

Original Paper

A Study on Normal Siblings of Mentally Retarded Persons

Hiromitsu MIHARA

*School of Nursing
Yamaguchi Prefectural University
3-2-1 Sakurabatake
Yamaguchi-City 753-8502, Japan
(Accepted Sept. 24, 1997)*

Key words : normal siblings, mentally retarded siblings, research, parents

Abstract

This study examined how normal people perceive their mentally retarded siblings and what they see to be their future relationship. Normal siblings of mentally retarded persons were given a questionnaire regarding their relationships with their parents and mentally retarded siblings during childhood and how they introduced their mentally retarded siblings to their fiancées. In most cases, they had good relationships with their mentally retarded siblings during childhood. Most of them also intend to take care of their mentally retarded siblings after their parents pass away. However, some seemed to have ambivalent feelings about their mentally retarded siblings in connection with marrying and starting their own families. Half of the married normal siblings had informed their partners about their mentally retarded siblings before they married. Some of the married normal siblings were worried that they might have a mentally retarded child.

Introduction

Mothers have been the primary care-givers for mentally retarded children. The field of social work tends to concentrate on the parent (mothers) -child relationship and the counseling of slightly mentally retarded children.^{1)~5)} Recently, some researchers have suggested the need for an in-depth study of siblings of mentally retarded persons.^{6)~8)} Through informal observations, interviews and conversations, it is apparent that the siblings of mentally retarded persons are very

involved in their care. Many have helped their parents care for them since childhood. Furthermore, it appears that normal siblings often take their mentally retarded siblings into account when making crucial decisions, such as taking a job or getting married. Thus, it is important to study how normal siblings viewed their parents and mentally retarded siblings during childhood and how they perceive their future with them for the following three reasons.

First, some have hostility and jealousy toward their parents and mentally retarded

siblings. Seifert⁹⁾ reported that during childhood some felt deprived of their parents attention, which seemed to be more focused on their mentally retarded siblings. That is, they seemed to think that their parents were always busy taking care of their mentally retarded siblings and therefore had very little time for them. Some of them carried these unresolved feelings into adulthood. In some cases, they insisted that their mentally retarded siblings should be sent away to a special institution because they created disturbances with improper behavior, such as crying and self-destructive actions. It is common for mentally retarded children to be institutionalized, not because of severity of retardation, but because of great stress within the family¹⁰⁾. However, this kind of intervention is incompatible with the Normalization Principal.¹¹⁾ This problem needs to be addressed in a different way.

Second, normal siblings can assist their parents in the care giving process. In the past, because of the amount of time mothers spent with their children, they were trained to play a key role in the children's psychotherapy.¹²⁾ It was thought that if mothers were given therapy training, quality and quantity of care would improve for their children.¹³⁾ However, it is sometimes difficult for mothers to care for their mentally retarded children. Some mothers claimed that they tended to be over-protective and could not be rational because of their emotional involvement. In such cases, normal siblings can assist the mothers in giving care.

Third, the number of aged people is increasing rapidly in our society. The mentally retarded persons and their parents are no exception. It becomes very difficult to care for mentally retarded adults at home. Ichimon et al.¹⁴⁾ reported that the most common reasons for 74 suicides involving parents

of mentally retarded children or adults were pessimism about prospects for their future, exhaustion from taking care of their mentally retarded children and worry over their own mental health. It was pointed out that the number of such suicides would increase as both parents and mentally retarded children become elderly. However, normal siblings could spare them from this tragedy by helping their parents take care of their mentally retarded siblings.

Because of the three reasons given above, normal siblings can no longer be left out of the planning for the long term care of the mentally retarded. This paper reports on a preliminary study focusing on normal siblings.

Method

The subjects were 118 normal siblings, 65 females and 53 males. Their ages ranged from 13 to 66 and the mean age was 29.8 (s. d. = 12.6). Fifty subjects were in their 20s and 23 were in their 30s. The mean number of children per family was 2.5 (s.d. = 0.686), ranging from two to five. Their occupations were as follows: 52 office workers, 29 students, 19 housewives. Thirty-eight subjects were married and 80 were unmarried. Eighty-five subjects had profoundly retarded siblings and 27 had moderately retarded siblings. Fifty-two mentally retarded siblings lived in institutions for the mentally retarded while 47 lived in their own homes with their parents and attended sheltered workshops or day service centers for the mentally retarded.

The subjects were given a questionnaire consisting of 49 items divided into three categories: (1) relationship with the mentally retarded siblings during childhood, (2) relationship with their parents, (3) their own marriage.

The questionnaire was distributed in two

Table 1 Items of question

(1) Relationship with mentally retarded siblings during childhood
① Had they played with their mentally retarded siblings?
② Had they gone out with their mentally retarded siblings?
(2) Relationship with their parents,
① Had they talked with their parents about problems involving their mentally retarded siblings?
② How did they feel about the way their parents were rearing their mentally retarded siblings?
③ What about the care of their mentally retarded siblings after the death of the parents?
(3) Marriage of normal siblings.
① Had they informed their fiancée about their mentally retarded siblings before they were married? (question to the married subjects).
② Will they inform their fiancée about their mentally retarded sibling before they marry? (question to unmarried subjects).
③ Were they worried about whether they would have mentally retarded children after they marry? (question to married subjects).

ways. One batch was sent to two organizations for parents of mentally retarded children in Nishinomiya-city and Higashiosaka-city. Both organizations distributed the questionnaire to families with retarded children and collected those returned. A second batch was sent to two institutions for the mentally retarded in Okayama-city and Hyogo-prefecture. The directors of these institutions also distributed the questionnaire to families with mentally retarded children and collected those returned.

Result

(1) Relationship with the mentally retarded siblings during childhood

Forty subjects (33.9 %) had played often with their mentally retarded siblings during their childhood while 45 subjects (38.1 %) had played sometimes. Most of the subjects had played with their mentally retarded siblings. While 86.2 % of female subjects had played often with their mentally retarded siblings, 67.9 % of the male subjects had. The subjects' sex significantly influenced the result ($\chi^2=5.65$, $p<.05$).

Thirty-seven subjects (31.4 %) had gone out often in public with their mentally retarded

siblings while 51 subjects (43.2 %) had gone out sometimes. About 75 % of the subjects reported that they had gone out in public with their mentally retarded siblings. Female subjects played and went out more often with their mentally retarded siblings than the male subjects. While 43.1 % of the female subjects had gone out often with their siblings, only 17 % of the male subjects had ($\chi^2=9.24$, $p<.01$). From this result, it appears that the female subjects took care of their mentally retarded siblings more often than the male subjects. It seems that normal female siblings play a greater role in taking care of their mentally retarded siblings.

(2) Relationship with their parents.

While 97 subjects (82.2 %) had discussed problems, including problems related to their mentally retarded sibling, with their parents, 16 subjects had not. Sixty subjects (50.9 %) had a favorable impression about the way in which their parents reared their mentally retarded siblings while 35 subjects (29.7 %) had a moderate impression. Furthermore, 97 subjects (82.2 %) answered that they took care of their mentally retarded siblings after their parents passed away. Thus, it seems that normal siblings usually had good rela-

tionships with their parents.

(3) Marriage of normal siblings.

About 20 subjects (52 %) answered that they had the courage to inform their partner about the existence of their mentally retarded siblings before they married. Sixteen married subjects (42 %) were concerned that they could have retarded children. Thirty-three unmarried subjects (41.3 %) reported that their mentally retarded siblings are obstacles to their marriages while 38 subjects (47.5 %) did not think so.

The unmarried subjects showed ambivalent feelings toward their mentally retarded siblings in connection with their own marriage. Thirty-two subjects (40 %) felt that they would have the courage to inform their partners of their mentally retarded siblings before marriage while 44 subjects (55 %) would not. It is clear that the presence of a mentally retarded sibling was not, in itself, an obstacle to marriage, but it cannot be denied that it has effects on marriage plans.

Discussion

The results of this study revealed that most normal children have played and gone out with their mentally retarded siblings during childhood. However, the sex of the normal sibling was a significant factor. Other researchers reported very similar results, i. e. normal female siblings take care of their mentally retarded siblings more than normal male siblings.¹⁵⁾¹⁶⁾ It seems that the parents have reared their normal female children from childhood to help them care for their mentally retarded siblings. It is very important to take the sex of the normal sibling into account when they are to be a part of the care team for the mentally retarded.

The fact that most normal siblings have had good relationships with their parents indicates that there were less problems in

their life than one might suppose. They seemed to be open-minded and understanding of their parents situation with their mentally retarded siblings. Therefore, they probably would be good care-givers for their mentally retarded siblings when their parents become elderly or pass away.

Although the normal children have their own lives, they do take their mentally retarded siblings into account when making important decisions, such as taking a job or getting married. They seemed to have ambivalent feelings about their mentally retarded siblings in connection with their own marriages. On the one hand, they have their own lives apart from their mentally retarded siblings. On the other hand, they are aware that they can not disregard their mentally retarded siblings. Some normal female subjects mentioned that they had spent too much time taking care of their mentally retarded siblings and therefore missed their own life. The fact that about half of the subjects in this study were concerned about their mentally retarded siblings in connection with marrying and starting their own families, emphasizes a deep seated social attitude toward mentally retarded persons. Even though the Normalization Principle Program has been introduced in Japan, families with mentally retarded members are still experiencing some prejudice. It is necessary to enforce the principle, not only for mentally retarded persons, but also for their families.

One caveat to a study such as this is whether the subjects gave candid answers. They might have concealed their real feeling for their families and given positive responses to the questionnaire. It has been reported that some normal children conceal their hostility and jealousy for their parents and mentally retarded siblings.¹⁷⁾ But, the subjects in this study might have already come to terms with

their problems and conflicts in connection with their mentally retarded siblings and could participate in this study to give valid results. Nishimura and Hara¹⁸⁾ suggested that if normal people have had difficulties in their life that are not yet resolved, they would not have participated in a study such as this.

In any case, this study revealed that in addition to their mothers, the normal siblings would be good care-givers for mentally retarded persons. To include them as part of the care team for mentally retarded persons, an in-depth study of normal siblings is needed.

References

- 1) Polansky NA, Boone DR, Desax and Sharlin SA (1971) Pseudostoisicism in mothers of the retarded. *Social Casework*, **52**, 643—650.
- 2) Nurse J (1972) Retarded infants and their parents: A group for fathers and mothers. *British Journal of Social Work*, **2**, 159—174.
- 3) Kratochvil MS and Devereux SA (1988) Counseling needs of parents of handicapped children. *Social Casework*, **69**, 420—426.
- 4) Hartman SS and Hyres J (1975) Marriage education for mentally retarded adults. *Social Casework*, **5**, 280—284.
- 5) Empey LJ (1977) Clinical groupwork with multi-handicapped adolescents. *Social Casework*, **58**, 593—599.
- 6) Wane J and Fine SB (1986) Group work with retarded mothers. *Social Casework*, **67**, 195—202.
- 7) Schreiber M (1984) Normal siblings of retarded persons. *Social Casework*, **65**, 420—427.
- 8) Klein SD and Schleifer MS (1993) It isn't Fair ! Siblings of children with disability. Bergin and Garvey, Westpost, Connecticut, 1—2.
- 9) Seifert M (1989) Geschwister in Familien mit Geistig Behinderten. Julius Klinkhardt, Bad Heilbrunn, 52—111.
- 10) Fowle M (1968) The Effect of the severely mentally retarded child on his family. *American Journal of Mental Deficiency*, **73**, 468—473.
- 11) Egusa Y (1982) The way to the normalization. National Council of Social Welfare, Tokyo, 41—61 (in Japanese).
- 12) Raieri RF and Pratt TC (1978) Siblings therapy. *Social Work*, **23**, 418—419.
- 13) Takeda K and Tatsuki S (1981) Casework with the behavior modification approach for the parents-children, Minerba-shobo, Kyoto, 9—21 (in Japanese).
- 14) Ichimon K, Urano E and Katsumata H (1985) The suicide of mentally retarded family. *Kumamoto University Journal of education*, **34**, 171—179 (in Japanese).
- 15) Fischer J and Roberts SC (1983) The effect of the mentally retarded on his siblings. *Education*, **103**, 399—401.
- 16) Douglas W and Miller CN (1977) Attitude and life commitments of older siblings of mentally retarded adults: An exploratory study. *Mental Retardation*, 38—41.
- 17) DeMyer MK (1979) Comments on siblings of autistic children. *Journal of Autisms and Developmental Disorder*, **9**, 296—298.
- 18) Nishimura K and Hara K (1996) Siblings of handicapped children. *Developmental Disorder*, **18**, 56—66 (in Japanese).