

Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong

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Abstract

Background: the empirical Dignity Model has profoundly influenced the provision of palliative care for older terminally ill patients in the West, as it provides practical guidance and intervention strategies for promoting dignity and reducing distress at the end-of-life.

Objective: to examine the concept of ‘living and dying with dignity’ in the Chinese context, and explore the generalisability of the Dignity Model to older terminal patients in Hong Kong.

Methods: using qualitative interviews, the concept of dignity was explored among 16 older Chinese palliative care patients with terminal cancer. Framework analysis with both deductive and inductive methods was employed.

Results: the three major categories of themes of the Dignity Model were broadly supported. However, the subtheme of death anxiety was not supported, while two subthemes of generativity/legacy and resilience/fighting spirit manifested differently in the Chinese context. Furthermore, four new emergent themes have been identified. They include enduring pain, moral transcendence, spiritual surrender and transgenerational unity.

Conclusion: these findings highlight both a cultural and a familial dimension in the construct of dignity, underline the paramount importance of cultural awareness and competence for working with ethnically diverse groups, and call for a culturally sensitive and family oriented approach to palliative care interventions with older Chinese terminal patients.

Keywords: Chinese, elderly, dignity, palliative care, qualitative research, older people

Introduction

Hong Kong is facing a rapidly ageing population and the demand for palliative care among older terminally ill patients has surged over the past decade [1]. This increase in service demand has led to growing concerns over care quality. While the defining principles of palliative care including symptom control and psycho-spiritual support aim to optimise quality of life and promote death with dignity [2], there is little consensus on the underlying construct of dignity and how dignity can be achieved [3]. Such ambiguity ultimately constrains the delivery of dignified care at the end-of-life.

Although a review of conceptual literature on dignity offered a range of definitions including those related to innate human quality, merit, identity, moral structure, self-esteem, self-control, self-worth, pride and respect [4–7]; these definitions lack an empirical foundation to guide clinical practice. In the handful of studies that have examined the concept from a clinical perspective with healthcare workers, dying with dignity was defined as adequate symptoms control, maintaining body integrity, putting one’s affairs in order, involvement of a palliative care team and dying in peace [8–11]. The few studies with older adults and dying patients further reported that dignity translates into privacy and autonomy, integrity and respect,

involvement in care, being free from pain, remaining active and having permission to die [12–14]. Despite their empirical merits, this body of research does not provide a robust framework to inform care provision and interventions that enhance patient dignity at the end-of-life.

One approach to dignity-oriented care that focuses specifically on end-of-life care is Chochinov’s Dignity Model [15]. Via interviews with older people with advanced cancer, Chochinov *et al.* identified a broad range of physical, psychosocial and existential issues that may support or undermine their sense of dignity. The model comprises of three major categories of themes and subthemes including (i) illness-related concerns; (ii) dignity-conserving repertoire and (iii) the social aspect of being terminally ill. These will be described in detail in the results section of this paper (Boxes 1 and 2).

The Dignity Model provides not only descriptive and explanatory accounts of how terminal patients experience dignity, but also prescriptive frameworks for multidisciplinary team approaches to integrate and address the psychological and spiritual aspects of patient care, help them live

as actively as possible and enhance their overall quality of life, all of which, are central to the WHO definition of palliative care [16]. Furthermore, a novel and promising dignity-enhancing psychotherapy for diminishing terminal patients’ existential distress has been developed using this model [17, 18]. However, the Dignity Model and dignity therapy are established within a Western paradigm with views from Caucasian cancer patients in Canada. Hence, their application to other cultural groups with different values and belief systems is questionable. The aim of this study is to examine the generalisability of the Dignity Model to older Chinese palliative patients, and to explore cultural influences on the conception of dignity under a different ethic context.

Methods

Design

This study adopted a qualitative descriptive design to identify factors that constitute ‘living and dying with dignity’

Box I. Dignity themes

Illness-related concerns

- Level of independence^a
- Cognitive acuity^a
- Functional capacity^a
- Symptom distress
- Physical distress^a
- Psychological distress^a
- Medical uncertainty^a
- Death anxiety^b
- Enduring pain^d

Dignity conserving repertoire

- Dignity conserving perspectives
- Continuity of self^a
- Role preservation^a
- Generativity/legacy^c
- Moral transcendence^d
- Maintenance of pride^a
- Hopefulness^a
- Autonomy/control^a
- Resilience/fighting spirit^c
- Fortitude/Spiritual surrender^d

Dignity conserving practices

- Living in the moment^a
- Maintaining normalcy^a
- Seeking spiritual comfort^a

Social dignity inventory

- Privacy boundaries^a
- Social support^a
- Care tenor^a
- Burden to others^a
- Aftermath concerns^a
- Transgenerational unity^d

^aA priori theme from the Dignity Model supported in the current study.

^bThemes not supported in the current study.

^cThemes manifested differently in the current study.

^dNew emergent themes.

Box 2. Quotes from participants

Illness-related concerns

1. Stanley: I am totally dependent on my wife to carry me down the stairs, out of my home and into the outside world ... My friends just seemed to have disappeared in my life.
2. Hinley: My children and grandchildren visit me often ... I still remember the exact date and time they last visited ... I keep myself updated on the news and current events so we that we have something to talk about when they are here.
3. Fanny: I was so angry that no one told me about my cancer, not even my doctor or my children ... I have the right to know ... I want to make my own care decisions and I don't want any more painful medical procedures.
4. Betty: I am 84 years old and I have lived a long happy life ... I feel blessed watching my children growing up and having their own children ... I am not afraid of dying because it is only natural ... Imagine what would happen to the world if no one dies.
5. Stanley: It is okay to live with pain because it remains me that I am alive ... Like the old Chinese saying, 'If you wish to be the best man, you must be prepared to suffer the bitterest of the bitter (chī dé kǔ zhōng kǔ, fāng wéi rén shàng rén)' ... Sometimes the medicine makes me so numb that I cannot feel anything ... like I am not even here.
6. Wai: I have lived here long enough (nursing home) to see the pains of many other. Knowing that I am not alone and that my sufferings are small and insignificant in comparison, I begin to feel for them ... I am beginning to understand the true meaning of humanity (*rén'ài*).

Dignity conserving repertoire

7. Ming: I have nothing of value to leave behind for my son and my grandson, but I want pass on to them the values and wisdoms that I have learned through my father and throughout my lifetime ... I hope that my advice can help them in their future, making them into strong, upstanding persons.
8. Sue: Life is impermanence and I don't know how long I shall live. So I gave up fighting knowing that nothing is for certain. I am not giving up but just allowing nature to take its course and be happy with every new day ... this way I feel much more at peace.
9. Pui: I stopped worrying about this and that as I really have little control over things ... all I am concern about is living in the moment and spending time with my family.
10. Wai: Dignity is really about living a normal life ... being able to eat what I like, do things that I enjoy, and be with my family give me dignity.
11. Vicki: Reading the Buddhist scriptures brings me a sense of peace ... Dignity is about practicing what you preach and being a morally upright person.

Social dignity inventory

12. Hinley: I mostly keep to myself here (nursing home) because I enjoy my privacy. Sure I would smile and greet others, but I don't like them gazing or coming into my personal space ... I mean my room is small enough and its partitioned by low wooden boards, it doesn't even have an actual door.
13. Yung: The nurses and doctors at the palliative care unit are the kindest souls. They take their time in telling me every detail about my cancer and how my children can help to me to feel better ... but things change quickly once walk out the door. The everyday nurses and doctors just don't care.
14. Jane: I am happy whenever my grandchildren comes visit. I would make them their favor food and hearty soup ... they love my cooking. Watching them grow up and being a part of their lives is my biggest satisfaction ... My connection with them makes me feel dignified.
15. Ngan: Most of my children and grandchildren have immigrated and are now living overseas. I rarely get the chance to see them but I still talk to them regularly ... They grow up so quickly I just don't want them to forget about me ... I am always thinking about them and they will always be in my hearts.

from the perspectives of older Chinese terminally ill patients. This approach is appropriate for exploring the generalisability of an existing theoretical model [19].

Sampling

The sample composed of 16 older people with terminal cancer receiving palliative care services in a major public

hospital in Hong Kong. The inclusion criteria included patients aged 60 and above, diagnosed with Stage IV cancers with a life expectancy of no >6 months and living in the community either at home or at a nursing home. The head nurse of the palliative care unit was asked to identify potential patients who would benefit from a narrative encounter, and excluded those were unable to provide informed consent, were too ill or too distressed to participate.

The interviews

The interview schedule included the eight questions that were used to develop the Dignity Model [15], as well as a series of meaning-oriented questions to facilitate deeper introspection regarding the illness experience for generating additional meanings of dignity [20]. Specifically, patients were asked to recall the significant events leading up to their cancer diagnosis, the immediate aftermath, their eventual coping and adjustment processes, as well as their reflections on how dignity was achieved and maintained throughout their illness trajectories. Each interview took 90–120 min to complete, and all interviews were recorded and transcribed verbatim.

Analysis

Framework analysis was used, which is appropriate for our comparative approach [21]. Specifically, analysis was both deductive such that it was informed by the framework of priori themes derived from the Dignity Model, as well as inductive with new emergent themes that were not captured by the Dignity Model but that arose from participants' views. To address issues of rigour and trustworthiness, the coding framework was agreed by the first, second and third authors such that codes and themes were discussed and constantly compared with potential deviant cases during regular meetings.

Results

Characteristics of the 16 participants are shown in Table 1. Their ages ranged from 61 to 92 with a mean age of 77.7. Nine participants were living at home and cared for by their family members, and the remaining seven participants were living in nursing homes and highly dependent on institutional care.

Table 1. Characteristics of patients

Name ^a	Age	Gender	Cancer type	Place of living
Vicki	61	Female	Lung cancer	Home
Ming	64	Male	Lung cancer	Home
Lisa	68	Female	Lung cancer	Home
Sam	68	Male	Lung cancer	Home
Stanley	72	Male	Lung cancer	Home
Jane	78	Female	Colorectal cancer	Home
Yung	78	Female	Colorectal cancer	Home
Wai	81	Male	Prostate cancer	Nursing Home
Pui	82	Female	Lung cancer	Nursing Home
Pong	82	Female	Lung cancer	Home
Wu	82	Male	Pancreas cancer	Nursing Home
Sue	83	Female	Lymphoma	Nursing Home
Betty	84	Female	Colorectal cancer	Nursing Home
Hinley	84	Male	Liver cancer	Nursing Home
Fanny	85	Female	Lung Cancer	Home
Ngan	92	Female	Lymphoma	Nursing Home

^aName has been changed to protect confidentiality.

Most themes from the three defined categories of the Dignity Model were supported in our findings. However, the subtheme of death anxiety was not supported, while the subthemes of generativity/legacy and resilience/fighting spirit manifested differently in our Chinese sample. Four new themes also emerged, including (i) enduring pain, (ii) moral transcendence, (iii) spiritual surrender and (iv) trans-generational unity.

Illness-related concerns

The first of the two main themes included in this category of the Dignity Model is *level of independence*, and it comprises the two subthemes of *functional capacity* and *cognitive acuity*. All participants in our study expressed a deep loss of independence owing to their limited functional capacity, as they could no longer carry out many of their everyday activities independently. These physical limitations had greatly affected participants' overall quality of life as some felt that they were no longer able to enjoy food, engage in hobbies, and most importantly, maintain close relationships. For instance, Stanley described his deep resentment for not being able to enjoy the company of his old friends due to his dependency and limited mobility (Quote 1). In terms of cognitive acuity, while only a few participants expressed disappointment for not being as lucid-minded, others like Hinley took pride in his good memory and cognitive functioning despite sickness and old-age (Quote 2).

The second main theme of the illness-related concerns category is *symptoms distress* and it includes the two subthemes of *physical distress* and *psychological distress*. Psychological distress stems from *medical uncertainty* and *death anxiety*. Different from the common belief that Chinese elderly patients do not want to learn or talk about their prognosis due to anxiety and fear of death, most participants in our study considered such communication vital, as they felt that knowing what to expect in their illness trajectory enabled them to make advance care plans. Fanny described her apprehension with medical uncertainty where she demanded her prognosis from her attending nurse so that she could make informed care decisions (Quote 3). Furthermore, no participants displayed any distress during our conversation regarding morality as they believed that death is a natural part of life, whereas others like Betty felt that they had lived long and fulfilling lives and death was not something to be ashamed of (Quote 4).

In terms of physical distress, all participants expressed some form of bodily discomfort such as pain, fatigue and loss of appetite, yet, the severity of these symptoms did not translate into the loss of will to live. In fact, many participants perceived physical pain as an inevitable element of illness and old age, which served as a critical reminder that they are still living (Quote 5). Some participants even took pride in their ability to endure pain as they believed that accepting and living contently with *tolerable* discomfort, physical and/or psychological, helped to strengthen their

moral and spiritual character. In fact, enduring pain is considered a virtue in Chinese teachings from Buddhism and Confucianism [22]. Wai talked about his experience of living with pain which provided him a better understanding of the sufferings of other patients, cultivating his compassion towards humanity (Quote 6). Thus, 'enduring pain' emerged as a new defining theme of dignity in our study.

Dignity conversing repertoire

Dignity conserving perspective is one of the two major themes that fall under this category of the Dignity Model. It further consists of eight subthemes that relate to personal worldviews that protect individuals' sense of dignity in the face of mortality. Our findings supported most of these subthemes as all participants expressed the need for *continuity of self, role preservation, pride, hopefulness, autonomy/control and acceptance*. However, the two subthemes of *generativity/legacy* and *resilience/fighting spirit* manifested differently in our Chinese sample.

Generativity/legacy refers to the need to leave behind something of value that transcends death. Although most participants in our study expressed a desire to create something meaningful to be shared, the goal of such engagement is more complex than identifying past achievements and contributions. To leave behind something lasting for older Chinese terminal patients meant passing on values and traditions from generation to generation; in other words, the transmission of a moral belief system that would nourish and sustain the family lineage. Ming described his desire to pass on his wisdoms and values as well as those of his forefathers to his children and grandchildren (Quote 7), an aspiration shared by many. Thus, 'moral transcendence' has emerged as the second new theme of dignity. *Resilience/fighting spirit* refers to patients' ability to rally against their illness-related concerns for enhancing their sense of well-being and optimising their quality of life. While all participants shared their stories of coping and resilience, few upheld a fighting spirit to enhance their sense of well-being. Instead, many spoke of surrendering to life impermanence and its forever changing circumstances, a spiritual awakening that demands greater mental strength than pure acceptance. Spirituality in this context does not translate to a specific religion but rather the Chinese mandate of heaven, or *T'ien-ming*. For Sue, her fortitude to give up fighting meant letting go of impermanence, which enabled her to find inner peace and comfort at the end-of-life (Quote 8). As such, 'spiritual surrender' emerged as the third new theme in our study.

Dignity conserving practices is the second major themes of this category and it represents various life practices or techniques that help buffer the impact of dying. It comprises three subthemes including *living in the moment, maintaining normalcy* and *seeking spiritual comfort*. All three of these subthemes emerged vividly in our study as most participants spoke of the need to maintain normality while coping with

their terminal illness, to be mindful and focus on the here and now and not worrying about the future, as well as to find spiritual peace by forgiving, relinquishing grudges and broadening their life perspective (Quotes 9–11).

Social dignity inventory

This category refers to the interpersonal factors and social dynamics that can either erode or bolster individuals' sense of dignity at the end-of-life. It includes the five themes of *privacy boundaries, social support, care tenor, burden to others and aftermath concerns*. Our findings revealed that *privacy boundaries* was one of the utmost dignity concerns of participants living in nursing homes as they felt deprived from the lack of personal space and constrained by the bureaucracy of institutional care (Quote 12). *Care tenor* was another salient concern, as participants' sense of dignity was greatly undermined when they were attended by healthcare workers who lacked palliative care knowledge and awareness (Quote 13). Moreover, the need for *social support* as well as the desire to reduce *burden to others* and *aftermath concerns* were all identified through our participants' narratives. While these five themes are mainly concerned with the relational dynamics of dignity of the external social world, the fourth new emergent theme of '*transgenerational unity*' in our study highlights the importance of family connections. All participants in our study expressed a yearning to be closer, both physically and emotionally, with their descendants, especially with their grandchildren. As described by Jane and Ngan, the strengthening of this bond between and across generations fostered a sense of existential wholeness and spiritual connectedness in spite of the constant reminder of death, which help to promote a sense of dignity for older Chinese palliative care patients during the final chapter of life (Quotes 14 and 15).

Discussion

This study set out to identify the underlying factors that constitute 'living and dying with dignity' from the perspective of older Chinese terminal patients, and is the first study to examine the generalisability of the Dignity Model in the Chinese context. Overall, the three main categories of Chochinov's Dignity Model were supported; however, the theme of death anxiety was not found to be a defining factor of dignity, which coincides with the findings from Hall *et al.* in their study with UK older nursing home residents whom were not imminently dying [23]. In fact, our participants were not distressed by the idea of death but wished to engage in advanced care planning so as to relieve their sense of burden on their families [24]. Moreover, the capacity of *enduring pain*, the intrapsychic attributes of *moral transcendence* and *spiritual surrender*, as well as the relational dynamics of *transgenerational unity* have emerged as four new themes that constitute dignity in the Chinese context. The

underlying nature of these emergent themes are evidently culturally-specified and family oriented, stemming from a traditional value system that emphasises moral conduct, filial obligations and spiritual harmony for cultivating personhood and existential meaning [25, 26].

These emergent themes pinpoint the paramount importance of cultural competence and awareness for working with ethnically diverse groups. In particular, one must understand the meaning of pain and the ability to endure pain among older Chinese patients. While pain control is a central goal in palliative care, the rationale of such intervention is to make terminal patients less aware and conscious of their distress. In effect, patients are offered the equivalent of emotional analgesia without necessarily addressing the source and cause of the underlying psychic pain of dying [17]. Although the need to manage pain and bodily symptoms cannot be undermined, eliminating the experience of pain entirely can deny Chinese patients the opportunity for spiritual growth through suffering. Moreover, our findings reveal that the meaning of dignity is highly related to the notion of spirituality in the Chinese context, where one complements the other to promote high-quality-of-life at the end-of-life. In fact, investigators have found that dignity and spirituality are two imperative and inseparable concepts in palliative care [27, 28]. Hence, palliative practices must move beyond the physical and the psychosocial to place much greater emphasis on spiritual care; for Chinese patients specifically, interventions that facilitate acceptance, letting go, reconciliation, meaning making and continuing bonds can prove invaluable for them to achieve dignity and inner peace in the face of mortality [29, 30].

A limitation of this study is that it only reflects the experiences of a small proportion of older Chinese palliative care patients in Hong Kong and those who were able to participate. The views on dignity may be different for frailer patients who are in the final days of life. Further studies are needed to explore the generalisability of our findings to other groups of older Chinese people.

Conclusion

Our findings demonstrate the utility as well as the limitations of the Dignity Model in a new cultural context. As dignity is a value- and culture-laden concept that encompasses a wide spectrum of physical, psychosocial, spiritual, familial and cultural issues, greater awareness of ethnic diversity is required for all palliative care workers. Yet, most end-of-life interventions still focus prominently on pain and symptoms control, while holistic care and familial support are limited. The need to develop culturally sensitive and family oriented interventions for reducing the existential pain of dying among Chinese patients in Hong Kong are clear and imminently urgent for addressing the challenges of an rapidly ageing population.

Key points

- The understanding of dignity at the end-of-life is generally similar among Western and Chinese palliative care patients.
 - However, Chinese older patients were not anxious about death, but instead desire advance care planning to relieve family burden.
 - Culture and family play significant roles in the experience of dignity and dignity-related concerns among Chinese patients.
 - Four new themes of dignity are identified: enduring pain, moral transcendence, spiritual surrender and transgenerational unity.
 - Palliative care workers must develop greater cultural sensitivity when working with ethnically diverse patient groups.
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Conflicts of interest

None declared.

Ethical approval

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