



Introduction & Objectives:

Thanks to the development of prophylactic treatment for the patients with hemophilia, they have been able to live healthy lives. However, they have to continue periodical infusions to sustain it. It is necessary for children or adolescents who go to school to be accommodated to participate in the physical education or the school events being a burden to them. Then, our study's objective is to clarify the present status of participation in school events or physical education and the countermeasures against them.

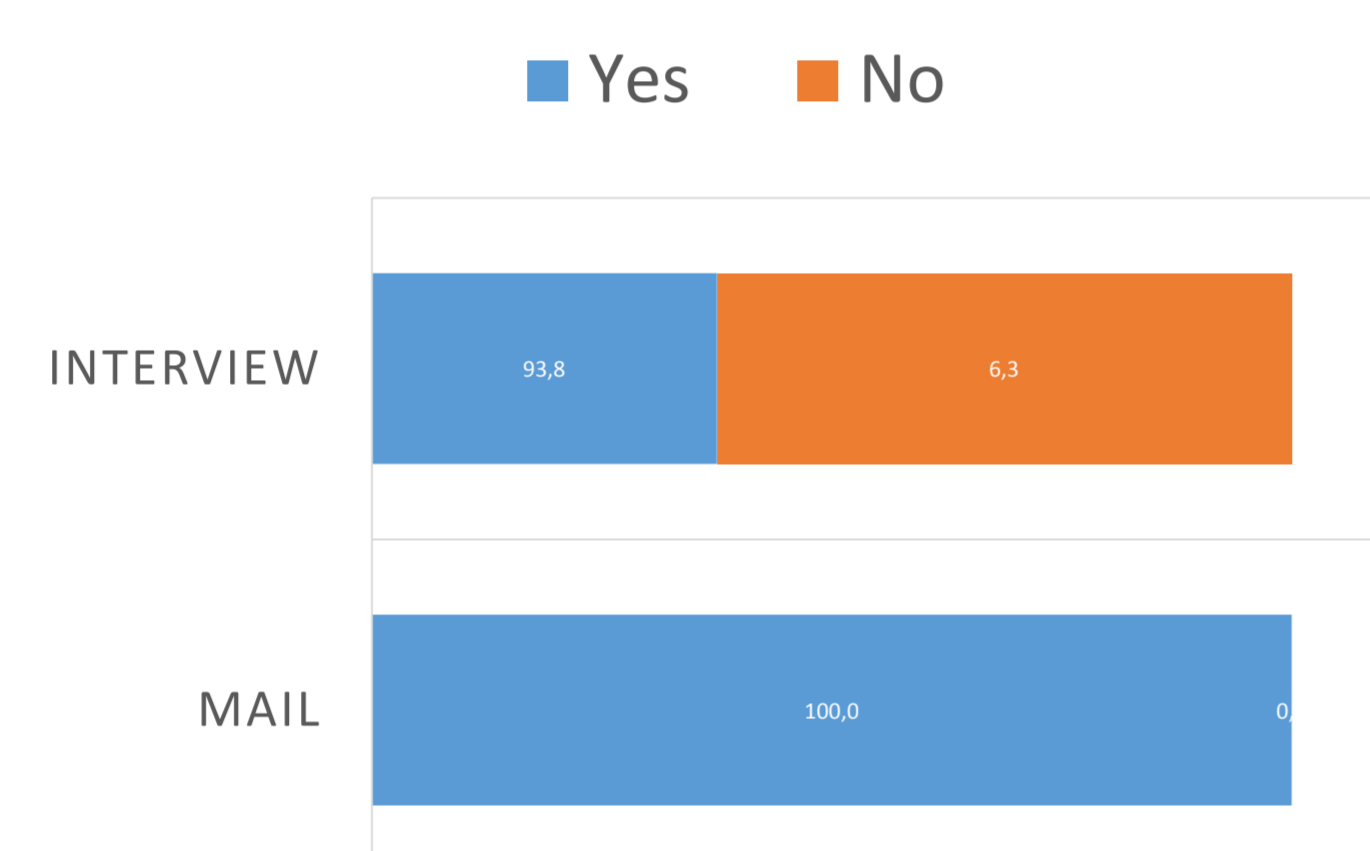
Results:

Participants of Attribution n=27

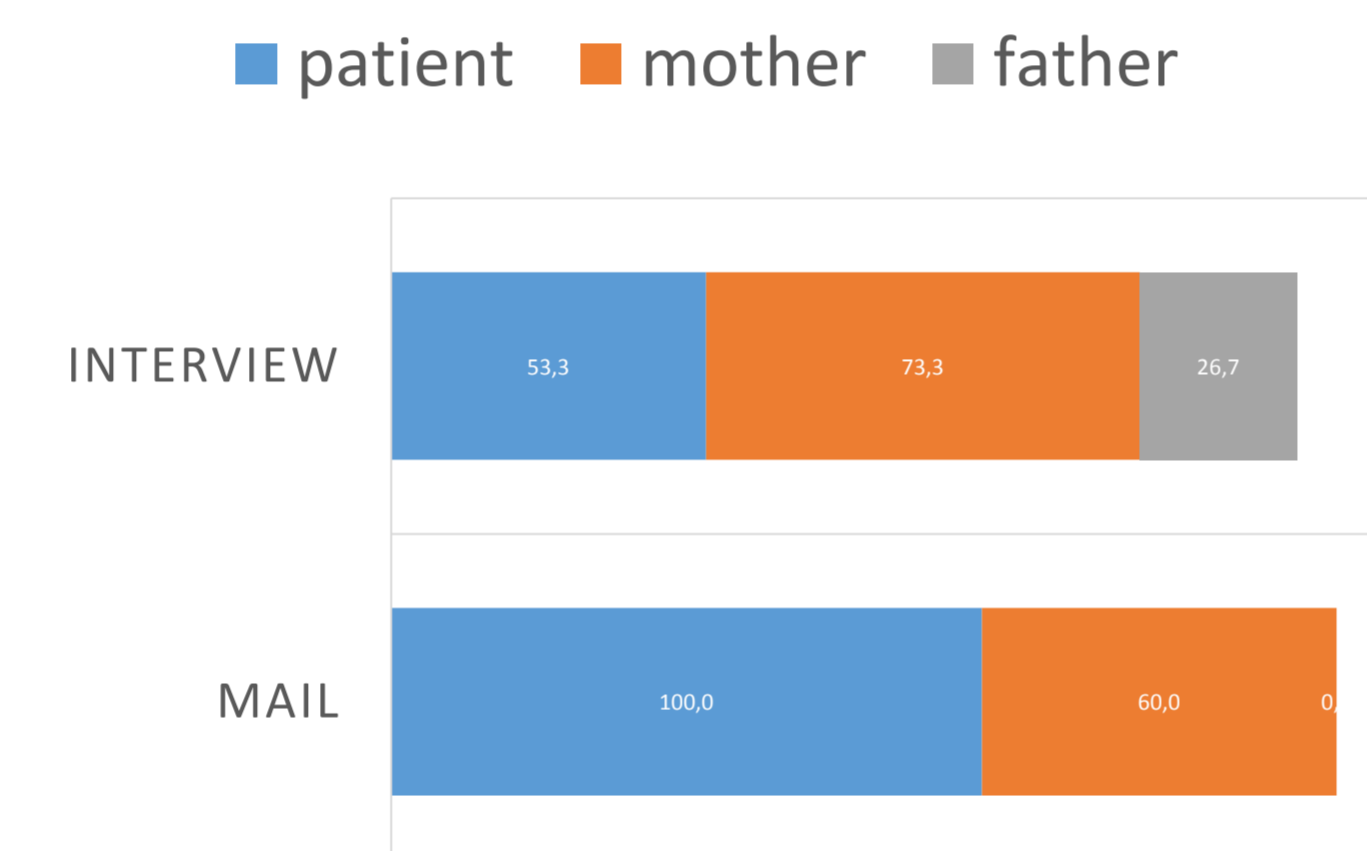
Survey item	itemize	interview n (%)	mail n (%)
Age group	30 ~ 39	12	8
	40 ~ 49	4	3
	50 ≤	0	0
Age group of Hemophilic children	< 1	0	0
	1 ~ 3	2	0
	4 ~ 6	4	0
	7 ~ 9	3	0
	10 ~ 12	4	0
	13 ≤	5	11
	Non-response	1	0

Worry about the life with the patient

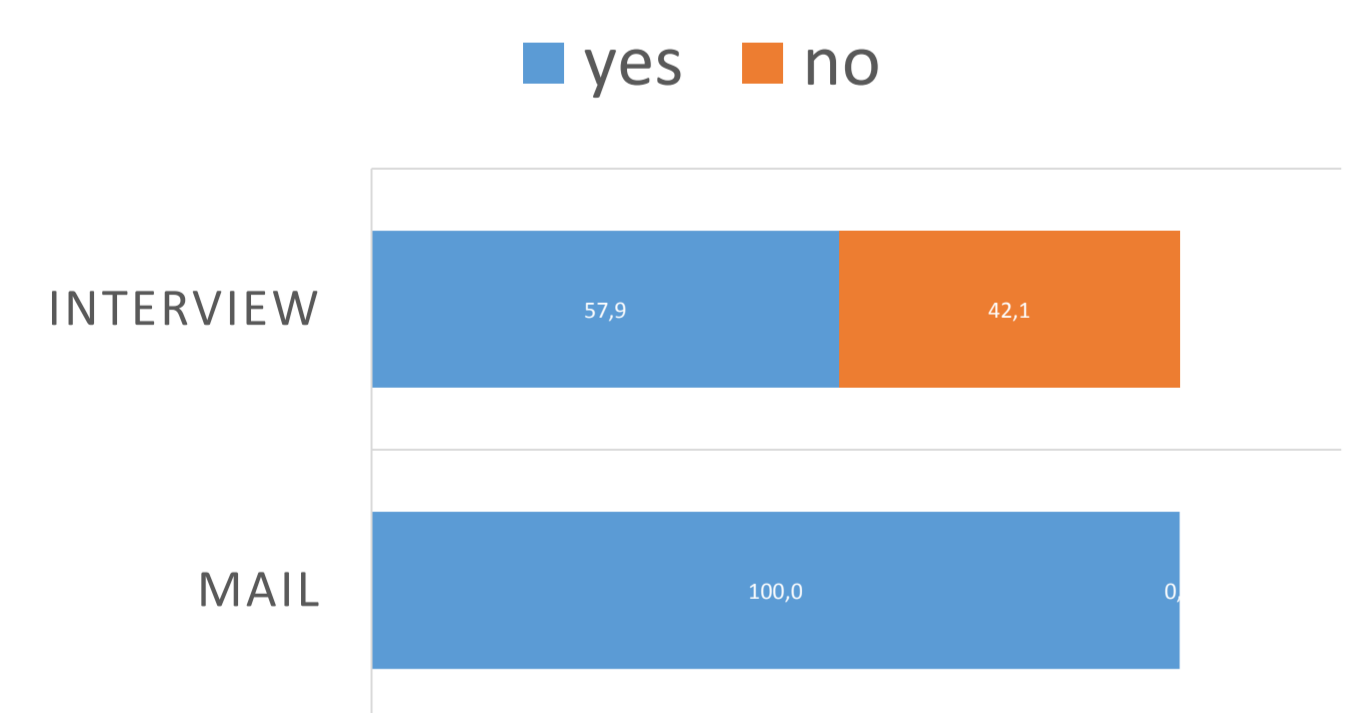
HAVING PROPHYLAXIS AT THE HOME OR NOT



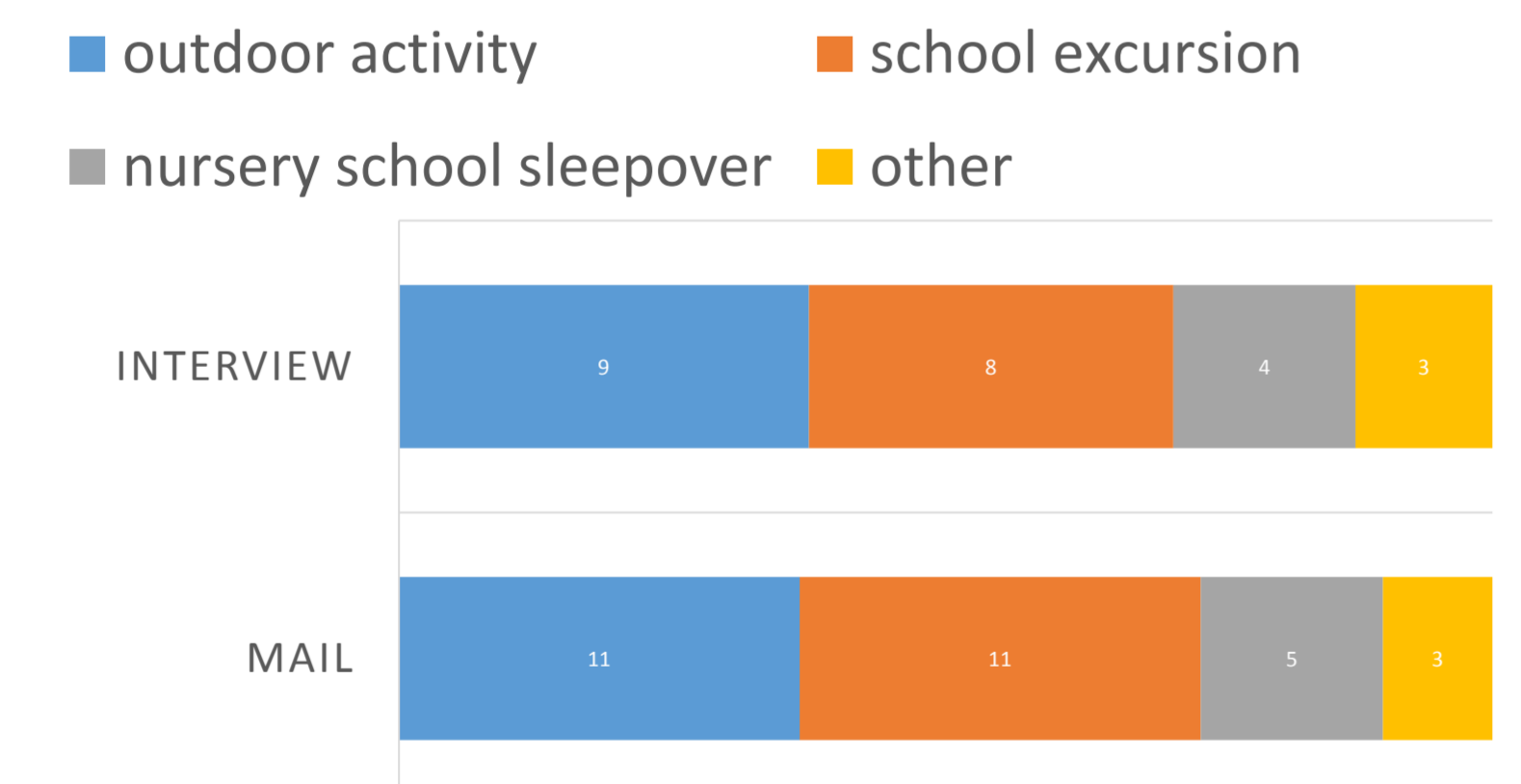
WHO INJECTS IT AT THE HOME?



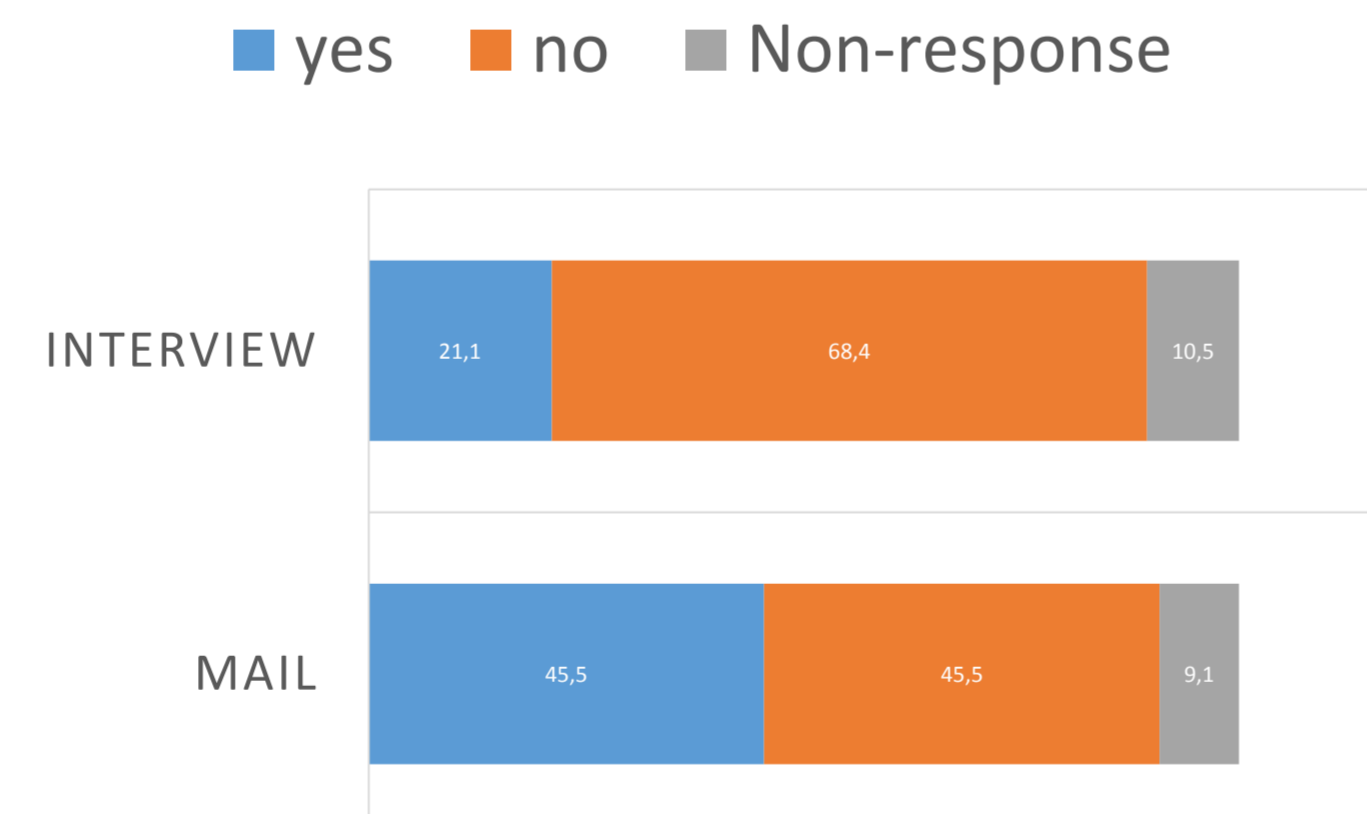
THE PATIENT PARTICIPATED IN SCHOOL EVENTS OVERNIGHT



THE PATIENT PARTICIPATED IN SCHOOL EVENTS



DID NOT PARTICIPATED IN SCHOOL EVENTS



Prophylaxis of the patient in accommodations :

Where ?	interview
mail	room of school nurses
interview	Prepared in another room
mail	hotel's room or on a bed (high-school)
interview	hotel's room or on a bed (high-school)
mail	hospital
interview	university hospital
mail	at the home

When ?

When ?	interview
mail	The before departure
interview	During the overnight stay
mail	departure morning
interview	night of the stay
mail	morning of the staying (before the breakfast)
interview	departure morning
mail	morning of the stay (before the breakfast)

Who ?

Who ?	interview
mail	patient (since high-school)
interview	patient (since high-school)
mail	mother(until junior-highschool)
interview	mother(until junior-highschool)
mail	medical staff
interview	father
mail	others (father , teacher , nurse)
interview	nurse

Free writing

All children who went to school participated in school events regardless of overnight stay.

Prophylaxis was carried out in the morning of the periodical day or night.

In their high-school student days, the patients didn't depend on the support for school and had self-infusion of factor concentrates by themselves.

There were many mothers who had asked school nurses or medical caregivers in the hospital close to the staying place to support their children until they were junior high school students.

The details of the event (Did not participate)

mail	interview
sport event	mountaineering
physical education	marathon
Marathon	vaulting horse
sking	

Materials & Methods:

Participants were hemophilic children's mothers. A questionnaire survey for them was conducted anonymously after obtaining the informed consent from them. The Questionnaire survey was self-administered anonymously, data were obtained from the interview method or mailing method.

the interview : when the patient who did outpatient department medical exam
the mail : sent from a cooperator of the patients association's acquaintance

Items of the questionnaire are about prophylaxis and participation in school events, and by whom or where the childrens are infused in the occasions.

We surveyed from July to September in 2012.

Attribution Participants : (1)Age of Participant (2)Children of patients (3) Age of patient

Items of the questionnaire

- Worry about the life with the patient (1)The patient having prophylaxis or not (2)The patient having experience participating or not overnight school events
- Injection of the patient in accommodations: (1)where (2)when (3)who —Having a person of support or not
- In school events : (1) participated (2) did not participate

Data Analysis (1)The quantitative data were aggregated. (2)The qualitative data were classified with similarity

Discussions & Conclusions:

- Most of the patients injected the prophylaxis at home. → We think that some of the patients injected the prophylaxis at a hospital.
- In the mail group, self-injections were most common. In the interview group, the most enforcer of the injections were mothers of patients. Some enforcers of the injections were fathers of patients.
- Both groups tended to participate in school events. → If a patient can self-inject, we think that student will be able to participate in overnight school events. However, if patient can't self-inject, the prior adjustment such as the hospital with patient injection is necessary. → In Japan, overnight school events are carried out in the upper grades of the elementary school. Therefore, it is desirable that patients can self-inject before becoming fifth graders of the elementary school.
- In the mail group, there were the school events that the half of patients did not participate in. In the interview group, there were not the school events that patients did not participate in. → We think that the patients of the interview group can live a life as the normal child thank to Prophylaxis.
- There were the patients who did not participate, in events that required much leg power such as mountain climbing or the marathon. → We think it is necessary to consider the ankles joints even if the patient is using Prophylaxis.

- It is suggested by our investigation that most hemophilic children and adolescents can participate in school events without paying special attention to anything the same as healthy people. However, some children cannot help but limit the participation in school events because they have to take into consideration the need to evade their bleeding risk.
- We, nurses or medical caregivers, have to ensure that the patients have an environment they can do self-injection comfortably because self-injection by themselves led to disturbance for safety and poor adherence.

References:

- Drake JH. et al : High school completion rates among men with hemophilia. Am J Prev Med. 38(4), 489-494, 2010
- Tomie Fujii, et. al : A questionnaire survey about the needs in mothers of children with hemophilia for the purpose of supporting them, J. Genet. Nurs. Jpn, 13(2), 83-90, 2015