Review Article

Advanced Care Planning for Patients with End Stage Renal Disease: An Integrative Review

Devaka Kumari Acharya,[1] Kittikorn Nilmanat[2,*], Umaporn Boonyasopun[3]

[1]Assoc. Prof. Maharajgunj Nursing Campus, Institute of Medicine, Kathmandu, Nepal
[2,3]PhD, Prince of Songkla University, Thailand
***Correspondence:** kittikorn.n@psu.ac.th

ABSTRACT

Introduction : Patients with end stage renal disease have a high rate burden of disease and mortality. Advance care planning is important for improving the end-of life care for these patients but it is complex and challenging. This review aims to find out the interventions, context and experiences of advance care planning for end stage renal disease.

Methods: Databases ProQuest Nursing and Allied Health, Cumulative Index to Nursing and Allied Health Literature, Google Scholar, PubMed were searched for 15 years' period from 2006-2020 yielded 10 articles. We included the studies with adult patients, diagnosed with end stage renal disease, have hemodialysis, peritoneal dialysis or without dialysis, any setting and any design quantitative and qualitative, any interventions and outcomes, qualitative studies, and family members and significant caregivers.

Results : We included ten studies that involved 1526 participants (one study not mentioned the participants) which investigated advance care planning to the patients with end stage renal disease and their families/friends/surrogates. The interventions used were Patient-centered Advance Care Planning, Peer-mentoring, Printed material, Booklets and patient expert, Sharing Patient's Illness Representations to Increase Trust, Model test. Patients and caregivers felt the more need of advance care planning.

Conclusion: Advance care planning needs to include as important component of renal care for management of patients with end stage renal disease though it is inadequately used. More interventional studies are needed to be carried out to find the most effective intervention and context to manage this trajectory illness.

Keywords: Advance care planning, advanced directive, ESRD, hemodialysis, interventions

INTRODUCTION

End stage renal disease (ESRD) is a chronic and progressive illness [1] that requires lifelong dialysis or transplantation [1,2] and dietary and fluid restriction.[1] ESRD causes a high rate of mortality and disease burden [2] and unpleasant consequences for patients, families, and society. [3]

Advance care planning (ACP) "is the process of continuing communication among patients, their family and health care professionals about what plans for future care are preferred in the event that patients become unable to make their own decisions. [4] ACP "is a conversation a person has in advance of a medical crisis with a loved one and/or a health care provider (HCP) about his/her values, goals of care, preferences for future health care, and the designation of a surrogate decision maker for the potential case that one loses decisional capacity". [5] ACP gives priority to ethical, psychosocial, and spiritual issues relevant to starting, continuing, withholding, and stopping dialysis. [6] ACP integrating palliative care improves the patients' physical, mental, and psychological care needs. [7] ACP that focused on communication may better meet the needs of people who have diverse culture. [8] It enables the patients to become empower and communicate their preferences of future treatment relevant to their goals and values.

However, internationally, it is estimated that only 6%-49% of patients with CKD receive ACP. [9] ACP improves patient and family outcomes through identifying, documenting, and enacting patients' EOL preferences. [8] It is associated with overall cost reduction. [10] Therefore, it is necessary to find the interventions and context and experiences of patients with ESRD and their family members or primary caregivers about ACP to manage patients' health issues, support the patients and families.

METHODS

Eligibility criteria

Studies that include ACP, original articles or review articles that included original articles, design both quantitative or qualitative, full article available, published in peer review journal, in English language, adult patients diagnosed with ESRD, under the treatment of hemodialysis and peritoneal dialysis or without dialysis, studies that included family members or significant caregivers.

Searching method

We searched the electronic databases ProQuest Nursing and Allied Health, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Google Scholar, PubMed were searched using key words related to ESRD and ACP includes ESRD, hemodialysis, ACP, advance care planning, advanced directives, strategies, interventions etc.

Review Questions

1. What interventions are used as a part of ACP among the patients with ESRD and their family members or primary/significant caregivers?
2. What is the context and experiences of patients with ESRD and their family members or primary caregivers about ACP?

FINDINGS

This study included ten studies: Systematic review[1], Randomized controlled trial[11,12], Interventional descriptive [13], ACP discussion and document review[14] and costs and outcomes evaluation[15], Grounded theory[16], Qualitative, interpretative descriptive[17], Ethnography[18], and semi-structured qualitative interview study.[19] Of them four studies were from USA, two Canada, two UK, one Australia, and one Hong Kong. All studies included patients with ESRD and or their surrogates/caregivers. Interventions used were Patient-Centered ACP (PC-ACP), Peer mentoring, Printed Material Intervention, Sharing Patient's Illness Representations to Increase Trust (SPIRIT), Communication and discussion and provided peer support at the time of ACP completion and subsequently by telephone, assisted where necessary by the ACP nurse. The number of participants included in each study were ranges from minimum 9 to maximum 620.

Systematic review

Systematic review was conducted to determine whether ACP in haemodialysis patients, compared with no or less structured forms of ACP, can result in fewer hospital admissions or less use of treatments with life-prolonging or curative intent, and if patient's wishes were followed at end-of-life (EOL). Both RCTS Kirchhoff (2010) and Perry (2005) were conducted in USA with a total of 337 patients. Kirchhoff (2010), 70 patients received PC-ACP and 64 in control group received usual care. Intervention group participants completed 60 to 90 minute interviews with a trained facilitator. PC-ACP assessed understanding and experiences of patients and surrogates about illness; provided information about disease-specific treatment options and their benefits and burdens; assisted in documenting patient preferences for treatment; and assisted surrogate partners to make decisions in line with patients' preferences. Control group received usual care consisted ACP facilitation; standard advance directive counselling; assessment of advance directive (AD) on admission; more information if patient needed. Study reported that there was improved understanding of patient goals and preferences for future medical decisions among surrogates who received PC-ACP than control group. Higher percentage of surrogates in the intervention group knew about decision making authority that a patient wished to grant the chosen surrogate than control group. Higher rates of concordance between patients' preferences and end-of-life care among intervention group participants compared with the control group, including cardiopulmonary arrest. [1]

Perry (2005) involved 203 patients; 63 provided peer-mentoring intervention, 59 provided printed material intervention, and 81 control group received usual care. Peer intervention group were contacted by peers eight times (five telephone calls and three face-to-face meetings) to discuss about important of completing AD, attended workshop and discussed issues of AD. Peer mentors and patients discussed the program, shared their experiences with chronic illness, goals outside ESRD; spiritual orientation and fears; EOL considerations and barriers to complete AD; contribution to others and patient's strength. Patients on printed material intervention group received literature developed by the US National Kidney Foundation and control group received routine care provided by the dialysis unit (not described). Peer support intervention resulted in a higher proportion of participants completing an AD or expressing a desire to complete, greater levels of comfort about discussion of AD than printed material and routine care group participants.[1]

Randomized controlled trial

Randomized trial examined the efficacy of ACP intervention on preparation for EOL decision making for dialysis patients and surrogates and for surrogates' bereavement outcomes of 420 participants (210 dyads of prevalent dialysis patients and their surrogates) in 20 dialysis centers of USA. Control group received usual care where as intervention group assigned to SPIRIT (Sharing Patient's Illness Representations to Increase Trust) had an in-depth ACP discussion at the center and a follow-up session at home after 2 weeks. Dyad congruence surrogate decision-making confidence were better in SPIRIT than controls, but patient decisional conflict did not differ between groups. Surrogates in SPIRIT had less anxiety depression and posttraumatic distress than controls. SPIRIT was associated with improvements in dyad preparation for EOL decision making and surrogate bereavement outcomes.[11]

Nurse-led ACP was conducted to determine the feasibility of conducting a deferred entry randomized controlled trial of ACP with patients who have ESKD having hemodialysis aged 65 years or older. It incorporated an economic evaluation and mixed methods process evaluation in two renal haemodialysis units in Northern Ireland, UK. Sixty-seven patients invited to participate, 30 declined and 36 were randomized to immediate or deferred ACP groups. Twenty-two made an ACP and completed data collection at 12 weeks; 17 were able to identify a surrogate willing to be named in the advance care ACP document. The intervention was well-received and encouraged EOL conversations, but did not succeed in helping patients to fully clarify their values or consider specific treatment choices. There was no significant difference in health system costs between the immediate and deferred groups.[10]

Descriptive interventional

An interventional descriptive study explored the experience on ACP for ESRD patients in secondary care hospital, Hong Kong with sample of 600 patients (265 renal replacement therapy (RRT) & 335 renal palliative care (RPC). Patients were empowered to make an informed choice of future medical care through structured ACP and followed up overs a median of 782 days. Majority of patients and relatives declined dialysis due to physical burden, 1.6% of palliative care patients started dialysis. Structured ACP could empower the patient to make an informed decision on the management of ESRD. [12]

A document review on ACP discussion assessed dialysis withdrawal preferences among 61 patients from 2 hemodialysis centers, USA. Patients were engaged in ACP on EOL discussions, completion of AD and 'do not resuscitate' or 'do not intubate' (DNR/DNI) orders were ascertained by a questionnaire and record of dialysis unit. Overall, 57% of participants reported having an EOL discussion with a health care provider, 38% had completed an AD and 10% had a DNR/DNI order in their dialysis chart. Among the individual aspects of ACP, there were significant differences in EOL discussions and DNR/DNI orders by race/ethnicity, with Blacks and Asians being more likely to engage in EOL discussions and Latinos less likely to engage in EOL discussions as compared with Whites. Conversely, no Black or Latino participants completed DNR/DNI orders as compared with 10% of Asians and 24% of Whites. There were trends for lower completion rates of AD and DNR/DNI orders among participants <50 years, but no statistical significance. [13]

A study evaluated the costs and outcomes of nurse-led ACP with usual care to the patients with hemodialysis using hospital data, and modelled the effect of nurse-led ACP on EOL care. Outcomes were assessed in terms of patients' EOL treatment preferences being met or not, and costs included all hospital-based care. The proportion of patients in the model who received end-of-life care according to their preferences was higher in the ACP group compared with usual care (68% vs. 24%). Model suggests nurse-led ACP leads to receipt of patient preferences for EOL care, but at an increased cost.[15]

Qualitative Study

A Grounded theory among 13 patients and 9 families/ friends was used for understanding patients' and families' diverse needs can strengthen systematic efforts to improve ACP in dialysis units, USA. Patients and families said ACP discussions rarely occur, yet most patients desire them. Factors that may affect perspectives on ACP included a desire for more of a connection with the nephrologist, positive and negative experiences with the dialysis team, disenfranchisement, life experiences, personality traits, patient-family/friend relationships, and power differentials. Most patients and family/friends felt that the nephrologist should lead ACP discussions, all of the options available for EOL care should be discussed as part of ACP, ACP discussions should be held in a private space at the dialysis unit on a non-dialysis day and ACP should be an iterative process started early in the disease course and followed up annually.[16]

A qualitative, interpretative descriptive study was conducted to understand hope in the context of ACP from patients' perspective among 19 patients in Canada. Patients' hopes were highly individualized and shaped by personal values. They identified hope as central to the process of ACP, hope helped them to determine future care goals and provided insight into the perceived benefits of ACP and their willingness to engage in EOL discussions. More information at earlier stage of illness that focus on impact of daily life, patients' empowerment, enhancement of professional and personal relationships were key factors for sustaining patients' hope. Potential barriers for hope were reliance on professionals to initiate EOL discussions and daily focus of clinical care.[17]

Ethnography was conducted among 24 patients on salient elements of ACP discussions in Canada. Patients required more information and earlier initiation of ACP discussions. Information are needed to focus more on the individual and how his or her illness and interventions would affect his or her life and relationships and what he or she values most. Empathetic listening also was viewed as an integral component of facilitated ACP. Physicians clearly were seen as having the responsibility for initiating and guiding ACP. The role of patients and family within ACP is complex and varies significantly between patients. For most, family was an integral component of ACP, and many relied extensively on family to make EOL decisions. [18]

Qualitative interview was uesd to explore the experiences of people with ESKD regarding starting haemodialysis, its impact QOL and their preferences for future care and to explore the ACP needs and timing of this support among 20 patients in UK. Emerged themes were: looking back, emotions of commencing haemodialysis; current experiences, illness and treatment burdens; and looking ahead, facing the realities. Challenges were get information, communication with staff and the 'conveyor belt' culture of haemodialysis units. Patients reported a lack of opportunity to discuss their future, when their health deteriorated, and variable involvement in treatment decisions. However, some accepted more the discussion of these sensitive issues.[19]

CONCLUSION

ACP is important for the managing the care, delaying the complications, avoiding the conflict, taking appropriate care decision, reduce health care cost and economic burden, and improve QOL and death. Still there is little discussion about ACP and interventions for ESRD.

RECOMMENDATIONS

Although descriptive and qualitative studies explore context of ACP and few facilitators and barriers; RCTs are needed to find out what kinds of interventions can apply to individual patient and context, reduce decisional conflict and improve health and QOL. It is necessary to keep ACP as a component of renal care. Facilitated ACP through using timely appropriate information can positively uplift the patients' hope. Adequate discussion and clear communication is necessary among renal health care teams, ESRD patients, family members and significant caregivers.

REFERENCES

1. Lim CE, Ng RW, Cheng NC, Cigolini M, Kwok C, Brennan F. Advance care planning for haemodialysis patients. *Cochrane Database of Systematic Reviews.* 2016; (7). https://doi.org/10.1002/14651858.CD010737.pub2
2. O'Halloran P, Noble H, Norwood K, Maxwell P, Shields J, Fogarty D, Murtagh F, Morton R, Brazil K. Advance care planning with patients who have end-stage kidney disease: a systematic realist review. *Journal of Pain and Symptom Management.* 2018; 56(5):795-807. https://doi.org/10.1016/j.jpainsymman.2018.07.008
3. Malekmakan L, Tadayon T, Roozbeh J, Sayadi M. End-stage renal disease in the Middle East: a systematic review and meta-analysis. *Iranian Journal of Kidney Diseases*. 2018; 12(4):195-203. www.ijkd.org

4. Chan CW, Ng NH, Chan HY, Wong MM, Chow KM. A systematic review of the effects of advance care planning facilitators training programs. *BMC Health Services Research*. 2019;19(1):1-4. https://doi.org/10.1186/s12913-019-4192-0
5. Bigger S, Haddad L. Advance care planning in home health: a review of the literature. *Journal of Hospice & Palliative Nursing*. 2019; 21(6):518-23. https://doi.org 10.1097/NJH.0000000000000591
6. Davison SN. Quality end-of-life care in dialysis units. *In Seminars in Dialysis* 2002; 15(1), 41-44. https://doi.org/10.1046/j.1525-139x.2002.00015.x
7. Bender, N. (2021). Palliative care and improving quality of life with end stage renal disease: An integrative review.*Doctoral Dissertations and Projects*. 3235. https://digitalcommons.liberty.edu/doctoral/3235
8. McDermott E, Selman LE. Cultural factors influencing advance care planning in progressive, incurable disease: a systematic review with narrative synthesis. *Journal of Pain and Symptom Management*. 2018; 56(4):613-36.https://doi.org/10.1016/j.jpainsymman.2018.07.006
9. Sellars M, Clayton JM, Morton RL, Luckett T, Silvester W, Spencer L, Pollock CA, Walker RG, Kerr PG, Tong A. An interview study of patient and caregiver perspectives on advance care planning in ESRD. *American Journal of Kidney Diseases*. 2018;71(2):216-24. https://doi.org/10.1053/j.ajkd.2017.07.021
10. Bond WF, Kim M, Franciskovich CM, Weinberg JE, Svendsen JD, Fehr LS, Funk A, Sawicki R, Asche CV. Advance care planning in an accountable care organization is associated with increased advanced directive documentation and decreased costs. *Journal of Palliative Medicine*. 2018;21(4):489-502. https://doi.org/10.1089/jpm.2017.0566
11. O'Halloran P, Noble H, Norwood K, Maxwell P, Murtagh F, Shields J, Mullan R, Matthews M, Cardwell C, Clarke M, Morton R. Nurse-led advance care planning with older people who have end-stage kidney disease: feasibility of a deferred entry randomized controlled trial incorporating an economic evaluation and mixed methods process evaluation (ACReDiT). *BMC Nephrology*. 2020; 21 (478):1-7. https://doi.org/10.1186/s12882-020-02129-5
12. Song MK, Ward SE, Fine JP, Hanson LC, Lin FC, Hladik GA, Hamilton JB, Bridgman JC. Advance care planning and end-of-life decision making in dialysis: a randomized controlled trial targeting patients and their surrogates. *American Journal of Kidney Diseases*. 2015;66(5):813-22. https://doi.org/10.1053/j.ajkd.2015.05.018
13. Yuen SK, Suen HP, Kwok OL, Yong SP, Tse MW. Advance care planning for 600 Chinese patients with end-stage renal disease. *Hong Kong Journal of Nephrology*. 2016; 19:19-27. https://doi.org/10.1053/j.ajkd.2013.12.007
14. Tamura MK, Goldstein MK, Pérez-Stable EJ. Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrology Dialysis Transplantation.* 2010;25(1):237-42. https://doi.org/10.1093/ndt/gfp430
15. Sellars M, Clayton JM, Detering KM, Tong A, Power D, Morton RL. Costs and outcomes of advance care planning and end-of-life care for older adults with end-stage kidney disease: A person-centered decision analysis. *PLoS One*. 2019;14(5): e0217787. https://doi.org/10.1371/journal.pone.0217787
16. Goff SL, Eneanya ND, Feinberg R, Germain MJ, Marr L, Berzoff J, Cohen LM, Unruh M. Advance care planning: a qualitative study of dialysis patients and families. *Clinical Journal of the American Society of Nephrology*. 2015;10(3):390-400.https://doi.org/10.2215/CJN.07490714
17. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *British Medical Journal*. 2006;333(7574):886. https://doi.org/10.1136/bmj.38965.626250.55
18. Davison SN. Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clinical Journal of the American Society of Nephrology*. 2006;1(5):1023-28. doi: 10.2215/CJN.01050306
19. Bristowe K, Horsley HL, Shepherd K, Brown H, Carey I, Matthews B, O'Donoghue D, Vinen K, Murtagh FE. Thinking ahead–the need for early advance care planning for people on haemodialysis: a qualitative interview study. *Palliative Medicine.* 2015;29(5):443-50. https://doi.org/10.1177%2F0269216314560209