Health-Promoting Dignified Palliative Care
The Application of Social Media and Information Technology in Life and Death Education

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There is now growing awareness among the profession that dying patients and families must not only be cared for and feel comfortable in the last phases of life:

- There is a renewed commitment to “the affirmation of life”
- Palliative care is characterized as care that “honor and protects those who are dying, and conveys by word and action that dignity resides in people”
- Dignity through Compassionate Care has become the overarching goal that dictates the delivery of palliative and hospice services to advanced cancer patients and their families facing the end-of-life.

Hospice and palliative care has become an integral part of the Hong Kong public health care system.

- Hospital Authority is providing comprehensive palliative care to advanced cancer patients through an integrated multi-specialties, multi-disciplinary service approach.

Hong Kong ranked 20th out of all 40 regions investigated, lagging behind both Taiwan [14th] and Singapore [18th], with the UK [1st] and Australia [2nd] leading the way.

Hong Kong: Current State of the Problem

1. Negative cultural attitudes towards death
2. Absence of a Government-led National palliative care Strategy
3. Low availability of hospice and palliative service for a aged (and rapidly aging) population
4. High financial burden of patients and families requiring End-of-Life care
5. Insufficient public awareness of End-of-Life care
6. Lack of volunteer workers for End-of-Life care support

Has dying well and with dignity become a privilege?

Local Study on Dignity: A Critical Review of Service & Policy

A Triangulation of Data Sources:

1. Meaning-oriented Interviews with 18 Chinese terminal-cancer patients (8 living in nursing homes, 10 living at home) and 18 of their Family Members to elicit narratives of their illness and service experiences
   - All interviews were digitally recorded, transcribed verbatim, edited for accuracy and coded independently by 3 researchers using the framework method qualitative analysis – deductive approach
2. Ethnographic Data including clinical observations, field notes and researcher reflexivity
   - To provide supplementary information about the meaning and the context of the interviews as well as those concerning the interviewees
3. Comparative Analysis on existing policies
   - To provide a framework of reference for understanding and contrasting palliative care provision and service regulations in Hong Kong
Findings from Narratives and Reflectivity

**Fragmented levels of palliative services within hospitals and the greater public health sector:**
- “The nurses and doctors at the palliative care unit are the kindest souls. They take their time in telling me every details about my cancer and how my children can help to me to feel better.”
  
  (78 year-old home-dwelling patient)

- “Things change quickly once you are outside of the palliative department, your everyday nurses and doctors just don’t care.”
  
  (58 year-old caregiving daughter)

- “I told the doctor (outside of PC) that my father feels a great deal of pain at night and all he said was, “the x-ray looks fine, there is nothing wrong” and he never even looked me in the eye!”
  
  (30 year-old caregiving son)

**Findings from Comparative Analysis**

**Great disparity between policy of palliative care provision and regulations of LTC institutions.**
- Section 3.1 of the Code of Professional Conduct of the Medical Council of Hong Kong (54 pages) stated that:
  - “Where death is imminent, it is the doctor’s responsibility to take care that a patient dies with dignity and with as little suffering as possible…”
- Section 11.5.5 of the Code of Practice for Residential Care Homes of Hong Kong (59 pages) stated that:
  - The dignity and privacy of each resident should be respected…
    Process such as screen or curtain should be used during delivery of personal care services, including bathing, change of clothes…etc.”
- Section 11.6.3 further stated that:
  - “The right to live in dignity and to have freedom of movement should always be taken into consideration…”
  - When applying physical constraint to a resident.”

Findings from Narratives and Reflectivity

**Remarkable high cost of and poor care quality at the EoL rendered through private long-term-care institutions**
- “My life revolves around the working routine of the nursing home and schedule of their staffs... I have no privacy whatsoever.”
  
  (36 year-old male nursing home patient)

- “They (nursing home) charge me $200 each time their staff accompany my father to a doctor visit. He lives just around the corner from the doctor’s office…. They charge you even more if you need to go the hospital.”
  
  (46 year-old caregiving daughter)

- “The first thing that I noticed was the smell… an elderly man without pants was lying naked in his bed while others next to him were having dinner. They are treated like beggars… being feed like dogs… a total living hell.”
  
  (57 year-old caregiving son)

A Public Health Strategy

- Integrate palliative care into all levels of society through a Public Health Strategy that facilitates bilateral involvements:
  - a bottom-up approach starting from the community level
  - a top-down approach starting from the public policy level

- Advocates and community organizers to commit themselves to interacting with policy makers, health care professionals and the general public on a consistent basis.

- An Ecological Approach that involves all facets of society.

Health Promoting Palliative Care (HPPC)

- HPPC translates the hospice palliative ideals of whole person care into broader public health language and practices that relate to prevention, harm reduction, early intervention, education, community development and partnership.
  1. Enhancing autonomy and active participations amongst individuals and groups in facing mortality;
  2. Creating 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; and ultimately
  3. Fostering greater community involvement in the governance of death and loss to preserve dignity at the end-of-life.
HPPC via Information Technology & Social Media

Launched in April 2011, the aims of HOSPICEHOME.HK are:

1. To establish an online interactive platform to facilitate knowledge transfer, communal support and resource creation in palliative hospice care;
2. To facilitate experience sharing among healthcare and allied health workers, and volunteers in the field of palliative hospice care so as to advance the quality of service provision;
3. To enhance self-care and caregiving competence amongst advanced-cancer patients and their families so as to relieve distress and improve their overall quality of life; and
4. To enhance greater social awareness on issues concerning palliative hospice care in the context of Hong Kong.

讓不幸的患者依傍著關懷的臂彎走畢人生的旅程，也讓他們疲憊的家人得到慰藉，讓愛心為患者映亮出一道美麗的最後風景。
Resource Library (資料室)

1) Palliative Care Data Base
2) Book Reviews and Recommendations
3) Web Links and Downloads
4) Community-Based Support Networks

我感到無助,坊間有什麼機構可以協助我?

醫生跟我說媽媽得了末期絕症,我應不應該告訴她?

該如何告訴她?

我朋友的爸爸因病去世,我很想幫上一點忙,但不知道該做些什麼才好?

我該如何跟家中的小孩子解釋什麼是死亡?

E-learning videos on the physical, psychological emotional and spiritual needs and concerns of palliative care patients and their families.

E-Learning Corner (自修室)

Self-Assessment Tools (自助測試工具)

4 Simple online self-assessment tools with instance feedbacks for patients and families to better understand and manage their psycho-social needs.

- Hospital Depression & Anxiety Scale
- McGill Quality of Life Questionnaire
- Patient Health Questionnaire
- Caregiver Self-Assessment Questionnaire

Share & Involve

A place for Patients, Families, Health and Allied Health Professionals, and Volunteers to share their experiences and insights to all members of the public so as to promote greater communal awareness, understanding and compassion.

Hearty Blogs (打開心窗)

A place of love and creativity

E-couragement (憑片寄意)

Encouragement and Support through Short Videos
A place of love and creativity
Remembering Life (窝心窝)

- An online interactive engagement that enables patients and families to carry out a self-help life review exercise to achieve ego-integrity and a sense of completion at life's final margin.
- Based upon the life course model and through the articulation and assimilation of photos and stories, users can share the beautiful and bittersweet memories of their lives with their families, friends as well as the public.

Interact & Support

Lonely no more (不再寂寞)

- Online Forum for facilitate dialogue and knowledge exchange between patients, families and professional carers.
- Forum topics include:
  - Cancer Survivors 癌症同路人
  - Living with Cancer 癌症與生活 – Diet, Exercises, Social Activities
  - Self-help Discussions自理心得 – Stress, Emotions, Pain

Wish You Well (祝安好)

- 10 Free E-cards for spreading love and support.

Volunteer Registration (网上義工登记)

- Registration Process:
  
  Online Registration Form → Hospice Centres

Community Education (社區教育)

- Public Education and Life Review Workshops were rendered in the community for patients and families, health and allied health professionals, volunteers.
- More than 450 people had attended these public talks and workshops.
- Participants feedback:
  - 90% will visit the website
  - 60% will register an account
  - 84% will recommend the website to others
  - 100 of them left email address for further contact
Societal-Wide Campaigns

Short Film Competition & Social Media

Multi-Agency Involvement

Use of Social Media

- Internet-based tools for creating, sharing, and discussing
- Facebook (online promotion); YouTube (video hosting)

Web-Based Short-Film Competition

「未知死，焉知生」短片比賽

101 entries (35 secondary, 32 tertiary, 34 open)

Voting Period Website Hitrate (Within 1 week's time)
- 11,680 Site Visits
- 119,137 Page Views
- 115,23 Registered user

Public Wide Involvement
Further Promotional Materials & Publications

Promotion Leaflets  Life Review Book  Press & Media

Overall Achievements

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The Way Forward

- Health promoting palliative care facilitate active engagement from all members of society to create a sense of ownership within the community that embraces existing social support networks and health care system
- Effective utilization of Information Technology and Social Media can ultimately ensure the sustainable development of dignified palliative care for liberating dying individuals and bereaved families in the 21st century.

Thank you!
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