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The Course of Quality of Life in Patients on Peritoneal Dialysis: A 12-month Prospective Observational Cohort Study

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Abstract
Background Quality of life (QOL) impairments are common in patients undergoing dialysis, and have been strongly associated with significant clinical outcomes like mortality and morbidity. Despite this, little is known about the course of QOL over time, especially for patients on peritoneal dialysis (PD).
Purpose This prospective study was set to explore course and determinants of QOL over 12 months in PD patients.
Methods A total of 115 PD patients completed the SF-12 and Kidney Disease Quality of Life Short Form (KDQOL-SF) at baseline and 12 months later. Intra-individual changes in physical (physical component summary, PCS), mental (mental component summary, MCS), and Kidney Disease Component Summary scores (KDCS) were identified based on the minimally important clinical difference threshold. Clinical information was extracted from medical records.
Results Of the patients, 74–80 % reported physical QOL impairments, as compared to 29–33 % who reported mental/emotional QOL impairments. PCS and MCS scores remained stable across 12 months. Significant deterioration was noted in the domains of patient satisfaction, staff encouragement, and social support, while there were significant increases in the perceived effects of kidney disease. Intra-individual trajectory analyses indicated that one in three patients reported deteriorating QOL. No sociodemographic or clinical variables were found to be associated with course of outcomes.
Conclusions Although PD offers the convenience of home-based care, it is associated with persisting QOL impairments and diminishing QOL over time, especially in domains related to quality of care and support. This highlights the need for improving or maintaining standards of care and support for PD patients as they become increasingly established on their regimes.

Keywords End-stage kidney disease · Peritoneal dialysis · Quality of life · Asia

Introduction

For the majority of patients with end-stage renal disease, dialysis is a lifelong treatment commonly associated with increased impairments in their quality of life (QOL) [1, 2]. Home-based modalities like peritoneal dialysis (PD) are thought to offer enhanced opportunities for autonomy, rehabilitation, and return to work, with flexibility in dialysis schedules in addition to cost savings and good clinical outcomes [3]. Attention has therefore been directed to increase the uptake of PD, which, in most settings, still remains underutilized relative to hemodialysis (HD) [4].

From the patients' perspective, however, the PD regimen is often seen as time- and labor-intensive [5, 6]—involving the onerous commitment to daily self-care or caregiver-administered dialysis exchanges, alongside fluid and diet restrictions, and the management of multiple medications [7]—which often results in dwindling motivation, non-adherence, and a deteriorating QOL. Because of strong associations between poor QOL and clinical endpoints [8–10], such as

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hospitalization and mortality [11–14], QOL measures provide important information on the effectiveness of PD [15]. Various efforts have been initiated to improve patients' QOL, such as adjusting dialysis prescription, controlling comorbidities, treating anemia, and alleviating depression [16]; however, while necessary [17], little is known about the progress of QOL over time.

The literature on QOL in PD patients is dominated by cross-sectional studies [18–20], with only a handful of longitudinal studies investigating the course of QOL over time [21], and even then, with conflicting evidence. Studies on incident PD patients in Brazil, USA, or Netherlands reported either no change for patients [22], improvements [23], or declines in physical but not mental health-related QOL (HRQOL) over 12 months [24]. Studies on prevalent PD patients reported either no changes [25] or steady declines in both physical and mental HRQOL, as well as in disease-specific QOL (DSQOL) of symptoms and burden of kidney disease and patient satisfaction over 2 years [15]. At present, there are no longitudinal studies in Asian PD patients, despite suggestions that Indo-Asian immigrants score lower on QOL measures than their Caucasian counterparts [15]. This is particularly important given the higher prevalence rates of ESRD in Asian populations, the growth of PD in China and Asia [26], and the surge of Asian minorities in Western settings.

Furthermore, only limited conclusions can be drawn from previous work, as group-based analyses may mask variation in individuals; it is thus possible that while QOL improves over time for some patients, for others, QOL impairments can persist or even worsen. It is therefore imperative to document both group and individual patterns of change and identify factors that may be associated with course of QOL outcomes to guide clinical care.

The aims of this prospective study were (1) to document the course of QOL outcomes over 12 months in Asian patients already on PD in Singapore, (2) to determine individual trajectories of QOL outcomes over time, and (3) to investigate the associations between course of outcomes and various sociodemographic and clinical variables. Because evidence is lacking and inconsistent, no a priori directional hypotheses with respect to changes of QOL over time or potential correlates were formulated; this exploratory study therefore sought to generate hypotheses for future research.

Methodology

Design

This study is part of a larger prospective study on maintenance dialysis patients receiving outpatient treatment from the largest national PD center in Singapore [27, 28]. The present study reports data on PD patients from the baseline cohort (N=201) that were reassessed 12 months later using the same instruments.

Participants and Procedures

All eligible participants from baseline cohort were recruited for follow-up during their regularly scheduled appointments at the Peritoneal Dialysis Centre at Singapore General Hospital between October 2011 and June 2012 (at 12.0±3.3 months since baseline assessment). Patients were included if aged 21 or over, on PD for a minimum of 3 months, and able to communicate verbally and provide informed consent. Patients who were no longer on PD, those diagnosed with dementia or other cognitive impairment, or those hospitalized at the time of assessment were excluded. The study was approved by Centralized Institutional Review Board, SingHealth Research Facilities (reference number: 2010/588/E), and informed consent was obtained from all individual participants included in the study.

Of the 201 patients recruited at baseline, a total of 86 (43 %) were no longer eligible or available to participate: 19 were deceased (survival rate=91 %), 18 were no longer on PD (14 switched to HD and 4 had a kidney transplant), 11 were uncountable, hence lost to follow-up, and the remainder declined participation (n=38), most commonly citing loss of interest or motivation. Non-responders were found to be older (p=0.004), and those who had passed away reported lower levels of physical QOL at baseline as compared to those who had followed-up (p=0.1); no other significant differences were found. The final study sample comprised the 115 patients on PD (55 % continuous ambulatory PD [CAPD]; 55 % women; 70 % married; 67 % unemployed) who completed both the baseline and 12-month follow-up questionnaires (follow-up rate=54 %; response rate=75 %). Table 1 summarizes the participants' baseline sociodemographic and clinical characteristics of the total sample at follow-up used in the present study.

Study Instruments

Quality of Life

HRQOL was operationalized with version 1.3 of the Kidney Disease Quality of Life Short Form (KDQOL-SF) [29]. The SF-36 in the original KDQOL-SF questionnaire was replaced by its shorter version [30], SF-12 [31], as done elsewhere [32], to reduce participants' burden of completion. As per scoring procedures [33], two summary scores, the physical component summary (PCS) and mental component summary (MCS) scores were calculated. PCS and MCS scores ranged from 0 to 100, with higher scores representing better physical and mental/emotional well-being, respectively. These scores were then compared against available local SF-36 PCS and

Table 1 Baseline demographic and clinical characteristics of PD patients for the total sample and across PD modalities

Variables	Total (N= 115)	
Age in years	56.9±12.5	
<65	81	(70)
≥65	34	(30)
Male	52	(45)
Marital Status		
Married/living with partner	81	(70)
Not married/single/other	34	(30)
Ethnicity		
Chinese	85	(74)
Malay	20	(17)
Indian	5	(4)
Other	5	(4)
Education		
No/primary	44	(38)
Secondary	47	(41)
Post-secondary	24	(21)
Employment status		
Employed/student	38	(33)
Unemployed	77	(67)
Total household income		
$0–$1999	44	(52)
$2000–$3999	22	(26)
$4000–$5999	7	(8)
$6000 and more	12	(14)
Housing condition		
1- to 4-room flat	75	(65)
5-room flat	26	(23)
Condominiums or bigger	14	(12)
Dependent on carer	29	(25)
Primary cause of ESRD		
Diabetes	42	(37)
Hypertension	23	(20)
Glomerulonephritis	37	(32)
Other	13	(11)
Time on RRT (years)	3.7±3.5	
<1 year	30	(26)
1–2 years	17	(15)
>2 years	68	(60)
Modality		
CAPD	63	(55)
APD	52	(45)
Previously on HD	66	(57)
On transplant waiting list	22	(19)
Pill burden	10.1±2.4	
CCI	5.2±1.7	
High (≥6)	34	(30)
Albumin (g/dL)	3.0±0.5	
Low (<3.5)	81	(70)
Urea (mg/dL)	46.8±15.1	
Creatinine (mg/dL)	9.8±3.3	
Potassium (mEq/L)	4.1±0.6	
Phosphate (mg/dL)	4.9±1.5	
Hemoglobin (g/dL)	10.9±1.5	
Dialysis adequacy (Kt/V_{urea})	2.3±0.7	
eGFRmL/min/1.73 m^2	11.5±3.7	
Urine output (L/m^2 per day)	0.78±0.46	

Data is expressed as either M±SD or as n (%). Percentage values used are valid percentages (of respondents) and not exact percentages (of total sample). Conversion factors for units: urea in mg/dL to mmol/L, ×0.357; creatinine in mg/dL to μmol/L, ×88.4; phosphate in mg/dL to mmol/L, ×0.3229

APD automated peritoneal dialysis, *CAPD* continuous ambulatory peritoneal dialysis, *Dependence on carer* carer accomplishing most treatment tasks (e.g., performing dialysis), *RRT* renal replacement therapy, *ESRD* end-stage renal disease, *HD* hemodialysis, *Pill burden* number of prescribed medicines, *CCI* Charlson Comorbidity Index

MCS norms [34, 35], as justified elsewhere [19]; scores below one standard deviation of local norms were considered impaired. The ESRD-specific portion of the KDQOL-SF measuring DSQOL consisted of 31 items across six domains: symptoms, effects, and burden of kidney disease; patient satisfaction; staff encouragement; and social support. Scores on each domain was transformed to a scale of 0–100, with higher scores indicating better QOL. As per scoring guidelines [29], an aggregate was also calculated to determine a Kidney Disease Component Summary (KDCS) score.

Demographics and medical information

Participants reported information on age, gender, relationship status, race/ethnicity, employment status, educational level, and household monthly income. Medical notes were reviewed to record serological data (e.g., serum potassium and phosphate levels), comorbidities, and other relevant clinical or treatment details (e.g., primary cause of ESRD, PD modality, dialysis vintage, residual renal function markers, etc.). The Charlson Comorbidity Index (CCI) was used to consolidate comorbidity burden, computed pursuant to ESRD-specific methods [36, 37].

Data Analysis

Data were analyzed using SPSS Version 22 (SPSS Inc., Chicago, IL), and all p values below .05 were considered statistically significant. Missing data were infrequent and randomly distributed; mean scores were computed only if

patients answered at least half of the items in the same domain. McNemar's test determined changes in the proportions of QOL impairments over time. QOL was determined to have improved or declined if it exceeded the threshold for the clinically significant difference (i.e., ±0.5 SD of baseline) [38, 39].

Previous work has used various statistical techniques to evaluate the course of QOL over time. Because of the modest sample size, as previously done elsewhere [15], the present study employed analyses of covariance (ANCOVAs) to determine changes in QOL over time, controlling only for sociodemographic and clinical variables that were significantly associated with QOL at $p<.05$. To determine these univariate associations, Pearson's correlations, independent samples *t* tests, one-way analyses of variance (ANOVAs) with Tukey-corrected post hoc analyses, and chi-square analyses were employed (as appropriate for data).

Results

Prevalence of HRQOL Impairments from Baseline to Follow-up

Preliminary analyses revealed that close to four in five patients (baseline, 74 %; follow-up, 80 %) experienced significant physical QOL impairments (as compared to the general local population) over 12 months (PCS, $Z=-0.5$, $p=0.6$). One in three patients (baseline, 33 %; follow-up, 29 %) experienced mental/emotional QOL impairments across the same time period (MCS, $Z=-0.7$, $p=0.5$). Both PCS and MCS scores were thus significantly lower than local population norms at both baseline and follow-up (PCS, ts[113]=−16.2, ps< .001; MCS, ts[114]=−2.8 to −16.2, ps≤.006); PCS scores were also significantly more impaired than MCS scores across the time period (t[113]=−7.8 to −8.0, $p<.001$; see Table 2).

Associations between QOL and Sociodemographic and Clinical Variables

There were some significant associations between QOL domains and socio-demographic and clinical parameters, albeit not consistently across all QOL domains.

PCS scores were affected by age (r[114]=−.22, $p=.03$), dependence on caregiver (t[112]=2.58, $p=.01$), diabetes as a primary cause for ESRD ($p<.001$), pill burden (r[114]=−.22, $p=.02$), CCI (r[114]=−.36, $p<.001$), creatinine levels (r[114]=−.25, $p=.009$), and dialysis adequacy (r[114]=.27, $p=.003$). MCS scores were significantly associated with unemployment (t[112]=−2.66, $p=.009$), dependence on a caregiver (t[112]=2.03, $p<.05$), pill burden (r[114]=−.21, $p=.03$), and albumin levels (r[114]=.19, $p=.04$).

KDCS scores and symptoms of kidney disease were associated with dependence on a caregiver status (t[113]=2.03, $p=.02$) and CCI (r[115]=−.19, $p=.04$). Effects of kidney disease was only significantly associated with male gender (t[113]=−2.11, $p=.04$), and burden of kidney disease was only significantly associated with unemployment (t[113]=−2.07, $p=.04$) and CCI (r[115]=−.25, $p=.008$). Finally, staff encouragement was significantly associated Chinese ethnicity (t[90.05]=4.54, $p<.001$), dependence on a caregiver (t[113]=2.18, $p=.03$), and time on dialysis (r[115]=−.22, $p=.02$). All these variables were controlled for in subsequent analyses examining the course of QOL over time.

Changes in QOL Over 12 Months

Repeated measure ANCOVAs indicated that HRQOL remained stable across time for PCS (F[1,102]=0.77, $p=0.38$) and MCS scores (F[1,108]=0.50, $p=0.48$; see Table 2). Intra-individual analyses, however, revealed that almost one in three patients had deteriorating HRQOL across 12 months (31–32 %), although a similar proportion of patients also reported HRQOL improvements (35–37 %; see Table 2).

ANCOVA findings revealed significant decreases in DSQOL (indicative of worse DSQOL), particularly in the domains of: satisfaction with care (F[1,113]=6.33, $p=0.01$), staff encouragement (F[1,111]=16.17, $p<0.001$), and effects of kidney disease (F[1,113]=4.62, $p=0.03$). A marginally significant decreasing trend was noted for social support (F[1, 114]=3.64, $p=0.06$) (see Table 2).

MCID analyses revealed variation in outcomes with deterioration DSQOL for at least a third of participants (24–42 %) with highest rates for the domains of satisfaction with care and staff encouragement, although almost a third (22–38 %) were observed to report DSQOL improvements.

Associations with Intra-individual Trajectories of QOL Change

No baseline sociodemographic and medical variables (presented in Table 1) were associated with mean change scores or intra-individual trajectories of change in any of the QOL domains or summary scores.

Discussion

This study is one of the few to examine and compare the course of QOL over time in patients on different PD modalities. Similar to other studies [40, 41], our data shows poorer HRQOL in PD patients relative to the general population; a recent review revealed that PD patients' HRQOL are influenced by a wide range of concerns related to body image, sleep disturbances, family burden, physical limitations, and inability to fulfill social roles [6]. Our data also suggests that

Table 2 Means and frequencies for QOL measures at baseline and follow-up

KDQOL-SF subscale	Baseline	Follow-up	*p* value	Change scores	Declined	Stable	Improved
SF-12							
PCS	37.2±9.2	37.9±9.5	.38	0.6±10.7	35 (31)	43 (38)	35 (31)
MCS	47.3±11.5	47.5±9.6	.48	0.05±12.3	36 (32)	40 (35)	77 (33)
KDCS	63.4±14.1	61.1±13.6	.96	−2.2±12.4	25 (30)	58 (50)	22 (20)
Symptoms of kidney disease[a]	70.2±18.8	72.2±16.6	.13	1.9±17.3	27 (24)	50 (43)	38 (33)
Effects of kidney disease[a]	67.8±21.9	65.3±20.2	.03	−2.5±20.6	35 (30)	55 (48)	25 (22)
Burden of kidney disease[a]	35.3±27.0	40.4±23.5	.12	5.2±25.3	23 (20)	56 (49)	36 (31)
Patient satisfaction	63.9±21.2	57.5±25.4	.01	−7.0±37.0	48 (42)	41 (36)	25 (22)
Staff encouragement	72.5±31.6	65.5±26.8	.001	−4.6±25.9	42 (37)	51 (44)	22 (19)
Social support	70.6±22.3	66.0±24.1	.06	−6.6±27.9	38 (33)	54 (47)	23 (20)

Data is expressed as either M±SD or as *n* (%). *p* values are significance over time based on repeated measures analyses of covariance (ANCOVAs) controlling for significantly associated sociodemographic and clinical variables

KDQOL-SF Kidney Disease QOL (Short Form), *SF-12* Medical Outcomes Study Short Form (12 items), *PCS* physical component summary, *MCS* mental component summary, *KDCS* Kidney Disease Component Summary, *Declined* patients whose follow-up scores were below the minimally clinical significant difference of $0.5SD_{baseline}$, *Stable/Improved* patients whose follow-up scores were, respectively, within or above the minimally clinical significant difference of $0.5SD_{baseline}$

[a] Scores are reverse-coded, e.g., a higher symptom score indicates better QOL due to lower perceived symptoms

these impairments are more pronounced in physical, relative to mental/emotional, HRQOL [18–20]: over the 12 month observation period, impairment rates for PCS scores ranged 74–80 %, while the rates of MCS impairments ranged 29–33 % across the 12 months. These physical QOL impairments may perhaps be related to poor nutritional status in our sample: a total of 70 % of patients in our sample were malnourished (indicated by an albumin level of <3.5 g/dL); nutritional status has been shown to be a critical determinant of physical QOL in previous work [42, 43]. The less dramatic impact on emotional HRQOL is encouraging as it suggests a less profound effect of treatment on emotional well-being in established PD patients. As our sample comprised stock PD patients, it is likely that over time, the negative impacts on mental QOL may have been ameliorated, given that patients may have psychologically adapted to the chronic condition and demands of treatment [44]. This is also consistent with the theory of cognitive adaptation to life-threatening events [45]. However, while there may not have been a worsening HRQOL, patients in our sample still reported increasing effects of the kidney disease on their lives.

Our study findings also indicate that the observed HRQOL impairments do not improve over time. While the lack of further decline is positive, the persistence of QOL impairments is disconcerting: it suggests that these remain largely undetected or unresponsive to usual renal care over 1 year. As shown in other settings [11–13], poor physical HRQOL may explain: first, the lowered 1- and 5-year survival rates for PD (87 and 35 %, respectively), compared to HD patients (90 and 60 %, respectively); second, why only 17 % of incident dialysis patients opted for PD as of 2009; and third, why only 13 % of prevalent dialysis patients were found to be on PD in Singapore [28]. With a rising trend worldwide for the utilization of PD over HD, especially amongst the less independent [46], and with the Singapore government estimating that it would save SGD 25 million per year if the PD utilization rate increases to 40 % [47], the issue of improving QOL is becoming an increasingly pertinent one.

Clinical care in PD is typically structured around achieving clinical targets, reducing PD infections, and improving retention and technique survival; however, more attention should therefore be directed to monitoring QOL levels and potentially tailoring care and services towards incentivizing QOL improvements, strategically expanding the focus on improving patient experience, as these are linked to clinical outcomes like mortality and hospitalization [11–13].

Paramount to this goal is the delivery and perceived quality of care for the established PD patients. Study findings indicate significant declines over the 12 months of observation in patient-reported satisfaction with care and perceived staff encouragement, but stable HRQOL levels. Reduced care satisfaction in stock PD patients was noted in previous work alongside greater HRQOL decline [15], contrasting with cross-sectional data from the CHOICE study in which incident PD patients were 50 % more likely than HD patients to rate their care as excellent [48].

It is thus interesting to speculate on plausible explanations about the deterioration in interpersonal aspects of QOL for prevalent patients. It is plausible that may reflect methodological issues: in the present study, participants were recruited from the largest PD center in Singapore which caters for over more than 500 PD patients [28]. Although it is likely that large

settings in general may be linked to increased waiting times and time-restrained consultations, which may influence patient satisfaction [49], all patients were seen by the same consultant and team, so there was continuity in care and, presumably, in rapport. Renal care and support services for PD in the center are in line with other renal settings. These include care by a multi-disciplinary team comprising nurses, clinicians, social workers, and renal dieticians, PD training course for patients and at least one family member to ensure PD competency in the household followed by home visits by nurses, and routine clinic appointment and access to 24-h support line for any queries or emergencies. As such, the observed declines in patient satisfaction and ratings of staff encouragement may reflect aspects of care other than organizational factors or availability of services.

Thus, it may be likely that, over time, with patients becoming long established on PD, the content of front care and consultations may either change towards a format that is no longer as well-aligned with, or not swiftly adapting to, the expectations and needs of PD survivors (e.g., care remaining too static and stale, or becoming more routinized). Pertinent to this are the expectations of both parties, recipients, and providers of care. The success in PD technique survival, albeit commendable and indicated by a reduction in the perceived burden of kidney disease in our sample, may lead to assumptions or expectations of mastery and self-sufficiency in renal health care teams. For instance, healthcare providers (HCPs) may assume mastery of PD procedures for their long-term established patients and hence may not as actively pursue further support and encouragement as with incident patients. The reassurance that patients have been maintained on PD for long might also lead HCPs to become less vigilant or responsive to patients' needs for sustained education, guidance, empowerment, or affirmation.

Likewise, it could also be that expectations of patients for support by HCPs may increase over time, either due to complications, PD-related burnout in themselves or their family [50–52], or dwindling support from their family. There was a trend of decreased social support in our sample, which implies that as family/interpersonal support wanes over time, patients may place higher expectations towards their renal team. More work is clearly needed to explore these important issues and inform the efforts to maintain and improve quality care over the course of PD.

Study limitations should be noted. Because of the overall attrition rate, sample may have been biased; this is partly due to the high turnover of PD patients, with close to 5 % of the original sample being switched to HD, another 5 % not contactable, and 20 % who were not interested in participating in the follow-up assessment because of poor health and hospitalization. These may have led to an underestimation of the magnitude of QOL effects. Caution should also be taken in interpreting the study findings, as significance levels were not adjusted for multiple comparisons, thereby inflating type I error. The strategy adopted in this study was to be exploratory and generate hypotheses for further research. Because of the modest sample size and power of the analyses, the present study only controlled sociodemographic and clinical variables with significant associations with QOL. Replication with larger samples is hence warranted. Finally, this is a single center study that may limit generalizability in other settings, although the hospital from which the sample was drawn has the largest PD unit catering for the majority of PD patient in Singapore; it is important to note, however, that the socio-demographic and clinical profile (i.e., comorbidities) was comparable to the national PD registry data, allowing some confidence concerning the generalizability of our findings [28] While our Asian patient population is of particular interest due to its high incidence of ESRD and the substantial rates of Asian minorities in Western countries, the widespread generalizability of our observations to other settings or other ethnic populations is unknown and should be explored in future work. Future studies should also look to the influence of caregivers on QOL outcomes; as PD is a home-based therapy, the QOL of the caregivers or cohabiting family members may affect patient outcomes.

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Authors' Contributions KG and MWYF were responsible for the research idea and study design. YZ and AWCK were involved in the data acquisition. HAL and KG participated in data analyses/interpretation. HAL was responsible in statistical analyses. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved. KG takes responsibility that this study has been reported honestly, accurately, and transparently; that no important aspects of the study have been omitted; and that discrepancies from the study as planned (and, if relevant, registered) have been explained.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethics Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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