

SUPPORTIVE CARE IN ADVANCED KIDNEY DISEASE: PATIENT ATTITUDES AND EXPECTATIONS

Maria Da Silva-Gane, Ken Farrington

Renal Unit, Lister Hospital, E&N Herts NHS Trust, Stevenage, Hertfordshire, UK

Da Silva-Gane M., Farrington K. (2014). Supportive care in advanced kidney disease: Patient attitudes and expectations. *Journal of Renal Care* 40(Suppl. 1), 30–35.

SUMMARY

Treatment with dialysis has benefitted large numbers of patients with advanced kidney disease. It is though highly intrusive and demanding and some elderly, frail patients may tolerate it poorly. Some of these patients who are either approaching 'end-stage' kidney disease or 'failing' despite being on dialysis may choose to pursue supportive or palliative approaches, partially or fully replacing the dialysis option. Here, we describe some of the challenges confronting these patients and present data on the attitudes and perceptions to supportive care and end-of-life care planning of patients on haemodialysis including some whose prognosis was poor. The main focus for these patients appeared to be on holding on to what they had, adapting by living 'from day to day' in the present, and continuing to hope for the best. Advance care planning was seen as potentially useful by patients, once clarity surrounding its purpose had been established.

KEY WORDS Chronic kidney disease • Haemodialysis • Palliative care • Withdrawal

INTRODUCTION

Dialysis is a highly effective treatment for patients with advanced kidney disease but the demands it makes on patients—many of whom are elderly and frail—can be very high. Choosing not to start dialysis or, if already receiving the treatment, to reduce or discontinue it in favour of supportive or palliative management options, are not uncommon responses. This paper will outline some of the factors underlying the development of this state of affairs, some of its challenges, and attempt to synthesise some

of the attitudes and perceptions to supportive care and end-of-life care planning of patients on haemodialysis.

DECISION-MAKING AND DIALYSIS

The last half-century has brought forth dramatic changes in the prospects for survival of people with advanced kidney disease. Before this time a diagnosis of advanced kidney disease was tantamount to a death sentence. The advent of renal replacement therapy by means of dialysis and transplantation has transformed this outlook. Most with this condition can now look forward to an extended survival.

When dialysis first became available for the treatment of patients with advanced kidney disease, access was limited to include younger patients without significant comorbidities (Challah *et al.* 1984). Over the past decades the continued success of the therapy in developed economies has led to a broadening of the range of patients with advanced kidney disease considered suitable for the treatment. Potential coverage is now generally all-inclusive. Since the prevalence of kidney disease rises dramatically with age, and since age is associated with increasing comorbidity, the patient population receiving or considering renal replacement therapy is becoming increasingly old and frail (Shaw *et al.* 2013). For such patients, transplantation is usually not a viable option, and many will not be able to undertake home-based therapy such as CAPD. UK Registry data shows that the older a patient is, the more likely centre-based haemodialysis is to be the preferred renal replacement therapy modality (Shaw *et al.* 2013).

BIODATA

Maria Da Silva-Gane has experience with renal patients dating back to 1991. She is the lead Clinical Counsellor and has been responsible for setting up the Renal Support Team at Lister Hospital; the team offers a social and psychological service to patients under the care of the renal department. She was also part of the team that established the Renal Supportive Care Service for those patients who have either opted not to have dialysis or who are 'failing despite dialysis'. She has been involved in research, and presented at national and international conferences on this subject.

CORRESPONDENCE

Maria Da Silva-Gane,
Renal Unit, Lister Hospital, E&N Herts NHS Trust,
Stevenage, Hertfordshire SG1 4AB, UK
Tel.: +44(0) 1438 284233
Fax: +44(0) 1438 284130
Email: maria.dasilvagane@nhs.net

Though haemodialysis is a life-extending treatment for the majority, life on dialysis can be very demanding. Patients are required to dialyse thrice weekly for around four hours at a time (Eknoyan *et al.* 2002). This requires travelling, sometimes considerable distances to the dialysis centre. Dialysis sessions can be frequently complicated by hypotensive episodes (Henderson 2012). Patients frequently have a 'hangover' after the session and it has been estimated that the average time taken to recover from these post-dialysis symptoms is over seven hours (Lindsay *et al.* 2006). The symptom burden is also high with over 40% of patients experiencing severe lack of energy and over 20% severe breathlessness (Murtagh & Addington-Hall 2007). Furthermore, haemodialysis offers imperfect replacement of kidney function. Mortality is high, especially for the older, more frail patient, with the mean survival of patients who are more than 75 years of age, around two years (Pruthi & Steenkamp 2013).

This presents some difficult choices for some older, fragile patients who are either approaching 'end-stage' kidney disease or 'failing' despite being on dialysis. Respectively, the main issues are whether to start dialysis or not and whether, having started, to continue or not. Increasing numbers of patients are surviving long enough to necessitate confrontation of these issues. Such considerations do not take place in a vacuum. There is now an emphasis on ensuring good support for patients and carers during and beyond these decisions.

END-OF-LIFE CARE IN ADVANCED KIDNEY DISEASE

In the last decade much work has been done to raise the profile of end-of-life care in advanced kidney disease. Its importance was acknowledged in the National Service Framework for Renal Services in the quality standard that patients should 'receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences' (NSF 2004). Subsequent work emphasised that end-of-life care is an essential part of kidney services, and highlighted the stages of End-of-Life Care Pathway—identifying triggers to initiate discussions, assessment and planning, coordination of quality care across boundaries, care in the last days and bereavement—as applied to patients with advanced kidney disease. There was particular reference to patients 'choosing not to dialyse' and those deteriorating or 'failing despite dialysis' (NHS 2009).

CHOOSING NOT TO DIALYSE

Some patients at or approaching 'end-stage' may choose to forgo dialysis and opt for 'conservative management'. These patients are usually elderly and are often frail with high comorbid loads (Smith *et al.* 2003). The rate of deterioration of renal function is also a major factor; those whose renal function is declining slowly are much more likely to choose this option than patients whose function is declining more rapidly.

Most renal units in the UK have conservative management pathways, though there are many variations in their organisation and content. Most will provide full medical treatment including measures to prevent or manage the complications of kidney failure such as anaemia and fluid retention, and treatment of comorbid conditions and intercurrent illnesses. Advance care planning for end-of-life care is an important aspect together with ongoing support for patients and carers involving the wider multidisciplinary team. Adequate planning depends on timely referral to the nephrology clinic.

Survival on conservative management is variable, but comparative cohort studies have suggested that dialysis may not significantly enhance survival of elderly patients with high comorbid burdens (Smith *et al.* 2003; Murtagh *et al.* 2007; Chandna *et al.* 2011; Hussain & Mooney 2013). Quality of life may compare favourably in some respects to dialysed counterparts (Da Silva-Gane *et al.* 2012) and functional status appears to be maintained until the last few weeks before death (Murtagh & Addington-Hall 2011).

FAILING DESPITE DIALYSIS

Life on dialysis can be demanding. In addition to the issues described earlier—time constraints, travelling, intra- and post-dialysis complications and high symptom burden—patients also have to contend with significant fluid and dietary changes, and the highest 'pill-burden' of any chronic disease. Older patients on dialysis who are becoming progressively frail because of increasing comorbidity may find dialysis an increasing struggle. Intercurrent medical events such as a stroke or new diagnosis of cancer or life-events such as the death of a spouse or carer may trigger a need to reconsider treatment goals to life-extending to those focussed on care and symptom control (GSF 2011).

The benefits of end-of-life care planning for people who are 'failing despite dialysis' are now widely recognised, as is supportive care as an appropriate care pathway. However,

	Intensity of care during the final month of life		
	Dialysis	Cancer	Heart failure
Hospitalisation (%)	76.0	61.3	64.2
Days in hospital (mean)	9.8	5.1	NA
ICU admission (%)	48.9	24.0	19.0
Days in ICU (mean)	3.5	1.3	NA
Any intensive procedure (%)	29.0	9.0	NA
Hospice use (%)	20.0	55.0	39.1
Death in hospital (%)	44.8	29	35.2

Table 1: Intensity of care during the final month of life.

approaching discussions with patients and their family is often complex and difficult for renal teams. Such conversations are often ignored during clinical consultation, in spite of the obvious 'elephant in the room'. The focus is often on maintaining or indeed escalating interventions rather than on shifting to a more supportive and palliative-care approach. Wong *et al.* highlighted this in showing that escalation of treatment intensity in the last month of life was much greater in the dialysis population than in either cancer or heart failure (Wong & Kreuter 2012). They concluded that the pattern of end-of-life care among older patients receiving dialysis seemed to be driven by practice-related factors (Table 1) rather than palliative measures.

SHIFTING FOCUS

The preceding paragraphs have demonstrated that the benefits of dialysis for the older and more frail patient may not be clear cut. Dialysis can impose additional burdens, including invasive interventions, time commitment, and what may be considered over-medicalisation of dying. Addressing these issues presents a number of challenges, including the sensitivity of the subject, difficulty of identifying 'at-risk' patients and differences in the way patients, families and clinicians perceive and communicate about end-of-life issues. The next section will explore some of the attitudes and perceptions to supportive and end-of-life care planning with patients undergoing haemodialysis.

OBSERVATIONS ON PATIENT ATTITUDES AND PERCEPTIONS

The following paragraphs outline the findings from a patient survey and from patient interviews the purpose of which were to explore the attitudes and perceptions to future end-of-life care planning of patients receiving haemodialysis.

QUESTIONNAIRE DEVELOPMENT AND FINDINGS

Questionnaire development was informed by existing literature, patient and family focus groups and a pilot to address

feasibility issues such as patient acceptance, understanding and ease of completion. Patients aged 18+ years, receiving haemodialysis who were able to complete the questionnaire in English without a translator, were eligible. The questionnaire was distributed to all 320 patients undergoing HD. The response rate was 75%. Responders were predominately male (64%), white European (79%). The mean age was 67 years and many (43%) were assessed as having severe comorbidity.

The value of involvement in discussions about future options when their health was deteriorating was supported by the vast majority (88% positive responses). However, many fewer patients responded that they had already given consideration to the types of future treatments they may or may not find acceptable (45% positive, 17% equivocal, 38% negative responses).

The vast majority of patients (83% positive) responded that they would wish to be admitted to intensive care in the event of a dramatic deterioration in their health and would wish for everything possible to be done for them. Likewise most patients indicated a wish for resuscitation to be attempted in the event of cardiac arrest (78% positive). Those patients who indicated a wish to forego attempts to resuscitate were older and had a higher symptom burden. Fewer of them thought that dialysis had benefitted them and even fewer that the treatment had helped them achieve life-goals (Table 2).

Attitudes to having a personal end-of-life care plan were generally positive (59% positive, 19% equivocal, 22% negative) and similar numbers thought that their family would benefit. Eighty-five percent of those positive about a personal plan also were positive about benefits for the family. Support for a personal end-of-life care plan was more evident among younger patients (<60 years of age).

If you were unwell and your heart stopped beating suddenly would you want vigorous attempts to be made to revive you?				
	No	Equivocal	YES	p-Value
Number	38	13	177	
Mean age (years)	70	65	62	0.011
Sex (% male)	58	85	65	ns
Ethnicity (% White)	89	77	78	ns
High comorbidity (%)	53	38	42	ns
Symptom score	21	15	17	0.040
Depressed (%)	30	8	26	ns
Dialysis benefits (%)	71	77	86	0.032
Dialysis and life goals (%)	13	23	43	0.001

Table 2: Patient wish concerning resuscitation.

INTERVIEW FINDINGS

Semi-structured interviews were conducted by an experienced qualitative interviewer, on a one-to-one basis and at a time and location of the participants' choice. All interviews were transcribed and interpreted using a constructivist grounded theory approach (Glaser & Strauss 1967; Charmaz 2006) Twenty patients were interviewed. All had a poor prognosis (adverse response to Surprise Question). The mean age was 68 years, and mean length of time on dialysis was six years. Sixteen had severe co-morbidity.

Three main themes were identified:

i. Living one day at a time

Patients appeared to lack insight into their current situation. They did not see themselves as terminally ill. They appeared to assume that dialysis would keep them alive indefinitely. Their focus was on coping with the challenge of day-to-day living in the face of an intrusive treatment. A number of factors underpinned this: information, which was ambiguous and lacking in realistic prognostic detail; unrealistic expectations of the limitations of dialysis and a genuine lack of understanding.

'I don't really talk about it that level. Whether it is avoiding it don't know but I don't feel in that situation ... Fingers crossed anyway.'

ii. Complex relationship with dialysis

In general patients experienced severely altered lives and had negative views regarding the impact of dialysis. Confounding this was the role of dialysis as life-giving and prolonging, which had become a normal part of life. Patients appeared

willing to endure the consequences and the many associated burdens, in return for staying alive.

'It's something that just gets into your lifestyle ... you just can't do anything about it.'

iii. The words are important

Patients denied having discussed end-of-life issues with family except in the context of social aspects of death, such as wills and funeral arrangements, and that these were felt to be personal and private matters. This led to confusion, for a number of patients, about the meaning of 'Advance Care Planning'. Once a clear understanding of this had been established, the majority felt that discussion around their health status and what options they may have in relation to their current situation would potentially be of benefit. It was felt it could benefit them, family and the renal team.

'If I were in hospital and something happened, the doctors tell my family this is what your Mum wanted'

SYNTHESIS

Despite the struggle and complexities of living with advanced kidney disease, the haemodialysis treatment and the resulting burdens, including high levels of uncertainty, the main focus for the patients appeared to be on to holding on to what they had, adapting by living in the present, and by continuing to hope for the best. This was the prevalent approach and overrode considerations of and planning for the end of their lives.

OVERALL CONCLUSIONS

Dialysis is a hugely beneficial treatment for the majority of patients with advanced kidney disease but is highly intrusive. The patient population approaching 'end-stage' kidney disease or receiving

dialysis is growing and a high proportion is elderly and frail. A supportive or palliative approach, supplementing or replacing the dialysis option, may be appropriate for at least some patients.

Realistic discussions and information for patients may help to reduce the barriers in approaching future care planning. Discussions should include the limitations of dialysis, particularly for the elderly and frail. Whilst clinicians tend to feel that this is accomplished, the apprehension expressed by patients regarding end-of-life care and advance care planning alongside their apparent lack of insight into the seriousness of their condition tends to suggest that such discussions are not communicated in a way that is necessarily understood. Provision of credible and sensitive prognostic information prior to initiation of treatment might facilitate more realistic insight of the limitations of dialysis in this setting.

Advance care planning was seen as useful by some patients, at least once clarity surrounding their purposes had been established. Most would welcome a holistic care plan based on realistic goals of treatment, which may or may not involve dialysis and that would resonate with their life goals. Words are

important in this context. Use of the word 'Advance' introduces, for some, apprehension and pre-conceived ideas. We feel that the accent should be on a 'care plan', the fruit of focussed discussions on realistic options taking account of the patients' current health status, and likely future prognosis. Depending on the particular circumstances, the plan may reflect a focus on care provision and symptom management rather than longevity. Open and realistic communications between members of the renal team, patients and families both facilitate planning and are facilitated by the plan. Both fully acknowledge the 'elephant in the room'. Such discussions should be embedded in practice and the resulting decisions regularly reviewed.

ACKNOWLEDGEMENTS

None.

CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHOR CONTRIBUTIONS

MDG and KF wrote and approved the final manuscript.

REFERENCES

- Challah S., Wing A.J., Bauer R. *et al.* (1984). Negative selection of patients for dialysis and transplantation in the United Kingdom. *British Medical Journal (Clinical Research Ed.)* **288**, 1119–1122.
- Chandna S.M., Da Silva-Gane M., Marshall C. *et al.* (2011). Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrology Dialysis Transplantation* **26**, 1608–1614.
- Charmaz K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage Publications.
- Da Silva-Gane M., Wellsted D., Greenshields H. *et al.* (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* **7**, 2002–2009.
- Eknoyan G., Beck G.J., Cheung A.K. *et al.* (2002). Effect of dialysis dose and membrane flux in maintenance hemodialysis. *The New England Journal of Medicine* **347**, 2010–2019.
- Glaser B.G., & Strauss A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. USA: Transaction Publishers.
- Gold Standards Framework. (2011). *Prognostic Indicator Guidance*, 4th edn. The Gold Standards Framework Centre CIC. www.renalreg.com.
- Henderson L.W. (2012). Symptomatic intradialytic hypotension and mortality: an opinionated review. *Seminars in Dialysis* **25**, 320–325.
- Hussain J.A., Mooney A., & Russon L. (2013). 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. *Palliative Medicine* **27**, 829–839.
- Lindsay R.M., Heidenheim P.A., Nesrallah G. *et al.* (2006). Minutes to recovery after a hemodialysis session: a simple health-related quality of life question that is reliable, valid, and sensitive to change. *Clinical Journal of the American Society of Nephrology* **1**, 952–959.
- Murtagh F.E., Addington-Hall J., & Higginson I.J. (2007). The prevalence of symptoms in end-stage renal disease: a systematic review. *Advances in Chronic Kidney Disease* **14**, 82–99.
- Murtagh F.E., Addington-Hall J.M., & Higginson I.J. (2011). End-stage renal disease: a new trajectory of functional decline in the last year of life. *Journal of the American Geriatrics Society* **59**, 304–308.
- Murtagh F.E., Marsh J.E., Donohoe P. *et al.* (2007). Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrology Dialysis Transplantation* **22**, 1955–1962.
- NHS Kidney Care. End of Life Care in Advanced Kidney Disease: A Framework for implementation; 2009.
- National Service Framework for Renal Services Part 2.: UK Department of Health, 2004.

Pruthi R., Steenkamp R., & Feest T. (2013). UK Renal Registry 16th annual report: chapter 8 survival and cause of death of UK adult patients on renal replacement therapy in 2012: national and centre-specific analyses. *Nephron Clinical Practice* **125**, 139–169.

Shaw C., Pruthi R., Pitcher D. *et al.* (2013). UK Renal Registry 15th annual report: chapter 2 UK RRT prevalence in 2011: national and centre-specific analyses. *Nephron Clinical Practice* **123** (Suppl 1), 29–54.

Smith C., Da Silva-Gane M., Chandna S. *et al.* (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**, c40–c46.

Wong S.P., Kreuter W., & O'Hare A.M. (2012). Treatment intensity at the end of life in older adults receiving long-term dialysis. *Archives of Internal Medicine* **172**, 661–663.