

Quality of life and emotional distress in patients and burden in caregivers: a comparison between assisted peritoneal dialysis and self-care peritoneal dialysis

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Accepted: 14 July 2015 / Published online: 21 July 2015
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Abstract

Purpose Assisted peritoneal dialysis (PD) involving caregivers allows more patients to get started on home-based dialysis with good clinical outcomes, but evidence on patient-reported and caregiver-reported outcomes is lacking. This study aimed to compare assisted PD versus self-care PD on quality of life (QoL) and psychosocial outcomes for patients and caregivers. The effect of PD modality [automated PD (APD); continuous ambulatory PD (CAPD)] in relation to self-care or assisted care was also examined.

Methods A cross-sectional sample of 231 PD patients [142 self-care (57 APD/85 CAPD) and 89 assisted care PD (45 APD/44 CAPD)], 72 caregivers of assisted PD patients and 39 family members of self-care PD patients completed the Kidney Disease Quality of Life Short Form (KDQOL-SF), World Health Organisation Quality of Life Instrument-brief and the Hospital Anxiety and Depression Scale. Caregivers and family members completed the Lay Care-Giving for Adults Receiving Dialysis questionnaire and Zarit Burden Interview.

Results Case-mix-adjusted comparisons indicated comparable QoL in all dimensions with the exception of physical SF-12 ($p = .001$) and the KDQOL effects of

kidney disease in favour of self-care PD. Levels of anxiety (9.72 ± 4.90 ; 8.25 ± 5.22) and depression (8.63 ± 3.80 ; 6.35 ± 4.76) were equivalent in assisted PD and self-care PD, respectively. Assisted PD caregivers reported more task-orientated duties ($p = .007$), yet levels of perceived burden were equal to those reported by family members of self-care PD.

Conclusion Our findings of mostly comparable patient and caregiver outcomes in assisted PD and self-care PD suggest that caregiver burden and QoL should not be a barrier to using assisted PD.

Keywords Assisted peritoneal dialysis · Burden · Caregiver · Quality of life · Self-care peritoneal dialysis

Introduction

Peritoneal dialysis (PD) is the most common form of home-based dialysis for patients with end-stage renal disease (ESRD) [1]. PD ideally requires some degree of mobility and vision, a peritoneum not disrupted by surgery, and the ability to learn and independently perform a rigorous daily medical procedure or support by others (e.g. caregiver) when self-care ability may be at question. With increased numbers of older adults with ESRD and in need of renal replacement therapy [1–4], assisted peritoneal dialysis is an emerging trend among ESRD patients. Although the availability and rates vary, assisted PD can dramatically expand the range of candidates for home-care dialysis. Such approaches, involving predominantly family members or home-care nurses, allow patients with great comorbid burden, limited mobility and poor physical and/or cognitive functioning [5], to perform dialysis care in comfort of home with good clinical outcomes [6] and lower

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cost [7]. Caregivers involved in assisted PD have the primary responsibility for the performance of the dialysis exchanges, with daily activities including but not limited to the handling of catheter connections and dialysis solutions, setting up and operating the dialysis machine, record keeping, monitoring of care recipient's health and coordination of care [5]. Community initiatives [5, 8] have been set up to support patients and families and hence increase preference for and utilisation of PD. Prior work indicates that assisted PD is feasible, safe and effective [5–7, 9], making it a viable option especially for the elderly. However, evidence on patient-reported outcomes is largely lacking.

Among patient outcomes, quality of life (QoL) is commonly evaluated in the provision of healthcare as it provides a good measure of treatment effectiveness by revealing how well an individual is functioning upon receiving treatment [10]. The importance of evaluating QoL is even more salient as most elderly and frail patients on assisted PD are unlikely to receive renal transplantation and hence would most likely remain in dialysis till the end of life. Moreover, poor QoL has been linked to adverse clinical outcomes in PD such as higher mortality and incidence of peritonitis [10–12]. Emotional distress (i.e. symptoms of anxiety and depression) is another key outcome that is associated with poor treatment adherence and lower survival rates [13–17].

Outcomes related to PD caregivers are also important to consider. Responsibilities for caregivers on assisted PD are likely to be heavy given the poorer physical and mental functioning of assisted PD patients. Prior research had established that caregivers of patients undergoing dialysis experience a significant amount of burden [18] and are prone to physical and mental disturbances [18, 19]. This may potentially affect care and technique survival.

Patients undergoing PD can choose between automated PD (APD) and continuous ambulatory PD (CAPD). CAPD typically requires patients to manually perform exchanges of dialysate fluid four to five times a day, whereas in APD, dialysis is typically performed continuously for 8–10 h when the patient is asleep using an automated machine (cycler). APD is advocated as ideal for assisted PD [20] as burden of treatment is lower, yet comparisons of patient and caregiver outcomes of assisted versus self-care PD across the PD modalities have not been undertaken.

Currently, there is a paucity of research in comparing self-reported patient and caregiver outcomes across assisted and self-care PD. Therefore, the aims of the current study were to compare assisted and self-care PD on patient- and caregiver-reported outcomes and to evaluate the effects of PD modality.

Subject and methods

Participants

Participants in this study were recruited between October 2010 and October 2013 from the Peritoneal Dialysis Centre, Singapore General Hospital. The inclusion criteria for the study were: (1) having undergone PD for a minimum of 3 months, (2) aged 21 years or above, (3) not hospitalised at the time of assessment or the preceding 3 weeks, (4) no dementia or psychiatric diagnosis and (5) able to communicate in English, Mandarin or Malay. Family members and caregivers of consenting patients were recruited only if they were residing with patients and met the above-stated criteria.

Approval for the study was obtained from the SingHealth Centralised IRB (CIRB ref: 2010/588/E), and all study participants provided written informed consent.

Procedure

Eligible PD patients were approached and recruited at the PD centre during their routine clinic appointments. To broaden participation and to minimise selection bias for literate patients only, questionnaire administration methods included either self-completion at the PD centre ($n = 67$), self-completion at home ($n = 67$) or interviews conducted by research assistants at home ($n = 97$) as per patients' preference. Patients were free to choose their preferred language of questionnaires (English or Mandarin). Linguistically validated instruments were used with the exception of the "Lay Care-Giving for Adults Receiving Dialysis" included in carers' assessment where standard forward/backward translation procedures were applied. Consenting patients who could only speak Chinese dialects (e.g. Hokkien) or Malay were interviewed by language competent research assistants.

Caregivers and family members of PD patients were also recruited using similar procedures to those of patients. We have tried to approach at least one family member per consenting patient at the time of recruitment/assessment or via patient solicitation. As eligible (cohabiting) caregivers and family members did not always accompany patients at clinic or were not available at home visits, it was not possible to obtain consent and recruit caregivers/family members for every patient enrolled in the study. Where possible (i.e. patients being agreeable), relevant study materials were handed for dissemination to their family members/caregivers. Some patients, however, were reluctant to facilitate this, citing their relatives' busy work schedules ($n = 7$) or lack of interest ($n = 3$). Consenting caregivers/family members had the option to self-complete

the questionnaires at the hospital ($n = 13$), self-complete at home ($n = 51$) or have the questionnaire administered through interview ($n = 47$). All procedures and instruments were tested in a pilot study [21]. Mode of administration had no effect on reported outcomes.

Measures

Patient questionnaire

Socio-demographical information Patients were asked to report on age, gender, ethnicity, marital status, education, current employment status, housing (as indicated by type and size of residence) and household monthly income.

Medical information Information on PD modality, dialysis vintage, comorbidities and cause of ESRD were extracted from medical records. The Charlson Comorbidity Index [22] was used to consolidate comorbid burden pursuant to the method described by Beddhu et al. [23] for ESRD patients.

Dependency status Dependency status was established through hospital records and verified by renal healthcare professionals (HCPs) and respondents at the time of recruitment. Patients who had listed caregivers in hospital records were identified to be on assisted PD. On the other hand, patients without listed caregivers were identified to be on self-care PD. As per hospital procedures, the PD training course is undertaken jointly by patients and at least one family member regardless of preference for self-care or assisted PD to ensure PD competency in the household. Patients listed as self-care PD in hospital records have undergone training and identified themselves as responsible for PD performance at home. In assisted PD, the family members are identified as responsible for PD. The self-care and assisted PD status is determined based on both pre-training and post-training interviews with all parties (patients; family members) and regularly evaluated and verified during the subsequent routine consultations with renal HCPs. Patients were assigned to the PD type (assisted vs. self-care) they were receiving when approached for the study. Patients also confirmed dependency status and provided additional information on level of assistance and delegation of responsibilities across various treatment aspects, i.e. dialysis, diet and medication (data not shown).

Disease-specific QoL The Kidney Disease Quality of Life Short Form (KDQOL-SF) [24] that has been validated in Singapore's ESRD population [25, 26] was used to assess disease-specific QoL. The 12-item Short-Form Health Survey version 2 (SF-12) was used in place of the SF-36 to reduce burden of completion [27]. We calculated all eight individual SF-12 subscales and two summary scores: a

physical component summary (PCS) score and mental component summary (MCS) score which reflect physical and emotional health-related QoL, respectively. The ESRD-specific portion consists of 31 items across six domains: symptoms, effects and burden of kidney disease; patient satisfaction, staff encouragement and social support. All subscales and summary scores range from 0 to 100. Higher scores indicate better QoL. Internal reliabilities were adequate ranging from 0.71 to 0.85.

Global QoL The abbreviated version of the World Health Organisation QoL (i.e. WHOQOL-BREF) was used to measure patients' global QoL [28]. This provides a score on patients' overall QoL and QoL in four domains: physical health, psychological health, social relations and environment. Domain scores range from 4 to 20 with higher scores signifying higher QoL. The instrument had been validated across many countries including Asian cultures [28]. Cronbach's alphas for our sample were acceptable (0.61 to 0.82).

Emotional distress Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) [29]. The HADS is a well-established, standardised instrument comprising one subscale for depression and one for anxiety. The omission of somatic items makes it an appropriate measure for medical patients [30, 31]. Higher scores indicate more severe symptoms with scores ≥ 8 indicating the presence of clinically relevant anxiety or depressive affect [32]. Cronbach's alphas in our data set were 0.85 and 0.78 for anxiety and depression, respectively.

Caregiver questionnaire

Socio-demographical information Caregivers and family members were asked to report age, gender, education, ethnicity, marital status, employment, monthly household income and relationship with patient.

Caregiving activities The Lay Care-Giving for Adults Receiving Dialysis (LC-GAD) [33] was used to capture the types and quantity of caregiving activities performed. The Think-LC-GAD component measures abstract and cognitive tasks and comprises five subscales. The Task-LC-GAD component measures concrete and observable tasks related to caregiving for dialysis patients and comprises seven subscales. Scales ranged from 0 to 5 with higher scores indicating higher involvement in caregiving. Internal reliabilities of the subscales and summary scores in our sample ranged between 0.67 and 0.96.

Burden Levels of burden were measured using the Zarit Burden Interview (ZBI) [34] which has been validated in Singapore [35]. The ZBI consists of 22 items summed up to

an overall burden score ranging from 0 to 88. Scores below 21 indicate little or no burden; scores between 21 and 40 represent mild to moderate burden; scores between 41 and 60 indicate moderate to severe burden; and scores above 60 indicate severe burden [36]. A cut-off score of 24 and above has been established to represent a risk of depression [37]. Cronbach's alpha in our study was 0.91.

Statistical analyses

Statistical analyses were done using SPSS version 21.0 [38]. To assess the need to incorporate case-mix adjustments in the comparative analyses, Pearson's χ^2 test for categorical variables and independent *t* test for continuous variables were performed to compare assisted PD patients versus self-care PD and caregivers of assisted PD versus family members of self-care PD on socio-demographical and clinical variables.

For primary analyses, QOL, emotional distress and burden outcomes were compared using either one-way ANOVAs or ANCOVAs (when significant case-mix differences between the groups) with *p* values, uncorrected for multiple comparisons, considered significant if $p < .05$ (Cohen's *d* was used to signify effect size). Mixed models were employed to explore the effects of PD modality across dependency status for patient and caregiver outcomes. As secondary analyses, comparisons were repeated using Bonferroni adjustments to control for multiple comparisons. The *p* value was reduced to $p < .002$ for patient comparisons and $p < .003$ for comparisons between caregivers/family members.

Results

Study sample

PD participants

A total of 318 PD patients were approached, but $N = 24$ of them were excluded due to stroke ($n = 3$), dementia ($n = 12$), hearing difficulty ($n = 7$) and hospitalisation ($n = 2$). Of the remaining 294 eligible patients, 63 declined to participate due to lack interest ($n = 51$), lack of time ($n = 11$) and poor health ($n = 1$). Among the final sample of 231 patients (response rate 72.6 %), $N = 89$ were on assisted PD (45/44 on APD and CAPD, respectively) and $N = 142$ were on self-care PD (57/85 on APD and CAPD, respectively). The final sample with majority of patients being ethnic Chinese (74.3 %) was representative of the ethnic distribution in the country's population. Access to treatment in local context is universal due to a range of financial aids (e.g. Medifund and NKF subsidies)

available, and study participants represented well the different social strata (as indexed by education, housing and income).

Assisted PD patients were significantly older, less likely to be employed, had lower levels of education, shorter dialysis vintage and higher comorbid burden than self-care PD patients (Table 1). Primary cause for ESRD differed with higher rates of diabetic nephropathy for assisted PD and higher rates of glomerulonephritis for self-care PD patients (Table 1). As case-mix differences are likely to impinge upon QOL [39], they were controlled for in subsequent comparisons.

PD caregivers and family members

Of the 111 participants, $n = 72$ were caregivers of assisted PD patients and $n = 39$ were family members of self-care PD patients. The two groups had a similar socio-demographical profile in terms of age, gender, education, ethnicity, marital status, employment status, income and relationship with patients (Table 2) indicating no need for case-mix adjustments. Majority of the participants were female (75.9 %), either spouses (39.6 %) or children (50.5 %) of the patients, and had a mean age of 46.26 ± 14.26 . CAPD was more commonly noted as patients' PD modality by family members of self-care PD patients ($p = .02$).

Patient-reported outcomes between assisted and self-care PD

A series of ANCOVAs were performed to compare assisted and self-care PD patients across PD modalities on QOL indicators and symptoms of emotional distress. Covariates controlled for included age, employment, education, dialysis vintage, primary kidney disease diagnosis and comorbid burden.

Disease-specific QoL Case-mix adjusted comparisons indicate significant differences in favour of self-care PD mainly in physical dimensions of QoL (see Table 3): PCS ($p = .001$, $d = 0.67$), physical functioning ($p = .04$, $d = 0.48$), physical role limitations ($p = .001$, $d = 0.63$), bodily pain ($p = .005$, $d = 0.49$), social functioning ($p = .01$, $d = 0.59$). Self-care PD patients were also found to have a significantly higher QoL in terms of effects of kidney disease ($p = .007$, $d = 0.42$) and staff encouragement ($p = .038$, $d = 0.23$).

Emotional QOL scores, i.e. MCS, role limitations due to emotional problems, vitality and mental health, were not different between assisted and self-care PD. There were also no significant differences in any of the remaining KDQOL specific subscales, i.e. symptoms, satisfaction with care, social support or burden of kidney disease.

Table 1 Socio-demographical and clinical characteristics of patients by dependency status (as derived from hospital records)

	Total (<i>n</i> = 231)	Assisted PD (<i>n</i> = 89)	Self-care PD (<i>n</i> = 142)	<i>p</i> value ^a
Age in years [mean (SD)]	59.84 (12.37)	65.99 (9.88)	55.99 (12.25)	<.001
Gender [<i>n</i> (%)]				.279
Male	107 (46.3)	37 (41.6)	70 (49.3)	
Female	124 (53.7)	52 (58.4)	72 (50.7)	
Married [<i>n</i> (%)]	172 (74.5)	65 (73.0)	107 (75.4)	.757
Employed [<i>n</i> (%)]	56 (24.6)	3 (3.4)	53 (37.6)	<.001
Education level [<i>n</i> (%)]				.001
No/primary	89 (39.2)	46 (53.5)	43 (30.5)	
Secondary	91 (40.1)	31 (36.0)	60 (42.6)	
Tertiary	47 (20.7)	9 (10.5)	38 (27)	
Ethnicity [<i>n</i> (%)]				.062
Chinese race	171 (74.3)	59 (67.0)	112 (78.9)	
Non-Chinese race	59 (25.7)	29 (33.0)	30 (21.1)	
Monthly household income ^{b,c} [<i>n</i> (%)]				.572
S\$0–S\$2000	75 (43.4)	24 (39.3)	51 (45.5)	
S\$2001–S\$4000	54 (31.2)	22 (36.1)	32 (28.6)	
S\$4001–S\$6000	19 (11.0)	8 (13.1)	11 (9.8)	
S\$6001 and above	25 (14.5)	7 (11.5)	18 (16.1)	
Housing				.885
1–4 rooms HDB flat ^d	141	56	85	
HDB 5 room executive	59	22	37	
Private residence ^d	31	11	20	
Time on dialysis in months [mean (SD)]	40.34 (37.80)	32.21 (31.42)	45.44 (40.59)	.006
CCI [mean (SD)]	6.00 (2.16)	7.25 (2.00)	5.22 (1.88)	<.001
PD modality [<i>n</i> (%)]				.135
APD	102 (44.2)	45 (50.6)	57 (40.1)	
CAPD	129 (55.8)	44 (49.4)	85 (59.9)	
Primary ESRD cause [<i>n</i> (%)]				<.001
Diabetes	101 (44.7)	54 (63.5)	47 (33.3)	
Hypertension	43 (19.0)	18 (21.2)	25 (17.7)	
Glomerulonephritis	58 (25.7)	9 (10.6)	49 (34.8)	
Others	24 (10.6)	4 (4.7)	20 (14.2)	

Missing variables are excluded on an analysis by analysis basis

CCI Charlson Comorbidity Index, PD peritoneal dialysis, APD automated peritoneal dialysis, CAPD continuous ambulatory peritoneal dialysis, ESRD end-stage renal disease

^a Proportions were compared using χ^2 tests. Means were compared using independent *t* tests

^b *n* = 40 chose the option “do not know” and *n* = 18 chose the option “do not wish to answer” when responding to question on monthly household income

^c Income equivalent to US dollars as follows: S\$2000 = US\$1600; S\$4000 = US\$3200

APD patients scored significantly higher than CAPD patients for PCS ($p = .02$, $d = 0.26$), physical functioning ($p = .02$, $d = 0.25$), general health ($p = .02$, $d = 0.32$) and KDQOL symptoms ($p = .02$, $d = 0.31$) (see Table 5). There were no significant interaction effects ($p > .05$) between dependency status (i.e. assisted vs self-care PD) and PD modality in any of the SF-12 and KDQOL subscales or summary scores.

Analyses using Bonferroni-adjusted significance levels indicated a significant difference only in physical role limitation (SF12). No other effects were deemed significant.

Global QoL Comparisons indicated comparable outcomes for assisted and self-care PD for all dimensions of WHOQOL-BREF (see Table 3). Neither PD modality nor

Table 2 Socio-demographical characteristics of caregivers and family members of assisted and self-care peritoneal dialysis patients, respectively

	Total (<i>n</i> = 111)	Caregiver (<i>n</i> = 72)	Family member (<i>n</i> = 39)	<i>p</i> value ^a
Age in years [mean (SD)]	46.26 (14.26)	45.13 (14.01)	48.42 (14.65)	.251
Gender [<i>n</i> (%)]				.355
Male	26 (24.1)	19 (27.1)	7 (18.4)	
Female	82 (75.9)	51 (72.9)	31 (81.6)	
Married [<i>n</i> (%)]	81 (73)	53 (73.6)	28 (71.8)	1.00
Employed [<i>n</i> (%)]	65 (58.6)	44 (61.1)	21 (53.8)	.546
Education level [<i>n</i> (%)]				.594
No/primary	17 (15.3)	9 (12.5)	8 (20.5)	
Secondary	49 (44.1)	33 (45.8)	16 (41)	
Tertiary	45 (40.5)	30 (41.7)	15 (38.5)	
Ethnicity [<i>n</i> (%)]				.555
Chinese race	64 (57.7)	40 (55.6)	24 (61.5)	
Non-Chinese race	47 (42.3)	32 (44.4)	15 (38.5)	
PD modality [<i>n</i> (%)]				.017
APD	52 (46.8 %)	40 (55.6 %)	12 (30.8 %)	
CAPD	59 (53.2 %)	32 (44.4 %)	27 (69.2 %)	
Monthly household income ^{b,c} [<i>n</i> (%)]				.739
S\$0–S\$2000	31 (37.3)	21 (38.9)	10 (34.5)	
S\$2001–S\$4000	28 (33.7)	18 (33.3)	10 (34.5)	
S\$4001–S\$ 6000	14 (16.9)	10 (18.5)	4 (13.8)	
S\$6001 and above	10 (12.0)	5 (9.3)	5 (17.2)	
Relationship with patient ^d [<i>n</i> (%)]				.061
Spouse	44 (39.6)	23 (31.9)	21 (53.8)	
Child/child in-law	56 (50.5)	40 (55.6)	16 (41.0)	
Others ^e	11 (9.9)	9 (12.5)	2 (5.1)	

Missing variables were excluded on an analysis by analysis basis

^a Proportions were compared using χ^2 tests. Means were compared using independent *t* tests

^b *n* = 15 chose the option “do not know” and *n* = 12 chose the option “do not wish to answer” when responding to question on monthly household income

^c Income equivalent to US dollars as follows: S\$2000 = US\$1600; S\$4000 = US\$3200; S\$6000 = US\$4800

^d For relationship with patient, only spouse and child/child in-law were included for the χ^2 test. Other relationships with patient were excluded from the χ^2 test due to low expected cell count

^e *n* = 2 were siblings of patients; *n* = 3 were relatives of patients; *n* = 1 was parent of the patient; *n* = 5 were related to patients in other ways (including domestic helpers)

interaction effect between dependency status and PD modality was significant (see Table 5).

Emotional distress Mean anxiety for self-care patients was in the normal range, but the mean for assisted PD patients was above the clinical cut-off suggesting borderline anxiety disorder. Depression scores for both assisted and self-care PD patients were in the range for borderline depression. There were no significant differences in anxiety and depression between assisted and self-care PD (see Table 3). The PD modality main effect and the interaction effect between dependency status and PD modality were also non-significant.

Caregiver/family member outcomes between assisted and self-care PD

As there were no case-mix differences between caregivers of assisted PD and family members of self-care PD (see Table 2), there was no need to include covariates in comparative analyses for caregiver outcomes (i.e. caregiving tasks and burden).

LC-GAD Levels of cognitive caregiving tasks (i.e. Think-LC-GAD total and subscales) were equivalent between caregivers of assisted PD and family members of self-care PD (see Table 4).

Table 3 Means of QoL and emotional distress in assisted and self-care PD patients

	Assisted PD (<i>n</i> = 89) Mean (SD)	Self-care PD (<i>n</i> = 142) Mean (SD)	<i>F</i>	<i>p</i> value
KDQOL-SF				
Symptoms	65.50 (19.39)	71.99 (18.61)	3.24	.073
Effects of kidney disease	59.60 (22.52)	69.28 (21.15)	7.34	.007
Burden of kidney disease	26.62 (24.12)	34.29 (25.44)	1.37	.244
Patient satisfaction	65.17 (23.79)	64.79 (20.06)	3.36	.068
Staff encouragement	69.66 (29.61)	76.41 (27.78)	4.37	.038
Social support	68.16 (21.30)	71.36 (10.69)	0.49	.485
SF-12				
Physical functioning	31.47 (11.91)	37.65 (11.11)	4.15	.043
Physical role limitations	33.37 (12.37)	40.89 (10.73)	10.74	.001
Bodily pain	37.18 (15.40)	44.17 (12.37)	7.96	.005
General health	30.98 (9.45)	34.28 (9.81)	0.01	.920
Vitality	41.92 (11.24)	46.45 (9.77)	3.59	.059
Social functioning	34.78 (15.06)	42.63 (12.54)	6.08	.014
Emotional role limitations	36.16 (15.88)	40.64 (12.22)	2.28	.132
Mental health	44.87 (11.70)	47.06 (11.15)	<0.001	.997
PCS	31.15 (9.92)	38.19 (9.33)	11.48	.001
MCS	43.37 (12.82)	46.47 (11.10)	0.58	.447
WHOQOL-BREF				
Overall QoL	2.93 (0.91)	3.13 (0.84)	0.99	.321
Physical health	10.67 (3.30)	12.51 (2.94)	3.21	.074
Psychological well-being	12.58 (3.16)	12.97 (2.94)	0.002	.965
Social relations	12.85 (3.23)	13.37 (3.06)	0.53	.466
Environment	13.18 (2.62)	13.39 (2.55)	<0.001	.999
HADS				
Anxiety	8.25 (5.27)	6.35 (4.76)	2.63	.106
Depression	9.72 (4.90)	8.63 (4.38)	0.98	.322

PD peritoneal dialysis, *KDQOL-SF* = Kidney Disease Quality of Life Short Form, *SF12* Short Form Health Survey 12, *PCS* physical component score, *MCS* mental component score, *WHOQOL-BREF* World Health Organisation Quality of Life Brief, *HADS* Hospital Anxiety and Depression Scale

Significant differences were noted only for the task-related duties. Caregivers of assisted PD patients reported higher overall Task-LC-GAD ($p = .009$, $d = 0.51$) and greater involvement in managing personal hygiene relatively to family members of self-care PD ($p < .001$, $d = 0.92$).

There were no significant effect for PD modality or the interaction between dependency status and PD modality (see Table 5).

Only the effect on managing personal hygiene was deemed significant based on Bonferroni-adjusted significance levels ($p < .003$).

Burden The mean ZBI scores for caregivers and family members were in the mild to moderate range. ZBI scores were comparable between caregivers and family members. However, both scores lie above the cut-off of 24 and hence indicate that both groups are at risk of depression.

There were no main or interaction effects between dependency status and PD modality on burden.

Discussion

Although PD is advocated to be a home-based treatment that can be performed by patients independently, the responsibility for performance of PD exchanges is often shared or undertaken by others than patients independently [40]. Given the increase in prevalence and need for assisted PD, evaluation of patient-reported outcomes become particularly pertinent in informing patient education and healthcare provision. This is the first study to document the effects of dependency status on patient and caregiver outcomes.

Comparisons indicated that QoL differences in favour of self-care PD were only limited to the physical QoL

Table 4 Levels of involvement in caregiving activities and burden in caregivers of assisted PD patients and family members of self-care PD patients

	Caregivers (<i>n</i> = 72) Mean (SD)	Family members (<i>n</i> = 39) Mean (SD)	<i>F</i>	<i>p</i> value
Think-LC-GAD	3.88 (0.68)	3.82 (0.96)	−0.39	.70
Appraisal	3.78 (0.81)	3.81 (1.01)	0.15	.88
Advocating	3.86 (1.06)	3.66 (1.18)	−0.90	.37
Coaching	4.30 (0.66)	4.18 (1.05)	−0.63	.53
Juggling	3.84 (0.94)	3.85 (1.09)	0.02	.99
Routinising	3.81 (0.82)	3.75 (1.07)	−0.33	.74
Task-LC-GAD	3.64 (0.71)	3.22 (0.91)	−2.66	.01
Providing transport	3.62 (1.38)	3.09 (1.44)	−1.87	.06
Performing dialysis	3.84 (1.22)	3.36 (1.22)	−1.99	.05
Personal hygiene	2.99 (1.35)	1.82 (1.18)	−4.56	<.001
Managing diet	3.75 (0.97)	3.71 (1.27)	−0.21	.84
Symptom relief	3.48 (1.03)	3.03 (1.35)	−1.98	.05
Comfort measures	3.99 (0.85)	3.83 (1.22)	−0.73	.47
Teaching self-care	3.76 (0.97)	3.71 (1.20)	−0.28	.78
ZBI	27.73 (14.86)	27.13 (14.85)	−0.20	.84

PD peritoneal dialysis, LC-GAD Lay Care-Giving for Adults Receiving Dialysis, ZBI Zarit Burden Interview

dimensions. The finding is not surprising given that assisted PD patients are likely to have physical difficulties such as decreased vision, strength, manual dexterity and mobility [39], factors that were not directly measured in this study nor captured in the comorbidity index. Such difficulties explain the need for and possibly led to dependence on a caregiver. Therefore, the lower physical QoL in assisted patients would probably have been present before treatment and is unlikely to be the consequence of depending on a caregiver.

The lack of significant differences in emotional dimensions of QoL or symptoms of anxiety and depression is noteworthy as it suggests that dependency on caregivers does not seem to affect emotional wellbeing. Although emotional distress is reported by carer-dependent patients—often fuelled by perceptions of burden [41]—study findings suggest that such concerns are not greater in assisted PD compared to self-care PD. Worries about being a burden may be shared by both assisted and self-care PD patients with the latter perhaps worrying that despite personally administering treatment, the requirements around storage of equipment or the sterilisation procedures may be imposing upon family. Despite equal levels of satisfaction with care, assisted PD patients reported lower encouragement from staff than self-care PD. As this may adversely impact on adherence [42], our findings suggest that more attention should be given on interpersonal aspects of care and ways to foster motivation and engagement in carer-dependent PD patients.

Caregiving activities are reported in the context of both assisted and self-care PD. Family members of self-care PD

patients albeit uninvolved in dialysis exchanges per se are as equally involved as caregivers of assisted PD patients in tasks such as coaching, advocating for the patient, evaluating patients' health, providing transport and managing patients' diet. Besides involvement in health management, issues such as medicalisation of home environment and likely interference or changes in home life/routines and family dynamics, not the least in the form of hypervigilance, coupled with the financial/psychosocial strain related to chronic disease may contribute to burden even in context of self-care PD [18]. In assisted PD, however, practical demands are greater. Caregivers of assisted PD patients reported greater involvement in task-oriented activities (i.e. managing patients' personal hygiene) relative to the family members of self-care PD. Due to the high levels of physical impairment among assisted PD patients [39], caregivers are required to provide assistance with personal care in addition to renal-specific care (dialysis). Despite the greater involvement in such practical tasks, caregivers of assisted PD patients did not experience higher burden than the family members of self-care PD patients. This was consistent with previous research which concluded that caring for PD patients did not negatively affect caregivers' QoL [43].

Mean levels of burden for both assisted PD and self-care PD caregivers or family member were in moderate range—lower than those reported by caregivers of dementia patients [35]. This may reflect the relatively lower intensity of caregiving demands for PD—in terms of types or frequency of tasks relative to conditions with a progressive downward trajectory or an unpredictable course that may

Table 5 Patient and caregiver outcomes across PD modality and dependency status (as derived from hospital records)

	Assisted PD (patient <i>n</i> = 89) (caregiver <i>n</i> = 72)		Self-care PD (patient <i>n</i> = 142) (family members <i>n</i> = 39)		Main effects of PD modality ^a		Interaction effect	
	APD (P: <i>n</i> = 45) (C: <i>n</i> = 40) Mean (SD)	CAPD (P: <i>n</i> = 44) (C: <i>n</i> = 32) Mean (SD)	APD (P: <i>n</i> = 57) (C: <i>n</i> = 12) Mean (SD)	CAPD (P: <i>n</i> = 85) (C: <i>n</i> = 27) Mean (SD)	<i>F</i>	<i>p</i> value	<i>F</i>	<i>p</i> value
	KDQOL-SF							
Symptoms	67.50 (18.23)	63.45 (20.52)	76.90 (18.60)	68.70 (17.98)	5.79	.017	0.66	.416
Effects of kidney disease	59.24 (21.84)	59.96 (23.45)	72.09 (22.15)	67.40 (20.37)	0.45	.503	0.84	.360
Burden of kidney disease	26.11 (23.70)	27.13 (24.82)	35.20 (26.50)	33.68 (24.85)	0.01	.941	0.14	.710
Patient satisfaction	65.56 (20.23)	64.77 (27.19)	62.28 (19.29)	66.47 (20.50)	0.34	.563	0.71	.399
Staff encouragement	73.33 (25.78)	65.91 (32.95)	76.97 (27.22)	76.02 (28.30)	1.16	.283	0.70	.405
Social support	67.77 (23.27)	68.56 (19.35)	70.03 (20.94)	72.25 (20.59)	0.28	.600	0.64	.801
KDCS	59.92 (11.27)	58.30 (13.34)	65.58 (15.70)	64.09 (12.63)	0.73	.393	0.001	.971
WHOQOL-BREF								
Overall QoL	2.91 (0.92)	2.95 (0.90)	3.19 (0.76)	3.09 (0.89)	0.06	.816	0.36	.549
Physical health	10.66 (3.28)	10.67 (3.36)	12.78 (2.73)	12.34 (3.08)	0.26	.610	0.28	.596
Psychological well-being	12.30 (3.34)	12.88 (2.98)	12.67 (3.19)	13.17 (2.75)	1.73	.190	0.01	.922
Social relations	12.61 (3.39)	13.09 (3.07)	13.08 (3.27)	13.57 (2.91)	1.31	.254	<0.001	.991
Environment	12.86 (2.81)	13.51 (2.40)	13.01 (2.85)	13.65 (2.30)	3.44	.065	<0.001	.991
SF-12								
Physical functioning	33.18 (12.77)	29.72 (10.84)	39.89 (11.80)	36.15 (10.42)	5.43	.021	0.01	.928
Physical role limitation	33.32 (12.85)	33.41 (12.00)	43.11 (10.13)	39.40 (10.92)	1.38	.242	1.51	.220
Bodily pain	37.06 (15.21)	37.29 (15.77)	46.18 (11.18)	42.82 (13.01)	0.71	.400	0.94	.334
General health	31.32 (9.46)	30.63 (9.53)	37.40 (9.72)	32.18 (9.36)	5.22	.023	3.05	.082
Vitality	41.58 (11.31)	42.26 (11.29)	47.11 (9.62)	46.00 (9.91)	0.02	.878	0.40	.526
Social functioning	35.03 (15.16)	34.54 (15.13)	43.28 (11.79)	42.19 (13.07)	0.18	.671	0.03	.872
Emotional role limitation	35.20 (16.83)	37.14 (14.98)	41.17 (12.20)	40.29 (12.30)	0.08	.777	0.56	.454
Mental health	45.47 (12.68)	44.26 (10.72)	48.63 (9.95)	46.01 (11.82)	1.53	.218	0.21	.650
SF-12 PCS	31.95 (10.10)	30.34 (9.77)	40.90 (8.69)	36.37 (9.36)	5.74	.017	1.29	.257
SF-12 MCS	42.85 (14.96)	43.90 (10.33)	46.76 (10.08)	46.28 (11.79)	0.03	.859	0.23	.634
HADS								
Anxiety	8.64 (5.27)	7.84 (5.30)	6.19 (4.84)	6.46 (4.74)	0.16	.690	0.63	.430
Depression	10.09 (5.00)	9.34 (4.83)	8.58 (4.50)	8.66 (4.32)	0.28	.595	0.44	.510
Think-LC-GAD	3.84 (0.66)	3.94 (0.71)	3.75 (0.64)	3.86 (1.08)	0.40	.527	0.001	.974
Appraisal	3.70 (0.83)	3.88 (0.78)	3.85 (0.93)	3.79 (1.07)	0.09	.759	0.43	.515
Advocating	3.80 (0.80)	3.92 (1.32)	3.36 (0.87)	3.79 (1.29)	1.38	.243	0.45	.505
Coaching	4.25 (0.67)	4.35 (0.67)	4.29 (0.59)	4.13 (1.21)	0.03	.857	0.57	.453
Juggling	3.84 (0.85)	3.84 (1.06)	3.78 (0.76)	3.88 (1.22)	0.06	.812	0.52	.819
Routinising	3.83 (0.81)	3.78 (0.85)	3.50 (0.91)	3.85 (1.13)	0.65	.422	1.07	.304
Task-LC-GAD	3.69 (0.76)	3.58 (0.65)	3.26 (0.62)	3.21 (1.02)	0.22	.637	0.04	.850
Providing transport	3.69 (1.30)	3.53 (1.49)	2.68 (1.47)	3.26 (1.42)	0.49	.486	1.49	.226
Performing dialysis	3.99 (1.22)	3.66 (1.21)	3.75 (0.97)	3.19 (1.30)	3.09	.082	0.21	.648
Personal hygiene	3.08 (1.37)	2.89 (1.34)	2.29 (1.20)	1.61 (1.14)	2.55	.114	0.84	.362
Managing diet	3.79 (0.89)	3.70 (1.07)	3.79 (1.03)	3.67 (1.37)	0.21	.649	0.01	.929
Symptom relief	3.39 (1.07)	3.59 (0.98)	2.75 (1.18)	3.15 (1.43)	1.55	.216	0.16	.693
Comfort measures	4.04 (0.87)	3.94 (0.83)	3.79 (0.96)	3.85 (1.34)	0.01	.925	0.15	.704
Teaching self-care	3.80 (0.93)	3.72 (1.03)	3.63 (0.77)	3.74 (1.36)	0.01	.939	0.19	.660

Table 5 continued

	Assisted PD (patient $n = 89$) (caregiver $n = 72$)		Self-care PD (patient $n = 142$) (family members $n = 39$)		Main effects of PD modality ^a		Interaction effect	
	APD (P: $n = 45$) (C: $n = 40$) Mean (SD)	CAPD (P: $n = 44$) (C: $n = 32$) Mean (SD)	APD (P: $n = 57$) (C: $n = 12$) Mean (SD)	CAPD (P: $n = 85$) (C: $n = 27$) Mean (SD)	F	p value	F	p value
ZBI	29.85 (15.28)	25.09 (14.11)	29.60 (14.51)	26.04 (15.13)	1.78	.185	0.04	.849

QoL quality of life, PD peritoneal dialysis, APD automated peritoneal dialysis, CAPD continuous ambulatory peritoneal dialysis, KDQOL-SF Kidney Disease Quality of Life Short Form, KDCS kidney disease component summary score, PCS physical component summary score, WHOQOL-BREF World Health Organisation Quality of Life Instrument, Short Form, MCS mental component summary score, HADS Hospital Anxiety and Depression Scale, LC-GAD Lay Care-Giving for Adults Receiving Dialysis, ZBI Zarit Burden Interview

^a Main effects of dependency status on patient-reported and caregiver-reported outcomes were not reported in this table as they had previously been reported in Tables 3 and 4

require more intense surveillance and monitoring of care recipient and a range of tasks. In context of PD, the most highly endorsed tasks other than dialysis were providing comfort or coaching the patient. It is also posited that the moderate levels of burden may be due to cultural norms and expectations on a cohesive family unit and filial piety among Asian cultures [44]. The moral obligations for spouses or children, representing the vast majority of caregivers in our study, to care and shelter elderly parents, may explain the low levels of perceived strain. Replications to other settings and with longitudinal design are warranted to investigate responses over time.

PD modality did not differentially affect patient- or caregiver-reported outcomes in assisted or self-care PD, hence suggesting that both CAPD and APD may be well suited for both dependent and self-care patients. This is in line with previous work documenting equivalent QoL, sleep quality and depression across PD modalities [45–47].

Collectively, the cardinal finding in this study was that self-reported patient and caregiver outcomes were largely comparable between assisted and self-care PD. Only physical QoL differed, but this is unlikely to be due to treatment. Therefore, assisted and self-care PD are equally suitable for PD patients without compromising emotional or psychosocial outcomes for patients and caregivers. Study findings indicate that concerns for caregiver burden and QoL should not be a barrier to using assisted PD, adding to prior work on success of assisted PD for survival and peritonitis outcomes [6, 7, 9, 48, 49]. Assisted PD can make PD a viable treatment option for more patients, including those who are not able to self-care or lack confidence in ability to self-administer treatment, without adverse impact on patient or caregiver [50]. This is especially important, given the increasing numbers of ESRD patients and the need to shift dialysis care away from overburdened HD centres and to reduce healthcare costs [51].

Study findings should be viewed with the consideration of several limitations. The cross-sectional design of the study precludes any causal inferences. Course of outcomes over time is also unknown. Secondly, although our overall sample size was large, the numbers across the PD modality by self-care/assisted status subgroups were fairly small, highlighting the need for replication. Responder bias may also be a significant consideration in interpretation of data in any study. There may be bias in the recruitment of family members of self-care PD as despite efforts to expand recruitment, most family members were intercepted at hospital. Patient self-selection bias is also likely as the more emotionally or physically frail patients or caregivers may not have volunteered for the study. Due to data protection procedures, it was not possible to obtain any data on non-responders so as to ascertain how study sample compared to caregivers of patients not included in the study. Related to this, our sample comprised prevalent PD patients/PD survivors (with mean time on dialysis being over 3 years); hence, study participants may have been self-selected for better clinical outcomes such as technique survival or lower burnout for patients and caregivers alike. Questionnaires administered by research assistants may also be subject to social desirability bias compared to self-completed questionnaires. As randomisation across modalities is not possible, comparisons were made controlling for all measured (medical and socio-demographical) case-mix differences, yet the risk residual confounding remains high. The two patient groups are essentially different. Assisted PD serves mainly the non-ambulatory, frail or medical needy patient segments, whereas self-care PD is favoured by younger and healthier patients—hence, the distribution of other unknown confounders may be different. In this context, however, the lack of significant differences in emotional QoL or caregiver burden is particularly compelling.

The strategy adopted in this first comparative study was to be exploratory and generate hypotheses for further

research; hence, primary analyses were uncorrected for multiple comparisons. Replication of analyses using adjusted significance levels confirmed and extended findings of mostly comparable outcomes for patients and caregivers. More work is clearly needed to evaluate the merits of assisted and self-care PD in different settings. Finally, this is a single-centre study that may limit generalisability in other settings although the hospital has the largest PD unit that caters for the majority of PD patient in Singapore. It is of note though that the socio-demographical and clinical profile (i.e. comorbidities) was comparable to the national PD registry data allowing some confidence concerning the generalisability of our findings [1]. 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 generalisability of our observations to other settings or other ethnic populations is unknown and should be explored in future work.

This is the first study to evaluate both caregiver- and patient-reported outcomes between assisted and self-care PD. Despite their worse health profile and more complex health needs, assisted PD patients and their caregivers reported comparable emotional QoL, symptoms of distress and caregiver burden to self-care PD patients and their family members. More work is needed to explore the longitudinal course of outcomes and likely predictors. Focus should also be expanded on issues related to treatment adherence and quality of care, as well as identifying the changing needs and challenges for patients and caregivers over the course of illness with a view of developing effective programs of support to sustain home-based care.

Acknowledgments The study was funded by grants from NUS cross-faculty research Fund and NUS Academic Research Fund (start-up) [FY2007-FRC5-006] and conducted with the help and support of staff of the specialist PD clinics in Singapore General Hospital. The authors would also like to thank all patients, family members and Dr. Tonia Griva for their support for this study.

Compliance with ethical standards

Conflict of interest None to declare.

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