

Strategies by Japanese Mothers of Children with Hemophilia Regarding Hemophilia Disclosure at School

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Background

In Japan, most students with hemophilia study at mainstream schools. However, fearing possible discrimination and prejudice, many mothers find it difficult to decide whether to inform teachers of their children's hemophilia. After press reports in the 1980s regarding some hemophiliacs who were HIV positive, it has become more difficult for parents to inform teachers that their children have hemophilia.

The aim of this study:

Described the strategies employed by mothers regarding disclosure of their children's hemophilia.

Hemophiliacs and HIV/AIDS in Japan

In the 1980s, about 40% of hemophiliac patients (about 1500 people) in Japan contracted HIV via imported unheated blood products. More than 650 patients died by 2013.

- ◆ 1985: the government permitted heated blood products, but did not stop the sale of unheated products until 1987.
- ◆ 1989: Lawsuits were filed against national government and pharmaceutical companies.
- ◆ 1996: Legal settlements were reached.



Methods

Subjects: Nineteen mothers of hemophiliacs (12 were HIV positive and 7 were HIV negative).

Data Collection: Semi-structured interviews were conducted.

Analysis: Kinoshita's (1999/2003) Modified Grounded Theory Approach (M-GTA) was conducted using the transcripts.

Results and Discussion

The era before the advent of the HIV/AIDS crisis

Did mothers fear that mainstream schools would refuse to admit hemophiliacs?

NO
Full disclosure (disclosed all details of their children's hemophilia)

I shared all the details of my son's hemophilia with his teacher. After that, the teacher allowed him to wear special shoes at school, which fitted his feet.

Conditional full-disclosure (tried to find an appropriate school for their child, then disclosed all details)

I tried to find a Christian school for my son, because I thought Christian schools never refused children with chronic diseases.

YES
Partial disclosure (provided minimal information to teachers regarding hemophilia in case of emergency.)

I just told my son's teacher that he had hemophilia, and asked the teacher to call me whenever he experienced pain.

After the era of HIV/AIDS crisis

Were the children HIV positive? **NO** Did mothers fear that their children would be discriminated against because they were associated with being HIV positive? **YES**

NO
Full disclosure (disclosed all details pertaining to hemophilia and HIV/AIDS)

I explained hemophilia and HIV infection to my son's teacher, and asked the head teacher to do something, something regarding HIV medication.

Limited disclosure (did not add new information about hemophilia, namely the connection to HIV/AIDS.)

I had told my son's teacher that he had a disease which made it difficult to stop bleeding. But, after this HIV/AIDS issue, I could not say 'hemophilia' to the people around us.

YES
Non-disclosure (withheld all information pertaining to hemophilia and HIV/AIDS from schoolteachers.)

I did not tell my son's teacher about hemophilia. I injected my son with the clotting factor at home before going to school, did physical exercise, and so on. So he never had bleeding during school hours.

Conclusion

The strategies employed by mothers depended on the level of fear of discrimination against hemophiliacs or people with HIV/AIDS at schools. This means that public schools were not comfortable places for hemophiliacs if they disclosed details pertaining to their children's hemophilia. If the children are to feel safe when attending school, public schools must establish care management and anti-discrimination systems for students with chronic diseases.

