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Dignity amidst Liminality: Healing within Suffering among Chinese Terminal Cancer Patients

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Abstract

This study critically examines the concepts of dignity and liminality at the end-of-life, in an effort to better understand the processes of healing within suffering among Chinese terminal cancer patients receiving palliative care services in Hong Kong. Meaning-oriented interviews were conducted with 18 Chinese terminal patients, aged 44 to 98, to elicit the narratives and stories of their illness experience. All interviews were analyzed using grounded theory and supplemented by ethnographic observations and field notes. Two major themes and eight sub-processes of healing adopted by patients to achieve and maintain dignity were identified: (1) Personal Autonomy, which encompasses the need to (i) regain control over living environments, (ii) maintain self-sufficiency despite institutional care, (ii) make informed care decisions to reduce sense of burden, and (iv) engage in future planning to create a lasting legacy; and (2) Family Connectedness, which encompasses the need to (i) maintain close ties with family members to express appreciation, (ii) achieve reconciliation, (iii) fulfill family obligations, and (iv) establish a continuing bond that transcends generations. Implications of these themes for advanced care planning and life review interventions were discussed with the goal of enhancing patient autonomy and family connectedness, and thereby providing structure and meaning for Chinese terminal patients and their families at the end of life.

Keywords: Chinese, cancer, dignity, meaning, liminality, palliative care, end-of-life
Dignity amidst Liminality: Healing within Suffering among Chinese Terminal Cancer Patients

Medical advances of the contemporary era have not only changed how we live, but also have transformed the way we die. As death and dying are prolonged and institutionalized, individuals and families find it increasingly difficult to deal with the many ambiguities of the end-of-life. Patients with severe illness often experience a cloud of confusion as the structures and routines of their everyday life unravel and dissolve into the indistinct fixtures of hospitals and care institutions (Frank, 1995; Murphy, Scheer, Murphy, et al., 1988). Terminal patients in particular can progressively lose their sense of identity and personhood as their illness becomes more and more alienating and incommunicable (Froggatt, 1997; Leder, 1990). This indeterminate state of existence has been referred to as liminality by anthropologists who research rites of passage between identifiable social statuses associated with critical life transitions (Leech, 1976; Turner, 1969, 1977, 1982; van Gennep, 1960).

Van Gennep (1960) described and distinguished three clusters of behavior or rites of passage common to different transitional life events: separation, liminality, and aggregation. Drawing on van Gennep, Turner (1969) described the transition of young pilgrims into adulthood as “neither living or dead from one aspect, and both living and dead from another… their condition is one of ambiguity and paradox, a confusion of all the customary categories” (pp. 96-98). Turner’s account of liminality made it a fitting concept to understand the experience of death, and especially the extended transitional period from living to dying in the modern context (Braude, 2012). For instance, Frankenberg (1986) regarded liminality as a phase of suspended space and time where the lives of terminal patients are overturned in confusion. Little et al (1998) further described the dying process of advanced cancer patients as acute and sustained liminality that begins with disorientation, leading to a sense of loss, loss of control, uncertainty, and finally suspension in existential pain until death ensues.
Finally, Sibbert (2004) elaborated on the experience of terminal cancer as immersion in the physicality of pain and suffering, the structural inferiority of power, the disorientation of stigma, and the embodied experience of liminality.

The mounting body of research that examines the existential and psychosocial pain of terminal patients has illuminated the paramount importance of maintaining dignity during such suspended states of space and time. Several studies have found that an enhanced sense of dignity is associated with a greater sense of meaning in life and increased will to live among advanced cancer patients trapped in liminality (Abbet, Froggatt, Parker, et al., 2006; Agich, 2007; Allmark, 2002). Moreover, a sense of spiritual peace, relief from burden and strengthened relationships with loved ones have been associated with preservation of dignity and death acceptance at the end of life (Baillie, Gallager, & Wainwright, 2008; Bayer, Tadd, & Krajcik, 2006; Field & Cassel, 1997; Neimeyer, Currier, Coleman, Tomer & Samuel, 2011). Conversely, an undermining of dignity is found to be strongly associated with depression, anxiety, hopelessness, loss of will to live, desire for death, feeling of being a burden on others, and overall poorer quality of life (Chochinov, 2004; Chochinov, Hack, McClement, et al, 2002; Hack, Chochinov, Hassard, et al., 2004; McClement, Chochinov, Hack, et al., 2004). Several studies have further linked terminal patients’ heightened request for a hastened death with the sense of being a burden on others, loss of meaning, and loss of dignity (Brietbart, Rosenfeld, Passik, 1996; Wilson, Grahan, Viola, 2004).

Seemingly, liminality and dignity are different yet closely related concepts in the end-of-life. While being confined in the indeterminate state of existence between living and dying can lead to a wide range of existential, spiritual and psychosocial concerns, the ability to experience dignity appears to mitigate the suffering associated with terminal illness and death. Hence, understanding how terminal patients maintain dignity in the face of mortality can suggest ways to improve the quality of hospice and palliative care to attend to their
existential needs and wishes. However, there is a dearth of empirical research that investigates the various ways in which patients strive to preserve dignity at end-of-life, and very little is known about the experiences of Chinese patients in general. This study draws on qualitative and ethnographic methods to fill this knowledge gap by examining the processes by which Chinese terminal cancer patients achieve and maintain a sense of dignity while living with dying, with the goal of suggesting ways to enhance clinical practice with this population.

**Methods**

This study draws from ethnographic research on the lived experience of Chinese terminal cancer patients and their families receiving palliative care services in Hong Kong conducted between late 2009 and early 2011 (Ho & Chan, 2010). Ethics approval was obtained through the Institutional Review Board of the authors’ university and the local health authority that oversees public palliative care programs. As part of the ethics approval process, a formal protocol was developed for identifying participants based on willingness and capacity to participate. The sampling frame comprised patients currently enrolled in the outpatient palliative care program of a major public hospital. Inclusion criteria required that patients be diagnosed with stage IV cancer, with a life expectancy of no more than six months, and that they be living in the community either at home or in a long-term-care institution (i.e. nursing home). The head nurse and the principal homecare nurse of the palliative care unit were briefed on the study and were asked to identify potential participants. They were also asked to consider for inclusion only those patients who were cognitively intact, were able to talk freely about their experience, would benefit from a narrative encounter, were willing to participate in the study and were capable of providing consent. Based on this purposive sampling frame, eighteen patients were selected. An introductory letter and information sheet about the study were provided to each selected participant.
through the homecare nurse, and followed up by a telephone call by trained interviewers to answer questions and to ascertain participations. All eighteen patients agreed to participate in the study.

Interviews were conducted either at the home of the patient, at the nursing homes where the patient resided, or in a quiet room at the hospital. Upon granting informed consent, patients were invited to engage in a meaning-oriented interview that focused on eliciting the stories and narratives of their experiences with terminal illness, through which the processes of introspection and articulation served to generate renewed meanings that illuminate the concept of dignity at the end-of-life (Leung & Chan, 2006), in keeping with a meaning reconstruction approach to loss and transition (Neimeyer, 2001, Neimeyer & Sands, 2011). Specifically, participants 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 could be achieved and maintained throughout their illness trajectories. Each interview took approximately 90 to 120 minutes to complete. All interviews were digitally recorded, transcribed verbatim and edited for accuracy by three researchers. Qualitative content analysis based on the grounded theory approach was adopted, where hypotheses were reflectively modified in the light of progressive observations (Strauss & Corbin, 1990). Transcripts were coded for significant themes by three core researchers. To address issues of rigor and trustworthiness, the coding framework was agreed by all researchers so that codes and themes were discussed and constantly compared with potential deviant cases during regular meetings. In addition, ethnographic methods were used to elicit the temporal orientations of experience to include retrospective assessment as well as pre-reflective, real-time unfolding of social life (Throop, 2003). This included participant observations and field notes, which provided supplementary information about the meaning and the context of the interviews. The final step of analysis involved revisiting the literature
Results

Transcripts of completed interviews were obtained from eight men and ten women whose mean age was 74.1 years, with a range of 44–92 years where thirteen interviewees were above the age of 65. Nine patients were diagnosed with terminal lung cancer, three were diagnosed with terminal colorectal cancer, two with terminal lymphoma and the remaining were diagnosed with terminal liver cancer, prostate cancer, pancreatic cancer and nasopharyngeal cancer. All eighteen patients had stopped curative treatments and were only receiving palliation for pain control and symptoms management. Eight patients were residing in nursing homes and relied mainly on institutional care, while the remaining ten were living at home and were cared for by their families. Characteristics of the eighteen patients are shown in Table 1.

[Insert Table 1 about here.]

In all of the narratives, patients expressed their subjective experience and the relevant interactive processes of maintaining dignity in the liminal space between living and dying through two main categories of theme, each of which subsumed four sub-processes. These included:

1. Personal autonomy, which encompasses the needs of patients to: (i) regain control over their seemingly uncontrollable lives through altering their living environments; (ii) maintain self-sufficiency by not surrendering to the bureaucracy of institutional care; (iii) make informed care decisions to reduce the sense of burden to others; and (vi) engage in future planning to create a lasting legacy for themselves and their families.

2. Family connectedness, which encompasses desires of patients to: (i) express appreciation for strengthening familial ties; (ii) achieve reconciliation by mending unresolved family conflicts; (iii) fulfill family obligations by reestablishing their roles and
emotional connection within the family system; and (iv) establish a *continuing bond* that would link them with their future generations of decedents in spite of the limits of time and space through the transmission of values and life wisdom. Each of these categories will be considered in turn.

**Maintaining Dignity through Personal Autonomy**

All patients spoke of the need for personal autonomy throughout their illness experience in order to maintain their sense of dignity. Regaining control and self-sufficiency to make informed care decisions and plans for the future enabled them to attain healing from within suffering. Subcategories with illustrative quotations from participants follow.

*Regaining control.* In the words of one 78-year-old home-dwelling female patient, “When I first got sick and was admitted to the hospital, I came out of surgery feeling very weak.... I couldn’t eat under my own strength and the nurses came by a few times offering to feed me. I have never been fed since childhood, but if life has come down to this, I would want my daughter to do it.” The need to *regain control*, even in a minimal form, was shared by all patients as they felt that their lives were increasingly being consumed by their illness. This patient continued, “When I got out of the hospital my daughter became very conscious and restrictive of my diet. She didn’t allow me to eat fatty food or go out for tea at my favorite restaurant…. I got so angry at one point that I said, “I am going to die soon, so just let me eat what I want, and let me die a happy and fulfilled woman.”

*Self-Sufficiency.* The overwhelming sense of loss and loss of control is constantly contested by an innate desire of not wanting to give in, either to the constraints of rehabilitation or the politics of institutional care. “It was my decision to move here after my cancer diagnosis,” said a 56-year-old male nursing home patient. “I don’t want to be a burden to my family and I want to have a say in the kind of care that I receive.... But life here is harsh. I have no say in what to eat or when to eat, and my life revolves around the working
routine of staff members. I have to wake up and eat breakfast at five o’clock every morning because this is when the morning shift starts working.” This man kept cookies and candies in his cupboard to assist him in his silent resistance to institutional bureaucracy.

Although some patients might appear to have resigned themselves to the system, they were able to find small ways to maintain their personhood and self-sufficiency. One 84-year-old elderly male nursing home patient commented that, “I am old and sick, and I have to rely on the nursing home staff for most of my daily activities. That’s life. But it doesn’t mean I have no freedom or have to follow every rule that they set…. When I first moved here I requested a room with a window so that I can look out to the street…. My son helped me set up a small television set so that I can watch the news…. I have placed a curtain to cover the light above my bed so I that I can sleep longer in the morning if I wanted to.” As with many other terminal cancer patients living in nursing homes who occupy a small living space of no more than four by six square feet, partitioned by slender barriers less than five feet tall, a curtain over an unwelcoming fluorescent light or a small barred window to the outside world are perhaps the closest semblance of liberty and dignity one can create in a bureaucratic and oppressing system of institutional care.

Informed Care Decisions. Apart from living adjustments, making informed care decisions is one of the most tangible means for patients to secure a sense of autonomy in spite of illness. “No one told me that I had cancer in the beginning, not my doctor or my children,” said an 82-year-old home-dwelling female patient. “They didn’t want me to be upset, I guess, but I have a right to know. I finally got the answer from a second doctor that I consulted, and honestly, I wasn’t upset to hear the news. I mean I have lived a long life and all my children have grown up. I am not afraid of dying…. but I don’t want any more painful medical procedures. After talking to my attending nurse, I signed off my advanced care directives so that my family members don’t have to make those difficult decisions for me.”
Being able to consult with doctors and families about care decisions and treatment options were of great importance to most patients, as such open communication helped to remove the sense of ambiguity and being a burden to others that commonly accompany a terminal prognosis.

**Future Planning.** One 61-year-old female home-dwelling patient commented, “My daughter accompanied me to the hospital. It was difficult, but I asked the doctor to explain clearly to us about my diagnosis and the options that I have…. I feel much more secure knowing what to expect and how to prepare for it.” It is evident that patients are empowered by having adequate knowledge about their illness with some degree of certainty of their prognoses, as being able to plan for the future promised hope and a temporary return to normalcy, autonomy and self-determination. This patient continued, “Having cancer, even terminal cancer, is not the end. I still have time to accomplish many of the things I have always wanted…. to spend quality time with my family, to create more beautiful memories for myself, and for my loved ones to remember me by.” Her plan for the following day was a long-awaited visit with her daughter to the Big Buddha statue of the temple near Lan Tau, a favorite spiritual and natural pilgrimage for residents of Hong Kong.

**Maintaining Dignity through Family Connectedness**

Being confined in space and time, while having to surrender their social roles due to limited mobility and increased dependency, caused sadness and distress for all patients. Thus, the need to reestablish their identities within the context of their families was of paramount importance for them to find healing amidst the existential pain of dying.

**Expressing Appreciation.** One 72-year-old home-dwelling male patient said, “I used to have tea with my longtime friends and colleagues every morning, but ever since I got sick, I haven’t been able to go out as much…. They just seemed to have disappeared from my life.” As a result, the need and desire for family connectedness became vital. “My wife and
children are most important to me now; they visit me almost every day and they are my main source of support. Without them, I don’t know where I’d be. I truly cannot thank them enough.” Expressions of gratitude and love strengthened family connectedness between patients and families. This patient continued, “I, being sick, have actually drawn my family closer…. I feel blessed seeing my two sons being more united and caring towards one another.”

Achieving Reconciliation. There is also an intrinsic yearning to achieve reconciliation and forgiveness for patients to achieve dignity at the end-of-life. In the words of a 78-year-old female home-dwelling patient, “Out of all of my ten children, my eldest daughter is the only one who came back to care for me after I got sick…. I can’t be and don’t want to be a burden to her…. I sold her to a wealthy family for two hundred dollars during the war. I was desperate, but she was only a baby. I felt so guilty that I brought her back within a few days.” Consumed by feelings of guilt and shame from enduring unresolved family conflicts, some patients shared a similar longing for catharsis. However, bound by traditional family values that emphasized rigid control and hierarchy, they often failed to communicate their compunctions, let alone express their profound emotions. The resulting feelings of helplessness and dejection manifested themselves through tears, agitation, refusal to eat and other self-sabotaging behaviors.

Fulfilling Family Obligations. Fulfilling obligations became essential to all respondents in their quest for dignity during the last phases of life. One 84-year-old female nursing home patient said, “I wish to spend some quality time with my granddaughter…. I want to hold her, play with her, take her to the park, and do all the little things that other able grandmas would do. But I live here now and being in a wheelchair doesn’t help…. Well at the very least, I still get to see her every weekend, and listening to her calling me grandma, running towards me with her open arms and beautiful smile puts my pain away.” Restoring
and reestablishing family roles was also important for terminal patients to maintain a sense of hope and reunion. “The happiest times in my life now are when my youngest daughter comes and visits,” said another 82 year-old nursing home male patient, “I didn’t spend a lot of time with her when she was young as I used to travel a lot in my work. We barely had any time to talk or see other back then…. I hope that she understands me and that I am a good father who cares deeply about her.”

When families live far apart and physical contacts become difficult, patients would make vigorous attempts to maintain a sense of connectedness. “I call my children every week and ask the nursing home volunteers to help me purchase long distance phone cards,” said one 92-year-old nursing home female patient, “They sometimes send me pictures too. I keep pictures of all of my grandchildren. I feel blessed and warm every time I look at their faces.” The rows of aging family portraits pinned up against the skeletal walls of her partitioned room bear testament to the need for family affirmation among terminally-ill patients, especially those whose self and social identities have been threatened and undermined within the bounds of institutional care.

*Establishing Continuing Bond.* As awareness of mortality grows increasingly prominent, the desire to establish a bond with family members that can survive death becomes pronounced. A 64-year-old home-dwelling male patient said, “I am most grateful to my son who had quit his jobs to care for me at home. But I am more than just a dying person…. I am still a husband and I am still the head of this family…. I tried my best to talk to him about his career and his marriage, share with him my experiences, and offer him my advice which I hope can help him in his future.” Restoring family values and passing on wisdom form the fundamental basis of continuing bond. These processes not only empower patients to reorganize their life narratives and to construct new meanings for coping with the ambiguity of death, they also aid surviving family members in creating a living legacy of the
dying patients, bolstering and reinforcing their sense of dignity.

**Discussion**

Under the rubric of modern medicine where death and dying is prolonged and institutionalized, terminal cancer patients helplessly and feebly enter a social realm of betwixt and between where confusion and disorientation reign. Inhabiting the liminal threshold between living and dying, they risk slowly losing themselves and their identities through the complicating discourse of treatment and palliation, the oppressing bureaucracy of institutional care, and the ambiguity of pending mortality. In this paper we sought systemically to link the concepts of dignity enhancement and liminality. Analyzing narratives of terminal patients’ experiences of suffering and coping, we have identified two thematic categories and their relevant sub-processes through which the meaning of illness and existence was constructed and reconstructed, in an attempt on the part of patients to minimize the pain of dying and to make sense in a liminal space and time.

Specifically, our findings show that the main themes of personal autonomy and family connectedness form the major pillars of dignity among a Chinese group of terminal cancer patients. Personal autonomy encompasses the needs of patients to gain a degree of control over their lives through altering their living environments, maintain a degree of self-sufficiency to not become totally dependent on institutional care, make informed care decisions to reduce the sense of burden to others, and engage in future planning to create lasting memories and a legacy for themselves and their families. Moreover, family connectedness encompasses the ways in which patients maintain close ties with their families to express appreciation, achieve reconciliation, fulfill their family obligations, and to establish a continuing bond with their descendants that transcends generations. Figure 1 illustrates the interactive processes that enable terminal patients to achieve and maintain dignity amidst the liminal dimension at the end-of-life.
Upon further analysis, it is apparent that the two major themes of personal autonomy and family connectedness can also serve as the foundation for developing procedures to minimize the pain and suffering caused by liminality. In their classic work on rites of passage, van Gennep (1960) and Turner (1979) both emphasized the importance of rituals to support individuals and communities during critical lifecycle events and transitions. In the Chinese context of death and dying, rituals for transformation from body to corpse such as highly orchestrated funeral rites that help the deceased terminate their relationship with this world and aid their passage into the next, while providing their surviving families a structure for continuing the family lineage and social status, have long been established. Likewise, rituals of reintegration such as elaborate mourning during the Ching-Ming festival can help the deceased spirit transform into ancestor status, while providing surviving families a structure for venerating their ancestors. However, customary rituals for recognizing the distinction from living to dying are non-existent. This liminal identity is further compounded in a death-denying and death-avoiding culture that alienates dying people from society. Yet, our study reveals that Chinese terminal patients do attempt to create structure within this indeterminate state of existence. Particularly, the eight interactive dignity-preserving processes operate as informal ritual actions for patients to reestablish both their individual and collective identities within the liminal, enabling them to find healing despite suffering.

In the era of biomedicine, terminally ill persons lack ‘legal’ or ‘formal’ rites of passage to navigate the liminal state of separation marked by the transition from living to dying. Yet, based on two critical themes for achieving and maintaining dignity as well as the eight dignity-preserving processes as identified in this study, it is evident that such tools already exist and are readily available in many societies. The purpose of Advanced Care Planning (ACP) is to galvanize patients to take control over their care preferences, relieve
burden and make informed care decisions at the end-of-life. The aspiration of Life Review (LR) interventions is to empower patients to express gratitude and achieve reconciliation, both of which are critical aims in light of evidence that past-related regrets predict greater death anxiety and diminished well-being at the end of life (Neimeyer et al., 2011). Clearly, ACP and LR can both function as legal and formal ritual actions to create structure and diminish liminality at the end-of-life, while at the same time promoting “living and dying with dignity” through enhancing self-autonomy and family-connectedness to yield a positive continuing bond. These two clinical tools can prove invaluable for facilitating dignity-conserving care in the provision of palliative services in the Chinese context.

Unfortunately, despite years of public consultation that highlight the imperative to implement standardized advanced care planning in palliative care practice, the Hong Kong Government has yet to carry through with its legalization. In the Consultation Paper published by the Food and Health Bureau (2006), the Government stated that “it would be premature to attempt to formulate a statutory framework and to embark on any legislative process for advance directives, without greater public awareness of the issues involved… and the Government has no intention to actively advocate or encourage the public to make advance directives” (p.5). In more detail, the consultation paper ascribes patients’ reluctance to engage in ACP to a Chinese cultural taboo to talk about death-related issues. However, as Hui (2010) also contends, the real causes for infrequent practice of ACP are the lack of training, patience and time, as well as and the sense of insecurity among health care workers in raising death and dying issues with their patients. Such inaction and lack of leadership in public governance deprive terminal patients of the opportunity to attain greater self-autonomy and structure within the liminal threshold of mortality, critically reflecting the need for more professional training and government led initiatives on the use of ACP in the
local context.

In terms of life review interventions, although some hospice and palliative care services in Hong Kong adopted LR to help terminal patients articulate what gives meaning to their lives, these interventions are heavily based on a Western individualistic paradigm with limited practicality in Asian cultures (Ho & Chan, 2011). In order to truly enhance family connectedness so as to bolster patients’ sense of dignity, family must become the driving force of LR interventions in the Chinese context. In particular, LR intervention should be built upon an Eastern collective framework that emphasizes the values of filial piety, transcendental wisdom and transgenerational bonds. The ultimate goal of such intervention is to facilitate meaningful dialogue between patients and their families who are not strong in the articulation of emotions and intimacy to express love, gratitude and forgiveness. This recommendation is compatible with evidence that higher levels of family support at the end-of-life are associated with greater patient well-being as death draws near (Neimeyer et al., 2011).

**Conclusion**

This study adds to the body of knowledge on hospice and palliative care by critically examining the concepts of dignity within liminality in a Chinese context. Despite their qualitative nature, the findings shed new light on the experience of “living and dying with dignity” from the perspectives of terminal cancer patients, and carry important implications for both clinical practice and policy formulation in end-of-life services. In essence, ritual actions that promote personal autonomy and family connectedness are essential for helping Chinese terminal patients attain healing within suffering, while preserving dignity amidst the liminal space of mortality. Advanced care planning and culture-specific life review interventions can both function as such ritual actions, and as such should be standardized to make them accessible in all hospice and palliative care settings.
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Ethical approval

Institutional Review Board of the University of Hong Kong / Hospital Authority Hong Kong West Cluster (HKU / HA HKW IRB / UW 08-446).
References


Table 1. Characteristics of Patients

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<td>YCW</td>
<td>72</td>
<td>Male</td>
<td>Lung Cancer</td>
<td>Home</td>
</tr>
</tbody>
</table>
Figure 1. Interactive Dignity-Preserving Processes to attain Healing within Suffering
### Figure 2. Structuring the Liminal Space between Living and Dying

<table>
<thead>
<tr>
<th>Separation</th>
<th>Liminality (Ritual Actions)</th>
<th>Aggregation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living</td>
<td><em>Advanced Care Planning and Life Review Intervention</em></td>
<td>Dying</td>
</tr>
<tr>
<td>Body</td>
<td>Funeral Rites</td>
<td>Corpse</td>
</tr>
<tr>
<td>Spirit</td>
<td>Mourning Rituals</td>
<td>Ancestor</td>
</tr>
</tbody>
</table>