ORIGINAL ARTICLE

Opinions about Death in People Receiving Dialysis

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ABSTRACT

Objective: *People receiving dialysis have a high mortality rate due to life-threatening, chronic renal failure. These patients experience the fear of pain and suffering, loneliness and death in the haemodialysis unit. This research aimed at determining the perception of death in people receiving dialysis.*

Methods: *A cross-sectional, descriptive research was conducted under the supervision of the Ministry of Health in public hospitals in the cities of Mersin, Izmir, Antalya, Erzurum, Samsun and Gaziantep. A total 240 patients were treated in the dialysis units of these hospitals. Participants were selected with stratified random sampling. For data collection, a patient information form was prepared by the researcher. Data from the study were analysed with Tukey Honest Significant Difference and one-way ANOVA, using an SPSS version 11.5 software package (Statistical Package for the Social Sciences Windows, IBM Corp., Armonk, NY). The statistical significance level was defined as* $p < 0.05$.

Results: *People receiving dialysis were found to be in a mildly depressive emotional state and they had death anxiety. Death-related anxiety and depression were more common among the female study participants compared to the male participants. Single patients exhibited higher levels of death anxiety compared to married patients.*

Conclusion: *We recommend a holistic and personalised care to allow people receiving dialysis to express their feelings and to overcome the death anxiety. Further research is needed to improve dignified person-centred care for people receiving dialysis.*

Keywords: Anxiety, chronic renal failure, death, depression, dialysis, holistic care

INTRODUCTION

Chronic renal failure is a life-threatening disease that causes loss of workforce and other complications; it affects all age groups, has a poor prognosis and is associated with a risk of death (1). Despite the increasing knowledge and technology aimed at treating this disease, its high morbidity and mortality still persist. Furthermore, the gradually increasing number of patients with chronic renal failure is associated with the growing importance of the disease. Based on these data, chronic renal failure may be considered an important public health problem (2, 3).

In Turkey, a total of 60 000 patients live with a kidney transplant or are on dialysis, and this number is expected to reach 110 000, 6 years later (4). According to a Turkish Society of Nephrology report, in 2013, there were 52 675 haemodialysis patients in Turkey (5). The global prevalence of dialysis patients is 215 patients per one million. According to a US Kidney Disease Statistics report, in 2012, there were more than 365 566 haemodialysis patients in the United States and haemodialysis patients' death rate was 20% (6). The incidence of chronic renal failure in China was found to be 120 000 cases per year. It was announced that a large number of these patients died in a short period of time, while they were waiting

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for a transplant. In a research on the life expectancy of haemodialysis patients in Lithuania, 722 out of the 2418 patients who participated in the research lost their lives. One-, two-, five-, seven-year life expectancies in haemodialysis patients were found to be 79.9%, 69.8%, 49.9%, and 38.8%, respectively (7). The challenges of finding a donor in Turkey lead the patients with kidney failure to compulsory dialysis treatment (8). One-year survival in these patients after the onset of the dialysis treatment has been reported to be 80%, while 5-year survival is reduced to 35% among these patents (6). The length of dialysis sessions is one of the most important factors in determining the mortality rate. According to the Turkish Society of Nephrology report, a total of 8260 haemodialysis patients died in 2013 in Turkey (5). Among the causes of death, cardiovascular diseases account for approximately 50% of death in dialysis patients (9, 10). Among the haemodialysis patients dying of cardiovascular disorders, hypertension is responsible for 90% of sudden deaths (11, 12). Infections, malignant diseases, liver failure, pulmonary embolism, anaemia, high serum phosphate levels, malnutrition, gastrointestinal bleeding, non-adherence, psychological distress, and refusal of dialysis are the factors that may contribute to the risk of death (10–13).

In research studies, the reasons for refusing dialysis have been found to be the fear of pain and suffering, loneliness and fear of death (13–15). In addition, the patients who refused dialysis did not comply with their diet and this attitude may be interpreted as a passive method to commit suicide (14, 15). In addition, dialysis patients are left with their death fear, because almost all professional nurses are exposed to a stressor in the form of feeling connected with the dying of patients (13).

There are not enough quantitative and qualitative researches on the perception of death in dialysis patients. This research aimed at determining the perception of death in dialysis patients.

SUBJECTS AND METHODS

This is a cross-sectional descriptive research. The universe of research consisted of the patients who were being treated in the dialysis units of the public hospitals of the Ministry of Health in the cities of Izmir, Samsun, Gaziantep, Erzurum, Mersin and Antalya between December 1, 2010 and July 30, 2011. The sample of the study was selected using a simple random and stratified sampling method.

Patients under 18 years of age, patients with speech and hearing difficulties, prisoners, patients who were unable to speak and understand Turkish, patients with mental disability or dementia, and patients who refused to participate in the study were excluded from the study. In addition, the permission to conduct research in the public hospitals could not be obtained in Ankara and Istanbul and the patients from these cities were not included in the study sample. A total 240 patients who were being treated in the haemodialysis units in the public hospitals in Izmir, Samsun, Gaziantep, Erzurum, Mersin and Antalya agreed to participate in the research and constituted the sample for this study.

Patient data were collected from the Thorson–Powell Death Anxiety Scale, Death Related Depression Scale and Patient Information Form. The Thorson–Powell Death Anxiety Scale is a scale developed by Thorson and Powell. The validity and reliability study of this scale were conducted by Karaca and Yıldız in Turkey; the Cronbach alpha value was found to be 0.84 (16, 17).

The Death-Related Depression Scale is a scale developed by Templer *et al* in 1990, and the validity and reliability study for the adaptation of this scale to Turkish was done by Yaparel and Yıldız and the Cronbach alpha value was found to be 0.74 (17).

The ethics approval was obtained from the Ethics Committee of Mersin University, and necessary approvals were obtained from the institutions in which the study was conducted. In addition, the patients and nurses were informed about the purpose and methodology of the research and their individual written and verbal consents were obtained. Data were collected from face-to-face interviews. A preliminary test was administered to 20 patients attending the Dialysis Unit of the Health Research and Applications Centre of Mersin University, in order to evaluate the reliability of the Patient Information Form. Necessary adjustments were made in the data collection form, based on the results of this preliminary test.

The sample size of the study was calculated on the basis of a model comparing the averages of two independent groups using the MedCalc version 11.0 statistical software. The minimum sample size required for a study with a minimum 80% power of determining the difference between the groups was found to be 100 patients (19).

Data from the study were analysed with Tukey HSD and one-way ANOVA using an SPSS version 11.5 software package (Statistical Package for the Social Sciences Windows IBM Corp., Armonk, NY). The statistical significance level was defined as $p < 0.05$.

RESULTS

The ages of 30% of the patients who participated in the study ranged from 36 to 50 years, and mean age of the patients was 49.76 ± 16.42 years. Of the patients, 52.9% were female, 58.8% were married, 41.7% were primary school graduates, 37.1% spent most of their lives in rural areas, 39.6% had a strong belief in religion, 91.3% were spending more than they were earning, and 40.4% of the patients were being treated with haemodialysis for 19 to 60 months.

Patients who participated in the study had mild death anxiety and were in a depressive emotional state. A statistically significant difference was found between the age groups in the mean scores of the Thorson–Powell Death Anxiety Scale ($p = 0.022$). The mean death anxiety score of the patients, aged 63 years and older, was found to be less than the mean death anxiety score of the patients aged between 18 and 35 years. A statistically significant difference was found between the age groups in the mean scores of the Death-Related Depression Scale ($p = 0.003$). The level of the depressive emotional state of the patients, aged 63 years and older, was milder compared to that of the patients aged between 18 and 35 years (Table).

A statistically significant difference was found between female and male patients in the Thorson–Powell Death Anxiety Scale scores and the Death-Related Depression scale scores ($p < 0.001$; $p = 0.010$, respectively). Based on these results, the level of death anxiety was found to be higher in female patients compared to male patients.

A statistically significant difference was found between the married and single patients in the Thorson–Powell Death Anxiety Scale scores ($p = 0.001$). Single patients were more likely to develop death anxiety than married patients ($p = 0.001$). There was no statistically significant difference found in the statistical analysis between married and single patients in the Death-Related Depression Scale scores ($p = 0.148$).

There was no statistical difference in the Thorson–Powell Death Anxiety Scale scores and the Death-Related Depression Scale scores between the groups stratified based on the education level, the area of residence where they spent most of their lives and monthly income (Table).

There was a statistically significant difference in the Thorson–Powell Death Anxiety Scale scores and the Death-Related Depression Scale scores between the groups stratified, based on the dialysis time ($p = 0.011$ and $p = 0.007$, respectively).

Table: Socio-demographic characteristics of dialysis patients, the treatment period, Thorson–Powell Death Anxiety Scale and Death-Related Depression Scale Average Points (n = 240)

Socio-demographic characteristics	Thorson–Powell Death Anxiety Scale	Death-Related Depression
	Total Points ($\overline{X}$ ± SD)	Total Points ($\overline{X}$ ± SD)
Age groups		
18–35	54.52 ± 20.99	10.74 ± 4.49
36–50	48.35 ± 20.74	9.32 ± 4.40
51–62	46.63 ± 21.12	9.18 ± 5.23
63 or above	42.71 ± 17.91	7.41 ± 4.41
	$p = 0.022$	$p = 0.003$
Gender		
Female	52.84 ± 20.24	9.89 ± 4.59
Male	42.50 ± 19.53	8.31 ± 4.78
	$p < 0.001$	$p = 0.010$
Marital status		
Married	43.63 ± 20.95	8.63 ± 4.98
Single	56.22 ± 19.15	10.41 ± 4.51
Deceased wife/husband	51.26 ± 17.08	9.19 ± 3.42
Divorced. lives alone	53.53 ± 18.32	9.63 ± 5.05
	$p = 0.001$	$p = 0.148$
Level of education		
Illiterate	50.09 ± 18.77	9.44 ± 4.98
Literate	49.35 ± 22.41	9.39 ± 4.53
Primary school	48.41 ± 22.17	9.35 ± 4.81
Secondary school	41.89 ±18.16	8.22 ± 4.25
Higher education	37.38 ± 15.00	6.00 ± 2.33
	$p = 0.238$	$p = 0.277$
The place where they spent most of their lives		
City	45.42 ± 19.84	9.12 ± 4.40
Province	51.04 ± 21.66	9.44 ± 4.91
Village	50.72 ± 20.92	9.10 ± 5.19
	$p = 0.129$	$p = 0.948$
Monthly income status		
Less	47.98 ± 20.59	9.16 ± 4.80
Equal	47.86 ± 20.36	8.95 ± 4.18
	$p = 0.979$	$p = 0.845$
Dialysis treatment period		
1–6 months	48.15 ± 19.63	7.85 ± 4.48
7–18 months	53.95 ± 22.58	10.37 ± 5.35
19–60 months	42.96 ± 19.67	8.22 ± 4.74
	$p = 0.011$	$p = 0.007$
Religious beliefs		
Very strong	39.02 ± 19.69	7.54 ± 4.72
Strong	55.84 ± 16.20	9.86 ± 4.43
Average	55.68 ± 18.94	10.49 ± 4.26
Weak	53.58 ± 18.87	12.00 ± 5.98
Not believer	19.43 ± 13.46	8.14 ± 2.73
	$p < 0.001$	$p < 0.001$

Based on a post hoc analysis, a statistically significant difference was found in the Thorson–Powell Death Anxiety Scale scores and the Death-Related Depression Scale scores between the groups stratified, based on the religious beliefs ($p < 0.001$; $p < 0.001$, respectively). The non-believer and very strong believer patients were less likely to develop death anxiety and death-related depression compared to the other groups.

DISCUSSION

This study aimed at determining the opinions of dialysis patients on death, and the results of the study are discussed in the light of literature. The mean death anxiety score of the patients, aged 63 years and older, was found to be less than that of the patients aged between 18 and 35 years, and the depressive emotional state of the patients aged 63 years and older was milder in comparison to that of the patients aged between 18 and 35 years. In a study conducted by Karaca, differences were observed in the prevalence of death anxiety between the different age groups. Death anxiety was more common in the 16–22 years age group compared to the other age groups (20). These data were in line with the data from several studies on the same issue in the medical literature (18, 21).

Death-related anxiety and depression were more common among the female study participants compared to the male participants. A literature review revealed similar results (22, 23). In a study conducted by Suhail and Arkam, female patients had a higher level of anxiety about death than male patients (24). In his research, Dağlı asserted that women displayed a higher level of anxiety about death compared to men (19). This phenomenon may have cultural origins, as the male gender role is associated with courageous behaviour and the female gender role is associated with an emotional behaviour; therefore, women may more easily express their anxiety about death compared to men.

In this study, single patients exhibited higher levels of death anxiety compared to married patients. This suggests that a family and a spouse may have positive effects on dealing with hardships in life. As an explanation of the less likelihood of death anxiety in married people with children, Yalom says that 'children can, in a sense, make you live until the eternity' (25). Furthermore, single patients were younger than married patients in this study and, as mentioned above, younger age groups were associated with higher levels of death anxiety (18). On the other hand, single patients were dependent on their family, while married patients were responsible for their family and their quality of life might be affected by financial stress.

There was no statistical difference in the Thorson–Powell Death Anxiety Scale scores and the Death-Related Depression Scale scores between the groups stratified on the basis of education level, the area of residence where they have spent most of their lives, and monthly income. In a study conducted by Erdoğdu and Özkan, higher levels of education were associated with lower levels of death anxiety. This finding was believed to be related to the association between higher levels of education and having a job that kept the patients busy in the fast pace of life (26). The significant correlation between the level of education and death anxiety was further confirmed by the study conducted by Dağlı, while no significant relationship was found between the financial status of patients and death anxiety (19). Moreover, in a study conducted by Karaca, no significant relationship was found between the socio-economic status of patients and their level of death anxiety (21).

Based on the data from the medical literature, dialysis patients pass through several challenging phases during the course of their disease. The first phase starts before the treatment. In this phase, some physical and psychological complications occur due to chronic illness and patients feel that their life is under threat. The second phase is the honeymoon phase for the patients who start dialysis treatment. In this phase, patients believe that the treatment is not as bad as they expected and dialysis makes them physically better. For the first 1 to 2 months, patients feel that they have escaped death. The restrictions (fluid and dietary intake) are milder than before. Patients feel happy. After a short period of time, nearly all the patients face the challenges and restrictions caused by dialysis and move to the depression phase. The feeling of losing control over their lives and thoughts of death further contribute to the depression. This phase lasts approximately 5 to 12 months. The last phase is the phase when patients accept the truth (27, 28). According to Kübler-Ross, in the terminal phase, individuals pass through the denial, isolation, anger, bargaining, depression, and acceptance phases (29).

Patients with weak, average or strong levels of faith had significantly higher levels of death anxiety and death-related depression levels compared to patients who do not believe in any religion, or who have a very powerful faith. Based on this observation, very faithful or non-believer patients were less likely to develop death anxiety and death-related depression. In a study conducted by Karaca, a negative correlation was found

between the level of faith and anxiety about death (21). In this study, individuals with very strong faith had less anxiety about death and death-related depression, while higher levels of death anxiety and death related depression were observed in the individuals with strong, average, or weak faith. This finding might be related to the inability of the patients to perform their religious rituals and their consequent anxiety about life after death. In addition, their fears about the pain and suffering at death and the uncertainty of what lies beyond; being buried in the soil and decomposition, losing physical and spiritual functions; leaving a place where they are used to and comfortable are among the factors that produce the fear of death in the patients (20). Tanhan concluded that the individuals who had no religious beliefs had less death-related anxiety because they did not believe in any rewards or punishments in the afterlife.

The lower level of death anxiety in atheists compared to the very strong believers can be explained by Yalom's statements: 'Religious beliefs which tell us we have to believe in miracles and incomprehensible ideas have always surprised me. I have no doubt that religious beliefs ease many fears. However, it seems to me like strolling around death. Death is denied, it is made powerless'. According to Yalom, a real confrontation with death can only be possible for individuals who act in the light of science. Hence, individuals who do not avoid confronting death directly can fight the anxiety about death easily (25).

CONCLUSION

In this study, people receiving dialysis were found to be in a mildly depressive emotional state and they had death anxiety. We recommend a holistic and personalised care to allow people receiving dialysis to express their feelings and to overcome the death anxiety. Further research is needed to improve dignified person-centred care for people receiving dialysis.

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AUTHORS' NOTE

The authors have declared that no competing interest exists. Study design: ÇFD and MY; data collection: ÇFD; data analysis: ÇFD and İH; manuscript preparation: ÇFD and MY.

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