Evaluating nurses’ action outcomes and exploring their perspectives of implementing the POS-S (Renal) assessment tool for haemodialysis patients

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Abstract

Background Globally, nurses working in haemodialysis settings face challenges caring for a growing population of older and sicker people with end-stage kidney disease (ESKD). This study aimed to formally evaluate nurses’ action outcomes and explore their perspectives of the implementation of the Patient Outcome Scale-symptom (Renal Version) (POS-S [Renal]) assessment tool as a strategy to assist with addressing symptom burden, advance care planning (ACP) and quality end-of-life (EoL) care for patients, their families and carers in an Australian regional location.

Method An ethics-approved, sequential, mixed-method design was used comprising two-year retrospective audit of patient symptom reporting followed by thematic analysis of focus groups with nurses.

Findings Between 11% and 24% of patients (n=54) indicated moderate to severe symptom burden. Half or more of these ratings had a corresponding progress note and a nursing action. Analysis of focus groups discussions revealed increased confidence/willingness to take ownership to effect change within nursing roles, co-existing with prevailing personal, cultural and structural barriers which create a sense of powerlessness to effect further change.

Conclusion The POS-S (Renal) tool is useful for identifying and tracking symptom deterioration, supporting nurse-led actions to address chronic symptom burden and as a prompt for commencing conversations about EoL. Renal nurses in regional dialysis settings face many challenges and require ongoing support and assistance to progress towards the adoption of timely ACP and the provision of patient-centred EoL care to their patients.

Keywords Renal nurse, supportive care, haemodialysis, POS-S (Renal) tool, ACP, EoL.

Introduction

Internationally, the notion of a ‘good death’, which is planned and focused on the patients’ individual needs and wishes, is becoming an accepted goal for clinical care. Timely, sensitive and individualised advance care planning (ACP) discussions are valued by patients with specific life-limiting conditions, such as end-stage kidney disease (ESKD). This allows them to avoid unwanted medical interventions, helping them prepare for death, achieve a sense of control and relieve burden on others (Holley & Davison, 2015; Stallworthy, 2013; Patel & Baharani, 2016). Early initiation of ACP discussions is especially

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important for people with ESKD, who may lose the capacity to make decisions or communicate about their end of life (EoL) wishes and preferences (Detering et al., 2010). Even though ACP is now becoming embedded into Australian health service funding, and early and regularly updated ACP discussions are widely recommended, health care professionals (HCP) at all levels find this a difficult concept to implement. The culture around death discussion and preparation for dying has been slow to change (Egan et al., 2015; Goff et al., 2015; Bristowe et al., 2015).

Although the incidence rates are stabilising in developed countries, the prevalence of people dying with ESKD in Australia remains significant (Wetmore & Collins, 2016; ANZDATA, 2016). These patients are generally older, have complex care needs and multiple comorbidities with symptom burden similar to patients with cancer or end-stage heart failure (Murtagh et al., 2007; Brown et al., 2013). Providing good EoL care, which incorporates the management of symptom burden and emotional changes to help the patient and those around them prepare for death, is dependent on recognising patients who are reaching EoL (Davison et al., 2015). In practice, issues relating to death and dying are first considered only when there is significant deterioration or a medical crisis occurs (Schell et al., 2012; Pollock & Wilson, 2015; Lazenby et al., 2016). This is often due to the discomfort of their HCPs who may avoid these conversations or assume someone else is responsible (Davison et al., 2015; Hancock et al., 2007). The international nephrology community recognises the difficulty and importance of EoL care, and has been responding to the growing demand to develop recommendations and guidelines that will embed renal supportive care into practice (Davison et al., 2015; Brown et al., 2013; PCA/KHA, 2013; Department of Health Victoria, 2013; WA Department of Health, 2012; Josland et al., 2012).

For renal nurses, implementing these new directions requires a significant shift in practice. Traditionally, the predominant focus of their practice has been on the biochemical, mechanical, monitoring and evaluative aspects of dialysis therapy, with the aim of optimising treatment outcomes for patients with chronic kidney disease (CKD) (Johnson & Bonner, 2004; Patel, & Baharani, 2016). Active treatment remains an important aspect of the renal nurses’ role, but as more patients move towards advanced ESKD, nurses face new emotive and ethical challenges in managing complex physical and psychological symptom burden, facilitating ACP and delivering quality physical and psychological symptom care at EoL (Kane et al., 2013; Smith et al., 2016).

While there has been limited exploration of the issues encountered by renal nurses, (Smith et al., 2016) the international literature does indicate that general nurses encounter difficulties managing EoL care, with death anxiety and personal attitudes towards death and dying influencing the quality of care that nurses provide during the terminal stages of a person’s life (Peters et al., 2013). In Australia, patient withdrawal from dialysis has a seriously under-recognised impact on renal nurses (Johnson & Bonner, 2004), amplified by the long-established and intense nurse–patient relationships and nurses’ difficulty coping with death and dying contributing to high levels of burnout (Hayes et al., 2015). There has also been an increased geographical distribution of services over the last two decades, with a disproportionate number of the population receiving kidney replacement therapy (KRT) in rural and regional satellite services. These services are staffed by nurses who often have limited access to specialist multidisciplinary expertise and guidance to implement supportive care models (May, 2013).

Given that patients with ESKD rely heavily on their HCPs as a source of information and support (Davison, 2010; Goff et al., 2015), it is concerning that nurses, as part of the health care team, may often be unaware of the magnitude of symptom burden in their patients (Feldman et al., 2013) even though treatable symptoms such as pain, depression and anxiety have been identified as some of the most prevalent high-rating symptoms for people with ESKD (Brennan et al., 2015; Murtagh et al., 2007) Nurses highlight barriers, such as management structures, which may lead to a lack of ownership for assessing and treating symptoms, accompanied by a perception that some symptoms are “untreatable” (Lazenby, 2016; Feldman et al., 2013).

The provision of structured guidance and practical tools (You & Fowler, 2014), to regularly identify, manage and track symptom burden with their patients, offers a meaningful starting point for enhancing nurses’ confidence to address EoL issues, allowing active treatment to sit alongside supportive care. One internationally recommended tool for assessing symptom burden in renal care is the Patient Outcome Scale symptom module (Renal Version) (POS-S [Renal]). This tool was adapted and validated for renal patients from the Palliative Outcome Scale assessment tool, originally developed for palliative care by Hearn and Higginson in 1999 (Kane et al., 2013; Murphy et al., 2009). It is a simple 17-item scale requiring the patient or HCP to rate physical, psychological and emotional symptoms, using a Likert scale where 0 is best and 5 is worst. This tool allows information about symptoms to be collated (Murphy et al., 2009; Brennan et al., 2015; PCA/KHA, 2013) so that HCPs and patients can address symptoms and track deterioration over time.

Following concerns raised by patients and families, a regional dialysis service and community palliative care service
commenced a collaboration to improve EoL care for dialysis patients with ESKD. At this time, there were no formal processes in place to support the multidisciplinary team (MDT) to systematically identify, address and track patient symptom burden or to identify when patients were approaching EoL. The community palliative care clinical nurse specialist recommended to the MDT, comprising the community palliative care team, renal nurses, social worker and nephrologist, that renal nurses would introduce the POS-S (Renal) tool into their practice. Given the limited resources of the social worker and nephrologist, this became a nurse-led partnership, supported by the MDT. The aim was for the renal nurses to identify and address patients’ symptom burden, track symptom deterioration and use this information to start conversations with patients about EoL issues. The community palliative care nurse provided education introducing contemporary palliative approaches and how and when to use the POS-S (Renal) tool. Implementation was managed by the renal nurse champion and nurse unit manager and supported by the community palliative care clinical nurse specialist.

Initially, patients were encouraged to complete the tool independently, but it was quickly found that conversations about symptom deterioration and EoL would be more effectively broached when nurses and patients completed the tool together. A framework was developed which described the use of the tool at pre-dialysis, six weeks post commencing dialysis and on a 6- to 12-monthly basis, or as needed, based on nurses’ clinical judgement. The framework described the specific actions nurses could take to address patient-identified symptom burden, including recommending further assessment by the nephrologist, modifying the care plan and making referrals to other medical/allied services. Nurse-led referrals were introduced. Patients were able to access both active treatment from the dialysis unit and palliative care from the community palliative care team for the first time, supported by regular multidisciplinary clinical review of shared patients.

The aim of this study has been to formally evaluate renal nurses’ action outcomes and explore their perspectives on the implementation of the POS-S (Renal) tool as a strategy for identifying and addressing symptom burden, facilitating ACP and improving quality EoL outcomes for patients in receipt of KRT.

**Methodology**

A two-phase, sequential, mixed-method approach was used. Phase 1 was a two-year retrospective audit of completed POS-S (Renal) tools. The audit tracked whether pain, depression and anxiety were rated 3 or greater on the POS-S (Renal) tool, indicating moderate to severe symptom burden, and whether this was documented in the corresponding progress notes with nursing action outcomes relating to the three symptoms. The audit results informed Phase 2, which comprised two facilitated focus groups with dialysis nurses using open-ended questions and follow-up probes. The other members of the MDT (social worker, nephrologist and community palliative care team) were excluded from the focus groups because they had not completed POS-S (Renal) tools with patients during the audit period.

**Analysis**

Descriptive statistics were used to summarise the patient demographics. Documentation was reviewed to assess whether contemporaneous progress notes and nursing action outcomes corresponded with the POS-S (Renal) tool patient rating. The facilitator and note taker independently summarised the key points of discussion from the focus group transcripts using thematic analysis. The transcripts were coded into clusters of common elements. The use of positive and negative terms was also coded, in context, to provide a meaningful overview of nurses’ perspectives. These clusters were aligned under two global themes.

**Ethical considerations**

This study was approved by the Human Research Ethics Committee (HREC) board of Ballarat Health Services and St John of God Hospital on 16 March 2015. Data collected from the patient records were de-identified. An exemption for patient consent was obtained. Informed consent was obtained in writing, from the focus group participants, including advice that participants were free to withdraw from the study at any time. The transcripts were anonymised.

**Findings**

**Phase 1:** Ninety-six per cent (n=54) of patients completed at least one POS-S (Renal) tool. Sixty-nine per cent (n=39) of patients were male and 74% of patients were aged 60 years or over. Eighteen per cent of patients had a dual diagnosis of malignant carcinoma including multiple myeloma, lymphoma, colon, liver carcinoma, metastatic prostate carcinoma.

Forty-two patients (77%) completed between two and five POS-S (Renal) tools within the audit period. Seven patients died within the study period. Three of those patients were concurrently accessing a palliative care service. Two of the three new patients who commenced dialysis during the audit period completed a POS-S (Renal) tool pre-dialysis. When a further POS-S (Renal) tool was completed three to six months later, both patients rated improved symptoms of depression and anxiety. Between 11% and 24% of patients rated pain, depression or anxiety at 3 or greater, indicating moderate
to severe symptom burden. Half or more of these ratings had a corresponding progress note and a nursing action, as shown in Figure 1. Nursing actions included completion of the Depression & Anxiety Symptom Scale (DASS) assessment tool (Lovibond & Lovibond, 1995), referral to a social worker, referral to a palliative care service or a care plan review.

**Phase 2:** Following the completion of the audit, two independently facilitated focus groups were conducted with seven and four participants respectively, which equates to a 61% participation rate.

Two key themes emerged from the focus group discussions:

1. **Where the implementation and use of the tool has clarified aspects of the dialysis nurses’ role there has been increased nurse confidence and a willingness to take ownership to effect change.**

Implementing the POS-S (Renal) tool was a nurse-led initiative which helped nurses to address their concerns about starting EoL conversations.

Nurses reported that the POS-S (Renal) tool triggers good conversations with patients and helps them to link symptoms together. It has helped nurses who aren’t comfortable speaking with patients about EoL and provides a guide for new staff.

“We previously if we became concerned about patients, they were having too much trouble and we were going to stop dialysis, we had trouble opening up the conversation”

Using the tool with patients helps both nurses and patients to pinpoint chronic symptoms of concern especially when patients have become used to their symptoms.

“They are so used to feeling like that, they forget it is troublesome”

While nurses continue to identify and act on acute symptoms, without reference to the POS-S (Renal) tool, using the tool provides data about chronic symptom deterioration, which allows nurses to share care more effectively with the MDT.

“We can refer to a social worker, dietician, address constipation, or advise nephrologist who can adjust treatment”

Nurses identified problems and made process improvements.

Nurses made changes to the way the tool was administered to make it more effective in starting conversations with patients about EoL.

“Initially just gave the tool to patients, but that didn’t start the conversations, so now nurses do it with patient”

When nurses had issues with identifying actions to address symptoms, they changed the process to make it easier for nurses to use.

“We changed the tool to include the DASS [Depression and Anxiety Symptom Scale]”

“We now have plans to make this simpler and link patients to social worker”

Establishing a framework for renal and community palliative care nurses to use led to more effective collaboration across the MDT. It opened up a nurse-led referral pathway to community palliative care and regular clinical reviews of
shared patients, which had not existed before. Using a nurse champion model within the dialysis unit and a coordinating nurse within the community palliative care service was perceived as an effective implementation strategy.

After implementation of the POS-S (Renal) tool nurses wanted more ownership.

“During implementation we needed someone to keep track, now we need to be given ownership and responsibility”

Nurses want the symptom data from the tool to be collated and to be more accessible within the medical record. Nurses described the benefits of regular monitoring, measuring and documentation, to enable them to track and report on the trajectory of symptoms over time.

Nurses did not want the tool to replace their experience and professional judgement and wanted to be able to incorporate their own style and timing for starting EoL conversations.

Nurses also reported volunteering for a nurse-led ACP trial within the health service.

2. Implementation and use of the POS-S (Renal) tool has brought to the surface prevailing personal, cultural and structural obstacles around good EoL care, highlighting the areas where there is a perceived sense of powerlessness to effect further change.

Personal obstacles

Nurses noted the limitations of implementing a tool, to deliver improvements in symptom identification, as a method for prompting EoL care discussions.

“They are like family”

“It is hard to say there isn’t much more we can do for you”

“[The] reality is, not everyone is comfortable having these conversations”

In some cases, nurses may have known the patient for 10 years, and there is a perception that this makes the conversation harder to broach.

Cultural obstacles

Nurses’ comments highlighted the normalisation of symptoms for both nurses and patients and the perceived reluctance of patients to engage in conversations about their symptoms and EoL.

“We have many healthy patients who don’t have many symptoms and just want to be normal”

“Patients have a culture of not wanting to bother nurses”

“You may have an] “angry family who don’t want to stop [dialysis]”

Nurses’ comments also highlighted their dilemma about how to manage their changing roles and responsibilities. Nurses did not highlight lack of time as a significant issue in relation to completing the tool. However, nurses did indicate some resistance to the expansion of their role in relation to having difficult conversations about EoL, described as a lack of allocated time.

“We have no time allocated to having these discussions”

“Our role is to administer dialysis”

Nurses also noted that EoL discussions need to be conducted in private and the open setting of the dialysis unit makes this impossible.

Structural obstacles

Nurses noted that the policy of the health service requires doctors, such as the nephrologist, to complete an ACP, which includes Goals of Care (a clinical framework for the limitation of medical treatment) (Thomas et al., 2014). This means that nurses are not permitted to complete or review ACP documentation, even if they had commenced an EoL conversation with the patient, using the POS-S (Renal) tool as a prompt. Nurses agreed that discussion about EoL should start before dialysis commences, suggesting that the patient’s general practitioner (GP) may be better placed to complete ACP documentation.

“Are we the best people to be having the conversation with patients?”

Discussion

The findings support the concept that regular tracking of symptom burden can help raise renal nurses’ awareness of the need to support and prepare the patient, and those around them, for EoL. Without adequate tools and guidance, nurse-led discussions with patients about their symptom burden and EoL care needs do not regularly take place, despite the knowledge that the patient group is becoming older, experiencing multiple comorbidities and increasing symptom burden. With the support of clear decision pathways, nurses report improved confidence and willingness to take action to address chronic symptoms and commence EoL conversations with their patients.

The findings demonstrate that most nurses in the dialysis unit did want to effect change. The introduction of the POS-S
(Renal) tool was initiated by the nursing staff at the ‘grassroots’ level, to address their concern that patient needs were not being met. Being involved in the decision-making process provided an incentive to actively implement change, delivering increased confidence and a willingness to take more ownership of symptom management and commencing EoL conversations with patients. Using a nurse-led approach, managed by a nurse champion working in close collaboration with the community palliative care team, has been an effective method for driving change in practice. However, integrating the tool into the medical record and delegating more responsibility to nurses for managing regular reviews earlier may have led to more consistent documentation of patient symptom ratings and nursing action outcomes. One of the benefits of using a standardised tool, highlighted by the nurses, is the capacity it provides to track and monitor symptoms over time. As the team of renal nurses take more responsibility for identifying and addressing symptom burden with their patients, the nurse champion could continue to support the nurses by collating and reporting data and facilitating ongoing nurse education and support.

This study has brought into focus some of the personal, cultural and structural barriers renal nurses experience, as the obligations of their role expand. Nurses are required to continue to provide active treatment, as well as consider the impact of the disease, the efficacy of the treatment and the individual needs and wishes of the patient as they approach EoL. Personal attitudes towards death and dying are uncovered, and the reluctance to broach EoL care needs with patients is expressed as uncertainty about the demarcation of roles within the treating team.

The other barriers to changing practice identified in this study are consistent with the literature. Nurses describe aspects of the dialysis unit culture which make initiating EoL discussion problematic for them, including the lack of privacy, the unique, long-standing nature of renal nurses’ relationships with patients, patients’ perceived desire not to ‘bother’ the nurses and patients’ perceived reluctance to talk about their health. Resistance to expanding the nursing role, to include having difficult conversations, was expressed as a lack of allocated time. Interestingly, lack of time in relation to completing the tool, was not highlighted as an issue by these nurses, which suggests that it is a simple and quick tool to use. Given that patients rely heavily on their treating team for information, and nurses have substantial influence on the culture of their workplace, the onus is on nurses to establish an environment that delivers the information and support needs to each patient in a holistic, patient-centred manner. The high participation rate of patients completing the POS-S (Renal) tool in this study suggests that they are willing to discuss their symptoms and accept referrals to specialised support, including community palliative care. It also indicates the willingness of nurses’ to find time to support their patients to complete the tool.

The findings support the literature which suggests that there is currently no coordinated approach to ACP in nephrology, despite existing policies and funded programmes, and EoL conversations are often avoided until a crisis occurs. In this setting, renal nurses were able to commence conversations about EoL using the tool as a prompt, but were unable to progress with formal ACP documentation because of health service policy. The implementation of the tool encouraged nurses to question the nature and timing of these discussions; the time required for these discussions; the scope of their responsibilities when access to the MDT is limited and the role of specialists and GPs. Nurses are aware that failure to communicate with patients in a timely manner, about the realities of their prognosis, the effectiveness of dialysis and planning for EoL care can lead to unnecessary distress for patients and those around them, including the treating team. The high mortality rate of those receiving dialysis makes the preparation of patients for EoL a crucial aspect of their care.

It is clear that EoL plans of care need to become an integral part of practice and best practice guidelines and tools can support health care teams in achieving this. The findings suggest that introducing the POS-S (Renal) tool has raised nurses’ awareness of the importance of ACP, leading the unit to volunteer for a planned trial in nurse led ACP. This will provide the additional time required for nurses to conduct conversations about EoL and acknowledge renal nurses’ expanding roles and responsibilities. This exemplifies nurses’ willingness to take on more responsibility, when access to a MDT is limited, in order to deliver patient-centred care at the EoL. The provision of further education, tools and guidelines to support renal nurses to complete ACP and EoL discussions with their patients will empower them to embrace the notion of a ‘good death’ as a goal of professional practice.

**Limitations of the study**

Although this study was at a single site with a small sample sizes for both the retrospective chart audit and the focus groups, and the results not generalisable, it does add valuable insights to the growing awareness of the need for quality, compassionate, patient-centric supportive renal care for people with ESKD. The methodology limits the ability to draw causal links between implementation of the tool and the outcome of the nurse actions. This study tracked pain, depression and anxiety; however, other symptoms such as itch, tiredness, nausea, restless legs and poor appetite also warrant further investigation, when considering QoL. This study only
explored the actions and perspectives of renal nurses. It is acknowledged that the perspectives of other members of the MDT may have added further insights about the impact of the implementation of the POS-S (Renal) tool. Finally, the quality of the EoL discussions between nurses and patients was not measured in this study, which would be a priority for investigation in the future.

Implications for practice

These findings support the 2013 Palliative Care Australia & Kidney Health Australia’s Joint Position Statement call for a “National implementation of a validated tool, such as POS-S (Renal) to objectively measure the symptom burden associated with ESKD”. Successful implementation requires leadership from management, a shared care approach and a key conduit who can support nurses to adopt new approaches into their every-day practice, such as a nurse champion. In rural and regional areas, renal nurses and the community palliative care nurses form the core of the MDT, when access to allied health and specialists is limited and therefore have a significant role in identifying and addressing the changing needs of patients. These findings suggest that implementation strategies need to be regularly reviewed to ensure renal nurses’ changing needs, confidence, awareness of the issues and barriers and their willingness to increase their ownership of policies and processes as they are introduced. Utilising an action learning approach (Pedler et al., 2008) may enhance the change process.

Renal nurses, particularly those working in rural and regional dialysis settings are well placed to play a front-line role in facilitating and co-ordinating patients’ transition from a curative, restorative phase of chronic illness to a palliative, terminal phase, given adequate supports and assistance. When implementing the POS-S (Renal) tool, as part of the renal supportive care approach, consideration should be given to the quality of pre-dialysis ACP and EoL discussions; privacy in the dialysis setting; the unique nature of relationships between renal nurses and patients; renal nurses’ cultural and personal perspectives on death; supporting nurse-led referrals to other support services; and increasing responsibilities for nurses in relation to ACP and EoL, particularly where access to medical specialists and allied services may be limited.

Conclusion

This study has provided insights into the value of the POS-S (Renal) tool as a strategy for not only identifying and tracking symptom deterioration and supporting nurse-led actions to address chronic symptom burden, but also as a prompt for commencing conversations about EoL. It has also highlighted the gaps in ACP, allowing nurses to appreciate the value of timely ACP and to actively identify ways in which this area of practice can be improved to ensure their patients experience a ‘good death’.

Renal nurses in dialysis settings face a range of challenges and require ongoing support and assistance that empowers them to progress the adoption of timely ACP and the provision of quality, compassionate, patient-centric supportive renal care for people with ESKD.

References


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