

In-Depth Clinical Review

The impact of end-stage kidney disease (ESKD) on close persons: a literature review

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Keywords: caregiving/caring; end of life care; end-stage kidney disease; review

Introduction

Kidney disease is defined as end-stage when a patient's glomerular filtration rate has fallen to <15 ml/min/1.73 m² [1]. Mortality associated with end-stage kidney disease (ESKD) is high [2]. The incidence of treated ESKD is rising in the western world, with a corresponding increase in the incidence of diabetes and cardiovascular disease, especially in ethnic minority groups. Survival on dialysis has been shown to be poorer in the older age group, especially in patients with increased comorbidity and in those whose functional status at the start of dialysis is poor [3]. Whilst renal transplant rates vary between different countries [4], the liberalization in the acceptance of older people into renal replacement therapy (RRT) programmes, together with changes in population demographics and the fact that kidney transplantation is less suitable for this group of older patients, means that dialysis may be the only treatment option available for an increasing number of patients aged 65 years and over [5]. Recent health policy changes in the OECD countries [6,7] acknowledge that end of life care may be more appropriate for some of these people, and maximum conservative management programmes (where residual renal function is supported, haemoglobin levels maintained and symptoms relieved) have been introduced into many renal units, particularly in the United Kingdom [6].

The onset of ESKD and subsequent recommendation of dialysis as a treatment option involves a change in lifestyle for both patients and close persons [8]. Even before end-stage disease is reached, as renal function deteriorates,

patients frequently require additional support, and it is often family members who provide this [9]. In the UK it is estimated that 9 out of 10 carers of patients with either physical or neurological disabilities will be close relatives. In particular when home haemodialysis is undertaken, family members have been involved in supporting patients [10,11]. Studies have shown that good family support is associated with successful adaptation to dialysis and compliance with dietary restrictions [12,13]. Conversely, one of the main factors associated with patients discontinuing dialysis is patients' perception that they have become a 'burden' to close family members [14]. There is therefore a need for health professionals to be aware of the important contribution that close persons make to the care of renal patients, to communicate effectively with them and to provide bereavement support for this group when appropriate [15].

The literature on close persons of patients with renal disease has identified two main areas of impact. Firstly, both haemodialysis and peritoneal dialysis may have a disruptive influence on family members' social lives [16] and the structure of the week may be geared towards dialysis sessions. Secondly, some patients become frail and lose functional independence, leaving family members to provide greater physical support. Family members may have health and social care needs of their own that need to be addressed [16,17]. Qyinan [18] reported that close persons commonly felt overwhelmed and stressed, although this review was limited to an evidence base of four articles and considered home dialysis only. Campbell [19] used findings from the general carer literature to illustrate demands of ageing partners with ESKD. In other chronic illnesses such as stroke [20] or in palliative care for cancer and mental health [21], interventions aimed at providing family members with training to support patients with their rehabilitation, or to address unmet needs as a result of the patient's illness, have been developed and evaluated. Results have been mixed. In the case of stroke, carers in the intervention group experienced less depression and anxiety and better quality of life [20], whilst in the palliative care study, no statistically significant differences were found between the intervention and control group on carers' psychological outcomes [21]. However, before such interventions can be

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developed in ESKD, it is important to understand better the emotional and physical needs of close persons.

This review aims to identify all studies involving close persons caring for ESKD patients, to describe the main findings and critique the methodology. Specific attention has been paid to (a) studies exploring the impact of ESKD on close persons, in particular for those close persons where the patients are either withdrawing from dialysis or being provided with end of life care and (b) studies looking at the provision of health care for close persons.

Methodology

Search strategies

A literature search for relevant articles was conducted in five databases: Medline (1950–2006), Embase (1991–2006), CINAHL (1982–2006), PsycINFO (1970–2006) and AMED (1985–2006), employing the following key words: *carers, caregivers, end-stage kidney disease, end-stage renal disease, haemodialysis, peritoneal dialysis and renal replacement therapy*. These keywords were used both in word search options and exploded as thesaurus terms to obtain the maximum number of articles. The abstracts for each article were read to check for inclusion into the main review, using the following criteria:

- (1) Published in peer-reviewed journals.
- (2) Research studies with an introduction, a methodology and results section and a conclusion.
- (3) Involve close persons, defined as either a family member or the person identified by the patient as an informal carer. By an informal carer, we mean a person who provides the majority of a patient's physical and emotional care needs and who is neither a volunteer nor in the employment of statutory services.
- (4) Use a sample of close persons caring for adult ESKD patients (over 18 years).
- (5) Non-English language articles were considered if the English translation of the abstract met the above criteria.

Using these criteria, 334 articles were identified from the five databases (139 in Medline, 121 in Embase, 80 in CINAHL, 8 in AMED and 34 in PsycINFO). J.L. went through the abstracts of each of the 382 articles, of which 37 initially met the inclusion criteria. One was later excluded on closer inspection, as it was specifically a validation study of a fatigue severity scale. Of the remaining 36 studies, 16 exclusively looked at family members, 12 specifically at the patient-family dyad and 3 at the family-health professional dyad. Whilst the latter two types of studies did not concentrate solely on family concerns, we decided to include them in the analysis, because these findings further contribute to the limited number of studies in this field. Thirty-six studies were included in the review.

Both J.L. and G.S. first went through the remaining 36 studies independently and extracted the following information for each study: the number of carers in the study sample, the RRT population they were caring for, authors' definition of a carer, demographic details of the sample, patients' dialysis history, caring history, study design,

outcome measures used and main findings. J.L. and G.S. then met together to discuss these findings and obtain an initial consensus before meeting with A.B. and L.J. to obtain a final consensus.

Results

Initial exploration of the 36 reviewed studies

We undertook an exploration of the aims of these studies, their study design, the sample of participants and the outcome measures highlighted in the quantitative studies.

Main aims of the reviewed studies. The three main themes explored were (a) the impact of caring for a patient with ESKD on dialysis on close persons, in particular quality of life, psychological morbidity, close person responsibilities—which authors often referred to as 'burden' or 'carer burden'—and their life situation; (b) the coping strategies employed by these close persons and (c) factors that influence psychological morbidity. No studies of health provision for close persons of patients with ESKD were identified.

Four studies looking at end of life issues explored the following themes for close persons: (a) their perceptions of patients' terminal symptoms; (b) their reasons for why patients decided to stop dialysis; (c) the long-term impact of patient death following dialysis cessation and (d) their perceptions of advance directives. End of life care may be provided by the renal multi-disciplinary team alone, or it may involve referral for specialist palliative care advice. Such advice is likely to include symptom control, attention to spiritual and psychological issues for patients and, where possible, involvement of their families in decision-making.

Whilst most studies were interested in the direct impact on close persons only, one triangulated close person data with patient data.

Study designs. The majority of studies reviewed used a cross-sectional design; there was only one longitudinal study. Whilst most were quantitative (24/36), there were some qualitative studies (11/36) and one used a mixed methods approach.

Sample. The total sample was predominantly female, with mean ages ranging from 41 to 68 years (analysis possible in only 18 studies). Sample sizes also tended to be small, with a median sample of 55 participants for the quantitative and 15 participants for the qualitative studies.

Most of the sample was recruited in studies where associated patients were undergoing haemodialysis or peritoneal dialysis. Three studies also involved kidney transplant patients. Only five studies looked at close persons dealing with end of life issues or with patients withdrawing from dialysis. Many studies did not focus on close persons in their potential role as 'informal carers'. Thirteen studies actively sought close persons who also considered themselves to be informal carers, of which eight provided full definitions of what they meant by this term.

All studies included spouses as part of their sample, of which eight specifically concentrated on this group alone. Adult children were included in seven of these studies and parents in five.

Outcome measures (quantitative studies). A wide variety of outcome measures were used to rate health-related quality of life, anxiety, depression, coping strategies and patient disease severity. Some studies used standardized outcome measures; others used simple self-rated tools.

The most commonly used standardized measures were the Zarit Burden Interview [22] to evaluate the sense of carer responsibility (3/8), the Beck Depression Scale [23] to evaluate depression (2/5), SF-36 [24] to evaluate health-related quality of life (3/8), Jalowiec Coping Scale [25] to evaluate close persons' use of coping strategies (3/3) and End-Stage Renal Disease Severity Index [26] to evaluate patients' disease severity (2/4).

Country of origin. A breakdown of the country of origin for each study showed that over half originated from either the USA (11/36) or Canada (7/36), with five originating from Australia and only seven from the European Union, of which only one was conducted in the UK. The remaining six studies came from the following countries: Japan (2/36), Brazil (2/36), China (1/36) and Turkey (1/36).

Main findings

The 36 studies have shown mixed results. They have mainly explored the following areas associated with caring for an ESKD patient: the impact on close persons and their social life and the factors affecting close persons' psychological health. There have been very few studies looking at palliative care issues and these have primarily concentrated on dealing with end of life issues rather than the provision of supportive care in the pre-terminal phase.

Family life (Tables 1 and 2). In only one study, close persons rated their quality of life as excellent and reported few pressures resulting from their carer responsibilities [27], whilst in all others, ESKD and dialysis were shown to increase the close person's sense of responsibility and lead to a poorer quality of life when compared with age-matched controls [28]. Close persons found living with an ESKD patient on dialysis stressful [29] and experienced increased fatigue [30]. The dominating effect of caring for an ESKD patient often led close persons to neglect their own health. For those who took time to have a break from their carer responsibilities, there were health benefits [31]. Other issues that close persons reported included isolation through the loss of social activity [30–36], life restrictions [36–38], increased workload, negative economic consequences [39,40], changed relationship with the patient [30,34] and sexual problems for spouses [41].

The treatment modality may also have an impact on family members. Studies have highlighted that spouses of transplant patients were more assertive, self-sufficient and able to handle the physical, social and existential aspects of the illness better than dialysis spouses [33,42]. Despite these pressures, close persons recognized that they play

a positive role in promoting patients' well-being [11,43]. They recognized that health care professionals were important in providing support to discuss their problems [39] and would like to have more information about the care being provided to patients [44]. However, they also reported poor communication with professionals, felt that their needs were not always addressed [30,39,45] and felt themselves uneducated and poorly equipped to deal with the regimented lifestyle associated with the dialysis regimen [14].

Caring and psychological Health (Table 3). Whilst some studies have shown that close persons display few signs of psychological distress [40,46–49], others have identified the following:

- (1) A negative association between close persons' psychological health and their sense of carer responsibility [28,46,50,51], their use of emotionally focused coping strategies (i.e. strategies that reduce the symptoms of stress without addressing the source of the stress) [33,52], the close person's age [53] and the social [40] and financial changes [40,54] imposed as a result of ESKD onset.
- (2) A positive association between good mental health and the following factors: low marital strain [55,56], a lack of perceived intrusiveness of dialysis [56], the type of dialysis patients are on [57], availability of social support [40,46,49] and reduced sense of carer responsibility [46].
- (3) The sense of carer responsibilities are lower if patients are independent in activities of daily living (ADL) [48], have less severe dialysis-linked complaints [41] or lower comorbidity [29,50]. This was further emphasized in studies in patients receiving home haemodialysis or awaiting transplant [33,47,48] where close persons not experiencing anxiety or depression [47] felt less troubled by their carer responsibility [48] and had a comparable quality of life to the age-matched population [33]. Further associations were found between higher levels of responsibility and other outcomes such as quality of life [27] and neuroticism [51].
- (4) The use of emotionally focused coping was found to have a negative correlation with marital adjustment, but a positive correlation with the number of years on dialysis [54].
- (5) Close persons were more likely to have negative feelings towards patients if they had no prior experience of the dialysis process and had a high level of involvement with the caring process whilst living in a rural environment [53].

End of life and end-stage kidney disease (Table 4). We identified five studies that explored end of life issues, but only one focused specifically on close persons. This study examined the long-term impact of death occurring on families when dialysis was discontinued. It found that most families felt that patients had a good death (defined as dying at home, pain free and with close people present) and most family members showed only low levels of distress. However, principal carers and spouses, i.e. those

Table 1. Impact on family life (quantitative and mixed methods studies)

| Authors | No. of carers | Population involved in the study | Carer definition | Demographic details (1) mean age (years) (2) female (%) (3) spouses (%) (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) | Country of origin | Study design | Outcomes (carer) (a) 'burden' (b) disruptions to daily life (c) family adjustment (d) quality of life (e) psychological (f) patient-related (g) miscellaneous | Main findings |
|------------------------------|---------------|---|---|--|-------------------|--|--|--|
| Devins <i>et al.</i> [42] | 19 | Dialysis and transplant spouses | Not defined | (1) 41 (2) 52 (3) 100 (4) 68 (5), (6) not reported | Canada | Cross-sectional | (b) IIRS (c) FES (a), (d), (e), (f), (g) N/A | Spouses of transplant recipients more assertive, self-sufficient and able to make own decisions compared with dialysis spouses. |
| Ekelund <i>et al.</i> [41] | 35 | Home HD spouses and patients | Not defined | (1), (2), (4), (6) not reported (3) 100 (5) 8 | Sweden | Longitudinal | (a) self-construct (b), (c), (d), (e), (f), (g) N/A | Spouses report major sexual problems. |
| Kaye <i>et al.</i> [35] | 21 | HD and CAPD family members and patients | Closest person with whom the patients lived with | (5) 1.5 (1), (2), (3), (4), (6) not reported | USA | Longitudinal, follow-up at 7–14 months | (c) FES (f) PAF (physical); PAIS (psychosocial) (a), (b), (d), (e), (g) N/A | Family members show a loss in independence and a reduction of recreational activities on follow-up. |
| Lindqvist <i>et al.</i> [33] | 55 | HD, CAPD and transplant spouses | Not defined | (1) 56 (2) 62 (3) 100 (4), (5), (6) not reported | Sweden | Cross-sectional (mixed) | (d) SwQoL (e) VAS (coping) (a), (b), (c), (f), (g) N/A | HD spouses less able than the other two groups in handling physical, social and existential aspects of illness CAPD and HD spouses had lower QoL than age-matched general population. |
| Page and Weisberg [43] | 37 | Family members and patients | Not defined | (1) 42 (3) 43 (4) 35 (5) 1.5 (2), (6) not reported | USA | Cross-sectional | (c) FES; self-construct (family cohesiveness), MAES (d) self-construct (mental) (a), (b), (e), (f), (g) N/A | Home partners encouraged more direct expression of feeling, although less active in recreational pursuits Home partners were more sensitive towards patient needs to feel in control and to be given more attention. |
| Shimoyama <i>et al.</i> [28] | 34 | CAPD family carers | Family defined as a unit of two or more carers, are mutually related through emotional intimacy and conscious of being a family | (2) 59 (3) 56 (4) 68 (5) 6 (6) 3.9 (1) not reported | Japan | Cross-sectional | (a) ZBI (d) SF-36 (b), (c), (e), (f), (g) N/A | Carers had poorer mental health and social functioning than general population 'carer burden' associated with increasing age and decreasing health-related QoL. |
| Wagner [44] | 10 | Family members and nurses | Not defined | (1) 32–49 (2) 90 (3) 60 (4), (5), (6) not reported | USA | Cross-sectional | (g) modified NGQ (family needs) (a), (b), (c), (d), (e), (f) N/A | Families identified most important needs as information about patient care and comfort. |
| Wicks <i>et al.</i> [27] | 96 | Transplant family carers | Person who patients could depend on to care for them if they could no longer care for themselves | (1) 47 (2) 76 (3) 62 (4) 67 (5) 1.6 (6) 1–46 | USA | Cross-sectional | (a) CBI (d) General QoL (g) self-construct (general health) (b), (c), (e), (f) N/A | Carer QoL associated with 'carer burden', their self-reported health and employment status. Family carers reported both little 'burden' and excellent QoL. |

CAPD = Continuous Ambulatory Peritoneal Dialysis; CBI = Caregivers Burden Interview; FES = Family Environment Scale; HD = Haemodialysis; IIRS = Illness Intrusiveness Ratings Scale; MAES = Marital Attitudes Evaluation Scale; NGQ = Norris & Groves Questionnaire; PAF = Physicians' Assessment Form; PAIS = Psychosocial Adjustment to Illness Scale; SF-36 = Short-Form 36; SwQoL = Swedish Health-Related Quality of Life Survey; VAS = Visual Analogue Scale; ZBI = Zarit Burden Interview.

Table 2. Impact on family life (qualitative studies)

| Authors | No. of carers | Population involved in the study | Carer definition | Demographic details (1) mean age (years) (2) female (%) (3) spouses (%) (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) | Country of origin | Study design | Themes explored | Main findings |
|---------------------------------|---------------|---|--|--|-------------------|------------------------------------|---|--|
| Beanlands <i>et al.</i> [11] | 37 | Home PD, home HD, hospital HD and in-centre self care HD carers | Family member or friend responsible for providing most of dialysis and health care at home | (1) 58 (2) 68 (4) 49 (5) 3.9 (3), (6) not reported | Canada | Longitudinal follow-up at 6 months | (1) exploration of carers' abilities and activities | Carers 'grow into the job' with their caring skills developing over time The amount of care that carers' need to give patients is inversely related to patients' ability to self-care for themselves Carers play pivotal role in supporting patients in the management of their disease. |
| Friesen [32] | 8 | Home HD spouses | Not defined | (1) 33–66 (2) 100 (3) 100 (4) 63 (5), (6) not reported | Canada | Cross-sectional | (1) experience of being a carer (2) factors influencing response to living with home HD partner | Lack of socialization opportunities due to the lack of time due to patient poor health Marital relationship strengthened if spouse considered their involvement as cooperative. |
| Luk [39] | 30 | Home HD carers | Person responsible for providing the majority of the carer tasks without pay | (1) 68 (2) 70 (3) 57 (6) 1.9 (4), (5) not reported | China (HK) | Cross-sectional | (1) impact of home dialysis on carers' life and relationships with extended family, friends and community (2) carers' health status | Carers feel exhausted and withdraw from job market and social life to accommodate caring duties Carers want opportunities to discuss problems with staff, but feel informational support is inadequate. |
| Pelletier-Hibbert and Sohi [29] | 41 | HD/CAPD family members | Not defined | (1) 55 (2) 85 (3) 73 (4) 56 (5), (6) not reported | Canada | Cross-sectional | (1) stressful situations around renal failure and dialysis treatment (2) management of stress sources | Main source of carer stress identified as uncertainty about patients' declining health, the lack of spontaneity pursuing family activities and the after-effect of dialysis treatment Carers cope by living each day as it comes and by finding meaning in illness. |
| Wellard and Street (1999) [36] | 3 families | Home HD family members and patients | Not defined | (1), (2), (3), (4), (5), (6) not reported | Australia | Cross-sectional | (1) exploration of families' experiences of living with home-based dialysis (2) issues around restructuring family life around treatment | Family members report social isolation due to strict timetabling of treatments. Female family members not asked about their willingness to assume the caring role Family members report a lack of effective support from health services. |
| White and Grenyer [30] | 22 | HD and CAPD (home and hospital) partners and patients | Support member for someone on dialysis | (1) 62 (2) 55 (4) 23 (5) 3.5 (3), (6) not reported | Australia | Cross-sectional | (1) relationship between patient and partner dyad (2) perception on life situation | Partners expressed positive aspects of relationship, though recognizing its negative impact. |

Table 2. (Continued.)

| Authors | No. of carers | Population involved in the study | Carer definition | Demographic details (1) mean age (years) (2) female (%) (3) spouses (%) (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) | Country of origin | Study design | Themes explored | Main findings |
|------------------------------------|-------------------------|--|------------------|--|-------------------|-----------------|--|--|
| White, Richter, <i>et al.</i> [38] | Number involved unclear | HD carers, patients and additional family members | Not defined | (5) 2–5 (1), (2), (3), (4), (6) not reported | USA | Longitudinal | (1) impact of illness stressors on the family (2) resources associated with the dialysis experience | Family resilience achieved through social support and by maintaining a sense of “normalcy” through open communication between family members, keeping busy, maintaining a sense of control and finding meaning in illness. |
| Wright and Kirby [37] | 5 | CAPD family members, patients and health professionals | Not defined | (1) 56 (3) 80 (5) 0.7 (2), (4), (6) not reported | UK | Cross-sectional | (1) patient adjustment to ESKD | Family members agreed that patients had adjusted to their illness but were frustrated by the life style restrictions. |
| Ziebert <i>et al.</i> [31] | 13 | HD spouses | Not defined | (1) 61 (2) 85 (3) 100 (6) 2.7 (weighted) (4), (5) not reported | Sweden | Cross-sectional | (1) health experiences in everyday life (2) how spouses maintain good health | Three types of experiences identified: (1) arduousness experienced when spouses' lives dominated by caring; (2) stamina reflects spouses' willingness to help at the expense of own health and (3) independence acknowledges the importance of spouse caring for themselves which in turn benefited their own health. |
| Ziebert and Fridlund [34] | 12 | HD family members | Not defined | (1) 46–65 (2) 75 (3) 42 (5) 4 (4), (6) not reported | Sweden | Cross-sectional | (1) impact of ESKD on emotional, behavioural, work, biophysical, existential and family situation | Family members' daily life affected as result of feeling confined (limited social activity) and fear of patients' death Family members recognize the potential impact that they have in promoting patients' well-being. |

CAPD = continuous ambulatory peritoneal dialysis; HD = haemodialysis; PD = peritoneal dialysis.

Table 3. Caring and psychological health

| Authors | No. of carers involved in the study | Population involved in the study | Carer definition | Demographic details | Country of origin | Study design | Outcome (carer) | Main findings |
|--------------------------------|-------------------------------------|--|--|--|-------------------|-------------------------------|---|--|
| Alvarez-Ude <i>et al.</i> [46] | 221 | HD and PD carers and patients | Family member identified as mainly responsible for looking after the patient and most closely involved in their care | (1) 57 (2) 77 (3) female (%) (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) | Spain | Cross-sectional, quantitative | (a) psychological morbidity (b) psychological (others) (c) 'carer burden' (d) quality of life (e) social support (f) patient outcomes (g) miscellaneous | Carers' mental health was worse in those with lower social support, higher subjective 'burden' of work on those caring for patients with poor mental health. |
| Asti <i>et al.</i> [49] | 65 | CAPD carers and patients | Not defined | (1) 44 (2) 82 (3), (4), (5), (6) not reported | Turkey | Cross-sectional, quantitative | (c) ZBI (d) SF-36 (e) DFSS (f) BI (functioning) (a), (b), (g) N/A | Most carers were not depressed and had high levels of perceived social support. Depression was inversely associated with the level of perceived family social support. PD carers had worse mental health than HD carers. Carers of younger patients had potentially poorer access to transport and health services. Burden for PD carers associated with their mental composite scores (SF-36), whereas burden for HD carers associated with vitality, pain and social aspect. |
| Belasco <i>et al.</i> [57] | 201 | In-centre HD and home PD carers | Person mainly responsible for both looking after patient during course of disease and caring for them | (1) 42–58 (2) 80 (4) 32 (5) 1.8–3.8 (6) 1.5–3.9 (3) not reported | Brazil | Cross-sectional | (a) CBS (d) SF-36 (e) CID (f) KPS (b), (c), (g) N/A | 'Carer burden' correlated with the number of patient comorbidities and the length of time spent as carers. Perceived 'carer burden' was explained by carers' mental health, patient vitality, relationship type and carer pain. |
| Belasco and Sesso [50] | 100 | HD carers and patients | Person responsible for looking after the patient during the course of the disease and most closely involved in caring for the patient for a period of > 3 months | (1) 47 (2) 84 (3) 49 (4) 34 (5) 2.8 (6) 2.5 (median) | Brazil | Cross-sectional, quantitative | (c) CBS (d) SF-36 (a), (b), (e), (f), (g) N/A | Perceived intrusiveness of ESKD significantly associated with greater 'marital role' strain, poorer marital adjustment and decreased individual well-being of both the spouse and the patient. Increased symptoms of psychopathology significantly associated with perceived intrusiveness into marital and non-marital aspects of life and increased marital strain. |
| Binik <i>et al.</i> [56] | 89 | Pre-dialysis, HD and post-transplant spouses | Not defined | (3) 100 (1), (2), (4), (5), (6) not reported | Canada | Cross-sectional, quantitative | (a) GSI, ABS, SEI (b) MRQ, KDS-15 (marital role strain), L-WMAT (marital adjustment) (c) self-construct (objective and perceived intrusiveness) (d), (e), (f), (g) N/A | |

Table 3. (Continued.)

| Authors | No. of carers | Population involved in the study | Carer definition | Demographic details | Country of origin | Study design | Outcome (carer) | Main findings |
|----------------------------|---------------|----------------------------------|--|---|-------------------|---|--|--|
| Blogg <i>et al.</i> [53] | 61 | Home HD carers | Person who cares for a patient at home | (1) 45–49 (2) 69 (3) 93 (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) | Australia | Cross-sectional, quantitative | (a) GHQ-28 (b) psychological morbidity (c) RSS (d), (e), (f), (g) N/A | Main variables associated with carer distress were younger age (<45 years) and having a low involvement in the dialysis procedure. Other associated variables include no prior experience of the dialysis process and high involvement levels in a rural setting. Most home dialysis partners had little psychological distress. However, partners perceived home HD to be stressful but preferred HD at home. |
| Courts [47] | 14 | HD partners and patients | Not defined | (1) 47 (median) (2) 93 (3) 71 (4), (5), (6) not reported | USA | Cross-sectional, quantitative and qualitative | (a) CAS, STAI, GCS (b) PAIS-SR (psycho-social adjustment), HSS (HD stressor) (c) CBS (d) SF-36 (e) description of HD experience (interview) (f) N/A | |
| Daneker <i>et al.</i> [55] | 55 | HD carers and patients | Not defined | (1) 52 (2) 76 (3) 34 (4) 34 (5) 2.9 (6) not reported | USA | Cross-sectional, quantitative | (a) BDI, CBI (b) JCS (coping); DAS, DAS-S (marital adjustment) (c) QoLI (e) MSPSS (d) KPS (functioning), ESRDSC (comorbidity) (e), (f) N/A | Spousal depression inversely correlated with their marital dissatisfaction but correlated with patient depression. Spouses' perceived social support inversely related to both spousal depression and spousal marital dissatisfaction. Spouses' psychosocial variables not correlated with patients' disease severity. |
| Dunn <i>et al.</i> [54] | 38 | CAPD spouses | Not defined | (1) 58 (2) 58 (3) 100 (4) 2.6 (5) 2.6 (6) not reported | USA | Cross-sectional, quantitative | (a) JCS (coping); DAS (marital adjustment) (b) QoLI (f) ESRDSI (disease severity) (c), (e), (g) N/A | QoL influenced by marital adjustment and income. Emotional coping was negatively correlated with marital adjustment but positively correlated with years on dialysis. |

Table 3. (Continued).

| Authors | No. of carers involved in the study | Population involved in the study | Carer definition | Demographic details (1) mean age (years) (2) female (%) (3) spouses (%) (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) | Country of origin | Study design | Outcome (carer) (a) psychological morbidity (b) psychological (others) (c) 'carer burden' (d) quality of life (e) social support (f) patient outcomes (g) miscellaneous | Main findings |
|-----------------------------|-------------------------------------|----------------------------------|---|--|-------------------|-------------------------------|--|--|
| Ferrario <i>et al.</i> [51] | 50 | Carers and patients | The main person responsible for patient care outside the hospital | (1) 54 (2) 80 (3) 70 (4) 26 (5) 4.7 (6) not reported | Italy | Cross-sectional, quantitative | (a) STAI; DQ (b) EPQ (personality) (c) FSQ (f) SWLS (life satisfaction) (d), (e), (g) N/A | Carers' sense of burden and satisfaction correlated with their neuroticism, anxiety and depression. |
| Harris <i>et al.</i> [48] | 78 | Transplant family members | Person identified as providing assistance to patient who is unable to self-care | (1) 21–88 (2) 76 (3) 53 (4) 70 (5) 2.3 (6) not reported | USA | Cross-sectional, quantitative | (c) ZBI (a), (b), (d), (e), (f), (g) N/A | Most carers reported little 'burden'. Both personal strain and role strain were lowest in carers with patients who were independent in ADL. |
| Piira <i>et al.</i> [52] | 38 | HD and PD carers and patients | Person who plays a significant role in the dialysis process and in caring for the patient | (1) 54 (2) 56 (3) 68 (5) 2 (4), (6) not reported | Australia | Cross-sectional, quantitative | (a) DASS (b) JCS (coping); LCB (f) ESRDSI (comorbidity), SIP (functioning) (c), (d), (e), (g) N/A | Carers' psychological morbidity was positively associated with the use of external locus of control and emotion-focused coping strategies. |
| Rideout <i>et al.</i> [40] | 40 | CAPD spouses and patients | Not defined | (1) 51 (2) 65 (3) 100 (5) 0.2 (4), (6) not reported | Canada | Cross-sectional, quantitative | (a) CES-D (b) IFS (family impact); DAS, DAS-S (marital adjustment) (c) PSS (f) SIP (functioning) (c), (d), (g) N/A | Whilst most spouses were not depressed, the lack of perceived social support from their ill partner and social/financial changes were major significant predictors of spouse depression. |

ABS = Affect Balance Scale; BDI = Beck Depression Inventory; BI = Barthel Index; CAPD = Continuous Ambulatory Peritoneal Dialysis; CAS = Clinical Anxiety Scale; CBI = Caregivers Burden Interview; CBS = Caregiver Burden Scale; CES-D = Center for Epidemiologic Studies Depression Scale; CID = Cognitive Index of Depression; DAS = Dyadic Adjustment Scale; DAS-S = Dyadic Satisfaction Sub-scale; DASS = Depression, Anxiety and Stressor Scale; DFSS = Duke-UNC Functional Social Support Questionnaire; DQ = Depression Questionnaire; EPQ = Eysenck Personality Questionnaire; ESRDSI = End-Stage Renal Disease Severity Index; ESRDSC = End-Stage Renal Disease Severity Coefficient; FSQ = Family Strain Questionnaire; GCS = Generalized Contentment Scale; GHQ-28 = General Health Questionnaire 28; GSI = Global Symptom Index; HD = haemodialysis; HSS = Haemodialysis Stressor Scale; IFS = Impact on Family Scale; JCS = Jalowiec Coping Scale; KPS = Karnofsky Performance Status Scale; LCB = locus of control of behaviour; L-WMAT = Locke-Wallace Marital Adjustment Test; MRQ = Marital Role Questionnaire; MSPSS = Multidimensional Scale of Perceived Social Support; PAIS-SR = Psychosocial Adjustment to Illness Scale—Self Report; PD = peritoneal dialysis; PSS = Perceived Social Support Scale; PSSFFS = Perceived Social Support for Friends and Family Scale; QoLJ = Quality of Life Index; RSS = Relatives' Stress Scale; SEJ = Self Esteem Inventory; SF-36 = Short-Form 36; SIP = Sickness Inventory Profile; STAI = State Trait Anxiety Inventory; SWLS = Satisfaction with Life Scale; UCLALS = UCLA Loneliness; ZBI = Zarit Burden Interview.

Table 4. End of life care

| Authors | No. of carers involved in the study | Population involved in the study | Carer definition | Demographic details (1) mean age (years) (2) female (%) (3) spouses (%) (4) in employment (%) (5) mean patient dialysis duration (years) (6) mean length of caring (years) (7) mean post-dialysis survival time (days) | Country of origin | Study design | Main study aims for carers | Main findings |
|-----------------------------|-------------------------------------|---|------------------|---|-------------------|-------------------------------|---|--|
| Ashby <i>et al.</i> [14] | 5 | Family members, patients and health professionals | Not defined | (3) 100 (1), (2), (4), (5), (6), (7) not reported | Australia | Qualitative, cross-sectional | Reasons on decisions to stop dialysis | Family members did not feel adequately educated or equipped by hospital to prepare for lifestyle associated with dialysis regimen. |
| Cohen <i>et al.</i> [58] | 86 | HD carers | Not defined | (3) 49 (1), (2), (4), (5), (6), (7) not reported | USA | Quantitative, cross-sectional | To explore the perceptions of bereaved family members about patients' terminal symptoms and the quality of their end of life care | Family members perceived that most patients were in pain in last week of life. Fatigue was reported as second most disturbing symptom Death at home was associated with less pain, more peace and completion of a living will Those who completed a health care proxy felt it had helped them ensure that patients' wishes were followed. |
| Miura <i>et al.</i> [59] | 398 | Family members, patients and health professionals | Not defined | Not reported | Japan | Quantitative, cross-sectional | To assess how accurately family members predict patients' wishes about medical care and treatment under various medical scenarios | Family members were poor at assessing both patients' current and future preferences for cardiopulmonary resuscitation or dialysis continuation. |
| Perry <i>et al.</i> [60] | 46 | Carers | Not defined | (1) 53 (2) 63 (5) 5.4 (3), (4), (6), (7) not reported | Canada | Quantitative, cross-sectional | To describe the opinions of their family members/friends regarding advance directives | Relatives/friends felt that routine visit to the health professional was the best time to discuss advance directives, though over half felt that the final decisions about major treatments should be left to physicians. |
| Phillips <i>et al.</i> [45] | 26 | Family members | Not defined | (1) 47 (3) 27 (5) 3 (7) 8 (2), (4), (6) not reported | USA | Quantitative, cross-sectional | To explore the long-term impact on families of deaths preceded by cessation of dialysis | Most family members showed little long-term psychological distress, though principal carers and spouses had significantly higher intrusive thoughts. Good death was perceived as being pain free, with the patient being mentally alert, able to remain at home and dying while asleep. Many felt that health professionals had not provided sufficient information. |

HD = haemodialysis.

with potentially higher levels of caring responsibility for the patient, did report significantly higher intrusive thoughts [45].

The remaining four studies focused on patient outcomes such as reasons for withdrawing from dialysis [14], the quality of death [58], the accuracy of close persons in predicting ESKD patients' preference to present and future medical care [59] and use of advance directives (defined as a legal document, prepared in advance by patients, which specifies the course of treatment to be taken by health care providers once a patient is unable to provide informed consent due to that person's lack of capacity) [60]. These studies found that close persons thought that whilst most patients had a peaceful death, many patients were perceived to be in pain and suffering from fatigue [58]. Health care proxies supported family members in ensuring that patients' last wishes were followed and most relatives recognized the importance of living wills, which they felt were best discussed during routine health care professional visits [60]. Close persons were poorly prepared for caring for a dying dialysis patient, and patients did not want to be a burden on their families [14]. They were also poor at assessing both patients' current and future preferences for cardiopulmonary resuscitation or dialysis continuation [59]. No studies were identified for carers of patients with supportive care needs, e.g. those on maximum conservative management programmes.

Methodological critique

General. The main criticism of most studies included in this review is the lack of detail and analysis of the demographic information. Just over half of the studies give demographic details of close persons' ages and gender or details of their relationship to patients (19/36). Reporting of other relevant demographic variables such as employment status (13/36), ethnicity, educational level or social class is sporadic and only seven studies report the time that close persons had spent as carers.

Whilst all studies recorded the type of dialysis received, half (18/36) had reported the length of time a patient has been on dialysis, with very few recording patients' functional status, although carer studies in other specialities suggest that this has an impact on carers' quality of life [61]. In total, only 18 quantitative, 9 qualitative and 1 mixed methods study gave clear details of their sample sizes.

Quantitative studies. Nineteen of the 20 quantitative studies included in the analysis used cross-sectional designs and were predominantly descriptive. Such studies are useful in exploring associations between variables but are limited as they do not allow causal relationships to be established. As only five studies provide the full details of sample recruitment, it is therefore not possible to assess response rates or how representative the sample was. The sample sizes were generally small with a median of 55 participants, and details of statistical power were reported in only one study. Finally, the diversity of the tools used to assess the different outcomes makes it difficult to do any meaningful comparison between the different studies.

Qualitative studies. We identified that most studies gave poor descriptions of their sampling methods and a lack of detail of their data analysis process. Most used opportunistic samples of family members (6/11), with five studies using purposive strategies, but only one gave specific details of their sampling method. Seven studies gave detailed descriptions consistent with their analysis plan. Two studies gave vague descriptions consistent with their plan; one gave a description of their analysis but without stating their analysis approach. One study gave no details of their analysis.

Overall, the studies were poorly written, meaning that the writing style was unclear and overly complicated. Several authors were unsure as to how to use qualitative data effectively, with the depth and richness of the qualitative data lost amongst under-analysed demographic detail, long explanations of data collection scales and poor use of supporting quotes.

Conclusion

This study reviewed the current literature exploring the experience of close persons of patients with ESKD, from which several points can be made regarding the quality of past research and recommendations for the direction of future research in this area.

Firstly, studies exploring end of life issues are limited, with only four identified. Although these four studies are mostly patient-centred, they do suggest that health professionals' routine visits are the best time for informal carers to discuss patients' preferences about end of life care and, additionally, report little long-term distress of close persons resulting from the patients' deaths. However, little remains known about how such end of life issues affect close persons, and we recommend future studies in this area.

Secondly, definitions of close persons were problematic since there were some subtle, but fundamental differences identified between the different groups. While the current literature supports the impression that most close persons are closely related to patients, the situations in relation to patients who were single and those with alternative family and relationship arrangements were not explored. Furthermore, not all close persons decide to take on the role of the informal carer, and the development of this role can be a gradual process as illness progresses. Although our review did not identify any differences between informal carers and family carers in the outcome measures used (we included both groups under the umbrella term of 'close person'), differences may exist in their perceived role, with 'informal carers' having a more active role, whereas 'family members' may be perceived as being more passive. Again, this needs further investigation.

Thirdly, serious issues that need to be addressed concerning the use of methodology were identified in the literature. Most quantitative studies were exploratory and descriptive, with no intervention studies being identified. Studies had sporadic reporting of demographic details and response rates and all were cross-sectional with small sample sizes that used standardized measures. Whilst the use of standardized measures increases the robustness of the results, the findings from cross-sectional studies are limited in that

they can only establish associations between variables. We recommend the use of longitudinal methods in future research that would ensure that causality between key variables could be explored in more depth. This would also enhance insight into the long-term experience of close persons. In those studies using qualitative methods, most used opportunistic samples, with poor reporting and understanding of demographic details, sampling methods, analysis and social and cultural context. Many authors used the term 'burden' or 'carer burden' without questioning how such terms may influence our understanding of the relationship between close person and patient. It was not clear whether they were prompted by close persons to use the term 'burden' or whether it was a term coined by the authors to describe the responsibilities of caring. Such methodological and theoretical considerations affect the confidence of applying study findings beyond the original setting.

Fourthly, half of the studies originated from either the USA (11/36) or Canada (7/36). This North American dominance makes it difficult to generalize the results of these studies outside their context, due to variations in the organization of health care provision in other countries.

Lastly, while there is emerging evidence that suggests maintaining the psychological health of close persons enables them to continue to care effectively, which in turn can benefit the mental health of patients, we failed to identify studies in our review that looked specifically at how health services supported close persons of patients with ESKD. Our review has clearly identified shortcomings in the published literature that need to be filled. Future research is therefore needed to explore the relationship between health services and close persons in order to develop practical empowering interventions.

Acknowledgements. We would like to acknowledge Marie Curie Cancer Care for funding this review and Beth Downe for her administration support in completing this manuscript.

Conflict of interest statement. None declared.

References

- Steddon S, Ashman N, Cunningham J *et al.* *Oxford Handbook of Nephrology and Hypertension*. Oxford, UK: Oxford University Press, 2006
- Ansell D, Roderick P, Udayaraj U *et al.* Survival of incident RRT patients in the UK. *UK Renal Registry Report 2006 (Chapter 12)* [http://www.renalreg.com/Report%202006/Cover_Frame2.htm], 2006
- Chandna SM, Schulz J, Lawrence C *et al.* Is there a rationale for rationing chronic dialysis? A hospital based cohort study of factors affecting survival and morbidity. *BMJ* 1999; 318: 217–223
- Caskey F, Steenkamp R, Ansell D. International comparison of UK registry data. *UK Renal Registry Report 2006 (Chapter 17)* [http://www.renalreg.com/Report%202006/Cover_Frame2.htm], 2006
- Farrington K, Rao R, Steenkamp R *et al.* All patients receiving renal replacement therapy in the United Kingdom in 2005. *UK Renal Registry Report 2006 (Chapter 4)* [http://www.renalreg.com/Report%202006/Cover_Frame2.htm], 2006
- Department of Health. *The National Service Framework for Renal Services. Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care*. [<http://www.dh.gov.uk/assetRoot/04/10/26/80/04102680.pdf>], 2005
- Cohen LM, Moss AH, Weisbord SD *et al.* Renal palliative care. *J Palliat Med* 2006; 9: 977–992
- Levy JB, Chambers EJ, Brown EA. Supportive care for the renal patient. *Nephrol Dial Transplant* 2004; 19: 1357–1360
- Department of Health. *Caring about Carers: A National Strategy for Carers*. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006522], 1999
- Brunier GM, McKeever PT. The impact of home dialysis on the family: literature review. *ANNA J* 1993; 20: 653–659
- Beanlands H, Horsburgh ME, Fox S *et al.* Caregiving by family and friends of adults receiving dialysis. *Nephrol Nurs J* 2005; 32: 621–631
- Kimmel PL. Psychosocial factors in adult end-stage renal disease patients treated with hemodialysis: correlates and outcomes. *Am J Kidney Dis* 2000; 35(Suppl 1): S132–S140
- Dobrof J, Dolinko A, Lichtiger E *et al.* Dialysis patient characteristics and outcomes: the complexity of social work practice with the end stage renal disease population. *Soc Work Health Care* 2001; 33: 105–128
- Ashby M, Hoog C, Kellehear A *et al.* Renal dialysis abatement: lessons from a social study. *Palliat Med* 2005; 19: 389–396
- Robert Wood Johnson Foundation. ESRD workgroup final report summary on end-of-life care: recommendations to the field. *Nephrol Nurs J* 2003; 30: 59–63
- Auer J. Dialysis—a family matter. A personal tribute to the relatives of kidney patients. *EDTNA ERCA J* 2002; 28: 141–144
- Binkley L. Caring for renal patients during loss and bereavement. *EDTNA ERCA J* 1999; 25: 45–48
- Qinlan P. Home hemodialysis and the caregivers' experience: a critical analysis. *CANNT J* 2005; 15: 25–32
- Campbell AR. Family caregivers: caring for aging end-stage renal disease partners. *Adv Ren Replace Ther* 1998; 5: 98–108
- Kalra L, Evans A, Perez I *et al.* Training carers of stroke patients: randomised controlled trial. *BMJ* 2004; 328: 1099–1101
- Walsh K, Jones L, Tookman A *et al.* Reducing emotional distress in people caring for patients receiving specialist palliative care. *Br J Psychiatry* 2007; 190: 142–147
- Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980; 20: 649–655
- Beck AT, Ward CH, Mendelson M *et al.* An inventory for measuring depression. *Arch Gen Psychiatry* 1961; 4: 561–571
- Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Med Care* 1992; 30: 473–483
- Jalowiec A, Murphy SP, Powers MJ. Psychometric assessment of the Jalowiec Coping Scale. *Nurs Res* 1984; 33: 157–161
- Craven J, Littlefield C, Rodin G *et al.* The end stage renal disease severity index (ESRD-SI). *Psychol Med* 1991; 21: 237–243
- Wicks MN, Milstead EJ, Hathaway DK *et al.* Subjective burden and quality of life in family caregivers of patients with end stage renal disease. *ANNA J* 1997; 24: 527–528, 531–538
- Shimoyama S, Hirakawa O, Yahiro K *et al.* Health-related quality of life and caregiver burden among peritoneal dialysis patients and their family caregivers in Japan. *Perit Dial Int* 2003; 23: S200–S205
- Pelletier-Hibbert M, Sohi P. Sources of uncertainty and coping strategies used by family members of individuals living with end stage renal disease. *Nephrol Nurs J* 2001; 28: 411–419
- White Y, Grenyer BF. The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners. *J Adv Nurs* 1999; 30: 1312–1320
- Ziegert K, Fridlund B, Lidell E. Health in everyday life among spouses of haemodialysis patients: a content analysis. *Scand J Caring Sci* 2006; 20: 223–228
- Friesen D. A descriptive study of home hemodialysis spouses. *Dial Transplant* 1997; 26: 310–325
- Lindqvist R, Carlsson M, Sjöden P. Coping strategies and health-related quality of life among spouses of continuous ambulatory peritoneal dialysis, haemodialysis, and transplant patients. *J Adv Nurs* 2000; 31: 1398–1408
- Ziegert K, Fridlund B. Conceptions of life situation among next-of-kin of haemodialysis patients. *J Nurs Manag* 2001; 9: 231–239

35. Kaye J, Bray S, Gracely EJ *et al.* Psychosocial adjustment to illness and family environment in dialysis patients. *Fam Syst Med* 1989; 7: 77–89
36. Wellard SJ, Street AF. Family issues in home-based care. *Int J Nurs Pract* 1999; 5: 132–136
37. Wright SJ, Kirby A. Deconstructing conceptualizations of ‘adjustment’ to chronic illness: a proposed integrative framework. *J Health Psychol* 1999; 4: 259–272
38. White N, Richter J, Koeckeritz J *et al.* ‘Going forward’: family resiliency in patients on hemodialysis. *J Fam Nurs* 2004; 10: 357–378
39. Luk WS. The home care experience as perceived by the caregivers of Chinese dialysis patients. *Int J Nurs Stud* 2002; 39: 269–277
40. Rideout EM, Rodin GM, Littlefield CH. Stress, social support, and symptoms of depression in spouses of the medically ill. *Int J Psychiatry Med* 1990; 20: 37–48
41. Ekelund M, Westman K, Andersson SI. Dialysis-linked complaints and burdens of illness on patient and spouse as predictors of survival in end-stage renal disease patients with home hemodialysis: a 10-year follow-up study. *Stress Health* 2004; 20: 29–34
42. Devins GM, Hunsley J, Mandin H *et al.* The marital context of end-stage renal disease: illness intrusiveness and perceived changes in family environment. *Ann Behav Med* 1997; 19: 325–332
43. Page S, Weisberg MB. Marital and family characteristics of home and hospital dialysis patients. *Loss Grief Care* 1991; 5: 33–45
44. Wagner CD. Family needs of chronic hemodialysis patients: a comparison of perceptions of nurses and families. *ANNA J* 1996; 23: 19–26
45. Phillips JM, Brennan M, Schwartz CE *et al.* The long-term impact of dialysis discontinuation on families. *J Palliat Med* 2005; 8: 79–85
46. Alvarez-Ude F, Valdés C, Estébanez C *et al.* Health-related quality of life of family caregivers of dialysis patients. *J Nephrol* 2004; 17: 841–850
47. Courts NF. Psychosocial adjustment of patients on home hemodialysis and their dialysis partners. *Clin Nurs Res* 2000; 9: 177–190
48. Harris TT, Thomas CM, Wicks MN *et al.* Subjective burden in young and older African-American caregivers of patients with end stage renal disease awaiting transplant. *Nephrol Nurs J* 2000; 27: 383–391
49. Asti T, Kara M, Ipek G *et al.* The experiences of loneliness, depression, and social support of Turkish patients with continuous ambulatory peritoneal dialysis and their caregivers. *J Clin Nurs* 2006; 15: 490–497
50. Belasco AG, Sesso R. Burden and quality of life of caregivers for hemodialysis patients. *Am J Kidney Dis* 2002; 39: 805–812
51. Ferrario SR, Zotti AM, Baroni A *et al.* Emotional reactions and practical problems of the caregivers of hemodialysed patients. *J Nephrol* 2002; 15: 54–60
52. Piira T, Chow J, Suranyi M. The role of cognitive factors in the adjustment of home dialysis carers. *Psychology Health* 2002; 17: 313–322
53. Blogg A, O’Shaughnessy DV, Cairns DR. Levels and predictors of distress in home hemodialysis caregivers. *Dial Transplant* 1999; 28: 507–517
54. Dunn SA, Lewis SL, Bonner PN *et al.* Quality of life for spouses of CAPD patients. *ANNA J* 1994; 21: 237–246
55. Daneker B, Kimmel PL, Ranich T *et al.* Depression and marital dissatisfaction in patients with end-stage renal disease and in their spouses. *Am J Kidney Dis* 2001; 38: 839–846
56. Binik YM, Chowanec GD, Devins GM. Marital role strain, illness intrusiveness, and their impact on marital and individual adjustment in end-stage renal disease. *Psychology Health* 1990; 4: 245–257
57. Belasco A, Barbosa D, Bettencourt AR *et al.* Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *Am J Kidney Dis* 2006; 48: 955–963
58. Cohen LM, Germain MJ, Woods AL *et al.* The family perspective of ESRD deaths. *Am J Kidney Dis* 2005; 45: 154–161
59. Miura Y, Asai A, Matsushima M *et al.* Families’ and physicians’ predictions of dialysis patients’ preferences regarding life-sustaining treatments in Japan. *Am J Kidney Dis* 2006; 47: 122–130
60. Perry LD, Nicholas D, Molzahn AE *et al.* Attitudes of dialysis patients and caregivers regarding advance directives. *ANNA J* 1995; 22: 457–463, 481
61. Low JTS, Roderick P, Payne S. An exploration looking at the impact of domiciliary and day hospital delivery of stroke rehabilitation on informal carers. *Clin Rehabil* 2004; 18: 776–784

Received for publication: 20.9.07

Accepted in revised form: 13.12.07