



Hsiao-Ling Lou, MS
Pei-Fan Mu, PhD, RN
Tai-Tong Wong, MD
Hsin-Chun Mao, MS

A Retrospective Study of Mothers' Perspectives of the Lived Experience of Anticipatory Loss of a Child From a Terminal Brain Tumor

KEY WORDS

Brain tumor
Child
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Background: The family of a child with an advanced brain tumor may undergo serious physical and psychological impacts as the child's conditions worsen. It is important for health professionals to understand the mother's experiences when facing a child with cancer recurrence or who is dying. **Objective:** A retrospective study using Husserl's phenomenological approach was used to explore the essence of the maternal experiences related to the anticipatory loss of families of a child with advanced cancer. **Methods:** Data were collected through in-depth face-to-face interviews. Colaizzi's method for analyzing phenomenological data was used to elicit an invariant description of the interviews' meaning. **Results:** Ten mothers were enrolled in this study. Five themes emerged: (1) losing hope of a cure, (2) encountering death, (3) establishing a protective role toward the child, (4) the intertwining chaos and strengths of family life, and (5) contending against death. **Conclusions:** These findings represent the experiences of mothers when facing the impending loss of a child and involve the dynamic relationships between the parents' belief concerning death, the parent-child relationship, the empowerment of family resilience, and maintaining the child's dignity. **Implications for Practice:** Nursing and medical staff need to develop a better understanding of each child's and

Author Affiliations: Taipei Veteran General Hospital (Mrs Lou); Institute of Clinical and Community Health Nursing, National Yang-Ming University (Dr Mu); Department of Surgery, Cheng Hsin General Hospital, and Faculty of Medicine, National Yang-Ming University (Dr Wong); and Health Science and Management, Chung Jen College of Nursing (Mrs Mao), Taipei, Taiwan, Republic of China.

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Correspondence: Pei-Fan Mu, PhD, RN, Institute of Clinical and Community Health Nursing, National Yang-Ming University, #155, Sec. 2, Li-Nong St, Taipei, Taiwan, Republic of China (peifan@ym.edu.tw).
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each family's belief systems with respect to treatment, their relationship, and their experience of being on the divide between hope and death, while at the same time caring for the family who is facing the anticipatory loss of a child with advanced cancer.

Knowing that their child is approaching death because of a brain tumor, families inevitably encounter anticipatory loss and have to prepare to bid farewell to the child in the future.¹ As the disease progresses, a child with an advanced brain tumor gradually experiences physical symptoms, such as a deterioration of consciousness, acute hydrocephalus, cranial nerve palsy, dysphagia, limb weakness, and excretion difficulties, which eventually lead to death.¹ Previous studies concerning children experiencing the advanced stages of cancer have mainly focused on family decision-making experiences,²⁻⁴ the nurse-patient relationship,⁵⁻⁷ the quality of life of the dying child and family,⁸ caring for the symptoms of advanced cancer,⁹⁻¹² palliative care for children with cancer,¹³⁻¹⁵ and care-related spiritual needs.^{16,17} However, studies have seldom investigated the nature of the mother's experiences when facing the anticipatory loss of a child due to a terminal brain tumor.

Loss is a separation and termination process whereby an individual is deprived of someone who is familiar or some part or parts of a person who is important to them.¹⁸ Rolland¹ defined anticipatory loss as the family's realization of the meaning of the disease and the process of facing the loss of their child in the future.¹ Parents of a child with advanced cancer experience ongoing loss and feel perplexed by how their child is experiencing death, disability, and suffering. Rolland¹ indicated that, when it is certain that a disease cannot be cured, family members develop a strong sense of uncertainty, together with an endeavor to construct a meaning for the disease, namely, the construction of family beliefs. It is obvious that a family's interpretation of the meaning of disease-induced disability and death will affect how the family members face anticipated loss. In Taiwan, mothers are the primary caretakers of child with cancer. Thus, understanding a mother's experiences of facing the anticipatory loss of a child due to a brain tumor should provide a blueprint for the experience process, from becoming aware of the limitation of treatment to the embodiment of the death of their child.

As the child's condition worsens, the family of a child with an advanced brain tumor is affected physically and psychologically.^{19,20} Kars et al²¹ used qualitative research methods to investigate the lived experiences of parents of a child with an advanced stage tumor. Even though parents inevitably have to face loss, they do not accept the death of their child. Saiki-Craighill²² investigated the transformation undergone by mothers of children with an advanced-stage brain tumor in Japan. The findings indicated that mothers reframed the meaning of life and death throughout the process. Zelcer et al¹⁵ used the focus group method to investigate the experiences of families of a child with an advanced-stage brain tumor. The findings were as follows: (1) owing to gradual deterioration in nerve function, the most difficult issue was that the parents were unable to use language to communicate with their children; (2) parents drew hope and strength from religious beliefs; (3) parents found that talking to

their child about death was a challenge; and (4) parents faced the predicament of palliative care at home.

■ Aim

A retrospective study using Husserl's phenomenological approach was used to explore the essence of maternal experiences related to the anticipatory loss in families where a child is suffering from advanced-stage cancer.

■ Methods

A retrospective study using Husserl's phenomenological approach was conducted to investigate the experiences at the level of consciousness without predetermined expectations. Phenomenology sets out to systemically adopt an open-minded attitude to facilitate reflecting on the experiences in terms of their integrity and nature through continual questioning, reflection, concentration, and intuition.²³ The findings are represented without establishing any predetermined stance or judgment in order to authentically demonstrate and probe various aspects of consciousness.²⁴

■ Participants

Because of the sensitive nature of the painful experiences felt by parents who have a child who is terminally ill with brain tumor, we used a retrospective study design. Purposive sampling was used to identify the participants. The inclusion criteria were as follows: (1) a mother of a child who had died within the previous 3 years due to a brain tumor and (2) a member of the Childhood Brain Tumor Association-Taiwan (CBTA-Taiwan). Ten mothers participated in this study.

■ Data Collection and Analysis

After the study was approved by the Research Ethics Committee of CBTA-Taiwan (94-000024), the secretary of the CBTA-Taiwan made a phone call to the potential participants to seek their permission for their personal contact information to be given to the study team. After the eligible participant indicated willingness to the study team to participate in the study, the first author arranged a time and location for a face-to-face interview. The interview of each participant started with the question: "Would you please talk about how you felt and how your family members interacted with one another when the doctor informed you that the tumor was too big for your child to undergo surgery, radiation therapy, or chemotherapy, and the only option was

palliative care?” Subsequent probing questions were guided by each participant’s narrative content with the aim of more fully eliciting further descriptions and elaborations of each mother’s experiences. The interviews lasted from 1½ to 2½ hours. Colaizzi’s²⁵ method was used to analyze the data obtained. Two researchers independently reviewed the transcripts line by line, dwelling on the information before identifying significant meanings. Furthermore, phrases and sentences with similar meanings were extracted to help formulate meanings. The aggregate formulated meanings were sorted into the subthemes, and the aggregated meaning subthemes were then sorted into themes as a means of exhaustively describing the participants’ experiences. Four standards of trustworthiness have been proposed by Lincoln and Guba,²⁶ namely, true value, transferability, dependability, and conformability, and these were used to achieve trustworthiness of the findings.

■ Findings

Of the 10 deceased children, 5 were male. The children experienced the onset of the disease between 1 year and 8 months of age to 14 years, with the majority between 6 to 11 years (n = 7). They experienced the recurrence of the disease at ages 2 to 16 years. The age at death was between 5 and 20 years. Among the 10 mothers, most were aged 34 to 55 years (mean, 42 years). Six of the mothers were college graduates. In terms of religious belief, most of the mothers were Buddhists (n = 8), 1 was Protestant, and 1 was I-Kuan Tao. The parents of the patients were all married.

The 5 main themes that emerged were as follows: (1) losing hope of a cure, (2) encountering death, (3) establishing a protective role toward the child, (4) intertwining the chaos and strengths of family life, and (5) contending against death (Table).

Losing Hope of a Cure

When parents realized that their child’s physical functions were deteriorating, their suspicion and fear of recurrence reappeared. Even if they experienced a loss of hope of a cure, they still grasped at the hope of life extension and were concerned about the quality of life that their child had. The 3 subthemes in this theme are

confirmation of their fear and desperation concerning recurrence, grasping the hope of life extension, and adjustment of expectations toward comfort care.

CONFIRMATION OF THEIR FEAR AND DESPERATION CONCERNING RECURRENCE

The recurrence of the disease completely shattered all their hopes, and their confidence in the hope of a cure collapsed. The forgotten shadow of death reappeared. Parents had undergone a setback with respect to saving their child’s life and now suffered from the pain associated with the coming of death and their separation from their child. They were fearful as they faced a future without their child and expressed a need to make their life meaningful after the child’s death. Although they had been psychologically prepared since the preliminary diagnosis of the disease, they still could not withstand the helplessness and desperation caused by the anticipated loss of their child. Mother (A) said, “When Director X. said that, I really felt helpless and frightened. I wondered if it was true that I could not save my daughter.”

GRASPING THE HOPE OF LIFE EXTENSION

When hope of a cure was shattered, leaving the parents with no choice and no potential way out of the situation, the parents were willing to try everything to save their children’s life, although they knew that all endeavors were in vain. They still prayed for miracles and sought any opportunity to extend their child’s life. Mother (B) said, “I tried everything I could to save my child at any cost. Knowing that my child was sick, I no longer cared about spending the money; I was willing to spend all my savings to save my child.”

ADJUSTMENT OF EXPECTATIONS TOWARD COMFORT CARE

In their unremitting effort to extend the life of their child, mothers started to understand that they had to accept death after they had tried everything; they eventually saw their child withering away. Parents were unable to withstand the suffering experienced by their child, and they chose palliative care to alleviate the child’s pain; at the same time, they faced the fact that their child was going to die. Moreover, they allowed their child to live the life the

❁ **Table • Themes and Subthemes of Mother’s Perspectives of the Lived Experience of Anticipatory Loss of a Child of a Terminal Brain Tumor**

Theme	Subtheme
(1) Losing hope for a cure	1.1. Confirmation of their fear and desperation concerning recurrence 1.2. Grasp the hope of life extension 1.3. Adjustment of expectations toward comfort care
(2) Encountering death	2.1. Communicating about death with a child 2.2. Children meeting death
(3) Establishing a protective role toward the child	3.1. Bearing the self-blame in order to manage the child’s condition 3.2. Keeping the child company in order to experience self-achievement
(4) The intertwining chaos and strengths of family life	4.1. Turmoil of family relationships 4.2. Empowerment through family resilience
(5) Contending against death	5.1. Negotiating over life and death 5.2. Obtaining a death with dignity 5.3. Bidding farewell to a child in pain

child wanted with the conscious hope that the child would be happy and satisfied. The whole family would keep the child company in order to sustain life's pleasures for the child. Mother (D) said, "I knew that it was her fate. We were sorry and felt helpless knowing that we could do nothing for her, but we accepted the truth. It is hard to define whether we spent enough time with her in her life. She left us, and I still cannot accept it."

Encountering Death

When the doctor confirmed that the tumor recurrence was incurable, the parents saw that their child would face death, and an atmosphere of death enveloped the entire family. The families were unfamiliar with death and feared death; as a result, the way the parents communicated with their children about death reflected their level of acceptance of the inevitable loss of their children as well as their belief concerning death. The 2 subthemes are communicating about death with a child, and children meeting death.

COMMUNICATING ABOUT DEATH WITH A CHILD

The confirmation of the disease being incurable was a pronouncement of death with respect to their child, which was cruel to both the parents and their child. Parents had no idea how to properly discuss death with their child, and they were helpless and frightened. Most of the parents believed that children of their age were not able to fully understand death, and they therefore did not give a detailed explanation about it. How each parent communicated about death with their child depended on the parent's acceptance of the limited life of their child. Some parents used indirect metaphors to tell their children that the disease could not be cured. As death was no longer a secret in the family, children were able to express their fear without any burden. Moreover, parents could assist them with their emotions to support them mentally. Mother (E) said, "I would sleep by his side at night and chat with him. He sometimes would say, 'Mom, I am very afraid of death. I am afraid of dying alone.' I would tell him that there was nothing to be afraid of because we all will die one day. He gradually accepted that. After the third recurrence, I frequently talked to him about death and described the world after death. I certainly told him about the bright side because I believe in Buddhism. I told him that there is still another world, and we will meet each other one day even though he would go there before I do."

CHILDREN MEETING DEATH

Children indirectly asked questions concerning death and their confusion or obtained answers from other people because they were afraid that their parents would feel sad. The sad face of their parent made them unable to pose their questions and express their fear of death; rather, they hid their fears and emotions, bearing them alone. The mothers noticed that their children were fully aware of the coming of death regardless of their age. Some children expressed their concerns about death, and others narrated their wills, even though they did not explicitly talk about their death. Some children mentioned that they feared being alone in their postdeath world. Mother (A) said, "She did not talk much about death with me. She tried not to talk about it because A.A. was aware of it all the time. I was very reluctant to have her silently

bear it alone. She told her older sister: 'Sister, this is for you because I may no longer use it in the future.' She spoke to her older sister in this way.... At that moment, her older sister had no idea what to say, and asked her, 'How is your body? How do you feel now?' Her sister told me that afterward. She answered, 'Sister, my situation is bad,' and ended the conversation."

When children knew that their life was limited, they made use of all their time to do what they wanted to do and cherished the time they had in order to live happily even though their physical functions were limited. The mothers mentioned that their children were pure and were braver and calmer than adults when they faced death. Children were able to overcome trying situations without dwelling on them. Moreover, they saw every obstacle as a stepping stone and appreciated the experience. Mother (F) said, "As far as I knew about my daughter, I think she was able to accept it in the end. I thought that we should not treat her as a 9-year-old child, but an independent living soul. She might not have mature thoughts in some areas or might not have the ability to respond to the world, but her attitude toward death seemed to be as mature as that of an adult."

Establishing a Protective Role Toward the Child

When parents are facing the loss of their child, they move through the process from being completely unable to manage the thought of their child dying and being full of self-blame through to being able to acknowledge that death will happen when their child says something about it that acknowledges the fact that they are aware of their impending death. They played a role as guardians of their child's health and provided spiritual support as they faced the fact that their child was going to die. Parents experienced 2 subthemes, namely, the bearing of self-blame in order to manage the child's condition and keeping the child company in order to experience self-achievement.

BEARING OF SELF-BLAME TO MANAGE THE CHILD'S CONDITION

Mothers blamed themselves for failing to provide their children with a healthy body and for negligence in taking care of them. They felt a responsibility to protect their child, and they felt an obligation to make decisions about medical treatments. They pushed themselves to be strong in order to monitor the changes that were occurring in their child's condition. Families began to treat the disease as a part of their life and coexisted with it. The parents would lift all the restrictions placed on their children with the aim of keeping them happy, helping them to fulfill their dreams and creating opportunities for personal achievement. Mother (F) said, "At that time, I was really alone. If I had not been strong enough, I would have failed to deal with anything that the future held. How could I help my child? I thought that I would do anything as long as it was beneficial to F.F."

KEEPING THE CHILD COMPANY TO EXPERIENCE SELF-ACHIEVEMENT

Mothers tried to leave behind all regrets in life. In the company of their child, parents encourage their child to experience self-achievement. During this process, they appreciated their child's

matured attitude and life values as they optimistically faced the threat of death. Nonetheless, they were aware of the impending death of the child. Mother (B) said, “The pictures she painted before she died were completely different from those she painted after experiencing the disease. In those colors, I could see the courage and tranquility in her mind; those colors were bright. She was brave, and she was spiritually free.”

The Intertwining Chaos and Strength of Family Life

When families are going to lose their beloved child, they found themselves experiencing a chaotic family life involving an intertwining turmoil of family relationships; this strengthened their resilience. The 2 subthemes are turmoil of family relationships and empowerment through family resilience.

TURMOIL OF FAMILY RELATIONSHIPS

Everything in the family was oriented toward the child’s needs and sustaining their life. Family relationships would become closer in order to provide the child with stable support and to keep them company as they faced difficulties together. However, as the disease progressed, parents needed to concentrate on taking care of the child and temporarily asked other family members to take care of their other healthy children. As death came, the parents were unable to help with the emotional collapse of other family members, nor could they take into consideration the feelings of their spouse; this led to an intense relationships between spouses. Mother (E) said, “I could not feel relieved, so I kept going to the hospital to see my child. I thought that my husband was careless, and he would take care of him in a rough manner, such as turning his body over. I did not like that. . . . We had a lot of arguments in the hospital.”

EMPOWERMENT THROUGH FAMILY RESILIENCE

Family resilience was more present during the final stages of the child’s disease, and this would bring a feeling of support to the family, making them more courageous and helping them to face their child’s death. The professional credibility and truth-telling of doctors, tolerance and sympathy toward the child’s parents, respect for the parents’ therapeutic choices, acceptance and consideration of the parents’ intention to save their child, and nurses being attentive to the child and caring for parents, together with a close family-like relationship, enabled parents to feel that the medical team was with them as they fought the child’s illness. Mother (J) said, “It lasted 2 years. I still remember every facial expression of Director X. a year and a half ago. The medical professionals had no idea how they affected us with a simple facial expression or gesture. They had serious influences on us.”

Psychological consultations provided by social workers and the resources of social welfare groups, which facilitated contact and experience exchange among patients, enabled parents to have support and warmth. The empathy and experiences shared with the families of other children helped parents find a safe emotional outlet and provided psychological support. Religion also endowed them with hope and provided a positive meaning for life after the children’s death; in addition, religion provided the children

with hope that mentally appeased them as well as providing a bastion against death-related fears and anxieties. Mother (F) said, “I found it miserable when my child experienced a recurrence. We went to Chung Tai World because we thought that the serenity of a Buddhist temple might be beneficial to her. I found peacefulness there (the Buddhist temple) and felt relaxed, which made me brave enough to face the future. Her disease condition rapidly and significantly declined. I took her to the old monk on September 1. She asked many questions, such as ‘Is there a heaven?’ The old monk answered, ‘Heaven is in your heart.’ The reply was helpful to her because she found her own heaven in her mind.”

Contending Against Death

During the course of fighting against death, the parents experienced the child’s death process. The 3 subthemes are negotiating over life and death, obtaining a death with dignity, and bidding farewell to a child in pain.

NEGOTIATING OVER LIFE AND DEATH

Although the family members did not want to accept the fact, they were forced to face the unchangeable fact that death was coming. As death approached, any change in the child’s condition made the parents panic, and they would constantly experience the torture of intertwined hope and desperation and as a consequence felt pain. Mother (B) said, “On that day, Dr Y. asked me to have a talk with him and told me that I had to learn to face death. That was 1 week or thereabouts before B.B. passed away. I could not tell my husband. When I took a shower that day, I sat on a chair and cried in the shower. . . . I could not bear it because I had no idea how it could be.”

At this moment, parents were afraid that their children would die at any moment and stayed by their sickbed all day long. Any slight change made parents collapse emotionally and led to the development of irrational behaviors. If their child’s condition changed unexpectedly, this made the parent’s emotions swing between joy and grief. Most of the parents did not give up on any therapeutic treatment until the final moment. Although they had learned to coexist with the threat of death every day, they still found it hard to live with losing a child and found it difficult to grasp how limited was time that their child had left. Mother (G) said, “I prepared every day, . . . I had to prepare for it very often. I was thinking what should I do and how I should deal with it when the day came. However, when I was mentally well prepared, it did not take place. In the end, I was unwilling to prepare for it. However, once he started to use an oxygen mask, I realized the day would come soon. His condition sometimes improved and sometimes worsened until the last week of his life. I had no idea which stage he was experiencing. I even would wonder whether he might survive to July. However, I knew it was impossible. I had the feeling that he was destined to pass away.”

OBTAINING A DEATH WITH DIGNITY

When parents realized that their child was undergoing only a meaninglessly extension of their life, they would not allow their

children to suffer by undergoing further treatment. They aggressively helped their child to understand about God (Buddha or Bodhisattva), reconstructed the attachment between their child and God (Buddha or Bodhisattva), and promised to meet again in the next life. This enabled the child to have psychological comfort and die more peacefully. Parents believed that when their children were in God's (Buddha's or Bodhisattva's) hands, their fear and the children's fear of being alone in their postdeath world were alleviated. Any separation between the mothers and the children would be temporal, and they would meet their children once again in a future world. Mother (D) said, "I told him that we have been making efforts so long; if the Bodhisattva intends to take you away, you should follow him without hesitation. He loved Bodhisattva and prayed to him every time he experienced pain until he fell asleep. I knew that he could pass away any minute. That was all right. We would pray for him, and Bodhisattva would come to take him away... I told him that he would be healthy and happy in heaven. He answered, 'Yes.'"

It was important for families to be with their child at the end of their life, and all the family members were expected to participate. While waiting for the onset of death, parents felt closely attached to their child. They were able to experience their child's fear and agitation because they were mentally connected. It was very important for the family to ensure that their child would leave the world peacefully.

BIDDING FAREWELL TO A CHILD IN PAIN

However, at the moment when death really took place, parents were astonished and were unable to face the fact that their child's life was over. The parents suffered from pain because of their endless helplessness and grief. However, to enable their child to die with dignity, they withstood sorrow and abided by folk custom rituals in order to complete their last mission of protecting their children. They bade farewell to their children with tears in their eyes and promised to meet once again in the next life. Mother (H) said, "I could not help but cry, even though I had been mentally preparing myself, when the moment came, I was just thinking how could it happen? It did happen. When I saw H.H. becoming different from how she used to be, I was very sad because she is my beloved one. It was really hard for me to accept the fact that she was... dead."

■ Discussion

This research describes the lived experiences of mothers when anticipating the loss of a child who was suffering from a terminal-stage brain tumor. In the beginning, they became suddenly aware of the recurrence, and the completeness of the entire family was menaced. All of the family expressed unfamiliarity, fear, hope, and courage as they jointly faced shattered hope and encountered death. Even though the relationship between the mothers and their family would become intense, each mother would still try to do her best to protect the child and to adjust family life according to the child's needs. In the end, they would jointly face the coming of the child's death.

In the Chinese culture, children are the future hope of parents and family. When hope of a cure is shattered, families face turmoil and agitation. Most parents seemed to struggle with the challenge of facing the reality of death and lost their sense of control in life. As they faced the setback in their children's treatment, they became aware of fear and desperation connected to the death of their child. This was linked to the parents perceiving the gradual decay of the child's neurological system, which represented to them the ambiguity of the child's life span. During the final stage of the child's life, recurrence or aggravation of the child's conditions contributed to parents experiencing intertwining feelings of hope and desperation. Psychologically, they were gradually accepting of the reality that they could not extend their child's life. When encountering death, they hid their grief in order to maintain the dignity of their child. Moreover, they gave their child into the hands of God (Buddha or Bodhisattva), bidding farewell and making a promise to meet once again in the next life.

The openness of communication between parents and children concerning the meaning and consequence of death relied on the parents' belief about death, the parents' perception of their child's understanding of death, and the children's perception of their parents' sadness. If death was no longer a secret in the family, children were able to express their fear of death, and parents were able to also console and deal with their child's fears in a timely manner; this enabled the children to find strength and an inward stability. Furthermore, the children expressed courage and innocence as they faced death. They sometimes hid their fear and sorrow when facing death as they did not want to make their parents feel sad; however, they would take some actions that expressed their courage when facing death and seemed to cherish their life more until the day they died.

While the families faced the loss of their child, their family life had both chaos and strength. This study found that increased external resources were able to enhance family resilience. Nurses became an energy supplier for the parents and children on the final journey of life. The company of nurses, paying attention to the child, and the sharing of care experience were also able to lighten the load on families. Moreover, when saying farewell to their child, religious feelings were able to guide parents toward a view where the life meaning of their child was positive. This also enabled the children to experience an inward peace, to let go of the fear and anxiety associated with death, and to prepare for the future. In terms of bidding farewell to children, funerals were able to heal pain and make families feel more comfortable and safe.^{16,17} There are some limitations to this study: the sample was limited to children whose parents were members of a brain tumor family association. Furthermore, the information gathered was retrospective and thus relied on the participants' memories of their experiences.

■ Implications

When mothers are suddenly informed of a disease's recurrence, it is important to evaluate the child's physical functions and to identify physiological and pathological means of alleviating their concerns. Moreover, it is necessary to understand the mothers'

attitude, to listen to them, and to support them and their families. When they have access to clear information on the disease, the parents are then able to choose a hospice or advanced treatment for the child. It is important to relieve the mother's feelings of guilt and empower them in their protective role toward their child; this can be done by showing respect to mother's efforts and hard work, approving the attention they are paying to the child in the hope that their child will survive, improving the parent-child relationship, and emphasizing the importance of alleviating their child's pain.²⁷ When parents and families accept the fact of their child's inevitable death, the parents' sorrow at losing their child should be recognized, and information related to the process of palliative care should be provided. Owing to unfamiliarity with and fear of death, understanding the child's and family's acceptance of death, together with their readiness to communicate about death, should help with planning how to provide the parents with concrete suggestions on coping with the separation as well as on how to show respect when they explain the situation to their child. The parents should also be encouraged to discuss the issue of death with any other children in the family, to understand the behavior of the children with disease, and to realize the current status of the family. When children fall into a coma, most parents believe that the children still have feelings; hence, guidance should be provided to the parent or family on providing palliative care. The parents' religious or ritualistic needs should be respected and supported, especially the belief that their child will be in God's (Buddha's or Bodhisattva's) hands and that the parent-child relationship will continue in the next life.

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