

Barrier Assessment in Establishing Comprehensive Client-Level Coordination for Treatment and Medical Welfare of People Living with Hemophilia and HIV/AIDS in Japan

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Background: 1,432 Japanese hemophiliacs had contracted HIV/AIDS via the contaminated blood products in 1980's, out of which, about a half already has passed away. 760 current survivors are facing pressing issues of aging, long-term treatment of HIV/HCV co-infection and other co-morbidities; it is integral to provide diverse client-level support in response to each case. Comprehensive coordination of treatment and medical welfare is indispensable to promote clients' long-term QOL.

Aim: In planning comprehensive client-level coordination for treatment and medical welfare, the study group aimed to assess and understand current state of diverse hemophiliac people living with HIV/HCV in Japan, using medical, psychological and social information.

Methods: A Qualitative Case-Control Study. In 95 hemophilia outpatients at AIDS Clinical Center out of the current 760 survivors of the Japanese HIV-contaminated blood products, 9 cases with 9 elements were extracted by theoretical sampling of clinical and psychosocial information from clients' Medical Records data for further matrix analysis (Fig. 1).

Fig.1 How 9 cases of each analysis element were extracted

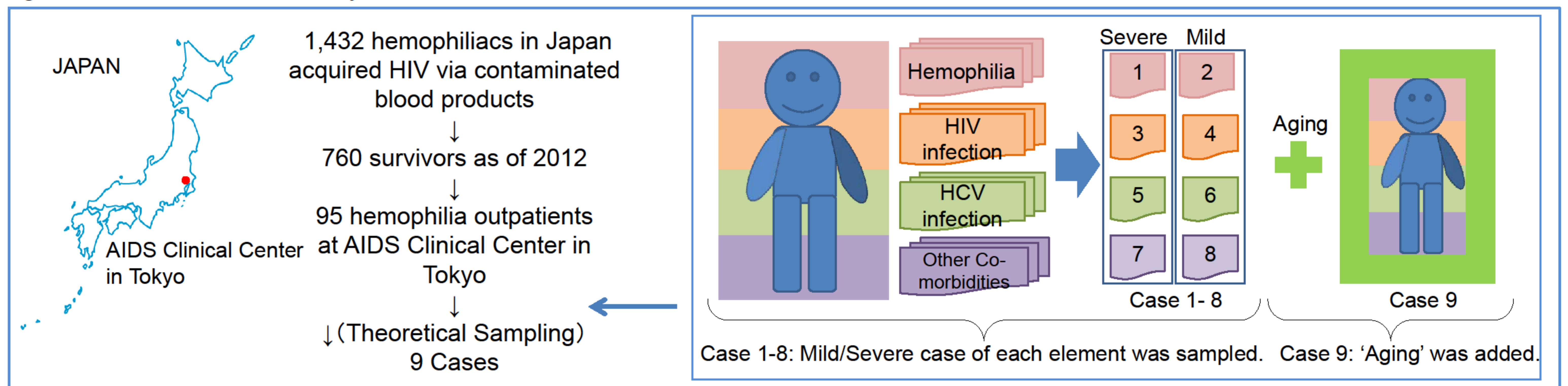


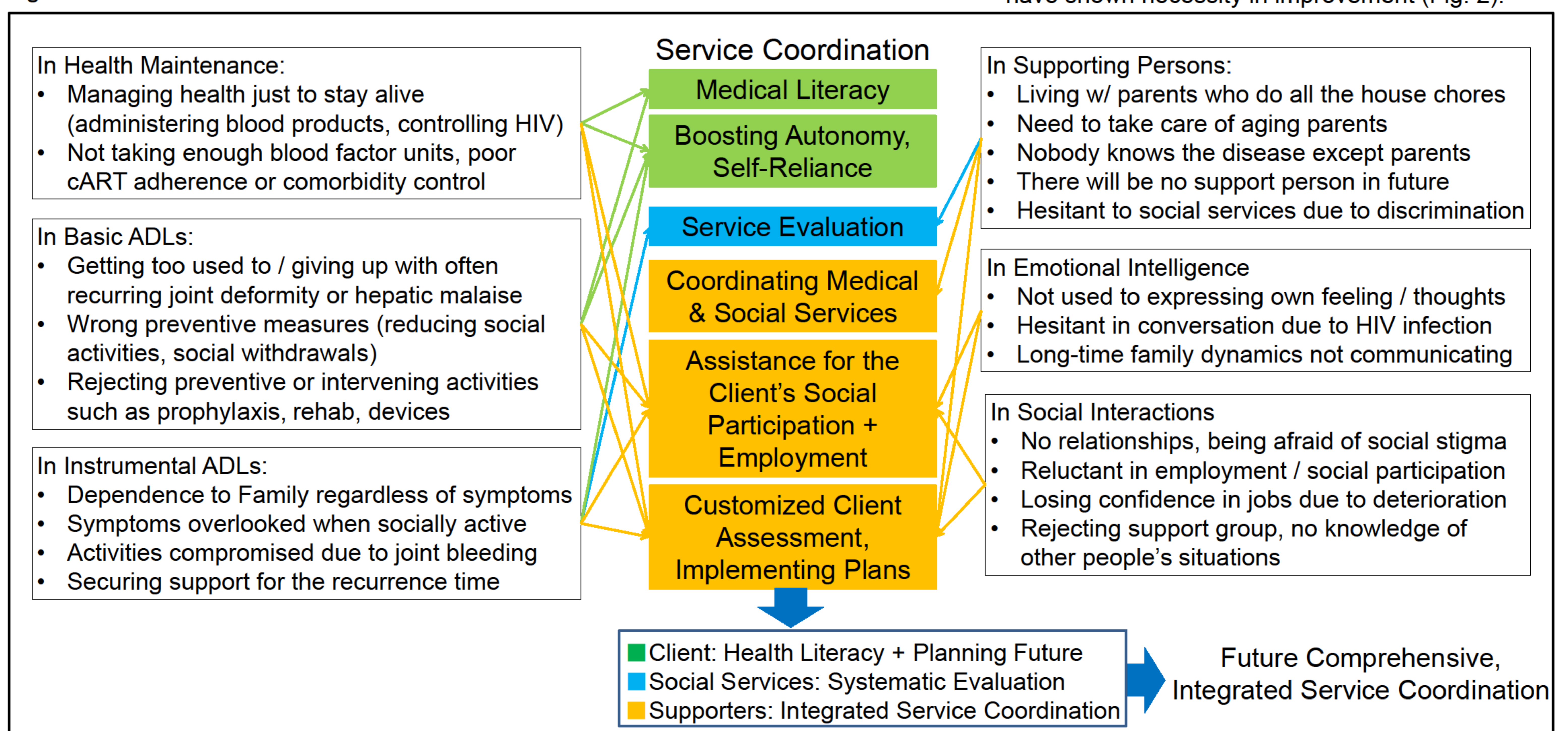
Table 1. Sampled cases with 9 analysis elements according to conditions and severities

Hemophilia	Case 1	Needs support for everyday activities due to joint deformity
	Case 2	Confined to bed, needs nursing service due to ICH
HIV infection	Case 3	Uses local professional support for bleeding control, adherence
	Case 4	Confined to bed, needs nursing service due to PML
HCV infection	Case 5	Needs support for daily activities due to hepatic malaise
	Case 6	Needs nursing service, managing liver cirrhosis
Other Co-morbidities	Case 7	Needs medical, adherence management for psychiatric illnesses
	Case 8	Uses nursing management for hemodialysis catheter due to DM
Aging	Case 9	Needs daily activity support due to aging / multiple co-morbidities

Results: Client's average age was 47.9±10.7.

Treatment and medical welfare modules clarified challenges at client level, family/key persons level and social system level. Out of various elements, 1) health maintaining support (complications, injection or adherence support), self-reliance in ADL, preventive measures, mental health relief and intervention, psycho-social and educational support, employment support for social independence for the clients, support for family/key person, navigating in medical systems, outreaching, education, 2) comprehensive evaluation system in the social services, and 3) assisting staff's comprehensive service coordination have shown necessity in improvement (Fig. 2).

Fig.2 Barriers in Service Coordination



Discussion: This study's scheme was able to clarify various barriers in current service coordination in Japan, such as "literacy in health and planning future", "customizing support evaluation" and "developing integrated medical and social services". From now on, further evaluation of the future improvement or larger population outside Tokyo can be possible and comparable, applying this analysis scheme.