Support interventions for caregivers of people with chronic kidney disease: a systematic review

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Abstract

Background. A growing number of patients with chronic kidney disease (CKD) rely on non-professional healthcare providers, such as family and friends, to manage their long-term condition throughout the trajectory of CKD. These informal caregivers can experience stress, depression, lack of confidence and poor quality of life. Yet, the needs of caregivers are often neglected and under-prioritized. The objective of this review is to evaluate the effectiveness of interventions aimed at providing support to caregivers of people with CKD.

Methods. We conducted a systematic review of studies that evaluated any intervention for informal caregivers of CKD patients. We searched five electronic databases (up to January Week 5, 2008) including Medline, EMBASE, PsychINFO, CINAHL, Cochrane Central Register and reference lists of relevant articles.

Results. Three studies were identified that evaluated an intervention for caregivers of CKD patients. All three only assessed the effect of educational material on caregivers’ knowledge. Two evaluated information provided to caregivers of dialysis patients using a pre- and post-test study design. The other study used participatory action research methods to develop and evaluate an information handbook for transplant patients and their caregivers. Studies consistently found that the provision of information improved caregivers’ knowledge. No other outcomes were reported.

Conclusions. Despite the growing recognition of the burden and adverse effects of CKD on caregivers, no high-quality evidence is available about the effect of information or support interventions on the physical or psychosocial well-being of informal caregivers and the patients. More attention towards the development and evaluation of services that respond to the support and informational needs of caregivers is needed, and this may also lead to improved outcomes for patients.

Keywords: chronic kidney disease; informal caregiver; quality of life; systematic review

Introduction

A growing number of patients with chronic kidney disease (CKD) are receiving home-based care and require support from non-professional healthcare providers, often family members, to manage CKD [1]. There is concern that caregiving demands, especially in managing dialysis that has a profound and pervasive effect on family and friends, exact a toll on the physical, social and emotional well-being of caregivers [2]. Yet, caregivers’ needs are often neglected and under-prioritized in the medical management of CKD [3].

Informal caregivers can experience stress from the added responsibilities of managing the patients’ medical treatments, dietary requirements, clinic appointments and psychosocial issues [1,4,5]. Increasingly, caregivers are required to provide complex technical care in the home due to the improved clinical outcomes, lower costs and staffing and convenience associated with home-based-dialysis regimens [6]. Research has consistently shown that caregivers experience depression, anxiety, fatigue, social isolation, relationship strains and financial strains [7–11].

Support interventions are likely to improve caregivers’ quality of life, satisfaction and ability to cope, which can indirectly improve medical and psychosocial outcomes for the care recipient. Findings from randomized controlled trials (RCTs) in stroke [12,13], dementia [14–16], asthma [17] and cancer [18,19] suggest that support and information for informal caregivers can reduce caregiver burden and anxiety and improve the quality of life and psychosocial outcomes for patients and carers.

The effectiveness of support interventions targeting informal caregivers of patients with CKD has not been systematically assessed. The objective of this review is to evaluate the effectiveness of interventions aimed at providing support to informal caregivers of people with CKD, including predialysis, dialysis and transplantation.
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Table 1. Inclusion criteria

<table>
<thead>
<tr>
<th>Study design</th>
<th>Any study reporting the development or evaluation of an intervention for informal caregivers of CKD patients, including predialysis, dialysis and transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>Informal caregivers of adult and paediatric patients with CKD. Informal caregivers are unpaid carers who include spouses, siblings, relatives, friends</td>
</tr>
<tr>
<td>Intervention</td>
<td>● Information and educational interventions—skills training, written materials, web-based resources, lectures</td>
</tr>
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<td></td>
<td>● Psychological support—counselling, specialized psychological support, psychotherapy</td>
</tr>
<tr>
<td></td>
<td>● Social support—support groups, meetings, telecommunication or internet-based support</td>
</tr>
<tr>
<td></td>
<td>● Practical support—financial, domestic, transport, respite</td>
</tr>
<tr>
<td>Outcomes</td>
<td>● Physical status—e.g. fatigue, specific health problems</td>
</tr>
<tr>
<td></td>
<td>● Psychological and emotional status—e.g. depression, anxiety, stress, self-esteem, coping</td>
</tr>
<tr>
<td></td>
<td>● Caregiver knowledge and skills</td>
</tr>
<tr>
<td></td>
<td>● Social outcomes—e.g. isolation, family dynamics</td>
</tr>
<tr>
<td></td>
<td>● Caregiver burden—e.g. strain, perceived burden, adjustment</td>
</tr>
<tr>
<td></td>
<td>● Patient outcomes—e.g. psychosocial outcomes (anxiety, coping, stress, attitudes towards caregivers), physical health, knowledge, satisfaction, attitudes, relationship with caregiver</td>
</tr>
</tbody>
</table>

Methods

Inclusion criteria

Studies were included if they met the criteria specified in Table 1. Non-English articles were included. Anecdotal reports, case studies, editorials, letters, paid or professional caregiver assessments and studies that included over 50% of illnesses other than CKD were excluded.

Search strategy

Electronic searches were performed in Medline (1950 to January Week 5, 2008), EMBASE (1980 to January Week 5, 2008), CINAHL (1982 to January Week 5, 2008), PsychINFO (1806 to January Week 5, 2008) and the Cochrane Central Register of Controlled Trials by using optimally sensitive search strategies for the identification of randomized trials developed by the Cochrane Collaboration (see the Appendix). Medical subject headings and text words used were relevant to the population (informal caregivers) and the condition (CKD). Abstracts and studies were screened and discarded if they did not fit the inclusion criteria. Studies that appeared to include relevant information were retrieved and their full-text versions were examined for study eligibility. Reference lists from the identified articles were searched.

Data extraction and trial quality assessment

From the included studies, we extracted information on study designs [RCTs, quasi-RCTs (allocating participants to different forms of care that is not truly random), non-RCTs, controlled before-and-after study, prospective cohort study; retrospective cohort study, historically controlled trial, nested case-control study, case-control study, before-and-after comparison, case report/case series, interrupted time series and qualitative research], setting, participant characteristics, interventions and outcomes assessed. Standard criteria developed by the Cochrane Collaboration [20] and the Cochrane Effective Practice and Organisation of Care Group (EPOC) [21] were used to assess the methodological quality of studies if relevant. These questions included the following:

1. How was the comparison made? (Between two or more groups receiving different interventions, or with the same group over time?)
2. Were participants allocated to groups? (e.g. concealed randomization, quasi-randomization, action of researchers, time differences, location differences, treatment decisions, patient preference, basis of outcome)
3. Which parts of the study were prospective? (Identification of participants, assessment of baseline and intervention allocation, assessment of outcomes, hypothesis generation)
4. On what variables was comparability between groups assessed? (Potential confounders, baseline assessment of outcome variables)
5. Who were blinded? (Participants, investigators, outcome assessors)
6. What was the rate of follow-up?

We extracted the data on the sample size, variances and mean differences from baseline in outcome variables. If summary statistics for change from baseline were not available, the mean, standard deviation and number of people in each group were extracted. We anticipated a wide heterogeneity of interventions and outcomes measure and therefore reported the data separately for each study. If applicable, the summary estimate of effects was calculated with 95% confidence intervals, which is a weighted average of the summative intervention effect across all studies.

Results

Literature search (Figure 1)

Our search yielded 1178 articles. Of these, 1086 were excluded after title and abstract review because they were ineligible. Of the remaining 92 potentially eligible studies, 89 were excluded after full text review for reasons including no caregiver intervention assessed, non-research articles, no caregiver assessments, non-CKD or duplicate articles. Of
the 92 full-text articles we reviewed, 56 (61%) explored the physical and psychosocial well-being (quality of life, burden, depression, fatigue, marital stress, loneliness), adjustment, needs and concerns of informal caregivers but were excluded because no caregiver intervention was assessed. Of these, 24 had focussed only on caregivers of dialysis patients. We identified three studies that could be included in the review, which assessed the effectiveness of an intervention for informal caregivers of patients with CKD [22-24].

Characteristics of the studies
The three eligible studies examined the effect of informational material on caregivers’ knowledge and were not RCTs. The characteristics of these studies are provided in Table 2. None of these study designs could be assessed according to EPOC criteria for validity or risk of bias.

Two studies used a pre- and post-test study design. One of these studies assessed the effect of an information booklet provided to caregivers of patients on haemodialysis on their knowledge of home care management [22]. The content of the booklet and structure questionnaire was developed from a literature review and input from experts. The caregiver’s physiological function, self-concept, role function and interdependence were evaluated. The post-test evaluation was conducted 1 week after the pre-test and the study found that overall knowledge score was significantly improved after the information booklet was provided. The overall pre-test knowledge scores were 50.35 and 86.25 in the post-test. The overall improvement in the mean score was 35–89 (t = 13.4, P < 0.001). An analysis of variance demonstrated no correlation between selected demographic variables and post-test knowledge scores.

A similar study evaluated the impact of an educational intervention, delivered by nurses, on the knowledge of caregivers of patients on haemodialysis and peritoneal dialysis [23]. The post-test assessment was conducted 5 months after the pre-test assessment. Four domains of knowledge were assessed that included general knowledge, diet, treatment and pharmacological treatment. In caregivers of haemodialysis patients, there was an increase in all domains of knowledge assessed, general (P = 0.018), diet (P = 0.016) and treatment (P = 0.040) domains. In the peritoneal dialysis group, caregivers’ knowledge was significantly increased in the general knowledge (P = 0.066), diet (P = 0.039) and pharmacological treatment (P = 0.046) domains.

The third study used participatory action research methods in which paediatric kidney transplant recipients and caregivers were given a proactive role in developing, evaluating and modifying an information handbook on self-care over an 8-year period [24]. Their opinion and suggestions were obtained by semi-structured interviews. The handbook intervention focussed on prevention of immunosuppression-related illnesses, management of side effects and adapting to the illness, and facilitating social support. The participants helped to structure the content and language to the appropriate cognitive level for patients and caregivers. The topics considered to be important to the participants included diet, immunosuppressive medication, secondary effects, protecting the graft, monitoring side-effects and importance of self-care. The participants’ suggestions and opinions were incorporated into the
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Table 2. Characteristics and results of evaluation studies

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Study design</th>
<th>Setting</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes assessed/endpoint</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fathima 1996 [22]</td>
<td>Pre- and post-test</td>
<td>Single centre, India</td>
<td>30 caregivers of adult HD patients</td>
<td>Information booklet</td>
<td>Post-test difference in knowledge score</td>
<td>Overall knowledge score improved. Knowledge increased in all four domains</td>
</tr>
<tr>
<td>Gonzalesa 2005 [23]</td>
<td>Pre- and post-test</td>
<td>Single centre, Spain</td>
<td>95 caregivers of adult (53 HD, 42 PD) patients</td>
<td>Oral and written information delivered by nurses</td>
<td>Post-test difference in four domains of knowledge, caregiving load</td>
<td>Knowledge increased in all four domains</td>
</tr>
<tr>
<td>Tornay 2007 [24]</td>
<td>Participatory action research: patient and caregiver opinions and suggestions were obtained to evaluate and modify an information handbook</td>
<td>Single centre, Spain</td>
<td>135 caregivers paediatric Tx patients</td>
<td>Information booklet</td>
<td>Knowledge self-confidence</td>
<td>Clarified doubts, diminished stress and fear, facilitated adaptation</td>
</tr>
</tbody>
</table>

Development of the handbook. The handbook was evaluated after being redistributed to paediatric post-transplant patients and caregivers.

Discussion

Despite the growing recognition of the burden and adverse effects of CKD on informal caregivers, very little evidence is available about the effect of information or support interventions on their physical or psychosocial well-being. The lack of evidence may be due to inadequate advocacy, funding and support resources available to develop, implement and evaluate support and information interventions for informal caregivers. Core clinical services usually involve responding to the medical needs of the individual patient but often do not include meeting the support and informational needs of their informal caregivers.

Although RCTs are considered to be the gold standard in evaluating the effects of interventions, non-RCT studies can yield clues regarding the effects of interventions. The current, very small evidence base is characterized by a participatory action research study and pre- and post-test studies in which the outcomes before the intervention are compared with the outcomes measured after the intervention. They only assessed an educational intervention and focused on a single outcome of caregivers’ knowledge, and two were short-term. The other interventions and outcomes provided in Table 1 have not been assessed. Collectively, caregiver intervention studies in CKD have a very narrow focus.

In comparison, studies in other disciplines have assessed a more comprehensive range of caregiver interventions and outcomes. Several RCTs on caregiver support and information interventions have been conducted in other disciplines, particularly in stroke, dementia and cancer. In one study, 300 caregivers of patients with stroke were randomized to either conventional caregiver instruction or structured caregiver training. Caregiver training reduced cost and caregiver burden while improving psychosocial outcomes in caregivers and patients at 1 year [12]. Another RCT for stroke concluded that family support improved the quality of life for carers [13]. Similarly, caregiving burden was reduced in caregivers of patients with dementia who received occupational therapy, which included cognitive and behavioural interventions, compared with those who did not receive occupational therapy [14]. A three-group RCT conducted with family caregivers of cancer patients found that the coping skills intervention improved caregiver quality of life significantly more than standard hospice care and supportive visits [18].

As there is insufficient evidence to confirm the benefit of interventions that aim to provide support for caregivers of patients with CKD, we are unable to make recommendations for practice. However, studies exploring CKD caregiver experiences, including caregiving burden, depression and quality of life, suggest that effective support interventions are needed [25,26].

To extend beyond understanding the needs and perspectives of informal caregivers, we suggest the use of participatory action research methods. Recognized as an ‘empowering methodology’, it allows participants to be involved in decision-making, planning, implementing and evaluating interventions [27,28]. Participatory action research, used in one of the included studies [24], is a method by which research and action are coupled together to plan, implement and monitor change. The participants become ‘co-researchers’ and the researcher’s role is to participate in the initiatives and use their research knowledge and expertise to support and facilitate the participants in the research program [29]. This enables the development of programs that considers and incorporates the specific situation and conditions that will influence the outcome of the programmes. Because of these reasons, we would contend that these methods are appropriate at this stage, for developing effective support interventions and programs for caregivers of patients with CKD.

Future research can assess a broader range of caregiver interventions including internet-based information, online support groups, psychological therapy, practical support...
and can elicit suggestions for improving caregiver support from patients and caregivers. In addition to caregivers’ knowledge, other outcomes should be measured including physical, psychological and emotional status, social outcomes, caregiver burden and patient outcomes, as detailed in Table 1.

Given the nature and treatment of CKD, support for caregivers is critical. This is particularly important for caregivers of dialysis patients, especially home-based therapies. These therapies are time consuming, technologically complex and have a profound effect on the patient and caregiver’s physical and psychosocial well-being, relationships and lifestyle [5,8,25].

The underlying premise of patient-centred care includes responding to the unique needs of individual patients and supporting their informal caregivers in their healthcare provider roles. Our review highlights the current lack of evidence to guide support and well-designed studies are needed to develop effective support interventions for caregivers of CKD patients. Until this is achieved, CKD services may be helping their patients while contributing to health and social problems for the carers. We hope these findings will draw more attention from the professional renal community, towards the development and evaluation of services to respond to the support and informational needs of informal caregivers.

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Conflict of interest statement. None declared.


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22. Fathima L. The effect of information booklet provided to caregivers of patients undergoing haemodialysis on knowledge of home care management. Nurs J India 2004; 95: 81–82

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## Appendix

### Search strategies

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