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# Status of Families of Children Hospitalized for Childhood Cancer in Japan: Nurse Viewpoints

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## Abstract

**Background:** The families of children with childhood cancer experience significant anxiety and psychological and physical impacts, which vary throughout the child's hospital stay until discharge. Nurses are often unable to perceive emotions such as distress of the sick child's parents. Therefore, it is necessary to show the nurses specific impacts on families and when such incidents occur. This would enable them care better for the child and their family and engage with them from the viewpoint of observation. **Objective:** To clarify nurse viewpoints on family status over time from hospitalization to discharge of their sick child. **Methods:** A questionnaire survey was administered to 1,100 nurses across 110 childhood cancer treatment facilities in Japan. **Results:** We received 208 valid responses. Factorial analysis of the items resulted in the identification of three factors: "family status", "critical psychological status of families", and "differences in perspectives between parents". For all the three factors, mean values were lower after initial treatment had been completed compared to the period up until initial treatment. This indicated that completing initial treatment improved family status and reduced the sense of psychological crisis. "Differences in perspectives between parents" in the phase until initial treatment did not correlate with "family status" and "critical psychological status of families" in the phase from completion of initial treatment onward. **Discussion:** The investigation revealed the challenges in classifying family status during their child's hospitalization into two time periods. Based on the results, the viewpoint of observing "family impact over the course of the sick child's hospitalization" was created. Future studies should investigate the possibilities of practical utilization of these findings.

## Keywords

Childhood Cancer, Hospitalized, Families

## 1. Introduction

In 1959, the U.K. Department of Health and Social Care recommended that, when a child is hospitalized, a parent/guardian should accompany him/her because of the possible emotional consequences of separation from parents [1]. Many hospitals in Japan also allow a parent or guardian to accompany hospitalized children. This not only alleviates the emotional effects on the child but also respects the parent's wish to be at their child's side.

When a child develops childhood cancer and undergoes inpatient treatment, family members experience significant strain. This includes changed lifestyle, psychological burden, and altered roles at home, in addition to the concern about the child's illness.

The impact on families changes over time, from the child's hospitalization to discharge. We felt the need to clarify the challenges experienced by families at specific time points and to conduct regular assessments of these challenges. The impact on families could be mitigated via early understanding and involvement with them based on the viewpoint discussed above. This would promote family health maintenance and support the sick child cope with the disease.

Studies targeting families clarified that the impact on families during the course of their child's hospitalization differed depending on whether it was the period "Hospitalization to initial treatment" or "Completion of initial treatment to hospital discharge".

During the period "from hospitalization to initial treatment", families remain in a state of psychological confusion. In this state, they care for their sick child and attempt to adapt to life during hospitalization together with their child while adjusting the roles and lifestyles of family members who remain at home. During the period "from completion of initial treatment to hospital discharge" of their child, families are affected by the state of their child's disease, but they appreciate the course of the treatment and experience some flexibility with their daily lifestyles. During both these periods, parents experience psychological and physical fatigue as well as financial burden due to caring for their recuperating child, performing housework, and caring for their child's sibling(s) [2].

It has been reported that nurses often fail to perceive a child's symptoms that may include fatigue, sadness, anxiety, fear, depression, or sleep disorder [3]. Additionally, nurses are often unable to perceive emotions such as distress in the parents of children with childhood cancer [4]. In Japan, many hospitals allow parents to accompany their hospitalized child. Families want to accompany their child and care for them. Therefore, nurses provide care not only for the child who has childhood cancer, but also for the accompanying parents. Therefore, the author considered it necessary to investigate the impacts on the families of such children from the perspective of nurses to determine how nurses perceive such situations. This study integrated the results of studies targeting families with the results of the present study to identify specific issues experienced by families.

## 2. Methods

### 2.1. Definitions of Terms

**Childhood cancer:** Generally, leukemia, brain tumors, neuroblastomas, lymphomas, and renal tumors are common. Childhood cancer is a general term encompassing these diseases. In this study, it refers to a malignant tumor that develops during childhood.

**Initial treatment:** The first treatment received upon hospitalization after disease onset.

### 2.2. Study Design

This is a quantitative study based on a self-administered questionnaire.

### 2.3. Questionnaire Creation

We prepared a questionnaire based on a previous study [2] regarding the impact of hospitalization of children on families during the period "from hospitalization to initial treatment" and the period "from completion of initial treatment to hospital discharge" of their sick child. The study results revealed physical, psychological, and lifestyle-related effects on the parents, siblings, and grandparents when parents accompany a sick child during hospitalization. Questions were created based on 40 items extracted from these results (**Table 1**).

The questionnaire had six responses: "6 = Very strongly agree", "5 = Strongly agree", "4 = Agree", "3 = Disagree", "2 = Strongly disagree", and "1 = Very strongly disagree". Subjects were asked to respond separately depending on the two periods of "from hospitalization to initial treatment" and "from completion of initial treatment to hospital discharge". Response time was 20 minutes.

### 2.4. Survey

#### 2.4.1. Study Subjects

The subjects comprised 1100 nurses engaged in nursing care for childhood cancer patients at a total of 110 facilities in Japan that treat childhood cancer patients. These included university hospitals, childhood cancer core hospitals, and childhood cancer medical facilities.

#### 2.4.2. Data Collection Methods

Data were collected from July 2019 through March 2020. The study purpose, methods, and other details were explained in writing to the nurses in charge at each facility and they were requested for their cooperation. Nursing department directors who agreed with the purpose of the study and consented to cooperate requested—through the head nurse of the relevant ward—the eligible nurses to participate in the research. Eligible nurses were provided a written document that explained the study's significance, purpose, methods, ethical considerations, as well as the differences between the periods "from hospitalization to initial treatment" and "from completion of initial treatment to hospital discharge".

The survey investigated subject attributes (age, number of years of experience) and subjects' facility attributes (whether parental accompaniment was allowed). The questionnaire was titled "Questionnaire on Family Status during Two Time Periods of Their Sick Child".

### 2.4.3. Analysis Methods

Exploratory factorial analysis was performed on the question items. The reliability of the extracted items was investigated. Analysis was performed using the SPSS ver. 30.0 analysis software.

**Table 1.** Questionnaire on family status over two time periods during hospitalization of their sick child.

1. Strong pressure on parents regarding treatment selection
2. Light pressure on parents regarding treatment selection
3. Strong psychological instability in parents
4. Parents are calm
5. Strong psychological instability in mother
6. Strong psychological instability in father
7. Most parental accompaniment provided by mother
8. Most parental accompaniment provided by father
9. Many families have someone who can help accompany the child
10. Many families have someone who can help the parent who remains at home
11. The accompanying parent appears not to be sleeping well
12. The accompanying parent appears not to be eating well
13. The accompanying parent is in tears
14. The accompanying parent is so worried about their sick child that they cannot leave their side
15. Many parents take time off from work or quit their job in order to accompany their child
16. The job of the parent who stays at home is impeded
17. The parent who stays at home is forced to make changes at work such as reassignment
18. The parent who stays at home has to quit their job in order to perform housework/childrearing, etc.
19. Each parent accepts their sick child's illness/treatment differently
20. Parents are very anxious about danger to their sick child's life
21. Parents have different levels of anxiety regarding their sick child's life
22. Parents are very anxious about their sick child's treatment
23. Parents have different levels of anxiety regarding their sick child's treatment
24. There is a major psychological impact on siblings
25. Some parents talk about how siblings refuse to go to kindergarten or school
26. Some siblings suffer from PTSD
27. Some parents suffer from PTSD
28. Some mothers suffer from PTSD
29. Some fathers suffer from PTSD
30. The accompanying parent omits one meal per day because of financial concerns
31. The meals of the accompanying parent are not nutritionally balanced

**Continued**

32. The accompanying parent suffers from stress related to meals
33. The accompanying parent has strong fatigue
34. The parent who stays at home has strong fatigue from going to hospital visits and looking after siblings
35. The parent who stays at home does not visit the sick child often
36. The parent who stays at home often visits the sick child
37. The father and mother communicate well
38. Communication is lacking between the father and mother
39. The father and mother cooperate well
40. There is a major financial burden on the parents

#### 2.4.4. Ethical Considerations

This study was approved by the Ethical Review Board of the affiliated facility (approval no. 2273). Participants were considered to have provided consent to participate by returning the completed questionnaire. Participants were informed in writing that participation was voluntary; that they would not suffer any disadvantages if they did not participate; that the questionnaire was anonymous, and individuals could not be identified from the study content; that, because it was an anonymous questionnaire, they could not revoke their consent; that data obtained in the study would only be used for research purposes; that data would be strictly managed; and that data would be destroyed after being stored for five years.

## 3. Results

### 3.1. Study Subject Outline

In terms of age, we identified that 80% of the study subjects were in their 20s, 30s, or 40s, and the number of subjects was similar for each age range. On average, participants had 12.5 years of experience as nurses and seven years of experience in childhood cancer nursing. Accompanying sick children was allowed at 89.6% of the subjects' affiliated facilities and not allowed at the remaining 10.4%.

### 3.2. Analysis Results

We distributed 272 questionnaires (valid responses: 208; valid response rate: 76.5%).

Factorial analysis was performed on the question items. Next, correlation analysis was performed on the periods "from hospitalization to initial treatment" and "from completion of initial treatment to hospital discharge" to clarify relationships amongst the factors.

Exploratory factorial analysis was performed on the 40 items. Consequently, three factors and 19 items for these three factors were identified (Table 2). The contribution ratio of each factor was as follows: 4.32% for factor 1, 3.38% for factor 2, and 2.0% for factor 3. The Kaiser-Meyer-Olkin sampling adequacy precision (hereinafter: KMO value) was 0.796 and Bartlett's test of sphericity was significant ($\alpha < 0.001$).

Factor 1 had 12 items and was named "family status". Factor 2 had four items and was named "critical psychological status of families". Factor 3 had three items and was named "differences in perspectives between parents".

Mean values, standard deviation, and Cronbach's $\alpha$ for the three factors are presented in Table 2 and Table 3.

Table 2. Status of families of children hospitalized for childhood cancer in Japan: Nurse viewpoints (n = 272).

| | Factor Loading | | |
|---|---|---|---|
| | Factor I | Factor II | Factor III |
| **Factor I: Family status (Cronbach's $\alpha$ 0.849)** | | | |
| 13. The accompanying parent is in tears | **0.721** | 0.036 | 0.026 |
| 20. Parents are very anxious about danger to their sick child's life | **0.687** | −0.122 | −0.087 |
| 14. The accompanying parent is so worried about their sick child that they cannot leave their side | **0.669** | 0.001 | 0.036 |
| 11. The accompanying parent appears not to be sleeping well | **0.632** | 0.091 | −0.021 |
| 17. The parent who stays at home is forced to make changes at work such as reassignment | **0.552** | 0.051 | 0.139 |
| 22. Parents are very anxious about their sick child's treatment | **0.546** | −0.111 | 0.023 |
| 5. Strong psychological instability in mother | **0.521** | −0.025 | −0.05 |
| 33. The accompanying parent has strong fatigue | **0.514** | 0.027 | −0.021 |
| 6. Strong psychological instability in father | **0.51** | −0.014 | −0.192 |
| 16. The job of the parent who stays at home is impeded | **0.504** | 0.028 | 0.089 |
| 24. There is a major psychological impact on siblings | **0.484** | 0.055 | −0.06 |
| 15. Many parents take time off from work or quit their job in order to accompany their child | **0.45** | −0.053 | 0.195 |
| **Factor II: Critical psychological state of families (Cronbach's $\alpha$ 0.894)** | | | |
| 28. Some mothers suffer from PTSD | 0.024 | **0.915** | 0.008 |
| 27. Some parents suffer from PTSD | 0.026 | **0.885** | 0.032 |
| 29. Some fathers suffer from PTSD | −0.024 | **0.884** | −0.134 |
| 26. Some siblings suffer from PTSD | −0.084 | **0.631** | 0.157 |
| **Factor III: Differences in perspectives between parents (Cronbach's $\alpha$ 0.784)** | | | |
| 21. Parents have different levels of anxiety regarding their sick child's life | −0.054 | −0.106 | **0.903** |
| 23. Parents have different levels of anxiety regarding their sick child's treatment | −0.036 | 0.049 | **0.718** |
| 19. Each parent accepts their sick child's illness/treatment differently | 0.09 | 0.134 | **0.597** |
| **Factor correlation matrix** | | | |
| **Factor 1** | 1 | 0.346 | 0.143 |
| **Factor 2** | - | 1 | 0.146 |
| **Factor 3** | - | - | 1 |

Note: factor loading > 0.40 are in boldface. Cronbach's alpha for the total score was 0.834. Factor extraction method: Principal factor method Rotation method: Promax method with Kaiser normalization.

**Table 3.** Mean values and standard deviation.

| | "Hospitalization to initial treatment" | | "Completion of initial treatment to hospital discharge" | |
|---|---|---|---|---|
| | Mean | Standard deviation | Mean | Standard deviation |
| Family status | 5.047 | 0.58502 | 3.6205 | 0.68203 |
| Critical psychological status of families | 3.1278 | 1.14544 | 2.721 | 0.97879 |
| Differences in perspectives between parents | 3.2948 | 1.00984 | 3.0458 | 0.87773 |

### Family Relationships during the Periods "from Hospitalization to Initial Treatment" and "from Completion of Initial Treatment to Hospital Discharge"

"Differences in perspectives between parents" during the period from hospitalization to initial treatment did not correlate with "family status" and "critical psychological status of families" from completion of initial treatment to hospital discharge (**Table 4**).

**Table 4.** Correlations between families during the periods from hospitalization to initial treatment and from completion of initial treatment to hospital discharge.

| | | "Completion of initial treatment to hospital discharge": Family status | "Completion of initial treatment to hospital discharge": Critical psychological status of families | "Completion of initial treatment to hospital discharge": Differences in perspectives between parents |
|---|---|---|---|---|
| "Hospitalization to initial treatment": Family status | Pearson's correlation coefficient | 0.287** | 0.128* | 0.115 |
| | P value (two-tailed) | <0.001 | 0.044 | 0.073 |
| | Frequency | 239 | 247 | 244 |
| "Hospitalization to initial treatment": Critical psychological status of families | Pearson's correlation coefficient | 0.259** | 0.751** | 0.187** |
| | P value (two-tailed) | <0.001 | <0.001 | 0.002 |
| | Frequency | 240 | 267 | 262 |
| "Hospitalization to initial treatment": Differences in perspectives between parents | Pearson's correlation coefficient | 0.106 | 0.118 | 0.712** |
| | P value (two-tailed) | 0.103 | 0.056 | <0.001 |
| | Frequency | 236 | 262 | 260 |

**Correlation coefficient is considered significant at 1% (two-sided). *Correlation coefficient is considered significant at 5% (two-tailed).

## 4. Discussion

### 4.1. Investigation of Survey Results

For all three factors, the mean values were lower during the period from completion of initial treatment to hospital discharge than during the period from hospitalization to initial treatment. This indicated that completing initial treatment improved family status and reduced the sense of psychological crisis. During the initial period of hospitalization, parents experience overwhelming psychological confusion as they are forced to make choices regarding their child's sudden illness, hospitalization, and treatment [5]. Additionally, parents experience the pressure of having to rapidly make medical decisions for their child despite not yet being able to accept or understand their child's illness [6]. However, when the initial treatment is completed, and this is particularly true for diseases such as leukemia, parents display understanding, including offering support for their child when they experience side-effects of chemotherapy. They begin appreciating and accepting their child's condition. These findings indicate the gradual alleviation of parents' psychological confusion [7] [8].

"Differences in perspectives between parents" during the period until initial treatment did not correlate with "family status" and "critical psychological status of families" during the period from completion of initial treatment onward. This suggested that, during the period until initial treatment, psychologically confused parents exhibited differences in perspectives regarding their child's illness and treatment. However, during the period from completion of initial treatment onward, these differences in perspectives decreased. Greater social support for parents enables families to overcome challenges better [9]. During this period, parents, who are in a state of psychological confusion, are able to comprehend the situation and cooperate with one another better, which facilitates a convergence of perspectives.

There is no major difference in situations between "families during the period from hospitalization to initial treatment" and "families during the period from completion of initial treatment to hospital discharge". However, it is assumed that there is a slight reduction in family confusion during the period after completion of initial treatment compared to family confusion during the period when their child's illness first appeared.

### 4.2. Investigation of Observation Viewpoints of Families during the Sick Child's Hospitalization Course

We prepared the category, "Families during the sick child's hospitalization course" based on existing research results [3] and the results of the present study (**Table 5**). During the period "from hospitalization to initial treatment", many observation viewpoints are related to parents' acceptance and understanding of their child's illness and treatment, parents' psychological state as their sick child's disease progresses, and family functions.

The period "from completion of initial treatment to hospital discharge" was a time of increasing psychological instability and fatigue due to the psychological and physical burdens placed on the parents and siblings. Therefore, observation viewpoints focused on psychological aspects.

**Table 5.** Observation viewpoints of families during the sick child's hospitalization course.

| "Hospitalization to initial treatment" | "Completion of initial treatment to hospital discharge" |
|---|---|
| **Parents' understanding of illness/treatment** | |
| · Have they accepted their sick child's illness? | |
| · Worries related to treatment selection | |
| · How have they understood the doctor's explanation? | · Have they deepened their understanding of the illness and treatment? |
| · Do the parents understand what is happening with their child's treatment? | |
| · How have the parents explained the disease to their sick child? | |
| **Parents' psychological state** | |
| · Parents' confusion, guilt, anxiety, worries, and regret over treatment selection | · Do the parents appear psychologically unstable?<br>Do they have any symptoms that appear to be PTSD? |
| · Are the parents communicating with each other? | |
| · Do the mother and father have the same opinion on the treatment strategy? | |
| · Do they calm down as treatment starts? | |
| **How parents interact with their sick child** | |
| · Mothers' feelings about and interaction with their sick child | |
| · Fathers' feelings about and interaction with their sick child | |
| **Parents' changes to environment** | |
| · Has the father's work been affected? | |
| · Has the mother's work been affected? | |
| · Distance from home to hospital | · Parents' level of physical fatigue |
| **Family cooperation with parent who is accompanying the sick child** | |
| · Accompaniment status | |
| · Family support system for parent's meals, etc. | |
| · Family support system for parent's psychological state | |
| · Family support system for parent's physical fatigue | |
| **Family functions** | |
| · Is there support for the parents? (the parents/siblings, etc., of the parents themselves) | · Has a support system for the parents been established? (the parents/siblings, etc., of the parents themselves) |
| · Are there any issues with family role changes at home? | · Are there any changes in the siblings? (refusing to go to school, bed-wetting, feeling ill, regression, etc.) |
| · Is the family communicating well? | · Contact between siblings and parents |
| · Are they taking care of the child's siblings? | · Contact between siblings and the sick child |
| · How have they explained the illness of the sick child to their siblings? | |
| · Siblings' words and actions (anxious words, asking about why their sick child is not at home, etc.) | |

## 5. Conclusions

1) During the period "from hospitalization to initial treatment", families are in

a state of psychological confusion, and during the period "from completion of initial treatment to hospital discharge", they experience mental and physical fatigue. Our results also demonstrated that, depending on the child's illness and treatment course, the impact of the hospitalization of the child on the family could not always be neatly categorized into the two time periods discussed above. There were also cases in which the impact of hospitalization experienced by families during the initial hospitalization lasted for the entire period.

2) We prepared observation viewpoints of "families during the sick child's hospitalization course". Going forward, possibilities for leveraging these results need to be investigated.

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## Conflicts of Interest

There were no conflicts of interest related to this study.

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