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Development and Validation of Caregivers' Perspectives Questionnaire in Comatose Patients

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Abstract: The caregiver's perspective about care in comatose patients is different among different caregivers, and thus the question is how it is perceived by caregivers. Among the health staff and family members, perspective of caring is obviously different. Thus, the current study was carried out to develop a valid and reliable instrument to assess of caregiver's perspective in comatose patient care. For gathering the data used from the questionnaire consisted of items of Van Manen's hermeneutic phenomenology, then these items combined and validated by content, face and construct validity and by split half and Cronbach α coefficient for reliability. The results showed that the four factors were labeled living with client, efforts for survival, professional conscience and responsibility and respect of human dignity. The perspective of caring of comatose patient questionnaire had 32 items and 4 dimension and showed validity and reliability, but it need to test more and more to multiplication of it's' validity and reliability.

Key words: Development, validation, questionnaire, caregivers' perspectives, comatose patients

INTRODUCTION

Caregivers of comatose patients are considered as the perspective of health care systems. They have positive effect on caring and play a key role in improvement of caring of comatose patients (Villanueva, 1997). Moreover, they are in charge of providing care to comatose patients without any prejudice and judgment. Respecting people's rights and treating people with regard to their dignity is an inseparable part of health care systems (Menck, 1998). To direct the caring and experience, a sensitive perspective is needed; thus it is an important item for health care providers (Dahlqvist *et al.*, 2009). Caregiver's perspective is the foundation of caring and influences private and professional life (Sanea Pour, 2010). Perspective originates from the living experience and is a part of our daily and professional life (Johnston, 2006). An interview with nurses showed that when they are asked to narrate the challenges in comatose patient care situations, they mostly refer to their perspectives. The caregiver's perspective precludes them from some acts and orders them to do some acts and they have to assess themselves and their acts. While talking about lived experience in comatose patient's caring, we should consider that

perspective is different among different individuals and thus the question is how perspective is perceived by caregivers. This perspective is related to the qualities and acts of caring and how the individuals encountered with the origin of lived experience. Depending on the perspective of caring, some caregivers opt out of their job, and some experience long-term distress but some manage these stresses. It is necessary to know the viewpoints of caregivers on the caring of comatose patients, the quality and acts of perspective (Johnston, 2006). Dahlqvist *et al.* (2009) showed that the perspective of caring was significantly different among the Swedish health care staff and by main component analysis, they found that perspective of caring can be considered as the authority and alarming signal that is the required sensitivity for nursing and perceived asset and burden and depends on the individual cultural background. In other hand, it was showed that perspective of caring plays a role in the caregiver's acts, which affects the comatose patient's caring. It sometimes directs the acts of nurses toward good values and thus perceived as a motivation act in an attempt to provide high quality care and sometimes limits low quality acts. In an attempt to provide high quality care, it is necessary to be aware of the effect of perspective of caring on caregiver's activities. However,

there is not enough information about the perspective of caring in comatose patients and there is no validated and culturally adapted instrument in this regard. Thus, the current study was carried out to develop a valid and reliable instrument to assess of caregiver's perspective in comatose patient care.

The caregiver's perspective about care in comatose patients is the most significant criteria for evaluation of nursing experiences because this is important and very effective on caring process as they said, therefore, of this the aim study was to validate the perspective of caregivers of comatose patients.

MATERIALS AND METHODS

All teaching hospitals in Iran have only registered nurse, from novice to expert, according to the Iranian ministry of health, even in critical care units specially in caring of comatose patients; in addition, many patients have nursing care from the teaching health care facilities. On the one hand, hard working conditions and units overcrowding result in nurses' lack of experience in comatose caring patients. On the other hand, expert nurses who cannot transfer any caring experiences to novice nurses are employed in critical care units.

In addition to our professional grounding; Approximately, I spent 1 month in caring for my terminally ill wife and my father until they died of traumatic coma in 2008 and 2009. I also have experience in caring for comatose patients at ICUs for 4 years between 2003 and 2007. This interest eventually led to my doctoral studies and to my choice for the topic of study.

For development questionnaire, a quantitative methodological research was carried out in two steps. First, the items of questionnaire were determined and then the questionnaire was validated. The items of phenomenological study (it carried out in another study) added to systematic review and existing questionnaire items. The items extracted based phenomenological study that made a 127 items questionnaire and then similar items were deleted or combined and used for psychometric process. For determination of validity, content, face and construct validity were used. The Waltz and Basel index for content validity were used and the sum of scores were calculated for every item (Polit *et al.*, 2005), then the items above 75% maintained (held) and the items under the 75% deleted. In the first step based on nature of the research, different experts were participated. The 12 professors of nursing, 10 caregivers of comatose patients and 2 Ph.Ds of psychology completed Waltz and Basel index for relevancy, clearance and simplicity. Each item took a score from 1 for least relevancy to 4 for best relevancy. Then the

sum of scores divided on possible sum of scores. The score of each item determined and recommendation for every item considered. In next steps the questionnaire completed by 8 nursing teachers for judging about content based on Waltz and Basel index. The scores above 75% maintained (held) and the items under the 75% deleted, however the items took scores over the 90%. For face validity, plus to appropriate face of questionnaire, the opinion of nursing teachers were used and the questionnaire completed by 20 nurses for content, clearance and simplicity and these opinions were considered. By using version 16 of SPSS software, the factor analysis was done. Based on Nunnally and Bernstein (1994) recommendations, the exploratory factor analysis was used and the Kayser-Meyer-Olkin (KMO) and Bartlett's Test of Sphericity were done before factor analysis. The KMO index is between 0 and 1 and numbers closest to 1 represent model of correlation and factor analysis is fit to be doing (Hutcheson and Sofroniou, 1999). The 268 caregivers of comatose patients completed questionnaire for factor analysis. After factor analysis, the items with coefficient correlation lower than 40% were deleted. The Cronbach Alpha and split-half were done for reliability too.

RESULTS

After content validity, the 48 items questionnaire was made. Then the opinion of nurses and experts were considered for face validity and the questionnaire corrected based on their opinion. Before factor analysis, the internal consistency calculated and the items lower than 40% were deleted and hence the items decreased to 32 items. Content validity was calculated by Cronbach Alpha, again (Table 1). The KMO test showed 0/872 and Bartlett's test of Sphericity was significant $p \leq 0.001$.

Then, item weighting was done. Factor analysis showed 4 dimensions (Factors) of questionnaire. The 62% of total variance of questionnaire covered by these 4 factors and 38% were covered by 12 remaining factors. For determination of background dimensions, the orthogonal varimax was done and item weighting between each item and factors calculated. Dimensions of questionnaire named based on items. The first dimension was living with client and consisted of 12 items and 43% of total variance was covered by this factor. The second dimension was efforts for survival and consisted of 9 items and 7% of total variance was covered by this factor. The third dimension was professional conscience and responsibility and consisted of 7 items and 6% of total variance was covered by this factor. The fourth dimension was respect of human dignity and

Table 1: Item weighting and Cronbach alpha if item deleted

No. of question	Cronbach alpha	Item weight	No. of question	Cronbach alpha	Item weight	No. of question	Cronbach alpha	Item weight	No. of question	Cronbach alpha	Item weight
1	0.941	0.441	9	0.937	0.538	17	0.935	0.756	25	0.935	0.725
2	0.938	0.618	10	0.937	0.536	18	0.935	0.629	26	0.935	0.700
3	0.939	0.754	11	0.936	0.652	19	0.936	0.634	27	0.937	0.740
4	0.941	0.655	12	0.937	0.741	20	0.936	0.646	28	0.935	0.650
5	0.940	0.700	13	0.936	0.634	21	0.934	0.718	29	0.937	0.669
6	0.936	0.512	14	0.935	0.703	22	0.935	0.721	30	0.937	0.721
7	0.937	0.536	15	0.941	0.674	23	0.940	0.702	31	0.934	0.674
8	0.935	0.711	16	0.936	0.649	24	0.937	0.716	32	0.936	0.645

Table 2: Result of factor extraction rotated component matrix

No. of questions	Raw component					Rescaled component				
	1	2	3	4	5	1	2	3	4	5
1	0.042	-0.010	0.466	0.045	0.035	0.053	-0.013	0.589	0.057	0.044
2	0.104	0.115	0.261	0.129	0.306	0.160	0.177	0.403	0.199	0.473
3	0.069	0.236	0.081	0.041	0.604	0.087	0.296	0.101	0.051	0.758
4	0.130	-0.036	0.023	0.107	0.683	0.158	-0.044	0.027	0.130	0.829
5	0.036	-0.115	0.310	0.454	0.188	0.045	-0.145	0.389	0.570	0.236
6	0.210	0.263	0.400	0.149	0.117	0.276	0.346	0.525	0.196	0.154
7	0.293	0.288	0.585	0.018	0.087	0.320	0.316	0.640	0.020	0.096
8	0.537	0.055	0.319	0.274	-0.064	0.599	0.061	0.356	0.305	-0.071
9	0.191	0.233	0.537	0.309	0.020	0.229	0.279	0.644	0.371	0.024
10	0.108	0.832	0.075	0.258	0.134	0.109	0.836	0.076	0.259	0.134
11	0.187	0.701	0.189	0.231	0.146	0.193	0.724	0.195	0.239	0.151
12	0.592	0.603	0.131	0.049	-0.010	0.601	0.612	0.133	0.050	-0.010
13	0.436	0.561	0.336	0.043	0.068	0.479	0.617	0.369	0.047	0.075
14	0.553	0.300	0.275	0.009	0.161	0.640	0.347	0.318	0.010	0.186
15	0.406	0.232	0.398	-0.031	0.074	0.512	0.293	0.502	-0.039	0.094
16	0.559	0.136	0.202	0.156	0.032	0.701	0.171	0.253	0.196	0.040
17	0.557	0.490	0.207	0.116	0.101	0.611	0.538	0.228	0.128	0.111
18	0.479	0.371	0.287	0.072	0.140	0.581	0.449	0.349	0.087	0.170
19	0.265	0.369	0.235	0.603	0.087	0.283	0.393	0.251	0.643	0.093
20	0.522	0.265	0.098	0.512	0.059	0.570	0.289	0.107	0.560	0.065
21	0.237	0.238	0.011	0.769	0.082	0.249	0.251	0.012	0.810	0.087
22	0.420	0.307	0.049	0.442	0.130	0.483	0.353	0.057	0.507	0.149
23	0.540	0.059	0.032	0.256	0.176	0.673	0.074	0.039	0.319	0.220
24	0.505	0.059	0.049	0.218	0.174	0.684	0.080	0.066	0.295	0.235
25	0.181	0.223	0.535	0.301	0.023	0.219	0.249	0.634	0.351	0.025
26	0.512	0.235	0.097	0.515	0.057	0.573	0.249	0.117	0.530	0.064
27	0.459	0.361	0.277	0.071	0.141	0.584	0.447	0.345	0.083	0.176
28	0.234	0.235	0.012	0.767	0.081	0.247	0.250	0.013	0.811	0.084
29	0.423	0.305	0.044	0.432	0.133	0.482	0.352	0.054	0.501	0.143
30	0.181	0.232	0.517	0.301	0.022	0.224	0.269	0.634	0.373	0.023
31	0.211	0.261	0.402	0.144	0.115	0.271	0.345	0.522	0.194	0.151
32	0.501	0.057	0.044	0.214	0.175	0.681	0.082	0.065	0.291	0.232

consisted of 3 items and 6% of total variance was covered by this factor. The result of reliability by Cronbach Alpha showed $r = 0.945$ for internal consistency and the Guttman's split-half coefficient for this criteria was $r = 0.906$ and correlation coefficient between forms showed the internal consistency of component of questionnaire, $r = 0.848$. Spearman-Brown and Guttman split-half coefficient showed internal consistency of questionnaire, $r = 0.917$. Finally, Cronbach Alpha coefficient showed internal homogeneity for each factor of questionnaire, $r = 0.945$ (Table 2).

DISCUSSION

Unfortunately, there is not any instrument or study like our study and we couldn't compare our findings with

them. By the way, the results showed 4 dimensions (factor) of questionnaire. The first dimension was living with client. This dimension emphasis on every task and duties in caring of comatose patients, each caregiver lives with comatose patients and in every place and every time, they think about their patients. The caregivers have a closest fleeing and believe that their patients are themselves. This fleeing is origin of caring or necessary for doing every thing. With this concept, the caregivers can feel and percept the comatose patients, understand their needs, meet them and evaluate the outcomes. The caregivers are instead of their patients and live with them. The second dimension was efforts for survival. Each caregiver of comatose patients tries to rescue and survive her or his patient and he or she does any thing for rescue of them. Each caregiver believes that the comatose

patients are on terminal line in life and they are between life and death so he or she has to do any thing for rescue of them. This caring process is much exhausted but the caregivers are hopeful and effort for life. The third dimension was professional conscience and responsibility. Norberg named conscience as metaphors such as internal voice and voice. These voices experienced from numinous (Norberg, 2002) and most inner nucleus and sanctuary of human being that sanctum with its god and reflect from inner, as Hoose (1999) said it is conscience and claims every person has overlord rules that carving on the heart and determined by conscience. However conscience described as inductor of self developer and protector of self integrity. When caring of patients, the conscience must be referred as consultant (Childress, 1979). Von Post said that conscience is critical for human being and is alarming for hurting others (Von Post, 1998). The items of this dimension had theoretical bases and in the single questionnaire there are some similar sentences.

The fourth dimension was respect of human dignity and consisted of concepts such as commitment to care, sensitive to patients' needs and closing to patient. This dimension is expected from caregivers to do works ethically. Nursing literature stresses on this dimension. No doubtfully, nursing is an ethical commitment and can't been done in without ethics space. All nursing procedures have ethical importance and potential dangerous ethical results (Johnston, 2006). Nurses as participating in dynamic profession have ethical choices that impact on the profession (Thompson *et al.*, 2006). All nursing procedures need to ethic and respect and must be motivated in professional subjects (costing) and respecting to self and others, self evaluation and continuous learning, appropriate communication with clients, having a sense of responsibility and responsiveness in nursing role, helping others and health promotion had defined as professional ethics (Vanaki and Memarian, 2009). Ethical challenge in caring of comatose patients makes an ethical subject and caregivers like to do works that are good and consonant with their conscience (Juthberg *et al.*, 2007). Caring dimension of conscience and respect to patient's dignity is the fundamental of nursing and stressed on by nursing literature.

CONCLUSION

The caregivers of comatose patients present their perspective in a range from living with patients, efforts for survival, professional conscience and responsibility and

respect of human dignity that caregiver's percept meanwhile caring of comatose patients. The caregiver's perspective of caring of comatose patient questionnaire showed degrees of validity and reliability, nevertheless, more validation of questionnaire and more studies about similar concepts such as moral sensitivity, resiliency and burnout is needed.

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