

Human dignity in patients with terminal illness

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Dignity in Chinese populations

Some people may argue that dignity is a western concept, and may not apply to Chinese populations. Zhai¹ and Chan² interviewed Chinese elderly persons, family members, and staff of long term care facilities in Beijing and Hong Kong respectively, on what the word 'dignity' means to them. All respondents thought that the concept of dignity was important. Respect for autonomy was important in preserving dignity. Even the way one was greeted could affect one's dignity. Maintaining independence was also important. For people who had become dependent, family care and concern could help to restore dignity. Apart from autonomy and independence, preservation of social relationships was also a critical element of dignity. Dignity was also embodied in the filial piety of their children. Lack of concern from the family members would produce a loss of worthiness. Dignity also depended on one's financial capacity, or the financial support provided by the family. However, one family member commented that *'if you provide materialistic support to parents but you do not respect and care for them at all, you would be treating parents like animals'*.² Elderly people were concerned whether children would give them a phone call, take them to restaurants for dim sum, and bring them home for dinner during festivals. Chan² quoted an administrator of a long term care facility, *'A few days ago, an old lady living here was asked by another elderly person, "The Moon-Cake Festival is coming. Are you going home?" The old lady said "No!" and she was very upset'*.

Dignity in palliative care

Enes³ explored dignity in palliative care in England. She interviewed patients, relatives and staff of an inpatient hospice unit. She found that dignity involved respect for privacy and autonomy. Having control was an important feature of dignity. Symptom control could improve a patient's sense of control. While restrictions in an institution could rob people of their dignity, maintaining individuals' routines might help to maintain the individual self and the sense of control. Dignity was also about how people were treated. Empathy could improve a person's self-worth. On the other hand, the busy staff lacking time might make patients feel like a nuisance.

Chochinov⁴ interviewed terminally ill patients with cancer in Canada, to explore the patient's sense of dignity. Dignity involved respect for autonomy and control, with the patients' requests and decisions taken seriously. Maintaining independence was also important, so that patients did not feel like a burden to others. Dignity also involved a sense of pride, through their accomplishments or the accomplishments of their children. Some people considered life with severe symptom distress as life without dignity, which was no longer worth living. Dignity might also mean dying in peace, not suffering too much. Spiritual support also enhanced dignity, such as prayers or religious activities. Dignity was preserved when there was something to look forward to, like a family member's wedding; and something worth living for, which might just be simple things. A patient commented that seeing flowers growing outside the window, or children playing in the street already made life worth-living. To preserve dignity, it was important to respect privacy boundaries in providing care. The staff attitude was thus of utmost importance.

Chochinov⁵ also studied terminally ill cancer patients who indicated a loss of dignity. He found that these patients were more likely to report psychological and symptom distress, with intense dependency needs and loss of the will to live.

Dignity-conserving care

Hence, from the literature, it is clear that to preserve dignity in the terminally ill patients, we have to provide holistic care, focusing on symptom management, psychosocial care, and rehabilitation. Spiritual support is essential. We have to show respect to patients, noting how patients like to be called, and respecting their privacy. We should try to maintain their routines, so as to enhance their sense of control. We should respect their autonomy, and maintain their sense of pride. It is also important to take care of the patient's family and significant others.

Szeto⁶ studied our patients receiving palliative home care and found that the most common symptoms were pain, loss of appetite, fatigue, constipation and lower limb weakness. Clinical guidelines have been drafted for every day use in our unit, so that doctors could manage the symptoms properly. Maintaining independence is an important element of dignity. Patients' physical mobility not surprisingly decreased towards death, despite our rehabilitation program. They might, however, have deteriorated even more rapidly without rehabilitation.⁷

Szeto⁶ also studied the psychological issues of our patients, with a scale of 0 to 10, '0'

representing the least and '10' the most desirable situation. She found that patients commonly felt depressed, nervous, worried or sad. Some of them felt that every day seemed like a burden. However, they were not very fearful of the future, and did feel respected to a certain extent. Wong⁷ also studied the psycho-spiritual issues of patients in our palliative home care program. She found that patients commonly had stress, fear, anger, grief, anxiety, spiritual distress and guilt. What is more important is that these psycho-spiritual problems improved with our intervention.

The patients' concerns about their family have been investigated, which included feeling like a burden to the family, worries about the future of the family, sadness about separation, feeling abandoned by the family, communication and relationship problems with the family.⁸ Wong⁷ also studied social issues including social contact, role change, mobilization of community resources, caretaking and interpersonal relationships. All problems improved with intervention, while role change, mobilization of community resources and caretaking achieved statistical significance.

Szeto⁶ also studied existential issues of our patients, again with a scale of 0 to 10, '0' representing the least and '10' the most desirable situation. She found that the patients' lives were fairly purposeful and meaningful, fulfilling and worthwhile, and they felt fairly good about themselves as a person. While a lot of our patients have no religion, some have traditional beliefs, worshipping heroes in the past and local gods. A significant proportion of our patients are Christians, either Protestants or Catholics. Some are Buddhists. Others have other religions.⁸ In our unit, spiritual care is provided by pastoral care workers from the Catholic Diocese, chaplains from the Protestant church, volunteers from the Buddhist community, and the whole palliative care team, including personal care workers. Palliative care units in Hong Kong often have a quiet room where patients, family members and staff can settle their emotions, do some personal reflections, or conduct religious activities, such as thanksgiving parties for patients to express gratitude to God.

As mentioned before, we should respect our patients, addressing them in the way they prefer, and respecting their privacy. On admission, we would note how the patient preferred to be called. It is not easy to respect privacy in a general ward, though. It has been reported in the United Kingdom that 92% of patients' families overheard from hospital staff conversations relating to personal information about other patients!⁹ Hence, if possible, sensitive conversations should be conducted in the interview room.

Maintaining individual's routines may help to maintain the individual self and the sense of control. Hence, we would like to maintain the patients' routines as far as possible, such as reading newspapers daily, watching TV, playing chess, having parties for birthday as well as for festival celebration, with occasional outings.

It may not be easy to respect the patients' autonomy. The patients are welcomed to wear their own clothes, but the families have to take the clothes home for washing themselves. We may or may not be able to entertain requests from patient on the time of meals and the time for bathing. Even more difficult are medical issues, and we face ethical dilemmas in nearly every patient.

Patients may demand treatment. We are of course not obliged to provide any treatment that is harmful to the patient. Ms A was a 45-year-old lady with breast cancer. She had severe right-sided chest pain, shortness of breath, and dry cough. Because she was short of breath, she could not lie flat, and could not sleep. She requested euthanasia, and claimed that her sons agreed. Should we respect her autonomy and perform euthanasia? Of course not. Ms A was empathized. She was reassured that we appreciated why she requested euthanasia. We persuaded her to try pain killers. In that afternoon, we started ketamine and morphine by subcutaneous infusion through a syringe driver. She was smiling the next morning, saying that the pain was much improved, but she felt very sleepy. Her sons, who were said to have agreed to put their mother to death, were very anxious, seeing that she was asleep. They kept asking why she slept all the time. They were reassured that it was just because she was tired from lack of sleep for a few months. She became much less sleepy on the third day.

Other patients may refuse treatment. Mr B was a 70-year-old man. He had cancer of the floor of his mouth, and was on nasogastric tube feeding. He had repeated vomiting despite anti-emetics. He was dehydrated and was given intravenous fluid. However, he later refused intravenous fluid or tube feeding. He was mentally sound and not depressed. Should we respect his autonomy? I think we should, because we cannot possibly tie him up to force nutrition and hydration. He had minimal intake and died 3 days later.

The situation is even more difficult when the patient's wish is unknown. Ms C was a 78-year-old woman with brain tumour. She was comatose, on nasogastric tube feeding. Her daughter demanded removal of nasogastric tube so that she no longer had to suffer. Ms C's preference was unknown. Should we respect her daughter's

autonomy? We discussed with the daughter and tried to balance between the benefit and the burden. The patient was comatose and not seen to be suffering. Hence, feeding could prolong life but did not add burden to the patient. Therefore we advised the daughter that feeding should be continued, and the daughter's feelings were empathized.

Mr D was a 40-year-old man with lung cancer. He gradually deteriorated. When he was dying, he became stuporous and could not eat or drink. His son requested intravenous drip or nasogastric tube feeding. The patient's wish was unknown. Should we respect his son's autonomy? We again balanced between benefit and burden. The son was informed that the patient was dying. Artificial hydration and nutrition would add burden to the patient but would not prolong life. The son was also reassured that the patient, while dying, was unlikely to feel hungry or thirsty. However, he could still suffer from dry mouth and the son was advised to moisten his father's mouth frequently using a syringe.

The patients' sense of pride could be maintained by their accomplishments. A 58-year-old woman with lung cancer had extensive bone metastases, with broken legs and arms. Despite the fractures, she could still manage to make some souvenirs, for her friends and significant others. Another patient submitted an article to Kung Kao Po, to fulfill his duty as a Catholic.

Families have an important role in preserving the patients' dignity. In Hong Kong, palliative care units are often decorated to be as homelike as possible, with a family room where the patient's family, including children, can stay overnight.¹⁰ We always assess the needs of the family. We provide psychosocial support, facilitate communication between the patient and the family, respect their personal space, protect their privacy, and allow flexible visiting hours.

Visitors include pets, which are considered one of the patient's significant others. This was appreciated by our patients, as illustrated in this letter, '*Very grateful to the staff, especially the collaboration between various departments in facilitating the visit of his two grand-daughters*'. The grand-daughters were actually dogs! One point worth noting is that visits by pets are possible only with collaboration between not just clinical departments, but also administrative and supportive departments.

Antecedents of dignity-conserving care

To do all these, we need a team consisting of multi-disciplinary members, such as doctors, nurses, social workers, clinical psychologists, physiotherapists, occupational therapists, pharmacists, dietitians, speech therapist, pastoral care workers, personal care workers, administrators and volunteers.

But not all teams can preserve the patient's dignity. To be able to preserve dignity, we need professional knowledge in palliative care, including symptom management, and psychosocial and spiritual care. Facing death all the time, the caregiver's personal reflection is essential in their work to preserve the patient's dignity. The environment must facilitate the staff to connect with the patient. As mentioned before, palliative care units often have quiet rooms for personal reflection, and handling the staff's own emotions. Studies have shown that a flattened hierarchy with participative management increases job satisfaction and the palliative care team's performance. The team, of course, need to have shared value, emphasizing on patient-centered care instead of just focusing on physical care, economic priorities and ward routines.^{11,12}

Conclusion

Dignity is an important concept even in the Chinese population. Loss of dignity is associated with loss of the will to live. Dignity can be preserved by holistic care, focusing on not just physical, but also psychosocial and spiritual aspect; respecting the patient's privacy and autonomy; maintaining independence, sense of control and pride. The family's contribution is crucial, and their support for the patient should be facilitated.

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