RESEARCH ARTICLE

Grief Management and Death Education: A Study of Families of Potential Organ Donors and Recipients

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ABSTRACT

Introduction: Chronic kidney disease (CKD) contributes significantly to global morbidity and mortality. Even in its early stages, it increases the risk of death, cardiovascular events, cerebrovascular disorders, hospitalization, reduced health-related quality of life, anxiety, depression, fear of death and suicidal ideation. Poverty and other socioeconomic disadvantages, such as unemployment or poor housing conditions, were determining factors in lack of treatment or discontinuation of care, because families could not cope with this considerable burden.

Aim: The purpose of this study is to investigate families of Potential Organ Donors and Recipients, who are confronted daily with experiences of death, grief and fear of death, as well as their attitudes toward death, in order to answer the question of whether they need further education on death-related issues. At the same time, the demographic determinants that affect the quality-of-life level of these families were examined.

Methods: A cross-sectional interventional study was conducted in a sample of 50 families (30 women and 20 men) of Potential Organ Donors and Recipients. The Death Attitude Profile-Revised (DAP-R) instrument was used to assess the Death Profile, while factor analysis was used to analyze and create auxiliary variables, with Bonferroni correction applied to control for multiple comparisons among variables.

Results: Analysis of the data showed that participants mainly adopted attitudes of fear (M=3.43, SD=1.68) and avoidance (M=3.31, SD=1.30) toward death. At the same time, better physical health tended to be associated with the adoption of avoidance, neutral acceptance, approach acceptance and escape acceptance behaviors toward death, whereas better mental health was associated with escape acceptance toward death. In addition, graduates of compulsory education (M=31.87, SD=8.63) had significantly poorer quality of life (95% CI: [-23.3, -6.01], p=0.000) than graduates of higher education (M=46.55, SD=7.40). At the same time, graduates of compulsory education (M=2.71, SD=1.29) tended to adopt death-avoidance behaviors to a lesser extent (95% CI: [-3.59, -0.36], p=0.010) than holders of a postgraduate or doctoral degree (M=4.68, SD=0.91). Finally, graduates of compulsory education (M=2.08, SD=1.00) adopted approach-acceptance behaviors to a lesser extent (95% CI: [-2.86, -0.18], p=0.013) than graduates of higher education (M=3.61, SD=1.29).

Conclusions: This study addresses an extremely sensitive issue that is often treated as taboo, attempting to contribute to a better understanding of views surrounding death among families of individuals who either suffer from chronic diseases and rely on organ transplantation or are potential donors. In any case, practical support and more comprehensive information for caregivers/families are expected to have positive consequences for the attitudes they develop toward death, although further research is necessary.

Keywords: Death Profile, Family, Chronic Renal Failure (CRF), Fear, Care

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INTRODUCTION

Worldwide, chronic kidney disease (CKD) affects approximately 500 million people, almost 80% of whom live in low- and middle-income countries (LMICs). In addition, approximately 3 million people with end-stage kidney disease (ESKD) receive renal replacement therapy (RRT), either through hemodialysis or transplantation.(1-3) At the same time, increasing pressure is being placed on healthcare systems by the continuously growing elderly population. In the USA specifically, approximately 40% of the population aged >60 years has CKD,(4) and these numbers are expected to increase.(5)

A considerable amount is now known about the pathophysiological and therapeutic trajectories of CKD, as well as the associated symptom burden experienced by patients. According to more recent studies, there is increasing interest in the way complex long-term conditions require patients and their families (their caregivers) to invest in self-care and self-management of their disease.(6-11) At the same time, the experience of families (caregivers) in managing the disease and its treatment, including their choices and expectations, is influenced by structural, relational and resilience-related factors, the interactions among which remain insufficiently understood.(12)

In the case of end-stage chronic renal failure, transplantation is the only treatment option, with a positive effect on the patient and his or her family.(13) Living-donor kidney transplantation includes aspects of physical and emotional care for all those involved in the process, taking into account possible and experienced adjustments, with spirituality considered a contributing factor. Spirituality and religiosity improve resilience in managing stressful situations and chronic illness,(14-16) while courage, coping ability and spirituality, as a representation of death as a passage, have been found to have a positive effect on patients.(17, 18)

Living-donor transplantation contributes to reducing waiting-list time and increasing patient survival, while also promoting quality of life and family relationships.(19) At the same time, however, it is a time-consuming process because it involves ethical issues and specific assessments of the recipient and the donor. These factors can affect the highly important family system, since the family faces dilemmas both regarding the possibility of organ removal from a healthy family member and regarding surgical risk.(20, 21) Therefore, it is important to understand the expectations of the individuals involved in donation and in the recipient's acceptance of the organ, as fundamental mutual family support that enables transplantation.(20)

As mentioned above, organ donation can generate a negative feeling known as «fear of death,» «death anxiety» or «death distress.» In psychoanalysis and clinical psychology, the term death distress deals with a theoretical reality concerning the death drive. The focus of this distress (death) is no longer clearly identified by the individual, because it is pushed back into the subconscious. It can lead to more or less intense distress and may be displaced onto other instinctive impulses, such as phobia, or onto anxiety about the dissolution of the body. Death anxiety, however, is a term that refers to a more psychological emotional state, corresponding to fear of, or a more or less well-recognized object (death). It is used in differential psychology or social psychology because it allows self-assessment and therefore the quantification of comparisons between subjects.(22) The term fear of death refers to an emotion connected with a clearly identified theme. It concerns only people who have become aware of the origin of death distress and does not involve unconscious mechanisms.

Through organ donation, a person may attempt to «tame» a frightening phenomenon associated with the unknown aspects of death. However, the negative feelings that accompany it may not be fully resolved, and death distress remains present to varying degrees depending on the individual. One of the causes of death distress lies in fear of the end itself. This distress, which is less intense and more or less conscious among individuals, can be restrained or counterbalanced by adherence to social prohibitions known as taboos or by controlling fear through magical thinking and superstitious rituals.

Taboos are defined by Sabri et al. (2010)(23) as «a cultural production that is sacred (religious) or magical (profane), which dictates prohibited behaviors and/or conversations, is associated with individuals with emotional ambivalence, and whose violation leads to sanctions because of the contagious nature of taboos.» The taboo of death leads to avoidance of discussions about organ donation, in the hope of complying with rules of social and moral integrity.(24, 25) At the same time, adherence to the taboo of death and superstition constitute two competing psychological mechanisms triggered by death anxiety, with speech being transformed into a magical act that can release people from their death distress.(26)

These difficulties place a significant burden on those directly responsible for care, especially family members («caregiver/family burden»). The family burden increases significantly, as functional and cognitive impairments imposed by chronic illness limit the patient's ability to care for himself or herself. Additional factors related to the family (caregiver) burden include the relationship between the caregiver (and their career) and the patient, behavioral and psychological symptoms presented by the patient, gender and adverse life events. This is a multifactorial role, and the interdependence of these factors must be assessed in order to determine the impact of the family burden.

The association of CKD with a variety of comorbid

conditions, which compromise patients' overall functional and cognitive capacity and add an increasing burden to the family, presents particular challenges. Among patients aged 65 years and older who began hemodialysis, 40% had five or more comorbidities (USRDS, 2007). In addition, they were often impaired in ways that directly affected hemodialysis treatment (vision problems, inability to drive, difficulty with arousal, mood disorders, cognitive impairment).(27, 28) In particular, moderate to severe cognitive impairment among patients over 55 years of age undergoing hemodialysis was observed at a rate of 70%.(27)

Alongside the physical burden of performing peritoneal dialysis (PD) and administering medication, families are also responsible for transporting their loved ones to clinic or hospital appointments, and they are responsible for providing special diets and nutritional supplements. In addition, they bear the emotional and psychological burden of having a loved one with a chronic illness.

The caregiving burden for a hemodialysis patient presents specific problems, depending on whether the patient is maintained on in-center or home hemodialysis, as difficulties in ensuring transportation to the dialysis center must also be taken into account. Recovery time after an HD session is also an important issue.(29) On average, HD patients require 6 hours to recover after a treatment, with older patients often reporting difficulties until the following day. With regard to home dialysis, although some home dialysis (PD) regimens are ostensibly self-care therapies, caregivers often assume some, if not total, responsibility for managing dialysis.(30) Stress, fatigue, depression, deterioration of family relationships, social isolation, anxiety and fear of death may occur when caregivers undertake home dialysis for adult patients or children.(19, 30-32) Consequently, a stronger negative impact is likely to be observed on the emotional and social aspects of caregivers' and families' lives.(33)

The subject of the present study is the study of families of Potential Organ Donors and Recipients, who are confronted daily with experiences of death, grief and fear of death. The aim is to determine their attitude toward death, the degree of acceptance of the possibility of death, and any need for further education on this topic. At the same time, demographic determinants that may affect the quality-of-life level of these families are investigated.

MATERIAL AND METHOD

Study Design

For the purpose of the study, a cross-sectional interventional follow-up study was conducted, examining, at a specific point in time, families of Potential Organ Donors and Recipients with regard to their experiences of death, grief and fear of death, their attitudes toward death, whether they need more education, and at the same time investigating the demographic determinants that affect the quality-of-life level of the families of Potential Organ Donors and Recipients.

Nursing staff are usually the first choice to whom families turn for issues related to the donation of organs from a relative, and this relationship may be decisive in reaching the final decision. Therefore, it was considered important to determine the family's attitude and to attempt to improve it.

To collect the necessary information, the Death Attitude Profile-Revised (DAP-R) questionnaire was used. It was developed by the research team of Gesser, Wong and Reker in 1987-1988 and examines the attitudes of healthcare professionals toward death. For its translation into Greek, the translation procedure recommended by the Trust Scientific Advisory Committee (SAC) was followed (double back-translation), with cultural adaptation and validation of the questionnaire. After the DAP-R was validated and translated by Malliarou and colleagues (2011), the reliability, validity and structural testing (factor analysis) of the questionnaire were assessed with psychometric tools.(34)

Data Collection

To achieve the objectives of the study, a sample of 50 families of potential organ donors and recipients was recruited from hospitals in Larnaca and Nicosia, following a personal visit to the hospitals and an explanation of the purpose of the questionnaire. Difficulties in obtaining objective answers from the family arise from identifying the center of decision-making (patriarchal or matriarchal family), the family's educational level, and other ethical, religious and cultural barriers.

Overall, 30 (60%) women and 20 (40%) men participated in the study; 48% (n=24) were older than 65 years, while 30% (n=15) were aged 50 to 64 years. Lower participation was observed among individuals aged 20 to 34 years (n=7, 14%) and 35 to 49 years (n=4, 8%). In addition, the overwhelming majority of participants were of Cypriot origin (n=47, 94%), while 4% (n=2) were Greek and 2% (n=1) were of another nationality. A total of 38% (n=19) of participants were graduates of compulsory education, 30% (n=15) were graduates of secondary education, 20% (n=10) were graduates of higher education, and 12% (n=6) held a master's or doctoral degree.

No ethical or legal problems are expected to arise during the conduct of this study, as the data come from questionnaires completed voluntarily and anonymously by the families of Potential Organ Donors and Recipients. The study is being conducted in accordance with the Bioethics Committee, the Scientific Committee for the Promotion of Research of the Ministry of Health, and the Personal Data Protection Committee.

RESULTS

The resulting data were analyzed using the IBM SPSS 21 statistical analysis program, while the extracted information was categorized according to the corresponding category of interest.

Exploratory factor analysis and reliability analysis

Initially, the suitability of the data for factor analysis was examined using the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy(35, 36) and Bartlett's test of sphericity(37). The KMO index ranges from 0 to 1, with values above 0.50 considered satisfactory for analysis, while suitability according to Bartlett's test of sphericity is determined by the significance of the results ($p<.05$).(38)

For factor extraction, the Principal Component Analysis method was selected(39), in order to simplify the factor structure of a group of items or, alternatively, the high item loadings on a factor.(40) In addition, the Kaiser criterion (eigenvalue greater than 1) and the cumulative/total percentage of explained variance were used.

The rotation procedure maximizes high loadings and minimizes low item loadings, leading to a more interpretable and simplified solution. In this study, the Varimax orthogonal rotation method was selected.(39) In addition, after the completion and evaluation of the analysis, loadings that could not be assigned to any other factor, according to the factor loadings, were examined in order to decide whether the corresponding items should be rejected. Loadings greater than 0.7 are considered significant. Finally, the reliability of the extracted factors was examined using Cronbach's alpha reliability coefficient, with values >0.7 considered acceptable.

According to the results, a problem was identified with questions 8, 22 and 31 of the dimensions concerning approach acceptance of death (loadings below 0.5), and for this reason these questions were excluded from the calculation of the approach-acceptance dimension. In addition, factor analysis was found to be statistically significant (KMO>0.6, Bartlett's $p<0.01$), while the reliability of the five dimensions of the instrument was considered very satisfactory (Cronbach's alpha>0.7 in all cases).

Descriptive results for attitudes toward death (death profile)

Based on the participants' answers to the items of the instrument assessing attitudes toward death, scores were calculated for the five dimensions of the instrument. The dimensions can take values from 1 to 7, with a higher mean value indicating greater adoption of the corresponding attitude.

Data analysis showed that participants primarily adopted attitudes of fear (M=3.43, SD=1.68) and avoidance (M=3.31, SD=1.30) toward death, while to a lesser degree they adopted attitudes of escape acceptance (M=2.90, SD=1.55), neutral acceptance (M=2.67, SD=1.27) or approach acceptance (M=2.65, SD=1.26) of death.

Association between attitudes toward death and quality of life

In addition, physical health-related quality was found to be positively associated, at a significance level of alpha=0.05, with death avoidance ($r=0.371$, $p=0.014<0.05$), neutral acceptance ($r=0.314$, $p=0.030<0.05$), approach acceptance ($r=0.433$, $p=0.002<0.05$) and escape acceptance ($r=0.423$, $p=0.003<0.05$), while mental health-related quality was positively associated, at a significance level of alpha=0.10, with escape acceptance ($r=0.261$, $p=0.076<0.10$). These results indicate that better physical health is associated with the adoption of avoidance, neutral acceptance, approach acceptance and escape acceptance behaviors toward death. Conversely, better mental health is associated with the adoption of escape acceptance toward death.

Comparisons by gender

Next, the possible differentiation of quality-of-life and death-attitude outcomes by gender was investigated. For this purpose, an independent-samples t-test was used; no statistically significant differentiation in quality-of-life and death-attitude outcomes by gender was found at a significance level of alpha=0.05 (Table 1).

Table 1. Results of the t-test for the dimensions of attitudes toward death and quality of life by gender

	Gender				t	p
	Men		Women			
	M	SD	M	SD		
Fear of death	3.65	1.85	3.29	1.59	0.729	0.475
Death avoidance	3.26	1.47	3.35	1.20	-0.214	0.832
Neutral acceptance	2.53	1.17	2.75	1.33	-0.579	0.565
Approach acceptance	2.85	1.43	2.53	1.15	0.838	0.406
Escape acceptance	2.99	1.67	2.97	1.51	0.035	0.972
PCS-12	38.40	10.84	37.38	9.06	0.362	0.719
MCS-12	39.04	11.37	36.99	13.40	0.562	0.577

Comparisons by age

Subsequently, the possible differentiation of quality-of-life and death-attitude outcomes by age was examined as the next analysis category, using one-way ANOVA for more than two independent samples. A statistically significant differentiation of quality-of-life outcomes by age group was observed at a significance level of alpha=0.05. More specifically, physical health-related quality of life (F=17.81, p=0.000<0.05) and mental health-related quality of life (F=7.717, p=0.001<0.05) differed significantly by age. Bonferroni's multiple-comparison test was used to investigate the existence of statistically significant differences among age groups for each dimension of quality of life.

The test results showed that individuals aged up to 49 years (M=49.3, SD=5.0) had significantly better quality of life (95% CI: [5.13, 19.87], p=0.000<0.05) than individuals aged 50-64 years (M=36.8, SD=8.56). Similarly, individuals aged up to 49 years (M=49.3, SD=5.0) had significantly better quality of life (95% CI: [9.41, 22.92], p=0.000<0.05) than individuals aged 65 years and over (M=33.13, SD=7.67). In contrast, no significant difference was observed between individuals aged 50-64 years and those aged 65 years and over (95% CI: [-2.45, 9.78], p=0.429>0.05). Similarly, individuals aged up to 49 years (M=49.41, SD=9.85) had significantly better quality of life (95% CI: [3.23, 125.15], p=0.007<0.05) than individuals aged 50-64 years (M=35.22, SD=11.67). In addition, individuals aged up to 49 years (M=49.41, SD=5.0) had significantly better quality of life (95% CI: [5.233, 25.33], p=0.001<0.05) than individuals aged 65 years and over (M=34.12, SD=11.29). No significant difference was observed between individuals aged 50-64 years and those aged 65 years and over (95% CI: [-10.17, 7.99], p=0.999).

With regard to the dimensions of attitudes toward death, no significant difference emerged by age group for any form of attitude. However, the results showed that the differences in the dimensions of neutral acceptance (p=0.066), approach acceptance (p=0.087) and escape acceptance (p=0.085) were not significant at alpha=0.05, with individuals aged up to 49 years adopting behaviors related to neutral acceptance, approach acceptance and escape acceptance to a marginally greater degree (Table 2).

Table 2. ANOVA results for the dimensions of attitudes toward death and quality of life by age group

	Age							
	Up to 49		50-64		Over 65			
	M	SD	M	SD	M	SD	F	p
Fear of death	3.34	1.70	3.26	1.36	3.57	1.90	0.157	0.855
Death avoidance	4.20	1.24	3.34	1.33	3.01	1.21	2.399	0.104
Neutral acceptance	3.46	1.51	2.29	1.24	2.57	1.07	2.890	0.066
Approach acceptance	3.43	1.03	2.46	1.46	2.43	1.12	2.581	0.087
Escape acceptance	3.94	1.58	2.69	1.46	2.73	1.49	2.612	0.085
PCS-12	49.30	5.00	36.80	8.56	33.13	7.67	17.81	0.000
MCS-12	49.41	9.85	35.22	11.67	34.12	11.29	7.717	0.001

Comparisons by educational level

Finally, the possible differentiation of quality-of-life and death-attitude outcomes by educational level was investigated using one-way ANOVA for more than two independent samples.

The results showed a statistically significant differentiation in quality-of-life outcomes in the physical health dimension, at a significance level of alpha=0.05, by educational level. More specifically, physical health-related quality of life differed significantly by educational level (F=8.485, p<0.001). In contrast, no significant difference emerged in mental health-related quality of life (F=1.679, p=0.185).

In addition, Bonferroni's multiple-comparison test was used to identify the educational levels between which a statistically significant difference was found in the physical health dimension of quality of life. The test results showed that graduates of compulsory education (M=31.87, SD=8.63) had significantly poorer quality of life (95% CI: [-23.3, -6.01], p<0.001) than graduates of higher education (M=46.55, SD=7.40). Similarly, graduates of compulsory education had significantly poorer quality of life (95% CI: [-22.17, -1.40], p=0.018) than holders of a master's or doctoral degree (M=43.66, SD=9.63). In addition, graduates of secondary education (M=34.65, SD=13.01) showed significantly poorer quality of life (95% CI: [-18.49, -0.39], p=0.036) than graduates of higher education. At the same time, no significant difference was observed between graduates of compulsory education and graduates of secondary education (95% CI: [-2.42, 12.89], p=0.395>0.05), or between graduates of secondary education and holders of a master's or doctoral degree (95% CI: [-17.26, 4.15], p=0.590).

Regarding the dimensions of attitudes toward death, a significant difference by educational level emerged in the behaviors related to avoidance (F=4.561, p=0.008), approach acceptance (F=4.007, p=0.013) and escape acceptance (F=4.073, p=0.012). As above, a Bonferroni multiple-comparison test was performed to investigate the educational levels between which statistically significant

differences were found in the dimensions of avoidance, approach acceptance and escape acceptance. As observed, graduates of compulsory education (M=2.71, SD=1.29) tended to adopt death-avoidance behaviors to a lesser extent (95% CI: [-3.59, -0.36], p=0.010) than holders of a master's or doctoral degree (M=4.68, SD=0.91). In addition, graduates of compulsory education (M=2.08, SD=1.00) adopted approach-acceptance behaviors to a lesser extent (95% CI: [-2.86, -0.18], p=0.013) than graduates of higher education (M=3.61, SD=1.29), while finally, graduates of compulsory education (M=2.24, SD=1.11) adopted escape-acceptance behaviors to a lesser extent (95% CI: [-3.52, -0.35], p=0.009) than graduates of higher education (M=4.18, SD=1.27) (Table 3).

Table 3. ANOVA results for the dimensions of attitudes toward death and quality of life by educational level

		Educational level				F	p
		CE	SE	HE	MSc/PhD		
Fear of death	**M**	3.10	3.60	2.95	4.69	1.717	0.178
	SD	1.94	1.45	1.22	1.44		
Death avoidance	**M**	2.71	3.40	3.83	4.68	4.561	0.008
	SD	1.29	.80	1.40	.91		
Neutral acceptance	**M**	2.26	2.51	3.58	2.97	2.627	0.062
	SD	1.06	1.22	1.06	1.74		
Approach acceptance	**M**	2.08	2.61	3.61	3.29	4.007	0.013
	SD	1.00	1.15	1.29	1.41		
Escape acceptance	**M**	2.24	3.02	4.18	3.43	4.073	0.012
	SD	1.11	1.68	1.27	1.86		
PCS-12	**M**	31.87	37.10	46.55	43.66	8.485	0.000
	SD	8.63	6.96	7.40	9.63		
MCS-12	**M**	35.81	34.65	41.46	45.99	1.679	0.185
	SD	10.21	13.01	14.63	12.51		

DISCUSSION

The family, as a complex system governed by rules of homeostasis and development, seeks points of balance between maintenance and the development of its members.(21) Therefore, understanding family experiences in the process of living-donor kidney transplantation reflects the need to reconsider the care provided to the recipient, the donor and the family, in both physical and emotional aspects.

In the study by Goreti et al. (2015), it was observed that treatment of chronic kidney disease leads to partial loss of autonomy and changes in mood, with the result that patients become temporarily dependent on their family, for whom they become a priority. Consequently, the daily lives of both sides are modified with the aim of promoting treatment in clinics and/or at home.(41) The results of other studies highlight the consequences, for family unity, of the experience of a family affected by chronic kidney disease and undergoing living-donor transplantation within the family environment.(42, 43)

Both the diagnosis(44) and the hemodialysis process have a direct effect on families and their dynamics.(45) At the same time, the organ transplantation process, as well as the period of waiting for it, is accompanied by intense feelings of anxiety and fear of death for both patients and their families.(46-50) In addition, nephrology patients have to face both the typical problems of transplantation(50-53) and the impairment of quality of life (QoL) due to renal failure.(54, 55) Fear of death, regardless of pathology, may assume a specific role, as high anxiety contributes to lower levels of patient recall and increases the risk of non-adherence to treatment, with patients believing that death would be a solution.(56)

The pain and suffering of families in serious illnesses, as well as fear of death as a consequence of mortality, increase anxiety levels, which in turn worsen health conditions.(57) In previous studies related to organ donation, the issue of death is mentioned only briefly and without a theoretical basis. Quantitative studies in the field measure death-related concepts such as religiosity, bodily integrity and death anxiety,(58-60) while qualitative studies identify statements referring to fear of death and the concept of taboo.(61)

Death taboos and superstition constitute the two main psychological mechanisms associated with how individuals cope with the possibility of their own death. Therefore, and because current results are mixed, a better understanding of the link between anxiety surrounding death and discussion is required. None of the existing studies has described the psychological mechanisms involved when dealing with a phenomenon related to death and that may influence behaviors during discussions with family members.

The impact of providing care to patients with chronic diseases has been studied for various illnesses. Caregiving may be associated with emotional difficulties, such as depression, a variety of symptoms related to anxiety, fear of death, excessive medication use, a negative impact on perceived physical health and reduced quality of life.(62-64) Investigating ways to support caregivers may have beneficial effects for both the patient and the caregiver. Emphasis has been placed on identifying family caregivers and assessing their caregiving burden in order to optimize caregiver well-being.(65-67) Discussion of coping skills can improve the caregiver's QoL even in the difficult environment of end-of-life care.(65) Psychosocial intervention may have significant positive effects on caregiver burden and improve caregivers' satisfaction with their role.(65-67)

After a systematic review of the literature, only three articles were identified describing interventions for caregivers of patients with CKD. In all cases, the effect of educational material provided to the caregiver was evaluated and an improvement in knowledge was described, without reference to other outcomes. Overall, it is concluded that the burden of CKD care is similar to that observed with other chronic diseases.(68)

STUDY LIMITATIONS

The main limitation of the study was the small sample size (50 families) and the fact that the sample was selected using convenience sampling. The small sample size and non-random sample selection are important limiting factors associated with the external validity of the research. Failure to achieve external validity is a limitation that prevents the generalizability of the results to the entire population of families of Potential Organ Donors and Recipients.

CONCLUSIONS

CKD is a long-term disease accompanied by numerous different morbidities, with significant physical and psychological effects both on the person who is ill and on the family environment, which assumes the role of caregiver. Living-donor organ transplantation is of key importance in disease management. However, beyond the expected positive consequences for the health and quality of life of the patient and caregivers, the transplantation process is associated with significant difficulties at various levels, which are a source of stress and fear. To address them, positive psychology and the attitude of the family, both of Potential Organ Donors and of Potential Organ Recipients, are decisive parameters.

These families are confronted with experiences of death, grief and fear of death, while limited and non-in-depth studies have been conducted on the issue of death in the case of organ donation. At the same time, studies dealing with ways to help caregivers of individuals with CKD are also limited, and those that have been conducted focus mainly on the educational material provided.

Within the context of this study, the aim was to determine, through the DAP-R questionnaire, after appropriate translation and validation into Greek, the attitudes toward death of the families of Potential Organ Donors and Recipients. At the same time, demographic factors (gender, age group, educational level) that may be related to quality of life and the adopted attitude toward the possibility of death were examined. Overall, the analysis of the data collected yielded important conclusions, which should be confirmed by newer, larger-scale studies, possibly including more countries and health systems.

Given the importance of the family's opinion and the value of support from the family environment both when making important decisions, such as organ donation, and when dealing with difficulties arising from chronic conditions, the adoption of appropriate measures for the practical support of families of patients and of potential organ donors is considered crucial. In order for this to be integrated into clinical practice and maintained, it is necessary to train nursing staff, who are the first people to whom these families turn for help, as well as physicians. In addition, it would be useful to facilitate corresponding studies in the future, possibly by informing and encouraging patients and their caregivers through the healthcare structures that monitor them to participate voluntarily by completing questionnaires or providing anonymous interviews. Finally, emphasis should also be placed on nurses' views and on investigating the practices followed to date, in order to identify points that could be improved.

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