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KDIGO Workshop on the Nurse's Role in Managing the Symptoms of People Receiving Dialysis

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ABSTRACT

Adults with kidney failure receiving dialysis frequently report high symptom burden that can limit life participation and decrease quality of life. Fatigue, itch, pain, anxiety, depressive symptoms, sleep problems, nausea, vomiting, muscle cramps, breathlessness, and decreased cognitions can negatively impact important daily activities. Nurses are the majority health professional group providing care for people receiving dialysis and have a major role in managing these symptoms. However, routine symptom management by nurses is not universal or standardized in dialysis care. In December of 2023, Kidney Disease: Improving Global Outcomes (KDIGO) held a workshop on the Nurse's Role in Managing the Symptoms of People Receiving Dialysis. Discussion focused on the current barriers nurses face when identifying and assessing symptoms, strategies for identifying symptoms, and the ongoing monitoring and management of symptoms. Nephrology nurses are pivotal in supporting the person with kidney failure receiving dialysis to minimise symptoms, optimise symptom management, decrease dialysis treatment burden, and improve life participation and quality of life.

INTRODUCTION

Adults undergoing maintenance dialysis for kidney failure frequently experience a wide range of symptoms, such as fatigue, pain, anxiety, and itch, which can negatively impact important daily activities and the quality of life.[1,2] Yet, despite symptom frequency and impact, dialysis-associated symptoms can be challenging for healthcare professionals to assess, evaluate, and manage. When symptoms are identified, they may have uncertain causes and few or no specific treatments. With increasing treatment options specifically indicated for dialysis, recognition and acknowledgment of symptoms by healthcare professionals is a necessary first step toward alleviating them.

Kidney Disease: Improving Global Outcomes (KDIGO) held a Controversies Conference on Symptom-Based Complications in Dialysis in May 2022 to focus on strategies for assessment, management, and follow-up of symptoms associated with maintenance dialysis.[3] Participants included physicians, patients, behavioural therapists, nurses, pharmacists, and clinical researchers. Throughout the meeting, participants emphasized communication between patients and healthcare providers as a vital step for eliciting patient experiences and perspectives to best prioritize management of symptoms associated with maintenance dialysis.[3]

Nephrology nurses are uniquely positioned to establish the essential rapport and open communication with adults undergoing dialysis to optimise quality healthcare.[4, 5] Reflecting on their experience at the 2022 KDIGO Controversies Conference, participating nephrology nurses discussed in a 2023 paper key issues related to symptom assessment and management that nephrology nursing can address.[6] To build on this discussion, in December of 2023 KDIGO held a one-day workshop, The Nurse's Role in Managing the Symptoms of People Receiving Dialysis, to collaboratively develop and recommend processes for nurses in capturing and managing dialysis-associated symptoms. Among the 20 participants were

nephrology nurses, individuals with kidney failure, nephrologists, a psychologist, and representatives from dialysis providers. Here we summarize deliberations amongst participants and describe strategies for supporting nurses in caring for individuals undergoing maintenance dialysis.

CURRENT BARRIERS TO IDENTIFYING SYMPTOMS

Nephrology nurses are pivotal to identifying the symptoms suffered by people receiving dialysis. Despite this critical role, some barriers may limit nurses' ability to effectively recognise and assess these symptoms. The key barriers faced by nurses in identifying and measuring dialysis-associated symptoms include the varying diversity of symptoms,[7] knowledge limitations,[8] lack of privacy in the dialysis unit,[9] cultural issues,[10] and, for home dialysis, fewer clinician/patient interactions.[11]

Symptom Diversity

The symptoms experienced by individuals undergoing dialysis are diverse and can arise from various physiological and psychosocial factors. Common symptoms include fatigue, nausea, vomiting, muscle cramps, itch, breathlessness, decreased cognition, anxiety, depression, and sexual difficulties.[12] This diversity reflects the reality that clusters of symptoms have demonstrated interrelationships.[13] Also, validated questionnaires for specific symptoms are not always available or translated for target languages. Symptoms may have multiple underlying causes, including electrolyte imbalances, fluid overload, various pathophysiologies, and dialysis treatment factors.[14] Moreover, the severity and burden of symptoms can vary significantly among patients, depending on factors such as age, comorbidity burden, dialysis modality, self-management skills, and treatment adherence.[15] Symptoms may be highly prevalent and severe but not frequent or distressing. This variability adds to the complexity of recognition, assessment, and measurement of symptoms.

Knowledge Limitations

Nurses require knowledge of the many potential impacts of CKD and the mechanisms and complications of dialysis as well as strategies for shared decision-making and self-management support. However, studies have indicated gaps in nurses' knowledge regarding CKD and dialysis management, particularly among those with limited experience or education in nephrology nursing.[16] The reality in many dialysis programs is a variation in nursing qualifications, knowledge, and experience, leading to an over-reliance on local, historical, and non-evidence based practices.[17] This may lead to nurses being unable to differentiate between dialysis-related and non-dialysis related symptoms (for example different types of itch[18]). To complicate this even further, patients can have emotional or psychological challenges beyond the scope of nephrology nurse education, which includes limited mental health education.[19]

Dialysis Clinic Privacy

Privacy concerns in the dialysis environment can hinder open communication between patients and nurses, impeding the accurate identification and management of dialysis-related symptoms. Dialysis clinics can be non-private clinical environments where patients receive treatment near one another, limiting opportunities for confidential discussions and assessments.[20] Patients may feel uncomfortable discussing sensitive symptoms or concerns in such settings, fearing embarrassment, multiple subsequent investigations, or being labelled as a needy patient.[21] Where resources allow, efforts should be made to facilitate private discussions in spaces away from the main dialysis treatment area.

Cultural Factors

Cultural factors play a crucial role in shaping patient experiences of dialysis and willingness to report symptoms to healthcare providers. Cultural beliefs, values, support

networks, and practices related to health and illness can influence an individual's perceptions of symptoms, their help-seeking behaviours, and their interactions with healthcare professionals.[22] Some patients may feel that they are bothering nurses reporting subjective symptoms that are not a priority in the nurse's workload.[23] Language barriers, cultural taboos, and mistrust of the healthcare system may further complicate communication between nurses and patients from diverse cultural backgrounds.[24] Nurses must be culturally competent, sensitive, and responsive to the needs of diverse patient populations to effectively identify and address dialysis symptoms.[25]

Home Dialysis Context

The increasing prevalence of home dialysis modalities presents unique challenges for nurses in identifying and managing symptoms. Having fewer in-person interactions with nurses and other healthcare providers reduces the frequency of face-to-face visits, limiting opportunities to assess symptoms, monitor treatment adherence, and provide timely discussions, support, and interventions for complications.[26] In addition, in some regions people dialysing at home may under-report symptoms for fear of having to go back to centre dialysis.[27] Opportunities for automated and digital applications may improve communication, thus supporting dialysis symptom reporting and assessment.[28]

STRATEGIES FOR IDENTIFYING AND MANAGING SYMPTOMS

Identifying, recording, and reporting symptoms requires a comprehensive understanding of underlying causes, proficiency using technology and measurement tools, and communication skills. Strategies to enhance the identification and recording of dialysis symptoms include the use of patient-reported outcome measures (PROMs), technology-assisted approaches, nursing education in dialysis symptoms, and the development of communication competencies and patient education strategies.

Patient-Reported Outcome Measures

PROMs enable patients to self-report the presence and extent of symptoms.[29-31] PROMs collection provides opportunities for patients to identify symptoms, which nephrology nurses can then address in relation to what is important in the patient's life. Nurses are then in a position to support the person on dialysis in shared decision-making and self-management of symptoms.[32] Validated tools such as the Integrated Palliative Care Outcome Scale Renal (I-POS Renal), the Dialysis Symptom Index (DSI), and the Edmonton Symptom Assessment System (ESAS), have been developed specifically for assessing symptomatology in people receiving dialysis (Table 1).[33] If a symptom is identified, then a more specific symptom-focussed tool can be used. Frequently, symptoms could overlap (e.g. fatigue and depressive symptoms), which can limit the addressment of a specific symptom.[34] Furthermore, challenges to PROM tool implementation have been consumer indifference to PROMs, scepticism on the benefits of PROM data, and the limited treatment options open to clinicians.[35] Strategies that nurses can use to increase use of tools include education regarding the use of PROMs during the implementation, quick gains from using PROMs such as receiving instant feedback, and a clear ambition on patient care such as a shared view on patient involvement and management support.[35, 36]

Technology-Based Strategies

Integrating PROMs with technology offers a valuable approach to identifying and documenting symptoms.[29] Technology-enabled platforms, including mobile applications and web-based portals, may facilitate the collection of PROM data, ideally allowing nurses to monitor symptoms remotely and intervene proactively. Using an application for data storage with the nurse entering patient report at the dialysis session has shown promising feasibility.[37, 38] Thoughtful implementation is important to avoid mobile applications or checklists from becoming time-consuming, bureaucratic tasks.

Despite the potential benefits of technology in symptom monitoring, several challenges hinder widespread implementation in dialysis settings. These include financial constraints, interoperability issues between different health information technology systems, and concerns regarding data privacy and security.[39] Additionally, technological solutions may not be accessible or user-friendly for all patients.[40] Addressing these challenges necessitates collaborative efforts between healthcare stakeholders, including policymakers, technology developers, nephrologists, and nephrology nurses to develop sustainable and scalable solutions that meet the unique needs of people requiring dialysis.

Self-Management Support

While proficiencies in dialysis machine operation, cannulation skills, and patient safety are essential, nephrology nurses must possess a broader knowledge base to effectively identify, document, and develop a shared plan with the patient experiencing the symptoms.[41] This requires nurses to have the knowledge, skills, and confidence in implementing patient-centred approaches and shared decision-making principles.[42] This includes a mutual understanding of the multifactorial nature of dialysis-related symptoms, the interplay between comorbidities and dialysis treatment, and the psychosocial factors influencing symptom experiences.[43] Thus, nurses require competency in symptom management and self-management approaches along with the more traditional dialysis competencies.

Nurse Coaching

The capacity for nurses to act as “patient coaches” can empower nurses to engage effectively with patients, elicit symptom information, identify barriers to self-management, and foster therapeutic relationships.[44] Specific directive techniques such as motivational interviewing can help successfully activate patients to self-manage their care.[45] Empowering nurses to engage more effectively with improved communication techniques can increase

their confidence to facilitate collaborative communication, coordinate care efforts, and address complex symptom management challenges.

Patient Peer Support

Patient peer education programmes can provide comprehensive and easy-to-understand information on the causes and manifestations of dialysis symptoms, as well as practical strategies for symptom mitigation and self-management.[7] To enhance patient empowerment, structured, resourced peer support programmes, facilitated by trained peer mentors or support groups, can offer valuable informational, emotional, and social support to patients navigating dialysis treatment.[46, 47] Given that many patients receive poor-quality web-based dialysis information, peers can promote reputable online resources and help patients make informed decisions about their symptoms and care. Furthermore, peer support can validate symptoms as likely being dialysis-related and give individuals confidence to report them and seek help.[48]

ONGOING MONITORING OF DIALYSIS SYMPTOMS

Nurses are pivotal in the ongoing monitoring of symptoms following treatment. Leveraging technology and PROMs can enhance symptom monitoring and contribute to nursing management. Mobile applications and digital platforms offer opportunities for patients to self-report their symptoms and communicate with clinicians.[49] These technologies enable healthcare providers to adjust treatment plans based on symptom severity and progression.

The IPOS-Renal, DSI, and ESAS facilitate symptom monitoring and enable longitudinal tracking of symptom trajectories over time, allowing for early identification of worsening symptoms and adjustment of treatment strategies.[50] The DSI was selected by Dutch patients as the optimal questionnaire for routine symptom assessment given its low-burden and symptom completeness.[51] The completeness is especially important given the

broad spectrum of physical and emotional symptoms that people on dialysis experience, with many common symptoms bundling and interacting, such as fatigue, itch, sleep disturbances, and depressive symptoms.

Beyond the generic symptom tools, more specific ones for common symptoms can be used to individualise care. These provide information on symptom occurrence, severity, and burden and can be used for assessment over time. For example, fatigue, the most prevalent distressing symptom for chronic kidney disease, can further be assessed with fatigue-specific scales such as Fatigue Severity Scale[52, 53] and the FACIT Fatigue Scale.[54] For another prevalent and often severe symptom, chronic kidney disease-associated pruritis (CKD-aP), there are short scales that nurses can use to track and measure an individual's CKD-aP trajectory. Measurement tools range from one-item tools such as the Worst Itching Intensity Numeric Rating Scale,[55] Numeric Rating Scale,[56] Visual Analog Scale,[57] Verbal Rating Scale,[56] Dynamic Pruritus Score,[58] Patient Global Impression of Change,[55] through to the 5-D Itch Scale that measures the duration, degree, direction, disability, and distribution of pruritus.[59]

Frequency and Timing

Measuring the effectiveness of interventions (pharmacological and non-pharmacological) and making timely adjustments to treatment plans is critical. Evaluation should be conducted at regular intervals based on the severity and stability of symptoms as well as the patient's response to treatment.[36, 60] For acute symptoms requiring immediate intervention, evaluation (e.g., using a symptom-specific PROM) may occur within hours to days, whereas for chronic symptoms, reassessments may be scheduled at longer intervals (e.g., weeks to months, using a more complete dialysis-symptoms PROM). It is imperative that nurses use opportune moments throughout their day to assess, manage, and informally loop back with individuals regarding their dialysis symptoms.[6] Although evaluation can be

led by nurses, they should involve multidisciplinary collaboration between nephrologists, dialysis technicians, dietitians, pharmacists, and other allied healthcare professionals to ensure comprehensive symptom management.[21] Additionally, patient engagement and shared decision-making are paramount in determining the frequency and timing of reassessments, as patient preferences and priorities may vary depending on their individual circumstances and treatment goals.

THE ROLE OF NURSING IN DIALYSIS SYMPTOM MANAGEMENT

Among clinical professionals, nurses spend the most time with individuals receiving dialysis.[17] The Symptom Management Theory simplifies the role into three interactive steps: 1) symptom experience, which is a simultaneous perception, evaluation, and response to a change in one's usual feeling; 2) symptom management strategies, which are efforts to avert, delay, or minimise the symptom experience; and 3) symptom outcomes, which are clear and measurable outcomes to assess before and after implementing an intervention strategy.[61] Expanding the capacity of nurses to manage symptoms requires leadership skills, advanced practice education, and visibility within governing bodies.

Empowering Nurses to be Leaders

Empowering nurses to take on clinical leadership roles in symptom management is paramount. In many regions of the world, the role of nurses in dialysis predominantly involves carrying out physician orders.[62] However, because nurses spend the most time with people receiving dialysis, they can act as advocates to ensure symptom management needs are effectively communicated and addressed by other members of the healthcare team.[63] With education and experience regarding dialysis and its associated symptoms, nurses are well-equipped to lead symptom management initiatives throughout the patient pathway.[64] This

collaborative approach enhances the overall quality of care provided on dialysis, ultimately leading to improved clinical and patient-reported outcomes and patient satisfaction.

It is important to recognise that there are differing roles with nephrology nursing. All nephrology nurses working in a dialysis setting regardless of job title require skills and education to actively lead and manage symptom burden. There is some evidence supporting use of advanced and specialised roles to enhance the management of complex symptoms associated with dialysis.[6] Although advanced roles may not be feasible in less-resourced regions, the advantages of advanced roles that take on previous medical domains can establish strong therapeutic relationships with patients and their families, ensuring ongoing support and education regarding symptom management strategies. This continuity of care can enhance patient adherence to treatment regimens and also fosters trust and rapport between patients and healthcare providers.[65]

Nephrology Nursing Leadership

To advocate effectively for the symptom management needs of people receiving dialysis, nurses must provide leadership and increase visibility within governing bodies and policy-making organizations, including dialysis provider organisations. Nurses possess valuable insights and perspectives derived from their frontline experiences caring for people receiving dialysis, making their input essential in shaping healthcare policies and guidelines related to symptom management.[6] Increasing the profile of nephrology nurses requires drawing attention to the unique set of skills, knowledge, and expertise they offer to patient care; advocating for their representation in debates about healthcare policy; and raising the general understanding of kidney disease and its complications.

The 2023 Nurse's Role in Managing the Symptoms of People Receiving Dialysis one-day workshop was convened to collaboratively develop and recommend processes for nurses in capturing and managing dialysis-associated symptoms. Scope for discussion was focused

and therefore limited. Important aspects such as symptoms in children receiving dialysis and the role of the caregivers were not covered. These aspects are recommended to be included in future meetings and reports. Furthermore, it was beyond the scope of this workshop and paper to report on all previous nursing-led research on dialysis symptoms.

By actively participating in quality improvement in providing dialysis, professional organizations, and advocacy initiatives, nurses can advocate for patients and for their crucial role in symptom management and can influence decision-making processes at local, national, and international levels. This enhanced leadership can enable nurses to advocate for policies that prioritize patient-centred care and support innovative approaches to symptom management in dialysis settings. Enhanced leadership can promote the optimal requirements in the patient/nurse relationship, nurse education, care by dialysis clinics and providers, and nursing profession domains (Table 2).

CONCLUSION

Nephrology nurses play a crucial role in alleviating the symptom burden for people with kidney failure receiving dialysis. Nurses can address barriers when identifying and assessing symptoms and provide strategies for managing symptoms in partnership with the person receiving dialysis. Thus, nephrology nurses are pivotal in supporting the person to optimise symptom management, minimise symptoms, decrease dialysis treatment burden and improve life participation and quality of life.

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Table 1. Clinically pragmatic tools for capturing patient-reported symptoms

Tool name	Web link	Descriptor	Applicability
Integrated Palliative Care Symptom Renal	https://pos-pal.org/maix/ipos-renal-in-english.php	Eleven items: symptoms and concerns	Can be tracked longitudinally; available in many languages
Edmonton Symptom Assessment System-r	https://www.albertahealthservices.ca/assets/info/peolc/if-peolc-ed-esasr-admin-manual.pdf	Nine common symptoms	Short, can be tracked longitudinally; available in many languages
Dialysis Symptom Index	https://www.jpsmjournal.com/article/S0885-3924(03)00517-7/pdf	Thirty items: physical and emotional	Can be tracked longitudinally; available in many languages
Chronic Kidney Disease Symptom Burden Index	https://onlinelibrary.wiley.com/doi/full/10.1111/jorc.12152	Assesses the prevalence, distress, severity, and frequency of 32 symptoms. Other symptoms can be added	Can be tracked longitudinally. Assesses symptom burden at all CKD stags and treatment modalities

Table 2. Elements of symptom management

Context	Elements	
	Minimal	**Additional optimal**
Nurse/patient moments	• Ask, affirm, assess, alleviate. • Trust and rapport development • Face-to-face education • Refer symptoms to multi-disciplinary team	• Structured nurse/patient symptom assessment
Nephrology nurse education	• Continuous professional development	• Evidence-based research education • Knowledge of assessment tools • Leadership of symptom quality improvement projects • Onboarding of nurses that includes focus on symptom assessment and management
Dialysis clinic	• Informal symptom meetings/huddles • Management support for routine symptom assessment	• Informal/formal symptom meetings/huddles • Leadership, coaching, mentorship • Patient peer support facilitation • Patient acuity system
Dialysis provider	• Programs for staff education • Symptom assessment tools (paper/digital)	• Mandatory symptom education • Digital symptom management systems • Professional external education and support • Support for research projects on symptom assessment and management • Development of key performance indicators including symptom assessment and management
Nursing profession	• Nursing professional organisation advocacy • Continued professional development programs	• Nephrology nursing patient symptom competencies • Nurse-led symptom research support

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