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Liberating Dying Persons & Bereaved Families from the Oppression of Death and Loss in Chinese Societies

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Oppression of Death & Loss in Chinese Societies



Thou should not listen

非禮勿聽

Thou should not talk

非禮勿言

Thou should not see

非禮勿視

Death has become an imposing taboo leading to fear, anxiety and avoidance; whilst elaborative mourning rituals for honoring the dead consist of unspoken agendas that in reality further reinforce these taboos, producing tensions between social control and empowerment.



Oppression of Death & Loss in Chinese Societies

- **Death Taboos** – Not talking about death; no contact with the sick and dying and their family members; euphemisms of death are avoided.
- **Death Pollution** – Mortuary rites are unclean, unlucky, and contaminated by the spirit of the death; bereaved individuals are isolated and prevented from social contact.
- **Unnatural Death** – Immature deaths such as the death of children and young people are seen as punishment for one's own wrongdoings or the sins of ancestors.
- **Death Rituals** – Protect traditional moral values; safeguard family hierarchy and social status; demanding formalities and repression of emotions leaving behind unfinished business and causing family conflicts.

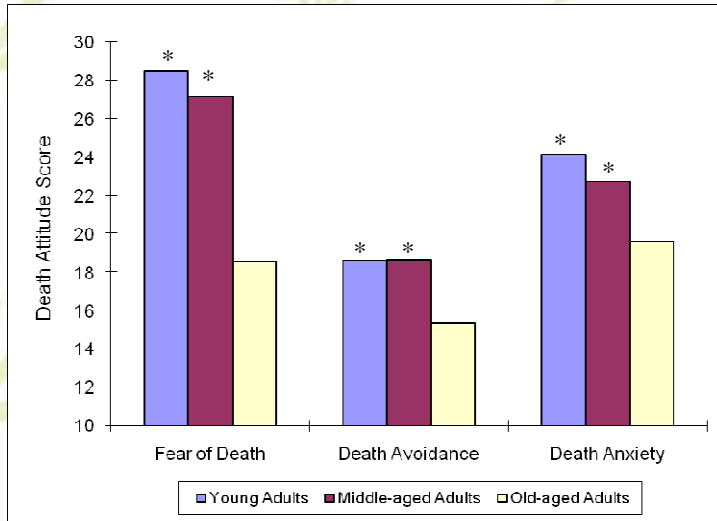


Study on the Perception of Death & Loss in Hong Kong

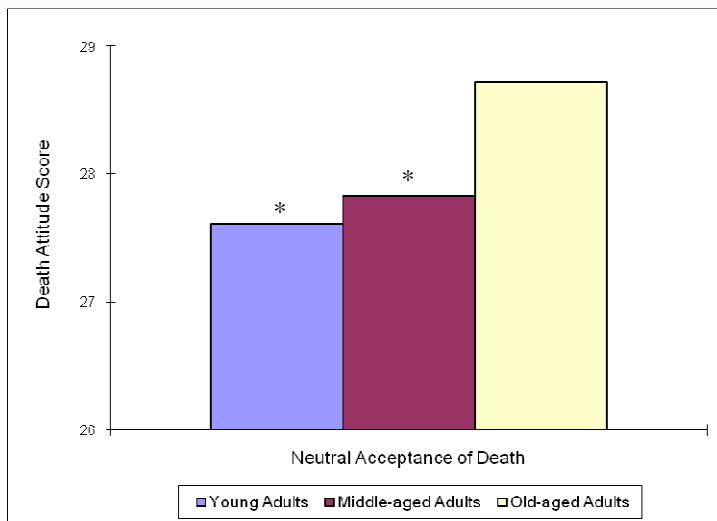
- A cross-sectional study on Transgenerational death attitudes with 792 Hong Kong Chinese residents was conducted in 2007 with the aim to better understand the current state of death perception and its relations to the oppression of death and loss across three generation groups:
 - Young adults (aged 18-29; N=327)
 - Middle-aged adults (aged 30-59; N=247)
 - Older adults (aged 60 and above; N=191)
- Participants were either asked to complete a standardized questionnaire package by self-administration or through a face-to-face interviewing format. Measures include:
 - Death Attitude Profile-Revised (DAP-R; Wong et al., 1994)
 - Chinese Version of the Death Anxiety Scale (Templar, 1970; DAS)
 - 8 items on Traditional Chinese Death Beliefs.



Perception of Death across Three Generations



- Findings reveals that both young and middle-age adults are significantly more afraid of death compared to older adults; they are also much more likely to avoid the topic of death and experience greater sense of death anxiety. Conversely, older adults are much more open in talking about death-related issues and feel less threaten by the idea of death.



- Older adults are more likely to accept death as a natural process of life compared to young and middle-aged adults. This intergenerational disparity inevitably impedes communication between adult children and elderly parents and prevents adequate preparation as one approaches death and sickness.



Perception of Death across Three Generations

Traditional Death Beliefs	Disagree	Agree
Thinking or talking about death can bring bad luck	89.0%	11.0%
Seeing a dead body or a coffin can bring misfortune	82.4%	17.6%
A painful or early death is a result of past misdeeds	83.5%	16.5%
Bereaved families should not be socially active	61.7%	38.3%
Visiting the home of the deceased can bring misfortune	83.8%	16.2%
Parents should never attend his or her children's funeral	78.7%	21.3%
Talking about death in the presence of a dying person would hasten death	76.8%	23.2%
Dying without a son is "losing face"	86.5%	13.5%

- Chinese death taboos such as 'death brings bad luck', 'bereaved families should not be socially active' and 'talking about death with a dying person will hasten death' has been transmitted across generations and are still prominent in contemporary Hong Kong.
- These taboos limit communication and open exchanges on death-related issues between dying patients and their families, limiting social support for bereaved individuals, and ultimately lead to greater misunderstanding, disharmony and resentments.



Perception of Death across Three Generations

		Fear of Death	Death Avoidance	Death Anxiety	Neutral Acceptance
Young Adults	T. Chinese Death Beliefs	0.29***	0.23***	0.12*	-0.28***
Middle-aged Adults	T. Chinese Death Beliefs	0.31***	0.27***	0.24***	-0.24***
Elderly Adults	T. Chinese Death Beliefs	0.30***	0.25***	0.20***	-0.25***

*p<.05, **p<.01, ***p<.001

- Chinese death taboos are positively associated with higher levels Fear of Death, Death Avoidance and Death Anxiety, while negatively associated with Neutral Acceptance of Death.
- These taboos prevent the exploration of life meanings and life reviews on the part of the dying patients, both of which are critical for individuals to achieve ego integrity, the last developmental task at end-of-life.



Effects on Dying persons & Bereaved families

- **Chinese people often feel powerless and demoralized in the face of mortality and loss:**
 - Families prefer non-disclosure to elderly patients with terminal illness (Fielding & Hung, 1996)
 - Dying persons and their families relies heavily on health authorities for making choices in the end-of-life (Chan & Pang, 2007)
 - Bereaved families when planning for burial and rituals often falls victims to spiritual expert with a hidden profit agenda (Cheung, et al., 2006).
- **Health care and Allied health care professionals finds themselves ill-equipped to support and assist those facing death and loss:**
 - Palliative care trainings are heavily medically-oriented
 - Lack of formal death education for frontline workers
 - Inadequate to carry out psycho-social-spiritual care



Palliative Care Development in Hong Kong

- **Through 30 years of rapid development, palliative care has become an integral part of the Hong Kong public health care system:**
 - Hospital Authority is providing comprehensive palliative care to terminally-ill patients through an integrated multi-specialties multidisciplinary service approach that aims at rendering holistic care to patients and families.
 - 10 palliative care centers and 6 oncology centre under HA to provide palliative care, which includes in-patient service, out-patient service, hospice palliative day care services, home care service and bereavement counseling.
 - Hong Kong was ranked the top 35 places with the most developed palliative care system among the 234 places assessed (Clark & Wright, 2007).



Palliative Care Development in Hong Kong

- **However, service delivery is largely dedicated to patients with incurable cancer and provided through specialist palliative teams:**
 - Service outside the mainstream healthcare system is fairly limited, and community support is scarce.
 - Individuals with other incurable illnesses and older persons with multiple chronic illnesses have little or no access to palliative care.
 - There is great reluctance amongst cancer patients themselves in seeking formal palliative services (Chan, Siu, & Leong, 2003):
 - Only 60% of all patients with incurable cancer actually received palliative services
 - Over 99% of all hospital deaths occurred in acute hospital beds with less than 1% occurring in palliative beds
 - These statistics reflect the apprehension and misconception brought about by the social stigma of death and dying



Liberating the Dying and the Bereaved from the Oppression of Death and Loss in Hong Kong

The widespread negativity surrounding death

+

The prominence of traditional Chinese death taboos

+

The gaps in palliative care provision

+

The paucity of community support

=

The need for a community empowerment programme to liberate dying people and bereaved families from the oppression of death and loss in Hong Kong.



Public Health Strategy

- **Health promoting palliative care** translates the hospices ideals of whole person care into broader public health language and practices related to prevention, harm reduction, support, education and community action (Kellehear & O'Conner, 2008):
 - To facilitate interdisciplinary partnership to expand service beyond the limits of medicine and institutional individualized care
 - To incorporate palliative care ideals into the contexts of community care, family services and all relevant human service sectors
 - To advocate social and policy changes using both a bottom-up approach from the community level and a top-down approach from the public policy level to consistently interact, inform and educate policy makers, healthcare and human services workers and the general public about concepts on death, dying, hospice and palliative care.



The ENABLE Project

The Empowerment Network for Adjustment to Bereavement and Loss in the End-of-Life:

1. Promote public awareness on death, dying and bereavement
2. Facilitate older adults as well as individuals with terminal illnesses and their family members to better prepare for death, dying and bereavement;
3. To develop and enhance the overall professional competence in palliative, end-of-life and bereavement care;
4. To established a community networking model to push forth a social movement for integrating end of life care into all levels of societies.



The ENABLE Project

Evidence-based Death Education and Community Organizing becomes the main impetus of the ENABLE project for:

- Enhancing autonomy and active participations amongst individuals and groups in facing mortality
- Create a communal platform for people to assess and reflect on their own perceived needs at the end-of-life and develop strategies to address them
- Fostering greater community involvement in the governance of death and loss in Hong Kong.



A Model for Death Education

The ENABLE 8A Model of Death Education

TTM Stages	Processes in 8A Model	State of death preparedness (Knowledge, Attitude & Practice)	Possible themes and interventions in Life & Death Education
Pre-Contemplation	Alienation	People feel indifferent to death because it is too distant.	Introduce positive terms & concepts in talking about death.
	Avoidance	People try to avoid death for it is the source of bad luck.	Nurture positive atmosphere to eliminate cultural taboos on death.
Contemplation	Access	People do not have access to information on death preparation.	Provide relevant information.
Preparation	Acknowledgement	Triggering of emotions during death preparation makes people uncomfortable.	Provide psycho-education and promote expression and acceptance of feelings.
Action	Acceptance	People treat death as a natural part of life.	Facilitate personal life review and promote sense of life integrity.
	Action	People actively involve in life and death planning.	Support implementation of action plan.
Maintenance & Transformation	Appreciation	People appreciate life and search for life meaning.	Promote personal reflections and discussions on existential and life meaning.
	Actualization	People can readjust life priorities, live in the present moment and integrate life meaning in future goals.	Facilitate forgiveness and lettingmg go of attachments; promote continuing bond and transcendent wisdom.

(Chan et al., 2010)



Community Organizing

Formation of the **ENABLE Alliance**

- To create a sense of ownership within the community that embraces existing social support networks and health care system to ensure the project's sustainability.
- A community networking model was established to integrate death education into all level of society. Emphasizing bilateral strategies and involvements:
 - 1) One-day workshop on death education for over 40 Directors & Chief of Staff of leading hospital groups, elderly care & family service units, social service agencies and NGOs , to encourage dialogue and cross-agency partnership (Top-Down)
 - 2) Multiple one-day workshop for over 200 frontline health care and human service workers, represented by the Directors and CoS in the previous events, to facilitate intellectual exchanges and commitment (Bottom-Up)





Workshop for Agency Directors and CoS



Workshop for Frontline Workers



Sharing Session



ENABLE Alliance



The ENABLE Alliance

- With over 40 members, the ENABLE alliance is to build and strengthen the connection and cooperation between organizations, and to facilitate better strategic development between the profession and academia.
- Each allied organization will pass on the knowledge of bereavement, life, and death in the community to increase public awareness, and to empower and support the dying and the bereaved when they are preparing for death and loss.
- Notable members include:
 - Social Service Division of the HKSAR Government
 - The Hong Kong Society for Rehabilitation
 - Tong Wah Group of Hospital & Caritas Medical Centre
 - The Salvation Army of Hong Kong and Macau
 - YMCA & YWCA of Hong Kong
 - Li Ka Shing Foundation Hospice Service Program



The Primary ENABLING Programme

- **Death Education to increase awareness and facilitate death preparation among the general public through a Train-the-trainer approach**
- Basic training were provided for 2,000 frontline workers whom delivered death education workshop to more than 74,000 members of the general public
- All PEP trainees received continuous support upon graduation:
 - Standard teaching protocol and booklets
 - Updates on related services and developments,
 - Research findings in death and dying
 - Further training and consultation
 - Online audio-visual resources
 - Use of Death Education Library





Death Education Workshop



Life Review Workgroup



"Sightseeing" at Funeral Parlors



Active Participation

美善
生命計劃
PROJECT
ENABLE



The Secondary ENABLING Programme

- **Specialized and Comprehensive Training to Enhance Professional Competence in the field of palliative, end-of-life and bereavement care**
- Specialized training were provided for over 300 healthcare and human service workers in relevant fields, which aimed at increasing 3 levels of professional competences including:
 - Emotional + Knowledge + Practical competence
- The SEP provided a platform for greater intellectual exchanges between professionals while strengthening inter-sector participation.
- The SEP also sparked off a series of collaborative empirical research on death and dying including:
 - Dignity at the End-of-Life (with CMC & Dr H. Chochinov)
 - Psycho-social-spiritual needs of dying patients (with LKS Foundation & Dr. R. Neimeyer)



ENABLE Website, Publications & Publicities

- **The ENABLE Website (www.enable.hk)**
 - The First Ever Online Interactive Platform on Life Planning & Bereavement Support
 - Received the 2010 Best Communicator Award from the International Academy of Visual Arts



- Publication of multiple self-help books including, “In Celebration of Life: A Self-help journey on preparing a good death and living with loss and bereavement” were widely distributed in the community
- ENABLE Symposiums on death and dying, press conferences, mass media programming including radio, newspaper and TV as well as other publicity campaigns were also carried out to raise public awareness





ENABLE Symposium 2007 - Death and Bereavement



ENABLE Symposium 2008 - Community Partnership



ENABLE Symposium 2010 - Living a Legacy



ENABLE Press Conference



Evaluation of the ENABLE Project

- Efficacy evaluation of the PEP and SEP shows that ENABLE death education and professional training models are successful in:
 - Reducing participants' fear of death and death avoidance
 - Enhancing their death-related knowledge and competence
 - Facilitating more open communication on death-related issues
 - Elevating trainees' perceived level of self-efficacy in conducting life and death education workshops with the general public
- Qualitative assessment based on written comments and dialogue exchanges between ENABLE trainees shows that:
 - The programme material and all related books, manuals and publications are informative and intellectually stimulating
 - The training contents are rich and vigorously address the general public's needs and concerns related to death and dying
 - Experiential activities and multimedia teaching materials are innovative with great practicability to facilitate interactive learning



Evaluation of the ENABLE Project

- The ENABLE Alliance has received the unwavering support from 46 leading hospitals, community service agencies and NGOs:
 - They have worked collaboratively and in harmony to promote death education in Hong Kong
 - Some have begin to develop and implement their own collaborative programmes in death education
 - Smaller social service agencies that are not part of the ENABLE Alliance have also developed their own unique end-of-life care planning activities to serve specific target groups (i.e. field trips to cemeteries and crematories for elders)
 - New community self-help and volunteer groups have been established to provide various kinds of death preparation services to the public (i.e. family portrait for elders and patients with terminal illness)

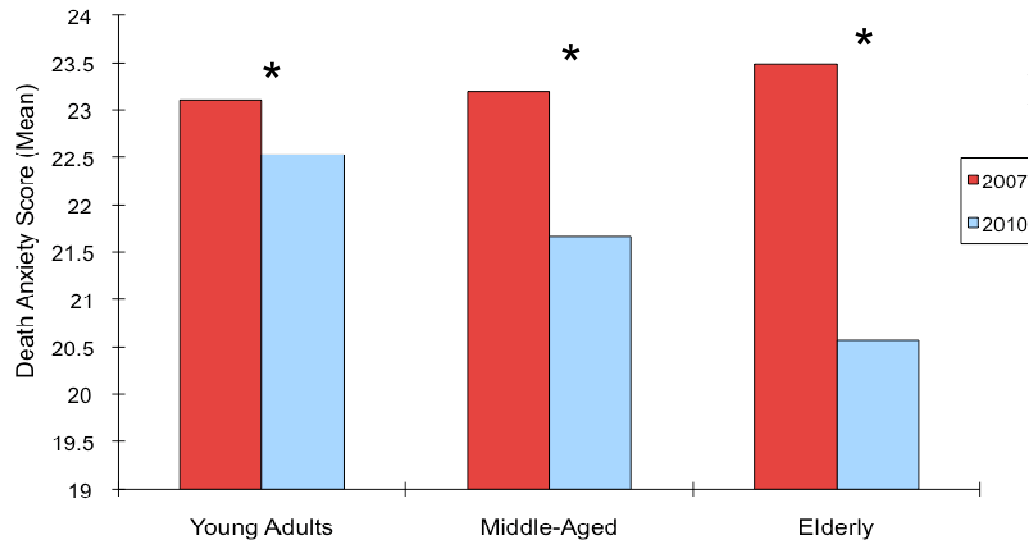


Cultural Changes brought by ENABLE

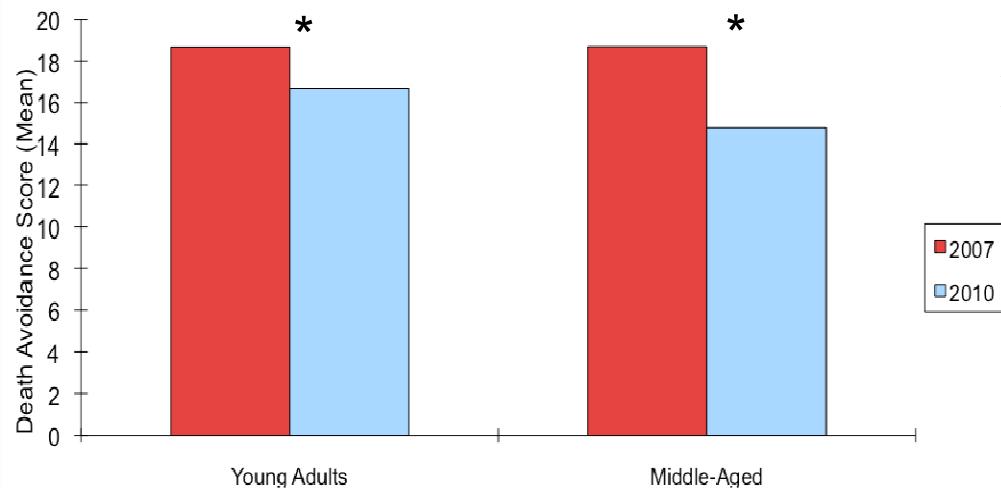
- The ENABLE team again conducted a Transgenerational death attitude study with 683 Hong Kong Chinese residents in 2010, using the same assessment tools of those from the 2007 study.
- Data collected from of 192 young adults, 359 middle aged adults and 132 elderly adults (N=683), were compared to those collected in 2007 (N=792).
- **This prospective cohort study reveals very encouraging results that show positive attitude, behavioral and social changes on death and dying amongst the general public of Hong Kong.**



Results of 3-year Prospective Cohort Study



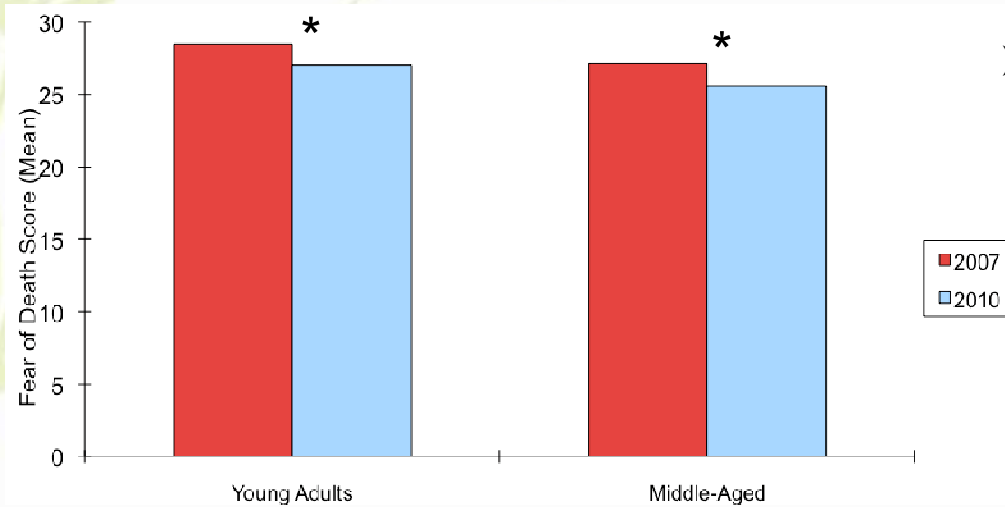
➤ All 2010 respondents, regardless of age, showed a significant reduction in their anxiety level towards death when compared to the 2007 respondents.



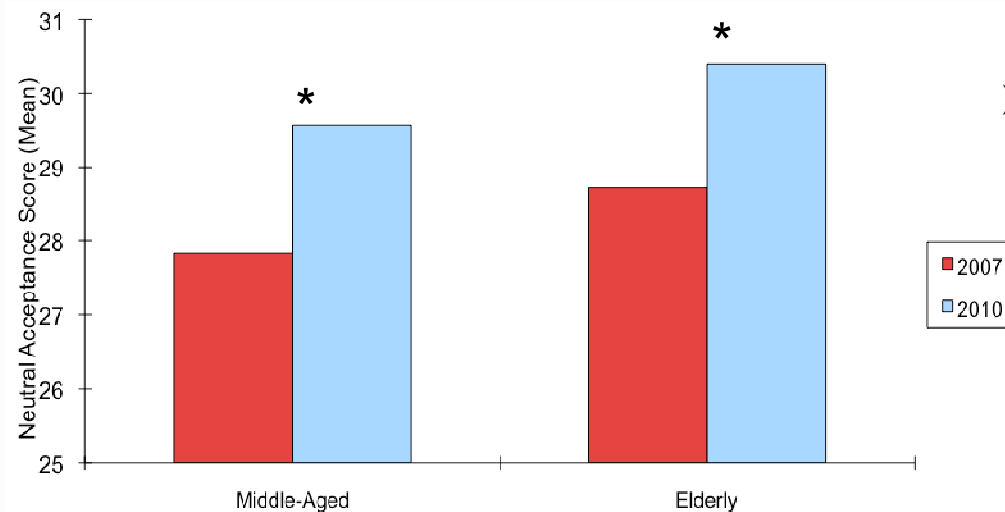
➤ Death avoidance amongst young and middle-aged adults showed a significant dropped between 2007 and 2010.



Results of 3-year Prospective Cohort Study



- Fear of death amongst young and middle-aged adults showed a significant dropped within a three year timeframe.



- Neutral Acceptance of death amongst middle-aged and elderly adults have significantly increased between 2007 and 2010.



Results of 3-year Prospective Cohort Study

	2007	2010
Traditional Death Beliefs	Disagree	Disagree
Thinking or talking about death can bring bad luck	89.0%	92.0%
Seeing a dead body or a coffin can bring misfortune	82.4%	88.4%
A painful or early death is a result of past misdeeds	83.5%	78.2%
Bereaved families should not be socially active	61.7%	68.4%
Visiting the home of the deceased can bring misfortune	83.8%	89.0%
Parents should never attend his or her children's funeral	78.7%	80.6%
Talking about death in the presence of a dying person would hasten death	76.8%	82.1%
Dying without a son is "losing face"	86.5%	93.0%

- Also, study found that more middle-aged and older adults had engaged in death preparation such as purchasing life insurance, setting up a will, making plans for burial arrangement and organ donation.
- In general, the people of Hong Kong has endorsed a more positive outlook when dealing with death related issues, while death has become less of a cultural taboo in Hong Kong.



The Way Forward

- To eradicate a long-standing 'death avoiding' 'death fearing' culture and to push forth the concept of health promoting palliative care in Chinese Societies relies not on a uni-dimensional strategy, but a comprehensive community empowerment programme guided by a public health agenda that emphasise prevention, harm-reduction and early intervention.
- Such agenda also needs to recognise that public education, professional training, interdisciplinary partnership, community ownership, research and policy advocacy, are all essential elements in determining programme success and sustainability.
- The ENABLE project offers a viable and practical framework to integrate the ideals of health promoting palliative care into a broad spectrum of society.



The Way Forward

- Our experience illuminate the vital significance of applying a public health approach in such undertaking; one that encompass :
 1. Empirical research in amplifying the voices and identifying the needs of dying people and bereaved families
 2. Development of evidence-based public death education and specialist training that enhance personal autonomy and professional competency in the face of mortality,
 3. A social networking regime to facilitate community involvement, empowerment and participation in the governance of death and dying.



Thank you.

For more information,
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Or visit: www.enable.hk

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