

Restructuring and improving QOL in Japanese HIV victims with hemophilia and their families: How do we rebuild our life with effective support?

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BACKGROUNDS

About 40% of Japanese hemophiliacs infected with HIV through contaminated blood product in the early 1980s. This incident have effected on their psychosocial aspects over a long time, thus restructuring their living is important issue.

It can have a tremendous negative impact on not only HIV victims with hemophilia but also current HIV-free generation with hemophilia and their families.

METHODS

Aim: In order to support their life, KEY factor findings were conducted as follows.

- 1) Clarify their experiences in difficulty.
- 2) Build the framework for an effective support.
- 3) Gain practical suggestions from multidisciplinary and permanent support.

Methods: Action research (triangulation) method; interview records are analyzed by Case Study and KJ method

Interviewee: families of HIV victims, including as follows

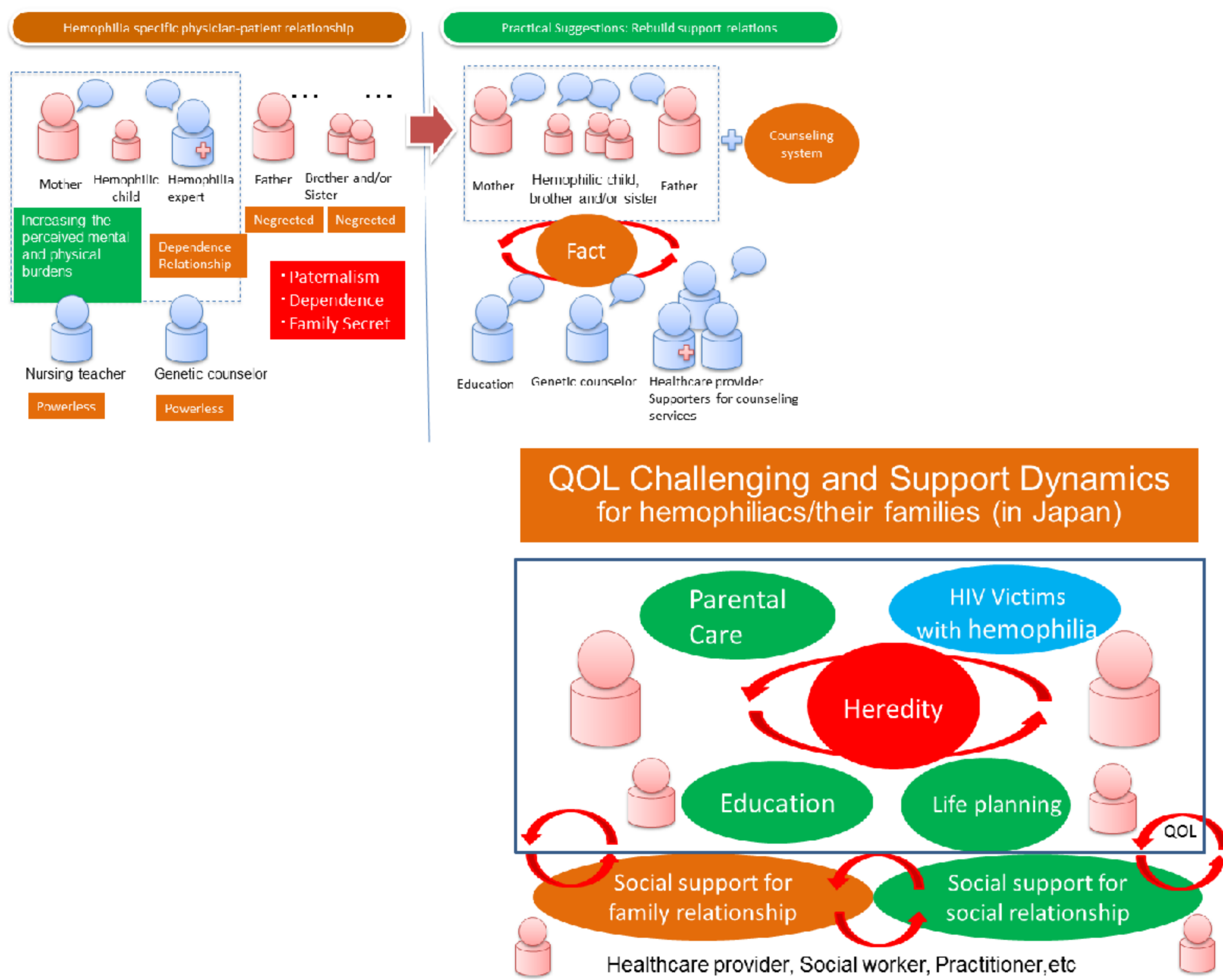
- mothers (n=19)
- fathers (n=16)
- brothers (n=6)
- mothers with non-HIV hemophiliacs (n=10)
- health care professionals (n=6)
- (involved in genetic counseling/hemophilia (n=6))

Questionnaires: Educators (at school) (n=37).

Discussion: The illness experiences

- ★ Cultural BACKGROUND were Paternalistic Medical relationships, Powerless social support (in Japan)
- ★ Double burden of hemophilia family members: Hemophilia problems and Hereditary problems.

Future challenging is Empowerment, counseling systems and information sharing.



RESULTS

HIV victims with hemophilia and their families have experienced a heavy burden of life and been exposed to psychosocial stressors such as follows

- Stigma
- Guilty
- Difficulties in family dialogue
- Self-Expression of negative experiences
- Self-blaming
- Coping
- Lack of social support.

They were also confronted with a negative correspondence from healthcare professionals.

DISCUSSION and CONCLUSIONS

Discussion:

HIV victims with hemophilia and their families require a preliminary future plan corresponding to individual life stage with permanent issues such as hemophilia heredity, parental care, education, life planning and HIV victims with hemophilia.

Conclusions

We propose dynamic support scheme with social and family relationship.

It is expected that our study will contribute to restructure and improve QOL in Japanese HIV victims with hemophilia and their families.

TAKE AWAY MESSAGE

HIV-Tainted blood scandal (as known as “YAKUGAI AIDS” in Japan) was a significant hazard in the long history of hemophilia.

- 1) We never forget this Tragedy.
 - 2) We should learn from this tragic experience.
- There is still a big gap among our hemophilia community or society.

(This fact is sometimes called the safety myth of the HIV-tainted blood scandal, which is referred to the hazard of the explosion and meltdown of Fukushima Daiichi nuclear power plant on March 11, 2011.)

