Quality of life

GUIDELINES

No recommendations possible based on Level I or II evidence

SUGGESTIONS FOR CLINICAL CARE

(Suggestions are based on Level III and IV evidence)

- **A discussion of the effect of dialysis on quality of life (QOL) should be included in the decision-making process for undertaking dialysis treatment.**
- **The discussion should include effect on physical function, burden of treatment, and effect on family and social life. This is best accomplished by a multidisciplinary team of appropriate health professionals.**
- **Age alone should not be interpreted as being predictive of poorer QOL.**
- **Poorer physical and mental health should be considered predictive of poorer QOL on dialysis.**
- **No single QOL measure should be used to recommend acceptance or denial of dialysis.**

IMPLEMENTATION AND AUDIT

It is suggested that there be a routine QOL discussion at the decision-making stage.

BACKGROUND

Dialysis treatment results in prolongation of life for most patients. However, patients on dialysis face limited survival combined with considerable loss of Health Related Quality Of Life (HRQOL). In addition, dialysis treatment itself generates considerable burden on daily life in terms of chores to be completed, time taken to obtain dialysis, expense of treatment and hospitalization for surgical procedures or complications. QOL is greatly influenced by HRQOL, and is probably just as, if not a more important determinant of successful treatment as is survival. This guideline subtopic aims to explore the evidence base and assist discussions about QOL with patients as they consider dialysis as an option for treatment. Due to the lack of systematic evidence, the recommendations are presented as 'Suggestions For Clinical Care'.

SEARCH STRATEGY

Databases searched: MeSH terms and text words for haemodialysis, peritoneal dialysis and pre-dialysis were combined with MeSH terms and text words for QOL, psychological stress or adaptation, depression, anxiety and combined with MeSH terms and text words for randomized controlled trial and systematic review. Transplantation topics were removed from the search and it was limited to 1997–2008 year of publication. The search was carried out in Medline (1950–January, Week 1, 2008). The Cochrane Central Register of Controlled Trials (CENTRAL) was also searched for clinical trials not indexed in Medline.
Date of search: 10 January 2008.

WHAT IS THE EVIDENCE?

While there is a considerable amount of published literature on QOL, there is a paucity of longitudinal studies across the continuum from the earlier stages of chronic kidney disease (CKD) through to dialysis and survival on dialysis. Individual studies have, however, looked at various factors like stage of kidney disease, QOL at the start of and with continued dialysis, age, mental status and other psychosocial factors.

Rocco et al.[1] showed in the Modification of Diet in Renal Disease study that QOL was impaired in those with CKD and correlated with glomeruler filtration rate (GFR). In a cross-sectional study comparing QOL (scored by using the SF-36 Health Survey) between end-stage kidney disease (ESKD) patients aged 70 years or older, and age-matched controls with other chronic medical conditions, Loos et al.[2] showed that physical function and vitality were significantly lower in ESKD patients at first dialysis. There are no studies addressing the question of whether the QOL of patients with CKD improves with the start of dialysis per se. There are also no data supporting the use of QOL measures to recommend acceptance or denial of dialysis treatment.

Other studies also show that HRQOL is significantly reduced in dialysis patients when compared with the general population. De Oreo[3] compared HRQOL in 1000 patients with that of healthy individuals using the SF-36 and showed

that physical function (but not mental function) was seriously affected. Fukuhara *et al.*[4] have reported significant reductions in all domains of SF-36 scores in comparison to population norms for USA, European and Japanese haemodialysis populations, using data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) cohort. Korevaar *et al.*[5] reported reduced scores for all domains of SF-36 and the EuroQOL visual analogue scale for Dutch pre-dialysis patients compared with the general population.

Age is strongly related to QOL in patients undergoing dialysis treatment. Most studies show that physical aspects of QOL deteriorate with advancing age as reported by Moreno *et al.*[6] in the Spanish multicentre study of dialysis patients and by Mingardi[7] in the Italian Dialysis-Quality of Life (DIA-QOL) study. However, this has not uniformly resulted in reduction of QOL. Rebollo *et al.*[8] reported less loss of HRQOL in dialysis patients older than 65 years compared with younger patients. This study, the Italian DIA-QOL study and the North Thames study reported by Lamping *et al.*[9] also show that while the physical component scores (PCS) of the SF-36 instrument are lower, the mental component scores (MCS) are similar to normal population means. Kimmel *et al.*[10] further show that using the satisfaction with life scale, older haemodialysis patients are more satisfied with life in the face of deteriorating physical function. These studies appear to suggest that older people may compensate for deteriorating function by a psychological adjustment.

Poor perceived mental health at the start of dialysis has been shown to be associated with mortality and hospitalization as reported by Lopez Revuelta *et al.*[11] This study was conducted in a predominantly diabetic (65.4% of patients) and relatively younger population (mean age: diabetic 61.9 years and non-diabetic 57.0 years) and included haemodialysis and peritoneal dialysis modalities. Kalantar-Zadeh *et al.*[12] showed in a small group of prevalent haemodialysis patients that a 10-unit decrease in mental health conferred a 2.46 OR of death in 12 months and also increased hospitalization. Merkus *et al.*[13] from the Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) group showed lower PCS and MCS to be associated with a poor outcome in terms of mortality and hospitalization. Lower PCS had 7 times and lower MCS had 5 times greater risk for poor outcome. Mapes *et al.*[14] showed a similar effect from the DOPPS data in their prevalent haemodialysis population. The response rate in this study for completing the KDQOL-SF was 58.2%, with non-responders having had much shorter time on dialysis and higher comorbidity characteristics.

Racial and cultural factors are likely to impact on QOL. Unruh *et al.*[15] showed that African-American patients on haemodialysis report significantly better psychological well-being and lower burden of disease than non-African-Americans. Mapes *et al.*[16] reported differences in several physical and mental component scores between Japanese patients and those from Europe and America. They also showed significant differences between American white, black and Hispanic patients. No published QOL data for Australian and New Zealand dialysis patients are available.

A number of QOL instruments have been used in patients with progressive kidney disease and in patients on renal replacement therapy. In a structured literature review, Cagney *et al.*[17] found that of the 53 different instruments used, 82% were generic and 18% disease-specific, with Sickness Impact Profile and Kidney Disease Questionnaire having been more thoroughly validated than others. Because of the non-standardized use of multiple instruments, comparability between studies was limited. The Medical Outcomes Study Short Form-36 (MOS SF-36) has been widely used in the kidney disease population, other disease states and in the general population. The Kidney Disease Quality Of Life (KDQOL) instrument combines the generic SF-36 with specific questions to assess symptom burden of patients on dialysis.

SUMMARY OF THE EVIDENCE

No evidence is available to guide the use of QOL data for acceptance onto dialysis. In particular, there are no reliable data for change in QOL across the transition period from pre-dialysis to dialysis to allow an assessment of impact of start of dialysis on QOL. Available literature indicates that QOL reduces as GFR decreases, particularly in the domains of physical function. HRQOL is lower in incident and prevalent dialysis patients compared with the general age-matched population. Although age has a significant influence on physical function, older people report less loss of HRQOL and greater satisfaction with life than do younger patients. Racial and cultural factors may influence QOL but no data are available from Australian and New Zealand communities. While no universally accepted or standardized instrument is available to study QOL, the SF-36 and KDQOL have been used extensively in nephrology literature.

WHAT DO THE OTHER GUIDELINES SAY?

Kidney Disease Outcomes Quality Initiative: No recommendation.
UK Renal Association: No recommendation.
Canadian Society of Nephrology: No recommendation.
European Best Practice Guidelines: No recommendation.
Scottish Intercollegiate Guidelines Network: No recommendation regarding use of QOL assessment in decision analysis. Recommend use of physical activity and of psychosocial interventions to improve QOL in advanced CKD.

SUGGESTIONS FOR FUTURE RESEARCH

1. Measures of QOL should be studied in the presence of progressive kidney disease in relation to emerging complications and their treatment.
2. Longitudinal studies should be undertaken to study the change in QOL with the start of dialysis. These studies are likely to be of an observational nature.
3. Longitudinal studies of QOL should include patients who opt for non-dialysis therapy.

CONFLICT OF INTEREST

Krishan Madhan has no relevant financial affiliations that would cause a conflict of interest according to the conflict of interest statement set down by CARI.

REFERENCES

1. Rocco MV, Gassman JJ, Wang SR *et al.* Cross-sectional study of quality of life and symptoms in chronic renal disease patients: The Modification of Diet in Renal Disease Study. *Am. J. Kidney Dis.* 1997; **29**: 888–96.
2. Loos C, Briancon S, Frimat L *et al.* Effect of end-stage renal disease on the quality of life of older patients. *J. Am. Geriatr. Soc.* 2003; **51**: 229–33.
3. De Oreo PB. Hemodialysis patient-assessed functional health status predicts continued survival, hospitalization, and dialysis-attendance compliance. *Am. J. Kidney Dis.* 1997; **30**: 204–12.
4. Fukuhara S, Lopes AA, Bragg-Gresham JL *et al.* Health-related quality of life among dialysis patients on three continents: The Dialysis Outcomes and Practice Patterns Study. *Kidney Int.* 2003; **64**: 1903–10.
5. Korevaar JC, Jansen MA, Merkus MP *et al.* Quality of life in predialysis end-stage renal disease patients at the initiation of dialysis therapy. The NECOSAD Study Group. *Perit. Dial. Int.* 2000; **20**: 69–75.
6. Moreno F, Lopez Gomez JM, Sanz-Guajardo D *et al.* Quality of life in dialysis patients. A Spanish multicentre study. Spanish Cooperative Renal Patients Quality of Life Study Group. *Nephrol. Dial. Transplant.* 1996; **11** (Suppl 2): S125–29.
7. Mingardi G. From the development to the clinical application of a questionnaire on the quality of life in dialysis. The experience of the Italian Collaborative DIA-QOL (Dialysis Quality of Life) Group. *Nephrol. Dial. Transplant.* 1998; **13** (Suppl 1): S70–75.
8. Rebollo P, Ortega F, Baltar JM *et al.* Is the loss of health-related quality of life during renal replacement therapy lower in elderly patients than in younger patients? *Nephrol. Dial. Transplant.* 2001; **16**: 1675–80.
9. Lamping DL, Constantinovici N, Roderick P *et al.* Clinical outcomes, quality of life, and costs in the North Thames Dialysis Study of elderly people on dialysis: A prospective cohort study. *Lancet.* 2000; **356**: 1543–50.
10. Kimmel PL, Peterson RA, Weins KL *et al.* Aspects of quality of life in hemodialysis patients. *J. Am. Soc. Nephrol.* 1995; **6**: 1418–26.
11. Lopez Revuelta K, Garcia Lopez FJ, Moreno F *et al.* Perceived mental health at the start of dialysis as a predictor of morbidity and mortality in patients with end-stage renal disease (CALVIDIA Study). *Nephrol. Dial. Transplant.* 2004; **19**: 2347–53.
12. Kalantar-Zadeh K, Kopple JD, Block G *et al.* Association among SF36 quality of life measures and nutrition, hospitalization, and mortality in hemodialysis. *J. Am. Soc. Nephrol.* 2001; **12**: 2797–806.
13. Merkus MP, Jager KJ, Dekker FW *et al.* Predictors of poor outcome in chronic dialysis patients: The Netherlands Cooperative Study on the Adequacy of Dialysis. The NECOSAD Study Group. *Am. J. Kidney Dis.* 2000; **35**: 69–79.
14. Mapes DL, Lopes AA, Satayathum S *et al.* Health-related quality of life as a predictor of mortality and hospitalization: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int.* 2003; **64**: 339–49.
15. Unruh M, Miskulin D, Yan G *et al.* HEMO Study Group. Racial differences in health-related quality of life among hemodialysis patients. *Kidney Int.* 2004; **65**: 1482–91.
16. Mapes DL, Bragg-Gresham JL, Bommer J *et al.* Health-related quality of life in the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am. J. Kidney Dis.* 2004; **44** (5 Suppl 2): S54–60.
17. Cagney KA, Wu AW, Fink NE *et al.* Formal literature review of quality-of-life instruments used in end-stage renal disease. *Am. J. Kidney Dis.* 2000; **36**: 327–36.