Observational study for improving adherence with prophylaxis in haemophilia

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Abstract

Introduction: Regular replacement therapy (prophylaxis) has been becoming a standard therapy for child patients with severe haemophilia in Japan. The primary goal of prophylaxis is to prevent the development of chronic arthropathy as long-term benefit. Some reports show that adolescents with haemophilia have a lower adherence with prophylaxis and indicated that measures to improve adherence during adolescence are critical as adolescents often take responsibility for self-infusion. One of the reasons for the lower adherence rate is lack of patient's knowledge on disease and its treatment. The aim of this study is to evaluate the re-education can improve adherence with prophylaxis. Questionnaire "Assessment Checklist for Patients" was prepared as the educational material. We present the current status of the correlation between the knowledge level and adherence at entry time point as the interim report.

Method: This was a prospective multicenter study performed in seven haemophilia treatment centers in Japan. Self-infused haemophiliacs were enrolled. Patients answered the questionnaire to check the knowledge level. Afterwards, patients were educated thoroughly by health care workers. This procedure will be performed three times at entry time point and post 6, 12 months. Statistical analysis was used by Chi Square Test.

Result: 115 self-infused haemophiliacs were enrolled from April to October 2011. 84 patients (haemophilia A: 74, haemophilia B: 10) with prophylaxis was evaluated for the adherence rate. 68 patients were in good adherence group (more than 80%), and 16 patients were in poor group (less than or equal to 80%). There was no significant difference between both adherence groups for answering the questions correctly. It should be noted that even in the good group, the rate of correct answer on the question about "long-term benefit with prophylaxis" was very low at 21%.

Discussion: Results show that the patients did not understand well about the disease and its treatment. Investigation will be continued to seek whether it is possible to improve the adherence rate by re-education using the Assessment Checklist.

Purpose of the study

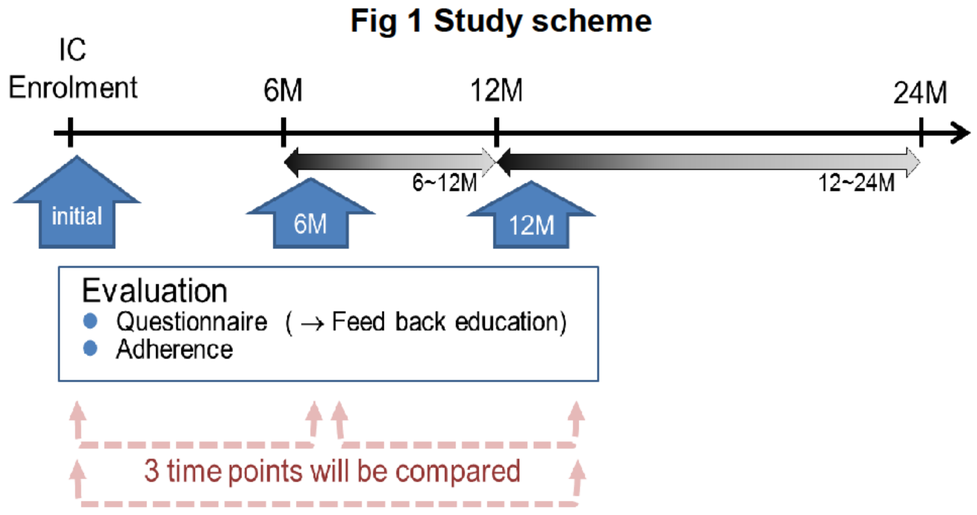
- The aim of this study is to evaluate the re-education can improve adherence with prophylaxis.
- Correlation of change in the knowledge level on the disease and in adherence will be evaluated.
- We present the current status of the correlation between the knowledge level and adherence at entry time point as the interim report.

Study design & Methods

Subject:	Patients who injects coagulation factor at home with consent
Target patient number:	200 pts
Questionnaire:	3 times (initial, 6M, 12M)
Adherence:	Evaluated on the basis of injection record and interview

Correctness of answer to questionnaires was compared between good- and poor-adherence groups by chi-square tests.

Fig 1 Study scheme



Questionnaire

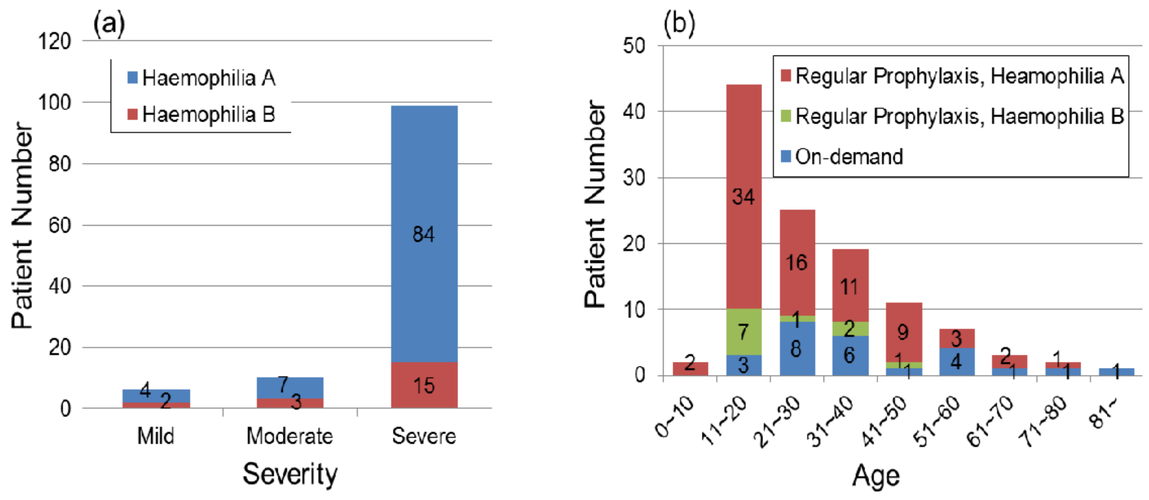
#	Short Name	Questionnaire	Choice
1	Disease Type	What is the name of your disease?	☐ Hemophilia A / ☐ Hemophilia B / ☐ IDNK
2	Deficient Factor	What coagulation factor is deficient for you?	Factor ( )
3	Activity	How much % is the activity of your deficient factor?	Activity: %
4	Severity	What is the severity of your disease?	☐ Severe / ☐ Moderate / ☐ Mild / ☐ IDNK
5	Product	What is the name of coagulation factor product you are using ?	Name of the product :
6	Regular Prophylaxis	Do you inject the factor regularly regardless of bleeding ?	☐ Yes, ( ) times per week, ( ) unit / ☐ No
7	Usual Dose	What unit of factor do you usually inject upon bleeding?	( ) units per time
8	Temporary Prophylaxis	Do you inject the factor beforehand before special activity ?	☐ Yes, ( ) units per time / ☐ No
9	Activity Increase	How much % does the activity increase when you inject usual dose (unit) ?	☐ I know, it increases by ( )% ☐ IDNK
10	Body Weight	Do you know that the amount of factor needed is proportional to the body weight ?	☐ Yes ☐ No
11	Injection Record	Do you fill your injection record table ?	☐ Yes, I do. / ☐ My family does / ☐ Nobody does / ☐ What is injection record table ?
12	Visit Frequency	How often do you visit hospital for evaluation or examination ? (visit only for receiving drug is not included)	( ) times per year
13	Vial Stock	Do you know how many vials of the product you have at home ?	☐ Yes, I have ( ) vials. ☐ IDNK
14	Self Injection	When, and from whom, did you learn self injection ?	When: Year ( ) Month ( ) From whom: Name of hospital:
15	Long-term benefit with Prophylaxis	Is there any benefit with prophylaxis injection other than prevention of bleeding ?	(Free answer)
16	Health status	What is your health status of today ?	☐ Very good / ☐ Good / ☐ Not so good / ☐ Bad

Results

Population

- Young patients with severe haemophilia A were the major population of this interim analysis (Fig 2a, 2b)

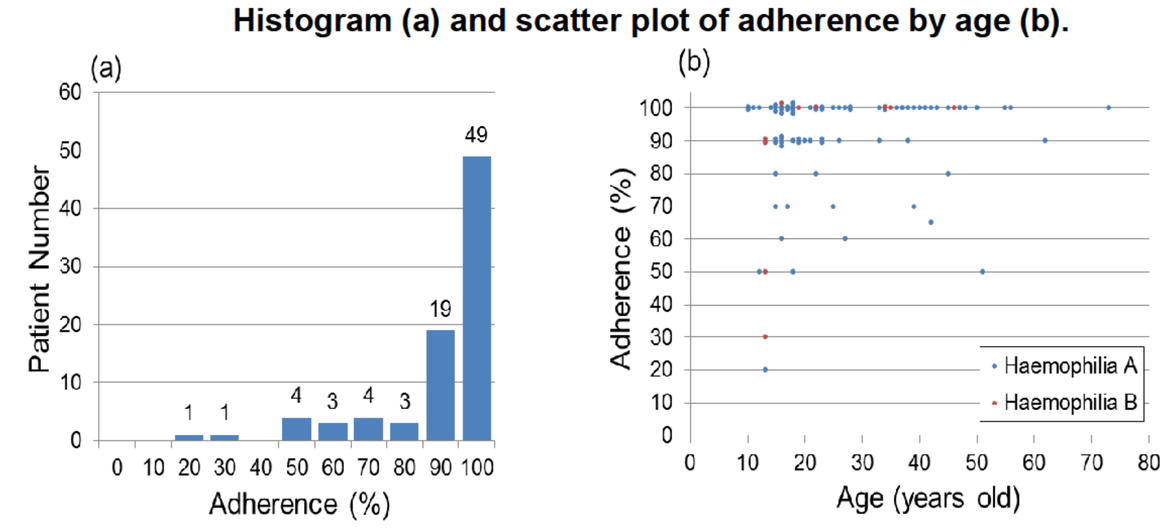
Fig 2 Severity (a) and age (b) of the enrolled population (n=115)



Adherence

- Adherence was poor (0~80%) in 19% (16/84) of evaluable patients (Fig 3a)
- No clear correlation was seen between age and adherence (Fig.3b)

Fig 3 Adherence of the patients with regular prophylaxis (n =84) Histogram (a) and scatter plot of adherence by age (b).

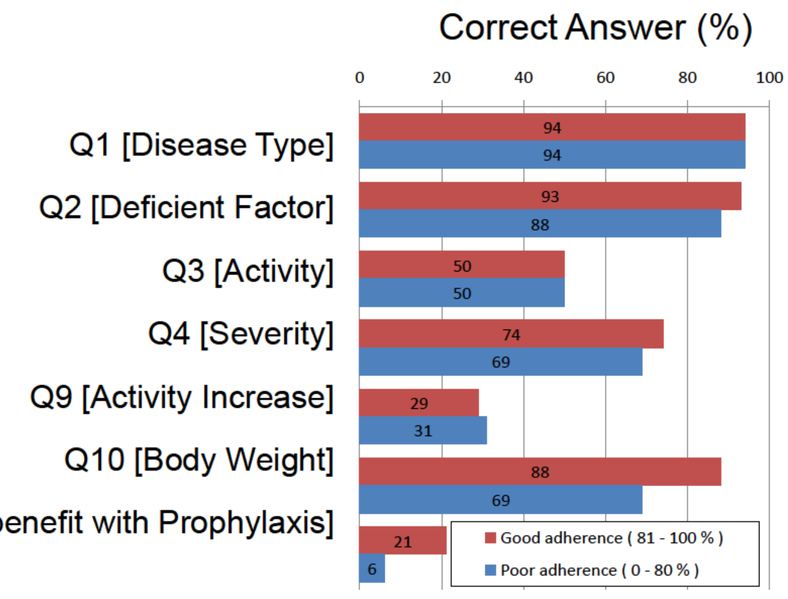


Adherence is shown by 10% interval except one plot at 65%. Multiple plots with minor deviation around auxiliary lines indicate the same value.

Correctness of answer and adherence

- Correctness was low in several questions (Fig.4):
  - Q3 Activity
  - Q4 Severity
  - Q9 Activity Increase
  - Q15 Long-term benefit with Prophylaxis
- Difference of correctness was not significant between good- and poor- adherence groups (Fig.4)

Fig 4 Correct answer rate of good- and poor- adherence group



Conclusion

- It should be noted that even in the good adherence group, the rate of correct answer on the question about "long-term benefit with prophylaxis" was very low at 21%.
- We should realize that the patients did not understand well about the disease and its treatment rather than we consider.
- Future result is awaited whether Improvement of knowledge /awareness correlates with improvement of adherence or not.

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