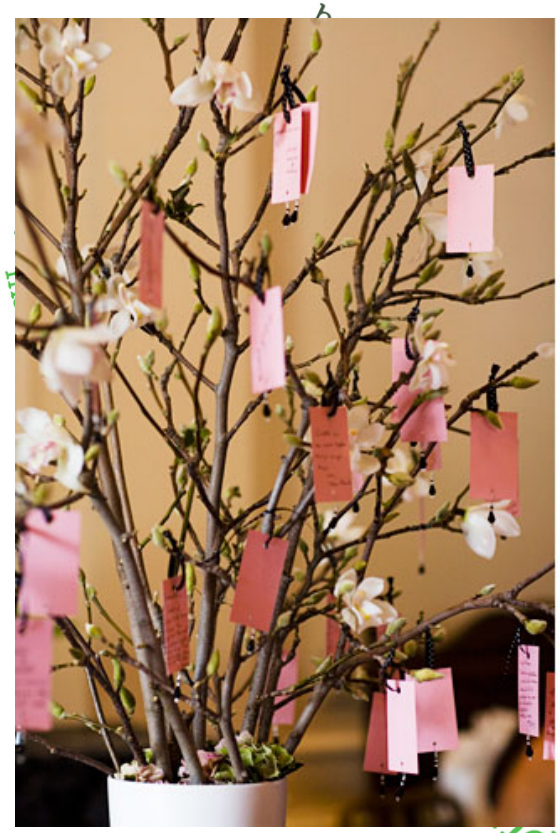
賽馬會安寧頌
JCEcc
Jockey Club End-of-Life Community Care Project

Workshop on Rejuvenating Personhood at the End-of-life

Dr. Vivian W. Q. Lou
Associate Professor, Department of Social Work and Social Administration
The University of Hong Kong
June 22, 2017




Cuddle on
the couch together
every single
day.
Love,
Karen Renwick

Agenda

Time	Activity
9:30-11:00	Understanding Dignity among Chinese Elderly
11:00-11:15	Tea Break
11:15-13:00	Model of Relational Personhood - CORE-UPHOLD
13:00-14:00	Lunch Break
14:00-15:30	Assessment / Case study
15:30-15:45	Tea Break
15:45-16:30	Intervention Strategies
16:30-17:00	Q & A

Understanding Dignity among Chinese Elderly

Reserving Dignity at the End-of-Life

- Dignity in the Hong Kong Chinese context – related to interdependent self and familial connectedness (Ho et al., 2013; Lou, 2015; Kong, Fang and Lou, 2016)
- Concept of the self in Hong Kong Chinese – deeply rooted in the familial culture, which locates oneself, bodily and socially, in hierarchical relations subordinating the younger to the older and women to men (Holroyd, 2003; Kong, Fang and Lou, 2017)
- The actualization and maintaining a sense of the relational self – not only essential but also critical to achieve an optimal quality of death in Hong Kong (Fang et al., 2015; Kong, Fang and Lou et al., 2017)
- Achieving dignity at EoL – nurturing and supportive relationships built around the dying elderly are the primary condition

Relational Personhood

- "Self" of dying older adults – constructed in:

1. Time (past, present, and future), and in
2. Relationships (proxy, family, and friends)

- Kong et al. (2016) proposed three categories of strategies which are found to effectively sustain the preferred sense of self of the dying and bring psychological comfort to them:

(1) resuming social connectedness,

(2) expression of the self in supportive relationships and

(3) bringing psychological comfort alongside medical care.

- All these strategies share the identical assumption that nurturing and supportive relationships built around the dying elderly are the primary condition for achieving dignity at the end of life.

Model of Relational Personhood

CORE-UPHOLD

Model of Relational Personhood

- Highly individualized
- Captures the fluid and changing nature of "self" as constructed in the deterioration of health and consciousness, which is common in people facing the EoL.
- Ultimate goal of promoting relational personhood – to prime the family carers and empower them to become the "personhood-proxy" of the dying older adult.

CORE-UPHOLD

- Consists of three major care steps namely:

(1)Identifying Personhood **Co**nfiguration,

(2) **Re**juvenating Relational Personhood and

(3) **Uphold**ing personhood + legacy.

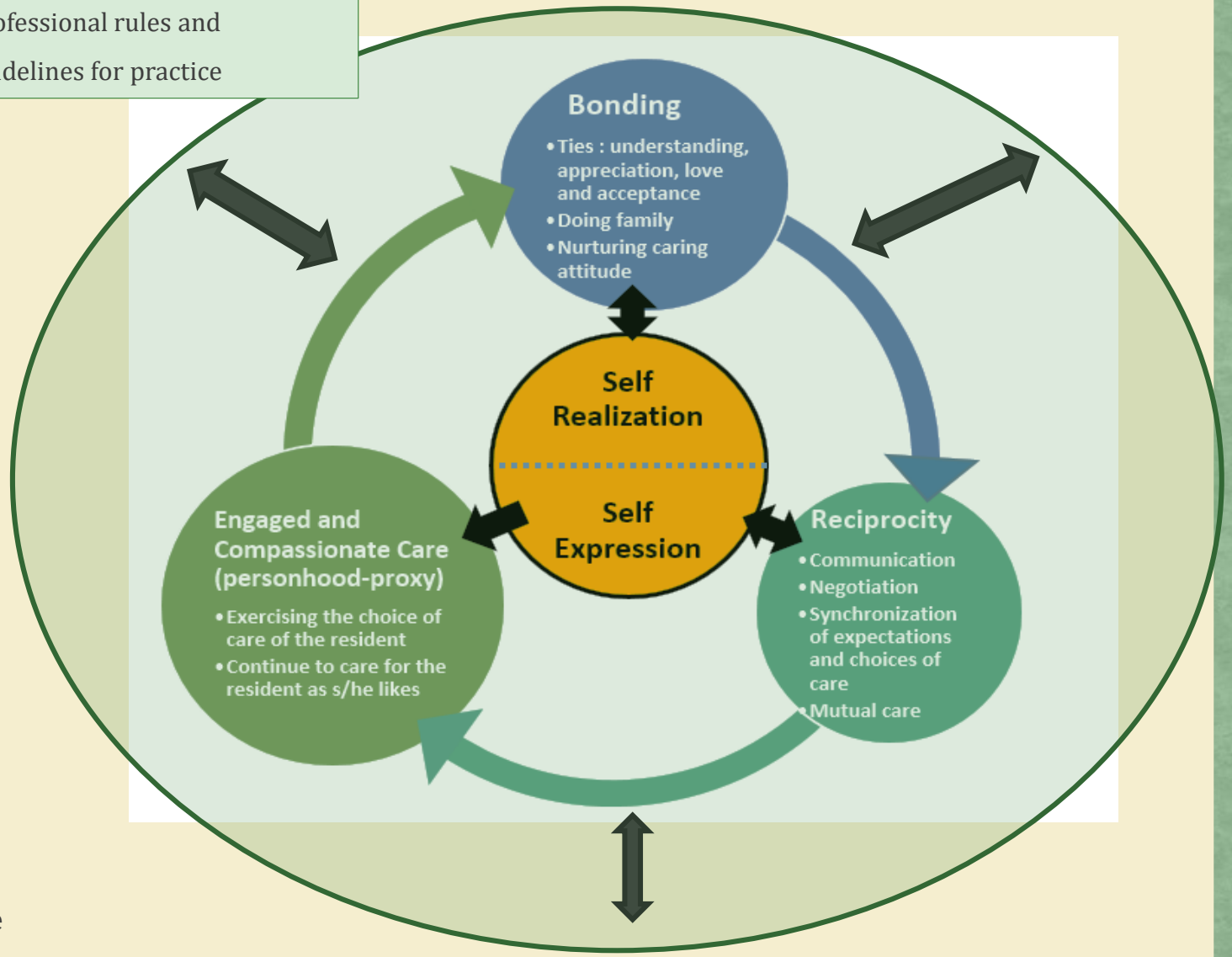
A Modified Ring Theory for Achieving Relational Personhood in EoL Care

Societal Ring – care tenor, care practitioners' roles, and professional rules and guidelines for practice

Individual Ring:
Self-Realization and Self-Expression

Relational Ring:
Bonding, Reciprocity and Engaged & Compassionate Care

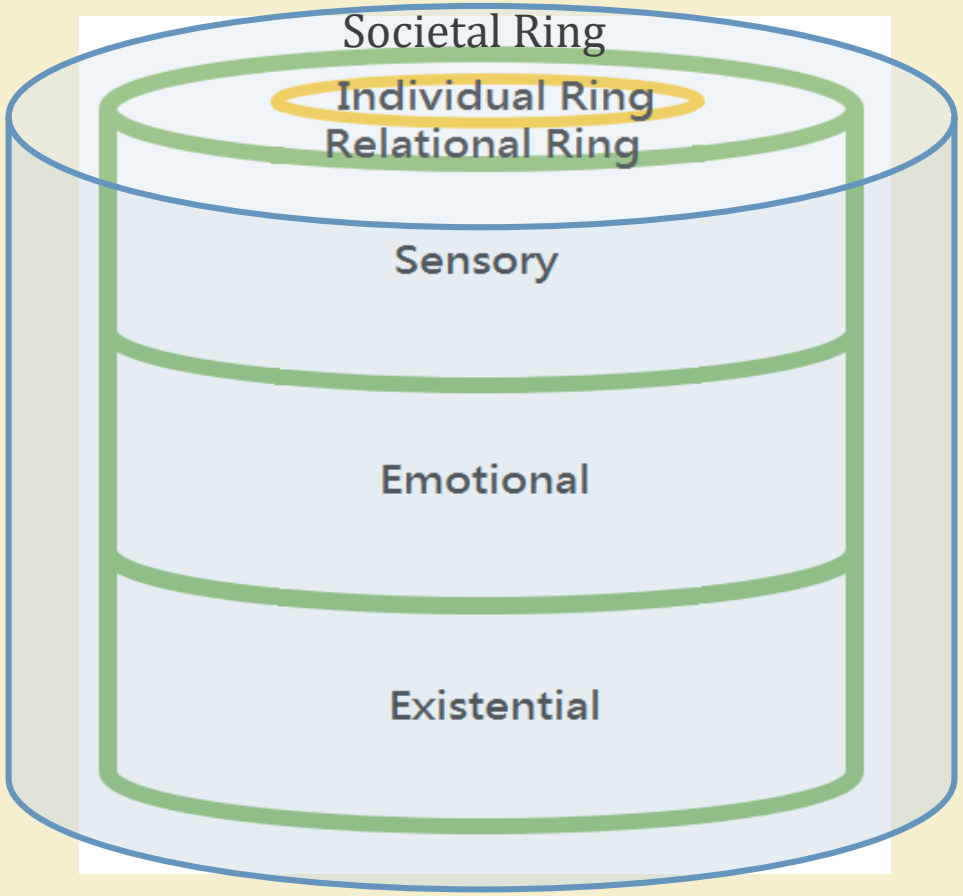
Societal Ring: Care Tenor, Care Practitioners' Roles, and Professional Rules and Guidelines



- Krishna, R. K. L. (2014). Accounting for personhood in palliative sedation: **the Ring Theory of Personhood**. *Medical humanities, 40*(1), 17-21.

The Multi-dimensional and Multi-layer Model (IRS+SEE):

CORE-UPHOLD



Individual Ring (I-Ring)

- **I-Ring** of Personhood involves the following through *verbal, action and material forms*.

a) Realization of Self – helping the individual to come to understand and ascertain his/her value about life and death, beliefs (moral, religious and spiritual), goals of life, experienced illness and deterioration (diagnosis & prognosis) and care preferences when death is nearing.

b) Expression of Self – to discover the personality traits and preferences of the individual and to empower the individual to express and live out the 'individuality' in the care setting through verbal, action and material means, e.g. talking, singing, going to places, eating, cooking etc.

Relational Ring (R-Ring)

- **R-Ring** includes:

a) Bonding with Significant Others - Attain understanding, appreciation, love and acceptance for the dying older adult's Self (as discovered in the individual ring); continue to perform family practices (Smart, 2011; Lau, 1981) (e.g. yum cha together, cooking, spending CNY together etc.) and nurture caring attitudes of the family particularly when reciprocity is sabotaged by dwindling communicability and health.

b) Reciprocity - Communication and negotiation of mutually acceptable goals (synchronization) and preferences with trust and compassion

c) Engaged and compassionate care (priming) - involved in care, act as proxy and support care decisions according to the Self (as discovered in the individual ring and in the process of doing (c) and (d)) when 'individual ring' is shrunk to the minimal.

Societal Ring (S-Ring)

- **Societal Ring** of Personhood consists of two elements:

1) people who are relevant to but not considered as part of the relational ring of the older adults

2) norms, roles, expectations, rules and guidelines which exist outside the person while residing in the societal, professional or institutional culture

For examples:

- the care tenor - environment, resources and culture in the RCHEs
- the roles of care practitioners, rules and guidelines for practices in the RCHEs
- the social-medical interface care as adjusted to accommodate the changing personhood of the older adult in the process of dying

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 care-giver'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

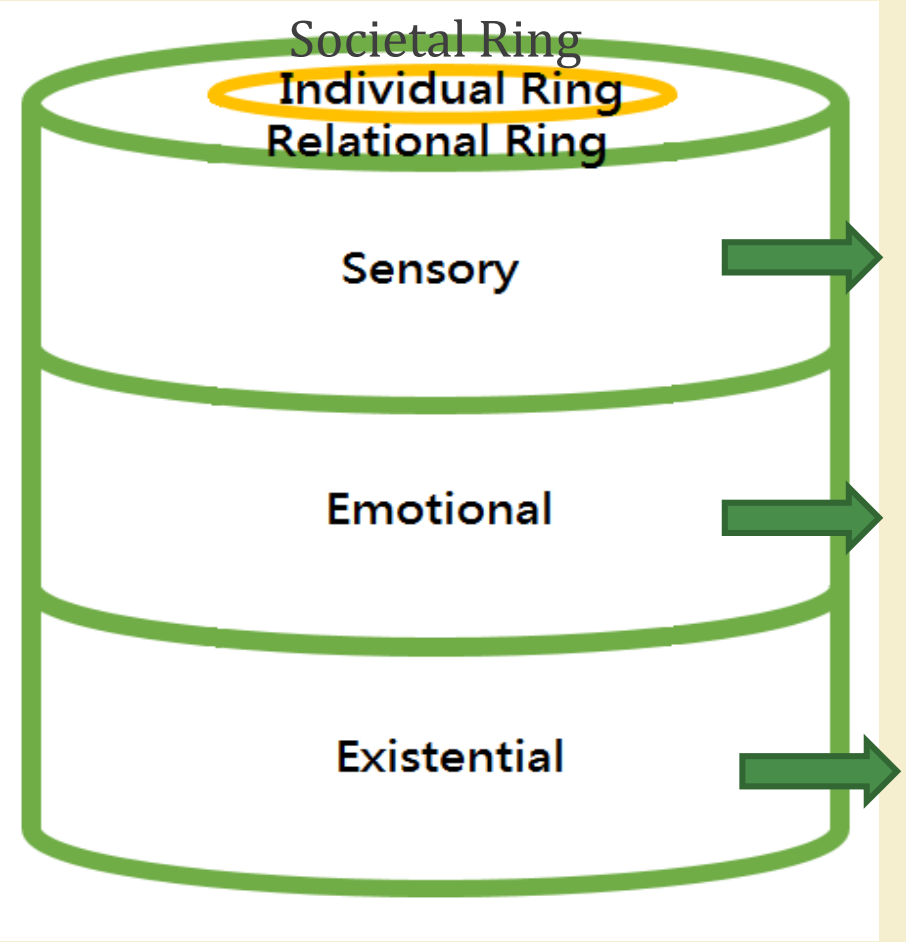
- What - Hearing function deteriorating while vision and taste remained
- How – Providing favourite food; Facilitating non-verbal communication; Hobby - Watching movie
- Challenges – Communication gap between resident and family before intervention; Swallowing difficulty
- Outcome – Increased social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



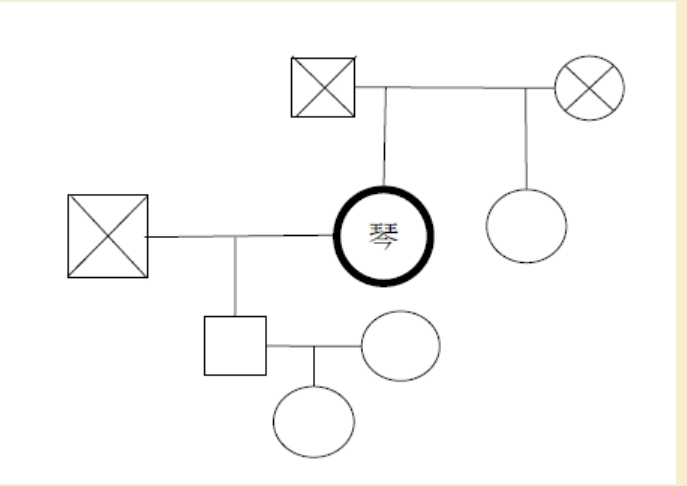
• Before	• Intervention	• After
Deteriorating Functioning	**Social activities e.g. garden tour**	Increased family care capacity and involvement (Relational); Staff's new means of communication (Societal)
Negative Emotion: Sadness, self-blame, uselessness	**Individual Counseling**	Self-realization (Individual); expression to family and health care professionals (Relational)
Self-identity: ambiguous	**Life Review**	Construction of religious self; Acceptance to death and dying (Individual)


?
WILL RETURN
A
!

Assessment
Case study

個案

- 琴婆婆　91 歲
- 精神良好，但行動不便，需坐輪椅。
- 診斷病症：高血壓，慢性腎病，慢性心衰竭，左胸有腫瘤(懷疑是惡性)
- 入住院舍一年後常常因肺積水而入醫院。她指每次入院都會經歷在急症室裡漫長的等待，亦會住院兩、三個星期，更試過出院數天便再度入院，其實自己都不希望經常進出醫院，只是怪自己的身體不爭氣。後加入安老院舍完善人生關顧計畫。
- 婆婆後生時常到加拿大探親。喜歡的食物包括魚翅、蛇羹、香蕉和榴蓮等。也喜歡看電影，尤其是舊的西片。
- 以前曾與妹妹一同在中環居住，在娛樂戲院及皇后戲院附近，每星期會到樓下飲茶。因身體轉差而入住院舍後，妹妹亦有經常探望。
- 平日在院舍時，婆婆會參加崇拜；也會讀經、祈禱，藉信仰得到平安。



- 家庭方面，婆婆的丈夫早年已去世。有一兒子、媳婦、孫女。兒子因為工作忙碌，工作時間亦不穩定，但堅持盡量每星期到院舍探望媽媽，不過媽媽需要坐輪椅後，就較難帶媽媽外出飲茶。其他親人都已過身或不在港。

	I	R	S
S	IS	RS	SS
E	IEm	REm	SEm
E	IEx	REx	SEx

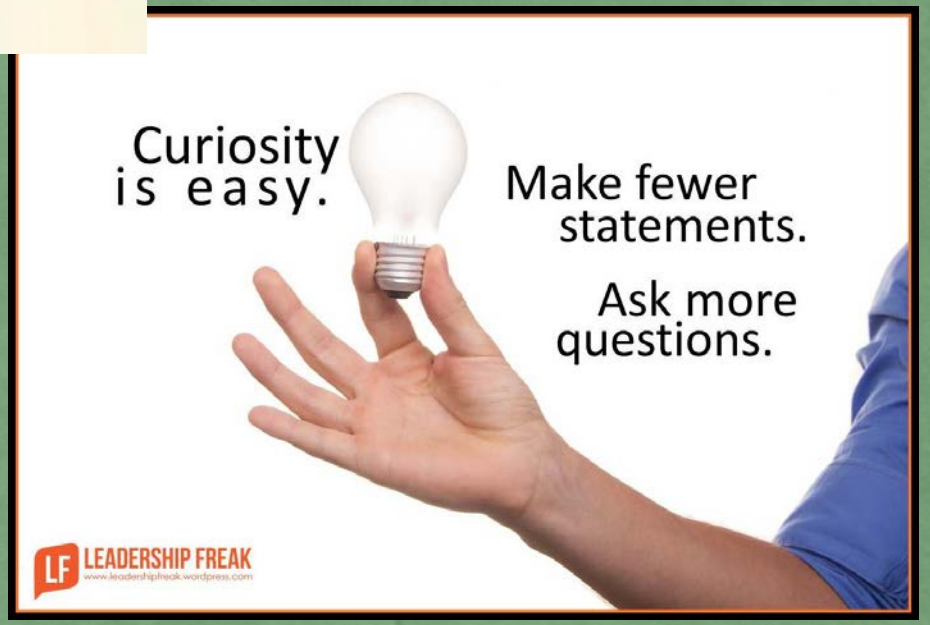

Tea Time Talks

Intervention Strategies

for Psychosocial ACP

~~Impossible~~

I'm possible



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 a strong familial culture

3. **ACP meetings: Enabling the family, the proxy and the care institution** to understand and perform the care preferred by they dying older adults

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**

Research Team

Sui-Ting Kong
Christine M.S. Fang
Vivian W.Q. Lou
Shirley Leung
Bobby H.K. Chan
Katherine K.P. Lau
T.T. Wong
Y.M. Yeung

References

Fang, M. S., Lou, V. W. Q., & Kong, S. T. (2015). *Four Medical-Social Shared Care Models Providing End-of-Life Care in Residential Care Homes.* Hong Kong: Salvation Army.

Ho, A., Chan, C., Leung, P., Chochinov, H., Neimeyer, R., Pang, S. and Tse, D. (2013). Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and Ageing*, 42(4), pp.455-461.

Holroyd, E. (2003). Hong Kong Chinese Family Caregiving: Cultural Categories of Bodily Order and the Location of Self. *Qualitative Health Research*, 13(2), pp.158-170.

Kong, S., Fang, C. and Lou, V. (2016). Solving the "Personhood Jigsaw Puzzle" in Residential Care Homes for the Elderly in the Hong Kong Chinese Context. *Qualitative Health Research*, 27(3), pp.421-433.

Kong, S., Fang, C. and Lou, V. (2017). Organizational capacities for 'residential care homes for the elderly' to provide culturally appropriate end-of-life care for Chinese elders and their families. *Journal of Aging Studies*, 40, pp.1-7.

Lou, V. (2015). *Spiritual Well-Being of Chinese Older Adults*. Berlin, Heidelberg: Springer Berlin Heidelberg.

Thank You Very Much!

香港大學秀圃老年研究中心
Sau Po Centre on Ageing
The University of Hong Kong

2/F, The Hong Kong Jockey Club Building for Interdisciplinary Research,
5 Sassoon Road, Pokfulam

Tel : (852) 2831 5210
Fax : (852) 2540 1244
Email : ageing@hku.hk
Website : ageing.hku.hk

Designed by Dr. Andy Ho (Honorary Research Fellow)

Oct2016