

Life events, support taking experiences and health readiness; psychosocial difficulties among hemophilic carriers in Japan (A pilot).

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Background:

Hemophilic carriers still have a variety of psychosocial burdens as well as insufficient social support resources and support taking experiences (Kakinuma, WFH, 2012).

Aim:

This study attempts to develop social support readiness scale such as hemophilia knowledge, support experience and needs for social support, and to explore explanatory empirical model among Japanese hemophilic carriers as a pilot study.

Method:

Our data on 30 hemophilic carriers, comprising of obligate carriers (n=21, 70.0%) and possible carriers (n=9, 30.0%) was collected by snowball approach to sampling. The variable of hemophilic carriers was marital status, childbirth experience, age (20-39, n=7, 23.3%), (40-59, n=7, 23.3%), (60+, n=16, 53.4%).

The original developed scales were

- 1) knowledge about hemophilia (6 items, range score 6-30, Cronbach's $\alpha=0.906$),
- 2) experienced social support (8 items, range score 8-40, Cronbach's $\alpha=0.837$), and
- 3) social support needs (8 items, range score 8-40, Cronbach's $\alpha=0.842$).

A multiple regression was performed to estimate the relationships among variables or scales.

Result:

We obtained these results as follows:

- 1) Age-adjusted social support needs were strongly explained by experience of childbirth.
- 2) The effect of childbirth experience was diminished by addition of knowledge factor.
- 3) Strong effect of experienced social support was found and the effect of knowledge factor was decreased.
- 4) In full model, explanatory model was improved.

Discussion and conclusion:

The effect of knowledge and social support taking experience, the model suggests the importance of health readiness when applying a diverse of social support resources to hemophilic carriers. Based on our study, we need to develop future planning program and multidisciplinary advices for hemophilic carriers in Japan, focusing on health literacy, disease prevention, genetic counseling as well as emerging social support resources and network.

Table 1 Backgrounds

		N=30	
		N	%
sex	women	30	100.0
age	20-29	1	3.3
	30-39	6	20.0
	40-49	5	16.7
	50-59	2	6.7
	60-69	13	43.3
	70-	3	10.0
classification of carriers	comprising of obligate carriers	21	70.0
	possible carriers	9	30.0
marital status	marriage	23	76.7
	single person	3	10.0
	divorce	1	3.3
	widowhood	3	10.0
Life Events(experienced)	marriage	27	90.0
	childbirth	25	83.3
	Stillbirth, miscarriage, artificial abortion	12	40.0

Table 2 Scale item properties

		N=30		
		score		
1. knowledge about hemophilia (range score 6-30, Cronbach's $\alpha=0.906$)				
	Unknown[1]/Unclear[2]			
	n	%	mean (S.D)	
1	There are not only male but also female patients with hemophilia.	4	13.3	3.53 (1.22)
2	The childbirth possibility of male baby with hemophilia is one-fourth when carrier gives a birth.	8	26.7	3.47 (1.57)
3	Some carriers are frequently bleeding.	8	26.7	3.17 (1.89)
4	Any people are allowable to ask issues of hereditary and carrier by genetic counseling.	14	46.7	2.73 (1.51)
5	Blood clotting test is not directly proved to be diagnosis of possible carrier.	12	40.0	2.87 (1.50)
6	In the event of that first son in family is hemophilia, the possibility of his mother with carrier is approximately 80%.	13	43.3	2.60 (1.30)
2. experienced social support (range score 8-40, Cronbach's $\alpha=0.837$)				
	sometimes[3]/often[4]/always[5]			
	n	%	mean (S.D)	
1	Experts of hemophilia specialist(Treatment and support towards patients and carriers)	16	53.3	2.40 (1.43)
2	Psychological counseling	3	10.0	1.33 (0.84)
3	Genetic counseling/information service and information exchange about hereditary and disease)	7	23.3	1.67 (0.99)
4	Study meeting and information exchange meeting regarding hemophilia.	18	60.0	2.77 (1.52)
5	Social support group (association of patients and patients family)	23	76.7	3.27 (1.51)
6	Peer counseling (Support from hemophiliacs and hemophiliacs family)	11	36.7	1.97 (1.27)
7	Telephone counseling	4	13.3	1.50 (1.01)
8	Mailing list and online community among hemophiliacs	6	20.0	1.57 (1.04)
3. social support needs (range score 8-40, Cronbach's $\alpha=0.842$)				
	somewhat[3]/very[4]/extremely[5]			
	n	%	mean (S.D)	
1	Experts of hemophilia specialist(Treatment and support towards patients and carriers)	27	90.0	3.93 (1.26)
2	Psychological counseling	14	46.7	2.60 (1.65)
3	Genetic counseling/information service and information exchange about hereditary and disease)	22	73.3	3.43 (1.52)
4	Study meeting and information exchange meeting regarding hemophilia.	19	63.3	3.00 (1.51)
5	Social support group (association of patients and patients family)	19	63.3	2.93 (1.48)
6	Peer counseling (Support from hemophiliacs and hemophiliacs family)	18	60.0	2.80 (1.61)
7	Telephone counseling	13	43.3	2.27 (1.44)
8	Mailing list and online community among hemophiliacs	12	40.0	2.07 (1.39)

[number] is Likert-type scale response anchors.
 1 Unknown[1]/unclear[2]/somewhat[3]/moderately[4]/extremely[5]
 2 never[1]/rarely[2]/sometimes[3]/often[4]/always[5]
 3 not at all[1]/slightly[2]/somewhat[3]/very[4]/extremely[5]

Table 3 multiple regression models

(factor findings toward social support needs)

model1	β	p
	age	-.203
marriage	.097	.651
childbirth	.471	.043 *
Stillbirth, miscarriage, artificial abortion	-.056	.782
divorce	-.077	.697
model2		
age	-.201	.284
marriage	.185	.338
childbirth	.213	.333
Stillbirth, miscarriage, artificial abortion	.066	.719
divorce	-.189	.297
knowledge about hemophilia	.512	.010 *
model3		
age	-.275	.124
marriage	.094	.606
childbirth	.277	.181
Stillbirth, miscarriage, artificial abortion	.057	.735
divorce	-.221	.190
knowledge about hemophilia	.330	.092 +
experienced social support	.389	.034 *

dependent variable was "social support needs" (8 items scale)

+ <0.01 * <0.05

adjusted $R^2=0.069$ (model 1)

adjusted $R^2=0.274$ (model 2)

adjusted $R^2=0.384$ (model 3)

