Overview of the Legal and Administrative Barriers to Caring and Dying-in-Place in Residential Care Homes for the Elderly (RCHEs)  Fang, M.S., Lou, W.V. & Kong, S.T.

End-of-Life Care Policy Issue Brief 4

ABSTRACT

The Issue

● Currently, there is a lack of policy in place in Hong Kong to align and coordinate different care systems in the provision of End-of-life (EoL) care. Specifically, there is no mandate to support dying-in-place in RCHEs

● Improving relevant legal provisions and removing administrative barriers is a priority if we are to provide more options in the place of care and death for an ageing population

The Concerns

● Legal and administrative barriers to caring and dying-in-place in RCHEs are identified across four key phases of End-of-Life (EoL) care: (i) the preparation of death and advance care planning; (ii) the care delivery to ensure consistency and continuity in honouring the dying person’s preference of care; (iii) the dying process, including the certification of death and the cause of death; (iii) the registration of death and the handling of the body

The Solutions

● Legislate on Advance Directives (AD) and Do-Not-Apply-Cardiopulmonary-Resuscitation (DNACPR) in order to give mandate to both hospitals and non-hospital care systems to fully acknowledge and honour the medical and care preferences of the dying

● Enduring Powers of Attorney in personal care (EPA-personal care) should include the use and non-use of life sustaining treatments as well as post-mortem funeral and burial arrangements

● Amend the Coroner’s Ordinance (Cap 504) to exempt RCHEs from reportable death given that dying elders are registered in a recognized EoL program and that a medical practitioner who has attended the dying person within 14 days prior to his death can issue the medical certificate on the cause of death

● Align and share information of AD and care plans through electronic health system to ensure synchronization of dying residents’ care preferences across systems

● Enhance the physical, people and medical capacities of RCHEs to support caring and dying-in-place

## Overview of the Legal and Administrative Barriers to Caring and Dying-in-Place in RCHEs

### Legal Barriers
- **Anticipatory & Preparation of Death**
  - AD receives no legislative backing. Concerned about HA AD model forms do not cover care decisions in RCHEs
  - Increasing dementia cases cannot sign ADs before losing cognitive capacity
  - AD cannot assign proxy and the future EPA (personal care) will not include life sustaining treatment (LST), thus creating a gap in care decisions

- **Care Delivery**
  - Ambulance under FSD do not follow HA DNACPR and have no knowledge of dying patients ADs on the use of LST
  - Possibility of registration of individual RCHEs as "healthcare providers" in the future eHRSS and adding in of ACP and AD information into the shared health data

- **Death**
  - Coroner’s Ordinance (Cap504) classification of deaths in non-nursing home RCHEs as “reportable death” deters dying-in-place
  - Unclear if death resulting from age-related health deterioration be considered as “terminally ill” for Type2 exemption as “reportable death” under the Coroner’s Ordinance

- **Post Death**
  - Death in RCHEs unable to use public and hospital mortuaries for certified natural deaths, hence only those that can afford private funeral parlours can die in place
  - License requirement for body storage facilities in RCHEs

### Presenting Problems
- **Anticipatory & Preparation of Death**
  - Wishes of dying elders are not respected, lack of choice, care decisions are dominated by professionals, resulting in frustrations and complaints
  - Care systems working in silos, duplicate and disjointed efforts in soliciting care preferences and planning. Confusing and distressing to dying elders & families
  - Increasing dementia cases, too late for ACP and AD
  - HA requires too many forms (hospitalized/non-hospitalized) and guidelines (review periods, revocation) on DNACPR, AD and ACP. Confusing to patients and RCHEs

- **Care Delivery**
  - Gaps in following care preferences of dying elders in care transitions, especially during emergencies. Ambulances (FSD) cannot follow HA patient-signed DNACPR and can only deliver patients to HA AandE admission
  - RCHEs limited access and usage of eHealth system, affect delivery of timely and appropriate care
  - RCHEs wary of liabilities and lack care capacities to follow ACPs and ADs
  - Private VMOs and onsite MOs, responsible for primary care in RCHEs have difficulties aligning hospital support and access drugs for EoL cases

- **Death**
  - Cultural taboos and social considerations not conducive to dying-in-place in RCHEs
  - Avoid death in RCHEs, due to cumbersome reporting and police investigation for “reportable death”
  - Families, at a time of grief, want to avoid autopsy and investigation,
  - Difficult for RCHEs to access physician to certify death & cause of death on-site

- **Post Death**
  - Hassle to grieving families, time pressured to handle immediate death registration
  - No facilities and not used to handling dead bodies in RCHEs
  - Hygiene concerns without cold storage facilities to hold bodies
  - Extra costs to families to die in RCHEs for private mortuary and funeral services

Note 1: Data from an exploratory study on caring and dying-in-place in RCHEs.
| Administrative Barriers & Practice Issues | Lack of understanding and established protocols between RCHEs and HA on when to start death preparation with frail elders and how to collaborate in conducting ACP & making AD | Cumbersome procedures to extend patient’s consent and allow RCHEs to access and use the shared eHealth records  
Problem with transportation to extended care facility for clinical admission of EoL cases  
EoL cases identified by non-HA physicians have problem aligning CGAT support & public hospital clinical admission  
Code of Practice (Cap459) on storage of non-designated drugs in RCHEs, affect timely relief of symptoms | Inadequate physician support to attend to imminently dying elders & to certify death on-site, especially when death occurs off office hours  
Extra work for staff in RCHEs to counsel bereaved families and accompany them to handle death registration  
Cumbersome administrative reporting on certified deaths in nursing homes | No provision of facilities in RCHEs for holding place of bodies for at least 24 hrs after death  
No after-office hours issuing of death registration & cert for removal of bodies to allow for transportation of bodies to holding places / mortuaries  
Unaware and limited use of non-office hour burial permit issued by Police, for certified natural death by a registered medical practitioner (Type 2) |
Suggestions for Improvements

1. Legislative Improvements

1.1 Legislate to give a clear scope and legal status on the application of Advanced Directives (ADs) to ensure individual’s care preferences pertaining to the use and non-use of life sustaining treatment is known and followed by all care providers, including RCHEs and Ambulances under Fire Services Department. Legislation should be coupled with efforts in public education to promote public awareness and usage of ADs and the training of different care disciplines in conducting Advanced Care Planning and the administration of Ads.

1.2 The future Enduring Powers of Attorney in personal care (EPA-personal care) should include in its scope: (i) use and non-use of Life Sustaining Treatments and (ii) post-death funeral and burial arrangements. Reduce the cost and administration of assigning an EPA-personal care to meet the needs of growing population of single elders or couples without children as well as for the increasing number of dementia cases to designate proxies for care decisions. Reference can be taken from the UK Lasting Powers of Attorney – personal welfare, which is now an online service.

1.3 Consider one of the followings in the amendment to the Coroner’s Ordinance (Cap 504):

(i) Include in the Type 16 exemption under Reportable Death to include RCHEs operated by non-profit making charitable organizations registered under Section 88 of the Inland Revenue Ordinance.

(ii) Include deaths in RCHEs in the Type 2 exemption under Reportable Death to include “any death of a person (before his death, joined a recognized EoL programme, which can be defined in the Ordinance) & when a registered medical practitioner has attended the person within 14 days prior to his death will issue the medical cause of death”

(iii) Non-legislative version of (ii) is for the Coroner to accept the certification of the medical cause of death by a registered medical practitioner who has attended the person within 14 days prior to his death in the RCHE and create a fast track of no autopsy and release for death registration. The certification of Form 18 (medical cause of death) can be amended to accommodate situations where the Form can be signed by doctors under a recognized EoL programme. These doctors may include both primary care doctors and hospital doctors.

2. Administrative and Practice Improvements

2.1 Collaboration between medical and social care practitioners in conducting Advance Care Planning and signing of ADs. Develop common understanding of the criteria of when to start the EoL programme and division of responsibilities in care, clear protocols of care transitions and communication of changes in health status.

2.2 Clear and timely documentation in a shared IT system, recording ADs and care plans (if not the full medical records through the eHRSS), accessible to all care providers including emergency services, with consent from the dying person.

2.3 Align the work of CGAT teams with the RCHEs’ visiting / onsite medical officers (V/OMOs), who may need to be resourced and include duties for EoL care for dying elders in RCHEs. Set up simple referral protocols by these V/OMOs for direct clinical admission of the dying elders, if situations require.
2.4 Transportation for emergency direct clinical admission and transportation for removal of bodies after death in RCHEs.

2.5 Enhancement of the physical (PC room, access to mortuary), people (additional staff, training, support) and medical capacities (access to medical advice, training in nursing and symptom management, availability of drugs & equipment) of RCHEs to support caring and dying-in-place. \textsuperscript{Note 2}

2.6 Provisions for Hospital Authority registered patients who have ADs and ACP in the public hospital and who will eventually die in RCHEs the right to use the hospital mortuary and that CGAT doctors can outreach to RCHEs to certify deaths on-site.

2.7 Streamline procedures for permit to remove body from RCHEs to funeral homes especially after office hours to relief time pressure on families & staff.
The Dying Processes in RCHEs

1. The feasibility of dying-in-place is restricted by the legal capacity of the home to allow for dying-in-place.

![Diagram of dying processes in RCHEs with and without legal mandate for Certified Natural Death]

The Coroner Ordinance (Cap 504) states that deaths in nursing homes can be exempted from being categorized as reportable death.

‘Any death of a person where the death occurred in any premises in which the care of persons is carried on for reward or other financial consideration (other than in any premises which comprise a hospital, nursing home or maternity home registered under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance (Cap 165))’

Dying in other types of residential care homes is otherwise categorized as ‘reportable death’, which requires an investigation by the Police and subject to the Coroner’s decision on whether an autopsy is required to determine the cause of death. This is a big deterrence to dying elders and their families who do not want the autopsies and it is also a deterrence to care homes that have to handle cumbersome investigations and reporting.
1.1 The Dying Process in Nursing Homes

Fig. 2  
Process of dying-in-place for Nursing Homes

*Notes: Form 18—Medical Certificate of the Cause of Death
Form 2—Medical Certificate (Cremation)

1.2 The Dying Process in Non-Nursing Home Registered RCEEs

For those RCEEs that are NOT registered under Cap 165, including Care and Attention Homes, Homes for the Aged, Hostels for the Elderly, Contract Homes and Private Care and Attention Homes, they are required to go through other dying pathways, i.e. clinical admission, the normal A&E transfer and reportable death if the resident dies at home.

The dying in hospital experience can be improved through direct clinical admission to geriatric ward or an extended care facility. First of all, it honours and is aligned with the medical choices of the residents. Medical staff in the extended care facility is equipped with necessary knowledge and skills in pain and symptom management. The ward is designed to allow family care, such as manual feeding, in the last few days of life. As compared to dying in care homes, the presence of hospital mortuary allows family members more time to digest the bad news instead of rushing through the post-death logistics. The pre-death collaboration and communication between RCEEs,
the extended facility and CGATs is crucial. For example, CGAT’s involvement in the initial ACP meeting and ACP reviews held by residential care homes would allow CGAT to communicate residents’ spiritual needs to the extended care facility EoL ward in the last few days of the resident’s life. The resident would be offered direct pass to go to the EoL extended care facility. However, transportation in the care transition would remain to be a problem.

1. The Physical, People and Medical Capacities Necessary to Support Dying-In-Place in RCHEs

For **physical capacity**, it is important for care homes to be equipped with a **Palliative Care (PC) room** to allow family members to accompany dying residents in the last few days of life. The space ensures privacy and the necessary personal care without disturbing other residents in the communal living environment of RCHEs. **Access to mortuary** facility for body storage is a serious concern for hygienic reasons and the absence of a mortuary creates time pressure and extra costs for transporting the body to the funeral services where cooling facilities are available.

**People Capacity** means **extra staff** for the extra workload involved in giving care to dying residents and their families; **basic training** for all staff in carrying out EoL care and proper after death debriefing and **emotional/psychological support** for staff members.

**Medical capacity** requires round-the-clock **access to physician** for consultation and advice and also on-site certification of deaths in RCHEs. **Training in nursing and personal care** to handle pain and dying symptoms are essential for staff in RCHEs in managing the dying process with provisions of EoL care **drugs and special medical equipment** be added to the RCHEs facilities.

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