Solving the 'Personhood Jigsaw Puzzle' in Residential Care Homes for the Elderly in the Hong Kong Chinese Context

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Abstract
End-of-life care studies on the nature of personhood are bourgeoning; however, the practices utilized for achieving personhood in end-of-life care, particularly in a cultural context in which interdependent being and collectivism prevail, remain under-explored. This study seeks to examine and conceptualize good practices for achieving the personhood of the dying elderly in residential care homes in a Chinese context. Twelve interviews were conducted with both medical and social care practitioners in four care homes to collect narratives of practitioners' practices. Those narratives were utilized to develop an 'end-of-life case graph'. Constant comparative analysis led to an understanding of the practice processes, giving rise to a process model of 'solving the personhood jigsaw puzzle' that includes 'understanding the person-in-relationship and person-in-time', 'identifying the personhood-inhibiting experiences', and 'enabling personalized care for enhanced psychosocial outcomes'. Findings show how the 'relational personhood' of the elderly can be maintained when physical deterioration and even death are inevitable.

Key words: End-of-Life care, Dignity, Personhood, Residential Care Homes

Introduction

Conserving human dignity is recognized as the bedrock of all human services and shared as the fundamental value of end-of-life (EoL) care in both local and overseas practices (Chochinov, 2002; Ho, Chan, & Leung, 2014; Fang, Lou & Kong, 2015; Lothian & Philp, 2001). This established focus on honouring dignity as a component of basic human rights is also considered to be a response to well-identified sufferings experienced by the aged in Hong Kong (Ho et al., 2013; Lee, 1999; Lou & Ng, 2012). Loneliness, alienation, lack of privacy and a dwindling sense of autonomy are experienced by the physically deteriorating elderly and can be exacerbated in the context of institutional care, which is primarily designed for communal living (Lee, 1999).

To achieve the dignity of the imminently dying elderly in residential care homes for the elderly (RCHEs), some scholars have attempted to employ Chochinov's dignity-conserving model to examine specialized EoL care practices to reduce physical and psychological distress, enhance the personal dignity-conserving repertoire and maintain necessary social/environmental/care conditions to develop a sense of respect and a modicum of psychological relief (Ho et al., 2014). Despite the demonstrated positive results of the well-being of both RCHE residents and their families, Chochinov's Dignity Model was nevertheless observed to be too individualistic and culturally inadequate to examine dignity in the Hong Kong Chinese context where interdependent self and familial connectedness prevail (Ho et al., 2013; Lou, 2015). This echoes Leininger's (1995) call for culturally congruent care in promoting health or wellbeing of people in face of unfavourable human conditions, illness or death. This culturally sensitive approach is nursing further demonstrates its relevance in promoting the psychosocial health and 'social dignity' of the dying residents in RCHEs.

Chinese people are found to emphasize more on interpersonal connection and social hierarchy so as to achieve an interdependent self, and to endure their pain in relation to their connection with destiny, moral transcendence and the nature (Ho et al., 2013; Chen et al., 2008; Cross, Gore, & Morris, 2003; Holroyd, 2003). Ho et al. (2013) discovered that, for Chinese elders, 'legacy' means passing on their moral systems of the previous generations to the next generations, and to maintain their connectedness with their grandchildren. Pain is argued to be endured in Taoist, Buddhist and Confucian terms (Chen et al., 2008) that pain endurance can transcend one's morality and to pass the tests in one's life (天命 *t'ien min*, destiny). The socio-cultural peculiarities of Chinese elders mark the urge for developing EoL care practices to

reduce discomfort and pain, as well as to promote the wholeness of the being as appropriate for their culture.

Reformulating the individualistic concept of dignity, as we argue, requires a conceptualization of the process by which dignity is achieved in the Chinese collectivist/familial culture. This study therefore attempts to fill this knowledge gap by capturing how 'dignity' is achieved by filial or interpersonal relationships in EoL care. Data collection was conducted in one of the few EoL projects in Hong Kong's RCHEs, seeking to examine good practices that rebalance the medical focus of EoL care in Hong Kong with enhanced and integrated psychosocial care. Findings suggest the importance of sustaining 'relational personhood', as opposed to the 'individualistic personhood' upheld by Chochinov. We contend that without attending to relational personhood in cultures in which collectivism and familialism prevail, the choices and autonomy that denote dignity would simply be buzz words.

Background: The Transforming EoL Care Landscape in Hong Kong

Developing culturally sensitive, dignity-conserving EoL care strategies has never been so timely in Hong Kong because the hospital-based EoL provision is currently being extended to the community and residential care homes for the elderly (RCHEs). This transformation inevitably challenges the traditional medically inclined palliative care and requires greater social and cultural sensitivity to enable 'good death' to occur. The latest developing EoL care services in Hong Kong are more psychosocially aware because more natural relationships of the dying are engaged in caregiving practices, particularly in RCHEs and the community.

A panorama of palliative care services in Hong Kong

Palliative care in Hong Kong was first provided by nuns in the Catholic Church, nurses, and doctors in individual hospitals. At that time, the only existing independent hospice was Bradbury Hospice (Yeung, 2013). During this stage of development, EoL care was provided according to individual uncoordinated initiatives. The first transformation in EoL care development occurred in the 1990s, when EoL care became more institutionalized: the medical system began assigning hospice beds in hospital oncology wards and establishing more palliative care units in hospital settings (Ho et al., 2014). The strong historical link between local EoL care and the medical system shapes the former into a more medically inclined approach.

The second transformation arose from the growth of patient self-help groups,

voluntary organizations and charities for cancer patients, also in the 1990s. The medically inclined approach to EoL care gradually became more psychosocially aware because of the voices of users and volunteers (Chan & Fielding, 1999). This influence is also evident in the increasingly prominent topics on psychosocial EoL care on the major knowledge exchange platform for Hong Kong palliative care, the Hong Kong International Cancer Congress. Currently, a wide range of challenges to advancing psychosocial care, such as the new trends in palliative social work (2010); collaboration with users (2011); a cross-disciplinary alliance (2012); holistic care, innovative research and community exploration (2013); and the arts of palliative social work, researched practices and a vision into the future (2014) were covered in recent congresses.

The third major transformation observed in palliative care in Hong Kong concerns changing from an exclusively hospital-based mode of delivery to a more community-based mode that also serves the imminently dying elderly in RCHEs. To date, four EoL care programmes have been organized by the Community Geriatric Assessment Teams (CGATs) in different hospital clusters to provide outreach medical support to RCHEs for pain and symptom control for imminently dying residents (Chu, 2014; Hui, Lai, Au, & Leung, 2014). These teams also provide dying residents in RCHEs a new hospital admission pathway, clinical admission, which allows bypassing the admission to A&E and acute wards for specialized medical treatments.

The non-hospital based service responses

Despite the lack of an overall regional strategy in guiding Hong Kong's EoL care, a handful of EoL care projects have been conducted in Hong Kong RCHEs. These projects differ significantly from the medically inclined model but facilitate more holistic personhood-centred EoL care in Hong Kong.

Our research partner is one of the few projects that seek to provide holistic end-of-life (EoL) care to the dying elderly in RCHEs. The project aims at empowering RCHEs in Hong Kong, in terms of environment, equipment, training and cross-system partnership, to provide quality EoL care for the dying residents and their families. As the project began its second phase, the project agency commissioned the research team to conduct an analytical study of 'the four medical-social partnerships providing EoL care in RCHEs', in order to look at how dignity of the residents had been achieved in different (cross-)organizational contexts, at both the structural and the practice levels. Findings presented in this paper are the practice component of this study and with a strong focus on good practices that honour 'social dignity' by achieving 'relational personhood' in EoL care.

Methodology

Cooperative Grounded Inquiry (CGI) (Kong, 2015) proposes a careful combination of constant comparative analysis of Grounded Theory Methodology with Cooperative Inquiry which presumes the intersubjective being of the researcher and the participants and the significance of different forms of knowing, including experiential, practical, presentational and propositional forms in problem solving (Heron, 1996; Heron & Reason, 1997). Guided by CGI, researchers of this study facilitated the reflection-action-reflection cycles by creating space to collaboratively develop practical and experiential knowledge in EoL care into practice-near presentational and propositional knowledge in aid of on-site constant comparative analysis. In-depth interviews are therefore not merely tools for research but also the space for articulation and construction of understanding regarding practitioners' practice experiences. This space is critical for giving the disorganized experiences meaning and sustaining the reflection-action-reflection cycles (Kirkman, 2002; Kong, 2015).

To facilitate the co-construction of meaning with the participating practitioners, an 'EoL case graph' was utilized to facilitate the development of a 'plot' during the interview. Kirkman (2002) argued that a plot is a 'narrative device that confers order, sequence, and meaning on a collection of otherwise isolated events' (p. 33). Using this technique, the researcher explored with the practitioners their practices at different time points, within and across systems, and with different professionals and stakeholders (Goldsmith, Wittenberg-Lyles, Rodriguez, & Sanchez-Reilly, 2010). The 'EoL case graph' also helps visualize the practice experiences for scaffolding the construction of the meanings of 'dignity' as experienced and understood by participating practitioners from their particular social vantage points. Interviews are open-ended but 'oriented to sequences of interconnected activities' conducted with 'people located throughout [the] institutional complexes in order to learn "how things work"' (DeVault & McCoy, 2003:375). However, this approach possibly restricts participants to narrate along the linearity of time and with a focus on their professional role instead of personal engagement/life stories in performing their practices.

The 'EoL case graph', as shown in Fig. 1a and 1b, is not intended to suggest a generalizable dying trajectory, but is an example of how a graph can help explore the three key features of a plot of the practice experiences. First, a time dimension enables a thorough exploration of best practices across disciplines, focusing on how social dignity may be achieved throughout the process, from service admission to post-mortem care. Second, the vertical dimension of physical conditions (illness development and clinical symptoms) offers a reference on how the changing

conditions seriously affect the development of a personalized care plan and its implementation. Third, because the interviewed informants were formal service providers, the researcher was quite mindful to ask probing questions regarding how the dying residents and their families were engaged in the entire process of delivering EoL care. The role and participation of both residents and their families can be visualized in an 'EoL case graph'.

Fig. 1a An example of 'EoL case graph' constructed with the practitioner (original)

Fig. 1b An example of 'EoL case graph' constructed with the practitioner (Re-constructed and simplified from Fig. 1a)

Before admission, Mr Luk had been living in the RCHE for 2-3 years...(life story of Mr Luk)

Physical Conditions

a. Physical drop was observed

b. Psycho-social care

c. First hospitalization and the handling of physical fluctuations

New Proxy: due to disagreement on legacy handling

Proxy empowerment

d. Spiritual, psychosocial and family support rendered across the care home and hospital settings

ACP meeting organized by the EoL team (with details of attendees and content...)

Timeline

Fever

Hospital admission

Admission to the acute ward

Family meeting with the EoL team, the family and the RCHE social worker

CGAT (Community geriatric assessment team from the district hospital) prescribed medication

Final hospital admission (clinical admission bypassing A&E)

a. Psychological and spiritual care: e.g. aligning with the church for weekend church mass arrangements, details of the EoL care plan and delivery

b. Assisting the new proxy to plan and implement the plan for attending weekend mass, learning about the life hisotry of Mr. Luk (former general in the army) and the food he liked

c. Experiences of the first hospitalization were captured in detail, in terms of the practitioners' practies and interactions with different professionals, the family and the residents

d. Details of the rendering of spiritual support (anointing of the sick, praying and blessing), planning for family gathering, bringing the resient his favourite food (herbal jelly) to the hospital ward
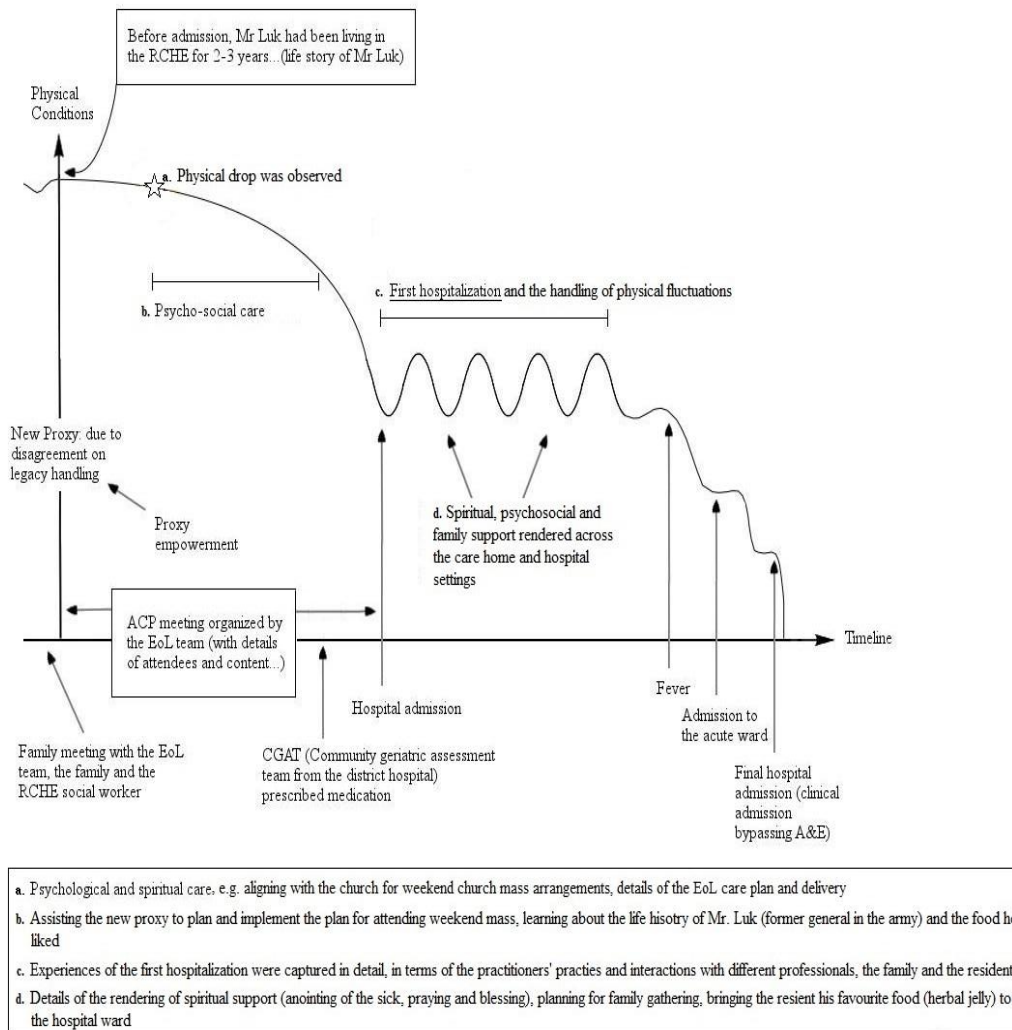
Fig. 1b An example of 'EoL case graph' constructed with the practitioner (Re-constructed and simplified from Fig. 1a)

The research team is also aware of the social positions of each research member and how those positions might affect the dialogical space intended in the interviews. The researcher who was deemed the least likely to suggest academic superiority and create pressure on the interviewees to continue the interviews (a junior academic who is specialized and experienced in conducting participatory action research), was assigned to solicit consent and conduct the interviews. Equal partnership in making sense of the practice experiences is facilitated by inviting feedback and comments from the practitioners in the final analysis.

Data collection and analysis

In this study, 12 interviews were conducted with 10 EoL care practitioners (Table 1),

including a project coordinator, EoL team social workers, residential home nurses and social workers. The interviewees were representatives of the EoL project and the participating RCHEs with various partnerships with the hospital setting. We purposively sampled both nursing and social work practitioners who have been participating in the EoL care project, from the four representative partnerships with the hospital settings, to participate in this study. This sample offers maximum variations of context regarding where EoL care is delivered. The duration of the interviews ranged from 1 to 3 hours.

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

Table 1. Demographics of Research Participants

All interviews but one (because of a technical problem) were tape-recorded and transcribed. An interview summary was prepared for the unrecorded interview and triangulated by the interviewee until no further amendment was necessary. In addition to the interviews, the researcher collected official materials from the EoL care project as well as documents from the individual residential care homes. These documents included assessment and intervention protocols, practice guidelines and work flow, documentation of emerging practices, memoranda of EoL cases and personalized EoL care guidelines for specific home staff. The documents collected are all anonymized with pseudonyms and obtained with the interviewees consent.

Data analysis of this study follows the logic of emergence; the study borrows the technique of constant comparative analysis from Ground Theory Methodology to facilitate co-construction of the meaning of lived experiences with research participants by sustaining a collaborative partnership (Kong, 2015). Immediate conceptualization of lived experiences was conducted during the interviews and rendered available in writing/drawing for comments and further articulation by the research participants. Practitioner participants were also encouraged to provide feedback on the researcher's understanding of their experiences and the EoL care practices conducted in their care homes, within and beyond the interviews. This technique maintains dialogical space for both the researchers and the practitioners to identify the best EoL care practices in Hong Kong RCHEs.

Ethical approval was obtained from the Ethics Review Committee of the University of Hong Kong before the commencement of this study. Signed consent was also obtained from all participants before the interviews. Research participants could withdraw from the research at any time by terminating the interview or withdrawing their interview data. No personal data were collected, and anonymity was ensured throughout the research process.

Findings

'Solving the personhood jigsaw puzzle' is a cyclical process conceptualized in this study to illustrate the social-structural processes involved in identifying, constructing and sustaining the 'social dignity' of the dying elderly by achieving 'relational personhood' in Hong Kong RCHEs. This process comprises three interacting social-structural processes that constantly inform one another to solve the 'personhood jigsaw puzzle'. These social-structural processes are (1) identifying personhood-inhibiting experiences: how practitioners identify processes in which the elderly experience a loss of self by ageing in institutional care; (2) understanding the person-in-

relationships and the person-in-time: how an understanding of the elderly's sense of self can be captured by extended assessments; and (3) enabling personalized care for enhanced psychosocial outcomes: how to balance the current medically inclined care with enhanced psychosocial outcomes in institutional care settings.
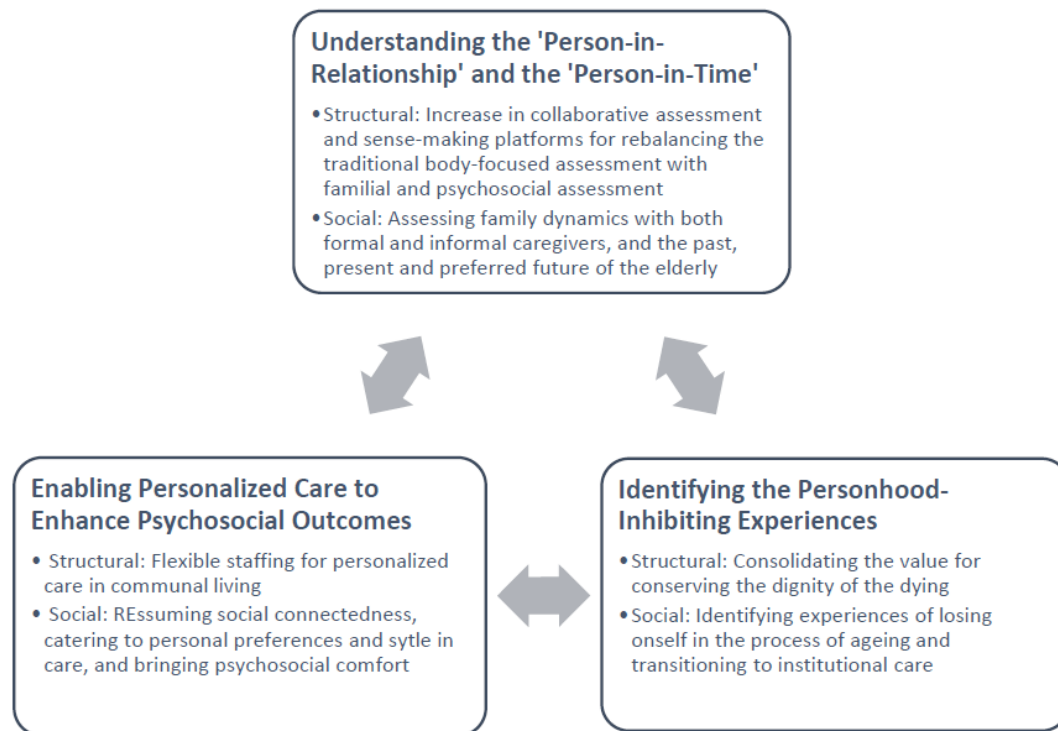

Fig. 2 A cyclical process model of 'solving the personhood jigsaw puzzle'

The repeated use of the terms 'the person' (嗰個人), 'personalized' and 'humane' care (個人化/人性化服務) by the interviewed practitioners in describing their unusual EoL care practices in RCHEs reveals their practices for achieving personhood for the elderly.

Identifying personhood-inhibiting experiences: A critical reflection on ageing in institutional care

Institutional care in Hong Kong is largely designed for 'collective living' in which residents' personal care preferences are not the priority. In this regard, the EoL care project, which sought to honour personal choices and individual characteristics within the limited space of current residential care homes, was perceived to be introducing unusual care practices to institutional care settings. By attitude and skills training in conducting personalized care, the project helped the home care practitioners consolidate the core values of respecting human worth and personal characteristics despite ageing and the multi-comorbidities or even death that ageing may bring.

Structural changes in terms of organizational value, care protocol and manpower arrangement for personalized care sensitized the practitioners to the suffering experienced by the dying elderly in institutional care. These experiences were then conceptualized as 'experiences of losing oneself' because all the experiences indicate a damaged image of self, including *'stripping of personal qualities', 'uprooting', 'proceduralizing care'* and *'marginalizing residents' voices and choices'*.

Stripping of personal qualities ('I am no longer the same person as I was' 今時唔同往日喇) is associated with the reduced physical functioning (mental fitness, speech, touch and temperature, smell, hearing, taste and vision), mobility and communicability of the elderly because these functions limit the feasibility of one's social life and the realization of personal preferences in living. Personal qualities that are realized and recognized by bodily performance, i.e., eating, knitting, shopping, singing, exercising and churchgoing, may also be undermined in the process of physical deterioration.

> *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 how long he can participate in the mass at the church'. This gives the social care practitioners an idea of how to arrange Mr Luk's visit to the church in the community' (from field notes, 15 July 2015).*

Uprooting. The majority of the residents' lives are spent outside of residential homes. When the elderly are placed in institutional care, they are uprooted from the natural habitats in which their abilities, achievements, personal qualities and life practices are appreciated.

> *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).*

Although uprooting does not necessarily translate into a poor quality of life, uprooting creates a condition in which significant social relationships, preferable self-perception and self-expression may be disrupted.

Proceduralizing. As mentioned previously, residential care settings in Hong Kong are designed to accommodate collective living in which standardized care procedures and routines are established for more efficient care coordination within the care homes

and across systems. For example, 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.

However, when procedures become routines that inhibit the elderly from being themselves and instead are simply one of the many, those procedures curb the goal of honouring humanity. This realization drove care practitioners to 'give a pause, and give a thought' (停一停，諗一諗) to how personal choices and preferences could be incorporated into communal care for aged residents, particularly when death is approaching.

> A colleague asked me how to shower our resident. I told her to wash the resident the way you wash yourself. She asked me about the procedures, you know? What are the procedures you think you need? Do you want to dry your body after a shower? Would you put on your clothes before drying yourself? No! Right? That's it!' (Ms Si).

Marginalizing. The residents' personal perceptions of illness and attitudes towards care can easily slip away in the current medically focused and professionally led care in residential care home settings. Long-term submission to professional decisions can lead to a sense of helplessness and loneliness in the residents. These feelings can also develop into frustration in family members, who can be similarly marginalized.

> 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).

The tension and mistrust that develop between the residents/families and the care professionals in residential care homes may result in further anger, grievances and resistance to care advice. These feelings negatively affect the quality of life and quality of care of the dying residents.

Understanding the person-in-relationships and person-in -time

The dying elderly's sufferings identified by the care practitioners reveal the relational and temporal dimensions of 'self', substantiating the need to expand the conventional comprehensive geriatric assessment to include an assessment of the (1)

appropriateness and the care capacity of the proxy, (2) the care dynamics of the family and the family's dynamics with the care home, and the (3) residents' history. These additional assessments can be further conceptualized as assessing the 'person-in-relationships' (proxy, family and friends) and 'person-in-time' (past, present and future).

Structural changes in assessment protocol and communication systems such as newly timetabled palliative care conferences and family meetings enabled a holistic understanding of the residents and their needs, allowed for on-going data collection from practitioners at all levels, and created a collaborative understanding of the residents' 'preferred self' and family participation in the care that was possible in RCHEs.

Assessing the person-in-relationships

Appropriateness and the care capacity of the proxy. Our findings indicated that identification and assessment of the proxy were conducted before admitting the elderly to the EoL project. These practices serve, first of all, to ensure the point of contact when critical care decisions, such as signing an Advance Directive (AD) and Do Not Apply Cardiopulmonary Resuscitation (DNACPR) order, must be made on behalf of the resident. Second, this process assesses the relationship between the resident and the proxy, particularly with regard to the extent to which the resident finds the proxy an appropriate person to honour the resident's choices of care and handling of the resident's legacy.

> *Mr Luk always donated money to the Catholic Church. However, this wealth-handling practice was not supported by his niece [YS2]. YS2 persuaded Mr Luk to keep the money for himself instead of donating it all to others. The difference between YS2 and Mr Luk in handling wealth turned out to be unresolvable. Alternately, another niece of Mr Luk, YS1, supported his donating his wealth and later became his proxy (from field notes, 15 July 2015).*

To translate good will into practice, the care capacity of the proxy and the family is equally important. This capacity is defined as the proxy and the family's attitude, knowledge/skills, readiness for the resident's death, availability and social support. Attitude is the commitment to honour the choice of the resident and honour the resident's worth despite physical deterioration; knowledge and skills are the ability to cope with emerging care needs such as feeding a resident who is a choking risk and

responding to signs of pain or discomfort when the resident is no longer alert; readiness for irreversible downturn and nearing death signals the extent to which the family can handle separation; availability to care for the resident is perceived as the caregiver's emotional and physical health as well as an abundance of time for care; finally, the social support of the proxy at difficult times is also considered, to assist the practitioners in formulating a care plan that can be feasibly implemented with/by the proxy and the family.

The care dynamics of the family and the care home are assessed in terms of the residents' relationship distance, the presence of conflicts and tensions, and attitudes and communication quality with their families and the formal care practitioners. These dynamics do not only affect the care rendered to the residents but also how the residents define themselves and the extent to which their preferred selves may be expressed.

> *After giving birth to the children, she completely focused on them. She therefore is very concerned that caring for her would become a burden to others. For example, she once said that her son would go to visit her when she was sick, whereas she couldn't do that to her son when he was sick. She doesn't want to overload her son… She loves this family a lot… Similarly, her children and children-in-law all love her, and they always visit her [at the residential care home] (Mr Yan).*

Loving, caring and respectful attitudes of the proxy and the families are positive factors contributing to the opportunity for self-expression and the improvement of the psychosocial health of the residents. Conversely, disagreements and conflicts among family members may curb the 'synchronization of care choices', which is considered optimal for critical life and death decision-making. However, synchronization of care choices cannot be forced because synchronization may reflect the underlying value clashes between various family members and the values of EoL care. For example, for some family members, ending intrusive treatments when the illness is irreversible remains understood as abandoning the effort to save the life of their loved one.

> *Mr Yan   The AD (advance directive) did not include the exemption for the feeding tube…because we hadn't confirmed it back then…but the orange label [record for EoL case in the hospital] [has this item checked].*
> *We then talked to the families and asked them to synchronize the two medical records, like renewing the AD we did before.*
> *Interviewer   Sure…*

> *Mr Yan*   *So the family had a meeting, but was worried about the disagreements among the family members over the same decision. As the family members could not agree on the decision, we just put it on hold, as agreed to by the proxy.*

Assessing the person-in-time

Practitioners' practices demonstrated that knowing the person had to be extended from 'here-and-now' to one's history and preferred future. History and preferred future shaped the behaviours and practices of the residents in the present and gave the 'here-and-now' sense of self a character. Assessing the (social-relational) person-in-time was observed to help construct a parallel understanding regarding the person as opposed to the illness trajectory supported by biomedicine.

> *I mean there were loads of photos taken on the beach… She was in a swimming suit in the photos… Back in those years, she was really fashionable and trendy. She was with a group of classmates, and they were all guys in swimming pants [laughing]. So…we understood that she had had a beautiful life in the past. However, the moment she is living [now] is drastically different from that history. Indeed she has a lot of needs now…but looking back in time, she knows she has lived [her life] well. She has done all she wants… Meanwhile, we need to know how far she can appreciate herself in this reviewing process' (Mr Yan).*

Knowing the history of the person is the primary manner in which to achieve a sense of achievement and pride. Unlike the superficial appreciation that derives from immediate observation and momentary displays of strength, having a previously developed sense of achievement and pride in oneself requires reviewing one's history to construct a self-understanding that captures a more persistent display of preferable personal qualities, as perceived and recognized by oneself and one's significant others.

> *They stayed inside [the palliative care room] and sang their mum some children's rhymes. They used their iPads to Skype their family members from overseas…Those who couldn't make it to see their mum the last time… After all, we eventually recognized that the rhymes they sang were actually those their mum taught them when they were kids… They did the last performance for their mum… At the moment, those adults in their fifties and sixties all turned back to their childhood (Ms Lam).*

Exploring the history of the dying residents with their families enabled care practitioners to understand the care and funeral choices of the residents and to draw support from the families in realizing those choices. For example, Mr. Luk wished to be cremated and his ashes scattered in the sea, which the family and the care practitioners perceived as a way for Mr. Luk to enjoy the freedom he once lost because of his history of 'political imprisonment'. Reverse investigation is also conducted when EoL care practitioners explore the physical, emotional, social and spiritual aspects of the person and delve into the residents' personal preferences and styles; this process allows care practitioners to investigate the resident's history and, ideally, create a space for the integration of the past, the present and the future.

Enabling personalized care to enhance psychosocial outcomes

By examining the sufferings of the dying elderly in RCHEs and how their concept of 'self' was constructed in time and in relationships, corresponding care strategies were devised to mitigate their suffering. The ultimate goals are to sustain the preferred sense of self of the dying elderly and bring psychological comfort by enabling personalized care in RCHEs. These strategies were documented and conceptualized into three categories: (1) resuming social connectedness, (2) expression of the self and (3) bringing psychological comfort. 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.

Resuming social connectedness. Dwindling physical functioning and communicability because of ageing and the development of illness can render the dying elderly more vulnerable to social isolation. This situation becomes exacerbated when the staffing in RCHEs is thin and interactions with the uncommunicative aged residents are difficult and time-consuming. However, instead of defining a person by body functioning, the expanded geriatric assessment enables practitioners to see the dying residents as persons. Despite the patients' minimal ability to communicate, practitioners continued to talk to and gently touch the dying residents and observed residents' minute physical/facial expressions and responses. This process helps convey their concern and care towards the possibly unconscious, bed-ridden and uncommunicative elderly.

> *For example, when I went into the room to see Ann [unable to communicate because of dementia and bedridden], she would make some… hmmm… groaning noises …I meant you can feel that she wasn't feeling very comfortable… At that moment she wasn't at peace. Yeah… I am used to talking to her and saying like 'Hi Ann, this is Ms Kung…'… Now I pass by her*

room every day and still go in to say hi to Ann (Ms Kung).

Families were helped to become involved in attending to, observing and responding to the residents' small expressions. Families would also talk to the verbally non-communicative elderly and initiate new care practices according to the elderly's residual sensory or mental functioning, i.e., massaging (touch), manual feeding/sweet treats (taste), playing a DVD of their beloved Chinese opera (sight/hearing) and making care decisions (alertness). For those who were admitted as elderly singletons, the care practitioners would arrange volunteers' visits to ensure there would be someone talking to the elderly when the end of life was approaching. For example, a care practitioner arranged regular volunteer visits for an aged singleton who enjoyed sunbathing outside the residential home.

Facilitating self-expression through nurturing, supportive relationships. Feeling loved and cared for and being listened to are all important in honouring the innate value of human beings. However, these can be sustainable only when the people surrounding the residents are prepared to enable the residents' self-expression through 'food', 'music', 'lifestyle' (i.e., colours, fashion and decoration) and 'body performance' (i.e., knitting, outings, sunbathing and hand-shaking).

> *She did sing the song 'Let's Get Drunk Today'… Then, we planned to do a life review with her, and we used the song as the background of her life video. It's like a theme song for her… and we played the video with the song [in the family meeting]… I found out about [the song] in a palliative care doctor visit… As I passed by, she just sang, 'I am just aged 18, still fresh and crunchy [卜卜脆, a metaphor of youthfulness]'… Then, I searched for the lyrics online and found out that song is called 'Let's Get Drunk Today', which matches her life perfectly (Mr Yan).*

In this study, we have observed that self-expression was rendered possible by organizational/structural changes that allow a flexible design for the personalized care environment, manpower redistribution for personalized intensive care in EoL cases, and improvised cross-professional care planning systems for balancing life preferences and quality of care.

> *Because Ms Sau's eating ability is decreasing… normally the care home offers limited time for feeding. The question is whether we would like to increase the care rendered to her? You know we can arrange for an agent nurse when the case is transferred to the palliative care room [in the RCHE], so that Ms Sau can have someone feeding her one on one. Given this extra*

manpower in feeding, she ate much better... but that needs a lot of effort (Ms Lam).

Personalized care also requires changes in terms of the quality of relationships (both formal and informal) that help substantiate 'autonomy', which contributes to the residents' sense of self.

> *I mean, people surrounding her are the priority. She doesn't want to be a burden to others. So...the (psychological) intervention should not be advocating for the ultimate power of her 'individual' choice, but talking to her to know her concerns...[which] are actually 'relational autonomy' that means it's about not just what she wants but also other things around her...[so the question is] what would I [the resident] do given such a situation? (Mr Yan).*

Given this new orientation in understanding the self and the expression of the self, the social care practitioners committed a huge portion of time to addressing the relationships surrounding the dying residents and attempted to carve out a space for the family members to understand the residents' views and to consider their own. Residents' preferred medical care options at the end of life, such as cardiopulmonary resuscitation and the use of a feeding tube, were more likely to be observed and honoured when those choices were also endorsed by family members.

Bringing psychological comfort. In all, 'pride/sense of achievement', 'departure without regret', 'peace of mind and existential security' and 'hope' were achieved with extra attention to the dying elderly's suffering, relationships and histories.

a. Pride and a sense of achievement were engendered by practitioners and families who were ready to listen to the residents' stories, from which they extracted the residents' achievements from a wealth of lived experiences, i.e., being the first few policewomen in Hong Kong, being able to choose one's own husband and being a general in the army.

b. Departure without regret was achieved by fulfilling the last wishes of the dying elderly as well as reconciling/reconnecting with their loved ones, i.e., visiting the grave of a friend for the last time, receiving a diamond ring once in one's life, being less of a burden on others and not being isolated by practitioners and family members in care decision-making.

c. Peace of mind and existential security were supported by pain and symptom control as well as by fulfilling one's spiritual needs with the help of religious practitioners. Family gatherings and life review were also useful in helping non-religious residents integrate their lived experiences into a preferred autobiographical narrative.

d. Instilling hope concerns adjusting the expectations of the dying elderly, their developmental tasks, acceptance of ageing and deterioration, and appreciation of life and personal contribution.

> *She has to accept the changes, and the hope will follow. It means that she does not only look at her deterioration, but to have space to hope for [someone to] care about her. She is just transiting from the colourful past to a caring present… She has raised many children, and it is the happy moment [for harvesting] (Mr Yan).*

Discussion

We have conceptualized how personhood can be achieved in RCHEs by both structural and social changes. This is an increasingly significant focus in EoL care study; personhood is emerging as the foundation upon which the imminently dying may achieve dignity (Chochinov, 2002; Chochinov et al., 2014; Hockey, 2008; Krishna, 2014; Nelson, 2000). Achieving dignity in medically led EoL care, as argued, requires shifting the focus from 'patienthood' to 'personhood' (Chochinov, 2014). Personhood is a call for care and caring practices which require tremendous attention to the person's peculiarities, including one's cultural and social structures, i.e. religious/philosophical, kinship and social, political and legal, and cultural and lifestyle factors. This is especially important when curing no longer exists (Leininger, 1996).

Personhood is understood variously in the literature. In some studies, personhood stems from the tradition in which 'consciousness' is considered the pre-requisite of personhood (Nelson, 2000); some other studies emphasize that personal and social relationships are where identities are constituted, the realization of personhood (Ho, 2008; Kabel, 2013; Kitwood & Bredin, 1992). Krishna (2014) constructs a 'ring model' to embrace the different types of personhood, namely innate personhood, individual personhood and relational personhood, and the relations among them. The relational personhood highlighted in Krishna's ring theory resembles the personhood presumed by the EoL care practices examined in this study; findings illuminate culturally sensitive practices for sustaining relational persons in institutional care.

Understanding the person-in-relationships and the person-in-time helps explain the inadequacy of the individualistic concept of self that underpins Chochinov's Dignity Model. Individualistic personhood is formed either independent of or at most, in interaction with significant others. The mutually constitutive relationship between the 'self' and 'important others' prevailing in the Chinese culture in fact hinges on a revision of not merely a list of items (Ho, 2008), but a necessary move to 'relational personhood'. This recognition is important, particularly when life is approaching its end; and sustaining relational personhood assumes a dominant position compared with the individual personhood that relies on cognition and consciousness (Krishna, 2014).

Not surprisingly, RCHEs as a care setting designed for communal living render the realization of personhood particularly challenging. Rather than using the relationships around the dying to enable personalized care, RCHEs tend to standardize care practices for all patients. The proposal of Chochinov et al. (2014) to elicit 'personhood' by focusing on how the person describes him/herself to the care practitioners therefore does not sufficiently explain how 'choices', 'autonomy' and 'freedom of expression', which constitute a sense of self, are enabled by the relationships that surround the 'person'. However, 'social dignity', as purported by this EoL project, clearly indicates a new focus on relational personhood in performing EoL care (Krishna, 2014). This focus aligns with the concept of 'relational self', which perceives the 'self' as sustained by the continuous constitution of an account of lived experiences in relation to significant others (Gergen & Gergen, 2004; Kirkman, 2002).

Solving this personhood jigsaw puzzle is therefore, if not impossible, challenging in residential care settings. Ageing, dwindling physical functioning, increasing bodily fluctuations, life risks and dependency may hinder residents from living their preferable forms of life and connecting with the natural habitats in which their histories and social networks are deeply rooted. The findings of this study indicate that Illness may be perceived to have 'stripped off the personal qualities' of the dying residents because illness severely affects their mobility, communicability, and the feasibility of social activities. Coupled with the medicalization of the ageing and dying, our services are limited to focusing on physical health; we largely marginalize psychosocial health and its effect on both the residents and their families.

Similar to the findings obtained in the study by Lee (1999), transition from home to residential care can engender a plethora of emotional reactions from feeling relieved

to fright and helplessness because of 'the obvious disruption of their previously established daily "routine" and social relationships' (p. 1121). It resembles the findings of studies which examine care home transitions, showing that transitions 'require a person to incorporate new knowledge, to alter behaviour, and therefore to change the definition of self in the new social context' (Davies, 2005: 659). Ellis (2010) also affirmed the importance of building a new narrative of self and personal life for elderly in care home transitions for their psychological health. These studies confirm that re-engaging with the elders' history, achievements, valuable relationships and life wisdom, all of which developed in the presence of the residents' families, friends, colleagues and neighbours, are critical for sustaining the residents' preferable self in RCHEs.

Attention should also be paid to the possible sampling bias caused by the screening process of the project. This project, as a pilot project in nature, targeted residents with strong family support, and the perception of institutionalized care can be affected by such a background; such as upward comparison may be easily observed in these elderly who are well supported by their families and friends outside of residential homes. As sensitized by Lee's (1999) study, elderly singletons could perceive being admitted to residential care homes a great chance to 'have someone to talk to' and mitigate their long-term loneliness.

Findings of this study further challenge the modern discourse of 'life course' that limits the understanding of life and existence within the presence of the body as defined by the bio-medical model. Resources that support the development of social existence when physical death is approaching, as argued by Hockey and Draper (2005), enable people to exist beyond the womb and the tomb. Our study examines EoL care practices such as assessing the person-in-relationship and person-in-time, by which person-specific and self-indicating language/artefacts/things are collected to substantiate the construction of the social existence of the dying. Folk rhymes, photo collections of the past, life review videos, a diamond ring presented by one's children, the religious cross on the wall and the very presence of family members who signify an important stage in the life of the dying are observed to be the linguistic, religious, cultural and material representations of a person's body that 'resource' their existence beyond the normal conception of body. Producing resources for personhood construction through EoL care can also power the post-mortem 're-membering' practices (Carr, 1998); for example, in our study, children sang folk rhymes, (re)discovered in the EoL care programme, at the bedside of their deceased mum.

The EoL care practices conceptualized in this study also echo Kitwood and Bredin's (1992) theory of personhood. Those authors identified the problems associated with the loss of personhood as being in patients' surrounding relationships rather than in the demented elderly themselves. The 'pathology of normality' tends to blame the deteriorating elderly for being unable to talk, act and respond normally and can be amplified by the ideology of extreme individualism prevailing in Western culture. Although our study does not reveal the same extreme judgement of the dependent elderly, the bio-medical discourse on a normal body nevertheless influences how practitioners perceive and interact with the severely demented or bedridden elderly, particularly when those practitioners reflected on their practices before the EoL care programme. The process of 'solving the personhood jigsaw puzzle' therefore empowers both formal and informal caregivers to work collaboratively to assume new caregiving responsibilities, learn techniques to maintain communication with unconscious residents and recollect the social and historical aspects of the residents' lives for holistic care planning.

Conclusions

This study enriches our understanding of how relational personhood can be achieved in RCHEs and provides a (relational) personhood-focused and family-oriented framework for enhancing quality of life and quality of care for the dying elderly in the Hong Kong Chinese context. Practices examined within this framework can also generate resources for developing personhood beyond the conventional understanding of a 'normal body' and 'life course' so that the families may nevertheless have symbolic material for 'connecting with' and 'remembering' their loved ones in the presence of physical deterioration and even death.

The framework developed in this study notes the structural and social changes necessary for the dying elderly in RCHEs to re-assume their sense of self. Cultivating values of respect, care and humanity in the staff of EoL care facilities equips the organizations with the critical competence to identify the suffering of the elderly, particularly with regard to their loss of the sense of self. By identifying the 'personhood-inhibiting experiences', care practitioners also identified barriers to dignified care and the structural and social changes necessary to achieve care with dignity. Assessment of the family, the person-in-relationships and the person-in-time were developed in this project to collect data ignored or marginalized in previous body-focused assessments. An understanding of dying persons as constructed in this extended assessment allows more holistic care planning to enhance psychosocial outcomes.

This study, however, originally aimed at investigating organizational and professional practices, was unable to engage the dying residents and their families directly for their experiences in undergoing this 'relational-personhood' oriented EoL care. The high degree of family involvement in assessing, planning and delivering care for the dying elderly, as revealed in this study hence suggesting further research with the dying residents and their families is needed, in making sense of the relation between Chinese familial culture and EoL care. The involvement of users in EoL care research will definitely enhance our knowledge of the effect of our specific cultural underpinnings on the construction, exercise and evolution of personhood in EoL care (Davies, 2005).

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