Best Practice to Achieving Personhood in End-of-Life in Long-term Care Facilities

Lou Vivian W. Q.
Fang Christine M. S.
Kong Shirley S. T.

November 30, 2015
Contents

Conserving Dignity at the End of Life

Personhood – from Individual to Interpersonal

Best Practices to Achieving Personhood
Where is Hong Kong?

- **Quality of death index 2015**
  (Economist Intelligence Unit, 2015)

The chart compares the quality of death index across various factors including overall quality, palliative and healthcare environment, human resources, affordability of care, quality of care, and community engagement for Hong Kong, Taiwan, Singapore, Japan, and South Korea.
Where is the Gap?  
(Economist Intelligence Unit, 2015)

With the overall low score in the quality of death in Hong Kong, 

Only the quality of care can merely catch up with South Korea, but still fall behind the standards of the other economically comparable places in Asia, such as Japan, Taiwan and Singapore.

This is certainly related to the amount of human resources and the government support available for palliative care, as shown above Hong Kong is also running low in other aspects, including palliative and healthcare environment, human resources and affordability of care.

Palliative and healthcare environment are the lowest among all.
Dignity (Krishna, 2014; Chochinov, 2002)

- Innate / inherent right to be

Personhood

- Valued
- Recognized worthiness
- Ethically treated
- Respected
Personhood

- Define

- Individual

- Interpersonal

Personhood in Chinese context

Krishna, 2014
Achieving Optimal Dignity

Healthy  Frail  End-of-Life

Empowering Personhood
Objectives of the Study

1. Identify challenges for achieving optimal dignity among end-of-life long-term care facility residents
2. Consolidate best practices of achieving optimal personhood in long-term care facilities
Methodology

Objective 1:
- Questionnaire survey on long-term care facility (n=100; 64% successful rate)
- Measures: institution features, end-of-life service needs; service provision and perceived challenges

Objective 2:
- Case study via in-depth interview on pilot end-of-life care schemes
- Measures: vision, service scope, implementation strategies, and evaluation
Challenges of Achieving Personhood among Long-term Care Facility Residents

- Institutional constrains
- Formal caregivers’ voices on areas that need to be improved
- Lacking of Service Delivery Capacity

Fang, Lou and Kong, 2015
# Institutional Constrains – Medicalization of End-of-Life Care Needs

<table>
<thead>
<tr>
<th>Description</th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>The <strong>average annual percentage of deaths</strong> in the last 3 years</td>
<td>16.6%</td>
<td>3-28</td>
</tr>
<tr>
<td><strong>Number of deaths</strong> in the last year</td>
<td>Average number of deaths: 23 persons</td>
<td>-</td>
</tr>
<tr>
<td>The <strong>average number of hospitalization of each person in the last 6 months of life</strong> (according to the data of the last 10 deaths happened in the RCHE)</td>
<td>~3 times</td>
<td>1-10</td>
</tr>
<tr>
<td>The <strong>average number of days of hospitalization of each person in the last 6 months of life</strong> (according to the data of the last 10 deaths happened in the RCHE)</td>
<td>28 days</td>
<td>3-103</td>
</tr>
</tbody>
</table>
Perceived Areas that Needs to be Improved that will facilitate EoL Care

- Organizational readiness
- Holistic care for both the residents and the family
- Manpower and resources
- Professionally directed services
- Assessment tools and care protocols

percentage of respondents who either strong agree or agree
## Lacking of Service Delivery Capacity

<table>
<thead>
<tr>
<th></th>
<th>Yes (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your home devised any procedures/protocol for end of life service?</td>
<td>44.0</td>
<td>56.0</td>
</tr>
<tr>
<td>In the last year, <strong>has your home offered training</strong> to the staff</td>
<td>42.0</td>
<td>58.0</td>
</tr>
<tr>
<td>In the last 3 years, <strong>has your home systematically provided any advanced care plans?</strong></td>
<td>34.0</td>
<td>66.0</td>
</tr>
</tbody>
</table>
Best Practices

- Institutional Readiness
- Empowered Personhood (Individual & Relational)
- Standardized protocol
Institutional Readiness

1. Value driven
2. A shared optimal goal of dying well
3. Trust
4. Communication as a catalytic agent
5. Continuity of care across systems

Lou, Fang and Kong, 2015
Value Driven

- Achieving *personhood* at the end-of-life is everybody’s *right*
  - Ways of personhood manifestation various from culture to culture
  - In Chinese context, personhood includes both individual and interpersonal aspect

- Value / respect
  - Choices
  - Preferences

*How to live!*
A Shared Optimal Goal of Dying Well

Balancing Quality of Life & Quality of Care

+ Symptom control
+ Strengthen psycho-social health
+ Honor Dignity and Choice

DYING-IN-PLACE

CARE-IN-PLACE until Death

- Deteriorating health
- Burdensome care transitions
Trust as the FOUNDATION

INFORMATION

Mobile EoL Team

The Elderly

RCHEs

Hospital /medical outreach

Families

INTENTION

INVolVEMENT

INSISTENCE
Communication as a Catalytic Agent

- Identifying **Triggers** for starting the EoL discussion
- **Making-sense and interpretation** of the dying experience to the care systems
- **Managing expectations**
- **Formalizing and articulation** of the communication into agreed goals and plans of care
- **Disseminate care preferences** to all aspects of care
- **Incorporate and routinize** into daily care implementation
- **Facilitate continual dialogue** on revising care plans to meet changing needs
- **Empowering residents and family to understand, connect and rapport** with the care systems
Continuity of Care Across Care Systems

Enablers

| Information+ Communication system | Care Transitions protocols | Align work in Assessment, Care Planning, Advanced Directives | Collaboration knowledge + competencies |

Hinders
Empowering Personhood (Individual & Relational)

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensory* – touch, taste, smell, etc</td>
<td>Dynamics Communication</td>
</tr>
<tr>
<td></td>
<td>Biological* – signs of physical drop, losing functionality</td>
<td>Trust</td>
</tr>
<tr>
<td></td>
<td>Psychological – health induced emotions, mood, anxiety</td>
<td>Conflicts/disagreements</td>
</tr>
<tr>
<td></td>
<td>Social- communicability</td>
<td>Family’s role in fulfilling individual needs</td>
</tr>
<tr>
<td></td>
<td>Spiritual</td>
<td>Who is the proxy of care ?*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Planning</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Resident as a key stakeholder – solicit wishes &amp; preferences – acknowledge limits &amp; capacities</td>
<td>Family as another key stakeholder</td>
</tr>
<tr>
<td></td>
<td>Decision-maker</td>
<td>Proxy’s care capacity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Continuous communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Joint decision-making (mediating differences between resident-family)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Implementation</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Multi-disciplinary</td>
<td>Multi-disciplinary</td>
</tr>
<tr>
<td></td>
<td>Continuous assessment</td>
<td>Facilitate continuous contribution to achieve ultimate goals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enhance the Family Care Capacity*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Review</th>
<th>Individual</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Transparent</td>
<td>Well-prepare family for emergency</td>
</tr>
<tr>
<td></td>
<td>Well-prepare for emergency</td>
<td>Respect family’s expectations</td>
</tr>
</tbody>
</table>
Empowering Personhood (cont’)

<table>
<thead>
<tr>
<th>Inhibitors</th>
<th>Enablers</th>
<th>Intervention (empowerment strategies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Past</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unfinished business</td>
<td>Self-recognition</td>
<td>Life review–self affirmation</td>
</tr>
<tr>
<td>Family conflicts</td>
<td></td>
<td>Family reconciliation</td>
</tr>
<tr>
<td>Sense of loss</td>
<td></td>
<td>Resuming Social Connection</td>
</tr>
<tr>
<td>Losing Control</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Present</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical symptoms</td>
<td>Positive affection</td>
<td>ACP + Family conference</td>
</tr>
<tr>
<td>Unintended hospitalization</td>
<td>Meaning of life</td>
<td>Symptom management</td>
</tr>
<tr>
<td>Family disagreement</td>
<td></td>
<td>Nurture trusted + supportive relationship</td>
</tr>
<tr>
<td>Financial constrain</td>
<td></td>
<td>Sensory stimulation + Empowering family to care,</td>
</tr>
<tr>
<td>Institutional constrains</td>
<td></td>
<td>Psychological comfort experiencing positive emotions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spiritual enhancement</td>
</tr>
<tr>
<td><strong>Future</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death anxiety</td>
<td>Legacy</td>
<td>Work out Financial + Burial arrangement with Family support</td>
</tr>
<tr>
<td>Anticipatory grief</td>
<td>Family acceptance and consensus</td>
<td>Facilitate peaceful “goodbye”</td>
</tr>
<tr>
<td></td>
<td>Last moment</td>
<td></td>
</tr>
</tbody>
</table>

---

Inhibitors, Enablers, and Intervention strategies for Empowering Personhood.
Standardized Protocol

Holistic Well-being: bio-psycho-socio-spiritual

- Individual care plan

- Medical Care

- Symptom management

PSYCHO-SOCIAL –SPIRITUAL HEALTH

- Social connectedness
- Expression of self in relation
- Family engagement
- Psychological /spiritual comfort

Lou, Fang and Kong, 2015
Conclusion

- Relational personhood as essential
- Institutional Readiness as solid foundation
- Individualized Care as mechanism
Key References


- Fang, C. M. S., et al. (2015). The provision, concerns and improvement priorities in providing end-of-life (EoL) care in residential care homes for the elderly (RCHEs). *The 12th Hong Kong Palliative Care Symposium*. Hong Kong.


Thank You Very Much!

wlou@hku.hk
fangmsc@gmail.com
stk503@hku.hk