

Beyond Believing: Thoughts on end of life from haemodialysis patients at the end of life.

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Introduction

The illness trajectory of many patients on haemodialysis (HD) is similar to those suffering from cancer. For those, in whom transplantation is not possible, death is inevitable (1). The concern register is a national quality measure that allows earlier identification of dialysis patients with a poor prognosis. Its aim is to ensure that HD patients who are predicted to have a poor prognosis have multidisciplinary communication about end of life (EOL) issues along with their carers. This includes implementation of advance care planning and strategies to improve quality of life. Locally, we have ensured all patients on the register are screened stringently and have in-depth conversations on prognosis and rationale for placement on the register.

Having adopted the register 24 months ago we wished to discern if patients active on the register had more insight into EOL than previously documented in the renal literature.

Aim

To explore the thoughts of patients on the concern register about end of life.

Method

A semi-structured interview was developed to explore patient attitudes towards EOL, thoughts on death, advance care planning and current quality of life. A single operator administered the interview in English after obtaining informed consent.

Interview Questions:

How do you feel about the future? What are your expectations for the future?

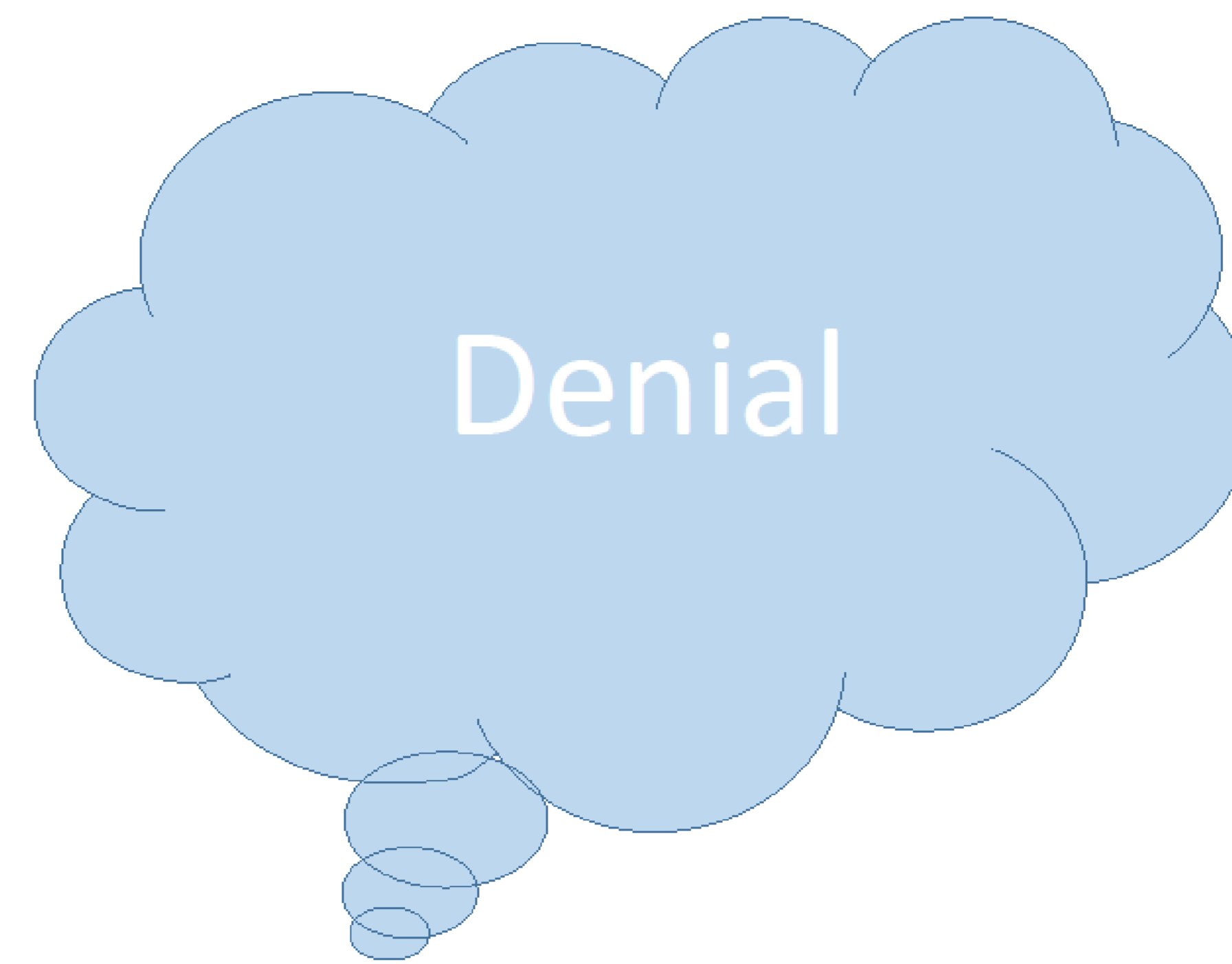
Would you consider yourself to be at the end of life?

What concerns and hopes do you have for the future?

Advanced care planning (ACP) is an important aspect of care, do you feel discussing ACP has changed how you feel about the future?

What helps you cope with your health and haemodialysis?

What things are important to you at the moment? In relation to life, health and dialysis. What would you like to change?



Results

- At the time of the study, 50 patients were active on the concern register. A random sample of 20 patients were approached of whom 14 agreed to interview. Of the 14 interviewed 8 (57.1%) were female and 6 (42.9%) male. 10 (71.4%) were Caucasian and 4 (28.6%) Indian. Median age of patients at time of interview was 76.5 years (range 36-92 years). Patients had been on HD a median duration of 3.6 years (range 0.6 – 8.6 years).
- Most patients despite their communicated poor prognosis were ambivalent about end of life issues and death. The majority were insouciant about advance care planning despite describing relatively poor quality of life.
- Of the 14 patients interviewed, only 4 (28%) considered themselves to be at the EOL and spoke candidly about death, their fears for the future and dialysis withdrawal.

Only 4 (28%) of patients interviewed considered themselves to be at the EOL.

Conclusion

Despite this being a highly selective group of HD patients at the EOL who have received information in a structured format we noted that patients were reluctant to acknowledge that they are approaching the end of life. This raises the interesting question as to why this is the case.

Avoidance and “denial like” processes have been described in the literature previously (2). Perhaps despite pro-active measures to discuss end of life care and advanced care planning through the concern register, patients have an overarching coping mechanism of denial. Is the lack of acceptance of reaching the end of life a reflection of patients’ sense of hope?

It is essential to strike the right balance between end of life communication to raise patient awareness, and allowing patients to foster a sense of hope.

Patients’ Thoughts – Themes Identified

- Waiting to die – “could be any time”
- Constant uncertainty, every new symptom is a worry
- Constant uncertainty, even young people dying
- Dialysis is Just keeping me alive
- Frightening thinking about the future
- Losing mobility is distressing
- Concerned more dependent on family and friends
- Don’t want to be in pain
- Wish sickness and cramps more bearable
- Life is lonely
- Hope keeps me going
- Hopeful health will get better
- Don’t think about dying, take one day at a time
- Strong faith is way of coping
- Want more quality time with family
- Much happier since dialysis reduced to twice a week

References

- 1) The prevalence of symptoms in end-stage renal disease: a systematic review. Murtagh F.E., Addington-Hall J., Higginson I.J. Adv Chronic Kidney Dis. 2007;14
- 2) Denying The Dying: Advance directives and Dialysis Discontinuation. Cohen et al. Psychosomatics. 1997;38(1).

