A Longitudinal Study of Burden, Quality of Life and Emotional Distress in Caregivers of Peritoneal Dialysis Patients

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Abstract

Caregivers of Peritoneal Dialysis (PD) Patients may face a high degree of burden and distress as factors such as a strict adherence to treatment for patients and medicalization of the home environment may affect the entire family unit. This is the first longitudinal study examining levels of and factors affecting Burden, Quality of Life and Emotional Distress in caregivers of Singaporean PD patients. Data was collected between 2009-2013 from a sample of 44 caregivers, recruited through outpatient PD clinics in Singapore. Participants completed the World Health Organization Quality of Life Brief (WHOQOL-BREF), Zarit Burden Interview (ZBI) and the Lay Care-giving for Adults Receiving Dialysis (LC-GAD). Additionally, participants also completed Hospital Anxiety and Depression scale (HADS) at followup. Longitudinally, an increase caregiver burden was documented, along with increasing QOL impairments in psychological health. Overall QOL levels were found to be below general population norms. Additionally, high-burden caregivers were found to have a moderate degree of depression and anxiety. PD regimes offer flexibility and autonomy for patients, but may result in increasing caregiver burden over time. Further research is needed to explore how ways of intervention to address psychosocial needs in the PD caregiver population.

Introduction

Peritoneal Dialysis (PD) has seen much evidence supporting its utility in improving clinical and psychological outcomes and there is an increasing adoption of PD following a response to a call to action for the "PD First" policy. However, the treatment regime is strict and requires a change in behavior to ensure adherence. The requirement for adherence to treatment has been documented to affect the entire family environment along with their caregivers. With time elapsed, psychological and physical problems that patients face may change and develop.

However, it is currently not completely clear how these problems affect caregivers. In addition, PD is a home-based therapy that provides patients with independence from treatment centers. The convenience would mean that more elderly patients would be established on the dialysis modality. Elderly patients have greater co-morbid diseases and would in turn require greater caregiver involvement. Furthermore, patients typically require caregivers to ensure a sterile fluid exchange during PD. A "medicalization" of a PD patient's home would also demand substantial attention from caregivers to the logistical arrangements of the medical supplies.

Overall, PD has the potential to negatively affect caregivers, but studies on outcomes for caregivers of PD patients are scarce. Existing studies document various degrees of caregiver burden and impairment in quality of life and there is a lack of consistency in documented results

Methods (1/2)

Participants

This is a longitudinal study in which a baseline sample of PD caregivers was reassessed after 12 months using the same instruments. Participants were recruited from the PD Center, Singapore General Hospital. The Center caters for the majority of PD patients in Singapore.

Sociodemographic information including age, ethnicity, education, marital and work status and perceived ability to work, income and living arrangements were collected using a self-report questionnaire.

The breadth and quantity of caregiver activities were measured with the Lay Care-Giving for Adults Receiving Dialysis (LC-GAD). The scale is separated into two components; the first systematically measures the abstract and cognitive work of caregiving (THINK) through subscales of appraisal, advocating, coaching, juggling, routinizing.

Methods (2/2)

The second component measures concrete tasks of caregiving (TASK) which includes providing transportation, performing dialysis, personal hygiene, diet, symptom relief, comfort measures and teaching self-care subscales. Higher scores in the scales suggest a higher frequency with which specific caregiving activities are undertaken. LC-GADS were empirically validated and showed positive correlations between caregivers and the perceived burden of caregiving and self-reported self-care abilities.

To reflect the stresses experienced by caregivers, the Zarit Burden Interview (ZBI) was utilized. Caregivers are asked to respond to a series of 22 questions about the impact of the patient's disease on their life. Each item elicits the caregiver's response on a 5-point scale, ranging from 0 (Never) to 4 (Nearly Always). Total scores are then classified into 4 categories of severity (see Table 4). The scale has been widely used as a measure of caregiver burden and has been empirically validated.

QOL was evaluated with the World Health Organization Quality of Life Instrument, Short Form (WHOQOL-BREF). The mean of the first two items indicates patients' overall QOL/health, ranging from 1 to 5. The rest 24 items measure patients' QOL in four domains: physical health, psychological health, social relations, and environment. All domain scores range from 4 to 20, with higher scores indicating better QOL.

In addition to the ZBI, clinical instruments such as measures of depression have been suggested as a supplement.

Symptoms of depression and anxiety were assessed with The Hospital Anxiety and Depression Scale (HADS. The HADS has been shown to have good psychometric properties and discriminatory value for anxiety and depressive disorders in various health settings and in the general population.

Results (2/2)

More than half of the caregivers were employed full time whereas previous work has been based mainly on vis-à-vis caregivers that typically are the next-of-kin. This may be understood in the context of the dual-income household climate in Singapore along with the subsequent high employment rate of domestic helpers

ANOVA comparisons indicated that caregiver activites (LC-GAD scores) remained largely undifferentiated over time, with the exception of *Teaching Self-Care* that increased significantly over the 12 months (p = 0.007)

Perceptions of burden also increased over time (p = 0+) (see Table 2) with means scores at baseline being in range of mild to moderate burden and increasing to moderate and severe burden 12 months later.

Results (2/3)

Study variables	Baseline	Follow-up	p-value
LC-GAD			
Appraisal	39.04±5.98	40.11±5.83	0.398
Advocating	27.43±3.94	27.99±3.90	0.505
Coaching	18.05±2.86	18.68±1.88	0.225
Juggling	12.25±1.25	12.65±1.20	0.129
Routinizing	17.13±2.02	17.96±2.15	0.065
Providing Transportation	6.96±0.85	7.01±0.85	0.783
Performing Dialysis	6.24±1.24	5.73±1.33	0.066
Personal hygiene	3.44±0.44	3.55±0.29	0.169
Diet	3.07±0.87	3.14±0.84	0.702
Symptom Relief	7.83±1.14	7.69±1.49	0.621
Comfort Measures	9.22±1.06	9.66±1.60	0.132
Teaching Self-Care	4.44±1.17	5.10±1.08	0.007 *
ZBI			
Total ZBI Score	36.15±5.55	41.39±5.44	0+ *

data expressed **as M ± SD)**

Observed QOL levels at baseline and follow-up were significantly lower than a comparative Singaporean Study (p = 0.03),suggesting QOL impairments in the caregiver group. The only significant change in QOL was in psychological health with mean scores decreasing over time (indicative of QOL decline) (p = 0.011). All other QOL scores remianed unchanged across the 12 months.Mean depression levels howver were in the normal range of depression and anxiety (HADS depression/anxiety 0-7).

Study variables	Baseline	Follow-up	p-value
WHOQOL			
Overall	3.88±0.78	3.81±0.83	0.684
Physical health	17.43±3.94	17.99±3.33	0.473
Psychological health	17.05±3.86	15.18±2.88	0.011 *
Social Relations	14.33±2.33	14.65±2.20	0.509
Environment	14.99±2.98	14.55±2.15	0.429
HADS			
Anxiety	NIL	5.13±1.53	NIL
Depression	NIL	6.55±2.55	NIL

Results (3/3)

The mean ZBI score at follow-up was 41.39 ± 5.44. To further explore the An understanding of the relationship between caregiver burden and emotional distress/QOL may be achieved by dividing the population into "high-burden caregivers" (defined as scores greater than or equal to the mean) or "low-burden caregivers" (defined as those with scores less than mean). The following table compares the mean QOL and HADS scores of high and low-burden caregivers. The results reveal that high-burden caregivers have significantly lower scores for psychological health (p = 0+) and higher scores for anxiety and depression (p = 0+ & p = 0.01).

Burden Severity	Baseline (n = 44)		1 year Follow-up (n =44)	
	n	%	n	%
Little or no Burden [0-20]	4	9%	0	0
Mild to Moderate Burden [21-40]	34	77%	3 / 2	72%
Moderate to Severe Burden [41-60]	6	13%	1 / 2	28%
Severe Burden [61 – 88]	0	0	0	0

Conclusion

Overall, the findings indicate an increase in caregiver burden over the 1-year period and the need for mental health support for the caregivers. The results of this study raise pertinent questions on the findings that caregivers report greater burden, poorer psychological health and emotional distress. This suggests that along with the increasing advocacy for PD today, future complementary research has to be conducted on identifying and targeting areas for intervention for caregivers.

References

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