Needs Analysis of a Health Information Service System for Dementia Care

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Summary

The purpose of this study was to identify educational need of families with dementia patient for development of health information service system. This study focused on the families of 117 elderly dementia patients who were admitted to Hospital and to the Senile Ward. The collected data were analyzed by t-tests, ANOVA and Pearson's correlation using SPSS 17.0. Findings is that: 1) The score is higher in educational needs and burden who are old aged dementia patients' families and low grade in IADL; 2) There was a difference in the burden depending on whether the patients lived with them or not; 3) There was a difference in the educational needs according to the age of the families, education level, and monthly income. Since the families of dementia patients feel more burdened when they lack the knowledge and information needed to care for the patients. Dementia information service system is needed to provide a better understanding of dementia and how to respond to it. This study based on educational needs should be provided to dementia patients' families to reduce their burden.

Key words:

dementia, family, burden, educational needs

1. Introduction

As Korea becomes a society that is ageing with unprecedented speed, it will face a super aged society and increased health problems among the elderly. As the number of elderly members of the population rapidly increases, the prevalence of dementia is also increasing and is becoming a significant social issue from both medical and social perspectives [1].

Dementia is characterized as a chronic and degenerative disease, and elderly patients with dementia depend on their caregivers 24 hours a day. Therefore, the burden on caregivers accumulates; they experience various difficulties, feeling burdened both mentally and physically [2]. When the families of dementia patients do not have

access to systematic or in depth knowledge in dementia, the burden becomes more severe.

The Internet has quickly become one of the most consulted sources of information about diseases, medical treatment and health promotion. The availability of the health information through the Internet website is dramatically increasing.

The Internet survey for the general public was general public ranked disease(81.8%), self diagnosis(79.2%), general health(79.1%), emergency(78.7%), highly and most health professionals needed education(90.5%), academic(88.5%), disease(88.4%) [3].

An estimated 43% of Internet users go on-line to gather health care information and obtain answers to health problems from more than 34,000 health-related websites. The Internet has moved beyond distributing passive text-based facts and become a communication medium that allows users to interact with information [4].

Using the Internet, increasing numbers of health care providers and consumers gain free access to an expanding volume of information that previously was inaccessible. Tools such as Internet directories, indexes, and search engines assist health care providers and consumers in their search for health information [5].

The Internet can also be a worth source of information for consumers [6] [7] [8]. For patients and their family or close friends, particularly in cases of newly diagnosed lifethreatening diseases, electronic mailing lists, online support groups, and Web sites devoted to their particular disease can provide worth information and emotional support [9] [10] [11]. Therefore we decide development of a user-centered web-based an information service system for dementia care. The user-centered system development included a needs assessment, analysis, design/ development/testing, and the application release. The principle of user-centered design ensures that the needs of the end users are best met and the resulting application is truly user-friendly [12] [13]. The first step in this process was to conduct a needs assessment. The purpose of this study was

to identify educational needs of families with dementia patient for development of health information service system.

2. Methods

This study focused on the families of 117 elderly dementia patients who were admitted to D Hospital in B City and to the Senile Ward of D Hospital in Y City between March 31, 2006 and April 30, 2006.

The collected data were analyzed using the SPSS statistics program, and general characteristics concerning the study's subjects were analyzed using frequency and percentage. The burden on and educational needs of the patients' families were analyzed using mean and standard deviation. The relationship between the burden on and educational needs of the subjects and all variables were compared using t-tests and ANOVA tests. Correlations between the burden and educational needs were analyzed using Pearson Correlation Coefficients.

3. Result

1. The general characteristics

A total of 117 usable questionnaires were collected. 86 patients (73.5%) in women, 31 (26.5%) in male and two times more common in females than males, and age distribution of 44-97 years the average age was 76.7 years. Bereavement and 62 patients (53.0%), married the 50 patients (42.7%), respectively. Other dementia diseases 64 (54.7%) have majority picks diabetes, hypertension, etc. had a physical illness. Dementia disease duration less than 13-36 months, 53 patients were surveyed, accounting for 45.3% of patients 48 (41.1%) were more than 36 months.

More than 50% of patients less than 5 points lower was with activities of daily living skills. Instrumental activities of daily living skills than the 1-5 score in 36 patients (30.8%) was the most common, accounting for 0 points in 31 patients was 26.5%<Table 1>.

Table 2 shows the characteristics of dementia patients and family members. Gender is a woman, 81 patients (69.2%), male 36 (30.8%) and two times more common in females than males. The mean age of 48.3 years of age and a high percentage of age was 40-50. Caregivers have a daughter of 36 (30.8%), son of 32 patients (27.4%), daughter-in law of 32 patients (27.4%) as well as descendants of the stimulus rate was the highest. Whether premorbid living with dementia in 49 patients (41.9%)

living with dementia by a substantial caregiving burden is expected to be had.

2. Burden and educational needs of families with dementia patients

The score for the burden on dementia patients' families ranged from 20 to 80, with a mean score of 52.3 (8.22). The score for educational needs ranged from 23 to 115, with a mean score of 86.1 (14.69) < Table 3>. There was a difference in the burden on the dementia patients' families according to the age of the patients (F=4.24, P=.007) and IADL (F=4.07, P=.002) < Table 1>. There was a difference in the burden on the dementia patients' families depending on whether the patients lived with them or not (t=6.55, t=0.012) < Table 2>.

There was a difference in the educational needs of the dementia patients' families according to the age of the families (F=3.70, p=.007), their education level (F=4.90, p=.003), and their monthly income (F=5.32, p=.002) <Table 6>. Based on the characteristics of the patients' families, the need for information differed according to the families' total income (F=6.31, p=.001) and education level (F=4.08, p=.009), while the need for education about treatment differed according to educational needs (F=3.93, p=.010). The need for education about welfare differed according to age (F=4.46, p=.002), total income (F=6.15, p=.001), and education level (F=6.34, p=.001), while the need for emotional education differed according to age (F=4.66, p=.002) <Table 7>.

3. Correlations among burden and educational needs

The positive correlation between the educational needs and the burden on dementia patients' families (r=.40, p=.000) demonstrates that families with a heavier burden had a higher need for education. All four sub-categories showed positive correlation <Table 8>.

4. DISCUSSION

With recent aging progress, dementia is a growing health and social issue with the number of people affected, directly and indirectly. Dementia is a syndrome of progressive cognitive impairment that results in a decreased ability to perform activities of daily living [14] [15]. It is a clinical syndrome characterized by a widespread loss of mental function, memory loss,

language impairment, disorientation, change in personality, self-neglect and behavior which is out of character [16].

Many of those with severe dementia, especially those over 85, have a combination of mental and physical problems [17]. More than 10% of people age 65 and older and at least 20% of those older than 80 years have dementia severe enough to impair ability to live independently [18]. In addition to progressive cognitive impairment, up to 90% of persons with dementia will be affected by other neuropsychiatric symptoms, and up to 50% also experience depression [19]. Due to the severity and complexity of needs of people with dementia, it is likely that professional care in the community costs will be higher and more nursing home care will be required than for other groups [20].

In some overseas communities, it is reported to be around 2 to 10% at the age of 65years, depending on the diagnostic criteria being used [21]. It is estimated that 40% of people with dementia reside in long-term care, meaning that some 300,000 are cared for in institutional settings [23].

Many of care givers of older people with dementia are themselves fairly old. Up to 60 per cent are husbands or wives [24]. It seems that caregivers of elderly parents usually lack training in care giving [25]. Many family caregivers choose to care for their demented relatives at home for as long as they can [26] [27]. But, they are unaware of their availability and have difficulty in identifying appropriate medical and community support and identified a perceived lack of education about dementia and ways of dealing with difficult situations [28].

They are often exhausted by challenges [29]. Moreover, family caregivers wish to manage their dementia patient behavioral and psychological symptoms, delusions, depression, wandering, screaming, physical or verbal aggression [30] [31] [32].

Scott, Lewis, Loughlin (2005) identified a perceived lack of education about dementia and ways of dealing with difficult situations [28]. It is important to meet the informational needs of caregivers to better enable them to care for their families. Information about how to manage stressors, emotional issues, as well as available instrumental support, is essential to the success of family care giving [33]. Braithwaite (1990) defined caregiving burden as "distress arising from dealing with the dependant's physical dependence and mental incapacity and over the effects of caregiving on one's life" [34].

Many consider relinquishment of caregiving when their dependants' care needs become unmanageable at home

and most experience significant grief, guilt and despair during this most psychologically painful care transition [35]. Good quality information should be available for people with dementia and their carers.

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<Table 1> Burden on of the dementia patients' families according to the characteristics of dementia patient (N=117)

					(11-117)
Variable	Characteristics	N (%)	Mean(SD)	t or F	p
Gender	Male	31(26.5)	51.6(6.62)	0.31	.577
	Female	86(73.5)	52.5(8.75)		
Age(years)	Below 60	9(7.7)	44.9(9.06)	4.24	.007*
	61-70	18(15.4)	49.6(7.61)		
	71-80	49(41.9)	53.2(7.49)		
	Above 81	41(35.0)	54.0(8.24)		
Marital status	Married	50(42.7)	50.6(7.83)	2.39	.096
	Divorced/Separation	5(4.3)	50.4(5.68)		
	Bereaved	62(53.0)	53.8(8.49)		
Educational level	Illiteracy	38(32.5)	53.4(9.29)	0.50	.739
Zademional level	Elementary school	47(40.2)	52.3(8.04)	0.00	.,,,
	Middle school	21(17.9)	50.3(6.82)		
	High school	10(8.5)	52.4(8.20)		
	University	1(0.9)	50.0(8.22)		
Religion	Christian	21(17.9)	48.3(5.71)	2.37	.057
Tiong.on	Buddhist	55(47.0)	53.5(8.11)	2.5 /	.007
	Catholic	9(7.7)	49.4(8.64)		
	Absent	29(24.8)	53.1(9.31)		
	Other	3(2.6)	58.0(1.00)		
Occupation	Yes	1(0.9)	47.0(8.22)	0.42	.521
Occupation	No	116(99.1)	52.3(8.24)	0.42	.521
Disease other than dementia	Yes	64(54.7)	53.5(8.06)	3.36	.069
Disease other than dementia	No	53(45.3)	50.8(8.24)	3.30	.009
D 2 CT				1.00	20.4
Duration of illness	Below 12	16(13.7)	50.3(6.02)	1.22	.304
(month)	13-24	28(23.9)	50.1(5.84)		
	25-36	25(21.4)	53.6(12.20)		
	37-48	12(10.3)	55.1(4.29)		
	49-60 Above 61	12(10.3)	51.5(9.21)		
		24(20.5)	53.9(7.41)		
ADL	Above 0-Below 1	26(22.2)	54.4(9.18)	3.09	.019
	1-5	34(29.1)	52.5(8.52)		
	6-10	22(18.8)	55.0(8.43)		
	11-15	21(17.9)	50.0(6.52)		
	Above 16-Below20	14(12.0)	47.0(4.11)		
IADL	Above 0-Below 1	31(26.5)	55.6(8.23)	4.07	.002**
	1-5	36(30.8)	54.4(7.91)		
	6-10	17(14.5)	49.2(6.53)		
	11-15	8(6.8)	48.8(5.54)		
	16-20	4(3.4)	49.0(4.32)		
	Above 21	5(4.4)	44.0(5.14)		

< Table 2> Burden on of according to the characteristics of dementia patient families

					(N=117)
Variable	Characteristics	N (%)	Mean(SD)	t or F	p
Gender	Male	36(30.8)	52.0(7.98)	0.01	.782
	Female	81(69.2)	52.4(8.37)		
Age(years)	Below 30	9(7.7)	47.3(6.28)	1.81	.132
	31-40	22(18.8)	50.7(7.13)		
	41-50	38(32.5)	54.6(9.38)		
	51-60	35(29.9)	52.4(7.10)		
	Above 61	13(11.1)	51.5(9.20)		
Marital status	Unmarried	7(6.0)	50.0(4.32)	0.48	.624
	Married	103(88.0)	52.3(8.60)		
	Divorced/Separation	7(6.0)	54.3(4.53)		
Educational level	Illiteracy	0(0.0)		0.60	.614
	Elementary school	14(12.0)	52.6(9.49)		
	Middle school	16(13.7)	53.4(7.97)		
	High school	52(44.4)	52.9(8.25)		
	University	35(29.9)	50.7(7.90)		
Religion	Christian	25(21.4)	50.8(5.21)	1.20	.316
	Buddhist	55(47.0)	52.6(7.65)		
	Catholic	11(9.4)	49.1(9.32)		
	Absent	24(20.5)	54.3(11.10)		
	Other	2(1.7)	57.5(2.12)		
occupation	Yes	68(58.1)	51.1(7.35)	3.63	.059
	No	49(41.9)	54.0(9.10)		
Relationship	Spouse	8(6.8)		2.09	.060
1	Son	32(27.4)	50.4(8.66)		
	Daughter-in-law	32(27.4)	51.8(6.30)		
	Daughter	36(30.8)	54.1(8.82)		
	Son-in-law	5(4.3)	51.7(8.11)		
	Grandson/Granddaughter	3(2.6)	49.6(4.92)		
	Brothers and Sisters	1(0.9)	46.7(15.37)		
Monthly Income	Below 100	13(11.1)	50.8(9.40)	1.20	.314
(10,000 Won)	101-300	71(60.7)	53.4(8.03)		
	301-500	26(22.2)	50.7(7.46)		
	Above 501	7(6.0)	49.4(10.32)		
Live together	Yes	49(41.9)	54.5(9.67)	6.55	.012*
-	No	68(58.1)	50.7(6.61)		

< Table 3> Scores of burden on educational needs

	Range (minimum-maximum)	Mean(SD)	Mean grade (Range)
Burden	20.0-80.0	52.3(8.22)	2.6(1-4)
Education needs	23.0-115.0	86.1(14.69)	3.7(1-5)
- Information	7.0-35.0	26.1(4.89)	3.7(1-5)
- Treatment	5.0-25.0	18.6(3.68)	3.7(1-5)
- Welfare	5.0-25.0	18.8(3.56)	3.8(1-5)
- Emotion	6.0-30.0	22.6(4.07)	3.8(1-5)

<Table 4> Scores of education needs item

Items	Mean(SD)	
Education needs about Information	26.1(4.89)	
1 Toilet training	4.0(0.91)	
2 Wander	3.8(1.04)	
3 Repetitious activity	3.8(0.96)	
4 Dependent behavior	3.7(0.84)	
5 Inappropriate behavior	3.7(1.03)	
5 Decrease of settle a problem	3.7(1.09)	
7 Change of appetite, weight, habit	3.6(0.93)	
Education needs about Treatment	18.6(3.68)	
1 Memory impairment	4.0(0.93)	
2 Sleep disturbance	3.9(0.90)	
3 Indifference	3.6(0.96)	
4 Delusion	3.6(1.03)	
5 Hallucination	3.6(1.02)	
Education needs about Welfare	18.8(3.56)	
1 Family role about dementia patient	4.1(0.91)	
2 Help a meal	3.9(0.79)	
3 Bath	3.8(0.88)	
4 Use of a means of transportation	3.5(1.16)	
5 Use of an instrument	3.5(1.09)	
Education needs about Emotion	22.6(4.07)	
1 Conversation a way about Dementia patient	4.2(0.80)	
2 Conflict settlement about family	4.1(0.90)	
3 Personality change	3.8(0.94)	
4 Anxiety	3.6(0.99)	
5 Depressive mood	3.5(1.01)	
6 Euphoric	3.3(0.89)	

<Table 5> Educational needs of the dementia patients families according to the characteristics of dementia patient

				(11-117)
/ariable	Characteristics	Mean(SD)	t or F	p
Gender	Male	83.6(14.66)	1.25	.267
	Female	87.0(14.68)		
Age(years)	Below 60	88.4(17.83)	0.50	.687
	61-70	89.2(13.42)		
	71-80	85.9(15.48)		
	Above 81	84.5(13.78)		
Marital status	Married	83.8(14.17)	1.14	.324
	Divorced/Separation	86.4(25.83)		
	Bereaved	88.0(14.04)		
Educational level	Illiteracy	85.7(15.78)	0.40	.807
	Elementary school	85.8(14.34)		
	Middle school	89.1(12.22)		
	High school	83.5(18.30)		
	University	77.0(14.69)		
Religion	Christian	81.6(16.20)	0.77	.547
-	Buddhist	87.2(14.88)		
	Catholic	83.4(17.31)		
	Absent	88.0(12.11)		
	Other	87.7(17.78)		
Occupation	Yes	92.0(14.69)	0.16	.689
	No	86.1(14.74)		
Disease other than dementia	Yes	85.2(14.05)	0.59	.446
	No	87.2(15.48)		
Duration of illness	Below 12	83.8(11.53)	1.95	.092
(month)	13-24	82.7(11.20)		
	25-36	86.0(20.75)		
	37-48	97.5(10.93)		
	49-60	87.8(9.07)		
	Above 61	85.1(14.86)		
ADL	Above 0-Below 1	86.1(17.41)	0.82	.516
	1-5	82.9(14.57)		
	6-10	89.7(15.69)		
	11-15	86.2(11.09)		
	16-20	88.2(12.71)		
IADL	Above 0-Below 1	88.5(12.69)	0.86	.514
	1-5	88.4(13.85)		
	6-10	85.6(10.30)		
	11-15	96.0(13.04)		
	16-20	91.8(4.50)		
	Above 21	84.6(18.21)		

< Table 6> Educational needs of according to the characteristics of dementia patient families

				(N=117)
Variable	Characteristics	Mean(SD)	t or F	p
Gender	Male	87.1(15.06)	.22	.642
	Female	85.7(14.59)		
Age(years)	Below 30	86.6(9.97)	3.70	.007*
	31~40	90.6(12.17)		
	41~50	90.0(16.27)		
	51~60	83.1(14.39)		
	Above 61	75.0(10.65)		
Marital status	Unmarried	81.7(8.63)	1.21	.302
	Married	86.9(15.10)		
	Divorced/Separation	79.3(11.45)		
Educational	Illiteracy		4.90	.003**
level	Elementary school	75.0(15.23)		
	Middle school	84.6(12.85)		
	High school	90.6(13.95)		
	University	84.6(14.06)		
Religion	Christian	85.0(15.30)	0.26	.901
	Buddhist	85.4(14.55)		
	Catholic	86.2(18.20)		
	Absent	88.8(12.42)		
	Other	87.0(29.69)		
Occupation	Yes	86.8(13.22)	0.41	.526
	No	85.1(16.60)		
Relationship	Spouse		1.54	.172
·	Son	77.6(13.56)		
	Daughter-in-law	86.9(15.15)		
	Daughter	88.8(14.77)		
	Son-in-law	85.7(13.27)		
	Grandson/Granddaughter	81.4(8.32)		
	Brothers and Sisters	75.0(27.22)		
Monthly Income	Below 100	76.2(14.69)	5.32	.002**
(10,000 Won)	101~300	88.2(14.13)		
	301~500	88.9(13.56)		
	Above 501	72.4(11.22)		
Live together	Yes	86.0(15.25)	0.01	.929
	No	86.2(14.38)		

< Table 7> Educational needs items of according to the characteristics of dementia patient families

			(N=117
Characteristics	Mean(SD)	t or F	p
Monthly Income (10,000 Won)		6.31	.001**
Below 100	22.2(5.67)		
101~300	27.1(4.46)		
301~500	26.7(4.49)		
Above 501	21.9(3.76)		
Educational level		4.08	.009*
Elementary school	22.9(5.69)		
Middle school	25.4(4.85)		
High school	27.6(4.47)		
University	25.7(4.54)		
Educational level		3.93	.010*
Elementary school	16.8(3.84)		
Middle school	19.1(2.40)		
High school	19.7(3.36)		
University	17.6(4.07)		
Age(years)		4.46	.002**
Below 30	19.4(0.88)		
31~40			
41~50			
51~60	17.7(3.42)		
Above 61	16.2(2.27)		
Monthly Income (10,000 Won)		6.15	.001**
	16.2(3.62)		
301~500			
Above 501	15.3(3.35)		
Educational level		6 34	.001**
	15.8(2.91)	0.51	.001
University	19.0(3.50)		
Age(years)		4.66	.002**
	23.0(4.15)		
above 61	19.1(3.27)		
	Monthly Income (10,000 Won) Below 100 101~300 301~500 Above 501 Educational level Elementary school Middle school High school University Educational level Elementary school Middle school High school University Age(years) Below 30 31~40 41~50 51~60 Above 61 Monthly Income (10,000 Won) Below 100 101~300 301~500 Above 501 Educational level Elementary school Middle school High school	Monthly Income (10,000 Won) Below 100 22.2(5.67) 101~300 27.1(4.46) 301~500 26.7(4.49) Above 501 21.9(3.76) Educational level Elementary school 22.9(5.69) Middle school 25.4(4.85) High school 27.6(4.47) University 25.7(4.54) Educational level Elementary school 16.8(3.84) Middle school 19.1(2.40) High school 19.7(3.36) University 17.6(4.07) Age(years) Below 30 19.4(0.88) 31~40 20.1(2.67) 41~50 19.7(4.19) 51~60 17.7(3.42) Above 61 16.2(2.27) Monthly Income (10,000 Won) Below 100 16.2(3.62) 101~300 19.3(3.29) 301~500 19.4(3.33) Above 501 15.3(3.35) Educational level Elementary school 19.8(3.18) University 19.0(3.50) Age(years) Below 30 23.0(4.15) 31~40 24.0(3.45) 41~50 23.7(3.94) 51~60 21.7(4.04)	Monthly Income (10,000 Won) Elow 100 22.2(5.67) 101-300 27.1(4.46) 301-500 26.7(4.49) Above 501 21.9(3.76) Educational level 4.08 Elementary school 25.4(4.85) High school 27.6(4.47) University 25.7(4.54) Educational level 3.93 Elementary school 19.1(2.40) High school 19.7(3.36) University 17.6(4.07) Age(years) 4.46 Below 30 19.4(0.88) 31-40 20.1(2.67) 41-50 101-300 19.3(3.29) 301-500 19.4(3.33) Above 501 15.8(2.91) Middle school 17.4(3.79) High school 19.8(3.18) University 17.6(4.07) Age(years) 6.34 Elementary school 15.8(2.91) Middle school 17.4(3.79) High school 19.8(3.18) University 19.0(3.50) Age(years) 4.66 below 30 23.0(4.15) 31-40 24.0(3.45) 41-50 23.7(3.94) 51-60 23.7(3.94) 51-60 23.7(3.94) 51-60 21.7(4.04)

< Table 8> Correlations among burden on and educational needs

	Education needs				
	Information	Treatment	Welfare	Emotion	Total
Burden	.39***	.38***	.34***	.34***	.40***
	(.000)	(.000)	(.000)	(.000)	(.000)

^{*} p <.01 ** p <.005 *** p <.001