Abstract

Background
Living with end stage kidney disease and having dialysis is burdensome, and there is a need for support from informal caregivers (i.e. family members and friends). Renal health professionals readily acknowledge and value the support provided by caregivers although the activities and experiences of caring for a loved-one who is receiving dialysis is less well understood.

Objectives
To review studies about the perspectives and experiences of family members and friends who provide support for adults receiving either haemodialysis or peritoneal dialysis.

Methods
A mixed methods systematic review was conducted. Eight databases (Medline, CINALH, EMBASE, PsycINFO, Proquest, Web of Science, Cochrane Library and JBI library) were comprehensively searched using relevant key words for studies regardless of design published in English from January 2006 to July 2017.

Results
Twenty studies were included in this review. Informal caregivers undertake many everyday activities as well as a range of dialysis-specific activities, report an elevated level of burden, feel overwhelmed experience social isolation, and also need to consider their own health. A unique finding was that caregivers also experienced personal growth that may defuse the impact of caregiving burden and to help them develop a sense of resilience to sustain the support through the tough times and for many years.
Conclusion

This review substantiates that caregiver burden is due to the unrelenting nature of complex dialysis-specific activities although resilience often develops. Additional research is necessary to understand social support in this context and how health teams can assist caregivers further.

Keywords List: caregivers, dialysis, end stage kidney disease, family support, social support
INTRODUCTION

Chronic kidney disease progresses along a five-stage trajectory towards terminal kidney failure, which is called End Stage Kidney Disease (ESKD) (Chang et al. 2012). Globally, the numbers of people with ESKD is expected to double from 4.9 million by the year 2030 (Liyanage et al. 2015). At this late-stage of kidney failure, people require lifelong replacement of kidney function, which includes dialysis (e.g. haemodialysis or peritoneal dialysis) and transplantation to sustain their life (Jha et al. 2013). According to Liyanage et al. (2015), there are approximately 2.6 million people receiving kidney replacement therapy, and 78% of them receive dialysis (either peritoneal- or haemodialysis). Living with ESKD and being treated with dialysis causes a great deal of burden (e.g. financial problems, work conflicts, family dysfunction) for patients as well as their family and/or caregivers (Gerogianni & Babatsikou 2014).

As ESKD and dialysis are burdensome for people, having informal caregivers is crucial. Studies have shown that greater support from family members and/or close persons is associated with improved survival, more successful treatment adherence, and better quality of life for those living with ESKD (Kimmel et al. 1998; Kara et al. 2007; Ahrari et al. 2014; Ibrahim et al. 2015). Indeed, the importance of family caregivers is recognized by governments as a valued resource in sustaining frail elders and adults living with disabilities and chronic illnesses to live at home (Paolucci & Garcia-Goni 2015; James et al. 2016; Williams et al. 2016).

Informal caregivers can be members from the patients’ families and/or people who have a close relationship with the patient (Low et al. 2008; Buck et al. 2015). These people volunteer and dedicate their time, work and energy to support physical, emotional and financial needs for their loved ones (Low et al. 2008). The term ‘informal caregiver’ is also used in the literature to describe non-professionals providing care (From et al. 2015). For people receiving dialysis
treatment, informal caregivers (term used throughout this paper) provide support for practical purposes such as travelling (e.g. providing transportation or assisting the patients to travel), diet and fluid adherence (e.g. shopping for correct food, meal preparation), medical appointment arrangement, organisation of supplies, and symptom management (Welch et al. 2014). Beanlands et al. (2005) described informal caregivers’ roles as entailing monitoring and evaluating the patients’ medical conditions and their response to treatment (appraisal); communicating with health professionals on behalf of the patients (advocacy); managing all care activities and creating daily routines (juggling and routinising); and teaching, encouraging, and enforcing the patients’ self-care (coaching).

Low et al. (2008) conducted a systematic review to examine caregivers’ support for people with ESKD; the review addressed the impact of ESKD on social life and psychological health in ‘close persons’ (family members or informal caregivers). This review included research published prior to 2006 and found that informal caregivers’ responsibilities contributed to their poorer quality of life and greater psychological distress. However, this review failed to identify positive effects which might suggest support that would empower informal caregivers to continue in the role, which in turn can benefit patients (Low et al. 2008). Health policies worldwide have addressed support to assist informal caregivers to care for older people, such as providing financial support, allowing flexible employment and offering family caregiver support programs (Bauer & Sousa-Poza 2015; James et al. 2016). However, there are lack of policies regarding informal caregivers in ESKD. Thus, more evidence regarding informal caregivers (i.e. their experience and feelings) is needed to assist health care stakeholders in supporting informal caregivers.

More recently, a review of qualitative studies was conducted examining the experience and perspectives of informal caregivers in caring for patients receiving home haemodialysis (Walker et al. 2015). This review highlighted that isolation from medical and other supports, and family
burden caused caregivers’ anxiety and fear about home haemodialysis. However, the patients and caregivers had more freedom, flexibility and the patient-caregiver relationship had been strengthened. This current review updates and extends the two previous reviews by: i) expanding the inclusion criteria to include peritoneal and haemodialysis and a broader range of study designs; and ii) mixing (i.e. integrating) the results from these studies. Thus, the systematic review aims to review recent studies in which the perspectives and experiences of informal caregivers (family members/close persons) when providing support for people receiving dialysis.

METHODS

The review method was guided by the Joanna Briggs Institute (JBI) guideline for mixed methods systematic reviews (2014).

Inclusion criteria

Studies were included if they involved family members and/or close friends providing any type of support for adults (≥18 years old) with ESKD receiving either haemodialysis (HD) or peritoneal dialysis (PD); and reported on the burden, stressors, and impact of being a caregiver. Exclusion criteria were caregivers of paediatric patients or kidney transplant recipients. Support provided by family members and/or close relatives must have been the primary outcome of quantitative studies or the phenomenon of interest in qualitative studies. In this review, qualitative, quantitative or mixed-method studies were included. Excluded papers were reviews, discussion papers, case studies and conference abstracts.

Search strategy

A search strategy was developed based on JBI systematic review guideline (The Joanna Briggs Institute 2014) to locate relevant publications. Eight electronic databases (Medline, CINALH, EMBASE, PsycINFO, Proquest Nursing & Allied Health, Health and Medicine collection and
Proquest dissertation, Web of Science, Cochrane Library and JBI library) were searched. The search strategy employed the following main key words: social support, family support, family, caregiver, end-stage kidney disease, renal replacement therapy, haemodialysis, and peritoneal dialysis. Subheadings and thesauruses were used to broaden the search according to each database and were combined with the key words using Boolean phrases (i.e. ‘and’, ‘or’) (see Table 1). The search was limited to English language studies published between 1 January 2006 and 31 July 2017. The search for literature during this period of time was conducted in order to update the evidence, as the review by Low et al. (2008) is more than 10 years old. Reference lists of included studies were also checked for eligible studies.

**Inclusion and evaluation process**

The identification and screening process is illustrated in Figure 1. Following removal of duplicates, all three co-authors screened titles and abstracts for eligibility for full-text retrieval. A large number of articles were excluded (n=1,788) and we re-screened a second time to be certain that we had not excluded an article prematurely. Among studies selected for full-text appraisal, 61 studies were excluded. Of these, 40 studies did not include caregivers, 4 involved ESKD patients who were not yet receiving dialysis, and 11 did not focus on caregivers’ support. Two studies measured social support but this was not the primary focus of the study. In 2 studies, the abstract was in English; however, after receiving the full-text the articles were not in English and were also excluded.

The next step involved appraising the research quality of the remaining 22 articles using JBI critical appraisal tools. The JBI has a range of critical appraisal tools to suit different research designs. These tools are accessible (see http://joannabriggs.org/research/critical-appraisal-tools.html). Three appraisal tools (cross-sectional studies, qualitative research and quasi-experimental studies), were used to appraise the quality of the included studies in this review (The Joanna Briggs Institute 2017a, 2017b, 2017c).
quality assessment of the full-texts. Two authors (AB and TG) independently reviewed the initial assessment and any discrepancies in assessment were resolved through discussion of the author team. As a result of the evaluation process, two of these studies (Aghakhani et al. 2014; Grapsa et al. 2014) were deemed of low quality and were excluded from the review (see Supplementary table 1).

Data extraction

Data extraction processes included publication year, study location, purpose, design, sample size, key findings/outcomes and study strengths and limitations (see Table 2). Further details about informal caregivers (age, gender relationship to patient, education, income and employment) were extracted. Caregiver burden mean scores were extracted where available (see Supplementary table 2). For qualitative data, we extracted themes and/or categories with participant quotes for each study (guided by The Joanna Briggs Institute 2017d) (see Level 1 findings, Supplementary table 3).

Data synthesis

We conducted a mixed methods synthesis of results from the 20 included studies. According to JBI guideline for mixed method reviews (The Joanna Briggs Institute 2014), first a separate synthesis for the quantitative and qualitative studies are completed then the reviewer mixes the synthesis. For quantitative synthesis, it was not possible to conduct a meta-analysis due to the heterogeneity of study populations and instruments used. Thus, the synthesis followed a narrative method where similar findings of the included studies were grouped into textual descriptions. For qualitative synthesis, extracted qualitative data (i.e. original interview excerpts presented in the article) were coded then conceptualised into sub-themes (Level 2 findings) and subsequently into final themes (Level 3 findings) (see Supplementary table 3). One author (VH) performed the initial coding. The other two authors (TG and AB) independently reviewed the codes and developed the sub-themes. All authors then collaborated
to synthesis the codes into the final themes. The last step involved mixing the quantitative and qualitative syntheses by comparing and contrasting the data in each to find the similarities and differences in order to provide deeper understanding of how informal caregivers provided care and support for their loved ones on dialysis.

RESULTS

Characteristics of included studies

Of the included studies, 13 were quantitative and 7 were qualitative studies (see Table 2). With one exception (Mollaoglu et al. 2013), all quantitative studies used a cross-sectional design. All seven qualitative studies used a descriptive qualitative design. Eleven different countries were represented in the included studies; of these, five countries had more than one study (Turkey, n=4; Jordan, n=3; Brazil, n=3; Canada, n=2; USA, n=2). The majority of studies examined caregivers of patients having HD (n=13), PD (n=3), both HD and PD (n=3), and 1 study compared caregivers of patients having HD with those following kidney transplantation (Avşar et al. 2015). The number of participants recruited within the 20 research studies varied from 6 (Rodrigues de Lima et al. 2017) to 225 participants (Jiang et al. 2015).

Most of caregivers were female between 30 to 60 years of age. The majority of caregivers were spouses (e.g. wife, husband or partner) followed by children or children in-law and brother/sister. In some studies, a minority of caregivers were labelled as other family members and friends (Belasco et al. 2006; Rioux et al. 2012; Alnazly & Samara 2014; Bayoumi 2014; Alnazly 2016a, 2016b; Cantekin et al. 2016; Griva et al. 2016). Other characteristics of participants are presented in Supplementary table 4.
**Quantitative synthesis results**

**Informal caregivers’ activities**

Two studies reported activities provided by informal caregivers (Alnazly 2016a; Griva et al. 2016) who were responsible for dialysis specific tasks, daily living activities, household tasks, advocacy tasks, teaching tasks and emotional support. Details about the activities performed by informal caregiver is provided in Supplementary table 5. The most frequent activities provided by caregivers of the patients on PD were related to coaching and comfort measure tasks (Griva et al. 2016). Highly dependent patients on PD required caregivers to focus more on personal hygiene and dialysis-related activities (Griva et al. 2016). However, the hardest task identified by caregivers of the patients on HD was finding a replacement caregiver so that the primary caregiver could have a break (Alnazly 2016a).

**Informal caregiver burden**

Nine of the 13 quantitative studies measured caregiver burden. Three different instruments were used: Zarit Burden Interview (ZBI - 6 studies), Caregiver Burden Scale (CBS - 2 studies), and Oberst caregiving burden scale (OCBS - 1 study). Overall, there was a medium level of burden (mean score ZBI 21- 88; > 30 on the CBS and OCBS). Three studies reported high levels of caregiver burden (Washio et al. 2012; Avsar et al. 2015; Cantekin et al. 2016). Three studies also compared type of dialysis therapy and caregiver burden (Belasco et al. 2006; Avsar et al. 2015; Cantekin et al. 2016), with those caring for patients receiving HD having a higher burden than PD (Cantekin et al. 2016) and kidney transplantation (Avsar et al. 2015) (33.3% and 14.7% versus 16.7% and 0%, respectively). However, Belasco et al. (2006) reported no difference in burden level for those caring for people receiving HD or PD. Only one study reported a significant decrease in burden following an educational intervention for caregivers, however the level of burden remained high overall (Mollaoglu et al. 2013). None of the studies measured caregiver burden longitudinally.
Demographic factors associated with caregiver burden

Demographic characteristics of both caregivers and patients and level of caregiver burden have been studied but the findings were inconsistent. For instance, female caregivers reported more burden than male caregivers (Mollaoglu et al. 2013), however Washio et al. (2012) found no gender difference. Greater levels of caregiver burden were associated with being a spouse [either husband or wife] of the patient (Washio et al. 2012), or by being a daughter (Mollaoglu et al. 2013). Regarding caregivers’ age, one study found that younger caregivers reported higher levels of burden (Mollaoglu et al. 2013); however, Bayoumi et al. (2014) found the opposite. While more highly educated caregivers reported greater burden (Mollaoglu et al. 2013; Bayoumi et al. 2014), caregivers’ actual employment and income status was not shown to be related to burden (Washio et al. 2012; Mollaoglu et al. 2013). Duration of being an informal caregiver was not associated with burden (Mollaoglu et al. 2013; Alnazly 2016a), but more caregiving hours per week did contribute to increased burden (Bayoumi et al. 2014). As patients’ level of functional ability deteriorated, there was increasing burden on caregivers (Washio et al. 2012; Griva et al. 2015). Most studies used a cross-sectional design, thus additional longitudinal studies or studies with larger sample size are needed to be able to compare results, generalise findings and indicate predictors of caregiver burden.

Impact on the informal caregiver

Four studies focused on the effects of caregiver burden. Depression and anxiety were related to caregiver burden (Belasco et al. 2006; Rioux et al. 2012; Washio et al. 2012; Avsar et al. 2015). Approximately 3-25% of informal caregivers self-reported having depression across these studies. Other studies found that high levels of caregiver burden were associated with lower quality of life and poorer sleep quality (Belasco et al. 2006; Avsar et al. 2015). Only one study examined the association between caregiver burden and coping strategies (Alnazly...
This study found that religious beliefs assisted caregivers to cope with the burden of having a family member on HD.

Social support for caregivers was reported in three studies (Asti et al. 2006; Jiang et al. 2015; Pereira et al. 2017). Support sources (from family members and others outside family) and types (instrumental, financial, practical and emotional support) were examined from caregivers’ perspectives. It was reported that a high level of support by family members and friends (Asti et al. 2006; Jiang et al. 2015), and a medium level of practical and emotional support was provided to the caregivers (Pereira et al. 2017); however, no study examined the relationships between support for the informal caregivers and burden.

Qualitative synthesis results

A total of 34 findings were extracted from seven qualitative studies. Following JBI techniques, these findings were analysed for similarities and differences and categorised based on similarity of meaning. The findings were grouped into 8 categories which were synthesised into 3 overarching themes (see Supplementary table 6).

Theme 1 - Having an active role

This finding synthesised the complex practical and emotional roles of caregivers for patients receiving dialysis treatment. These roles required an active commitment to learn about and to do the dialysis. Three studies captured the in-depth practical role of caregiving (De Rosenroll et al. 2013; Rajkomar et al. 2014; Welch et al. 2014). There were multiple caregiving roles such as learning how to do dialysis (e.g. non-touch hygiene technique); preparing the dialysis machine/equipment (De Rosenroll et al. 2013); dealing with the problems of the HD machine (e.g. blood clot, leaking water) (Rajkomar et al. 2014); monitoring for dialysis complications (Welch et al. 2014); and arranging the alternative caregiver for patients while the main caregiver was away (Rodrigues de Lima et al. 2017). Patience and compassion to care for the
patients were key emotional roles. These were described as being with loved persons (De Rosenroll et al. 2013), and giving encouragement when the loved ones felt distressed or hopeless (Welch et al. 2014). Moreover, moral support (e.g. empathy) from other family members and also from the patients, was considered an important support for both the person receiving dialysis as well as the caregiver (Welch et al. 2014; Williams 2017).

**Theme 2 - Struggling with caregiving responsibilities**

The second theme synthesised the negative effects of being an informal caregiver. These included being overwhelmed with caregiving responsibility, social isolation, and suffering decline in personal health and well-being. Due to the ongoing, unrelenting demands of dialysis therapy and its often-unpredictable complications and symptoms, caregivers described being overwhelmed with the responsibility for their family members (Welch et al. 2014; Alnazly & Samara 2016; Rabiei et al. 2016; Rodrigues de Lima et al. 2017; Williams 2017). Informal caregivers described feelings of uncertainty, stressfulness and being frightened when their family member’s health was unstable. Welch et al. (2014) described this as the caregiver’s life being ‘sucked out’. The feelings of helplessness, frustration and fear of the future revealed how burdensome the responsibilities were for caregivers.

One of the biggest difficulties informal caregivers experienced was social isolation (Alnazly & Samara 2016; Rabiei et al. 2016; Williams 2017). It was described as feelings of loneliness, conflicting with other family members regarding decisions, having lack of support from the family, being unable to fulfil other normal social activities outside the sick person (e.g. the caregivers’ children), and having to put their own social life on hold.

Another effect on informal caregivers was a decline of their own health and well-being. Caregivers suffered varied health problems such as physical injuries (e.g. back injury, joint aches from lifting the patient), restlessness and stress, depression and anxiety because of witnessing the health decline of their loved ones (Alnazly & Samara 2016; Rodrigues de Lima...
et al. 2017; Williams 2017). In addition, caregivers claimed to have insufficient time for self-care activities such as maintaining a healthy diet, doing exercises or taking their own medication properly (Alnazly & Samara 2016).

**Theme 3 - Experiencing personal growth**

The final synthesised theme was experiencing personal growth. This theme encompassed two categories: i) gaining and having confidence in caring, and ii) inner strength. In all 7 qualitative studies, family members and/or close persons reflected on their time as caregivers as a process of gaining and finally having confidence in caring for their loved one. They described the process of gaining confidence in caregiving as similar to learning how to drive (Rajkomar et al. 2014) and then becoming second nature for them (Welch et al. 2014). Caregivers showed a high level of confidence, describing their ability to respond quickly and accurately in an emergency situation (Alnazly & Samara 2016; Rodrigues de Lima et al. 2017; Williams 2017), having adequate understanding of the dialysis treatment (Welch et al. 2014), and their strong will in fighting for patients’ benefits (De Rosenroll et al. 2013). These experiences afforded caregivers an opportunity to develop a sense of self-worth and strength in being a caregiver. In three studies, caregivers described having hope and a positive outlook for their family member (De Rosenroll et al. 2013; Rabiei et al. 2016; Williams 2017). In order to cope with the burden of caring, caregivers used religion, spirituality and meditation to keep them strong (Alnalzy & Samara 2014; Welch et al. 2014; Rabiei et al. 2016; Williams 2017). Thus, the caregivers were able to recognise positive outcomes of caregiving, despite the caregiving burden and its negative impacts on them.

**Mixed methods review**

When integrating the results from this review, the quantitative studies described the most frequent or difficult everyday activities undertaken by informal caregivers, however the
complexity and onerous dialysis-specific activities were revealed in the qualitative studies. Overall, informal caregivers reported an elevated level of burden and identified the caregivers’ perspectives and emotional responses towards this burden. Caregivers noted they must deal with feeling overwhelmed, being socially isolated, and need to consider their own health problems as well as those of their family member with ESKD. Additionally, a unique finding was that personal growth experienced by informal caregivers may defuse the burden experience.

**DISCUSSION**

This review provides updated information on the informal caregivers’ multiple roles and activities, caregiving burden and the impact of caring for patients receiving either haemodialysis or peritoneal dialysis. The provision of support from informal caregivers, who are generally family members and friends, has been emphasised as an important role in helping people with ESKD to adjust to the illness and to increase adherence to the treatment regimen (Low et al. 2008; Gerogianni & Babatsikou 2014). The results from this review highlights that the provision of support from family members and friends is a complex role with multiple dialysis-specific caregiving activities provided. The caregiver has to be involved in assisting with daily life activities, including hygiene, providing meals and financial resources, as well as potentially dealing with other chronic illnesses, such as stroke and dementia (Tseng et al. 2015; Petriwskyj et al. 2016). However, the review findings highlight several specific caregiving tasks related to the dialysis therapy, particularly home dialysis, which the caregivers have to carry (i.e. preparing the dialysis machine and equipment, and monitoring the dialysis process). These findings are in line with the recent systematic review of caregiver perspective on home haemodialysis (Walker et al. 2015). The involvement in doing the dialysis treatment as an advanced medical procedure is likely to add weight to the informal caregivers’ role.
The caregivers of the patients having dialysis generally have an elevated level of burden. They identified the burden as being overwhelming caregiving tasks, social isolation and health decline. This finding aligns with previous reviews of caregivers with home dialysis (Low et al. 2008; Walker et al. 2015). The burden of caring role is common in informal caregivers and it affects their health and well-being (Corry et al. 2015). Thus, caregiver burden might have effects on patients as care-recipients as well. Indeed, it has been reported that caregiver burden was associated with less social support and lower health related quality of life for both patients and caregivers (Alvarez-Ude et al. 2004; Griva et al. 2016).

The unique finding in this review is the positive impact of caregiving experience among the informal caregivers and benefits to patient care. It was apparent that the caregivers’ emerging confidence and strength contributed to their ability to cope with the burden of caregiving. These coping strategies can be identified as resilience (Ross et al. 2003), a term that refers to the ability of individuals and groups to respond in a positive manner to a challenging situation through a complex process of adaptation and adjustment (Howe et al. 2012; Aburn et al. 2016). Resilience has been studied in caregivers of stroke survivor and patients with dementia (Sophie et al. 2014; Petriwskyj et al. 2016). The informal caregivers’ development of resilient abilities during their caregiving experiences is an important factor that strengthens and sustains the caregiving relationship.

The review findings address some of the limitations of previous reviews by including all studies regardless of design or research paradigm. However, the review has certain limitations that must be acknowledged. First, most of the included studies provided inconsistent and descriptive evidence due to study design. Thus, facts presented about the provision of support from informal caregivers might be inconclusive. Most quantitative studies were cross-sectional with samples of convenience, with only one intervention study identified. While all studies used well-validated measurements, which increases the robustness of the results, the findings
from cross-sectional studies precludes establishing any causal relationships between variables. The included qualitative studies also did not provide clear social and cultural context, which limits transferability of the results. The consideration of research methods may affect the confidence of applying findings beyond the study setting.

Second, over half of the studies originated from high–income countries (e.g. USA, Canada, Jordan, or Singapore). Therefore, it is difficult to generalise the results of these studies to other contexts with socioeconomic and cultural differences. Lastly, due to limitation of time and resources, only English language papers were reviewed. Thus, evidence regarding familial caregivers presented in other languages could not be included in the review.

**IMPLICATIONS FOR PRACTICE**

The informal caregivers’ role for patients receiving kidney dialysis is an essential and valuable one, however renal health professionals should be aware of the complexity and burden associated with this role. Therefore, renal teams ought to consider and assess caregivers’ needs when the decision to implement dialysis is made, since these informal carers will provide much of the care. Based on the informal caregivers’ needs and concerns regarding caregiving tasks, renal health professionals might conduct training sessions providing information, guidance and preparation for the tasks and how to seek help if needed. Caregiver training may reduce the burden in caring the patients and therefore improve caregiver quality of life. Additionally, the assessment of caregivers’ burden and emotional responses may help with early identification of any potential triggers of stress.

**IMPLICATION FOR RESEARCH**

Despite the fact it is the patients with ESKD who are the ones in receipt of care provided by healthcare professionals, informal caregivers also require support. Future research to develop
and test interventions designed to sustain resilience amongst caregivers are urgently required. In addition, more research is required to understand the effects of informal caregiver activities on the health and well-being in both caregivers and patients.

**CONCLUSION**

This review has been conducted to synthesis the recent evidence about activities and burdens of informal caregivers for people with ESKD undergoing either peritoneal or haemodialysis. Despite informal caregiver burden still being a focus of research, the review found that there is an impact on the health and well-being on them. Notably, the role of resilience in adjusting to the personal and family- associated demands of providing dialysis-related care was identified in this review and this warrants further research. Multidisciplinary renal practitioners should also provide support for informal caregivers and this in turn, may result in better health outcomes for patients receiving dialysis regardless of whether it is in the dialysis centre or at home.
REFERENCES


