

Narrative survey of renal nurses - an enquiry of challenging clinical situations with adults on haemodialysis approaching end of life

Author

Bublitz, Lorraine, Fowler, Kim-Leigh, Fulkco, Daniel, Henderson, Saras, Grealish, Laurie

Published

2017

Journal Title

Renal Society of Australasia Journal

Version

Version of Record (VoR)

Rights statement

© 2017 Renal Society of Australasia. The attached file is reproduced here in accordance with the copyright policy of the publisher. Please refer to the journal's website for access to the definitive, published version.

Downloaded from

<http://hdl.handle.net/10072/353453>

Link to published version

<http://www.renalsociety.org/journal/volume-13-no-2/>

Griffith Research Online

<https://research-repository.griffith.edu.au>

Narrative survey of renal nurses — an enquiry of challenging clinical situations with adults on haemodialysis approaching end of life

Lorraine Bublitz, Kim-Leigh Fowler, Daniel Fulkco, Saras Henderson & Laurie Grealish

Submitted: 28 January 2017, Accepted: 16 June 2017

Abstract

Background

As the population is ageing, and with the rising incidence of type 2 diabetes, the demographics of people on dialysis therapy are changing, with an older population living with multiple co-morbidities. As such, the meaning of haemodialysis (HD) has shifted from a short-term therapy for those awaiting a kidney transplant to a palliative therapy that focuses on quality of life.

Methods

A narrative inquiry focused on nurses' experiences of caring for adult persons on HD approaching end of life. Registered and enrolled nurses working in HD inpatient and outpatient units at one tertiary level hospital service in Southeast Queensland constituted the sample.

Results

Fifty-five of a possible 130 nurses (40% response) completed narratives. Just over half of the nurses had 10 or more years of nephrology nursing experience. Nurses experienced moral discomfort when challenges associated with: (1) poorly implemented end-of-life care; (2) contested decisions to start or stop HD; and (3) limited opportunities to settle disagreements within the service context.

Conclusions

Nephrology nursing practice has not kept up with changing patient demographics, leaving nurses unprepared for the emotional and moral decisions to be made in everyday practice. It is timely to make explicit the palliative intent of HD therapy for persons with multiple co-morbidities, providing a space for advance care planning, open and supported discussions about quality of life, and transparent shared decision making when patients are considering to cease therapy.

Keywords

End of life, haemodialysis, nephrology, nurses, renal.

Lorraine Bublitz, NP Trainee, Renal Supportive Care, Gold Coast Health, QLD, Australia

Kim-Leigh Fowler, Renal and Respiratory Nurse Educator, Gold Coast Health, QLD, Australia

Daniel Fulkco, Cancer, Access and Support Services Nurse Educator, Gold Coast Health, QLD, Australia

A/Professor Saras Henderson, School of Nursing and Midwifery Griffith University; the Hopkins Centre Research for Rehabilitation and Resilience; Women's Wellness Research Group, Menzies Health Institute Queensland, Australia

Laurie Grealish, Associate Professor Subacute and Aged Nursing, School of Nursing & Midwifery and Menzies Health Institute Queensland, Griffith University and Gold Coast Health, QLD, Australia

Correspondence to: Lorraine Bublitz, D3W Renal Administration, NP Trainee Renal Supportive Care Gold Coast Health, QLD, Australia

Email: lorraine.bublitz@health.qld.gov.au

Introduction

People living with end-stage kidney disease (ESKD) have significantly increased morbidity and mortality (Fassett *et al.*, 2011). While medical advancement has enabled people to live longer on dialysis (Tallis, 2005), recent studies report that co-morbidities and symptoms negatively impact on their health-related quality of life (HRQoL) (Brown & Crail, 2013; Feldman *et al.*, 2013). Symptom burden in advanced and life-limiting chronic kidney disease is comparable to many malignant conditions (Almutary, Bonner, & Douglas, 2016; Lowney *et al.*, 2015; Manns *et al.*, 2014; Saini *et al.*, 2006; Yong *et al.*, 2009) and is identified to be similar or the highest amongst chronic disease populations (Feldman *et al.*, 2013; Kidney Health Australia, 2016; Murtagh, Addington-Hall, & Higgins, 2007).

Since 2009, there has been a gradual increase in renal palliative care services nationwide to improve the management of symptom burden and care at end of life (EOL) (Josland, Brennan, Anatsiou, & Brown, 2012; Smith, Potts, Wellard, & Penney, 2015). Palliative care is defined as an “approach to improve the health-related quality of life for patients and their families facing the problem of life-threatening illness” (WHO, 2017). In the nephrology field, the term supportive care is preferred over palliative care (Davison, Levin, Moss, Jha, Brown *et al.*, 2015). While supportive care may be the preferred term, and does address the problems posed by the significant symptom burden of ESKD, nurses who use the term ‘supportive’ rather than ‘palliative’ care may not be adequately prepared for the EOL phase of ESKD. Specialist nephrology nursing curricula primarily focus on the delivery of active dialysis treatment (Johnson & Bonner, 2004; Smith *et al.*, 2015) and the introduction of advance care planning (ACP) and EOL care to curricula is relatively new (Davison, 2012). For dialysis nurses, the capacity to manage the transition from active dialysis treatment to EOL care may be limited, potentially reducing the HRQoL for the patient on dialysis and family near the EOL.

Background

In the 50 years between 1964 and 2014, the number of older people, aged 65 years and older, in Australia has tripled to 3.4 million, with older people accounting for 15% of the population compared to 8% in 1964 (Australian Bureau of Statistics, 2014). The risk of developing ESKD rises with age, and is more prevalent in those aged 75 years and over (Australian Institute of Health and Welfare [AIHW], 2016). Further, the burden of co-morbid conditions, such as hypertension and type 2 diabetes, increases the risk of developing ESKD (AIHW, 2014). Subsequently, the age of people on dialysis has also increased from an average of 43 years in 1977 (Australian New Zealand Dialysis and Transplant Registry [ANZDATA], 1978) to 65 years in 2014 (ANZDATA, 2015).

The primary cause of kidney disease has shifted from glomerulonephritis (34%) and analgesic nephropathy (22%) in 1977 (ANZDATA, 1978) to diabetic nephropathy (38%) and glomerulonephritis (20%) in 2014 (ANZDATA, 2015). With the rise in prevalence of type 2 diabetes, it is expected that increasing numbers of older people will require dialysis in the future.

Conservative therapy, or no dialysis, may be an option for many frail, older people (Davison *et al.*, 2015) and this decision is made before dialysis treatment begins. For those people who begin dialysis, the transition from active treatment to EOL care may be confounded by health care staff who are focused on the dialysis treatment rather than the person (Davison *et al.*, 2015). Some of the key issues in the transition to EOL care are overoptimistic estimations of prognosis (Wachterman *et al.*, 2013), dominance of medical procedures over patient-initiated decisions (Kaufman, Shim, & Russ, 2006), and when to begin ACP (Davison *et al.*, 2015).

There is a need for integration of supportive and EOL care into dialysis care, with the decision to stop dialysis treatment becoming part of a trajectory of care (Axelsson, Randers, Jacobson, & Klang, 2012; Davison *et al.*, 2015; Smith *et al.*, 2015). However, there is a paucity of literature discussing nephrology nurses’ challenges related to caring for patients and their families when approaching EOL (Smith *et al.*, 2015).

Historically, specialist nephrology nursing education has focused on active renal dialysis treatment, with limited consideration of palliative and EOL care (Johnson & Bonner, 2004; Smith *et al.*, 2015). The nature of haemodialysis (HD) means that nurses have lengthy and regular contact with the person, leading to familiarity and relaxed, informal relationships (Hayes & Bonner, 2010; Dolan, Strodl, & Hamernik, 2012). When people express a wish to stop HD, moral concerns are raised for nurses, especially when those decisions are not consistent with medical orders (Hermesen & van der Donk, 2009). Moral concerns that are not resolved can lead to moral distress. The phenomenon of moral distress is a distinct expression of a person’s emotional sensitivity (Mareš, 2016), which can limit the ability to respond effectively to a patient’s needs (Brown, Bain, Broderick, & Sully, 2013).

Moral distress could be aligned to some form of ethical awakening, where the nurse feels a disconnection between knowing the ethically appropriate course of action to take but associated factors relating to the organisational context prevent the nurse from performing those actions (Barlem & Ramos, 2015; McCarthy & Gastmans, 2015). In ethically difficult situations, the nurse may experience feelings of powerlessness, which is a key characteristic of moral distress (Barlem & Ramos, 2015).

Given their regular and frequent contact with HD patients, it is timely to develop a deeper understanding of the specific moral challenges that nephrology nurses might experience when their patients are approaching EOL. This information may guide health services on how to integrate EOL care with dialysis management, and provide important information to enhance nephrology nursing education. The aim of this study was to describe nephrology nurses' perspectives on challenging clinical situations with people on HD approaching EOL.

Methods

Research design

The qualitative narrative inquiry method (Emden, 1998) was used to develop a core story that encompassed the amassed collective wisdom of participants' individual stories. A purposive sample of nurses working in HD inpatient and outpatient units at one tertiary level hospital service in Southeast Queensland was selected. The selection of nurses working in HD only was based on convenience. Nephrology nurses including enrolled nurses, registered nurses, clinical nurses, clinical facilitators, clinical nurse consultants, and nurse unit managers were invited to participate.

Data collection

Specifically convened meetings were arranged in the ward areas for nurses to gather and write their narratives. In keeping with Emden's (1998) narrative method, participants were invited to reflect and write a narrative guided by reflective questions. The questions centred on asking participants to describe a challenging situation or situations that they experienced whilst caring for a patient on HD and approaching EOL. Participants were asked to write down their feelings during and after the situation; state the roles of people involved; their perception of what they did well; describe the strategies they used to address the challenges; and identify any specific education and training that would support people managed on dialysis at end of life. Data were collected over a two-month period in 2015. Demographic data identifying age group and years of work experience in renal services were also collected. Approval to conduct the study was obtained from the Human Research Ethics Committees at Gold Coast Hospital and Health Service (HREC/14/QGC/184) and Griffith University (NRS/01/15/HREC).

Data analysis

The narratives were transcribed verbatim from handwritten accounts into a Word program. Emden's (1998) six-step process of analysis was used. Initially, two researchers independently read the transcripts over several times to get a good grasp of the content. The data were then prepared for further analysis by first deleting all questions from the text

and then deleting all words that detracted from the main idea of each sentence or sentences. In the fourth step, the text was reread to make sense of each nurse's story. The two researchers independently identified themes and sub-themes and then met to discuss their findings. Areas of disagreement were discussed with the lead researcher, who assisted with negotiating the final themes. In step six, a fourth member of the research team worked with the reviewers to cluster similar themes into a core story. The findings were authenticated in presentations to groups of nephrology nurses from inpatient and outpatient settings.

Data validation

Data validation is considered an important element in qualitative research (Mays & Pope, 2000). In this study, the preliminary themes and core story were shared in three presentations to nurses from across the renal areas in the local health service. While not all attendees participated in the research, they were invited to indicate whether the findings resonated with their personal experiences.

Findings

Fifty-five nurses participated in the study of a possible 130 (40% response). The majority of nurses were female ($n=52$; 94%), with a median age range of 41–55 years (55%). Just over half (53%) of participants had 10 years of more of nephrology nursing experience. Nurses' responses are grouped into three areas: when challenges arise, the emotions associated with these challenging situations, and the strategies used to respond to the challenges.

When challenges arise

Three situations, in which challenges arose, were commonly shared among the participants. Firstly, a common situation found to be challenging was when there was clinical evidence that the patient was dying but the patient did not want palliative care. In one situation, the doctor recommended EOL care but the person resisted, believing that they were improving:

"Hearing the patient say they have done better today. Having the consultant say, she will die soon. Having the patient refuse input from palliative care ... and watching her collapse ..." [CN14]

Secondly, nurses feel challenged when decisions to stop, and sometimes when decisions are made to start, HD and the decision is contested between the decision-makers including nurse, doctor, patient and family member(s):

"[He] decided that when he was no longer able to go for walks with his wife, he wanted to stop dialysis. He developed dementia ... and was no longer able to go for

walks. He and his wife decided to stop treatment but were advised by ... that he was not able to make that decision [due to dementia] ...” [CN45]

“We had a patient recently on daily dialysis where they would present daily and ... you saw they were deteriorating. I would have a conversation with them and their daughter and they wanted to discuss ceasing dialysis, but the doctor always felt they should continue.” [CN02]

Thirdly, nurses described situations when disagreements existed, and there was limited opportunity to resolve the disagreement, with mutual respect, as challenging. For example:

“... last minute decision to commence dialysis, then after a severe CVA [cerebrovascular accident] dialysis was continued ... seemed so futile.” [CN35]

Challenging situations were related to difference in individuals’ perceptions, understanding, and action, especially when opportunities to negotiate an agreement are limited.

Emotions associated with challenges

When describing how they felt as the event was happening, nurses often upheld personal values such as spiritual beliefs, values they placed on patient autonomy, and judgements as to whether conservative care should be offered as an option to HD. If values aligned with the situation, nurses reported positive feelings. However, if nurses’ values did not align with the situation, nurses reported feelings of moral distress. Positive feelings that emerged when the decisions made in a situation aligned with nurses’ perceptions of what ‘should’ happen included:

“Pleased that the patient had the capacity to make an informed decision ...” [CN19]

“... I feel very privileged to be in the role where we can help ... people ... and family through end of life.” [CN02]

“I felt empowered ... patient has the right to refuse as long as patient is aware of the consequences of decision.” [CN23]

When nurses’ personal values or beliefs did not align with decisions made in a situation, nurses reported negative feelings such as:

“I didn’t really know what I could do to help him.” [CN18]

“I felt overwhelmed and angry as I felt I was out of my depth and the system could not fulfil my patient’s end of life wishes.” [CN32]

“Useless, abandoned ...” [CN14]

“Frustrated and incompetent.” [CN28]

When reflecting on the events, powerful feelings of alignment or continued moral unease emerged:

“It has made me a stronger advocate for the patient’s wishes.” [CN45]

“Satisfied that this patient autonomously managed her own death in her own time and own special way.” [CN16]

“I still believe his end of life care could have been planned and discussed sooner.” [CN20]

“Still upsets me to think back on it.” [CN53]

“Still saddens me ...” [CN13]

Strategies used to respond to challenges

Overall, nursing strategies employed were limited. Nursing interventions that were described frequently focused on supporting the patient and family through listening, understanding, and being compassionate. Some participants identified the importance of working within a health care team but were not specific about aspects of teamwork that were used to respond to the challenges presented in their stories. Several participants suggested that they would like to learn more about palliative care principles, the dying trajectory when a person ceases HD, legal and ethical implications of ceasing HD, and respectful ways to resolve different perspectives with colleagues.

The core story

The collective wisdom from these participants was gathered into the following core story:

Nurses, who are caring for patients facing EOL decisions and care, sometimes experience differing views from patients, family and medical staff.

Nurses experience moral discomfort with some decisions made by patient, family, and some colleagues when such decisions conflict with their own personal values.

The majority of nurses use their role as collaborative caregivers and patient advocate to best meet the physical and psychological needs of patients and family.

Nurses recognise they need further education in the holistic care of patients with end stage renal disease facing EOL, conflict resolution and the moral and ethical issues surrounding decisions about treatment.

When these themes and core story were shared with nurses working across the renal services of the local hospital, there was agreement that the reported findings resonated with their personal experiences.

Discussion

In this study, experienced nephrology nurses were struggling with the differing perspectives among patients, family members, doctors, and other nurses on the decision to start or withdraw HD therapy and other aspects of EOL care. When other people's decisions or actions did not align with those of the nurses, the nurses experienced moral discomfort. Unresolved moral discomfort can lead to withdrawal of self from patients, poor quality care, and decreased job satisfaction (Pauly, Varcoe, & Storch, 2012). Nurses in this study were experiencing moral distress, a feeling of powerlessness, whereby the process of moral deliberation is obstructed, compromising advocacy and moral sensitivity (Barlem & Ramos, 2015; McCarthy & Gastmans, 2015). In an earlier review of the literature, nephrology nurses' lack of action in the transition to EOL care was attributed to lack of confidence (Johnson & Bonner, 2004). In this study, the nurses' strategies to respond to the challenges raised in their stories were limited. It may be lack of confidence, but like Barlem and Ramos (2015), we suggest that further research into the reasons why nurses allow themselves to accept certain contexts as unchangeable or natural is required.

In this study, nurses experienced moral discomfort when communication between doctors and patients around prognosis was not effective and it was evident that there was non-alignment between the goals of the health care team and patient preferences. The KDIGO Controversies Conference on Supportive Care in CKD identified key areas for improving quality in EOL care: earlier recognition of the functional decline associated with EOL; promote shared decision making and ACP; and develop a clear process for withdrawing dialysis (Davison *et al.*, 2015). A flexible approach to re-evaluation and redirection is required to accommodate changes in patients' health status, preferences and treatment options (Davison *et al.*, 2015). Nephrology nurses are well positioned to listen to patients' preferences and advocate for review of treatment goals. However, this must be done in a cultural environment of shared understanding about shared decision making.

Changing the culture in renal care settings requires health professional teams to review and revise expert-led practices, and associated deeply held beliefs and values about expertise in ESKD. Since this study, we have introduced nephrology nurse discussions, facilitated by a clinical ethicist, that have focused on issues related to the palliative approach and EOL care. Continuing education for nephrology nurses and other

health professionals is required to collaboratively develop a philosophy of care that is focused on shared decision making, and the transition from active treatment to EOL care. Nephrology clinicians also require more sophisticated ethical knowledge to support patients and families during the transition from active dialysis to EOL.

The findings of this study illustrate the significant need for curriculum review in postgraduate nephrology nursing programmes. Despite the international recommendations on how to support patients to transition from active treatment to EOL care (Davison *et al.*, 2015), specialty education in nephrology continues to focus on active dialysis treatments and the associated technical and clinical knowledge and skills (Smith *et al.*, 2015). It is timely to emphasise the value of the palliative approach, shared decision-making, and ACP in nephrology nursing curricula. Exploration of the common physical, social and psychological issues that arise for older people, as part of the ageing process, is also necessary given the ageing of the dialysis population generally. In addition to this content, communication skills for managing complex cases where there are differing perspectives (Schmidt & Moss, 2014) should be included.

Finally, there is a need to continue research in the area of EOL care for people once they are considering or decide to cease dialysis treatment. The development of collaborative decision-making models and heuristics (rules of thumb) around starting and stopping dialysis treatment are urgently required. Qualitative research that explores older patients' and families' experiences of continuing with dialysis therapy, while considering ceasing the treatment, would contribute to our understanding of shared decision making.

Limitations

Consistent with qualitative research, the small sample size and isolation to nephrology nurses working in HD services of one hospital in one health service limits generalisations. Further studies into the experiences of nurses working with people on peritoneal dialysis are recommended. However, the insights from nurses who participated in this study resonated with others in the unit, who may not have participated, during data validation presentations. Feedback from clinicians who have attended the presentation of the nurses' experiences at conferences has also confirmed that these experiences are not unique to the nurses in this health service.

Conclusion

The changing demographics of people on dialysis have a significant impact on nephrology nursing practice. This study has illustrated the impact of the changes on everyday nursing practice, and the emotional toll that EOL decisions

carry for nephrology nurses. It is timely to undertake a national review into nephrology nursing education to integrate palliative care into curriculum design. Most importantly, given the consequence of patients' demographics and the rising incidence of type 2 diabetes in our community, research into how to effectively use HD as a palliative therapy for older people with multiple co-morbidities is urgently required.

Acknowledgements

We acknowledge the contributions of Dr Balaji Hiremagalar to support this study and clinical nurse Kerry Robinson for data collection. We also thank the nurses who shared their experiences with us.

References

- Almutary, H., Bonner, A., & Douglas, C. (2016). Which patients with chronic kidney disease have the greatest symptom burden? A comparative study of advance CKD stage and dialysis modality. *Journal of Renal Care*, *42*(2), 73–82.
- ANZDATA. (1978). The First Annual Report retrieved from <http://www.anzdata.org.au/anzdata/AnzdataReport/HistoricScans/ANZDATA1stReport1978.pdf>
- ANZDATA. (2015). 2015 Annual Report retrieved from http://www.anzdata.org.au/v1/report_2015.html
- Australian Bureau of Statistics. (2014). Australian historical population statistics. Cat. No. 3015.0.65.001. Canberra: ABS.
- Australian Institute of Health and Welfare. (2016). Incidence of end-stage kidney disease in Australia 1997–2013. Cat. No. PHE 211. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2014). Cardiovascular disease, diabetes and chronic kidney disease — Australian facts: Morbidity — Hospital care. Cardiovascular, diabetes and chronic kidney disease series no. 3. Cat. No. CDK 3. Canberra: AIHW.
- Axelsson, L., Randers, I., Jacobson, S., & Klang, B. (2012). Living with haemodialysis when nearing end of life. *Scandinavian Journal of Caring Sciences*, *26*(1), 45. DOI: 10.1111/j.1471-6712.2011.00902.x-52.
- Barlem, E., & Ramos, F. (2015). Constructing a theoretical model of moral distress. *Nursing Ethics*, *22*(5), pp 608–615.
- Brown, M., & Crail, S. (2013). ANZSN Renal Supportive Care Guidelines 2013. *Nephrology*, *18*, 401–454. DOI: 10.1111/hep.12065_20
- Brown, S., Bain, P., Broderick, P., & Sully, M. (2013). Emotional effort and perceived support in renal nursing: A comparative interview study. *Journal of Renal Care*, *39*(4), 246–255. DOI: 10.1111/j.1755-6686.2013.12023.x.
- Davison, S. (2012). The ethics of end of life care for patients with ESRD. *Clinical Journal of the American Society of Nephrology*, *7*(12), 2049–2057. DOI: 10.2215/CJN.03900412.
- Davison, S. N., Levin, A., Moss, A. H., Jha, V. et al. (2015). Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: developing a roadmap to improving quality of care. *Kidney International*, *88*, 447–459. DOI: 10.1038/ki.2015.110
- Dolan, G., Strodl, E., & Hamernik, E. (2012). Why renal nurses cope so well with their workplace stressors. *Journal of Renal Care*, *38*(4), 222–232. DOI: 10.1111/j.1755-6686.2012.00319.x.
- Emden, C. (1998). Conducting a narrative analysis. *Collegian*, *5*(3), 34–39.
- Fassett, R. G., Robertson, I. K., Mace, R., Youl, L., Challenor, S., & Bull, R. (2011). Palliative care in end stage kidney disease. *Nephrology*, *16*(1), 4–12.
- Feldman, R., Berman, N., Reid, M. C., Roberts, J., Shengelia, R. C., Eiss, B., & Adelman, R. D. (2013). Improving symptom management in hemodialysis patients: Identifying barriers and future directions. *Journal of Palliative Medicine*, *16*(12), 1528–1533. DOI: 10.1089/jpm.2013.0176.
- Hayes, B., & Bonner, A. (2010). Job satisfaction, stress and burnout associated with haemodialysis nursing: A review of the literature. *Journal of Renal Care*, *36*(4), 174–179. DOI: 10.1111/j.1755-6686.2010.00194.x.
- Hermesen, M., & van der Donk, M. (2009). Nurses' moral problems in dialysis. *Nursing Ethics*, *16*(2), 184–191. DOI: 10.1177/0969733008100078.
- Johnson, A., & Bonner, A. (2004). Palliative care challenges: Implications for nurses practice in renal settings. *Contemporary Nurse*, *17*(1), 95–101.
- Josland, E., Brennan, F., Anatsiou, A., & Brown, M. (2012). Developing and sustaining a renal supportive care service for people with end-stage kidney disease. *Renal Society of Australasia Journal*, *8*(1), 12–18.
- Kaufman, S. R., Shim, J. K., Russ, A. J. (2006) Old age, life extension, and the character of medical choice. *Journal of Gerontology: Social Sciences* *61*(4), S175–84.
- Kidney Health Australia. (2016). Palliative care for chronic and end-stage kidney disease: Position statement. Retrieved August 14, 2016, from Kidney Health Australia: http://kidney.org.au/cms_uploads/docs/pdf-palliative-care-and-ckd-position-statement.pdf.
- Lowney, A., Myles, H., Bristoew, K., Lowney, E., Shepherd, K., Murphy, M., O'Brien, T., Casserly, L., McQuillan, R., Plant, W. D., Conlon, P. J., Vinen, C., Eustace, J. A., & Murtagh, F. E. M. (2015). Understanding what influences the health-related quality of life of hemodialysis patients: A collaborative study in England and Ireland. *Journal of Pain and Symptom Management*, *50*(6), 778–785. DOI: 10.1016/j.jpainsymman.2015.07.010.
- Manns, B., Hemmelgarn, B., Lillie, E., Crowe, S., Cyr, A., Gladish, M., Large, C., Silverman, H., Toth, B., Wolfs, W., & Laupacis, A. (2014). Setting research priorities for patients on or nearing dialysis. *Clinical Journal of the American Society of Nephrology*, *9*(10), 1813–1821. DOI: 10.2215/CJN.01610214.
- Mareš, J. (2016). Moral distress: Terminology, theories and models. *Kontakt*, *18*, 137–e144.
- McCarthy, J., & Gastmans, C. (2015). Moral distress: A review of the argument-based nursing ethics literature. *Nursing Ethics*, *22*(1), 131–152.
- Murtagh, F. E., Addington-Hall, J., & Higgins, I. J. (2007). The prevalence of symptoms in end-stage renal disease: A systematic review. *Advances in Chronic Kidney Disease*, *14*, 82–89.
- Pauly, B. M., Varcoe, C., & Storch, J. (2012). Framing the issues: moral distress in health care. *HEC Forum* *24*, 1–11. DOI 10.1007/s10730-012-9176-y
- Mays, N., & Pope, C. (2000) Qualitative research in health care. Assessing quality in qualitative research. *BMJ* *320*(7226), 50–52
- Saini, T., Murtagh, F., Dupont, P., McKinnon, P., Hatfield, P., & Saunders, Y. (2006). Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. *Palliative Medicine*, *20*(6), 631–636.
- Schmidt, R. J., & Moss, A. H. (2014). Dying on dialysis: the case for a dignified withdrawal. *Clinical Journal of the American Society of Nephrology* *9*(1), 174–180.
- Smith, V., Potts, C., Wellard, S., & Penney, W. (2015). Integrating renal and palliative care project: a nurse-led initiative. *Renal Society of Australasia Journal*, *11*(1), 35–40.
- Tallis, K. (2005). How to improve the quality of life in patients living with end stage renal failure. *Renal Society of Australasia Journal*, *1*, 18–24.
- Yong, D. S., Kwok, A. O., Wong, D. M., Suen, M. H., Chen, W. T., & Tse, D. M. (2009). Symptom burden and quality of life in end-stage renal disease: A study of 179 patients on dialysis and palliative care. *Palliative Medicine*, *23*, 111–119. DOI: 10.1177/0269216308101099
- Wachterman, M. W., Marcantonio, E. R., Davis, R. B., Cohen, R. A., Walker, S. S., Phillips, R. S., & McCarthy, E. P. (2013). Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Internal Medicine* *173*(13), 1206–14. DOI: 10.1001/jamainternmed.2013.6036.
- World Health Organization. WHO Definition of Palliative Care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/> on 17 March 2017.