Developing Psychosocial Advance Care Planning

To Achieve Personhood and Dignity at the End of Life for Dying Older Adults
Background of the Research

Objectives

• proposing **components and best practices** for sustaining older adults’ personhood in relation to their families alongside the deteriorating health.

• contribute to the development of a more **personhood-oriented Advance Care Planning**

Method

• 18 end-of-life cases are selected by experienced social work specialists on the basis that they are rich in psychosocial intervention.

• The data set comprise case recordings of 900+ pages are coded according to the framework set out by the ‘Ring Theory of Personhood’ that captures the interactive nature of individual and relational constructs of self.
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)

• The ‘history’ and ‘relationships’ are the essential constituents of one’s ‘personhood’, for example, ‘a General of the war time’, ‘the first policewoman in Hong Kong’, ‘a widowed mum of many children’...etc.
A Modified Ring Theory for Achieving Relational Personhood in EoL Care

**Individual Ring:**
Self-Realization and Self-Expression

**Relational Ring:**
Bonding, Reciprocity and Engaged & Compassionate Care

**Societal Ring:**
Care Tenor; Care Practitioners’ Roles, and Professional Rules and Guidelines

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**Sensory** – low communicability

**Emotional** – Depression-Anxiety/Anger-Loss (DAL); Guilt-Ambivalence-Disagreement (GAD)

**Existential** – Sense of hopelessness, enmeshed self and difficulty to pass on one’s legacy

<table>
<thead>
<tr>
<th>Sensory (with proper pain and symptom control):</th>
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<tbody>
<tr>
<td>(1) Assessment of residual sensory functioning,</td>
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<tr>
<td>(2) Appropriate sensory practices,</td>
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<tr>
<td>(3) Innovating non-verbal form of communication through sensory engagement</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Emotional:</th>
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<tbody>
<tr>
<td>(1) Anticipation of negative emotions,</td>
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<td>(2) Ventilation of negative emotions and</td>
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<td>(3) Promoting moments of joy</td>
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<table>
<thead>
<tr>
<th>Existential:</th>
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<tbody>
<tr>
<td>(1) Connecting to the past,</td>
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<tr>
<td>(2) Connecting to significant others and passing on love and legacy,</td>
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<tr>
<td>(3) Connecting to the spiritual self</td>
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The Multi-dimensional and Multi-layer Model

For Psychosocial Advanced Care Planning

Societal Ring
Individual Ring
Relational Ring

Sensory
Emotional
Existential
Individual-focused & Family-Oriented Approach

Individual
Relational
Societal/Institutional
In
Multi-Layered Intervention

Sensory
Emotional
Existential

Case Illustration
Background of the Case

- Kam, 91/F
- Mentally sound, wheel-chair bound
- Widowed
- Next-of-kin: Son, Daughter-in-law
- Medical History: Hypertension, Chronic Kidney Disease, Atrial Fibrillation, Chronic Heart Failure, Chronic Renal Impairment, Lt. Breast Lump (Highly suggestive of malignancy)
IRS Interventions

**Individual (I)**
- **What** - Facilitate self-realization & self-expression
- **How** - Enhancing knowledge of diagnosis; articulation and construction of illness experiences, social self and religious self
- **Challenges** - Lack of control/autonomy before intervention; sense of uselessness; self-blame
- **Outcome** - Increased sense of self; Enhanced emotional acceptance of illness

**Relational (R)**
- **What** - Bonding/Social connectedness & Engaged and compassionate care
- **How** - Connecting the elder with outer world – e.g. tour to the garden; increasing literacy of care – food enjoyment delivered by family
- **Challenges** - Declining caring capacity of family
- **Outcome** - Reduced caregiver’s stress; Increased familial involvement in direct care

**Societal/Institutional (S)**
- **What** - Care practitioners’ role at RCHE
- **How** - Working with the elder’s expressed need: minimizing hospital stay; Discussing ACP on treatment plan; Establishing new routine of daily care
- **Challenges** - Unaligned expectations: usual practice v.s. resident’s expressed wish
- **Outcome** - Institutionalized change for personalized care
SEE intervention

**Sensory**
- **What** - Hearing function deteriorating while vision and taste remained
- **How** – Providing favourite food; Facilitating non-verbal communication; Hobby - Watching movie
- **Challenges** – Communication gap between resident and family before intervention; Swallowing difficulty
- **Outcome** – Increased social connectedness with staff and family members

**Emotional**
- **What** – Feeling of self-blame & uselessness due to worsening health
- **How** – Ventilation & Reflection of feeling; Enhancing; Facilitation of expressing expectation on treatment plan and prognosis
- **Challenges** – Assisting resident to learn about the expression of negative emotions to significant others
- **Outcome** – Resident expressed to have heightened understanding of physical condition and acceptance of self; being able to articulate her needs during end-of-life stage

**Existential**
- **What** – Construction of social self & religious self
- **How** – Life review & Religious activities
- **Challenges** – Difficult communication due to decreasing hearing function
- **Outcome** – Increased self-assurance on her familial role and achievement in the past ➔ Increased sense of self; Increased acceptance towards death

香港安老院舍完善人生關顧計劃
Palliative Care in Residential Care Homes for the Elderly
Some of the Good Practices for Psychosocial ACP
1. Expanding the conventional geriatric assessment to include (1) residual sensory functioning, (2) emotions and care capacity of family and proxy and (3) staff support for continuous sensory engagement

2. Empowering the dying older adults to express their care and treatment preferences in supported familial and institutional care environments

3. ACP meetings: Enabling the family, the proxy and the care institution to understand, reciprocate and perform the care preferred by they dying older adults
<table>
<thead>
<tr>
<th>Before</th>
<th>Intervention</th>
<th>After</th>
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<tbody>
<tr>
<td>Societal Ring</td>
<td>Societal Ring</td>
<td>Increased family care capacity and involvement (Relational); Staff’s new means of communication (Societal)</td>
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<tr>
<td>Individual Ring</td>
<td>Individual Ring</td>
<td>Self-realization (Individual); expression to family and health care professionals (Relational)</td>
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<tr>
<td>Sensory</td>
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<td>Existential</td>
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<tr>
<td>Deteriorating Functioning</td>
<td>Social activities e.g. garden tour</td>
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<tr>
<td>Negative Emotion: Sadness, self-blame, uselessness</td>
<td>Individual Counseling</td>
<td>Self-realization (Individual); expression to family and health care professionals (Relational)</td>
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<tr>
<td>Self-identity: ambiguous</td>
<td>Life Review</td>
<td>Construction of religious self; Acceptance to death and dying (Individual)</td>
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4. Sensory engagement for creating non-verbal communication between the older adults and his/her family when communicability is low.

5. Individual sessions for emotional ventilation and family gathering for more moments of joy.

6. Life review to promote (1) continuity of life (individual construction of preferred self) and (2) social connectedness (with the presence of friends in the RHCEs), and (3) to assist the (in a family gathering) family to make sense of the uniqueness of the older adult and uphold his/her legacy.