Problems of Child Care in Prolonged Hospitalization

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PROBLEMS OF CHILD CARE IN PROLONGED HOSPITALIZATION

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THE problems inherent in child care outside the family become highlighted most dramatically when a hospital has to take over child care functions, especially when, as so often happens, no preparation is possible.[1] In addition to the illness itself and to separation, the traumatic experience of some hospital procedures, whether the child is subjected to them himself or is merely an onlooker and suffers in fantasy, complicates his adjustment. All this is intensified in long hospitalization. Further problems arise when a child who is ready for discharge has to stay on because of family breakdown during his illness, or because factors of neglect have come to light through the illness and placement has to be planned.

The Child Care Worker's Role

We use the term "child care worker" to refer to a person on the clinical team who is responsible for the children at play or in the hospital school and at meal time but is not involved in nursing functions, though she may help to prepare children for medical procedures or surgery through such activities as dramatic play or earnest conversation in the playroom. In our hospital the whole clinical team, of which the child care worker is a member, decides on the living patterns of the children in the different wards.

I cannot stress strongly enough how much good child care depends on a team that works spontaneously and passes information quickly and informally between disciplines in a continuous flow rather than waiting for conferences and consultations.

The role of the family in supporting the hospitalized child has been forcefully described in many studies. The study by Reingold and Hartley highlighted the beneficial effects of intensive casework with parents, visits by siblings, and home visits of the patient.[2] We found this true. But if, for various reasons, the family cannot give this basic emotional support, the clinical team has to take on a very difficult additional task.

With so much stacked against success, what can a child care worker do in caring for children in long-term hospitalization? In a modern teaching hospital, it is almost impossible to uphold one crucial tenet of good child care—the continuity of nursing care by one or two women who should function as mother substitutes. Regular daily contact unfortunately has to be restricted to the child care staff, that takes part in only some sections of the child's life.

The child care worker focuses on the child as such rather than on the child's sickness. She has to understand the illness, the child's reaction to it, and the defenses the child uses to cope with his reaction. She works with the strength in the child's ego, and she has to learn to recognize and to develop it so that she can help him in dealing with the often grim reality. What in the ego structure of different children comes to her assistance? She finds that the children on the ward behave differently from other children, both individually and in groups, and she therefore has to modify her concepts and techniques.

One area in which we believe such a modification is necessary is in the grouping of the children. The common denominator at the hospital is neither age nor sex, nor the socio-

1 The observations which encouraged me to write this paper were made over a period of five years in the Department of Pediatrics and Contagious Diseases at Cleveland Metropolitan General Hospital, specifically in its Child Life and Education Program, which I have directed since its inception.

2 Jacob Reingold and Beatrice Hartley, "Parents' Participation While Their Child Is in Care," CHILD WELFARE, November 1956.

cultural background: It is the anxious uncertainty in a treatment situation which creates a strong tie. The support children give each other works in both directions: Older children can function as protectors or playmates for younger ones, while the helplessness of the very young and delight in seeing developmental changes in a young child can act as a morale builder for children from age three up. Through developing empathy, they can reduce their denial of the illness to a more wholesome level. We feel strongly that the age range on a ward should be wider than usual since children profit from at least part-time contact with children of different age levels.

We will try to illustrate what can be done through a child care program by selecting observations of three medically different types of long-term cases: children who suffer from tuberculous meningitis, patients in the Respirator Care and Rehabilitation Center, which serves polio patients, and children who were hospitalized for other medical reasons often connected with neglect. We will illustrate the problem of identity as it develops in this last group. We will also discuss the benefits of educational work geared to the sick child, and will describe therapeutic gains through the spontaneous interaction of children, showing how this interaction can be used in the program directed by the child care worker. While there is rich literature on both casework and group work with hospitalized children, little has been written about the value of the children's spontaneous interaction and how to utilize it.

Empathy as Defense against Anxiety

Our most dramatic case illustrates how both the age differential and spontaneous interaction can play a part in the child's use of empathy as defense against anxiety:

Howard, age ten, and Frank, four and one-half years old, were both hospitalized for tuberculous meningitis. They shared an isolation room for about two months. Frank's parents, who were separated and lived about fifty miles from the hospital, could visit him only rarely. He was much more severely affected by the illness than Howard. He had been comatose for about four weeks and was still semicomatose when Howard was admitted and this observation began. It was extremely difficult for the nursing personnel to care for Frank in the semicomatose stage. Any attempt to touch him for comfort, treatment, or nursing purposes brought piercing screams. Howard, separated by a glass partition, had not been unconscious but was completely inactive. He had just begun to look at television programs for short periods as his only activity.

My contact with these children was a very fleeting one. I would stop at their room once or twice a day, trying to find signs of responsiveness to see when they would profit from more stimulation. During one of those visits Frank screamed again when his linen had to be changed. Howard called to the nurse, "If you cover him up he'll stop screaming," and true enough Frank stopped. When I visited the next time and asked Howard how they were, he said, "If I tell Frank to look at TV he'll look," and the little boy who otherwise was completely rigid did turn his head and look.

From then on we decided to let Howard be the one to tell us when Frank was ready for a new step. He would know at which angle the child could drink through a straw (he had had to be fed by tube for a long time before), which juices he preferred, and finally proceeded to help Frank say a word or two. The medical staff was deeply touched by Howard's empathy and his unfailing intuition about Frank's needs. He would demonstrate to Frank how to stretch his legs for his exercises in physical therapy, which the skillful therapist had not been able to do, and Frank, as if in a trance, followed the example. When Frank cried the only thing that could comfort him was Howard's voice.

When Howard was ready to be transferred to the convalescent unit, we decided to move Frank along even though he was completely immobile and had only partially recovered his vision. We feared a setback if he lost his only friend and protector at this point. At the same time we made it clear to Howard that he could get up now and join other children at play. But the two boys still shared their room for sleeping and Howard would stop by to share an occasional meal or play a little with Frank. When Frank just started to sit up, discharge time for Howard approached. One day when I fed Frank and needed an implement I asked Howard to get it for us. "Get it yourself," was the answer, a very appropriate one for a ten-year-old who now could let his defenses down and did not have to help the other child constantly in order to keep his own anxiety in check.

Both children did well after Howard's discharge. When Frank left two months later he had formed strong relationships with several adults and had learned to talk and play again.

The strong bond between these children did not stem from saintly altruism. It was produced by Howard's anxiety, but nevertheless was most helpful to both children in their very difficult time in the isolation room. The child care staff had to decide on the right moment to relieve Howard of his self-sought function and let an adult form the bridge between Frank and the outside world. (One of the touching elements of this case was the looks of the two boys: Ten-year-old Howard was a Negro, and little Frank a Eurasian.)

Another example of empathy as a defense against anxiety—in a way a denial of the patient's own helplessness—was the interaction of two children in our respirator center.

Kathy, seven, had been hospitalized for almost two years with a most severe case of paralytic polio and marked respiratory deficiency. A charming, lively girl, she was encased in an array of braces and machinery, had a tracheotomy and was in constant need of respiratory aid. Roger, eight, was a new child on the ward. He was bedbound but only his legs were paralyzed. As we knew from his history, he was an anxious child prior to his illness. Though coming to this ward with its many incomprehensible gadgets brought about an almost unbearable anxiety, he, too, found an outlet. He asked that his bed be moved close to Kathy's. He got permission to feed her and devotedly spent most of his time next to her during the two weeks these children shared their hospital experience. Roger's anxiety was far from removed, but it was temporarily relieved.

Roger's case was similar to Howard's; the close give-and-take with a sicker child helped these two boys hold the anxiety and their own illness in check. Both Howard's and Roger's I.Q.'s were below average, but they had amazing intuitive insight and power of observation.

Counteracting Regressive Tendencies

There is another area in which illness presents special problems of child care. Children who undergo serious body changes and are severely restrained in their motility through illness develop a distorted image of their body and its functions. Since they are unable to carry out independently such functions as eating or elimination, they at times are thrown back into feelings of the pre-oedipal phase. We found it very important to use all available substitutes, meager as they may be, to allow children to function on their proper developmental level. Food is served family style and the children have some choice. They may visit the hospital kitchen or have some foods prepared on their ward, or are taken out for picnics. They are encouraged to assist in their bath, particularly to wash their own genitals. A mirror was hung in the tub room so that those children who are completely paralyzed and have no way to see or feel their body shape can, without having to ask and to believe others, see for themselves that the damage done to muscle functioning does not distort the rest of their body.

Another experience which counteracts regression by giving children reassurance that only part of their self is afflicted by the illness is their schooling. Bedbound children observe very sharply. This can be used in a creative approach to learning, fully utilizing the child's observations and thinking. Such vital participation in the learning process can make up for some of the enforced passivity and dependence. Learning can also represent a link between the *before* and *after* of a hospital stay. It can at least reassure the child that his thinking was not damaged by the illness and that the hospital, his own school and his parents are planning for a future. For these reasons learning has to be challenge and satisfaction, not rote learning.

Children do not need diversion, but opportunities to participate with all available emotional and intellectual energy in their daily living. The term *diversional activities* which is often used in hospitals is unfortunate, as it is a static concept rather than a dynamic one.

Let me give you one short illustration of the value of a learning experience:

Twelve-year-old Mark, a patient with severe paralytic polio and respiratory deficiency, started his school work two weeks after the onset of illness, while in the iron lung. His main interest was science, and we started in this field.

Many departments of the hospital cooperated. The plumbers and electricians collected old faucets and appliances we could disassemble. We began a collection of insects, including a pair of live praying mantises. When the mantises died in winter, there remained a nest of eggs from which hundreds of nymphs hatched early in February.

Mark prepared book reviews and reports. Since he couldn't write, we recorded them by tape recorder and sent the tape to his home school. After about a year in the hospital he was strong enough to sit up for an hour daily. When passing the doctors' laboratory on his way to the schoolroom he always tried to look in. We suggested he might like to use the doctors' equipment to study micro-organisms from his aquarium. He could not use his hands, but the teacher demonstrated how to stain slides and he could see them under the microscope. The doctors saved slides of disease-causing bacteria for him. This led to many questions about diagnosis and diseases, some of which were answered by trips to the virus research department and bacteriology laboratory. A research assistant learned of Mark's interest and arranged for a high school Science Club to hold meetings at the hospital where Mark could participate.

For Mark the hospital environment itself was a source of stimulation and exploration, thereby counteracting the isolation and depression brought about by long hospitalization.

Children Awaiting Placement

Different, ego threatening problems arise when children have to stay in the hospital beyond medical need. Finding good foster homes for young children after hospitalization for tuberculosis is particularly difficult. Therefore, many children stay on our convalescent tuberculous service longer than medically indicated. The child care worker in this unit functions like a nursery school teacher. She utilizes equipment and materials as well as relationships to give these children a chance for development in all areas.

These children often find the family constellation changed while they are away from home. Families move, new babies are born or a parent leaves the home because of illness or other reasons. It is almost trite to mention that if a new baby arrives while the child is hospitalized it must seem to him like a substitute for himself who is "no good any more." This experience confronted us vividly in little Johnny's case:

Three-year-old Johnny was waiting to be placed in a foster home. After an interval of many months, his mother, a shiftless and promiscuous woman, came unannounced for a visit and took Johnny home for the day. He was overjoyed to see his older sister but was confronted with a new-born baby girl for the first time, though he had been told about her. Upon his return to the hospital he was sad and listless, and in an almost panicky way insisted that he be dressed in girls' clothing, including girls' shoes. It was obvious that this was not a playful whim but had some deeper meaning. When the same thing happened the next day we told him that we had lots of dress-up clothes he could use if he wanted to pretend that he was a girl, but that he was Johnny, a little boy, and we liked him and knew his mother liked little boys, too. We let him choose his shirt and pants but would not dress him as a girl.

Poor Johnny. Though he could not depend on his mother at all and had seen her only once or twice during his eighteen-month hospital stay, he was so gripped by his visit home that he felt if only he were a girl mother would take him home to stay. Only after his favorite adult had assured him that she liked little boys, and liked Johnny particularly, could he give up pretending to be a girl and resume his identity.

The child care worker thus must be able to deal with a wide range of problems. She must know how to function as a member of the clinical team, and must be capable of facing emotionally exhausting situations. She plays different roles, depending on the child, the illness and the family constellation.

Her background must have equipped her for the job. We believe that the child care worker can come to her work from any of the three obvious professions—nursing, education or social work. The most important thing is identification with the job, to help the child to come through the ordeal with as little adverse effect as possible.

We have found a background as an educator (grade school or nursery school teacher) to be particularly helpful. Both child and parents are able to relate the educator to persons who play a role in the child's outside life. The doctor, the nurse, the social worker come into the child's life with the illness. In contrast to these figures "connected with the hospital," the educator can be a figure "connected with health." The child care worker can, and should, become a symbol of the child's future.