

**What are the experiences and concerns raised on an international online forum by
caregivers of patients with chronic kidney disease?**

Natalie Tuckey

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School of Psychology

University of Adelaide

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Abstract

Chronic kidney disease (CKD) is a health condition which has prolonged symptoms and treatment options which impact a patient's quality of life. Research has addressed the psychosocial impacts for patients living with CKD, however psychological and physiological impacts on the patient's caregiver have been overlooked. Social support can improve caregivers' quality of life, with emerging research exploring online social support. This study employed qualitative content analysis to examine 159 posts on an online international forum: *Caregivers of Patients with Kidney Disease*. The Research Question addressed by this study was: *What are the experiences and concerns raised on an online international forum by caregivers of patients with chronic kidney disease?* The process included collection and familiarisation of posts, which were then coded using verbatim words and phrases. Next, codes were arranged into 71 sub-categories, 12 categories and then grouped into three themes: *Experiences of caregivers of patients with kidney disease*, *Use of online social support* and *Caregiver knowledge*. Findings from this study highlight the psychological and physical challenges that caregivers of patients with CKD experience. This study provides valuable insight into the gap in caregiver knowledge and their need to seek online peer support on topics including: advice on patient diet; clinical management; symptoms; and how to support the patient to adhere to diet and medications. This study highlights how caregiver forums can inform support strategies from healthcare professionals to increase caregiver involvement in treatment and education options, as well as tangible assistance to support the caregiver and patients' needs.

Key Words: kidney disease, caregiver, online social support

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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Date: 24/9/2020

Contribution Statement

In writing this thesis, my supervisors and I collaborated to generate research questions of interest and design the appropriate methodology. I conducted the literature search, completed the ethics application, undertook the search for the data corpus and manually collected all the data. My supervisors and I collaborated in selecting the forum and relevant psychological theory. I was responsible for manually coding all the posts, creating the categories and identifying the relevancy of this research. I wrote up all aspects of the thesis.

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1.1 Chronic Kidney Disease

Chronic Kidney Disease (CKD) is a progressive and debilitating chronic illness which results in irreversible loss of kidney function. In Australia, there were 237,800 people diagnosed with kidney disease in 2018, an increase of 30% since 2012 due to population growth and ageing (Australian Bureau of Statistics, 2018a). CKD is fatal without treatment. End stage kidney disease (ESKD) is when a patient's body can no longer remove extra water and waste products from their blood (Kidney Health Australia, 2020). Life expectancy can be prolonged, however, with treatments including peritoneal dialysis (PD), haemodialysis (HD) or a renal transplant (Baillie & Lankshear, 2015; Bennett, Schatell & Shah, 2015). PD treatment can be administered in two ways: automated overnight dialysis (APD) or continuous ambulatory dialysis (CAPD) involving four exchanges of treatment throughout the day via a drain bag (Baillie & Lankshear, 2015; Kidney Health Australia, 2020). HD can be undertaken at home or in a specialised centre. It is typically administered three to four times a week, each session lasting up to five hours (Glover, Banks, Carson, Martin & Duffy, 2011; Kidney Health Australia, 2020; Tong, Sainsbury & Craig, 2008). It is widely acknowledged that dialysis for CKD is one of the most onerous medical treatments due to the prolonged and time-intensive process, which encompasses medical interventions, along with mental, physical, financial, and social demands (Gilbertson et al., 2019). To preserve the kidney function patients and prevention of comorbidities, the patient will be prescribed a multi-faceted treatment plan, which includes adherence to medication, diet and fluid intake (Clarke, Yates, Smith & Chilcot, 2016)

A systematic review of the experiences and quality of life of patients with CKD found that quality of life declined as symptoms increased. The most common physical symptoms included

fatigue, drowsiness, pain, and feeling washed out, which are said to negatively impact the patient's physical, psychological, and social well-being (Yapa, Purtell, Chambers & Bonner, 2019). Studies have shown that patients with CKD have higher rates of depression and anxiety than patients with other chronic conditions, which have negative treatment outcomes and mortality rates (Goh & Griva, 2018). A qualitative study of patients undergoing APD found that patients experience a loss of autonomy from the gastrointestinal symptoms commonly found from medical side effects, uraemia, and comorbidities. The loss of autonomy has significant physical and psychosocial impacts to the patient's daily routine including feelings of frustration, powerlessness, social isolation, and avoidance behaviour due to frequent and unexpected bowel movements (Duncanson, Chur-Hansen & Jesudason, 2019). Studies have also shown that patients with CKD reported concerns about the strict diet restrictions, limited treatment options, uncertainty as they navigate life changing circumstances, and the inability to control the disease progression (Noble, Kelly & Hudson, 2013; Subramanian et al., 2017). Patients with ESKD, have also reported negative impacts on their close relationships, such as feeling like an imposition, withdrawing from friends and social outings, and having a decreased interest in sex (Duncanson et al., 2019). A qualitative study found that the most frequently used coping strategies of patients with CKD to manage their disease included "taking care of myself, following doctors' orders," "accept it," and "rely on family and friends" (Subramanian et al., 2017, p. 5)

An early study by White & Grenyer (1999) reported that caregiver support enables the reduction of adverse experiences associated with dialysis on patients with CKD. Additionally, research has found that caregivers and strong family support can improve the outcomes of patients with CKD, particularly with improved adherence to dietary restrictions and dialysis treatment (Gayomali, Sutherland & Finkelstein, 2008; Low, Smith, Burns & Jones, 2008). A supporting

study has shown that social support is a significant modifiable risk factor for noncompliance of medication, dialysis, lifestyle, and dietary modification in males with low self-reported health scores (Cohen, et al., 2007). Additionally, one of the main factors relating to non-adherence or discontinuing dialysis is the perceived burden on the family (Low et al., 2008). There is additional reliance upon family members to support dialysis treatment and the symptoms of CKD and to make decisions about treatment options, particularly when patients have comorbid conditions (Bennett et al., 2015; Gilbertson et al., 2019). Patients with CKD can experience a sense of indebtedness to their partners with many patients considering the effect on their immediate family members when deciding which treatment to undergo (Shah et al., 2020; Wilson-Genderson, Pruchno & Cartwright, 2009).

1.2 Caregivers

Caregivers have been described as “the individual(s) who during the course of treatment are most closely involved in caring for the patient and helping the patient cope with and manage their chronic illness” (Gayomali et al., 2008, p. 3749). In 2018 there were 2.65 million unpaid caregivers in Australia, representing 10.8% of the population, with over 70% being female (Australian Bureau of Statistics, 2018b). Caregivers of patients with chronic disease are integral to providing physical and psychological support to the person being cared for, such as personal care, dressing and lifting, administering medications, providing transport, attending clinic appointments, managing dietary requirements, as well as financial, emotional, and social support (Tong et al., 2008).

Studies have shown that without assistance, caregivers can suffer from caregiver burden, resulting in poor physical, psychological, emotional, and functional health. Caregiver burden is described as subjective and objective. Subjective burden refers to fatigue, stress, altered self-

esteem and limited social contact. Objective burden is tangible disruptions to family life and activities (del-Pino-Casado, Frias-Osuna, Palomino-Moral, Ruzafa-Martinez & Ramos-Moricillo, 2018; Mollaoğlu, Kayataş & Yürügen, 2013). Caregiver burden is said to be influenced the caregiver's age, gender, mental acuity, behaviour, perceived social support, perceived burden of care, intellectual understanding of the patient's disease and accepting of self (Jafari, Ebrahimi, Aghaei & Khatony, 2018; Sajadi, Ebadi & Moradian, 2017; Solomi & Casiday, 2017).

Recent literature on what is termed “the sandwich generation” articulates that caregivers, nominally women, are caring for elderly parents and young children as life expectancy has increased, and childrearing delayed (Steiner & Fletcher, 2017, p.133). A significant time commitment is required by sandwich generation caregivers to be available, or on call for care recipients to provide physical and emotional care. The multiple roles are argued to create competing demands from the workplace, as sandwich generation caregivers are commonly of working age (Steiner & Fletcher, 2017). The largest barrier for caregivers to remain in paid employment is managing work hours and the need for flexibility to manage the caring role, with 53 percent of primary caregivers aged between 15-64 years in paid employment (Australian Bureau of Statistics, 2018b). The benefits to caregivers maintaining employment is the reduction in social isolation, financial benefits, self-esteem, and a form of respite from the role as a caregiver (Carers Australia, 2020). Maintaining social networks outside of the caring environment allows the person to have an identity outside of a caregiver and engage with others. However, due to the challenges in managing paid employment and caring responsibilities, 65% of primary caregivers reside in households in the lowest two quintiles, with 36.9% of all caregivers supported by a government allowance or pension as their main source of income (Australian Bureau of Statistics, 2018b).

1.2.1 Caregivers of chronic disease

Caregivers can experience additional stress when the person for whom they are caring has multiple chronic conditions, particularly aging adult carers who may also be managing their own health decline (Polenick et al., 2020). Caregivers of chronic conditions, other than CKD, have reported common themes, such as concealing their own feelings of sorrow and fatigue to avoid the patient from feeling like a burden, waiting for further health decline of the patient, and waiting for the experience to end (Hoffman, Tranter, Josland, Brennan & Brown, 2017). Caregivers may recognise the importance of self-care for their well-being and that of the patient for whom they are caring for; however, it has been reported that caregivers typically engage minimal external support (Solomi & Casiday, 2017). Research indicates that older caregivers are less likely to accept external support from community groups or professional services despite the additional challenge of managing their health (AndréAsson, Andreasson & Hanson, 2017; Colvin & Bullock, 2016; Wilson-Genderson et al., 2009). Additionally, studies have shown that caregivers either lack the education about home care services available to alleviate the carer burden, or they cannot afford them (Colvin & Bullock, 2016; Mollaoğlu et al., 2013). It is argued that health professionals focus on the medical aspects of the patient rather than discussing the broader psychosocial elements of the chronic condition with the patient and their caregiver (Yu, Seow, Seow & Tan, 2016).

In recent oncology studies, the relationship between the oncologist and caregiver was found to improve the caregivers' experiences with patient end of life care. The reason for the improved experiences, was the caregiver had a sense of alliance with the oncologist which satisfied an intrinsic desire to feel heard and supported (An, Ladwig, Epsetein, Prigerson & Duberstein, 2020). Additionally, it has been argued that caregivers play an integral role in communicating between cancer patients and their clinicians, which can be enabled through routine family meetings (Datta

et al., 2017). Research in CKD examining the relationship between the nephrologist, the caregivers and patient outcomes is yet to be conducted.

1.2.2 Caregivers of patients with kidney disease

Caregivers of patients with CKD play an important role in providing support to the patient in adjusting to CKD and treatment options, including adhering to strict dietary requirements (Beanlands et al., 2005; Low et al., 2008; Shortridge & James, 2010). Research has shown that caregivers of patients with CKD are primarily spouses of male patients, followed by daughters and other female relatives (Burckhardt & Padman, 2015; Gilbertson et al., 2019; Mollaoğlu et al., 2013). It has been argued that caregivers of patients with CKD are affected by two primary factors. Firstly, the interference to their social lives from both HD and PD dialysis treatments and secondly, greater physical support once the patient loses functional independence (Low et al., 2008). Despite dialysis modalities designed to be performed independently and self-administered by the patient or through hospital care, research has found that caregivers take on much of that responsibility (Beanlands et al 2005; Duncanson et al., 2019).

A systematic review of 61 quantitative studies of 5,000 caregivers of adult dialysis patients found that the caregivers' burden and quality of life were worse for caregivers of dialysis recipients in comparison with patients of other chronic health conditions (Gilbertson et al., 2019). There were comparable impacts to the caregiver when the patient was receiving either HD or PD, however caregiver burden and quality of life was poorer in caregivers of patients undertaking HD in a specialised centre. The quality of life of caregivers was found to have improved once the patient had a transplant. Furthermore, this study found that caregivers of patients with CKD are primarily females caring for older males. It is argued that that female sex and being younger in age are higher

risk factors for poorer quality of life, and that spousal relationships and high literacy are protective factors (Gilbertson et al., 2019).

A further literature review of 36 studies by Low et al. (2008) found that caregivers who lived with a patient with ESKD experienced fatigue, stress, isolation, life restrictions, increased workload, financial impacts, changed relationship with the patient, and intimacy problems for spousal relationships. It was commonly reported that caregivers neglected their own health, but caregivers who had taken a break from the carer role reported a positive impact on their health. Despite the negative impacts, caregivers still played a positive role in enhancing the patient's well-being. The study found that caregivers wanted more communication with health care professionals, as their needs were not always addressed. There were also reports of caregivers lacking education and information on how to manage the lifestyle adjustments because of the patient undertaking dialysis (Low et al., 2008).

Beansland et al. (2005) undertook a qualitative study of 37 caregivers of home dialysis and in-center dialysis patients. The outcome of this study showed that caregivers experienced a range of emotions from being bitter, proud, and growing into the role. One of the main findings was the overwhelming emotional impact of watching a loved one deteriorate as treatment continued, with the reality that the health of the patient was not going to improve. The study showed that caregivers felt the need to regularly monitor the patient, including going home from work during a lunch break, maintaining regular phone contact or coordinating family and friends to check in with the patient when they could not. The most reported tasks by caregivers was meal preparation, transportation, coordinating appointments, managing supplies, and providing physical and

emotional comfort. It was recognised that many caregivers absorb this caring role in addition to family and work-related responsibilities (Beanlands et al., 2005).

Research has shown that caregivers of patients receiving HD and PD experience a negative impact on employment, leisure activities, and social outings (Cantekin, Kavurmacı & Tan, 2016). It has been reported that the impact of dialysis on caregivers resulted in an increase in the daily activities including food preparation, diet monitoring, ordering medications, organising appointments, and cleaning and preparing the dialysis machine (Duncanson et al., 2019). In addition, the psychological impacts to caregivers of patients with CKD included negative reactions to the patient's situation, and the patient's mental changes, such as worry and resentment, as well as the loss of partnership, and poor sleep quality (Avsar, et al., 2015). Patients with comorbid conditions and who had more physical dependencies have reported to contribute to more significant caregiver burden (Walker et al., 2015).

Despite the negative effects on the caregiver and patient relationship, there are also studies which show greater health benefits and good quality of life (Low et al., 2008). This is supported by research by Solomi & Casiday (2017) where spouses acknowledged their caregiver role had improved their practical and emotional experience with their loved one and reciprocity of looking after one another through "thick and thin" (p. 82). A systematic review on 24 qualitative studies by Walker et al. (2015) looked at the patient and caregiver perspectives on home HD and identified several positive themes. It was reported that some relationships between the caregiver and patient had strengthened, as a result of patients being at home more and thus being able to contribute to the household routine. It was also reported that home HD enabled caregivers to re-establish a healthy self-identity and increased freedom without the impact of travelling to and from dialysis

appointments. The impact of travel was consistent with a qualitative study of 22 patients and 20 of their identified caregivers receiving in-centre HD, looking at the expectations of home HD (Tong et al., 2013). Participants perceived home HD would provide them with greater freedom and minimise wasted time travelling to and from dialysis centres. Additionally, the rigid dialysis schedule was perceived to be stressful and burdensome. Despite the perceived benefits, the concerns raised about home HD included the additional burden placed on caregivers and disrupted sense of normality (Tong et al., 2013).

1.3 Social Support

Social support has positive effects on physical and psychological health through sharing concerns, experiences, and opportunities as well as guidance to navigate stress (Demirtepe-Saygılı & Bozo, 2011; Flynn & Stana, 2012). Research has demonstrated that social support creates positive effects on caregiver burden and quality of life through psychological factors including appraisals, emotions, and feelings of control (Brand, Barry & Gallagher, 2016; del-Pino-Casado et al., 2018; Shukri, Mustofai, Yasin & Hadi, 2020). Tardy (1985) proposed a social support model which outlines four types of support content: emotional, instrumental, informational, and appraisal. Emotional support is described as an individual's emotional experiences and satisfaction, such as trust, love, and empathy. Visible help such as physical assistance, financial support, time, and social networks can be described as instrumental support. Informational support relates to advice or education provided, and appraisal support is the evaluative feedback, such as providing guidance for improvement or specific comments on the efforts undertaken (Tardy, 1985).

A randomized control trial of 29 pairs of patients with CKD and their caregivers by Chan et al. (2016) were provided with enhanced psychosocial support over a period of up to 6 months. The

study found that the enhanced psychosocial support program significantly reduced anxiety and burden for caregivers. The psychosocial support included family counselling, marital counselling, coping skills training, community social support, and bereavement and spiritual counselling during palliative care (Chan et al., 2016). The study reported that after the six month period caregivers showed significantly better anxiety and quality of life scores compared to the control group.

Furthermore, a qualitative study undertaken by Taylor, Gutteridge & Willis (2016) of 15 patients with CKD and 11 of their caregivers found that peer support offered more benefits over and above existing support by family and friends. Caregivers also reported to not wanting to burden their family and friends with the realities of their carer role (Taylor et al., 2016). Additionally, the benefits extended to learning experiences of other patients and caregivers, to improve their feelings of isolation, provide clarity of the disease progression, and thus have more control over the future (Taylor et al., 2016).

There is limited research available on the effects of psychosocial well-being from support interventions specifically for caregivers of people with CKD as the primary focus has been on patients, despite the increasing acknowledgment of the undesirable effects on caregivers (Tong et al., 2008).

1.4 Online social support in health

Online health communities involve knowledge sharing, using an online platform which allows posters to operate with autonomy and choosing how to interact with others (Shen, Zhu & Xu, 2018). Online connectivity is argued to be one of the most important trends for health care professionals, patients, and caregivers for providing consistent care, building relationships

between providers, and sharing important information (Piraino, Byrne, Heckman & Stolee, 2017). It is argued that social connectivity in healthcare is an important platform for engaging and supporting patients and their families, creating awareness, and introducing new technologies (Burckhardt & Padman, 2015). Online social support (OSS) has growing potential to enable people to engage with the community regardless of geographical location and transportation barriers, and it is affordable, accessible, and allows users to respond at their own speed (Ahmed et al., 2017; Bennett et al., 2015; Pinsk & Nicholas, 2017). OSS is an important aspect in health care to create awareness, education, and patient and caregiver engagement to manage health outcomes (Ahmed et al., 2017).

This study used the theoretical framework as proposed by LaCoursiere (2001) to understand the role of the internet in providing social support. OSS is said to have evolved from dialup bulletin board services through transmitting messages and support by way of local operators. Through the evolution of the internet, online community groups progressed, allowing larger numbers of people to communicate online (LaCoursiere, 2001). Researchers have claimed that OSS groups provide a network of support when the needs are not being met through conventional means (Wright & Bell, 2003). In her theoretical framework, LaCoursiere (2001) outlined that OSS is made up of four elements: initiating events, mediating factors, social support, and outcomes. The first element relates to the motive to engage in online support. LaCoursiere (2001) argued that the trigger for an individual to seek OSS was a change or perceived change in health status. The second element of the theoretical framework is the mediating factors, which influence the OSS. The mediating factors relate to the individual's health, demographics, perceived individual factors and internet use. LaCoursiere (2001) argues the third element is OSS, which is consistent with the four classifications of traditional social support, as outlined previously, with the addition of entities,

connotations, and tones present in a virtual setting. The effect of OSS is unconsciously processed and evaluated for personal relevancy through three filters: perception (feeling state), cognition (intellectual processing) and transaction (evaluation of all information), which then determine the outcomes, which is the fourth element of OSS (LaCoursiere, 2001). Outcomes from OSS are argued to fall into qualitative and quantitative outcomes. Quantitative outcomes relate to tangible measures such as increased quality of life, improved psychological and physiological status, and perceived health including factors such as hope and empowerment. In contrast, qualitative outcomes relate to how interactions online are perceived, such as self-awareness through implicit and explicit messages (LaCoursiere, 2001).

LaCoursiere (2001) proposed that women seek OSS more frequently and are attracted to practical tools, advice, and emotional relief to support themselves or on behalf of others, whereas men are more likely to look for support about their condition. Furthermore, research has found that online users with lower life satisfaction or higher stress levels are more likely to request advice on online platforms (Utz & Breuer, 2017).

OSS is argued to improve quality of life through perceived health, valuing life processes, acceptance, as well as improved psychosocial processing associated with decreased stress, depression, and increased coping (LaCoursiere, 2001). In a discourse analysis of an online forum for caregivers of patients with mental illness, it was found that posters were able to offer and receive support from a peer community (Perron, 2002). Posting online immediately after an emotionally charged event was described by posters as being therapeutic, which is unique feature of online social support. A sense of catharsis was also reported through writing out experiences and emotions. This study found that many new participants had been following the online

community for a while before introducing themselves (Perron, 2002). It has been postulated that active posters learn coping strategies through disclosing personal ordeals, whereas passive readers benefit from enhanced communication and knowledge about the illness and peer experiences (Hansen, Sheehan & Stephenson, 2016).

It is argued that caregivers can experience optimism and hope through reading alternative perspectives and successful strategies, to similar situations as their own (Darcy, Brunsten & Hill, 2011). Studies have shown that caregivers search for and receive support on internet-based platforms, which provide an integration into a meaningful online social network. The benefits of such platforms are argued to provide an increased sense of belonging, social inclusion, confidence, and self-efficacy in caregiving (Newman, Wang, Wang & Hanna, 2019). Additionally, interacting on online communities enables posters to share sensitive content, freely disclose personal information with less judgement being imposed from traditional nonverbal cues and privacy factors, and the posting can be anonymous (Jowett, 2015). Additionally, information shared on community health forums can extend to information about the disease, community resources, behaviour management and caregiver coping skills as well as support, education, disease modification, disease diagnosis and disease management (Patel, Chang, Greysen & Chopra, 2015).

Burckhardt & Padman (2015) used semantic ontologies to analyse the content of two online kidney forums, DaVita Kidney Care and KidneySpace, which has now closed. The study captured over 60,000 posts between the two sites to identify the experiences of patients, and preferences of treatment options. A considerable amount of the content related to the discussion of modalities of dialysis, receiving a kidney transplant from a donor, dietary requirements, and the preference for dialysis to be at home (Burckhardt & Padman, 2015). It was also found that significantly more

posts contained reference to male partners, than that of female partners, and that more women than men were using the online forum. The study also identified comments from posters caring for their ancestor, primarily their mother or father. Due to the sizable amount of content relating to a relative with kidney disease, this study recommended further analysis of the needs and experiences of caregivers of patients with kidney disease (Burckhardt & Padman, 2015). This recommendation formed the basis for the rationale for the current study's research question.

A subsequent study by Ahmed et al. (2017) analysed a Facebook kidney dialysis forum using qualitative thematic analysis. The major themes identified on the forum were: sharing information, seeking, and providing emotional support, and sharing experiences with others (Ahmed et al., 2017). In a recent study by Benson et al. (2020) a randomised clinical trial of an online support intervention for hospice cancer caregivers was analysed, using qualitative content analysis. The study found that emotional support was the predominate type of support offered, with emotional self-disclosure the most frequently elicited support. Participants found the online forum a useful platform to connect to peers, whilst some participants noted a desire for more appraisal support. It was also noted that some participants longed to create a stronger connection and friendship with other caregivers, which was not attainable using the online support group (Benson et al., 2020).

Whilst there are limited qualitative studies on the perspectives of caregivers using online forums, it is argued that OSS has shown promising effects that can enhance the caregiver function through social support and feelings of competence (Dam, de Vugt, van Boxtel & Verhey, 2017). As demonstrated by caregivers of patients with chronic conditions, other than kidney disease, caregivers may be drawn to seeking support online due to time constraints, privacy concerns, travel

requirements, the need to arrange care or leave the patient, and stigma associated with receiving support from a professional (Ploeg et al., 2018).

1.5 The current study

In summary, current literature has focused on the quality of life of the patient with the psychosocial challenges of caregivers of patients with CKD lacking in-depth research (Flynn & Stana, 2012; Tong et al., 2008). Caregivers are integral to providing patients with CKD support with dialysis treatment, physical and emotional support as the disease progresses as well as to encourage adherence with diet and medications (Gayomali et al., 2008; White & Grenyer, 1999). Social support can enhance a caregiver's quality of life through social inclusion by sharing experiences with those in similar situations (Brand et al., 2016; del-Pino-Casado et al., 2018; Shukri et al., 2020). OSS is an important direction for enabling caregivers to connect with peers to seek information, share experiences and provide emotional support despite geographical and travel limitations (Ahmed et al., 2017; Bennett et al., 2015; Pinsk & Nicholas, 2017; Piraino et al., 2017; White & Dorman, 2001). There is a gap in the literature in the use of OSS by caregivers of patients with CKD, which can provide valuable insight into their experiences and psychosocial challenges. Findings from such research are relevant to patients, caregivers and health professionals to improve education and support programs in treatment decision making, dialysis therapy and improved quality of life for both patients and caregivers (Beansland et al., 2005; Cantekin et al., 2016; Flynn & Stana, 2012). As such, this study aims to contribute to the literature through the research question: *What are the experiences and concerns raised on an international online forum by caregivers of patients with chronic kidney disease?*

Chapter 2: Method

2.1 Ethical considerations

Low Risk Ethics approval was granted (University of Adelaide School of Psychology HREC Sub-committee #20/32) with the stipulation anonymity of participants (i.e. posters to the forum) was maintained. Forums that were not public and required the researcher to join in order to view posts were excluded from the search criteria (Braun & Clarke, 2006; Jowett, 2015; Rodham & Gavin, 2006). This research was conducted in collaboration and registered with the Central Northern Adelaide Renal & Transplantation Service (CNARTS) Clinical Research Group, a multi-disciplinary team which conducts patient-centered studies to influence clinical care through evidence-based practice.

Whilst obtaining consent from forum posters was neither possible, nor required, all were given a pseudonym and any information that could compromise anonymity was excluded from the analysis. When posters joined the forum, from which data was collected for this study, they were required to agree to terms and conditions, including that the forum is public, that care should be taken in providing private information and that the forum was not intended to provide or substitute for medical advice (see Appendix A for DaVita Kidney Care Terms of Use).

2.2 Online forum selection

As part of the data collection process, a number of librarians from the University of Adelaide Library were consulted to assist with the formulation of search terms, which included “kidney”, “renal”, “dialysis”, “caregiver”, “care”, “chronic illness”, “forum”, “online”, “support”, “discussion”, “health”. This resulted in 19 forums being identified, 11 were excluded due to

minimal content on kidney disease, three were not public forums and thus excluded, three were excluded due to minimal posts from caregivers of patients with kidney disease, and one was excluded due to inactivity. The remaining forum was *Caring for Someone with Kidney Disease*, sponsored by DaVita Kidney Care (2020) which is one of the largest private kidney care service providers in the United States. Participants (posters to the forum) were members of DaVita Kidney Care who made posts between October 2006 and April 2020. At the time of data collection for this study (May 2020) there were 10,836 topics, 55,808 posts and 7,069 active members on the website with 200 threads on the forum consisting of an opening post and each of its corresponding responses.

2.3 Data analysis

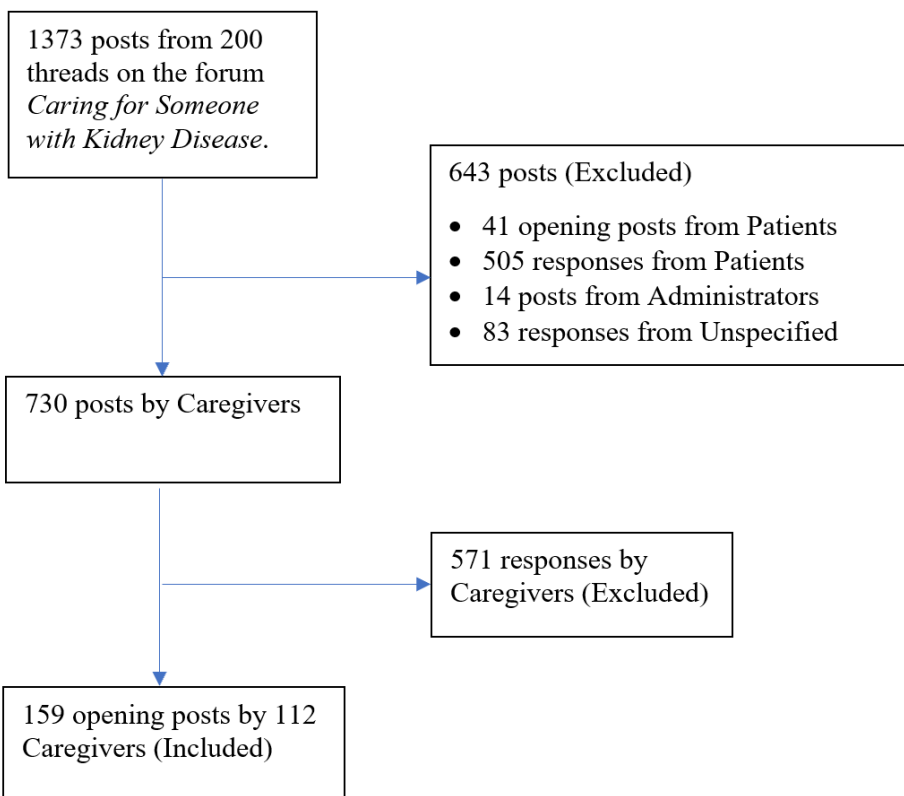
Qualitative content analysis was used to categorise data obtained from the online international forum which is a systematic process to review the content of the text data, then process into codes using subjective interpretation of the content (Hsieh & Shannon, 2005). Qualitative content analysis was suitable for the present study which was used to classify large amounts of text into efficient categories. The process was broken into three phases.

Firstly, 200 threads between October 2006 and April 2020 were collected, de-identified and manually copied verbatim into Microsoft Excel for analysis. A thread consists of an opening post and each of its corresponding responses. In total, 1,373 posts were captured, made up of 200 opening posts and 1,173 responses. The data was repeatedly read by the researcher to achieve immersion and to obtain an understanding of the context of the data. As part of this process, posters were categorised into “caregivers”, “patients”, “administration” or “unspecified”. Caregivers were defined as a person posting about a patient with CKD, or about their experience of caring for a

patient with CKD. The data was refined to exclude posts made by patients, administrators or those unspecified, leaving only the posts from caregivers. Only opening posts were used for this study, as data saturation was reached, thus excluding responses by caregivers. This resulted in 159 opening posts made by 112 caregivers (See Figure 1).

Figure 1

Post inclusions and exclusions



All opening posts were used for this study, meaning multiple posts from the same member were included (See Table 1).

Table 1*Number of members and number of posts*

Number of Members	Number of Posts
4	1
12	2
1	3
1	4
1	6
1	7
1	8
1	14
112	159

Secondly, the 159 posts were analysed and coded using an inductive approach (Andersson, Sjöström-Strand, Willman, & Borglin, 2015). The inductive analysis began by further familiarisation with the data by re-reading the data to check and refine understanding, which allowed for early identification of categories. Data familiarisation was necessary to gain an understanding of the context and the content within each post. The posts were broken into verbatim words or short phrases, in which 1,140 codes were identified. The codes were then sorted according to similarities and differences to form seventy-one sub-categories. Those sub-categories were then grouped into broader clusters resulting in 12 categories. The frequency of codes within sub-categories and categories were then calculated.

Thirdly, whilst focusing on the purpose of this study, further analysis was undertaken to identify similarities between the categories and to identify overlap, resulting in three overarching themes. Once the sub-headings and categories were established, 20% of the codes, sub-categories and categories were examined against the raw data by the primary and secondary supervisor as a reliability check. As a result of this process only minor changes were made to five codes and one sub-category.

An audit trail was maintained throughout the research to refine the research question to document about data collection and to demonstrate self-reflexivity and transparency. In conducting qualitative research Tracy (2010) acknowledges that self-reflexivity is an important practice for researchers to be transparent with the audience in disclosing why this topic was chosen. The researcher had no personal experience with kidney disease or with caring for someone with a chronic illness. The researcher has a personal interest in the overall health and well-being of individuals.

Chapter 3: Results

3.1 Overview

This study aimed to explore the experiences and concerns raised on an international online forum by caregivers of patients with CKD. As disclosed by the poster in the opening post, the patient details as defined by the caregiver are shown in Table 2. The largest group of posters (48%) were caregivers of a husband or a male partner, contributing to 48% of posts. The second largest group (34%) contributing to the opening posts were caregivers to a parent, contributing to 32% of opening posts.

Table 2

The patient details identified by the poster

Patient Type	Number of Posters	% of Posters	Count of Posts	% of Posts
Husband or Male Partner	54	48%	76	48%
Parent	38	34%	51	32%
Sibling	7	6%	8	5%
Child	5	4%	5	3%
Wife or Female partner	5	4%	11	7%
Friend	2	2%	2	1%
Grandparent	1	1%	6	4%
Total	112	100%	159	100%

3.2 Categories

Seventy-one sub-categories were observed, which were grouped into 12 categories (as shown in Table 3 below). Support Network was the largest category representing 15.26% of total codes (See Appendix B for count and illustrative quotes of sub-categories). Between the categories there was overlap as multiple categories and sub-categories were present within each post. Analysis of the categories resulted in the identification of three themes: *Experiences of Caregivers of Patients with CKD*, *Use of Online Social Support* and *Caregiver Knowledge* (as shown in Figure 2 below).

Figure 2

Map representing the three themes, and overlap between categories

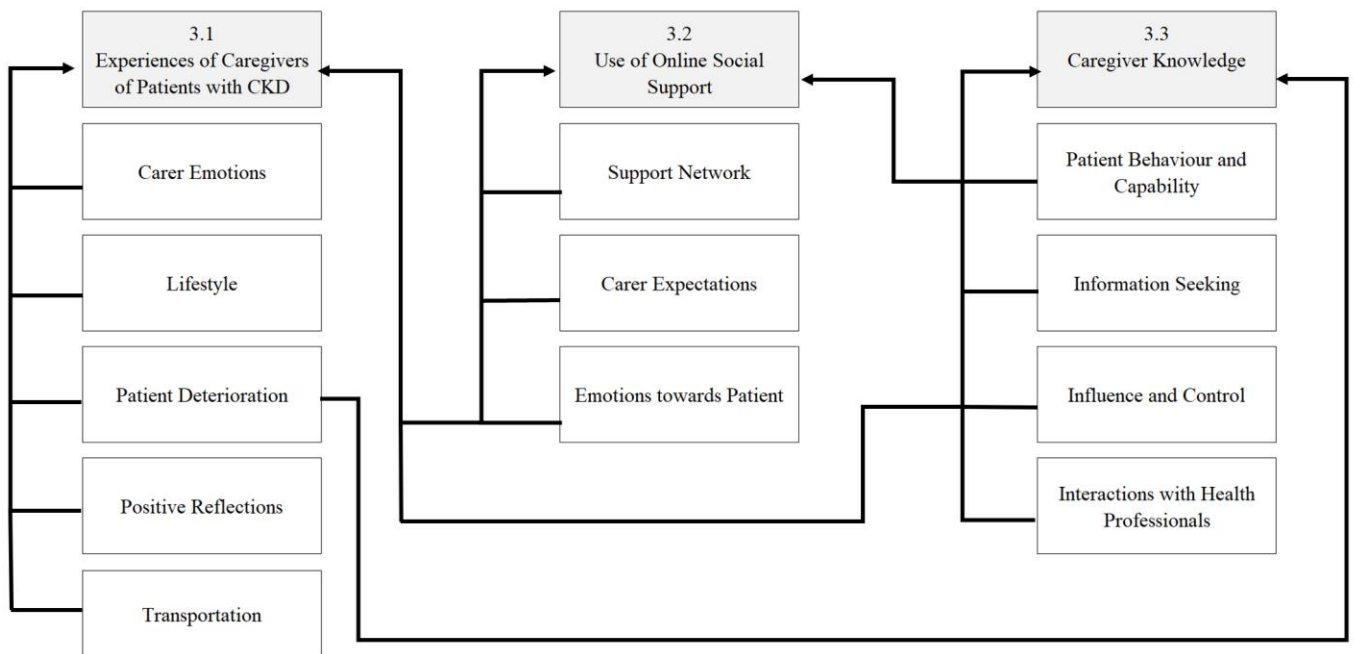


Table 3*Categories, descriptions, percentage of total codes and sub-categories*

Category	Description	% of Total Codes	Sub-category
Support Network	Social support interactions and comments	15.26%	Forum community Reaching out to people with similar experiences Negative carer support New to forum Asking for network support Isolation Positive carer support Social interactions
Carer Emotions	Expressed negative emotions by caregivers	14.82%	Not coping Worried Scared

			Exhaustion
			Overwhelmed
			Burnout
			Stress
			Disbelief
			Depression
Carer	Expectations of carers and the	10.70%	Self-doubt
Expectations	patient, and questioning		Obligation
	abilities		Guilt
			Not sure what to do
			Committed
			Concealing emotions
			Recognition from patient
			Better carer
			Always thinking of patient
			Selfish
			Expectations of patient
Lifestyle	Impact to lifestyle and	10.44%	Livelihood
	recreation of the caregiver		Employment
			Support provided to
			patient

			Money
			Health
			Sleep
			Holidays
			Feeling older than age
			Carer diet
			Intimacy
Influence and Control	Ability to influence and control the patient and situation	10.00%	Patient not helping themselves
			Observer
			Helplessness
			Communicating with patient
			Patient noncompliant
Patient Behaviour and Capability	Describing the mental and physical state of the patient	8.95%	Patient capability
			Patient behaviour and mood
			Patient wants to be with carer
			Patient feels like a burden

Information Seeking	Seeking information and knowledge from the forum community	8.60%	Advice on symptoms Training & education Advice on clinical management Advice on helping patient Advice on diet New to carer
Patient Deterioration	Caregiver expressing thoughts on further deterioration of the patient	6.49%	End of life Resignation Religion Hope Cannot take it anymore Heartbroken
Positive Reflections	Positive comments from the caregiver about their situation	4.56%	Positive feelings Admiration for patient Perspective
Emotions towards Patient	Expressed negative emotions towards the patient	3.60%	Frustration Anger Resentment Vent

Transportation	Logistics of appointments and treatment	3.33%	Transport and appointments Location of patient Driving
Interactions with Health Professionals	Positive and negative interactions with health professionals	3.25%	Health professional discussions Negative comments about health professionals
		100%	

The following section provides examples of opening posts, coded into each of the categories. All extracts were transcribed verbatim and are presented as posted by their authors, including with any spelling and/or grammatical errors.

3.2.1 Experiences of caregivers of patients with CKD

Posters shared the psychological and physiological impacts of being a caregiver to a patient with CKD. The daily struggles associated with their personal emotions, lifestyle impacts, end of life preparation, supporting others through positive expressions, and transportation were captured in this theme. Posts relating to the category *Carer Emotions* represented 14.82% of codes reflected

the negative emotions expressed by caregivers about their situation and that of the patient. As captured in the sub-category *Not coping* posters shared thoughts about how they need to navigate their role in caring for a loved one with CKD:

“Im struggling on what, when, how to cope and understand what is all going on. I feel like my world is collapsing. I dont know what I should be cooking, what other medications he should be taking besides his regular that we had before he started treatments. I have so many questions that i dont know who to talk to.” (Post ID 1061).

Posters commented on the role of caring for elderly parents and young children concurrently: the below post demonstrates the overlap between the sub-categories *Not coping* and *Worried*:

“I am having a very hard time. I just moved back close to my dad about a month ago. I have a three year old as well. I am so worried about him - I am afraid of sudden death mainly..it is consuming me with worry.” (Post ID 407).

The experiences of caregivers had significant impacts on quality of life as reflected in category *Lifestyle* which made up 10.44% of codes. The factors within this category included posts about their livelihood, employment, recreation and feeling older than they were. Posters commented on how CKD has influenced how they see the future as noted in the sub-category *Livelihood*:

“Our whole life course has changed. My biggest challenge is not feeling sorry for myself for how our lives have changed. Some days it’s really hard and other days it’s fine. I have moments where I get angry and want to run away.” (Post ID 1209).

Other posters commented on the impact to paid employment: in this post the overlap of the sub-categories *Employment* and *Sleep* can be seen:

“I sleep A LOT in my sofa due to my husband getting up every night and I have to work two jobs (full time and part time job). I am very desperate. (frown emoji)” (Post ID 874).

Posters identified the extent of their duties as a result of the health deterioration of the patient, as captured in the sub-category *Support provided by carer*:

“I’ve been around for nearly 3 months helping him out, cooking for him, taking care of things around his house, helping with dry skin, circulation, the knots in his back, and various other health related things.” (Post ID: 1290).

Additionally, posters commented on the financial burden of a partner having CKD as captured in the sub-category *Money*.

“Why doesn’t anyone talk about money here? I am freaking out about how to pay my bills now...My husband has been unable to work for the past month and started dialysis about 10 days ago. How do people live?” (Post ID: 1293).

Posters commented on their own health decline, and the concern about how to care for a patient when they are suffering from their own health issues, as captured in the sub-category *Carer health*:

“Im not going to get any help and the unfortunate thing is I NEED to see my heart doc and am afraid I am due for more heart surgery. But I cant. Ive ask[ed] for help once and wont again. When I am dead and gone she will end up in a nursing home.” (Post ID: 196).

Additionally, the impact to recreational activities can be seen in the sub-category *Holidays*:

“We have a motorhome and love to go camping, but we can’t go for more than two nights at a time because we have to be home for dialysis.” (Post ID: 611).

Furthermore, posters shared experiences regarding the deterioration of the patient and the slow decline of CKD, as reflected in category *Patient Deterioration* which made up 6.49% of codes. This included comments relating to the death of the patient, resigning to the fact the patient will not get any better, religious statements, and statements of hope. This category overlaps with the theme *Caregiver Knowledge* as discussed further below. As reflected in the sub-category *End of Life* posters discussed concerns about how to support the patient leading up to death:

“I just want her near me in her last days but don't know how to go about it. (confused emoji)” (Post ID 1264).

Other posters commented on the reality that the patient will not get any better through the sub-category *Resignation*:

“I’ve sorta numbed myself to the fact that things are what they are and they aren’t going to change anytime soon. It’s depressing to know that things will never be the same. I haven’t turned the corner yet to see that things can be better but different.... I’m hanging in there doing the best I can.” (Post ID 547).

Additionally, through sharing experiences, posters provided positive comments to the forum community about their situation as captured in the category *Positive Reflections*, which made up 4.56% of codes. This category included the sub-categories of *Positive feelings*, *Admiration for the patient* and *Perspective*:

“My hubby has now been on dialysis for a month and a half, and so far, it has been much more pleasant than we had even hoped for. We have been able to keep a pretty upbeat attitude about it as we are just so happy to be alive!!” (Post ID 133).

Comments relating to the physical burden and lack of support relating to appointments and dialysis treatments were captured in the category *Transportation*, which made up 3.33% of codes. Posters commented on where the patient resided in proximity to where they lived in order to provide adequate support in sub-category *Location of patient*:

“My dad was on PD for approx. 5 years which he handled himself as he lived alone. Then just over a year ago, it was found that the PD was failing and he was put on hemo dialysis.My dad does not live with us, but he only lives a block from our house, so he comes 3 evenings a week when we are both done work for the day and we do his dialysis.”
(Post ID 611).

Additionally, posters commented on the impact of the patient’s inability to drive and the burden to transport patients to appointments in sub-categories *Driving* and *Transport and appointments*:

“Since she and my dad are divorced. I’m left with taking care of her. And since she doesn’t drive, I take her to her appointments, do the groceries, run errands, etc.” (Post ID 803).

3.2.2 Use of online social support

Through engaging in an online community, posters shared experiences relating to their personal support network and that of the forum itself. This was reflected in the category *Support Network* making up 15.26% of codes. The impact the online community had on them as captured in the sub-category *Forum community*:

“I have been watching this forum for a few days and was so grateful to read that there are others out there that have some of the same frustrations, fears and experiences I am having. I wish our health care team had told me about support groups like this one” (Post ID 143).

Posters commented on the importance on connecting with people in similar situations as reflected in the sub-category *Reaching out to people with similar experiences*:

“I just wanted to post here, and say thank you for a place where I can read that others are feeling the same frustration, same guilt, same confusion, same weariness. There's comfort in knowing I'm not alone. Thanks!!!!” (Post ID 415).

Others commented on how their existing network no longer understands the situation as reflected in the sub-category *Negative carer support*:

“People graciously ask me how he is doing but they really don't want me to tell the truth...they want to hear good things, improvement, etc...so what do you say? after awhile they are tired of the negative stuff...well I'm sorry it's not any better..do I just lie to make them feel better?” (Post ID 445).

There were comments on the social support being provided by family and friends, as well as respite services as captured in the sub-category *Positive carer support*:

“He recently had a heart attack, and toes removed so we are now getting visits 3x a week by a nurse, home health aide and pt [personal therapy]...” (Post ID 158).

Furthermore, posters commented on feeling socially isolated from family and friends as a result of taking care of parents as captured in the sub-category *Isolation*:

“I just feel frustrated that I can’t live my life the way my friends live theirs. They don’t have to worry about taking care of their parents. Most everyone is independent and live in their own little apartments. I miss having my own place. I miss my freedom.” (Post ID 803).

Posters discussed their expectations of themselves and of the patient, as well as disclosing emotions associated with caring for their loved one. The category *Carer Expectations* made up 10.70% of codes. As reflected in the sub-category *Self-doubt*, posters commented on their inability to deal with their caregiver role:

“The big question is: Can I handle it? I love him and don't want to him to die, but I am not sure I can deal with home dialysis, changing bandages two or three times a day (in addition to when he has a bowel movement- he is currently has diarrhea and his bandages are being changed 10 times a day), cooking special meals and maintaining our home.” (Post ID 1331).

Posters disclosed their feelings to the forum community as captured in the category *Emotions towards Patient* making up 3.6% of total codes. This category is also applicable to the theme *Experiences of caregivers of patients with CKD* as discussed above, as posters shared their emotions towards the situation and patient:

“I don’t feel as if I can vent to anyone, because everyone thinks he is such a nice man (and most of the time he is) - but at home he can be extremely nasty, noncompliant and demanding. Any advice? (Post ID 335).

Posters commented on their inability to release their emotions as captured in sub-categories *Frustration and Anger*:

“Not sure if this is the right location, but I don’t know where else to go. I have anger, frustrations, fear and other feelings in me that I don’t know how to release much less don’t know how to talk about it without babbling. Thanks for listening.” (Post ID 1361).

Posters commented on how life had changed course and the impact that was having on them personally in the sub-category *Resentment*:

“Life wasn't suppose[d] to be like this. He shouldn't be this sick. I shouldn't have to give up my life long dream. I'm just so sad right now.” (Post ID 1039).

3.2.3 Caregiver knowledge

As posters shared their experiences with the forum community there were categories relating to gaps in caregiver knowledge, specifically relating to seeking information, the patient’s behaviour and physical capability, the ability to influence the patient to adhere to dietary requirements and medication, and interactions with health professionals. As outlined in the category *Patient Behaviour and Capability*, which made up 8.95% of codes, comments were made

on the complexity of the patient having multiple comorbidities as captured in the sub-category *Patient capability*:

“He is not a candidate for transplant (they said too many co-morbidities)....quadruple bypass...fistula surgery....Type 2 diabetes, thyroid and recently told vascular blockages from one end to the other....I cry when I am alone. (Post ID: 120).

Changes to the patient’s psychological and physiological state were categorised in the sub-category *Patient Behaviour and Mood*, which captured patient changes from dialysis treatment and a lack of understanding by the poster on how to address the changes:

“.... BUT, his attitude and outlook on life has turned from a fun loving, happy go lucky guy, to a complete negative, everyone is evil type of outlook. It's like Dr. Jekyll and Mr. Hind. I don't know what to do or say to him, he finds fault in everything, yells at me, and is very short tempered. I can't seem to do anything right, and if I "talk back" or try to explain, he goes over the top and gets very agitated.

Has anyone else experienced these personality shifts from their spouses on home hemo? (Post ID 943).

Posters sought the advice from other caregivers relating to their situation, the condition itself and managing the knowledge and education required to provide the patient with adequate care, as reflected in the category *Information Seeking* which made up 8.60% of codes. Whilst there is overlap under the theme *Use of online social support*, this category represented a gap in

knowledge. As represented in the sub-category *Advice on symptoms* posters sought specific advice from peers on CKD side effects:

“My wife’s latest symptoms are severely impacting both our lives. I’m wondering if these are common or not so common. Nasal congestion which has her sleeping in a sitting position every night. Insomnia, restless legs, neck and lower back muscular pain. I’ve been trying to help with these symptoms but I’m not even sure if they are associated with ESKD [end stage kidney disease]. Any comments are welcome.” (Post ID 553).

Posters shared experiences and concerns relating to the experiences with training they have had to manage home dialysis treatments in the sub-category *Training and education*:

“When the travel got to be too much, my hubby and I took the plunge and went for the 8 weeks of training to do home hemo dialysis for my dad, which we completed in 4 weeks....We have been doing home hemo dialysis now for a year and have found that our renal program that trained us and got us going has basically said, here is your machine, you have been trained and have at it! We go to see them once every three or four months but that's about it.” (Post ID 611).

Additionally, posters sought advice on medical procedures and treatment options in the sub-category *Advice on clinical management*:

“He has a fistula is his left upper arm that is working pretty good so far. He is currently using 15 gauge fistula needles and using the button hole technique. Just curious about if that is a good way to go ?..have heard some don’t like the button hole technique...Also curious about aneurisms in the fistula ..is there ways to prevent those or what there caused from or if there more common with the buttonholes..any info is appreciated...thanks.” (Post ID 766).

Posters also commented on how they were new to being a caregiver, and how certain events promoted them to use this forum as categorised in the sub-category *New to carer*:

“My stepfather is going to undergo dialysis in a few months. (Tomorrow he gets a fistula.) I need a serious education here about dialysis.... I only know tiny, useless bits of information, like that it removes toxins, that it can be done at home or in a clinic, nocturnally, through a catheter in the chest, or through the belly. But I know nothing else.....Again, I know next to nothing. I am a true newbie.” (Post ID 1162)

Posts relating to the gap in knowledge and abilities for caregivers to be able to support patients to adhere to dietary restrictions and medications were captured in the category *Influence and Control* which made up 10.00% of codes. Comments within this category reflected the patient’s nonadherence to medical advice, the caregivers’ feelings of helplessness and abilities to influence the patient, which overlapped with the theme *Experiences of caregivers of patients with CKD*. The comments concerned about the refusal, by the patient, to accept help can be reflected in the sub-category *Patient not helping themselves*:

“I'm beside myself with anxiety, guilt, grief... she can turn her life around but refuses to. Does anyone have any advice on how I can help her or get her help? The hospital will release her soon and it could ultimately mean her demise. I don't want to lose her but how do you help someone that is in denial and refuses to get help?” (Post ID 1006).

Additionally, posts relating to the *Interactions with Health Professionals*, making up 3.25% of codes reflected their experiences and exchanges with the patient's health professional team. Posters asked for opinions from the forum community whether it was reasonable to make contact with the health professionals as categorised in sub-category *Health professional discussions*:

“He says he has not been offered dialysis yet but for all I know he has but refused it. He is close to moving in with me and at that point I feel it is reasonable to ask him to allow me to speak with his physicians. Thoughts?” (Post ID 35).

Others expressed concern with not being involved in treatment options and openly expressed poor experiences with health professionals as captured in sub-category *Negative comments about health professionals*:

“He is adamant about staying on dialysis and to a great degree is in denial of his situation despite his great unhappiness. His dr.'s do not keep me well informed on what's going on with him...I feel like I cannot bear another second of this madness, and feel irate that his dr.'s aren't talking to him about possibly stopping dialysis.” (Post ID 180).

Chapter 4: Discussion

4.1 Overview

Caregivers are integral to the psychosocial well-being of patients with CKD, despite their views and needs being commonly overlooked. The main objective of this study was to explore the experiences and concerns raised on an international online forum by caregivers of patients with CKD. Qualitative content analysis was employed using inductive analysis to form categories and calculate frequencies of the online posts from the sponsored forum: *Caring for Someone with Kidney Disease*. The three themes identified from the analysis included: *Experiences of caregivers of patients with CKD*, *Use of online social support*, and *Caregiver knowledge*. This research has offered valuable insight into the unfiltered experiences and concerns of caregivers of patients with CKD using online social support. Consistent with previous research, there are significant psychological and physical factors that impact the caregiving experience. This study provided critical awareness of the challenges caregivers of patients with CKD are navigating.

The present study extended the prior research of Burckhardt & Padman (2015), who analysed the DaVita Kidney Care forum for patient experiences. An incidental finding of that study found that a significant contribution of posts referred to male partners and ancestors. Consistent with Burckhardt & Padman's (2015) study, the primary posters from this study were caregivers of male partners or husbands, and parents.

Prior studies have identified that patients with CKD experience significant impacts to their quality of life due to one of the most onerous medical treatment interventions, as well as physical symptoms of dialysis and kidney disease (Gilbertson et al., 2019; Goh & Griva, 2018). The present study confirmed that caregivers play a central role in supporting the patient with physical and

emotional needs. Posters in this study shared experiences of increased home duties, food preparation and physical support as well as the need to always be with the patient to provide emotional support and companionship. Additionally, experiences from sandwich generation caregivers commented on their parenting responsibility and the added burden of caring for an elderly parent and young child (Steiner & Fletcher, 2017). Due to the significant reliance on caregivers and lack of the patient's independence, posters disclosed feeling as if their own life was being put on hold as they wait for the further deterioration of the patient. Caregivers can remain in this holding period for many years, as the treatment for CKD enables the life of a patient to be prolonged (Baillie & Lankshear, 2015).

The impact on a caregiver's quality of life has been demonstrated by this study. Subjective burden was expressed, with many posters disclosed feelings of stress, fatigue, social isolation, and depression. Lifestyle disruptions to employment and recreational travel relating to the objective burden was also stated by caregivers (del-Pino-Casado et al., 2013). Posters reported providing patients with CKD the necessary social support to encourage adherence to medications, dietary restrictions, and to help the patient cope with their illness (Gayomali et al., 2008).

Application of the OSS theoretical framework by LaCoursiere (2001) enabled the use of the online forum to be conceptualised. Whilst recognising the diversity of posts, there was a consistent theme which saw many of the posters commenting on an upcoming procedure for the patient, or a recent change to the patient's treatment. The impact of the procedure and treatment was described to have significant emotional or physical implications to the caregiver, which is consistent with the first element of the theory where a change or perceived change in health status is the trigger to using OSS (LaCoursiere, 2001). Whilst the scope of this study did not capture potential mediating

factors of the poster, the second element in LaCoursiere's (2001) theory, many commented on their health, employment, and relationship status, which may have contributed to the purpose of engaging with the forum.

The third element in the OSS theory is social support (LaCoursiere, 2001). Evidence of social support was captured through emotional support as posters shared personal stories and the psychological effects of not coping, feeling worried, scared, and burnout. Additionally, posters commented on preparing emotionally for patient's life to end, as well as positive reflections on current and past situations (LaCoursiere, 2001). Posters commented on the financial stress, lack of physical support provided by friends and family, as well as the burden of transporting patients to appointments and dialysis treatment, which is consistent with sharing instrumental support (LaCoursiere, 2001). Similarly, posters sought advice and information from the forum community on medical procedures, how to cope with the disease progression, and how to provide improved emotional and physical support to the patient. By using the online forum as a means of social support, posters shared intimate and private emotions such as anger and resentment towards the patient, which may not have been possible in a face to face social setting (Perron, 2002). Online forums enable to connect with peers and obtain the necessary social support, without the transportation barriers and time constraints (Ahmed et al., 2017; Bennett et al., 2015; Pinsk & Nicholas, 2017). Furthermore, as posters to the forum were able to connect with peers with similar experiences, they demonstrated vulnerability and disclosed fears of not feeling adequate as a caregiver.

Despite appraisal support being an essential factor of social support, it can be challenging to satisfy in an online setting, as posts on online forums tend to be episodic (Benson et al., 2020).

This study found that evaluative feedback was sought from the group to seek direction, reassurance, and empathy, however it was unknown how appraisal support was received by the caregiver (Benson et al., 2020). Whilst the outcomes of OSS, the fourth element in the theoretical framework, was not the primary aim of this study, posters commented on the importance of connecting with peers on the online forum to alleviate feelings of isolation (LaCoursiere, 2001). Posters also shared stories on the positive outcomes to their psychological well-being as a result of caring for their loved one.

As research has shown, patients with CKD can experience significant symptoms, which can impair their quality of life and ability to maintain regular activities (Yapa et al., 2019). The necessity to transport the patient to and from dialysis treatments, medical appointments, and run errands contributed to caregiver burden, which is consistent with prior research (Tong et al., 2013). Posters commented on the emotional and physical effects such as fatigue when taking on the additional responsibility of transporting the patient. The impact on paid employment and recreation activities was most significant as the patient's disease progressed, and independence was lost.

One of the key findings of this study was the gap in caregiver knowledge and education, which was highlighted by the information and advice requested by posters. Posters sought advice and information from the forum community on how to improve their abilities as a caregiver and provide more optimal support to the patient. Posters requested advice on diet management and strategies on how to influence the patient so that the patients adhere with treatment, medication, and dietary restrictions. Consistent with prior research, caregivers played an instrumental role in supporting patient adherence (Gayomali et al., 2008; Low et al., 2008). Additionally, advice was sought about specific patient symptoms such as personality changes, memory loss, sweating, and

urination. Information on clinical management such as the use of catheters and fistulas, fluid management, stopping dialysis, and nursing home care was requested. Advice was also sought on general education and training on the disease, and subsequent comorbid conditions. Posters commented on the negative interactions with health professionals, suggesting that some caregivers were not receiving the information or support they required by the patient's health professional team (Wright & Bell, 2003). As demonstrated in recent oncology studies, a strengthened relationship between the caregiver and health professional can see benefits to the patient and caregivers' quality of life (An et al., 2020).

4.2 Strengths

Despite the considerable research in analysing the experiences of patients with CKD and the impact on family and close persons, the literature on the perspectives of their caregivers is limited. This research provided an opportunity to voice the experiences and concerns of caregivers of patients with CKD in an unrefined manner. Qualitative content analysis enabled category frequencies to be tabulated, which was realistic with regards to the nature of the data. Categories were formed using an unbiased approach as the application of a theoretical framework was not required, which may have caused a misrepresentation of the context of the data (Hsieh & Shannon, 2005).

Researcher bias is limited when analysing online forums, allowing the raw, uncensored posts to occur naturally (Jowett, 2015). Participants often excluded from research due to transportation and geographical barriers can be included using online forums. Additionally, as users create an alias to join the forum, information posted is private, allowing sensitive content to be shared (Jowett, 2015). The asynchronous communication style, and the ability to share an emotionally

charged event in real-time is a unique feature of online forums. The confidential nature of the forum also allows for personal stories and experiences to be shared, which is shown to be cathartic (Perron, 2002). Due to limited research on online social support for caregivers of patients with CKD, this study provided unique insight into the experiences of those caregivers. Whilst this study looked specifically at the caregivers of patients with CKD, these experiences could be applied to caregivers of patients with other chronic conditions.

4.3 Limitations & further research

Although the ability to use online forums to capture raw, uncensored data is a strength, it means that the implicit thoughts of posters were unable to be captured. As a result, further elaboration on unclear posts, and verification for accuracy was not possible (Ahmed et al., 2015). In-depth qualitative interviews would have yielded opportunities to ask questions. Capturing the caregiver demographics and the patient's stage and dialysis modality would have formed more comprehensive data (Jowett, 2015). Although limited bias was imposed on the categories, by applying qualitative content analysis, the researcher may have failed to develop a deep understanding of the context and identify additional categories (Hsieh & Shannon, 2005). Whilst inter-rater reliability was not required, if the research method, qualitative thematic analysis was employed greater accuracy of the categories through additional auditor reviews may have been achieved (Hsieh & Shannon, 2005).

Additionally, a limitation to using the OSS theory was the inability to capture the outcomes of OSS using the data from the online forum. Incidental comments were captured by posters on the benefits of using the forum community, however, follow up qualitative interviews or quantitative analysis on the implications of OSS to quality of life or stress levels would prove valuable

(Newman et al., 2019). Additionally, this study did not seek to explore the type of support that is offered by posters on the online forum. In subsequent studies, undertaking a discourse analysis on the responses of both patients and caregivers may provide additional insight into the quality and benefits of OSS.

This study captured the views of caregivers who actively posted to the online forum. The views of passive readers and caregivers who do not use online forums were not captured (Hansen et al., 2016). Individuals who do not post to online forums may suffer from low literacy, lack of internet access, or not experiencing a significant change in health status or perceived health status as argued by LaCoursiere (2001). As such, the frequency count in categories may reflect a negative bias than what would be expected across all caregivers. Many posters contributed to one opening post, however, there were a minority of posters who contributed multiple times. As lower life satisfaction and higher stress levels have been associated with users of online forums, it would be worthwhile to explore the motivators for using OSS, and the impact to well-being, using a longitudinal design (Utz & Breuer, 2017). Furthermore, as found in the literature, more women than men are drawn to using online forums, which may have influenced the categories and experiences (LaCoursiere, 2001). Follow up on the differences between male and female posts may prove insightful and inform the difference in needs between male and female caregivers.

Analysis of a private forum may yield alternative findings, compared to public forums where content is widely accessible. The forum chosen for this study was sponsored by an organisation in the US. Whilst demographics were unable to be validated it would be prudent not to assume that recipients of the organisation's services may over-represent this data, or that a large proportion of

posters resided in the US. Further studies could explore multiple forums, or forums which are not associated with a corporate organisation, such as a self-management site.

Further research into the relationship between the nephrologist, the caregivers and patients could be explored to triangulate the data using qualitative analysis. This research may provide greater understanding between the patient and caregiver and create insight for support strategies by health professionals. Engagement with patients and caregivers into the study design can allow the co-creation of knowledge of both the user and researcher (Bernstein, Getchell & Harwood, 2019; Duncanson, et al. (2020). Research in examining the relationship between the nephrologist, the caregivers and patient outcomes is yet to be conducted.

4.4 Implications of this study

The findings of this study present several implications for future clinical practice and research related to online social support for caregivers of patients with CKD. To this researcher's knowledge, this study is the first to use the OSS theoretical framework by LaCoursiere (2001) to analyse the experiences of caregivers of patients with CKD. Insight into the experiences of caregivers of patients with CKD can be used to educate health professionals about the importance of engaging the caregiver throughout the disease progression, as well as for comorbidity conditions, as they arise. Promotion of available respite services for home dialysis, and education on early prevention strategies enable caregivers to plan and decide how to connect and utilise available support services (del-Pino-Casado et al., 2018). Furthermore, dedicated counselling services for caregivers of patients with chronic disease may provide caregivers with the necessary coping skills to manage the psychological and social challenges. The findings from this study lay the foundations for further qualitative analysis on the role OSS has on caregivers, which can be

used to inform Government policy and funding, to alleviate the caregiver burden and improve quality of life. Investment into online support platforms to strengthen the connectivity between caregivers of chronic conditions can improve social support and isolation (Ahmed et al., 2017). Additionally, funding for tangible support for the patient undergoing dialysis treatment at a specialised centre by way of funded transportation services, can alleviate the caregiver burden and improve their quality of life.

It is recommended that nephrologists and other health professionals should consider a patient's support system and provide holistic advice to the patient and caregiver, rather than focusing exclusively on clinical treatment (Chan et al., 2016; Yu et al., 2016). Engaging the caregiver in the dialysis unit, and additional appointments can strengthen the relationship between the health professional team and the caregiver, building caregiver knowledge and education to provide improved outcomes for the patient (Hansen et al., 2016; Low et al., 2008). The findings of this study can be applied to local patients and caregivers by developing practical tools and resources with the support of the CNARTS Clinical Research Group.

4.5 Conclusion

This study contributed to a gap in the literature by capturing the experiences of caregivers of patients with CKD. This study advocates for caregivers who have poor quality of life and using OSS to reach out to others. The present findings provided valuable insight into the psychosocial and physical challenges of caregivers of patients of CKD, as well as identified a gap in caregiver knowledge. Such insights can be used to inform Government policy and funding towards caregivers of patients with chronic conditions, to improve quality of life and alleviate caregiver burden. Recommendations for better engagement between the caregiver and the health

professional team can see an increase in education and training for caregivers, as well as tangible assistance to support the outcomes of patients. Application of the OSS theory by LaCoursiere (2001) provided a robust framework to conceptualise the use of OSS. Importantly, qualitative content analysis categorised the experiences of caregiver of patients with CKD and exposed the gap in knowledge that prompted posters to engage in online social support with their peers. Further qualitative studies to extract the implicit thoughts of posters and assess the benefits of OSS are recommended.

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Appendix B - Sub-category count and illustrative quote*Sub-category count and illustrative quote*

Category	Sub-Category	Count	Sub-Category Illustrative Quote
Support Network	Forum community	47	<i>“I have been watching this forum for a few days and was so grateful to read that there are others out there that have some of the same frustrations, fears and experiences I am having. I wish our health care team had told me about support groups like this one” (Post ID 143)</i>
	Reaching out to people with similar experiences	27	<i>“I just wanted to post here, and say thank you for a place where I can read that others are feeling the same frustration, same guilt, same confusion, same weariness. There's comfort in knowing I'm not alone. Thanks!!!!” (Post ID 415)</i>
	Negative carer support	26	<i>“People graciously ask me how he is doing but they really don't want me to tell the truth...they want to hear good things, improvement, etc...so what do you say? after awhile they are tired</i>

of the negative stuff....well I'm sorry it's not any better..do I just lie to make them feel better?" (Post ID 445)

New to forum 24

"I'm brand new to this website, actually all forum sites in general, but after a really bad night I found myself wondering how other people in these situations get through, and found this website after doing some Google searches." (Post ID 728)

Asking for network support 21

"Anyhow, any advice would be greatly appreciated. I'm new to all this, can be very overwhelming." (Post ID 1361)

Isolation 15

"I'm sorry about the whining, but I have no one else to talk to or share these concerns with." (Post ID 1293)

Positive carer support 7

"We try to keep a positive attitude and have a good group of friends." (Post ID 128)

Social interactions 7

"I can't make plans to hang out with my friends or spend the night over at my boyfriend's sometimes." (Post ID 883)

Carer Emotions Not coping 31

"I'm struggling on what, when, how to cope and understand what is all going on. I feel like my world is collapsing. I dont know what I

		<i>should be cooking, what other medications he should be taking besides his regular that we had before he started treatments. I have so many questions that i dont know who to talk to.” (Post ID 1061)</i>
Worried	24	<i>“I worry because he is not eating like he should. I try to help out as much as I can so that it makes things a little easier on my mom. I am constantly worrying about my dad.” (Post ID 1242)</i>
Scared	22	<i>“It is hard for me because I don't know what to expect or where to turn to for support or general questions. All that runs through my mind is that I may lose him. Just so full of fear!” (Post ID 158)</i>
Exhaustion	21	<i>"I am scared, lonely, and so exhausted." (Post ID 53)</i>
Overwhelmed	20	<i>There's so many details I want to talk about, but the thought of typing them all out completely overwhelms me right now. (Post ID 231)</i>
Burnout	16	<i>Totally mentally and physically burned out.....exhausted.....need a few days at the beach or somewherenot possible.....cannot stop crying</i>

			<i>today.....one of those days I guess.....anybody else having a bad day? (Post ID 93)</i>
	Stress	14	<i>Anxiety literally eats me up at night and don't want to rely on sleeping pills. (Post 855)</i>
	Disbelief	13	<i>I am having a hard time coming to terms with my dads decline. He is so tired and has become weaker. I know I sound like a broken record but he seems like is slowing down a lot. I wish there was something that could be done. I don't understand why he is getting weaker and feeling the worst on his dialysis days. (Post ID 169)</i>
	Depression	8	<i>"I really get depressed sometimes then feel guilty about it. My family hardly ever comes around as I don't think they can cope. Is this normal. I have support from one Niece but she lives a ways away. Just need some support. (Post ID 1078)</i>
Carer Expectations	Self-doubt	21	<i>"The big question is: Can I handle it? I love him and don't want to him to die, but I am not sure I can deal with home dialysis, changing bandages two or three times a day (in addition to when</i>

- he has a bowel movement- he is currently has diarrhea and his bandages are being changed 10 times a day), cooking special meals and maintaining our home.” (Post ID 1331)*
- Obligation 17 *“so now I'm not sure I can do this.....it is for my husband whom I love ..shouldn't that be enough to make me?” (Post ID 996)*
- Guilt 14 *“I feel sooooo guilty for whining. But my gosh, I feel like I have to take care of all his needs.” (Post ID 889)*
- Not sure what to do 13 *“I just don't know what to do. This is a total shock to me and all I have left right now is posting on internet forums at 4 in the morning.(frown emoji) I hope things turn out.” (Post ID 92)*
- Committed 11 *He has been my rock, my hero and I love him with all of my heart. Now it's my turn to be his rock. (Post ID 191)*
- Concealing emotions 11 *“My parents would get worried about me if I tell them how I feel, and sometimes I just need to vent. (Post ID 128)*
- Recognition from patient 10 *I feel like the maid and need his love to keep myself going so I can lift him up and take care of things. (Post ID 967)*

	Better carer	9	<i>"I just want to be a better caregiver, and learn to be more patient with him and not let his insults make me upset, or cry, or get angry." (Post ID 728)</i>
	Always thinking of patient	9	<i>"I am consumed with the fact that she needs to take care herself better today so that she does get her kidney transplant." (Post ID 395)</i>
	Selfish	4	<i>"I miss my freedom. I sound so selfish right now, but trust me, my mom is always in my mind." (Post ID 844)</i> <i>"Do you all have a caregiver that takes care of you and do you return the favor when they are sick? Or am I expecting too much? All I need from him is to take over some chores, take care of the animals, feed me when I'm too weak and drive me to the doctor. If this is asking for too much, please tell me." (Post ID 1247)</i>
	Expectations of patient	3	
Lifestyle	Livelihood	25	<i>"Our whole life of course has changed. My biggest challenge is not feeling sorry for myself for how our lives have changed. Some</i>

- days it's really hard and other days it's fine. I have moments where I get angry and want to run away.” (Post ID 1209)*
- Employment 24 *“I sleep A LOT in my sofa due to my husband getting up every night and I have to work two jobs (full time and part time job). I am very desperate. (frown emoji)” (Post ID 874)*
- Support provided by carer 21 *“I am not only caretaker for my son on dialysis, among other things. I am a counselor, a nurse, a friend, an everything to try my best to see my son through this ordeal. also an advocate in search of a donor, blood type 0+” (Post ID 80)*
- Money 19 *“Why doesn't anyone talk about money here? I am freaking out about how to pay my bills now. To get food stamps I'll have to cash in my life insurance policies. (Not that they are very much) My husband has been unable to work for the past month and started dialysis about 10 days ago. How do people live?” (Post ID 157)*

Health	13	<i>"I have my own health issues which totally exhaust me and some days I am so wiped out that I have to lay down when I do get home before I can even think about something to eat." (Post ID 906)</i>
Sleep	5	<i>"Let me tell you, there's no scarier feeling than being jolted awake by her screaming from the cramps. I jump up and stretch them out. Some nights, 1 or 2. Others, a half dozen." (Post ID 1048)</i>
Holidays	5	<i>"We like to travel in our truck across country and would like not to have to give it up, thus we are seriously thinking of CAPD. If doing CAPD and traveling across country, any ideas/suggestions where my husband would do the procedures during the day? Is it ridiculous to think that once set up he could ride "shot gun" while I did the driving?" (Post ID 1061)</i>
Feel older than age	3	<i>"I am his 54 (feels like I'm 154) yr old divorced daughter, and his live-in primary caregiver." (Post ID 180)</i>

	Carer diet	2	<i>"are we putting ourselves at risk by consuming a renal diet as well? I am afraid I might be missing out on the nutrients I need." (Post ID 12)</i>
	Intimacy	2	<i>"There is no more sexual intimacy.....it is gone...my spouse talks about it as usual but not able to any longer.....and I guess it's just came to terms with me that it may not ever be any different.....there are so many things they don't tell you about dialysis." (Post ID 928)</i>
Influence and Control	Patient not helping themselves	32	<i>"When I go to buy kidney friendly food he whines like a baby in the store and begs for other food. My husband would rather NOT EAT than eat kidney friendly food." (Post ID 149)</i>
	Observer	27	<i>No matter how much I talk to him and try to understand why he does it, he is still eating salt (plain salt not just on food), still smoking cigarettes, and also eating junk food. Every time he goes into the hospital I wonder if this will be the time he doesnt come home. (Post ID 225)</i>

	Helplessness	23	<i>"I told him I was going to fully support him, but when he took up smoking again. I told him that Im not going to watch him kill himself he was diagnosed with emphazema." (Post ID 915)</i>
	Communicating with patient	19	<i>I don't know what to do or say to him, he finds fault in everything, yells at me, and is very short tempered. I can't seem to do anything right, and if I talk back" or try to explain, he goes over the top and gets very agitated." (Post ID 735)</i>
	Patient noncompliant	13	<i>"Still he is not following his dietary restrictions, and swears that he isnt having that much fluids. He just doesn't seem to understand that he is putting himself into heart failure through his own actions." (Post ID 382)</i>
Patient Behaviour & Capability	Patient capability	54	<i>My father has zero quality of life living like this yet he chooses to undergo all these horrific procedures. He is not living in my opinion but rather in a suspended painful drawn out death process. He barely gets around with a walker, and I worry constantly about him falling." (Post ID 895)</i>

- Patient behaviour and mood 41 *“He has always been up and down in the way of moods and depression and going through phases where he wont take his meds cos he doesnt see the point (when he was depressed)..... Yes, there’s problems with getting and maintaining an erection sometimes and sometimes coming to climax for him, and I know this can be embarassing and many mixed feelings about this for men....So, anyway, since dialysis and apart from those few times, our sex life has been going downhill and most of the time its non exisistant.”*
(Post ID 1168)
- Patient wants to be with 5 *"I have tried to find rides for my husband, but he doesn't want*
carer *anyone else to take him. While he is in dialysis he wants me to sit*
with him as much as allowed." (Post ID 335)
- Patient feels like a burden 2 *My dad always says don't worry about it you have a life of your*
own. (Post ID 906)

Information Seeking	Advice on symptoms	31	<p><i>“My wife's latest symptoms are severely impacting both our lives. I'm wondering if these are common or not so common. Nasal congestion which has her sleeping in a sitting position every night. Insomnia, restless legs, neck and lower back muscular pain. I've been trying to help with these symptoms but I'm not even sure if they are associated with ESKD. Would dialysis help to alleviate some of her problems?Any comments are welcome.” (Post ID 553)</i></p>
	Training & education	23	<p><i>“When the travel got to be too much, my hubby and I took the plunge and went for the 8 weeks of training to do home hemo dialysis for my dad, which we completed in 4 weeks....We have been doing home hemo dialysis now for a year and have found that our renal program that trained us and got us going has basically said, here is your machine, you have been trained and have at it! We go to see them once every three or four months but that's about it.” (Post ID 611)</i></p>

- Advice on clinical management 21 *“He has a fistula is his left upper arm that is working pretty good far. He is currently using 15 gauge fistula needles and using the button hole technique. Just curious about if that is a good way to go ?..have heard some dont like the button hole technique...Also curious about anurisms in the fistula ..is there ways to prevent those or what there caused from or if there more common with the buttonholes..any info is appreciated...thanks.” (Post ID 766)*
- Advice on helping patient 9 *“He has a mindset to skip dialysis. For two straight sessions, he expressed not wanting to go, but went eventually. The last session, he skipped....Is there any kind of intervention or resource I could go to resolve this, or quite frankly, am I forced to watch him deteriorate and/or die? I've exhausted pretty much all the options I can think of. Thank you so much for any help or suggestions.”(Post ID 391)*
- Advice on diet 7 *“Does anyone have a good diet/what to eat not eat list for 1) a kidney failure patient and 2) a post-transplant patient? My husband*

				<i>and I are seeing their new dietitians next week, but thought I'd ask if someone has found a better site to research these things. Seems like my dad and mom have to be on different diets since one is still on the list, and the other one has a transplant kidney.” (Post ID 398)</i>
	New to carer	7		<i>“My wife is going for surgery consultation tomorrow with the surgeon. What should I expect from that visit? I have read about asking where the incision will be placed, etc.? Is that OK to ask the surgeon WHERE he will place the catheter? Sorry, if that question seems elementary. This is very new to us.” (Post ID 336)</i>
Patient	End of life	20		<i>“I just want her near me in her last days but don't know how to go about it. (confused emoji)” (Post ID 1264)</i>
Deterioration	Resignation	14		<i>“I've sorta numbed myself to the fact that things are what they are and they aren't going to change anytime soon. It's depressing to know that things will never be the same. I haven't turned the corner yet to see that things can be better but different. Just doesn't seem realistic. I'm hanging in there doing the best I can.” (Post ID 547)</i>

	Religion	15	<i>“she was strong the whole time trusted god the whole time and my thought was if this was gods will who am i to be mad or upset so i think that is what got me thru” (Post ID 1153)</i>
	Hope	13	<i>" I hope I meet some people here to correspond with." (Post ID 398)</i>
	Cannot take it anymore	7	<i>“It has been a rough road for both my father and I. Some days, I feel like running away. (Post ID 594)</i>
	Heartbroken	5	<i>"I am heart broken and overwhelmed. I am lost and scared. I want to scream from frustration of not knowing." (Post ID 69)</i>
Positive reflections	Positive feelings	18	<i>“My hubby has now been on dialysis for a month and a half , and so far it has been much more pleasant than we had even hoped for. We have been able to keep a pretty upbeat attitude about it as we are just so happy to be alive!!” (Post ID 133)</i>
	Admiration for patient	18	<i>“I am 34 years old, and married the man of my dreams 7 months ago.... I knew that what he had been through did not crush him, but he allowed it to make him a better and stronger man. I hope that I am that strong too.” (Post ID 547)</i>

	Perspective	16	<i>“My biggest challenge is not feeling sorry for myself for how our lives have changed. I need to be grateful for what I have, and that is my husband” (Post Id 144)</i>
	Frustration	14	<i>“Not sure if this is the right location, but I dont know where else to go. I have anger, frustrations, fear and other feelings in me that I dont know how to release much less dont know how to talk about it without babbling. Thanks for listening.” (Post ID 1361)</i>
Emotions towards Patient	Anger	10	<i>“Thing seriously irritate me. He started smoking again which has really upset me, made me mad!” (Post ID 779)</i>
	Resentment	9	<i>“Life wasn't suppose[d] to be like this. He shouldn't be this sick. I shouldn't have to give up my life long dream. I'm just so sad right now” (Post ID 1039)</i>
	Vent	8	<i>“now I see this is the place to vent and get support from those who are going through the same things.” (Post ID 928)</i>

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|----------------|--------------------------|----|--|
| Transportation | Transport & appointments | 14 | <i>“Since she and my dad are divorced. I'm left with taking care of her. And since she doesn't drive, I take her to her appointments, do the groceries, run errands, etc. She prefers me over my siblings to take her to her appointments because they can be very impatient with her and she feels a lot of pressure from them.” (Post ID 803)</i> |
| | Location of patient | 12 | <i>“My dad was on PD for approx. 5 years which he handled himself as he lived alone. Then just over a year ago, it was found that the PD was failing and he was put on hemo dialysis.....My dad does not live with us, but he only lives a block from our house, so he comes 3 evenings a week when we are both done work for the day and we do his dialysis.” (Post ID 611)</i> |
| | Driving | 12 | <i>“I have a friend who is taking dialysis three times a week. Up until a few days ago, she was driving herself to and from her treatments, until her car broke down on her. This caused more issues than expected. The obvious question was, "how was she going to get back and forth to dialysis?" (Post ID 395)</i> |

Interactions with Health Professionals	Health professional discussions	21	<i>“He says he has not been offered dialysis yet but for all I know he has but refused it. He is close to moving in with me and at that point I feel it is reasonable to ask him to allow me to speak with his physicians. Thoughts?” (Post ID 35)</i>
	Negative comments about health professionals	16	<i>“He is adamant about staying on dialysis and to a great degree is in denial of his situation despite his great unhappiness. His dr.'s do not keep me well informed on what's going on with him, and It is so scary living like this....I feel like I cannot bear another second of this madness, and feel irate that his dr.'s aren't talking to him about possibly stopping dialysis.” (Post ID 180)</i>
12		1140	
