

**Health Promoting Palliative Care through Higher Education Reform:  
Development and Evaluation of a New Humanities Course in Thanatology**

**HO ANDY HAU YAN**

B.A., *U.B.C.*; P.G.D.E., *U.B.C.*; M.Soc.Sc., *H.K.U.*, Ph.D., *H.K.U.*

Thesis submitted to the University of Nottingham  
for the Degree of Doctor in Education (EdD) in Lifelong Education

JUNE 2016



## ABSTRACT

### **Health Promoting Palliative Care through Higher Education Reform: Development and Evaluation of a New Humanities Course in Thanatology**

Under a socio-cultural backdrop where death and loss is heavily stigmatized and community resources for the dying and the bereaved are lacking, Hong Kong requires a public health approach for empowering its people to become active participants in the governance of mortality. “Health-promoting palliative care” (HPPC) translates the hospice ideals of total person care into much broader public health languages and practices, focusing not only on palliation but also prevention, harm reduction, community action, policy advocacy, and most importantly, education and research. Despite their significance, life and death education and Thanatology research has received little attention in Hong Kong. The recent General Education (GE) reform for tertiary institutions, which aims to nurture students’ creativity and civility through the liberal arts, provides a timely opportunity to actualize HPPC.

The current study provides a formative account of the development and implementation of a new thanatology course, “The Last Dance: Understanding Death and Dying” offered by the University of Hong Kong, and critically examines its efficacy for reducing negative death perceptions and enhancing positive life attitudes among a group of undergraduate students. Adopting a mixed methods research design and a holistic approach to education evaluation, it utilizes: 1) a quantitative pretest-posttest survey to assess course effectiveness with the standardized tools of Death Attitude Profile-Revised, Meaning-in-Life Scale and Spirituality Scale, as well as a series of ad hoc items on traditional

death taboos and death preparedness behaviors; and 2) a qualitative analysis of 100 randomly selected students' reflective writings for identifying factors that facilitate effective learning.

Results from paired-sample t-test with 85 students who have successfully completed the pretest-posttest survey provide robust evidence that The Last Dance was effective in significantly reducing students' fear of death, death avoidance tendency, and taboo beliefs that oppress death, while promoting active participation in the governance of mortality through increased death preparedness behaviors. Moreover, The Last Dance was found to be effective in enhancing students' sense of meaning in life, spirituality and interconnectedness.

Framework analysis of Students' reflective writing revealed 12 themes that illuminate the specific learning contents, pedagogy activities, key attitudinal and behavioral changes, as well as significant learning outcomes which supported the quantitative results. These 12 themes were organized into four categories: 1) "Mortality Matters", which includes Consideration of Palliative Care and Euthanasia, Expression of Death via Arts and Media, and Exploration of Death Rituals and Spirituality; 2) "Teachable Moments" which includes Multi-Media Lectures, Funeral Home Visitation, and Examination of life; 3) "Shifting Perspectives", which encompasses Cultivating Insights, Renewing Meaning, and Applying Knowledge; and 4) "Ego Awakening" which encompasses Normalization of death, Appreciation of Life, and Recognition of Common Humanity.

These 4 categories and their respective 12 themes together form a “Thanatology Pathway to Transformative Growth”, highlighting the vital significance of carefully integrating stimulating learning contents with engaging pedagogical activities for developing an effective and holistic thanatology curriculum; one that focuses not only on skills and knowledge transfer, but also on cultivating life appreciation and compassionate living through an enhanced understanding of death, dying and bereavement.

(500 words)



## ACKNOWLEDGMENTS

To my kind and beautiful wife, Geraldine, thank you for your unconditional love and unwavering support throughout this voyage of learning, I am truly blessed to have you in my life. To my parents, Agnes and Joe, thank you for your patience and invaluable teaching that directed me towards a life of purpose and integrity; my love and my gratitude. To Dr Gary Winship, Professor John Holford and Professor Roger Murphy, thank you for your many inspirations and guidance throughout my EdD studies; this has been a greatly rewarding experience of lifelong learning. To my students of The Last Dance, thank you for embarking on life's most important exploration with me, and openly sharing with me your fears, hopes and dreams. To every patient and family that I have worked with over the years, thank you for giving me the opportunity to journey with you in the final chapter of life, and ever so kindly teaching me the values of compassion, perseverance and humility.

This study was generously funded in part by the Common Core Teaching Development Grant, The University of Hong Kong (Ref no: 10100434.12172.30300.339.01).





## TABLE OF CONTENTS

|  |           |
|--|-----------|
| Abstract .....   | i         |
| Acknowledgments.....   | iv        |
| Table of Contents .....  | v         |
| Abbreviations .....  | viii      |
| List of Figures .....  | ix        |
| List of Tables .....   | x         |
| List of Appendices .....   | xi        |
| <b>CHAPTER ONE: Introduction .....</b>                                   | <b>2</b>  |
| Statement of the Problem .....   | 4         |
| A Death Denying Ethos .....  | 6         |
| Evolving Attitudes toward Death and Dying in Western Worlds .....        | 8         |
| Taboo and Stigma of Mortality in Chinese Culture .....                   | 19        |
| The Oppression of Death and Loss in Hong Kong.....                       | 27        |
| Purpose and Objectives of Research .....                                 | 31        |
| Chapter Summary.....   | 33        |
| <b>CHAPTER TWO: Literature Review &amp; Curriculum Development .....</b> | <b>34</b> |
| Palliative Care Practices and Policies in Hong Kong .....                | 34        |
| Overview of Palliative Care Development.....                             | 35        |
| Current State and Quality of Palliative Care .....                       | 38        |
| Sustainability Challenges of Palliative Care .....                       | 41        |
| The Rise of Health Promoting Palliative Care .....                       | 44        |
| The Expansion of Palliative Care .....                                   | 45        |
| The Foundation of Health Promotion.....                                  | 48        |
| The Integration of Health Promoting Palliative Care.....                 | 50        |
| The Imperative of Life and Death Education.....                          | 53        |
| Early Development of Life and Death Education .....                      | 54        |
| Life and Death Education for Health and Allied Health Professionals .... | 57        |
| Life and Death Education in Primary, Secondary and Tertiary Schools..    | 59        |
| A Thanatology Curriculum for Hong Kong Higher Education Reform .....     | 61        |
| The Common Core Curriculum.....  | 63        |
| The Last Dance: Understanding Death and Dying.....                       | 64        |

|   |           |
|---|-----------|
| Pedagogy, Assessment and Learning Outcomes .....                          | 69        |
| Chapter Summary .....   | 75        |
| <b>CHAPTER THREE: Methodology .....</b>                                   | <b>76</b> |
| Research Design .....   | 77        |
| Participants Recruitment and Procedures .....                             | 78        |
| Pretest-Posttest Survey - Quantitative Measures .....                     | 79        |
| Analysis of Students' Reflective Writing on Learning and Teaching.....    | 85        |
| Data Analysis .....   | 85        |
| Ethical Considerations.....   | 88        |
| Chapter Summary .....   | 90        |
| <b>CHAPTER FOUR: Results, Findings &amp; Analysis .....</b>               | <b>91</b> |
| Results from Pretest-Posttest Student Survey .....                        | 91        |
| Sample Characteristics .....  | 91        |
| Results from Paired-Sample T-Test .....                                   | 94        |
| Findings from Qualitative Analysis of Students' Reflective Writings ..... | 98        |
| Major Theme Category of "Mortality Matters" .....                         | 98        |
| <i>Considerations of Palliative Care and Euthanasia</i> .....             | 99        |
| <i>Expressions of Death via Arts and Media</i> .....                      | 101       |
| <i>Exploration of Death Rituals and Spirituality</i> .....                | 104       |
| Major Theme Category of "Teachable Moments" .....                         | 106       |
| <i>Multi-Media Lectures</i> .....   | 107       |
| <i>Funeral Home Visitation</i> .....                                      | 109       |
| <i>Examination of Life</i> .....  | 112       |
| Major Theme Category of "Shifting Perspectives" .....                     | 114       |
| <i>Cultivating Insights</i> .....   | 115       |
| <i>Renewing meaning</i> .....   | 117       |
| <i>Applying Knowledge</i> .....   | 118       |
| Major Theme Category of "Ego Awakening" .....                             | 121       |
| <i>Normalization of Death</i> .....                                       | 122       |
| <i>Appreciation of Life</i> .....   | 124       |
| <i>Recognition of Common Humanity</i> .....                               | 126       |
| Chapter Summary .....   | 129       |

|   |            |
|---|------------|
| <b>CHAPTER FIVE: Discussion &amp; Conclusion.....</b>           | <b>130</b> |
| Discussion of Quantitative and Qualitative Findings.....        | 131        |
| Student Enrollment, Death Preparedness and Perceptions.....     | 131        |
| Changes in Attitudes and Behaviors towards Mortality.....       | 134        |
| Transformation of Worldviews towards Life and Spirituality..... | 139        |
| Thanatology Pathway to Transformative Growth.....               | 143        |
| Limitations of Research.....                                    | 146        |
| Concluding Remarks.....   | 150        |
| References.....   | 152        |
| Appendices.....   | 175        |

## ABBREVIATIONS

|         |  |
|---------|--|
| ADEC    | Association for Death Education and Counseling             |
| CCC     | Common Core Curriculum                                     |
| DAP-R   | Death Attitude Profile-Revised                             |
| DPB     | Death Preparedness Behaviors                               |
| EOL     | End of Life  |
| GE      | General Education  |
| HA      | Hospital Authority   |
| HPPC    | Health Promoting Palliative Care                           |
| HKU     | The University of Hong Kong                                |
| HRECNCf | Human Research Ethics Committee for Non-Clinical Faculties |
| IWGDDb  | International Work Group on Death, Dying and Bereavement   |
| M       | Mean   |
| MLQ     | Meaning in Life Questionnaire                              |
| SD      | Standard Deviation   |
| SPS     | Spirituality Scale   |
| TDT     | Traditional Death Taboos                                   |
| TPTG    | Thanatology Pathway to Transformative Growth               |
| WHO     | World Health Organization                                  |

## LIST OF FIGURES

|                   |   |     |
|-------------------|---|-----|
| <b>Figure 1.1</b> |   |     |
|                   | Dance of the Dead – The Three Living and The Three Dead...    | 10  |
| <b>Figure 1.2</b> |   |     |
|                   | Dance of Death – Surmatants (Totentanz).....                  | 11  |
| <b>Figure 1.3</b> |   |     |
|                   | Bourgeois Death – De efficacy Medicina.....                   | 13  |
| <b>Figure 1.4</b> |   |     |
|                   | Clinical Death – Safety Coffin.....                           | 14  |
| <b>Figure 1.5</b> |   |     |
|                   | Health as Commodity – Public Health Campaigns.....            | 16  |
| <b>Figure 1.6</b> |   |     |
|                   | Death in Intensive Care – Self Portrait with Dr. Langley..... | 18  |
| <b>Figure 4.1</b> |   |     |
|                   | Thanatology Pathway to Personal Growth.....                   | 144 |

## LIST OF TABLES

|   |    |
|---|----|
| <b>Table 4.1</b>  |    |
| Characteristics of Student Participants.....                  | 92 |
| <b>Table 4.2</b>  |    |
| Death Preparedness Behaviors at Baseline.....                 | 93 |
| <b>Table 4.3</b>  |    |
| Views on Traditional Death Taboos at Baseline.....            | 94 |
| <b>Table 4.4</b>  |    |
| Paired Sample T-Test results on Mortality Perception.....     | 95 |
| <b>Table 4.5</b>  |    |
| Paired Sample T-Test results on Death Taboo & Preparedness... | 96 |
| <b>Table 4.6</b>  |    |
| Paired Sample T-Test results on Meaning & Spirituality.....   | 97 |

## LIST OF APPENDICES

|  |     |
|--|-----|
| <b>Appendix 1</b>                                    |     |
| Publications Related to this Study.....              | 175 |
| <b>Appendix 2</b>                                    |     |
| Course Outline for The Last Dance.....               | 177 |
| <b>Appendix 3</b>                                    |     |
| Assessment Rubric for Student Reflective Log.....    | 189 |
| <b>Appendix 4</b>                                    |     |
| Assessment Criteria for Group Presentation.....      | 190 |
| <b>Appendix 5</b>                                    |     |
| Assessment Criteria for Group Written Report.....    | 191 |
| <b>Appendix 6</b>                                    |     |
| Letter of Ethical Approval for Current Research..... | 192 |
| <b>Appendix 7</b>                                    |     |
| Letter of Informed Consent for Current Research..... | 193 |
| <b>Appendix 8</b>                                    |     |
| Pretest-Posttest Student Survey Questionnaire.....   | 195 |





## CHAPTER ONE INTRODUCTION

Anxiety and fear of death among Chinese individuals, and most individuals in general, are prominent and manifested from a wide range of deep rooted taboos that stem from various cultural and religious ideologies as well as their interpretations (Ho & Chan, 2011). Such negative undertone towards life's end is also influenced profoundly by the evolving social structure of modernity, marked by the rise of medical markets and the decay of communities, whereby the management of dying and grief has become the bureaucratic responsibilities of health authorities rather than the benevolent duties of families and neighborhoods. As such, the contemporary experience of loss and end-of-life is often oppressive because the provision of care for the dying, the traditional rituals for honoring the dead, and the conventional practices for supporting the bereaved consist of invisible forces that nurture taboos. All together, they have created a culture of apathy and avoidance that inevitability weakens the social and moral fabric of society when lives are lost. It is in this depressing context that individuals, families, patients and even healthcare professionals often find themselves ill-informed and ill-equipped to cope with the many demands and challenges of dying, death and bereavement. With fear and anxiety succeeding hope and compassion, the health and psychology of our local and global communities have suffered immensely in the face of mortality.

Under a socio-cultural backdrop where death and loss is heavily stigmatized and community resources for the dying and the bereaved are greatly lacking, Hong Kong requires a public health approach to empower its people to become active participants in the governance of mortality (Conway, 2012; Ho

and Chan, 2011). “Health-promoting palliative care” (HPPC) translates the hospice ideals of total person care into much broader public health languages and practices, focusing not only on palliation but also prevention, harm reduction, community action, policy advocacy, education and research (Kellehear, 1999; 2005). In particular, life and death education serves as the main impetus that facilitate individuals and families to assess their own needs and concerns at the end-of-life so as to develop strategies to address them; whilst research on Thanatology (i.e. the scientific study of death) becomes the vehicle that drives educational initiatives and informs policy advocacy to bolster and ensure the sustainable development of palliative care (Meiwer & Beresford, 2007).

Despite their paramount importance, life and death education and Thanatological research has received little attention in Hong Kong as its education system has perpetually emphasized the injection of marketable skills and knowledge into the minds of students, over the cultivation of whole persons through holistic development. The recent General Education (GE) reform for tertiary institutions which aims to promote a comprehensive learning experience for nurturing students’ creativity and civility through the liberal arts (Education and Manpower Bureau, 2005), is a breath of fresh air and provides a valuable and timely opportunity to actualize the ideals of HPPC. The current study develops a new undergraduate humanities course on thanatology and evaluates its effectiveness in reducing longstanding taboos and oppressive thinking towards death, as well as promoting death preparedness behaviors, sense of personhood and civil responsibility for the governance of mortality among a sample of university students in Hong Kong. It fills an important knowledge gap

on public health palliative care in Chinese societies and sheds lights on the future development of life and death education in a global context.

### **Statement of the Problem**

To most people, death is an inconvenient truth, but to all living beings, it is an undeniable one. Death is the only certainty in a lifetime filled uncertainty. It is the single constant in our impermanent existences where each one of us will eventually vanish from this physical world, leaving nothing behind but the atoms and ashes that we once belong. But despite the fact that every human being will experience death, either through dying or vicariously through the loss of a loved one, death remains as a shadowy figure that most people have difficulty facing, discussing or even considering. In between our anxiety and avoidance toward mortality, we have relegated death to the periphery of our lives, to keep it out of sight and out of mind. Yet in doing so, we inevitably become victims of our own fear as we turn weak and powerless in the face of death, dying and bereavement.

I still remember vividly the look of sadness and despair in my mothers' eyes when her own mother fell critically ill, how a strong willed woman turned desperately hopeless in the face of loss, and how my mother was utterly lost for words in her fertile attempt to comfort my grandmother in her dying days. I still remember vividly the sense of regret and sorrow when my father lost his own father, how a successful and brilliant man turned feeble and dependent in the face of grief, and how my father's spirit was defeated and crushed in the wake of my grandfather's death. I still remember vividly the faces of all terminal-ill patient that I have interviewed with as an thanatology researcher, how each one of them wished to feel more in control of their lives in the end of life, but often

failed to effectively communicate their needs and concerns to their families and care providers due to avoidance and fear (Chan, Ho, Leung, et al., 2012). I still remember vividly of all the conversations I have had with bereaved families as a grief counselor, how everyone of them wished to feel more connected to their dying loved ones at life's most precious moments, but often failed to express appreciation and find reconciliation due to stigmas and taboos (Ho, Leung, Chan, et al., 2015). I still remember vividly of the tired and weary eyes of all palliative care doctors, nurses and social workers that I have worked with as a clinical supervision trainer, how they suffered from burnout and compassion fatigue but were unable to garner support and understanding from their colleagues, as the entire profession were under extreme duress with little time and resources allocated to the alleviation of stress and the promotion of self-care (Potash, Ho, Chan, et al., 2014).

Having experienced countless mortalities over the past decade through my work in end-of-life care settings; having witnessed firsthand the dread and desolation of the dying and the bereaved due to a death denying culture; having encountered the grief and sorrows of hospice and palliative professionals under an oppressing healthcare system, and having published more than twenty articles, chapters and books to promote and advocate for dignified palliative care (*Please see Appendix 1 for a list of thanatology publications related to the current research*); it has become clear to me that we, as a people, desperately need to enhance our knowledge, understanding and emotional capacities in managing our own deaths, as well as those of our loved ones. It is based upon these observations, as well as my conviction to empower individuals to find

meaning in the face of mortality, that I embark on this empirical journey in developing and evaluating a new life and death curriculum for higher education.

### **A Death Denying Ethos**

Philosophers and researchers have long argued that we as a species must balance between accepting and denying death so as to maintain a grasp on reality while remaining committed to a future limited by mortality. Death acceptance however has never been a forte of the human race, as attitudes towards death and dying in modern societies has generally accentuated the scent of fear, anxiety and rejection. In his highly influential book *The Denial of Death*, anthropologist Ernest Becker (1973) established that,

“The idea of death, the fear of it, hunts the human animal like nothing else; it is a mainspring of human activity – activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man (p. xi).”

Based on the works of Becker, social psychologists Solomon, Pyszczynski and Greenberg (1989) established the Terror Management Theory (TMT), which purported that as humans struggle between the supreme desire to live and the awareness of life’s finite nature, a basic psychological conflict emerges and produces primal and extraordinary terror. Solomon et al. (1989) further purported that this terror is unique to human beings and we do have the capacity to manage it, specifically through finding meaning and values in our existences by identifying with prevalent cultural and religious beliefs, political views, social structures and other symbolic systems. Such identification elevates our sense of self-esteem and makes us believe that we can indeed be immortal,

albeit symbolically and dependent upon external factors rather than internal convictions.

Renowned sociologist Talcott Parsons (1963) had also observed that it is human tendency in “brining to bear every possible resource to prolong active and healthful life”, and only accepting the defeat of death when “it is felt inevitable” (p. 62). He argued that the repugnant association between mortality and grief, “not only in the sense of pain, but also in the frustration of disability and the various aspects of mental suffering” (p. 63), would cause people with fatal illness to mitigate and even numb their agony through widespread use of medical sedatives. Moreover, the spiritual distress and existential anguish related to the end-of-life would inevitably lead individuals to emotionally distance themselves from the reality of death, creating to a widespread phenomenon of apathy. Parsons further warned that the “renunciation of the moral responsibility” on mortality would ultimately conduce to the “privatization” and “institutionalized provision of coping” for the dying and the bereaved, as well as the “complete dependence on higher authority” in the occurrence of fatality among the masses (p. 64).

Despondently, both Becker and Parsons forecasted a death-denying culture that negates and undermines the strengths of the individual, the family, as well as the community in facing, overcoming and governing the challenges of mortality. Together they have painted a future of oppression in dying, death and bereavement; a painting that has been produced repeatedly albeit in different forms by countless artists across our modern history.

## **Evolving Attitudes toward Death and Dying in Western Worlds**

Since the origin of men, death has long been seen as a spiritual event deemed religiously predestined, a divine act of god or of a higher power, experienced not only by the individual but also felt and shared through the community. Cave excavations in Northern Spain recorded the earliest human funeral behaviors colored by spiritual symbolism, dating back as early as 100,000 years prior and belonging to the species of *Homo heidelbergensis*, the ancestor of all modern humans (Carbonell, Mosquera, Qlle et al., 2003). However, such longstanding spiritual and religious nuance in understanding mortality has evolved radically since the early modern era.

In his seminal work *Limits to Medicine: Medical Nemesis*, philosopher Ivan Illich (1976) maintained that human attitudes toward death and dying are determined largely by the prevalent social contexts, specifically its political economies, institutional structures, social actors and enduring myths. The vision of a ‘natural’ death in old age with years of preceding good health is only a contemporary ideal, as Illich postulated that the dominant image of death of every society is intricately linked to the prevalent concept of health. Based on this notion, he elaborated on six progressive stages in the evolution of attitudes toward mortality in the modern Western worlds.

### ***Dance of the Dead***

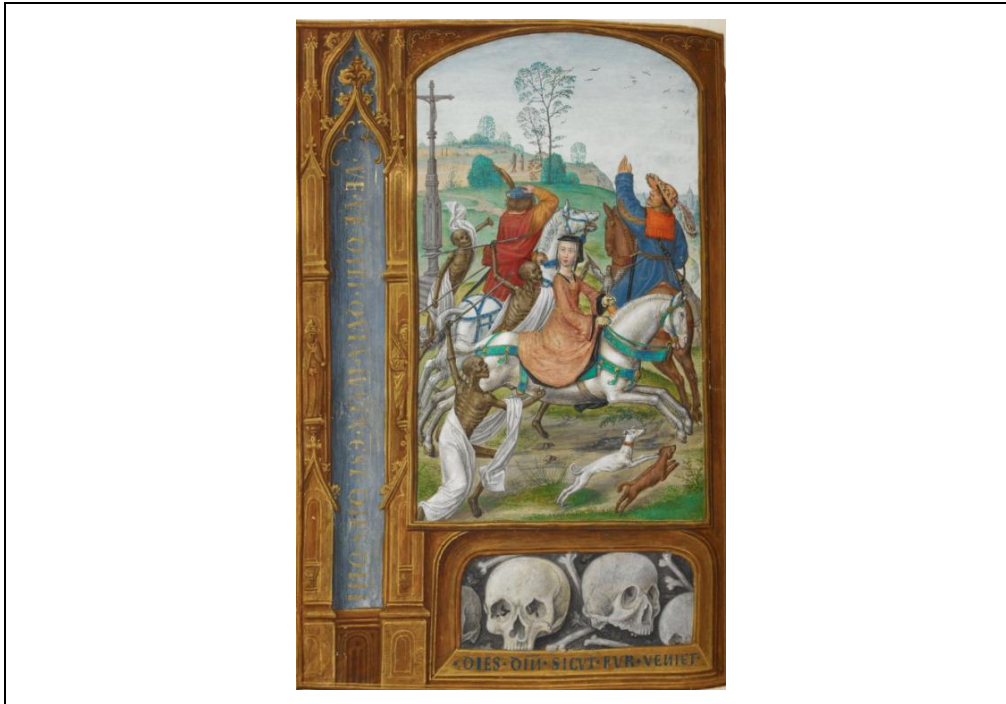
Illich (1976) posited that the first paradigm shift in how human beings perceived and understood death began in the 15<sup>th</sup> Century, a period coined “Dance of the Dead”. Before the middle ages, death has long been seen as a *divine intervention of god*, a higher power or a foreign agent, in which

individuals had no control over and were dependent upon the protection of faith. However, with the historic separation between the Church and the State marked by the beginning of the Reformation movement, people began to find religious liberty, freedom and autonomy in living their lives.

Death at this juncture of time had also become autonomous, a coexisting but separate agent with the immortal soul and divine providence (O’Gorman, 1998). This radical transformation marked the realization of the universality of death among the masses, with increasing and widespread acknowledgement that each and every living soul is united through mortality. The “Dance of the Dead” is best illustrated by popular paintings of the time which captured men and women dancing with mirror images of their older or deceased selves and embracing their own impermanence (See Figure 1.1). As death was represented as a macabre self-consciousness and a constant awareness of the gaping grave, Illich (1976) proposed that society was also ready to accept death as a ‘natural event’.



Figure 1.1 Dance of the Dead – The Three Living and The Three Dead



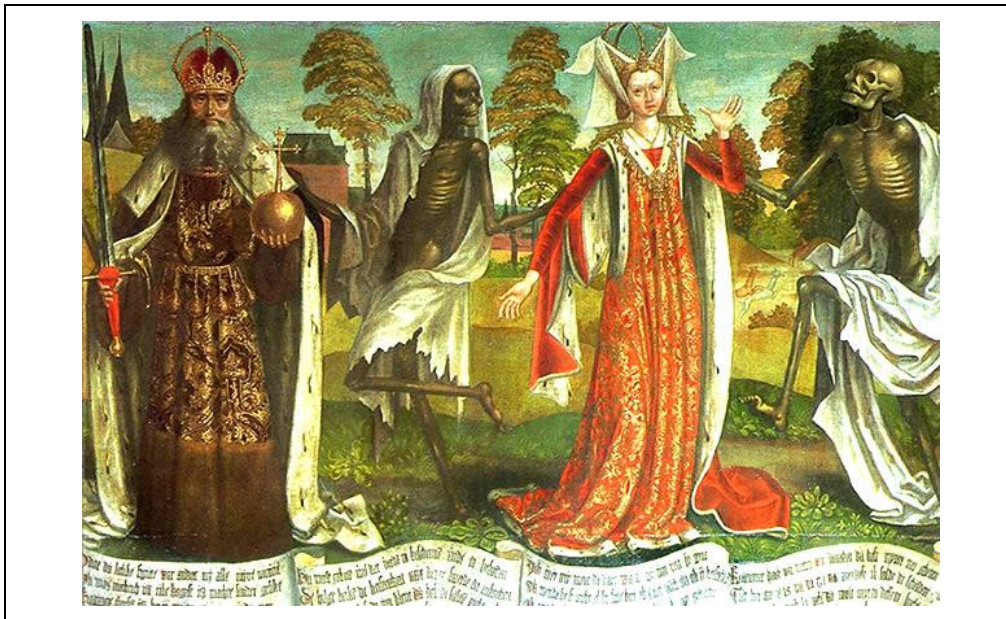
*Men and women dancing with mirror images of their older or deceased selves, embracing their own impermanence. British Library, Add MS 35313, f. 158v (The Three Living and the Three Dead). Book of Hours, Joanna I of Castile. c.1500*

### ***Dance of Death***

The 16<sup>th</sup> to 17<sup>th</sup> Century witnessed the rise of the “Dance of Death” (Illich, 1976), an era artistically illustrated by paintings of skeletons dancing amongst men and women while carrying a scythe waiting to harvest lives regardless of powers and ranks (See Figure 1.2). During this period, death transformed into an independent figure, a *force of nature*, calling on every human being, young and old, rich or poor, to be in its grip and with which to battle. As society became preoccupied with mortality, a significant change also took place in which death was no longer seen as a transition into heaven or the underworld as its religious relevance diminished, but understood as the ultimate end of one’s life where people were left to find meaning and purpose for their existence. Social turmoil such as the proliferation of Protestant Reformation that shook Europe and undermined the legitimacy of the Church, and pandemic such

as the Black Death and the Great Plaque that killed hundreds of millions and demoralized the sanctity of life, was debated as the main cause of this profound shift in death perception (McNeill, 1976; Helegeland, 1985); what is certain is that people became less dependent on formal institutions to find comfort at life's final margin. Instead, overt emphasis was placed on identifying ways to ensure a good death, a death not prolonged and without agony, as the lack of a trusted and dependable agent of faith made mortality even more devastating and terrifying for the individual. Unsurprisingly, people turned to superstitious rituals, medical folk-practices and the secular procedures offered by *Ars Moriendi* (*art of dying*) and other parodies to acquire some form of security measures that promised an easy and speedy death.

Figure 1.2 Dance of Death – Surmatants (Totentanz)



*Skeletons dancing amongst men and women, carrying scythes waiting to harvest lives regardless of powers and ranks. Bernt Notke: Surmatants (Totentanz) in St. Nicholas' Church, Tallinn.*

### ***Bourgeois Death***

The dawn of Industrial Revolution during the 17<sup>th</sup> to 18<sup>th</sup> Century created unseen wealth as well as unprecedented social segregation between the rich and

the poor. This radical social transformation marked by significant advancements in medicine allowed the wealthy to purchase health and to keep death away. Yet, the lack of institutional justice or social welfare also marked the end of equality in mortality established in the previous era, as the deprived and underprivileged were often left for dead with the stroke of illness. This period, coined “Bourgeois Death” (Illich, 1976), saw the emergence of medical markets as well as the dismantling of old charitable institutions that provided respite for the sick and dying (See Figure 1.3). This transformation added a seemingly impossible but divine role for doctors; on top of the curation of disease, the prolongation of life became a new expected task of medicine. Such unprecedented power essentially placed doctors on the pedestal of the prevalent societal hierarchy, propelling them not only to the role of healers, but also those of political and social reformers (O’Gorman, 1998). During this era, medical care for protracting illnesses was deemed a mark of distinction, and the health of a nation became an obvious apparatus to ensure the economic productivity of its people (Foucault, 1991). However, without a social collective to instill an overall policy that safeguarded population wellbeing, good health of children became a responsibility borne by parents; old age became a privilege defined through class and economic power; and death became an *untimely event* for those who were neither frail nor old (Illich, 1976).

Figure 1.3 Bourgeois Death – De efficacy Medicina



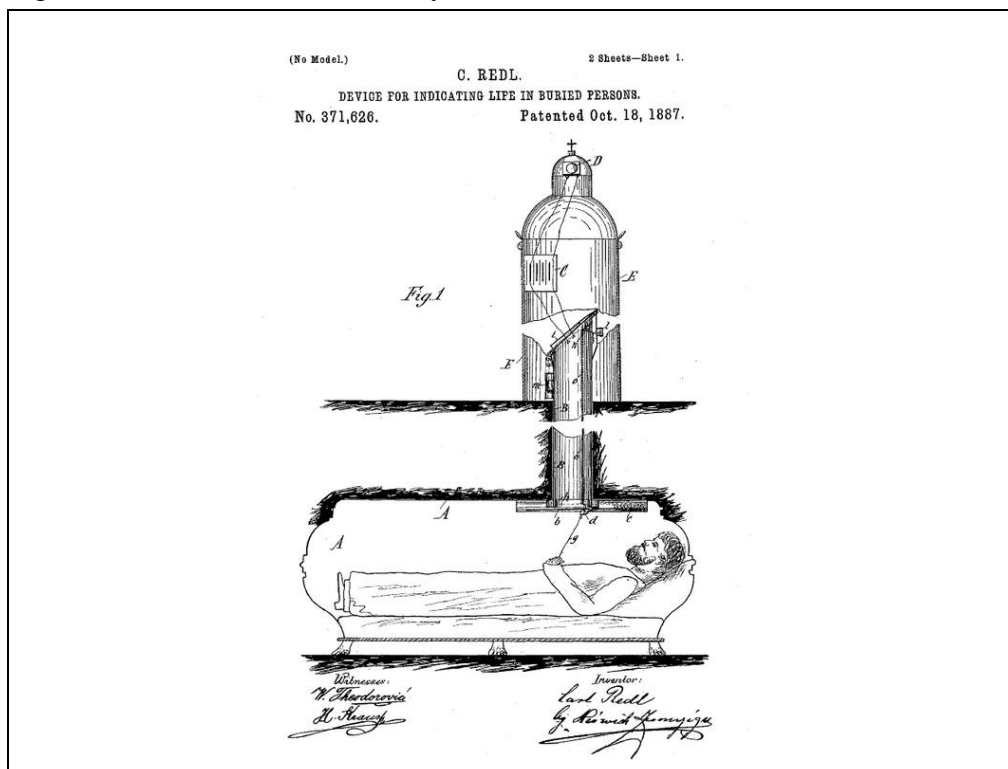
*A physician giving medicine to a sick man in bed, and a surgeon, supervised by a physician, amputating the leg of seated patient, representing the efficacy and supremacy of pharmacy and surgery, respectively. Engraving, 1646. By Matthaeus Merian, De efficacy medicina. Wellcome Library Image M0007909.*

### ***Clinical Death***

By the 19<sup>th</sup> Century, medical books began to emerge with recurring drawings that illustrated doctors and personified diseases battling against one another at the bedside of those befallen by illness (O’Gorman, 1998). Magazines and newspapers also vastly published advertisements of safety burial devices that enable those who were pounced dead to be saved in case of error in prognoses (See Figure 1.3). When doctors began to certify death as the outcome of specific ailment, their supremacy over health inevitably thrust them into the prestigious and powerful middle class. The prevalent belief and hope that doctors had the ability to control disease progression also gave rise to the myth that they had control over death, and hence the new elite status of the clinician (Shryock, 1947). This urban legend saw society progressing into the period of

“Clinical Death” (Illich, 1976), marked by the proliferation of hospitals as well as the emergence of a new consciousness of the scientifically trained health professional. Under their “medical gaze”, the human body became objectified, whereby individuals were no longer perceived as social entities but as constellations of objects that were constantly under medical scrutiny (Foucault, 1973). When death ceased to be a spiritual figure but had transmuted into medically identifiable germs and viruses (Bauman, 1992), a timely death with clinical symptoms had become the ideal end-of-life scenario among the masses. This transition marked the emergence of a novel health-denying culture (Illich, 1976), one that “destroys the potential of people to deal with their human weakness, vulnerability and uniqueness in personal and autonomous ways... the ultimate backlash of hygienic progress and consists in the paralysis of healthy responses to suffering, impairment and death (p.34).”

Figure 1.4 Clinical Death – Safety Coffin



Device for indicating life in buried persons. Carl Redl, of Vienna, Austria-Hungary. No 371626 Patented October 1887. United States Patent Office

### *Health as Commodity*

Following extraordinary social progress after the First and Second World Wars, the United Nation and the Universal Declaration of Human Rights were established, with the 20<sup>th</sup> century being celebrated by the germination of trade and workers' unions that uplifted the welfare of the working class. During this period, named "Health as Commodity" (Illich, 1976), good health as well as good death through public health regimes and institutionalized medical care had become a service that society owed to all its members (See Figure 1.5). This new image of mortality endorsed new forms of social control, where the state was now responsible for the proper deaths of all men and women, while deaths without appropriate medical treatment were liable to legal inquiries. As doctors and hospitals borne increasing power and accountability for the health of ordinary citizens, individuals' responsibility and duty for upholding their own well-being diminished. As Illich (1976) observed, "Medical consumption became a device to alleviate unhealthy work, dirty cities, and nerve-racking transportation. What need is there to worry about a murderous environment when doctors are industrially equipped to act as life-savers (p. 202)". Such growing dependency on the medical profession had also created a spiritual vacuum in how people perceived and understood mortality (Sacks, 1982; Seedhouse, 1992). In the epoch of medicine dominance, death no longer served as a spiritual passage but was converted into a scientific event controlled by medical professionals, so much so that deathbeds had moved away from homes and communities into hospitals and institutions, and the sacred offices of priests and pastors were taken over by doctors and physicians (Walter, 1994). The medicalization of death had extended beyond the dying person to survivors, as

early writings by George Engel (1961) identified and compared grief as a form of psychological disease with specific symptomatology and management strategies, “a legitimate and proper subject for study by medical scientists” (p.20). In essence, the commodification of health had severely undermined “the unique spiritual and intellectual strength of the human race which enables them to rise to the challenges of dying and death” (O’Gorman, 1998, p.1130).

Figure 1.5 Health as Commodity – Public Health Campaigns



Cover coughs and sneezes. National Tuberculosis Association, United States, ca. 1962.

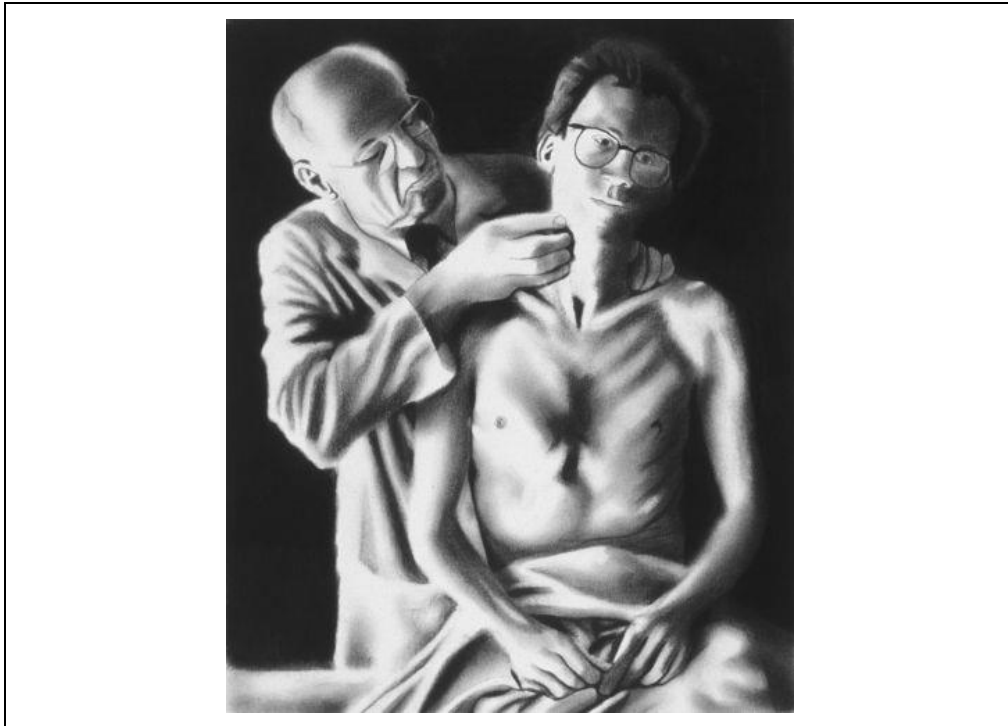
### *Death in Intensive Care*

Nearing the turn of the twenty-first century, medical knowledge and technology had reached unprecedented heights, stretching the human lifespan by an average of 36.7 years (Ham, 1994). Such increase in life expectancy was not without its cost, as Illich (1976) coined this final stage in the evolution of attitude towards mortality, “Death in Intensive Care”. Celebrated paintings by young Canadian Artist, Robert Pope, who died of Hodgkin’s disease after a decade-long battle with the illness, epitomized the ever common stage of a

*mechanical death* in modernity, where patients in critical conditions wait helplessly and often unconsciously with heavy anesthesia for their final demise in the intensive care unit of hospitals (See Figure 1.6). In the blooming midst of the medical industry, patients are no longer able to set the scene for their own deaths as the mandate of doctors and healthcare systems protect them against dying. The pioneering research on death and grief by Cicely Saunders had further transformed the personal and communal experiences of mortality into a public discourse where doctors and psychiatrists claimed authority and expertise. Yet, medical professionals often cannot agree among themselves the finality of death as they continue to administer aggressive yet futile treatments in light to prolong life without realizing their power is nothing more than temporal (Sweeting & Gilhooley, 1992). In fact, doctors and nurses have become so preoccupied with curation and saving lives that when a patient dies, they consider themselves a failure, so much so to the extent of fearing death more than those who are sick and actually dying (Acring, 1971). In her landmark research that examined the psychosocial aspect of oncology care, Elisabeth Kubler-Ross (1969) revealed that hospital staffs often withdrew from the bedsides of dying patients because they do not have the capacity to cope with the emotions and psycho-spiritual processes of death, let alone support patients in their final and most vulnerable moments. Others have also observed that because of our obsession with living, we have gone to extraordinary efforts to conceal death, to use euphemisms such as ‘passed away’ or ‘gone to a better place’ to keep death at bay (Helgeland, 1985; Barley, 1995). Such fear and avoidance have subjugated any meaningful dialogue on, acceptance of, or preparation for the one’s imminent mortality (O’Gorman, 1998).



Figure 1.6 Death in Intensive Care – Self Portrait with Dr. Langley



Self-Portrait with Dr. Langley. Charcoal on paper. Robert Pope, 1990.

From a divine act of God evolving into a natural event, a force of nature, an untimely event, a clinical death and ultimately a mechanical death, the attitudes and perceptions towards death have transformed dramatically with the rise of medicine and the emergence of the medical market. With even more accelerated progress in health technologies and pharmaceutical agents, increasing voluntary enslavements of personal health to the hands of doctors and the bureaucracies of healthcare institutions are now commonplace, leaving little or no room for human responsibility in the governance of death and dying (Conway, 2012). Illich (1976) offered perhaps the most appropriate allegory to illustrate this bleak reality in contemporary society,

“Medical produces turn into black magic when, instead of mobilizing his self-healing powers, they transform the sick man into a limp and mystified voyeur of his own treatment.

Medical procedures turn into sick religion when they are performed as rituals that focus the entire expectation of the sick on science and its functionaries instead of encouraging them to seek a poetic interpretation of their predicament or find an admirable example in some person – long dead or next door – who learned to suffer. Medical procedures multiply diseases by moral degradation when they isolate the sick in a professional environment rather than providing society with the motives and disciplines that increase social tolerance for the troubled. Magical havoc, religious injury, and moral degradation generated under the pretext of biomedical pursuit are all crucial mechanisms contributing to social iatrogenesis. (pp. 114-115).

Evidently and regrettably, Becker's and Parsons' prediction of a death-denying ethos that oppresses the experience of death, dying, and bereavement have been realized in the modern Western era.

### **Taboo and Stigma of Mortality in Chinese Culture**

The dispiriting evolution of death attitudes observed by Illich and supported by clinicians and researchers such as Kubler-Ross and O'Gorman is far reaching, prominent not only in the Western worlds but also apparent in many Eastern societies. Under the context of medical advancements and growing dependency in health care around the globe, developed Asian countries and cities such as China, Taiwan and Hong Kong are profoundly affected by the erosion of individual and community agency for coping with illness, loss and end-of-life (Ho & Chan, 2011). Compounding the problem of weakening social

structures and support among these Chinese communities is the continuing presence of longstanding death taboos, those that enforce patriarchal social control, stigmatize the experience of grief, and undermine the desolation of bereavement.

With a social and political history filled with poverty, famine, disasters and wars, death and loss is commonplace in Chinese life. Yet, the ideological representations and practices of mortality are by no means unguarded. To the Chinese, death is fiercely perceived as the opposition to life, failure, bad luck, and is often met with avoidance and resistance. This is especially true among the young and middle-age populations, where elderly parents find it extremely difficult to openly discuss with their children on issues related to care planning for the end-of-life and death preparation such as advanced directives and funeral arrangements (Ho, Ng, Chow et al., 2007). On the contrary, the occurrence of death is treated with great precautions and formalities where customary rituals are seen as the procedural safeguard that protects traditional values, family hierarchy and social status (Tong, 2004). In order to understand the apparent paradox in the Chinese social construction of death, one that is both ‘death-avoiding’ and ‘death-worshipping’, the relevant cultural underpinnings must first be examined (Seale, 1998). The three most significant religious and philosophical thoughts that have influenced and inspired the people of Chinese origins include Taoism, Buddhism and Confucianism. The combined ethos of these traditions have not only created an enigmatic view on mortality, but also served to both restore and weaken the fabric of society with its foundation is quavered by death and loss.

## *Taoism and Death*

Taoism is the oldest indigenous religion in China, originating around 400-500 B.C. and continues to be a dominant force that affects spiritual values and beliefs among the Chinese in the twenty-first century (Lo, 1999). Central to Taoist practices is the emphasis on nourishing and protecting life through establishing a harmonious relationship between men and nature; this connection then serves to cultivate health and prolong life in order to avoid death for reaching the state of *Xian* (immortal) (Lai, 2006). Numerous health-cultivating practices that are gaining increasing worldwide recognition today such as Traditional Chinese Medicine, Acupuncture and Qigong all originated from Taoism (Hansen, 2003). Such intense focus on life from the Taoist tradition has irrevocably created a death-avoiding tendency among Chinese people. Nonetheless, the foundational philosophies of *Yin-Yang* (production and destruction) *Wu-Hsing* (five elements) and *Feng-Shui* (geomancy), underscore the relative and cyclical view on life and mortality in Taoism, one that place equal importance on caring for the dying and mourning for the dead.

Death, to the Taoist, is viewed as a natural part of life, inevitable but not final. It serves as a point of transition into the afterlife, of which does not signify the end of an individual's participation in the lives and activities of his family, nor they with him (Tong, 2004). Perhaps the doctrine of *Chengfu*, often regarded as the central tenant of Taoism, can illuminate the unbreakable bond shared between the surviving generations and their deceased ancestors. *Chengfu*, synonymic to the concept of retribution, predicates that rewards and punishments for good and bad deeds are shared across the family lineage to the extent that present generations can be given honor or be made to suffer for the

charity or malevolence of past generations (Madsen, 1990). Hence, ancestors continue to play crucial roles in the lives of their descendants upon death (Tong, 2004). This mutual interdependence between the living and the dead elucidate the need for elaborative mourning rituals in the Taoist tradition, as the salvation of the dead is for the living to accumulate merits of retribution through ancestor worship and penitential litanies (Lai, 2006).

Based on the doctrine of Chengfu, it is not surprising that unlike those with a Judeo-Christian upbringing, Chinese people typically link death, especially those of untimely and traumatic fashions, to ghostly actions and sinful punishments subjugated from hell for the wrong acts ones have committed during their lifetime (Cheung, Chan, Fu et al., 2004). Chinese people also believe that the spirit of the dead would influence, or even intervene in, the fate and fortune of the living. This recurrent theme of retribution can be found among the many Chinese death taboos that associate life-threatening illness, disease, epidemics, and unnatural deaths with bad luck, misfortunes, and poor Feng-Shui caused by the pain of ancestors in the netherworld (Hendrischke, 1991; Strickmann, 2002). The very enactment of death rituals then assures living descendants that they have fulfilled their obligation in transferring merits to their ancestors, and in exchange, receive blessings and spiritual security.

### ***Buddhism and Death***

Buddhism flourished in China during the Han dynasty from 206 B.C. to 220 A.D., and has since undergone a long process of evolution and acculturation to become a critical part of Chinese life (Hsieh, 2002; Poceski, 2004). Similar to Taoism, the Buddhists' view on life and death is a causal and cyclic one, where life does not begin at the moment of birth, and death does not signify the

end but the beginning of the next life. However, different from the Taoist emphasis on life cultivation, Buddhists see life as fundamentally suffering. It is believed that men's inherent cravings for earthly attachments, either material, physical, relational or emotional, can never be sated with the impermanence nature of life, leading to a vicious cycle of birth, death and rebirths filled with unrelenting desires, delusions and dissatisfactions (Schobert & Taylor, 2003). This concept of reincarnation and transmigration of the soul into different realms of existence is known as *Samsara*. The ultimate goal of the Buddhist is to break free from desires and delusions, end the unending cycle of rebirth, and finally reaching the realm of *Nirvana*; a lucid state of mind, free from all human bondage and sufferings (Anderson, 2004).

Buddhists also believe that one's last thought at the moment of death can actively influence the next; hence, it is of vital importance for the dying to relinquish all yearnings and attachments so as to enter the process of reincarnation peacefully and in equanimity (Jing-Yin, 2006). This emphasis on serenity at the last rite of passage has led to a highly controlled Buddhist ceremony at the end of life, one that has become an integral part of the prescribed death rituals widely practiced by Chinese around the world. When an elderly parent is dying, all descendants and family members are obligated to be present by his or her bedside; joined together with reserved emotions, they are required to offer their final blessings so that their elder can die in peace. Such practices have also solidified the inclination to suppress emotional expression among Chinese people when faced with mortality and loss.

Understanding death and dying in Chinese Buddhism further requires the comprehension of the religious doctrine of *Karma*. Similar to the Taoist

tenet of *Chengfu*, Karma embodies the consequences of individuals' volitional actions that manifest as wholesome or unwholesome. The accumulation of these acts then becomes the impetus for ascending or descending within the six realms of existence in the *Samara* (Hsu, O'Conner, & Lee, 2009). The practice of true wisdom and morality through the *Eightfold Path* of right view, right thought, right speech, right action, right livelihood, right effort, right mindfulness, and right concentration would result in good karma leading to a good rebirth closer to the realms of demi-gods and nirvana; while evil acts and bad deeds would accumulate bad karma resulting in a stagnate or poor rebirth into the realms of humans, animals, hungry ghosts and hell. It is also believed that by conducting proper memorial rituals during death anniversaries and ghost festivals, living descendants can transfer merits and good karma to their ancestors to facilitate a better rebirth (Jing-Yin, 2006). Similar to Taoism, the Buddhist doctrine of Karma reinforces the notion of mutual interdependence between the living and the dead, fortifying a death-worshipping culture in the Chinese way of life.

### ***Confucianism and Death***

For more than ten centuries, Confucianism has been the dominating force in casting the cosmology, political philosophy, and moral ethics that unify Chinese people (Hsu et al., 2009). It is a protocol for proper family life; one that prescribes a patriarchal family system defined by an individual's statuses, roles, privileges, duties, and liabilities within the family order. The Analects of Confucius plays a particularly crucial role in cementing various oppressing death beliefs and coercing mourning rituals prescribed by the teachings of Taoism and Buddhism. Concisely, the Analects avow that the greatest achievement in the Confucius life is for one to attain the noble status of

Gentlemen (*Chun-Tze*), through practicing the five ethic principles of Benevolence (*Ren*), Righteousness (*Yi*), Propriety (*Li*), Wisdom (*Zhi*), and Fidelity (*Xin*). The first ethic of Benevolence refers to generosity, kindness, and compassion for mankind with the conscious intention to avoid harm or envy towards one's neighbors. *Ren* can best be understood as the Confucius version of the Golden Rule: What one does not wish for oneself, one ought not to do to others. The second ethic of Righteousness denotes the ideals of justice and loyalty for preserving one's integrity. In effect, *Yi* is the moral disposition to do good and maintain harmonized relationships. Under these two ethic principles, individuals must avoid talking about extraordinary things or engage in disorderly acts (Chung, 2003). Thus, discussions of death are tabooed and deep emotions associated with grief are suppressed as these expressions are deemed disharmonizing and destructive. Such abstaining values and practices can be found in both Taoist and Buddhist traditions, and Confucius ethics solidify the reserved undertone attached to mortality in Chinese culture.

The third ethic of Propriety refers to the ritualized norms of conduct that regulate all social interactions according to one's family position and social rank. Among all forms of *Li*, Filial Piety is most celebrated as it embodies the highest honor and respect to paternity, requiring the complete obedience of children to their parents during their lifetime, taking the best possible care for them as they age, as well as carrying out proper mourning rites upon their deaths (Gerber, 1999). Hence in the Confucius tradition, the enactment of elaborative funerals and mourning rites after the death of a parent not only bequeath great honor to the family name, but also serve the critical function of realigning family hierarch while enabling descendants to inherit the power, authority and social



status of the dead. In return, descendants are obliged to fulfil their filial obligation by accumulating the merits of retribution and or karma for their deceased parents through penitential litanies (Tong, 2004). Clearly, these death-worshipping practices are correspondingly important in both Buddhism and Taoism, of which have long been reinforced into Chinese life through the ethic of Propriety. Apart from ancestor worship and morning rituals, the virtue of Filial Piety also requires the family patriarch – the eldest son – to sustain the family lineage. Therefore, dying without a son especially on the part of the family patriarch, and not being able to bear a male child to continue the family lineage especially on the part of the patriarch’s wife, are two critical offenses in traditional Confucius thoughts (Brians, Gallwey, Hussain et al., 1999). Such persecuting beliefs have certainly casted further negativity on the way mortality is perceived among the Chinese.

The fourth ethic of Wisdom refers to one’s proper mindset and knowledge to judge right versus wrong and act good versus bad. Derived from teachings of past generations, *Zhi* reminds individuals to steadfastly practice moral and righteous acts, to think no evil, speak no evil, and see no evil. The fifth ethic of Fidelity encapsulates the virtue of honesty, where one’s deed should match one’s word, and one’s word should match one’s mind. In Confucius thoughts, *Xin* is the key to authenticity and the vessel for realizing the perfection of human nature. Perhaps the renewed quote from the Analects of Confucius, “While you do not know life, how can you know about death? (Confucius & Waley, 1938; Book 11:11)”, can best capture the seemingly immovable avoidance tendency towards mortality in the Chinese culture. Confucius believed that while individuals are obliged to revere deities and

ancestral spirits, these mystical beings should be kept at bay because it is useless to speculate on metaphysical questions, as men should focus their attention on living a virtuous and orderly life in the world in which they belong (Duiker & Spielvogel, 2008). In sum, the five Confucius principles of *Ren*, *Yi*, *Li*, *Zhi*, and *Xin* have all together fortified the ‘death-avoiding’ yet ‘death-worshipping’ culture originally instilled by Taoist and Buddhist thoughts.

### **The Oppression of Death and Loss in Hong Kong**

The influential teachings of Taoism, Buddhism and Confucianism have unmistakably cemented the intricate beliefs and traditions of death and loss in Chinese life. However, with the passage of time and the ashes of war, most significantly through the Cultural Revolution which left the country corrupted and its people denied of a moral compass, the underlying philosophies that gave meaning to the practices of mortality are lost. The resulting ethical vacuum have transformed death into an unknown but imposing anathema leading to fear, anxiety, avoidance, and ultimately oppression. Common taboos on mortality among the Chinese include not taking or thinking about death as such can bring bad luck; having no contact with the sick and the dying for they are infected with calamity; avoiding proximity to coffins and corpses including clothing and belongings of the dead as these are deemed unearthly and transcend the depressing aura of the underworld; as well as, not mentioning the names of those who passed on for fear of calling back their angry and malicious spirits. Contact with family members of the deceased is also avoided, as they are believed to be ritually polluted and the bearers of mishaps. Death taboo is so powerful that even words that sound like death (*sǐ*), such as four (*sì*) in both Cantonese and Mandarin are believed to be inauspicious, so much so that the floors of fourth,

fourteenth, twenty-fourth, and so on are often removed from buildings in many Chinese cities, and especially in Hong Kong (Sieh, 2011).

In fact, a recent study with 792 Chinese individuals of various age cohorts found that death taboos are still vastly prominent in the Special Administrative Region of the People's Republic of China (Ho et al., 2008). Particularly, about one-fifth of respondents still believed that talking or thinking about death as well as seeing a dead body bring bad luck; thus limiting open communication, information sharing, and intellectual exchanges on death-related issues. More than one-third of respondents also believed that members of recently bereaved families should not be social active and should remained in their own home; thus greatly restricting the amount of social support grieving families receive during times of loss and vulnerability. Finally, about a quarter of respondents still believed that talking about death with a dying person will accelerate his or her death; thus preventing adequate end-of-life care planning and death preparations such as setting up wills and establishing advanced medical directives. It is not surprising that Hong Kong, apart from being famous for its food, shopping and yellow umbrellas in its push for true democracy, is also notorious for its many high profile inheritance court battles (Yan, 2011). In essence, the many taboos of death have together created a stigmatizing and oppressive ethos of mortality in this international metropolis.

### *A Demoralized Populace*

Under a cultural backdrop of stigmatization, Hong Kong people often feel powerless and demoralized when facing mortality and loss. Despite the fact that Hong Kong possesses one of the most advanced palliative care systems in the world with state-of-the-art hardware and medical techniques (Clark and

Wright, 2007), the same cannot be said for its software and human capital, as doctors and nurses often lack the knowledge and capacity for awareness and empathy over the needs and concerns of terminally-ill patients and their families (Ho, Leung Chan, 2015). According to a recent report that examined the current state of end-of-life services in Hong Kong, referral for patients to palliative care usually come much too late in the disease trajectory, as general physicians and medical practitioners still hold negative views about hospice and palliation, seeing it as the absolute last resort when all other curative measures have been depleted (Lam, 2013). This practice blatantly limits and undermines the vital need for palliative support among those facing mortality. Findings from a pertinent study on end-of-life service utilization further reveal that only 60% of all patients with terminal illness actually received palliative care, and over 99% of deaths occurred in acute hospital beds (Chan, Siu & Leong 2003). These are astonishing figures compared to the United Kingdom whereby 75% of terminally-ill patients received adequate palliative care (Hughes-Hallet, Craft, Davies, et al., 2011), and only 53% of deaths occurred in hospitals as home was the preferred place of death (Marie Curie Cancer Care, 2013). The reason for the underutilization rate of palliative care in Hong Kong is evidently due to the apprehension and misconception brought on by the social stigma of mortality, there is vast reluctant among patients with incurable illness to seek formal palliative care (Ho & Chan, 2011). Whilst the overtly high hospital death rates can be attributed to the notion of death pollution, whereby mortality is deemed bad luck and can contaminate the lives of the living; hence seldom would Hong Kong people wish to die at home as such can greatly depreciate the value of their properties (Yun, 2014).

For dying patients as well as older individuals who are more open-minded and wish to take greater control over their care in the final margins of life, they are often dejectedly barred from exercising control and autonomy as a result of death taboos. Repeated studies have shown that although Chinese patients with life-limiting illnesses want to know the diagnosis and prognosis of their conditions, many families and even healthcare professionals prefer non-disclose to patients in light to protect them from the experience of despair and hopelessness (Fielding & Hung, 1996). In reality however, the lack of communication and honest information exchanges between patients, families and care providers actually create greater fear, anxiety and dependency, as health illiteracy prevents dying individuals from making informed decision of care at life most vulnerable moments (Ho, Leung, Tse et al., 2013). Chinese elders also finds it difficult to discuss issues pertaining to hospice or palliative care and other mortality concerns with the adult children, who often avoid any topics related to death and dying (Chan, Ho, Leung et al, 2012). Obviously, this limits the possibility for patients and elders to plan and prepare for the end-of-life; the lack of preparation and planning are major sources of pain and anguish for those facing mortality (Cappeliez, O'Rourke & Chaudhury, 2005).

While life and death education for health and allied health professionals is fairly limited, the training of palliative care experts is heavily medically oriented with little emphasis on psycho-social-spiritual care. As a result, they often find themselves ill-informed and ill-equipped to support and assist those facing the end-of-life. Yet, Hong Kong people still rely heavily on an untrained body of health authority for making important care choices at life's final margins, instead of being independent and autonomous in decision making

(Chan & Pang, 2007). With the absence of control, planning and preparation, the moments as well as the aftermaths of death can be devastating and traumatizing. When having to decide on funeral arrangements after the heartbreak of losing a loved one, grieving individuals can easily fall victims to businessmen of the funeral industry casted in the light of spiritual experts who ride on grief and sorrow to earn extra profits (Cheung, et al., 2006), spending large sum of money on elaborative but eccentric rituals in the futile pursuit of mending unfinished business and reconciling love. Evidently, deep-rooted taboos and stigmas have created difficulties for even the most experienced clinicians in providing adequate support and guidance at life's end, causing feelings of ineptitude and confusion among frontline workers of acute and community-based settings when caring for dying patients and bereaved families, and leaving the general public in a state of shock, uncertainty, chaos and existential pain in the face of terminal illness, grief and loss (Tse, Wu, Suen, et al, 2006).

In order to reduce and eradicate stigmas and taboos; to garner and enhance greater community awareness and empathy for supporting those facing the end-of-life; as well as to establish a stronger foundation of social responsibility and active participation in the governance of mortality; a public health approach that underscore the importance of life and death education is imminently needed to empower and liberate the people of Hong Kong from the oppression of death, dying and bereavement.

### **Purpose and Objectives of Research**

The aim of this study is to provide a formative account of development and implementation of a new thanatology curriculum in Hong Kong's higher

education system, one that is driven by the principles of Health Promoting Palliative Care. Furthermore, it critically examines the effectiveness of the course, “The Last Dance: Understanding Death and Dying” offered by the University of Hong Kong, in reducing death taboos and enhancing positive attitudes towards mortality among a group of undergraduate students. Adopting a mixed methods approach, this study utilizes a quantitative pretest-posttest research design, complimented by qualitative analysis of students’ reflective writings for identifying factors that facilitate effective learning and teaching. The expected findings would generate new knowledge contributing to advancement in theories and practices in the field of Life and Death Education and Lifelong Learning. The specific objectives of this study are in three-folds:

- 1) To evaluate the effectiveness of the “The Last Dance: Understanding Death and Dying” for enhancing attitudes towards mortality, life and spirituality, as well as promoting death preparedness behaviours and reducing death taboos, among a group of undergraduate students;
- 2) To understand the processes of learning that enhance students’ awareness and self-reflection on the social, cultural and political impact of death and loss in contemporary society; and
- 3) To identify formative factors for improving pedagogy practices and curriculum design for pushing forth life and death education via lifelong learning in Chinese societies.

## **Chapter Summary**

This introductory chapter has provided a comprehensive overview of the evolving attitudes and perceptions of mortality contemporary society. It has also synthesized both Western and Chinese literature on the beliefs and philosophies that drives the practices and taboos of death, dying and bereavement, identified the knowledge gap in the implementation of life and death education in Hong Kong, while laying out the purpose of the current research.



## **CHAPTER TWO**

### **LITERATURE REVIEW & CURRICULUM DEVELOPMENT**

This chapter presents a review of the literature that examines and illuminates: (a) the shortcomings in the contemporary practices and policies of palliative care in Hong Kong, (b) the theoretical foundation of Health Promoting Palliative Care, and (c) the current standing of life and death education. It also provides a formative account of the developmental and implementation processes of a new undergraduate humanities course on death, dying and bereavement under the context of higher education reform. Essentially, this chapter elucidates the theoretical foundation and direction of the present study.

#### **Palliative Care Practices and Policies in Hong Kong**

The development of palliative care in Hong Kong entails a short yet profound history, one that is closely similar to the 1960s Hospice Movement initiated in the United Kingdom. In parallel, they were both ignited by passionate healthcare professionals who were committed to expand the narrow and limiting ethos of curative medicine to include palliation, upon witnessing firsthand the pain and anguish of dying patients who became victims of healthcare systems that emphasized cure at the expenses of individual experiences (Saunders, 1967). Moreover, they were both marked by the establishment of a modern hospice that catered only to dying patients and operated as a standalone institution outside of the mainstream healthcare system (Saunders & Kastenbaum, 1997). Finally, they were both fueled by the ideals of ‘total pain’ and ‘whole person care’ in creating a new regime of care that respected and promoted human dignity, one that did not aspire to prolong life nor hasten death, but focused on providing medical interventions for controlling

the physical pain associated with dying, while emphasizing the alleviation of social, psychological and spiritual sufferings experienced by patients and their families at life's end (World Health Organization, 2002).

### **Overview of Palliative Care Development**

Before the 1970s, the Hong Kong healthcare system focused solely on providing remedies and cures to those who were sick, often rejecting patients with terminal illnesses and incurable diseases as they were deemed the medical failures (Chung, 1997). Consequently, these helpless patients, abandoned by their professional caregivers, were attended to by their untrained and uninformed family members; suffering at home while receiving poor physical care and little emotional support, and only returning to the hospitals to die during the final moments of life. At this crossroad of time, deaths were agonizing and painful as the practices of symptom control and psychosocial care were virtually non-existent. Having witnessed the unbearable sufferings of terminal patients, Lucy Chung, a nurse specialist, was determined to obtain formal hospice training from the United Kingdom through St. Christopher's Hospice, the first standalone hospice in England, and Marie Curie Foundation, the pioneers of home hospice care, so as to become competent in providing optimum care to those facing mortality (Thompson, 2000). Upon her return in 1982, Chung joined Our Lady of Maryknoll Hospital to set up the first palliative care support team in Hong Kong, dedicated to provide counseling and specialized care to dying patients and their families (Chung, 1993). This initiative was well received by the public and its success had raised greater public awareness on end-of-life issues as increasing numbers of patients and families turned to this group for help and counsel. Chung's instrumental work

later led to the establishment of a small volunteer-based training team at the Ruttonjee Hospital, which offered hospice awareness and educational programmes to local nurses and provided home care support to patients and families.

By 1986, the Society for the Promotion of Hospice Care was established with the mission to adopt a holistic approach in caring for the dying, as accentuated in its motto, “When days cannot be added to life, add life to days”. Two years later, the Society established the first hospice home care programme; and in 1992, it further erected the first independent hospice which modeled the blueprint of St. Christopher’s Hospice, and formally known as Bradbury Hospice. Between 1986 and 1988, four other hospital-based hospice palliative care programmes were also initiated at the Ruttonjee Sanatorium, Haven of Hope Hospital, United Christian Hospital and Nam Long Hospital (Fielding & Chan, 2000). As the hospice movement in Hong Kong gained increasing momentum in the early 1990s, palliative care became a top priority in the government’s healthcare agenda. With the support of public funding, growing numbers of palliative care units were established across Hong Kong, while the number of public educational events and programmes that focused on the promotion of hospice and palliative care increased more than six-folds from 47 in 1986 to 300 in 1994 (Chung, 1994).

In 1995, the Hospital Authority (HA), a statutory body that manages all public hospitals in Hong Kong and is accountable to the Hong Kong Special Administrative Region (HKSAR) Government, began organizing certification courses in hospice nursing. A local diploma course in palliative medicine was also established through the College of Medicine of the University of Wales in

1996. As the field expanded with more doctors and nurses entering the palliative profession, two professional societies, the Hong Kong Society of Palliative Medicine and the Hong Kong Hospice Nurses Association, were established in 1997. These societies not only provide continuous training and supervision for practicing clinicians, but also regulate and ensure the healthy development of palliative care services locally. By 1998, palliative medicine was finally established as a medical specialty through the Hong Kong College of Physicians, and with it came the development of a two-year structured training programme for physicians interested in the field. Bearing the original hospice philosophies, the programme consisted of modules in pain management, symptom control, ethical principles, issues surrounding death and dying, as well as communications skills for working with dying patients and grieving families (Sham, Chan, Tse, et al, 2006).

In order to cope with increasing service demand and to facilitate professional development, structured long term courses on specialist and multi-disciplinary training have recently been developed and provided to palliative care professionals through the Institute of Advanced Nursing Studies and the Institute of Advanced Allied Health Studies of the Hospital Authority (Hong Kong Legislative Council, 2008). Working collaboratively with charitable groups and other health organization such as the Society for the Promotion of Hospice Care, the Hospital Authority also organizes training workshops, seminars and annual conferences on hospice palliative care that feature local and overseas experts. The aims are to enhance the expertise in end-of-life care among health and allied health professional in the field, including but not

limited to doctors, nurses, social workers, clinical psychologist, counselors and pastoral workers.

### **Current State and Quality of Palliative Care**

Today, hospice palliative care has become an integral part of the Hong Kong public healthcare system. The Hospital Authority maintains that comprehensive palliative care is provided to terminally-ill patients through an ‘integrated multi-specialties multidisciplinary service approach’ with a holistic orientation (Hong Kong Legislative Council, 2014). Service provision also includes psychological counseling and spiritual support to patients and families. Currently, there are sixteen hospitals under Hospital Authority providing palliative and hospice care services, which includes in-patient service, out-patient service, hospice palliative day care services, home care service and bereavement counseling. There are also 38 hospice beds per million populations serving mostly patients with terminal cancer. This spectrum of care provision allows greater flexibility for dying patients to receive pain control, symptom management, as well as supportive palliative service while living at home and staying active in the community.

Under the existing structure, hospice palliative care is mainly rendered through palliative care physicians, oncology specialists, nurses and social workers. According to recent statistics (Hong Kong Legislative Council, 2008), there were 23 palliative medicine specialist, 172.53 full-time nurses and 31.76 full-time allied health professionals serving in palliative care centers under the Hospital Authority. In terms of service utilization, between 2007 and 2008, 6,311 patients received palliative in-patient service, 5,676 patients received palliative specialist out-patient service; 8,491 patients received palliative day

care service; palliative home visits and home care services were provided to 24,938 patients and their families; and bereavement services were provided for 3,121 patients and their families. In practice, doctors of various specialties make referral for patients to receive the most suitable form of palliative care after the diagnosis of a life-threatening condition. Patients who are deemed suitable for in-patient service would receive detailed assessment and treatment by doctors of the palliative care department within three days of referral. Those who are fit for discharge will be contacted by home care nurses for arrangement of home visitations, so that patients and families would receive effective symptom management and psychosocial support during their stay at home. Generally, the home care nurse will make home visits to patients within three to seven days upon referral.

Overall, the development of palliative care services in Hong Kong has made immense progress over the past three decades. Emulating the philosophies of the Hospice Movement and modeling after the United Kingdom practice paradigm, Hong Kong now possesses one of the most advanced palliative care provisions in Asia and across the globe. As assessed and reported by the International Observatory on End-of-Life Care in 2006, Hong Kong was ranked 35<sup>th</sup> with the most developed palliative care system among the 234 places assessed (Clark & Wright, 2007). The assessment criteria for this evaluation was based on eight domains including: 1) the degree of development of a critical mass of palliative care activism; 2) degree of comprehensive provision of all types of palliative care by multiple service providers; 3) level of awareness of palliative care on the part of health professionals, local communities and society in general; 4) degree of unrestricted availability of morphine and all other strong

pain-relieving drugs; 5) degree of substantial impact of palliative care on policy, in particular on public health policy; 6) the development of recognized education centers; 7) academic links forged with universities; and 8) the existence of a national palliative care association. Although Hong Kong ranked high on most clinical care domains, as echoed by other researchers who repeatedly found that the standards of in-patient palliative care among public hospitals are of esteemed quality which elevated the well-beings of terminally-ill patients (Sham, Chung & Humphries, 1989; Sham, et al, 2006; Tse, Chan, Lam, et al., 2007); it scored comparatively low in three structural domains, namely the degree of comprehensive provision of palliative care by multiple providers, the level of awareness of palliative care in society, as well as the impact of palliative care on public health policy. These findings underscore serious macro level concerns related to the accessibility of palliative services, highlighting the lack of a government led initiative for promoting greater community discourse and involvement in end-of-life care, as well as vastly limited social participation and active engagement among the general public on issues pertaining to death, dying and bereavement (Ho & Chan, 2011).

In fact, according to a recent report published by the Economist Intelligence Unit (2010) that appraised the ‘quality of death’ among 40 major regions across the globe, Hong Kong was merely ranked at number 20, lagging behind both Taiwan and Singapore, which ranked 14 and 18 respectively. The four assessment criteria used in this appraisal included: 1) basic end-of-life healthcare environment; 2) availability of end-of-life care; 3) quality of end-of-life care; and 4) cost of end-of-life care. The report revealed that although Hong Kong ranked near the top at number 8 in the domain of quality of end-of-life

care, which included quality indicators such as training for end-of-life care in medical schools, availability of pain killers and accreditation for end-of-life care providers; it ranked poorly on the remaining three domains. Specifically, Hong Kong ranked lowly at number 31 in the domain of care environment as assessed by quality indicators such as healthcare spending, social security expenditure on health, old age dependency ratio, and national pension scheme coverage. This clearly suggests the lack of strategic planning for achieving healthy and positive aging despite that Hong Kong's population is aging rapidly (Census and Statistic Department, 2012); it further reflects a negative outlook and an avoidance tendency towards civil responsibility in the management of death and loss. Hong Kong also ranked low at number 24 in both the domains of availability of palliative care and cost of end of life care, providing more evidence that care inaccessibility due to limited resources and low health literacy is by far the greatest threat to one's well-being and quality of life at the final margins of life. In sum, these rankings allude to the very fact that not only has death remained a prominent taboo in the Hong Kong Chinese culture, dying well and with dignity has become a privilege for those who are informed and open-minded, have access to resources and services, and are encouraged and ushered toward participating in the governance of mortality.

### **Sustainability Challenges of Palliative Care**

According to Hong Kong Censuses and Statistic Department (2012), the number of persons older than 65 years has surged over 40% in the past 2 decades and is expected to reach 2.58 million within the next 30 years to account for 30% of total population. Hong Kong residents are also living longer with the highest life expectancy at birth around the world, which stood at was 84.97 years



for female and 79.32 years for male (United Nations, Department of Economics and Social Affairs 2010). With this trend of population aging affecting not only Hong Kong but also the rest of the world, palliative care for older people has emerged as a public health priority. The WHO (2008) reported that conventional healthcare systems often under address the physical symptoms and psychological distress experienced by older people, and emphasized on the importance of timely action to cope with the palliative care needs of a rapidly aging population.

Although Hong Kong has a developed and well-structured provision of palliative care, service delivery is still largely dedicated to patients with incurable cancer as well as certain life-limiting illnesses such as AIDS and end-stage organ failures (Hong Kong Legislative Council, 2014). Older persons are often faced with multiple chronic diseases nearing the end-of-life that may or may not include cancer or renal disease, but the palliative care needs or symptom burdens from age-related diseases such as dementia and heart diseases are no less than those of a malignant diagnosis. Yet, with the current emphasis on serving those with terminal cancer and organ failures, older people have much difficulty in accessing palliative care (Fitzsimons, Mullan, & Wilson, 2007). While the current care regime still has the capacity to provide adequate palliative services to older people with terminal illness, service quality and capacity will be exceedingly difficult to maintain under the context of population aging, and along with it the greater prevalence of chronic progressive diseases. Palliative care provision in Hong Kong must be expanded to include both cancer and non-cancer patients, with an emphasis on addressing the specific needs of older people facing the last phases of life.

This is, however, easier said than done. Major attitudinal, behavioural, educational, and institutional barriers have been described in the literature for developing palliative care for non-cancer patients and the elderly population. These include the difficulty for patients and families to accept palliative treatment due to fear of the uncertain; the reluctance of clinicians to identify the palliative phase; apprehension of healthcare providers towards inducing pain control due to misunderstanding and misconceptions about pain tolerance and opiates addiction; acceptability of palliative care among non-cancer and elderly patients and their families; and tension in resource allocation are all serious obstacles for broadening the service spectrum of palliative care (Foley, 2002). Moreover, bureaucratic procedures within organizations, the time required for arranging homecare technology, and the difficulties to obtain extra care to dying patients within the community are all real-life impediments for pushing forth a primary palliative care agenda (Groot, Vernooij-Dassen, Verhagen, et al., 2007).

From an economic standpoint, the extension of palliative care provision in Hong Kong is also seemingly difficult and may impose enormous burden for sustaining an already exhausted universal healthcare system. As previously noted, while hospice and palliative care services are mostly dedicated to malignant diseases, only 60% of cancer patients and their families actually received palliative care; while over 99% of all hospital deaths occurred in acute hospital beds instead of palliative care beds (Chan, et al., 2003). With the current structure of healthcare still heavily inclined on acute in-patient services that are innately financially taxing, one must move beyond the conventional healthcare system for expanding palliative care to all sectors of society. Fundamentally,

remodelling of medical and social care structures and procedures via integrative public policy initiatives; amalgamating care provision and support into local communities through greater coordination and partnership between hospitals and social service agencies; enhancing health and allied health workers' knowledge and competency in palliative end-of-life via greater professional training; as well as strengthening public knowledge and preparedness on issues concerning mortality and loss through greater formal and public life and death education are all viable strategies to push forth this crucial transformation.

In essence, the sustainability of palliative care for terminal patients, older individuals, and all people in Hong Kong, rests upon health policies and practices that extend beyond the rim of in-patient care. This requires a renewed commitment to the promotion of palliative care for all, fuelled by a public health approach that harnesses the power of an informed and educated populace for bolstering the collective strengths of individuals, families, neighbourhoods, and communities in supporting the dying and the bereaved.

### **The Rise of Health Promoting Palliative Care**

While 'health promotion' has long been a celebrated strategy for improving population health through policy advocacy and education for illness prevention (Sindall, 1992), 'palliative care' on the other hand emphasizes the care of those whose health have failed and are entering the final stage of illness. By definition, these two terms appear rather contradictory. However, Jan Stjernsward, Director of WHO Collaborating Centre for Palliative Cancer Care, had alluded that in order to ensure sustainable development, there is an imminent need to adopt a 'rational approach' to palliative care, one that

transcends the boundaries of institutionalized processes to those that foster public participation (in Doyle, Hanks & MacDonald, 1992, p. 814).

### **The Expansion of Palliative Care**

Over the years, researchers and clinicians have begun to realize that while palliative care has made immense strides in mastering clinical practices such as pain control and symptoms management, these progresses are rather restrictive, as its development has largely neglected the multidimensional nature of care including those concerning the psychological, emotional, spiritual and particularly, social (Saunders, 1987; Kearney, 1992; Clark, 1994). Within the contemporary experience of institutionalized dying (Kubler-Ross, 1969), where terminally-ill patients progressively lose their sense of autonomy, dignity and personhood within the sterilizing haze and pale-colored walls of hospital and hospice beds, social care has become a crucial instrument for one to find peace and solace within the betwixt and between of living and dying (Ho, Leung, Tse, et al., 2013). Strong community support and interpersonal care throughout the course of illness is vitally important for maintaining wellbeing and hope, these include but are not limited to establishing helpful and constructive communications between patients and healthcare workers, developing support systems for patients and their families, eliminating misconceptions and ignorance about death and dying, cultivating kindness and compassion towards those facing mortality, and establishing meaningful rituals for end of life transitions (Chiverton, 1997; Foley, Flannery, Graydon, et al., 1995; Grande, Tood, Barclay, et al, 1997).

Upon acknowledging the social imperative in the provision of quality care to those challenged by terminal illnesses, at the turn of the twenty-first

century, the World Health Organization (WHO) redefined the foundational underpinnings of palliative care as:

“An approach for improving the quality of life of individuals and their families facing problems associated with life-threatening illness, through the prevention and relief of distress and suffering by identification of and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.” (WHO, 2002, p.84)

And in 2004, the WHO further emphasized that,

“Palliative care is an important *public health* issue. It is concerned with the suffering, the dignity, the care needs and the quality of life of people at the end of their lives. It is also concerned with the care and support of their families (p.6)... good quality care towards the end of life must be recognized as a *basic human right* (p.16).” (WHO, 2004)

Most recently in 2013, the WHO published an even more detailed guideline for palliative care, highlighting a renewed philosophy of care that expands beyond traditional disease-model medical treatments to include the goals of enhancing quality of life, supporting active living, optimizing functioning, helping with decision-making, as well as providing opportunities of personal growth. Specifically, the core values that underpinned palliative care include (WHO, 2013, para. 2):

1. Provides relief from pain and other distressing symptoms;
2. Affirms life and regards dying as a natural process;

3. Intends neither to hastens nor postpones death;
4. Integrates the psychological and spiritual aspects of patient care;
5. Offers a support system to help patients live as actively as possible until death;
6. Offers a support system to help the family cope during the patient's illness and in their own bereavement;
7. Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
8. Will enhance quality of life, and may also positively influence the course of illness;
9. Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Clearly, the role of palliative care in modern healthcare is redefined by its ability to reach beyond patients with a life-limiting illness to include those with chronic and long-standing illnesses, and furthermore, those with acute and potentially curable illnesses, to provide not only palliative interventions, but also curative interventions, alongside illness prevention and social care interventions (Kuebler, Davis, & Moore, 2005). Such a transformative and encompassing view of palliative care necessitates a public health approach in

service provision and care delivery, and particularly, a health promotion paradigm that pushes forth palliative care as a basic human right.

### **The Foundation of Health Promotion**

According to the Ottawa Charter, the first international agreement issued by the World Health Organization in 1986 to encourage global pursuit of the goal of ‘Health for all’, health promotion is defined as:

“...the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.” (WHO, 1986, p.1)

Intrinsically, health promotion requires advocacy, empowerment and mediation so that individuals, families and communities can achieve their fullest health potential within a safe, stable and impartial ecosystem as responsible citizens. The Ottawa Charter further includes five major action statements for realizing the goals of health promotion:

1. Build healthy public policy that support health.
2. Create supportive environments.

3. Strengthen community action.
4. Develop personal skills.
5. Reorient health services.

The first statement underscores the need to develop policies for identifying and removing obstacles to health so as to enable and empower people to make healthy choices that nourish their lives. The second statement highlights the necessity to create an environment that is politically, socially, culturally and naturally conducive to health. The third statement accentuates the vital significance of participation in health decisions and behaviors, stressing the importance of social networks and social relationships for achieving health and well-being. The fourth statement underlines the need to enhance population health literacy through education and information dissemination so that people becomes more aware and prepared to live in wellness as well as in illness. The final statement illuminates the imperative to foster partnerships and interdisciplinary collaborations between all members of society so that health becomes a responsibility of individuals, families, communities, healthcare providers, and the government.

In sum, social participation, civil responsibility and informed citizenry form the bedrocks of health promotion (Porter, 2011; Spoel, Harris, & Henwood, 2014). Whilst the success of health promoting strategies depends not only upon policy advocacy and public education, but also the recognition that the state of wellbeing is much more than a physical affair, one that requires the careful considerations of its social, cultural and environmental characteristics and manifestations.



## **The Integration of Health Promoting Palliative Care**

The aspirations of health promotion can clearly provide the social science and public health perspectives that palliative care sorely needs in order to realize the ideal of quality end of life care for all (Kellehear, 1999; 2005). First, the social concepts of health promotion for enhancing individual livelihoods, via relational, environmental and community-based strategies, can serve as a roadmap for advancing the underdeveloped ‘social aspect of care’ in palliative care. This is especially useful for identifying individual and family strengths, establishing social support networks, and guiding individualized regime of health management during the early-stages of terminal illnesses. Second, the education and information emphasis of health promotion, which enables people to achieve well-being via making healthy choices, can play an equally important role for helping individuals and families to become more knowledgeable about the illness that they face, empowering them to make informed decisions of care and treatments for maintaining high quality of life at the end of life.

Third, the participatory approach of health promotion can become the impetus for palliative care to cultivate greater involvement in the governance of mortality among every member of society. Sharing, education and learning of illness and death must not be limited to professional caregivers or those who are terminally-ill, but for all persons because death is a common experience shared by all humanity. Finally, the structural approach of health promotion for developing policies that are conducive to health and well-being can be adopted in palliative care, serving as a framework to promote public discourse for raising

awareness while eliminating the taboos and stigmas of mortality that marginalize the experience of death, dying and bereavement.

As delicately defined by Allan Kellehear (1999), the amalgamation of the principles of health promotion and the practice of palliative care ultimately translate into the following goals for Health Promoting Palliative Care (p.19-20):

1. Health promoting palliative care should be about providing education and information for health, dying and death. It might perform this function with people who live with a life-threatening or terminal illness by providing not only health education but also death education.
2. Health promoting palliative care should provide social supports, especially personal and community supports. In other words, support groups might play an important role in this form of health care, but so too will coordinating wider support services that are not normally associated with health – for example, solicitors or funeral professionals.
3. Health promoting palliative care should encourage interpersonal problem-solving, where this is relevant. Those with terminal or life-threatening conditions need sometimes to be prepared for personal changes so that social skills are developed to cope with those changes. Problems, where these are perceived as problems, might be shared with others in the same predicament.

4. Health promoting palliative care should develop policies that encourage a reorientation of traditional palliative care services to see the benefits of a health promoting approach.
5. Health promoting palliative care should foster environments that combat death-denying health policies and attitudes in wider society.

Together, the goals of Health Promoting Palliative Care (HPPC) encourage the development of public policies that support the health of individuals living with life-threatening illnesses; inspire the creation of caring and compassionate environments; strengthen personal skills and social participation; as well as promote the reorientation of health and palliative care services to become more accessible, sustainable and beneficial to those who require them now, and imminently in the future (Kellehear, 1999; Ho & Chan, 2011). As such, HPPC translate the hospice ideals of ‘total pain’ and ‘whole person care’ into much broad public health languages and practices that focus not only on palliation, but also prevention, harm reduction, community action, policy advocacy, research and education (Kellehear & O’Conner, 2008).

Distinctively, advocacy that leads to effective policy change must be supported and informed by community engagement and root cause analysis that identify and elicit the needs and voices of all members of society, with a sensitivity that recognizes the assumptions, positions, references, values and beliefs of local cultures. The success of advocacy therefore begins with the introductory work of promoting public discourses through formal and informal education, particularly on the concepts of death, dying, hospice and palliative

care (Meier & Beresford, 2007). Evidence-based life and death education then becomes the impetus for enhancing active participation among societal members who will inevitably be confronted with the challenges of mortality. Learning and sharing through educational experiences in turn create communal platforms for all persons to reflect and assess their own perceived needs and wishes at life's end, develop strategies to address them, and ultimately leading to greater personal change and community support (Ho & Chan, 2011). Effectively, life and death education serves to build an informed and responsible citizenry, strengthen social capacity and human capital in the management and governance of death and loss, and lay the critical foundation for a basic human right to palliative care.

### **The Imperative of Life and Death Education**

Education is widely defined as the transmission of knowledge, a right for all to attain the necessary skills and tools to live a productive and fulfilling life (Warren, 1989). According to the United Nations Declaration on the Rights of Children and specifically Principle 6 and Principle 10,

“The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education, which will promote his general culture, and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgment, and his sense of moral and social responsibility, and to become a useful member of society... He shall be brought up in a spirit of understanding, tolerance, friendship among peoples, peace and universal

brotherhood, and in full consciousness that his energy and talents should be devoted to the service of his fellow men.”

(UN General Assembly, 1959, p.19-20)

With the aforesaid, if society is obligated to provide the knowledge and means to a good life for its citizen, it must then also provide the knowledge and means for its citizen to attain a good death (Ladd, 1979). For life and death are intertwined, with one illuminating the other, allowing us to recognize and appreciate the finiteness as well as the limitless possibilities of existence. An awareness of mortality provides clarity for us to see what is important, to prioritize goals, to find meaning, and to actualize our potentials while within the boundaries of being alive. In this sense, education about life and death should certainly happen sooner than later.

As eloquently put by Herman Feifel (1990), founder of thanatology and pioneer of the modern death awareness movement, “just as it is belated to start reading sex manuals on the marriage bed, it is rather tardy to begin developing a philosophy of life and death when one is terminally ill or newly bereaved” (p.541). Despite such wit and wisdom, the full potential of life and death education has yet to be realized in most education systems around the world.

### **Early Development of Life and Death Education**

Education on life and death in the contemporary era begin with the pioneering work of Herman Feifel, who organized and presented at the first ever scientific symposium on “Death and Behavior” during the 1956 Annual Meeting of the American Psychological Association. The powerful and inspirational works generated was later published in the seminal book, ‘The Meaning of

Death' (Feifel, 1959), of which had broken the longstanding taboos that discouraged scientific studies on mortality, asked provocative questions, and urged re-examinations of fundamental beliefs, fears and anxieties about death and dying from multiple disciplines including psychology, anthropology, religion, history and philosophy (Lamers, 2012). Hereafter, since the 1960s, the field of thanatology has seen a proliferation of publications that examined the many topics of mortality from multidisciplinary perspectives, unprecedentedly expanding the horizons of death studies.

Perhaps the most notable developments in thanatology include: the publication of Elisabeth Kubler-Ross's highly influential book "*On Death and Dying*" in 1969, which critically investigated the lived experience and provision of care of dying cancer patients in hospital and health institutions at the time that sparked the modern hospice movement; the formation of the International Work Group on Death, Dying and Bereavement (IWGDDDB) in 1974, which served to drive thanatology research and continues to be the premiere think tank of death studies; as well as the establishment of the Association for Death Education and Counseling (ADEC) in 1976, which cultivated alliance between academics, researchers and health practitioners to develop and expand life and death education. In 1970, the academic journal *Omega: Journal of Death and Dying* was published as the first of its kind; and in 1977, the second journal *Death Education* (now known as *Death Studies*) was in print. According to Fulton (as cited in Lamers, 2012), these two journals had published over 1,000 professional papers on death, dying, bereavement and related fields over the past 30 years. As since 1991, the journal of *Death Studies* alone has published 942 articles inclusive of quantitative and qualitative studies, meta-analysis, conceptual and

theoretical papers that cover topics on attitudes, education, grief and bereavement, suicide and traumatic deaths, end of life issues, as well as cultural social psychology and epidemiological studies (Neimeyer & Vallerga, 2015).

With the rise of academic interest in mortality, considerable efforts have also been expended to develop and expand death education programmes. These efforts include the articulation of educative goals, consideration of content and perspectives, teaching methods, teacher competencies, as well as evaluation (Wass, 2004). Particularly in terms of the goals of death education, the early writings by Leviton (1977) defined three specific goals, including (a) *primary prevention*, which serves to prepare individuals for eventual experience of loss and mortality; (b) *intervention*, which serves to help people face personal aspects of death; and (c) *rehabilitation*, which serves to enhance learning and understanding from death-related experiences. In terms of the contents of death education, Pine (1977) identified two distinctive types related to the applied and the pure. *Applied death education* refers to the clinical interests in the management of dying and adjustment following bereavement such as those concerning symptom control, pain management, hospice care, palliative practices, and grief counseling. *Pure death education* involves the more humanistic components that educate individuals about attitudes on death, understanding on grief and mourning, euthanasia and suicide, the effect of illness and loss on children, as well as the meaning of one's own mortality, and ultimately the meaning of life.

Pine (1977) further observed that the efforts devoted to life and death education have passed through three critical periods in history, including *exploration* from 1928 to 1757, *development* from 1958 to 1967, and *popularity*

from 1967 to 1977. However, others would argue that education on life and death is still trying hard to gain popularity in many formal educational settings (Wass, 2003; Dennis, 2009).

### **Life and Death Education for Health and Allied Health Professionals**

Since the 1970s, there has indeed been a consistent rise in the number of death education programmes offered to health and allied health professionals, specifically those who specialize in care pertaining to the end of life. However, despite attempts to balance the clinical and the humanistic components of death education, the focus of these programmes is mainly applied in nature with its content heavy geared towards the transfer of practical skills and knowledge on clinical care, with little room for personal exploration and contemplation on the philosophical science as well as the affective domains of death and dying. It is therefore not surprising that there is an apparent lack of awareness and empathic understanding towards the psychological and spiritual needs of the dying and the bereavement even among hospice and palliative care professionals. Repeated studies have found that doctors and nurses tend to avoid or even withdraw from clinical encounters that carry deep emotions related to mortality, for they lack the education and capacity to face and work with their own sense of grief and loss as well as those of their patients (Klenow & Young, 1987; SUPPORT/Investigators, 1995; Ho, Leung, Tse et al., 2013).

Even more troubling is the fact that there is inadequate attention given to death and dying in medical and nursing curricula at all levels among all developed countries including the United States, the United Kingdom and Canada. Research have shown that full-course electives are only taken by a fourth of all medical students in the US and Canada (Dickinson & Mermann,



1996), while the average medical students in the UK only receive 6 hours of life and death-related instructions and at best 20 hours in a 5-year curriculum (Doyle, 1991). In terms of training of professional grief workers, it was reported that less than 50% of graduate programs in clinical psychology and related disciplines in North America cover death-related topics (Bongar & Harmatz, 1991), leading to questionable professional competence as well as low levels of empathy among grief counselors (Kirchber, Neimeyer, & James, 1988). And while there are gradual increases in the number of specialized certificate and diploma programmes in end-of-life care and death-related counselling, it is difficult to establish their quality and consistence as there is great variability in training formats with most being didactic without experiential practicums (Wolfe, 2003). As such, despite steady improvements made to incorporate life and death education into the training of health and allied health professionals, current instructions are still highly inadequate, as “it offers little opportunity for participants to become knowledgeable about death and grief, to deal with the own feelings, or to develop empathy” (Wass, 2004, p.295).

The above sentiment can be felt in the Chinese context of Hong Kong, as there is a genuine lack of life and death instructions for professional caregivers that focus on both the clinical and the humanities. A recent study of the lived experiences of Chinese terminal-ill patients and their family carers revealed that doctors and nurses often lack awareness and empathy of their unique needs and concerns, while some had even been treated with disrespect and insolence, making their end of life journey ever more difficult (Ho, et al., 2015). Without holistic life and death education to cultivate compassionate

providers of care, achieving “dignity has become a far-reaching goal for patients at the end-of-life” (p.329).

### **Life and Death Education in Primary, Secondary and Tertiary Schools**

Cruse and Cruse (1985) assert that if education contributes to the ultimate goal of human happiness and wellbeing, then learning about death needs to be part of the process; as life and death education is much a requisite of a complete education as learning about health, nutrition and our relationships with the environment. And with the high and ever increasing suicide and attempted suicide rates among children and adolescent in developed countries, and most prominently found among Asian societies (Ho, Chui & Borshel, In-press), the need for young people to learn about mortality cannot be overstated. In recent decades, much effort has been placed on implementation death education programmes in both primary and secondary schools in the West and especially the US; but despite these efforts, only a minority of the hundreds of millions of children actually receives them (Dennis, 2009). While one may expect that territory students will get more exposure to life and death education, a recent survey of 161 colleges and universities in the Midwestern states of US found that only 20% offered a course on Death, Dying and Bereavement in the last five years (Eckerd, 2009).

Many theorists believed that the major reason for such discouraging figure found in life and death education in primary and secondary schools is that death has replaced sex as the ‘last taboo’ in formal education (Chadwick, 1994; Wagner, 1995; Basu & Heuser, 2003). And this well may be the result of a lack of proficiently trained teachers combined with general misconception that death education could led to dangerous outcomes. According to a number of studies

that examined teachers' readiness in offering support to students challenged by the loss of a loved one, the majority felt that they are weakly prepared to support bereaved students, most believed that they would not be able to answer questions on issues related to death, and less than one-third believed that they were qualified to teach death education (Mahon, Goldberg, & Washington, 1999; Pratt, Hare & Wright, 2001; Papadatou, Metallinou, Hatzichristou, et al., 2002). This is the least surprising giving the very fact that learning about mortality is not a training requirement of teachers. However, when teachers do feel competent and are passionate to offer life and death education, they are often questioned by parents and even the media about their methods of instructions as well as the effects of their curriculum.

In fact, countless articles dating back to the 1990s have doubted the effectiveness of death education, with frequent queries about the potential harms that it may cause (Finn, 1990). On Twenty-first of September 1994, a US national news programme, ABC's 20/20, reported on '*Death in the Classroom*', whereby its anchor Barbara Walters and journalist Hugh Downs stated that a curriculum on death seems 'overly morbid', questioned whether "parents know if their kids are emotionally ready for it", and insinuated a plausible connection between death education in school and suicide among teenagers. While these negative depictions still exist today (i.e. Citizens Commission on Human Rights Florida, 2015), public opinions are progressively favoring the inclusion of life and death education in schools (Wass, 2004), as students, parents and teachers increasingly recognize the important role that it plays in suicide and violence prevention (Surgeon General's Report, 2000), in serving as antidote for correcting the distorted images that glorify or trivialize death (King & Hapslip,

2001), and in helping children and adolescence cope with the overwhelming presence of violence deaths showcased by social media and the entertainment industry (Wass, 2003).

Although the structure of Hong Kong's public education system is largely similar to those of the West, it does not share the same aspiration in promoting life and death education in its primary, secondary or tertiary curriculums. Instead of focusing on whole-person development, education has perpetually emphasized the transfer of practical knowledge and marketable skills to cultivate a populace of young entrepreneurs, accountants, bankers, engineers and other profitable professionals to ensure and sustain its economic development; whilst the social, moral and personal aspects of education have largely been neglected (Yip, 2000). The recent General Education (GE) reform for secondary and tertiary institutions which aims to promote a comprehensive learning experience to nurture students' creativity and civility through the liberal arts (Education & Manpower Bureau, 2005), provides a timely opportunity to develop and launch a Thanatology curriculum in the higher education system of Hong Kong, one that aspires towards the ideals of Health Promoting Palliative Care in pushing forth the basic human right of care at the end-of-life.

### **A Thanatology Curriculum for Hong Kong Higher Education Reform**

The recent Education Reform Paper published by the Hong Kong Curriculum Development Council (2011) entitled, 'Learning to Learn – The Way Forward in Curriculum Development: Lifelong Learning and Whole-Person Development', highlighted the requisite for education to place greater weight on helping students learn how to learn in order to develop "their

independent learning capabilities leading to whole-person development”; and called on “the use of different methods of learning and teaching to achieve these learning targets” (p. 10). Such aspiration is supported by replacing the longstanding British academic structure that comprises of five-years of secondary school, two-years of advance levels and three-years of university; to three-years of junior secondary, three-years of senior secondary and four-year of undergraduate. This new 3-3-4 structure, that aimed to establish a more flexible, coherent and diversified curriculum, begun implementation in 2009 and was fully assimilated across all eight universities in 2012. The Hong Kong Education Bureau (2011) stressed that goal of this reform is to enable universities to develop a more holistic and student-oriented approach to undergraduate education, for which a well-rounded curriculum necessities the invaluable teaching on thanatology, life and mortality,

“The first and foremost objective of school to implement life education is to help student develop their positive values and attitudes towards life, and know how to deal with their emotions when facing difficult [life and death] situations. Life education should also enhance students’ problem solving skills, equip them to learn how to get out of adversities, and guide them to explore and search for the meaning of life in order to have a happy, fulfilling and meaningful life.” (Education Bureau, 2011, n.p., para 2).

Despite the call for actions, only a few schools out of the four hundred secondary schools in Hong Kong have offered comprehensive life and death education (Sing, 2009). And although research have repeatedly shown that

university students support and value learning about mortality (Mak, 2010-2011; Mak, 2011), as “It is part of the pursuit of the meaning of human life that young people have curiosity and doubts about death and try to understand it” (Lai, Chen, Chen, et al., 2002), no universities are currently offering a full credit course on life and death in their general education programme. Consequently, “the present death attitude of university students is not satisfactory and death education is desperately needed (Wong, 2009, p.124).

### **The Common Core Curriculum**

In response to the Hong Kong higher education reform which urges universities to render a well-rounded and person-centered education to its students, one that highlights the imperative of interdisciplinary teaching and exploration of life and death, educators are increasingly drawing upon health promotion insights and strategies. In particular, the University of Hong Kong had entirely revamped its undergraduate curriculum based on the principles of social participation and civil responsibility so as to develop students’ capabilities in: 1) pursuit of academic/professional excellence, critical intellectual enquiry and life-long learning; 2) tackling novel situations and ill-defined problems; 3) critical self-reflection, greater understanding of others, and upholding personal and professional ethics; 4) intercultural understanding and global citizenship; 5) communication and collaboration; and 6) leadership and advocacy for the improvement of the human condition (University of Hong Kong, 2011).

The University has also taken a holistic and student-driven approach in the design of the undergraduate curriculum, which provides greater flexibility for students to design their own academic programme and participate in a range

of learning experiences that are integral to their academic studies (University of Hong Kong, 2011). In addition to major-specific studies, all students from every disciplines are required to take a minimum of six courses within the new Common Core Curriculum (CCC) during their foundation years, in the four inter-related Areas of Inquiry including: 1) Scientific & Technological Literacy, 2) Humanities, 3) Global Issues and 4) China: Culture, State and Society. The CCC seeks to: 1) arouse students' intellectual curiosity and stimulate their enthusiasm for learning; 2) enable students to have a broader perspective, and a critical understanding of the complexities and the interconnectedness of the issues that they are confronted with in their everyday lives; 3) cultivate students' appreciation of their own culture and other cultures, and the inter-relatedness among cultures; 4) enable students to see themselves as members of global as well as local communities and to play an active role as responsible individuals and citizens in these communities; and 5) enable students to develop the key intellectual skills that will be further enhanced in their disciplinary studies.

### **The Last Dance: Understanding Death and Dying**

With the emergence of the Common Core Curriculum, the Centre on Behavioral Health of the University of Hong Kong, together with the Department of Social Work and Social Administration as well as the Department of Sociology of HKU, jointly developed a new CCC Humanities course on Thanatology in 2010. “The Last Dance: Understanding Death and Dying” was inspired by the values and principles of teaching and learning in life and death as laid out by the International Work Group on Death, Dying and Bereavement (IWGDDB, 2005, pp. 383-384):

1. Death education should help people develop the knowledge, attitudes, and skills they need in relation to dying, death and bereavement.
2. Death education needs to focus on increasing the availability of individuals, families, communities, and other groups to provide support to individuals and families as they face life's crisis.
3. Death education should be incorporated as part of the regular curriculum in educational institutions as well as programs for the preparation and advanced training of health and human service providers.
4. All forms of media should be utilized in death education in order to reach more people.
5. It bears repeating that all those involved with the care of the dying and bereaved will need training and education to be culturally, spiritually, socially, and emotionally sensitive.
6. Death education should be provided to all persons so that they too can be culturally, spiritually, socially, and emotionally sensitive to the dying and bereaved.

Based on the IWGDDB paradigm, the core objectives of *The Last Dance*:

Understanding Death and Dying include:

1. Providing students' with proficient knowledge on death, dying and bereavement as well as issues concerning spirituality and meaning of life;



2. Developing students' awareness on the psychological, social, cultural and political-economic impact of death and loss among different ethnic groups with a particular focus on the Asian Chinese experience;
3. Enhancing students' understanding on mortality through the lens of developmental, social, and community psychology, sociology, social work and social administration;
4. Equipping student with practical-skills for working with individuals, families and communities facing the challenges of death, dying and bereavement; and
5. Cultivating students' self-reflection on their personal beliefs, attitudes and experiences with death and loss to develop compassion and appreciation of life and personhood.

In essence, *The Last Dance* aims to provide an integrative overview of the major themes and theories in death and dying with a critical focus on the Chinese experience. It also explores the socio-political, cultural, psychological and spiritual issues raised by mortality through a range of cultural lenses, and examines areas of commonality and diversity to enhance students' competence and reflection in their personal and professional lives as they deal with the inevitability of illness, loss and death. In order to realize these broad and encompassing goals, *The Last Dance* was developed not by a single department, but by an interdisciplinary team comprising of scholars and professors in the fields of psychology, sociology, social work and social administration. Together,

they designed a ten-week curriculum that incorporates a broad spectrum of topics on mortality including:

1. *Death and its Impact on Individuals, Families and Communities* – Overview of the physical, emotional, psycho-social, spiritual and communal responses to death, dying and bereavement; with a phenomenological appraisal of death in relation to culture, gender and marginalized groups.
2. *Death systems in contemporary society* – Critical examination of the institutionalization, management and legislation of death with debates over advance care planning, pain control, life prolongation and palliative care, rights to die and assisted suicide, dying at home and dying in institution.
3. *The Historical Perspectives on Mortality* – Exploration of cultural diversity and social oppression in the expression of acceptance, fear and anxiety of death as well as those related to grief and mourning across time; together with a critical review on the history of social justice and mortality.
4. *The Evolving Attitudes toward Death, Dying and Bereavement* – A comparative analysis of the social and cultural discourses of death attitudes, beliefs and taboos; coupled with a review on suicide and suicide prevention, as well as threats of horrendous deaths and natural disasters.

5. *Death as a Business in China and America* – A comparative analysis of the ideological logic of pricing human life and commercializing death through financial risks and protection, estate management and the insurance industry
6. *Death in the News and Popular Media* – An overview of the processes of social distancing and commoditization of mortality in news and popular media, as well as its impacts on individuals and societal conceptualization of death.
7. *Vision of the Afterlife and the Function of Death Rituals across Cultures and Religions* – A psycho-anthropological analysis of their function as rites of passage, adjusting and re-establishing kinship, and facilitating the grieving process of the living; together with a critical examination of ethical teachings, meritorious deeds and spiritual pathways,
8. *Spiritual Inquires surrounding Human Existence and their Meanings to Personhood* – An exploration over the meaning of life and death that highlights an empirical discourse on existential and spiritual research; with a review of the secular concepts of immortality and near death experiences.
9. *The Experiences of the Dying and Bereaved for Understanding Life and Death* – A qualitative empirical review on the narratives and lived experience of loss, grief and bereavement among terminally-ill patients and bereaved families, accentuating the concept of dignity and compassion of a good life and a good death.

10. *Meaning reconstruction and continuing bond in the face of death and dying* – A critical discussion over the theories on attachment, continuing bond and meaning reconstruction in the face of mortality; together with a review over various intervention strategies for grief work and bereavement care.

In sum, this comprehensive curriculum covers both the *applied* and the *pure* domains of life and death education (Pine, 1977), interweaving theoretical and practical knowledge transfer with humanistic and introspective explorations. It embodies a holistic and well-rounded thanatology curriculum for higher education in Hong Kong (*Please see Appendix 2 for a detailed Course Outline of The Last Dance*).

### **Pedagogy, Assessment and Learning Outcomes**

Accentuating the essential goals of Health Promoting Palliative Care, which include strengthening of personal skills and social participation in death and dying as well as creating a caring and compassionate environment for those facing mortality and loss, the design of *The Last Dance* was driven by Briggs's Deep Learning Approach (1987; 1989) for cultivating genuine interests and intrinsic motivation to learn among students (Watkins, 1996). Specifically, the Presage-Process-Product (3P) model was adopted to promote optimal teaching and learning interactions (Biggs & Moore, 1993; Briggs, 1999). Concisely, the 3P model describes a progression of learning from presage to process to product, where each component interacts with all other components, forming a system of equilibrium and a conducive pedagogical environment.

The 'Presage' domain comprises of 'Student presage' and 'Teaching presage', where the former includes factors that reflect the relatively stable and typical learning characteristics of students such as prior knowledge and experience relevant to the task, intellectual abilities, values and expectations concerning achievement; while the latter refers to the context and superstructure set by teachers and the institution such as teaching competence and teaching style, the classroom climate, course structure, curriculum content, methods of teaching and assessment. The 'Process' domain refers to the ways students actually engage with the learning tasks, of which is determined by their perceptions of the teaching context, their motives and predispositions, their level of interests in the subject matter, as well as the method of instruction set by teachers, the actual activities that take place in the classroom, and the quality and quantity of exchanges and feedbacks between students and teachers. The 'Product' domain refers to the outcomes of learning as a result of the interplays between all presage and process factors, of which may be may be of low-levels of cognitive outcome (or surface learning) such as quantitative recall and choosing the right multiple choice answers, or high-levels of cognitive and introspective outcomes (or deep learning) that reflect a solid conceptualization and synthesis of abstract ideas presented in a coherent manner with meaningful personal reflections and applications.

### ***Pedagogical Approaches***

Given the fact that *The Last Dance* is offered under the Common Core Curriculum and enrolls students from all academic disciplines with varying backgrounds and learning characteristics, refining the Teaching presage becomes most critical. Thus, to ensure that students are well supported to engage

in deeper level of learning, instructional scaffolding was implemented in the design of pedagogy practice (Hogan & Pressley, 1997). Specifically, each two-hour lecture of *The Last Dance* covered the fundamental theories and practice concepts of the prescribed topic, supported by relevant multi-media materials as well as in-class discussions. Upon obtaining the necessary foundational knowledge through classroom instructions and assigned readings, students need to attend a one-hour tutorial session right after every lecture whereby they are asked to lead and engage in a variety of interactive activities such as small group discussions, debates and problem-solving tasks that require them to put theory into practice. Tutorials are facilitated by experienced tutors who provide modeling and guidance so as to foster autonomous learning, group-based learning and experiential learning (Sawyer, 2006).

### ***Assessment Tasks***

Apart from pedagogical instructions, the design of assignment tasks also geared towards the promotion of deep learning. Apart from a small percentage of course grades allocated to participation and less than one-third allocated to a final written exam, the bulk were allocated to activities that promote personal reflections, creative engagements and knowledge application. First, students are required to keep a bi-weekly individual reflective log to ruminate upon their own beliefs, values and attitudes on the various topics on death and dying covered in *The Last Dance*. This deliberate cognitive activity necessitates students to connect their thoughts, feelings and experiences related to their learning from all lectures, in-class discussions, tutorials, autonomous and group learning tasks. This activity further provides students with the opportunities to critically explore and reflect upon issues concerning mortality, spirituality,

personhood, society and greater humanity through acknowledging and understanding the nature of life and death (*Please see Appendix 3 for the Assessment Rubric of Student Reflective Log*).

Second, Students are required to work in groups of four to six to develop a creative project that tackles the various socio-cultural-political issues related to death and dying including but not limited to: alleviating Chinese death taboos; eliminating the oppression of death for widows and orphans; finding meaning in the face of death; promoting spirituality through mortality. Students are first required to conduct a literature review on the chosen topic, of which will serve as the empirical foundation of their project. They are then encouraged to adopt a public health promotion approach for tackling the issue at hand by using a variety of creative mediums including short-film, arts, photography, and other audio-visual tools. Each group is required to create a three-four minute multi-media production with a segment on learning reflection and present their work to the entire class at the final lecture (*Please see Appendix 4 for the Assessment Rubric of Group Presentation*). Finally, based on the creative project, each group is required to submit a written report of 4,000-6,000 words, inclusive of a detailed synthesis of the theoretical background, conceptual approach of the work undertaken, the public health impact of the project, and personal reflections on learning (*Please see Appendix 5 for the Assessment Rubric of Group Presentation*).

### ***Intended Learning Outcomes***

The aforementioned pedagogy approach and assessment tasks of *The Last Dance* are designed to achieve the following four Intended Learning Outcomes (ILO):

- ILO1. Describe and explain the fundamental knowledge, myths, attitudes, practices and ideological contradictions of death, dying and bereavement with a cultural sensitivity to the Chinese experience; and critically appraise the oppressive social norms, rituals, discourses and portrayals of death and dying in contemporary societies.
- ILO2. Demonstrate an understanding of the emotional concerns, family issues and psychosocial aspects of death and dying on the individual level; and critically examine the inequality of access to care and services among vulnerable groups such as widows, minors, orphans, the poor and people with contentious disease such as AIDS and other life-limiting infections.
- ILO3. Appraise the impact of death and loss on the societal level; and critically examine the future development of social policies, service provisions, education programs as well as the commercial industry on the management and commodification of death and dying.
- ILO4. Reflect on the meaning of life through a heightened awareness of death and an enhanced spiritual orientation; and create a more profound understanding of the 'self' through an appraisal of personal beliefs, cultural ideologies and popular religions and philosophies on spirituality and immortality.
- ILO5. Develop compassion and understanding for individuals, communities and the larger world as well as a commitment



to activism, equity and social justice during those most vulnerable moments in human experience; and challenge the hypocrisy of pricing human life and commercializing death in the modern era.

ILO6. Integrate theories into practice in developing creative health promotion projects on tackling the various socio-cultural issues concerning death, dying and bereavement.

Essentially, *The Last Dance* ultimately aspires towards actualizing Health Promoting Palliative Care through the Hong Kong's Higher Education system, to facilitate active engagement and participation in death and life among the younger generations of society, and empowering them to assume greater responsiveness in the governance of mortality. With the establishment of this first-of-its-kind life and death curriculum, there is a critical need to examine its efficacy in promoting positive changes among students, as well as to identify ways to enhance teaching, learning and future provisions.

## **Chapter Summary**

This chapter has provided a thorough review on the development of and challenges to palliative care provision in Hong Kong. It has also examined the prevalent social discourses and the conceptual foundation of Health Promoting Palliative Care, presented on the current standing of life and death education both international and locally, as well as elaborated on the vital role that life and death education plays in pushing forth palliative care as a basic human right. Finally, it provided a formative account of the processes involved in developing a new thanatology curriculum amidst higher education reform in Hong Kong, and accentuated the relevant pedagogy, assessments and intended outcomes for *The Last Dance: Understanding Death and Dying*.

## CHAPTER THREE METHODOLOGY

This chapter elaborates on the methodology employed in the current study, of which involved a mixed method design that combines both quantitative and qualitative inquires to examine the effectiveness of a new undergraduate thanatology curriculum for promoting positive death-related attitudinal and behavioral changes among university students, as well as to identify pertinent factors that augment the experience of learning and teaching. Such broad scope of inquires necessitates an epistemological stance that acknowledges both the strengths and limitations of Positivist and Constructivist investigations, and assumes the paradigmatic position of *Pragmatism* with its central tenant which accepts that “there are singular and multiple realities that are open to empirical inquiry and orients itself towards solving practical problems in the real world” (Feilzer, 2010, p.8).

Pragmatism emerged in the early twentieth century and challenged previously held assumption that knowledge could only be generated by conscious thoughts or experimentations. It instead postulated that knowledge is borne of the interactions between one’s actions, their consequences and the subsequent reflections upon them (Dewey, 1929). Under the worldview of Pragmatism, researchers can focus on “what works as the truth regarding the research question under investigation” (Tashakkori & Teddlie, 2003, p.713), and thus are freed from the mental and practical constraints imposed by the dichotomy of traditional research paradigms (Creswell & Plano Clark, 2007; Rotry, 1999). With the aforesaid, the preceding sections describe in detail the research design and methods employed.

## Research Design

Guided by the Pragmatic epistemology, this study adopts a *Holistic Approach to Education Evaluation* (Chinapah & Fagerlind, 1986), one that gives equal weight to *Impact Evaluation* for measuring the extent to which a program produces desired changes, as well as to *Process Evaluation* for pinpointing the factors that either foster or hinders learning. According to Chinapah and Miron (1983), the deterministic characteristics of survey technique in education evaluation “ensures that the causal relationship between independent predictors (input), intervening (process), and dependent (output) variables be simultaneously analyzed” (p. 17); and therefore satisfy the basic scientific characteristics for evaluation in the social sciences (Babbie, 1973). Chinapah and Miron (1983) further emphasized the need to complement surveys with qualitative evaluation techniques such as analysis of written documents for tapping on important information that relates to the quality of curriculum design, pedagogy practices and learning processes. Such in-depth descriptive and narrative types of data are critical for identifying the determinants of success and failures of education programs, and thus must be included in a holistic education evaluation.

As such, multiple methods and data sources for evaluating course effectiveness and for identifying processes that facilitate learning and teaching was utilized in the current study. The specific methods and data sources include:

- 1) a *pretest-posttest student survey* for assessing the effectiveness of course content and pedagogy practices in promoting positive attitudinal and behavioral changes towards mortality, life and spirituality among students through clearly

defined and measurable constructs; and 2) *analysis of students' reflective writings* on learning and teaching.

### **Participants Recruitment and Procedures**

Ethical approval for this study was granted by the Human Research Ethics Committee for Non-Clinical Faculties (HREC/NCF) of the University of Hong Kong (*Please see Appendix 6 for Letter of Ethical Approval of current research*). Participants of the present study included all first year undergraduate students from the University of Hong Kong (HKU) who enrolled in the course, "The Last Dance: Understanding Death and Dying". The inclusion criteria included students of Chinese ethnicity who did not suffer from any mood or psychotic disorders. As course enrollment reached its maximum size of 100 students, and all enrolled students agreed to participate, the sample size was 100 (N=100). During the first lecture of *The Last Dance*, all students were explained of the aims and objectives of the study, and informed of the complete voluntary nature of their participation, the protection of their confidentiality, the anonymous use of their written assignments as part of study data, and that their participation in the study would not in any way affect the assessments of their coursework nor their final course grades. Upon acknowledging such information and having agreed to participate, students were asked to sign an informed consent form (*Please see Appendix 7 for Letter of Informed Consent*) and thereafter engaged in two major research activities.

First, students filled out a self-administered pretest questionnaire with standardized measures that assessed their attitudes and beliefs towards mortality, life and spirituality in the beginning of the first lecture (Baseline = T0). After completing all required lectures, tutorials and educative activities at twelve

weeks (Follow-up = T1), students were again asked to fill out a self-administrated posttest questionnaire comprised of the same measures for detecting potential attitudinal and behavioral changes as a result of learning about death and dying. Each questionnaire took approximately 20 to 30 minutes to complete, and the collected data were assimilated for statistical analysis by the researcher. Although the sample size for this pretest-posttest quasi-experiential design is predetermined by course enrollment limits, 100 student participants with an anticipated attrition rate of 20% at twelve week follow up would provide a final sample size of 80, which allowed 80% power to detect an effect size of 0.80 standard deviation units in the main outcome measure at 5% level of significant (two-tail test).

Second, a core assignment of *The Last Dance* – Bi-Weekly Reflective Logs – was used as part of the research data. All students were required to submit 4 reflective logs, and these narratives and experiences of learning and teaching were collected and assimilated by the researcher for qualitative analysis at the end of the course.

All data collection was conducted between the months of September to December 2011.

### **Pretest-Posttest Student Survey - Quantitative Measures**

Each student participant was required to complete a self-administrated survey before and after attending *The Last Dance*. The aim of this survey is to assess potential changes in one's perception and understanding towards mortality, life and spirituality. Particularly, death attitude and death preparedness behaviors are the primary outcomes of this study, while secondary outcomes include life-meaning and sense of spirituality. Furthermore, the

survey included items for assessing potential changes in the one's views on traditional death taboos as well as death preparedness behaviors. The following provides a detailed description of all standardized measures and ad-hoc items used in the pretest-posttest survey (*Please see Appendix 8 for the Pretest-Posttest Student Survey Questionnaire*).

### **1. Death Attitude Profile-Revised (DAP-R)**

Students' attitudes towards death were assessed by the Death Attitude Profile-Revised (DAP-R; Wong, Reker, & Gesser, 1994), a popular tool for measuring both positive and negative views and beliefs on mortality (i.e. Bluck, Dirk, Mackay et al., 2008; Payne, Dean, & Kalus, 1998). Comprises of 32 items, the DAP-R covers five specific domains including: 1) Fear of Death (7 items) which measures one's feelings of terror and distress towards the idea of mortality; 2) Death Avoidance (5 items) which measures one's anxiety and apprehension towards thinking and talking about death; 3) Approach Acceptance (10 items) which measures the extent to which one views death as a gateway to a happy afterlife; 4) Neutral Acceptance (5 items) which measures the extent to which one views death as a reality that is neither feared or welcome; and 5) Escape Acceptance (5 items) which measures the extent to which one views death as an escape from a painful existence. Each item is scored on a 7-point Likert Scale, and the scores of all items for each domain are combined and recalculated to form a subscale-score with a range of 1 to 7, with high scores indicating higher levels of fear, avoidance and acceptance.

The DAP-R has been examined by numerous researchers around the globe with both general populations and clinical samples; repeated findings have confirmed its factor structure, reliability and validity (Clements & Rooda,

199-2000; Niemeyer, 2004). Ho, Chan, Chow et al (2010) have also validated the DAP-R in Hong Kong with 300 young, middle-aged and older adults, and their findings revealed two additional domains that are culturally sensitive to the Chinese context. They included: 1) Personal Acceptance (2 items drawn from the original Neutral Acceptance domain) which measure the extent to which one accept their own deaths personally and intrinsically rather than basing their acceptance on a grand and extrinsic worldview; and 2) Afterlife Beliefs (2 items drawn from the original Approach Acceptance domain) which measure the extent to which one believes there will be life after death without the religious connotations of heaven and eternal blessed existence as found popular among Christianity, Catholicism and Judaism. Given the ethnicity of the current sample population, the Chinese version of the DAP-R together with its seven domains of fear of death, death avoidance, approach acceptance, neutral acceptance, escape acceptance, personal acceptance and afterlife beliefs, were used in the analysis.

## ***2. Traditional Death Taboos (TDT)***

Student's views on the traditional taboos of mortality were assessed by 8 ad hoc items that depict the most common death oppressing beliefs prevalent in Chinese societies. Sample items include, "Thinking or talking about death brings bad luck", "A painful or early death is a result of past misdeeds", and "Talking about death in front of a dying person would accelerate death". Each item is scored on a 4-point Likert scale; individual item scores that range from 1 to 4 are analyzed independently, with higher scores indicating higher levels of negative death perceptions. These eight items were developed through an expert panel of social workers, sociologists and psychologists from the University of



Hong Kong, and they have repeatedly been used in previous research on Chinese death attitudes (Ho et al., 2007; Ho & Chan, 2011).

### ***3. Death Preparedness Behaviors (DPB)***

Students' death preparedness behaviors were assessed by 4 ad hoc items that represent that most common form of death preparation actions. Specifically, students were asked whether they have considered or arranged for: 1) purchasing 'Life Insurances', 2) setting up a 'Legal Will', 3) committing to 'Organ Donations', and 4) planning for their own 'Funeral'. Each item is scored on a 4-point Likert scale, with 1 corresponding to 'never considered', 2 corresponding to 'some considerations', 3 corresponding to 'currently arranging' and 4 corresponding to 'already arranged'. Individual item scores are analyzed independently, with higher scores indicating higher levels of death preparedness.

### ***4. Meaning in Life Questionnaire (MLQ)***

Students' attitudes towards life and their efforts to find existential meaning were assessed by the Meaning in Life Questionnaire (MLQ; Steger, Frazier, Oishi et al., 2006). Comprises of ten items, the MLQ covers two specific domains including: 1) Perceived Life Meaning (5 items) which measures the extent to which one feels that their life is meaningful; and 2) Search for Meaning (5 items) which measures the extent to which one is actively seeking meaning in life. The MLQ Each item is scored on a 7-point Likert Scale, and the scores of all items for each domain are combined and recalculated to form a subscale-score with a range of 1 to 7, with higher scores indicating higher levels perceived meaning and search for meaning.

The MLQ has been validated and displayed strong factor structure, reliability and internal consistency with multiple populations across the globe including college students (Duffy & Raque-Bogdan, 2010), members of the general public (Park, Park, & Peterson, 2010), and clinical populations such as people living with mental illness (Schulenberg, Strack, & Buchanan, 2011) and caregivers of patients with chronic illness (Chan, 2014). The reason for choosing the MLQ rather than other instruments is its ability to assess search and presence of meaning independently, of which allows for greater theoretical flexibility that support the objectives of current research; “it is now possible to identify those who feel great meaningfulness yet still seek to further their understand of life’s meaning and compared them with those who feel their life is meaningful and are not engaged in any further search for meaning” (Steger et al, 2006; p. 89).

##### **5. *Spirituality Scale (SPS)***

Students’ beliefs, intuitions, lifestyle choices, practices and rituals that are representative of the human spiritual dimensions were assessed by the Spirituality Scale (SPS; Delaney, 2003). Comprises of 23 items, the SPS covers three specific dimension of spirituality including: 1) Self-Discovery (4 items) which measure the extent to which one engages in inner reflection within their search for meaning so as to attain growth, healing and transformation; 2) Relationships (6 items) which measure the extent to which one possesses an integral connection to others based on a deep respect and reverence for life and is known and experienced within relationships; and 3) Eco-Awareness (13 items) which measure the extent to which one possesses an integral connection to nature based on a deep respect and reverence for the environment and a belief

that earth is sacred. Each item of the SS is scored on a 4-point Likert Scale. The scores of all items for each domain are combined to form a subscale-score that range from 4 to 16 for Self-Discovery, 6 to 24 for Relationships, and 13 to 52 for Eco-Awareness; all subscale-scores are further combined to form a total score that ranged from 23 to 92, with higher scores indicating higher levels of self-discovery, relationship, eco-awareness, and overall spirituality.

The SPS has been validated with multiple population groups across the globe and displayed strong factor structure, internal consistency and reliability (Delaney, 2005; Monod, Brennan, Rochat, et al., 2011; Edwards, 2012). The reason for choosing the SPS rather than other instruments is its holistic theoretical foundation which defines spirituality as “a multidimensional phenomenon that is universally experienced, in part socially constructed, and individual developed throughout the lifespan... encompasses a personal, interpersonal and transpersonal context” (Delaney, 2005, p.152). Hence, the three domains of spirituality are interconnected and interdependent within a dynamic relationship with self, others and earth; such conceptualization allows researchers to assess the essence of spirituality in a format that can be used to guide spiritual interventions.

### ***Demographic Information***

7 additional items that measured the socio-demographic backgrounds were included in the self-administrated questionnaire. They include questions on age, gender, place of origin, religious background, frequency of thinking about death, as well as past experience of loss.

## **Analysis of Students' Reflective Writing on Learning and Teaching**

In order to attain a deeper understanding on students' learning processes, as well as to explore the many facets of knowledge acquisition and factors related to attitudinal changes in the perceptions of mortality, one core assessment artifact of 'The Last Dance' was examined. Specifically, students were required to keep a Bi-Weekly Reflective Log to contemplate upon their own beliefs, values and attitudes on the various death-related topics covered in class. This deliberate cognitive activity necessitated students to connect their thoughts, feelings and experiences related to their learning from all lectures, in-class discussions and experiential exercises. This activity further provided students with the opportunities to critically explore and progressively reflect upon issues concerning mortality, spirituality, personhood, society and greater humanity through understanding the values of life and death. The required length of each reflective log was 250 to 300 words, and each student was required to submit four reflective logs throughout the course. As such, 400 reflective logs from 100 students were received between September and December 2011; they were categorized into 4 different batches based on the time of submission. 25 reflective logs were then randomly selected from each batch, and a total of 100 reflective logs were analyzed.

### **Data Analysis**

#### **Quantitative Analysis Methods for Pretest-Posttest Survey**

Data collected from the pretest-posttest survey which assessed potential changes in students' attitudes towards mortality, life and spirituality before and after attend *The Last Dance* were analyzed using the Statistical Package for the

Social Sciences SPSS v.19 (IBM Corp., 2011). First, descriptive analysis were carried out on all baseline socio-demographic variables including age, gender, place of origin, religious background, frequency of thinking about death, experience with loss, views on traditional death taboos and death preparedness behaviors. Second, baseline (T0) and follow-up (T1) comparisons of the primary outcome of death attitude (i.e. fear of death, death anxiety, approach acceptance, neutral acceptance, escape acceptance, personal acceptance, and belief in afterlife) and the secondary outcomes of life meaning (i.e. perceived life meaning, and search for meaning), sense of spirituality (i.e. personal discovery, relationship, and eco-awareness), death taboos, and death preparedness behaviors (i.e. purchasing life insurance, setting up a will, committing to organ donation and preparing for one's funeral) were tested for statistical significant differences using paired-sample t-test. Means (M), Standard Deviations (SD), t-values (t) are reported for each significant outcome variables. A level of  $p < 0.05$  was considered significant.

### **Qualitative Analysis Methods for Students' Reflective Writing**

All selected written narratives generated through Students' Bi-Weekly Reflective Logs were systemically analyzed using Framework Analysis (Ritchie & Spencer, 1994). Framework Analysis involved with both deductive and inductive approaches for analyzing data as so to generate important factors and themes that illuminate the provision of life and death education in Hong Kong's higher education system. Framework Analysis is specifically developed in the context of applied policy research, one that has specific questions, a pre-designed sample and a priori issue, and aims to meet specific information needs and provide outcomes or recommendations (Ritchie & Spencer, 1994). While

the general approach in Framework Analysis is inductive, it allows for the inclusion of emergent concepts as well as a priori questions. (Srivastava & Thomson, 2009). The NVivo software assisted in coding, cross-referencing, storing and retrieval of data (QSR International, 2012).

The particular process for exploring narratives of learning involved several steps of data reduction, coding and assimilation. First, multiple readings and line-by-line coding of 20 selected students' reflective logs were carried out independently by a three-member team including the principle researcher of this study and two additional researchers with proficient training in qualitative analysis. Based on an initial coding framework guided by four a priori questions: 1) critical learning contents; 2) effective learning processes; 2) key attitudinal and behavioral changes; and 4) significant learning outcomes, each researcher developed their own codes with written explanatory summaries. Through regular meetings, the codes generated from each researcher were compared, contrasted and discussed so as to derive at a consensual coding scheme. Based on this consensual scheme, each researcher continued to code the remaining 80 student reflective logs independently. Further meetings were held to deliberate on any uncertainties, challenges and deviant cases that may have emerged, and the process of coding only continued when agreements were reached to resolve such problems.

Second, once line-by-line coding for all 100 student reflective logs were completed, axial coding was carried out independently again by the three-member team to further refine and develop possible clustering of codes. Specifically, individual codes comprising of similar contents, meanings and constructs were grouped into higher level of abstractions, and eventually

categorized into emergent themes and subthemes that illuminate critical learning contents, effective learning processes, key attitudinal and behavioral changes, as well as significant learning outcomes. Text files containing illustrative and descriptive quotes supplementing the identified theme(s) were also created. Each researcher individually reviewed and delineated the emergent themes and sub-themes, and presented to each other for discussion and confirmation of preliminary findings.

Third, the preliminary findings were presented to the larger HKU research team based at the Department of Social and Social Administration, of which consisted of ten members including two social work professors, two doctoral students, as well as six experienced research staffs that specialized in palliative care, psychosocial oncology, and life and death education. During regular bi-weekly research meetings, the HKU team discussed and compared openly on the preliminary findings, and inputs from all team members were carefully considered in the naming, revision and categorization of each and every themes and sub-themes so as to enhance rigor and trustworthiness. Finally, upon reaching consensus by every member of the HKU team, all major categories, themes and sub-themes were defined and operationalized.

### **Ethical Considerations**

The current research is bounded by the codes of ethics and the major ethical concerns as laid out by major scholarly associations; these include informed consent, deception, privacy and confidentiality (Christians, 2005). First and with regards to informed consent, I thoroughly informed potential participants on the purpose of my research and all the relevant procedures

involved in person. Once I obtained verbal consent, I asked participants to sign an informed consent form for participating in the research and to obtain permission to use their written assignments as part of research data. I also informed them that they have the right to ask me any questions during the process and their participation is totally voluntary, meaning that they have the right to withdraw without any negative consequences. Second and with regards to deception, the research did not comprise of any deception and thus was not an issue. Third and with regards to privacy and confidentiality, the identities of all informants are protected through the use of pseudonyms that replace their real names in all analyzed assignments, report writing and publication materials. Participants are also ensured that their participation and expressions would not in any way affect the assessment of their assignments, and that analysis of their bi-weekly reflective logs would only take place after their final grades have been approved and disseminated by the University. Finally, raw data are stored securely and were only made available to the members of my research team.



## **Chapter Summary**

This chapter has provided a detailed elaboration on the epistemological stance and the theoretical approach with which the current research is formulated. A discussion on the strengths and limitations of a Pragmatic paradigm is presented, while reasons for adopting a holistic approach to education evaluation are highlighted. This chapter has also specified in detail the research methods involved including those pertaining to sampling, data collection and data analysis, and explained the various ethical considerations taken in the pursue of the present study.

## **CHAPTER FOUR**

### **RESULTS, FINDINGS & ANALYSIS**

This chapter reports on the results of the pretest-posttest survey which assessed the potential attitudinal and behavioral changes on mortality, life, spirituality, death taboo and death preparedness among undergraduate students who completed 'The Last Dance: Understanding Death and Dying'. It also presents the qualitative findings derived from Framework analysis of students' reflective writings on the experiences of learning and teaching.

#### **Results from Pretest-Posttest Student Survey**

##### **Sample Characteristics**

Of the 100 students who had enrolled in *The Last Dance* and agreed to participate in the study, 87 have successfully completed both pretest and posttest assessments (N=87), yielding an attrition rate of 13%. According to Table 4.1 and in terms of their demographic backgrounds, 42.5% were male and 57.5% were female. Their age ranged from 17 to 25 years, with a mean age of 17.6 years. 28.7% of students majored in nursing in their undergraduate studies, 16.1% majored in the Arts, 14.9% majored in both Dentistry and Science respectively, and 12.7% majored in both Economics and Social Sciences respectively. Moreover, 79.3% were local students who grew up in Hong Kong and the remaining 20.7% were Mainland students who grew up in various provinces across China. The majority did not have a religious belief (73.5%), while others were Christians (14.9%), Catholics (4.6%), Buddhists and Taoists (4.6%) or ancestor worshippers (2.4%). Finally, 63.2% of students reported that they had sometime or often pondered upon issues related to mortality; 75.5%

reported that they had experienced the loss of a family member, and 11.1% had experienced the loss of a close friend.

Table 4.1 Characteristics of Student Participants (N=87)

| Characteristics           | n  | %    | Characteristics            | n        | %    |
|---------------------------|----|------|----------------------------|----------|------|
| <b>Gender</b>             |    |      | <b>Age (range/mean)</b>    | 17 to 25 | 17.6 |
| Male                      | 37 | 42.5 | <b>Religion</b>            |          |      |
| Female                    | 50 | 57.5 | Non-religious              | 64       | 73.5 |
| <b>Place of Origin</b>    |    |      | Christian                  | 13       | 14.9 |
| Hong Kong                 | 69 | 79.3 | Catholics                  | 4        | 4.6  |
| Mainland China            | 18 | 20.7 | Buddhist/Taoist            | 4        | 4.6  |
| <b>Thoughts of Death</b>  |    |      | Ancestor Worship           | 2        | 2.4  |
| Often                     | 10 | 11.5 | <b>Undergraduate Major</b> |          |      |
| Sometimes                 | 45 | 51.7 | Nursing                    | 25       | 28.7 |
| Seldom                    | 31 | 35.6 | Arts                       | 14       | 16.1 |
| Never                     | 1  | 1.2  | Dentistry                  | 13       | 14.9 |
| <b>Experience of Loss</b> |    |      | Science                    | 13       | 14.9 |
| Family member             | 65 | 75.6 | Economics                  | 11       | 12.7 |
| Close friend              | 10 | 11.6 | Social Sciences            | 11       | 12.7 |

In terms of students' death preparedness behaviors at baseline and according to Table 4.2, 8.1% had purchased life insurance, 54.0% had considered the need for or were in the process of purchasing life insurance, and 37.9% had never considered such need. No students had set up a will, 42.5% had considered the need for or were in the process of setting up a will, and 57.5% had never considered having such need. Moreover, 14.9% had already signed up for and were committed to organ donation, 72.5% had considered or were arranging to sign up for organ donation, and 12.6% had never considered donating their organs. Finally, only one student reported having planned their funerals, 32.2% had considered or were arranging their funeral plans, and 66.6% had never given their funerals any thoughts.

Table 4.2 Death Preparedness Behaviors at Baseline (N=87)

| <b>Behaviors</b>                    | n  | %    | <b>Characteristics</b>              | n  | %    |
|-------------------------------------|----|------|-------------------------------------|----|------|
| <b>Life Insurance</b>               |    |      | <b>Organ Donation</b>               |    |      |
| Already arranged                    | 7  | 8.1  | Already arranged                    | 13 | 14.9 |
| Currently arranging/<br>considering | 47 | 54.0 | Currently arranging/<br>considering | 63 | 72.5 |
| Never Considered                    | 33 | 37.9 | Never Considered                    | 11 | 12.6 |
| <b>Arranging Will</b>               |    |      | <b>Funeral Planning</b>             |    |      |
| Already arranged                    | 0  | 0.0  | Already arranged                    | 1  | 1.2  |
| Currently arranging/<br>considering | 37 | 42.5 | Currently arranging/<br>considering | 28 | 32.2 |
| Never Considered                    | 50 | 57.5 | Never Considered                    | 58 | 66.6 |

With regards to students' views on common traditional death taboos that are prevalent in the Asian Chinese context, Table 4.3 shows that the majority did not agree with most culturally oppressing beliefs of mortality at baseline. In particular, over 90% rejected the ideas that talking about death brings bad luck, seeing a dead body brings ill fortune, recently bereaved families should not socially active, and that dying without a son is a "loss of face". Over 80% also opposed the notions that a painful or an early death is a result of past misdeeds, parents should not attend their children's funeral, and that talking about death with the dying would accelerated death. Despite these encouraging findings, one particular taboo which declares that visiting homes of recently bereaved families is not appropriate was still supported by more than 30% of students. While this could be a result of the lingering effects of a traditional view that homes which experienced recent deaths could be haunted, conversely, it could also be reflective of the customary practice for respecting the dead and giving peace to the bereaved.

Table 4.3 Views on Traditional Death Taboos at Baseline (N=87)

| Death Taboo Items   | Agree/<br>Strongly<br>Agree<br>(%) | Disagree/<br>Strongly<br>Disagree<br>(%) |
|---|------------------------------------|--|
| Thinking or talking about death brings bad luck.                | 8.1                                | 91.9                                     |
| Seeing a dead body or a coffin brings ill fortune.              | 9.2                                | 90.8                                     |
| A painful or early death is a result of past misdeeds.          | 16.1                               | 83.9                                     |
| Recently bereaved families should not be socially active.       | 8.1                                | 91.9                                     |
| Visiting homes of recently deceased persons is not appropriate. | 32.2                               | 67.8                                     |
| Parents should not attend their children's funeral.             | 17.2                               | 82.7                                     |
| Talking about death with a dying person would accelerate death. | 16.1                               | 83.9                                     |
| Dying without a son is a "loss of face".                        | 3.4                                | 96.6                                     |

## Results from Paired-Sample T-Test

### *Primary Outcomes*

Results from paired-sample T-test revealed significant differences in the primary outcome of mortality perceptions as assessed by the Death Attitude Profile-Revised, as marked improvements were found among students' attitudes towards death and dying before and after attending *The Last Dance*. According to Table 4.4, students' Fear of Death had significantly decreased from baseline (M=3.77, SD=1.01) to follow-up (M=3.49, SD=1.06);  $t(86)=2.906$ ,  $p=.005$ , while their sense of Death Avoidance had also reduced substantially from baseline (M=3.15, SD=1.08) to follow-up (M=2.85, SD=1.17);  $t(86)=2.63$ ,  $p=.010$ ). Our results further show that, not only did students become less fearful and less avoidant of mortality, they had also developed a more positive perception towards life's end, viewing death as a spiritual pathway for transmigration of the soul into another realm of existence with positive and affirming beliefs in the afterlife, both religiously and secularly. This is reflected in the significant changes in their scores in the Approach Acceptance domain

which increased from baseline (M=4.01, SD=0.98) to follow-up (M=4.26, SD=1.03);  $t(86)=-2.95$ ,  $p=.004$ , as well as the their scores in the Afterlife Belief domain from baseline (M=3.79, SD=1.34) to follow-up (M=4.08, SD=1.43);  $t(86)=-2.19$ ,  $p=.031$ . Finally and encouragingly, students had established greater intrinsic recognition that death is a natural part of their lives, as reflected by their scores in the Personal Acceptance domain which increase from baseline (M=4.79, SD=1.25) to follow-up (M=5.10, SD=1.20) at post-test;  $t(86)=-2.26$ ,  $p=.027$ .

Table 4.4 Paired Sample T-Test Results on Mortality Perception

| DAP-R Domains       | T0 Mean | SD   | T1 Mean | SD   | t     | P             |
|---------------------|---------|------|---------|------|-------|---------------|
| Fear of Death       | 3.77    | 1.01 | 3.49    | 1.06 | 2.91  | <b>.005**</b> |
| Death Avoidance     | 3.15    | 1.08 | 2.85    | 1.17 | 2.63  | <b>.010*</b>  |
| Neutral Acceptance  | 6.02    | 0.79 | 5.95    | 0.99 | 0.67  | .506          |
| Approach Acceptance | 4.01    | 0.98 | 4.26    | 1.06 | -2.95 | <b>.004**</b> |
| Escape Acceptance   | 3.53    | 1.06 | 3.28    | 1.28 | 1.88  | .062          |
| Personal Acceptance | 4.79    | 1.25 | 5.10    | 1.20 | -2.26 | <b>.027*</b>  |
| Afterlife Belief    | 3.79    | 1.34 | 4.08    | 1.43 | -2.19 | <b>.031*</b>  |

Notes. \*\*\* $p<0.001$ ; \*\* $p<0.01$ ; \* $p<0.05$ ; † $p<0.1$ ; N=87

In addition to the reduction of fear and avoidance as well as the elevation of acceptance of mortality, Table 4.5 also shows that students' beliefs on Traditional Death Taboos had significantly decreased while their Death Preparedness Behaviors had markedly increased upon completing *The Last Dance*. In particularly, the death oppressing view that visiting homes of recently bereaved persons is not appropriate has reduced from baseline (M=2.09, SD=0.74) to follow-up (M=1.86, SD=0.77);  $t(86)=2.49$ ,  $p=.014$ , while the death preparedness behaviors of setting up a will, organ donation and funeral arrangements have also increased significantly with a p level of  $<.001$ .

Table 4.5 Paired Sample T-Test Results on Death Taboo and Preparedness

| Scales & Items   | T0 Mean | SD   | T1 Mean | SD   | t     | P              |
|--|---------|------|---------|------|-------|----------------|
| <i>Death Taboo</i>   |         |      |         |      |       |                |
| Talking about death brings bad luck.                                   | 1.59    | 0.64 | 1.68    | 0.69 | -1.11 | .270           |
| Seeing a dead body brings ill fortune.                                 | 1.66    | 0.65 | 1.75    | 0.75 | -1.52 | .132           |
| A painful death is due to past misdeeds.                               | 1.85    | 0.67 | 1.84    | 0.61 | .129  | .897           |
| Bereaved families should not be active.                                | 1.91    | 0.66 | 1.80    | 0.66 | 1.27  | .209           |
| Visiting homes of recently deceased persons is not appropriate.        | 2.09    | 0.74 | 1.86    | 0.77 | 2.49  | <b>.014*</b>   |
| Parents should not attend children's funeral.                          | 1.70    | 0.61 | 1.76    | 0.66 | -.712 | .478           |
| Talking about death in front of a dying person would accelerate death. | 1.85    | 0.74 | 1.74    | 0.71 | 1.18  | .241           |
| Dying without a son is a "loss of face".                               | 1.51    | 0.57 | 1.67    | 0.73 | -2.01 | .063           |
| <i>Death Preparedness</i>  |         |      |         |      |       |                |
| Life Insurance   | 1.84    | 0.87 | 1.98    | 0.82 | -1.59 | .116           |
| Set-up Will  | 1.49    | 0.61 | 1.75    | 0.64 | -3.28 | <b>.001**</b>  |
| Organ Donation   | 2.20    | 0.85 | 2.40    | 0.86 | -3.49 | <b>.001***</b> |
| Funeral Arrangement  | 1.36    | 0.57 | 1.83    | 0.58 | -7.24 | <b>.001***</b> |

Notes. \*\*\*p<0.001; \*\*p<0.01; \*p<0.05; †p<0.1; N=87

### ***Secondary Outcomes***

Apart from the primary outcome of mortality perception and death preparedness behaviors, significant differences were observed in the secondary outcomes of life meaning and spirituality. First, students' sense of life meaning was assessed by the Meaning in Life Questionnaire, of which comprises of the two domains of: 1) Presence of Meaning, and 2) Search for Meaning. Table 4.5 shows that students' scores in the Presence of Meaning domain has significantly increased from baseline (M=4.69, SD=1.06) to follow-up (MD=5.06, SD=0.97) at post-test;  $t(86)=-3.307$ ,  $p=.000$ . However, no significant changes were

observed for the domain of Search for meaning, as the scores at baseline (M=5.54, SD=0.79) and follow-up (M=5.53, SD=0.76) remain consistently high. Second, students' sense of spirituality was assessed by the Spirituality Scale, of which comprises of the three subscales of: 1) Self-Discovery, 2) Relationships; and 3) Eco-Awareness. As shown, students' sense of Self-Discovery has significantly increased from baseline (M=11.66, SD=1.56) to follow-up (M=12.20, SD=1.49);  $t(86)=-3.307$ ,  $p=.001$ , while their sense of Eco-Awareness had also raised markedly from baseline (M=35.35, SD, 4.80) to follow-up (M=37.53, SD=4.54); with sense of eco-awareness from (M=35.34, SD=4.80) to (M=37.53, SD=4.54);  $t(86)=-5.637$ ,  $p=.000$ . Although no differences were found for the domain of Relationship as the scores at baseline and follow-up remain consistently high, significant increase in students' overall Spirituality score were observed at baseline (M=66.78, SD=6.55) as compared to follow-up (M=69.51, SD=6.46);  $t(86)=-4.685$ ,  $p=.000$ .

Table 4.6 Paired Sample T-Test Results on Meaning and Spirituality

| Scales & Domains             | T0 Mean | SD   | T1 Mean | SD   | t      | P              |
|------------------------------|---------|------|---------|------|--------|----------------|
| <i>Meaning in Life Scale</i> |         |      |         |      |        |                |
| Presence in Meaning          | 4.69    | 1.06 | 5.06    | 0.97 | -3.71  | <b>.001***</b> |
| Search for Meaning           | 5.54    | 0.79 | 5.53    | 0.76 | .109   | .913           |
| <i>Spirituality Scale</i>    |         |      |         |      |        |                |
| Self-Discovery               | 11.66   | 1.56 | 12.19   | 1.46 | -3.307 | <b>.001***</b> |
| Relationships                | 19.78   | 2.05 | 19.78   | 2.15 | .000   | 1.000          |
| Eco Awareness                | 35.35   | 4.80 | 37.53   | 4.54 | -5.627 | <b>.001***</b> |
| Total Spirituality           | 66.78   | 6.55 | 69.51   | 6.46 | -4.685 | <b>.001***</b> |

Notes. \*\*\* $p<0.001$ ; \*\* $p<0.01$ ; \* $p<0.05$ ; † $p<0.1$ ; N=87



## **Findings from Qualitative Analysis of Students' Reflective Writings**

100 randomly selected students' reflective writings, 25 from each of the four submission time points, were systemically analyzed to identify common experiences that illuminate critical learning and teaching processes of *The Last Dance*. Results from Framework analysis using the four a priori of: 1) critical learning contents; 2) effective learning processes; 2) key attitudinal and behavioral changes; as well as 4) significant learning outcomes, reveal a total of 12 themes. These themes elucidate the specific domains of death-related knowledge, pedagogical practices and activities that cultivate deep levels of reflections and erudition on mortality among students, leading to enhanced sense of personhood, life meaning and spirituality as revealed by the quasi-experimental study. These 12 themes are further organized into four major theme categories of: 1) Mortality Matters, 2) Teachable Moments, 3) Shifting Perspectives, and 4) Ego Awakening, all together informing the future development of life and death education. Each of these categories is considered in turn and supported by illustrative quotations from students' reflective writings.

### **Major Theme Category of "Mortality Matters"**

The first major theme category derived from students' reflective writing is "Mortality Matters", of which encompasses three prominent themes relevant to *significant learning contents* as well as the particular domains of death-related knowledge and relevant social issues that fostered critical thinking among students:

- I. ‘Considerations of Palliative Care and Euthanasia’, which involves the critical examination of the practical and moral dilemmas of individuals’ rights to live with dignity and die with autonomy, as well as the implications on society;
- II. ‘Expressions of Death via Arts and Media’, which involves examinations of the ways in which the arts and news media articulate and communicate the occurrences and emotions associated with death, dying and bereavement;
- III. ‘Discussions of Death Rituals and Spirituality’ which involves the exploration of traditional and contemporary practices of death rituals and mourning rites, as well as their impact on spirituality.

### ***Considerations of Palliative Care and Euthanasia***

Among the many topics covered in *The Last Dance*, the Consideration of the clinical practice of palliative care and the moral dilemmas of Euthanasia is viewed as one of the most valuable learnings of mortality. Many students reflected on the pain and suffering of those faced with chronic and terminal illness, as well as the spiritual and existential struggles that they face between survival and desire for death. Amy [*reflective log 1*] shared her feelings towards the potential negative outcome of euthanasia and the importance of dignified palliative care,

“I think that if euthanasia is legal in Hong Kong, it would be abused by patients as a way to be relieved physical pain or simply end their life when confronting bad times... good

palliative care would better serve patients with permanent and irreversible health problems... high quality care enables them to live and die with dignity.”

Louis [*reflective log 1*] expressed his views on not surrendering to the hardships of life and how such difficulties can bring a renewed understanding to life,

“I think we should never give up in times of difficulties or even illness, bravely facing these challenges can help us to learn the meaning of life. Therefore I do not agree with euthanasia, especially when palliative care is available.”

Chun [*reflective log 1*] also commented on the scarcity of life and the critical role that that palliative care plays in protecting one’s dignity,

“Beyond doubt, life is valuable, but only on the basis that the life is dignified, self-controlled and acceptable in terms of living standard... elements of palliative care needs to be implemented to attain these goals.”

Yet, Chun further pointed out that euthanasia may be acceptable in case of devastating illnesses,

“But by no means should euthanasia be considered necessarily evil. Provided that the patients’ decisions are fully informed and objectively legitimate, euthanasia can restore the dignity of those facing painful and horrendous conditions such as ALS or vast deformities.”

Ceci [*reflective log 2*] supported the notion of euthanasia, emphasizing the need to respect individuals' choices over the medical mandate of saving lives,

“For me, I would surely support euthanasia. The meaning of life is not dependent on the length of life. When someone has lost consciousness and can't even enjoy the beauty of life, it is meaningless to use life-sustaining technologies to sustain... the physical body but lock the soul.”

Despite different contentions, students also found the debate on euthanasia and palliative care thought-provoking and perspective widening. Shing [*reflective log 2*] commented on the value and importance of such discussions,

“We have discussed the right of a patient to take assisted suicide or euthanasia, my group mates and I have different point of views... But this makes the discussion even more interesting and fruitful, as everybody has their own opinions, I can learn to listen to others' thought and generate a conclusion with different views. I think these are the useful skill for me to learn in my university study, or even for the life-long learning.”

Clearly, discourses over the rights to palliative care and the rights to euthanasia are not only meant for the social and political debates, they are also invaluable for a thanatology curriculum that aspires towards the cultivation of personhood and responsible citizenship among young adults.

### ***Expressions of Death via Arts and Media***

The second defining theme for Mortality Matters is the Expression of Death via Arts and Media. Many students believed that it is critically important

to examine the ways in which the arts and news media articulate and report on death occurrences, death-related thoughts and emotions. This is because mortality is a topic that most have difficult discussing, as words and language can limit and constraint one's expressions of feelings towards death and loss. Christine [*reflective log 2*] explained,

“To me, art acts like a mirror which can reflect the inner personality of one... art is also a way for people to express their feelings about life and death, and to give a message to others, in which it could not be described by words. It is an important way for people to communicate.”

Vincci [*reflective log 4*] elaborated on the importance of art in helping the dying and the bereaved to convey their emotions and concerns to their loved ones as well as to the rest of world,

“I was impressed by the painting of Robert Pope shown during the lecture. They are beautiful and make me feel very peaceful. The message I receive is that life is unpredictable and death has nothing to be afraid of.”

Eva [*reflective log 2*] shared the same sentiments as she felt that art can foster greater understanding and connection between the living and the dying,

“Seeing the death in arts makes me realize that death can be beautiful... death connects all of us.”

While the arts were deemed imperative for individuals to find common humanity through mortality, many students also commented on the framing and reporting

practices used by news media and how such expressions could impact one's perspectives on death and loss. Susan [*reflective log 3*] explained,

“The lecture on media communication and death is very reflective for me... I have always thought of my own view of death as a very personal and unique one which has limited influence from others. It is therefore shocking to discover that my ways of perceiving death is indeed much manipulated by the media.”

Helen [*reflective log 3*] also discussed the power of mass media in shaping individuals' views on mortality and issue of biased reporting,

“It seems like media controls everything. We seem to be one-way receiving the message or the news of the society through different mass media. The value of death tends to be judged by their reports which do not always reflect facts.”

Wing [*reflective log 3*] reflected on the expression of death among mass media and pondered on the possibility for them to play a role in life and death education,

“I discover from the lesson that death has been shaped and framed by the media whose perspectives govern what to be emphasized in the presentation of different death cases... this reminds me the power of media, we can, and should use it positively to promote the meaning of life and to encourage people to confront death in their early ages.”

From these reflections, it is clear that exploring how the arts and news media portray and report death and loss is a vastly important undertaking in life and death education, as such provides a critical focus for discussion and reflection on mortality leading to new perspectives and growth.

### ***Exploration of Death Rituals and Spirituality***

The final defining theme for Mortality Matters is the Exploration of Death Rituals and Spirituality. As expressed by most students, exploring and understanding the origins of traditional rituals of death and contemporary mourning rites can shed light on important cultural and family values that defines one's belief system, meaning in life and sense of spirituality. Ngan [*reflective log 3*] explained,

“Funeral ceremonies are actually part of the culture and history of our nation... I realized that funeral is not only about one's death, but also about his beloved ones. It is a chance for them to memorize their love and blessings to the dead.”

Andy [*reflective log 4*] also reflected on the evolving practice of death rituals and the important meanings that it bears for the deceased and the bereaved,

“Admittedly, some traditions have lost their meaning in the modern world because people just treat them as a routine... Yet, funerals and death rituals have their meaning and I think we dare not to lose... it is a way for showing our respect and love to the deceased.”

Kathleen [*reflective log 3*] further commented that mourning rites can serve to sustain family lineage and strengthen family bonds,

“Family members should hold death rituals with respect and sincerity, and we should visit the graves regularly especially on Ching Ming and Chung Yeung Festivals. These are good chances for the younger generation to commemorate their ancestors and show gratitude for their ancestors’ devotion to the family.”

Wing [*reflective log 2*] reflected on the intricate connection between death ritual, spirituality and meaning of life,

“Apart from the religious implications such transforming the dead to a renewal of life, I believe the existence of death rituals is to allow family members to acknowledge the death, to share the sadness, to encourage each other, and finding new meaning from their loss.... By teaching me to perform death rituals, my parent taught me to respect life and face death with courage and compassion.”

Upon contemplating on the meaning of rituals and their religious underpinnings, Christine [*reflective log 4*] also noted her new learning about spirituality,

“The idea of spirituality doesn’t have to be related to the religion. I can now imagine the “spirit” in terms of being energetic and having the passion on living... You can be tough, kind and live happily in this world if you have spirituality.”

Portraying similar sentiments, Wayne [*reflective log 4*] shared his renewed perspective on life and the important role that spirituality and meaning will play in his life journey ahead.



“While religion and rituals may provide answers to many unanswerable problems, including death, I now want to focus more on my own experiences and to find grater meaning in life. I want to connect myself with life itself, such as nature, to the one that I love, and to help people.”

As the above students’ reflections show, examination and exploration over the meaning and purpose of death rituals can lead to profound reflections on one’s religiosity and spirituality, paving the way for meaning-making and reestablishing connection with self and family. Hence, this topic must become a fixture of a proficient thanatology curriculum in higher education.

### **Major Theme Category of “Teachable Moments”**

The second major category of theme derived from students’ reflective writing is “Teachable Moments”, of which encompasses three prominent themes relevant to pedagogical activities that foster *effective learning processes*, particularly those that amalgamate theories with current social phenomena and in-depth personal experiences:

- I. ‘Multi-Media Lectures’, which involves the use educational videos, films, news articles, art and other creative mediums to compliment teaching and discussions;
- II. ‘Funeral Home Visitation’, which involves a field trip to a traditional and a modern funeral parlour, seeing the various mortuary items used in death rituals, and meeting with owners and funeral directors;

- III. 'Re-examination of Life', which involves an autobiography timeline activity for students' to carry out a personal life review, as well as a self-eulogy exercise where students were invited to write a tribute to celebrate their own lives.

### ***Multi-Media Lectures***

Of the various pedagogy activities employed in *The Last Dance*, the use of multi-media materials such as movie clips, short-film documentaries, health-promotion advertisements and up-to-date news reports were found to be one of the most effective methods to convey important ideas, facilitate meaningful discussions and foster personal reflections. For example, through integrating the opening segment of the animated Disney motion picture "UP" (Rivera & Docter, 2009) in the first lecture of *The Last Dance*, which exemplifies a life course perspective on life and death, students were able better understand and identify with subject matter. Choi [*reflective log 1*] commented on her learning via the viewing a short clip "UP",

"I was really impressed by the presenting techniques of the professor. I love watching movies and clips more than just listening to lengthy lectures. I have never thought that the morbid topics of loss and death can be presented in such interesting way."

Kong [*reflective log 1*] shared his reflections on his own mortality upon viewing a BBC short film documentary "Human Body – Death" (Dale & Spencer, 1998) in the second lecture of *The Last Dance*,

“The video of Herbie’s Death has really inspired me... I have never watched anyone die before, but seeing Herbie dies so peacefully at home, in the arms of his wife, and with the support of homecare nurses makes me think about how I want to die when I grow old.”

Yui [*reflective log 1*] had similar contemplations upon her own death from viewing the BBC documentary,

“The death of Herbie was very moving. I was most impressed with his calmness and acceptance towards death... I wonder if I can be as brave and as calm with I face my own death.”

Apart from movie clips and documentaries, the showing of innovative commercials can also spark profound introspection. Pui [*reflective log 2*] wrote about her own experience with loss upon viewing a short Singapore commercial, “Funeral oration. Surprising memories” (Foo & Ahmad, 2009), which featured a wife’s last tribute to her late husband during a funeral,

“The advertisement capturing a funeral in Singapore shown during lecture was very inspirational to me... this has provoked me to reprioritize what is important to me, instead of mourning for dying, we should celebrate life triumphing over death and treasure every single moment with our beloved ones.”

Integrating news reports of current events into multi-media lectures was another effective tool for igniting philosophical discussions and debates on life and death. Daniel [*reflective log 2*] reflected on the moral dilemma of celebrating

death after viewing a CBS News report that portrayed how the people of New York City reacted to the killing of Osama bin Laden (CBS, May 2<sup>nd</sup>, 2001):

“Some Americans celebrated for the death of Osama bin Laden. This may be the human nature of “an eye for an eye”. Not only is this immoral, it is also unwise as this will just introduce more hatred between both sides.”

Man [*reflective log 2*] shared a similar but more empathic response upon viewing the CBS report,

“From my perspective, celebrating death of an enemy is undoubtedly a barbaric and uncivilized act. But at the same time, that day signifies the emotional relief of millions of people, who had once suffered and longed for an answer to their loss of relatives.”

From these narratives, it is evident that by complimenting traditional lectures and thanatological contents with a wide spectrum of contemporary, up-to-date and relevant multi-media materials can greatly augment students’ learning experience, while creating important teachable moments that deepen self-reflection and social connection.

### ***Funeral Home Visitation***

The second defining theme of Teachable Moments is Funeral Home Visitation. During the mid-term break, a class fieldtrip was organized for students to visit both a modern and traditional funeral parlor, personally meet and talk with the owners as well as the funeral directors, so as to gain a better understanding of the death industry in Hong Kong. Kathleen [*reflective log 3*]

wrote about the significance of this visitation as it opened her eyes to the pressing social problem of providing a final resting place for the dead,

“From the sharing of the CEO, there was a sentence which struck to my head like a lightning rod - Hong Kong’s funeral service is really bad - and I can relate it to current problems in Hong Kong regarding insufficient number of funeral homes or graveyards for the placement of the ashes of the dead.”

Han [*reflective log 3*] also reflected upon the lack of governance and regulation in funeral homes which led to the common dilemma faced by bereaved families wishing to respect the dead properly and with filial piety,

“At present the government has not had any discreet laws to regulate private funeral homes in Hong Kong, that’s why Hong Kong funeral services have so much discrepancy. With nothing standardized, how can bereaved families find peace when paying final respect to their deceased loved one?”

Instead of seeing only the negative side of the funeral industry, Matthew [*reflective log 3*] comments on his learning about the idea of funeral parties as introduced by the modern funeral parlor,

“The modern funeral home shows that death can be an advanced business with many opportunities... I really appreciate the idea of funeral party before death... it can draw a beautiful end to one’s life and let him leave with loads of wonderful memories.”

For Leung [*reflective log 3*], the funeral home visitation reminded him of the noble jobs that funeral directors and morticians commit themselves to, but these professionals are often undermined and discriminated against due to death taboos,

“The society thinks it is not a proper job, no one wants to do it. But for the dead, this is vital. They help the deceased resume their faces and cleanse their body so that they can go beautifully... Dirty business is indeed an unfair term, I believe we should treat people in the death industry as well as how we treat others.”

Candyce [*reflective log 3*] shared similar sentiments,

“Upon meeting them and listening to their stories, I would say I have much higher regard for those working at a funeral home. People may see this job as dirty and unfortunate, but I see it as an honorable profession.”

For Vincci [*reflective log 3*], the field visit reminded her of the importance of death rituals and paying respect to the deceased,

“Seeing all the burial items at the funeral homes reminded me that death rituals are part of our culture, and it allows us to show our respect to the deceased and to show our support to the surviving families.”

Drawing from these reflective writings, it is clear that the funeral home visitation is an essential pedagogy activity that fosters experiential learning and perspective widening for better understanding the magnitude of mortality in a

real life context. Similar activities should be a staple in a comprehensive thanatology curriculum.

### ***Examination of Life***

The final defining theme of Teachable Moments is the Re-examination of Life. As part of the programme of in-class activities, students were invited to complete a Life Review exercise using Autobiographical Timeline (Leung, 2010). Life review is often used as a psychosocial intervention in palliative care to provide terminally-ill patients with the opportunity to reconstruct meaning and to establish continuing bond (Neimeyer, 2001). In the context of *The Last Dance*, this activity was employed so that students can obtain first-hand experience in using a palliative care intervention, while at the same time, ruminate and reflect upon important memories and experiences that define their lives ManYee [*reflective log 4*] shared on the valuable experience of carrying out a life review,

“It was indeed a treasurable chance to review our life and discuss our birth and childhood with others as we seldom have the time or mood to do so. Maybe we should have life review regularly, for instance yearly?”

Kong [*reflective log 4*] also commented on the significance of examining his life, and how the wisdom gained from revising the past can guide him in the future,

“Childhood is the best memory for me and I hope that I can always look back and learn from the past. I know there are more challenges in my life and also in my career, but I hope that I can overcome the problems calmly and confidently.”

For MiuYu [reflective log 4], the experience of life review fostered a deep sense of familial connectedness as she aspired to know more about the life stories of her parents and elders,

“I realized that actually I have quite limited knowledge about my parents' or my grandparents' past. Knowing that not everyone would have the chance to make their own life review and wanting to know their lives, I therefore asked my parents to tell me more about their stories that Wednesday night.”

Apart from life review, students were also invited to write a Self-Eulogy (Nash & Murray (2010), a form of narrative therapy that enables students to consolidate their life experiences, articulate their learning of self, and express the defining purpose of their lives. Shing [reflective log 5] shared her profound experience of thinking and writing about her own mortality,

“The writing of eulogy really helps me a lot... the whole process struck me to think of the most important thing about myself. That night, I tried to rewrite the eulogy and thought how I wanted to be remembered.”

FangHang [reflective log 5] also commented that writing a self-eulogy helped her find purpose,

“After doing this activity, I will pay more attention to the importance of my own purpose... because I realize that life is not meaningless, and that I still can change things that I don't like about my life.”



Reflecting on his own experience with life review and self-eulogy, Louis [reflective log 5] appreciated the usefulness of these tools for assisting the dying and the bereaved in times of loss and grief,

“Through reviewing and writing about their own lives, patients with terminal illness and their family members can reconstruct their meaning of life, reconcile conflict, and let go.”

These revealing narratives show that exercises for examining one’s life are useful and powerful tools for facilitating self-discoveries, fostering sense of connectedness, and generating meaning and purpose. Hence, they must become part of a holistic curriculum of life and death education in higher education.

### **Major Theme Category of “Shifting Perspectives”**

The third major theme category derived from students’ reflective writing is “Shifting Perspectives”, of which encompasses three prominent themes relevant to *significant learning outcomes* of *The Last Dance* that led to new cognitive perceptions, attitudes and behaviors:

- I. ‘Cultivating Insights’ entails the novel views and perspectives students have gained about life, mortality and their relationships with others;
- II. ‘Renewing Meaning’ entails the revitalized attitudes and understanding students have achieved towards living a fulfilled life through reflecting on hardships; and

- III. ‘Applying Knowledge’ entails the behaviours and actions that students have partake for exercising greater autonomy and responsibility in the governance of their own mortality.

### *Cultivating Insights*

From learning various curriculum contents (mortality matters) and through effective pedagogy activities (teachable moments), many students began to view mortality from a renewed standpoint, as they grew more enthusiastic about life and being alive, valuing more of living in the present moment, savoring things that are important to them, and letting go of the trivial. Eva [*reflective log 2*] wrote about her changing perspectives on life upon learning about death,

“Watching a man dying in front of me in the first lecture (*BBC Documentary: Human Body – Death*) lets me understand how fragile and short our life is. So I have decided to figure out the most important and meaningful things in my life instead of wasting time on the things which have little meaning to me.”

YiuYin [*reflective log 3*] also obtained new insights on life upon reflecting upon her own mortality,

“On top of imaging how my funeral should look like, I think it is far more important to consider how the rest of my life should be spent... I must treasure what I have and never give a single chance for myself to regret in the future.”

For Helen [*reflective log 3*], understanding the impermanence of life allows her to see what is most important,

“I know I would die one day so I seize every moment in life to improve myself, to be closer to my family and my friends, and to create better change in society.”

By recognizing life’s finite nature, Sarah [*reflective log 5*] saw also the need to cherish the limited time that she has for realizing her potentials and aspirations,

“I agree with the view that we should not waste time on mundane pursuits while we live, as we have a purpose to do the best work that we can, to be the best person that we can be.”

In her pursuit of happiness in a timed existence, Betty [*reflective log 5*] realized that she needs to maintain a positive mindset and let go of the small and inconsequential,

“Being happy every day is my way to cherish my life because I do not want to waste time on unhappy things given that my life is limited.”

For Candyce [*reflective log 5*], family and loved ones became her first priority knowing that life will come to an end,

“Life is short and unpredictable, therefore I have decided that, from this day onwards, I have to spend more quality time with my parents and family and give them more care.”

### ***Renewing meaning***

The second defining theme of Shifting Perspectives is Renewing Meaning. Many students expressed in their writing of achieving a new attitude and understanding on mortality, through which the purpose of life is illuminated. Kit [*reflective log 3*] shared his thoughts on the neutrality of death, and that life and death could perhaps be a mirror of each other, both equally important in a meaningful existence,

“Death is a nature process which no one can avoid. I believe death is not the end but the transformation of life to another form. What we should do now is to treasure and search the meaning of life.”

For ChunLok [*reflective log 3*], being conscious of the reality of death enables him to become more tolerant of life’s limitations, and to bring loving kindness to himself and those he loves and cares for,

“Death is a non-escapable fate of everyone, marking the end of one’s life. Such a time-limiting thought will always encourage people to accept the little imperfections of their family and friends, and of themselves.”

For Ceci [*reflective log 4*], being conscious of the reality of death had a profound impact on her attitudes towards life’s adversities, and how facing and overcoming challenges can create meaning that defines one’s personhood,

“Being awareness of death help me to think in a positive way all the time. When I face difficulties and setbacks, I

will regard them as the experience of life which makes my life unique and different from others.”

Sona [*reflective log 4*] shared similar sentiments about the vital significance of hardships,

“At this moment, I am actually pleased to have gone through tough times. I learnt that I need to be optimistic and need to view my problems from a wider angle... knowing that my problems defines me as an individual.”

Recognizing that life is limited, Louis [*reflective log 3*] commented not only on the need to find meaning, but also the need to establish goals in order to live a purposeful life,

“I think that meaning in life is very important. For me, I think that I am still searching for my meaning of life though different challenges that I face. I think this is time for me to set up some goals in my life.”

Such renewed attitudes, future-oriented thinking and felt need of constructing a meaningful existence was shared by ChunKit [*reflective log 4*],

“From all the learnings I have obtained from this course, I know it is time for me to think more about my future, to plan for it, rather to only look forward to it.”

### ***Applying Knowledge***

The final defining theme of Shifting Perspectives is Applying Knowledge, of which entails the planning and actions that students have taken to become more prepared for their own end of life as well as those of their loved

ones. These death preparedness behaviors reflect students' ability to put leaning into practice and to become more responsible in the governance of mortality, underscoring the effectiveness of *The Last Dance* in facilitating not only positive attitudinal changes but also positive behavioral changes. Cherry [*reflective log 4*] wrote about her personal research on palliative care and the need for greater promotion of such services,

“I went home and researched about hospices in Hong Kong... Although hospice services are available, not many people realize they exist. I found out that my own parents know little about palliative care... I think there should be more advertisements of these services in Hong Kong in order to increase public awareness.”

Through learning more about palliative care, Kong [*reflective log 4*] reflected on the death of his grandfather and felt the need to plan for his own end of life,

“If my grandfather received hospice care at the time, he could seek advices from professionals... Maybe he could do the things he wanted while my family didn't have to feel regret of making a wrong decision... This made me realize the importance of advance directives, it is something that I must think about and act upon.”

Wing [*reflective log 4*] also carried out research on palliative care, began to ponder about her end-of-life care needs, as well as to plan for her own funeral if death is to come,

“The lecture on palliative care made me think about my own care needs if I am to become seriously ill... the discussion also raised my curiosity about funerals... I hope my own funeral will be a place where my favorite music will be played so that my dearest family members and friends will not feel sad or cry for a long time with grief, but share what I like when I am alive”

For OnKi [*reflective log 3*], thinking and planning for his own funeral and body disposal arrangement was deemed a meaningful endeavor, one that made him feels more connected to his loved ones,

“What he (funeral director) said in the funeral home visit indeed inspire me to think of my own last show. What I want to do after my death is crystallize my ash to a diamond and give it to my love one. It is meaningful to extent my life and give it to my family, symbolizing I am with my family.”

YuenYee [*reflective log 3*] expressed the need to plan for her last rites and how such planning can reduce the burden of death.

“After all, all of us have to die, early planning in fact helps to increase efficiency of funeral procedures, reduce burden to our families, and enhance effectiveness of allocation of resources, which fit our modern society’s needs.”

For a nursing student like Kit [*reflective log 5*], reflecting on all the death-related knowledge obtained facilitated her to talk about her clinical work in the future,

and how she would conduct herself to ensure the best possible care for her patients,

“As a health care provider in the future, we should not only deal with the physical problems of patients, but also focus on psychological, social and spiritual aspect of care in order to achieve the goal of holistic care.”

All of the above narratives exemplify the proficiency of *The Last Dance* in cultivating positive cognitive, attitudinal and behavioral changes among students in their understanding and perspectives towards death, dying and bereavement. They further underscore the significance of carefully integrating intellectually stimulating learning contents with participatory and engaging pedagogical activities to ensure an effective thanatology curriculum.

### **Major Theme Category of “Ego Awakening”**

The fourth and final major category of theme derived from students’ reflective writing is “Ego Awakening”, of which encompasses three prominent themes relevant to *significant learning outcomes* that reflect deep learning and profound reflections which led to growth and transformation. Particularly, those central for developing a new and constructivist worldview on life, mortality and the interdependent nature of humanity:

- I. ‘Normalization of Death’ entails the acknowledgement and acceptance of death as a natural process of life, as well as the reduction of fear and avoidance towards mortality;



- II. ‘Appreciation of Life’ entails the heightened sense of gratitude towards self and significant others, as well as the renewed desire to live life with purpose and conviction; and
- III. ‘Recognition of Common Humanity’ entails the deepened sense of connection and intrapersonal bond to all sentient beings, as well as the realization of the universality of suffering and the desire to live with compassion.

### ***Normalization of Death***

Longstanding death fear and death avoidance have led to a death-denying culture that undermines the strengths of individuals and families in facing the challenges of mortality, while fueling the oppression of death, dying and bereavement in modern society. One of the major goals of *The Last Dance* is to minimize and eliminate the potential apprehension students have towards death so as to view life’s end as a natural process of living. Based on Riki’s narratives [*reflective log 5*], the new thanatology curriculum has palpably achieved its goals,

“At the beginning of this course, I was afraid of death. After studying this course, I understand that we should not fear of death because death is a part of our lives.”

Betty [*reflective log 4*] also reflected on the naturalness of death, and by examining her own mortality she was able to see life with a more positive light,

“I think death is a normal process of life and so, we should have more knowledge or think more about death. When we

think more, we would be able to treasure our life more and have better planned for it.”

For Ceci [*reflective log 4*], understanding and being awareness of the finality of death allows her to live mindfully and be fully present in every moment of her living days,

“If we have the awareness of death, we will be aware that life is limited and try to treasure every moment of life.”

Echo [*reflective log 2*] shared similar sentiments on the interconnectedness between life and death, and how one illuminate the other towards positive intent,

“Death is not a depressing end; it is part of life. It deserves our attention, it requires us to live with integrity and treat other people with dignity.”

Repeatedly and profoundly, many students came to the same conclusion that as human beings, we need to accept that death is a part of life, and though facing it without avoidance or aversion, can we find true meaning and purpose. YuenYee [*reflective log 4*] shared,

“The most important thing is for people to accept death as a destined and natural process in our lives. Only by realizing and accepting this can we lead a meaningful life without regrets”

LokLing [*reflective log 4*] eloquently summarized the connection between life and death in her narratives,

“Death’ is not an independent concept, it is connected with living. Together, life and death form a beautiful journey that defines the human existence.”

### ***Appreciation of Life***

The second defining theme of Ego Awakening is Appreciation of Life. With the acceptance of death, many students were able to develop a more positive and affirmative view on life, themselves and their relationships with loved ones. OnKi [*reflective log 1*] shared his moment of epiphany and renewed attitudes towards caring for those that he love upon seeing death as it occurs,

“I really started to learn to appreciate and treasure things and people around me. When I watched Herby’s story (*BBC Documentary: Human Body – Death*), I hugged my girlfriend and cried. To treasure the one who had made a great change in my life. I believe it is a good start to change my attitude toward the ones I care for.”

Kathleen [*reflective log 1*] reflected on the need to appreciate the things that have been bestowed upon her and to accepting herself wholesomely with less judgment, criticism and cynicism,

“Life is too short to be anger and cynical, we should treasure and appreciate what we are have right now rather than complaining, rather than seeing ourselves being not good enough at the time... this should be the correct attitude we have towards our life.”

Similarly for MinYin [*reflective log 4*], acknowledging death enables her to value life at a much deeper level, and to develop greater sense of self-acceptance,

“I think understanding death can help us to know the value of life and to treasure it. Knowing that life is so limited, we must treasure what we have, we must cherish our families, and most important of all, we must love and be kind to ourselves... Life becomes invaluable especially when we know we will inevitably lose it.”

HoiMan [*reflective log 3*] wrote about the need to cherish people that we love and care about, to express appreciation when they are still alive,

“Why do we have to praise people only after they are dead? I think the society now is always focusing on someone’s faults rather than their contributions. So it is more appropriate to try and appreciate people when they are still alive, and not at their funerals.”

PoYing [*Reflective log 2*] shared parallel thoughts and feelings about the need to love and be grateful to loved ones before life’s end,

“In the face of death in the unknown future, I will treasure everything including my family, friends, work and relationship each day. I will tell my family and friends that I love them and affirm their importance in my life. Life is too short, I do not want any regret at the time I die.”

The renewed appreciation of life, self and others shared among students may be described by Susan [*reflective log 5*] in her narratives,

“There is a motto that I will bear in mind always, ‘When days cannot be added to life, add life to days’. Therefore from this day forth, I will live to love, to learn and to leave a legacy.”

### ***Recognition of Common Humanity***

The final defining theme of Ego Awakening is Common Humanity. With a ten-week curriculum that explored the many facets of death, dying and bereavement from multiple angles including the more micro perspectives of dying patients, bereaved families and end-of-life care providers, as well as the more macro perspectives relevant to social policy, health equality and political economy, students were not only able to gain new meaning and appreciation to their own lives, but also develop greater sense of connectedness towards their fellow human beings. In fact, many students reckoned that their thoughts and actions can have profound impacts on the lives of others, and felt the need to become a better and kinder person. Ching [*reflective log 5*] reflected on his interdependency with the greater collective,

“In my opinion I think that the way you live your life will eventually have an impact on the people around you. Having a positive influence on the people that you love by the way you live your life is the biggest award that you can get.”

Tony [*reflective log 5*] shared similar sentiments about playing a more prominent role for the betterment of society,

“The value of life is not a question of how long you live. Instead it is how you make good use of the time to do some worthwhile deeds. Despite the chaotic world that we live in, each one of us can play a part to make it better, to help people through difficult times, and to give more love to all.”

For PuiYu [*reflective log 5*], gaining a deeper sense of connection to the world, and seeing that pain and sufferings is shared across humanity, has transformed and enhanced her self-perception,

“I hate the little imperfections I have and I cannot always accept the imperfect me. However, this course has brought me insight that I am not alone in my pain, that many people have similar experience as me, and this made me feel that there is indeed a kind of love that defines humanity, that is strong enough to cover all my imperfections, and that this love transforms my imperfections into my perfection.”

Choi [*reflective log 5*] also experienced similar transformation in his understanding of love and common humanity,

“To me, I think relationship is an essential part of our lives. It gives meaning to our life. One of the motivations for me to live my life fully is due to my parents’ unconditional love and care for me. Their love and care make me feel that I am important to them and to the society.”

Such elevated sense of interdependence and interconnectedness has not only enhanced students’ outlook on lives, but also the sense of urgency to help those

in need. This was particularly apparent among those who aspire to become a healthcare provider. Louis [reflective log 5] shared,

“It is important for me to care for the patients’ psychological and emotional health... I too will die one day, and when I do, I want to be cared for holistically and compassionately. I think this may be one of the challenges for me and I hope that I can perform my duties when I practice as a nurse.”

Wayne [*reflective log 5*], another nursing student also commented on his desire to feel more connected with his patient and care for them with loving kindness,

“I wish to connect myself with life, with nature, with the ones I love, and with my patients... to help others, and to be more kind and compassionate to patients who are dying, suffering and in pain. This is my calling as a future nurse.”

The success of a thanatology curriculum is defined not only by its effectiveness in transferring knowledge and skills, but more importantly, whether it can foster introspection and reflection on personal beliefs, attitudes and experiences with mortality so as to cultivate appreciation and compassion for living a fulfilling life of kindness and integrity. The above narratives demonstrate that *The Last Dance* has adequately achieved such goals.

## Chapter Summary

This chapter has summarized and elaborated on this study's significant findings. Results from the Pretest-Protest Student Survey show that *The Last Dance* was effective in reducing fear of death, avoidance and taboos, while at the same time, promoted greater sense of life meaning, spirituality and death preparedness behaviors. Qualitative analysis of Students' reflective writing revealed 12 themes that accentuate the critical learning contents, specific learning processes and pedagogy activities, key attitudinal and behavioral changes, as well as significant learning outcomes that supported and elucidated the quantitative results. These 12 themes were carefully organized into 4 major theme categories of Mortality Matters, Teachable Moments, Shifting Perspectives and Ego Awakening, all together serve to inform the advancement of health promoting palliative care in higher education.



## CHAPTER FIVE DISCUSSION & CONCLUSION

In a society where death and loss is greatly stigmatized due to longstanding cultural taboos, and community support for the dying and the bereaved are scarce under a heavily medically-oriented healthcare system, Hong Kong necessitates a public health approach to empower its people to become more active and engage in the governance of mortality. The foundation of public health is built upon an educated and responsible populace: one that possesses the knowledge to make informed health choices and care decisions to live in wellness and in sickness, through an in-depth understanding of the concepts and practicality of mortality; as well as one that bears the capacity for empathy and compassionate actions towards others in times of illness, death and bereavement, through an enhanced awareness of the emotional facets of loss and grief. Hence, life and death education is the principle driver for promoting and advancing public health palliative care.

This is the first study that has provided a formative and comprehensive account on the development and implementation of a new life and death education course, “The Last Dance: Understanding Death and Dying” for the higher education system in Hong Kong, one that is founded upon the principles of Health-Promoting Palliative Care. This is also the first ever study that has systematically assessed the effectiveness of such a novel thanatology curriculum for promoting positive life attitudes and reducing negative death perceptions among its Chinese graduates, using a holistic mixed methods approach to education evaluation. The quantitative findings from this body of work have generated robust evidence to support the efficacy of *The Last Dance*,

while the qualitative findings have illuminated the specific elements of teaching and processes of learning that contribute to course effectiveness. Together, they have led to the development of a “Thanatology Pathway to Transformative Growth”. All of these important discoveries are elaborated in the preceding section, with implications for advancing the future development of life and death education. This chapter ends with a concise discussion on research limitations and concluding remarks.

### **Discussion of Quantitative and Qualitative Findings**

#### **Student Enrollment, Death Preparedness and Perceptions**

Descriptive findings from baseline assessments of 85 students who completed the pretest-posttest student survey reveal that they came from a great variety of concentrations, not limited to the usual suspects of nursing and social sciences, but also those majoring in the arts, natural sciences, dentistry and even economics. Course registration statistics since the first inauguration of *The Last Dance* also show constant increase in enrollment rates, from 100 students in 2011-12, to 120 students in 2012-13, and reaching the maximum enrollment quota of 130 students in 2013-14 with an extended waiting list. The ever increasing popularity of *The Last Dance* suggests that younger people of Hong Kong are ready and eager to learn about mortality and loss with openness and curiosity, evidencing a Thanatology curriculum in higher education is appreciated by and can benefit a wide spectrum of undergraduate students with various backgrounds and trainings.

Despite the encouraging findings on course enrollment however, baseline descriptive findings show that the majority of students had not actively

engaged in death preparedness behaviors. Specifically, while 8% of students had purchased life insurance as a form of health protection and 15% had made plans for organ donation for sustaining the lives of others, only one student had made funeral plans and no students had set up a will. These numbers may suggest that students, while ready to talk and learn about death, were only in the ‘Contemplation stage’ of the Transtheoretical model of behavior change (Prochaska & DiClemente, 1983); or more precisely, the ‘Access stage’ of the 8A model of death education training (Ho, Tin, Chan, et al., 2010).

As postulated by Ho and his colleagues (2010), individuals move through eight sequential stages of death preparation, beginning from the early stages of (i) *alienation* (i.e. indifferent to death), (ii) *avoidance* (i.e. avoiding death), (iii) *access* (i.e. acquiring information on death), and (iv) *acknowledgement* (i.e. coming to terms with negative emotion of death), before concrete behavioral and attitudinal changes emerge in the later stages of (v) *acceptance* (i.e. seeing death as a natural process of life), (vi) *action* (i.e. actively engaging in life and death planning), (vii) *appreciation* (i.e. appreciating life and searching for meaning), and (viii) *actualization* (i.e. integrating life meaning in future goals). Seemingly, student of *The Last Dance* were situated in the *access* stage at baseline, and in order for them to become actively engaged in death preparedness behaviors, a Thanatology curriculum that fosters both cognitive and affect learnings is required (Pine, 1977; Wass, 2004).

Although students had only reached the initial stage of death-related behavioral change at the time of course enrollment, baseline descriptive findings show that their perceptions on mortality were generally positive. In other words, most students did not believe in traditional Chinese death taboos nor ascribe to

the culturally oppressing views that they carry. This is reflected by the fact that over 80% of students disagreed with the most common death taboo items such as ‘thinking or talking about death brings bad luck’, or ‘talking about death with a dying person would accelerate death’. That being said, the positive outlook found among students of *The Last Dance* may simply indicate that they possessed greater openness towards mortality as compared to those who did not enrolled in the course, and thus these findings must be viewed with caution. Moreover, it must also be noted that one specific death taboo, ‘visiting homes of recently deceased persons is not appropriate’, was still believed to be true by more than 30% of students. This perhaps positively indicates students’ desires to respect the dead and not disturbing the bereaved, or, negatively insinuates that death pollution is still a prevalent stigma in Hong Kong.

According to Ho and Chan (2011), death is considered extremely polluting in traditional Chinese culture, as the ‘curtain’ between the living and the dead is deemed permeable whereby spirits can affect the lives of the living, and so many strategies has been developed to ensure that the dead stay on their side of the curtain (Chan, 2009). For example, white lanterns are traditionally hung outside homes of recently bereaved to warn passersby, grieving families are encouraged to stay confined to their houses for one hundred days after the death of their loved ones, and celebratory events such as weddings or birthdays must be cancelled to avoid disrespecting the dead. If the latter speculation is true where over one-third of the student sample still ascribed to certain oppressing and stigmatizing death beliefs, the need to expand the Thanatology curriculum in higher education cannot be overstated as such efforts would serve to reduce

and ultimately eliminate fears and taboos of mortality among young minds of our future generation (Feifel, 1990; Dennis, 2009).

### **Changes in Attitudes and Behaviors towards Mortality**

Results from paired sample T-test of the pretest-posttest study survey provided robust evidence that *The Last Dance* has achieved its primary objectives of reducing negative death perceptions, promoting positive attitudes towards mortality, and inspiring death preparedness behaviors.

#### ***Reduction of Negative Death Perceptions***

First, as assessed by the Death Attitude Profile-Revised (Ho, Chan, Chow, et al., 2010), students' scores on the domains of 'fear of death' and 'death avoidance' had significantly decreased from baseline to follow-up. Also, students' scores of the death taboo item, 'visiting homes of recently deceased persons is not appropriate' and were rated high at baseline, had also dropped significantly upon course completion. These encouraging results can be attributed to the fact that students were able to attain greater understanding over the practical, psychological and emotional facets of dying and loss from multiple perspectives, as based on the findings derived from qualitative analysis of students' reflective writing. Such positive attitudinal changes are clearly indicative of the importance to provide an open and explorative platform for learners to investigate, contemplate and discuss upon current and pressing issues of mortality with an interdisciplinary approach. This is in line with the proposition of Interdisciplinary Teaching which suggests that an educational process in which two or more subject areas are amalgamated to produced curriculum integration, social integration, experience integration and the

integration of knowledge can foster deep and enhanced learning from each area (Beane, 1997; Jackson & Davis, 2000).

In the context of *The Last Dance*, students were provided with ample opportunities to examine contemporary death issues including but not limited to: *palliative care* via the standpoints of medicine, health policy and social work; *euthanasia* via the standpoints of ethics, philosophy and patients' narratives; *expression of death* via the standpoints of art history, aesthetics and patients' experiences; the *expression of loss* via the standpoints of news media, popular culture and mass communication; as well as *death rituals* via the standpoints of religious and cultural thoughts, business economics and environmental protection. Accordingly, such integrative and interdisciplinary approach to teaching coupled with engaging learning content and activities were deemed profoundly critical for widening perspectives, normalizing death, fostering personal connections, and cultivating a sense of common humanity among students. As Christina Gillis (2001) eloquently put, "*While death may be the vanishing point of medical knowledge and representation, it is also a point of mediation. Neither doctors nor humanists, nor artists nor policy makers, can provide answers where death is concerned; any inquiry into its cultural, scientific, and perhaps even spiritual contours must be a plural one*" (p.4). In this sense, the present thanatology curriculum has certainly achieved plurality and embraced diversity in its mission to cultivate knowledgeable and responsible young citizens to take on a more active role in the discourse and governance of mortality.

### ***Promotion of Positive Death Attitudes***

Second, paired sample t-test results further reveal that students of *The Last Dance* were able to attain a more positive outlook towards life's end, as their scores on the DAP-R domains of *approach acceptance*, *personal acceptance*, and *afterlife beliefs* had significantly increased from baseline to follow-up. Approach acceptance is defined as the individual being psychologically prepared for the inevitability of mortality with a view that death is a passage to eternal bliss and a union with god (Wong et al., 1994); personal acceptance is defined as the individual recognizing that death is a natural process of life and intrinsically accept his or her own mortality; while afterlife beliefs is defined the individual's secular conviction that there will be life after death – a sense of symbolic immortality that epitomize the death and life continuity (Ho, et al., 2010). Increase in all three of these domains of death acceptance – religious, personal or secular – may well signifies the elevated sense of meaningfulness and hopefulness towards life among students, as repeated studies have found positive associations between death acceptance and afterlife belief with optimism, personal meaning and well-being (Stenitz, 1980; Dixon and Kinlaw, 1983; Drolet, 1990).

Given the meaning-oriented focus of *The Last Dance*, where students were provided with numerous experimental activities for the *re-examination of life* via autobiography timeline, life review and self-eulogy exercises, it comes as no surprise that they were able to find hope and purpose in their existence. As many students had shared in their reflective writings, by revisiting significant life experiences, important relationships and cherished memories, they were able to better understanding the neutrality of death, recognizing the finiteness of life,

and appreciating hardships and adversities as so to restore and replenish their sense of self-worth, self-esteem and personhood. Alluding to Erik Erikson's theory of personality development (1963; 1980), where the final stage of a harmonious life is differentiated between despair and ego-integrity, findings from this study show that establishing the virtues of wisdom and self-acceptance do not have to wait till old-age, but can begin as early as young adulthood with the assistance of a programme of life and death education that accentuate affective and experiential learning. As Irvin Yalom (2008) famously stated, "although the physicality of death destroys us, the idea of death may save us... *as such can be an awakening experience*" (p. 33, 132).

### ***Enhancement of Death Preparedness Behaviors***

Third, results of paired-sample T-test of items related to death preparedness reveal that students' scored significantly higher on their intentions and behaviors towards setting up wills, planning for organ donations, as well as preparing for funeral arrangements. These inspiring results further underscore the critical need to integrate interdisciplinary teaching with experiential learning for promoting and fostering behavioral changes, as the testimonies derived from students' reflective writings allude to the value of utilizing *multi-media lectures* and incorporating *funeral home visitation* in the curriculum of *The Last Dance*. Particularly, students reported that movie clips such as those drawn from the Disney movie 'UP' (Rivera & Docter, 2009), documentaries such as the 'Human Body – Death' produced by the BBC (Dale & Spencer, 1998), news reports such as the coverage of 'Bin Laden's Death' by the CBS (May 2<sup>nd</sup>, 2001), as well as visiting funeral homes and talking to managers of funeral parlors were



tremendously helpful, as these experiences complemented and enriched their learning.

In fact, many students commented that learning through multi-media contents and engaging in real life exchanges with those working in the death industry, coupled with the opportunity to reflect on the relevant subject matter and encounters, they were better able to comprehend textbook knowledge and theories, apprise literatures and policies on mortality, as well as connect and embody the experience of those going through death and bereavement to derive behavioral change. These narratives are in line with the renowned model of Experiential Learning Cycle developed by David Kolb (1981, 1984), which postulates that effective learning transpires through four sequential and mutually supportive stages: obtaining (i) *concrete experience* on a learning subject, followed by (ii) *reflective observation* on the learning experience, leading to (iii) *abstract conceptualization* and generalization of the learning subject, and finally reaching (iv) *active experimentation* to apply what has been learnt in different contexts, ultimately resulting in new experiences. Kolb (1984) further argued learners can enter into the cycle at any stages but can only learn effectively by completing all four stages. Based on the rich collection of students' narratives as well as their elevated death preparedness behaviors, it is evident that the curriculum and the structure of *The Last Dance* provided appropriate learning opportunities for students to experience, reflect, conceptualize and experiment with many essential domains of mortality and life, resulting in personal growth and transformation.

## **Transformation of Worldviews towards Life and Spirituality**

With the *normalization of death* which enabled students to *apply knowledge* and to be engaged in their own mortality as well as those of their loved ones, they were allowed the space to truly reflect upon their lives, appreciate all that life have to offer, while developing a renewed sense of meaning and personhood. Results from paired sample t-tests of the pretest-posttest study survey clearly show that *The Last Dance* has succeeded in accomplishing its secondary objectives of enhancing positive attitudes towards life and spirituality.

### ***Cultivation of Meaning in Life***

First, as assessed by the Meaning in Life Scale (Steger et al., 2006), students' scores on the domain of 'presence in meaning' had significantly increased from baseline to follow-up. However, no significant changes were observed in the domain of 'search for meaning'. While the latter can be attributed to the fact that students were already actively searching for meaning before enrolling in *The Last Dance* and continued to do so upon course completion, the reason for the former may well be a result of students' capacity to develop new insights into their lives through engaging curriculum contents and effective pedagogy activities. From the narratives drawn from students' reflective writing, it is apparent that many had become much more enthusiastic about being alive through learning to live in the present moment and letting go of rigidity, anger and resentments. And through looking deep in to their own experiences of loss and adversities, while at the same time recognizing that life is finite, they saw how fruitless it was to dwell on old grudges, to feel desolated due to past regrets, and to become overly concern about a future that has yet to arrive. Instead,

students learnt to value self-love and self-kindness so as to nurture inner resilience, whilst acknowledging the essentiality to adopt a positive outlook on life, nourish existing relationships and develop new ones that are defined by love rather than gains, and to establish goals for living a purposeful existence.

Referring once again to Erikson's classical theory of personality development (1963), young adults are often confronted by the psychosocial crisis of intimacy and isolation. In order for them to successfully complete this critical developmental stage, they must feel loved and connected to the world as well as those around them. However, in the context of Hong Kong as well as many other advanced societies in the world, where physical human contact is gradually becoming a relic of the past and social relationships are progressively being built and dependent upon the often treacherous and segregating space of social media, young people may well find it difficult, if not impossible, to establish true friendships that are essential for intimacy. Young people of developed East Asia including Hong Kong, Singapore, Japan and South Korea, are also confronted with immense stress to succeed academically and in their careers, but at the same time, are challenged by bleak opportunities and grievous difficulties in launching themselves in an increasingly competitive global market (Ho, et al., in-press).

The race towards affluence and the battle against peers can result in depressing isolation, impoverished social networks, poor physical and psychological health, and even the elevated risks of suicide amongst younger populations (Yip, Liu, Lam, et al., 2004; Samaritans of Singapore, 2013; Kawashima, Ito, Narishige, et al., 2012; Lee, Hong, Espelage, 2010). It is within this context that self-love, self-kindness and inner resilience become that much

more pertinent to the healthy psychosocial development of youth and adolescence. This clearly highlights the immense value of *The Last Dance* for cultivating more positive and purposive mindsets among future generations, while underscoring the critical significance to integrate a thanatology curriculum in not only higher education, but education at all levels.

### ***Nurturance of Spirituality***

Second and as assessed by the Spirituality Scale (Delaney, 2003), students' scores on the domains 'self-discovery', 'eco-awareness' and 'total spirituality' had raised significantly from the beginning of course enrollment to course completion. Self-discovery is defined as the extent to which one develops self-acceptance, gratitude and appreciation for attaining growth and healing through reflection and introspection; while ego-awareness is defined as the extent to which one holds an integral connection to nature with utmost respect for earth's sacredness. These aspiring quantitative findings are complimented by many students' narratives that had reflected on the need to truly accept themselves as who they are without judgement and criticism, to openly express kindness and gratitude to those whom they care for and loved, as well as to establish greater empathy and engage in more compassionate actions for helping those less fortunate and the world at large. In fact, numerous students had shared that by understanding not only the micro but also the macro perspectives of death and loss, especially those related to health equity, social justice and political economic, they were able to attain a deeper sense of interconnectedness with their fellow creatures and with the society in which they reside.

However, living in a world decremented by war, terrorism, environmental destruction, racial segregation, inequality and widespread apathy

can be terrifying and isolating. Particularly in Hong Kong and developed East Asia where economic disparities and fierce competitions for wealth continue to corrupt the morale and mental health of its youth; where the foundation of social solidarity, family integrity and filial conviction continues to crumble; where cultural stigma and taboos towards illness and mortality continue to prevail; the weakening of the human spirit accentuate the imperative to cultivate greater kindness and compassion among its people (Ho et al., in-press). Compassion, the central essence that defines morality and our common humanity, is the wish that all sentient beings be freed from suffering. In order to achieve this goal, one must enact the Golden Rule of reciprocity, where “one should treat others as one would like others to treat oneself”. In other words, the ability to dethrone ourselves from the center of our universe and put another there, to step into the shoes of the other and see the world through their eyes, allows us the faculty to attend deep awareness of human suffering and fuels our innate desire to alleviate it. The need for compassion is none greater than in times of death, dying and bereavement.

In recent years, a global movement has emerged to bring compassion back into the lives of all people and every facets of society. The Charter of Compassion (2013) is a “cooperative effort to restore not only compassionate thinking but, more importantly, compassionate action to the center of social, political, spiritual and family life. The Charter seeks to put forward compassion as a key word in both public and private discourse; to encourage a positive appreciation of cultural and religious diversity; and to cultivate an informed empathy with the suffering of all human beings” (papa.1). Such a global movement of compassion promotes transcultural understanding of the human

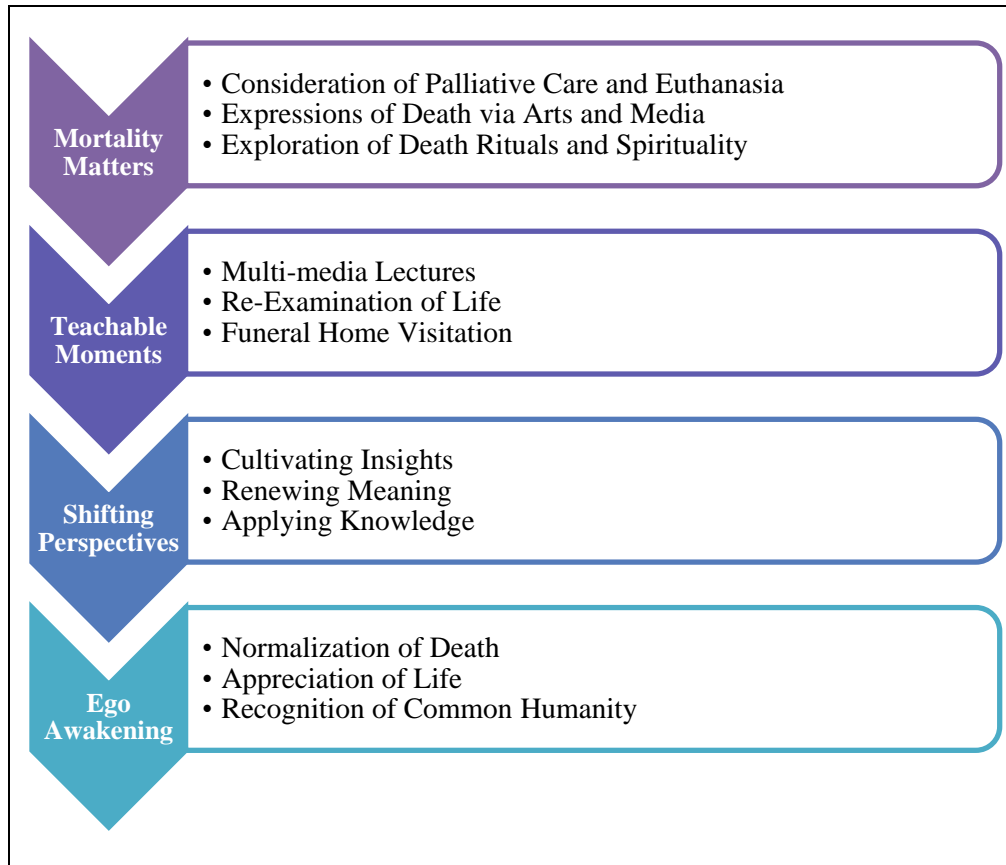
experiences, and serves as the exact antidote needed for protecting individuals and families troubled by death and loss. Up till March 2015, 58 cities around the world have signed the Charter for Compassion, while 278 cities around the world are actively organizing local initiatives, policies and projects that foster compassionate actions through city-wide innovation, social entrepreneurship, community engagement and civic governance. Unfortunately, Hong Kong is missing in action; giving the gravity of mental, psychosocial and spiritual duress faced by the local population, it is clearly the time for her to join this cause and to bring compassion back into the lives of its people. *The Last Dance*, with its efficacy to cultivate life meaning, self-kindness, compassion and spirituality through a holistic thanatology curriculum that brings about real attitudinal and behavioral changes, can humbly and competently serve as the initial step of such a noble and worthy cause.

### **Thanatology Pathway to Transformative Growth**

By integrating the findings from both the quantitative and the qualitative components of this study have led to the establishment of the “Thanatology Pathway to Transformative Growth” (TPTG). This pathway provides an important roadmap to elucidate the essential components and processes of effective learning that foster positive attitudinal and behavioral changes towards life and mortality. As illustrated in Figure 5.1, the initial phase of the TPTG begins with “Mortality Matters”, which involves the assimilation of contemporary and intellectually stimulating topics of death and loss as learning contents, those that learners can identify and connect with on a personal basis so as to heighten learning interest. Based on the current findings, such content could

include but not limited to issues concerning palliative care, euthanasia, art expression of death, media portrayal of loss, death rituals and spirituality.

Figure 5.1 Thanatology Pathway to Transformative Growth



The second phase of the TPTG, named “Teachable Moments”, involves the conveyance of *Mortality Matters* through meaning-oriented approaches that exemplify multidisciplinary teaching and experiential learning, those that enable learners to truly experience and reflect upon the learning content. These could include but not limited to multi-media lectures that make use of film, documentaries and news reports; exercises for the re-examination of life such as autobiographical timeline, self-eulogy, life-review and reflective writing; as well as funeral home visitation that allow learners to experience and communicate with people working in the death industry. Other notable and potential useful *Teachable Moments*, that were not included in the present version of *The Last*

*Dance* but can certainly be adopted in future offerings as well as other thanatology curricula, include expressive art techniques such as those stemming from narrative therapy and art therapy techniques, as well as reflective mindfulness mediation.

The third phase of the TPTG, coined “Shifting Perspectives”, involves the delicate integration of *Mortality Matters* and *Teachable Moments* through facilitated discussions, personal introspection and opportunities for translational application so as to activate and synthesize knowledge-based, emotive-based and action-based learning (Bloom, 1956). The goals of these activities are to foster emotional and affective engagements between the learner and the learning content so as to stimulate deep learning, personal reflections, as well as positive changes in attitudes and behaviors. Through such engagements, learners are offered the opportunities for cultivating insights to death and loss, renewing meaning to life and spirituality, as well as applying knowledge to enhance participation in their own mortality.

The fourth and final phase of the TPTG, named “Ego-Awakening”, involves the ultimate integration of teaching, learning and reflective experiences to construct an expansion of perspective, a revolution of thought, and a change in worldview. At this phase, learners are empowered to see death as a normal and natural process of life whereby their existences are limited and finite. But instead of facing the reality of their mortality with fear and avoidance, they are able to find solace by taking on a more active role in planning and preparing for their own end of life, and by appreciating the beauty that life has to offer through the practice of living in the present moment, being non-judgmental and kind towards oneself, letting go of grudges and resentments, as well as nurturing relationships



that are founded upon love rather than gains. And upon recognizing that death is the common bond that unites humanity, learners will develop greater empathy and compassion for others as well as themselves, while their innate capacity to alleviate pain and suffering will ignite, fusing their individual consciousness with the collective world.

In essence, the TPTG can serve as a proficient framework to guide the future development of life and death education and related curricula in both formal and public education settings for realizing the goals of health promoting palliative care, for cultivating an educated and responsible citizenry to enhanced the governance of mortality, as well as for bringing back compassion into the livelihood of civil society.

### **Limitations of Research**

Despite its merits, this study has a number of limitations pertaining to sampling, quantitative data collection and qualitative methodology. In terms of sampling, participants of this research comprised only of undergraduate students from one English-based public university in Hong Kong; given the diversity in educational and cultural backgrounds as well as the differences in language and communication competencies among students of other major universities in the region (there are eight public and private universities in Hong Kong with a mixed of English and Chinese as primary teaching languages), the generalizability of the findings may be limited to those studying within a similar context of the University of Hong Kong. Moreover, even though the quantitative findings generated from this study are significant and provide an adequate representation of the Hong Kong undergraduate student population, the sample

size of this study is relatively small compared to other large scale studies on education evaluation. As such, future research should consider recruiting a larger pool of participants from different higher institutions to present a more generalizable view.

In terms of quantitative data collection, the data generated from this research were based on self-report measures, of which is an effective method for obtaining responses related to individual-relevant information (Roger, Kuiper, Kirker, 1977). This method is thus suitable for understanding students' perceptions of their own values and beliefs towards life and death, while the assessment tools adopted were all standardized and validated across cultures. However, matched paired samples were not included in the current study as the development and implementation of a new undergraduate curriculum did not allow the research team to recruit a control group for comparison. In similar vein, the research sample were not randomly selected but were based on convenient sampling (those who registered for the course based on learning interest and intent), and therefore, the data collected from self-report measures may be biased towards students who possess greater openness towards mortality and less affected by traditional Chinese death taboos. To remedy the limitations of response bias and inferring causality, future research should consider adopting random sampling with control groups, or utilizing a randomized control trial design, or a wait-list control design that span across two sequential academic semesters so that students assigned to both the intervention group and the wait-list control group would receive and benefit from a Thanatology curriculum.

Finally, the qualitative nature of this research consists of a number of limitations. First, as with any other qualitative study, there is limitation in generalizability. Nonetheless, the current research generated “*moderatum* generalizations”, which allow for interpreting structures that can be applicable in similar settings, with similar populations, and in theory building (Williams, 2002, p. 131). The benefits of such *moderatum* generalizations are in that it allows for:

“...both the richness of interpretation and the ability to move beyond this to make claims about processes and structures. The interpretations one makes of any given situation have an ideographic character, a picture that has not only blurred edges, but also sharp features. It is these which we pick out, either as a result of striking characteristics we had not anticipated, or (more likely) as a result of some previous informal conceptual schema or more formally held theory” (p. 139).

Second, inherent in qualitative research with a focus on interpretation is the possibility that researcher bias and subjectivity will affect the analysis. Hence, I have employed three ways to minimize such bias. One, by the triangulation of research methods and research data as well peer debriefing, I minimized researcher bias (Patton, 1990). Two, when offering interpretation of students’ reflective writings and learning experiences, I referenced students’ actual words and narratives to provide transparency and to reflect how conclusions are reached. Finally, I was honest by stating my assumptions during

the research process and in my conclusions (Walkerdine, Lucey & Melody, 2002).

Third, when students are asked to respond to questions related to personal insights on illness, life, death, bereavement, as well as healthcare and welfare policies, there is a possibility of social desirability. Students may feel the need to give specific answers to achieve good evaluation outcomes. Individuals from the Chinese cultures that emphasize collectivism and “face” may further be at risk for providing answers they think are expected (Johnson & Van de Vijver, 2003). In order to reduce the potential of social desirability, I ensured confidentiality and anonymity so as to ensure students’ self-expressions would not in any way affect the assessment; moreover, students were informed that the analysis of their reflective writing would take place only after their final grades have been approved by the University.

Finally, adopting an interpretive paradigm and framework approach to analysis introduce various limitations (Willing, 2001). Since the emphasis is on researcher interpretation of students’ narratives as described by them, it is dependent on the students’ ability to adequately express their experiences. Willing (2001) makes note that this particular form of inquiry is suitable for those with average to high verbal abilities. I believed this limitation was minimized as all students involved in this study possessed high levels of verbal and written competencies given the very fact that they are enrolled in undergraduate studies in a world-class international university where English is the primary teaching language. Moreover, the format of the reflective writing assignments was meaning-focused which allowed students the opportunity to

review and appraise on their learning experiences through an introspective approach, one that enabled them to articulate and express their thoughts and emotions fluently without ideological constraints and hesitations.

### **Concluding Remarks**

Despite its success and efficacy, *The Last Dance* is only a starting point for pushing forth the ideals of Health Promoting Palliative Care in Hong Kong. Continuous health-promoting and educative initiatives with a much wider spectrum of audiences are essential for integrating palliative care into all levels of society; especially for Hong Kong and other Asian societies where death is still met with much fear and resistance. Equally important is the imperative to amplify the voices of individuals and families who are in need of holistic care at life's end but have limited access to appropriate services due to the constraints of a medically oriented healthcare system that often neglects the social aspect of care. This can only be achieved through a comprehensive programme of research that elicits the specific needs of different population cohorts for formulating advocacy strategies and action plans so as to enhance public awareness, facilitate education and training, advance service provision, foster policy change, and ultimately, promote individual participation and community involvement .

Palliative care in Hong Kong has matured rapidly and purposefully within the past two decades, as the development of the field has surpassed numerous developed countries while gaining international recognition for its service quality. Yet, the many challenges of the twenty-first century require further development in the practices and philosophies of public health palliative care, which would be impossible without an unshakeable commitment to human

life and human right. The goal to empower all people to achieve a good and dignified death through democratic and responsible governance of their own mortality, as well as through the cultivation of caring and compassionate communities, must be at the forefront of all advocacy, research and education efforts. In essence, mortality must be recognized not only as a medical and individual issue, but also as a social and collective issue that bonds humanity. Hence, the success of care for those facing death, dying and bereavement do not rest solely on a small group of specialists or the medical profession, but the concerted efforts of every citizen, groups, communities and government bodies of our society.

## REFERENCES

- Acring, C.D. (1971). *The Understanding of Physician*. Detroit, MI: Detroit Wayne State University Press.
- Anderson, C. S. (2004). Four noble truths. In R. E. Buswell, Jr (Ed.) *Encyclopedia of Buddhism* (Vol. 1, pp. 295-298). New York, NY: Macmillan Reference.
- Babbie, Earl (1973). *Survey Research Methods*. Belmont, California: Wadsworth Publishing Company
- Barley, H. (1995). *Dancing on the Grave*. London, UK: John Murray.
- Basu, S., & Heuser, L. (2003). Using service learning in death education. *Death Studies*, 27(10), 901-927.
- Bauman, Z. (1992). *Mortality, immortality, and other life strategies*. Cambridge, UK: Polity Press.
- Beane, J. (1997). *Curriculum Intergration*. New York, NY : Teachers College Press.
- Becker, E. (1973). *The Denial of Death*. New York, NY: Simon & Schuster.
- Bluck, S., Dirk., J., Mackay, M. M., & Hux, A. (2008). Life experience with death: relation to death attitudes and to the use of death-related memories. *Death Studies*, 32, 524-549.
- Bongar, B., & Harmatz, M. (1991). Clinical psychology graduate education and the study of suicide: Availability resources and importance. *Suicide and Life-Threatening Behavior*, 21, 231-245.
- Brians, P., Gallwey, M., Hussain, A., & Law, R., (Eds.) (1999). *Reading about the world*. Vol. 1 (3<sup>rd</sup> ed.) Texas: Harcourt Brace College Publishing.

- Biggs, J. B. (1987). *Student approaches to learning and studying*. Hawthorn, Vic.: Australian Council for Education Research.
- Biggs, J. B. (1989) 'Approaches to the enhancement of tertiary teaching', *Higher Education Research and Development* 8, 7-25.
- Biggs, J. B. (1999). *Teaching for Quality Learning at University*. Buckingham, UK: SRHE and Open University Press.
- Biggs, J. B., & Moore, J. M. (1993). *The process of learning*. New York: Prentice Hall.
- Cappeliez, P., O'Rourke, N., & Chaudhury, H. (2005). Functions of reminiscence and mental health in later lifer. *Aging & Mental Health*, 9, 295-301.
- Carbonell, E., Mosquera, M., Ollé, A., Rodríguez, X.P., Sala, R., Vergès, J.M., Arsuaga, J.L. & Bermúdez de Castro, J.M. (2003). Les premiers comportements funéraires auraient-ils pris place à Atapuerca, il y a 350 000 ans? *L'Anthropologie*, 107, 1-14
- CBS News. (May 2<sup>nd</sup>, 2001). Osama Bin Laden is Dead. Retrieved from <http://www.cbsnews.com/news/osama-bin-laden-is-dead/>
- Census and Statistics Department. (2012). *Hong Kong Population Projections 2012-2041*. Hong Kong: Hong Kong Special Administrative Region Government.
- Chadwick, A. (1994). *Living with grief in school: Guidance for primary school teachers*. Biggin Hill, Kent: Family Reading Centre.
- Chan, C.L.W. (2009). Chinese death taboo. In Dennis Peck and Clifton D. Bryant (eds). *Encyclopedia of Death and the Human Experience, Vol. 1*. (pp. 190-192). London; Sage.



- Chan, C. L. W., Ho, A. H. Y., Leung, P. P. Y., Chochinov, H. M., Neimeyer, R. A., Pang, S. M. C., & Tse, D. M. W. (2012). The Blessing and Curses of Filial Piety on Dignity at the End-of-Life: Lived Experience of Hong Kong Chinese Adult Children Caregivers. *Journal of Ethnic and Cultural Diversity in Social Work, 21*, 277-296.
- Chan, H. Y. L., & Pang, S. M. C. (2007). Quality of life concerns and end of life care preferences of aged persons in long term care facilities. *Journal of Clinical Nursing, 16*, 2158-2166.
- Chan, K. S., Siu, Y., Leong, C. H., (2003). *Development of Hospice Palliative Care in Hong Kong*. Proceedings for the Fifth Asia Pacific Hospice Conference. Osaka, Japan
- Chan, W. C. (2014). Factor Structure of the Chinese version of the Meaning in Life Questionnaire among Hong Kong Chinese caregivers. *Health and Social Work, 39*(3), 135-143.
- Charter for Compassion (2013). *The charter for compassion*. Retrieved from <http://charterforcompassion.org/the-charter/#charter-for-compassion>.
- Cheung, P. K. H., Chan, C. L. W., Fu, W., Li, Y., & Cheung, G. Y. K. P. (2006). "Letting Go" and "Holding On": Grieving and traditional death rituals in Hong Kong. In C.L.W. Chan, & A. Y. M. Chow (Ed.) *Death, dying and bereavement: A Hong Kong Chinese experience* (pp. 87-92). Hong Kong: Hong Kong University Press.
- Chinapah, V., & Fagerlind, I. (1986). *The Design and Elaboration of the Evaluation and Monitoring Technique for the Implementation of Educational Policies, Report Studies, S, 123*. Paris, France: UNESCO Division of Educational Policy and Planning.

- Chinapah, V., & Miron G. (1989). *Education Evaluation Manual - Approaches, Designs, and Techniques in Evaluating Educational Programs and Projects*. Sweden: University of Stockholm, Institute of International Education.
- Chiverton, E. (1997). Social support within the context of life threatening illness. *International Journal of Palliative Care*, 3, 107-110.
- Christians, C.G. (2005). Ethics and politics in qualitative research. In N.D. Denzin & Y.S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3<sup>rd</sup> ed., pp. 139-164). Thousand Oaks, California: Sage Publications.
- Chung, D.K. (2003). Confucianism. In J. J. Ponzetti Jr. (Ed.), *International encyclopedia of marriage and family* (2<sup>nd</sup> ed. Vol. 1, pp. 368-375). New York: Macmillan Reference USA.
- Chung, L. (1993). Setting up a nursing service in a new hospice: A Hong Kong experience. *Asian Journal of Nursing Studies*, 1, 46-51.
- Chung, L. (1994). *Statistical report on hospice education programs*. Unpublished manuscript.
- Chung, L. (1997). The hospice movement in a Chinese society – A Hong Kong experience. In D. C. Saunders, & R. Kastenbaum (eds.), *Hospice care on the international Scene*, pp. 206-214. New York: Springer.
- Citizens Commission on Human Rights Florida (2015). *School classes on death and dying lead to student suicide*. Retrieve from <http://cchrflorida.org/school-classes-on-death-and-dying-lead-to-student-suicides/>

- Clark, D. (1994). At the crossroads: Which direction for the hospices?  
*Palliative Medicine*, 8, 1-3.
- Clark, D., & Wright, M. (2007). The International Observatory on End of Life Care: A global view of palliative care development. *Journal of Pain and Symptom Management* 33, 542-546.
- Clements, R., & Rooda, L. A. (1999-2000). Factor Structure, Reliability, and Validity of the Death Attitude Profile-Revised. *Omega*, 40(3), 453-463.
- Confucius, & Waley, A. (1938). *The Analects of Confucius*. New York, NY: Random House.
- Conway, S. (Ed.) (2012). *Governing Death and Loss: Empowerment, involvement and participation*. Oxford, UK: Oxford University Press.
- Cruse, D. R., & D. Cruse (1985). Death education in the schools for older children. In H. Wass & C. A. Corr (Ed.), *Childhood and death*, 345-61. New York: Hemisphere.
- Crewell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: SAGE.
- Curriculum Development Council HKSAR (2001). *Learning to learn – the way forward in curriculum development: Life-long learning and whole-person development*. Hong Kong: Author.
- Dale, R. (Producer), & Spencer, C. (Director). (1998). *The Human Body – Death*. [Television Series]. United Kingdom: British Broadcasting Corporation One.
- Delaney, C. (2003). *Spirituality: Development, refinement, and psychometric testing of an instrument to assess the human spiritual dimension*. Unpublished doctoral dissertation, University of Connecticut, Storrs.

- Delaney, C. (2005). The spirituality scale: Development and psychometric testing of a holistic instrument to assess the human spiritual dimension. *Journal of Holistic Nursing*, 23(1), 1-23.
- Dennis, D., (2009). The past, present, and future of death education. In D. Dennis (Ed.), *Living, dying, grieving*. Burlington, MA: Jones & Bartlett Learning.
- Dewey, J. (1929). *The Quest for Certainty: A study of the relation of knowledge and action*. New York, NY: Milton Balch and Company.
- Dickinson, G. E., Mermann, A. C. (1996). Death education in U.S. medical schools, 1975-1995. *Academic Medicine*, 71, 1348-1349.
- Dixon, R. & Kinlaw, B. (1983). Belief in the existence and nature of life after death: A research note. *Omega*, 13, 287-292.
- Doyle, D. (1991). Palliative care education and training in the United Kingdom: A review. *Death Studies*, 15, 95-103
- Doyle, D., Hanks, C. W. C., & MacDonald, N. (Eds.). (1993). *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press.
- Drolet, J. L. (1990). Transcending death during early adulthood: Symbolic immortality, death anxiety, and purpose in life. *Journal of Clinical Psychology*, 46, 148-160.
- Duffy, R. D., & Raque-Bogdan, T. L. (2010). The motivation to serve others: Exploring relations to career development. *Journal of Career Assessment*, 18(3), 250-265.
- Duiker, W. J., & Spielvogel, J. J. (2008). *The Essential World History* (3<sup>rd</sup> Ed.). Belmont, CA: Thomson, Wadsworth.

- Eckerd, L. M. (2009). Death and dying course offerings in psychology: a survey of nine Midwestern states. *Death Studies, 33*(8), 762-770.
- Economist Intelligence Unit. (2010). *The quality of death: Ranking end-of-life care across the world*. A report from the Economist Intelligence Unit, The Economist, Commissioned by the Lien Foundation. Retrieved from <http://graphics.eiu.com/upload/eb/qualityofdeath.pdf>
- Education and Manpower Bureau. (2005). *The New Academic Structure for Senior Secondary Education and Higher Education Action*. Hong Kong: Education and Manpower Bureau, Hong Kong SAR Government.
- Engel, G. L. (1961). *Is grief a disease? A challenge for medical research*. *Psychosomatic Medicine, 23*(1), 18-22.
- Erikson, E. H. (1963). *Childhood and society*. New York, NY: W. W. Norton & Company, Inc.
- Erikson, E. H. (1980) *Identity and the Life Cycle*. New York, NY: W. W. Norton & Company, Inc.
- Edwards, S. D. (2012). Standardization of a Spirituality Scale with a South African Sample. *Journal of Psychology in Africa, 22*(4), 649-658.
- Fielding, R., & Chan C.L.W. (Eds.) (2000) *Psychosocial Oncology and Palliative Care in Hong Kong: The First Decade*. Hong Kong: Hong Kong University Press.
- Fielding, R., & Hung, J. (1996). Preferences for information and involvement in decision during cancer care among a Hong Kong Chinese population. *Psycho-Oncology, 5*, 321-329.

- Fitzsimons, D., Mullan, D., & Wilson, J.S. (2007). The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliative Medicine, 21*, 313-322.
- Feifel, H. (Ed.). (1959). *The meaning of death*. New York, NY: McGraw-Hill.
- Feifel, H. (1990). Psychology and death: Meaningful rediscovery. *American Psychologist, 45*, 537–543.
- Feilzer, M. (2010). Doing mixed methods research pragmatically: Implications for the rediscovery of Pragmatism as a research paradigm. *Journal of mixed methods research, 4*(1), 6-16.
- Finn, P. (1990, September 23). The Facts that many schools today teach death education – and opinion about that is sharply divided. *The Inquirer Daily News*. Retrieved from <http://www.philly.com>
- Foley, F. J., Flannery, J., Graydon, D., Flintoft, G., & Cook, D. (1995). AIDS Palliative Care - Challenging the palliative care paradigm. *Journal of Palliative Care, 11*, 19-22.
- Foley, K. (2002). Dismantling the barriers: Providing palliative and pain care. *Journal of the American Medical Association, 283*, 115-115.
- Foo, M. (Producer), & Ahmad Y. (Director). (2009). *Funeral oration – Surprising memories*. [Television broadcast]. Singapore: Rights and Freedom.
- Foucault, M. (1973). *The birth of the clinic*. London, UK: Tavistock.
- Gerber, L. (1999). *Examples of filial piety (14<sup>th</sup> century CE)*. Retrieved from [http://www.wsu.edu:8080/~wldciv/world\\_civ\\_reader/world\\_civ\\_reader\\_1/filial.html](http://www.wsu.edu:8080/~wldciv/world_civ_reader/world_civ_reader_1/filial.html)

- Gillis, C. M. (Ed.) (2001). *Seeing the difference: Conversation on Death and Dying*. Occasional Papers of the Doreen B. Townsend Centre of the Humanities, nos. 24-25. Berkley, CA: University of California and the Doreen D. Townsend Centre for the Humanities.
- Grande, G. E., Tood, C. J., Barclay, S. I. G., & Doyle, J. H. (1996). What terminally ill patients value in the support provided by GPs, District and Macmillan Nurses. *International Journal of Palliative Nursing*, 2, 138-143.
- Groot, M.M., Vernooij-Dassen, M.J.F.J., Verhagen, S.C.A., Crul, B.J.P., & Grol, R.P.T.M. (2007). Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliative Medicine*, 21, 697-703.
- Ham, C. (1994). *Health Policy in Britain*. London, England: MacMillan Press.
- Hansen, C. (2003). Taoism. *The Stanford encyclopedia of philosophy*. Retrieved from <http://plato.stanford.edu/archives/spr2003/entries/taoism>
- Helegeland, J. (1985). The symbolism of death in the late Middle Ages. *Omega*, 15, 145-157.
- Hendrichske, B. (1991). The concept of inherited evil in the Taipingjing. *East Asian History*, 2, 1-29.
- Ho, A. H. Y., & Chan, C. L. W. (2011). Liberating dying people and bereaved families from the oppression of death and loss in Chinese societies: A public health approach. In S. Conway (Ed.) *Governing Death and Loss: Empowerment, involvement and participation* (pp.119-128). New York, NY: Oxford University Press.

- Ho, A. H. Y., Chan, C. L. W., Chow, A. Y. M., Pon, A. K. L., & Ng, S. M. (2010). Psychometric Properties of the Chinese Version (C-DAP-R) of the Death Attitude Profile-Revised. *Illness, Crisis & Loss, 18*(2), 95-110.
- Ho, A. H. Y., Chui, C. H. K., & Borshel, M. (In-Press). Understanding and managing youth and elderly suicide in Developed East Asia: The imperative of compassion in public health. In G. Cox & N. Thompson (eds.), *Managing Sudden and Traumatic Grief*. UK: Routledge.
- Ho, A. H. Y., Leung, P. P. Y., & Chan, C. L. W. (2015). Dignity and Quality of Life in Community Palliative Care. In K. W. Tong, & K. N. Fong (Eds.), *Community Care in Hong Kong: Current Practices, Practice-research Studies and Future Directions*. Hong Kong: City University of Hong Kong Press.
- Ho, A. H. Y., Leung, P. P. Y., Tse, D. M. W., Pang, S. M. C., Chochinov, H. M., Neimeyer, R. A. & Chan, C. L. W. (2013). Dignity amidst Liminality: Suffering within Healing among Chinese Terminal Cancer Patients. *Death Studies, 37*(10), 953-970.
- Ho, A. H. Y., Ng, S. M., Chow, A. Y. M., Chan, C. H. Y., Tang, A. C. W., Tin, A. F., Yan, E. C. W., & Chan, C. L. W. (2007). *Perception of Death across the Adult Lifespan: A Close Examination of the Death Attitude Profile among the General Hong Kong Population*. Keynote Lecture in the ENABLE International Symposium on Death, Dying and Bereavement. Hong Kong: 11 July 2007.
- Ho, W. C. H., Tin, A. F., Chan, C. H. Y., Chan, C. L. Y., & Tang, A. C. W. (2010). Introducing the 8A model in death education training: Promoting



- planning for end-of-life care for Hong Kong Chinese. *Illness, Crisis and Loss*, 18(1), 49-62.
- Hogan, K., & Pressley, M. (1997). *Scaffolding student learning: Instructional approaches and issues*. Cambridge, MA: Brookline Books.
- Hong Kong Education Bureau (2011). Life education. Retrieved from <http://www.edb.gov.hk/index.aspx?nodeID=7122&langno=1>
- Hong Kong Legislative Counsel. (2008). *Hospice service*. Retrieved from <http://www.info.gov.hk/gia/general/200812/03/P200812030111.htm>
- Hong Kong Legislative Counsel. (2014). *Joint Subcommittee on Long-Term Care Policy - Hospice care services*. Retrieved from <http://www.legco.gov.hk/yr13-14/english/panels/ltcp/papers/ltcp0624cb2-1820-1-e.pdf>
- Hsieh, D. H. (2002). Buddhism: China. In D. Levinson, and K. Christenten (Ed.) *Encyclopedia of modern Asia* (Vol 1., pp. 337-341). New York, NY: Charles Scribner's Sons.
- Hsu, C. Y., O'Conner, M., & Lee, S. (2009). Understanding of death and dying for people of Chinese origin. *Death Studies*, 33, 153-174.
- Hughes-Hallet, T., Craft, A., Davies, C., Mackay, I., & Nielsson, T. (2011). *Funding the right Care and support for everyone: the final report of the Palliative Care Funding Review*. Government of the United Kingdom: Secretary of State for Health.
- IBM Corp. (Released 2011). IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.
- Illich, I. (1976). *Medical Nemesis: The Exploration of Health*. New York, NY: Pantheon Books.

- International Work Group on Death, Dying and Bereavement (2005). Future trends in dying, death and bereavement: A call to action. *Illness, crisis and loss*, 13, 377-385.
- Jackson, A. W., & Davis, G. A. (2002). *Turning Points 2000: Educating adolescents in the 21<sup>st</sup> century*. New York, NY: Teachers College Press.
- Jing-Yin. (2006). Death from the Buddhist view: knowing the unknown. In C.L.W. Chan, & A. Y. M. Chow (Ed.) *Death, dying and bereavement: A Hong Kong Chinese experience* (pp. 93-103). Hong Kong: Hong Kong University Press.
- Johnson, T. P. & Van de Vijver, F. J. R. (2003). Social desirability in cross-cultural research. In J. A. Harkness, F. J. R. Van de Vijver, & P. Ph. Mohler (Eds.), *Cross-cultural survey methods*, (pp. 195-204), Hoboken, NJ: John Wiley and Sons.
- Kawashima, K., Ito, T., Narishige, R., Saito, T., & Okubo, Y. (2012). The characteristics of serious suicide attempters in Japanese adolescents-comparison study between adolescents and adults. *BMC Psychiatry*, 12, DOI: 10.1186/1471-244X-12-191
- Kearney, M. (1992). *Palliative medicine: Just another speciality?* *Palliative Medicine*, 6, 39-46.
- Kellehear, A. (1999). *Health promoting palliative care*. Oxford, UK: Oxford University Press.
- Kellehear, A. (2005). *Compassionate cities: Public health and end of life care*. New York, NY: Routledge.
- Kellehear, A., & O'Conner, D. (2008). *Health-promoting palliative care: A practice example*. *Critical Public Health*, 18, 111-115.

- Klenow, D. J., & Young, A., Jr. (1987). Changes in doctor/patient communication of a terminal prognosis: A selective review and critique. *Death Studies, 17*, 411-425.
- King, J. & Hayslip, B. (2001). The media's influence on college students' views of death. *Omega Journal of Death and Dying, 44*, 37-56.
- Kirchberg, T. M., Neimeyer, R. A., & James, R. K. (1988). Beginning counselors' death concerns and empathetic response to clients situations involving death and grief. *Death Studies, 22*, 99-120.
- Kolb, D. A. (1981). Learning styles and disciplinary differences. *The modern American college, 232-255*.
- Kolb, D. A. (1984). *Experiential learning: Experience as the source of learning and development* (Vol. 1). Englewood Cliffs, NJ: Prentice-Hall.
- Kubler-Ross, E. (1969). *On Death and Dying*. London, UK: Tavistock.
- Kuebler, K., Davis, M., & Moore, C. (Eds.) (2005). *Palliative practices: An interdisciplinary approach*. Philadelphia: Saunders.
- Ladd, J. (1979). *Ethical Issues Relating to Life and Death*. Oxford: Oxford University Press.
- Lai, C. T. (2006). Making peace with the unknown: A reflection on Daoism funerary. In C.L.W. Chan, and A. Y. M. Chow (Ed.) *Death, dying and bereavement: A Hong Kong Chinese experience* (pp. 87-92). Hong Kong: Hong Kong University Press.
- Lai, M. L., Chen, J. R., Chen, H.-H., & Chao C. C. S. (2002). The attitude to death among students in a medical school at southern Taiwan. *Taiwan Journal of Hospice Palliative Care, 7*(3), 197-204 (in Chinese).

- Lam, T.L. (2013). Practical challenges in ambulatory palliative care services in regional hospital in Hong Kong. *The Hong Kong Practitioner*, 35, 52-58.
- Lamers JR, W. M. (2012). Herman Feifel, The Meaning of Death. *Mortality*, 17(1), 66-67.
- Lee, S. Y., Hong, J. S., & Espelage, D. L. (2010). An ecological understanding of youth suicide in South Korea. *School Psychology International*, 31(5), 531-546.
- Leung, P. P. Y. (2010). Autobiographical Timeline: A narrative and life story approach in understanding meaning-making in cancer patients. *Illness, Crisis and Loss*, 18, 111-127.
- Leviton, D. (1977). The scope of death education. *Death education*, 1(1), 41-56.
- Lo, Y. C. (1999). The relationship between the Taoist School and Taoism. *Journal of Chang Gung Institute of Nursing*, 1, 145-154.
- Madsen, R. (1990). The Politics of Revenge in Rural China during the Cultural Revolution. In J. N. Lipman, & S. Harrell (Ed.) *Violence in China: Essays in Culture and Counterculture* (pp. 175-201). Albany, NY: State University of New York Press.
- Mahon, M. M., Goldberg, E. Z., & Washington, S. K. (1999). Concept of death in a sample of Israeli Kibbutz children. *Death Studies*, 23, 43-59.
- Mak, M. H. J. (November, 2011). The Forum: Life-death education – Taiwan, Mainland China and Hong Kong. *Christina Times*, pp.1253 (In Chinese).

- Mak, M. H. J. (2010-2011). Quality insights of university students on dying, death, and death education – A preliminary study in Hong Kong. *Omega Journal of Death and Dying*, 62(4), 397-405.
- Marie Cure Cancer Care (2013). *Death and Dying in England: Understanding the Data*. United Kingdom: Marie Cure Cancer Care.
- McNeill, W. (1976). *Plagues and Peoples*. Basil, UK: Blackwell, Oxford.
- Meier, D., & Beresford, L. (2007). Advocacy is essential to palliative care's future development. *Journal of Palliative Medicine*, 10, 840-844.
- Monod, S., Brennan, M., Rochat, E., Martin, E., Rochat, S., & Bula, C. J. (2011). Instruments measuring spirituality in clinical research. *Journal of General Internal Medicine*, 26(11), 1345-1357.
- Nash, R. J., & Murry, M. C. (2010). *Helping College Students Find Purpose: The Campus Guide to Meaning Making*. San Francisco, CA: John Wiley & Sons, Inc.
- Neimeyer, R. A. (2001). *Meaning Reconstruction and the Experience of Loss*. Washington, DC: American Psychological Association.
- Neimeyer, R. A. (2004). Construction of death and loss: Evolution of a research program. *Personal Construct Theory & Practice*, 1, 8-20.
- Neimeyer, R. A. & Vallerger, M. (2015). Publication patterns in Death Studies: 40 years on. *Death Studies*, DOI: 10.1080/07481187.2015.1064292
- O'Gorman, S.M. (1998). Death and dying in contemporary society: An evaluation of current attitudes and the rituals associated with death and dying and their relevance to recent understanding of health and healing. *Journal of Advanced Nursing*, 24, 1127-1135.

- Papadatou, D., Metallinou, O., Hatzichristou, C., & Pavlidi, L. (2002). Supporting the bereaved child: Teacher's perceptions and experiences in Greece. *Mortality*, 7, 324–339.
- Park, N., Park, M., & Peterson, C. (2010). When is the search for meaning related to life satisfaction? *Applied Psychology: Health and Well-Being*, 2, 1–13.
- Payne, S. A., Dean, S. J. & Kalus, C. (1998). A comparative study of death anxiety in hospice and emergency nurses. *Journal of Advanced Nursing*, 27(4), 700-706.
- Parsons, T. (1963). Death in American Society: A Brief Working Paper. *American Behavioral Scientist*, 6, 61-65.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2<sup>nd</sup> ed.). Newbury Park, CA: Sage.
- Pine, V. R. (1977). A socio-historical portrait of death education. *Death education*, 1(1), 57-84.
- Poceski, M. (2004). China. In R. E. Buswell, Jr (Ed.) *Encyclopedia of Buddhism* (Vol. 1, pp. 139-145). New York, NY: Macmillan Reference.
- Porter, D. (2011). Physical culture and health citizenship. *In Health citizenship: Essays in social medicine and biomedical politics* (p.65-83). San Francisco, CA: University of California Press.
- Potash, J.S., Ho, A.H.Y., Chan F., Wang, X.L., & Cheng C. (2014). Can art therapy reduce death anxiety and burnout in end-of-life care workers? A quasi-experimental study. *International Journal of Palliative Nursing*, 20(5), 233-240.

- Pratt, C. C., Hare, J., & Wright, C. (2001). Death and dying in early childhood education: Are educators prepared? *Education, 107*(3), 279-286.
- Prochaska, J., & DiClemente, C. (1983). Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal of Consulting and Clinical Psychology, 51*(3), 390-395.
- QSR International (2012). *NVivo qualitative data analysis software: Version 10*. QSR International Pty Ltd.
- Richie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In Bryman and Burgess (eds). *Analyzing Qualitative Data*. London: Routledge, p173-194.
- Rivera, J. (Producer), & Docter, P. (2009). *Up*. [Motion Picture]. United States: Walt Disney Pictures/Pixar.
- Rogers, T. B., Kuiper, N. A., & Kirker, W. S. (1977). Self-reference and the encoding of personal information. *Journal of Personality and Social Psychology, 35*(9), 677-688.
- Rorty, R. (1999). *Philosophy and social hope*. London: Penguin Books.
- Sacks, O. (1982). *Awakenings*. London, UK: Picador.
- Samaritans of Singapore. (2013). *Number of Suicides in the Age Group 20-29 increases by 80%*. Retrieved from: <https://sos.org.sg/jul2013>
- Saunders, C. (1967). St. Christopher's Hospice. *Nursing Times, 28*, 988-999.
- Saunders, C. (1987). What is a name? *Palliative Medicine, 1*, 57-61.
- Saunders, C., & Kastenbaum, R. (Eds.) (1997). *Hospice care on the international scene*. New York: Springer.
- Sawyer, R. K. (2006). *The Cambridge Handbook of the Learning Sciences*. New York: Cambridge University Press.

- Schobert, F. M., & Taylor, S. W. (2003). Buddhism. In J. J. Ponzetti, Jr. (Ed.) *International encyclopedia of marriage and family* (2<sup>nd</sup> ed., Vol. 1, pp. 176-181). New York, NY: Macmillan Reference.
- Schulenberg, S. R., Strack, K. M., & Buchanan, E. M. (2011). The meaning in life questionnaire: Psychometric properties with individuals with serious mental illness in an inpatient setting. *Journal of Clinical Psychology*, *67*(12), 1210-1219.
- Seale, C. (1998). *Constructing Death: The Sociology of Dying and Bereavement*. Cambridge, UK: Cambridge University Press.
- Seedhouse, D. (1992). *Health, the foundation of achievement*. New York, NY: J. Wiley and Sons.
- Sham, M.K., Chan, K.S., Tse, M.W., & Lo, S.K. (2006). Impact of palliative care on the quality of life of the dying. In C.L.W. Chan, & A.Y.M Chow (Eds.) *Death, Dying and Bereavement: A Hong Kong Chinese Experience*. Hong Kong: Hong Kong University Press.
- Sham, M.K., Chung, J.P.S., & Humphries, M.J. (1989). The hospice care programme at Ruttonjee Sanatorium – the first 2 years' experience. *Journal of Hong Kong Medical Association*, *41*, 288-291.
- Shryock, R.N. (1947). *The development of modern medicine. An interpretation of social and scientific factors involved* (2<sup>nd</sup> Ed). New York, NY: Knopf.
- Sieh, M. (2011, November 23). Taboos – the things we don't talk about. *South China Morning Post*. Retrieved from <http://www.scmp.com/article/985624/taboo-things-we-dont-talk-about>



- Sindall, C. (1992). Health Promotion and Community Health in Australia. In R. Baum, D. Fry, & I. Lennie (eds.), *Community Health: Policy and Practices in Australia*. Sydney: Pluto Press.
- Sing, T. D. (30 November 2009). Life education against the suicide group. *Sing Tao Daily*, A18. (In Chinese)
- Solomon, S., Greenberg, J., & Pyszczynski, T. (1989). The critical role of self-esteem in adaption: A terror management analysis. In C. R. Snyder & D. Forsyth (Eds.), *Handbook of social and clinical psychology: The health perspective*. New York: Pergamon Press.
- Spoel, P., Harris, R., & Henwood, F. (2014). Rhetorics of Health Citizenship: Exploring Vernacular Critiques of Government's Role in Supporting Healthy Living. *Journal of Medical Humanities*, 35, 131-147.
- Steinitz, L. Y. (1980). Religiosity, well-being, and weltanschauung among the elderly. *Journal of the Scientific Study of Religion*, 19, 60-87.
- Steger, M.F., Frazier, P., Oishi, S., & Kaler, M. (2006). The Meaning in Life Questionnaire: Assessing the presence of and search for meaning in life. *Journal of Counseling Psychology*, 53, 80-93.
- Strickmann, M. (2002). Disease and Taoist law. In M. Strickmann (Ed.) *Chinese magical medicine* (pp.1-57). Stanford, CA: Stanford University Press.
- SUPPORT/Investigators. (1995). The study to understand prognosis and preferences for outcomes and risks of treatment: A controlled trial to improve care for seriously ill hospitalized patients. *Journal of American Medical Association*, 272/29, 1591-1598.

- Surgeon General's Report. (2000). *Youth Suicide*. Retrieved from [www.surgeongeneral.gov/library/youthviolence/report.html](http://www.surgeongeneral.gov/library/youthviolence/report.html)
- Srivastava, A. & Thomson, S. B. (2009). *Framework analysis: A qualitative methodology for applied research note policy research*. *Journal of Administration and Governance*, 4(2), 72-79.
- Sweeting, H.N., & Gilhooley, L.M. (1992). Doctor, am I dead? A review of social death in modern societies. *Omega: Journal of Death and Dying*, 24(2), 251-269.
- Tashakkori, A. & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: SAGE.
- Thompson, K. (2000). The wider philosophy of palliative care: How it is applicable in the General Ward. In R. Fielding, & C.L.W. Chan (eds), *Psychosocial Oncology and Palliative Care in Hong Kong: The First Decade*, (p.13-28). Hong Kong: Hong Kong University Press.
- Tong, C.K. (2004). *Chinese death rituals in Singapore*. London, UK: Routledge Curzon.
- Tse, D.M.W., Chan, K.S., Lam, W.M., Lau, K.S., & Lam, P.T. (2007). The impact of palliative care on cancer deaths in Hong Kong: a retrospective study of 494 cancer deaths. *Palliative Medicine*, 21, 425-433.
- Tse, D. M., Wu, K. K., Suen, M. H., Ko, F. Y., & Yung, G. L. (2006). Perception of doctors and nurse on the care and bereavement support for the relatives of terminally ill patients in an acute setting. *Hong Kong Journal of Psychiatry*, 16, 7-13.
- United Nations General Assembly, Declaration of the Rights of the Child, 20 November, 1959, A/RES/1386(XIV).

- United Nations, Department of Economics and Social Affairs. (2010). *World population prospects, the 2010 revision*. Retrieved from [http://esa.un.org/unpd/wpp/Sorting-Tables/tab-sorting\\_fertility.htm](http://esa.un.org/unpd/wpp/Sorting-Tables/tab-sorting_fertility.htm)
- University of Hong Kong. (2011). *Teaching and Learning*. Retrieved from [http://www0.hku.hk/acad/ugp/studying\\_teaching.html](http://www0.hku.hk/acad/ugp/studying_teaching.html)
- Wagner, P. (1995). Schools and pupils: Developing their responses in bereavement. In R. Best, P. Lang, C. Lodge, & C. Watkins (Eds.), *Pastoral care and personal-social education entitlement and provision*. London: Cassell.
- Walkerdine, V., Lucey, H. & Melody, J. (2002). Subjectivity and qualitative method, In T. May (Ed.), *Qualitative research in action*, (pp. 179-196), London: Sage.
- Walter, T. (1994). *The Revival of Death*. New York, NY: Routledge.
- Warren, D. M. (1989). The impact of nineteenth century social science in establishing negative values and attitudes towards indigenous knowledge system. In D. M. Warren, L. J. Slikkerveer, & S. O. Titilola (Eds.), *Indigenous knowledge system: Implication for agriculture and international development, studies in technology and social change, No 11*, (pp. 171-183), IA, Iowa State University.
- Wass, H. (2003). Children and media violence. In R. Kastenbaum (Ed.), *MacMillan encyclopaedia of death and dying* (vol.1, pp.1337138). New York: Macmillan.
- Wass, H. (2004). A perspective on the current state of death education. *Death Studies*, 28, 289-308.

- Watkins, D. A. (1996). Learning Theories and Approaches to Research: A Cross-cultural Perspective. In D.A. Watkins, & J.B. Biggs (eds.) *The Chinese Learner: Cultural, Psychological and Contextual Influences* (p. 3-24). Hong Kong / Melbourne: Comparative Education Research Centre / Australian Council for Educational Research.
- Williams, M. (2002). Generalization in interpretive research. In T. May (Ed.), *Qualitative research in action*, (pp. 126-143), London: Sage.
- Willing, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and practice*. Buckingham: Open University Press.
- Wolfe, B. (2003). Grief counseling and therapy. In R. Kastenbaum (Ed.), *MacMillan encyclopedia of death and dying* (vol. 1, pp. 389-393). New York: Macmillan.
- Wong, P. T. P., Reker, G. T., & Gesser, G. (1994). Death Attitude Profile-Revised. In R. A. Neimeyer (Ed.), *Death anxiety handbook: Research, instrument, and application* (pp. 121-148). Philadelphia: Taylor & Francis.
- Wong, W.T. (2009). The growth of death awareness through death education among university students in Hong Kong. *Omega Journal of Death and Dying*, 59(2), 113-128.
- World Health Organization. (1986). *Ottawa Charter for Health Promotion*. Geneva: World Health Organization.
- World Health Organization. (2002). *National Cancer Control Programmes: Policies and managerial guidelines (2<sup>nd</sup> Eds)*. Geneva: World Health Organization.

- World Health Organization. (2004). *The solid facts: Palliative care*. Geneva: World Health Organization.
- World Health Organization. (2008). *Ageing and life course*. Retrieved from <http://www.who.int/ageing/en>
- World Health Organization. (2013). *Definition of palliative care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>
- Yalom, I. D. (2008). *Staring at the sun: Overcoming the terror of death*. San Francisco, CA: Jossey-Bass: A Wiley Imprint.
- Yan, C. (2011, January 11). Hong Kong's Feuding Families. *The Wall Street Journal*. Retrieved from <http://blogs.wsj.com/hong-kong/2011/01/27/hong-kongs-feuding-families/>
- Yip, N. M. (2000). Service learning. In S. L. Chan & C. Fong (Eds.), *The joy of learning and teaching* (pp. 69-82). Foundations in Education Series. Hong Kong: Longman (in Chinese).
- Yip, P. S. F., Liu, K. Y., Lam, T. H., Stewart, S. M., Chen, E., & Fan, S. (2004). Suicidality among high school students in Hong Kong, SAR. *Suicide and Life-Threatening Behavior*, 34(3), 284-297.
- Yun, M. (2014, November 20). Ghosts Create Bargains in Hong Kong. *Bloomberg Business*. Retrieved from <http://www.bloomberg.com/bw/articles/2014-11-20/in-hong-kong-haunted-housing-sells-for-a-discount>

## APPENDIX 1

### Publications Related to this Study

- Ho, A.H.Y., Chui, C.H.K., Borshel, M. (In-Press). Understanding and managing youth and elderly suicide in Developed East Asia: The imperative of compassion in public health. In G. Cox & N. Thompson (eds.), *Managing Sudden and Traumatic Grief*. UK: Routledge.
- Ho, A.H.Y., & Tan, G.X.L. (2016). Protecting Dignity at the End of Life: An Agenda for Human Rights in an Ageing World. In D. Harris & R. Bordere (eds.), *Handbook of Social Justice in Loss and Grief: Exploring Diversity, Equity, and Inclusion*. New York: Routledge.
- Thompson, N., Allan, J., Carverhill, P.A., Cox, G.R., Davies, B., Doka, K., Granek, L., Harris, D., Ho, A.H.Y., Klass, D., Small, N., & Wittkowski, J. (2016). The case for a sociology of dying, death, and bereavement. *Death Studies*, DOI: 10.1080/07481187.2015.1109377
- Ho, A.H.Y., Hong, Y.W., Tam, M.Y.J., & Chan, C.L.W. (2015). *Dignified and Compassionate End-of-Life Care: A Self-Help Journey*. Hong Kong: Centre on Behavioral Health, The University of Hong Kong. [In Chinese]
- Ho, A.H.Y., & Tam, M.Y.J., & Chan, C.L.W. (Eds.) (2015). *A Path We Shared: Experiences from the Hospice Palliative Care Community in Hong Kong*. Hong Kong: Centre on Behavioral Health, The University of Hong Kong. [In Chinese]
- Ho, A.H.Y., Dai, A.A.N., Lam, S.H., Wong, S.W.P., Tsui, A.L.M., Tang, J.C.S., & Lou, V.W.Q. (2015). Development and Pilot evaluation of a novel dignity-conserving end-of-life (EoL) care model for nursing homes in Chinese societies. *The Gerontologist*, DOI: 10.1093/geront/gnv037.

- Ho, A.H.Y., Luk, J.K.H., Chan, F.H.W., Ng, W.C., Kowk, C.K.K., Yuen, J.H.L., Tam, M.Y.J., Kan, W.S., & Chan, C.L.W. (2015). Dignified palliative care in long-term care settings: An interpretive-systemic framework of end-of-life integrated care pathway for terminally-ill Chinese older adults. *American Journal of Hospice and Palliative Medicine*, DOI: 10.1177/1049909114565789.
- Leung, P.P.Y., Wan, A.H.Y., Lui, J.Y.M., Ho, A.H.Y., Liu, K.H., So, A., Chan, O.K.M., Kwan, J.C.Y., & Wong, T.K.H. (2015). An evaluation of a death education group for Chinese people with chronic diseases. *Illness, Crisis and Loss*, 23, 5-19.
- Ho, A.H.Y., Chan, C.L.W., Leung, P.P.Y., Chochinov, H.M., Neimeyer, R.A., Pang, S.M.C., & Tse, D.M.W. (2013). Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. *Age and Ageing*, 42(2), 455-461.
- Ho, A.H.Y., Leung, P.P.Y., Tse, D.M.W., Pang, S.M.C., Chochinov, H.M., Neimeyer, N.A. & Chan, C.L.W. (2013). Dignity amidst liminality: Suffering within healing among Chinese terminal cancer patients. *Death Studies*, 37, 953-970.
- Chan, C.L.W., Ho, A.H.Y., Leung, P.P.Y., Chochinov, H.M., Neimeyer, N.A., Pang, S.M.C., & Tse, D.M.W. (2012). The blessing and curses of filial piety on dignity at the end-of-life: Lived experience of Hong Kong Chinese adult children caregivers. *Journal of Ethnic and Cultural Diversity in Social Work*, 21, 277-296.
- Ho, A.H.Y., & Chan, C.L.W. (2012). Liberating bereaved persons from the oppression of death and loss in Chinese societies: examples of the public health approaches. In S. Conway (ed.) *Governing Death and Loss: empowerment, involvement and participation* (pp. 119-128). UK: Oxford University Press.

## APPENDIX 2

### Course Outline for The Last Dance

---

THE UNIVERSITY OF HONG KONG

Department of Social Work and Social Administration & Department of  
Sociology  
Common Core Curriculum

### CCHU9024 THE LAST DANCE: UNDERSTANDING DEATH AND DYING

COURSE OUTLINE 2011/2012

#### Course Details

---

|                   |   |  |
|-------------------|---|--|
| Date              | : | 07 September – 07 December 2011  |
| Time              | : | Every Wednesday Afternoon 14:00 to 16:55<br>(Except 05/10 – Public Holiday)  |
| Venue             | : | Library Extension Room 5 (LE5)   |
| Course Website    | : | <a href="http://cbh.hku.hk/death/">http://cbh.hku.hk/death/</a>  |
| Online Assessment | : | <a href="http://www.surveygizmo.com/s3/628638/CCHU9024-Student-Assessment-BASELINE">www.surveygizmo.com/s3/628638/CCHU9024-Student-Assessment-BASELINE</a> |
| Required Textbook | : | Chan, CLW & Chow, AYM (eds.) (2006)<br><i>Death, Dying and Bereavement: The Chinese Experience</i> . Hong Kong: Hong Kong University Press.                |

#### Course Information

---

##### 1. Course Description:

The study of death of dying is concerned with questions that are rooted at the core of the human experience. Individuals who set out to increase their knowledge of mortality are embarking on life's most important exploration, a constructive journey of personal discovery and spiritual awakening. While acknowledging the finite nature of existence allows individuals to reflect upon the meaning of life for a more profound understanding of personhood, mortality also plays a pivotal role in defining cultural and family values as well as the organization of social structures. This course provides an interdisciplinary overview of the major themes and theories in death and dying from a global perspective with a critical focus on the Chinese experience. It also explores the socio-political, cultural, psychological and spiritual issues raised by mortality through a range of cultural lenses, and examines areas of commonality and diversity to enhance students' competence and reflection in their personal and professional lives as they deal with the inevitability of illness, loss and death.



### Course Objectives:

- 1) Provide students' with basic knowledge on death, dying and bereavement (thanatology studies) as well as issues concerning mortality, spirituality and meaning of life.
- 2) Develop students' awareness on the social, cultural and political impact of death and loss among different ethnic groups with a particular focused on the Chinese experience.
- 3) Enhance students' understandings and practical-skills for working with individuals, families and communities facing the challenges of death, dying and bereavement.
- 4) Enhance students' self-reflection on their personal beliefs, attitudes and experiences with death and loss to create a more profound appreciation of life and personhood.

### 2. Topics Covered:

- 1) Death and its impacts on individuals, families and communities
- 2) Death systems in contemporary societies
- 3) The historical perspectives on mortality
- 4) The evolving attitudes toward death and dying
- 5) Death as a business in China and America
- 6) Death in the news and popular media
- 7) Vision of the afterlife and the functions of death rituals across cultures and religions
- 8) Spiritual inquires surrounding human existence and their meanings to personhood
- 9) The narrative experiences of the dying and bereaved for understanding life and mortality
- 10) Meaning reconstruction and continuing bond in the face of mortality

### 3. Attendance Requirement:

80% for lectures and 100% for Tutorials

You have to attend at least 80% of the lectures. **Attendance in tutorials is compulsory.** Students who fail to comply with the attendance requirements will not be permitted to sit for the year-end examination and would not be able to complete the course.)

### 4. Assessment Ratio:

70% Coursework and 30% Examination

## Course Schedule

### 5. Schedule of Lectures:

| Date / Lecturer                      | Content / References  |
|--------------------------------------|---|
| (1) 07.09.2011<br>Prof. Cecilia Chan | <p><b><u>Death and its Impact on Individuals, Families and Communities</u></b></p> <p>The physical, emotional, psycho-social, spiritual and communal responses to death, dying and bereavement. Inclusive of a phenomenological and anthropological appraisal of death in relation to culture, gender and marginalized groups.</p> <ul style="list-style-type: none"> <li>♦ Required Readings: Chapters 1, 2, 3</li> </ul>  |
| (2) 14.09.2011<br>Prof. Cecilia Chan | <p><b><u>Death Systems in Contemporary Societies</u></b></p> <p>Critical examination of the institutionalization, management and legislation of death with debates over advance care planning, pain control, life prolongation and palliative care, rights to die and assisted suicide, dying at home and dying in institution</p> <ul style="list-style-type: none"> <li>♦ Required Readings: Chapters 7, 10, 12</li> </ul>  |
| (3) 21.09.2011<br>Prof. Cecilia Chan | <p><b><u>The Historical Perspectives on Mortality</u></b></p> <p>Cultural diversity and social oppression in the expression of death anxiety and fear, grief and mourning, and death acceptance. Together with a critical review on mortality and social injustice.</p> <ul style="list-style-type: none"> <li>♦ Required Readings: Chapters 18</li> <li>♦ Ho, A.H.Y., &amp; Chan, C.L.W. (2011). Liberating bereaved persons from the oppression of death and loss in Chinese societies: examples of the public health approaches. In S. Conway (ed.) <i>Governing Death and Loss: empowerment, involvement and participation</i> (Ch. 12, 119-128). UK: Oxford University Press.</li> </ul> |
| (4) 28.09.2011<br>Mr. Andy Ho        | <p><b><u>The Evolving Attitudes toward Death, Dying and Bereavement</u></b></p> <p>A comparative analysis of the social and cultural discourses of death attitudes, beliefs and taboos and their impact on individuals' and families' experiences with death, dying and bereavement. Coupled with a theoretical review on suicide, and threats of horrendous deaths and natural disasters.</p> <ul style="list-style-type: none"> <li>♦ Required Readings: Chapters 8, 22</li> </ul>  |
| (5) 12.10.2011<br>Dr. T. Abraham     | <p><b><u>Death in the News and Popular Media</u></b></p> <p>Processes of distancing and commoditization and its impact of individuals and societal conceptualization of death.</p> <ul style="list-style-type: none"> <li>♦ Required Readings: TBA</li> </ul>   |
| 26.10.2011                           | Site Visit  |

| <b>Date / Lecturer</b>                                   | <b>Content / References</b>  |
|--|--|
| (6) 02.11.2011<br>Dr. Cheris Chan                        | <p><b><u>Death as a Business in China and America</u></b><br/>Comparative analysis of the ideological logic of pricing human life and commercializing death through financial risks and protection, estate management and the insurance industry</p> <ul style="list-style-type: none"> <li>♦ Required Readings:</li> <li>♦ Chan, C. (2009). Creating a Market in the Presence of Cultural Resistance: The Case of Life Insurance in China.” <i>Theory and Society</i>, 38(3):271-305.</li> <li>♦ Chan, C. (2009). Invigorating the Content in Social Embeddedness: An Ethnography of Life Insurance Transactions in China. <i>American Journal of Sociology</i> 115(3):712-54.</li> </ul> |
| (7) 09.11.2011<br>Mr. Andy Ho                            | <p><b><u>The Narrative Experiences of the Dying and Bereaved for Understanding Life and Death</u></b><br/>A life course perspective on mortality that underlines the concept for dignity, and informed by state-of-the-art research that examines the narratives and lived experiences of terminally-ill patients and bereaved families.</p> <ul style="list-style-type: none"> <li>♦ Required Readings: 9, 11, 16</li> <li>♦ Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L., &amp; Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. <i>Social Science &amp; Medicine</i>, 54, 433-443.</li> </ul>   |
| (8) 16.11.2011<br>Dr. David Palmer                       | <p><b><u>Vision of the Afterlife and the Function of Death Rituals across Cultures and Religions</u></b><br/>A psycho-anthropological analysis of their function as rites of passage, adjusting and reestablishing kinship, and facilitating the grieving process of the living. Together with a critical examination of ethical teachings, meritorious deeds and spiritual pathways</p> <ul style="list-style-type: none"> <li>♦ Required Readings: Chapter 5, 6, 7</li> </ul>  |
| (9) 23.11.2011<br>Dr. David Palmer &<br>Dr. Pamela Leung | <p><b><u>Spiritual Inquires surrounding Human Existence and their Meanings to Personhood</u></b><br/>An exploration over the meaning of life and death that highlights an empirical discourse on existential and spiritual research. Secular concepts of immortality and near death experiences will also be discoursed</p> <ul style="list-style-type: none"> <li>♦ Required Readings: Chapter 4</li> </ul> <p>Leung, P. P. Y. (2010) Utilizing Eastern spirituality in clinical practice: a qualitative study of Chinese women with breast cancer. <i>Smith College Studies in Social Work</i>, 80, 159-183.</p>   |

| Date / Lecturer                     | Content / References  |
|-------------------------------------|---|
| (10) 30.11.2011<br>Dr. Pamela Leung | <p data-bbox="644 237 1318 300"><b><u>Meaning reconstruction and continuing bond in the face of death and dying</u></b></p> <p data-bbox="644 304 1318 456">A critical discussion over the theories on attachment, continuing bond and meaning reconstruction in the face of mortality. Together with a review over various intervention strategies in dealing with anticipatory grief and bereavement care.</p> <ul data-bbox="644 461 1318 622" style="list-style-type: none"> <li data-bbox="644 461 1318 501">♦ Required Readings: Chapters 18, 19, 20</li> <li data-bbox="644 506 1318 622">♦ Leung, P. P. Y. (2010) Autobiographical timeline: a narrative and life story approach in understanding meaning-making in cancer patients. <i>Illness, Crisis, and Loss</i>, 18, 111-127</li> </ul> |
| (11) 07.12.2011<br>All Teachers     | <b>Creative Group Project – Student presentation</b>  |

#### 6. Schedule of Tutorials

1-hour Tutorials will be held at the end of each 2-hours Lecture.

### **Intended Learning Outcomes, Teaching and Learning Activities, & Assessment Details**

---

#### 7. Intended Learning Outcomes (ILOs)

On Completion of this course, students will be able to:

IOL1: Describe and explain the fundamental knowledge, myths, attitudes, practices and ideological contradictions of death, dying and bereavement with a cultural sensitivity to the Chinese experience; and critically appraise the oppressive social norms, rituals, discourses and portrayals of death and dying in contemporary societies.

ILO2: Demonstrate an understanding of the emotional concerns, family issues and psychosocial aspects of death and dying on the individual level; and critically examine the inequality of access to care and services among vulnerable groups such as widows, minors, orphans, the poor and people with contentious disease such as AIDS and other life-limiting infections.

ILO3: Appraise the impact of death and loss on the societal level; and critically examine the future development of social policies, service provisions, education programs as well as the commercial industry on the management and commodification of death and dying.

ILO4: Reflect on the meaning of life though a heightened awareness of death and an enhanced spiritual orientation; and create a more profound understanding of the 'self' through an appraisal of personal beliefs, cultural ideologies and popular religions and philosophies on spirituality and immortality.

ILO5: Develop compassion and understanding for individuals, communities and the larger world as well as a commitment to activism, equity and social justice during those most vulnerable moments in human experience; and challenge the hypocrisy of pricing human life and commercializing death in the modern era.

ILO6: Integrate theories into practice in developing creative health promotion projects on tackling the various socio-cultural issues concerning death, dying and bereavement.

8. Teaching and Learning Activities (TLAs)

TLA1: Interactive lectures

- ◆ Lectures
- ◆ In-class discussions

TLA2: Tutorials

- ◆ In-class experiential exercises
- ◆ In-class skills training

TLA3: Site Visit

- ◆ Funeral Home, Graveyard and Memorial Garden
- ◆ Presentation by Funeral Home Owner

TLA4: Group project and outside-classroom activities

- ◆ Group discussions and field visit
- ◆ Group project presentation
- ◆ Lecturer and tutor consultations

9. Assessment Ratio

| <u>Assessment Tasks / Activities</u>          | <u>Assessment Ratio</u> |
|---|-------------------------|
| Bi-Weekly Individual Reflective Log (AT1)     | 20%                     |
| Creative Group Project - Presentation (AT2)   | 25%                     |
| Creative Group Project - Written Report (AT3) | 25%                     |
| Final Written Examination (AT4)               | 30%                     |

10. Assessment Details

***AT1. Bi-Weekly Individual Reflective Log (20%)***

Students are required to keep a bi-weekly individual reflective log to ruminate upon their own beliefs, values and attitudes on the various topics on death and dying covered in this course. This deliberate cognitive activity necessitates students to connect their thoughts, feelings and experiences related to their learning from all interactive lectures, in-class discussions and experiential exercises. This activity further provides students with the opportunities to critically explore and reflect upon issues concerning mortality, spirituality, personhood, society and greater humanity through acknowledging and understanding the nature of life and death.

**Specifically, a short written response (between 250-300 words) to two consecutive lectures of all 10 lectures is required from every student (a total of 5 reflective log entries per student). Log entries are due one week after the lectures date, and student are required to submit log entries to their assigned tutor through email.**

The assessment criteria for the individual reflective log entries are as follows:

Grading Criteria for Bi-Weekly Individual Reflective Log

| A+ A A-<br><i>Reconstructing</i>  | B+ B B-<br><i>Reasoning</i>  | C+ C C-<br><i>Relating</i>  | D+ D D-<br><i>Responding</i>   | F<br><i>Reporting</i>  |
|---|--|---|--|--|
| The student displays a high level of abstract thinking to generalize and apply her/her learning. He/she draws original conclusions from reflections, generates principles and formulates a personal theory in taking a stance on an issue. He/she further deliberates upon the personal significance of his/her learning and plans further learning on the basis of such reflections. | The student integrates his/her learning into an appropriate relationship involving a high level of transformation and conceptualization. He/she seeks deep understanding of why something has happened, exploring the relationship of theory and practice in some depth. | The student identifies aspects of his/her learning which have personal meaning, connecting with his/her experience. The student gives superficial explanation of the reason why something has happened or identifies something that they need or plan to do, or change. | The student uses his/ her learning in some way, but with little transformation or conceptualization. | The student describes or reports his/her learning with no added insights and minimum transformation. |

***AT2. Creative Group Project - Presentation (25%)***

Students will work in small groups of 4-6 persons to develop a creative public health promotion project on tackling socio-cultural issues related to death and dying such as: Alleviating Chinese death taboos; Eliminating the oppression of death for widows and orphans; Finding meaning in the face of death; Promoting spirituality through mortality; Health promoting palliative care, etc. Students will first be required to conduct a literature review on the chosen topic, of which will serve as the empirical foundation of their project. They are then encourage to adopt a public health promotion approach for tackling the issue at hand by using a variety of creative mediums including art, photography, and other audio-visual productions. Each group is required to create a 1-2 minute multi-media production and present their work through a 10 minute presentation. The presentation should include theoretical background, conceptual approach, the outcome product and personal reflections. **Deadline for submission of group member list: September 22<sup>nd</sup> 2011. Date of the presentation: December 7<sup>th</sup> 2011.**

|  |     |
|--|-----|
| <b>Assessment criteria for Group Presentation:</b>   |     |
| <i>Synthesis of theories and conceptualization</i>   | 30% |
| <ul style="list-style-type: none"> <li>- Understanding and analysis of the topic/issue/phenomenon by reviewing evidence in the current literature</li> <li>- Ability to conceptualize the topic/issue/phenomenon with relevant theories</li> </ul> |     |
| <i>Public health impact</i>  | 30% |
| <ul style="list-style-type: none"> <li>- Ability to bring new perspective of the project's impact on public health as well as its effect on the pertinent stakeholders</li> </ul>  |     |
| <i>Creativity and innovation</i>   | 20% |
| <ul style="list-style-type: none"> <li>- Being inventive in the way of conducting the project</li> <li>- Being inventive in the way of presenting the work</li> <li>- Ability to bring new perspective to undertaking the project</li> </ul>       |     |
| <i>Articulation of reflection and learning</i>   | 20% |
| <ul style="list-style-type: none"> <li>- Reflective use of and ability to relate learning to everyday life experiences</li> </ul>  |     |

***AT3. Creative Group Project - Written Report (25%)***

Each group is required to submit a written report of 4,000-6,000 words discussing the creative group project. The report should include a detailed synthesis of the theoretical background, conceptual approach of the project work, the public health impact of the project, and personal reflections on learning. The report has to follow academic writing style (e.g. APA), with full referencing and comprehensive review of the updated literature on the topic of discussion. Please use one-and-a-half line spacing and have page numbers printed on each page. **Deadline of submission of Written Report: 23:59 of December 7<sup>th</sup>, 2011.** Please submit the paper through the **Turnitin system. [Class ID: 4106099, password: lastdance]** Marks will be deducted for late submission. Paper that contains plagiarized materials will be penalized in accordance to the University regulations on academic dishonesty.

|  |     |
|--|-----|
| <b>Assessment criteria for Group Written Report:</b>   |     |
| <i>Literature Review and conceptualization</i>   | 40% |
| <ul style="list-style-type: none"> <li>- Understanding and analysis of the topic/issue/phenomenon by reviewing evidence in the current literature</li> <li>- Ability to conceptualize the topic/issue/phenomenon with relevant theories</li> <li>- Coverage of relevant literatures</li> </ul> |     |
| <i>Critical thinking and analysis of public health impact</i>  | 20% |
| <ul style="list-style-type: none"> <li>- Critical, reflective, and/or original thought</li> <li>- Cultural integration, understanding of local situation</li> </ul>  |     |
| <i>Personal Reflection</i>   | 20% |
| <ul style="list-style-type: none"> <li>- Reflective use of and ability to relate learning to everyday life experiences</li> </ul>  |     |
| <i>Clarity, logic and structure of presentation</i>  | 10% |
| <ul style="list-style-type: none"> <li>- Adherence to a commonly accepted logical presentation</li> </ul>  |     |
| <i>Use of Language and Referencing</i>   | 10% |
| <ul style="list-style-type: none"> <li>- Accuracy and clarity of language</li> <li>- Adherence to a commonly accepted academic reference system</li> </ul>   |     |

***AT4. Final Written Examination (30%)***

Students are required to take a final written exam at the end of the course. The exam will cover all assigned readings as well as notes from all lectures and tutorials. It will comprise of 25 Multiple Choice Questions (1 marks each) and 3 'Seen' Short Questions (25 marks each, 3 out of 6 choices; the seen questions will provided to students at the final lecture). The exam is open-book and it will take approximately 120 minutes to complete.

11. Submission of Assignments

All assignments should be submitted on time. According to the Departmental regulations, late submission of assignment will receive the following penalties:

***Penalty for late submission***

| Late for         | % of marks to be deducted |
|------------------|---------------------------|
| 1 day            | 10%                       |
| 2 days           | 20%                       |
| 3 days           | 30%                       |
| 4 days           | 40%                       |
| 5 days           | 50%                       |
| 6 days           | 60%                       |
| 7 days           | 70%                       |
| More than 7 days | No mark will be given     |

12. Important Dates

- ◆ Deadlines of submission of written assignments and/or assessment materials
  - ◆ Creative group project - presentation: 7 December 2011
  - ◆ Creative group project - written report 7 December 2011
- ◆ Date of Site Visit 26 October 2011
- ◆ Date of Final Written Exam TBA



### 13. Standards of Assessment

| Marks        | Grade | Grade Standard | Grade Description  |
|--------------|-------|----------------|--|
| 80 & above   | A+    | Excellent      | Strong evidence of superb ability to fulfill the intended learning outcomes of the course at all levels of learning: describe, apply, evaluate, and synthesize   |
| 75-79        | A     |                |  |
| 70-74        | A-    |                |  |
| 67-69        | B+    | Good           | Strong evidence of the ability to fulfill the intended learning outcomes of the course at all levels of learning: describe, apply, evaluate, and synthesize  |
| 63-66        | B     |                |  |
| 60-62        | B-    |                |  |
| 57-59        | C+    | Satisfactory   | Evidence of adequate ability to fulfill the intended learning outcomes of the course at low levels of learning such as describe and apply but not at high levels of learning such as evaluate and synthesize |
| 53-56        | C     |                |  |
| 50-52        | C-    |                |  |
| 46-49        | D+    | Pass           | Evidence of basic familiarity with the subject   |
| 40-45        | D     |                |  |
| Less than 40 | F     | Fail           | Little evidence of basic familiarity with the subject  |

### 14. Academic Conduct

The University Regulations on academic dishonesty will be strictly enforced! Please check the University Statement on plagiarism on the web: <http://www.hku.hk/plagiarism/>.

Academic dishonesty is behavior in which a deliberately fraudulent misrepresentation is employed in an attempt to gain undeserved intellectual credit, either for oneself or for another. It includes, but is not necessarily limited to, the following types of cases:

- a. Plagiarism - The representation of someone else's ideas as if they are one's own. Where the arguments, data, designs, etc., of someone else are being used in a paper, report, oral presentation, or similar academic project, this fact must be made explicitly clear by citing the appropriate references. The references must fully indicate the extent to which any parts of the project are not one's own work. Paraphrasing of someone else's ideas is still using someone else's ideas, and must be **acknowledged**.
- b. Unauthorized Collaboration on Out-of-Class Projects - The representation of work as solely one's own when in fact it is the result of a joint effort. Where a candidate for a degree or other award uses the work of another person or persons without due acknowledgement.

#### ***Penalty***

1. The relevant Board of Examiners may impose a penalty in relation to the seriousness of the offence.
2. The relevant Board of Examiners may report the candidate to the Senate, where there is *prima facie* evidence of an intention to deceive and where sanctions beyond those in (1) might be invoked.

15. Recommended Readings

**Recommended Textbook**

DeSpelder, L. A., & Strickland, A. L. (2009). *The Last Dance: Encountering Death and Dying* (8<sup>th</sup> ed.) New York: McGraw-Hill.

**Recommended Readings**

Allmark, P. (2002). Death with dignity. *Journal of Medical Ethics*, 28, 255-257.

Centre on Behavioral Health (2009). *In Celebration of Life: A self-help journey on preparing a good death and living with loss and bereavement*. Hong Kong: Centre on Behavioral Health, The University of Hong Kong.

Bowlby, J. (1980). *Attachment and Loss. Vol. III: Loss: sadness and depression*. Harper Collins: Basic Books.

Bryant, C. D., & Peck, D. L. (Ed.) *Encyclopedia of death and the human experience*. California: SAGE Publications, Inc.

Chan, C.L.W. & Chow, A.Y.M. (2005). The pathway of bereaved persons in Hong Kong. In Leung, M.Y. & Cheung, C.F. (eds) *Gazing death* (pp. 398-406). Hong Kong: The Chinese University Press.

Chan, C.L.W., Chow, A.Y.M., Ho, S.M.Y., Tsui, K.Y.Y., Tin, F.A., Koo, W.S.B. (2005). The experience of Chinese bereaved persons: A preliminary study of meaning making and continuing bonds. *Death studies*, 29, 923-947.

Chan, W.C.H., Tin, A.F., Chan, C.H.Y., & Chan, C.L.W. (in press). Introducing the 8A model in death education training: Promoting planning for end-of-life care for Hong Kong Chinese). *Illness, Crisis and Loss*.

Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, 54, 433-443.

Dalai Lama. (2002). *Advice of dying: and living a better life*. New York: Atria Books.

Doka, K.J., & Morgan, J. D. (1993). *Death and spirituality*. New York: Baywood Publishing Company.

Field, M., & Cassel, C.K. (1997). *Approaching Death: improving Care at the End of Life*. Washington DC: National Academy Press.

Fielding, R., & Chan C.L.W. (Eds.) (2000) *Psychosocial Oncology and Palliative Care in Hong Kong: The First Decade*. Hong Kong: Hong Kong University Press.

Hsu, C. Y. , O'Conner, M., & Lee, S. (2009). Understanding of death and dying for people of Chinese origin. *Death Studies*, 33, 153-174.

Kelleheara, A., & O'Conner, D. (2008). Health-promoting palliative care: A practice example. *Critical Public Health*, 18, 111-115.

Kubler-Ross, E. (1970). *On death and dying*. London: Tavistock.

Kuhl, D. (2002). *What dying people want: Practical wisdom for the end of life*. Canada: Anchor Canada.

- Neimeyer, R.A. (2002). *Lessons of loss: A guide to coping*. Memphis, TN: Centre for the Study of Loss and Transition.
- Neimeyer, R.A. (2001). *Meaning reconstruction and the experience of loss*. Washington DC: American Psychological Association.
- Tomer, A., Eliason, G.T., & Wong, P.T.P. (Eds.) (2007). *Existential and Spiritual Issues in Death Attitudes*. New Jersey: Lawrence Erlbaum Associates Inc.
- Wass, H. (2004). *A perspective on the current state of death education*. *Death Studies*, 28, 289-308

### ***Recommended Websites***

The ENABLE Website - The Enable Journeys (Empowerment Network for Adjustment to Bereavement and Loss in End-of-life)  
<http://www.enable.hk>

American Academy of Hospice and Palliative Medicine (AAHPM)  
<http://www.aahpm.org>  
American Hospice Foundation (AHF)  
<http://www.americanhospice.org>

Association of Death Education and Counseling (ADEC)  
<http://www.adec.org>

International Psycho-Oncology Society (IPOS)  
[http://www.ipos-society.org/education/core\\_curriculum/core\\_curriculum\\_en.aspx](http://www.ipos-society.org/education/core_curriculum/core_curriculum_en.aspx)

Association of Life-Death Education, Taiwan (Chinese)  
<http://210.60.194.100/life2000>

Society for the Promotion of Hospice Care  
<http://www.hospicecare.org.hk>

GriefNet  
<http://www.griefnet.org>

Growth House  
<http://growthhouse.org/>

The Samaritan Befrienders Hong Kong  
<http://www.sbhk.org.hk/>

APPENDIX 3

**Assessment Rubric for Student Reflective Logs**

---

CCHU9024 – THE LAST DANCE: UNDERSTANDING DEATH AND DYING  
**BI-WEEKLY REFLECTIVE LOG**

**Assessment Criteria**

- (A) **Reconstructing:** The student displays a high level of abstract thinking to generalize and apply her/her learning. He/she draws original conclusions from reflections, generates principles and formulates a personal theory in taking a stance on an issue. He/she further deliberates upon the personal significance of his/her learning and plans further learning on the basis of such reflections.
- (B) **Reasoning:** The student integrates his/her learning into an appropriate relationship involving a high level of transformation and conceptualization. He/she seeks deep understanding of why something has happened, exploring the relationship of theory and practice in some depth.
- (C) **Relating:** The student identifies aspects of his/her learning which have personal meaning, connecting with his/her experience. The student gives superficial explanation of the reason why something has happened or identifies something that they need or plan to do, or change.
- (D) **Responding:** The student uses his/ her learning in some way, but with little transformation or conceptualization.
- (F) **Reporting:** The student describes or reports his/her learning with no added insights and minimum transformation.
- (G)

|  | A                         | B                  | C                  | D                    | F                                      |
|--|---------------------------|--------------------|--------------------|----------------------|--|
| <b>Knowledge of Concepts</b><br>Discussion of issues including references to course and lecture materials. | Abstract Thinking         | Deep Understanding | Some Understanding | Little Understanding | Simple Descriptions/ Mis-understanding |
| <b>Synthesis of Ideas</b><br>Critical, reflective original thought.  | Draws Original Conclusion | Clear Evidence     | Some Evidence      | Little Evidence      | None                                   |
| <b>Personal Insight</b><br>Personal significance and meaning of course materials to one's own life.        | High level                | Some               | Superficial        | Minimal              | No Added Insights                      |
| <b>Clarity in Presentation</b><br>Spelling, grammar.   | Eloquent                  | Clear              | Unclear            | Weak                 | Many Mistakes                          |
| <b>General Comments:</b>   |                           |                    |                    |                      |  |

## APPENDIX 4

### Assessment Criteria for Group Presentation

---

CCHU9024 – THE LAST DANCE: UNDERSTANDING DEATH AND DYING  
CREATIVE GROUP PROJECT PRESENTATION

#### Assessment Criteria

| Assessment Criteria   | Grade       |
|---|-------------|
| <b>1) <i>Synthesis of theories and conceptualization</i></b> <ul style="list-style-type: none"> <li>- Understanding and analysis of the topic/issue/phenomenon by reviewing evidence in the current literature</li> <li>- Ability to conceptualize the topic/issue/phenomenon with relevant theories</li> </ul> | <b>/30</b>  |
| <b>2) <i>Public health impact</i></b> <ul style="list-style-type: none"> <li>- Ability to bring new perspective of the project's impact on public health as well as its effect on the pertinent stakeholders</li> </ul>   | <b>/30</b>  |
| <b>3) <i>Creativity and innovation</i></b> <ul style="list-style-type: none"> <li>- Being inventive in the way of conducting the project</li> <li>- Being inventive in the way of presenting the work</li> <li>- Ability to bring new perspective to undertaking the project</li> </ul>                         | <b>/15</b>  |
| <b>4) <i>Articulation of reflection and learning</i></b> <ul style="list-style-type: none"> <li>- Reflective use of and ability to relate learning to everyday life experiences</li> </ul>  | <b>/15</b>  |
| <b>5) <i>Clarity, logic and structure of presentation</i></b> <ul style="list-style-type: none"> <li>- Teamwork, time-management, overall effectiveness in conveying central message, etc.</li> </ul>   | <b>/10</b>  |
| <b>Total</b>  | <b>/100</b> |
| <b>General Comments:</b>  |             |

## APPENDIX 5

### Assessment Criteria for Group Written Report

---

CCHU9024 – THE LAST DANCE: UNDERSTANDING DEATH AND DYING  
CREATIVE GROUP PROJECT WRITTEN REPORT

#### Assessment Criteria

| Assessment Criteria   | Grade       |
|---|-------------|
| <b>1) Literature Review and conceptualization</b><br>- Understanding and analysis of the issue/phenomenon by reviewing evidence in the current literature<br>- Ability to conceptualize the case/issue with relevant theories<br>Coverage of relevant literatures | /40         |
| <b>2) Critical thinking and analysis</b><br>- Critical, reflective, and/or original thought<br>Cultural integration, understanding of local situation   | /20         |
| <b>3) Personal Reflection</b><br>- Reflective use of and ability to relate learning to everyday life/personal experiences   | /20         |
| <b>4) Clarity, logic and structure of presentation</b><br>- Adherence to a commonly accepted logical presentation   | /10         |
| <b>5) Use of Language and Referencing</b><br>- Accuracy and clarity of language<br>- Adherence to a commonly accepted academic reference system   | /10         |
| <b>Total</b>  | <b>/100</b> |
| <b>General Comments:</b>  |             |
|   |             |

## APPENDIX 6

### Letter of Ethical Approval

---

THE UNIVERSITY OF HONG KONG

香港



大學

September 8, 2011

Mr. Ho Hau Yan Andy  
Centre on Behavioral Health

Dear Mr. Ho,

**Reference No. EA320811: Application for Ethical Approval**

I refer to your application for ethical approval of your project entitled "An ethnographic study on student learning process and outcome of a new common core curriculum (CCC) course on death education in higher education - The last dance: Understanding death and dying".

2. I am pleased to inform you that the application has been approved by the Human Research Ethics Committee for Non-Clinical Faculties regarding the ethical aspect of the above-mentioned research project, and the expiration date of the ethical approval is September 7, 2013.

3. Please be reminded that you are required to submit, as appropriate, an annual progress/final completion report on the prescribed report form available at the HRECNCf website. For extension of the ethical approval and/or amendments to the approved project, please also ensure to submit an application, on the same form, prior to the above-specified expiration date.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'JB' or similar initials.

Professor J. Bacon-Shone  
Chairman  
Human Research Ethics Committee for Non-Clinical Faculties

THE REGISTRY 教務處

POKFULAM ROAD, HONG KONG. TEL:(852)2859 2111 FAX:(852)2858 2549

Printed on environmentally friendly paper

## APPENDIX 7

### Letter of Informed Consent

---



### A Study on Student Learning Process and Outcome of a New Common Core Curriculum Course on Death Education in Higher Education - The Last Dance: Understanding Death & Dying

---

#### STUDENT INFORMED CONSENT FORM

##### Research Objective

This study aims to 1) to evaluate the effectiveness of the newly developed Common Core Curriculum course, “The Last Dance: Understanding Death and Dying”, in enhancing students’ knowledge and understanding on mortality, spirituality and meaning of life; 2) to understand the processes of learning and teaching that develop and augment students’ awareness and self-reflection on the social, cultural and political impact of death and loss in contemporary society; and 3) to identify formative factors for improving pedagogy practices and curriculum design.

##### Procedures

You are invited to complete two self-administrated assessment questionnaires during the first and final lecture; the time required is approximately 15-20 minutes. You are also invited to complete two brief student evaluation forms during the final lecture; the time required is 5-10 minutes. Finally, you are invited to have your bi-weekly individual-reflective logs (part of course assessment) analyzed for identifying important themes that enhance student learning process and outcome. Data analysis will only take place after your final grades have been approved and disseminated by the University.

##### Potential Risks or Discomforts

Your participation in this study will not in any way affect your coursework assessment or your final grade. Also, the focus of this study is on your personal attitude and beliefs around issues of life, death and spirituality. No known or anticipated risks or discomforts are expected.

##### Potential Benefits

Participation in this study will help you to identify and consolidate your personal attitude, beliefs and values concerning mortality, spirituality and meaning of life. In addition, this study will provide valuable information for enhancing pedagogy practices and curriculum design for death education in higher education.

##### Confidentiality

All personal information and responses that you provide through the self-administrated assessment questionnaire and the individual reflective logs will be treated as strictly confidential. Data will be stored securely and will be made available only to persons conducting the study unless participants specifically give permission in writing to do otherwise. No reference will be made in oral or written reports which could link you to the study. No part of this study will be recorded.

##### Participation and Withdrawal

Your participation is voluntary. This means that you can choose to stop at any time without negative consequences.



**Questions and Concerns**

If you have any questions about the research, please feel free to contact Mr. Andy H.Y. Ho (Tel: 2589-0507; Email: andyho@hku.hk). If you want to know more about your rights as a research participant, please contact the Human Research Ethics Committee for Non-Clinical Faculties, the University of Hong Kong (Tel: 2241-5267).

-----

By signing below, you have read and understood the information described above and agree to participate in this research study.

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Date of Birth

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's Date

## APPENDIX 8

### Student Pretest-Posttest Assessment Questionnaire

---



### A Study on Student Learning Process and Outcome of a New Common Core Curriculum Course on Death Education in Higher Education - The Last Dance: Understanding Death & Dying

#### BASELINE-OUTCOME ASSESSMENT QUESTIONNAIRE

**STUDENT NUMBER:** \_\_\_\_\_

#### Part A. Death Attitude Profile-Revised

This following contains a number of statements related to different attitudes toward death. Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

|  | 1                            | 2               | 2                              | 4                | 5                           | 6            | 7                         |
|--|------------------------------|-----------------|--------------------------------|------------------|-----------------------------|--------------|---------------------------|
|  | <b>Strongly<br/>Disagree</b> | <b>Disagree</b> | <b>Moderately<br/>Disagree</b> | <b>Undecided</b> | <b>Moderately<br/>Agree</b> | <b>Agree</b> | <b>Strongly<br/>Agree</b> |
| 1. Death is no doubt a grim experience.  | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 2. The prospect of my own death arouses anxiety in me.                             | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 3. I avoid death thoughts at all costs.  | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 4. I believe I will be in heaven after I die.                                      | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 5. Death will bring an end to all my troubles.                                     | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 6. Death should be viewed as a natural, undeniable, and unavoidable event.         | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 7. I am disturbed by the finality of death.  | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 8. Death is an entrance to a place of ultimate satisfaction.                       | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 9. Death provides an escape from this terrible world.                              | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 10. Whenever the thought of death enters my mind, I try to push it away.           | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 11. Death is deliverance from pain and suffering.                                  | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 12. I always try not to think about death.   | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 13. I believe that heaven will be a better place than this world.                  | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 14. Death is a natural aspect of life.   | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 15. Death is a union with God and eternal bliss.                                   | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 16. Death brings a promise of a new and glorious life.                             | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 17. I would neither fear death nor welcome it.                                     | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 18. I have an intense fear of death.   | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 19. I avoid thinking about death altogether.                                       | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 20. The subject of life after death troubles me greatly.                           | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 21. The fact that death will mean the end of everything as I know it frightens me. | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 22. I look forward to a reunion with my loved ones after I die.                    | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 23. I view death as a relief from earthly sufferings.                              | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 24. Death is simply a part of the process of life.                                 | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 25. I see death as a passage to an eternal and blessed place.                      | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 26. I try to have nothing to do with the subject of death.                         | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 27. Death offers a wonderful release of the soul.                                  | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 28. One thing that gives me comfort in facing death is my belief in the afterlife. | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 29. I see death as a relief from the burden of this life.                          | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |
| 30. Death is neither good nor bad.   | 1                            | 2               | 3                              | 4                | 5                           | 6            | 7                         |

- |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|
| 31. I look forward to life after death.                                 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 32. The uncertainty of not knowing what happens after death worries me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

### Part B. Meaning in Life Questionnaire

Please take a moment to think about what makes your life feel important to you. Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

|   | <b>1</b>                 | <b>2</b>           | <b>3</b>               | <b>4</b>         | <b>5</b>             | <b>6</b>           | <b>7</b>               |
|---|--------------------------|--------------------|------------------------|------------------|----------------------|--------------------|------------------------|
|   | <b>Absolutely Untrue</b> | <b>Mostly True</b> | <b>Somewhat Untrue</b> | <b>Undecided</b> | <b>Somewhat True</b> | <b>Mostly True</b> | <b>Absolutely True</b> |
| 1. I understand my life's meaning.  | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 2. I am looking for something that makes my life meaningful.                | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 3. I am always looking to find my life's purpose.                           | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 4. My life has clear sense of purpose.                                      | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 5. I have a good sense of what makes my life meaningful.                    | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 6. I have discovered a satisfying life purpose.                             | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 7. I am always searching for something that makes my life feel significant. | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 8. I am seeking a purpose or mission for my life.                           | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 9. My life has no clear purpose.  | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |
| 10. I am searching for meaning in my life.                                  | 1                        | 2                  | 3                      | 4                | 5                    | 6                  | 7                      |

### Part C. Spirituality Scale

Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

|  | <b>1</b>                 | <b>2</b>        | <b>2</b>     | <b>4</b>              |
|--|--------------------------|-----------------|--------------|-----------------------|
|  | <b>Strongly Disagree</b> | <b>Disagree</b> | <b>Agree</b> | <b>Strongly Agree</b> |
| 1. I find meaning in my life experiences.  | 1                        | 2               | 3            | 4                     |
| 2. I have a sense of purpose.  | 1                        | 2               | 3            | 4                     |
| 3. I am happy about the person I have become.  | 1                        | 2               | 3            | 4                     |
| 4. I see the sacredness of everyday life.  | 1                        | 2               | 3            | 4                     |
| 5. I meditate to gain access to my inner spirit.   | 1                        | 2               | 3            | 4                     |
| 6. I live in harmony with nature.  | 1                        | 2               | 3            | 4                     |
| 7. I believe there connection between all things that cannot see but can sense.              | 1                        | 2               | 3            | 4                     |
| 8. My life is a process of becoming.   | 1                        | 2               | 3            | 4                     |
| 9. I believe in a Higher Power / Universal Intelligence.                                     | 1                        | 2               | 3            | 4                     |
| 10. The earth is sacred.   | 1                        | 2               | 3            | 4                     |
| 11. My life is process of becoming.  | 1                        | 2               | 3            | 4                     |
| 12. I use silence to get in touch with myself.   | 1                        | 2               | 3            | 4                     |
| 13. I have a relationship with a Higher Power / Universal Intelligence.                      | 1                        | 2               | 3            | 4                     |
| 14. My spirituality gives me inner strength.   | 1                        | 2               | 3            | 4                     |
| 15. My faith in a Higher Power/Universal Intelligence helps me cope with challenges in life. | 1                        | 2               | 3            | 4                     |
| 16. Prayer is an integral part of my spiritual nature.                                       | 1                        | 2               | 3            | 4                     |
| 17. I often take time to assess my life choices as a way of living my spirituality.          | 1                        | 2               | 3            | 4                     |
| 18. I believe that all living creatures deserve respect.                                     | 1                        | 2               | 3            | 4                     |
| 19. I value maintaining and nurturing my relationships with others.                          | 1                        | 2               | 3            | 4                     |
| 20. I believe that nature should be respected.   | 1                        | 2               | 3            | 4                     |
| 21. I am able to receive love from others.   | 1                        | 2               | 3            | 4                     |
| 22. I strive to correct the excesses in my own lifestyle patterns / practices.               | 1                        | 2               | 3            | 4                     |
| 23. I respect the diversity of people.   | 1                        | 2               | 3            | 4                     |

**Part D. Chinese Death Taboos Scale**

Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

|   | <b>1</b>                 | <b>2</b>        | <b>2</b>     | <b>4</b>              |
|---|--------------------------|-----------------|--------------|-----------------------|
|   | <b>Strongly Disagree</b> | <b>Disagree</b> | <b>Agree</b> | <b>Strongly Agree</b> |
| 1. Thinking or talking about death brings bad luck.                       |                          |                 |              | 1 2 3 4               |
| 2. Seeing a dead body or a coffin brings ill fortune.                     |                          |                 |              | 1 2 3 4               |
| 3. A painful or early death is a result of past misdeeds.                 |                          |                 |              | 1 2 3 4               |
| 4. Recently bereaved families should not be social active.                |                          |                 |              | 1 2 3 4               |
| 5. Visiting homes of recently deceased persons is not appropriate.        |                          |                 |              | 1 2 3 4               |
| 6. Parents should not attend his or her children’s funeral.               |                          |                 |              | 1 2 3 4               |
| 7. Talking about death in front of a dying person would accelerate death. |                          |                 |              | 1 2 3 4               |
| 8. Dying without a son is a “loss of face”.                               |                          |                 |              | 1 2 3 4               |

**Part D. Death Preparedness Behaviors**

Have you made/considered the following arrangements?

- 1. Life Insurance     1 Never considered     2 Some considerations     3 Arranged
- 2. Setup a Will     1 Never considered     2 Some considerations     3 Arranged
- 3. Organ Donation     1 Never considered     2 Some considerations     3 Arranged
- 4. Funeral plans     1 Never considered     2 Some considerations     3 Arranged

**Part E. Socio-Demographic Information (Baseline Only)**

- 1. Age: \_\_\_\_\_
- 2. Gender:  1 Male     2 Female
- 3. Place that you grew up in:  
 1 Hong Kong     2 Mainland China     3 Others: \_\_\_\_\_
- 4. Your religious background:  
 1 Buddhism     2 Ancestor worship     3 Christianity     4 Catholic  
 4 Taoism     5 Others: \_\_\_\_\_
- 5. How often do you think about issues surrounding your own deaths?  
 1 Never     2 Seldom     3 Sometimes     4 Often
- 6. Have you ever experienced the loss of a loved one?  
 1 Yes (go to 8)     2 No (End)
- 7. If yes, who is your relationship with him/her/them (can be more than one)?  
\_\_\_\_\_

**-END-**