Quality of life of caregivers and patients on peritoneal dialysis

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Abstract

Peritoneal dialysis is the archetypal home-based therapy and is often favoured by patients. However, as patients with end-stage renal failure become more elderly with greater co-morbidity, their dependence on carers to provide physical, emotional and logistical support increases. The effect of this chronic burden has not been systematically studied. We have prospectively studied patients with end-stage renal failure starting peritoneal dialysis and their carers over a 1-year period.

We selected a cohort of caregivers that are actively involved with the care of their partners’ dialysis. Quality of Life (QoL) assessed by SF-36 questionnaires showed the patients and carers had impairment of QoL at the start of dialysis. As expected, the baseline QoL Physical Component Scores highly correlated with co-morbidity and assessment of functional capacity. Scores of all QoL domains improved after 1 year and this reached statistical significance for social functioning for both patients and carers. When we compared carers of highly dependent patients (required to perform daily dialysis) with carers of less dependent patients, we noted that the former had a statistically significant worsening of their mental health but other parameters were not different.

We have shown that despite increasing the burden for caregivers, with careful selection, education and support, we did not adversely impact on the QoL of carers whilst there was some evidence of improvement, especially in social functioning. This gives reassurance that establishing dependent patients on PD is compatible with a holistic approach to the patients and their families.

Keywords: CAPD; caregivers; peritoneal dialysis; quality of life; SF-36

Introduction

Peritoneal dialysis (PD) is a form of dialysis treatment utilized by approximately 15% of patients with end-stage renal failure (ESRF) worldwide. As opposed to the more commonly used haemodialysis (HD) treatment, PD is a home-based therapy that allows the patient to regain greater independence from the hospital and treatment centres. Increasingly the incident patients established on dialysis are more elderly, have greater co-morbidity (especially increased proportion of diabetics) and are more dependent on caregivers, who are often spouses or other family members.

For successful PD, a sterile technique is critical to reduce infections (peritonitis). Often, patients depend on carers to perform the daily exchanges of continuous ambulatory peritoneal dialysis (CAPD) or to connect onto, disconnect from and troubleshoot problems with an automated peritoneal dialysis (APD) machine. The patients and carers also have to manage fluid balance through daily assessment and adjustment of their dialysis. Homes may also have to be adapted to accommodate the supplies required for PD. Attention to stock-take of supplies, arranging and receiving fortnightly or monthly deliveries are also integral to successful PD. It is easy to imagine that in many cases, the home environment is often ‘medicalized’, with family members becoming the main carers, burdened with many duties related to PD. These also include helping with the physical aspects of moving heavy boxes of dialysis fluids and disposing of waste drain-out bags.

PD has the potential to dramatically affect the lives of carers but the effect of this extra burden has been rarely studied in great detail. We have conducted a study to examine the changes in quality of life of patients and partners assessed by the SF-36 questionnaire [1].

Methods

The study was performed in accordance with the Ethics Committee guidelines as set out by the East London and The City Health Authority.

Patients starting PD at Barts and The London Hospital NHS Trust between June 2003 and June 2006 were considered for this study. Our PD programme consisted of approximately 250 patients at any one time.

Clinical data, including co-morbidity data submitted to the Renal Registry, United Kingdom [2], were collected from our quarterly updated detailed computerized records and review of patient medical and nursing notes. Co-morbid conditions collected included history of angina, myocardial
infarction within the previous 3 months, myocardial infarction more than 3 months ago, cerebrovascular disease, diabetes (not causing established renal failure), chronic obstructive pulmonary disease, malignancy (excluding basal cell carcinoma), current claudication, smoking (current or history of smoking within the previous year) and angioplasty/stenting/vascular grafts (all non-coronary). This Renal Registry score has been used to compare co-morbidity between PD patients in a number of published clinical studies [3,4]. Functional Karnofsky performance scores were made during clinic appointments. Patients were also asked if they performed the dialysis independently of their partner or if their carer was required on a daily basis to help with the dialysis.

Prior to starting PD, patients were introduced to our multi-disciplinary team comprising nurses, clinicians, social worker, dietician, psychologist and home care manager. Patients attended individualized PD training programme and we also encouraged partners who were interested or who were closely involved with the care of the patients to attend this 3–5 day’ PD training course. During the PD training, they were taught how to perform the dialysis procedure, how to care for the PD catheter exit site and how to assess fluid status and to adjust dialysis accordingly. Patients requiring subcutaneous injections of erythropoietin stimulating agents were encouraged to self-administer or the partners were taught how to inject. The patients and partners attending were also taught how to order, store and safely dispose of the dialysis consumables (dialysate fluids, lines, dressing, needles and syringes).

The Medical Outcomes Study 36-Item Short Form Survey (SF-36) questionnaires were given to patients and partners attending the pre-PD training course or during their initial PD clinic. They were subsequently given to patients and partners to complete when they attended at their routine PD clinic appointments ~1 year later. The patients and partners were encouraged to complete and return the questionnaires on the day, although a small minority chose to post the questionnaires back to the PD unit or returned them at their next visit. To minimize the risk of coercion, no reminders were sent to patients or partners who did not return completed questionnaires. The questionnaire was only available in English. The SF-36 scores for eight domains: Physical Functioning (PF), Physical Role (PR), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Emotional Role (EM) and Mental Health (MH). In addition, summary scores are calculated for physical (PCS) and mental (MCS) components. The results were expressed with the norm-based scoring such that a normal US population would score a mean of 50 (SD 10) for each domain.

**Statistics**

Paired and unpaired *t*-tests were used to calculate differences between mean values within and between groups (patients versus carers). Pearson’s correlation coefficients were calculated to assess correlation between variables of interest. *P* of 0.05 was considered the level of significance.

**Results**

**Subjects**

Between the study period of June 2003 and June 2006, 240 new patients started PD. During this time, that 112 pairs of patients and carers completed and returned a SF-36 questionnaire within 3 months of starting dialysis (Figure 1). There were 36 pairs of patients and carers (Group A) who attended the clinic 1 year later and who completed a follow-up questionnaire. There were nine patients (Group B) who completed the follow-up questionnaire but whose partners did not. The likeliest reason was that the partner did not accompany the patient to the follow-up clinic (in support of this hypothesis is that these patients had the lowest co-morbidity scores, highest Karnofsky score and none needed the partner to perform dialysis—see the next section). These nine patients were excluded from final analysis because we wished to study only patients and carers who jointly managed the PD. Of the remaining 68 pairs of patients and carers who did not complete a follow-up questionnaire, 20 patients were transferred to HD within 18 months of starting PD, 6 were transplanted and 8 died (Group D). However, 34 were still on PD, but they declined to participate in the repeat survey (Group C). Not all 34 patients would have had carers actively involved in their PD. Nevertheless, successful return of both completed questionnaires occurred in only 36 of a total 79 possible pairs of patients and partners.

Of the 36 patients and partners returning completed questionnaires in accordance with protocol, there were 12 highly dependent patients who could not perform their own daily dialysis without help from their carers.

**Baseline QoL and co-morbidity for patients and carers**

The baseline QoL scores for Mental and Physical Component Summaries for all groups of patients are given in Table 1. There were no statistically significant differences in the QoL scores between the patients or carers in the four groups. There were also no differences in the Karnofsky or co-morbid scores between the Group A and Group C patients (Table 2). The lower co-morbidity in the patients who were transplanted (Group D-TP) and higher co-morbidity and greater dependence on carers of the patients who subsequently developed PD technique failure within 18 months (Group D-non-TP) was expected.

**Table 1. Baseline scores for Groups A–D (mean and SEM values are given)**

<table>
<thead>
<tr>
<th>Group</th>
<th>Patients</th>
<th></th>
<th>Partners</th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>PCS</td>
<td>MCS</td>
<td>PCS</td>
<td>MCS</td>
</tr>
<tr>
<td>A</td>
<td>36</td>
<td>31.5 (1.5)</td>
<td>35.9 (2.1)</td>
<td>48.5 (2.3)</td>
</tr>
<tr>
<td>B</td>
<td>3</td>
<td>35.2 (3.6)</td>
<td>32.4 (5.4)</td>
<td>47.7 (3.2)</td>
</tr>
<tr>
<td>C</td>
<td>34</td>
<td>36.2 (1.9)</td>
<td>37.7 (2.5)</td>
<td>46.5 (1.9)</td>
</tr>
<tr>
<td>D</td>
<td>34</td>
<td>31.7 (1.3)</td>
<td>37.3 (2.2)</td>
<td>47.7 (2.3)</td>
</tr>
</tbody>
</table>

No statistically significant differences were found between the groups.
QoL in peritoneal dialysis

Because the aim of this study is to examine the longitudinal changes in QoL scores, further results are restricted to Group A patients.

**Group A: QoL of patients and relationship with co-morbidity/Karnofsky score**

For all domains, SF-36 scores of patients starting PD were substantially below norm (Figure 2). The lowest scores were seen for Physical Functioning, Role Physical, Social Functioning and Emotional Role. The overall score for the Physical Component Summary (31.2 ± 1.5) was lower than for the Mental Component Summary (35.9 ± 2.1, P = 0.05)

There were statistically significant correlations between some domains and the patients’ co-morbidity and Karnofsky performance score. These are listed in Table 3. Most striking was the fact that there was a statistically significant correlation between the Physical Component Summary and co-morbidity and Karnofsky but Mental Component Summary did not correlate with these parameters (Figure 2).
Fig. 2. Baseline QoL scores for patients and carers. A score of 50 (line) represents normality for general US population. PF = Physical Functioning, RP = Physical Role limitation, BP = Bodily Pain, GH = General Health, VT = Vitality, SF = Social Functioning, RE = Emotional Role limitation, MH = Mental Health, PCS = Physical Component Score, MCS = Mental Component Score.

Fig. 3. Correlation of the baseline QoL summary score (PCS = Physical Component Score, MCS = Mental Component Score) with co-morbidity and functional capacity (Karnofsky score). (A) and (C) represent correlation of Patients. (B) and (D) represents correlation of Carers.
### Table 3. Correlation between QoL domains and co-morbidity or functional status (Karnofsky) of Group A patients

<table>
<thead>
<tr>
<th></th>
<th>Regression analysis with co-morbidity score</th>
<th>Regression analysis with Karnofsky score</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>$R^2$</td>
<td>$P$</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>0.17</td>
<td>0.02</td>
</tr>
<tr>
<td>Role Physical</td>
<td>0.10</td>
<td>0.08</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>0.06</td>
<td>0.16</td>
</tr>
<tr>
<td>General Health</td>
<td>0.04</td>
<td>0.24</td>
</tr>
<tr>
<td>Vitality</td>
<td>0.01</td>
<td>0.54</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>0.02</td>
<td>0.39</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>0.01</td>
<td>0.67</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0.18</td>
<td>0.01</td>
</tr>
<tr>
<td>Physical Component Score</td>
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<td>1</td>
</tr>
<tr>
<td>Mental Component Score</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**Group A: baseline QoL scores for carers**

The carers’ baseline QoL scores are shown in Figure 2. In all domains, the carer’s QoL was better than that achieved by the patients. As expected, this was most marked for the physical domains (Physical Functioning, Role Physical, Bodily Pain, General Health) and hence the summary PCS score. Although statistically significantly better for Vitality, Social Functioning and Emotional Health, statistical significance was not reached for Mental Health.

There were no correlations between the QoL of the carers’ and partners’ QoL for any domain. Scatter plots of the patients’ and carers’ summary scores (PCS and MCS) are shown in Figure 4.

**Changes in patients’ and carers’ QoL over 1 year**

Figure 5 shows the changes in QoL domains over the study period (mean 48 weeks). There was statistically significant improvement in social functioning domain for both the patient and the carers. There were no other statistically discernable changes in their QoL.

We also compared the changes in the QoL of carers that performed daily exchanges with carers of less dependent patients. We found that there were no statistically significant differences except in a single domain: Mental Health (Figure 6). Although the co-morbidity scores of the patients cared for by these two groups of carers were similar ($1 \pm 0.4$ versus $1.4 \pm 0.4$, $P = \text{ns}$), there was a significant difference in their functional performance (Karnofsky score: $77 \pm 4$ versus $49 \pm 8$, $P < 0.002$).

**Discussion**

When possible, home-based care for patients with chronic illnesses are generally considered best for patients. Care at home can improve the level of rehabilitation, eliminate travel time to hospitals and reduce the risk of cross-infections. However, we may be increasing the burden on family members who have to contribute to the patients’ care. This is particularly true for patients on peritoneal dialysis. Partners are often required to help with physical aspects of moving large volumes of dialysis fluids and the technical aspects of performing dialysis exchanges using sterile techniques. In some cases, they are also needed to make clinical decisions on how to adjust dialysis prescriptions to achieve euvolaemia. PD units are therefore set up to provide multi-disciplinary support from in-house doctors, nurses, dieticians, psychologists and social workers, for patients and their family. We also employed a home care manager to liaise with local government agencies and help coordinate holiday supplies. It is extremely reassuring that our study shows that with our level of support, despite the responsibility and burden placed on carers of successful PD patients, there was no negative impact on their quality of life. In fact, we found that despite the dependence of the patients on the carers, the latter’s social functioning improved, as did the patients’.

Nevertheless, we must continue to carefully select and support patients and their families. We found that the Mental Health domain scores worsened in carers with most dependent patients (Figure 5). But we cannot necessarily attribute this to the need to provide care. These partners may suffer similar or greater decrements in their MH if their highly dependent partners underwent hospital-based haemodialysis.

Our study is the first to prospectively examine the impact of domiciliary dialysis on the patient’s family. We
deliberately restricted our study to patients and carers who
shared the dialysis care (assessed by their joint attendance
during the week of dialysis training or subsequent dialysis
clinics). This encompassed a range of patient dependence
and allowed us to sub-divide the carers into those that did
or did not need to perform daily dialysis for the patients.

SF-36 is a widely used and validated questionnaire for
assessing QoL in populations including patients with ESRF
[5]. Although there are disease-specific versions of health-
related QoL questionnaires [6,7], they have not been uni-
versally adopted for studies of patients on dialysis. Disease
specific QoL questionnaires are more sensitive in detecting
differences in domains that have been targeted as ‘dialysis-
related’. But the relative importance of the ESRD domains
(Bodily Pain, Travel, Diet Restriction and Dialysis Access)
over the generic domains (Physical Functioning, Vitality
and Mental Health) is unclear.

We considered how to assess QoL of caregivers. In a
study of caregivers of patients with dementia, QoL was
assessed through individual interviews with the investigator
scoring for health, social and family life, paid employment
and stress. There are, however, few questionnaires designed
and validated specifically for caregivers; The Alzheimer’s
Carers’ Quality of Life Instrument by Galen Research is
a rare exception but this has not been used for caregivers
of patients with renal failure. Thus, we decided to apply
the same generic SF-36 questionnaire for both the patient
and carer to simplify the conduct of the study. The SF-36
is available in several languages including Bengali, which
is the most common language of patients who do not speak
English at this unit. However, failure to communicate in
English for out-of-hours emergencies is a relative contra-
indication for home-based dialysis, and in the main, carers
are conversant in English. Therefore, the demand for the
translator was very low and the SF-36 is not validated under
such conditions.

Our results are in keeping with other studies of QoL in
PD patients. Incident PD patients in the Netherlands have
reduced scores for all domains of QoL compared with gen-
eral population [8]. Moreover, other studies have suggested
that over time, for these patients, physical health deterio-
rated faster than mental health [9,10].

There are also studies comparing QoL of patients un-
dergoing different dialysis modalities (HD versus PD).
However, QoL scores from HD and PD patients must be in-
terpreted with caution, as there are differences in case mix.
Therefore, propensity score analyses can be performed,
whereby patients are given a score that represents their
expected probability of receiving HD versus PD. QoL re-
results can then be compared between patients who have a
similar propensity to receive a particular treatment [11]. U-
sing this method of analysis, patients on PD had statistically
better generic QoL scores for BP, MH and SF at the start
of dialysis and consistently scored better after 1 year.
Disease-specific scores showed similar trends favouring PD with significantly better disease effect on daily life, burden of disease, dialysis staff encouragement and satisfaction with dialysis care scores at 1 year [12]. However, not all studies agree. The NECOSAD group suggested that in Dutch dialysis patients, the physical component scores declined more rapidly in PD patients although they started with significantly higher QoL [10]. Meanwhile the CHOICE group [7] (that studied US patients) and the UK North Thames Dialysis Study [13] failed to demonstrate substantial differences between the two dialysis modalities.

A cross-sectional study of dialysis patients and family caregivers has been conducted in Brazil [14]. Carers of elderly PD patients showed worse scores in several domains compared with the carers of non-elderly and elderly HD patients including PF, VT and SF. However, there were important and significant differences in the sociodemographic characteristics between the patients and carers of elderly HD and PD patients. The elderly PD patients also had lower functional capacity, as judged by statistically significantly lower Karnofsky scores and greater incidence of diabetes mellitus. Therefore, it is difficult in this Brazilian study to determine that having to give PD care caused the decline in the caregivers’ QoL. Nor did their study examine longitudinal changes in QoL of the carers.

A significant limitation of our study was the large number of pairs of patients and carers who completed the initial SF-36 questionnaire but who did not complete the follow-up questionnaire (Groups B, C and D). This might have biased our findings but it is extremely difficult to design a study to examine changes in QoL without the risk of bias. By attempting to capture all incident patients, we risked a high dropout rate. But, any effort to chase/coerce patients to complete the questionnaires would invalidate results. However, the alternative is to selectively recruit compliant patients, but this strategy is equally flawed for obvious reasons. Nevertheless, it is important to note that the baseline QoL scores for the patients and carers in the ‘dropout’ group (C) did not differ significantly from the scores from patients and carers who provided longitudinal data (Group A). This suggests that our results can be generalized to dependent patients who survive on PD. It is also possible that the carers of patients who ‘failed’ PD (died or transferred to HD) experienced decline in QoL. A study of the impact of PD on caregivers of these ‘high-risk’ patients needs to be performed separately.

If we wish to examine the impact of delivering home care on caregivers, we could study differential changes of HD versus PD carers’ QoL. But patient selection will bias such a study, unless they are randomized to dialysis modality. It is extremely difficult to perform such a study as evidenced by the attempt by NECOSAD [15]. Thus, although imperfect, our study suggests that PD can be a good choice for dependent patients. The impact on carers of these patients must be carefully considered, but with careful selection and support, is not necessarily negative. In fact, somewhat counter-intuitively, the social functioning of carers increased despite their increased responsibilities and the reliance of the patients to perform daily dialysis.

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References


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