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Structure and Process of the Paternal Role of Very Low Birth Weight Infants

Rika Nakatomi¹, Satoshi Takada²

Abstract

The purpose of this study was to clarify the structure and developmental process of the paternal roles in the family with a very low birth weight (VLBW) infant. Subjects were eight fathers of VLBW infants among the 14 fathers who had been interviewed when their children were in the neonatal intensive care unit (NICU) and at one month after discharge. Follow-up interviews were conducted, when their children were nine years old. Six fathers dropped out of follow-up interviews because of their moving to remote area or private reasons. Qualitative semi-structured interviews were completed focusing on structure and developmental process of paternal role. Two of the eight children developed cerebral palsy. Fathers of VLBW infants were 《Building the child regular life》 together with their wives on the premise that the child would have <Growth peculiarities>. They also wished for further self-reliance, i.e., <Adding a zest for life>. Values were transformed, and the child rearing path dictated from there. Fathers of normally developed children proceeded in the direction of <Growth development>, while fathers of children with cerebral palsy proceeded in the direction of <Growth stability>. The foundation of the fathers' sense of parenting and paternity was formed in the NICU; suggesting the influence of change in values toward the paternal role after discharge and development of family functioning.

Key words:

Grounded theory approach, Paternal role, VLBW, Cerebral palsy, Growth stability, Growth development

I. Introduction

The survival rate of infants with very low-birth-weight (VLBW) has improved in Japan due to progress in neonatal and perinatal treatment. In particular, the survival rate of children with extremely low-birth-weight (less than 1000g) has been dramatically improving¹⁾²⁾. Presently, many VLBW infants are discharged from the neonatal intensive care unit (NICU) to live at home with their families, although there are reports of a high incidence of neurological aftereffects, delays in motor function, mental development and behavior, and a susceptibility to learning problems during school age amongst these children³⁾⁴⁾. The families of VLBW infants experience anxiety and stress even after their children's discharge from NICU. Kono et al pointed out that a more detailed follow-up system for long-term prognosis and providing child rearing support to parents is required⁵⁾⁶⁾.

In addition, there are reports concerning the stress and child rearing experience of the father, apart from the mother, with regard to the support of families with VLBW infants⁷⁾⁸⁾. Paternal role is commonly defined as a prescribed or expected behavior associated with a father in family. Fathers not only experience anxiety about their

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VLBW infants but also a heavy mental burden such as the conflict between their roles, including those at work and in the family. In addition, the images of children they held when their children stayed in NICU, continue to exist for some time after discharge.

However, few reports of longitudinal studies of the involvement of the father with the child and the development of paternal role after the child's discharge from the NICU exist. The Ministry of Health, Labour and Welfare in Japan has been emphasizing the importance of paternal role and father's participation in child rearing in Healthy Family Project of 21 Century⁹⁾. As father's support is essential to rear a high risk infant, it is extremely important to examine the paternal role of VLBW infants and analyze the family support of high-risk infants from the father's perspective.

We recently studied 14 fathers of VLBW infants concerning the developmental process of paternal roles and related factors in the period from birth until one month after discharge. We reported that the father of a VLBW infant is the first family member to be involved with the child and medical professionals after the birth. From our previous study, it became clear that fathers formed a strong bond as a family member amidst the special birth situation and environment. They built up an understanding of their VLBW infants, and started family life by focusing on their partnership with their wives. In this study, we tried to expand our longitudinal study of VLBW infants until the age of nine, as nine years old is a key age in behavior development ⁵⁾.

II. Research method

1. Study design

Qualitative inductive method was utilized in this study, because qualitative method is appropriate to understand unknowing phenomenon. We had examined the structure and developmental process of paternal roles of VLBW infant by using grounded theory approach, which clarified the paternal roles in the period from their child's birth until one month after discharge.

2. Subjects

Eight out of 14 fathers who had participated in our previous study took part in this study. Six of 14 fathers dropped out of this study. Four of them moved to remote area, and two fathers did not consent due to their private reasons. All families were nuclear families with a mother and a father, and the VLBW infants subject was the parents' first child born in a comprehensive perinatal care center.

3. Data collection

Semi-structured interviews based on the conceptual framework obtained from the previous study were conducted for this study. Questions regarding 'feelings towards the child and wife, feelings towards childcare, the father's personal experience with changes in lifestyle and work, and so on' were asked. A focus was placed on 'role behavior' and 'behavioral factors' that are central to raising VLBW infants. The mothers were asked questions to supplement and confirm the opinion of fathers. The interviews were conducted during a home visit and lasted between one and one and a half hours. These interviews were recorded with the consent of the subjects, and data was collected from October 2010 to March 2011.

4. Data analysis

Analysis was conducted according to the grounded theory approach. The texts created from the interviews were divided into the smallest units that could be interpreted concerning the 'paternal role' analysis theme; the properties and dimensions of each section were extracted, and labels were created to represent the section name based on those properties and dimensions. Following this, similar labels were put together in categories. Next, these categories were classified as circumstances, action/interaction, and outcomes using a paradigm, and story lines were created. All process of analysis in this study was completed under the supervision of specialists in pediatrics and neonatal nursing to ensure validity.

5. Ethical considerations

This study was conducted with the consent of Ethics Committee of the Kobe University Graduate School of Health Sciences. The subjects' consent was obtained after they were informed, orally and in writing, of the purpose and content of the study. Their cooperation in this study was voluntary, and cancellation of their participation during the study was possible; thus, no disadvantage would arise in such a scenario. Furthermore, we promised the subjects that data would not be used for any purposes other than research, and their anonymity and personal information would be protected.

III. Results

During the follow-up period after discharge, it became clear that there were two cases of cerebral palsy (one complicated by chronic lung disease) amongst the eight subjects. The remaining six subjects were diagnosed as being normal at the age of nine years. Table 1 displays the attributes of these fathers and children. Obvious differences were observed in the structure of the paternal role between the group of subjects who progressed normally and those who developed cerebral palsy. As such, the groups were separated, and a conceptual diagram was created. Both groups shared a «core category» as the core concept of the phenomenon, and 7 <categories>-related core category, and 15 {concepts}. The fathers' remarks are shown in italics with “ quotation marks”.

«Build a regular life with the child» was made the core category from the proposition<Growth peculiarities> being a process of the paternal role structure in both groups. The result of <Growth development> in the group of fathers of normally developed children and <Growth stability> in the group of fathers of children with cerebral palsy was extracted in three stages (Figure 1). The process and structure of paternal role is described below while clarifying the shared and unshared concepts of both groups.

1. <Growth peculiarities>

Both groups of fathers, i.e., those of normally developed children and those of children with cerebral palsy, began child rearing with the recognition that their VLBW infants were different from normal newborns and were {Starting from behind}. Because their children were {Starting from behind} they were involved with their children while bracing themselves for the possibility of future disabilities or disadvantages in growth and “*not being surprised at whatever may occur.*” Both groups developed a relationship with their children with a premise of <Growth peculiarities>.

Table 1: Outline of subjects

Subject	Age (Years)	Occupation	Gestational period	Birth weight	Existence of Complications	Outpatient status	School
Case 1	41	Company employee	36 weeks, 4 days	1446 g	None	Complete	Regular school
Case 2	44	Company employee	28 weeks, 3 days	1302 g	Cerebral palsy	When necessary	Special needs school
Case 3	47	Self-employed	25 weeks, 4 days	734 g	Cerebral palsy, chronic lung disease	Regular	Special needs school
Case 4	39	Self-employed	32 weeks, 4 days	862 g	None	Complete	Regular school
Case 5	37	Company employee	23 weeks, 6 days	1) 567 g	Chronic lung disease	When necessary	Regular school
				2) 618 g	None	When necessary	Regular school
Case 6	39	Company employee	34 weeks, 2 days	1398 g	None	Complete	Regular school
Case 7	47	Teacher	36 weeks	1497 g	None	Complete	Regular school
Case 8	41	Teacher	28 weeks, 4 days	840 g	None	Complete	Regular school

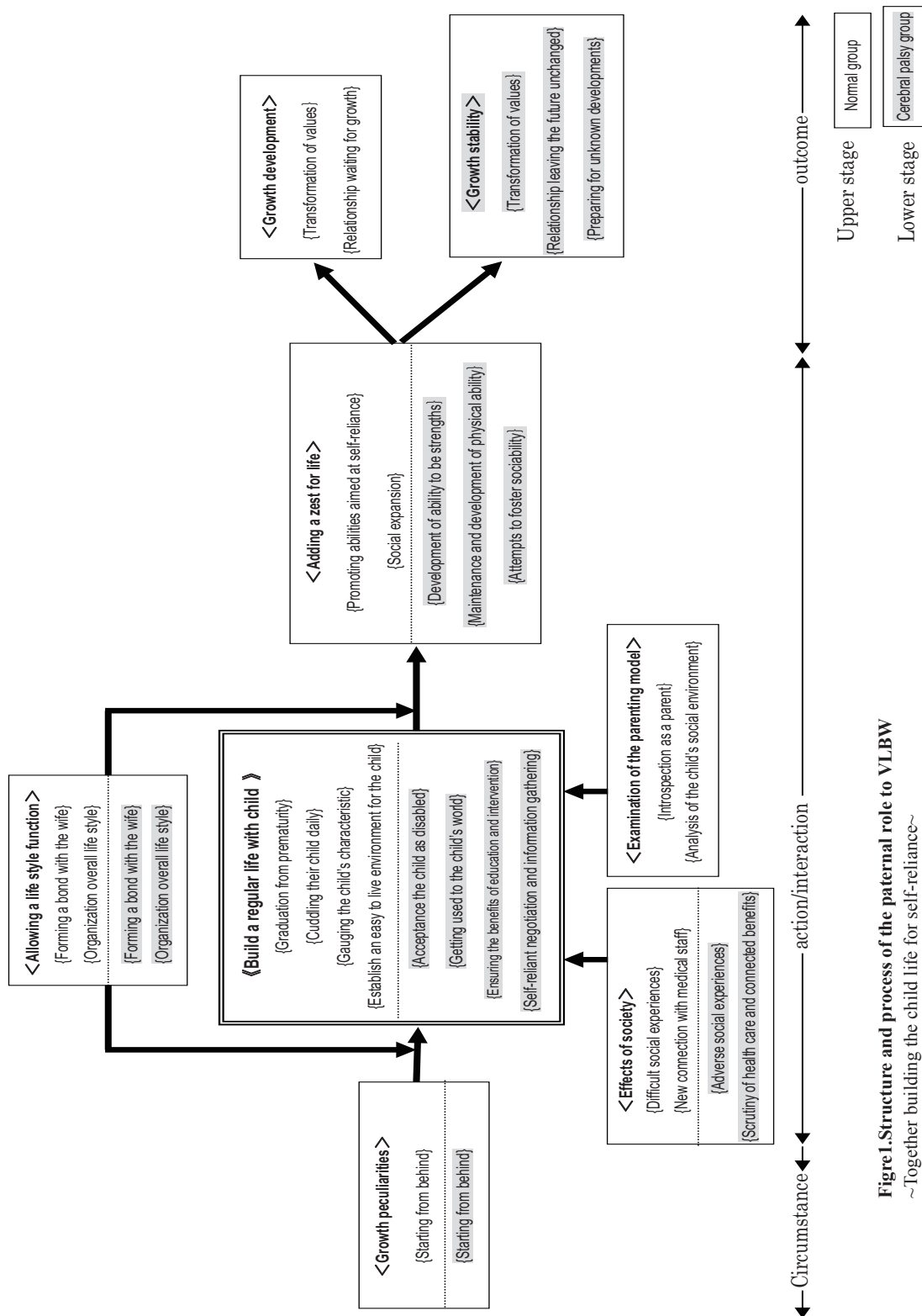


Figure 1. Structure and process of the paternal role to VLBW
~Together building the child life for self-reliance~

2. 《Build a regular life with the child》

The group of fathers of normally developed children responded to their children's normal progress at the age of nine years by continuing child rearing with the attitude of *"they are still young and fortunately normal"* and {Graduation from prematurity}. On the other hand, the group of fathers of children diagnosed with cerebral palsy during the course of their growth stated that they had a feeling of *"When the doctor said 'Your child has cerebral palsy,' instead of shock, I had a feeling of 'Ah, just as I thought'."* Because they were braced to {Start from behind} and had expected a diagnosis from the strangeness of their child's movements, they continued child rearing with an {Acceptance of the child as disabled}.

While children were thought of as having {Graduated from prematurity} their fathers were concerned about their steady growth; they {Cuddling their child daily} and *"enjoyed asking them about their day at school although they were concerned as to whether they were participating properly with other children"* due to their <Growth peculiarities>. The strengths and weaknesses of the children were discovered during school and daily life: {Gauging the child's characteristic} i.e. *"The children may be slower than others, but it's good that they never give up."* In addition, these characteristics were considered factors of the premature child's <Growth peculiarities> and the fathers endeavored to {Establish an easy-to-live environment for the child} so the children could be themselves in group living by *"explaining to their teacher that the child is premature and making the teacher aware of the child's characteristics."* Furthermore, the fathers endeavored to 《Build a regular life with the child》.

Children are exposed to <Effects of society> such as {Difficult social experiences} during school life *"I am concerned that children could become a target of bullying and teasing because of their small physique."* Children are also exposed to {New connection with medical staff} *"it's OK to go and ask when necessary"* and *"the child's roots are at the hospital"* were related to factors affecting 《Build a regular life with the child》. Furthermore, <Examination of the parenting model> was performed through {Introspection as a parent} *"noting what other parents have said," "what is important in raising a child?" and analyzing the child's environment "growing children are like robots that do not think for themselves" and "children have a strange way of playing."* The father gained feedback to {Establish an easy-to-live environment for the child}. This <Examination of the parenting model> also influenced <Adding a zest for life>.

On the other hand, the group of fathers of children with cerebral palsy gradually {Getting used to their child's world} *"the child's state has already become normal,"* while struggling to have a mutual understanding with their children *"what do you think, what kind of condition should I infer from the behavior and situation at the time?"* Simultaneously, the fathers suffered {Adverse social experiences} such as discrimination and inexpediency from public institutions in the selection of the child's school and intervention facilities and {Scrutiny of health care and connected benefits} became necessary to receive appropriate intervention. These <Effects of society> caused great difficulties in {Ensuring the benefits of education and intervention} *"We have moved several times in search of places that will accept my child with little information," and "the doctors' policies and our wishes are completely different. We have visited many different places and feel like rehabilitation refugees," "Even if we finally met people like us in follow-up meetings regarding the growth of premature children, they had a different purpose, and there was no meaningful information."*

To deal with the <Effects of society> and {Ensure the benefits of education and intervention} fathers repeatedly engaged in {Self-reliant negotiation and information gathering}. By means of accumulation *"I have gathered information in every possible way, but the information available is limited"* and *"the only option is to repeatedly negotiate by ourselves and be prepared,"* the fathers could 《Build a regular life with the child》.

In addition, both groups of fathers, by 《Build a regular life with the child》 wished for a future in which the child could live under their own power <Adding a zest for life>. The fathers of the normal group of children {Promoting abilities aimed at self-reliance} by encouraging their child's perseverance *"Even if you are clumsy,*

you can do it. You can do it if you try" and fostering independence *"By making them do it themselves no matter how long it takes,"* *"Wanting to give them extra abilities,"* and the development of physical function *"Athletics and swimming are good for the lungs."* By devoting their time to allow their children to be exposed to various experiences {Social expansion}, they provided their children with a catalyst for change: *"It looks like something will trigger a change, I am expecting it,"* and {Social expansion} was linked to <Adding a zest for life>.

The group of fathers of children with cerebral palsy had perceived abilities of their children in mind {Development of ability to be strengths} and desired for them to be able to live despite their disability. *"Their memory is astonishing, similar to that of the children on television; can it not be used somehow?"* *"It is not worthwhile doing anything halfway. If they are amiable, it is better to do things properly while being helped by everybody."* In addition, they engaged in {Self-reliant negotiation and information gathering} to try to recover and maintain ability as much as possible while assessing their child's symptoms and functional level in daily life. Furthermore, they strived for {Maintenance and development of physical ability} through devices and movement support in daily family life as well as in appropriate places of treatment and intervention: *"Should we try the hospital recommended by the teacher? Maybe it will help my child to grow?"* *"The child does not stand often; hence, I changed the position of the TV and installed hand rails."* Furthermore, fathers {Attempts to foster sociability} while watching the reactions of their children to allow them to understand the ethics and morals needed to live in society: *"Do they understand a scary face? It seemed as though they were calm,"* *"They think it's playing when they thump someone's head, they do not understand. What should I do?"*

3. <Growth development> and <Growth stability>

As a result of <Growth peculiarities>, a {Transformation of values} toward child was observed in fathers of both groups, and it dictated the way they related to their children. The fathers of normally developed children ended at <Growth development> while those of children with cerebral palsy ended at <Growth stability>.

The most important value for fathers of normal children was the health of the child, and they attempted to respect the child's pace by {Gauging the child's characteristic} from their <Growth peculiarities>. *"I do not have a sense of duty that I should do things this way."* *"It is a shame they can not do it, but I wonder what effect excessive pressure has on them. They may be able to do it once they reach puberty."*

On the other hand, the fathers of children with cerebral palsy recognized their <Growth peculiarities> as a disabled child, their unstable physical symptoms, and the lack of future prospects: *"Initially I tried to treat it somehow, but then the reality became obvious. Are things ok as they are? What will gradually happen? I do not know what will happen in the future, and I try not to think about it. It is good that the child attends school now, but there are no plans for future."* On the basis of coming to terms with reality without thinking about the future {Relationship leaving the future unchanged} they took a stance of thinking that it is alright if there is no change in the child's health and physical condition and desired <Growth stability>. Here, {Preparing for unknown developments} could be seen: the fathers were always mindful of their experience of the child's unstable symptoms and unforeseen events. *"Further epileptic seizures may occur or other illnesses may arise."*

4. <Categories> observed in the complete process of 1–3

<Allowing a life style function> categories were seen in both groups in a three stage process. In daily life, fathers adopted a collaborative system together with their wives and strived to <Allowing a life style function> with a focus on {Forming a bond with the wife} on the basis of gratitude, consolation, and trust toward them. Complimentary marital relationships with a strong sense of support were observed in the fathers of children with cerebral palsy: *"I use information from my wife in negotiations,"* *"my wife is my greatest supporter."* It was also observed that the fathers of normally developed children primarily viewed their marital relationship as a partnership *"My wife and I always have a mutual understanding of the child"* and *"I value the mere existence of my wife."*

Simultaneously, fathers practice {Organization overall life style} so all family members could live smoothly in order to <Allowing a life style function>. When organizing, fathers of children with cerebral palsy made specific

arrangements centered on their child's daily life *"I moved to a home with no elevators or steps in an area where the child can attend a special needs school"* and *"I installed hand rails in the room to make it easy for my child to stand;"* attempted to balance work and family care *"we both felt like we would collapse, so I took two months off work with the welfare system "* invested in support resources *"I got a helper to assist with bathing;"* and set an environment where the family could function. Fathers of normally developed children arranged roles within the family moment to moment *"I come home as early as possible to do the housework and childcare"* and aimed at balancing work and family care.

IV. Discussion

The feature of this study was that it longitudinally analyzed paternal role of VLBW infants over a period of nine years. In addition, two subject children developed cerebral palsy, and we were able to clarify what kind of transition occurs in the paternal role with respect to normally developed children versus children with cerebral palsy. A qualitative data analysis was applied in this study, because it provides depth and detail even though the sample size was limited. Although the number of subjects was limited, it is thought that these will be considered significant findings upon analysis of numerous examples in the future.

A structure of coming to terms with reality while switching between past and present and developing child raising and the family was found as the role of fathers of very low-birth-weight infants. Family subsystems such as the marital unit and the social environment influenced that process.

The <Growth peculiarities> of children born prematurely are superimposed on daily life and were looked at as the origin of the nature and behavior of the child. The fathers had to reconcile their hopes as a father with the actual condition of the child. On that basis, the fathers attempted to *《Build a regular life with the child》* in order to construct a stable daily life for the child; this was done with an interaction between the father and child and joint interaction with both parents. Fathers complemented the characters of their very low-birth-weight infants, encouraged their abilities and <Adding a zest for life> so the child could live independently in society. Their values changed, and they decided on the path to raise their child. These factors were at the center of the structure and process common to both groups.

In general, paternity consisting of the father's early developmental history and self image forms the core of the father's parenting, and it has been established that their marital relationship and work-life balance also has an influence^{(11) (12)}. In addition to this, a connection with the child's nature and development has also been reported⁽¹³⁾. The results of this study were similar but instead of the early developmental history and self image passed on to paternity, negotiation and direct interaction with the child rooted with growth peculiarities formed the core and *《Build a regular life with the child》* with the wife and child was required for parenting. Parents of VLBW infants are required to be flexible without sticking to the standards and methods of the hospital in order to support their children, who change on a daily basis⁽¹⁴⁾. In our previous study, fathers had the same kind of flexibility and developed their parenting from direct interaction with their children⁽¹⁰⁾. From these circumstances, it is thought that there are no differences observed at the heart of fathers' parenting. Kawai et al identified that paternity, which forms the core of parenting, is influenced by the father's own relationship with his parents and pointed out the importance of the intergenerational transmission of the parent-child relationship⁽¹²⁾. However, fathers of VLBW infants relied not only on their relationships with their parents but also on fathers of the same generation and their experiences for <Examination of the parenting model>. This is thought to be because they had built up the role of a father by themselves based on recognitions during admission to the NICU such as *"My child does not fit the criteria"* and *"My child is special"*⁽¹⁰⁾. Therefore, it may be possible to recapture intergenerational paternal transmission in this study as transmission from the father at the time during NICU to the father at present after discharge. Simultaneously, the structure of parenting development while switching between past and present observed in

this study is thought to be a phenomenon common with intergenerational transmission. The reason <Examination of the parenting model> was not observed in fathers of children with cerebral palsy is because their thoughts of “*My child does not fit the criteria*” resulted from the fact that their VLBW infants developed into children with disabilities; their strong tendency of parenting centered on the function of the marital unit.

Fathers of VLBW infants <Adding a zest for life> to their children and attempted to encourage their child’s ability. According to Lamb, fathers nourish their child’s sociability and sense of independence from childhood, promote their growth, and adopt the role of connecting their child and society¹⁵⁾. Furthermore, fathers of VLBW infants attempted to nourish their child’s sociability and sense of independence, although this was done with the strong implication of compensating for the child’s weakness as a VLBW infant. It is reported that there are tendencies of a strong sense of control by pampering and excessive interference in parental attitudes toward child rearing in very low-birth-weight infants due to the constitution of children¹⁶⁾. However, although the fathers in this study tried to protect their children, they tended to respect them without being overprotective and interfering excessively. This is because their acceptance of the reality observed within the structure and achievement of a {Transformation of values} directed them towards a parental attitude of respecting the child’s growth.

The marital relationship, apart from influencing the role of the father of VLBW infants, contributed to <Allowing a life style function>. This is because, fundamentally, a marital relationship is always a joint structure. Maternal support is given as a role of the father in child rearing support for VLBW infants. However, rather than simply support for the mother, it was thought that this role is more specific and functioned to develop the father’s own role and family function.

On the other hand, although the fathers of children with cerebral palsy gave similar support as the fathers of VLBW infants with normally developed children, they received greater and different <Effects of society> due to their children’s sequelae. As a result, they devoted a lot of energy to {Self-reliant negotiation and information gathering} when they 《Build a regular life with a child》. However, this also resulted in a change to a more supportive marital relationship. A tendency for fathers of children with a disability to try to overcome whatever may happen with just the marital unit has also been reported¹⁸⁾. This study also suggested that marital units worked effectively to <Allowing a life style function> with the {Organization overall life style}. In addition, the meaning of <Adding a zest for life> for the group of fathers of children with cerebral palsy was uncovering their children’s specialties and strengths to allow them to live amidst the unknown future and simultaneously achieving a {Transformation of values}. A transformation of values has been observed in parents who have accepted their child’s disability¹⁹⁾. In this study, the fathers had the attitude of {Starting from behind} from the birth of their children and had predicted a disability in their child from their regular life. The accumulation of regular life with their child while having these attitudes and predictions was thought to be connected to a {Transformation of values} as well as one of the factors leading to acceptance. This {Transformation of values} was speculated to have led to <Growth stability> a conclusion different from the group of fathers of children with normal development.

This study further suggests the possibility that the basis for the transformation of values and flexibility required for paternity and child care may be formed when the child is in NICU. In addition, as little information is available, it is difficult for fathers of children with cerebral palsy to ensure a location or a suitable education/intervention environment; a tendency of detachment from continued follow-up was observed. It is necessary to review the follow-up system and the provision of information regarding intervention closely linked to daily life in cases where there is the possibility of neurological sequelae. Further studies with more sample size data will be required to clarify this point.

V. Conclusion

1. The fathers of VLBW infants took the behaviors such as 《Build a regular life with the child》, <Adding a zest

for life> based on the assumption <Growth peculiarities>.

2. The group of fathers of normally developed children aimed at <Growth development>, while the fathers of children with cerebral palsy aimed at <Growth stability> as conclusion of parenting.
3. The structure of the paternal role was changed as time passed. Paternal role was transformed according to the values of family, which was influenced by the child's past and present condition.

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