are their future recommendations. Five key themes emerged from the interviewing data:

4.2.1. Parents' emotional state/attitude:

- Parents' knowledge depends on their background and educational level.
- Most parents first go through denial, with hope that their child has speech and communication problems but not autism.
- Very few parents come to the diagnosis knowing their child has autism and they are ready to face the challenge. These parents are relieved when their child is diagnosed with autism, to know from where to start and what to do.

- Parents that has no work and no diplomas put all their hopes on the center and professionals, and they can't understand what autism is.

4.2.2. Lebanese parents background knowledge about autism:

- Some educated parents these days come to the center of diagnosis with all the knowledge about autism, because they research and read a lot on the internet in order to know where to go and seek help.
- Mostly, all parents do not have knowledge about the early intervention program, they know about the program from the center of diagnosis.
- In Lebanon, we need a lot of awareness campaigns about autism. Centers wish parents come as early as possible for the intervention program.
Lebanese parents' do not have knowledge about autism and early intervention at all.
 - “Parents of children with Down Syndrome seek help as early as possible since the disability is obvious. While, for autistic children there are features that need to be observed in the child's behavior in order to know that the child needs to be diagnosed.”

4.2.3. Referring responsibility:

- Normally, the pediatrician figures out the child has features of autism, then the pediatrician refers the child to a neuro-pediatric where the child is diagnosed with autism then referred to us for intervention.
- The child's pediatrician plays a big role in identifying autistic signs and referring parents to a neuro-pediatric and a diagnostic center.

- In Lebanon, physicians are not aware enough about the features of autism, that's why most autistic children are diagnosed when they go to a daycare or to school which is too late because the early intervention age passed.
- The number of Autistic children in the early intervention programs is too little, since these children are still at home and they are figured out when they are enrolled in their first school year.

4.2.4. Challenges of parents' of Autistic children

- When the child is diagnosed with autism, parents start thinking about what their family and friends think, what will happen to their child in the future, and how they are going to cover all the financial cost for the early intervention programs.
- The main challenges parents face with their children are as follows:
 - Communication problems
 - Children lack social skills: that's why parents can't go and visit friends with their children or take them to the supermarket. Also, parents are accused by the society, especially when the child is not behaving or throwing a tantrum.
- In Lebanon, there is limited awareness about autism. Most awareness campaigns happen in Universities and places in Beirut where the vast majority of people do not attend because of their socioeconomic status.
- Media awareness takes place only on April 2nd on the Autism World Day.
- Lebanese of low income do not go to a pediatrician, they go to a public clinic, and there is no one that can give advice for parents with autistic child.

- The early intervention programs are too expensive in Lebanon, and not everything is covered by the government.

4.2.5. Recommendations for the future

1. Interviewers agreed that the government should support parents of children with Autism since interventions cost a lot approximately 12 thousand dollars a year. According to the interviewers there should be a special law that covers the costs of interventions for autistic children.
2. Also, interviewers suggest that all centers across Lebanon and the government should agree on awareness campaigns that should be done all year in all public schools and universities not only in private schools and private universities.

4.3. Content Analysis Results

I analyzed documents prepared by a center for special needs children that work with autistic children, and documents published by the Ministry of Social Affairs about Lebanese parents' of autistic children.

The documents that were found in the Ministry of Social Affairs, were three booklets prepared by the Ministry of Social affairs with the collaboration of the North Autism Center (NAC). Also, I only found one article published by OPENMINDS. OPENMINDS fund AUBMC special kid's clinic.

The first booklet was prepared in April 2014, the second one in April 2015, and the last one was in April 2016. They are all distributed in April, since April is the Autism Awareness Month.

4.3.1. The first booklet (April 2014) and the second booklet (April 2015), titled “Autism”:

These booklets were compiled by the psychiatrist Dr. Abass Alam Aldein, the director of the North Autism Center (NAC) Sabine Saad and the psychologist Nayla Al Hussein. These booklets start with an introductory page written by the Ministry of Social Affairs, and they explain that the ministry’s main objective is to have more awareness campaigns in order to help families of children with disabilities become more aware about their children’s disability and help them cope with the challenges they face with their kids. Moreover, the first booklet is done coinciding with the launch of the national campaign for 2014 named “ways of supporting families of children with Autism” done by the Ministry of Social Affairs and the North Autism Center (NAC), and the second booklet done in April 2015 in order to continue the campaign they started in 2014. The objective of these booklets is to spread main information about autism, and to make it a source of information for the families of autistic children. These booklets can help parents of autistic children how to deal with their autistic child. These booklets can also be used as a source of information for practitioners and social workers that work in daycares affiliated with the centers of service development and centers who has a contract with the Ministry of Social Affairs.

Both booklets are written in Arabic and divided into units. The first unit explains the definition of Autism, symptoms of autism which are social skills problems, communication challenges, language disabilities, and behavior problems explained in details with examples. The second section clarifies the reasons why the child has autism, when and how can the child be diagnosed with autism, why early intervention is

needed, what are the interventions used in the early intervention program, and how can early intervention help children with autism. The second section also explains about the inclusion of children with Autism in normal schools, what are the skills that the child need to learn in order to fit in a normal school, and what are the steps needed to include the child with autism in a normal school. The third section explains the challenges parents of autistic children face with their children and ways of dealing with these challenges. The fourth section describes the future of autistic children, as how long can they live, if siblings should get information about their autistic brother/sister case, and if there is any medication that an autistic child can take.

In the last section, it's about the child growth not just physically but also mentally. This section explains how the child's physician should track the child's growth, since the first evaluation should be done in the pediatrician clinic before going to a diagnostic center. Also, in this section there are symptoms that can be tracked in the child's development from 2 months old till 4 years old. These symptoms should be tracked by the physician. If not by the physician then parents should be aware of these symptoms and communicate their concern to their physician.

4.3.2. The third booklet was published in April 2016, titled (Child “with Autism”... is also my Friend...):

This booklet was also written by the psychiatrist Abass Alam Aldein, the director of the North Autism Center (NAC) Sabine Saad and the psychologist Nayla Al Hussein. Also, this booklet is done to continue the campaign “ways of supporting families of children with Autism”, that the ministry of social affairs with the collaboration of NAC started in 2014. In the introductory unit the Ministry of Social

affairs explains, that this booklet is considered to reach all generations in an attractive, scientific, and educational way. This booklet give parents with autistic kids the opportunity to learn know more about autism, helps them create a loving environment at home for an autistic child, and makes it easier for parents to deal with their child using easy strategies.

This booklet explains and covers the following topics:

- When can a child with autism be diagnosed.
- How autism affects a child's life.
- If all children with autism has the same features, and if autism is contagious.
- The difficulties a child with autism face in communication and socially.
- Behavior of autistic child.
- If an autistic child can learn.
- Who are the specialists that a child with autism should visit.

4.3.3. Article: Prevalence of Autism Spectrum Disorder in Nurseries in Lebanon: A Cross Sectional Study.

As written in this article, in 2010, The Center for Disease Control and Prevention (CDC) estimated the prevalence of autism to be 1 in 68 children, approximately two times higher than the estimate of 2000. These estimates come from data collected from health and special education records of 8 year-old children in 11 areas in the United States in 2010 through the Autism and Developmental Disabilities Monitoring (ADDM) network (CDC 2014a).

The authors in this study explain that despite the big number of research done on autism world-wide, there is a shortage of studies on autism in the Eastern Mediterranean

Region. Even so the small scale studies that are conducted report a high number of prevalence of autism. In the United Arab Emirates, autism is estimated to be 29 per 10,000 compared to 4.3 per 10,000 in Bahrain. While in Oman there is a lower prevalence of 1.4 per 10,000 in children less than 14 years old. On the other hand, in the Kingdom of Saudi Arabia the prevalence of Autism is very high, which is 1250 per 10,000 in children younger than 18 years old. “In Lebanon and neighboring Arab countries (Syria, Jordan and Palestine), there are no estimates on the prevalence of autism” (Chaaya et al., 2016, p.515). Also, the authors add that according to the studies done at the American University of Beirut Medical Center (AUBMC) Special Kids Clinic show that number of pediatric patients with autism is increasing. “The lack of data coupled with the increasing number in clinics underscores the necessity of studying the prevalence of ASD in Lebanon” (Chaaya et al., 2016, p.515).

In this study the objective of the authors was to evaluate the prevalence of autism in toddlers aged between 18 and 30 months, from both genders and all ethnic groups going to nurseries in Lebanon, specifically Beirut and Mount Lebanon.

The study was conducted in 177 registered and unregistered nurseries in Beirut and Mount Lebanon. Participants were parents of 1216 children between 9 and 74 months. Two instruments were used for data collection: A screening instrument called M-CHAT (modified screening tool for Autism Spectrum Disorder), and a short questionnaire developed by the authors.

Results have shown, that “out of 998 toddlers, 263 failed 3 or more items of the 23 items of the M-CHATE, and hence were labeled as possibly having ASD” (Chaaya et al., 2016, p.518). The authors add, that out of the 15 children diagnosed by a

physician as having ASD, 10 were captured by the M-CHAT. The number of toddlers diagnosed with Autism is higher than Arab nations such as the United Arab Emirates, Bahrain and Sultanate Oman. Moreover, the prevalence of autism in Lebanese toddlers is higher than Israel Arabs which is 12 per 10,000. “The prevalence of 153 per 10,000 in this study is almost seven times higher than the average prevalence of 20.6 per 10,000 reported in a 2009 review by Fombonne” (Chaaya et al., 2016, p.518). The authors add that in their study they chose to study toddlers from 16- 48 months old attending nurseries while most studies include school children with a mean age of 8 years old.

As written in this research, the main strength of this study is that it is the first prevalence study to be conducted in Lebanon. The authors include that there are no national surveillance system or national registries that can help them get information about the prevalence of autism. Since this study is based on only on two governorates, the magnitude should be of concern and a follow up by researchers and policy makers on this issue is necessary. The authors add that since there has been an increase in the prevalence of autism globally and regionally, increasing awareness of parents should increase and more efforts should be given for systematic assessment and early screening programs at the primary care levels done by pediatricians or family doctors is called for.

Moreover, the interviewers are asking in their research to increase awareness in parents and physicians for early diagnosis and implications for early interventions. The increase of awareness will result in a better outcome for children with autism and reduces stress for parents.

After a long search for documents or studies conducted on autism in Lebanon, only one article was found about autism in Lebanon done by AUBMC last year. The ministry of social affairs had only awareness booklets prepared every year in April since 2014. Autism is increasing in a high rate, and after interviewing special educators they all agreed on the same point that parents are not aware of the signs of autism, and children are diagnosed at school age where they can't benefit from early intervention anymore. More research about autism should take place in Lebanon, and all year long awareness campaigns should be planned in order for Lebanese parents to be aware of the signs and symptoms of autism.

Three booklets and one research study were analyzed in order to evaluate the prevalence of autism, and awareness about autism and early intervention. After analyzing the content, the results revealed that Lebanon needs more awareness and research about autism and early intervention.

4.4. Conclusion

In conclusion, and based on this research, the surveys showed that most parents (32%) didn't go through the denial phase, they accepted the situation and started seeking help. On the other hand, the interviewers explained that parents' knowledge depends on their background and knowledge and most parents go through denial. Also, the survey and the interviewers pointed out that Lebanese parents do not have background knowledge about early intervention programs they knew about the program from the center of diagnosis. Parents' challenges are the child's behavior at home and social events, and therapies cost. Moreover, the interviewers explained that the challenges parents' face are also the financial cost for the intervention program, their

family and friends view about their child, the child's behavior, and lack of awareness campaigns in Lebanon.

In the next chapter, the discussions of the results are presented followed by the limitations, recommendations and suggestions for future research.

CHAPTER FIVE

Discussion

The purpose of this study was to examine Lebanese parents of autistic children's attitude when their child is diagnosed with autism. This study explored Lebanese parents of autistic children's knowledge about early intervention. Moreover, this study discovered what challenges and difficulties parents of autistic children go through and what do they recommend for the future. This study is a qualitative study using statistics, where a survey was used to collect quantitative data, interviews with special educators were used to collect qualitative data, and content analysis of documents and research were done about autism in Lebanon. This chapter discusses the results obtained from parents' surveys, special educators' interviews and content analysis, and links them to previous research and findings in the literature.

The results of this study are compatible with previous research (Hallahan et al., 2009, p. 120) who found that many parents report that they don't engage in denial. In fact, they're often the first to suspect the problem. Similar results were obtained in this study. Results showed that most parents (32%) somehow accepted the truth about their children and started seeking help from professionals. They started to adjust their life and time according to their child's need. On the other hand, a limited number of parents (11%) lived in denial, were shocked (21%) or got angry and started blaming others. This partially concurs with the literature as Landa (2007) for instance adds that "at present, however, caregivers are usually the first to note disrupted development in children later diagnosed with autism. Parents usually express concern to their pediatrician around 18 months of age, often because their child is a late talker" (p.19).

Data from the interviews show that most parents first go through denial, with hope that their child has speech and communication problems but not autism. This result is compatible with previous research (Hijazi, 2014) who stated that “According to some local Arab American parents with children who have been diagnosed with autism, getting a parent to admit that a child suffers with the disorder is a major problem in this community and could result in setbacks for those children.” Also, the interviewers added that minority of parents’ come to the diagnosis knowing their child has autism and they are ready to face the challenge.

Moreover, parents’ feedback on their knowledge about early intervention showed that most parents (55%) knew about the early intervention program from the place they diagnosed their child in, and the least number of parents’ (10%) had already background knowledge about autism and that their child’s pediatrician did not inform them that there is an early intervention service. Heidgerken et al. (2005) reported that delays in diagnosis may lead to harmful effects and thus recommend early intervention. The results of this study concur with the research conducted by Chaaya et al. (2016) who found that the prevalence of autism should be of concern for researchers and policy makers in order to raise more awareness about features of autism, detection of autism and early intervention programs. Also, as my study shows most parents (55%) did not find their child’s physician knowledgeable about autism, and parents’ main source of information about their child’s case is the center of diagnosis. Heidgerken et al. (2005, p. 325) add in their study that the American Academy of Pediatrics (2001) concern is that “primary health care professionals were less likely to endorse the need for special education services. Health professionals that demonstrate inaccurate perceptions as

noted above regarding the treatment and prognosis of autism, are less likely to be aware of and advocate for these much needed services in the areas of behavior, education, and development, The diagnosis of autism is increasing in Lebanon, and according to Chaaya et al., (2016), awareness should be increased for early diagnosis and the implications of early intervention in Autism. When parents were asked if the child's physician is knowledgeable about autism, 55% answered that their pediatrician is not knowledgeable about autism since they felt their physician did not figure out their child's case, and their pediatrician never gave them advice when the child was diagnosed with autism. These results are compatible with a study conducted by Heidgerken et al. (2005, p. 330) who state that primary health care providers of autistic children should be able to recognize the signs of autisms in children and refer them to specialists in the field as early as possible and in a timely manner. Moreover, the special educators added that in Lebanon, physicians are not knowledgeable about the features of autism, that's why autistic children are diagnosed at a school age when it's too late for early intervention. These finding were well-matched with Eapen, Mabrouk, Zoubeydi, and Yunis (2007) in Obeid et al., (2015, p. 3521) reported that "none of the preschoolers that they identified as having autism had been identified as autistic prior to their study," in the United Arab Emirates. Previous research also determine that "many cases of ASD may go unidentified in Arab countries due to insufficient understanding of ASD among the public and a lack of trained professionals" (Al-Farsi et al. 2011; Imran et al. 2011; Taha and Hussein 2014) as cited in (Obeid et al., 2015, p.3521) "As the professional best situated to identify infants with developmental delays or disabilities, the primary care pediatrician is urged by increasing numbers of early

childhood advocacy groups to refer such children to early intervention programs” (Shonkoff & Hauser-Cram, 1987, p.650).

As for the challenges and difficulties that the parents’ go through, according to the results more than half of the parents are facing challenges with their autistic child as behavioral problems, communication problems, lack of social skills, and the expenses and time they need for their autistic child. This result matched with the research of Quine and Paul (1985) and Heiman (2002, p.160). The latter reported that “parents of children with disabilities experience greater stress and a larger number of caregiving challenges, such as more health problems, greater feelings of restriction, and higher levels of parental depression than parents of nondisabled children.” Moreover, the results are compatible with previous literature that shows that “of all the disabilities, autism is one of the biggest challenges for parents. Autism is a complex developmental disorder with a neurobiological character, characterized by problems of communication and relating to others as well as interests, activities and behaviors that are restricted, repetitive and stereotypical” (Grasu, 2015, p. 87). Also, Azar and Bader (2006) claim in their literature that “the stress is often generated by the direct effects of the illness and its treatment as well as the social stigma that it produces” (p. 357).

According to the results from the survey and the interviews done by special educators, the main challenge that parents of autistic children face is the high cost of therapies in Lebanon. The results of this study are compatible with the study of Obeid et al. (2015, p.3521) who add that “Mothers also reported stress due to financial burdens, perceived stigmatization associated with ASD, and their own lack of knowledge about the etiology and treatment of ASD.” The obtained results are also

consistent with the study conducted by Azar and Badr (2006) that attributed the high levels of stress and depression observed among mothers of children with intellectual disabilities in Lebanon to stigma associated with disability and to financial burdens associated with caring for their children.

In conclusion, the findings of this study were partially compatible with previous literature. Although the sample of this study is small and in no means can be generalized, the overall results show that most parents (42%) are the first to suspect that their child has a problem that's why they do not go through the denial phase. Also, Lebanese parents need more awareness campaigns about autism and early intervention services in all socioeconomic levels. Moreover, there should be more social and economic support for parents of children with autistic children in order to decrease the challenges and stress the parents face. However, further research should be conducted for more accurate and generalized results.

CHAPTER SIX

Conclusion

Based on this study, it may be concluded that parents' attitude toward their child's disability is taking a curve to be more positive if Lebanese parents get the awareness campaigns and knowledge before having a child, so that they identify symptoms or any concerning signs when they occur. More awareness campaigns in Lebanon as in media, schools and universities will help Lebanese parents in not going through a denial phase and to start coping with their situation earlier, seek help, and enroll their child in an early intervention program as soon as possible.

6.1. Limitations of the Study

The first limitation of this study was the small sample size of 19 participating parents, and three special educators. Therefore, the study is a humble attempt to research early interventions regarding autism in Lebanon. It does not in any way attempt to generalize its results.

The second limitation is that there is only one research done in Lebanon about Autism, which limited my review of literature and discussion chapter.

The third limitation is that I couldn't be present when parents were filling the surveys. I am not aware if the parents had any concerns while filling the questionnaires.

The fourth limitation is that I had access to a limited number of centers which resulted in small sample.

6.2. Recommendations for Future Research

Based on the results of the study, the following recommendations for future research are presented:

- 1- Further studies on the prevalence of autism in Lebanon in all Lebanese governorates should be carried out in order to generalize the results to the Lebanese population.
- 2- Further studies on parents' awareness about autism and early intervention programs that cover all the Lebanese governorates.
- 3- Further research on family doctors and pediatricians role in identifying their patients with autism and referring them to diagnosis as early as possible.
- 4- Further studies must examine the effectiveness of early intervention programs in Lebanon.

6.3. Recommendations for Future Practices

Based on the results of the study, the following recommendations for future practices are presented:

- 1- It is important to have more awareness campaigns in all Lebanese governorates, all year through media, private and public schools, and private and public universities where everyone can be reached in order to educate all Lebanese citizens about the symptoms, challenges and treatment.
- 2- Autism children should be financial funded by private and public sectors, since the treatment and interventions of an autistic child is expensive and need a lot of money.

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Appendix A



Chartered in the State of New York

Department of Education

Survey for Parents of Children with Autism Ages 2 to 4

The information provided will be used for research purposes. Your names will not be shared and only the researchers will have access to it.

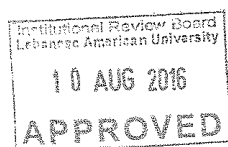
Date of Birth: ____/____/____

Directions: Please circle the letter that best answers the question

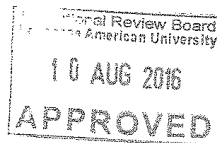
1. Your gender
 - a. Male
 - b. Female

2. From which part of Lebanon are you from?
 - a. Beirut
 - b. North Lebanon
 - c. South Lebanon
 - d. Southern Mount Lebanon
 - e. Northern Mount Lebanon
 - f. Bqaa
 - g. Kesrwen
 - h. Jbeil

Page 1



3. Did you attend school in Lebanon
- Yes
 - No
4. What is the highest level of education you have completed?
- High school diploma or equivalent
 - Bachelor degree
 - Graduate degree
 - PHD
5. Your age is between
- 18 – 23
 - 24 - 29
 - 30 – 39
 - 40 – 49
 - 50-59
 - Over 60 years



6. Your relationship to the child

- a. Parent mother / father / step mother / step father
- b. Grandparent
- c. Relative
- d. Guardian

7. Number of children in your home:

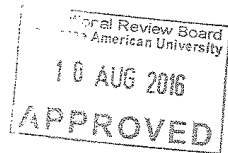
_____ Children

8. Number of children with autism:

_____ children with autism

9. Number of children with other developmental disabilities

_____ children with other disabilities



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10. What did you feel when you were told your child may have AUTISM?

- a. You were Shocked
- b. You lived in denial that this is not true
- c. You were angry and started blaming others
- d. You felt ashamed and started hiding the truth from your relatives and people who are close to your family
- e. You accepted the truth and started seeking help from professionals
- f. You directly adjusted your life and time according to your child's needs

11. Who pinpointed to you that your child may have autism?

- a. Yourself
- b. Pediatrician
- c. Relative
- d. Friend

12. Do you find your child physician knowledgeable about your child's disability?

- a. Yes
- b. No

Please verify your answer:



13. Who were your main source of information about your child's case?

- a. Pediatrician
- b. Center of diagnosis
- c. Special educators

14. At what age you were told your child has AUTISM?

- a. 1 year
- b. 2 years
- c. 3 years
- d. 4 years
- e. 5 years

15. How old is your child that has AUTISM

- a. 1
- b. 2
- c. 3
- d. 4
- e. 5



16. How did you know about the early intervention program?

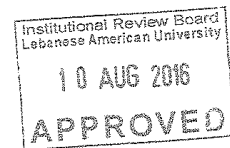
- a. Relatives
- b. Friends
- c. Pediatrician
- d. From the place I diagnosed my child in
- e. Myself (Please specify From where did you know
_____)

17. Did you directly accept to enroll your child in an early intervention program?

- a. Yes
- b. No (please specify why not)

18. What program(s) does the center your child goes to use for early intervention for your child?

- a. Applied Behavioral Analysis (ABA)
- b. Occupational Therapy (OT)
- c. Speech Therapy
- d. Sensory Integration Therapy (SI)



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e. Physical Therapy

f. Not sure

g. Other program not listed Please describe below:

19. How many hours a week does your child attend the early intervention program

a. 0-5

b. 6-10

c. 11-15

d. 16-20

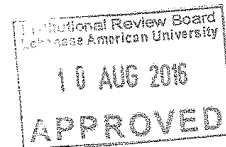
e. 21-25

f. 26 or more

20. Are you facing challenges with your autistic child?

a. Yes

b. No



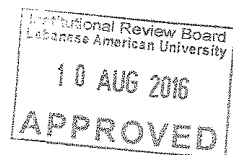
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If yes, please specify what are the challenges you already faced and facing.

Appendix B

Interview Questions

- 1) What are parents' emotional state/attitude when they know that their child has features of Autism or diagnosed with Autism?
- 2) Do some parents come to you convinced that their child has a disability or they all come with a denial state? Please explain.
- 3) Do parents living in Lebanon have background knowledge about developmental disabilities or Autism? Explain.
- 4) Do parents of children with developmental disabilities or Autism have background knowledge about the Early Intervention Program? Explain.
- 5) Who refers parents' of children with disabilities to your center for diagnosis?
- 6) Do you have an idea about the challenges parents face with their autistic child?
- 7) What plans do you recommend for the future, in order to raise more awareness in Lebanon about early intervention programs and Autism?



Appendix C



Chartered in the State of New York

APPENDIX B

إستبيان لأهالي الأطفال الذين يعانون من التوحد والذين تتراوح أعمارهم بين سنتين وأربعة سنوات.

ملاحظة: لن يتم ذكر أسمائكم و أسماء اولادكم في الأطروحة.

تاريخ الميلاد: ____ / ____ / ____ (اليوم/الشهر/السنة)

من فضلك ضع دائرة حول الإجابة المناسبة

1. الجنس:

أ. ذكر

ب. أنثى

2. حدّد مكان السكن؟

أ. بيروت

ب. شمال لبنان

ج. جنوب لبنان

د. جبل لبنان الجنوبي

هـ. جبل لبنان الشمالي

و. البقاع

ز. جبيل

3. هل درست في لبنان؟

أ. نعم

ب. لا



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4. ما هي درجة التحصيل العلمي؟

أ. الشهادة الثانوية أو ما يعادلها

ب. البكالوريوس

ج. ماجستير

د. الدكتوراه

5. العمر:

أ. 18-23

ب. 24-29

ج. 30-39

د. 40-49

هـ. 50-59

و. فوق 60

6. صلة القرابة مع الطفل:

أ. الأم / الأب

ب. زوجة الأب / زوج الأم

ج. جد / جدة

د. قريب

هـ. وصي

7. عدد الأطفال في منزلك:

أطفال _____



8. عدد الأطفال الذين يعانون من التوحد:

يعانون من التوحد _____

9. عدد الأطفال الذين يعانون من إعاقات نمائية أخرى:

يعانون من إعاقات أخرى _____

10. ما كان شعورك عندما قيل لك ان طفلك قد يكون مصابا بمرض التوحد؟

أ. صدمت

ب. عشت حالة نكران للواقع

ج. شعرت بالغضب وبدأت بإلقاء اللوم على الآخرين

د. شعرت بالخجل و تعمدت إخفاء الحقيقة عن الأقرباء و الأشخاص المقربين من عائلتك

هـ. تقبلت الحقيقة و بدأت البحث عن المساعدة من مختصين

و. قمت بتعديل حياتك و وقتك وفقاً لإحتياجات طفلك

11. من أشار إليك بأن طفلك قد يعاني من مرض التوحد؟

أ. أنت

ب. طبيب الأطفال

ج. قريب

د. صديق

12. هل ترى أن طبيب طفلك لديه معلومات كافية عن حالة طفلك؟

أ. نعم

ب. لا



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13. من كان المصدر الأساسي للمعلومات عن حالة طفلك؟

أ. طبيب الأطفال

ب. مركز التشخيص

ج. أستاذ الإحتياجات الخاصة

14. كم كان عمر طفلك عندما علمت بأنه قد يعاني من مرض التوحد؟

أ. سنة

ب. سنتان

ج. ثلاث سنوات

د. أربعة سنوات

هـ. خمس سنوات

15. كم يبلغ طفلك من العمر الآن؟

أ. سنة

ب. سنتان

ج. ثلاث سنوات

د. أربعة سنوات

هـ. خمس سنوات



16. كيف علمت عن برنامج التدخل المبكر؟

- أ. أقارب
- ب. أصدقاء
- ج. طبيب الأطفال
- د. من المركز الذي شخّص طفلك
- هـ. نفسي (يرجى تحديد من أين لك المعرفة)

17. هل وافقت تسجيل طفلك على الفور في برنامج التدخل المبكر؟

- أ. نعم
- ب. كلا (يرجى ذكر السبب)

18. ما هو البرنامج المتبع في مركز التدخل المبكر الذي يذهب إليه طفلك؟

- أ. تحليل السلوك التطبيقي (ABA)
- ب. العلاج الانشغالي
- ج. علاج النطق
- د. علاج التكامل الحسي
- هـ. علاج الفيزيائي
- و. غير متأكد ما هو العلاج
- ز. برامج أخرى غير مذكورة. نرجو تحديدها:



19. كم ساعة يمضي طفلك أسبوعيا في برنامج التدخل المبكر؟

- أ. 0-5
- ب. 6-10
- ج. 11-15
- د. 16-20
- هـ. 21-25
- و. 26 و أكثر

20. هل من صعوبات تواجهها مع طفلك المصاب بالتوحد؟

أ. نعم

ب. كلا

إذا كانت الإجابة نعم، حدد التحديات التي واجهتها وواجهها؟



Appendix D

Interviewers Consent Form

Caretakers of ASD Children: Challenges and Recommendations

Dear special educators,

I am a student at the Lebanese American University. I would appreciate it if I can interview you as part of my research that aims to determine what parents' attitude were when their child was diagnosed with autism, how they knew about early intervention, what challenges are they facing and their recommendations.

The information you provide will be used to enhance and improve awareness about Autism in Lebanon. Completing the interview will take 10 minutes of your time.

By continuing with the survey, you agree with the following statements:

1. I have been given sufficient information about this research project.
2. I understand that my answers will not be released to anyone and my identity will remain anonymous. My name will not be written on the interview nor be kept in any other records.
3. I understand that all responses I provide for this study will remain confidential. When the results of the study are reported, I will not be identified by name or any other information that could be used to infer my identity. Only researchers will have access to view any data collected during this research however data cannot be linked to me.
4. I understand that I may withdraw from this research any time I wish and that I have the right to skip any question I don't want to answer.
5. I understand that my refusal to participate will not result in any penalty or loss of benefits to which I otherwise am entitled to.
6. I have been informed that the research abides by all commonly acknowledged ethical codes and that the research project has been reviewed and approved by the Institutional Review Board at the Lebanese American University
7. I understand that if I have any additional questions, I can ask the research team listed below.
8. I have read and understood all statements on this form.
9. I voluntarily agree to take part in this research project by completing the following survey.

I _____ have read and understood the above information.

Signature

Date

If you have any questions, you may contact:

Name (PI)	Phone number	Email address
Mira Al Shurafa	70 960 955	mira.alshurafa@lau.edu

If you have any questions about your rights as a participant in this study, or you want to talk to someone outside the research, please contact the:

IRB Office,
Lebanese American University
3rd Floor, Dorm A, Byblos Campus
Tel: 00 961 1 786456 ext. (2546)



Appendix E

نموذج موافقة للمشاركة في استبيان استطلاع

Caretakers of ASD Children: Challenges and Recommendations

أنا طالبة في الجامعة اللبنانية الأميركية وسأكون ممتنا إذا كنت تستطيع إجراء مقابلة كجزء من بحث يهدف الى تحديد ما هو موقف الأهل عندما تم تشخيص أطفالهم المصابين بالتوحد ، كيف تم تعريفهم عن برنامج التدخل المبكر ، وما هي الصعوبات التي يواجهونها وما هي توصياتهم .

سيتم استخدام المعلومات التي تقدمها لتعزيز وتحسين الوعي حول مرض التوحد في لبنان .
اكمل الاستبيان. سوف يتطلب 5 دقائق من وقتك.

من خلال الاستمرار في الاستطلاع أو الاستبيان ، فإنك توافق مع العبارات التالية :

1. لقد أعطيت ما يكفي من المعلومات حول هذا المشروع البحثي .
2. لن يتم التصريح أو الإفراج عن اجاباتي الى اي شخص ، وسوف تبقى هويتي مجهولة. لن يكتب اسمي على الاستبيان ولن يحفظ في أي سجلات أخرى.
3. جميع اجاباتي التي اقدمها لهذه الدراسة سوف تظل سرية . عندما يتم تقديم نتائج الدراسة ، لن يتم التعرف الي بالاسم أو أي معلومات أخرى يمكن أن تستخدم للاستدلال الى هويتي. الباحثون فقط لديهم الحق في الاستطلاع على البيانات التي تم جمعها خلال هذا البحث لكن البيانات لا يمكن أن تكون مرتبطة بي.
4. ادرك ان مشاركتي طوعية وبإمكاني الانسحاب من هذا البحث في أي وقت اشاء أو تخطي أي سؤال لا اشعر بالرد عليه.
5. انا ادرك بان رفضي للمشاركة لا ينتج عنه أي جزاء أو فقدان أي من الحقوق التي أنا مؤهل لها.
6. لقد تم ابلاغي ان البحث يلتزم بجميع القوانين الأخلاقية المعترف بها. وبان هذه الدراسة تمت مراجعتها والموافقة عليها من قبل مكتب اللجنة الأخلاقية في الجامعة اللبنانية الأميركية.
7. أنا أفهم أنه إذا كان لدي أي أسئلة إضافية يمكنني ان اطلب من فريق البحث المدرجة اسمائهم في القائمة ادناه.
8. لقد قرأت وفهمت كل البيانات الواردة في هذا النموذج
9. أنا أوافق طوعا للمشاركة في هذا المشروع البحثي من خلال استكمال الاستبيان التالي.

انا _____ لقد اطلعت على استمارة الموافقة وأدركت مضمونها .

التاريخ

الأمضاء

إذا كان لديك أي أسئلة يمكنك الاتصال :

الإسم	رقم الهاتف	البريد الإلكتروني
ميرا الشرفا	70960955	mira.alshurafa@lau.edu

إذا كان لديك أي أسئلة حول حقوقك كمشارك في هذه الدراسة ، أو كنت تريد التحدث إلى شخص خارج البحث ، يرجى الاتصال :

IRB Office, Lebanese American University 3 rd Floor, Dorm A, Byblos Campus Tel: 00 961 1 786456 ext. (2546)	الجامعة لجنة مكتب الأخلاقية، اللبنانية الأميركية Tel: 00 961 1 786456 ext. (2546)
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Appendix F

Parental Consent Form

Caretakers of ASD Children: Challenges and Recommendations

Dear parents,

I am a student at the Lebanese American University. I would appreciate it if you can complete the following survey as part of my research that aims to determine what parents' attitude were when their child was diagnosed with autism, how they knew about early intervention, what challenges are they facing and their recommendations.

The information you provide will be used to enhance and improve awareness about Autism in Lebanon. Completing the survey will take 5 minutes of your time.

By continuing with the survey, you agree with the following statements:

1. I have been given sufficient information about this research project.
2. I understand that my answers will not be released to anyone and my identity will remain anonymous. My name will not be written on the questionnaire nor be kept in any other records.
3. I understand that all responses I provide for this study will remain confidential. When the results of the study are reported, I will not be identified by name or any other information that could be used to infer my identity. Only researchers will have access to view any data collected during this research however data cannot be linked to me.
4. I understand that I may withdraw from this research any time I wish and that I have the right to skip any question I don't want to answer.
5. I understand that my refusal to participate will not result in any penalty or loss of benefits to which I otherwise am entitled to.
6. I have been informed that the research abides by all commonly acknowledged ethical codes and that the research project has been reviewed and approved by the Institutional Review Board at the Lebanese American University
7. I understand that if I have any additional questions, I can ask the research team listed below.
8. I have read and understood all statements on this form.
9. I voluntarily agree to take part in this research project by completing the following survey.

I _____ have read and understood the above information.

Signature

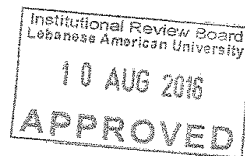
Date

If you have any questions, you may contact:

Name (PI)	Phone number	Email address
Mira Al Shurafa	70 960 955	mira.alshurafa@lau.edu

If you have any questions about your rights as a participant in this study, or you want to talk to someone outside the research, please contact the:

IRB Office,
Lebanese American University
3rd Floor, Dorm A, Byblos Campus
Tel: 00 961 1 786456 ext. (2546)



Appendix G

نموذج موافقة للمشاركة في استبيان استطلاع

Caretakers of ASD Children: Challenges and Recommendations

أود أن أدعوك للمشاركة في مشروع بحثي. يطلب منك ملء استبيان قصير. أنا طالبة في الجامعة اللبنانية الأميركية وسأكون ممثتا إذا كنت تستطيع إكمال الدراسة كجزء من بحث يهدف الى تحديد ما هو موقف الأهل عندما تم تشخيص أطفالهم المصابين بالتوحد ، كيف تم تعريفهم عن برنامج التدخل المبكر ، وما هي الصعوبات التي يواجهونها وما هي توصياتهم .

سيتم استخدام المعلومات التي تقدمها لتعزيز وتحسين الوعي حول مرض التوحد في لبنان .
اكمل الاستبيان. سوف يتطلب 5 دقائق من وقتك.

من خلال الاستمرار في الاستطلاع أو الاستبيان ، فإنك توافق مع العبارات التالية :

1. لقد أعطيت ما يكفي من المعلومات حول هذا المشروع البحثي .
2. لن يتم التصريح أو الإفراج عن اجاباتي الى اي شخص ، وسوف تبقى هويتي مجهولة. لن يكتب اسمي على الاستبيان ولن يحفظ في أي سجلات أخرى.
3. جميع اجاباتي التي اقدمها لهذه الدراسة سوف تظل سرية . عندما يتم تقديم نتائج الدراسة ، لن يتم التعرف الي بالاسم أو أي معلومات أخرى يمكن أن تستخدم للاستدلال الى هويتي. الباحثون فقط لديهم الحق في الاستطلاع على البيانات التي تم جمعها خلال هذا البحث لكن البيانات لا يمكن أن تكون مرتبطة بي.
4. ادرك ان مشاركتي طوعية وبإمكاني الإنسحاب من هذا البحث في أي وقت اشاء أو تخطي أي سؤال لا اشعر بالرد عليه.
5. انا ادرك بان رفضي للمشاركة لا ينتج عنه أي جزاء أو فقدان أي من الحقوق التي أنا مؤهل لها.
6. لقد تم ابلاغي ان البحث يلتزم بجميع القوانين الأخلاقية المعترف بها، وبان هذه الدراسة تمت مراجعتها والموافقة عليها من قبل مكتب اللجنة الأخلاقية في الجامعة اللبنانية الأميركية.
7. أنا أفهم أنه إذا كان لدي أي أسئلة إضافية يمكنني ان اطلب من فريق البحث المدرجة اسمائهم في القائمة ادناه.
8. لقد قرأت وفهمت كل البيانات الواردة في هذا النموذج
9. أنا أوافق طوعا للمشاركة في هذا المشروع البحثي من خلال استكمال الاستبيان التالي.

انا _____ لقد اطلعت على استمارة الموافقة وأدركت مضمونها .

التاريخ

الأمضاء

إذا كان لديك أي أسئلة يمكنك الاتصال :

الإسم	رقم الهاتف	البريد الإلكتروني
ميرا الشرفا	70960955	mira.alshurafa@lau.edu

إذا كان لديك أي أسئلة حول حقوقك كمشارك في هذه الدراسة ، أو كنت تريد التحدث إلى شخص خارج البحث ، يرجى الاتصال :

IRB Office, Lebanese American University 3 rd Floor, Dorm A, Byblos Campus Tel: 00 961 1 786456 ext. (2546)	لجنة مكتب الأخلاقية، البنانية الأميركية الجامعة : Tel: 00 961 1 786456 ext. (2546)
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National Review Board
Lebanese American University

10 AUG 2016

APPROVED

Page 2 of 2

Appendix H



Institutional Review Board (IRB)

لجنة الأبحاث

NOTICE OF IRB APPROVAL – EXEMPT STATUS

To: Ms. Mira Al Shurafa
Advisor: Dr. Rima Bahous
School of Arts & Sciences

APPROVAL ISSUED: 10 August 2016
EXPIRATION DATE: NA
REVIEW TYPE: EXEMPT

Date: August 10, 2015

RE: **IRB #:** LAU.SAS.RB8.10/Aug/2016

Protocol Title: Caretakers of ASD Children: Challenges and Recommendations

Your application for the above referenced research project has been approved by the Lebanese American University, Institutional Review Board (LAU IRB). This research project qualifies as exempt under the following category:

B. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:

(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and

(ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

This approval is limited to the activities described in the Protocol Exempt Application and all submitted documents listed on page 2 of this letter. **Enclosed with this letter are the stamped approved documents that must be used.**

APPROVAL CONDITIONS FOR ALL LAU APPROVED HUMAN RESEARCH PROTOCOLS - EXEMPT

LAU RESEARCH POLICIES: All individuals engaged in the research project must adhere to the approved protocol and all applicable LAU IRB Research Policies. PARTICIPANTS must NOT be involved in any research related activity prior to IRB approval date or after the expiration date.

EXEMPT CATEGORIES: Activities that are exempt from IRB review are not exempt from IRB ethical review and the necessity for ethical conduct.

MODIFICATIONS AND AMENDMENTS: Certain changes may change the review criteria and disqualify the research from exemption status; therefore, any proposed changes to the previously approved exempt study must be reviewed and approved by the IRB before implementation.

NOTIFICATION OF PROJECT COMPLETION: A notification of research project closure and a summary of findings must be sent to the IRB office upon completion. Study files must be retained for a period of 3 years from the date of notification of project completion.

IN THE EVENT OF NON-COMPLIANCE WITH ABOVE CONDITIONS, THE PRINCIPAL INVESTIGATOR SHOULD MEET WITH THE IRB ADMINISTRATORS IN ORDER TO RESOLVE SUCH CONDITIONS. IRB APPROVAL CANNOT BE GRANTED UNTIL NON-COMPLIANT ISSUES HAVE BEEN RESOLVED.

BEIRUT CAMPUS		BYBIOS CAMPUS		NEW YORK OFFICE	
P.O. Box: 13-5053 Chouran Beirut 1102 2801 Lebanon	Tel: +961 1 78 64 56 +961 3 60 37 03 Fax: +961 1 86 70 98	P.O. Box: 36 Byblos Lebanon	Tel: +961 9 54 72 62 +961 3 79 13 14 Fax: +961 9 54 62 62	475 Riverside Drive Suite 1846 New York, NY 10115	Tel: +1 212 870 2592 +1 212 870 2761 Fax: +1 212 870 2762 www.lau.edu.lb

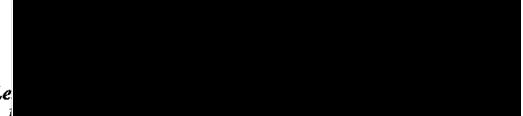


If you have any questions concerning this information, please contact the IRB office by email at christine.chalhoub@lau.edu.lb

The IRB operates in compliance with international guidelines of Good Clinical Practice, the US Federal Regulations (45CFR46) and (21CFR56) of the Food and Drug Administration. LAU IRB Identifier: FWA00014723 and IRB Registration # IRB00006954 LAUIRB#1



Dr. Costantine Daher



Le

IRB Registration # IRB00006954 LAUIRB#1

DOCUMENTS SUBMITTED:

IRB Exempt Protocol Application	Received 5 August 2016
Cover Letter	Received 5 August 2016
Interview Questions	Received 5 August 2016
Letter To Centers	Received 5 August 2016
Interviewers Consent Form English & Arabic	Received 5 August 2016, Modified 9 Aug 2016
Parental Consent Form English & Arabic	Received 5 August 2016
Questionnaire – English	Received 5 August 2016
Questionnaire – Arabic	Received 5 August 2016
NIH Training – Rima Bahous	Cert. # 2058296 (Date 18 April 2016)
NIH Training – Mira Al Shurafa	Cert. # 1557727 (Date 23 April 2016)