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Unique Insights Regarding Pain in People with Kidney Failure: A Qualitative Exploration

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ABSTRACT

This study describes the lived experience of pain in people with kidney failure receiving supportive care. Fifteen people completed in depth interviews. Participants were also invited to utilize a reflective picture card technique to help them articulate their experiences of pain. Inductive analysis used the framework approach. Participants encountered many barriers to pain management that resulted in a need to devise their own solutions. Living with chronic pain was described as an experience to be endured rather than managed and resulted in a loss of control and restriction of daily functioning. The results indicate pain management strategies used by this cohort have limited effectiveness, with far-reaching consequences on the physical, social, emotional health of those with kidney failure.

INTRODUCTION

Chronic kidney disease (CKD) is the consequence of diverse pathogenic processes, which result in irreversible functional and structural changes to the kidney (Webster et al., 2017). CKD is an increasing global health issue, affecting approximately 10 – 15% of adults worldwide (Datar et al., 2021). Further, it is estimated that 1.5% of deaths globally were attributable to CKD (Webster et al., 2017).

People with kidney failure experience a high symptom burden attributed to the disease and its treatments. The symptom burden is comparable to that observed in other palliative conditions, such as metastatic cancer and heart failure (Gemmell et al., 2016; Moore et al., 2023). A systematic review of 59 studies reporting symptom prevalence in people with kidney failure identified the most common symptoms as: fatigue/tiredness weighted mean prevalence of 71% (range: 12%–97%), anxiety 38% (12%–52%), constipation 53% (8%–57%), and pain 47% (8%–82%)(Murtagh et al., 2007). This review was limited by having no studies that explored symptom burden in those with kidney failure receiving conservative management or supportive care.

The definition of "pain" was revised in 2020, and is now defined as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020). This is an important development, as the consensus statements that accompany the new definition include acknowledgement that the experience of pain is a highly personal and has adverse impacts on function, as well as social and psychological well-being (Raja et al., 2020).

The highly personal nature of the pain experience may partially explain the wide variation in the reported prevalence of pain with kidney failure. The prevalence, reported in the largest study to date of 48,678 people with kidney failure, was found to be 60% (Lambourg et al., 2021), although some individual studies reported a prevalence as high as 92% (Moore et al., 2023). Similar studies indicate rates ranging from 60.5% to 92% in patients with kidney failure (Davison et al., 2014; Davison et al., 2021; Lambourg et al., 2021; Pham et al., 2009; Pham et al., 2010; Santoro et al., 2013). Moreover, increasing evidence indicates that not only the presence, but the severity of pain experienced by people with kidney failure are major contributors to diminished health-related quality of life (HRQoL)(Davison et al., 2006).

A recent study of 143 Australian people with kidney failure found that 84% reported pain, with 54% describing the pain as "moderate-to-severe"; however, 48% did not regularly take analgesics (Lambert et al., 2021). Additionally, Moore et al. (2023), in a similar population, found that 62.3% of participants self-reported pain as "severe" or "excruciating." The high prevalence of non-adherence to analgesics among people with kidney failure was also highlighted in the Dialysis Outcomes and Practice Patterns Study (DOPPS), which reported that 74% of subjects with moderate-to-severe pain did not take prescribed analgesic medications regularly (Bailie et al., 2004). Considering that the 5-year survival rate for kidney failure is below 50% and the prevalence of pain reaches up to 92%, a compelling argument emerges for comprehensively exploring the lived experience of pain in people with kidney failure, akin to those with other palliative conditions (Combs et al., 2021).

Pain is an unnecessary and inadequately managed symptom in many patients with kidney failure (Barakzoy & Moss, 2006; Davison, 2003). Numerous factors involving patients, providers, and healthcare systems have been identified as barriers to appropriate pain management (Davison & Ferro, 2009). At the physical level, there is altered drug metabolism and renal excretion of analgesic medications, which result in increased risk of side effects and toxicities as CKD progresses (Davison & Ferro, 2009). In addition, polypharmacy is common and, when combined with altered pharmacodynamics and pharmacokinetics, adverse drug reactions are increasingly common (Bailie et al., 2004; Chen et al., 2016). Other factors at the individual level have also been identified. This includes the diverse types of pain with CKD, including neuropathic, nociceptive, or mixed pain (Jhamb et al., 2020). These are related to the high comorbid disease burden, as well as treatment-related complications.

Provider-related barriers to pain management of kidney failure include inadequate skills and experience of general practitioners in handling complex pharmacokinetics. This may lead them to refrain from modifying analgesic medication regimens (Bourbonnais & Tousignant, 2020; Koncicki et al., 2017). While 78% of primary care providers (PCPs) perceive symptom management to be “very” important, less than half report actively treating pain (Green et al., 2012). For example, drugs are often avoided due to their addictive properties (Manchikanti, 2007). In addition, nephrology staff also under-recognize the prevalence, severity, and impact pain has on their patients (Davison & Ferro, 2009). Finally, systemic factors, such as fragmentation of care and lack of guidance regarding appropriate pain management for kidney failure, are contributors (Jawed et al., 2019).

Increasing evidence indicates that symptoms experienced by people with CKD are severe, and major contributors to diminished HRQoL (Davison et al., 2006). Accessibility of adequate pain management for kidney failure is also affected by social and physical factors. Barriers such as fatigue, poor sleep quality, social isolation, low socio-economic status, inadequate access to psychosocial support and low health literacy hinder the pursuit effective treatment. Depression and anxiety in people with CKD range from 20–58.3% and 12–52% in patients with kidney failure, respectively (Goh & Griva, 2018; Mosleh et al., 2020; Murtagh et al., 2007; Ng et al., 2015). Psychological disorders hinder treatment-seeking behaviors by diminishing motivation, increasing stress, and causing social anxiety in patients (Gemmell et al., 2016; Jhamb et al., 2020). Psychological symptoms worsen pain, increase pain-related disability, and create additional obstacles to pain management (Cukor et al., 2006; Lerman et al., 2015).

Given this background, the aims of this study were to (i) explore and describe the lived experience of pain in people with kidney failure accessing kidney-supportive care in a regional health district in Australia; (ii) utilize a reflective picture card technique to help people with kidney failure articulate their experience of pain; and (iii) provide recommendations for health professionals to improve pain management in people with kidney failure.

MATERIALS AND METHOD

This qualitative study assumed a relativist ontological position and utilized visual images as a technique to enable researchers to obtain a deeper understanding of participants’ lived experiences (Budig et al., 2018).

This qualitative study was approved by the joint Illawarra Shoalhaven Local Health District and University of Wollongong Human research Ethics Committee.

The individual, semi-structured interviews were conducted by either the first (AB) or last (KL) author. Interviews were conducted between March 2020 and March 2023, with data collection paused or halted due to COVID-19-related research restrictions. Interviews were conducted in person in the participants’ homes or via phone, after informed consent was obtained. The semi-structured interview questions were not pilot tested prior to data collection, but did undergo peer review with members of the research team prior to study commencement. Interview questions and prompts are shown in **Table 1**. Prompts were used to ensure all interviews were conducted in a similar manner. Participants were invited to verify their transcripts, but no one wished to do so. Information relating to participant demographics was obtained directly from the participants. Recruitment ceased when no new concepts or themes were described by study participants in subsequent interviews (data saturation was achieved).

Participants in this study were people receiving Kidney Supportive Care (KSC). This multidisciplinary service is available to all people with kidney failure in Australia, regardless of whether they are undertaking a renal replacement therapy or not. The intent of the service is to improve quality of life by addressing symptoms and supporting patients and families. Invitations to participate were sent by the KSC Nurse to patients of the KSC service in the Illawarra Shoalhaven Local Health District (n = 88). The inclusion criteria were: adults ≥ 18 years of age; managed by a nephrologist; and undertaking kidney supportive care in the Illawarra Shoalhaven Local Health District. Exclusion criteria were: patients identified by staff to have cognitive impairment; were unable to give informed consent; unwilling to participate; unable to speak or understand English; did not have access to a telephone; were in the terminal phase of their illness; and hospitalized or residing in a nursing home. Interested participants contacted the last author (KL) to arrange an interview time.

Interviews were audiotaped and transcribed verbatim by Otter ai (2024). Transcriptions were checked by the first author (AB) for accuracy with the recording. Dedoose software was used to manage, store the coding index, and code the data (Sociocultural Research Consultants, 2021). The framework approach was used to guide the thematic analysis (Smith & Firth, 2011). This involved line by line in vivo coding of the transcripts by AB and KL, who formed their own initial codes. Coding authors then met to compare and refine these codes (core concepts) and to organize them into the initial categories. These categories were then further refined via an iterative discussion between the authors to produce the final analytical framework. This analytical framework was then applied to the transcripts and facilitated the identification of

the main themes. This process was used to enhance study rigor and to ensure that the analysis reflected the full range and breadth of data. Illustrative quotes that best captured the

essence of the main themes were identified by the first (AB) and verified by the last author (KL), and the final quotations included in the manuscript were agreed upon by all authors.

Semi-structured interview questions were adapted from the validated provocation/palliation, quality, radiation, severity, and timing (PQRST) scale pain assessment tool (Barnard & Gwyther, 2006) (**Table 1**) and explored impact, prevalence, management, experience, and control regarding participants' pain. In addition to these interview questions, all face-to-face participants were invited to participate in a reflective activity using picture cards (**Figure 2**) to assist study participants with articulating their experience of pain. A series of high-quality picture cards (Innovative Resources, 2024) were provided to the participants, and they were invited to choose and discuss several cards that they felt reflected their lived experience of pain.

FINDINGS

Fifteen adults attending the Kidney Supportive Care service consented to participation. Three caregivers were present during the interviews. Seven were interviewed at home and eight via phone (due to COVID restrictions or patient preference). Ten (66%) were male and most were undertaking conservative management of their kidney failure (80%). The majority were age 70 years or older (**Table 2**). Interview times ranged from 25 minutes to 75 minutes (mean interview time 45 minutes).

Five themes were apparent from the data that characterised the lived experience of pain in kidney failure. Participants described encountering many barriers to pain management that resulted in a need to devise their own solutions. Living with chronic pain was described as an experience to be endured rather than managed and resulted in a loss of control and restriction of daily functioning. These themes and subthemes are shown in **Figure 1**. Exemplar quotes for the themes and subthemes identified are shown in **Table 3**.

Theme 1. Barriers to Pain Management

Even though all particpants were managed by the Kidney Supporitve Care service, most participants felt that the lack of access to physicians specializing in pain was a significant obstacle to receiving appropriate pain management. Patients reported fragmented care, with specialists and primary care physicians focusing on their own areas rather than the larger picture to achieve effective pain management. This approach resulted in missed opportunities for effective pain relief. Patients frequently experienced intolerable side effects from pain medications, which, combined with their altered physiology, increased the risk of drug toxicities and dangerous drug interactions.

"I've talked to dietitians. Well, that's not for pain. I talk to the nurse, but that's not for pain either. I have the community nurse[s'] number. I also have the doctor, but that's only for my kidneys. There is no one for pain." (Male, 73 y.o. (years old), conservative management)

"The doctors change around a bit. I find that a bit hard to handle, because you tell one and then you got to tell the other, then you got to tell the other … repetitious what you do there." (Male, 75 y.o., conservative management)

Subtheme: Managed in isolation

Pain management was felt to be isolated due to the narrow focus of medical specialists. This "siloed" approach to healthcare resulted in participants feeling frustrated, unheard, and underserved. A common plea voiced by participants was a desire for their treatment team to work together and address pain holistically.

"Having more cohesion between the team to make sure that they've actually covered the entire picture, not just their tiny little areas." (Male, 73 y.o., conservative management)

Subtheme: Negative side effects

The unacceptable negative side effects from pain medications led to treatment discontinuation. Patients chose to discontinue medications, especially if experiencing dizziness, drowsiness, constipation, and nausea, even fearing addiction.

"The more I take [pain medications] the more they impact my body." (Male, 77 y.o., conservative management)

"I take two tablets. I don't take them all the time. I just take two in the morning when I go to dialysis. My doctor says I can take three, but I don't want to take three because I need to concentrate for driving." (Female, 88 y.o., hemodialysis)

Subtheme: Restricted access

A common problem encountered by participants was difficulty accessing suitable pain medications without side effects. Many patients voiced concerns about hesitation among healthcare providers to prescribe pain medications, due to a fear in doctors that this may exacerbate kidney injury. However, participants perceived this as a risk they were willing to take.

"They [doctors] say 'your kidneys are just too bad to prescribe better pain relief." (Female, 84 y.o., conservative management)

"I have trouble getting in to see the GP [general practitioner; primary care physician] … sometimes you can't get in for a week or a fortnight." (Female, 88 y.o., hemodialysis)

Theme 2. Devising their own solutions

Given the barriers encountered to pain management, particpants frequenetly voiced their experiences with devising their own solutions. Long-term inadequate pain relief, enduring symptoms, despite exhausting analgesic options, and feeling powerlessness led to patients to seek their own solutions to manage their pain. Many of the solutions trialed by participants lacked an evidence base. These included utilising herbal or homeopathic medicines. Other harmful changes, like resuming cigarette smoking, or going against medical advice, such as withdrawing from certain medications and exacerbating symptoms, were also often at the patients' own financial expense.

"I find myself relying on a few stiff drinks to tale the edge off the pain on dialysis nights." (Male, 58 y.o., home hemodialysis)

"I've been doing it in just, like, a foot bath. I do think it helps [cramps]." (Female, 82 y.o., conservative management)

Subtheme: Compromise

Participants discussed how they needed to compromise optimal pain relief to remain functional. For example, pain relief caused nausea, drowsiness, and dizziness. This, in turn, impeded their capacity to engage in daily activities or social events. Consequently, participants opted to discontinue pain relief medications. Some participants also refused life-extending treatments, due to misconceptions that pain associated with treatments was worse than the consequences of not taking the prescribed medications.

"They've reduced the medication by half; it's heightened the hypertension, but the quality of life is more important." (Male, 81 y.o., conservative management)

"We try to rest so we don't need to go to the doctor for pain, because we know that there is nothing they can do." (Caregiver of male,77 y.o., conservative management)

Subtheme: Desperate for relief

Several participants described undertaking in desperation a range of strategies to achieve pain relief. This included taking up smoking, seeking illicit cannabis, and sleeping in chairs to manage their pain. Additionally, self-soothing remedies such as excessive drinking or eating, were perceived by some as necessary measures to provide relief.

"I just want to remind everybody [medical team], we are willing to try anything." (Male, 77 y.o., conservative management)

Subtheme: Non-pharmacological support

Study participants commonly utilized nonpharmacological and alternative pain relief modalities as supplements to physician-prescribed treatments for pain. Mindfulness courses, physiotherapy, massage therapy, hot- and cold-water immersion, and postural modifications were described as common non-pharmacological approaches for managing untreated pain.

"I've attempted a few mindfulness courses to help cope with the pain." (Male, 73 y.o., conservative management)

"I swore by it [capsaicin cream]. And it was actually somebody else from dialysis that put me on to it." (Female, 76 y.o., transplant recipient)

"I'll use ice. I've used heat. They all give a little bit of relief, but it's not ever … resolving the issues." (Male, 73 y.o., conservative management)

Theme 3: Endured rather than managed

The experience of pain is subjective and was described as a burden and phenomenon to be endured, rather than something that could be managed effectively. The chronic nature of the pain in kidney failure appeared to lower expectations of relief and was worsened when medical professionals were dismissive of their concerns.

"They [doctors] are listening, but they are not really understanding the impact it [pain] has." (Female, 88 y.o., hemodialysis)

Subtheme: Invalidated and frustrated

There was a perception that doctors (especially general practitioners) lacked a true understanding of the need for pain management. This, in turn, led to a sense of disillusionment and the belief that their pain was not taken seriously. This was described by many as resulting in a sense of hopelessness and despair. When invalidated and dismissed, patients were reluctant to seek additional medical attention or alternative approaches, leading to exacerbation of pain and reduction of their overall quality of life.

"I had 4–5 videos of him [husband] in pain to prove [it] to them and showed the doctor. He said 'OK' and looked at the first for a few seconds, and then put it down." (Caregiver of male, 77 y.o., conservative management)

Subtheme: Hopelessness and acceptance

The inability to manage pain, coupled with the feeling of a loss of control over their lives and health, led patients to perceive pain as an insurmountable obstacle. Patients reported a sense of hopelessness and resignation and acceptance of their condition as an inescapable fact of life with kidney failure.

"What else [can I do] ? You got to keep going?" (Male, 79 y.o., conservative management)

"Just living, that's all it is. Just living. Pain is just part of my situation … there is nothing you can do." (Male, 77 y.o., conservative management)

Subtheme: Ineffective treatment

Study participants consistently reported ineffective pain relief. Most described having tried numerous classes and doses of medications, yet experiencing little relief. As a result, many participants expressed feelings of desperation and frustration at the lack of effective treatments.

"You can take so much pain medication and get to the point where if you take any more pain medication, they do nothing for you. You're still in pain.'" (Male, 75 y.o., conservative management)

"They keep prescribing me the same tablet that doesn't work."(Male, 77 y.o., conservative management)

<u>Theme 4: Loss of Control</u>

Participants described powerlessness, frustration, and distress, stemming from the complex and evolving nature of their condition. When combined with multiple appointments with multiple physicians, this further contributed to a sense of helplessness and despair. The uncertainty surrounding their pain management further exacerbated these feelings, leading to a reluctance to report ongoing health complaints for fear of compromising their therapeutic relationships. Patients also described the importance of active listening in their care, and how shared decision-making was perceived to be a marker of high-quality care.

"Nothing I can do. Just hope that they can figure it [pain] out." (Male, 75 y.o., conservative management)

"There is nothing I can do. It's put up and shut up." (Male, 77 y.o., conservative management)

Subtheme: Loss of ownership

Patients feel powerless in their pursuit of solutions to their problems. A complex interplay of medical, psychological, and social factors contributes to this sense of helplessness. The heavy reliance on various doctors, medications, and interventions, coupled with the limited control patients have over their own health, can result in a feeling of loss of autonomy and self-efficacy.

"I feel like they are playing with his body." (Caregiver of male, 77 y.o., conservative management)

"Sometimes I'll take the pills, and it works. And sometimes I take the pills and it doesn't work. And I dread the days that it doesn't work." (Female, 88 y.o., hemodialysis)

Subtheme: Burden

Patients described their reluctance to ask questions or repeatedly discuss the same concerns, as they may have been perceived as "difficult" or that it may jeopardize their relationship with the treatment team. This resulted in patients not getting the information they needed and not having their pain management concerns addressed adequately.

"I don't want to bother doctors and tell them how much pain they are in during the consult." (Caregiver of Female 76 y.o., transplant recipient)

Subtheme: Varying quality of care

Patients described varying quality of care for pain. Some doctors asked more questions and demonstrated genuine interest in helping the patients manage their pain or seek alternative options, while others had an attitude of superiority and were perceived as not effectively addressing the concerns or experiences of the patients. Patients appreciated doctors who showed empathy and willingness to collaborate in their pain management, rather than those who exhibited dismissive attitudes.

"I go to this young doctor GP [general practitioner; primary care physician]. They seem to be interested in you and what you have going on. Having a young doctor that knows everything new is much better." (Male, 79 y.o., conservative management)

Theme 5: Restriction of daily function

Participants described how pain significantly affected their quality of life, especially their ability to mobilize, socialize, and perform basic activities of daily living.

"I am just sort of nearly like a hermit; just withdrawn from things." (Male, 75 y.o., conservative management)

Subtheme: Restriction of life activities

Pain resulted in limitations undertaking essential daily tasks, like chores, personal hygiene, and basic self-care activities. These included cleaning, cooking, shopping, exercising, sleeping, and eating. Participants described a dependence on others (families or other social networks), leading to a pervasive feeling of reliance and dependency.

"Even just picking up a cup of coffee hurts." (Male, 74 y.o., conservative management)

"When I go the toilet, she [wife] needs to take me." (Male, 77 y.o., conservative management)

Subtheme: Restriction of mobility

Mobility was frequently restricted by pain. The lived experience of pain and restricted mobility led to social isolation, significant impediments to performing daily tasks, and sedentary lives. Restricted mobility compounded social isolation.

"I wish I could just get out and see people." (Male, 84 y.o., conservative management)

"I want to go down the street to get the bloody paper, but I wouldn't because it would be too much trouble." (Male, 81 y.o., conservative management)

Subtheme: Restriction of social activities

Pain led to restriction of social interactions, with fatigue in particular as a major contributor.

"Can't get out to the club with my mates. I just don't have the energy for it anymore." (Male, 79 y.o., conservative management)

Picture card technique findings

The use of picture cards (Innovative Resources, 2024) enabled unique insights into the lived experience of pain. Frequently used images were barbed wire, a ferris wheel, a roller coaster, shredded paper, and a house on fire. While several images were selected by multiple people, the metaphors used were different for each participant. Other images demonstrated a feeling of detachment from their care and the world around them. These are shown in Figure 2 with accompanying reactions from participants. Multiple participants described how the cards were able to show the real impact of pain and became animated when describing their choice of card and metaphor.

DISCUSSION

This qualitative study identified valuable insights into the lived experience of pain among people with kidney failure. The dominant theme emergent among participants was that pain was an accepted burden, despite prescribed analgesics. Pain affected many aspects of participants' daily lives, including sleeping, socializing, mobilizing, and mood. Achieving sufficient pain relief was hindered by systematic barriers, such as fragmented multidisciplinary collaboration, risk-averse medical practitioners, and patient uncertainty about which doctor to approach for pain management.

The frustration felt by participants about which healthcare professionals to consult for pain management is not unique. Previous work has found that recurrent interactions with kidney specialists diminished relationships with primary care providers (PCPs) (Jhamb et al., 2020). In addition, while the involvement of multiple sub-specialties is essential, this may complicate a holistic focus on care (Sloan et al., 2020). This study reported similar findings, with patients describing conflicting approaches between specialists in managing their pain. These findings also align with a national survey indicating that, while over 90% of American nephrologists provided primary care services, including pain relief, 60% believed this should be the responsibility of primary care physicians (Bender & Holley, 1996). This underscores the need for increased collaboration and communication between treatment teams and specialists in pain to coordinate pain management. This is particularly important as contact with nephrologists is less frequent and accessible than contact with primary care physicians (PCPs).

In Australia, Kidney Supportive Care Services (KSC) were developed in response to the significant symptom burden and needs of nephrology patients (Davison et al., 2015; Josland et al., 2012; Tonelli et al., 2018). KSC works to improve quality of life via integration of palliative care principles within existing kidney care services (Ducharlet et al., 2021). While palliative caregivers are key stakeholders in KSC, these services may be underutilized according to a recent Australian study of 382 nephrologists. The findings indicated that 17% mistakenly believed palliative care was only for patients in the last few weeks of their lives, subsequently missing a large portion of patients needing specialists in pain relief management (Ducharlet et al., 2021). Interestingly, 55% agreed that all patients with advanced CKD would benefit, while 67% agreed that earlier referral would be beneficial for symptom control (Ducharlet et al., 2021). Patients in the present study expressed a desire for more integrated, coordinated care between practitioners, including palliative measures to manage the extensive symptom burden. Interestingly, a recent cross-sectional study described the use of patient-reported symptom measures to directly inform clinical care (Morton et al., 2020). Despite being an important aspect of KSC, only 65% of nephrology units routinely measured symptoms in patients with advanced kidney disease (Morton et al., 2020). It is concerning that, in this study, many patients described how staff would only focus on kidney-disease-related symptoms. Embedding the collection of patient-reported measures regarding symptom burden more broadly into nephrology services could facilitate services, improve patient outcomes, and enable earlier action to provide pain relief.

There are several strengths to this study, including the qualitative design, allowing unique and in-depth insights into the lived experiences of pain in people with kidney failure. Additionally, the use of the picture card technique enabled deeper articulation of their experiences. However, this study was not without limitations. The research occurred in a single supportive care service in one geographic location, with participants being mostly male; this may hinder generalizability to the wider Australian supportive care population. Response bias may have also occurred with those who experienced pain being potentially more likely to agree to participate in the research. Conversely, patients living with kidney disease who did not experience pain may have been less likely to participate, as the research posed no benefit to their condition. In terms of thematic analysis, while a rigid analysis framework was utilized, codes and themes were subject to interpretation by only two researchers (AB and KL). In addition, we did not record patients' length of time involved with the KSC team, which may have influenced perceptions. We also did not record cultural background, which may also influence how individuals experience, express, and cope with pain.

The study identified several opportunities to improve services to optimize patient care. These are summarized in **Table 4**. Study participants frequently reported untreated pain that resulted in poorer medication adherence, missed dialysis sessions, and increased emergency department admissions. This is consistent with previous reports of missed treatments, increased health service use, and hospitalization arising from poorly controlled pain (Weisbord et al., 2014). Furthermore, the loss of agency reported in this study suggests the implementation of a multidisciplinary approach to high-quality, standardised care with suggested improvements from this study, including incorporating pain specialists within the RSC team to specifically address patient pain concerns (Taberna et al., 2020). However, this may be challenging due to long waiting times to access specialist pain services in some geographic areas. The "Ask Me 3®" method (https://www.ihi.org/resources/tools/ask-me-3-good-questions-your-good-health) may also be a useful strategy to improve agency and confidence for patients to ask questions (Institute for Healthcare Improvement, 2019). In brief, this involves the patient writing the answer to three key questions prior to each appointment: "What is my main problem?"; "What do I need to do about it?"; "Why is it important for me to do this?" This approach can be initiated by the health professional and adds structure to the patient-provider communication.

Pain may be used as a proxy term by patients for physical and psychosocial suffering, including weakness, fatigue, frustration, and hopelessness (Turk et al., 2016). This suggests that routine access to psychosocial support is critical to supporting the needs of people receiving KSC. In the present study, access to social work and psychologists are not funded by public hospitals in Australia, and are available on an emergency basis only. This is clearly problematic, as the experiences suggest social isolation, relationship changes, changes in self-perception, and a lack of social support increasing the emotional distress experienced by KSC patients. The invisible nature of chronic pain, combined with depression and anxiety, suggests that social work services are intrinsic to helping patients develop effective coping strategies and indicates the need for advocacy with and on behalf of patients for access to appropriate care.

CONCLUSION

Pain is common in people with kidney failure. This study identified that, for the patients sampled, current pain management strategies were largely ineffective, with far reaching consequences for the physical, social, emotional health of participants. A greater recognition and understanding of the lived experience may assist nephrology staff in empowering patients, improving care coordination, and optimizing quality of life.

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TABLE 1. INTERVIEW QUESTIONS AND PROMPTS

Question 1. The presence of pain
Can you tell me about whether you experience pain? Prompts: Where on your body do you have pain?
Question 2. Pain management
How intense is the pain? Probes: How would you describe its severity?
Question 3. Help with pain
Have you faced any issues or problems getting help to manage your pain? Probes: Can you describe what these were? How did these problems affect your life?
Question 4. The lived experience of pain
Can you tell me how pain affects your day-to-day life, about whether you experience pain? Probes: How would you describe its severity? How does it affect your life? Your mood? Your sleeping? Your appetite? How you socialize with others? Your overall quality of life? Are there other ways pain affects your life that I have not asked about?
Question 5. Understanding self-management
Do you feel like you have control over your pain? Probes: What strategies do you or your carer use to help you manage your pain? Why? Do you agree with the approach the team has taken to manage your pain?
Question 6. Beliefs
Do you have any suggestions for the kidney care team about how we can help manage yours and other people's pain?

TABLE 2: CHARACTERISTICS OF STUDY PARTICIPANTS (N = 15)

Characteristics	**Number (%)**
Age range of participants in years	58–89
Age category of participants	
50–59 years	1 (6.7)
60–69 years	0 (0)
70–79 years	5 (33.3)
80–89 years	5 (33.3)
Did not specify	4 (26.7)
Gender (male, %)	10 (66.0)
Treatment modality:	
Conservative management	12 (80.0)
Hospital-centered-based hemodialysis	1 (6.7)
Home dialysis	1 (6.7)
Kidney transplant	1 (6.7)
Peritoneal dialysis	0 (0)

TABLE 3. EXEMPLAR QUOTES FOR THEMES AND SUBTHEMES

Theme	Exemplar quotes
1. Barriers to pain management	
Managed in isolation	"My kidney doctor doesn't worry about that [pain] because that's not his problem." "They're all trying to do their thing without really understanding the whole picture, the whole problem. You know I have four on the team, the dietitian, the community nurse, the doctor, and whoever but they don't work in a togetherness sort of way." "If they [doctors] are uncertain, then they should be saying, 'Well I can't help him here so let's send him to someone who can help.'
Negative side effects	"In my case, I hate painkillers and the way they make me feel. Now, the more I take, the more it impacts my body." "I took Lyrica® and when I got home and went to sleep, my granddaughter called in and she couldn't wake me up." "The treatment for pain, either the side effects are just not worth it, so you don't take it or they don't do anything. It's not helping, so why are you really taking them?"
Restricted access	"Doctors said it [pain medication] will do more damage to the kidneys, so I still got my pain." "When you've got bad kidneys, you can't sort-of take many pills for pain."
2. Devise their own solutions	
Compromise	"I don't want to go through any more pain than I'm already enduring. I imagine there's quite a bit of pain associated with dialysis." "He [doctor] said 'Have you ever thought about dialysis?' I said, 'No thanks, mate, too much pain. It's … not worth it.'"
Desperate for relief	"I sleep here in this chair in the living room to avoid the pain from lying down." "I began to take up smoking again after I gave up for a while." "I am just hoping. All I can do is hope, because I have tried everything else to manage the pain." "Sometimes I am nearly in tears with it [pain]."
Non-pharmacological support	"I get a physiotherapist; I asked for one a few years ago but the public system didn't really provide it." "I often use a hot wheat bag to try and manage it [pain]." "I roll on a football to stretch my back after dialysis, and I do Pilates twice a week."
3. Endured rather than managed	
Invalidated and frustrated	"I find it hard to handle, because you tell one [doctor], and then you go in again [dialysis unit] and have to tell the next doctor what's happening, and then a new one. It gets repetitious what you do there." "They ask me what my pain is. I say 9–9.5 and they seem to say 'Nah get rid of the 9 you really have 0.5 pain.' They don't believe it." "I don't think a lot of them believe how much pain I am in."
Hopelessness and acceptance	"There is nothing I can do about it. It will be there whether I like it or not'. "What can I do about it? I just have to put up with it [pain]. There's nothing I can do." "I guess you do what most people do and put up with it." "I have got no choice, so I put up with it and shut up." "But I just do it because I have to." "That's just the way it is may [sic]. I can't have a magic wand. Unfortunately, this is what I got." "I just have to deal with it." "I can't stand it anymore." "Pain controls me."

Ineffective treatment	"I am on like two, maybe three [analgesics], but it [pain] is always there." "I have trialed three different tricyclics. We are going on 10 years, you know, so I have trialed and errored a whole lot. I've tried opiates, various other things, right up to CBD oil." "Even on all this medication, I still have pain." "I take Panadol every day, and they do no good." "I have been through a lot of pain medications."
4. Loss of control	
Loss of ownership	"Just the way it is, terrible." "I can't do anything about my situation." "I would like to have an answer. I wish they had a plan. We do this, and stop that, and 'We should be okay.'" "I don't have any control over it."
Burden	"I feel like I shouldn't keep bothering them all the time with my issues [pain]." "Told us [that] when he [husband] is close to the end, then they would manage his pain. Then they will make him feel comfortable." "They [kidney doctors] don't like being bothered with non-renal problems."
Varying quality of care	"Yes, this new doctor has been a breath of fresh air."
5. Restriction of daily function	
Restriction of life activities	"I can no longer do anything; like, I love the shops." "I can't do the washing up and things like that because it becomes difficult to stand at the sink." "I can only shower when I have a helper." "My daughter got upset with me saying, 'I can't eat this rubbish' … but that's all I can manage to make." "I don't know what it is. I'd just love to be able to do things, but I can't." "I have abandoned chores because of the pain." "Just going to the toilet is difficult." "Now we do everything together because he can't do anything on his own." "She [wife] is doing most of the work. Well, all of the work. She mows the lawns, does the gardening, all sorts of things."
Restriction of mobility	"Can no longer walk 100 steps." "I can't walk much further than the back fence; it just really knocks me about." "He doesn't walk because of the pain in his back." "The girl who comes walks [with] him, but he can only walk to the front gate." "Cannot use the recliner because he cannot support the pain because his legs are too heavy." "My biggest complaint is I've just got no 'get up and go.' I just can't do anything." "I can't go anywhere much." "I need a walker permanently now."
Restriction of social activities	"I don't go out." "I don't go outside much. I don't go anywhere much." "I just watch a lot of television." "We don't do as much now as we used to, partly because it's just too difficult to get around comfortably." "I have only left the house twice in the last 2–3 months."

TABLE 4. RECOMMENDATIONS FROM STUDY FINDINGS

Characteristics
Routine involvement of specialist pain physicians in the care of patients with kidney failure
Education for non-nephrology health professional staff about suitable pain relief for those with kidney failure
Educate and encourage patients about when and how to voice concerns regarding pain at medical appointments.
Provide clear expectations to patients that the goal of pain relief is to provide functional independence and is unlikely to resolve the pain completely.
Proactive regular questioning from all nephrology staff to determine the presence and severity of pain
Regularly perform patient reported symptom measures that include pain and pain rating scales (with consideration to avoiding survey fatigue).
Holistic approach to pain, including psychosocial support. Advocate for multi-disciplinary meetings that include allied health professionals (including social workers, psychologists, and other counsellors where appropriate), as well as other medical specialists to avoid "siloed" care planning.

FIGURE 1. CONCEPTUAL DIAGRAM OF MAIN THEMES REGARDING THE LIVED EXPERIENCE OF PAIN IN PEOPLE WITH KIDNEY FAILURE

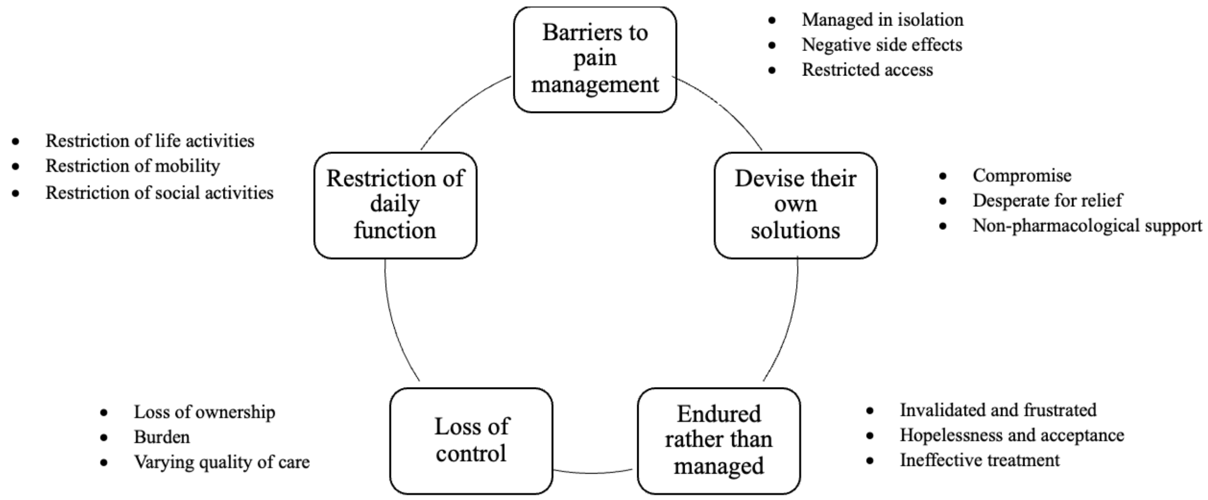


FIGURE 2. SELECTED IMAGES REPRESENTING THE EXPERIENCE OF PAIN IN KIDNEY FAILURE USING THE PHOTOVOICE TECHNIQUE. IMAGES REPRODUCED FROM PICTURE THIS WITH THE PERMISSION OF THE PUBLISHER, INNOVATIVE RESOURCES: WWW.INNOVATIVERESOURCES.ORG. ALL RIGHTS RESERVED.

Endured rather than managed (Ineffective treatment) "It's as if what is supposed to help causes as much damage as doing nothing at all."

Endured rather than managed (Ineffective treatment) "It's as if what is supposed to help causes as much damage as doing nothing at all."

House on fire – permission not granted for image to be reproduced

Endured rather than managed (Ineffective treatment) "It's as if what is supposed to help causes as much damage as doing nothing at all."

Shredded paper – permission not granted for image to be reproduced

Endured rather than managed (Hopelessness and acceptance) "I feel like this shredded paper that cannot be put back together again."

Loss of control (Loss of ownership) "My life is like a ferris wheel. I have no control of it." OR "I can't get off." OR "Like a medical merri-go-round [sic]." OR "This is my life...up and down like a roller coaster."

Loss of control (Loss of ownership) 'When you are in deep trouble and can't swim, so you must stay where you are and just hope someone notices you and saves you."

Loss of control (Loss of ownership) "This describes me not being able to control my life and it scares the life out of me. I am not afraid to die, just afraid I have no control of my life."

Looking through window – permission not granted for image to be reproduced

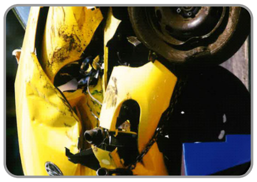
Loss of control (Loss of ownership) "I am on the outside looking through the window, missing the good parts of life."

Koala – permission not granted for image to be reproduced

Barriers to pain management (Negative side effects) "I am like the koala, exhausted all the time."

Loss of control (Loss of ownership) "I feel this is me because I don't have every part of me working properly, watching the world go by and not doing anything about it."

Restriction of daily function (Restriction of life activities) "I feel tethered to my house. I can't go anywhere because [of the] pain.



Endured rather than managed (Hopelessness and acceptance) "This is my body – a car crash that is all crumpled and broken and a write- off."

Person experiencing homelessness – permission not granted for image to be reproduced

Endured rather than managed (Hopelessness and acceptance) "This homeless man is me ... a rough sleeper."

Shredded paper – permission not granted for image to be reproduced

Loss of control (Loss of ownership) "My health is a jumbled mess and no one knows how to untangle it."

Holding baby's finger – permission not granted for image to be reproduced

Endured rather than managed (Hopelessness and acceptance) "This represents my struggle. I need tenderness ... to really deal physically with the burden ... I can feel it inside."