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Who joins support groups among parents of children with autism?

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Abstract

This study identified factors associated with support group participation among families of children with autism. A survey was administered to 1005 caregivers of children with autism in Pennsylvania. Two-thirds of respondents (66.4%) had ever participated in an autism-specific support group. In adjusted analyses, demographic characteristics, including age and sex of the child, ethnicity and parental education and income, were associated with support group participation. Parents of children with self-injurious behavior, sleep problems or severe language deficits were more likely to belong, as were parents whose diagnosing clinician referred them to a support group. The results of this study suggest the importance of clinician referrals to groups, and the need to make groups available to under-served populations.

Keywords

autism; support groups; family stress

Introduction

Families of children with autism confront a host of difficulties in obtaining appropriate care (Knapfl et al., 1995; Krauss et al., 2001; 2003; Smith, 1994), including obstacles such as learning where and how to obtain services, paying for services, negotiating with disconnected service systems (Bailey et al., 2000; Coonrod and Stone, 2004), and making decisions about a bewildering array of treatment options (Levy et al., 2003; Mandell and Novak, 2005). In their survey of 2200 families of children with special healthcare needs, Krauss et al. (2003) found that 35 percent of children with autism had difficulty in obtaining needed medical services. More than twice as frequently as families of children with other special healthcare needs, they struggled to obtain referrals and appointments, find appropriate providers, and coordinate care. Smith et al. (1994) found that parents had difficulty accessing specialty services when they suspected their child of having a delay, obtaining an appropriate diagnosis, and accessing care after the diagnosis was made. Knapfl et al. (1995) found that only 16 percent were able to access appropriate services quickly, while 30 percent experienced extended periods of inappropriate care.

The lack of an effective, coordinated care system for children with autism that provides accurate information (Jacobsen and Mulick, 2000), combined with the symptoms of the disorder itself, can manifest in high levels of stress for families, social isolation, negative health outcomes, and marital dissatisfaction (Dunn et al., 2001; Sivberg, 2002). While these problems are

common to many families of children with special health care needs, families of children with autism may experience these negative outcomes to a greater extent than families of children with other disabilities (Dunn et al., 2001; Sivberg, 2002).

For families like these, for whom sources of instrumental, informational and emotional support are critical to wellbeing, support groups can be a powerful adjunctive resource, as they are for millions of other Americans who are dealing with chronic health conditions (Davison et al., 2000). In the early 1980s, support groups for families of children with developmental disabilities were identified by several researchers as one of the most noteworthy developments in the field (Schilling, 1988). The value and impact of such groups are based on a solid foundation of psychological and sociological theories, including social comparison theory, the helper-therapy principle, theories of experiential knowledge, and social support theories (Salzer et al., 2002). Studies have found that parents of children with developmental disabilities are highly satisfied with the sense of agency and belonging they achieve from participating in groups (Solomon et al., 2001), and report that their parenting skills improve as a result of participation, their sense of isolation is reduced, they obtain important information about services, and they feel a greater sense of emotional support (Kerr and McIntosh, 2000; Law et al., 2001).

Despite the acknowledged importance of support groups and small studies showing their benefits, there is no literature on the extent of the participation of parents of children with any health condition – much less autism – and factors associated with their use. This study aimed to document the extent to which families of children with autism use support groups, and perhaps more importantly, to identify factors associated with support group participation, such as basic family demographics and clinical characteristics of the child. Knowledge of the factors associated with participation would allow both for targeted referrals to support groups and the preliminary identification of barriers to participation.

Methods

Data collection

Data were collected as part of a state-sponsored effort to improve the quality of care for individuals with autism in Pennsylvania (Mandell et al., 2005). Survey data were collected from June through September 2004 using a snowball sampling approach. Participants were recruited through a mailing to caregivers of individuals with autism who had participated in previous quality improvement efforts and had indicated their willingness to participate in this research. Caregivers were asked to share information about the survey with other caregivers. Providers of autism-related services were identified through the Pennsylvania Department of Public Welfare and county offices of Mental Health and Mental Retardation, and were requested to distribute a letter asking families to complete the survey. The letter described the purpose of the survey, provided a web address for completing the survey over the Internet and a toll-free number to call to receive a paper copy with a postage-paid return envelope, and explained that all responses would be confidential. Participants could enter a draw in which 40 people won cash prizes of \$50 each.

Survey description

The larger survey from which the data for this study were obtained comprised 92 questions designed to measure the quality of autism-related services and took approximately 30 minutes to complete. Questions about clinical and socio-demographic characteristics were also included. The survey was developed based on information gathered from seven focus groups with parents; it was pilot tested with 10 parents of children with autism of varying ages, and

subsequently altered for comprehensibility and content. This study relied only on responses to the questions described below in the 'Variables' section.

Sample

There were 1018 survey respondents, 713 of whom were obtained through the Internet; 13 respondents did not complete the question regarding support group participation and were removed from the sample, leaving 1005 subjects. Respondents were asked to complete the survey for their oldest child with autism. Mothers comprised 86 percent and fathers 7 percent of respondents. The remainder included other relatives and legal guardians. Participants ranged from 23 to 70 years of age (mean = 42, SD = 8), while the individuals with autism about whom they responded ranged from 2 to 53 years (mean = 10, SD = 6). Consistent with epidemiologic findings, 83.4 percent of the subjects were male. The majority was white (83.5%); the remainder was African American (9.8%), Latino (3.0%), Native American (2.4%), or Asian American (1.9%).

To determine the representativeness of the survey sample, demographic characteristics were compared with those of children ages 3–21 in Pennsylvania who received autism-related special education services in 2003 (US Department of Education, 2003). The two groups deviated by no more than 1 percent in any ethnic category. Because children with autism in Pennsylvania often are eligible for Medicaid-reimbursed services regardless of income, the service use of the sample was compared with Medicaid-reimbursed claims for autism in Pennsylvania. Ten percent of the survey sample had a psychiatric inpatient episode compared with 8 percent indicated in the Medicaid claims; 46 percent used a psychotropic medication compared with 42 percent indicated in the claims. These results suggest the similarity of the survey sample and children with autism in Pennsylvania.

Variables

Support group participation—Respondents were asked, 'Are you a member of a support advocacy group for parents?' Responses included 'yes, autism specific (41.3%)', 'yes, both autism specific and not autism specific groups (12.5%)', 'no, but was a member in the past (12.5%)', 'yes, not autism specific (3.5%)', and 'no, have never been a member (30.1%)'. For these analyses, the first three groups were combined, because the question of interest related to participation in an autism-specific support group, and compared with the latter two groups.

Clinical characteristics—Respondents were asked to endorse all symptoms from a list of 15 that applied to their child. Those that were hypothesized a priori to have some relationship with support group participation, in that they might cause particular parental distress, were included in the analysis. Parents also were asked to provide information on their child's primary diagnosis and the presence of other health conditions.

Health system interactions—Respondents were asked whether the professional who diagnosed their child with autism had referred them to a support group. They were also asked whether their child had ever had an inpatient or residential episode due to their autism.

Demographics—The survey included a list of questions regarding respondents' income in \$20,000 increments, ethnicity, age of the child about whom they were responding, and type of area in which they lived (urban, suburban, rural).

Analyses

Chi square analyses and t-tests were used to compare categorical and continuous variables, respectively, as a function of support group participation. Logistic regression was used to determine the adjusted association between each independent variable and support group

participation. Because of the large number of variables considered for the analysis, only those significant at p < 0.25 in the bivariate analysis were included in the regression model (Hosmer and Lemeshow, 2001).

Results

Table 1 provides the sample characteristics as a function of whether subjects ever or never belonged to an autism-specific support group. Two-thirds of the sample (66.4%) had ever participated in an autism-specific support group. The groups significantly differed on most variables. Those who belonged to a support group were more likely to have male children (86.5% vs 80.3%), be white (87.3% vs 75.7%), have an annual income above \$40,000 (73.2% vs 55.6%), live in a suburban area (65.0% vs 55.4%), be a college graduate (64.5% vs 46.2%), be married or living with a partner (83.6% vs 73.7%), and report that the diagnosing clinician referred them to a support group (24.8% vs 18.9%). They were also more likely to have children who were self-injurious (42.9% vs 36.0%), had sleep problems (56.9% vs 47.3%) or had severe language deficits (70.3% vs 62.8%).

A number of differences persisted in the adjusted logistic model (Table 2). Adjusting for demographic and clinical characteristics, children whose parents ever belonged to a support group were more likely to be older (odds ratio [OR] = 1.04 per year) and male (OR = 1.72) than children whose parents did not. African Americans were less likely than whites to belong to support groups (OR = 0.39), while parents with household incomes between \$40,000 and \$80,000 per year (OR = 1.50) and those with college degrees (OR = 1.90) were more likely to belong than those with incomes below \$40,000 and no college education, respectively. Parents of children with self-injurious behavior (OR = 1.49), sleep problems (OR = 1.83) or severe language deficits (OR = 1.51) were more likely to belong, as were parents whose diagnosing clinician referred them to a support group (OR = 1.60).

Discussion

Findings from this study suggest that two-thirds of families of children with autism have participated in autism-specific support groups and more than half are currently participating. One might reasonably assume that current participation reflects some degree of perceived benefit, especially given the competing time and resource demands of caring for a child with autism.

The results of the adjusted analysis suggest that support group participants are more likely than non-participants to be middle income and well educated, and less likely to be African American. These findings are similar to those from studies in substance abuse and cancer, which suggest, with some exceptions (Humphreys et al., 1991), that support groups generally appeal to middle-and upper-income, more educated, married, suburban whites (Katz et al., 2002; Osborne and Glaser, 1981; Powell, 1987). People with these characteristics may have greater comfort in discussing private feelings and experiences with others, possibly due to cultural factors. They may also have greater resources and time to find or initiate such groups in their communities, thereby increasing access. It may also be that poor, less educated, urban and rural residents, as well as African American parents, think that these groups will not address their specific needs.

Support group participants also were more likely than non-participants to have children who engaged in self-injurious behaviors, had sleep problems and had severe language deficits. These symptoms may represent some of the most distressing of those manifested in autism, and may precipitate parents to turn to other parents who have had similar experiences for help. The fact that parents of older children were more likely to participate may be a function of the additional time it takes to establish routines and identify resources. The finding that parents of

male children were more likely to participate is puzzling; it may be that parents of girls with autism, who are in the distinct minority (Fombonne, 2003), think that support groups will not address their needs.

Finally, the results suggest that providers play a critical role as a referral source (Salzer et al., 1994). Group participants were more likely to have been referred by their diagnosing clinician; however, fewer than 1 in 4 parents reported that they were referred, suggesting that most parents find groups on their own.

Limitations

A number of study limitations should be considered. Perhaps primary among them is the validity of autism diagnoses and reporting of related symptoms, which were not standardized or validated. Studies have found good to excellent reliability associated with both the diagnosis of autism by healthcare professionals and the differentiation of subtypes, however (Eisenmajor et al., 1996; Fombonne et al., 2004; Hill et al., 2001; Mahoney et al., 1998). A second limitation is potential bias in survey respondents. Despite the similarities between the experiences and ethnicity of survey respondents and children with autism in Pennsylvania, families that completed this survey may have characteristics different from those of non-responders, which in turn may be associated with support group participation. For example, an indication of bias towards higher-functioning children in this sample is the large number of responding families relative to the community prevalence of children with Asperger's disorder and without mental retardation (Fombonne, 2003). A related limitation is that the majority of respondents were mothers; these findings may not be generalizable to fathers or other caregivers. Finally, caregivers were asked to recall whether they had been referred to a support group. Differential recall may have been associated with support group participation.

Implications

Despite these limitations, there are important implications related to these findings. Participation in support groups is most likely indicative of the perceived need for such supports. While this study does not explain why people participate, it suggests that families require more than professionally delivered supports. This should not be perceived as a failing on the part of professional services. Instead, it should be viewed as validation for the benefits of peer support for families of children with autism. Family members who have 'been there' and shared similar experiences can support one another, provide critical information about where and how to obtain services, and, in some cases, can come together to advocate for needed resources and supports.

This study suggests that clinicians can be an important referral source. Clinicians may wish to actively seek out information about groups in their region to share with families, assist groups in starting if they do not already exist, and provide knowledge and support (e.g. marketing resources, space) to those already in existence. Service systems should also consider such groups as part of the system of care available to families and provide supports and referrals.

Our data also indicate that these groups are underutilized by certain segments of the population, especially those from lower socioeconomic backgrounds and African American families. It is plausible that more groups exist in communities with more economic and social resources, thereby increasing access in these communities. One implication would be the need to increase the availability of groups in these communities. Again, clinicians and service systems could facilitate this as part of their efforts to expand the continuum of care.

While research on the Parent-to-Parent program (Ainbinder et al., 1998; Silver et al., 1997; Singer et al., 1999) and other 1:1 mentoring and peer support programs (Chernoff et al.,

2002) has demonstrated positive effects for parents and their children with special needs, there has been little systematic study of whether and how family-led support groups influence parents' treatment and service decisions, access to care, and family wellbeing. As with 1:1 mentoring, support groups offer members contact with families in similar situations, which may decrease social isolation, reduce stress, and increase access to information about appropriate care. Groups may have an advantage over 1:1 support in that they involve more participants, thereby increasing the pool of information available, the chances of interactions with others who share specific experiences, and opportunities to give and receive support. The increase in the pool of knowledge may be particularly important for families of children with autism where appropriate resources may be more difficult to access than for other childhood conditions. On the other hand, reliance on support systems outside the traditional medical establishment may increase the use of alternative treatments and decrease the use of treatments with proven efficacy (Levy et al., 2003). The common use of support groups demonstrated in this study suggests the need for this type of research and inclusion of these groups as part of the system of care.

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 $\label{eq:Table 1} \textbf{Table 1}$ Sample characteristics by support group participation (n = 1005)

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	Ever belonged (n = 667)	Never belonged (n = 338)	p-value
Demographics			
Age of child (years, SD)	10.3 (6.0)	9.6 (6.0)	0.070
Sex (male)	86.5%	80.3%	0.011
African American	5.3%	16.2%	< 0.001
Asian/Pacific Islander	1.8%	0.3%	
European American	87.3%	75.7%	
Native American	2.1%	2.1%	
Latino	2.3%	3.6%	
Other	1.2%	2.1%	
Income less than \$40,000/year	22.8%	40.2%	< 0.001
Between \$40,000 and \$79,000/year	41.1%	32.8%	
More than \$80,000/year	32.1%	22.8%	
Live in rural area	19.1%	25.7%	< 0.001
Live in suburban area	65.0%	50.4%	
Live in urban area	15.9%	23.9%	
College graduate	64.5%	46.2%	< 0.001
Married/cohabiting	83.6%	73.7%	< 0.001
Clinical characteristics			
Autistic disorder	37.0%	30.9%	0.014
Asperger's disorder	22.5%	18.7%	
PDD-NOS	33.6%	38.3%	
Other diagnosis	6.9%	12.1%	
Mental retardation	20.9%	23.4%	0.409
Hearing impairment	2.5%	3.7%	0.313
Seizures	9.7%	8.0%	0.478
Self-injurious behavior	42.9%	36.0%	0.041
Sleep problems	56.9%	47.3%	0.005
Aggressive towards others	49.8%	46.7%	0.384
Severe language deficits	70.3%	62.8%	0.018
Health system interactions			
Clinician referred family to a group	24.8%	18.9%	0.038
Child had an inpatient/residential stay	9.9%	10.8%	0.659

Table 2

Factors predicting support group participation a,b

	Odds ratio	95% CI
Demographics		
Age of child (years)	1.04	(1.01, 1.07)
Sex (male)	1.72	(1.17, 2.52)
African American	0.39	(0.23, 0.66)
Asian/Pacific Islander	4.28	(0.93, 19.71)
Native American	1.43	(0.52, 3.94)
Latino	0.70	(0.30, 1.66)
Other	0.67	(0.20, 2.28)
Between \$40,000 and \$79,000/year	1.50	(1.04, 2.18)
More than \$80,000/year	1.35	(0.88, 2.08)
Live in rural area	0.74	(0.52, 1.08)
Live in urban area	0.95	(0.62, 1.43)
College graduate	1.90	(1.40, 2.60)
Married/cohabiting	1.22	(0.81, 1.84)
Clinical characteristics		
Asperger's disorder	1.08	(0.70, 1.67)
PDD-NOS	0.81	(0.58, 1.12)
Other diagnosis	0.50	(0.30, 0.83)
Self-injurious behavior	1.49	(1.11, 2.00)
Sleep problems	1.83	(1.33, 2.51)
Severe language deficits	1.51	(1.05, 2.15)
Health system interactions		
Clinician referred to a group	1.60	(1.12, 2.29)

 $^{^{}a}{\rm Reference\ group\ is\ European\ American,\ incomes\ under\ \$40,000/year,\ rural\ diagnosed\ with\ autistic\ disorder.}$

 $[^]b\mathrm{Odds}$ ratios significant at p<0.05 are presented in bold typeface.