ORIGINAL ARTICLE

DEATH DISTRESS AND END OF LIFE IN OLDER ADULTS LIVING ALONE

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Abstract

Introduction: Even if it is not perceived as such in real life, death is a natural part of life. Many factors, such as age, medical history, religious beliefs, and culture, affect the perception of death and cause distress. Investigating the factors that cause death distress in older adults is a prerequisite for developing support mechanisms. This study aimed to determine whether living alone is one of the conditions that causes death distress.

Materials and Method: This descriptive study was conducted. A sociodemographic information form created by the researchers and the Death Distress Scale were used. After obtaining the necessary institutional and ethical permission, face-to-face data were collected from 1189 older adults registered at a university's aging studies application and research center.

Results: The Death Distress Scale mean total scores of older adults was 28.18±4.14. The scale scores of the older adults living alone were found to be statistically significantly higher ($p \leq 0.01$). The scale scores of the women were significantly higher than those of the men ($p < 0.01$). Older adults living alone had higher rates of pet ownership. In both groups, those with pets had significantly lower Death Distress Scale scores than those without pets.

Conclusion: Social awareness is important in reducing the death stress experienced by older adults who live alone because of the loss of their relatives, living far away, and other reasons. Activities should be conducted to socialize and improve the quality of life of older adults.

Keywords: Aged; Ethics, Medical; Death; Advance Care Planning.

INTRODUCTION

Many definitions of death have been made in different cultures, societies, and disciplines, which also differ depending on the personality, age, religion, and cultural position of the individual. In individual and social terms, death has never been understood as a simple event; therefore, death creates anxiety for both the person himself/herself and his/her relatives (1). As older adults are closer to the end of their life expectancy, they are more associated with the concept of death, and it is a fact that young deaths are fewer than older adults, so older adults are more exposed to the theme of death and are more likely to experience anxiety and stress related to death than younger individuals (2-4). When we examine the factors affecting the views and approaches of older adults regarding the concept of death, we come across the concepts of understanding death and life after death. Every adult is curious about the uncertainty of life after death. This situation is listed among the causes of death anxiety among individuals and may shape their wishes about the last process of life. These wishes and demands may be shaped according to cultures and perhaps lifestyle (whether they live alone or not), and beliefs of older adults may affect their thoughts about the end of life and death. Death distress is a broad spectrum that encompasses anxiety, obsession and depression related to death, that is, negative attitudes and thoughts about death (5,6). Death distress can potentially contribute to suicidal acts (7), making it extremely dangerous for older adults. It is important to determine the factors that cause death distress and to investigate what to do to preventive measures. Some studies have shown that loneliness increases stress levels (8,9) by increasing cognitive, emotional, and behavioral problems (10,11) and depressive symptoms (12). It has been shown that the feeling of loneliness increases among older adults, especially due to age-related changes in social relationships (13), and the risk of suicide increases due to emotional loneliness in older adults who experience problems in their social relationships and their environment (14,15). Therefore, it is important to investigate the sociodemographic characteristics of the effects of death distress experienced by older adults; whether feelings of loneliness and death distress are related; and whether the feelings, thoughts, and wishes of older adults living alone at the end of life differ from those of those living with someone else, in terms of identifying and preventing risk factors.

METHOD

Sample

This is a descriptive study. Data were collected from older adults registered at a university's aging research center who agreed to participate in the study between January 10, 2024, and June 10, 2024, after obtaining the necessary ethical permissions. A total of 1189 older adults participated in this study. A questionnaire of approximately 30 min duration was administered in a location deemed appropriate by participants who provided informed consent. While collecting data, the researcher and participants were allowed to meet alone. They were assured that their identities would be kept confidential by explaining the importance of reflecting on their true and sincere thoughts and the purpose of the study.

Data Collection Tools

Sociodemographic data form: The researchers created sociodemographic data forms for older adults. The sociodemographic characteristics of the older adults included age, sex, income, whether they lived alone or with someone, marital status, educational status, number of social activities, having a chronic disease, having a pet, and end-of-life wishes.

Death Distress Scale: The Death Distress Scale (DDS) is a 9-item self-report measure designed to evaluate thoughts and feelings concerning death and dying (16). Each item was rated on a five-point rating scale (1=never to 5=always), and as the total

DDS score increased, death distress increased. A previous study indicated that this scale has strong internal reliability in a Turkish sample. Confirmatory factor analysis affirmed the factor structure of the scale with the sample of this study, suggesting good-data-model fit statistics (χ^2=78.64, df=22, p<0.001, CFI=0.96, TLI=0.95, SRMR=0.04, RMSEA [95% CI]=0.06 [0.05, 0.08]; λ range=0.27 [item 3]-to-0.90; α range=0.60-to-0.85).

Statistical Evaluation

Data obtained from the study were analyzed using SPSS software (version 20.0; IBM Corp., Armonk, NY, USA). The Kolmogorov–Smirnov test was used to determine the fit of the normally distributed data, and frequency, percentage, and averages were used to examine the demographic characteristics of older adults. Independent sample t-test for paired groups, ANOVA test for more than two groups, and correlation tests were used to compare demographic variables as independent variables and DDS scores as dependent variables. Cronbach's alpha and item-total correlation analyses were performed to test the reliability of the DDS. All statistical tests were evaluated at a 95% confidence interval (CI) with a significance level of p<0.05 significance level.

Ethical Dimension of Research

Before initiating the study, ethical approval was obtained from the Burdur Mehmet Akif Ersoy University Non-Interventional Research Ethics Committee (No: GO2024/01-89).

RESULTS

The mean age of the older adults was 77.4±9,7 years, 58,6% were female, 35.7% were primary school graduates, 64,8% were married, 63.2% had an income equal to their expenses, 55,8% participate in 1-2 social activities a week, 81.4% have a chronic disease, and %8,9 have a pet. The mean total scores of older adults was 28.18±4.14. The DDS scores of the older adults living alone were found to be statistically significantly higher (p≤0.01), so it can be said that older adults living alone experience more death distress. When the total scale scores for older adults were compared to live alone or with someone, a significant difference was found between the two groups for sociodemographic variables except educational status (p≤0.05) (Table 1). When the mean DDS scores were evaluated separately for the two groups, it was found that the mean DDS scores of older adults aged 85 years and older were significantly lower in both groups than in the other age groups (p<0.001), and participants in this age group experienced less death distress. Women's DDS scores were significantly higher than those of men (p<0. 01), that is, women experienced more death distress than men in both groups; respondents with income higher than their expenses experienced more death distress (p≤0.02); those who were married had significantly higher DDS scores than the other groups (p≤0.01); social activities (visiting relatives, shopping, meeting friends, going to courses, cinema, theatre, concert activities, etc.) are effective in terms of death distress, the DDS scores of those with 3 or more social activities per week are statistically significantly lower than the other groups (p≤0.01), the DDS scores of those with bachelor's degree and higher education in older adults living alone are significantly higher than the others (p≤0. 02), those with primary school education had significantly lower DDS scores than the other groups (p≤0.01); in both groups, those with chronic diseases experienced more death distress (p≤0.01); older adults living alone had higher rates of pet ownership and in both groups, those with pets had significantly lower DDS scores than those without pets (Table 1).

The participants were asked open-ended questions about their wishes and demands regarding the end of life, and the answers were grouped into seven categories, as shown in Table 2. When the answers given by the older adults were

Table 1. Examination of within-group and between-group mean scores of the Death Distress Scale in older adults living alone and living with others according to sociodemographic data

Socio-demographic data		n (%)	Death Distress Scale mean total scores		
			Live alone (n (%); Mean±SD)	Live with someone (n (%); Mean±SD)	P Value (within the group)
Age	65-74	696 (58.5)	124 (59.3; 36.64±8.12)	572 (58.4; 32.16±8.23)	≤0.04
	75-84	385 (32.4)	45 (21.5; 29.75±5.16)	340 (34.7; 26.52±4.14)	
	85 +	108 (9.1)	**40 (19.2; 21.26±4.22)***	**68 (6.9;18.35±6.32)***	
	(p)		**≤0.001****	**≤0.001****	
Sex	Women	697 (58.6)	141 (67.5; 32.45±4.62)	556 (56.7; 26.75±6.32)	≤0.02
	Men	492 (41.4)	68 (32.5; 35.26±6.36)	424 (43.3;29.68±7.34)	
	(p)		≤0.01**	≤0.01**	
Income	Income less than expenditure	299 (25.1)	42 (20.1; 27.63±7.54)	257 (26.3;24.12±7.14)	≤0.05
	Income equals expenditure	751 (63.2)	124 (59.3; 29.14±6.24)	627 (63.9; 26.06±4.32)	
	Income more than expenditure	139 (11.7)	**43 (20.6; 32.18±5.12)***	**96 (9.8; 30.36±5.62)***	
	(p)		**≤0.01****	**≤0.02****	
Marital Status	Married	771 (64.8)		771 (78.6; 33.56±6.84)	≤0.001
	Single	418 (35.2)	209 (100; 30.96±4.26)	209 (21.4; 27.16±3.38)	
	(p)			**≤0.01****	
Weekly Social Activities	0	86 (7.3)	24 (11.5; 33.16±7.08)	62 (6.3; 28.44±8.42)	≤0.01
	1-2	664 (55.8)	82 (39.2; 21.84±6.38)	582 (59.4; 23.26±6.32)	
	3 +	439 (36.9)	**103(49.3;17.02±4.56)***	**336(34.3; 19.16±6.32)***	
	(p)		**≤0.01****	**≤0.01****	
Education	Elementary school	424 (35.7)	**99 (47.4; 23.22±7.61)***	325(33.2; 21.82±4.24)	≥0.05
	Intermediate school	306 (25.7)	48 (22.9; 29.06±6.09)	258 (26.3; 25.52±5.82)	
	High school	254 (21.4)	46 (22.0; 30.08±7.28)	208 (21.2; 24.36±6.56)	
	Undergraduate and above	205 (17.2)	16 (7.7; 30.48±4.54)	**189(19.3; 28.58±5.16)***	
	(p)		**≤0.02****	**≤0.01****	
Chronic Ciseases	yes	968 (81.4)	180(86.1; 34.17±6.66)	788 (80.4; 28.68±9.16)	≤0.01
	no	221 (18.6)	29 (13.9; 23.16±7.22)	192 (19.6; 21.17±5.32)	
	(p)		**≤0.01**	**≤0.01**	
Pet Ownership	yes	106 (8.9)	34 (16.2; 22.85±4.16)	72 (7.3; 21.73±4.36)	≤0.001
	no	1083 (91.1)	175 (83.8; 32.05±2.22)	908 (92.7;27.16±3.42)	
	(p)		**≤0.001**	**≤0.001**	
Total		1189 (100.0)	209 (17.6; 30.96±4.26)	980 (82.4; 25.36±4.32)	**≤0.01**

n: number, SD: standard deviation

* According to the Post Hoc Tukey test results, the group is the source of the statistical difference within the group.

** Statistical significance of comparisons within the group

Table 2. Distribution of end-of-life requests according to groups

Wishes and requests *	Live alone (n=209)	Live with someone (n=980)
Painless death and end-of-life processes	%96.2	%98.3
Peaceful death in one's own environment	%83.4	%95.4
Having the opportunity to say goodbye to their loved ones	%68.8	%89.6
Fulfilment of wishes and desires after death	%76.9	%65.2
Wishes and requests related to religious beliefs	%86.3	%82.7
Request for medical support at a health facility	%72.6	%57.4
Requests related to pets	%16.2	%3.5

* All items expressed by the participants were evaluated and summarized under the headings.

evaluated, it was observed that the demand for the end-of-life process to be painless was ranked first in both groups, and the demands related to pets were ranked last place, and it was determined that all (16.2%) respondents living alone with a pet (n=34, 16.2%) and almost half (3.5%) the respondents living with someone and a pet (n=72, 7.3%) had demands for the care of their pets after their death.

DISCUSSION

As is the case worldwide, Turkiye's population is aging. Therefore, it is necessary to identify older adults' needs and develop solutions accordingly. In this context, revealing the situations that increase death distress in older adults is the first step towards a solution. This study found that living alone was an important factor that increased death distress. Similarly, in Japan and India, living alone is a source of chronic stress and is associated with depression (17,18).

In a study conducted in Turkiye on death anxiety among older adults, no relationship was found between death anxiety and age. The same study found that the presence of mood disorders increased death anxiety. In addition, a weak positive correlation was found between death anxiety and general loneliness, social loneliness and emotional loneliness (19). In our study, death distress was lower among older adults over 85 years of age. This may be due to the decrease in stress with acceptance when the end-of-life expectancy is approached.

In a study conducted on patients with cancer in Chile, the Death and Dying Distress Scale scores of women were found to be higher than those of men (20). In our study, the scale scores of women were also higher. Women may experience more distress owing to their gender roles. In a study conducted among hospitalized older adults, death anxiety was found to be high (21). In our study, the scale scores of participants with chronic diseases were high. It is believed that older adults experience distress owing to social isolation and physical limitations caused by their existing diseases.

In a study conducted during the Covid19 pandemic, positivity reduced death distress (16). In a study of 400 patients diagnosed with depression and anxiety living in the Canary Islands, death distress was found to be closely related to religious beliefs (22). Additionally, individuals with negative religious coping have higher scores for death distress than those with positive religious coping (23). In our study, although older adults were not asked about their religious beliefs, the scale scores changed as education and income levels changed. Socioeconomic status plays an

important role in making sense of life. It is believed that the differences between the groups were due to different ways of perceiving life.

Verbal cognition was found to be better in studies conducted on older adults living alone with pets (24). In our study, the scale scores of pet owners were lower. Emotional support from pets for older adults may have played a role in coping with death distress.

When older adults were asked about their wishes for an end of life with an open-ended question, painless death, whether they lived alone or with someone else, came first. Older adults living with someone else ranked peaceful death second in their own environment, whereas those living alone ranked death according to religious beliefs. At this point, it can be considered that quality of life is prioritized at the end of life. These findings reveal the necessity of conducting more in-depth qualitative studies on end-of-life care. Thus, it was possible to reveal the factors related to death distress more clearly.

CONCLUSION

Older adults who are left alone because of the shrinking of their social environment, the loss of family members, or distance from family members have difficulty coping with the thought of death in the last period of their lives. In an increasingly aging population, it is important to support older adults. Social support systems and services play crucial roles in providing the social connections that older people living alone need. Practices such as social inclusion, community events, volunteer visits, and support groups can help reduce feelings of loneliness and alleviate the fear of death. Increasing the societal awareness of this group and creating effective support mechanisms will improve individuals' quality of life and empower them to cope with these fears.

However, it is important to prepare public service announcements that emphasize the importance of children, grandchildren, and other young family members visiting their older relatives regularly and raise awareness of this issue. Although it is preferred that these visits be voluntary visits from the heart, legal regulations that make this a legal obligation are also being implemented worldwide. In fact, in 2013, the "Law on the Protection of the Rights and Interests of the Elderly" was enacted in China, which stipulated that the older adults should be visited regularly, and the "good child" law, which made it mandatory for children to visit their older parents, was enacted.

Pets can play an important role in reducing feelings of loneliness and improving the quality of life. Pets can be useful in coping with death distress by providing emotional support, encouraging social interaction, encouraging owners to be physically active, and providing older people with daily routines and responsibilities. Of course, older adults may find it difficult to care for animals or may find it difficult to meet the needs of animals due to physical health problems. Therefore, it is important to provide appropriate support and services. Therefore, it is important for society to recognize the needs of older adults and provide support and resources to keep them active throughout their social lives.

Limitations and Implications

Despite the important contributions of this study to the field of aging, some limitations must be addressed. First, it uses self-reported data and a cross-sectional approach. These are important limitations regarding the generalizability of this study. Second, the sample comprised older adults living in a small Turkish city. This limitation can also be considered in terms of the generalizability of findings. Therefore, further studies are required to investigate the effects of death distress in older adults. Although we found that social activities and pet ownership decrease death distress, and loneliness increases death distress, studies on factors that decrease death distress in older adults in different samples can be expanded.

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