

Burden of Care and Quality of Life Among Caregivers for Adults Receiving Maintenance Dialysis: A Systematic Review

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Rationale & Objective: Dialysis is a burdensome and complex treatment for which many recipients require support from caregivers. The impact of caring for people dependent on dialysis on the quality of life of the caregivers has been incompletely characterized.

Study Design: Systematic review of quantitative studies of quality of life and burden to caregivers.

Setting & Study Population: Caregivers of adults receiving maintenance dialysis.

Selection Criteria for Studies: The Cochrane Library, Embase, PsycINFO, CINAHL, PubMed, and MEDLINE were systematically searched from inception until December 2016 for quantitative studies of caregivers. Pediatric and non-English language studies were excluded. Study quality was assessed using a modified Newcastle-Ottawa scale.

Data Extraction: 2 independent reviewers selected studies and extracted data using a prespecified extraction instrument.

Analytical Approach: Descriptive reports of demographics, measurement scales, and outcomes. Quantitative meta-analysis using random effects when possible.

Results: 61 studies were identified that included 5,367 caregivers from 21 countries and assessed the impact on caregivers using 70 different scales. Most (85%) studies were cross-sectional. The largest identified group of caregivers was female spouses who cared for recipients of facility-based hemodialysis (72.3%) or peritoneal dialysis (20.6%). Caregiver quality of life was poorer than in the general population, mostly comparable with caregivers of people with other chronic diseases, and often better than experienced by the dialysis patients cared for. Caregiver quality of life was comparable across dialysis modalities.

Limitations: Heterogeneity in study design and outcome measures made comparisons between studies difficult and precluded quantitative meta-analysis. Study quality was generally poor.

Conclusions: Quality of life of caregivers of dialysis recipients is poorer than in the general population and comparable to that of caregivers of individuals with other chronic diseases. The impact of caring for recipients of home hemodialysis or changes in the impact of caring over time have not been well studied. Further research is needed to optimally inform dialysis programs how to educate and support caregivers.

Complete author and article information provided before references.

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Caregivers and partners play an integral role in the management of many chronic diseases.¹⁻⁵ In the United States, there are an estimated 14.7 million family and unpaid caregivers for people living in the community with disabilities and an estimated 78% of caregivers incur out-of-pocket expenses averaging US \$6,954 annually.⁶

Dialysis for the management of kidney failure represents perhaps one of the more burdensome ongoing medical interventions, encompassing mental, physical, financial, and social demands. The adverse impact of kidney failure on patient quality of life (QoL) is widely acknowledged.⁷⁻¹¹ The potential impact of caring for people with kidney failure treated by dialysis on the QoL of the caregivers is less often discussed.

The prevalence of dialysis dependence is increasing, with the greatest growth among the elderly, who typically have increased comorbid conditions and potentially greater care needs.¹²⁻¹⁶ The older age among dialysis recipients is often associated with advancing age among caregivers, who are often lifetime partners.^{17,18} Although most dialysis therapy is administered in facilities by professional health staff, a substantial minority of recipients

undertake dialysis therapy at home. There is some evidence that home dialysis therapy, either as peritoneal dialysis (PD) or home hemodialysis (HD), is associated with improved QoL for recipients.^{19,20} However, improved health outcomes for recipients and lower costs for providers may risk medicalizing the home and imposing increased responsibility on caregivers.^{19,20}

Our primary aim was to systematically review studies that quantitatively evaluated caregiver QoL and burden of caregiving for adult dialysis recipients. Secondary aims included demographic profiling of caregivers, details of measurement scales used by investigators, and comparing QoL of caregivers of dialysis recipients with other caregivers, the general population, and the dialysis recipients themselves. Last, we compared QoL of caregivers of people undergoing different dialysis modalities.

Methods

Search Strategy and Inclusion Criteria

A prespecified search strategy (Item S1) was used to identify studies published before January 1, 2017, that

reported the burden or QoL of caregivers of dialysis (facility HD, home HD, or PD) patients. Electronic databases including The Cochrane Library, Embase, PsycINFO, CINAHL, PubMed, and MEDLINE were systematically searched with an English language restriction. Unpublished studies were identified, when possible, by abstracts of conference proceedings, as well as reference lists of relevant studies and review articles.

Two investigators independently evaluated the title and abstract of each study identified from the search for potential inclusion. Any citations without electronically available abstracts were discarded unless the title was convincing of the study's relevance. When there was disagreement between the 2 reviewers, a third investigator adjudicated. A second round of title and abstract review was undertaken to select only quantitative studies involving caregivers of adult patients.

Inclusion criteria limited the systematic review to original investigations, with review articles and commentaries excluded. Other excluded studies used qualitative measures to assess QoL. Studies with >50% of participants being caregivers for non-dialysis-dependent patients (patients with earlier stages of chronic kidney disease, kidney transplant recipients, or patients with other chronic diseases) were also excluded. Caregivers of pediatric dialysis patients were excluded because the issues for children were considered unique.

Full-text articles of each manuscript considered for inclusion based on title and abstract were reviewed independently by 2 investigators. If there was disagreement about whether a study should be included, a third reviewer adjudicated.

Data Extraction and Trial Quality Assessment

A prespecified data extraction instrument was used to collect data from identified studies. Data extraction was completed independently by 2 reviewers with disagreements resolved by consensus. When more than 1 publication of one study existed, reports were grouped together to include the most complete data.

Specific data collected included study design, country, recruitment era, sample size, and dialysis modality. Caregiver data collected included age, sex, relationship to patient, time spent caregiving, education level, and employment status. The scales used to measure various aspects of QoL and/or burden were documented. Comparator groups or any interventions used were noted.

Study quality and risk of bias were assessed using the Newcastle-Ottawa scale,²¹ which has been validated for use in both case-control and cohort studies.^{22,23} Two authors independently assessed each study for risk of bias using a modified scale including sample representativeness; sample size; comparability with nonrespondents; ascertainment of QoL, burden, or depression; and quality of descriptive statistics reporting (Item S2). Studies were judged low (≥ 3 points) or high (< 3 points) risk of bias.

Continuous data were analyzed using mean differences and their 95% confidence intervals, and dichotomous data were expressed as relative risk and 95% confidence interval. When possible, meta-analysis using a random-effects model was planned using the DerSimonian-Laird approach with sensitivity analysis using the method of residual maximum likelihood. All statistical analyses were conducted using Review Manager (RevMan), version 5.3 Copenhagen (The Nordic Cochrane Centre, The Cochrane Collaboration, 2014) and R, version 3.5.1. $P < 0.05$ was considered to be significant.

Results

Literature Search and Study Characteristics

The search strategy yielded 1,072 articles, of which 86 underwent full-text review (Fig 1). Another 25 were excluded, leaving 61 papers meeting the inclusion/exclusion criteria (Tables 1 and S1). There were 17 studies published before 2000²⁴⁻⁴⁰ and 44 from 2000 to December 2016.^{17,41-83}

Fifty-two studies were cross-sectional and 9 studies reporting 897 caregivers were longitudinal.^{39,40,49,59,67,68,70,74,76}

Eight longitudinal studies were prospective cohort studies, with follow-up ranging from 3 months to 2 years.^{40,49,59,67,68,70,74,76}

The remaining longitudinal study reported 60 caregivers included in a quasi-randomized controlled trial design.³⁹ One of the cohort studies collected data pre- and posttransplantation for 67 caregivers.⁶⁸ Four studies reporting 221 caregivers collected data before and after an intervention for caregivers and/or patients.^{39,59,70,80}

The modified Newcastle-Ottawa Scale revealed that 85% of studies were at high risk of bias (Table S2). Only 3 studies enrolled more than 200 participants,^{41,57,67} whereas 2 studies had more than 200 participants but included data previously reported.^{43,76} There were frequent methodological flaws in sample representativeness, comparability between respondents and nonrespondents, and poor-quality descriptive statistics. Twenty-seven studies used infrequently used measurement scales, as defined in Item S2.

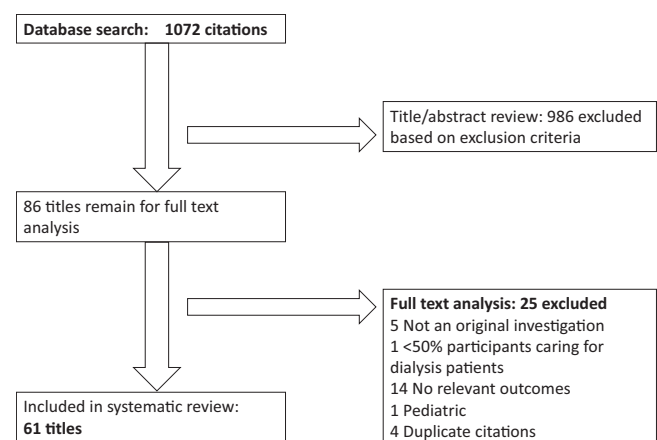


Figure 1. Literature search.

Study Settings

The 61 studies included 5,367 caregivers from 21 countries (Fig 2), most commonly the United States (22% of caregivers, 17 studies) and a single French study (18.4% of caregivers).⁵⁷ Thirty-three studies included multiple centers, and only 1 study was multinational in design.⁷⁶

Caregiver Definition

Few studies provided a definition of a caregiver. When reported, definitions were not comparable and included “the person mainly responsible for looking after the patient during the course of the disease and most closely involved in caring for the patient” as identified by the patient,^{44(p806)} “family member caregiver,”^{46(p519)} “dialysis partner,”^{47(p179)} the “person who principally cared for the patient outside the hospital, regardless of family relationship,”^{64(p333)} “the person they could depend on to assist them if they could no longer care for themselves” as identified by the patient,^{52(p386)} “a key member of the care-providing team who is expected to be an ever-present source of psychological as well as material support,”^{57(p1670)} “dialysis helper,”^{28(p16)} and an individual who played “a significant role in the dialysis process and in caring for the patient.”^{58(p314)}

Caregiver Demographics

Table 1 summarizes clinical and demographic characteristics in all 61 studies. Study sample size ranged from 3 to 988 caregivers. The mean age of caregivers ranged from 31.5 to 67.9 years. When reported, the majority of

caregivers were female (70.8%; range, 31%-100%). Education level was reported in 26 studies with 1,766 participants, with 15.6% (range, 11.1%-63.1%) reaching tertiary-level education and 12.6% (range, 1.4%-50.8%) illiterate. Employment status was reported in 23 studies with 2,754 participants, with 34.5% (range, 9.8%-88.3%) employed in an occupation outside of their caregiving role. Only 7 studies (13.9% of total participants) reported the mean hours of caregiving, which ranged from 26 to 69 hours per week.

Dialysis Modality

Fifty-seven studies reported dialysis modality in 5,166 (96.3%) patients. Of these, 3,734 (72.3%) were managed with facility HD; 1,066 (20.6%), with PD; and 366 (7.1%), with home HD. Table 2 shows caregivers' age, sex, and relationship to patient by dialysis modality.

Measurement Scales

A total of 70 different quantitative measurement scales were used to assess QoL and caregiver burden (Table S3). The most frequently used scales were the Zarit Burden Interview (ZBI; 1,316 caregivers in 13 studies), the Medical Outcomes Study 36-Item Short Form Survey (SF-36; 835 caregivers in 8 studies), the Center for Epidemiologic Studies Depression Scale (CES-D; 781 caregivers in 7 studies), and the Beck Depression Inventory (BDI; 606 caregivers in 9 studies). Figure 3 shows numbers of caregivers assessed using the most commonly used measurement scales.

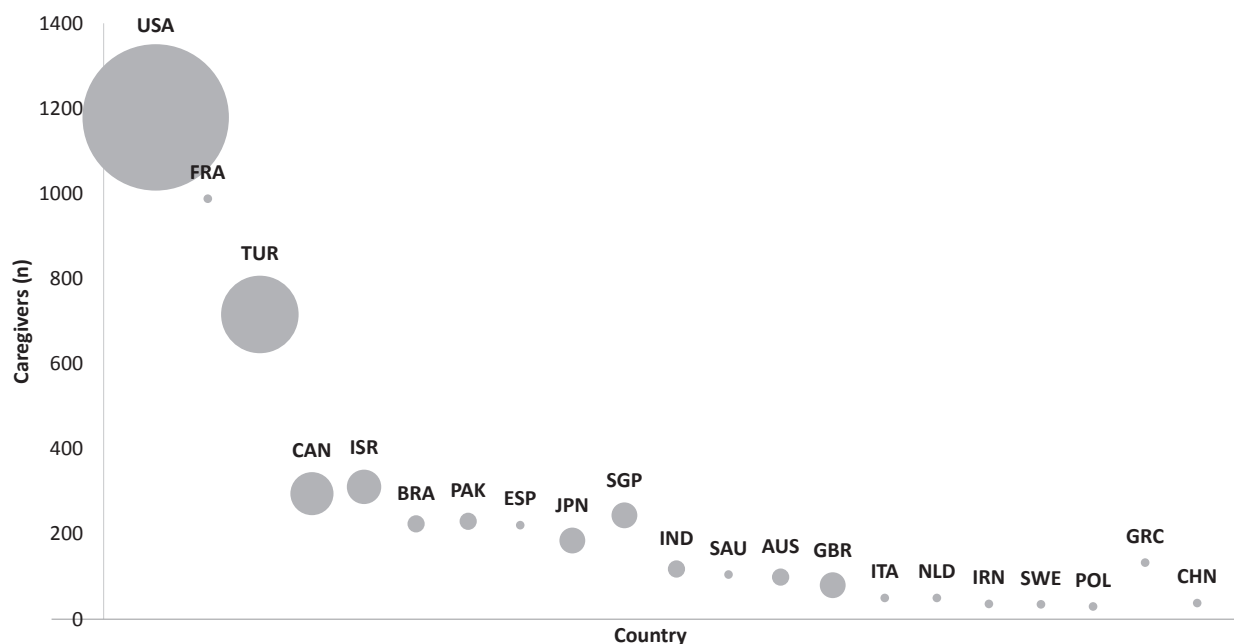


Figure 2. Number of caregivers and studies according to countries (size of bubble in graph represents number of studies). Abbreviations: AUS, Australia; BRA, Brazil; CAN, Canada; CHN, China; ESP, Spain; FRA, France; GBR, Great Britain; GRC, Greece; IND, India; IRN, Iran; ISR, Israel; ITA, Italy; JPN, Japan; NLD, Netherlands; PAK, Pakistan; POL, Poland; SAU, Saudi Arabia; SGP, Singapore; SWE, Sweden; TUR, Turkey; USA, United States of America.

Table 1. Characteristics of Included Studies

Study	Country	Design	N	Caregiver			Dialysis Modality		
				Female	Age ^a	Employed	FHD	HHD	PD
Blogg ²⁴ (1999)	AU	CS	61	68.9%	NA	36.67%	0%	100%	0%
Piira ⁵⁸ (2002)	AU	CS	38	52.6%	HHD: 51.11 ± 8.77; PD: 54.55 ± 17.17	NA	0%	39.5%	60.5%
Belasco ⁴⁴ (2002)	BR	CS	100	84%	46.4 ± 1.6	34%	100%	0%	0%
Belasco ⁴³ (2006)	BR	CS	124	80.1%	FHD: 57.5 ± 16; PD: 52.1 ± 14.1	32.34%	80.1%	0%	19.9%
Rideout ²⁹ (1990)	CA	CS	40	65%	51 ^b	NA	25%	0%	75%
Rioux ⁶¹ (2012)	CA	CS	32	66%	51 ± 11	NA	0%	100% ^c	0%
Srivastava ³⁵ (1988)	CA	CS	30	76.7%	55.4 (28-75)	NA	0%	0%	100%
Starzomski ⁶⁸ (2000)	CA	CS, LC	67	68.7%	NA	NA	65.7%	0%	34.3%
Suri ⁷⁶ (2014)	CA, US	LC	188	NA	NA	NA	68.4%	31.6%	0%
Jiang ⁷⁸ (2015)	CN	CS	38	52.6%	55.8 ± 12.9	60.5%	100%	0%	0%
Morelon ⁵⁷ (2005)	FR	CS	988	72%	60.8 ^b	78.6	100%	0%	0%
Antonaki ⁷⁷ (2016)	GR	CS	133	55.6%	NA	NA	100%	0%	0%
Khaira ⁵³ (2012)	IN	CS	49	65.3%	41.9 ± 12.5	NA	100%	0%	0%
Raj ⁶⁰ (2011)	IN	CS	69	NA	NA	NA	100%	0%	0%
Rahim ⁵⁹ (2009)	IR	LC	36	50%	NA	55.6%	100%	0%	0%
Hener ³⁹ (1996)	IL	RCT	60	66.7%	51.1 ± 10.7	NA	0%	0%	100%
Soskolne ³² (1984)	IL	CS	120	62.5%	48 ^b	NA	100%	0%	0%
Soskolne ³³ (1987)	IL	CS	63	79.4%	HHD: 50.2 ± 10.1; PD: 54.5 ± 10.7	NA	0%	46%	54%
Soskolne ³⁴ (1989)	IL	CS	68	76.5%	♀: 53 ± 11.6; ♂: 58.5 ± 11.4	NA	100%	0%	0%
Ferrario ⁵⁰ (2002)	IT	CS	50	80%	54.16 ± 13.22	26%	100%	0%	0%
Matsuo ⁵⁶ (2001)	JP	CS	43	88%	25%, 42%, & 33% are age 50-59, 60-69, & ≥70	NA	100%	0%	0%
Shimoyama ⁶⁵ (2003)	JP	CS	34	61.7%	Primary group (n = 22): 50.7 ± 11.7; respite group (n = 12): 38.5 ± 19.2	67.63%	0%	0%	100%
Washio ⁷² (2012)	JP	CS	108	76.9%	Heavy burden group (n = 48): 64 ± 12; light burden group (n = 60): 61.7 ± 12.5	29.5%	100%	0%	0%
Parlevliet ⁷⁵ (2012)	NL	CS	50	NA	NA	NA	76.6	0	23.4
Anees ⁴² (2011)	PK	CS	50	NA	59.46 ± 12.56	NA	100%	0%	0%
Saeed ⁷¹ (2012)	PK	CS	180	43.3%	48 (19-76)	39.44	100%	0%	0%
Klak ⁵⁴ (2008)	PL	CS	30	80%	65 ± 11.21	NA	83.3	0	16.7
Al Wakeel ⁸³ (2016)	SA	CS	105	FHD: 70%; PD: 78.2%	FHD: 40.6 ± 11; PD: 37.5 ± 9.1	35.24	47.6	0	52.4
Griva ⁸² (2016)	SG	CS	111	72.9%	45.13 ± 14.01	61.1	0%	0%	100%
Kang ⁷⁴ (2014)	SG	LC	CS: 86; LC: 44	NA	NA	NA	0%	0%	100%
Yu ⁹⁰ (2016)	SG	Case series	3	NA	NA	NA	0%	0%	100%
Alvarez-Ude ⁴¹ (2004)	ES	CS	221	76.8%	56.5 ± 14.9	33.8	68.8	0	31.2
Lindqvist ⁵⁵ (2000)	SE	CS	35	57.1%	FHD: 60.8 ± 15.1; PD: 62.7 ± 9.9	NA	57.1	0	42.9
Asti ¹⁷ (2006)	TR	CS	65	81.5%	43.9 ± 8.52	NA	0%	0%	100%
Avsar ⁶⁹ (2013)	TR	CS	60	45%	♂: 47.39 ± 15.9; ♀: 36.74 ± 13.6	NA	0%	0%	100%
Avsar ⁷⁹ (2015)	TR	CS	68	58.8%	43.1 ± 8.5	NA	100%	0%	0%

(Continued)

Table 1 (Cont'd). Characteristics of Included Studies

Study	Country	Design	N	Caregiver		Employed	Dialysis Modality		
				Female	Age ^a		FHD	HHD	PD
Cantekin ⁸¹ (2016)	TR	CS	114	FHD: 31%; PD 34%	FHD: 38.24 ± 12.3; PD: 36.64 ± 15.08	NA	47.4%	0%	52.6
Celik ⁴⁶ (2012)	TR	CS	142	62%	46.1 ± 10.9	NA	100%	0%	0%
Mollaoglu ⁷⁰ (2013)	TR	LC	122	80.3%	52.4 ± 8.9	9.84%	0%	27.9	72.1
Sezer ⁶⁴ (2003)	TR	CS	60	46.7%	FHD: 50.9 ± 12.1; PD: 47.1 ± 12.5	NA	55%	0%	45%
Sezer ⁷³ (2013)	TR	CS	40	NA	NA	NA	100%	0%	0%
Yilmaz ⁶⁶ (2009)	TR	CS	45	68.9%	45.2 ± 10.3	31.1%	100%	0%	0%
Daly ³⁸ (1970)	UK	CS	15	NA	NA	NA	0%	100% ^c	0%
Fan ⁴⁹ (2008)	UK	LC	36	NA	NA	NA	0%	0%	100%
Brackney ³⁷ (1979)	US	CS	12	100%	NA	NA	0%	100%	0%
Byers ⁴⁵ (2011)	US	CS	75	100%	NA	NA	100%	0%	0%
Courts ⁴⁷ (2000)	US	CS	14	92.9%	47 [21]	NA	0%	100%	0%
Daneker ⁴⁸ (2001)	US	CS	55	76.4%	51.9 ± 13.3	56.4%	100%	0%	0%
Dunn ²⁵ (1994)	US	CS	38	NA	58.4 ± 14.5	NA	0%	0%	100%
Finkelstein ²⁶ (1976)	US	CS	17	58.8%	46 [17.5]	88.2%	58.8%	41.2%	0%
Harris ⁵² (2000)	US	CS	78	74.2%	Younger group (n = 56): 39.7 ± 9.78; older group (n = 22): 64.45 ± 7.23	70.23%	NA	NA	NA
Harris ⁵¹ (2003)	US	CS	120	75.8%	52.2 ± 15.9	51.7%	94.2%	0%	5.8%
Lowry ⁴⁰ (1984)	US	LC	29	72.4%	48 ± 13	62.07%	0%	100%	0%
Page ²⁷ (1991)	US	CS	37	NA	42.18 ^b	35%	NA	NA	NA
Peterson ²⁸ (1985)	US	CS	19	100%	49.6 ^b	57.9%	100%	0%	0%
Pruchno ⁶⁷ (2009)	US	LC	315	73%	67.9 ± 9	NA	100%	0%	0%
Schneider ⁶² (2002)	US	CS	45	100%	62 ± 13.8	NA	100%	0%	0%
Schneider ⁶³ (2004)	US	CS	80	81.2%	62.6 ± 15.3	NA	100%	0%	0%
Schoeneman ³⁰ (1983)	US	CS	56	100%	52.2 ± 10.6	NA	100%	0%	0%
Simone ³¹ (1986)	US	CS	15	NA	31.5 ± 6.4	NA	NA	NA	NA
Wicks ³⁶ (1997)	US	CS	76	63.2%	46.7 ± 11.4	67%	76.3%	2.6%	21.1%

Abbreviations: AU, Australia; BR, Brazil; CA, Canada; CN, China; CS, cross-sectional; ES, Spain; FHD, facility-based hemodialysis; FR, France; GR, Greece; HHD, home hemodialysis; IL, Israel; IN, India; IR, Iran; IT, Italy; JP, Japan; LC, longitudinal cohort; NA, not available; NL, Netherlands; PD, peritoneal dialysis; PK, Pakistan; PL, Poland; RCT, randomized controlled trial; SA, Saudi Arabia; SD, standard deviation; SE, Sweden; SG, Singapore; TR, Turkey; UK, United Kingdom; US, United States.

^aValues given as mean ± SD, median [interquartile range], or mean (range).

^bMean (no SD available).

^cNocturnal HD.

The 70 measurement scales used in the studies can be categorized into outcome domains (Table S4). The most frequently studied domain was mental health, including depression, anxiety, and psychological distress.

QoL/Burden Data

When compared with population norms for the SF-36 and accepted thresholds for the ZBI, CES-D, and BDI, caregivers generally experience significant burden and have poorer QoL, but rates of depression are not elevated (Fig 4). However, studies that reported only categorical results (not included in Fig 4) found depression rates of 34.7% to 55% among caregivers.^{45,52,56,64} Less frequently used scales reported significant impairment of QoL.^{55,57,74} Dyadic adjustment scale scores^{25,48,53,67} were consistent with poor marital adjustment, although there were no data

for divorce rates. One study reported higher rates of marital dissatisfaction and distress among caregivers than in a control population.³¹ Pittsburgh Sleep Quality Index scores^{46,69} reflected poor sleep.

Longitudinal studies had varied outcomes, with one showing no change in QoL over time⁴⁹ while others showed a decline in psychosocial adjustment,³⁹ increasing burden,^{74,76} poorer marital adjustment,⁶⁷ and worsening QoL.⁷⁴

Caregivers' QoL Compared With a Control Group or General Population

Thirteen studies compared caregiver results with a control group or general population norms. Three of the studies used the SF-36 and showed poorer QoL in caregivers when compared with a control group or the country

Table 2. Demographic Data for Caregivers and Patients According to Dialysis Modality

Demographic Characteristic	Facility-Based Hemodialysis	Home Hemodialysis	Peritoneal Dialysis
Range of mean patient age, y	43.7-74.2 (n = 1,859)	47.1-52.5 (n = 146)	44.7-72.1 (n = 463)
Range of mean caregiver age, y	38.2-67.9 (n = 2,891)	47.3-55.0 (n = 224)	36.6-62.7 (n = 721)
Female sex of caregiver	71.4%; range, 43.3%-100% (n = 3,147)	72.3%; range, 26.7%-100% (n = 155)	66.1%; range, 45.0%-81.5% (n = 649)
Spousal patient-caregiver relationship	90.4%; range, 49%-100% (n = 2,425)	92.8%; range, 60%-100% (n = 222)	77.1%; range, 31.5%-100% (n = 580)

norm.^{55,62,65} The remaining studies used various measurement scales yielding results of either similar or poorer QoL,⁷⁴ similar or higher rates of depression,^{26,56,64} greater anxiety,⁵⁰ poorer adjustment,^{31,39,78} and higher rates of stress^{32,39,68,78} in caregivers compared with either a control group or the broader community norm.

Caregiver Compared With Dialysis Patient QoL

Twenty-five studies compared caregiver QoL with that of dialysis patients. Figure 5 shows forest plots (using the DerSimonian-Laird approach) comparing caregivers with the dialysis patients they care for as measured with the BDI and SF-36 physical and mental component score. Comparable results were found in the sensitivity analysis using the method of residual maximum likelihood. Nine studies suggested that caregivers were less depressed and had better QoL than the dialysis patients.^{17,43,44,46,48,49,53,61,71} The remaining studies used various measurement

scales showing either similar or better QoL or less depression in caregivers compared with patients.^{25-27,29,34,38,40,42,47,50,65-68,73,78} A single study reported sleep duration and quality as inferior to that of patients in a group of 142 caregivers of facility HD patients.⁴⁶

Impact of Dialysis Modality on Caregivers

Seventeen studies reported data for caregivers of patients from more than 1 dialysis modality,^{26,29,33,36,41,43,51,54,55,58,64,68,70,75,76,81,83} of which most only reported combined results, making comparison impossible.^{26,29,36,51,54,55,58,68,70,75} Two studies reported on the ZBI and found no difference in caregiver burden between HD or PD. The SF-36 was reported by 2 studies,^{41,43} with no difference found between HD and PD caregivers for physical component score. The mental component score was worse for PD caregivers in the smaller study,⁴³ but comparable in the larger study.⁴¹ A

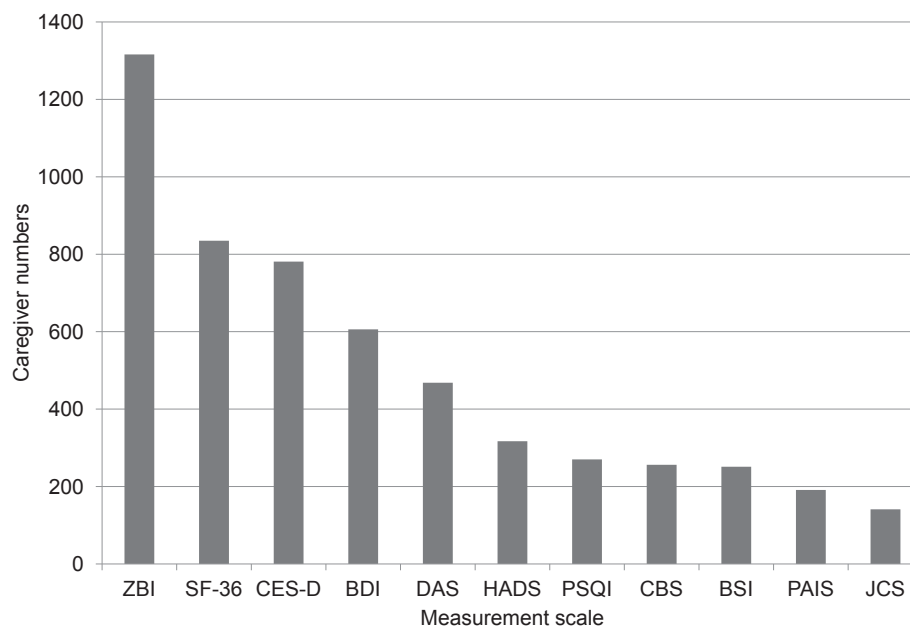


Figure 3. Caregiver numbers assessed by measurement scales in 3 or more studies and 100 or more caregivers. Abbreviations: BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; CBS, Caregiver Burden Scale; CES-D, Center for Epidemiologic Studies Depression Scale; DAS, Dyadic Adjustment Scale; HADS, Hospital Anxiety and Depression Scale; JCS, Jalowiec Coping Scale; PAIS, Psychosocial Adjustment to Illness Scale; PSQI, Pittsburgh Sleep Quality Index; SF-36, Medical Outcomes Study 36-Item Short Form Study; ZBI, Zarit Burden Interview.

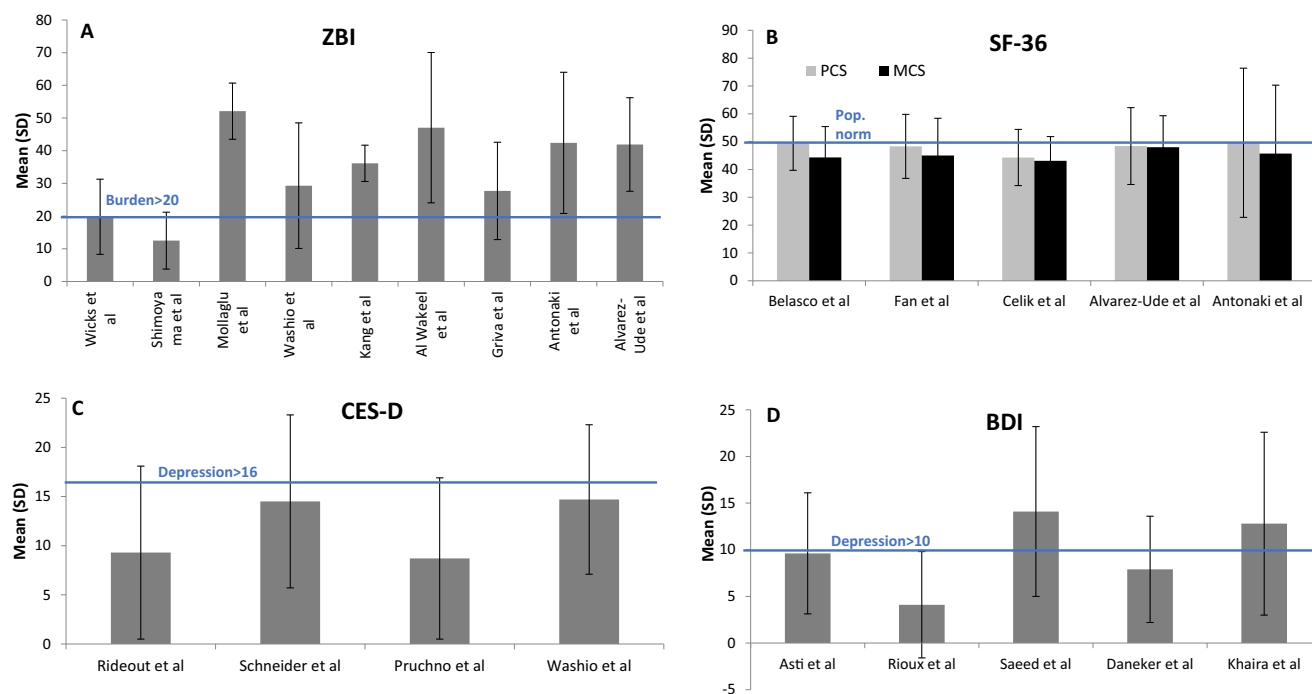


Figure 4. Burden, quality of life, and depression in caregivers of dialysis patients compared with population norm or threshold using the: (A) Zarit Burden Interview (ZBI), (B) Medical Outcomes Study 36-Item Short Form Survey (SF-36), (C) Center for Epidemiologic Studies Depression Scale (CES-D), and (D) Beck Depression Inventory (BDI).

small study from Turkey reported greater somatization and depression among caregivers of facility HD compared with PD patients.⁶⁴ The burden on caregivers of assisted PD patients compared with self-care PD patients in Singapore has been reported as equivalent.⁸²

The Frequent Hemodialysis Network (FHN) Study showed no difference for caregivers of frequent in-center HD patients, but a nominally increased burden for caregivers of home nocturnal HD when compared with caregivers of standard facility HD patients, although this difference was not statistically significant.⁷⁶ However, a study of caregivers of nocturnal home HD patients reported a low BDI score of 4.1 ± 5.7 (75% of caregivers had no depression), but there was no comparator group.⁶¹

Dialysis Caregivers Compared With Other Caregivers

Seven studies compared QoL of dialysis caregivers with that of other caregivers.^{36,55-57,69,75,79} Four studies showed poorer outcomes for dialysis caregivers compared with caregivers of renal transplant recipients.^{55,57,69,79} However, transplant recipient caregivers were younger than dialysis caregivers⁵⁵ or the patients cared for were not described,^{69,79} leading to probable bias. A large French study reported better QoL for caregivers of transplant recipients compared with caregivers of dialysis patients awaiting transplantation.⁵⁷ One study showed no difference in 76 dialysis caregivers' QoL compared with

caregivers of non-dialysis-dependent patients with chronic kidney disease, although the authors suggested possible sampling bias.³⁶ Other studies showed no difference in rates of depression in dialysis caregivers compared with caregivers of the frail elderly,⁵⁶ but increased burden compared with caregivers of oncology patients.⁷⁵

Discussion

This systematic review has found that caregiver QoL and burden is worse than in the general population and comparable to caregivers of patients with other chronic diseases. Depression is less common than among the cared for dialysis patients and comparable or slightly greater than for the general population. Furthermore, the impact on caregiving for facility HD patients is similar to that of PD patients. QoL is better for caregivers of transplant recipients than dialysis patients.

Despite the breadth of research to date investigating the QoL and burden of dialysis caregivers, a systematic review of the literature is difficult due to the heterogeneity of studies. We found a total of 70 quantitative measurement scales used to assess caregivers across 61 studies, suggesting no consensus among researchers regarding which scales are ideal. Some scales were adapted to suit the study setting or sample, potentially affecting their validity.^{44,46,70} Furthermore, caregivers have been studied from various countries and cultures, and it is possible that some scales were not validated in these populations. Numerous studies used

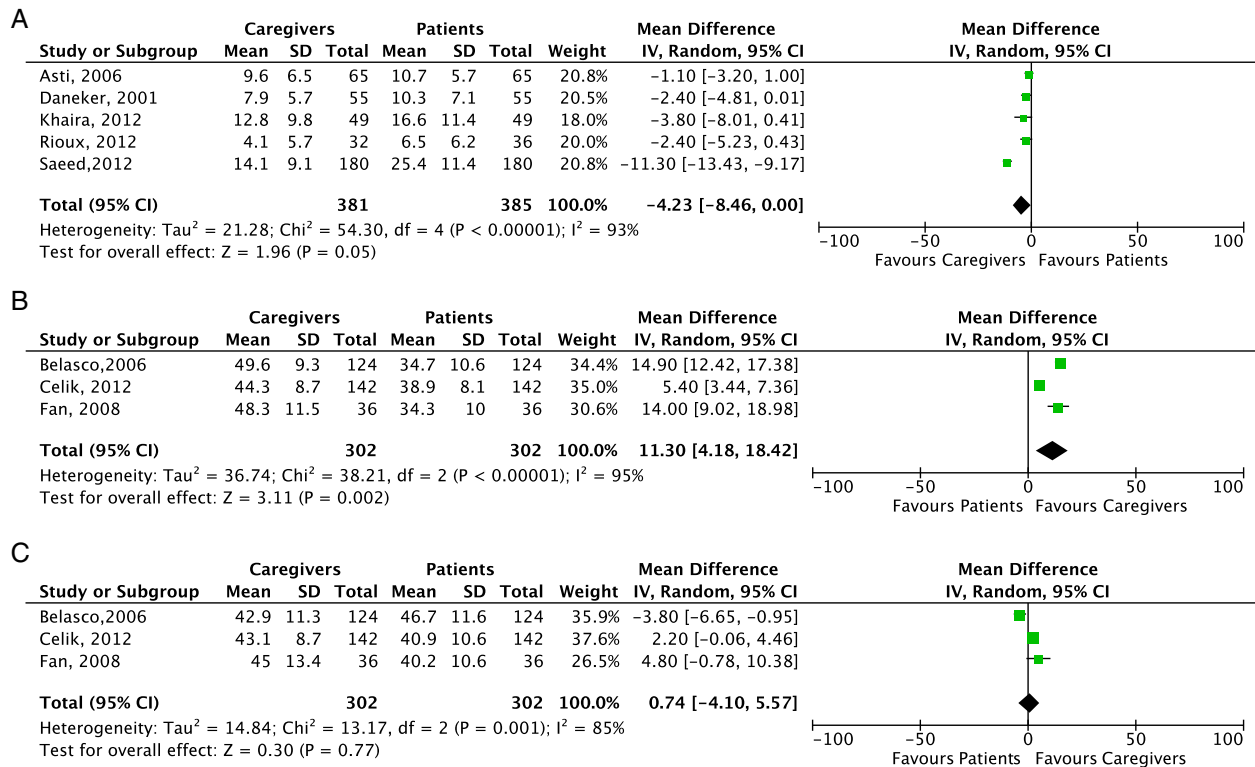


Figure 5. Forest plot comparison of depression and quality of life between caregivers of dialysis patients versus dialysis patients using the: (A) Beck Depression Inventory, (B) Medical Outcomes Study 36-Item Short Form Survey physical component score, and (C) Medical Outcomes Study 36-Item Short Form Survey mental component score. Abbreviations: CI, confidence interval; SD, standard deviation.

multiple scales to measure impact on caregivers, further suggesting a lack of consensus regarding the ideal scales to use. Although the most commonly used scales were the SF-36, ZBI, CES-D, and BDI, recommending a preferred measurement scale is difficult. A preferred scale would be simple, brief, and validated across countries and languages and allow comparison with other caregiver and general populations. It is also important that it detects some of the unique issues of caregivers of patients on different dialysis modalities. We suggest a role for qualitative studies and an approach such as used by the SONG (Standardized Outcomes in Nephrology) HD initiative⁸⁴ to determine and possibly develop the best scales.

Overall, this review suggests that QoL of caregivers of dialysis patients may not be as poor as some qualitative research suggests.⁸⁵⁻⁸⁷ However, the scales used may not assess QoL, human emotion, mental state, and relationships, as well as qualitative research. Furthermore, the included studies often do not report the severity of illness of the dialysis patients and the associated caregiving demands.

QoL of dialysis patients undertaking home HD and PD has been reported to be comparable or better^{19,20} than for patients undertaking facility HD.⁸⁸ This review has found that the burden and QoL of caregivers is comparable between HD and PD. This finding may be confounded by self-selection of people undertaking home dialysis who

tend to be younger and may need less caregiver support. Furthermore, the number of caregivers of home HD patients studied is relatively small. Further work is needed to adjust for differences in patient profiles of home dialysis therapies (especially home HD) and facility HD and the assistance they require from caregivers to allow valid comparison.

Secondary outcome data of this systematic review served to build the profile of a dialysis caregiver. This group is dominated by female spouses of often older male patients. Although female sex and younger age are thought to be risk factors for higher levels of burden, the spousal relationship may be protective.⁷⁰ A lower education level is also protective, but a significant rate of illiteracy in this systematic review was surprising given the importance and complexity of the caregiving role in maintenance dialysis. When reported, one-third of caregivers were employed, but results from included studies did not allow for comparison of QoL between employed and unemployed caregivers. One study suggests that employment outside the caregiving role may be protective against depression.⁷¹ Caregivers with more health problems have been reported to experience greater burden.⁷⁰

Few studies trialled an intervention to reduce caregiver burden or improve QoL. A previous systematic review found just 3 studies, which all showed that an education

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intervention led to improved knowledge of caregivers, but no other outcomes were measured.⁸⁹ Among studies in this systematic review, an education program reduced burden,⁷⁰ a continuous care model improved perceived QoL,⁵⁹ and supportive and cognitive behavioral therapy aided maintenance of psychosocial adjustment over time.³⁹ These studies are small and require replication, and further work is needed, perhaps by qualitative interviews, to identify which supports are needed and have the greatest impact.

This systematic review has a number of limitations. Despite using quantitative measures of QoL, many studies only reported data graphically or categorically, which limited our ability to examine the data further. Studies did not report data to allow assessment of the caregiver role and the impact of caregiver age, marital and employment status, or dialysis vintage on caregiver burden and QoL. Overall study quality was generally poor and there is a high likelihood of recruitment or participation bias. Refusal to participate by the most affected patients is an inherent problem with studies that may include those with depression, anxiety, distress, or significant burden.²⁹ The limitation to English publications may reduce data available from some cultures or ethnic backgrounds that will not have been included. Caregivers of pediatric dialysis recipients were excluded from this analysis and our findings may not be applicable to this population.

Relatively few studies in this systematic review were longitudinal in nature or trialled an intervention. These issues must be addressed in future research. Does the caregiver's QoL reflect the severity of illness and QoL of the dialysis patient or the duration and demands of caregiving? There is also a relative paucity of data surrounding home HD caregivers in comparison to facility HD. Another important area lacking data is the effect of increasing HD frequency or extending HD hours, including at night. Patients enrolled in the FHN trials perceived caregiver burden to be high, but the caregivers themselves did not participate in the study.⁹⁰ The enthusiasm for home HD among some nephrologists, as well as opportunities for novel regimens, highlights a need to explore the impact on caregivers.

In conclusion, caregivers have an important role in the management of people undergoing dialysis. This review demonstrates that caregiver QoL is adversely affected compared with the general population and comparable to other chronic disease caregivers. Suggestions that home-based therapies strain the caregiver psychosocial well-being⁴⁴ are not supported by this systematic review, although further work is needed with better longitudinal and case-matched studies. Consensus on the best scales to measure QoL and burden will also assist interpretation of results and reproducibility of data. Last, studying and implementing interventions to assist caregivers and improve their QoL will hopefully enable them to persist in their role and support the dialysis recipient in the long term.

Supplementary Material

Item S1: Search strategy.

Item S2: Modified Newcastle-Ottawa risk of bias scoring guide for caregivers of dialysis patients.

Table S1: Measurement scales and results of included studies.

Table S2: Risk of bias assessment for included studies using Newcastle-Ottawa scale.

Table S3: Measurement scales—frequency of use.

Table S4: Summary of outcome domains by number of measurement scales.

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