

Quality of life in peritoneal dialysis patients: Decline over time and association with clinical outcomes

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Background. Quality of life (QoL) is increasingly well recognized as an important measure of treatment outcome. The aim of this study was to determine which key factors affect QoL, which aspects of QoL change over time, and if measurements of QoL were associated with clinical outcome in our peritoneal dialysis (PD) population.

Methods. The results of 88 patients (70% of our PD population) enrolled in longitudinal studies of dialysis adequacy, nutrition, and quality of life were reviewed. The sample comprised Indo-Asian [$N = 35$ (diabetic $N = 18$)], and white Europeans [$N = 53$ (diabetic $N = 18$)] heritage. At enrollment (>3 months on PD) demographic data was recorded. At enrollment, and six-month intervals, the dialysis adequacy, nutritional status, QoL (using the KDQOL-SF™ instrument), hospital admissions, PD infections, and changes in treatment modality were recorded.

Results. Male gender, Asian ethnicity, and poor nutritional status as measured by Subjective Global Assessment were the most significant characteristics independently associated with worse overall QoL dimension scores (physical health, mental health, kidney disease issues, patient satisfaction). Comorbidity, months of renal replacement, social deprivation and serum albumin were related to some of the 19 health domains measured. QoL declined steadily during the two-year study period. The most significant changes were for the items general health symptoms/problems, burden of kidney disease, emotional well-being, and patient satisfaction. Increased hospital admissions were associated with a worse QoL.

Conclusions. Quality of life declines in patients on PD over time. Certain aspects of QoL are especially poor in Asian and male patients. This study suggests that further research is necessary to determine the effects of interventions directed at enhancing emotional and social support.

Interest in health-related quality of life (HrQoL) in patients with end-stage renal disease (ESRD) has risen in recent years. Traditional assessments of patient out-

come on treatments for ESRD are based on aspects such as patient biochemistry, hospitalization rates, technique survival, and mortality. However, in recent years measuring the impact of ESRD treatment on patient's quality of life (QoL) has become increasingly recognized as an important outcome measure [1].

Quality of life is difficult to define, and the term used broadly refers to well being. It is generally accepted that the best tools to measure QoL should include measures of psychological and social function, in addition to the patient's physical function [2]. Previous studies have shown that hemoglobin and modality of treatment (dialysis vs. transplant) are strongly associated with QoL [3–5]. However, it has not been possible to demonstrate an association between dialysis adequacy and QoL.

Research regarding the effectiveness of QoL questionnaires to predict patient outcomes and detect changes in QoL over time in those treated for ESRD is somewhat limited. The majority of studies examining QoL in ESRD patients have used generic questionnaires such as the Short Form 36 (SF 36) [6], which has been shown to be a good screening tool for patients at high risk of hospitalization, poor attendance for treatment, and depression [7, 8]. Few studies have been published to date on the effectiveness of ESRD-specific QoL measures. A large prospective QoL study using a renal disease-specific questionnaire, the Kidney Disease and Quality of Life questionnaire Short Form (KDQOL-SF™) instrument [9], was carried out in hemodialysis patients in the United States and Europe (abstract; Mapes et al, *J Am Soc Nephrol* 10:249A, 1999). The study found a five-point higher score for the QoL dimensions; physical health, mental health and kidney disease targeted issues were associated with a 4 to 8% reduction in risk of hospitalization, and a 9 to 23% reduction in mortality. The majority of QoL studies to date have focused on the effect of ESRD treatment modality, and physical function on QoL [1], and many factors that affect QoL are present before patients start their treatment for ESRD [10, 11]. It is questionable that disease-specific QoL measures

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provide meaningful results that can be interpreted to improve patient care, and the association between patient characteristics and QoL and patient outcome and QoL needs to be addressed further.

Longitudinal studies of QoL using renal specific measures, taking factors such as ethnicity and gender into consideration have not been carried out in the United Kingdom. The aim of this prospective study was to determine which key factors affect patient QoL, which aspects of QoL change over time, and if clinical outcome could be predicted from QoL data. QoL was measured using the KDQOL-SF™ version 1.1 [9].

METHODS

Study population

The results of 88 patients on peritoneal dialysis (PD) for more than three months who were enrolled in either the diabetic or the Indo-Asian prospective studies of adequacy, nutrition and quality of life at Walsgrave Hospital in Coventry, between November 1996 and December 1999, were reviewed. The study population comprised Indo-Asian [$N = 35$ (diabetic $N = 18$)] and white Europeans [$N = 53$ (diabetic ($N = 18$))]. This sample ($N = 88$) was approximately 70% of our PD population during the study period. Patients were excluded if they (1) were unable to give informed consent, (2) had a living-related kidney transplant in the following six months, or (3) were on PD for less than three months. Enrollment to the study was delayed by four weeks if the patient had a peritonitis, and/or following discharge from the hospital for an emergency admission.

Data collection

At the time of enrollment, demographic data were recorded on age, gender, ethnic origin, and time on renal replacement therapy. Social deprivation, and comorbidity were assessed. At enrollment and six monthly intervals data were collected on adequacy of dialysis, biochemistry, nutritional status and QoL. The target for adequacy of PD for all our patients was a total creatinine clearance of >60 L/week/1.73 m², and serum albumin >35 g/L.

Comorbidity was scored using the accepted method of Davies et al [12], where a score of 1 was given for each of the following: ischemic heart disease, peripheral vascular disease, diabetes mellitus, systemic collagen vascular disease, malignancy, and specified other conditions. A cumulative score of 3 to 4 indicated severe comorbidity. Blood pressure was measured on the day adequacy was assessed. Mean arterial blood pressure (MAP) was calculated as diastolic pressure plus one third of pulse pressure (systolic minus diastolic pressure).

Adequacy of dialysis was calculated from 24-hour dialysate, and urine collections for urea and creatinine. Peritoneal creatinine clearance (pC_{Cr}) was corrected to a

body surface area of 1.73 m², and urea clearance was expressed as the dialysis dose (Kt/V) using the Watson formula for body water [13]. Renal creatinine clearance (rC_{Cr}), was calculated from the mean of creatinine and urea clearance [14] corrected to a body surface area of 1.73 m².

Nutrition was assessed using Subjective Global Assessment (SGA) [15], serum albumin and prealbumin. SGA is based on a medical history of weight changes, appetite and gastrointestinal symptoms, and a physical examination of body fat and muscles. The patient is classified as well nourished, mild to moderately malnourished, or severely malnourished using a three-point scale. In this study the more recently modified and validated seven-point SGA scale was used [16]. A low SGA score indicated a worse nutritional state. Serum albumin was measured using the bromocresol purple method (normal range 34 to 48 g/L), and serum prealbumin (normal range 0.18 to 0.45 g/L) using a Bayer Advia 1650 Analyser (Newbury, UK).

Quality of life was measured using the self-administered KDQOL-SF™ Version 1.1 [9]. It is composed of measures of 79 items of HrQoL, and was developed from the 134-item KDQOL™ after concerns regarding how long it took to administer the original version. The 79 items rated by patients in the KDQOL-SF™ measures 19 health related domains. The domains are categorized as four dimensions of HrQoL. Physical health (PH) was composed of measures of seven domains: physical functioning, work status, role limitations due to physical health, general health perception, pain, energy/fatigue, social function. Mental health (MH) was composed of emotional well-being, quality of social interactions, burden of kidney disease, social support, and role limitations due to emotional problems. Kidney disease targeted issues (KDI) were composed of cognitive function, symptoms/problems, effect of kidney disease, sexual function, and sleep. Patient satisfaction (PS) was composed of patient self-satisfaction, and perceptions of staff encouragement. The generic core (SF 36) has been validated for use in UK populations [17]. The original KDQOL (long version) has been validated in the United States in a sample that included several ethnic groups [18]. The questionnaire took around 25 minutes to complete. Patients who needed assistance to complete the questionnaire were identified and assisted by the research nurse or close family member instructed on how to administer the questionnaire.

Townsend scoring was used as an index of social deprivation. The patients' postal addresses were classified according to their electoral ward, and it was assigned a Townsend score [19]. The variables used to calculate Townsend scores collected from the 1981 population census data included households that were not owner-occupied, residents aged 16 to 59/64 (female/male) who

Table 1. Baseline characteristics

	All patients (N = 88)
Age years	48 ± 14
Male	61 (69%)
Female	27 (31%)
Indo-Asian	35 (40%)
White European	53 (60%)
Months peritoneal dialysis	18.4 ± 19
Months renal replacement therapy	27.5 ± 45
Comorbidity	0.8 ± 0.84
Diabetes mellitus	36 (41%)
Total creatinine clearance L/week/1.73 m ²	74 ± 29
Renal creatinine clearance L/week/1.73 m ²	31 ± 30
Total urea clearance/week Kt/V	2.2 ± 0.6
Renal urea clearance/week Kt/V	0.6 ± 0.6

Data are mean ± standard deviation or %.

are unemployed, households lacking a car, and households with more than one person per room. The Townsend scores in the West Midlands region ranged from -8.5 to + 8.76, with a higher score indicating a higher level of social deprivation.

Information was recorded on hospital admissions and infections from the date of enrollment into the study. Peritonitis was diagnosed on white blood cell count of >100 in the dialysis effluent, with or without a positive culture [20]. An exit site infection was diagnosed as exudate and redness around the exit site with or without positive culture [21].

Statistical analysis

Values are expressed as means ± standard deviations. The non-parametric Mann-Whitney U test and the parametric analysis of variance test (ANOVA) were used to test for differences between groups and scores with repeat measures. Pearson's rank correlation was used to test for an association between variables. Significant variables at univariate level ($P < 0.05$) were used in multiple regression analysis, performed using the backward selection method. The internal consistency of the QoL item scores was calculated by Cronbach's Alpha. It is generally accepted that Cronbach's Alpha should be in excess of 0.70 [22]. Analyses were performed using SPSS for Windows 9.0 (SPSS Inc, Chicago, IL, USA).

RESULTS

Study population and enrollment characteristics

The characteristics of the study population at enrollment (>3 months on PD) are shown in Table 1.

Gender/ethnicity and enrollment characteristics/results

Classification of patients according to gender showed that the number of diabetics was similar, but overall comorbidity was significantly higher in males (0.97) compared to females (0.44; $P = 0.007$). Females studied were

younger than males (41 years vs. 51 years; $P = 0.002$). Weekly creatinine clearance was significantly better in males ($P = 0.03$) compared to females. Other measures such as social deprivation, nutrition (SGA, albumin) and hemoglobin were similar in males and females. Classification of patients according to ethnic group showed comorbidity, adequacy of dialysis, nutrition, and hemoglobin results were similar for Asian and white European patients. There was a higher incidence of insulin dependent diabetes in white patients compared to Asians. Social deprivation was significantly higher in Asian patients compared to white patients ($P < 0.0001$).

Quality of life

Enrollment and demographic data. Male gender was independently associated with a significantly worse score for all four QoL dimensions: PH, MH, KDI, and PS. The nine QoL domains that were significantly lower in males on multivariate analysis are shown in Table 2. Ethnicity was independently associated with the QoL dimensions PH, MH, and KDI. Indo-Asian patients had significantly lower scores than whites for 10 of the 19 domains measured (Table 2). QoL dimension scores categorized according to gender and ethnicity are shown in Table 3. Increased social deprivation as measured by the Townsend score was independently associated with a worse pain score, reduced social interaction score, and reduced staff encouragement score. There was a negative inverse correlation between comorbidity, and QoL. On multivariate analysis comorbidity was associated with physical function, and work (PH), social interaction, and emotional well-being (MH), and the KDI domain cognitive function. Time on renal replacement therapy/PD was independently associated with PS. Patients treated for ESRD for a longer period of time received less staff encouragement, and patients on PD for a longer period of time had a significantly lower score for social support. Patient age was associated with the QoL domains of physical health and work, but this was not significant on multivariate analysis.

Enrollment and clinical results. There was no correlation between creatinine clearance and QoL. A lower Kt/V was independently associated with a lower score for sleep and role-physical. A low SGA scoring of nutritional status correlated independently with lower PH and KDI. A significant independent relationship was found between SGA and the PH domains of work, social function, energy fatigue, and pain, the KDI domain of sleep, and the MH domain of emotional well-being. A lower serum albumin was independently associated with a lower score for general health ($P = 0.004$). There was no significant association between hemoglobin levels and any of the 19 QoL domains. On multivariate analysis, serum pre-albumin, C reactive protein and hemoglobin were not independently associated with QoL.

Table 2. Quality of life (QoL) domains comprising the four overall QoL dimensions measured by the KDQOL-SF™

Physical health (PH)	Mental health (MH)	Kidney disease issues (KDI)	Patient satisfaction (PS)
Physical function ^b	Emotional well being ^a	Cognitive function ^b	Patient satisfaction ^a
Work status ^a	Quality social interact ^a	Symptoms/problems ^b	Staff encouragement ^a
Role-physical ^a	Burden kidney disease ^a	Effects of kidney disease ^b	
General health ^a	Social support ^{ab}	Sexual function ^a	
Pain ^a	Role-emotional ^{ab}	Sleep	
Energy/fatigue			
Social function ^b			

^aSignificantly worse in males than females
^bSignificantly worse in Asians than whites

Table 3. Quality of life (QoL) dimension scores according to gender and ethnicity

	Physical health	Mental health	Kidney disease issues	Patient satisfaction
Asian male (N = 26)	30 ± 15 ^{ab}	42 ± 22 ^{ab}	42 ± 18 ^{ab}	72 ± 23 ^b
White male (N = 35)	42 ± 21 ^b	62 ± 22 ^b	58 ± 15 ^b	77 ± 20 ^b
Asian female (N = 9)	39 ± 17	56 ± 12 ^c	53 ± 18	81 ± 12
White female (N = 18)	53 ± 20	71 ± 20	67 ± 15	86 ± 10

Data are % score ± SD.
^aSignificantly lower in Asian males compared to the other groups
^bLower in all males compared to all females
^cLower in Asian females compared to white females

Changes in QoL between enrollment and six months

Seventy-five (85%) of the 88 patients enrolled in the study remained on PD at six months post-enrollment. Four patients were transplanted, seven transferred to hemodialysis, and two died. Of the 75 patients on PD, 68 (91%) completed the QoL questionnaire at both enrollment and six months. Analysis of the questionnaires for those 68 patients showed 17 of the 19 domains measured decreased, and this reached statistical significance for the domain work (*P* = 0.03).

Changes in QoL between enrollment, six and 12 months

Fifty-seven (65%) of the 88 patients enrolled in the study remained on PD at 12 months after enrollment. Ten patients were transplanted, 13 transferred to hemodialysis, and eight died. Of the 57 remaining on PD, 39 (68%) completed the QoL questionnaire at enrollment, 6 and 12 months. Analysis of the questionnaires for those 39 patients showed that most domain scores decreased over time, and for symptom/problems of kidney disease, this decline was statistically significant (*P* = 0.034).

Patients remaining on PD at two years after enrollment

Of the 36 patients remaining on PD at two years post-enrollment, 20 (56%) completed questionnaires at enrollment, 6, 12, 18 and 24 months (11 male and 9 female; 6 diabetics). All 19 domain scores decreased between

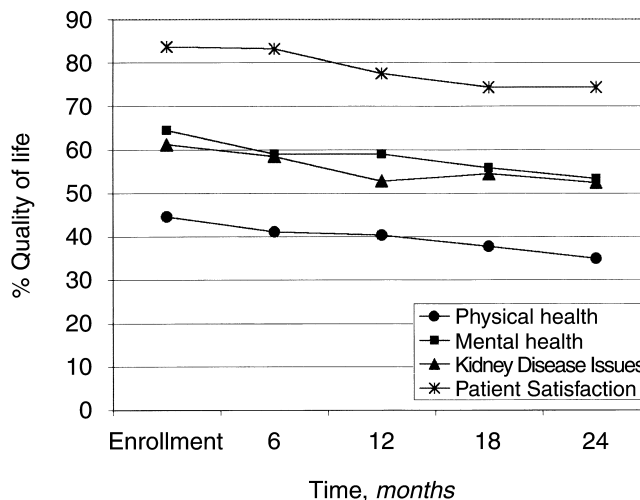


Fig. 1. Quality of life (QoL) dimension scores from the time of enrollment (mean months on PD 22 ± 14) to 24 months later, in the 20 patients who completed all five questionnaires. Decline over time was significant for all four QoL dimensions.

enrollment and 24 months, and this reached significance for symptoms/problems, physical function, burden, general health, emotional well-being, and patient satisfaction. The mean KDQOL dimension scores, shown in Figure 1, all decreased significantly between enrollment and 24 months.

Completion of the KDQOL-SF™

All of the 88 patients in the study completed and returned the KDQOL instrument at enrollment. The number of patients remaining on PD who completed the questionnaire at each time interval varied (64% to 91% response rate). Sixty-eight patients (91%), completed the questionnaire at 6 months, 40 patients at 12 months (70%), 33 patients at 18 months (64%), and 27 patients at 24 months (75%). Twenty patients (56%) completed the questionnaire at each of the six-month intervals from enrollment. Patients on PD and in the study for two years who returned all five questionnaires (good responders, *N* = 29) were compared to those who did not return all of the questionnaires (poor responders, *N* =

Table 4. Baseline characteristics of patients, grouped according to outcome one year post-enrollment

	On PD	Kidney transplant	Transfer to hemodialysis	Deceased
Number of patients	57 (65%)	10 (11%)	13 (15%)	8 (9%)
Age years	48 ± 13	38 ± 13 ^a	50 ± 12	58 ± 15
Male/female	36/21	7/3	10/3	8/0
Indo-Asian/white European	26/31	1/9 ^a	7/6	1/7 ^a
Months peritoneal dialysis	19 ± 17	11 ± 7	19 ± 15	27 ± 39
Months renal replacement therapy	32 ± 53	11 ± 7	23 ± 18	27 ± 39
Townsend score	1.48 ± 3.4	-1.1 ± 2.7	1.42 ± 3.1	-0.6 ± 4.5
Comorbidity	0.70 ± 0.78	0.40 ± 0.51	1.07 ± 0.86	1.63 ± 1.06 ^a
Diabetes mellitus	23 (40%)	2 (20%)	9 (69%)	2 (25%)
Mean arterial pressure	108 ± 15	106 ± 8	114 ± 11	113 ± 10
Subjective global assessment score	5.4 ± 0.6	5.0 ± 1.9	5.2 ± 0.8	5.0 ± 0.9
Serum albumin g/L	31.5 ± 4.2	33.7 ± 4.5	28.9 ± 4.5	31.5 ± 3.9
Prealbumin g/L	0.38 ± 0.08	0.43 ± 0.14	0.32 ± 0.07 ^a	0.37 ± 0.10
Total creatinine clearance L/week/1.73 m ²	71 ± 27	79 ± 25	85 ± 37	74 ± 34
Renal creatinine clearance L/week/1.73 m ²	28 ± 29	35 ± 23	41 ± 38	29 ± 36
Total urea clearance/week Kt/V	2.2 ± 0.6	2.3 ± 0.4	2.2 ± 0.7	2.1 ± 0.8
Renal urea clearance/week Kt/V	0.6 ± 0.6	0.6 ± 0.3	0.8 ± 0.7	0.6 ± 0.7
Physical health (PH)	40.7 ± 20	54.1 ± 21	28.0 ± 18 ^a	41.3 ± 18
Kidney disease targeted issues (KDI)	55.3 ± 18	62.4 ± 17	43.4 ± 20	55.9 ± 21
Mental health (MH)	57.6 ± 25	64.1 ± 19	50.5 ± 21	59.1 ± 15
Patient satisfaction (PS)	79.3 ± 18	82.2 ± 17	70.6 ± 27	78.3 ± 18

Data are mean ± standard deviation or %.

^aSignificant difference between the groups on enrollment

16). There was no difference between comorbidity, age, social deprivation, adequacy of dialysis, nutrition by SGA, or time on treatment in good responders compared to poor responders. Poor responders were more likely to be male. The main reason patients gave for not returning the questionnaire was that their QoL had not changed since the previous visit. Psychometric evaluation of the questionnaire showed the internal consistency of items measured by the KDQOL (tested by Cronbach's alpha) was >0.80 for 13 of the domains. Only items measuring the domains sleep and social function fell below the recommended minimum alpha of 0.70 (social function 0.65, and sleep 0.51). Cronbach's alpha was similar in both Asian and white patients when separate analyses were performed, and this was true also for patients who had assistance to complete the questionnaire compared to those who did not have assistance.

Changes in clinical results over time

The mean total C_{Cr} decreased from 70 to 60 L/week between enrollment and 6 months ($P = 0.001$), and remained at around 58 L/week for the remainder of the follow-up period. Serum albumin and pre-albumin values did not alter significantly during the study. SGA scores worsened from 5.4 to 5.0 ($P = 0.008$) between enrollment and 12 months, and then remained fairly constant. Of the 36 patients remaining on PD at two years after enrollment, there was no significant difference between any of the dialysis adequacy, and nutritional parameters in those patients who completed all questionnaires ($N = 20$), compared to those who only

completed some of the questionnaires ($N = 16$). The mean hemoglobin in the 20 patients who completed the study was 10.5 g/dL at enrollment, rising to 10.8 at 24 months. The number of patients treated with erythropoietin increased from 10 at enrollment to 15 patients at 24 months.

Patient outcome at one year post-enrollment

The outcomes measured were hospitalizations, infections, switches in treatment modality and death. Patient characteristics at enrollment grouped according to treatment outcome after one year in the study are shown in Table 4. Eight patients died (9%); five were cardiovascular deaths, two were sepsis following perforated bowel and neurosurgery, and one from cancer. Ten patients (11%) had a kidney transplant (KT), one of which was from a living related donor.

Thirteen patients (15%) transferred to hemodialysis (HD). The main reasons for transfer included repeat episodes of peritonitis/tunnel infection ($N = 5$), ultrafiltration problems ($N = 3$), under-dialysis ($N = 3$), hernia/leak ($N = 1$), and drainage/catheter problems ($N = 1$). Five of the patients who transferred to HD completed the QoL questionnaire as part of another study three to six months after their transfer. A significant improvement was shown for KDI.

The causes and number of hospital admissions during the first year of the study are shown in Table 5. The number of hospital admissions was independently associated with PH ($P = 0.005$), MH ($P = 0.035$), and KDI ($P = 0.004$). Increased patient age, and worse scores

Table 5. Cause and number of hospital admissions during first year of the study

Cause of hospital admission	Number of admissions
Infections (peritonitis, exit site, tunnel)	21
Fluid overload	15
Diabetic and cardiac admissions	14
Renal related surgery	22
Other surgical	2
Other medical	38

for comorbidity, SGA, albumin, and pre-albumin were associated with more admissions and time spent in the hospital. Thirty-seven episodes of peritonitis (in 27 patients), and 97 exit site infections (ESIs) occurred in 40 patients during the first year of the study. Peritonitis was independently associated with a worse PS score. ESIs were not independently associated with QoL.

DISCUSSION

This study found that the most significant characteristics independently associated with QoL were gender, ethnicity, and nutritional status as measured by SGA. Comorbidity, time on renal replacement, social deprivation and serum albumin, although not independently associated with any of the four overall QoL dimension scores (physical health, mental health, kidney disease issues, and patient satisfaction), were related to between 1 and 5 of the 19 health domains measured.

Male gender was independently associated with a lower score for all four QoL dimensions. On multivariate analysis, male gender was associated with worse scores for almost half of the domains measured (Table 2). In contrast to our findings, studies in North America have shown female gender to be associated with worse QoL [23–27]. However, one of the studies had a population sample of predominantly black females from deprived districts [24], and another showed that females had worse scores than males for several clinical parameters [24]. European studies using the SF 36 [6] also found an association between female gender and worse QoL [3, 28]. The studies do not highlight the particular domains that were significantly worse in females or provide detailed reasons for these gender differences. The most significant negative impact of male gender found in our study was for domains measuring male role (emotional and physical) and support/encouragement received. One possible explanation for this may be that men find it more difficult to adapt to changes brought about by chronic illness. The perceived role of the male as the head of the household may still exist in Britain today. In his role as head of the household, a man who becomes unemployed as a result of ESRD may feel a greater burden of illness than a female. The World Health Organization (WHO)

recognizes that the individual's perception of their position in life, their goals, and personal relationships are important aspects of QoL [2]. Individuals who become unemployed, particularly if they are the primary source of financial income, are often faced with family conflict and role confusion [29]. Unemployment is high among ESRD patients even after successful transplantation, and the benefits of rehabilitation and counseling have been identified in recent studies [30, 31]. About one third of the patients in our study aged <60 years were gainfully employed. Unemployment was higher in males compared to females, with only 30% of the males aged <60 years in our study in paid employment compared to 39% of the females. Several women in the study were caring for child dependents at home, compared to just one male subject. It appears that the females in our study had a higher level of work rehabilitation. It is fairly well documented that there are gender differences in health in the United Kingdom [32, 33]. Women live longer than men, but also suffer more from health problems, many of them specific to females. Studies have shown that women are disproportionately affected by depression for various reasons [34]. It is thought that this increased incidence of depression is a result of gender inequalities leading to a lack of opportunities in all spheres of life. Gender roles are not rigid or fixed, and it may well be that the women in our study were better able to adapt to life on peritoneal dialysis than their male counterparts. Further studies of QoL and gender are needed to analyze more qualitative issues that affect QoL, such as family dynamics, coping mechanisms, as well as educational and social factors.

Ethnicity was the other key demographic variable that was an independently associated with QoL. Asian patients on PD had significantly lower scores than whites for three of the four QoL dimensions measured (all but PS). Ethnicity was independently associated with each of the five domain measures comprising MH and the KDI domains of the effect of kidney disease, cognitive function, symptoms/problems; and the PH domains of physical health and social function. All the Asian patients in this study were from the Indian Subcontinent, mainly from the Punjab region, and most had lived in Coventry for around 30 years. It is acknowledged that they did not all share the same culture, language and religion. The Asian patients in this study were included in a larger study looking at ethnicity and treatment modality, in which the issues of language and efficacy of the KDQOL have been addressed [35]. It is still widely assumed that extended Asian families are support systems for the elderly and ill within their family, and this misconception may be a contributing factor to the provision of inadequate services for this group [36]. The finding of this study that social support, burden, and effect of kidney disease were worse in Asians than whites, suggests that

Asians do not receive the support that they need to cope with ESRD. One of the factors shown to improve acceptance of illness, coping, and compliance in people with chronic conditions is a good understanding of their condition and treatment [29]. Research looking at Asian patients with other chronic conditions such as diabetes and asthma, shows that Asians had a poor understanding of their illness compared to white patients [37, 38]. Increasing Asian patients' and their families' understanding of kidney disease may be one way of improving attitudes and understanding of this chronic disease. There is some information suggesting that elderly Asians have a higher incidence of mental illness compared to Caucasians in the UK, but cultural factors are often used to explain these ethnic differences [32, 36]. Although the epidemiology of diseases such as diabetes and renal failure in different ethnic groups is well documented, much less is known about other issues relating to culture and peoples experience of coping with these diseases. Adapting to chronic illness is a complex and ever changing psychological and social process that is difficult to measure. In retrospect, using additional tools such as an acceptance of illness scale, self-esteem score, or social support questionnaire may have benefited our study and highlighted reasons for the ethnic differences in aspects of QoL that were found.

A low SGA scoring of nutritional status correlated independently with lower PH and KDI. This might be predicted, as the scoring tool comprises mainly subjective questions relating to the patient's functional ability, appetite, and gastrointestinal symptoms, as well as looking at objective measures of weight. Albumin, the other marker of nutrition used in the study, was independently related to general health, but not with any of the other domain scores. This is in keeping with arguments that albumin is not a particularly useful marker of nutritional status [39], and like many clinical variables is not a true predictor of QoL. No association was found between hemoglobin levels and QoL. Although this finding is in contrast with studies carried out over a decade ago, it is in keeping with more recent studies [4, 28]. Treatment and prevention of anemia in renal patients using erythropoietin is now standard practice in many renal clinics. The low hemoglobin levels associated with poor physical and cognitive function were not present in our patients, and therefore we did not find any significant association between hemoglobin and QoL.

Higher comorbidity was independently associated with worse scores for physical function, work, social interaction, emotional well-being and cognitive function. The most common comorbid condition for patients in our study was diabetes. The association between poor physical health and the presence of comorbid conditions in particular diabetes also has been found in other studies [24, 28]. Although comorbidity was related to some QoL

domain scores, it lacked significant association with the four overall dimension scores, which supports the theory that QoL is determined not merely by the absence or presence of disease conditions, but is influenced by the persons' perception of themselves. There are other possible reasons for the lack of a significant association between QoL dimension scores and comorbidity. In our study comorbid diseases were each given a score of one point if present [12], but were not graded according to their severity. In those patients with diabetes the presence of one or more diabetic complications potentially could have a significant negative impact on QoL. Older patients had worse scores for physical function and work, as might be expected, but these were not significant independent factors affecting QoL. In a study where groups of dialysis patients were compared with age-matched healthy populations, older dialysis patients obtained scores that were nearer to that of the healthy groups than the younger patients, suggesting better acceptance of the limitations of illness in older patients [40]. As expected, a higher number of young patients received a transplant and patients who died tended to be older. Increased social deprivation as measured by the Townsend score was independently associated with worse scores for pain, social interaction, and staff encouragement. The results of a study focused on people with musculoskeletal pain found that social deprivation was associated with more symptoms of pain, especially back pain [41]. In keeping with other studies, we found social deprivation was associated with increased hospital admissions [42, 43]. The association between socioeconomic status and health has been the topic of much discussion and is well documented [19]. Employment not only provides financial benefits, but increased self-esteem and a sense of control. As already discussed, unemployment was high in our patient group and in keeping with the findings of other studies. It can be difficult to get a true estimate of patient's household income as not everyone wants to divulge this type of information. Another factor not measured in our study, which has been shown to have a negative affect on QoL, is a poor educational status. Many patients on dialysis are unable to cope with heavy manual jobs and need retraining for jobs they could manage physically [44].

In the second part of the study, changes in QoL over time were examined. Analysis of the QoL results in those patients who remained on PD for the duration of the study showed a steady decline in each of the four QoL dimensions over the two-year study period (Fig. 1). Although the patients who completed all five questionnaires were on PD for different periods of time, their decline in QoL was uniform. The most significant changes were for the domains: symptoms/problems, burden of kidney disease, emotional well-being, general health, and patient satisfaction. The items measuring the domain "burden of kidney disease" that declined most signifi-

cantly over time were those relating to how much time is spent dealing with kidney disease, and the feeling of being a burden on one's family. The strain that ESRD places on the patient and their family is well documented [45, 46]. The effects of family involvement are not always beneficial to the patient, and can vary from the extreme of giving no assistance, to taking control of the patient's life [46]. Social support, depression, and adjustment to illness have all been linked to survival [47–49], and their roles in determining patient outcome are probably as important as measures of dialysis adequacy. A study that examined changes in QoL in PD and HD patients over time using the SF 36 [17] found that social functioning and vitality declined significantly from three months on treatment to 18 months on treatment [47]. The study also showed that physical health declined in both HD and PD patients, with the greatest decline in the PD group [50]. Our study was not designed to measure QoL in the PD patients following their transfer to HD or following a kidney transplant, which in retrospect was an oversight. Five of the patients who transferred to HD completed the QoL questionnaire as part of another study three to six months after transfer, and a significant improvement was shown for KDI. During the course of the study the number of patients remaining on PD who completed the QoL questionnaire varied (**Results** section). There is a risk of bias when those who drop out of any follow-up study differ from those who continue. It is difficult to establish the true reason for dropout from the questionnaire, but the main reason given by patients when asked was that their QoL was unchanged.

Poor responders were analyzed and no difference was found between their comorbidity, age, social deprivation, adequacy of dialysis, nutrition by SGA, or time on treatment compared to good responders. Poor responders were more likely to be male.

Creatinine clearance, SGA score, albumin and pre-albumin declined during the study period. The changes in these clinical variables were significant in the 12 months from enrollment, and then remained fairly constant. PD prescriptions were altered throughout the course of the study in an attempt to meet dialysis adequacy targets. However, attempts to improve dialysis adequacy did not halt the steady decline in QoL over time, and the added burden of extra dialysis may even have contributed to it, although this was not measured.

The final part of the study examined the relationship between QoL at enrollment and subsequent patient outcomes such as hospitalizations, infections, treatment modality changes, and mortality. The number of hospital admissions our patients had during the first year of the study was independently associated with PH, MH, and KDI. This finding is in keeping with the results of the study validating the KDQOL, which showed a correlation between hospital admissions and 14 of the 19 do-

main measures [18]. There was no correlation between admissions and patient satisfaction in our study or the KDQOL study. Other studies (using the SF36) have shown measures of physical health and mental health to be good predictors of hospitalization rates [7, 8]. Another outcome examined was the incidence of PD infections. The association between PD infections and QoL does not appear to have been considered in other studies. During the first year of the study 30% of the patients had one or more episodes of peritonitis, and 45% had an exit site infection. A higher incidence of peritonitis was independently associated with a lower score for the dimension patient satisfaction. Exit site infections were not independently associated with QoL. The association between QoL and the number of switches in treatment modality and deaths during the study also was analyzed. A low score for the dimension PH on enrollment was associated with transfer to hemodialysis (Table 4). The relationship between worse physical health and increased mortality has been shown in multicenter studies with large patient numbers [7, 8]. It was not possible to analyze the ability of the QoL dimension scores to predict patient survival using a regression model, as the patient numbers did not meet the test criteria [51]. Survival is the crudest outcome measure and the association between better adequacy of dialysis and improved survival has been studied [52]. However, it is generally agreed that it is the quality rather than quantity of life on dialysis that is important. Therefore, it is reasonable to suggest those intermediate outcomes such as infections, time spent in the hospital, and QoL are more important than survival as outcome measures.

Previous research has indicated that renal transplantation is a beneficial outcome, which usually achieves an improvement in QoL, but there is a shortage of cadaveric renal transplants. There are currently no objective allocation systems that target dialysis patients for cadaveric transplantation on the basis of their QoL. In those patients who transferred from PD to hemodialysis, there was an improvement in domains measuring the effects of kidney disease and symptoms/problems; however, several domains remained poor. Lastly and perhaps more importantly for those patients who remain on PD is the determination of those QoL domains most affected by dialysis, and further research examining interventions with potential for improving QoL is needed.

CONCLUSION

This study highlights the decline in QoL in patients on peritoneal dialysis over time. As time passed, patients were more burdened by their kidney disease, feeling more frustrated by the time spent dealing with their disease, and the way it interfered with their life. Patient satisfaction with their care also declined over time. The

study also identifies subgroups such as male patients who might benefit from more emotional support, and ethnic patients who might benefit from additional social support. Studies of adequacy of PD have highlighted the importance of optimizing dialysis prescriptions to improve patient survival [52]. In striving to meet adequacy targets it is easy to lose sight of the fact that patient's mental health and satisfaction with their treatment are as important—if not more important—to many patients than meeting clinical targets. By focusing on QoL domains that are poor (identified by the 19 domains measured by the KDQOL), it may be possible to plan interventions that could improve specific aspects of an individual patient's QoL.

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