Satisfaction With Primary Health Care Received by Families of Children With Developmental Disabilities

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ABSTRACT

Objective: To evaluate the perceptions of families of children with developmental disabilities regarding their primary care physicians and to determine if differences exist for different conditions.

Methods: Mailed survey to families of children who had autism, physical disabilities (cerebral palsy or spina bifida) and mental retardation that included the Multidimensional Assessment of Parental Satisfaction for Children with Special Needs.

Results: One hundred twenty-one families responded. Families rated physicians highest on their ability to keep up with new aspects of care and on their sensitivity to the needs of children. Parents had the lowest ratings for the primary care physicians’ ability to put them in touch with other parents, understanding of the impact of the child’s condition on the family, ability to answer questions about the child’s condition, and information and guidance for prevention. Physicians’ knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities ranked worse than neutral. Families with a child with autism had more spontaneous negative comments and rated their primary care physicians lower on several aspects of care. They requested more information on complementary and alternative medicine and more support in the community.


Children with special health care needs (McPherson et al., 1998) have complex medical needs. The American Academy of Pediatrics (AAP) and Maternal and Child Health Bureau (MCHB) have stated, “All children with special health care needs will receive regular ongoing comprehensive care within a medical home” provided by the primary care physician.
In describing the medical home, the AAP has stated that it should be “accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care” (AAP, 2003, p. 1).

Patient satisfaction is an important measure of quality of care (Donabedian, 1992). The patient’s perspective in defining the quality of health care is increasingly being used to develop policies for service delivery and financing. Evaluating patient satisfaction can enhance the involvement of patients and families in decisions that concern them (self-management) (Law et al., 2003; Rosenbaum, King, Law, King, & Evans, 1998; Wagner, 1998). Also, satisfaction with medical encounters is related to outcomes such as adherence (compliance) with medical regimens (Auslander, Thompson, Dreitzer & Santiago, 1997; Freed, Ellen, Irwin, & Millstein, 1998; Oermann, Swank, & Sockrider, 2000; Parhiscar & Rosenfeld, 2002).

Based on clinical experience, it was hypothesized that families who have a child with autism would be less satisfied with primary care than families of children with other conditions. In addition to our clinical impressions, a number of studies have documented higher than typical levels of stress for families who have a child with autism (Duarte, Bordin, Yazigi, & Mooney, 2005; Koegel et al., 1992). In one study, families who had children with autism had higher levels of stress than did families who had children with cystic fibrosis (Bouma & Schweitzer, 1990). Holroyd and McArthur (1976) found that, in comparison with mothers of children with Down syndrome, mothers of children with autism were more upset and disappointed with their child and more anxious about obtaining appropriate services. In addition, families of children with autism have a high utilization of complementary and alternative therapies (Levy & Hyman, 2005), suggesting dissatisfaction with conventional care. Finally, significant differences between parental perception and professional assessments of the cognitive level of children with autism have been documented (Geiger, Smith, & Creaghead, 2002), suggesting at least some discord between these parents and professionals. The purpose of this study was to evaluate the perceptions of families with a child with a developmental disability regarding their primary care physicians and to determine if differences exist for families who have children with different conditions.

METHODS

The sample for this survey included patients who currently receive services at the Kirch Developmental Services Center, Golisano Children’s Hospital, University of Rochester Medical Center. This program provides care to children who have physical disabilities such as spina bifida and cerebral palsy, as well as developmental disabilities such as autism and mental retardation. Individuals with these four conditions were identified through a centralized database, and surveys were mailed to them. Children were classified as having mental retardation only if they did not have autism as well.

Families were identified from a database of encounters from the previous 12 months. Three hundred surveys were mailed to the homes of these families during the winter of 2003-2004: 100 to families with a child with mental retardation (without autism), 100 to families with a child with physical disability (50 each to families with a child who had cerebral palsy and spina bifida), 100 to families with a child with autism, and 100 to families with a child with mental retardation (without autism). Surveys were color coded by diagnosis. A raffle was used to try to increase the return rate. Reminder cards were sent 4 weeks after the initial mailing.

Survey Instrument

The survey was designed to be completed by the child’s primary parent and was reviewed prior to the survey by nonstudy parents and professionals for clarity, language, ease of completion, and length of time for completion. It was translated into Spanish to encourage greater subject response. The Spanish version of the survey was printed on the reverse side of the English version. Participants were able to complete the survey within 10 to 15 minutes. The mailing consisted of a letter of introduction, a consent form, the survey, a self-addressed stamped envelope for survey return, and a separate stamped postcard that families could return to be entered in a drawing for five cash prizes. The study was approved by the University of Rochester Research Subjects Review Board.

The survey consisted of three parts: (a) demographic information, (b) the Multidimensional Assessment of Parental Satisfaction (MAPS) for Children with Special Needs (Ireys & Perry, 1999), and (c) general questions regarding health care. The MAPS for Children with Special Needs (Ireys & Perry)
**Table 1. Characteristics of the sample**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s condition (No. and percent of sample)</td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>41 (33%)</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>36 (30%)</td>
</tr>
<tr>
<td>Physical disability</td>
<td>44 (36%)</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>24</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>20</td>
</tr>
<tr>
<td>Sex of person filling out survey</td>
<td></td>
</tr>
<tr>
<td>Female (percent)</td>
<td>107 (88%)</td>
</tr>
<tr>
<td>Highest grade of school</td>
<td>College degree (median)</td>
</tr>
<tr>
<td>Total children in the family (mean)</td>
<td>2.8 [2.6&lt;CI&lt;3.0] (median = 3)</td>
</tr>
<tr>
<td>No. of children with special needs (mean)</td>
<td>1.3 [1.2&lt;CI&lt;1.5] (median = 1)</td>
</tr>
<tr>
<td>Black/African-American, non-Spanish/Latino (percent)</td>
<td>7 (6%)</td>
</tr>
<tr>
<td>Age of child (mean)</td>
<td>6.9 years [6.1&lt;CI&lt;7.8]</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>Between 1 and 3 years (median)</td>
</tr>
<tr>
<td>No. of years with current primary care physician</td>
<td>3 to 4 years (median)</td>
</tr>
<tr>
<td>Health insurance (No. and percent)</td>
<td></td>
</tr>
<tr>
<td>Medicaid (with or without other coverage)</td>
<td>70 (58%)</td>
</tr>
<tr>
<td>Medicaid only</td>
<td>40 (33%)</td>
</tr>
</tbody>
</table>

is a short, validated tool for measuring satisfaction with physicians at the individual level of care. The MAPS evaluates care in five areas: care coordination, developmentally appropriate care, family-centered care, interpersonal competence, and technical competence. The MAPS can be used for identifying areas for quality improvement. For example, if parents are dissatisfied with their clinicians’ efforts to link them with other families, a program could be developed to improve the clinicians’ knowledge and ability to address this aspect of care. Subjects were instructed to fill out the survey with respect to their primary care physician. The MAPS has been shown to have a standardized alpha coefficient, a measure of internal consistency, of 0.87 (Ireys & Perry). In terms of validity, Pearson correlation coefficients ranging from 0.85 to 0.91 were found between the satisfaction scale and the mean score of three items. Also, correlations between the MAPS and a separate satisfaction scale were 0.79 for the entire group.

Seven additional questions were added to assess baseline attitudes toward physicians in primary medical care (Hulka, Zyzanski, Cassel, & Thompson, 1970). Finally, families were asked to note what type of services or support could improve the health and well-being of their children. Hand-written comments were categorized by the authors after reaching consensus.

**Data Management**

Results of the survey were entered into a Microsoft Excel Form and then transferred to SPSS Version10.0 (SPSS, 2005) for statistical analysis. All information was anonymous. Statistical analyses included descriptions of the responses (means and confidence intervals) and computation of summary scores for the two instruments in the survey. Analyses of responses by subgroups, including age of child, race/ethnicity, level of education, diagnosis, and type of insurance, were performed using analysis of variance and Chi square.

**RESULTS**

**General Analyses**

Three hundred surveys were mailed. Twenty surveys were returned by the postal service because the addresses were no longer valid; two children were deceased. A total of 121 surveys were returned for a corrected return rate of 44%. To satisfy Health Insurance Portability and Accountability Act regulations, we did not have demographic information on the individuals when the surveys were mailed. Therefore, we could not compare characteristics of those who did and did not return the survey. Table 1 shows the characteristics of the sample. Roughly, one third each had autism, mental retardation, and physical disability. The vast majority of the surveys (88%) were completed by female adult caregivers. Eighty percent of the respondents had completed high school. The median number of children in the family with special needs was one, and the median total number of children was three. Eleven percent of the sample were Latino and 6% were Black, non-Latino. The mean age of the child with special needs at the time of the survey was 6.9 years, and the median age at the time of the diagnosis was between 1 and 3 years of age. Although 13 respondents identified themselves as being Latino, only two used the Spanish version of the questionnaire.

More than half the sample had Medicaid with or without other insurance coverage, while 33% had Medicaid only. Approximately 29% of families who had a child with autism had Medicaid, compared with 64% of the families who had a child with physical disabilities, and 68% with mental retardation, and 68% with mental retardation, \( \chi^2(2, N = 121) = 11.23, P = .04 \).

The MAPS was scored using the method of Ireys and Perry (1999), whereby those answering fair or poor were combined into one group. Table 2 shows the percent answering fair or poor to the 12 questions, ranked by the highest percent. In the current study, 33% of the sample rated the primary care physician’s ability to put them in touch with...
other parents as being fair or poor (which is lower than the percentages noted by Ireys and Perry in their two samples). More than 20% of our sample rated the physicians as fair or poor on the following items: (a) understanding of the impact of the child’s condition on the family, (b) ability to answer questions about the child’s condition, and (c) information and guidance for prevention. The last two were rated worse by our sample than by those in either one of Ireys’ samples. Our sample also had a worse rating of the physicians’ ability to provide care coordination (16.5% answering fair or poor) than did the samples of Ireys and Perry. “Sensitivity to Background and Beliefs” and “Providing General Health Care” were rated the highest.

Table 3 shows ratings on general attitudes towards physicians, ranked from worst to best. Physicians’ knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities ranked worse than neutral (3.59, where 1 = strongly agree, 3 = neutral, and 5 = strongly disagree). Families rated physicians highest on their ability to keep up with medical skills and knowledge of new things (2.28) and about their caring more about the needs of children than what is convenient for them (2.48). Families believed that they should take primary responsibility and not rely so much on doctors (2.35) and that they should investigate all options rather than just accepting a doctor’s advice (1.77).

Analyses by Subgroups
With $\alpha = .05$, and using analysis of variance for three groups, the current sample has a power of 0.98 to detect a large effect size and a power of 0.68 to detect a medium effect size. We were uncertain about the effect size that we would find. However, in the study by Bouma and Schweitzer (1990), the difference in the mean stress scores between families with autism (29.1) and families with cystic fibrosis (20.0) was greater than one
standard deviation (7.3). This would be considered a large effect size. Likewise, in the study by Holroyd and McArthur (1976), the difference in mean negative attitude between those with autism (13.0) and those with Down syndrome (8.6) also was greater than the standard deviation (3.6).

Families who had a child with autism were smaller in size (mean number of children 2.33) than were families who had a child with physical disabilities (3.07) or mental retardation (3.03), $F(2, 118) = 4.03, P = .02$, but no significant differences among these groups were found in the mean age of the affected child. The answers to the MAPS were evaluated by the child’s condition (see Table 4). Families with a child with autism rated their primary care physician’s ability to answer their questions regarding their child’s condition worse (mean score 2.78) than families with children who had physical disabilities (2.24) or mental retardation (2.08). $F(2, 116) = 3.24, P = .04$; 41% of families with autism rated this question as fair or poor, compared with 19% for physical disabilities, and 17% for mental retardation. Families of children with autism also rated their physicians worse (2.97) on their ability to understand how the child’s condition affects the family than did families of children with physical disabilities (2.27) or mental retardation (2.31). $F(2, 105) = 3.12, P = .04$; 40% of families with autism rated this question as fair or poor, compared with 16% for physical disabilities, and 17% for mental retardation. No other significant differences were found on the MAPS questions by diagnosis. Neither race nor ethnicity was associated with the MAPS.

The answers to the questions regarding attitudes toward physicians and primary medical care were evaluated. Families of children with autism were more likely to disagree with the statement that most doctors are well qualified to manage medical conditions like their child’s (mean score 3.64) than were families of children with physical disabilities (3.05) or mental retardation (3.11). $F(2, 118) = 4.00, P = .02$. They also rated most physicians in general worse on their knowledge of complementary and alternative medicine (mean score 3.88) than did families of children with physical disabilities (3.48) or mental retardation (3.42). $F(2, 118) = 3.90, P = .05$. No other significant differences were found on the attitudinal questions. Neither race nor ethnicity was associated with the questions on attitudes.

More families of children with autism spontaneously volunteered that additional information on complementary and alternative medicine would be helpful to improve the health and well-being of their child (14%) than did families of children with physical disabilities (2%) or those with mental retardation (3%). $\chi^2(2, N = 121) = 6.14, P = .05$. Families of children with autism volunteered a mean of 1.0 negative comments about their primary care compared with 0.5 for families of children with physical disabilities and 0.6 for those with mental retardation, $F(2, 118) = 3.68, P = .03$. More families of children with autism believed that they would benefit from support in the community (24%) than did families of children with physical disabilities (5%) or those with mental retardation (17%). $F(2, 118) = 3.23, P = .04$.

**DISCUSSION**

Few studies of patient satisfaction have been performed with families of children who have developmental disabilities (Breslau &

**Table 4. Comparison (means) among subgroups on Multidimensional Assessment of Parental Satisfaction (MAPS) for Children With Special Needs (Ireys & Perry, 1999) (1 = excellent, 3 = good, 5 = poor), and attitudes toward physicians (1 = strongly agree, 3 = neutral, 5 = strongly disagree)**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Autism</th>
<th>Physical disability</th>
<th>Mental retardation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to answer questions about condition</td>
<td>2.78</td>
<td>2.24</td>
<td>2.08</td>
<td>$F(2, 116) = 3.24, P = .04$</td>
</tr>
<tr>
<td>Understanding condition’s impact on family</td>
<td>2.97</td>
<td>2.27</td>
<td>2.31</td>
<td>$F(2, 105) = 3.12, P = .04$</td>
</tr>
<tr>
<td>Most doctors are well qualified to manage medical conditions like my child’s</td>
<td>3.64</td>
<td>3.05</td>
<td>3.11</td>
<td>$F(2, 118) = 4.00, P = .02$</td>
</tr>
<tr>
<td>Most doctors know a lot about complementary and alternative medicine</td>
<td>3.88</td>
<td>3.05</td>
<td>3.42</td>
<td>$F(2, 118) = 3.90, P = .05$</td>
</tr>
</tbody>
</table>

**Physicians’ knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities ranked worse than neutral.**
In this study, families who had children with developmental disabilities expressed the opinion that the general care provided by their child's primary care physician was excellent/very good. However, they were less happy with certain aspects of care. More than 20% rated four activities on the MAPS as fair or poor. These included the following: (a) putting parents in touch with other parents, (b) understanding the condition’s impact on the family, (c) the ability to answer questions about the condition, and (d) information and guidance for prevention. Activities three and four were considerably worse in this sample than they were in the two samples surveyed by Ireys and Perry. These activities are similar to the ones noted years ago to be a problem in the Rochester community both in 1974 (Kanthor, Pless, Satterwhite, & Myers, 1974), and in 1989 (Liptak & Revell, 1989). Providing help in coordinating care was rated worse in this sample than it was for the samples used by Ireys and Perry (1999). Other activities from the MAPS were comparable among the three samples. These findings can direct future community-based interventions. Although 53% of the sample rated the primary care physician’s ability to put them in touch with other parents as being fair or poor (the highest percentage of negative rating in this study), it is important to acknowledge the positive as well, and note that even in this category 67% rated their providers as excellent, very good, or good.

Families rated physicians' knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities worse than neutral. Use of complementary therapies has been increasing among children (Apel, 2002; Davis & Darden, 2003; Levy & Hyman, 2005; Sawin-Sikand, Schubiner, & Thomas, 2002). However, primary care physicians may not be well versed in this area (AAP Committee on Children with Disabilities, 2001; Whelan & Dvorkin, 2003). Families in the study also supported the concept of self-management by noting that they should take primary responsibility and not rely so much on doctors and that they should investigate all options rather than blindly accepting a doctor's advice.

Although a few studies have been published on patient satisfaction with disclosure of the diagnosis in autism (Brogan & Knussen, 2003) or satisfaction with educational and psychological services (Boyd & Corley, 2001; Doherty, Fitzgerald & Matthews, 2000), very little has been published on satisfaction with health-related care for families who have a child with autism. In this study, families who had a child with autism rated their primary care physicians lower than did families who had a child with a physical disability or mental retardation on the physician's ability to answer their questions regarding their child's condition and their ability to understand how the child's condition affects the family. They also rated physicians in general lower on their qualifications to manage medical conditions like their child's or of having adequate knowledge of complementary and alternative medicine. They specifically wrote that more information on complementary and alternative medicine and more support in the community would be helpful to improve the health and well-being of their child. They had more spontaneous negative comments about their child's medical care in general than did other families in the study.

Several factors may account for the dissatisfaction expressed by parents of children with autism. One possibility is that parents of children with autism may feel as if they have less stability and more doubts and uncertainty related to their child's disability. This feeling of helplessness may negatively affect their interaction with their...
child's care providers. Another possible reason for the level of dissatisfaction for parents of children with autism may be related to a need for complete and unbiased information regarding various treatment options for autism. Our findings are consistent with other studies that have found that parents of children with autism experience more problems when accessing needed specialty care (Krauss, Gulley, Sciegaj, & Wells, 2003).

This study has several limitations. The findings are based on a convenience sample of families who receive care in a specialty center and elected to return their survey. Thus, they may not be representative of other families who have children with disabilities. On the other hand, the findings are consistent throughout the study; that is, whenever a statistically significant difference among diagnostic groups was found, families who have children with autism were more dissatisfied with care or requested more services to help them. It appears, therefore, that at least in the Rochester, New York region, these families have more unmet needs and are less happy with the medical care they receive than are families who have children with other developmental disabilities. This study evaluated physicians only. In many instances parents consider a nurse or other nonphysician clinician to be the child's primary source of care.

Based on the findings of this study and consistent with the model developed by Wagner (1998), families and children should be targeted to enhance self-management, and providers should be targeted to enhance decision support. Improving the delivery system design and enhancing clinical information systems may help as well. Quality standards are being developed and are starting to include feedback from consumers, similar to the questions used in this study. The findings also suggest the importance of simplifying and strengthening links among primary care clinicians, specialists, and therapists, as well as schools, community organizations, and governmental agencies. Medical home programs (Strickland et al., 2004) and other changes in the systems of care may play a role in improving these interactions (Law et al., 2003).

Pediatric nurses in advanced practice may utilize the findings of this study to augment the way in which they deliver services to children who have developmental disabilities. Topics not well addressed by the physicians in this study included connecting parents to other parents, understanding the impact of the child's condition on the family, being knowledgeable about the child's condition, providing information and guidance for prevention, and knowing about complementary and alternative medicine. Satisfaction appears to be highly dependent on service delivery structure. For example, Law et al. (2003) found that parental satisfaction with services was higher in centers that were perceived to be more family centered and when care could be provided in fewer places. Likewise, Hasnat and Graves (2000) found that parents were more likely to be satisfied with the initial diagnosis of autism if they received a large amount of information, when the disclosing professional communicated well with the parents, had an understanding of parental concerns, and was direct in manner.

Evaluation of the satisfaction levels expressed by families impacts important information that may be used to enhance the way care is provided to families and children. Concerns identified by families may be addressed by care practitioners. Particular attention may be given to those variables, some disability-specific, that affect quality of care. Comprehensive care coordination and delivery may be improved when evaluative measures are examined and creative solutions are developed.

**REFERENCES**


