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## Process of parenting a child with retinoblastoma while guiding him or her toward disease acceptance

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### SUMMARY

Background :

Retinoblastoma (RB) occurs at a very young age. Since the disease is diagnosed at an early age, the family is responsible for the care of the child's disease acceptance.

Objective : This study aims to explore the parenting process of children with RB toward disease acceptance.

Methods : Parents of eleven children with RB living in Japan were interviewed, and the data were analyzed using the Modified Grounded Theory Approach of Kinoshita (M-GTA).

Results : There were twenty-one concepts representing the process of parenting a child with RB while guiding him or her toward disease acceptance, and nineteen of them were classified into ten categories based on semantic similarities. The two other concepts showed similar interpretability to categories. These categories and concepts were summarized into two core categories : "Helping the child develop a positive mindset to define the disease as a part of him/herself" and "Paving the way in advance for the child to live comfortably when his or her living space expands".

Conclusions : In a cyclical framework of parenting, consisting of two core categories described in Results, the parents coordinated these two approaches while maintaining balance by "Avoiding saying anything that does not need to be said" and established their process of parenting a child with RB while guiding him or her toward disease acceptance, according to their household situation. The results suggest the necessity of recognizing that in childhood-onset cancers, such as RB, and diseases involving genetic issues, problems tend to occur not only during the treatment period but also at the time of life events and providing support from a comprehensive perspective.

Key words : Experience, Family nursing, Genetic, Parenting, Retinoblastoma

## 1. INTRODUCTION

Retinoblastoma (RB) is known as the most intrusive intraocular cancer in children, with an incidence of approximately one in 15,000 globally<sup>1)</sup>. RB is a genetic disease, 75% of which has been reported to develop unilaterally and the remaining 25% being bilaterally<sup>2)</sup>. Specifically, 80-100% of bilateral RB and 10-15% of unilateral RB are considered heritable<sup>3)</sup>. Patients are treated by either enucleation or conservative treatment on the basis of multiple factors such as the size of the tumor, condition of the other eye, and systemic complications<sup>4,5)</sup>. In general, bilateral RB is often treated by enucleation of the eye affected more severely. The other less-affected eye is treated by conservative methods which specifically target the tumor<sup>6)</sup>. Prognosis of RB has best cure rates among childhood cancer with more than 95% and approximately 90% of them survive into adulthood. However, patients with bilateral RB are at a high risk of secondary cancer ; the risk for secondary cancer increases with age, and 35.2% of patients with bilateral RB develop cancer within 40 years of the initial diagnosis<sup>7)</sup>. Since secondary cancer site is not specific, there is no effective screening strategy, and patients need to be monitored throughout their lifetime<sup>8)</sup>. Treatments for RB are often performed at specialized institutions where pediatric oncologists and ophthalmologists are engaging, which will require most patients to travel far from their residence for treatment. After treatment they have to receive local follow-up examinations to check whether recurrence and metastasis develops or not. Thus, after the treatment during early childhood, they tend to lose connection with specialized physicians and hospitals. These treatment patterns are also reflected in the limited number of studies focusing on the care and support of patients after the treatments. In fact, most of the studies involve inpatients during hospital admission and include topics such as nursing practice during chemotherapy and radiation therapy<sup>9,10)</sup>, nursing practice in perioperative care<sup>11)</sup> and enucleation<sup>12,13)</sup>, general nursing practice<sup>12)</sup>, and education in genetics<sup>14)</sup>.

As RB is a childhood-onset disease, parents need to make decisions on which treatments should be chosen immediately after the onset. Many of them tell their children with RB about the disease after several years to ensure that the children have mentally grown up. During this period, it is necessary for parents to teach the children how to live with their disease, which includes telling them about their disease, showing the method to appropriately handle their artificial eye/eyes, and addressing genetic issues because of limited connections with specialized physicians and medical institutions by that time. Currently it is not too much to say that peer support networks supported by families' associations mainly follow the families of children with RB. Under these situations it has been shown that parenting of patients too much burden their parents, which indicates the necessity of nursing in long-term family follow-up<sup>15,16)</sup>. Specifically, support systems specializing in RB are required because of high probability of secondary cancer in case of bilateral RB and transmission of mutation to the next generation even if a complete cure was achieved in childhood. By exploring the parenting process of children with RB in view of how their parents guide patients toward acceptance of intrusive disease during early childhood, it may be possible to make clear the current status of parenting and to develop frameworks for the above-mentioned support. This study aims to explore the parenting process of children with RB toward disease acceptance.

## 2. MATERIALS AND METHODS

### 2.1. Study design

This is a qualitative descriptive study using Kinoshita's Modified Grounded Theory Approach (M-GTA)<sup>17,18)</sup>. In the M-GTA, data-based analysis is conducted to generate a substantive theory. It is suitable for a region that is characterized by a process-like phenomenon of the participants within the limited range<sup>17,18)</sup>. The phenomenon that is clarified in this study is a series of processes for parenting of children with RB through their parent's guiding them toward acceptance of

disease. In addition, considering that the data were limited to children with RB who took parenting at home after hospitalized treatment, an analytical procedure with M-GTA was thought to be suitable for our study.

## 2. 2. Participants

Subjects were included in this study if they met the following inclusion criteria : parents whose children under the age of 20 with unilateral or bilateral RB that had told their children about the intrusive disease. Such subjects were excluded if their children were in unstable condition under the treatment, or if the parents were unable to understand the purpose of the study.

## 2. 3. Data collection

The researchers contacted parents who belonged to a family group for children with RB. Data were collected through individual semi-structured interviews from November 2013 to April 2018. The interviews were conducted at the participants' workplaces or homes. The interviews lasted 95 min on average, ranging from 65 to 165 min. A semi-structured interview guide with open-ended questions was used to facilitate reminding them of past events. Interviewers were nurses with long experience of having written qualitative research papers. The interview guide was developed based on previous research and was pilot-tested. The guide covered the following topics : parents' emotions, thoughts, and reasons why they think or perceive so in the process of parenting of their children with RB in view of how they guided their children toward acceptance of the disease. The interviews were audio-recorded and transcribed verbatim by the first researcher. Field notes were taken to supplement the recordings.

## 2. 4. Analysis

To analyze the data, we used the M-GTA<sup>18)</sup>, which is a tool for data analysis developed by Kinoshita in Japan based on the Glaser and Strauss<sup>19)</sup> grounded theory approach (GTA). In the analytical procedures of M-GTA, an analysis focus and analysis theme are established before data analysis. Kinoshita explained that 'an analysis focus and analysis theme were to indicate the direction that the person would clarify

by an analysis'<sup>17, 18)</sup>. We collected data based on the study theme and established and adjusted the analysis focus and theme while confirming all the collected data. Our study's analytic focus was how parents who had told their children about their disease bring up their children. The analytic theme was the process of parenting of children with RB in view of how they guide their children toward acceptance of the disease. In addition, Kinoshita explained that 'data collection would end when we reached saturation (i.e., there was no further concept, category, [or] relationship between categories to be added in the analysis process)' <sup>17, 18)</sup>. In our study, we judged that the data had achieved saturation when data collection from eleven participants was completed, and therefore, we ended data collection.

Data was analyzed by (a) carefully and repeatedly reading and interpreting the meaning of the data, focusing on that which is relevant to the analytical theme and analytical focus to generate concepts using the analysis worksheet. One worksheet was prepared per concept, including the definition of the generated concept and the specific examples. (b) Considering the cases with generated similar or opposing concepts, we generated the next concept while continuously comparing them. (c) The data collected from the viewpoint of generated concepts were confirmed. The data that were judged as specific examples of the generated concept were added to the field of specific examples on the analysis worksheet. (d) Confirmation of the relationship between the generated concepts and generated categories. (e) Concepts that were unclassifiable as categories based on semantic similarities were classified as concepts <sup>17, 18)</sup> with similar interpretability to categories. (f) The mutual relation among the categories was examined, and a relationship diagram and storyline were prepared. (g) Core categories were generated to summarize the multiple original categories. All the transcription, categories, and concepts were initially provided and analyzed in Japanese. We then translated them into English and discussed and verified the comprehensibility and accuracy of the translation with a native English-speaking researcher.

## 2. 5. Trustworthiness

We confirmed the accuracy of the data by having the members check whether the captured articulations matched what the informants intended. In addition, the actual situations investigated and the contexts surrounding them were described in detail. The first researcher conducted all the analyses and discussed the interpretation and completeness of the data with the second researcher, who was a specialist in cancer care. Furthermore, the cancer care specialists were continuously committed to peer review using the generation method of concept and categories, along with assessments of the adequacy and relationships between the categories.

## 2. 6. Ethical considerations

Ethics approval for the study was obtained through the ethics review board of the University of Tokushima (1735–4). Before the study, we informed each participant verbally and in writing about the study purpose and assured them of independence and confidentiality. We removed identifying characteristics of participants, and potential participants were assured that nonparticipation would not disadvantage them in any way and that they could stop the interview at any

time. If they decided to withdraw consent, they could do so. None of the participants chose to do this.

## 3. RESULTS

### 3. 1. Participant

As shown in Table 1, the participants were parents of eleven children with RB. Mainly mothers participated in the interviews, and their age was approximately 35 to 50. In many cases, the mother told the child about the disease when they were in kindergarten. Six of them were unilateral RB and five were bilateral, and a further five among them were recurrent. Nine children had undergone enucleation operations and were equipped with an artificial eye or eyes. By the time of the present study, all children had completed treatment for RB. Their past treatments other than enucleation were chemotherapy, photocoagulation, thermotherapy, and intravitreal injection.

### 3. 2. Core categories and categories

As shown in Table 2, twenty-one concepts were generate, and nineteen concepts were classified into eight categories based on semantic similarities. The remaining two concepts were regarded as independent

Table 1 Participant characteristics

Interviewees	Disclosed Time	Disclosure	Part	Recurrent	Artificial eye	Treatment	
A	Mother, Father	Kindergarten	Mother	Unilateral	×	○	Enucleation of eye, Chemotherapy
B	Mother	Primary School	Doctor	Bilateral	○	-	Radiotherapy, Photocoagulation
C	Mother	Kindergarten	Mother	Unilateral	×	○	Enucleation of eye
D	Mother	Kindergarten	Mother	Bilateral	×	○	Enucleation of eye, Radiotherapy, Photocoagulation, Thermotherapy
E	Mother	Kindergarten	Mother	Unilateral	×	○	Enucleation of eye
F	Mother	Kindergarten	Mother	Unilateral	○	-	Radiotherapy, Chemotherapy, Photocoagulation, Thermotherapy
G	Mother	Kindergarten	Mother, Father	Bilateral	○	○	Enucleation of eye, Radiotherapy, Intravitreal injection, Photocoagulation, Thermotherapy
H	Mother, Father	Primary School	Mother	Unilateral	×	○	Enucleation of eye
I	Father	Primary School	Father	Bilateral	○	○	Enucleation of eye, Thermotherapy
J	Mother	Kindergarten	Mother, Father	Bilateral	○	○	Enucleation of eye, Radiotherapy, Intravitreal injection, Photocoagulation
K	Mother	Kindergarten	Mother	Unilateral	×	○	Enucleation of eye

Table 2 Categories and concepts

Core categories	Categories	Concepts
Helping the child develop a positive mindset to define the disease as a part of him/herself	Explaining to the child that enucleation was the inevitable choice to save his or her life	Explaining that it was a life-threatening, critical situation
		Teaching that nothing is more important than life
	Telling the child about his or her eye condition as a part of daily life	Mentioning the child's eye in ordinary scenes of daily life
		Handling the child's artificial eye as part of his or her body
	Helping the child understand the disease in a natural manner according to his or her growth stage	Considering the possible genetic influences of the disease, as the child grows
		Considering its impact on siblings
	Letting the child take care of him/herself as much as possible	Believing that the child will realize
		Neither hiding anything from the child nor regarding him or her as different
	Telling the child about the disease for his or her own sake	Telling the truth when answering questions
		Explaining to the child until he or she fully understands
Showing differences between the child and other children		
	Avoiding saying anything that does not need to be said	
Paving the way in advance for the child to live comfortably when his or her living space expands	Bearing the cross of having made the decision themselves	Feeling distressed and blaming oneself for not having given birth to a child with healthy eyes
		Only parents can protect their children
		Seeking knowledge to appropriately manage the child's disease for his or her benefit
	Facing the idea on impairment	
	Taking proactive actions for the child to lead his or her social life comfortably	Creating comfortable environments for children with visual impairment
		Helping the child become mentally prepared not to get hurt by others
Telling the child to seek help when having difficulty in doing something by him/herself	Using this experience to raise awareness of RB in society	
	Allowing the child to tell his or her parents even trivial matters	
		Creating an environment for the child to learn from his or her peer friends

categories. These categories and concepts were summarized into two core categories. A relationship among these ten categories and two core categories is comprehensively illustrated in Figure 1.

3.2.1. *Core categories ; “Helping the child develop a positive mindset to define the disease as a part of him/herself”*

This core category explains that in the process of parenting of children with RB while they guide their children toward acceptance of the disease, the parents hoped that the children would accept their current situation as positively understanding their disease and conditions rather than negatively perceiving differences

from other children.

3.2.2. *categories ; “Explaining to the child that enucleation was the inevitable choice to save his or her life”*

This category consists of explaining that the disease was a life-threatening, critical situation and teaching them that nothing is more important than life. It also explains that the parents kept explaining to the children that their lives had been saved by sacrificing their eyes. Therefore, they did not need to feel ashamed of their visual impairment.

*I carefully explained to my child that he wouldn't have survived if his eye had not been removed, and his eye had been sacrificed for his precious life. (K)*

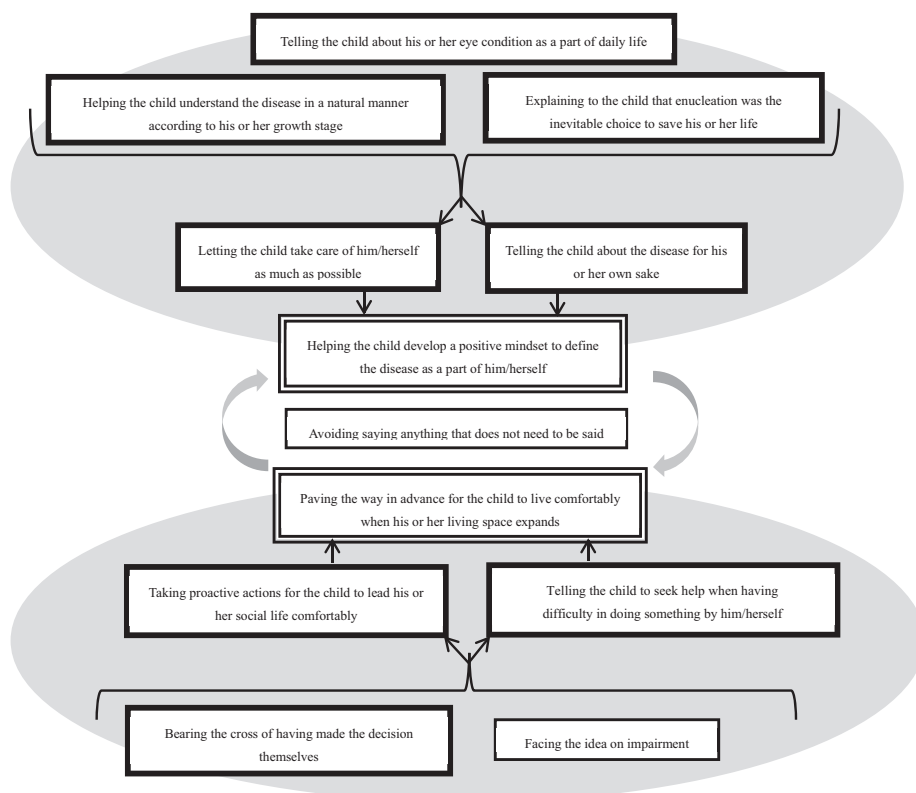


Figure Legend

▣ core categories, ■ categories, □ concepts with similar interpretability to categories, ← influencing direction, ⇄ circulating direction

Figure 1 Process of parenting a child with retinoblastoma while guiding him or her toward disease acceptance

3.2.3. categories ; “Telling the child about his or her eye condition as a part of daily life”

This category consists of mentioning the child’s eye in ordinary scenes of daily life and making them handle the child’s artificial eye as a part of his or her body. It explains that the parents guided the children toward the acceptance of their impaired eyes without a sense of resistance, making connections with everyday life activities.

*I have begun to wash his eye when we take a bath, considering that if he takes his eye out at another place, he might do the same at preschool. I hope he may learn to take his eye out only in the bathroom and never to do the same when he doesn’t take a bath. (A)*

3.2.4. categories ; “Helping the child understand the disease in a natural manner according to his or her growth stage”

This category consists of considering the possible genetic influences of the disease according to the child’s

growth and its impact on siblings. It explains that the parents helped the children understand the disease according to their growth stages considering the psychological influences given that RB is a hereditary disease and a form of cancer.

*I have been choosing topics according to the growth stage of my child. I have already told him that it is a bad thing. I pay attention to making sure that he understands what I tell him. When I found that he was too young to understand some topic, I decided to wait until he became old enough to understand it. (K)*

3.2.5. categories ; “Letting the child take care of him/herself as much as possible”

This category consists of believing that the child will realize and neither hiding anything from the child nor regarding him or her as different. It explains that the parents kept an appropriate distance from the children and watched over them believing in their strengths and tried to bring them out.

*I suppose that he will take care of himself. If he has a problem, he will say something to me. Therefore, I dare to leave it to him. (C)*

3.2.6. categories ; “Telling the child about the disease for his or her own sake”

This category consists of telling the truth when answering questions, explaining to the child until he or she fully understands, and showing differences between the child and other children. It shows the parents’ thoughts that it was their responsibility to help the child understand the disease for his or her own life and that they tried to face the child sincerely.

*For the sake of the child’s future and fulfilling my responsibility as a parent who made the decision to remove his eye, I think I should tell him why I made such a decision. (E)*

3.2.7. Core categories ; “Paving the way in advance for the child to live comfortably when his or her living space expands”

As the child grows, his or her living space will expand in parallel to kindergarten, elementary and junior high school, which means that children spend more time away from their parents, and need to take care of themselves. This core category explains that the parents took proactive actions for the children to lead their social lives without worrying about their disease while taking care of themselves.

3.2.8. categories ; “Bearing the cross of having made the decision themselves”

This category consists of feeling distressed and blaming themselves for not having given birth to the child with a healthy body, and seeking knowledge to manage the child’s disease appropriately for his or her benefit. It explains that even though the onset of the disease had occurred in early childhood, the parents continued to have a sense of guilt and felt responsible for making all treatment decisions for the children.

*I felt conflicted about making treatment decisions without consulting my child. I kept questioning myself, “Is this correct?” (G)*

3.2.9. categories ; “Facing the idea on impairment”

This category explains that as the parents were shocked when facing the fact of their children

becoming visually impaired, the parents realized that they had been prejudiced against impairment, and then they began to reflect their attitudes toward visual impairment and accepted the presence of such impairment in their children.

*To be honest, it took me a while to accept the fact that my child’s eye had been removed and that he had become visually impaired. It was not six months or a year. Actually, for the first couple of years, the thought that he was going to have an artificial eye for the rest of his life kept lingering somewhere in my mind, even though I tried to look cheerful. It was not easy for me to truly accept it, and I think it took me a while. (H)*

3.2.10. categories ; “Taking proactive actions for the child to lead his or her social life comfortably”

This category consists of creating comfortable environments for the child with visual impairment, helping the child become mentally prepared not to get hurt by others, and using this experience to raise awareness of RB in society. It explains that as anticipating difficulties in social life with visual impairment, the parents worked on the social environment in advance to create comfortable environments for the children to lead their daily lives.

*After all, I told the mothers around me about my child’s visual impairment first. If I clearly explained to other parents before they asked me about it, there would be no misunderstanding, I supposed. (A)*

3.2.11. categories ; “Telling the child to seek help when having difficulty in doing something by him/herself”

This category consists of allowing the child to tell his or her parents even trivial matters and creating an environment for the child to learn from his or her peer friends. It explains that the parents taught the children how to rely on the people around them, rather than keeping the disease-related problems to themselves, to prevent their loneliness.

*I said to my child, “You can seek help from your friends. If you tell them about your condition and ask them to help you, they will surely do so. You can also do the same with your teacher. All you need is to do this without feeling frustrated or ashamed of your difficulties. (B)*

### 3.2.12. categories ; “Avoiding saying anything that does not need to be said”

This concept helped keep the balance between “Helping the child develop a positive mindset to define the disease as part of him/herself” and “Paving the way in advance for the child to live comfortably when his or her living space expands”. It also created the uniqueness of each household based on the child’s condition, age, values, family structure, and regional characteristics.

*I thought, if I tell people that my child has cancer, they might be worried, so it would be better to avoid saying anything that doesn’t need to be said than causing unnecessary worries. (C)*

## 4. DISCUSSION

Based on the results, this section discusses the characteristics of the process of parenting a child with RB while guiding him or her toward disease acceptance.

### 4. 1. Process of parenting a child with RB while guiding him or her toward disease acceptance

Coordinating “Helping the child develop a positive mindset to define the disease as a part of him/herself” and “Paving the way in advance for the child to live comfortably when his or her living space expands” as a cyclical framework of parenting, while keeping balance by “Avoiding saying anything that does not need to be said”, the parents established their process of parenting a child with RB while guiding him or her toward disease acceptance according to their household situation.

“Helping the child develop a positive mindset to define the disease as a part of him/herself” indicates the necessity for patients with childhood cancers, which develop without subjective symptoms, to face their diseases as part of themselves. The process of facing one’s disease was also reported in a previous study examining the experiences of pediatric cancer patients, who tended to be unsatisfied with their current situation due to physical influences that remained even after treatment<sup>20)</sup>. Particularly, in

childhood-onset diseases, such as RB, parents make decisions, and treatments are performed based on them, as the patients are still very young. When these patients reach the age of reason, they have already returned to social life. Therefore, many of them grow up without understanding their diseases. In addition, in the case of eye diseases that others and patients themselves easily notice, the latter begins to wonder why they are different from others. Considering such difficulties, in the present study, the parents helped the children with RB accept their current situation as part of themselves and live their own lives with the disease. At the same time, as parents cannot protect their children forever, “Helping the child develop a positive mindset to define the disease as a part of him/herself” may be important for these patients to become able to take care of themselves when their social lives expand and establish the life task of establishing the ego as they grow up<sup>21)</sup>. Facing oneself as a person with a disease is also important to live independently and in his or her way both as a person and as a patient<sup>20)</sup>. This core category suggests that the parents attempted to prevent the children with RB from developing negative emotions by helping them accept their disease as part of themselves. Patients with RB as a hereditary disease also need to accept the possible future influences of the disease on the next generation and their current physical conditions due to their past cancer treatments. From a future perspective, the ability to manage one’s own body with concern is indispensable for accurately detecting and reporting secondary cancers that have occurred. In this respect, and to become able to take care of themselves, disease acceptance may be essential for children with RB. Some issues should be taught to these children at an early stage, as arrangements for them have been made based on their parents’ decisions thus far, and their eye disease influences their appearance. In contrast, other issues that are still difficult for them to understand, such as heredity, should be told to them according to their age. In the present study, the parents examined appropriate topics on the disease to convey to the children according to their growth stage. They waited



until the children became old enough while considering the necessity of continuously telling them about these issues and desiring to nurture their independence through parenting.

The other core category, "Paving the way in advance for the child to live comfortably when his or her living space expands", represents the parents' proactive actions to prevent the children from getting hurt in new social settings as their social lives expanded. It may have been based on the parents' desire to prevent further distress in the children, as they felt sorry and heavily responsible for these children, who had been suffering from RB, receiving treatment from early childhood, enduring inconvenient situations due to eye disease, compared with other children, and facing an increased risk of heredity.

Parents keep questioning whether what they are doing to their children is truly right and desire to be a good, full-fledged parent. Parenting is recognized as a matter of course and priority for everyone<sup>22)</sup>. Therefore, it is common to all the world that parents are regarded as responsible for the problems faced by their children, and parents tend to feel anxious and unsure about whether what they are doing is appropriate or hurting their children<sup>23,24)</sup>. The parents' concern over increased burdens on their children observed in the present study is not limited to RB but common to parenting cases. It may have arisen from the abovementioned parental responsibility as a characteristic of parenting.

Being concerned about their children, parents improve their parenting approaches, and they develop ideas for the early identification of abnormalities/illnesses and attentive care. For these reasons, worry is said to be the driving force for parenting<sup>25)</sup>. However, it has been reported that the parents of children with disabilities tend to be overburdened<sup>26)</sup>. Such burdens can be reduced by using highly specialized medical services. It has been reported that such services can be attained only through improving the quantity and quality of education among the healthcare professional team<sup>27)</sup>. Continuous support may be essential for these parents to make the most of their inherent parenting

abilities without an excessive feeling of guilt or anxiety. "Helping the child develop a positive mindset to define the disease as a part of him/herself" as an approach to promote disease acceptance and independence in the children and "Paving the way in advance for the child to live comfortably when his or her living space expands" representing the parents' proactive actions to protect the children seem to be contrary to each other. However, it was important for the parents to coordinate these to help the children accept themselves on a step-by-step basis, and the cyclic framework consisting of the two approaches was indispensable for the parents to support the children to live with the disease from early childhood. The parents controlled such circulation by "Avoiding saying anything that does not need to be said". When considering the children's levels of understanding RB as a hereditary disease, in addition to their status of disease acceptance, the parents needed to consider appropriate topics for them according to their growth stage. Therefore, they coordinated the two approaches according to the children's growth status, and such coordination may have been a background factor in the parenting differences among households of children with RB. Kujiraoka<sup>28)</sup> examined parents' independence from the perspective of parent-child relationships and noted that closed independence and open independence interact, maintaining an ambiguous, inseparable relationship. According to him, parents coordinate two parenting approaches: one based on closed independence, where parents regard themselves as responsible for actions and make parental decisions, and the other based on open independence, where parents recognize children's independence and keep their parent-child relationships in balance. This may be similar to the cyclic framework of parenting, consisting of "Helping the child develop a positive mindset to define the disease as a part of him/herself" and "Paving the way in advance for the child to live comfortably when his or her living space expands" observed in the present study.

#### 4. 2. Implementations for practice

The core category "Paving the way in advance for the child to live comfortably when his or her living

space expands” suggests that helping children with RB expand their social lives at the time of life events is an effective intervention approach. Specifically, as there are various issues related to this disease, such as cancer, artificial eye/eyes, and heredity, parents need to tell the children about their disease once and at various times, according to their age. Therefore, it may be important to provide information for these parents, such as the children’s learning ability levels and understanding at each developmental stage. Moreover, “Paving the way in advance for the child to live comfortably when his or her living space expands” indicates the necessity of considering anxiety and a sense of guilt in parents as a background factor.

More importantly, in RB as a childhood-onset disease involving issues related to heredity, nurses themselves should recognize that problems tend to occur at the timing of life events and provide support from a comprehensive perspective, rather than focusing only on the treatment period.

## 5. Limitations of the study

More extensive RB research should be collected to generalize the results. Additional data collected during each period based on the children’s age will also be required to examine changes according to growth stage, as the parents’ approaches also changed with the children’s growth in the study. In addition, the influence of being heredity or not should be taken into account in the future.

## 6. Conclusion

By analyzing the process of parenting a child with RB while guiding him or her toward disease acceptance, twenty-one concepts were created, and nineteen concepts were classified into ten categories based on semantic similarities. The two other concepts showed similar interpretability to categories. These categories and concepts were summarized into two core categories : “Helping the child develop a positive mindset to define the disease as a part of him/herself”

and “Paving the way in advance for the child to live comfortably when his or her living space expands”. These two core categories constituted a cyclical framework of parenting, where the parents coordinated these two approaches while keeping balance by, “Avoiding saying anything that does not need to be said” and established their process of parenting a child with RB while guiding him or her toward disease acceptance, according to their household situation. The results suggest the necessity of recognizing that in childhood-onset cancers, such as RB, and diseases involving genetic issues, problems tend to occur not only during the treatment period but also at the time of life events and providing support from a comprehensive perspective.

The researchers confirm that there is no conflict of interest related to the manuscript.

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