

Radically Rethinking Renal Supportive and Palliative Care in South Africa



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The incidence of end-stage kidney disease (ESKD) is increasing worldwide; however, because of resource constraints, access to lifesaving kidney replacement therapy (KRT) remains limited in the state sector in South Africa. National guidelines mandate that only patients who are transplantable be accepted into state chronic dialysis programs. Once a patient is transplanted, there is an opportunity for a new patient to access a chronic dialysis slot. Given the resource scarcity, the South African Constitutional Court has ruled that rationing of dialysis is appropriate; however, this is not without cost both to patients and decision makers. Patients, both adults and pediatric, are often placed on a palliative care (PC) pathway not through choice but through circumstance. Renal supportive care (RSC) and PC involve an interdisciplinary approach to manage patients with ESKD to ensure that symptoms are managed optimally and to provide support during advanced disease. Innovative ways to address patient care at any age must be sought to ensure nonabandonment and adequate care with our limited resources.

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The incidence of ESKD is increasing worldwide, with the poorest populations contributing to the highest risk.¹ The Global Burden of Disease Study (2013) estimated that 956,200 deaths worldwide were directly attributable to chronic kidney disease (CKD), representing a 134.6% increase since 1990.² In South Africa (SA), the burgeoning epidemics of HIV and noncommunicable diseases, particularly hypertension and diabetes mellitus, contribute to the growing burden of ESKD in the country.³ It has become a major public health problem with an enormous economic burden. Despite the rise of CKD, access to lifesaving KRT remains limited in the state sector in SA in adult and even more so in pediatric patients because of significant resource constraints.

Decision making regarding the provision of chronic dialysis is contentious. The South African Constitutional Court has ruled that rationing of dialysis is appropriate, given the resource scarcity.⁴ The resource limitations provoked national guidelines to mandate

that only patients who are transplantable be accepted into chronic dialysis programs in the state sector. In many government facilities, dialysis slots are full, and a new patient can only be accommodated once an existing patient is transplanted or demises. Because of the difficulties involved in decision making, the Western Cape province has developed specific guidelines for selecting patients for KRT. These guidelines were developed after extensive consultation with stakeholders, including patient representatives and ethics experts. The accountability for reasonableness approach and the overarching ethical principle of utilitarianism formed the backbone of this process.⁵

A retrospective review of patients presented to the selection committee for chronic dialysis was conducted at Groote Schuur Hospital, Cape Town, SA, a state sector tertiary center. There were 564 adolescent and adult patients assessed over a 5-year period (1 January 2008–31 December 2012). Half of the patients came from low socioeconomic areas, and presentation was often late with either overt uremia or fluid overload occurring in 44.4% and 43.9% of cases, respectively. More than half (53.9%) of the patients were not selected for the chronic dialysis program.⁶ Consequently, the majority of patients were placed on a PC pathway not through choice but through circumstance.

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PC is an essential and increasingly recognized component of health care. In alignment with the World Health Organization universal health coverage, all patients of any age with ESKD (regardless of whether dialysis is an option) should have access to the health services they require to ensure adequate care for themselves and their families.⁷ The World Health Assembly Declaration 67.19 states that PC is “fundamental in improving quality of life” and there is an “urgent need to include PC along the continuum of care.”⁸ PC is also directly aligned with universal health coverage, which states “All people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective.”^{9,10} Nonetheless, a PC approach should not excuse government bodies from investing in adequate renal services, exploring innovative thinking such as public-private partnerships, and supporting renal transplantation programs.

RSC and PC involve an interdisciplinary approach involving the integration of nephrology (adult and paediatric), PC, family medicine, pediatricians, and social work to ensure that symptoms of ESKD are managed optimally in a supportive framework. The care should assist patients not able to gain access to dialysis as well as provide care for patients when dialysis is not the best option for the patient or their families. There are recommendations that can assist a clinician in deciding whether dialysis be commenced at all or withdrawn.¹¹ There are also patients on dialysis or awaiting dialysis who may have severe biopsychosocial symptoms and require comprehensive care to improve their symptoms and relieve suffering. RSC/PC should be initiated timely in any chronic renal patient whose life expectancy may be shortened and not only at the very end of a patient’s life and should include both advance care planning and end-of-life care.¹²

SA: The Current Situation

The South African Health Structure

South African health care is composed of both private and state health sectors. The private health sector is composed of private-for-profit hospitals and general practitioner practices and serves 36% of the population. Private health care is funded on a fee-for-service basis through either out-of-pocket payments or medical insurance schemes. Forty-six percent of all SA’s health care expenditure is in the private health care sector, with the major cost drivers being the private hospitals.¹³

The state sector (government funded) is focused on primary health care that is distributed in the district health system. The district health system is further

supported by regional state-run secondary, tertiary, and quaternary hospitals. Care is free of charge for those unable to afford it, but renal care, especially in children and adolescents outside of major cities, may not be readily available. Although the national government is responsible for national health policy, the 9 provincial governments are responsible for provincial policy development and health service delivery.

Although there is a state-funded health care sector, PC services are mainly found in community nongovernment nonprofit organizations limited to only a few recognized state hospitals in the country.¹⁴ In 2019, PC guidelines were first introduced into the South African Standard Treatment Guidelines and Essential Medicine Lists for hospital settings and primary care ensuring that PC essential drugs are made available. However, PC is still not aligned with many life-threatening conditions in these guidelines, including ESKD.¹⁵

Renal Care Across the Health Care Continuum

Globally, steps are being taken to integrate PC into the care continuum of renal patients.¹⁶ However, innovative ways to address patient care in a South African setting are urgently needed to ensure adequate care with our limited resources. A multidisciplinary approach that identifies and tackles common problems using shared skill sets across the care continuum is imperative to ensure that all patients receive adequate care at the right place and at the right time.

Nephrologists mainly work within a tertiary health care setting and predominantly see patients who have been referred from primary and secondary levels of care. These clinicians are tasked with making complex decisions on who qualifies for dialysis and thereafter coordinating their ongoing care. Many nephrologists feel unequipped with the knowledge and skills to ensure excellent renal care for patients when dialysis is not an option.¹⁶ RSC/PC is currently not a component of the nephrology curriculum.

In contrast to tertiary care, primary care physicians and nurses are at the forefront in making decisions on which patients are referred to tertiary institutions and commonly manage patients and families who do not receive dialysis. Currently, in the primary care setting, there is a lack of trained PC providers and limited PC resources, expertise, and guidelines to palliate ESKD in the South African setting.

Barriers to Providing This Care

There are numerous barriers that currently prevent the optimal care of patients with ESKD in SA. First, there is a vast disparity of access to KRT in the state versus the private sector. The degree of disparity can be seen by the dramatic increase in private sector dialysis facilities

compared with the state sector. SA had a national renal registry that collapsed in 1994 and was reinstated in 2014. During this period, there has been a 200% increase in private dialysis facilities. In contrast, there has been limited growth in the state sector, which currently accommodates approximately 80% of the population.¹⁷

Second, there is also a huge problem of late referral for nephrology care, with most patients entering tertiary- or quaternary-level care at the point of ESKD. ESKD is often asymptomatic and a silent killer in both adults and children alike. There is a lack of integration of care between primary, secondary, and tertiary state facilities in the country. Early identification and management of renal disease are essential at primary- and secondary-level care because renal function preservation is vital in a system with limited access to KRT. Third, trajectories of CKD are often difficult to predict. Compounding this is a high use of health resources as patients recirculate into services once the decision for PC has been made. It also emphasizes the underuse of home-based care and community-oriented primary care workers.

Renal care may be localized in tertiary centers and not available in the community, often requiring long-distance traveling to a center far from home, especially in pediatrics where there are very few pediatric renal centers (4 or 5 only) in the country.

Lastly, before the initiation of an RSC/PC consensus workshop, there was a lack of any guidelines to assist primary care physicians working in a South African context to assist with patients with ESKD. A challenging concern from nephrologists has been that providing guidelines may excuse government bodies from investing in adequate renal services and supporting renal transplantation programs. RSC/PC guidelines should not be an excuse for poor care nor an excuse for restricting dialysis. It is essential that lobbying for more dialysis slots must remain paramount, and transplantation needs to be strengthened.

Pediatrics and a Unique Set of Challenges

Pediatrics has a unique set of challenges when it comes to pediatric palliative care (PPC) and RSC. The decision regarding dialysis modality, transplantation, and RSC/PPC needs to be individualized. It will be influenced by community infrastructure, family stability, financial resources, existing health care systems, compliance record, and quality of life. RSC/PPC should be considered through a shared decision-making process. However, it is essential that the nuclear family and, if possible, the extended family be involved in the decision-making process; this is true even for adolescents.

Neonates and infants with ESKD and additional comorbidities have a poorer prognosis and are challenging from an access and surgical perspective. RSC/PPC may often be the care pathway for many patients in this group. Psychosocial support, including anticipatory bereavement and perinatal advance care planning, should be integrated into the management plan from diagnosis.¹⁸ PPC specialists are rare in low- and low-middle income countries. Therefore, it is imperative that the generalist pediatrician or neonatologist (or general practitioner) assist with PC, thereby forming part of the nephrology team.¹⁹ There is a heightened recognition of the benefits of a palliative approach across the neonatal, pediatric, and adolescent life span. Many pediatric patients with ESKD may survive for many years even without dialysis; thus, management of their symptoms, growth, and schooling may need attention. Another particularly vulnerable group is adolescents who are reaching the end of their kidney life span and require transition into adult services. Unfortunately, there is still no government PPC policy implementation in SA. PPC in SA is currently provided by the nongovernmental organization sector.

Need for PC for ESKD in SA

The high demand for PC is never more recognizable than in the current South African setting. Nephrology is unique in that the rationing strategy is overt, and clinicians need to regularly make tough decisions to fill open dialysis slots. There have been policies developed to integrate PC into the government health system, but, to date, minimal funding has been available to start this process.²⁰ The lack of available KRT together with limited PC services leave many patients and their families unjustifiably suffering in their last days of life. Besides the intense emotional trauma, this shortage also leads to legal cases and complaints against the public health care sector for not providing dialysis or appropriate care once dialysis is withdrawn or denied.⁴ This is compounded by the moral injury experienced by medical teams in which the feeling of abandonment of their patients within the system is profound.²¹

Creation of the RSC/PC Guidelines in SA

The integration of PC within renal care is an active process. Clear RSC/PC guidelines are required to assist with optimal care within the context with which we practice. In Cape Town, a process of consensus was undertaken between multiple stakeholders from across the country including nephrology, primary-level care, PC providers, patient family members affected by ESKD, and hospital management to create a consensus statement to assist with RSC/PC. It was salient that the document remained cognizant of the unique challenges

Table 1. Key points from the “Renal palliative and supportive care in South Africa—a consensus statement”

1.	Prognostication and communication around ESKD with patient and families
2.	How to manage breaking bad news and serious illness conversations
3.	Patient-centred decision making within the multidisciplinary team
4.	When to consider a conservative pathway in patients with ESKD
5.	Strategies on how to preserve residual kidney function
6.	Symptom management for patients with ESKD: including validated scoring tools
7.	Advance care planning and managing end-of-life care
8.	Service provision and collaborative care—models of how to provide care
9.	Dedicated section for pediatrics (including neonates and adolescents)
10.	Future areas of research

ESKD, end-stage kidney disease.

and resource constraints faced in SA.²² Table 1 outlines the key topics that were included in the document.

The main areas discussed included decision making regarding the initiation of KRT, symptom management and complications of ESKD, communication with patients and families, advance care planning, preservation of renal function, service provision, and collaborative management of end-of-life care. During this meeting, a consensus was reached; however, the multiple barriers to care were identified. The guidelines have been circulated and are currently being used at all levels of care.

Possible Ways to Create an RSC/PC Platform

Health care use in advanced CKD is high. A prospective study including 2 ESKD cohorts (i.e., dialysis and supportive care only) reported a high use of acute care services in the last year of life. The majority (79%) visited the emergency department, multiple visits were common, and 84% required in-patient admission.²³ There are limited data on the cost effectiveness of RSC frameworks²²; however, there is a well-established cost benefit in oncology.²⁴ RSC/PC may decrease hospitalizations, intensive care, and emergency department admissions. The aim is to reduce the deaths in acute care facilities through better symptom management and planned care pathways.²³ Further research evaluating cost and health outcomes in ESKD is required.

Cost benefit needs to be analyzed in terms of personal cost as well. The burden experienced by families has been reported in the literature including significant physical, emotional, social, and economic dimensions. An integrated service from the commencement of dialysis until death and into bereavement to support families was reported as an option to improve clinical care.²⁵

Models of RSC/PC also need to coordinate care for patients with multiple comorbidities who are treated across different health care settings by numerous care providers. Perceived barriers reported by primary care

physicians to collaborate with nephrologists include (i) a lack of adequate information exchange, (ii) unclear roles and responsibilities, and (iii) limited access to nephrologists. Family physicians expressed a desire for better communication tools and clear CKD care plans.²⁶

Proposed models of care need to be cost-effective with strong collaborative efforts and teamwork. In a resource-limited setting, upskilling staff from all health care levels through education and exposure is essential. A multidisciplinary RSC/PC service could serve as a platform to expand training. Additionally, it will increase exposure and awareness of the need for PC. It would be ideal for the team to include a nephrologist, primary caregiver (general practitioner/family physician), PC physician, social worker, and nursing staff. This clinic could be established at a tertiary center, with primary health care physicians rotating through the service and nephrologists supporting community physicians with outreach. Once a care plan is formulated, then it could be continued at primary-level care including home-based services.

Improved communication is essential between all health care levels. This can be achieved with a simple patient booklet (roadmap), which would detail advanced care planning and current treatments. Electronic health platforms are also becoming increasingly used. Technology (e.g., Zoom/Skype) can link off-site health professionals to the expertise of the RSC/PC multidisciplinary team. This could assist with complex clinical and symptom management.

The effectiveness of using a Web-based approach to deliver health care interventions has been demonstrated^{27,28} and recommended as a medium to help increase awareness and improve capacity regarding the provision of PC.²⁹ Ireland reported on their creation of an eHEALTH information resource for family carers supporting a patient receiving PC. The information needs of the families included knowledge on the condition, medication, patient hygiene, nutritional care, and contacts for support (emergency and emotional) for both the patient and the carer.³⁰ This could act as a tool to connect family and relatives to resources and support structures in both the private, public, and nongovernmental organization sectors.

The team approach is essential. This includes home-based care and community nurses and may involve trained volunteers as a possible innovative solution. The presence and availability of nurses has been found to be crucial for the success of a volunteer’s program.³¹ Upskilling community-based nurse practitioners to train, monitor, and supervise lay counselors, volunteers, or home-based carers remains a viable option to enhance care within our communities.

Continued advocacy is essential for RSC/PC to grow. In the state sector, adequate resource allocation, lobbying for restricted medications accessible at all levels of care (i.e., morphine, gabapentin, and fentanyl patches), and the development of expertise within this field is essential to grow and encourage an environment for skills development.³² Further research is essential in this growing field to improve RSC/PC for patients and provide the basis for policy development.^{33,34} Key areas that have been identified for review include guideline uptake, validation of prognostication tools within our unique SA-specific context, and future comparison of symptom burden after the implementation of PC platforms.

SA is a country with huge socioeconomic and health disparities, but the omission of palliative care in ESKD in all health sectors can be regarded as an abuse of patients' basic human rights.³⁵ The ethical principal of beneficence, to alleviate suffering for patients and families, by including PC in the continuum of care is essential. Ensuring nonabandonment is also critical for optimal care of patients with ESKD. It is important to emphasize that PC should not be an excuse for improving preventative and curative medicine.

Conclusion

The increasing need for improved RSC/PC led to the first consensus statement in SA, which has been published.²² This was a monumental first step in providing education regarding the fundamentals of RSC/PC for health care providers. The guidelines focus on prognostication, communication strategies, advance care planning, and treatment for adults and children with ESKD. Importantly, it also discusses strategies to optimize service provision in a resource-limited environment. For RSC/PC to flourish in SA, there needs to be commitment from the government, hospital management, pharmacy, and medical insurance companies to support this fundamental aspect of patient care. The consensus statement gives clinicians a scaffold to provide patients with better care and to challenge existing practices.

DISCLOSURE

All the authors declared no competing interests.

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REFERENCES

- Jha V, Garcia-Garcia G, Iseki K, et al. Chronic kidney disease: global dimension and perspectives. *Lancet*. 2013;382:260–272.
- Naghavi M, Wang H, Lozano R, et al, GBD 2013 Mortality and Causes of Death Collaborators. Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet*. 2015;385:117–171.
- Mayosi BM, Lawn JE, van Niekerk A, et al. Health in South Africa: changes and challenges since 2009. *Lancet*. 2012;380:2029–2043.
- Moosa MR, Wearne N. Invited commentary should we be rationing dialysis in South Africa in the 21st century? *Perit Dial Int*. 2018;38:84–88.
- Moosa MR, Maree JD, Chirehwa MT, et al. Use of the 'accountability for reasonableness' approach to improve fairness in accessing dialysis in a middle-income country. *PLoS One*. 2016;11:e0164201.
- Kilonzo KG, Jones ES, Okpechi IG, et al. Disparities in dialysis allocation: an audit from the new South Africa. *PLoS One*. 2017;12:e0176041.
- Available at: https://www.who.int/health_financing/universal_coverage_definition/en/: Health Financing. Accessed June 24, 2020.
- Available at: https://apps.who.int/gb/e/e_wha67.html. Accessed June 24, 2020.
- World Health Assembly. Strengthening of palliative care as a component of integrated treatment within the continuum of care. EB134.R7, (Sixty-seventh World Health Assembly, 9.4); 2014, World Health Assembly, Geneva, Switzerland.
- World Health Organisation. *Declaration of Astana. Global Conference on Primary Health Care: The World Health Organisation and the UNICEF, Astana, Kazakhstan*. 2018.
- Renal Physician Association. *Guideline recommendations and their rationale for the treatment of adult patients. Shared Decision-Making in the Appropriate Initiation of and Withdrawal From Dialysis*. 2nd ed. Rockville, MD: Renal Physicians Association; 2020.
- Sepúlveda C, Marlin A, Yoshida T, et al. Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage*. 2002;24:91–96.
- Coovadia H, Jewkes R, Barron P, et al. The health and health system of South Africa: historical roots of current public health challenges. *Lancet*. 2009;374:817–834.
- Gwyther L, Krause R, Cupido C, et al. The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. *S Afr Med J*. 2018;108:86–88.
- National Department of Health. *Hospital Level (Adults) Standard Treatment Guidelines and Essential Medicines List*. 5th ed. Pretoria, South Africa: National Department of Health; 2019.
- Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int*. 2015;88:447–459.
- Davids MR, Marais N, Jacobs JC. South African renal registry annual report 2015. *Afr J Nephrol*. 2017;20:201–213.
- Rees L. Management of the infant with end-stage renal failure. *Nephrol Dial Transplant*. 2002;17:1564–1567.
- Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med*. 2013;368:1173–1175.

20. The South African Department of Health. *National Policy Framework and Strategy on Palliative Care 2017-2022*; 2017. Available at: <http://www.health.gov.za/policies-and-guidelines/>. Accessed January 8, 2021.
21. Talbot SG, Dean W. Physicians aren't 'burning out.' They're suffering from moral injury. *STATNews*. 2018;7:18.
22. Wearne N, Krause R, Davidson B, et al. Renal palliative and supportive care in South Africa—a consensus statement. *Afr J Nephrol*. 2020;23:86–107.
23. Chambers S, Healy H, Hoy WE, et al. Health service utilisation during the last year of life: a prospective, longitudinal study of the pathways of patients with chronic kidney disease stages 3-5. *BMC Palliat Care*. 2018;17:57.
24. Smith S, Brick A, O'Hara S, et al. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. 2014;28:130–150.
25. Maddalena V, O'Shea F, Barrett B. An exploration of palliative care needs of people with end-stage renal disease on dialysis: family caregiver's perspectives. *J Palliat Care*. 2018;33:19–25.
26. Greer RC, Liu Y, Cavanaugh K, et al. Primary care physicians' perceived barriers to nephrology referral and co-management of patients with CKD: a qualitative study. *J Gen Intern Med*. 2019;34:1228–1235.
27. O'Halloran P, Scott D, Reid J, et al. Multimedia psycho-educational interventions to support patient self-care in degenerative conditions: a realist review. *Palliat Support Care*. 2015;13:1473–1486.
28. Gustafson DH, DuBenske LL, Atwood AK, et al. Reducing symptom distress in patients with advanced cancer using an e-alert system for caregivers: pooled analysis of two randomized clinical trials. *J Med Internet Res*. 2017;19:e354.
29. Street AF, Swift K, Annells M, et al. Developing a web-based information resource for palliative care: an action-research inspired approach. *BMC Med Inform Decis Mak*. 2007;7:26.
30. Scott D, Hudson P, Charnley K, et al. Development of an eHealth information resource for family carers supporting a person receiving palliative care on the island of Ireland. *BMC Palliat Care*. 2019;18:74.
31. Vanderstichelen S, Cohen J, Van Wesemael Y, et al. Perspectives on volunteer-professional collaboration in palliative care: a qualitative study among volunteers, patients, family carers, and health care professionals. *J Pain Symptom Manage*. 2019;58:198–207.e7.
32. Stanley S, McDougall A, Chapman L, et al. Development of a hospice research culture through staff development, education and collaboration. *BMJ Support Palliat Care*. 2019;9:359–360.
33. Etkind S, Bone A, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med*. 2017;15:102.
34. Payne S, Preston N, Turner M, et al. *Research in palliative care: can hospices afford not to be involved. A report for the commission into the future of hospice care*. London, UK: National Council for Palliative Care; 2013.
35. Brennan F. Palliative care as an international human right. *J Pain Symptom Manage*. 2007;33:494–499.