The Reintegration into Daily Life of Parents Who Have Experienced the Loss of a Child, Starting from Building Another Lifestyle with Their Deceased Child

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The Reintegration into Daily Life of Parents Who Have Experienced the Loss of a Child, Starting from Building Another Lifestyle with Their Deceased Child

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Abstract

[Objective]: To clarify culture of parents who have lost a child from the bereavement experiences.

[Methods]: Ethnography was adopted. Data was collected from semi-structural interviews of parents who had lost a child (25 informants), participant observations of self-help groups and their newsletters. Data analysis was conducted according to Leininger's data analysis guide.

[Results]: As a result of analysis using data from interviews and that of observations and newsletters as supplementary data, the following 5 themes were clarified; [Ordinary response that amplifies grief], [Child's absence becomes a reality of the daily life of parents], [Attenuation of the child's image], [use of two clocks and two faces] and [life as parents of a lost child]. The inclusive theme describing the culture of parents who have lost a child is that [we continue to live daily life as parents of a lost child using two times and two faces after bereavement].

[Discussion]: Parents who have lost a child had multiple loss experiences such as loss from social relationships and their memories. Parents recognized the continuance of grief positively and meaningfully. And they regard it as an important bond that continues for the rest of their lives. It became clear that the parents are confused at existent aid based on grief processes focusing on recovery from grief. Therefore, it is indicated as important from the nursing viewpoint to accept the parents' wish to continue their incomplete child's life and support the parents' life living with a lost child, without the parents being forced to pretend to be living an ordinary existence.

Key words

parents, culture, mourning work, death of a child, ethnography

Introduction

For parents, the death of a child is difficult to accept as reality. Kauffman¹⁾ states that the initial reaction to such a traumatic event is not denial but dissociation. The loss of a child is identified as a high-risk variable in the development of complicated mourning. Research findings document that, when compared to other types of bereavement, for example the loss of a parent, spouse, sibling, or friend, parental mourning is particularly intense,

complicated, and long-lasting, with major and unparalleled symptom fluctuations occurring over time²⁾. Therefore, it is said that an understanding of the loss of parents and professional help are required.

Since Freud's³⁾ description of the difference between grief and depression in the loss of a loved one, professionals have discussed whether grief should be treated medically or not⁴⁾. Freud's classic paper, "Mourning and Melancholia" provided

the first systematic analysis of bereavement. The paper discusses reactions to the death of a loved one from Freud's psychoanalytic viewpoint, and his theoretical ideas became highly influential in shaping subsequent understanding of healthy and unhealthy coping with bereavement. On the basis of clinical and research literature, the inclusion of a complicated grief category in diagnostic nomenclatures has much to recommend it; and while a significant gap separates the clinical spectrum of complications of bereavement from current proposals being advanced to conform to the requirements of the Diagnostic and Statistical Manual of Mental Disorders (DSM; e.g., 4th ed., DSM-IV: American Psychiatric Association, 1994), some researchers favor a diagnostic spectrum addressing bereavement in the DSM⁵.

Freud argued that 'mourning work' is required for recovery from grief and Deutsh⁶⁾ emphasized the importance of the expression of grief, while Bowdby⁷⁾ explained grief as the loss of an object of attachment. 'Mourning work' is understood as the grief recovery process in which the standard models of mourning work, such as "stage models"⁸⁾ and "task models"⁹⁾ are applied. Many different types of supportive intervention are available for bereaved persons in Western society, including grief therapy¹⁰⁾, self-help groups¹¹⁾, family focused group therapy¹²⁾ and so on.

However, I found through communication with families who have experienced the loss of a child conditions for which professional help is ineffective and sometime harmful¹³. I also realized that parents call themselves 'we', form their own culture and separate themselves from ordinary people without the experience of bereavement. Therefore, my goal in this study was to clarify the background of such conditions and explain the issues involved.

In Japan, research on families who have lost a child mainly apply standard European models, and there has been limited discussion about the experience of bereavement among parents in Japanese parent-child relationships^{14)·15)·16)}.

Therefore, one purpose of this study is to clarify the experience of child loss and bereavement, and how parents experience, accept, and form the notion of 'we' and the culture of parents who have lost a child. This research provides nurses a foundation for respecting the culture of parents who have lost a child, an understanding of their grief and a direction for care.

Methods

1. Design

This study employed a qualitative research design, referring to the ethnography of Leininger¹⁷⁾. Ethnography is the describing of a culture. The essential core of this activity aims to develop an understanding of other ways of life and others' relation to life, in order to realize their vision of their world. To consider nursing for parents who have experienced the loss of a child, it is important to understand the meaning of loss, care and life as culture from the parents' view point. Therefore, ethnography is considered to be appropriate for the purpose of this study.

2. Subjects

Subjects are parents who have lost a child. There has been much discussion in the literature concerning the child's age at death as a determinant of parental grief. Evidence can be provided supporting claims that it is the loss of the young child, the loss of the adolescent child, or the loss of the adult child that presents the most difficult bereavement for the parent to experience. But Rando suggests that the question is meaningless to bereaved parents. No matter what the age of their child was, parents have lost their hopes, dreams, expectations, and wishes for that child²⁾. Parents think that he or she owes the obligation of the upbringing until the child becomes independent economically. Therefore child in this study is defined as an unmarried person up to 25 vears of age.

3. Data collection

Subjects were parents who have lost a child. Data was collected primarily through interviews, and observations of self-help groups and their newsletters were added as supplementary data. To collect accurate and reliable data, interviews and observations were conducted via self-evaluation

using the stranger-friend model and the observationparticipation-reflection model.

1) Interviews

25 informants participated in the present study; 20 informants from 3 self-help groups for individuals who have lost a child (in A prefecture · Sudden Infant Death Syndrome · Influenza-encephalopathy) and 5 informants from a support-group organized by the author. The background of the informants is summarized in Table 1.

Semi-structured interviews were conducted during the period from September, 2004 to July, 2008. I started interviews with the question 'Would you please talk about yourself since your child passed away?' then deepened the content, confirmed it and carefully proceeded. Interview frequency and time ranged from 1 to 10 times / person and 90 minutes to 5 hours, respectively. Interview frequency and time were influenced by how the interview progressed. Interviews were recorded with informants' permission, and word-

Table 1. Background of informants n = 25Items Informants Sex Female 14 Male 11 Age 30's 8 10 40's 50's 7 Child's death age 0 - 2 years old 9 3 2 - 6 years old 2 7 - 12 years old 12 - 18 years old 8 18 - 25 years old 3 Time since child's death 0 - 1 years 5 7 1 - 5 years 6 5 - 10 years 7 10 years -Cause of death 6 Cancer Sudden Infant Death Syndrome 4 Influenza-encephalopathy 7 Accidental deaths 3 Other 5 Presence of surviving siblings 23 Yes 2 No

for-word transcriptions were made of each recording. Content clarified from interviews were repeatedly confirmed by informants along with data collection.

2) Observations

I attended quarterly meetings of the self-help group in A prefecture and conducted participant observation from October, 2004 to April, 2008. Each meeting was approximately 120 minutes long. During the meeting, participants talked about how they had been doing recently and the loss of their child to share their pain. The self-help group had approximately 20 members; however, the actual number of participants at regular meetings was 7 to 10 on average. I recorded the content of the observation in a field notebook after the meeting was finished. Please note that I attended the meeting as an observer since October, 2001.

3) Newsletters

Content from the Influenza-encephalopathy selfhelp group's quarterly newsletters (a total of 45 issues, from no. 32 to 77 from 2001 to 2008) were used as data.

4. Ethical considerations

Prior to the start of research, the research aims and methods, the right to refuse and decline participation, the use of information limited for research purpose, and the cautious and detailed handling of collected data were explained orally and in writing to the informants, and signed informed consent was obtained from each participant. Interview venues were carefully selected and ethical consideration was given to securing and protecting privacy.

5. Data analysis

Data analysis was conducted according to Leininger's data analysis guide. In the first stage, raw data was collected, described and recorded. In the second stage, components were clarified and categorized. In the third stage, patterns which repeatedly appeared in the first and second stages were further clarified. In the fourth stage, whole research results and clarified themes from the first to the third stages were abstracted.

6. Qualitative evaluation of research

Analysis proceeded along with the confirmation

of result with informants according to the qualitative assessment criterion of Leininger's ethnography¹⁷⁾. Advice was obtained from a

research supervisor experienced in the research methods of ethnography throughout all processes of the research.

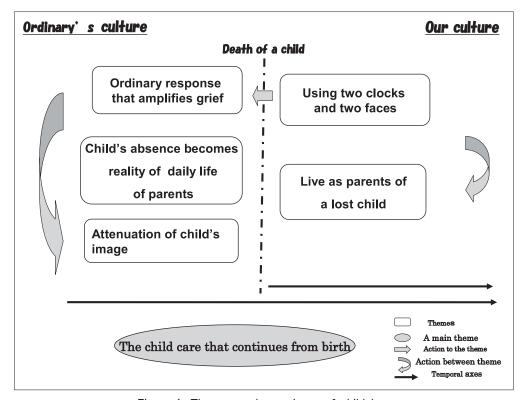


Figure 1. The parental experience of child loss

Table 2. Structure of themes and examples of talks

Table 2. Structure of themes and examples of talks		
Themes & component	Examples of talks	
Theme 1: Ordinary response that amplifies grief 《ordinary recognition of grief》 《responses of ordinary people》 《ineffective profession al help》	 Expression 'overcome the death' is frequently used in mass-media and books. I think difficulty and accidents can be overcome, but expressions such as 'overcome', 'heal' or 'recover' about child's death make me feel different and disgusted. I feel my grief being amplified. I could finally start being myself again with thoughtful words such as 'I want you to cherish yourself'. Please don't deny this part of me. To avoid being asked 'Are you fine now?' or 'Are you calm now?', I went shopping with my walkman. I feel upset being told that 'It is a pity that you can not go forward as you are so involved in self-help groups.' 25 years since I lost my child at the age of 2. This grief will never end until my life finishes. I shouldn't have talked because I felt clinical psychotherapist evaluated me as 'not yet recovered as this patient is still at this stage in the grief process'. I was told 'You can air out your feelings', but I thought 'What do you mean air out?' The doctor just gave me sleeping pills. As my condition is not a disease it can't be helped, but,, I secretly threw away the pills to stop milk. I feel sad about C-section scar, but it is a proof of my child and also a decoration. I feel hurt by the attitudes of the people in medical field. They think they do things for us, they are helping side and we are being-helped side. When people come to know that I lost my child, they show too much concern about me. I hate it. When I tell people 'My child has passed away', people back up saying 'I'm sorry'. It's troublesome to have this constraint. 	

Theme 2: Child's absence becomes reality of daily life of parents

《different degree of grief》 (reality where child's absence is recognized

- · Although the parents continue to feel the pain, as time passes, grief becomes lighter among daughter's friends. After 9 years, it has become the past for the people around me.
- · I hope the people around me do not forget my child, and send some things such as birthday card.
- · My mother in law, being asked 'how many grandchildren?', answers the no. only the living grandchildren only. I feel angry my child is already not included in the no. of grandchildren.
- · I feel 70 % of joy that my child's friends coming for the anniversary, but feel 30 % of sadness that my child is absent although the friends are growing.

Theme 3: Attenuation of child's image

«condition of forgetting the memory of the child》 《discoloration of child's presence》 the child's growth

- «a limit to the ability to imagine
- «efforts to fix impressions of the lost child》
- · While realistic grief remains, I start to forget feelings for my child. Voice or weight that I felt when I was giving a bath fades away.
- · There are pajamas and underwear in the bathroom. If I clear them up, nothing will be left. I cannot do that.
- · When visiting a family restaurant, we talk about how the child was eating and we took turns holding the child. But I am forgetting. It cannot be helped, but I feel very sad.
- · I am counting his age. Even as his younger brother exceeds his age, he is still the elder brother. But it is difficult to imagine him as 20 years old wearing a suit as his face remains as that of 14 years old.
- · I tried to talk about days that I spent with my daughter not to forget her memory, but not matter how much I try to remember, it fades away.

Theme 4: Using two clocks and two faces

«separate themselves from the ordinary wearing ordinary faces being moved by the image of the lost child

(reality where child's absence is recognized》

- · I lose confidence in myself looking at other people who are raising their children.
- · I can't enjoy things that PTA people and my classmates can enjoy. I'm miserable.
- · Refusing my friend's invitations, I realized the no. of new-year cards has unbelievably decreased. Friendships that I have built before bereavement are vanishing. It is shocking.
- · I tried to attend the celebrations of ordinary people so as not to be thought as a person who is grieving all the time. But keeping a forced smile eventually ruins me. When I thought 'I don't have to attend any more as refusing invitations is also a burden.', I felt relieved.
- · At the meeting, we frequently miss the ordinary time in the past.
- · When I am asked 'Are you fine?', I just say 'Nothing has changed.' implying 'Of course I am not fine.' and walk away.
- · We wear two faces; 'pretending to be ordinary' and 'parents of a lost child and two times; 'before bereavement' and 'after bereavement'. Though grief can never be healed, I am coming to handle well my daily life and my feelings. There is a switch that turns on and off in myself.

Theme 5: live as parents of a lost child

《continue parents' roles》 (follow child's life cycle) «a life's gift from a child» «transmitting a child to a society»

- · We prepare milk every morning and evening. We put a piece of bone from the cremation into a portable bag and one of us holds it.
- · When a birthday becomes close, I buy a cake and make a present. Happy.
- · My 2 year-old child and my child in the 5th grade now, both exists in myself. I sent a telegram to celebrate entrance to elementary school. I would like to send it again to celebrate that of junior high school.
- · I hope my child can feel the beauty of this flower through my eyes and ears. I every year go to the concert that my child loved.
- · My child fades away in daily life, but if I talk, the memory comes back and I feel satisfied with my child's presence. Although I cannot see, it is child raising in my heart.
- · I have been struggling to find a way to live with my child and finally got it after many times of trial and error. That is to study clinical psychology and support people with mental pain.
- · My child has taught me that 'It is already great to be alive' at the risk of his life.

I hope what I say becomes useful for doctors and researchers. If it is useful, it means the presence of my child is accepted. That is child raising for me.

Results

As a result of analysis, 5 themes clarified from patterns which repeatedly appeared in the daily lives of parents since their child's death, and 1 inclusive theme abstracting whole research results was obtained. They are summarized below. (Figure1)

The inclusive theme is shown in $\lceil \rfloor$ brackets. Themes and their basic structure are expressed in $\lceil \rfloor$ and $\langle \rangle$ brackets, respectively, and examples of talks are summarized in Table 2.

1. Inclusive theme

The inclusive theme describing all 5 themes is [We continue to live daily life as parents of a lost child and a new life using two times and two faces after bereavement].

2. Structure of the 5 themes

Theme 1: [Ordinary response that amplifies grief]

People around the bereaved parents in daily life, such as friends, acquaintances and relatives, are individuals who have never experienced a child's death. Such ordinary people see grief as something that can be healed. However, parents feel that "grief is a child" and feel unpleasant and disgusted about (ordinary view of grief). The meaning of "grief is a child" is as follows. In place of child's body, grief becomes the proof of the child's existence. Parents interpret the recovery from grief as oblivion of their child, and they feel that it is guilt. And parents resist recovering from grief. Therefore they insist that "grief is a child". Also «responses from ordinary people» to parents with bereavement experience tend to become awkward, avoiding and prejudiced. As a result, the parents feel isolated and alienated from them. Furthermore, the parents receive pharmaceutical treatment or mental care based on the existing grief process, become confused and hurt by having amplified grief and view this as «ineffective professional help).

Theme 2: [Child's absence becomes reality of the parents' daily life]

As time passes after the child's death, «reduction of bereavement grief» occurs to the people around the bereaved parents. A «different degree of grief occurs between parents and relatives, for example the relatives omit a dead child from family celebrations. Also the parents experience the reality in which the child's absence is recognized by seeing his/her classmates grow.

Theme 3: [Attenuation of child's image that happens to parents]

As more time passes, the parents experience the 《loss of memory about the child》 or a 《discoloration of the child's presence》 such as weight and voice "although they do not want to forget". Then, the parents, although still counting age of a lost child, experience 《a limit to the ability to imagine the child's growth》 from death age to an adult. Then, the parents make 《efforts to fix impressions of the lost child》 by keeping articles and exploring memories associated with the lost child.

Theme 4: [Using two clocks and two faces]

After the child's death, the parents begin to feel unpleasant about the sense of value they had before bereavement, the sense of value about the people around them and in their continuing daily lives. Therefore, the parents regard the passing of time and daily life before bereavement and of the people around them as "ordinary", and «separate themselves from the ordinary. While the parents live their daily lives (wearing ordinary faces), they also start to live as parents who have lost a child. Although the parents miss the time before bereavement and experience (being moved by the image of the lost child, they live their daily lives according to two types of time; ordinary life and life after bereavement, wearing two faces; as ordinary people and as parents who have lost a child.

Theme 5: [live as parents of a lost child]

The parents 《continue parental roles》 and 《follow the child's life cycle》 by celebrating the child's anniversaries, preparing meals for the child to share enjoyment etc. Also, the parents build their lives by regarding the way of living learned from their child's death as 《life's gift from the child》 finding meaning in it and 《transmitting the child to society.

Discussion

The 5 themes shown will form the basis for a discussion on the culture of parents who have lost a child and what care potentials exist.

1. The characteristics of the parents' experience of child loss

A death is the end of a life. However, the death of a child was not the end of its life but the beginning of grief because of loss for the child's parents. The first loss is the physical loss coming from the death of a child. After the child's funeral, the parents return to their social life. With the relation among the people in the work place or community, the parents feel the social loss of their child through the experience that [Child's absence becomes reality of the parents' daily life because of reality where child's absence is recognized), (reduction of bereavement grief) and different degree of grief. In addition, with the time passing, [Attenuation of child's image that happens to parents happens and they undergo such psychological loss as «condition of forgetting the memory of the child and discoloration of child's presence. The shock of the experience of child loss is the most at the time of losing and it continues for a long time. Therefore, the parents have it for a long period and in forms of complex, folding and intermittent. As for the lost child, it had specific characters that it was on the way of growing and developing, and had only a small amount of common time with its parents when died young.

2. The child death in Japan

The parents live with very little perception of losing their child. In that type of society, the parents who lost a child feel powerlessness such as overthrown sense of value and world, and are heavily conscience-smitten by the distress that "why only I must have such a crucial experience?"

Also, the modern society is said to be a society which sees a death as a taboo (concealment, isolation, exclusion, denial, or restraint), and is willing to "make the dead persons forgotten" ¹⁹⁾. People around the bereaved parents are embarrassed in how to stand by or talk of, and are only able to tell formal external words.

As the base of Theme 1 [Ordinary response that amplifies grief], there are examples of talks like "When people come to know that I lost my child, they show too much concern about me. I hate it", "When I tell people 'My child has passed away', people back up saying 'I'm sorry'. It's troublesome to have this constraint". These responses make the parents who lost a child feel estranged or isolated. Then, they name the passing of time and daily life of them before bereavement and of the people around them as "ordinary", and «separate themselves from the ordinary». The parents who have lost a child are driven to live "our lives" which is difficult to pass without drawing a line of demarcation between of themselves and of those who have not lost a child.

3. Grief and bond with the lost child

The basic structure (ordinary view of grief), one of the components of Themel. [Ordinary response that amplifies grief], indicates that the grief for losing someone is a negative state of mind. Therefore, it is seen to be a desirable mourning process to recover from the grief quickly. However, the bereaved parents recognized the continuance of grief positively and meaningfully. This means that the grief for the lost child is a proof for him/her and the parents can actually feel the lost one in the grief. They were afraid of [Attenuation of child's image that happens to parents, and had a sense of guilt when it happened to them. They thought that recovery from grief was, as shown at the top of the examples of talks for theme 1 in the table 2, to exclude the lost child and losing him thoroughly.

Klass¹⁹⁾ suggests that a continued bond with the lost person is important for recovery from grief. However, the bond of parents with the lost child was not a bond of the past which continued for overcoming from grief. It was a bond necessary for them to continue the parental roles and live as parents. Because of it, they meant their life after the loss to be <code>%a</code> life's gift from a child, though accepting the physical death of the child. The parents with loss perceived the grief equal to their lost child and also as an important bond with him.

4. Structure of parents' time and life

Parents of a lost child started to have two ways of time: ordinary life time continuing before child's death and the time [living as parents of a lost child] which started after its death.

Similarly, the parents began to live a double-life after the loss: a standard ordinary life and the life as parents of the lost child learned from his/her death. This type of parents' double-life was a culture specific with such bereaved parents and was not understood by ordinary people with ordinary culture. The parents came to know it through [Ordinary response that amplifies grief]. They lived the cultural life of [living as parents of a lost child] avoiding being denied by surrounding people through [Using two clocks and two faces].

5. The meaning of self-help group

The members of self-help groups for disabled children or children with chronic diseases were helping one another and are banded together strongly. The groups were active to exchange information necessary for such children's life, planed study meetings to get knowledge about the diseases or impediments and tried to construct asocial systems for curing diseases and helping them. Yet, the self-help groups for the parents who have lost a child had different character, as their child has died already, from those of handicapped children. In many cases, the new comers attended the groups, saw the parents with the same experiences and feelings, and then went back to their own society without continuing attending.

The self-help groups for the parents with child loss carried out a role of a catalysis; to help the members to reduce the time to be wielded by surrounding people, to decide to live as parents of the lost child, and to accept the life [Using two clocks and two faces].

There were sometimes such new comers who attended the groups for the first time after 10 or 20 years since the loss and were passing their life calmly. They could confirm in the group that their feelings and life structures were in common with other parents with loss. The parents who have lost

a child had crucial demand to express their emotion for the lost one because they had to seal it in the daily social life. The groups could offer them the chances to express and wash their distress.

Though the relation and cooperation among the members of self-help groups for parents with loss was thin compared to other types of self-help groups, there was seen a strong bond of "we" among them. It seems to originate from the smallness of their number.

6. Suggestions for nursing care

The parents needed a place where they could talk about their lost child and confirm their feelings which were not common among ordinary parents. However, there were few chances to meet the parents of the same situation. In addition, their relation was not so strong as that of parents in other types of self-help group which helped each other during the long term of diseases and promoted deep bond through constructing the curing and help systems. As they wanted to meet only once or so, it was not easy for the parents concerned to continue the meetings of self-help group for the parents with child loss. Consequently, it was suggested that nurses should offer the places to meet the parents and inform how the senior parents have coped with social matters and grief.

The parents told their grief and distress of losing, but they did not wish such "recovery" as eliminating their grief. This was consistent with Neimeyer, R²⁰⁾ who argued the risk to deal with the losing grief in the process of disease recovery or in an accomplished grief model. Accordingly, the following points were indicated as important; not to impose the ordinary passing of time and life structure but to respect the culture of parents who have lost a child, to minimize a threatening condition in which the [child's absence becomes reality of the daily life of parents] and in which the [child's image becomes attenuated] and to positively accept and support their way of life [living as parents of a lostchild].

It should be argued the influence of different causes of death on parents' grief. There is a reference which indicates the difference between the expected death (chronic diseases such as AIDS, infantile cancer) and unexpected death (such as SIDS and suicide). The factors influential on parents' grief were the age of dead child, parents' growing history and characters, and the relation between the couple and among the family.

All the parents suffered, "Why my child has died?", whichever the cause of the death was. The parents need to know the detailed evidences; the cause of the child's death, the situation of that, the process of that, to confront the death of the child, however hard for them to know it. It is important for nurses to support the parents to understand the loss.

Study limitations and issues for future prospects

This study focused on parents who have experienced the loss of a child death.

In the future, I would like to continue to attend family meetings and conduct further research on changes over an extended period.

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死別体験から始まる子どもを亡くした親の日常生活の構築

井上ひとみ

要 旨

【目的】:子どもを亡くした親が、どのような体験をし、どのように受け止め、どのような 経緯で『私たち』を形成し、社会生活を立て直していくのかを明らかにする。

【研究方法】: エスノグラフィーによる質的研究を行った。研究対象は、子どもを亡くした親である。データは、25名の情報提供者による半構成的面接を基盤とし、家族会に対する参加観察と、家族会の会報を補完データである。

【結果】:子どもを亡くした親の文化を表す包括的テーマは、『子どもの死後、私たちは、2つの時間と2つの顔を使い分けながら、亡くなった子どもの親として新たな日常生活を生きる』である。【悲嘆を増幅する普通の対応】【子どもの不存在が日常生活に浸透してゆく現実】【親自身に生じる子ども像の希薄化】【2つの時計と2つ顔を使い分ける】【亡くなった子どもの親として生きる】の5テーマが明らかになった。

【考察】: 親は、子どもの死による身体的喪失の後、時間差で生じる社会的・心理的な多重構造の喪失を体験する特徴があった。また、親は、悲嘆を肯定的に意義あること、親の生を支える子どもとの絆と認識していた。そのため、悲嘆の回復は、子どもの排除と解釈し、「悲嘆の回復」に焦点を当てた既成の悲嘆モデルの適用を《役に立たない専門家援助》と感じていた。親は、【死んだ子どもの親として生きる】新たな生活時間と生活様式を守るために、【2つの時計と2つ顔を使い分ける】方略で周囲に対処していた。

上記のことをふまえ、親が、新たに社会生活を統合できるような看護の視点をもって援助することの必要性が示唆された。