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Integration of palliative care with other medical specialties — opinions of nephrologists

Abstract

The palliative and hospice care in Poland is offered mostly to patients with cancer in its terminal stages. According to the modern definition of palliative care, it should include patients with other chronic and advanced diseases. The goal of the study was to evaluate the knowledge and awareness in Polish nephrology specialists, concerning the problems of palliative care in patients with chronic renal failure. Anonymous surveys were carried out among 59 nephrologists (30 men and 29 women, with an average age of 42). Sixty percent of the respondents claimed that the quality of life is the criteria for effective treatment, while only 25% put biochemical parameters in the first position. Almost 80% of the respondents believe that dialysis patients do not receive proper psychological care and almost 90% state the same in relation to social care. Similar answers are given in relation to satisfying the spiritual needs and family support. More than 66% of nephrologists believe that doctors and nephrology nurses should be involved in the palliative care. More than half of nephrologists were forced to make the decision to abandon the dialysis therapy in patients with chronic haemodialysis and most of them think that there should be clear rules of conduct for such situations. More than 96% of the respondents believe that palliative care can be applied in nephrology, albeit 40% of nephrologists objected to putting palliative care training in the nephrology specialisation programme. After a presentation aimed at introducing the aspects of palliative care in nephrology, the percentage of specialists with a critical attitude was reduced to 16%.

Palliative hospice care is not offered to chronic renal failure patients, although they would most probably benefit from it. Nephrologists acknowledge the necessity of training in the aspects concerning such care, as well as defining the ethical and legal guidelines concerning the withdrawal of dialysis therapy.

Key words: chronic renal failure, dialysis, palliative and hospice care, dialysis withdrawal

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Introduction

Palliative care is identified with patients suffering from cancer. Hospices providing palliative care are perceived as institutions which offer such patients a decent death. Such care is also associated with children suffering from severe metabolic defects and genetic diseases, and even, to a smaller extent, with patients with AIDS, patients with neurological diseases and people of advanced age. Palliative medicine often evokes negative emotions among healthcare professionals of various medical specialties, as the death of a patient is considered as the failure of medicine. Nowadays, in the world

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characterised by the advancement of medical techniques and life prolongation, dying has become almost unacceptable, to both the patient and doctors. Even more so, as the dying of a patient faces the doctor with an enormous number of problems, inter alia, elimination of symptoms typical for this stage of disease, and also having to convey bad news. The skills related to those activities, acquired during their studies and as part of specialist training, leave a lot to be desired.

It must be remembered, that the definition of palliative care is not confined only to the patients with cancer, but it also includes patients with advanced chronic diseases. It focuses on the quality of life, improved by influencing physical, psychosocial, and spiritual symptoms. It is a philosophy of conduct at the time of struggling with a chronic disease, using active therapy, with the emphasis put particularly on the broadly understood end-of-life care [1, 2]. According to the method of refunding specified by the National Health Fund, the palliative and hospice care in Poland is offered mostly to patients suffering from cancer in its terminal stages. In comparison in the USA, from among the patients admitted to hospices in 2006, only half were diagnosed with cancer (44.9%). Among 55.9% of non-cancer patients, 15.4% were diagnosed with neurological diseases (Alzheimer disease, stroke, dementia), 12.2% were diagnosed with a chronic heart disease, 7.7% with chronic lung disease, and 2.9% with chronic renal failure [3]. In the USA, the number of patients with chronic non-cancer diseases who take the advantage of palliative and hospice care grows each year. This data is in contrast with the number of reports on non-cancer patients presented during the meeting of European Research Forum of the European Association for Palliative Care, which took place this May in Trondheim, Norway. Among 357 poster presentations, only 10 concerned patients with non-cancer diseases, and only 2 of a total of 18 oral sessions presented seven reports [5].

Among the advantages of the palliative and hospice care for patients with chronic diseases, we can list the following:
— appropriate information and communication;
— psychological support;
— social care;
— spiritual support;
— support for the family;
— treatment of symptoms.

It seems that the growing number of patients with chronic diseases and the advantages of taking them under palliative care should lead to the future integration of the activities of specialist healthcare professionals from various fields, family doctors and palliative medicine specialists. The goal of such integration is the improvement of the quality of life for patients with advanced diseases in each moment of their life, until death.

Epidemiological studies show that chronic renal failure occurs frequently and includes 6–16% of the world's population. This data suggests that this disease may concern as many as 4 million people in Poland [6]. The increase in the frequency of renal diseases is caused by the significant prolonging of the lifespan, the epidemic of diabetes (especially type 2) and hypertension. Fifteen thousand patients in the final stages of renal failure are provided with haemodialysis or peritoneal dialysis [7]. Those patients suffer from numerous symptoms of the disease and the therapy, and they face a much higher risk of death, when compared to the rest of the population [8–10]. The role of palliative care in nephrology has been given due credit in the United States, where the palliative care module was introduced to the obligatory nephrology specialisation programme in 2004 [11]. The nephrology specialisation programme in Poland does not include the issues of palliative care, and the stand of nephrologists on this matter seems to be unclear.

The goal of the study was to evaluate the knowledge and awareness in Polish nephrology specialists, concerning the problems of palliative care in patients with chronic renal failure.

Material and methods

Anonymous surveys, which included the aspects of palliative care in patients with chronic renal failure, have been sent to 70 nephrology specialists and doctors that specialise in nephrology. All of them were taking care of patients with chronic renal failure as part of the conservative treatment, and also dialysis therapy. Almost half of them also had patients who had had a kidney transplant. The questions in the survey concerned:
— the opinion on including patients with chronic renal disease in palliative care;
— criteria for evaluating treatment results;
— satisfying the psychological, social and spiritual needs of patients with chronic renal failure;
— the issue of patients' death and withdrawal of the dialysis therapy;
— opinion concerning the necessity to include the module of palliative care in the nephrology specialisation curriculum.

Results

We received 59 answers from 30 men and 29 women. The average age of the respondents was 42 years old.

Fifty-seven nephrologists (96.6%) were affirmative about the question concerning the implementation of palliative care aspects for patients with chronic renal failure. Table 1 includes the answers to the question concerning the main criteria of adequancy of treatment of patients with chronic renal failure. Almost 60% of the respondents listed the quality of the patient's life as priority number one, while only 25% of the nephrologists believe that biochemical parameters, including the recommended dialysis adequacy measure, clearance of urea in the form of Kt/V, are the most important criteria of proper therapy.

The survey included a question concerning the opinion on the level of satisfying the psychological, social and spiritual problems of patients with chronic renal failure in stage V, subject to dialysis treatment. The answers were given in the 0–10 scale, where [zero] 0 meant "They are not solved at all" and 10 "They are completely solved". The answers were divided in three groups: 0–3 — the problems are not solved; 4–7 — they are partially solved, and 8–10 — they are properly solved. The results are shown in Table 2. They show that almost 80% of the respondents believe that dialysis patients do not receive proper psychological care and almost 90% state the same in relation to social care. Similar answers are given in relation to satisfying spiritual needs of the patients and family support.

As for the answer to the question of the responsibility for palliative care in patients with chronic renal failure, they are shown in Table 3. More than 66% of nephrologists believe that doctors and nephrology nurses should be involved in palliative care.

All the respondents have witnessed more than four deaths of dialysed patients during their professional practice. Table 4 includes the answers to the

Table 1. Opinions of nephrologists concerning the criteria of effective treatment

Criteria	Level of importance		
	1 (the most important)	2 (neutral)	3 (least important)
Biochemical parameters, e.g. Kt/V	2.7%	21.6%	75.7%
Quality of life	59.5%	35.1%	5.4%
Survival	32.4%	48.7%	18.9%

Table 2. Solving problems and providing for psychological, social and spiritual needs in dialysis patients and the level of supporting families of patients, according to nephrologists

Problems of patients	Level of support		
	Lack of support (0–3)	Average level (4–7)	Full support (8–10)
Psychological needs	47/59 (79.7%)	12/59	0/59
Social needs	53/59 (89.8%)	6/59	0/59
Spiritual needs	49/59 (83.1%)	9/59	1/59
Support for patients' families	45/59 (76.3%)	14/59	0/59

Table 3. Opinions of nephrologists concerning the specialty of doctors/nurses who should perform palliative care over nephrology patients (more than one answer is possible)

Who should carry out palliative care in nephrology patients?	Positive answers
Nephrologist/nephrology nurse	67.8%
Primary health care doctor/nurse	35.6%
Hospice/palliative medicine doctor/palliative nurse	77.8%
Psychologist	64.9%
Social worker	46%
Priest	35%

Table 4. The issue of dialysis withdrawal in Poland and opinions of nephrologists concerning the legitimacy of implementing the ethical and legal principles of withdrawing/withholding from dialysis therapy

	Yes	No	
"I made the decision to withdraw dialysis therapy as a nephrologist"	33/59 (56%)	26/59 (44%)	
	Of little importance (0–3)	**Of average importance (4–7)**	**Important (8–10)**
"The implementation of the ethical and legal principles of withdrawing/withholding fromdialysis therapy is…"	1/59 (1.7%)	9/59 (15.3%)	49/59 (83%)

Table 5. The opinion of nephrologists on the issue of introducing the module of palliative care in the nephrology specialisation curriculum and the education in it, according to the group of 22 nephrologists, who completed the survey before the lecture in comparison to the group of 37 nephrologists, who took the survey after the lecture on the role of palliative care in nephrology

The need for education	Level of importance		
	Irrelevant (0–3)	**Of average importance (4–7)**	**Required (8–10)**
Before the lecture	9/22 (40.9%)	8/22 (36.4%)	5/22 (22.7%)
After the lecture	6/37 (16.2%)	14/37 (37.8%)	17/37 (46%)
Total	15/59 (25.4%)	22/59 (37.3%)	22/59 (37.3%)

question concerning the decision on withdrawing or withholding of the dialysis therapy and the opinion on the necessity to provide ethical and legal guidelines relating to the issue. More than half of nephrologists made the decision to withdraw the dialysis therapy in patients with chronic haemodialysis and most of them think that there should be clear rules of conduct for such situations.

Table 5 presents the opinion of nephrologists on the issue of introducing the module of palliative care in the nephrology specialisation curriculum. Seventy-five percent of the respondents confirmed that such a curriculum should include training on palliative medicine aspects in relation to patients with chronic renal failure. Since some of the surveys have been completed before the convention of the Polish Society of Nephrology, which included a detailed lecture on the aspects of palliative medicine and care in nephrology, the answers have been divided into two categories: pre- and post-convention answers. The percentage of people, who were reluctant towards the introduction of the module into the specialisation curriculum, has been reduced from 40% of respondents before the lecture, to 16% after the lecture.

Discussion

The majority of nephrologists believe that palliative care is important in nephrology. They noticed the inadequacy in dialysed patients care, *i.e.* lack of psychological, social and spiritual support. In addition they also realise that patients' families are also insufficiently supported. Nephrologists are aware that patients with chronic renal failure must be provided with comprehensive support, especially in a crisis situation, including: being diagnosed with chronic renal failure, commencement of dialysis therapy, the period of 4–6 months from the beginning of dialysis therapy, long duration of treatment, characterised by the "burnout syndrome". The situations requiring extraordinary support also include: hospitalisation/surgery (including kidney transplantation), change in therapy as part of the same method/change of treatment method, complications/deterioration of health conditions, change of dialysis centre (especially transferring youngsters from child centres to centres for adults) [12].

Particularly surprising is the fact that almost 66% of the respondents believe the quality of life to be the most important criteria of optimum therapy, having in mind that today the quality of therapy is measured by biochemical indicators and the life span of patients. The interest in the quality of a patient's life has been growing since the 1980s, which is confirmed by numerous research and scientific reports [13–15]. The research on the quality of life resulted in the dissertations dealing with the evaluation of negative emotions, particularly depression [16–18]. It has been demonstrated that depression is frequent in patients receiving dialysis and its level affects their lifespan. However, in spite of numerous studies and

implementation of many surveys with a proper psychometric profile, the quality of patients' lives is rarely evaluated in clinical practice.

Nephrologists believe that they should provide the broadly understood palliative care for nephrology patients, if not by themselves, then in cooperation with palliative care teams. In view of that, it is particularly surprising that a large part of the respondents consider the training in palliative care as part of nephrology specialisation to be of little importance, or irrelevant. However, we must underline the role of education: after having heard the lecture on the aspects of palliative medicine in nephrology, more nephrologists acknowledged the necessity to put those issues in the specialisation programme. In 2003, Holley and associates published the results of surveys carried out among doctors participating in the nephrology specialisation internship [19]. Those surveys demonstrated an insufficient knowledge on the principles of supportive care, including its effect on physical, psychological, social and spiritual symptoms in patients with chronic renal failure, and a great need to supplement that knowledge. As a result of the discussions on the subject in the USA, palliative care has been included in the nephrology specialisation programme [11]. This programme includes the therapy of pain and other symptoms, procedures — the so-called "advanced care planning" — psychosocial and spiritual support for patients and their families, as well as ethical and legal aspects of refusing dialysis therapy [20]. In Great Britain, elements of palliative care — in the form of end-of-life care — were included in the nephrology curriculum as late as May 2007.

It would seem that elements of palliative care should be included in the curricula of many other specialisations. In Great Britain, this module has been included in pneumology, with attention being paid to not only patients with lung cancer, but also patients with chronic obstructive pulmonary disease and cystic fibrosis. This module is not found in the curricula of cardiology or gastroenterology, although patients with chronic heart failure, chronic inflammatory bowel or pancreas diseases require such care. Polish specialisation programmes for internal diseases, lung diseases, neurology and paediatrics include elements of palliative care, but only as part of oncological courses. Specialisation programmes for nephrology, cardiology and gastroenterology do not include education in the scope of palliative care and end-of-life problems.

The results of the survey also demonstrated that nephrologists frequently witness deaths of their patients. As for the Unites States, it has been demonstrated that an average of 17 deaths per year are pronounced in each dialysis centre, and each nephrologists is witness to at least 5 deaths resulting from dialysis withdrawal [21]. As of yet, Poland has no systematic data concerning deaths resulting from dialysis withdrawal. The present study showed that more than 50% of nephrologists have been faced with such a decision and that the majority of them believe that dialysis withdrawal should be done according to ethical and legal guidelines. The issue of stopping dialysis therapy has become an inherent part of the discussion on the definition of medical futility and the limits of life. Twenty percent of dialysed patients in the United States die as the result of dialysis withdrawal [22]. This decision is made by the patient and/or their family, in agreement with the nephrologist in the situation when cancer has propagated, and/or patients are suffering from dementia, progressing cachexia, pain resistant to treatment, which result in the worsening and unacceptable quality of life. Stopping dialysis therapy does not mean that the treatment as such is terminated or suspended, but it marks the beginning of the implementation of intensive care aimed at preventing and relieving the suffering [23, 24]. The guidelines of the Renal Physicians Association and the American Society of Nephrology concerning withdrawing or withholding dialysis therapy have been implemented in the USA. A total of nine recommendations includes the following issues: Shared decision making on the therapy method; informed consent or refusal; estimating prognosis; conflics resolutions; advance-care planning procedure — *i.e.* a written will of the patient concerning treatment in the terminal stage; the situation and groups of patients about whom the decision concerning refraining and abandoning from dialysis therapy is being considered; implementing dialysis therapy for a specified period of time, and providing professional palliative care [25]. In Great Britain, this decision is made by the patient. If they are unable to do that, it is made by a therapeutic team. Patients' families participate in the discussion concerning the issue, but they are relieved from the burden of making the decision to abandon the therapy. Polish nephrology circles have initiated a discussion on the ethical and legal aspects of such action. It would seem that the objective for the future is the integration of the activities of palliative-hospice teams and nurses and nephrologists and a joint effort to take care of those patients. Nephrologic patients should

have access to all the benefits of palliative and hospice care.

In conclusion, one must say that patients with chronic renal failure, just as any other patients with chronic and advanced disease, require palliative care, both in the period of active treatment and at the end of life. Nephrologists must be acquainted with the aspects of this care, and they must be included in specialisation programmes. Palliative care, particularly at the end of life, should be performed by a nephrologist and a specialist palliative and hospice team, with precisely defined reasons and principles of dialysis withdrawal. The concept of palliative care should be passed on, through the education about its aspects, as part of pre-diploma education. It appears that the subject of palliative care, taught in many Polish medical universities in year 6, should be preceded by classes in other subjects, which include the aspects of palliative care in patients with advanced chronic diseases. Proper communication with patients and their families, the ability to inform them about prognoses, conveying bad news, awareness of the psychosocial and spiritual problems caused by the disease, its influence on the family and the principles of care in the period of dying should become an integral part of their education on patients with chronic heart, lung or renal failure. With this system of education, we may create hope that the essential needs of chronic patients and their families are provided for, in the period from disease diagnosis, through the treatment, until death.

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