Working With the Parent of a Dying Child

***By Linda Goldfogel**

During the eight weeks her child was dying, a mother adapted, in her own way, first to the threatened loss, and then, finally, to his actual death. In assisting this mother, the author was able to assess the mother's varying forms of coping behaviour, determine the reasons behind it, and provide her with reassurance and support in situations where it was most required. However, the author recognized that if she had had less difficulty in dealing with her own negative feelings and some of her emotional responses, she might have been able to spend more time helping Mrs. C. On the other hand, she learned that to partake in the care of the dying, a nurse must first engage in the process of introspection—to become aware of and understand her own attitudes and feelings towards death and dying.

One of the most difficult problems in nursing is dealing with a fatally ill patient and his family. When that patient is a child, his death is even more emotion laden for most of the nursing staff.

I took care of such a child for six weeks. The nursing goals were to help him to achieve and maintain a state of equilibrium and also to help his mother deal with her adaptation to his illness and anticipated death. I will present here only the nursing care given in relation to the second goal.

If I am to help parents in situations like this one, I must first be clear about what I mean by "adaptation." Hofling and Leininger define adaptation as the striving of an individual to find an equilibrium not only within himself, but also in his interaction with the environment(1). More specifically, adaptation may be viewed as personal or interpersonal. Personal adaptation is subjective : the individual experiences an event as he conceives it. The experiences are viewed and incorporated into the individual without his being influenced by the thinking of significant others. Interpersonal adaptation, on the other hand, is the social interactive aspect of adaptation. In this instance, an individual experiences an event in terms of the meaning attributed to the experience by those who are significant others.

Although these two aspects of adaptation may be viewed separately, they act together and are influenced by one another. For example, a mother experiences the threat of impending death of her child not only in terms of the meaning it subjectively holds for her, but also in terms of the meaning attributed to it by the child's physician and other individuals involved in the situation. Inasmuch as each aspect of adaptation may influence the other, one may be predominant over the other as well. The child's physician may inform the mother that her child will die very soon, but she may still experience the event as she conceives it, say, for example, as if the impending death is not occurring.

As an individual strives to adapt to the event he is experiencing, the processes he uses may be cognitive, behavioural, or both. Thus, an individual strives to adapt to an event by carrying out the processes of thinking or doing or, in many instances, both.

Each parent of a fatally ill child adapts, in his own way, first to the threatened loss and then to the actual death of his child. If a nurse is to help a parent deal with his adaptation to the anticipated death of his child, then the nurse must assess the parent's initial and present responses to the anticipated death, along with his present patterns of coping behaviour.

The coping behavior of the mother in this paper tended to be characteristic of the three phases of adaptation described by Natterson and Knudson: initial, intermediate, and terminal(2). In the initial phase, "denial was the most prominent response. In the intermediate phase, she tended to accept the reality of the situation but directed her energy toward realistic measures that appeared to offer hope. Finally, in the terminal phase came acceptance of the impending death. This triphasic response pattern has been referred to as a process of anticipatory grieving—an emotional rehearsal of the expected reactions following the child's death.

According to Friedman, the nature of adjustment to the threatened loss of a child reflects, in varying degrees, a parent's mode of coping with past crises, his previous experience with illness and death and the special meaning this particular child may have for him(3). Assessment, therefore, of a parent's responses to past crises gives cues to the types of coping behaviour he may manifest in this new situation. If, for example, the nurse finds that he had denied the seriousness of a spouse's illness right up to the time of his death, then she may speculate that this type of coping behaviour could be manifest as the parent adapts to his child's impending death. However, he may show a very different type of coping behaviour in this new situation simply because the child may hold a very different meaning for him than did the spouse who died. Also, the conditions that prevail may be unlike those that occurred in his past ex-

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periences. For example, he may now be prepared to deal with the child's eventual death, and he may not have been as he awaited his spouse's death. And for some parents, this also may be a first experience with death.

The responses to past crises of the mother in this paper and her coping behaviour in relation to her child's anticipated death reveal many implications for nursing care.

Mrs. C. was a 52-year-old Caucasian woman of Italian parentage whose husband had died of Hodgkin's disease in November, 1967, at the City of Hope Medical Centre. There were three children: Frankie, the patient, six and one-half years old; Angela, 18 years old; and the oldest son, Carmen, age 20. All were Roman Catholic. Frankie was first admitted to the pediatric unit of the City of Hope Medical Center in 1966 with a diagnosis of lymphoblastic leukemia. Five months after his father's death, Frankie was admitted for the third time—in relapse.

I anticipated that Mrs. C. would still be grieving over the death of her husband and now would also be grieving over the impending death of her son ; would manifest specific types of coping behaviour in attempting to adapt to her son's anticipated death; might be fearful of returning to this particular hospital because her husband had died here; would be affected by her religious beliefs in her manner of coping with her child's impending death; would be more fearful of the implication of his disease because this was Frankie's third relapse; and might or might not be prepared for Frankie's eventual death.

I learned on an initial interview with Mrs. C. that she had told Frankie she would visit him every day. In spite of this, he continued to fuss when she told him why she had to leave. His response to his mother's leaving might have been out of fear of being left alone in a strange environment, but it might also have been a reaction to a feeling of loneliness because of the recent loss of his father.

I also learned that Mrs. C. seemed overwhelmed. She said with tears in her eyes, "Along with my husband's death, I don't believe that all this is happening to me... While I know what Frankie's illness means, I still hope that he'll pull through." Engel refers to this type of response as shock and disbelief(4). Mrs. C. appeared to have accepted her son's diagnosis on an intellectual level, but not on an emotional one. Mrs. C.'s reaction to her husband's death appeared to be one of partial denial. Specifically, she said, "His physician never told us what Hodgkin's disease implied, except to say that it needed a long course of treatment.....When he died only six months after the diagnosis was made, I couldn't believe that it actually had happened. I know I still haven't gotten over it." Her response also indicated that she had not gone through the process of anticipatory grieving and, therefore, was not prepared to deal with his death and still was having much difficulty in working through her feelings.

Mrs. C's reactions to Frankie's illness appeared to manifest denial. "If he will not be with us much longer, then I want to make the most of all the time that we have left together," she remarked. She then said rather angrily that she considered it highly unfair for popular magazines to publish information on new drugs, like asparaginase, found to be effective as a possible cure for leukemia, when there was only enough of the medicine available to treat two or three children. "Who's to say which child is to get the drug when there are so many children who have leukemia," she remarked bitterly. Because Mrs. C. could not remove the source of her anger—her child's fatal illness—she often displaced this anger onto someone or something in the external environment. Awareness of these feelings of anger are of particular importance to nurses because such feelings may be manifested behaviorally as well as verbally, and nurses should be prepared to deal with them.

Initially, Mrs. C. exhibited two specific types of behaviour. First of all, she spent most of her time at the hospital at her son's bedside. She volunteered to assist the nurses with Frankie's care, and was always receptive to offering him help with any of the play activities he chose. Her close involvement in his care served to give her a feeling of having done everything possible for Frankie. However, we also know that expenditure of personal effort in the care of the child helps to relieve feelings of guilt(5). Although Mrs. C. spent the majority of her time with Frankie, she did manage to eat her meals with one of her two older children in the hospital cafeteria, and during Frankie's after-noon rest period, she would read in the parents' lounge on the unit.

Second, Mrs. C. sought the companionship of other parents whose children were hospitalized, particularly parents of other children with leukemia. She often asked these parents to join her for coffee or lunch and always inquired about each child's condition, offering comfort and support where needed. It was evident that the relationship between Mrs. C. and the other parents provided them with significant emotional support in the form of tactful and sympathetic listening as well as her offers to be of service. As Mrs. C, expresred it, "We share many of the same feelings and concerns." In this respect, one might say that there was a communal feeling : they were all in it together.

Friedman et al, point out, that parents they observed learned from one another and could profit from observing the coping behaviour manifested by others in the group. Sometimes, the common fear of "going to pieces" when their child became terminally ill was greatly alleviated by watching others successfully, albeit painfully, go through the experience (6).

It seemed to me that I needed to keep in mind that the threatened loss of Mrs. C.'s fatally ill child had probably revived a reservoir of unfinished grief work relating to the recent loss of her husband ; that the threatened loss of her child had resulted in the use of denial as a coping mechanism in the process of grieving and that removal of certain psychic and behavioral activities characteristic

of this mother's pattern of copying might result in disturbance of her process of adaptation.

Thus, the general aim of the nursing regime was to assist Mrs. C. to deal with the grieving process in relation to her child, through use of the coping behaviour *she* manifested. Since Mrs. C. was aware of the implication of leukemia—information she did not have in regard to her husband's diagnosis—I believed she would be better prepared to deal with Frankie's eventual death if I helped her in the process of anticipatory grieving.

Denial

In the first three weeks of our relationship, it became evident that Mrs. C. was attempting to deny the seriousness of Frankie's illness. Even though she had been specifically told by her son's physician that his periodic episodes of rectal bleeding were due to leukemic infiltration of his gastrointestinal tract, she denounced this fact by attributing this bleeding to the "rapture of internal hemorrhoids." In the same way, she periodically referred to his cold and black necrotic right forearm as feeling "warm" to the touch, even as it became increasingly necrosed. She was even more direct when she said, "I do not choose to ask the doctor epecific questions regarding Frankie's prognosis. I honestly don't want to know the answers. I guess when it comes right down to it, I'am a coward."

Even though she chose not to seek information from Frankie's doctor, she did question me several times about his hematocrit level. Interestingly enough she did this at a time when such information was not available—within five minutes following the blood test. When I said, I do not know the results," and invited her to express herself further by saying, "What makes you concerned about this test?" Mrs. C. did not pursue the conversation. It certainly seemed obvious to me that she did not want the answer made explicit because she did not seek it later when it *was* available.

I was aware of Mrs. C.'s need to use denial as her way of adapting to the demands of Frankie's illness at this time. Nonetheless, her overt and covert denial produced certain difficulties which impeded some of my nursing care efforts. For example, I had mounting feelings of frustration and anger as Mrs. C. continued to use denial. My frustration was related to the fact that the mother's reaction differed from my own. and also, in part, from my expectation of what the mother's reaction should be. I found it increasingly difficult to listen to Mrs. C. and to help her communicate her feelings. At one time, I even wanted to make her recognise the fact that she was denying. However, I was helped by my perceptor to realize that my attempt to point out her denial, or to remove or interfere with this coping behavior, could result in her withdrawal from me or a breakdown of a mechanism that was sustaining her in her grieving. A question also came to mind : did I have the right to attempt to remove or interrupt this coping behavior when Mrs. C. did not have a more effective mechanism to replace it ? Facing Mrs. C. with the manner in which she was coping could well have increased any guilt involved in her grief reactions (7).

Learning to understand my own feelings in this situation and clarifying Mrs. C.'s desperate need for denial, I was able once again to work with her as she expressed her feelings of denial. Finally, at the end of three weeks, Mrs. C. no longer denied the reality of Frankie's necrotic arm. With unsteadiness in her voice she said. "When I finally faced up to the situation, I was able to muster my courage and approach his doctor. I let him know that he had my permission to amputate Frankie's arm if he felt this would at all increase his chances of going into another remission."

Hope

Throughout the next two weeks of our relationship, Mrs. C. manifested a different mode of coping behavior. Hope was predominant in her expressions. Unlike denial, hope is compatible with an intellectual acceptance of reality (8). Characteristic of Mrs. C's responses during this time was this comment, "I know his arm is slowly dying each day, but I still hope that the powder being put on it will get rid of the infection." She also made the same type of comment in reference to the treatment being given him for the "infection" in his blood stream.

Verwoerdt says that "events anticipated in the future affect current feeling states ; the expectation of pleasurable things to come exerts an energing effect." (9) Concurrent with her feelings of hope, Mrs. C's increased expenditure of energy was put forth in a desire to participate in Frankie's nursing care. I gave her an opportunity to participate in nursing measures directed toward relieving pain and discomfort, such as bathing and feeding. As a result, she came to experience a general feeling of comfort in knowing that she had in some way contributed to her son's sense of well-being. She also wanted Frankie to partake in Holy Communion as rendered by the Catholic priest. Mrs. C. said that her religion "helped her to be more accepting of Frankie's situation because she had something to believe in." Knowing this, I was able to arrange for the priest to come and see Frankie every week.

When Frankie became increasingly ill and was placed in an oxygen tent, Mrs. C.'s hope began to wane. Whereas, at first, she expressed hope for the development of a new curative drug, her hope as the disease progressed was for one further remission. She began to live in a day-to-day basis. "When I just take each day as it comes, and do not think of what lies in the future, death seems further away," she commented.

Some of Mrs. C.'s strongest feelings in regard to her late husband came forth when Frankie was placed in the oxygen tent. She said that both her mother and her husband had died in oxygen tents

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and when Frankie was put into one. she felt that this was the end. As time passed, however, she appeared to become more accepting of the tent and spoke of it as being "life-saving," especially to the extent it kept his temperature down. Obviously, she was striving to adapt to this situation by looking for such reassuring elements as "his temperature is down." and "he can still get out of bed to sit in a chair." The fact that she was looking for hopeful signs at a time when Frankie's condition was deteriorating rapidly appeared to reinforce the conclusion that the period was one of hope for her.

Unlike the period of denial, this time was a sorrowing phase ; crying accompanied Mrs. C.'s expressions of hope. According to Engel, "crying denotes the development of awareness.. the reality of the anticipated death and its meaning as a loss begins more and more to penetrate the consciousness." The crying is a communication by the grieving person, a call for help to which his fellowmen must respond (10). Knowing why Mrs. C. was crying enabled me to indicate to her through verbal and nonverbal means, that I would be willing to listen to what was on her mind.

When the physician finally said, "Nothing more can be done to prevent Frankie's death from taking place", I began to experience a high level of anxiety. To defend myself against these feelings, I began to spend shorter and shorter periods of time in direct contact with both the patient and his mother. I withdrew. At one time it became especially anxiety-producing for me to allow Mrs. C. to communicate her feelings about Frankie's necrotic right arm, because to talk about his "dying" arm was, in a sense, the same as talking about him.

I realized that, in a sense, I was experiencing some of the same feelings of grief that Mrs. C. had experienced. My withdrawal from the situation was my way of attempting to deny the reality of the prognosis : "If I'm not able to see him dying, then it isn't going to happen." Once I became aware of my actions and, the reasons for their occurrence, I was able to begin to take steps to alter my behaviour.

Resolution

The onset of petit mal seizures, coupled with the physician's saying that nothing more could be done for Frankie, brought forth the terminal phase of Mrs. C.'s coping behaviour. She began the process of resigning herself to the inevitable outcome of his illness (11). At first, the feelings she expressed about Frankie contained overtones of ambivalence. For example, while talking to the priest, she cried, "My husband died here too. I guess I shouldn't say it that way. I still have hope." It appeared that to some extent, she had "pronounced Frankie dead," while still hoping he would live. Within a few days, however, she no longer expressed hope. Instead, she spoke about Frankie in terms of "wishing it were all over.', "If there were something that could be done to save him, I'd say let him live. But since nothing can be done, I don't want to see him suffer. I wish he would just die in his sleep".

Verwoerdt suggests that parents "are grateful for being with thier child as long as there is hope and as long as the child's suffering can be controlled. When hope is gone and suffering is the only prospect, parents wish to prolong life no longer" (12).

During the two weeks before Frankie's death, Mrs. C. began to exhibit some very distinct form of adaptive behaviour. There were almost no episodes of crying. Instead of being involved solely with Frankie, she showed a strong desire to comfort other dying children and their parents as well. By feeling sorry for and giving comfort to other grieving parents, Mrs. C. may have been able to temporarily reduce her preoccupation with Frankie and, in turn, receive some respite from the painful task of constantly having to dwell on his forthcoming death. While Mrs. C. showed interest in other children on the unit, she in no way physically abandoned her own child, and his need for psychologic comfort.

In the week prior to his death, Frankie spent most of his time simply resting. He no longer showed any interest in wanting to play with his games or toy cars. Mrs. C., therefore, packed most of his belongings and had them sent home. The day after she did this, she was able to verbailze her feelings about it and, as expected, they were expressions of gui t.

In helping Mrs. C. work through these guilt feelings, I knew it was necessary for her first to be able to express them. When she commented on the guilt she felt, she said, "I feel guilty because it's so final. It's like giving up before the end has come. It's saying good bye to him and he's still here." Reassurance was then given to her in the following vein : "It's quite human to feel that way. The important thing, however, is not so much that you had these thoughts, but more that you went ahead and did what you felt was best." In this way, Mrs. C. was helped to see that hostile wishes toward the sick are human and accceptable, and that thoughts and actions should be kept distinctly separated in her mind. Mrs. C.'s ability to begin putting away some of Frankie's belongings was indicative of a beginning in reintegrating his eventual loss.

One day Frankie came very close to death but did not die. That episode placed me in the most vlunerable position I had been in since begining to care for him. I experienced great difficulty in trying to deal with my own feelings of helplessness, anger and guilt. I felt helpless because I was unable to give him fluids of any kind during a time when he constantly pleaded for them but couldn't have them because he was having grand mal seizures every half hour. I felt angry because my wish for his

death had not come true and, yet, I felt guilty for wanting him to die. Quint points out that whenever "a patient takes a long time to die and is not camatose, the nurse is extremely vulnerable to feelings of helplessness, especially if there is uncontrolable pain or psychological distress for the patient. Under these conditions, the nurse may find herself caught in the double mind of feeling angry at the patient because he does not die, yet also feeling guilty for wanting death to come" (13).

My feelings in relation to Mrs. C. were of even greater intensity. According to Holsclaw's concept of professional involvement, "the distinctive feature is to enter into the meaning of the emotion without entering into the emotion itself...to participate with the patient in the meaning and impact of his situation, but to maintain a conscious recognition of one's part so as not to shift focus and begin to participate in the emotion" (14) For 12 hours, I had participated with Mrs. C., both physically and emotionally, in the meaning and impact of the near death of her child. While I wanted to stay with Frankie and his family beyond the 12 hours (I believed his death might come soon and I wanted to be there when it did), I realized that to do so would be at the expense of my own emotional stability at the expense of beginning to participate in the emotion itself. I had reached my saturation point in the giving of physical and emotional care to this child and his mother. I needed to withdraw from the situation for a period of time in order to replenish my resources.

I finally left Frankie and his mother at the end of the 12 hours, but did so with feelings of guilt. I felt guilty about leaving Mrs. C. at a time when I believed she needed me most.

In time, with the help of my preceptor, I was able to recognize my deep involvement with this mother and child and begin to work through my own feelings of guilt.

At 3.00 a.m., six weeks after his admission, Frankie died. The night nurse said he had died in his sleep, with his mother at his bedside. His mother had recited a prayer and had wept softly to herself. Although I, too, had wished for his death once he had reached the point of suffering, I too, felt the hurt when death actually came.

(Courtesy American Journal of Nursing)

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RAY'S APOLOGY

New Delhi : Mr. Satyajit Ray, the noted film Director, has said that he had at no point intended to cast aspersion on the profession of nursing, still less on the WBNS, as such, in his film *PRATIDWANDI* based on Sunil Ganguly's novel.

In a letter to the Secretary, TNAI, he said : "Bad people in novels, plays and films have always been shown as belonging to some profession or the other. There are numerous instances in Indian literature—notably in Tagore—of corrupt priests, school teachers, political leaders, doctors, barristers, business executives and so on. This does not mean that the writers set out to degrade these professions. Their aim —as that of any serious film maker —is to show all aspects of human nature, good as well as bad. Latika in the film represented an individual, not a prototype, and cannot by any stretch of imagination be said to be representative of the nursing profession. For that matter, both the hero's sister and his girl friend appear in his dream in the uniform of WBNS, with no hint of degradation about them.

"Latika episode, although a very brief one, is crucial to the film, and leaving it out would seriously upset the balance of the film."

Mr. Ray was replying to a protest note sent by Miss M. Philip, Secretary, TNAI, in which she demanded withdrawal of the film until the scene relating to the Latika episode was recast.

In a letter to Mr. I.K. Gujaral, Minister of State for Information and Broadcasting and the Chairman, Film Censorship Board, Miss Philip expressed concern at the way in which the nurse was protrayed in the film and said that whenever nurses or the nuring profession was included in a film the TNAI should be given representation in the Censorship Board with a view to ensure that "the noble profession" was not degraded. □