Increasing Demands for End-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 etc ².

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.

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) 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) at service intake and three month after the service respectively. Level of grief was assessed by the Chinese “Inventory of Complicated Grief” (ICG) 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.

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.
Overcoming grief through a family approach

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. I followed the social worker’s instructions and I have no regrets. My brother seemed to tear up at that 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 bereavement after the patients passed away.

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
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
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**

**Services**

- **Nursing and Personal Care**
- **End-of-Life Counselling by Social Workers**
- **Emotional Support by Volunteers**

**Discussions on End-of-Life Care Plan**
Building a viable framework for medical-social collaboration

- The Project has established close collaboration with 13 public hospitals in 6 clusters of Hospital Authority
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](http://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.
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.

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.
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](http://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/project-highlight

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 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 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 systematically:

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
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 教授多年來配同輔導及家人照護的豐富經驗，她在講座中分享了孩子及青少年的情緒、疾病關係的經歷的以下五個階段，家長及照護者相關應對的技巧。

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自己關係的平衡，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

公眾講座

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
堪薩斯大學教授

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，能幫助病人和家屬克服疾病和死亡帶來的挑戰，也能幫助減低專業護理人員的倦怠感。

他們在工作坊中帶領了專業同工進行「靜觀」練習，讓護理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源及工具。

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
趙可式博士素有「臺灣安寧療護之母」之稱，多年來力致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眾的生死教育；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眾教育；
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

公眾講座

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
為推廣公眾對安寧照顧及生死教育的認識，本計劃拍攝了一齣名為《媽媽和我的小事》的微電影，電影中患癌的母親選擇與女兒在家中渡過生命晚期，樂在平凡簡單的生活小事。

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。

公眾講座
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

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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「賽馬會安寧領」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

賽馬會安寧頒 - 「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緩緩內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

賽馬會安寧頒 - 「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，帶領公眾認識他們的生命故事，並提升本地公眾對安寧照顧計劃的關注。

「安• 好」居家寧養服務

賽馬會安寧頒「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，最後甚至不能處理財產及照顧事宜，不願向照顧者帶來負擔，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，本服務與會內其他長者服務同工於2017年起了解及熟讀有關條例草案內容，並邀請律師講解條例的條文，及早向長者講解有關議題。為配合法例改革委員會（法改會）就《持續授權書條例草案》進行的公眾諮詢，服務更於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擔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。
安寧服務培訓及教育計劃

在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，為護理人員、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名公衆及護理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

賽馬會安寧會－「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緩緩及臨終照顧服務。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位院友接受緩緩及臨終照顧服務，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，於社區開闢推廣「預設照顧計劃」的概念及重要性，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「晚期認知障礙症緩緩臨終照顧」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知障礙症之緩緩及臨終照顧。

安居晚晴照顧計劃

賽馬會安寧會－「安居晚晴照顧計劃」已展開2年半，至今已服務超過167位晚期病友及其家屬。秉承基督教靈實協會創辦人司徒教士「尊重生命，改變生命」的精神，靈實司務部寧養院家居緩緩服務部竭力為晚期病友及其家屬，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，將養老支援服務帶到晚期病友家中，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。

他們分享了眾多寶貴訊息，歸納要點如下：

一）全球視野下緩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
生命晚期病人緩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緩緩
治療服務提供者數量，明顯不如歐美等已發展國家
多。為推動緩緩治療於全球的發展，已發展地區應
多向發展中國家分享更多包括研究、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和印度喀拉拉邦的
「Neighborhood Network in Palliative Care」、孟
加拉Korail的「Compassionate Communities」等社
區為本緩緩治療的服務模式，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
及專業護理人員的支援等元素，也許能為全球視野下
的緩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
的緩緩治療，需要護理人員、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
諧協調地合作，其經驗也能供其他地區作參考。

國協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居家安寧照顧的經驗、
如何優化相關研究及台灣的緩緩治療發展；而會議
後的探訪則分別到訪慈山寺、寶馬會善業之家及安
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、研究人員及公眾人士提供了一個溝通平
台，交流理論知識、實踐經驗和最新的研究發展、
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/
conf2018/presentation-materials.html
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。

賽馬會安寧基金計劃香港大學團隊設計了一套名為「心有寧say」的遊戲咭，目的是以輕鬆有趣的手法令公衆人士認識安寧照顧，鼓勵大家一起展開有關死亡和安寧照顧的對話。遊戲咭主要使用於公衆教育，但只需了解咭的設計，其實專業同工和義工同樣能靈活運用本遊戲咭，輕鬆地於病人打開與安寧照顧相關的話匣子。

遊戲咭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
心有靈犀。每個人都有獨特的性格和生命故事，而日常生活的喜好往往反映著一個人的價值觀或信念。這部份讓玩家互相認識，發掘對方鮮為人知的一面。

紅心
冷知識知多少。對於生死大事和安寧照顧，坊間有很多不同的討論和意見。這部份有十項冷知識，測試玩家們對安寧照顧的認識有多深入。

梅花
童話新編。童話故事中內有玄機，蘊含了安寧照顧意願和價值觀。這部份與玩家重溫原著故事，並代入角色，思考和討論主角的決定。

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，如何展開安寧照顧話題。

遊戲咭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咭，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，輕鬆展開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」遊戲咭，可以電郵至jcecc@hku.hk查詢及了解詳情。
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

服務

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
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)
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眾意識
◆ 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
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，這例子帶來的重要訊息是：「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，社工會因應個別案例的需要及采取不同行動及支援；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」，卻是實實在在纏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。
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%，顧慮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）摸愛哥哥（病人）嘅，同佢按摩呀，傾計呀，掃除佢個頭，佢會feel（感受）到，雖然佢答佢唔到……咱一路跟佢做，咱我就做晒，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，『你嘅孫又點啊？』、諗嘅時候孫去邊度食咩嘅、玩咩嘅……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。

「寶馬會安寧頌」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
安寧照顧
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%，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。

評估質量並重 多面了解成效

次評估質量並重，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；質性評估則在訪問間，微觀地發現每個個案獨特的生命經驗。

第一部分是以量性結構式問卷，對病人及家屬進行臨床評估。『寶馬會安寧』香港大學團隊分別在晚期病人開始使用服務前、使用服務一個月及三個月後，以「緩緩照顧綜合結果量表」(IPOS - Integrated Palliative care Outcome Scale)翻譯而成的繁體中文版，追隨病人在接獲服務前後的身體症狀、社交需要、心理需要、心靈需要、實務需要等多方面身心狀態的變化。至於家屬方面的評估，研究團隊主要採用了「照顧者壓力評估」(CSI - Caregiver Strain Index)*及「複雜性哀傷量表」(ICG - Inventory of Complicated Grief)的中文版本，於開始使用服務前及服務三個月後評估家屬的照顧壓力，及於病人逝世兩個月後評估家屬的喪親適應狀況。另外，團隊亦邀請病人及其家屬參與電話訪問跟進情況。

第二部分則以質性研究，與病人及家屬進行深入訪談。「寶馬會安寧」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以及家庭為中心、基督教靈實協會著重實體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。