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The Role That Autism Parent-Led Support Groups Play In Facilitating Advocacy

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Abstract

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Dissertation Submitted in Partial Fulfillment
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Abstract

In this study, autism parent-led support groups and the contribution these groups had in creating parental advocacy were studied. The primary purpose of the study was to determine if autism parent-led support groups promoted advocacy skills of parents of children with autism. The secondary purpose of the study was to evaluate the level and extent of support provided by parent-led support groups. The qualitative data collection was done through individual interviews of parents of children with autism whose children were of any age. Through data analysis 6 major themes were identified: advocacy, emotional support, difficulty with funding, informational support, instrumental support, and appraisal support. Parents indicated that parent-led support groups assisted them in acquiring advocacy skills and provided good emotional support, informational support, and appraisal support. This research was important because parents of children with autism have greater problems with treatments than parents of children with other chronic developmental disorders, and many parents felt they needed to obtain advocacy skills in order to find the best interventions for their child. The social change implication of this study is that people can better understand the impact that parent-led support groups can have in facilitating advocacy among parents who participate in the groups. This study also brings to light the support these groups provide, and how this support impacts their lives.

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Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Introduction

Autism is a social disorder that is caused by neurological and psychiatric problems that begin to show up in childhood through abnormal speech and social development (Palermo, Pasqualetti, Babati, Intelligente, & Rossini, 2006; Windham, Zhang, Gunier, Croen, & Grether 2006), affecting a child's ability to function socially, learn language, use imagination, communicate, and use cognitive skills (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). The therapies that are traditionally employed for children with autism are very time consuming and include an assortment of different types of therapists (Hayhurst, 2008) which can cause parents to become confused and frustrated because they believe that treatments do not work (Altiere & Von Kluge, 2009). The Committee on Children with Disabilities (2001) proclaimed that because these therapies are time consuming many parents and family members have resorted to alternative treatments that have not been proven to be effective and may actually be dangerous (Centers for Disease Control and Prevention, 2012; Health Resources Commission, 2008). The treatments will be discussed in greater detail in Chapter 2.

An advocate is a person who stands up and brings attention to a condition that needs change (Law, King, Stewart, & King, 2001). Advocacy is an empowering skill which assists parents of children with autism get a correct diagnosis, better treatment and education for a child, increased visibility, new awareness for the disease, and reduces the stigma associated with autism (Chamak, 2008; Woodgate, Ateah, & Secco, 2008). Advocates may form groups in order to be more effectively heard (Law et al., 2001).

Through social advocacy groups greater awareness about childhood disabilities can be attained, and activities such as lobbying legislative leaders and raising funds for these activities are conducted (Law et al., 2001).

Parents of children with autism reported greater problems with treatments, more difficulty coping with the disease, and that they felt more isolated than other parents who have children with chronic developmental disorders (Blanchard, Gurka, & Blackman, 2006; Schieve et al., 2007). Twoy, Connolly and Novak (2006) found that parents of children with autism spent a great deal of time per week coordinating interventions, educating themselves, speaking to professionals, and advocating for their children. It is very time consuming for parents to become proficient in parental advocacy since they must learn about the disability, federal and state laws, school district specific information, new interventions that can be implemented, and available networks such as parent-led support groups (Paikoff, Casey, & Wodlinger-Cohen, 2005). Wildman (2006) contended that parents must educate themselves in order to be able to make sound decisions about services and treatments that children will receive, understand the positive and negative impact these treatments will have on the children's development, and become advocates for their children. According to Paikoff et al. (2005), parental advocacy is an important set of skills that parents need to work towards in the struggle to get services for a disabled child.

The results of a study by Mandell and Salzer (2007) indicated that parents of children with autism used parent-led support groups because parent-led support groups provided social support and needed information to parents of children with disabilities

(Altiere & Von Kluge, 2009). Moreover, the parent-led support groups also made parents feel accepted and welcome, helped to relieve stress, and promoted the perception of power and self-efficacy within the group members (Law et al., 2001), thus providing a foundation that can lead to child advocacy (Law et al., 2001; Pickett, Heller & Cook, 1998).

In this study, I explored parental advocacy within parent-led support groups. Additionally, the constructs of the social support theory were examined against the structure and guidelines of parent-led support groups. Studies by Banuch, Iudice, Conway and Couse (2010), Law et al. (2001) and Mandell and Salzer (2007) asserted the need for more research into the influence of parent-led support groups on parental decision making. There is a gap in the literature regarding parent-led support groups and whether they can serve parents of children with autism in their quest for parental advocacy. Many studies have been conducted that describe parent-led support groups in association with different diseases (Mead & MacNeil, 2004), but few studies have been conducted that relate to parent-led support groups and advocacy in autism (Banuch et al., 2010; Law et al., 2001; Mandell & Salzer, 2007; Siklos & Kerns, 2006). As noted, it has been established in the literature that parents of children with autism reported greater issues (Blanchard et al., 2006; Clifford, 2011), and scored higher in frustration than parents of children with other developmental disorders due to a greater sense of isolation, lack of societal understanding, the difficulties that many children with autism have in communicating with others, and the necessary care of the child (Clifford, 2011; Schieve et al., 2007). A more detailed discussion of the needs of parents to become advocates for their children and the information obtained from the literature that emphasizes the importance of parent-led support groups promoting advocacy among parents of different childhood mental disorders will be presented in Chapter 2.

Autism rates have increased significantly since Kanner (1943) identified autism as a separate disorder from schizophrenia (Chamak, 2008; Neely-Barnes, Hall, Roberts, & Graff, 2011). Kanner (1943) studied 11 children, some of whom had been previously diagnosed with schizophrenia, and concluded that the children had unique symptoms of a disease called autism. For the next 40 years, autism was viewed as a rare disorder (Chamak, 2008). The prevalence of autism in 1943 was between two and four in 10,000 (Potter & Wing, 2002). In the 1990's researchers found yearly increases in the incidence of autism (Potter & Wing, 2002). The prevalence of autism has increased substantially over the past 20-30 years (Centers for Disease Control and Prevention, 2012; Kabot, Masi & Segal, 2003). Individuals in California born in 2003 had a 16.6 % greater chance of being diagnosed with autism than individuals born in 1992 (Keyes, Susser, Cheslack-Postave, Fountain, Liu, & Bearman, 2011). Yearly increases may be due to an increase in the diagnosis of high-functioning individuals with the autism spectrum disorder (Centers for Disease Control and Prevention, 2014; Chamak, 2008; Keyes et al., 2011). In 1994, Asperger's was included under the umbrella of autism spectrum disorders (King & Bearman, 2009). The inclusion of Asperger's dramatically increased the prevalence of autism and changed the diagnostic criteria (Chamak, 2008). These changes have increased the caseload of professionals (Chamak, 2008; King & Bearman, 2009). King and Bearman (2009) estimated that 26.4% of an increase in caseloads for autism spectrum disorders can be attributed to the changes in diagnostics.

Changes in diagnostics may also be associated with the increased prevalence of autism (Chamak, 2008; Health Resources Commission, 2008; King & Bearman, 2009; Potter & Wing, 2002). According to King and Bearman (2009), one in four cases of autism would not have been diagnosed prior to 1993. Even so, King and Bearman do not dismiss the role that environmental factors and genetics play in the increase of autism. Most researchers agree that we do not know enough about the environmental triggers that bring on the symptoms associated with autism (Kabot et al., 2003). Researchers hypothesize that increase in the prevalence of autism is due to increased knowledge of parents and professionals about autism, new procedures in diagnosing autism, the inclusion of other behavior disorders under the umbrella of autism spectrum disorders, and the possibility of an actual rise in the cases of autism (Potter & Wing, 2002).

There are no medications that can treat the overall symptoms of autism (Centers for Disease Control and Prevention, 2012; Health Resources Commission, 2008). Parents in partnership with medical professionals must choose between available treatments based on specific behaviors (Centers for Disease Control and Prevention, 2012; Kabot et al., 2003; Palermo et al., 2006). Once a treatment has been selected, careful monitoring must take place because the same treatment does not work with all children (Centers for Disease Control and Prevention, 2012; Health Resources Commission, 2008; Kabot et al., 2003). Therefore, parents play an important role in determining if a treatment is effective (Centers for Disease Control and Prevention, 2012; Kabot et al., 2003).

In the 1970s, the prevalence of autism was one in 2,500 (Centers for Disease Control and Prevention, 2000) whereas in 2012 the prevalence grew as high as one in 88 (Centers for Disease Control and Prevention, 2012). According to Healthy People (2012), autism is a public health concern because of the increased number of children with autism who must be treated with speech, hearing, and communications impairments. This is important because these impairments affect a child's ability to become successful in school, with life skills, and finding work as an adult (Healthy People, 2012). Further, the inability to communicate creates isolation, and unmet health needs because people need communication to express their needs (Healthy People, 2012). Such a high increase in prevalence over the years has become a challenge for professionals to find treatments that work for the different behaviors associated with autism and the increased diagnosis of the disease (Committee on Children with Disabilities, 2001; Palermo et al., 2006; Kabot et al., 2003), so there are no treatments that work on all individuals with autism (Palermo et al., 2006). Kanner (1943) was the first researcher to describe the symptoms of autism exhibited by children that had previously been diagnosed with schizophrenia, as "the combination of extreme autism, obsessiveness, sterotypy, and echolalia" (p. 248). The 11 children that Kanner (1943) studied were considered a part of a new syndrome in which children did not pay attention to physical contact, and could not communicate with others. Since then, increased classification of milder forms of the disease under the autism spectrum disorder has made the treatment of autism based on the presence or absence of a large list of symptoms that a professional must take into account (Committee on Children with Disabilities, 2001; Kabot et al., 2003). Public health professionals and parents are overwhelmed because autism has many symptoms and some children will exhibit certain symptoms that others do not (Kabot et al., 2003). With the increase of the disease, there has been a great deal reported in the media and the Internet of new treatments that are supposed to work, making it very difficult for parents and professionals to decide which treatments will work and which will not (Kabot et al., 2003; Palermo et al., 2006).

In many cases, the responsibility of choosing a caregiver, coming to terms with the results of tests, choosing the proper treatments, and determining the barriers that prevent good treatments, are experiences that parents face (Siklos & Kerns, 2006; Wildman, 2006). The Diagnostic and Statistical Manual of Mental Disorders (DSM) or DSM-IV-TR has been the standard for the diagnosis of mental illness for many years, providing a list of criteria necessary to diagnose mental disorders such as autism (American Psychiatric Association, 2012; Centers for Disease Control and Prevention, 2000). The list of professionals that use DSM-IV-TR and the new DSM-V, released in May 2013, is extensive. Professionals include psychiatrists, medical doctors, therapists, nurses, counselors and many other multidisciplinary specialists as well as facilitators and participants of support groups (American Psychiatric Association, 2012). The therapies that are traditionally employed for children with autism are very time consuming and include an assortment different types of therapists (Association for Science in Autism Treatment, n. d.; Hayhurst, 2008). The Committee on Children with Disabilities (2001) proclaims that because these therapies are time consuming many parents and family members have resorted to nontraditional treatments.

Problem Statement

Parent-led support groups, which are organized to provide information and support, have been reported in studies to facilitate parental advocacy for parents of children with other disabilities (Banuch et al., 2010; Law et al., 2001; Pickett et al., 1998). Yet parents of children with autism continue to indicate greater issues with treatments than parents of children with other disabilities (Blanchard et al., 2006; Schieve et al., 2007). Research by Pistrang, Barker, & Humphreys (2008) indicated the need to reassess the findings of previous research about the health outcomes of mutual support groups and the need for research to be disease specific. A review of the literature found that few studies have specifically examined autism parent-led support groups (Banuch et al., 2010; Law et al., 2001; Mandell & Salzer, 2007), and no study was found that examined group dynamics in autism parent-led support groups against the main ideas of support as described in the social support theory. The problem is that it is not known whether autism parent-led support groups meet the needs of parents of children with autism in their quest towards advocacy. This study is potentially significant to organizers of parent-led support groups and to parents of children with autism, who participate in parent-led support groups. An assessment of parent-led support groups may assist support groups in tying in social support with the quest of parental advocacy which many parents of children with autism seek (Woodgate et al., 2008).

Nature of the Study

This qualitative research study was conducted using a phenomenological approach. The phenomenon studied was the lived experiences of parents that participated in autism parent-led support groups as they journeyed to become advocates for their children. Parental testimony about the role that parent-led support groups play in developing parental advocacy was the central focus of the study. In this study the perceptions and impressions related to the development of advocacy of parents who participated in autism parent-led support groups were examined.

The phenomenological inquiry can be used to examine the rich meaning behind the lived experience (Zolnierek, 2011), such as the experiences towards parental advocacy, where a parent becomes a spokesperson for a child as well as a caregiver (Paikoff et al., 2005). The experiences of individuals are discussed in this type of study, emphasizing what they have experienced and how this experience changed their lives (Zolnierek, 2011). Zolnierek (2011) identified 1,366 studies that used the phenomenological inquiry. Eighty eight of those studies examined persons with mental illness and interviews were the most common data collection process used (Zolnierek, 2011).

I interviewed individuals who participated in autism support groups and considered themselves parental advocates. Interviews were semistructured using open-ended questions (Appendices E and F) which captured the thoughts and perceptions (Gill & Liamputtong, 2011; Zolnierek, 2011) of parents being interviewed. Interviewed parents were asked about the role of autism parent-led support groups in facilitating parental advocacy. In Chapter 2, I will expand the explanation of the interview questions that will guide my exploration into the topic. According to Chamak (2008), a better understanding can be ascertained of parental struggles with autism through a qualitative inquiry. The qualitative approach was selected because of the importance for parents of children with autism to be heard and their stories recorded.

Ultimately, I solicited information about parent-led support groups and whether these groups met the needs of parents of children with autism who wanted to become advocates for their children. The literature indicates that parent-led support groups both provide information and emotional support (Altiere & Von Kluge, 2009; Law et al., 2001). Parent-led support groups provide an open forum where parents may question present treatments, and encourage parents to speak freely which can lead to self-efficacy and empowerment (Chamak, 2008; Hoagwood, Cavaleri, Olin, Burns, Slaton, Gruttadaro, & Hughes, 2010; Law et al., 2001; Mandell & Salzer, 2007; Pickett et al., 1998). Purposive sampling was used to select the participants of my study. Purposive sampling will be discussed further in Chapter 3.

According to Brady and Dolan (2007), the framework of theory and the framework of good practice must be analyzed and understood in order to apply the theory and practice together in pursuit of greater health outcomes. The possibility exists that participants of parent-led support groups can gain a better understanding of the effective dynamics involved in support groups that contribute to parental advocacy through this study. Interviews were conducted within the Oklahoma City Metropolitan Area, the state of Texas, and online. The interviewees were parents of children with autism who belonged to parent-led support groups.

Research Questions

1. What is the perception of parents who participate in autism parent-led support groups about the value of the support group as a resource for information and support?
2. How do informal (parent-led) support groups impact parental advocacy?
3. How does parental advocacy impact decision making in caring for a child with autism?
4. What tangible results do parents gain from their participation in parent-led support groups?

Purpose of the Study

The purpose of the study was to determine if autism parent-led support groups promote advocacy skills of parents of children with autism. Parent-led support groups serve as a resource to parents of children with autism (Mandell & Salzer, 2007). The benefits of this resource have not fully been studied (Banuch et al., 2010; Law et al., 2001; Mandell & Salzer, 2007). Therefore, in this study I interviewed participants in order to examine parent-led support groups and the impact that participation in these groups has on parents of children with autism. This point will be discussed more in Chapter 2.

Theoretical framework

The theoretical foundation for this research was the social support theory which originated in the 1970's; it was enhanced in the 1980's and 1990's, and presently continues to be the foundation of social support research (Davis, Gavazzi, Scheer, &

Uppal, 2011; Houston & Dolan, 2008; Pinkerton & Dolan, 2007). According to Davis et al. (2011), the social support theory is one of two theoretical perspectives that are highly relevant to the research of parent-led support groups. The four main ideas of the social support theory are emotional support, instrumental support (concrete support), appraisal support (esteem support), and informational support (advice support) (Campbell-Grossman, Hudson, Keating-Lefler, & Fleck, 2005; Houston & Dolan, 2008; Pinkerton & Dolan, 2007).

Emotional support relates to support that a person gives another whether the ties are intimate or not (Campbell-Grossman et al., 2005; Pinkerton & Dolan, 2007). It can comprise one person listening to another as may be the case when an individual is bereaved and needs an affective listener (Houston & Dolan, 2008). Instrumental support represents real and existent support which can be monetary assistance or facilitating an action such as setting up office visits with a professional (Campbell-Grossman et al., 2005). Appraisal support, where a person reinforces another, is used to increase self-esteem, (Campbell-Grossman et al., 2005). The last main idea of the social support theory is informational support, which refers to giving advice that is needed (Campbell-Grossman et al., 2005; Pinkerton & Dolan, 2007). The social support theory provides a foundation for the premise that social support is a necessary factor for improved mental health (Pinkerton & Dolan, 2007). Pinkerton and Dolan (2007) described the social support theory as a theory that has been thoroughly developed and used in practice because of its simplicity and ease of use.

I assessed parent-led support groups use the social support theory. Interviews of parents determined if parent-led support groups influenced them in acquiring advocacy skills. The four main ideas of the social support theory were compared with the support that parents reported receiving. Questions in the interviews addressed the theoretical constructs of the social support theory as they were applied by parent-led support groups. The interviews explored whether parent-led support groups provided emotional support, instrumental support, appraisal support and information support, and how social support found in parent-led support groups facilitated parental advocacy. The social support theory will be discussed in greater detail in Chapter 2.

Another theory that could serve as the foundation for this study is the health belief model. According to Hayden (2009) the health belief model is “the most commonly used theory in health education and health promotion.” (p. 31). Based on the perceptions of individuals, the health belief model can predict the actions that parents take in making choices, such as, “acceptance of their diagnosis; impact of the disorder; benefits of treatment; barriers to pursuing treatment; and their self-efficacy.” (Wildman, 2006, p. 1). The original theoretical constructs of the health belief model began with four main principles based on perceptions of individuals. These constructs can be divided into perceptions of seriousness, perceptions of susceptibility, perceptions of benefits, and perceptions of barriers (Hayden, 2009). Later, additional theoretical constructs were expanded to include modifying variables, cues to action, and self-efficacy (Hayden, 2009; Wildman, 2006).

Assumptions, Limitations, Delimitations

Assumptions

An assumption of this study was that parents who participated in parent-led support groups would be interested in participating in this study and would honestly present their opinions.

Limitations

There were certain limitations in this research that indicated weaknesses of the study. A limitation was that group meetings were monthly and gave me limited access to the autism parent-led support groups unless I attended multiple meetings with each parent-led support group. To address this limitation, I attended group meetings for more than one group. Another limitation was due to the fact that I interviewed between eight to 10 members of a support group but not all group members, so I may have missed a pertinent concept. A more comprehensive study would have to take place for a longer time in order to overcome these limitations.

Delimitations

Bounds for this study were that members interviewed were parents of children between 2 and 12 years of age. The reason for this restriction was that the diagnosis of autism spectrum disorders in children is highest between these years (Schieve et al., 2007). Only one parent of a child with autism above 12 years of age was recruited for interviews because the rates of diagnosis are lower between the ages of 11 and 17. The diagnosis of these children may have occurred many years before, possibly making recollection of events more difficult.

Significance of the Study

In this study, the role of autism parent-led support groups in facilitating parental advocacy and if they provided the tools that lead to parental advocacy was examined. Parents of children with autism want solutions that will show progress in their child's development and feel frustrated by the present interventions (Siklos & Kerns, 2006). Reoccurring themes from the study by Woodgate et al. (2008) indicated that parents felt they must be very vigilant, be able to take care of the family and self, and maintain a sense of being involved in a constant struggle as caretakers of a child with autism. Therefore, this study assists in closing the gap in the literature by researching how parent-led support groups facilitate parental advocacy for parents of children with autism, which will be helpful to participants of parent-led support groups and professionals.

Positive social change may occur through this study because this study may provide answers to parents who want to change the lives of their children and are frustrated because they perceive that their options in advocating for their children are limited. Results from this study may assist parents and professionals in understanding the experiences of parents who perceive themselves as empowered and may provide avenues for parental advocacy that have not been considered. As previously shown, parents must be knowledgeable about the disease, laws, treatments, and the community support available. There is much that is unknown about the effects of parental advocacy and better treatments. Not enough research has focused on parental advocacy to make a positive change in decision making and parental influence.

Summary

Autism is a disease that presents a great struggle to parents of children with autism. Parents of children with autism indicate having more problems acquiring support and proper interventions for their children (Blanchard et al., 2006; Schieve et al., 2007). Because of these problems, parents feel that they must become more knowledgeable about treatments and services available for their children (Woodgate et al., 2008). The literature indicates that parent-led support groups provide support, information, and enhance advocacy for parents of children with autism (Banuch et al., 2010; Pickett et al., 1998). However, in the literature it is difficult to find studies that research autism parent-led support groups and the influence that these groups have on parental decision making and parental advocacy (Banuch et al., 2010; Law et al., 2001; Mandell & Salzer, 2007). Therefore, this study examined the assertions that autism parent-led support groups do serve as a forum for advocacy. This study was conducted using the qualitative approach. The theoretical basis for this study was the social support theory. In Chapter 2, I will provide a much more thorough explanation of the process of this study, the gap in the research and the theoretical basis of this study. Chapter 2 also thoroughly explains the problems that parents of children with autism encounter in finding treatments that are effective interventions for the disease.

Chapter 2: Literature Review

Introduction

In this literature review, I provided an overview of the research performed on the support that parent-led support groups give parents of children with autism in becoming advocates for their children. Five areas were reviewed in the literature: (a) autism in children; (b) parental needs of parents with children that have autism; (c) traditional and alternative treatments available to parents for treating autism; (d) benefits of support groups (formal and informal); and (e) the need for parental advocacy.

The literature review included mostly peer-reviewed articles. The Walden Library was used to access peer-reviewed articles, through searches in the EBSCO Databases, PsycARTICLES, PsychINFO, Academic Search Complete, Proquest Databases, Medline, SocioINDEX, and the Sage Databases. Key words used in the search for articles included *autism*, *autism spectrum disorders*, *support groups*, *parent-led support groups*, *social theory*, *autism treatments* and *advocacy.*

Autism in Children

According to the Health Resources Commission (2008), “No two people with ASD are exactly alike and therefore there is no single treatment protocol for all individuals with ASD” (p. 9), so the therapies are tailored to the individual needs of the patient and the patient’s family. “A wide range of psycho-educational, speech therapy, occupational therapy and physical therapy interventions are available, incorporating a mix of behavioral, developmental and education approaches” (Health Resources Commission, 2008, p. 9). Kanner (1943) explained that individual differences existed among the children studied; some children manifested the syndrome in greater degree, and developed their disease over the years differently. One common symptom was that they all exhibited difficulties in relating to others and were happiest when left alone in their own world and oblivious to their surroundings (Kanner, 1943). The various symptoms of autism make it a disease that is difficult to treat and involves many different therapies.

The costs associated with treating autism have risen substantially. The reason for rising costs has been the addition of nonmedical interventions which supplement medical interventions (Ganz, 2007). New interventions such as diet, genetic testing, behavior modification programs and some unorthodox interventions are being used in the treatment of autism and add to the cost of care (Chamak, 2008). Although autism is viewed as a childhood disease, the costs continue into adulthood, thereby creating a burden for parents and governments (Ganz, 2007). The costs of interventions are greater for children, however they continue into adulthood making it difficult for parents to plan for retirement (Ganz, 2007). Therefore, costs have risen with the implementation of new procedures. These new therapies may provide hope to families.

The skills that most children develop through play, in school, and interaction with others is below normal levels in children with autism (Altiere & Von Kluge, 2009; Friedlander, 2009). A child with autism may exhibit lack of expression or over talking, and a withdrawn, introverted, or extreme outwardly behavior (Friedlander, 2009). Children with autism may not be successful with the school experience and fail to connect emotionally in the classroom in many cases (Friedlander, 2009). Autism can manifest itself as a disease where there exists an emotional disconnect with others despite high intelligence and the ability to excel in one focus area (Darrow, 2009; Friedlander, 2009). Some children may have great reading skills and the ability to decode literature without parents teaching these skills (Friedlander, 2009). Autism is a disease under the category of disorders called autism spectrum disorders or ASD (Friedlander, 2009; Rice, 2007). Other associated disorders are called Asperger's disorder and pervasive developmental disorder – not otherwise specified, commonly known as PDD-NOS (Rice, 2006). Asperger's disorder and PDD-NOS have milder diagnostic symptoms than autism (Rice, 2007). Asperger's disorder shows up in highly intelligent children who have some of the symptoms of autism (Darrow, 2009). Many of the children with Asperger's have great abilities in music and the arts (Darrow, 2009), while children with PDD-NOS have problems with social interaction and communicating with others (Centers for Disease Control and Prevention, 2012).

The problems associated with autism are recognized by 36% to 55% of parents during the child's first year, (Goldberg, Thorsen, Osann, & Spence, 2008). In some cases parents do not know that their child is developing abnormally and fail to get help until the child has undergone active regression, which usually occurs between the ages of 2-3 years old (Goldberg et al., 2008). Active regression is a period of time in which a child with autism loses already acquired skills (Goldberg et al., 2008). During active regression parents provide the most important data in diagnosing ASD (Goldberg et al., 2008). Parents are a very important resource in the diagnosis and treatment of autism. They assist professionals with information about the child.

The Centers for Disease Control and Prevention (2011) suggested that parents know the symptoms of autism and understand the milestones of healthy child development. The developmental milestones for healthy children are broken down for ages 2 months, 4 months, 6 months, 9 months, 1 year, 18 months, 2 years, 3 years, 4 years, and 5 years (Centers for Disease Control and Prevention, 2011). Some of the major signs of developmental problems are being unresponsive to being called by name at 12 months, no pointing response to objects of interest at 14 months, unable play pretend at 18 months, and at different ages, no eye contact, a desire for solitude, difficulty understanding the feelings of others, delayed communications skills, repetitive phrases, inability to give direct answers to questions, unable to accept changes in routines, obsessions with ideas, repetitive movements such as spinning, and difficulties accepting differing smells, textures, sounds, and looks (Centers for Disease Control and Prevention, 2012; Kanner, 1943). The earlier the problem is detected, the greater chance that interventions may have a positive effect on the child (Centers for Disease Control and Prevention, 2011; Kabot et al., 2003). Professionally administered tests assess the milestones that children should display at various ages (Centers for Disease Control and Prevention, 2011).

The assessments for autism begin with medical evaluations in an attempt to determine if a child has sensory or physical illnesses that could account for delays in normal development (Kabot et al., 2003). Once the medical assessment is concluded the next step is to assess the child for autism using psychological assessments (Kabot et al., 2003). These assessments are conducted by a psychologist or mental health professional and may take 2 or more hours to complete (Kabot et al., 2003). Teams of psychologists and diagnosticians specializing in behaviors (adaptive and social), language, verbal and nonverbal communications, and professionals in other specialized disciplines may be employed during the initial and subsequent assessments and treatments (Committee on Children with Disabilities, 2001; Kabot et al., 2003; Palermo et al., 2006). Selecting the right diagnostician can be an overwhelming event and a very stressful time for a parent (Paikoff et al., 2005; Wildman, 2006).

Traditional versus Alternative Treatments

Selecting proper treatments can be a difficult task for parents because there are many types of treatments and interventions that parents have to choose from (Centers for Disease Control and Prevention, 2012; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Thomas et al. (2007) reported that therapies and services varied greatly depending on the form of ASD and its severity. Some of the major treatments for autism available to parents can be broken down into behavior and communications approaches, dietary approaches, medication, and complementary and alternative medicine (Centers for Disease Control and Prevention, 2012).

The most popular approach for autism is the behavior and communications approach (Centers for Disease Control and Prevention, 2012). Applied behavior analysis (ABA) is identified as a behavior and communications approach that is widely accepted among health care professionals and the objective is to promote positive behaviors and reduce negative behaviors with the goal of increasing functional skills in people/children with autism (Centers for Disease Control and Prevention, 2012). Lovaas (1987) has been credited as one of the pioneers of ABA and helped to build intensive early intervention using this approach (Smith & Eikeseth, 2011). Interventions based on this approach promote positive behaviors such as making eye contact, listening, sitting still, paying attention, and building on a child's interest by using repetition (Hayhurst, 2008). Teams of occupational therapists, psychologists, speech-language pathologists, and pediatricians are generally involved in treatments such as ABA (Hayhurst, 2008). Service providers can be (a) board certified behavior analysts (BCBAs) who design and analyze interventions and are licensed and certified; (b) counselors and psychologists who provide an assortment of training and support activities; (c) early intervention providers that concentrate on children's needs from birth until 3 years of age; (d) general education teachers who have a diverse background and teach an assortment of skills; (e) occupational therapists who conduct interventions that require fine motor skills; (f) paraprofessionals who support the teachers in their daily interventions; (g) physical therapists who work with muscle strength, motion, movement, coordination, and balance; (h) special education teachers who work closely with general education teachers and manage the case; and (i) speech and language pathologists who work with persons with autism in the development of language and communications (Association for Science in Autism Treatment, n. d.). Examples of prominent and comprehensive models presently used for the treatment of autism are the Lovaas Model, the Early Start Denver Model, and the learning experiences and alternate program for preschoolers and their parents (LEAP) model (Odom, 2014). Each of these models has been successful in decreasing the symptoms of autism and increasing language skills (Odom, 2014). Similar outcomes of the Lovaas Model and the Early Start Denver Model are increases in IQ and a positive increase in adaptive behaviors (Odom, 2014). The LEAP Model has shown a positive outcome in visual reception and social behavior (Odom, 2014). Lovaas (1987) and other researchers agreed that (a) interventions must be provided at an early age, (b) these interventions must be intensive in order to produce positive outcomes, (c) parents are essential to the interventions because they will be with the child as the child grows, (d) communications and social skills must be addressed in the interventions, (e) planning of the interventions must be individualized, and (f) the skills taught must be applicable at home or in the community (Kabot et al., 2003). Popular approaches such as ABA have been used by certified professionals for behavior modification, and the treatment of symptoms associated with autism (Centers for Disease Control and Prevention, 2012; Hayhurst, 2008; Smith & Eikeseth, 2011). A diverse group of professionals work together to implement interventions (Association for Science in Autism Treatment, n. d.). Other models such as the Lovaas, Early Start Denver, and the LEAP have produced positive outcomes in child development (Odom, 2014). Interventions have been designed specifically for each child, and follow science based guidelines that have proven to be effective (Kabot et al., 2003).

Dietary approaches and medication are used less than the behavior and communications approaches (Centers for Disease Control and Prevention, 2012; Thomas et al., 2007). Dietary approaches have been used by therapists and have not been fully accepted because there is no scientific proof that changes in diet can generally affect the symptoms of ASD (Centers for Disease Control and Prevention, 2012). However, some parents believe that changes in diet have a significant effect on behavior (Centers for Disease Control and Prevention, 2012; Thomas et al., 2007). According to Thomas et al. (2007) dietary treatments are used twice as much in children 4 years and under than children 5 to 8 years old.

Medications used to treat autism are categorized as Food and Drug Administration (FDA) approved medications and off-label medications (National Institute of Mental Health, 2011). Off-label medications are medications used to treat other disorders and are used by doctors with the prospect of successfully treating a patient with autism (National Institute of Mental Health, 2011). According to the National Institute of Mental Health (2011) and the Centers for Disease Control and Prevention (2012), the only two medications approved to treat certain characteristics of ASD are antipsychotic rispiradone (Risperdol) and aripripazole (Abilify). These medications are used to treat the ill temper of children between the ages of 5 and 16 years old with psychiatric diseases including autism (Lofthouse, Hendren, Hurt, Arnold, & Butler, 2012). At the present time there are no medications that treat the predominate symptoms of autism or cure ASD, so the FDA approved medications are used to treat only severe behaviors that can be detrimental to a child’s safety (Centers for Disease Control and Prevention, 2012; Health Resources Commission, 2008; Lofthouse et al., 2012). More research is needed to increase available medications for use in the treatment of autism since children with autism may not respond the same way to a medication as children with other disorders (National Institute of Mental Health, 2011). There are few medications that have been approved by the FDA that may work on some of the more severe symptoms associated with autism. Since there are no medications that specifically treat autism, off-label medications are being used.

Therapies and treatments for autism that are traditionally employed, such as the behavior and communications approach and medication, can be frustrating to parents because they are very time consuming and patient progress can be slow (Lofthouse et al., 2012). Therefore, parents supplement the traditional treatments with alternative treatments called complementary and alternative medical treatments (CAM) in hopes of achieving better outcomes (Association for Science in Autism Treatment, n. d.; Centers for Disease Control and Prevention, 2012; Hayhurst, 2008; Lofthouse et al., 2012). The term complementary relates to a treatment that is used in conjunction with other treatments; alternative is when the treatment completely replaces other treatments (Lofthouse et al., 2012). CAM treatments can be divided into mind-body medicine, energy medicine, biological-based approaches, and manipulative and body practices approach (Levi & Hyman, 2008). The most frequently used treatment for children with autism is the biologically based CAM which consists of dietary supplements such as vitamins, minerals, and other nutritional compounds (Levi & Hyman, 2008). Parents of children with autism use dietary supplements because of concern about vitamin and mineral deficiencies due to food aversion, to control seizures, and to modify challenging behaviors that parents believe can be altered with CAM treatment (Perrin, Coury, Hyman, Cole, Reynolds, & Clemons, 2012). The next most commonly used treatment is manipulative and body practices approach CAM which consists of chiropractic, chraniosacral massage, therapeutic massages, and audio-integration treatments (Levi &

Hyman, 2008). Other examples of CAM treatments are yoga and music therapy which fall under mind-body medicine CAM, and transcranial magnetic stimulation which falls under energy CAM (Levi & Hyman, 2008). Some of the CAM treatments produce lackluster results (Committee on Children with Disabilities, 2001; Health Resources Commission, 2008; Levi & Hyman, 2008) while other CAM approaches such as dietary supplements can interact with medication and create drug interactions, making them dangerous (Gilmour, Harrison, Asadi, Cohen, & Vohra, 2011). According to Brown, Willis, Omalu, and Leiker (2006), two children ages 2 and 5, and one adult female age 53, died between 2003 and 2005 due to cardiac arrest while undergoing CAM called chelation therapy. Chelation therapy is a procedure where chemicals called chelation agents are intravenously administered into a patient's bloodstream with the objective of excreting toxic heavy metals such as lead and mercury from the patient (Brown et al., 2006; Health Resources Commission, 2008; Lofthouse et al., 2012). Brown et al. (2006) reported that the scientific community does not support the use of chelation therapy for autism. Chelation therapy is an expensive treatment which can cause liver and kidney toxicity, exhaustion, and diarrhea (Lofthouse et al., 2012). Lofthouse et al. (2012) identified at least 60 CAM treatments that have not shown positive effects or lack sufficient evidence of their worth. Parents must be aware that CAM treatments can be dangerous and many do not produce positive results. Parents often try CAM treatments with the hope that these treatments will produce quick results.

Understanding CAM can be an ordeal for parents who have to educate themselves and also serve as caretakers (Health Resources Commission, 2008). Both parents and health professionals feel that more effective interventions are necessary for a child with ASD to improve (Health Resources Commission, 2008; National Institute of Mental Health, 2011). Parents try CAM in the hope that something will work more effective and expeditiously (Centers for Disease Control and Prevention, 2012; Committee on Children with Disabilities, 2001; Health Resources Commission, 2008). The National Institute of Mental Health (2011) suggested that parents must be proactive and informed about treatments available for children with ASD. Comprehensive record keeping of doctors' appointments and conversations with professionals, as well as contact with local community organizations and advocacy groups about the array of services available can greatly enhance parental decision making concerning treatments (National Institute of Mental Health, 2011).

Parental Needs

Parents of children with autism face many stresses and these stresses can create disharmony in the family unit (Altiere & Von Kluge, 2009; Twoy, 2006). Children with autism may not be able to do certain tasks for their age and require more than normal assistance and supervision (Altiere & Von Kluge, 2009). Other stresses relate to finding information on interventions that treat specific symptoms and acquiring funding to pay for available interventions (Thomas et al., 2007).

In many cases private insurance companies do not cover tests and parents must incur these costs themselves (Thomas et al., 2007). Families that have access to medical care through government sponsored medical assistance such as Medicaid, receive more services than families using private insurance companies (Thomas et al., 2007; Wang, Mandell, Lawer, Cidav, & Leslie, 2013). Families using Medicaid have two to 11 times the odds of having access to services that provide medication, therapy, supportive assistance, case managers, and much more, than families that relied on private insurance (Thomas et al., 2007). Studies indicated that Medicaid provided more services than private insurance (Mandell & Salzer, 2007; Thomas et al., 2007; Wang et al., 2013) Parents have to pay for out of pocket expenses for certain treatments not covered by private insurance (Thomas et al., 2007). These expenses were incurred during childhood and in many cases into adulthood (Ganz, 2006).

Parents of children with autism live with the disorder daily. It is not something that is temporary or goes away with time and age (Wildman, 2006). It is an obligation that encompasses 24 hours of a day, every day of the week (Altiere & Von Kluge, 2009). In families with children four and under, there is a greater variety of diagnostic strategies and treatment utilized than any other age group (Thomas et al., 2007). Parents must make decisions finding a good diagnostic center, and acquire services that are effective and competently administered (Wildman, 2006; Woodgate et al., 2008). Since there are a great variety of treatments, parents must be vigilant and aware that use of too many treatment can cause over treatment (Altiere & Von Kluge, 2009). Over treatment of children is frustrating and confusing to parents because parents find it difficult to discern between what works and what does not work, if too many treatments are utilized (Altiere & Von Kluge, 2009). Most complaints made by parents of children with autism relate to finding professionals who are sufficiently knowledgeable about the disorder to provide consistent therapies that will help children (Siklos & Kerns, 2006). Woodgate et al.

(2008) found that many parents felt that professional agencies and institutions lacked knowledge and training about autism and provided little support because of lack of resources, and funding. Parents of children with autism want solutions that will show progress in their children's development and feel frustrated by present interventions (Siklos & Kerns, 2006). Social support is important to parents because frustration can lead to isolation (Siklos & Kerns, 2006; Thomas et al., 2007; Wildman, 2006).

Social Support

Social support can be defined as "emotional, instrumental, and informational assistance from others" (Gerard, Landry-Meyer, & Roe, 2006, p. 361). Because caring for a child with autism can require a great amount of social support, theories such as the social support theory validate the need for emotional support, instrumental support (concrete support), appraisal support (esteem support), and informational support (advice support) (Houston & Dolan, 2008; Pinkerton & Dolan, 2007; Davis et al., 2011).

Parents seek social support along with professional support for information gathering and stress relief (Altiere & Von Kluge, 2009; Thomas et al., 2007). Twoy (2006) indicated that social support comes from inner circles of individuals such as family, friends, professionals, and parents who share the same goals and aspirations for their special needs children. Positive social relations can create a protective environment where people feel safe around others, help to promote better healthy behaviors, alter certain physiological processes, and provide resources (Altiere & Von Kluge, 2009). Parents of children with autism perceive that society does not acknowledge the difficulties that they live with daily (Blanchard et al., 2006; Neely-Barnes et al., 2011;

Schieve et al., 2007; Woodgate et al., 2008). In many instances a lack of acceptance of autism by families and friends is common (Altiere & Von Kluge, 2009; Neely-Barnes et al., 2011). Additionally, parents have reported losing the support from their church, due to the lack of acceptance and understanding by church leaders and church members as reflected through stares and disapproving looks if their child misbehaves, making them even more isolated (Altiere & Von Kluge, 2009; Neely-Barnes et al., 2011). In some cases parents of these children cannot maintain the ties to these informal social support groups because of their obligations as caretakers (Altiere & Von Kluge, 2009), so parents feel the stress of not being able to do activities that they enjoy (Altiere & Von Kluge, 2009; Woodgate et al., 2008). The lack of social interaction causes parents to feel isolated (Altiere & Von Kluge, 2009; Schieve et al., 2007). They may lose support from friends and family while caring for their child (Altiere & Von Kluge, 2009; Woodgate et al. 2008).

According to Altiere and Von Kluge (2009), family acceptance is even more critical than church acceptance in the establishment of social support. Parents indicated problems with the extended family, such as the inability of grandparents to understand autism, or family members keeping their distance because of the embarrassment that it brought them (Altiere & Von Kluge, 2009; Neely-Barnes et al., 2011). Lack of acceptance within the same household exists in some cases where families with non-autism siblings reside in the same household as a child with autism; sibling perspectives expose the feelings of non-autism children due to the added attention that a child with autism requires (Altiere & Von Kluge, 2009). Parents need social support (Altiere &

Von Kluge, 2009; Schieve et al., 2007). This support can come from family, friends and autism groups which can help parents deal with the difficulties of raising a child with autism (Twoy, 2006). In some cases, parents do not get adequate support from family and friends, so they turn to parent-led support groups for support (Altiere & Von Kluge, 2009; Woodgate et al. 2008).

Support Groups

Support groups offer information and emotional support that parents may not find with friends and family (Law et al., 2001; Pickett et al., 1998). Support groups such as informal (parent-led) support groups provide a place where parents feel accepted, and welcome (Altiere & Von Kluge, 2009; Law et al., 2001; Mandell & Salzer, 2007). These groups reduce parental stress, improve psychological well-being, and make available information to parents (Law et al., 2001; Mandell & Salzer, 2007). In informal support groups lead by parents, the participants share a common experience because they are all living with autism (Altiere & Von Kluge, 2009; Law et al., 2001). Parent-led support groups provide a forum where parents can bounce ideas off other parents, create an environment of working together to share the load in caring for a child with autism, provide an information network which collectively makes medical personnel and politicians accountable for their actions, and create a community that supports each other (Mandell & Salzer, 2007). Parent-led support groups provide parents with a feeling of self-efficacy, by increasing confidence to deal with the daily struggles of raising a child with disabilities (Law et al., 2001). Not enough professionals are referring parents to parent-led support groups and that is problematic (Kerr & McIntosh, 2000). Only one in four parents surveyed indicated that their participation in parent-led support groups was a result of professional referrals (Mandell & Salzer, 2007). Kerr and McIntosh (2000) found that parents perceived parent-led support groups as providing parents with "experiential learning" (p. 320), so the lack of encouragement from professionals to join parent-led support groups presents a loss of an additional resource. In essence parent-led support groups provide a unique environment for support that cannot be duplicated in other settings (Kerr & McIntosh, 2000).

Advocacy and Parent-led Support Groups

Advocacy for the child with autism takes a parent through processes of learning, and the realism that ensues when a parent accepts the diagnosis and becomes proficient in living with the disorder (Woodgate et al., 2008). Choosing treatments can be overwhelming to parents who must decide what is best for their child so many parents become parental advocates; thus, parental advocacy serves parents well in getting the services needed for a disabled child (Paikoff et al., 2005). Parents who become advocates can better navigate the maze of system and social services for a child with ASD, while reducing family stress associated with the disease (Thomas et al., 2007; Woodgate et al., 2008). Advocacy gives parents greater access to quality healthcare for a child with autism, through the development of skills that assist in the acquisition of services and proper treatments (Thomas et al., 2007). Parent advocates engage in acquiring knowledge about the disease, their rights according to state and federal laws during different phases of their children's lives (newborn, toddler, young adult, and adult), information about education programs, new technologies, treatments and interventions, and the supportive services that communities offer (Paikoff et al., 2005; Woodgate et al., 2008). Reoccurring themes from a study by Woodgate et al. (2008) indicated that parents felt they must be very vigilant, be able to take care of the family and self, and maintain a sense of being involved in a constant struggle as caretakers of a child with autism. Twoy et al. (2006) found that parents of children with autism spend a great deal of time per week coordinating interventions, educating themselves, speaking to professionals, and advocating for their child. Nearly 45 % of parents spent five hours a week, 33% of parents spent at least 11 hours a week and 22 % of parents spend more than 12 hours a week just coordinating intervention activities despite working full time (47%), working part-time (27%), or staying at home with their child (25%) as a full-time caregiver (Twoy et al., 2006). Parent-led support groups can give parents a foundation from which advocacy can grow (Hoagwood et al., 2010; Mandell & Salzer, 2007).

Banuch et al. (2010), Law et al. (2001) and Mandell and Salzer (2007) reported that not enough research has been conducted into the influence that parent-led support groups have in creating advocacy. Few studies have been performed on parent-led support groups for children with disabilities (Banuch et al. 2010; Law et al. 2001; Mandell & Salzer 2007). Banuch et al. (2010) reported that a review of the literature found there were no studies that examined the effectiveness of parent-led support groups in helping parents to deal with autism. Further, Banuch et al. (2010) indicated that at the time of their study, no other study was found in the literature review that researched parent-led support group's influence on creating advocates of parents of children with autism, conducted in a school setting. Banuch et al. (2010), in a co-facilitated parent support group setting, conducted a study consisting of experts in different disciplines, graduate students, and parents of newly diagnosed children with autism. They found that autism support groups do assist parents in making decisions and reducing stress. The participants exchanged ideas and information under the direction of the facilitators (Banuch et al., 2010). Banuch et al. (2010) administered pretest and posttest questionnaires to parents of recently diagnosed children. The study concluded that six sessions of advocacy training, and parental interaction increased the perception of awareness, empowerment, and advocacy among the parents who participated in the study (Banuch et al., 2010). Although parents gave the training high ratings, parents felt they would benefit more if the support group lasted a longer period of time (Banuch et al., 2010). Banuch et al. (2010) described certain limitations of the study, since the outcomes of seeking services after the training were not studied. Mandell and Salzer (2007) found there is sparse research into whether parent-led support groups influence parental decisions or how these groups play a role in decisions about treatments, increasing care, and the health and wellness of parents and children. There is a gap in the literature regarding parent-led support groups and whether they can serve parents of children with autism in their quest for advocacy.

Studies have been conducted of parent-led support groups that are associated with many different diseases. In one study, Gottlieb and Wachala (2007) found that cancer support groups lasting more than 6 months were beneficial to people suffering from cancer, and that these groups provided emotional support and a sense of self-efficacy in dealing with their disease. Yet despite the benefits found in their study, Gottlieb and

Wachala (2007) reported that 20% of people declined invitations to join support groups and 20% who joined dropped out because they felt that support groups in general did not meet their needs. Gerard et al. (2006) found that grandparents raising young children with health issues benefited from grandparent-led support groups because of the social networking between the group members. Hoagwood et al. (2010) evaluated parent-led support groups for mental disorders in general, while Law et al. (2001) conducted a study of the perceived effects of participation in parent-led support groups for parents with children with disabilities. Both studies reported the achievement of parental advocacy due to participation in parent-led support groups. Law et al. (2001) researched the perception of advocacy in parents of children with disabilities who participated in parent-led support groups. This study was broader in scope than the study I conducted because it examined the participation of parents of children with a range of disabilities in parent-led support groups. In my study, I focused on parent-led support groups for parents of children with autism only. Therefore, research into the parental advocacy for autism is important because few studies were found in the literature in which the role that autism parent-led support groups play in the quest for parental advocacy was examined (Banuch et al., 2010; Clifford, 2011; Mandell & Salzer, 2007).

Among the few studies in which the role that autism support groups play in facilitating advocacy was examined, were studies by Banuch et al. (2010), Clifford (2011), and Mandell and Salzer (2007). Several major differences can be made between my study and these studies. One major difference is that in my study, I examined the perspectives of parents who participated in long running parent-led support groups. I also screened participants in the study to ensure they had participated in parent-led support groups for at least six months. Law et al. (2001) selected participants for their study based on the length of time in a support group and attendance to ensure that participants were knowledgeable about the support group. Another major difference is that I studied participants of informal autism parent-led support groups who had children with autism primarily between the ages of two and twelve years of age. In the study by Banuch et al. (2010), a short term formal support group was organized specifically for the study, and the advocacy skills of parents belonging to a support group after a six session pilot study was examined. This is distinctively different from my study because I interviewed participants of informal parent-led support groups that had been in operation for significantly longer than the study by Banuch et al. (2010). In the study by Mandell and Salzer (2007), the objective of the study was to examine the demographics of those who participated in autism parent-led support groups. I had the participants fill out a demographics questionnaire at the beginning of the interview. Clifford (2011) conducted a study about the well-being of parents that participated in an online support group setting, while in my study I examined the potential for advocacy in regularly scheduled direct contact and online parent-led support groups. Each of these studies examined autism parent-led support groups with a different objective or a different setting than my study. I focused on the advocacy skills that parents of children with autism have developed through participation in already established parent-led support groups.

Summary

Autism is a disorder that affects the neurobiological function of the metabolism of children (Palermo et al., 2006; Windham et al., 2006). The disease involves many different aspects of a child's development in the physical, emotional, neurological and psychiatric domains and problems begin to show up in childhood though abnormal speech and social development (Palermo et al., 2006). Children with autism have difficulty with school and need special attention in order to be successful in the school environment (Friedlander, 2009).

Many parents of these children have reached a point of desperation because of the difficulties in finding treatment that work and parents feel that more can be done to create better interventions (Wildman, 2006; Woodgate et al., 2008). Parents spend a great amount of time as caregivers and interfacing with professionals in order to meet their needs (Twoy et al., 2006). Treating autism is difficult because there are no medications that will help in treating the symptoms of autism, and traditional treatment such as ABA is lengthy (Association for Science in Autism Treatment, n. d.; Centers for Disease Control and Prevention, 2012; Hayhurst, 2008; Lofthouse et al., 2012). In many cases parents work with professionals such as occupational therapists, psychologists, speech-language pathologists, and pediatricians (Hayhurst, 2008), making it essential that parents keep good records and become well organized (National Institute of Mental Health, 2011). Some of the specific strategies that are used to treat autism include behavioral management, parent training, speech training, occupational and physical therapies, medical therapies, and community support (Committee on Children with Disabilities, 2001). The slow progress of treatment has brought about an industry that brings hope to parents of children with autism in the form of complementary and alternative treatments which may work for some children and not others (Committee on Children with Disabilities, 2001).

Parents of children with autism are concerned with meeting their emotional needs and improving the health of the child and use social support such as family, friends, church, and support groups (Gerard et al., 2006). Parents may decide to join support groups to enhance their knowledge about autism, reduce stress, and make better decisions in choosing appropriate treatment for their child (Law et al., 2001; Mandell & Salzer, 2007). In the literature review few studies were found which examined the advocacy skills that parents developed through participation in parent-led support groups (Banuch et al. 2010; Clifford, 2011; Law et al. 2001; Mandell & Salzer 2007). As a result, my study examined the effects that participation in autism parent-led support groups had on parents who wanted to become parental advocates.

Chapter 3: Research Method

Introduction

The primary purpose of the study was to explore whether autism parent-led support groups promoted parental advocacy. A secondary purpose of the study was to document the experiences of parents who participated in parent-led support groups. These experiences were important in finding answers to the research questions about the needs of parents and why they participated in parent-led support groups. It was important to the research to find what those needs were and whether the parent-led support groups met those needs. According to Thomas et al. (2007), parents who become advocates for their child can better navigate the maze of system and social services for the child with ASD, and reduce the family stress associated with the disease. Thus, parents find greater services and treatments and make better decisions in choosing quality healthcare for a child with autism (Thomas et al., 2007; Woodgate et al., 2008). However, a gap exists in the literature review since few studies have researched autism parent-led support groups and their influence in helping parents to become advocates (Banuch, et al., 2010; Mandell & Salzer, 2007).

Research Design and Rationale

Research Questions

To ascertain if parent-led support groups facilitated advocacy the following research questions were used in my study:

1. What is the perception of parents who participate in autism parent-led support groups about the value of the support group as a resource for information and support?

2. How do informal (parent-led) support groups impact parental advocacy?
3. How does parental advocacy impact decision making in caring for a child with autism?
4. What tangible results do parents gain from their participation in parent-led support groups?

Central Concept of the Study

Parent-led support groups have been described as providing many different types of support; among these are emotional and instrumental support (Woodgate et al., 2008). The literature shows that social support can be divided into different support domains; emotional support, instrumental support (concrete support), appraisal support (esteem support), and informational support (advice support), which make up a comprehensive support system (Davis et al., 2011; Houston & Dolan, 2008; Pinkerton & Dolan, 2007). Parent-led support groups have been described as providing social support that meets the needs of participants who want to become advocates (Hoagwood et al., 2010; Mandell & Salzer, 2007). Advocacy can be achieved through the development of skills that fall under the social support theory domains (Pinkerton & Dolan, 2007). Identified skills are knowledge of legal rights, and knowledge of technical information about cutting edge programs in education, treatments, and technology (informational support), access to the latest medical programs (instrumental support), the supportive services that communities offer (emotional support) for psychological well-being (Paikoff et al., 2005; Woodgate et al., 2008), and a feeling that others can relate to their situation (appraisal support) which is created through bonds that are developed (Campbell-Grossman et al., 2005). If autism parent-led support groups provide the social support that leads to advocacy, how do parents acquire personal growth and become advocates? What events occur within the parental experience that leads to advocacy? This was the central concept of my study.

Research Tradition

This study was qualitative and used the phenomenological approach. According to Chamak (2008) and Woodgate et al. (2008), a qualitative study can achieve a better understanding of parental struggles with autism and the personal changes that a parent undergoes due to the disease. Through phenomenological inquiry, the stages that a person undergoes as they become more proficient in their endeavors can be examined (Zolnierek, 2011). By examining the experience of a parent as that parent becomes an advocate for their child, some insight may be acquired into the stages that a parent takes in the pursuit of parental advocacy (Paikoff, Casey, & Wodlinger-Cohen, 2005). Phenomenological studies give individuals a voice through the recording of personal experiences and the changes that these experiences have made in their lives (Zolnierek, 2011; Gill & Liamputtong, 2009). They have become a leading research approach in medical studies (Woodgate et al., 2008). I conducted the study using the hermeneutic phenomenological method. Hermeneutic phenomenology necessitates an in depth description, assessment, and interpretation of the experience so that the full meaning of the experience can be understood (Woodgate et al., 2008). I used interviews to collect the data.

Woodgate et al. (2008) conducted a hermeneutic phenomenological study to find the deep meaning of a lived experience. The purpose of the study by Woodgate et al. was to examine and record the experience of parents of children with autism who participate in parent-led support groups and the life that they live while caring for a child with autism. My study focused on support groups and parental advocacy through the experiences of parents as they participated in parent-led support groups to have their needs met. Woodgate et al. developed three main themes from their interviews of parent advocates; they were vigilance, taking care of the family, and never giving up. Woodgate et al. used tape recordings during the interviews and unstructured questions. The recording transcripts as well as the notes were transcribed using Microsoft Word (Woodgate et al., 2008). Woodgate et al. compared the interviews with the tapes concurrently and reviewed the data over and over in order to develop themes. Kerr and McIntosh (2000) conducted a phenomenological study on parent-led support groups for children with congenital upper limb deficiencies. The researchers examined whether the outcome of participation in parent-led support groups served to promote coping skills, emotional support, and instrumental support (Kerr & McIntosh, 2000). Kerr and McIntosh found that instrumental support (concrete support) and emotional support was always less than they expected, and therefore, parents turned to parent-led support groups which they considered a powerful avenue where this type of support could be found.

Gill and Liamputtong (2009), using in depth interviews, conducted a phenomenological study about the experiences of mothers of children with autism. The phenomenological inquiry was chosen for their study because this method gave meaning and understanding to the perspective of the mothers interviewed (Gill & Liamputtong, 2009). Gill and Liamputtong asked the participants to keep a diary for a week and used the diaries as a tool for discussion during their interviews. The solicited diaries provided the researchers with the pertinent information needed to understand the experience that mothers of children with autism face (Gill & Liamputtong, 2009). Portway and Johnson (2005) also used interviews to collect data. In their study, purposive sampling was used to recruit the participants of the study, unstructured interviews were conducted to gather information, and the researchers constantly evaluated the data to ensure that the common themes had been properly developed based on the data (Portway & Johnson, 2005). Onwuegbuzie and Leech (2007) explained that the purposive sampling strategy encompasses 19 different sampling techniques. One of these techniques is called homogeneous sampling. Homogeneous sampling is used when studying one group or more in great detail that have similarities or differences (Onwuegbuzie & Leech, 2007).

Methodology

Participant Recruitment Logic

The participants of this study were parents with children primarily age 2 to 12 who participated in autism parent-led support groups. The reason that I chose this age is because, according to Ganz (2006), the cost for direct medical treatment, direct nonmedical costs, and indirect costs for children with autism is highest between the ages of 3 and 7 and second highest between the ages of 8 and 12 years of age. Direct medical costs are the costs for hospital and emergency care, prescriptions, medical equipment, and travel costs associated with medical care (Ganz, 2006). Direct nonmedical costs include transportation, child care and babysitting, special education programs, and modifications to the home and vehicle (Ganz, 2006). Indirect costs can be loss of income or benefits due to increased parental care and the hiring of household services (Ganz, 2006). Nine parents were recruited to participate in individual interviews during which they were asked about their experiences within autism support groups and their assessment of the influence that these groups have in creating self-efficacy and advocacy. Many phenomenological researchers have conducted their studies with 10 or less participants. Groenwald (2004) indicates that phenomonological studies can acquire the desired outcome with the interview of only 10 participants. Mason (2010) conducted a study of sample sizes and saturation in which 25 phenomnological studies were examined. The review indicated that at least six participants were interviewed in each of the studies and two thirds of the researchers interviewed between five and 25 participants in their studies (Mason, 2010). Zolnierek (2011) identified 20 phenomenological studies that used purposive sampling and conducted in depth interviews with 10 or less participants. Researchers conducting phenomenological studies have a problem in that large records can accumulate due to interview notes and tape recordings, therefore small numbers of participants are beneficial in order to identify key themes (Groenewald, 2004). Based on the literature that describes the sample size in phenomenological studies, I interviewed nine participants to identify if parent-led support groups lead to parental advocacy.

In order to reach the research participants I contacted 25 to 30 autism support groups that were located throughout the Oklahoma City Metropolitan Area, Kansas, Texas, and online. Each in-person group met at different times during the month, therefore, I had to schedule a meeting with the groups that fit my time frames for completing the study. I used two groups to solicit participants for the pilot study and three groups for recruiting participants. Once permission was given to attend the support groups, I asked the group participants to complete a short questionnaire (Appendices A and B) to determine eligibility for the study. Purposive sampling was used in my study to recruit participants (Portway & Johnson, 2005). This sampling strategy is used in qualitative studies because the specific purpose is to understand a problem in great detail (Kerr & McIntosh, 2000; Neely-Barnes et al., 2011). I used a technique of purposive sampling called homogeneous sampling which is a sampling whereby participants are recruited based on similar characteristics. By limiting the participants in the study to those who met the established criteria, it was easier to focus on the issues that they had in common (Neely-Barnes et al., 2011). The Institutional Review Board (IRB) approval number for this study is 01-04-16-0063040.

Instrumentation

I have developed the instruments of data collection in English and Spanish which are the screening questionnaire (Appendices A and B), demographics questionnaire (Appendices C and D), interview questionnaire (Appendices E and F) and possible following questions (Appendices G and H). During the interviews, I asked the interview questions and audio taped the interviews so I could capture the interviews completely. I used the audio recordings to create the interview transcripts. I sat in on one parent-led group meeting per group. The screening questionnaire was used to determine study eligibility and interest in participating. The interview questionnaire was used during the interviews with the purpose of examining the role that parent-led support groups had in facilitating advocacy. In order to receive feedback on my study questionnaires, I solicited help from experts who work for the Lee Mitchener Tolbert Center for Developmental Disabilities and Autism in Oklahoma City.

The experts completed the *Form for Review and Evaluation of Validity and Reliability by a Panel of Experts for Qualitative Instrumentation* (Appendices I and J). The expert panel suggested that I use people first language in order to remove bias from the study and the questionnaires. The premise of people first language is to change the perception of people towards people with disabilities (Snow, 2013). This includes how people with disabilities are described or labeled (Snow, 2013). The recommendation from the expert panel was to use the term *child with autism* instead of *autistic child*, which conforms with people first language. I have incorporated people first language in my study. The expert panel also indicated that the instructions for completing the instrument were clear, they agreed that the survey instrument had content validity, construct validity, face validity, and consequential validity.

Other recommendations by the expert panel were that Interview Question 3 (Appendices E and F) and Screening Question 2 (Appendices A and B) be changed because they appeared to be leading questions. I made changes to both questions. I also added a question to the interview questions asking study participants for their definition of advocacy, which was another recommendation of the panel. The panel also recommended that it would be appropriate to provide a yes or no response for the participant screening questions (Appendices A and B), since this questionnaire would be handed out for the participants to complete. Moreover, they pointed out grammatical errors. I made the recommeded changes.

Woodgate et al. (2008) used open-ended interviews in a qualitative phenomological study examining the lives of parents of children with autism and their experiences. I used open-ended interviews in my study. The use of open-ended interviews allows the study participants to fully describe their experiences in their own words (Woodgate et al., 2008). To ensure content validity, Gill and Liamputtong (2009) recommend that the researcher use open-ended questions. The researcher should also ensure that the participant is explaining their beliefs and perspectives and not someone else's, and encourage the participant to respond in detail instead of generalities (Gill & Liamputtong, 2009). I followed those recommendations.

The use of the Critical Appraisal Skills Programme (CASP) questions (Appendix K) can also help the researcher ensure content validity in a qualitative study (Singh, 2013). Validity and reliability of the study can be reviewed using the CASP, which are 10 questions that are designed to assist researchers in ensuring trustworthiness of the data (Critical Appraisal Skills Programme, n. d.; Singh, 2013).

According to Singh (2013), CASP was created by the national CASP collaboration for qualitative methodologies. Of the ten question areas in CASP (Appendix K), the first two questions address the aim of the research and the appropriateness of the methodology. These are called screening questions. The next eight questions are related to the way in which the study is conducted. CASP assists researchers examining the trustworthiness of the sampling strategy, data collection, data analysis, research partnership relations, findings, justification of data interpretation, transferability, and relevance and usefulness of the research (CASP, n. d.; Singh, 2013). I used the CASP screening questions to assess the appropriateness of using the qualitative design for this study and to evaluate the sampling strategy. By using the other set of eight questions I asked myself if I followed the qualitative methodologies deemed important in conducting a qualitative study. CASP allows researchers to self-evaluate how they are conducting the study.

I used open-ended questions and CASP to increase the validity of my study. I also used an expert panel to review my interview questionnaire. Additionally, I conducted a pilot study with two participants who met the same inclusion criteria as the larger study. Based on the results of the pilot study the questions were deemed adequate. The interview questions were modified based on the expert panel feedback.

Procedures for Recruitment, Participation, and Data Collection

There were three major phases for conducting my study. In Phase 1, I contacted 25-30 parent-led support groups from a list of parent-led support groups in the Oklahoma City area, Kansas, Texas, and online. I attended a meeting for each in-person group that responded and recruited a sample of participants from three groups. Participants were recruited for this study within a week after the group meeting, and were contacted immediately after being recruited into the sample. I recruited parents whose children are between the ages of 2 and 12 years of age first, because the cost of care is more expensive during these years (Ganz, 2006). I also recruited parents of children between the ages of 12 and 16 years because more participants were needed. Phase 1 took 8 months to complete.

Before I conducted the interviews I recruited two parents for a pilot study. Pilot studies allow researchers to test the instruments used in a study by setting up interviews to test the interview questions (Chenail, 2011). Through the pilot study I assessed whether the interview questions were understood and how I could make the questions better. Pilot studies serve as a trial run to the research, which can produce new ideas for the subsequent interviews used in the study (Chenail, 2011).

Phase 2 of my study was the interview/data collection phase. I contacted the parents by phone or email to schedule an interview date and time. Phone interviews were conducted in a private location. During the interviews the parents were asked to respond to 10 open-ended interview questions (Appendices E and F). I audio recorded the interviews. Each interview lasted no more than 1 hour. This phase lasted 3 months.

Phase 3 was the data analysis phase. Woodgate et al. (2008) emphasize the importance of organizing the data by making typewritten transcripts of the audio recordings and grouping the data. Portway and Johnson (2005) and Woodgate et al. (2008) used recorded interviews to assure the accuracy of the data. I typed all transcripts of interview recordings.

Reducing is the sorting of data into content and themes (Namey, Guest, Thairu, & Johnson, 2007). Displaying the data means extracting the common themes and the variations between experiences (Namey et al., 2007). These steps allow the researcher to take a closer examination of the data. I used NVivo software to reduce and display the data from the transcripts. Themes can be identified by taking the coded data and looking at it more closely in order to find similarities or differences in the responses (Namey et al., 2007). This is done in qualitative studies by giving specific attention to word usage, since in conversations certain words can add intensity to a discussion while others are more passive (Namey et al., 2007).

Shenton (2004) recommends the researcher read all the transcripts thoroughly and often in order to establish a general meaning for what the participants are trying to say. By reading all the transcripts carefully, I got a general perception about the information contained in the data. Reading the transcripts is the first step in identifying data quality and patterns found in the data (Bowen, 2005; Morrow, 2005). Transcripts should be read soon after they are created, and many times over, so researchers can become thoroughly familiar with the information they contain (Morrow, 2005; Shenton, 2004). While reading, the researcher can also make note of similarities or differences found in the transcripts which can lead to identifying themes (Morrow, 2005; Woodgate et al., 2008).

First I transcribed the audio tapes verbatim into a Microsoft Word document. Then I reviewed all recordings with the transcriptions to be sure there were no errors or inconsistencies. Next I used NVivo to code data and determined the common themes. Programs such as NVivo help with the coding and theme development (Bowen, 2005). This phase of the study took one month to complete.

Issues of Trustworthiness

In order to better assess the trustworthiness of the study, I requested the assistance of two experts who reviewed the interview questions of my study. These experts work with the Lee Mitchener Tolbert Center for Developmental Disabilities and Autism.

The four criteria of trustworthiness in a qualitative study are credibility, dependability, confirmability, and transferability; they promote validity and reliability (Bowen, 2005; Morrow, 2005; Shenton, 2004). Validity in a qualitative study does not have the same meaning as it does in a quantitative study (Bowen, 2005; Trochim, 2006). Morrow (2005) considers internal validity in a quantitative study analogous to credibility in a qualitative study. Credibility is described as establishing that the findings are true and provide an accurate insight and understanding of the context of the data (Bowen, 2005). The perspectives of the participants must be credible or believable in order to ensure credibility (Shenton, 2004; Trochim, 2006). Therefore, the researcher must understand the problem in order to ensure credibility. In order to ensure credibility and better understand the perspective of the participants, I read the transcripts many times.

In qualitative studies, dependability is the parallel to reliability in quantitative studies (Morrow, 2005; Trochim, 2006). Dependability is the assurance that the process of the study was carried out in a careful manner, according to the rules and practices of qualitative studies (Morrow, 2005). A rule that qualitative researchers pay close attention to is the logical connection between the research questions and the intended purpose of the study (Shenton, 2004). The ability to make side by side comparisons of the data acquired from different sources, when researchers employ similar techniques, is dependable when they are consistent over time (Shenton, 2004). I ensured the dependability of the study by comparing the data that I acquired to the outcomes of similar studies found in the literature review. Bowen (2005) used the assistance of an expert in coding and qualitative research to serve as an auditor to accomplish dependability and confirmability of a study. The expert performed an audit trail of the transcripts and the theory. Any differences in perspectives between the expert and Bowen (2005) were discussed and resolved before Bowen (2005) was convinced that the results of the study were rigorous. I asked the assistance of an expert in Phase 3 of the study. The expert and I discussed the results of the interviews as a way to address credibility and dependability of the study and arrived at a consensus. I also used CASP to address the credibility and dependability of my study.

Confirmability can be compared to objectivity in quantitative studies (Morrow, 2005; Trochim, 2006). It is the degree that one researcher can support the findings of another after evaluating the same data (Bowen, 2005). Confirmability can be assessed by using audit trails of data, notes, different products of the study, motives and expectations and instruments (Bowen, 2005; Shenton, 2004; Trochim, 2006). According to Shenton (2004), information such as the researcher's background, training, and professional credentials, along with other important information such as changes in techniques, changing the interview questions based on new knowledge, and any other information that could be pertinent in assessing the replication merits of the study, should be included in the report, and facilitates the use of audit trails. I ensured confirmability by procuring the assistance of another researcher to check the data and question the results.

Transferability is analogous to external validity in a quantitative study (Malterud, 2001). To assess transferability, any conclusions must be drawn out methodically and carefully, using the data of the study, and a comprehensive description of the participants is critical, along with descriptions about locations, culture, and environment (Malterud, 2001). I enhanced the transferability of the study by being thorough with the descriptions of the settings, participants, the culture, and the environment, so that my suppositions could be checked by other researchers. The use of CASP and the assistance of three experts was used in my study to assess and analyze trustworthiness of the study.

Role of the Researcher

In my study, I attended different parent-led support groups to recruit participants for the pilot study and the main study. According to Malterud (2001), by attending meetings researchers can get close to the people interviewed allowing researchers to put the participants at ease. The researcher should communicate the objectives of the study so the group understands the researcher's purpose (Malterud, 2001). I ensured that I divulged every interest that I had in attending the meeting, performing the study, and conducting interviews. I let them know that I had an interest in their well-being, and the well-being of their children. I made it clear to the participants of the study that I did not have any authority over them.

I managed bias in two ways. One way was by establishing boundaries (Shenton, 2004). Researchers can establish a boundary that distinguishes their role from the role of the study participants in order to prevent the introduction of bias (Malterud, 2001). This can be done by reflecting about any preconceptions based on previous experiences, and ensuring that these preconceptions are not introduced into the study (Malterud, 2001). The boundaries should be flexible enough to allow the researcher to adapt to the culture of the group while carrying out the purpose of the study (Malterud, 2001). A second way was to keep good notes, which can be used by other researchers to conduct an audit trail of the data (Shenton, 2004). Audio recordings were made during the interviews with permission from the participants, and transcribed into Microsoft Word documents.

With regard to ethics, there was strict confidentiality of the names of the participants of the study and their families. All considerations were taken to ensure that no harm came to anyone participating in this study. Before the study was conducted an IRB application was approved by the Walden University IRB. There were no ethical issues that could have been a result of conflicts of interest or compensation.

Ethical Procedures

The IRB reviewed the design of the study before it was administered to the respondents because the IRB serves as consultants reviewing the process from an objective source (Food and Drug Administration, 2014). The board constitutes people who are not involved in the design of the program methods, and clearly can provide an opinion that is impartial (Food and Drug Administration, 2014). Participants were asked to sign an informed consent form. Participants were not identifiable since their names were changed. The data was reported in aggregate form, no participant was identifiable from the final report. I was the only person that had access to the master record and the data collected. The master record and the data were stored at my residence in a locked cabinet. The master record (soft copies and hard copies) will be archived for five years after the completion of the study and later destroyed.

Summary

The study that I conducted pertained to parents of children with autism and their quest to get services that work. Parent-led support groups have been reported to facilitate advocacy for parents who strive for self-efficacy and become advocates for the children they care for. In this study, I examined if parent-led support groups assisted parents in becoming advocates and allowed the parents who were interviewed to share their experiences. The study was conducted as a qualitative study, with a phenomenological approach. The participants in the study were parents of children with autism who are advocates for their children or want to become advocates. The sampling was purposive and homogeneous in nature in order to select individuals with similar characteristics. The instruments used were questionnaires and recordings that were created during the interviews. The data was coded and analyzed using NVivo software. CASP for qualitative studies and other techniques were used to assess the trustworthiness of the study. The participants of the study were assured strict confidentiality, treated appropriately, and in accordance with IRB requirements. In Chapter 4 I report the execution of the study and provided feedback about the process.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to explore the influence that autism parent-led support groups may have in promoting advocacy among parents who have participated in the groups. Parents who participated in this study were involved in autism parent-led support groups for at least 6 months and some were involved with these groups for many years. These parents were the primary caregivers for their children. The study included parents of children with autism primarily from the ages of 2 to 12. Two participants were interviewed for the pilot study, and nine participants were interviewed for the main study. The participants were recruited using a form of purposive sampling called homogeneous sampling where participants are included based on similar characteristics (Neely-Barnes et al., 2011). All names in the pilot study and main study are fictitious to maintain confidentiality and protect the participants' identities.

In this chapter, I discuss the process of recruiting the participants of the study, conducting the interviews, data collection, and data analysis. I used the CASP questionnaire (Appendix K) during the data collection as a checklist and internal appraisal tool. Use of the CASP questionnaire assisted me in examining the trustworthiness of the sampling strategy, interviews, and data collection. Singh (2013) stated that CASP could help the researcher ensure that the qualitative study has content validity and reliability. From the interview transcripts, themes and patterns were identified as a part of the analysis of the data. The tools that were used in the interviews, coding, and analysis of the data will be described in this chapter. Ten interview questions (Appendices E and F) were based on four research questions.

Research Questions

The research questions were designed to evaluate the influence that parent-led support groups have on parents of children with autism and whether they facilitate advocacy among parents who participate in these groups.

Research Question 1. What is the perception of parents who participate in autism parent-led support groups about the value of the support group as a resource for information and support?

Research Question 2. How do informal (parent-led) support groups impact parental advocacy?

Research Question 3. How does parental advocacy impact decision making in caring for a child with autism?

Research Question 4. What tangible results do parents gain from their participation in parent-led support groups?

Purpose of the Study

The primary purpose of this study was to examine if autism parent-led support groups facilitate advocacy for parents who participate in the groups. Through interviews, parents gave their perspective about the value of parent-led support groups in providing social support. The domains of the social support theory—emotional support, instrumental support (concrete support), appraisal support (esteem support), and informational support (advice support)—make up a complete and inclusive support system that assists parents caring for a child with autism (Davis et al., 2011; Houston & Dolan, 2008; Pinkerton & Dolan, 2007). Social support is an important influence for parents who want to be advocates (Hoagwood et al., 2010; Mandell & Salzer, 2007). The interview questions (Appendices E and F) were used to examine the perceptions of social support within autism parent-led support groups.

Another purpose of the study was to document the experiences of parents who participate in autism parent-led support groups. Parents of children with autism believe that few people understand the difficulties that they live with daily and that their needs have not been met (Blanchard et al., 2006; Neely-Barnes et al., 2011; Schieve et al., 2007; Woodgate et al., 2008). In this study, it was important to find what those needs are and whether parent-led support groups meet those needs. If autism parent-led support groups provide the social support that leads to advocacy, how do parents acquire personal growth and become advocates? What events occur within the parental experience that leads to advocacy? These are the central concepts of my study.

Pilot Study

I recruited the first two participants of my study for the pilot study. The purpose of the pilot study was to test the instruments of the main study (Chenail, 2011) and to ensure the interview questions elicited a thoughtful and thorough responses. The pilot study participants were recruited with the same criteria as the participants in the main study. Sampling was purposive and homogenous. This sampling technique was used because it is an effective technique when studying one or more groups in great detail that have similarities or differences (Onwuegbuzie & Leech, 2007). Data from the pilot study interviews was not used in the main study. Conducting the pilot study helped me decide if the letter of informed consent, the screening questions (Appendices A and B), the demographics questions (Appendices C and D) and the interview questions (Appendices E and F) were appropriately worded and understandable. The participants of the pilot study found the letter of informed consent and questions clear and understandable. No changes were made to the letter of consent or any of the questions.

The pilot study participants were Ana and Dee. Ana is a mother of a 14-year-old and has participated in autism parent-led support groups for 7 years. Ana at times assists others who call seeking advice. The interview with Ana lasted 17 minutes. Dee was the second participant in the study. Dee is the mother of an 18-year-old and has participated in autism parent-led support groups for 2 years. Dee is a school counselor. The interview with Dee lasted 21 minutes. Ana and Dee responded to the questions quickly and had no problems understanding the questions. Both were recorded phone interviews conducted while they were at home. There were minor problems with the phone interviews. Finding a date and time to interview two participants was difficult due to their personal issues.

Setting

All participants in the main study were interviewed by phone. The interviews were scheduled through email. I initiated the phone calls to the participants at the agreed time. The phone interviews allowed the participants to interview from home or work. Rhonda, Diane, Cathy, Laura, Donald, and Nancy interviewed from home. John and Mabel were interviewed at work and Mary was interviewed from her car sitting outside her home to prevent interruptions. Most of the interviews went smoothly except for a few minor problems. Several participants commented about how smooth the phone interviews went. All the recordings were audible and understandable. During the interview with Donald, I lost the phone connection twice. I called Donald after each interruption and completed the interview. During the interview with John, the interview had to be delayed for 2 hours because John was very busy at work. After the delay, the interview commenced. I encountered a problem when I called Cathy for the interview. I could not reach Cathy even though the phone company ringtone indicated that the call was going out. The phone reception was poor in the location that I chose. I had to reschedule with Cathy after the first attempt to contact her and two more times after that because Cathy became ill. The interview with Mary also had to be rescheduled twice, due to family obligations.

The participants of the study were extremely interested in being interviewed. There were many emails and phone calls sent between the participants and myself. The questionnaires and consent forms had to be completed via email or by phone. None of the participants backed out of the study due to their busy schedules. Despite work, illness, caring for a child, the minor inconveniences of the phone interviews, and interruptions, they rescheduled and completed the interviews. Participants would apologize for having to reschedule interviews. On occasion, I would hear a child interrupting the mother or father during the interview and the parent would calmly speak to the child and then apologize for the interruption. During some of the interviews parents would laugh and other times they would cry as they responded to the interview questions. After the interviews, the gift cards were sent to the addresses that they gave me. One of the participants had me send the gift card to his son.

On my end, I conducted four interviews from work and seven interviews from my home office. At work, I conducted interviews during lunch. I made the phone calls using my cellphone, and the cellphone speaker was used for recording purposes with the recorder next to the speaker. At work, the rooms that I selected for the interviews were private rooms designed for training. All participants agreed to be on speaker and recorded. The participants were assured that the room was a private location. Before the interviews, they were reminded of my obligation to maintain their privacy and confidentiality. Upon completion of the interviews, the recordings and transcripts were locked in a storage cabinet within my home.

Demographics

Of the nine participants in the main study, seven participants were mothers, and two participants were fathers of children with autism. Four of the parents were participants of in-person, parent-led support groups, and five parents belonged to both in-person and online support groups. The demographics of the parents are contained in Table 1. The ages of the children of the participants ranged from 2 years old to 16 years old, and all of the children were boys. The length of participation in parent-led support groups ranged from 7 months to 7 years. Parents in this study participated in parent-led support groups from one to 20 or more meetings per year. All the participants were over 18 years old.

Table 1.

Descriptive Demographics for the Study Participants

Participant Code	Age of Child with Autism	Length of Participation in Parent-led Support Group	Group Type	# of Meetings Attended this Year	Length of the Interview	Gender
Ana (Pilot 1)	14	7 years	B	20	17:32	Female
Dee (Pilot 2)	18	2 years	I	1	21:40	Female
Rhonda	8	6 years	B	Extensively	29:14	Female
Diane	4	2 years	I	8	22:34	Female
John	5	7 months	I	2	16:22	Male
Mabel	6	18 months	I	6	32:22	Female
Cathy	10	7 years	B	20	14:21	Female
Laura	16	4 years	B	7	22:58	Female
Donald	9	7 years	B	12	50:52	Male
Mary	12	6 years	B	14	55:45	Female
Nancy	2, 3, 6	1 year	I	1	13:22	Female

Note: Lengths of interviews stated in minutes and seconds. Group Type I is for in-person, and B is for both online and in-person support groups.

Data Collection

To establish contact with possible participants, emails were sent to in-person parent-led support groups in Oklahoma, Texas, and Kansas, and to online support groups, as well. In Oklahoma and Texas, facilitators for in-person support groups responded to my emails and scheduled me as a guest speaker. I visited three parent-led support groups in Oklahoma and two in Texas. Letters of cooperation were signed giving me permission to attend the meetings. In the meetings, I briefly discussed my study and distributed interview packets. The interview packets contained a cover letter with my information, a demographics questionnaire (Appendices C and D), a screening questionnaire (Appendices A and B), and a letter of informed consent. I created interview packets in English and Spanish. The online groups were closed groups, so posting directly to the group was prohibited. The group moderators posted my information to the group. Collectively, I was able to recruit 11 participants, two for the pilot study and nine for the main study.

After receiving IRB approval, I began attending meetings. The IRB approval number for this study is 01-04-16-0063040. From January 2016 to October 2016, I attended parent-led support groups. From August 2016 to October 2016, I conducted interviews. I recruited the participants for my study from three autism parent-led support groups. One group was an in-person group in Texas and the other two groups were closed online groups.

For the first half of 2016, I experienced difficulties in finding participants for my study. Some of the difficulties that I experienced were due to weather and scheduling.

Difficulties in scheduling occurred because many groups were already booked with guest speakers. On several occasions, I waited months to speak to the groups. Since the support groups only met once a month, scheduling presented challenges.

After my visit to a support group in April 2016, I reached the conclusion that I would have to expand my study because several group members showed interest in participating; however, the criteria for participating in my study was too restrictive to include them. I had limited the participation in my study to parents of children with autism between the ages of 2 and 12 and from the Oklahoma City area. I requested IRB approval to include parents of children with autism of any age, and expanded the study to Texas, Kansas, online, and provided compensation for participation in the form of a $25 gift card. I received IRB approval for these changes to the study. After expanding the study, I was able to recruit sufficient participants for my study.

The first two participants who responded were in the pilot study. One participant was from both an online group and had participated in an in-person group before. The other participant was from an in-person parent-led support group from Oklahoma. These were the first two participants. Of the nine participants in the main study, four were recruited from an in-person group from Texas, and five were recruited from closed online groups and had participated in both types of groups. Interested participants contacted me via email or phone.

I used a screening questionnaire (Appendices A and B) to screen participants in the pilot study and the main study. The inclusion criteria for participating in my study was having a child of any age with one of the ASDs, current participation in parent-led support groups for at least six months, interest in my study, age at least 18 years, and the ability to speak and understand English or Spanish.

All participants preferred to be interviewed by phone. Since most of the participants lived at least 3 hours away, this was a convenient way for me to interview them. Telephone interviews also made it easier for me to reschedule interviews when they had to be postponed. The participants chose where they would be during the interview. Seven participants were at home while two were at work. A specific date and time were scheduled for the interviews.

At least a few days before each interview, I emailed an interview packet containing the screening questionnaire (Appendices A and B), a demographics questionnaire (Appendices C and D) and a letter of consent which had to be completed before the start of the interview. The packets containing the documents were emailed back to me. The letter of consent explained the purpose of the study, the interview process, and the participants' rights. Each of the participants was reminded that the interviews were confidential and they could back out of the interview at any time. Every participant received a $25 gift card by mail.

All interviews were conducted in English. Interviews lasted from 13 minutes to almost an hour. All participants consented on the recorder to being recorded. Before the interviews, I asked if there were any concerns or questions about the letter of consent. Four of the participants had to reschedule due to time constraints, or family illness. Two interviews had to be rescheduled more than once. I made sure that the participants were comfortable with the interviews and could spare the time to be interviewed. If it was a bad time for the participant, I rescheduled the interview.

For the interviews, I used my cellphone to place the calls. I put the phone on speaker and assured the participants that no one else was in the room. I chose a room in my house or a private room at work to conduct the interviews. With the phone on speaker and a Sony ICD-PX440 digital recorder, I recorded the interviews. After the interview, I thanked the participant and asked where I could mail the $25 gift card. All gift cards were sent out to the participants.

Data Analysis

The Process

The interviews were conducted as described in Chapter 3. Interview transcriptions were verbatim. Participants responded to 10 questions. I did not use follow up questions (Appendices G and H), during the interviews. The questions were open-ended allowing the participants to respond openly and give as many details as they could (Gill & Liamputtong, 2009). Some interviews had emotional moments causing discomfort to the participants. One participant cried during most of the interview. When I could hear participants were experiencing discomfort, they were given time to respond and were asked if they wanted to continue with the interview. All participants continued with the interview.

The interviews were transcribed verbatim by listening to the recordings numerous times to capture the exact words and phrases of the responses. Microsoft Word was used as the text editor. Shortly after completion of each transcript, I reviewed it for errors.

Spelling errors were corrected, and a comparison was made between the transcript and the recorded interview. Another review was performed after all transcriptions were completed to obtain general ideas and conceptual information contained in the transcripts which could lead to identifying themes (Morrow, 2005; Woodgate et al., 2008). The interviews were read thoroughly to retrieve the meaning of the participants (Shenton, 2004). Data quality and patterns were identified by reading the transcripts often (Bowen, 2005; Morrow, 2005).

QSR International's NVivo 11 was used to code the data based on the text in the participant responses. Programs such as NVivo help with the coding and theme development (Bowen, 2005). To code the data, the transcripts were imported into QSR International's NVivo 11. Familiarity with the transcripts made it possible to establish codes (QSR, n. d.). I coded the sentences or passages of text into one or more codes and modified the codes based on the emergence of new meaning and new categories. After establishing the codes, I compared each piece of text and assigned it into one code. I checked the codes again and added text next to the code to make sure the code and data were consistent. In a phenomenology study, a code can be established right away, and nodes can be created based on each code (QSR, n. d.). Similar nodes were grouped together to form themes. I extracted themes by looking at the data and finding similarities or differences in the responses (Namey et al., 2007). Throughout the analysis process, I made sure that I followed the steps to consider for a rigorous data analysis. I described the analysis process, and developed clear themes from the data, I noted contradictory data, and examined my role as the researcher to reduce bias by following the guidelines for the study that I set up in Chapter 3. Table 2 shows the codes with the greatest number of references.

Table 2.

Emerging Codes from Participants' Interviews

Code	# of References
I joined a support group to meet people who have gone through it, who understand	20
Difficultly funding child care	9
Groups provide emotional support	9
Groups provide informational support	9
Support groups assist in becoming an advocate	9
Groups assist with caring for child	7
Groups facilitate empowerment	7
Groups do not provide instrumental support	7
Parent-led support groups provided appraisal support	7
I joined a parent-led support group to get more information	6
Ensuring son gets what he needs	5
Promoting a better future for your child, similar children	5
Groups provide instrumental support	5
Had to pay out of pocket for a lot of things, hundreds of thousands of dollars	4
Benefits of support groups are friendships, connecting with other mothers or families	4
A lot of treatments not funded by Medicaid or insurance	3
Appraisal support is the same as emotional support	3
Groups connect us with resources, equip with tools	3

To increase the dependability and confirmability of the study, I consulted with a researcher who is an expert in using NVivo. We reviewed the codes and arrived at a consensus about the codes. According to Bowen (2005), dependability and confirmability of a study can be enhanced by utilizing an expert to discuss the coded data, and arrive at a consensus on the coding. Based on the data, six main themes were identified.

Emerging Themes

The emerging themes were developed from the codes. The themes were developed by grouping the codes into groups based on the similarity of the responses (Table 3).

Table 3.

Themes

Advocacy	Codes Associated
	Ensuring son gets what he needs
	Promoting a better future for your child, similar children
	Groups facilitate empowerment
	Support groups assist in becoming an advocate
Emotional Support	Codes Associated
	Groups provide emotional support
	I joined a support group to meet people who have gone through it, who understand
	Benefits of support groups are friendship, connecting with other mothers or families
Difficulty with Funding	Codes Associated
	Difficulty funding child care
	Had to pay out of pocket for a lot of things, hundreds of thousands of dollars
	A lot of treatments not funded by Medicaid or insurance
Informational Support	Codes Associated
	Groups provide informational support
	I joined a parent-led support group to get more information
	Groups connect us with resources, equip with tools
	Groups assist with caring for child
Instrumental Support	Codes Associated
	Groups do not provide instrumental support
	Groups provide instrumental support
Appraisal Support	Codes Associated
	Parent-led support groups provided appraisal support
	Appraisal support is the same as emotional support

Themes

Theme 1: Advocacy

The term advocacy had a similar meaning to all the parents. All participants professed to advocate for better resources, medically and financially for their children and other children. Finding services for their children and the children of other parents was the primary reason for becoming an advocate. Most parents stated that parent-led support groups facilitated two facets of advocacy, providing the knowledge necessary to advocate for their child, and empowerment. Participants stood up for their children when the schools did not provide the proper services. They believed that without their active participation in meetings with school officials, the school programs would fall short of their needs. Some parents moved from one school district to another in order to better meet their child's needs. Parents were active in finding doctors, making referrals, and finding ways to increase the quality of life of their child.

Mabel indicated her resolve to advocate for her son so that he got what he needed. Mabel indicated her concern with her son being lost and scared, since he has limited verbal skills. She said:

> When I think of advocacy I think of what we have tried to do in order to change our lives and to find a better life for our son. For example, where we lived previously, the school did not have a good program for him, so we moved the whole family so he could attend another school; a school that would be better for him. Another example of advocating for my child was to get him a GPS transmitter. We have a GPS on him because he runs. The problem is that he will

> hide and get into a small space. My child is limited verbal and will not respond to his name. So if we lost him he would be terrified. No one can be a better advocate for him than we are. Nobody loves him like we do. So I don't think that anyone else could be his advocate. I have to be the principal advocate for him. I let people help but they don't care as much as I do.

Mary indicated that she has been advocating for her son's needs and the needs of other children in order to make a change to society. She had to fight to get more than the minimum services in the state that she lives in. Mary explained that becoming an advocate required identifying the needs first, then performing an action to meet those needs. She said:

> From the beginning you learned that you were just given the minimum services and then you have to go and identify what you need and fight for it to get a more appropriate level. The first phase is to identify what the issues are, in order to promote and support someone in getting something they need, or to advocate for a cause, something that you believe in. Aside from getting help from others, advocacy means to persuade society or the people in a profession to understand something in a new way so there is change.

Diane indicated that advocating for medical resources and services has her scheduling many referrals. Diane, a special education professional, indicated having formal advocacy training. Diane participated in parent advocacy training through a parent-led support group. She explained:

> I have had to advocate for my son and find the right medical resources. I find

> out what types of resources and services are available and then I advocate for my child by seeking the resources and services. I schedule a lot of medical, school related or therapy type of referrals. Sometimes I battle with the insurance company because the insurance company has decided that it will not give approval to see another neurologist. I am a special education professional myself and so I've seen more what other children are getting. I attended a parent advocacy training that they offered here and it was 10 weeks long, I think it was 6 hours a week.

Rhonda emphasized the importance of parent-led support groups in assisting with promoting a better future for her child. Her son has been integrated into a regular classroom where he is doing fine. Rhonda indicated that the next step is to include her eight year old son as a participant in Individual Education Program (IEP) meetings so he can give input into designing his future. She said:

> My son is working well in a regular classroom. He has improved socially, academically, and behaviorally because of the advice and information that was given to me by parent led support groups. Recently, I have been thinking about self advocacy and I am trying to teach him how to advocate for himself. I just spoke in a IEP meeting about how to incorporate him into future meetings. I think it is very important that the kids have a say in designing their future.

Laura indicated that parent-led support groups facilitate empowerment depending on the personality of the parents who attend the meetings. Laura stated that her group had a core collection of parents who were motivated and their attendance empowered others. She stated:

> There is a core group of us who are very motivated to empower and advocate. There are other parents who are either very new to the journey or tend to be a little more introverted, and meek. If the motivated group of parents are at the meeting, the group is empowering. Empowerment is driven by the personality, experiences, and advocacy skills of the parents that have been through it. These parents can engage with, motivate, and give power to the parents who aren't sure, don't know, are overwhelmed, are introverted, or don't have an assertive personality. In my opinion, you need to have those powerful personality types in the group to facilitate empowerment.

Mary felt that parent-led support groups do empower group participants. Interacting with others in a group who have overcome obstacles increases the confidence and give encouragement. She stated: "It gives you greater confidence that others can do it. You feel that you can learn something from them. They serve as role models."

Diane also felt that parent-led support groups facilitated empowerment. She stated: "Getting information about what resources and services are out there gives you a feeling of empowerment. It is empowering to know that there is something that I can do."

Mabel believed strongly in parent-led support groups. She said: "I think from a scale of 1 to 10, it is going to be a 10 for facilitating empowerment. You hear what others are doing and this gives you something to think about."

Theme 2: Emotional Support

Parents indicated that emotional support was a primary reason for attending parent-led support group meetings. Both in-person and online parent-led support groups provided emotional support based on common experiences, according to all the parents interviewed. Parents found that other parents understood the difficulties associated with raising a child with autism and provided empathy and encouragement. All parents stated that parent-led support groups provided emotional support. This support made it easier for parents to cope with their situation. Making a connection with others who understood their situation was important to parents. These connections assisted parents emotionally and gave them confidence.

Cathy responded that people who participate in these groups can relate to what you are going through. She said:

> You always feel like there is somebody else out there that understands what is going on within the support groups. Since my son has a severe form of autism, there are always constant challenges. Being able to talk to fellow parents that are going through the same thing as us gives us emotional support. Support groups give us the ability to connect with other people who understand what we are going through because we share a common experience.

Diane felt that parents who have been through these experiences can give emotional support by sharing successes and assurances that life may get easier as the child ages. She stated:

> You hear from other parents that they will accept my call if I need to talk. Hearing from other parents who had the same experiences and who provide support by telling you that you are doing a great job is very helpful. This makes support groups a great resource.

Rhonda revealed that she belongs to many online groups and these online groups can provide emotional support at midnight when she can find time to participate online. Rhonda communicates with several Facebook and Yahoo! support groups. These groups help her to vent and interface with others who understand and identify with the issues that parents of children with autism face. She stated:

> Communicating with a parent-led support group can help navigate all those emotions and help keep you steady on the right path. Just the fact that you can access people who have gone through that before can really help you through the dark moments and help you appreciate the positive moments. This can help you make it through the next challenge. So I think it is very important to share our successes with each other. This builds the parent's esteem and supports the perception that the parent is doing okay.

Mary stated that not all parents are capable of providing emotional support. The personality of the parent plays an important part in their ability to extend emotional support to another parent. She stated:

> I think that there's been so many times that I have been crying on somebody's shoulder, because I am exasperated and fearful. Any parent that has been in a similar position as mine at one point or another can provide emotional support.

> They may show empathy and understanding based on their own experiences. They can validate what you are going through. Compassion and understanding is just greater from someone who has been there versus a professional who is educated in autism and may see a lot of families. Also, parents who are willing to be open and seek to support others, can provide emotional support. Conversely, there are parents out there who are experiencing the same issues and can be cold and withdrawn and if we don't look at the issues in the same way, they could have the opposite effect.

Theme 3: Difficulty with Funding

Funding for the treatments and therapies was a problem for parents, since private insurance and Medicaid did not pay for many of the expenses. These expenses were a burden to parents who over the years spent thousands of dollars in out of pocket expenses. All parents except John indicated having problems with funding for the treatments. Parents who moved from one state to another said the number of services available varied from state to state. Parents felt that out of pocket costs were high because of difficulties in finding the right type of funding. Other parents could not work because they stayed home to provide care. Parents mentioned diverse types of treatments that presented a burden because either they were not covered by insurance or they were very expensive. Rhonda specified certain treatments that Medicaid and health insurance would not pay. She explained:

> Yes, funding is always an ongoing issue. Many of the treatments that a lot of parents are finding helpful are not funded by Medicaid and mainstream

> insurances. You have to go out of pocket for those and I have to learn which treatments are tax deductible, where I can get discounts, and what scholarships are available. We have had to pay out of pocket for a lot of different things over the years. One of our out of pocket costs have been special diets. There is no funding for a child who needs a special diet. Some of it can be tax deductible, which does help. A valuable reason to join different mentoring groups is because they can guide you through the process of getting things funded. Over the years we have paid tens of thousands of dollars on different therapies and supplements and other things, like iPads. It is costly to have a kid with developmental disabilities.

Cathy who also has Medicaid indicated problems in finding good doctors. Cathy indicated that she was going to move to another state so that she could get better services for her son. She said:

> The medical care in this town is awful. I do not trust the doctors here and hope that will change when we move to another state. My son has autism and also suffers seizures. In this town there is only one neurologist that deals with neurological problems and also accepts Medicaid. For over a year now we have been trying to see the doctor and each appointment is cancelled. My fiancée is now looking for a job, we are unemployed. The only income coming in right now is my son's SSI check and food stamps. So we are having funding issues especially in this town where nobody wants to take Medicaid.

Laura had funding issues also. She and her family moved from a state with good resources to a state that presented funding problems. She stated:

> In the previous state that we lived in the funding was much better than in this state. Here we have out of pocket expenses. I have chosen not to put my child in the public school system, so I have to pay for his one-on-one aide. My son has special needs that are not covered by insurance.

Diane indicated that funding was a problem because her income was too high for services. The out of pocket expenses are high because there has been very little assistance. She stated:

> I do fall into the upper part of the mid salary range. There is absolutely no financial support, and there are so many extra supplements. We try everything to get our child back from regression. We have paid thousands of dollars on therapies and co-pays for therapies and doctors. Our costs are already in the thousands per year, and we are only in the third year of this.

Donald reported having funding problems due to medical insurance nonpayment. Donald has to call the insurance company to resolve issues with his insurance on a monthly basis. He stated:

> My main difficulties with funding have been dealing with the insurance. The difficulties have been with getting services reimbursed in accordance with the health insurance plans. The health insurance administrators make errors. Fortunately, I haven't had to call them in several months. But there have been times when I have had to call them every month to work out clerical and billing

> errors and try to get appropriately reimbursed for my child's healthcare. That is the main challenge that we have. For a while, I worked for a company that didn't have a very good health insurance program and some services that my son needed we could not afford.

Nancy has three children on the Autism Spectrum Disorders. The problems that Nancy faces with funding are because her family is not considered low income. She said:

> We have been declined for speech and occupational therapy at different times. This therapy is absolutely necessary for my boys. Just recently, we were turned down for speech therapy because my son is bilingual. They are not taking into consideration he is on the autism spectrum. I also tried to get social security three times. It is only for very low funded people and if you have an extra vehicle or anything of value, you are turned down. Because I have three boys on the spectrum it is hard for me and the respite care waiting list is 10 to 11 years long. So things are difficult sometimes.

John did agree with other parents that treatments were expensive, although his family was not having problems with funding the treatments. He said: "The treatments and services are costly; however, we are doing OK, and have found ourselves financially able to meet those costs."

Theme 4: Informational Support

All parents indicated the importance of receiving timely information to find treatments that would help their children. Parents indicated that parent-led support groups provide a great deal of information. Parents believe that information fosters advocacy and empowerment.

Parents stated that in-person parent-led support groups invite guest speakers to the meetings from the medical and legal professions, education professions, insurance professions, and advocate groups. Donald indicated the information provided by the guest speakers helped him to navigate through the school system, the legal system, and therapies. He stated:

> The informational support is informational support about the local schools, the local school districts, local therapists, doctors, quality of attorneys and advocates. There is information on how the state support system works and how to utilize those services. I think what is most valuable for me as a parent advocate has been attending the sessions with attorneys who outlined the laws and empowered me and gave me a lot of information so that I can advocate for my son.

Diane gave the most importance to getting information about resources. As a parent Diane wants to try new treatments that can make a difference. She stated:

> Parent-led support groups provide information that helps parents find good resources within the area. The groups help parents find the better resources. There are many things that we want to try and sometimes the groups will have information about nutritional supplements, various doctors, or various parent-led support groups. They have helped us find information.

Rhonda made a statement that, collectively, parent-led support participants have more knowledge and a better understanding of how the system works than state case workers. She said:

> The greatest source for information to parents is other parents. Parents have been through the challenges before, and they know how to navigate the system, even more so than a state-funded worker or a case worker. Parents are the foot soldiers on the ground and are motivated because it impacts their lives. The motivation is true and honest with a goal of getting answers and solving problems. Parents pass that information to others because once you live through an experience, you want others to gain from your knowledge.

Some parents recalled when they first learned that their child had autism. They felt alone, without support and did not know which way to turn. From that experience parents learned of the importance of timely information. Donald indicated that he and his spouse knew very little about autism. As a result, Donald took his son to four different places for the diagnosis. The second neurologist he visited recommended a parent-led support group. He stated:

> When my son was diagnosed with autism. I didn't know anything about autism. I had no idea what it was or how to treat it. Unfortunately, we had our son diagnosed in four different places. First time by a neurologist who gave us a screening questionnaire which was just a number of questions from a sheet of paper. His diagnosis was immediate he said "your son has severe autism." So come back in 30 days and we'll talk more. That was kind of scary, we did not

> have a lot of support. We were just told that our son had autism and no support. So my wife found a pediatrician for a second opinion and a pediatric neurologist. The pediatrician provided us with a reference to start with, talked to us about the IEP, and recommended a parent-led support group. The parents of the support group were parents in similar situations with children diagnosed at an early age and they were basically the experts on how to treat these kids.

Diane explained a similar experience when her son regressed, she did not know where to turn. She stated:

> When he was two, not knowing what to do with a sudden regression and major developmental problems which happened at 18 months old, prompted me want to talk to other parents to get ideas, resources, support and encouragement. When a child is young it is important to weed out the resources. When he first experienced the regression, it took a lot of the joy of parenting away and we had some hard months. As we got support, it became easier to accept the difficulties that he was having. Before regression he was developing normally and then suddenly he was not. It was very difficult to accept a lot of what was going on. As we worked with some of the parents in the groups, got ideas and heard their stories we felt better. It helped us move forward, it helped us make progress and it made for a much better situation overall.

Rhonda spoke about the success that she had with the information learned in parent-led support groups. Her child is successful socially and academically due to the information sharing within the parent-led support groups. She said:

> I think that parent-led support groups are far and away the most valuable resource to me in my autism journey. I would never have made it where I am today with my kid, to be able to function in a regular classroom, to be where he is at socially and academically and just behaviorally without having the advice and information that was given to me by the parent-led support groups. Parents have been through it before and they want to share their information and experience to help other people. It is a very genuine love that they have for other parents who are going through a similar situation. It has been invaluable.

Theme 5: Instrumental Support

Instrumental support is monetary support such as scholarships and stipends, or other support, such as making phone calls, and writing emails on behalf of the parent. Many parents had not received this type of support from their groups. Donald, John and Rhonda responded that parent-led support groups do provide instrumental support, while Cathy, Diane, Mabel and Nancy responded that parent-led support groups did not provide instrumental support. Laura indicated that both in a previous state and the present state that she has lived in, the parent-led support groups provided instrumental support; however, the type of instrumental support varied.

Donald responded that he did not receive money from the support group. The instrumental support was with a lawyer that was set up by the support group. He stated:

> We've not received any monetary support from the support group, but at one point they had an in-house attorney that was providing customized assistance to

> parents who were interested. And she would provide limited advocacy services that were valuable and otherwise would cost something.

Rhonda indicated that parent-led support groups are becoming very resourceful in getting products that would normally cost money. She stated:

> A lot of the parent mentoring and parent led organizations are also getting very savvy about finding funding for different things such as communications devices and event monitors. One of the organizations that I am involved with is very good at outlining things and where to get these items. They tell you who pays for what and how to get this funded. So they don't provide the funding themselves, but they can provide resources and links of places where you can go to get funding for certain things.

Cathy responded that she has not experienced instrumental support. She said: "At least not that I have come across yet."

Mabel felt that parent-led support groups may point to services, but they do not make phone calls or set up appointments for you. She said:

> For them to be doing something for me, that would be a no, I don't think that they do something for me. They give me ideas and I have to take the ideas and go with it. They are not going to make phone calls for me. There is some support from the community called TLC, paid by the state. I have been on the waiting list since he was diagnosed four years ago. Eventually, they help to find therapies but we are waiting for them to do that and we are missing early intervention because of this.

Laura compared the differences in instrumental support between the two states she has lived in. Both states that Laura has lived in provided funds for respite care. She stated:

> Once a year I have received $100.00 for respite care. The autism society funded respite care in both states I have lived in. In the present state the autism society has a fulltime staff person that assists in getting resources for the parents once the parents say what resources they need, which was not available in the previous state that I lived in.

Theme 6: Appraisal Support

Appraisal support provides a parent with greater self-esteem. This type of support gives parents confidence, knowing that they are doing the right thing, and that they are good parents. Laura, Nancy, John, and Rhonda said that parent-led support groups provided appraisal support. Cathy, Diane, and Mary agreed and added that they viewed appraisal support the same as emotional support. Mabel and Donald responded that some parent-led support groups did not provide appraisal support for them.

Laura indicated that parent-led support groups do provide appraisal support. She felt that other people in the group understood what she was going through and they did not judge her as a parent. She stated:

> I think that the collective job of the parent led support group is to provide appraisal support. We do not go there to judge. Everybody is in a different spot in their journey. Everybody has a different educational background, and different family support. Their kids are attending different types of schools where there

> may or may not the same services, so part of what we try to do is not to make people feel stupid because they don't know. So we build each other up and say, hey we are here to help each other.

Rhonda responded that parent-led support groups can create enthusiasm and lift the emotions, thereby, providing appraisal support. She stated:

> Definitely, they can really uplift emotions, boost your enthusiasm. A common cause can produce new energy and you are able to accomplish more and feel more empowered. So by going to different groups or chatting with people online, you feel empowered, feel confident and you feel ready to take that next step.

Mabel responded that parent-led support groups did not provide appraisal support because sometimes she feels worse after the meetings. Mabel has tried many treatments and none seem to work. She said:

> It is more difficult for me and sometimes I feel worse after I go to the support group and the reason I feel worse is because I hear about what this kid is doing, this kind of therapy or dietary intervention and I never feel like we are doing enough. I think if he would get the right therapy he would be fixed. I read different things I want to try. We have done gluten free, dairy free and many other diets. I am always looking for that one thing that is going to fix him. I have tried many different things for my son. So when I hear about a parent trying something, I think that I have missed it. It is an emotional issue for me, so I cry.

Donald noted that in-person parent-led support groups do provide appraisal support whereas, a local listserv does not. Donald made a distinction between online support groups which are a good resource for information and do help others with appraisal support and listserv groups that do not. He said:

> Some dad oriented groups are online listserv support groups. In my opinion, they tend to invite people to express their thoughts in negative ways and allow group members to be very critical about the ways that other parents are trying to help their children. I think when I attend an in-person group, I feel more appraisal support. Generally, online support groups are a good source of information and can provide appraisal support to other parents. Parents ask questions online, such as, looking for a good doctor, a good attorney, or a good advocate in the area. In many cases they get immediate answers on the same day or the next. Basically, online support groups fulfill a need and I think that it helps parents that are feeling down, get information and lift their spirits.

Discrepant Cases

There were two discrepant cases in this study. The first discrepant case involved appraisal support. Two participants, Mabel and Donald responded that some parent-led support groups did not provide appraisal support for them. Donald stated that the online group in which he participates provided appraisal support, but the local listserv did not. All other participants responded that parent-led support groups did provide appraisal support.

The second discrepant case involved difficulty with funding. John indicated that although his child’s treatments were expensive, his family had no problems with funding.

No other participant in this study shared this view. All other participants stated that they had difficulty funding their child's treatment.

Evidence of Trustworthiness

Credibility

Bowen (2005) described credibility as understanding the context of the data, an accurate perception of the data and establishing that the findings are true. Likewise, the perspectives of the participants must be credible or believable in order to ensure credibility (Shenton, 2004; Trochim, 2006). Shenton (2004) recommended the scrutiny of others who may be experts in the field. In order to better assess the architecture of the study, I consulted with a panel of experts who work with parents of children with autism, before conducting my study. These people work for the Lee Mitchener Tolbert Center for Developmental Disabilities and Autism in Oklahoma City. My purpose was to get feedback from them on the study questionnaires. I created an interview guide which they scrutinized. I also requested they provide written response by completing the *Form for Review and Evaluation of Validity and Reliability by a Panel of Experts for Qualitative Instrumentation* (Appendices I and J).

Based on their recommendations I modified the language to include People First Language in all the documents that I created. The People First Language was helpful when communicating with parents during the interviews, leaders of support groups, advocates that I met while visiting support groups and recruiting participants. The premise of People First Language is to change the perception of people towards people with disabilities (Snow, 2013). Using People First Language changes the labels that are hurtful to people with disabilities (Snow, 2013).

Another step that I took to increase the credibility of my study was to record the interviews and accurately transcribe the language of the participants. Shenton (2004) describes recording interviews as a measure to increase the credibility of a study.

Transferability

To assess transferability, conclusions must be drawn out methodically and carefully using the data of the study; a comprehensive description of the participants of the study is critical, along with descriptions about locations, culture, and environment (Malterud, 2001). I discussed the locations, culture and environment in this chapter where I discussed the setting. With the descriptions of the settings, participants, the culture and the environment, my suppositions can be checked by other researchers. The use of CASP (Appendix K) questions and the assistance of an expert were also used in my study to ensure the trustworthiness of the study.

Dependability

Shenton (2004) indicated that dependability relies on describing the process of recruiting the participants, conducting the interviews, analyzing the data, and reporting the data in great detail. I kept detailed records of the process, allowing other researchers to follow the same process and repeat the work. I established a plan in Chapter 3 that outlined how I would conduct the study and executed it accordingly to the plan. I also described in this chapter how I gathered the data, the effectiveness of the plan and modifications that I had to make to the plan.

Confirmability

Confirmability can be assessed by using audit trails of data, notes, different products of the study, motives and expectations, and instruments (Bowen, 2005; Shenton, 2004; Trochim, 2006). I requested the assistance of an expert in qualitative studies who is an experienced researcher. The expert has worked with graduate students for 16 years as a committee member and Chair. We discussed my study and arrived at a consensus about the codes. I followed the recommendations of the expert in developing the themes of the study. Bowen (2005) noted that the use of an expert increases the dependability and confirmability of a study.

Results

The findings reported in this chapter show that parent-led support groups provided informational, emotional, and appraisal support, as well as the tools necessary for the participants to become advocates for their children. In regards to parent-led support groups providing instrumental support, five of nine participants agreed. The majority of the participants stated that funding for their child's treatments and services was difficult to obtain.

Research Question 1

For the first research question regarding the value of the support groups as a resource for information and support, participants of the study indicated that support groups were a valuable resource for information, emotional support, and appraisal support. Participants stated getting information about schools, therapies, doctors, and attorneys. The information assisted parents in finding resources shortly after the initial diagnosis and throughout their child's development. Participants stated that parent-led support groups provided emotional support because other parents understood the difficulties of raising a child with autism. Participants also stated that parent-led support groups provided appraisal support by lifting parents' spirits and creating enthusiasm.

Research Question 2

For the second research question regarding how informal parent-led support groups impacted parental advocacy, participants stated that parent-led support groups gave parents the tools needed to advocate for their children and the children of others. Participants indicated that parent-led support groups empowered parents and provided them with the confidence needed to advocate for resources.

Research Question 3

For the third research question regarding the impact of parental advocacy on decision making in caring for a child with autism, participants indicated that advocacy was a necessary skill that parents needed to acquire to provide the resources and therapies that were available and difficult to get. Parental advocacy was developed as parents searched for different solutions that could be implemented. Participants stated that information sharing was an invaluable aspect of attending parent-led support groups.

Research Question 4

Regarding the fourth research question about the tangible results parents gained from their participation in parent-led support groups, participants stated that parent-led support groups yielded tangible results shortly after the initial diagnosis, when it was critical to begin early treatment. Through participation in parent-led support groups, participants were able to find the right doctors and therapies. Participants also indicated finding good schools that met their needs. Finding funding for treatments from third parties was also discussed as an important tangible result of parent-led support group participation.

Summary

In this study, I examined parent-led support groups and whether these groups facilitated advocacy. Data collection for this study was acquired through nine recorded interviews from in-person and online parent-led support groups. From the interviews verbatim transcripts were created that were used for coding of the data. Data was coded using NVivo 11 and six themes were created from the codes. The major themes were advocacy, emotional support, difficulty with funding, and informational support, instrumental support and appraisal support.

As primary caregivers, parents described the difficulties in finding services, medical care, and funding. Parents also emphasized their resolve to continue the journey regardless of the challenges and hurdles. Each parent felt that parent-led support groups were very effective in providing emotional and informational support. They also felt empowered because of their participation in parent-led support groups.

During the interviews parents spoke openly about information sharing, connecting with others, assisting others, and the common experience that brought them together. Parents realized that they could not go through the journey alone, so they connected with each other through in-person and online parent-led support groups. Technology provided more options to access the information they needed through online support groups.

Parents felt that information sharing facilitated advocacy. In Chapter 5 the findings, conclusions, and recommendations are discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Purpose of the Study

The main purpose of this study was to examine the effect that autism parent-led support groups had in facilitating advocacy skills among participants. To understand the relationship between participation in parent-led support groups and advocacy, I conducted this qualitative study. I used a phenomenological approach with purposive sampling for the study. To accomplish data collection, I created 10 open-ended questions and conducted digitally recorded interviews, using my cellular phone as my communications tool. In the interviews, participants (parents) described the role that parent-led support groups had in assisting them as they advocated for better services and treatments for their child. All participants of this study reported having participated with in-person parent led support groups and half participated with online groups.

Key Findings

The themes developed from the data were advocacy, emotional support, difficulty in funding, informational support, instrumental support, and appraisal support (Table 3). In the study, I used the constructs of the social support theory to examine the support provided by parent-led support groups. According to the literature, the components of the social support theory, emotional support, informational support, instrumental support, and appraisal support, could be acquired through parent-led support group participation (Davis et al., 2011; Houston & Dolan, 2008; Pinkerton & Dolan, 2007).

Interpretation of the Findings

Extending Knowledge

Few studies have examined the relationship between participation in parent-led support groups and parental advocacy. The findings of this study extend the knowledge about the effectiveness of parent led support groups in facilitating advocacy, and the role of the support groups in influencing parental decisions regarding treatments, doctors, and funding. According to most of the participants of this study, the emotional, informational, and appraisal support provided by parent-led support groups assisted in parents becoming advocates for their child. Most parents stated that the external knowledge provided by guest speakers and the parental experiences of other group members were synergistic and influenced decision making for resources.

Most parents saw themselves as advocates for their child. They felt they could advocate better than anyone else. Parents felt that their knowledge of their child's condition, and the concern they maintained for the welfare of their child, made them the best advocates. Two participants indicated having formal advocacy training and another participant had an interest in getting that training. Those parents regarded advocacy training as an important educational opportunity which provided useful information for navigating the system, and increased their ability to advocate for better resources. A study by Banuch et al. (2010) concluded that six sessions of advocacy training made participants more aware and empowered although, participants felt they would benefit more from longer lasting training.

All but one participant stated having difficulty in funding their child's treatments and therapies. All parents felt that out of pocket expenses were costly. Parents spoke of having health insurance that covered some of the costs, but did not cover nutrition, supplements, diverse treatments, doctors, and therapies. Two participants stated that Medicaid would not pay for certain treatments and one participant indicated having problems finding a doctor that accepted Medicaid. This information can assist society in understanding the medical needs of children with autism and the difficulties that parents experience in acquiring resources.

In this study, I also gathered information about the benefits of online support groups. Online support groups in the form of Facebook and Yahoo! online support groups were described as convenient tools for communication and support at any time, day or night. Participants stated that online support groups gave them the flexibility to participate according to their schedules. Parents valued the flexibility and the ease of information gathering of online support groups.

Confirmed Findings

One of the findings of this study that was supported by the literature was related to the value of parent led support groups in assisting parents in becoming empowered to advocate for their child. Participants of this study indicated that parent led support groups made them feel empowered and gave them confidence to become an advocate. Chamak (2008), Hoagwood et al. (2010), Law et al. (2001), and Mandell and Salzer (2007) concurred that parent-led support groups lead to self-efficacy and empowerment through the questioning of treatments, and the free expression fostered by the group.

Mandell and Salzer (2007) found that support groups provided a platform for the exchange ideas, created a community that helped each other, and built a collective information network. Consistent with this in my study was that participants indicated that parent-led support groups afforded them an opportunity to expand on the knowledge through the sharing of ideas. Meetings became brainstorming sessions and avenues for collective information gathering. They indicated that groups became a forum for discussions, where parents learned about treatments that worked for others, and recommended medical professionals. Participation in meetings also gave parents a sense of belonging and parents felt less isolated. Consequently, parents strengthened their resolve to seek better medical treatments, finding better schools, and a better education for their child. The exchange of ideas and information also led to the discovery of funding alternatives to relieve the cost of raising a child with autism. Some parents described their experience as a journey which would make a difference in their lives, and the lives of others. Law et al. (2001) stated that people seeking to become advocates form into groups with the purpose of raising awareness about childhood disabilities, and conducting activities that lobbies legislators. Through their participation in parent-led support groups, parents of my study learned about more resources, and better treatments. They then used this information to engage with other parents, doctors, school administrators, lawyers, and others.

As parents became more connected with others, they became more skilled in advocating for resources. Parents indicated becoming better at advocating through the interaction with people of many different professions such as doctors, lawyers, school administrators, insurance providers, and parents like themselves. They also stated that advocating for their child took a great deal of time and effort. Parents set up medical appointments and referrals, participated in meetings with teachers to create an individualized education program (IEP), called the insurance companies to receive reimbursement, and many other time consuming tasks. Paikoff et al. (2005) agreed that honing advocacy skills were very time consuming because parents needed to learn about the disability, the available networks of support groups that provided information, new treatments, state and federal laws, and school information. Connolly and Novak (2006) found that parents of children with autism spent a great deal of time per week advocating and coordinating medical treatments, communicating with professionals, and educating themselves. Thomas et al. (2007) affirmed that parents became advocates by acquiring the certain skills they learned as they engaged in the acquisition of proper services and treatments. Several parents interviewed stated that parent-led support groups were composed of motivated people who connected with each other in a positive way, transferred the feeling of empowerment. The temperament, skills, personalities, experiences, and motivation of the participants of the group were important factors in assisting others. Those parents were role models who helped others to feel confident, and encouraged them due to their own experiences and understanding; this provided a safe environment where open dialog and sharing of ideas was prevalent. The support from these groups cannot be duplicated anywhere else since these are unique environments (Kerr & McIntosh, 2000). Participation in these groups gave the parents more confidence and motivated them to become advocates for their child and other children.

Another confirmed finding was that parent-led support groups provided emotional support for parents struggling with caring for a child with autism. Participants of the study indicated that one of the primary reasons for participating in parent-led support groups was for emotional support. Altiere and Von Kluge (2009) and Law et al. (2001) indicated that parent-led support groups provided emotional support due to the common experience of living with autism. Parents interviewed stated that the shared common experiences between the group participants, connected participants of these groups with each other, resulting in the exchange of empathy and encouragement. Law et al. (2001) noted that the level of emotional support found in these groups is difficult to find elsewhere. When parents could not find emotional support elsewhere, they turned to parent-led support groups as an avenue for emotional support (Kerr & McIntosh, 2000). Through the interaction with others, participants said they felt better about their role as parents of a child with autism. Parents who provided emotional support in group meetings were compassionate, understanding, willing to be open, and share their own experiences with others.

All parents interviewed agreed that the costs for the care of a child with autism was very high. Ganz (2006) explained that the reason for the rising costs in treating autism was the increase in nonmedical interventions which supplement medical interventions. Parents in this study stated that certain treatments such as special diets or nutritional supplements were not covered by private insurance or Medicaid. Chamak (2008) noted that new interventions such as genetic testing, diet, behavior modification programs, and some unconventional treatments have added to the cost of care for autism.

Parents interviewed pointed out they had spent thousands of dollars of their own money for therapies, treatments, insurance copayments, and doctors. Ganz (2006) conducted a study on the costs associated with caring for a child with autism. The results of the study revealed that the cost for direct medical treatment, direct nonmedical costs, and indirect costs for children with autism was the highest between the ages of 3 and 7, and second highest between the ages of 8 and 12 years of age (Ganz, 2006). According to the demographics data (Table 1) in this study, the ages of the children of the study participants were between the ages of 2 and 16. Eight out of nine parents in this study had children between the ages of 2 and 12. One parent indicated having three children under the ASD, ages 2, 3, and 6. The majority of children of parents who participated in this study covered the age group identified by Ganz (2006) as experiencing the highest medical costs.

Parents stated that informational support was one of the most important reasons for joining a parent-led support group. They recognized the importance of prompt treatment of children soon after noticeable developmental problems. It is important to get medical interventions as soon as possible, at an early age, in order to produce positive outcomes, and address the problems associated with autism (Association for Science in Autism Treatment, n. d.; Kabot et al., 2003). Children must be treated at an early age in order to increase the chance that the intervention will be successful (Centers for Disease Control and Prevention, 2012; Kabot et al., 2003). In this study, parents indicated the importance of early intervention. Parents worried that the time waiting on lists for services was idle time that delayed treatments.

Some participants of the study noted difficulties in dealing with active regression because of lack of informational support. Active regression generally occurs between the ages of 2 and 3 years old and is a period where a child loses acquired skills (Goldberg et al., 2008). Active regression is a very stressful time for parents because they have to select the right doctor to make the diagnosis (Paikoff et al., 2005; Wildman, 2006). Many parents recognized developmental problems during the child's first year (Goldberg, et al., 2008). In this study, three parents shared their struggles as their child underwent active regression, because they had little information about the symptoms exhibited during active regression. They indicated having nowhere to turn for assistance or informational support. One parent described taking his son to four different doctors just after active regression because he and his spouse knew very little about autism and did not have any informational support. A pediatrician referred this father to a parent-led support group which provided information and support. Another parent stated that going through active regression was sudden, difficult to deal with, and difficult to understand. Paikoff et al. (2005) and Wildman (2006) indicated that active regression is a very stressful time for parents, and selecting the right diagnostician can be overwhelming. Parents who had been through this before were able to share information which pointed the way to available doctors and treatments. These parents were described as problem solvers who were determined to get answers and assist others.

Disconfirmed Findings

Thomas et al. (2007) stated that, in North Carolina, families who were on Medicaid received more services and had greater access to therapies, medication, case managers, supportive assistance, and other medical related assistance for autism than families with private insurance. Wang et al. (2013) found that across the United States Medicaid provided more medical services and therapies specific to autism spectrum disorders than private insurance. In Pennsylvania, Mandell and Salzer (2007) found that most children with autism qualified for Medicaid inpatient and outpatient treatments and medication, despite the level of income, race, or ethnicity. However, in this study two participants under the Medicaid program indicated having many of the same problems as participants with private insurance in finding funding for treatments, including special therapies, diets, and supplements. One participant indicated difficulties in acquiring useful medical treatments which Medicaid or private insurance would not fund. Another parent gave a detailed account of obstacles in finding more than one doctor that accepted Medicaid and could provide proper treatment for her son who suffered from autism and epilepsy. She conveyed planning a move to another state that contained a better pool of doctors who accepted Medicaid. Many participants indicated uprooting their families to other communities in search of better medical and educational programs.

Theoretical Interpretations

Social Support Theory

The social support theory establishes that social support is comprised of emotional support, informational support, instrumental support, and appraisal support (Davis et al., 2011; Houston & Dolan, 2008; Pinkerton & Dolan, 2007). In this study, the constructs of the social support theory were explored. Participants were asked about each construct of the social support theory. All participants confirmed that parent-led support groups provided emotional support, informational support, and appraisal support. Only five participants acknowledged that parent-led support groups provided instrumental support. Four of these participants were connected with both in-person groups and online groups.

Most participants indicated that in-person parent-led support groups provided good emotional support. Online support groups also provided good emotional support. Facebook and Yahoo! support groups provided forums where parents could vent if they needed to, and boast about the progress of their child. One participant felt that in-person groups provided better emotional support than online groups. Another participant felt that online support groups gave greater access to more people who could provide greater emotional support, especially when the positive responses were in the hundreds. Some participants revealed a preference for one type of group or another for emotional support, and also revealed that group dynamics was very important in whether the group effectively provided emotional support.

All participants indicated that parent-led support groups provided informational support. Parents discussed guest speakers that attended the in-person support groups as very informative. The guest speakers were doctors, lawyers, educators, therapists, and others who provided information that would be helpful to parents. Participants who were a part of both in-person and online parent led support groups, perceived that participation in online groups gave access to more information, quicker. Since online support groups had access to many more people who could share more perspectives on what treatments worked well for them, online support groups were described as good resources for informational support.

Most parents agreed that parent-led support groups provided appraisal (esteem) support. However, some parents felt that appraisal support was the same as emotional support and both types of support made parents feel better about themselves.

The level of instrumental support depended on the group. Half the parents felt that they had received instrumental support, while the other half felt that they had not received it from parent-led support groups. Many parents were able to compare this level of support based on groups that they participated in, while living in other states. One parent indicated receiving instrumental support from online groups.

Participants felt that both forms of parent-led support groups provided emotional, informational, and appraisal support. However, when it came to instrumental support it was not unanimous as to whether parent-led support groups provided instrumental support. It depended on the individual group whether this type of support was available, and some participants had never received instrumental support.

Limitations of the Study

The study had several limitations. Initially, my original intent of this study was to recruit participants from parent-led support groups located in the Oklahoma City Metropolitan Area, under the umbrella of a local organization, which would limit the geographical range of the recruitment, and provide groups for this study with a similar organizational structure. However, due to difficulties in recruiting locally, I expanded the study recruitment to Kansas, Texas, and online. Expanding the study made it easier to recruit volunteers, but made it difficult to get a sense of the organizational structure of the support groups, especially the online groups which denied my access to the group forum. Additionally, the participants of this study lived in cities across the central, eastern, and western parts of the United States. Therefore, participants were from different geographical areas, and generalization of the findings for future studies will not be possible.

Since group meetings were only held once a month for in-person support groups and online support groups were closed groups, my access to participants was limited. In-person groups were booked with a guest speaker months in advance, and squeezing me into the meetings was difficult. Additionally, I was given about 10 minutes to describe my study in most in-person groups. With online groups, I gave the group moderator a flyer describing my study and my contact information, and missed the opportunity to make contact and answer questions. Attending more than one group meeting would have given me a chance to recruit more diverse group members. Access to the online groups would have given me a chance to interface with the parents of the groups. I may have been able to find participants that held different viewpoints about the value of parent-led support groups in facilitating advocacy. Volunteers for the study held similar views about the value of parent-led support groups providing emotional support, informational support, appraisal support, self-efficacy and empowerment.

Another limitation was that the study interview questions (Appendices E and F) were designed for in-person support group participants. A majority of participants were members of both in-person and online groups. Questions were not directed towards examining online parent-led support groups. Therefore, a thorough evaluation of online support groups may not have been conducted. Participants described some online groups as local groups while other groups covered large geographical areas.

The study results cannot be generalized to any population, or geographical location. Without being asked, all participants who belonged to online groups gave the geographical location where they lived. They indicated being from cities and states from the east coast, west coast, and the central parts of the United States.

Participants discussed participating in various forums in the online environment, and numerous in-person groups. The purpose of the groups varied. The sizes of the groups were described as small or large, with some groups hosting thousands of members. Some of the online groups specialized in specific information, whereas, the in-person groups provided general and specific information about various topics.

Recommendations

For future studies, researchers should evaluate the value of online parent-led support groups. These groups can serve as resources for parents who could not get away to participate in in-person meetings. A comparison of onsite and online support groups may show specific advantages to participating in one type of group versus another.

Future researchers should also involve more diverse populations. This study was limited to English and Spanish speakers and I did not recruit with a focus on ethnicity. Additional studies could be performed to be more inclusive, and provide a greater diversity of participants.

Another area of focus for future studies should be instrumental support within autism parent-led support groups. Findings from this study show that autism parent-led support groups were given positive reviews from participants for emotional, appraisal, and informational support. However, parents felt that instrumental support was less available in these groups. Most parents felt that better funding of parent-led support groups would allow for the creation of paid positions that could be utilized in assisting parents to find better resources, making phone calls for appointments, and finding funding.

Social Change

Implication of the Findings

Social change is the use of knowledge for the greater good in communities, peoples' lives, and the world (Walden University, 2017). One implication for social change from this study is that this study provides a better understanding of the role that parent-led support groups play in facilitating advocacy among parents of children with autism. Banuch et al. (2010), Law et al. (2001), and Mandell and Salzer (2007) indicated the need for more research into the influence that parent-led support groups have on parental decision making. Participants of this study described their struggles with finding treatments that work, having access to therapies, and finding funding for them. This study gave an opportunity to parents of children with autism to voice their lived experience as they raise and care for a child with special needs. Parents were compelled to advocate for their child's medical, educational, and social needs.

The impact of the findings of the study may be conducive to positive social change by providing more information, and a greater understanding about the value of parent-led support groups, in assisting with the needs of parents. Professionals, group facilitators, and parents who have participated in this study, have indicated to me their interest in reading the findings of the study. I will disseminate this information by preparing a summary of my findings, and will provide digital copies of the summary to all of the support groups. Also, I will volunteer to speak at conferences, seminars, and group meetings. This may allow experts, group facilitators and moderators to gain a better understanding of the value of parent-led support groups. Researchers can also use the findings, and build on the study, thereby, expanding the knowledge about the participants' needs to advocate, and the driving force behind their role as advocates. There is a gap in the literature because not enough research has focused on the power of parental advocacy to make a positive change in decision making.

Participants of this study were given a chance to describe the barriers they encountered while caring for a child with autism. They faced problems finding medical treatments that work, funding for medical treatments, therapies, and funding for nonmedical treatments. Several years ago, I attended a yearly autism conference. During the conference, I received information about free advocacy training funded by the State of Oklahoma. I am interested in attending this training. Upon completion of this training, I plan to advocate legislators for resources that would assist parent-led support groups in providing funding for medical and nonmedical treatments for parents who care for a child with autism, or other developmental conditions. I will speak about the findings of the study and disseminate the summary of my findings to key legislators working on public health legislation. Publication of this study to journals such as the *Journal of Autism and Developmental Disorders* and *Autism*, could lead to a better understanding by scholars of the difficulties parents face, the importance of better research into treatments and therapies, and enhanced insurance and Medicaid coverage for both medical and nonmedical treatments. Blanchard et al. (2006), and Schieve et al. (2007) reported that parents of children with autism feel more isolated, have more problems finding treatments, and more problems coping with the disease than other parents of children with chronic developmental disorders. It would also be helpful if society had a better understanding of why parents advocate so strongly for their child with autism.

Recommendations for Practice

Participants of this study were asked what could be changed about parent-led support groups, and what limitations existed within these groups. Many responses indicated that there was a need for more funding of parent-led support groups. Increased funding would allow for more paid positions that would assist with the instrumental support within the groups. Specifically, greater funding would give access to more speakers, access to more resources, utilization of volunteers that would care for the children at the meeting location, more local meeting places, paid positions for the facilitators and moderators of meetings, and the ability of groups to conduct advocacy training.

Other recommendations from a participant was, divide the groups based on age of the child so parents could get more pertinent information, specific to the needs of their child. This participant indicated that sometimes topics such as the prom for the older children were discussed which do not pertain to the younger ones. Another recommendation was to establish more online meetings because online meetings remain an untapped resource. One participant stated the need for more inclusion, inside and outside of the classroom, so that children with autism could interact with more children their age, and have friends who do not have autism.

Conclusion

Based on the findings of this study, all participants felt that parent-led support groups provided informational support, emotional support, and appraisal support. Not all parents felt that parent-led support groups met the needs for instrumental support (concrete support). Most parents felt that parent-led support groups could be better funded to provide these services.

All of the participants of this study except for one, had problems finding funding for medical and nonmedical services, and equipment. All participants agreed that the costs associated with caring for a child with autism was very high and many out of pocket expenses were incurred by the parents. Nutritional services and supplements, which parents indicated were necessary for overall health and wellness of their child, were the number one nonmedical expense that parents required, and were not covered by private insurance or Medicaid. These approaches have not been fully accepted as treatments of ASD (Centers for Disease Control and Prevention, 2012).

In conclusion, parents in this study defined advocacy as finding better resources for medical and nonmedical treatments, educational programs, and funding. Parents described their struggles in acquiring these resources, and developed their advocacy skills to meet their child's needs. Parent-led support groups were an avenue to get informational, and emotional support, which gave participants the confidence to engage with others. Both in-person and online support groups provided informational support, emotional support, and appraisal support. Instrumental support was not provided in all parent-led support groups, possibly due to funding.

This study may result in positive social change by revealing the value and limitations of parent-led support groups. Upon dissemination of these findings, medical professionals, educators, legislators, insurance providers, and group facilitators and moderators, can gain a better understanding of the perspectives of parents with regards to parent-led support groups, and the need to advocate for better treatments and funding for those treatments.

References

Altiere M. J., & Von Kluge, S. (2009). Searching for acceptance: Challenges encountered with raising a child with autism. *Journal of Intellectual & Developmental Disability, 34*(2), 142-152. doi:10.1080/13668250902845202

American Psychiatric Association. (2012). DSM-5 development. Retrieved from http://www.dsm5.org/about/Pages/Default.aspx

Association for Science in Autism Treatment. (n.d.). Description of service providers. Retrieved from http://asatonline.org

Banuch, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups. 33,* 69-83. doi:10.1080/01609510903437383

Blanchard, L. T., Gurka, M. J. & Blackman, J. A. (2006). Emotional, development, and behavioral health of American children and their families: A report from the 2003 national survey of children's health. *Pediatrics, 117*(6), 1202-1213. doi:10.1542/peds.2005-2606.

Bowen, G. A. (2005). Preparing a qualitative research-based dissertation: Lessons learned. *The Qualitative Report, 10*(2), 208-222. Retrieved from http://nsuworks.nova.edu/tqr/vol10/iss2/2

Brady, B., & Dolan, P. (2007). Exploring good practice in Irish child and family services: Reflections and considerations. *Practice, 19*(1), 5-18. doi:10.1080/09503150701220457.

Brown, M. J., Willis, T., Omalu, B., & Leiker, R. (2006). Deaths resulting from hypocalcemia after administration of edetate disodium; 2003-2005. *Pediatrics*, *118*(2), e534-e536. doi:10.1542/peds.2006-0858.

Campbell-Grossman, C. C., Hudson, D. B., Keating-Lefler, R., & Fleck, M. O. (2005). Community leaders perceptions of single low income mothers' needs and concerns for social support. *Journal of Community Health Nursing, 22*(4), 241-257. Retrieved from http://www.jstor.org/stable/3427849

Centers for Disease Control and Prevention. (2000). Autism Spectrum Disorders. Retrieved from http://www.cdc.gov/ncbddd/autism/hcp-dsm.html

Centers for Disease Control and Prevention. (2011). Learn the signs. Act early: Developmental milestones. Retrieved from http://www.cdc.gov/ncbddd/actearly/milestones/index.html

Centers for Disease Control and Prevention. (2011). New data on autism spectrum disorders. Retrieved from http://www.cdc.gov/Features/CountingAutism/

Centers for Disease Control and Prevention. (2012). *Autism and developmental disabilities monitoring network – 2012.* Retrieved from http://www.cdc.gov/ncbddd/autism/documents/ADDM-2012-Community-Report.pdf

Centers for Disease Control and Prevention. (2012). Autism Information Center: Treatment. Retrieved from http://www.cdc.gov/ncbddd/autism/treatment.html

Centers for Disease Control and Prevention. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years; Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *Morbidity and Mortality*

Weekly Report (MMWR). Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w

Chamak, B. (2008). Autism and social movements: French parents' association and international autistic individuals organisations. *Sociology of Health & Illness*, *30*(1), 76-96. doi:10.1111/j.1467-9566.2007.01053.x

Chenail, R. J. (2011). Interviewing the investigator : Strategies for addressing instrumentation and researcher bias concerns in qualitative research. *The Qualitative Report, 16*(1), 255-262. Retrieved from http://www.nova.edu/ssss/QR/QR16-1/interviewing.pdf

Clifford, T. (2011). Support groups of parents of children with autism spectrum disorders: Predictors and effect of involvement. Retrieved from http://qspace.library.queensu.ca/bitstream/1974/6561/1/Clifford%20Tessen%20201106%20PhD.pdf

Committee on Children with Disabilities, (2001). Technical Report: The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children. *Pediatrics, 107*(5), 1-18. Retrieved from http://pediatrics.aappublications.org/content/107/5/e85

Critical Appraisal Skills Programme. (n. d.). Critical Appraisal Skills Programme: Making sense of the evidence. Retrieved from http://www.casp-uk.net/

Darrow A. (2009). Adapting for students with autism. *General Music Today, 22*(2), 24-26. Retrieved from Academic Search Complete. (AN 36002646)

Davis, S. T., Gavazzi, S. M., Scheer, S. D., & Uppal, R. (2011). Measuring individualized parent advocate services in children's mental health: A contextualized theoretical application. *Journal of Child and Family Studies, 20,* 669-684. doi:10.1007/s10826-010-9443-y.

Food and Drug Administration. (2014). Institutional review boards frequently asked questions – information sheet. Retrieved from http://www.fda.gov/RegulatoryInformation/Guidances/ucm126420.htm

Friedlander, D. (2009). Sam comes to school: Including students with autism in your classroom. *The Clearing House, 82*(3), 141-144. doi:10.3200/TCHS.82.3.141-144.

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archive of Pediatrics and Adolescent Medicine 161*(4), 343-349. doi:10.1001/archpedi.161.4.343.

Gerard, J. M., Landry-Meyer, L., & Roe, J. G. (2006). Grandparents raising grandchildren: The role of social support in coping with caregiving challenges. *International Journal of Aging and Human Development, 62*(4), 359-383. doi:10.2190/3796-DMB2-546Q-Y4AQ.

Gill, J., Liamputong, P. (2011). Being the mother of a child with Asperger's syndrome: Woman's experiences of stigma. *Healthcare for Women International, 32*(8), 708-722. doi:10.1080/07399332.2011.555830.

Gilmour, J., Harrison, C., Asadi, L., Cohen, M. H., & Vohra, S. (2011). Natural health product-drug interactions: Evolving responsibilities to take complementary and alternative medicine into account. *Pediatrics, 128*(4), S155-S160.

doi:10.1542/peds.2010-2720C.

Goldberg, W., Thorsen, K., Osann, K., & Spence, M. (2008). Use of Home Videotapes to Confirm Parental Reports of Regression in Autism. *Journal of Autism and Developmental Disorders, 38*(6), 1136-1146. doi:10.1007/s10803-007-0498-6

Gottlieb, B. H., & Wachala, E. D. (2007). Cancer support groups: a critical review of empirical studies. *Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 16*(5), 379-400. doi:10.1002/pon.1078.

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods, 3*(1), 2-26. Retrieved from https://sites.ualberta.ca/~iiqm/backissues/3_1/pdf/groenewald.pdf

Hayden, J. A. (2009). Health belief model. In *Introduction to Health Behavior Theory* (pp. 31-36). Wayne, NJ: Jones and Bartlett. Retrieved from http://www.jblearning.com/samples/0763743836/chapter%204.pdf

Hayhurst, C. (2008). Treating Kids with Autism. *Physical Therapy, 16*(12), 20-27. Retrieved from www.apta.org

Health Resources Commission. (2008). Effectiveness in treatment of ASD in children and adolescents. Retrieved from http://www.oregon.gov/oha/OHPR/HRC/docs/executive.summaries/asd.pdf

HealthyPeople. (2012). 2020 topics and objectives. Retrieved from http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=20

Hoagwood, K. E., Cavaleri, M. A., Olin, S. S., Burns, B. J., Slaton, E., Gruttadaro, D., & Hughes, R. (2010). Family support in children’s mental health: A review and synthesis. *Clinical Child Family Psychological Review, 13,* 1-45. doi:10.1007/s10567-009-0060-5.

Houston, S., Dolan, P. (2008). Conceptualising child and family support: The contribution of Honneth's critical theory of recognition. *Children and Society, 22*(6), 458-469. doi:10.1111/j.1099-0860.2007.00126.x.

Kabot, S., Masi, W., & Segal, M. (2003). Advances in the diagnosis and treatment of autism spectrum disorders. *Professional Psychology: Research and Practice, 34* (1), 26-33. doi:10.1037/0735-7028.34.1.26.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250. Retrieved from http://www.neurodiversity.com/library_kanner_1943.pdf

Keyes, K. M., Susser, E., Cheslack-Postave, K., Fountain, C., Liu, K., Bearman, P. (2011). Cohort effects explain the increase in autism diagnosis among children born from 1992 to 2003 in California. *International Journal of Epidemiology, 41*(2), 495-503. doi:10.1093/ije/dyr193.

Kerr S. M. & McIntosh, J. B. (2000). Coping when a child has a disability: Exploring the impact of parent to parent support. *Child Care Health and Development. 26* (4), 309-322. doi:10.1046/j.1365-2214.2000.00149.x.

King, M., & Bearman, P. (2009). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology. 38,* 1224-1234. doi:10.1093/ije/dyp261.

Law, M., King, S., Stewart, D., & King, G. (2001). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and*

Occupational Therapy in Pediatrics, 21(2/3), 30-48. doi:10.1080/J006v21n02_03.

Levi, S. E., & Hyman, S. L. (2008). "Complementary and alternative medicine treatments for children with autism spectrum disorders." *Child and Adolescent Psychiatric Clinics of North America, 17*(4), 803-820. doi:10.1016/j.chc.2008.06.004.

Lovaas, O, I. (1987). Behavioral treatment and normal educational and intellectual functioning in \bung autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3-9. Retrieved from http://psycnet.apa.org

Lofthouse, N., Hendren, R., Hurt, E., Arnold, L. E., & Butler, E. (2012). A review of complementary and alternative treatments for autism spectrum disorders. *Autism Research and Treatment, 17*(4), 803-820. doi:10.1155/2012/870391.

Malterud, K. (2001). Qualitative research: standards, challenges and guidelines. *Lancet, 358,* 438-488. doi:10.1016/S0140-6736(01)05627-6.

Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism. *Autism, 11*(2), 111-122. doi:10.1177/1362361307077506.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research, 11*(3), 1-19. Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1428

Mead, S., & MacNeil, C. (2004). Peer support: What makes it unique? *International Journal of Psychosocial Rehabilitation, 10*(2), 29-37. Retrieved from http://www.psychosocial.com/IJPR_10/Peer_Support_What_Makes_It_Unique_Mead.html

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250-260. doi:10.1037/0022-0167.52.2.250.

Namey, E., Guest, G., Thairu, L., & Johnson L. (2007). Data reduction techniques for large qualitative data sets. Retrieved from http://www.stanford.edu

National Institute of Mental Health. (2011). A parents guide to autism spectrum disorder. Retrieved from http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/index.shtml

Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14*, 208-225. doi:10.1080/10522158.2011.571539.

Odom, S. L. (2014). Evidence-based interventions for children and youth with ASD. Retrieved from http://www.cdc.gov/cdcgrandrounds/pdf/gr-autism-4-22.pdf

Onwuegbuzie, A. J., & Leech, N. L. (2007). Sampling designs in qualitative research: Making the sampling process more public. *The Qualitative Report, 12*(2), 238-254. Retrieved from http://www.nova.edu/ssss/QR/QR12-2/onwuegbuzie1.pdf

Palermo, M., Pasqualetti, P., Babati, G., Intelligente, F., & Rossini, P. (2006). Recognition of schematic facial displays of emotion in parents of children with autism. *Autism. 9*, 485-499. doi:10.1177/1362361306064431.

Paikoff, R.L., Casey, M. & Wodlinger-Cohen, R. (2005). Parental Advocacy. In Albrecht, G. L., (Ed.), *Encyclopedia of Disability* (1202-1206). Thousand Oaks, CA: Sage Publications.

Perrin, J. M., Coury, D. L., Hyman, S. L., Cole, L., Reynolds, A. M., & Clemons, T. (2012). Complementary and alternative medicine use in a large pediatric autism sample. *Pediatrics, 130*(2), S77-S82. doi:10.1542/peds.2012-0900E.

Pickett, S. A., Heller, T., & Cook, J. A. (1998). Professional-led versus family-led support groups: Exploring the differences. *The Journal of Behavioral Health and Research. 25*(4), 437-445. doi:10.1007/BF02287513.

Pinkerton, J., & Dolan, P. (2007). Family support, social support, resilience, and adolescent coping. *Child and family social work, 12,* 219-228. doi:10.1111/j.1365-2206.2007.00497.x.

Pistrang, N., Barker, C., & Humphreys, K. (2008). Mutual help groups for mental health problems: A review of effectiveness studies. *American Journal of Community Psychology, 42,* 110-121. doi:10.1007/s10464-008-9181-0.

Portway, S. M., & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risk of a non-obvious disability. *Health, Risk and Society. 7*(1), 73-83. doi:10.1080/09500830500042086.

Potter, D., & Wing, L. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews, 8,* 151-161. doi:10.1002/mrdd.10029.

QSR. (n.d.). NVivo 11 Pro for Windows. Retrieved from http://download.qsrinternational.com/Document/NVivo11/11.3.0/en-US/NVivo11-Getting-Started-Guide-Pro-edition.pdf

Rice, C. (2007). Prevalence of autism spectrum disorders---Autism and developmental disabilities monitoring network, United States, 2006. *Morbidity and Mortality Weekly Report (MMWR), 58*(SS10*),* 1-20. Retrieved from www.cdc.gov

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. E*ducation for Information, 20*(2), 63-75. doi:10.3233/EFI-2004-22201

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics, 119*(1), S114-S121. doi:10.1542/peds.2006-2089Q

Siklos, D., & Kerns, K. A. (2006). Assessing need for social support in parents of children with Autism and Downs Syndrome. *Journal of Autism Development Disorder, 36,* 921-933. doi:10.1007/s10803-006-0129-7.

Singh, J. (2013). Critical appraisal skills programme. *Journal of Pharmacology & Pharmacotherapeutics, 4*(1), 76-77. doi:10.4103/0976-500X.107697.

Smith, T., & Eikeseth, S. (2011). O. Ivar Lovaas: Pioneer of applied behavior analysis and intervention for children with autism. *Journal of Autism Developmental Disorders, 41,* 375-378. doi:10.1007/s10803-010-1162-0.

Snow, C. (2013). People First Language. Retrieved from http://www.disabilityisnatural.com/images/PDF/pfl09.pdf

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism related services. *Journal of Autism and Developmental Disorders, 37,* 1902-1912. doi:10.1007/s10803-006-0323-7.

Trochim, W. (2006). Research methods knowledge base: Qualitative validity. Retrieved from http://www.socialresearchmethods.net/kb/qualval.php

Twoy, R., Connolly, P.M., & Novak, J. M. (2006). Coping strategies used by parents of children with autism. *Journal of the American Association of Nurse Practitioners, 19*(5), 261-260. doi:10.1111/j.1745-7599.2007.00222.x.

Walden University. (2017). Walden 2020: A vision for social change. Retrieved from https://www.waldenu.edu/-/media/Walden/files/about-walden/walden-university-2017-social-change-report-final-v-2.pdf?la=en

Wang, L., Mandell, D. S., Lawer, L., Cidav, Z., & Leslie, D. L. (2013). Healthcare service use and costs for autism spectrum disorder: A comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders, 43*(5), 1057-1064. doi:10.1007/s10803-012-1649-y.

Wildman, H. E. (2006). ASA's 37th National Conference on Autism Spectrum Disorders: #2189- The health belief model and prediction of parents' choices of autism treatment. Retrieved from http://asa.confex.com/asa/2006/techprogram/AAG.HTM

Windham, G., Zhang, L., Gunier, R., Croen, L., & Grether, J.K. (2006). Autism spectrum disorders in relation to distribution of hazardous air pollutants in the San Francisco Bay area. *Environmental Health Perspectives. 114*(9), 1438-1444. doi:10.1289/ehp.9120.

Woodgate, R.L., Ateah, C., Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Quality Health Research, 18*(8), 1075-1083. doi:10.1177/1049732308320112.

Zolnierek, C. D. (2011). Exploring lived experiences of persons with severe mental illness: A review of the literature. *Issues in Mental Health Nursing, 32,* 46-72. doi:10.3109/01612840.2010.522755.

Appendix A: Screening Questions

For the Screening Questions (Please Circle Yes or NO). Please answer all questions even if your response is No.

1. Do you have a child officially diagnosed with any of the Autism Spectrum Disorders?

   YES NO

2. Do you participate in parent led support group meetings?

   YES NO

3. Have you participated in parent led support groups for more than six months?

   YES NO

4. Do you speak English or Spanish fluently?

   YES NO

5. Do you currently take online classes?

   YES NO

   If you answered Yes to question 5, what university?

6. Are you interested in participating in this study?

   YES NO

Appendix B: Preguntas de Cribado (Screening Questions in Spanish)

Para las preguntas de cribado por favor círculo (Sí o No). Responda a todas las preguntas, incluso si su respuesta es No.

1. ¿Tienes un niño oficialmente diagnosticado con alguno de los trastornos del espectro autista?

Sí No

2. ¿Participa en las reuniones del grupo de apoyo de padres?

Sí No

3. ¿Ha participado en los grupos de apoyo de padres durante más de sies meses?

Sí No

4. ¿Habla el inglés o el español con fluidez?

Sí No

5. ¿Actualmente toma clases en línea?

Sí No

Si has contestado "sí" a la pregunta 5, ¿Qué universidad?

6. ¿Está usted interesado en participar en este estudio?

Sí No

Appendix C: Demographics Questions

Participants of this study will fill out this questionnaire at the beginning of the interview.

1. What age is the age of your child with autism?

2. How long have you participated in this parent-led support group?

3. How many meetings have you attended this year?

4. Are you over the age of 18?

5. What is your gender?

Appendix D: Preguntas Demograficas (Demographic Questions in Spanish)

Los participantes de este estudio van a rellenar este cuestionario al comienzo de la entrevista.

1. ¿Qué edad es la edad de su niño con autismo?
2. ¿Cuánto tiempo ha participado en este grupo de apoyo para padres?
3. ¿Cuántas reuniones asistieron este año?
4. ¿Estás por encima de los 18 años de edad?
5. ¿Cuál es su sexo?

Appendix E: Interview Questions

1. Why did you join a parent-led support group?

2. What is the primary purpose of the support group that you participate in?

3. Have you had difficulties with funding for your child's care?

4. Do you feel that parent-led support groups provide any of the following types of support?

(Check all that apply).

___a. emotional support

___b. instrumental support (concrete support such as monetary support, or an action such as assistance in setting up appointments)

___c. appraisal support (esteem support)

___d. informational support

5. What does advocacy mean to you?

6. If the parent-led support groups provide support, does this support assist you in becoming an advocate for your child?

7. How well would you say that the parent-led support group assists parents in meeting the following challenges?

    a. caring for a child with autism
    b. facilitating empowerment
    c. increasing satisfaction of the parenting role

8. Are there other benefits that you find by participating in parent-led support groups?

9. What would you change about parent-led support groups that would better meet the needs of parents who want to become advocates?

10. What are the limitations of parent-led support groups and how can they be overcome?

Appendix F: Las Preguntas de la Entrevista (Interview Questions in Spanish)

1. ¿Por qué te unes a un grupo de apoyo dirigido por padres?

2. ¿Cuál es el objetivo principal del grupo de apoyo en que participa?

3. ¿Has tenido dificultades con el financiamiento para el cuidado de su niño?

4. ¿Cree usted que los grupos de apoyo proporcionan cualquiera de los siguientes tipos de apoyo? (Marque todas las que correspondan).

___a. apoyo emocional

___b. apoyo instrumental (apoyo concreto como apoyo monetario, o una acción como ayuda para establecer citas)

___c. soporte de estima

___d. apoyo informativo.

5. ¿Qué significa para usted la promoción (abogar)?

6. ¿Si los grupos de apoyo dirigidos por padres proporcionan apoyo, ¿este apoyo le ayuda convertirse en un defensor de su hijo?

7. ¿Qué bien diría que el grupo de apoyo para padres les ayuda a los padres en el cumplimiento de los siguientes retos?

a. el cuidado de un niño con autismo

b. facilitar el empoderamiento

c. aumento de la satisfacción del función parental

8. ¿Hay otros beneficios que puede encontrar al participar en grupos de apoyo dirigidos por padres?

9. ¿Qué te gustaría cambiar de los grupos de apoyo dirigidos por padres que pueda satisfacer mejor las necesidades de los padres?

10. ¿Cuáles son las limitaciones de los grupos de apoyo dirigidos por padres, y cómo pueden superarse estas limitaciones?

Appendix G: List of Possible Follow-up Questions (For each interview question)

1. Does the parent-led support group meet your needs?

2. How does your support group fulfill that primary purpose?

3. If so, what type of difficulties?

4. Describe the type and extent to which you receive support.

5. Would you consider yourself an advocate.

6. If yes, explain how the support group assists you in becoming an advocate for your child.

7. Do you think it is important for parent-led support groups to assist parents in meeting those challenges?

   Which if any of these challenges are most important to you?

8. If there are other benefits to participating in parent-led support groups, have they been influential in helping you meet the challenges you face? Why or why not?

Appendix H: Lista de Posibles Preguntas de Seguimiento (Para cada pregunta de la entrevista)

1. ¿El grupo de apoyo para padres dirgido por padres les satisface sus necesidades?

2. ¿Cómo tu grupo de apoyo cumple el propósito principal?

3. En caso afirmativo, ¿Qué tipo de dificultades?

4. Describa el tipo y grado en que recibes apoyo.

5. ¿Te consideras un defensor?

6. Si la respuesta es afirmativa, explique cómo el grupo de apoyo le ayuda a convertirse en un defensor de su hijo(a).

7. ¿Crees que es importante que un grupo de apoyo para padres dirgido por padres ayude a los padres a afrontar esos retos?

¿Cual si alguno de estos retos son más importantes para usted?

8. Si hay otros beneficios por participar en grupos de apoyo dirgido por padres, ¿Han sido influyentes en ayudarle a satisfacer los desafíos a que se enfrenta? ¿Por qué sí o por qué no?

Appendix I: Expert Feedback- Expert 1

FORM FOR REVIEW AND EVALUATION OF VALIDITY AND RELIABILITY BY A PANEL OF EXPERTS FOR QUALITATIVE INSTRUMENTATION

Instructions: Please review the attached survey instrument and respond to the following questions regarding the construction, validity and potential reliability for the survey in light of the phenomenon being researched.

Section A. VALIDITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is valid to the extent that the instrument measures the construct(s) that the instrument purports to measure.

1. *Instrument Construction:*

a. Are the instructions for completing the instrument clear?

Yes No

Yes, Appendix B. Consider adding yes / no so they can circle unless you are going to administer the questionnaire.

b. Is the application and use of the results of the survey instruments adequately reflected in the instructions?

Yes No

Yes, Appendix C

c. What instructions or items would you recommend adding?

none

d. What instructions items would you recommend be deleted?

Rather than using "autistic," use people first language. "children with autism" rather than "autistic child."

2. *Content Validity:*

Will the scores yielded by survey instruments adequately represent the content or conceptual domain of the construct being measured? In other words, does the instrument have adequate and appropriate items that constitute a representative sample of the complete domain of items used to generalize the construct being measured?

Yes No

I believe so. The interview questions are likely to address your research questions.

3. *Construct Validity:*

The survey instrument is designed to … *(fill in)*

a. Does the survey represent concepts or constructs it should represent and does not represent concepts or constructs it should not represent? In other words, does the survey instrument adequately represent the constructs it purports to represent?

Yes No

Yes

b. Is the survey inclusive of the important dimensions or facets of the constructs it purports to measure?

Yes No

Yes

c. Does the survey avoid excess reliable variance, ensuring no items are easier or harder for some respondents in a manner relevant to the interpreted construct?

Yes No

Question #7 regarding “what other values…” do you mean benefits?

D. *Face Validity:*

Does the survey look valid? Does it appear to represent a measure of the construct it purports to measure?

Yes No

Yes

E. *Item Bias:*

Does the wording or placement of an item avoid affecting someone’s response?

(This includes the avoidance of double-barreled items, words or phrases, which raise emotional red flags, ambiguous wording, gender bias, racial/ethnic bias, and the manipulative placement of an item or wording of an item)

Yes No (if no, please explain)

Explained above. Use people first language. Parents and advocates prefer it.

F. *Consequential Validity:*

Does the survey instrument embody desirable values and have potentially positive consequences for the discipline or field it reflects?

Yes No

Yes

Section II. RELIABILITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is reliable to the extent that whatever construct(s) the instrument measures, it measures the construct(s) consistently.

A. *Internal Consistency:*

Are the items that make up the survey instruments internally consistent with each component and/or the constructs being examined, assessed, evaluated or measured?

Yes No

Yes

B. *Potential for Reliability:*

Understanding that research participants completing this instrument will vary in their understanding and experience with the (*concept – fill in*) and thus vary in their responses, is there anything about this instrument that would lead you to believe that this instrument would not consistently measure (*concept – fill in*) consistently?

Yes No

I'm not sure. Maybe the age of the child, but it's hard to say.

Please provide any additional comments, suggestions for improvement, and/or any other thoughts regarding the construction, validity and/or reliability of the survey instrument.

I'm very interested in the results of this research. Having information to better support parents and address the needs is important.

Appendix J: Expert Feedback- Expert 2

FORM FOR REVIEW AND EVALUATION OF VALIDITY AND RELIABILITY BY A PANEL OF EXPERTS FOR QUALITATIVE INSTRUMENTATION

Instructions: Please review the attached survey instrument and respond to the following questions regarding the construction, validity and potential reliability for the survey in light of the phenomenon being researched.

Section A. VALIDITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is valid to the extent that the instrument measures the construct(s) that the instrument purports to measure.

1. *Instrument Construction:*

a. Are the instructions for completing the instrument clear?

Yes No

b. Is the application and use of the results of the survey instruments adequately reflected in the instructions?

Yes No

c. What instructions or items would you recommend adding?

d. What instructions items would you recommend be deleted?

2. *Content Validity:*

Will the scores yielded by survey instruments adequately represent the content or conceptual domain of the construct being measured? In other words, does the instrument have adequate and appropriate items that constitute a representative sample of the complete domain of items used to generalize the construct being measured?

Yes No

3. *Construct Validity:*

The survey instrument is designed to … *(fill in)*

a. Does the survey represent concepts or constructs it should represent and does not represent concepts or constructs it should not represent? In other words, does the survey instrument adequately represent the constructs it purports to represent?

Yes No

b. Is the survey inclusive of the important dimensions or facets of the constructs it purports to measure?

Yes No

c. Does the survey avoid excess reliable variance, ensuring no items are easier or harder for some respondents in a manner relevant to the interpreted construct?

Yes No

D. *Face Validity:*

Does the survey look valid? Does it appear to represent a measure of the construct it purports to measure?

Yes No

E. *Item Bias:*

Does the wording or placement of an item avoid affecting someone's response?

(This includes the avoidance of double-barreled items, words or phrases, which raise emotional red flags, ambiguous wording, gender bias, racial/ethnic bias, and the manipulative placement of an item or wording of an item)

Yes **No** (if no, please explain)

Number 3 seems like it is leading. I might ask a question about services and then ask if they have had difficulty receiving services before implying they need to be an advocate.

I might also add what they believe an advocate is-what is the definition.

F. *Consequential Validity:*

Does the survey instrument embody desirable values and have potentially positive consequences for the discipline or field it reflects?

Yes No

Section II. RELIABILITY EVALUATION

A test, survey, questionnaire, evaluation or assessment instrument is reliable to the extent that whatever construct(s) the instrument measures, it measures the construct(s) consistently.

A. *Internal Consistency:*

Are the items that make up the survey instruments internally consistent with each component and/or the constructs being examined, assessed, evaluated or measured?

Yes No

B. *Potential for Reliability:*

Understanding that research participants completing this instrument will vary in their understanding and experience with the (*concept – fill in*) and thus vary in their responses, is there anything about this instrument that would lead you to believe that this instrument would not consistently measure (*concept – fill in*) consistently?

Yes **No**

I realize this is going to be a subjective survey, but I'm curious about how you will analyze your data.

Please provide any additional comments, suggestions for improvement, and/or any other thoughts regarding the construction, validity and/or reliability of the survey instrument.

I would recommend reading about People First Language. I would use the term child with autism instead of autistic.

http://www.disabilityisnatural.com/explore/people-first-language

Edits/typos

5. If the parent-led support group provides support, how has this support **assisted** you in becoming an advocate for your child?

6. How well would you say that the parent-led support group **assists** parents in meeting the challenges of caring for a **child with autism**, facilitating empowerment, and **increasing** satisfaction of parenting role?

7. What other **benefits** do you find in participating in parent-led support groups?

Screening questions

1. Are you asking for an official diagnosis? I would be specific about your criterion for having autism.

2. Most parents would consider themselves an advocate-this seems leading. Do you want to know if they feel like they need to do more?

Appendix K: Critical Appraisal Skills Programme (CASP) Qualitative Checklist

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?