TITLE

Quality of life, fatigue, and activity in Australians with chronic kidney disease: A longitudinal study

AUTHORS

Professor Ann Bonner PhD, MA, B.App.Sc(Nurs), RN, MRCNA
School of Nursing
Queensland University of Technology
Victoria Park Rd
Kelvin Grove QLD 4059
Australia
Email: ann.bonner@qut.edu.au

Associate Professor Marie Caltabiano PhD, BA(Hons)
School of Psychology
James Cook University
Cairns QLD 4870
Australia

Ms Lois Berlund
Renal Unit
Cairns Base Hospital

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ABSTRACT
Aims and objectives
This study sought to determine the relationship between health related quality of life (HRQoL), fatigue and activity levels of people with anaemia secondary to chronic kidney disease (CKD) over a 12 month period following the introduction of an erythropoietin stimulating agent (ESA).

Background
CKD occurs in five stages and it is a complex chronic illness which severely impacts on an individual's HRQoL, and ability to perform everyday activities. Fatigue is also a common symptom experienced by people with CKD.

Design and methods
Using a longitudinal repeated measures design, 28 people with CKD completed the SF-36, human activity profile and fatigue severity scale at the commencement of an ESA and then at 3, 6 and 12 months.

Results
Over a 12 month period, people reported a significant change in HRQoL in relation to role physical, vitality, mental health/emotional well-being and overall mental health. However activity levels did not significantly improve during that time. Both the amount of breathlessness and level of fatigue were highest at baseline and declined over time. Both fatigue and breathlessness were correlated with less reported general health over time.

Conclusion
Renal nurses, in dialysis units and CKD outpatient clinics, have repeated and frequent contact with people with CKD over long periods of time, and are in an ideal position to routinely assess fatigue and activity levels and to institute timely interventions. Early detection would enable timely nursing interventions to optimise HRQoL and independent activity.

Relevance to Clinical Practice
Drawing on rehabilitation nursing interventions could assist renal nurses to minimize the burden of fatigue and its impact on simple everyday activities and a person's quality of life. These interventions are important for people who are living at home and could assist in lowering the burden on home support services.

Keywords
Renal failure, everyday life, fatigue, renal nursing, chronic illness, Australia

Acknowledgements
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Contributions
Study design: AB, MC; data collection: AB, LB; data analysis: MC, AB; manuscript preparation: AB, MC, LB

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INTRODUCTION

Chronic kidney disease (CKD) is rapidly increasing globally (Zhang & Rothenbacher 2008), and is predicted to affect 11.5% of the adult population (23 million people) in the United States (Coresh *et al.* 2011), and other countries have detailed similar or higher prevalence estimates (AIHW 2009, White *et al*, 2010). CKD is classified into five stages of severity, with stage 5 also referred to as end stage kidney disease (ESKD) where survival may be dependent on renal replacement therapy (dialysis & transplantation) (Vassalotti *et al.* 2007). No matter what the stage of CKD, people experience a range of symptoms that affect all body systems (Murtagh *et al.* 2007), and they are required to invest considerable time in managing their health, including modifying their diet, managing numerous medications, undergoing renal replacement therapies (if required) and attending medical and hospital appointments. CKD, its treatment and concomitant complications also impact significantly on a person's lifestyle, family responsibilities, their ability to work, and financial status. The impact of CKD and its treatment on physical, emotional, social and overall HRQoL is, therefore, profound.

At least 45% of people with CKD, particularly those who are in stages 4 and 5, develop anaemia (Gandra *et al.* 2010). According to Lasch, Evans and Schatell (2009) people with anaemia due to CKD commonly report decreased energy, tiredness, shortness of breath and weakness. In addition, anaemia in CKD contributes to significant co-morbid complications such as left ventricular hypertrophy, congestive heart failure, and ischaemic heart disease (Brattich 2007, Schimid & Schiffl 2010). As a consequence, people have increased hospitalizations and a shorter life expectancy (Palmer *et al.* 2010, Voormolen *et al.* 2010). An erythropoietin stimulating agent (ESA) is frequently prescribed to increase haemoglobin levels in order to reduce these complications (Rathi *et al.* 2010, Schmid & Schiffl 2010, Mikhail *et al.* 2011). In addition there is some evidence to suggest that increasing haemoglobin levels from between 110 to 120 g/L (11-12 g/dl) in people with CKD stages 3-5 will lead to improvements in patient reported HRQoL (Finkelstein *et al.* 2009, Hansen *et al.* 2009).

BACKGROUND

Fatigue and CKD

Fatigue is a complex, subjective experience (McCann & Boore 2000) and is reported by 70-97% of people with CKD (Murtagh *et al.* 2007, Jhamb *et al.* 2008, Bossola *et al.* 2011). Despite advances in renal health care, fatigue remains ranked as one the most troublesome symptoms for people with CKD (Danquah *et al.* 2010). Factors associated with the fatigue experienced in CKD include: prescribed medications and their side effects; nutritional deficiencies; physiological alterations, particularly abnormal urea and haemoglobin levels; psychological factors such as depression, sleep dysfunction and those associated with haemodialysis treatment (low dialysate sodium and excessive ultrafiltration) (Welch 2006). Fatigue has been extensively examined, particularly in haemodialysis patient populations (McCann & Boore 2000, Jablonski 2007, Danquah *et al.* 2010). Not surprisingly fatigue due to CKD has a considerable effect on a person's HRQoL and is viewed as being more important than survival by some patients (Jhamb *et al.* 2008). Using the fatigue severity scale, Bonner *et al.* (2008) found people with varying stages of CKD who were prescribed an ESA for anaemia reported higher fatigue levels than those who were not prescribed an ESA. These findings provided the impetus for this study.

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Activity and CKD
There is a reduced capacity of people with CKD to engage in activities of daily living including exercise activity (Bonner *et al.* 2009, White *et al.* 2009) which is likely to be due to a number of factors including anaemia, fatigue, lengthy treatment commitments, and debilitating co-morbid conditions. While ESA has profoundly improved the potential for higher activity levels in people with CKD (Painter *et al.* 2002, Gandra *et al.* 2010) there has not been a corresponding increase in activity levels amongst this population (Painter *et al.* 2011). Increasingly the promotion of activity including exercise programs has been argued as an integral component of rehabilitation programs towards the optimisation of health for people with CKD (Kosmadakis *et al.* 2010). While there have been some reports of successful increase in levels of activity, there has been little adoption of these interventions into routine nursing care (Bennett *et al.* 2010). Although there are several methods to measure activity and/or exercise capacity in people with CKD (Koufaki & Kouidi 2010), the Human Activity Profile (HAP), developed by Fix and Daughton (1988) has been demonstrated to be a valid and reliable instrument for assessing the levels of human activity (Wellard 2003, Davidson & de Morton 2007, Bonner *et al.* 2009).

Health Related Quality of Life and CKD
It is no longer adequate to measure only morbidity and mortality associated with chronic disease; HRQoL is particularly important in determining health outcomes for people with CKD (Soni *et al.* 2010). Survival is longer in people with a better HRQoL, and better health status and less morbidity are associated with higher HRQoL (Untas *et al.* 2011). There are several instruments available for measuring HRQoL in people with CKD, and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) and the Kidney Disease Quality of Life [KDQOL], a renal specific version of the SF-36, are the most frequently used (Lowrie *et al.* 2003, Unruh *et al.* 2005). Finkelstein *et al.* (2009) used the KDQOL to examine the relationship between different haemoglobin levels and HRQoL in 1200 people with CDK stages 3-5, and reported that greater improvements in quality of life occurred when haemoglobin levels were higher. Using the SF-36, Hamilton and Hawley (2006) found that a nurse-led anaemia clinic for patients with CKD significantly improved levels of quality of life three to six months later.

Surprisingly the relationship between haemoglobin, HRQoL and fatigue levels and their impact on actvity levels has not been reported. Given the increasing involvement of nurses in the aggressive symptom management of people with CKD, particularly as Nurse Practitioners (Holcomb 2005, Douglas & Bonner 2011), nursing research examining HRQoL, activity and fatigue is warranted. This is important for renal units where nursing roles are expanding to include advanced practice functions. In addition, increased knowledge about these health indicators has the potential to guide the development of nurse-led interventions specifically targeted at early symptom identification and management.

STUDY
The aims of this study were to:
- Determine the HRQoL, activity and fatigue levels of people with anaemia secondary to CKD.
- Compare HRQoL, activity and fatigue levels of people with anaemia secondary to CKD and in normal healthy population.
- Determine the changes in HRQoL, activity and fatigue over twelve months following the introduction of ESA.

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METHODS

A longitudinal repeated measures design was used to assess HRQoL, current levels of activity and fatigue in people with CKD over a twelve month period. Data was collected from patient hospital records and measured by self-report questionnaires.

Sample

A convenience sample of patients was recruited from two renal units in Australia; one in Queensland and the other in New South Wales. The inclusion criteria for the study were: 1) patients 18 years of age or older; 2) CKD with an estimated glomerular filtration rate < $60ml/min/1.72m^2$ (i.e. stages 3-5) with a haemoglobin <100g/L; 3) prescribed an ESA by a nephrologist; 4) able to understand English; and 5) willing to give informed consent and participate in the study. There were no specific exclusion criteria.

Ethical considerations

Human Research Ethics Committees at both hospitals and a university provided ethical approval for the study. Signed informed consent was obtained from all participants prior to commencement of the study.

Instruments

Three instruments were used to measure HRQoL, activity and fatigue. HRQoL was measured by the SF-36 (Ware 2011) which gives scores on eight scales, and which then form the two summary measures of physical health and mental health. The scales within the physical health summary measure are physical functioning, role-physical, bodily pain and general health. The mental health summary measure consists of the following scales: vitality, social functioning, role-emotional and mental health/emotional well-being. Reliability in the present study for the individual scales ranged from a Cronbach alpha of .54 (general health) to .72 (mental health/emotional well-being) to .91 (role physical; bodily pain), and .93 (physical functioning; role emotional).

The Human Activity Profile (HAP) developed by Fix and Daughton (1988) is a self-report instrument comprising 94 items of daily activity ordered according to metabolic demand (e.g. sitting, walking, dressing, running etc); it requires respondents to indicate which activities they still undertake, those they have stopped doing and those they have never undertaken. The HAP has four activity subscales: Self-care, Personal/Household work, Entertainment/ Social, Independent exercise. The subscales had high reliability in the current study as evidenced from the following Cronbach alphas: Self-care (α= .98), Personal/Household work (α=.97), Entertainment/Social (α=.92), Independent exercise (α =.94). The dyspnoea scale (DS) consists of 8 items in which respondents indicate either no, little, clearly noticeable or severe shortness of breath when undertaking physical activity. The reliability for the DS was .80.

Lastly, fatigue was measured by the fatigue severity scale (FSS), a 9 item self-report instrument which requires respondents to indicate on a 7-point Likert scale the degree of agreement with the statement (Krupp *et al.* 1989). The FSS in the current study had a high reliability with a Cronbach alpha coefficient of .88.

Data Collection

After consenting, the following data were collected at 0 (immediately prior to commencing an ESA), and then at 3, 6 and 12 months. A review of a person's medical records yielded: 1) demographic information (age and gender); 2) biochemistry and haematology results

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(including haemoglobin, calcium, phosphate, potassium, urea, creatinine, albumin, parathyroid levels, iron studies, B12 & red cell folate); and 3) ESA therapy. At each time point, the questionnaires were provided to each participant by a member of the research team. If required, participants received assistance with completion of the questionnaires by one of the research team. Assistance was needed for participants with limited literacy, poor visual acuity or with restricted movement related to dialysis equipment. Questionnaire items were read aloud and response options sought.

Analysis

Data were analysed using SPSS Version 19® (SPSS Inc., Chicago, IL, USA). Within-subjects analysis of variance (ANOVA) was used to measure HRQoL, fatigue and activity levels of patients with CKD at commencement of ESA, and then at 3, 6 and 12 months later, as the means tested are derived from repeated measurements. HRQoL, fatigue and activity levels were assessed in relation to demographics using t-tests and ANOVA. Probability (p) values less than 0.05 were considered significant.

RESULTS

Of the 28 patients with CKD initially in the study, five became deceased during the time of the research, two withdrew and one was lost to follow-up. Data were collected at 4 time points – baseline, 3 months, 6 months and 12 months. Baseline data were available for 28 of the patients. Table 1 indicates the number of patients at each time period. Of the longitudinal sample, 15 were female and 13 were male. Age ranged from 31 to 84 years (mean = 64 years). 23 patients were not yet receiving renal replacement therapy; 4 were receiving haemodialysis and 2 patients were receiving peritoneal dialysis. At baseline, haemoglobin levels ranged from 75 to 106 g/L (mean = 94 g/L).

Table 1 Number of patients at each time period

Baseline	3 months	6 months	12 months
28	26	21	19

Differences of HRQoL, activity, fatigue and breathlessness over time

Table 2 provides the means and standard deviations across time for each of the SF-36 scales and the two summary measures (CKD sample). The population norms (normative sample) for each of the SF-36 scales also appear in Table 2. The SF-36 uses norm-based scoring with linear transformation of scores to a mean of 50 and a standard deviation of 10 (Ware, 2011). The CKD sample have much lower physical functioning, role-physical and general health compared to the normative sample of healthy adults. Bodily pain and overall physical health summary was comparable to the normative sample. For the emotional well-being scales, the CKD sample was lower on the vitality and social functioning scores than the normative sample. For the role-emotional subscale, the CKD sample was lower than the normative sample only at baseline. For the mental health subscale, the CKD sample was higher than the normative sample at 6 and 12 months. For the overall mental summary component, the CKD sample was higher than the mean of 50.

Several one-way repeated measures ANOVAs were used to measure whether there were changes over time in the SF-36 component scores (physical health, mental health) and each of the subscales of the SF-36, these being physical functioning, role physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health. There was a

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significant improvement over time for the role physical, vitality and mental health subscales. Results of the repeated measures ANOVA also appear in Table 2.

Question 1 (Q1) from the SF-36 ('In general would you say your health is excellent, very good, good, fair or poor') is often used as a reliable indicator of a person's overall quality of life (Ware 2011). Table 3 shows the correlation between SF-36 Q1 and total physical activity, HAP subscale scores, fatigue and breathlessness at each time point. Total number of physical activities still being done correlated positively with reported health at 6 months. Self-care did not correlate significantly with responses on the SF-36 Q1 at any time point. Responses to general health correlated with personal/household work at baseline and at 3 months. People with CKD who engaged in these activities reported good health generally. The level of general health also correlated with reported entertainment/social activity at baseline, 3 and 6 months, indicating that those who are able to do these activities report good health. Independent exercise was correlated with responses on the SF-36 Q1 only at baseline, indicating those engaging in fewer exercise activities also reported poorer general health. Breathlessness as measured by the dyspnoea subscale was correlated with lower reported general health over time. Higher levels of fatigue were (negatively) correlated with lower health in general at each time point and this was significant at 3, 6 and 12 months. Finally using repeated Measures ANOVA, to examine reported differences in general health over time, did not find any significant differences [$F(3,12)=.626$, *n.s*.].

The HAP total activity and each subscale's mean and standard deviation are summarized in Table 4. The CKD sample engaged in considerably less physical activities across all time periods compared to healthy adults. While 100% of the normative sample were walking ½ block uphill (Fix & Daughton 1988), only 51.8% of the CKD sample was doing this activity at baseline, and by 12 months this had dropped to 44.4% still walking ½ block uphill. Similarly walking 1 block on level ground, non-stop by the CKD sample also dropped from 62.5% at baseline to 44.4% at 12 months, compared to 100% of normal adults doing this activity. Only 13.4% of the CKD sample could climb steps (2 1/2 floors) at baseline compared to 84.2% of normal adults. By 6 months this had dropped to only 7.4% of the renal sample still engaging in this physical activity. The CKD sample was similar to the normative sample in self-care activities. Across all time points the CKD sample engaged in considerably less personal/household work and entertainment/social activities compared to healthy adults. The activities which appeared to distinguish between people with CKD and healthy adults the most were independent exercise activities. Normal adults engaged in three times more of these activities compared to the CKD sample.

A repeated measures ANOVA was used to examine whether activity, dyspnoea or fatigue changed from baseline and at 12 months (Table 4). There were no significant differences in total activity over time [$F(3,13)=2.14$, n.s.]. In relation to breathlessness (dyspnoea score) this decreased over time though the change was not significant [$F(3,13)=2.44$, n.s.]. There was a significant difference for fatigue [$F(3,11) = 3.78$, $p<.05$]. Fatigue was highest at baseline ($M=47.69$, $SD=13.23$) and declined to 42.35 ($SD=13.19$) at 12 months. Fatigue was lowest at 6 months.

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Table 2 SF-36 means, standard deviations and repeated measures ANOVA scores

SF-36 Scales	CKD Sample				Normative sample	*F*	*p*
	Baseline	**3 months**	**6 months**	**12 months**			
Physical Health							
Physical functioning (PF)	42.7 (28.05)	47.39 (31.14)	54.75 (27.6)	25.45 (13.68)	84.2 (23.3)	3.96	ns
Role-physical (RP)	41.17 (40.44)	10.85 (4.44)	80.76 (32.52)	63.63 (34.21)	80.9 (34.0)	12.29	p<.05
Bodily Pain (BP)	70.09 (33.23)	74.43 (26.85)	50.75 (24.13)	48 (20.85)	75.2 (23.7)	.084	ns
General health(GH)	41.66 (18.6)	44.31(21.45)	15.19 (4.5)	14.12 (4.45)	71.9 (20.3)	.640	ns
Physical health summary	56.6 (20.57)	44.58 (15.88)	72.13 (21.79)	56.38 (14.09)	50 (10)	-	-
Mental Health							
Vitality (VT)	38.04 (20.65)	46.42 (24.55)	52.61 (24.0)	50.0 (22.06)	60.9 (20.9)	3.93	p<.05
Social functioning (SF)	61.05 (32.46)	69.04 (28.94)	78.12 (31.38)	75.73 (26.32)	83.3 (22.7)	1.96	ns
Role-emotional (RE)	63.88 (44.95)	85.0 (29.56)	94.11 (13.09)	86.66 (27.6)	81.3 (33.0)	.718	ns
Mental health (MH)	71.52 (15.24)	74.95 (15.64)	78.85 (21.05)	82.13 (12.9)	74.7 (18.1)	3.62	p<.05
Mental health summary	60.18 (21.84)	71.57 (17.85)	80.46 (13.98)	73.48 (15.7)	50 (10)	-	-

ns = not significant

Table 3 Correlations between SF36 Question 1 (Q1), HAP, Dyspnoea and Fatigue

	SF-36 Q1 Baseline	SF-36 Q1 3 months	SF-36 Q1 6 months	SF-36 Q1 12 months
HAP				
Total activity	-.20	.16	.55**	.21
Self-care	.11	.37	-.10	-.24
Personal/household/work	.46*	.49*	.39	.15
Entertainment/social	.44*	.54**	.58**	.47
Independent exercise	.64**	.35	.26	.08
Dyspnoea Score (DS)	-.26	-.69**	-.63**	-.48*
Fatigue (FSS)	-.26	-.51*	-.66**	-.66**

* p<.05, ** p<.01

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Table 4 Human Activity Profile, Dyspnoea and Fatigue mean and standard deviation scores

	Baseline M (SD)	3 months M (SD)	6 months M (SD)	12 months M (SD)	Normative sample	F	p
HAP scores							
Total activity	43.4 (17.76)	47.95 (20.07)	47.61 (23.68)	48.22 (23.23)	83	2.14	ns
Self-care	7.31 (1.12)	7.04 (1.77)	7.52 (.98)	7.6 (.77)	7.8	1.30	ns
Personal/Household work	14.19 (6.7)	15.48 (7.2)	17.19 (6.03)	17.27 (4.52)	24.1	2.99	ns p=.07
Entertainment/Social	7.88 (2.87)	8.04 (2.53)	8.85 (2.61)	9.05 (2.53)	13.6	2.47	ns
Independent Exercise	6.35 (5.26)	7.3 (5.04)	7.9 (6.17)	8.10 (6.34)	22.2	1.02	ns
Dyspnoea scores							
Dyspnoea	14.28 (7.61)	13.12 (8.34)	11.59 (7.74)	11.10 (7.90)	-	2.14	ns
FSS Scores							
Fatigue	47.69 (13.18)	47.61 (12.87)	38.7 (17.18)	42.35 (13.19)	-	3.78	p<.05

Table 5 Correlations between fatigue, physical activity, and breathlessness with SF-36 physical health and mental health over time

	Baseline Physical health	Baseline Mental health	Physical health 3 months	Mental health 3 months	Physical health 6 months	Mental health 6 months	Physical health 12 months	Mental health 12 months
Activity (HAP)	.057	.245	.129	-.227	.676**	.166	.475*	-.407*
Dyspnoea (DS)	-.693**	-.461 *	-.738***	-.585**	-.68**	-.239	-.305	-.426*
Fatigue (FSS)	-.812***	-.666**	-.525**	-.688**	-.76***	-.809***	-.557**	-.838***

*p<.05, **p<.001, ***p<.0001

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Correlations between activity, fatigue and breathlessness with quality of life over time
Next we wanted to see if activity, breathlessness and fatigue impacted on physical health and mental health at different time points. The results of these analyses appear in Table 5. As can be seen from Table 5 activity was positively correlated with physical health at both 6 and 12 months. Activity was negatively correlated with mental health at 12 months (-.407). Breathlessness as measured by the Dyspnoea subscale of the HAP was strongly and negatively correlated with physical health across all time points except at 12 months (-.305, p>.05). Breathlessness was negatively correlated with mental health, with a lower correlation between these variables at 6 months (-.239). Increased breathlessness was associated with lower mental well-being (-.426). Lastly fatigue was strongly negatively correlated with both physical (-.557) and mental health over time (-.838). Higher fatigue levels lead to lower HRQoL for both physical health and mental well-being at 12 months.

Age differences over time
In examining whether there were differences over time on the SF-36 mental and physical health components for those aged younger than 65 versus aged over 65 we used mixed between-within analyses of variance. There were no significant differences in score changes over time for the two age groups for physical health or mental health [F(3,9)=1.78, ns; F(3,9)=.256, n.s.]. There were also no age differences in activity [F(3,12)=1.94, n.s.], breathlessness [F(3,13)=1.71, n.s.] or fatigue over time [F(3,10)=.388, n.s.].

These higher order analyses confirm t-test results on the effects of age on the SF-36 physical health summary and on the mental health summary. Age differences were only found for SF-36 mental health at 3 months (t=-2.41, df=14, p<.05). Those younger than 65 years had lower emotional well-being (M=63.32, SD=18.41) compared to those aged over 65 (M=82.17, SD=10.55). There were no age differences on physical health at any time point.

We were also interested if age was correlated with physical activity, fatigue and breathlessness over time. At baseline age was positively correlated with breathlessness (r=.536, p<.01); that is older CKD patients reported being more breathless. At 6 months, age was negatively correlated with activity (r=-.451, p<.05) (i.e. those over 65 years undertook fewer activities) and remained positively correlated with breathlessness (r=.457, p<.05). Age was negatively correlated with physical activity (though non-significant) and was positively correlated with breathlessness (r=.518, p<.05) at 12 months.

Correlation of Haemoglobin with SF-36 subscales, activity, fatigue and breathlessness over time

At baseline haemoglobin (Hb) was not significantly correlated with any of the SF-36 subscales or the physical and mental health summary components, though the correlation with vitality approached significance (r=-.395) as did the correlation with physical functioning (r=-.382). However at baseline, Hb (< 100 g/L) was positively correlated with physical activity (r=.426, p<.05) and with fatigue (r=.393, p<.05). Breathlessness was negatively correlated with activity (r = -.413, p<.05) and positively correlated with fatigue (r=.553, p<.01) at baseline. That is, the more breathless CKD patients reported undertaking fewer activities and having higher levels of fatigue. At 3 months Hb was not significantly correlated with well-being (SF-36 subscales), activity, fatigue or breathlessness. At 6 months, Hb was not significantly correlated with the SF-36 scales. Hb was also not significantly correlated with activity, fatigue or breathlessness at 6 months, though less activity was

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engaged in by those who experienced breathlessness (r=-.579, p<.01). At 12 months Hb was negatively correlated with the SF-36 physical health summary (r=-.586, p<.01) and correlated -.414 (p<.05) with mental health summary. Hb was not significantly correlated with activity, fatigue or breathlessness at 12 months.

DISCUSSION

A consequence of impaired renal function is the development of persistent, and at times, severe anaemia. While anaemia affects normal physiological function, it also causes people to experience increased tiredness and reduced ability to undertake daily activities including exercise. We found that people with CKD prior to commencing an ESA reported having lower HRQoL when compared to healthy people and this was particularly apparent in the physical components. Levels of physical functioning and general health, as well as being able to undertake fewer physical roles, contributed to lower HRQoL. In addition, people in this study also indicated that they had lower levels of vitality and experienced more difficulty undertaking social functions than healthy people. Mental health aspects associated with HRQoL were, however, higher than for healthy people. These findings are consistent with Perlman *et al.* (2005) who found low levels on similar subscales as well as higher mental health scores. The reason for higher mental health scores in some people with CKD (i.e. our study as well as Perlman *et al.* 2005) is not known, and further research is warranted.

The capacity to perform routine living chores, and to participate in and enjoy everyday life is clearly reduced as a result of having CKD. In this study, activity levels, measured by the HAP, also supported the lower physical scores seen with the SF-36. In this study, people were only able to perform similar levels of self-care as healthy people but the ability to perform personal/household work, being able to undertake social, entertainment or independent exercise were substantially less than healthy people. This finding is consistent with two other studies of the activity levels of people with CKD using the HAP (Bonner *et al.* 2009, Johansen *et al.* 2010).

Management of anaemia by ESA therapy is believed to lead to a better quality of life for people with CKD (Parfrey & Wish 2010). The strength of this study is that we used repeated measures over a 12 month period to examine HRQoL as well as levels of fatigue and activity following commencement of an ESA. We found that when people with anaemia due to CKD are commenced on ESA treatment there are some improvements in HRQoL, breathlessness and levels of fatigue over 12 months although their ability to undertake more activities does not change. Our results found a slight improvement in the physical health component of the HRQoL measured by the SF-36, although only the role-physical subscale demonstrated significant improvement over 12 months. However there were more improvements in the mental health components (vitality & mental health/emotional well-being). In a similar longitudinal study involving 34 patients who had recently commenced ESA therapy and who completed only the SF-36 at the same time points, Hamilton and Hawley (2006) found improvements in several but different subscales of the physical and mental health components although most of these improvements were at 3 and 6 months. Leaf and Goldfarb (2009), however, suggest that greatest improvements are seen in the HRQoL domains of physical symptoms and social functioning. In a recent systematic review of 14 studies, Gandra *et al.* (2010) reported that in people with CKD not yet receiving dialysis (i.e. CKD stage 4) who were treated with ESA therapy for anaemia tended to have improvements in the physical function and vitality domains associated with HRQoL.

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In the TREAT study, the largest randomized control trial of anaemia correction with an ESA in CKD patients, fatigue scores were statistically improved at 26 weeks following the correction of Hb (Pfeffer *et al.* 2009). In addition Johansen *et al.* (2011) recently published a systematic review of the impact of ESA therapy on fatigue in dialysis patients showing that the level of fatigue is reduced as haemoglobin levels are corrected. Our study is consistent with these publications with respect to improvements in fatigue levels.

ESA treatment for people with CKD, nevertheless, has improved the potential for higher activity levels (Painter *et al.* 2002, Gandra *et al.* 2010) however several authors report that there has not been a corresponding increase in activity levels (Painter *et al.* 2011). The findings of the present study seem to concur with the latter at three, six and twelve months following commencement of an ESA. We found that physical functioning, general health, social functioning and overall physical health components in the SF-36 as well as total activity levels and three out of the four sub-scales from the HAP did not significantly improve over time.

There seems to be consistency between the vitality component of the SF-36 which evaluates a person's self-reported feelings of being tired, worn out or full of energy (Ware 2011) and the FSS (Krupp *et al.* 1989). The present study found a significant improvement in participant reported vitality as well as fatigue levels 12 months after commencing an ESA. We also found that higher fatigue levels were significantly and negatively correlated with lower physical and mental health components associated with HRQoL. Not surprisingly high levels of fatigue are experienced by people with CKD which impacts on a person's quality of life. A larger study involving both instruments may be helpful in determining if the FSS should be included when using the SF-36 in studies of people with CKD.

Study Limitations

There are some limitations to this study which must be acknowledged. First, participants were from two renal units in Australia which may limit the generalizability of the findings to other countries. Second, the instruments rely on self-report which may lead to bias in reporting quality of life, the level of activity actually undertaken, and the level of fatigue experienced by an individual. Inclusion of the opinion of partners and carers of people with CKD may minimize this bias. Lastly and even though the sample size was small, we used repeated measures to increase the study's reliability. The results are suggestive of a better quality of life and lower fatigue levels but no significant improvements in levels of activity where found. Further studies investigating strategies to enhance activity are clearly needed.

CONCLUSION

Renal nurses, in CKD clinics and dialysis units, have repeated and frequent contact with people with CKD over long periods of time; in some cases over decades. Renal nurses, therefore, are in an ideal position to routinely assess fatigue and activity levels and to institute timely interventions. Drawing on energy conservation interventions and promoting simple physical activity strategies, which are more familiar to nurses who work in rehabilitation wards, could be incorporated into routine nursing practice in dialysis units. Renal nurses, although having a limited knowledge of rehabilitation, ought to consider innovative and efficient ways to provide energy conservation interventions for patients while they attend for regular clinic appointments and dialysis treatment.

RELEVANCE FOR NURSING PRACTICE

There are several important areas for renal nursing practice arising from this study. There is a

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need for increased focus and assessment to identify and monitor both fatigue and activity levels and the impact these seem to have on people's quality of life. In particular regularly assessing a person's inability to engage in normal self-care, household and, in particular, social activities, may give rise to concern about a person's overall well-being. This could assist in instituting interventions for maintaining or increasing everyday activity promptly before other physical, social and emotional problems develop and affect a person's quality of life. Early detection of lowered capacity for and or changes in activity levels would enable timely interventions such as referral to allied health staff to optimise independent activity. This is particularly important for people who are living at home as optimal independence with routine activity is needed, and could assist in lowering the burden on home support services. For many people with CKD who opt to receive conservative management (Stage 5), continued engagement in routine activity is an important aspect of maintaining well-being and quality of life. Finally, experimental research by renal nurses is needed to explore the effect of innovative nursing interventions specifically targeting simple fatigue reduction strategies that maintain levels of activity.

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