

Title:

Self-Management Education for Hemophiliac Patients in Japan

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Session Title:

Clinical Posters Session 2

Keywords:

education, hemophilia and self-management

References:

1 Srivastava A, Brewer AK, Mauser-Bunschoten EP, et al. (2013) Guidelines for the management of hemophilia. *Haemophilia*.19(1):e1–e47.

2 Mannucci PM, Tuddenham EGD. (2001)The hemophilias – from royal genes to gene therapy. *N Engl J Med*. 344(23):1773–1779.

3 Schrijvers L, Beijlvelt-Van der Zande M, Peters M, et al. (2016) Achieving self-management of prophylactic treatment in adolescents: The case of haemophilia. *Patient Educ Couns*. 99(7):1179-83.

4 Schrijvers LH, Schuurmans MJ, Fischer K. (2016) Promoting self-management and adherence during prophylaxis: evidence-based recommendations for haemophilia professionals.*Haemophilia*. 22(4):499-506.

5 Jordan J, Briggs M, Brand A, Osborne R. (2008) Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. *Medical Journal of Australia*.189(10 Suppl)S9-S13.

Abstract Summary:

Hemophilia is an inherited bleeding disorder characterized by a deficiency in clotting factors and expressed predominantly in males. The aim of this study was to gain insight into how professionals educate self-management skills of hemophiliac in Japan.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
The aim of this study was to gain insight into how professionals educate self-management skills of hemophiliac in Japan.	The content of narratives could be grouped and coded into seven categories: education about knowledge of hemophilia, confirmation understanding about type of hemophilia or bleeding tendency, self-infusion skills, acute bleed or emergency procedures, information about prophylactic treatment regimens, introduction hemophiliac association to get peer support, and promotion engage with hospital routinely.

Acceptance of the disease and self-management skills were important aspects that may require tailored professional support.	Self-management skills were important aspects that may require tailored professional continuous support and education.
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Abstract Text:

OBJECTIVE

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

METHODS

We conducted semi-structured interview from July 2015 to July 2016 with 8 nurses and 5 doctors about their experiences of hemophilia treatment. This study focused on narrative information told by the interviewee about their experiences how they educated for hemophiliac about skills and self-management. The human subjects' approval was received from the institutional review board of the University.

RESULTS

The content of narratives could be grouped and coded into seven categories: education about knowledge of hemophilia, confirmation understanding about type of hemophilia or bleeding tendency, self-infusion skills, acute bleed or emergency procedures, information about prophylactic treatment regimens, introduction hemophiliac association to get peer support, and promotion engage with hospital routinely. The bleeding tendency is classified as mild, moderate, or severe. 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.

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.

ACKNOWLEDGEMENT

This work was supported by JSPS KAKENHI Grant Number JP 15K11598.