



Addressing the inequalities and growing needs of kidney palliative care

Introduction

Around the world, chronic kidney disease (CKD), which is frequently progressive and typically irreversible, affects up to one in ten persons. By 2040, CKD is expected to rank as the fifth most frequent cause of years of life lost globally due to its growing global burden (1). CKD would advance to end-stage kidney disease (ESKD) if it is not treated and the patient endures the effects of cardiovascular disease and other comorbidities. Therefore, CKD makes a sizable contribution to catastrophic health spending (2). About 0.03% of the population in high-income nations is impacted by the expense of organ transplantation and dialysis, which makes up 2% to 3% of the yearly healthcare budget (3).

Palliative care, which focuses on helping patients who are dealing with a serious illness improve their quality of life by minimizing their symptoms, has increased significantly, according to the World Health Organization. Advanced CKD patients are the target group for kidney palliative care (KPC) (4). Patients who are nearing the end of their life are more likely to receive palliative care as a result of diseases like cancer and, to a lesser extent, circulatory and neurological illnesses (5). Innovative models of care that offer comprehensive care with a focus on quality of life (QOL), support conservative management (non-dialytic therapy of ESKD with incorporation of palliative care), and are patient-centered are necessary for the best management of kidney disease (6,7). These models can be physician-led, palliative care-led, integrated, or nurse-coordinated. The most effective delivery strategy is still a mystery.

Benefits of KPC for conservative therapy

In Hong Kong and other countries, they had initiated different corporate KPC projects as to provide more comprehensive care for those ESKD patients opted for conservative treatment, for more than 10 years. They have conducted different kinds of studies to show the baseline characteristics and clinical outcomes of KPC. Collaboration with the nephrology team improved clinical outcomes in one of their studies, especially pain management for KPC (8). Anemia is a prevalent symptom of ESKD patients that contributes to fatigue and acute admissions. They demonstrated that erythropoietin-stimulating drugs could improve hemoglobin levels, diminish fatigue, and cut down on all-cause hospitalizations in KPC patients (9). Fluid overload is common in ESKD patients who are not on dialysis (10). When combined with loop diuretics, their findings suggested that metolazone could successfully manage fluid overload in KPC patients (11). The advanced care planning (ACP) and enhanced psychosocial support (EPSS) programs, along with an intense follow-up schedule under a particular KPC outpatient service, were introduced as approaches to reduce unnecessary casualty admissions (12,13). These results showed that increasing outpatient follow-up boosted clinic attendance and reduced unnecessary hospital admissions for high-risk patients (12). Therefore, the benefits of KPC included symptom relief, the use of healthcare services, and the psychosocial well-being of patients and their families.

Inequalities in access to palliative care for elderly, dialysis and kidney transplant

Although treatments for renal illness have advanced significantly, there are still some palliative care gaps that must be filled, particularly for elderly patients. One of the biggest gaps in KPC for elderly patients is the lack of awareness of the importance of ACP among healthcare providers, patients, and their families (13). ACP is strongly encouraged, especially when beginning dialysis, as elderly have a poor prognosis for survival and maintaining functional status and are the dialysis patient demographic with the highest rate of increase (14). Therefore, early nephrology participation is essential for the management of ESKD and the selection of the dialysis modality, including the choice not to begin dialysis as requested by patients and families. It is not generally known how these elderly patients' ACP is carried out. Recent study showed that effective decision making intervention could help patients with glomerular filtration rate (GFR) category 5 CKD to make choices for dialysis and other treatments (15). In order to create clinical models that may be widely applied, more study on ACP implementation theories, the effectiveness of the palliative care that is afterwards provided, and the adherence to the ACP decisions made

would be advantageous. Different patient groups may have varying levels of acceptance for ACP, but in order to provide our patients and their families with the greatest care possible, it is crucial to look beyond the cutting-edge literature and into the realms of implementation and efficacy. Studies have defined the facilitators and barriers of the ACP in details (16). Future research must focus on clinically relevant outcomes (i.e., those that matter to patients and their loved ones) as well as healthcare systems and practices when implementing and assessing ACP (16). Concerns of costs and sustainability must also be addressed. One recent analysis of the effects of ACP at a single dialysis center found increased hospice utilization and a decrease in hospital deaths among dialysis patients (17).

Given the high level of comorbidity among dialysis patients in particular, it is essential to link patients' healthcare objectives with the care they get throughout the course of their illness. When patients and their families participate in iterative talks about ACP over the course of their illness, patients' care objectives are more likely to be met (18). For some dialysis patients and their families, ACP contacts with medical providers have been connected to better patient outcomes (19). Despite the existence of tools to promote such conversations, ACP for dialysis patients still falls short (19).

Few studies have recorded the experiences of families with dialysis (20). Several research have contrasted the perspectives of dialysis patients and families on ACP or asked these dyads for guidance on how to approach ACP. It may be especially crucial to know how dialysis patients from lower socioeconomic and racial/ethnic minority communities see ACP given the variations in morbidity and mortality that these groups experience (21).

According to a recent study, there is a significant and persistent difference between the care given to nursing home residents receiving dialysis and what is usually accepted as standard of care for patients with serious illnesses—eliciting and documenting patient goals. Over the same time span, advance directives have increased in other population categories, making this discrepancy substantial (22).

Another problem, especially for patients in distant areas, is access to specialized palliative care treatments or interventions. Elderly patients with renal disease may have a range of symptoms, including pain, fatigue, nausea, and shortness of breath. Effective symptom management is essential to improve patients' quality of life and ensure their maximum comfort. Palliative care may not be accessible for a number of reasons, such as financial constraints, a lack of skilled medical personnel, and geographical limitations (9). The communication between medical staff, elderly patients, and their families might be seriously lacking in KPC for the elderly. Effective communication is crucial to ensure that patients and their families fully understand their diagnosis, prognosis, treatment options, and what to expect as the disease progresses (23). It is possible that some nephrologists lack the palliative care experience required to assist their patients in managing their symptoms and making difficult end-of-life decisions (23). This suggests that these doctors often put off having these discussions till the point when the patient is on the verge of passing die. Therefore, even the frailest and most elderly patients are regularly started on dialysis by some nephrologists, despite research suggesting the practice may not actually significantly prolong patients' lives. These people sought hospice care substantially less frequently as a result. According to one study (24), only 2.3 percent of the 1.55 million Medicare beneficiaries in the U.S. receiving hospice care for those with ESKD. Research indicates that these patients are more likely to require further costly and frequently uncomfortable procedures if they are not assigned to hospice care very once. A recent study found that only 20% of Medicare dialysis participants used hospice care. However, because the majority of these patients only received hospice care for 3 days or less before passing away, their outcomes did not differ significantly from those of patients who did not receive hospice care at all. Patients who used hospice for 15 days or longer, however, were less likely to undergo invasive procedures or be admitted to an intensive care unit. and throughout the final week of life received less expensive medical treatment (24). The carers of elderly patients with CKD may be under a lot of financial, emotional, and physical strain. However, caregivers frequently lack access to resources to assist them in overcoming these challenges.

Similar to this, KPC is an essential part of kidney transplant patient care, particularly when the transplant is failed or the patient, including minors, is not an ideal candidate for the surgery (25). Nevertheless, there are many gaps in the KPC delivery to this group of transplant patients (awareness, palliative care access and coordination issues). Not all hospitals provide palliative care, particularly in remote or rural areas. It could be difficult for some kidney transplant recipients to get the treatment they need as a result. The knowledge and experience necessary to provide kidney transplant patients with proper palliative care may be lacking in some medical practitioners (25). Patients could encounter substandard care due to disparities at different levels (26).

These gaps of KPC must be filled if elderly, dialysis/kidney transplant patients are to receive outstanding, compassionate

care that meets their needs on a physical, emotional, and spiritual level.

Acknowledgments

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the editorial office, *Annals of Palliative Medicine* for the series “Kidney Palliative Care: Accessibility and Clinical Outcomes”. The article did not undergo external peer review.

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-378/coif>). The series “Kidney Palliative Care: Accessibility and Clinical Outcomes” was commissioned by the editorial office without any funding or sponsorship. K.Y.C. serves as an unpaid editorial board member of *Annals of Palliative Medicine* from February 2022 to January 2024 and served as an unpaid Guest Editor of the series. D.Y.H.Y. served as an unpaid Guest Editor of the series. The authors have no other conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Foreman KJ, Marquez N, Dolgert A, et al. Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016–40 for 195 countries and territories. *Lancet* 2018;392:2052–90.
2. Davison SN, Jhangri GS, Koffman J. Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. *BMJ Support Palliat Care* 2016;6:66–74.
3. Vanholder R, Annemans L, Brown E, et al. Reducing the costs of chronic kidney disease while delivering quality health care: a call to action. *Nat Rev Nephrol* 2017;13:393–409.
4. Murtagh FE, Sheerin NS, Addington-Hall J, et al. Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clin J Am Soc Nephrol* 2011;6:1580–90.
5. Robinson MT, Holloway RG. Palliative Care in Neurology. *Mayo Clin Proc* 2017;92:1592–601.
6. Brown MA, Collett GK, Josland EA, et al. CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *Clin J Am Soc Nephrol* 2015;10:260–8.
7. Lakin JR, Sciacca K, Leiter R, et al. Creating KidneyPal: A Specialty-Aligned Palliative Care Service for People with Kidney Disease. *J Pain Symptom Manage* 2022;64:e331–9.
8. Chan KY, Yap DYH, Yip T, et al. Palliative Care Consultation in Advanced Chronic Kidney Disease with Pain. *J Palliat Med* 2018;21:809–14.
9. Chan KY, Li CW, Wong H, et al. Effect of erythropoiesis-stimulating agents on hemoglobin level, fatigue and hospitalization rate in renal palliative care patients. *Int Urol Nephrol* 2014;46:653–7.
10. Chan KY, Yip T, Yap DYH, et al. A Pilot Comprehensive Psychoeducation Program for Fluid Management in Renal Palliative Care Patients: Impact on Health Care Utilization. *J Palliat Med* 2020;23:1518–24.

11. Au HY, Chan KY, Yap DYH, et al. Letter to the Editor: Effects of Add-On Metolazone to High-Dose Oral Frusemide on Refractory Fluid Overload in Patients with End-Stage Kidney Disease Opting for Conservative Management. *J Palliat Med* 2023;26:163-4.
12. Chan KY, Chiu HY, Yap DYH, et al. Impact of structured advance care planning program on patients' wish items and healthcare utilization. *Ann Palliat Med* 2021;10:1421-30.
13. Chan KY, Yip T, Yap DY, et al. Enhanced Psychosocial Support for Caregiver Burden for Patients With Chronic Kidney Failure Choosing Not to Be Treated by Dialysis or Transplantation: A Pilot Randomized Controlled Trial. *Am J Kidney Dis* 2016;67:585-92.
14. Goff SL, Eneanya ND, Feinberg R, et al. Advance care planning: a qualitative study of dialysis patients and families. *Clin J Am Soc Nephrol* 2015;10:390-400.
15. Ladin K, Tighiouart H, Bronzi O, et al. Effectiveness of an Intervention to Improve Decision Making for Older Patients With Advanced Chronic Kidney Disease : A Randomized Controlled Trial. *Ann Intern Med* 2023;176:29-38.
16. Smith C, Da Silva-Gane M, Chandna S, et al. Choosing not to dialyze: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract* 2003;95:c40-6.
17. Joly D, Anglicheau D, Alberti C, et al. Octogenarians reaching end-stage renal disease: cohort study of decision-making and clinical outcomes. *J Am Soc Nephrol* 2003;14:1012-21.
18. Verberne WR, Geers AB, Jellema WT, et al. Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis. *Clin J Am Soc Nephrol* 2016;11:633-40.
19. Tam-Tham H, Ravani P, Zhang J, et al. Association of Initiation of Dialysis With Hospital Length of Stay and Intensity of Care in Older Adults With Kidney Failure. *JAMA Netw Open* 2020;3:e200222.
20. Murtagh FE, Bausewein C, Verne J, et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2014;28:49-58.
21. Carson RC, Juszczak M, Davenport A, et al. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol* 2009;4:1611-9.
22. Kurella Tamura M, Liu S, Montez-Rath ME, et al. Persistent Gaps in Use of Advance Directives Among Nursing Home Residents Receiving Maintenance Dialysis. *JAMA Intern Med* 2017;177:1204-5.
23. Davison SN, Jhangri GS, Holley JL, et al. Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol* 2006;1:1256-62.
24. Wachterman MW, Hailpern SM, Keating NL, et al. Association Between Hospice Length of Stay, Health Care Utilization, and Medicare Costs at the End of Life Among Patients Who Received Maintenance Hemodialysis. *JAMA Intern Med* 2018;178:792-9.
25. Murakami N, Gelfand SL, Sciacca KR, et al. Inpatient Kidney Palliative Care for Kidney Transplant Recipients With Failing Allografts. *Kidney Med* 2021;4:100398.
26. Chan KY, Yap DYH, Singh Harry Gill H. Rethinking Palliative Care in Psychiatry. *JAMA Psychiatry* 2023;80:1089-90.



Kwok Ying Chan



Terence Yip



Desmond Y. H. Yap

Kwok Ying Chan, MD, MRCP, FHKCP

Palliative Medical Unit, Grantham Hospital, Hong Kong, China. (Email: cky842@yahoo.com.hk)

Terence Yip

Renal Unit, Tung Wah Hospital, Hong Kong, China. (Email: yipterence@gmail.com)

Desmond Y. H. Yap

Division of Nephrology, Department of Medicine, Queen Mary Hospital, University of Hong Kong, Hong Kong, China.

(Email: drdesmond yap@gmail.com)

Keywords: Palliative care; advanced chronic kidney disease; caregiver support

Submitted Apr 12, 2023. Accepted for publication Nov 20, 2023. Published online Jan 05, 2024.

doi: 10.21037/apm-23-378

View this article at: <https://dx.doi.org/10.21037/apm-23-378>

Cite this article as: Chan KY, Yip T, Yap DYH. Addressing the inequalities and growing needs of kidney palliative care. *Ann Palliat Med* 2024;13(1):13-17. doi: 10.21037/apm-23-378