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### Development of a Parent Advocate Program as Part of a Pediatric Hematology/ Oncology Service

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# Development of a Parent Advocate Program as Part of a Pediatric Hematology/Oncology Service

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**ABSTRACT.** The provision of peer support by individuals who have had personal experience with a particular crisis can be a vital component in facilitating the adjustment process of others who are confronted with the same crisis. There is growing interest in using such peer support for the parents of children and adolescents with

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diseases such as cancer. This article describes the historical development and current focus of the Parent Advocate Program within the Division of Pediatric Hematology/ Oncology at the University of Rochester Medical Center, Rochester, New York. The authors discuss potential pitfalls, such as emotional involvement with families on the parent advocate's part, and present ingredients for the development of a successful program, including careful selection of individuals who can interact successfully with various staff members and learn the professional role of parent advocate.

The physical and emotional impact of childhood cancer on patients, their parents, and other family members poses a major challenge to their adaptive and coping skills (Stehbens, 1988). Not only must these children and their families endure a stressful course of medical treatment, they also must endure the uncertainty and fright over the meaning of the disease itself and its implications for their future. Because onset of childhood cancer is sudden, unexpected, and often life threatening, the experience can often leave all family members with an extreme sense of hopelessness, helplessness, and isolation (Chesler & Barbarin, 1987; Figley, 1983).

Being told that their child has cancer throws parents into a frightening new existence of uncertainty. Some parents learn of the diagnosis almost immediately; for others, however, the hours of waiting for the final diagnostic test results that will confirm their worst fears seem endless. Parents attempt to work through myriad emotions, which may include shock, denial, anger, and guilt. They repeatedly ask questions such as, "Why is all this happening to our family?" Most parents have questions, fears, and feelings that they are unable to express to the medical staff during the early phases of the family crisis (Adams & Deveau, 1984).

The importance of a person's support network during times of crisis has been well documented (Caplan, 1974; Chesler & Barbarin, 1987; Morrow, Carpenter, & Hoagland, 1984; Rowland, 1989). Because cancer in children is relatively rare, support systems for information and sources of guidance are limited (Figley, 1983). Several studies, however, have underscored the importance of uniting patients and families with other individuals who have been through or who are going through a similar experience for mutual

guidance and support (Borman, 1985; Caplan, 1974; Chesler & Barbarin, 1987; Patterson & McCubbin, 1983; Winch & Christopher, 1988). Such "peer support" has proved to be especially helpful in "buffering" the effects of extreme stress (Dean & Lin, 1977). Caplan (1974) reported that people benefit from peer support by learning from those who have already been through the same crisis. By learning adaptive behavior and coping strategies from "veterans," patients and parents receive more personal advice and understandable information than professionals can give. They also can experience empathy from individuals who can personally identify with them. Thus, interest in developing formal peer support networks and programs for parents who are dealing with such diseases as childhood cancer is receiving greater attention (Bogue & Chesney, 1987; Pitel et al., 1985; Protocic, 1983; Stuetzer, Fochtman, & Schulman, 1976). This article describes the historic development and current focus of the Parent Advocate Program within the Division of Pediatric Hematology/Oncology at the University of Rochester Medical Center in Rochester, New York.

## **PARENT ADVOCATE PROGRAM**

### ***Historical Development***

The Parent Advocate Program was initiated as a result of a longstanding relationship between members of the CURE Childhood Cancer Association and the staff of the Division of Pediatric Hematology/Oncology at the medical center. CURE is a family oriented, self-help organization established to help meet the psychological, emotional, and financial needs of families in which a child has been diagnosed as having an oncologic disease. It is composed of a network of approximately 400 families that have had personal experience with childhood cancer.

The mission of the organization is symbolized by its name (CURE: Counseling, Understanding, Research, and Education). Its primary objectives are to provide (1) a structure for parental involvement, (2) public education about childhood cancer, (3) financial support to the Pediatric Hematology/Oncology Division at the

medical center for maintaining and improving patient treatment and care, and (4) financial assistance to families in need of emergency funds.

In 1983 members of CURE volunteered their time to help with the children and visit with their parents during outpatient treatments in a special room designated for the volunteers. As a result of feedback from families about the helpfulness of such peer support in the hospital setting, CURE initiated a series of meetings with the professional staff of the Division of Pediatric Hematology/Oncology to implement a more formal parent advocate program. After these discussions, the division staff recommended incorporating the program as a clinical component of the psychosocial support services offered by the Division of Hematology/Oncology. Because of concerns about the appropriate professional role of individuals whose children had been treated, the division chief decided to pilot the program. The division staff and members of CURE also decided that the Parent Advocate Program would be staffed by two parents who would share the position of parent advocate to facilitate mutual support and avoid emotional burnout.

Because the pilot program proved to be an important addition to the psychosocial care offered to families in the hospital setting and because of the ease with which the two parent advocates developed professional identities and relationships with families and the professional clinical staff in the hematology/oncology division and the other hospital divisions, the chief of the division recommended that the division formally adopt the Parent Advocate Program. A part-time position of 24 hours per week, shared by two people, was subsequently funded by CURE. During the pilot and part-time phases of the program, the parent advocates worked closely with the division's social worker. Through a combination of this formal supervision and consultation with the social worker, daily interaction with other members of the clinical staff, and their own past experiences with cancer treatment, the advocates learned the following:

- The variable emotional reactions that different families can have after learning that their child has cancer and during the subsequent therapies that follow.

- The appropriate time and manner in which to approach newly diagnosed families and the need to respect their individual needs.
- The way to listen and interact with parents.
- The professional role that parent advocates play as members of the medical team.

Because of the on-going success of the program, it was expanded to full-time two years later.

### ***Focus of the Current Program***

The Parent Advocate Program is currently staffed by two parent advocates who have held their positions since its inception. One advocate is the mother of a 16-year-old boy who was diagnosed with acute monocytic leukemia in 1982 at age 8 and underwent bone marrow transplantation a year later with tissue donated by his brother. The son has remained in continuous remission since the transplant. The other advocate is the mother of a 14-year-old boy who was diagnosed with Wilms' tumor in 1982 at age 6. Her son's treatment involved both surgery and chemotherapy, and he is currently leading a normal life.

Because both advocates had children who were treated for cancer in the Division of Pediatric Hematology/Oncology and because both had volunteered in the playroom before the pilot program began, they had some knowledge of the day-to-day routines of the division and the hospital. Both factors contributed to the ease with which the advocates developed their professional identities and success with patients and their families. Furthermore, their clear understanding of the importance of confidentiality and their knowledge of when to share appropriate information regarding their contacts with families added to the staff's confidence in the advocates. Beyond the advocates' personal experiences and professional qualities, their transition from layperson to professional was further facilitated by their warm and empathic demeanor. Finally, because the division also recognized that the special relationship between the advocates and parents is based on trust and confidentiality, the advocates are not required to enter information in patients' medical records.

The specific responsibilities of the parent advocates have evolved to include the following:

- Meeting the parents of all pediatric hematology/oncology patients soon after initial diagnosis and having regular visits with parents on the inpatient units, the outpatient clinic of the Department of Radiation Oncology, and the Bone Marrow Transplant Unit.
- Reporting to appropriate medical or psychosocial staff all situations and concerns that arise during visits with parents who need attention.
- Explaining support services available through various community agencies and organizations.
- Acting as liaisons between the nurse in the Department of Radiation Oncology and the medical or psychosocial staff in the Department of Pediatrics, especially regarding children with brain tumors.
- Using funds supplied by CURE to provide parents with television, telephone, and parking while their children are hospitalized.
- Helping professional staff prepare for support group meetings and facilitating the meetings.
- Attending weekly meetings pertaining to the psychosocial care of patients and attending monthly divisional staff meetings.
- Visiting parents involved with the division's program of providing home care for terminally ill patients.
- Attending wakes and funerals.
- Making follow-up telephone calls and visits to parents whose children have died.

The two advocates who share the position are members of the Division of Pediatric Hematology/Oncology's psychosocial team, which consists of a full-time clinical psychologist, a social worker, a child-life specialist, and an education liaison specialist. The advocates interact extensively with clinical personnel throughout the hospital, participate in all appropriate divisional meetings and clinical rounds relating to the psychosocial care of patients, and often serve as liaisons between parents and the medical staff. When par-

ents are reluctant to discuss or raise specific issues or concerns with medical staff, the advocates help parents overcome their reluctance.

Each advocate works independently two days a week; the two work together one day a week. Working together one day a week allows them to discuss their interactions with families and to support one another. Because they share office space with other division staff, they have ample opportunity to ask questions and to receive support and guidance that helps them cope with job-related stress.

The primary thrust of the current Parent Advocate Program is to provide peer support for parents in both the inpatient and outpatient services of the hospital and to help them understand and cope more effectively with the crises associated with the experience of pediatric cancer. In helping parents through the diagnostic and therapeutic process, the division's professional staff advocates a model of "optimistic realism" that maintains honest and open communication about the patient's disease and treatment status and facilitates an attitude of genuine hope.

The parent advocates also help parents deal effectively with the family disruption and turmoil that can often result in marital, sibling, and peer conflicts. When the advocates have specific concerns about a given family, they consult other members of the psychosocial and pediatric team and ask them to see a particular family. The advocates often help families obtain the assistance they need from the various members of the psychosocial team.

The advocates also help coordinate and facilitate support groups that address parents' needs and the crises parents experience. For example, they hold a weekly "coffee hour" developed primarily for the parents of children who are currently hospitalized. Initial hospitalizations and subsequent hospitalizations for treatment and treatment-related side effects can sometimes be lengthy and emotionally provoking for parents and disruptive for the family. The coffee hour provides an informal way for the advocates and other division staff (e.g., social worker, psychologist, and educational liaison) to discuss parents' concerns. This informal meeting also provides parents with an opportunity to interact with other parents whose child has been recently diagnosed.

Three years after the Parent Advocate Program was established,

CURE sent a questionnaire to its 350 members requesting feedback on the support services that the organization helps to provide. The survey was conducted informally; no provisions were made to obtain a scientifically based sample. Of the 75 questionnaires returned, the comments about the Parent Advocate Program were unanimously positive. The following were representative comments:

The parent advocates were very helpful and supportive. Having a person who has already been there to talk to after early diagnosis is the best thing for parents.

\* \* \*

Having someone tell you they personally know and can understand what's happening to you is a gift in itself.

\* \* \*

The parent advocates were wonderful. They were there immediately and helped throughout the entire time in the hospital.

\* \* \*

Some days when you can't seem to get through, the parent advocate would bring you back.

When planning a parent advocate program such as the one at the University of Rochester Medical Center, ensuring the complete support of the staff, both medical and psychosocial, is important. The staff must be available to answer an advocate's questions and concerns and to provide collegial support. Beyond this, the key to a successful program is careful selection of the people who will assume the role of parent advocate. They may have different skills and varying educational backgrounds, but they must have an innate ability for empathy, serve as an example of a coping model, and have high professional standards.

The success of the program at our institution can be attributed to a number of factors, including the compatibility of the division's staff, the advocates' role as members of the psychosocial team, the advocates' ability to learn new techniques and approaches from

working with each new family, the advocates' shared responsibility for the program, and the staff's confidence that the advocates will share information and concerns about families.

Despite the success of the program, certain pitfalls can be identified. Parent advocates may become emotionally involved with families, overextend themselves, and lose sight of the limitations on their own time and energy. Furthermore, if they blur the boundaries between professionals and peers, excessive demands can be placed on them, which in turn can lead to emotional burnout. These pitfalls need to be outlined at the onset of a program.

### *CLINICAL EXAMPLES*

The following vignettes illustrate the role that parent advocates play in providing psychosocial support to families served by the Division of Pediatric Hematology/Oncology.

#### *The D Family*

The advocates met Mrs. D, mother of 9-year-old Diane, soon after her child had been diagnosed with leukemia. After the diagnosis, Diane spent a long period in the hospital. The advocates spent many hours visiting and providing support to Mrs. D during her daughter's months of treatment in the outpatient clinic. When Diane and Mrs. D were in another city for a bone marrow transplant, the advocates spoke to Mrs. D by telephone on a weekly basis. The advocates were there for her when she learned that Diane had relapsed, and they provided support when Diane's medical condition deteriorated and the child chose to be at home. After Diane's death, the advocates continued to make periodic contacts with her mother.

Not until the advocates received a letter from Mrs. D did they realize what their visits and telephone calls had meant to the family:

When you first walked into our hospital room, my first evaluation of you was: PUSHY, INTERFERING, UNWANTED, AND UNNEEDED. As a result of our frequent interactions my impression of you changed to: HELPFUL, NEEDED,

CARING, PERCEPTIVE, KIND, ATTENTIVE, UNDERSTANDING, COMPASSIONATE, VERY SPECIAL NOW, AND A TRUE FRIEND.

The D family also was the first one involved in the division's home care program for patients with end-stage disease. Members of the division realized that parents who chose to have their child die at home felt cut off from the support systems available at the hospital. Beginning with the D family, the parent advocates began to extend their visits to the home on a more consistent basis as part of a comprehensive division-based home care program.

### *The F Family*

The F family was introduced to the parent advocates in the outpatient clinic when their 14-month-old daughter was having a bone marrow aspiration. The medical tests confirmed a diagnosis of leukemia, and the child was immediately admitted to the hospital to begin chemotherapy.

The child's initial hospitalization was lengthy—lasting approximately three months. During this time, Mrs. F had great difficulty accepting and coping with her daughter's disease and developing a trusting relationship with the medical staff. As a result, she was extremely apprehensive about leaving the child's care in the hands of the medical team and rarely left the child's hospital room.

After the parent advocates began visiting her on a daily basis, Mrs. F began meeting other hospitalized children and their parents and began asking the parents questions about their children's disease and treatment. She also began to participate in the weekly coffee hours for parents and in a support group facilitated by a nurse practitioner.

Mrs. F's child is currently in remission and is doing well. Mrs. F actively participates in CURE by volunteering her time, and she is now eager to provide support to other families.

### *CONCLUSION*

Provision of peer support to parents who are struggling with the emotional crises associated with having a child who has cancer by

people who have had personal experience with the crisis can be a vital component of the psychosocial services offered to families within the medical center setting. The successful incorporation of the Parent Advocate Program as one important psychosocial support service offered to families by the Division of Hematology/Oncology at the University of Rochester Medical Center can be attributed to several important factors: (1) a close working relationship with community-based childhood cancer support organizations such as the CURE Childhood Cancer Association and Camp Good Days and Special Times, (2) recognition by professional staff of the importance of peer support within the hospital setting, (3) careful selection of individuals who can interact successfully with various staff members and learn the professional role of being a parent advocate, and (4) recognition of the advocates' need for guidance and support. This article provides a model for developing a parent advocate program by other institutions that care for children with chronic, life-threatening diseases.

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