

[Review]

Terminal care for dying children

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Introduction

The need for terminal care for children arises due to cancers and congenital diseases. The terminal stage refers to the period when palliative treatments are given to dying children (Ozawa and Hosoya, 1997). Unfortunately, presently available palliative treatments may not be adequate to alleviate the painful conditions of dying children. Also, there are conditions which cause added burden to these children and their families (Nomaguchi et al., 1993 ; Sugimoto et al., 1994 ; Fujii et al., 1996 ; Saiki, 1998 b) : (1) judgment of the terminal stage differs among physicians ; (2) children's physical conditions often change suddenly due to their weak resistance to disease ; (3) liaison nurses, psychiatrists, and counselors in many Japanese hospitals are not sufficiently involved in the care of dying children and their families. These conditions can cause much worry and uneasiness.

This article reviews research on the terminal care of children in order to find how better assistance can be extended to dying children and their families. The papers reviewed were mainly those published from January 1989 to March 2000, but some earlier important papers have also been included.

The papers were classified into three categories ; (1) studies on the dying children's QOL (Quality of life) ; (2) studies on the dying children's families and bereaved families ; and (3) studies on nurses involved in the terminal care of the dying children. There are relatively few papers focusing on the nurses' awareness of the seriousness of terminal care and practice.

1. Studies on dying children's QOL (Quality of life)

These studies could be classified into two main types : (1) studies on physical issues, and (2) studies on psychological and social issues. Almost all of the former type suggest that pain control during the terminal stage is indispensable for the improvement of QOL. Studies of the latter type deal with the children's reactions and needs.

(1) Studies on physical issues

Bernadette (1997) suggested the following four points in the control of children's cancer pains : (i) the necessity of correct judgment of the degree of the pain caused by the disease ; (ii) the necessity of judgment of what should be restricted in daily life and the fear caused by pain ; (iii) the use of the WHO cancer pain relief program ; (iv) the use of non-medication treatment to promote not only pain control but also management of stress or pain accompanying progression of the disease.

In Japan, Kaneko et al. (1995) and Kasai et al. (1995) clarified the actual conditions of pain control of child

cancer patients with questionnaire surveys of pediatricians. Pediatricians were found to irregularly prescribed painkilling medicines for the patients and did not give them in advance, even to children who suffered from the sharp pain caused by cancer. Moreover, Takaya et al. (1997) and Ousaki et al. (1997) investigated the actual conditions for control of the sharp pain with questionnaire surveys of nurses, and reported that : (i) it took time to administer painkilling medicine to the patients after nurses had judged that the children were suffering from sharp pain ; (ii) no effective nursing care was available for non-medication treatment ; (iii) nurses did not have sufficient knowledge about the use of narcotic drugs and cancer pain relief programs based on the three-step ladder of the WHO Cancer Pain Relief (1986). These reports reveal that child cancer patients are subjected to conditions in which they are forced to tolerate sharp pain. Four reasons can be pointed out for this (Kasai et al., 1995) : (i) cancer pain can be effectively reduced by successful chemotherapy and radiotherapy administered before a certain stage of cancer development ; (ii) there are no commonly used, concrete methods for evaluating the sharp pains suffered by child patients ; (iii) cancer symptoms have often become irreversibly worse at the time when sharp pain management is applied ; and (iv) the method of pain relief varies depending upon the patients' age.

(2) Studies on psychological and social issues.

Bluebond-Langner (1978) interviewed 32 children of 3 to 9 years old who suffered from leukemia. She pointed out that the children had acquired much information which they had not had before being diagnosed. The information included the structure of hospitals, the medical system, the medical treatment, the prognosis, and the possible time of death. She also reported that the children, parents and medical staff all knew that the children's death could not be prevented. However, they acted and behaved as if children should continue to live by relying on their parents and medical staff, and thus tried to fulfill their responsibilities, i. e. children should grow up, parents should bring up children, and medical staff members should do their best to cure illness.

Martinson and Yi-Hua (1992) investigated the situation of 55 Chinese children who suffered from cancer. They pointed out that most of the 14 children who had little possibility of survival knew the name of their disease and felt its seriousness. These children expected the nurses to offer mental as well as physical care. For example, they said "Please stay with me," "Please encourage me more," "Please take good care of me," or "Please improve my daily life". This research by Martinson and Yi-Hua (1992) offers valuable information about children with malignant diseases. Also, their study deals with the children of the Peoples' Republic of China who share culture attributes with Asian children including the Japanese. In Japan, since notification of the name of a malignant disease is not yet common, there are only few studies on children suffering from such diseases. There are only a few papers reporting on the QOL of dying children.

Miyamoto (1994) studied ten Japanese children suffering from malignant diseases, trying to find how they understood the seriousness of the disease and adapted themselves to the condition of the illness. He reported the following findings ; (i) even if children are informed of the name of the disease, they understand very little of the mechanism of the disease ; (ii) children are aware of symptoms which they are able to link with their daily lives, depending on their cognitive-developmental stage, and try to cope with the symptoms ; (iii) children somehow adapt themselves to the condition of the illness, although they feel powerless about not being given the right to choose the medical treatments ; (iv) children think that their lives in the hospital are isolated ones which are completely different from their normal lives at home, and they always want to return home to live their ordinary lives ; (v) children want to be thought of as a human being rather than as a sick person ; (vi) they are deeply worried about the delay in their studies at school, no interchange with their friends, or possible changes in their appearances that could be caused by their illness or medical treatments, and (vii) they rely upon their families. Miyamoto's study (1994) shows that in response to the psychological and social needs of the children who have malignant diseases, we should respect what children intend to do and that hospitalized children should be allowed to live ordinary lives as much as possible. Practical ways to realize these points by the medical staff include : (a) allowing the children and their families to

come into mutual contact ; (b) arranging conditions that enable the children to enjoy interchange with their friends ; and (c) enabling the children to continue their school studies.

To realize (a) and (b), the nurses' judgments concerning child care are indispensable and should not be restricted to merely carrying out physician instructions.

Home care of dying children has been discussed by Martinson et al. (1978), Lauer et al. (1980, 1983), and Chambers et al. (1989). Their reports point out that home care for dying children has become common in the USA and Europe since the latter half of the 1970's and home terminal care can significantly fulfill the psychological and social needs of dying children and their families.

In Japan, the Department of Nursing of St. Luke's International Hospital and the Department of Pediatric of Hamamatsu University, School of Medicine Hospital have tried to promote home terminal care systems for dying children since 1990 (Hongou et al., 1993 ; Nishida et al., 1994 ; Oshikawa, 1994). Terminal care in the home for children in Japan is being developed through the efforts of these institutions. However, many issues remain because : (i) much is dependent on the individual efforts of physicians, nurses, and the patients' families. As no payment is expected for those physicians and nurses who are expected to be on 24-hour call ; (ii) the visiting nurse service in Japanese hospitals is not sufficient ; (iii) the cooperation is inadequate between the hospital where children receive medical treatments and the hospitals or clinics in the neighborhood of their homes ; (iv) there is no support system for families who care dying children at home ; (v) there is no evaluation method of home terminal care practice.

2. Studies on dying children's families and bereaved families.

The majority of studies on children's terminal care deal with dying children's families and bereaved families. This points to the importance of assistance with the psychological condition of families with children in the terminal stage and children's QOL.

Bluebond-Langner (1978) reported that the families who have dying children suffer from a feeling of powerlessness when facing their children who have little possibility of recovery. Mertinson and Bi-Hui (1994) investigated the reaction of 22 Chinese parents who had children at the terminal stage of cancer. It turned out that the medical treatment of childhood cancers is a great burden to the family and most families do not have insurance or health-care coverage from their place of employment. Therefore, families who have children with cancer are in great need of both financial and emotional support.

Tahara et al. (1994, 1995), Honma et al. (1996), and Sotoyama et al. (1995) investigated the reaction of Japanese parents who have dying children and pointed out that they have serious worries and uneasiness about their children's prognosis. In Japan, children are not usually informed about the diagnosis and prognosis if they have a lethal disease. On the other hand, in the United States, parents and dying children can talk openly about their illness (Hosoya, 1994 ; Kaneko et al., 1995 ; Fujii et al., 1996 ; Saiki, 1998 a). With respect to the role of nurses in caring for children at the terminal stage, the mothers consider the physical care to be satisfactory but not the mental care. They also consider the nursing care performed by the nurses to be inadequate. The mothers wish for ; (a) mental care of the dying children and also consideration about the health condition of their families ; (b) more allowance for nurse judgment in terminal care practice ; (c) a system for the practice of terminal care at home and (d) grief-work by liaison nurses or counselors. The mothers' concerns about their family relations and social support include housekeeping, child care, and the relationships among family members when three generations live together, the relationships with neighbors, and the issue of whether or not the mother should continue to work. The mothers also state that there are only few places where they can obtain information about social resources and where they can consult with liaison nurses or counselors on how to cope with ill children.

3. Studies on nurses involved in terminal care of dying children.

In studies on nurses involved in the terminal care of children, about half of the reports described nursing practice with some examples. Analyses were done using process-records or described using a nursing process. The reports described nursing practices in relation to the reactions of dying children and their families. What remains unclear is whether or not only the practices of the nurses influenced the results.

There are only few reports on such cases although there are some studies using questionnaires or interviews of nurses. Shiota et al. (1994, 1995) conducted a questionnaire survey on the actual conditions of nurses who take care of dying children in the terminal stage. The results suggested that the nurses feel a great responsibility toward the children and their families but also feel that they can not provide adequate attentive assistance. Furthermore, Shiota et al. (1994, 1995) tried to clarify the factors which influence nursing practice but found no detailed description related to the validity of the conceptual framework and question items in their investigation.

Descriptive work such as that of Nakajima (1993), who used structured interview guide developed in the United States, has been done concerning the role of clinical nurse specialists (CNS) in pediatric oncology and the factors affecting their practices in situations of ethical dilemma. The former includes recommendations for patients, supporters, educators and witnesses, and the latter presents the factors such as mutual support among pediatric oncology CNS (clinical nurse specialist) in their work and the need for recognition of their roles by physicians. As Japan does not yet have pediatric oncology CNS (clinical nurse specialists), such findings can be useful when planning future practice.

Saiki et al. (2000) interviewed 33 experienced pediatric nurses to find how they approach families who have children in the terminal stages of cancer. They pointed out that the nurses try to alleviate family anxieties and uncertainties. At the same time, they try to lead the families toward accepting the fact that they are losing their children and also encourage them to make their own decisions concerning their children's prognosis. When the children reach the stage very close to death, the nurses try to encourage the families to create "a peaceful passing away" situation. As the respondents in this research were the so-called expert's nurses, the results cannot be generalized to all pediatric nurses. However, this study offers indicators for developing nurse expertise in terminal care practice. What needs to be done is to clarify the factors which influence terminal care pediatric nursing practice in order to develop expertise.

Davis et al. (1996) interviewed 25 nurses in their study of grounded theory and showed that nurses struggled with both grief distress and moral distress when they recognized that a child's death was inevitable. Their distress occurred within the context of the nurse-patient relationship, and the nurses employed a variety of strategies to manage their distress. Their strategies are affected by several factors including their professional and personal conditions. This study is useful when considering CNS and chief nurses of wards who support those in terminal care nursing for dying children and their families. However, it may be difficult to apply these results for a conceptual framework to directly support nurses who work in terminal care because there is not enough detail on the nurses' strategies, such as those discussed by Davis (1996).

Hinds et al. (1994) compared the stress responses by new and experienced pediatric oncology nurses using of a structured interview guide. They indicated that experienced nurses showed a greater number of different types of coping reactions with remarkable results than new nurses whose common reactions are resignation and a passive attitude. Thus, not only the labor environment, which is an external factor, but also the nurses' personal factors, such as clinical experience, greatly influence the behavior of nurses. To help nurses control stress, there is a need to not only to improve the working environment but also to provide opportunities to improve clinical proficiency and perceived competency.

4. Future issues for studies on terminal care for dying children

This survey of past studies on terminal care for children has revealed the great expectations of nurses by the dying children and their families. Thus, the attitude of the nurses should be directly related to the QOL of the children and their families. Of great importance is the support from the chief nurses of the wards and CNS (clinical nurse specialists). Also essential is the study of nurse attitudes and the conditions influencing their work.

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