

A Novel Dignity-Conserving End-of-Life Model For Nursing Homes in the Chinese Context of Hong Kong 創建本地賦尊嚴臨終照顧新模式

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Elderly Services & End-of-Life Care Policies

- One of the most confounding challenges of health care providers today is to optimize quality of life and promote death with dignity
 - ▣ Hong Kong government, and many Asian societies including Singapore, Taiwan and Mainland China, have based its elderly policy on the **Confucian value of Filial Piety**, which requires adult children to take care of their aging parents
 - ▣ **'Filial Responsibility'** and the principles of **'Aging in Place'** has become the impetus that drives the coordination of elderly services in Hong Kong, as with numerous Western countries including the U.S., U.K. and Australia
- Such policy agenda essential places family, and especially adult-children, at the forefront of caregiving for older terminal patients

Chen, H.M., & Pang, S. (2001) Long-Term Care, Dignity, Autonomy, Family Health, and Social Sustainability: The Hong Kong Experience. *Journal of Medicine and Philosophy*, 27, 401-413

Social Change and Filial Practice

- Modernization have led to the decay of filial piety
 - ▣ Filial piety do not protect against caregiver burden
 - ▣ A declining adherence to filial commitments among younger generations
 - ▣ Financial subsistence becomes a primary expression of filial obligation
- Vast dissonance between government policies that are based upon traditional values and the social realities of family practices
 - ▣ Authoritarian vs Egalitarian
 - ▣ Obedience vs Pragmatic
 - ▣ Unconditional vs Utilitarian

Chen, C.W., Liu, X.Y., Liang, T.P., et al. (2012) The Ideological Decay of Filial Piety in China of the End-of-Life. *Journal of Ethics and Cultural Diversity in Health Care*, 11, 277-286

Intersection of Nursing Home and EoL Care

- 6.8% of Hong Kong elders are living in Nursing Homes (NHs)
 - ▣ Families do not have the capacity or resources to provide ageing care
 - ▣ Much greater need for EoL Care Provision in LTC settings
- A Study with 1,600 Hong Kong NH residents showed:
 - ▣ 94% preferred to be informed of a terminal diagnosis
 - ▣ 88% in favor of having an advance directives
 - ▣ 59% wished to receive palliative care in nursing home settings
 - ▣ 35% desired to die in their present nursing home

Chen, L., W. Liu, L.K.H., Ho, C., et al. (2012) Advance Directives and End-of-Life Preferences among Chinese Nursing Home Residents Living Long. *Journal of American Medical Association*, 307, 2411-2419

A Revolving Door of Dissatisfaction

- NHs are only required to provide basic medical and nursing care
 - ▣ Most lack the expertise and personnel to render adequate palliation and psycho-socio-spiritual support to terminally-ill residents
 - ▣ Despite the Government's call to enhance service provision, the field are ultimately incapable to provide quality EoL care in LTC settings



A Revolving Door Syndrome

Griffin, A. (2005). Revolving door syndrome. *Older Care*, 7, 9-10

A New Standard of Quality Care at EoL

- Theoretical underpinnings of Dignity-Conserving Care
 - ▣ Holistic approach to address the physical, psychological, social and spiritual concerns of patients facing mortality and loss

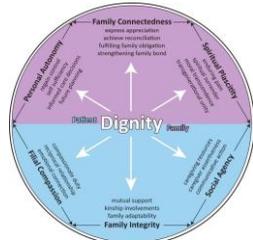
Illness Related Concerns	Dignity Conserving Repertoire	Social Dignity Inventory
Level of Independence - Cognitive Acuity - Functional Capacity Symptom Distress - Physical Distress - Psychological Distress - Medical uncertainty - Death anxiety	Dignity Conserving Perspectives - continuity of self - role preservation - generativity / legacy - maintenance of pride - hopefulness - autonomy / control - acceptance - resilience / fighting spirit Dignity Conserving Practices - Living in the moment - Maintaining normalcy - Seeking spiritual comfort	Privacy Boundaries Social Support Care Tenor Burden to Others Aftermath Concerns

Chickson, H.M. (2002). Dignity-conserving care: A new model for palliative care. *Journal of American Medical Association*, 287, 2703-2709

A New Culture of Care Orientation in EoL

□ Conceptual Foundation of Patient-Family Dignified Care

- Patient-Family-Centered approach to promote participation and partnership in end-of-life caregiving and decision making



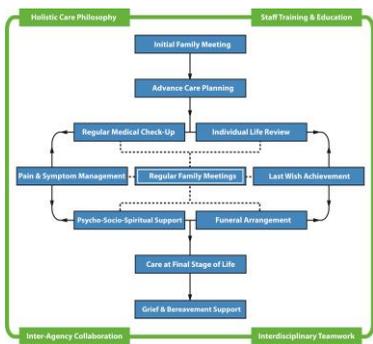
Ho, A.H.Y., Chen, C.L.W., Chan, A.Y.M. (2016). Living and Dying with Dignity: An Systems Intervention Framework. BMC Conference, Baltimore, MD, USA, 23 - 25 April, 2016

A Novel EoL care programme for Hong Kong

□ Four driving principles of EoL provision:

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 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 programme development.

Dignity-Conserving EoL Care Model for Nursing Homes



Ho, A.H.Y., Dai, A.A.N., Lam, S.H., Wong, S.W.P., Tsui, A.L.M., Tang, J.C.S., & Lou, V.W.D. (Under Review). Development and Pilot evaluation of a novel dignity-conserving care model for nursing homes in Hong Kong. The Gerontologist.

Pilot Programme Evaluation

□ A pre-and-post-intervention study design was adopted to evaluate the effectiveness of this novel EoL care model for improving residents' well-being and quality of life at the end-of-life.

- Data were collected from 9 residents who enrolled in the EoL programme from 3 TWGHs Nursing Homes in Tai Po (Response rate = 52.9%)
- 2 Male and 7 Female residents
 - Mean age was 92 years (SD=7.54; Range=82 to 102)
- Life-limiting condition(s)
 - Chronic Frailty, Cancer, Dementia, COPD, Renal Failure
 - Barthel ADL Index with 8 below a score of 40
- Assessment Measures
 - McGill Quality of Life Questionnaire & Nursing Facilities Quality of Life Questionnaire
- Data Analysis
 - Wilcoxon signed rank test to detect significant changes in QoL domains

Changes in Quality of Life across Time

Measures	Baseline		6 months		Z	P-value
	Mean (SD)	Median	Mean (SD)	Median		
McGill QoL (1-4)						
Physical	1.90 (0.45)	1.31 (0.55)	1.81	1.32	2.19	.028*
Psychological	3.53 (0.52)	3.73 (0.40)	3.60	3.80	1.08	.279
Existential	2.26 (0.75)	2.49 (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 (0.60)	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*
Relationships	2.11 (0.36)	2.40 (0.60)	2.00	2.40	1.88	.061*
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<0.05; †p<0.05; ‡p<0.1

Discussion

□ Our findings show that the novel EoL Care model did not effectively enhance residents' physical quality of life:

- This finding does point towards the imperative of timely assessment, monitoring and detection of residents' health-related need so that adequate pain and symptom control can be rendered.
- This can only be achieved through enhance interdisciplinary teamwork, care coordination, care management, and inter-agency collaborations, especially with hospitals.

Discussion

- Conversely, our findings reveal that the EoL care model was effective in promoting residents' Support Quality of Life:
 - ▣ This can be attributed to the holistic care philosophy instilled into every facet of service provision, as well as the emphasis on the family-centered approach in EoL care planning and decision-making.
- Furthermore, our findings indicate that the model has great potential in enhancing residents' individuality and personhood:
 - ▣ This was achieved through respecting their care preferences, as well as improving their relationships with family carers, professional caregivers and fellow nursing home residents via cultural-specific psycho-socio-spiritual support.

Implications

- Family-centered care practice is essential for promoting Chinese terminal patients' and their families' sense of dignity at end-of-life.
 - ▣ Recognize and respect the legitimacy of terminal patients' and family caregivers' strengths and uniqueness to form effective care partnership
 - ▣ Promote participatory care in caregiving and decision making
- Family-based Advance Care Planning (ACP) is imperative for enhancing participatory care between patients and families.
 - ▣ To make informed care decision
 - ▣ To serve as a mean for psychosocial support
 - ▣ To create structure and relieve burden
 - ▣ To live as actively as possible in the Community

Implications

- Need to strengthen multidisciplinary collaboration between and within nursing homes, hospitals and other social service agencies.
 - ▣ Enable terminally-ill NH residents and their families to access the entire spectrum of care in the community
 - ▣ Expand provisions of palliative homecare services beyond office hours
 - ▣ Develop and foster the expertise of Palliative Social Work
 - ▣ Promote a culture of compassion in caring for those facing EoL



Compassion at the Core of Dignified EoL Care in Nursing Homes

Apart from medical skills and competence, a **compassionate and empowering environment** that nurtures intrapersonal and interpersonal relationships, as well as participatory care between residents and family members is critical and essential for the successful implementation of EoL care in NHs, for Chinese and all ethnic groups around the world.

Thank You
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