

Urgency for Kidney Palliative Care in Chinese Maintenance Hemodialysis Patients



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Introduction: The aim of this study is to understand nephrology medical staff's awareness of, basic knowledge of, practical ability of, and the barriers to palliative kidney care to patients on maintenance hemodialysis (HD) in mainland China.

Methods: This cross-sectional descriptive study employed convenience sampling of medical staff (physicians and nurses) working in nephrology departments in mainland China. Independent predictors of self-assessment ability for palliative care (PC) were determined using multivariate binary logistic regression.

Results: Responses were received from medical staff in 28 provinces and 657 questionnaires were analyzed. Among the participants, 53.1% (349/657) were doctors, and only 4.3% claimed to be confident in providing PC to patients on HD. The average score of self-assessing ability for PC was 2.65 ± 1.15 (range 1–5). Among the 580 participants who experienced patient withdrawal from dialysis, only 16.0% reported that their patients had well-planned withdrawal from dialysis. Male (odds ratio [OR] [95% confidence interval [CI], 0.585 [0.34–0.99], $P = 0.048$), nurse (OR [95% CI], 1.81 [1.01–3.27], $P = 0.047$), more experience in dealing with deceased cases (OR [95% CI], 1.28 [1.02–1.61], $P = 0.034$), less experience of medical disputes before/after withdrawal from dialysis (OR [95% CI], 0.62 [0.40–0.98], $P = 0.041$), and PC training experiences (OR [95% CI], 2.33 [1.86–2.91], $P < 0.001$) were independently correlated with significant better self-assessing ability for PC.

Conclusion: This study demonstrates that the nephrology medical staff had a positive attitude but lacked relative knowledge and training in PC. Institutionalized education, training models, practice guidelines for kidney PC, and guidelines for well-planned withdrawal from dialysis according to cultural background are urgently needed in mainland China.

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KEYWORDS: dialysis; end-stage renal disease; kidney palliative care; survey; withdrawal from dialysis

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Patients with chronic kidney disease (CKD) have high morbidity and mortality and are at a high risk of developing a wide range of symptoms and complications, including pain, fatigue, depression, anxiety, difficulty sleeping, and impaired quality of life.¹ Therefore, the need for the integration of PC into

CKD care to fulfill the needs of patients with high symptom burden and limited life expectancy has been proposed.^{2–4} Kidney PC is a growing field of healthcare that focuses on providing comfort, symptom relief, and support to patients with CKD, especially in maintenance HD patients.^{4,5}

In recent years, there has been an increased focus on kidney PC, as more healthcare providers have recognized the importance of providing PC to patients with CKD. In 2013, a Kidney Disease: Improving Global Outcomes Controversies Conference on Supportive Care in CKD proposed that “Supportive care is an essential component of the continuum of quality care for CKD and end-stage renal disease (ESRD) patients and should be provided with sensitivity to cultural and religious values as well as patient and family comfort and

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dignity.”¹ Despite the efforts of the government and scholars to promote PC, the development of PC in mainland China still has a long way to go. As a result of the special cultural background, it is taboo to discuss death, and public education on death and dying is rare.⁶

Despite the increased focus on palliative kidney care, many challenges remain. Furthermore, despite current recommendations, referral rates to PC consultation services among patients with advanced CKD remain low.⁷ In mainland China, insufficient attention has been paid to kidney PC, including patients undergoing maintenance HD. As a direct care provider for this group of patients, the correct recognition of PC by nephrology medical staff is critical to the successful facilitation of kidney PC. Therefore, the purpose of this study was to understand the awareness and perspectives of nephrology medical staff regarding facilitators and barriers to PC, withdrawal from dialysis, basic knowledge, and the need for PC in maintenance HD patients. The study findings may draw attention to the barriers and urgent needs of kidney PC, support the development of kidney PC in mainland China, and provide directions for future interventional studies.

METHODS

Study Design

This cross-sectional descriptive open study was performed using data collected from an online survey. The questionnaire was designed by nephrologists and palliative center specialists. The Checklist for Reporting Results of Internet E-Surveys was applied to ensure comprehensive reporting. The usability and technical functionality of the electronic questionnaire had been tested in some groups of nephrology medical staff (including 14 doctors and 10 nurses) from Peking Union Medical College Hospital before fielding the questionnaire. The questionnaire was organized into the following categories: basic information, experiences of caring for patients with ESRD undergoing HD, attitudes toward and experiences with kidney PC, attitudes toward and experiences of withdrawal from dialysis, and knowledge of PC. Both confidence and needs were assessed on a 5-point Likert scale (1 = not at all confident/needed, 2 = not very confident/needed, 3 = fairly confident/needed, 4 = very confident/needed, and 5 = strongly confident/needed).

Participants

The study employed convenience sampling of medical staff (physicians and nurses) working in nephrology departments in mainland China. The invitation to participate in the study was distributed at a national nephrology conference via a web link to a self-reporting questionnaire for medical staff caring for patients undergoing maintenance HD. The inclusion

criteria were as follows: (i) nephrology medical staff with experience of caring for patients on maintenance HD and (ii) voluntary agreement to participate in the study. The exclusion criteria were participants who returned incomplete questionnaires. Ethical approval was obtained from the Research Ethics Committee of the Peking Union Medical College Hospital (No. K2326), and digital written informed consent was obtained from each participant.

A total of 667 questionnaires were returned and 657 were analyzed after excluding 10 questionnaires with insufficient responses. These participants were from 196 different medical facilities.

Data Collection

We recruited participants from July 1, 2022, to October 31, 2022, in mainland China. The survey was administered as an online questionnaire using the professional online questionnaire software platform Questionnaire Star (Changsha Ranxing Information Technology Co., Ltd.) (wjx.cn). The researchers explained the study to the potential participants and encouraged them to make voluntary decisions regarding their participation. The questionnaire was completed by the participants online. No financial incentives were offered for participation.

Statistical Analysis

All statistical analyses were performed using SPSS software (version 25.0; SPSS Inc., Chicago, IL). Data are presented as the mean \pm SD for normally distributed continuous variables, the mean and range for skewed-distributed continuous variables, or the number and proportion (%) for categorical variables. Data were compared between groups using Fisher's exact test or χ^2 test for categorical variables and *t*-test or Wilcoxon–Mann–Whitney test for continuous variables. All variables that might play roles according to prior knowledge were included in the univariate analysis and logistic regression analysis, including age, sex, job, educational qualifications, years in profession, experience dealing with end-stage HD patients, number of deceased cases, and medical disputes with patients or relatives before or after withdrawal from dialysis. After univariate analysis of variables was performed with methods mentioned earlier, independent predictors of self-assessment ability for PC were determined using multivariate binary logistic regression. Statistical significance was set at $P < 0.05$.

RESULTS

Demographic Characteristics

A total of 657 questionnaires were completed and analyzed. The mean \pm SD age was 37.6 ± 8.3 years. Most of the respondents were women (80.2%). Among

all the participants, 53.1% (349 out of 657) were doctors, with an average age of 40.7 ± 8.2 years, and the remaining participants were nurses (46.9%, average age \pm SD 34.0 ± 6.9 years). Nurses were predominantly female (97.4%) compared to doctors (65.0%). Compared with nurses, doctors had higher educational qualifications, longer professional experience, and managed a larger annual number of terminal patients involved in end of life care (Table 1).

Attitudes Toward and Experiences With Kidney PC

In the past 3 years, most of the participants reported that their average annual ESRD patient numbers were more than 100 (43.8%) and 11 to 100 (41.7%). Of the medical staff, 79.3% had experience in dealing with ESRD patient deaths. When faced with patients with ESRD at the end of life, the medical staff reported feeling powerless (66.2%), helpless (53.3%), struggling with decision-making (45.8%), anxious (20.4%), and wanting to escape (12.3%). Only 4.3% claimed confidence in their ability to deal with these patients. As many as 93.3% of the participants agreed that clinical

decisions at the end-of-life stage should be shared with medical staff, patients, and relatives. Participants' attitudes toward topics related to kidney PC are shown in Figure 1a. Notably, only 155 (23.6%) of the participants declared that there was PC service at their hospital or area, the others responded: "no available palliative care" (35.9%) or "do not know" (40.5%).

Knowledge of PC Among Nephrology Staff

The knowledge and awareness of PC were further investigated in the survey. When asked to receive palliative training, only 4.1% of the respondents reported that they had participated in the PC training program and/or practiced PC on patients, and 42.5% had heard of PC from others or attended PC lectures without practice (Table 1). As many as 95.6% of the participants agreed that PC should be included in the nephrology medical staff training program. A self-assessment of PC knowledge is shown in Figure 1b. Notably, the average score of self-assessing ability for PC was only 2.65 ± 1.15 (range 1–5) among the nephrology medical staff. Detailed knowledge of PC among nephrology staff is shown in Table 2. Only 18 out of 208 nurses and 9 of 349 doctors claimed that they received formal training in PC courses and very proficient in supportive care area. The results also revealed that better communication skills training was important for kidney PC practice.

Table 1. Characteristics of participants

Medical staff type	Total (N = 657)	Doctors (n = 349)	Nurses (n = 308)	P
Age (yrs \pm SD)	37.6 \pm 8.3	40.7 \pm 8.2	34.0 \pm 6.9	0.003 ^a
Male:Female	130:527	122:227	8:300	<0.001 ^a
Educational qualification				<0.001 ^a
Below college degree	46 (7.0)	6 (1.7)	40 (7.0)	
College degree	411 (62.6)	147 (42.1)	264 (85.7)	
Graduate degree	200 (30.4)	196 (56.2)	4 (1.3)	
Years in the profession (n, %)				<0.001 ^a
≤5 yrs	127 (19.3)	55 (15.8)	72 (23.4)	
6–10 yrs	121 (18.4)	45 (12.9)	76 (24.7)	
11–20 yrs	263 (40.0)	146 (41.8)	117 (38.0)	
>20 yrs	146 (22.2)	103 (29.5)	43 (14.0)	
Working institutions (n, %)				0.160
Primary/secondary hospitals	187 (28.5)	94 (26.9)	93 (30.2)	
Tertiary hospitals	413 (62.9)	230 (65.9)	183 (59.4)	
Dialysis facility	57 (8.7)	25 (7.2)	32 (10.4)	
Mean annual number of terminal patients involved in end of life care (n, %)				<0.001 ^a
None	136 (20.7)	42 (12.0)	94 (30.5)	
1–3 cases	282 (42.9)	142 (40.7)	140 (45.5)	
4–10 cases	153 (23.3)	107 (30.7)	46 (14.9)	
>10 cases	86 (13.1)	58 (16.6)	28 (9.1)	
Knowledge about palliative care (n, %)				0.044 ^a
No knowledge of PC	351 (53.4)	181 (51.9)	170 (55.2)	
Fairly knowledge of PC ^b	279 (42.5)	159 (45.6)	120 (39.0)	
Familiar with PC ^c	27 (4.1)	9 (2.6)	18 (5.8)	

PC, palliative care.

^aWith statistical significance.

^bFairly knowledge of PC, heard of PC from others or attended PC lectures without practice.

^cFamiliar with PC, participated in the PC training program and / or practiced PC on patients.

Attitudes Toward and Experiences With Withdrawal From Dialysis

Of the 580 participants who experienced patient withdrawal from dialysis, only 16.0% reported that most patients undergoing HD had a well-planned withdrawal from dialysis. Common reasons for withdrawal from dialysis included severe cardiovascular or cerebrovascular diseases (83.1%, 433/521), acute complications (72.9%, 380/521), as well as chronic debilitating problems, or failure to thrive or frailty (55.3%, 288/521) (Figure 2). Only 28.6% of participants strongly agreed that there was a locally recommended withdrawal from dialysis (that is, a clinical pathway of withdrawal from dialysis, which could be a guideline, a hospital policy, or legal document). The attitudes toward withdrawal from dialysis are shown in Figure 3. The top reasons constraining doctor-patient shared decision were the patients and relatives bearing moral pressure, such as viewing withdrawal as "giving up" or "death." and 75.5%, patients' and relatives' unrealistic hopes for disease prognosis (58.6%), and patients' and relatives' or medical staff's lack of knowledge about the care process after withdrawal from dialysis (58.6% and 40.5%, respectively). Other reasons included a lack of withdrawal from

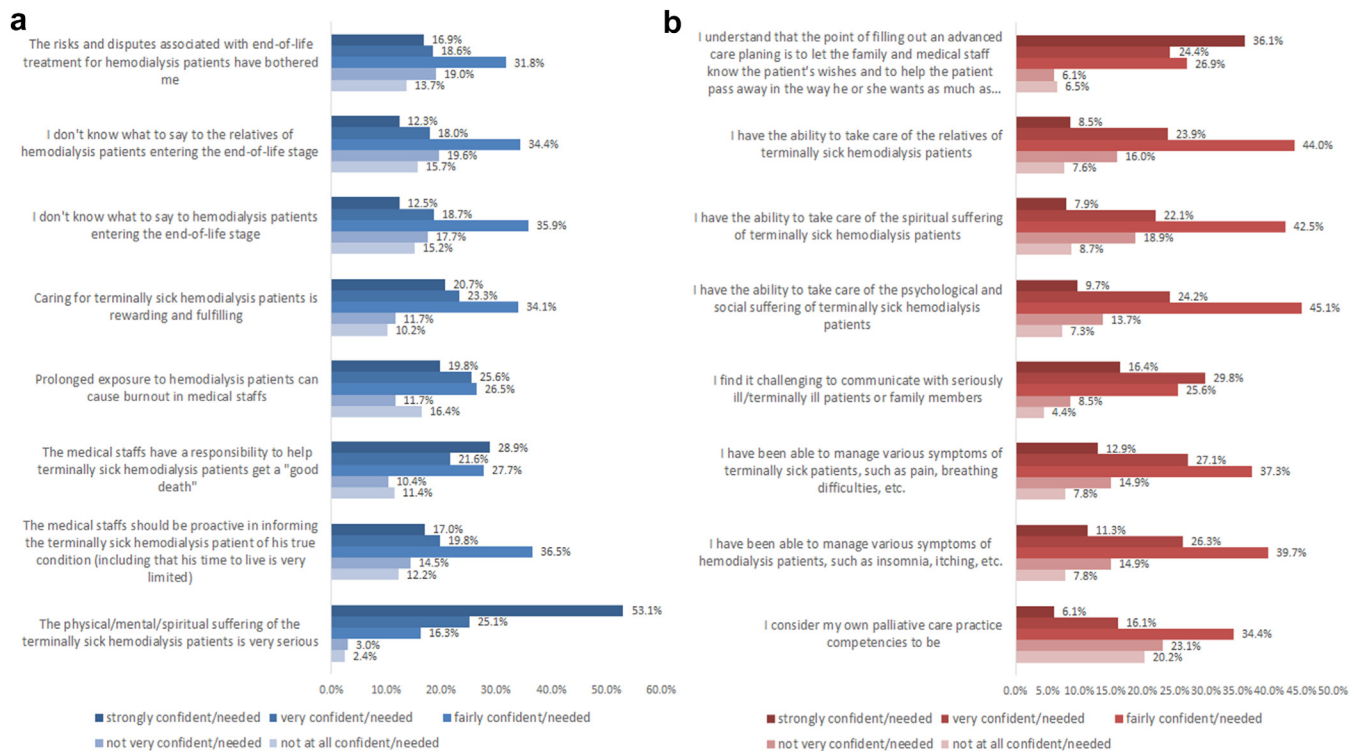


Figure 1. Attitudes toward and experiences with kidney palliative care. (a) Attitudes toward and experiences with kidney palliative care. (b) The self-assessment of knowledge of palliative care in nephrology staffs.

the dialysis procedure, no medical insurance support, and withdrawal from dialysis being forbidden by law.

Influence of Region of the Country and Level of Hospital

Attitudes toward and experiences with withdrawal from dialysis and PC among nephrology staff in different provinces are shown in [Supplementary Table S1](#). The correlation analysis (for provinces with equal to or more than 5 responders) revealed that the rate of sudden withdrawal from dialysis was negatively correlated with the rate of local recommended withdrawal from dialysis process ($r = -0.628$, $P = 0.022$). When taking hospital level into consideration, although the ratios of sudden

withdrawal from dialysis and locally recommended withdrawal from the dialysis process were comparable, there were more dissatisfaction or disputes with patients or their family members before and after withdrawal from dialysis in dialysis centers (40.5%) than in tertiary hospitals (24.5%) or primary/secondary hospitals (31.0%) ($P < 0.001$). Surprisingly, medical staff from dialysis centers had a higher percentage of awareness of PC (50.9%) ([Figure 4](#)).

Factors Influencing the Self-Assessing Ability for Kidney PC Among Nephrology Staff

A multivariate analysis of parameters independently associated with a significantly better self-assessment

Table 2. Knowledge of palliative care in nephrology medical staffs

Self-assessment score (range 1–5)	Total (N = 657)	Doctors (n = 349)	Nurses (n = 308)	P
Ability of PC practice	2.65 ± 1.15	2.61 ± 1.12	2.69 ± 1.12	0.386
Ability of dealing with ESRD and dialysis-related symptoms	3.18 ± 1.07	2.27 ± 1.01	3.09 ± 1.12	0.035 ^a
Ability of dealing with end-stage of life related symptoms	3.23 ± 1.10	3.31 ± 1.05	3.13 ± 1.14	0.036 ^a
How challenging it is to communicate with a seriously ill/terminally ill patient or family member in clinical practice	3.45 ± 1.01	3.50 ± 0.91	3.41 ± 1.11	0.260
Ability to take care of the psychological and social suffering of terminally ill dialysis patients	3.15 ± 1.02	3.12 ± 0.96	3.19 ± 1.08	0.418
Ability to take care of the spiritual suffering of terminally ill dialysis patients	3.02 ± 1.04	2.97 ± 0.99	3.07 ± 1.09	0.207
Ability to take care of the relatives of terminally ill dialysis patients	3.10 ± 1.02	3.06 ± 0.95	3.14 ± 1.09	0.287
When I encounter end-stage dialysis patients that I cannot handle, I will proactively seek palliative medical consultation	3.38 ± 1.22	3.29 ± 1.22	3.49 ± 1.21	0.036 ^a

ESRD, end-stage renal disease; PC, palliative care.

^aWith statistical significance.

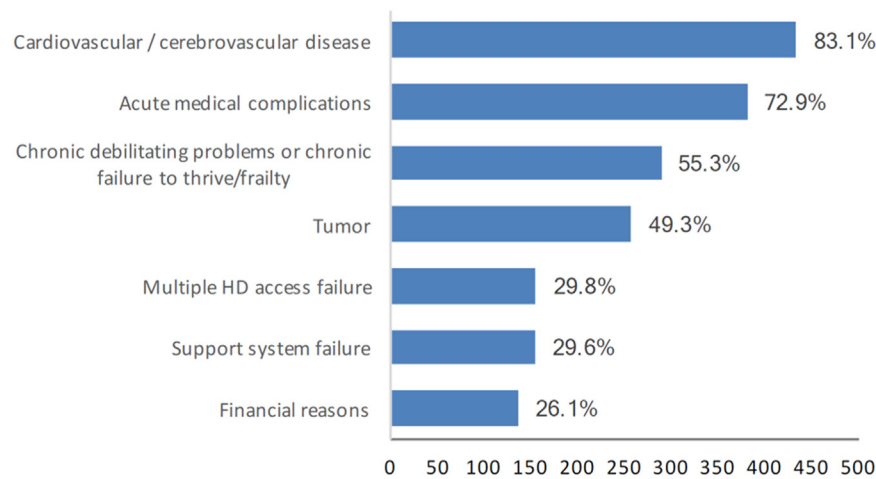


Figure 2. Reasons for withdrawal from dialysis according to nephrology medical staffs' responses in China. Support system failure, inability to continue family support, financial support, social support, etc.

ability for PC was performed. All variables that might play roles according to prior knowledge were included in the logistic regression analysis, including age, sex, job, educational qualifications, years in profession, experience dealing with end-stage HD patients, number of deceased cases, medical disputes with patients or relatives before or after withdrawal from dialysis, and PC training experiences. Male (OR [95% CI], 0.59 [0.34–0.99], $P = 0.048$), nurse (OR [95% CI], 1.81 [1.01–3.27], $P = 0.047$), more experience in dealing with deceased cases (OR [95% CI], 1.28 [1.02–1.61], $P = 0.034$), less experience of medical disputes before/after withdrawal from dialysis (OR [95% CI], 0.62 [0.40–0.98], $P = 0.041$), and PC training experiences (OR [95% CI], 2.325 [1.86–2.91], $P < 0.001$) were independently correlated with significantly better self-assessing ability for PC (defined as self-rating 4 or 5, very confident to strongly confident). (Supplementary Table S2)

DISCUSSION

The results of this nationwide survey of nephrology medical staff highlight the urgent need for kidney PC among patients on maintenance HD in mainland China. The survey revealed that most medical staff felt that there was a lack of access to PC services for these patients, and that there was a need for more comprehensive and integrated care. The survey also highlighted the need for better communication between medical staff and patients, as well as improved access to information about PC services. To the best of our knowledge, this is the first study to survey the experiences and attitudes of nephrology medical staff toward kidney PC in mainland China.

It has been widely accepted that patients on maintenance HD suffer from high symptom burden and limited life expectancy.^{2–4} The unadjusted annual mortality rate

of dialysis patients is 22% to 25% in the United States in 2013, and the expected survival later on dialysis is less than 3 years.¹ Previous studies have shown that, for patients who started dialysis at age 75, the average 1-year and 3-year adjusted survival rates were only 63% and 33%, respectively; in patients older than 80 years, initiation of dialysis does not prolong survival compared with active medical therapy.⁵ However, nephrology medical staff in mainland China are poorly prepared for patients with end-of-life ESRD, from the knowledge dimension to the psychological dimension. Only 4.3% claimed to have confidence in their ability to deal with these patients. Although highly recommended by the Kidney Disease: Improving Global Outcomes and World Health Organization,^{8,9} and pioneering countries such as Canada, the United Kingdom, Australia, New Zealand, and Hong Kong,⁵ the development of kidney PC worldwide is unsatisfactory. In the United States, only 0.2% of nephrology fellows pursuing fellowship in PC as a subspecialty training according to the 2019 American Society of Nephrology's Nephrology Fellow Survey.¹⁰ Only 39% of 360 nephrologists from the United States and Canada perceived that they were well prepared to make end-of-life decisions.¹¹ Disappointingly, training specific to kidney PC during nephrology fellowships has not increased in quantity or quality from 2005 to 2015 in a survey from the USA.¹² In Germany, only 20% of physicians from adult renal centers reported that they had successfully established integrated PC approach for patients with ESRD.¹³ Therefore, there is still a long way to go to raise awareness with a global effort to develop kidney supportive care.

Weighing the risks and benefits of maintenance dialysis therapy and initiating withdrawal from dialysis at the right time has become a special and important issue in PC for patients with ESRD.¹⁴ In this study, only 16.0% responders reported that most of

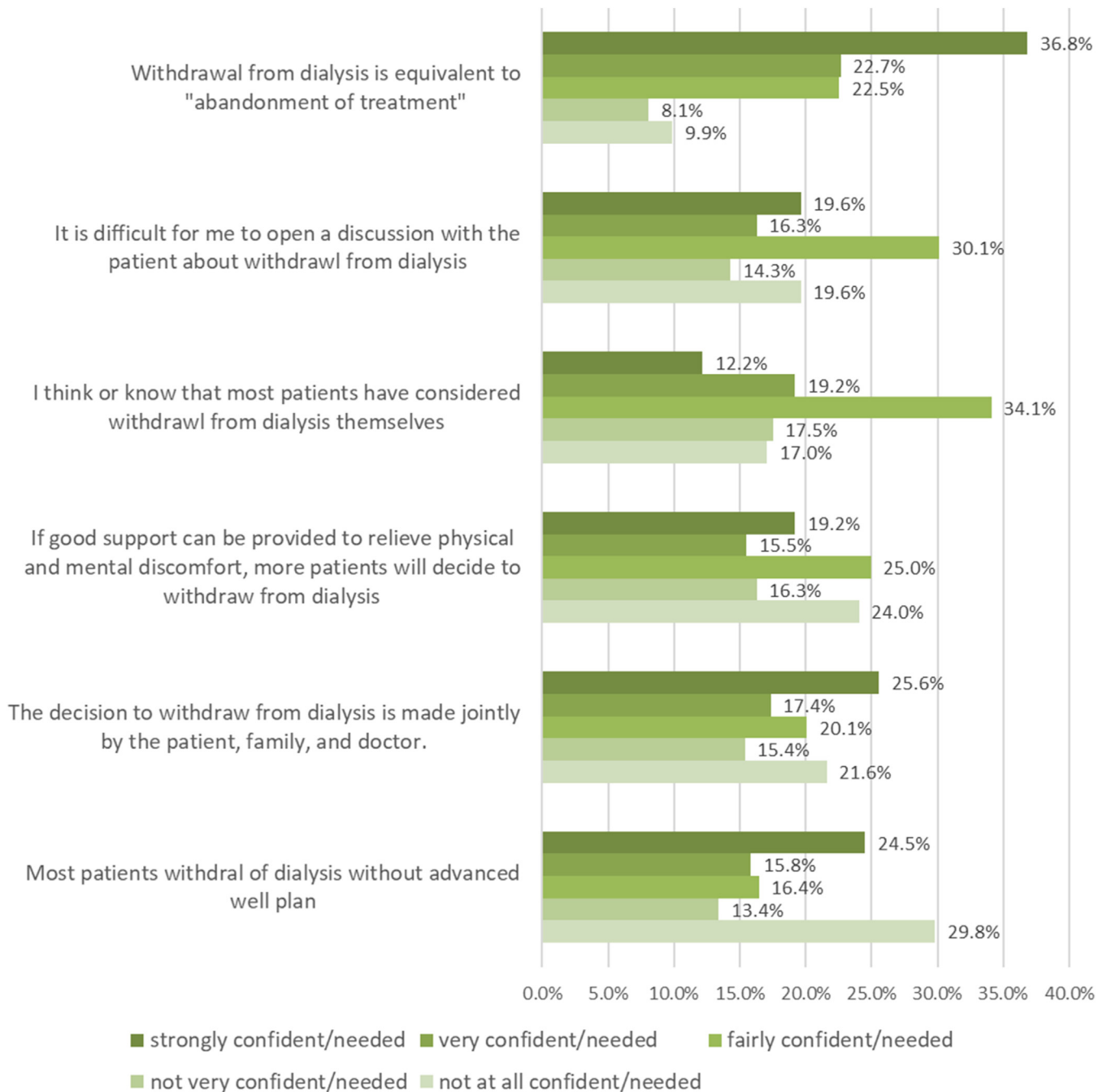


Figure 3. Current nephrology medical staffs' attitudes toward and experiences with withdrawal from dialysis

their patients had well-planned withdrawal from dialysis. A protocol for locally recommended withdrawal from the dialysis process has not been established or followed well in most areas of China. In different cultural backgrounds, the decision to discontinue dialysis is challenging and emotionally burdensome for patients, their families, and medical staff. Some scholars have suggested that when considering withdrawal from dialysis, the following factors need to be considered: the reason for withdrawal, the source and reversibility of pain, the patient's decision-making ability, and the support of

family members. It is important to emphasize that medical care should continue after dialysis is stopped, with a focus on symptom management after dialysis is stopped.⁵ Multidisciplinary collaboration, including nephrologists, nurses, PC teams, dietitians, and social workers, is necessary.⁵ Withdrawal from dialysis and end-stage PC should be considered as an important aspect of generalized renal PC. Successful withdrawal from dialysis should be considered to ensure a dignified death with minimal distress and grief, soothing and supportive family members based on the patient's individual needs.^{15–17}

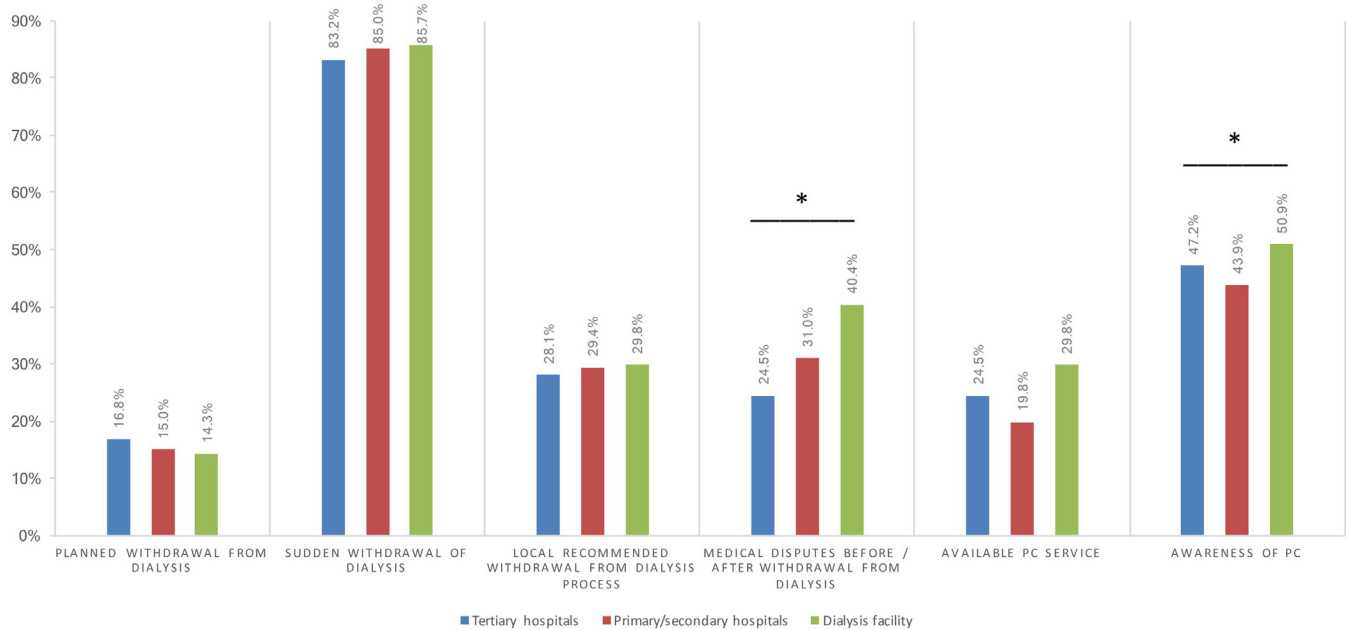


Figure 4. The influence of level of hospital on nephrology medical staffs' attitudes toward and experiences with palliative care and withdrawal from dialysis. *, $P < 0.05$.

In the analysis of the factors influencing kidney PC, this study revealed that sudden withdrawal from dialysis was negatively related to the rate of locally recommended withdrawal from dialysis. Although there was good awareness of PC, local dialysis centers still had more medical disputes before and after withdrawal from dialysis than hospitals. Male nurses had more experience in dealing with deceased cases, less experience with medical disputes before or after withdrawal from dialysis, and PC training experience were independently correlated with a significantly better self-assessing ability for PC. PC training is a key factor related to medical staff attitudes and clinical practice. In a cross-sectional study of nurses caring for noncancer patients in Korea, knowledge was an important factor that significantly correlated with attitudes toward PC, and previous training in hospice, palliative, and end-of-life care positively affected nurses' confidence.¹⁸ Therefore, continuous and integrated kidney PC education programs should be developed to assist in the development of kidney PC and improve the welfare of patients with ESRD. In our study, 95.6% of participants endorsed the addition of PC to the nephrology medical staff training program.

These findings suggest the urgent need for increased access to PC services for patients undergoing maintenance HD in China. To address this need, it is important to ensure that medical staff are adequately trained in PC and have adequate access to information regarding PC services. In addition, it is important to ensure that there is adequate communication between medical staff and patients, and that there is a clear understanding of patients' needs and preferences.

The strengths of this study are its large sample size and multicenter study design, which involved respondents from different areas of China and different levels of medical facilities. Meanwhile, the study's findings could be generalized and representative of both physicians and nurses in nephrology departments. However, this study had some limitations. First, the regional distribution of the participants was not equal, especially considering the regional population and medical resources, leading to potential respondent bias. Second, because renal PC requires teamwork, the opinions of hospital administrators and social workers are critical, but these factors were unfortunately not included in this survey. This topic should be addressed in future studies.

CONCLUSION

In conclusion, the results of this study demonstrate an urgent need for palliative kidney care in patients on maintenance HD in mainland China. The nephrology medical staff had a positive attitude toward kidney PC, but with relatively insufficient PC-related knowledge. To assist in the development of kidney PC and improve the welfare of patients on maintenance HD in mainland China, policymakers should establish institutionalized education and training models, and formulate practice guidelines for kidney PC and withdrawal from dialysis according to cultural background.

DISCLOSURE

The authors declare no conflict of interest.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the manuscript or revising it critically for important intellectual contact, and all authors approved the final version to be published. YQ and XS had full access to all data in the study and take responsibility for the integrity and accuracy of the data analysis. Study conception and design was done by ZS, QY, and NX. Acquisition of data was done by ZS, XJ, and QY. Analysis and interpretation of data was by ZS.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Table S1. Attitudes toward and experiences with withdrawal of dialysis and palliative care in nephrology medical staffs according to different provinces.

Table S2. The multivariate analysis of parameters independently associated with significant better self-assessing ability for palliative care.

Questionnaire Survey on Healthcare Professionals' Awareness of Palliative Care for Hemodialysis Patients.

Checklist for Reporting Results of Internet E-Surveys (CHERRIES).

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