

Functional Status of Older Adults with Dementia at the End of Life: Is there Still Anything to do?

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Abstract

Aims: There is a lack of data on physical functional status near death of patients with different types of dementia that can contribute to decisions about what kind of care is needed. The aim of this study was to investigate the course of functional status along with the documented reasons for death in participants with dementia who had regularly been followed at a geriatric outpatient unit. **Setting and Design:** A retrospective observational cohort study was done using the database of a geriatric outpatient clinic. **Subjects and Methods:** Sociodemographic and medical records of patients with Alzheimer's disease (AD), vascular dementia, mixed dementia, and dementia with Lewy bodies (DLB)/Parkinson's disease dementia (PDD) who had received routine care in a geriatrics outpatient setting for a minimum of 12 months before death were analyzed. Scores for activities of daily living and documented probable causes of death were recorded. **Results:** Of the 258 participants, 111 (42 female and 69 male) were included in this study. AD was the leading cause of dementia (51.8%). The median duration of survival with dementia was 4 years. The leading causes of death were cardiovascular disease (CVD) (27.0%) and dementia (27.0%) followed by infections (21.6%) and stroke (10.8%). Disability was the highest in patients with DLB/PDD. **Conclusions:** This study found relatively shorter survival after the diagnosis of dementia when compared to other populations. CVD still appeared as a major cause of that in this particular disease. Most debilitating type of dementia was DLB/PDD.

Keywords: Dementia, functionality, older adults

INTRODUCTION

Today, dementia is an important public health challenge.^[1,2] The longer the life of people, the more likely they are demented.^[1] The number of people with dementia is growing rapidly, and this disease is estimated to be more than 35 million people worldwide.^[2] Participants with dementia have shorter life span and higher mortality rate than the general population due to the severity of disease and comorbid conditions.^[3] However, understanding of the specific causes of death in patients with dementia may be beneficial in improving prognosis and establishing appropriate care plans.^[4,5]

The investigation and identification of predictors of mortality in these patients are a critical perspective in the management of this population.^[6] Of those, functional limitations have been shown to predict worse health outcomes and mortality in older people.^[7,8] Assessment of functional status has been, particularly targeted for the evaluation of older adults with dementia because functionality refers to current health status,

psychological well-being, and the need for supportive care.^[9] Inconsistent results have been obtained from previous studies that have examined the relationship between functionality and mortality in patients with dementia.^[10,11] A prospective observational study conducted in ten nursing homes in the USA reported that residents who died were more commonly physically restraint in bed in comparison with those who survived up to 3 months before death.^[11] Furthermore, there is a lack of data on physical functional status near death of patients with different types of dementia that can contribute to decisions about what kind of care is needed. Providing appropriate end-of-life care may improve the comfort and quality of life in these patients and thus decrease caregiver stress.^[12]

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Causes of death in chronic conditions including dementia may differ across countries or regions due to many reasons. The prevalence of dementia is estimated to be around 8.5% in the elderly population in Turkey,^[13-16] but there is limited information on the causes of death among these patients. Based on data from prevalence and incidence studies, dementia-related mortality rates increase dramatically in all regions worldwide.^[1,10]

Focusing on functionality in the care of older adults is a critical issue. Maintaining activities of the person as much as possible may improve the quality of life and may also contribute significantly to outcomes in health care during the death process. In this study, we investigated the course of functional status along with the documented reasons for death in participants with dementia who had regularly been followed at a geriatric outpatient unit.

SUBJECTS AND METHODS

Study design and samples

We conducted a cohort study to examine the characteristics and probable causes of death of older adults with dementia at the end of life, using the database of the Division of Geriatrics of Gulhane Training and Research Hospital.

In this study, patients with a clinical diagnosis of dementia aged over 65 years were identified from the medical records. All participants were regularly admitted to the geriatric outpatient clinic between 2006 and 2016 years.

Patient characteristics

Data on demographic factors and clinical history were collected from the records. Demographics included were age and body mass index (BMI) at the diagnosis of dementia and survival in months after the diagnosis of dementia (years). Subsequently, we categorized age as follows 65–74, 75–84, and 85+ years. Variables related to clinical history were hypertension (yes or no), diabetes mellitus (yes or no), stroke (yes or no), coronary artery disease (yes or no), and chronic obstructive pulmonary disease (COPD) (yes or no).

Functional status

Basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs) are routinely used scales to assess physical functioning as a part of the geriatric evaluation. The results of two scales, which were based on the report of families and/or caregivers, in the last visit before death were identified from the records.

BADLs were consistently measured by the Barthel scale,^[17] where the ten performance items used are feeding, bathing, grooming, dressing, continence of bowel and bladder, toilet use, transfers (bed to chair and back), mobility (on level surfaces), and climbing stairs. Each item is scored on this scale, and the sum is obtained by adding the score of each item (range, 0–100; higher scores show better performance). Final scores were classified to determine the level of dependence as follows: total (0–20 points), severe (21–60 points),

moderate (61–90 points), slight dependence (91–99 points), and independence (100 points).^[18] Then, participants were dichotomized to simplify scoring by constitute two groups: high risk (0–60 points) and low risk (61–100 points).

IADLs were measured for all patients by Lawton scale,^[19] where the eight performance items used in this questionnaire are ability to use telephone, shopping, food preparation, housekeeping, laundry, transportation, taking medication, and ability to handle finances. Each item on this scale is scored, and the sum is obtained by adding the score of each item (range, 0–17; higher scores show better performance).

Diagnosis of dementia

As part of a routine assessment, history, physical and mental status examination, blood tests, and radiographic studies (computed tomography or magnetic resonance imaging) if needed were used in clinical assessment of dementia. The Mini-Mental State Examination (MMSE) screening test at the diagnosis of dementia was performed to evaluate mental status (range, 0–30; higher scores show better cognitive performance).^[20] The final diagnosis and type of dementia (Alzheimer's disease [AD], mixed dementia [MXD], vascular dementia [VaD], dementia with Lewy bodies [DLB]), and Parkinson's disease dementia (PDD) were based on consensus in an expert panel using the "Diagnostic and Statistical Manual of Mental Disorders Definition" criteria.^[21,22] Since DLB and PDD have the same biological and clinical characteristics and motor features, they are considered as a single group, "DLB/PDD." The degree of the severity of dementia at the diagnosis was assessed using the Clinical Dementia Rating scale (CDR) and rated as 1 (mild dementia), 2 (moderate), and 3 (severe).^[23]

Cause of death

For each participant, date of death and primary cause of death were ascertained through the records. Relevant probable causes of death were categorized as cardiovascular (myocardial infarction, arrhythmia, congestive heart failure, and embolism), stroke, dementia, cancer, digestive (gastrointestinal bleeding and ischemia), infection (septicemia due to bronchopneumonia, urinary tract infection, and infected decubitus ulcer), and renal (end-stage renal failure).

Data analysis

The data were analyzed using PASW Statistics 18.0 (SPSS Inc., Chicago, IL, USA) statistical program. Results were given as number or percentage or mean \pm SD or median (minimum–maximum). The Kolmogorov–Smirnov test was used to evaluate normal distribution for continuous variables. Independent samples *t*-test and Mann–Whitney U-test were used for comparisons between two groups for continuous variables [Table 1]. Analysis of variance (ANOVA) and Kruskal–Wallis test were used for comparisons between four groups for continuous variables [Table 2]. Categorical variables were analyzed using Chi-square test [Tables 1 and 3]. Differences were considered to be statistically significant when $P < 0.05$.

Table 1: Characteristics of all participants

Variables	Total (n=111)	Female (n=42)	Male (n=69)	P
Age at death	n=109	n=40	n=69	0.041 ^a
65-74	14 (12.8)	1 (2.5)	13 (18.8)	
75-84	57 (52.3)	22 (55.0)	35 (50.7)	
85+	38 (34.9)	17 (42.5)	21 (30.5)	
BMI at the diagnosis (kg/m ²)	n=90	n=32	n=58	0.001 ^a
27.1±4.7		29.2±4.4	25.9±4.4	
Hypertension	n=111	n=42	n=69	0.963 ^c
Yes (%)	79 (71.2)	30 (71.4)	49 (71.0)	
Diabetes mellitus	n=111	n=42	n=69	0.183 ^c
Yes (%)	34 (30.6)	16 (38.1)	18 (26.1)	
Stroke	n=111	n=42	n=69	0.327 ^c
Yes (%)	38 (34.2)	12 (28.6)	26 (37.7)	
Coronary artery disease	n=111	n=42	n=69	0.719 ^c
Yes (%)	42 (37.8)	15 (35.7)	27 (39.1)	
COPD	n=111	n=42	n=69	0.976 ^c
Yes (%)	16 (14.4)	6 (14.3)	10 (14.5)	
Dementia diagnosis	n=110	n=41	n=69	0.105 ^c
AD (%)	57 (51.8)	22 (53.7)	35 (50.7)	
MXD (%)	28 (25.5)	12 (29.3)	16 (23.2)	
VaD (%)	8 (7.3)	0 (0.0)	8 (11.6)	
LBD/PDD (%)	17 (15.5)	7 (17.0)	10 (14.4)	
MMSE score at diagnosis	n=107	n=42	n=65	0.022 ^b
19 (0-28)		15.5 (0-27)	20 (0-28)	
CDR score at the diagnosis	n=111	n=42	n=69	0.223 ^c
Mild	60 (54.1)	20 (47.6)	40 (58.0)	
Moderate	31 (27.9)	11 (26.2)	20 (29.0)	
Severe	20 (18.0)	11 (26.2)	9 (13.0)	
Duration of survival with dementia (years)	n=105	n=37	n=68	0.453 ^b
4 (0-12)		5 (0-11)	3 (0-12)	
Causes of death	n=111	n=42	n=69	0.842 ^c
Cardiovascular	30 (27.0)	11 (26.2)	19 (27.5)	
Dementia	30 (27.0)	12 (28.6)	18 (26.1)	
Cancer	4 (3.6)	1 (2.4)	3 (4.3)	
Stroke	12 (10.8)	6 (14.3)	6 (8.7)	
Digestive	6 (5.4)	2 (4.8)	4 (5.8)	
Infection	24 (21.6)	9 (21.4)	15 (21.7)	
Renal	5 (4.5)	1 (2.4)	4 (5.8)	

^aIndependent samples *t*-test, ^bMann-Whitney-U test, ^cChi-square test. Results are mean±SD, median or percentage. COPD: Chronic obstructive pulmonary disease, LBD: Dementia with Lewy bodies, PDD: Parkinson's disease dementia, MMSE: Mini-Mental state examination, CDR: Clinical dementia rating scale, AD: Alzheimer's disease, VaD: Vascular dementia, MXD: Mixed dementia, BMI: Body mass index, SD: Standard deviation

Ethical considerations

All study procedures were in accordance with the ethical standards of the institutional and/or national research committee and with the revised Helsinki declaration in 2013. The study was approved by the Local Ethics Committee (1491-403-16/1648-1523). Informed consent was not obtained due to the retrospective study design.

RESULTS

The study included 258 patients. Of those, 111 patients' death was recorded, and they were studied in the final analyses. Participants with missing data (*n* = 147, 57.0%) were excluded. Table 1 shows the characteristics of participants. The mean age

at death was 82.0 ± 6.2 years; 62.2% of the participants were male. Female participants had higher mean BMI than male participants at the diagnosis of dementia (*P* = 0.001). Mean age at death was similar in both gender (83.4 ± 5.7 in female and 81.2 ± 6.3 in male, *P* = 0.077); however, there was a difference in age categories (*P* = 0.041). The rate of diabetes mellitus, hypertension, stroke, coronary artery disease, and COPD did not differ in both groups.

AD was the leading cause of dementia (51.8%). MMSE score at the diagnosis of dementia was lower in females (*P* = 0.022). The majority of participants at the diagnosis of dementia was CDR 1 (mild dementia). The median duration of survival with dementia was 4 (0–12) years. Overall, the

Table 2: Functional status according to dementia type before death

Functionality	AD (n=57)	MXD (n=27)	VaD (n=8)	LBD/PDD (n=16)	<i>p</i>
BADLs (0-100)	65.4±25.1	63.2±22.1	74.3±24.3	56.9±22.3	0.381 ^a
IADLs (0-17)	2 (0-57)	1 (0-15)	9 (0-14)	0.5 (0-7)	0.079 ^b

^aANOVA test, ^bKruskall-Wallis test. Results are mean±SD or median. Two person had missing functionality data. BADLs: Basic activities of daily livings, IADLs, Instrumental activities of daily livings, LBD, Dementia with Lewy bodies, PDD: Parkinson's disease dementia, VaD: Vascular dementia, MXD: Mixed dementia, SD: Standard deviation, AD: Alzheimer's disease, ANOVA: Analysis of variance

Table 3: Death causes according to dementia type

Death causes	AD (n=57)	MXD (n=28)	VaD (n=8)	LBD/PDD (n=17)	<i>P</i> ^a
Cardiovascular	20 (35.1)	6 (21.4)	1 (12.5)	3 (17.6)	0.271
Dementia	17 (29.8)	8 (28.6)	2 (25.0)	3 (17.6)	0.795
Cancer	2 (3.5)	0 (0.0)	1 (12.5)	1 (5.9)	0.377
Stroke	3 (5.3)	6 (21.4)	2 (25.0)	1 (5.9)	0.068
Digestive	3 (5.3)	0 (0.0)	0 (0.0)	3 (17.6)	0.072
Infection	9 (15.8)	6 (21.4)	2 (25.0)	6 (35.2)	0.374
Renal	3 (5.3)	2 (7.1)	0 (0.0)	0 (0.0)	0.638

^aChi-Square test. LBD: Dementia with Lewy bodies, PDD: Parkinson's disease dementia, AD: Alzheimer's disease, VaD: Vascular dementia, MXD: Mixed dementia

leading causes of death were cardiovascular disease (27.0%) and dementia (27.0%) followed by infection (21.6%) and stroke (10.8%).

Although statistically not significant, the DLB/PDD group had the lowest mean score of BADLs and the greatest prevalence of participants with high risk for functionality (64.7%) among dementia groups ($P = 0.381$ and $P = 0.080$, respectively). Although IADLs scores did not differ by dementia subgroups, there was a tendency toward a decrease in those of the DLB/PDD group ($P = 0.079$) [Table 2].

Cardiovascular disease in patients with AD (35.1%), dementia in those with MXD (28.6%), and infection in those with DLB/PDD (35.2%) were the most common causes of death (the percentage in VaD group not given due to small sample size) [Table 3].

DISCUSSION

Functional disability in patients with dementia is a progressive and detrimental process together with increase in impairment of cognition and behavioral problems. The predeath cognitive impairment was often studied in various studies. The present study investigated the predeath last status in basic and instrumental activities in these patients. Our findings suggest that physical performance tended to be lower in DLB/PDD group in the last visit before death. The main difference between our study and other studies was how functional impairment is seen at predeath in terms of different types of dementia.

After the mild stage of dementia is passed, functional impairment is expected due to the natural progress of disorder. Previous studies examining the relationship between functional impairment and mortality in dementia have shown inconsistent results. In a community-based prospective cohort of 1670 older

adults, IADL impairment was found as a significant predictor of mortality in AD patients.^[24] Likewise, according to the results of PRIME longitudinal study, functional impairment at baseline and greater decline in function over 6 months predicted mortality in patients with dementia.^[25] In contrast, a recent study demonstrated that the level of activities of daily living was not associated with the risk of mortality in a relatively young cohort of AD patients with a mean age of 67 years.^[26] Moreover, functional status was demonstrated not to be associated with mortality in a small sample of nursing home residents.^[11] Overall, different types of dementia, age, and sample size may be underlying reason for variations in research findings. Thus, it is important to identify the underlying specific dementia type which may have different clinical features, course, and prognosis. Therefore, our research is original that indicates DLB/PDD patients seem as the most influenced population of dementia by disability before death although statistical significance of this is not.

There is a growing interest in the implementation of care approaches in dementia in recent years.^[27,28] The goal of establishing appropriate care plans by health-care providers is a constantly updated issue during the diagnosis of dementia and the course of the disease. However, medical and physical management of dementia patients near death can vary among patients depending on the progression of the disease and also on its subtype.^[29-31]

Remarkably, the addition of disability in DLB/PDD patients in the advanced stage of disease may lead to more complicated and challenging care.^[32,33] Our findings suggest that the tendency for function to decline in DLB/PDD group before death may provide several important contributions to the care management plans. For example, it may be considered that the patient's life will end soon. In this case, in turn, drugs without indications may be discontinued. These patients

may obtain benefit from physiotherapy in a palliative care setting. In addition, care plans can be revisited, and the increased caregiver burden can be attempted to be relieved.^[34] Appropriate placement in group psychotherapy may alleviate discomfort due to dementia in caregivers.^[35]

Similar to other studies, cardiovascular causes (27.0%) and dementia (%27.0) were the most common underlying causes of death in the whole group, followed by infections (21.6%).^[14,36,37] In our study, mortality from infections was high in DLB/PDD group (35.2%), as shown in another research and based on respiratory infections; however, little is known about the main causes of death in this population.^[14] DLB has motor features of Parkinsonism which trigger respiratory muscle weakness, leading to decreased cough and impaired swallowing. Given this comorbidity, our result may be useful for further studies in the development of care plans which aim at decreasing the risk of infection in DLB patients.

Several limitations of the present study should be acknowledged. The retrospective design might introduce selection bias into results. The second limitation was the lack of a control group; however, different dementia subtypes allowed us to create comparison groups. Third, the sample size of the total group was small, and the number of participants in VaD group was few.

CONCLUSIONS

Our findings from a Turkish geriatric unit underline the importance of screening functional performance and administering appropriate care plan in dementia, particularly in patients with DLB or PDD. Providing appropriate care is complex management at advanced stages of dementia patients. This could help reduce suffering of patient and be critical for the family and caregivers to be aware of the progression of this disease and to prepare for the death of loved ones.

Further longitudinal studies are needed to identify the underlying reasons for variations in the trend of decrease in functionality before death among dementia subtypes. Just as important is to develop and test a tailored management plan with families and caregivers that can enhance functional limitations and quality of life at the end of life in different types of dementia.

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Conflicts of interest

There are no conflicts of interest.

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