

CHAPTER 14

CHANGING MINDS AND COMMUNITIES: THE USE OF INNOVATIVE STRATEGIES IN COMMUNITY ENGAGEMENT FOR END-OF- LIFE CARE IN HONG KONG

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This chapter outlines how a health promotion approach in end-of-life care (EoLC) can be applied to developing compassionate communities and better engaging communities in EoLC in Hong Kong.

BACKGROUND

THE HEALTH PROMOTION APPROACH IN EoLC

Life-threatening illnesses touch not only the patient, but also their family caregivers and the community around them. Byock et al. (2001) described the experiences of serious illness, dying, caregiving, grieving and death as “personal, but also fundamentally communal”. A large volume of evidence has demonstrated that patients and caregivers at the end-of-life face tremendous physical, psychosocial and spiritual challenges, including anxiety, depression, existential crisis and other forms of psychiatric disorders (Badr, Smith, Goldstein, Gomez & Redd, 2015; Dumont et al., 2006; Mehnert et al., 2014; Rumpold et al., 2016; Zabora, BrintzenhofeSzoc, Curbow, Hooker & Piantadosi, 2001). The health promotion approach to EoLC considers the challenges faced by patients and caregivers, such as loneliness, stigma and other social issues. These are best addressed by friends, neighbours or community members instead of healthcare professionals (Sallnow, Richardson, Murray & Kellehear, 2016).

The health promotion approach to EoLC originated from the Healthy Cities concept by the World Health Organization (WHO) (Kellehear, 2005). The Ottawa Charter for Health Promotion in 1986 stated that:

health is created by caring for oneself and others, by being able to take decisions and have control over one’s life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members (WHO, 1986)

Five health promotion actions were identified:

1. Highlighting the important role of engaging the community in building healthy public policy;
2. Creating supportive environments;
3. Strengthening community actions;
4. Developing personal skills; and
5. Reorienting health services (WHO, 1986).

Kellehear first incorporated health promotion principles in 1999, when building the movement for compassionate communities to improve health and well-being for patients and families living with life-limiting illnesses (Kellehear, 2005). The movement encompasses large-scale, international and social efforts by communities, governments, state institutions and social or medical care organisations (Sallnow et al., 2016).

Death is now recognised as a natural process of human life that should not be hastened, nor life prolonged (Kellehear, 2005). A life-course perspective for integrative EoLC throughout disease evolution has been proposed (Gómez-Batiste et al., 2017). EoLC, in particular, is conceptualised as a series of changing needs through different stages of a patient’s life. As a patient progresses from diagnosis of a life-limiting illness to death, his/her needs for disease-modifying and supportive care decrease, while palliative care (PC) needs increase.

Bereavement care for the patient's loved one after the patient's death is also included as part of EoLC, which is consistent with the WHO's definition for PC as: "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses" and should aim to offer "a support system to help the family cope during the patients' illness and in their own bereavement" (WHO, 2002).

THE ESSENCE: COMMUNITY ENGAGEMENT IN EoLC

The key to supporting a life-course approach to integrative EoLC is community-wide effort and collaboration among different professionals and community members. Abel et al. (2013) proposed a community-centred model that envisions the patient as the centre of a series of concentric circles of care. The Circles of Care model "appreciates the persons with illness in their everyday context of living within their communities" (Abel et al., 2013, p. 385). Patients living with life-limiting illnesses are supported by an inner circle consisting of a small group of family and friends. The inner circle is supported by an outer circle of a larger group of family, friends and neighbours; and this outer circle is supported by a further circle of community networks, health and social care professionals in care systems, and social security and policy frameworks. The model emphasised a de-professionalised approach in EoLC that patients, family members, health and social care team members, and all community members participate as partners in the caring process in ways that enhance meaning and value (Abel et al., 2013).

The unique contribution of community in EoLC is acknowledged; however, the question remains as to how to effectively engage the community. The WHO noted that education is one of the core pillars supporting the development of a public health PC model, articulating the need for community capacity building through media and public advocacy, and family caregiver training and support (Stjernswärd, Foley & Ferris, 2007). Sallnow & Paul (2014) considered community capacity building to be embedded within the community engagement process, which "enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related well-being" (Sallnow & Paul, 2014, p. 233). The authors emphasised that EoLC should move beyond "working in the community" to "working with the community" (Sallnow & Paul, 2014, p. 233). They specified a spectrum for community engagement, including information, consultation, co-production, collaboration and empowerment, with a range of factors inhibiting and/or supporting the process. The later work of these authors summarised existing community engagement projects into several strategies, including exploring and changing perceptions and reactions to death and dying; increasing awareness and competence of the public; mobilising community resources and advocating policy reform (Sallnow et al., 2016). These strategies have intertwining relationships with one another, and exploring public perceptions form the essential basis for community campaigns, education programmes and training activities for increasing awareness and competence and changing perceptions and reactions. An open and positive attitude facilitates the mobilisation of community resources to support patients and families living with life-limiting illnesses, and the empowerment of communities to advocate for policies that support EoLC. This eventually contributes to building compassionate communities.

COMMUNITY ENGAGEMENT: THE GLOBAL AND LOCAL SCENE

The spectrum of compassionate communities, and supportive strategies suggested by Sallnow et al. (2016), provide a useful framework for understanding contemporary community engagement activities. **Table 14.1** provides a brief summary of representative international projects for community engagement that have been conducted in recent years. Surveys of different scales were conducted in different countries, with the aim of developing a general understanding about public knowledge, attitude and preferences, as well as behaviours related to EoLC. Multiple innovative methods have been employed to increase awareness, enhance competence and nurture an atmosphere of openness for EoLC discussions. Although traditional one-way communication of health information remains common, there is clear evidence of the need to develop more interactive approaches, such as multi-purpose platforms, creative media and audio-visual materials, as well as community campaigns. Such approaches allow two-way communication to occur between different community members, and they provide flexibility for the content of community capacity building to be tailored to individual preferences and the range of cultural norms. Flexible responses to contextually specific cues are believed to enable greater efficacy through personalised communication, and they help health and social care professionals reach historically underserved populations more effectively (Ostherr, Killoran, Shegog & Bruera, 2016).

Increasingly popular game-based conversation tools have been introduced. These serve as important starters to facilitate daily dialogues in EoLC and help to break death taboos in fun and relaxing ways. Evaluation research often goes hand-in-hand with these innovative methods, providing preliminary evidence for their effectiveness in community capacity building and engagement (e.g. Lambert South & Elton, 2017; Lankarani-Fard et al., 2010; McLoughlin et al., 2016; Pazart et al., 2011). Projects about mobilising community resources and policy advocacy are relatively scattered and localised and are usually initiated by small groups of passionate community members within their communities. These programmes can then spread haphazardly to other communities.

Table 14.1 *The Global Scene of Contemporary Community Engagement Activities*

COMMUNITY ENGAGEMENT STRATEGIES (ROLE)	PROJECTS	EXAMPLE
<p>Explore perceptions and reactions (Consult)</p>	<p>Public surveys on end-of-life care and death issues</p>	<ul style="list-style-type: none"> » European countries: <i>Burden to others survey</i> (Bausewein et al., 2013), PRISMA survey in end-of-life cancer care (Gomes et al., 2012; Higginson et al., 2014) » UK: British Social Attitude Survey (Shucksmith, Carlebach & Whittaker, 2013), The Choice in End-of-Life Care Public Engagement Exercises (Choice in End of Life Care Programme Board, 2015), The VOICES Survey (Office for National Statistics, 2015) and <i>A time and a place: What people want at the end of life</i> (Ryder, 2013) » US: <i>Final chapter: Californian’s attitudes and experiences with death and dying</i> (California HealthCare Foundation, 2012) » Canada: <i>What Canadians say: The way forward survey report</i> (Canadian Hospice Palliative Care Association, 2013) » Singapore: <i>Death attitude survey</i> (Lien Foundation, 2014a) » Taiwan: A cross-sectional survey with terminally ill cancer patients in 23 teaching hospitals in Taiwan (Liu et al., 2015) » Japan: A pilot survey of the 5th national survey in end-of-life care (Kissane et al., 2015)
<p>Increase awareness and competence, and change attitude (Inform, co-production, collaborate and empower)</p>	<p>Online/published resources and education materials Audio-visual materials, including videos for patients’ and caregivers’ education, documentaries and movies Platforms for information and experience exchange, and health management Innovative tools for conversation Community campaigns</p>	<ul style="list-style-type: none"> » Multi-purpose online platforms: <i>Dying matters</i> (National Council for Palliative Care, 2009), <i>The conversation project</i> (Institute for Healthcare Improvement, 2010), <i>Death over dinner</i> (2013) and <i>Good life, good death, good grief</i> (2011) » E-health management systems: Comprehensive Health Enhancement Support System (CHESS) (Gustafson et al., 2013); Making your wishes known: Planning your medical future (Green & Levi, 2011); and Together website project (Vogel et al., 2013) » Conversation tools: <i>Five wishes</i> (Aging with Dignity, 2011), <i>The one slide project</i> (Engage with Grace, 2008), PREPARE prototype website (PREPARE, 2012) » Game-based conversation tools: <i>Go wish</i> (Coda Alliance, 2006), Card sorting technique (in France for Alzheimer patients) (Pazart et al., 2011), <i>Dying to talk discussion starter: Online card game</i> (Palliative Care Australia, 2017), <i>Hello</i> (previously named ‘My Gift of Grace’) (Common Practice, 2018), <i>Heart2Heart</i> (Discuss Directives, 2018), <i>Have the talk of a lifetime</i> (National Funeral Directors Association, 2018), <i>Care planning cookies</i> (Life & Death Matters, 2015) and <i>Advance care planning origami fortune teller game</i> (Good life, good death, good grief, 2011) » Community campaigns: Death Cafe (Impermanence, 2011), Before I Die Walls (Ritual Fields, 2013) and Die Die Must Say (Lien Foundation, 2014b)

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COMMUNITY ENGAGEMENT STRATEGIES (ROLE)	PROJECTS	EXAMPLE
Mobilise community resources (Co-production, collaborate and empower)	Neighbourhood/ community support networks	<ul style="list-style-type: none"> » Good Neighbour Partnership (Milford Care Centre, 2015) » Beauty Bus makeshift salon (Beauty Bus Foundation, 2018) » “The Wish Ambulance” Project (Ambulance Wish Foundation, 2007)
Advocate in policy reform (Empower)	Policy advocacy and changing social environment	<ul style="list-style-type: none"> » The advocacy of pain and PC policy of the government of Kerala (Paleri, 2008) » The WISE project on designing dementia-friendly outdoor environments (Mitchell & Burton, 2006) » The advocacy of PC policies across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes in the 67th World Health Assembly (World Health Assembly, 2014)

COMMUNITY ENGAGEMENT IN EoLC IN HONG KONG

Community engagement in EoLC is relatively underdeveloped in Hong Kong. The *Quality of Death report* released in 2015 showed that Hong Kong scored 32.5/100 in community engagement, ranking 38 out of the 80 countries surveyed. This ranking is much lower than nearby Asian countries (e.g. Taiwan, Japan and Singapore) (Economist Intelligence Unit, 2015). This low score can be partially explained by cultural taboos in discussing end of life (EoL) and other death issues among Hong Kong Chinese. Talking about death is often considered to bring bad energy and evil spirits to an individual and/or the family (Chan, 2009). People avoid mentioning “death” directly, with the use of subtle and implicit euphemistic words (Qi, 2011). A local survey found that more than 20% respondents still believed that “talking about death in the presence of a dying person would accelerate death” (Ho et al., 2007, p. 5). Reluctance to engage in EoLC discussions has also been acknowledged in the Hospital Authority (HA) Advance Care Planning (ACP) and Advance Directives (AD) public education pamphlets. People may want to defer such discussions due to a lack of necessary communication and emotional skills; fear that healthcare workers are too busy for ACP discussions; worry that patients will become down-hearted and depressed as the initiation of ACP discussion can be a reminder of death; and/or they may become anxious over healthcare workers “giving up” on a patient because they refuse life-sustaining treatments.

The taboos and reluctance to discuss death reflect misunderstandings, unexplained myths, insufficient communication skills and incompetence in handling emotional triggers in the EoLC communication process (HA Clinical Ethics Committee, 2016).

Fortunately, a number of innovative projects have been established recently to engage the broader community in EoLC and death discussions. Multi-purpose online platforms have been established since 2006.

- » The website for the ENABLE Project was the first award-winning platform to focus on promoting life and death education in local communities (Centre on Behavioral Health, 2010b). It contains online education resources, information on training courses and public events, and a platform for peer support and experience-sharing.
- » Similar platforms such as “Hospice home” (Centre on Behavioral Health, 2010a) and “I can plan ahead” (Chinese University of Hong Kong, 2016) have also been launched, which have more interactive elements such as apps and e-workbooks.
- » A number of community campaigns have also been initiated. The Death Cafe and Before I Die Wall ideas have received increasing attention. Moreover, local creative projects integrating experiential activities, creative arts, exhibitions and peer exchange elements have become popular. These have been organised by groups such as DEAtHFEST (Sheung Kung Hui Holy Carpenter Church District Elderly Center, 2015), Endless Care Services (Tung Wah Group of Hospitals, 2009) and Big Silver (Big Silver, 2015).
- » Documentaries and mini-movies such as *Snuggle* (Wong Siu-pong, 2016) and *The Tail Before* (Wong Fei-pang, 2016) have been produced, and a magazine has been published about these projects. These have been widely publicised in the local community.
- » Other community organisations such as Life and Death Education Society; Comfort Care and Concern; Haven of Hope; and St James’ Settlement are also active in organising education activities and producing education materials. Some of them have initiated volunteer projects for family photo-taking and wish fulfilment.
- » HA published public education pamphlets on ACP in 2016, helping patients and family caregivers gain an understanding on the medical decisions to be made at EoL and the relevant documentation related to this (HA Clinical Ethics Committee, 2016).

Overall, these projects have increased public awareness and helped develop an open attitude on life and death issues, which creates significant momentum for community engagement in EoLC.

THE JCECC PROJECT: A LIFE-COURSE APPROACH TO COMMUNITY ENGAGEMENT IN HONG KONG

Building upon the groundwork and experience of other projects, the (Jockey Club End-of-Life Community Care) JCECC Project has expanded the life-course perspective to community engagement in EoLC. Life is ultimately seen as a walk from the “community” ring of the circle towards the centre of the circles, in the Circles of Care Model (Abel et al., 2013). With an ageing population, every healthy community member may need to eventually assume the role of family caregiver, and inevitably the role of EoL patient themselves. The JCECC Project therefore aims to engage everyone in the community, including healthy community members, patients living with chronic or life-limiting conditions, and family members. A wide range of community engagement strategies have been adopted to tailor the variety of interests and needs for individuals from all walks of life. These approaches echoed Kellehear’s contemporary health promotion strategies of “participatory; recognises the social character of health and illness; emphasises education, information, and policy development; is designed for the well and the ill; is everyone’s responsibility, not just the individuals” (Kellehear, 1999, p. 12). **Figure 14.1** provides an overview of the JCECC Project community engagement components.

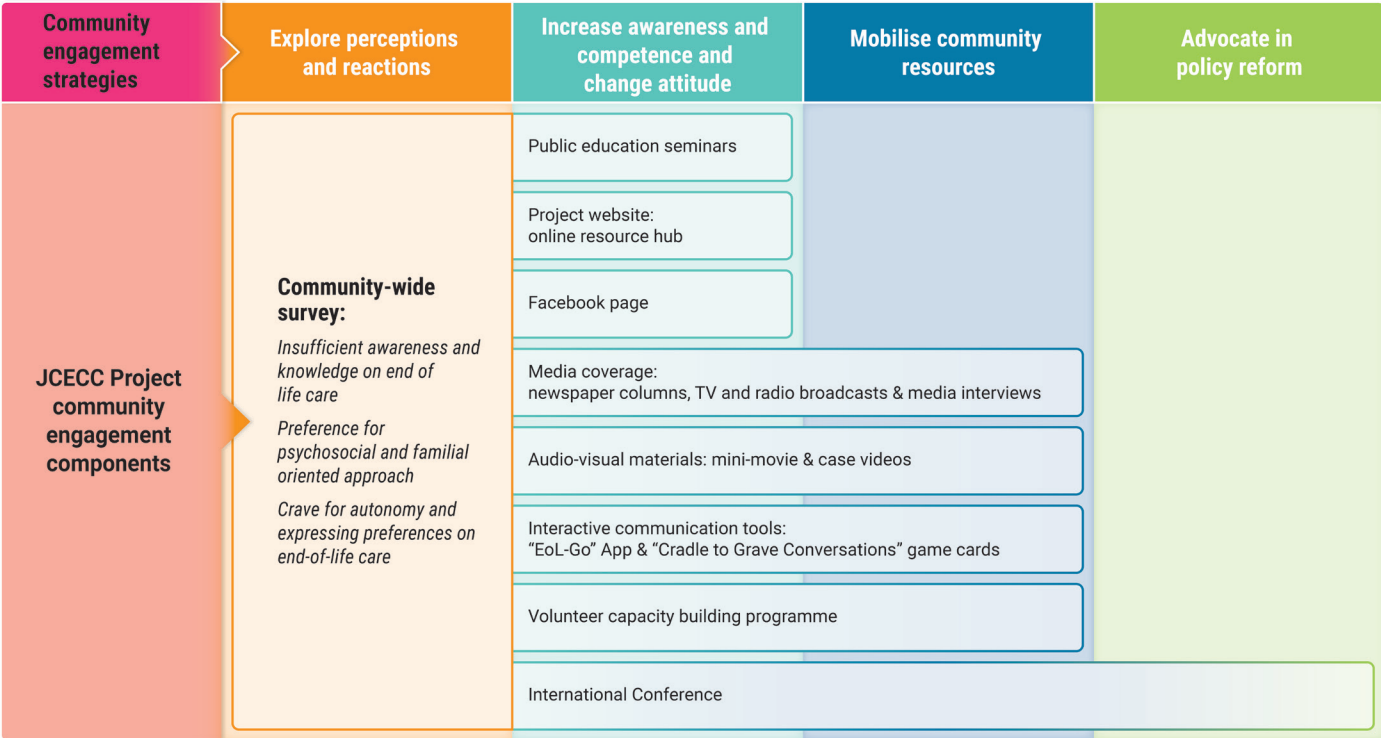


Figure 14.1 Overview of JCECC Project Community Engagement Components

THE JCECC PROJECT COMMUNITY-WIDE SURVEYS

Community-wide surveys have been conducted in the JCECC Project three times so far (2016, 2017 and 2018) in order to understand the Hong Kong public's knowledge, attitudes and preferences on EoLC. A population-based simple random sampling approach was adopted and data was collected by telephone survey. Although the results from the first wave serves as baseline data for planning community engagement activities, results from the second and third waves have been helpful in evaluating the impact of community engagement activities, and in reflecting changes on knowledge, attitudes and preferences on EoLC. Findings from the first wave survey, with 1,515 respondents, highlighted the following challenges and opportunities for community engagement in EoLC (JCECC, 2016).

Insufficient awareness and knowledge on EoLC. People in Hong Kong generally have low awareness and limited understanding of the terms and services related to EoLC. Respondents were asked whether they had heard of three terms describing support and care services for patients and families, including hospice care “善終服務”, PC “紓緩治療” and EoLC “安寧照顧”. The majority of respondents had heard about hospice care (86.6%), as the term is associated with the early development of services for dying patients in Hong Kong. Only about one-third had heard of the more recent terms PC (37.6%) and EoLC (30%). This finding is in line with the latest trends in developing care services for chronic and advanced disease conditions, and in adopting an integrated care approach that addresses physical, psychosocial and spiritual needs as illnesses progress. The percentage of respondents who were aware of PC and EoLC was relatively low compared with other countries (see **Figure 14.2**), including the UK, the US, Canada and Singapore. Many respondents were also unaware of the key basic components in EoLC. Less than half of them had heard of “grief counselling” and “Do Not Attempt Cardiopulmonary Resuscitation”, and even fewer were aware of ADs (18.5%) and “bereavement support” (12.4%).

These findings echoed findings from another local Hong Kong survey, which showed that 80% survey respondents had not heard of hospice or PC services, and over 60% did not understand how these services might help EoL patients (Federation of Medical Societies of Hong Kong, 2016). The community's limited awareness and knowledge about PC and EoLC may contribute to the taboos, misunderstandings and myths around death and dying, which in turn may restrain the community's engagement in care and support for patients and families living with life-limiting illnesses.

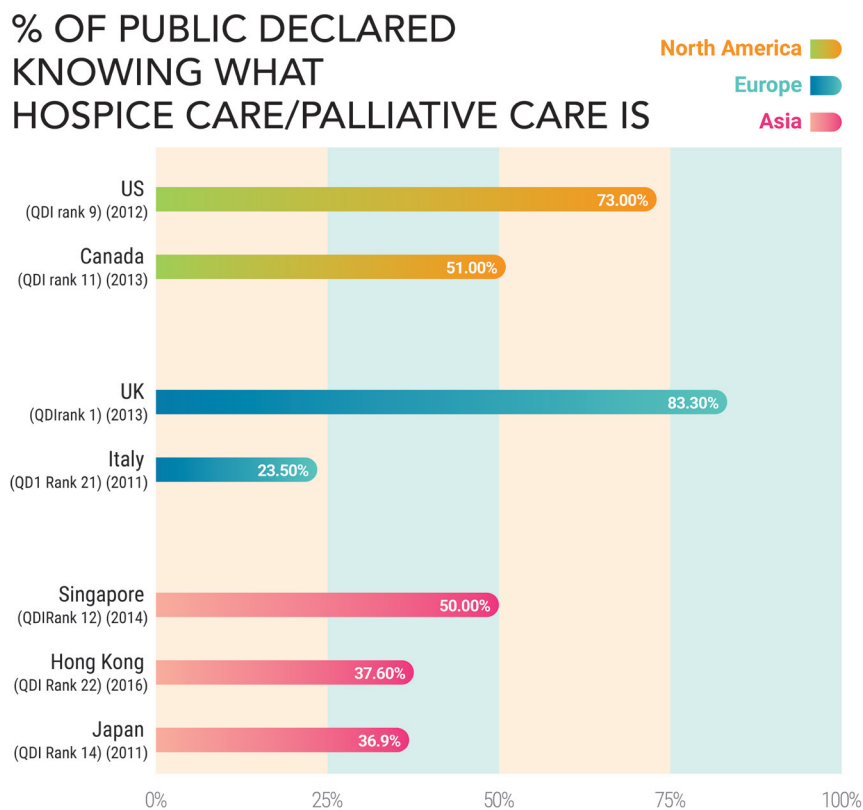


Figure 14.2 Comparison of Public Awareness on Hospice/Palliative Care with Other Countries (Benini et al., 2011; California HealthCare Foundation, 2012; Canadian Hospice Palliative Care Association, 2013; Hirai et al., 2011; JCECC, 2016; Lien Foundation, 2014a; Shucksmith et al., 2013). Adapted from JCECC, 2016, p. 20.

Preference for psychosocial and familial-oriented approach. The public indicated clear preferences towards psychosocial and familial approaches to EoLC. When being asked about the service components of care at EoL, a significant proportion of respondents mentioned counselling and psychological support (30.4%) and spiritual care (14.7%). They are, in fact, the top two service components that respondents thought were important in EoLC, and these percentages were higher than those for medical services (such as hospitalisation, home care and day care services). The responses to a hypothetical scenario when a person had only six months to live indicates what psychological and spiritual support means in the EoL stage. Having family and friends around (40.6%) and that the family lives a happy life (9.1%) were two of the top five concerns at EoL; the remaining concerns were living a meaningful life (11.7%), absence of pain or suffering (8.5%) and fulfilling wishes (4.6%). Respondents also expressed wishes to spend their remaining time creating happy memories (19.6%) and saying goodbye (11.7%) to family and friends. Consistently, respondents were happy to consider being cared for in settings outside hospital, including the family home, RCHes and social service agencies, where psychosocial care and family and social networks were more accessible. While medical care is often emphasised in EoLC, our results highlighted that psychosocial and family care can be of equal, if not greater, importance.

Craving autonomy, choices and communication on EoLC. The survey clearly indicated that the public treasured autonomy and choices in the EoLC decision-making process. The majority of respondents (84%) wanted to make their own EoLC decisions, while the remaining 16% believed that doctors, family members and others should be the decision-makers. People indicated that they wanted to have a choice about whether they would receive EoLC (79.4%); sign an AD (74.4%), and decide the place of death (73.1%). The majority (70%) wanted to discuss these decisions with their families. Not only did respondents generally accept the construction of EoLC facilities near their home (82.1%), having neighbours receive EoLC at home (76.1%) and dying at home (59.2%), but a significant percentage also showed interest in attending educational activities related to EoLC (40.4%). Over 90% felt it was acceptable to talk about death. The open attitude among respondents possibly reflected the continuous efforts of local community projects to raise awareness around the topic. The next step for community engagement in EoLC should move towards creating interactive platforms to facilitate knowledge and skills exchange, enhance communication on personal preferences and generate new ideas for service development.

CORE COMPONENTS OF COMMUNITY ENGAGEMENT IN THE JCECC PROJECT

Based on the survey findings, the JCECC Project has made use of four major components to engage local community members in EoLC:

1. Enhance EoLC literacy by provision of education activities and resources;
2. Stimulate awareness through creative media and audio-visual materials;
3. Engage all in dialogue, conversations and discussion regarding the development of innovative and interactive tools; and
4. Nurture volunteers in the community via training and service projects.

With its pilot efforts, the JCECC Project seeks to turn a new page in EoLC community engagement in Hong Kong.

Enhancing end-of-life care literacy by experts and professionals. Educational activities and resources are key to providing information and enhancing EoLC literacy in the JCECC Project. Public seminars have been frequently hosted, with the content covering a wide range of important topics in EoLC including basic terminologies; concepts and values; symptom management; psychosocial–spiritual care; family communication; decision-making and bereavement support. The seminars have been delivered by local and international experts.

Online resources, audio-visual materials, case sharing and experiential exercises have been integrated into these seminars to make the learning process interesting and interactive. All public seminars have been opened to community members on a first-come, first-served basis at no monetary cost, and English–Cantonese bilingual simultaneous interpretations were provided for seminars delivered by non-Cantonese speaking international speakers. In total, 30 public and invited events were held from December 2015 to April 2018, reaching 4,692 participants.

Participants were generally satisfied with the seminars, with a mean overall satisfaction score of 4.4 out of 5 in evaluation surveys. It was observed that a significant proportion of participants in these public events had been, or were currently, caregivers for patients living with chronic or life-limiting conditions. They were often eager to ask questions and share their caregiving experiences. As such, the public seminars provided much more than an information-provision session, as they also provided a platform to engage caregivers in experience-sharing and obtaining (and providing) peer support.

People who were not able to attend public seminars could refer to the JCECC Project online education resources, which had updates on project events, archival educational materials, research progress, as well as useful links and information on local community EoLC services, international best practices and guidelines. The JCECC Project Facebook page and social media platforms reach out to younger people and the more electronically literate public. The website hit rate (since inception date to final date of calculation) was 307,842 and the Facebook page has reached 168,436 accounts up to April 2018.

Promoting awareness and discussion through creative media and audio-visual materials.

In addition to conventional education activities and resources, the JCECC Project also engaged creative media and produced audio-visual materials to stimulate awareness and discussion in EoLC. Special collaborations have been established with a major local newspaper Ming Pao, prominent local radio and television broadcast stations including Radio Television Hong Kong (RTHK), Commercial Radio Hong Kong (CRHK) and Now-TV. Experts and frontline professionals in health and social care, such as doctors, nurses, social workers, researchers and academics, have been invited to contribute to the content of articles and interviews. They have shared their experiences on working with real cases, and have provided essential information, practical tips and advice with respect to the themes in each column or interview. Sometimes, patients and/or family members have been invited to join interviews to illustrate their experiences in working as core partners with the EoLC team. A total of 19 newspaper articles have reached an estimated 140,000 readers per issue, and 22 media interviews provided 900 minutes of radio-show airtime.

Original films have been produced, including five case stories, three documentaries on services of the JCECC non-government organisation (NGO) partners and a 16-minute mini-movie *My Little Story with Mom*. The mini-movie presented a story of a mother–daughter dyad living with advanced cancer. It was developed with reference to a real-life story and emphasised the possibility of living a quality life through maintaining autonomy and dignity at EoL. The movie was launched in November 2017, with the premiere attracting 1,092 participants and guests. YouTube, the JCECC Project website and the Facebook page view rate reached over 70,000 up to April 2018.

Engaging all in dialogue, conversations and discussion with the development of innovative and interactive tools. Innovative communication and interaction tools provide unique contributions to engage community in EoLC dialogues and conversations by the JCECC Project team. The public survey showed that people in Hong Kong treasured family times and happy memories at EoL. However, Chinese culture does not favour direct communication on tabooed topics (such as death and dying) or verbal expression of emotions (Qi, 2011). The team designed tools to integrate family activity planning, knowledge and mini-games with the purpose of facilitating family communication on EoLC. A travel-guide mobile app “EoL-Go” was developed and made available on both Google Play and Apple’s App Store. The app consists of practical tools and information on trip planning, tips on pre-trip preparation and destination recommendations for patients and caregivers planning excursions in Hong Kong and overseas. It is the first of its kind in Hong Kong and is expected to help generate meaningful family dialogues and create happy memories via the trip planning process.

The “Cradle to Grave Conversations” card game is a useful starter tool for daily dialogues and conversations about EoL. The deck comprises four sections according to the four suits of poker. “How well do you know me?” helps players to break the ice and understand each other; “Interesting facts from cradle to grave” shares interesting knowledge on medical, legal and social aspects of EoLC and death in an effort to debunk common misconceptions and myths; “From fairy tales to EoL” includes well-known stories such as the Three Little Pigs and Journey to the West to engage players in reflecting on a variety of EoLC decisions; and “Your wishes” inspires players to review their life experiences and preferences on EoL wishes. Conversation prompts, mini-games and engagement exercises are scattered over the 52 cards, not only to encourage dialogue and conversations but also to suggest actions to express love and care. A total of 1,500 packs of cards have been printed and disseminated free to the public. Although the card-game content has been designed for use by lay people, many health and social care professionals make use of them tactfully in clinical practice as ice breakers in education activities or conversation tools to prepare patients, caregivers and volunteers for more in-depth EoLC discussions.

Nurturing volunteers in the community via training and service projects. The JCECC Project has underpinned the development of volunteer programmes to mobilise community volunteers in supporting patients and families living with chronic and advanced illness. An EoLC Volunteer Collaborative Leadership model has been developed to enhance volunteer personal competences, motivations, and knowledge and skills. This has occurred through a capacity building process ranging from project promotion, recruitment and screening, training and continuous support. In collaboration with the four community NGO partners, the project team piloted a volunteer competence building curriculum in EoLC in January 2018. The trained volunteers are important partners in the EoLC team, providing tangible and timely support for patients and family caregivers, accompanying them through critical moments, empowering them in health management, enriching their life experience and relieving caregiving burdens. More details of the JCECC Project Volunteer Collaborative Leadership model can be found in Chapter 15.

CONCLUSION AND IMPLICATIONS

Building on the health promotion principle of compassionate communities, the JCECC Project has pioneered a life-course perspective to engage local community members in EoLC. The Project has proactively responded to needs and characteristics of the local community, and considered global and local development trends in community engagement. Conventional education activities remain important and well-received methods of enhancing EoLC literacy. More efforts are devoted to the use of information, communication technologies and creative media (such as websites, Facebook, newspaper, radio and television broadcasts, and audio-visual materials). These platforms have helped to extend the reach to community members, allow proactive responses to the needs of the community and deliver messages effectively in a fast-paced environment. Special highlights are the production of a mini-movie, game cards and a mobile app, which have done much to initiate community dialogues and actions in EoLC to debunk common misconceptions and myths. All community engagement components in the JCECC Project have a clear focus on psychosocial–spiritual care, communication and decision-making. Such focus does not only match the needs reflected from the baseline community-wide survey, but it also complements the recent progress of HA to educate the public on medical decisions in ACP.

The JCECC Project's community engagement components have great potential for further development. Although the Project website serves as an online resource hub, there is the possibility of further development of self-initiated learning platforms. More structured and interactive education curricula can be designed to meet the needs of different community members, who are in different aspects of the Circles of Care. Examples include health management materials for patients; daily and home care resources for caregivers; skills-drilling courses for volunteers; and community support tips for healthy community members. Learning log books, self-evaluation tools and interactive tutorials can be incorporated to allow learners to keep track of their progress, and therefore increase their motivation and effectiveness. The mini-movie and game cards can also be expanded into other community capacity building tools. Online and paper workbooks and self-help books can be published and workshops can be delivered to help community members articulate and document their EoLC preferences. The card game can potentially evolve into an interactive online tool and mobile app for self-exploration, family communication and peer exchange. Ambassador schemes to promote these tools may be feasible, in addition to volunteer programmes. The JCECC Project team should look at this to ensure that these ideas can be implemented in the Phase 2.

To establish evidence-based practice, evaluation research should be undertaken, in conjunction with community engagement activities. The JCECC Project includes a number of components to evaluate the effectiveness of its community engagement activities. The three timepoint community-wide surveys provide a robust reference frame regarding how the community engagement activities, in general, have impacted on public knowledge, attitude and preferences. The statistics on the number of participants attending education activities, visitors on website and Facebook, readers and viewers for media coverage, game cards distributed, and the amount of airtime for broadcasts provide multipronged estimates of the potential reach of the programme. Nonetheless, there is a lack of evaluation on expected outcomes and effectiveness, specific to each community engagement activity. However, this is a worldwide issue that has been identified in the use of information and communication technologies in EoLC (Ostherr et al., 2016) and interprofessional education (Institute of Medicine, 2015). Establishing comprehensive and feasible frameworks to evaluate the outputs, learning outcomes, and health and system outcomes is thus a crucial next step to advance community engagement in local contexts.

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