

A Preliminary Exploration of Support Systems for Parents of Children with Special Needs

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Raising a child with special needs exacerbates the inherent challenges of parenting. Although the needs of children with special needs are addressed frequently in the literature, the needs of the parents of children with special needs are often neglected. In order to offer effective and useful services for parents of children with special needs, this article examines the types and nature of support services used by the parents of children with special needs and the effectiveness of those support services in reducing the parents' stress levels and/or increasing their coping skills. Seventy-four parents of special needs children were assessed and results revealed that low-cost services, particularly those that resulted in mutual support, were a significant priority among parents. The article concludes with a discussion of clinical implications and needed directions for future research.

Keywords: parenting, children, special needs, support services, counseling

Parenting involves much effort and countless responsibilities. Child rearing can be one of the most challenging tasks with which a person is confronted. Raising a child with special needs intensifies the challenge significantly. However, although the needs of children with special needs are addressed frequently in professional literature and in the media, the needs of parents of children with special needs are addressed far less often. In order to offer effective and useful services for parents of children with special needs, their experiences with common issues and concerns and how their needs can be met must be investigated and understood because such information is essential to enable parents to feel empowered in raising their children with special needs.

Parents of children with special needs often experience high levels of stress from both internal and external factors. For example, a study conducted by Heiman (2002) revealed that 84.4% of the participants who had children with various special needs experienced feelings including “depression, anger, shock, denial, fear, self-blame, guilt, sorrow, grief, confusion, despair, [and/or] hostility” at the time of their children’s first diagnoses. Barnett, Kaplan-Estrin, and Fialka (2003) reported a study of parents of children who were mildly or moderately impaired that showed about half of the parents were still experiencing negative responses to their children’s diagnoses two or more years after the initial diagnosis.

In addition, parents of children with special needs may suffer being stereotyped by others. For example, Goddard, Lehr, and Lapadat (2000) used focus groups to collect individual narratives from parents of children with special needs. They found that, more than the parents’ guilt or the condition of the child, being perceived as a victim of a tragedy and the sole advocate for the child as well as a lack of understanding from others, including professionals, contributes to parental stress. Financial concern is another external factor which contributes to high stress levels in parents raising children with special needs. Looman, O’Conner-Von, Ferski, and Hildenbrand (2009) found that the severity of a child’s special needs increased the odds of financial burden experienced by the family. Clearly, there are a variety of both internal and external stressors, and accompanying emotional reactions, with which parents of children with special needs are confronted. Therefore, providing services to reduce the stress and negative feelings to minimum levels would lead to better quality of life for the parents of children with special needs.

Given the relative lack of attention to the support service needs of parents raising children with special needs, the purpose of this study was to conduct an exploratory investigation of the types of services used by parents of children with special needs and the effectiveness of those services for reducing parents’ stress levels and increasing their coping skills.

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Four primary research questions were addressed in this study:

1. What are the types of services used by parents of children with special needs?
2. How effective are services in reducing stress levels of such parents?
3. How effective are services in increasing the coping skills of parents?
4. What are some of the needs of parents which may be met by counseling services?

Method

There were two major parts to this research. The first involved distribution of a survey to parents of children with special needs and the second involved an extensive interview with a representative parent of a child with special needs. In the first part of the study a survey was used to collect data for approximately one year. Potential respondents included parents and/or primary caregivers of preschool or school-age children with special needs who resided in a Midwestern state. No restriction was placed on the potential respondents based on the type or number of special needs their child had. Participants were recruited through contact with organizations for families of children with special needs (e.g., local associations for learning disabilities, pervasive developmental disabilities, and physical disabilities) and snowball sampling with assistance of professionals at local public schools who work with children with special needs and their parents. An online survey, the primary means of data collection, was created using a commercial website (www.surveymonkey.com), and potential respondents were directed to the survey webpage from either the websites of the organizations or by typing in the website address found on a distributed survey invitation flyer. A paper version of the survey was prepared for participants from a university clinic for speech and hearing.

The second part of the study involved an individual follow-up interview. Initially, the intent was to garner enough participants for a focus group activity. Unfortunately, however, of all the survey respondents, only one expressed interest in participating in a focus group. Therefore, this respondent was selected and interviewed in order to explore the stressors, challenges, and supports available for the parents in greater depth. The interview was audio-taped and transcribed by the investigator.

Results

There were a total of 74 respondents. Among the respondents, 70 (94.6%) completed the survey online and 4 (5.4%) completed the paper form of the survey. Selected survey items and the resultant data are shown in Table 1.

Table 1

Selected Survey Items and the Resultant Data

Survey Items	No. of Responses	% Responses
Items for all the respondents ($N = 74$)		
<i>How would you rate your degree of stress on the following scale?</i>		
In the last month?		
Very low	0	0.0
Low	8	10.8
Moderate	22	29.7
High	33	44.6
Very High	9	12.2
<i>In the last year?</i>		
Very low	0	0.0
Low	5	6.8
Moderate	23	31.1
High	24	32.4
Very High	21	28.4

Survey Items	No. of Responses	% Responses
<i>What would be the ratio of each factor that might be contributing to your stress level?</i>		
Raising a child(ren) with special needs		
About 1–25%	9	12.2
About 26–40%	15	20.3
About 41–60%	15	20.3
About 61–80%	23	31.1
About 81–100%	11	14.9
Financial concerns		
About 1–25%	15	20.3
About 26–40%	20	27.0
About 41–60%	12	16.2
About 61–80%	7	9.5
About 81–100%	15	20.3
<i>Have you sought professional services (i.e., therapies) in dealing with your stress of raising a child(ren) with special needs?</i>		
Yes	30	40.5
No	43	58.1
<i>If you answered No to the previous question, what was (were) your reason(s) for not seeking professional services (i.e., therapies)? (n = 43)</i>		
Unable to afford the service	5	11.6
Schedule conflict	7	16.3
Did not know about any service available	7	16.3
Unable to find a service that seemed helpful for your needs	12	27.9
Counseling as a category of received service (n=30)		
<i>Type of service you have received:</i>		
Individual counseling	22	73.3
Couples counseling	3	10.0
Family counseling	7	23.3
<i>How helpful was the service for dealing with your stress?</i>		
Very helpful	7	23.3
Somewhat helpful	12	40.0
Neutral	2	6.7
Somewhat unhelpful	2	6.7
Very unhelpful	3	10.0
<i>Compared with your stress level before receiving service, how much has it changed after receiving service?</i>		
Not changed at all	2	6.7
Greatly reduced	12	40.0
Somewhat reduced	7	23.3
Unsure	2	6.7
Somewhat increased	2	6.7
Greatly increased	2	6.7

Survey Items	No. of Responses	% Responses
<i>Compared with your outlook on raising your child(ren) with special needs before receiving service, how much has it changed after receiving service?</i>		
Not changed at all	3	10.0
Greatly more optimistic	12	40.0
Somewhat more optimistic	4	13.3
Unsure	6	20.0
Somewhat more pessimistic	1	3.3
Greatly pessimistic	0	0.0
Group as a category of received service (n=16)		
Group counseling	2	12.5
Support group	14	87.5
<i>How helpful was the service for dealing with your stress?</i>		
Very helpful	6	37.5
Somewhat helpful	8	50.0
Neutral	1	6.3
Somewhat unhelpful	0	0.0
Very unhelpful	1	6.3
<i>Compared with your stress level before receiving service, how much has it changed after receiving service?</i>		
Not changed at all	0	0.0
Greatly reduced	10	62.5
Somewhat reduced	3	18.8
Unsure	1	6.3
Somewhat increased	2	12.5
Greatly increased	0	0.0
<i>Compared with your outlook on raising your child(ren) with special needs before receiving service, how much has it changed after receiving service?</i>		
Not changed at all	1	6.3
Greatly more optimistic	8	50.0
Somewhat more optimistic	2	12.5
Unsure	3	18.8
Somewhat more pessimistic	1	6.3
Greatly more pessimistic	0	0.0
Items for the respondents who sought a professional service(s) in the past for dealing with their stress of raising their children with special needs (n=30)		
<i>What have you gained from receiving service(s)?</i>		
Peer support	8	26.7
Professional support	7	23.3
Network	10	33.3
Specific knowledge about the child(ren)'s disability(ies)	14	46.7
Specific skills for dealing with the child(ren)'s needs	13	43.3

Survey Items	No. of Responses	% Responses
<i>What are some of the factors that you consider when choosing a service?</i>		
Cost (including transportation and session fees)	20	66.7
Schedule/frequency	21	70.0
Format (e.g., individual vs. group vs. psychoeducational vs. counseling)	16	53.3
<i>How likely are you to seek an additional service(s) in the future?</i>		
Very likely	9	30.0
Likely	8	26.7
Unsure	6	20.0
Unlikely	1	3.3
Very unlikely	0	0.0
<i>If you were to receive an additional service(s), what would be the most likely format/venue?</i>		
Individual counseling	15	50.0
Couples counseling	4	13.3
Family counseling	8	26.7
Group counseling	1	3.3
Support group	13	43.3
Parenting training individual sessions	4	13.3
Parenting training group sessions	6	20.0
Individual psychoeducational sessions	0	0.0
Psychoeducational group sessions	3	10.0
Coping skills—individual sessions	5	16.7
Coping skills—group sessions	3	10.0
Stress management—individual sessions	8	26.7
Stress management—group sessions	4	13.3

Note. Some of the items allowed multiple answers by a single respondent. Percentage of respondents for each item was measured based on the number of respondents corresponding to specific items.

Some of the 74 respondents did not provide responses for all items. The respondent group included 67 females (90.5%) and 63 (85.1%) participants who identified themselves as Caucasian/White. Thirty-five respondents (47.3%) were between ages 31 and 40, and 58 (78.4%) were married. Fifty-nine of the respondents (79.7%) had one child with special needs and 31 (41.9 %) reported the child's disability as moderate.

In regard to stress levels, 33 respondents (44.6%) indicated that they had experienced a high degree of stress in the past month, and 45 (60.8%) indicated that they had experienced either a high or very high degree of stress in the past year. Twenty-three respondents (31.1%) indicated that raising their child with special needs contributed to about 61–80% of their total stress level, and 20 (27.0%) indicated that their financial concerns contributed to about 26–40% of their total stress level. In regard to help seeking, 45 (60.8%) indicated that they had never sought professional services (e.g., various possible therapies) to cope with the stress of raising a child with special needs. The most frequently cited ($n = 12$, 27.9%) reason for not seeking support services was that they were unable to find services that they perceived to be helpful for their needs.

Among the 30 respondents who had sought professional services, 22 (73.3%) indicated that they had sought individual counseling (which also was the most used type of service). The second most used type of service was support groups, in which 14 respondents (46.7%) indicated that they had joined or were current members of a support group. Among those who had received individual, couple, family, or any combination of counseling, 19 (73.1%) indicated that their stress levels were reduced to some or a great extent after receiving such service(s) and 16 (61.6%) responded that their outlook on raising their child with special needs became somewhat or greatly more optimistic.

Specifically, among the 16 (53.3%) who had received either group counseling, participated in support groups, or both, 13 (81.3%) indicated that their stress levels were somewhat or greatly reduced and 10 (62.5%) indicated that their outlook on raising their child) with special needs became somewhat or greatly more optimistic. Finally, 14 (46.7%) responded that they had gained specific knowledge about the child's disability from receiving the services and 13 (43.3%) responded that they had gained specific skills for coping with the child's needs.

Although the respondents in this latter subgroup had participated in a wide variety of support services, it appears that most were psychoeducational in nature. Seventeen respondents (56.7%) also reported that they were either likely or very likely to seek additional services in the future. The three most selected types of services that these respondents would most likely seek were individual counseling ($n=15$, 50.0%), support groups ($n=13$, 43.3%), and family counseling ($n=8$, 26.7%). Session schedule and frequency, cost (including transportation and session fees), and format of the service were all important factors considered in use of support services.

The second part of the study was an interview with the mother of a son with cerebral palsy in order to gather information about personal experiences, particularly those contributing to her level of stress. The interview was conducted at a house close to the hospital to which she periodically brought her son for treatment. At the time of the interview, Amy (a pseudonym), the mother, was 39 years old, and Michael (a pseudonym), her son, was two years old. Amy was Caucasian, between 31 and 40 years old, married, and had one child with special needs; therefore, she was "typical" of the majority of the respondents to the survey. Specific interview questions were not prepared in advance. Rather, Amy was asked to convey her most important and/or strongest experiences and emotions as a mother of a child with special needs.

A wide variety of issues were discussed during the interview, but the most pressing issue mentioned by Amy was the lack of available resources for parents of children with special needs. Amy related that large cities might have many resources available, "but especially not my little small town—the resources are so limited." She talked about how in attempting to acquire information and resources to aid in Michael's care, she had asked many different people. Importantly, she did considerable research on her own, primarily using the Internet. She felt that many, or perhaps most professionals did not know more than she did, regardless of their formal education and training. She gave the example of having told one of Michael's doctors about Euro-Pēds, a facility specializing in physical therapy for children with cerebral palsy and other neuromuscular disorders. The doctor did not know about this resource. Amy also related how shocked she was when a receptionist at a local mental health facility was not aware of a "respite" fund provided by the facility. She expressed that it was "disheartening that these people are supposed to guide me, and they just couldn't." Then she went on to describe a situation in which parents of children with special needs could not obtain the service they wanted because they did not use the technical term:

I was told that there were even situations where people who aren't articulate would call and say, 'I need a babysitter.' And they say, 'We don't do babysitting services.' Click. Because they didn't say 'respite,' they were turned away.... It's their job to be in tune with, maybe there's something I'm not getting here. Let me figure out what's wrong with this person that's calling my mental health facility.

Amy was often disappointed in seeking resources and help, probably because of the lack of understanding and education among professionals.

Amy lamented that resources external to the family should not cause more stress because parents of children with special needs already are overwhelmed by feelings of guilt, helplessness and stress. She believed that Michael was not the cause of her issues, but rather that the actual problems were the by-products of his having a disability:

It's not always directly related to the child, but all the side effects that how they affect you... A lot of it is just the overwhelming feeling that sometimes you wake up in the morning and say, 'I can't believe that he has so many problems.' And you feel sorry for him, and you feel stressed out about it.

Amy also felt guilty about not being able to spend as much time as she would have liked with her other two children; the demands of Michael's situation dominated all her plans. Amy had tried to be with her other children whenever she could, but still felt that she was not doing enough for them. Thus, she believed that Michael's disability affected not only her, but also everyone else in the family. Amy also felt tremendous pressure when talking to Michael's doctors:

Michael's doctors say, 'We don't know if he can ever walk. But we don't know if he won't. It's gonna be up to you, Mom. It's gonna be, if he's got the potential to do it. You're the one that's gonna push him...' It's a lot of pressure and I don't think that these doctors meant to give me that unneeded pressure... But I work very hard to push Michael, you know, everyday. But it scares me. It scares me that, 'Am I pushing him enough? Am I pushing him too hard?'

Obviously Amy (and other parents of children with special needs like her) suffers from high levels of stress from both internal and external factors. To Amy, taking care of Michael was like "not knowing how to swim and you get thrown into a pool with another person who doesn't know how to swim." When Michael was born, Amy had to teach herself how to raise a child with special needs because "these children don't come with an instruction manual...or a book of resources." She believed that knowledge about Michael's disability would be particularly important in order for her to take care of him properly and effectively. She also was aware that the process of accepting her son's disability and learning how to take care of a child with special needs could be "a nightmare for some people," because "even someone with formal medical training struggles with these children." Amy related that she thought a support group to provide opportunities for the parents of children with special needs to discuss and share experiences and feelings would be beneficial. She also believed that inviting a professional such as a social worker to the group who could help the parents fill out paperwork for requesting funds and other assistance would be beneficial because many parents of children with special needs struggle with understanding and completing formal documents properly. At the end of the interview, Amy indicated that she felt like she was contributing at least in a small way to improving the lives of parents of children with special needs by participating in the research and that the interview was helpful in reducing her stress.

Discussion

This preliminary research was conducted to gather data, collect descriptive personal information, and, from the data, suggest future practices for gaining understanding of the unique needs of parents of children with special needs. Suggested in the results of this exploratory study, is that counseling services for parents of children with special needs are both warranted and needed. The format of such services likely should be group counseling because of lower cost and potential for mutual support among group members. Such group counseling sessions should be in part psychoeducational and in part intended to foster support to meet the goals of knowledge and skill acquisition for parenting children with special needs and sharing personal experiences with others. Individual and/or family counseling might be used as a follow-up service, especially for parents or families of children with special needs who appear to need intensive care. Finally, parents of children with special needs should be able to choose how they would like to interact, such as by phone, home visit, or face-to-face because they often struggle with finding child care for when they are away from home. Having support group meetings at each other's homes also can be an option so that parents can take turns watching children during meetings.

Limitations of this study included a small number of male participants. Whether more responses from fathers would have changed the results is only a matter of speculation. Thus, future research that includes significantly more input from fathers of children with special needs is needed. Also, to be noted is that some participants reported confusion about terms such as psychoeducation, which may have influenced their responses. Therefore, future research should identify specific services rather than the categories of services. Any online survey is limited to those who have access to the Internet and are comfortable using computers. Future studies can overcome this limitation to a great extent by incorporating multiple methods involving several types of data collection. Finally, the case interview was perhaps the most valuable part of the study in terms of revealing the reality and challenges faced by parents of children with special needs. Thus, qualitative, phenomenological research also would be beneficial, especially for understanding the unique and complex concerns of parents of children with special needs.

References

- Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: *Supporting parents' adaptation to their child with special needs*. *Infants and Young Children, 16*, 184–200.
- Ergüner-Tekinalp, B., & Akkök, F. (2004). The effects of a coping skills training program on the coping skills, hopelessness, and stress levels of mothers of children with autism. *International Journal for the Advancement of Counselling, 26*, 257–269.
- Goddard, J. A., Lehr, R., & Lapadat, J. C. (2000). Parents of children with disabilities: Telling a different story. *Canadian Journal of Counselling, 34*, 273–289.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities, 14*, 159–171.
- Looman, W. S., O'Conner-Von, S. K., Ferski, G. J., & Hildenbrand, D. A. (2009). Financial and employment problems in families of children with special health care needs: Implications for research and practice. *Journal of Pediatric Health Care, 23*, 117–125.