

DEATH, DYING and BEREAVEMENT

A Hong Kong Chinese Experience

Edited by

Cecilia Lai Wan Chan and Amy Yin Man Chow



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Photograph on cover courtesy of Mr Timothy H. Y. Chan

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The image shows four vertical columns of square word calligraphy. Each character is contained within a square frame. The characters, from top to bottom, are: 香 (Xiang), 港 (Gang), 大 (Da), and 學 (Xue). The style is highly stylized and modern, characteristic of Xu Bing's work.

Hong Kong University Press is honoured that Xu Bing, whose art explores the complex themes of language across cultures, has written the Press's name in his Square Word Calligraphy. This signals our commitment to cross-cultural thinking and the distinctive nature of our English-language books published in China.

“At first glance, Square Word Calligraphy appears to be nothing more unusual than Chinese characters, but in fact it is a new way of rendering English words in the format of a square so they resemble Chinese characters. Chinese viewers expect to be able to read Square word Calligraphy but cannot. Western viewers, however are surprised to find they can read it. Delight erupts when meaning is unexpectedly revealed.”

— Britta Erickson, *The Art of Xu Bing*

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1

Introduction

Amy Yin Man CHOW and Cecilia Lai Wan CHAN

Chinese Culture and Death

Fear marks the boundary between the known and the unknown. Some Chinese people believe that talking about death will increase the likelihood of occurrence. Also, by talking about death, evil spirits will be attracted to haunt people.^{1,2} In facing death, individual response is inevitably moulded by the values, attitudes, and beliefs of one's culture.^{3,4} Despite the large Chinese emigrant population in major cities in the world, available material in English on death, dying and bereavement among Chinese people is scarce. Only recently has a book, Fielding and Chan's⁵ *Psychosocial Oncology and Palliative Care in Hong Kong: The First Decade* addressed cancer deaths, psychosocial and palliative care, in English. Leung and Cheung's⁶ book, *Viewing Death*, in Chinese, is a collection of papers presented at a 2002 conference on life and death. Bagley and Tse's⁷ book is on suicide and bereavement of adolescents in Hong Kong. Other Chinese books on the topic of death and dying are translated works from the West⁸⁻¹⁰ or from Japan.¹¹⁻¹³ There are a number of Chinese books on thanatology in Taiwan¹⁴⁻¹⁸ and Hong Kong.^{19, 20} However, Chinese people in different communities may hold very different beliefs and practices related to death and dying. For example, Chinese in Taiwan want to die at home,² whereas their counterparts in Hong Kong would prefer to die in a hospital.²¹ As Hong Kong is a place where East meets West, most professionals working in the field of death, dying and bereavement adapt knowledge from the West to their practice with the Chinese population. The intention of this volume is to consolidate and disseminate valuable practical wisdom with professionals in the local and international communities who serve Chinese patients and their family members.

Death: A Chinese Experience

Chinese people are known for their inability to articulate their feelings and for commonly resorting to somatization in times of stress and emotional difficulties.²² Grief and bereavement is even harder to articulate than are feelings, as death is seen as a curse in the Chinese culture.^{1, 23} The intensity of the loss, pain, guilt and shame can be so acute that Chinese bereaved persons are unable to put their feelings into words. As well as somatizing their suffering, the pragmatic and action-oriented Chinese people focus on the performance of funeral and burial rituals, in the hope that such action can contribute to the smooth reincarnation of the diseased person. Thus, active participation in rituals and religious compliance to advice from authority are common. As a result of heavy reliance on experts and medical technology, ordinary people are excluded from taking a meaningful role in end-of-life decisions both for themselves and for their loved ones. What is left after death is a strong sense of helplessness, frustration and guilt among bereaved family members.

Disclosure of grief to non-family members might be perceived as inappropriate. Chinese family members are very close to each other. Discussing family matters in public would be disloyal to the family. Survivors should say only good things about the deceased family member. Sibling rivalry, interpersonal tensions or conflicts previously hidden may surface soon after a death in a family, as death is a stressful and traumatic event for everyone. There are also conflicting role expectations, alliances as well as questions of power and control, especially when it comes to the division of the estate and for rights over the items the deceased person has bequeathed.

Death Denial

Despite the knowledge that everyone dies, there is a general denial of death among the Chinese population. It is believed that death will come knocking if the word “death” is called or mentioned.²¹ Even the thought of the word “death” would bring bad luck. As people do not talk about death, they do not prepare for it. When people die without preparing for it, they die with unfinished business. Such denial of death may result in deep regret and severe self-blame among the bereaved loved ones.²⁴

Similar to saying “Your Excellency” or “Your Honour”, people addressed the emperor in China as “Ten Thousand Years Old, Ten Thousand Years Old”. Princes and princesses are “Thousand Years Old, Thousand Years Old”, to signify that they are close to heavenly gods who are immortal. Death is not acceptable to those in power. The attending doctors who failed to heal the emperor would have to be buried with him, for their incompetence at curing disease. Enormous resources were invested in the construction of tombs for

kings and emperors, even when they were young. The most scenic places in China are the tombs of ancient emperors. Most of the treasures recovered from tombs are now being turned over to heritage museums all over the world. The tombs at Xi'an are a good example of the magnificence of an emperor's tomb.

Talking about death is taboo in the Chinese culture. Words that sound like "death" are avoided as far as possible. For example, the number "four" (四) sounds like "death" (死) and so is avoided. Car registration numbers with the number four may invite accidental death. The numbers "fourteen" and "twenty-four" on car plates are worse, because fourteen sounds like sure (ten) death (four), and twenty-four like easy (two) death (four). Some car-owners will withdraw their randomly assigned plate number if it includes the number four, even at the expense of paying extra, to have another chance of a licence plate without four. The number "9413" will never appear, as it means nine out of ten will die (four), and only one out of ten will live (three). Flats on the fourth, fourteenth and subsequent floors ending in four in multistorey buildings in Hong Kong usually cost less than do flats on other floors. Some developers even deliberately omit all floors that end with the number four. More superstitious developers also remove the thirteenth floor from the numbering. Living on a floor that ends in the number four is seen as unlucky, as it can hasten death in the family, although there is no empirical evidence of this.

Death: A Failure to Care

In the midst of the rapid advancement of medical technology, people are given a false impression that modern medicine can cure all previously incurable diseases, and people do not have to die. Doctors see terminal illness as a "failure" of medical treatment, and family members see death as an "unsuccessful" cure. No matter how old the patients are, family members usually believe that their loved ones have died too young. This strong refusal to accept death reinforces prolonged grief among family members, because their loved ones continue to fight vigorously until the very last moment of life. When we get an injection, if we relax our arms and muscles, there is very little pain after the injection. If we are tense and tighten up, the insertion of the needle will bring greater and prolonged pain. The same phenomenon takes place in death and dying. If one is willing to accept death and relax, there is greater comfort and peace. If one fights death vigorously, the death can leave severe damage and suffering, not only on the deceased but also on the loved ones. Thus, if one is more willing to let go of life, one has more energy to live and die with peace of mind. A study on cancer patients found that fatalism and a fighting spirit is a continuous positive variable in the Chinese population.²⁵ Accepting fate can actually free up one's energy to cope more effectively with life-threatening illness and trauma.

Chinese family members are closely knit by a sophisticated web of mutual obligations and responsibilities.²⁶ The refusal to embrace death is also driven by a survivor's guilt at failure to fulfil filial obligations towards elderly parents, the duty of a husband to care for his wife, and the responsibility of parents to look after their children. For failure to protect loved ones from ill health and death, Chinese persons may indulge in self-blame, shame and guilt.²⁷

The Case of a "Crazy" Doctor

Dick was a well-known TCM (traditional Chinese medicine) practitioner who had a very good relationship with his wife and mother. He lost both of them to cancer in one year. He felt that he was totally "useless", as he could not cure his mother and his wife. He closed his clinic and lived in self-blame. Ten years later, a community worker identified him as a "crazy herbalist" who was living on welfare in a slum and spending his time talking to insects.

Death: Isolation of Bereaved Family Members

According to old traditions, a white lantern is hung outside the house if someone in that family has died. Then, the neighbours and others in the community will know what has happened. People would come to mourn and offer their condolences to the family during the first two days. Then the corpse would be buried. The children, friends and relatives will stay awake in the house, burn paper money continuously and chat until the next day. Stories around the deceased person were told, and people felt the re-establishment of connections. In psycho-social-spiritual terms, such a ritual is a debriefing experience as well as an occasion for the living trying to pave the way for the deceased to move into the next world. Burning paper money is seen as a way to provide the deceased person with the necessary financial support so that he or she can buy his or her way through the guards and gods of the underworld, to ensure a good reincarnation in the subsequent life assignment. Daoists and Buddhists describe the elaborate punishments in hell for the various crimes one commits, as deterrents for the living to violate the social expectations of a good citizen.[#]

[#] Books and other publications on what punishments in hell are like can be obtained from temples in China, Taiwan and Hong Kong. Buddhists believe that, by promoting knowledge of karma (causes and consequences), one can accumulate credits in Heaven. Thus, they would sponsor books to be given out freely to temple visitors. Some of these books can also be found in vegetarian restaurants run by practising Buddhists.

After the burial, people will stop visiting. In fact, the house in which a person dies will be seen as a place that radiates bad energy (*qi*, 氣). It may be difficult to understand this from a Western viewpoint. Why do peers shy away when the family needs support most? In the old rural communities in China, a significant number of deaths might have been caused by infectious diseases. The bad *qi* around the family of someone who died might have been bacteria and virus that may spread infection and illness. Naturally, the community would tend to avoid going near that household.

Also because of the fear of infectious diseases, all clothes worn by the family members during the funeral and burial will have to be burnt. The family will have to eat a good meal after going to the burial, take a bath in hot water with herbs, and then burn all clothing. Although the original intention of such rituals was to stop infection, these measures reinforced the traditional concept that there is negative energy around death. Anything related to the funeral and burial rituals carry bad luck or evil energy and thus have to be destroyed. Therefore, for three months after the death, neighbours and friends will not visit a home where someone died. They have to walk over a burning fire before entering their own home, in order to burn away the “bad” or “toxic” energy that they might have picked up in the home of the deceased person. If we look at it from the perspective of modern medicine, these measures were performed for the prevention of the spread of epidemics in olden days.

Bereaved family members may not be able to concentrate and be accident-prone. If something goes wrong, the hypothesis that the bereaved person carried “bad luck” is confirmed. Without trying to find out the true reasons for cultural myths, the concepts of toxic energy and bad fate around bereaved family members continued into modern society. The fear of death and the reluctance to go near a house in which someone died are still very common, despite the fact that very few people actually die of infections in modern Chinese cities such as Hong Kong. The mass infection of SARS in Toronto during the SARS outbreak in 2003 reminded us of the possibility of infection at funeral services.

When friends are not willing to visit, the bereaved are left to grieve alone. Besides the loss of a loved one, bereaved persons have to bear social isolation from friends and peers. They are expected to stay away from happy celebrations such as weddings and birthday parties, because the bereaved will bring bad luck. It is a stressful experience to have someone die in the family, especially when the bereaved are seen as carrying negative energy around them.

Funerals and burial rituals give bereaved family members a sense of security, as it creates structure for the bereaved to hold on to. There are specific tasks to carry out during each day after death until the forty-ninth day, when the deceased is supposed to be reincarnated. Traditional Chinese mourning rituals last for three years, according to Confucius’ teaching. Widows

in traditional China are expected to mourn for the rest of their lives, because a woman can be married to only one man. Details of the Daoist rituals can be found in Chapter 4.

Death: The Great Teacher of Life

Death is often seen as a bad experience, yet there can be precious discoveries. The positive reaction to the book *Tuesdays with Morrie*²⁸ is a good example. Through the pain of facing death, we can appreciate the blessings in life. It is in the midst of the fear of death of our beloved family members that we treasure each and every one of them more dearly. In fact, death is not necessarily sad and miserable. Death can be a precious moment of completion, fulfillment and a perfect ending to lifelong learning. Our funeral is equivalent to our graduation ceremony to celebrate a life worth living and the legacies we leave. Awareness of death leads us to the appreciation of the vulnerability of life and life itself.

Life

Life is an opportunity, benefit from it.
 Life is beauty, admire it.
 Life is bliss, taste it.
 Life is a dream, realize it.
 Life is a challenge, meet it.
 Life is a duty, complete it.
 Life is a game, play it.
 Life is love, enjoy it.
 Life is mystery, know it.
 Life is a promise, fulfil it.
 Life is sorrow, overcome it.
 Life is a song, sing it.
 Life is a struggle, accept it.
 Life is tragedy, confront it.
 Life is an adventure, dare it.
 Life is life, fight for it.

Author Unknown

If we replace the word “life” in the above verse with the word “death”, most of the sentences in the passage still make sense. Death is part of life. Life is uncertain. The only certain promise in life is that all of us will die. According to Eastern philosophers, life is a difficult journey full of suffering. Infants start the journey by crying and end with a sense of relief when they

die. Most people refuse to acknowledge the inevitability of death. As we become attached to people, to possessions, to power, to material comfort, it is hard to say goodbye to life.

Life and death, sickness and health, meeting and parting, love and hate, attachment and letting go, apathy and involvement, disengagement and integration, dependency and alienation are part of the reality of our existence. We have an impression that these facts of life are opposites, like the sun and the moon. In reality, we can always find the moon shining in the sky before the sunset. Life is interesting because of its impermanence and unpredictability. The processes of gain and loss can be both joyful and painful. For example, when a couple gets married, they are happy and joyful. Despite the wish to live happily ever after, one certain outcome of marriage is that it will end. In pre-marital classes, couples learn to handle matters of trust, intimacy, in-law relationships, family planning and asset management. However, there have yet to be offered anticipatory divorce or bereavement courses to help people prepare for the end of marriage, through spousal death or marital breakdown.

Death, Dying and Bereavement

In the first part of the book, we focus on the discussion of **death**. Chapter 2 is the recollections of our clinical experiences in the area of death, dying and bereavement. At times we witnessed the pain of the family when a family member faced death. Some patients isolated themselves or used all their energy to fight the unbeaten enemy — death. There are those who use their final days to attend to unfinished business, to reconcile and to forgive their loved ones as well as to realize their dreams. Those that can give the patient permission to die have an easier bereavement. Effective communication among family members seems to be a crucial step to restructure a mutually accepted way of facing the impending death.

In Chapter 3, Yvonne Mak shares her personal experience as a patient, a hospice physician, a researcher and a care-giver of her own family members with life threatening illness. She affirms that death can be transformational. There can be growth through the process of confronting our death and end of life and that of our loved ones and the people we serve.

In addition to social workers and physicians, a professional actively involved in the area of death is the funeral director. The funeral arrangements in Hong Kong are quite different from those in the West. Usually, different rituals dominate funerals. Based on an interview with a funeral consultant in Hong Kong, personal reflections as well as literature review, Ka Hing Cheung and colleagues contribute the fourth chapter of this book, unveiling some of the mysteries around the Daoist funeral rituals in Hong Kong. Using the

continuum of *letting go* and *holding on*, they analysed the meaning behind the different rituals and how they contributed to the adjustment to bereavement. Chapter 5 is also about funeral rituals, but from an academic point of view. Chi Tim Lai shares his reflections on Daoist funerary liturgy. A chapter by Jin Yin follows, on the Buddhist view of death, dying and bereavement.

Forensic pathologists deal with unnatural deaths such as suicide, homicide and accident. About thirty percent of deaths in Hong Kong involve pathologists in identifying the causes of death. Philip Beh, an experienced forensic pathologist, briefs us on the procedures in handling unnatural deaths, in Chapter 7. Facing the deep-rooted traditional belief of being buried whole, he shares the interaction and dynamics with family members on the negotiation of autopsies.

Wing Shan Cheung and Samuel Ho share their study on the personal meaning of death among Chinese, through the images or metaphors of death. The most common theme in the drawings of death among their respondents is “a separation from the loved one”. The interpersonal nature of death and bereavement is obvious. Although the majority of the respondents used negative adjectives to describe death, as well as black and white to draw images of death, a substantial percentage of respondents used positive adjectives or bright colours. The perception of death among Chinese is not necessarily all negative. Wallace Chan and his colleagues reconsider the topics of good death through a historical review of traditional philosophy and public opinion studies. Physical and psychosocial well-being are the two key factors contributing to a good death.

The second section of our book is on the process of **dying**. About one-third of the deaths in Hong Kong are caused by cancer. Palliative hospice care is for those who have incurable cancer. Through home care and hospice beds, professionals address the physical, psychosocial, and spiritual needs of their patients through the last months, weeks and days of their lives. The Chinese name for hospice care has been translated as *xian zhong* (善終, literally, good ending). More recently, there has been a change in the use of term, because the public resents the concept of the hospice and equates it with death and the termination of life. New terms, such as *xian ning* (善寧, literally, good and peaceful), *ning yang* (寧養, peaceful and nurturing) and *shu huan* (紓緩, relax and relief) are being used in the name of service units instead of the old term of “good ending”. Chinese in Hong Kong probably find the term “*zhong*” (終, ending) hard to accept. No matter what name is used, the professionals of palliative hospice care in Hong Kong are committed to providing quality care to all who are facing death. When we first shared our idea of editing this book, responses from the palliative care teams were very positive. Contributors of the second section of this book are from the palliative hospice care professionals in Hong Kong.

Michael Sham, Doris Tse, Kin Sang Chan and Raymond Lo are leaders of

hospital and palliative care in Hong Kong. Their chapter, “Impact of Palliative Care on the Quality of Life of the Dying”, succinctly describes the key concerns from the perspective of health care providers. With a rich historical review and detailed research findings, Chapter 10 guides us through a timeline of palliative care development in Hong Kong. Raymond Lo further elaborates on the medical and psycho-social-spiritual aspects of the final month of a dying patient. After discussing the problems faced by patients and families, he proposes strategies to relieve both the physical symptoms and psychosocial distresses.

Chinese people use the terms “euthanasia” and “palliative hospice care” interchangeably. The confusion lies in the similarities in their Chinese name and poor public knowledge of what death, euthanasia and palliative hospice care are about. Chun Yan Tse and Samantha Pang offer the term “euthanasia” from medical, legal and cultural points of view in Chapter 12. They further differentiate the term from “palliative care” and “forgoing life-sustaining treatment”. Though forgoing life-sustaining treatment seems to be a patient’s individual decision, such a decision affects the whole family as well.

Nursing and community care are two significant components in palliative hospice care. Faith Liu, an experienced nurse specialist in palliative care, highlights the development of community palliative care in Hong Kong, in Chapter 13. Because of her extensive experience in caring for families with end-stage cancer, this chapter blends her expert knowledge and her devotion to promoting humanity. At the end of her chapter, she suggests practical tips that health-care professionals should note.

Despite the fact that Western medicine dominates the health-care delivery system in Hong Kong, patients pragmatically seek different sources of care, including Chinese medicine, when disease progresses. Siu Man Ng, a registered practitioner in Chinese medicine with rich experience in the field of mental health, describes the contribution of Chinese medicine to cancer palliative care, in Chapter 14. For those unfamiliar with the concepts of Chinese medicine, this chapter is an excellent start. Chinese medicine can be a complimentary treatment and helps to reduce undesirable side effects of chemotherapy, radiotherapy and surgery. Chinese medicine can also enhance the total well-being of the dying patients and increase the participation of family members, by helping them to accept the inevitability of death.

Human resources are the most important assets in the health-care system, especially in palliative care. Peter Lee and Tracy Kwan remind us of the importance of staff support in palliative care. Compared with other units in health care, palliative hospice care has the highest “death rate”. In repeatedly confronting death, which might be taken as professional failure, health-care professionals respond with great emotional and spiritual pain. Lee and Kwan share their vision of how appropriate staff support can facilitate greater effectiveness in the delivery of palliative care.

Death can also be caused by illnesses other than cancer and can happen

in wards other than hospice wards. Amy Chow and nurses in Kwong Wah Hospital describe ways of handling death in acute wards like medical, surgical and intensive care units, in Chapter 16. Strategies in working with patients and families facing death with little time to prepare for it are described through two case stories. A CDE model is introduced for working with families facing impending death.

Although the majority of deaths take place in late life, children and adolescents can die. In Chapter 17, Vivian Lou and Cecilia Chan discuss their study of grieving parents of children with cancer in Shanghai, where couples are allowed only one child. Thus the impending death of the only child may mean an end to their future as parents. The parents may spend all their money or even get themselves into heavy debt, as there is limited financial support for medical care in China. The parents grieve the loss of the child as well as the end of their dreams. It is hoped that this chapter can raise the concern of policy-makers on the establishment of proper medical insurance and protection for the population in mainland China.

The third section of this book focuses on **bereavement**, the loss of loved ones through death. In Chapter 18, we describe the development of bereavement care in Hong Kong. As there is no equivalent Chinese term for bereavement, we increase the awareness of the needs of bereaved persons and generate guiding principles in working with the Chinese population. These strategies have been well received by professionals all over the world and can be applied to Chinese who are migrants to other countries.

Agnes Tin, Brenda Koo, Elaine Koo, and See Man Lee of the Jessie and Thomas Tam Centre (JTTC), the community-based bereavement counselling centre in Hong Kong, contributed to Chapters 19 and 20. Chapter 19 integrates the traditional Eastern values and cultures into counselling models and offers practical guidelines in serving different bereaved groups of widows, widowers, parents, children and grandchildren. Chapter 20 discusses the theoretical background, design, application and implementation of structured therapeutic bereavement groups in Hong Kong. The authors introduce creative and culturally sensitive group activities as well as outcome evaluation on the effectiveness of these groups.

In addition to professional care, volunteers provide bereavement services. Eddie Chan, from the Comfort Care Concern Group, a volunteer-oriented organization in providing services for terminally ill and bereaved persons, shares his experience in using volunteers in bereavement care. Chan discusses the difficulties encountered in recruitment, selection, training and mobilizing volunteerism in the Chinese culture. Contrary to common beliefs that bereaved Chinese person is well supported by the family, Chan saw growing demand for volunteers in bereavement care as well as in guidance through funeral and burial rituals.

Suicide is considered a family shame. Along with guilt, shame, confusion, the traumatic scene of the suicide and the complicated criminal investigations before getting a death certificate, the pathway to recovery for the bereaved family of a suicide is often prolonged and difficult. In the last chapter, Chow portrays the pathway of the bereaved families of suicides in Hong Kong. A SUICIDE bereavement model is proposed as the intervention with this special target group.

We hope the rich cultural illustrations on a different temporal frame of death can help to paint an impressionist picture of death among Chinese, a forbidden and mysterious yet necessary path that we all have to take in our lifetime. Let's start the adventurous journey ...

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