

賽馬會安寧頌
JCECC 
Jockey Club End-of-Life Community Care Project

Leadership Training Programme
2017/18





JCECC Leadership Training Programme 2017/18



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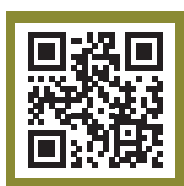
JCECC

Jockey Club End-of-Life Community Care Project

Hong Kong is facing a rapidly ageing population, and the number of elderly suffering from terminal illnesses has also escalated correspondingly. In view of the growing demand for end-of-life care services in the community, The Hong Kong Jockey Club Charities Trust approved HK\$131 million to launch the "Jockey Club End-of-Life Community Care Project" (JCECC) in 2015. The project is a three-year initiative aimed at improving the quality of end-of-life care, enhancing the capacity of service providers, as well as raising public awareness.

JCECC is a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. Five service models are being developed and piloted in the community to provide holistic support to elderly people suffered from terminal illness. The goal is to enable the city's older people to have informed choices of care and enjoy an improved quality of life.

The Trust's partners in JCECC are The University of Hong Kong Faculty of Social Sciences, The Chinese University of Hong Kong Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Services, The Hong Kong Society for Rehabilitation, St James' Settlement, and S.K.H. Holy Carpenter Church District Elderly Community Centre.



Please visit <http://www.JCECC.hk/>

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THE HONG KONG SOCIETY FOR REHABILITATION
香港復康會



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for Rehabilitation



聖公會聖匠堂長者地區中心
S. K. H. HOLY CARPENTER CHURCH
DISTRICT ELDERLY COMMUNITY CENTRE
(由香港聖公會福利協會有限公司營運)



聖雅各福群會
St James' Settlement

Programme Outline

Aims

Tomorrow's leaders in end-of-life care (EoLC) are expected to be effective, innovative, strategic and flexible in responding to the emerging challenges of global ageing. The JCECC Leadership Training Programme 2017 aims to nurture a group of leaders in community EoLC. The programme will recruit professionals in a supervisory role in the community to review the international best practices and standard of clinical excellence in community EoLC. The participants in the programme will be exposed to state-of-the art, evidence-based and innovative practices in quality community EoLC for patients and their family caregivers. The practice-based learning approach will empower the participants to develop EoLC services in their own work settings, through exemplary clinical care, international best practices, and evidence-based skills training.

Programme Objectives

- To empower the participants with state-of-the-art, evidence based and best practices in quality care for patients and family caregivers locally and globally.
- To enable the participants to develop clinical and supervisory competencies in community EoLC.
- To facilitate the participants to design innovative EoLC service programme appropriate to their respective work settings and to Hong Kong.

Learning Outcomes

Upon completion of the JCECC Leadership Programmes, participants are expected to be able:

1. To master the latest developments of best practices in community EoLC
2. To demonstrate their knowledge and capacity with evidence-based practices in quality EoLC for patients and family members.
3. To develop collective vision on scalable service models and innovative programmes for patients or/ and family members in their end-of-life.

Programme Components

The programme consists of four learning components including Knowledge Enrichment sessions, Tutorials, Exchange sessions with International Experts, and Capstone Project.

1) Knowledge Enrichment Sessions

There are eight knowledge enrichment sessions in EoLC. Educational domains of background and basic concepts of EoLC, psychosocial and spiritual care, communication, decision-making and self-reflection as well as self-care in EoLC are covered. Each session consists of a lecture and learning activities. The participants are required to prepare for each session by reading the assigned portfolio before attending the session.

2) Tutorials

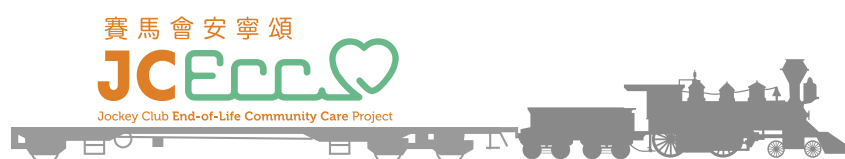
Tutorial sessions will be held before the end of each knowledge enrichment session. Participants will be divided into small groups and to discuss the assigned readings with discussion points provided by the speaker. The discussion aims to facilitate the integration of relevant knowledge and learning experiences into service planning and development.

3) Exchange Sessions with International Experts

There are occasional sessions for meeting with international experts. Participants are expected to prepare questions on their own challenges encountered related to the topic before they join the session. After meeting with the international experts, the participants have to reflect on what they have learned and how they will apply into their work settings.

4) Capstone Project

The capstone project is the key project of integration of knowledge and learning experience for all participants in the Leadership Training Programme. It provides the participants with the opportunity to actively integrate and apply all their learning from the programme to their respective work settings. Through the creation of a project design for the development, knowledge enrichment and implementation of end-of-life care service, participants can reflect on their own professional development and critically examine their respective work setting's unique capacity for social impacts in the community.





Chan Chung Ho

General Manager of Elderly Core Business
Hong Kong Christian Service

Chan Chung Ho, Karrie, is a registered social worker. She has worked with diverse target groups, including at-risk youth, ethnic minorities and the elderly. She is now the General Manager of the Elderly Core Business in Hong Kong Christian Service, in which capacity she oversees the operation and development of multiple community and residential services to support the elderly.



香港基督教服務處
HONG KONG CHRISTIAN SERVICE

全人關心 卓越創新
care for all excel in all



Communicating Advance Care Planning with Elder Couples

Chan Chung Ho
Hong Kong Christian Service



Background

Recent tragedies about homicides of sick family members by their beloved caregivers significantly alarmed public awareness on caregivers' burden. A report revealed that 26.3% of frail elders' key caregivers were their spouses (Census and Statistics Department, 2009). Considering rising number of dual-old families, there were over 200 thousand as reported by 2011 Census and many were the main caregivers of their frail spouses. For married couples, the spouse has an integral role in helping a partner to manage the end of life experience. Deciding the end-of-life care of their spouses would be stressful to the elders. Through early communication on Advance Care Planning (ACP) between the older married couples, the distress in handling the dying of their spouses is ameliorated.

Literature Review



Figure 1. Literature review on the issues and proposed solutions

Description

Target: Cognitively capable old couples (age 60 or above) living in the community and with one or both of them suffer from progressive non-malignant illnesses

Objectives: To enhance the knowledge, skills, and readiness of old couples in preparing ACP.

Contents: The project will use "the significant banquets among Chinese families" namely "Marriage" (婚宴), "New Born" (滿月宴), "Graduation" (畢業宴), "Retirement" (退休宴), "60th Birthday" (壽宴) and "Goodbye" (善別宴) as analogy to facilitate the communication of end-of-life care preference.



Social Workers

Facilitate life review & contribution, express love, thanks, anxiety, wishes, and conciliate conflicts.

Give information / support on medical, legal & APC related issues.



Other Professionals

Older Couples Dialogue on ACP



Volunteers

Help to record the ACP & facilitate to acquire new skills for their survival after death of partner.

Join the "Goodbye Banquet" to know the old couples' wishes and lasting wills.



Family members

Figure 2. Project outline

Social Impacts



- The readiness to face the distress caused by the loss of spouse will be better managed which will reduce the risk of further physical and mental health problems.
- Involvement of volunteers, relatives and friends in the project will help to promote public awareness on end-of-life care.
- Early involvement of old couples in advance care planning will help to identify high-risk couples for early intervention and may prevent further social problems.



Leaders

JCECC Leadership Training Programme 2017/18



Chan Lo Yan

Manager (Special Projects)
Senior Citizen Home Safety Association

My beloved grandmother was a wonderful woman. She raised me, and we lived together until she passed away. She was also a lucky woman. On her last trip to A&E, she was sent to a doctor who was courageous enough to offer her “good death” after reviewing her condition. The doctor then arranged for a ward for her so that she would be surrounded by her family while receiving limited life-sustaining treatments.

I believe that policy and standard practice, rather than luck, should govern the receipt of hospice palliative care within the patient’s discretion. I am a social worker by training. My mission at work is to enhance the quality of life of the elderly in the community. I hope I will be able to apply the knowledge and insights I gain from the JCECC Programme in the planning and execution of a meaningful project within my work setting so as to support the confident stay of more elderly people in the community, even in the last stages of their lives.



SENIOR CITIZEN
HOME SAFETY ASSOCIATION



How Digital Solution Enables End-of-Life Planning for the Elderly in the Community

Chan Lo Yan
Senior Citizen Home Safety Association



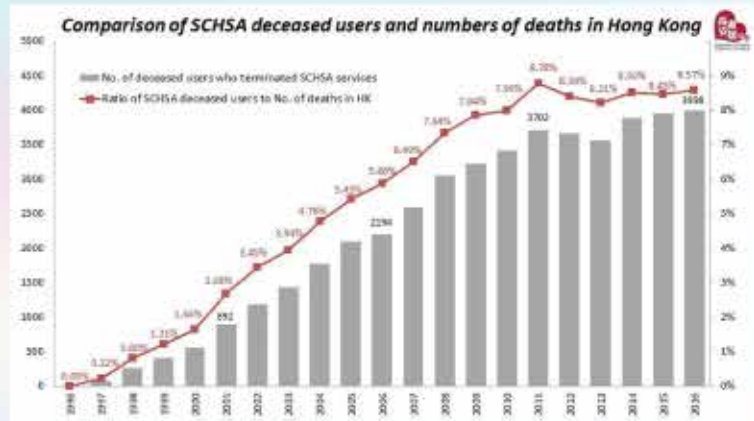
Background

Established in 1996, Senior Citizen Home Safety Association (SCHSA) provides 24-hour personal caring and emergency assistance services to elderly and people in need through its core service, Personal Emergency Link (平安鐘). The number of deaths has risen significantly among SCHSA users. In 2016, a total of 3,998 SCHSA users terminated services due to death, which was 8.57% of the total number of deaths in Hong Kong. In other words, SCHSA can be a gateway to engage one-tenth of end-of-life elderly.



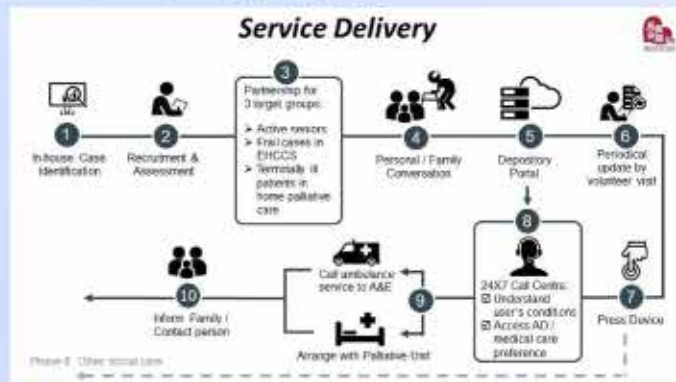
How digital solution enables end-of-life planning?

“Shared records” is one of the success factors for developing an innovative model of integrated hospice palliative care (Canadian Hospice Palliative Care Association, 2013). In US, significant number of digital companies have been established to engage individuals and families to consider all end-of-life options and document their preferences through electronic records (Mobi-Health News, 2017). Some widely-recognized advocacy campaigns are also moving toward electronic records, for examples, POLST and Five Wishes.



The Bucket List: a service to record personalized wishes within online depository portal

Objective - The project acts as a showcase in Hong Kong that enables people to record their end-of-life wishes and preference, in order to make electronic profile available for coordinating emergency services and social care with more recognition of their voice.



Social Impacts

Level	Social Impacts
The elderly and their families	More respect on their wishes and preference
	More confidence to live in the community during EoL through 24/7 service and fully accessible depository portal
Care service providers	Better communication between medical setting and social care units in out-of-office time
	Enable timely care transitions
Social / Community	Empower people to take actions and accommodate their personal decisions
	Showcase of a community-based hospice palliative care model that potentially offers support to 1/10 EoL elderly



Cheung Bo Ping

Resident Doctor
Jockey Club Cancer Rehabilitation Centre
The Hong Kong Anti-Cancer Society

Cheung Bo Ping received his Bachelor of Medicine and Bachelor of Surgery degrees from the University of Hong Kong in 1985. He started taking care of terminal stage cancer patients in 2012 while working as the Center Physician of the Hong Kong Anti-Cancer Society's Jockey Club Cancer Rehabilitation Center, which was previously known as the Nam Long Hospital. He works closely with his team to ensure the best symptomatic control for his patients.



香港防癌會
HONG KONG ANTI-CANCER SOCIETY
Since 1963





Background

The Hong Kong Anti-Cancer Society (HKACS) is a non-profit making cancer organisation with the longest history in Hong Kong since 1963. The mission is: To fight against cancer by advocating, engaging, empowering and supporting all. The HKACS provide a wide range of services, including a residential care facility of the HKACS Jockey Club Cancer Rehabilitation Centre.

Description

The Project Wish was launched to help patients in wish fulfilment during their end-of-life. Project officially launched in 2009. Served a total of 36 families in 2017 and a total of 210 families since 2009.

Project Wish Output 2017:

- Family outing to Disneyland: 12 (33%)
- Family outing to Ocean Park: 5 (14%)
- Family dinners (new year, birthdays and important festivals): 11 (31%)
- Wedding in the hospice: 2 (6%)
- Go home: 2 (6%)
- Hair cut for a dignified death: 2 (6%)
- Family album: 1 (2%)
- Life review story book: 1 (2%)

Charity Schemes / Services	Accumulated Number of Cases Served
Prof HC Ho Memorial Medical Assistance Programme	5,658 cases (since 2006)
Portia Cheung Breast Cancer Support Programme	368 cases (since 2007)
HKACS Jockey Club Cancer Rehabilitation Centre (JCCRC)	1,597 inpatients (since 2006)
HKACS - Hong Kong Baptist University Chinese Medicine Centre (CMC)	27,050 patients (since 2009)
Walking Hand-in-Hand Cancer Family Support Project	3,323 cases (since 2011)
Charity Bed Programme	902 cases (since 2011)
Integrated Chemotherapy Centre	833 cases (since 2012)



Social Impacts

The patients died with wish fulfilled. Family members were most grateful to the holistic intervention offered by the HKACS. A lot of photos were taken during the occasions which served as record of their loved ones living life to their fullest until the last moments of life. They have sweet memories and their bereavement risks reduced.

Case Illustration: A 51 years old man with end-stage Mediastinal Cancer wanted to bring his family to a trip. His wife and daughter went on a HK tour with him.





Chow Suk Kuen

Service Manager (Endless Care Services)
Endless Care Services, Elderly Services
Tung Wah Group of Hospitals

Chow Suk-kuen, Rita, is the Service Manager (Endless Care Services) of the Tung Wah Group of Hospitals. She is keen on the service development of end-of-life services and life-and-death education projects in the community. There are currently eight services, including the "Funeral Care" service for the childless elderly, the "Be-with" funeral support service for the bereaved, the "Present for You" life review for elderly and terminally ill patients and the "Life X" life-and-education project under Endless Care Services.



東華三院

Tung Wah Group of Hospitals



A Retrospective Study on the Effectiveness of "Be-with" Service to Alleviate the Grief of the Bereaved

Chow Suk Kuen
Tung Wah Group of Hospitals

Background

The death of a significant others can create high distress for many people. Funeral can play an important role for the bereaved including: acknowledges the death, provides a setting for dead body disposition, recognizes the lived experience of other lives, demonstrates reciprocal environment and social obligation, and offers a chance to gather and recall the deceased's life (Despelder & Strickland, 2011; Worden, 2010).

Description

The "Be-with" service of Endless Care Services was established under the Tung Wah Group of Hospitals in 2012, with the aim to provide continuous psychosocial support for the bereaved persons throughout the funeral process. This project is a retrospective analysis on "Be-with" service effectiveness and impact on about 100 bereaved people. A focus group with 5 workers of the service was conducted in March 2018, commenting on service users' satisfaction and direction for service improvements. The workers highlighted that the project is effective in helping the bereaved to learn about the funeral procedures, manage the funeral budget and provide emotional companionship and bereavement care. The service received a large number of compliments by service users.



Demographic of Service Users (2012-2017)

Gender of Service User	%	Age of Service User (M=56.7)	%
Male	39.2%	60 or below	58.7%
Female	60.8%	61 or above	41.3%
Relationship with deceased	%	Financial Condition	%
Spouse	16%	CSSA	60%
Father/Mother	4%	Non-CSSA	40%
Son/Daughter	45%	Source of Clients	%
Others (i.e.brother/sister/nephew/niece)	35%	Referral	60%
		Self-approach	40%

Compliments from service users

Social Impacts

This proposed study will help to formulate a service model for free funeral support and consultation services in Hong Kong. It will identify needs of the bereaved people in the different stage of lose and explore how the funeral procedures may help the bereavement adjustment of Chinese bereaved persons.





Chu Cheuk Yan

Social Worker (End of life care project)
Methodist Centre

As a social worker providing end-of-life care (EoLC) to elderly people with terminal illness and their families, my role is to be with the families and to help them have better experiences of separation.

I am glad to have the opportunity to join the JCECC End-of-Life Care Leadership Training Programme. With the knowledge-enrichment sessions, I have gained more comprehensive EoLC-related knowledge. I have also developed more conceptualized knowledge of international practices.

Most importantly, I have met a group of workers who are passionate about providing and enhancing EoLC in the community. This programme has empowered and equipped me to provide higher quality service.



循道衛理中心
Methodist Centre



Using Clinical Data Mining to Develop a Framework to Guide Psychosocial-spiritual Care for Chinese Elders in End of Life and Their Family Members

Chu Cheuk Yan
Methodist Centre

安寧
手冊

Background

Culturally-sensitive psychosocial-spiritual care is as important as medical care in holistic End-of-life Care (EoLC) (National Institute for Health and Care Excellence, 2017). Despite the Hospital Authority's provision of day hospice and home care services to end-of-life (EoL) patients, the lack of indigenous intervention guideline on psychosocial-spiritual support for EoL patients in the community makes monitoring and quality assurance of services difficult. This project aims at building a practical framework on psychosocial-spiritual care for EoL patients, which will be developed to a practice handbook in future.



Figure 1. Literature review on the issues and proposed solutions.

Sample and Analysis Plan

The Blissful Life Project (the Project), conducted by the Methodist Centre in Hong Kong, has provided 70 community-dwelling EoL patients and their families with psychosocial support since 2016. Clinical data mining will be conducted on the service data of patients (Table 1) who passed away between 2016 and 2018. A three-step procedure will be carried out to develop the framework of psychosocial-spiritual care for Chinese elders in EoL (Figure 2).

Table 1. Sources of data and data included in the CDM analysis

Sources of data	Data
Application form	Patient demographics: age, gender, marital status, financial condition, core physical symptoms Service records: intake date, service start date
Service record form	Psycho-social assessment: mental condition, social, financial and environmental support, patients and carers' wishes towards care plans and funeral Service records including types and frequencies of services provided
Outcome assessment form	Results from the annual assessments on death anxiety, general wellbeing, quality of life of patients and carers' stress

Figure 2. Three-step procedure of developing psychosocial-spiritual care framework



Social Impacts

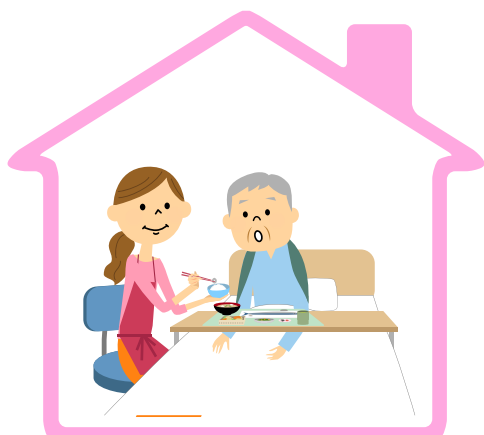
- Community**
 - Psychosocial-spiritual support to EoL patients will be advocated
 - The handbook will benefit the EoL psychosocial-spiritual care development in other Chinese communities
- Professionals**
 - Professionals will be encouraged to provide high quality psychosocial-spiritual support to EoL patients
 - Professionals' confidence in providing psychosocial-spiritual support in EoLC will be enhanced
- Patients and family members**
 - Patient's quality of life will be enhanced due to better psychosocial-spiritual support in the community
 - Risk of caregiver burnouts will be reduced



Huang Wai Ka

Operation Manager
Po Leung Kuk Fuk Wai Home for the Elderly

Huang Wai Ka, Tony, a registered social worker, joined the Po Leung Kuk after graduating from the Chinese University of Hong Kong. He is currently working at the Po Leung Kuk Fuk Wai Home for the elderly. For more than 10 years, he has been engaged in the provision of elderly services, including community support, community care and self-financing life-education services. In recent years, he has been responsible for promoting palliative care services in the Po Leung Kuk residential homes.





Background

Autonomy is crucial to quality end-of-life care. Allowing choices in the place where care and death can take place, through the implementation of advance care planning and advance directives (Dixon, Matosevic & Knapp, 2015; Scott et al., 2013) and expansion of psycho-social care in the process can facilitate good death with wishes and preferences of elderly being respected. However, given the legal and cultural constraints, death in locations other than hospitals challenging in Hong Kong. Nearly 90% of the total 46,000 deaths in Hong Kong happened in public hospitals in 2014.

Description

The project aims to make dignified death in place possible in Hong Kong through expanding choices in end-of-life care in Residential Care Homes for Elderly (RCHEs). The team organized briefing session for the residents and relatives in regular meetings and staff training with the JCECC team to promote the project rationale. The key components are:

- Co-work with JCECC nurse and social work, resident and relatives to have direct discussion on advance care plan.
- Apply for legal document to fulfill the requirement of Births and Deaths Registration Ordinance.
- Work done with multidisciplinary team to alleviate distressing physical symptoms and provide psycho-social-spiritual support.
- Prepare appropriate equipment and facilities such as ECG machine and freezer.
- Renovate an end-of-life care room - a warm environment for residents and family members to say goodbye.
- Negotiate with funeral company on the transportation and storage of the body, including contingency plan in public holidays.

Result and Conclusion

The project was implemented from April, 2017 to April, 2018, with 86 RCHE residents signed their DNR forms and indicated preference to receive palliative treatment. Three residents passed away peacefully in residential home in according to their wishes, accompanied by family and friends. Family of residents and staff were generally satisfied with the arrangement with no regrets.

Social Impacts

The project demonstrates the feasibility to expand end-of-life care in RCHEs, maintaining autonomy for elderly residents who have indicated preference for caring and/or pass away at RCHEs. It also enhances staff competence in providing end-of-life care to RCHE residents and increase public awareness on advance care planning.





Leaders

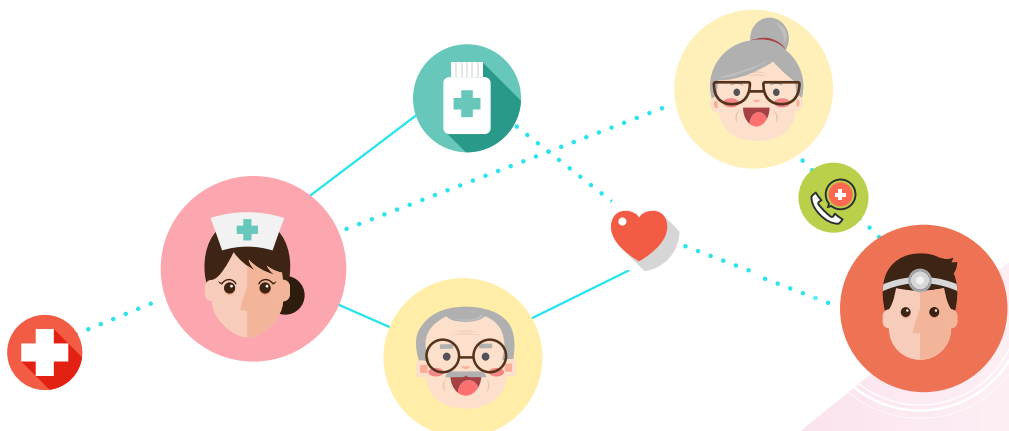
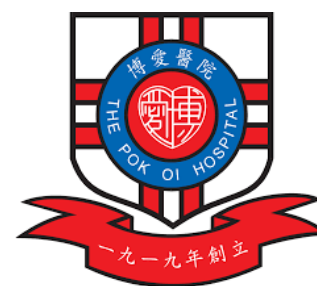
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Kong Wai Lin

Officer in Charge
Patient Resources Centre, Pok Oi Hospital

Rita Kong is a registered social worker and holds a master's degree in social work from McGill University. She has twenty years of hospital experience working in a patient resource center with a focus on health promotion via patient empowerment. Rita is particularly interested in working with patients with chronic diseases and those at the end-of-life stage. In practice, she enjoys facilitating disease self-management and various support and therapeutic groups. Rita is also an executive member of the Hong Kong Remotivation Therapy Association and an honorary consultant with the Hong Kong Association for Specific Learning Disabilities.



Community Network on Life and Death Education: Medical-social Collaboration

Kong Wai Lin
Pok Oi Hospital, Hospital Authority



Background

Death is often considered a tabooed topic among Chinese communities. Yet, the compassionate community concept advocated community engagement in preparing one's own death and expressing individual wishes and preferences (Kellehear, 2016). The Pok Oi Hospital initiated a life and Death education program in hospital and set up a community network for promoting medical social collaboration in the community engagement in end-of-life care.

Description

The project aims to engage the community in end-of-life care conversation and raise the public awareness on death preparation through a series of education and training activities. In addition to direct services to patients and carers, the project extended the public education component in collaboration with NGOs service network to increase social participation based on the pilot experience with patients and carers since 2010. A scaffolding strategy is adopted in which each members in the community are encouraged to promote life and death education within their social and community network, breaking the death taboo, normalizing the experience of death and facilitating cross sector collaboration in promoting ACP.



Result

Very inspiring, encourage worker to provide training on life and death in difference ways, also have a deep reflection. Also very informative!

The participants in the projects include patients, carers, professional staff, community organizations and general public. Both qualitative and quantitative evaluation was carried out for all training and education activities. Participants generally have positive feedback on the activities:

讓我感覺能令多些人了解死亡, 及早準備, 如預設醫療指示、信仰和靈性的準備、身後事安排、與家人道別, 明白到怎樣才是一個理想的死亡。

Social Impacts

The Life and Death Education network demonstrated how medical and social sector could be collaborated at the hospital and community level, through establishing network with NGOs. The project increase staff competence in providing end-of-life care and bereavement related information, as well as public awareness in life and death issues.

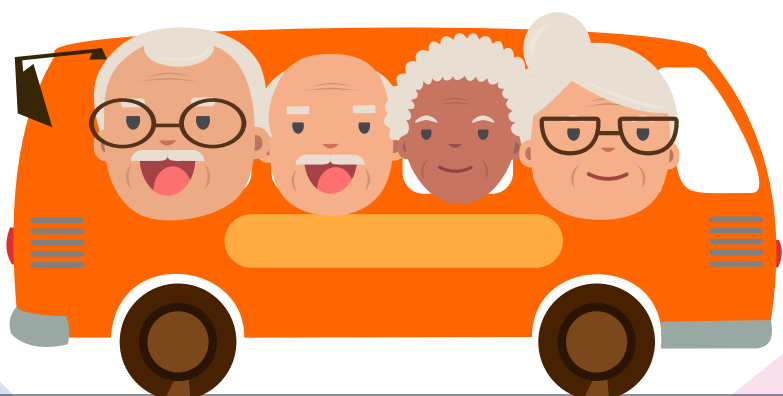




Lai Yuk Kit, Rosanna

Supervisor
Hong Kong YWCA Elderly Service Department

Rosanna Lai is a veteran social worker with twenty years of working experience in youth and elderly services. At the Hong Kong YWCA, Ms Lai is responsible for supervising both the community and residential care services of the Elderly Service Department.





Background

The project aims at encouraging the elders who are frail and home alone in the community to openly discuss with their family members on their preferences for the arrangement after death and to access the knowledge of Advance Directive, Enduring Power of Attorney and will, to share their last wishes & unfinished affairs.

The frail elderly service users of the HKYWCA Integrated Home Care Services Team were invited to participate in this project to discuss their advance care planning.

Description

This project aims to widen participants' horizon through a series of experimental games, activities and case study. Before the launch of games, a talk on Advance Directive, Enduring Power of Attorney and will was organized for volunteers and frontline staff. A focus group was organized to collect the opinion on 'good death' by community elders and their family members. Participants suggested that public education in the community and in schools were greatly needed to reduce the taboo of talking death.



Social Impacts

Over 90% of participants reported that the games and activities helped them to change their attitude towards death and would become more proactive in initiating death discussions. The program provided an open platform to enable elderly participants to share their views on the death arrangement and planning continuously with different family members so that they can build consensus with their families to determine the best treatment in end-of-life. The project proposed that the elderly can make good use of the technology to well record their wishes.



Hong Kong Young Women's Christian Association has newly developed an app called AngeLINK. By using AngeLINK mobile application, the elderly, with or without the help from his/her family member, could create his/her 'Memoir' by inserting past data such as texts, photos and videos into different chapters in the memoir which could then be enriched with feedbacks and shared among family members everywhere and anytime.





Leaders

JCECC Leadership Training Programme 2017/18



Law Miu yee

Advanced Practitioner of Social Worker
Haven of Hope Christian Service

Ms Law is an experienced clinical social worker who has worked in hostel-based rehabilitation for adults with intellectual disabilities for about twenty years. She is experienced in training adults with intellectual disabilities, case management and hostel management.



尊重生命 • 改變生命



Communicating Advance Care Plan with Persons with Intellectual Disabilities by the Use of Technology

Law Miu Yee
Haven of Hope Christian Service

Background

In advance care planning (ACP), good communication between persons with intellectual disabilities (PwID), their families and professionals can enhance better sharing of information and identification of patients' perceived needs and expectations. Understanding patient's preferences and wishes contribute to better psychological adjustment facing medical treatment, yet PwID are usually excluded from the ACP process because of their communication and intellectual barriers (Voss et al., 2017). This proposal aims to develop a new ACP tool which can be used with PwID.

Literature Review

Issues Identified for Persons with Intellectual Disabilities (PwID)

Exclusion from the process of care planning in EoL due to intellectual and communication barriers (Voss et al., 2017)	Psychosocial-spiritual needs of PwID in EoL are receiving little attention (Todd, 2013)	There are storytelling books on issues related to death and dying for PwID produced in UK, (Read et al., 2013)	No locally developed educational or conversation tools on ACP for PwID
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Proposed Solutions

Virtual environment which is created through virtual reality (VR) technology enables individuals with moderate to severe intellectual disabilities to explore, control and learn (Jeffs, 2009)	The use of text with graphic images and videos have been found to improve comprehension of some PwID (Davis & Wilson, 2006; Jones et al., 2007)	Create communication tools with VR technology and multimedia to educate PwID about death and dying, and communicate ACP with PwID
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Figure 1. Literature review on the issues of care planning with persons with intellectual disabilities and the proposed solutions

Description

Communication tools using VR and mobile or computer applications (Apps) technology can be developed to engage PwID in ACP, covering 4 important care domains in EoL:

- Need and process of different examinations
- Common symptoms of their diseases
- Available choices of care
 - Choice of attending spiritual service
 - Choice related to funeral arrangement



- Persons that they want to meet/to give thanks/give gift/to say sorry to
- Their wishes
 - What to do to make oneself happy
 - Persons to be included in one's own commemorative book

Figure 2. Description of project

VR movies allow PwID to "experience" the process of various medical examinations and episodes of hospital stay, helping them better understand different situations in EoL. Story-telling through videos with interactive functions in Apps can help PwID understand the symptoms of diseases, different choices of care and funeral arrangements, and facilitate their expression of preference and wishes.

Social Impacts

This project is expected to bring about the following impacts:

Medical care system	<ul style="list-style-type: none"> • Professional care teams will understand the preference of PwID better and able to provide high quality care
Family	<ul style="list-style-type: none"> • Family will understand more the wish and preference of the PwID • Family will be able to arrange care to the PwID which is consistent to his/her wish, and thus leave family no regrets and facilitate adjustment in bereavement stage.
Persons with Intellectual Disabilities (PwID)	<ul style="list-style-type: none"> • Wish of PwID will be respected. • After understanding the treatment, PwID will be less resistant towards treatment, and exhibit lower level of challenging behavior.

Figure 3: Impacts expected to bring to society by the project



Lee Wing Sum

Supervisor
Jockey Club Tsin Ngai Day Activity Centre cum Hostel
Tung Wah Group of Hospitals

Sandra Lee, the supervisor of a day activity center-cum-hostel, serves fifty people with different levels of intellectual disability. In 2017, a service user with severe-grade intellectual disability got end-stage lung cancer, and all hostel members of staff were anxious about taking care of him as they had never come across that end-of-life situation. This inspired Sandra to rethink end-of-life care for people with intellectual disabilities.



東華三院

Tung Wah Group of Hospitals





Background

Many family caregivers believe that persons with intellectual disabilities (PwID) have insufficient intelligence to make their own end of life (EoL) decisions. Care plans are therefore often made by their families, friends, paid caregivers, and physicians instead of by the PwID themselves (Wiese et al, 2014; Wiese et al, 2015). However, there is growing evidence that PwID can understand death (Chow et al., 2017) and their rights to be included in the discussion of their own EoL decisions have been advocated (Tuffrey-Wiine et al., 2007). This project aims to encourage the inclusion of PwID in EoL decision making by improving an existing care planning tool.

Literature Review



Figure 1. Literature review on the issues of care planning with persons with intellectual disabilities and the proposed solutions.

Description

Rehabilitation services of TWGHs developed a booklet called 《星願家書》 (Family Will) in 2017. It allows family members to record their preference in caring for the PwID, and can be passed on to other caregivers to communicate care arrangements of the PwID after the main caregiver passes away. A new edition titled 《星語心願》 (My humble wish) is proposed by expanding the Family Will to capture both the wishes of PwID and of the family. Alternative means for communication will be added to facilitate a multi-tier decision making process.



Social Impacts

This project is expected to bring about the following impacts:

- | | |
|--|--|
| Community | <ul style="list-style-type: none"> The experience and tool can be shared to other PwIDs The movement will facilitate the promotion of respect of autonomy as a whole |
| Care Providing Organizations and Staff | <ul style="list-style-type: none"> Staff will be more competent in carrying out ACP for PwID Autonomy of PwID will be further promoted in organizations |
| PwID and Family Members | <ul style="list-style-type: none"> Autonomy of PwID will be respected Preference of PwID will be articulated Family member will be less stressful when the PwID approach end of life Family members will have less regrets |



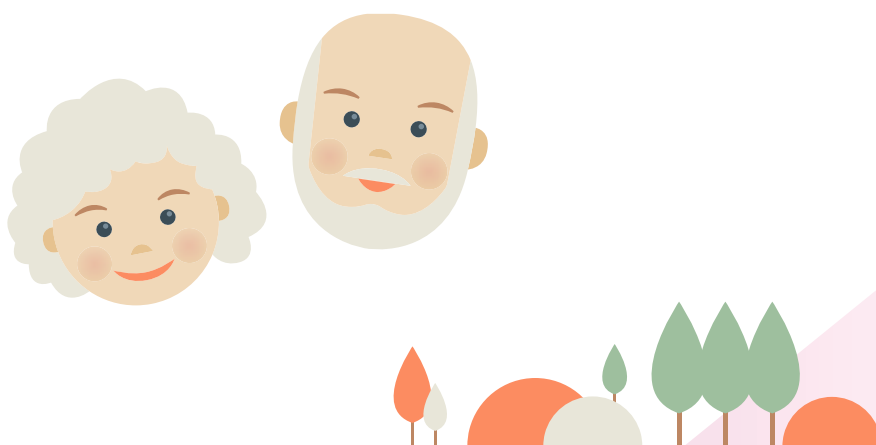
Figure 2: Impacts expected to bring to society by the project



Leung Wai Ping

Bereavement Counsellor
Jessie and Thomas Tam Centre
The Society for the Promotion of Hospice Care

Apple Leung received her bachelor's degree in social work from CUHK and her master's degree from HKU. She has worked for youth and elderly service organizations. At present, she is the Clinical Social Worker at the Society for the Promotion of Hospice Care. Committed to the field of end-of-life care, she has specialized in the area of bereavement counselling.



EAST Project: Preparing For A Better Future For Ageing Parents

Leung Wai Ping
The Society for the Promotion of Hospice Care



Background

Adult children caring for their aging parents in the end-of-life have complicated psychosocial needs. They often have intimate yet ambivalent relationship with their parents (Bouchal, et al. 2015), and suffer from emotional distress, caregiving burden and anticipatory grief (Bambauer, et al., 2006; Holley & Mast, 2009; Nijboer, 1999). They are also likely to experience intensive grief reactions following the death of the parents (Bert, et al., 2015). This project aims to use the EAST framework to enhance support for adult children caregivers, and improved their transition to end-of-life care, death and bereavement of their parents.

Literature Review



Figure 1. Issues identified and proposed solutions

Description

The EAST framework consists of four components: education, advocacy, support and target intervention. **E**ducation refers to a mutual platform for adult children and their parents, functioning as a knowledge sharing hub and support network for adult children and parents. **A**dvocacy helps adult children appreciate their own efforts in the caregiving process as fulfillment of filial obligations. **S**upport is the establishment of comprehensive end-of-life care service portal, mobile app and telephone hotline to provide tele-support to adult children and parents. **T**arget intervention is tailored for those who are deprived of family or community resources. Physical-psychosocial assessment will be provided by a designated case coordinator during proactive home visits.

Social Impacts

This project is expected to bring about the following impacts:

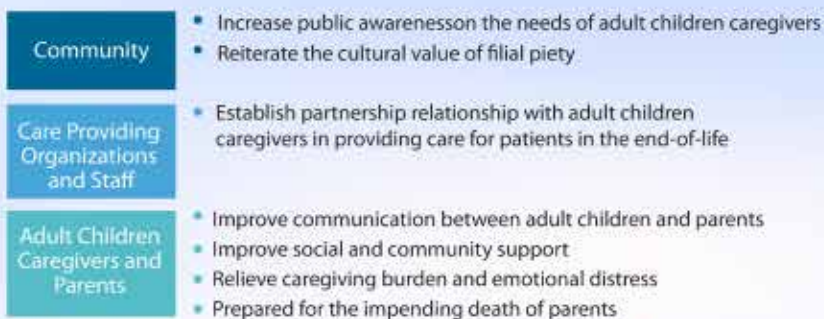


Figure 2. Expected Social impacts

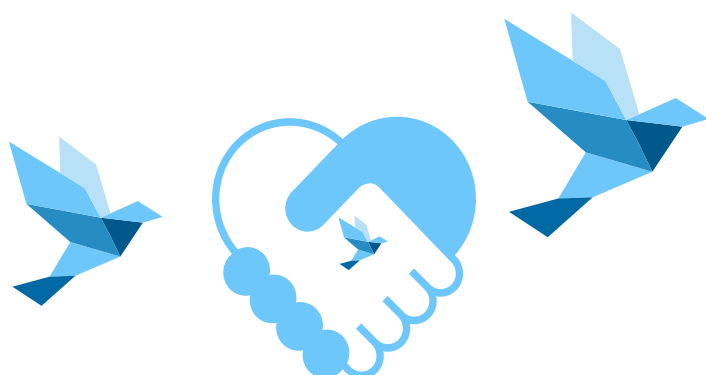


Mok Lai Ying, Susan

Registered Nurse
Jockey Club Home for Hospice Care
Society for the Promotion of Hospice Care

I am Susan Mok, a nurse working at the Jockey Club Home for Hospice Care.

The essence of end-of-life care entails promoting choice, showing respect and becoming a companion to the patient and his whole family through the difficult period of impending separation. This journey can start much earlier, before the patient needs palliative care. The ongoing discussion of his preferences with his family and communication with the professional team help with advanced care planning. With intensive support and care, the patient can spend his remaining days enjoying good quality of life and have his wishes fulfilled, ultimately passing away in dignity and peace.





Background

A public survey showed that the general public in Hong Kong have various preferences on place of death, and around one-fourth wished to die at home (Chung et al., 2017; The University of Hong Kong, 2017). Advance care planning (ACP) has been found to help promote patient autonomy and choices, and reduce unnecessary hospital admissions (Klingler, Schmittgen & Marckmann, 2016). A programme named "Journey of Choice, Peace, Respect (CPR)" is proposed to encourage elders to express their EoL care preferences and fulfill the wish of those who hope to die at home.



Description

Objective: To assist patients who wish to die at home, and help them pursue a dignified home death under intensive home care support.

3 Distinct Features:

- 1) Early Engagement (Figure 1)
- 2) Continuous Assessment of Strengths and Needs of Patients and Families (Figure 2)
- 3) Intensive Professional Home Care Support (Figure 3)

Criteria of CPR friends	<ul style="list-style-type: none"> Members from Evangelical Lutheran Church Elderly Centres in Shatin Cognitively sound Diagnosed with a life-limiting condition inclusive of cancer, chronic heart, lung, renal disease
Initial assessment	<ul style="list-style-type: none"> Patients' physical, psychological, social and spiritual needs will be assessed
Preparation for the journey	<ul style="list-style-type: none"> Patients will be invited to join activities and talk on End of Life care and Advanced Care Planning Social worker, as a case manager, helps to explore their wish, liaise with family and reinforce respect for their choice Home care team meet with the patients/family to understand their preferences over care
Start of the journey	<ul style="list-style-type: none"> Eligible clients who wish to pursue home death are recruited to the CPR program

Figure 1. Early Engagement

Stable state	<ul style="list-style-type: none"> Explore personal values Life review Family involvement with Advanced Care Planning
Physical decline state	<ul style="list-style-type: none"> Multi-disciplinary approach to provide holistic care Build trust and partnership with respect Regular family conference to allow discussion and come to consensus
Preparation for terminal stage	<ul style="list-style-type: none"> Review of their resources and home environment Explanation of the dying process and care involved Alternative measures to fulfill the last wish of Home death Logistics for transfer of the body
Terminal stage	<ul style="list-style-type: none"> Regular home visit by Doctor and nurse to provide comfort care Care of the carer: reassurance, empowerment, support Psychological preparation of whole family to 'let go' with peace and dignity of the elder
Post death	<ul style="list-style-type: none"> Nurse assists in last office and psychological support for the family Doctor will do death certification Reassurance that they have done the best for their beloved one Arrangement of the body to our hospice home mortuary
Journey ends	<ul style="list-style-type: none"> CHOICE, PEACE, RESPECT Bereavement care

Figure 2. Continuous Assessment of Strengths and Needs of Patients and Families

CHALLENGES	INTERVENTIONS
Complications of disease progress	<ul style="list-style-type: none"> 24hours clinical support Continual assessment by nurses and symptom management by Doctor Care training
Burnout of carers: social isolation, disruption of routines	<ul style="list-style-type: none"> Respite care in Hospice home if needed Arrangement of on-site care workers for relief
Lack of equipment such as hospital bed, oxygen concentrator	<ul style="list-style-type: none"> Arrangement for loan of equipment in advance Training on the use of equipment
Inadequate knowledge of impending symptoms and care	<ul style="list-style-type: none"> Preparation of family to take care of the dying patient Advice on signs of imminence death and care
Emotional burden on carers, such as anticipatory grief	<ul style="list-style-type: none"> Provide psychological support Bereavement support given prior to patient's death
Emergency situations	<ul style="list-style-type: none"> Prompt response and support to family with respect Transfer to Hospice Home if needed
Post death arrangements	<ul style="list-style-type: none"> Doctor and nurse visit for death certification Advice for transfer of body to JCHH mortuary

Figure 3. Intensive Professional Home Care Support

Social Impacts

Community

- Public awareness on patient's choice and autonomy will be raised.

Patients and Family Members

- Last wish of patient will be respected
- Unnecessary hospital admissions of patients in EoL will be reduced.
- Family members will feel 'no regrets' and will have lower risk of complicated grief.
- Patients will be able to enjoy more chances for bond development with family members.



Shing Siu Fan

Deputy Home Manager
Haven of Hope Nursing Home
Haven of Hope Christian Service

Shing Siu Fan, Florence, is the Deputy Home Manager of Haven of Hope Nursing Home under Haven of Hope Christian Service. She has been working in residential care for the elderly for over a decade. She graduated with a degree in nursing from the Chinese University of Hong Kong and a Master of Social Science in counselling from the City University of Hong Kong. Her passion is serving the elderly and enhancing their quality of life.



尊重生命 • 改變生命



Advance Care Planning Group in Nursing Home

Shing Siu Fan
Haven of Hope Christian Service



Background

The Haven of Hope Nursing Home serves older adults with severe impairment level and most of them suffered from various chronic illnesses.

Advanced Care Planning (ACP) in nursing home aims to promote shared decision making between elders and families as preparations for their end of life. It also enhances medical care which will meet elders and families' needs and expectation in nursing home.

- 01 around 1/3 old age home residents accept dying in place and majority prefer comfortable treatment (Chu et al., 2011)
- 02 ACP discussion should focus on but not limited to the condition of disease, treatment and patient's preferences, family value and concern should be considered as well (Hospital Authority, 2015)
- 03 Life review approach would help residents feel their lives were positive and happy and had a good conclusion



Description

Advance Care Planning Group in Nursing Home

Target group:

- Target group: Mentally competent clients (~15.6% of 270 residents in the nursing home)

Rationale:

- The ACP process involves the appraisal of personal values. Family members' readiness to engage in the group could enhance the discussion and group process. Moreover, volunteers with essential knowledge in the end of life care would show compassion and emotional support to residents.

Objectives of the program:

- To facilitate elderly to plan for and communicate their own wishes at end of life
- To encourage families to understand and concern residents' preferences and value

Content:

Designed with referencing 「自主晚晴心願」之生命紀錄影集 (Society for the Promotion of Hospice Care, 2017)

Session	Content
1	• Discussion on "what is a good death."
2	• Life review: Let residents express their lives in the past in four perspectives: 1) Happiness 2) Difficult 3) In the time of trouble 4) Sorrow
3	• Shared the relationship with their loved one • Encourage residents say words to their loved one
4	• Shared their wishes • Discussion on their funeral and burial arrangement
5	• Various kinds of life-sustaining treatment options are introduced • Encourage residents to express their preferences of end-of-life care

Details of the group:

• Group size:	6 residents and 2 family members
• Manpower:	The pilot group: 2 social workers, 1 nurse, 2 chaplains and 7 volunteers Future groups: 2 staff and 6 volunteers will hold a group
• No. of sessions:	5 sessions

Post-group follow up:

- Nursing home social worker, health care staff or chaplain will work with family members to understand and accept the choice of the life-sustaining treatment of residents made.
- Nursing home staff, social workers and chaplains will document their wishes

Evaluation:

- Each session comprised of too much issues in content to work on. Spiritual care and more group sessions will be considered in future group.

Game on relative importance in end-of-life



Group member's drawings



Exercise to facilitate family communication

Social Impacts

- Residents have opportunities to express their preferences
- Family members can alleviate burden in decision making in care when the residents are unable to make decision.
- Nursing home medical staff could make arrangement for residents at EoL according to their choice in life-sustaining treatment



So So Chi

Assistant Centre-in-charge
Ma On Shan District Elderly Community Centre
Evangelical Lutheran Church Social Service -Hong Kong

Life stories collector: I enjoy encountering different people and learning from their life experiences.

I believe in love and my favorite quote about life is "The most important thing in life is to learn how to give our love and to let it come in" (by Mitch Albom, the author of Tuesdays with Morrie).



基督教香港信義會
社會服務部





Background

A call from a bereaved daughter beside our years-long observation inspired the idea of this project. The daughter called to say "Thank You" as we had recorded the words, wills, and wishes of her father through our life and death educational project. After the conversation, we sent her back the photos and videos we had taken during the programs, the daughter was grateful. No matter what ways we used to record the words, wills, and wishes, it could be artworks, letters, videos or photos, but the point is all those things contain the heartfelt messages to connect the deceased and the bereaved. It is priceless for a family and what we could do at an earlier stage.

Rationale:

- It is very common that after one passed away, the bereaved would feel deep regrets. The regrets originate from the incomplete feeling about the unsaid and undone of both (Byrock, 2004; 蓮花基金會, 2013)
- The unfinished business may severely affect the relationship of the deceased and the bereaved. Those regrets could critically impact the bereavement adjustment and hinder the bereavement process(黃慧英, 2015)
- Good communication among the family at the end-of-life stage or even earlier could help to connect the family
- Any means which contains one's concerns, blessings, appreciation, and hope is the "BEST GIFT" to family(夏承捷, 2012; 堀繪里香, 2014; 黃慧英, 2011)
- For the deceased, to say the words, wills, and wishes by any means could soothe their fear of being forgotten. For the bereaved, the "GIFT" contains the concerns, blessings, appreciation, and hope of the deceased is kind of emotional connection and relationship extension (台灣安寧照顧基金會, 2014; 紀潔芳、鄭瓊宜, 2010)
- The "GIFT" can complete the family and is very powerful to fix and transform the family relationship as well as reconstruct the meaning of death(夏承捷, 2012; 基督教香港信義會, 2016)

Description

Target: Elderly and their families or caregivers

Objective:

1. To help elders record their heart words wishes, wills and hopes about life and death in the form of artworks, then share with the family
2. To strengthen the connections among the family even after the death of elders Content



Art based life & death experiential workshops

- use various arts to express wishes, wills and hopes or anything about life & death

Arts can tell

- after sharing or discussion on life and death issues, elders do their own creations



Connect the family

- After exhibition, artworks will return to the family as a kind of heritage



Public Exhibition

- exhibit the artworks of the elders
- invite the families to attend and share elders' life and death thoughts
- open to public as kind of life and death education



Social Impacts

- Talking about death is still taboo in Chinese society. To visualize and articulate the thoughts about life and death by artworks is a way to promote a cultural change.
- By choosing an appropriate means to let the elders express without a barrier and bridge them with their families to open the conversations of the hidden but wanted topic, is a kind of "revolution."
- The conversation not only reduces the regrets of death but also ensures better bereavement process which may prevent mental health issues including depression caused by complicated grief.



Wan Kit Lee, Wendy

Superintendent
Yam Pak Charitable Foundation King Lam Home for the Elderly
Christian Family Service Centre

I have over twenty years of working experience in the field of social work. I graduated with a Bachelor of Social Work from the City University of Hong Kong, an Executive Diploma in Advanced Business Management from the Chinese University of Hong Kong and a Master of Quality Management from the Polytechnic University of Hong Kong.



基督教家庭服務中心
Christian Family Service Centre



My Choice, My Wish, Your Promise

Wan Kit Lee
Christian Family Service Centre

Background

Yam Pak Charitable Foundation King Lam Home for the Elderly established in 1991, providing residential care to 104 elder persons. Most of the residents suffer from more than 3 chronic illness and around 50% are demented. Most residents at the home around 3 years before they die. All the staff is well trained in E-o-L.



Literature Review



Figure 1. Literature review on the issues and proposed solutions

Description

Aims :

- To enhance the sense of autonomy of the residents and their families at end of life
- To promote the concept of ACP among the residents and their families
- To build up own service model to implement ACP

Target : Residents and carers of Yam Pak Charitable Foundation King Lam Home for the Elderly

System Infrastructure

- Assess the needs of end of life care in admission
- Develop a system for staff to initiate ACP conversations with the residents and their carers
- Develop a system for documenting ACP
- Set up guideline and protocol

Engagement

- Understand family members' attitudes on ACP through a survey
- Engage the support from the top management to frontline staff and stakeholders in the community

Quality Improvement

- Develop indicators for measuring the effectiveness
- Hold supportive programme for staff and family members
- Share the experience with the public

Education

- Provide training to the staff, residents and carers
- Develop information resources
- Promote ACP and mutual support among the residents and their family members through different activities

Figure 2. Project Framework

Social Impacts

- With ACP conversations, individuals' preference is respected in end of life and reduce families' stress
- Frail elders can die at place of choice and avoid unnecessary hospitalization.





Wong Kin Shing

Deputy Medical Superintendent
Haven of Hope Annie Skau Holistic Care Centre

Wong Kin Shing, Paul, graduated from the University of Hong Kong's Faculty of Medicine in 1985. He is now the Deputy Medical Superintendent of Haven of Hope Sister Annie Skau Holistic Care Centre. He also serves as Honorary Consultant Physician and Nephrologist in the Department of Medicine at Pamela Youde Nethersole Eastern Hospital and Honorary Clinical Associate Professor in the Department of Medicine at the University of Hong Kong.



尊重生命 • 改變生命



Evaluation of Holistic Well-being and Spiritual Needs in Chinese Patients Receiving End-of-life (EOL) Care in Hong Kong

WONG Kin Shing Paul
 Haven of Hope Sister Annie Skau Holistic Care Centre

Background

Rationale for evaluating spiritual needs

Spiritual needs of patients are often overlooked in medical care planning. In the arena of EOL Care, omission of spiritual needs and care could have serious impact on the well-being of the patients and their care-givers. Spirituality and spiritual needs are defined as: "the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (Puchalski, et al., 2009).

Description

Methodology

A 30-items Holistic Well-being Scale developed for Chinese patients (from 20 to ≥ 60) by Chan et al. (2014) was used for measuring the Holistic well-being and spiritual needs of the patients and care-givers. This instrument was designed and validated based on a holistic view of health and well-being which emphasized on the interconnectedness of body, mind and spirit, under an Eastern cultural and philosophical framework. The focuses are on the dual goal of alleviating suffering and achieving enduring happiness (Eastern notions of "affliction" and "equanimity"). These 7 factors (domain) are grouped under "Affliction" and "Equanimity" (peace of mind). Medical records of patients under the HOHSASHCC JCECC Home Care (HC) program from January 2016 to December 2017 were reviewed for the holistic wellbeing and spiritual needs of the patients and caregivers by our professional team.

Results and Analysis

The record of 120 patients were reviewed. The mean age was 76.15 (range 60-105) years, male to female ratio 1:1.31 and the mean Palliative Performance Scale (PPS) was 62.83/100 (range 30-100). The mean number of symptoms was 2.45 (range 0-6) with 45% of the patients having 3 or more symptoms. Of the 120 patients, 27(22.5%) were surviving at the end of the study period, and 101 (84.2%) had ACP discussion with our home care workers.

Table 1: The Prevalence of Spiritual Distress

Dimension	Domain	Patients		Care givers	
		Frequency	Valid %	Frequency	Valid %
Affliction	Emotional vulnerabilit	35	29.7	28	23.9
	Body Irritation	46	39	38	32.5
	Spiritual disorientation	28	23.7	7	6
Equanimity	Non-attachment	50	42.4	51	43.6
	Mindful awareness	78	66.1	45	38.5
	General Vitality	99	83.9	86	73.5
	Spiritual Self-care	97	82.2	87	74.4

Social Impacts

Even though bodily symptoms can be controlled by medication or other physical therapy in EOL care, the overall spiritual distress, especially those related to peace of mind or equanimity in patients requiring EOL care (42.4 – 83.9%) and their care givers (38.5 – 74.4%) are very high. Spiritual needs in EOL care patients and their care givers are prevalent and spiritual workers should be incorporated as one of the main player in the EOL Care team.



Wong Oi Kau

Social Work Consultant
Hong Kong Family Welfare Society - Wanchai Office

Stephanie Oi Kau WONG, R.S.W., M. Soc. Sc. (Gerontology), M.S.W., Pg. D. in Mental Health, B.S.W., Accredited Mediator and Supervisor (Family), Certified Dementia Care Planner and Social Work Consultant of the Hong Kong Family Welfare Society, established the Elders and Caregivers Mental Health Service and, over time, has initiated projects on elderly depression, dementia and advanced care planning.



香港家庭福利會
Hong Kong Family Welfare Society





Background

With rising aging population, increasing chronic disease and filial piety beliefs, Advance Care Planning (ACP) is important to prepare elders facing their end of life, and communicate their wishes with their families for better quality of life and reduce family distress. Discussion of Advance Care Planning (ACP) can result in enhanced respect for personal EoL, reduced costs, improved patient and family satisfaction in hospitalized elderly patients and reduce stress in surviving families.

Hong Kong Family Welfare Society (HKFWS) has over 20 elderly service units serving about 4,000 elders. As at 7.12.2017, among those receiving our IHC & EHCC service, majority (64%) are 80-years-old or above, singletons (43%) or lived with spouse (25%) and lack of social support. Thirty-four percent of the users' reported chronic diseases are life-threatening diseases. It is a good opportunity to discuss with these users on End of life care (EoL) when their physical condition is relatively stable.



Description

Objective:

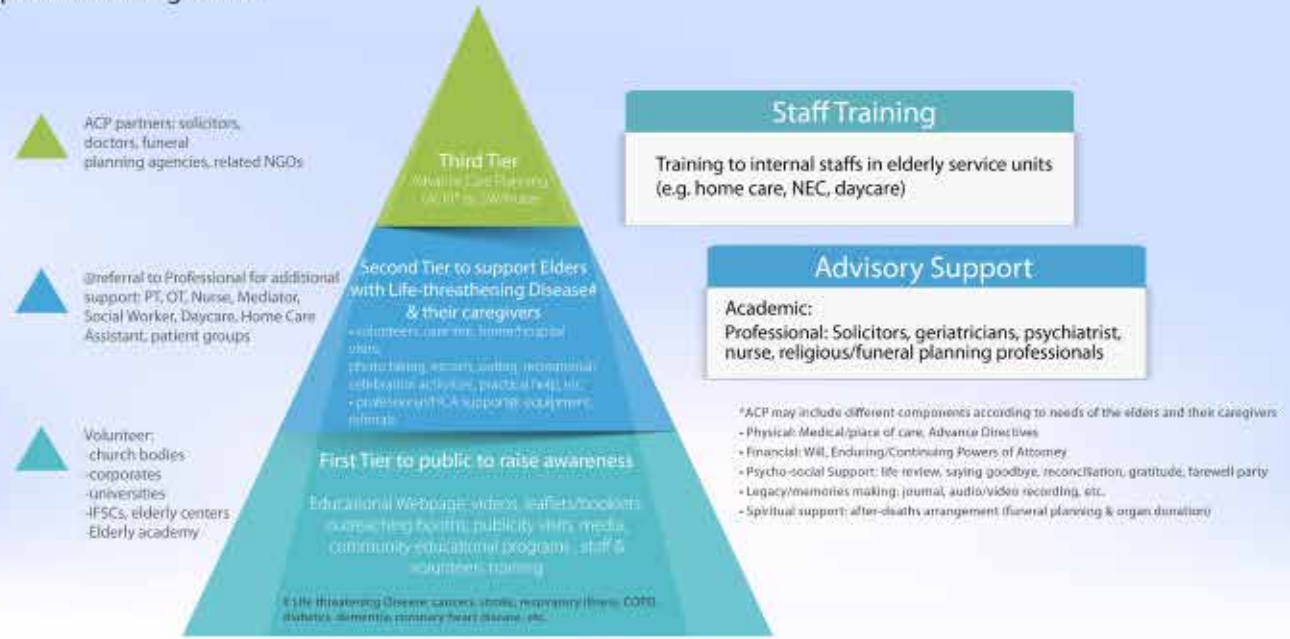
HKFWS planned to pilot an "ACP" Project to raise community awareness and support elders with life-threatening disease to face EoL for improving their quality of life and reduce caregivers' distress.

Target:

- The first tier aims at raising general public's understanding on ACP by different outreaching efforts.
- The second and third tiers target elders with life-threatening disease (e.g. cancers, stroke, respiratory illness, COPD, diabetes, dementia, coronary heart disease). Upon social worker's assessment, elders with mental capacity will be invited to do ACP.

Output and Impact

- Over 25 social workers/nurses received basic training on ACP and will start to do ACP cases. We have adopted similar three-tiers model in our Dementia and Depression Projects with favorable feedback.
- 36 volunteers were trained and 19 life reviews (LR) were completed with elders with life-threatening disease. According to self-report of the elders, they indicated improvements in mental-health well-being, self-acceptance, meaning in life, life completion, face illness and death, and social connection. For volunteers, they reported positive impact after doing the LR.





Wong Sui Kam

Pastoral Care Worker
Caritas Medical Centre Pastoral Catholic Care Unit
Diocesan Commission for Hospital Pastoral Care

Ivy Sui Kam Wong is a pastoral care worker. She is currently the Clinical Pastoral Education Assistant Supervisor of the Diocesan Commission for Hospital Pastoral Care. Over the years, she has been involved in the training of pastoral care volunteers. She is also a CPE supervisor in the Asia Association for Clinical Pastoral Education.



Good Death Movement Volunteer Training: Everyone in the Church Can Play a Role

Wong Sui Kam
Diocesan Commission for Hospital Pastoral Care



Background

End-of-life care is a matter for everyone in the community. Churches with a mission to care for the sick people are at good position to increase public awareness on the needs of patients with advance illnesses and their family, provide direct care and services, as well as to organize and train volunteers to build a compassionate, caring environment for end-of-life care.

Description

The project is initiated by The Diocesan Commission for Hospital Pastoral Care established in 1991 by the Catholic Diocese of Hong Kong. It is designed specifically to train parishioners who are interested in becoming end-of-life care volunteers in the church. It adopts collaborative approach to foster care partnership with hospitals, family members, and parish, professional and neighborhood volunteers to support families in need. The aim of the project is to mobilize parish resources in raising public awareness on life and death issues, empowering volunteer network to support patients and family members influenced by advance illnesses, relieving caregiving burden and enhancing quality of life. Main service components of the project included:

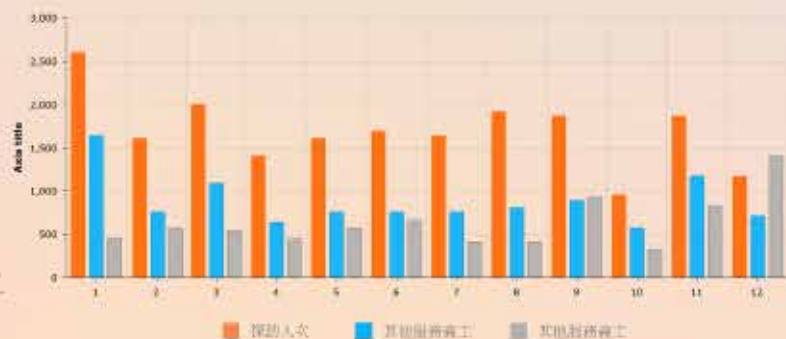


Result

2017 Number of Volunteers



2017 Volunteer Service Statistics



Social Impacts

The project is an initial attempt to promote good death through mobilizing parish resources. While established end-of-life support in important for patients and family members affected by advance illnesses, the role of the church should not be overlooked. The well-developed network in hospitals and NGOs, with medical and social professionals and the crucial function in providing spiritual support make it a perfect partner in holistic, integrative and collaborated end-of-life care in the community.



Leaders

JCECC Leadership Training Programme 2017/18



Wong Suk Han

Assistant Service Supervisor
The Salvation Army Kim Tin Residence for Senior Citizens
The Salvation Army

Avis Wong Suk Han is the Assistant Service Supervisor of the New Territories Integrated Residential Service for Senior Citizens under the Salvation Army. She has worked in the elderly service sector for over a decade. She graduated with a master's degree in social work from the University of Hong Kong. Her passion for serving the elderly gives her the strength to press on, and she continues to look into ways of enhancing quality of life for the elderly.

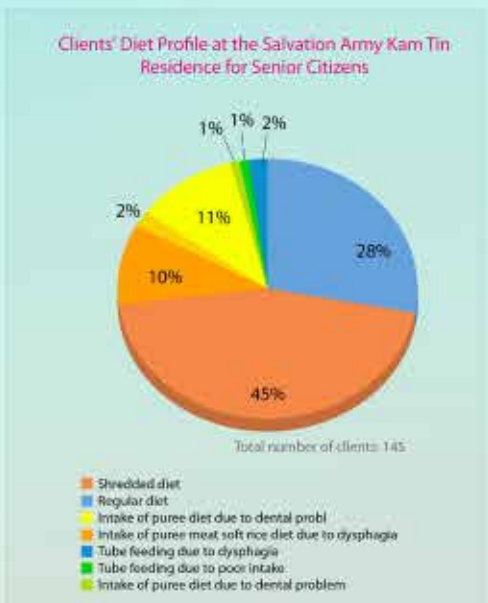


Dysphagia Management for Frail Elders

Avis, Wong Suk Han
The Salvation Army Kam Tin Residence for Senior Citizens

Background

Dysphagia is a prevalent difficulty among aging adults. Conservative estimates suggest up to 68% of residents in long-term care settings suffer from dysphagia (American Speech-Language-Hearing Association, 2018). In the Salvation Army Kam Tin Residence for Senior Citizens, about 70% of our 145 residents suffer from dysphagia requiring either thickening of fluids and/or alternation of diets to facilitate safety in oral intake. Modified diets lead to distortion of the food's original shape and texture. Some elders show strong resistance to "congee like" puree foods leading to poor intake and malnutrition. Upon admission to hospital, many may be put on tube feeding.



Literature Review



Improved puree diet

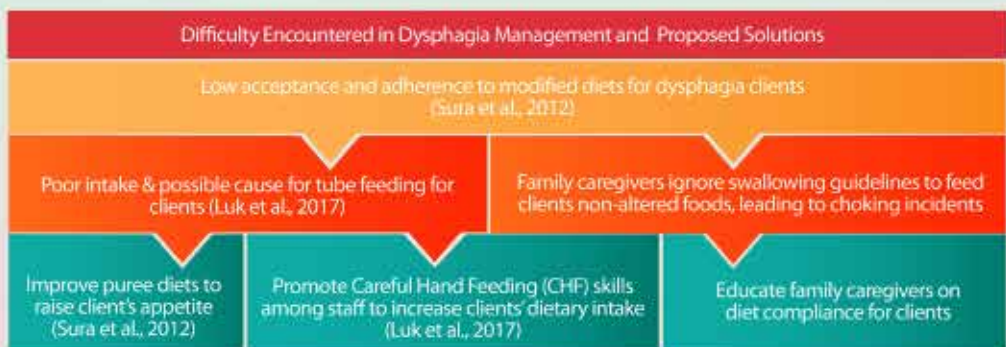


Figure 1: Literature review on the issues of difficulty encountered in dysphagia management and proposed solution

Description

This Project will initially be launched for 1 year in long-stay facilities of Salvation Army. Dietitian will be consulted to coach the chefs to use food molds to improve puree foods' traditional "congee-like" outlook. Speech therapists or nurses will deliver talks to 1) family caregivers on dysphagic information; and 2) our staff on CHF techniques. Newsletters will also be sent to educate family caregivers on importance of diet compliance. Measurement on the elders' intake level will be taken for project evaluation. Besides, questionnaires will also be distributed to evaluate the knowledge of the staff and family caregivers after training.

Social Impacts

This project is expected to bring about the following impacts:

- Community**
 - Increase public awareness on issue of dysphagia management
- Formal Caregivers**
 - Enhance staff competencies in applying CHF techniques to feed residents with dysphagia
- Elderly Residents and Family Members**
 - Increase residents nutritional intake through improved puree diets
 - Enhance family members' knowledge on symptoms of dysphagia and associated risks to enlist their support for diet compliance for dysphagic residents



Experiential learning in feeding skills



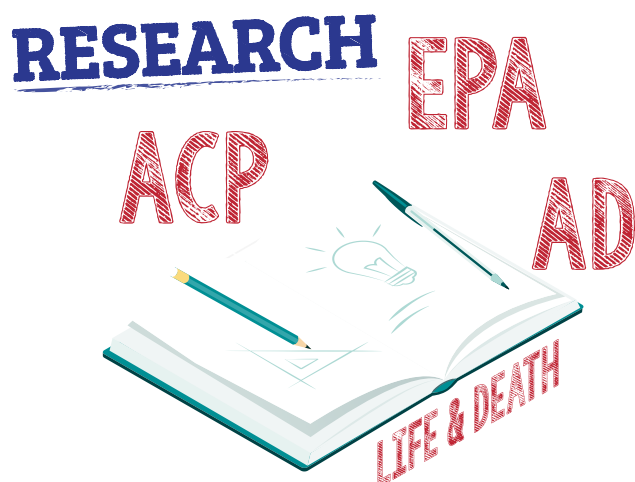
Workshop conducted by speech therapist on use of thickeners



Yeung Shou Fong, Annie

Superintendent
Buddhist Li Chong Yuet Ming Nursing Home for the Elderly
Heung Hoi Ching Kok Lin Association

After graduating from the CUHK MB ChB Programme in 1990, Dr Annie Yeung started her medical career at the Hospital Authority. She took up the Superintendent post at the HHCKLA Buddhist Li Chong Yuet Ming Nursing Home for the Elderly, the first of its kind, in 1998. Dr Yeung is now in charge of the nursing home and two community care services for the elderly. In addition to offering professional services, Dr Yeung devotes her time to serving the community and was awarded the Chief Executive's Commendation for Public Services in 2008 in recognition of her contributions.



AD, ACP & EPA – what do we need for End-of-Life care? A reflection of caring professions

Dr. Yeung Shou Fong
Heung Hoi Ching Kok Lin Association

Background

Cross sectional study with anonymous questionnaire survey was carried out in March 2018. Caring professions including doctors, nurses, social workers, physiotherapists and occupational therapists working at nursing home were invited to reveal their views on end-of-life care (EoLC) plans for themselves and close relatives and assess their view and knowledge of advance directive (AD), advance care planning (ACP) and enduring power of attorney (EPA).

RESULTS:

62 staff were being invited. The response rate was 90.3%. Most respondents had worked in own field for 5 years or more (Figure 1).

Views on Own EoLC Discussion	Views on Their Close Relatives' EoLC Discussion
<ul style="list-style-type: none"> 84% expressed willingness to discuss own EoLC 	<ul style="list-style-type: none"> 79% reckoned their close relatives were ready to discuss own EoLC
<ul style="list-style-type: none"> When would like to discuss? <ul style="list-style-type: none"> 53% when they were diagnosed with life-threatening illnesses 32% when they reach certain age (ranging from 40-80y.o.; 50-60y.o. in majority) 	<ul style="list-style-type: none"> Who to discuss with? <ul style="list-style-type: none"> Majority: with spouses Adult children become more significant
<ul style="list-style-type: none"> Who to discuss with? <ul style="list-style-type: none"> 70%: with spouses 	

(Figure 2)

RESEARCH

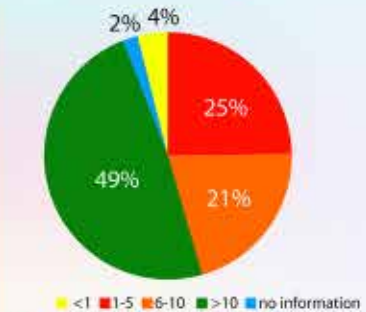
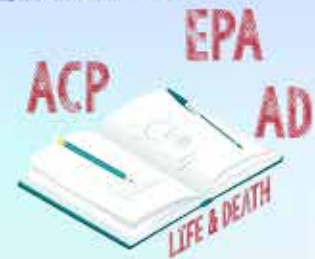


Figure 1. Year of Services in profession



Concerns in EoLC: Personal and nursing care was placed as the top priority (Figure 3).

Views and knowledge on AD, ACP & EPA:

Subjects were asked to weight 0 to 4 on the importance and knowledge of AD, ACP and EPA on EoLC

Importance:	3.14	3.16	2.79
Knowledge:	2.33	2.02	1.33



Figure 3. Key Concerns on EoL plan

Simple "Yes/No" questions on the legal status of AD, ACP and EPA were used to test the knowledge of the subjects on these three areas. Only 21% could correctly answer all three questions.

DISCUSSION:

This study shows that the subjects are ready to discuss own EoLC issue. This reflects that professions, with their knowledge on aging and disease process, prefer early planning. And they are more concern about the nursing and personal care being received during their last stage. This finding gives a reflection to the profession on what and when to discuss with own patients.

Despite caring professions consider AD, ACP and EPA having value in EoLC, this study exposes the inadequacy in the knowledge and applications of these means. In order to enhance the acceptance and utilization of EoLC plan,

- Legal aspects in EoLC shall be included in the curriculum of professional training.
- Continuous education programmes shall be arranged for professions.
- The Government shall promote the concept AD, ACP and EPA as part of public education.
- "Life and Death" topics can be incorporated in the General Education of secondary school.

CONCLUSION:

This study explores the attitudes and knowledge of caring professions regarding EoLC. The findings indicate that care professions are ready to discuss own care and engage close relatives in discussion. The overall fair knowledge of AD, ACP and EPA suggests "Life and Death" as part of professional training, public education and General Education of secondary school is crucial to get the community prepared for the aging population.



Leaders

JCECC Leadership Training Programme 2017/18



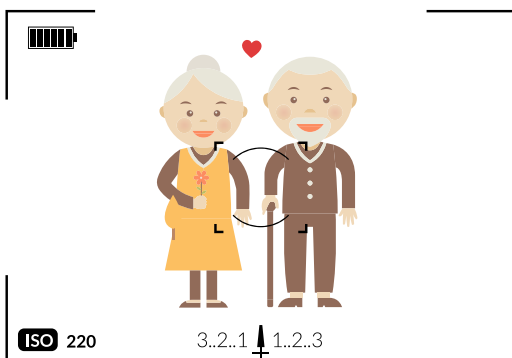
Yiu Lai Shan, Iddy (BSW, MCS)

Service Director
Hong Kong Sheng Kung Hui Welfare Council Limited

Iddy Yiu was a service supervisor of a primary school counseling service and a superintendent of a residential care home for the elderly. She is now the Superintendent (Service Director) of Hong Kong Sheng Kung Hui Nursing Home. Her belief that "God's grace is sufficient, and life is full of hope" has motivated her to walk closely with her residents, clients and colleagues. She loves and cherishes life. Thus, she always wants to contribute more and to dedicate herself to meaningful service.



香港聖公會福利協會有限公司
HONG KONG SHENG KUNG HUI WELFARE COUNCIL LIMITED





Background

Elderly residents in nursing home are at an average age of over 90. Their frailty conditions can be imagined: many of them have medical, functional and even cognitive and emotional impairments; their ability to live independently decline; and are suffering from multiple illnesses and the side effects of treatment. Communication problems are also common, residents may have difficulties in sharing their memories and life stories verbally. The use of photography could be an innovative, visual and artistic way to help the elders to review lives, fulfill wishes and leave a legacy.

Description

One of the nursing homes under Hong Kong Sheng Kung Hui Welfare Council Limited introduced the **Life Story Photography**. The project aims to facilitate frail elders to re-tell their life stories, fulfill their wishes and leave a legacy, and ultimately promote their wellbeing. The process would not be simple. Social workers and photographers have to work together, conducting interviews with residents and their core family members to elicit life stories and capture the significant moments of the elders. Photographers will then use their creative instincts to create images photographic tale which is unique to each resident.



A 93 years old bed-ridden lady shared her last wish was to scatter her cremated ashes at the field, capturing the meaning of "The fallen petals, in return, will transform into the soil to nourish the flower in spring" (「化作春泥更護花」)



Social Impacts

The project engages frail elderly residents to talk about their life stories and wishes, facilitate mutual communication between residents and family members. As an extended activity, Life Story Photography Roving Exhibition will be held at different venues. This serves as an excellent platform to increase public awareness on aging and end-of-life care issues.





Yu Mei-ying

Superintendent
Tsang Shiu Tim Home for the Elderly & Lee Quo Wei Day Rehabilitation & Care Centre, The Hong Kong Society for Rehabilitation

- Superintendent:
The Hong Kong Society for Rehabilitation
Tsang Shiu Tim Home for the Elderly
- Supervise home services and a day rehab center
- Social worker
- Graduated with a Master of Social Sciences in Social Work (City University of Hong Kong)
- Have worked in the elderly residential setting for over ten years

The field of elderly services is challenging. I enjoy working in the field.



香港復康會
The Hong Kong Society
for Rehabilitation





Background

Most of the residents in residential homes are frail elders and suffered from varies of chronic illness such as dementia, stroke, heart disease and cancer. "Love your life" aims to encourage elders to talk and express their thoughts towards life and death issues. A series of programs are designed to promote the life and death education as well as enhance the quality of life of these residents.

Literature Review

The Scope of Death (1977), Daniel Leviton identified the goals of death education and defined death education as a developmental process in which death-related knowledge and the implications resulting from that knowledge are transmitted. He identified the following goals of death education: *primary prevention* (preparing individuals for eventual death events), *intervention* (helping people face personal aspects of death), and *rehabilitation* (understanding and learning from death-related crises). More specific goals included promoting comfortable interactions with the dying, removing taboos and reducing anxiety.

Description

"Love your life" -Life and Death Education

1. Objectives of the project:

- To encourage elders to have a better understanding of life and death issue.
- To prepare elders for the end of life through different programs and to enjoy their life with a positive attitude.
- To enhance elders' quality of life.

3. Details of the project

First year (Primary prevention):

A special care team (關顧小組) is established to promote and carry out the project.

Activities	Target
"Life and Death" movies sharing give elders a platform to discuss and see other people's views.	40 elders and their relatives
Life and Death education to residents and family through talk and group.	40 elders and their relatives
"Spiritual Health Group" is launched and eight sessions included. It aims to help elders to face their loss with positive attitude and treasure every moment they live.	6-8 elders

2. Rationale

- Well understanding of life and death issue as companioned with positive attitude bring elders "good death" and "no regret".
- 'Integrative Body-Mind-Spirit Model' is proved has a significant positive effect on chronic illness patients.

Second year (Intervention and Rehabilitation):

Activities	Target
Carry out horticultural therapeutic group, enhance positive emotion and gain the happiness from planting.	8 elders
Selected elders (with chronic illness) will be matched to team members and receive their regular visits and companionship. A series of bed-side activities are designed to serve frail elders including massage, story/essay telling, etc. to release their discomfort and enrich daily life.	10 elders
Volunteers will help elders to make their own life story books. It aims to let elders ensure their past life's contribution.	3 elders
"Clap for Our Lives" group: It helps elders face death issue with positive attitude and prepare the end of life.	6-8 elders

Evaluation

Individual interview and questionnaire are designed to collect the participant's feedback and change.

Social Impacts

"Life and Death" is still a taboo among elders. There is a need to promote life and death education. Attitude change brings the change of quality of life. People may have a broader mind-set when encounter life and death issue.





Notes

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