

**Title:**

Decisions of Chinese Dialysis Patients and Caregivers About Care Priorities at Final Stage of Life

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**Session Title:**

Rising Stars of Research and Scholarship Invited Student Poster Session 3

**Slot (superslotted):**

RSG STR 3: Sunday, 30 July 2017: 9:45 AM-10:15 AM

**Slot (superslotted):**

RSG STR 3: Sunday, 30 July 2017: 12:00 PM-1:15 PM

**Slot (superslotted):**

RSG STR 3: Sunday, 30 July 2017: 2:00 PM-2:30 PM

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**Keywords:**

Culture care, Decision-making at end-of-life and Dialysis patient and carer

**References:****References**

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**Abstract Summary:**

This research is a qualitative driven mixed methods study to discover, describe and analyse the culture care meanings of renal dialysis patients and carers during their decision-making about end-of-life care

priorities. The decision outcomes are individualised, situational, and contextual in which culture plays a central influence.

**Learning Activity:**

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
1. The learner will be able to understand the culture care meanings of renal dialysis patients and carers during their decision-making about end-of-life care priorities.	The interrelated effects of communication barriers, family dynamics, sharing burdens and existential distress were formulated from the emic views of the informants. The main theme of the decision-making process of care priority is established as "dying with dignity".
2. The learner will be able to identify the strategies to empower the decision-making process of dialysis patients and carers at end-of-life care.	Enhancing the communication channel among dialysis patients, carers and healthcare professionals; facilitating shared decision-making; and promoting advance care planning for the patients at their final stage of life.

**Abstract Text:**

**Decisions of Chinese dialysis patients and carers about care priorities at final stage of life**

**Background:** End-stage renal disease involves progressive and irreversible kidney damage leading to permanent loss of renal function. The progression of the underlying disease, emergence of complications, and gradual decline in functional status and quality of life leads many patients to withdraw from dialysis, and in Hong Kong, this withdrawal is a common cause of death (28.5%) (Hong Kong Renal Registry, 2013). Despite this high mortality rate, the decision-making process about care priorities at end-of-life (EOL) has not been stressed within this dialysis population (Bristowe et al., 2015; Ceccarelli, Castner, & Haras, 2008; Haras, 2008). Traditionally, death and dying that has long been a taboo in Chinese culture and patients and health care professionals avoid discussion of the topic (Leung, 2010). Therefore, healthcare professionals and the patients' family members often encounter dilemmas when patients undergoing dialysis reach the terminal phase of their disease but have never discussed their end-of-life care priorities or made decisions related to withdrawal of life-sustaining therapy (Baharoon et al., 2010; Davison, 2012; Kurella Tamura, Goldstein, & Perez-Stable, 2010). In addition, the mixed Eastern and Western culture in Hong Kong as it was the British colony for over 150 years, might affect the thought and belief of the local population towards the decision-making process at end-of-life.

**Purpose:** Given that few studies have explored the decision-making processes of dialysis patients and their carers regarding end-of-life care, especially in the Chinese context, the purpose of this study was to fill this research gap. This study also aimed to explore the effect of culture on communication about the decision-making process, to learn more about a previously hidden topic in Hong Kong. The findings of this study will also 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 mixed methods, sequential, explanatory design was adopted and purposive sampling was used to recruit dialysis patient and carer informants in a regional renal dialysis centre in Hong Kong. The quantitative, descriptive data were analysed and Spearman's rho correlation was applied to test the associations between the characteristics of dialysis patients and their carers as well as the variables of decision-making. The results were used to guide the formulation of the questions to be asked in subsequent focus group interviews. As the researcher adopted a qualitative driven mixed methods design in this study, by applying the ethn nursing qualitative research method, the researcher identified the domain of inquiry, formulated the research questions, reviewed the literature to distinguish gaps related to the domain of inquiry, and developed the research plan and method of data analysis. Likewise, the

qualitative data were analysed according to the Leininger's phases of ethnonursing data analysis. Themes were synthesised to inform the renal speciality practice.

**Results and findings:** Of the 121 dialysis patients and 61 carers informants who participated in this research project, 86% of patients and 80.3% of carers preferred their family members to make treatment decisions when reaching the terminal phase of their disease. However, majority of the patient informants had not discussed their preferences or care priorities with anyone. While 42.1% of dialysis patients reported knowledge of the end-of-life care, the majority (81.8%) were not aware of advance directives but 83.5% of them claimed would adopt advance directives if it were available. Comparing with the dialysis patients, it seems carers had more knowledge on end-of-life care (50.8%) and advance directives (36.1%). Whereas, 90.2% of carers were willing to make an advance directive if it were available. Both groups expressed their opposition to life-sustaining measures, such as mechanical ventilation, in the event of terminal illness. However, they felt constrained from asking or talking to medical professionals about EOL care during the clinic consultations. Based on the findings from the focus group interviews, the patient informants considered communication barriers, Chinese cultural norm and dying in dignity were the major themes in the decision-making process at their EOL domain. Whereas, personalising care, normalising life, sharing burdens and carer's plight were expressed and delineated from the carer informants.

**Discussions:** There are universalities and diversities in the findings between the present study and the current literature. As shown, majority of the dialysis patient and carer informants preferred their families to make the decision of EOL care for them that is similar to other local studies (Chu et al., 2011; Mok, Ting, & Lau, 2010; Wong et al., 2012). In fact, the majority of the American dialysis patients chose to make the decision themselves (Davison, 2012). 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. Commonly, dialysis patients seldom discuss EOL care preferences with others (Davison, 2010; Janssen et al., 2013; Miura et al., 2006). Whenever there are discussions on the preferences of care, the majority of the patients and carers in this study would like to involve the families as first priority, comparing with some oversea studies that doctors would be primarily involved (Lockett et al., 2014; Morton, Tong, Howard, Snelling, and Webster, 2010). In the present study, the interrelated effects of communication barriers, family dynamics, sharing burdens and existential distress were formulated from the emic views of the 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". The end-of-life communication allows patients to express their preferences for life-sustaining treatments, knowing and respecting the end-of-life wishes can improve the patients' sense of control as well as preparing for good death. Efficient and honest communication among patients, carers and healthcare professionals not only can enhance the independency and autonomy in making medical decision but also can facilitate the family-centred system for the purpose of shared decision-making. Importantly, it should be acknowledged that the dialysis patients and carers always have tension and struggle in the decision-making process, shifting between Eastern and Western culture in the context of Hong Kong. Moreover, the family relationship and filial piety are the major components of the traditional Chinese culture although there is growing demand for the western autonomy system from the patient informants. By knowing the specific cultural pattern in Hong Kong, healthcare professionals can be more understandable from the emic & etic views of care priorities at dialysis patients' final stage of life. Hence, the decision outcomes are perceived as individualised, situational, and contextual in which culture plays a central influence.

**Implications for practice:** Throughout the research process, informants in the quantitative and qualitative strands were surely stimulated and affected by the survey questions or the questions asked in the focus group interviews. In fact, 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. It helps to focus on the discussions about the dialysis patients' understanding of their illness, personal experiences with death, their goals and values towards the final stage of life. Further, service innovation project is recommended to develop culturally oriented

advance care planning 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 derived from the domain of inquiry. 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.