CARING FOR OLDER PATIENTS ON PERITONEAL DIALYSIS AT END OF LIFE

Frédérique Meeus¹ and Edwina A. Brown²

Nephrology Departement,¹ Clinique Edouard Rist, Paris, France; and Imperial College Renal and Transplant Centre,² Hammersmith Hospital, London, UK

End of life is the last phase of life, not merely the last few days. For many older patients on peritoneal dialysis (PD), the end-of-life phase commences with the start of dialysis. The principal aim of management of this phase should be optimizing the quality of life of the patient. Evidence suggests that patients on dialysis mostly want involvement in decisions at this stage, but most do not have the opportunity to do so. Management should therefore include discussions with the patient and their family to determine lifestyle goals, treatment wishes, and ceilings of care (including resuscitation and dialysis withdrawal). Care should also include symptom identification and management, psychosocial support, and adaptation of dialysis to the ability and needs of the patient. By doing this, quality of life at end of life is achievable.

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End of life describes the last phase of life, not just the last few days. The majority of older patients on peritoneal dialysis (PD), unless transplantation is a realistic option, will remain dependent on dialysis of one type or another until they die (either on dialysis or after dialysis withdrawal). For these patients, dialysis is, therefore, the end-of-life phase or final destination as discussed by Vandecasteele and Tamura (1). Focus of care, therefore, should be on quality of life and not on targets of dialysis delivery, achieving random blood test levels, or preventing future complications, unless they result in symptomatic improvement. Rather, care should focus on what matters to the patient so that they can achieve their goals for their remaining life. The key components of management of this end-of-life stage are shown in Box 1. This paper is based on the output of the Kidney Disease Improving Global Outcomes (KDIGO) Controversies Conference on Palliative Care in Chronic Kidney Disease Populations (2). The major recommendations emerging from the conference were:

- The need for supportive care for kidney patients is equal to that for cancer patients and should be available based on need, not prognosis, for patients at any stage of kidney disease.

Correspondence to: Professor Edwina Brown, Hammersmith Hospital, Du Cane Road, London W12 0HS United Kingdom.
e.a.brown@imperial.ac.uk

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- Supportive care is an essential component of the continuum of quality care for chronic kidney disease (CKD) and end-stage kidney disease (ESKD) patients and should be provided with sensitivity to cultural and religious values as well as patient and family comfort and dignity.
- Research in supportive care is critical to build new knowledge so that patient outcomes can be improved.
- Kidney patients have a high symptom burden, and treatment of their symptoms is a high priority for them. Nephrologists should routinely ask patients about symptoms so they can be identified and treated.

SUPPORTIVE CARE

Supportive care, as defined by the British National Council for Palliative Care “helps the patient and their family to cope with their condition and treatment of it—from pre-diagnosis,

BOX 1 — Achieving good quality of life at end of life

1. Focus on supportive care. This includes:
 - a. Determining factors that affect quality of life of patient—symptoms, potential depression, social issues, physical mobility, falls, cognitive function. This may require a comprehensive geriatric assessment
 - b. Enabling holistic multiprofessional support to manage these issues; this includes rehabilitation to maximize physical and social functioning
2. Recognize predictors of poor survival and be realistic about prognosis
3. Be realistic about benefits, risks and potential harm of active interventions
4. Discussion with patient and family:
 - a. Prognosis
 - b. Determine goals for remaining life and how they can be achieved
 - c. Establish ceiling of care, including resuscitation status
 - i. Advance care planning
 - ii. Advance directives
 - d. Establish preferred place of care for last few days: home, hospice, hospital
5. Early referral to palliative care team to assist with symptom control, support in the community, and management of the last few days

through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment" (3). Ideally, it should be part of routine management of all patients on dialysis but is particularly key to managing older patients on dialysis as they approach end of life. For these patients, geriatric assessment and rehabilitation are a key part of supportive care and are discussed separately in this supplement by Jassal (pp. 630–634).

SYMPTOM ASSESSMENT AND MANAGEMENT

Symptom assessment and management are a key part of care for older patients on PD. The BOLDE (Broadening Options for Long-Term Dialysis in the Elderly) study showed that the median number of symptoms for patients on PD over 65 years old was close to 9 and that the symptom score independently determined all measures of quality of life in the study: SF12 (physical and mental scores), illness intrusiveness, and depression (4). Symptoms should therefore be routinely enquired about, either as part of routine history taking or by regularly administering one of the symptom assessment forms which have been validated for CKD, e.g., the Palliative Care Outcome Scale-Renal (POS-renal) which has been translated into several languages (5). It is particularly important to enquire about pain, which is common in older patients on dialysis because of their high burden of comorbidities including arthritis and ischemic problems related to vascular disease. It is beyond the scope of this article to discuss in detail the management of symptoms, pain, and psychosocial issues such as depression, and readers are directed to the full review in the executive summary from the KDIGO conference (6).

REALISTIC ASSESSMENT OF PROGNOSIS

Realistic assessment of prognosis is a key part of supportive care both to inform discussions with patients and families about future planning and to plan emphasis of management between active and supportive interventions. A number of prognostic scores are emerging (7–10); these can be used to support clinical intuition based on age, comorbidities, nutritional status, physical and cognitive functioning, and the answer to the surprise question ("would you be surprised if the patient died in the next number of months of your choosing?"). Although these mostly have evolved in the hemodialysis population, there is no reason to believe that they would not also be valid for patients on PD.

HONESTY

Truth-telling about prognosis and efficacy of potential treatments is essential to avoid unrealistic expectations on the part of patients and their families. However, this needs to be delivered with sensitivity and cultural awareness (11). Much of

the renal palliative care literature is US- and UK-dominated and emphasizes individual patient autonomy with inherent rights of truth-telling and decision-making. In many other parts of the world, the cultural norm is protection of the patient from the truth, decision-making by the family, and a tradition of familial piety where it is dishonorable not to do as much as possible for parents (12).

ADVANCE CARE PLANNING

Advance care planning enables patients and families to be involved in decisions around ceilings of care, potential withdrawal of dialysis, and place of care at end of life. In a Canadian study, less than 10% of patients reported having had a discussion about end-of-life care issues with their nephrologist in the past 12 months, while 83% thought that it was important to be prepared and plan ahead in case of death (13). Failure to have these discussions can result in inappropriate optimism; interviews of seriously ill hemodialysis patients have shown that they were significantly more optimistic than their nephrologists about their prognosis and transplant candidacy (14). Only 6% of patients in this study thought they had less than a 50% chance of being alive in 5 years, whereas actual survival at just less than 2 years of follow-up was only 56%. This discrepancy was hardly surprising as not a single patient reported receiving an estimate of life expectancy from their nephrologist.

Advance care planning is not a single process achieved at a one-off discussion; rather it is the culmination of a series of discussions along the patient trajectory (15). As shown in Box 2, these discussions can be incorporated into routine care when discussing overall management with patients but should be initiated when patients start dialysis; after key events such as stroke, falls, and dialysis difficulties; or whenever the patient appears to be deteriorating and the answer to the surprise question becomes "no." A randomized controlled trial in an elderly general medical population has shown that advance care planning improves end-of-life care, patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives (16). A similar study has yet to be done

BOX 2 — Timing of end-of-life discussions

1. When patient is deteriorating clinically from comorbidities despite dialysis
2. Increasing frailty requiring increasing support for activities of daily living
3. Onset of cognitive dysfunction as reported by patient or family
4. After new serious clinical event, e.g. stroke, diagnosis of malignancy, hip fracture, etc.
5. After episode of delirium while hospital in-patient
6. Failing peritoneal dialysis and patient does not want to transfer to hemodialysis and transplantation not feasible
7. Recurrent admissions to hospital
8. Patient wants to withdraw from dialysis

in the dialysis population; yet patient interviews suggest that most participants felt that advance care planning is important and should start early in the disease course, but that it rarely takes place at all (17).

MANAGEMENT OF PD PATIENT AT END OF LIFE

When a patient is found to be deteriorating in the absence of reversible medical factors and death appears likely in the coming weeks to months, it is necessary to establish appropriate end-of-life care using the components of supportive care discussed above. This requires open communication with the patient and family about care preferences and dying wishes (at home, in a hospice, in a palliative care unit, in a nursing home). The discussion should include the feasibility of these wishes by determining the social support, living conditions and physical and cognitive capacities of the patient. As PD is a home treatment, most of the care of the patient is inevitably in the community. It is therefore important to involve and communicate with the primary care team including general practitioner, community nurses and community palliative care team; this will obviously depend on local healthcare factors and organization.

Decisions will also need to be made regarding dialysis: Can the patient continue to manage their own PD? Or will assistance by the family or paid carers enable the patient to continue PD? If not, it is necessary to determine whether the patient and family accept withdrawal of dialysis when it is technically no longer feasible, or whether they want to transfer to hemodialysis (HD) (if available and technically feasible). If the latter, the discussion should include realistic outcomes (patient well-being in addition to survival) on HD. Interestingly, French data suggest that patients prefer to die on PD (18).

In addition to planning discussions around wishes and dialysis, goals of care during the end-of-life phase should focus on achieving the optimal quality of life given the burdens of underlying morbidities, frailty, and psychosocial concerns. As summarized in Box 3, this entails a review of and discontinuation of 'no longer needed' medications; identification and treatment of symptoms, pain, and depression; and support for nutritional needs. Finally, a recognition of the "last few days" with appropriate anticipatory prescribing is necessary (19). This latter phase is best managed in conjunction with a palliative care team. Finally, the spiritual needs of the patient and their family should be recognized both while the patient is dying and into bereavement. Failure to recognize that death is inevitable results in a poorer quality of death for patients, with fewer having palliative care, symptom control, or dying without their loved ones being able to say their "good-byes" (20).

KEY POINTS

- Patients want discussions about prognosis and management at the end of life
- Factors affecting prognosis include age, comorbidities, nutritional status, physical and cognitive function

BOX 3 — Management of symptoms at end of life

Pain

- Common—usually related to comorbid conditions, such as vascular disease, arthritis, or immobility
- Use local guidelines for analgesics that are "safe" to use in advanced kidney disease
- Strong opioids are often needed; they should be given continuously and intermittently as needed to keep the patient pain-free

Nausea and vomiting

- Often exacerbated by use of opiate-related analgesics
- Use local guidelines for anti-emetics considering potential side-effects and dose adjustments for advanced kidney disease
- Consider pre-emptive prescription of anti-emetics when prescribing opiates for pain relief

Shortness of breath

- If pulmonary edema is present, peritoneal dialysis regime can be adjusted to use more high-strength dextrose dialysate or an extra icodextrin exchange; potential long-term complications do not matter at this stage
- Often due to or exacerbated by anxiety, in which case the following may be helpful:
 - cool fan on the face
 - oxygen
 - reassuring presence of family or staff
 - explanation to family and patient
- Strong opioids can be used if needed
- Cheyne–Stokes respiration is usually a terminal event and the patient is often unconscious. Important to explain this to relatives so that they are reassured that the patient is not suffering

Retained respiratory tract secretions

- Medications such as hyoscine, scopolamine or glycopyrrolate can be useful; use local palliative care guidelines
- Suction may be needed

Terminal restlessness and agitation

- Tranquilizers such as midazolam or quetiapine are useful at this stage and are often administered by syringe driver; use local palliative care guidelines

- Symptoms should be recognized and treated
- Ceiling of care—including resuscitation status and dialysis withdrawal—should be discussed with patients
- Targets of care (dialysis and medications) should focus on current well-being and not on long-term complications

DISCLOSURES

The authors have no financial conflicts of interest to declare.

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