

Research Article

Conservative Care, Dialysis Withdrawal, and Palliative Care: Results from a Survey of a Non-Profit Dialysis Provider in Germany

Wolfgang Pommer^a Sarah Wagner^b Julia Thumfart^c^aKfH – Kuratorium für Dialyse und Nierentransplantation, Neu-Isenburg, Germany;^bINWT Statics, Berlin, Germany; ^cCharité Universitätsmedizin Berlin, Clinic for Pediatric, Gastroenterology, Nephrology, and Metabolic Diseases, Berlin, Germany**Keywords**

Conservative renal care · Dialysis withdrawal · Survey · Non-profit provider · Palliative care

Abstract

Background: In Germany, practice patterns of conservative renal care (CRC), dialysis withdrawal (DW), and concomitant palliative care in patients who choose these options are unknown. **Method:** A survey was designed including 13 structured and one open questions on the management and frequency of CRC and DW, local palliative care structure, and fundamentals of the decision-making process, and addressed to the head physicians of all renal centers ($n = 193$) of a non-profit renal care provider (KfH – Kuratorium für Dialyse und Nierentransplantation, Neu-Isenburg, Germany). **Results:** Response rate was 62.2% ($n = 122$ centers) comprising 14,197 prevalent dialysis patients and 159,652 renal outpatients. Two-thirds of the respondents were men (85% in the age group between 45 and 64 years). Mean time of experience in renal medicine was 22.2 years in men, 20.8 years in women. 94% of all centers provided CRC with a different frequency and proportion of patients (mean 8.4% of the center population, median 5%, range 0–50%). Mean proportion of DW was 2.85% per year (median 2%, range 1–15%). Physicians and center features were not significantly associated with utilization of CRC or DW. Palliative care management varied including local palliative teams, support by general physicians, or by the renal team itself. Hospice care was only established in patients undergoing CRC. Fundamentals of the decision-making process were the desire of the patient (90% in CRC, 67% in DW). Patients undergoing CRC changed their opinion towards treatment modality “frequently” in 18% of the cases, “occasionally” in 73%. Physicians’ deci-

Prof. Dr. med. Wolfgang Pommer
KfH – Bildungszentrum
Martin-Behaim-Str. 20
DE-63263 Neu-Isenburg (Germany)
E-Mail wolfgang.pommer@kfh-dialyse.de

sions were mostly driven by presumed fatal prognosis and poor physical or mental conditions of the individual patient. Different barriers to provide palliative care for the renal population like lack of education in palliative medicine, shortness of staff, lack of financial resources, and local palliative care structures were reported. **Conclusion:** Compared to international numbers, in Germany, proportion of CRC and DW reported by non-profit renal centers is in the lower range. Center practice of palliative care management varies and is driven by availability of local palliative care resources and presumably by attitudes of the renal teams. Quality of palliative care and the decision-making process need further evaluation.

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Introduction

Patient centered care to improve quality of life and not only prolonging survival is one of the main purposes of caring for patients in a non-profit organization. As in many countries, in Germany, the age of renal patients with advanced stages of chronic kidney disease (CKD) has increased significantly in the last decades. Numbers of dialysis patients have doubled in the last two decades to about 80–90,000 [1] reaching a median age of 69 years in men and 73 years in women [2]. Focusing on the limited survival time and insufficient quality of life on renal replacement therapy (RRT) in some of these individuals, the option of conservative treatment or withholding or stopping dialysis treatment with the consequence of providing palliative care may be considered by many renal professionals [3–9].

In Germany, data on current practice patterns and attitudes of nephrologists using this approach are lacking. Results from an international data base show marked differences in the use, and in part increasing rates, of dialysis discontinuation [10, 11]. European survey results indicated a broad range of conservative treatment utilization between 5 to 20% in countries with different incidence levels of RRT [12]. More recently, a European survey on dialysis withdrawal and palliative care revealed significant differences in practice pattern by profit and non-profit centers, legal regulations, training in and reimbursement of palliative care [13]. Furthermore, differences of nephrologists' perceptions of their role, patient autonomy, and successful and unsuccessful encounters contribute to variation in decision-making results concerning starting or stopping RRT [14]. Although symptom prevalence in CKD equals to conditions of other seriously ill patients [15] the palliative care approach is rarely considered in training and education of German nephrologists. Despite sufficient reimbursement of palliative care in Germany, current shortness of palliative care professionals and structures for non-cancer patients, including hospice and in-patient care, results in an underuse of palliative care in renal patients.

Decision making to withhold or withdraw a treatment has to be done in accordance with the principles of end-of-life care provided by the German Medical Association (Bundesärztekammer). For patients who are not yet dying, but are likely to die in the foreseeable future, according to medical knowledge, a change in the treatment goal is required if life-support measures only extend suffering. Palliative care, including nursing measures, takes the place of life extension and life support. The decision to stop or continue medical measures must be evaluated in a decision-making process between the physician and the (competent) patient. In the case of non-consenting patient, the alleged will must be the legal representative's declaration. If the will of the patient is not known, the caregiver must decide as the patient would have done (presumed will). In the conflict between doctor and legal representatives about medical decisions, the district court has to decide. Active euthanasia is prohibited. The will of the patient is always paramount even if his or her decision does not coincide with the recommendation of the doctor.

To get more detailed information on the current practice pattern concerning conservative care, dialysis withdrawal, and palliative care support, a survey was designed and addressed to the responsible nephrologists of all dialysis centers of a German non-profit organization (KfH). Conservative treatment in this approach was defined as withholding any measurement to prepare patients with advanced CKD for dialysis treatment and refraining from dialysis treatment even when frank uremia occurs. Irrespective of decisions made in the course of pre-dialysis treatment, patients are given freedom to change option from conservative to active (dialysis) treatment and vice versa at any time even when discordant decisions were made before start of dialysis. Standard renal care like anemia management, medical treatment for hypertension, diabetes and other conditions, and nutritional and social counseling was continued according to individual patient's requirements. Information on practice pattern about the cooperation with local palliative teams, hospice care, established palliative training in the individual renal centers, or palliative care support by other physicians for the group of patients undergoing conservative treatment care or after dialysis withdrawal was requested.

Methods

Description of Study Base, Survey Design, and Distribution

A survey with seven items on conservative treatment pattern and six questions on current dialysis withdrawal practice was designed including one question on suggested barriers to the palliative treatment approach (details Table 1). Additionally, one open question was given to allow a more detailed statement on demands and supports requested from the provider organization. Respondents were free to add more information on current palliative practice pattern of the individual center. For descriptions of the specific center features, the following items were also requested: age, sex, and number of years practicing in renal medicine of the respondent renal physician, number of current in-center dialysis and out-center CKD patients, and center region.

The survey was developed in LimeSurvey™ [16] and sent out on May 3, 2018 by intranet mailing to the head physicians of all renal centers of the organization. At time of study $n = 193$ adult renal centers with 19,080 dialysis patients and 21,532 pre-dialysis patients were operating. All replies received by May 31 were included in the analysis. Mailing attached a personal letter from the CEO and followed by an introduction and two reminders of the main investigators (W.P., J.T.) to empower response rate.

The non-profit provider organization KfH (Kuratorium für Dialyse und Nierentransplantation, Neu-Isenburg, Germany) was founded in 1969 to establish coverage dialysis care in Germany. The mission of the organization is to provide full renal and high-quality care irrespective of patients' age (from youngest to oldest), socioeconomic situation, education, and national background. Employed renal physicians and nursing staff are paid equally independently from the economical result of the individual center. Physicians are free in their medical practice but starting with home dialysis and preparing for kidney transplantation in eligible patients is promoted.

The survey was anonymous. Participation was voluntary and no individual patient information was requested. Ethical approval and a formal informed consent process were not initiated.

Statistical Analysis

All statistical analyses were performed using the R statistical software (version 3.5.1.) [17]. Descriptive univariate statistics were used for every individual question. Total number of answers (n) and percentages (rounded values) are shown. Not every question was answered

Table 1. Questions regarding palliative care in conservative treatment and dialysis withdrawal

Conservative care (CC)	Dialysis withdrawal (DW)
How often do you use the option of CC in pts who are eligible for dialysis treatment? (%)	What is the approximated yearly proportion of dialysis withdrawal at your center? (%)
<i>What is the main reason for your decision*</i> (a) assumed fatal prognosis (b) patient's desire (c) desire of family/partners (d) decision of the renal team (e) others	<i>What is the main reason for your decision*</i> (a) physician's judgment (b) patient's desire (c) desire of family/partners (d) decision of the renal team (e) others
<i>How important are the following aspects regarding your decision?</i> (a) patient's age (b) severely impaired physical function (c) request of the family (d) cognitive impairment (e) vascular dementia (f) lack of social support (g) bad physical condition (1–6 = important–unimportant)	<i>How important are the following aspects regarding your decision?</i> (a) patient's age (b) severely impaired physical function (c) request of the family (d) cognitive impairment (e) vascular dementia (f) lack of social support (g) bad physical condition (1–6 = important–unimportant)
<i>If CC is appropriate, how often do you discuss this option with the patient?***</i> (a) always (b) many times (c) sometimes (d) never	<i>If you are considering DW, what is the basis of your decision?***</i> (a) physician's decision (b) patient's desire (c) request of family/partners (d) decision of the renal team (e) others
<i>If you discuss this option with your pt, how often does he/she changed his/her mind?***</i> (a) always (b) many times (c) sometimes (d) never	<i>How do you manage DW usually?*</i> (a) repeated conversation with pt, family, and partners (b) tapering dialysis time and intensity (c) limitation of dialysis course to give pt more time for decision making (d) stopping dialysis if pt's condition worsens (e) stopping dialysis by legal demands
<i>What measurements are established to provide palliative care for CC pts at your center?*</i> (a) care by defined members of the renal team (b) cooperation with palliative outpatient team (c) hospice care (d) providing care by general physician (e) hospital-based palliative care (f) none	<i>After DW decision making, who mainly provides palliative care for this pt?***</i> (a) outpatient palliative care (b) general physician (c) renal team (d) no special care
<i>What measurement is routinely established to provide palliative care in your team?*</i> (a) regular team meetings (b) occasional case debates (c) structured education in palliative medicine (d) none	

* Multiple answers possible. ** Only one answer allowed. pt(s), patient(s).

by all respondents. Therefore, the number of answers to every item do not always sum up to 100% ($n = 122$ centers). As for bivariate statistics, the dependence between the answers to a pair of questions was tested using Fisher's exact test for count data. Questions with Likert scale were analyzed by using the Kruskal-Wallis rank sum test. A p value <0.05 was considered as significant. Otherwise ns (no significant difference) is stated.

Table 2. Response rate, center features, and proportion of conservative treatment and dialysis withdrawal

Study base	<i>n</i>
Renal units addressed	193 (100%)
Respondents	122 (response rate 62.2%)
Prevalent dialysis patients (total)	14,197
Prevalent ambulatory patients (total)	159,652
Respondents by age group*	
<44 years	14 (12%)
>45–64 years	104 (85%)
>65 years	1 (1%)
Sex* (male/female)	77 (63%)/39 (32%)
Years working in renal medicine (male/female)	22.2/20.8 (ns)
<i>Center size (prevalent patients)</i>	
In-center dialysis patients	
<50	8 (7%)
>50–100	45 (37%)
>101–150	47 (39%)
>150	22 (18%)
Ambulatory renal patients	
<500	83 (68%)
500–1,000	33 (27%)
>1,000	6 (5%)
Proportion of centers with patients undergoing conservative care	
None	7 (6%)
1–5%	72 (59%)
>5%	43 (35%)
Proportion of dialysis withdrawal per year	
1–2%	72 (59%)
>2%	48 (39%)
No answer	2 (2%)

* Missing values. ns, nonsignificant.

Results

Response Rate, Center Features

Out of 193 renal centers, 122 completed surveys were received (response rate 62.2%). 63% of the respondents were male, 32% female. Age group of the respondents was: <44 years 12%, 45–64 years 85%, >65 years 1% (missing values) (Table 2). Mean time of working in renal medicine was 22.2 years in male physicians and 20.8 years in female doctors (ns). Proportion of in-center dialysis patients of the responding centers was <50 patients 7%, 50–100 patients 37%, 101–150 patients 39%, >150 patients 18% (mean *n* = 117, median 109). Numbers of out-patients under regular ambulatory renal care at time of study were: <500 68%, 500–1,000 27%, >1,000 5% (mean *n* = 1,319, median 350) (Table 2).

Proportion of Conservative Care and Dialysis Withdrawal

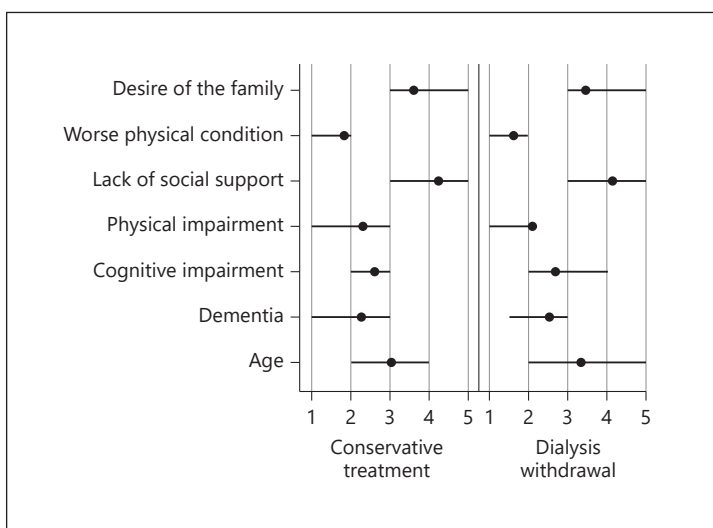
Option of conservative care was reported in 94% of all centers. The proportion of patients under conservative care ranged widely (mean 8.4%, median 5%, range 0–50%). 35% of the centers reported a proportion of patients undergoing conservative treatment of more than 5%

Table 3. Fundamentals of decision making

Item	Responses, n
<i>Conservative care*</i>	
(a) assumed fatal prognosis	78 (69%)
(b) patient's desire	110 (90%)
(c) desire of family/partners	31 (25%)
(d) decision of the renal team	37 (30%)
(e) others	12 (10%)
<i>Dialysis withdrawal**</i>	
(a) physician's judgment	9 (7%)
(b) patient's desire	82 (67%)
(c) desire of family/partners	1 (1%)
(d) decision of the renal team	22 (18%)
(e) others	6 (5%)
Missing value	2 (2%)

* Multiple answers possible. ** Only one answer allowed.

Fig. 1. Ranking of patient's features which mainly influence renal physicians' decision making (1 = most important, 5 = least important). Lines represent interquartile differences of each item.



(Table 2). Same variations occurred with regard to dialysis withdrawal. Mean proportion of dialysis withdrawal per year reached 2.85% (median 2%, range 1–15%) (Table 2). 2% of the respondents stated never using this option, 93% occasionally, 3% frequently, 3% regularly.

Bivariate analysis of the distribution of conservative care and dialysis withdrawal showed no significance differences by center size, regions, physician's age, sex, and time in renal practice (results not detailed in this paper).

Attitudes of the Responding Renal Physicians regarding Decision Making

Responses regarding the fundamentals which indicate mainly physicians' choice of conservative treatment were given as follows (multiple answers possible): (a) physicians' choice suggesting fatal prognosis 69%, (b) wish of the patient 90%, (c) wish of next family members 25%, (d) renal team decision 30%, (e) others 10% (Table 3).

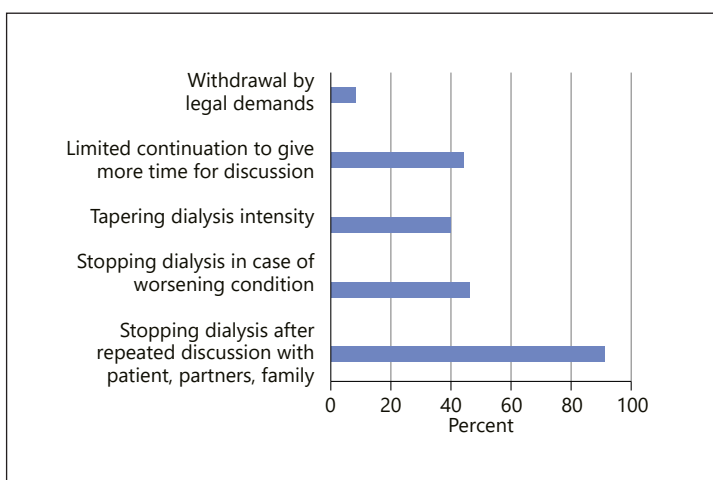


Fig. 2. Procedures of dialysis withdrawal (%).

Fundamentals regarding dialysis withdrawal were described in Table 3; physicians' decisions were mainly driven by wishes of the patients (67%) and in a smaller proportion by decision of the renal team (18%).

Ranking of patient's features which mainly influenced physician's decision to conservative care and dialysis withdrawal (see Table 1) was requested by grading between "very important = 1 to unimportant = 5." Proportion of "very important and important" statements on conservative care (rsp. dialysis withdrawal) was as followed: patient's age 45% (40%), physical functional impairment 63% (76%), wish of the family 20% (24%), cognitive impairment 49% (52%), vascular dementia 65% (56%), lack of social support 6% (11%), worse physical condition 72% (85%). Mean ratings and interquartile differences of responses are displayed in Figure 1.

According to decision making in conservative care approach, center information was requested on the frequency of discussion made between renal physicians and the patient. Statements were as followed: "always" 62%, "frequently" 30%, "occasionally" 3%. Responses to the question: "How often does the patient change his/her opinion" to conservative care were: "frequently" 18% ($n = 22$), "occasionally" 73% ($n = 89$), "never" 3% ($n = 3$) ($n = 8$ centers with missing values).

Palliative Care Approach in Patients Undergoing Conservative Treatment and after Dialysis Withdrawal

According to the procedure for stopping dialysis, the following methods are described (multiple answers possible): (a) stopping after repeated discussion with patient, partners, and family 91% ($n = 111$), (b) tapering dialysis by reduction of treatment time and intensity 40% ($n = 49$), (c) limited course of treatment to give more time for patients' decision making 44% ($n = 54$), (d) stopping dialysis by worsening of patient's condition 46% ($n = 56$), (c) withdrawal by legal demands 8% ($n = 10$) (multiple answers possible) (Fig. 2).

Centers who provided conservative care gave information about local palliative care support: (a) back-up by renal team 24% ($n = 29$), (b) co-working with an out-patient palliative team 62% ($n = 76$), (c) hospice care 44% ($n = 54$), (d) care by a general physician 79% ($n = 85$), (e) none of them 6% ($n = 7$) (multiple answers possible). After dialysis withdrawal patient's care was provided in 10% of centers ($n = 12$) by local palliative teams, by general physicians in 46% ($n = 38$), by the renal center itself 49% ($n = 60$), no special care 2% ($n = 2$) (Fig. 3).

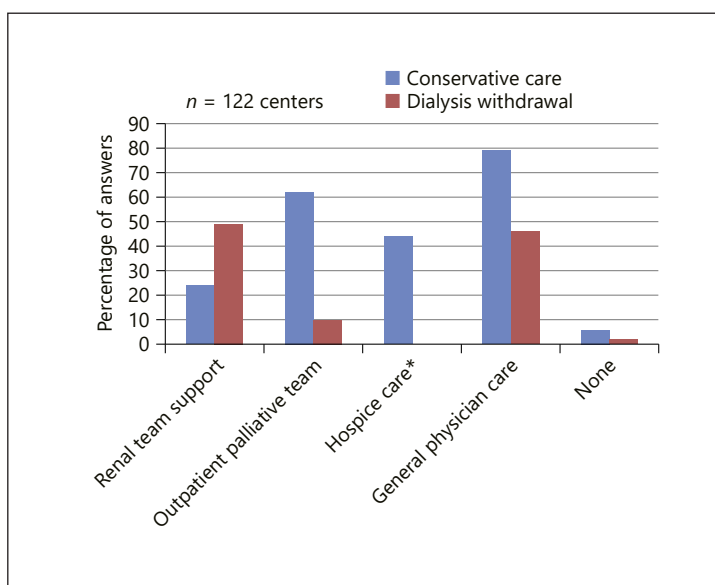


Fig. 3. Established palliative care support in the situation of conservative care and dialysis withdrawal. * Item not requested in case of dialysis withdrawal (see text).

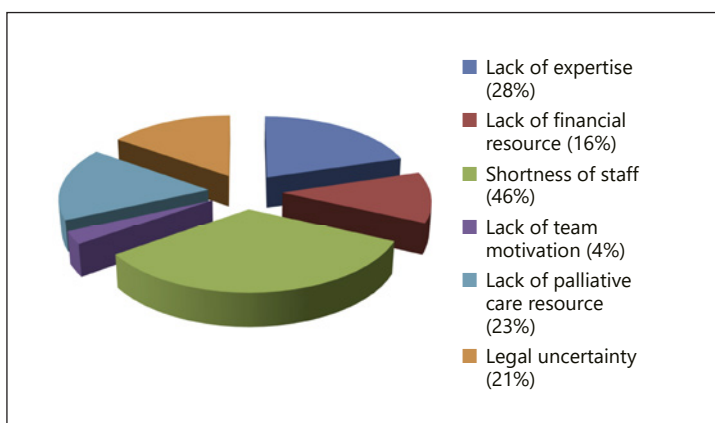


Fig. 4. Barriers to palliative care as reported in the survey ($n = 122$ centers).

The following team measurements on education in palliative medicine were established in the renal centers: (a) regular team meetings 24% ($n = 29$), (b) occasional case debates 55% ($n = 67$), (c) structured education and qualification 5% ($n = 6$), (d) none of them 21% ($n = 25$).

Barriers to Palliative Care in Renal Medicine

Answers to barriers which hamper establishment or improvement of palliative care in renal practice were: (a) lack of expertise 28% ($n = 34$), (b) lack of financial resources 16% ($n = 19$), (c) shortness of staff 46% ($n = 56$), (d) lack of team motivation 3% ($n = 4$), (e) lack of local palliative care resources 23% ($n = 28$), (f) legal uncertainty 21% ($n = 25$), (g) not known 25% ($n = 31$) (multiple answers possible) (Fig. 4). Additional information was derived from an open question of current palliative practice experiences given by 94 centers; educational aspects and need of more information ranked first ($n = 29$ responses), followed by requests for improving structural conditions ($n = 15$), more resources (staff, financial aspects) ($n = 14$), and support in ethical and legal issues ($n = 7$).

Discussion

In this survey, practice pattern of conservative renal care, dialysis withdrawal, and the attending of palliative care were evaluated in a non-profit organization. Two-thirds of all addressed centers responded to the questionnaire. This response rate is high in relation to a multi-center European survey [12], but in the same range as a national study from the United Kingdom [18]. Two-thirds of the respondents are men, predominantly in the age group between 44–65 years with long-term experience in renal care. The majority of centers provide conservative care (94%) with a mean proportion of 8% of the prevalent pre-dialysis population which is in the range of European results [13]. Dialysis withdrawal is reported in less than 3% per year (maximum 15%). A recently published systematic review including more than fourteen million dialysis patients of six countries identified a broad range of withdrawal between 3 per 1,000 person-years in 1966 to 49% per 1,000 person-years in 2010 [19]. More recently, in a single center study of more than 1,200 incident dialysis patients in the United States withdrawal is evaluated in up to 49% of the deaths which is twice as frequent as described previously [20].

The acceptance of a conservative care approach and the option of dialysis withdrawal is affected by different structural, cultural, legal, and behavioral aspects. With respect to European results, significant differences of withholding dialysis are found by comparing for-profit to non-profit centers and low and high-incidence countries [12]. Nephrologists' perception regarding dialysis withdrawal is reported twice higher in countries where stopping life-prolonging treatment is allowed [13]. According to these aspects, the results presented here reflect a similar or in part lower utilization of a conservative care approach and rate of dialysis withdrawal compared to European findings [12, 13] with similar legal obligations. In Germany, life-prolonging or life-stopping treatment is allowed only by the consent of a competent patient. Legal regulations exist for procedures in incompetent individuals. But, if treatment is not or no longer indicated (with respect to current medical guidelines or recommendations) physicians are free to decide to stop or withhold treatment by their own responsibility. Most conflicts derive in the decision-making process in the case of severely impaired incompetent patients and their families if, in view of the physician, treatment should be withheld or stopped and family members disagree. Stopping or withholding active treatment (as dialysis) does not indicate stopping medical care. If life span is limited, palliative care is advised to ease disease burden and symptoms.

Palliative symptoms and their management in CKD patients equal individuals with advanced cancer or severe non-cancer conditions [review by 15]. As recommended for many medical disciplines, in renal medicine combination of general plus special palliative care in a sustainable model should be preferred [21]. Maintained quality of life but shorter survival is described in CKD patients undergoing conservative treatment attending by palliative care management in prospective studies [22, 23]. Hospice care after dialysis discontinuation shows lower survival rates and a great variation in survival time compared to other hospice patients [24]. Two-thirds of the centers in this study reported co-working with a palliative team, almost half the centers use hospice predominantly in the situation of conservative care. Low utilization of hospice care in the present study in individuals in whom dialysis was suggested to be discontinued is a result of the German reimbursement system; active treatment (such as dialysis) is not paid during hospice care where only doctors' visits and symptom treatment are reimbursed. Otherwise, ambulatory palliative care is reimbursed add-on to renal care if a certified palliative team is in charge. Considering end-of life care as part of renal treatment reimbursement system in Germany favors an out-patient model even if most of the capacity of palliative care medicine so far is taken by cancer patients. Improvement may derive from continuous networking between renal centers and palliative care teams. In

our study this approach is established in two-thirds of the centers for patients treated with a conservative approach but only in ten percent of the subjects where dialysis is discontinued. This may be explained by the role of the renal physician and the approach to stopping dialysis. Tapering dialysis intensity or waiting for the deterioration of patient's general condition after the decision is made to discontinue dialysis treatment seems to be a suitable approach in almost half of the centers. Obviously, additional resources in palliative care were derived from the cooperation with general physicians (up to 80% percent) and from renal team support. Thus, awareness to palliative care in the renal centers of this non-profit institution seems to be high which is also reflected by the high response rate in our study. There are no published data in Germany to compare differences of these features to other non-profit, private or for-profit renal institutions.

Different roles in the decision-making process for conservative care and dialysis withdrawal derives from these study results. Renal physicians lead this process by recognition of patients' general condition and worsening. Age itself seems to not be an indicating factor but cognitive impairment or dementia ranks high and might be more important than lack of social support or family burden although some aspects yield an overlapping pattern (Fig. 1). Team statements are considered in a higher proportion to the decision for dialysis withdrawal (30% of the centers) than for conservative treatment (18% of the centers). The patient's desire clearly dominates decision to the treatment option which is in line with the need for complying with legal demands. A significant proportion of patients in this report changed their opinion towards conservative care. Reasons for that are not distinctively stated by the respondents but insufficient communication, change of perspectives of patients' at the end of life, and presumed benefits of prolonging life by dialysis treatment may contribute to this attitude as discussed in different studies [6, 8, 9, 14, 25].

Despite guideline recommending shared decision making, nephrologists vary significantly in their approaches to discuss aspects of conservative care or stopping active treatment [12–14]. In this study we control treatment and decision pattern for physician's age, sex, center size, region, and prevalence of palliative care network without finding significant differences. This may be related to the design of the study which was not designed to control different individual approaches of decision making in physicians as done in a recent qualitative study [14]. Also, the aspect of longstanding practice in our non-profit institution may contribute to a cultural related homogenous approach to the study issue. Physicians' ethical attitudes and preferences of end-of-life care were not evaluated in the study but no ethical conflicts with regard to the different treatment options were displayed in replies to the open question. Furthermore, differences in offering individual treatment choices to their patients might be influenced by the long-term practice of the participating nephrologists who may hold on conventional "standard treatment."

The latter aspects are part of the limitations of the study. Controlling for qualitative aspects as quality of provided palliative care in view of the patients and their families, compliance to the fundamentals of palliative medicine, quality of care-giving, procedure and documentation of decision-making process have been not evaluated. Expertise in palliative medicine in the centers is limited and structured education is infrequently reported. This raise concern as to what extent demands of the patients and their families are met according to the different dimensions of palliative care. These quality aspects may contradict the impression given by some respondents (complete statements not detailed here) that the current situation is sufficient to cover the complex conditions of palliative care in our institution.

Barriers to improve or establish palliative care in renal practice are reported. Shortness of staff in almost half of the centers, followed by educational shortcomings, and deficiency of local palliative care structures are mentioned. Shortness of staff is a general problem in

German medical practice which hampers innovative approaches in renal care [26]. Education along with practice guidelines of palliative care and improvement of nephrologists' perception may help to overcome some barriers detailed in this study [27, 28].

Conclusion

In summary, in this report nephrologists' perception of their patients' demands according to conservative care or dialysis withdrawal is high although compared to other countries the proportion of cases in which these options are realized – by some variations in between the centers – seems to be low. Fundamentals of the decision comprise patients' autonomous judgment and their general physical and mental conditions. In the participating study centers, palliative care is provided in different settings like local palliative networks, co-operation with family doctors, or by the renal team itself. Formal education of nephrologists and their renal team in palliative medicine is low and should be improved to realize a higher quality of the decision-making process and optimizing the management of different dimensions of palliative care for renal patients and their families. A study approach including the evaluation of the process of decision making, quality of life in renal patients undergoing conservative care, and quality of palliative care (in view of the patients and their families) is needed to confirm the – in part – very positive view concerning the current practice in our non-profit institution.

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Disclosure Statement

Authors stated no conflict of interests.

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