Research Article



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Experiences of mothers who have children with cancer in the event of loss of their children's friends with similar condition: A qualitative study

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Abstract

Background: Although the psychological difficulties of parents of children with cancer who have lost their children have been observed and studied, there are limited studies regarding the emotional effects on parents of surviving pediatric cancer patients who have lost their friends to similar conditions. The purpose of this study was to understand the experiences and identify the support needs of mothers of children with cancer who have experienced the death of another patient who participated in activities in the playroom and received cancer treatment in the same room at the same time.

Methods: Between March 2016 and April 2017, semi-structured interviews with parents of children with cancer were conducted to explore emotional changes, thought processes, and actions taken when their child's friend passed away. Seventeen mothers of children with cancer who had experienced death of their children's friends with similar conditions were recruited from four different hospitals in Japan. Transcripts of the interviews were thematically analyzed using the grounded theory approach.

Results: The analysis produced four domains: "Fearing and Grieving Death," "Considering the Best Support," "Sharing Grief," and "Neglecting the Event and Focusing on Caring." Considerable emotional changes were observed when the mothers had to face the death of their child's friend. Multiple participants observed that opportunities to address their emotions are particularly helpful.

Discussion: Health care practitioners should attend to the emotional needs of parents of children with cancer who have lost a friend and help them develop coping strategies to manage these emotions.

Introduction

Although recent improvements in the medical field have prolonged the survival of children with cancer [1,2], the mortality rate remains at 15% [3]. In 2015, 449 malignant neoplasm-related deaths occurred in Japan in patients aged ≤ 19 years [4], most of which occurred in hospital. The failure to reduce lengths of hospital stays is a deep-rooted problem in Japan. Due to the lack of childhood home care provision in Japan, the majority of childhood cancer treatments are provided in hospitals, regardless of the severity of the disease, creating an environment in which life and death co-exist. Since 2014, 15 medical institutions have been designated as pediatric cancer care hospitals, aiming to provide enhanced quality of treatment and support. These pediatric cancer care hospitals focus on treatment of relapse, which often results in death. Previous studies on the quality of life (QOL) and coping with death among children with cancer have predominantly focused on children with end-stage cancer and their families [5,6]. Illness uncertainty, but not illness attitudes, demonstrated a direct effect on parent-reported child's general quality of life [7]. Parental mental status and attitudes affect a child's quality of life. Therefore, caring for parents' grief is important.

There are limited studies on the experiences of mothers who have hospitalized children with cancer in the event of loss of their children's friends with similar conditions; therefore, the factors required to improve QOL of such mothers have been rarely explored. Because the death of children in hospital is considered a taboo topic, hospitalized children are often not informed of the death of their peers. Previous studies have reported that children with cancer can vaguely sense the meaning of an empty private room where another pediatric cancer patient was admitted if they experience the situation multiple times [8].

In addition, although children with cancer can sense the death of their friends, based on the condition, symptoms, and/or changes in the atmosphere inside a ward, they are hesitant to ask nurses and parents about it because they assume that the true reason will not be disclosed to them or that it is upsetting to nurses and parents [9]. Although a previous study has suggested the importance of providing high-quality and accurate information to children with cancer in a timely manner [10], such children in Japan often deal with the anxiety and fear of death alone—without speaking to anyone openly. Parents choose when and how much of the illness-related information should be shared with their children [11].

Health care practitioners (HCPs) understand the need of providing grief care to children with cancer who have lost their friends to cancer;

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however, HCPs face difficulties in providing appropriate support due to the sensitivities in the situation, such as the decisions to disclose the death of their friends [12]. In practice, the nurse will modify their interactions with children about the loss of a friend to suit the parents' wishes [13]; thus, the parents of children with cancer play a key role in shaping nurses' actions.

When a child is diagnosed with cancer, the parents go through a painful experience of overwhelming shock [14,15]. Studies have reported that parents of children with cancer can be in a chaotic condition at the time of diagnosis, facing depression, anxiety, and insomnia while readjusting the family functions [16]. Parents often believe that they are the best person to discuss the illness with their children [17]; moreover, they have to manage complex issues such as providing support for the physical and psychophysiological needs of their children, making decisions on medical treatment strategy, and fulfilling additional responsibilities of communication, for which they are not prepared and which add a great burden on them as they have little or no assistance [18]. There are limited studies on the experience of parents of children with cancer who lost their friends to pediatric cancer, though such studies may help to identify the support needs of these parents. Therefore, this study aimed to explore the personal experiences of parents in such situations to understand their needs and identify appropriate coping strategies.

Methods

Ethical considerations

This study was approved by the ethics review committee of the graduate school where the researchers worked. In addition, in a situation where a doctor or a child life specialist was needed, this study was also approved by the hospital's ethics review committee. The parents received both verbal and written information about the aim of the study and were told that participation was voluntary, that they had the right to withdraw from the study at any time, and that all data were confidential. The investigators assured participants that the contents of the interviews would not be communicated to the child or the child facility specialist who referred them. The voice data were anonymized and transcribed.

Data collection

We recruited participants from March 2016 to April 2017. The inclusion criteria were as follows: (1) parents of children with cancer who experienced death of their friends who were admitted to the same hospital during the same period <5 years previously; (2) parents of children with cancer who were receiving current outpatient therapy or had completed chemotherapy treatment; (c) parents of children with cancer who were not in a terminal stage of their disease. Participants' demographic details are summarized in Table 1.

All participants were recruited from outpatient settings and were screened by the primary researcher. The participants were recruited through an invitation letter handed out by pediatric cancer experts (physicians or child life specialists) in four facilities, of which two were urban pediatric cancer care hospitals, one was an urban university hospital, and one was a rural university hospital. A total of 25 individuals were invited, of which 17 responded with the first consent to be contacted by the investigators and be formally introduced to the research objectives. The researchers contacted the participants via telephone or email and explained the research objectives. After the official introduction of the research by investigators, second consent was obtained from all 17 participants to be included in the analysis. The logistics of the interviews were explained to participants, followed by their signed consent. Though both mothers and fathers were invited, only mothers participated (This was because it is generally the mothers attend treatment with their children.). The interviews were conducted at the homes of participants or in hospital examination rooms. Interview times varied between 30 and 120 minutes. All interviews were conducted by the primary researcher who is a female nurse RN M.S.N., using a semi-structured interview method based on a discussion guide (Table 2). The principal investigator has a lot of experience in interviewing mothers. The interview was recorded with the permission of the participants and transcribed. The interview made field notes after the interview. The summary of the interviews was communicated to the participants via mail or email for their confirmation. and confirmed any unclear points. Therefore, the face-to-face interview was conducted only once.

Table 1. Participant demographics

No.	Sex	Cancer type	Age at discharge	Hospitalization period (months)	Announcement of death	No. of friends who died
1	Male	Leukemia	14	14	Yes	4
2	Female	Ewing sarcoma	13	30	Yes	13
3	Male	Leukemia	13	12	Yes	6
4	Male	Malignant lymphoma	6	6	Yes	3
5	Female	Leukemia	16	60	Yes	8
6	Female	Germinoma	8	7	No	3
7	Male	Neuroblastoma	15	12	No	6
8	Male	Leukemia	10	6	No	1
9	Male	Leukemia	7	5	Yes	5
10	Female	Leukemia	8	6	Yes	5
11	Male	Leukemia	16	15	Yes	2
12	Male	Leukemia	8	7	Yes	1
13	Female	Leukemia	19	16	Yes	2
14	Female	Leukemia	6	8	Yes	1
15	Male	Leukemia	13	12	No	2
16	Female	Leukemia	6	11	Yes	2
17	Male	Malignant lymphoma	7	24	Yes	4

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Table 2. Interview questions related to the death of the children

1. How did you feel when your child's friend died?				
2. How did you communicate with your child when your child's friend died?				
3. How did you respond to changes in relationships with your child and family?				
4. What sort of things helped you?				

Table 3. A description of categories and subcategories

Category	Subcategory					
Fearing and grieving death	Deep sorrow	Confronting death				
Considering the best support	Identifying the need to disclose death	Predicting the ability of children to accept death	Consulting with others			
Sharing grief	Having capability and commitment to share grief	Empathy	Realizing the feeling of their children	Not being able to assess the feelings based on the reaction of their children		
Neglecting the event and focusing on caring	Being absorbed in caring	Keeping a distance	Telling a lie	Searching for differences		

Data analysis

We used the principles of grounded theory with the goal of eliciting salient categories and concepts within communication surrounding diagnosis and treatment [19]. Two researchers reviewed transcripts sentence-by-sentence and labeled categories. When there were differences in interpretations, discussions were continued until the researchers reached consensus. Trustworthiness of the analysis was attained through two researcher meetings and full agreement on the final categories. Saturation was confirmed when no new categories appeared.

Results

The analysis on mothers' emotional changes, thought processes, and actions taken in the event their children lost a friend produced four domains: "Fearing and Grieving Death," "Considering the Best Support," "Sharing of Grief," and "Neglecting the Event and Focusing on Caring." These four categories were further divided into subcategories as shown in Table 3.

Fearing and grieving death

Mothers of children with cancer felt deep sorrow about the loss of their child's friends, largely due to the realization that their child, too, may not beat the cancer. Although they sometimes felt guilty for such thoughts, some mothers were desperate to look for any difference between their children and the children who had passed away, such as differences in treatments, recurrence, types of diseases, etc.

Deep sorrow: When mothers of the children with cancer had to face a loss of the friends of their children, they demonstrated concerns for the remaining family members, including deep sorrow. Some attended the funeral or visited the grave.

I wonder why the child had to pass away while everyone hoped that he would recover. He tried his best. We all know that his parents and his older brother also tried their best to support him, but he wouldn't make it. God can be cruel [16].

Confronting death: Mothers were forced to confront the reality that their child might die when they witnessed the death of their child's friends with cancer. Particularly at the time of the first death of a pediatric cancer patient after the child's hospitalization, mothers were terrified that their child might die. Some mothers had difficulty in accepting the reality that their child's friend had passed away, whereas some became apathetic.

The death of my child's friend reminded me of the reality that pediatric cancer may be fatal. Till then, I had vague distant view of death and seeing the child actually die from cancer was a terrible shock. The thought that the same thing could happen to my child terrified me. I was depressed for about a week or so [4].

Though I did not hear about the fact that the child has passed away, a part of me sensed it. But I didn't want to admit it; I was not ready to hear. I wanted to believe that he was still alive and fighting with cancer in ICU or some sort [2].

Considering the best support

Even in the shock of the death of other children with cancer, the mothers focused on ensuring that their children received treatments in the best possible environment. To judge if they should tell their child about the death of the friends, the mothers considered the psychological aspect of the children as well as the relationship of their children with the child who had passed away. They also considered their view of whether their child could emotionally handle the grief. The mothers were also concerned about the affirmation and support they might get from others on their particular decision about disclosure.

Identifying the need to disclose death: The mothers decided to disclose about the death of their child's friend based on the children's relationship, whether their child had sensed his or her friend's death, if they had unwittingly acquired the information from others, or even whether their child could learn from the friend's death. Some mothers believed that their children had the right to know the death of their friends so that they could properly bid them farewell.

I thought that I should tell my daughter (about the death of her friend), she will know the truth sooner or later. My daughter and the child who passed away were very close friends since they were admitted to the hospital. I thought that she would appreciate the chance to bid farewell. It is up to the parents whether to inform their children on the loss of their friends, but I decided to tell her because I think my daughter had the right to know [16].

Predicting the ability of children to accept death: Mothers are afraid of their children imagining death after hearing about the loss of their friends. They predicted the ability of their children to be able to handle the loss of their friends based on the child's reaction at the time of their own diagnosis and/or how they had dealt with their own disease and treatment.

After all, a friend's death makes children imagine their own mortality. Especially if those friends who passed away had the same disease, children get terrified of the potential of death. They might get upset and cry. I would not tell the truth if that makes my child worry about his own death [5].

Though my son is at an age that he can separate himself to what happened to his friend, I did not think he was ready to control his fear of death. That is why I did not tell him (about the death of his friend) [15].

Consulting with others: Mothers often consulted with others, such as other mothers who had the same experience, medical personnel who knew their children well, and their husbands, to determine whether they support the decisions of disclosing/not-disclosing the loss of the child's friend, and whether they could help support the child after learning about the death of their friend. No mother disclosed the fact when the person consulted did not support the idea of doing so; i.e., they took the consultation very seriously.

I opposed my husband (to the idea on disclosing the death of our son's friend). After our son's discharge from the hospital, my husband is the only person I can consult with. He said if our son attends the funeral of his friend, he would be devastated and think that he himself is going to die. I thought about telling my son the truth and bringing him to the funeral without telling my husband, but I had qualms about that idea. If I decided something on my own, and something goes wrong, I would not be able to accept full responsibility [8].

Sharing grief

The mothers shared their grief with their husbands, the mothers of the child who passed away, and even their own child. However, the mothers were afraid that the child would be afraid of death but still wanted to know what their child thought of their absent friend.

Having capability and commitment to share grief: The mothers' capacity to deal with their child's sorrow after learning about the loss of their friend was analyzed. However, mothers who were afraid to face their child with the fear of death, or who were afraid to hear the child's true emotions, could not analyze their ability to cope with their sadness; in other words, they were in denial about their own feelings.

Even if my child got upset at the funeral, I thought I would be able to help him out [8.].

My daughter had become a Christian just five days before she was diagnosed. I felt at ease as I thought she was to discuss these sensitive matters (about her friend's death) while looking on the bright side, and that was good. However, I found it difficult to discuss my daughter's friend's death with her since I have not come to terms with the death of her friend myself [5].

Empathy: The mothers shared memories of the friends of their child who had passed away and visited the house of the child who had passed away. They also shared sorrows with their husbands and other mothers who had the same experience.

My child often talked about "the friend" who passed away to me. She talked about her friend's favorite things and the memories of playing together. By doing so, I and my daughter reaffirmed how important her friend was to us [2].

When a mother cannot bring herself to tell her child the bad news, the only thing she can do is to talk with other mothers. We found solace in talking to other mothers. We would not talk with our husbands, because we thought it would be a futile effort [5]. **Realizing the feeling of their children:** The mothers were trying to help their children face the death of their friend, and they understood their children's feelings about their loss through their remarks and behavior.

It was good that I took my daughter to the funeral of her friend. I believe that it helped her to sort out her feelings and move forward. I thought this might be too much for a second-grade child to bear, but I realized she was much more thoughtful and perceptive. My daughter said she was afraid but wanted to say a final goodbye to her dear friend [16].

Not being able to assess the feelings based on the reaction of their children

Some mothers did not know how to assist their child when they did not express their feelings very much in the face of their friend's death.

I don't know how my son took the news. Definitely, it must have been a shock to him. Because he is sensitive, even though I am his mother, it was hard for me to understand what is going through in his mind [9].

My daughter would not talk about the loss of her friend even when I asked her how she felt. So, I decided not to pry her anymore. It seems that she was able to discuss it with other friends, so I thought that it was enough for her [2].

Neglecting the event and focusing on caring

Some mothers found it hard to accept the fact that the friend of their child had passed away because it reminded them of the possible death of their own child. They then tried to focus on taking care of them.

Being absorbed in caring: Some mothers tried to not focus on their feelings of concern, as they were too intense. Admitting the death of a child's friend indicated that the mothers felt their own child was about to die. When the mothers focused on taking care of their child, they were able to overcome the fear of losing them.

Most children returned home with successful treatments, and almost all the children who passed away had experienced recurrences. That's why the fear of recurrence was overwhelming. The word "recurrence" is so heavy. It made me break down in tears. This situation came in waves. I kept thinking to myself what if my child had a recurrence too; I knew it was not helping. I tried to believe that my daughter would be fine [6].

Keeping a distance: Some mothers focused on caring for their child in order to maintain a distance not only from the mother of the child who had passed away, but also from the mothers of children with cancer who were still in treatment. They hesitated to contact mothers, particularly those whose child had passed away, because they could not find the right words to say.

I try to convince myself that all kids discharged from the hospital are doing just fine. I have been avoiding contact with other parents because I am not very keen on learning what has happened to their children. I greet them when I meet them at the outpatient ward, but that's about it [13].

Telling a lie: Even though mothers suspected that their children were aware of the death of their friend, they did not disclose it to them. Mothers seemed to be afraid to face the grief of their children. Not mentioning the subject of their friend's death was a way for the mothers and their children to forget the fear of relapse.

Because our children have no way to contact each other, my child would not know that they have passed away. But because he has not seen them at the outpatient clinic for a while, I do not know if he sensed something or not. Maybe, I am too busy to care enough, or rather, I am too afraid to find out how he is feeling [13].

Because the experience of losing someone (who she knows from hospital) to cancer would give my daughter the fear that she could die, I absolutely did not want that to happen to her. I didn't want her to realize that her disease could be fatal [6].

Searching for differences: Mothers looked for differences between the child who had passed away and their own, for example, in terms of treatment strategy and recurrence, although they were ashamed of searching for such differences.

It is terrifying to see the child with the same disease as my kid pass away. I looked for the differences of them from my kid, like my son is in remission from chemotherapy or even if recurrence happens, he can still try bone marrow transplantation. I tried to see the bright side although I knew I was running away in a bad manner [4].

Discussion

Recruiting participants was one of the most difficult processes in this study, as loss of children is a taboo topic to discuss in public in Japan. Participating in this study was the first opportunity for some mothers of children with cancer who had lost their friends in the hospital to pediatric cancer to discuss their experience. This research demonstrated that the mothers were constantly considering the best support possible for their children while going through a period of grief and fear of death themselves. They received support from their peers (the other mothers of children with cancer), their husbands, nurses, child life specialists, and hospital schoolteachers. The analysis indicated that the subsequent course of the mother-child interactions was strongly influenced by the assumptions of mothers regarding the ability of their children to accept the death of their friends and their confidence to be able to share their grief with their child.

Ability of children to accept the death of their friends

As mothers were confident that they are closest to their children, they believe that they have the appropriate insight to assess whether the children are capable of accepting the death of their friends. Mother's indicators of the assessments were comprehensive and included age, the course of the treatment that children had experienced, further treatment plans, and children's understanding of their diseases including the disclosure of cancer. This judgment seemed to be influenced by the mothers' own grief. They thought that their child would feel the same, as they reflected on death of other children with cancer and considered the possibility of their own child's death.

At several hospitals in Japan, parents' attendance at pediatric cancer in-patient treatments is obligatory at a certain stage of childhood cancer treatment. By spending time together all day with their children, the mothers and children form a bond similar to that in infancy [20,21]. However, parents believe that adolescent children are psychologically unstable and tend to suppress thoughts and feelings, so it is risky for someone other than a parent to let them know the death of a friend [22]. Mothers of adolescent children experienced difficulties in assessing the ability of their children to accept the changing situations and felt that follow-up engagement was challenging. Due to contradictory information from peers during hospitalization and growing psychological independence, the mothers judged the ability of their children to accept the death of their friends to be low. For similar reasons, some parents strongly hesitated to disclose the true diagnosis to their children. Meanwhile, the importance of peers has been recognized

in children's ability to cope with the death of a familiar person [23]. It is easier for children to express their emotions to peers, especially those who do not want to express such emotions to their parents or adults [24]. Parents or family members are not the only people to whom children express their emotions.

Through optimal "grief care," the death of friends of children with cancer can be an experience that can strengthen their will to live. It is important to provide mothers with confidence so that they and their children can obtain the necessary care and support. Such care and support will help parents and their children accept the death of the child's friend. Safe places to discuss grief or death are few in Japan. Nurses may offer such opportunities or introduce existing groups to patients and parents. Abilities of HCPs to provide grief care should also be strengthened.

Confidence in capacity to share grief

The death of children with cancer who were friends of their own children made mothers further realize the severity of the disease of their own children and lower their expectation of recovery. They desperately tried to find differences between their children and children who had passed away in order to rebuild the hope for recovery. Without hope for recovery, they were not confident enough to face the grief of their children. Parents tended to think that what they believe to be the best course of action is the best for their children. In the case of pediatric patients with cancer, which is sometimes associated with death, the best interests of the child (Art. 3, Convention on the Rights of the Child) may be replaced by the parents' subjective or value-based opinion of what should be good for their children [25]. Some mothers did not disclose the loss of friends to their children no matter how many of them had passed away. They could not rebuild the hope for their children's recovery due to the death of other children with cancer. Thus, they felt that information about the loss of their children's friends was unnecessary, as it could also affect their own children's hope for recovery. This situation is similar to the situation of when and how parents disclose diagnosis and prognosis [11]. However, the method of disclosure tends to depend on the individual needs of children and parents [26]. The mothers sometimes felt they were not prepared enough to tell their children the truth. In most cases, the mothers felt that they had no assistance on how they could communicate the diagnosis to their child [18]. Therefore, parents have the burden of determining the appropriate amount of information to share with their child [18]. HCPs play a supporting role in reducing the burden of parents who feel responsible for conveying information to their child and other family members [27,28]. HCPs also play a role of coordinating parents' preferences and children's best interest such that they can share their goals. None of the 13 mothers who disclosed to their children the loss of their friends was strongly confident from the beginning that she was capable of sharing the grief with her child. Rather, as they watched their child's reactions, the mothers became more confident in supporting them during the course of the event. They also gained confidence through input from HCPs and other mothers, who assured them that their children could receive appropriate support from other adults in addition to themselves. This survey showed that the mothers of children with cancer struggled with their own grief and fear of death while constantly trying to provide the best support for their children.

It is challenging for doctors to provide information including disclosure of true diagnosis to children with cancer without consent of parents in Japan because of its culture [29,30]. To provide a therapeutic environment to children with cancer, it is necessary for their parents to feel comfortable first, through appropriate grief care. This study reveals that no mothers received grief care from their HCPs. However, none of them insisted upon support. This indicates that the HCPs failed to recognize the mothers' grief and did not feel the need to care for them; it seems that those mothers thought any expression of need for care of their sorrow were inappropriate. Therefore, HCPs should be alert about paying attention to the grief of mothers of children with cancer who have experienced the loss of a friend of their child.

Limitations

This study only included mothers who had children in a relatively stable condition. Therefore, future studies should include mothers who lost their child and investigate their experiences and the significance of the death of their child's friend. Furthermore, analysis including all family members should be performed to identify the differences in the response to losing a friend of their children to cancer to provide appropriate individualized support. Moreover, a separate study focusing on the child's own experience should be conducted. Also, because this study was conducted in Japan, the generalizability of the results is limited. We also need a comparison with other countries with fewer taboos on this topic.

Conclusion

HCPs must provide close support to mothers who need care to ease their sorrow and fear of recurrence and potential death of their own children who have experienced the loss of their friend due to similar conditions. Supporting mothers to cope with such events and establishing a good relationship with them will mark the beginning of genuine support for children with cancer who have experienced death of their friends.

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