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Organizational capacities for 'residential care homes for the elderly' to provide culturally appropriate end-of-life care for Chinese elders and their families

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ABSTRACT

Developing culturally appropriate end-of-life care for Chinese elderly and families is not an endemic challenge for Hong Kong, but that of the Western countries with a noticeable trend of rising Chinese population. The particular development of Hong Kong healthcare system, which is currently the major provider of end-of-life care, makes Hong Kong a fruitful case for understanding the confluence of the West and the East cultures in end-of-life care practices. This study therefore aims at building our best practice to enhance the capacity of residential care homes in providing culturally appropriate end-of-life care. We conducted two phases of research, a questionnaire survey and a qualitative study, which respectively aims at (1) understanding the EoL care service demand and provision in RCHEs, including death facts and perceived barriers and challenges in providing quality end-of-life care in care homes, and (2) identifying the necessary organizational capacities for the 'relational personhood' to be sustained in the process of ageing and dying in residential care homes. Findings shed light on how to empower residential care homes with necessary environmental, structural and cultural-resource-related capacity for providing quality end-of-life care for Chinese elders and their families.

Introduction

The majority of deaths in many developed countries occur after the age of 65 (Australian Institute of Health and Welfare, 2013; Centre for Disease Control and Prevention, 2007; Office for National Statistics, 2014) and in institutional settings, including hospitals, nursing homes and other types of care homes (Cohen et al., 2015; Gomes & Higginson, 2008). Similarly, In Hong Kong, 79% of deaths involve people aged over 65; 40% are aged over 80. Among the counts of deaths in hospitals each year, approximately one-third are elderlies who live in residential care homes for the elderly (RCHEs) (Hospital Authority, 2015). This change in the demography of death poses new challenges to end-of-life care because the imminently dying older adults are more likely to have developed multi-comorbidities at the end of life as a result of ageing (Kwan, Lau, & Cheung, 2015; 何孝恩, 2014); additionally, the intersectionality of ageing and dying is deeply culturally entrenched and requires culturally appropriate services to meet demands.

Cultural sensitivity in handling dying in ageing is affected by globalization and the increasingly culturally diverse societies observed in many developed countries (Oliviere & Monroe, 2004; Seymour, Payne, Chapman, & Holloway, 2007). In Chinese society, the actualization of the relational self is emphasized, and ageing and dying strongly intersect with filial piety, familial hierarchy and the relational self. Bellamy and Gott (2013) recognized that the practices purporting the individualistic culture in the West can run counter to many Chinese-specific practices, such as 'a tendency to withhold prognostic information on the basis that it might cause a loss of hope', having family members channel the information regarding personal care and having the extended family come and see the older adults for the last time (p.28). Maintaining and enhancing a sense of the relational self is considered not only essential but also critical to achieve an optimal quality of death in Hong Kong's context (Fang et al., 2015).

Hong Kong is considered to be a good case in understanding the confluence of Western and Eastern cultures in end-of-life (EoL) care. The majority of the population in Hong Kong is Chinese, whereas its EoL care primarily occurs in the formal healthcare system, which began to develop in the colonial period and runs on Western medical concepts. Previous literature on organizational impacts on EoL care, which were developed in the West, has focused on the impact of primary care for dying residents (Kayser-Jones et al., 2003) or risk-adjusted quality measures (Temkin-Greener, Zheng, & Mukamel, 2012) for patient outcome, such as the reduction of unnecessary hospitalization, quality of EoL care and commitment of staff in quality improvement. However, this system neglects the conservation of the residents' cultural-social integrity, in

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this case the 'relational personhood', alongside physical deterioration due to ageing and dying. The Hong Kong healthcare system is currently extending its EoL care to residential care homes for the elderly (RCHEs). Now is thus the best opportunity to examine which actions are needed to adapt the westernized healthcare system to provide Chinese appropriate EoL care, especially in residential care home settings.

Relational personhood among older Chinese adults

The concept of the self in Hong Kong Chinese is deeply rooted in the familial culture, which locates oneself, bodily and socially, in hierarchical relations subordinating the younger to the older and women to men (Holroyd, 2003). Refocusing on the family (which very often serves as a major reference point for the formation of a socially appropriate self and is a site for passing on the family traditions and the ancestors' legacy) is essential to understand 'Chinese-ness' as performed in EoL care (Ho et al., 2013). Familial values and virtues are hence the 'nodal points' for Chinese older adults and their families to construct their concept of self, which we term 'relational personhood'.

Family involvement in nursing home care is more common in Chinese culture because filial piety creates the social expectation for children to take care of their aged parents (Brown & Walter, 2013; Holroyd, 2003); this practice bridges the gap between home care and institutional care. These care-related acts also form part of the moral self of the caregivers by fulfilling filial virtues. However, in reality, older adults' experience of institutional care disengages them from their families and communities; this stands in contrast with their interpersonal attachment with significant others in their construction of spiritual fulfilment (Lou, 2015). Nonetheless, despite the international move to reduce hospital stays in the end of life, only in a few countries, such as the U.S., Canada and the United Kingdom, manage to halt or reverse the trend of dying at the hospital (Higginson et al., 2013). Rather than promoting 'dying-at-home', creating 'home-like' environment for people from different cultures to die well, disregarding the place of death, has become a rule of thumb to guide service development. Given a comparatively high institutionalization rate of older adults (6.8%) in Hong Kong, and that Hong Kong Social Welfare Department has started new tender requirement for new RCHEs to provide end-of-life care, improving the organizational capacity of RCHEs to carry out culturally appropriate quality EoL care can significantly improve quality of death of the ageing population.

Sustaining the dying older adults' relational personhood in residential care homes in the Hong Kong Chinese context

With the awareness that more and more older adults would prefer ageing at home globally, dying at home is still not a preferred option among terminally ill Hong Kong Chinese. Only 14%–19% of patients treated in palliative care prefer home deaths (Lam, 2013; Woo et al., 2013), while dying at home is considered as 'contaminating' the property and making it a 'haunted house'. A public survey though finds 30.8% of Hong Kong Chinese participants would like to die at home, 51.8% still prefer dying in the hospital (Chung, 2016). Nonetheless, Lam (2013) also contemplated that the preference of dying of home is obscured by the micro living space, such as small-size apartment homes and subdivided rooms, in Hong Kong. Rather than dying at home, Hong Kong Chinese older adults seem to prefer ageing at home and dying at the hospital or the residential care homes (Luk, Liu, Ng, Beh, and Chan (2011) discovered that 28.8%–35% of institutionalized older adults prefer dying at the residential care homes).

Organization as a key factor determining the service quality of long-term care (LTC) facilities has been well recognized in the literature. Blevins and Deason-Howell (2002) conceptualize the organizational factor at the microsystem and mesosystem levels in Bronfenbrenner's Ecological Model, which acknowledges the multidimensional and multilevel nature of EoL care that is provided in nursing homes. This approach highlights LTC facilities' interactions with other district care systems and the local community in providing EoL care, leading to the urban-rural differences. In nursing home studies, organization is understood variably. The environmental-, structural- and resource-related aspects are most studied, highlighting the importance of the physical environment, the existence of local competition, conformance to social expectations, institutional leadership, client mix, facility, staffing and availability of supervision (Kayser-Jones et al., 2003; Lucas et al., 2005; McGregor et al., 2011; Temkin-Greener et al., 2012).

Environmental factors, such as the privacy rendered and the design and the size of the home, set the material foundation for achieving the older adults' preferred image of self. These factors affect how Chinese older adults live and the ability of their families to continue to care for them (Frey, Raphael, Bellamy, & Gott, 2014; Lee et al., 2013), thereby maintaining the relational personhood of the deteriorating residents. These factors impact the users' happiness as well as the job satisfaction of staff in the homes (Castle & Engberg, 2006). The availability of EoL care is also higher in places where the market of private nursing homes is mature and money incentives are offered for EoL care (Petrisek & Mor, 1999).

Structural factors in the literature refer to the institutional leadership and client mix of nursing homes. They respectively highlighted the importance of top-down management support and precise appropriation of skilled staff to the implementation of quality EoL care. These structural factors are critical elements for coordinating services to meet the complex care needs of dying older adults and their families. Resources, such as facilities, staffing, turnover rate and the availability of supervision for the care home practitioners are considered to affect both the stability and quality of care. Poor supervision may even lead to negligence in care, particularly when the bed ratio is high (Kayser-Jones et al., 2003). Hong Kong's RCHEs mirror many of the organizational concerns studied in the international literature; additionally, the cultural challenges for sustaining the older adults' 'relational personhood' in relation to those organizational factors remain insufficiently addressed.

Developing culturally appropriate end-of-life care for Chinese older adults and families is not an endemic challenge for Hong Kong but that of Western countries with a noticeable trend of an increasing Chinese population. The unique Hong Kong healthcare system, which is currently the primary provider of end-of-life care, makes Hong Kong a fruitful case for understanding the confluence of Western and Eastern cultures in end-of-life care practices. This study therefore aims to contribute to our knowledge to enhance the capacity of residential care homes in providing culturally appropriate end-of-life care. We conducted two phases of research, a questionnaire survey and a qualitative study, which, respectively, aimed to (1) understand the EoL care service demand and provision in RCHEs, including death statistics and perceived barriers and challenges in providing end-of-life care in care homes and (2) identify the necessary organizational capacities for the 'relational personhood' to be sustained in the process of ageing and dying in residential care homes. The findings shed light on how to empower residential care homes with necessary environmental, structural and cultural resource-related capacities for providing end-of-life care for Chinese older adults and their families.

Research methods: design, processes and data analysis

This study consists of two phases that make up a secondary data analysis of a quantitative survey conducted with all government-subvented RCHEs (156 homes in total) and a qualitative study of four chosen care homes that provide EoL care to aged residents. The former is to understand the death statistics and challenges as perceived by the service providers in delivering EoL care in residential care; the latter is an in-depth qualitative study to determine how the challenges as revealed in the survey study are met by emerging best practices. A mixed method of this type is argued to be effective in understanding organizational culture (Frey, Boyd, Foster, Robinson, & Gott, 2015), in this