

System Dynamics in Community Care Pathways at the End of life: A Hong Kong Experience

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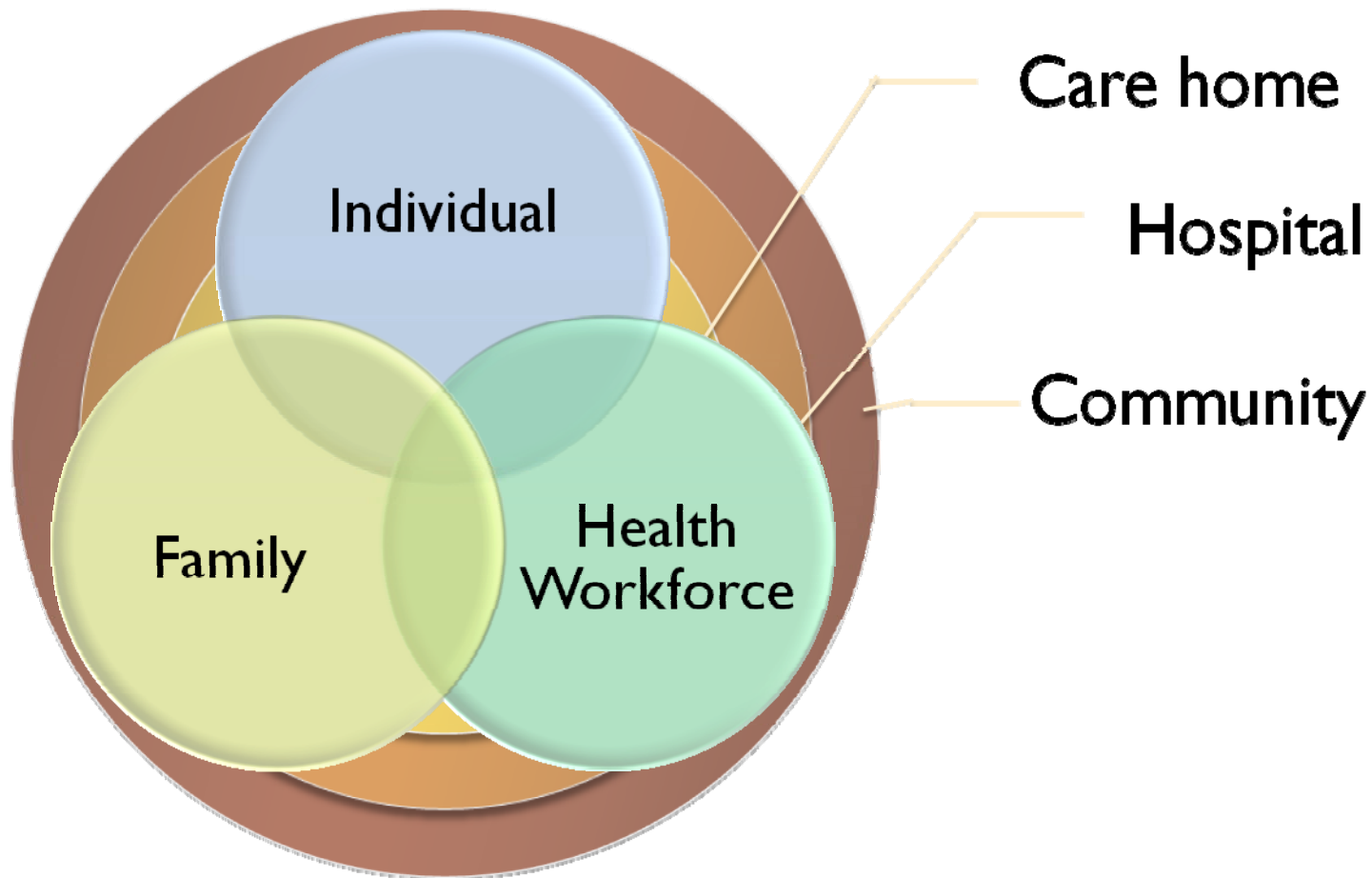
7th June, 2011

Background

- ▶ Hong Kong's population is aging: 12.4% in 2006, expect to increase to 24% by 2031
 - ▶ Around 70 000 currently live in residential care homes for the elderly (RCHE)
 - ▶ When residents get sick, RCHE usually send them to acute hospital: 10% will eventually die in hospitals
 - ▶ BUT, study showed 28.8% of RCHE resident prefer to stay in RCHE till last days of life
 - ▶ Better EOL care planning (e.g. advanced directives) is necessary
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Background: Participants in EOL care



Background: Decisions in EOL care

- ▶ Forms of decisions:

- ▶ advanced directives
- ▶ resuscitative efforts
- ▶ life-sustaining treatment

- ▶ Phases of decision making:

- ▶ Recognition of futility
- ▶ Coming to terms
- ▶ Shouldering role of decision maker
- ▶ Facing the question

- ▶ Strategies used:

- ▶ Protecting life
- ▶ Creating comfort
- ▶ Relying on religion
- ▶ Honouring wishes
- ▶ Seeking guidance



Background: Decisions in EOL care

- ▶ Factors affecting EOL decisions:
 - ▶ clarity of patient's preference
 - ▶ certainty of prognosis
 - ▶ family's perception of suffering
 - ▶ family's attitude
 - ▶ family management style
 - ▶ physician's attitude
 - ▶ existing legal framework on EOL decisions

- ▶ **Trust and Communication is crucial!**



Background: Missing piece of puzzle

- ▶ **Most research comes from literature on:**
 - ▶ Critical care setting (e.g. ICU)
 - ▶ Terminal cancer
 - ▶ Western cultures

- ▶ **What about:**
 - ▶ Care setting that is also home of patient? (e.g. RCHE)
 - ▶ Chronic illness?
 - ▶ Culture who place more emphasis on family?



“Dying-in-Home” pilot scheme

晚晴服務試驗計劃

- ▶ Held in collaboration with TWGHs Fung Yiu King Hospital at the Jockey Club Care and Attention Home
- ▶ Put forth the “dying-in-RCHE” initiative
- ▶ Since 2009, provided palliative service for 23 residents (advanced cancer, organ failure, advanced dementia)
- ▶ 7 residents have chose the “dying-in-RCHE” option, two of them passed away peacefully in 2010



Research objectives

- ▶ What are the experiences of these residents in C&A home in making EOL care decisions?
- ▶ Role of family in EOL care decision making?
- ▶ Ideally, EOL care decisions are made in collaboration between 3 parties (residents, family, healthcare workforce):
 - ▶ what are the system dynamics?
 - ▶ sources of conflicts?
 - ▶ what help to release tension, and what make things worse?
 - ▶ what more can we do to extend this scheme to other settings?



Methodology

- ▶ Qualitative approach
- ▶ Purposive sampling – parties involved in the “Dying-in-Home” scheme
 - ▶ Residents & family members
 - ▶ Health workforce – doctors & nurses
 - ▶ Allied health professions – e.g. occupational therapists, speech therapists, clinical psychologists
- ▶ Data collection:
 - ▶ Interviews
 - ▶ Focus groups



Research objectives: how we want to impact with this study?

- ▶ Develop a culturally relevant framework to understand family and system dynamics in EOL care decision making in Hong Kong, especially residents in less acute settings
- ▶ Provide culturally relevant information for developing guidelines and intervention for holistic palliative care practice for Chinese patients.
- ▶ Providing information that examines existing policy in healthcare settings that may have prevented patients from experience “quality death”.



Thank you for listening!

