



Support for adult patients with hemophilia from the lifecycle perspective ~Voices of hemophilia nurses~

Mika Kogayu^{1,2}, Michiyo Kobayashi², Kazufumi Matsumoto³, Koji Kobayashi², Hideyuki Takedani², Ariko Noji¹

¹Graduate School of Nursing, Chiba University, Japan ²Hospital of the Institute of Medical Science, the University of Tokyo, Japan

³Tokyo Health Care University, Tokyo, Japan

E-mail kogamika7@chiba-u.jp

Introduction:

World Federation of Hemophilia (WFH) predicted the number in the world would around be 400,000 (Fig.1), and over 300,000 of them did not have enough opportunities for diagnosis and treatment. In Japan patients with hemophilia (PwH) numbered 6,200, and the medical costs are all expressed by the government (Table.1).

Until adolescence, Japanese PwH usually attend summer camp and other activities to learn about hemophilia and self-injection. After adolescence, they can presumably manage the disease by themselves, requiring less contact with healthcare providers. However, adding patient support to the patient's life cycle should be considered (Table2).

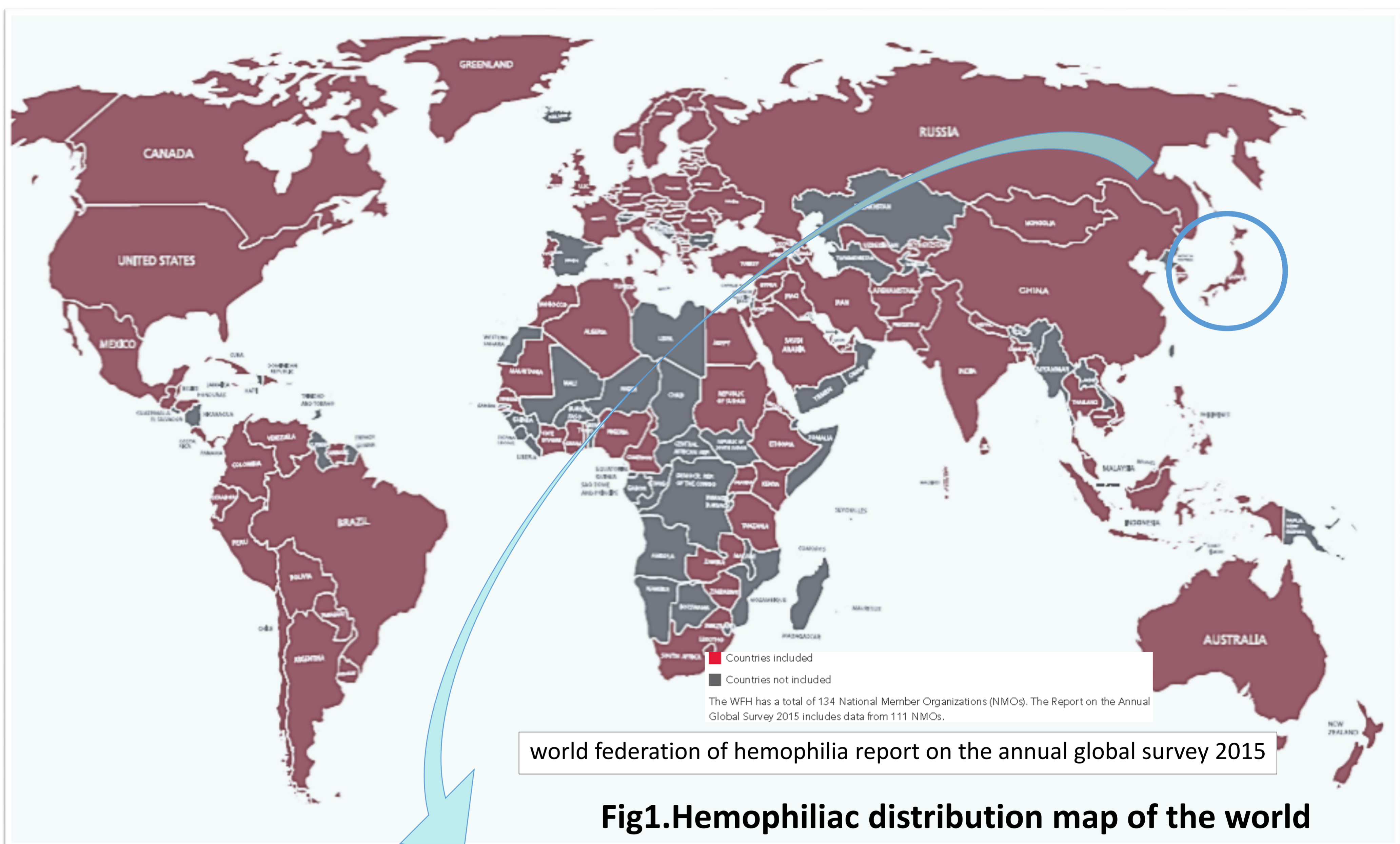


Table1. The Japanese hemophilia type and sex (person)

	Male	Female	Total
PWH A	4,517	39	4,556
PWH B	914	16	930
With HIV	714	0	714
Total	6,145	55	6,200

Table2. Self-injection and age group (person)

Injection	age(y)				
		0~9	10~14	15~19	20~
By oneself		0.7%	39.2%	76.6%	91.3%
By Family		95.8%	55.3%	21.8%	3.5%
By Nurse		1%	1.9%	0%	1.3%
By Other		2.5%	3.6%	1.6%	3.9%

Project entrusted by Ministry of Health, Labour And Welfare. Nationwide Survey on Coagulation Disorders 2016. Published by Japan Foundation for AIDS Prevention.

Objectives:

This study aimed to identify problems of PwH from the perspective of nurses caring for them through their life cycle.

Methods:

We collected data using a self-developed questionnaire comprising 23 questions from 20 participants recruited from a nurses' study meeting in Tokyo, which became a center for specialty nurses of hemophilia care in September 2016. Of the 20 nurses, 13 (65%) completed the questionnaire. The questionnaire included questions regarding patient support program, support for patient in responding to significant life events, health education program for adults with hemophilia, and nurses' difficulties in caring for patients.

Results:

Of the nurses, 53% reported that they had patient support programs in their hospital, 71% reported that their hospital provided life event support, and 57% provided health education programs. With regard to difficulties in nursing care, 4 nurses mentioned "difficulty in self-management in aging," "lack of time for consulting at outpatient office," and "need for development of next-generation hemophilia nurses."

Conclusion:

The development of a system for supporting adults PwH from the life cycle perspective and educating the next-generation hemophilia nurses are necessary.

Keywords:

life cycle, patient support program, hemophilia, next-generation hemophilia nurses, a self-developed questionnaire