

End-of-life issues in renal medicine

Simon Watson

This was the Renal Association's first meeting devoted entirely to an ethical issue, and many attendees had non-nephrological backgrounds. The presence of a protester, demonstrating against voluntary euthanasia, marked another 'first' for the association. The meeting comprised invited lectures and an interactive session in which real-life cases were discussed and courses of action voted upon by audience and speakers.

Dialysis was once available only to the lucky few, but now it is the treatment for most patients with end-stage renal disease (ESRD). Some patients facing a poor quality of life agree not to start dialysis. Others simply do not want it, despite it being in their best interests clinically. This conference addressed the ethical and legal issues concerning the non-dialytic, or 'conservative', management of ESRD.

Legal perspectives

The first speaker, Lord Joel Joffe, is currently sponsoring the Assisted Dying for the Terminally Ill Bill, which aims to give patients who make 'desperate and repeated requests' medical assistance to end their lives. The Bill has been influenced heavily by the Physician Assisted Suicide Law in the US state of Oregon. Lord Joffe believes that some suffering cannot be relieved by palliative care professionals, for example loss of personal autonomy or control of bodily functions, and assisted dying should be available in such circumstances. He acknowledged the concerns of his Bill's opponents but pointed out that 70–80% of the public supports assisted dying. Furthermore, no evidence of abuse of vulnerable people or diminishment of palliative care has been observed in Oregon since its 1994 law was passed. Lord Joffe concluded that assisted dying was deeply humane and valued life by giving new rights to terminally ill people.

The present laws on consent and refusal of treatment were outlined by Mr Robert Francis QC, a leading barrister specialising in clinical ethics and medical negligence. He explained that all contact with patients requires consent, which must be given freely and without pressure from others. The legal right to refuse treatment is absolute, and both consent and refusal require a patient to have the mental capacity to make an informed decision. The Refusal and Mental Capacity Act (2005), which has yet to receive Royal Assent, is designed to clarify these rights and the procedures to be followed in making

treatment decisions. Mr Francis also explained that the right to demand treatment, where it is considered inappropriate by a doctor, does not exist, as demonstrated in the recent case of *General Medical Council v. Burke* (2005).

The laws governing consent and refusal recognise an individual's right to personal autonomy. Some believe that the illegality of assisted suicide constitutes an infringement of this right. However, Dr Piers Benn, a lecturer in medical ethics and law at Imperial College London, argued that this was not the case. Dr Benn suggested that other rights, including those to dignity or freedom from suffering, may be used as ethical justifications for the legalisation of assisted suicide.

Evidence for conservative care in end-stage renal disease

It is extremely difficult to make accurate predictions of the quality and quantity of life that individual

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Conference programme

- **Assisted dying is deeply humane**
Lord Joffe, House of Lords
- **Choices and dying**
Deborah Duval (patient)
- **Withdrawal of treatment and human rights**
Robert Francis QC, Three Serjeants' Inn, London
- **Does conservative management necessarily shorten life expectancy in elderly patients with ESRF?**
Dr Aine Burns, London
- **Measuring quality of life in ESRF: can we do this accurately?**
Dr Liam Plant, Cork
- **My choice is not to dialyse. I want my choice respected.**
Ms Sehnaz Hanslot (patient)
- **Conservative management of ESRF is a euphemism for rationing dialysis**
Professor Terry Feest, Bristol
- **Is a randomized controlled trial of dialysis versus maximum conservative management of ESRF ethical and possible?**
Dr Andy Stein, Coventry
- **The moral theorist's view**
Dr Piers Benn, London
- **Osler Oration: In the wake of progress – ethics in renal failure**
Dr Chris Winearls, Oxford

patients starting dialysis can expect to enjoy. The evidence base for similar predictions concerning conservative care in ESRD is small but growing.^{1,2} Dr Aine Burns of the Royal Free Hospital, London, discussed the Maximal Conservative Management Service provided at her hospital. A patient's biochemistry, uraemia, haemoglobin and residual renal function are optimised without dialysis, and psychological support is offered in preparation for death. Preliminary data have shown that most patients who died did so at home, achieving an average of 17.5 months of life without dialysis. Dr Burns concluded that the Royal Free's model showed that high-quality conservative care was a viable alternative for dialysis in some patients.

Many feel that the lack of a randomised controlled trial (RCT) before the widespread introduction of dialysis has led to much uncertainty about its true benefits. Dr Andy Stein of Walsgrave Hospital, Coventry, warned against repeating this mistake. He is about to start a pilot study comparing conservative and dialysis therapy for appropriate patients, which he hopes to follow with a UK-wide RCT. Dr Stein appealed for cooperation, support and funding from the renal community for his ambitious project.

Quality of life is harder to measure than quantity of life, but

quality is probably more important in relation to palliative and end-of-life care. Dr Liam Plant of Cork University Hospital explained that well-validated and useful questionnaires exist for measuring components of a person's quality of life. However, the health scores produced by such questionnaires frequently lead to limited, rather unsurprising conclusions. Dr Plant argued that more interesting information often lies within individual answers provided, but many doctors mistrust this type of qualitative analysis. Furthermore, factors including a patient's spiritual beliefs and the extent of the patient's social support network are important predictors of quality of life.³ These factors reside outside the traditional medical model and, hence, are accorded low importance by doctors. Dr Plant concluded that physicians should adopt a more patient-centred perspective of quality of life.

The worrying possibility that conservative treatment for ESRD is merely a ruse for rationing dialysis was addressed by Professor Terry Feest of Southmead Hospital, Bristol. Professor Feest said that doctors already make judgements on individual patient care based upon awareness that rationing is a reality within the NHS. He cited non-clinical factors, including the percentage of gross domestic product (GDP) spent on healthcare, the number of nephrologists per head of population, and the proximity of patients to their local renal unit, as predictors of the dialysis provision in particular regions. Professor Feest also disputed the equivalence of conservative and dialysis therapies for ESRD in frail patients. His belief is that the evidence is overwhelmingly in favour of dialysis. He concluded by warning that despite the good intentions of many, the economic pressure for conservative treatments may prove hard to resist.

The patient's perspective

The most compelling talks were given by two patients with renal disease. Deborah Duval had suffered greatly on dialysis in her thirties, spending much of her life in hospital 'existing but not really living'. This and the consequent distress for her family led Deborah to decide to stop dialysis and end her life. Her nephrologist disagreed strongly with her decision and, after fierce arguments, Deborah agreed to postpone her plan in the hope of receiving a renal transplant. Deborah received a transplant shortly before her self-imposed deadline. More than a decade later, she enjoys an active life and is a vigorous advocate for renal patients in Britain. She was at pains to thank her consultant for adopting what some might regard as a paternalistic attitude. She believes it saved her life.

Equally eloquent and courageous was Sehnaz Hanslot, who has Fanconi syndrome. At the age of 8 years, she travelled alone from Zambia to the UK for medical treatment. Overcoming multiple metabolic, skeletal and renal problems, Sehnaz obtained a master's degree and works as a professional artist (Fig 1). Sadly, her condition has progressed to ESRD and, despite her young age and remarkable life, she has decided not to have dialysis. Her reasons are complex and shaped by a lifetime of chronic disease. Sehnaz wants the medical profession to 'support, respect and nurture' the full life she now enjoys,

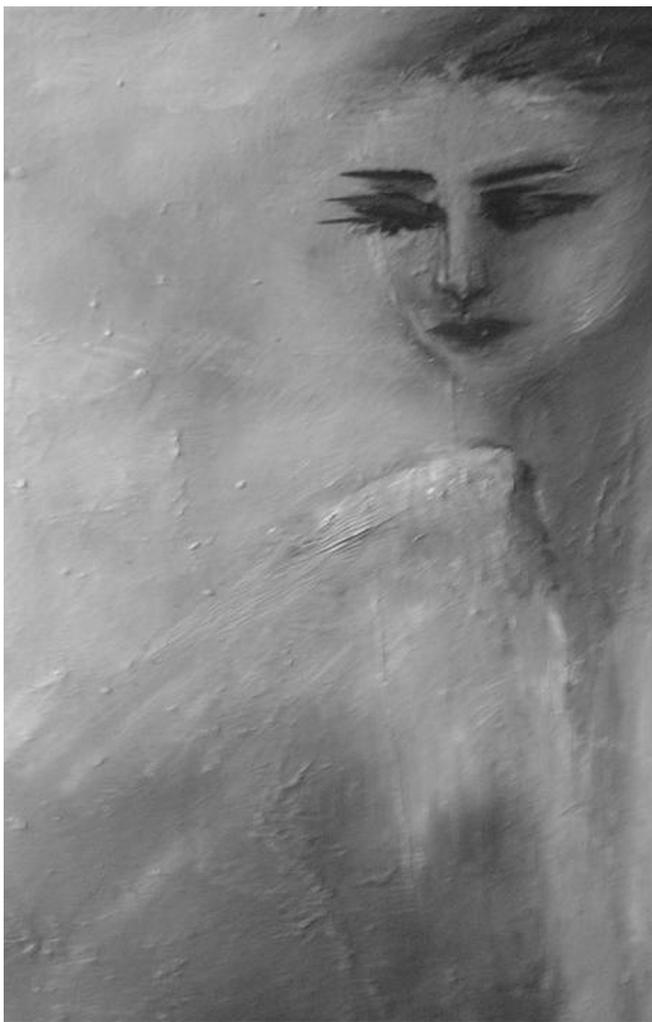


Fig 1. 'Girl 1', Sehnaz Hanslot, 2005. To contact the author, telephone 020 7931 9899.

'rather than prolonging the trauma and agony of a difficult life [on dialysis]'. From the outset, she decided to face ESRD 'on my own terms' and believes this has helped her to survive without dialysis. Nonetheless, she praised the nephrologists and others within her renal unit for supporting her decision, despite their misgivings.

Conclusion

The interaction between audience and speakers suggested broad support for more conservative care in ESRD, more focus on end-of-life issues, and closer links between palliative and renal medicine. The quality of the speakers and the debate in the interactive sessions made the meeting a memorable event. The concerns raised about conservative care becoming a means of rationing dialysis were unsettling but injected a dose of realism into a very idealistic meeting. It seemed that from the outset, those in favour of extending conservative care were largely preaching to the converted. Whether palliative care achieves a greater prominence in

renal medicine remains to be seen. The meeting's organisers, Dr Rob Higgins and Dr Aine Burns and the Renal Association, should take pride in their contribution to an important debate that may herald great changes in nephrology.

References

- 1 Chandna SM, Schulz J, Lawrence C, Greenwood RN, Farrington K. Is there a rationale for rationing chronic dialysis? A hospital based cohort study of factors affecting survival and morbidity. *BMJ* 1999; 318:217–23.
- 2 Smith C, Da Silva-Gane M, Chandna S, Warwicker P *et al.* Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract* 2003;95:c40–46.
- 3 <http://promotingexcellence.org/esrd/index.html>.