

*A Case Study on the Lifeline of a Mother of Multiple Children with Disabilities and Faced Limitation of Prenatal Diagnosis*

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## **Introduction**

Having child with disability impacts on his/her parents' life, especially on mothers' quality of life (QOL). Gray (2003) reported that traditional gender role remain and most of child-rearing burden on mothers, and Oelofsen & Richardson (2006) found that mothers of children with disabilities have higher stress than those of fathers. However, the influences of other important events (eg; subsequent pregnancy, decision making about prenatal diagnosis, child birth and facing disability of another child) on mothers were not fully investigated. The purpose of this study was to examine the QOL trajectory of a mother of multiple children with disabilities by using the lifeline method.

## **Methods**

### **Data collection**

With the cooperation of an association for parents of children with disabilities, a mother of multiple children with disabilities was contacted in 2007. I performed the first semi-structured interview and asked her to draw a lifeline on a sheet of paper containing a vertical axis (psychological state: worst = -10 to best = +10) and a horizontal axis (time and event). In 2014, the second semi-structured interview was conducted and the mother was asked to report any changes since the first interview. In 2015, the third semi-structured interview was performed and the mother was asked to confirm the lifeline that she had drawn at the first interview, and add to the lifeline based on her current perspective.

### **Data analysis**

All transcripts were created based on the recorded data and the memos, after each interview. Comparing with the lifeline, I identified what events were related to up and down of the lifeline, and how the mother expressed these events and assessed own psychological state.

### **Ethical considerations**

This study was approved by the review boards of two universities in 2007 and 2014. Prior to each interview, informed consent was obtained.

### **Results and discussion**

In December 2007, the mother was in her 40's, and had three children (boys): a high school student without any disabilities, and two elementary school students, one with autism and the other with a pervasive development disorders, unspecified. In July 2014 and January 2015, her first child had graduated university, while the second child had graduated from special needs school and was receiving daily welfare services for people with disabilities. The third child was a student in a special needs class in a public junior high school. The mother was still a homemaker, but her husband had taken an early retirement since the spring of 2014. At all three interviews, they were living in Tokyo, Japan. The lifeline of the mother is shown in figure 1, which illustrated time (T1-T9), main events and psychological states.

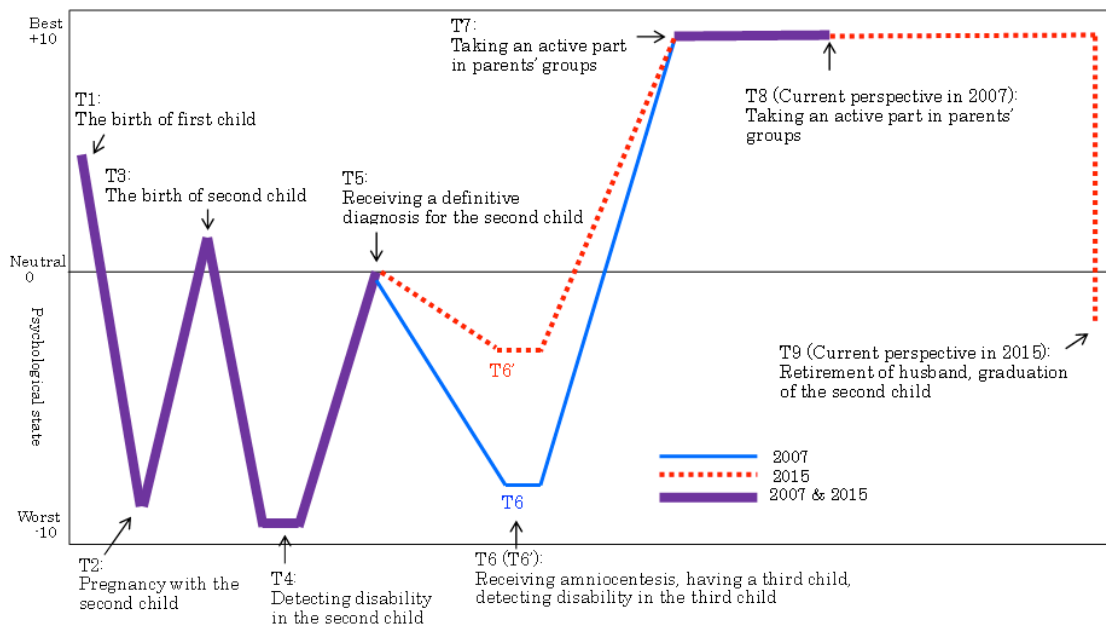


Figure 1: The lifeline of the mother of multiple children with disabilities

### The worst point of the mother's QOL

Throughout the mother's lifeline, the worst point of her psychological state was detecting disability in the second child (T4, -9.5).

*I took my second child to the healthcare center for his year-and-a-half physical examination, and a public health nurse said, "Your child did not look at me even when I called him, so he might be deaf, or if not so, it's too late." What? Too late? I didn't understand what she meant, but it really shocked me.*

Before the physical examination, the second child gave the mother a lot of trouble, but she did not consider any possibility of disabilities. I asked her whether she had compared the first child (who had no disability) with the second child, but she denied do so. She stated that because the first child had not had any disability, she had not believed that it was possible for the second child to have one. Thus, receiving the indication of disability was an unexpected event for her.

### The impact of subsequent pregnancy and decision making about prenatal diagnosis, child birth and facing disability of another child

The mother congregated various events at this stage (T6), and gave it a -8 in terms of psychological state. She expressed her strong desire to have another child and prenatal screening without any hesitation.

*I decide to have a third child because I wanted to reduce the first child's burden, but if the third had a disability, his burden would be increased. That's why I strongly desired a prenatal diagnosis. I decided to have an abortion if the result was positive, as raising multiple children with disabilities would be impossible for me.*

The mother had prenatal screening (amniocentesis), and its result was negative. Since the mother knew the prenatal screening was unable to detect developmental disabilities, she tried to believe, “It’s OK.” However, after the third child’s birth, characteristics of developmental disabilities gradually appeared.

*But...then...the third child, at about one-and-a-half years old, I had doubted his disability... I said, uh-oh, uh-oh... When I faced my second child’s disability, I had waves where I didn’t want to accept it. You’d think it’d be easier to accept the third child’s disability because I had already overcome the waves, wouldn’t you? But, when I faced my third child’s disability, I also had waves...different waves...people may say, “What? The sibling too?” I imagined that...*

Facing children’s disabilities multiple times must be difficult experience for the mother, but facing child’s disability for the first time had a more negative impact on her than did the second time. In addition, after this event, her lifeline rose to its highest level, below.

### **The best point of the mother’s QOL**

The best point of the mother’s psychological state was taking an active part in parents’ groups for disabled (T7, +9).

*I was depressed for almost half a year, after the disability in my third child was discovered. However, I prepared to immerse myself in a world of disability...I had no choice... the third child was maybe three years old, and that’s when the lifeline rose to its highest level. I had already begun participating in an association of parents of children with disabilities, and was becoming an activist in parent groups [laughs].*

After facing disability of the third child, the mother had prepared to become immersed in the world of disabilities and taking an active part in the parents’ groups that enhanced her QOL. At this stage, she seemed to have accepted the disabilities of both children.

### **The different perspective from the first interview**

In 2015, although eight years had passed since the first interview, the mother reported almost the same life history and confirmed that the lifeline from the first interview was mostly correct. However, she did point out that one event—detecting the third child’s disability (T6)—was less severe (at -3 rather than -8) from her current perspective.

*Yeah, maybe...here? [pointing to -3, T6]. Of course, my feelings always go up and down, and I can’t draw an exact line. But...yeah, it was not so low. Because, I had a lot of positive friends who had children with disabilities in parents associations, including mothers of multiple children with disabilities. I was not so bad at that time.*

*I was a main member of the PTA (parent-teacher association), so even after the second child graduated from the special needs school this past spring, I still had*

*some remaining work to hand over to the next member. But now, I have no remaining work for the PTA, so my schedule was blank. Also, I don't have enough money or any opportunity to go out with members of the parents association of children with disabilities, because of my husband. I can't think positively, and I may become depressed. My lifeline must have declined...*

Nowadays, the mother had no opportunities to participate PTA activity and her retired husband had prevented her from pursuing activities in parents' associations for children with disabilities. Indeed, at this point, her psychological state had decreased from +9 to -2. Thus, depend on interview point; the same event could be different perspective. Moreover, latest event and condition may influence such perspective.

### **Conclusion**

Facing the disabilities of multiple children had a negative impact on the mother, but it did not overwhelm her QOL entirely, rather, having relationships with other parents seemed to be an influential factor. In the most recent interview, the mother had lost opportunities to be active and her lifeline had declined, which resulted in a change in her perspective regarding facing the third child's disability such that it became more positive (-8 to -3). Thus, the perception of one's own past QOL could be changed by the current situation, and the lifeline method was useful to understand this process visually.

## **Acknowledgement**

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