


# Experiences of Caregivers of Patients With Conservatively Managed Kidney Failure: A Mixed Methods Systematic Review

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## Abstract

**Background:** Older people with kidney failure often choose conservative kidney care. The experiences and quality of life (QOL) of caregivers who support them are incompletely characterized.

**Objective:** To determine the burden, QOL, and understand experiences of caregivers supporting patients managed conservatively.

**Design:** Systematic review of quantitative and qualitative studies.

**Sources of information:** PubMed, Embase, PsycINFO, CINAHL, and MEDLINE electronic databases were systematically searched for quantitative and qualitative studies published between January 2000 and July 2020.

**Subjects:** Caregivers of adults with kidney failure (estimated glomerular filtration rate < 15 mL/min/1.73 m<sup>2</sup>) managed conservatively.

**Methods:** Data were extracted by 2 independent reviewers using a prespecified extraction tool. Study quality was assessed using the Critical Appraisal Skills Program (CASP) tool.

**Measurements:** Descriptive reports of demographics, measurement scales, and outcomes. Thematic synthesis of qualitative data.

**Results:** Six studies met inclusion criteria, including 3 quantitative and 3 descriptive qualitative studies. Caregivers of patients receiving conservative kidney management (CKM) experienced significant caregiver burden and similar impacts to their QOL as those caring for patients receiving dialysis. Thematic synthesis revealed 5 themes: Understanding the concept of CKM, Need for involvement in the decision for CKM, Identifying available supports, Uncertainty about the future and negotiating deteriorations and dying, and Burden of care impacting on QOL.

**Limitations:** Low numbers of included studies, data collection and recruitment biases in qualitative studies and small caregiver numbers in quantitative studies, limit transferability of findings. Heterogeneity in study design and outcome measures precluded meta-analysis.

**Conclusions:** Caregivers of patients with conservatively managed kidney failure suffer significant burden and experience QOL comparable with those caring for patients on dialysis. Limited understanding and involvement in conservative management decision making, and a fear of deterioration and dying, result in anxiety in caregivers. Further research into the experiences of caregivers will help support both caregivers and the patients who choose conservative management.

**Registration:** PROSPERO registration number CRD42021209811.

## Abrégé

**Contexte:** Les personnes âgées atteintes d'insuffisance rénale optent souvent pour des soins rénaux conservateurs, mais on en sait peu sur l'expérience et la qualité de vie (QV) de leurs soignants.

**Objectif:** Mieux comprendre l'expérience des soignants de patients pris en charge de façon conservatrice, particulièrement en ce qui concerne la qualité de vie et le fardeau de l'aidant.

**Type d'étude:** Revue systématique d'études quantitatives et qualitatives.

**Sources:** PubMed, Embase, PsycINFO, CINAHL et MEDLINE ont fait l'objet d'une recherche systématique afin de répertorier les études quantitatives et qualitatives publiées entre janvier 2000 et juillet 2020.

**Sujets:** Les soignants d'adultes atteints d'insuffisance rénale (DGF<sub>e</sub><15 mL/min/1,73 m<sup>2</sup>) et pris en charge de façon conservatrice.



**Méthodologie:** Deux réviseurs indépendants ont procédé à l'extraction des données d'intérêt à l'aide d'un outil préétabli. La qualité des études a été évaluée à l'aide de l'outil du Programme de développement des compétences en évaluation critique (CASP — *Critical Appraisal Skills Program*).

**Mesures:** Les rapports descriptifs sur les données démographiques, les échelles de mesure et les résultats. Synthèse thématique des données qualitatives.

**Résultats:** Six études répondaient aux critères d'inclusion, soit trois études quantitatives et trois études qualitatives descriptives. Les soignants de patients recevant des soins rénaux conservateurs (SRC) rapportaient un important fardeau de l'aidant et des effets sur leur QV similaires à ceux rapportés par les personnes qui s'occupent de patients sous dialyse. La synthèse thématique a révélé cinq thèmes: 1) la compréhension du concept de SRC; 2) le besoin de participer à la décision d'opter pour des SRC; 3) l'identification des ressources de soutien disponibles; 4) l'incertitude quant à l'avenir et à la façon de composer avec la dégradation de l'état de santé et le décès; et 5) l'incidence du fardeau de l'aidant sur la qualité de vie.

**Limites:** La transférabilité des résultats est limitée par le faible nombre d'études incluses, ainsi que par la méthode de collecte de données et les biais de recrutement dans les études qualitatives, et par le faible nombre de soignants dans les études quantitatives. L'hétérogénéité dans la conception de l'étude et les mesures des résultats a empêché une méta-analyse.

**Conclusion:** Les soignants de patients atteints d'insuffisance rénale et pris en charge de façon conservatrice rapportent un important fardeau de l'aidant et une QV comparable à celle des soignants de patients sous dialyse. Le fait de ne pas bien comprendre le concept de SRC, d'avoir une participation limitée dans la prise de décisions, ainsi qu'une crainte liée à la détérioration de la santé et au décès, entraîne de l'anxiété chez les soignants. Des recherches plus approfondies sur l'expérience des soignants contribueront à mieux soutenir les patients qui optent pour une prise en charge conservatrice et leurs soignants.

**Enregistrement de l'essai:** Numéro d'enregistrement PROSPERO CRD42021209811.

## Keywords

kidney failure, chronic, conservative treatment, caregivers, caregiver burden, quality of life

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## Introduction

Chronic kidney disease (CKD) is a progressive and irreversible decline in kidney function and its prevalence increases with advancing age. Treatment options for kidney failure include kidney replacement therapy (KRT), which includes dialysis and kidney transplantation, and conservative kidney management (CKM). CKM involves a broad range of interventions designed to manage the symptoms and complications arising from advancing CKD, but without the use of KRT. In the past 20 years, interest in CKM has increased due to awareness of the burden faced by older people receiving dialysis, the poor survival of patients having dialysis, and knowledge that conservatively managed patients retain a similar quality of life (QOL) compared with patients on dialysis.<sup>1-3</sup> Consequently, research from Canada and Australia demonstrates that approximately half of all older patients with a diagnosis of kidney failure choose CKM as compared with those who pursue dialysis or transplantation.<sup>4,5</sup>

Advanced CKD and associated comorbid conditions may result in cognitive and functional impairments that restrict the capacity of the patient to care for themselves. As a result, many patients rely on a caregiver, usually unpaid, to assist with activities and instrumental activities of daily living.<sup>6,7</sup> Caregiver burden, characterized by the physical, psychological, and financial consequences of caring for an individual with a medical condition, is well described among those caring for patients on dialysis.<sup>8</sup> Furthermore, caregiver QOL is adversely impacted by caring for someone undergoing dialysis.<sup>8</sup> However, QOL, burden, and experiences for caregivers of someone with kidney failure choosing CKM is less well described, despite increasing rates of kidney failure in the older population and the growing importance of CKM. Therefore, the primary aim of this mixed methods systematic review was to define the QOL and caregiver burden among caregivers of adults with kidney failure managed conservatively and to synthesize qualitative data to further understand the caregiver experience.

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## Methods

This article reporting our mixed methods systematic review was prepared in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guideline and prospectively registered with PROSPERO (CRD42021209811).

### Search Strategy and Inclusion Criteria

PubMed, Embase (Elsevier), PsycINFO, CINAHL, and MEDLINE (Ovid) electronic databases were searched using a prespecified search strategy which was developed and refined with support from a librarian with skills in systematic reviews (Table S1). The search was limited to English language studies published between January 1, 2000, and July 31, 2020, reflecting the increased focus on CKM in the last few decades. Inclusion and exclusion criteria are shown in Table S2. Inclusion criteria were original investigations, either observational or interventional, that used objective tools to assess caregiver QOL and burden, or studies using qualitative methods to describe the experiences of caregivers of adult patients with kidney failure (estimated glomerular filtration rate of  $<15$  mL/min/1.73 m<sup>2</sup>) managed conservatively or CKD G5C. Studies including only caregivers of patients already undertaking or planning on undertaking KRT, patients with an undefined treatment choice for kidney failure or patients withdrawing from dialysis, were excluded. Similarly, studies including caregivers of people with other medical conditions where it was impossible to extract data for caregivers of people with CKD, and studies examining caregivers of patients where kidney failure was not the dominant life limiting problem, were excluded. Reference lists of relevant studies were reviewed for further studies that met the inclusion criteria.

Two authors (A.W. and N.G.) evaluated the title and abstract of each study for inclusion using the record management software Covidence.<sup>9</sup> Conflict between the two reviewers was resolved through consensus. Full text articles of each manuscript considered for inclusion based on title and abstract were reviewed independently by 2 authors (A.W. and N.G.), with disagreement resolved through consensus.

### Data Extraction and Trial Quality Assessment

Data were extracted using a prespecified data extraction tool, by 2 independent reviewers (A.W. and N.G.) with disagreements resolved by consensus. Data collected included study design, country, sample size, and caregiver age, sex and relationship to patient. Study quality was assessed using the Critical Appraisal Skills Program (CASP) tool<sup>10</sup> for qualitative, cohort, case control, and randomized controlled trials (RCT) with a modified CASP tool used for cross-sectional studies.

For quantitative studies, results of measures of QOL and burden were recorded. Meta-analysis was not possible due to

different scoring scales in each study. Extracted data from qualitative studies were analyzed through a process of thematic synthesis, described by Thomas and Harden (2008),<sup>11</sup> with initial analysis performed by 2 researchers (A.W. and N.G.) and confirmed by a third author (A.C.). Text, statements, and quotations from caregivers and individual themes and subthemes were extracted from the results and discussion sections of included studies and were coded to develop descriptive themes in a level 2 qualitative synthesis. Level 3 synthesis of qualitative themes then followed, transforming the qualitative evidence to move beyond the individual findings of the included studies. These higher order themes were verified with the source data by all authors with analysis of conflicting evidence before drawing conclusions. These results were integrated (where possible) with the results from the quantitative analyses, to support and provide context for, and deeper understanding of the findings, following Sandelowski et al's (2006)<sup>12</sup> segregated approach to mixed methods systematic review.

## Results

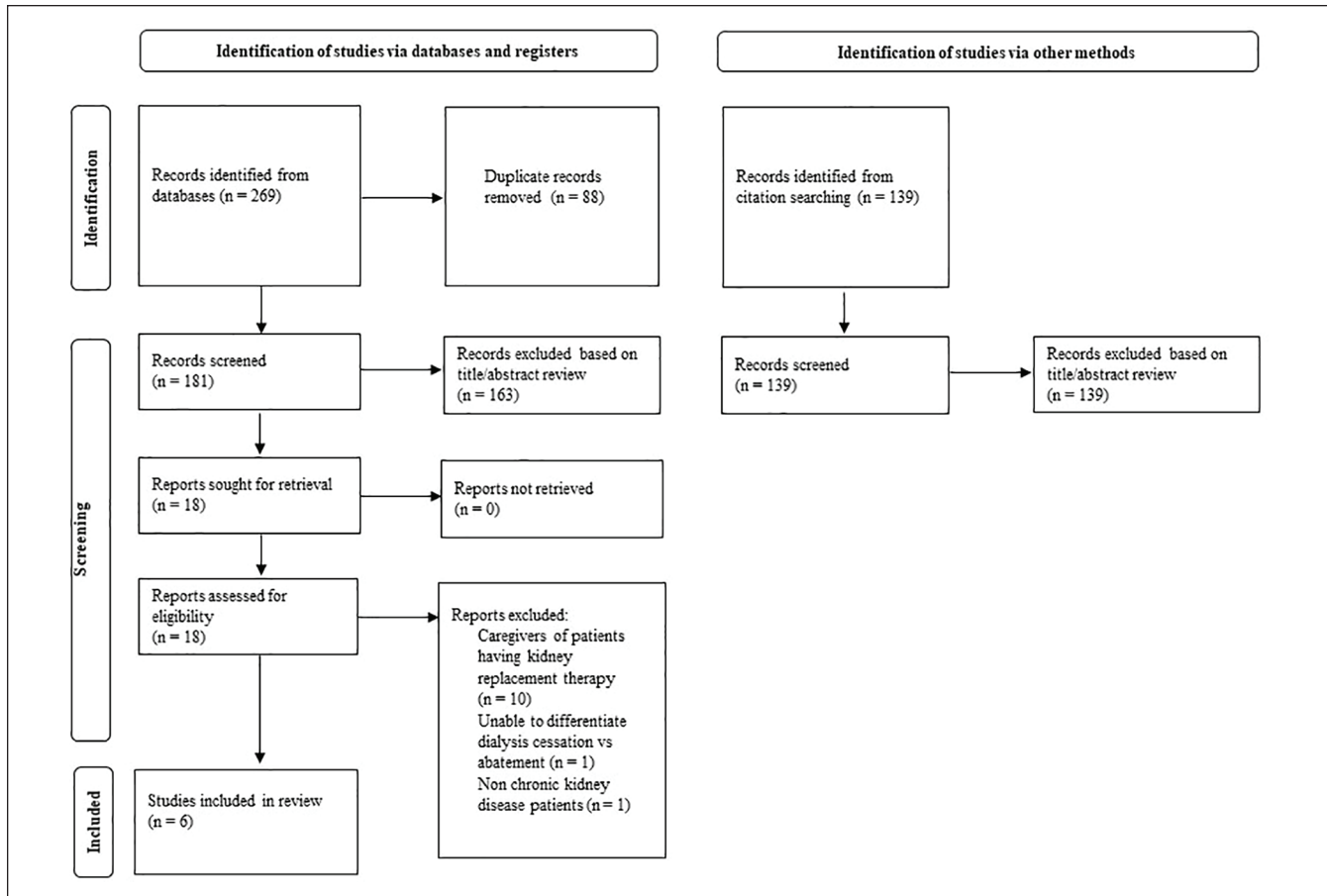
### Literature Search and Study Characteristics

The search strategy identified 181 articles, and after title and abstract review 18 met inclusion criteria and underwent full text review. Six were included in the final analysis (Figure 1). There were 3 quantitative studies including 1 RCT, 1 cohort study, and 1 cross-sectional study (Table 1). Three descriptive qualitative studies were included. Of the included studies, 2 were from the United Kingdom, 1 each from Australia, Hong Kong, and Italy, and 1 was a multicenter study from the United Kingdom and Australia.<sup>13-18</sup>

The mean patient age in the included studies ranged from 81.5 to 84 (Table 1) and, when reported, the majority of caregivers were female (ranging from 58% to 76% of all caregivers). The mean age of caregivers ranged from 50.7 to 69 years. Generally, studies with an older mean caregiver age had a larger percentage of spouse or sibling caregivers as compared with those with a younger mean caregiver age, where children formed a greater proportion (Table 1).

### Risk of Bias and Study Quality

The qualitative studies had well documented aims, methodology, design, data analysis, and consideration of ethical issues. However, data collection in the studies by Hoffman et al<sup>17</sup> and Noble et al<sup>18</sup> were performed by clinicians who may have been involved in patient care and in the presence of the patient in Low et al,<sup>16</sup> hence findings may have been impacted. The recruitment method in the study by Noble et al<sup>18</sup> included a convenience sample of caregivers but had limited details of people who chose not to participate and similarly, the study by Hoffman et al<sup>17</sup> had a high noninclusion rate, which was not detailed.



**Figure 1.** Literature search.

With regard to the quantitative studies, the methods of recruitment of subjects in Shah et al<sup>15</sup> were not clearly specified. There was limited discussion and reporting of caregiver specific potential confounding factors in the cohort study by De Biase et al,<sup>14</sup> and the single RCT by Chan et al<sup>13</sup> had limited reporting of cost-effectiveness data and harms of the intervention. All the quantitative studies had small sample sizes ranging from 11 to 37, resulting in large confidence intervals with reported results. The single-center design and limited geographic region of the studies necessitates caution in applying the findings to other populations.

### Quantitative Study Findings

**Quality of life.** QOL was assessed by 2 quantitative studies (Table 2); the cohort study by Shah et al<sup>15</sup> compared the caregivers of conservatively managed patients, with those on dialysis and found no significant difference in health-related QOL as assessed by the Short Form 6-Dimensions (SF-6D). Caregiver-related QOL as measured by the Carer Experience Scale (CES) score was lower for caregivers of patients on dialysis. Significantly lower mean CES scores were also noted for caregivers residing in the United Kingdom rather than Australia,

and for spouse/partner caregivers compared with children of patients. Similar results were noted by the cohort study by De Biase et al<sup>14</sup> who compared caregivers of conservatively managed patients with caregivers of patients on dialysis, finding that caring for conservatively managed patients was associated with a negative impact on caregiver QOL (as measured by the 36-Item Short Form Survey [SF-36]), especially in domains of “physical role,” “vitality,” and “emotional role” compared with age matched norms (Table 2). Results were similar for caregivers of patients on hemodialysis except for better scores in the “physical functioning” domain which may be explained by a younger mean age in that group.

**Caregiver burden.** Burden was measured by De Biase et al,<sup>14</sup> where the Caregiver Burden Inventory (CBI) showed high scores for objective burden in both caregivers of patients on dialysis and those managed conservatively. The study by Chan et al,<sup>13</sup> which examined the effects of a comprehensive psychosocial support program with caregivers of conservatively managed patients demonstrated a baseline Zarit Burden Index (ZBI) score was  $28.3 \pm 10.7$  in the control group and  $32.8 \pm 12.2$  in the intervention group (ZBI >17 consistent with high levels of burden).<sup>19</sup>

**Table 1.** Characteristics of Included Studies.

Study	Country	Design	Purpose	N	Patient age (mean)	Caregiver age (mean)	Female	Relationship
Chan et al <sup>13</sup>	HK	RCT	Investigate the effectiveness of enhanced psychosocial support in reducing caregiver burden in patients with chronic kidney failure opting for conservative management	29	81.6 ± 14.2	59.8 ± 14.2	76%	SP: 52%; SB: 45%; FM: 4%
De Biase et al <sup>14</sup>	IT	CO	Report on the clinical results, disease progression, burden of care, and QOL of patients and caregivers on prolonged conservative treatment	11	81.5 (mean) (median) 75-88 (range)	50.7 (mean)	NA	NA
Shah et al <sup>15</sup>	AU, UK	CS	To assess and compare the health-related QOL and care-related QOL among informal caregivers of older people with end-stage kidney disease, managed with dialysis or comprehensive conservative care	37	NA	76 (median) 68-82 (range)	70%	SP: 63%; CH: 28%; FM: 9%
Low et al <sup>16</sup>	UK	DS	To show how the discourses around aging and old age play an implicit role in shaping the experiences of close persons caring for someone on conservative management	26	83.7 (mean) 61-96 (range)	63 (mean) 38-91 (range)	58%	SP: 30%; CH: 53.8%; FM: 7.6%
Hoffman et al <sup>17</sup>	AU	DS	To gain a greater understanding of the experiences of conservatively managed patients and their carers/families	11	84 (mean) 77-91 (range)	69 (mean) 42-89 (range)	64%	SP: 55%; CH: 45%
Noble et al <sup>18</sup>	UK	DS	Explore the impact of being a family carer to patients with stage 5 chronic kidney disease managed without dialysis	19	NA	20-30: 3 30-40: 1 40-50: 3 50-60: 6 60-70: 1 >70: 5	68%	SP: 21%; CH: 68%

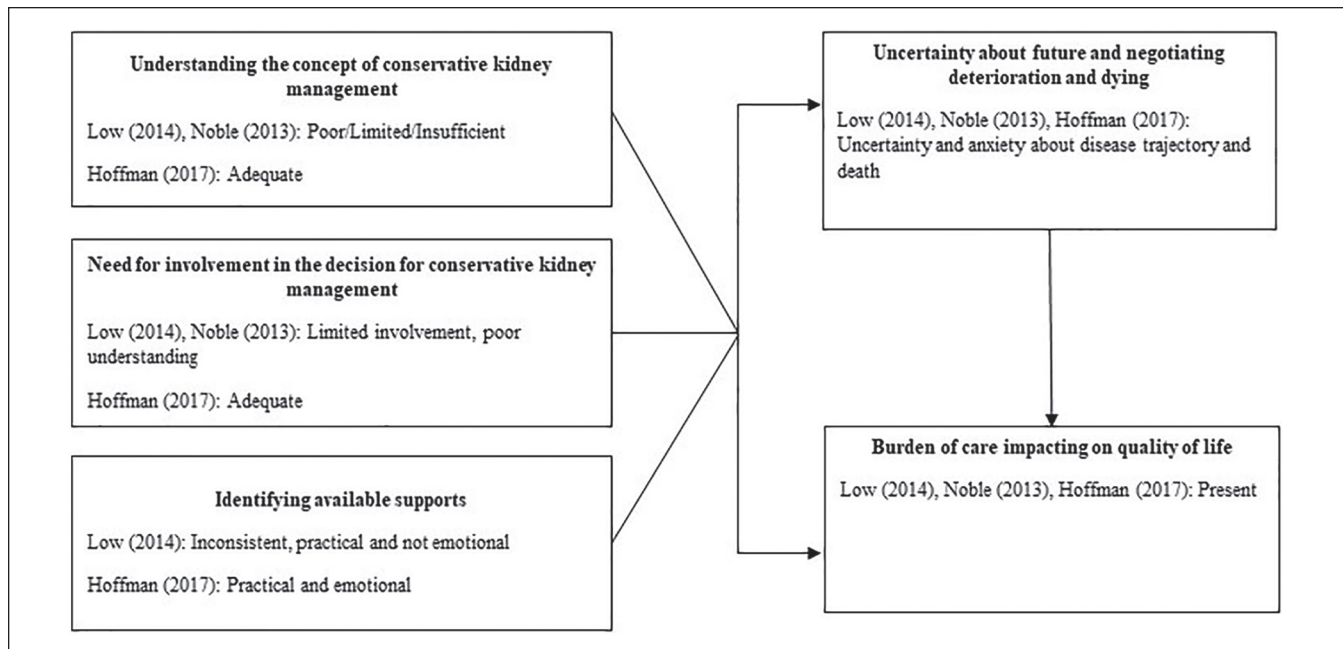
Note. RCT = randomized control trial; SP = spouse; SB = sibling; FM = family (other); CO = cohort study; NA = not available; CH = child or child-in-law; CS = cross-sectional study; DS = descriptive.



**Table 2. Results From Quantitative Studies.**

Study	Intervention/comparison	Mean score (control)	Mean score (comparator)	Conclusion
Chan et al <sup>13</sup>	Comprehensive psychosocial intervention	Baseline	Baseline	Enhanced psychosocial support led to an early and significant reduction in caregiver burden, as evidenced by lower ZBI and HADS anxiety scores at 1 and 3 months with insignificant reductions at 6 months.
		ZBI = 28.3 ± 10.7	ZBI = 32.8 ± 12.2	
		HADS anxiety = 9.1 ± 2.3	HADS anxiety = 9.9 ± 3.3	
		HADS depression = 6.4 ± 2.9	HADS depression = 5.4 ± 4.5	
		1 month	1 month	
		ZBI = 31.6 ± 9.5	ZBI = 22.0 ± 5.3	
		HADS anxiety = 10.1 ± 2.2	HADS anxiety = 7.1 ± 3.2	
		HADS depression = 5.9 ± 3.2	HADS depression = 4.4 ± 3.1	
		3 month	3 month	
		ZBI = 33.4 ± 7.2	ZBI = 21.3 ± 6.6	
De Biase et al <sup>14</sup>		HADS anxiety = 11.0 ± 3.1	HADS anxiety = 6.5 ± 4.5	Conclusion Caregiving for conservatively managed patients was associated with a negative effect on QOL especially in physical role, vitality, and emotional role scales—similar to HD patients but scoring better in physical functioning (possibly explained by a younger mean age). No evidence of significant impact of conservative care on depression or anxiety.
		HADS depression = 6.7 ± 3.6	HADS depression = 3.8 ± 3.1	
		6 month	6 month	
		ZBI = 31.6 ± 7.2	ZBI = 24.3 ± 6.3	
		HADS anxiety = 10.6 ± 1.8	HADS anxiety = 8.5 ± 1.9	
		HADS depression = 7.4 ± 3.0	HADS depression = 4.5 ± 1.9	
		Mean score (conservative care)	Mean score (dialysis)	
		BDI identified 1 case of depression among caregivers	BDI identified 1 case of depression among caregivers	
		STAI-Y 1-2 did not identify evidence of anxiety	STAI-Y 1-2 did not identify evidence of anxiety	
		CBI showed high score for objective burden SF36:	CBI showed high score for objective burden	
Shah et al <sup>15</sup>		Physical functioning = 77 (vs age matched 88.69 ± 14.93)	Physical functioning = 51.25 (vs age matched 67.28 ± 26.00)	No significant difference in health-related QOL as assessed by the SF-6D between caregivers of dialysis and conservatively managed patients. Care-related QOL as measured by the CES score was lower for caregivers of patients on dialysis. Significantly lower mean CES scores were also noted for caregivers residing in the United Kingdom and for spouse/partner compared with children of care recipients.
		Role physical = 60 (vs 81.71 ± 30.27)	Role physical = 75 (vs 60.00 ± 40.43)	
		Bodily pain = 72.8 (vs 75.26 ± 24.07)	Bodily pain = 72.75 (vs 62.81 ± 29.05)	
		General health = 68.6 (vs 66.45 ± 17.49)	General health = 62 (vs 51.63 ± 21.54)	
		Vitality = 52 (vs 63.36 ± 18.19)	Vitality = 55 (vs 55.01 ± 21.09)	
		Social functioning = 72.2 (vs 78.37 ± 20.38)	Social functioning = 68.5 (vs 72.86 ± 24.86)	
		Role emotional = 46.4 (vs 79.2 ± 33.58)	Role emotional = 58.25 (vs 70.45 ± 36.82)	
		Mental health = 68 (vs 67.76 ± 18.18)	Mental health = 65 (vs 60.44 ± 21.04)	
		CES = 80.91 (SD = 15.20)	CES = 64.39 (SD 16.75)	
		SF-6D Mean utility = 0.77 (SD = 0.12)	Mean utility = 0.70 (SD = 0.13)	

Note. ZBI = Zarit Burden Interview; HADS = Hospital Anxiety and Depression Scale; BDI = Beck Depression Inventory; STAI-Y 1-2 = State Trait Anxiety Inventory; SF36 = Short-Form 36 Health Survey Questionnaire; CBI = Caregiver Burden Inventory; QOL = quality of life; HD = hemodialysis; CES = Carer Experience Scale; MQOL = McGill Quality of Life; SF-6D = Short-Form 6-Dimension.



**Figure 2.** Thematic synthesis of qualitative studies.

**Depression and anxiety.** De Biase et al<sup>14</sup> compared caregivers of conservatively managed patients with caregivers of patients on dialysis, finding no difference in the number of cases of depression or anxiety, as measured by the Beck Depression Inventory (BDI) and the State Trait Anxiety Inventory (STAI-Y 1 and 2), respectively. The study by Chan et al<sup>13</sup> also reported caregiver anxiety and depression; the Baseline Hospital Anxiety and Depression Scale (HADS) anxiety score was  $9.1 \pm 2.3$  and  $9.9 \pm 3.3$  and HADS depression score was  $6.4 \pm 2.9$  and  $5.4 \pm 4.5$  in the control and intervention groups respectively (HADS score 0-7 normal, 8-10 borderline abnormal, 11-21 abnormal).<sup>20</sup> The enhanced psychosocial intervention led to a lower ZBI and HADS anxiety scores at 1 and 3 months but with insignificant reductions at 6 months (Table 2).

### Qualitative Study Findings

The qualitative studies included 3 descriptive studies investigating the experiences of caregivers for conservatively managed patients, recruited from renal supportive care clinics in 2 studies,<sup>17,18</sup> and in general tertiary renal centers.<sup>16</sup> Recruitment was in the United Kingdom<sup>16,18</sup> and Australia.<sup>17</sup> Data were collected using semi-structured<sup>17,18</sup> and narrative interview<sup>16</sup> techniques.

Thematic synthesis of the qualitative studies revealed 5 themes: (1) Understanding the concept of CKM, (2) Need for involvement in the decision for CKM, (3) Identifying available supports, (4) Uncertainty about the future and negotiating deterioration and dying, and (5) Burden of care impacting on QOL (Figure 2, Table S4).

**Understanding the concept of CKM.** The concept of CKM was difficult for caregivers to understand. Caregivers reported confusion regarding CKD, the treatment options available, and the reasons to not commence dialysis. Low et al<sup>16</sup> described a limited understanding by caregivers about what CKM involved; a possible factor being the absence of a definite change in duties as a caregiver with the transition to a conservative approach. Caregivers were appreciative of good communication between kidney clinics and primary care, particularly in light of conflicting advice from different medical specialties involved in the patients' care.<sup>16,17</sup>

**Need for involvement in the decision for CKM.** Some caregivers reported a lack of involvement in the decision to choose not to undertake dialysis, a lack of understanding behind the reasoning for a conservative approach and subsequently, difficulties with coming to terms with the person's decision to not have dialysis.<sup>16,18</sup> Other caregivers felt well informed in this regard.<sup>17</sup> Reasons for acceptance of the decision for CKM were similar across all studies, with convenience (in terms of time commitment and travel for dialysis), noninvasive nature of care, lack of perceived benefits from dialysis, and impact on patient's QOL influencing caregiver acceptance.<sup>16,17</sup>

**Identifying available supports.** Caregivers were appreciative of medical and emotional support provided by kidney clinics and good communication with primary care.<sup>17</sup> Some caregivers described a need for more emotional support, particularly with end of life issues and were confused about the role and remit of social service departments.<sup>16</sup> While the study by Noble et al<sup>18</sup> did not report directly on support service utilization, older participants in the study reported a reliance on

wider family and social networks to support patients in their activities of daily living and accessing health care.

*Uncertainty about the future and negotiating deterioration and dying.* Caregivers reported specific anxiety about the process of deterioration and dying, concerns about managing the practicalities of death itself, particularly managing death at home. This was compounded by the uncertainty of the timing.<sup>16-18</sup> Caregivers reported coping strategies including living in the present and discounting the future, but this also manifested as a reluctance to discuss the issue with patients and manage differences of opinion.<sup>16,18</sup> Uncertainty of disease trajectory and prolonged decline resulted in a sense of frustration and disappointment with associated guilt about this disappointment, which contributed to relationship problems in younger caregivers.<sup>18</sup> Caregivers were appreciative of these topics being broached by renal teams and of any practical and emotional support available.<sup>16</sup>

*Burden of care impacting on QOL.* There was an apparent difference in the caregiving duties of younger caregivers (usually children), with greater participation in comprehensive caregiving and performance as intermediaries between older patients and professional services.<sup>16</sup> Younger caregivers experienced difficulties balancing their own lives with caregiving whereas older caregivers reported difficulties managing their own health in addition to that of the patient.<sup>17</sup> Caregivers reported a sense of responsibility to provide a level of care that permitted the patient to remain at home and subsequently, caregiver burnout was found to be associated with patient admission to residential aged care facilities.<sup>16,18</sup> Caregivers across all studies reported a sense of worry about the trajectory of deterioration and specifically of unexpected death.<sup>16-18</sup> At the same time, caregivers found themselves vulnerable when patients were medically ill, specifically when deciding what constituted an urgent problem requiring medical attention, given the decision to minimize medical intervention.<sup>16</sup>

## Discussion

This systematic review found caregivers of patients having CKM experience significant burden, and suggests that they suffer depression, anxiety, and negative impacts on QOL comparable to caregivers of patients having dialysis. These findings are complemented by our thematic synthesis that demonstrates that there are several unique factors that shape the experience of these caregivers, including the age and relationship of caregivers, the degree of involvement in, and understanding of the decision for CKM and the fear and uncertainty about the trajectory of kidney disease. Caregivers also experience personal and physical impacts as a consequence of their caregiving duties, express a need to be supported by health care providers, and demonstrate significant

anxiety with regard to deterioration and dying of the person in their care.

Our analysis revealed a distinct divergence in the experiences of caregivers of conservatively managed patients. Caregivers in 2 studies reported a lack of involvement in the decision to not undertake dialysis. This was reflected in confusion about CKM as a concept and consequent difficulty in coming to terms with the patient's decision not to undergo dialysis.<sup>16,18</sup> In contrast, Hoffman et al reported caregivers were well informed and comfortable with the decision to not undergo dialysis.<sup>17</sup> The difference in experience could potentially reflect the support caregivers received under the dedicated renal supportive care program reported in that study.<sup>17</sup> However, the study by Hoffman et al<sup>17</sup> was at a single center, with a high noninclusion rate, potentially reflecting bias in data collection. In addition, their means of data collection, which included interviews performed by a senior nurse from the service, may have resulted in a positive bias to the reported experiences.<sup>17</sup> The renal supportive and palliative care position statement by Crail et al<sup>21</sup> recommends the involvement of caregivers in the process of decision making. Findings from our analysis support this and suggest a need to address caregiver anxieties and concerns at the time.

Caregiver concern about supporting a deteriorating patient was a recurrent theme. Caregivers reported a lack of understanding of services which, together with a sense of responsibility to provide care at home, resulted in anxiety and ultimately, patient institutionalization in situations of crisis. Specific concerns included managing the practicalities of death—an issue compounded by the uncertainty of the timing, frustration, and/or guilt with regard to the prolonged disease trajectory, and a reluctance to verbalize their concerns. Similarly, Harrison et al reported the top 10 quality indicators of CKM for patients and caregivers included ensuring a peaceful death for the patient, availability of a key contact person in the CKM program, access to clinic staff during and after hours, and referrals for home care services.<sup>22</sup> Providing support to these caregivers, therefore, would require a comprehensive, multifaceted approach with a focus on emotional support in addition to practical support. This is supported by the RCT by Chan et al,<sup>13</sup> where a comprehensive intervention comprising support with advanced care planning, psychological support, and counseling, respite care, and community support resulted in a significant reduction in burden of care and anxiety measures in caregivers. Shah et al<sup>15</sup> also noted lower scores in the care-related QOL domains of “assistance from organizations and government,” reflecting low levels of uptake in existing services among caregivers or a need for further services.

Caregiver QOL, depression, and anxiety were generally comparable for caregivers of patients managed conservatively or with dialysis. Di Biase et al<sup>14</sup> reported a difference in physical functioning, attributed to a difference in caregiver age between the two groups in that study. Univariate analyses



in data collected from Shah et al showed significantly lower CES (Caregiver QOL) scores in caregiver partners compared with children of care recipients.<sup>15</sup> This is supported by qualitative studies with an apparent difference in the experiences of younger and elderly caregivers. Younger caregivers (predominantly children of the patient) experience difficulty balancing their own lives as compared with older caregivers who struggle managing their own health and consequently relying on wider supports.<sup>16,17</sup> Overall, the impact of caring for a patient with kidney failure is driven more by the advanced disease and process of aging, rather than the benefits or burdens of supporting a patient on dialysis compared with CKM.

Caring for a person with kidney failure has similarities to caregiver experiences of other diseases. Uncertainty, difficulty negotiating the process of deterioration and dying, and the need for continuity of care and emotional support around end of life have been reported in advanced liver disease,<sup>23</sup> severe chronic obstructive pulmonary disease (COPD),<sup>24</sup> and advanced heart failure.<sup>25</sup> Similarly reduced QOL and high burden of care have been reported in caregivers of patients with advanced heart failure, COPD, cancer,<sup>26-28</sup> and CKD on dialysis.<sup>8,29</sup> Evidence around supporting caregivers in end-of-life roles, through palliative and supportive services, has historically focused on patients with cancer. However, the care needs of noncancer advanced illnesses such as CKD at the time of referral to a palliative service can exceed those with cancer.<sup>30</sup> While this reflects a bias in referring patients with noncancer diseases to palliative and supportive care services, it also manifests due to the ambiguity in defining a transition point to supportive care in diseases that have a less predictable and slower course. The decision to not undertake dialysis could be a trigger point to introduce patients and caregivers to palliative and supportive services. Given the similar experiences of caregivers of patients with CKD to other chronic diseases, established models of care that integrate primary and specialist care with palliative care in other diseases, may help guide the creation of renal supportive care services in areas where the practice is not yet established.

### **Gaps in the Literature**

As the move to personalized medicine and shared decision making is emerging and the limited use of RCTs in this field (mainly to trial interventions to impact experiences), a predominance of cohort and qualitative studies are to be expected and consistent with our results.

There was limited information in the available studies with regard to positive aspects of providing care to patients undergoing CKM, an understanding of which could form a vital part of decision making with regard to pursuing CKM. While our review describes some of the influence of factors such as age (of the caregiver) and relationship with the patient, there is a need for further research into education, employment, and the impact of the health and comorbidities

of patients on the negative aspects of caregiving. We identified only 1 study trialing an intervention related to caregiver burden; this needs to be expanded further with more research into the cost-effectiveness of these interventions.

### **Strengths and Limitations**

This study had several strengths, including the use of a comprehensive search strategy across multiple databases, and the use of a mixed methods review such that thematic synthesis of qualitative data provided understanding of the quantitative findings. To the best of our knowledge, this is the first systematic review focusing on the experiences of caregivers supporting patients receiving CKM.

Our review had several limitations. While we tried multiple search strategies, research in this field is limited with only 6 studies meeting our inclusion criteria. Studies were of moderate quality, with small caregiver numbers, from mainly single centers in developed countries. Consequently, the findings are not transferable to caregivers in different settings where cultural and socioeconomic factors might influence the caregiver experience. It is also likely that these studies are from sites with a focus on CKM and caregivers, and hence the experience of caregivers in other sites without that focus is likely to vary. The included qualitative studies had significant biases in recruitment of subjects and collection of data, and in the quantitative studies, key data including patient and caregiver age, comorbidities, education, and employment status were poorly reported. Study heterogeneity precluded meta-analysis.

### **Conclusion**

Caregivers of patients with conservatively managed kidney failure experience similar impacts on QOL and burden as caregivers of patients undergoing dialysis. However, understanding and involvement of caregivers in the patient's decision-making process leading to conservative management are lacking. This, together with the prospect of deterioration and dying, leads to fear, uncertainty, and anxiety for the caregiver. This burden of care is increasingly relevant in the setting of an aging population and as more patients opt for CKM. The role played by caregivers is a vital one and further research into their experiences, particularly focused on diverse populations, and into interventions that improve caregiver burden, is a critical part of supporting people with kidney failure choosing CKM.

### **Ethics Approval and Consent to Participate**

Ethics approval not applicable to this study type.

### **Consent for Publication**

All authors consent to publication of this study.

## Availability of Data and Materials

Data available on request.

## Author Contributions

Research idea and study design: N.G.; data acquisition: A.W., N.G., and A.C.; data analysis/interpretation: A.W., N.G., and A.C.; supervision or mentorship: N.G. and A.C.

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## Supplemental Material

Supplemental material for this article is available online.

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