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A Study on the DEMENTIA Awareness and the Dementia Needs in a District

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Abstract

Purpose: *Since the level of positive perception of dementia in Korean society is still very insufficient, it is difficult to detect diseases early and actively intervene in treatments. Supporting this situation, many studies have shown that there is a lack of basic knowledge and a lack of proper perception of dementia. This study is to investigate basic data for presenting the direction of establishing and developing the dementia policy in the future by seeking the effective operational plan for a dementia care center through surveying the dementia awareness and needs in a region.*

Method: *This study is a cross sectional study. This study targeted 498 people who are dwelling in G city of Gyeonggi Province. The research period is from May 1, 2018 to September 15, 2018. The data were analyzed by SPSS Win. 21.0 program.*

Results: *The dementia perception questions showed a significant difference according to participants' age, education level, interest degree, dementia knowledge level, and information contact appearance. As a result of surveying the demand for the dementia-related policy that is most necessary for research participants, a support for medical expenses had the highest need.*

Conclusion: *A large-scale research has rarely been done at home so far targeting city citizens in a region excluding Seoul Metropolis. Hence, this study will be able to be applied to useful basic data afterward for the establishment of a domestic dementia policy and for a dementia-related research. Especially, a change in the perception on dementia and in the use of a care service will become a very important source data.*

[Keywords] ***Dementia, Awareness, Needs, Satisfaction, Demand***

1. Introduction

Owing to the economic growth and the medical technology development throughout the world, the average life expectancy of a human being was extended, resulting in being increased the population aged over 65 years. This rapid aging led to a continuous rise in dementia prevalence rate. Even patients are predicted to likely grow about twice as much every 20 years with 540,000 people in 2012, about 1,270,000 people in 2030, and around 2,710,000 people in 2050[1]. According to this, the number of families taking care of the elderly with dementia are also presumed to probably reach approximately 2,700,000 people[2].

A surge in the elderly population brought about an increase in number of dementia patients. Thus, total annual medical expenses due to dementia mounted as well. Total annual national dementia management expenses for dementia patients in 2018 amounted to 15.3 trillion won, thereby having possessed nearly 0.8% of GDP(gross domestic product)[3]. The social cost caused by dementia for 2050 is estimated to increase even to about 1.5% of the real GDP[4]. Especially, a family caregiver of a dementia patient for 2017 was surveyed to use around

20,740,000 won per annum in order to take care of a dementia patient. Thus, a disease burden as of 2017 was reckoned to probably reach approximately 15 trillion won. Furthermore, the problem is that the comprehensive cost comes to double every year because the bigger economic scale leads to the more growth in medical care cost. In terms of this, the upsurge in dementia patients caused by aging will lead to the more rise in relevant expense hereafter. Hence, there is necessity for the development in community-oriented services and for the national countermeasure preparation available for maintaining and improving the function of patients who are in the early stage of dementia, not the service of centering on protecting and supervising dementia patients.

Dementia has no certain treatment method yet. Thus, early detection is crucial above all. And because our society is lacking in the understanding or the positive prevention activity and in the early discovery & treatment in terms of dementia, there are many cases of being not involved proactively in early detection and treatment. In the survey of National Dementia Awareness that was conducted by the central dementia center in 2014, dementia was selected as the scariest disease in more than 50 years old. Even in all age groups less than 50 years old, it was picked as the second scariest disease after cancer. Thus, even if the national fear of dementia is great, the half among dementia patients or families were grasped to fail to use due to having no information on whether the services required by them exist.

The awareness on dementia may be varied depending on individual factors(gender, age, education level, a coping style, etc.) and social elements(family function, medical system level, social publicity level, etc.). In addition, the perception on illness can be changed through the social publicity even though the individual factor is important as well[5].

Therefore, to make our society recognize a fact that dementia is 'one of the diseases available for prevention and treatment,' not 'an aging phenomenon that naturally occurs when one is old,' the Ministry of Health & Welfare(2008) is making a positive effort of proceeding with guiding in order to improve the social atmosphere that has concealed the dementia disease of the person in question or of the family so far in our society, and to be capable of receiving early medical checkup and cure. As part of this exertion, the government enacted and proclaimed the Dementia Management Act in August of 2011, established a national dementia center in 2012, and declared 'National Responsibility for Dementia' in 2017. The Metropolitan Center for Dementia has been established and operated 17 places including Ulsan and Sejong so far. The operation of 256 Dementia Care Centers[3] leads to giving a help to families as well as to the elderly with dementia.

Despite this endeavor, though, the awareness level on dementia in Korean society is in the real situation of being very deficient yet. Thus, it is difficult to detect a disease early and to actively engage in therapeutic intervention. As if backing up this situation, it was indicated to be short of basic knowledge on dementia and to be ill-conceived in correct perception on dementia. For this, the necessity was suggested for the development and publicity of a program, for the improvement in the standardized tool available for understanding the knowledge and attitude toward dementia, and for the education in relation to the proper knowledge based on the medical grounds, to a precautionary measure, and to an early detection.

Accordingly, this study is aimed to offer basic data for presenting the direction of establishing and developing the dementia policy in the future by seeking the effective operational plan for a dementia care center through surveying the dementia awareness and needs in a region.

2. Research Method

2.1. Research design

This study is a descriptive survey research in order to analyze the perception on dementia, the use of care services, and the demand & satisfaction for the dementia works.

2.2. Research subjects and period

This study targeted 498 people who are dwelling in G city of Gyeonggi Province. The research period is from May 1, 2018 to September 15, 2018.

2.3. Instrument

The research tool that measures the dementia knowledge level was used 12 items, which were developed by conducting a preliminary survey targeting 50 people as for the tool that was verified by receiving the content validity test from 4 professors of psychiatry with a major in dementia and 1 professor with a major in nursing science that were composed of experts relevant to the corresponding field at the Seoul Metropolitan Dementia Center in 2010. The items of the measurement tool on the awareness of dementia comprise 5 questions about the knowledge on disease, 3 questions about the knowledge on symptom, 2 questions about the knowledge on treatment, and 2 questions about the knowledge on nursing. The question about the dementia perception level was set to be a 'yes' or 'no' answer. With being set to be 1 point given being right and to be 0 point given being wrong, the scope of the total score becomes 0-12 points. It implies that the higher score leads to the higher knowledge level. And the tool on the demand and satisfaction for a dementia-related project was used by modifying and supplementing the tool that the Seoul Metropolitan Dementia Center itself developed.

2.4. Data analysis

The collected data were analyzed by using SPSS for windows 21.0 program that is a statistical program. The research subjects' demographic characteristics, dementia-related features, use of care services, and demand & satisfaction for a dementia project were parsed with frequency and percentage. The dementia knowledge level was resolved with the mean and the standard deviation by item. The difference verification in dementia knowledge level according to the demographic characteristics and the dementia-related features was unpacked by using t-test, ANOVA. The analysis of factors, which showed a significant difference in a percentage of correct answers to the dementia awareness question, was made by using multiple regression. The difference verification in a percentage of correct answers to the dementia awareness question was analyzed by using t-test, ANOVA.

3. Results

3.1. Dementia awareness level

3.1.1. General characteristics

Research subjects' general characteristics are as follows <Table 1>. Examining the research subjects' gender, women were 433 people(86.9%). Men were 65 people(13.1%). Thus, there were more males than females. Age ranged from more than 10 years old to more than 80 years old. The ages of 50-59 years stood at 189 people(37.9%), thereby having been the highest. The ages of 60-69 years amounted to 112 people(22.5%). The ages of 40-49 years came to 77 people(15.5%). The ages of 70-79 years stood at 55 people(11.0%). The ages of over 80 years amounted to 36 people(7.2%). The ages of 10-19 years reached 2 people(0.4%), thereby having been the fewest. The education level was the most in 10 years~above 12 years with 195 people(39.1%). The next came to more than 13 years with 156 people(31.3%). 7 years~9 years took up 92 people(18.4%). Even illiteracy possessed 14 people(2.8%). Job was occupied by a housewife with 288 people(57.8%), joblessness with 67 people(13.6%), and a student with 17 people(3.4%). Monthly income was held by less than 1 million won with 139 people(27.9%), 2,010,000-3,000,000 won with 115 people(23.1%), and 1,010,000-2,000,000 won with 114 people(22.9%). The research subjects with the experience of giving a care to a dementia

patient were 136 people(27.3%). The research subjects without the experience of giving a care were 362 people(72.7%).

Table 1. The characteristics of the study subjects. (n=498)

Variable	Categories	n	%
Gender	Male	65	13.1
	Female	433	86.9
Age(years)	10-19	2	0.4
	20-29	18	3.7
	30-39	9	1.8
	40-49	77	15.5
	50-59	189	37.9
	60-69	112	22.5
	70-79	55	11.0
	over 80	36	7.2
Education(years)	0	14	2.8
	1-6	32	6.4
	7-9	92	18.4
	10-12	195	39.1
	≥13	156	31.3
Occupation	Employee	41	8.2
	Self-employment	43	8.6
	Housewife	288	57.8
	Student	17	3.4
	Inoccupation	67	13.6
	Other	42	8.4
Income (ten thousand won)	≤100	139	27.9
	101 - 200	114	22.9
	201-300	115	23.1
	301-400	49	9.8
	401-500	50	10.1
	≥501	31	6.2
Care experience for dementia	Yes	136	27.3
	No	362	72.7

3.1.2. Demographic difference in dementia awareness level

In terms of the difference level in the dementia perception, women stood at 8.9±1.9 points, thereby having been higher than 8.6±2.0 points in men and having been statistically significant. Seeing it by age, the older age led to the lower dementia recognition level. The average score in their 10s reached 11.0±0.0 point. The average score in their 20s came to 10.2±1.6 points. The average score in their 30s accounted for 8.8±3.1 points. The average score in their 40s stood at 9.2±1.6 points. The average score in their 50s reached 9.1±1.7 points. The

average score in their 60s amounted to 8.9±1.9 points. The average score in their 70s stood at 8.2±2.4 points. The average score in more than 80 years old came to 8.5±2.4 points.

Even a difference in dementia awareness depending on age was statistically significant. Even a difference in dementia perception according to education level was indicated to be statistically significant. A case of illiteracy stood at 9.3±2.5 points. Academic career in less than 6 years amounted to 8.8±2.3 points. 7 years~9 years reached 8.83±1.9 points. 10 years~12 years came to 8.7±1.8 points. A case of more than 13 years stood at 9.5±1.6 points. In addition, a difference in dementia awareness level according to medical security was also shown to be 9.0±1.9 points in medical insurance, 8.3±2.5 points in Type-1 medical aid, 7.8±1.5 points in Type-2 medical aid, and 8.4±2.1 points in others, but appeared not to be statistically significant. A difference in recognition depending on the interest level in dementia came to 9.0±2.0 points in 'indifferent, 9.0±1.9 points in 'interested,' and 8.9±2.0 points in 'very interested.' A difference according to dementia knowledge showed 8.8±1.9 points in the average score of respondents with the answer saying 'don't know well,' 9.1±1.8 points in the respondents with the answer saying 'know a little,' and 8.5±2.2 points in the respondents with the answer saying 'know very well.' Even in the score of dementia recognition depending on whether or not having the information contact, the case of having ever received information relevant to dementia amounted to 9.1±1.8 points, thereby having been higher than 8.4±2.0 points in the case of having never received information. The interest & knowledge level on dementia, the dementia-related information contact appearance, and the difference in dementia perception were not all statistically significant <Table 2>.

Table 2. Relationship between knowledge scores and demographic characteristics. (n=498)

Variable	Categories	Mean±SD	t or F
Gender	Male	8.6±2.0	17.231*
	Female	8.9±1.9	
Age (years)	10-19	11.0±0.0	76.78**
	20-29	10.2±1.6	
	30-39	8.8±3.1	
	40-49	9.2±1.6	
	50-59	9.1±1.7	
	60-69	8.9±1.9	
	70-79	8.2±2.4	
	over 80	8.5±2.4	
Education (years)	0	9.3±2.5	57.401**
	1-6	8.8±2.3	
	7-9	8.8±1.9	
	10-12	8.7±1.8	
	≥13	9.5±1.6	
Health insurance system	Medical insurance	9.0±1.9	13.584
	First class of medical protection	8.3±2.5	
	Second class of medical protection	7.8±1.5	
	Other	8.4±2.1	
Interest in dementia	Not interested	9.0±2.0	1.295
	Neutral	9.0±1.9	
	Interested a lot	8.9±2.0	
Knowledge of dementia	None	8.8±1.9	21.372

	a Little	9.1±1.8	
	Very well	8.5±2.2	
Information contact status	Yes	9.1±1.8	26.382
	No	8.4±2.0	

Note: *p<.05; **p<.01; ***p<.001.

3.1.3. Factors of affecting the dementia awareness

A percentage of correct answers to the dementia perception questions showed a significant difference according to subjects' age, education level, interest degree, dementia knowledge level, and information contact appearance. To evaluate the influence of the above elements upon dementia perception, the total score of dementia recognition was set to be a dependent variable. Age, education level, interest degree, dementia knowledge level, and information contact appearance were set to be an independent variable and then were transformed into dummy variable. After it, the regression analysis was carried out. R^2 value of the model was 0.059. As a result of the analysis, The regression equation of the model in order to explain the total recognition score was statistically significant(F=5.432, *p*<.001). Multicollinearity between each independent variables was not problematic(the tolerance limit range in 0.712-0.948, the scope of dispersion expansion factor in 1.054-1.405). In consequence of the regression analysis, if each age, education level, interest degree, dementia knowledge level, and information contact appearance are all included in regression equation, the dementia awareness score gets higher in the younger age, in the higher dementia knowledge level, and in case of having the information contact experience on dementia. This was statistically significant <Table 3>.

Table 3. Demographic characteristics affect knowledge about dementia. (n=498)

Variable	B	SE	β	t
(constant)	9.782	.832		11.761***
Age	-.212	.076	-.153	-2.780**
Education	.083	.100	.046	0.836
Interest in dementia	.018	.098	-.187	-.187
Knowledge of dementia	.374	.177	.106	2.113*
Information contact status	.515	.172	.143	2.991**

Note: p<.05; **p<.01; ***p<.001.

3.2. Dementia needs

3.2.1. Recognition level on a dementia-related institution

A case of knowing a dementia care center possessed 304 people(61.0%). An institution that the person in question or a family member visits first of all when being doubtful of dementia was in order of a public health center with 247 people(49.6%), a neighboring hospital·clinic with 95 people(19.1%), a dementia care center with 91 people(18.3%), a university hospital with 54 people(10.8%), and an internet with 5 people(1.0%). Among respondents, the people who gave the answer as saying of having ever used a dementia care center amounted to 135 people (27.1%). The people who gave the answer as saying of having never used reached 363 people(72.9%) <Table 4>.

Table 4. Degree of awareness of dementia-related organizations. (n=498)

Variable	Categories	n(%)
Dementia center awareness	Yes	304(61.0)
	No	194(39.0)
Priority visit facility rank	Public Health	247(49.6)
	Dementia safety center	91(18.3)
	City office	4(0.8)
	Nearby Hospital	95(19.1)
	University Hospital	54(10.8)
	Nursing hospital, nursing home	2(0.4)
	Internet	5(1.0)
	Other	0(0)
Use of dementia center	Yes	135(27.1)
	No	363(72.9)

3.2.2. The actual condition of using dementia-related institutions and services

Among 135 people who have the experience of using a dementia care center in G city, the respondents who have ever used the dementia-related facility came to 72 people(52.9%). The service to use was the most in counseling(a public health center, a dementia center, a community welfare center, etc.) with 37 people(30.6%). The next was the larger in order of the hospital care with 26 people(23.6%), the facility use(daytime/nighttime/short-term/long-term facility) with 25 people(20.7%), and the in-home care service(a caregiver/a visiting nursing service) with 23 people(19.0%). A reason of having rejected the use of the relevant service included the lack of information on the facility and the program with 15 people(30.6%) and an economic burden with 10 people(20.4%). What there is no appropriate facility or program in a near place or the failure to recognize the need to use was surveyed to be 7 people, respectively(14.3%) <Table 5>.

Table 5. Dementia-related institutions and services. (n=135)

Variable	Category	n(%)
Use of dementia facilities	Yes	72(52.9)
	No	64(47.1)
Use service*	Counselling(public health, dementia center, welfare center)	37(30.6)
	Hospital treatment(outpatient or admission)	26(23.6)
	Facility use(day/night/short/long term care facility)	25(20.7)
	Home care service(caregiver/visiting nursing service)	23(19.0)
	Provision of sanitary goods(diper ect.)	5(4.1)
	Free dementia screening service	2(1.7)
	Provide wondering rescue bracelet	1(0.8)
	Other	2(1.7)
Reasons for denying service*	Lack of facility/program information	15(30.6)
	No suitable facility/program nearby	7(14.3)
	Because of the social aspect	1(2.0)
	Economic burden	10(20.4)
	Failure to recognize the need to use	7(14.3)
	Other	9(18.4)

3.2.3. A demand for the dementia-related policy

As a result of surveying the demand for the dementia-related policy that is most necessary for research participants, a support for medical expenses had the highest need with 271 people(22.5%). And it was in order of the expansion in the dementia-related facilities with 252 people(20.9%), a support for the nursing expenses for dementia patients with 238 people(19.8%), training of dementia specialists with 142 people(11.8%), free examination for dementia with 119 people(9.9%), establishment of a dementia counseling center with 90 people(7.5%), and a perception change project with 88 people(7.3%) <Table 6>.

Table 6. Policy needs of dementia patient and family. (n=498)

Category	n(%)
Dementia-related recognition conversion project	88(7.3)
Expansion of dementia-related facility	252(20.9)
Supporting the cost of treating dementia patients	271(22.5)
Supporting the cost of caring dementia patient	238(19.8)
Training of dementia specialists	142(11.8)
Establishment of counseling center(or telephone, homepage) for dementia	90(7.5)
Free dementia screening service	119(9.9)
Other	·4(0.3)

Note: Multiple response.

4. Discussion

This study is a descriptive survey research in order to grasp the dementia awareness and the needs for the community care service and for the dementia project in a region targeting G city of Gyeonggi Province. At the point of time that develops the integrated support project ranging up to dementia-related counseling, checkup, management and service connection through opening a dementia care center at 252 public health centers nationwide as one of the National Responsibility Plan for Dementia that was enforced from September of 2017, the inspection on the dementia awareness and the dementia demand are needed.

Total average score of dementia awareness in the subjects of this study stood at 8.9±1.9 points(12-point perfection), thereby having reached 74.1 points given coming to be converted into a perfect score of 100, resulting in having appeared to be higher than 51.9 points[6] in dementia awareness, which was executed targeting post-75 years of age or older people in a district, and 61.9 points[7] of corresponding to the dementia perception, which was implemented targeting six regional groups over the age of 65. It was indicated to be similar to 74 points[8] of corresponding to the outcome of the dementia recognition that was conducted targeting Seoul citizens. This is analogized to be the result that was shown because of being the similar research subject groups as this study and the research by Lee Dong-yeong et al.[8] are involved in the research that was carried out targeting citizens in a region without age limit.

A difference in dementia awareness according to subjects' general characteristics was indicated to have a significant difference depending on gender. This was seen to be consistent with what[9] was executed targeting Irish citizens. What appeared to be significant in the dementia perception depending on age backed up a previous research[10][11]. The higher education level led to the higher dementia awareness, thereby having supported the outcome of a preceding research[9][11][13].

Factors of influencing the dementia recognition appeared to include age, the dementia knowledge level, and the dementia information contact experience. The elements of affecting the dementia awareness in a research that was conducted targeting health professionals in China were indicated to be age and the experience of having looked after a dementia patient[14]. In a research that was carried out targeting citizens in Germany, the subjects with the experience of having attended to a dementia patient were reported to have influence upon the dementia recognition[15]. In this way, the dementia awareness was understood to be influenced by the experience of having taken care of a dementia patient or by the experience of contacting information on dementia.

As a result of analyzing the demand level for a dementia-related project in research subjects, the subjects with the response as saying of 'knowing a dementia care center' accounted for 61%. An institution with the first visit when being doubtful of dementia was the most in a public health center, a dementia center, and a community welfare center with 49.6%. This is considered to be settled citizens' recognition on a dementia care center.

As for the highest demand for the future dementia-related policy, the demand degree was higher in order of a support for medical expenses with 22.5%, the expansion of the dementia-related facilities with 20.9%, a support for the nursing expenses with 19.8%. The objective of National Responsibility for Dementia, which is in progress from 2017, is to give a help to patients and families who suffer a difficulty caused by dementia, thereby being driven the contents such as strengthening a medical support for dementia patients and mitigating the burden of medical and nursing expenses for dementia. In case of the expenses for treating dementia, the self-burden rate of medical expenses for severe dementia patients was reported to have been lessened in August of 2018. There is current implementation in order to expand even the subjects for the cost sharing reduction benefit out of the long-term nursing insurance[16][17][18]. However, a proper support fails to be received sometimes because there are also citizens who do not know the appearance of this policy. Hence, it is considered to require the offer of information on the dementia-related policy along with the perception education.

Accordingly, based on the results of this study, an opportunity was arranged that recognizes the importance of an effort to get rid of a prejudice, along with the right perception on dementia, through developing dementia-related programs and services, improving the customized education by education level and by age group, and continuing the dementia awareness education.

5. Conclusion and Suggestion

Through this study, the following conclusions will be able to be elicited.

First, the factors, which have influence upon the dementia awareness in a region, appeared to include the age, the knowledge level on dementia, and the experience of the dementia information contact. Thus, the subjects require the dementia perception education in consideration of these things.

Second, citizens are demanding the dementia policies such as backing up medical expenses, expanding the dementia-related facilities and supporting the care expenses for dementia patients. The policy relevant to a cost support is being requested because of a rise in the social economic cost caused by dementia patients and of a climb in a family burden according to this.

Third, a cause for refusing the use of the dementia-related services appeared to be high in the lack of information on facilities and programs and in the economic burden. This needs to make it available for reducing a family burden by being offered the information on both facilities and programs in which the dementia-related services can be used given the dementia

awareness education. Also, to mitigate the economic burden for dementia-related services, even the policy support available for assisting this is considered to be necessary.

A large-scale research has rarely been done at home so far targeting city citizens in a region excluding Seoul Metropolis. Hence, this study will be able to be applied to useful basic data afterward for the establishment of a domestic dementia policy and for a dementia-related research. Especially, a change in the perception on dementia and in the use of a care service will become a very important source data.

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7. Appendix

7.1. Authors contribution

	Initial name	Contribution
Lead Author	MRS	-Set of concepts ☑ -Design ☑ -Getting results ☑ -Analysis ☑
Corresponding Author*	SYP	-Make a significant contribution to collection ☑ -Final approval of the paper ☑ -Corresponding ☑ -Play a decisive role in modification ☑
Co-Author	YJS	-Significant contributions to concepts, designs, practices, analysis and interpretation of data ☑ -Participants in Drafting and Revising Papers ☑ -Someone who can explain all aspects of the paper ☑