
Report on

**COMMUNITY-WIDE SURVEY
ON END-OF-LIFE CARE IN
HONG KONG 2016**



The University of Hong Kong

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同心 同步 同進 RIDING HIGH TOGETHER



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COMMUNITY-WIDE SURVEY ON END-OF-LIFE CARE IN HONG KONG 2016

EXECUTIVE SUMMARY

The three-year Jockey Club End-of-Life Community Care (JCECC) Project aims to increase community awareness and engagement in End-of-Life Care (EoLC) through the pilot testing of different service models, professional training and public educational activities. To examine the impact of the public educational activities specifically, a three-wave study is carried out to compare the changes in the public's knowledge, attitude and preferences with regard to community EoLC in Hong Kong. The present report summarizes the findings on the first wave of the study, which is based on data from a community-wide, population-based random sampling telephone survey. The survey ran from January to March, 2016, and included 1600 participants residing in Hong Kong. An overview of the key results is presented below.

- The general public in Hong Kong is open to discuss EoLC related issues;
- The general public has limited knowledge about EoLC concepts and related issues;
- Core features of EoLC, as perceived by the general public in Hong Kong, are:
 - ◆ Self-participation in the decision making process;
 - ◆ Family is the major focus;
 - ◆ Psychosocial dimensions of care are equally important as medical care;
 - ◆ Community is an acceptable place for care and death

Four core features of EoLC



The findings of the survey suggest that the public is prepared to discuss and learn about EoLC issues. There is, however, a significant gap in knowledge and skills, which offers the JCECC Project clear directions for a public education plan. Coincidentally, these core features identified are in line with the major foci of the JCECC project. With the finding from the second and third wave of study, the impact of the project can be properly assessed. The study is the first random-sampling population survey on the topic of EoLC, which contributes to the knowledge building about status quo of the Hong Kong general public.

COMMUNITY-WIDE SURVEY ON END-OF-LIFE CARE IN HONG KONG 2016

BACKGROUND

In Hong Kong, similar to global demographic trends, an increasingly aging population poses new challenges for health and social care services. This is particularly true for the provision of end-of-life care (EoLC), which is the care and support services for patients and family members living with life limiting illnesses (Hong Kong Census and Statistics Department 2009; 2010; 2015; WHO, 2015). The growing demand on EoLC overloaded the medical system, and the government is actively looking for community collaborations to improve the quality of EoLC. In order to address the challenges and strengthen the EoLC community services, the three-year Jockey Club End-of-Life Community Care (JCECC) Project aims to enhance community EoLC services through a series of educational activities. Currently, there is still very little known about the level of knowledge, attitude, and preferences related to community EoLC among the Hong Kong general public.

OBJECTIVES

To assess the impact of the educational activities on EoLC, community-wide surveys will be carried out at three time points (2016, 2017 and 2018). The three-wave study will measure the changes in knowledge, attitudes and preferences with regard to EoLC, so as to evaluate the impact of the public education programme for the general population of Hong Kong. This report is

about the baseline survey that took place in 2016. The specific objectives of the study in this report are:

- to set a baseline measure for future comparison;
- to depict current knowledge, attitude, and preferences of the general public, with regard to EoLC.

METHODOLOGY

A population-based simple random sampling telephone survey was conducted from January to March, 2016. Eligible respondents were residents in all districts of Hong Kong aged 18 above who spoke Cantonese, Putonghua or English. The questionnaire took approximately 20 minutes to complete, and included questions on: 1) Health and Lifestyle; 2) Knowledge of EoLC; 3) Attitudes towards and experience with EoLC, and; 4) Personal Information. Among 2,580 eligible participants, 1600 were successfully interviewed (n=1,600), 225 respondents completed part of the survey, and 755 refused. The overall response rate for the survey was 62%.

PARTICIPANTS

Most participants were female (61.1%), aged 45 and above (68.2%), and married (62.8%). They have been living in Hong Kong for over 10 years (98.1%). The majority of them attained secondary school-level education or higher (80.5%), and were living in private flats (64.3%) with 1 to 4 cohabitants. Over half of the participants were non-religious (58.8%). Of the participants who had religious beliefs, most of them adhered to Christianity (25.1%), followed by Protestants (18.5%) and Catholic (6.6%). These statistics are compatible with the general population in Hong Kong.

KEY FINDINGS

1. Openness to discuss EoL related issues

- 1.1 **Less than 10%** of the participants felt uncomfortable talking about death.



- 1.2 Overall, people in Hong Kong were willing to talk with their families about signing an Advance Directive (69.1%), receiving EoLC (65.8%) and choosing their place of death (63.2%).

7 out of 10

people in Hong Kong
 were ready to talk with
 families about EoLC
 decisions



Sign an AD



69.1%



Choose to receive EoLC



65.8%

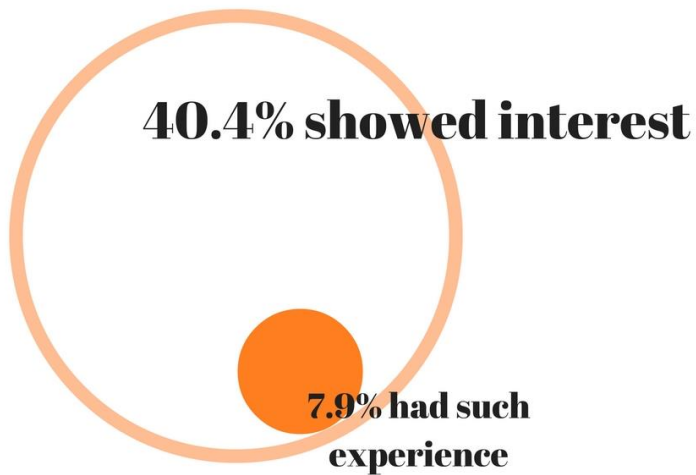


Choose the place of death



63.2%

- 1.3 Four in ten people showed an interest in EoLC related educational activities, but less than one in 10 had actually attended such an event.



More than 40%

interested in joining EoLC seminars or activities, only 7.9% have actually attended them

Summary:

- ◆ The general public feels **comfortable** and **ready** to talk about death and EoLC related issues.
- ◆ The general public is **prepared to learn** about EoLC.

2. Inadequate knowledge in EOL related issues

2.1 Even though the majority of the general public (86.6%) had heard of the term “hospice”, only **37.6%** and **30%** heard about palliative care and EoLC respectively.

Only 30% had heard of EoLC



2.2 Most people were not aware of the basic components of EoLC. Comparatively more people had heard of grief counselling (42.6%) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) (41.2%), than about advanced directives (18.5%) or bereavement support (12.4%).



Grief Counseling

哀傷輔導

42.6%



DNACPR

不作心肺復甦術

41.2%



Advance Directives

預設醫療指示

18.5%



Bereavement Support

善別服務

12.4%

Most people did not know about the various EoLC components and services

Summary:

- ◆ There is a **gap** in the knowledge related to EoLC concepts

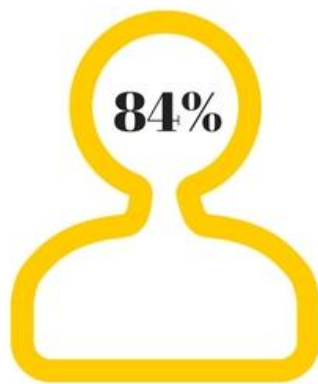
3. Four core features of EoLC





3.1 Self participation in the decision making process

3.1.1 84% of people assumed they are the one making their own EoLC decisions, while 16% of people thought doctors, family members and others are the decision makers.



84%

Me



16%

**Doctors, family and
others**

3.1.2 74.4% would choose to sign an Advance Directive, 79.4% would choose to receive EoLC, and 73.1% would like to plan ahead for a preferred place to die if they were diagnosed with terminal illness and still had six months to live.



Sign an AD



74.4%



Choose to receive EoLC



79.4%



Choose the place of death



73.1%

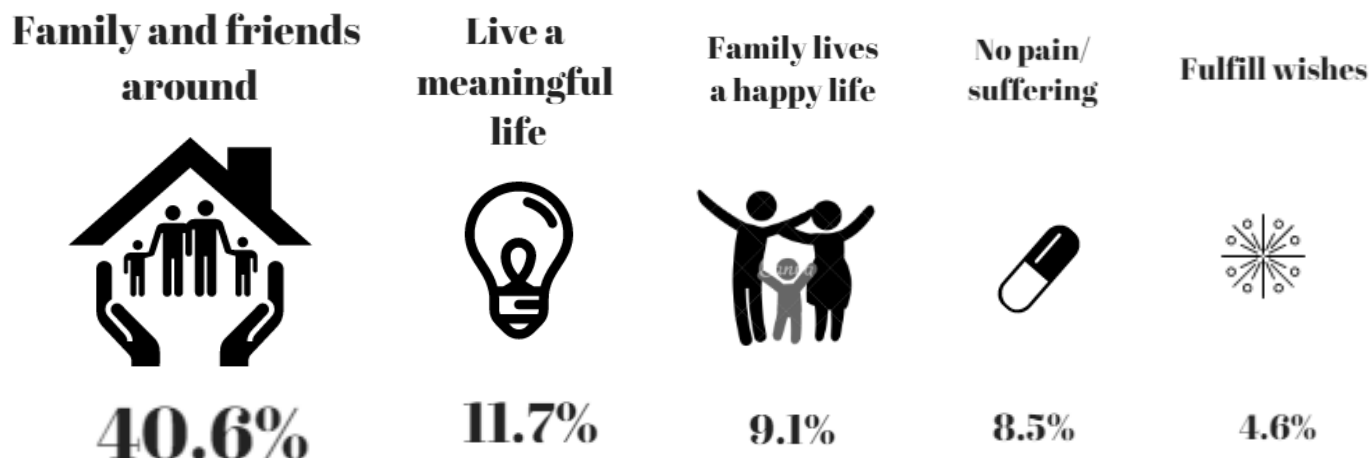
7 in 10

would choose to sign an AD, receive EoLC and choose their preferred place of death



3.2 Family as the major focus

3.2.1 When people were asked to imagine the scenario where they were at the end of their lives, about 40% of people thought that having family members or friends around would be the most important. This top concern was followed by: living a meaningful life, wishing my family lives a happy life, no pain or suffering, and fulfilling my wishes.



Having family around and family live a happy life were two of the top five concerns at EoL

3.2.2 If people had only six months to live, they thought that creating happy memories with family and friends would be the top priority.

**Create happy memories
with family and friends**



19.6%

Live as usual



16.3%

Go traveling



13.9%

**Say goodbye to family
and friends**



11.7%

**Treasure the
remaining time**



10.4%

Creating happy memories with family and saying goodbye to them were two of the priorities that people wish to do at the last six months of their life

3.2.3 Approximately 7 out of 10 people in Hong Kong were ready to talk with their families about signing an Advance Directive, receiving EoLC, and choosing their preferred place of death.



Sign an AD



69.1%



Choose to receive EoLC



65.8%



Choose the place of death



63.2%

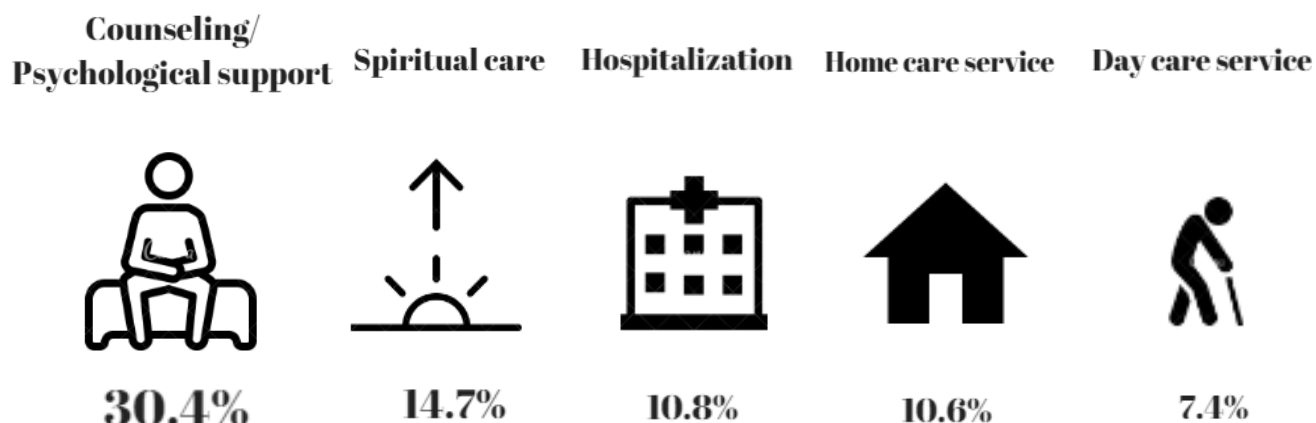
7 out of 10

in Hong Kong were ready to talk with their family about EoLC decisions



3.3 Psychosocial dimensions of care are equally important as medical care

3.3.1 When being asked about the components that are, according to the respondents, currently part of EoLC, people thought counseling or psychological support, and spiritual care are included in EoLC, along with hospitalization.

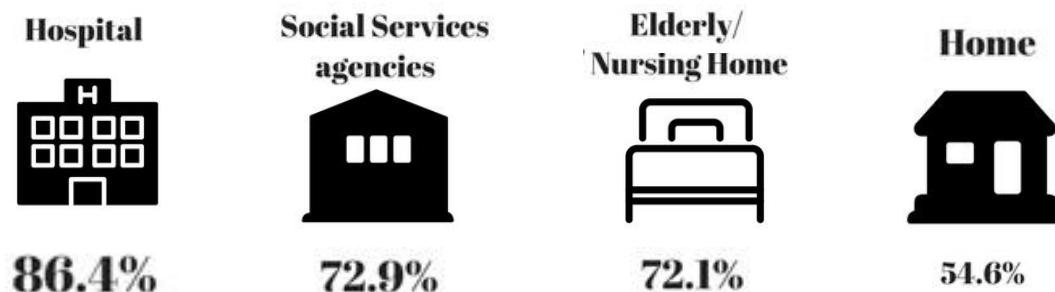


Top two EoLC service components were related to psychosocial dimensions

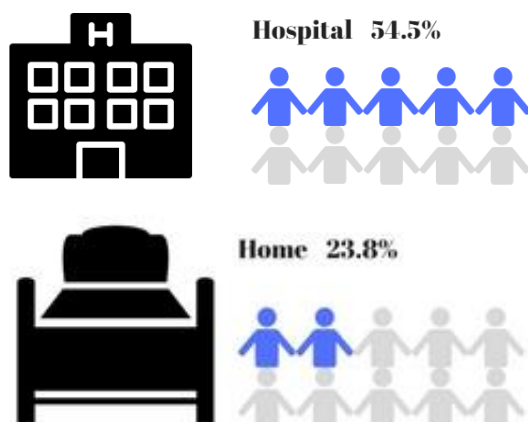


3.4 Community is an acceptable place for care and death

3.4.1 Hospitals remained the most popular choice for receiving EoLC (86.4%). Community settings such as social service agencies (72.9%), elderly and nursing homes (72.1%) and domestic homes (54.6%) were also deemed as acceptable choices.



3.4.2 Over half of the people preferred to die in a hospital. However, about one-fourth of the people would prefer dying at home.



About one-fourth of the people

showed preference to die at home, instead of a hospital

3.4.3 Over 80% of people would support the building of EoLC facilities near their home. More than three-fourths of people would support their neighbors' choice to receive EoLC at home. Nearly 60% of people would support their neighbors' choice to die at home.



EoL facilities near home



82.1%

8 in 10

would support EoLC community facilities near their home



Neighbor receives EoLC at home



76.1%

8 in 10

would support neighbours receiving EoLC at home



Neighbor dies at home



59.2%

6 in 10

would support neighbours who choose to die at home

Summary:

- ◆ According to the general public's perception, EoLC involves self-participation in the decision making process, being family focused, with an emphasis on psychosocial aspects and being community based.

DISCUSSION AND IMPLICATIONS

The time is now

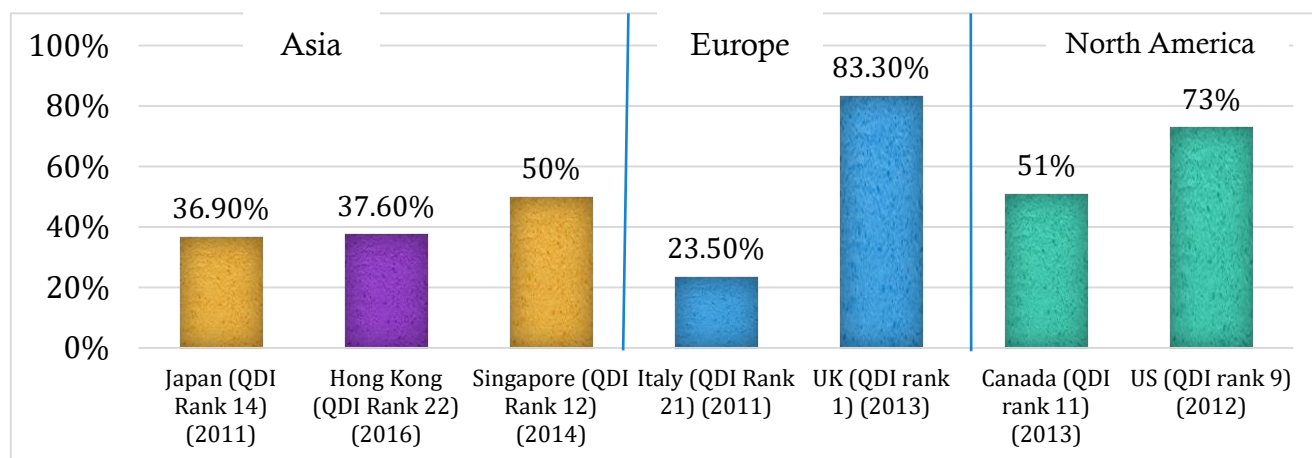
The public is ready to talk about death and EoLC issues. The public would like to have autonomy in making EoLC decisions and they are willing to communicate their preferences and decisions with family. They also expressed interests in joining educational activities on EoLC. A recent local survey also found that over 85% of the public agreed that EoLC is important for patients suffering from terminal illnesses (The Federation of Medical Societies of Hong Kong, 2016). Taken together, it seems to be a good moment for initiating conversations and educational activities on EoLC.

The need to raise the knowledge of the public

Hong Kong's general public has limited knowledge of the terms and services related to EoLC. This echoed with the findings of another local survey, pointing out that as much as 80% have not heard of hospice and palliative care services (寧養紓緩服務) and advanced directives; and over 60% do not understand how hospice and palliative care services can help patients and family members at the end-of-life (The Federation of Medical Societies of Hong Kong, 2016). In fact, compared with other countries, the public awareness of hospice/palliative care in Hong Kong is still at a relatively low level (see figure 1), but, similar to the conditions in other Asian countries. Possible focuses of public education include the promotion of the term “End-of-Life Care” and service components of EoLC. Currently, the public had rarely

joined public education programmes on EoLC in the community. This may imply a lack of community education programmes in EoLC, or a lack of interest to join the programmes. All things considered, there is still a large space to fill related to EoLC education programmes for the general public.

Figure 1. Comparison of public Awareness on Palliative/Hospice Care with other countries (Benini et al., 2011; California Healthcare Foundation, 2012; Canadian Hospice Palliative Care Association, 2013; Hirai et al. 2011; Lien Foundation, 2014; NatCen Social Research, 2013)



*QDI refers to Quality of Death Index (The Economist Intelligence Unit, 2015)

Participation in EoLC decision-making

Remaining autonomous in EoLC is one of the major concerns in EoLC. The public would like to participate in their own EoLC decision-making, and choose whether to sign an advanced directive, receive EoLC, and choose their place of death. They also showed clear preferences for the features that should be included in EoLC: family focused, emphasize psychosocial care, and be community based.

Family as the unit of care

Family is considered to be the unit of care in the hospice philosophy. The cultural emphasis on interdependent self-construal (i.e. if my family is well, I am well), also suggest that we should pay attention to the whole family. Therefore, facilitating family communication, strengthening family cohesiveness, completing family's unfinished business, and leaving a legacy can be extra focuses of EoLC.

Psychosocial care is an important component of EoLC

While EoLC has been offered mainly by health care settings that put emphasis on medical care, the public voices their opinion that psychosocial care is of equal, if not greater, importance. In EoLC, psychosocial care was perceived to be an essential component, in addition to physical care. Not only do patients need psychosocial care, but also the caregivers need psychosocial support to cope with stress in caregiving. With respect to the perceived outcomes of EoLC, most participants believed that EoLC could improve the quality of life. The findings on the importance of psychosocial care are similar to a survey done in the UK, which shows that the public thinks that psychosocial needs in EoLC (36%) (Spiritual and religious needs, privacy and peace, dignity and preferred places to die) are as important as medical care and pain relief (18%) (NatCen Social Research, 2013). In short, psychosocial care in EoLC should be further developed, with more education and research being carried out on this topic. Only then can EoLC achieve its intended goal of balanced, holistic care.

The community is considered a plausible place for EoLC and dying

It is clear that the Hong Kong general public preferred both receiving community EoLC, as well as dying in the community. Even though people assumed that social services agencies can provide better psychosocial support to both patients and their family members, they also recognized that hospitals can provide sufficient medical support. This result also aligns with the study from UK, in which 31% of respondents thought that EoLC in a hospice (outside hospital), where holistic physical, psychological, social and spiritual care are emphasized, can retain their dignity. On the contrary, only 20% of respondents thought hospital can retain a person's dignity (NatCen Social Research, 2013). Consistent with another recent, local survey, being cared for and dying at home had been raised as one acceptable choice, yet, most people acknowledged the insufficiency in existing medical, social, home and family support (The Federation of Medical Societies of Hong Kong, 2016).

CONCLUSION

This community survey pinpoints the features and needs of development in community EoLC in Hong Kong: (1) The general public is open to discuss EoL related issues; (2) The general public has limited knowledge about EoL concepts and related issues, and; (3) In line with the major foci of the JCECC project, in the public's perception, core features of EoLC involve self-participation in the decision making process, being family focused, an emphasis on psychosocial aspects, and being community based. . It seems to be the right moment to adopt a health promotion approach, prioritizing EoLC as one of the health concerns that everyone in the community should care about (Kellehear, 2013; Rosenbery & Yates, 2010; Sallnow & Paul, 2015). The very first step can be promoting terms and service components of EoLC through various public education events and programmes, such as discussion platforms, campaigns, seminars and talks. After all, strengthening and expanding psychosocial and community support would allow a seamless transition from medical palliative care to benefit patients and family members. Social changes in EoLC can only happen with help from active and engaged communities.

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