

Recent literature in Renal Supportive Care – some highlights

Elizabeth Josland
Renal Supportive Care CNC

Frank Brennan
Palliative Care Physician

Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease

Morton, R. Snelling, P. Webster, A. Rose, J. Masterton, R.
Johnson, D & Howard, K.

Canadian Medical Association Journal 2012

Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease

Rachael L. Morton PhD, Paul Snelling MBChB, Angela C. Webster MBBS, PhD, John Rose PhD, Rosemary Masterson MBBS PhD, David W. Johnson MBBS PhD, Kirsten Howard PhD

Correspondence to:
Rachael L. Morton,
rachael.morton@sydney.edu.au

**CMAJ 2012. DOI:10.1503/
cmaj.111355**

Background

- For every one patient with CKD who undergoes renal replacement therapy, there is one who undergoes conservative management (Australian Institute of Health and Welfare)
- Stage 5 CKD is a major health issue worldwide and has a mortality that exceeds many cancers
- Treatment choices include dialysis, transplant or supportive (nondialytic) treatment

Method

- Assessed the influence of treatment characteristics on patients' preferences for dialysis versus conservative care (105 patients surveyed, stage 3-5 CKD, 8 renal clinics in Australia).
- Treatment characteristics investigated were:
 - Life expectancy
 - Number of visits to hospital per week
 - Ability to travel
 - Time spent undergoing dialysis
 - Time of day treatment occurs
 - Availability of subsidized transport
 - Flexibility of treatment schedule

Method

- Assessed the influence of treatment characteristics on patients' preferences for dialysis versus conservative care (105 patients surveyed, stage 3-5 CKD, 8 renal clinics in Australia).
- Treatment characteristics investigated were:
 - Life expectancy
 - Number of visits to hospital per week
 - Ability to travel
 - Time spent undergoing dialysis
 - Time of day treatment occurs
 - Availability of subsidized transport
 - Flexibility of treatment schedule

Results

- Patients were more likely to choose dialysis than conservative care if dialysis:
 - Increased life expectancy
 - They are able to dialyse during the day or evening rather than day only
 - Subsidized transport was available

Results

- Patients were less likely to choose dialysis over conservative care if:
 - An increased number of visits to hospital was required
 - There were more restrictions on their ability to travel

Results: Calculated benefit-to-harm trade-offs

- Patients approaching end stage kidney disease are willing forgo:
 - 7 months (95% CI 11-22) of life expectancy to reduce the number of required visits to hospital and
 - 15 months (95% CI 11-22) of life expectancy to increase their ability to travel (e.g. from very restricted to somewhat restricted).

Results: Calculated benefit-to-harm trade-offs

- Patients made specific reference to five characteristics investigated in the survey
 - Life expectancy
 - Travel
 - Time spent undergoing dialysis
 - Time of day
 - Transport
- Two other sociodemographic factors identified as influential on decision making
 - Age and comorbidity

Results: Calculated benefit-to-harm trade-offs

- Patients made specific reference to five characteristics investigated in the survey
 - Life expectancy
 - Travel
 - Time spent undergoing dialysis
 - Time of day
 - Transport
- Two other sociodemographic factors identified as influential on decision making
 - Age and comorbidity

Conclusion

- Dialysis should not be presumed as treatment of choice for all patients
- Availability of subsidized transport is an incentive to start dialysis
 - Efficient provision of transport is a continuing problem for renal centres
 - It is an important principle in equity of access to dialysis
- Study limited power which limited ability to test for interactions between variables
- Dated collected on preferences rather than actual choices which may not reflect the actual choice made

When and How Should Dialysis be Discontinued ?

Seminars in Dialysis 2012 ; 25(1) Jan-Feb.

Discernment Rather than Decision-Making Among Elderly Dialysis Patients

Russ AJ, Kaufman SR. *Seminars in Dialysis*
2012 ; 25(1): 31-32.

- Increasing numbers of elderly patients commencing on dialysis
- USA – mean age of commencement is 65 years.
- Most rapidly growing cohort are patients 75 years and above.

Summarised qualitative research on the actual decision-making that occurred at the time patients over 70 years commenced dialysis.

NIH study

- No alternative to dialysis was offered, other than death.
- Physicians and dialysis centre staff prepared patients for the eventuality of dialysis in predialysis clinics or dialysis commenced following a medical emergency.

Patients felt that they did not so much *decide* to commence dialysis as *accept* dialysis

“Their acquiescence reflects standard clinical pathways that they did not generally question.”

“Although the values of patient autonomy and informed decision-making are prominent in all health care settings...they are rarely consciously expressed or exercised by older dialysis patients. Instead, patients’ movements into and along the therapy are responses to the more fundamental imperatives brought by physical illness and deterioration.”

“They remain confused about the goals of treatment and what to expect from their lives on dialysis. If they choose anything at all they choose to authorise death “later”.

What were their attitudes to withdrawal/
death ?

- Most patients were reluctant to discuss discontinuation or death.
- Many patients decide “not to decide”, or to decide later - “I’ll cross that bridge when I come to it.”

What do these older patients want ?

At the time dialysis is being first discussed :

More information about prognosis.

How long they can expect to be on dialysis.

What would happen if they ceased dialysis.

“Patients desire an acknowledgement from clinicians that dialysis is a form of treatment that to a great extent shapes, even becomes, their experience of illness and life.”

Non-dialysis Therapy : A Better Policy Than Dialysis Followed by Withdrawal ?

Brown EA. *Seminars in Dialysis* 2012 ; 25(1): 26-27.

Examines the non-dialysis- conservative pathway.

Review of literature comparing the survival of older patients with ESKD who have dialysis versus those who take a non-dialysis pathway.

Review of literature on the frail elderly commencing dialysis

“Starting frail older patients on dialysis frequently, and predictably, results in deteriorating physical function, increasing dependence, deteriorating quality of life, increasing symptoms and eventually death.”

“Having realistic discussions with patients and families will enable them to choose not to have dialysis.”

What is Conservative Care ?

Combination of management of anaemia, fluid status, symptom management and preparation for end-of-life care and care of the dying.

Providing Optimal Care Before and After Discontinuation of Dialysis

Holley JL. *Seminars in Dialysis* 2012 ; 25(1): 33-34.

Examines the reasons for withdrawal :

Acute medical episodes

Patient request

*Clinical Practice Guidelines on Shared
Decision-Making in the Appropriate
Initiation of and Withdrawal from Dialysis*

Renal Physicians Association of the USA 2010.

The importance of palliative care involvement

Perceptions Regarding Death and Dying of Individuals with CKD

Molzahn A et al. *Nephrology Nursing Journal*
2012; 39(1): 197-204.

Exploration of the perception of death and dying in patients with ESKD.

Methodology :

In depth narrative interviews

On 2 occasions

Secondary analysis of interview data

- 14 patients
- Mean age = 66 years old. M(10), F(4)
- Time from diagnosis = 1 – 50 years.
- 9 (HD); 3 (T); 2 (Conservatively)
- 6 had major co-morbidities (Ca, HIV/AIDS)

4 Themes

**Awareness of death as a consequence
of kidney disease**

- All participants aware that death was a possible consequence of kidney failure.
- Range of emotions when discussing this
- Reflection on the death of fellow patients
- Varying involvement of Advance Care Planning

The “close calls” they experienced in living with the uncertainty of their illness.

Experience of major sentinel events

**Contemplating withdrawal from dialysis
/ suicide**

Most admitted they had contemplated suicide at one time.

Participants know that withdrawing from dialysis will lead to death

Some saw withdrawal as suicide.

Preparing for death while living life

- Pragmatic plans for funeral
- Living life to the fullest...trying not to dwell on the illness and the constraints of dialysis
- Life stories

- Awareness of death as a consequence of kidney disease
- The “close calls” they experienced in living with the uncertainty of their illness.
- Contemplating withdrawal from dialysis / suicide
- Preparing for death while living life