

Renal supportive care

Ratnapala DUS¹

Journal of the Ceylon College of Physicians, 2020, **51**, 111-119

Chronic kidney disease burden

Global prevalence of chronic kidney disease (CKD) is on the rise. Approximately 8-16% of the world population is affected by CKD. The situation in low and middle-income countries including Sri Lanka is worse as nearly 78% of global CKD population reside in these countries.¹ CKD shows a high prevalence in the elderly population and is associated with high cardiovascular risk at all ages.²

Further to the increase in its prevalence, patients with advanced CKD depict an enormous burden of physical and psychosocial symptoms, poor outcomes, and huge costs of care. The life expectancy on dialysis is poor and the advanced disability and symptom burden in some patients with advanced CKD is not essentially improved by dialysis therapies. Most patients on dialysis die in acute care facilities, receiving high-intensity care which may not be beneficial.¹ CKD is a disease which not only affects the individual patient, but the family members and caregivers as a whole. Due to the mammoth cost involved with different renal replacement therapies, it is a huge economic burden for the country as well.

Therefore, selecting the appropriate patient with advanced CKD for the suitable renal replacement therapy (RRT), identifying patients who will not benefit from RRT and integrating palliative care principles to the routine management of advanced CKD has become a global necessity. Further, concentrating on patients' wishes and quality of life (QOL) may be more important than controlling the biochemical parameters in a patient

with advanced CKD. This article will illustrate the essential components of renal supportive care, a treatment modality developed to solve these issues.

What is supportive care?

Supportive care is a treatment modality applicable for any patient with a life limiting illness targeted to improve the QOL of the patient and family. This patient-centred method helps throughout the continuum of the disease beginning from pre-diagnosis and continuing to death and bereavement.¹ It helps the patient and family to maximise the benefits of treatment and to live as comfortable as possible with the effects of the disease.


What is renal supportive care?

Renal supportive care is the service provision aimed at raising the health-related QOL of a patient diagnosed with CKD. It can be provided to a CKD patient at any age, due to any aetiology, in parallel with or without life-prolonging therapies such as dialysis.¹ The ultimate goal is the reduction of suffering of the patient and family throughout the trajectory of illness, including (but not limited to) the end of life. Figure 1 illustrates the essential competence domains of renal supportive care.

Renal supportive care and renal palliative care are synonymous. Yet, renal supportive care is replacing the term palliative care, because it is still a commonly held view by both patients and health care providers that palliative care and end of life care are identical.¹

¹ *Consultant Nephrologist, Provincial General Hospital, Badulla, Sri Lanka.*

Correspondence: E-mail: udana752@yahoo.com

 <https://orcid.org/0000-0002-4655-3298>

Received 16 April 2020, accepted 20 June 2020.



This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

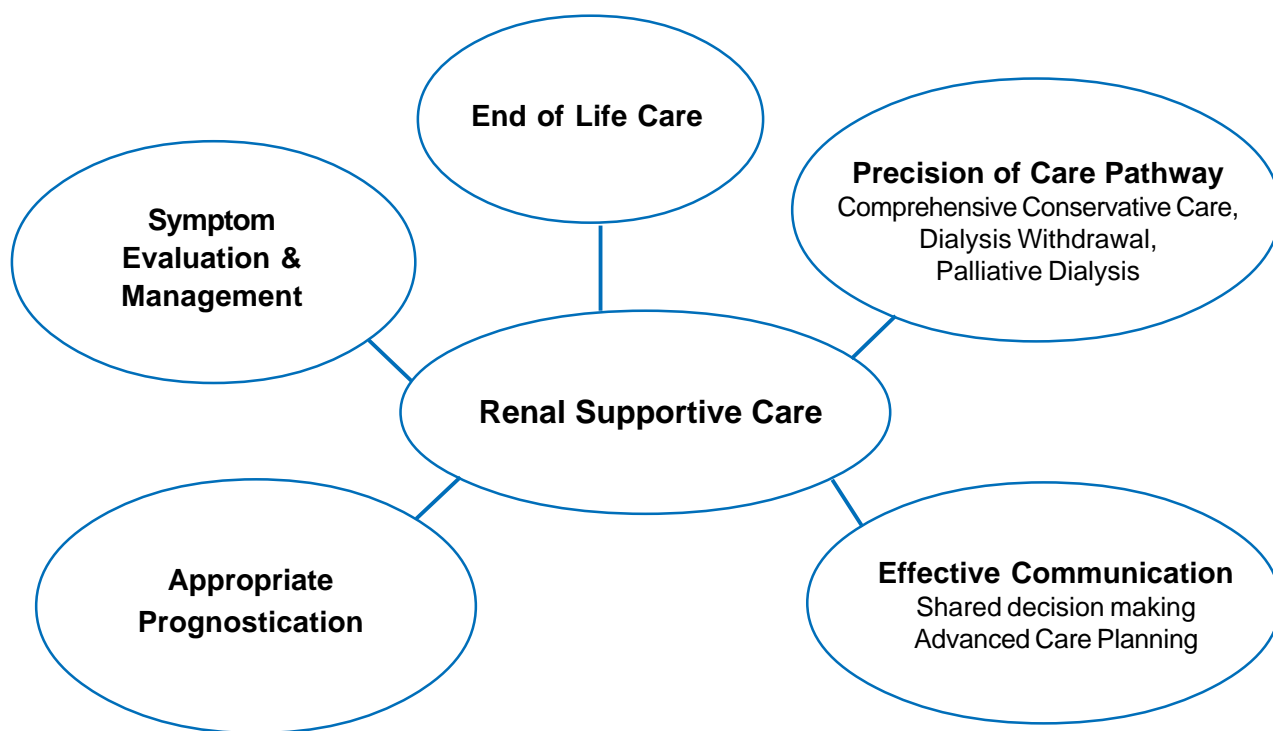


Figure 1. Competence domains of Renal Supportive Care.

Competence Domain 1: Symptom Evaluation and Management

Patients with advanced kidney disease, with or without dialysis therapies, are heavily burdened with symptoms that may interact and compound each other. Most symptoms arise in complex clusters with an exponentially negative effect on overall QOL. Others may present as a form of syndrome patterns such as depression, frailty, and/or functional decline and falls. Moreover, treating this complex symptomatology is difficult and need continual assessment and modification.¹

Regular symptom assessment could be per-

formed using validated global symptom assessment tools. Eight such tools of variable length and usage exist for CKD patients, including the Edmonton Symptom Assessment System-revised: Renal, the Palliative Care Outcome Scale-Renal, and the Dialysis Symptom Index.

Symptom management in renal supportive care is a stepwise approach starting from non-pharmacological interventions and subsequently progressing to more complex pharmacological therapies. Consideration should be given to low-dose pharmacological therapy that have shown efficacy across several symptoms. Table 1 depicts commonly encountered symptoms and proposed management.²

Table 1. Considerations for symptom management in patients with advanced CKD²

Symptom	Initial considerations for management
Fatigue	Assess for modifiable contributing factors: vitamin D deficiency, metabolic acidosis, tertiary hyperparathyroidism, hypothyroidism, anaemia, mood disorders, (depression, anxiety), sleep disorder, malnutrition, polypharmacy
	Post-dialysis fatigue: consider modifications to the dialysis prescription such as increased frequency
	Consider low-intensity resistance and aerobic exercise where appropriate
	Ensure the appropriate supports are in place to assist with activities of daily living and that nursing care is available where appropriate
Sleep disorders	Assess for modifiable contributing factors and symptoms such as restless leg syndrome (RLS), pruritus, pain, dyspnoea, mood disorders (depression and anxiety), obstructive sleep apnoea, medications
	Consider non-pharmacologic management first: exercise if appropriate; cognitive and psychologic approaches (e.g., relaxation therapy, CBT; promote good sleep hygiene (avoid napping during the day, avoid stimulants such as caffeine, alcohol and nicotine in the evening)
	Consider pharmacologic therapy if non-pharmacologic interventions are unsuccessful and poor sleep is adversely affecting QOL: e.g., low dose gabapentin starting at 50-100 mg post-dialysis (potentially also beneficial for RLS, neuropathic pain, and pruritus); melatonin; zaleplon 5-10 mg nightly; or doxepin 10 mg nightly
RLS	Assess for modifiable contributing factors such as anaemia and iron deficiency; medications such as dopamine antagonists, antidepressants (SSRIs, SNRIs, TCAs); calcium channel blockers, opioids
	Consider nonpharmacologic management first: e.g., intradialytic aerobic exercise
	Consider pharmacologic therapy if nonpharmacologic interventions are unsuccessful and RLS is adversely affecting QOL: e.g., low dose gabapentin starting at 50-100 mg post-dialysis (potentially also beneficial for sleep, neuropathic pain, and pruritus); second-line options include non-ergot derived dopamine agonists such as ropinirole at a starting dose of 0.25 mg/d and a maximum recommended dose of 3 mg/d
Pruritus	Assess for modifiable contributing factors: anaemia, iron deficiency, hypercalcaemia hyperphosphataemia, xerosis, allergies, drug sensitivities, contact dermatitis
	Promote good skincare: avoid soap, but if used, use gentle soap; keep skin cool by wearing light and cool clothing; avoid excessive bathing or bathing in hot water and use emulsifying lotions in the bath; avoid scratching – keep fingernails short and encourage massage rather than scratching, wear gloves at night; maintain a humid home environment, especially in the winter
	Topical emollients (moisturizers) are the first-line treatment. They should have high water content and be free from fragrance and additives
	Agents that help cool skin such as a fan, especially at night, or the use of topical camphor/menthol in the moisturizing base

(Continued)

Review

Symptom	Initial considerations for management
	<p>Consider other topical therapies: gamma-linolenic acid 2.2% cream applied twice daily; capsaicin 0.025% or 0.03% ointment applied 2-4 times daily (may cause initial burning sensation)</p> <p>Consider pharmacologic therapy if the above is unsuccessful and pruritus is adversely affecting QOL: e.g., low dose gabapentin starting at 50-100 mg post-dialysis (potentially also beneficial for sleep, RLS, and neuropathic pain); second-line treatment – consider the TCA doxepin 10 mg nightly</p> <p>Other therapies to consider with less evidence include UVB phototherapy x3 times / week and acupuncture</p>
Nausea and vomiting	<p>Manage associated reversible symptoms such as constipation</p> <p>Consider non-pharmacologic management: good oral hygiene; smaller, more frequent meals; minimize aromas; avoid foods that are greasy, spicy, or excessively sweet; relax in an upright position after eating to facilitate digestion; apply a cool, damp cloth to forehead or nape of neck; loose fitting clothing; complementary therapies such as relaxation, imagery, acupressure, or acupuncture</p> <p>Consider pharmacologic therapy if the above is unsuccessful and nausea and vomiting are adversely affecting QOL: metoclopramide 2.5 mg PO/SC q4h PRN; ondansetron 4 mg POx3/d; haloperidol 0.5 mg PO/SC q4h PRN; olanzapine 2.5 mg PO q4h PRN</p>
Depressive symptoms	<p>Manage associated reversible symptoms such as pain, poor sleep, pruritus</p> <p>Assess and optimize social support</p> <p>Consider nonpharmacologic treatments: more frequent dialysis; CBT; exercise programs</p> <p>Consider pharmacologic therapy with antidepressants if the above is unsuccessful and depressive symptoms are adversely affecting QOL</p>
Pain	<p>Assess for modifiable contributing symptoms such as sleep and mood disorders (depression and anxiety)</p> <p>Consider non-pharmacologic management: exercise if appropriate; cognitive and psychologic approaches (e.g., relaxation therapy, CBT)</p> <p>If considering analgesics, establish whether the pain is neuropathic or nociceptive to direct analgesic approach</p> <p>Adopt a step-wise approach to analgesics such as that is outlined in the World Health Organization Analgesic Ladder</p> <p>Analgesic selection, the initial dosing, and titration must be individualized according to the patient's health, previous exposure to analgesics, attainment of therapeutic goals, and predicted harms</p> <p>Consider a trial of chronic opioid therapy if the pain is moderate to severe, is affecting the function or QOL, and therapeutic benefits are likely to outweigh the potential harm</p> <p>Before initiating chronic opioid therapy, assess risks of substance abuse, misuse, or addiction</p>

RLS, restless legs syndrome; CBT, cognitive behavioural therapy; QOL, quality of life; SSRI, selective serotonin reuptake inhibitor; SNRI, serotonin and norepinephrine reuptake inhibitor; TCA, tricyclic antidepressant; UVB = ultraviolet B; PO = by mouth; SC = subcutaneous; q4h = every 4 hours; PRN = when necessary.

Competence Domain 2: Appropriate Prognostication

Communication of accurate prognosis is vital in planning and individualizing appropriate renal supportive care. Overoptimistic prognostication may lead to higher expectations and inappropriately aggressive treatment. Validated integrated prognostic tools help in recognizing and prioritizing patients with whom conversations about care goals and conservative options would be useful.

At the individual level, the surprise question "Would you be surprised if the patient died in the next 6 or 12 months?" has been described to improve prognostic prediction even though it has the limitation of being subjective and dependent on clinician perception.³ In one prospective study, the probability of dying within 1 year were 3.5 times higher in the 'no' patient group compared to the 'yes' patient group.⁴

Current evidence suggests that the predicted life expectancy is strongly correlated with advanced age, high comorbidity score, poor functional status and malnutrition.^{2,5} There are predictive models and risk calculators produced upon using these variables, yet there is no consensus on one predictive model.

The Modified Charlson Score (MCS) is such a model designed to identify the subpopulation of sicker dialysis patients with a 50% 1-year mortality rate. It is a simple scoring system which adds scores for comorbidities found.⁶

The concept of frailty is fast becoming one of the useful prognostic indicators for hospitalization, complications of procedures, and mortality in the general population.⁷ Clinically, frailty manifests as a complex of deprived physical function, exhaustion, reduced physical activity, and weight loss and is associated with an increased risk for falls, cognitive impairment, hospitalization, and death. It is more common in the CKD population and not surprisingly, a strong predictor of mortality.⁸

Globally, these prediction models had been incorporated together to help decision making on renal supportive care. Renal Physician Association, USA recommends withholding dialysis treatment if the patient is over 75 years of age with two or more of the following risk factors:

- A response of 'No, I would not be surprised if my patient died within the next 12 months' to the Surprise Question.

- Patients with high comorbidity scores (e.g. MCS \geq 8).
- Marked functional impairment (e.g. Karnofsky performance status score < 40). Severe chronic malnutrition (serum albumin < 25 g/L using the bromocresol green method).⁹

Nonetheless, a predictive model that comprehensively integrates variables related to the prognostic outcome of the non-dialysis population is yet to be developed.

The utility of prognostic tools is limited as they provide an estimate of average survival for a population of similar risk but not for the individual. Before utilising a particular tool, it is important to know whether the patient concerned is comparable to those used for the development of the tool in terms of age, ethnicity, renal replacement therapy etc. Therefore, it is proposed that individual renal units be developed, and validate an appropriate survival predictive model to facilitate the selection of an accurate candidate for renal supportive care.

Competence Domain 3: Effective Communication

Good communication is pivotal in all stages of advanced CKD management. Sharing vital information such as prognosis, realistic outcomes of potential treatments and their limitations throughout the continuum of the disease will aid patient and family to optimise their QOL and ease the later discussions on end of life planning. However, the evidence suggests that communicating prognosis is not routinely practised by physicians, yet patients often want to have conversations about life expectancy.

Shared decision making

Shared decision making is an extension of patient-centred care, which is a process of communication where clinician and patient agree on a specific course of action based on patient's treatment goals, benefits and harms of each treatment option, the likelihood of achieving the patient expected outcomes. Therefore, shared decision making is a continuous and repeated process, where decisions are taken with the patient, not for the patient. In current day clinical practise, this process is commonly adopted at dialysis initiation, which is an important stage of CKD continuum. This discussion should be modified according to the patient's cultural context, education level, health literacy, socioeconomic background and presence of cognitive dysfunction.⁸

Based on the available evidence, it is postulated that shared decision making is poorly incorporated into CKD care and that many CKD patients are inadequately prepared for either living with CKD or dealing with end-of-life issues.¹⁰

Advanced Care Planning

Advanced care planning (ACP) is a process of communication and decision making between a patient, the family, and clinician to determine preferences for end-of-life care. It lays out a clear platform for approaching end-of-life decisions in liaison with ethical, psychosocial and spiritual issues. Failure of ACP results in patients' treatment preferences not being respected and in potentially unwanted suffering, and overuse of limited healthcare resources. ACP should be a continuous education process, where discussions are conducted on different occasions such as dialysis initiation, hospital admission, vascular access problems, failing transplant, worsening frailty or cognitive function.

Most CKD patients welcome the opportunity to engage in these discussions with their care team. Latest evidence proves that that open, honest discussions with patients with advanced CKD about prognosis and end-of-life care promote self-reliance, relieve fear and uncertainty, and strengthen both trust and hope. Hence, ACP is regarded as a pathway of improving

end-of-life care, decreasing inappropriate life-sustaining treatment, increasing the use of hospice and supportive care, preventing hospitalizations, and enhancing compliance with patients' end-of-life wishes.^{11,12} Further, bereaved families who have been part of ACP experience better adjustment, with fewer psychological symptoms.

Competence Domain 4: Renal Supportive Care Pathways

Comprehensive Conservative Care

Conservative or non-dialytic kidney care is a widely recognized practice, but a consensus definition was reached only recently. The nomenclature of this care pathway was changed to "comprehensive conservative care" denoting the full extent of care expected. Box 1 shows the full definition of CCC.⁸

In simple terms, Comprehensive conservative care is a viable, quality treatment option for patients with advanced kidney disease who are unlikely to benefit from dialysis.

The standpoints on comprehensive conservative care may vary between countries according to the availability of RRT. KDIGO conference on controversies in conservative care proposed 3 groups to address this concern¹³; (1) those receiving comprehensive conservative care, where conservative care is either chosen

Box 1. Definition of Comprehensive Conservative Care

Comprehensive conservative care is planned holistic patient-centred care for patients with stage 5 (glomerular filtration rate category 5) chronic kidney disease that includes:

Interventions to delay the progression of kidney disease and minimize risk for adverse events or complications

Shared decision making

Active symptom management

Detailed communication, including advance care planning

Psychological support

Social and family support

Cultural and spiritual domains of care

Comprehensive conservative care does not include dialysis.

or medically advised; (2) those receiving 'choice-restricted' conservative care, where resource constraints have prevented or limited the access to renal replacement therapy (and therefore a choice for conservative care cannot be recognized); and (3) those with unrecognized G5 CKD, where CKD is present but has not yet been recognized or diagnosed.

It is challenging to compare survival between patients on comprehensive conservative care with dialysis therapy. It is due to the selection bias, as weaker, frailer patients are selected to the conservative arm. Although pooled evidence shows a substantial survival advantage with dialysis, patients older than 75 years with comorbidity much of this survival advantage is lost.^{9,14,15,16}

QOL is generally similar between patients on dialysis and patients receiving conservative care, although there may be some decrease in life satisfaction in relation to dialysis adjustment. However, with good renal supportive care, many of the conservatively managed patients have stable or improved symptoms and QOL according to current evidence.¹⁷

Withdrawal from dialysis

Withdrawal from dialysis is an ethically and clinically acceptable methodology of stopping dialysis, which occurs after a process of shared decision making.¹⁸ It equipoises the ethical principles of

beneficence, non-maleficence and justice. The median time to death after stopping dialysis is 8 to 9 days but can be considerably longer if there is significant residual renal function.¹⁹ (See Box 2)

There should be written guidelines in each dialysis unit on withdrawal of dialysis and more importantly, access to appropriate supportive and/or hospice care should be accessible for a planned withdrawal. It is vital to address potentially remedial factors like depression, pain or reversible social factors. The withdrawal process should be sensitive to local cultural norms and values, preferences and values of individual and family.⁸

Palliative dialysis

Palliative dialysis is an approach to dialysis that prioritizes QOL and relief of symptoms over survival. It is a form of patient-centred dialysis aligned mainly with patient preferences. Interventions are essentially to control immediate symptoms and distress while promoting wellbeing and social functioning. Special consideration is paid to delivering emotional and family support and to aiding patients and their families come to terms with the progressive nature of their disease. Palliative dialysis is frequently, erroneously, perceived as being similar to less dialysis or a precursor to the withdrawal of dialysis. Even though alteration dialysis timings or eventual withdrawal from dialysis may be a component, this alone will rarely improve symptoms or suffering for patients.²

Box 2. Situations in which withdrawal of dialysis is appropriate⁸

Withdrawal of dialysis can be accomplished in the following situations,

- Patients with decision-making capacity, who is fully informed and making voluntary choices, refuse dialysis or request that dialysis is discontinued
- Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis through appropriate ACP
- Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis or request that it be discontinued
- Patients with an irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behaviour, and awareness of self and environment

Competence Domain 5: End-of-life care

End of life care has mainly 4 components.

The physical component consists of careful assessment of symptoms and appropriate management. Bowel, bladder and skincare, hydration and nutrition are all mandatory components. End of life for patients with advanced CKD (with or without dialysis) is associated with high symptom burden. In a prospective cohort study of conservatively managed patients, the last two months of life were characterized by an increase in symptoms, especially lack of energy, pruritus, drowsiness, dyspnoea, agitation, and pain.^{8,19}

The psychological component consists of providing mental support in the preparation of death. The place of death is also an important aspect of this domain. The patients' values and preferences should be taken into consideration. In the same study, it was noted that patients and caregivers experienced high levels of psychological concerns near the end of life, including high anxiety, low mood, family anxiety, and increased information needs and practical concerns.²⁰

The social component consists of providing support for the family and social workers input in the preparation of a dignified and comfortable death.

The spiritual component is met according to patient's and families' spiritual beliefs and requirements which helps to accept death and bereavement support.

Towards the end of life, both patient and family frequently need much more information and explanation. Encouragement to ask questions, straightforward yet sensitive responses, regular evaluation of concerns and anxieties will aid patient and family immensely at a difficult and challenging time.

Who should provide renal supportive care?

The renal supportive care team should be a multidisciplinary team, which is primarily an amalgamation of renal and palliative medicine, using the skills of both disciplines to ensure optimal nephrology care while concentrating on symptom control, holistic physical and spiritual care and facilitation of a 'good death' at the end.

The ideal team should consist of a nephrologist, palliative care physician, supportive care nurses, dietitian, and social worker. Renal supportive care clinic should be able to communicate effectively with the nephrology services and palliative care services. Different renal units have tried varying models of supportive care with variable success. Renal supportive

care remains a poorly studied care of renal medicine and need more research to validate the optimal model.

Currently, it is recommended to develop a model that suits the local renal service settings and available human resources respecting the principles of nephrology care and palliation.²¹

Conclusion

Renal supportive care should be an integrated component of advanced CKD management, concentrating on both populations undergoing conservative care and renal replacement therapy. It should be continuous throughout the continuum of the disease. Renal supportive care becomes rewarding for patient, family and clinician if five pillars of this care path i.e. symptom management, appropriate prognostication, effective communication, precise care pathway selection and end of life care are properly dealt with.

References

1. George C, Mogueo A, Okpechi I, Echouffo-Tcheugui JB, Kengne AP. Chronic kidney disease in low-income to middle-income countries: the case for increased screening. *BMJ Glob Health*. 2017; **2**(2):e000256. doi:10.1136/bmjgh-2016-000256
2. Haileamlak A. Chronic Kidney Disease is on the Rise. *Ethiop J Health Sci*. 2018; **28**(6): 681-2. doi:10.4314/ejhs.v28i6.1
3. Murray AM, Arko C, Chen SC, et al. Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 2006; **1**: 1248-55.
4. Davison SN, Jassal SV. Supportive care: Integration of patient-centred kidney care to manage symptoms and geriatric syndromes. *Clin J Am Soc Nephrol*. 2016; **11**: 1882-91.
5. Tamura MK, Meier DE. Five policies to promote palliative care for patients with ESRD. *Clin J Am Soc Nephrol*. 2013; **8**: 1783-1790.
6. Davison SN, Jhangri GS, Koffman J. Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. *BMJ Support Palliat Care* 2016; **6**: 66-74.
7. Davison SN, Jhangri GS. Impact of pain and symptom burden on the health-related quality of life of haemodialysis patients. *J Pain Symptom Manage*. 2010; **39**: 477-85.
8. Davison SN, Levin A, Moss AH, et al. Improving Global Outcomes: 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**: 447-59.

9. Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guidelines. Renal Physicians Association, USA.2010; 2nd Edition.
10. Couchoud C. Dialysis: Can we predict death in patients on dialysis? *Nat. Rev. Nephrol.* 2010; **6**: 388-9.
11. Foote C, Ninomiya T, Gallagher M et al. Survival of elderly dialysis patients is predicted by both patient and practice characteristics. *Nephrol. Dial. Transplant.* 2012; **27**: 3581-7.
12. Murtagh FEM, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol. Dial. Transplant.* 2007; **22**: 1955-62.
13. Hemmelgarn BR, Manns BJ, Quan H, Ghali WA. Adapting the Charlson Comorbidity Index for use in patients with ESRD. *Am. J. Kidney Dis.* 2003; **42**: 125-32.
14. Clegg A, Young J, Iliff S, et al. Frailty in elderly people. *Lancet.* 2013; **381**: 752-62.
15. Alfaadhel TA, Soroka SD, Kiberd BA, et al. Frailty and mortality in dialysis: evaluation of a clinical frailty scale. *Clin J Am Soc Nephrol.* 2015; **10**: 832-40.
16. O'Hare AM, Armistead N, Schrag WL, et al. Patient-centred care: an opportunity to accomplish the "Three Aims" of the National Quality Strategy in the Medicare ESRD program. *Clin J Am Soc Nephrol* 2014; **9**: 2189-94.
17. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014; **28**: 1000-25.
18. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; **340**: c1345. doi: <https://doi.org/10.1136/bmj.c1345>
19. Murtagh FE, Burns A, Moranne O, Morton RL, Naicker S. Supportive Care: Comprehensive Conservative Care in End-Stage Kidney Disease. *Clin J Am Soc Nephrol.* 2016; **11**(10): 1909-14.
20. O'Connor NR, Kumar P. Conservative Management of End-Stage Renal Disease without Dialysis: A Systematic Review. *J Pall Med.* 2012; **15**(2): 228-35.
21. Hussain JA, Mooney A, Russon L. Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Pall Med.* 2013; **27**(9): 829-39.