

# Palliative Care for Children and Grief Care for Families: Practice, Research and Education

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## Palliative Care for Children

### 1. Background of Children with Severe Illness in Japan

In Japan, advancements in medical technology have made it possible to save the lives of children with severe illness, improving both the curative rate and survival rate of various illnesses. However, an increasing number of children with serious illnesses and disabilities are receiving medical care with ventilators, aspiration and tube nutrition.

While hospitals can treat diseases, children who are continuing to grow and develop with these diseases or disabilities face, many limitations and restrictions, impacting the quality of life of children and their families.

Children who are ill and are receiving such medical care at home are inadvertently placing a huge care burden on their families. As such, there is also much concern about how this could influence the growth and development of their siblings.

The current system and resources available to support such children and their families are not sufficient. The challenge we are faced with is thus ensuring these children are able to grow and develop in spite of concurrent serious illnesses and disabilities, and supporting their families.

Therefore, my goal was to improve the QOL of children with life-threatening conditions and their families in Japan, by adopting the concept of child hospices that originated in the UK.

### 2. Children's Hospice and Palliative Care for Children

The first children's hospice in the world was established in 1982 in the United Kingdom. Currently, there are more than 50 children's hospices in the UK, more than 10 in

Germany, Australia and Canada. Children's hospice is a place where palliative care is provided.

"Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life and death. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks, and care through death and bereavement." [1]

Palliative care focuses on children with life-threatening conditions (LTCs) and life-shortening conditions (LSCs), which are divided into four types [2]. These conditions include diseases such as cancer, heart failure, cystic fibrosis, Duchene muscular dystrophy, mucopolysaccharidoses and severe cerebral palsy etc.

Children's hospices not only provide physical care for children with LTCs and LSCs, but also ensure the children are able to play and undergo various experiences, as well as providing family care and bereavement care. The ultimate goal of pediatric palliative care is to provide the best quality of life for children with serious diseases and their families.

In Japan, hospices for adults started in 1981, and national medical insurance has been applied since 1990. However, there are only a few hospices for children and although the need for such institutions is finally beginning to be recognized, none have all the functions of children's hospices.

In addition, children's hospices in Japan are mainly supported by activities from voluntary organizations where insurance is difficult to obtain, unlike in adult hospices. Consequently, I hope to establish a hospice for children with LTCs / LSCs and their families in Fukuoka, Japan.

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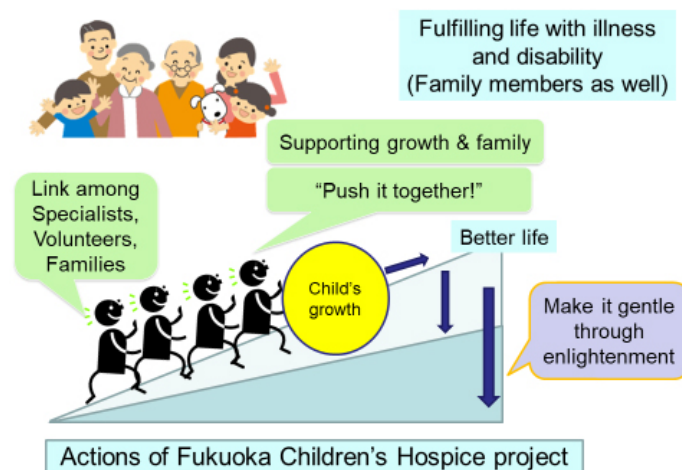
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### 3. Activities of Fukuoka Children's Hospice Project

We started the children's hospice project in 2010 in Fukuoka, Japan, then continued as a Nonprofit Organization in 2014. However, given the difficulties of creating a children's hospice, we started with smaller step-wise goals. Our project consists of four aspects: 1 research, 2 education and enlightenment activities, 3 events for children and families, 4 networks. Firstly, we studied various children's hospices in Europe, compared similarities and differences of the medical and social systems between UK and Japan, and clarified the current situation of children with LTC in Japan. Next, we organized public forums in Japan to raise awareness and clarify misconceptions about pediatric hospices. Furthermore, we continue to hold various events for children and their families several times a year for them to enjoy. Additionally, we cooperate with organizations in other areas, such as through charity runs, information exchanges, and holding a children's hospice summit in Japan.

Our activities can also be described as a form of health promotion for children with severe illnesses or disabilities and their families. Figure 1 compares the activities of the Fukuoka Children's Hospice Project with the concept of health promotion [3].

I believe that educational activities such as forums and study sessions will enable our society to better understand the situation of children with severe illnesses. Such events and exchange activities for the children and their families will help to support the growth of the children together with their families, professionals and volunteers.



**Figure 1.** Actions for children and families as health promotion.

## Grief Care for Families

### 1. Child's Death

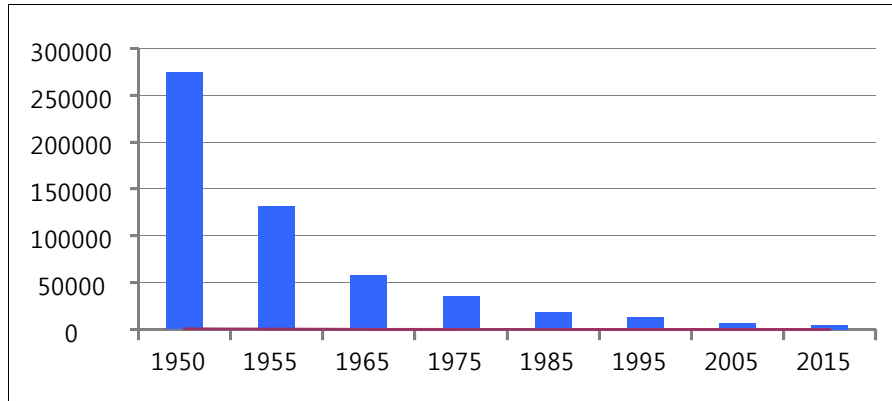
While there are more children living with serious illnesses and disabilities, there is a limit to what current medical technology can do. The number of deaths of children under 19 years of age and mortality rate in Japan has decreased dramatically from 274,111 and 721 per 100,000 children, respectively, in 1950, to 4,834 and 22 per 100,000 children, respectively, in 2015 (Figure 2) [4,5].

Given this decrease in death toll and mortality rate of children, there are fewer families who have experienced loss of a child, and these families may be isolated.

### 2. Greif's Definition and Theory

"Grief" refers to the process of experiencing the psychological, behavioral, social, and physical reactions to the perception of loss [6]. Grief is a normal experience and everyone grieves in their own way and own time. Loss is change that includes being without someone or something. Physical loss could be of something tangible like a person, a car, a house, or a breast, while psychosocial loss could be of something intangible like a divorce, an illness, a job, a dream, or a hope.

"Bereavement" defines the loss to which the person is trying to adapt [7]. Worden also states that the adaptation process to deal with loss is the achievement of mourning tasks (task model) [7]. The tasks are ① to accept the reality of the loss, ② to process the pain of grief, ③ to adjust to a world without the deceased, ④ to find an enduring connection with the deceased in the midst of embarking on a



new life.

Stroebe M. & Schut H. reviewed past studies and proposed a more realistic alternative, “The Dual Process Model of Coping with Bereavement” [8]. They assume that the bereaved not only has to deal with the death of the person itself, but also with the changes resulting from the secondary consequences of death. Dealing with the former is called loss-oriented coping, and dealing with the latter is called restoration-oriented coping. People repeatedly move between these points and shift their center of gravity toward recovery (restoration-oriented coping) with the passage of time, but they are not rectilinear and thus repeat in cycles.

### 3. Issues about the Death of a Child and the Family Left Behind

A child’s death is regarded a Taboo because children are meant to be icons of a “bright future”. Even in the face of serious conditions, parents typically remain hopeful and thus do not expect the possibility of their child's death and are often emotionally overwhelmed in such situations. Parents are often hopeful of a positive outcome, and doctors prioritize saving the life of the child such that parents usually do not expect the passing of their child.

As such, in unfortunate cases where a child passes away, the family experiences profound loss and grief.

However, people often avoid talking about the child and their memories, partly because it is difficult to understand what the parents are experiencing. In addition, few are able to provide appropriate grief care. Therefore, if parents lose their children, they tend to experience complicated grief [6].

I researched on grief and interviewed parents who had lost their children. They alluded to feeling “a sudden loss of function of their hands or feet “it’s a darkness in my life...Something like land mines are everywhere” [9]. They

do not want to forget about their child, often wanting to tell others about their child. They also constantly ask themselves about the meaning of a child’s birth and life, and find a way to live proudly in memory of their child. Many parents continued to celebrate their child's birthday even after their child’s passing and are eventually able to accept the absence of their child.

As part of palliative care for children, it is important to support families through the bereavement process following death of the child.

### 4. Grief Care for Families: Education, Practice and Research

I am particularly interested in education, practice of grief care and research from a new perspective.

#### 1) Education and practice about grief care

Given the limited recognition of the family’s experience following the loss of child in our society, I started a class for nursing students to engage family’s with such experience. Every year, I invite 3 families who have lost their children to my “pediatric nursing” class and ask them to talk about their feelings and experience. For students who have inadequate experience, such encounters would greatly benefit them by allowing them to gain insight of the family's perspective. Therefore, I invite families with a range of experiences such as children with different diseases, with children of varying age. Students will then be better able to think about nursing from a patient's or family's point of view.

On the other hand, speaking in front of students is an opportunity for families to share their experiences. After the lecture, we provide an opportunity for families to interact over tea. The goal is thus two-fold: education for students and providing grief care for families.

In addition, we hold a grief meeting once or twice each

year with participation of approximately 10 to 15 families. These participants may be newcomers or previous attendees, where they are introduced and divided into small groups to share their experiences and feelings with each other. The goal of these sessions is to ensure that these participants are in an environment where they feel comfortable to share freely. The deceased's siblings attended a workshop for children in the next room. After the meeting, we received positive feedback and some said that "[they were] not alone" and "It was happy to talk about my child".

## 2) Research about grief care for families

I have conducted qualitative research through interviews in parallel with practice and educational activities. I made a grief support book with 24 families going through the grieving process, representing the voice of each family. Part one comprised of photographs and a narrative of each family's memories. In the midst of creating this book, I felt that it would be easier for the family to talk about their child and their experiences through a medium, and that sharing narratives with each other could become grief care.

Therefore, I am currently working on combining research and practice using a visual narrative methodology. It is said that narratives allow people to connect the present and the past in their own terms, creating an opportunity to look into the future, explore the meaning of life, and eventually changing oneself [10]. Recently, Narrative Based Medicine (NBM) has become increasingly popular and is often contrasted with Evidenced Based Medicine (EBM). The need for NBM with a focus on patient-centered care has been recognized in clinical practice.

The traditional narrative model thus far is a dialogue based on binary relations. One of the models, a coordination model, is based on ternary relations, where one person becomes a coordinator or interpreter and connects the other two people. Another ternary relation is the joint attention model, which is when people create relationships through an item. This is called a visual narrative in which sharing a story is aided through a relationship involving objects.

Presently, I am conducting a research entitled "Grief care through synchronous dialogue using visual narratives~the relationship between mothers/fathers who have lost their children: drawing pictures of the present, past and future with children~". The purpose of this study is to focus on the experiences accompanying grief of the bereaved families through visual narratives and to investigate the efficacy of visual narratives in bereavement care.

Methods: I interviewed mothers or fathers who had lost their child by a semi-structured method. Next, I asked them to draw pictures about their relationship in past, present and future. Then, I asked questions and listened to the narrative accompanying the picture from the interviewee (mom or dad). Results: Participants included 2 fathers and 8 mothers, and this research is currently ongoing. The age range of parents: 34 to 57y. The age range of children: 8m to 17y. The elapsed time since their death: 2 to 9y. The images about the past were depicted with the parent holding the child in his or her arms, watching over the child. The drawings of the current relationship were often the opposite, depicted with the child holding the parents in his or her arms, where the parent watched from afar. Lastly, drawings of the future often depicted the parents being together with the child. Discussion: The relationship between mothers/fathers and children was found to be dynamic, with an evolving depiction of the past to the present and future. The visual narrative methodology reveals the parents' perspective of the parent-child relationship at the subconscious level, and the results might aid in grief care. Conclusion: As mentioned above, I have been working with the Fukuoka Children's Hospice Project to support children with severe illnesses and disabilities, as well as their families. We have not yet reached the goal of establishing a child hospice, but I will continue to work hard to achieve that goal.

Finally, my work is a form of action research in nursing, and I believe that education, research, and practice will be meaningful only when they are organically coordinated.

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