Operating on a Child's Heart: A Pedagogical View of Hospitalization

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There are many occasions during a child's hospitalization when tensions run high. But none seem as tense as when the child's needs appear to be ignored by the surrounding medical personnel. I recall, for instance, my child being brought into the children's ward from the Intensive Care Unit (ICU) where, for the past 24 hours, he has been recovering from heart surgery. My child, after being monitored so closely, is left in a room with only a parent watching over him—watching as he sleeps, watching as he stirs, and listening as he begins to complain of the soreness in his chest and arm. The last of the morphine is wearing off, so I ring for the nurse to come and give him some more medication. "I'm sorry," says the nurse, "but I can only give him Demerol every six hours, and it is only four hours since he came out of the ICU. All I can give him now is Tylenol. I'll come back in a few minutes with it." He falls asleep waiting for her to return, sleeping for over an hour. It is now close to two hours since he first indicated his discomfort. As he wakes it is clear that the discomfort has turned to pain. I go to the nurses' station to seek some assistance for my child and am told that someone will be there shortly. Again we are left waiting as the pain grows steadily worse. I wonder why there can be so much paperwork to be done when my child is in such distress just down the corridor. Why does it take so long for someone to attend to my child? The system is askew—the priorities and procedures seem so removed from the care of my child. Strong words are said and they have a beneficial effect. From then on there are more visits to his room. Nurses check on him regularly; the residents inquire after him; and the woman who cleans his room stays a while to talk with him. My child is on their minds. He is being looked after.

I guess it pays to complain; however, this is not the main lesson to be drawn from this situation. There are times during a child's hospitalization when he must be spoken for, when those closest to him must speak up to ensure that medical attention is responsive to his needs. At issue here is the matter of responsibility for the care of the child, the issue of who is ultimately

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responsible for the child and who is best placed to know what is best for the child. At issue is a view of the child's hospitalization which is more expansive yet inclusive of a medical view, indeed, a view of hospitalization which may provide a corrective to the excesses and neglects of a predominantly medical view.

The purpose of this article is to describe phenomenologically what such a view of hospitalization might entail. By writing about a particular child who undergoes a heart operation, my aim is to show that the health of the child is not solely determined by the medical intervention that takes place. In fact, through a critique of the medical view of the child and by attending to the child's experience of hospitalization, I want to show how an orientation to the good of the child can make sense of what we may think is good for the child. I wish, in other words, to describe a broadening of the medical view of hospitalization and the formulation of what I shall call a pedagogical view of hospitalization.

The Medical View

In the CBC program *Heroic Measures: Dilemmas in the Care of Sick Children* (1987), attention is drawn to the possibility of a one-sided medical view. The chief of pediatrics at Toronto's Hospital for Sick Children says:

> I have to look through the eyes of a physician who looked at a child and said, "I think that we have a treatment for that child that I think could benefit that child." And whether the outcome for success, however we are going to define that, was 40% or 16%, I think that those are the sorts of decisions that we have to make every day. I think my role is to try and ask what any reasonable person would try and do for that child who's in the situation that he or she can't make up their mind for themselves. I think we have to divest ourselves from what's in the best interests of everybody else and focus on that child. What would the child, given the ability to make this decision, prefer?

The interviewer on the program then asks:

> Do you think it's possible to do that? Do you think it's possible for you to in effect separate the child from what he is not actually separate from, that is his parents, and say what is in the best interests of the child as opposed to what is in the best interests of the family?

The interviewer does not simply ask a question of whose interests are being served—the parents' or the child's? But rather, he asks, how can a medical decision be made in presumably the best interests of the child by ignoring those of us who have been responsible until now for the welfare of the child? If we, the parents of a particular child, want to remain close to our child, what might we be up against when a crucial medical decision is made as to what should be done for our child? What sort of logic would deny the fundamental responsibility we feel for our child?

A Path of Logic

"So, how long has your son had a heart murmur?" asks the GP during what we think is merely a routine checkup. From this point on we must face the fact of having a defective child. "But he has always seemed so healthy. Why wasn't the murmur detected before? Why weren't there any signs of a problem earlier on?" Tests are carried out: blood tests, ECG, X-ray, 2-D Color Echogram. The child is physically and comprehensively examined. A diagnosis is made—Patent Ductus Arteriosus, PDA for short. "You can be thankful. It could have been a lot worse," says the physician. "At least this is one thing we can operate on where you'll end up having a 100% healthy child. You want a perfect child, don't you?"

Is there no way out of this child having a heart operation? "Well there is no need to rush," says the pediatric cardiologist. "He's had this condition for four years already, so a month or two won't make a great deal of difference. You can discuss with the surgeon a convenient time for the operation." The operation is a fait accompli. The physicians seem so sure of its necessity; they seem to know thoroughly the condition of this child and the conditions under which we will continue to have him. Their diagnosis of a congenital heart defect is an utterly distinguishing, discerning, determining, inescapable decision about the nature of this child. And yet, do they really know *this* child, or do they only know what type of child this child should be? What view of the order of things is at stake here in this diagnosis of our child?

Foucault (1973) says:

> Up to the end of the eighteenth century medicine related much more to health than to normality; it did not begin by analysing a "regular" functioning organism and go on to seek where it had deviated, what it was disturbed by, and how it could be brought back into normal working order; it referred, rather, to qualities of vigour, suppleness, and fluidity, which were lost in illness and which it was the task of medicine to restore. To this extent, medical practice could accord an important place to regimen and diet, in short, to a whole rule of life and nutrition which the subject imposed upon himself. This privileged relation between medicine and health involved the possibility of being one's own physician.

> Nineteenth-century medicine, on the other hand, was regulated more in accordance with normality than with health; it formed its concepts and prescribed its interventions in relation to a standard of functioning and organic structure, and physiological knowledge—once marginal and purely theoretical knowledge for the doctor—was to be established ... at the very centre of all medical reflexion. (p. 35)

With this "birth of the clinic" came a profound change in the way we look at individuals and especially children. The medical gaze superimposes the "body" of knowledge about disease on the body of the child (Foucault, 1973, p. 3), which is to say it is based on a way of thinking about the course of a disease which likely overlooks the circumstances of particular children. The medical view of the child constitutes a pathology, a path of logic, which so easily leaves the child behind.

Logically speaking, there is not a great deal of risk to this operation. "It's the appendectomy of heart operations," they tell us. "Of course there is always risk in any major surgery; but at this hospital we have one of the best surgeons in the field. Really, there is no need to worry. Besides, the risks of the operation are less than the risks of leaving the child's heart condition untreated." These words of reassurance do not offer much comfort. To contemplate not operating implies dooming the child to a shortened life span and having him face the prospect of congestive heart disease, frequent pulmonary infections, and restricted physical capacity; on the other hand, thinking about the operation means thinking about the procedure that will literally open this child up, the surgery this child is yet too young to understand, the operation that risks taking away the innocence of this child. As parents, we are fearful for our child. "Look, don't worry," chides the physician, "he'll be in good hands. We have a very good record in treating this problem." But can our fears be so unfounded? It seems that within this technologic of medicine there is no body of knowledge that addresses any real difference between having a child and having an operation on a child. Nobody speaks for the child, for preserving not only the biology that is important for being a child, but also the experiences that make a good childhood possible. Inevitably the condition of the child, his childhood, comes down to the problem of his medical condition. The question of this child's existence is reduced to the risks of a surgically operable problem.

We accept that this heart operation must go ahead. Having come this far, there is no turning back. Sure, we request a second opinion just to see if the condition has improved, but this willfulness on our part only confirms the direction in which we are headed. Nothing has changed medically; the murmur is as loud as ever. Our task now is to face the scheduled operation and to prepare the child; in other words, to put the best possible face on the situation. "By the way, the boy must be free of dental caries," the surgeon's office warns us. "His teeth will have to be checked before he is admitted. The surgeon will not operate if there is any risk of infection. And a cavity is as bad as an infection." His front teeth—there are cavities in many of them. His dentist said they could be left because the second ones would soon come in to replace them. Now it seems imperative to have them attended to. But what should be done? His dentist advises extracting all the suspect teeth. He says: "My position is a conservative one. Extract the teeth and do away with any risk of infection at all. If it was my child, that's what I would do. Still, if you're worried, I'll refer you to a pediatric specialist who may know some whiz-bang way of saving the teeth." The pediatric specialist is more conciliatory. He agrees that extracting the teeth is rather drastic and that restoration is quite possible; nevertheless, he says: "Keeping the teeth is really for aesthetics." Tell this to the child who cries on being told he will lose his teeth, the child who wonders how he will be able to talk, the child who becomes distraught at the thought of his friends all laughing at him. For this dentist it may be largely a matter of preserving the look of the child, but for the child it is a matter of self-preservation. So we see other dentists who each give different advice. What do we do? To whom do we listen? The pediatric cardiologist comes to the rescue with some good advice. He says: "Just do what you would normally do for your child in repairing his teeth. After all, it is your responsibility that they are the way they are." The decision of what to do is now ours to make. In preparing the child for his operation, it is we who must take ultimate responsibility. We must do what we think is best for the child; we must preserve the integrity of the child's smile in the face of the inevitable operation.

Cracks in the Logic

"The medical establishment has become a major threat to health," writes Illich (1976, p. 3); and yet to attempt to dismiss the medical view of one's own child exposes us to charges of gross neglect and almost criminal irresponsibility. Such critical posturing as that of Illich's *Limits to Medicine* fails to acknowledge the power of the medical view in situations of real existential conflict, such as having to respond to a child with an operable heart condition while knowing the medical diagnosis of his preoperational life expectancy. Nevertheless, it *is* possible to still be critical in those situations where it appears that the body of the child, his corporeality, and his physically-constituted relations to the world are being denied altogether. Here, where we find blind spots in the medical perception, we also find ways of seeing what is actually being done to the child. Here, within these cracks in the logic of medicine, we can reflect on what might be best for the child.

What is required is a way of seeing which reconciles two things: the image of a child in his or her generality as an organism with a medically-defined problem, that is diagnosed within the context of professionally-defined relations, and that is resolvable by means of technologically-defined solutions, with the reality of a child in his or her uniqueness, as someone who lives first and foremost within the context of particular family and community relationships. Thus, when a child is being spoken about medically, we should know that this child has already been spoken for existentially. And it is this authorship (this authority) which takes precedence when considering what can be done for his or her sake, especially when medical intervention is being considered.

Perhaps one of the most routine procedures is that of admission to the hospital. There are a number of forms to sign—registration forms, health insurance forms, hospital indemnity forms—before our child is admitted. Then, once admitted to the wards, there are more forms. On one it asks: "Has your child been in hospital before? How does your child react to strangers? How does your child react to pain?" Soon there are frequent visits by hospital personnel. Nurses, doctors, nurses' aides look in, take measurements, give instructions. Meal orders are taken. For a while there is even a stream of medical students, each one saying that he or she will only take a minute or two as he or she starts prodding and poking the child, listening to his chest, taking his blood pressure, and generally keeping the child from doing the things he would rather do. "Is all this necessary?" we wonder. The child has been admitted to the hospital. We have admitted him, and in so doing we have admitted our compliance to the rule of the hospital. And yet I do not think that this admission takes away our obligation to stand up for the child, especially when the logic of things done to him seems unclear.

Cousins (1983) in his book *The Healing Heart* admits:

> There are qualities beyond medical competence that patients need and look for in their doctors. They want reassurance. They want to be looked after and not just looked over. They want to be listened to. They want to feel that it makes a difference to the

> physician, a very big difference, whether they live or die. They want to feel that they are in the doctor's thoughts. In short, patients are a vast collection of emotional needs. Yes, psychological counselors are very helpful in this connection—and so are the family and clergy. But the patient turns most of all and first of all to the physician. It is the physician who has the most to offer in terms of emotional needs. It is the person of the doctor and the presence of the doctor—just as much as, and frequently more than, what the doctor does—that create an environment for healing. The physician represents healing. The physician holds the lifeline. (p. 136)

On the other hand, although these sentiments may stand up to some scrutiny in certain cases of adult hospitalization, such a relation does not seem possible in cases of children's hospitalization. In fact, Petrillo and Sanger (1972) state:

> Physicians who may spend considerably less time with the children [than nurses do], are correspondingly less involved, though their decisions can have momentous effects. Lacking the satisfactions to be enjoyed from intensely developed interactions with young people, they may not be stimulated toward gaining knowledge of the child's world. (p. 62)

What Cousins (1983) says about the quality of the physician-patient relation does not really apply to children, not just because physicians spend little time with children, nor because they don't enjoy interacting with them, nor even because their world is separate from the world of children, but simply because they are not the parents of the children they operate on, they are not part of their family, and they are not part of the communities from which the children come. Except for a child who is chronically hospitalized, any relation a physician has with a child is at best a mediated one.

A better approximation of the physician-patient relation which Cousins holds up would seem to be the parent-child relation. In fact, there are clear indications in the literature on child hospitalization and in changing hospital regulations that the adult-child relation has come to be recognized as crucial to the welfare of the child (Hardgrove & Dawson, 1972; Robinson & Clark, 1980; Thompson & Stanford, 1981). For example, Anderson (1985) recounts:

> The most significant step ever taken toward reducing patient fear at Children's was the lifting of all restrictions on parental visiting. Today the benefits seem obvious. Yet historically parents were not welcome in pediatric hospitals or wards. Their presence, it was thought, would contribute to the spread of infec-

> tion and to the demoralization, according to someone writing in 1907, of "the discipline of the hospital and the other children." Mothers who insisted on remaining at their sick children's bedsides were sometimes viewed with irritation. Hospital staff of the period, noting that patients shed tears when their parents left, concluded that visits from parents made children unhappy.... Open visiting became a fact of life on general floors at Children's in the mid-1960s and in the intensive care units in 1975, though parents are still asked to check with a nurse before entering ICU. By lifting the restrictions, hospital administrators in essence acknowledged that children even as patients belong first and foremost to their mothers and fathers. (pp. 48-50)

Still, the significance of the adult's presence has yet to be recognized medically. Parents, family, community are still regarded as, at best, supportive of the medical processes of child hospitalization. I would argue that in order to make sense of what is being done to a child, especially when he or she faces an operation, it is necessary to move beyond such a spatially- and temporally-limited medical view and to consider the health of the child in the context of how he or she lives with others beyond the hospital. After all, the child's medical treatment only makes sense when it is consistent with his or her treatment by those with whom he or she lives. And the success of the medical treatment is dependent on an acknowledgment that a meaningful adult-child relation needs to be made the focus of the child's hospitalization.

Beyond the Medical View

I look to Cousins (1983) for ways in which this relation can be understood. At the level of methodology, he says:

> Few words in the medical vocabulary carry more connotations of scorn and even contempt than the term "anecdotal." Not to the writer. The writer makes his living by anecdotes. He searches them out and craves them as the raw material of his profession. No hunter stalking his prey is more alert to the presence of his quarry than the writer looking for small incidents that cast a strong light on human behavior. If nothing is valid to the physician except as it proceeds from masses of data, very little has meaning to the writer except as it is tied to the reality of a single person, and except as that reality can illustrate a larger lesson or principle.
>
> A single case may be suspect to the medical scientist. To the writer, the universe begins with a single case, a single emotion, a single encounter—in short, a single person. (p. 140)

The methodology suggested here involves accenting a single case of a child being operated on and working out where we stand as concerned adults in situations that arise where a medical logic is transcended. It involves interpreting this stance in a way that allows for a public discourse on the hospitalization of children.

The task of writing such an account is to keep in mind the flesh and blood child—my child, your child, the child we know, and the child for whom a heart operation makes us feel personally responsible. The anecdotes on which this writing is based should enable us to draw closer to the child, to see things as the child might see them, to open up the cracks in a medical view that would deny the child's sense of what is happening to him or her. Writing about a particular hospitalization would constitute, therefore, a child-oriented view—a perspective that acknowledges the child's experiences. In Petrillo and Sanger (1972) when the child says

> Some people think they know it all. I tried to tell the doctor that I couldn't hold still in that position but she said I was being silly. I said it was cold; she said it was just right. O.K. for her, she was dressed up to her ears in a gown, cap and mask and there I was cold and practically naked. She said I wouldn't feel any pain; I said I did. She said she'd get it (the specimen) the first time; I know she didn't. So who the hell would know better? (p. 106)

we should acknowledge what the child knows and speak with him against the procedure to which he has been subjected.

A Child-Oriented View

How does the child understand his hospitalization? What things stand out in his mind? Perhaps they are the little things that would otherwise go unnoticed unless one is attentive to the fact that the medical account is not the only story that can be told. The seemingly trite incidents that stand out in the child's mind may in fact constitute a narrative of greater significance than the medical record alone. Let us consider, therefore, some anecdotes of a child's experience of hospitalization, some little things like having to wear the hospital gown, seeing the scar from the operation, and taking things home from the hospital.

Wearing the Gown

While flipping through the television channels I come across a medical program. It features a heart operation, a documentary of a coronary bypass procedure. A timely feature, I think, as I call my son over to watch it with me so that he can see what having an operation means. And yet as he sits beside me I wonder if this might not be too much for him. He may see things for which both he and I are ill prepared. But even before I think I must shield him from certain sights, he begins to cry. "Do I have to wear that?" he asks in reference to the surgical gowns worn by the surgeons appearing on the program. "Only girls wear dresses. My friends will all laugh at me." Can this be his concern? It seems so minor in comparison to that which I thought might bother him as he watches the program. "Well, when your friends come to visit you they will have to wear a gown as well," I tell him. His good humor returns. He smiles at the suggestion of Dorian and Diego getting dressed up to see him. Soon he forgets his concern over the gown and leaves me to go back to what he was doing before I called him over.

Nothing more is said of the hospital gown until the day of the operation when the time comes for him to be wheeled over to surgery. The nurse in attendance asks me to help him put on his gown. For the past day and a half he has lived in the clothes he brought from home; now he must change into the costume set aside for him. But he refuses. He cries, he kicks, he screams as we force the gown on him. He cries inconsolably for all the ward to hear. So we strike an agreement: He can wear his shorts underneath the gown until we get to the operating theater.

On the way to the theater various people pass by. They smile as people are wont to smile at a young child who is obviously going for an operation or to have some technical procedure performed. But the child thinks they are laughing at him, staring at him, seeing his nakedness. He pulls the gown down over his knees and does not stop crying until we move out of the main corridors and reach the surgical preparation room. Here we distract him with talk of presents and gifts that might come after his operation. Here we play "I spy" while waiting for him to be taken from us. He appears happy for the moment. Then he remembers the gown, "that dumb old gown" he calls it. He cries again. "Why do I have to have this operation?" he asks pleadingly. Is this what the gown is about? Is this the reality which the gown can only partially hide? "Look, we have gowns on too," I say, not really knowing what to say. We, too, are trying to disguise the operation, this rupture, this separation, and all the risks that go with it. We, too, are party to the way medical procedures are disguised and dressed up so that we lose sight of the stark reality of exposing the flesh of the child.

This incident suggests that the child already understands the magnitude of what is happening to him, and that our task is to deal with his fearfulness in a language that recognizes and mollifies his fears. Of course, it may have been better to prepare the child for hospitalization through some less traumatic means—through one of the "many existing methods of preparation which have been devised to help children and their parents cope with hospital admission or a medical procedure" (Rodin, 1983, pp. 21, 22; see also chapter two). But at a more practical level, the incident makes us wonder if hospital staff might not attend more closely to the child's words and to the situations where they are most suggestive. Why, for instance, when so many professionals have visited the child, is the task of taking the child to surgery left to the hospital orderly? Why is the preparation for surgery reduced to a scrubbing of the hands—a washing off of the dirt and grime of everyday life? Perhaps the preparation of a child for a heart operation may be enhanced if the child's concerns are not dismissed so readily.

Seeing the Scar

Five days after the operation, when my child is able to move with much greater ease, he goes to clean his teeth before settling down for the night. I hear him calling to me in the adjoining room, and by the sound of his voice all is not well. I rush into the bathroom to find him standing on the stool in front of the washbasin with his back turned toward the mirror above it and his neck craned in order to get a good look at the sutured incision from the operation. Suddenly I realize this is the first time he has seen it. What with the medications he has been taking, coupled with his immobility, all he knew of the incision was what he could feel of the three stitches lower down where a tube had been inserted to drain fluids from his chest. The real incision had been hidden from view and out of touch. Now, however, he can see it for the first time. He can see it extend from his back all the way around under his arm.

"How did they do that?" he asks nervously. "Did they do it with a scalpel?" I am reminded as he asks these questions of the day he and Michael found a scalpel in the garbage and of how Michael sliced his finger before we could get it away from him. I suspect he also remembers this occasion and the pain Michael felt. I recall this being the first time he saw a scalpel and how he found it so hard to understand that this particular sort of knife is used to open up the body. So when he asks "How did they do that?" his question seems more a statement of incredulity at the thought of being intentionally cut than a question of procedure. His question brings Michael to mind, along with the anxiety he felt about this implement. Now, seeing his body disfigured, he cannot fathom how it is that someone would treat him in his manner.

I try to calm him down by telling him that it will soon disappear, even showing him my own operation scar. Still he remains tense. "When did they do it to me?" he asks. Such a strange question. I would have thought the timing of the operation was now perfectly clear to him, but apparently he does not see his stitched incision as I do. "When did they do it to me?" In an objective sense, they did it five days ago, but according to the child's sense of things, they have done it only now that he can see their handiwork.

That evening he does not sleep well. He moans and groans and tosses in his bed. Half-asleep, he calls for us. "What's up? Does your chest feel sore? Is anything wrong?" "No, nothing," he replies to our ministrations. But something is wrong. He is cut, mutilated, mutated, changed. In his eyes something looks strange, something looks foreign. There is something the matter. But when asked what the matter is, there is nothing, nothing, to be said.

When he sees the scar, it is not so much the medical procedure that matters to him as it is his awareness of how the procedure affects his relation to those around him. Throughout his hospitalization, the child is having things done to him, and yet he strives to maintain an identity in the face of such intrusions of his body. For instance, we speak to the surgeon immediately after the operation. She tells us that "the child has a small to medium ductus that was ligated and a metal clip was used between the ties." A metal clip! She left a metal clip inside! What effect will this metal clip have? Will it cut into his tissue? Will it affect his magnetism? For the child, however, there are different concerns for normalcy. While we are concerned about the metal clip, his first concern in the Intensive Care Unit is that we should bring his pyjamas. He wants to wear his pyjamas. Even as we leave the ICU with the morphine taking its toll, he protests at having to wear the hospital outfit. And by the second day back in the ward room, no more is to be seen of the green-striped pyjamas. By this time he is looking fairly normal. The ECG monitor is all that he has attached, and yet he protests at having to carry the monitor in a bag slung around his neck. He wants to carry it. "I'm sorry," says the nurse, "but you have to put this around your neck if you want to go to the playroom." He complies, but as soon as he reaches the playroom he takes the bag from around his neck and hides it under the table where he sits down. Later on the nurse brings a wheelchair to take him to the X-ray clinic, but he wants to walk by himself. "You can sit back and enjoy the ride," she tells him in an attempt to entice him onto the chair. Still he insists on walking even though she warns him, "it is such a very long way." In each of these situations the child chooses the path of normalcy, of familiarity. Wearing pyjamas brought from home, holding the ECG monitor under the table, and walking to the X-ray clinic—each action defies the strangeness of the hospital. Each preference allows him to feel himself in this foreign place. Consequently we can appreciate how seeing his scar for the first time can be so traumatic. It cuts through the attempts he is making to act normally and to be the child he thinks he is. It makes him a stranger to himself and to those around him.

Taking Things Home

The child comes home with a new lease on life. Through the operation he has been given the chance of a normal life span. For him, however, there are more immediate things to be concerned with. There are the souvenirs of the hospital to be remembered. He must take home the identification band he wore on his wrist and the gauze hair covering which came from the operating room. These mementos of hospital life take precedence over the expensive gifts from well-wishing friends, the get-well balloons that filled the room for the past few days, even the toys, crayons, and books which he brought from home to occupy himself during his stay in the hospital.

The usual things of childhood are attended to after he has been home for a while. Here they have their place. But at the hospital their place is uncertain, or at least it is for him. A plastic tube decorated with cartoon characters is not meant to be played with, but to serve a particular medical purpose as a spirometer for clearing the mucus from his lungs. What appears to be a toy is actually a device that causes the child some distress. I ask him, as we make ready to leave the hospital, if he wants to take the spirometer home. His indifference to my question takes me back a few days to the second day after the operation when the intravenous tubes have been disconnected and all that remains attached is a telemetric electrocardiogram monitor. The child is now disconnected from machines for the most part, from home, and perhaps even from us. I see him lying on his bed in the ward room when only a day ago he was in the Intensive Care Unit, monitors attached, and a nurse constantly monitoring his vital signs. Now he is alone, resentful of the pain those around him have caused. "Listen, Dad," says the nurse who has just entered the room, "we've got to clear that mucus from his chest. You've got to get him to blow into the tube at least five times every hour. Otherwise I have to use the suction. And he certainly won't like that. Here, you hold his chest and we'll get him to cough it up." I do as I am told, although I am apprehensive at the thought of being co-opted in a seeming conspiracy against him. I touch his wound, but not in the way I would like. I hold his chest firm in what seems to be an act of betrayal. "I can't do it," he tells the nurse, sobbing at the suggestion of a few more tries. "It hurts. I can't do it." "Of course you can," she says. "Did you ever hear about the little red engine who says, 'I think I can, I think I can'?" "But I can't," he says, turning in my direction and perhaps hoping I will intervene for him. "Sure you can do it," the nurse chides him. "Just five more coughs." She turns to me and says. "See if you can get him to cough a bit, and make sure he blows into his tube." I look at the tube again—the cylinder with its cartoon characters indicating the varying pressure levels, and I think that for the child even Disneyland conspires against him. Maybe it would be less confusing if he had his chest suctioned and be done with it.

The things around him bring little comfort. They fail to acknowledge the pain of his recuperation. Even the playroom, this supposed sanctuary of childhood within the hospital, has a look of sickness to it. The children hobbling around with their IV drip machines in tow, the hospital toys so carefully selected, the children who disappear and then reappear from their required therapies—this place is not like the rumpus room or the backyard where the child plays at home. So when it is time for the child to leave the hospital, he takes home the only things that make sense to him—the wrist band and the gauze hair covering.

His taking home these seemingly inconsequential things has us wonder what we should give him to hang onto. What should we give a child to help him through the difficult times of hospitalization? We begin to wonder if perhaps the thinking about the hospitalization of children has more to do with accoutrements of childhood than it does with ensuring that the conditions necessary for children to accept medical intervention are met. Here amid toys, a playroom, and equipment designed with children in mind the child finds his own attachments—his wrist band and the gauze hair covering. These become the props of his childhood. Although there is a need to fashion a childlike landscape—a ward designed for children with things children normally like—there must be an awareness that what are more important are the things and the experiences they evoke which the child takes home with him. By attending to such things perhaps we may even see that the child's experience is much closer to our own than our designs would have us believe.

A Child's Story

Some weeks later I ask my son to tell me a story about going to hospital. He uses his felt pens to draw a series of four pictures and then he tells me the words that go with them. His story is called "Peter is Going to Hospital."

> Peter is going to the hospital room now to have his operation. And someone is pushing him, too.
>
> Peter is lying in his bed, and there is a door behind him. There is a window on the door. A nurse is coming in.
>
> There is a shelf underneath Peter's bed and there is a suitcase on it. There are clothes in the suitcase. A pillow is behind Peter's head. Peter feels good.
>
> The nurse feels Peter's chest. She has tools in her pocket, and she is going to look into his ear. Peter has a sore arm.
>
> Peter and his Mom are walking home. Peter has grown up. But he still has a sore arm.

This story, which resonates with the discussion of some critical incidents of the child's hospitalization, serves to keep us in touch with the child's experience of hospitalization. It brings us back to the life world of the child and helps us see what is at stake. For the child, the correction of a medical defect is much less comprehensible than the wearing of a hospital gown, seeing the scar of an operation, and taking things home. And yet the child understands through these experiences of hospitalization that his life has been profoundly altered. As he says in his story: "Peter has grown up. But he still has a sore arm." For him, just as for Peter, there seems to be little difference medically, although there has been a profound change experientially. His story reminds us that it is his maturity which is fundamentally at issue, and that it is our concern for the direction of his maturity which authorizes our actions on his behalf, including our acceptance of those medical interventions which we see as being necessary.

A Pedagogical View

The question remains: To what extent does this child-oriented understanding of medical procedure carry its share of responsibility for the child's life? It would seem to me that we must not only hear what the child has to say about the things happening to him or her, but we must also gain from our attunement to the child's experiences in the here and now an awareness, which medicine claims to have, of the child's future. The task of writing about a child's experiences of hospitalization is thus to explicate a pedagogical view that recognizes the child's future as contingent on the quality of his or her treatment (his or her care) in the here and now. For example, a nurse comes in first thing in the morning to take some blood from the child. "Can you come back in an hour or so?" his mother asks the nurse. "He has only just woken up." The nurse does not seem too put out by this request and agrees to return later on. But a few minutes later a second nurse enters the room and asks if the child has had a blood sample taken. An explanation is given of what has only just transpired; however, this nurse is not happy with this flagrant change in procedure. She insists on doing the job herself, at once.

Now there may very well be good reasons for taking blood first thing in the morning, and if so, then these reasons could be explained to the mother. On the other hand, there are also very good reasons for waiting until a child has woken up and had time to himself before a needle is inserted into his arm. Which reasons ought to prevail will depend on whose interests are being served, the child's or someone else's. Of course, this does not mean that the child's comfort is being placed above his medical care; on the contrary, the health of the child is profoundly affected by the atmosphere of his hospitalization. To be woken up by a needle in the arm is not only discomforting, but it also denies the child the opportunity to wake up feeling somewhat invigorated for the recuperation that lies ahead. And even if there is little chance of the child's awakening in what Bollnow (Vandenberg, 1975) calls a mood of "morningness," of cheerful expectancy for the coming day, the responsibility of the adult in attendance is to at least ensure that the possibility is not denied him.

This remembering of the child's experience, and on this basis, advocating what is thought to be best for the child in light of a medical knowledge which purports to make the child better, is what a pedagogical view of hospitalization entails. Accordingly, when wearing the gown, seeing the scar, and taking things home stand out as critical incidents in this child's hospitalization, they are occasions for trying to understand the child's predicament and for coming to terms with the nature of a caring relation to the child during and beyond his hospitalization. These situations matter to us both; moreover, it is through a reflective participation in the type of situations I have described that a pedagogical view of child hospitalization can be taken. Our task is to see how maturity is gained through hospitalization and how it is that we can help the child when medical procedures make the child grow up too quickly. In particular, we need to question those procedures of hospitalization that undermine our pedagogic relatedness to the child.

We might ask: How is it that such procedures can be so removed from a knowledge of the particular child? For instance, the surgeon comes into the ward on the afternoon prior to the operation. She has not seen the child before; this was the responsibility of the cardiologist. "Is this Peter's room?" she asks no one in particular. There are two beds in the room, each with a boy in it. She walks past the first bed and looks at the child in the second bed. "This is Peter, is it? I thought he was going to be smaller." It seems, from these words, that a personal knowledge of the child has no real bearing on the conduct of the operation. All the tests have been done; the only surprise is that the child is a little bigger than expected. But this is of no consequence because the body to be operated on need not be any particular child's body.

And yet the consequences of this anonymity soon become apparent. After the operation the surgeon visits the child on her daily rounds. Yes, she admits, the boy is doing well. "But he has got to start using his left arm more. We don't want the muscles that were cut to knit too tightly." "Can you lift your arm over your head?" she asks him. He holds his arm close to his chest and tries to lift it up with the other hand. "No, see if you can touch the top of your head." He tries, leaning his head to one side, and manages to touch his ear. But the surgeon is not happy. "You want to go home, don't you?" she says sternly. "You can't go home until you can raise your hand up in the air. You might have to stay here over Christmas. You don't want that, do you? Tomorrow I'm coming back and I want to see how high you can raise your arm." The surgeon leaves the room and continues her rounds of the children's ward. He looks at me through moist eyes. I reassure him: "Yes, you will be out of here very soon." But first he must raise his arm. He must still make the gesture that will let him out of this place. He must excuse himself from the presence of the one he barely knows.

What is required in such situations is a mindfulness of the child, a sensitivity to the child's experience of being hospitalized, and an understanding of how the child is placed when medical procedures seem necessary. Perhaps by acknowledging a relation to the child we might also see how his hospital care can be most beneficial. We might see how certain episodes of a child's hospitalization, such as wearing the gown, seeing the scar, and taking things home, show a more complete perspective than the narrowly medical one, each episode suggesting a view of medical intervention which balances what is thought to be good for the child against the more fundamental question of what is the good of this particular child. Even when we give the child over to the medical specialists for the operation itself, even when our part in the child's hospitalization is diminished, still we must ensure that "the child is in good hands"—that he is in the hands of one who is both technically proficient and caring of the good of this particular child. Perhaps for the most part no dramatic changes need occur in hospital settings for such a pedagogical view to be adopted, merely a greater sensitivity to the child's experience. The important thing is that we attend to the child's experience and that we who are reflectively engaged in his daily life learn how to speak up for the child during his hospitalization.

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