





Initiated and Funded by:



香港賽馬會慈善信託基金 The Hong Kong Jockey Club Charities Trust 心向步同進 RIDING HIGH TOGETHER

Partner Institution:





Partners:













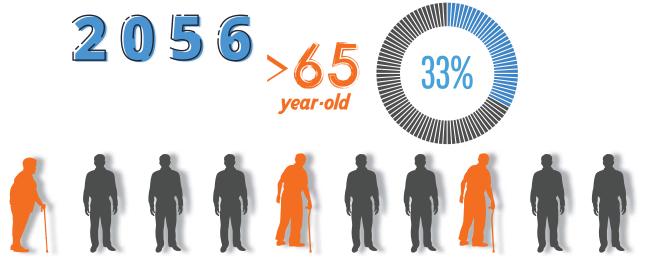


Feature

Increasing Demands for Engl-Of-Life Care

Quality Improvement in Research-based Services

What if three out of ten seniors were living on the street one day? It is not unimaginable. According to the HKSAR Census and Statistics Department, (2017), the proportion of the population aged 65 and over is projected to increase to 33% in 2056 ¹.



It is typical for elderlies to be living with disabilities at the end of their lives. For example, nearly 80% of deaths were elderlies aged 65 and over in 2017. Around half of the leading causes of death were chronic illnesses such as malignant neoplasms, pneumonia, diseases of the heart, and cerebrovascular diseases etc².

Demands for community end-of-life care (EoLC) are expected to increase accordingly.

There are several hospitals, hospices and Non-Governmental Organisations (NGOs) providing EoLC services. However, there is a lack of uniform guidelines and unified long-term developmental directions. In order to understand the effectiveness of different service models and improve the quality of EoLC, rigorous and empirical research is critical.

Therefore, five NGO partners under The Jockey Club End-of-Life Community Care Project ("JCECC") have provided community-EoLC services since January 2016, thereby, closing the service gap with five different service models respectively. Among the five service models, one will be carried out at elderly homes and four focused on providing home-based support through different interventions. The Faculty of Social Sciences at HKU has led the programme evaluation and impact assessment to review the effectiveness of five different service models. The evaluation results provide references and directions for future development as well as strategies for EoLC in Hong Kong. The simplified results of the report are in the following sections.

^{&#}x27;HKSAR Census and Statistics Department. (2017). Hong Kong population projection 2017-2066. Retrieved at: https://www.statistics.gov.hk/pub/B1120015072017XXXXB0100.pdf

²HKSAR Centre for Health Protection, Department of Health. (2018). Number of deaths by leading causes of death by sex by age in 2017. Retrieved at https://www.chp.gov.hk/en/statistics/data/10/27/340.html



Feature

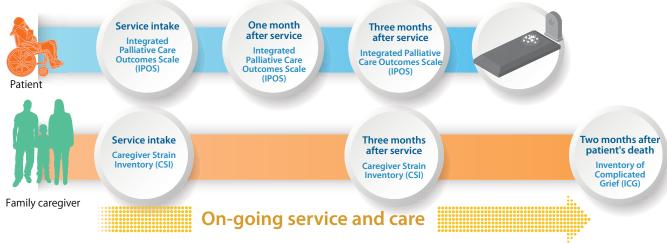
Evaluation with a Dual Emphasis on Quality and Quantity, Multi-level Understanding of the Effectiveness

The service objectives are centred around enhancing the quality of life for patients and family caregivers, though the four home-based service models differ in intervention strategies. In order to evaluate the effectiveness of each model, a common evaluation framework was developed.

The evaluation was divided into two parts. The quantitative part was carried out to observe and record psycho-social changes of patients and family caregivers statistically utilising evidence-based questionnaires. The qualitative part was to discover the unique experience of different cases through in-depth interviews.

The first part consists of a quantitative structured questionnaire, with a pre-post-follow up clinical assessment conducted with patients and caregivers using standardised measurements. For patients, their physical symptoms, emotions, practical concerns, perceived family anxiety, barriers in sharing feelings with family members and information needs were assessed by "The Integrated Palliative Care Outcomes Scale" (IPOS)³ at service intake, one month after service, and three months after the service respectively. For family caregivers, their stress around caregiving was assessed by the "Caregiver Strain Inventory" (CSI)⁴ at service intake and three month after the service respectively. Level of grief was assessed by the Chinese "Inventory of Complicated Grief" (ICG)⁵ at two months after the patient's death. Moreover, all patients and family members were invited to participate in the satisfaction surveys through phone interviews.

The second part consists of qualitative in-depth interviews. The HKU research team has interviewed eight families using systematic random sampling annually in order to understand the unique experiences and feelings of service users more in-depth.



The above evaluation framework was applied with four service models within four NGOs that focus on different areas. "St. James' Settlement" puts emphasis on organising family activities using a family approach; "Haven of Hope Christian Service" specialises in the care in spirituality and provides strong home-care support; "The Hong Kong Society for Rehabilitation" focuses on EoLC for non-cancer patients at home and empowers patients and families in symptom self-management; "S.K.H. Holy Carpenter Church District Elderly Community Centre" concentrates on volunteer training and medical-social collaboration.

³Cicely Saunders Institute, King's College London. (2012). Integrated POS (IPOS) in English. Retrieved at https://pos-pal.org/maix/ipos_in_english.php

⁴Chan, W. C. H., Chan, C. L. F., & Suen, M. (2013). Validation of the Chinese version of the Modified Caregivers Strain Index among Hong Kong caregivers: An initiative of medical social workers. Health & Social Work, 38(4), 214 – 221. Doi: 10.1093/hsw/hlt021

Tang, S. & Chow, A. Y. M. (2017). How do risk factors affect bereavement outcomes in later life? An exploration of the mediating role of dual process coping. Psychiatry Research, 255, 297-303.



Feature

Evaluation Results: All-rounded Physical, Psychological, Social and Spiritual Improvement

There were 203 patients and 128 family caregivers that completed the assessments in 3 time-points up to June 30, 2018.

The close relationship between mind and body

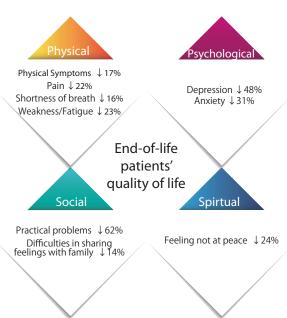
Results showed that patients experienced a significant reduction of problems in all realms of physical symptoms, emotional symptoms, communication of feelings, and practical problems. In physical aspect, the overall "Physical Symptoms" of patients have dropped by 17%, and the differences are statistically significant in "Pain", "Shortness of breath" and "Weakness/Fatigue". It is noteworthy that all patients were at the end of life, meaning that their conditions continually deteriorate. Despite this, their physical conditions have reversed from deterioration to improvement "abnormally" under the help of the services. It reflects the effectiveness of EoLC. In psychosocial and spiritual aspects, "Patient Depression" and "Patient Anxiety" have been reduced by 48% and 31% respectively, and their "Feeling not at peace" have been reduced by 24%. There was also improvement in communication of feelings with family members.

"My heart disease 'disappeared' when the social worker played chess with me." A patient shared his experiences in an in-depth interview. Heart diseases would not disappear simply through playing chess, the message behind is: mind and body are closely related. Though the services mainly provided psychosocial support, they offered help physically as well.

Practical support to relieve burden of care

"Patients' Practical Problems" such as financial difficulties and medical arrangements have dropped by 62% drastically. Most families indicated that they have received practical supports like outpatient escort services, assistance in the shopping, lending of hospital beds and wheelchairs, hearing aids or home-cleaning, etc.

The seemingly small practical problems are in fact significant energy consuming issues towards patients' and caregivers'. Therefore, resolving practical concerns are believed to improve patients' physical and mental health.





For family caregivers, their anxiety and caregiver strain have decreased by 19% and 16% at 3 months after service respectively. 88.5% of interviewed caregivers had low risks of complicated grief 2 months after the patient's death, which reflected the service was

effective in helping family caregivers to overcome grief.

A caregiver shared in the in-depth interview: "(The social worker taught me) simple nonverbal communication skills such as a touch. My brother could feel that even though he couldn't answer me.

moment, probably not real, but I felt really touched."

The experience reflected that the service has helped patients and family members to express love and care in time, which helps them better adjust to be reavement after the patients passed away.

I followed the social worker's instructions and I have no regrets. My brother seemed to tear up at that

Patient-centered end-of-life care

How to provide all-rounded physical, psychological, social and spiritual improvement to patients and caregivers in our community-EoLC services? The below sharing by a caregiver in the in-depth interview would bring some insight: "They treated her (the patient) as an ordinary elderly (not a patient), and asked her about her grandchildren, if she had thought of going somewhere with her grandchildren rather than only talking about her disease. This helped us not to solely focus on the disease."

With the advanced illness being acknowledged, the healthcare professionals continue to treat the patients as human beings, and illness is just a small part of them. It is likely that the feeling of being respected can improve patients' health in all aspects. Consistent with the positive reviews above, 97.6% patients and 95.3% caregivers indicated that they were satisfied with the services in the "Satisfaction surveys".

Different service models with different strengths

The above findings showed that the overall physical, psychosocial and spiritual status of patients and their families have improved significantly under all service models. As analysed, the models share a few common components but also have their unique elements, resulting in a different level of impacts on the differentiated outcomes. The ultimate goal of this project is to develop a comprehensive and holistic community-based EoLC model for Hong Kong.

The detailed research findings will be released later, please pay attention to our website: www.jcecc.hk





Since the JCECC Project's launch in 2016, it has created impact and made meaningful progress in enhancing the capacity of end-of-life healthcare and social care professionals through training, increasing awareness of and disseminate knowledge amongst the general public and developing a compassionate community through public education and volunteering activities. The project's service provisions to end-of-life patients and family members through its five service models were also significant. The following briefly presents the overall project achievement in the past two and a half years.

Professional Training for Health and Social Care Professionals

Nurturing health and social care professionals and leaders in end-of-life care

- Over 5,300 medical and allied healthcare professionals in hospitals have been trained
- Over 2,100 health and social care professionals in the community have been trained
- Enhanced competence of professionals in end-of-life care after training





Public Education

- ◆ 22,500 members of the public were reached through public education programmes
- ♦ Over 350,000 public views through multi-media channels were recorded









JCECC Mini-movie



Professional Training for Residential Care Home for the Elderly (RCHE) staff



Developing end-of-life care practices in 36 elderly homes

- 36 elderly homes operated by 18 NGOs have participated in the project
- Over 1,900 professional and frontline workers of elderly homes have been trained
- (Relief of medical care burden in public hospitals





Training for Volunteers

Promoting community engagement and raising public awareness of end-of-life care services

560 volunteers have been engaged to support end-of-life care services in the community



Volunteer Sharing and Appreciation Event





Fulfillment of last wishes



Service Provision

First large scale quality support services to address the needs of dying patients

♦ About 3,800 patients and their family members have been served through five service models



Family Capacity Building Model Cheering@Home End-of-Life Care Services



Enhanced Community-based Health Care Model **Hospice at Home**





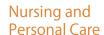
Non-cancer Patient Capacity Building Model "Life Rainbow" End-of-Life Care Services



Community Volunteer Capacity Building Model "Hospice in Family" Home Care Support Services



Residential Care Homes for the Elderly (RCHE) Model **End-of-Life Care in Residential Care Homes for the Elderly**





End-of-Life Counselling by Social Workers



Emotional Support by Volunteers



Discussions on End-of-Life Care Plan



Services





Project's Medical-social Collaboration

Building a viable framework for medical-social collaboration

◆ The Project has established close collaboration with 13 public hospitals in 6 clusters of Hospital Authority











Key Highlights

A Brief Review on JCECC International Conference 2018





The International Conference 2018 which was organised by the Jockey Club End-of-Life Community Care Project (JCECC), titled "Innovation and Impact: The Review and Vision of Community End-of-Life Care", concluded successfully on June 20th and 21st. The conference, including workshops or visits before and afterward, has attracted more than 450 participants from 10 countries or regions.

The 3 renowned keynote speakers from 3 different continents were: Dr Stephen Connor, the Executive Director of Worldwide Hospice Palliative Care Alliance (WHPCA); Professor Irene Higginson, the Professor of Palliative Care and Policy in King's College London and Dr Wang Ying Wei, the Associate Professor of Tzu Chi University. They shared lots of precious idea and information which can be concluded as follows:

- 1. Palliative and healthcare development and review from a global perspective. According to the research by World Health Organisation in 2014, only around 14% of those needing palliative care receive palliative care services at the end of life worldwide. And the per capita number of palliative care service providers in developed regions is much larger than those in developing regions. Therefore, palliative and healthcare professions in developed regions should share more about the experience of research, education, and care, to foster the development of EoLC in developing regions.
- 2. The importance of community engagement. Developed countries like the UK have launched the "Compassionate Communities" movement for years, and there were numerous related activities to arouse public awareness and engagement in EoLC. However, the EoLC public engagement experience in developing countries such as "Neighborhood Network in Palliative Care" in Kerala, India and "Compassionate Communities" in Korail Slum, Bangladesh shared by Dr Connor, might bring more insights to regions in a similar context. Dr Wang shared Taiwan's experience in making good use of the media in promoting EoLC.
- 3. The importance of team-cooperation and building human capacity. The holistic EoLC needs the cooperation of medical professions, social workers, educators, and scholars. Professor Higginson shared about the experience of "Cicely Saunders Institute at King's College London" in the UK. It is a physical hub that brings academics, healthcare professionals, community organisations, patients and carers together for a network of translation and applied research, which might be the reference in EoLC to other regions.

The 3 keynote speakers have also held 3 interactive pre-conference workshops to share and discuss about the global trend of community based home care models in palliative care, how to improve researches in EoLC and the development of EoLC in Taiwan respectively. There were visits to Tsz Shan Monastery, Jockey Club Home for Hospice and elderly homes after the conference, to introduce the situation of spiritual care and hospice care in Hong Kong.

The Conference has provided a platform for local and international practitioners, educators and researchers exchanging inspiring practice and research wisdom as well as establishing a partnership in EoLC, thus improving the quality of EoLC worldwide. Presentation materials in the conference can now be reviewed in the official website: www.jcecc.hk/conf2018/presentation-materials.html







Life and death are inevitable stages of life. Everyone may have different ideas and wishes of how to be treated in their end of life, yet it is not easy to talk about death in daily life, especially we always have an inexplicable fear of death in traditional Chinese society.

JCECC has designed the "Cradle to Grave Conversations" Card Game, to transform traditional poker cards into game cards supporting EoLC conversations. These game cards contain interesting questions, facts, and activities that encourage bonding between players to gain a better understanding of each other's values and preferences. Players can go through the cards from beginning to end, shuffle them, or start with cards most relevant to their concerns to making EoLC conversations more engaging. Players can feel free to invent your own creative ways to use them as conversation starters.

The game cards are designed according to the traditional card game "Poker". The cards are divided into four categories of Spades, Hearts, Clubs, and Diamonds, and each category has different themes:



Spades: How well do you know me? Everyone has unique life stories and personalities, with their values and beliefs permeating their everyday choices and preferences. Players can make use of questions on cards to get to know each other better.



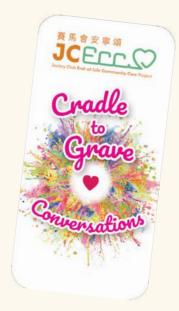
Hearts: Interesting facts from cradle to grave. There are many different discussions and suggestions on EoLC and Life and Death. These ten interesting facts about death and EoLC could shed light on issues surrounding myths and cultural preconceptions.



Clubs: From Fairy Tales to End of Life. There are common end-of-life issues and values behind fairy tales and famous stories. Players can take part in role play as the main characters of these stories, to re-think and discuss the decisions of those characters in end of life.



Diamonds: Your wishes. This part encourages players to review their own life stories, communicate their end-of-life wishes to others and begin EoLC conversations.



There are several suggested games in the guide to strengthen players' relationship. And the two Jokers have been re-designed into gift cards which allow players to write their own messages to express their feelings and love. The team also encourages everyone to design and develop their own games by creativity and to start a discussion on Life and Death issue with the help of the card game.

For more information on the "Cradle to Grave Conversations" Card Game, please contact jcecc@hku.hk.



Project partners



The JCECC: "Hospice in Family" Home Care Support Services have trained nearly 100 volunteers to provide end-of-life support, such as home visiting and outing services to patients and families. As of July 2018, the project has served 410 patients and families, as well as provided 2,127 counseling and service sessions.

The service has also provided professional training and public talks to 75 NGOs, schools, churches and hospitals (Tuen Mun Hospital and Pok Oi Hospital) with 2,964 participants. Furthermore, the service has worked closely with the Medical Palliative Medicine Team, and Hospice Center of Tuen Mun Hospital. Nearly 500 end-of-life patients and families have joined the group and outing, such as Disneyland visit.





香港復康會 The Hong Kong Society

for Rehabilitation

The JCECC: "Life Rainbow" End-of-Life Care Services provides quality community end-of-life care to people with late stage chronic illness and their family members who live in Wanchai and Eastern District. As of end-August 2018 the project has served 174 end-of-life patients and 325 family members. The project successfully mobilised 125 community volunteers, 40 professional

volunteers and 80 members of self-help organisations to care for and contribute into the end-of-life care service development. In September 2018, "A Moment: Art Exhibition of End-of-Life Care

Service" was launched as a signature event in this round-up year for public members to join and understand more about the life stories of end-of-life patients and their families through the patients' artworks and meaningful objects, so as to promote the awareness on end-of-life care service in the local community.





The JCECC: Cheering@Home End-of-Life Care Services discovered that some EoL elderlies without children who have fixed assets are unable to take care of themselves and their financial matters as they become mentally incapacitated. This not only burdens their caregivers but also potentially creates unwanted family conflicts. As a result, St. James' Settlement's social workers began to study and understand related bills and legal terms since 2017. The organisation has also invited solicitor Ms Angelina Luk for her guidance and professional opinions. Through public seminars and focus groups, they have educated elderlies on EoL arrangements and actively encouraged them to ask questions and express their

opinions. Corresponding to "The Consultation Paper on the Continuing Powers of Attorney Bill" by the Law Reform Commission of Hong Kong, St. James' Settlement organised a brainstorming meeting

in March 2018 with around 50 elderlies. Attendees expressed that the Social Welfare Department with high credibility is a suitable choice as an authorised organisation for elderlies who have no children or relatives. They thought other social welfare organisations that have served those elderlies for years could also be suitable alternatives.



Project partners





Under JCECC, the CUHK Jockey Club Institute of Ageing (IoA) has worked closely with the hospital network in the Hospital Authority (HA) New Territories East Cluster (NTEC); RCHEs; Community Organisations and Patients' Association. From November 1, 2015 to August 31, 2018, 279 information sessions and workshops for healthcare staff, patients and their relatives, volunteers and public have been organised with more than 9,900 attendees.

An educational booklet on "Good Death" was published with the goal of empowering and supporting the public to prepare for EoLC matters. Please visit online version at www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Good_Death_Booklet.pdf. Two large-scale public events on EoLC

education were held on March and August 2018. Nearly 800 public and healthcare professionals were attracted to join various seminars, followed by several interactive workshops with over 630 participants in total.





The JCECC: End-of-Life Care in Residential Care Homes for the Elderly are serving 36 subvented RCHEs to deliver quality EoLC services in Kowloon East, Kowloon Central and Kowloon West respectively. Total 324 training sessions with over 1,900 RCHEs staff received training since 2016. From July 2016 till September 2018, a total of 136 EoL cases received services and 114 residents signed Advance Directive. The project organised 8 public talks to arouse the awareness of the importance and concept of Advance Care Planning to the public; provide choices and update information

on dying at home etc. Over 1,000 general public attended the talks and positive feedback was received.

A professional seminar on EoLC for late-stage dementia was held on 27 April 2018 with 245 attendances of social services and allied health colleagues. Psychogeriatric specialists, community nurses, RCHEs staff and family members of residents were invited to share their experience and practice wisdom in the seminar.





The JCECC: Hospice at Home has been launched for two and a half years. To this day, "Hospice at Home" service has served more than 167 end-of-life patients and their family caregivers. The Haven of Hope Sister Annie Skau Holistic Care Centre's Palliative Care Department strives to provide holistic medical care, rehabilitation and all-rounded spiritual care to its

end-of-life patients and their family. The plan is implemented through a case management model, cooperating closely with referral organisations, thus bringing palliative care support to patients' homes;

and also strengthens support and communications between hospitals and the community. It helps to decrease and avoid unnecessary hospital admissions amongst patients. Patients can, therefore, stay in their familiar home environment with their loved ones, being respected, achieving spiritual peacefulness and enjoying quality time at the end of their lives.







JCECC has helped
enhance EoLC in Hong Kong
by professional training, public
education, academic research and
support to NGO partners through
multi-disciplinary, multi-institutional
and cross-sectoral collaboration in
the past three years. A video on the
overall project impact can now
be viewed at JCECC website
online: www.jcecc.hk/projecthighlight

Past Events

From January to August
2018, the JCECC project team
has invited numerous renowned
local and international experts to
conduct 10 professional workshops
and 14 public seminars (including the
international conference held in June),
to enhance professional competence
on psychosocial and spiritual care,
communication and end-of-life decision
making, and increase public awareness
on EoLC.

Related materials can be found at www.jcecc.hk







Professor Danai Papadatou

Professor of Clinical Psychology Faculty of Nursing National and Kapodistrian University of Athens Professor Danai Papadatou has extensive experience in childhood bereavement support and pediatric palliative home care services. She shared five "Seasons" in the family's trajectory parallel to the course of illness, and how patients and caregivers can accompany children and adolescents:

- 1. "Season of major Life Disruptions" caused by the diagnosis of life-threatening illness;
- 2. "Season of establishing a New Normalcy" in adaptation to the challenges of illness and treatment;
- 3. "Season of Liminality" when the decline of patients' health condition;
- 4. "Season of Separation" when facing death;
- 5. "Season of Relearning the World" in bereavement.

Moreover, she shared about how to reduce professional burnout by making use of "Meaning Attribution" to interpret death and striking a balance concerning patients/parents and self.

Professional Trainings

March 7, 2018

Workshop on Distress at the End-of-Life Care: Fostering a Culture of Care and Support for Professionals and Teams

Public Seminars

March 6, 2018

Seminar on Supporting Children and Adolescents through the Dying Process and the Death of a Family Member





Professor Edward Canda

Professor and Director Spiritual Diversity Initiative The University of Kansas



Ms Hwi-Ja Canda Medical Social Worker Lawrence Memorial Hospital in Lawrence, Kansas

Professor Edward Canda is the expert in connecting cultural diversity, spirituality, and resilience in health and mental health, and Ms Hwi-Ja Canda is an experienced medical social worker. They shared that spiritual care should not be limited to religion, but should be a process of human life and development in searching for a sense of meaning, purpose, morality, and well-being. Spirituality in EoLC can help patients and families to overcome the challenges of death and illness, as well as help health care professionals to reduce burnout.

They led a meditation in the workshop to help healthcare professionals to find meaning and achieve acceptance, enabling them to live in the moment with spiritual peace. Moreover, they introduced tools to access spirituality in EoLC settings and gave practical information on Advance Care Planning.

Professional Trainings

May 16-18, 2018

Workshop on: Spiritually Sensitive Assessment and Interventions in End-of-Life Care: Theory, Practice, and Experience

Workshop on: Preventing Burnout and Promoting Well-Being for Helpers in End-of-Life Settings

Seminar on: Making End-of-life Wishes Known to Family and Health Care Providers

Public Seminars

May 19, 2018

Seminar on Spiritual Growth at the End of Life





Professor Chantal Co-Shi Chao

Emeritus Professor National Cheng Kung University, Taiwan Professor Chao was named "Mother of Palliative Care in Taiwan" and has helped establish Taiwan's palliative care service model, education curriculum, and policy. Attendees in her seminars could take Taiwan's experience as a reference for EoLC development in Hong Kong.

She shared her views on what constitutes good quality of EoLC in the context of a team approach, and Taiwan's experience of promoting EoLC in four ways systemically:

- 1. The first way: Ensure the high quality of **Clinical** services;
- 2. The second way: **Training** for health professions and **Education** for the public;
- 3. The third way: Reform in law, policy, and system such as standardisation of EoLC facilities, related laws like "Natural Death Act" and "Patients' Self-determination Act";
- 4. The fourth way: **Research** in the local context.

Professional Trainings

August 14 -15, 2018

Seminar on: Good Quality of End-of-Life Care through A Team Approach

Professional Seminar on End-of-Life Care in Acute Setting

Public Seminars

August 13, 2018

Seminar on: Society Engagement in Building a Fulfilling End of Life Care- Experience of Taiwan





Professor Cecilia Chan

Project Director
"Jockey Club End-of-Life Community Care Project"
Chair of Health and Social Work
Department of Social Work and Social Administration
Faculty of Social Sciences, HKU



Dr Amy Chow

Project Director "Jockey Club End-of-Life Community Care Project" Associate Professor Department of Social Work and Social Administration Faculty of Social Sciences, HKU



Miss Phyllis Leung

Registered Nurse, Lecturer "Jockey Club End-of-Life Community Care Project" JCECC produced a mini-movie: "My Little Story with Mom" to raise public awareness of EoLC. The story incorporates an elderly's final journey of life with her daughter, and how they made EoLC decisions together at home.

The story has shed light on elements in EoLC. Professor Cecilia Chan shared concepts that enhance the quality of EoLC like "The Integrative Body-Mind-Spirit (I-BMS) approach" and "Advanced Care Planning".

Dr Amy Chow shared communication skills in a family approach and the importance of wish fulfillment. Miss Phyllis Leung shared practical information and tools in EoLC from the four primal concerns of the Chinese - clothing, food, shelter and transportation. All these tips improve the quality of EoLC.

Public Seminars August 24, 2018

End-of-Life Community Care Seminar: "My Little Story with Mom"





Danai Papadatou 教授 雅典大學護理學院臨床心理學教授

Danai Papadatou 教授有多年兒童善別輔導及家居舒緩照顧的豐富經驗,她在講座中分享,孩子及青少年的情緒會隨病人病情發展經歷的以下五個階段,家長及照顧者相關應對的技巧:

一,確診之時,適時告知;

二, 暗湧之時,表達情緒;

三, 臨終之前,處理失落;

四, 分離之時,釋放哀傷;

五, 喪親之後,重新適應。

此外,她亦在工作坊中分享了專業醫護人員可如何 運用意義歸因(Meaning Attribution)以多元角度詮 釋死亡的原因及意義,及在面對死亡衝擊時掌握對 人對己關係的平衡,以減低倦怠感。

專業能力培訓

2018年3月7日

Workshop on Distress at the End-of-Life Care: Fostering a Culture of Care and Support for Professionals and Team

公衆講座

2018年3月6日

安寧照顧講座:童行有您 - 如何支援兒童 及青少年面對家人生命的晚期





Edward Canda 教授 ^{協薩斯大學教授}



Hwi-Ja Canda 女士 堪薩斯勞倫斯紀念醫院醫務社工

Edward Canda 教授是致力於研究文化、心靈、抗逆能力與身心健康相互關係的專家、Hwi-Ja Canda 女士則是具多年前線安寧照顧經驗的醫務社工。他們分享了敏感於心靈需要的安寧照顧應不限於宗教和信仰層面,而應包括人專注於尋找生命意義及目標的過程。當「心靈」應用於安寧照顧上時,既能幫助病人和家屬克服疾病和死亡帶來的挑戰、也能幫助減低專業醫護人員的倦怠感。

他們在工作坊中帶領了專業同工進行「靜觀」練習,讓醫護人員能在忙碌的工作中,透過經驗與當下、自己、別人、自然及天人的關係,接納自己及一切,「活在當下」及獲得心靈平安,以面對重返工作崗位時的挑戰。此外,他們亦介紹了如何量度院舍環境及文化在心靈關顧層面上的敏感度、及各項預設照顧計劃的實用資訊及工具。

專業能力培訓

2018年5月16-18日

Workshop on: Spiritually Sensitive Assessment and Interventions in End-of-Life Care: Theory, Practice, and Experience

Workshop on: Preventing Burnout and Promoting Well-Being for Helpers in End-of-Life Settings

Seminar on: Making End-of-life Wishes Known to Family and Health Care Providers

公衆講座

2018年5月19日

安寧照顧講座:生命晚期的心靈成長和轉化





趙可式博士 國立成功大學醫學院名譽教授

趙可式博士素有「臺灣安寧療護之母」之稱,多年來致力建立台灣 安寧照顧的服務模式、教育課程、制度、及政策,又推動台灣醫護 人員及學生和公衆的生死教育;講座出席者可參考其分享的台灣經 驗,以供香港借鏡。

趙博士除了分享如何以團隊合作帶來高質素安寧照顧服務,又有系統地分享了台灣如何以臨床、教育、政策及研究四路並進策略,推 動善生善終善別的經驗:

第一路,確保臨床服務的高品質;

第二路,為醫社專業同工提供相關培訓及進行公衆教育;

第三路,倡議政策、制度、及法律的改革,如醫療護理設備軟硬件的設置及操作標準、醫社照顧團隊必備的知識技能態度、質素評核制度、相關法例如安寧緩和醫療條例 (Natural Death Act)及病人自主權利法(Patients'Self-determination Act);

第四路,建立本土模式的相關研究。

專業能力培訓

2017年8月14-15日

Seminar on: Good Quality of End-of-Life Care through A Team Approach

Professional Seminar on End-of-Life Care in Acute Setting

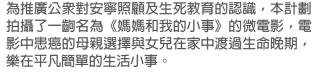
公衆講座

2018年8月13日

以四路並進策略推動善生善終善別——台灣經驗



陳麗雲教授 賽馬會安寧頌項目總監 香港大學社會工作及社會行政學系講座教授



藉着晚期病人和家人相處的故事為切入點,陳教授 分享了「身心靈全人健康模式」護理原則、預設照 顧計劃的理念等;周博士分享了家人溝通的技巧、 圓滿心願的意義等;梁護士則從衣食住行出發,分 享了不少家居護理的實用工具和資訊。以上提升晚 期病人生活質素的小貼士,均有助病人家屬善生善 別、珍惜相處時光。



周燕雯博士 賽馬會安寧頌項目總監 香港大學社會工作及社會行政學系副教授

公衆講座

2018年8月24日

安寧照顧講座:安寧照顧・從微電影《媽媽和我的小事》談起



梁佩嫻姑娘 註冊護士 賽馬會安寧頌講師





過去三年間,本計劃在專業培訓、公衆教育、學術研究及對服務機構支援上的點滴,已剪接成總結回顧影片,有興趣人士可到以下網址瀏覽:http://www.jcecc.hk/project-highlight

活動回顧

而由2018年1月至8月,香港大學「賽馬會安寧頌」團隊先後共邀請了多位國際及本地知名講者,舉辦或協辦了10場培訓工作坊予專業同工及14場講座予公衆(包括6月舉行的國際會議),以提升專業同工在「安寧基本概念」、「全人身心社靈」、「溝通相處之道」及「關愛照顧自己」等範疇的能力及認識,及提高公衆對安寧照顧的關注。

相關資料:www.jcecc.hk





「安寧在家」居家照顧支援服務



賽馬會安寧頌 - 「安寧在家」居家照顧支援服務截至2018年7月底已服務了410位晚期病 人及家屬,提供了2,127次輔導及探訪服務,並訓練了約100位安寧義工。服務主要透過 個案經理及義工上門探訪,與個案完成晚期心願,與他們攜手走完人生路。

服務亦為75間主要位於新界西的非牟利機構、學校、教會及兩間醫 院(屯門醫院及博愛醫院)的 2,964 位同工及服務使用者提供生死教育 講座及專業培訓。另外,本服務亦與屯門醫院紓緩内科及寧養中心 緊密合作,與近500位個案及家人舉辦小組及外出活動,包括參觀 迪士尼樂園等。



「安晴・生命彩虹」社區安寧照顧計劃



for Rehabilitation

賽馬會安寧頌 - 「安晴 ・ 生命彩虹」社區安寧照顧計劃為港島灣仔 區及東區的晚期長期病患者及其家人提供支援,以提升他們的生活 The Hong Kong Society 質素。截至2018年8月底,本計劃共服務174位晚期長期病患者及

325位家屬。本計劃亦積極建立 義工團隊,一共推動了125位 地區義工、40位專業義工及80

位病人自助組織成員關注及參與安寧照顧服務的發展。計劃踏入第三 年,項目團隊於2018年9月舉辦「感覺有時:安寧照顧藝術展」,透 過展示晚期病人及家人的作品及其有意義物品,帶領公衆認識他們的 生命故事,並提升本地公衆對安寧照顧計劃的關注。



「安•好」居家寧養服務



賽馬會安寧頌「安・好」居家寧養服務發現部分臨終長者擁有固定資產而沒有子女・ 在面對身體及精神狀態日漸衰退,失去照顧自己的能力,最後甚或不能處理財產及照 顧事宜,不僅為照顧者帶來負擔,阻礙長者按其意願安排臨終生活,也可能引致家庭 糾紛。因此,本服務與會内其他長者服務同工於2017年起了解及熟讀有關條例草案内 容,更邀請了陸文慧律師賜教和協助,透過講座及焦點小組,及早向長者講解有關訊

Settlement 息,並鼓勵他們積極提問和發表意見。為配合法律 改革委員會(法改會)就《持續授權書條例草案》

進行的公衆諮詢,服務題於2018年3月舉行集思分享會,近50名長者 出席。他們認為由社會福利署擔任承權團體對於無親無故的長者具有 公信力,而關顧長者多年的社會服務機構亦是另一合適選擇。



合作夥伴



安寧服務培訓及教育計劃



在「賽馬會安寧頌 — 安寧服務培訓及教育計劃」下,香港中文大學賽馬會老年學研究所與醫院管理局新界東聯網醫院、護理安老院、社區團體及病人組織緊密聯繫,由2015年11月1日至2018年8月底,為醫護

人員、病患者及其家屬、義工乃至公衆人士舉辦了279場講座及工作坊,超過9,900人次參加。

其中,為加深公衆對「安寧照顧」的了解,鼓勵公衆以積極的態度面對人生至最後一刻,本研究所出版了《吾該好死》一書,歡迎有興趣人士瀏覽網上版本www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Good_Death_Booklet.pdf。在公衆教育方面,今年2018年3月及8月舉辦了兩場大型公衆活動,吸引合共接近800名公衆及醫護界專業人士參與公衆活動的講座。附設的多場工作坊亦有630多名人士參加。



安寧在院舍



賽馬會安寧頌 - 「安寧在院舍」計劃為36間位於九龍東、中及西區政府資助院舍提供優質紓緩及臨終照顧服務。由2016年至今,舉辦了324次員工培訓並有超過1,900位院舍員工參加。計劃由2016年7月開始至2018年9月,共有136位院友接受紓緩及臨終照顧服務,亦有114位院友在計劃安排下,簽訂「預設醫療指示」。計

劃亦總共舉辦了8場大型公衆教育講座,於社區層面推廣「預設照顧計劃」的慨念及重要性,亦介紹「在家寧養」之服務,共有超過1,000位公衆人士參加,並得到正面回應。於2018年4月27日舉辦了「晚期認

知障礙症紓緩臨終照顧」研討會,共有245位業界同工出席。研討會亦由老人精神科醫生、社區老人評估組資深護師、院舍同工及院友家屬角度分享對於晚期認購障礙症之紓緩及臨終照顧。



安居晚晴照顧計劃



尊重生命•改變生命

HAVEN OF HOPE 重生命·改變生命」的精神,靈實司務道寧養院 家居紓緩服務部 ,竭 力為晚晴病友及其家屬,提供整合醫療護

賽馬會安寧頌 - 「安居晚晴照顧計劃」已展開2年半,至今已服務超過

力為晚睛病友及其家屬,提供整合醫療護理、復康及靈性關懷的全人照顧。計劃以個案管理模式,透過與轉介服務機構的緊

密合作,將寧養支援服務帶到晚晴病友家中,加強醫院和社區支援服務之聯繫,減少或避免不必要的急症入院,讓他們能與所關愛的人,在熟悉的家居環境中,獲得尊嚴的照顧和心靈的平安,共度優質的歲月。







「賽馬會安寧頌」 安寧照顧國際會議2018

「賽馬會安寧頌」主辦的2018年度「創新・成效 社區安寧照顧的回顧與前瞻」國際會議,已在6月 20至21日圓滿結束。連同於會議前後舉辦的6個工 作坊或探訪團,吸引逾450位來自10個國家及地區 的參加者出席。

會議由3位來自三大洲的知名專家擔任主講嘉賓, 包括世界安寧緩和照護聯盟(WHPCA—Worldwide Hospice Palliative Care Alliance) 主席Stephen Connor博士、英國倫敦國王學院紓緩治療及政策 Irene Higginson教授、及台灣慈濟大學人文醫學科 主任王英偉副教授。

他們分享了衆多寶貴訊息,歸納要點如下:

- 一) 全球視野下的紓緩治療發展回顧與前瞻-據世 界衛生組織2014年的調查顯示,全球只有14%的 生命晚期病人紓緩治療需要得到滿足; 而發展中地 區如中南美洲、非洲、中國及東南亞洲的人均紓緩 治療服務提供者數量,明顯不如歐美等已發展國家 多。為推動紓緩治療於全球的發展,已發展地區應 多向發展中地區分享更多包括研究、教育和護理的 相關經驗及心得。
- 二) 社區參與的重要性 已發展國家如英國早已 推行關愛社區(Compassionate Communities) 運動多年,響應而生的生死教育組織和活動如雨後 春筍,其經驗固然值得我們參考及學習;Stephen Connor博士分享了發展中國家如印度喀拉拉邦的 「Neighborhood Network in Palliative Care」、孟 加拉Korail 的「Compassionate Communities」等社 如何優化相關研究及台灣的紓緩治療發展;而會議 區為本紓緩治療的服務模式,其中領袖的重要性、家 居為本的護理焦點、義工參與、家庭照顧者自我充權 及專業醫護人員的支援等元素,也許能為全球視野下 的紓緩治療發展帶來更多啟示。而王英偉副教授亦分 享台灣如何善用媒體推廣安寧照顧概念的創新經驗, 更是值得所有華語地區借鏡。
- 三) 團隊合作及人力資源運用的重要性 全人照顧 台,交流理論知識、實踐經驗和最新的研究發展、 的紓緩治療,需要醫護人員、社工、教育界人士、學 者等多方配合;Irene Higginson教授分享有機構揉 合研究、教育及臨床服務於一身(如英國皇家學院的 「Cicely Saunders Institute」)以讓各團隊成員更和 conf2018/presentation-materials.html 諧協調地合作,其經驗也能供其他地區作參考。











國際會議前後亦有不同活動,讓與會者能以互動形 式更了解安寧照顧。會議前工作坊由3位主講嘉賓 主持,分別分享了全球化下家居安寧照顧的經驗、 後的探訪則分別到訪慈山寺、賽馬會善寧之家及安 老院舍,讓參加者了解到本港靈性關顧及安寧院舍 的現況。

「創新・成效 社區安寧照顧的回顧與前瞻」 國際 會議為來自世界各地的安寧照顧前線工作者、教育 工作者、研究人員及公衆人士提供了一個溝通平 促進夥伴關係的建立,相信能為改善全球安寧服務 的質素帶來嶄新的機遇。會議部分演講資料已上載 至官方網站,有興趣人士可瀏覽:www.jcecc.hk/

焦點回顧





生老病死是人生的必經階段,對於自己的生命晚期希望得到怎樣的照顧,每個人都可能有不同的想法和意願。不過在日常生活中,要跟身邊的家人、朋友談生論死,談何容易?尤其在傳統華人社會,我們總是對死亡有著莫名的忌諱和恐懼。

賽馬會安寧頌計劃香港大學團隊設計了一套名為「心有寧say」的遊戲店,目的是以輕鬆有趣的手法令公衆人士認識安寧照顧,鼓勵大家與家人、朋友展開有關死亡和安寧照顧的對話。雖然遊戲店主要使用於公衆教育,但只需了解店的設計,其實專業同工和義工同樣能靈活運用本遊戲店,輕鬆地於病人打開與安寧照顧相關的話匣子。

遊戲店依照傳統撲克牌的設計,分別有黑桃、紅心、梅花和方塊四種花色,而每個花式都有不同的主題:

黑桃





紅小





梅花





方塊



您的心願。這部 分鼓勵玩家回顧 及反思生命,互 相了解彼此對於 生命晚期的意願 及想法,練習如 何展開安寧照顧 話題。





遊戲店更特別加入一些小遊戲,幫助玩家增進感情;而傳統撲克牌中的兩隻小丑牌就設計成兩張心意時,讓大家向身邊的家人表達心聲。團隊亦鼓勵大家可以發揮創意、設計屬於自己的玩法,藉著借玩遊戲的機會,輕鬆開展有關死亡和安寧照顧的議題。

大家如欲更深入了解「心有寧say」遊戲店,可以電郵至jcecc@hku.hk查詢及了解詳情。



安寧服務

首個針對晚期病人的大型優質支援服務

◆ 約3800名病人及家屬受惠於五個服務模式。



家庭功能強化模式

「安•好」居家寧養服務





社區為本健康擴展模式 **安居晚晴照顧計劃**



非癌症病人能力強化建設模式 「安晴·生命彩虹」社區安寧照顧計劃



社區義工功能強化模式 「**安寧在家」居家照顧支援服務**



安老院舍模式 **安寧在院舍**



看護及個人護理



社工提供的安寧輔導服務



義工支援



安寧照顧計劃的討論





醫社合作

建立可行的醫社合作框架

◆本計劃與13間公立醫院於醫管局下的6個聯網建立緊密合作關係











自「賽馬會安寧頌」計劃於2016年推行後,為本港的安寧照顧帶來正面的影響。計劃透過培訓增強醫護及社會工作專業人士的能力。此外,計劃的公衆教育活動和義工培訓有助增加公衆對安寧照顧的認知,促進關愛社區的發展。而計劃中五個創新服務模式所提供的安寧照顧服務更讓不少晚期病患者及家屬受惠。下文簡述有關計劃開展兩年半後的成果:

醫護人員及社工的專業培訓

培育安寧照顧醫護人員和社會工作者及領袖

- ◆超過5300名醫院醫護人員接受培訓
- ◆超過2,100名社區醫護人員及社工接受培訓
- ◆提升專業人士的安寧照顧水平。





公衆教育

- ◆22,500名公衆人士參與公衆教育活動
- ◆透過多媒體渠道觀看公衆教育影片(超過350,000次公衆觀看次數)









賽馬會安寧頌微電影

計劃成果



安老院舍職員在安寧照顧服務的專業培訓



於36間安老院舍發展安寧照顧

- ◆由18個非政府機構營運的36間安老院舍參與是次計劃
- ◆ 超過1,900名於安老院舍工作的專業人士及前線工作人員接受培訓
- ◆減輕對公立醫院的醫療負擔





義工培訓

促進社區參安寧照顧與和提高公衆意識

◆560名義工參與安寧照顧服務



義工感謝日





幫助病人達成最後心願





評估結果:身心社靈 全面改善

截至2018年6月30日,四間機構中合共有203位接受服務的病人及128位家屬,完成了三個時間點的量性評估。

樂而忘病 身心同源

身體症狀方面,病人的整體身體症狀顯著減少了17%,特別在「疼痛」、「氣促」和「虛弱乏力」三方面,更是分別顯著減少22%、16%及23%。值得留意的是,使用服務的病人本身處於生命晚期,按常理身體素質只會每況愈下;但在本計劃下卻「反常」地「逆境反彈」,可見安寧照顧的成效。而在心理及心靈層面,病人的抑鬱及焦慮症狀分別減少了48%及31%,心境不平和的情況亦下降24%。至於溝通方面也有改善,病人認為自己更能開放地與家人分享內心感受。

一名受訪長者在深入訪談中表示,與社工下象棋令他覺得「心臟病消失咗」。心臟病當然不可能因為下棋就消失了,這例子帶出的重要訊息是:「身心互為影響」——縱使服務以情緒支援為主,卻能對病人的身體症狀帶來正面影響。另外,社工會因應不同個案的情況而採取不同行動及支援;是次個案中「下象棋」不只是娛樂,更重要的是「娛樂」背後的心理治療效果。

實務支援 減輕煩惱

病人所遇到實務上的困難如財政、照顧器材或醫療安排等等,更大幅下降了62%。受訪家庭當中,大部份都接受過各樣的實務支援,例如陪診、協助購物、申請助聽器、出借醫院床或輪椅,以及上門清潔等。

同樣道理,以上實務支援看似是「小事」,卻是實實在在縈繞在病人和家屬身邊、讓他們消耗心神去處理的事。因此實務困難的減輕,相信同樣有助病人改善身心健康。



實務困難 ↓62% 難以與家人分享感受 ↓14%

心境不平和 ↓24%

家庭為本 走過哀傷

家屬方面,他們在使用服務三個月後焦慮症狀減少了19%,照顧壓力也在短短數月間下降了16%。病人逝世兩個月後,88.5%受訪喪親家屬的複雜性哀傷反應屬低風險水平,反映服務有效地協助大部份家屬渡過哀傷。

有家屬於訪談時分享,服務團隊的適時介入協助他提供最好的照顧,令他無悔無憾。他在喪親後的深入訪談中回憶道:「(社工教我)摸吓哥哥(病人)呀,同佢按摩呀,傾計呀,掃吓佢個頭,佢會feel(感受)到,雖然佢答你唔到……咁我一路跟佢做,咁我都做晒,都無遺憾」。

這段分享反映出團隊協助家屬及時向病重的家人表達關懷,讓生者善別;而善別有助喪親者更佳地適應哀傷反應、更正面地去面對喪親後的生活。

安寧關鍵 以人為本

安寧照顧到底有何特別之處、有助病人全面改善身心社靈狀態呢?以下深入訪談資料,或可帶來啟迪。其中一位受訪家屬表示:「佢(社工及義工)會當佢(病人)一個(普通)老人家咁,同佢傾偈,『你啲孫又點啊?』、誌吓同啲孫去邊度食吓嘢、玩吓咁樣……就唔係淨係講佢病情。」

雖然病人已來到生命最後一段路,安寧照顧團隊仍注重病人的個人獨特性,讓病人覺得自己是一個「人」,疾病只是生活的一部份。病人感到受尊重,相信有助他們改善身心健康。與上述的正面評價一致,97.6%的受訪病人及95.3%的受訪家屬均對服務表示滿意。



不同模式 突顯長處

以上綜合各機構評估的研究結果,顯示整體病人及家屬的身、心、社、靈狀況,在使用安寧照顧服務後均有顯著改善。而在各機構分別採用四種服務模式的情況下,個別機構的評估結果亦能彰顯不同服務特色的長處。團隊將根據研究結果,整合出一套綜合各服務特色長處的安寧照顧模式,供日後發展參考。

「賽馬會安寧頌」計劃的詳細研究結果將於稍後發佈,詳情請密切留意本計劃網頁:

www.jcecc.hk



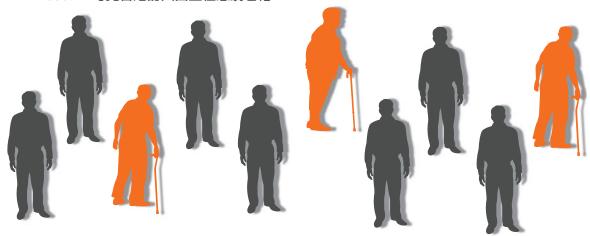


特載



需求大 改善質素靠研究

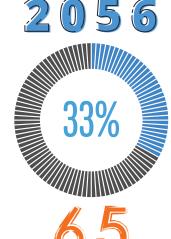
你能夠想像,某天走在街上時,十位路人中有三位都是長者嗎?這並非遙不可及的景象,研究發現至2056年,本港65歲以上長者人口會佔總人口的33%¹,可見香港的人口正在急劇老化。



而大部份長者在生命晚期都曾與殘疾共存一段日子,以2017年為例,本港總死亡人數中近八成為65歲或以上長者,當中近半數主要死因為癌症、心臟病、腦血管病等慢性疾病²。他們步入疾病晚期至死亡的過程中,主要待在社區;可以預計,社區安寧照顧服務的需求將會日益增加。

本港近年已有不少醫院、院舍及社福機構陸續及零散地提供社區安寧 照顧服務,卻缺乏統一指引、各機構的發展方向亦不一。為了解不同 服務模式的成效,以提升晚期病人及家屬的生活質素,嚴謹及實證為 本的研究非常重要。

有見及此,自2016年1月起,「賽馬會安寧頌」四間夥伴社福機構分別以四種安寧照顧模式,為689位60歲或以上的居家晚期病人、及602位家屬提供全面支援;而香港大學團隊則設計及採用一套統一評估框架,以達至有效檢討四種照顧服務模式的成效。是次通訊誌搶先為大家報導精簡評估結果,相信能為本港未來安寧照顧的發展及策略,提供參考及方向。



65 歲佔總人口

'HKSAR Census and Statistics Department. (2017). Hong Kong population projection 2017-2066. Retrieved at: https://www.statistics.gov.hk/pub/B1120015072017XXXXB0100.pdf

²HKSAR Centre for Health Protection, Department of Health. (2018). Number of deaths by leading causes of death by sex by age in 2017. Retrieved at https://www.chp.gov.hk/en/statistics/data/10/27/340.html

特 載

評估質量並重 多面了解成效

是次評估量質並重,及分為兩個部分。量性評估以實證為本,宏觀地統計及觀察病人和 家屬的身心變化;質性評估則在訪談間,微觀地發現每個個案獨特的生命經驗。

第二部份則以質性研究,與病人及家屬進行深入訪談。「賽馬會安寧頌」香港大學團隊每年均會以系統隨機抽樣的方法,在所有服務使用者中抽取八個家庭進行訪談,以深入了解服務使用者的經驗及感受。

以上評估框架,均統一應用於四個機構的四種照顧模式中,而各機構的個別服務特色分別為:聖雅各福群會主力組織家庭活動及以家庭為中心、基督教靈實協會著重靈性關顧及提供密集居家護理支援、香港復康會側重為居家的非癌症晚期病人及家屬提供症狀處理教育及情緒支援、聖公會聖匠堂長者地區中心則與醫院緊密合作及培訓大量社區義工。



³Cicely Saunders Institute, King's College London. (2012). Integrated POS (IPOS) in English. Retrieved at https://pos-pal.org/maix/ipos_in_english.php ⁴Chan, W. C. H., Chan, C. L. F., & Suen, M. (2013). Validation of the Chinese version of the Modified Caregivers Strain Index among Hong Kong caregivers: An initiative of medical social workers. Health & Social Work, 38(4), 214 – 221. Doi: 10.1093/hsw/hlt021

⁵Tang, S. & Chow, A. Y. M. (2017). How do risk factors affect bereavement outcomes in later life? An exploration of the mediating role of dual process coping. Psychiatry Research, 255, 297-303.



2019年 第三期



策劃及捐助:



香港賽馬會慈善信託基金 The Hong Kong Jockey Club Charities Trust 同心同步同進 RIDING HIGH TOGETHER

合作院校:



Faculty of 香港大學社會科學學院

合作夥伴











