

End of Life Care in Residential Care Homes in Hong Kong – Research Findings and Implications for Practice

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Outline

1. Long Term Care and End of Life Care
2. The Project 'End of Life Care in LTC Institutions'
3. The Study
4. Findings

1. Long Term Care and End of Life Care

- ❑ End of life care is crucial for the wellbeing of dying person & family members
- ❑ Rising rate of institutionalization as a result of failing family support system
- ❑ Residents of long term care homes are more likely suffering from chronic and disabling illnesses, sometime terminal conditions
- ❑ Increasingly care homes need to face the issue of death and choice of death

Health status of older people in the community and in residential homes in HK (2005)

□ Community

- 71.6% - chronic disease
- 28.3% - 1 disease
- 21.0% - 2 diseases
- 11.6% - 3 diseases
- 10.8% - 4+ diseases

□ Residential Homes

- 95.7% - chronic disease
- 16.7% - 1 disease
- 24.4% - 2 diseases
- 23.1% - 3 diseases
- 31.4% - 4+ diseases

Source: Thematic Household Survey No 21, October 2005, Census and Statistic Department, HK

Types of chronic illnesses

Disease	Community	Residential Home (LTC)
Hypertension	55.6%	51.3%
Arthritis	34.9%	23.2%
Diabetes	22.1%	21.7%
Eye Diseases	21.8%	28.7%
Heart Diseases	14.8%	24.1%
Asthma	6.0%	10.9%
Stroke	5.1%	30.7%
Dementia	1.6%	32.1%
Fracture	3.3%	10.3%

Mortality in Old Age Homes

Age	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+
Community	2224.23	2379.73	2595.73	3338.63	4705	5428.09
Old Age Home	4402.52	7894.74	5711.7	5808.58	7094.39	6703.6

End of Life Issues in Chinese Communities

- ❑ Death and Dying – a subject often avoided in many Chinese societies
- ❑ Institutionalization of death – most people will be sent to hospital when they are dying at home or in residential homes
- ❑ Admission to acute hospitals causes unnecessary interventions to terminally ill patients
- ❑ Quality of care and continuity of care would be much improved if End of Life Care could be practiced in long term care institutions

2. The Project 'Promotion and Development of End of Life Care in LTC institutions' (EoL Care Project)

- Hong Kong Association of Gerontology joined as an international partner in International Collaboration for the Care of Elderly (ICCE) and NICE Canada since 2007 on knowledge exchange in elderly care for China
- End of Life Care Project for Hong Kong and Chinese Communities funded by ICCE from 2007-2009

EoL Care Project - Objectives

- ❑ To promote the recognition of importance of end of life care for older people amongst professional carers and informal carers in China and Hong Kong
- ❑ To translate and develop instruments for educating public and professionals on end of life care issues for older people
- ❑ To promote the concept and knowledge of end of life care in conferences locally, regionally and internationally through workshop sessions
- ❑ To research, develop and implement an end of life care project in residential care institutions in Hong Kong

EoL Care Project – dissemination

- ❑ A Symposium in the 8th Asia/Oceania Regional Congress of Gerontology and Geriatrics, Beijing, October 22-25, 2007.
- ❑ Seminar on ‘End of Life Decision Making in Elderly People in Hong Kong’, Hong Kong, March 2008
- ❑ One Plenary Speech in Annual Congress of Gerontology, Hong Kong, 29 Nov 2008
- ❑ Advance Directive Workshop, Hong Kong, 22 June 2009
- ❑ A Poster Presentation in World Congress of Gerontology and Geriatrics, Paris, July 2009
- ❑ Sixth World Congress on Long Term Care in Chinese Communities, Taipei, December 03-04, 2009

EoL Care Project - Research Study 2008

- Literature review
- Focus Group and Roundtable
- Project Report and Recommendations

EoL Care Project – deliverables

- ❑ A Model of End of Life Care in Residential Care Homes will be developed after the study
- ❑ 4-6 residential care homes will be identified to participate in a pilot project on end of life care
- ❑ A package of training materials, implementation strategies will be developed and submitted to the relevant government bodies for further implementation

EoL Care Project - Research Study Working Group

- Set up since April 2008
- Membership & their major professional expertise
 - Dr. Alice Chong (Convenor), Social Work Educator
 - Dr. MF Leung, Geriatrician & President of HKAG
 - Prof. Samantha Pang, Nursing Educator
 - Dr. Y M Wu, Geriatrician
 - Dr. C B Law, Geriatrician
 - Dr. Karen Ngai, Social Work Educator
 - Dr. Fok Shiu Yeu, Social Work Educator
 - Dr. K H Ng, Geriatrician
 - Ms. Helen Chan, Nursing Educator
 - Ms. Stella Cheung, nursing, HKAG
 - Mr. Tsang Wai Ming (secretary), HKAG

3. The Study - Study Method

- Literature review
- 5 focus groups
- 2 round table forums



3.1 Focus Group Discussion

- ❑ August 2008 to September 2008
- ❑ 5 focus groups
- ❑ 30 participants from 5 institutions: including 1 superintendent, 4 supervisors/care managers, 2 medical officers, 6 registered nurses, 3 social workers, 8 care workers, 3 family members, and 3 residents.
- ❑ Nature of institutions: including 2 nursing homes, 2 C&A Cum Nursing Homes, and 1 C&A Home.

Types of Institutions

No.	Palliative Care	EoL Care	Types of institutions
1	✓	✓	1 Nursing home
3	✓	X	1 nursing home, 2 C&A Cum Nursing Homes
1	X	X	1 C&A Home
		End-of-Life Care	16

Focus Group Content

- To explore their attitudes to EOL services
- To identify the concerns, difficulties and challenges if their institution implement end of life care.
- To invite suggestions on solutions

3.2 Round Table Forum - 1

- 19 September 2008
- 12 participants:
 - members of HK Association of Senior Citizens
 - staff of 4 NGOs: supervisor, nurses, social workers.
- Discussion guideline:
 - attitude about launching end-of-life care in their institutions
 - Prerequisites & support in launching end-of-life care in RCHE

3.3 Round Table Forum - 2

- Date: November 5, 2008
- Participants: important stake-holders: high level policy makers, related professionals, NGO administrators & experts in end of life care.
- 12 representatives coming from Elderly Commission, Cemeteries and Crematoria unit of Food and Environmental Hygiene Department, Social Welfare Department (SWD), Hong Kong Council of Social Service, Hong Kong Medical Association, Forensic Pathologist, experts in end-of-life care and service, lawyer, managers of NGOs.

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- Discussion guideline:
 - To share with them NGOs' concerns and support required.
 - To suggest ways to handle issues raised in focus group discussion and Round Table 1.
 - To solicit their support for policy change & resource support.

4. Findings

- **Older people and their family** members support the idea of EoL care
- Though seldom initiate discussion, most older people are not afraid or anxious about death, it is not a taboo to them but they are more concerned about other people's feelings and reservation.
- Respondents of different levels of **care homes** (including senior management, nurses, social workers & health care workers) are very positive about EoL care in their institutions; they are, however, concerned about some logistic arrangements that require support & planning, and legal & accountability issues that require clarification.
- **Policy makers & professionals**: generally positive. Have clarified some of the uncertainties.

Main Concerns on End of Life Care Issues in RCHE

- 4.1 Care homes: Logistics & administrative arrangement
- 4.2 Legal and policy issues
- 4.3 Staff: Training and support

4.1 Care homes: Logistics & Administrative Arrangement

4.1.1 Lack of end-of-life care planning:

- decisions regarding the use of life-sustaining treatment are often postponed until health crisis arises.
- By that time, the resident is usually too ill to express his/her care preferences. Thus, the decisions are left in the hands of the family and healthcare team, which go against the notion that treatment decisions have to be reached by consensus building with the patient
- **Solution:** Advance directive/patient consent must be obtained with family, preferably on admission to care homes.

4.1.2 Insufficient space for elders & family

- Insufficient space for elders:
 - A space, such as an isolation room, is needed for the resident to rest in his/her last few days.
 - **Problem:** that room may become stigmatized
 - **Solution:** May use the isolation room in each care home.
 - **Prerequisite:** SWD's support to the change in use of the room is required.
- Insufficient space for family members (to keep dying elder company):
 - Space limitation
 - Allowing outsiders to stay overnight may violate the RCHE regulations as stipulated by the SWD.

4.1.3 Inadequate care and equipment

- Extensive care is required for the dying residents to ensure his/her comfort and dignity, but this would increase the workload of the staff and further tighten the manpower.
- The drugs provided in the RCHE are insufficient for symptom management e.g. severe pain.
- **Solution:**
 - Part-time nurse employed by resident's family
 - Support from Hospital Authority & local hospital is needed, e.g. supply of drugs & information about patient.
 - End of life care may be limited to elders whose dying process is relatively stable & free from complications.

4.1.4 Insufficient space for keeping deceased bodies

- A place, such as a mini-mortuary or a room with low-temperature is needed to keep the corpse before the deceased bodies can be sent to funeral house.
- **Solution:** Use of the isolation room, with very strong air-conditioning

4.1.5 Difficulties in transporting the deceased bodies Within RCHE

- ❑ Insufficient lifts or elevators facilities in care homes
- ❑ **Solution:** can transport the body in a sitting position
- ❑ Fellow residents may feel uneasy about the deceased bodies transportation

4.1.6 Transportation between care home and funeral home/mortuary

- ❑ Ambulance (free of charge) would not transport dead bodies.
- ❑ The transportation of deceased bodies becomes expensive.
- ❑ The neighbors of the care home may feel uneasy about the deceased bodies transportation
- ❑ The properties owners may worry about the value of their properties.
- ❑ **Solution:** community education to raise acceptance

4.1.7 Heavy follow-up works

- ❑ Rigid procedures in handling Reportable Death (RD) or 'Death Before Arrival (DBA)' if resident dies in care homes.
- ❑ Need to go through police investigations and coroner procedures.
- ❑ Complicated documentations are required by the Social Welfare Department for each RD or DBA resident.

Should understand the rationale for Reportable Death specified in CORONERS ORDINANCE - SECT 16 : main objective is to prevent against abuse, especially if the death occurs in places that should not incur death, e.g. reformatory school / mental hospital

In the past: care homes are for more healthy elders, but with continuation of care, residents are becoming increasingly frail & death become more common. There is a need to review the Coroners Ordinance to give exemption to care homes (at present only nursing homes are exempted).

4.2 Legal and policy issues

4.2.1 Certifying death

- ❑ If death occurred in hospital, the hospital authorities will issue the 'Medical Certificate of the Cause of Death' (death certificate) and the dead body stored in mortuary to await for picking up by Funeral Parlour
- ❑ If death in care homes: Not all care homes have resident doctors to issue the death certificate & body can't be moved away.
- ❑ **Solution:** Registered doctor can issue a death certificate, on condition that the physician has conducted regular consultation with the patients, and the last consultation is within **14 days** before patient's death.
- ❑ Visiting Medical Officer or resident doctor should better be connected with the local hospital, in order to obtain comprehensive support, e.g. drugs, medical records, even sending outreaching team of medical professionals.

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- The birth and death registration section of Immigration Department HKSAR closes on weekend and public holiday. The deceased bodies may have to be kept in the care homes for several days before the death registration.
 - **Solution:** Special permit could be obtained from Police Station & then can move dead body to Funeral Parlour

4.2.2 Death Body Transportation:

Assumption: Deceased bodies need to be handled by the Food & Environmental Hygiene Department (FEHD) and they have to be sent to “Public Mortuary” before funeral

- Clarified by FEHD: can arrange with funeral home to take the body immediately.
- But should enter into some collaboration with funeral homes beforehand.

4.2.3 Liability of care homes: accusation of negligence

- Reportable Death may result in complaints or negligence accusation towards the institution staff if communication with the resident's family members is ineffective or if any suspicion arises.
- **Solution:**
 - advance directive / shared consent by patient & family is required
 - End of life care may be limited to elders whose dying process is relatively stable & free from complications
 - If in doubt: send to hospital

4.3 Training and support



4.3.1 Lack of relevant training for care home staff

- ❑ Most of the care home staff are not familiar with end-of-life care. Yet, relevant training and education, including advance care planning, grief and bereavement, and nursing care for dying patients, are scarce nowadays.
- ❑ The care home staff may feel uneasy with care of dying residents. This may increase the staff turnover rate.
- ❑ Due to the difficulty in prognostication, it is also difficult for the care home staff to ascertain if the patient's deteriorating conditions is reversible or not, particularly if there is no resident doctor in the institution.

4.3.2 Low community awareness

- Death and dying have been medicalized in recent decades. The community, including the residents and their families, may not be familiar with the concept of “Dying in Place” and thus result in misunderstandings.

Thank You

The Way Forward

- We successfully obtained the financing support from La Caixa Foundation and BEA Foundation for commencing 'Palliative Care in Residential Care Homes for the Elderly in Hong Kong' from April 2010 till September 2013
- The project is to pilot palliative care in Nursing Homes in HK in 6 homes through development of care protocol, care guidelines, training and education, enhancing manpower support to nursing homes