Providing dialysis in India - many missing pieces in the puzzle

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Every year, approximately 225,000-275,000 people die of advanced kidney failure in India every year (1). Most of these deaths can be avoided if these patients had access to regular good quality treatment to replace the lost kidney function.

Ever since the passage of the Medicare Act by US Congress in 1972, access to dialysis for patients with advanced kidney failure has become the benchmark for societal willingness to pay for medical care (2). According to the Ethical Considerations section of the Australian Guidelines: "*Availability of resources should not be a reason to deny a patient access onto dialysis. Decisions to recommend or not to recommend dialysis should not be influenced by either availability of resources or potential litigation* (3)." Mindful of similar principles, governments around the world have been setting up dialysis facilities for their populations. A survey carried out by the International Society of Nephrology in 2017 found that dialysis was available in all of 162 countries from where data could be collected (4). This is despite the fact that long-term dialysis is one of the most expensive treatments. The World Health Organization uses dialysis as an exemplar of a cost-ineffective treatment (5), suggesting it should not be prioritised by health systems that want to maximise the utility of limited funds available for healthcare delivery to their populations.

Despite the high cost, governments consider it their duty to improve access to dialysis for their populations, largely because it is a major cause of catastrophic out-of-pocket healthcare expenditure and disproportionately affects the disadvantaged sections of the society. Treatment of kidney diseases is associated with an estimated 188 million cases of catastrophic health expenditure (defined as >40% of monthly non-food spending) in low- and middle-income countries, *more than that for any other disease condition* (6). A study from Kerala, one of the more prosperous states in India, showed that families of more than 90% of patients on dialysis suffered catastrophic healthcare expenditure. About three-fourths were forced into distress-financing (borrowing, selling possessions) (7). There are heart-rending stories of families pulling children out of school, pushing them into labour market and being reduced to surviving on handouts, because they do not want to abandon a loved one (8). In light of these facts, a case can be made for creating a safety net to protect the worst-off and most vulnerable from such consequences.

Having decided to provide dialysis, the next question that governments need to tackle is how to provide this treatment in an equitable, cost effective and socially acceptable way. The first thing to say here is that the best treatment, superior to dialysis by miles and miles - both for the patient and for the healthcare system - is kidney transplantation (9). So, the healthcare system needs to invest in maximising the availability of transplantation to all suitable subjects by removing the financial barriers to this treatment and improving availability of organs, by developing efficient program to retrieve organs from deceased donors.

Many patients, however, must remain on dialysis - either because they are not medically suitable for a transplant, or because an organ is not available (9). Dialysis comes in two flavors: hemodialysis in which a patient has to visit a bricks and mortar dialysis centre two or three times a week, get hooked to a dialysis machine and undergo a 4-5 hour session of cleaning of blood each time. Dialysis centers are typically concentrated in urban locations (including those proposed in the National Program), which forces patients from rural remote locations to undertake long and expensive travel, often with a caregiver resulting is loss of productivity and wages (10).

The other modality is peritoneal dialysis (PD). This modality takes advantage of a natural membrane lining the inside of our bellies (also called the peritoneal cavity) that is rich with capillary network through which blood is running constantly. PD involves 3-4 daily dialysis exchanges, each lasting 15-20 minutes. Dialysis fluid stays in the belly in between exchanges, allowing movement of the accumulated toxins from the blood flowing in peritoneal capillaries to the dialysis fluid. PD can be done at home, needs the patient or a caregiver to learn a simple technique and does not require any equipment or skilled personnel.

Setting up hemodialysis requires capital investment to create a facility, purchase dialysis machines, water purification plant, and employing trained manpower (11). None of this is needed for PD. It is generally accepted that for a vast majority of patients, both forms of dialysis are equally good in terms of outcome. Generally, peritoneal dialysis costs much less to the healthcare system, and provides a better quality of life to a vast majority of patients.

It makes sense, therefore, for countries intending to set up mass based dialysis programs to focus on PD. When Thailand introduced universal coverage for dialysis in 2008, it did so through a 'PD First' policy (12). All patients eligible for dialysis under the Thai Social Security scheme are required to receive PD, unless there is a compelling medical reason to not to do so. This policy was adopted after a rigorous health technology assessment, which favoured PD (13). Similar programs exist in Hong Kong and parts of Mexico and South Africa (14). China has a less strict policy, but still favours use of PD (PD-preferred). Other countries that have state funded health programs (Australia, New Zealand, UK, Canada) have taken steps to increase the use of PD to reduce the cost of care while maintaining quality of care (15-18). The use of home dialysis, including PD, has increased substantially in Australia after a systematic effort (19). Importantly, the outcome of patients on PD continues to improve year-on-year in these countries, whereas it seems to have plateaued for those on HD. Even USA, the last bastion of HD, has seen a recent surge in uptake of PD following introduction of a reimbursement strategy to incentivize dialysis providers to place more patients on PD (17).

When the National Dialysis program (now called the Pradhan Mantri National Dialysis Programme) was announced in India, the focus was entirely on hemodialysis (20) - the government envisaged setting up a 8-station dialysis facility in each district (21). Given that there are 688 districts in India, the program will have 5504 dialysis stations. If all stations run three 4-hour shifts a day, 16,512 patients will be treated daily. If each patient were to get 2 sessions of dialysis every week (the global standard is three sessions a week), the program would be able to provide dialysis to 49,536 patients at full capacity. Even if we assume that about 50-60% of all new patients with end-stage kidney failure are eligible to receive dialysis under this scheme, this number will have to be increased at least 3 times just to accommodate the patients that will develop kidney failure just in the first year of the scheme. As these patients survive to the next year, an equal number will get added in the second year, immediately doubling the demand. One expects the number of patients surviving to show an year-on-year increase till the prevalence rises to about 5 times the number in the first year, before the number of patients being added is balanced by those either dying or dropping out due to other reasons (10).

It is clear therefore that if the promise of the Pradhan Mantri National Dialysis Programme is to be realised, alternatives to hemodialysis, especially PD, must be included. The recent announcement by the Union government (22) recognises this reality and creates an enabling environment to develop mass-based PD programs. A lot of work lies ahead, however. Community-based teams need to be trained in supporting patients on PD in their homes. Use of remote monitoring technologies hold promise (23). We and others have shown that simple technologies that allow patients to share important health data and stay in touch with care providers, have the ability to improve the quality of care and increase patient confidence. PD programs around the world are developed around non-physician care providers, with nurses typically being the focal point. Doctors are needed for specific reasons - like deciding when to start dialysis, inserting the dialysis catheter and writing the prescription. After this, the routine care can be fully supervised by nurses or clinical co-ordinators using standardised protocols, with appropriate referral to the nephrologist for periodic evaluation or in case of any complication. Community health workers can visit patients in their homes and using check lists, determine whether the therapy is progressing as expected.

Reforms are needed in financing and reimbursement. Most of the expenses in PD are related to the cost of dialysis solution bags. It is hard to imagine why should a bag of salt and sugar solution be so expensive. According to the manufacturers, most of the cost goes in producing the bags used to package the dialysis solution because they need to meet a certain standard. It is hard to understand why none of the famed Indian entrepreneurs and innovators have found a cheaper way of manufacturing these plastic bags. Indigenous manufacturing has the potential to bring down the cost by a few orders of magnitude.

The other required reform is in the way nephrologist are reimbursed. At this time, nephrologists have an incentive to prefer HD because they are reimbursed for every session of dialysis (2-3 times a week) whereas for PD, they only get paid for a consultation, which may be once a month or even less frequently. It is important that this differential be removed, and nephrologists receive the same reimbursement for taking care of a patient on dialysis whose treatment costs are funded by the state, *irrespective of the modality of dialysis*. This will remove the currently existing perverse incentive in favour of HD. In UK, Australia and Canada, the healthcare facility (and the nephrologist) receive the same payment for a patient

irrespective of the modality of dialysis. As noted earlier, the recent growth in the number of PD patients in USA was possible only because of reimbursement reforms.

Irrespective of what modality of dialysis is offered, sustained success is only possible if the treatment meets with expectations of patients and healthcare providers. This can be facilitated through monitoring of quality and proper capture and reporting of outcomes. Registries perform this function in countries with established dialysis programs. Tracking, fed into a quality improvement loop, led to a cutting down by half the rates of infectious complications of PD (peritonitis) in Australia (19). Each $1 of expenditure on the Australia and New Zealand Dialysis and Transplant Registry has yielded $7 of benefits through improved outcomes and reduced spending on complications (24).

Just because dialysis is available does not mean that all patients with advanced kidney failure should be offered this treatment. Many patients, especially the very old, those with multiple co-existing diseases that limit the lifespan or quality of life, do not stand to have any meaningful gains in their length or quality of life by dialysis. Such patients should not be offered dialysis, rather should receive non-dialytic comprehensive conservative care to manage symptoms and are able to spend the last phase of their lives in the comfort of their homes or in a hospice (9). It is important that these decisions are made in a shared manner after fully understanding personal preferences and life goals of the patient. In Australia and Canada, where dialysis patients are typically in their 70s and 80s, every other new eligible patient chooses not to start dialysis. For this to be a viable option, however, supportive care services should be available and nephrologists should offer them to suitable patients. This requires change in mindset of physicians typically trained to provide curative services who believe not offering an available treatment is an admission of defeat. It must be noted that majority of dialysis patients in India are younger and have fewer comorbidities, so they will likely benefit more from dialysis than the older patients.

Finally, no country, no matter how rich, can afford to support indefinitely the ever increasing population on dialysis. The viable long-term solutions to stem the growing burden of kidney disease is to identify and intervene early, so that the development of kidney disease can either be entirely prevented or at least substantially slowed down. Effective prevention

options are available, but we need reforms in our healthcare system to make sure that these options can reach the people who need them the most - i.e. the vulnerable and the marginalised.

References:

1. Modi GK, Jha V. The incidence of end-stage renal disease in India: a population-based study. Kidney Int. 2006;70(12):2131-3.
2. Fox RC, Swayze JP. The Courage to Fail. 2nd edition ed: Routledge; 2001 2001.
3. Kainer G, Fetherstonhaugh D, Cari. The CARI guidelines. Ethical considerations. Nephrology (Carlton). 2010;15 Suppl 1:S12-4.
4. Bello AK, Levin A, Tonelli M, Okpechi IG, Feehally J, Harris D, et al. Assessment of Global Kidney Health Care Status. JAMA. 2017;317(18):1864-81.
5. World Health Organization. Making fair choices on the path to universal health coverage. Final report of the WHO Consultative Group on Equity and Universal Health Coverage. Geneva 2014.
6. Essue BM, Laba M, Knaul F, Chu A, Minh HV, Nguyen TKP, et al. Economic Burden of Chronic Ill Health and Injuries for Households in Low- and Middle-Income Countries. In: rd, Jamison DT, Gelband H, Horton S, Jha P, Laxminarayan R, et al., editors. Disease Control Priorities: Improving Health and Reducing Poverty. Washington (DC)2017.
7. Bradshaw C, Gracious N, Narayanan R, Narayanan S, Safeer M, Nair GM, et al. Paying for Hemodialysis in Kerala, India: A Description of Household Financial Hardship in the Context of Medical Subsidy. Kidney Int Rep. 2019;4(3):390-8.
8. Ramachandran R, Jha V. Kidney transplantation is associated with catastrophic out of pocket expenditure in India. PLoS One. 2013;8(7):e67812.
9. Harris DCH, Davies SJ, Finkelstein FO, Jha V, Donner JA, Abraham G, et al. Increasing access to integrated ESKD care as part of universal health coverage. Kidney Int. 2019;95(4S):S1-S33.
10. Jha V, Ur-Rashid H, Agarwal SK, Akhtar SF, Kafle RK, Sheriff R, et al. The state of nephrology in South Asia. Kidney Int. 2019;95(1):31-7.
11. Kaur G, Prinja S, Ramachandran R, Malhotra P, Gupta KL, Jha V. Cost of hemodialysis in a public sector tertiary hospital of India. Clin Kidney J. 2018;11(5):726-33.
12. Chuengsaman P, Kasemsup V. PD First Policy: Thailand's Response to the Challenge of Meeting the Needs of Patients With End-Stage Renal Disease. Semin Nephrol. 2017;37(3):287-95.
13. Tantivess S, Werayingyong P, Chuengsaman P, Teerawattananon Y. Universal coverage of renal dialysis in Thailand: promise, progress, and prospects. BMJ. 2013;346:f462.
14. Davidson B, Crombie K, Manning K, Rayner B, Wearne N. Outcomes and Challenges of a PD-First Program, a South-African Perspective. Perit Dial Int. 2018;38(3):179-86.
15. Choy AS, Li PK. Sustainability of the Peritoneal Dialysis-First Policy in Hong Kong. Blood Purif. 2015;40(4):320-5.
16. Li PK, Chow KM, Van de Luijtgaarden MW, Johnson DW, Jager KJ, Mehrotra R, et al. Changes in the worldwide epidemiology of peritoneal dialysis. Nat Rev Nephrol. 2017;13(2):90-103.
17. Mehrotra R, Devuyst O, Davies SJ, Johnson DW. The Current State of Peritoneal Dialysis. J Am Soc Nephrol. 2016;27(11):3238-52.
18. Kwong VW, Li PK. Peritoneal Dialysis in Asia. Kidney Dis (Basel). 2015;1(3):147-56.
19. Mudge DW, Boudville N, Brown F, Clayton P, Duddington M, Holt S, et al. Peritoneal dialysis practice in Australia and New Zealand: A call to sustain the action. Nephrology (Carlton). 2016;21(7):535-46.

20. Jha V. Setting up a national dialysis service in India: Change, choice and principles. Nephrology (Carlton). 2016;21(11):913-5.
21. Essue BM, Jha V, John O, Knight J, Jan S. Universal health coverage and chronic kidney disease in India. Bull World Health Organ. 2018;96(7):442.
22. Padmanabhan S. New guidelines released for peritoneal dialysis services. The Hindu Business Line. 21 October 2019. Available at https://www.thehindubusinessline.com/news/science/new-guidelines-released-for-peritoneal-dialysis-services/article29759883.ece. Accessed 24 October 2019.
23. John O, Jha V. Remote Patient Management in Peritoneal Dialysis: An Answer to an Unmet Clinical Need. Ronco C, Crepaldi C, Rosner MH, editors. Basel: Karger; 2019.
24. Australian Commission on Safety and Quality in Health Care (ACSQHC). Economic evaluation of clinical quality registries: final report. Sydney: ACSQHC; 2016.