



## Observed Experiences: Cultural Differences in Caring for Dying Patients in Malaysia

Loh Ee Chin\*

Department of Medicine, Faculty of Medicine, University of Malaya, Malaysia

\*Corresponding author: Loh Ee Chin, MRCP, University of Malaya, Lembah Pantai, 50603 Kuala Lumpur, Malaysia, E-mail: [loheechin@gmail.com](mailto:loheechin@gmail.com)

### Abstract

Little has been described about the cultural differences in caring for dying patients in Malaysia. This paper outlines three case studies in which the simple action of hair combing for patients by relations of different ethnicity, language, and cultural background may convey very different meanings to the people involved. The cases add insight to our understanding as practitioners on how we should seek to understand and be aware of the differences between ourselves and the people we care for in order to personalize the delivery of palliative care.

### Sources and selection criteria

I searched PubMed from January 2010 to August 2015 in the English language by using the term “the needs of dying for palliative care patient”. The search yielded 132 references, but only a limited number of articles were directly related to the *care* of dying patients, mainly focused on *cure* instead and the participants are mainly health care providers. This review is also based on personal experience gained as a specialist in palliative medicine based in a hospice and a university teaching hospital over 17 years.

### Introduction

The word ‘culture’ comes from the Latin word *colere*, which means to cultivate [1]. It is a set of norms, values and beliefs of a particular group of the community that is shared by its members [2]. Culture plays an important role in one’s life. It encompasses religions and rituals, as well as languages under diverse ethnicities. Malaysia is a multicultural country consisting of three main ethnic groups, the Malays, Chinese and Indians, who comprise 50.1%, 22.6% and 11.8% of the population respectively [3]. The Malaysian constitution grants freedoms of religion to its citizens and Islam, Buddhism, Christianity, Catholic, Hinduism, Taoism form the main religions.

During my 17 years of being a palliative care physician, I became acutely aware of the cultural differences in caring for dying patients in Malaysia. There are various religions that cross languages and cultural boundaries. Cultural practices towards the death and dying may have originated over thousand years ago and been passed down through generations. This may have been through ancestors, religions or individual observations that have transcended. It could be local practices or even personal desire (*personhood*) [4] to death and dying.

Few studies have reported on the cultural aspects of dying among the different ethnic groups in Malaysia [5]. The exploration and management of pain and suffering has been well described among palliative care patients, caregivers and healthcare providers [6]. The cultural needs of dying patients and how death is perceived remains undescribed. An awareness of cultural competence is crucial for healthcare providers in practice. If we are able to focus more on multiculturalism [7] among the patients, we will be able to improve our cultural sensitivity, cultural knowledge and cultural skills [8].

### Case studies

Three cases are outlined below that describe the same activity of hair combing but viewed from different perspectives of the participants. They are interpreted through their own culture, ethnicity and beliefs and carry very different meanings to the people involved.

#### Case Scenario One

A young Chinese mother in her 30s with advanced breast cancer was admitted to an inpatient hospice for symptom control and end of life care. She requested a single room due to her fungating wound which required daily dressing, and she also wished for more privacy in order to spend quality time with her family. She was staying in an apartment with her husband and 5 year old son before admitted. She perceived herself as a Buddhist by following her parents’ belief.

The husband and son visited her regularly. Her son desired to do something personal for his mother and in order to occupy him, she requested he to comb her long hair. The simple task was both fulfilling and created a sense of contentment and satisfaction for him. The son did his utmost to maintain the same routine every time he visited his mother and this continued for several weeks. As her condition deteriorated and she was dying, the father and the son were not present. When they arrived later, the father told his son to bid farewell to his mother. The little boy however requested to comb his mother’s hair instead. This simple action demonstrated his care and love for his mother and was the only thing he felt he could do for his mother at his tender age.

#### Case Scenario Two

A Malay lady, who is a Muslim in her late 40s was diagnosed with advanced breast cancer. She was married and had several young children under the age of 10. Having seen the breast surgeon and

oncologist, she was not keen on having any surgery, chemotherapy or radiotherapy. Her main concern was losing her breast and as a result, she declined medical treatment. Her relationship with her husband did not change after the diagnosis and she subsequently gave birth to another child.

After 4 years, she presented again with an enlarging fungating breast wound. She was admitted to the palliative care ward as the wound was bleeding and she was also very weak. At this point she consented to radiotherapy to shrink the tumor and reduce the associated bleeding. After the treatment, she openly discussed her illness and recognized that her prognosis was poor. She also requested for a blood transfusion for symptomatic relief and also with the hope of extending her life to complete some unfinished matters for her young children.

During her final admission, she was having the same problem as mentioned above and her appetite was reduced. She also requested to stay in the ward until she died as she was afraid that her young children could not cope with her death. Not being a burden to her relative was also important which influenced her decision to remain in hospital. She wished to take a shower when death was imminent to ensure that she presented a clean image before the *Day of Judgment* by Allah (God) and her husband agreed to assist her. When she suspected time was short, the nurse assisted her to shower and wash her hair. Without hesitation, her husband helped to comb her hair and dressed her in white garments. She expressed a calm reliance on the death and accepted death as God's will. "*Saya Reda*", she said, - meaning 'I am willing to submit myself to the God'. She died on that day.

After she parted, my colleague *Dr. Ummi Affah Mahamad* told me the origin of the word "*Reda*" refers to the concept of complete self-submission to Allah (God) from verse 8:30 of the *Holy Quran*; supported by the 6<sup>th</sup> pillars of *Iman* (faith) of the Muslim. They believe in predestination by Allah (God) of all things (*Qada'* and *Qadar*), both the seemingly good and seemingly bad, thus rendering calamities and pains easier to bear.

### Case Scenario Three

A man from China migrated to Malaysia in his early 20s. He was a devoted Buddhist, so as his family. They will pray and give offering to the Buddha statue at home on every 1<sup>st</sup> and 15<sup>th</sup> of the Chinese lunar calendar. He was happily married and had more than 20 descendants. When he was diagnosed with advanced lung cancer in his 80s, his family members colluded to withhold this information from him. He did not enquire further about his diagnosis or prognosis and his only physical concern was breathlessness. Throughout his treatment, he never openly discussed death and dying with his family. In Chinese culture, people tend to avoid the topic of death, possibly due to the taboo or fear of the unknown [9].

His condition deteriorated and on a subsequent home visit, he was wheelchair bound, requiring home oxygen and assistance with his activities of daily living. Several days later he gathered his family in his bedroom and requested for everyone to queue up according to seniority. He then passed them a comb and asked them to comb his hair. The first person who combed his hair was his wife, followed by his eldest son, and this continued from the oldest to the youngest. As they combed his hair, some realized he was very ill and their eyes were filled with tears. The old man imparted words advice to each of his family members as they were combing his hair. After the *ceremony*, the old man had tea and he died later on the same day. After the funeral, his family members told me it might be a ritual that the old man had witnessed from his hometown in China, where people comb the hair for an ill person as a *farewell ceremony* before depart. It could be an act he desired to adopt and complete as closure while he was still able.

### Discussion

There are different types of ways to care for a dying patient. Examples of basic physical care are bathing, combing hair, wearing

clothes and repositioning. Usually these are the daily routine performed by the care giver or health care providers. Everyone is doing it as part of the duty of care; however, it might have significant meaning to the patients when it comes to terminal stage. The simple act of hair combing in each of these cases represented different things to each person involved in the meaningful action. The author communicated and clarified with patient and care givers for the meaning of hair combing in each case. Information was obtained through direct open-ended questions in order to capture the perception of hair combing by patients and the family.

To the young boy, it was a heartfelt demonstration of care and love in action towards his mother for whom he felt he could do little else. Research had shown that children are not well in expressing love and grief verbally in general [10]. The act of caring was beyond words and the action of hair combing became the bond between the young boy and his mother.

For the husband of the lady in her 40s, combing his wife's hair was more than just an act of care and love; it was a preparatory ritual as part of her religion which was very important to her as a Muslim. On the other hand, hair combing can be easily done by the nurse who bathed the patient. However, the nurse was aware of the close relationship between the patient and the husband, therefore allowing her husband to take part in the process of caring.

In the final case, hair combing was seen in different context; it presented an opportunity for the old man to share words of wisdom and bid farewell to his family. Being the oldest man in the family, patient did not feel comfortable neither to express his feelings nor to discuss about his diagnosis/prognosis openly with the family. When he asked the family members to comb his hair, he was allowing himself and the family to prepare for death; which is also a taboo in Chinese culture.

In practicing in a multicultural setting, our own preconceived ideas and assumptions about people based on their language, ethnic background, religion or nationality may only limit us from exploring and communicating effectively with the patient and care giver regarding their own perspectives; hence serve to impair the delivery of person-centered care.

A study in Japan was conducted based on nurses' perceptions on disclosure of information to dying patients [11]. According to the researcher, it is a tradition in Japan not to disclose any impending death information to patients and nurses are perceived as keepers of family secrets. However, some patients who were not being informed often became suspicious, isolated, and angry or died unprepared. Thus, a conflict of non-disclosure of death information to the terminal illness patient created tension among the nurses. It caused a drift between nurses who believed in local traditional practices and nurses who adapted the Western values. It was a challenging process for nurses to alter their perception about disclosure of information to dying patients. These nurses wished that there will be a change of attitude among the health care providers from *curing* to *caring*.

### Conclusion

Practitioners must have a self-awareness to recognize the diversity between ourselves and our patients as well as a curiosity and openness to learn. This is vital in order to explore, and to understand how patients and families may wish to be treated before, during and after their death, rather than interpreting patient wishes and actions through our own understanding. Some people might not consider cultural practices as something significant in their lives; however when life-threatening illness strikes and facing death is a reality, certain practices, rituals or beliefs may reassume a vital place. From the cases above, the action of hair combing had a unique meaning to each individual. To truly deliver individualized palliative care, an understanding of the meaning of care to dying patient is imperative.

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