

Title of presentation:
Self-management education for
hemophiliac patient in Japan

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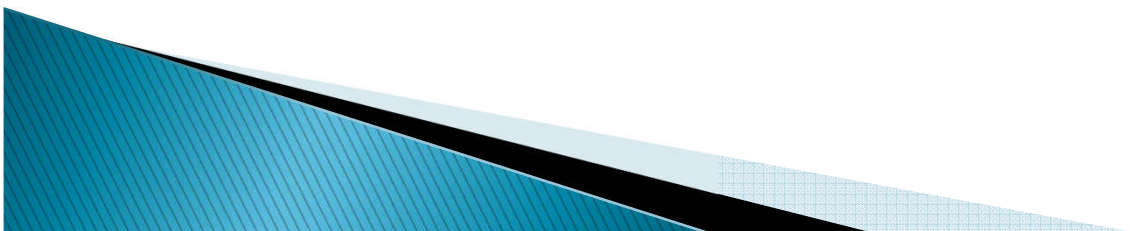
Disclosure slide

- ▶ Presenter's name: Masami Kutsumi
- ▶ Learner objectives: Identify self-management education offered by professionals for hemophiliac in Japan
- ▶ Conflict-of-interest: none
- ▶ Employer: University of Hyogo
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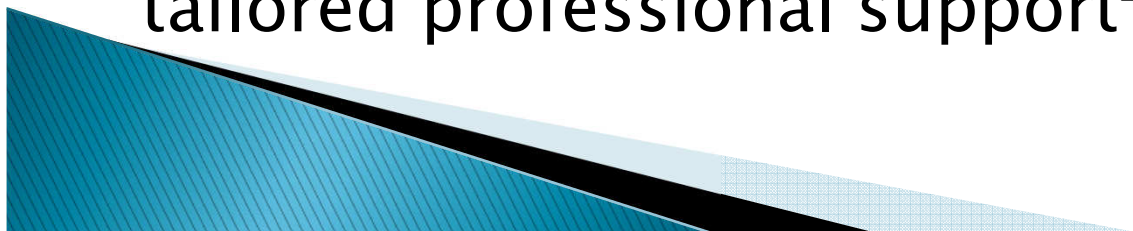
What is hemophilia?

- ▶ Hemophilia is an inherited bleeding disorder characterized by a deficiency in clotting factors and expressed predominantly in males¹⁾.
- ▶ The prevalence is approximately 1 in 10,000 live births for hemophilia A (factor VIII deficiency) and 1 in 60,000 for hemophilia B (factor IX deficiency)²⁾.
- ▶ In Japan, Hemophiliac patients were 6,068 in 2014. Self-infusion was initiated at a median age of 12.3 years and self-management was achieved 9.6 years later, at a median age of 22.6 years³⁾.



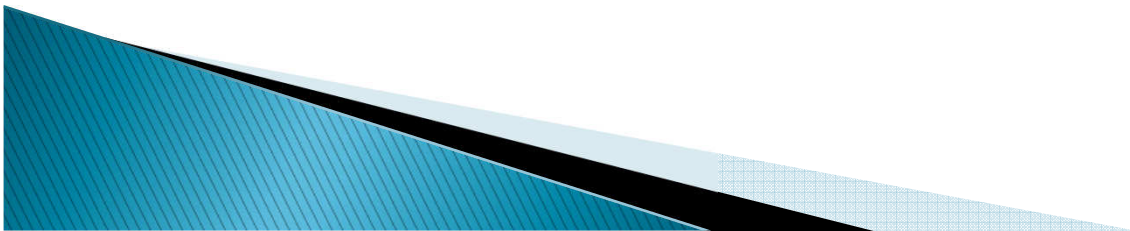
Background: Self-management of hemophilia

- ▶ The first steps in self-management with regard to self-infusion are taken in early adolescence, complete self-management was achieved in late adolescence after almost 10 years³⁾. Insight in this transitional process helps to provide individualized support and emphasizes the need for continued education with regard to self-management skills³⁾.
- ▶ Acceptance of the disease and self-management skills were important aspects that may require tailored professional support⁴⁾.




Aim of this research

- ▶ The aim of this research was to gain insight into how professionals educate self-management skills of hemophiliac in Japan.



Methods

- ▶ **Data collection:** We conducted semi-structured interview from July 2015 to July 2016.
 - ▶ **Participants:** 8 nurses and 5 doctors about their experiences of hemophilia treatment. We called them professionals in this research.
 - ▶ **Ethical consideration:** The human subjects' approval was received from the institutional review board of the University.
 - ▶ **Data analysis:** This study focused on narrative information told by the interviewee about their experiences how they educated for hemophiliac about skills and self-management.
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Results: Elements of self-management education for hemophiliac patient

Education about knowledge of hemophilia

Self-infusion skills

Acute bleed or emergency procedures

Confirmation understanding about type of hemophilia or bleeding tendency

Promotion engage with hospital routinely

Information about prophylactic treatment regimens

Introduction hemophiliac association to get peer support

Education about knowledge of hemophilia

- ▶ Participants stated that lack of knowledge of hemophiliac, so they provided knowledge. An example quotes include:
 - “I give booklets about scheme of disease or clotting factor concentrate FVIII/FIX for patients.”

Self-infusion skills

- “When we educate for self-infusion skill for a child, we coach him intravenously infusion for himself.”

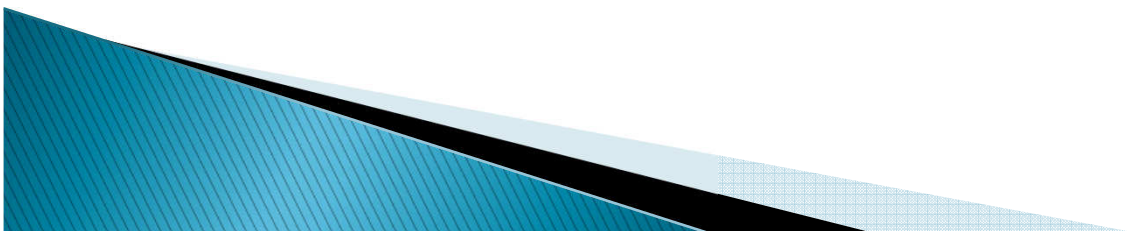


Acute bleed or emergency procedures

- ▶ Participants asked hemophiliac about acute bleed or emergency procedures. Participants' statement included:
 - “Bleeding don't occur only in joint. If you suffer bleeding in the brain, what to do?”
 - “What is sign about bleeding in the brain?”

Confirmation understanding about type of hemophilia or bleeding tendency

- “What is your type of hemophiliac?”



Promotion engage with hospital routinely


- ▶ Analysis of participants' interviews revealed that self-infusions of clotting factor to prevent bleeds (prophylaxis) have been routinely utilized in the pediatric population with severe hemophilia. However, it was cleared that mild hemophiliac have few bleeding episode and, are comfortable with “on-demand” treatment (infuse clotting factor only when having a bleed), so they keep away hospital. Participants' statement included:
 - “Mild hemophiliac are keep away hospital...”



Information about prophylactic treatment regimens

- ▶ Participants are suggest prophylactic treatment regimens for patients who selected treatment with replacement therapy ‘on-demand’ when bleeds occur, they stated:
 - “We recommend prophylactic treatment when bone malformation become advanced.”

Introduction hemophiliac association to get peer support

- “I introduce patients’ association for patients and their families to get peer support .”
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Conclusion

- ▶ Jordan et al. ⁵⁾ describe self-management as a ‘patient’s health literacy’: their capacity to ‘seek, understand and utilize health information to participate in decisions about health’.
- ▶ Self-management skills were important aspects that may require tailored professional continuous support and education.



References

- 1) Srivastava A, Brewer AK, Mauser–Bunschoten EP, et al. Guidelines for the management of hemophilia. *Haemophilia*. 2013;19(1):e1–e47.
 - 2) Mannucci PM, Tuddenham EGD. The hemophilias – from royal genes to gene therapy. *N Engl J Med*. 2001;344(23):1773–1779.
 - 3) Schrijvers L, Beijlevelt–Van der Zande M, Peters M, et al. Achieving self–management of prophylactic treatment in adolescents: The case of haemophilia. *Patient Educ Couns*. 2016 Jul;99(7):1179–83.
 - 4) Schrijvers LH, Schuurmans MJ, Fischer K. Promoting self–management and adherence during prophylaxis: evidence–based recommendations for haemophilia professionals. *Haemophilia*. 2016 Jul;22(4):499–506.
 - 5) Jordan J, Briggs M, Brand A, Osborne R. Enhancing patient engagement in chronic disease self–management support initiatives in Australia: the need for an integrated approach. *Medical Journal of Australia*. 2008;189(10 Suppl):S9–S13.
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