

Feelings of siblings having a brother/sister with Down syndrome

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Introduction

The people children first encounter in their lives are their family, such as their mother and father. A person can grow up and form relationships with others through rich family experiences. Especially, relationships with siblings may be the most significant, the longest lasting, and most unique. Having a disabled child is a challenge for many families, and as such requires external support. Research revealing the reality of families with disabled children is well reported, and has focused primarily on the mothers. However, recent research has begun to focus attention on the plight of siblings and grandparents in addition to the primary caregivers.

The negative effects on the siblings of a disabled child include emotional problems such as loneliness due to the parents spending too much time with their disabled brother/sister, guilt from envy of such circumstances and resentment as a result of taking too much time taking care of the brother/sister and doing housework; these lead to maladjustment, or a decrease in self-esteem (Konda & Sano, 2010; Lobato, 1983; Mandleco & Webb, 2015; McHale & Gamble, 1989; Mihara, 2000; Rossiter & Sharpe, 2001; Stoneman, Brody, Davis, & Crapps, 1987; Stoneman, Brody, Davis, Crapps, & Malone, 1991; Takano & Okamoto, 2011). On the other hand, positive effects may be an increase in self-esteem, empathy and sincerity through helping the family (Blacher & Hatton, 2001; Konda & Sano, 2010; Mandleco & Webb, 2015; McHale & Gamble, 1989; McHale, Sloan, & Simeonsson, 1986; Meyer & Vadasy, 2008; Takano & Okamoto, 2011).

Some contributing factors to the above problems are related to economic circumstances, the birth order of siblings, and the type and level of the child's disability (Blacher & Hatton, 2001; Lobato, 1983). It

is necessary to deal with the unique qualities of each child's situation. Due to Down syndrome's unique characteristics, the positive effects on the siblings such as patience and empathy are more prominent (Dyches & Braddick, 2005; Mandleco & Webb, 2015). However, it is predicted that siblings of a disabled child may have a variety of experiences as they mature in a society that is not yet completely free of prejudice.

Most of the subjects in studies of this kind have been parents, teachers, and the people surrounding the disabled child, with the exception of the siblings themselves. Research on siblings is lacking, not just in terms of general perspectives, such as positive or negative effects, but also the siblings' types of emotional experiences and the changes they go through.

The purpose of this study is to clarify the experiences of a disabled child's siblings and their thoughts toward their disabled brother/sister.

Methods

Participants

Eight siblings of children with Down syndrome (DS) were recruited for the study with the cooperation of the Yamanashi branch of a parents' DS association in Japan. One of the authors of the study cultivated a close relationship with this branch through her support of families.

Design

The study incorporated a qualitative descriptive exploratory design incorporating essays and focus group interviews to clarify the experience of siblings of children with DS.

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Period

The essays took place from August 1, 2014 to January 31, 2015, and the focus group interviews from November 9, 2016 to January 31, 2017.

Data collection

As the exact number of siblings was not known by the association, a letter of request was delivered to the families through the association. The request asked if there were any siblings of children with Down syndrome, and if there were, we asked them to write essays and return them to us anonymously. The titles of essays were 1) Feelings for Brother/Sister with DS, 2) Learning from Brother/Sister with DS, 3) Daily Life with Brother/Sister with DS, and 4) Others. Eight siblings sent us their essays by mail voluntarily. One of them replied to two essay prompts, so nine essays were gathered.

The focus group interview in the study was set up to extract more detailed information about the siblings' daily life and to confirm their feelings. Letters requesting participation in the focus group interview were delivered to the families through the association, and six siblings from 8 to 38 years old voluntarily attended it. Prior to the interview, the older siblings organized games to get to know each other. Upon completion of the games, the interview was carried out in a quiet room at University of Yamanashi. All participants received an explanation regarding the overview of the results from the essays and the aim of the interview. Then they consented to being recorded, and a verbatim transcription of the recordings was made. Interviewers were study's authors K.T. and Y.Y., and the duration of the interview was about 2 h. Interview questions were as follows: 1) Can you describe some episodes with your brother/sister with DS?;

2) How do you feel or what do you think about your brother/sister with DS?; 3) When do you notice that your brother/sister has DS; and 4) Do you have any request to your father and mother?

Data analysis

KJ method (Kawakita, 1967, 1970) was used for a qualitative data analysis. At first, analysis of the essays' content and interview data was carried out, and the essays and transcripts of the interview were analyzed repeatedly to gain a holistic sense of the data, with a focus on the subjects' feelings and thoughts. Then, the authors independently summarized the descriptions of the siblings' experiences into concise expressions and sub-themes. Finally, a relational diagram was created from categories based on these sub-themes.

These sub-themes were then combined into major themes, and repeated analyses of similarities and differences were carried out through 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 siblings to maintain coherence and reliability of the analysis.

Results

1. Thoughts of siblings revealed through the essays

The participants were 8 siblings who were between ten and twenty-nine years old: 4 males (M) and 4 females (F) (Table 1). One sibling chose two essay titles, so three siblings (F1, F2, and F3) chose 'Feelings for Brother/Sister with DS', one (M1) chose 'Daily Life with Brother/Sister with DS', and 5 chose Others: 3 (M2, M3, F2) which were 'Prenatal diagnosis', (M3) 'Understanding Society', and (F4) 'Good Points About my Sister'.

Through analyzing the essays, five themes emerged: 1) negative acceptance of the existence of a brother/sister with DS, 2) accepting my brother/sister with DS as person, 3) indignation toward society, 4) the

Table 1
Attributes of siblings of brother/sister with Down syndrome who wrote essays.

	M1	M2	M3	M4	F1	F2	F3	F4
Sex	Male	Male	Male	Male	Female	Female	Female	Female
Age/School	Junior high school student	High school student	Junior high school student	Junior high school student	College student	High school student	20's	Elementary school student
Relationship with their brother/sister with Down syndrome	Older brother	Younger brother	Older brother	Younger brother	Older sister	Older sister	Older sister	Younger sister
Title of essay	Life	Others: the life not chosen	Others: understanding of society	Others: prenatal diagnosis	Feelings for my brother	1. Feelings for my sister 2. Others: prenatal diagnosis	Feelings for my sister	Others: good points of my sister

Table 2
Feelings of siblings toward brother/sister with DS from analysis of essays.

Theme	Category	Quotation
Negative acceptance of the existence of a brother/sister with DS	Brother/sister with DS acting disproportionately to his/her age	My brother did whatever he wanted without hesitation (F1) When I can't make her understood her homework well, I get irritated and realize that she is handicapped after all (F2). My younger DS brother has been at the top of the family and has been treated as a king since he was born (F1). It is hard to be with my sister with DS every day and I often wish that she would develop normally (F2). My classmates never experienced school life with disabled people, so they talk ill of them. Now I understand that people around us discriminate against the disabled, but I was always upset about my life with my sister because I was too young to talk about it with my mother back then (F2).
	The attitudes of family toward a brother/sister with DS The wishes that my brother/sister with DS would develop normally	The life with my younger DS brother is very upsetting and I don't understand why my family spoils him. On the other hand, I am also upset at myself when I see him behaving like a dependent child, and I find him cute (F1). My sister is very influential to people around her. Her classmate is the sweetest elementary school student that I have ever seen (F2). When I came home, I was saved by her smile (F2). I receive a lot of power from my sister, so I want to protect her forever in the future (F2). My sister always amazes me by making people happy; she comforts not only family members or friends but also people she doesn't see often (F4).
Accepting my brother/sister with DS as person	Ambivalent feelings	There are many complaints about my brother but I understand it is not avoidable to find defects in him as long as we live together (F1). Every person with DS has a different disabled situation. I sometimes ask for someone's help but deal with my sister with DS just like the other sibling and ask her a favor, and have her listen to my problems occasionally (F2). My sister died from leukemia, but I never wished she shouldn't have been born (M4). I love my brother as the one and only thing in the world (F1).
	Good points of my brother/sister with DS	Because my sister joined my family, there have been more smiles at home. She is not a burden but an angel who brought happiness to our family. I feel grateful for her (M3). My parents and older brother said there has been a lot of happiness as we raised my sister with DS and on the contrary, she has supported us (M4). To protect my younger sister with DS is to protect myself. Her existence is one of my reasons to live (M3). Because the growth of my sister with DS makes my family smile, we are here now as a family (M3).
	Accepting brother/sister with DS as he/she is	Being delayed intellectually and not being good at sports are characteristics of a person just like height. I don't want people to have negative images of DS without knowing the reality (F2). People with DS are just slower than others and live lives just as others do (M4). I have an older sister with DS. She is very cute. 90% of people have abortions as a result of prenatal diagnosis. Some people with DS accept their disabilities and say 'Thank you for giving birth to me' (M4). DS is not a disability but a characteristic. We will protect people with DS until the world protects them (M3).
Indignation toward society	Appreciating existence of brother/sister with DS	The value of life should be fair and shouldn't be judged by others, but that is not how people actually feel (M2). Even children with DS have right to live. Every child born is a blessing (F2). I want to tell everyone in the world that living is wonderful and we should not select who should live (M4). We are all human beings, but why do we still discriminate? (M3) Looking at my DS sister's situation, I felt life unfair more than before. I hope our society will be fairer (F3). It is necessary for as many people as possible to communicate with disabled people (M4, F2).
	Understanding Down syndrome	Since my brother with DS entered junior high school, he has calmed down but still doesn't listen to me. I have to be mature to deal with him (M1). My mother says its good enough if we know the quality of my sister with DS (F2). I occasionally went to school along with my younger sister with DS and went to class observations instead of my mother (F2). When my parents got divorced at the age of twenty, my sibling who was in junior high school took care of my sister with DS (F3). I just adore my brother with DS no matter how selfish or inconvenient he is. It's unconditional love. If he needs my help, I want to support him (F1).
The process of growing up	The society where handicapped children and people experience discrimination	
The process of growing up	The process of growing up	
Taking a role as a guardian	Taking a role as a guardian	

process of growing up, and 5) taking a role as a guardian (Table 2). Each theme is examined below. Categories are included with < > . Quotations from the participants are written in italics.

1) Negative acceptance of the existence of a brother/sister with DS

< Brother/sister with DS acting disproportionately to his/her age >

Siblings sometimes became irritated by their brother/sister with DS, because he/she behaved more childishly than his/her age would indicate, and he/she failed to change his/her behavior. They finally admitted their brother/sister with DS was disabled and gave up trying to

change his/her attitude.

'My DS brother didn't want to hear anything I said, or came into my classroom without permission. Stuff like that happened over and over, every day and that always made me upset.'

(M1)

< The attitudes of family toward a brother/sister with DS >
Siblings also couldn't understand why the family accepted him/her.

'My younger DS brother has been at the top of the family and has been treated as a king since he was born.'

(F1)

< The wishes that my brother/sister with DS would develop normally >

Although siblings are not always aware of their brother/sister's disability, they are reminded of it when he/she is with other children and makes a comparison; that shows his/her late development. One participant wishes her brother/sister were not disabled as she gets busier taking care of him/her. On the other hand, she wonders about herself being prejudiced toward her brother/sister because people at school show prejudice around the disabled, and she can't tell anyone about it including parents.

< Ambivalent feelings >

The sibling of this essay often gets upset about her brother/sister as they spend a lot of time together, but she also gets confused through the existence of conflicting feelings such as adoration.

'The life with my younger DS brother is very upsetting and I don't understand why my family spoils him. On the other hand, I am also upset at myself when I see him behaving like a dependent child, and I find him cute.'

(F1)

2) Accepting my brother/sister with DS as person

< Good points of my brother/sister with DS >

As they are living together, this subject finds her brother/sister is kind to everyone, can do things the essay writer can't do and has something the essay writer doesn't have. Therefore, the essay writer has begun to accept the existence of her brother/sister positively.

'My younger DS sister is kind-hearted and nice to anyone with a smile, which I cannot do.'

(F2)

'My younger sister gets angry and becomes irritated easily, but my older DS sister rarely gets upset but is always smiling, which impresses me.'

(F4)

< Accepting brother/sister with DS as he/she is >

The siblings started understanding the fact there are both good and bad points of their brother/sister as a person by recognizing his/her good points. Furthermore, they have accepted their brother/sister with DS as the way he/she is by seeing his/her supported by many people, and also his/her giving those people pleasure in return.

'There are many complaints about my brother but I understand it is not avoidable to find defects in him as long as we live together.'

(F2)

< Appreciating existence of brother/sister with DS >

One of the siblings acknowledged the way her sister is and appreciated being able to learn that everyone has strong and weak points, and that it's important to accept each one's personality.

'I learned from my younger DS brother that we all have strong and weak points and we should acknowledge that everyone has their own personality and find their strong points.'

(F1)

'I'm also supported by a lot of people through my younger DS sister. I'm so glad I have her.'

(F2)

3) Indignation toward society

< Understanding Down syndrome >

The siblings hope that people in society won't have a negative image of DS, due to the lack of correct knowledge of DS, as they have started respecting their brother/sister with DS who has good points which they don't have as one individual.

'People only have negative images of DS, but my sister has many good points that they don't know. I don't have such a tender and pure heart like her.'

(M4)

< The society where handicapped children and people experience discrimination >

The siblings are angry about prenatal screening and discrimination against DS due to the preceding negative images of them in the society. People don't look at disabled individuals' true selves.

'People discriminate against and feel superior to DS just because they are different from everyone.'

(M3)

'Pregnant women have 'the right to know' and knowledge is important but this right is limited and meaningless if all the pregnant women who test positive from prenatal screening choose abortion.'

(M2)

4) The process of growing up

The siblings admitted to being more mature than their brothers/sisters with DS who are not growing as they are supposed to in order to get along with them. On the other hand, the siblings tend to hide their brothers/sisters against their will from others who discriminate against those with DS. Their mothers help them in those situations by understanding the feelings that they can't accept.

'When I hear my good friend who I hang out with every day say something discriminating, I get really sad.....I know I should say something about it, but I am not brave enough to do so and get ashamed of myself. I hope I can be a person who can say what he wants to say clearly.'

(F2)

5) Taking a role as a guardian

Some siblings take the part of guardians of their brother/sister with DS, as they are more mentally mature and become satisfied about their brothers/sisters' growth.

'I'm very happy if what he can do increases.'

(F1)

'I can finally live alone since my grandmother moved in to live with my family two years ago. She's home all day, so I can leave our brother/sister with her without worrying.'

(F3)

The siblings wrote about the future of their brothers/sisters with DS after the parents' death even if they don't have a concrete idea of that future; however they thought they would take care of their brother/sister with DS in some way.

'If my parents are gone.....I am trying not to think about it now, but it will be an issue to think about some time in the future.'

(F3)

2. Siblings' feelings toward their DS brothers/sisters from group interviews

Table 3
Attributes of siblings of brother/sister with Down syndrome for focus group.

	F1	F2	F3	F4	M1	M2
Gender	Female	Female	Female	Female	Male	Male
Age	38	20	22	14	17	8
Numbers of siblings	3	3	3	3	3	3
Relationship with their brother/sister with DS	Older sister	Older sister	Older sister	Younger sister	Older brother	Younger brother
Age of their brother/sister with DS	34	14	16	16	14	11
Gender of their brother/sister with DS	Male	Male	Female	Female	Male	Male

Table 4
Siblings' experiences and feelings for their brother/sister with DS from group interviews.

Theme	Category	Quotations
Relationship with a brother/sister having DS	Agony of being the middle child Brothers/sisters are brothers/sisters Quarreling between brothers/sisters	Being a middle child is agony and hard (M1, F2). First as a brother/sister before being disabled or not (F2). How can I win when we are squabbling? (M1, F2) Maybe fights with my brother with DS can be good stimulation for him (F1). My brother with DS usually tries to control himself, but I swear he uses dirty words when we fight (M2). It's good to have fights because we can let out our emotions (F1).
	Changing relationship with brother/sister with DS	There is more distance between me and my brother with DS as we get older (F4). We used to play outside together, but now he watches TV alone. I can't help it (F1). I already have friends, and my sister with DS has many opportunities to go out in play groups. Recently, my middle sibling takes her out to movies, and so on with the money the middle sibling saved. It is not impossible for me to approach her (F3). The parents are so occupied with a child having DS that his/her siblings were left alone (F1, F2, F3). As for being left alone, I can get used to the situation (F2). I like my parents to spend time with my sister with DS because I like to have a little distance from them and I can do many things.....It is beneficial for both parents and the child (F2, F4).
Parents' attitudes toward siblings	Siblings left alone	I was satisfied with the compliments the people around gave me even though I was not prioritized (M1). I was all right since I had a grandmother, too (F3). My grandparents helped a lot (F1). Even when I went to the class of my sister with DS, I thought it was a little special and didn't wonder about things such as friends, and so on (F4). My older brother with DS is rather short compared to others (M2). When I was in elementary school and watching my brother in there, I noticed he was different (F1).
	Siblings satisfaction due to those around them noticing they are trying hard The existence of family members besides parents	My parents hesitated to tell grandparents about my brother was born having DS, because my grandmother was prejudiced against DS (F2). I'm glad I could accept the situation positively at first. If the parents can't stop being overprotecting, they don't have to (M1, F1, F2). I want them to be aware of other people's eyes (M1, F2).
The meanings of disabilities of their brothers/sisters with DS for siblings	Awareness of brother/sister's disability	People around my brother try to adjust to him to prevent him from panicking (M1, F2). My brother is calming down and his requests are getting better (M1, F2) My brother becomes selfish with people outside of the family if he feels close to them (M1, F1, F2). My brother acts cute because my mother treats him like a pet (M1). My brother pretends he can't do that which he is able. He judges whether it is ok not to do it (F2). My brother/sister doesn't do things if my mother is around (F2, F3). I'm not sure if my sister wanted to be independent or not, but I noticed there was a time when she wanted to do things independently (F3). My parents cannot keep up with the child's growth. These children with DS go through puberty too (F1).
	Affection of parents' attitudes	My perspectives are more like those of my parents (F1, F3). The mental gap between my brother and me becomes wide, so I have become a guardian more than a sister (F1). I'm a capable sister (F1). I'm older, so there are times when I think I have to be in charge (M1). My parents ask me for advice/I'm a listener (F1, F2).
Parents' attitudes toward a child with DS	Special brother/sister Overprotective parents Parents' inappropriate attitudes regarding brother/sister's age	I'm worried about his health and obesity (M1, F2). I wonder how long he can live. Will we have to take care of him? He doesn't let us check his blood (F2).
	Troubled behavior of brother/sister with DS	
Growth of brother/sister with DS	Brother/sister with DS pretending to be "DS"	
	Siblings recognize the growth of their brother/sister with DS	
Siblings' positions	Siblings who take on a role as guardian	
	Siblings have met people's expectations	
	Siblings take on a role in family management Siblings care about DS brother/sister's health	

The participants were 6 siblings (2 males 4 females) (Table 3) of brothers/sisters with DS. Six themes emerged from the analysis: 1) relationship with a brother/sister having DS, 2) parents attitudes toward

siblings, 3) the meaning of disabilities of their brothers/sisters with DS for siblings, 4) parents' attitudes toward a child with DS, 5) growth of brother/sister with DS and 6) siblings' positions (Table 4). Categories

are inserted in < > , and main quotations are in italics below.

1) Relationship with a brother/sister with DS

< Agony of being the middle child >

Four of six participants were middle children; those having an older brother/sister with DS were expected to be more mature, while those having a younger brother/sister with DS had disappointed in their relationships with their mothers because they did not have the opportunity to monopolize their parents.

Siblings thought that both the first-born and youngest child obtained parents' attention regardless of whether he/she had some handicaps, and that the middle child tended to be left alone because parents were busy caring for the youngest child.

'Even without my sister having DS, my younger sister takes time of my parents.'

(F3)

One sibling (F4) said that she had to be more mature than her chronological age because the older sister had DS. However, she didn't like to be mistakenly thought of as the oldest.

'When we three play together, I'm like the oldest of the three.'

(F4)

'When people mistake me for the oldest, I correct them.'

(F4)

< Brothers/sisters are brothers/sisters >

The siblings were unable to think too much about their brother/sister with DS. Their situations were nothing new, so they lived their lives as usual. They could not dwell on their brother/sister being disabled during the process of growing up.

'I can't treat my brother with DS special just because he is disabled.'

(F2)

< Quarreling between brothers/sisters >

Because of gender, big age differences, or the personality of a brother/sister with DS, some siblings fought with their brother with DS while others did not. In such fighting situations, the older children tended to be blamed and felt it was unfair, which was similar to other families without any disabled children.

'The personality of my sister with DS is such that she doesn't get angry.'

(F1, F3, F4)

'Why do I have to be scolded by my parents for fighting although I'm already twenty?'

(F2)

'It's always me who got yelled at by my parents in the end.'

(F2)

However, upon reflection, siblings believed such conflict was a good stimulus for them even if they didn't fight with their brother/sister with DS.

'I am envious that you can quarrel with siblings.'

(F1)

'I think fighting is necessary for experiencing different emotions such as being upset, depressed, or sad rather than just being calm.'

(F1)

< Changing relationship with brother/sister with DS >

Siblings without large age differences from their brothers/sisters with DS grow up playing together, but gradually spend less time with each other as they become junior and high school students and engage in different activities.

'We used to play outside together, but now he/she watches videos alone.'

It can't be helped.'

(M1)

On the other hand, parents' time was taken up by a brother/sister with DS like going away somewhere. However, junior high school students or older were happy if the parents didn't interfere with them.

'Now I'm in junior high school. It's not a suitable time to play with my sister.'

(F3)

2) Parents attitudes toward siblings

< Siblings left alone >

Although some adolescent siblings want their parents to leave them alone, they seem to feel neglected while the parents are occupied with their brothers/sisters with DS when they were little.

'The hardest is when my sister is home with my older brother with DS, and my father is at work, which means I'm neglected.'

(M2)

One sibling thought that there would be some negative effect on siblings when a brother/sister with DS had medical complications and parents were overwhelmed by it.

'If my brother with DS has to stay in the hospital due to medical complications, it may affect us siblings.'

(F1)

However they seem to have understood their parents' situations and have to put up with it, as they had observed the difficult situations such as medical complications surrounding their brothers/sisters with DS.

'My mother was worried about medical complications more than DS.'

(F3)

< Siblings satisfaction due to those around them noticing they are trying hard >

Although the time parents could spend with the children without DS was limited, it was important for the siblings that adults around them pay more attention to them and recognize the effort they are making.

'Because people around me notice and recognizing my efforts, my feeling has been changing.'

(F1)

Especially, they were satisfied as long as their parents' admitted their efforts.

'I am happiest when my mother acknowledges me. If other people acknowledge me, I think 'what do you know?'

(M1)

'It's important that parents are watching me.'

(F1)

< The existence of family members besides parents >

If parents and those who are around the siblings acknowledge them, and if there are people who can stay with them during times of loneliness when their parents are occupied with their brothers/sisters with DS, the siblings can be supported and encouraged to mature.

'I wasn't lonely because my grandfather was still alive at that time.'

(F3, F4)

'My grandmother on my mother's side had always been very close to us, not simply after my brother with DS was born.'

(F2)

3) The meanings of disabilities of their brothers/sisters with DS for siblings

< Awareness of brother/sisters' disability >

Siblings understand their brother/sister's disability by listening to parents and people around them, but they actually become more aware how different their brother/sister with DS is through comparison with others.

'I have known that my brother with DS is unusual for some time through conversations with my family. The time I discovered the big difference between him and others was when I saw him spend time in kindergarten.'
(M1)

Even though siblings know that there are differences between them and their brothers/sisters with DS, they recognize them as brother/sister; they seem to have had unpleasant feelings depending on the reactions from people around them. Because of this, if people surrounding the siblings affirm their feelings, they can feel OK about themselves.

'At first I thought I got a cute little brother, but then I found that my parents were paying special attention to him. Then, when I entered elementary school, older kids told me my brother was retarded and I was shocked. I told my mother about this and she said 'Don't worry; you are you. He is special. It can't be helped.' So, after that, I realized nothing can change the fact and I accepted it. That's the way it is.'
(F1)

< Affection of parents' attitudes >

It is believed that parents' attitudes are very influential because siblings can sense others' reactions in the process of growing up. Siblings become who they are because their parents dealt well with those reactions.

'Parents who joined the support group with their child with DS felt welcomed, so they brought the siblings too.'
(F1)

'I think our parents have established a way to accept my DS brother through the support group.'
(F1)

Therefore, there may be cases where parents can't accept them, thus causing the siblings to worry.

'If the parents cannot accept a child with DS, the whole family atmosphere becomes negative.'
(F2)

< Special brother/sister >

One participant recognized her brother with DS as 'one child in a thousand', which means something unusually wonderful because she was so small, and told her grandmother about it happily while the parents were struggling to communicate about it. She said it was a good thing to have a positive image of 'Down syndrome'.

'I was listening to what the doctor was saying and understood that my brother was one child in a thousand. So I was excited and happy about my brother being special.'
(F2)

4) Parents' attitudes toward a child with DS

< Overprotective parents >

As children are growing up, siblings can observe parents-children relationships objectively; parents still treat the brother/sister with DS as a small child whereas he/she is trying to become independent from the parents. One sibling, she was working for a nurse and she noticed that the cause of continuous fighting between her mother and her younger brother with DS was her overprotection against him. She intervened and put him in a group home.

'Now my brother with DS lives away from home, so he is grown up enough to keep a little distance from my parents, although they try to take care of him a lot when he comes back home.'

(F1)

However parents may have to disconnect from their child with DS when they are too busy to deal with him/her. Siblings thought that such a situation helped the growth of children with DS.

'Both my parents are working so they have to leave my sister with DS alone. She has to take trains alone to commute to school.'
(F3)

< Parents' inappropriate attitudes regarding brother/sister's age >
Siblings criticized their parents as members of society for not changing their behavior in public.

'Even if they think my brother with DS is cute, I don't want them to cling to him in public. He is already a junior high school student.'
(M1, F2)

'My parents think my brother is cute, but they take care of him too much. He is a middle-aged man in his thirties.'
(F1)

Siblings hoped their brothers/sisters with DS would become independent, because they were concerned that they would be the care-taker instead of parents.

'Although my parents died before their child, my brother grew up as a dependent person because they took care of him too much. Siblings can't take care of their brother/sister with DS as much as parents do, so I want my brother to be more independent.'
(F1)

5) Growth of brother/sister with DS

< Troubled behavior of brother/sister with DS >

Five out of six siblings pointed out their DS brother/sister's stubbornness.

'My brother/sister is stubborn, and doesn't want to move.'
(M1, F1, F2, F3)

'My brother doesn't want to do anything, but only does things for himself.'
(M2)

However, they also admitted that their brother/sister calms down as he/she grows up and gains language skills.

'Because he understands what people say, he can be patient and is less aggressive. Before that, he had problems in various situations.'
(F2)

They also point out that he/she manipulates the family through recognizing people's facial expressions and subsequently making unreasonable requests.

'My brother becomes selfish with people outside of the family if he becomes close to them.'
(M1, F1, F2)

< Brother/sister with DS pretending to be "DS" >

Such manipulation stated above manifests itself in the relationship with parents. Those brothers/sisters with DS act helpless in their parents' presence. Some siblings described the situation as 'the brother/sister pretending to be a child with DS', and suspected that he/she doesn't show his/her abilities when it's more beneficial to hide them. The siblings don't think their brothers/sisters with DS try to be selfish around them, but they do around their parents.

'My brother exaggerates his condition, and he understands the situations he is in.'
(M1, F1, F2)

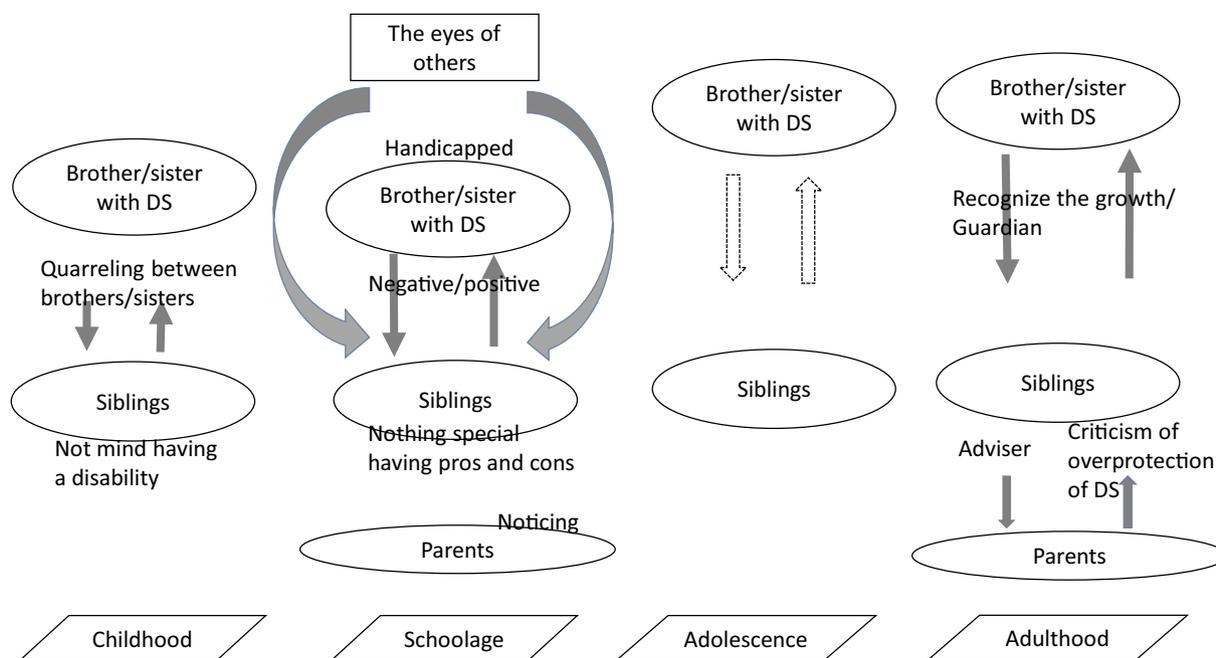


Fig 1. Change of the feelings of siblings in chronological order.

'My brother knows how to manipulate and make the parents compromise.'

(M1, F1, F2)

< Siblings recognize the growth of their brother/sister with DS >
Siblings acknowledge their brother/sister's growth by knowing that they had rebellious phases, which the parents didn't admit, and that they have learned how to control themselves gradually in their own ways.

'I can see that my brother has matured and become a patient individual.'
(F1)

'I think of my sister who is trying hard to control herself, so I root for her on the side.'

(F1, F3)

6) Siblings' positions

< Siblings take on a role as guardian >

As the siblings become junior high school or high school students, they spend less time doing activities with their brothers/sisters with DS. At the same time, the mental gap between them and their brothers/sisters with DS becomes wide, so siblings become guardians more than a sister or brother.

'I have naturally gained a parent's perspective by listening to the issues about my brother.'

(F1)

< Siblings have met people's expectations >

It is believed that siblings of children with DS have gained such attitudes not only from the relationship with their brothers/sisters but also from people around them who expect them to be mature.

'I feel that I am the most mature of all children, so I have to say there have been moments when I actually have to be the most mature because I am in this situation.'

(F4)

< Siblings take on a role in family management >

As siblings grow up and become reliable, their parents tend to consult with them in many matters. Siblings take on a role in family

management since they can observe brothers/sisters with DS more objectively than their parents, and brothers/sisters with DS respect the siblings more than their parents who tend to spoil their children with DS.

'I'm like my parents' advisor.'

(F1, F2)

'My parents work so hard to raise my brother, but they are at the bottom in the family hierarchy.'

(M1, F1, F2)

< Siblings care about DS brother/sister's health problems >

As brothers/sisters with DS grow up, siblings start worrying about their DS brother/sister's health problems. In particular, one participant whose adolescent younger brother is obese, is frustrated with her because he doesn't take care of himself.

'Unbalanced diet is a problem.'

(F1, F2, F3)

Their brothers/sisters with DS hated to take medical treatment and did not go to a hospital in addition not to taking care of themselves. One sibling could take care of her younger brother with DS when needed, however most of them could do nothing from themselves.

'When my brother got heatstroke, I gave him an intravenous drip at home since I am a nurse.'

(F1)

They worried about how long their brother/sister with DS could live in such a situation.

Thus, the feelings of siblings' changed, and Fig. 1 shows it in chronological order.

Consideration

Siblings are highly affected by the presence of their brothers/sisters with DS through various experiences. In an early report of siblings who have a brother/sister with DS, Cuskelly and Dadds (1992) states that there were negative influences on siblings such as maladaptation. However a more recent report states that the influences on siblings from their brother/sister with DS are no different from those who have

typically developing brothers/sisters, or those influences may even be more positive (Cuskelly & Gunn, 2006; Skotko & Levine, 2006; Van Riper, 2000). However, the matters they face and thoughts they get from them are not constant (Yamamoto, Kim, & Osada, 2000). It is believed that they will change as they grow.

Siblings mature with their brothers/sisters with DS, therefore the relationship between siblings and their brothers/sisters with DS is the longest. As siblings grow up they spend a lot of time playing with their brothers/sisters with DS until they are in elementary school; in some cases they fight each other like other normally developed siblings. In everyday life they could not keep in mind that their brothers/sisters have DS. However, they gradually maintain a distance and pursue their own lives, resulting in a change in the relationship. Siblings around the age of junior high school prefer to be left alone while the parents are busy taking care of the brothers/sisters with DS. Even prior to that age, they can be satisfied by being acknowledged by their parents for making efforts, or they don't have to feel lonely by the presence of the grandparents in the place of their parents. Thus, this study highlights the importance of the parents' attitudes and the presence of other people in the process of siblings' maturation.

In addition, parents' attitudes influence how siblings accept brothers/sisters' disabilities. Some siblings feel relieved by their parents who only seek understanding among family members; it doesn't matter if people around them speak ill of brothers/sisters with DS or that the siblings can't say anything back to those people. Those siblings realize their brothers/sisters with DS are different from other children around the same age by comparing them. Furthermore, they are also forced to be aware of their brothers/sisters with DS as an unusual existence by hearing such things as 'Your young brother is retarded.' However, they can accept them as one individual with both good and bad points through the parents' attitudes in which the parents are not embarrassed by the brother/sister's presence, and accept them as the way they are with sufficient affection. Not to mention that the attitudes of parents have an effect. There are things that came to light by living with DS brother/sister, and these things included meritorious points compared to themselves. Those siblings who grew up in such an environment are very angry about a society where there's discrimination against people with disabilities; they want people to understand "Down syndrome" correctly and protect them until the time when there's no discrimination. This is because they learned through their brother/sister with DS that there are many different kinds of people in the world, and helping each other is in the natural order of the things.

Yamamoto (2005) conducted the survey on 29 adult siblings of physical and intellectual disabled siblings, which states that among those siblings there were many who were teased about having disabled siblings and felt there were negative attitude toward disabilities in society. On the other hand, those brothers and sisters who tried to hide their siblings' disabilities and whose parents denied this attitude, or who challenged the society which discriminates against disabilities said that they had a long conflict with the scenario the parents and society presented: definition of disabilities, actions the siblings' have to take, or expectations.

Siblings throughout junior high school and high school days mature mentally as well reduce the time they play with their brother/sister with DS. As the child with DS matures, and the pickier and more stubborn they become, siblings can see objectively that their brothers/sisters with DS can change their behaviors depending on people. On the other hand, the siblings point out their brothers/sisters take advantage of the parents' overprotection and 'behave like DS' and criticize that the parents don't accept the growth of children and can't leave them alone. The maturing siblings are becoming reliable for their parents and take on a role as consultants or managers for the parents. Furthermore, it seems that siblings acknowledge the growth of their brothers/sisters with DS who try to suppress their behaviors for the people around them. Sometimes the siblings are happy for the brothers/sisters just as the parents are, thus gaining perspectives as parents rather than just as

siblings. As they become adults, they will naturally acquire the role of guardian.

Conclusion

These are revealed from this study;

- Siblings living with children with DS can't be concerned about their brothers/sisters' disabilities so they fight just as other families.
- Siblings accept their brothers/sisters as they are and try to understand so-called 'disabilities', for example, that it is normal for the children with DS to have good and bad points.
- Siblings feel angry about the gap between the society's attitude toward 'disabilities' and their own attitude. However, their attitude affects that of their parents'.
- The relationship between siblings and their brothers/sisters with DS change as they grow up; siblings' perspectives gradually become like those of their parents.

The limitation of the study

This was not longitudinal study but just investigated subjects in one moment, so as the subjects recalled their experiences, the researchers recorded them. Due to the limited number of participants, the effects of the following areas could not be considered: sex, age, and the order of birth.

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