Best Practices of Conserving Human Dignity – An Analytical Study of the Medical-Social Partnerships of EoL care in RCHEs

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Objective

- To consolidate the best practices of the four medical-social partnerships in conserving dignity in end-of-life care in Hong Kong residential care homes for the elderly (RCHEs).

- To analyze the four partnerships at the (a) structural and (b) practice levels, systematically identifying the shared vision, implementation mechanisms, complimentary care functions and the engagement of the dying residents and their families in enhancing dignity and quality of life.
Methodology

Data Collection:

- **Primary data:**
  - **12 Interviews** with major stakeholders in the elderly residential care homes, including project holders and social workers. The interview will be audio taped and transcribed for analysis.
  - **Field notes** were prepared by the researcher, to serve as observational data for further analysis

- **Secondary data:**
  - Salvation Army’s EoL **Project materials**
  - **Guidelines and/or procedures** devised by the residential homes in handling EoL cases

**Data analyses:** thematic analysis including open coding, selective coding, axial coding and theme construction

Informed consent was sorted from all participants before the interviews. Only participants who sign the consent form will be included in this study. All the data are anonymized and pseudonyms are used.
Foundation of the **BEST PRACTICES**

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
1. Value - Understand the “Sufferings” of approaching Death

- Stripping off personal qualities due to physical deterioration
- Uprooting from their natural habitat
- Proceduralizing by the care designed for communal living
- Marginalizing by medicalization (feeling like a passive recipient of care)
1.1 The Driving Value - Honoring Human Dignity

Operational Values:
- Comfort and Pain relief
- Honouring personal choices of care (意願) and sense of autonomy
- Recognizing the value of different aspects of life

Personhood Values:
- Appreciation of life/
- Living in the present
- Feeling socially connected
- Preparing the peace of mind of the resident and the loved ones for the departure
- Hope
2. An Optimal Goal of Dying Well ...

- The residents and the families are well-informed about
  - The different options of dying
  - The possible trajectories and consequences of the options
  - What if...

- Quality of Life and Quality of Care are both enhanced

- The residents and the families are continuously engaged in decision making

- Multidisciplinary engagement along the process of care and dying is maintained

- Reduction of Unnecessary care transitions and hospitalization
2.1 Dying Paths for Residents in RCHEs

with legal capacity

Dying in the familiar environment of the Nursing Home

without legal capacity

Dying in the hospital
• With EoL care programme in the hospital cluster --> clinical admission
• Without EoL care programme in the hospital cluster/out of CGAT's office hour --> A&E admission

OR

Dying in the Care Home
• EoL care supported by CGAT/VMO
• Reportable Death
2.2 Challenges

- Honoring of residents wishes & choice of care
- Managing the dying phase to minimize physical suffering
- Family can spend more time at death of the residents & immediately after death for moaning, remembering and saying goodbye
- Timely verification & certification of death
- Minimize burden of after death logistics for the family
- Care & support of carers & family, including emotional and practical bereavement support
3. Trust as a Foundation

- **Information**

- **Intention to Care**: Continuous Communication and Engagement

- **Intention to Help**: Capacity Building and Learning **TOGETHER**

- **Involvement** in practice
4. Communication as a Catalytic Agent throughout the Care process

(1) Formulation
(2) Dissemination
(3) Implementation
(4) Routinization
(5) Revision

(6) Managing physical conditions
(7) Empowering the resident and the family
4.1 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
5. Continuity of Preferred Care Across Systems

Enablers for the continuity of preferred care

CARE CO-ORDINATION
The continuity of preferred care

Inhibitors for the continuity of preferred care
5.1 Care coordination

- **case manager** as capacity builder, team builder + smooth out care & dying logistics

- **division of labour** between medical & social teams

- **synchronized assessment/understanding** across systems
  1. the resident
  2. The proxy
  3. RCHE social and medical practitioners
  4. HA EoL practitioners and general ward medical practitioners

(i) on the resident’s
  - EoL status
  - Medical preferences
  - Lifestyle/ personal preferences
  - Spiritual preferences (among the social and medical professionals and the family)

(ii) on family
  - Attitudes and care capacity (as it affects admission to EoL programmes and accessibility of services)
Best Practice – The Distinguishing Practices
TRI- Focus

6. Attention to Personhood and Family

7. Strengthening Psycho-Social Well-being

8. Empowering Formal and Informal Caregivers
6. Personhood + Family-Focused Holistic Assessment

Solving the ‘Personhood Jigsaw Puzzles’

Expand comprehensive geriatric assessment to exploring ...
- Sensory-bio-psycho-social-spiritual assessment of personhood
- Family dynamics and care capacity
- Knowing the Past, the Present and Connecting the Two
## 6.1 Individual + Family-Oriented Intervention

### Connecting The Past + The Present

<table>
<thead>
<tr>
<th></th>
<th>Individual</th>
<th>Family</th>
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</thead>
<tbody>
<tr>
<td><strong>Assessment</strong></td>
<td>Sensory* – touch, taste, smell, etc</td>
<td>Dynamics Communication</td>
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<tr>
<td></td>
<td>Biological* – signs of physical drop, losing functionality</td>
<td>Trust</td>
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<tr>
<td></td>
<td>Psychological – health induced emotions, mood, anxiety</td>
<td>Conflicts / disagreements</td>
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<tr>
<td></td>
<td>Social – communicability</td>
<td>Family’s role in fulfilling individual needs</td>
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<tr>
<td></td>
<td>Spiritual</td>
<td>Who is the proxy of care ?*</td>
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<tr>
<td><strong>Planning</strong></td>
<td>Resident as a key stakeholder – solicit wishes &amp; preferences – acknowledge limits &amp; capacities</td>
<td>Family as another key stakeholder</td>
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<tr>
<td></td>
<td>Decision-maker</td>
<td>Proxy’s care capacity</td>
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<td></td>
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<td>Continuous communication</td>
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<td></td>
<td></td>
<td>Joint decision-making (mediating differences between resident-family)</td>
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<tr>
<td><strong>Implementation</strong></td>
<td>Multi-disciplinary</td>
<td>Multi-disciplinary</td>
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<tr>
<td></td>
<td>Continuous assessment</td>
<td>Facilitate continuous contribution to achieve ultimate goals</td>
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<td></td>
<td></td>
<td>Enhance the Family Care Capacity*</td>
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<tr>
<td><strong>Review</strong></td>
<td>Transparent</td>
<td>Well-prepare family for emergency</td>
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<td></td>
<td>Well-prepare for emergency</td>
<td>Respect family’s expectations</td>
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6.2 Continuous Assessment & Adjustment of Care Plan

Source of data
- Daily observations
- Group activities, e.g. life review, last wishes, life and death education activities
- ACP meeting/ PC conferences
- Residential care home staff:
  - Healthcare workers’ daily care experiences;
  - Social workers who talk to the residents and their families on daily basis;
  - Nurses who care for the residents’ bodies
  - Case managers who coordinate care
- Talking to residents themselves
- Talking to residents’ families
- Personal records, e.g. individual care plans, Point-click system record, MDS etc.

Methods of analysis
- Personal hunches
- Collective sense-making
  - Head to head communication
  - Many to many communication
  - Head to team communication
7. Strengthen psycho-social well-being for optimal quality of life through **EMPOWERMENT Interventions**

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

- **Resuming social connection**
  - maintaining human contact
  - engaging families and/or volunteers to pay regular visits
  - reconciling with the significant others (family and care practitioners)

- **Nurturing supportive and trusted relationships** in the care network
  - Resuming communication between the residents and the care practitioners
    - Opening up new space for communicating the different views and information (e.g. ‘historically disenthralled’ carer)
    - Facilitating self-expression of the resident’s perception of the illness/dying/death & the care
      - Use of open questions
      - Listen and observe
  - Assuring the intention to care and honour care preferences
  - We-ness
7.1 Strengthening Psychosocial Well-being

- **Facilitating self-expression through sensory stimulation and family care support**
  - Eating and food
  - Music
  - Life style
  - Sensory functions (touch, taste, smell, sight, sound)

- **Bringing psychological comfort**
  - Pride/sense of achievement vs sense of loss and helplessness
  - Regretless departure vs sense of guilt and burden
  - Peace of mind vs loneliness and death anxiety

- **Spiritual care/existential comfort**
  - sense of being connected
  - life meaning
  - instill hope
8. Empowering both Formal and Informal Care

<table>
<thead>
<tr>
<th>Admissions to EoL care</th>
<th>Care Planning and Implementation</th>
<th>Revision of ACP</th>
<th>Close to the end of life/after death</th>
</tr>
</thead>
</table>
| For Informal Carers   | Programme content—purpose, service components, trajectories | To plan the care for the resident by understanding  
• the resident’s view on care preferences  
• the physical conditions of the resident  
• the temperament of the resident  
• the pros and cons of different treatments  
* Encouraging, facilitating and enabling the family to implement the care | Inviting the family in the discussion of ACP revision | Preparing the family and the home carers to face the departure |
|                       | Programme aim—understanding, consent and support |                             | Allowing revisiting the plans in the course of care | Informing the family and the home carers about the dying trajectory |
|                       |                                                   |                             | Allowing space for moaning and remembering | Supporting family in sorting out the funeral arrangements |
| For Formal Carers     |                                                   |                             | Multi-disciplinary communication and coordination platforms | Debriefing and Post-death Support for Carers |
|                       | To understand the history, personal preferences and medical preferences of the resident or/and the family |                             | | |
|                       | To enable caring for the residents and the family until the end of life (doing the unusual practices) | | | |
Conclusion

- Best practices in conserving human dignity
  - Five Foundation Pillars
  - Person-centred + Family-focused interventions to enhance Psychosocial Health
  - Empowering the Formal and Informal Caregivers
End of the Presentation