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Investigation of social supports for parents of children with Autism

Abstract

There has been an increase of children being identified with autism in the United States (Center for Disease Control, 2009), leading to an increased concern of how to best meet the needs of children with autism and their families. In response to each reauthorization of the Individuals with Disabilities in Education Act (2004), in which the roles of families have been strengthened in planning their child’s education and professionals have had more input, the field has tried to uncover the ‘best’ ways to support parents. Recommended practice suggests that parents are best able to identify their own support needs, with assistance from professionals in identifying supports to assist with these needs (Murray et al., 2007). The focus of this study was to identify the forms of social support that parents of children recently diagnosed with autism perceive as being important. Twenty parents of children recently diagnosed with autism participated in this study. These parents completed a Q-sort using the forms of social support, which allowed for a ranking from “most” to “least” important. Statistically significant correlations were found on five support items. Factor analysis was conducted to explore groups of participants with similar rankings of the Q sort items.

Keywords: Social Support, Q sort, Autism

Overview

According to the Center for Disease Control and Prevention in the US the prevalence of Autism Spectrum Disorder (ASD) is an approximate average of one child in every 88. The American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-IV-TR, 2000) includes in its classification of Autism Spectrum Disorders the related diagnosis of autistic disorder, Asperger’s disorder, and pervasive developmental

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disorder-not otherwise specified. For clarity and consistency, and unless otherwise stated, the term “autism” will be used throughout this paper to refer to those three disorders. Autism represents a spectrum of behaviorally defined conditions that are diagnosed by professionals using the DSM-IV-TR through clinical observation of development.

Children who have autism are mandated to receive services through the Individuals with Disabilities Education Improvement Act ([IDEA], 2004). Legislation includes families as critical partners in the education of the child. Support for the family’s emotional, physical, and educational needs has become an area of primary importance in programs, which address the ongoing needs of the child ((Murray et al., 2007; Staley-Gane, Flynn, Neitzel, Cronister, & Hagerman, 1996; Turnbull, Turnbull, Erwin, & Soodak, 2010). Support for families, including families of children with autism, should address the concerns, priorities, and resources of the family.

Social support is defined as being multidimensional, comprised of both ‘emotional’ (e.g., affection, sympathy and understanding, acceptance, and esteem from others) and ‘instrumental’ (e.g., goods, services, and information) functions that aid in mediating stress and dealing with day-to-day interactions (Dunst, Trivette, & Cross, 1986; Flynn, 1990; Krahn, 1993; Meadan, Halle, & Ebata, 2010; Valentine, 1993). The functioning of parents and child is enhanced when families receive the aid and assistance that match their identified needs and priorities (Dunst, Trivette, & Hambry, 2007; Trivette & Dunst, 1987). Both emotional and instrumental supports have been linked to reducing stress and improving the functioning and well-being of family members. Only families can identify the type of support that is important to them. Research underscores the importance of families’ having choices and decision-making opportunities about issues concerning their child and family (Allen & Petr, 1996; Trivette, Dunst, & Hamby, 2010); however, the professionals who often guide parents along this path do not receive training on deferring their own personal values (Murray & Mandel, 2004).

One of the first scales developed to document family support, The Inventory of Socially Supportive Behaviors ([ISSB] Barrera & Ainlay, 1983) suggests that the extent to which particular supports are considered important and the perceived satisfaction of recipients of those supports are key to assessing the efficacy of supports for families of young children with disabilities, including autism. Thus, family’s perspectives on the importance of support and their subsequent satisfaction with those supports should be the standard against which professionals measure their intervention behaviors. Professionals (i.e., teachers, therapists, and medical personnel) who understand the needs of families of children diagnosed with autism are better able to assist families in accessing the supports that will be most beneficial to the child and family (Croen, Grether, Hoogstrate, & Selvin, 2002; Gillberg, Cederlund, Lamberg, & Zeijlon, 2006; Fombonne, 2003).

The purpose of this study was to identify the social supports that fathers and mothers of young children recently diagnosed with autism perceive as important. This study

extends the literature by comparing the identified importance of specific support items of fathers versus mothers and with a population of families whose child had been recently diagnosed (within an 18-month period).

Method

Participants

Twenty parents consisting of mother-father dyads served as participants in the study. Inclusion criteria for parent participation were: (1) child's diagnosis of autism was within the last 18 months, and (2) child was between the ages of three and five years old at the time of data collection. Parents were recruited through advertisement in an Autism Society newsletter, flyers at clinics and conferences, and flyers distributed by regional special education coordinators across the state.

Demographic data was obtained including parent information (age and marital status) child information (age, gender, age at diagnosis, and diagnosis), and sibling data (gender, age, and diagnosis, when applicable). On average, both parents were in their mid-30s (fathers $M = 37$ years, range, 29 - 54 years old; mothers $M = 35$ years, range, 24 to 52 years old). All couples were married with the exception of one that was divorced. Children ranged in age from 3 years 1 month to 5 years 4 months ($M = 4$ years 1 month) comprised the children with autism (15 boys and 5 girls). The specific diagnoses varied with 12 children being diagnosed with autism, 1 child with Asperger's syndrome, and 7 children with pervasive developmental disorder- not otherwise specified. The children were all formally diagnosed through qualified professional individuals or teams utilizing the criteria set forth by the DSM-IV-TR. The length of time for being diagnosed ranged from one month to 18 months ($M = 10.7$ months).

Socioeconomic status was determined for each couple by using the Hollingshead Two Factor of Social Position (Hollingshead & Redlich, 1958). Hollingshead is an accepted research index to determine social economic status of individuals and families (Miller, 2002). Social position is assigned by occupation and education in the Hollingshead index. There are five social class categories in the Hollingshead, 'I' being the highest social class and 'V' being the lowest social class. Three families were in the highest social class, 13 families in the second social class, three families in the third social class and one family in the fourth social class. Thus, the majority of families were in the upper middle social class. Broken down by income and education, the majority of families had an income that was above \$60,000 and almost all families had at least one parent with some university education beyond high school.

Design and Instrumentation

The Q-methodology or Q-sort was used to gather data (Stephenson, 1953). The Q-sort is a ranking procedure used to identify an individual's subjectivity or personal point of view on a subject with the capability of quantitative analysis (McKeown & Thomas, 1988). The Q-sort consists of sorting items into categories using a Likert-type scale. This technique is a forced-choice method where individuals completing the sort must

place a specific number of items within columns. Ranking allows for comparison of items that may otherwise be seen as very similar or ranked similarly in importance (Stephenson, 1953).

A modified version of the copyrighted set of items from Flynn and Staley-Gane (1997) were used in this study (See Table 1). A literature review was conducted in order to determine new items that might be added to the Q-set from an extensive review of the literature on social supports for families of children with disabilities, perusal of social support family surveys (Bailey & Simeonsson, 1990; Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988; Park, Hoffman, Marquis, Turnbull, Poston, Mannan, Wang, & Nelson, 2003) and previous research (Flynn, 1990; Staley-Gane et al., 1996). No new social support items were added; only the wording a few items was modified to reflect current language.

The Q-set for this study was composed of 16 support items (modified from Flynn & Staley-Gane, 1997). The Q-set contained emotional (e.g., a friend to talk to about my concerns, a professional psychologist, involvement with a church) and instrumental (e.g., information, special equipment, financial assistance, educational services) support items (Flynn, 1990; Krahn, 1993; Unger & Powell, 1980), as identified in the previous tool.

Procedures

Q-Sort. The family's home was used as the location for data collection to make this process as convenient and comfortable for the parents as possible. Data was collected simultaneously from both parents; mothers and fathers were asked to separately rank Q-sort items. Parents and the investigator were seated so that only the investigator could see both of the Q-sorts. Parents could not see each other's responses and, therefore, were not influenced by one another. Parents were not previously known to the researcher and, thus, were thought to not be influenced by his presence.

Parents were instructed on the Q-sort procedure by the first author, who served as the primary investigator. Parents were given a Q-sort board with predetermined squares labeled "least to most". A set of 16 cards with one item written on each card was given to each parent. Parents were given step-by-step instructions (Appendix A) on how to complete the sorting procedure. Their responses were recorded by the primary investigator. Upon completion of the Q-sort, parents were asked if anyone or anything was missing from the set of items. Responses were recorded verbatim by the primary investigator.

Analysis

Descriptive and inferential statistics were used to analyze the data. Correlations were conducted to determine if fathers and mothers ranked the items similarly. A factor analysis was conducted to identify groups of participants with similar rankings of the Q-sort.

Results

Results of the Q-sort completed by fathers and mothers of children recently diagnosed with autism were calculated. Parent's responses in each column were assigned weighted values (-3 through 3) and the data was analyzed. Support Items for Both Parents. Descriptive statistics (M and SD) were calculated for each support item 1 through 16 for couples (see Table 1). Overall, the support item identified as "most" important by both parents was "information on how I can help my child" (M = 1.93, SD = 1.20). Two additional items were identified as "very important" for both parents were "involvement with early intervention (infant and toddler), preschool or school program" (M = 1.23, SD = 1.31) and "information about my child's future" (M = .70, SD = 1.18). The support item identified as least important was "help with child or respite care" (M = -2.25, SD = 1.37). Two additional items identified as "not being as important" for both parents were "help with transportation" (M = -1.98, SD = .947) and "help with independent living skills" (M = -1.17, SD = 1.39).

Table 1
Descriptive Statistics for Each Support Item for Couples

Support Item	M	SD
Information on how I can help my child	1.93	1.20
Involvement with early intervention (infant & toddler), preschool or school program	1.23	1.31
Information about my child's future	.70	1.18
Financial help for expenses	.66	.56
Relaxing and fun activities for my child and family	.23	1.10
Information about my child's condition or disability	.58	1.13
Contact with other parent(s) who experienced the same situation	.48	1.24
Counseling with a professional person	-.10	1.47
Discussions with medical people	.03	1.18
Help with child care or respite care	-2.25	1.37
Participation in an organized parent support group	-.23	1.08
Involvement with a church or strong religious beliefs	-.95	1.55
A close friend or family member to talk to about my concerns	-.40	1.27
Special equipment to help meet my child's needs	-.75	1.56
Help with independent living skills	-1.17	1.39
Help with transportation	-1.98	.95

Correlations between both parents were calculated to examine the relationships between them to examine similarities in rankings among couples (see Table 2). Correlations

ranged from a high of .73 to a low of .06 with five statements being statistically significant. The statistically significantly correlations statements included “special equipment to help meet my child’s needs”, “involvement with church or strong religious beliefs”, “information on how I can help my child”, “financial help for expenses”, and “participation in an organized parent support group.”

Table 2
Correlations for Couples for Support Items

Support Item	
Involvement with a church or strong religious beliefs	.730**
Special equipment to help meet my child’s needs	.534*
Financial help for expenses	.491*
Participation in an organized parent support group	.490*
Information on how I can help my child	.440*
Contact with other parent(s) who experienced the same situation	.443
Help with independent living skills	.365
Help with child care or respite care	.356
Involvement with early intervention (infant & toddler), preschool or school program	.344
A close friend or family member to talk to about my concerns	.282
Help with transportation	.282
Information about my child’s future	-.251
Information about my child’s condition or disability	-.162
Counseling with a professional person	.154
Discussions with medical people	-.127
Relaxing and fun activities for my child and family	.064

* $p < .05$, ** $p < .01$

Inferential Statistics

Factor Analysis An exploratory factor analysis was performed using Principal Components analysis (PCA). These solutions were rotated using Varimax procedure and examined interpretability and parsimony. A decision was made to look at all participants as individuals and not in terms of couples because only five items were found to be significantly correlated for the couples (see Table 2).

Inspection of the Scree plot obtained from the factor analysis indicated that solutions with three or four factor were possible to explain the variables in the instrument. The three-factor solution was selected as the one that was most interpretable and conceptually sound. Approximately 44% of the variance was explained by this three-factor solution.

Table 3
Factor Scores for Each Support Statement

Support Statement	Factor 1	Factor 2	Factor 3
A close friend or family member to talk to about my concerns		.435	.597
Discussions with medical people			-.505
Involvement with early intervention (infant and toddler), preschool or school program	.550		
Special equipment to help meet my child's needs	-.563		
Involvement with a church or strong religious beliefs			
Relaxing and fun activities for my child and family			.667
Information on how I can help my child		.712	
Financial help for expenses	-.687		
Information about my child's condition or disability			
Counseling with a professional person	.498		
Participation in an organized parent support group	.706		
Help with transportation		-.666	
Information about my child's future		.595	
Help with child care or respite care	-.425	-.481	
Contact with other parent(s) who experienced the same situation	.521		
Help with independent living skills		.460	-.508

Factor one relationship items included “involvement with early intervention (infant and toddler), preschool or school program,” “special equipment to help meet my child’s needs,” “financial help for expenses,” “counseling with a professional person,” “participation in an organized parent support group,” “contact with other parent(s) who experienced the same situation.” Factor two external resources included “information on how I can help my child,” “help with transportation,” “information about my child’s future,” and “help with child care or respite care.” Factor three services included “a close friend or family member to talk to about my concerns,” “discussions with medical people,” “relaxing and fun activities for my child and family,” and “help with independent living skills.”

Discussion

The purpose of this study was to examine the “most and least” important social supports of mothers and fathers of children recently diagnosed with autism. Q-sort, the data collection technique, gave a clear indication about the importance of support items as indicated by the ranking decisions made by parents. The following sections will discuss the support items ranked as most important, least important, additional support items identified through the Q-sort method, limitations of the current study, clinical implications, and future research.

Support Items Identified as Most Important

The top three support items ranked as most important by all participants were those in the category of instrumental supports (two were information needs and one was preschool services). When a child has a disability such as autism, parents may feel that ‘information is power.’ Information about how parents can help their child may give them the knowledge and skills they feel are necessary to support their child to be successful. Previous research supports parents’ need for information to better help their child (Keen, Couzens, Muspratt, Rodger, 2010; Whitaker, 2002). Information about the child’s future outcomes or prognosis may be particularly salient for parents of children with autism because, currently, several treatment plans claim that a child’s autistic behaviors may be significantly modified if a particular treatment is followed (Erba, 2000, National Professional Development Center on Autism Spectrum Disorders, 2009). In other words, some parents may be looking for a “fix.”

Along with support items about information, both parents reported “involvement with early intervention (infant and toddler), preschool or school program” as one of the top three supports, which is similar to other recent findings (Troy, Connolly, & Novak, 2007). All of these families had children that were either in the birth-to-three system or preschool program. Parents may have found that these services for their child were especially useful and, thus, very important in the months following their child’s initial diagnosis.

“Help with finances” was also reported by these parents as an important support. Even though most of the parents reported an annual income of over \$60,000, they still identified help with finances as a need. Raising a child with autism is expensive. In particular, the cost of therapy that is frequently recommended may be high (Feinberg & Vacca, 2000; Jacobson, Mulick, & Green, 1998, Sharpe & Baker, 2007). Regardless of level of income and/or insurance options, raising a child with autism takes a financial toll on families (Jarbrink, Fombonne, & Knapp, 2003, Sharpe & Baker, 2007).

Support Items Identified as Least Important

The support item identified as “least” important by both fathers and mothers was “help with child care or respite care.” Possible explanations of this finding could be that none of the participants were in Hollingshead’s lowest social class, which may indicate that they had resources to provide for child care. Additionally, mothers may have felt that

they were the primary caregiver for their child, and therefore, the best person to provide proper care and attention for their young child.

“Involvement with church or strong religious beliefs” was also rated as ‘least important’ by parents. Some previous researchers of families of children with disabilities (Crowley & Taylor, 1994; Tarakeshwar & Pargament, 2001; Valentine, 1993) reported that religion or spirituality (Schumacher & Bauer, 2010) was an important support. However, other studies (Jones, Angelo, & Kokoska, 1998; Flynn, 1990) found that parents of children with disabilities reported church members or strong religious beliefs as not important as a support priority. This may be attributed to cultural differences between groups sampled.

“Help with independent living skills” was identified by parents in this sample as ‘least important’. Although parents of recently diagnosed children reported being concerned about their child’s future, this support need may have been perceived to be something they would need when their child becomes a young adult. These children were all between the ages of three and five and, perhaps, more age appropriate developmental milestones such as talking and playing with other children were more critical to these families than independent living skills (Koegel et al., 1992). This finding is in contrast to a finding by Pisula (2007) who reported that mothers were most concerned with their child’s dependence on the care of others.

Other Supports Identified by Participants

The support items that participants identified as lacking or missing from the available supports in the Q-sort can be found in Appendix B. These items were generally very specific needs unique to the particular participant. For example, “information about specialty schools past early intervention” and “information on helping children adjust to a missing parent in the home” were both listed as support items that were missing from the Q-sort. Other items identified as missing could be interpreted as items that were contained already in other support items in the Q-sort in broader terms. For example, “financial help that does not tie into my income or disqualify my child because of it” would be a part of the “financial help for my expenses.” Overall, a recurring theme of additional support item was not supported by the parents in this sample.

Clinical Implications

Factor analysis revealed that sampled support items clustered into three groups; however, clustered groups did not appear to be conceptually related within each cluster. Previous literature (House, 1981) has identified support items into the categories of instrumental, informational and emotional. It is assumed that a larger sample may yield a more conceptually cohesive clustering of support items. However, it is important to note that practitioners should attend to the different dimensions of support by which families of children with identified special needs may benefit.

Limitations of the Current Study

The results of this study are from a small number of fathers and mothers of children recently diagnosed with autism from a limited geographical area. The majority of the participants in the study were from a higher social economic class, which may have impacted the supports identified by participants.

Recommendations for Future Research

This study examined the perceived importance of supports of fathers and mothers of children recently diagnosed with autism. Future research of parents of recently diagnosed children should include families from a wider variety of income and education levels, as these groups may rank support items differently.

Past research (Staley-Gane et al., 1996) has found that the length of time a child was diagnosed with Fragile X influenced parents' needs and needs varied over time. Researchers (Gray, 2006; Krahn, 1993) have cited the need for longitudinal research to determine the changing supports desired by parents of children with disabilities.

Previous research was conducted primarily with mothers rather than fathers (Meadan et al., 2010). Support priorities of both parents needs to be conducted to ensure that both perspectives are gathered. Additional studies comparing mothers and fathers are needed, especially mothers and fathers in the same family.

Future studies examining the relationship between the exact diagnosis (i.e., autism, PDD-NOS, Asperger's syndrome) and types of support identified as important would add to the knowledge base of families of children with an Autism Spectrum Disorder.

Summary

The focus of this study was to identify the social support that fathers and mothers of young children recently diagnosed with autism perceive as being important. Twenty families completed a Q-sort, which allowed for a ranking of support items that indicated the perceptions of support priorities of families. It is crucial to 'family-centered' practices that families of children with disabilities are allowed to identify their own priorities. By allowing the families to identify their priorities and needs, service providers will be able to better support these families in the delivery of services.

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Appendix A

Directions for completing the Q sort

Step 1: Take out the 16 cards and read each one. After reading the cards take out the six cards you feel are the most important to you and your family. Place the ten remaining cards to the left side of the board.

Step 2: From the six cards you feel are most important, take out the three cards you feel are most important out of these six. Place the three cards you didn't choose on the right side of the board.

Step 3: Now from the three you chose, take out the one you feel is the most important. Place the one card you chose into the blue column labeled most. Place the two other cards in the two orange columns. Now take the cards you placed on your right and place those in the three pink columns.

Step 4: Take the remaining cards you placed on the left side of the board and read each one. After reading the cards, take out the six you feel are the least important to you and your family. Place the four cards you didn't choose at the top of the board. Place the one card you chose into the yellow column labeled least. Place the two other cards in the two green columns. Now take the cards you placed at the left side of the board and place these in the three red columns.

Step 5: From the six cards you feel are least important, take out the three cards you feel are least important out of these six. Place the three cards you didn't choose on the left side of the board.

Step 6: Now from the three you are holding, take out the one you feel is least important. Place the one card you chose into the yellow column labeled least. Place the two other cards in the two green columns. Now take the cards you placed at the left side of the board and place these in the three red columns.

Step 7: Take the cards that you placed at the top of the board and place those in the four middle purple columns. Look at all of the cards and make sure you have placed them correctly.

Step 8: If there was something missing from or not included in the support items that should have been included, please write it on this note card. (additional support items identified by parents were recorded, see Appendix B).

Step 9: Now, turn the items over that you do not have or have not been available to you.

Appendix B

Additional Support Items identified by Parents as Missing

- Information about specialty schools past early intervention.
- Information on helping children adjust to a missing parent in the home.
- Financial help that does not tie into my income or disqualify my child because of it.
- Physical and alternative therapy.
- There is a gap between diagnosis and pediatric reviews
- A list of organizations who take kids with special needs (Autism), e.g., karate, dance, swim, etc.
- A church where I can go with my autistic son.
- Taking part in field trips with children and families with the same condition (autism).
- Balance time with child with autism and typically developing child.
- Therapy for interventions, such as eye contact.
- Alternate speech communication partners for child to give parents a break.
- Education professional who could refer a student who could come to our home to offer services.
- More available schooling options for my child.
- Earlier evaluation by school system to give more time to make a decision moving forward.
- A list of providers of Autism services in my community.
- Special instruction for pediatricians on the new science of autism.
- No pre-school ABA program in the parish.
- More information on adults with autism.

A broader explanation of all services available to my child's diagnosis; not simply what is available in our parish.