

Background

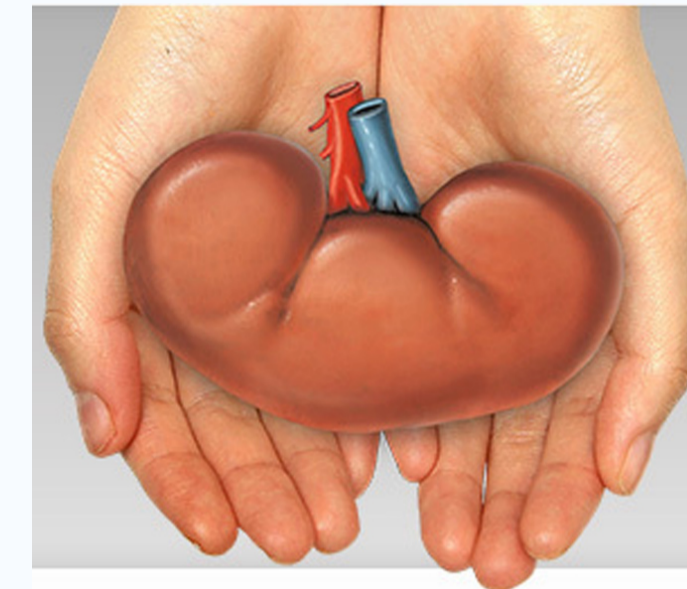
- End-stage renal disease patients on dialysis involves progressive and irreversible kidney damage.
- Progression of the underlying disease, emergence of complications, and gradual decline in functional status leads many patients to withdraw from dialysis.
- Talking about death and dying, traditionally has long been a taboo in Chinese culture.
- Patients reach the terminal phase of their disease seldom discussing their end-of-life care priorities.
- Mixed Eastern and Western culture in Hong Kong might affect the thought and belief of the local population towards the decision-making process.

Purpose

- To fill the research gap of exploring the decision-making processes of dialysis patients and their carers regarding end-of-life care, especially in the Chinese context.
- To study the effect of culture on communication about the decision-making process.
- To inform healthcare professionals about strategies for communication with Chinese renal dialysis patients concerning decision-making at the patient's final stage of life.

Methods

- A qualitative driven mixed methods, sequential, explanatory design was adopted.
- Purposive sampling was used to recruit dialysis patient and carer informants in a regional renal dialysis centre in Hong Kong.
- Quantitative results were used to guide the formulation of the questions in subsequent focus group interviews.
- Qualitative data were analysed by the Leininger's phases of ethn nursing data analysis.



Results and findings

Phase A: Quantitative survey

- 121 dialysis patients and 61 carers participated, 86% of patients and 80.3% of carers preferred their families to make treatment decisions when reaching the terminal phase of their disease.
- 83.5% of the patient informants and 90.2% of carers claimed would adopt advance directives if it was available.

Phase B: Qualitative focus group interviews

- 24 patients and 14 carers volunteered to join the focus group interviews.
- The dialysis patient informants considered communication barriers, Chinese cultural norm and dying in dignity were the major themes in the decision-making process at their end-of-life domain.
- Themes of personalising care, normalising life, sharing burdens and carer's plight were delineated by the carer informants.

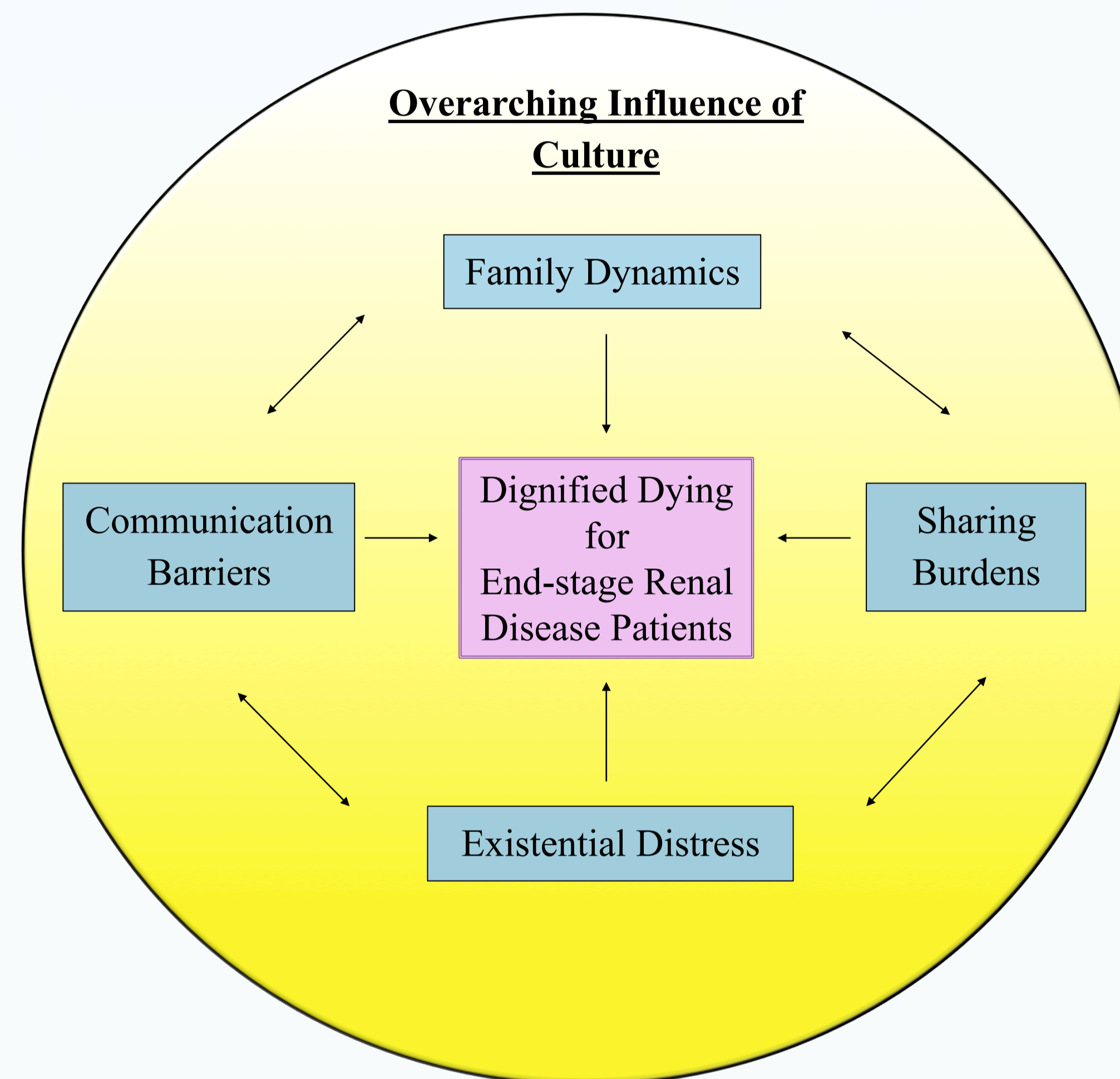


Figure 1 Overarching influence of culture in the decision-making process of end-stage renal disease patients at end-of-life

Discussions

- Showing in Figure 1, the interrelated effects of communication barriers, family dynamics, sharing burdens and existential distress were formulated from the emic views of the patient and carer informants.
- The central philosophy of the decision-making process of care priority at the final stage of life for dialysis patients is established as "dying with dignity".
- There are universalities and diversities in the findings between the present study and the current literature (Axelsson, Randers, Lundh Hagelin, Jacobson, & Klang (2012); Baharoon, Al-Jahdali, Al-Sayyari, Tamim, Babgi, & Al-Ghamdi, 2010; Bristowe et al., 2015; Chu et al., 2011; Davison, 2010; Mok, Ting, & Lau, 2010).
- As reflecting in the collectivistic Chinese culture that families should make important medical decision for the patients; contrary, patients with the belief of individualism from the Western culture grasp their autonomy in the decision-making process.

Implications for practice

- Informants in the study were surely stimulated and affected by the survey questions or the questions asked in the focus group interviews.
- Strategies have to be developed to enhancing the communication channel among dialysis patients, carers and healthcare professionals; and facilitating shared decision-making for the patients at their final stage of life.
- Culturally oriented advance care planning programme should be developed at the time of commencing the dialysis and in consultation with patients and carers.



Conclusions

The overarching influence of culture supports the main findings from the study and answers the research questions. Findings from the quantitative or qualitative strand could articulate the aim of this study, and they inform healthcare professionals about the culture related, perspectives of care priorities for dialysis patients. Moreover, the dialysis patients should have understood their physiological and psychological needs to face the changes in the trajectory of the disease process so as to prepare and plan appropriately and accordingly. Obviously, advance care planning should be promoted for the patient's body and mind. Let them have a sense of integrity and ready to die. Crucially, every dialysis patient should have the right to leave the world in the manner of dying with dignity.

References

- Axelsson, L., Randers, I., Hagelin, C. L., Jacobson, S. H., & Klang, B. (2012). Thoughts on death and dying when living with haemodialysis approaching end of life. *Journal of Clinical Nursing*, 21(15-16), 149-2159.
- Baharoon, S. A., Al-Jahdali, H. H., Al-Sayyari, A. A., Tamim, H., Babgi, Y., & Al-Ghamdi, S. M. (2010). Factors associated with decision-making about end-of-life care by hemodialysis patients. *Saudi Journal of Kidney Diseases and Transplantation*, 21(3), 447-453.
- Bristowe, K., Horsley, H. L., Shepherd, K., Heather, B., Carey, I., Matthews, B., ... Murtagh, F. E. M. (2015). Thinking ahead – the need for early advance care planning for people on haemodialysis: A qualitative interview study. *Palliative Medicine*, 29(5), 443-450.
- Chu, L. W., Luk, J. K., Hui, E., Chiu, P. K., Chan, C. S., Kwan, F., ... Woo, J. (2011). Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong. *Journal of the American Medical Directors Association*, 12(2), 143-152. doi: 10.1016/j.jamda.2010.08.015
- Davison, S. N. (2010). End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clinical Journal of the American Society of Nephrology*, 5(2), 195-204.
- Mok, E., Ting, F. H., & Lau, K-P. (2010). Advance directives and life-sustaining treatment: Informed attitudes of Hong Kong Chinese elders with chronic disease. *Journal of Nursing and Health care of Chronic Illness*, 2(4), 313-319.



Contact information

Paul Lee, PhD candidate
Yoni Luxford, PhD
Glenda Parmenter, PhD

School of Health
University of New England
Armidale NSW 2351, Australia

Please direct enquiries to Paul Lee
Ph: (852) 96682617
E: cleec37@myune.edu.au