The Roundtable Brief

Transitions between health and social care systems characterize end-of-life care. They bring both specialized services and risks of discontinuity of care. No matter how temporary it is, discontinuity of care could severely affect the health and quality of life/death of the frail patients, and even neutralize the previous care effort. Only seamless transitions across care settings can genuinely reflect the respect to the dying patients, and to honour their care and treatment preferences. This endeavour requires inter-professional collaboration which covers a range of concerns, including (1) the development of procedures and protocols for discharge/transfer and information communication, (2) division of labour in holistic care and (3) the involvement of patients and carers in decision making. In this roundtable, we will explore the challenges facing by inter-professional collaboration in end of life care, and to identify practices that can smooth the way for integrated care for both the dying persons and their loved ones.

Issues and concerns about the interface of medical and social service systems

(1) The development of procedures and protocols for discharge and information communication (Berlinger, Jennings, & Wolf, 2013)

- Common assessment tool to track the patients’ status and changes in the dying process
- Documentation of ‘care plans’, ‘care progress’ and ‘care preferences’ in a single portable file:
  - The divergence of terminology (lacking common language)
  - Familiarizing different professions to fill the forms in the file
  - How to ensure the secured transfer of data?
- Assignment of ‘a person with overall responsibility’ (like a case manager) for easy access to information by the patient, the proxy and the carers
- The development of an ‘ethical culture’ by preparing ethical guidelines and forming ethical consultation practice for conflicts over care plans
- Routinizing transfers in nursing home setting by training all the staff in doing proper transfer to hospitals

(2) Division of labour in holistic care (Handley, et al., 2014)

Dying is not just a physical process but also a social-psycho one. The need for collaboration is partly because of the multi-faceted need of a person nearing death. This collaboration is possible only when the professionals understand their own roles in
the dying process of the patients.

In **care homes without on-site nursing provision**, the care home staff and the visiting medical staff are found to have **a confusion of the division of labour in ACP**. Home care staff usually thinks dying is a physical process and they expect the medical practitioners to initiate the death talk. Meanwhile, the medical practitioners think that the home care staff have closer relationships with the persons in care, and are the most appropriate to initiate the death talk. Meanwhile, both of them agreed that the home staff’s fear of initiating the death talk is attributable to the lack of medical training and knowledge.

(3) The involvement of patients and carers in decision making (何孝恩, 2014)

As medical and social service practitioners may hold on to different views on the best care for the patients, we need a platform for communicating the differences and agreeing on a care plan. In case residents are composmenti, they should be involved in the decision making process, and their preferences should be respected wherever possible. Patients and their loved ones/carers are central in the ACP and its implementation, therefore, a common platform for the discussion of care plans and execution is need for critical events that hinge to the set-up of ACP, status changes and transitions across care settings.

Family conferences are suggested to be arranged regularly to make sure the care progress is communicated across the disciplines with the patients and their families. In this regard, ‘family conference’ becomes the platform for solving ‘disciplinary conflicts’ in the interface of the medical and social service systems.
Reference


Summary Report of the Roundtable Discussion

Speakers:
Dr Gilbert Fan  
Head, Department of Psychosocial Oncology  
National Cancer Centre Singapore

Professor Steve Iliffe  
Professor of Primary Care for Older People, University College London

Professor Jill Manthrope  
Professor of Social Work and Director of the Social Care Workforce Research Unit,  
King’s College London

Moderator:  
Professor Cecilia Chan, Head, Department of Social Work and Social Administration

Format of the Roundtable
The roundtable started off with the presentations by the three speakers, Dr. Gilbert Fan, Professor Steve Iliffe and Professor Jill Manthrope, from Singapore and the UK. The speakers unreservedly shared their local experiences about end-of-life care policy, services and research, while this momentum was then sustained by the floor’s active participation in expressing their views on issues that they encountered in providing end of life care in Hong Kong’s context. Within the very limited time space, we managed to have more than a third of participants (15 out of 39) talking about their views, experiences and challenges encountered in their own fields of practice. We also invited written feedback on (1) take away lessons and (2) suggestions for follow up actions from the participants by the end of the roundtable. 15 written feedbacks were eventually collected. A more comprehensive understanding about the possible forward actions as perceived by the multidisciplinary participants could then be sorted through this roundtable.

Composition of participants
A mixture of 39 practitioners and academics in the field of social and medical sciences/services turned up in the roundtable held on April 1, 2015. They represent a huge range of disciplines in the provision of end of life care in Hong Kong. These include elderly services, rehabilitation services, palliative care and medicine, Geriatric services/Gerontology, Oncology, Dementia care and nursing.
Their participation in this roundtable allows us to further explore the concerns about the quality and provision of end of life care in Hong Kong, in particular relation to the ‘social-medical interfacing’ of care.

Summary of the responses and feedbacks from the participants
The participants unequivocally agree that quality end of life services are increasingly important, and share the understanding that dying is not merely the matter of the dying person but also his/her family. To enhance the death quality and to protect the dignity of the dying, end of life care inevitably involves multidisciplinary collaboration, and sometimes legal amendments.

In the roundtable, participants have identified three categories of challenges/barriers facing the social care and medical care systems.

1. The uncoordinated manner in providing end of life service in Hong Kong, due to short term project-based funding, has aroused concern of the participants. This is said to have affected the quality and restricted the social impact of end of life care to the people in Hong Kong.

2. One core problem of coordination is the interfacing of the social care and medical care systems, that advance care plans and advance directives are not consistently honoured in care transitions. The need for deepening collaboration and coordination between care systems is hence being repeatedly raised by the participants. Unclear professional roles and division of responsibilities in providing end of life care, the lack of centralized platform for communication and lacking common language are then seen as the most prominent barriers for improving end of life care.

3. The existing legal framework is also found to be insufficient to make sure the advance directives are honoured at transitions, and to enable dying at home.

A number of FORWARD ACTIONS are suggested by participants in this roundtable to embrace the challenges as identified. They are listed below:

1. Developing a cross-professional task force or action circle to foster better communication, discussion, exchange of information, sharing of best practices, reaching consensus and coordinating efforts in service planning and practice enhancement.

2. Building collaborative service models which are more integrated in serving the multiple needs of end of life care users and carers.
(3) **Training healthcare and social care professionals** by strengthening their knowledge, especially in the end of life care for people dying with dementia and multiple comorbidities, and people with disabilities. Developing a standard curriculum for end of life care is raised.

(4) **Public education** on advance care planning, advance directives and procedures for obtaining the death certificate are helpful to reduce the attitudinal barriers of the public towards end of life care.

(5) **Consider legalization for enduring power of attorney and advance directives**, so as to ensure the best choice of care is maintained and respected for the dying.

(6) **Enhancing the current systems** is also necessary in order to take end of life care forward, i.e. allowing PPI-ePR to register advance directives.

(7) **Strengthening primary health care in the community**, supporting general practitioners to handle terminal physical symptoms and simplifying the existing advance directives protocol.
Appendix 1: Details of the responses and feedback from the floor

Part I: Identification of challenges and barriers

1. Social-medical interfacing
   i. **Unclear delineation of professional roles and responsibilities** in providing end-of-life care:

   ‘How can social workers involve in the planning of medical services?’—said AG
   ‘It will be great if you (social workers) can tell us how we could chip in. We are not the expert in handling the psychosocial aspect. It is always better to collaborate.’—said BB

   ii. **Lack of centralized platform** for dissemination of information about the care plans of the dying

   iii. **Lack of common language** for communicating across services, for example,

   ‘end-of-life care’ to medical practitioners is confined within the last 6 months before death while it may mean way more in advance for social workers/care home staff in order to complete the advance care plan.
   ‘There is [a] lack of common language in the health care services. Even the terms “palliative care”, “end of life care” and “terminal care”.’—said AK

2. Legal framework:
   i. Coroners Ordinance (Cap 504)―Certifying death at home/residential care may lead to dissection of the body;

   The lack of legal recognition to Advance Directives, so that the wishes of the dying person are not followed through when the dying person is transferred between care settings. For example, from home/residential care to hospitals.

3. Limited social impact
   i. Uncoordinated services
• Lacking a centralized platform for sharing information about resources, experiences and services
• Overlapping of services
ii. Time-limited and locality restrictive project-based funding

**Part II: Forward Actions**

1. Cross-professional action circle/task force/alliance/community/network

   **For**
   
   i. **Communication** between the medical and social sectors
   
   ii. **Understanding** each other’s role
   
   iii. **Facilitate discussion** and **identification of issues**
   
   iv. Deepening **collaboration and coordination**
   
   v. **Exchange** of information
   
   vi. **Sharing** best practices and resources
   
   vii. **Alignment** of service approach
   
   viii. **Reaching consensus** on important issues, concerns, actions and practice models
   
   ix. **Educating** social and medical care practitioners to execute ACP

   **On**
   
   i. Developing patient-centred end of life care
   
   ii. Advance care planning
   
   iii. Advance directives
   
   iv. Law Reform, e.g. Coroners Ordinance and Enduring power of attorney
   
   v. Public education on age-related morbidities, e.g. dementia

2. Developing collaboration and coordination:

   i. More integrated physical and social health services for end of life care for the elderly
      
      • Incorporate old age homes/hospices to major hospitals to provide one-stop service
      
      • Implement end of life care in old age homes
   
   ii. Model/protocol/procedures for collaboration and coordination between social and medical services
   
   iii. Developing case manager system

3. Professional training/capacity building for healthcare and social care professionals
i. Strengthening practitioners’ knowledge in special areas
   - ACP for people with dementia
     *ACP and AD should be carried out as early as possible and can be revised according to patients wish. I will be too late when the patient became demented and too ill to do so.*—said AJ.
   - End of life care specialized for people with disabilities
   - Palliative care

ii. Building a standard curriculum for care workers in the old age homes on end of life care

iii. Inter-professional sharing platform for exchange of practice models and experiences

4. Primary education and public awareness campaign

   For
   i. Social and medical practitioner
   ii. Family members/carers and care home staff

   On
   - Advance Care Planning
   - The procedures of obtaining the death certificate
   - Attitude for care but not merely welfare

5. Legalization

   i. ‘Advance Directives’
   ii. Enduring Power of Attorney and Lasting Power of Attorney

6. Enhancing the existing systems

   i. Improving the current PPI-ePR to allow registering information about Advance Care Plans and Advance Directives
   ii. Strengthening the community GPs in primary care to handle terminal physical symptoms, so as to reduce transfers to A&E or hospitalization
   iii. Simplifying the existing Advance Directives protocol for easier understanding by the terminally ill and their family members
   iv. Equipping the RCHEs with appropriate facilities for providing end of life care