

Original Article

Unmet Palliative Care Needs Among Patients With End-Stage Kidney Disease: A National Registry Study About the Last Week of Life

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Abstract

Context. End-stage kidney disease (ESKD) is characterized by high physical and psychological burden, and therefore, more knowledge about the palliative care provided close to death is needed.

Objectives. To describe symptom prevalence, relief, and management during the last week of life, as well as end-of-life communication, in patients with ESKD.

Methods. This study was based on data from the Swedish Register of Palliative Care. Patients aged 18 or older who died from a chronic kidney disease, with or without dialysis treatment (International Classification of Diseases, Tenth Revision, Sweden; N18.5 or N18.9), during 2011 and 2012 were selected.

Results. About 472 patients were included. Of six predefined symptoms, pain was the most prevalent (69%), followed by respiratory secretion (46%), anxiety (41%), confusion (30%), shortness of breath (22%), and nausea (17%). Of patients with pain and/or anxiety, 32% and 44%, respectively, were only partly relieved or not relieved at all. Of patients with the other symptoms, a majority (55%–84%) were partly relieved or not relieved at all. End-of-life discussions were reported in 41% of patients and 71% of families. A minority died in specialized palliative care: 8% in hospice/inpatient palliative care and 5% in palliative home care. Of all patients, 19% died alone. Bereavement support was offered to 38% of families.

Conclusion. Even if death is expected, most patients dying with ESKD had unmet palliative care needs regarding symptom management, advance care planning, and bereavement support. *J Pain Symptom Manage* 2018;55:236–244. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Dialysis, end of life, end-stage kidney disease, palliative care, registries, symptom

Introduction

The World Health Organization emphasizes the need for palliative care, comprising symptom management, team work, communication, relationships, and

family support. Palliative care aims to prevent and relieve suffering and enhance the quality of life of patients with a life-threatening illness, such as end-stage kidney disease (ESKD), and it can be combined with treatment aimed to prolong life,¹ for example, dialysis

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treatment. Patients with ESKD whether on conservative care (no dialysis) or on dialysis suffer from a variety of symptoms; for example, pruritus, pain, fatigue, sleep disturbance, nausea, muscle cramp, restless legs, anorexia, depression, and dyspnea.^{2–4} Many patients are old and have a multiplicity of comorbidities that add to their illness situation. The associated mortality is high even when the patients are on dialysis, about 20% annually.⁵ A review shows that for elderly patients starting dialysis (undifferentiated), one-year survival is about 73% and five-year survival is about 35%.⁶ It is problematic to predict end-of-life trajectories for patients with ESKD,^{7,8} but mortality rates imply that many patients with ESKD are living their last year of life. Hence, these patients will need discussions on prognosis and end of life to be able to make decisions and plan for end of life according to their personal values.⁹ Their trajectory may also involve decision making regarding withholding or withdrawing dialysis. A review of patients' and family members' perspectives of end-of-life care in chronic kidney disease highlights their situation with for example growing physical and psychosocial suffering, personal vulnerability, relational responsibilities, and existential issues.⁹ Regardless of their complex situation that highlights the need for palliative care, this is an approach that is seldom offered to patients with ESKD,^{10–12} although it is increasingly stressed internationally that palliative care should be integrated into nephrology care.¹³

With the goal to improve end of life for patients with ESKD, it is important to explore what end-of-life care they and their families' receive. There is a need for further comprehensive studies describing the care situation and key components of palliative care activities for this group of patients when close to death. Therefore, the aim of the present study was to describe end-of-life care of patients with ESKD in terms of symptom prevalence, relief, and management during the last week of life, as well as aspects of end-of-life communication for patients and families.

Methods

Design

This registry study is based on data from the Swedish Register of Palliative care (SRPC) (<http://palliativ.se>). The SRPC is a national quality register for end-of-life care for all deaths in Sweden, irrespective of diagnosis or health care setting. The goal of the SRPC is to improve quality of care for all people dying an expected death.^{14,15} The basis for the development of the register was the principles for end-of-life care put forward by the British Geriatrics Society, demanding, for example, competent symptom management and open end-of-life communication.¹⁶

The register includes a web questionnaire that contains information about care interventions associated to key components of palliative care in the last week of life. However, the questions about end-of-life discussions and the last expressed wish for place of death are not necessarily related to the last week of life. The responsible physician and/or registered nurse at the health care setting of the patient's death complete the questionnaire after the patient's death. The registered information is based on medical records, together with health care professionals' recalled memories of the care period during the patient's last week of life.

Study Population and Data Collection

To be included, patients had to be 18 years or older with a diagnosed chronic kidney disease according to the diagnosis registry International Classification of Diseases, Tenth Revision, Sweden (ICD-10-SE) (N18.5 or N18.9) by the Swedish National Board of Health and Welfare, which is a national interpretation of the international diagnosis registry ICD-10, reported by physicians as the mortality reason and/or underlying cause of death. Furthermore, the death of the patient had to be registered as expected in the SRPC. The Swedish Causes of Death Certificate Register (the Swedish National Board of Health and Welfare), which covers all deaths in Sweden, was used to ascertain identification of deaths of patients with chronic kidney disease corresponding to the inclusion criteria during the data collection period. Data between January 1, 2011 and December 30, 2012 were used. In 2011, 53% ($n = 47,670$) and in 2012, 62% ($n = 57,031$) of all deaths in Sweden were registered in the SRPC.

Variables

Background variables for the study sample included sex, age, place of death, and number of days enrolled to the health care setting of death. Place and/or health care setting of death was categorized into general home care, specialized palliative home care, nursing home (i.e., short- and long-term care facilities), hospital ward, hospice/inpatient palliative care, and other. Number of days enrolled at the care setting of death was categorized into 0–3, 4–14, 15–30, 31–365, and more than 365 days.

The study variables included the presence and relief of six predefined symptoms (pain, nausea, anxiety, respiratory secretion, shortness of breath, and confusion), the use of validated scales for symptom assessment (e.g., numeric rating scales), individual injection prescriptions as needed (pro re nata) for symptom relief (pain, nausea, anxiety, and respiratory secretion), consultation from other health care specialists (e.g., palliative care or pain management) for

symptom relief, end-of-life discussions with patients and/or family members, whether the patient's preference of place of death was met, bereavement support offered to family members, and having someone present at the moment of death. Prevalence and relief of each symptom were reported in the categories: *not present, totally relieved, partly relieved, not relieved at all, or do not know*. The other questions were reported in categories: *yes, no, or unknown*.

Data Analysis

Descriptive statistics were used to present background characteristics and study variables. Data were analyzed with STATA 14.1 (StataCorp LP, College Station, TX).

Results

Sample

A total of 472 patients with chronic kidney disease were included, of whom 188 (40%) were women and 284 (60%) were men. The mean age was 82.2 years (SD 8.7). Most patients (52%) had been enrolled for less than one month to the care setting of death and 13% for a very short period (zero to three days) (Table 1). Most (89%) of all the patients died in institutional care settings, of which 45% died in nursing homes (long-term 33% and short-term 12%). Thirty-five percent died in a hospital ward, and 8% died in a hospice/inpatient palliative care unit (Table 1).

Table 1
Background Characteristics (n = 472)

Background Variable	All Patients
Age, mean (SD) [range]	82.2 (8.7) [38–101]
Age categories, n (%)	
18–49	3 (0.6)
50–79	145 (30.7)
80 and older	324 (68.6)
Sex, n (%)	
Women	188 (39.8)
Men	284 (60.2)
Diagnosis (according to ICD-10-SE), n (%) ^a	
N18.5 chronic kidney disease, Stage V	19 (4.0)
N18.9 chronic kidney disease, unspecified	453 (96.0)
Place of death, n (%)	
General home care	26 (5.5)
Specialized palliative home care	25 (5.3)
Nursing home, short-term care facility	57 (12.1)
Nursing home, long-term care facility	157 (33.3)
Hospital ward	167 (35.4)
Hospice/inpatient palliative care	37 (7.8)
Other	3 (0.6)
Number of days enrolled to care unit, n (%)	
0–3	63 (13.4)
4–14	120 (25.4)
15–30	64 (13.6)
31–365	111 (23.5)
>365	114 (24.2)

ICD-10-SE = International Classification of Diseases, Tenth Revision, Sweden.
^aUnderlying cause of death and/or mortality reason.

Symptom Prevalence, Relief, and Management

According to registry reports by health care professionals, all six predefined symptoms in the questionnaire were prevalent during the last week of life. Pain was most frequently reported (69%), followed by respiratory secretion (46%), anxiety (41%), confusion (30%), shortness of breath (22%), and nausea (17%). Uncertainty about symptom prevalence was most frequent for anxiety (16%) (Table 2).

Reported symptom relief was highest for pain and anxiety. Despite this, 32% of patients with pain and 44% of patients with anxiety were only partly relieved or not relieved at all. Relief was lower for the other symptoms, with most patients being only partly relieved or not relieved at all: confusion 84%, nausea 62%, respiratory secretion 56%, and shortness of breath 55% (Fig. 1).

The reported use of validated scales for symptom assessment was low. For assessment of pain, validated scales (e.g., numeric rating scales) were used on one or more occasion in 14% of patients. For the other symptoms, the use was 9%. Individual prescriptions for injections as needed (pro re nata) for symptom relief (reported for pain, nausea, anxiety, and/or respiratory

Table 2
Symptom Prevalence During the Last Week of Life (n = 472)

Study Variable	All Patients, n (%)
Pain, n (%)	
No	118 (25.0)
Yes, but totally relieved	222 (47.0)
Yes, partly relieved	105 (22.3)
Yes, not relieved at all	0 (0.0)
Unknown	27 (5.7)
Respiratory secretion, n (%)	
No	243 (51.5)
Yes, but totally relieved	96 (20.3)
Yes, partly relieved	120 (25.4)
Yes, not relieved at all	3 (0.6)
Unknown	10 (2.1)
Anxiety, n (%)	
No	204 (43.2)
Yes, but totally relieved	109 (23.1)
Yes, partly relieved	84 (17.8)
Yes, not relieved at all	2 (0.4)
Unknown	73 (15.5)
Confusion, n (%)	
No	264 (55.9)
Yes, but totally relieved	22 (4.7)
Yes, partly relieved	79 (16.7)
Yes, not relieved at all	40 (8.5)
Unknown	67 (14.2)
Nausea, n (%)	
No	325 (68.9)
Yes, but totally relieved	31 (6.6)
Yes, partly relieved	48 (10.2)
Yes, not relieved at all	2 (0.4)
Unknown	66 (14.0)
Shortness of breath, n (%)	
No	343 (72.7)
Yes, but totally relieved	46 (9.8)
Yes, partly relieved	53 (11.2)
Yes, not relieved at all	3 (0.6)
Unknown	27 (5.7)

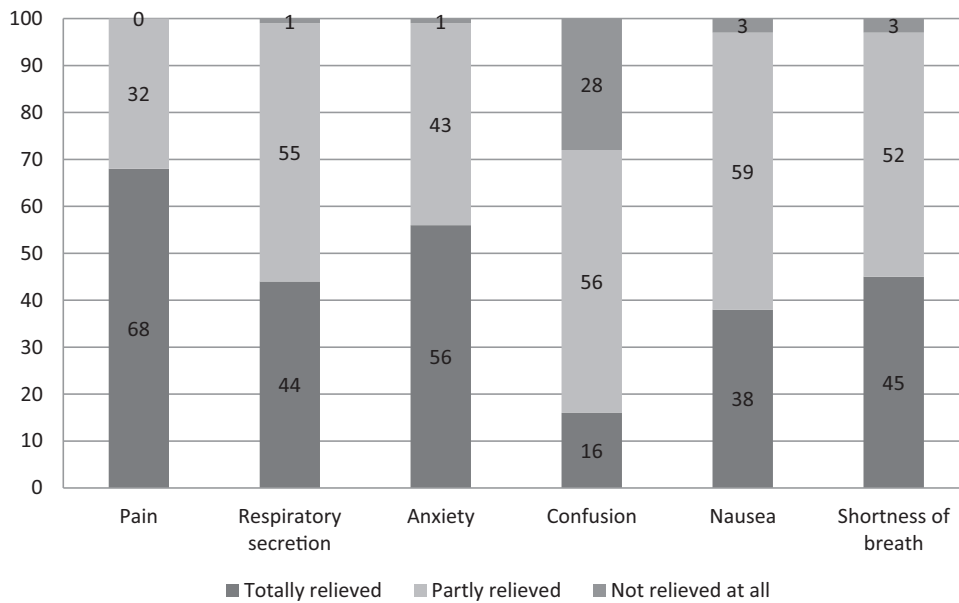


Fig. 1. Relative frequencies (%) of symptom relief among patients with reported symptom prevalence.

secretion) were common and varied between 80% (respiratory secretion) and 90% (pain). During the patient’s last week of life, external expertise in symptom relief was consulted for one-fifth (22%) of the patients (Table 3).

Table 3
Symptom Management During the Last Week of Life
(n = 472)

Study Variable	All Patients
Pain assessment with validated scales, n (%)	
Yes	67 (14.2)
No	364 (77.1)
Unknown	41 (8.7)
Symptom assessment with validated scales other than pain, n (%)	
Yes	42 (8.9)
No	377 (79.9)
Unknown	53 (11.2)
Individual injection prescription, PRN ^a , for symptom relief, n (%)	
Pain (opioids)	
Yes	425 (90.0)
No	39 (8.3)
Unknown	8 (1.7)
Respiratory secretion	
Yes	377 (79.9)
No	85 (18.0)
Unknown	10 (2.1)
Anxiety	
Yes	359 (76.1)
No	99 (21.0)
Unknown	14 (3.0)
Nausea	
Yes	272 (57.6)
No	179 (37.9)
Unknown	21 (4.5)
Consultation of external competence for symptom relief, n (%)	
Yes	103 (21.8)
No	345 (73.1)
Unknown	24 (5.1)

^aPRN = pro re nata, that is medication prescribed to be taken when required.

End-of-Life Communication and Having Someone Present at Death

End-of-life discussions with a physician were reported in 41% of patients and 71% of family members. Whether end-of-life discussions were performed or not was reported as unknown in 22% of patients and 13% of families. The patient’s preference for place of death was reported as met in 41% and unmet in 3%. However, 56% was reported as unknown (Table 4).

Table 4
Aspects of Communication and Presence at Death
(n = 472)

Study Variable	All Patients
End-of-life discussion with patients, n (%)	
Yes	193 (40.9)
No	177 (37.5)
Unknown	102 (21.6)
End-of-life discussion with family members, n (%)	
Yes	335 (71.0)
No	69 (14.6)
Unknown	59 (12.5)
No family members reported	
	9 (1.9)
Someone present at the moment of death, n (%)	
No	88 (18.6)
Health care professionals	136 (28.8)
Family members	164 (34.8)
Health care professionals and family members	74 (15.7)
Unknown	10 (2.1)
Patient’s preference for place of death was met, n (%)	
Yes	192 (40.7)
No	15 (3.2)
Unknown	265 (56.1)
Bereavement support offered family members, n (%)	
Yes	179 (37.9)
No	144 (30.5)
Unknown	140 (29.7)
No family members reported	9 (1.9)

About one-fifth (19%) of the patients died alone, whereas 51% had family members or family and health care professionals present. Health care professionals alone were present in 29% of patients' deaths (Table 4).

Bereavement support was reported to have been offered (one to two months after the death of the patient) to 38% of family members, whereas 31% had not been offered bereavement support and 30% was reported as unknown (Table 4).

Discussion

This registry study contributes to the growing literature on unmet palliative care needs of patients with ESKD and stresses that areas in which palliative care needs to be improved for these patients include symptom assessment and management, communication about end-of-life care including preferred site of death, and bereavement support.

The high symptom prevalence reported by clinicians is in line with earlier findings of a high symptom burden in patients with advanced kidney disease.^{2,4} However, the SRPC comprises only six predefined symptoms, which means that other symptoms that are common for patients with advanced kidney disease may have been present. For instance, a study of patients with ESKD managed without dialysis showed that lack of energy, pruritus, drowsiness/somnolence, and concentration difficulties were the most prevalent and distressing symptoms besides the SRPC included shortness of breath and pain. Notably, the average number of self-reported symptoms during the last month of life was as many as 20,¹⁷ pointing to significant interindividual variability in symptom patterns among dying people.¹⁸

Murtagh et al.¹⁷ found that in the last month of life, pain was reported by 73%. Also in the present study, the prevalence of pain was high. Moreover pain was reported as the most prevalent symptom, and about one-third of patients with pain were only partly relieved. Known reasons for pain are mineral bone disease secondary to chronic kidney disease and peripheral neuropathy but also comorbid conditions as, for example, peripheral artery disease. Moreover, some kidney diseases and also the dialysis treatment in itself may cause pain. The management of pain is complex (e.g., because of the risk of drug accumulation and the effect of dialysis treatment on pharmacokinetics) and requires more attention both clinically and in research.¹⁹ Importantly, severe pain is found to be one reason why patients consider hemodialysis withdrawal.²⁰ Bereaved family members²¹ have also described severe pain as an explanation for patients' decisions to withdraw dialysis. It should also be noted that besides pain, nausea and shortness of breath were also more prevalent in the study by Murtagh

et al.¹⁷ One explanation for this could be that symptoms were self-reported by patients in their study. There were also differences in the data collection periods (last week vs. last month) and treatment of kidney disease (in the present study, ESKD treatment was not specified).

Most importantly, our results show that validated symptom assessments seldom were used. Similarly, previous studies show that symptoms are underestimated and undertreated in renal care.^{22–24} This addresses a need for better symptom management. The use of validated assessment scales in clinical practice may contribute to an increased communication between patients and health care professionals.²⁵ Thus, regular assessment of symptom prevalence, intensity, and relief with validated scales combined with person-centered dialogues should be an important part of both early and late renal palliative care, as this could contribute to enhanced well-being at the end of life. For example, Edmonton Symptom Assessment System Revised: Renal (ESAS-r: renal)²⁶ and The Palliative Care Outcome Scale-Renal²⁷ are validated instruments recommended by the Kidney Disease: Improving Global Outcomes.¹³

Although death was reported as expected, end-of-life discussions with physicians were conducted with only about two-fifths of patients, whereas end-of-life discussions with family members were more common. More frequently reported discussions with family members may indicate that they were conducted in a late phase when the patient was too ill to participate in the discussion and decision making. In accordance with the present findings, lack of communication about the future and the end of life has also been described in interviews with patients or relatives.^{28–30} A survey showed that less than 10% of patients with kidney disease had partaken in a conversation about these matters with their nephrologist.³¹ Reasons for discussions with patients not taking place could be lack of shared decision-making processes together with prognostic uncertainty. Therefore, the approach of end of life may not be acknowledged, and patients are then less likely to receive the end-of-life care they wish for. However, there are tools such as the surprise question that aim to identify patients who may be nearing end of life.^{32–34} Nephrologists have described unease in connection with communication about prognosis and end-of-life discussions.^{35,36} Lazenby et al.³⁷ found that the reasons for the absence of these discussions may partly also be that renal physicians estimate that patients do not want or need this information. It has however been found that most patients want discussions about their prognosis³⁸ and the end of life³¹ and that knowledge and earlier discussions may help them to plan for their future.^{39,40} Many patients have been found to think that advance care

planning is important,⁴¹ although patients may wait for health care professionals to initiate end-of-life discussions.^{42,43} Yet, in a recent study of end-of-life care of patients with kidney disease dying in hospital wards, it was found that none of 100 patients had an advance care plan.⁴⁴

In the present study, the patients' preference of place of death was reported as met in about two-fifths of patients. These results may partly be because of a lack of end-of-life discussions and patient involvement earlier on during the disease trajectory, when the patient is still able to participate in a conversation. Lack of end-of-life discussions, that is, less possibility for both the patient and the family members to prepare, could also be one of the reasons why one-fifth of the patients died alone and that almost 50% died without family members present. Family members' presence may also be related to that even if death is reported as expected it may have been difficult to foresee the last days. Lack of end-of-life discussions may also be one reason why few patients died in specialist palliative care. Delayed or insufficient discussions may also partly explain why only about one-tenth of patients died at home, although dying at home is a common preference.^{31,45} In comparison, in Sweden, about one-fifth of all deaths occur at home.⁴⁶ A recent comprehensive study also showed that people with chronic kidney disease are less likely to die at home, compared with people without chronic kidney disease.⁴⁷

The results of the present study show a need for integration of palliative care with proactive actions in renal care earlier on in patients' illness trajectories (cf., e.g., Sawatzky et al.⁴⁸). This corresponds with health care professionals' perceptions of inadequate care of patients in dialysis care, in areas such as bereavement support, spiritual support, and end-of-life discussions.⁴⁹ Moreover in a European survey, most nephrologists reported that palliative care had not been part of their core curriculum or recent medical education.⁵⁰ Hence, both primary palliative care training of nephrologists and renal nurses and collaboration with palliative care specialists should be emphasized in future renal care. One example is a pilot study where Feely et al.⁵¹ found that collaborations such as palliative care consultations in an outpatient hemodialysis clinic were well received by both patients and care professionals and that documentation of care goals improved greatly. Furthermore, the value of palliative care has been shown in different contexts, as a review of randomized studies found that palliative care interventions improve patients' quality of life and satisfaction with care at the end of life.⁵²

Supporting the family is an important component of palliative care. Still, in the present study, bereavement support (at the health care setting of the

patient's death) was offered to less than half of the patients' families. Importantly, after a long period of dialysis treatment, close family members may also need confirmation and closure with dialysis staff who are well known to them, irrespective of conversations with staff at the setting of the patient's death.²⁹ Therefore, the nurse or physician at the dialysis clinic should contact the closest relative, independently of other bereavement support.

Methodological Considerations

The reason for the decision to include the ICD-10-SE codes N18.5 or N18.9 was to ascertain identification of the target patient group. The diagnosis code N18.5 according to the ICD-10-SE is ESKD regardless of whether the patient is on dialysis or not. The diagnosis code N18.9 when stated as the mortality reason or underlying cause of death should stand for ESKD because a kidney disease of less degree would hardly be considered as a cause of death according to the formulation in the Swedish cause-of-death registry. Together with the inclusion criteria of expected deaths, we believe that this is a strength as this population is likely to have been identified as a relevant target group for palliative care. Still, there is a possibility that there are patients with ESKD who were not included. However, this is a general problem with registry studies as the data quality depends on the validity of the registration. Another strength of the present study is that the end-of-life questionnaire had been validated repeatedly.^{14,53}

There are several limitations of this study. One is that not all care units report to the SRPC, which means that not all patients with ESKD are represented in the register. Reporting units actively decide to join the SRPC, which also means that they may be more attentive to end-of-life care, thus possibly resulting in selection bias. It has been shown that registration in SRPC is associated with improved quality of care.¹⁵ Hence, the general palliative care situation for these patients may be poorer than we report in this article. Even if 53% and 62% of all deaths in Sweden were reported in the SRPC during 2011 and 2012, respectively, the share of deaths of patients with chronic kidney disease that are registered is unknown. Another limitation is that the SRPC only comprises six symptoms, which means that other important symptoms may be missed; hence, there may be a need for an extended symptom measure in SRPC for diagnoses as ESKD. Validated scales were rarely used for symptom assessments, which may influence the accuracy of data. Recall bias, because the registry is completed retrospectively, is another limitation. The amount of reported unknown responses may be related not only to recall problems but also to a lack of documentation in

patient records. A further major concern is that data are clinician reported and not reported by the patient or family members. Hence, there is a need for further research into patient- and family reported data at the end of life. Still, retrospective data contribute to knowledge of end-of-life care,⁵⁴ and this study has made it possible to gain information on the last week of life in people with ESKD, thereby identifying areas for improvement. A disadvantage of registry studies is that available background characteristics are often limited. No information is available for important background or medical characteristics, such as ethnicity, socioeconomic status, causes of CKD, and others.

We were not able to differentiate data between those treated with dialysis or conservative care or if dialysis was withdrawn. The study sample had an advanced age and a high percentage of institutional deaths that influences generalizability. There is a need for further studies of palliative care not only in relation to age and setting but also in relation to other factors, such as gender and ethnicity.

Conclusion

Although dying an expected death, patients with ESKD had unmet palliative care needs. Reports from health care professionals about patients' last week of life showed insufficient symptom assessment and relief, and findings suggest a lack of end-of-life discussions and bereavement support. Altogether, the results contribute to the knowledge that there are remaining challenges in the provision of care for dying patients with ESKD and a need for integrated palliative care.

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