IN RECENT years more emphasis has been placed on comprehensive treatment of the person, and not his disease alone. There is strong reason to believe that comprehensive care, including attention to emotional and social needs, is especially important in the treatment of sick children. The death rate for infants under 1 year of age in foundling homes 45 years ago was almost 100% and infants fared poorly in hospitals at that time.1 The failure of infants in institutions to thrive was believed to be due mainly to lack of mothering;1 observations on infants in a foundling home corroborates this.2

The child's need for the mother increases during serious illness, and hospitalization significantly reduces the child's access to the mother. Consequently, efforts have been made to counteract this undesirable effect of hospitalization by the liberalization of visiting hours and by the development of programs for parent participation as part of hospital pediatric services. Spence3 instituted such a program in order to relieve a nursing shortage and then became aware that the maintenance of mother-child interaction was important to the child's well being. Richmond and Waisman4 discuss parent participation as part of the total care of hospitalized children fatally ill with leukemia and cancer, and they are convinced of the great value of such participation.

As Robertson5 points out, children under the age of 4 years suffer severe emotional trauma even when liberal maternal visiting is allowed. He believes that the only satisfactory method for handling this situation is to admit both mother and child to the hospital. A motion picture film produced by the Tavistock Clinic6 graphically illustrates the mechanics and results of this program, in which the mother lives with the young child throughout hospitalization. The growing awareness of the desirability of maternal presence during pediatric hospitalization is indicated in the report of the Committee on Hospitals and Dispensaries of the American Academy of Pediatrics.7 It is the purpose of the present paper to report on our experiences with a program for the participation of parents in the hospital care of fatally ill children.

FACILITIES AND PHILOSOPHY OF THE PROGRAM

Early Phase

In 1954, a 15-bed unit was established at the City of Hope Medical Center for the hospital care of children with leukemia or one of various malignant tumors. At the outset, attempts were made to render the hospital experience as tolerable as possible for the children. These attempts included the initiation of a program for the participation of parents in the hospital care of their children, largely as an intuitive response to the need of seriously ill children for their parents. Since its inception, the program has undergone noteworthy changes with respect to its organization, staff, operation, and philosophy. A preliminary report of the program as it existed prior to most of these changes has been published.8 The present report describes the operation of
the current program together with some observations on the patients, their mothers, and the staff.

Medical, nursing, educational, occupational therapy, social and psychologic services have been offered from the outset. During its first 2 years, the program was characterized by its informality. Lack of information in the medical literature and of personal experience of the staff with such a program necessitated a great deal of intuitive behavior by staff members. Mothers' duties and privileges were not clearly defined. Parent meetings with staff members, as well as weekly combined staff meetings, contributed significantly to group cohesion and understanding. The meetings were relatively structured and there was no consistent focus.

The preceding characterizes the early or searching phase of the parent participation program. During this period, which lasted approximately 2 years, the feasibility of the program was demonstrated, and belief in its value for parents and children was reinforced. Research potentials were strongly suspected, but no systematic investigation was undertaken.

Later Phase

The next period was that of systemization (of thought and practice) and of beginning research. It began with a greater definition of the program for the parents regarding such matters as responsibilities and restrictions.

The weekly staff meetings were changed from essentially group psychotherapy to clinical conferences, with flexible format to permit necessary variations. Primarily the emphasis came to be placed on comprehensive examination of all new cases, all deaths, and special problems of whatever nature. Consequently, the consulting psychiatrist plays a more active role in dealing with reality problems.

The weekly meetings with parents have been concerned with the practical aspects of operating the inpatient unit (meetings with nurse, schoolteacher, occupational therapist and social worker) or with the medical and scientific aspects of leukemia and cancer (meetings with the pediatricians).

Simultaneously, efforts were begun to organize and analyze the accumulating data relating to parent participation and to the psychology of patients, mothers and staff. This period of systemization and evaluation is now ending, since a stabilization of operation and method has been achieved.

This report has been prepared by the Chairman of the Department of Pediatrics (AGK) and the Consulting Psychiatrist (JMN), both of whom have participated in the program during the past 3 to 4 years.

OPERATION OF THE PROGRAM

The children who are patients in this setting are referred by outside physicians, who in almost every instance have made the correct diagnosis known to the parents. There is no cost to the family for the medical care rendered, although there is an economic eligibility requirement which is waived only in research cases.

The children are followed both as inpatients and outpatients. The inpatients are in a 15-bed unit consisting of five rooms containing three beds each, although critically ill children are often in a room alone. Those children who are well enough eat their meals in a recreation room. During the morning, the children 3 years of age and over attend a schoolroom off the nursing unit, under the supervision of a schoolteacher from the Duarte School District. In the afternoon, the children have a rest period, which is followed by a period of activities supervised by an occupational therapist, also in a room off the nursing unit. Daily activities often include outdoor play on a playground.

Parents may attend their children in the hospital from the hour of rising until bed time at night; and, in the cases of critically ill children, during the night as well. They aid in the dressing, bathing, feeding and nursing care of their children. They may observe medical activities in the treatment room. They receive information on the medical problem and on the research program from the staff physicians, either on an individual basis or in regularly scheduled parent-physician group conferences. They discuss operational problems of the unit with individual staff members or in regularly scheduled parent-staff conferences. A social worker is available for help with personal problems as well as for practical arrangements for transportation, housing and allied problems. There are two rooms near the inpatient unit available as a lounge for the parents.

The biweekly meetings of the inpatient par-
ents with a pediatrician have proven to be important to the parents. This is their principal opportunity to learn in a relatively formal way about the medical and scientific program for cancer and leukemia. Interest is keen and capacity for understanding relatively great. It is believed that our ability to conduct an investigative program is enhanced by these meetings. Attempts are made to review and analyze lay reports, both reputable and disreputable, on new developments elsewhere in this field. There is often discussion about the cause of the diseases in question, and parental expressions of guilt are common. The meetings incidentally help the pediatricians by minimizing the necessity for individual educational meetings. Of course, the pediatricians meet with individual parents often to discuss practical medical situations.

The inpatient parents also meet biweekly with one or more nurses, the schoolteacher, the occupational therapist and the social worker. These meetings are intended to give the parents an opportunity to discuss current problems on the unit, either physical or psychologic. Suggestions for operational changes and for improvements in the program are welcomed. Staff members are given an opportunity to interpret ward practice and so enhance parental co-operation to the maximum.

The social worker has individual conferences with the parents, both at their request and at her own request. These meetings serve not only to help solve external problems but also to deal with psychologic problems, especially those relating to the family unit. Very often mothers are eager to discuss personal problems and find the social worker the most readily receptive person with whom to have such discussions. Many mothers have commented on how useful these meetings have been to them at critical times. It is particularly helpful to have a staff person who can help them make decisions about the extent of their participation in a relatively guiltless way.

The children and their parents are thus seen to be under the observation of physicians, nurses, schoolteacher, occupational therapist and social worker. The social worker keeps a coordinated record for such observations. Observations are either recorded in charts or communicated orally. The social worker obtains much of this material informally from staff members. In addition, she utilizes scheduled weekly individual and group staff meetings to obtain further information. The individual meetings of staff members with the social worker serve to provide many details in accord with a planned attempt to discover more about the problems of parents with which the hospital might deal.

Each new patient and his family are evaluated in the staff conferences; the medical facts are reviewed and other concrete factors are considered, such as extent of need for the mother at home versus the need for her presence in hospital and acute or chronic economic stress. In addition, an effort is made to evaluate the nature of the mother-child relationship (e.g., overprotective mother and clinging child), as well as the prevalent psychologic trends within the total family. Thus, all professional personnel pool their observations and impressions. With this information, an informal psychosocial diagnosis is made; a prediction is attempted pertaining to the adaptive prognosis of patient, mother and family, and an attempt is made to establish the appropriate extent of parent participation. Also, the staff tries to anticipate special problems in ward management which may be presented by the family. This is important in meeting the special needs of the family as reflected in these problems and in maintaining smooth ward operation.

Similarly all recent deaths are reviewed at the staff meetings. These reviews are helpful to the staff in dealing with intense feelings of guilt, futility and depression in themselves, and thus aid the staff in better meeting the needs of bereaved parents. Information regarding the behavioral responses of the family at the time of death is recorded for future reference.

As the situation requires, intercurrent problems involving patients, families and staff are taken up at the staff conferences. As in the previously mentioned situations, information is pooled, strong feelings are ventilated, and some degree of resolution of the problem is obtained.

During the staff meeting, the social worker presents the agenda and initiates discussion. The psychiatrist is looked to by the group for authoritative opinions. He often is able to advise about practical approaches to problems, and he endeavors to help the staff recognize the psychologic elements of specific problems, as well as the significance of these problems in the context of the prevailing psychodynamics of the ward.
The coordinated record of observations maintained by the social worker has made possible the conduct of a social research program. This program is directed by a consulting research social worker. Although the latter's contacts are primarily with the pediatric social worker, he also makes direct contacts with other staff personnel, including the consulting psychiatrist. The aim of the social research program is to observe and to describe the family constellation in crisis under the conditions that prevail in this setting. It is hoped that the picture so obtained can be understood and interpreted as the response of a family, individually and collectively, to a particular stress, viz., the threatened loss of a child from leukemia or cancer. If the social workers and psychiatrists of the staff can achieve enough understanding to anticipate reactions with reasonable accuracy, they can hope to adopt a more active role in the rehabilitation of the family.

The staff, then, is strongly oriented toward the goal of maximal rehabilitation of the family following the death of the child. The staff is also strongly oriented toward the medical research program, which has the broad goal of achieving a better understanding and treatment of leukemia and cancer in childhood. The medical members of the staff attempt to keep the nursing and other staff members informed of, and identified with, the research program. The broad goal of the conquest of leukemia and cancer therefore serves as a motivating factor for all staff members; its value as such is unfortunately reduced by the extent to which it is thwarted.

**OBSERVATIONS**

During the past 3 years, over 100 children with leukemia or a malignant tumor have been patients in the unit. Of these, 60 or so have died while in the unit. The observations indicate that the program of parent participation is not only a practical operational arrangement, but also serves useful purpose for patients, parents and staff. We report here a summary of observations made during this period. A detailed report on fear of death in fatally ill children and their mothers will appear elsewhere.*

**The Patients**

For the ill children the program means the excruciating difficulty of separation from the family at a time of maximal stress is largely avoided. There is a decreased tendency for the withdrawal so often exhibited by hospitalized children. When they are too ill to attend school or occupational therapy, they are comforted greatly by their mothers. Their acceptance of treatment and their tolerance of procedures is generally better when mothers are present. The departure of parents is much less traumatic when early return can be anticipated. There has been less anxiety among outpatients concerning possible return to the hospital.

The comfort afforded by mothers varies with the age of the child to a notable extent. The fearfulness of the young child (less than 6 years old) in the hospital is greater than is that of the older child. Similarly, the comfort afforded the younger children by the mothers is greater for these children. Some children seem never to tolerate maternal absence; they are irritable and withdrawn and demonstrate social regression. These symptoms are less prominent when the mother is present, but such children demand the physical attention of their mothers. Severe separation reactions occur almost exclusively in children under the age of 6 years.

Children in the age group 6 to 10 years are less fearful of the hospital situation. Specifically, they tolerate maternal absence more than do the younger children. Their fearfulness is more closely related to physical discomfort. These children are particularly fearful of procedures such as venipunctures and bone marrow aspirations. Some, especially boys, actively struggle against procedures, requiring restraint. They often express anxiety about procedures at times when they are not being done. They may become very suspicious of the staff, and we have found it important to be quite honest in answering questions about scheduling of procedures. In general, the mother's presence during a procedure does not reduce fearfulness in these children as it often
does in younger children.

In the children over 10 years of age, maternal absence and the procedures are both tolerated relatively well. Nevertheless, these children are often fearful and anxious. This anxiety is not particularly relieved by the presence of the mother. They seem sometimes to resent their mother's inability to make everything right for them. These children ask questions about their own futures. They want to know if they will ever get well. They sometimes express fear that they will die. In one instance, two girls discussed the question of which of them would die first. These children tend to become withdrawn, anxious and depressed—especially when other deaths occur on the ward. They are not told that such deaths have occurred, but we have ample reason to believe that they are aware that sick children have not just “gone home.” Interestingly, however, children who probably know about the deaths of other children seldom asked specifically if death occurred.

It should be pointed out that younger children may exhibit more subtle evidence of death fear. Such evidence may be found in drawings and stories. For example, one 5-year-old girl related a dream in which she was put in a long covered box. She managed to go through the lid to get out. Such fear is definitely subordinate to separation fear in the youngest children, or to mutilation fear in the middle group.

There appears to be a maturational aspect to fear in the children. The younger children are threatened most by maternal separation; separation fear dominates, as it were, over mutilation fear and death fear. Children 6 to 10 years of age are most fearful of physical injury, while those over the age of 10 years resemble adults in that they are most fearful of death.

The Mothers

The mothers bring their fatally ill children to the City of Hope in a severely stressful situation. They come to an institution of which they had previously been unaware or about which they had only vague knowledge. Often, they are hundreds of miles from home. They encounter and must contend with staff persons who are total strangers and yet to whose care they submit their children. In addition, they are concerned with their responsibilities to well members of the family and may feel additionally disturbed by their current inability to fulfill all responsibilities. In opposition to these presumably negative factors are the referring physician and other familiar authoritative persons who have given the mothers strong support in the hope and expectation that the institution will provide the finest medical care to the child and will be responsive to other related problems. It should be noted that during the past 3 years there has been only one discharge against medical advice; this case involved the only frankly psychotic mother in the group, and her husband reluctantly complied with her demand to have the patient discharged.

For most mothers important psychologic changes occur through their experiences in the parent participation program. The pain and anxiety that accompany separation from a sick child are reduced for the mothers. Parents are enabled to vent the guilty and hostile feelings so commonly held by those with fatally ill children. They are also better able in this setting to identify with rational attempts to deal with a desperate situation and to maintain hope in a less neurotic way. They are much less suspicious of staff members, and, in fact, often become quite friendly with them.

When the initial diagnosis is made, most mothers are tense, anxious, withdrawn and readily inclined to weep. They react in a disbelieving manner, tending either to deny the diagnosis of the disease or its fatal outcome. They want to be with their own children as much as possible, often tending to cling to them physically. Sometimes they stay with the child without much regard for the needs of the remainder of the family. Hope for the child is stressed, but in a nonspecific way: “something will be discovered.” They want, often in an irrational
manner, to try anything in the way of new treatment. In this early stage, mothers often express some degree of guilt about the child’s illness, wondering whether they may have done something wrong. At this time the parent participation program seems to offer its greatest service. Probably several factors contribute to guilt reduction at this period. First, mothers on the ward identify intensely with each other, gaining renewed self-esteem, losing the sense of isolation which is so characteristic of persons in crisis, and thus becoming less vulnerable to negative trends such as guilt. Secondly, the opportunity to learn about the disease and to share actively in the efforts to combat the disease probably reduce guilt through rational learning and through a sense of expiation or undoing. Also, there are multiple opportunities to ventilate guilt feelings (to other mothers or to one or more staff members), thus reducing the pressure of accumulated guilt feelings. The social worker is perhaps the staff person most active with the mothers in this process of guilt reduction.

About 4 months or so after the diagnosis is made, there is a change in the behavior of mothers. They become less tense and anxious. They stop denying the diagnosis and its prognosis. Hope for the child becomes more specific and is often related to particular scientific efforts. A considerable interest in the scientific program often develops at this time. There is a tendency to see the medical problem in its broader aspects, with the beginning of an expressed desire to help all children. Mothers during this period tend to cling less to their own children, encouraging them to participate in school and occupational therapy activities. They often help in the care of other children on the ward. They are generally more social. They speak more about fulfilling family obligations. The mothers often begin to move away from the hospital and to face other concrete problems. The staff must take care not to make the mothers feel obligated to participate in the hospital activities.

The mothers subsequently develop a calmer acceptance of the fatal outcome. There is almost no tendency to weep. In some instances the mother expresses the wish that her child would die so his suffering may be ended. Hope is expressed for children generally rather than for the mother’s own child. The mother is with the child whenever possible, but with adequate consideration for the remainder of the family. There is no expression of guilt.

There seems, then, to be a phasic response of the mother to a fatal prognosis for her child. She manifests an anxious and somewhat irrational reaction initially, and an accepting, more calm, and relatively integrated reaction later.

The reaction of a mother to the death of her child is directly related to the phase of this sequence in which she happens to be at the time. If a mother is in the initial phase, her reaction tends to be hysterical; if she is in a later phase, her reaction tends to be one of calmly relieved sorrow. In the latter instance separation from the child is no longer an adaptive problem for the mother. In the beginning, the parent participation program is utilized actively; later, it appears to become less necessary for the mother.

The Staff

The professional composition of the staff has already been described. In a program such as this one, which requires a high degree of interprofessional co-operation, the importance of a stable professional population increases. Several unique problems instantly confront all staff members. Foremost is the fact that almost all patients die, and the satisfaction of curing illness is not available, in contrast to most hospital situations. This unwelcome fact is aggravated by the additional factor of the tender age of the patients. Secondly, the usual shielding from family distress, which is afforded in most hospital settings, is not present; not only sick children, but apprehensive, demanding and depressed mothers must be constantly encountered and responded to. Finally, the requirement of behavioral flexibility in this
program tends often to run counter to traditional, rigid and authoritarian hospital practices and attitudes, and may thus generate conflict and confusion in staff members.

On the other hand, there are compensating factors that probably account largely for the low turnover of personnel on the unit. There is a strong desire to solve the problems at hand. Furthermore, the burden for the staff of having to assume psychologic parentage to fatally ill children is largely reduced by the mother's presence. Finally, the parents have generally been helped through a difficult episode in life and are appreciative of staff efforts, and this makes the staff members feel they have accomplished something positive in the area of social rehabilitation. One of the most rewarding aspects for the staff are the many parents who return to the hospital after the death of their child to express their gratitude to the staff members.

DISCUSSION

The feasibility of a program for the participation of parents in the care of fatally ill children is amply demonstrated by its continued existence for 5 years and by its apparent permanence. However, it is more difficult to define precisely the nature and extent of the advantages afforded by such a program. One indication of the value of the program is the almost unanimous enthusiasm of parents and staff. It is the authors' impression that the rare individuals who have not shared the general enthusiasm have been influenced by serious emotional problems. The remarkably low turnover among the staff and the rarity of discharges against medical advice may also be attributed to parent participation. It is also our impression that maintenance of relative psychologic well-being in parents and children is significantly aided by the program. A potential teaching value for medical students, nurses and others is recognized in that parent participation increases the opportunity to observe the diverse effects of illness on a family. None of our experiences is incompatible with the current trend towards increasing parent participation in the hospital care of children.

We observe that the presence of the mother reduces the separation fear which is the major disturbing factor in the younger children, in agreement with the impression of Richmond and Waisman. We also agree with Robertson that separation fear is not eliminated thereby. Robertson uses the term "settling-in" to describe the changes in the behavior of children usually seen in hospitals. Following a brief initial phase of protest, the child despairs over the separation from his mother and is very withdrawn. In a third, "denial" phase, he takes more interest in his surroundings and seems happy, but he no longer requires mothering, and seems not to recognize his own mother. The subsequent abnormal behavior of the child at home belies his apparent "happiness" in the hospital. It is our impression that the denial phase of the "settling-in" reaction is largely avoided in the setting provided by our program.

Among children in the middle age range, sustained contact with the mother remains very important, but we find that fear of procedures is the most evident source of disturbance at this age. Beyond puberty, the value of contact with the mother is least evident to us, and the fear of death takes marked precedence. Richmond and Waisman also assume that death fear is important in this age range, but find no concrete evidence of its presence.

We further believe that the opportunity for the mother to participate in the care of her fatally ill child facilitates the resolution of her guilt and denial, which are so characteristic at the outset of the child's illness. Others have similarly noted denial and guilt as initial reactions to diagnosis. Our experience has been that after approximately 4 months from the time of the mother's being informed of the diagnosis, her mental health markedly improves, and in consequence her extreme need for the parent participation program diminishes. The bulk of the evolution in feelings of grief is usually accomplished by the mothers.
during this 4-month period, leading to improved acceptance of reality and increased sublimation. In a more quantitative way, our findings are similar to the anticipatory mourning reported by Richmond and Waisman.4

Robertson5 emphasizes the need for a guiding principle in the hospital management of children. He believes that such a principle is dictated by a consideration of the mental health of the child. This principle seems basically correct to us, although we would amplify it to include the mental health of the family. In the special circumstances surrounding these children, who are fatally ill, a consideration of the mother and of other members of the family seems to be more important than might otherwise be the case. This point of view is implied in Robertson's recommendation that very young, healthy siblings be admitted to the hospital along with ill children and their mothers.

For the staff, parent participation is preponderantly of constructive value, but it does present some stress. As reported by Solnit and Green11 and by Richmond and Waisman,4 the hazard of excessive identification of the staff with the parents, which leads to emotional disturbance and impaired professional efficiency, is also recognized by us. The sustained contact with parents in our setting frequently leads to close, friendly relationships between staff and parents, thus increasing the tendency to identification. On the other hand, the psychologic trauma of the death of a child is diminished by the reduced need for parental responses from staff. Also of compensating value to the staff is the satisfaction of aiding in the sustaining and rehabilitating aspects of the program for parents.

SUMMARY

A program for the participation of parents in the hospital care of fatally ill children is described. Such a program is practical and, in fact, serves useful purposes for patients, parents and staff.

The ill children are spared to a large extent from the great difficulty of separation from the parents. This has a maximally beneficial effect upon children less than 6 years of age. For the child 6 to 10 years of age, fear of procedures and of bodily harm seem to take precedence over separation fear, so that parent participation is less helpful. Parent participation is least helpful for the children over 10 years of age, where fear of death itself is the primary problem. There is apparently a maturation of death fear, whereby it evolves from separation fear and mutilation fear.

Parents, particularly mothers, are enabled to cope with their own separation anxiety and guilt feelings by participating in the hospital care of the child. This is especially important initially in the course of the child's illness, when the mother's reactions are conspicuously characterized by denial, guilt and hysterical emotionality. Later, when the mother's behavior becomes more rational, her desire to participate is balanced against her desire to support the rest of the family. There is apparently a phasic response in the mother, with an initial emotional and denying reaction and a later more rationally adaptive reaction.

Staff personnel, particularly nurses, are largely relieved of the burden of assuming a role of psychologic parentage. An opportunity to identify with a research program is afforded, thus providing constructive purpose. Compensation is also provided by the gratitude of parents who have come to know the staff and to appreciate their efforts and by the satisfaction of aiding in the psychologic rehabilitation of parents.

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PRACTICE OF PEDIATRICS: PARTICIPATION OF PARENTS IN THE HOSPITAL CARE OF FATALLY ILL CHILDREN
Alfred G. Knudson, Jr. and Joseph M. Natterson
Pediatrics 1960;26;482

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