

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/262042967>

Renal Supportive and Palliative Care: Position Statement.

Article in *Nephrology* · April 2013

DOI: 10.1111/nep.12064 · Source: PubMed

CITATIONS

33

READS

553

3 authors:



Su Crail

Royal Adelaide Hospital

5 PUBLICATIONS 72 CITATIONS

[SEE PROFILE](#)



Robert James Walker

University of Otago

364 PUBLICATIONS 11,006 CITATIONS

[SEE PROFILE](#)



Mark A Brown

UNSW Sydney

357 PUBLICATIONS 15,928 CITATIONS

[SEE PROFILE](#)

Some of the authors of this publication are also working on these related projects:



Dialysis Outcomes in those aged ≥ 65 years [View project](#)



The P4 Study [View project](#)

Review

Renal supportive and palliative care: position statement

SU CRAIL, ROB WALKER and MARK BROWN FOR THE RENAL SUPPORTIVE CARE WORKING GROUP*

Since the introduction of haemodialysis in the management of acute kidney injury in the 1940s and for chronic kidney disease (CKD) in the 1960s dialysis has become one of the most successful advances in medical technology, with almost 11 000 patients currently receiving dialysis in Australia and almost 2500 in New Zealand. Like all medical technologies, its place continues to evolve. For a time, dialysis was seen as a treatment best delivered only to younger patients without diabetes; today the greatest uptake of dialysis is in patients over age 65 and the most common cause of needing dialysis is diabetes. Along with these extended criteria for dialysis, that have evolved over many years, has come the recognition that the older dialysis patient often has considerable co-morbidity and frailty, that time spent on dialysis is not always beneficial to these patients and that their overall prognosis is considerably worse than their younger counterparts. CARI guidelines recommend that 'an expectation of survival with an acceptable quality of life' is a useful starting point for recommending dialysis.

Current practice should include three potential pathways for patients with end-stage kidney disease (ESKD): dialysis, transplantation and a (non-dialysis) supportive (conservative) care pathway. Nephrologists should be integral to the decision-making and ongoing management of patients in each of these pathways.

Not surprisingly, nephrologists, dialysis nurses and allied health staff, along with patients and families, are becoming less certain that dialysis will be the right choice for patients with multiple co-morbidities, poor quality of life (QOL), poor nutrition or poor functional status. There has been renewed interest worldwide in offering an alternative to dialysis for such patients. This has come about with recognition of the expertise that Palliative Care specialists can offer in the holistic management of such patients, with a strong emphasis on symptom control. Various programmes and guidelines have been developed, predominantly in the United Kingdom and the USA, to assist nephrologists and their patients in the non-dialysis option of treatment for selected patients with ESKD.

Many nephrologists have already made it part of their usual practice to offer a 'non-dialysis' pathway to selected patients but many are also understandably troubled when making such decisions. This issue has become more

prominent because of the increasing number of aged patients with co-morbidities, frailty, or poor functional status who present with ESKD, for whom decisions need be made as to the appropriateness of dialysis. Doctors should not offer a treatment which they believe (with their clinical skills and knowledge) will do harm; this is a very important principle in the dialysis decision-making pathway. While this document provides a structure around the process of helping doctors, patients and their families towards either a dialysis or non-dialysis pathway through a structured consideration of likely survival, co-morbidities and ethical principles, it cannot provide definitive answers for every case. Nephrologists will bring differing viewpoints themselves to these decision-making processes; it is usual that nephrologists begin by exploring the patient and family's goals of management, coming to a shared decision about the appropriateness of either a dialysis or non-dialysis pathway whenever possible. The important thing this position paper stresses is the need to remain open to the option that dialysis is not always in the patient's best interest. While having such discussions with patients and their families may be difficult and time consuming they have significant implications for patients' future well-being. The published evidence in making these decisions for an individual patient is limited at present but this is not an 'evidence free zone' and this document includes hundreds of published peer reviewed references and links to guidelines from various learned societies.

The purpose of this document is to outline an approach to the management of patients when dialysis is not considered in their best interests but it necessarily includes advice for the symptom management of patients who continue to have difficulties despite receiving apparently adequate dialysis. It includes an emphasis on the importance of providing informed consent, including expected survival times, for patients being offered dialysis as well as for those not receiving dialysis. The emphasis is on considering more than days survived on dialysis such as the likely QOL, the days survived outside of hospital, and the spiritual and cultural issues of the patient and their family that will be critical to such discussions. The section on the law hopefully provides reassurance to nephrologists that well-based decision-making done as usual in the best interests of the patient is all that the law asks; the likelihood of being sued, an often stated reason for not suggesting a non-dialysis pathway, is very small indeed.

We hope that readers of this document will (i) consider all this material in a new light; and (ii) recognize that it is not evidence free. The tools used in decision-making and management are imperfect both for selecting patients best suited

*Berquier Ilse, Brennan F, Brown MA, Cherian S, Crail S, Fassett R, Foote C, Glavish R, Healy H, Josland E, Katz I, Langham R, May S, Masterson R, Mathew T, Miller C, Morton R, Phipps L, Robins J, Sajiv C, Siva B, Stallworthy E, Stewart C, Urban K, Walker R.

to dialysis and for selecting those best suited to a non-dialysis pathway; research strategies to improve these are outlined in this document. There is a strong emphasis in this document on the incorporation of key ethical principles into the process of decision-making regarding dialysis or non-dialysis management pathways, clear guidelines as to how to manage specific symptoms that accompany ESKD and guidelines for end of life care. It is imperative that patients and families are enrolled in such a programme long before the end stage of their CKD pathway so that they are aware of future clinical trajectories and feel supported throughout. A key message we hope to impart is that a well-structured Renal Supportive and Palliative Care programme without dialysis is a very positive part of the management of ESKD for some patients and one that should not be overlooked.

This document has been endorsed by Kidney Health Australia and the Australian and New Zealand Society of Nephrology.

1. THE OFTEN DIFFICULT DECISION OF WHICH PATIENTS WILL BENEFIT FROM DIALYSIS

- Nephrologists seek to provide dialysis to those who will benefit most. There are some who are unlikely to benefit or even be harmed by dialysis and it is important that we try to recognize such patients; these can be very difficult decisions.
- In older patients with co-morbidities the decision to initiate dialysis can be very difficult; helpful things to consider include: the number of cardiac or other co-morbidities, nutritional status, functional status, whether or not the patient is in a nursing home, and how the nephrologist responds to the question: 'would you be surprised if your patient died within 12 months?' Taken together, these issues help identify patients at risk of a poor outcome on dialysis.
- A 'conservative' or 'not for dialysis' pathway is an important option for the management of ESKD patients; this option should be given to all patients and their families so that patients do not feel it is compulsory that they receive dialysis. The CARI guidelines clearly state that 'Supportive care is a recognized option for patients with ESKD'.
- Ideally, nephrologists should be consulted when patients with underlying CKD who are in the Intensive Care Unit are planned to commence acute dialysis; this allows some estimation of the likelihood of renal recovery and consideration of the appropriateness of long-term dialysis rather than just the acute dialysis.
- When patients with ESKD proceed down a non-dialysis pathway their treatment is best underpinned by a specific Renal Supportive Care (RSC) programme.
- Nephrologists need to lead realistic discussions about likely survival and the burden of dialysis with patients and their families before dialysis is instituted. In general terms, dialysis patients over 45 years of age have 5 year survival rates similar to patients with bowel cancer; older dialysis

patients have 5 year survival rates less than that of most cancers and less than that of heart failure. Considering survival in these terms is confronting but realistic and this provides a basis for informed consent before embarking upon either a dialysis or non-dialysis pathway.

- Key ethics principles are a good aid in this decision-making process; these include the principles of autonomy, beneficence, non-maleficence, and justice.
- A 'non-dialysis' RSC programme is a very positive way of offering holistic care for patients and their families; many of these patients live much longer without dialysis than might have been expected. The key principles are that the patient and their family are engaged early in the course of their CKD and supported from a time quite remote from when dialysis would normally be expected. They continue to attend all their usual nephrology appointments having standard ESKD medical therapies but have additional RSC, ensuring that they do not feel abandoned if choosing a non-dialysis pathway.

2. ISSUES SURROUNDING ESKD AND DIALYSIS IN THE ELDERLY AND THOSE WITH CO-MORBIDITIES

- There has been a significant increase in the number of elderly patients commencing dialysis, about 70% of whom have cardiovascular co-morbidities. 24% of prevalent dialysis patients are in the 65–74 age group and a further 24% above age 75. About half those aged over 75 have three or more co-morbidities.
- Population data suggest that for every elderly patient dying with ESKD who received dialysis there is another who dies with ESKD without receiving dialysis.
- In general it is likely that elderly patients receiving dialysis will live longer than those who do not. Survival on a non-dialysis pathway has been estimated between 6 and 23 months but data are limited. Some studies suggest that patients with high co-morbidity scores may not gain a survival advantage with dialysis *versus* a non-dialysis pathway.
- An important consideration is that hospital free survival may be similar in dialysis and non-dialysis treated groups; discussions around this issue should be included in the informed consent process when considering the appropriateness of dialysis.
- Late referral and lack of dialysis access are independent predictors of mortality in elderly patients commencing dialysis.
- It is important that ongoing studies assess not just days survived but also the QOL of dialysis or non-dialysis management pathways on patients, carers and staff.
- The elderly can have specific medical issues and needs that are best assessed by an Aged Care Physician. This is recommended particularly when assessment of cognitive function is a part of the considerations in determining whether dialysis is appropriate or not.

3. PREDICTIVE MODELLING RISK CALCULATORS AND THE NON-DIALYSIS PATHWAY

- One of the key issues in renal medicine is knowing when a patient will have renal dysfunction or symptoms severe enough to warrant dialysis if that is their chosen treatment pathway. A number of models have been tested to help predict the likelihood of progressing to ESKD from earlier stages of CKD.

- Reasonable but by no means exclusive recommendations are as follows:

For CKD stage 3–5 patients:

- The JAMA Kidney Failure Risk Equation in patients with CKD stages 3–5 helps predict progression through CKD stages.

For patients being considered for a non-dialysis pathway (particularly the elderly):

- The clinical score by Couchoud which provides a mortality risk score obtained from nine risk factors
- The recommendations of the Renal Physicians Association (USA) which stated it is reasonable to consider a non-dialysis pathway where there are two or more of the following factors when assessing the potential for dialysis in a patient over 75 years of age:

- 1 Nephrologist response to the Surprise Question of 'I would not be surprised if my patient died within the next 12 months'

- 2 High co-morbidity score (e.g. Modified Charlson Score ≥ 8)

- 3 Marked functional impairment (e.g. Karnofsky performance status score < 40)

- 4 Severe chronic malnutrition (chronic serum albumin < 25 g/L)

This system, although not perfect, may aid physicians in the decision process.

For dialysis patients being considered for transition to a non-dialysis pathway (particularly the elderly with co-morbidities):

- 1 Predictive testing as above, plus

- 2 The clinical score by Cohen involving a mortality score obtained from combining the answer to the 'Surprise Question' with four routine variables – age, serum albumin, presence of dementia and peripheral vascular disease

4. QUALITY OF LIFE. WHAT INFORMATION IS ALREADY AVAILABLE AND WHAT EVIDENCE IS THIS BASED ON?

- Patients with ESKD are known to have a worse QOL than an age-matched general population; sometimes this can be helped by better attention to dialysis delivery or anaemia

management but in some cases QOL on dialysis remains poor despite every effort to optimize dialysis and ESKD medical management.

- Without asking the right questions, or preferably using a validated tool to assess QOL, we will not really know which patients have satisfactory or poor QOL.

- What constitutes a poor QOL varies from person to person and the potential impact of dialysis on an individual will be unique for each person; it is important that this is discussed openly between the patient and his/her treating clinicians.

- Commonly reported dimensions of QOL surveys are: physical function, role limitations-physical, bodily pain, vitality, general health perceptions, role limitations-emotional, social function, and mental health. These self-reported dimensions are influenced by a multitude of outside factors such as social situation, environmental factors, financial situation, symptoms experienced, personal values and psychological factors.

- The SF-36 QOL questionnaire is a suitable tool that can be used in dialysis and non-dialysis patients to assess changes in QOL.

5. ETHICAL PRINCIPLES FOR PATIENTS, FAMILIES AND DOCTORS TO CONSIDER

- Medical ethics, like the law, can be intimidating to all medical practitioners, including Nephrologists. It may appear complex and driven by technical language. At its heart, however, it asks a simple question: in the circumstance of this patient what is the right thing to do?

- An approach based on the key ethical principles provides a structure in the decision-making process around the appropriateness of dialysis; in this way ethics can lead to better and more nuanced decision-making.

- Several guidelines on the initiation of and withdrawal from dialysis provide assistance in these deliberations, including the (USA) RPA guidelines and to a lesser extent the CARI guidelines.

- Each of the bioethical principles is important. Autonomy does not override the other principles. All clinicians, including Nephrologists, have a responsibility to carefully balance the benefits and burdens of treatment, including dialysis, and communicate that recommendation to the patient and family. The wishes and values of a patient should be considered but they should not, taken alone, be determinative. This issue arises when a patient or family wants treatment that is not felt to be appropriate by the nephrologist. In difficult cases Nephrologists should seek the advice and formal opinion of colleagues and, where available, a Bioethicist. This is particularly useful when conflict arises within families about which treatment pathway should be adopted.

6. ADVANCE CARE PLANNING

- Advance care planning is a process of patient-centred discussion, ideally involving family/significant others, to assist the patient to understand how their illness might affect them, identify their goals and establish how medical treatment might help them to achieve these. An individual must be competent to make decisions about their healthcare in order to participate in Advance Care Planning. Advance Care Planning discussions may result in the formulation of an Advance Care Plan which articulates the individual's wishes, preferences, values and goals relevant to their current and future health care.

- An Advance Care Plan is only one useful outcome from the Advance Care Planning process, the education of patient and family around prognosis and treatment options is likely to be beneficial whether or not a plan is written or the individual loses decision-making capacity at the end of life.

- Advance care planning should be available to all patients with CKD, including ESKD on renal replacement therapy. Such plans need to be reviewed regularly as patients' circumstances may change.

- Advance care planning provides benefits to patients as their end of life wishes are more likely to be known and followed when individuals have been through the Advance Care Planning process; feelings of isolation and lack of hope may be experienced when individuals are not able to honestly and openly discuss their hopes and fears for the future with loved ones. Having Advance care discussions does not result in loss of hope for patients. There are benefits too for the caregivers and family who experience better bereavement outcomes when the patient has not been exposed to aggressive medical interventions (e.g. artificial ventilation, resuscitation) near death and the burden of decision-making is reduced when the individual or family feel well informed of the patient's wishes.

- Facilitating Advance Care Planning discussions can be confronting for all who are involved; it requires an understanding of their purpose and communication skills which may need to be taught.

- Advance Care Planning needs to be supported by effective systems to enable the discussions and any resulting Plans to be available at all times of the day or night so they can be used to aid subsequent decision-making.

7. ASSESSMENT OF SYMPTOM BURDEN AND PROVISION OF PATIENT INFORMATION

- Patients with ESKD, with or without Renal Replacement Therapy (RRT), are heavily burdened with symptoms which may interact and compound each other. Patients may experience multiple symptoms simultaneously, some from the renal failure (e.g. pruritus or restless legs), some from co-morbidities (e.g. diabetic peripheral neuropathy, diabetes-

related gastroparesis, and angina) and others related to dialysis therapies (intra-dialytic hypotension, cramping, and sleep disturbance from Automated Peritoneal Dialysis (APD) alarms).

- The burden of symptoms experienced by patients on dialysis is rarely mentioned in patient information sheets despite being well documented in research data.

- There are significant barriers to medication use in ESKD including a lack of knowledge of pharmacokinetics in dialysis and conflicting information about drug dose and safety. Various treatment options are now available for management of the common symptoms of ESKD including pruritis, pain, constipation, anorexia, nausea, restless legs syndrome, depression, anxiety, fatigue, and sleep disturbance; these are addressed in detail in Section 7 of this document.

- Patients need clear information about the potential effects of dialysis and non-dialysis pathways on symptom burden and how this can change with time; it is prudent to acknowledge up front that many patients will need specific symptom management even when on dialysis.

- Standardization of tools used to collate information about symptoms can assist in the provision of information to patients. We recommend the POS-S (Renal) tool (accessible via <http://www.csi.kcl.ac.uk/postool.html>) for assessing symptom burden.

8. HOLISTIC PALLIATIVE CARE APPROACH – PHYSICAL, SPIRITUAL, RELIGIOUS AND PSYCHOLOGICAL NEEDS

- Many clinicians, patients and the general public are still of the view that Palliative Care is a process that is adopted very close to the time when a person dies. This is a major misconception. The WHO definition of Palliative Care is that of 'an approach which improves the QOL of patients and their families facing 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'.

- Understanding this concept allows nephrologists to engage Palliative care expertise early in the course of management of patients with ESKD who are suffering; this includes patients on dialysis and those on a non-dialysis pathway; critical to this management is that the nephrologist and other clinicians recognize the patient's suffering in the first place.

- The palliative approach to patients with ESKD includes managing all aspects of the physical, emotional and spiritual dimensions of the illness and care of the family. That breadth perfectly accords with modern medical beliefs in the interrelatedness of body, mind and spirit in the experience of illness for all human beings

- Health professionals dealing with patients with ESKD need to acquire skills in these areas. Given that no one health professional can provide all treatment, support and assist-

ance needed a critical ethos of the palliative approach is the multidisciplinary team (MDT).

- Continuing collaboration between renal medicine and palliative medicine is essential. Given that there is currently, and will for the foreseeable future be, a shortage of Palliative Care health professionals the onus should be on all disciplines, including Nephrology, to acquire and nurture basic skills in the palliative approach to patients, including skills in discussions around the possible withholding of and withdrawal from dialysis, symptom management, psychosocial support and the appropriate care of the dying patient.

- The cultural and religious beliefs of patients may inform or determine their view on medical decision-making including in relation to the withholding or withdrawing of dialysis and the care of the dying. It is therefore important that clinicians explore these beliefs with patients and their families. In modern societies patients may or may not have a religious faith but all patients have spirituality. Most religions believe that withdrawal from or withholding treatment, including dialysis, is acceptable when this is in the patient's best interests.

9. INAPPROPRIATE INTERVENTIONS IN THE DYING PATIENT

- A core competency of Nephrology should be the capacity to diagnose dying. Failure to do this or procrastination in this recognition may result in neither the clinicians nor the family being prepared for the possibility of death. That unpreparedness may have a significant impact on the bereavement of the family.

- Withdrawal of dialysis is ethically and legally valid; once the dying phase has been recognized and acknowledged it is important that invasive tests are ceased so as not to add to or prolong suffering.

- An increasing issue is the need to deprogramme AICD; this specific issue should be discussed with the patient and his/her cardiologist. It is important at this time to be specific that deprogramming AICD does not constitute euthanasia or physician-assisted suicide, that deprogramming AICD will not cause death and that the process of deprogramming is not painful or make the process of death more painful.

- The time to death after withdrawal varies considerably, averaging 10 days for most patients but 3 weeks or even longer for those with residual renal function.

10. RUNNING AND SETTING UP A RENAL SUPPORTIVE CARE PROGRAMME

- The key element of any RSC programme is the MDT; this is essentially an integration of Renal and Palliative Medicine, using the skills of both disciplines to ensure optimum nephrology care while adding a focus on symptom control, holistic physical and spiritual care and, when appropriate, the facilitation of a 'good death'.

- In the MDT team approach nurses (RSC and/or dialysis nurses), allied health and doctors all have roles in the decision-making and education aspects of such a programme.

- There are several possible models. One model has a team that consists of: RSC Clinical Nurse Consultant; Palliative Care Physician; Research assistant; Nephrologist; Renal advanced trainee; Social work and dietician support. Some Units prefer to run the RSC clinic separate from the patient's usual renal clinic consultation while others find it better to combine the treatment into one visit.

- To assist uniformity of management, treatment protocols are imperative; one example of such protocols is a 'palliative care' treatment list for ESKD non-dialysis management. This is available for use by any staff at any hour through online access at <http://stgrenal.med.unsw.edu.au/>

- Some clinicians express concern that establishing such models of care will result in bureaucratic limiting of dialysis resources; others have a different view and have found that engaging hospital and other health administration early in the establishment of RSC services leads to a much better integrated model of health care for all patients with ESKD, whether or not they are receiving dialysis; in other words, the establishment of a RSC service generally requires additional resources, not a reduction in available dialysis resources, in keeping with the ethical principle of justice.

- Suggested performance measures for a RSC service include: Uptake of the service by patients – this evaluates whether the service is meeting the needs of patients but also whether nephrologists and nursing staff are referring patients as needed; improvement in the symptom burden of patients; improvement in patients' QOL; Patient, family and carer satisfaction with the service; Education and research outputs.

11. END OF LIFE PATHWAYS

- Resuscitation status and Advance Care Plans need to be discussed and clearly documented, as per Section 6 above. A fall in performance status is an indicator of decline.

- Essential components of End-of-Life care include: Diagnosing dying; Determining the patient's desired place of death; Communication of the likely time frame and what to expect with patient and family; Assessment of needs and symptom management using practical guidelines/prescribing; Regular review of symptoms and patient/family needs; and After-death care.

- The Liverpool Care Pathway is one recognized model of EOL care, and has been adapted for patients with end-stage renal disease. This is available at <http://www.liv.ac.uk/mcpcil/>; other more local guidelines are available at <http://stgrenal.med.unsw.edu.au/>. These guidelines provide advice about the management of specific symptoms including nausea and vomiting, constipation, terminal agitation, Pruritus, Pain and dyspnoea.

12. CULTURAL CONSIDERATIONS WHEN PROVIDING CARE TO ABORIGINAL AND TORRES STRAIT ISLANDERS (ATSI) OPTING FOR CONSERVATIVE CARE

- The highest rates of chronic and end-stage kidney diseases occur within remote, regional and indigenous communities in Australia.
- Advance care planning is not common practice for most ATSI people. Family/kinship rules may mean that certain family members of an indigenous person, who in mainstream society would be regarded as distant relatives, may have strong cultural responsibilities to that person. It is imperative therefore to identify early in the planning stages who is the culturally appropriate person, or persons to be involved in the decision-making process so that they can give consent for treatment and discuss goals of care.
- There are many barriers to providing effective supportive care to ATSI people. One barrier is that failure to take culture seriously may mean that we elevate our own values and fail to understand the value systems held by people of different backgrounds.
- Choice of place of death, or being able to 'finish up' in the place of their choice, is very important to many indigenous Australians, with strong connections to traditional lands playing an important cultural role.
- Family meetings, preferably in the presence of a cultural broker to explain treatment pathways and care issues will lead to informed choices being made in an environment where all are able to participate freely.
- Each indigenous person is different and should not be stereotyped.

13. CULTURAL CONSIDERATIONS WHEN PROVIDING CARE TO NEW ZEALAND MĀORI OPTING FOR CONSERVATIVE CARE

- For Māori, as within any culture, there will be variation in the preferences of any individual influenced by iwi (tribal) variation, degree of urbanization of the individual and his/her whānau (extended family), ethnic diversity and personal experience among other factors.
- When providing end-of-life care to Māori it may be helpful to use the holistic Māori concept of 'hauora' or wellbeing.
- Many Māori will prefer to die at home and whānau often prefer to take their terminally ill relative home, although, as with other groups in society, the pressures of urbanization and geographical spread of modern whānau mean that this should not be assumed.
- Care of the tūpāpaku (deceased) can be a particularly sensitive area as it is generally highly ritualized in Māori culture. Whānau may have specific cultural and spiritual practices they wish to observe around handling of the body, including washing and dressing and staying with the

tūpāpaku as they progress from the ward, to the mortuary and to the funeral director then marae.

14. ISSUES AND MODELS OF RSC IN RURAL AREAS

- Patients in rural areas are both economically and medically disadvantaged
- Access to specialist services in rural areas is limited. More care is likely to be outsourced to local physicians, GPs and palliative care nurses who will need 'on the ground' outreach support from renal/palliative care services
- Patients want to be treated close to where they reside to avoid the cost of travel and dislocation involved in visiting metropolitan-based clinics. The implementation of renal palliative/supportive care services in rural areas requires a different model to metropolitan areas if these patients are to have the same standard of care as those in metropolitan areas.
- Referral to these services may be low because of lack of knowledge of availability and previous exposure of the referring physician to the use of these services. Providing specialist renal palliative/supportive care services will need to involve some on the ground outreach services to gain the trust and respect of the local physicians. Any model will need to enhance contact between palliative care services and local physicians.
- Metropolitan palliative care services should have a responsibility to provide outreach rural services and will need adequate resources. The same model is used to provide transplant services successfully in rural areas and not only allows rural patients to access these services locally but provides up skilling of the local workforce.
- The role of the supportive care nurse in this model is critical to the success of this model promoting a wider referral base especially from dialysis nurses and Allied health. The caring physician may not always be aware of the iceberg of symptoms that are very apparent to the dialysis staff that care for these patients during the long hours of dialysis or of patients on a non-dialysis pathway.
- Developments in Information Technology are likely to play a significant role in management (telemedicine), education and advice in these specialist areas. This can be easily performed with currently available technology including Skype.

15. RENAL SUPPORTIVE CARE AND THE PRIMARY CARE PHYSICIAN

- General Practitioners are important and should be involved in decision-making and Advanced Care Planning for patients with advanced kidney disease
- Advanced kidney disease has a biphasic trajectory, with an earlier stage focused upon the 'medical' issues aimed at preventing or slowing progression of the CKD, the later

phase being a more rapid acceleration towards the uremic symptoms, needing specific care as outlined above. Both phases require strong input from general practitioners, who are likely to know their patients and families better than most specialists.

- Not having dialysis does not equate to having no treatment for the patient with CKD. This is an important concept to emphasise to patients and their families; reaffirmation of this principle by their general practitioner is pivotal in ensuring that ESKD patients and their families continue to feel supported during their disease phases.

16. RESEARCH ISSUES: GAPS IN KNOWLEDGE AND SUGGESTED DIRECTIONS

Although there is an emerging body of research in the area of 'conservative' or 'non-dialysis' management, concentration of research is recommended in the following areas:

- Prospective studies of the appropriateness, relevance, timing and sustainability of dialysis in elderly patients
- Health-related quality of life (HRQoL) in older patients choosing not to dialyse and in those choosing to dialyse, with comparison to a matched population without renal disease
- Methods of communication of prognosis and factors affecting decision-making
- Comparative studies to delineate how best to deliver models of RSC
- Treatment preferences among indigenous patients
- Symptom control, focussing on those areas specific to the needs of renal patients

17. MANAGEMENT GUIDELINES FOR PATIENTS CHOOSING A RENAL SUPPORTIVE CARE PATHWAY

- Few guidelines exist for the management of patients choosing to not have dialysis apart from those covering end of life (EOL) management.

- Most guidelines are based on low level evidence, relying on expert opinion or current practice.

- Various aspects of the management of ESKD patients on a non-dialysis pathway are covered in guidelines that include:

- Liverpool Care Pathway
- St George Hospital web-site
- North America Mid-Atlantic Renal Coalition (MARC) and Kidney End of Life Coalition
- CARI Guidelines
- Canadian Society of Nephrology
- Renal Physicians Association (RPA) of USA
- UK Renal Association
- UK Renal National Service Framework
- NSW Department of Health – Conflict Resolution in End of Life

18. LEGAL ISSUES CONCERNING WITHHOLDING AND WITHDRAWAL OF DIALYSIS

- As a foundation principle, the law neither seeks nor expects perfection from doctors. What it does expect is that doctors, including Nephrologists, act reasonably in all aspects of diagnosis, investigation and management, where reasonableness is assessed by reference to competent peer, professional practice.

- A doctor incurs no civil or criminal liability if, on the basis of a refusal to commence or continue dialysis, the doctor does not give that treatment. To go ahead and give treatment to a patient who has refused consent constitutes a battery.

- Advance directives are recognized at common law in both Australia and New Zealand. There are some variations among jurisdictions in the application of advance care directives; these are tabulated in Section 18 of this document.

- For competent patients, the law expects that consent must be voluntary and made without undue influence and that consent should be informed. This means that the patient should be told about the material risk of having or not having dialysis.

- If the actions of a Nephrologist are reasonable in withholding dialysis or withdrawing from dialysis then it is highly unlikely that a successful action in negligence would occur.

- The law does not obligate a Nephrologist to provide treatment that they believe is of no benefit to the patient or that any benefit is outweighed by the burdens of the treatment, but best practice requires that the Nephrologist communicate with the substitute decision-makers regarding the patient's best interests.

- The withholding of or withdrawing from dialysis is not euthanasia. Equally it does not constitute Physician Assisted Suicide. Jurisdictions have variations on whether and which substitute decision-makers can consent to dialysis being withheld or withdrawn; these are tabulated in Section 18 of this document.

- Competency requires that the person understands what is being said to them, retains that information, and exercises reason to reach a conclusion. If a patient is competent the decision whether or not to consent to dialysis is that of the person. The family cannot insist on dialysis.

- If the patient is incompetent and the surrogate decision-makers or families have reached an impasse with the clinician then some simple preliminary steps may be taken, including seeking a second opinion but it may require seeking clarification with the Supreme Court of the jurisdiction.

19. EDUCATIONAL NEEDS IN SUPPORTIVE AND END OF LIFE CARE

- The curricula for Australian and New Zealand Nephrology advanced trainees (<http://www.racp.edu.au/page/>)

specialty/nephrology) describes under learning objective 2.3.8 the learning need to 'plan and manage the non-dialysis pathway'. The skills listed are:

- *Manage common ESKD problems – pruritus, fatigue, xerostomia, depression, constipation, insomnia, nausea, vomiting, dyspnoea and pain*
- *Adjust drug doses according to reduced GFR*
- *Liaise with allied health staff*
- *Describe reduced life expectancy to a patient with respect, empathy and dignity.*

• With limited availability of RSC programmes available throughout Australia and New Zealand, there is a need for provision of training in this area to be available to all medical, nursing and paramedical staff

• Online resources may be a potential source of training material for staff and information for patients and families. These are outlined in Sections 10, 11 and 16 above.

• The possibility of exchange programmes between renal medicine and palliative care should be explored as a way of enhancing education in both fields.

• The ANZSN and the ANZ Society of Palliative Medicine (ANZSPM) both have special interest groups in RSC. The potential for bringing these two groups together to facilitate cross-specialty training should be explored.

Accepted for publication 2 April 2013.

doi:10.1111/nep.12064