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Original Article

Analysis of the consistency of information received from Alzheimer's disease patients and their families in the quality of life and depression scales

Alzheimer hastalığında yaşam kalitesi ve depresyon ölçeklerinde hasta ve ailelerinden alınan bilgilerin tutarlılığının incelenmesi

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ABSTRACT

Aim: This study aimed to examine the consistency of quality of life and depression scales using information obtained from individuals with Alzheimer disease (AD) and the family members of these patients.

Material and Methods: Mini-Mental State Examination (MMSE) score was ≥14 points patients who were diagnosed with AD (n:86) and their families(n:86) participated in the study. All individuals took the Geriatric Depression Scale Short Form (GDS-SF), Nottingham Health Profile (NHP) and World Health Organization Quality of Life Instrument Elderly Module Turkish Version (WHOQOL-OLD). Data obtained from 78 patients and their relatives who have completed all of the questions in the scales were evaluated. Patient and family scale scores were compared using correlation analysis and difference analysis.

Results: A moderate to very high correlation was found between the GDS-SF, NHP, and WHOQOL results of the patients and their relatives (0.447-0.848). It was detected that while NHP correlation coefficients varied between 0.734 and 0.848, WHOQOL-OLD correlation coefficients varied between 0.447 and 0.696. When the difference between the scores of the answers given by the patient and his family was examined, a statistically significant difference was found only in the mean scores of NHP sleep, WHOQOL sensory ability, WHOQOL social participation and WHOQOL raw ($p < 0.05$).

Conclusion: In conclusion, NHP, GDS-SF, and WHOQOL-OLD consistency between the individual with AD diagnosis and their family. However, if information is to be obtained from the patient in evaluating the quality of life, choosing NHP instead of WHOQOL-OLD may lead to more accurate results.

Keywords: Alzheimer disease; Depression; Quality of Life; Consistency.

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ÖZ

Amaç: Alzheimer hastalığı(AH) tanısı olan bireylerden ve bu hastaların aile bireylerinden alınan bilgilerle doldurulan yaşam kalitesi ve depresyon ölçeklerinin tutarlılığının incelenmesi amaçlanmıştır.

Gereç ve Yöntemler: Mini-Mental Test (MMT) sonucu ≥14 puan olan, AH tanısı alan hastalar (n: 86) ve aileleri (n: 86) çalışmaya alındı. Tüm bireylere Geriatrik Depresyon Ölçeği Kısa Formu (GDS-SF), Nottingham Sağlık Profili (NHP) ve Dünya Sağlık Örgütü Yaşam Kalitesi Enstrümanı Yaşlı Modülü Türkçe Versiyonu (WHOQOL-OLD) uygulandı. Ölçeklerdeki tüm soruları tamamlayan 78 hasta ve yakınlarından elde edilen veriler değerlendirildi. Hastaların ve ailelerin ölçek puanları korelasyon analizi ve fark analizi kullanılarak karşılaştırıldı.

Bulgular: Hasta ve yakınlarının GDÖ, NHP ve WHOQOL sonuçları arasında orta ile çok yüksek korelasyon bulunmuştur (0.447-0.848). NHP korelasyon katsayıları 0.734 ile 0.848 arası değişir iken WHOQOL korelasyon katsayıları 0.447 ile 0.696 arasında değiştiği tespit edilmiştir. Hasta ve ailesinin verdiği cevapların puanları arasındaki fark incelendiğinde yalnızca NHP uyku, WHOQOL duyusal yetenek, WHOQOL sosyal katılım ve WHOQOL ham puanlarının ortalamalarında istatistiksel olarak farklılık saptanmıştır (p<0.05).

Sonuç: NHP, GDS-SF ve WHOQOL-OLD sonuçları AH tanısı olan birey ve ailesi arasında tutarlılık göstermektedir. Fakat yaşam kalitesi değerlendirilirken hastadan bilgi alınacak ise WHOQOL-OLD yerine NHP tercih edilmesi daha doğru sonuçlar verebilir

Anahtar kelimeler: Alzheimer hastalığı; Yaşam kalitesi; Depresyon, Tutarlılık.

Introduction

Alzheimer's disease (AD), characterized by cognitive loss, is a progressive neurodegenerative disease that causes various behavioral problems and impairment in quality of life of the patients. AD is the most prevalent type of dementia and constitutes 60% –70% of all dementia cases [1]. There are 46.8 million Alzheimer's cases worldwide in 2015, and it is estimated that this number will increase to 131.5 million in 2050 [2].

Cognitive, psychological, and behavioral problems that occur in individuals with AD negatively affect the quality of life of patients and their caregivers. Quality of life, which is a multidimensional structure, is one of the most important parameters that can be monitored in terms of disease progression. Thus, determining the quality of life of patients with dementia is an important subject [3]. However, there are discussions in literature on the definition of the quality of life of patients with dementia, its measurability, and from whom should the information be gathered while evaluating the quality of life [4-6]. Causes such as cognitive impairment, cognitive impairment, immediate memory impairment, verbal communication deficiencies, and loss of insight among dementia patients make it difficult for the individual to assess his/her own quality of life [7]. However, quality of life is a subjective concept, and it may be possible for the patient to perform a self-assessment with the right scales. In studies regarding the analysis of the quality of life of individuals with AD, it is stated that patients with mild to moderate cognitive impairment are able to give opinions regarding their subjective states [3, 8, 9].

Another subject that is as important as evaluating the quality of life in AD patients is the evaluation of depression statuses. It has been reported that depression is one of the most common neuropsychiatric syndromes among the geriatric population and depressive symptoms are prevalently observed in AD. Comorbidity of depression with dementia accelerates cognitive impairment and causes higher mortality and morbidity. Therefore, it is considered that the evaluation of depression and taking protective and reducing measures against depression in AD is important for the course of the disease[10, 11].

In literature, the issue: Which person should be taken as the source of information in the evaluation of quality of life and depression status in AD is still controversial. Therefore, this study aimed to examine the consistency of quality of life and depression scales using information obtained from individuals with a higher decision-making ability and with a diagnosis of mild and moderate AD at 14 and above score from the Standardized Mini Mental Status Exam (MMSE) and the family members of these patients.

Material and Methods

Our study was conducted in Neurology Clinic, Dementia Polyclinic of Training and Research Hospital. Among the patients who were admitted to the dementia polyclinic between the months of May 2019 and September 2019; individuals who were diagnosed with AD according to DSM 5 criteria, whose MMSE score was ≥14 points, who and/or whose family volunteered to participate were included in the study.

Patients who came to the clinic with at least one family member living with the patient, spending the most time or providing care were included in the study. 86 volunteers from the patients and their families participated in the study. However, eight patients were excluded from the study because they failed to complete the scales. Data obtained from 78 patients and their relatives who have completed all of the questions in the scales were evaluated.

Data Collection

The scales used in the study were applied to the patient in the neurology examination room while the families were also asked to fill the scales in the waiting room. Thus, it was ensured that the patient and the family responded independently from each other. The scales were filled by reading the questions out loud to all patients. All patients were given the MMSE according to their education status which had the Turkish validity and reliability performed[12]. Geriatric Depression Scale Short Form (GDS-SF) was used to evaluate the depression status of the patients; Nottingham Health Profile (NHP) and Turkish Version of the World Health Organization Quality of Life Instrument Older Adults Module (WHOQOL OLD) were used to evaluate the quality of life. Analysis of the consistency of the answers between the family and the patients for various areas regarding quality of life was ensured by the use of two different quality of life scales.

GDS-SF: The short form version, which was developed by Yesavage and the Turkish validity and reliability of which were conducted by Ertan and Eker, was used [13]. Depression symptoms were investigated with 15 questions in the scale. Yes answer was evaluated with a score of 1 and no answer was evaluated with a score of 0. It was accepted that there was no depression if the total score was 0-4, mild depression if the total score was 5-8, moderate depression if the total score was 9-11, and severe depression if the total score was 12-15.

NHP: First part of the scale, Turkish validity and reliability of which was conducted by Küçükdeveci et al. was applied [14]. By asking a total of 38 questions, information was obtained on six parts: pain (NHP P), physical activity (NHP PA), energy level (NHP EL), sleep (NHP S), social isolation (NHP SI), and emotional reaction (NHP ER). Each subsection was given a score between 0 and 100 points according to the answers. The total score (NHP T) ranging from 0-600 was calculated with the summation of the scores obtained from the subsections.

WHOQOL-OLD: 24 questions were asked and 6 facets were evaluated with the scale the Turkish validity was performed by Eser et al. [15]. The subscale of this scale consisting of 24 questions are sensory ability (WHOQL SAB), social participation (WHOQL SOB), death and dying (WHOQL DAD), intimacy (WHOQL INT), autonomy (WHOQL AUT) and past, present, and future (WHOQL PPF) activities. 4 questions were asked in each facet. Each question was answered by the patient and the family, with the lowest score being 1.0 and the highest score being 5.0. Each section received scores ranging from 4-20, and the raw score (WHOQL T) was calculated with the total score of the 6 facets.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Before the recruitment, a written informed consent was obtained from each participant Ethical approval was granted by Research and Training Hospital Ethics Committee (reference No.: 81/07).

Statistical analyses

In this study, analyses were carried out after the data were transferred to the IBM SPSS 23.0 program and organized. Descriptive statistics were evaluated with number (n), mean, and standard deviation (SD). Correlation analysis of the data with non-normal distribution was evaluated with Spearment test while the correlation analysis of the data with normal distribution was evaluated with (Red) Pearson test in the analysis of the relationship between the information gathered from the patient and the family.

The score difference between the patient and family responses to the scale results: the difference analysis in paired (dependent) groups in non-normally distributed data was evaluated with the Wilcoxon Signed Ranks Test, and the difference analysis in the paired (dependent) groups in the normally distributed data Paired T Test. Patient and family scale scores were compared in the analysis. In addition, regression analysis was performed to observe whether there was an effect of age, education, and MMSE results on the difference results in the three scales. In order to determine which variables will be included as a predictor (affecting) variable in the linear regression analysis which would be performed to evaluate the effect of age, education, and MMSE variables on GDS-SF Difference between patient and family, NHP T Difference, and WHOQOL T Difference variables, difference analysis was performed first. In data with non-normal distribution, difference analyses in the independent groups were evaluated with Mann–Whitney

U Test while the data with normal distribution, difference analyses in independent groups were evaluated with T Test.

Results

51.3% (n = 40) of the evaluated patients were female and 48.7% (n = 38) were male. The ages of the patients participating in the study ranged from 54 to 94 and the mean age was 72.76 ± 8.12. According to the World Health Organization classification 57.7% of the patients were young and old, 42.3% were old and very old individuals. 59% of the patients had moderate stage AD and 41% had mild stage AD. Mean MMSE of the patients was detected as 18.95 (Table 1).

Table 1: Demographics and clinical findings

		n	%	Min	Max	Mean	Median	SD
Gender	women	40	51,3					
	men	38	48,7					
Educational Background	absent	27	34,6					
	present	51	65,4					
Age				54	89	72,76	73,00	8,12
Age Groups	50-74	45	57,7					
	75-90	33	42,3					
MMSE				14,00	24,00	18,95	19,00	2,16
MMSE Groups	14-19	46	59,0					
	20-24	32	41,0					

(MMSE: Mini-Mental State Examination)

According to the correlation analyses regarding the relationship between the information obtained from the patient and the family, it was observed that the scale scores discussed in the study changed in the same direction for the patient and his/her relatives. In the scale scores, if the patient's score was high, the score of the relative was high as well, and if the patient's score was low, the score of the relative was also low . A moderate to very high correlation was found between the GDS-SF, NHP, and WHOQOL results of the patients and their relatives (0.447-0.848). It was detected that while NHP correlation coefficients varied between 0.734 and 0.848, WHOQOL correlation coefficients varied between 0.447 and 0.696 (Table 2).

Table 2: Correlation analysis of the relationship between the information gathered from the patient and the family.

	GDS SF Family	NHP P Family	NHP ER Family	NHP S Family	NHP SI Family	NHP PA Family	NHP EL Family	NHP T Family	WHOQOL SAB Family	WHOQOL AUT Family	WHOQOL PPF Family	WHOQOL SOB Family	WHOQOL DAD Family	WHOQOL INT Family	WHOQOL T Family
GDS SF_Patient	,633**														
NHP P_Patient		,806**													
NHP ER_Patient			,773**												
NHP S_Patient				,774**											
NHP SI_Patient					,768**										
NHP PA_Patient						,734**									
NHP EL_Patient							,789**								
NHP T_Patient								,848**							
WHOQOL SAB_Patient									,696**						
WHOQOL AUT_Patient										,532**					
WHOQOL PPF_Patient											,584**				
WHOQOL SOB_Patient												,700**			
WHOQOL DAD_Patient													,748**		
WHOQOL INT_Patient														,447**	
WHOQOL T_Patient															,681**

*p<0.05; **p<0.01

(GDS-SF: Geriatric Depression Scale Short Form, NHP P: Nottingham Health Profile Pain, NHP PA:physical activity, NHP EL: energy level, NHP S: sleep, NHP SI:social isolation, NHP ER: emotional reaction, NHP T: total score, WHOQOL SAB: World Health Organization Quality of Life Instrument Old Module Turkish Version sensory abilities, WHOQOL SOP social participation, WHOQOL DAD: death and dying, WHOQOL INT: intimacy, WHOQOL AUT: autonomy, WHOQOL PPF: past, present and future activities WHOQOL T:overall score)

When the difference between the scores of the answers given by the patient and his family was examined, a statistically significant difference was found only in the mean scores of NHP S, WHOQOL SAB, WHOQOL SOB, and WHOQOL T ($p < 0.05$). It was determined that the means of other scores were closer to each other and did not create a statistically significant difference ($p > 0.05$). According to the findings, while the scores of the patients in the NHP S score were higher than the scores of their families, the scores of the families in the WHOQOL SAB, WHOQOL SOB, and WHOQOL T scores were higher than the scores of the patients (Table 3).

Table 3: Difference analysis of the relationship between the information gathered from the patient and the family.

	n	Patient		Family		Difference		t/Z	P
		Mean	SD	Mean	Sd	Mean	Sd		
GDS SF	78	7,15	3,29	7,07	2,80	,07	2,56	-,092	,927
NHP P	78	34,68	28,68	35,69	27,03	-1,00	13,59	-,316	,752
NHP ER	78	44,83	25,95	43,35	22,44	1,47	16,64	-,244	,808
NHP S	78	43,96	35,00	38,22	28,85	5,74	20,02	-2,320	,020
NHP SI	78	45,37	26,89	40,75	27,55	4,62	17,98	-1,962	,050
NHP PA	78	41,54	25,59	41,57	25,55	-,02	18,30	-,050	,960
NHP EL	78	50,48	36,14	47,04	31,57	3,43	23,04	-1,083	,279
NHP T	78	260,89	139,62	247,39	123,48	13,49	67,21	-1,691	,091
WHOQOL SAB	78	9,25	2,90	10,41	2,90	-1,15	2,07	-4,921	,000
WHOQOL AUT	78	13,06	3,49	13,30	3,18	-,24	2,97	-,794	,427
WHOQOL PPF	78	12,43	2,93	12,43	2,82	,00	2,43	-,115	,909
WHOQOL SOB	78	11,07	3,80	12,08	3,29	-1,01	2,59	-3,194	,001
WHOQOL DAD	78	12,83	4,87	13,01	4,51	-,17	3,26	-,696	,486
WHOQOL INT	78	14,39	3,52	14,60	2,84	-,20	3,40	-,791	,429
WHOQOL T	78	73,06	11,10	75,85	8,82	-2,79	8,23	-2,998	,004

It was determined that there was no statistically significant effect of age, education, and MMSE variables on GDS-SF Difference and NHP T Difference variables between the patient and the family ($p > 0.05$) It was determined that only the education status created a statistically significant difference on the WHOQOL T. Difference variable ($p < 0.05$). According to this result, it was determined that the WHOQOL T scores of undereducated patients were lower than the scores of their families compared to the WHOQOL T scores of the educated patients ($p <0.05$) (Table 4).

Table 4: Linear regression analysis which would be performed to evaluate the effect of age, education, and MMSE variables on GDS-SF Difference between patient and family, NHP T Difference, and WHOQOL T Difference variables

		n	GDS SF Difference			NHP T Difference			WHOQOL T Difference		
			Mean	SD	P	Mean	SD	p	Mean.	SD	p
Age	50-74	45	-,08	2,35	,698	5,25	58,93	,208	-3,28	6,25	,494
	75-90	33	,30	2,84		24,74	76,61		-2,12	10,41	
Educational Background	absent	27	-,07	2,31	,911	8,66	62,50	,765	-5,48	7,37	,036
	present	51	,15	2,70		16,05	70,04		-1,37	8,37	
MMSE	14-19	46	-,06	2,52	,528	8,46	71,00	,431	-4,23	8,78	,063
		32	,28	2,64			61,73			6,98	

Discussion

Previous studies mostly examined consistency in quality of life scales. In these studies, while some scales show consistency in different sub-areas; there was no consistency in some scales or sub-areas[16].In this study, it was aimed to evaluate the consistency between patients and families in evaluating the quality of life and depression symptoms of patients in AD. By using two different quality of life scales, a comparison was made between sources of information in different sub-areas for quality of life. In addition, the effects of education, age, and cognitive status on the difference in the total scores of 3 scales between patient and family responses were also examined. In all scales and subsections of scales, there was a consensus found between patients and families as an increase and decrease in scores, and the scores of the scales showed moderate to very high correlation (what does a medium/ very high correlation mean?). However, it was considered that the increase and decrease in the scores were not sufficient to evaluate whether the results between the patient and the family were completely consistent. Therefore, when considering the difference between the scores obtained from the patient and the family, it was observed that NHP S, WHOQOL SAB, WHOQOL SOB, and WHOQOL T scores were inconsistent. While there was an inconsistency in 1 subsection in NHP, the presence of inconsistencies in 2 subdomains and raw scores in WHOQOL-OLD and lower correlation coefficients compared to NHP suggested that NHP could give more accurate results than WHOQOL in evaluating the quality of life. Especially in WHOQOL-OLD, observing that the raw score was affected by the education level and that the score difference with the family increased among the undereducated, showed that the application of WHOQOL-OLD on undereducated people should not be preferred as it may reduce the accuracy of the results. Since it was observed that the GDS-SF scale was consistent between the patient and the family even according to education, age, and gender, it was thought that the questions not being filled in by the family or the patient in GDS-SF would not affect the results. However, this is only be valid for moderate and mild stage AD because patients with advanced stage and MMSE below 14 were not included in our study.

There are studies in the literature that examine the consistency of scales among dementia patients and their relatives and use different scales to evaluate the quality of life. In the Quality of Life Assessment Schedule (QOLAS), which is a scale based on both patient and family reporting, it was observed that the consistency between the scores of the patient and the family was low [17]. Similarly, in a study using the Duke Health Profile (DHP) scale, the DHP forms filled in by mild and moderate Alzheimer's patients and their relatives were compared, and it was reported that there was no consistency between the patients and their relatives, especially in the subjective subtests of DHP [18]. However, it has been suggested that the results of Dementia Care Mapping (DCM), which can be applied to patients with all stages of dementia, and NHP, which can be applied more to moderate to mild stages, show consistency between families and patients [19, 20]. Among these scales, DCM was not used in our study because its validity and reliability in Turkish didn't exist. Finding a consistency (correlation) between the NHP scores of Alzheimer's patients and their relatives, as in our study, Boyer et al., in their study reported that there was consistency between patients and their relatives in five out of six subtests of NHP filled by patients with mild and moderate AD and their relatives. In their study, in which they included 99 dementia patients 66 of which had AD diagnosis with an MMSE score of 9 and above, they stated that that they found the subsections other than NHP ER and the NHP T scores consistent between the patients and their relatives. In order to examine the factors affecting the consistency of scores between the patient and the family, they analyzed the factors of under and above 80 years of age, MMSE result below and above 18, physical condition and place of residence. They suggested that age and physical condition are significant factors in discordant responses between the patient and their relative. In our study, physical condition was not evaluated, and it was observed that education had an effect on the inconsistency between the WHOQOL T score between the family and relatives. There was inconsistency found in the emotional reaction subsection in that study, while inconsistency was found in sleep subsection in our study [20]. In the evaluation of sleep disorders in Alzheimer's patients, existence of inconsistencies between sleep records and the statements of caregivers were shown with studies. Accordingly, it has been reported that caregivers' statements regarding sleep duration and quality are not objective [21, 22]. This explains the inconsistency in sleep status in our study. However, in the presence of primary impairment of mild to moderate cognitive functions, as in this study sample, it has been observed that it is possible for patients to express their opinions about their own health status.

In the literature, there was no study found using WHOQOL OLD used in our study to examine the consistency between Alzheimer's patients and their relatives. However, there are consistency studies between the patient and the caregiver for WHOQOL AD, which evaluates the quality of life with 13 parts. In the study conducted by Logsdon et al., when WHOQOL AD results of 77 patients and their families were compared, the correlations between the results were found to be moderate/no correlation. In their study, they also applied MMSE, Hamilton Depression Scale, and the long form of GDS and examined these scale results and the correlation between patient and family WHOQOL AD results as well. In their study, a significant correlation was found between the WHOQOL AD obtained from the patient and the GDS scores obtained from the family. They did not examine the consistency between the patient and family GDS results in their study. They stated that WHOQOL AD can be used to evaluate the quality of life in patients with MMSE between 10 and 28 [3].

Conclusion

NHP, GDS-SF, and WHOQOL-OLD results show moderate to very high consistency between the individual with AD diagnosis and their family. However, if information is to be obtained from the patient in evaluating the quality of life, choosing NHP instead of WHOQOL-OLD may lead to more accurate results. When applying NHP and GDS-SF, information can be obtained from individuals with mild and moderate AD or their families. The limitation of our study: by keeping the cut off points of the scales lower, whether there could be consistency in low MMSE results as well could be determined, and if so, the most appropriate MMSE cutoff score for the scales could be determined.

Compliance with Ethical Standards:

The authors declare no conflicts of interest. Informed consent was obtained from all individual participants and/or their families included in the study.

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