

Durham Research Online

Deposited in DRO:

16 June 2017

Version of attached file:

Accepted Version

Peer-review status of attached file:

Peer-reviewed

Citation for published item:

Kong, S.T. and Fanga, M-S.C. and Lou, W.V. (2016) 'Organizational capacities for 'residential care homes for the elderly' to provide culturally appropriate end-of- life care for Chinese elders and their families.', *Journal of aging studies.*, 40 . pp. 1-7.

Further information on publisher's website:

<https://doi.org/10.1016/j.jaging.2016.12.001>

Publisher's copyright statement:

© 2017. This manuscript version is made available under the CC-BY-NC-ND 4.0 license
<http://creativecommons.org/licenses/by-nc-nd/4.0/>

Additional information:

Use policy

The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a [link](#) is made to the metadata record in DRO
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Please consult the [full DRO policy](#) for further details.

Organizational Capacities for ‘Residential Care Homes for the Elderly’ to Provide Culturally Appropriate End-of-Life Care for Chinese Elders and their Families

Sui-Ting Kong

Christine M.S. Fang

Vivian W.Q. Lou*

Accepted on 6 December 2016, Journal of Aging Studies

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, Office for National Statistics, 2014, Centre for Disease Control and Prevention, 2007) and in institutional settings, including hospitals, nursing homes and other types of care homes (Gomes and Higginson, 2008, Cohen et al., 2015). 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 & Lan, 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 and Monroe, 2004, Seymour et al., 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 (Lou, 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 et al., 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 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 and 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 Kingdoms, 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 et al. (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 (Temkin-Greener et al., 2012, Kayser-Jones et al., 2003, McGregor et al., 2011, Lucas et al., 2005).

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 et al., 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 and 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 and 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-subsidized 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 et al., 2015), in this case barriers and best practices for promoting Chinese-appropriate EoL care in RCHes.

Phase 1

In the 1st phase of the study, our team collaborated with a non-governmental organization to conduct a survey study on the organizational readiness of RCHes in providing EoL care. The questionnaire was first designed by reviewing local literature on possible barriers and challenges facing EoL care service providers in Hong Kong. The first draft of the questionnaire was circulated among subsidized RCHes through the

non-government organization, and then deliberated and discussed in a 2-hour stakeholders' meeting held on 24 March 2015. Superintendents/deputy superintendents of RCHEs were invited to the meeting to comment on the appropriateness and relevance of the questionnaire to the service realities. Their comments were incorporated when revising the questionnaire. The final questionnaire covers questions on four areas, including (1) care home background information, (2) current service demand for EoL care, (3) current service provision and challenges and (4) priority for service improvement.

The non-governmental organization distributed the questionnaire to all subvented RCHEs in Hong Kong (N=156) in March 2015 through email, including subvented care homes and contract homes providing subsidized places for the older adults. A total of 100 completed questionnaires (64% response rate) were eventually collected, and the data were entered by the organization. Descriptive data analysis (frequencies, means and cross-tabulation) was performed by our research team with SPSS Statistics 23 software to determine death statistics, service demands and provision and the challenges as perceived as those most confronted by RCHEs in providing EoL care and to systematically implement advance care planning (ACP). The analysis was presented to all RCHEs superintendents/vice-superintendents who had completed the survey questionnaire in May of the same year for further understanding of their views on the findings.

Phase 2

This phase of research is carried out with one of the few local pilot projects, which supports RCHEs to provide quality EoL care by enhancing their care environment, building partnerships with other systems and equipping them with essential resources.

The project is run by a mobile EoL team, composed of an affiliated palliative doctor, an advanced palliative nurse, a senior social worker and 2 registered social workers, to provide services to local RCHEs. The participating RCHEs cover the full range of long-term care facilities that take care of older adults of different levels of frailty – Care and Attention Homes (C&A) ⁽¹⁾ and Nursing Homes (NH) ⁽²⁾, hence serving a good case to determine best practices available to overcome the challenges identified by the survey study. Interviewees are purposely sampled to maximize the diversity of the medical care home partnership to increase the applicability of the findings. In-depth interviews and an ‘end-of-life case graph’ were employed to collect practice narratives from EoL care practitioners to determine how the RCHEs went through social-structural changes, to meet the arising challenges, and to sustain the dying older adults’ ‘relational personhood’.

In this study, 12 interviews were conducted with 10 EoL care practitioners, including a project coordinator, EoL team social workers, residential home nurses and social workers. The interviewees were representatives of the EoL project and of participating RCHEs with various partnerships with the hospital setting. The sampled homes also differed from each other in terms of business model (self-financed and government-subvented), type of homes (care and attention home or nursing home) and partnership with the medical system (with and without hospital medical support). This sample of participants therefore offers maximum variations of context regarding where EoL care is delivered (see Table 1).

Participant Pseudonym	Gender	Age	Profession	Institution	Partnership Negotiated with Healthcare System
Ms. Lam	F	30-35	Social Worker	EoL Care Team	The pilot project (Mobile EoL Team)
Mr. Yan	M	25-30	Social Worker	EoL Care Team	The pilot project (Mobile EoL Team)
Ms. An	F	25-30	Social Worker	EoL Care Team	The pilot project (Mobile EoL Team)
Ms. Tam	F	30-35	Social Worker (Superintendent)	Nursing Home	24-hour medical care integrated in the RCHE
Ms. Kung	F	30-35	Social Worker	Nursing Home	24-hour medical care integrated in the RCHE
Ms. Ng	F	50-55	Nurse (Superintendent)	Care and Attention Home (Continuum of Care)	Well established support by the public hospital's geriatric team (with community EoL care programme)
Ms. Chan	F	25-30	Social Worker	Care and Attention Home (Continuum of Care)	Well established support by the public hospital's geriatric team (with community EoL care programme)
Ms. Woo	F	45-50	Nurse (Assistant Superintendent)	Care and Attention Home (Continuum of Care)	Supported by the cluster geriatric team (without community EoL programme)
Mr. Wong	M	35-40	Social Worker	Care and Attention Home (Continuum of Care)	Supported by the cluster geriatric team (without community EoL programme)
Ms. Si	F	40-45	Nurse (Superintendent)	Care and Attention Home (Continuum of Care)	Well established support by the public hospital's geriatric team (with community EoL care programme)

Table 1. Demographics of research participants involved in the qualitative study

The average duration of the interviews is 2.5 hours. All interviews with the exception of one (because of a technical problem) were tape-recorded and transcribed. An interview summary was prepared for the unrecorded interview and triangulated by the interviewee until no further amendment was needed. In addition to the interviews,

the researcher collected official materials from the EoL care project as well as documents from the individual residential care homes. These documents included assessment and intervention protocols, practice guidelines and work flow, documentation of emerging practices, memoranda of EoL cases and personalized EoL care guidelines for specific home staff. The documents collected are all anonymized and obtained with the interviewee's consent. Constant comparative analysis was employed to code and conceptualize data to generate locally relevant themes.

Ethics

Ethical approvals for both phases are separately obtained from the university ethics committee. Anonymity is ensured throughout the process for all participating members.

Findings

EoL care service demand and provision in RCHEs

The survey study shows that death is not uncommon in RCHEs which can be categorized into two layers, one for severe level of impairment and one for moderate level of impairment, namely Nursing Homes (NH) and Care and Attention Homes (C&A) respectively. The average annual death rate of care home residents is 17.2% (median 17%), while that of NH (6%) is 23.61% and that of C&A (94%) is 16.82%. The death rate of nursing homes in Hong Kong is comparable to those in England and Wales (26.2%) (Shah et al., 2013) and in the U.S. (20%) (Temkin-Greener et al., 2013). On average, 22.7 (median 19) residents die every year in each home. These residents experienced 2.9 hospitalizations on average in the last 6 months of their life with an average 28.2 days of hospitalization of each person in the last 6 months of life (according to the data of the last 10 deaths in the RCHE). RCHEs present noticeable revolving door syndrome.

Despite a significant rate of death and frequent hospitalization, more than half of the

respondents (56%) have no EoL care protocols and guidelines in their homes, whereas 66% had not systematically implemented ACP in the 3 years prior to the study. Only 27% of the respondents who carry out systematic EoL care in the most recent 3 years also have protocols/guidelines. However, 46% of the respondents claim that the residents/families expressed the need for EoL care services in the year prior to the study. Those needs include frequent demand for pain relief (52.2%), funeral arrangements (45.7%), social care (39.1%), psychological care (28.2%) and spiritual care (15.2%). Thus, as can be observed, the systematic provision of EoL care is substantially lagging behind the need.

Challenges facing RCHes in providing quality EoL care

In the survey study, we also compare the mean scores of the challenges facing the RCHes in providing EoL care (see table 1). With a cutting point at a mean score of 4, we found that respondents strongly agree/agree to (1) the lack of body handling facilities (mean=4.84), (2) communication and coordination between care homes and hospitals (mean=4.51) and (3) consensus, mission and culture among home staff (mean=4.54) as the most commonly encountered issues in carrying out EoL care. These three items indicate the environmental, structural and resource readiness that RCHes need to provide quality EoL care. Other environmental factors such as a lack of medical facilities and space for EoL care; structural factors such as flexibility in providing personalized care and concerns regarding possible autopsy when dying at a care home; and resource-related factors such as the residents' need for psychological comfort, the lack of manpower and medical support are also agreed upon by most respondents to reflect their practice realities. Best practices for providing RCHes with these necessary capacities are then sought in a qualitative investigation.

Challenges perceived by respondents (with mean scores 4 and above)	Strongly Agree/Agree	Neutral	Strongly Disagree/ Disagree	Mean scores (1-strongly disagree; 5-strongly agree)
<u>Environmental</u>				
Lacking body handling facilities, e.g. mortuary	<u>97.4%</u>	<u>1.7%</u>	<u>0.9%</u>	<u>4.84</u>
Lacking medical facilities and equipment for EoL care	76.7%	9.5%	13.8%	4.04
Lacking space to provide EoL care	45.8%	11.2%	12.9%	4.04
<u>Structural</u>				
Communication and coordination between care homes and the hospitals	<u>96.6%</u>	<u>3.4%</u>	<u>0%</u>	<u>4.51</u>
Needing flexibility in providing personalized care to fit the changing physical conditions when death is imminent	97.4%	2.6%	0%	4.42
The possibility of undergoing autopsy after dying at care home worries both residents and their families	79.8%	19.1%	1.1%	4.14
<u>Resources (Material, Staffing and Cultural)</u>				
Building consensus, common vision and culture among home staff should happen before the implementation of EoL care	<u>97.5%</u>	<u>2.6%</u>	<u>0%</u>	<u>4.54</u>
Home staff have to take care of the psychological needs of the dying residents and their families when death is imminent	99.1%	0.9%	0%	4.49
Home staff have to start advance care planning before residents become too frail or unable to make decisions	93.1%	6%	0.9%	4.31
Lacking manpower to visit/accompany/support the dying residents when they are hospitalized	82.8%	10.3%	6.9%	4.17
Understaffing of frontline workers to meet the service demand of EoL care	78.4%	8.6%	13%	4.11
Lacking night time medical support to handling emergency	81.9%	6.9%	11.2%	4.08

Table 2. Major challenges facing RCHEs in providing EoL care in Hong Kong

Empowering RCHEs to ‘get ready’ for culturally appropriate EoL care through a focus on ‘relational personhood’

The first phase of the study enables the mapping out of the organizational factors that set the necessary conditions for residents’ realization of self and for key players of the residents’ lives, including family, friends and neighbours, to maintain and enhance relational personhood in RCHEs. Embedded in these conditions are the residents’ sense of pride/achievement, enjoyment and desires.

The findings show how to conserve the personhood of Chinese residents by empowering RCHE with an appropriate environment, structure and resources. The best practices for resolving the identified problems are (1) equipping the environment with an appropriately located palliative care room that has sufficient space and privacy for family participation, (2) streamlining the structure to ensure continuous flexible, personalized and chosen care and (3) cultivating a common vision, mutual trust and suitable manpower for culturally appropriate relational personhood-focused EoL care in RCHEs. If the necessary organization capacities identified in this study were provided, EoL care practices could be transformed: conventional geriatric assessment could be extended to include communicability, spirituality, family dynamics, trust, conflicts/disagreements, understanding of the family’s roles, and the identification and the care capacity of the proxy; the individualistic model of care could be transformed into a culturally appropriate relational model.

Equipping the Environment for Good Death

The environmental capacity delineates the choice regarding the place of death. Practitioner-participants in this study repeatedly emphasize the importance of

'hardware' for dying to take place in the care home. For example, a fully equipped palliative care (PC) room enables family members to accompany the dying resident in the last few days and ensures that the flexibility given to the dying is not at the cost of other residents' living quality (Bellamy and Gott, 2013). In this regard, RCHes that do not have space for a PC room would, understandably, find it more difficult to involve family in the last few days as fully as those equipped with one and would thus be less likely to sustain the dying's relational personhood.

In addition to adequate space for Chinese extended families, as noted in the literature, our study finds that the location of the PC room also matters. The location can help balance the benefit of both the dying and the living residents and reduce fears and discomfort induced from witnessing the dying process. The room is ideally either located at the end of the corridor or equipped with a partition/curtain to reserve sufficient privacy, as well as distance from those who are not yet ready to break the cultural taboo.

'One of the participating care homes shared in a meeting, saying that the chef told them, "if that..I mean that PC room is next to the kitchen...there will be the chance that the older adults will die there...and the body could possibly stay there...I will immediately resign from this job,"' said Ms Tam.

Additionally, the absence of a mortuary presents a huge challenge to Hong Kong RCHes. Unlike in the UK and US, where transportation of the body is legal after the medical certification of death (DieSmart, 2007-2016; UK Government, 2015), the transportation of the body without obtaining a Death Certificate from the Death Registrar, which runs on limited service hours, is illegal in Hong Kong. Therefore, RCHes experience tremendous pressure in enabling dying-in-place in Hong Kong's extremely hot summer. Practitioners also admitted that the time pressure for transporting the

body to the funeral services, where cooling facilities were available, is further translated into a lack of time for the family members to grieve the death and rushes them into post-mortem logistics. The underequipped care home environment made some interviewed practitioners slightly doubtful regarding the benefit of 'dying-in-place' for the dying and the living residents and their families.

Streamlining the Structure to Enable Continuous Flexible, Personalized and Chosen Care

Advance directives (AD) and Do Not Apply Cardiopulmonary Resuscitation (DNACPR) orders, which were recently introduced to the Hospital Authority (HA) in October 2014, narrowly define 'EoL care' in medical settings. Psychosocial care is located at a marginal position, if not completely ignored in the currently hospital-based EoL care. Furthermore, many care staff in both the hospital and care homes are not yet prepared or equipped with the necessary knowledge for palliative care, rendering seamless EoL care transitions between hospitals and RCHEs similarly uneasy.

Coordinated and smooth care transition between the hospital and RCHEs is the cornerstone for institutionalized dying older adults to obtain timely specialized medical care in the hospital. These transitions are strongly associated with symptom management and physical stability, which are also prerequisites for easier self-expression, enhanced social connectedness and other psychosocial care intervention. In the qualitative study, the major contributing factors for the continuity of preferred care are identified: (1) 'secured and comfortable transfer between homes and hospitals', (2) 'seamless honouring of residents' ACP' and (3) 'effective care coordination'. Good practices such as case managers, the division of labour in terms of aspects of care and synchronized assessment/understanding also facilitate continuity of care across systems, particularly when the (a) medical support to the RCHEs is

limited, (b) the care capacity of the RCHEs drops, (c) personalized care is unlikely in the hospital setting and (d) the communication between the hospital and the care home is insufficient.

In contrast, 'limited service for smooth transitions', 'reduced care capacity of residential home', 'inflexibility for personalized care in the hospital' and 'lacking communication between the hospital and the care home' are inhibitors for the continuity of chosen care. Insufficient communication between the hospital and the care home, in particular, has proven to be detrimental to the quality of care and have worsened the revolving door syndrome.

Mr Yan said, 'The problem of high blood glucose level has made her hospitalized many times...you know, she's hospitalized when it's high, and it came down gradually (due to consistently low food intake). In the hospital, when the glucose level came too low, they stopped all medication for glucose control. This is a typical response from the medical system to prevent the blood glucose level from going too low as it can lead to immediate unconsciousness. So...after stopping medication and being discharged from the hospital, she returned to the care home, where the staff and family members perform comfort feeding. Her blood glucose level went up so quickly for sure...so...she was hospitalized again right after she was discharged. This pattern repeated many times...like 3 to 4 times in a month'.

In a few cases where the blood glucose level was the key to the residents' physical stability, a lack of communication regarding the differences in the residents' diet between the care home and the hospital led to repeated readmission to the hospital acute ward.

Aligning Multiple Resources for Good Death: Cultivating a Common Vision, Mutual

Trust and Suitable Manpower

Building consensus, common vision and culture for quality EoL care requires care practitioners to challenge RCHes' care routines, which are found to have 'proceduralized', 'uprooted' and occasionally even 'marginalized' the voice of the residents. A strong leadership is unanimously stated in the literature to be a contributing factor for improving the quality of EoL care. Quality EoL care as benchmarked by choice and autonomy poses further challenges for managers in RCHes to reformulate the communal care routines into personalized care for the dying older adults.

By attending to the personal preferences in EoL care, practitioners begin to realize the importance of 'the person' (嗰個人), as well as 'personalized' and 'humane' care (個人化/人性化服務) as it relates to the quality of life of the dying and their families. This also sheds new light on the understanding of dignity that is considered the bedrock for EoL care. In addition to pain/symptom management and post-mortem arrangements, social connectedness, self-expression in the Chinese familial culture, family engagement and psychological/spiritual comfort are perceived as equally crucial by practitioners for sustaining what they term 'social dignity'.

'Yes, actually having some connection is part of human dignity. It's like social dignity that should include not burdening the others [at the end of life].' Said

Mr Yan

With a clear goal of honouring the dying person's dignity in all aspects, practitioners begin to innovate new practices (i.e., understanding the 'person-in-time' and 'person-in-relationships') to carry out assessment beyond conventional geriatric assessment by exploring the residents' histories and significant relationships. This functions to collect symbolic, linguistic and experiential resources, which are socially relevant and

culturally appropriate to co-create a preferred self at the end of life in RCHEs. These strategies reflect the interdependent self that is favoured in the Chinese familial and collective culture (Lou and Ng, 2012).

Trust building among all stakeholders is also found to have paved a solid foundation for participating in this “new trail” of dying in RCHEs. The trust-building process is conceptualized as the ‘4-I model’—information, intention to care, insistence on capacity building and learning and involvement of all in practice (Fang, Lou & Kong, 2015).

- i. Information (稟): Transparency and disclosure serve as the basis for the resident, the family, the medical, the social and the primary care to communicate and make decisions that are best for the resident.
- ii. Intention to care through continuous communication and engagement (傾): Not doing active treatment is not giving up on a person but is instead a display of ‘intention to care’ when dying is definitely approaching. This message is delivered not merely by words but continuous communication and engagement with the residents and their families.
- iii. Insistence on dignity conservation and honouring preferences through building capacity and learning together (學): Building the necessary capacity for handling the ‘unusual practices’ is essential to trust building. This is performed by nurturing mutual helping and learning relationships among the members of all care giving systems, i.e., medical care, nursing, primary care and social care.
- iv. Involvement in practice (做): Involving multiple professionals and stakeholders and realizing that the plan is crucial for further embedding the trust into each one’s memory and practice experiences. This is the ultimate process to ensure that all plans, communications, decisions and capacities are workable and

replicable in practice.

'...so...now, our colleagues can handle this (PC cases)...they (colleagues) can start working on it by themselves (自動波, automatically without extra assistance)...I think in the period of training, we had real cases for them to watch how I handle it. Then, they had to practice. For example, in Sau's case, she once coughed a lot and had a lot of sputum...and she had times with a very low (blood oxygen) level...(after all) our colleagues just go automatic in handling these.' (From the interview with Ms Ng).

By being more hands-on with the care for the dying in RCHes, staff members and families are more prepared for death. Fear, anxiety and silence to death are also found to be eased through increased trust and supported engagement with the care for the dying.

Discussion

Higginson et al. (2013) have found Chinese and people living in Metropolitan areas are less likely to die at home, while Hong Kong showcases how the dying options and preferences of Chinese can be realized in fully urbanized cities (100% of Hong Kong population live in urban areas) (United Nations, 2014) where dwelling space per capita is small or getting smaller. For example, Hong Kong and the UK (Jayantha & Hui, 2010; Morgan & Cruickshank, 2014). This urban living conditions render dying well at home highly challenging, especially for Chinese older adults who emphasize the participation of extended family in important life events and see death as contaminating of the living space. Older adults who have developed Alzheimer's disease and multi-comorbidities due to advanced ageing, coupled with decreasing household size and/or low socioeconomic status, might find RCHes an inevitable place of care in the late stage of

life (Fang, Lou & Kong, 2016; Pereira et al., 2015). By highlighting the importance of cultural resources in this paper, we argue for the urge to acculturate the dying ‘environment’ and ‘structure’ to enable Chinese older adults to die with social dignity— retaining their preferred ‘relational personhood’ in the end of life. Findings not only contribute to the understanding of the most significant organizational elements for the global call for building a ‘home-like’ environment for dying, but also shed light on good practices for preparing organizations, including palliative care units and long-term care facilities for older adults, to facilitate ‘good death’ for people from a strong familial culture.

This study contributes to a new understanding of organizational readiness for quality EoL care for Chinese older adults. It highlights the importance of ‘relational personhood’ in fulfilling Chinese older adults’ preferred sense of self and the organizational capacities needed for such. The survey findings show that dying is common in RCHEs and observed revolving door syndrome in the last 6 months of life in institutionalized older adults. They further substantiate the environmental-, structural- and resource-related challenges facing local RCHEs; additionally, the institutionalization and medicalization of death are attested by our qualitative findings to have alienated the older adults and the families to ‘serve’ and ‘care for’ each other in daily life. The findings also challenge the imbalanced focus on the impact of organizational characteristics on primary care and hospitalization in residential care settings. Alternately, our study echoes the call to examine how to prepare an organization to involve both the residents and their families beyond medical decision-making (Allen et al., 2003) to include admission to EoL care, care planning and funeral arrangements.

The environmental, structural and resource capacities that are extensively discussed in this paper lay out a context in which older adults and families experience dying and death *together*. The environmental capacity discussed in this paper shows the importance of ‘appropriate distance for death to happen’ within a RCHE so that dying can be more acceptable in a culture that associates death with malevolent ghosts and misfortune (Leung and Chan, 2011). The structural capacity emphasizes an effective communication and care transition at the interface between RCHEs and the public health system. This emphasis looks beyond the care home’s internal leadership, management and client mix toward the larger service provision system when making sense of EoL care provision in care homes. On top of resources related to materials and skills, this study reveals the practitioners’ concerns regarding the availability of cultural and social resources for the home staff to deliver culturally appropriate EoL care. These concerns are translated into common care goals/vision and trust among care staff in delivering care for both the dying and the residents.

These organizational capacities nonetheless affect the possibility to reveal the psychosocial dimension of death and dying and to recognize and assimilate it into medicalized care for the dying. According to Timmermans (2005), rewriting the highly medicalized death scripts of resuscitated death and good death into more socio-relational scripts requires genuine participation by the dying and their families. Similarly, our study finds that the reorganization of care practices should enable preferable person-in-relationships person-in-time to be sustained and should help rebuild the emotion and love repertoire for both the older adults and the families via altered institutional care routines. These revise the medical-focused geriatric assessment into one that includes the care capacities of the proxy and the related care dynamics.

Achieving relational personhood in EoL care also addresses the reconstruction of cultural taboos. Preparing the environment for death at an appropriate distance from living in RCHes is an effective practice for improving RCHes response to death, and for easing the conversation about death among home carers, family members and friends. Additionally, bringing the families, friends and care home staff together to promote 'good death' and building trust through hands-on learning are also indispensable to break the silence about death and to encourage multi-disciplinary engagement. This also enables the family to redevelop a literacy for communicating love and care as such an expression is less overt in the Chinese family practices and channelled through 'small acts of kindness', e.g., preparing a nutritious soup (Leung and Chan, 2011). Although we do not assume that every Chinese family and older adults person uphold the same 'form' of 'Chinese-ness' due to the diversity in Chinese population, collective and relational self is found to be a prevalent self-construct at personal, familial and societal level. An examination on how 'Chinese-ness' is performed and captured by EoL care practitioners is worthwhile as it offers an understanding of the 'Chinese-ness' manifest in the context of EoL care. It possibly provides a foundation for looking at the necessary organisational capacities for developing care literacy and readiness for culturally appropriate EoL services/practices.

Reference

- ALLEN, R. S., DELAINE, S. R., CHAPLIN, W. F., MARSON, D. C., BOURGEOIS, M. S., DIJKSTRA, K. & BURGIO, L. D. 2003. Advance care planning in nursing homes: correlates of capacity and possession of advance directives. *The Gerontologist*, 43, 309-317.
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE. 2013. *Deaths* [Online]. Australia: Australian Government. Available: <http://www.aihw.gov.au/deaths/> [Accessed 30 June 2015].
- BELLAMY, G. & GOTT, M. 2013. What are the priorities for developing culturally

- appropriate palliative and end-of-life care for older people? The views of healthcare staff working in New Zealand. *Health & Social Care in the Community*, 21, 26-34.
- BLEVINS, D. & DEASON-HOWELL, L. M. 2002. End-of-life care in nursing homes: the interface of policy, research, and practice. *Behavioral sciences & the law*, 20, 271-286.
- BROWN, L. & WALTER, T. 2013. Towards a social model of end-of-life care. *British Journal of Social Work*, bct087.
- CASTLE, N. G. & ENGBERG, J. 2006. Organizational characteristics associated with staff turnover in nursing homes. *The Gerontologist*, 46, 62-73.
- CENTRE FOR DISEASE CONTROL AND PREVENTION 2007. Worktable 23R. Death rates by 10-year age groups: United States and each state, 2007. In: GMWK23R_2007 (ed.). USA: Centre for Disease Control and Prevention.
- CHUNG, R. 2016. Knowledge, Attitude and Preferences of End-of-Life Care and Advance Directive in Hong Kong. A Population-based Telephone Survey. *15th Anniversary of JC School of Public Health and Primary Care*. Hong Kong: The Chinese University of Hong Kong.
- COHEN, J., PIVODIC, L., MICCINESI, G., ONWUTEAKA-PHILIPSEN, B., NAYLOR, W., WILSON, D., LOUCKA, M., CSIKOS, A., PARDON, K. & VAN DEN BLOCK, L. 2015. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. *British journal of cancer*.
- DIESMART. 2007-2016. *DieSmart* [Online]. U.S.: DieSmart. Available: <http://diesmart.com/sayinggoodbye/immediately-after-death/> [Accessed 22 February 2016].
- FANG, M. S., LOU, W. V., & KONG, S. T. (2016). Empowering Residential Homes for the Elderly (RCHes) as a Key Strategy for Delivering Quality End-of-Life Care in Hong Kong (Policy No. 2). Hong Kong: Faculty of Social Sciences & Sau Po Centre on Ageing, University of Hong Kong. Retrieved from www.spcsc.hku.hk/pp/end-of-life-care-3/.
- FANG, M. S., LOU, V. W. Q., & KONG, S. T. (2015). Four Medical-Social Shared Care Models Providing End-of-Life Care in Residential Care Homes. Hong Kong: Salvation Army.
- FREY, R., BOYD, M., FOSTER, S., ROBINSON, J. & GOTT, M. 2015. What's the diagnosis? Organisational culture and palliative care delivery in residential aged care in New Zealand. *Health & social care in the community*.
- FREY, R., RAPHAEL, D., BELLAMY, G. & GOTT, M. 2014. Advance care planning for Māori, Pacific and Asian people: the views of New Zealand healthcare professionals.

- Health & social care in the community*, 22, 290-299.
- GOMES, B. & HIGGINSON, I. J. 2008. Where people die (1974—2030): past trends, future projections and implications for care. *Palliative Medicine*, 22, 33-41.
- HO, A. H. Y., CHAN, C. L. W., LEUNG, P. P. Y., CHOCHINOV, H. M., NEIMEYER, R. A., PANG, S. M. C. & TSE, D. M. W. 2013. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and ageing*, 42, 455-461.
- HOLROYD, E. 2003. Hong Kong Chinese family caregiving: Cultural categories of bodily order and the location of self. *Qualitative Health Research*, 13, 158-170.
- HOSPITAL AUTHORITY 2015 Hospital Authority Statistical Report 2012-13 Hong Kong: Hospital Authority.
- JAYANTHA, W. M. & HUI, E. C. 2013. Determinants of Housing Consumption and residential Crowding in Hong Kong. *Central Europe towards Sustainable Building 2010*. Prague: CESB10.
- KAYSER-JONES, J., SCHELL, E., LYONS, W., KRIS, A. E., CHAN, J. & BEARD, R. L. 2003. Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision. *The Gerontologist*, 43, 76-84.
- KWAN, J. S. K., LAU, B. H. P. & CHEUNG, K. S. L. 2015. Toward a comprehensive model of frailty: An emerging concept from the Hong Kong Centenarian Study. *Journal of the American Medical Directors Association*, 16, 536. e1-536. e7.
- LAM, P. T. 2013. Practical challenges in ambulatory palliative care service in a regional hospital in Hong Kong. *The Journal of Hong Kong College of Family Physician* [Online], 35. Available: http://www.hkcfp.org.hk/Upload/HK_Practitioner/2013/hkp2013vol35jun/update_article_1.html.
- LEE, J., CHENG, J., AU, K.-M., YEUNG, F., LEUNG, M.-T., NG, J., HUI, E., LO, R. & WOO, J. 2013. Improving the Quality of End-of-Life Care in Long-Term Care Institutions. *Journal of palliative medicine*, 16, 1268-1274.
- LEUNG, P. P. & CHAN, C. L. 2011. Palliative care in the Chinese context: An integrated framework for culturally respectful practice. In: ALTILIO, T. & OTIS-GREEN, S. (eds.) *Oxford Textbook of Palliative Social Work*. U.S.A.: Oxford University Press.
- LOU, V. W. 2015. *Spiritual Well-Being of Chinese Older Adults: Conceptualization, Measurement and Intervention*. Springer.
- LOU, V. W., & NG, J. W. (2012). Chinese older adults' resilience to the loneliness of living alone: A qualitative study. *Aging & Mental Health*, 16, 1039–1046.
- LUCAS, J. A., AVI-ITZHAK, T., ROBINSON, J. P., MORRIS, C. G., KOREN, M. J. & REINHARD, S. C. 2005. Continuous quality improvement as an innovation: Which nursing

- facilities adopt it? *The Gerontologist*, 45, 68-77.
- LUK, J., LIU, A., NG, W., BEH, P. & CHAN, F. 2011. End-of-life care in Hong Kong. *Asian J Gerontol Geriatr*, 6, 103-106.
- MCGREGOR, M. J., BAUMBUSCH, J., ABU-LABAN, R. B., MCGRAIL, K. M., ANDRUSIEK, D., GLOBERMAN, J., BERG, S., COX, M. B., SALOMONS, K. & VOLKER, J. 2011. A survey of nursing home organizational characteristics associated with potentially avoidable hospital transfers and care quality in one large British Columbia health region. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 30, 551-561.
- MORGAN, M. and CRUICKSHANK, H., 2014. Quantifying the extent of space shortages: English dwellings. *Building Research & Information*, 42(6), pp.710-724. OFFICE FOR NATIONAL STATISTICS. 2014. Mortality in the United Kingdom, 1983-2013 [Online]. UK: Office for National Statistics. Available: <http://www.ons.gov.uk/ons/rel/mortality-ageing/mortality-in-the-united-kingdom/1983-2013/mortality-in-the-united-kingdom--1983-2013.html#tab-Deaths-by-age-group> [Accessed 30 June 2015].
- OLIVIERE, D. & MONROE, B. 2004. Introduction: Working with death, dying , and difference. In: OLIVIERE, D. & MONROE, B. (eds.) *Death, Dying, and Social Differences*. United States: Oxford University Press.
- PEREIRA, M. S., COHEN, J., VAN DEN, B. L., DIRK, H. & DELIENS, L. 2015. Strong country-variation in nursing home as a place of death for older people. A study in thirteen countries across four continents using Death Certificate Data. *14th World Congress of the European Association for Palliative Care*. Copenhagen, Denmark.
- PETRISEK, A. C. & MOR, V. 1999. Hospice in nursing homes: a facility-level analysis of the distribution of hospice beneficiaries. *The Gerontologist*, 39, 279-290.
- SEYMOUR, J., PAYNE, S., CHAPMAN, A. & HOLLOWAY, M. 2007. Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK. *Sociology of health & illness*, 29, 872-890.
- SHAH, S. M., CAREY, I. M., HARRIS, T., DEWILDE, S. & COOK, D. G. 2013. Mortality in older care home residents in England and Wales. *Age and ageing*, 42, 209-215.
- TEMKIN-GREENER, H., ZHENG, N. T., XING, J. & MUKAMEL, D. B. 2013. Site of death among nursing home residents in the United States: changing patterns, 2003–2007. *Journal of the American Medical Directors Association*, 14, 741-748.
- TEMKIN-GREENER, H., ZHENG, N. T. & MUKAMEL, D. B. 2012. Rural–urban differences in end-of-life nursing home care: Facility and environmental factors. *The Gerontologist*, 52, 335-344.
- TIMMERMANS, S. 2005. Death brokering: constructing culturally appropriate deaths.

- Sociology of health & illness*, 27, 993-1013.
- UK GOVERNMENT. 2015. *What to Do After Someone Dies* [Online]. U.K.: GOV.UK. Available: <https://www.gov.uk/after-a-death/death-abroad> [Accessed 22 February 2016].
- UNITED NATIONS. 2014. *World Urban Prospects 2014 Revision*. New York: United Nations. Available: <https://esa.un.org/unpd/wup/Publications/Files/WUP2014-Highlights.pdf> [Accessed 27 September 2016].
- WOO, K. W., A.O.L., K., NG, D. K. H., KHEMLANI, M. H., YAU, C. W. S., C.Y., P. & D.M.W, T. 2013. The preferred place of care and death in advanced cancer patients under palliative care services. *10th Hong Kong Palliative Care Symposium*. Hong Kong: Hong Kong Society of Palliative Medicine.
- 何孝恩. 2014. 立法會福利事務委員會及衛生事務委員會：長期護理政策聯合小組委員會 – 善終服務公聽會議。立法會 [Online]. Available: <http://www.legco.gov.hk/yr13-14/english/panels/ltcp/papers/ltcp0624cb2-1888-4-e.pdf> [Accessed June].