



Service Priorities and Programmes
Electronic Presentations

Convention ID: 43

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Experience from establishing a “Community-based End-of-Life Integrated Care Pathway Program” for dignified end-of-life care

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Keywords:

Community-based End-of-Life Integrated Care Pathway
dignified end-of-life care

Introduction

Promotion of dignity is one of the major goals in palliative care. End-of-Life Integrative Care Pathway (EoL-ICP) has emerged as the gold standard for holistic and dignified care for older terminal-ill patients. Founded upon the principle of multidisciplinary person-centered care, EoL-ICP utilizes a system-wide approach to provide elders approaching EoL with quality health and social care that is well planned and coordinated while being responsive to individual needs and wishes.

Objectives

This study critically examined a local community-based EoL-ICP program that effectively manages care transitions between residential care homes (RCHes) and hospitals to enhance care quality and promote dignity at the EoL. Drawing upon the experiences of policy makers, medical administrators and health professionals, this study explored system dynamics and identified inter-relational factors between different institutions and stakeholders that affect the implementation of EoL-ICP in Hong Kong.

Methodology

Using purposive sampling, 15 government officials and executive personnel involved in the planning and consultancy of the “EoL Program for RCHes in Hong Kong West Cluster” were recruited to participate in a focus group interview. Guided by the interpretive-systemic framework of inquiry, the focus group provided a platform for multiple interpretations and debates on a single phenomenon from different system perspectives. The interview was recorded and transcribed verbatim was analyzed using thematic analysis.

Result

Three major systemic-themes with relevant sub process-themes have emerged from the analysis. These include: 1) Legislative Challenges pertaining to Death Certification, Advanced Care Planning and Political Priority of Public Health; 2) Care Continuum Challenges pertaining to Service Coordination, Infrastructure Boundaries and

Institutional Partnerships; and 3) Service Provision Challenges pertaining to Informed Decision Making, Staff Knowledge, and Public Awareness. There was a general consensus that EoL-ICP is important as human dignity ought to be upheld at the EoL. However, there were various views between different stakeholders over the needs and priorities on how and why EoL-ICP could and should be implemented. The tension between clinical governance and bureaucratic accountability clearly underscored the vital importance of government leadership in such undertaking. Moreover, against the backdrop of a rapidly aging population, increasing prevalence of chronic illnesses, as well as greater prominence over patients' autonomy and care quality, a government-led initiative on "palliative long-term-care" is imminently warranted. Overseas examples of best practices for integrating EoL-ICP into long-term-care settings will be discussed for illuminating sustainable development of EoL care in Hong Kong.