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| Title | Development and Pilot Evaluation of a Novel Dignity-Conserving End-of-Life (EoL) Care Model for Nursing Homes in Chinese Societies |
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| Citation | Ho, A. H. Y., Dai, A. A. N., Lam, S.-h., Wong, S. W. P., Tsui, A. L. M., Tang, J. C. S., et al. (2016). Development and Pilot Evaluation of a Novel Dignity-Conserving End-of-Life (EoL) Care Model for Nursing Homes in Chinese Societies. The Gerontologist, 56(3), 578-589. |
| Date | 2016 |
| URL | http://hdl.handle.net/10220/42217 |
| Rights |  |

[RUNNING HEAD: Dignity-Conserving EoL Care Model for Nursing Homes]

# Development and Pilot Evaluation of a Novel Dignity-Conserving End-of-Life (EoL) Care Model for Nursing Homes in Chinese Societies


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## Abstract

**Purpose of Study:** The provision of end-of-life (EoL) care in long-term-care settings remains largely underdeveloped in most Chinese societies, and nursing home residents often fail to obtain good care as they approach death. This paper systematically describes the development and implementation mechanisms of a novel Dignity-Conserving EoL Care model that has been successfully adopted by three nursing homes in Hong Kong, and presents preliminary evidence of its effectiveness on enhancing dignity and quality of life (QoL) of terminally-ill residents.

**Design and Methods:** Nine terminally-ill nursing home residents completed the McGill Quality of Life Questionnaire and the Nursing Facilities Quality of Life Questionnaire at baseline and 6-months post EoL program enrollment. Wilcoxon signed rank test was used to detect significance changes in each QoL domains across time.

**Results:** Although significant deterioration was recorded for Physical QOL, significant improvement was observed for Social QoL. Moreover, a clear trend towards significant improvements was identified for the QoL domains of Individuality and Relationships.

**Implications:** A holistic and compassionate caring environment, together with the core principles of family-centered care, inter-agency and interdisciplinary teamwork, as well as cultural-specific psycho-socio-spiritual support, are all essential elements for optimizing quality of life and promoting death with dignity for nursing home residents facing morality. This study provides a useful framework to facilitate the future development of EoL care in long-term-care settings in the Chinese context.



**Keywords:** end-of-life care, long-term care, clinical practice, care coordination, home and community based care and services, Asian culture

## Introduction

By year 2050, 22% of the world's population will be aged 60 and over (World Health Organization, 2014). Such dramatic rise in the number of older people will inevitably translate into much greater demands for long-term care services, as their ability to live independently will gradually diminish with increasing health deteriorations and disabilities. Although the ideals of ‘aging in place’ facilitated through enhanced community and home care services are widely promoted and advocated through elderly policies around the globe, nursing homes still play a vital role in meeting the supportive care needs of older adults, especially those who are weak and terminally-ill. The vast significance of nursing homes in caring for the frail and dying is reflected by the relatively high institutionalized rate worldwide, with Hong Kong ranked at the top with over 6.8% of its elderly population dependent on residential care, as compared to the other developed countries such as the United Kingdom at 4.2%, Australia at 4.4%, and the United States at 3.9% (Chui, Chong, Ko, et al., 2009). Hong Kong is also facing the unprecedented challenge of rapid population aging whereby the number of persons aged 65 and above has surged nearly 50% in the past two decades, and is expected to reach 2.58 million within the next thirty years to account for 30% of its total population (Census and Statistics Department, 2014). These drastic demographic changes reflect an imminent and continuous proliferation of supportive and palliative care needs among the aged. Not surprisingly, increasing attention has been directed towards developing and enhancing end-of-life (EoL) care provisions in nursing homes for promoting dignity and quality of life among terminally-ill older adults (Ho, Chan, Leung, et al., 2013; Tse, 2013).

While palliative care is traditionally rendered through hospitals and stand-alone hospices, a major shift has been observed in recent years where it is now increasingly common for elders to receive EoL care in long-term-care settings (Ersek & Wilson, 2003). In fact, the

provision of EoL care in nursing homes is gradually becoming standard practice in many Western countries, and evidence has supported its effectiveness in enhancing terminally-ill residents' quality of life though the introduction of advance care planning, pain and symptoms control, psycho-socio-spiritual support, as well as inter-agency care coordination (Murray, Fiset, Young, et al., 2009; Nochomovitz, Prince-Paul, Dolansky, et al., 2010). This comes as no surprise given the growing number of institutionalized elders around the globe, but what is disconcerting is that Hong Kong, with one of the highest institutionalization rates in the world, has done little to remedy the situation.

## Residential Care and EoL care in Hong Kong

There are two major types of Residential Care Homes for the Elderly (RCHEs) in Hong Kong. Care and Attention (C&A) Homes are designed for elders with poor health but require minimal assistance with Activities of Daily Living (ADLs); while Nursing Homes are designed for frail and disabled elders with limited mobility who require high degree of assistance with ADLs. In terms of financing, all Hong Kong permanent residents aged 65 or above and regardless of financial status are eligible to apply for residential care if they pass the Government's Standardized Care Need Assessment Mechanism for Elderly Services (SCNAMES). In other words, residential care services in Hong Kong are non-means tested and heavily subsidized. However, only 35% of the available 75,000 residential care places are actually funded through Government subvention and run by Non-Government Organizations with rich experience in elderly services, while the remaining 65% are self-financing and ran by for-profit private operators that are audited by the Government (Audit Commission, 2014). As a result, the waiting time for subsidized residential care services is long and averages between 22 to 40 months, and those who cannot wait and require immediate residential care would need to purchase services from the private sector through out-of-pocket payments combined with indirect Government subsidies (Chui, et al., 2009).

While subvented and private RCHEs vary in sizes and capacity, ranging from 50 to 250 residential care beds, they both provide meals, personal care and social support to their residents. With recent Government policies that emphasized the provision of a continuum of care among all RCHEs so as to promote aging in place (Legislative Council, 2013), most C&A homes have now been converted into nursing homes to provide regular medical and nursing support as well as enhanced personal care services to elders with varying degrees of frailty as well as physical and mental disabilities. Notwithstanding such advancements, the provision of EoL care has yet to become a mandatory requirement among RCHEs (Legislative Council, 2014). Numerous studies have reported that nursing home residents and their family caregivers in Hong Kong have become much more aware and knowledgeable of their needs and concerns at the end-of-life; as they are playing a progressively active role in the governance of mortality through the demand of informed care decision making and advance care planning, and calling for high quality care that enhance their quality of life and sense of dignity in the face of death, dying and bereavement (Ho & Chan, 2011; Ho, Chan & Leung, 2014).

According to a recent large-scale study with 1,600 elderly residents from 140 nursing homes across Hong Kong, 94% of respondents preferred to be informed of the diagnosis if they had terminal illness, 88% were in favor of having an advance directive; 59% wished to receive palliative EoL care in nursing home settings, and 35% desired to die in their present nursing home (Chu, Luk, Hui, et al., 2011; Chu, McGhee, Luk, et al., 2011). However, it was found less than 1% of older terminally-ill patients actually die at a place of their choosing as the majority of deaths occur in hospitals (Tse, Chan, Lam, et al., 2007). Evidently, dying in nursing home is not commonly expected because EoL care is not a required or a standardized provision of residential care services (Luk, Lui, Ng, et al., 2011). As a matter of fact, most nursing homes lack the expertise and personnel to render adequate palliation and

psycho-socio-spiritual support to those nearing the EoL (Chan, Ho, Leung, et al., 2012). As a result, nursing home residents with terminal illnesses often fail to participate in advance care planning or make informed decisions that best reflect their needs and wishes at the end-of-life. Instead, they are traumatized through the 'Revolving Door Syndrome' characterized by repeated hospitalizations when their conditions deteriorate (Gordon, 1995), and disempowered to maintain autonomy and achieve dignity at life's final margin (Ho, Leung, Tse, et al., 2013).

Conceivably, the call for establishing EoL care provisions in nursing home and long-term-care settings has been echoed widely among researchers and clinicians (Hong Kong College of Physicians, 2008). And although not without worries and apprehensions, research has encouragingly shown that nursing home staff seem to welcome and are ready to adopt a palliative care approach in caring for their older terminally-ill residents with collaboration from hospital medical practitioners (Lo, Kwan, Lau, et al., 2012). Ho, Luk, Chan et al. (2015) further reported that long-term-care operators are increasingly acknowledging the provisional imperative of dignified care, and numerous RCHEs have begun to launch pilot EoL care programs to better serve their residents with chronic life-limiting illnesses. This paper describes the development and implementation mechanisms of a novel "Dignity-Conserving EoL Care Model" that has been adopted by three nursing homes in Hong Kong. Preliminary evidence on the effectiveness of this model for improving the quality of life of nine terminally-ill residents are also presented to inform future developments of nursing home-based EoL care in the Chinese context. It is important to note that no C&A Homes were included in this study.

## Development of the Dignity-Conserving EoL Care Model

The Tung Wah Group of Hospitals (TWGHs) is one of the largest elderly service providers that operates 25 nursing homes across all 18 districts in Hong Kong. In 2011, and

in collaboration the University of Hong Kong, the group has developed and implemented a novel Dignity-Conserving EoL Care Model in three of their nursing homes located in the district of Tai Po as a response to the urgent need for establishing EoL care provision in long-term-care services. The theoretical underpinnings of this model are founded upon the basic tenets of dignity-conserving care (Chochinov, Hack, McClement, et al., 2002; Chochinov, 2007) and the framework of dignified palliative long-term-care (Ho et al., 2015), which together emphasize a holistic, interdisciplinary and family-oriented approach for addressing the broad spectrum of physical, psychological, social, and spiritual concerns faced by patients nearing death. The four driving principles of this novel model include: 1) respect older terminally-ill residents' needs for EoL care as well as their wishes on preferred place of death; 2) respect family members' needs to participate in EoL care decision making as well as their needs for grief and bereavement support; 3) incorporate principles and practices of holistic EoL care into all nursing home operations; and 4) facilitate all stakeholders to share their EoL care experiences for informing program development. The ultimately goal is to enhance terminally-ill residents' overall quality of life and promote death with dignity.

Structural Implementation

In the initial phase of model development, a series of critical steps were taken to ensure that all three nursing homes shared the same philosophy and had adequate manpower, service capacity and infrastructure support to provide palliative EoL care. First, the elderly service division of TWGHs called a series of meetings to facilitate open dialogue and knowledge exchange on the imperative of EoL care provision between participating nursing home directors and potential community partners such as head of hospitals, policy makers, clinical researchers and academicians. Based on these discussions, an initial implementation plan was drafted jointly by all involved stakeholders, detailing the rationale for EoL care in long-term-care settings, the renewed visions and mission statements for holistic

psycho-socio-spiritual care, the additional requirement for EoL care staff and infrastructures, as well as an estimated budget of program operation. This plan was then presented to the Board of Directors of TWGHs for review and deliberation. Further meetings were held to secure pledges of support from all community partners so as to ensure that all three nursing homes would be provided with palliative and medical care assistance as well as clinical research support. Once an agreement was reached between all stakeholders, a finalized implementation plan was approved for dissemination. Internal meetings and sharing sessions were then held between nursing home directors and their staff, whereby the renewed organizational visions and mission were communicated and discussed to accentuate the imperative of holistic physical-psycho-socio-spiritual care for residents facing the end-of-life. To strengthen this philosophy, an annual fieldwork attachment program with prominent overseas palliative care training institutes was developed and provided to managerial staff and senior care professionals of each nursing home. The rationale for this undertaking is that the skills and knowledge obtained by management could be transferred to all formal care workers through a train-the-trainer paradigm. This top-down approach to palliative care training serves to ensure sustainable program development.

Second, a readiness assessment with staff of all nursing homes were conducted to identify their knowledge, competence and supportive needs in delivering EoL care (Lou, Tsui, Lam, et al., 2012). Based on this assessment as well as further consultations to identify the specific EoL educative needs among frontline care staff, a tailored in-house training program was developed and launched through a bottom-up approach to equip all care and auxiliary workers with the awareness, skills and confidences required to render EoL services (For more information on the training program and the train-the-trainer tools, please visit: http://www.tungwahcsd.org/special/endlesscare/content_services_d.php). In more detail, the in-house training program consisted of two modules. First, a basic module including general

life and death education, communication skills training, and essential knowledge on the dying process and symptom management were provided to all nursing home employees including auxiliary workers such as chefs, drivers, cleaners and gardeners so as to heighten their awareness and understanding on the unique needs of dying residents and their families. Secondly, a comprehensive module included continuous education and supervision on pain and symptoms management, psycho-spiritual intervention such as life review, interpersonal and counseling skills, self-care strategies as well as opportunities for reflection and expression on one's own experiences of loss and mortality, were provided to frontline care staff including nurses, social workers and personal care workers so as to enhance their clinical skills, emotional competence and compassionate empathy for working with residents and families facing terminal illness. These two modules are combined to impart an overarching philosophy of holistic care in the daily operations of all three nursing homes.

Third, needs assessments with nursing home residents were carried out to explore their understanding, knowledge and levels of readiness for and acceptance of receiving EoL care (Lou, Tsui, Lam, 2013). Based on this assessment, tailored life and death education talks and seminars where offered to interested residents and their families, of which included topics on the fundamentals of palliation, advance care planning, holistic self-care, death preparation and funeral arrangements. The aims of these educative programming were to foster greater awareness, engagement and participation in the governance of death, dying and bereavement among all service recipients and within the entire nursing home environment.

Finally, on top of training and education, an inter-agency care coordination protocol was established with two partnering hospitals located within the same geographic district. They provided acute and convalescent care as well as medical advice and support for terminally-ill residents who registered for the EoL care program. Specifically, expedited clinical admissions, discharge care planning, outreach homecare services, together with EoL admission where

residents are offered a peaceful care environment that respects their advance care decisions for facilitating a dignified death, formed the community EoL care pathway between the nursing homes and the partnering hospitals. In essence, a culture shift was created among all involved organizations through a public health strategy of palliative care (Kellehear, 2005; Higginson & Koffman, 2005), one that cultivated a sense of ownership from every stakeholders to create a supportive and empowering community to implement EoL care in long-term-care settings.

Program Implementation

A designated interdisciplinary EoL Care Team consisting of three core members with expertise in social work, nursing and medicine was formed to facilitate program implementation across all three nursing homes. First, a Project Manager (PM) who was also a registered social worker was responsible for recruiting potential terminally-ill residents and their families into the EoL care program; the PM also provided direct psycho-social care and counseling services to program participants, as well as engaged in networking duties between all stakeholders. Second, a Project Officer (PO) with background in palliative nursing was responsible for providing nursing care to all program participants and delivering training to other nursing staff on clinical EoL care. Third, a Medical Practitioner (MP) experienced in palliative medicine was responsible for screening and providing regular medical check-ups for program participants, chairing meetings with all relevant staff involved in EoL care program, and liaising with the two partnering hospitals on all aspects of care coordination. The EoL Care Team was responsible for and shared between all three nursing homes.

Apart from establishing an interdisciplinary team, a standardized EoL care protocol was also developed for the three nursing homes. Figure 1 provides an illustration of the novel Dignity-Enhancing EoL Care Model with its structural foundation and its clinical procedures. The specific inclusion criteria for program enrollment included elderly residents who suffered

from at least one life-limiting conditions inclusive of cancer, chronic obstructive pulmonary disease, chronic heart failure, chronic renal failure, liver disease, stroke, neurological conditions, and chronic frailty; had a life expectancy of six months or less; were aware of their illnesses; were cognitively intact; were prepared to engage in advance care planning; and had a designated family caregiver as their health proxy. It is important to note that health proxy is not a pre-requisite for advance care planning in Hong Kong but is considered part of the advance care planning process. However, given the fact that major health decisions are often made collectively rather than individually in Asian cultures (Lai, 2010), and that Chinese elders are strongly dependent on their families in EoL care decision making (Bowman & Singer, 2001), the design of the Dignity-Conserving EoL care program aims to facilitate this important family process so as to encourage participation, garner care consensus and reduce confusions in the future execution of advance care plans.

Residents who fit the inclusion criteria were approached by the EoL care team and invited to participant; residents who are interested in the program could also approach any nursing staff and ask to be enrolled. Upon informed consent, a preliminary screening was carried out by the PM to assess residents' functional capacities was conducted to ensure program fit. Thereafter, an initial family meeting was arranged with individual resident and his or her primary family carers to explain the details of EoL care services, to garner a familial consensus on program participation, to elicit their needs and wishes with regards to care at the end-of-life, and to establish a preliminary individualized care plan. Once consensus was reached, the resident and his or her family would be formally registered in the EoL care program.

[Insert Figure 1]

The EoL care program within the nursing home involves ten core service elements. First, a series of life and death education workshops was provided to all EoL residents and their

families, which ultimately serves to facilitate advance care planning through joint and informed decision-making on preferences for life-sustaining treatments and preferred place of death. Second, tailor-made life review intervention was provided to individual EoL resident as the first step toward psycho-socio-spiritual support, initiating the critical processes of meaning-reconstruction and relational reconciliation that are imperative in promoting one's sense of dignity in the face of morality. Third, EoL residents were asked of any last wishes that they want to achieve, and a plan was put in place to fulfill these wishes so as to help foster ego-integrity and the sense of life completion. Fourth, funeral, memorial and burial arrangements were discussed and made with the aim to promote autonomy and minimize the sense of burden to others. Fifth, constant psychosocial support was provided by the PM for upholding residents' mental well-being. Sixth, continuous pain and symptoms management was provided by the PO for maintaining residents' physical well-being. Seventh, routine medical check-ups and physical assessments were provided by the MP to track residents' disease progressions and to adjust physical care regime as deemed appropriate. Eighth, regular family meetings with the EoL Care Team were held to update clinical progress, to revisit and reaffirm familial consensus on care preferences, to provide support, and to promote participation and partnership in care. Ninth, once an EoL resident entered the dying phase, the designated care team together with other nursing staff would follow the prescribed advance care plan, transport the resident to his or her preferred place of death, and provide close monitoring and continuous care until his or her passing. Finally, grief and bereavement support was provided to families upon residents' death. Table 1 provides a summary of the major clinical components of the dignity-conserving EoL care program, and compares its differences with conventional nursing home care.

[Insert Table 1]

## Methods

Since its establishment in 2011, 17 terminally-ill residents from three nursing homes have been enrolled into the EoL care program, and 9 residents have since passed away peacefully and with dignity under the new regime of care. To evaluate the effectiveness of this novel model for improving residents' well-being and quality of life at the end-of-life, a pre- and post-intervention study design was adopted. Ethical approval for this study was obtained through the Institutional Review Board of the University of Hong Kong. The following describes the research procedures and presents the results of this preliminary evaluation.

### Measures and Procedures

All 17 residents who were enrolled in the novel EoL programme participated in the evaluation study. Quantitative data regarding their well-being and quality of life were collected during screening and before program enrollment (baseline), as well as 6-month after program enrollment (post-test). However, only 9 residents had successfully completed the evaluation at both time points, as the remaining 8 residents had passed away before post-test or were admitted to the hospital due to the need for critical and intensive care. This yielded a completion rate of 52.9%. The Mann-Whitney U Test was used to detect any significant difference between the two groups on their socio-demographic and health-related variables including age, gender, education level, marital status, number of children, religion, type of life-limiting conditions and ADL scores; results show only a marginally significant difference on age ($z=1.93$, $p=0.054$), where the mean age of the 9 residents who had completed both assessments were greater than for those who only completed baseline.

Data collection was carried out using a standardized assessment package and through face-to-face interviews conducted by a trained research nurse and a trained research assistant,

and each interview took between 30 to 45 minutes to complete. For residents who could not fully engage in the interview due to illness (i.e. Dementia), their primary family caregivers served as their health proxy in completing the evaluation. The standardized assessment package included basic demographic and medical characteristics, as well as two comprehensive measures that examine residents' physical-psycho-socio-spiritual well-being as well as their overall quality of life. First, the McGill Quality of Life questionnaire (MQoL), which was developed and validated with strong internal consistency and reliability among palliative care patients in both Western (Cohen, Mount, Bruera, et al., 1995) and Chinese societies (Lo, Woo, Zhoc, et al., 2001; Hu, Dai, Berry, et al., 2003), was adopted to assess four QoL domains including physical, psychological, existential and support. It consists of 15 items and also a single item for rating overall QoL. The original items were rated on a 10-point visual analogue scale; however, residents in our study had great difficulty in understanding this format during pilot testing, an experience shared by others (Tierney, Horton, Hannan, et al., 1998). As such, responses were converted to a 4-point Likert scale with higher scores indicating greater QoL.

Second, the Nursing Facilities Quality of Life scale (NF-QoL), which was developed and validated with good internal consistency and reliability among long-term residents (Kane, 2003; Kane, Kling, Bershadsky, et al., 2003), was adopted to assess a wide spectrum of QoL domains that focus specifically on the outcome of nursing home care. Although the NF-QoL has not been validated in Chinese, its clinical importance and potential adaptability in Chinese contexts has been documented (Wen, Yu, & Kolanowski, 2008). As there is no other scale that specifically assesses nursing home quality of life, the research team translated the NF-QoL for used in the current study. The scale was first translated into Chinese by the second author who is fluently bilingual in Chinese and English. The translated version was then back-translated independently to English by the last author. Discrepancies in sematic

meaning between the original English version and the back-translated Chinese version were identified by two postgraduate students with expertise in mental health research, and minor amendments were made for correcting mistranslated words and improving item presentation. This version was then examined by the second and last author again for linguistic accuracy before confirmation of the final text. The NF-QoL consists of 54 items that cover 11 dimensions of nursing home life, including: comfort, functional competence, privacy, autonomy, dignity, security, individuality (individual preferences are respected), relationships (with nursing home staff and fellow residents), use of time, enjoyment of food, and spiritual well-being. An overall quality of life score was computed based a summary set of 12 questions that reflect all 11 dimensions. Items were rated on a 4-point Likert scale with higher scores indicating higher QoL.

## Results

Data were encoded and analyzed using the SPSS 15.0 computer. Descriptive statistics were used to summarize residents' demographic and medical characteristics. The Wilcoxon signed rank test was used to detect significant changes in each QoL domain across time.

As shown in Table 1, the mean age of the 9 EoL residents who completed both pre-and-post assessments were 92 years (SD=7.54) with a range from 82 to 102. The majority were female (78%), widowed (67%), and received no formal education (67%). Two-thirds had as least one child (66%), and over half had no religious belief (56%). Four residents suffered from chronic frailty, one suffered from a comorbidity of cancer, two were living with dementia, one with chronic obstructive pulmonary disease and one with renal failure. Moreover, 8 out of 9 residents were severely or totally dependent as their ability to perform activity of daily living were greatly undermined by illness and advanced age.

[Insert Table 2]

Table 2 provides a summary of the results from Wilcoxon sign test. Specifically for the

McGill QoL domains, EoL residents displayed a significant deterioration in physical quality of life with a mean score of 1.83 at baseline and 1.31 at 6-month post-test ($z = 2.19$; $p < 0.05$). However, significant improvement was detected in the support quality of life domain from 2.16 at baseline to 2.60 at 6-month post-test ($Z = 2.26$; $p < 0.05$). In terms of the NF-QoL domains, although no significant differences were found, a clear trend towards improvement was observed for the domains of relationships (pre-test, 2.11; post-test, 2.40; $Z = 1.88$; $p = 0.061$) and individuality (pre-test, 2.33; post-test, 2.63; $Z = 1.78$; $p = 0.075$).

[Insert Table 3]

## Discussion & Implications

This article has provided a detailed account of the developmental processes as well as the implementation mechanisms of a novel Dignity-Conserving EoL Care Model that has been feasibly adopted by three nursing homes in Hong Kong, filling an important knowledge gap on the significant integration between EoL care and long-term-care in the Asian Chinese context. Findings from the primary evaluation further offer initial evidence of this model's effectiveness in enhancing terminal-ill nursing home residents' quality of life at the end-of-life.

### The Importance of Care Coordination and Management

First, our findings show that the novel Dignity-Conserving EoL Care model did not effectively enhance residents' physical quality of life. While this is understandable given that physical deterioration is a nature process of dying, it may well point towards the fact that continuous trainings on practical care are needed for frontline staff so they can better detect residents' physical needs to provide adequate pain and symptoms control. Nonetheless and despite of the absence of physical improvement, the EoL care program was able to fulfill the needs and wishes of residents who desired to remain living at their current place of residence

and to receive continuous palliation as their conditions deteriorate. Such achievement can be exemplified through the experience of Mrs. Chan (pseudonym to protect identity), the only elder, among the 17 residents enrolled in the EoL care program, whose preferred place of death was her nursing home.

Mrs. Chan was a centenarian who suffered from chronic anemia but refused in-patient care as she had deep apprehension about spending time in the cold and unfamiliar environment of a public hospital. Understanding her concern and request, the EoL care team supported by constant medical assistance and advice of the partnering hospital was able to care for Mrs. Chan at her nursing home until the final month of her life, where her condition rapidly worsened and she was admitted for emergency care. Upon gaining consciousness from her medical procedures, Mrs. Chan asked to return 'home' as she wished to spend her remaining days peacefully and with dignity alongside the people whom she knew well. After several bedside meetings between Mrs. Chan, her seventy year old daughter who was also her primary family caregiver, the EoL care team of the nursing home, and the attending physician and the medical team, a consensus was reached and Mrs. Chan was discharged from the hospital, but not before she thanked all those that had cared for her during her stay. Mrs. Chan passed away in the solace and presence of her family three days after her discharge.

Mrs. Chan's narrative highlights the critical importance of timely health assessment and monitoring in the EoL phase, which can only be achieved through greater interdisciplinary teamwork, appropriate care coordination between all frontline and professional staff of the nursing home and its partnership hospital, as well as enhance care management through adequate inter-agency collaborations (Morris, 2012). Our study also underscores the significance of having a designated EoL care team for ensuring care continuity of terminally-ill residents, providing evidence that a nursing-home based palliative care model is feasible in the Asian Chinese context (Carlson, Lum, & Meier, 2011). Thus, future research

can serve to develop a systematic team-based approach to EoL care, one that effectiveness aligns nursing home care with hospital and community care for achieving the best possible care outcomes for residents facing morality.

The Imperative of Family-Centered Care

Second, despite the lack of improvement in the physical domains, our findings reveal that the Dignity-Conserving EoL Care model was effective in promoting terminally-ill residents' quality of life through elevating their sense of support. Much of this success can be attributed to the holistic care philosophy instilled into every facet of service provision, as well as the fundamental emphasis of a family-centered approach in all aspect of EoL care planning and decision-making. Particularly, regular family meetings facilitated open and constructive communications between the EoL care team, the residents and their families; and such dialogue served to create a positive feedback loop that cultivates and reinforces trust, engagement and partnership in care. The importance of family-centered care for promoting dignity and integrity in the face of mortality and loss can be best illustrated through the experience of Mr. Wong (pseudonym to protect identity) and his family, who like many others desired to be cared for in the nursing homes while healthy but chose the hospital as his preferred place of death.

Mr. Wong was eighty years old and suffered from early dementia and chronic frailty. Understanding the prognosis of these degenerative conditions, his family approached nursing home staff and requested to be enrolled in the EoL care program. After an initial screening, the EoL care team provided Mr. Wong and his family with a series of life and death education workshops, through which they were able to engage in advance care planning and made informed decisions on the type of care to be received in the case of rapid health deterioration. Mr. Wong expressed his desire to receive palliative care at his nursing home for as long as possible, while his family communicated their wish for him to spend his final days in a

partnering hospital under the close supervision of experienced EoL care personnel. With the support and advice of the EoL care team, a family consensus was reached and an advance directive was put in place in which Mr. Wong agreed to be cared for at the nursing home with only minimal level of life sustaining treatments; and upon entering the dying phase, he would be transferred to a partnering hospital to received comfort care only with a Do Not Resuscitate (DNR) order. While Mr. Wong's health progressively deteriorated during the next three months, he continued to receive nursing home care and was supported through feeding tube and oxygen assisted breathing. In the middle of the following month, Mr. Wong was admitted to the hospital as his EoL care team saw he condition worsen rapidly; he passed away several days later in the comfort of a palliative care bed and the presence of his family and friends. In remembrance of Mr. Wong, a wake was organized by the nursing home that all of his family members attended; they expressed their deep appreciation and gratitude for the unweathering support that they had received from the EoL care team and every nursing home staff.

The narrative of Mr. Wong and his family is consistent with previous literature demonstrating that honest communications between patients, family carers and professional caregivers, those that encourage participation and collaboration, are indispensable in alleviating dying patients' anxiety and depression, as well as reducing unnecessary treatments and clinician-family conflicts (Wiegand, Grant, & Choen, 2013). Hence, family-centered care must become the driving force in the development of all future nursing home-based EoL care program in the Asian collective context, and future research needs to explore and establish ways for engaging disengaged family members in this important process of death preparation.

The Significance for Community Palliative Care and Bio-Psycho-Socio-Spiritual Support

Third, our findings indicate that the Dignity-Conserving EoL care model has great potential in enhancing terminal-ill residents' relationship quality of life by improving their

interactions with formal caregivers and fellow residents through a supportive environment. These encouraging findings underscore the imperative to nurture a compassionate and empowering community for EoL care in the Asian Chinese context (Ho et al., 2015); and particularly in Hong Kong where there is a lack of government initiative for promoting partnership between hospital and nursing home in the care of dying patients and bereaved families (Economist Intelligence Unit, 2010). In order to remedy such structural and provisional limitations, community-based care must become an important direction in the further development of palliative care services. Specifically, terminally-ill patients should be encouraged and provided with greater support to live actively in the community. Expanding the provisions of home care services beyond office hours, networking with non-government organizations, and training of carers in nursing homes and elderly community centres are all valuable strategies to facilitate living and dying in place (Ho, Chan, & Leung, 2014).

Finally, our findings suggest that dying nursing home residents' quality of life in the domain of individuality can be enhanced through soliciting and respecting their personal wishes and preferences of care, of which are in line with previous research that demonstrates the vital significance of psycho-socio-spiritual interventions for promoting dignity and peace among Chinese families in the midst of death and chaos. Specifically, individualized care plans that respect Chinese nursing home residents' and their families' preferences in critical care areas such as appropriate pain control, timely hospital discharge, flexibility in living arrangements, and personalized dietary choices serve to enhance their sense of autonomy and existential integrity (Ho, Chan, Leung, et al., 2013; Ho, Leung, Tse, et al., 2013). Advanced care planning and engagement in funeral preparation allow them to make informed care decisions, relieve the sense of burden to others, and create structure in their seemingly uncontrollable lives (Ho & Chan, 2011; Chan, et al., 2012). Life review intervention and last wish fulfillment can enrich family connectedness, foster reconciliation, establish continuing

bonds and generate renewed meaning for reducing anxiety, bolstering ego-integrity and promoting spiritual health at the EoL (Neimeyer, Currier, Coleman, et al., 2011; Ho, Leung, Tse, et al., 2013). As such, further investigation is needed for establishing a cultural-specific family-centered model of psycho-socio-spiritual care, one that can be standardized and made accessible in all nursing home settings. Furthermore, future research would also need to explore and develop models of intervention for promoting dignity and quality of life among single elders, those with little or no family support and contact, but are still heavily influenced by the collective ethos of the Asian culture. The expanding fields of collective spirituality, mindfulness, compassion and self-compassion may be importance starting points for such critical endeavor (Allen & Leary, 2013; Imrie & Troop, 2012; Sinclair, Raffin, Pereria, et al., 2006).

## Conclusion

The findings presented in this article are based on a small group of residents of three nursing homes and excluded those who did not have a primary family caregiver; therefore, they may not be an accurate representation of the entire long-term-care population in Hong Kong. This study is also limited by the fact that completed data sets including baseline and six-month follow-up were collected from 9 out of all 17 residents who have participated in the EoL care program; this clearly reflects the need to establish a much shorter re-assessment schedule in future similar studies so that the health fluctuations of terminally-ill patients can be better detected and attrition rates can be reduced. Notwithstanding these limitations, our findings have demonstrated the feasibility and utility of the novel Dignity-Conserving EoL Care model, while its developmental and implementation mechanisms can serve as a useful framework to facilitate the future expansion of nursing home EoL care in other Asian Chinese contexts. Furthermore, an extended research base that centers on the intersection between EoL care and long-term-care can accelerate greater progress in this important area of health

and social care policy, as the need to advance palliative care beyond hospitals and hospices into communities and neighborhoods are clear and imminently urgent under the rubric of a rapidly aging population.

## Acknowledgements

This work was supported by the Tung Wah Group of Hospitals. The authors like to thank the TWGH Elderly Services' staff, nursing home residents and their families for their invaluable support and kindest participation in this study. At the time of writing this manuscript, the fifth author AT and the sixth author JT have both ended their formal employments with TWGHs, but have continued to contribute in reviewing and revising the paper.

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Figure 1. A Novel Dignity-Conserving EoL Care Model for Nursing Homes

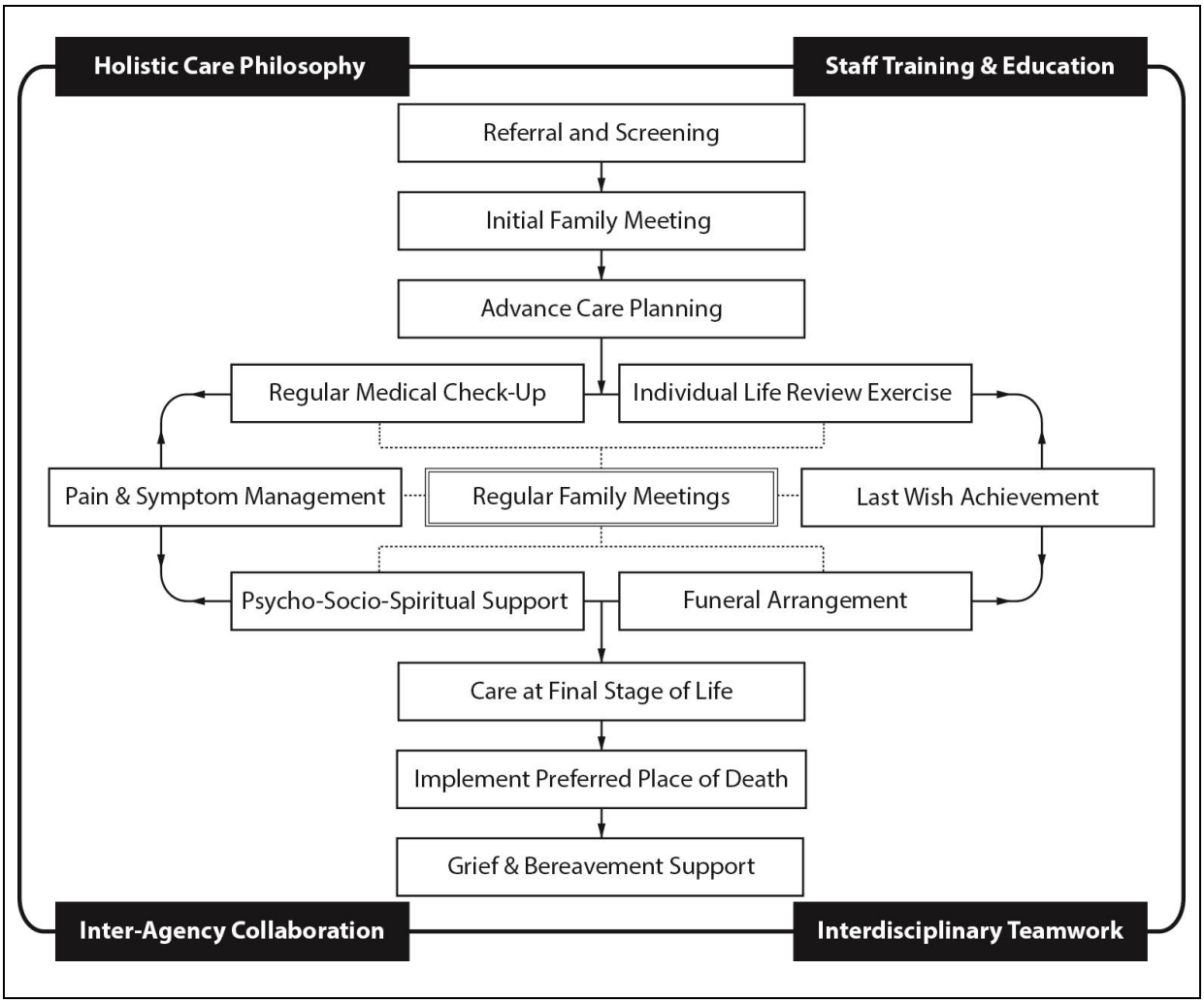

Table 1. Major Clinical Components of the Dignity-Conserving EoL Care Programme

| Clinical Components | Aims / Contrast to Conventional Nursing Home (NH) Care |
|---|---|
| 1. Life & Death Education | - To facilitate advance care planning and jointed decision making between EoL residents and their families<br>- *Not available in conventional NH care* |
| 2. Life Review Intervention | - To support meaning-reconstruction and reconciliation between EoL residents and their families<br>- *Not available in conventional NH care* |
| 3. Last Wish Achievement | - To foster ego-integrity and sense of life completion<br>- *Not available in conventional NH care* |
| 4. Funeral Arrangements | - To promote autonomy and minimize sense of burden<br>- *Not available in conventional NH care* |
| 5. Psycho-social-spiritual support | - To uphold EoL residents' mental well-being through continuous assessment and regular bedside visitations<br>- *Available in conventional NH care but limited to basic social support and family crisis counseling* |
| 6. Pain and symptom management | - To maintain EoL residents' physical well-being through continuous assessment and individualized nursing care<br>- *Available in conventional NH care but limited to basic nursing care, administration and supervision of medication* |
| 7. Regular medical check-up | - To track residents' disease progression and adequately adjust care regime, supported by 24-hour telephone consultations, emergency care, clinical admission pathway<br>- *Available in conventional NH care but through rotational doctors that are available only on fixed intermittent schedules with no other support services* |
| 8. Regular family meetings | - To provide clinical update, revisit advance care plan, reaffirm family consensus, and promote participation<br>- *Not available in conventional NH care* |
| 9. Care at final stage of life | - To execute advance care plan and implement preferred place of death<br>- *Not available in conventional NH care* |
| 10. Grief and bereavement support | - To provide continuous support to surviving families<br>- *Not available in conventional NH care* |

Table 2. Demographics and medical characteristics of EoL residents (N=17)

| | n=9 (%)<br>*Completed baseline and post-assessments.* | n=8 (%)<br>*Completed baseline assessment only.* |
|---|---|---|
| Age† (Mean±SD, range) | 92±7.52<br>(82 to 102) | 84±6.90<br>(73 to 91) |
| 70-80 | 0 | 2 (25) |
| 80-90 | 4 (44) | 4 (50) |
| 91-100 | 4 (44) | 2 (25) |
| Over 100 | 1 (11) | 0 |
| Gender | | |
| Male | 2 (18) | 3 (38) |
| Female | 7 (78) | 5 (63) |
| Education Level | | |
| No formal education | 6 (67) | 5 (63) |
| Primary School or above | 3 (33) | 3 (38) |
| Marital Status | | |
| Never married | 1 (11) | 2 (25) |
| Widowed | 6 (67) | 4 (50) |
| Married | 2 (22) | 2 (25) |
| Children | | |
| None | 3 (33) | 2 (25) |
| One | 1 (11) | 1 (13) |
| More than one | 5 (56) | 5 (63) |
| Religion | | |
| None | 5 (56) | 3 (38) |
| Christian / Catholic/ Taoism | 4 (44) | 5 (63) |
| Life-limiting condition(s) | | |
| Chronic frailty | 4 (44) | 3 (38) |
| Comorbidity of cancer and chronic frailty | 1 (11) | 1 (13) |
| Dementia | 2 (22) | 1 (13) |
| Chronic Obstructive Pulmonary Disease | 1 (11) | 2 (25) |
| Renal failure | 1 (11) | 1 (13) |
| Barthel ADL Index Score at baseline (0-100) | | |
| <20 | 3 (33) | 3 (38) |
| 20-40 | 5 (56) | 3 (38) |
| >50 | 1 (11) | 2 (25) |

Notes. †Marginal significant difference found using Mann-Whitney U Test and Chi-square Test ($p<0.1$).

Table 3. Changes in QoL of EoL resident from baseline to 6-months (n=9)

| Measures | Baseline | 6 months | Baseline | 6 months | | |
|---|---|---|---|---|---|---|
| | Mean (SD) | | Median | | Z | p-value |
| McGill QoL (1-4) | | | | | | |
| **Physical** | **1.90 (0.45)** | **1.31 (0.55)** | **1.81** | **1.32** | **2.19** | **.028*** |
| Psychological | 3.53 (0.32) | 3.73 (0.40) | 3.60 | 3.80 | 1.08 | .279 |
| Existential | 2.26 (0.75) | 2.43 (0.64) | 2.50 | 2.23 | 0.77 | .441 |
| **Support** | **2.16 (0.73)** | **2.60 (0.78)** | **2.09** | **2.18** | **2.26** | **.024*** |
| QOL in the past 2 days | 3.00 (0.71) | 3.00 (0.71) | 3.00 | 3.00 | 0.00 | 1.00 |
| Total | 2.45 (0.31) | 2.51 (0.37) | 2.46 | 2.61 | 1.01 | .314 |
| Nursing Facilities NF-QoL (1-4) | | | | | | |
| Comfort | 3.29 (0.59) | 3.18 (0.50) | 3.33 | 3.17 | 0.42 | .673 |
| Functional competence | 1.67 (1.04) | 1.46 (0.60) | 1.00 | 1.33 | 0.95 | .343 |
| Privacy | 1.81 (0.58) | 1.98 (0.93) | 1.50 | 2.00 | 0.30 | .767 |
| Autonomy | 2.67 (0.84) | 2.89 (0.40) | 2.75 | 3.00 | 1.05 | .292 |
| Dignity | 3.24 (0.49) | 3.62 (0.44) | 3.40 | 3.60 | 1.56 | .121 |
| Security | 3.49 (0.33) | 3.59 (0.28) | 3.40 | 3.60 | 0.63 | .528 |
| **Individuality** | **2.33 (0.47)** | **2.63 (0.71)** | **2.33** | **2.67** | **1.78** | **.075**$^{\dagger}$ |
| **Relationships** | **2.11 (0.36)** | **2.40 (0.60)** | **2.00** | **2.40** | **1.88** | **.061**$^{\dagger}$ |
| Use of time | 1.76 (0.52) | 1.51 (0.31) | 1.50 | 1.50 | 1.13 | .260 |
| Enjoyment of food | 2.42 (1.16) | 2.52 (0.77) | 2.33 | 3.00 | 0.11 | .916 |
| Spiritual well-being | 2.36 (0.42) | 2.29 (0.42) | 2.33 | 2.33 | 0.63 | .527 |
| Overall quality of life | 2.59 (0.88) | 2.72 (0.42) | 2.30 | 2.60 | 1.01 | .314 |

Notes. $^{**}p<0.01$; $^{*}p<0.05$; $^{\dagger}p<0.1$