WHERE TO DIE? DREAM AND REALITY

Community

RCHEs

Hospital
(90% of deaths, Hospital Authority of HKSAR, 2014)

In many developed countries, most of deaths happen in the hospital – medicalized, rigid routines, impersonal care despite more accessible palliative care. Interventions are designed to reverse this trend (Gomez & Higginson, 2008)
END-OF-LIFE CARE IN HONG KONG

• MAJORLY BASED IN THE HOSPITALS, PROVIDING PALLIATIVE CARE FOR PATIENTS OF SPECIFIC DISEASE GROUPS, SUCH AS CANCER, RENAL FAILURE AND COPD

• TRANSFORMING THE MODE OF DELIVERY TO A MORE COMMUNITY-BASED MODE THAT ALSO SERVES THE IMMINENTLY DYING ELDERLY IN RCHES IN THE RECENT 4 YEARS

• FOUR EOL CARE PROGRAMS HAVE BEEN ORGANIZED BY THE COMMUNITY GERIATRIC ASSESSMENT TEAMS (CGATS) IN DIFFERENT HOSPITAL CLUSTERS
  • OUTREACH MEDICAL SUPPORT TO RCHES FOR PAIN AND SYMPTOM CONTROL FOR IMMINENTLY DYING RESIDENTS (CHU, 2014; HUI ET AL., 2014).
  • A NEW HOSPITAL ADMISSION PATHWAY, CLINICAL ADMISSION – BYPASSING THE ADMISSION TO A&E AND ACUTE WARDS FOR SPECIALIZED MEDICAL TREATMENTS.
SALVATION ARMY PALLIATIVE CARE IN RCHES IN HONG KONG:
HOLISTIC END OF LIFE CARE IN RCHES

GOALS
• ENHANCED PSYCHOSOCIAL CARE AND FAMILY SUPPORT
• PUTTING THE CHOICE OF THE OLDER ADULTS IN THE CENTRE OF DECISION MAKING – MEDICAL, SOCIAL & PRIMARY CARE ; PER- & POST-MORTEM CARE

EXTRA SERVICE
• ONSITE-PALLIATIVE DOCTOR VISITS
• PALLIATIVE CARE ROOM IN RCHES
• EXTRA NURSING MANPOWER TO SUPPORT PHYSICAL FLUCTUATIONS IN THE LAST FEW DAYS
• EXTRA SOCIAL WORK MANPOWER TO FACILITATE CROSS-SYSTEM COMMUNICATION, PROMOTE PSYCHOSOCIAL WELLBEING OF THE OLDER ADULTS, EMPOWER THE FAMILY AND NEGOTIATE STRUCTURAL AND PROCESS CHANGES FOR MORE PERSONALIZED CARE
RESEARCH OBJECTIVES

• HOW DO MEDICAL AND SOCIAL CARE PRACTITIONERS MAKE SENSE OF ‘DIGNITY’ AND ‘GOOD DEATH’? PARTICULARLY
  • WHEN THEY DO NOT AGREE WITH EACH OTHER; AND
  • WHEN DIGNITY AND GOOD DEATH ARE UNDERSTOOD DIFFERENTLY (FROM THE INSTITUTIONAL UNDERSTANDING) BY OLDER ADULTS AND THEIR FAMILIES?

• HOW DIGNITY/GOOD DEATH OF THE DYING OLDER RESIDENTS HAD BEEN ACHIEVED?
  • IN DIFFERENT (CROSS-)ORGANIZATIONAL CONTEXTS
  • AT BOTH THE STRUCTURAL AND THE PRACTICE LEVELS
METHODOLOGY

- END-OF-LIFE CASE GRAPH (KONG ET AL., 2016)

- 12 PRACTICE NARRATIVES COLLECTED FROM 10 MEDICAL AND SOCIAL CARE PRACTITIONERS IN RCHES
  - SCAFFOLDING THEIR VIEWS ON ‘DIGNITY’ AND ‘GOOD DEATH’
  - EXPLORE CRITICAL INCIDENTS WHERE THEY SUCCEEDED AND FAILED TO PROMOTE ‘DIGNITY’/‘GOOD DEATH’ OF THE OLDER ADULT

- EXAMINING DECISION MAKING PATTERNS AND ORGANIZATIONAL RULES THROUGH CRITICAL REFLECTION

Figure 2. An example of “Eol case graph” constructed with the practitioner (reconstructed and simplified from Figure 1).
Note. Eol = end-of-life, RCHE = residential care homes for the elderly.
### DEMOGRAPHICS

#### 10 INTERVIEWEES:

- **3 SOCIAL WORKERS IN THE SALVATION ARMY TEAM,**
- **4 SOCIAL WORKERS & 3 NURSES FROM THE RCHES**

#### Table 1. Demographics of Research Participants

<table>
<thead>
<tr>
<th>Participant Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Profession</th>
<th>Institution</th>
<th>Partnership with Healthcare System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ms. Lam</td>
<td>F</td>
<td>30-35</td>
<td>Social Worker</td>
<td>EoL Care Team</td>
<td>The pilot project (Mobile EoL Team)</td>
</tr>
<tr>
<td>Mr. Yan</td>
<td>M</td>
<td>25-30</td>
<td>Social Worker</td>
<td>EoL Care Team</td>
<td>The pilot project (Mobile EoL Team)</td>
</tr>
<tr>
<td>Ms. An</td>
<td>F</td>
<td>25-30</td>
<td>Social Worker</td>
<td>EoL Care Team</td>
<td>The pilot project (Mobile EoL Team)</td>
</tr>
<tr>
<td>Ms. Tam</td>
<td>F</td>
<td>30-35</td>
<td>Social Worker (Superintendent)</td>
<td>Nursing Home</td>
<td>24-hour medical care integrated in the RCH</td>
</tr>
<tr>
<td>Ms. Kung</td>
<td>F</td>
<td>30-35</td>
<td>Social Worker</td>
<td>Nursing Home</td>
<td>24-hour medical care integrated in the RCH</td>
</tr>
<tr>
<td>Ms. Ng</td>
<td>F</td>
<td>50-55</td>
<td>Nurse (Superintendent)</td>
<td>Care and Attention Home (Continuum of Care)</td>
<td>Well established support by the public hospital's geriatric team (with community EoL care programme)</td>
</tr>
<tr>
<td>Ms. Chan</td>
<td>F</td>
<td>25-30</td>
<td>Social Worker</td>
<td>Care and Attention Home (Continuum of Care)</td>
<td>Well established support by the public hospital's geriatric team (with community EoL care programme)</td>
</tr>
<tr>
<td>Ms. Woo</td>
<td>F</td>
<td>45-50</td>
<td>Nurse (Assistant Superintendent)</td>
<td>Care and Attention Home (Continuum of Care)</td>
<td>Supported by the cluster geriatric team (without community EoL programme)</td>
</tr>
<tr>
<td>Mr. Wong</td>
<td>M</td>
<td>35-40</td>
<td>Social Worker</td>
<td>Care and Attention Home (Continuum of Care)</td>
<td>Supported by the cluster geriatric team (without community EoL programme)</td>
</tr>
<tr>
<td>Ms. Si</td>
<td>F</td>
<td>40-45</td>
<td>Nurse (Superintendent)</td>
<td>Care and Attention Home (Continuum of Care)</td>
<td>Well established support by the public hospital's geriatric team (with community EoL care programme)</td>
</tr>
</tbody>
</table>
RESOLVING THE PERSONHOOD JIGSAW PUZZLE

1. SUFFERINGS OF OLDER ADULTS AS PERCEIVED BY CARE PRACTITIONERS
2. UNDERSTANDING A PERSON BEYOND A BIOLOGICAL SELF
3. SOCIAL AND STRUCTURAL CHANGES NEEDED FOR ALLEVIATING THOSE SUFFERINGS
OLDER ADULTS’ SUFFERINGS: 
A CRITICAL REFLECTION ON AGEING AND DYING IN RCHES

The doctor assessed the mobility and the physical strength of Mr Luk, for evaluating the feasibility of spiritual activities. The practitioner said, ‘The length of time he can sit by himself is... practitioners an idea of how to arrange Mr Luk’s visit to the church in the community’ (from field notes, 15 July 2015).

There was a time we talked about how Madam Sau lived her past... The caseworker told us that she is dearly loved by a woman Westerner who always took her along to different activities...[I said,] ‘That’s awesome... It seems that she really appreciates you, [Ms Sau]’. She nodded her head although she couldn’t open her eyes or respond in other ways...’ [Mr Yan).

Normally in RCHES, food is prepared according to eating ability, showers are offered to all at a particular time of the day and A&E transfer is sorted when the residents’ blood glucose reading exceeds 20/25.

Researcher: Do you mean, before this project, all this information was not communicated to her? Mr Yan: Well... I thought...rarely. Because the residential home would just follow their routine care.

It is isolation. You know, who can actually help [the resident]? People around her either send her to the hospital or find themselves unable to help. The family also feels helpless as they are also pissed by [frequent hospitalization]’ (Mr Yan).
RELATIONAL PERSONHOOD (「為人」)

• DEPARTING FROM PATIENTHOOD WHICH SEES A PERSON AS BIOLOGICAL BEING – TREATS A PERSON BY DISEASE

• INFORMS US TO LOOK AT THE RELATIONSHIPS IN WHICH A PERSON UNDERSTANDS ONESELF AND IS BEING UNDERSTOOD (REFERENCE: THE RING THEORY OF PERSONHOOD)

DIGNITY: PATIENTHOOD & PERSONHOOD (CHOCHINOV, 2014)

BIOLOGICAL DEATH
(LUNNEY ET AL., 2003)

SOCIAL DEATH
(HOCKEY AND DRAPER, 2005; HOCKEY, 2008)

(Krishna et al., 2015)
Understanding the 'Person-in-Relationship' and the 'Person-in-Time'

- Structural: Increase in collaborative assessment and sense-making platforms for rebalancing the traditional body-focused assessment with familial and psychosocial assessment
- Social: Assessing family dynamics with both formal and informal carers, and the past, present and preferred future of the elderly

Enabling Personalized Care to Enhance the Psychosocial outcomes

- Structural: Flexible staffing for personalized care in communal living
- Social: Resuming social connectedness, catering personal preferences and style in care, and bringing psychological comfort

Identifying the Personhood-Inhibiting Experiences (Sufferings)

- Structural: Consolidating the value for conserving the dignity of the dying
- Social: Identifying experiences of losing oneself in the process of ageing and transiting to institutional care

(Kong et al, 2016)
CONCLUSION & REFLECTION

• **CULTIVATING VALUES** OF RESPECT, CARE AND HUMANITY IN THE STAFF OF EOL CARE

  • TO IDENTIFY THE SUFFERING OF OLDER ADULTS, PARTICULARLY WITH RESPECT TO THEIR LOSS OF THE SENSE OF SELF AS CATALYSED BY PHYSICAL DETERIORATION

• **BIOPSYCHOSOCIAL BEING/ INTER-CONDITIONALITY** OF THE BIOLOGICAL SELF AND PSYCHOSOCIAL SELF WHICH CONSTITUTE THE CONDITION FOR EACH OTHER TO THRIVE OR HALT
REFERENCE LIST


• HONG KONG COUNCIL OF SOCIAL SERVICE (2015). A SURVEY ON ORGANIZATIONAL READINESS FOR PROVIDING END-OF-LIFE CARE IN RESIDENTIAL CARE FACILITIES. HONG KONG: HKCSS.


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Thank You