Original paper

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Organizational issues and major problems of palliative care concerning treatment of end-stage renal disease in Polish residential hospices and hospital-based palliative medicine wards

Abstract

Background. Patients diagnosed with end-stage renal disease experience a significant level of symptom burden, including pain, nausea and vomiting, inability to urinate, fatigue etc. At this point in disease progression, it is important to establish what types and choices of therapy are most suitable for these patients, in particular, the value of continuing dialysis treatment.

Material and methods. A self-administered questionnaire was distributed among Polish residential hospices and hospital based palliative medicine wards. All responses obtained underwent statistical analysis using Pearson's Chi Square test.

Results. Permanent palliative care facilities, from which 73 out of 166 registered in Poland, took part in the survey. ESRD patients were identified to be cared by 81% of the aforementioned institutions. The most common treatment approach for these patients was highlighted as conservative treatment (68%), followed by hemodialysis (47%), whereas merely 11% provided peritoneal dialysis. Differences between facilities were identified relating to therapeutic recommendations for terminal ESRD patients with residential hospices more likely to recommend dialysis in conjunction with palliative care, whereas palliative wards advocated a withdrawal from dialysis followed by the initiation of palliative care.

Conclusion. All surveyed facilities considered ESRD patients eligible for guaranteed hospice and palliative care services. However, certain changes are needed to improve care for ESRD patients, including: the development of collaborative partnerships between hospices, dialysis centers and nephrologists, development of guidelines for withdrawing dialysis and applying conservative treatment, introducing better renal-based training for medical personnel as well as the introduction of transparency within rules relating to the financing of these services.

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Key words: end-stage renal disease, palliative care, hospice care, withholding treatment, hospices, dialysis

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Introduction

Chronic kidney disease (CKD) is a significant public health issue, with a growing incidence, attributed to an ageing population as well as an ever-increasing number of chronically ill individuals [1]. In Poland, the number of patients suffering from CKD has already exceeded 10% of the country's population [2]. As a condition associated with a high burden of illness as well as premature mortality, treatment provided to patients aims to provide the most benefit to quality of life [1]. According to the Report on Renal Replacement Therapy in Poland, in 2011, 21.956 people were provided with renal replacement therapy [3]. As of Dec 31st 2011, 17.963 patients had received hemodialysis or peritoneal dialysis (92.4% and 7.6%, respectively), whilst 1042 patients underwent renal transplantation [3, 4]. There is insufficient investigation data and research in Poland concerning the number of end-stage renal disease (ESRD) patients who either did not undergo renal replacement therapy or stopped receiving it. In those cases the most common form of therapy is conservative treatment.

As an alternative to dialysis-based therapy, the application of the 'conservative' approach in ESRD patients is gaining more interest [5]. Comprising of non-dialytic management of the condition, this form of treatment corresponds to palliative care, which is often regarded to be the most appropriate care setting for ESRD patients [6, 7]. The sole purpose of this type of therapy is focused on improving and maintaining patient's best possible quality of life, rather than prolonging a patient's life at all cost [8]. This is achieved through effective, individualized symptomatic treatment, consisting of good pain management, and the minimization of other burdensome symptoms, as well as providing patients and their families with psychosocial and spiritual support [9]. Furthermore, careful attention to fluid balance, blood pressure, acidosis, anaemia as well as dietary modifications have been recognized as important elements of this form of therapy [5]. A study by Lichodziejewska-Niemierko highlights that palliative care is required not only during the final stages of ESRD, but also during the period of active treatment, regardless of the type of individualized therapy [10]. Despite this fact, currently in Poland, the diagnosis of ESRD in an adult does not guarantee a patient with palliative and hospice care. However, this type of care is possible for children diagnosed under the age of eighteen.

In Poland there are no studies exploring the types of therapies provided to ESRD patients in hospice and palliative care. Furthermore, to our knowledge, there are no studies on a worldwide scale that investigate differences between ESRD patient care provided within residential hospices and hospital-based palliative medicine wards. Therefore, the purpose of this study is to address these gaps in knowledge and provide an insight into hospice and palliative care in patients with ESRD in Poland.

Material and methods

A self-administered, anonymous survey was distributed among hospices and palliative care units in Poland. This survey was designed on the basis of both specialist literature and the authors' own experience. The survey, along with a cover letter, was sent by mail to all residential hospices (n = 93) and hospital-based palliative medicine wards (n = 73) registered in the Polish Health Care Units Register (total = 166). The survey was asked to be completed by a representative of each unit and only one survey was completed per facility.

All data analysis was performed using STATISTICA Version 10 software (StatSoft, Inc., 2011). Pearson's Chi-square Test and was used to compare variables of interest.

Results

Overall, a total of 73 units participated in the study, with a survey response rate of 44%. The responses came from representatives of 42 stationary hospices and 31 palliative medicine wards.

Units treating esrd patients

It was found that 81% of all units surveyed treated patients with ESRD (n = 59), comprising 37 residential hospices (88%) and 22 hospital-based palliative medicine wards (71%). No statistically relevant differences were observed between the number of units taking care of ESRD patients ($p = 0.07$).

Per annum, more than half of surveyed institutions (37) reported that they cared for between 1 and 5 ESRD patients, 10 units (14%) admitted between 5 and 10 patients, 5 (7%) treated between 10 and 20 ESRD patients and 6 (8%) looked after between 20 and 50. The majority of surveyed units caring for ESRD patients did so in collaboration with a dialysis center. Alternatively, more than one third of facilities acted independently, making use of their own available methods and resources (Tab. 1).

Types of treatment

In terms of the types of therapeutic options offered and provided to ESRD patients in residential hospices and palliative wards, it was found that conservative management was applied in 68% of units, hemodialysis in 47% and only 11% of surveyed

Table 1. Cooperation between nephrologists and residential hospices/palliative medicine wards offering treatment to ESRD patients

While taking care of patients with ESRD the unit	residential hospices n = 42	hospital-based palliative medicine wards n = 31	total n = 73
collaborated with a dialysis center	27 (64%)	13 (42%)	40 (55%)
acted independently, making use of available methods and resources	14 (33%)	12 (39%)	26 (36%)
consulted patient's case with a nephrologist	15 (36%)	8 (26%)	23 (32%)
collaborated with a hospital nephrology ward	11 (26%)	7 (23%)	18 (25%)
no response	5 (12%)	9 (29%)	14 (19%)

Table 2. Treatment options for patients with ESRD in inpatient palliative care facilities

Treatment options	residential hospices n = 42	hospital-based palliative medicine wards n = 31	total n = 73
conservative management	30 (71%)	20 (65%)	50 (68%)
hemodialysis	20 (48%)	14 (45%)	34 (47%)
peritoneal dialysis	6 (14%)	2 (7%)	8 (11%)
no response	6 (14%)	9 (29%)	15 (20%)

Table 3. Medical strategies towards dialysis patients in terminal state recommended by the respondents

Medical strategy	residential hospices n = 42	hospital-based palliative medicine wards n = 31	total n = 73
providing the patient with palliative care and continuous dialysis	39 (93%)	21 (68%)	60 (82%)
withdrawal from dialysis and initiation of palliative care	1 (2%)	9 (29%)	10 (14%)
continuing dialysis without providing palliative care	2 (5%)	1 (3%)	3 (4%)

institutions utilized peritoneal dialysis. However, when used, peritoneal dialysis was employed by twice as many residential hospices as palliative medicine wards (Tab. 2). Nevertheless, in this area no statistically relevant discrepancies between residential hospices and hospital-based palliative medicine wards were observed ($p > 0.05$).

Participants were asked for their opinions on the types of treatment they believed should be provided to ESRD patients. Respondents from 63 (86%) facilities, made up of 35 residential hospices (83%) and 28 palliative medicine wards (90%), expressed the need to offer ESRD patients palliative care. Alternatively, 4 (10%) residential hospices and 1 (3%) palliative medicine ward disagreed. Opinions on this matter differed slightly, depending on the type of institution. However, no statistically relevant differences were observed between residential hospices and palliative medicine wards ($p = 0.49$). Furthermore, when questioned about therapy recommendations for terminal ESRD patients, palliative care and continuous dialysis therapy were the most frequently suggested therapeutic approaches, with significant statistical discrepancies between residential hospices and palliative medicine wards ($p = 0.005$) (Tab. 3). For non-dialyzed ESRD patients, 47 units (64%) advocated the provision of palliative care in accompaniment with conservative treatment of ESRD, whereas almost one third of respondents suggested the implementation of palliative care along with the initiation of dialysis. Regarding the former medical strategy, the provision of palliative care with only conservative treatment was observed more often in hospital-based palliative medicine wards than in residential hospices ($p = 0.04$) (Tab. 4).

Table 4. Medical strategies towards non-dialyzed ESRD patients in terminal state recommended by the respondents

Medical strategies	residential hospices n = 42	hospital-based palliative medicine wards n = 31	total n = 73
providing the patient with palliative care accompanied by conservative treatment	23 (55%)	24 (78%)	47 (64%)
providing the patient with palliative care along with initiation of dialysis	17 (40%)	6 (19%)	23 (32%)
conservative treatment without providing the patient with palliative care	2 (5%)	1 (3%)	3 (4%)
initiation of dialysis at a nephrological care facility without providing the patient with palliative care	0 (0%)	0 (0%)	0 (0%)

Patient expectations of care

Nearly half of respondents highlighted that ESRD patients expected dialysis therapy and other medical actions aimed at the prolongation of life to be continued until the end of life, and 70% maintained that patients families also expected this approach to be undertaken. Respondents identified that in their experience, 33% of patients and 14% of patient families preferred to undertake a conservative form of therapy, comprising withdrawal from dialysis and symptomatic treatment i.e. pain alleviating measures and minimization of other burdensome symptoms. There were major statistical differences ($p = 0.00000$) found when comparing opinions on the expectations of ESRD patients and those of their families (Tab. 5).

Specialised nephrology training for medical personnel

Overall, it is apparent that the performance of specialized nephrological training for health care professionals in these care settings was not highly implemented. Physicians were more likely to hold nephrological training than other health care professionals, with 13 of the 73 (18%) surveyed units employing physicians holding a completed course or training in hemodialysis and 11 of 73 (15%) in peritoneal dialysis. There were even less specially trained nurses, with only 7% and 6% (n = 5.4) of units respectively employing nurses with qualifications in hemodialysis and peritoneal dialysis.

However, nearly 90% of respondents acknowledged a need for the provision of training for medical personnel in residential hospices and palliative medicine wards on nephrology-based topics. Answers in the affirmative consisting of 'yes' and 'rather yes' were provided by 34 (47%) and 31 (42%) respondents respectively, whereas 2 (3%) decided that there was no need for training, and further 4 (6%) highlighted that they did not want such courses.

Barriers and changes needed to improve care

The most frequently mentioned barrier to providing care to ESRD patients in Polish residential hospices or palliative medicine wards related to the

Table 5. Expectations of ESRD patients and their families at residential hospices and hospital-based palliative medicine wards towards medical strategies

Expectations of patients and their families concerning medical strategies	residential hospices n = 42		hospital-based palliative medicine wards n = 31		Total n = 73	
	patients	families	patients	families	patients	families
continuing dialysis and other medical actions aiming at life prolongation until the end of life	24 (57%)	31 (74%)	12 (39%)	20 (64%)	36 (49%)	51 (70%)
withdrawal from dialysis and focusing instead on pain alleviating measures along with combating other burdensome symptoms	13 (31%)	7 (17%)	11 (35%)	3 (10%)	24 (33%)	10 (14%)
no response	5 (12%)	4 (9%)	8 (26%)	8 (26%)	13 (18%)	12 (16%)

Table 6. Major obstacles related with providing care to ESRD patients by residential hospices or palliative medicine wards

Obstacles related with providing care to ESRD patients	residential hospices n = 42	hospital-based palliative medicine wards n = 31	total n = 73
difficulties related with settling the financial costs with the National Health Fund	21(50%)	22 (71%)	43 (59%)
lack of specialist knowledge and/or qualifications of the facility's personnel	15 (36%)	12 (39%)	27 (37%)
lack of specialist equipment	15 (36%)	9 (29%)	24 (33%)
insufficient support from nephrologists, dialysis centers or hospital nephrology wards	7 (17%)	7 (23%)	14 (19%)
personnel's unwillingness to treat and nurse ESRD patients	2 (5%)	0 (0%)	2 (3%)
other	10 (24%)	7 (23%)	17 (23%)
no response	2 (5%)	2 (7%)	4 (6%)

settling of financial costs of such care with the National Health Fund, followed by a lack of specialized knowledge related to the care of ESRD patients and a lack of specialized equipment (Tab. 6).

When considering changes needed to improve care provided to ESRD patients, the most urgently perceived need related to the development and implementation of a collaborative partnership between institutions and hospices specializing in caring for ESRD patients (71% of all facilities). Additionally, 68% of respondents highlighted a need for greater transparency amongst regulations set by the National Health Fund, specifically those that govern the financing of services. Another recommendation indicated by 66% of units emphasized the need for organized professional training for personnel or the broadening of current palliative medicine programs to include topics related to the treatment of ESRD patients. Furthermore, 44% of units proposed the organisation of information campaigns for nephrological patients and their families relating to the possibility of receiving hospice and palliative care services.

Discussion

To our knowledge, this is the first form of scientific research that has been dedicated to exploring the type of hospice and palliative care provided to ESRD patients in Poland. Furthermore, this is the first national survey to take into account discrepancies occurring between residential hospices and palliative medicine wards. However, the obtained results do not concern all existing units, therefore they should be interpreted with caution. Naturally, there are pre-existing significant differences between hospices and palliative care wards, particularly when considering their organizational structure. Hospices are generally independent health care institutions, whilst the latter are hospital wards. Nevertheless, the scope and conditions of care services provided to patients are comparable across both types of facilities.

The study has demonstrated that the majority of Polish hospice and palliative care facilities recognize a need to provide care to ESRD patients. This is an important finding, as currently in Poland, the diagnosis of end-stage renal disease does not constitute sufficient basis for providing adult patients with hospice and palliative care. This study has highlighted that despite this, the facilities surveyed do in fact provide care to ESRD patients, albeit a small number. It is noted ,however, that the admittance of these patients to a residential hospice or palliative medicine ward depends on the co-occurrence of a disease (co-morbidity), which then entitles a patient to care. One such comorbidity is cancer, which in 2010 was responsible for 6.6% of deaths among dialysis patients in Poland [3]. All ESRD patients who died of cancer were entitled hospice and palliative care services during the final stages of their lives. Therefore, palliative care in Poland, unlike in Great Britain, is only available to ESRD patients under certain circumstances and not in conjunction with renal replacement therapy [11]. However, ESRD patients cared for at inpatient hospice and palliative care facilities who qualify for dialysis are eligible for publically-financed hemodialysis and peritoneal dialysis services provided by dialysis centers. In comparison, in the United Kingdom, once a patient is diagnosed with ESRD, they are able to be admitted to a hospice and are offered palliative care. Alternatively, ESRD patients treated within a hospital are

entitled to specialist services provided by a palliative care team [12]. Although in Poland these supporting teams are mentioned in legal regulations, with rare exceptions they are largely non-existent due to the lack of financing from the National Health Fund [13, 14]. This provides reasoning for the limited number of ESRD patients cared for by the surveyed institutions.

The findings of the study also identified a high ratio of conservative treatment compared to renal replacement therapy performed for ESRD patients. This indicates that for the majority of ESRD patients admitted to inpatient hospice and palliative care facilities, dialysis therapy was either never initiated or was terminated. As such, these results justify the establishment of reliable standards to guide conservative treatment provided to ESRD patients nearing the end of life, as suggested by Murtagh and her colleagues [15]. Interestingly, there was a discrepancy among the therapy recommendations suggested by residential hospices and palliative medicine wards. The most frequently recommended medical strategy in residential hospices for terminal dialysis patients, was the provision of palliative care in conjunction with continuous dialysis therapy. Alternatively, nearly one third of respondents from palliative medicine wards advocated the withdrawal from dialysis followed by the initiation of palliative care. Furthermore, respondents revealed that patients at residential hospices are much more likely to expect continuing dialysis and other life prolongation medical activities than those cared for at palliative medicine wards. Therefore, a conclusion can be drawn that dialysis is applied far more frequently at residential hospices than at palliative medicine wards.

The high percentage of participants who supported the continuation of dialysis in terminal patients may be attributed to the lack of specific guidelines related to the withdrawal of renal replacement therapy in Poland [16]. Doctors' unwillingness to terminate previously initiated dialysis therapy can also stem from the fact that there are no clear legal rules pertaining to this issue. It is worth mentioning that in accordance with the current law, a physician has no right to initiate renal replacement therapy without the patient's consent or in the face of the patient's strong opposition to this form of care. In cases where dialysis has already been introduced, only the patient's own objection to this therapy may exempt the physician from continuing. In all remaining cases — for example when a patient is unconscious or unable to express objection due to other causes — terminating renal replacement therapy entails the risk of rendering the physician liable to prosecution. In light of the above reasons, withdrawal from dialysis is not usually part of the medical strategy recommended to ESRD patients in a terminal state, although this option should also be made available to them [17]. Despite the abovementioned difficulties and expectations, the decision to reject or withdraw dialysis therapy in palliative ESRD patients is a commonplace practice, as evidenced by the scale of conservative treatment use.

The patient's right to withdraw from renal replacement therapy or to reject it altogether is observed in France, Canada, the United States and the United Kingdom, where the legal situation is not as complicated as it is in Poland. In the United States and France, withdrawal from dialysis is the cause of one in five deaths of dialysis patients, and is experienced by both nephrologists and general practitioners [18, 19]. In the United Kingdom the law draws attention to the patient's right to choose between continuing or withdrawing from dialysis therapy, while simultaneously offering support in the form of hospice and palliative care to both the patients and their families [20]. In Canada almost one fifth of deaths among patients receiving dialysis are caused by withdrawal from dialysis, and the decision to discontinue renal replacement therapy is most often determined by the patient's psychosocial condition or the development of cancer [21].

When considering any differences between hospices and palliative wards, it was found that patients in residential hospices underwent dialysis more often than those in palliative medicine wards. This can be attributed to the fact that the location of the palliative unit within the hospital structure was not necessarily conducive to the running of hemodialysis, due to the hospital running their own dialysis centers in a separate wing. The need to transport a patient from a hospice to an institution providing renal replacement therapy, (which can be an additional burden for the patient), was not seen to negatively affect the level of dialysis performance in residential hospices in comparison to palliative medicine wards. There is a similar relationship observed between the type and scope of collaboration between the surveyed institutions and nephrology units. Residential hospices were found to work in partnership with dialysis centers and nephrologists more frequently than palliative medicine wards, which typically operated independently. This need for a teamwork approach between palliative and nephrological care facilities is supported by a study conducted by Hobson et al. in the United Kingdom [12].

Participants described the types of barriers present in the current Polish system that limited care to ESRD patients. The most commonly reported issue related to the difficulties experienced with settling financial costs attributed to care with the National Health Fund. Other barriers identified included the lack of specialist renal knowledge and qualifications of per-

sonnel working in these facilities, as well as the lack of support from nephrological care institutions. Despite these barriers, inpatient hospice and palliative care institutions have demonstrated that they are ready to provide their services to ESRD patients. It is apparent, however that this could only become a reality subsequent to the introduction of legislative changes surrounding patient eligibility for hospice and palliative care services and the financing of this type of care from public resources.

The study has also identified the need for several changes to be implemented to improve the care of ESRD patients. Participants requested the development and establishment of a collaborative partnership between institutions specializing in treating ESRD patients and hospice and palliative care units (representatives of palliative medicine wards employees acknowledged this to a lesser degree than their residential hospice counterparts). Additionally, the introduction of greater transparency within the regulations set by the National Health Fund governing the financing of health services was commonly highlighted by participants — this was stressed more strongly by palliative medicine wards than by residential hospices. Both surveyed groups also equally supported the idea of organizing professional training sessions for medical personnel, and broadening the existing palliative medicine courses to include topics related to the treatment of ESRD patients.

This research has shown that the majority of the surveyed medical managers of wards in palliative care institutions, who are usually doctors by profession, advocate the provision of continuous dialysis to terminal patients. This perspective seems to oppose the principles of palliative care. When considering a terminal ESRD patient in a palliative care institution with significant symptom burden, the validity of continuing dialysis must be taken into account. The foremost concern when caring for ESRD patients, should be to improve and maintain the best possible quality of life [5]. Persisting with medical strategies aimed at prolonging life, violate the patients right to a peaceful and dignified death. As such, any therapeutic recommendations should seek to uphold this principle and promote an appropriate level of patient care.

Conclusions

The majority of surveyed facilities recognized the need to provide ESRD patients with guaranteed hospice and palliative care services. Current legislation and legal regulations that govern the financing of health care services in Poland were considered to be a major barrier to the provision of appropriate palliative care to terminal ESRD patients. Therefore, it is essential to introduce changes within the law to improve the financing health services from the public sector. Respondents also identified other changes needed to improve care for ESRD patients including: the need for implementing a collaborative partnership between hospices, dialysis centers and nephrologists, as well as the provision of specialist renal-based training of medical personnel. Furthermore, it was recognized that there is a need to establish standards or medical practice relating to withdrawal from dialysis and implement a conservative treatment. Further investigation is needed to develop appropriate care guidelines for ESRD patients and to promote the provision of appropriate palliative care services to this patient group.

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