Dignified Care in LTC Settings:
A Systemic-Interpretive Framework for Community-Based End-of-Life Care Pathway in Hong Kong

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The Challenges of an Aging Population

- Persons aged 65+ is projected to increase from 13% of total population in Hong Kong in 2009, to 28% in 2039, accounting for more than 2.4 million people

World ranking: 1/195

Life expectancy at birth:
83.42 years

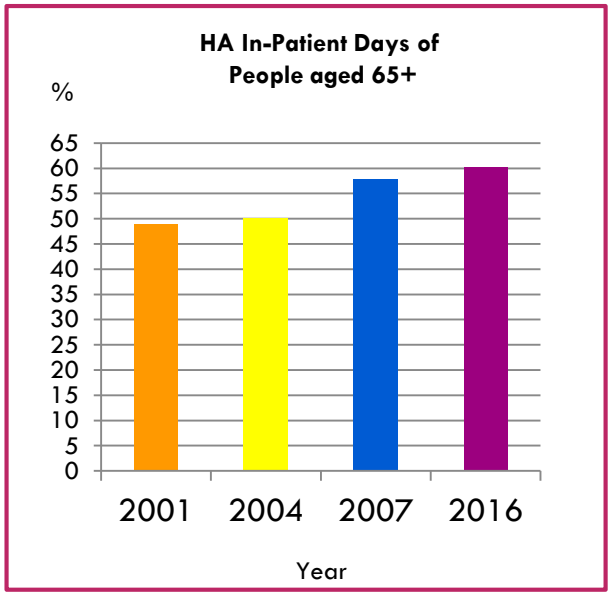
World ranking: 2/195

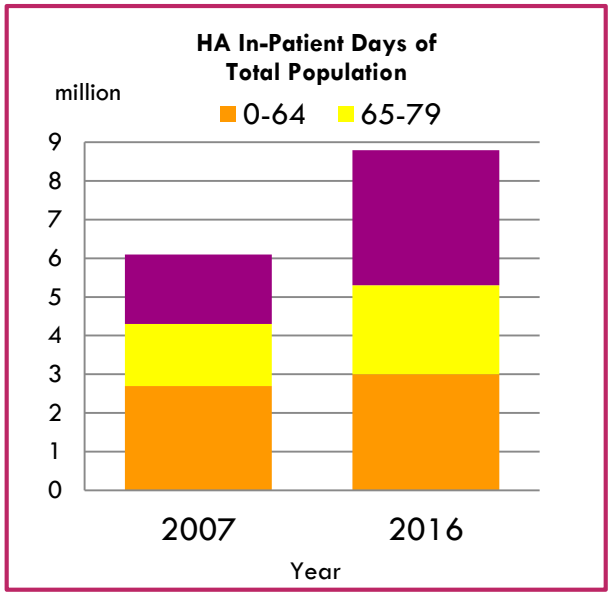
Life expectancy at age 60:
25 years

Global AgeWatch (2013)

Old Age Dependency & Health Care Needs

- Under the context of population ageing, **elderly dependency ratio** will dramatically increase from 180 to 450 in the next 30 years





- Currently, the Institutional rate of people aged 65+ stood at **6.8%**

  Compared to 2.8% in Japan, 2.9% in Singapore, 1.4% in Taiwan

Hospital Authority (2009)

Integrated End-of-Life Care Pathway Strategy

Integrated End-of-Life Care Pathway Strategy has emerged as the gold standard of holistic and dignified care for older people facing terminal illness.

- Multidisciplinary person-centered care
  - Improving care and support for dying patients in the final years of life
  - Starting as early as terminal diagnosis and continuing into bereavement
- A System-wide community-based approach
  - Moving beyond hospitals to include all health and social care agencies
  - Promote best practice, standardized care, multi-agency collaboration

National Health Services (2007)

晚晴照顧先導計劃

EoL Care Pathway for RCHE in HKWC

In 2009, the HKWC Community Geriatric Assessment Team, together with the TWGHs Jockey Club Care and Attention Home, Queen Mary Hospital and TWGHs Fung Yiu King Hospital piloted the **"End of Life Program for RCHE in HKWC"**.

- Providing Palliative Long-Term-Care to RCHE residents with irreversible chronic medical diseases and terminal Illness via a Structured End-of-Life Care pathway
  - Established upon existing medical and psycho-social care framework
  - Residents remain in a familiar environment during their last days of life
  - Manage care transition between RCHE and Hospitals
  - Reduce acute hospital admissions
  - Facilitate a dignified death

AED Pathway & FYHK Pathway

- Queen Mary Hospital Accident & Emergency (AED) Pathway (N=10)
  - AD and DNR are discussed and made to patients' electronic medical records
  - Patients receive care at the RCHE until their very last moment of life
  - Thereafter, transfer to the AED of Queen Mary Hospital
  - Involved medical staffs respect patients' wishes and autonomy
  - Death certificates are issued by the hospital to prevent unnecessary postpartum
  - Body is stored at the QMH mortuary and transported directly to funeral homes

- TWGHs Fung Yiu King Hospital (FYKH) Pathway (N=32)
  - Patients receive care at the RCHE until their last days of life
  - Transfer to the palliative and hospice ward of FYKH through an expedite pathway until they pass away
  - Death certificates are issued by FYKH where the body is stored until being transported to the funeral home

Current Study: Systemic-Interpretive Framework

A total of 32 RCHE residents have participated in programme, 10 in the AED Pathway and 32 in the FYKH Pathway. 3 residents had passed away with peace and dignity.

- System-Interpretive Focus Groups with multiple-levels stakeholders
  - To examine the concept of dignified care in LTC settings from multiple perspectives
  - To explore the 1) inter-relationships, 2) perspectives, and 3) boundaries between different stakeholders and institutions that either enhance or impede decision making, care coordination, service delivery and programme implementation
  - To provide a platform for multiple interpretations and debates on a single phenomenon from different system perspectives
- Data collection & analysis
  - All focus groups were conducted between October 2011 to April 2012
  - Each focus group was 90-120 minutes long, they were recorded, transcribed verbatim, edited for accuracy and coded independently by 3 researchers using Framework Analysis

Fuenmayer (1996a, 1996b)

Characteristics of Focus Groups Participants (N=30)

Stakeholder Groups	Male:Female Ratio	Stakeholder Roles
Service Users (n=6)	3:3	Family Caregivers
RCHE Staffs (n=6)	1:5	3 Social Workers 2 Personal Care Workers 1 RCHE Supervisor
Medical Professionals (n=9)	4:5	4 Geriatric Nurses 2 A&E Nurses 3 Doctors
Management Administrators (n=9)	4:5	1 Government Official 1 Health Professor 3 Hospital Superintendents 1 Hospital Supervisor 1 Hospital Manager 1 Hospital Cluster Chief 1 Hospital Chief Executive

Themes Emerged from Focus Groups

10 themes that elucidated the system dynamics required for successful implementation of dignified community-based EoL care pathway in Hong Kong have emerged from the analysis. These 10 themes are further organized into 3 major categories.

1. **Regulatory Empowerment**
   - Interdisciplinary Teamwork
   - Culture Building
   - Resource Allocation
   - Collaborative Policy Making
2. **Family Centered Care**
   - Continuity of Care
   - Care Partnership
   - Family Care Conference
3. **Collective Compassion**
   - Devotion in Care
   - Compassionate Action
   - Empathic Understanding

Interdisciplinary Teamwork

Interdisciplinary Teamwork includes the standardization of care procedures through effective communication and support between different care professionals, as well as enhanced care management coordination across all involved agencies.

"We need to strengthen the system of communication between different care departments including the RCHE, the hospital as well as ambulance services, so that when a patient has registered for the EoL care pathway program, every care personnel involved knows about it and can take appropriate actions for best possible care rather than introducing unnecessary medical procedures."

Natty [Nurse, Medical Professionals group]

Resource Allocation

Resource Allocation includes enhancing patients' privacy and greater accessibility to medical care, as well as the need to allocate more funding to sustain a consistent team of personal care workers in RCHE.

"One of the reasons why our EoL care pathway program has been successful is because we are collaborating with a nearby hospital; this reduces the time and space between nursing home care and medical care, making medical services much more accessible to our patients."

Josh [Doctor, Medical Professional group]

Culture Building

Culture Building includes the development of more knowledge capital in palliative long-term-care care via life and death education for professional caregivers, patients and their families.

"We need to educate patients and families early on in their illness trajectory about palliative care, starting with frontline staff training at RCHEs and hospitals, and have them pass on the knowledge to the patients and families that they serve… letting them know how to prepare for death with peace and dignity."

Jose [Hospital Manager, Management Administrators group]

Collaborative Policy Making

Collaborative Policymaking includes management support and leadership, evidence-based practice to guide program development, as well as a government-led policy initiative with a sustainable legal structure that supports EoL Care Pathways.

"I believe having a supportive leader is fundamental as workers need to know that they have someone to depend on when dealing with life and death situations… We also need to build up a strong data base to show the work that we are doing is useful and meaningful, this is the only way to obtained more funding and policy support."

Kathy [Supervisor, RCHE Staffs group]

Continuity of Care

Continuity of Care considers the patient and family as one unit of care, placing them at the forefront of holistic and personalized EoL care planning and deliver with one consistent care team for achieving the best care outcome possible.

"I think the consistency of care a patient receives is very important… If my wife is not in the EoL care pathway programme, she will need to go to different hospital departments to get the care that she needs… All the traveling, the waiting, the need to go to A&E can be very taxing… It is wonderful that my wife can receive all the care that she needs with the same care team."

Peter [Family Caregiver, Service Users group]

Family Conference

Family Conference requires professional care teams to meet and communicate accurate information with patients and families constructively with utmost respect and dignity, empowering them to reach care consensus that best address their needs.

"Family members play a critical role in the overall planning and delivery of EoL care, we involve them as much as we can in the care decision making process. We hold regular care conference with patients and famlies… and we organize of our work around their needs and wishes… It is imperative that we respect their choices."

Fong [Geriatric Nurse, Medical Professionals group]

Care Partnership

Care Partnership encourages patients and families to be actively involved and participate in every level of care, as their unique strengths are recognized and honored by their professional care team for forming care partnerships.

"Every patient and family are unique, they have their needs as well as their strengths. We have to identify their strengths and work with them as a team towards building it… We want them to be strong psychologically and emotionally so that they can support themselves during difficult times…"

Kathy [Supervisor, RCHE Staffs group]

Devotion in Care

Devotion in Care entails stakeholders' undivided devotion to achieving dignified care for dying patients and their families at the end-of-life.

"I think we are involved in this project because we all have a passion to help those facing death and dying, rather than a set of laws and regulations that requires us to … We all shared the same devotion and passion in helping elderly patients and their families… It will not work if don't share the same vision, the same passion."

Mann [Hospital Supervisor, Management Administrators group]

Empathic Understanding

Empathic Understanding requires stakeholders to truly understand the worlds of those facing mortality so as to derived at shared, relational understanding on the experience of death and dying.

"Being involved in the EoL care pathway program allowed me to see things from multiple perspectives, seeing things from my patients' eyes had opened my eyes… I now know what I want when I reached the age of my patients… In a way, I am setting my own path and helping myself in later life by pushing forth this meaningful program."

Hailey [Hospital Superintendent, Management Administrators group]

Compassionate Actions

Compassionate Action requires all stakeholders to act in harmony and in unison to provide dignified care to dying patient at the end-of-life.

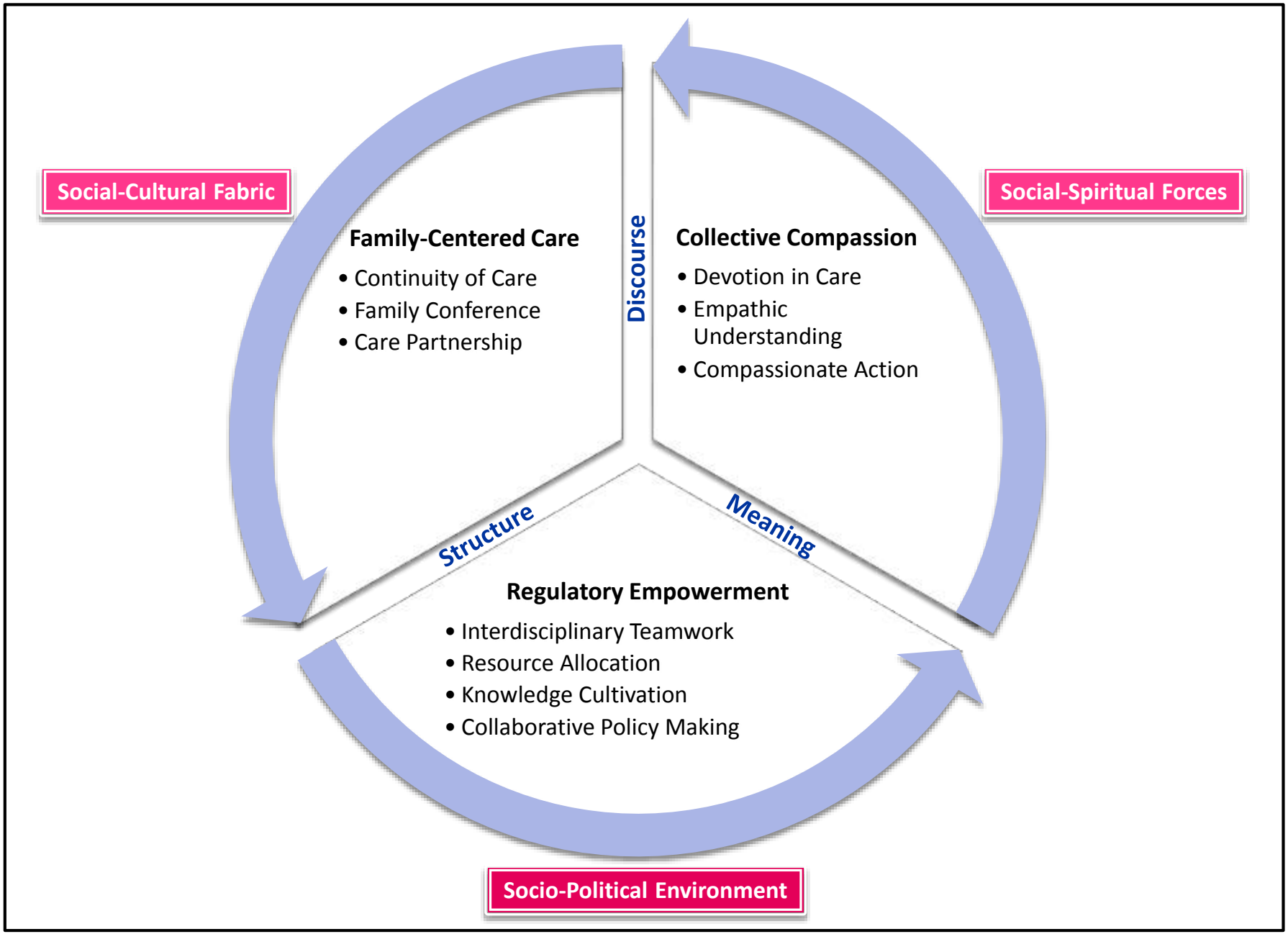
"Everyone of us has put a lot of effort into this, as we really do want to make a difference in the lives of our patients… And we can clearly see the changes and benefits, that the quality of life of older dying patients have improved at the end-of-life because of the care pathway programme."

Wendy [Doctor, Medical Professionals group]

Frequency of Themes & Categories Occurrences

	Service Users (n=6)	RCHE Staffs (n=6)	Med. Professionals (n=9)	Man. Administrators (n=9)
Interdisciplinary Teamwork	6	8	18	5
Resource Allocation	10	8	18	33
Knowledge Cultivation	3	21	10	8
Collaborative Policymaking	2	9	24	44
Regulatory Empowerment	**21**	**46**	**70**	**90**
Continuity of Care	13	13	19	6
Family Conference	10	7	9	4
Care Partnership	10	9	4	2
Family-Centered Care	**33**	**29**	**32**	**12**
Devotion in Care	22	20	28	22
Empathic Understanding	19	17	16	12
Compassionate Action	18	16	12	16
Collective Compassion	**59**	**53**	**56**	**50**

An Interpretive-Systemic Framework for Community-Based EoL Care Pathway (Ho, 2013)



Discussion

Promoting Dignified Palliative Care in LTC Settings

To push forth the aspiration of dignified care, **a common discourse** is needed among all stakeholders involved in the EoL care pathway program, one that penetrates all layers of structures and boundaries within a health and social care system.

- Discourse serves as an important channel of power and social control that governs interactions and dynamics between different societal members (Foucault 1926-1984; Barth, 1998; Powell, 2011)
- The discourse of **Compassion** can provide a connecting platform for all stakeholders to:
  - Share concerns openly with understanding
  - Build trust and partnership
  - Derive at a resolution that would addresses that needs of all parties

Conclusion

- The notion that long-term care facilities will become future hospices to care for older terminally ill people is fast becoming a reality.
- The sustainability of palliative long-term-care rested upon:
  - Holistic health care policies and practices that are rid of the pragmatic piecemeal approach
  - Commitment to the promotion of healthy ageing with that of appropriate end-of-life care
  - A public health discourse of compassion for it reminds us of our cultural, spiritual and political responsibilities towards one another in our shared experience of death and morality

Kellehear (2005); Kellehear & O'Conner (2008)

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Thank you.

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This body of work is funded by the Seed Funding Programme for Basic Research (Ref no: 201111159126) of the University of Hong Kong.
We would like to express our deepest appreciation and gratitude to all of our participants for sharing their stories on life's most precious moments; this has truly been a rewarding and humbling experience.

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