

A Longitudinal Case Study of the Quality of Life Trajectory: A Mother of Multiple Children with Pervasive Developmental Disorders

Miyako Kimura
St. Marianna University School of Medicine, Japan

Abstract

The purpose of this study was to explore the quality of life (QOL) trajectory of a mother of multiple children with pervasive developmental disorders (PDDs) using the lifeline method. In 2007, the first semi-structured interview was performed and the mother was asked to draw on a sheet of paper a lifeline containing a vertical axis (denoting psychological state: worst = -10 to best = +10) and a horizontal axis (denoting the time and event). At this point, the mother was in her early 40s and had three sons. In 2014, the second interview was performed, wherein the same mother was asked to report any changes/differences since the first interview. In 2015, the third interview was performed, wherein the mother confirmed the lifeline that she had drawn in the first interview and added to it based on her current perspectives. Throughout the mother's life, her psychological state was lowest (-9.5) after detecting disability in her second son for the first time. This negative experience was repeated when she detected disability in the third child, but the mother's psychological state only ranged between -8 (perspective in 2007) and -3 (perspective in 2015). Although having to face a child's having a PDD multiple times negatively influenced the mother's QOL, it did not overwhelm her. Peer support and an understanding husband were particularly important for enhancing the mother's QOL.

Keywords: lifeline, quality of life, amniocentesis, prenatal diagnosis, pervasive developmental disorders

Introduction

Having a child with a pervasive developmental disorder (PDD) greatly affects mothers' quality of life (QOL). According to the World Health Organization (2015), PDDs are a "group of disorders characterized by qualitative abnormalities in reciprocal social interactions and patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities." Depending on the diagnostic criteria used (whether the Diagnostic and Statistical Manual of Mental Disorders [DSM] or International Statistical Classification of Diseases and Related Health Problems [ICD]), PDDs includes a range of disorders, including but not limited to childhood autism, atypical autism, Rett syndrome, Asperger syndrome, and PDD unspecified (World Health Organization, 2015). Recently, the DSM-5 was published and most of the aforementioned disabilities are considered under the single umbrella of autism spectrum disorder (ASD; American Psychiatric Association 2013).

Children with PDDs often show emotional and behavior problems that can have detrimental impacts on their family members. For example, emotional and behavioral problems in toddlers with PDDs/developmental delay contributed to mothers' stress, parental mental health problems, and perceived family dysfunction (Herring et al. 2006), and behavior problems in young people with ASD were strongly associated with the stress of their caregivers (e.g., parents and teachers; Lecavalier, Leone & Wiltz, 2006). In particular, the mothers of children with PDDs are more stressed than are the fathers (Herring et al. 2006). The fact that mothers experience more stress is likely related to how they tend to bear most of the burden of childrearing due to traditional gender roles (Gray 2003). Yamada et al. (2012) investigated the QOL of parents of children with PDDs in Japan, and reported that mothers of children with PDDs had lower QOL than did those of the Japanese general population, particularly in the mental domains. Furthermore, children with PDDs have negative impact on their siblings. Ross and Cuskelly (2006) reported that 40% of non-disabled siblings of children with ASD placed on the borderline or clinical range of the Child Behavior Checklist, indicating that non-disabled siblings have a higher risk of developing internalizing behavior problems.

As shown by these previous studies, parents encounter considerable difficulty in raising children with PDDs and their siblings without PDDs. However, matters become even more severe when multiple children in the same family have PDDs. Confirming this point, Kimura and Yamazaki (2013) explored the lived experiences of Japanese mothers of multiple children with intellectual disabilities (ID) including PDDs; according to these mothers, taking care of multiple children with ID involves a considerable amount of effort and causes mothers to suffer extreme physical and mental fatigue. Kimura, Yamazaki, Mochizuki, and Omiya (2010) also pointed out that mothers of children with PDDs in Japan experience extreme psychological conflict when considering future pregnancies after the birth of a child with a PDD. Some of the obstacles these mothers reported that made them hesitant to have another child were feelings of uncertainty about PDDs, perceptions of PDDs recurrence risk in future children, and severity of PDDs including behavioral problems. Therefore, having children with PDDs may threaten mothers' QOL.

QOL appears to be correlated with disability acceptance (Zhang, Hu, Xu, Zheng, & Liang, 2013). When considering parents of children with disability, there are several theories of disability acceptance. According to Olshansky (1962), parents of children with disabilities experience chronic sorrow throughout their lifetimes, although this is a natural response. In contrast, Drotar, Baskiewicz, Irvin, Kennell, and Klaus (1975) introduced stage theory, which dictates that parental reactions to having a child with disability have several stages —"shock,"

“denial,” “sadness and anger,” “adaptation,” and “reorganization.” In Japan, Nakata (1995) insisted that disability acceptance should not be parents’ goal, and that most parents lived in a spiral of both positive acceptance and denial of disability (called the “spiral model of disability acceptance”). However, these theories focused on parents’ perceptions of a single child with a disability and the influences of other important events (e.g., subsequent pregnancies, decision making about prenatal diagnosis, childbirths, and facing the disability of another child) on mothers’ acceptance were not fully accounted for. In addition, Kimura and Yamazaki (2013) mentioned that “searching for the positive experiences in parenting multiple children with ID” is a common experience among mothers of multiple children with ID (including PDDs), and most such mothers seemed to accept their children’s disabilities; however, how their experiences influenced their QOL was uncertain.

To evaluate the QOL of such a complex sample, the lifeline method would be a useful tool. The lifeline method involves drawing a “lifeline” that consists of a horizontal axis (denoting time) and a vertical axis (denoting psychological state); then, the participant is asked the reasons for the rises and falls in the lifeline via interviews (Hirano & Yamazaki, 2013). According to Taguchi, Yamazaki, Takayama, and Saito (2008), the lifeline method can be used to create chronological personal histories consisting of experiences as perceived by participants in retrospect, thus presenting an overall visual illustration of a participant’s life. In their study, the experiences of patients with recurrent breast cancer and dynamic process of their subjective QOL were displayed using lifelines and verbal expression. Similarly, Hirano and Yamazaki (2013) used the lifeline method to elucidate the illness experiences—particularly various changes in psychological state and the positive and negative factors related to those changes—in amyotrophic lateral sclerosis patients under tracheostomy invasive positive pressure ventilation. These studies clearly indicated, visually and verbally, how patients’ psychological states changed, which suggests that the lifeline method may be appropriate for exploring mothers’ QOL after the birth of a child with disability. In particular, the impact of subsequent pregnancies and childbirths after the birth of a child with PDDs, which have not yet been longitudinally explored, could be clearly illustrated.

Given that QOL is constantly changing due to the circumstances of life, a longitudinal qualitative study design seems attractive for its study. According to Calman, Brunton, and Molassiotis (2013), a longitudinal qualitative study focuses on individual participants’ narratives and life trajectories and answers qualitative questions about individuals’ lived experiences of change over time. Lawton et al. (2014) performed in-depth interviews (a baseline and a six-month follow-up) with people with type 1 diabetes, and identified important issues related to bolus advisor usage. Additionally, Whitehead (2006) investigated the reconstruction of self-identity in people experiencing chronic fatigue syndrome/myalgic encephalomyelitis using three in-depth interviews, and reported a trajectory of identity reconstruction over a variety of stages. Therefore, a longitudinal qualitative study could be the ideal design for investigating the changing process of QOL.

The purpose of the present study was to explore the QOL trajectory of a mother of multiple children with PDDs by using the lifeline method. Particularly, I focused on (1) the events that triggered declines or rises in the mother’s lifeline; (2) how having another child after the birth of a child with a PDD influenced the mother’s lifeline; and (3) how the trajectory of the lifeline changed (or did not change) depending on the mother’s perspective at each interview.

Methods

Data collection

With the cooperation of a member of an association of parents of disabled children, a mother of multiple children with PDDs was introduced to me in December 2007. Before the interview, privacy assurances (verbal explanations and in written documentation) were given to the participant, and I obtained the signed consent form. At the first interview, I performed the semi-structured interview and asked the mother to draw, on a sheet of paper, a lifeline containing a vertical axis (denoting psychological state: worst = -10 to best = +10) and a horizontal axis (denoting time and specific events). Similar to Taguchi et al. (2008), the lifeline was considered a tool to express the subjective QOL of the participant at various times in her life. At the beginning of the interview, I asked the participant, "What events have mainly influenced your psychological state both currently and in the past? Please write down these events and evaluate your psychological state during them, and then draw a line between them to illustrate how your psychological state changed." After viewing the mother's lifeline, I asked about each event and the participant's experience of that event in detail. After completing the first interview, I kept in touch with the cooperator and obtained her support (e.g., information about the activities of association of parents of disabled children and parent-teacher association (PTA) in special needs school) from 2007 onwards. This cooperator also maintained a good friendship with the mother, such that she was informed about the mother's family life. In July 2014, I contacted the cooperator again, and asked the mother to participate in follow-up interviews. I obtained confirmation that the participant had willingly consented to participate in follow-up interviews, and the second semi-structured interview was performed. In this interview, I asked the participant to report any changes/differences since the first interview. During the analysis of the second interview data, I assumed that the mother's life had dramatically changed, and thus it would be necessary to confirm her lifeline. As such, I asked the mother to participate in a third interview, for which she gave consent. In January 2015, the final interview was performed. In the final interview, I asked the mother to confirm the lifeline that she had drawn in the first interview, and create a new lifeline from her current perspective. With the participant's permission, each interview was tape-recorded, and observation records (memos) were taken. Each interview lasted for approximately 150–180 minutes.

Data analysis

The transcripts were created from the recorded interview data and memos. Similar to previous studies (Hirano & Yamazaki, 2013; Taguchi et al., 2008), the Lofland and Lofland (1995) method of analysis was employed. The transcript of the first interview was read several times, after which I created categories of factors related to declines and improvements in the participant's psychological state. Since this was a case study, there was no need to compare with other participants' data; instead, I compared the lifeline and transcript obtained from the first interview with the transcript of the second interview, looking for differences and conflicting points, from which new codes and categories were created where appropriate. In addition, I asked about the same events in more detail if they were not fully explored in the first interview, and new categories were added where appropriate. I conducted a similar process of comparison between the first and third interviews, which yielded new codes and categories. Since I was interested in the trajectory of the participant's QOL, I investigated how the participant's lifeline and stories had changed (or had not changed) in the third interview; however, most parts of her stories were consistent. To increase the validity of the final analysis, I obtained confirmation about the accuracy of the interpretations and lifeline from the

participant.

Ethical considerations

This study was approved by the review boards of two universities in 2007 and 2014, and before each interview and the publication of the present paper, I obtained the participant's informed consent. In presenting the mother's verbatim responses, I have given her a fictitious name.

Findings

The following findings are presented chronologically (T1–T9) and in terms of psychological state (–10 to +10), events (bold), categories (single quotation marks), direct quotes (double quotation marks), and selected interview quotations from those categories (text in italics). To avoid repetition, I mainly present the findings of the first interview and describe only what was different in the second and third interviews.

In December 2007 (i.e., the first interview), the mother, Emi, was in her early 40s and had three children (all boys). She was a homemaker and her husband was a white-collar worker. The first child had no disability and was a high school student; the second child had autism and the third child with a PDD unspecified and both were elementary school students. 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. Emi 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.

Lifeline and experiences of mother of multiple children with PDDs

In the first interview, I asked Emi to draw a lifeline that encompassed from before the birth of her first child with a PDD (i.e., her second child) to the time of the interview; however, the start point was her decision. Without hesitation, she said “just after the birth of my first child,” for which she reported a psychological state of +4 on the lifeline sheet (T1, Figure 1).

T1: The birth of first child – T3: The birth of second child

After the birth of the first child, Emi ‘perceived ordinary happiness of having first child’ (T1, +4). However, during her second pregnancy, she ‘struggled with physical discomfort’ and reported ‘being angry with husband's unsupportive attitude,’ which rapidly decreased her lifeline (T2, –9) as follows:

During my second pregnancy, I was suffering from extreme stress. My lower abdomen felt bloated, and I couldn't stand up, so I did nothing but sleep. And my husband! It was different from my pregnancy with the first child; my husband didn't take care of me, that's why my stress was so elevated.

At the start point, Emi said, “When I gave birth to my first child, I felt an ordinary happiness” and talked about her experiences between T1 and T2. At this stage, she did not use the term “disability” and focused mainly on her own conditions and complaints about her husband. This implied that she perceived herself as living in an “ordinary” world at this stage. After the birth

of her second child, her lifeline raised because she ‘had a comfortable physical condition’ (T3, +1); however, ‘facing the difficulties of raising a second child’ gradually exhausted her mental and physical condition.

T4: Detecting disability in the second child

Before asking for a physical examination of the second child, Emi had considerable difficulty in rearing him, although she had not considered it possible that he had a disability. I asked her whether she had compared the first child (who had no disability) with the second child, but she denied doing so. She stated that because the first child had not had any disabilities, she had not even considered the possibility of the second child having one. Therefore, ‘receiving an indication of disability in the second child’ was an unexpected event for her (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.

After this event, feelings of ‘having a hard time believing that the second child has a disability’ continued for roughly half of a year, during which her psychological state remained at -9.5, which was her lowest point.

I kept thinking that the child might have a disability,...[but] no, it mustn’t...A half-year passed, and when my second child was 2 years old, he was diagnosed as having an intellectual disability. What’s that? I didn’t have any knowledge about disabilities, but the doctor introduced an education/care center and told me to go.

T5: Received a definitive diagnosis for second child

Emi took her second child to an education/care center (for disabled children), after which her life changed. However, her experiences of ‘meeting mothers of children with disabilities in the education/care center’ and ‘obtaining information related to disabilities’ facilitated a rise in her lifeline (T5, 0). Even though Emi’s psychological state was neutral at this point, it was still a 9.5-point increase from T4, and she mentioned herself as being “happy.” In addition, receiving a definitive diagnosis provided Emi with feelings of ‘being able to consider how to handle the second child’s autism’ as below:

...After my child turned 3 years old, he was diagnosed with autism. Yeah, I was relieved about that. I thought, “Now, I can start considering how to handle my child.”

At this stage, she could “start” a new life as a mother of two children—one with PDDs and one without—so she stepped into a world that was different from the “ordinary” world she had known before.

T6: Changed education/care center to day-care center for the second child – Detecting disability in the third child

Emi congregated various events at this stage, and gave it a -8 in terms of psychological state. First, she talked about moving her second child from an education/care center to day-care center, which led her to begin ‘missing friends,’ thereby triggering a decline in her lifeline as

follows:

A year after I had enrolled [my second child in] the education/care center, I moved him to a day-care center, so I had to say goodbye to the other mothers. Also, my friends started to work, so there was little opportunity to meet each other...they were scattered...yeah, at that time, my psychological state was getting worse.

After moving her second child to the day-care center, Emi's daily life changed and her free time increased. During this period, she considered having a third child, because she was worried about her first child.

'Worry about the future of the first child without disability'

I suddenly decided to have another child. The reason was that the first child was so timid [laughs]. If he had another brother without disability, they could share the responsibilities of the second child's care in the future.

During her pregnancy with the third child, she again 'struggled with physical discomfort.' Moreover, she 'worried about the possibility of disability in the third child,' which led her, in order to cope with this fear, to ask her doctor to undergo amniocentesis.

'Received amniocentesis to do everything I can'

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.

Researcher: What did you think about the result of the test?

Oh, it [the negative result] makes sense. But I knew the test couldn't detect various disabilities such as developmental disabilities. Yeah, but I could avoid some of the major disabilities. I could tell myself that I tried to do everything I could. I might have been accused, if the third child had had a disability of not having received a prenatal diagnosis; but I did the test, so I could excuse myself.

Researcher: Do you think that you needed the test?

Yes, if I didn't know the test, I would have been accused. In our current society, children with disabilities are a burden, a distraction, and a waste of tax money, right? The revenue from taxes is not enough, our country keeps getting deeper and deeper into debt, and so everybody thinks that we must cut waste.

According to Emi's explanations, obtaining a prenatal diagnosis was partly a defense against social disapproval of having multiple children with disabilities. These explanations also indicated how she viewed people with disabilities and their families in society. After the birth of her third child, she was relieved that everything about her third child was different from the second. This allowed her to continue 'believing that the third child did not have a disability.' However, upon detecting a disability in her third child, she reported only negative experiences:

'Having a hard time accepting the disability of the third child'

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...

She used “waves” as a metaphor to express extreme psychological states, although they also may imply obstacles. In addition, the second period of waves differed from the first because they were related to her fears of becoming known as a mother of multiple children with disabilities. Furthermore, ‘feeling sorry to place an even greater burden on the first child’ plagued Emi, because the situation had turned out exactly the opposite of how she had intended it to. However, by the third interview, when she added to her lifeline, she had a more positive perspective on this period of her life; she details this in T6’, below.

T6’: Different perspective on the events of T6 (third interview, 2015)

‘Had positive friends who had multiple children with disabilities’

Uh...let me see...now...I look back the period when I was facing the disability of my third child, and maybe it wasn't so low [pointing to the lifeline at around T6].

Researcher: You mean, it has become more positive since the first interview?

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.

In 2015, at T6’, Emi’s story focused on how she ‘had positive friends who had multiple children with disabilities’ and ‘had a purpose in life,’ and her psychological state was 5 points up (-8 to -3) from the corresponding period in the first interview. Although some of her friends from the “education/care center” had scattered at the beginning of T6, and Emi was ‘missing friends,’ she had other networks and was not lonely.

T7: Taking an active part in parents’ groups

After she had prepared to “become immersed in the world of disabilities” and realized that she ‘had a place and role in parents' groups,’ her lifeline rose substantially (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].

At this stage, she seemed to have accepted the disabilities of both children. She talked much about the associations of parents of children with disabilities, and emphasized the importance of admitting her children to a day-care center, which allowed her to continue her volunteer activities in parents’ groups because it ensured that her children with disabilities would be taken care of during the day.

T8 (Current perspective in 2007): Taking an active part in parents’ groups

As with the previous stage, Emi positively spoke of her current situation, and her

psychological state remained at +9 at T8. Her three children had a bad relationship, and all of them had problem behaviors, so she was 'facing difficulties in raising three children.' However, she still believed that she 'had a place and role in parents' groups' and used the term "happy" and 'had a positive perception of own life,' as mentioned below.

I am a different person and have a different way of thinking now. I have passed the hardest period of my life, and compared with such experiences, I can do a lot to overcome difficulties. I am happy now, and try to stay with group members who are positive and have purpose in their own lives.

Although she had a tight schedule and had much to do for her parents' groups, she enjoyed her current situation. However, she reacted sharply against being labeled:

Somebody told me that I had been selected [by God] as a parent of children with disability. No kidding! How do I fit the idea of a "parent of a child with disability"? These are the most irritating words for me to hear! I didn't want to be selected. I'd like to say, "You must be a better fit than me" [laughs].

Although this conversation was not related to her psychological state, it may illustrate that she had conflicts in accepting her children's disability itself; however, she refused to accept herself as "selected" to be a mother of children with disabilities. As already mentioned, she considered having children with disabilities to be a burden in current society, which suggests that she did not accept the status of their families in society. This was underpinned in the following interviews.

T9 (Current perspective in 2014 and 2015): Retirement of husband, graduation of the first and second children

Beginning in July 2014, I confirmed that the environment surrounding Emi had drastically changed since March 2014. The primary negative event of this period was the retirement of husband, which meant that she had to start 'living a restricted life with husband,' as follows:

After my husband suddenly decided to go into retirement early, he is always at home and says to me, "don't spend money" or "don't go out to do volunteer work such as activities in parents' associations for disabled." It's so stressful! Also, he sticks his nose into our sons' lives, which has worsened our sons' conditions.

Unlike in the first interview, at this point, the second and third children rarely exhibited behavior problems, and 'keeping a stable condition in multiple children with PDDs' had relieved Emi's burden. However, the presence of her husband had affected her peaceful everyday life, forcing her to 'cut down on taking part in the parents' groups', as mentioned below. At the same time, the graduation of her second child increased her burden in this situation. In January 2015, she elaborated on this issue, which had persisted until that time.

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....

Indeed, at this point, her lifeline had decreased from +9 to -2. According to Emi, children with

severe ID, such as Emi's second child, are enrolled in special needs schools from elementary to high school, which usually require students' parents to participate in PTA activities. However, children with mild to moderate ID such as Emi's third child could enroll in special classes in general public schools, which do not require parents to participate much in PTA activities. Thus, after her second child graduated from special needs school, Emi had no opportunity to participate in PTA. Moreover, Emi's retired husband had restricted the family budget and prevented her from pursuing activities in parents' associations for children with disabilities. Therefore, being unable to continue her active life, her lifeline declined. It was perhaps this situation that caused Emi's to recall her life at T6' in a more positive light—namely, despite being shocked at the thought of facing the task of raising multiple children with disability, she had had a purpose, was free to live an active life, and had had a place to be herself.

Nowadays, however, she stayed at home all day with her husband and had no place where she could be herself. In addition, although the first child (who had no disability) had graduated from university and Emi reported 'being happy that the first child had found a job' at the second interview, he had quit his job and was staying at home by the third interview. She reported that her first child's job had been extremely stressful, making him unable to continue with it. However, Emi's husband pressured him to work again to start paying back the loan on their house. As such, Emi was 'worried about the mental health of the first child', and recognized that living alone and becoming independent would be better for him. On the other hand, Emi mentioned that the first child was the only one who could understand her situation in the family, and if he left home, she would become lonely, depressed, and irritated, and begin to feel that there was no room in her heart. Therefore, although she did not intend to force him to take care of their family in the future, she was unable to let him leave. This dilemma made her 'worried about an uncertain future'.

Discussion

I examined the QOL trajectory of a mother of multiple children with PDDs by using the lifeline method. Throughout Emi's lifeline, facing her children's disability had a negative impact on her QOL, but handling the disability themselves did not appear to be overwhelming for her; rather, psychological support from friends—especially peer support—seemed to have a stronger impact on her QOL. According to Shilling, Morris, Thompson-Coon, Ukoumunne, and Logan (2013), who conducted a review of ten qualitative studies, (1) shared social identity, (2) learning from the experiences of others, (3) personal growth, and (4) supporting others were identified as primary themes relating to peer support for parents of children with chronic disabilities. All of these themes were reported by Emi, who said that being actively involved in parents' networks triggered an increase in her lifeline. Jandt (2010) explored the cultural dimensions of Japan, and noted that "the Japanese do not have the same perception of self as an individual that is typical in the United States; instead, the Japanese feel most comfortable with others who empathize" (p.168). This cultural dimension might relate to Emi's perceptions of QOL, because certain values inherent to a given population in a particular culture might be associated with their perceptions of better QOL (Urzu'a, Miranda-Castillo, Caqueo-Uri'zar, & Mascayano, 2012). Therefore, sharing similar experiences and cultures within a peer group, may have been essential for Emi to feel positive and maintain QOL.

The presence of her husband at home became an obstacle to her maintaining such networks and activities, and triggered a decline in her lifeline. Yamada et al. (2012) stated that the impaired QOL of mothers of children with PDDs in Japan is significantly associated with their

own personality tendencies and the relationship between spouses; Emi's case appeared to be a typical example of such findings. Particularly, there are still numerous gender issues in Japan, as most of the burden of parenting falls on mothers. Involving fathers in parenting and activities such as PTA and parents associations for people with disabilities may help them better understand mothers' situations. To do this, approaches targeting fathers and supportive working environments for them would be required.

The lifeline method in this study did not focus solely on disability acceptance, which means that it may add a new perspective on disability acceptance studies. Specifically, in this study, having a child with a PDD for the first time had a more negative impact on a mother's psychological state than did the second time. Furthermore, after each diagnosis in her children, Emi recognized the importance of friendship with other mothers of children with disability, resulting in a corresponding increase in her QOL. However, previous disability acceptance theories have not accounted for the complexity of the reactions of mothers facing multiple children with disabilities, which I was able to do using the lifeline method. Indeed, Emi explained that facing a child's PDDs multiple times came in "waves," and the lifeline clearly illustrates these waves and their impact on her QOL. In addition, although Emi attempted to view her children's disabilities positively and play an important role in parents' groups, she consistently used negative expressions in referring to people with disabilities in society. This may illustrate that acceptance of one's own children's disabilities and acceptance of the presence of people with disabilities in society are not the same—indeed, these may sometimes even conflict.

Emi had no dilemma related to obtaining a prenatal diagnosis and decision making about having another child after giving birth to a child with a PDDs. Having other children after having a child with a PDD is not an easy decision in Japan (Kimura et al. 2010), but Emi decided to have the third child because she wanted to reduce the burden that her first child, who did not have a disability, would experience. In addition, she decided that if the result of amniocentesis were positive, she would have an abortion. Mothers who regard having disability as a burden are more likely to undergo amniocentesis (Horii, 1998); indeed, Emi appeared to have an overall negative perception of people with disabilities and their families in society. Therefore, she needed to "pose" and take a "defensive attitude" by receiving a prenatal diagnosis, which she did not regret doing, and these experiences did not affect her QOL at all.

Surprisingly, in 2015, although eight years had passed since the first interview, Emi 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—was less severe (at -3 rather than -8) from her current perspective. At T6 (a decline in lifeline from the previous event) in the first interview, Emi related that her friends were scattered and she was missing them. In the third interview, she reported the same reason for a lower QOL (T6') as the first interview, but she emphasized how important the parents' associations of children with disabilities were for her (T6'). The importance of these associations doubtlessly influenced Emi's situation in 2015, when she had lost the opportunity to have an active life, thereby leading to a decline in her lifeline again (T9, -2). This, in turn, might have resulted in her changing her perception on T6 (i.e., detecting and facing the third child's disability) by the third interview to become more positive. Because 'had a place and a role in parents' groups' may have been the most important aspect of her life, when looking back at T6', when she was still involved in the parents' groups, she perhaps viewed the period as "not so bad." Thus, one's perception of their past QOL could be changed by their current perspective; to confirm this, longitudinal qualitative research would be helpful.

The difficulties and expected role of typically developing siblings of a child with a PDD were also observed in the present study. Walton and Ingersoll (2015) noted that the relationships between children with ASD and their siblings were characterized by less aggression but also less involvement and greater avoidance compared to the relationships between typically developing siblings. Additionally, older male siblings of children with ASD had a greater risk of experiencing relationship difficulties. As young adults, typically developing siblings of children with ASD may experience a strong sense of responsibility for their sibling with autism, which could make it difficult for them to leave home and begin an independent life (Autism society, n.d.). Some of these findings accord with Emi's story. However, because I did not directly interview the typically developing first child, it is unclear what he thought about his situation and mental health condition. Emi's dilemma, in contrast, was rather clear on this point: she felt that could not leave the typically developing first child because he was the only one who could understand her as a mother of multiple children with PDDs. In addition, Emi's husband expected financial support from this first child (e.g., paying back the loan on their house), making the first child have a rather central role in the family. To ensure the QOL of the typically developing siblings, providing family support targeted at siblings (e.g., consulting about their situations, future plans) at each developmental stage would be needed in Japan.

This study had several limitations. First, because this was a single case study, the sample size was very small. Second, although this study was longitudinal, it was still a retrospective study as well as a case study, meaning it could have been affected by recall bias. Third, while the lifeline method was useful for grasping the participant's QOL visually, in this case, the drawn line was very rough and did not reflect the timeline accurately. Fourth, Emi and I were like friends, which helped to her to talk about various topics, and I obtained a considerable amount of information about her life from herself and the cooperator of this study. However, this might have resulted in rater bias. Finally, I focused on child-related events, meaning that the lifeline did not illustrate the participant's life events as a whole.

Conclusions

This study contributes to our understanding of how the QOL of a mother of multiple children with PDDs changes based on her lifeline, which may add a new perspective on disability acceptance studies. Detecting her child's disability for the first time led to a decline in the mother's lifeline to her lowest point; however, receiving a definitive diagnosis and meeting other mothers of children with disabilities triggered rises in her lifeline. Although the mother underwent amniocentesis and received a negative result during her pregnancy with the next child, this child also had a PDD. Facing the notion of having another child with disability led to another decline in the mother's lifeline, but this decline was not as low as the one before. In addition, eight years after the first interview, her perspective on this event had improved because her current situation had changed. Taking an active role in parents' groups drastically improved her lifeline, suggesting that peer support would be important for her to maintain her QOL. Similarly, given that her husband made it difficult for her to take part in such activities, her husband's understanding of her reason for participating in parents' groups would no doubt benefit her QOL. Longitudinal qualitative research appears to be a useful approach for confirming an individual's changing perceptions of the same event, and the lifeline method is able to represent the QOL trajectory visually and verbally. A comparative study (e.g., fathers' and mothers' experiences) would be recommended, and more participants are needed in future studies.

Table 1

Categories related to rises and declines in the participant's lifeline

Time	Main event	Psychological-state	Categories related to rises in lifeline	Categories related to declines in lifeline
T1	The birth of first child	4	Perceived ordinary happiness of having first child	
T2	Pregnancy with the second child	-9		Struggled with physical discomfort Being angry with husband's unsupportive attitude
T3	The birth of second child	1	Had a comfortable physical condition	Facing the difficulties of raising a second child
T4	Detecting disability in the second child	-9.5		Receiving an indication of disability in the second child Having a hard time believing that the second child has a disability
T5	Received a definitive diagnosis for second child	0	Meeting mothers of children with disabilities in the education/care center Obtaining information related to disabilities Being able to consider how to handle the second child's autism	
T6	Changed education/care center to day-care center for the second child Considering having a third child Pregnancy with the third child Received amniocentesis Birth of third child Detecting disability in the third child	-8	Received amniocentesis to do everything I can Believing that the third child did not have a disability	Missing friends Worry about the future of the first child without disability Struggled with physical discomfort Worried about the possibility of disability in the third child Having a hard time accepting the disability of the third child Feeling sorry to place an even greater burden on the first child
T6'	Different perspective on the events of T6 (third interview, 2015)	-3	Had positive friends who had multiple children with disabilities Had a purpose in life	
T7	Taking an active part in parents' groups	9	Had a place and role in parents' groups	
T8	(Current perspective in 2007) Taking an active part in parents' groups	9	Had a place and role in parents' groups Had a positive perception of own life	Facing difficulties in raising three children
T9	(Current perspective in 2014 and 2015) Retirement of husband Graduation of the second child Graduation of the first child	-2	Keeping a stable conditions of multiple children with PDDs Being happy that the first child had found a job	Living a restricted life with husband Cut down on taking part in the parents' groups Worries about uncertain future Worried about the mental health of the first child

Note: T6' is the participant's perspective on T6 from the third interview

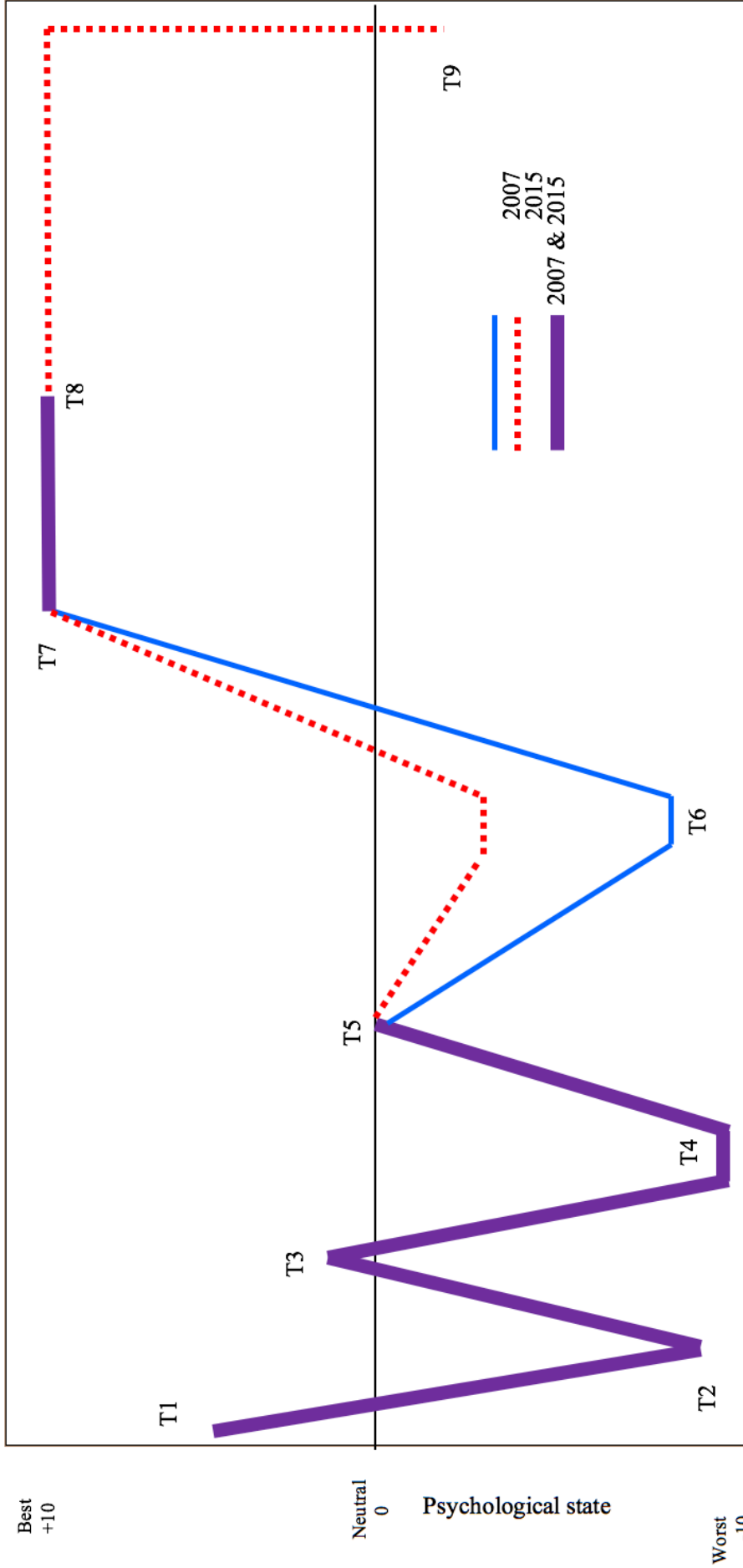


Figure 1. The lifeline of the mother of multiple children with pervasive developmental disorders

References

- American Psychiatric Association. (2013). Autism Spectrum Disorder. Retrieved from <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>
- Autism Society. (n.d.). Siblings. Retrieved from <http://www.autism-society.org/living-with-autism/family-issues/siblings/>
- Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Medical Research Methodology*, *13*, 14. doi:10.1186/1471-2288-13-14
- Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., & Klaus, M. (1975). The adaptation of parents to the birth of an' infant with a con-genital malformation: A hypothetical model. *Pediatrics*, *56*, 710–717.
- Gray, D. E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine*, *56*, 631–642. doi:10.1016/S0277-9536(02)00059-X
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, *50*, 874–882. 10.1111/j.1365-2788.2006.00904.x
- Hirano, Y., & Yamazaki, Y. (2013). The illness experience of amyotrophic lateral sclerosis (ALS) patients under tracheostomy invasive positive pressure ventilation (TPPV): Using the life-line method to study changes in psychological state and related factors. *Journal of Japan Academy of Nursing Science*, *33*, 29–39. doi.org/10.5630/jans.33.2_29
- Horii, Y. (1998). A fundamental problem of bioethics: Focusing on prenatal diagnosis. *Studies in Philosophical Anthropology*, *28*, 79–101.
- Jandt, F. E. (2010). *An introduction to intercultural communication: Identities in a global community* (6th ed.). California: Sage Publications.
- Kimura, M., & Yamazaki, Y. (2013). The lived experience of mothers of multiple children with intellectual disabilities. *Qualitative Health Research*, *23*, 1307–1319. doi: 10.1177/1049732313504828
- Kimura, M., Yamazaki, Y., Mochizuki, M., & Omiya, T. (2010). Can I have a second child? Dilemmas of mothers of children with pervasive developmental disorder: a qualitative study. *BMC Pregnancy Childbirth*, *10*, 69. doi: 10.1186/1471-2393-10-69
- Lawton, J., Kirkham, J., Rankin, D., Barnard, K., Cooper, CL., Taylor C., . . . REPOSE Group. (2014). Perceptions and experiences of using automated bolus advisors amongst people with type 1 diabetes: a longitudinal qualitative investigation. *Diabetes Research and Clinical Practice*, *106*, 443–450. doi:10.1016/j.diabres.2014.09.011
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, *50*, 172–183. 10.1111/j.1365-2788.2005.00732.x
- Lofland, L., & Lofland, LH. (1995). *Analyzing social settings: A guide to qualitative observation and analysis*. Belmont, CA: Wadsworth/Thomson Learning.
- Nakata, Y. (1995). A parental response to having a child with developmental disorders: A stage model or chronic sorrow? *Waseda Psychological Reports*, *27*, 83–92.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, *43*, 190–193.
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of intellectual*

- & *developmental disability*, 31, 77–86. doi:10.1080/13668250600710864
- Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., & Logan, S. (2013). Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine and Child Neurology*, 55, 602–609. doi: 10.1111/dmcn.12091
- Taguchi, R., Yamazaki, Y., Takayama, T., & Saito, M. (2008). Life-lines of relapsed breast cancer patients: A study of post recurrence distress and coping strategies. *The Japanese Society of Health and Human Ecology*, 74, 217–235.
- Urzu'a, A., Miranda-Castillo, C., Caqueo-Uri'zar, A., & Mascayano, F. (2012). Do cultural values affect quality of life evaluation? *Social Indicators Research*, 16, doi: 10.1007/s11205-012-0203-9
- Walton, K. M., & Ingersoll, B. R. (2015). Psychosocial adjustment and sibling relationships in siblings of children with autism spectrum disorder: risk and protective factors. *Journal of Autism Developmental Disorders*, 45, 2764–2778. doi: 10.1007/s10803-015-2440-7.
- Whitehead, L. (2006). Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: a longitudinal qualitative study. *International Journal of Nursing Studies*, 43, 1023–1031. doi:10.1016/j.ijnurstu.2006.01.003
- World Health Organization. (2015). International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10)-2015-WHO Version. Retrieved from <http://apps.who.int/classifications/icd10/browse/2015/en#/F80-F89>.
- Yamada, A., Kato, M., Suzuki, M., Suzuki, M., Watanabe, N., Akechi, T., & Furukawa, TA. (2012). Quality of life of parents raising children with pervasive developmental disorders. *BMC Psychiatry*, 12, 119. doi:10.1186/1471-244X-12-119
- Zhang, T. L., Hu, A. L., Xu, H. L., Zheng, M. C., & Liang, M. J. (2013). Patients after colostomy: relationship between quality of life and acceptance of PDDs and social support. *Chinese Medical Journal*, 126, 4124–4131.

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E-mail Miyako Kimura: mkimura@marianna-u.ac.jp