

Difficulties faced by haemophilic students in Japan

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Background

Most hemophilic students in Japan opt for general education. However, after graduating from school, some of them are unable to continue employment as they tend to lack the teamwork, communication, and leadership skills, usually developed during school life.

The aim of this study

- ◆ To assess the difficulties faced by hemophilic students during their school life
- ◆ To analyze why they cannot acquire these skills
- ◆ To determine why their teachers often provide insufficient support.



School Nurses in Japan

- ◆ A person who occupies the role of school nurse is called “Yogo teacher” in Japan.
- ◆ They are full-time teachers, not nurses.
- ◆ Yogo teachers are specially licensed educators and about half of them also hold nursing licenses.
- ◆ The role of these teachers is to ensure and maintain the health of all students in the school.



Hemophiliacs and HIV/AIDS in Japan

In the 1980s, about 40% of hemophilic patients (about 1500 people) in Japan contracted HIV via imported unheated blood products. More than 650 patients died by 2011.

- ◆ 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

Two qualitatively analyzed studies were conducted to explore the difficulties faced by hemophilic students.

- ◆ Mothers of twenty-seven 18 to 40 year-old hemophiliacs were interviewed in 2009.
- ◆ An open-ended questionnaire was conducted with thirty-seven school nurses in 2010.

Results and Discussion

Interviews of mothers of hemophiliacs

1. Their children were sometimes denied admission to nursery schools or elementary schools because of their medical condition



“A principal of a regular school told us that hemophilic students should go to a special needs school.”

“A city officer said that hemophilic children might be refused entry to day-care centers.”



2. Not only mothers of hemophiliacs with HIV/AIDS, but also those of hemophiliacs without HIV/AIDS tended to conceal information regarding their sons' medical conditions from the teachers because they were afraid their sons would face prejudice and discrimination.

“I said to new school teachers that my son had chronic arthritis, not hemophilia, because my son's teachers in the old school, friends and their friends' mothers treated us as if we were filthy.”



3. Some of the hemophiliacs were not allowed to participate in physical education, school trips or athletic meets even though they physically could have because their teachers were afraid they might get injured.

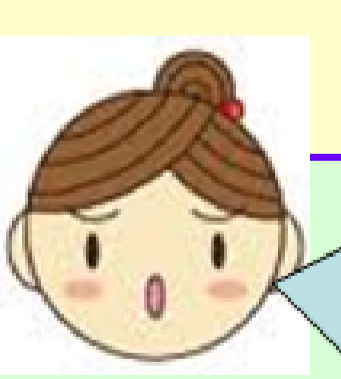


“Some of my son's teachers did not want him to join the school sports festival.”



“My son's teacher said if I came along and kept my son under close supervision in case of injury, they could allow him to go on a school trip”

4. Most of the hemophiliacs did not receive any educational support from teachers when they were absent from school. Some of the mothers provided more of their children's education at home rather than the teachers at school.



“My son was absent from school 30 or 40 days a year, so he could not get good grades.”

“When I went to see my son's classroom, I realized he could not understand fractions at all. After that, I taught him fractions from the beginning at home.”



Yogo teachers' explanations for why teachers often did not provide sufficient support to the students

1. For the students, treatment was more important than attending school. It is better for them to be absent from school and get medical support from their hospital or at home, until they can return to school.



However, basic education is a fundamental right of all children.

2. The students in regular classrooms did not appear to need help because they always kept quiet and seemed to be getting along well.



However, many of these students are unable to express their feelings or desires.

3. Teachers believed that there was no need for the students to get a lot of support from them, as the teachers thought that their doctors and medical staff were providing primary support.



However, more often than not, doctors and medical staff provided treatment only.

4. Recently, teachers have been busy taking care of students with developmental disabilities or absenteeism in regular classrooms. So, taking care of students with chronic illnesses was beyond their capacity.



However, this argument ignores the needs of the children with chronic illnesses while favoring students with other problems.

5. The regular teachers were not able to support the students because of the lack of budget, time, manpower, or knowledge of the condition. The teachers thought that it was not fair to give the students special support in a regular classroom.



However, the teachers' primary role is to help the all students in their class.

Conclusion

Most of hemophilic students do not develop academic abilities, athletic skills, or social skills in their schools.

This is because:

- some of them are not able to disclose their diseases to their teachers and friends
- they are not able to receive extra support from their schools

The reasons why teachers give inadequate support to the students are:

- the regular teachers have insufficient awareness of how to deal with students with chronic illnesses
- there is a lack of school resources allocated to the students

To provide adequate support for the students, the teachers need:

- to acquire accurate knowledge of the condition
- to understand what kind of difficulties the children face in their school
- to discuss what kind of support the children need

To improve the teachers' situations, the teachers also need various resources such as finance, time, human resources, provision of information to help students with diseases

