EPH - International Journal of Medical and Health Science
ISSN (Online): 2456-6063
Volume 04 Issue 03 September 2018

DOI: https://doi.org/10.53555/eijmhs.v5i2.67

SOCIAL AND FINANCIAL DIFFICULTIES OF CAREGIVERS FOR CHILDREN DIAGNOSED WITH AUTISM

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Abstract

Background: Autism Spectrum Disorder (ASD) is one of the most widely spread developmental disorders that has raised an urgent public health concern. Regardless of advances in modern technology and research studies there is more to the disorder to be considered in the endeavor of finding the cause and treatment. This study focuses on the caregiver's aspect of the problem. The quality of life for caregivers of children with an ASD is very crucial for developing their children's full potential.
Method: Forty-five participants (n=45) were recruited from the Southeastern Pennsylvania Autism Resource Center (SPARC), the Autism Society of America – Greater Philadelphia Chapter, and Autism Alliances to voluntarily contribute to an online survey assessing the social and financial difficulties/burdens that are facing caregivers of children with an ASD
Results: Caregivers of children with ASD are facing tremendous financial and social burdens.
No statistical difference in financial (U=24.0, z=-0.1, p=.340) or social burden (U=26.5, z=-0.8, p=.420) between caregivers having one vs. one or more children diagnosed with an ASD.
No statistical difference in financial (t=-1.1, p=.270) or social burden (t=-0.3, p=.764) among caregivers who had one child vs. more than one child
Conclusion: Findings suggest an urgent need for health administrators to advocate to find solutions to the financial and social difficulties facing caregivers who have children with autism.

Background

Autism is one of the most severe developmental disorders and considered an urgent public health concern. In spite of advances in technology and research studies this impairing chaos has no cure up till now. There is an alarming increase in the number of cases being diagnosed with autism. According to the National Center for Chronic Disease Prevention and Health Promotion, the prevalence of autism in recent studies from varying resources using up to date diagnostic tools that are carried out using different methods have indicated that the rang of ASD between 1 in 500 children and 1 in 166 children (CDC, 2007). In a multiple site study that has been conducted in the United States between 2000 and 2002, the prevalence of autism within participating sites was 6.7/1000 in 2000 and 6.6/1000 in 2002, and approximately 1 in 150 child. Autism is four times more likely to affect males than females (National Institute for Neurological Disorder and Stroke, 2009). In Pennsylvania 7,178 children are diagnosed with autism in 2003, 1 out of 222 (45/10,000) children has autism in 2003 (Fighting Autism, 2004).

Study Design

A cross-sectional survey design was used to assess the social and financial difficulties among caregivers of children with autism. This design was used so that all participants and all variables were measured at the same point in time. The survey was created and posted using online tool called Survey Monkey. This web site provides a web-based publishing tool that includes features to guarantee security and anonymity of participants, including the option of not storing any of the respondent's personal information and IP address.

Participants

In this study, a combination of two non-probability methods was used; convenience and volunteer sampling methods. Participants were invited from different areas in Southeastern Pennsylvania. Some participants were recruited from the Southeastern Pennsylvania Autism Resource Center (SPARC). In addition, an invitation was posted in Autism Society of America - Greater Philadelphia Chapter (ASA Philly) and Autism Alliance. Data were collected using a needs assessment survey placed on Survey Monkey on July 2009. Participation was anonymous, in that no identifying information was collected from participants such as name or computer IP address. Contributors were 45 volunteered caregivers age 20-69 who have one or more children with an ASD.

Measures

The 20-item Financial and Social Difficulties Survey was developed and edited with the direct feedback 2 experts including project adviser and site supervisor. The survey included 20 questions 9 demographic questions, 10 questions to assess the financial and social difficulties, and one open ended question for any additional information.

Demographic data about the caregiver and family were collected, including caregiver gender (Male, Female), caregiver age (20-29, 30-39, 40-49, 50-59, and 60+), caregiver level of education (Less than High school, High school, Bachelor, Beyond bachelor), caregiver marital status (Single, Married, Co-habituating, Separated/Divorced/Widowed), number of children you have including your child with an ASD (1, 2, 3, 4+), number of children you have that are diagnosed with an ASD (1, 2, 3, 4+), age of children diagnosed with ASD (measured continuously), age when your child was diagnosed with an ASD (measured continuously), and the annual household income (Under $30,000, $30.000-$50,000, more than $50,000).

Five questions were placed in the survey to assess the social difficulties. Social difficulties in this study are defined as the obstacles that face the caregiver when interacting with their family and the larger community. The following questions reflected this definition : I spend enough time connecting with friends and other relatives; My relationships with others are relaxed and positive; I feel comfortable taking my child to public places; My recreational activities time had not been cut short; I feel the community understands my child's situation.

In the fallowing section five questions were integrated in the survey to assess the financial difficulties. The financial difficulties are defined as the overall effect of expenses for the child with an ASD services and needs on the family financial status. These items included: I feel I have no financial difficulties taking care of my child; The services needed for my child with an ASD are not affecting the family budget; My primary insurance is covering all services needed for my child with an ASD; My secondary insurance is covering all services needed for my child with an ASD; Professional reliable services for my child with an ASD are being provided by my insurance. All social and financial difficulty questions were measured using 4-point Likert scale (strongly disagrees, disagree, agree, strongly agree).

Statistical Analyses

The data were analyzed by using the Statistical Package for Social Studies (SPSS) software Version 16.0. Descriptive analysis was first used to measure the demographic data among parents of children with autism. Categorical variables were summarized using frequencies and percents, and continuous variables were summarized using means and standard deviations. The 20-item survey assessed the financial and social difficulties of caregivers who have a child diagnosed with an ASD. Social difficulties were measured with five items, each measured on a Likert scale ranging from 1=strongly disagree to 4=strongly agree. The responses from the five items were added to create a social difficulty summary score ranging from 5-20, with 20 being the least difficulty. Caregiver financial difficulties were measured with five items each were measured on a Likert scale ranging from 1= strongly disagree and 4= strongly agree. Again the responses of the 5 items were summed to create a financial difficulty/burden summary score ranging from 5-20, with 20 being the least difficulty. Internal consistency/reliability of the two scales was assessed via Cronbach's alpha.

A None-parametric test (Mann-Whitney U) was implemented to assess if the social and financial summary scores (DVs) differ by having one child diagnosed with an ASD (IV) vs. having more than one child diagnosed with an ASD. An independent t- test was used to assess if the social and financial summary scores (DVs) differ if the caregiver had one child (IV) vs. more than one child.

Results

Table 1 shows the demographic characteristics of the participants. The majority of participants were married (82.2%), female (93.9%), fell within 40-49 years (46.7%), had a bachelor degree (55.6%), with two children (46.7%), and had only one child diagnosed with an ASD (93.3%). The annual income of most of the participants was over $50.000 (71.1%)

Table1: Demographic characteristics of caregivers for children with autism

	(n = 45)
Characteristic	***N (%)***
Gender	
Male	*3 (6.7)*
Female	42 (96)
Age Group (years)	
20-29	1(2.2)
30-39	11 (24.4)
40-49	21 (46.7)
50-59	10 (22.2)
60+	2 (4.4)
Marital Status	
Single	1 (2.2)
Married	37 (82.2)
Co-Habituating	2 (4.4)
Separated/Divorced/Widowed	5 (11.1)
Level of Education	
Less than High school	0 (0)
High school	7 (15.6)
Bachelor	25 (55.6)
Beyond bachelor	13 (28.9)

Table1: Demographic characteristics of caregivers for children with autism (continued)

Family annual income	
Under $30,000	4 (8.9)
$30,000-$50,000	8 (17.8)
More than $50,000	32 (71.1)
Number of children including child diagnosed with an ASD	
One	11 (24.4)
Two	21 (46.7)
Three	9 (20.0)
More than Three	4 (8.9)
Number of children diagnosed with an ASD	
One	42 (93.3)

Two	2 (4.4)
Three	0 (0)
More than Three	1 (2.2)

Table 2 displays the mean response for each social and financial difficulty item, the mean response for the two summary scale scores, as well as the Cronbach's alpha for the two scales.

Table 2 shows means and standard deviations for responses to questions regarding social difficulties as follows: The mean and standard deviation for spending enough time with friends and relatives were mean 1.80 (0.66); For being relaxed and positive in relationships with others the mean and standard deviation were 2.33 (0.67); For feeling comfortable taking child with ASD to public places the mean and standard deviation were 1.54 (0.76); The mean and standard deviation for having enough time for recreational activities were 2.48 (0.82), The mean and standard deviation for understanding the child's situation by community were 1.86 (0.69)

Means and standard deviations for responses to questions regarding financial difficulties are as follows:

For question addressing not having financial difficulties taking care of an ASD child the mean and standard deviation were 1.60 (0.61); The mean and standard deviation for the question regards family budget not being affected by services needed for child with an ASD were 1.77 (0.67); For question about primary insurance is covering all services needed for child with an ASD the mean and standard deviation were 1.43 (0.58); The mean and standard deviation for question about services needed for child with an ASD being covered by secondary insurance were mean 1.86 (0.77); For Professional reliable services being provided by insurance for child with an ASD the mean and standard deviation 1.88 (0.74).

The responses of the five items measuring social difficulties were moderately consistent with each other, showing a Cronbach's alpha of 0.6. Therefore, the social difficulties summary score was calculated and it showed in general a mean and standard deviation of 8.59 (2.61) reflecting lenient towards the disagree options in the Likert scale. The social difficulty item that caregivers reported the most difficulty with was the question of having time for recreational activities reflecting a mean and standard deviation of 1.54 (0.76).

The responses of the five items measuring financial difficulties were moderately consistent with each other, showing a Cronbach's alpha of 0.8. Therefore, the financial difficulties summary score was calculated and it showed in general that mean and standard deviation for the financial summary score were 10.09 (2.23) favouring the disagree and strongly disagree options in the likert scale. The financial difficulty item that caregivers reported the most difficulty with was the questions of having a primary insurance that covers all services needed for the child with an ASD, with a mean and standard deviation 1.43 (0.58).

Table2: Mean response for social and financial difficulty items

	(n = 45)	**Cronbach's Alpha**
Characteristic	***Mean (sd)***	
Social Difficulties Scale		**0.603**
I spend enough time connecting with friends and other relatives	1.80 (0.66)	
My relationships with others are relaxed and positive	2.33 (0.67)	
My recreational activities time had not been cut short	1.54 (0.76)	
I feel comfortable taking my child to public places	2.48 (0.82)	
I feel the community understands my child's situation	1.86 (0.69)	
Summary Score for Social Difficulties †	8.59 (2.61)	
Financial Difficulties Scale		**0.813**
I feel I have no financial difficulties taking care of my child	1.60 (0.61)	
The services needed for my child with an ASD are not affecting the family budget 1.77 (0.67)		

My primary insurance is covering all services needed for my child with an ASD	1.43 (0.58)
My secondary insurance is covering all services needed for my child with an ASD	1.86 (0.77)
Professional reliable services for my child with an ASD are being provided by my insurance	1.88 (0.74)
Summary Score for Financial Difficulties †	10.09 (2.23)

NOTE: individual items score ranges from 1 to 4, with 1 being the most difficulty/burden
† Summary scores range from 5 to 20, with 20 being the least difficulty/burden

Table 3 displays the responses to the open-ended question of (Use the space below for any additional information you would like to share). Twenty responses were supplied out of the 45 participants, and of these, 14 responses emphasized the financial difficulties related to the services needed for child with an ASD; 4 responses were focusing on the lack of understanding and awareness from the community; 3 responses reflected lack of school support and awareness; 1 response mentioned the need for more research and advocacy regarding ASD.

Table3: Main concerns responses for the open-ended question

(n = 20)

Additional comments	**Number of comments**
Financial issues	**14**
Lack of understanding and awareness from the community	**4**
Lack of school support and awareness	**3**
Need for more research and advocacy regarding ASD	**1**

The main research questions were assessed via Mann-Whitney U and Independent t-tests. A MannWhitney U test was done to assess if the social and financial summary scores differed by having one child diagnosed with an ASD vs. having more than one child diagnosed with an ASD. There was no significant difference in the social summary score (U = 26.500, z = -0.806 p = 0.420) nor the financial summary score (U = 24.000, z = -0.095 p = 0.340) between the two groups.

An independent t- test was used to assess if the social and financial summary scores differed if the caregiver had one child vs. more than one child. As shows in figures 1 and 2 there was no statistical differences between groups for the social summary score (t = - 0.303, p= 0.764) and financial summary score (t = - 1.119, p=0.270).

Discussion

Even though there is some literature that has investigated the social and financial difficulties of caregivers with children diagnosed with autism, they are not enough to formulate a thorough understanding of the problem. Therefore, this study assessed social and financial burdens in an effort to contribute to the limited literature in the field and to establish a starting point to unified solution for those two aspects.

According to State Health Improvement Plan, Family health encompasses the health of individuals along the entire lifespan continuum of the whole family. The poor health status of one member affects the others in many different ways, medically, physically, emotionally, socially, and financially. (Pennsylvania Department of Health, 2009). The results of my study reaffirm this statement and suggest that the caregivers of children with autism are facing social and financial challenges while providing for their child with an ASD.

Figure 1: Social summary scores for caregiver with one child vs. more than one child

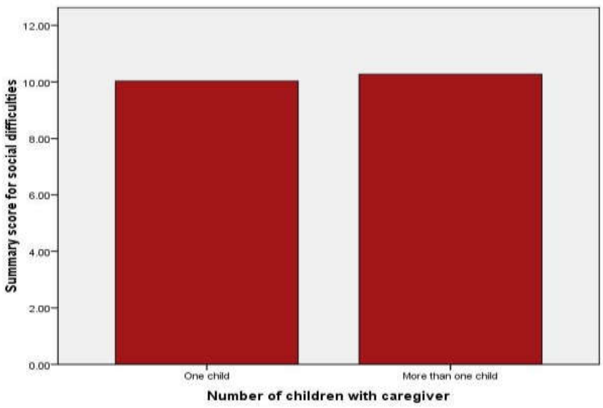
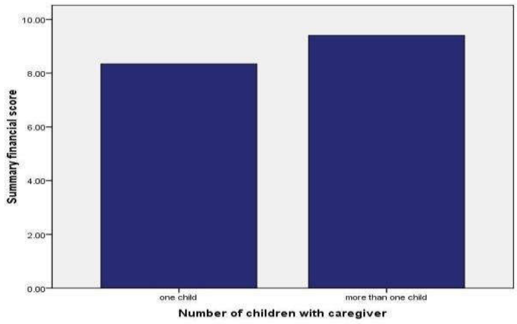


Figure 2 : Financial summary scores for caregiver with one child vs. more than one child



One of the goals in Healthy People 2010 is to, improve mental health and ensure access to appropriate, quality mental health services. (Healthy People 2010, 2001).

The findings of this study raise a red flag for how services for children with autism are provided and controlled.

The main results of this study reveal, caregivers of children with autism are not finding social and financial support, since summary scores range from 5 to 20, with 20 being the least difficulty, therefore social and financial difficulties summary score means suggest a tendency toward the most difficulty options.

In another main finding suggest, the social and financial difficulties comparison between having one child diagnosed with an ASD versus having more than one child diagnosed with as ASD showed no significant in the results which indicates that finical and social difficulties are associated with having a child with autism regardless of how many children the caregiver have. In addition there was no statistical difference in social and financial summary scores when caregiver have one child vs. more than one child including his child with an ASD, which support our first findings.

In addition, taking into consideration the responses from the open ended question at the end of survey, financial difficulties were the main concern among caregivers, including no adequate services are covered by insures the high expenses for most of services needed for child with an ASD which affect family budget. Followed a need for increasing public awareness regarding autism, as the responses emphasized lack of understanding and awareness from the community, which support the findings by Higgins, Bailey, &Pearce 2005, that families have difficulties when outing with there children with an ASD due to lack of understanding to there children difficulties by the community. To demonstrate the level of hardship in social and financial aspect, some individuals had to cut of there work hours to provide for there children as a result of lack of social support which leads to financial loss.

Strengths and Limitations of the Study

The limitations of this study arise from the data collection process. The survey consisted of well structured and inquiry driven social and financial assessments. However, in the demographic section of the survey two questions involving the age of children with an ASD confused some of the participants. Future studies should take into consideration composing the demographic questions in order to satisfy different levels of comprehension. A better approach to this item would be listing each child within an age range, instead of having an open-ended question for listing the children ages. In addition the nonrandomized small size of the sample has increased the threat of external validity and limited a more thorough investigation. This study strength comes from the Cronbach's alpha test that showed consistency for social and financial five items scales.

Implications for the Field of Public Health

Findings suggest an urgent intervention to call attention to the social and financial difficulties of caregivers with ASD children. Health administrator need to advocate finding solutions for financial and social difficulties. In addition policy makers need to allocate sufficient funds to cover the needed services for children with autism in order to ease the pressure on caregivers. Further research need to be implemented, focusing on caregivers' of children with an ASD needs. Future studies should address the question of the area where caregivers had to give-up good paying job to provide and support for their children with an ASD. In addition future study should follow a larger randomize sampling method to reflect the targeted population and to be able to generalize the results of the study?

Caregivers should be aware of the financial and social difficulties and utilize it to advocate for creating educational programs about autism to increase the community awareness. Also, they should organize advocacy groups to persuade officials on state and national levels to create financial packages specially designed for families of children with autism.

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