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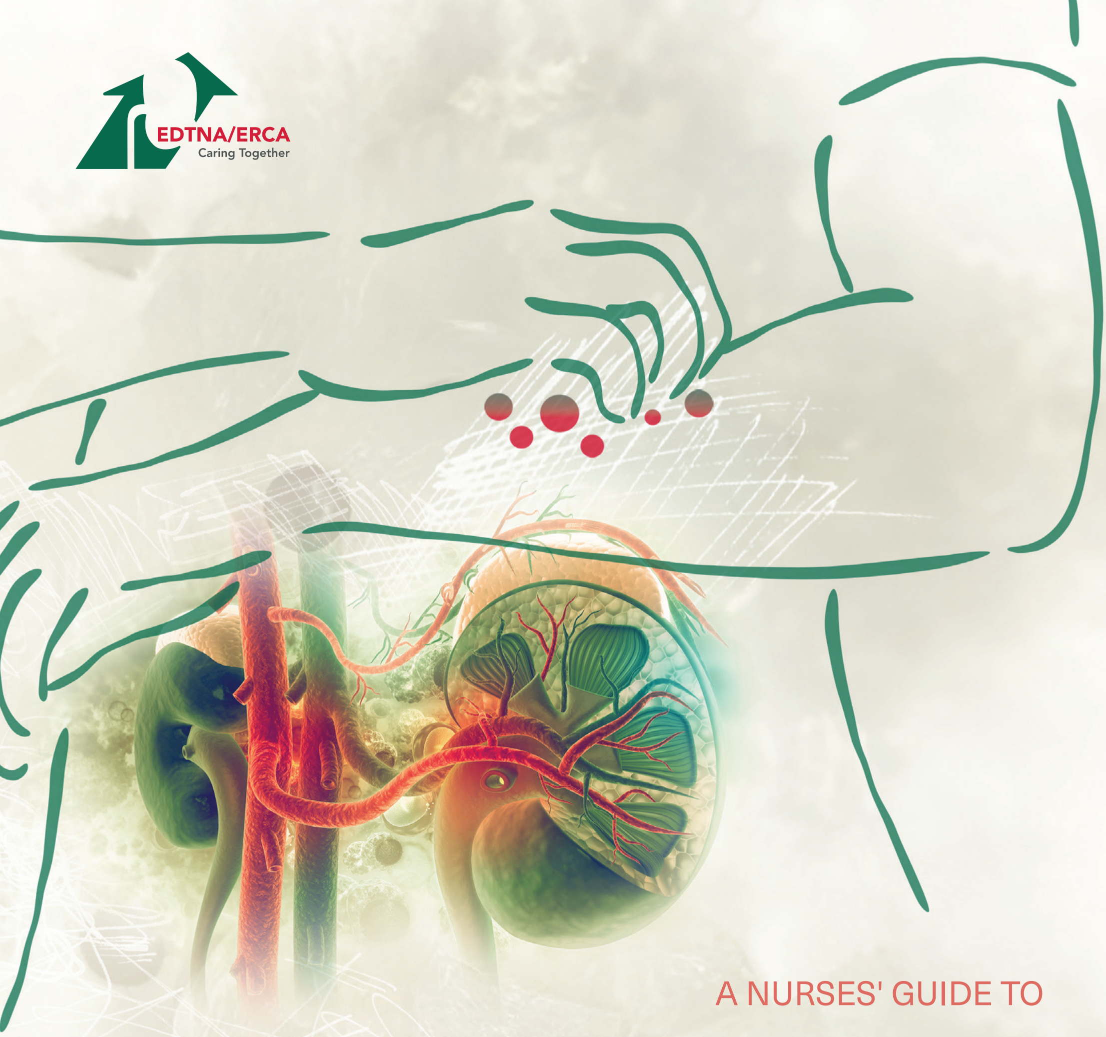

A NURSES' GUIDE TO

CHRONIC KIDNEY DISEASE ASSOCIATED PRURITUS

Understanding, Communication and Support

Editors
ANASTASIA LIOSSATOU | AFRA MASIÀ-PLANA

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A Nurses' Guide to CKD-associated Pruritus; Understanding, Communication and Support

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The purpose of this EDTNA/ERCA initiative is to create a nurses' guide that contains the most recent information on CKD-associated Pruritus; Understanding, Communication and Support. It is a guide specifically designed for nephrology nurses working in haemodialysis field.

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Chapter 1

CKD-associated Pruritus (CKD-aP) Prevalence and pathophysiology

Learning objectives:

- To examine the prevalence of CKD-associated pruritus across different time periods and countries
- To gain insight into the intricate and multifactorial pathogenesis of CKD-associated pruritus
- To acknowledge the uncertainty about the aetiology and treatment of pruritus associated with chronic kidney disease, despite its high prevalence and growing burden

Introduction

Pruritus, commonly referred to as itch, is an unpleasant skin sensation that triggers a strong urge to scratch. It can be classified as acute or chronic, with chronic pruritus defined as an itch persisting for six weeks or longer. Chronic pruritus can arise from various conditions, including dermatologic, systemic, neurologic, or psychogenic disorders, either in isolation or in combination.[1-3] chronic kidney disease (CKD) serves as a notable example of a systemic condition associated with chronic pruritus.[1,2]

CKD-aP, historically termed uraemic pruritus, is a distressing complication frequently observed in patients undergoing dialysis. Its detrimental effects on sleep, mood, and social functioning significantly impair the quality of life in affected individuals. Despite its high prevalence and substantial impact, CKD-aP remains poorly characterised and inadequately understood.[4,5] Furthermore, there are no standardised guidelines for its diagnosis and treatment, leading to frequent underdiagnosis and undertreatment.[6]

CKD-associated pruritus is not restricted to people on dialysis and is also prevalent among individuals with non-dialysis CKD. Data from the CKD Outcomes and Practice Patterns Study (CKDopps), the largest investigation of CKD-aP in nondialysis people with CKD, reveal that approximately 24% of people across all stages of CKD experience at least moderate pruritus, while 10–13% report severe to extreme pruritus. The severity of pruritus correlates with progressively poorer patient-reported outcomes.[7] This review focuses on the prevalence of CKD-aP among people on haemodialysis (HD) and explores its underlying pathophysiology.

Prevalence of CKD-associated Pruritus

Numerous studies have investigated the prevalence of CKD-aP globally, revealing significant variability across countries and even among dialysis centres within the same region. Additionally, prevalence rates have been reported to differ depending on the dialysis modality, whether HD or peritoneal dialysis.[6]

Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS), which included 35,452 adult people on HD from up to 17 countries between 2012 and 2015, demonstrated that 67% of these individuals experienced CKD-aP. Among those affected, 37% reported being at least moderately bothered by itch. The prevalence of moderate to extreme pruritus varied geographically, with the lowest rates observed in Germany (26%) and the highest in the United Kingdom (47%) (Figure 1).[8,9] Furthermore, longitudinal analysis from the DOPPS suggests that the prevalence of CKD-aP has remained relatively unchanged between 1996 and 2015 (Figure 2).[8]

Figure 1 – Self-reported pruritus, by country[9]

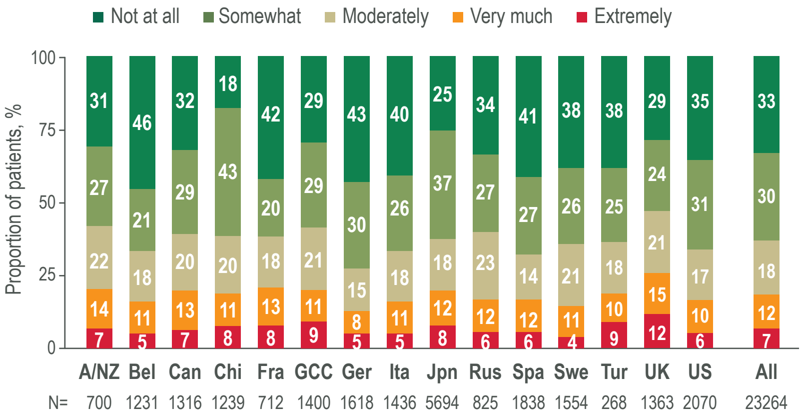
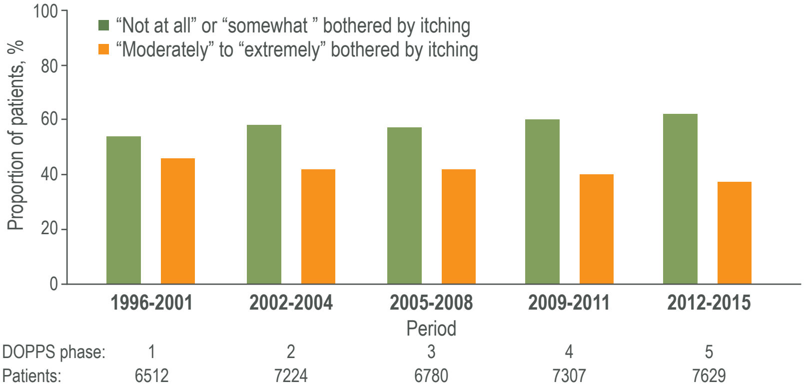


Figure 2 – Prevalence of CKD-associated Pruritus over time (DOPPS data)



Pathophysiology of CKD-associated Pruritus

The pathogenesis of CKD-aP is complex and not yet fully understood.[10-12] However, several mechanisms have been investigated, and broad hypotheses have been proposed to elucidate its aetiology. CKD-aP arises from opioid receptor dysregulation, immune system dysfunction, toxin accumulation, or peripheral neuropathy or a combination of these factors.[10-13]

Opioid receptor dysregulation

Opioids are compounds that modulate pain by binding to receptors located in the brain, peripheral nerves, keratinocytes, melanocytes, hair follicles, and immune cells. Beyond pain signalling, the opioid pathway is recognised as a key regulator of itching.[10] Evidence highlights the involvement of two primary opioid receptors, the mu-opioid receptor (MOR) and the kappa-opioid receptor (KOR), in the pathogenesis of CKD-aP.[13,14] Activation of MORs promotes itch perception, whereas KOR activation counteracts MOR-mediated itch signalling.[14] The opioid receptor dysregulation hypothesis posits that CKD-aP arises from an imbalance in MOR and KOR activity, favouring MOR action.[13,15] Specifically, overstimulation of MORs, coupled with under- expression or antagonism of KORs, contributes to heightened itch sensation.[10,16]

Immune system dysfunction

The second hypothesis proposes that CKD-aP is driven by dysregulated systemic inflammation. This theory is supported by elevated levels of pro-inflammatory mediators observed in people undergoing dialysis, including T-helper 1 cells, C-reactive protein, interleukin-6, and interleukin-2. Additionally, CKD-aP has been linked to immune function-related factors, such as increased white blood cell count, reduced albumin levels, and elevated ferritin concentrations.[6,10,16]

Furthermore, people with CKD-aP have been found to exhibit elevated levels of histamine, eosinophils, mast cells, and tryptase. These findings initially suggested that the accumulation of such pruritogenic substances may contribute to the condition. However, the lack of characteristic skin changes, such as wheals, and the frequent therapeutic ineffectiveness of antihistamines in managing CKD-aP cast doubt on the role of histamine as a central mediator in its pathogenesis.[10,15,16]

Toxin deposition

The toxin deposition hypothesis suggests that CKD-aP arises from reduced renal function and the consequent inadequate excretion of metabolic byproducts.[6] This leads to the accumulation of uraemic toxins, including vitamin A, aluminium, calcium, phosphorus, and magnesium, in the skin and subcutaneous tissue, triggering itch.[10,16] Evidence for this hypothesis includes observations that fewer people have CKD-aP over time, improvement in pruritus with enhanced dialysis efficiency, and correlations between CKD-aP and markers of suboptimal dialysis, such as elevated calcium, phosphorus, and parathyroid hormone levels.[10,16] However, data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) between 2012 and 2015 did not identify a significant association between these markers and pruritus. Moreover, no interventional study to date has demonstrated that lowering serum phosphorus alleviates CKD-aP.[8]

Peripheral neuropathy

Neuropathic itching can occur when sensory neurons or interneurons become dysregulated, leading to disproportionate or spontaneous activation independent of pruritogens.[10] Evidence suggests that individuals with CKD and CKD-aP exhibit increased expression of ion channels in peripheral nerve endings compared to those without CKD-aP.[17] Additionally, people with uraemic symptomatology have been shown to have elevated levels of neurotrophins, which are neurological mediators associated with pruritus.[6] The hypothesis that peripheral neuropathy contributes to CKD-aP is further supported by the high prevalence of paraesthesia and restless leg syndrome observed in people receiving HD suffering from CKD-aP. These findings underscore the potential role of altered nerve function in the pathogenesis of this condition.[10,16]

Other risk factors

Up to 85% of individuals on HD experience xerosis (dry skin). While xerosis is not considered a primary cause of CKD-aP, it is thought to exacerbate itch severity.[10] Consequently, many people with CKD-aP report relief and a reduction in itch intensity with the use of moisturising and rehydrating agents.[10,15]

It has also been proposed that elevated levels of parathyroid hormone (PTH) may contribute to CKD-aP. This hypothesis is supported by reports of itch improvement in some individuals following parathyroidectomy.[6,15,16] However, PTH does not appear to play a direct role in activating itch fibres, as studies have shown that PTH injections do not induce itching.[6]

Conclusion

CKD-aP is a common and burdensome comorbidity in people with end-stage renal disease undergoing dialysis. It is estimated that over 60% of these people experience CKD-aP, which significantly impairs their quality of life by negatively affecting sleep, mood, and social functioning.[4,5,9]

Several hypotheses have been proposed to explain the pathogenesis of CKD-aP, with opioid receptor dysregulation, immune system dysfunction, toxin deposition, and peripheral neuropathy being the most widely recognised.[10,13] However, the exact aetiology of CKD-aP remains largely unclear and incompletely understood.[10,12] Due to the uncertainty surrounding its pathophysiology and treatment, the condition is often neglected and continues to be one of the more challenging complaints reported by people.[10,18] Individuals with CKD-aP often find themselves trapped in a vicious itch–scratch cycle, where the sensation of pruritus triggers scratching, which in turn damages the skin and worsens the itching.[3]

References

1. Ständer S, Weisshaar E, Mettang T, Szepietowski JC, Carstens E, Ikoma A, Bergasa NV, Gieler U, Misery L, Wallengren J, Darsow U, Streit M, Metze D, Luger TA, Greaves MW, Schmelz M, Yosipovitch G, Bernhard JD. Clinical classification of itch: a position paper of the International Forum for the Study of Itch. Acta Derm Venereol. 2007;87(4):291-294.
2. Weisshaar E, Szepietowski JC, Dalgard FJ, Garcovich S, Gieler U, Giménez-Arnau AM, Lambert J, Leslie T, Mettang T, Misery L, Şavk E, Streit M, Tschachler E, Wallengren J, Ständer S. European S2k Guideline on Chronic Pruritus. Acta Derm Venereol. 2019;99(5):469-506.
3. Bathe A, Matterne U, Dewald M, Grande T, Weisshaar E. Educational Multidisciplinary Training Programme for Patients with Chronic Pruritus. Acta Derm Venereol. 2009;89:498-501.
4. Mathur VS, Lindberg J, Germain M, Block G, Tumlin J, Smith M, Grewal M, McGuire D. ITCH National Registry Investigators. A longitudinal study of uremic pruritus in hemodialysis patients. Clin J Am Soc Nephrol. 2010;5(8):1410-1419.
5. Pisoni RL, Wikström B, Elder SJ, Akizawa T, Asano Y, Keen ML, Saran R, Mendelssohn DC, Young EW, Port FK. Pruritus in haemodialysis patients: International results from the Dialysis Outcomes and Practice Patterns Study (DOPPS). Nephrol Dial Transplant. 2006;21(12):3495- 3505.
6. Agarwal P, Garg V, Karagaiah P, Szepietowski JC, Grabbe S, Goldust M. Chronic Kidney Disease-Associated Pruritus. Toxins. 2021;13:527.
7. Sukul N, Speyer E, Tu C, Bieber BA, Li Y, Lopes AA, Asahi K, Mariani L, Laville M, Rayner HC, Stengel B, Robinson BM, Pisoni RL. Pruritus and Patient Reported Outcomes in Non-Dialysis CKD. Clin J Am Soc Nephrol. 2019;14:673- 681.
8. Rayner HC, Larkina M, Wang M, Graham-Brown M, van der Veer SN, Ecder T, Hasegawa T, Kleophas W, Bieber BA, Tentori F, Robinson BM, Pisoni RL. International Comparisons of Prevalence, Awareness, and Treatment of Pruritus in People on Hemodialysis. Clin J Am Soc Nephrol. 2017;12(12):2000-2007.
9. Sukul N, Karaboyas A, Csomor PA, Schaufler T, Wen W, Menzaghi F, Rayner HC, Hasegawa T, Al Salmi I, Al- Ghamdi SMG, Guebre-Egziabher F, Ureña-Torres PA, Pisoni RL. Self-reported Pruritus and Clinical, Dialysis- Related, and Patient-Reported Outcomes in Hemodialysis Patients Kidney Med. 2020;3(1):42-53.e1.

10. Verduzco HA, Shirazian S. CKD Associated Pruritus: New Insights Into Diagnosis, Pathogenesis, and Management. Kidney Int Rep. 2020;5(9):1387-1402.
11. Swarna SS, Aziz K, Zubair T, Qadir N, Khan M. Pruritus Associated With Chronic Kidney Disease: A Comprehensive Literature Review. Cureus. 2019;11(7):e5256.
12. Combs SA, Teixeira JP, Germain MJ. Pruritus in Kidney Disease. Semin Nephrol. 2015;35(4):383-391.
13. Wieczorek A, Krajewski P, Kozioł-Gałczyńska M, Szepietowski JC. Opioid receptors expression in the skinof haemodialysis patients suffering from uraemic pruritus. J Eur Acad Dermatol Venereol. 2020;34:2368-2372.
14. Umeuchi H, Togashi Y, Honda T, Nakao K, Okano K, Tanaka T, Nagase H. Involvement of central mu-opioid system in the scratching behavior in mice, and the suppression of it by the activation of kappa-opioid system. Eur J Pharmacol. 2003;477(1):29-35.
15. Mettang T, Kremer AE. Uremic pruritus. Kidney Int. 2015;87(4):685-691.
16. Shirazian S, Aina O, Park Y, Chowdhury N, Leger K, Hou L, Miyawaki N, Mathur VS. Chronic kidney disease- associated pruritus: impact on quality of life and current management challenges. Int J Nephrol Renovasc Dis. 2017;10:11-26.
17. Momose A, Yabe M, Chiba S, Kumakawa K, Shiraiwa Y, Mizukami H. Role of Dysregulated Ion Channels in Sensory Neurons in Chronic Kidney Disease-Associated Pruritus. Medicines (Basel). 2019;6(4):110.
18. Abdelsalam M, Tawfik M, Reda EM, Eldeeb AA, Abdelwahab A, Zaki ME, Abdelkader Sobh M. Insulin Resistance and Hepatitis C Virus-Associated Subclinical Inflammation Are Hidden Causes of Pruritus in Egyptian Hemodialysis Patients: A Multicenter Prospective Observational Study. Nephron. 2019;143(2):120-127.

Chapter 2

The multifaceted impact on patients’ quality of life & Nursing management of CKD-associated Pruritus (CKD-aP) in relation to QoL

Learning objectives:

- To understand the multifaceted impact of pruritus on patients with CKD
- To identify key dimensions of quality of life, including physical and mental well-being of patients affected by CKD-associated pruritus
- To describe nursing management interventions aimed to achieve a better quality of life for patients affected by CKD associated pruritus

Introduction

Haemodialysis (HD) is a life-sustaining treatment for individuals with end-stage renal disease (ESRD), yet it profoundly affects patients' overall well-being and quality of life (QoL). Beyond its physiological benefits, HD introduces a complex array of physical, psychological, and social challenges that necessitate comprehensive care strategies.

Since the initiation of HD therapy, patients have experienced 'nonspecific symptoms' that health care professionals lacked the tools to identify and manage. As the years went by, the attention to symptoms has not only been focused on the pathophysiology of the disease, but a wider view has been achieved. For example, the beginning of research on nonspecific symptoms dates to 1980’s and included symptoms such as tiredness, cramps, pruritus, dyspnoea, headaches and joint pain. These symptoms were often not directly related to HD sessions and did not often correlate with patient's perception of severity.[1] During the same period, somatic symptoms were also examined with growing attention to the relationship of psychological and clinical factors and its impact on the manifestation of these symptoms. Somatic symptoms have gained relevance since the 80’s and the severity of each symptom was significantly related to the indices of affect and quality of life.[2]

More than half of adults on dialysis suffer from CKD-associated Pruritus (CKD-aP) and it is one of the most common discomforts experienced by patients with end-stage renal disease (ESRD).[3]

The prevalence of CKD-aP is 40%–70% and varies among different countries, which may be influenced by environmental factors and quality of healthcare.[4]

The complexity of assessing and managing CKD-aP is a challenge for all health providers and requires a wider perspective, along with an understanding of its specific characteristics, in order to provide appropriate treatment and support both patients and their family.

Multifaceted impact of pruritus on patients with CKD

According to the Dialysis Outcomes and Practice Patterns Study (DOPPS), 40% of HD patients suffer from moderate-to-severe pruritus which contributes significantly to the overall burden of HD and negatively affects quality of life. Addressing the multifaceted impact of HD on QoL requires a holistic, multidisciplinary approach. Latest research demonstrate how diverse and far-reaching poor outcomes are for patients who experience CKD-aP, specifically those with more severe pruritus.[5] A longitudinal study assessing patients undergoing HD for over a period of 1 year showed that for the patients in which itching was present at the initial assessment, in more than half of the cases the symptoms persisted until the end of the study. Those who developed itching during follow-up were more likely to experience depression, poor sleep, prolong recovery time after dialysis, and feeling faint or drained. These patients also rated their quality of life as poorer than those who did not experience itching. These findings emphasize the potential value of clinical detection of itching and the pursuit of effective treatments for patients receiving dialysis and experiencing these symptoms.[6]

Pruritus can have effects on the physical well-being in many different aspects. According to the severity it can promote sleep disturbances as CKD-aP is strongly linked to poor sleep quality. Studies indicate that 45% of patients with moderate to severe pruritus report disrupted sleep, leading to daytime fatigue and decreased vitality. This aspect can have serious influences on daily living and nurses need to be aware, assess and give support to cope with it. Moreover, persistent scratching can result in skin excoriations, increasing the risk of infections and further discomfort.[6]

When analysing the psychological impact that pruritus can have in patients who suffer from CKD-aP, the literature shows a notable correlation between pruritus severity and mental health issues such as depression and anxiety and the constant discomfort can lead to difficulties in concentration and cognitive function.[5,6]

In a large international cohort study, 47.9% of dialysis patients reported mild-to-severe CKD-aP. Increased CKD-aP severity was linked to lower physical and mental quality of life scores, higher use of antidepressants and antihistamines, more frequent missed dialysis sessions, and increased hospitalizations due to infections. Both mental and physical QoL scores were progressively lower as the severity of pruritus increased.[10] Pruritus can also have consequences on the dialysis adherence as severe itching has been associated with missed or shortened dialysis sessions, potentially compromising treatment efficacy.[7]

Since pruritus is a symptom that only patients themselves can report on, a patient-reported outcome measure (PROM) is required to evaluate the efficacy of any nursing intervention or new investigational treatment. Numerical Rating Scales (NRS) measuring worst itch intensity are commonly used in clinical trials and clinical practice. The use of validated and approved PROMs is vital for accurate assessment and effective management of patients with CKD-aP. Therefore, they should be incorporated into routine clinical care. A better understanding of the multiple pathophysiological mechanisms involved in CKD-aP needs to be combined with the latest advances in research into novel pharmacological therapies to create meaningful strategies to reduce the impact of CKD-aP on the quality of life of these patients.[8]

Quality of life, physical and mental well-being of patients who suffer from CKD-aP

The World Health Organization explains QoL as a subjective evaluation closely influenced by an individual’s perception of reality relative to their physical and psychological state, social relations and their relationship with the environment and their goals.[9]

CKD-aP is associated with significant psychological burden and many studies have shown that the prevalence of pruritus is high in HD patients. Moreover, suffering from pruritus significantly impairs their quality of life.[10] In Spain, a cross-sectional study involving 1,605 patients with advanced CKD found that 50.5% experienced pruritus, with 26.7% reporting moderate-to-severe symptoms. The itching often occurred throughout the body and was more intense at night, leading to sleep disturbances. As the severity of CKD-aP increased, patients reported greater mood changes, including feelings of depression and agitation, as well as impaired sexual function and desire.[11]

The assessment of Quality of Life (QoL) related to pruritus in individuals with CKD requires a step-by-step identification and exclusion of possible alternative or concomitant causes of itch. Several simple validated self-reported assessment scales are available to evaluate the presence and severity of the itch in a time-efficient manner, making them suitable for use in everyday clinical practice. Also, the assessment is crucial for all health care professionals and identifying the right instrument is key in order to design the right interventions and to ensure patient follow-up.

A range of objective and reliable instruments exist such as 5-D Itch questionnaire[12], Itch Severity Scale (ISS)[13] and Kidney Disease Quality of Life scale (KDQOL)[14] 36-item short-form health survey[15]. Some studies have shown that using 1 simple item question about the extent to which patients are bothered by itchy skin can be a feasible and efficient method for the routine assessment of pruritus and its impact on quality of life.[16] Among the multidimensional tools, the Skindex-10 multidimensional Quality of Life instrument is widely used in research. Its brevity, multidimensional scope, and ease of use support its integration into routine nursing assessments of pruritus and impact on QoL of patients with CKD. The instrument has 10 items questions that assess the “degree of bother”.[17] Another useful scale is The Worst Itching Intensity Numerical Rating Scale (WI-NRS) which it is a single-item patient-reported outcome measure in which patients indicate the intensity of the worst itching they experienced over the past 24 hours. The WI-NRS is a reliable, valid, and responsive measure of itch intensity for patients with moderate-to severe CKD-aP.[18]

The FDA’s Patient-Focused Drug Development Guidance suggests the use of mixed methods (quantitative and qualitative) to triangulate on defining meaningful within-patient change thresholds for clinical outcome assessments (COA).[19]

An emerging approach for evaluating meaningful within-patient change thresholds for COAs is to survey or interview patients to ascertain their experience of treatment, whether the change they experienced was meaningful, and to gather further interpretation of score changes on administered COA endpoints.[20] All of these measures give support to assess treatment efficacy, clinical evaluation and management of pruritus in CKD patients in order to improve quality of life, physical and mental wellbeing.

Nursing management aspects to achieve a better quality of life to patients who suffer from CKD associated pruritus

Dialysis nurses are in a unique position to identify effective strategies in clinical practice and lead the management of symptom burden experienced by patients with CKD-aP. Nurses can support and encourage patients with CKD-aP not only to talk about their symptoms but to cope with the complexity of condition and its impact.

Effective nursing management in patients with CKD-aP is crucial for improving clinical outcomes and enhancing quality of life. This involves a comprehensive approach that includes skin care, symptom assessment, patient education, and collaboration with the healthcare team.

Understanding that the pathogenesis of pruritus in CKD is multifactorial will help the health care team to manage and ensure appropriate clinical attention.[21] Symptom assessment should be a standard intervention for all healthcare professionals involved in the care of individuals with CKD. Regular assessment not only reduces symptom burden and distress but also supports more effective management and informed decision-making by both patients and their families or caregivers.

The following aspects are crucial for better care for patients with CKD-aP and fall within the renal nursing practice.

1- Symptom Assessment and Monitoring

Regular Assessment: Use validated tools to regularly assess, report and manage pruritus in patients.

Documentation: Keep detailed records of itch severity, skin condition, and the effectiveness of interventions to guide ongoing care.

2- Nursing Assessment and Monitoring

Pruritus Evaluation: Regular assessment for the presence, intensity, and impact of itching on the patient's quality of life. Document any changes and responses to interventions.

Skin Integrity: Monitor for signs of skin damage due to scratching, such as excoriations or infections. Encourage patients to report new or worsening symptoms.

Laboratory Values: Keep track of serum phosphorus, calcium, and parathyroid hormone levels, as imbalances can exacerbate pruritus.

3- Skin Care and Comfort Measures

Gentle Skin Care and Bathing Practices: Gentle skin care is essential for preventing further irritation and dryness in patients with CKD-aP. Advise patients to use mild, non-alkaline, fragrance-free soaps and to limit bathing to lukewarm water for no more than 20 minutes. After bathing, the skin should be gently patted dry rather than rubbed, and unscented moisturisers should be applied immediately to help maintain skin hydration and barrier function.[22,23]

Moisturizers: Regular application of emollients with high water content can alleviate dry skin and reduce itching and combat xerosis (dry skin). Products containing glycerol and paraffin have shown effectiveness in CKD-aP patients.[24]

Clothing and Environment: Encourage wearing loose-fitting, cotton garments to minimise skin irritation. Maintain a cool, humidified environment to prevent skin dryness.[23]

4- Patient Education and Behavioural Strategies

Avoid Scratching: Educate patients on the importance of minimising scratching to prevent skin damage. Suggest alternatives like applying cool compresses to itchy areas.

Nail Care: Advise keeping fingernails short and consider the use of gloves during sleep to reduce the risk of skin injury from scratching.

Dietary Guidance: Collaborate with dietitians to manage dietary phosphate intake, as elevated phosphate levels may exacerbate pruritus.

Sleep Hygiene: Address sleep disturbances caused by itching through patient education on sleep hygiene practices and, if necessary, the use of pharmacological aids.[25]

5- Dietary and Lifestyle Modifications

Phosphorus Management: Collaborate with dietitians to help patients adhere to low-phosphorus diets and consider phosphate binders as prescribed. Controlling phosphorus may not be sufficient to fully address pruritus but is important to ensure proper absorption to prevent bone disease and reduce cardiovascular risk.[26]

Hydration: Encourage adequate fluid intake within the limits set for each patient, as proper hydration can improve skin condition.

Stress Reduction: Suggest relaxation techniques and stress management strategies, as psychological stress can worsen itching sensations.

6- Pharmacological Interventions

Antihistamines: While commonly used, antihistamines may offer limited relief of CKD-aP and are not recommended by current guidelines. They may be considered for their sedative properties, which can help improve sleep in some patients.[27]

Gabapentinoids: Medications such as gabapentin and pregabalin have shown efficacy in reducing pruritus intensity in individuals with CKD. Moreover, most of them are off-label and their side effects may limit the use in CKD-aP taking into consideration neurological events, weight gain, angio-oedema and increase risk of alls and fractures.[28]

New specific therapies: Drugs like difelikefalin have been demonstrated efficacy as targeted treatments for CKD-aP, offering promising option for symptom relief as well as improving the quality of life.[26]

7- Collaboration with Healthcare Team

Medication Management: Collaborate with physicians to manage medications that may alleviate pruritus, such as difelikefalin, gabapentin or pregabalin, which have proven effective in reducing itch intensity. While gabapentin has demonstrated effectiveness in reducing itch intensity, its use may be associated with side effects such as dizziness, sedation, or fatigue, and they require careful dose adjustment based on renal function. Both gabapentin and pregabalin are not specifically approved for CKD-aP in Europe but are sometimes used off-label in clinical practice.

Phototherapy: In cases where pruritus is severe and unresponsive to other treatments, phototherapy with ultraviolet B (UVB) light may be considered under specialist guidance.[29]

Psychosocial Support: Recognise the psychological impact of chronic pruritus and refer patients to counselling services when appropriate to address issues like anxiety or depression.

Multidisciplinary Approach: Engage a team that includes nurses, nephrologists, dermatologists, dietitians, and mental health professionals to provide comprehensive care.

Conclusion

A comprehensive care model that addresses physical, psychological, and social dimensions and that extends beyond medical treatment, is crucial for improving the quality of life for HD patients.

CKD-associated pruritus is a common and debilitating condition that significantly impairs the physical and mental well-being of patients. Addressing this symptom is a challenge for improving the overall quality of life and health outcomes in individuals with chronic kidney disease, where nurses can make a significant contribution.

References

1. Parfrey PS, Vavasour HM, Henry S, Bullock M, Gault MH. Clinical features and severity of nonspecific symptoms in dialysis patients. Nephron [Internet]. 1988;50(2):121-8. Disponible a: https://pubmed.ncbi.nlm.nih.gov/3065660/
2. Barrett BJ, Vavasour HM, Major A, Parfrey PS. Clinical and psychological correlates of somatic symptoms in patients on dialysis. Nephron. 1990;55(1):10-5.
3. Hu X, Sang Y, Yang M, Chen X, Tang W. Prevalence of chronic kidney disease-associated pruritus among adult dialysis patients: A meta-analysis of cross-sectional studies. Medicine (Baltimore) [Internet]. maig 2018 [citat 6 maig 2025];97(21):e10633. Disponible a: https://journals.lww.com/00005792-201805250-00015

4. Zucker I, Yosipovitch G, David M, Gafter U, Boner G. Prevalence and characterization of uremic pruritus in patients undergoing hemodialysis: uremic pruritus is still a major problem for patients with end-stage renal disease. J Am Acad Dermatol [Internet]. novembre 2003 [citat 6 maig 2025];49(5):842-6. Disponible a: https://linkinghub.elsevier.com/retrieve/pii/S0190962203024782
5. Sukul N, Karaboyas A, Csomor PA, Schaufler T, Wen W, Menzaghi F, et al. Self-reported Pruritus and Clinical, Dialysis-Related, and Patient-Reported Outcomes in Hemodialysis Patients. Kidney Med [Internet]. gener 2021 [citat 7 maig 2025];3(1):42-53.e1. Disponible a: https://linkinghub.elsevier.com/retrieve/pii/S2590059520302314
6. Sukul N, Zhao J, Pisoni RL, Walpen S, Schaufler T, Asgari E, et al. Pruritus in Hemodialysis Patients: Longitudinal Associations With Clinical and Patient-Reported Outcomes. Am J Kidney Dis [Internet]. desembre 2023 [citat 7 maig 2025];82(6):666-76. Disponible a: https://linkinghub.elsevier.com/retrieve/pii/S0272638623007291
7. Thompson J, Kammerer J, Boshears T, Oliveira J, Johansen KL, Kovar A, et al. Chronic Kidney Disease-Associated Pruritus Burden: A Patient Survey Study. Kidney Med [Internet]. novembre 2024 [citat 14 maig 2025];6(11):100900. Disponible a: https://linkinghub.elsevier.com/retrieve/pii/S2590059524001110
8. Esteve-Simó V, Perez-Morales R, Buades-Fuster JM, Arenas Jimenez MD, Areste-Fosalba N, Alcalde Bezhold G, et al. Chronic Kidney Disease–Associated Pruritus and Quality of Life: Learning from Our Patients. J Clin Med [Internet]. 5 juliol 2023 [citat 7 maig 2025];12(13):4505. Disponible a: https://www.mdpi.com/2077-0383/12/13/4505
9. Development of the World Health Organization WHOQOL-BREF quality of life assessment. WHOQOL Group Psychol Med. 1998;(28):551-558.
10. Xie Q, Hu N, Chen Y. Chronic kidney disease-associated pruritus significantly impacts on quality of life of patients on haemodialysis and associates with increased levels of serum calcium and phosphorus. Postgrad Med J [Internet]. 1 juliol 2022 [citat 6 maig 2025];98(1161):e16-e16. Disponible a: https://academic.oup.com/pmj/article/98/1161/e16/6959181
11. Aresté N, Sanchez-Alvarez JE, Prieto-Velasco M, Molina P, Esteve-Simó V, Ojeda R, et al. Prevalence and severity of pruritus in Spanish patients with chronic kidney disease and impact on quality of life: a cross-sectional study. Clin Kidney J [Internet]. 31 maig 2023 [citat 7 maig 2025];16(6):1035-7. Disponible a: https://academic.oup.com/ckj/article/16/6/1035/7085006
12. Elman S, Hynan LS, Gabriel V, Mayo MJ. The 5-D itch scale: a new measure of pruritus: The 5-D itch scale. Br J Dermatol [Internet]. març 2010 [citat 9 maig 2025];162(3):587-93. Disponible a: https://academic.oup.com/bjd/article/162/3/587/6642582
13. C.J. Majeski, J.A. Johnson, S.N. Davison, G.J. Lauzon. Itch Severity Scale: a self-report instrument for the measurement of pruritus severity. British Journal of Dermatology. 1 abril 2007;156(4):667-73.

14. Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB. Development of the kidney disease quality of life (KDQOL) instrument. Qual Life Res. 1994;3(5):329-38.
15. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992;30(6):473-83.
16. Manenti L, Leuci E. Do you feel itchy? A guide towards diagnosis and measurement of chronic kidney disease-associated pruritus in dialysis patients. Clin Kidney J [Internet]. 24 desembre 2021 [citat 9 maig 2025];14(Supplement_3):i8-15. Disponible a: https://academic.oup.com/ckj/article/14/Supplement_3/i8/6482000
17. Lopes MB, Karaboyas A, Sukul N, Tsuruya K, Al Salmi I, Asgari E, et al. Utility of a Single Itch-Related Question and the Skindex-10 Questionnaire for Assessing Pruritus and Predicting Health-Related Quality of Life in Patients Receiving Hemodialysis. Kidney Med [Internet]. juny 2022 [citat 8 maig 2025];4(6):100476. Disponible a: https://linkinghub.elsevier.com/retrieve/pii/S2590059522000905
18. Vernon MK, Swett LL, Speck RM, Munera C, Spencer RH, Wen W, et al. Psychometric validation and meaningful change thresholds of the Worst Itching Intensity Numerical Rating Scale for assessing itch in patients with chronic kidney disease-associated pruritus. J Patient-Rep Outcomes [Internet]. desembre 2021 [citat 14 maig 2025];5(1):134. Disponible a: https://jpro.springeropen.com/articles/10.1186/s41687-021-00404-z
19. Patient-Focused Drug Development: Collecting Comprehensive and Representative Input. 2020;
20. Staunton H, Willgoss T, Nelsen L, Burbridge C, Sully K, Rofail D, et al. An overview of using qualitative techniques to explore and define estimates of clinically important change on clinical outcome assessments. J Patient-Rep Outcomes [Internet]. desembre 2019 [citat 14 maig 2025];3(1):16. Disponible a: https://jpro.springeropen.com/articles/10.1186/s41687-019-0100-y
21. Shirazian S, Aina O, Park Y, Chowdhury N, Leger K, Hou L, et al. Chronic kidney disease-associated pruritus: impact on quality of life and current management challenges. Int J Nephrol Renov Dis [Internet]. gener 2017 [citat 8 maig 2025];Volume 10:11-26. Disponible a: https://www.dovepress.com/chronic-kidney-disease-associated-pruritus-impact-on-quality-of-life-a-peer-reviewed-article-IJNRD
22. Krismi A, Danarti R, Setiabudi IIDPP, Wirohadidjojo YW. Chronic kidney disease-associated pruritus in patients undergoing hemodialysis: Xerosis and topical therapy. Hemodial Int [Internet]. abril 2023 [citat 8 maig 2025];27(2):91-104. Disponible a: https://onlinelibrary.wiley.com/doi/10.1111/hdi.13071
23. Manuel Buades J, Figueras-Nart I, Goicoechea M, Sánchez Villanueva RJ, Serra-Baldrich E. Information and consensus document for the diagnostic and therapeutic management of pruritus associated with chronic kidney disease in patients on haemodialysis in Spain. Nefrol Engl Ed [Internet]. juliol 2024 [citat 8 maig 2025];44(4):465-74. Disponible a: https://linkinghub.elsevier.com/retrieve/pii/S2013251424001342

24. Agarwal P, Garg V, Karagaiah P, Szepietowski JC, Grabbe S, Goldust M. Chronic Kidney Disease-Associated Pruritus. Toxins [Internet]. 28 juliol 2021 [citat 8 maig 2025];13(8):527. Disponible a: https://www.mdpi.com/2072-6651/13/8/527
25. Rehman IU, Chohan TA, Bukhsh A, Khan TM. Impact of Pruritus on Sleep Quality of Hemodialysis Patients: A Systematic Review and Meta-Analysis. Medicina (Mex) [Internet]. 17 octubre 2019 [citat 8 maig 2025];55(10):699. Disponible a: https://www.mdpi.com/1648-9144/55/10/699
26. Fishbane, Steven N., et al. Pruritus severity and serum phosphate in CKD: a post Hoc analysis of difelikefalin studies. Kidney360. 2024;10-34067.
27. Makar, Maria, Brendan Smyth, and Frank Brennan. Chronic kidney disease-associated pruritus: a review. Kidney and Blood Pressure Research. 2021;46.6:659-69.
28. Verduzco, Hector Alvarado, and Shayan Shirazian. CKD-associated pruritus: new insights into diagnosis, pathogenesis, and management. Kidney International Reports. 2020;5.9:1387-402.
29. Frazier W, Bhardwaj N. Atopic Dermatitis: Diagnosis and Treatment. ATOPIC Dermat. 2020;101(10).

Chapter 3

CKD-associated Pruritus (CKD-aP) and Communication

Learning objectives:

- To understand the effects of communication skills to an effective dialogue and quality of
- To identify and describe common barriers to effective communication in people with chronic kidney disease associated Pruritus and nurses
- To explain the impact of underreporting chronic kidney disease associated Pruritus on people’s well-being
- To describe how effective communication strategies can validate and uncover individual’s concerns regarding chronic kidney disease associated pruritus

Introduction

Chronic Kidney Disease associated Pruritus (CKD- aP) affects many people diagnosed with CKD or who are on maintenance haemodialysis (HD) treatment. Research from Dialysis Outcomes and Practice Patterns Study (DOPPS) indicate that around 42% of people on HD suffer either moderate or severe pruritus.[1] However, other studies show that the number of people on HD who suffer from pruritus is as high as 87%.[2] This indicates that a significant number of people with CKD - on a continuum of severe symptoms to mild - suffer to some degree or other with this condition.

Depending on the severity experienced by people with CKD the impact on the individual will vary from person to person. Studies show that CKD-aP reduces the Quality of Life (QoL) of those with CKD.[3] The condition affects sleep quality, can limit social functioning, can contribute to feelings of loss of independence, is associated with both non-adherence and depression and increased mortality and in some cases can lead to withdrawal from HD.[3,4,5] A study of people with CKD-aP in the United States on HD showed that many suffered severe distress and believed that the condition affected both their psychological and emotional wellbeing.[6]

As this condition significantly impacts on the QoL of people with CKD it would be expected that questions would be routinely raised or discussed at clinic appointments or when those with CKD attend their HD unit for treatment. Yet research shows this is not the case.

A study in seventeen countries showed that only 20% of people with CKD for whom the condition was an issue mentioned it when attending clinic or at their HD unit.[7] Furthermore, research shows that there is an underreporting of CKD-aP.[4]

On the one hand people with CKD who have symptoms of pruritus often do not report it. On the other, nurses or the medical team, in many cases, do not raise it. If this is put within the parameters of communication, it suggests some work needs to be done to ensure that clear communication is achieved between the person with CKD and their medical team about this condition.

The focus of this chapter is to allow for the development of a communication skill set for nurses so that they have the confidence and competence to engage those with CKD-aP in conversation about their symptoms and the impact it has on their life. The intention is to highlight some of the more essential skills required for effective communication. Also, to consider how structures and attitudes create barriers to good communication.

Good Communication Skills

Why good communication is important?

Good and effective communication is essential when working with people with CKD. Why? The purpose of effective communication is to ensure that optimal health outcomes are achieved, that uncertainty is reduced, that the person with CKD can engage in the decision-making process, that any threat to adherence is reduced, ensuring that the person with CKD is cared for medically, socially and psychologically.[8]

Building blocks to good communication

Communication is never straightforward, is often complex and is influenced by a number of factors.[9] In essence, communication is a dialogue between a nurse and a person with CKD.[10] To achieve effective communication, necessary qualities include; active and emphatic listening, ability to impart information in an appropriate way, use different means of communication, be prepared to answer questions to enhance understanding, and give space for the person with CKD to ask questions or express an opinion.

How can the nurse employ these communication skills to those with CKD-aP?

1. Each person is an individual

Recognise that each person is an individual with their own perceptions, outlook on life and needs. Each person will have an individual ‘take’ on their illness, that is, they will perceive their illness in a way that conforms to the way they view themselves in the world.[11] As research shows a diagnosis of a chronic condition like CKD has significant effects on the person’s capacity to function, introduces social changes and also emotional and psychological stress that requires the person to make adjustments and to employ a variety of coping skills.[12]

This significant change in a person’s life will have an impact on their capacity to communicate and their ability to receive communication. How a person views themselves, the confidence they have in themselves and how they view their place in the world diminishes when diagnosed with or on treatment for a chronic condition. This loss of confidence contributes to their difficulty in expressing themselves and in their capacity in receiving and retaining information.[13]

If good communication is to be achieved then it is vital that nurses acknowledge that caring for people with CKD-aP, requires sensitivity to the needs of the person, awareness of the ways the person is coping with their condition, acknowledgement that the trajectory of treatment is not always smooth and with the ability construct ways of communication that reflect empathy and understanding of the person’s needs.

2. The influence of culture and language

Many HD and nephrology units are staffed by nurses from a variety of cultural and linguistic backgrounds. Similarly, people with CKD come from a diverse number of cultures. This mixture is going to heavily influence the ‘how’ and the ‘way’ of communication.

Nurses, therefore, must never underestimate the importance of culture and language. As research by Lambert *et al* shows, ‘cultural beliefs around health and illness contribute to an individual's ability to understand and act on a health care provider's instructions’.[14] Culture plays an important part in an individual’s self-image and how people are seen within a particular culture. As Gropper points out ‘misunderstandings predicated on implicit cultural assumptions are a frequent potential hazard’.[15] As such, sensitivity in this area is of primary importance. People with CKD-aP, may, for a variety of reasons be unwilling to discuss their condition. It is important for the nurse to keep in mind if any cultural factors are at play that inhibit the person addressing their condition.

Within a cultural context language plays an important part. It is through language that communication is made and that understanding is achieved. As research from Canada shows, language and culture play a significant part in a person with CKD’s ability to understand, evaluate and communicate health information.[16] Nurses should take this into account when communicating with people with CKD-aP. Appropriate methods should be employed, for example using an interpreter, when imparting health information or in listening to the concerns of the person with CKD.[13] Failure to consider this presents a ‘potential hazard’[14] to communicating effectively and clearly.

3. Be prepared

In communicating with a person with CKD-aP preparation is important. Preparation includes:[17]

- Being clear about what is to be communicated.
- Having in mind a variety of methods of communication, for example, verbal and/or visual, written or the use of an interpreter.
- Sensitivity as to when and where the communication takes place. For example, if communication is to take place somewhere the nurse will be distracted or interrupted, then thought should be given to moving it to a place where distraction and interruption is unlikely.
- Sensitivity to the culture and language of the person. Avoid jargon as it can lead to misunderstanding.
- Repeat the key points as this aids the person’s understanding.
- Awareness of when is an appropriate time to end the communication.

4. Listen Attentively

Listening is a key component of good communication. Listening attentively includes:[17,18]

- Acknowledging what the person with CKD-aP is saying.
- Maintaining good eye contact.
- Giving the person with CKD-aP enough time to say what they wish to say.
- Be sensitive to the person's non-verbal communication. In this context the nurse needs to be aware of their own non-verbal cues as well.
- Avoid any distraction.
- Use any moments of silence to think about what the person is communicating.
- Ask questions if further understanding or clarification is required. Reflect back what is heard to ensure the meaning is understood.

5. Sensitivity to the person with CKD-aP

- Know the person with CKD. Be aware of any difficulties they may have in communicating especially in relation to CKD-aP as they may feel embarrassed about their itching.
- Be empathetic which means being able to view the world from the perspective of the person with CKD-aP. Included here may be issues around QoL, treatment in relation to CKD-aP, which the nurse may be unaware of.
- Accept the person with CKD-aP as they are, showing understanding and compassion even when certain behaviours or personality traits may be challenging.

6. Be proactive

Research and studies show that CKD-aP is underreported. With this knowledge the nurse can watch for any physical signs that the person has the condition. Also, it would seem appropriate given the extent of this condition to ask the question, 'is this an issue for you'?

This can result in alerting the person with CKD to their condition, bring relief to those who have the condition but have failed, for whatever reason, to report it and allow for whatever form of treatment to be offered to the person with CKD-aP.

7. Impact on QoL

Illness affects QoL. Because of this, people with CKD-aP can have difficulty communicating with either their nurse or medical team. A compromised QoL can be a barrier to communicating with others. Awareness of this simple yet significant obstacle can allow the nurse to tailor their approach and communication style accordingly.

Barriers to Effective Communication

One of the barriers to effective communication can be the health care institution and the health care system itself. Issues such as high workload and staff shortages can create barriers to effective communication. A 2019 study identified the following characteristics that impede effective communication: 'lack of knowledge, all-knowing attitude, work overload and dissatisfaction'.[19] Studies show that if communication is poor between nurses and people who are ill - be they those with CKD or not - it affects care outcomes and impacts on care quality.[18]

Outlined here are some of the more common barriers that can impede communication and it is prudent to be alert to them.

1. Staff shortages

According to the World Health Organisation (WHO) there is a global shortage of health workers, especially nurses.[20] Many nephrology departments have difficulty recruiting staff leading to staff shortages. Staff shortages mean less time with people with CKD, a higher workload and burnout.[21]

Staff shortages with the subsequent increase in workload can be a contributing factor in HD nurses experiencing burnout. A study in China found that burnout – reflected in high levels of emotional exhaustion and lack of personal accomplishment - created a further barrier to communication and was a factor is HD nurses leaving the profession.[22]

A study from an Iranian Intensive Care unit found that increased workload due to staff shortages resulted in nurses having less time with individuals thereby creating a barrier to good and effective communication.[21] Clinics and HD units are busy places. Staff shortages result in an increase in workload. Less time means fewer interactions with people with CKD, less time to listen to the person's concerns. This leads to poor communication which has a detrimental effect on quality of care. Studies have also shown that a combination of a heavy workload, staff shortages and limited time can cause in nurses a sense of despair, emotional detachment and loss of interest in their work. The consequence of this is poor interaction and communication.[21]

2. Miscommunication

Giving accurate factual information is important. Lack of time influences the way information is communicated, is often rushed, leading to the possibility of miscommunication. Additionally, less time may not allow the nurse to check whether the information communicated has been heard as intended.

Another important factor in miscommunication are cultural or language barriers. Nurses and people with CKD may come from different cultures, speak different languages and may have particular views about illness.[22] Various studies show that language barriers make communication more difficult leading to the possibility of miscommunication and misunderstanding.[24,25]

3. Environmental Barriers

The environment in which care takes place influences communication between nurses and those with CKD. An article written by Kwame and Petrucka concluded that 'environment related barriers are obstacles within the care setting that inhibit nurse-patient interaction and communication'.[26] The article goes on to list a number of obstacles, for example, a noisy environment and a lack of privacy. These and other factors prevent people expressing their healthcare needs. Another study showed that a noisy environment led to the person experiencing psychological stress thereby affecting their capacity to communicate.[27]

4. All knowing attitude

This occurs when the nurse believes they know what is best for the person with CKD without interacting or communicating with them. As the nurse believes they know what is best they fail to listen.[27]

Failure to listen removes the opportunity for the person with CKD-aP to express their concerns or ask questions about symptoms that concern them.

5. Culture and Language

Reading correctly non-verbal communication contributes to the nurses understanding and insight into the person's feelings and concerns. However, within the context of culture, non-verbal communication can invoke different meanings and interpretation which leads to communication mistakes.[28]

Language plays an important part in communication. Special care must be taken when communicating with someone whose first language is different. In this regard avoid using specialist language or jargon and consider using interpreters.

6. Cognitive ability of the person with CKD

Another common communication mistake is to assume the person with CKD-aP has the capacity to communicate clearly or articulate what their concerns are. It is unwise to assume the person has the cognitive ability and skill to communicate clearly.

7. Underreporting of CKD-aP

As has been noted earlier CKD-aP impacts upon QoL, can lead to depression, and increased mortality.[4] What is clear from many studies is that this condition goes underreported. This failure of either the person with CKD-aP to bring it up or staff failing to suggest it might be an issue creates a communication barrier.

The 'why' of underreporting includes; failure of the person with CKD-aP to mention it, the condition is not 'active' when the person attends clinic or HD, an assumption that it is just part of CKD, an assumption that nothing can be done about it, a lack of awareness of the association between pruritus and CKD, the assumption that as the nurse or nephrologist has not mentioned it, it is not considered a problem.[4,28]

These factors in underreporting suggest that the present model of clinical practice is not working as it fails to identify and treat many of those with CKD-aP.[4] And, as it is an underreported condition, it has significant adverse health outcomes.

Recommendation for practice

- What does this mean for practice? There may be many reasons why those with CKD-aP do not talk about their symptoms. Nurses, however, are tasked to be proactive and encourage them to speak about their symptoms. Two key factors in achieving this are; creating a safe space for the person with CKD-aP, and good communication skills.
- Some may be reluctant to talk about the condition out of embarrassment and suffer in silence. Questions, phrased sensitively, can open the conversation and lead to a more in-depth discussion on how CKD-aP is affecting the person. One way is to address aspects of their life, for example, their interaction with others (family, friends), or a question regarding their sleep pattern.
- Nurses need to be conscious of where the discussion about CKD-aP with the person takes place. At the person's bedside in a HD unit may not be the most appropriate place to discuss the issue. A consultation room, away from others, may create the safe place the person with CKD-aP needs to open the conversation.
- Noticing scratches on the skin or other indicators which point to CKD-aP should not be ignored but addressed. A simple question, for example, "what are these scratches from?" can allow for a conversation to take place.
- Nurses spend more face-to-face time with their patients than other health care professionals. Good communication skills allow for a sensitivity of approach especially regarding a condition that can be difficult and embarrassing to discuss.

Conclusion

Nurses have a unique relationship of trust and familiarity with those they care for. Their regular in a prime position to ask the question – *is CKD-aP an issue for you?* Asking this and other relevant questions allows for greater awareness of the condition, gives permission for the person with the condition to discuss it and offers the possibility of employing effective treatments. As a condition it remains under-recognised, underreported and under treated. The key to changing this, among others, is effective communication between nurses and patients and optimum communication within the nephrology care team for which nurses remain the main communication channel. Nurses, therefore, are uniquely placed to acknowledge, discuss, offer support to those who are living with CKD-aP in order to have an effective communication and therefore give the patients the opportunity to manage and cope better with their complex clinical condition.

References

1. Ronald L. Pisoni, Björn Wikström, Stacey J. Elder, Tadao Akizawa, Yashushi Asano, Marcia L. Keen, et al. Pruritus in haemodialysis patients: international results from the Dialysis Outcomes and Practice Patterns Study (DOPPS), Nephrology Dialysis Transplantation, Volume 21, Issue 12, December 2006, Pages 3495–3505, https://doi.org/10.1093/ndt/gfl461
2. Amatya B, Agrawal S, Dhali T, Sharma S, Pandey SS. Pattern of skin and nail changes in chronic renal failure in Nepal: a hospital-based study. J Dermatol. 2008;35:140-145. 11. Mettang T, Kremer AE. Uremic pruritus. Kidney Int. 2015;87
3. Aresi G, Rayner HC, Hassan L, Burton JO, Mitra S, Sanders C, van der Veer SN. Reasons for Underreporting of Uremic Pruritus in People With Chronic Kidney Disease: A Qualitative Study. J Pain Symptom Manage. 2019 Oct;58(4):578-586.e2. doi: 10.1016/j.jpainsymman.2019.06.010.
4. Rayner HC, Larkina M, Wang M, Graham-Brown M, van der Veer SN, Ecder T, Hasegawa T, et al. International Comparisons of Prevalence, Awareness, and Treatment of Pruritus in People on Haemodialysis. Clin J Am Soc Nephrol. 2017 Dec 7;12(12):2000-2007. doi: 10.2215/CJN.03280317.
5. Thompson, J., Kammerer, J., Boshears, T., Oliveira, J., Johansen, K. L., Kovar, A., Lee, L., & Yosipovitch, G. (2024). Chronic Kidney Disease Associated Pruritus Burden: A patient Survey study. Kidney Medicine, 6(11), 100900. https://doi.org/10.1016/j.xkme.2024.100900
6. Menzaghi F, Vernon MK, Mattera M, Cirulli J, Wen W, Spencer RH, et al. The Burden of Pruritus Associated With CKD: A Mixed Methods Analysis Among Patients Undergoing Dialysis. Kidney Med. 2023 Jul 1;5(9):100696. doi: 10.1016/j.xkme.2023.100696.
7. Jennifer E Flythe, Adeline Dorough, Julia H Narendra, Derek Forfang, Lori Hartwell, Emaad Abdel-Rahman. Perspectives on symptom experiences and symptom reporting among individuals on haemodialysis, Nephrology Dialysis Transplantation, Volume 33, Issue 10, October 2018, Pages 1842–1852, https://doi.org/10.1093/ndt/gfy069
8. Henly SJ. Health communication research for nursing science and practice. Nurs Res

9. Bello P. Effective communication in nursing practice: A literature review. BSc Nursing Thesis. Arcada; 2017. Available at https://core.ac.uk/download/pdf/84798372.pdf .
10. Boykins AD. Core communication competences in patient-centred care. The ABNF J. 2014 Apr 1;25(2):40 – 5.
11. Nichols KA. Psychological Care in Physical Illness - 2nd Edition. Chapman and Hall. London; 1993.
12. Schulz, K, Kroencke S. Psychosocial challenges before and after organ transplantation. Volume 2015:7 Pages 45—58. DOI https://doi.org/10.2147?TRRM.S53107
13. Campling F, Sharpe M. Living with Long-Term Illness - the facts. Oxford University Press Oxford; 2006.
14. Lambert S, Loban E, Li J, Nghiem T, Schaffler J, Maheu C, et al. Chronic Illness Management in Culturally and Linguistically Diverse Patients: Exploring the Needs, Access, and Understanding of Information. Qual Health Res. 2021 Nov;31(13):2426-2439. doi: 10.1177/10497323211040769.
15. Gropper, R. C. Cultural Basics and Chronic Illness. IN Advances in Renal Replacement Therapy. Volume 5, Issue 2 https://doi.org/10.1016/S1073-4449(98)70006-8
16. Hoffman-Goetz L., Donelle L., Ahmed R. Health literacy in Canada: A primer for students. Canadian Scholars' Press Inc. 2014
17. Fortnum, D (Ed), Kelly, M, Larkin, A. The Art of Communication – A Nurses Guide To Implementing Best Practice In Communication. EDTNA/ERCA. 2017
18. McCabe C. Nurse-patient communication: An exploration of patients' experiences. J Clin Nurs. 2004 Jan;13(1):41–9.
19. Ronald L. Pisoni, Björn Wikström, Stacey J. Elder, Tadao Akizawa, Yashushi Asano, Marcia L. Keen, et al. Pruritus in haemodialysis patients: international results from the Dialysis Outcomes and Practice Patterns Study (DOPPS), Nephrology Dialysis Transplantation, Volume 21, Issue 12, December 2006, https://doi.org/10.1093/ndt/gfl461
20. Boniol M, Kunjumen T, Nair TS, et al. The global health workforce stock and distribution in 2020 and 2030: a threat to equity and 'universal' health coverage? BMJ Global Health 2022;7:e009316.
21. Al-Kalaldeh M, Amro N, Qtait M. Barriers to effective nurse-patient communication in the emergency department. Emerg Nurse. 2021 Mar 2;29(2). doi: https://doi.org/10.7748/en.2020.e1969.
22. Guo W, Zhou L, Song L, Zhang G, Zhong M, Sun C, et al. Hemodialysis nurse burnout in 31 provinces in mainland China: A cross-sectional survey. Hemodial Int. 2021 Mar 21. doi: https://doi.org/10.1111/hdi.12926
23. Ruben BD. Communication theory and health communication practice: The more things change, the more they stay the same. Health Commun. 2016 Jan 2;31(1):1–11. doi:https://doi.org/10.1080/10410236.2014.923086.
24. Norouzinia R, Aghabarari M, Shiri M, Karimi M, Samami E. Communication barriers perceived by nurses and patients. Glob J Health Sci. 2016 Jun;8(6):65–4 https://doi.org/10.5539/gjhs.v8n6p65.

25. Loghmani L, Borhani F, Abbaszadeh A. Factors affecting the nurse-patients' family communication in intensive care unit of Kerman: A qualitative study. J Caring Sci. 2014 Mar;3(1):67–2. doi:https://doi.org/10.5681/jcs.2014.008.
26. Kwame, A., Petrucka, P.M. A literature-based study of patient-centred care and communication in nurse-patient interactions: barriers, facilitators, and the way forward. BMC Nurs 20, 158 (2021). https://doi.org/10.1186/s12912-021-00684-2
27. Amoah KMV, Anokye R, Boakye SD, Acheampong E, Budu-Ainooson A, Okyere E, Kumi-Boateng G, Yeboah C, Afriyie OJ. A qualitative assessment of perceived barriers to effective therapeutic communication among nurses and patients. BMC Nurs. 2019 Dec;18(4)1–8. https://doi.org/10.1186/s12912-019-0328-0.
28. Ruben BD. Communication theory and health communication practice: The more things change, the more they stay the same. Health Commun. 2016 Jan 2;31(1):1–11. doi:https://doi.org/10.1080/10410236.2014.923086.
29. Sukul N, Karaboyas A, Csomor PA, Schaufler T, Wen W, Menzaghi F, Rayner HC, Hasegawa T, Al Salmi I, Al-Ghamdi SMG, Guebre-Egziabher F, Ureña-Torres PA, Pisoni RL. Self-reported Pruritus and Clinical, Dialysis-Related, and Patient-Reported Outcomes in Haemodialysis Patients. Kidney Med. 2020 Nov 21;3(1):42-53.e1. doi: 10.1016/j.xkme.2020.08.011.

Chapter 4

CKD-associated Pruritus (CKD-aP): assessment tools and evidence-based interventions

Learning objectives

- To describe different pruritus assessment tools and apply them effectively to evaluate itch severity and impact on quality of life (QoL) in individuals with CKD-aP
- To evaluate the efficacy, limitations and clinical application of pharmacological and non-pharmacological interventions in the management of CKD-aP
- To integrate appropriate pruritus assessment scales with evidence-based interventions to optimise symptom control and enhance QoL in individuals with CKD-aP

Introduction

Chronic Kidney Disease-associated Pruritus (CKD-aP) is a frequently underreported yet burdensome condition that significantly impacts affected individuals, compromising their Quality of Life (QoL), mental health, and engagement in treatment.[1,2] The subjective nature of CKD-aP and the absence of standardised assessment tools make its identification challenging[3], often leading to inadequate management. This reinforces the need for effective assessment and intervention strategies.

Although no single gold-standard tool exists for assessing CKD-aP, several validated pruritus scales are available. A comprehensive approach that combines pruritus severity scales with QoL measures would ensure a holistic evaluation, enabling individualised treatment strategies. Additionally, considering pharmacologic treatment along with non-pharmacologic interventions is essential for addressing the multifaceted nature of CKD-aP and improving patient outcomes. This chapter provides a review of assessment tools and evidence-based management strategies, offering healthcare professionals and nurses practical guidance to optimise CKD-aP management and improve QoL of people with CKD-aP.

Importance of assessing CKD-aP

In the absence of objective diagnostic biomarkers, CKD-aP is primarily identified through clinical skin examination and patient-reported symptoms.[4] However, CKD-aP often presents without visible skin lesions, making diagnosis challenging[3] and reinforcing the need for patient-reported outcome measures (PROMs). It is not systematically diagnosed, contributing to underreporting.[5]

Underdiagnosis is further compounded by the lack of a standardised assessment approach and consensus on evaluation scales among healthcare professionals.[1] A comprehensive assessment of CKD-aP would include itch onset, duration, location (localised or generalised), severity, associated symptoms (e.g. rash, skin dryness) and its impact on QoL and sleep.[6] People with high itch severity report lower QoL scores, highlighting the need for comprehensive assessment and effective interventions.[7]

Pruritus severity and multidimensional assessment scales

As pruritus is a complex and subjective condition commonly experienced by patients with CKD, a variety of assessment instruments have been developed, each targeting different dimensions of the condition. The following self-reporting scales are among the most reliable available for pruritus assessment and are commonly used in CKD-aP evaluation.[6,8] However, CKD-aP differs from dermatological pruritus as it is often neuropathic and systemic in nature. These pruritus scales may not fully capture the unique characteristics of CKD-aP, particularly in relation to dialysis-associated pruritus patterns, neuropathic itch descriptors and the impact of systemic treatments (e.g., phosphate binders).[9]

1. **The Worst Itch Numeric Rating Scale (WI-NRS)** is a single question tool that asks patients to rate the worst itch intensity experienced in the past 24 hours on an 11-point scale, from 0 (no itch) to 10 (worst imaginable itch).
2. **The Numeric Rating Scale (NRS)** includes the WI-NRS as part of a two-questions assessment: (1) one assessing the average itch intensity within the past 24 hours and (2) one evaluating the worst itch intensity in the past 24 hours. It is an 11-point numeric scale, ranging from 0 (no itch) to 10 (worst

imaginable itch), where individuals select a single number to indicate itch intensity. A simplified 6-point version exists, ranging from 0 (no itch) to 5 (severe itch).

3. **The Verbal Rating Scale (VRS)** consists of two questions: (1) one assessing the average itch intensity within the past 24 hours and (2) one evaluating the worst itch intensity in the past 24 hours. It is a 5-point scale with adjectives describing different levels of symptom intensity (no itch, mild itch, moderate itch, severe itch and very severe itch).[8]
4. **The 5D itch scale** is a 5-point Likert questionnaire with 8 items assessing itch severity and its impact on QoL over the past two weeks. It evaluates five domains (Disability, Distribution, Duration, Degree, and Direction. The overall score ranges from 5 to 25, with lower scores indicating less itch severity and better QoL.[10]
5. **The Self-Assessed Disease Severity (SADS)** is a two-part self-report tool designed to assess both itch severity and impact on QoL. The first part consists of the single item WI-NRS. In the second part, patients are asked to categorise themselves into one of three groups based on itch severity and its impact on sleep and emotional well-being: A (absence of scratch marks, no sleep disturbance and no emotional distress), B (occasional scratch marks and sleep disturbance, but no emotional distress) or C (frequent scratching with possible bleeding or infection, poor sleep and emotional distress).[6]

Comparison of assessment scales

CKD-aP is characterised by fluctuating as well as multiple and complex symptoms, making single-point assessments insufficient for assessing its full impact.[9] The commonly used intensity scales, WI-NRS, NRS, and VRS, do not assess itch frequency, but they have all demonstrated high validity ($r > 0.8$) and acceptable test–retest reliability (intraclass correlation coefficient ICC: 0.74–0.80) for measuring itch severity. Among these, WI-NRS and NRS have been reported as the easiest to use even in adults ≥ 60 years old.

The 5-D Itch Scale, and the SADS are multidimensional tools designed to evaluate the impact of the itch on QoL.[6] They are more complex than intensity scales and time consuming to administer. Unlike NRS, and VRS (which assess itch severity over the past 24 hours), 5-the D Itch Scale, use a two-week recall period, providing a broader view of how itch affects daily life. Longer recall periods, such as four weeks, may not reflect daily fluctuations in symptom severity. Conversely, NRS (including both WI-NRS and average itch) appears to be more responsive to daily variations, making it useful for monitoring treatment response and symptom progression.[11] These findings highlight the importance of selecting appropriate assessment tools that are specific and time-sensitive like NRS for assessing CKD-aP in clinical practice.

Selecting the right assessment scale for CKD-aP

The use of the right assessment scale is key in order to create a good strategy and have the best outcomes and satisfy patients' quality of life. Moreover, it is relevant the methodology, the time and the interpretation of each scale as well as the nurses' intervention in order to have an effective assessment. Some scales such WI-NRS, NRS and VRS are simple to complete, thus potentially more practical for assessing CKD-aP in clinical settings. They demonstrated good reliability in populations who suffer from psoriasis (Cronbach's $\alpha = 0.80$; test-retest $r = 0.95$), suggesting their applicability in clinical and research contexts.[12] To date, only the WI-NRS has been specifically evaluated in haemodialysis (HD) patients with moderate-to-severe CKD-aP. Initial findings identified a reduction of approximately 3 points on the WI-NRS as a clinically meaningful improvement.[13] This threshold was subsequently confirmed and strengthened through psychometric validation, demonstrating strong test–retest reliability (ICC = 0.76–0.81), high construct validity ($r \approx 0.80$), and sensitivity to change.[14] Further validation would be helpful for the WI-NRS, NRS and VRS in the broader CKD-aP population, including patients not receiving HD and those with mild pruritus.

Using NRS, or VRS can support nurses to make informed decisions and monitor treatment response effectively. The WI-NRS captures the worst itch in the past 24 hours, reflecting peak symptom severity, which patients often find most distressing. However, it does not provide the itch severity experienced throughout the day. Including average itch intensity offers a more complete picture, particularly in chronic and fluctuating CKD-aP. Patients may report a high worst itch score due to a flare-up, while average itch remains low, suggesting most of the day was manageable. Average itch is often more sensitive to early treatment effects, even when worst itch scores remain unchanged. It also reflects the impact on daily functioning and emotional status, even in the absence of severe episodes. Overall, NRS (WI-NRS and average itch) offers a practical method for capturing daily symptom fluctuations and evaluating therapeutic progress.

While NRS, and VRS primarily assess itch intensity, they may be insufficient in capturing the CKD-aP fluctuating nature and its impact on QoL. The use of an intensity scales in combination with a multidimensional tool such as, the 5-D Itch scale or SADS may provide a more comprehensive evaluation.[9] SADS is quick and practical for assessing the multidimensional burden of CKD-aP, offering a simpler alternative to complex instruments like the 5-D Itch Scale. It is useful in clinical practice for monitoring CKD-aP impact on QoL and treatment response. Intensity and multidimensional scales may be applied at different time points to optimise assessment. However, the minimal clinically important difference (MCID) for changes in CKD-aP remains undefined.

Ethnic and cultural factors may influence itch perception and reporting, highlighting the need for further cross-cultural validations. Continued research is essential to develop validated CKD-aP-specific tools suited for both clinical and research use.

Evidence-based interventions in CKD-aP management

The pathogenesis of CKD-aP is complex, and likely multifactorial.[15–17] Current evidence-based interventions combines pharmacological and non-pharmacological therapies.

Pharmacological interventions

When using pharmacological interventions it is focused on the specific symptom of itch, however as the factor can vary, then the pharmacological component can also vary according to the effect the person needs. That is why pharmacological treatment can vary from the use of analgesics, antihistamines, anti-epileptics (pregabalin and gabapentin), novel opioid receptor modulators, and neurokinin-I inhibitors.[16,17] While oral antihistamines have been shown to have limited effect in the management of CKD-aP, topical antihistamines creams used in the case of CKD-aP xerosis showed efficacy.[17] Moreover, topical antihistamines creams used in the case of CKD-aP xerosis showed efficacy, unlike oral antihistamines that have been shown to have limited effect in the management of CKD-aP.[17]

Until recently, the limited availability of approved therapies for CKD-aP led to off-label use of treatments such as gabapentinoids. Pregabalin and gabapentin, can reduce the severity of CKD-aP but may cause significant side effects.[18–20] Gabapentin was associated with dizziness, somnolence, visual changes, and increased risk of suicide.[17,18]

Recent randomized controlled trials (RCTs) have demonstrated that peripheral kappa-opioid receptor (KOR) agonists, such as Difelikefalin (selective peripheral KOR agonist, reducing itch signal in sensory neurons and inflammation in the skin) improved CKD-aP symptoms over 2-9 weeks, as compared to placebo.[18,21] In clinical trials, Difelikefalin was shown to reduce itch by 3 points on the WI-NRS, in 74% of individuals with moderate to severe CKD-aP.[22] Its effect is maintained over longer periods[23], though some side effects such as transient dizziness, somnolence and a gait disturbances have been reported.[24,25] Difelikefalin has also demonstrated improvements in QoL[26] and sleep disturbance[27]. It is currently the only approved CKD-aP treatment in the US and Europe and is indicated for moderate to severe itch.[28] While long-term data, beyond 12 months, are still lacking, its effectiveness and safety are supported by real-world evidence (RWE) from the U.S., Europe, and Italy, confirming benefits in routine dialysis care across diverse populations.[29–31]

As for NK-1 inhibitors, like Serlopitant and Aprepitant, they may help treat CKD-aP by reducing neurogenic itch. However, additional trials are necessary to confirm the efficacy, optimal dosing, and long-term safety of these treatments.[16,17]

Non-pharmacological interventions

When using non-pharmacological interventions, we need to think of all the aspects associated that contribute to the development of pruritus and therefore worsen then quality of life of the patient. Therefore, we need to have a wide and holistic view in order to find the best strategy and management of the situation. By optimising dialysis efficacy by increasing dialysis dose (Kt/V) and using high flux dialyzers to enhance clearance of uremic toxins[15], along with improved serum phosphate and calcium balance[16,17] has been associated with a lower itch intensity in CKD-aP. However, the evidence is inconsistent, with recent findings showing no association between phosphate levels and CKD-aP severity.[32] This suggests that patients who meet recommended targets for dialysis adequacy and mineral metabolism may still experience pruritus. Therefore, while these factors may contribute to symptom relief, they are likely insufficient as standalone interventions. Topical skin rehydration agents are recommended as the first-line treatment in mild and localised CKD-aP, as they may lead to nerve desensitisation and provide localized relief.[33] Topical applications of baby oil[28] and ostrich oil[34] have been explored for skin rehydration, as they may help reduce dryness-related itching. However, there is no strong evidence supporting their effectiveness for managing CKD-aP. On the other hand, Ultraviolet (UV) B light therapy has also been suggested as a potential treatment for alleviating the itch in CKD-aP. However, its long-term benefits remain uncertain, and it carries an increased risk of skin cancer.[17,35]

There is a growing interest in the role of nutrition[15], Omega-3 Fatty Acids and vegetarian diet[28] in alleviating CKD-aP-related itch. These dietary approaches may have anti-inflammatory benefits, but specific research on their effectiveness for CKD-aP is limited. Although restricting dietary phosphate is often considered helpful in managing CKD-aP, there is no strong clinical evidence supporting this strategy. While correcting severe imbalances in phosphate, calcium, or parathyroid hormone (PTH) may be beneficial, routinely advising a restrictive diet is unlikely to alleviate itching. In fact, such restrictions may contribute to inadequate nutritional intake.[4]

Acupressure[28,33,36] and acupuncture[28,33] have also shown potential in alleviating CKD-aP symptoms. Acupressure and reflexology massage were associated with a 50% decrease in sleep disturbance and 38% decrease in fatigue among individuals with CKD-aP. Additionally, acupressure was reported to reduce CKD-aP itch by 78%, while acupuncture by 60%.[28] Nonetheless, acupressure was associated with intradialytic hypotension and dizziness in people with CKD, while acupuncture was linked to elbow soreness and bleeding.[28]

Cognitive behavioural therapy, mindfulness, and meditation may help individuals cope with CKD-aP-related stress and reduce perceived itch intensity[37].

Overall, additional research is required to establish the impact of various non-pharmacological interventions on CKD-aP management and outcomes.

Conclusion

CKD-aP is a complex, multifactorial condition that adversely affects QoL. Despite its high prevalence, CKD-aP remains underdiagnosed and undertreated, highlighting the need for standardised assessment tools and evidence-based management strategies. Several pruritus assessment scales demonstrate strong reliability; however, none is capable of fully capturing the multifactorial nature of CKD-aP and its impact on QoL. A combination of brief itch intensity scales and comprehensive itch QoL-related questionnaires would be ideal for CKD-aP symptom burden assessment. Nevertheless, the development of validated CKD-specific scales is essential to improve both clinical care and research quality.

Effective management requires a person-centred approach tailored to symptoms' severity and individual needs. People with mild CKD-aP may benefit from topical emollients and dietary modifications, while those with moderate to severe itch often require additional pharmacologic interventions. Combining pharmacologic and non-pharmacologic therapies provides more comprehensive symptom relief and improves patient well-being, especially since medications can alleviate symptoms but rarely lead to complete resolution of the itch.

Routine assessment and proactive management of CKD-aP are essential for optimising treatment strategies and improving patient outcomes. Developing CKD-specific assessment tools and advancing targeted therapies will lead to better symptom control and QoL.

References

1. Sukul N, Zhao J, Pisoni RL, Walpen S, Schaufler T, Asgari E, et al. Pruritus in Hemodialysis Patients: Longitudinal Associations With Clinical and Patient-Reported Outcomes. Am J Kidney Dis. 1 déc 2023;82(6):666-76.
2. Lee D, Vassalotti JA, Torres G, Singleton-Driscoll L. Burden of Pruritus in Advanced CKD and Hemodialysis: Results From National Kidney Foundation Surveys. Kidney Med. 25 mars 2023;5(6):100635.
3. Aresi G, Rayner HC, Hassan L, Burton JO, Mitra S, Sanders C, et al. Reasons for Underreporting of Uremic Pruritus in People With Chronic Kidney Disease: A Qualitative Study. J Pain Symptom Manage. 1 oct 2019;58(4):578-586.e2.
4. Rayner H, Sukul N. Fast Facts : Kidney Itch : CKD-associated pruritus: under-recognised and under-treated. 2022;1-72.
5. Lanot A, Bataille S, Rostoker G, Bataille P, Chauveau P, Touzot M, et al. Moderate-to-severe pruritus in untreated or non-responsive hemodialysis patients: results of the French prospective multicenter observational study Pruripreva. Clin Kidney J. 1 juill 2023;16(7):1102-12.
6. Manenti L, Leuci E. Do you feel itchy? A guide towards diagnosis and measurement of chronic kidney disease-associated pruritus in dialysis patients. Clin Kidney J. 14 oct 2021;14(Suppl 3):i8-15.
7. Poku E, Harnan S, Rooney G, James MMS, Hernández-Alava M, Schaufler T, et al. The relationship between chronic kidney disease–associated pruritus and health-related quality of life: a systematic review. Clin Kidney J. 1 mars 2022;15(3):484-99.
8. Phan NQ, Blome C, Fritz F, Gerss J, Reich A, Ebata T, et al. Assessment of Pruritus Intensity: Prospective Study on Validity and Reliability of the Visual Analogue Scale, Numerical Rating Scale and Verbal Rating Scale in 471 Patients with Chronic Pruritus. Acta Derm Venereol. 2012;92(5):502-7.
9. Schoch D, Sommer R, Augustin M, Ständer S, Blome C. Patient-Reported Outcome Measures in Pruritus: A Systematic Review of Measurement Properties. J Invest Dermatol. 1 oct 2017;137(10):2069-77.
10. Elman S, Hynan LS, Gabriel V, Mayo MJ. The 5-D itch scale: a new measure of pruritus. Br J Dermatol. 1 mars 2010;162(3):587-93.
11. Guedes M, Tu C, Sukul N, Asgari E, Guebre-Egziabher F, Ruessmann D, et al. Chronic kidney disease–associated pruritus: a comparison of instruments and associations with patient-reported outcomes using an electronic patient-reported outcome survey in Europe. Clin Kidney J. 1 oct 2024;17(10):sfae276.
12. Majeski CJ, Johnson JA, Davison SN, Lauzon GJ. Itch Severity Scale: a self-report instrument for the measurement of pruritus severity. Br J Dermatol. 1 avr 2007;156(4):667-73.
13. Vernon M, Ständer S, Munera C, Spencer RH, Menzaghi F. Clinically meaningful change in itch intensity scores: An evaluation in patients with chronic kidney disease–associated pruritus. J Am Acad Dermatol. 1 avr 2021;84(4):1132-4.

14. Vernon MK, Swett LL, Speck RM, Munera C, Spencer RH, Wen W, et al. Psychometric validation and meaningful change thresholds of the Worst Itching Intensity Numerical Rating Scale for assessing itch in patients with chronic kidney disease-associated pruritus. J Patient-Rep Outcomes. 24 déc 2021;5:134.
15. Arzhan S, Roumelioti ME, Unruh ML. Itch and Ache on Dialysis: New Approaches to Manage Uremic Pruritus and Restless Legs. Blood Purif. 2020;49(1-2):222-7.
16. Martin CE, Clotet-Freixas S, Farragher JF, Hundemer GL. Have We Just Scratched the Surface? A Narrative Review of Uremic Pruritus in 2020. Can J Kidney Health Dis. 1 janv 2020;7:2054358120954024.
17. Verduzco HA, Shirazian S. CKD-Associated Pruritus: New Insights Into Diagnosis, Pathogenesis, and Management. Kidney Int Rep. 1 sept 2020;5(9):1387-402.
18. Siemens W, Xander C, Meerpohl JJ, Buroh S, Antes G, Schwarzer G, et al. Pharmacological interventions for pruritus in adult palliative care patients. Cochrane Database Syst Rev [Internet]. 2016 [cité 10 sept 2021];(11). Disponible sur: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD008320.pub3/abstract?cookiesEnabled
19. Simonsen E, Komenda P, Lerner B, Askin N, Bohm C, Shaw J, et al. Treatment of Uremic Pruritus: A Systematic Review. Am J Kidney Dis. 1 nov 2017;70(5):638-55.
20. Yue J, Jiao S, Xiao Y, Ren W, Zhao T, Meng J. Comparison of pregabalin with ondansetron in treatment of uraemic pruritus in dialysis patients: a prospective, randomized, double-blind study. Int Urol Nephrol. janv 2015;47(1):161-7.
21. Jaiswal D, Uzans D, Hayden J, Kiberd BA, Tennankore KK. Targeting the Opioid Pathway for Uremic Pruritus: A Systematic Review and Meta-analysis. Can J Kidney Health Dis. 1 janv 2016;3:2054358116675345.
22. Weiner DE, Vervloet MG, Walpen S, Schaufler T, Munera C, Menzaghi F, et al. Safety and Effectiveness of Difelikefalin in Patients With Moderate-to-Severe Pruritus Undergoing Hemodialysis: An Open-Label, Multicenter Study. Kidney Med. 24 août 2022;4(10):100542.
23. Topf J, Wooldridge T, McCafferty K, Schömig M, Csiky B, Zwiech R, et al. Efficacy of Difelikefalin for the Treatment of Moderate to Severe Pruritus in Hemodialysis Patients: Pooled Analysis of KALM-1 and KALM-2 Phase 3 Studies. Kidney Med. 28 juin 2022;4(8):100512.
24. Fishbane S, Jamal A, Munera C, Wen W, Menzaghi F. A Phase 3 Trial of Difelikefalin in Hemodialysis Patients with Pruritus. N Engl J Med. 16 janv 2020;382(3):222-32.
25. Fishbane S, Mathur V, Germain MJ, Shirazian S, Bhaduri S, Munera C, et al. Randomized Controlled Trial of Difelikefalin for Chronic Pruritus in Hemodialysis Patients. Kidney Int Rep. 1 mai 2020;5(5):600-10.
26. Ständer S, Fishbane S, Schaufler T, Ruessmann D, Morin I, Menzaghi F, et al. Chronic kidney disease-associated pruritus and quality of life with difelikefalin treatment: a post hoc analysis of phase 3 data using the Skindex-10 questionnaire. Clin Kidney J. oct 2024;17(10):sfae274.

27. Weiner DE, Schaufler T, McCafferty K, Kalantar-Zadeh K, Germain M, Ruessmann D, et al. Difelikefalin improves itch-related sleep disruption in patients undergoing haemodialysis. Nephrol Dial Transplant Off Publ Eur Dial Transpl Assoc - Eur Ren Assoc. 28 juin 2024;39(7):1125-37.
28. Chu SWF, Ng WJ, Yeam CT, Khan RQ, Low LL, Quah JHM, et al. Manipulative and body-based methods in chronic kidney disease patients: A systematic review of randomized controlled trials. Complement Ther Clin Pract. 1 août 2022;48:101593.
29. Aucella F, Zerbi S, Monaco MP, Bonomini M, Alberici F, Losappio V, et al. Difelikefalin for CKD-aP: real world evidence of efficacy and safety in Italian patients. Clin Kidney J. 18 févr 2025;sfaf050.
30. Kraft L, Schanz M, Schricker S, Ketteler M, Mayer G, Rostoker G, et al. The first real-world experience of IV difelikefalin to treat chronic kidney disease-associated pruritus in haemodialysis patients. J Eur Acad Dermatol Venereol. 2023;37(8):e1059-61.
31. Ficociello LH, Lasky R, Arens HJ, Ruessmann D, Anger MS. Real-world use of difelikefalin in hemodialysis patients at a large dialysis organization in the United States: a retrospective database study. BMC Nephrol. 27 mars 2025;26(1):156.
32. Fishbane SN, Block GA, Evenepoel P, Budden J, Morin I, Menzaghi F, et al. Pruritus Severity and Serum Phosphate in CKD: A Post Hoc Analysis of Difelikefalin Studies. Kidney360. sept 2024;5(9):1270.
33. Lipman ZM, Paramasivam V, Yosipovitch G, Germain MJ. Clinical management of chronic kidney disease-associated pruritus: current treatment options and future approaches. Clin Kidney J. 1 déc 2021;14(Supplement_3):i16-22.
34. Sadeghnejad Z, Karampourian A, Borzou SR, Gholyaf M, Mohammadi Y, Hadadi R. The Effect of Ostrich Oil as a Complementary Medicine on the Severity of Pruritus and Quality of Life in Hemodialysis Patients. Complement Med Res. 2021;28(1):40-5.
35. Scherer JS, Combs SA, Brennan F. Sleep Disorders, Restless Legs Syndrome, and Uremic Pruritus: Diagnosis and Treatment of Common Symptoms in Dialysis Patients. Am J Kidney Dis. 1 janv 2017;69(1):117-28.
36. Rehman IU, Ahmed R, Rahman AU, Wu DBC, Munib S, Shah Y, et al. Effectiveness and safety profiling of zolpidem and acupressure in CKD associated pruritus: An interventional study. Medicine (Baltimore). 28 mai 2021;100(21):e25995.
37. Golpanian RS, Gonzalez JM, Yosipovitch G. Practical Approach for the Diagnosis and Treatment of Chronic Pruritus. J Nurse Pract. sept 2020;16(8):590-6.

Chapter 5

The pivotal roles of nurses in the identification and management of people with CKD-associated Pruritus (CKD-aP)

Learning objectives:

- To recognise the clinical pathway and validated tools used by nurses to identify and assess chronic kidney disease–associated pruritus (CKD-aP)
- To describe the nurse’s role in the multidisciplinary management of CKD-aP, including routine evaluation, communication with the care team, and patient follow-up
- To implement practical approaches for patient education on CKD-aP, including its renal origin, symptom monitoring, and the use of assessment tools like the Wi-NRS

Introduction

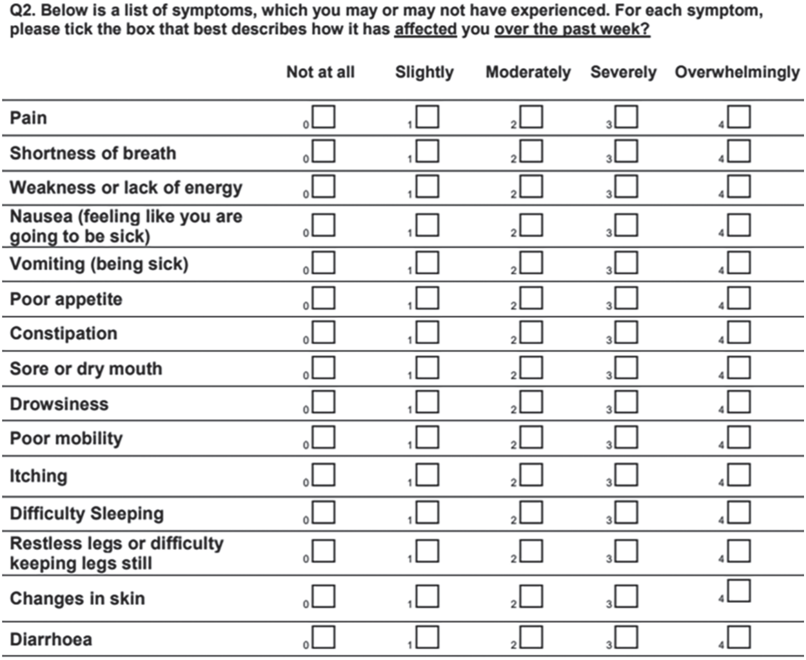
Chronic kidney disease-associated Pruritus (CKD-aP) is a prevalent yet often underdiagnosed and undertreated condition among individuals with chronic kidney disease (CKD). As frontline healthcare professionals, nurses play a pivotal role in the identification, evaluation, management, and follow-up of CKD-aP. Positioned within a multidisciplinary nephrology team, nurses are essential in ensuring that CKD-aP is recognised, assessed, and managed systematically to improve patient outcomes and quality of life. This chapter aims to provide a structured clinical pathway for nurses, including the use of validated tools, to facilitate the identification and management of CKD-aP. It will outline the nurse's responsibilities within the care team, practical guidelines for patient education, and the importance of symptom monitoring following the initiation of treatment.

Clinical Pathways and Assessment Tools for CKD-aP

Effective management of CKD-aP begins with accurate identification. Nurses should incorporate routine pruritus assessment into standard care procedures. Validated tools provide the necessary structure for consistent symptom identification. Such a measure must demonstrate good validity, reliability, and responsiveness to change. A variety of assessment tools exist, including both generic and disease-specific instruments.[1]

An exemplary tool in this context is the Integrated Palliative care Outcome Scale for renal patients (IPOS-renal).[2] This instrument is particularly advantageous as it is applicable across all stages of chronic kidney disease, not just for those undergoing dialysis, and is available in several languages. IPOS-renal does not only assess physical needs but also the psychological, social, spiritual and practical needs of patients. Notably, the questionnaire can be completed in under ten minutes, allowing patients to respond independently or with assistance from caregivers or healthcare professionals. In many clinical nephrology practices internationally, the IPOS-renal is used every three months. Using IPOS-renal someone gets information about the prevalence of the most common uraemic symptoms, their severity, how much these symptoms have affected the patient in the past week (See Figure 3).

Figure 3: The physical symptoms included in the IPOS-renal



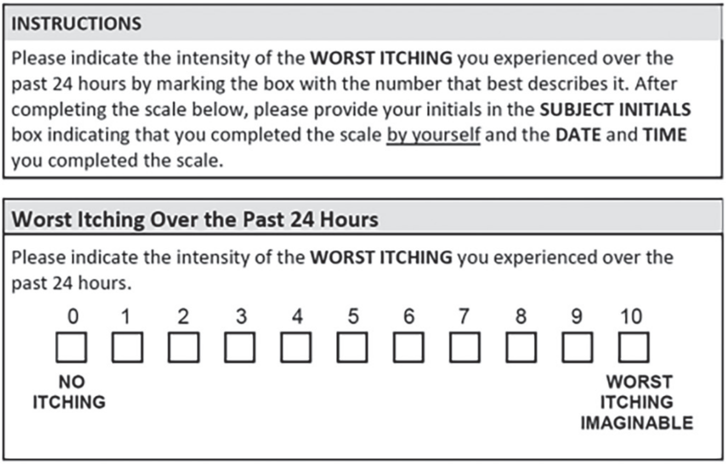
Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Itching	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Difficulty Sleeping	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Restless legs or difficulty keeping legs still	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Changes in skin	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Diarrhoea	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

If the patient answers either slightly, moderately, severely or overwhelmingly for itching, then you as a nurse have to conduct an in-depth investigation with a specific focus on itching.

The first step could be the Worst Itching Intensity Numerical Rating Scale (Wi-NRS)[3] (See Figure 4). It is a simple, validated instrument that allows patients to rate their itch severity on a scale from 0 to 10. It is ideal for this initial assessment, but also for tracking changes over time. Similar to IPOS-Renal, it measures the presence and severity of the itching, but Wi-NRS focuses on the last 24 hours and the worst itching, acknowledging that itching is not static. If patients rate their Wi-NRS score at 5 or higher, you should continue to investigate the itching.

Figure 4: The Worst Itching Intensity Numerical Rating Scale



INSTRUCTIONS

Please indicate the intensity of the **WORST ITCHING** you experienced over the past 24 hours by marking the box with the number that best describes it. After completing the scale below, please provide your initials in the **SUBJECT INITIALS** box indicating that you completed the scale by yourself and the **DATE** and **TIME** you completed the scale.

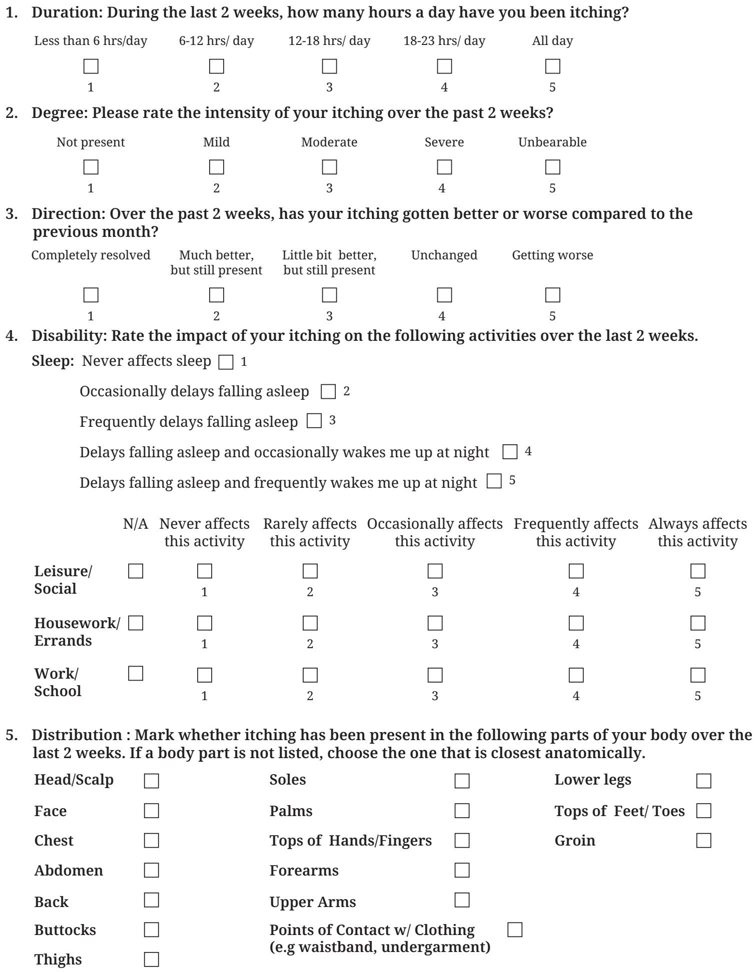
Worst Itching Over the Past 24 Hours

Please indicate the intensity of the **WORST ITCHING** you experienced over the past 24 hours.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
NO ITCHING										**WORST ITCHING IMAGINABLE**

For instance, a more comprehensive assessment can be conducted using the 5D itch scale[4] (See Figure 5), which assesses the itching across five domains: duration, degree, direction (change over time), disability (impact on activities), and distribution (location on the body).

Figure 5: The 5D itch scale



1. **Duration: During the last 2 weeks, how many hours a day have you been itching?**

Less than 6 hrs/day	6-12 hrs/ day	12-18 hrs/ day	18-23 hrs/ day	All day
☐	☐	☐	☐	☐
1	2	3	4	5

2. **Degree: Please rate the intensity of your itching over the past 2 weeks?**

Not present	Mild	Moderate	Severe	Unbearable
☐	☐	☐	☐	☐
1	2	3	4	5

3. **Direction: Over the past 2 weeks, has your itching gotten better or worse compared to the previous month?**

Completely resolved	Much better, but still present	Little bit better, but still present	Unchanged	Getting worse
☐	☐	☐	☐	☐
1	2	3	4	5

4. **Disability: Rate the impact of your itching on the following activities over the last 2 weeks.**

Sleep: Never affects sleep ☐ 1

Occasionally delays falling asleep ☐ 2

Frequently delays falling asleep ☐ 3

Delays falling asleep and occasionally wakes me up at night ☐ 4

Delays falling asleep and frequently wakes me up at night ☐ 5

	N/A	Never affects this activity	Rarely affects this activity	Occasionally affects this activity	Frequently affects this activity	Always affects this activity
Leisure/ Social	☐	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Housework/ Errands	☐	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Work/ School	☐	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. **Distribution : Mark whether itching has been present in the following parts of your body over the last 2 weeks. If a body part is not listed, choose the one that is closest anatomically.**

Head/Scalp ☐
Face ☐
Chest ☐
Abdomen ☐
Back ☐
Buttocks ☐
Thighs ☐
Soles ☐
Palms ☐
Tops of Hands/Fingers ☐
Forearms ☐
Upper Arms ☐
Points of Contact w/ Clothing (e.g waistband, undergarment) ☐
Lower legs ☐
Tops of Feet/ Toes ☐
Groin ☐

Chapter 4 provides an overview of different tools to use for identification of CKD-aP.

The last domain in the 5D-itch scale is distribution. The list does not include all anatomically places and maybe the itch is not the whole face, chest, abdomen etc, why it is easier for the patient to mark the distribution of itching on a figure of the forefront and back front of the body (See Figure 6). This task should be combined with an observation of the patient. You should observe whether the patient is actually itching, note the location of the itching, and also check for any itching marks on the patient.

This whole process needs to be recorded in the patient health record onsiteto communicate this important finding to the multiprofessional team, especially the nephrologist. This comprehensive assessment is the basis for making the clinical decision to consider the itching as a condition, named 'Chronic Kidney Disease Associated Pruritus (CKD-aP)'. This condition is defined as *'moderate to severe itching that is directly related to kidney disease, without the presence of any other comorbid condition such as liver or skin that includes itching'*.[5] When the decision has been made that this patient suffers from CKD-aP, a management plan has to be decided.

The Nurse's Role Within the Multidisciplinary Nephrology Team

Focusing specifically on CKD-aP, it is essential to consider non-pharmacological interventions alongside pharmacological approaches. Successful management of CKD-aP requires a synergistic relationship between these two strategies. Chapter 4 provides an overview of different interventions to use for the management of CKD-aP. Many of these interventions can be implemented by patients at home, reinforcing the importance of shared decision-making and self-management support in the management process of CKD-aP.

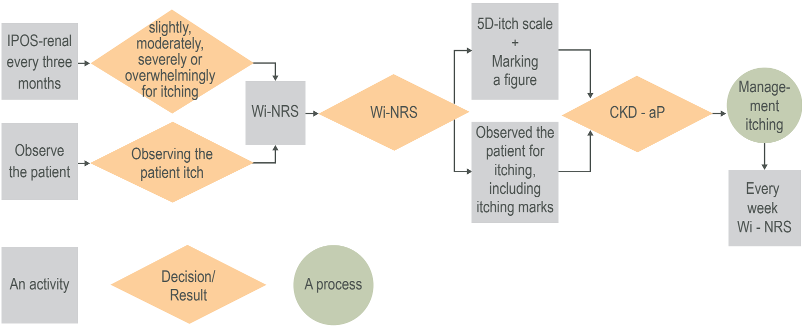
Self-management support facilitates people with chronic conditions in effectively managing their health and wellbeing on a daily basis. It is characterised by an active collaborative relationship between patients and healthcare professionals. Implementing self-management support necessitates empowering both patients and healthcare professionals to enhance their knowledge, skills, and confidence.[6] Specifically, those with chronic diseases must undertake three primary activities for effective self-management: 1) the pharmacological and non-pharmacological management of their symptoms; 2) the development and maintenance of new meaningful behaviours or life roles; and 3) the management of emotions, including anger, fear, frustration, and depression, which are often associated with living with a chronic condition that affects all aspects of daily life.[7] Tailored self-management interventions offer a structured means to support adults in managing their health effectively.[8] Evidence indicates that nurse-led self-management programmes for individuals with chronic kidney disease can delay disease progression and increase patient knowledge and self-management capabilities.[9] The cornerstone of successful self-management support is shared decision making, wherein people with chronic kidney disease actively participate in the decision-making process regarding the selection and implementation of CKD-aP management strategies.

Shared decision making transpires during the interaction between a patient and a nurse, constituting a dynamic process wherein both parties collaborate to select appropriate healthcare options. This process involves the exchange of information, deliberation over preferences, and the implementation of a mutually agreed-upon choice.[10] Prioritising patient choice through shared decision making is a critical element of symptom management, as it can mitigate doubts, misunderstandings, lack of confidence, and improve motivation to continue with long-term treatment and care.[11] A recent study has demonstrated that a tailored shared decision-making intervention can support adults with chronic kidney disease in deciding whether to commence dialysis.[12] The intervention involved a patient decision aid, structured meetings between patients and healthcare professionals, and training for nurses in the delivery of shared decision making.

To be sure that the management plan CKD-aP is effective for the patient, the itching needs to be re-evaluated every week and the Wi-NRS is appropriate for this because it is easy to use.

The whole clinical pathway for CKD-aP is showed below in Figure 6.

Figure 6: The clinical pathway for management of CKD-aP in a dialysis clinic

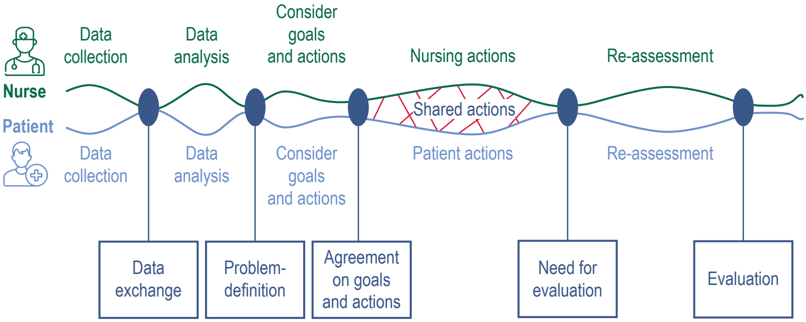


Nurse-Patient relationship

The Deliberative Nursing Process, suggested by Jean Ida Orlando[13] in 1961, has five stages: assessment, diagnosis, planning, implementation, and evaluation, to produce positive outcomes or patient improvement. Jean Ida Orlando stated: *“Patients have their own meanings and interpretations of situations, and therefore nurses must validate their inferences and analyses with patients before concluding.”*

Given that symptoms are self-reported, the relationship between patient and nurse is vital throughout the entire process. Both the patient and the nurse should collaborate in data collection and analysis, allowing for a shared understanding of goals and actions. This collaborative approach fosters a sense of ownership and empowerment among patients, ultimately leading to more effective management of their symptom burden. (See Figure 7)

Figure 7: The dynamic nurse-patient relationship[17]



Informal caregiver experience

The symptom burden affects the basic needs of informal caregivers when living with a person with chronic kidney disease.[14] Informal caregivers for adults with chronic kidney disease report high levels of caregiver burden and a substantial decrease in quality of life.[15] To reduce their feeling of inadequacy to support the patient and provide adequate care, informal caregivers seek advice and assistance from healthcare professionals.[16] A recent international guideline advises that symptom management interventions should address the needs of both patients and their informal caregivers.[17]

Conclusion

Nurses are at the forefront of recognising and managing CKD-aP. By using validated assessment tools, maintaining open communication within the multidisciplinary care team, and educating and empowering patients and caregivers, nurses can significantly impact the quality of care and life for individuals with CKD-aP. Routine evaluation, consistent follow-up, and a commitment to person-centred care are essential components of effective CKD-aP management in nephrology nursing.

References

1. Bennett P, Warren M, Aydin Z, Beige J, Bowes E, Cheung M, Finderup J, Gallego D, Hecking M, Hurst H, King JM, Kleophas W, Liossatou A, Martins P, Masià-Plana A, Meuleman Y, Neri L, Noruišienė E, Ortiz J, Rix M, Stuard S, Tsukamoto Y. Kidney Disease: Improving Global Outcomes (KDIGO) Workshop on the Nurse's Role in Managing the Symptoms of People Receiving Dialysis. Kidney Int Rep. 2024 Nov 28;10(2):313-320.
2. 2. Murtagh FE, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST, Denzel J, Guo P, Bernhardt F, Schildmann E, van Oorschot B, Hodiamont F, Streitwieser S, Higginson IJ, Bausewein C. A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). Palliat Med. 2019 Sep;33(8):1045-1057.
3. Vernon MK, Swett LL, Speck RM, Munera C, Spencer RH, Wen W, Menzaghi F. Psychometric validation and meaningful change thresholds of the Worst Itching Intensity Numerical Rating Scale for assessing itch in patients with chronic kidney disease-associated pruritus. J Patient Rep Outcomes. 2021 Dec 24;5(1):134.
4. Elman S, Hynan LS, Gabriel V, Mayo MJ. The 5-D itch scale: a new measure of pruritus. Br J Dermatol. 2010 Mar;162(3):587-93.
5. Osakwe N, Hashmi MF. Uremic Pruritus Evaluation and Treatment. 2024 Aug 8. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan–. PMID: 36508514.
6. Ahmad, N., Ellins, J., Krelle, H., & Lawrie, M. (2014). Person-centred care: From ideas to action. http://www.health.org.uk/publication/person-centred-care-ideas-action
7. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med. 2003 Aug;26(1):1-7.
8. Havas K, Douglas C, Bonner A. Meeting patients where they are: improving outcomes in early chronic kidney disease with tailored self-management support (the CKD-SMS study). BMC Nephrol. 2018 Oct 20;19(1):279.

9. Nguyen NT, Douglas C, Bonner A. Effectiveness of self-management programme in people with chronic kidney disease: A pragmatic randomized controlled trial. J Adv Nurs. 2019 Mar;75(3):652-664.
10. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med. 1999 Sep;49(5):651-61.
11. Stacey D, Lewis KB, Smith M, Carley M, Volk R, Douglas EE, Pacheco-Brousseau L, Finderup J, Gunderson J, Barry MJ, Bennett CL, Bravo P, Steffensen K, Gogovor A, Graham ID, Kelly SE, Légaré F, Sondergaard H, Thomson R, Trenaman L, Trevena L. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2024 Jan 29;1(1):CD001431.
12. Finderup J, Lomborg K, Jensen JD, Stacey D. Choice of dialysis modality: patients' experiences and quality of decision after shared decision-making. BMC Nephrol. 2020 Aug 5;21(1):330.
13. Orlando, Ida Jean. The Deliberative Nursing Process. USA, FITNE, 1997.
14. Deele M. Chronic Kidney Disease Symptoms: The Informal Caregiver's Experience. J Ren Care. 2025 Mar;51(1):e70007.
15. Chu SY, Ibrahim N, Amit N, Gafor AHA, Ismail R, Lee KW, Siau CS. Interventions to Reduce Caregiver Burden Among Caregivers of Chronic Kidney Disease (CKD) Patients: A Scoping Review. SAGE Open. 2023; 13(2).
16. Ania-González N, Martín-Martín J, Amezqueta-Goñi P, Vázquez-Calatayud M. The needs of families who care for individuals with kidney failure on comprehensive conservative care: A qualitative systematic review. J Ren Care. 2022 Dec;48(4):230-242.
17. Kalantar-Zadeh K, Li PK, Tantisattamo E, Kumaraswami L, Liakopoulos V, Lui SF, Ulasi I, Andreoli S, Balducci A, Dupuis S, Harris T, Hradsky A, Knight R, Kumar S, Ng M, Poidevin A, Saadi G, Tong A; World Kidney Day Steering Committee. Living well with kidney disease by patient and care-partner empowerment: Kidney health for everyone everywhere. J Ren Care. 2021 Mar;47(1):3-8.

Chapter 6

Voicing the Unseen: Communicating CKD-associated Pruritus (CKD-aP) Burden to the Nephrology Care Team. A Patient's Perspective

Introduction: Dignity on a Silent Burden

Chronic Kidney Disease-associated Pruritus (CKD-aP) is one of the most prevalent yet underrecognised condition in patients with kidney disease.[1] Despite its immense impact on quality of life, CKD-aP often remains silent without a holistic approach in clinical settings. Patients with CKD endure persistent itching that is described as unbearable, persistent, and life-altering, yet they rarely voice their struggles.[2] This chapter tries to amplify the voices of patients, emphasizing the importance of effective communication between care teams and people living with CKD-aP.

The objective is to educate and empower nephrology nurses to bridge this communication gap, foster patient trust, and collaborate with interdisciplinary teams to manage the burden and the impact of pruritus effectively.

The Hidden Impact of CKD-aP: A Patient’s Story

CKD-aP is not merely an itch, it is a debilitating condition that penetrates every aspect of a patient's life[7,8] such as:

- **Physical burden:** Patients often report scratching until they bleed, leading to skin injuries and infections. Actually, one of the first recommendations to patients with itching is to cut their nails.
- **Emotional and mental health:** Persistent pruritus contributes to depression, anxiety, lack of focus and feelings of helplessness.
- **Social and life participation barriers:** Visible scratching can evoke embarrassment, stigmatization, affecting relationships and self-esteem.
- **Sleep disruption:** Insomnia caused by relentless itching leaves patients fatigued, further impacting their daily lives.

For patients, the experience is captured in their own words:

“It’s like an itch beneath the skin, almost in the bone. You can’t reach it, and it drives you crazy.”

“It’s constant, like thirst. It stays with you all day, every day.”

These statements illustrate the overwhelming nature of CKD-aP and highlight the critical need for nurses to prioritize communication about this symptom.

Barriers to Addressing Pruritus in Clinical Settings

Patients with CKD often feel silenced by structural and personal barriers[5], including:

- Normalization of symptoms: Many believe that pruritus is an inevitable side-effect of CKD and feel resigned to endure it.
- Fear of dismissal: Patients may hesitate to mention pruritus, perceiving it as less urgent compared to other CKD complications.
- Limited time in consultations: Medical teams often focus on measurable parameters, leaving subjective symptoms like itching unaddressed.

The Nurse's Role: Starting the Communication Bridge

Nurses are specialist in caregiving, so they are uniquely positioned to identify and address CKD-aP due to their frequent and close interactions with patients with CKD. Effective communication begins with:

- **Proactive Asking & Monitoring**
  Incorporate questions about pruritus into routine assessments in and out of dialysis units. Asking about itching validates the patients’ experience and signals that their comfort matters. For example:
  Have you experienced any itching lately?
  How is itching affecting your daily life?
- **Empathetic Listening**
  Adopt an empathetic and active listening approach, with a nonjudgmental framework. Recognise that pruritus is not a simple discomfort or unpleasant situation, but a symptom that can severely impact the well-being of people living with kidney conditions.

- **Patients' Education**
  Provide clear, accessible information about CKD-aP, including its causes, treatments, and the importance of reporting symptoms. This empowers patients to seek, observe and ask for help proactively.
- **Using Normalized Tools**
  Implement assessment tools such as pruritus scales (validated tools) or questionnaires. These tools help patients articulate the severity and impact of their symptoms in a systematic way.

Communicating with the Multidisciplinary Team

Effective communication extends beyond patient interactions. Nurses play a critical role in advocating for patients within the nephrology, dialysis units and multidisciplinary team. By sharing detailed patient-centred observations and reports, nurses ensure that pruritus is prioritized in their caregiving plan. Key strategies include:

- **Documenting & Reporting symptoms:** Maintain detailed records of patients' lived experiences to update treatment adjustments.
- **Coordinating care:** Work closely with nephrologists, dermatologists, and other specialists to implement a holistic treatment plan.
- **Tracking treatment efficacy:** Monitor interventions and provide feedback to the team, adjusting strategies based on patient responses and preferences.

Practical Strategies for Managing CKD-aP[2,3]

Pharmacological Interventions

Inform patients about available treatments, such as:

- Gabapentin and pregabalin for neuropathic relief
- Difelikefalin, which is the only specifically indicated therapy for CKD-aP approved[4]
- Immunosuppressants
- Corticoids

Non-Pharmacological Options

Promote holistic care practices, including:

- **Haemodialysis session adjustment:** Modifying the dialysate, time, frequency, dialyzer and other aspects of the dialysis session.[5,6]
- **Skin care routines:** Moisturisers and emollients to address dryness and fragility.
- **Dietary adjustments:** Recommendations to manage phosphate and magnesium levels.
- **Lifestyle modifications:** Guidance on avoiding triggers like hot showers or harsh detergents.
- **Derivation to Dermatologist:** Interaction with specialized care of skin and treatments

A Call to Action: Amplifying Individual Voices

To transform care for CKD-aP, the nephrology team must prioritize the patients' voice. Nurses are pivotal in this shift, creating a safe space for patients to share their struggles and actively participating in symptom management. CKP-aP is not only an unpleasant symptom, which needs to be evaluated to measure the impact and severity of the humanistic burden on daily lives for people living with kidney conditions, especially those on kidney replacement therapies such as dialysis[9] and kidney transplantation.

The journey toward better communication begins with small steps:[10]

Making pruritus a routine part of the dialogue.

Advocating for focus on patient quality of life in multidisciplinary meetings.

Continuously educating both patients and team members about the impact, severity and management of CKD-aP.

In the words of one patient:

"We don't want to be victims, but we feel like we're at the mercy of this itch every single day."

By listening and acting with empathy and compassion, the nephrology care team, especially nurses, can transform kidney patients lives, empowering them and their families to improve their quality of life.

Conclusion: Listening for Healing

CKD-aP may be silent and invisible, but its impact is extremely profound affecting the quality of life of people living with kidney conditions. Nurses hold the key to uncovering and addressing this silent and hidden burden, ensuring that no patient with CKD suffers in silence. By voicing the unseen and unspoken, nurses can foster hope and dignity through healing, with a partnership in the journey of CKD care.

References:

1. Swarna SS, Aziz K, Zubair T, Qadir N, Khan M. Pruritus Associated With Chronic Kidney Disease: A Comprehensive Literature Review. Cureus. 2019 Jul 28;11(7):e5256. doi: 10.7759/cureus.5256. PMID: 31572641; PMCID: PMC6760874.
2. Aresté N, Sanchez-Alvarez JE, Prieto-Velasco M, Molina P, Esteve-Simó V, Ojeda R, Buades JM, Goicoechea M, Sanchez-Villanueva R, Bezhold GA, Pérez-Morales RE, Santos AB, Peiró-Jordan R, Arenas MD; Pruritus Week Group. Prevalence and severity of pruritus in Spanish patients with chronic kidney disease and impact on quality of life: a cross-sectional study. Clin Kidney J. 2023 Mar 23;16(6):1035-1037. doi: 10.1093/ckj/sfac246. PMID: 37260996; PMCID: PMC10229293.
3. Hector Alvarado Verduzco, S.S., CKD-Associated Pruritus: New Insights Into Diagnosis, Pathogenesis, and Management. Kidney International Reports, 2020. 5: p. 1387–1402.
4. Fishbane, S., et al., Randomized Controlled Trial of Difelikefalin for Chronic Pruritus in Hemodialysis Patients. Kidney Int Rep, 2020. 5(5): p. 600-610.
5. Molina, P., et al., Etiopathogenesis of chronic kidney disease associated pruritus: putting the pieces of the puzzle together. Nefrologia (Engl Ed), 2023. 43(1): p. 48-62.
6. Manenti, L. and E. Leuci, Do you feel itchy? A guide towards diagnosis and measurement of chronic kidney disease associated pruritus in dialysis patients. Clin Kidney J, 2021. 14(Suppl 3): p. i8-i15
7. Esteve-Simo, V., et al., Chronic Kidney Disease-Associated Pruritus and Quality of Life: Learning from Our Patients. J Clin Med, 2023. 12(13).
8. Orasan, O.H., et al., Hemodialysis Patients with Pruritus and Insomnia Have Increased Risk of Death. Blood Purif, 2020. 49(4): p. 419-425.
9. de Sequera, P., et al., Impacto del prurito asociado a la enfermedad renal crónica (Pa-ERC) en la calidad de vida de los pacientes en hemodiálisis en España. Nefrología, 2023.
10. Improving Chronic Kidney Disease-associated Pruritus (CKD-aP) patients' quality of life. European Kidney Patients

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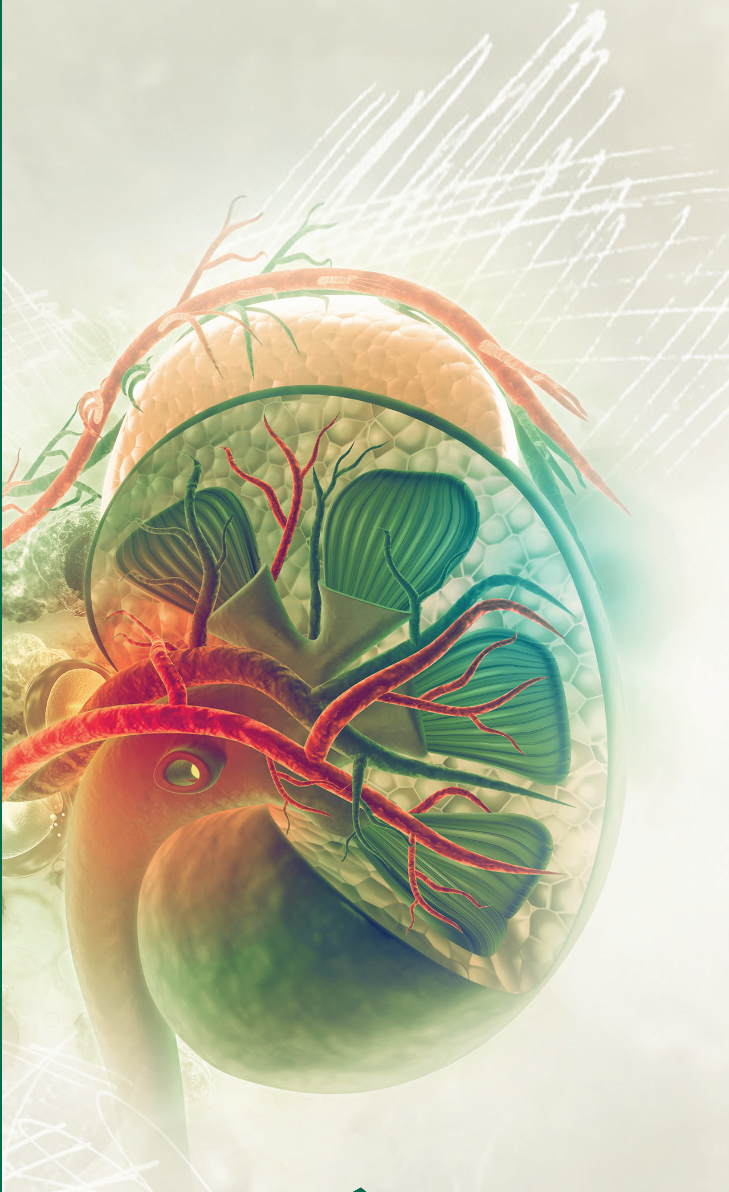

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