




The needs of families who care for individuals with kidney failure on comprehensive conservative care: A qualitative systematic review

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Abstract

Background: Integrating the family of patients with kidney failure on comprehensive conservative care could benefit patients, families, and the health care system. However, there is a knowledge gap in this phenomenon since no systematic review has focused on the families' needs who care for individuals with kidney failure on comprehensive conservative care.

Objectives: To understand the primary needs of families who care for people with kidney failure on comprehensive conservative care.

Method: A systematic literature review of qualitative studies, followed by a content analysis was carried out. PubMed, CINAHL, and PsycINFO databases were used to search for articles published in English and Spanish between 2010 and 2021. The ENTREQ guideline was used for reporting.

Results: Five relevant studies were included in this study. The analysis has allowed identifying key aspects of knowledge, psychological, social and spiritual needs of family members of patients with kidney failure on comprehensive conservative care.

Conclusions: This systematic review has revealed that families experience a lack of information and continuity of care by health care professionals. Added to this is the psychological burden they bear due to the feeling of indefinite care in time and uncertainty about the death of their loved one. All this, without the necessary support from their immediate family environment and social institutions. In light of these data, a paradigm shift in society and the health care received by these families is essential.

KEYWORDS

chronic kidney disease, conservative care, family, needs, systematic review

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INTRODUCTION

Chronic kidney disease (CKD) is a major global public health problem because of its high incidence and prevalence, significant morbidity and mortality and socioeconomic cost (Gorostidi et al., 2018; Hill et al., 2016; Saran et al., 2019).

In this context, the number of patients who require kidney replacement therapy upon progressing to kidney failure is high. The choice of haemodialysis, despite its proven effectiveness, has caused great controversy in the last decade due to poor results in patients over 75 years of age (Andreu et al., 2015; Kane et al., 2013; Murtagh et al., 2016) or with numerous comorbidities and/or frailty (Alston & Burns, 2015; Davison et al., 2015). Although conservative treatment may not be the best option for these patients in terms of survival, it seems advantageous in terms of quality of life (Andreu et al., 2015; Eckert et al., 2018; Engelbrecht et al., 2021; Gelfand et al., 2020; Gutiérrez & Correa-Rotter, 2019). These aspects are as important for patients and their families as survival (Murtagh et al., 2016).

According to an international consensus document (Davison et al., 2015), conservative treatment of patients with kidney failure is named 'comprehensive conservative care' (CCC). This care refers to holistic, patient-centred care that includes interventions to delay the progression of kidney disease and minimise complications as well as detailed communication, shared decision-making, advance care planning, and psychologic and family support. It does not include dialysis.

Patients with kidney failure experience a significant burden of symptoms (Eckert et al., 2018; Kane et al., 2013; Sánchez et al., 2018), which significantly impact their well-being, affecting all spheres of life (Niu & Li, 2005; Timmers et al., 2008). These patients live in an enormously complex situation that also affects their family environment, sometimes causing them more stress than the patients themselves experience (García-Vivar, 2019). Moreover, family caregivers contribute to solving the gaps and deficiencies in the networks of the social health services of these patients. They also play a crucial role in their care since providing around 80% of all care at home (Stajduhar, 2013).

In this sense and within the context of CCC, nurses should be aware of the important contribution of the family and include them in the care of patients with kidney failure. However, although the nursing discipline recognises the family as a key aspect of their care (Achury & Pinilla, 2016; García-Vivar, 2019), it is not always taken into account in daily practice (Ellington et al., 2018). Family-centred care has emerged as an innovative approach to respond to this situation, involving extending the care approach to the family unit, considering it a system (Hartmann et al., 2010; Martire et al., 2004). This perspective has shown important benefits for both family members and chronically ill patients (Hartmann et al., 2010; Martire et al., 2004). In this sense, and to achieve maximum benefit, it seems relevant to develop effective nursing interventions to support family members in understanding kidney failure and its management (Andreu et al., 2015). To address this issue properly, it is first critical to know the specific needs of the families in this process.

Interest in learning about these aspects has grown, with several recent reviews published on the experiences of family members of patients with CKD (Hoang et al., 2018; Low et al., 2008; Walker

et al., 2015). However, these studies have focused on reviewing the needs of the families of patients with CKD in general or those undergoing replacement treatments. No review could be found that specifically addresses the needs of the families of individuals with kidney failure on CCC. Thus, this study aimed to understand the primary needs of families who care for patients with kidney failure on CCC.

METHODS

Design

To reveal these families' needs, we first conducted a qualitative literature review using a systematic methodology, followed by a qualitative content analysis of the selected studies. This approach facilitates examining the data and interpreting their meaning (Schreier, 2012), allowing the obtention of a condensed and broad description of the phenomenon of interest (Elo & Kyngäs, 2008). This is particularly valuable for building a knowledge base and encouraging the proposal of research projects that cover the gaps identified on a particular topic. The Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guideline (Tong et al., 2012) was used for reporting. PICo framework was used to guide the review focus (Munn et al., 2018):

- Population: Families caring for people with kidney failure.
- Phenomenon of Interest: Families' needs.
- Context: Comprehensive conservative care.

Search methods

The search was performed in the CINAHL, PubMed, and PsycINFO databases. Each search was constructed differently to use the relevant search terms or MESH/Thesaurus/Keyword headings for each database. All searches essentially combined all terms found (and their truncated forms): 'family', 'needs', 'treatment', 'conservative' and 'CKD' (see Table 1). In addition, the searches were limited to the last 11 years (01 January 2010–31 March 2021) and language (English and Spanish).

A second search was accomplished in the journals with the most significant impact regarding this area of the topic. The reference lists of the selected articles were also reviewed through the snowballing technique to obtain other related studies (Figure 1).

Selection process

First, one of the authors (N. Ania-González) reviewed the articles selecting them by title and abstract. If a title appeared relevant but an abstract was not available, the full article was retrieved. Subsequently, two reviewers (N. Ania-González and M. Vázquez-Calatayud) critically read the possible articles selected for the qualitative review applying the selection criteria (Table 2). Disagreements regarding the inclusion of

TABLE 1 Terms used in the search strategy

Search terms								
Family OR		Needs OR		Conservative OR		Treatment OR		Chronic kidney disease OR
'Family' [Mesh]								'Kidney Failure, Chronic' [Mesh]
Family	A	Needs	A	Conservative	A	Care	A	'Kidney failure, chronic'
Relatives	N	Demands	N	Palliative	N	Treatment	N	'End stage kidney disease'
'Caregivers' [Mesh]	D	Requirements	D	Supportive	D	Management	D	'End stage renal disease'
Caregivers								
'Family system'								
'Family caregivers'								

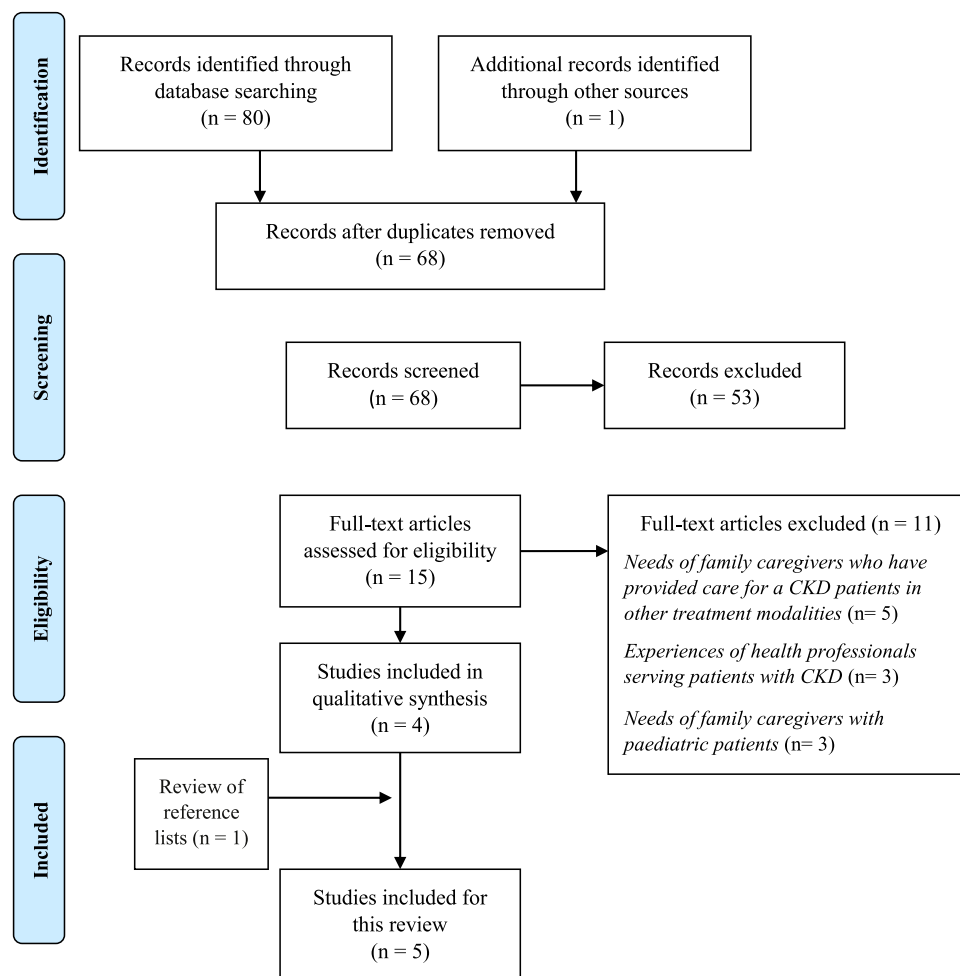


FIGURE 1 PRISMA flow diagram of the article selection process (Moher et al., 2009)

studies were resolved by discussion, and, in cases of persistent disagreement, a third reviewer (J. Martín-Martín) was consulted.

Quality assessment

The quality assessment of the qualitative research selected for the review was carried out. Currently, there are many tools available for

this purpose (Mays & Pope, 2000; Malterud, 2001; Dixon-Woods et al., 2004), although none have been considered a reference standard (Sale & Hawker, 2005). For this study, it was decided to use the 10 questions of the Critical Appraisal Skills Programme (CASP 2018) due to its wide use among researchers. Two authors (M. Vázquez-Calatayud and J. Martín-Martín) independently assessed the selected studies. In case of conflict or disagreement, a third author (N. Ania-González) was consulted.

TABLE 2 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Studies exploring the family needs of kidney failure patients on CCC.	Studies of the needs of patients on CCC.
Primary qualitative research, qualitative reviews of the literature in which primary studies were not included in the review, and doctoral theses of a qualitative nature.	Studies whose objective is to reveal the experiences of health professionals serving patients with CKD (doctors, nurses, psychologists, social workers...)
	Studies whose objective is to reveal the needs of family caregivers who care for CKD patients in other treatment modalities (e.g., haemodialysis or peritoneal dialysis)
	Studies focused on paediatric patients
	Grey literature (leaflets, editorials, news, publications in congresses)

Abbreviations: CCC, comprehensive conservative care; CKD, chronic kidney disease.

Data analysis

A qualitative content analysis process was performed following Elo and Kyngäs (2008). The analysis was conducted using an inductive approach, not starting from predefined themes based on existing literature. First, two authors (N. Ania-González and M. Vázquez-Calatayud) read the results of each article several times to familiarise themselves with the results. The next step was dividing the results section of each article into several codes, grouping words, phrases, or paragraphs relevant to the phenomenon of study. These codes were grouped into several sub-themes, according to their relationship. These sub-themes, in turn, were grouped into the main themes. In this sense, it is worth mentioning that the creation of the themes did not simply consist in gathering aspects that were similar or related, but the data were being classified according to their belonging to a particular theme, implying the comparison between these data and other observations that do not belong to it (Dey, 1993). The Nvivo software was used to carry out this whole process of open coding, creation of themes, and abstraction in an organised manner. To improve the reliability of the results, two researchers (N. Ania-González and M. Vázquez-Calatayud) carried out the coding and categorisation of the analysis, both individually and in joint sessions, to discuss, clarify and reach an agreement. Finally, the four main themes were cross-checked with the rest of the team, thus increasing their rigour and validity. The research followed the principles established in the Declaration of Helsinki (World Medical Association, 2018). In this sense, to prevent researcher bias, authors reflected upon personal biases and assumptions that may affect how they analysed the data and made them explicit in a document. Thus, they could continually consider and set them aside, trying to approach the analysis as openly as possible. In addition, the results are presented together with verbatim transcriptions of the interviews carried out in the different investigations to support the interpretations and meanings derived from the analysis, guaranteeing maximum objectivity.

RESULTS

Included articles

Eighty references were initially retrieved. After eliminating the duplicates, 68 studies were examined, of which 15 were retained. After their complete reading, four articles were selected for an analysis of the results. In addition, one new article was added by manually searching in the reference lists of the selected articles. Consequently, five articles were selected. This entire process is reflected in Figure 1.

Characteristics of the studies

The principal characteristics of the five studies that met the established inclusion criteria are summarised in Table 3. The studies were conducted in the United Kingdom ($n = 2$), United States ($n = 1$), Canada ($n = 1$), and Thailand ($n = 1$). In these studies, a total of 70 family caregivers participated. Frequently, their relationship to the patient was that of their spouse, partner or daughter. All the studies explored the needs of family caregivers who care for patients with kidney failure on CCC. In two studies (Hutchison et al., 2017; Oestreich et al., 2021), caregivers and patients were interviewed. In these articles, we only included the perceptions of the caregivers for the qualitative content analysis.

Quality assessment

The results of the quality assessment of the selected studies are shown in Table 4. All studies answered 'yes' to the first two screening questions before continuing with the rest of them. Along with this, all studies had 'yes' answers in at least 9 CASP questions, highlighting the quality of the qualitative research. However, it should be noted that only one study answered affirmatively to question 6 (Hutchison et al., 2017).

TABLE 3 Characteristics of the selected studies

Author; Year; Country	Objective	Data collection and analysis	Sample	Main results
Ostreich et al. (2021) United States	To know the perceptions of conservative care among patients with advanced kidney disease in the United States and family members	Interviews Thematic analysis	14 patients and 6 family members (female = 4, male = 2)	<ul style="list-style-type: none"> - Core elements of conservative care - Importance of how conservative care is framed - An explicit process to shared decision making - Relationship between conservative care and dialysis
Hutchison et al. (2017) Canada	To assess readiness for advance care planning and barriers and facilitators to advance care planning uptake in a renal context	Semi-structured interviews Interpretative description	9 patients; 7 relatives (no provided) and 9 health professionals	<ul style="list-style-type: none"> - Need for information: prognosis and nature of treatment - Need for advance care planning conversations: relief in future decision making, and awareness of current situation
Pungchoompoo et al. (2016) Thailand	To explore experiences and health care needs during the last year of life among older people with kidney failure, managed without dialysis, from the perspective of bereaved carers	Semi-structured interviews Framework analysis	12 relatives of deceased patients (5–10 months prior) (female = 11, male = 1)	<ul style="list-style-type: none"> - Need for clear information about the symptoms of the disease and its management - Feeling of a lack of support at the end of life: hopelessness and disappointment - Demand for home visits - Financial support - Spiritual support
Low et al. (2014) United Kingdom	To seek how the discourses around ageing and old age play an implicit role in shaping the experiences of this group of close persons caring for someone with ACKD on conservative management	Qualitative interviews Thematic and framework analysis	26 relatives (female = 15, male = 11)	<ul style="list-style-type: none"> - Early awareness of CKD: moral responsibility to care at home, fear of worsening, did not differentiate between problems arising from CKD and ageing - Conservative treatment: difficulties in understanding it; disagreement with the patient's decision, acceptance of seeing it as noninvasive - Ageing in relation to health and social support: need for continuity of care, feeling of insecurity, and dissatisfaction with social services - Ageing and death: lack of understanding about prognosis and anxiety, hopelessness, discussion about place of death

TABLE 3 (Continued)

Author; Year; Country	Objective	Data collection and analysis	Sample	Main results
Noble et al. (2013) United Kingdom	To explore the impact of being a family carer to patients with stage 5 chronic kidney disease managed without dialysis	Semi-structured interviews Approach described by De Wet and Erasmus for data analysis	19 family caregivers (female = 13, male = 6)	<p>Main theme: 'Caring from diagnosis to death'. 1. Inadequate preparation for uncertain death, 2. Inability to discuss death and 3. Concern about patient deterioration. Need for support and palliative care approach</p> <p>Identification of three sub-themes:</p> <ul style="list-style-type: none"> - Difficult situation of the caregiver: making sense of the illness and potential deterioration - Having to care indefinitely: frustration, disillusionment and panic - Avoid talking about death with patients.

Abbreviations: ACKD, advanced chronic kidney disease; CKD, chronic kidney disease.

Themes

After the qualitative content analysis of the studies included four themes of needs of families who care for patients with kidney failure on CCC were identified: knowledge, psychological, social, and spiritual needs. They are presented below. In addition, a summary of these findings and their conceptual relationship is provided in Figure 2. Table 5 contains the family members citations illustrating the results presented below.

Knowledge needs

These needs are linked to family members' knowledge of kidney failure and CCC and their relationship with health professionals (Hutchison et al., 2017; Low et al., 2014; Noble et al., 2013; Oestreich et al., 2021; Pungchoompoo et al., 2016). The five studies reviewed reflect that information is the main need expressed by families (Hutchison et al., 2017; Low et al., 2014; Noble et al., 2013; Oestreich et al., 2021; Pungchoompoo et al., 2016). Family members demand clear information about the symptoms of the disease, its management and expected evolution because they have difficulties understanding the initial diagnosis, treatment options and course of the disease (Table 5, Q1).

Family members also describe uncertainty and insecurity in the face of the possible worsening of the patient's situation and their inability to manage it at home, which would make it necessary to move to institutions with greater resources, causing family members great suffering (Low et al., 2014; Noble et al., 2013). Likewise, family members refer to difficulties in differentiating the symptoms of the evolution or worsening of kidney disease and those of ageing (Table 5, Q2).

Furthermore, family members should receive clear and understandable information on CCC so that they can understand its nature and purpose. On some occasions, family caregivers viewed this approach negatively since it was seen as a passive treatment perspective understood as equivalent to doing nothing (Table 5, Q3). Furthermore, several of the studies reflect that some family members were not involved in making decisions about the patient's treatment, which made it difficult to accept these decisions (Low et al., 2014; Noble et al., 2013; Oestreich et al., 2021). This was especially notable in those who disagreed with the decision not to dialyse, as they saw it as a decrease in life expectancy, causing them anxiety in the face of the expectation of impending death (Low et al., 2014). Other family members, however, were helped in their acceptance by the understanding that dialysis was not a good option for the patient and that due to their age, it would not benefit them. They perceived CCC as a noninvasive option that would not affect the patient's lifestyle or alter his or her health status (Table 5, Q4).

Another important issue was the continuity of care for the patient and the need for a good relationship with the professionals caring for their family members. For these family members, the same team of professionals should follow the patient throughout the process (Low et al., 2014; Noble et al., 2013) or know that medical information has been shared between kidney teams and other medical specialities. However, on many occasions, there has been an absence of a structured approach to care, making family caregivers feel abandoned and having

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Oestreich et al. (2021)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hutchison et al. (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pungchoompoo et al. (2016)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Low et al. (2014)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Noble et al. (2013)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

TABLE 4 Quality appraisal results

Abbreviations: Y, Yes; N, No; CT, Can't Tell.

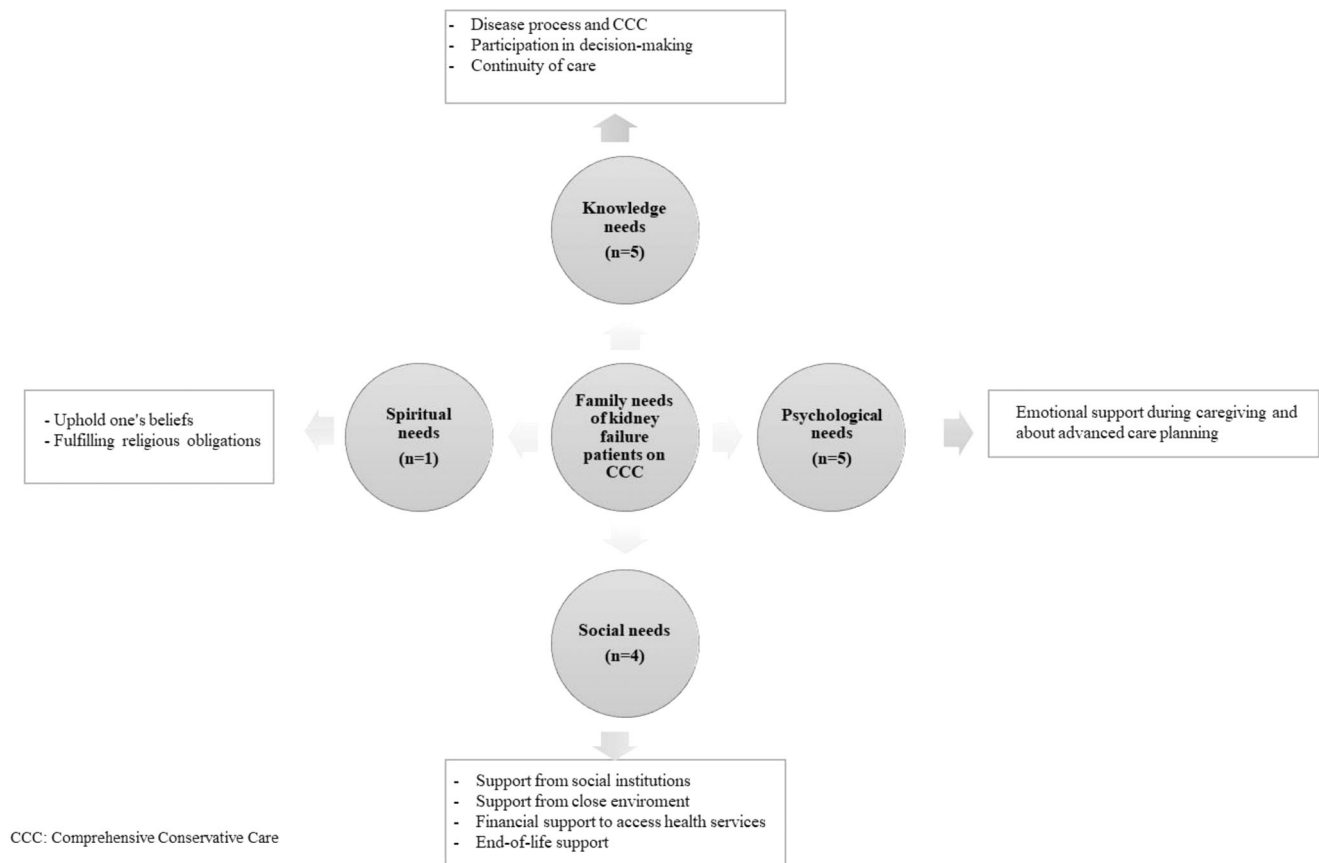


FIGURE 2 Summary of the main findings of the review

to fend for themselves (Oestreich et al., 2021). Due to this situation, contradictory or uncoordinated messages, which can cause confusion and discomfort, occur (Table 5, Q5).

In addition, other family members expressed regret that home visits were not available to all patients. They indicated that visits by nurses to the patient are key to assessing health problems at home, preparing and providing care at the end of life and helping relatives cope (Table 5, Q6).

Psychological needs

Psychological needs refer to the feelings and experiences of family members during the care of a patient with kidney failure on CCC

(Hutchison et al., 2017; Low et al., 2014; Noble et al., 2013; Oestreich et al., 2021; Pungchoompoo et al., 2016).

Noble et al. (2013) revealed the experience of 'having to care indefinitely', which reflects family members' concerns about their ability to manage the situation over an extended period, causing them frustration, disappointment, and panic. In general, this occurs since family caregivers were wary about the expected course of illness and treatment outcomes due to small improvements of their loved ones contrary to their nephrologists' predictions (Oestreich et al., 2021). This extension of the period of care, in some cases, can lead to changes in family roles, making it difficult for a couple to maintain a relationship after taking on the care of a parent (Table 5, Q7).

In addition, some family members reported a feeling of guilt in knowing that the end of their family member's life was approaching

TABLE 5 Family quotes about the identified themes

Quote number	Theme	Source	Quotes
Q1	Knowledge needs	Noble et al. (2013, p. 1834)	... but how long is this going to go on for?... They didn't tell me very much because they don't know either. I think that's the frustration not knowing how terminal is terminal. It's one thing if you know it's only going to go on for a fortnight or maybe a month, or six weeks, but ...months and months and months, then it gets panicky
Q2		Low et al. (2014, p. 618).	She's very small, very frail, doesn't eat a lot and somehow her body has adjusted with the aid of the medication, it adapted somehow. She doesn't feel ill with it, she, her problem is simply confidence in walking'
Q3		Oestreich et al. (2021, p. 359)	So you're just waiting to die? It doesn't sit well with me
Q4		Low et al. (2014, p. 620)	Research has shown that people his age who have had dialysis with kidney function of around 15% live on average 3 years and maybe these people who do this conservative management may be 2 to 3 years, so there is not a huge improvement. I think that results to (the nephrologist) statement it doesn't improve the quantity or quality. Dad is quite understanding now, that this sort of conservative management is the best.
Q5		Low et al. (2014, p. 622)	He went to see the renal doctor who prescribed him some medication for blood pressure and then the cardiology doctor a week later stopped it and said he didn't think it was good. But before him [the person] seeing the renal doctor when he was discharged from the hospital, cardiology actually put him on this medication. So they put him on, then they take him off then putting him on and at the moment, we are thinking who is going to give him what for his blood pressure
Q6		Pungchoompoo et al. (2016, p. 495)	During the time a patient is living at home, we need physicians or nurses to come to see the patient more often, not only 1-2 weeks before patient died
Q7	Psychological needs	Noble et al. (2013, p. 1833)	It is not good. (...) I don't really want to be in a position where we never talk... We just ignore each other because that is what we do. Silence. We just go quiet, and I can't bear the torment of it all
Q8		Noble et al. (2013, p. 1834)	I know it sounds awful, but the discharge letter said end stage renal failure. I thought, oh good it's got to the end stage... but when it seemed to be going on, I thought how long is the end stage. When will it end?
Q9		Low et al. (2014, p. 624)	His condition can improve. No situation is stable really nothing stays the same everything hopefully changes hopefully for the better. I think it is number one priority that he needs to eat a balanced diet. Not once in a while. Not once in a blue moon. Every day
Q10		Low et al. (2014, p. 624)	I wouldn't like, personally myself, I think it'd probably upset her. But she knows she's got kidney problems that could affect her yeah. But I don't know if it's a good idea to tell her
Q11		Hutchison et al. (2017, p. 178).	Oh yes, yeah. Because we didn't realise what we needed
Q12	Social needs	Low et al. (2014, p. 623)	I was concerned when she came out [of hospital] that she wouldn't be able to bath herself. So I phoned up the social services, and they said, 'well, we can't tell you [about progress] until the people have seen her in hospital.' And I said, 'well, can you assure me that if she comes out somebody will be able to help me?' They said, 'oh, I can't tell you'
Q13		Pungchoompoo et al. (2016, p. 497)	My patient couldn't have health check-up regularly since we did not have enough money to pay for transportation to the hospital
Q14	Spiritual needs	Pungchoompoo et al. (2016, p. 496)	... she loved to put fresh flowers and a small portion of food in front of Lord Buddha's image by herself at home. As you know, this indicates respect to put fresh flowers, water, and food in front of Lord Buddha's picture at home when you cannot go to pay respects to monks at the temple. This could also make her feel happy and released her tension in another way

and not being able to predict it. Moreover, they also reported guilt upon learning evidence that survival would be prolonged beyond the initial prognosis (Table 5, Q8).

Similarly, Low et al. (2014) showed the disparity of perspectives on the person's care with kidney failure. Some family members assumed the disease was part of the patient's old age and felt a moral responsibility to provide good care to remain at home. Others, however, reported a lack of understanding about the prognosis of kidney failure and an unwillingness to discuss the future, as it led to confusion and anxiety. Despite this, some family members managed this uncertainty by focusing on living in the present. Indeed, several participants used the lack of medical evidence about deteriorating kidney function to think about the future with hope rather than despair (Low et al., 2014; Oestreich et al., 2021): (Table 5, Q9).

Another recurrent feeling expressed by family members was the constant uncertainty and concern about deteriorating health and death, inadequate preparation for it, and the difficulty in discussing the issue with the patient, as they felt that such discussions could increase their family member's suffering (Low et al., 2014; Noble et al., 2013): (Table 5, Q10). On the other hand, they felt that discussions with professionals about advance care planning were necessary and described them as a relief, as these discussions prepared them to make future decisions. However, family members believed that professionals should initiate these conversations, as the patient and family could not see the need (Table 5, Q11). Other relatives suggested that these conversations should occur as early as possible in the course of the illness and not just at the end of life (Pungchoompoo et al., 2016).

Social needs

Social needs encompass family members' perceived need for support from social institutions and other people in their immediate environment (Low et al., 2014; Pungchoompoo et al., 2016). Some family members reported difficulties obtaining in-home help from social services. Even when they did obtain such help, they felt that it did not meet their needs (Table 5, Q12).

Along with this situation, other family caregivers reported financial difficulties that prevented patients from accessing health services regularly and achieving better control over their symptoms (Table 5, Q13). In addition, family members reported feeling a lack of support for patients at the end of their lives, which had negative consequences such as hopelessness and disappointment with service delivery (Pungchoompoo et al., 2016).

Younger relatives reported being able to participate more actively in the care of the patient, both physically and emotionally. In addition, they often acted as intermediaries between the patient and health professionals. However, family members who were older or had physical health problems needed wider networks of family members and neighbours to assist the patient with daily activities, shopping and access to medical care (Low et al., 2014).

Spiritual needs

This theme reflects the need of family members to maintain their own beliefs and fulfil the religious obligations they entail (Pungchoompoo et al., 2016). It is worth mentioning that although only one of the studies explored the spiritual dimension of life, relatives reported that it was an important aspect of support, both for the patients and themselves, as it allowed them to control their emotions, release tension and help them feel at ease. In this regard, family members tried to make it easier for patients to carry out religious activities at home, as symptoms were often a barrier to attending religious services (Table 5, Q14).

DISCUSSION

This review identified key aspects of adequately attending to the needs of family members of patients with kidney failure on CCC in health services. Although each caregiver's experience is unique and not all share every experience, this review comprises some common experiences that transcend them. Moreover, it represents the knowledge obtained from 70 family caregivers from four different countries. Likewise, these indications may be of great relevance, as they take into account the lines of research recommended by the KDIGO (Kidney Disease Improving Global Outcomes) Controversies Conference on Supportive Care in CKD, whose priorities include the study of the experiences of family members of patients treated with CCC (Davison et al., 2015). Furthermore, the issues identified in this study are considered of great value for the future development of programmes that guarantee adequate care for the families of patients with kidney failure undergoing CCC.

With respect to knowledge needs, a relevant finding was the need for family members to be involved in making decisions about the treatment options of individuals with kidney failure (Low et al., 2014; Noble et al., 2013). This lack of knowledge made it difficult for CCC to be accepted as a therapeutic option, as it was considered a threat to survival, with family members relating it to imminent death. This may be because any family member involved in end-of-life care may consider conservative management complex or threatening. It should be kept in mind that the family faces not only the burdens of care but also the pain associated with expecting the future loss of a loved one (Blumenthal, 2011). In this regard, the literature suggests that decision making about treatment options in patients with kidney failure should be shared with the patient and family, requiring an individualised decision-making process centred on the patient's perspective (Davison et al., 2015; Farrington et al., 2016; Koncicki & Schell, 2016). This can be facilitated by health professionals with good communication skills, such as advanced practice nurses (Eckert et al., 2018), who can inform the patient about his/her disease and prognosis, examine his/her preferences, facilitate the transmission of bad news and adequately address the emotional response (Koncicki & Schell, 2016; Sánchez et al., 2018). In fact, health professionals

have available some examples of guidelines (Griffiths et al., 2015) that may be effective in this area (Brighton & Bristowe, 2016).

Given all the above, it is, therefore, necessary to reflect on whether the care currently provided to the patient truly meets the definition of CCC (Davison et al., 2015), that is, holistic care focused on the patient and his/her family, considering their needs, preferences, and possibilities (Davison et al., 2015; Sánchez et al., 2018), or care focused only on biomedical management of the disease. As shown in this review, health professionals must become aware that families demand greater empowerment and involvement throughout the entire process of care of the patient with kidney failure, from diagnosis to death, with an emphasis on prognostic clarity and impact on quality of life and in which the main objective is the reduction of suffering, including (but not limited to) the end of life (Gelfand et al., 2020; Sánchez et al., 2018). This requires a multidisciplinary approach involving collaboration among the nephrology, palliative care, and primary care teams, with the patient/family being the focus of their attention. In this way, both groups participate actively in decision-making regarding the patient's circumstances, facilitating effective care at the end of life and subsequent bereavement (Gelfand et al., 2020; Gutiérrez & Correa-Rotter, 2019; Kane et al., 2013; Sánchez et al., 2018). In this process, it is necessary to emphasise that CCC must be framed within a perspective as an active, whole-person, team-based, and structured approach to caring for patients (Oestreich et al., 2021), which do not imply that care or survival will be of a lower quality (Tejedor & de las Cuevas Bou, 2008). In fact, it has been seen that when this occurs, family members and patients accept the uncertainty and see this as an opportunity to maintain their current health status and prepare for foreseeable health setbacks (Oestreich et al., 2021).

The results of this study also show that families have unmet psychological and social needs that give rise to feelings of frustration, uncertainty and guilt (Hutchison et al., 2017; Low et al., 2014; Noble et al., 2013; Oestreich et al., 2021; Pungchoompoo et al., 2016). These findings coincide with those reported in a previous review of the impact of this disease on closely related people (Low et al., 2008), identifying the poor quality of life and significant psychological distress among family members of patients with kidney failure. Along with this, this review coincides with other studies of terminal patients by showing a lack of organisation in care and its fragmentation over time, causing, as a result, that families experience a feeling of abandonment by the responsible healthcare professionals of their attention (den Herder-van der Eerden et al., 2017; Seamark et al., 2014). Despite the reality that these families face highlights the need to include them as recipients of care in the daily practice of health professionals (García-Vivar, 2019), and the patient's family has already been considered since 1990 by the WHO as a member of the team and object of care in its definition of palliative care; generally, as it has been seen, the family is not considered in daily practice and is even ignored (Achury & Pinilla, 2016). It is therefore urgent to address these unmet

needs, for which nurses must know the family structure and how the disease affects the patient's family. In particular, nurses need to know about the different family roles, the relationships established between family members and people outside the family nucleus and the context in which the family lives. To this end, from this review and following the recommendations of the International Council of Nurses (Schober & Affara, 2001), we advocate for the family nursing assessment using the Calgary model. This model could be incorporated into the nursing clinical practice, facilitating an understanding of the internal and external structure of the family using tools such as the genogram, the ecomap, and/or the therapeutic conversation (Wright & Leahey, 2009). In addition, the Calgary model allows the family to work on discovering their strengths and helps them identify their own objectives and resources as they seek solutions. In this way, the nurse guides and assists the family in adapting to chronicity, dependency, or the end of life and promoting health (Wright & Leahey, 2009). Using this approach, caregiving families can be seen, in addition to being a resource that facilitates care, as people who need help and intervention themselves to improve their own well-being (Canga & Esandi, 2016; García-Vivar, 2019).

Along with this, we also specifically recommend using the IPOS-renal in the clinical practice of these patients and families on CCC. This tool is based on the original Palliative Outcome Score (POS) and the Integrated Palliative Care Outcome Scale (IPOS), with the additional inclusion of symptoms common in CKD, making it serve to comprehensively assess the needs of these individuals (Raj et al., 2018). However, its use in the daily clinical practice of professionals will not only allow the identification of the negative symptoms that the disease has on the patient's functional status, their health perceptions, and feelings (Holmes et al., 2017; Raj et al., 2018) but will also facilitate the identification of their family's needs. This will favour appropriate management and improve the quality of life of both.

Another notable finding of this review is that there is a paucity of studies addressing spiritual needs (Pungchoompoo et al., 2016), although families emphasise that it is important to address the spiritual side in these cases, both for their own benefit and that of their family members. This finding could be attributed to the cultural heterogeneity of the research reviewed, having been identified in the study in Thailand, where religion is essential as part of the culture and daily customs. However, given the need to address individuals with kidney failure on CCC in a holistic way and throughout all the process (Sánchez et al., 2018), the spiritual aspect should be part of the palliative care to alleviate suffering and provide the highest possible quality of life for patients and their families (Centeno et al., 2018; Guerra-Martín et al., 2015; World Health Organization, 2014).

It should be noted the high quality of the selected studies. All of them had an appropriate research design to the research question posed, described in detail the sampling strategy and the data collection and analysis process carried out. However, in most studies, there was a gap in the information that examined the appropriate role

of researchers by describing how their possible assumptions and biases could influence the process and outcomes. The cause of this omission is unknown, but because it is a crucial aspect of assessing the confirmability of research (Lincoln & Guba, 2000), researchers should address it in their studies.

LIMITATIONS

Regarding the limitations of this study, some publications may not have been identified in the literature review due to language limitations (English or Spanish). It must also be said that the studies have been carried out in four countries with different cultures. Although this cultural difference may be understood as a limitation, at the same time, it can be considered a strength since the results between them have been integrated, enhancing their validity. Likewise, it is necessary to highlight the rigorous selection of articles that have been carried out through specific inclusion and exclusion criteria and their verification by various researchers. Furthermore, the realisation of the qualitative content analysis by two researchers gives the study quality and rigour. The knowledge that this study provides on the needs of families who care for patients with kidney failure on CCC is beneficial for nurses and other professionals involved in their attention.

IMPLICATIONS FOR CLINICAL PRACTICE

This review is an important tool to make health professionals aware of the needs and requirements of family members of patients with kidney failure on CCC. In particular, the development and effective implementation of future programmes to improve the care of these patients and their family members throughout the health-disease process requires changing the focus of care and extending it to the family unit. This change in approach will be key to ensuring that programmes are realistic and reflect the needs of both patients and families.

Based on the findings of this review, it is also recommended to design interventions aimed at (1) involving the family in decision making regarding the process of treatment and (2) providing family members with knowledge tools, as well as emotional, social and spiritual support, to ensure their contribution to the treatment.

CONCLUSIONS

This systematic qualitative review, for the first time, highlights the needs that families experience in the care of patients with kidney failure in CCC. Families experience a lack of clear and understandable information about the therapy their family member is receiving, as well as a lack of continuity of care from professionals. Added to this situation is the psychological burden they experience due to feelings of indefinite care over time and constant uncertainty and worry about deteriorating health and death. All this, without the necessary support from their immediate family environment and social institutions.

In light of these data, a paradigm shift in society and the health care received by these families is imperative. It is necessary to stop seeing the family as a mere patient care resource and incorporate them into the health care process.

CONFLICT OF INTERESTS

The authors declare no conflict of interests.

AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data: N. Ania-González, J. Martín-Martín, M. Vázquez-Calatayud. *Involved in draughting the manuscript or revising it critically for important intellectual content:* N. Ania-González, J. Martín-Martín, P. Amezcua-Goñi, M. Vázquez-Calatayud. *Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content:* N. Ania-González, J. Martín-Martín, P. Amezcua-Goñi, M. Vázquez-Calatayud. *Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any of the work are appropriately investigated and resolved:* N. Ania-González, J. Martín-Martín, P. Amezcua-Goñi, M. Vázquez-Calatayud.

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