

# Siblings as “Young Carers” for People with Disabilities

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## 1. Introduction: Research Purpose and Significance

This research examines the experiences of young carer siblings of individuals with disabilities in Japan. It will be achieved through having the (now adult) siblings reflect on their experience as young carers. Additionally, the process of establishing a sibling care role will be introduced.

A significant amount of research in Japan has focused on parental caregiving in families of people with intellectual and developmental disabilities (IDDs)<sup>1</sup> but the siblings of such individuals also play a significant role. Moreover, as sibling carers are the only immediate family members of similar age to the people with IDD, they have a specific care role from childhood to advanced years, as opposed to the parents. In fact, previous research on sibling carers highlights the psychological problems and stigma that emerge because of this specific care role (Grossman1972, Meyer and Vadasy1994, Bruke2010,etc).

Furthermore, previous Japanese research has focused on relatively simple care role relationships within the family. For instance, much has been said on the role of young carers<sup>2</sup> who

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<sup>1</sup> Intellectual and developmental disabilities hereafter abbreviated to IDD.

<sup>2</sup> There are a number of definitions of young carers. But Becker, who is at the center of research in this field, suggests young carers are children under 18 who support to a family member, and have significant responsibility for caring tasks that are like adult responsibilities. And that such care has a huge impact on the child's life (Becker2000).

look after their disabled parents, and also parents who care for their disabled children. Both of these situations are important but the care roles are quite easy to identify. In contrast, some sons and daughters have parents who need significant assistance from them when administering care to their siblings. Such cases are both more complex and under-researched. Consequently, this research will tackle such cases, identifying siblings' concrete care role.

## **2. Outline of Investigation**

### ***2-1. Data***

Data from 1 participant (Mr. A) was collected from,

- a Life Story Interview conducted in 2012,
- information shared at Mr. A's self-help group for siblings of people with disabilities in 2010,
- and Mr. A's personal history records.

### ***2-2. Background on Interviewee***

Mr. A is in his sixties. He is the eldest son of a farming family and had 3 brothers, all born 2 years apart from when Mr. A was 2 until when he was 6. All 3 brothers had IDD's.

### ***2-3. Methodology: Life Story Interview***

The life story interview is an unstructured interview where the interviewee is given a few topics to consider in advance and in the interview, talks freely about them with as little input and influence from the interviewer as possible.

In this case, our interviewee (Mr. A) was given 3 topics to prepare for the interview: firstly, the strength of the connections between various family members plus the social resources available at

different points in Mr. A's life; secondly, Mr. A's description of the actual care he gave during his life; and thirdly, his feelings about caring for his sibling (again, at the various points during his life).

The interview was approximately 2 hours, 10 minutes long. Questions from the interviewer were rare and were usually only to clarify.

#### ***2-4. Ethical Considerations***

This research is based on the ethical guidelines proposed by The Japanese Society for the Study of Social Welfare (JSSSW). Rights to investigate participants for this research were obtained by Doshisha University of Liberal Arts Research Ethics Review Committee regarding Human Subjects (Number:1139).

I explained the methodology to the interviewee and he agreed to it in advance.

### **3. Findings**

#### ***3-1. Experience as a Young Carer***

Similar to data from previous research on young carers (Dearden and Becker, 2004), Mr. A gave physical and psychological care. For example, he changed his brothers' clothes, fed and cleaned-up after them, helped them bath, dropped them off and picked them up from school and other institutions, played with them, and participated in meetings and events in schools and care institutions. Sometimes his workload was divided between his parents and himself and many times he was the sole carer because his parents had to engage in paid employment outside the home. At the same time, he took psychological care of his siblings, watching over his brothers and nurturing them.

In school, Mr. A and his brothers were discriminated against

because of stigmas attached to disabilities and poverty. If the brothers caused trouble in school, the teachers expected Mr. A to deal with it. Usually, teachers deal with challenging students in school but in this case, people seemed to think that the family members of disabled people should be responsible for the care of disabled people. This resulted in Mr. A not being able to behave like a child while at school.

### *3-2. Reflections on the Care Role*

In this investigation, Mr. A repeatedly said that he held a care role not as a sibling, but as a family member.

A : *(About the present care for brothers)* If my parents were alive, they'd be taking care of my brothers. But they died. So I take on a caring role, not as a sibling, but as a family member. Actually, the parental role was transferred from my parents to myself. It's reality. Yeah, yeah, yeah.

It's possible that Mr. A thinks the care role which family members take on is similar to the parental role. This means that he regards "sibling-carers" as those who don't hold a significant care role but that "parents" do hold such a role. It also suggests that he distinguishes between himself and siblings of other families<sup>3</sup>.

Also, Mr. A isn't at odds with being a carer because he has been taking on the care role from childhood.

I : For the role... uhh...I think that you take on a care role naturally as a family member, I think. How do you think about your care role ?

A : Uhh...honestly speaking, uhh...I'm not at odds with being a

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<sup>3</sup> Such families are probably connected to members of his self-help groups and his brothers' institutions.

carer.

I : I'm not at odds ? Oh, Really ?

A : Yeah. It's reason that I have been taking care role from childhood. Of course, I can think "my life is right?" . But I think I take care role naturally in my feeling.

In addition, his care role seemed to have changed and developed, as exemplified by the following 3 quotes from Mr. A,

"...I could not accept myself as a carer. Now, I don't know if I can accept it. Yeah. So it changes daily."

"I think of course I think about everything. Why did I do something?"

"I think, in the old days, I did things. Uhh. I can understand why a little. Yeah. I need to take a lot of time to think about it."

Here Mr. A is expressing how he questions his previous actions.

So it seems he continually thinks about and re-evaluates his care role.

### ***3-3. Relationships between Carer and Sibling with Disability***

On the other hand, he feels guilty about refusing to care for his family.

A : (About the 3<sup>rd</sup> son who could not walk after contracting measles) I could not accept the after effects of the measles. For instance, uhh, when my brothers had various kinds of incontinence, I cannot forget about when I couldn't move forward with my brothers [ed. Couldn't escaped from the care role]. Uhh...So...I still regret it and feel guilty about it. Yeah, yeah. Similar episodes have repeated themselves in my lifetime. Yeah.

Mr. A talked about not being able to “move forward with my brothers” so not only did he see himself as a ‘parent’ but he also saw himself as a sibling and therefore an equal, making his relationship more complex. This is probably because Mr. A is of similar age to his brothers.

#### **4. The Next Step**

##### ***4-1. Influence of Previous Experience as a Young Carer***

In the future, it may be useful to analyse the experiences of adult siblings who were not young carers, but who find themselves taking on a care role when their parents get old or die. Such sibling carers may find it more challenging than siblings who have been young carers. Consequently, analysing such ‘new’ adult sibling-carers may make it easier to identify the process of taking on a care role.

##### ***4-2. Growing up Each Other: Relationships between Sibling and Sibling with Disability***

It would also be beneficial to focus on how the care role changes and grows as opposed to it being fixed. Siblings in childhood who went to the same school share similar experiences for example, when playing and when going to school.

Such siblings help each other grow and mature and can understand what each other are going through as they are of a similar age and are often in the same environment. Nevertheless, the sibling carer still maintains her / his caring role. For instance, Mr. A often expressed concern that sometimes schools refused his brothers’ entry as pupils.

It is also important to consider the relationship of the law or social resources in future research to provide a 360° view of the forces acting on this aspect of caring.

## **5. Conclusion**

Through evaluating the experiences of a young carer of siblings with disabilities in Japan, it seems that, similar to previous research on young carers, the participant in this research, gave physical and emotional care.

It also showed that the participant experienced role-conflicts at school and, within the family, felt the care-role was complex, dynamic, and often changing. Consequently, it may be useful in the future to look at such changes, as well as the law and social resources.

Additionally, research on adult sibling-carers, who are new to the task, may identify the process of adopting a new care role.

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