

Carrier Career Counseling: Development of e-learning educational tool for hemophilia carriers and women in hemophilia extraction to support acquiring readiness for change

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OBJECTIVES

Hemophilia gene carriers or women in hemophilia extraction tend to isolate themselves from society or family due to guilty feeling. In addition, those women who have hemophilia children have burden as mother to raise them as well as siblings of hemophilia children, while mental social support is very scarce. These problems characteristically emerge at life stages such as their own hemorrhagic condition, gene examination, marriage, and family planning. In Japan, due to damage by the fallout from the HIV-tainted- blood scandal, the issues surrounding hemophilia gene carriers tend not to come up to the surface, and such social background have pushed the need for genetic counselling or any support before they go to medical institution. It has been found that closely-attached parental care by those mothers would affect self-sustainability of hemophilia patients. Thus, to support those hemophilia gene carriers and family to work through difficult life stages and prevent future problems, we develop e-learning educational tool for them to learn health condition and problem solving.

METHODS

1) Collaborate with hemophilia carriers, women in hemophilia family, genetic counselor, nurse, researcher, supporter, etc. 2) Develop the contents of e-learning tool based on the needs of hemophilia carriers and/or women in hemophilia family by collaborating with people and professionals above mentioned. 3) As learning framework, set milestones during the course of e-learning such as i) working through the reality of carrying the gene, ii) facts of hemophilia, iii) acquiring viewpoints of "living with hemophilia" as hemophilia carrier or family, and iv) zest for living, and develop correspondent contents. 4) Work with IT specialist to develop website system.

RESULTS

Main contents of e-learning tool are as follows; 1) Carrier Career Counseling: Provide motivator to work through hemophilia genetic issues and career (life) positively. Show commentary, support resource, and way to obtain appropriate consultation in accordance with each stage of life (childhood, adolescence, school, work, marriage, parental care, etc.). 2) Mapping of support: Provide way of thinking of "readiness" and case studies to decide own life. Set out following milestones as course to self-decision: "Start (facing with genetic fact)", "Fact (basic knowledge of hemophilia)", "Consult", and "Examination", and show five cases of self-decision process with described life stories and commentaries of preparation steps until they face with the problems .

Fig.1: Support mapping



Fig.2: Life Stage and Support



Fig.3: case study(five cases)

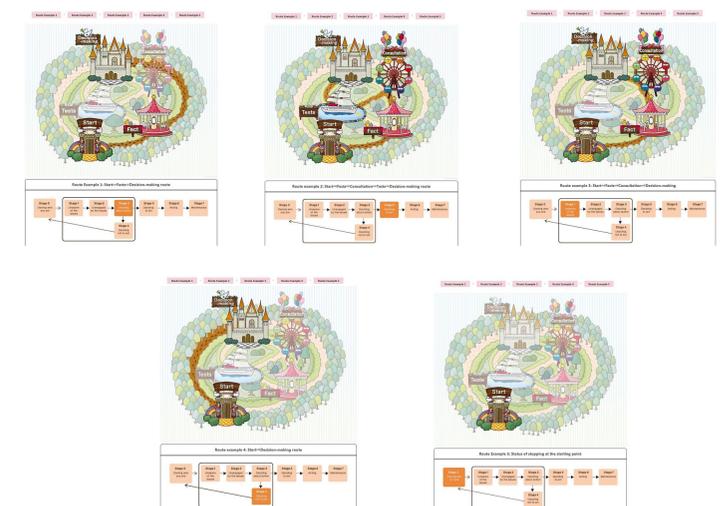
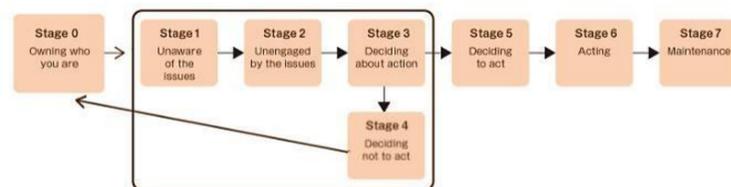


Fig4. Applied the Precaution Adoption Process Model. (PAPM)



Weinstein, N. D., and Sandman, P. M., 1992

We focused on "readiness" lack of awareness to action(stage1-4) and lack of perspective (stage0,newly applied in this study.)

please see also

Let's Build the Capacity to Thrive.
Information site for women in the family with hemophilia or hemophilia gene carriers.

<http://hemophilia-line.info/en/>

Conclusions

E-learning tool are designed and developed for hemophilia gene carrier and family to improve QOL, health awareness, and acquire readiness to prevent any future problems.