Aligning Medical and Social Care to Deliver Quality, Effective and Compassionate End-of-Life Care for the Dying in Residential Care Homes for the Elderly (RCHEs)

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End-of-Life Care Policy Issue Brief 3

ABSTRACT

The Issue

- RCHEs have become the last place of residence for many elders who are entering the final stages of their lives and the trend is increasing

- Living and dying well in RCHEs rely on coordinated medical and services to provide holistic, person-centred and integrated care that is grounded in comfort and dignity

The Barriers

- Inadequate medical support, unable to access physicians for emergency consultations, lack of on-site trained nursing and personal care capacity to manage the dying process affect the quality of End-of-Life (EoL) care

- Gaps in care coordination and communication such as inappropriate care, repeated assessments and inconsistencies in implementing the advance care plan and delayed care frustrate dying elders and their families

The Solutions

- Measures to improve care system structures include (i) increase medical and nursing care capacity in care homes; (ii) develop a shared IT system; (iii) establish a facilitated pathway to streamline care transitions and expedite hospitalization for imminently dying elders

- Align processes of care such as identification of target service recipients, jointly conducting holistic care assessment and engaging families in care planning, division of roles in managing the dying moment, post death certification and finally, support to bereaved families

- Enhancement of structures and processes of partnership is grounded on a common driving value, a shared goal and trusting relationships

Introduction

As older and frail elders become care-dependent, many have no choice but to move into long term care facilities. 7% of the elderly in Hong Kong live in care institutions, among which 68% are over 80 years old; 82% are living with co-morbidities of two or more kinds of chronic illnesses (hypertension, stroke and dementia being the top three chronic illnesses) and 44.6% suffers the highest level of impairment in managing activities of daily living (ADL), needing help with mobility, eating, toileting, bathing, dressing and transferring. To many frail elders, elderly homes are their last place of residence before their deaths. Hence, it is important to consider the dying experience, the availability and quality of EoL care in long term care facilities.

The aim of EoL care is to improve the quality of life of the dying in four core aspects: physical, social, psychological, social and spiritual. A good working definition of what constitutes a "good death" as identified by patients and families across the developed world is summarized as "maintaining control, good symptom management, an opportunity for closure, affirmation of the dying person, recognition of and preparation for impending death and not being a burden as being crucial." It is essential that medical and social services are coordinated to provide holistic and person-centred EoL care for the dying elders that is grounded in comfort and dignity.

Based on a quantitative survey of care home managers and a qualitative study of four medical-social partnership care models, this issue brief examines the structure, process and outcomes of integrated care that could be put in place to ensure older people can live and die well in residential care homes.

Perceived Challenges and Critical Areas Needing Improvement

98% of subvented care home managers surveyed (n=100) have identified the following as important or very important issues of inadequate medical support and coordination between medical and social care that need to be addressed:

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<th>Issues of Inadequate Medical Support</th>
<th>(%) Very Important</th>
<th>(%) Important</th>
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<tr>
<td>24 hour consultation/onsite support by either hospitals/CGAT</td>
<td>71.0</td>
<td>28.0</td>
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<td>Registered medical practitioners to arrive at the site to certify death</td>
<td>56.0</td>
<td>40.0</td>
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<td>Training to enable them to handle dying residents’ discomfort</td>
<td>54.0</td>
<td>44.0</td>
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<td>Regular weekly visits to sick residents</td>
<td>50.0</td>
<td>43.0</td>
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<th>Issues of Medical-Social Care Coordination</th>
<th>(%) Very Important</th>
<th>(%) Important</th>
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<td>Consistency in implementing the advance care plan, advance directives and the post-transition care</td>
<td>50.0</td>
<td>48.0</td>
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<td>Standardized assessment mechanism</td>
<td>45.0</td>
<td>52.0</td>
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1. **Increase medical and nursing care capacity** in care homes. Access to extended hours, if possible, round-the-clock medical advice and support is important. Fluctuating and sudden health deteriorations in the dying process are great stressors to nursing and care staff in care homes, especially at night or after office hours. Without immediate assurance and guidance from physicians and experienced nursing staff, dying patients would be transferred to hospitals to avoid risks and liabilities.

   Training and equipping staff in care homes with nursing knowledge and skills in handling dying discomforts is essential. This should be supplemented by the provision of necessary medical equipment and drugs to be administered in care homes.

2. **Shared information technology (IT) system** is essential to coordinate care. Different care giving parties have to be well informed of the wishes and health status of dying elders. The existing electronic health record sharing system (eHRSS) should be enhanced. The ability to capture and share timely information across all facets of care is important to integrated EoL care. Caregivers in RCHEs need to know and can assist to record the changes in health situations and care preferences of dying residents.

   **Facilitated pathway or mechanism for direct public hospital clinical admission** can minimize unnecessary procedures and interventions; thus, improve the quality of care transitions for dying elders from RCHEs. Care homes are supported by the Community Geriatric Assessment Team (CGAT), which provides on-site care to dying residents and the non-acute extended health care facility provide timely direct admission when death is imminent. These proven effective pilot models should be replicated and be used as benchmarks. The facilitated clinical admission pathway should also be extended to EoL cases identified by private visiting medical officers (VMOs) and on-site medical officers responsible for primary health care in RCHEs.

### Improving Structures to Enhance Care Systems Capacity

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<tr>
<th>Common understanding in when to start EoL care</th>
<th>40.0</th>
<th>54.0</th>
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<tr>
<td>Include AD and ACP in e-medical records communication</td>
<td>40.0</td>
<td>54.0</td>
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<tr>
<td>Improve the channels for information exchange</td>
<td>37.0</td>
<td>61.0</td>
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### Aligning Processes to Provide Appropriate Care

4. **A joined up approach to on-going holistic assessment** of their needs across the physiological, social, psychological and spiritual domains. Psychosocial needs assessment, caregivers and family assessments and the existing interRAI (Resident Assessment Instrument) from the social care system should be adapted for EoL care and integrated with the medical palliative care assessments. There
should be agreement on when to start the assessment, who to conduct the initial and on-going assessments, how to update and access the documentation.

5. **Advance care planning (ACP) should be a person-centred and coordinated process.** The concerns and wishes of dying elders and their families are significant and they need to be informed, involved and supported in the decision-making process in both social and medical care.

The social care workers in elderly care homes are well placed to identify triggers and initiate the “death talk”, are acquainted with the elders and their families and are experienced in handling relationships and practical livelihood matters for the elders. Home workers are responsible for the daily care and nurses in RCHEs are at the frontline of managing the discomforts experienced during the dying process. Medical practitioners play the critical role of informing elders and their families the prognosis, the possible deterioration process and options of treatment, symptom management and comfort measures. All parties should work together in conducting comprehensive advance care planning that straddles medical and social care for dying elders.

6. **Formal mechanisms of care coordination** like the use of a case manager. There should also be clear protocols, communication procedures and roles in care transitions. Last but not least is to provide a supportive work environment conducive to collaboration and mutual support for frontline caregivers and managers across systems.

**Outcomes of Care**

To the dying elders and their families, the following four outcomes of coordinated care have been iterated: (i) to be able to relief pain and discomforts; (ii) effective communication and shared decision-making as well as being informed and involved; (iii) reduce unnecessary hospital transfers; (iv) respectful of wishes and compassionate care.

**Conclusion**

Structures prescribe the capacity of the care system and aligned processes ensure the appropriateness of care to meet needs. Adequate structure and processes are grounded on core value foundations of medical – social partnership. These three foundation pillars are:

1. **Respect dignity and holistic well-being of the dying elders as the driving value**
2. **A shared optimal goal** of dying well, balancing quality of life and quality of care to achieve care-in-place until death and eventually dying in the place of choice
3. **Trust** as a core foundation, with the elderly at the centre, building trust among formal, informal caregivers and the care systems. The four “I”s for building trust is to Inform, Involve, share Intention (shared goal) and Insist on value (driving value) in the process of care for the dying.


