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 1 April 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.

Appendix1:   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 the 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