Parent Advisory Groups in Pediatric Practices

Parents’ and Professionals’ Perceptions

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Objective: To describe the benefits perceived by parents and professionals from their participation in parent advisory groups (PAGs).

Design: Retrospective telephone survey.

Setting: Parent advisory groups were established in 4 community-based pediatric practices. Each group included parents of children with chronic health conditions, health care providers, and a Department of Public Health staff member.

Participants: The mothers and fathers of children with chronic health conditions completed a telephone survey. These parents also were enrolled in a broader intervention aimed at providing primary care for children with chronic conditions.

Intervention: Groups met regularly in the pediatric office setting. Logistical arrangements and activities varied among the 4 groups.

Main Outcome Measures: Parents and professionals rated their perceptions of the PAGs based on a structured list of potential benefits.

Results: Mothers viewed the PAGs as most beneficial in diminishing their isolation, helping them to understand family concerns, increasing their influence on the pediatric care provided to their children, and improving their knowledge of community resources. Professionals believed that the PAGs enhanced their awareness of common family needs, increased their skills at collaborating with families, and helped them to feel more effective. All professionals and most parents were interested in continuing their involvement in a PAG.

Conclusions: Parent advisory groups may benefit families and professionals who care for them by (1) fostering collaborative relationships and communication, (2) increasing a sense of social support among families, (3) increasing families’ knowledge of community-based resources, and (4) increasing the families’ sense of efficacy and involvement in the care of their own and others’ children.


About 6% to 18% of children in the United States have a chronic health condition.1-4 They and their families experience many needs beyond health care requirements for the child’s condition. These needs include gathering adequate information about the child’s condition(s), treatment, and prognosis; making contacts with similar families; counseling; child care; and advice about insurance and legal matters.5-11 Many of these needs are experienced independent of a child’s particular diagnosis, while others are dependent, at least in part, on the nature and severity of a child’s condition(s).12 Other factors are also relevant, including the child’s age, the parents’ socioeconomic circumstances, and the services available to the child.13

Numerous groups that provide support and information to parents have been established to meet the varying needs of families of children with chronic health conditions. Parent groups differ along a number of dimensions, including their leadership, location, and goals, as well as the population they include.14-17 For example, some groups are specific to diagnostic categories while others are noncategorical or generic, and some are located in medical centers while others are community based. Regardless of the structure of the groups, their success seems to depend on “perceived sameness” among parents—the idea that families share similar daily experiences.14

The present article describes a group for parents of children with chronic health conditions that differed from previous interventions in 3 ways. First, these parent advisory groups (PAGs) were located within the context of 4 community-based pediatric offices. Second, the families involved in the groups represented an extremely wide range of diagnoses. These PAGs were based on the notion that parents have a lot to offer and to teach each
PARTICIPANTS AND METHODS

DESCRIPTION OF THE GAPS PROJECT

Parent advisory groups were part of a larger project that aimed to improve the coordination of care for children with chronic conditions in the context of community primary care settings. This program was entitled GAPS (Guiding Appropriate Pediatric Services for Children With Special Health Care Needs and Their Families). The GAPS program consisted of several parts. Central to the intervention were the 2 following requirements: (1) pediatricians and parents completed needs assessment questionnaires that described the child’s and the family’s condition, including their health needs and psychosocial concerns, and (2) parents subsequently participated in a planning meeting with their primary care physician (and nurse practitioner, if involved) to address the child’s and family’s short- and long-term health needs and care. In addition, a PAG was initiated in each of the participating community-based pediatric practices: 1 in a staff-model health maintenance organization, 1 in a small pediatric group, and 2 in multispecialty group practices. All of the families enrolled in the GAPS project were invited but not required to participate in PAGs. The participants in the GAPS project were 90 families of children with chronic health conditions. These families were recruited by the project coordinator from a list of 197 children identified by their pediatricians as having a chronic health condition. The pediatricians identified families who had a child with a chronic health condition using billing records from the previous 2 years and a broad range of International Classification of Diseases, Ninth Revision diagnostic codes. A chronic health condition was operationally defined as a condition that had lasted or was expected to last 1 year or more and that could be expected to require more than the usual amount of medical supervision. Because of the diverse epidemiology of chronic health conditions in children,2,3,20,21 the project was inclusive of children with a large variety of conditions.

The children enrolled in the GAPS project ranged in age from 2 months to 15 years, and 48% were female. Diagnostic information for the 90 children is as follows: 16 children had multiple conditions, 28 were identified as having a primary respiratory condition, 27 had a primary neurologic condition, and 19 had a variety of other conditions (eg, cardiac, renal, or orthopedic conditions). The range of diagnoses reported by participants is as follows: arthritis, asthma, attention deficit/hyperactivity disorder, autism, blindness, bronchopulmonary dysplasia, cerebral palsy, congenital anomalies, cleft lip/palate, complex syndromes (includes Down, Kallmann, DiGeorge), congenital heart disease, cystic fibrosis, deafness, diabetes, hypothyroidism, learning disabilities, leukemia, mental retardation/developmental delays, orthopedic abnormalities (including arthrogryposis, scoliosis, osteogenesis imperfecta), neurofibromatosis, neuropsychiatric conditions, nephrotic syndrome, seizure disorders, and systemic lupus erythematosus. Socioeconomic status was estimated using parental education and insurance information; the socioeconomic status of the majority of families was primarily middle class (79%). Participants in the GAPS project did not differ from nonparticipants in the sex or age of the children or the constellation of their children’s diagnoses. Further information about the nonparticipating children is not available.

DESCRIPTION OF THE PAGs

A single primary purpose of the PAGs was stated at the outset. These groups were to bring together parents of children with various chronic conditions, their primary care providers, and a staff member from the regional DPH to explore how they might together improve communication, provide mutual support, and create innovations in the provision of care in the practice. No guidelines were established as to the number of parents to be included, the frequency of their meetings, or their agendas. We anticipated that each group would develop differently.

RESULTS

DESCRIPTION OF SAMPLE

Of the 90 families enrolled in the GAPS project, either one or both parents of 78 children responded to the telephone interview—a participation rate of 87%. Of the 78 children, information was obtained from both mothers and fathers for 40 children, from mothers for 35, and from fathers for 3. The primary reason for nonparticipation was an inability to contact the family (eg, moved from area, disconnected telephone, transferred pediatric practices without forwarding information). Participants did not differ from nonparticipants in diagnosis, age, sex, or socioeconomic status. The 6 pediatricians and 1 nurse practitioner involved in the project completed the written questionnaire, as did the 5 members of the DPH staff.

AWARENESS-IN卷VOLVEMENT IN A PAG

Parents

We defined minimal involvement as a score of 2 to 4; moderate involvement, score of 5 to 7; and high involvement, score of 8 to 10 on the 10-point Likert scale. Forty-seven (61%) of the 75 mothers who responded to the questionnaire were aware of the existence of a PAG in their pediatrician’s office. Of the mothers who were aware of the groups, 9 (19%)...
As they developed, each PAG consisted of 4 to 15 mothers of children with chronic conditions, 1 to 4 of their health care providers, and 1 DPH staff member. Providers and DPH staff were active participants in all group meetings; they did not receive additional training in this area nor were they compensated for their participation. Outside guests and presenters participated at the request of regular group members.

Groups met biweekly, monthly, or bimonthly in the practice setting and their activities were varied. The products of these meetings were the results of collaborative efforts among parents, providers, and DPH staff. One group published a local directory of educational and recreational resources for children with chronic conditions. Another worked with local agencies, including the school system, to improve community awareness of and commitment to the special needs of children with chronic conditions. Several groups organized workshops for parents in the community about special education services, the impact of chronic health conditions on siblings, peer relationships, and interventions to address teasing and bullying by classmates. The PAGs also served as a general forum for families of children with chronic conditions to discuss their common needs and concerns and to identify ways to help the practice learn what is important to families of children with chronic conditions.

INTERVIEW PROCEDURES

The information obtained for this article was collected by 1 interviewer using a semistructured telephone interview. He attempted to contact all 90 families who had participated in the GAPS project, whether or not they had chosen to be involved in a PAG. He asked both mothers and fathers to participate in the interviews. They were interviewed in succession during the same telephone call or, if more convenient for the family or if the parents lived apart, during separate calls. The interview was approximately 15 to 20 minutes for each parent. All participants were informed that their responses were confidential and that their pediatricians would not have access to their completed interviews.

Past research has provided evidence that telephone interviews are a successful method for obtaining responses regarding the experiences of parents of children with special needs, and generate information comparable to that obtained by other methods of data collection, eg, in-person interviews. When it was impossible to interview a parent by telephone, a written questionnaire was mailed to the parent for completion. Six parents completed the questionnaire by mail. All of the physicians, the nurse practitioner, and the DPH staff members participating in the study completed a written version of the questionnaire.

The interview began with an assessment of the parent's awareness of the PAG in the pediatric practice. If parents acknowledged that they knew about the PAG, they were asked to describe their level of involvement in it on a 10-point Likert scale with 1 representing no involvement and 10 representing high involvement. If the involvement score was 2 or above, they were asked to respond to a series of questions about their experience with the PAG. These questions, all on a Likert scale ranging from 1 (not at all) to 10 (very much), addressed issues such as how the PAG may have affected the parents' involvement in their child(ren)'s health care, their contacts with and understanding of other parents of children with chronic conditions, and their desire to remain involved in a PAG. These potential benefits are listed in Table 1. Parents also responded to open-ended questions about the positive and negative aspects of their participation in the PAG.

The questionnaire provided to physicians and DPH staff members paralleled the parents' protocol. It was modified to include relevant questions about how involvement in a PAG may have affected these professionals' abilities to meet the needs of children with chronic conditions and whether the groups changed their work practices. Potential benefits are listed in Table 2.

reported minimal involvement in the groups and 19 (40%) reported moderate or high involvement.

Of the 43 fathers, 19 (44%) were aware of the existence of PAGs, with only 1 of these 19 fathers reporting at least moderate involvement and 18 reporting no or minimal involvement. Differences between proportions t tests confirmed that far fewer fathers who completed the questionnaire were aware of (t = 2.44, P < .04) and were at least moderately involved in (t = 2.92, P < .01) PAGs than were mothers. Due to the low level of involvement of fathers in these groups, we have excluded fathers from the analyses.

Professionals

All the medical professionals and DPH staff who completed the questionnaire were aware of the existence of PAGs. The reported level of involvement for these individuals ranged from a score of 2 to a score of 10, with a mean level of involvement of 6.8 (moderate). Because of the small sample size of medical professionals and DPH staff, only descriptive data are reported on these groups.

PERCEIVED BENEFITS OF PAGs

Mothers

The respondents were the 28 mothers who reported at least minimal involvement (score ≥ 2) in a PAG. For each of the 7 questions, response options ranged from 1 (no benefit) to 10 (highly beneficial). We categorized these scores into the following 3 levels of benefit: "minimally beneficial" (a score of 1-3), "moderately beneficial" (a score of 4-7), and "highly beneficial" (a score of 8-10).

Table 1 summarizes mothers' responses to each question. Overall, mothers viewed PAGs as at least moderately beneficial in all areas. More than half of the mothers viewed the PAG as having been highly beneficial in 3 areas. Sixty-four percent (18 of 28) claimed that the PAG had helped them to feel less isolated, and 16 (57%) of 28 mothers believed the PAG helped them to understand the concerns of other families that have children with chronic conditions. Fifty-four percent of mothers (15 of 28) reported that the PAG had helped them to influence how children with chronic conditions and their...
families were cared for at their pediatrician’s office. In addition, a substantial number of mothers (46%) stated that the PAG had helped them to get to know the resources available in the community for their children. Seventy-two percent of mothers were at least moderately interested in continuing to be involved in the groups (mean [SD], 5.36 [3.23]).

Professionals

Table 2 summarizes the responses of physicians and DPH staff. Physicians viewed PAGs as most successful in making them aware of the common needs of families of children with chronic conditions, in helping them to find ways to be more collaborative with these children and their families, and in helping them to feel more effective in caring for them. In contrast, physicians perceived PAGs as being less effective in increasing their use of services from DPH and in revising the ways they and their office staff care for children with chronic conditions. The staff from DPH viewed PAGs as highly successful in all 6 areas presented to them, with “finding ways to be more collaborative with children with chronic conditions and their families” being rated the highest. Ten of the 11 professionals stated that they were moderately to highly interested in continuing involvement in a PAG (mean [SD], 1.9 [2.54]).

QUALITATIVE RESPONSES

Mothers

In addition to rating these structured questions, mothers were asked to provide their ideas about the most positive and negative aspects of their experiences with the PAG. The 28 mothers who were involved in these groups provided 82 comments regarding the positive aspects of the PAG. Two themes were prevalent in these responses: (1) 47% of mothers’ responses (38 of 82) focused on the benefits of having a PAG as a place for support and the sharing of experiences, ideas, and frustrations. A number of mothers claimed that “it’s nice to know that you are not the only one out there” or that “it’s good to know that other parents have similar problems.” One mother said that it was a great place to “talk to other parents in the same situation . . . dealing with the everyday stresses of chronic illnesses,” while yet another stated, “it’s a really great place to vent.” (2) Twenty-seven percent of mothers’ comments (22 of 82) pointed to the success of the PAG in increasing families’ access to previously unknown resources and to new information from other parents, physicians, and guest speakers or programs. For example, 1 mother stated, “the programs offered through the PAG were invaluable,” while another claimed that “the greatest benefit of PAGs was the pooling of resources from a variety of individuals.” Another mother claimed that the best thing about the PAG was that it allowed her to interact with “parents who had a tremendous amount of experience with getting resources.”

Six mothers commented about the PAG as a mechanism by which parents became “closer to their pediatrician” and were able “to actually affect change in the care” of their children. A number of mothers claimed that one of the greatest benefits of a PAG was the ability to help other families that had a child with a chronic illness. Other
benefits reported by mothers included making friends; learning to deal with professionals at their level; having a night out; getting projects done; having a small, local, and informal group to attend; and learning how different children react to their situations.

Fifteen of the 28 mothers who were involved in the groups could not think of any negative aspects of PAGs. The remaining mothers provided 22 comments, reflecting 2 prevalent themes: (1) 45% (10/22) of mothers' comments focused on organizational or scheduling issues. Five mothers claimed that finding a time to meet was extremely difficult due to baby-sitting issues and the busy status of their lives. One mother stated that "the facilitator needs to be trained more extensively" while another said "it would be nice to have more guest speakers on a regular basis." (2) Thirty-one percent (7/22) of comments focused on the relatively small effect a practice-based group could be expected to have in meeting the needs of families with children with chronic conditions. For example, one mother stated "the expectations of parents about what a PAG should be doing were far greater than what the groups could actually do," while another claimed that "it was difficult to address some problems because the overall health care system leaves a small PAG helpless."

Three mothers commented about the difficulty of addressing the diverse needs of families. Specifically, they stated "some families ended up monopolizing all of the group's time because they had so many needs," "there were a lot of needs but the groups tended to cover only a few," and "the expectations and needs of families were so different." Other negative comments included that "the groups often became a place to complain rather than to move forward" and that mothers "wished the groups were better advertised so that more people had known about them."

Professionals

The 6 physicians and 1 nurse practitioner provided 18 comments about the positive aspects of being involved in a PAG. Nine of these comments focused on the influences of these groups on their medical practices and 6 referred to increased family participation and receiving feedback from families about their care. Other responses expressed appreciation for the programs being conducted in the groups and the development of a resource book, the opportunity to increase involvement with parents, and the chance to gain a better understanding of parents' needs.

The 15 responses made by the 5 DPH staff members reported the benefits of PAGs to include greater access to resources for families, cross-family support, heightening their own awareness of the situations of families, enhancing the relationships between families and providers, and enhancing the relationships between DPH and pediatric practices.

Scheduling and attendance issues were the most consistent negative aspects of the groups for both the physicians and DPH staff members. They claimed that maintaining interest and motivation among parents was also a problem. They also were concerned about the groups' ability to identify and carry out realistic projects. Other problems included unclear goals within the groups, funding issues, the ability of a PAG to meet everyone's needs, and staffing issues.

We have obtained systematic reports from parents, physicians, and DPH staff members regarding their experience with practice-based PAGs. These PAGs appear to have met their primary goal of providing 2-way communication between the professional staff at primary care physician offices and mothers of children with chronic health conditions. They appear also to have created a supportive environment for these families. The findings also highlight some of the challenges in establishing and maintaining effective groups that meet these families' needs.

PARENTS

The majority of mothers who participated in this survey were aware of the PAG in their pediatrician's practice, and most of those reported at least minimal involvement. Fewer fathers than mothers were aware of and involved in PAGs. The fathers' lack of involvement in the groups is regrettable, but consistent with past research. Mothers report a larger number of unmet health care needs than do fathers, and a greater desire for social contacts for themselves and their children with other families that include a child with a chronic health condition. Mothers may have been more motivated to become involved in the PAGs because they perceived their families as having more needs and because PAGs provided opportunities for social interaction.

Numerous investigators have reported that families of children with chronic conditions would like to have more information and better support at the familial, social, and professional levels. Mothers in this study viewed PAGs as successful in addressing these needs, especially in understanding other families' concerns, decreasing their isolation, and getting to know about community resources. Parent advisory groups were reported to provide a supportive arena for the sharing of experiences and increasing access to information about previously unfamiliar resources and knowledge. The majority of mothers who participated in these groups were moderately to highly interested in continuing.

These findings are particularly striking in the context of the diversity of children's diagnoses. Because these PAGs were intended to provide a support network within the context of a primary care pediatric practice, the children had conditions ranging from chronic ear infections to rare neurologic conditions. The sense of connectedness experienced by the parents and their perception that PAGs gave them important and usable information and strategies provides evidence that support services can be provided successfully to families living with a wide range of chronic health conditions.

Another benefit of the PAGs was the empowerment experienced by many mothers. More than half of the mothers involved in this study claimed that PAGs had helped them to influence care at their physicians' offices. Several mothers stated also that one of the most ben-
official aspects of the PAGs was the ability to help other families. Many mothers appear to be motivated to have an impact on the well-being of children with chronic health conditions (in addition to their own child). Such activities may provide mothers with a gratifying sense of control and success in a context that may often seem frustrating and beyond their command. On the other hand, many mothers expressed doubts about the ability of PAGs to be able to make necessary changes within the larger health care system.

PROFESSIONALS

Both the pediatricians and the DPH staff perceived PAGs as beneficial, especially in heightening their awareness of the needs of families with children with chronic conditions and increasing their collaboration with these families. These findings are important in light of research suggesting that physicians recognize fewer unmet needs than do parents of children with chronic conditions. Involvement of physicians in parent groups may improve their understanding of the nature and types of needs perceived by parents and thus increase collaboration between families and their pediatricians. All professionals were interested in continuing their involvement in PAGs.

Although mothers believed that PAGs increased their influence on their child’s care, physicians were less convinced that “PAGs changed the way I care for children with chronic health conditions and their families” or that “PAGs revised how my office staff cares for children with chronic health conditions.” This discrepancy between mothers’ and physicians’ perspectives may be due to the fact that for pediatricians PAGs were more helpful in other areas (eg, getting to know families’ needs) than in direct-care decisions. It is possible also that parents noticed subtle changes in their interactions with pediatricians, particularly regarding communication about issues of more relevance to them, that were not readily visible to the physicians (eg, an additional question about their need for social support). Families also may have noticed changes in physicians’ practices and misattributed them to the PAGs.

COMMON DIFFICULTIES

Pragmatic issues must be taken into consideration when developing interventions for families of children with chronic health conditions. In their anecdotal reports, mothers acknowledged the difficulties associated with attending and facilitating a group for these families. Their comments focused on scheduling issues and a desire to have more speakers and organized programs. Adequate child care is one of the most commonly reported needs among families of children with chronic conditions, making it difficult for mothers and fathers to plan and attend simultaneously any regular meetings or programs. Time constraints and child-care issues must be considered in the development of any successful intervention for these families. The majority of criticisms by professionals of PAGs focused on scheduling and attendance issues as well as on maintaining interest and motivation.

One creative way of maximizing connections between families and physicians while minimizing time commitments might be less frequent meetings associated with an online discussion group. Future groups could do better advertising on a continuous basis to ensure that all eligible families are aware of the groups and maximize their involvement. Parents’ suggestions included mailings to be sent out by the practice (eg, with bills), posters in the waiting room, and a systematic “telephone tree” system. Development of similar groups should continue to strive to find a way to include fathers.

CONCLUSIONS

There are several limitations to this study, mainly the absence of a preintervention assessment and an appropriate comparison group. These omissions preclude a direct evaluation of the impact of PAGs. The voluntary participation of particular self-selected mothers and the lack of participation of fathers limit the generalizability of our findings. It is possible, even likely, that mothers who are most involved in and knowledgeable about their children’s health care are those who become involved in groups such as PAGs. Thus, the self-selection of mothers to the groups makes it impossible to clarify the potential role(s) the PAG itself may have played in involving and empowering families. In addition, the small number of physicians and DPH staff allowed us to provide only limited descriptive data about these groups.

Nonetheless, the present study contributes some initial data about the benefits of practice-based PAGs to a literature that has few empirical outcome studies. Our findings support some of the basic principles of family-centered care. They also suggest that PAGs may benefit both families of children with chronic health conditions and the professionals who care for them by (1) fostering collaborative relationships and communication, (2) increasing a sense of social support among families, (3) increasing families’ knowledge of community-based resources, and (4) increasing families’ sense of efficacy and involvement in the care of their own and others’ children with chronic health conditions.

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