Developing Supportive Care Services for Patients with Kidney Failure: An Idea Whose Time Has Come

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Abstract

The number of patients developing kidney failure is increasing globally including in India. Dialysis is not the most optimal treatment for a number of these patients such as the elderly, the frail and those with multiple comorbidities and limited life expectancy. Moreover, some patients may prefer not to undergo dialysis. Supportive care focused on symptom management and improving the quality of life is a legitimate treatment option in these situations. It can be delivered alongside dialysis or to patients who choose to receive only conservative care and is being increasingly recognised as an integral component of holistic kidney care. Kidney care provider ecosystem needs to become aware of the principles of the principles of shared decision making, advanced care planning, understanding how to provide emotional, spiritual and information support to the patient and their families and when needed bereavement care. Supportive care facilities are underdeveloped in most low resource settings including in India. There is a need to develop capacity in this area so that our patients can derive the benefit of the full range of treatment options for kidney disease.

Keywords: Chronic kidney disease, kidney supportive care, palliative care

A 2015 systematic review in the *Lancet* provided numbers to one of the worst kept secrets in nephrology. The authors of the review estimated that in 2010, there were about 2.3 million people on kidney replacement therapy (dialysis and transplantation), worldwide. However, they estimated that another 2–7 million people who needed this life-saving treatment around the world died the same year because of lack of access. The number of people who died was disproportionately greater in the lower- and lower middle-income countries. Given the rising global incidence of kidney failure that will push kidney disease failure up the rank of causes of death from the current 16th to the 5th place around the world by 2040, we are staring at a disaster.

Kidney transplantation is the form of kidney replacement therapy (KRT) best in terms of cost-effectivity and quality of life in suitable subjects. However, only a minority of patients with kidney failure are able to get a transplantation. The overwhelming majority of patients with kidney failure will be advised to get dialysis. While dialysis has added a number of years to the lives of people with kidney failure, the limitations of these therapies have also been recognized.

Access this article online

Quick Response Code:

Website: www.jpalliativecare.com

DOI: 10.4103/ijpc.ijpc_105_21

The population developing kidney failure and needing dialysis is getting older, and these people have multiple comorbidities such as cardiovascular disease, cerebrovascular disease, peripheral vascular disease, general frailty, and visual disturbances and might have suffered from other illnesses such as cancers.

Are we serving all our patients optimally by putting them on dialysis? This question has been asked increasingly in recent years in the kidney health community. The trigger for this question is the recognition that dialysis does not help a significant proportion of patients achieve their life goals and may not even add to their lifespan. Therefore, it may not be the most appropriate treatment option for everyone. The International

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Submitted: 07-Apr-21 **Accepted:** 09-Apr-21 **Published:** 30-May-21

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How to cite this article: Jha V. Developing supportive care services for patients with kidney failure: An idea whose time has come. Indian J Palliat Care 2021;27:S3-5.

Society of Nephrology (ISN), as part of its strategic plan around developing optimal treatment for patients with kidney failure, has strongly advocated for health systems to developed kidney replacement therapy programs using the concept of integrated kidney care [Figure 1]. According to this, alongside dialysis and kidney transplantation, kidney supportive care should form an integral part of management of patients with kidney failure. Supportive care is focused on symptom management and aims to improve quality of life and can either be delivered alongside dialysis, or to patients receiving nondialytic conservative care.

Dialysis can be invasive and have a detrimental effect on patient's quality of life and productivity. Among the oldest individuals and those with major comorbidities, a number of observational studies have shown no clear net survival or quality of life benefit from preparing for dialysis compared with having comprehensive conservative care. These patients have high symptom burden and complex physical, mental, and social healthcare needs and are often hospitalized for extended periods of time, which raises cost of care for individuals and healthcare systems. Measures of health-related quality of life are far worse than for the general population and predict

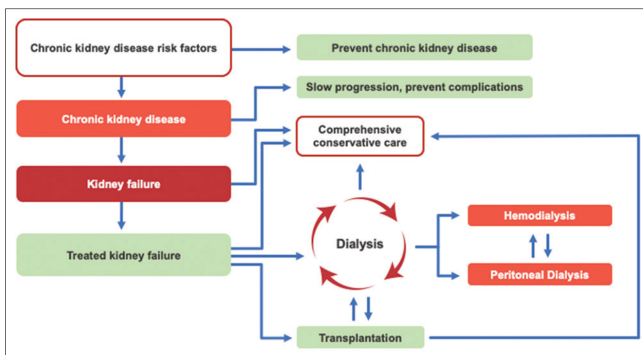

Figure 1: Integrated kidney replacement therapy. Source: Working Groups of the International Society of Nephrology's 2nd Global Kidney Health Summit. Increasing access to integrated ESKD care as part of universal health coverage. Kidney Int. 2019 Apr; 95 (4S):S1-S33

hospitalization and mortality. In older patients, initiation of dialysis may result in increased frailty, loss of independence, and decreased cognitive function.

The ISN has defined supportive care in the setting of kidney disease to make it consistent with the World Health Organization's description of palliative care ". an approach that improves the quality of life of (people with kidney disease) and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."

It is important to emphasize that during the journey through the continuum of clinical care, patients should start receiving supportive care for symptom control even before needing KRT [Figure 2]. Supportive care is the foremost domain of integrated kidney care for individuals receiving conservative care. For many of those on dialysis, a choice may need to be made to withdraw as the functional status deteriorates.

Supportive care is continuous through chronic kidney disease, kidney failure/KRT, end-of-life, and bereavement phases. While the role of shared decision-making has been emphasized in helping patients and families to choose the most appropriate KRT including supportive care, such choices may not be available for individuals with kidney failure in low- and lower middle-income countries who do not have the ability to cover the direct treatment costs. In such settings, where dialysis is unaffordable for many patients, the ability to engage in shared decision-making is limited and the only viable treatment choice is kidney supportive care. Paradoxically, kidney supportive care facilities are scarce in low-income countries. In the absence of such treatment, patients are often abandoned by the healthcare system.

Hence, what is the solution? Professionals in the developing countries engaged in providing care to patients with kidney disease need to develop supported care in the suite of

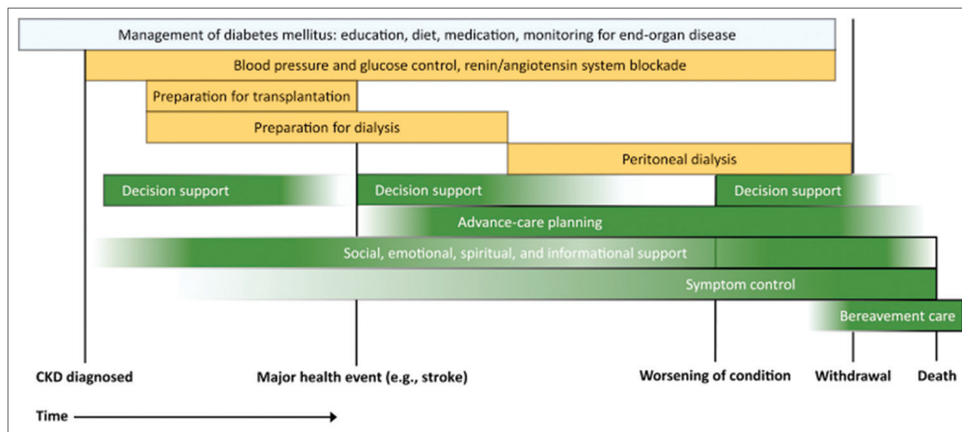

Figure 2: Hypothetical patient journey showing variation in components of kidney care with disease/time progression. Source: Hole B, Hemmelgarn B, Brown E, Brown M, McCulloch MI, Zuniga C, *et al*. Supportive care for end-stage kidney disease: An integral part of kidney services across a range of income settings around the world. Kidney Int Suppl (2011) 2020;10:e86-94

available services. This needs to start with better education and awareness. The science of supportive care has made rapid advances in recent years. Professionals in developed countries are increasingly comfortable raising nondialytic supportive care as a viable treatment option with their patients where they deem this to be the most appropriate course of action. Data from some high-income countries suggest that for every new patient who starts dialysis, another chooses to supportive care. A number of decision support tools that allow patients and families to better understand their options are now available to help with these conversations. Developing country nephrologists should get over the feeling that offering supportive care is somehow admitting defeat. It is an active treatment which has the ability to help patients achieve their life goals and improve their quality of life while avoiding unnecessary and wasteful expenditure. As kidney health professionals engage in the process of developing robust get any supportive care services, nephrology teams should seek out and engage with the available general or cancer palliative care experts.

The ISN's strategic plan for integrated KRT emphasizes the need to improve information on prognosis and support, develop context-specific evidence, establishing appropriate metrics for monitoring care, clear communication of the role of supportive care, and integrating supportive care into existing healthcare infrastructures.

As we move away from providing treatment that is decided by the medical team to one that is chosen by the patients and their families, we will find that an ever increasing scope for implementing supportive care services in the most appropriate manner. It is important that other stakeholders including funders and policymakers also recognize the importance of this modality and ensure its integration in the local healthcare systems and provide funding so that it can be implemented appropriately.

Financial support and sponsorship

Nil.

Conflicts of interest

VJ has research grants from Baxter, GSK and reports Consultancy and Advisory Board honoraria from Baxter Healthcare, and AstraZeneca, outside the published work. All monies are paid to the institution.