A renal supportive care service: the time has come

Rajesh Raj

Raj, R. (2013). A renal supportive care service: the time has come. *Renal Society of Australasia Journal, 9*(3), 112-114.

Submitted July 2013, Accepted September 2013

In May 2013, the Australian and New Zealand Society of Nephrology published the *Renal Supportive Care Guidelines*, similar to recommendations in the USA and Europe, marking an important step in the evolution of treatment for end-stage kidney disease (ESKD) (Brown *et al.*, 2013). The non-dialysis mode of therapy — alternately called conservative, palliative or supportive care — is increasingly emerging as a valid therapeutic option. As our populations become older and sicker, we are becoming more aware of the limitations and the non-curative nature of dialysis therapy, and of the significant burden it imposes on our patients' lives.

We now appreciate the concept of 'maximal conservative therapy', which stands for therapy that pays attention to all aspects of management of ESKD save for dialysis — including, but not limited to, management of chronic symptoms, anaemia, nutrition and mineral metabolism (Carson, Juszczak, Davenport, & Burns, 2009). Thought-provoking data is now emerging that throws light on relative survival of patients managed 'conservatively', as opposed to those that receive dialysis (Da Silva-Gane *et al.*, 2012; Wong, McCarthy, Howse & Williams, 2007). Using prognostic scores, quality of life assessments and targeted symptom management guidelines, we are in a position to offer a valid model of compassionate, patient-centric supportive renal care.

Patients with progressive chronic kidney disease (CKD) receive counselling regarding renal replacement as their estimated glomerular filtration rate (eGFR) approaches 20 to 25 ml/min. Those that are not candidates for renal transplantation are asked to choose, broadly, between dialysis and non-dialysis treatment. In the traditional model of care, patients choosing not to have dialysis return to primary care providers. They frequently lose contact with the nephrology service. Not enough was known about what happens to these patients — their symptoms, their progress or their eventual modes of death.

Our ability to counsel patients objectively has long been hampered by the lack of tools to estimate progression and prognosis. Patients considering renal replacement therapy (RRT) need to know their likelihood of progression to ESKD, and the time period in which this is likely to occur. One could roughly predict the future decline to ESKD from the rate of decline of renal function in the preceding months and years (Shah & Levey, 1992). However, we know that several factors affect the rate of progression to ESKD, and a validated, predictive model incorporating multiple factors is now available (Tangri *et al.*, 2011). With predictions of this nature, physicians and patients have a more realistic time frame and risk estimate to base decisions upon.

There are other questions when considering RRT, and especially conservative care. What about survival and outcomes on dialysis? Which patients do poorly — is it only the elderly? And how old is 'elderly'? A large series (O'Hare *et al.*, 2007) has suggested that above the age of 85, whatever the eGFR at presentation, death is more likely to happen before progression to ESKD. Studies such as this should inform our discussions with CKD patients in this age group. The elderly often have several comorbidities that worsen outcome — including frailty, malnutrition and cognitive impairment (Brown & Johansson, 2011). In fact, nursing home residents who start dialysis have amongst the worst outcomes of all dialysis patients (Kurella Tamura *et al.,* 2009). Sadly, older patients are more likely to be referred late to nephrology, and this negatively impacts outcome too (Schwenger *et al.*, 2006).

But we know that it is not just age, but a combination of factors that influence survival on dialysis. In daily practice, we have often relied on clinical intuition to generate 'a feel' of patients that will not do well — little wonder then, that the 'surprise question' has proven so accurate. This question asks if one would be 'surprised' if a patient died within the next six months — if clinical nurse practitioners felt they would not be surprised,

Author details: Rajesh Raj MBBS, MD, DM, MRCP(UK), MBA, FRACP, Consultant Nephrologist

Correspondence to: Dr Rajesh Raj, Renal Unit, Level 3, Launceston General Hospital, 289 Charles Street
Launceston, TAS 7250, Australia
rajesh.raj@dhhs.tas.gov.au

this identified haemodialysis patients 3.5 times more likely to die (Moss *et al.,* 2008). Cohen, Ruthazer, Moss and Germain (2010) have included this question along with others about age, malnutrition, peripheral vascular disease and dementia to evolve a prognostication tool that predicts six-month mortality in patients on dialysis. Another excellent tool to estimate prognosis in those over 75 starting dialysis, is derived from the French REIN Registry (Couchoud *et al.*, 2009). These and similar estimates, which take into account other comorbidities as well, strengthen the scientific temper of discussions regarding outcome on dialysis.

Naturally, a reliable estimate of prognosis is but one of the several components of a discussion regarding treatment options. It is always important to consider a patient's life priorities, goals and values (Brown, 2012). Dialysis, we should remember, is a highly intrusive treatment in our patients' lives. It significantly affects the quality of life of patients, and has negative impacts even on novel scores such as those that measure satisfaction with life (Da Silva-Gane *et al.*, 2012).

ANZDATA figures show us that withdrawal from dialysis is now the second most common mode of death for dialysis patients in Australia and New Zealand (ANZDATA Annual Registry Report 2011, Ch. 3, "Deaths", 2012). It can be anticipated that patients wanting to discuss withdrawal from dialysis will benefit from attending a formal renal supportive care service. An open and empowering culture within the dialysis unit will encourage patients to voice their concerns, and could trigger referral to such a service. We know that withdrawal from dialysis leads to death within one to two weeks in most patients (Fissell *et al.*, 2005). Patients' questions, anxieties and fears about dying can be specifically addressed in such a service. These discussions are also a useful time to introduce the concepts of advance care planning. Several resources exist today for help with advance care directives, nomination of health care proxies and the communication of these decisions to relevant health care facilities (Brown *et al.,* 2013; Davison, 2012). These are sensitive discussions, and need to be led by experienced people — otherwise, end-of-life discussions can be a source of significant stress for carers and families alike.

For those that choose to stop dialysis, arrangements can be made for end-of-life care — within the hospital, at a hospice, or at home, according to patient and family wishes. Similar services can be made available to patients on the conservative pathway who are nearing death. It provides patients and their families the opportunity to discuss and plan around these issues, enabling them to make the best possible decisions for themselves. A formal supportive care service increases the chances that patients die in a place of their choosing, often outside the hospital, (Smith *et al.*, 2003). We owe it to our patients to give them this choice.

We cannot treat what we do not know — and we are very poor in recognising the symptom burden in our dialysis patients (Weisbord *et al.,* 2007). Conservative care patients carry a symptom burden and impairment of quality of life that equals that of patients with cancer (Saini *et al.,* 2006). Pain of various kinds, poor mobility, itching, drowsiness and weakness are common complaints. Several scoring systems of symptom burden and quality of life are now available (Brown *et al.*, 2013). These tools allow us to periodically document, rather objectively, a holistic picture of a patient's health status. Crucially, they enable us to identify the patients doing poorly. Such patients will benefit from referral to a renal supportive care service. Within the service, access to a multidisciplinary team, including physicians, nurses, social workers and others can ensure efficient management of symptoms and related problems.

Some practical considerations apply. What constitutes an ideal team to run a supportive care service? Patients on a conservative pathway require maximum conservative management, with attention paid to various aspects of CKD and its medical management, and the nephrologist is best suited for this. Palliative physicians and nurses have experience and expertise in managing chronic symptomatology (including pain) and in providing care at the end of life. Renal nurses have an intimate knowledge of the patient journey, and are an integral part of such a service. Several problems require input from social workers, community nurses and psychologists/psychiatrists. The general practitioner or primary care provider is an important link. In short, a multidisciplinary model, with open lines of communication, works best in being able to provide a full spectrum of care. Perhaps leadership must come from renal personnel, since they are at the forefront of dealing with these patients.

We live and work in an environment where increasing competition exists for limited resources. Where does a renal supportive care service fit in this situation? Is it worth the effort? The latter question is easily answered — one has to merely look at the needs of patients on dialysis or on a conservative pathway to understand the dire and almost urgent need for such a service. A careful consideration will show us that there are patients who will do well with conservative treatment — provided we can offer them a comprehensive service. Indeed, for renal failure, a condition that is as fatal as several cancers (Kjellstrand *et al.*, 2010), we really should not be questioning the need to establish a service that provides support for end-of-life care.

A renal supportive care service: the time has come

The patients that we see in our clinics and in our dialysis units have chronic, irreversible disease, and are resigned to a life of suffering, followed by an early death. Kidney transplantation, which comes closest to a 'cure', is an option only for the minority. For the others, we need to move urgently from a 'curative' to a 'supportive' focus. The time has come for renal units everywhere to assess their resources and think about how well they provide renal supportive care. In the coming years, as we prepare to tackle the twin challenges of an ageing population and burgeoning disease incidence, such a service will ultimately become a vital part of our armamentarium.

References

Australia & New Zealand Dialysis & Transplant Registry. (2012). *ANZDATA Registry 2011 Report*. From http://www.anzdata.org.au/anzdata/AnzdataReport/34thReport/2011c03_deaths_v1.5.pdf

Brown, E. A. (2012). Non-dialysis therapy: a better policy than dialysis followed by withdrawal? *Seminars in Dialysis, 25*(1), 26–27. doi: 10.1111/j.1525-139X.2011.01044.x

Brown, E. A., & Johansson, L. (2011). Epidemiology and management of end-stage renal disease in the elderly. *Nature Reviews Nephrology, 7*(10), 591–598. doi: 10.1038/nrneph.2011.113

Brown, M. A., Crail, S. M., Masterson, R., Foote, C., Robins, J., Katz, I., ... & Crail, S. M. (2013). ANZSN Renal Supportive Care Guidelines 2013. *Nephrology, 18*(6), 401–454. doi: 10.1111/nep.12065

Carson, R. C., Juszczak, M., Davenport, A., & Burns, A. (2009). Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clinical Journal of the American Society of Nephrology: CJASN, 4*(10), 1611–1619. doi: 10.2215/CJN.00510109

Cohen, L. M., Ruthazer, R., Moss, A. H., & Germain, M. J. (2010). Predicting six-month mortality for patients who are on maintenance hemodialysis. *Clinical Journal of the American Society of Nephrology: CJASN, 5*(1), 72–79. doi: 10.2215/CJN.03860609

Couchoud, C., Labeeuw, M., Moranne, O., Allot, V., Esnault, V., Frimat, L., ... & Information Network, registry. (2009). A clinical score to predict 6-month prognosis in elderly patients starting dialysis for end-stage renal disease. *Nephrology, Dialysis, Transplantation, 24*(5), 1553–1561. doi: 10.1093/ndt/gfn698

Da Silva-Gane, M., Wellsted, D., Greenshields, H., Norton, S., Chandna, S. M., & Farrington, K. (2012). Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. *Clinical Journal of the American Society of Nephrology: CJASN, 7*(12), 2002–2009. doi: 10.2215/CJN.01130112

Davison, S. N. (2012). Advance care planning in patients with chronic kidney disease. *Seminars in Dialysis, 25*(6), 657–663. doi: 10.1111/sdi.12039

Fissell, R. B., Bragg-Gresham, J. L., Lopes, A. A., Cruz, J. M., Fukuhara, S., Asano, Y., ... & Young, E. W. (2005). Factors associated with "do not resuscitate" orders and rates of withdrawal from hemodialysis in the international DOPPS. *Kidney International, 68*(3), 1282–1288.

Kjellstrand, C., Buoncristiani, U., Ting, G., Traeger, J., Piccoli, G. B., Sibai-Galland, R., ... & Blagg, C. R. (2010). Survival with short-daily hemodialysis: Association of time, site, and dose of dialysis. *Hemodialysis International, 14*(4), 464–470. doi: 10.1111/j.1542-4758.2010.00475.x

Kurella Tamura, M., Covinsky, K. E., Chertow, G. M., Yaffe, K. Landefeld, C. S., & McCulloch, C. E. (2009). Functional status of elderly adults before and after initiation of dialysis. *New England Journal of Medicine, 361*(16), 1539–1547. doi:10.1056/NEJMoa0904655

Moss, A. H., Ganjoo, J., Sharma, S., Gansor, J., Senft, S., Weaner, B., ... & Schmidt, R. (2008). Utility of the "surprise" question to identify dialysis patients with high mortality. *Clinical Journal of the American Society of Nephrology: CJASN, 3*(5), 1379–1384. doi: 10.2215/cjn.00940208

O'Hare, A. M., Choi, A. I., Bertenthal, D., Bacchetti, P., Garg, A. X., Kaufman, J. S., ... Landefeld, C. S. (2007). Age affects outcomes in chronic kidney disease. *Journal of the American Society of Nephrology, 18*(10), 2758–2765. doi: 10.1681/ASN.2007040422

Saini, T., Murtagh, F. E. M., Dupont, P. J., McKinnon, P. M., Hatfield, P., & Saunders, Y. (2006). Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. *Palliative Medicine, 20*(6), 631–636. doi: 10.1177/0269216306070236

Schwenger, V., Morath, C., Hofmann, A., Hoffmann, O., Zeier, M., & Ritz, E. (2006). Late referral — a major cause of poor outcome in the very elderly dialysis patient. *Nephrology, Dialysis, Transplantation, 21*(4), 962–967. doi: 10.1093/ndt/gfk030

Shah, B. V., & Levey, A. S. (1992). Spontaneous changes in the rate of decline in reciprocal serum creatinine: errors in predicting the progression of renal disease from extrapolation of the slope. *Journal of the American Society of Nephrology, 2*(7), 1186–1191.

Smith C., Da Silva-Gane, S Chandna, P Warwicker, R Greenwood, & Farrington, K. (2003). Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron. Clinical Practice, 95*(2), c40–46

Tangri, N., Stevens, L. A., Griffith, J., Tighiouart, H., Djurdjev, O., Naimark, D., ... & Levey, A. S. (2011). A predictive model for progression of chronic kidney disease to kidney failure. *Journal of the American Medical Association: JAMA, 305*(15), 1553–1559. doi: 10.1001/jama.2011.451

Weisbord, S. D., Fried, L. F., Mor, M. K., Resnick, A. L., Unruh, M. L., Palevsky, P. M., ... & Arnold, R. M. (2007). Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clinical Journal of the American Society of Nephrology: CJASN, 2*(5), 960–967. doi: 10.2215/CJN.00990207

Wong C. F., McCarthy, M., Howse, M. L. P., & Williams, P. S. (2007) Factors affecting survival in advanced chronic kidney disease patients who choose not to receive dialysis. *Renal Failure, 29*(6), 653–9 (0886–022X (Print)).

Elisio™–H

WHY NOT CHOOSE THE BPA FREE OPTION?

- Gold standard clearance levels
- BPA free
- Comprehensive size range

With evidence showing health risks associated with BPA[1], why would you take a chance when it comes to your patients?

That's why Nipro developed the Elisio™–H:

- Completely BPA-free
- Gold standard clearance levels
- Comprehensive size range (0.9m² to 2.5m²) for higher clearance rates[2,3,4]

For a completely BPA free dialyser with gold standard clearance levels, choose the Elisio™–H.

Find out more at **niproaustralia.com.au**. Or contact your Nipro Representative on **1800 451 737**.

PERFORMANCE QF=0

Clearances (mL/min)[2]	Ob/Od (mL/min)	9H	11H	13H	15H	17H	19H	21H	25H
Urea	200/500	189	192	195	197	198	199	200	200
	500/800	332	363	388	406	417	427	432	457
Creatinine	200/500	175	183	191	194	196	197	198	200
	500/800	282	320	346	363	383	404	410	426
Phosphate	200/500	160	164	170	176	179	183	188	193
	500/800	254	282	315	333	352	368	373	400
Vitamin B12	200/500	114	125	137	148	156	162	165	177
	500/800	151	178	204	223	242	259	264	291
Inulin	200/500	77	82	90	97	105	115	120	149
	500/800	94	97	112	122	135	148	158	203
Myglobin	200/500	55	61	70	78	88	94	98	112
	500/800	65	81	90	104	110	117	124	141
KUF (mL/hr/mmHg)[3]		53	59	64	67	74	76	82	93

Sieving Coefficient[4]				
	Vitamin B12	0.99	Myoglobin	0.22
	Inulin	0.93	Albumin	0

SPECIFICATIONS

Effective Surface Area (m²)	0.9	1.1	1.3	1.5	1.7	1.9	2.1	2.5
Priming Volume (ml)	62	70	85	95	105	115	130	149
Effective Length (mm)	210	228	245	259	271	281	290	302
Inner Diameter (µm)	200	200	200	200	200	200	200	200
Membrane Thickness (µm)	40	40	40	40	40	40	40	40
Membrane Thickness (µm)	500	500	500	500	500	500	500	500
Sterilization Method	Dry Gamma							
Package	24 pcs/box							

1. Lang et al., 2008, Association of urinary bisphenol A concentration with medical disorders and laboratory abnormalities in adults. JAMA 300(11):1303-1310
2. In Vitro Test Condition (EN1283): Qf 0ml/min
3. KUF (EN1283): Bovine Blood Htc 32±Protein 60g/L, 37°C), Qb 300mL/min
4. SC (EN1283): Qb 300mL/min, Qf 60mL/min

NIPRO
Your Partner in Health Care