



Perceptions and Feelings of Fathers of Children With Down Syndrome



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A B S T R A C T

Purpose: This study aimed to obtain information about the lives of families with children with Down syndrome through interviews with the fathers.

Methods: The participants were 9 fathers who were recruited from the local Association of Parents of Down syndrome. Their children were born between 1996 and 2009. The study used a descriptive exploratory design utilizing a focus group.

Results: Through analysis of the fathers' transcripts, 7 major themes emerged: 1) crisis of life, 2) emotional turmoil, 3) attitudes toward the disability, 4) parental responsibility, 5) realization of fatherhood, 6) difference of feelings between mother and father, and 7) contact with people.

Conclusions: Fathers were upset with the fact that their children were born with Down syndrome. However, they accepted fatherhood through child-rearing in cooperation with others. The experience of fathers in this study provides practical points for caring for families with children with Down syndrome.

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All parents want their baby born healthy. The birth of a child with Down syndrome is a challenging event for a family. Although most parents experienced shock soon after they knew of their child's disability, they had to begin to raise their child. Raising a child itself produces stress and this is affected by many factors, such as child behavioral problems, infant temperament, and child characteristics. Developmental disabilities of children is also one of these factors. Dyson (1997) reported that parents of children with disabilities showed significantly greater amounts of parental stress compared to parents of children without disabilities. Parents of the children with Down syndrome also experienced more parent-related stress, difficulties in perceived parenting competence and more health problems (Roach et al., 1999). However, most of the studies that focused on the intellectual disabilities (ID) showed lower stress levels in mothers of children with Down syndrome than in those with other types of ID (Kasari & Sigman, 1997).

Although there are less studies on stress of fathers, the factors which contributed to the fathers' stress are said to be different from those of the mothers. Through path analyses from the results of a questionnaire of parents of school-aged children with disabilities, Keller & Honig (2004) revealed that children's demand and need for care was related more to maternal stress and the child's acceptability was related more to paternal stress. These differences possibly are caused by the degree of father's involvement in child care. Saloviita et al. (2003) said that the single most important predictor of parental stress was the negative definition of the situation. In mothers, the negative definition was associated with the behavioral problems of the child, while in fathers it was connected with experienced social acceptance of the child. Fathers are

perceived as peripheral or exterior members of the family system. In order to support mothers who are experiencing hardships, fathers may make important contributions to maternal, child and family well-being in families of children with developmental delays (Simmernan, Blacher, & Baker, 2001; Dyson, 1997; Saloviita, Itälänna & Leinonen, 2003).

During the last few decades, fathers have been required to participate more in child care in Japan. When fathers assumed greater responsibility, it is important to understand the fathers' role, and how they accept the situation of the child. However, even now mothers mainly take the child care role. To reduce the stress of mothers it is critical to temporarily release the burden of childcare (Suda & Sakata, 2006). Although Down syndrome is thought to be a major intellectual disability in only a minority of children, the support system in Japan is insufficient. In such a difficult situation the stress of mothers raising a disabled child varies according to participation of father (Asakura & Takahashi, 2007). Again, there is a very little research on fathers with disabled children in Japan.

Meanwhile, perspectives of the disabled have been changing recently. The World Health Organization approved International Classification of Functioning, Disability, and Health (ICF) for a classification of functioning in 2001. ICF highlights the association with environment. However, people's views of disability do not change so easily.

This study focuses on fathers' views, and has gathered information to consider what factors make fathers and their families adapt well. Special consideration will be made on the following points of fathers' feelings through rearing a child with Down syndrome: 1) how to become a father, and 2) thoughts and expectations on the other family members of having a baby with Down syndrome. To identify these two points, fathers were asked to reflect on the days of their child with DS from birth to toddler. Down syndrome is a congenital disorder. However, father's experience and feelings are similar to those of the child in terms of experiencing

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stigma. Thus, the findings from this study will help to support families with members suffering from psychiatric disorders, such as schizophrenia.

METHODS

Participants

Nine fathers of children with Down syndrome were recruited from the Local Association of Japan Down Syndrome Society. Their children were born between 1996 and 2009.

Design

Qualitative design; a descriptive exploratory design utilizing focus group interviews was used to clarify the experience of fathers.

Period

From Sep. 17, 2011 to Jan. 19, 2012.

Data Collection

One of the authors built a close relationship with the Local Association of Japan Down Syndrome Society through supporting families, and in August of 2011 a formal request to recruit participants of the focus group interview was delivered through the association. The reason of using a focus group was that the discussion and debate generated through group interaction would facilitate an understanding of participants and specific issues (Krueger & Casey, 2000). At first, three fathers agreed to attend the focus group interview. The age of children with Down syndrome in this group ranged from 9 to 18 years. Three infants' fathers attended the second group. The age of children with Down syndrome of the second group ranged from 3 to 7 years. The remaining three fathers participated on an individual basis by their request, however, these data were used to confirm the fundamental feelings of fathers. All interviews were carried out in a quiet room situated at University of Yamanashi or at a place appointed by the participants. All participants consented to having their interview recorded, and a verbatim recording was made. Interviewers were author's K.T & Y.Y. and the average duration of the interviews was between 1 and 2 hours. Interview questions were as follows: 1) how do you feel when your baby was born with Down syndrome, 2) are there any difference in feelings between you and your wife, 3) how the other family members react to the birth of a child with Down syndrome, and 4) under what circumstances do you feel you are father of your child with Down syndrome.

Data Analysis

KJ method (Kawakita, 1967, 1970) of content analysis of the interview data was carried out, and a transcript of the interview was analyzed repeatedly to gain a holistic sense of the interview, with a focus on the subjects' feelings and thoughts. Then, the authors independently summarized the descriptions of the father's experiences into brief expressions and sub-themes. These sub-themes were then compounded into major themes, and repeated analyses of similarities and differences were carried out through the discussions by the authors. When no new themes emerged, it was judged that data saturation had occurred. Moreover, the authors compared and contrasted the themes, and then confirmed them with the fathers to maintain coherence and reliability of the analysis.

Ethical Considerations

The present study was conducted with approval of the University of Yamanashi Faculty Ethics Committee (Approval number 838). Prior to the interview, attending researchers explained the purpose of the study, its voluntary participation and the confidentiality of the

information to the participants both orally and in writing. Written consent was obtained from all the participants.

RESULTS

The age of fathers varied from 30s to 50s. The mean age of the children with Down syndrome were 11.0 years (SD = 6.3, max = 20, min = 3). There were six families in which the first child was born with Down syndrome.

Through analysis of 9 fathers' transcripts, the fathers' experience revealed 7 major themes. Italics indicate each category within the theme (Table 1).

Theme 1: Crisis of Life

Crisis of Life

Some of fathers faced a possible child's death soon after he/she was born because of the child's situation. On the very day of the child's birth, one father had to go quickly to the hospital and stay there all night due to the critical condition of both the child and the mother. Five fathers related the experience of their child being brought to the neonatal intensive care (NICU) immediately after childbirth; they could not take the baby in their arms or see the child's face. They saw their child wearing an oxygen mask or something similar. Finally they knew that their child's life was saved, with the prospect that it would survive.

"My baby's life was finally saved (D)."

Theme 2: Emotional Turmoil

Shocked by the Child's Condition

Fathers were shocked by the fact that their child was born with Down syndrome. However, some said that there was no point in crying, and then tried to find some way to help the child.

"I wanted to cry, but there is no point in constantly crying (D)."

Following the initial shock, there was also a difficulty for fathers to accept the fact that their child was born with a disability because they could not see anything wrong with the child. Some fathers had sensed something wrong with the child, but they did not connect that feeling with the child having Down syndrome. Some wanted to deny the fact.

"My child has something wrong but I surely did not think he/she had Down syndrome (A, G)."

The definitive diagnosis took place about one month after childbirth. Although the fathers faced emotional turmoil during this period in accepting the fact that their child was born with Down syndrome, they recognized that they were needed at this time. The duration for acceptance varied among fathers.

Child's Life

After regaining hope of the child's life, fathers began to think about the meaning of the child's life. They wanted to know why the child was born with a disability.

"I want to know why my child is born with disability (C)."

Theme 3: Attitudes Toward the Disability

Image of Disability

Disability is incurable, and therefore, the image of disability was negative. One father said, *"considering my child's situation, Down syndrome was even more painful than heart disease for me (I)"*. One father heard of parents who refused to raise their child with Down syndrome, but he did not want to behave in such a way toward a human being.

"I can't believe that there is a parent who would deny to take care of their child with Down syndrome (D)."

Unusual Experience

Through the child's disability, most fathers had unusual experiences, like having to look at the child as if on TV since he was not able to hold

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