賽馬會安寧頌

JCECC

Jockey Club End-of-Life Community Care Project

# FINAL REPORT ON THE JCECC PROJECT

## (Jan 2016 – Dec 2018)

**The University of Hong Kong**
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香港大學社會科學學院

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# 1. EXECUTIVE SUMMARY

## 1.1 Introduction

In 2015, the Hong Kong Jockey Club Charitable Trust approved HK$131 million to launch the 3-year Jockey Club End-of-Life Community Care Project (“JCECC”), aimed at enhancing the end-of-life care (EoLC) in Hong Kong to improve the quality of life of older people with terminal illness. The project involves multi-level of intervention through capacity building for the public, patients and family members, volunteers, health care and social care professionals, direct service delivery of care in viable community-based service models and rigorous evaluation of the outcomes and impacts of the capacity building and direct care. Complementing the existing service provisions by the government in a coordinated manner, it is hoped to provide quality comprehensive care for individuals touched by terminal illness.

Each project component in the JCECC project targets on a specific type of service user (**Figure 1.1**). The **professional capacity building programmes** in the project are setting-specific. The **capacity building programme in the community**, led by the University of Hong Kong, Faculty of Social Sciences, emphasises on changing attitude, enriching knowledge and enhancing skills for health and social care professionals working in the wider community settings. The Hong Kong Association of Gerontology (HKAG) endeavored to enhance RCHE’s capacity to provide EoLC

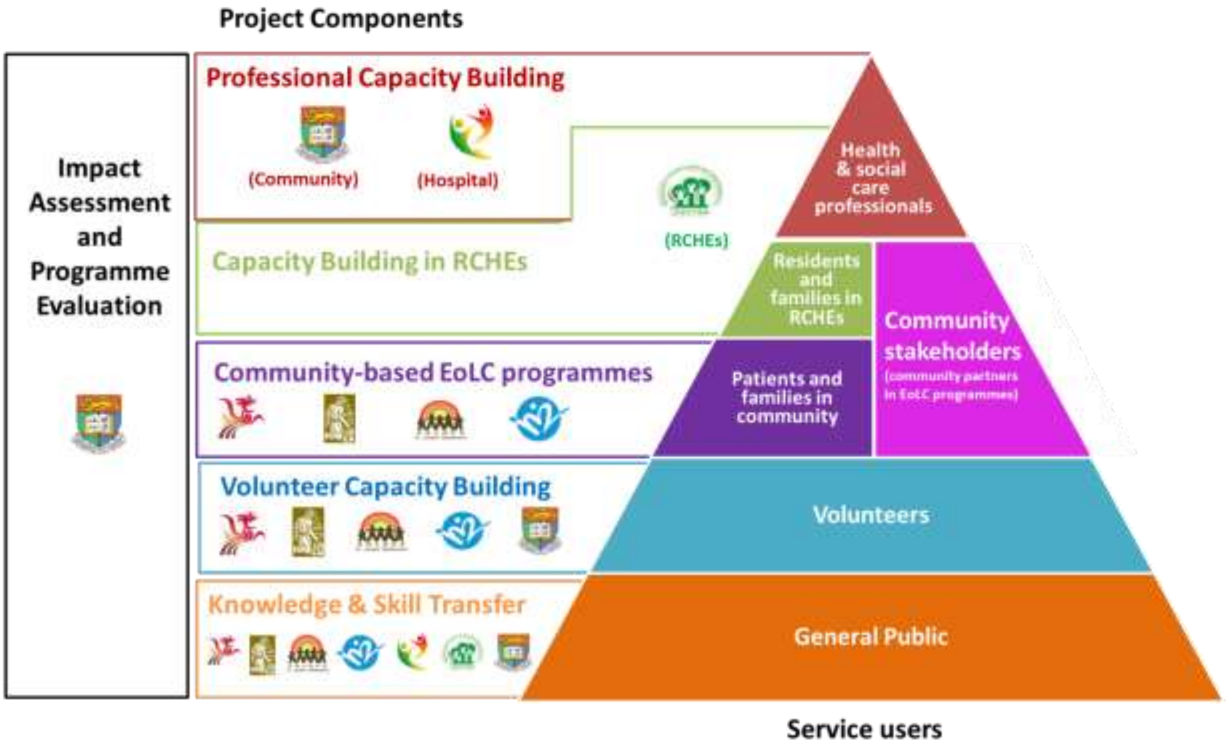

**Figure 1.1** JCECC Project components and respective service users

through a **capacity building programme in RCHEs**, while the Jockey Club Institute of Ageing of the Chinese University of Hong Kong implemented a **capacity building programme in hospitals**. The HKAG also targeted on improving quality of life of RCHEs residents with end-of-life issues and their family members.

On the other hand, four NGO partners, namely St James' Settlement (SJS), Haven of Hope Christian Service (HOH), Hong Kong Society for Rehabilitation (HKSR), and S.K.H. Holy Carpenter Church District Elderly Community Centre (HCCDECC), developed and piloted four different **community EoLC service models** which aim to promote quality of life of community-dwelling end-of-life (EoL) patients and their family members. All of these models involve medical-social collaboration between the NGO service teams and other community stakeholders including hospitals and other social services. Embedded in the Community-based EoLC programmes is the **volunteer capacity building programme**, in which community volunteers were recruited and trained by the four NGO partners and the University of Hong Kong to support EoL patients and their family members. **Knowledge and skill transfer** was jointly conducted by all partners of the project. The component increases public awareness on EoLC and promotes conversations and dialogues on EoL issues. Lastly, **Impact assessment and programme evaluation** was led by The University of Hong Kong. It is a unique component which provides an all-rounded assessment of the outcomes and impacts of the JCECC Project on multiple levels of stakeholders.

This final report seeks to report the output, outcomes and impacts of the JCECC Project on different service users, including health and social care professionals in the community and RCHEs, patients and family members in the community and RCHEs, community stakeholders, volunteers, and the general public in the first 3 years, between 2016 and 2018. The executive summary highlights the significant outcomes and impacts on each service user group.

## 1.2 Health and Social Care Professionals in the Community

*In the Professional Capacity Building Programme in the Community which was led by HKU, altogether 46 professional training workshops were delivered based on the JCECC EoLC 7-domain competence framework. These workshops significantly improved the competences of participants in all seven domains. Besides, leadership programme has lasting positive impacts on leaders. There is evidence that health and social care professionals at large perceived improved competence on end-of-life decision making, symptom management, and community EoLC. Overall, the outputs and outcomes of the Professional Capacity Building Programme greatly exceeded the pledged targets while the rippling effect was emerging but need more impetus. The evaluation suggested the differentiated level of training, use of distance learning to reach out to more professionals, and strengthening of training on basic values and knowledge, communication, EoL decision making, psychosocial care, and symptom management.*

### Output

- 46 professional training workshops were delivered by renowned local and international experts in EoLC, with over 1,500 health and social care professionals participated. (185% target met)
- Two 1-year leadership training programmes were delivered to 47 future leaders in EoLC nominated by leading NGOs in Hong Kong. (115% target met)
- Caregiver training workshops were held which benefited 404 caregivers. (102% target met)
- Two Chinese manuals "Basic Concepts" (安寧概念) and“Relaxatiuon Exercises" (放鬆練習) were published in 2018.

### Outcomes

- Participants of professional training workshops reported 23.4%⬆ in EoLC competences (234% target met)
- Leaders reported 31.6%⬆ in EoLC competences, 47.5% ⬆ in leadership skills. Aggregately, 40%⬆. (400% target met)
- Over 80% of the professioinal workshop participants and leaders were satisfied with the programmes.

### Impacts

- Health and social care professionals in community reported 3.1%⬆ in EoLC competences between 2016 and 2018. (31% target met)
- The two batches of leaders showed sustained and even further improved competences 6 months after completion of programme. 36.2% ⬆in EoLC competences and 50.5%⬆ in leadership skills were recorded compared to pre-training assessment.

### Future Plan

- Development of specialty level-differentiated curriculum in second phase project
- Strengthen skills training in domains of EoL decision making, psychosocial care, and communication in second phase project
- Use of online learning to reach out to more professionals

## 1.3 Staff, Residents and Family Caregivers in RCHEs

*The HKAG EoLC in RCHEs consists of a Capacity Building Programme targeting on RCHE staff as well as direct EoLC services for residents with end-of-life issues and their family members. The Capacity Building Programme has benefited more than 2,000 staff in RCHEs. Both professional and non-professional staff who have received training showed significant improvements in readiness and competence in providing EoLC in RCHEs. The enhanced competences were sustained after the programme has implemented for 2 years. On the other hand, EoL residents served by the programme showed significantly improved physical and psychological symptoms. Moreover, deceased residents showed remarkably reduced utlisation of medical services in the last 3 months of life when compared to EoL patients in general. It was estimated that the programme has saved 25.4 million medical cost in 3 years. Evaluation suggested that there was a high need for on-site clinical coaching and practical skill trainings among RCHE staff.*

### Output

- 36 RCHEs participated in the programme.(100% target met)
- 384 residents were admitted and served by the HKAG programme (86.5% target met)
- 2,256 professional and front line staff of RCHEs received EoLC training under the programme. (114% target met)

### Outcomes

- RCHE staff showed a 12.2%⬆ in EoLC competences (122% target met)
- After 6 months of service, residents showed a 15.8%⬇ in symptoms. (An average of 316% target met)
- Caregivers at 6 months: caregiver strain14.2%⬇ (An average of 284% target met)

### Impacts

- There was evdience that the HKAG programme had led to positive changes in the care home culture, such as increased awareness on the importance of psychosocial care and autonomy in elder care in the care homes.
- Deceased residents receiving EoLC showed a reduction of 13.25 days of hospitalisation as well as 18.4% reduction in A&E admission in the last 3 months of life when compared to EoL patients in general.
- The HKAG EoLC programme in RCHEs was estimated to have saved 25.4 million medical cost in 3 years.

### Future Plan

- Extend the EoLC service to 12 more RCHEs, altogether 48 RCHEs
- Engage Hospital Authority to develop a viable collaboration model
- Develop and deliver advanced EoLC training programmes for RCHE staff
- Establish validated quality standard for EoLC provision in RCHEs

## 1.4 Patients and Families in the Community

*The four NGO community-based end-of-life care models were effective in enhancing quality of life of patients and family members. Patients showed significantly reduced physical symptoms, emotional distress, practical problems, difficulties in sharing feelings, while caregivers showed reduced anxiety, caregiver strain, and felt more intimate with patients. Patients and caregivers on general highly satisfied with services. Evidence suggested that the models were effective in reducing medical service utilisation of patients in the last 6 months of life. It was estimated that the programmes have saved 20.6 million medical cost in 3 years. Each model has its specific strengths. A unified model will be developed by integrating effective service components identified from each service model, and engaging Hospital Authority and Social Welfare Department to explore a viable interface mechanism between the integrated EoLC service team and the existing social and medical services.*

### Output

- 777 end-of-life patients were admitted and served by NGO partners. (112.6% target met)

### Outcomes

- Patients at 3 months: practical problems 55%↓, depression 47%↓, anxiety 31%↓, physical symptoms 18%↓, difficulties in sharing feelings 15%↓. 98.7% felt their wish was respected. (An average of 578% target met)
- Caregivers at 3 months: anxiety 27%↓, caregiver strain19%↓, family intimacy 2.5% ↑ (An average of 322% target met)
- 89.9% bereaved caregivers reported low risk for complicated grief, i.e. 26.26% reduction in risk. (target met)
- ≥95% highly satisfied with services. (An average of 127% target met)

### Impacts

- Patients showed a reduction of 4.87 days of hospitalisation as well as 11.6% reduction in A&E admission in the last 6 months of life when compared to EoL patients in general.
- The 4 NGO programmes were estimated to have saved 20.6 million medical cost in 3 years.

### Future Plan

- An integrated model, which is developed through refining and integrating effective model components in each NGO service model, will be refined as the guiding model in the second phase. This model will be supported by a need-stratification assessment tool.
- Engage Hospital Authority, Social Welfare Department, and Food and Health Bureau on the development of integrated model and possible integration with existing support services.
- Further improve the rigor of evaluation by conducting cost-benefit analysis and calculation of cost per case.

## 1.5 Community Stakeholders

*Community partners who referred cases to JCECC community-based EoLC services found the service played a pivotal role in filling the current service gaps for EoL patients and their families in the community. Community partners were generally highly satisfied with the services. They observed positive changes in patients and caregivers supported by the services, and the shared care in turn promoted better communication and trust between the community partners, patients, and their family members. Overall, holistic and coordinated EoLC was provided by the services through the integration of medical and psychosocial care and bridging care across care settings and service providers. The sample in the stakeholder survey was a representative one as reflected by a relatively high response rate of 70.5%.*

### Outcomes

- High satisfaction rate of 8.19/10 on the JCECC NGO community-based EoLC services
- 89.8% would recommend the services to others
- Community partners described JCECC NGO EoLC services as "holistic", "service gap-filling", and "flexible"
- Positive changes on patients and famly members were observed: improved emotion, reduced stress, improved family relationship, more opened towards discussion on EoLC issues

### Impacts

- Observed reduced hospitalisation on some patients
- Observed enhanced trust and communication between community partners, patients and their family members
- Findings suggested that the JCECC community EoLC services made holistic, coordinated and continual community EoLC possible.

### Future Plan

- Continue the development of model of care to fill the gaps in the community.

## 1.6 Volunteers

*In the Volunteer Capacity Building Programme, the 4-session centralised volunteer core course was proved effective in building the EoLC competences among volunteers. An increase of 20.3% in EoLC competences was reported upon training completion; a mild but significant improvements in meaning in life (3%) and self-confidence in death work (2.4%) were also reported. The coordinated recruitment and standardised screening procedures implemented collaboratively by the HKU Project Team and NGO partners were found effective. Over 170 applications for the core course were received less than a month. With the use of screening tool and interviews, 91 volunteers were eventually enrolled. The course completion rate, as defined by an attendance rate of 80% or above, was 90.1%.*

### Output

- Over 170 applications received for the volunteer core course, 121 volunteers screened
- 82 volunteers were trained by the volunteer core course, with a completion rate of 90.1%
- The experience of volunteer recruitment, use of screening tool, and the core training programme were organised and published as a volunteer coordinator manual（義工組織）in June 2018.

### Outcomes

- 20.3% ⬆ in EoLC competences upon training completion. (180% target met)
- 23.9% ⬆ in EoLC knowledge upon training completion.

### Impacts

- 3% ⬆ in meaning in life which was statistically significant (target met)
- 1.2% ⬆ in quality of life (target met)
- 18.5% ⬆ in the likelihood in promoting EoLC to acquaintances who may need the service

### Future Plan

- Evidence on the impact of training on volunteers will be collected. Recording system on volunteer activities will be reviewed and refined.
- In a long run, further improvement of volunteer management for promoting sustainable and effective EoLC volunteer services will be developed as the goal of the phase two.

## 1.7 General Public

*Various public educational activities have been organised, and EoLC were promoted via various types of media with an aim to raise the public awareness on EoLC. Participants of public seminars generally showed high satisfaction with the activities. Three waves of annual community-wide public survey between 2016 and 2018 showed that the public had increased knowledge on the related terms and components in EoLC across time. However, 2018 survey revealed that only minority of the respondents knew about Advance Care Planning (ACP). Nevertheless, after relevant terms in EoLC were explained, over three-fourths of the respondents supported the signing of Advance Directives (AD), and around 80% would choose to receive EoLC if they were diagnosed with a terminal illness. The proportions of supporters also increased significantly between 2016 and 2018. In all three waves, majority of the respondents (>70%) were positive towards community EoLC, and the proportion of respondents who chose home as the most suitable place for EoLC significantly increased between 2017 and 2018. Overall, the public showed support towards community EoLC, high receptivity to the EoL related topics, and has become more ready to learn more about the subject of EoLC.*

### Output

- 48 public seminars/forums were organised with more than 7,300 participants (123% target met)
- Two international conferences with 840 participants. (140% target met)
- Promotions through various multimedia have an overall hit rate over 280,000 (236% target met)
- Media coverage encompassing 15 episodes of Radio programme, 19 issues of newspaper column, press conference with over 5,500,000 readers/audience(743% target met)
- Newsletter and e-newletters with over 91,000 readers (102% target met)
- Mini-movie Premiere with over 1,000 participants
- Production of communication card game with 1,000 sets distributed to the public

### Outcomes

- 96.4% of surveyed participants were satisfied with the education programme (53% "agree" and 43.4% "strongly agree" that they were satisfied with the education programme).

### Impacts

- 2.2%⬆ in public attitude favoring community-based EoLC in 2018 (preference for EoLC provided by social service agencies, and at home; support EoLC facilities built near home, support neighbor receive EoLC at home). (44% target met)
- Knowledge on terms related to EoLC increased by 10% among the public from 2016 to 2018
- The public showed 5.4%⬆ in confidence towards the effectiveness of EoLC, 34.7%⬆ in intention to join EoLC related education activities

### Future Plan

- A systematic way of dissemination of core messages will be carried out in the phase two.

# 2. HEALTH & SOCIAL CARE PROFESSIONALS

## 2.1 Professional Capacity Building in the Community

### 2.1.1 Programme descriptions

Professional Capacity Building Programme of the HKU Project team consists of two core levels of education, namely the leadership training programme targeting on middle management staff in leading NGOs which intended to develop EoLC services in the community, and professional training workshops for health and social care professionals in the community.

Leadership training programme

This is a one-year programme which aims to cultivate future leaders to promote future EoLC services in the Hong Kong community. Two leadership training programmes have been conducted, the 2016-17 and 2017-18 programmes. Leading NGOs in Hong Kong were invited to nominate staff to participate in the programme, and altogether 47 leaders were enrolled in the two programmes. Leaders received 90.5 hours of training consisting of lectures and interactive learning activities in the two leadership training programme combined. In the 2017-18 programmes, leaders completed a capstone project and presented their service proposal as posters in the graduation ceremony.

Professional training workshops for health and social care professionals in the community

The professional training workshops under JCECC HKU team was organised based on a multi-dimensional EoLC competencies framework with 7 diversified domains, namely, basic values and knowledge in EoLC, symptom management, (evidence-based) psychosocial-spiritual care, communication, EoL decision making, bereavement care, and self-reflection and self-care. These workshops were short-termed, with duration ranging between one to three training days, targeting on the EoLC competence domains mentioned above. Particularly, a standardised foundation course which covers basic knowledge in all competence domains has been developed and delivered twice. Between October 2016 and August 2018, altogether 46 workshops have been delivered by both renowned local and international speakers, benefiting over 1,500 health and social care professionals. Apart from the foundation course, each of the other workshops was designed to target on one to two competence domain(s). Apart from the trainings for professionals, 10 seminars and training were designed especially for family caregivers.

Publications

Two manuals “Basic Concepts” (安寧概念) and “Relaxation Exercises” (放鬆練習) were published in June 2018 which target on health and social care professionals to provide basic knowledge and concepts in EoLC.

### 2.1.2 Evaluation Framework

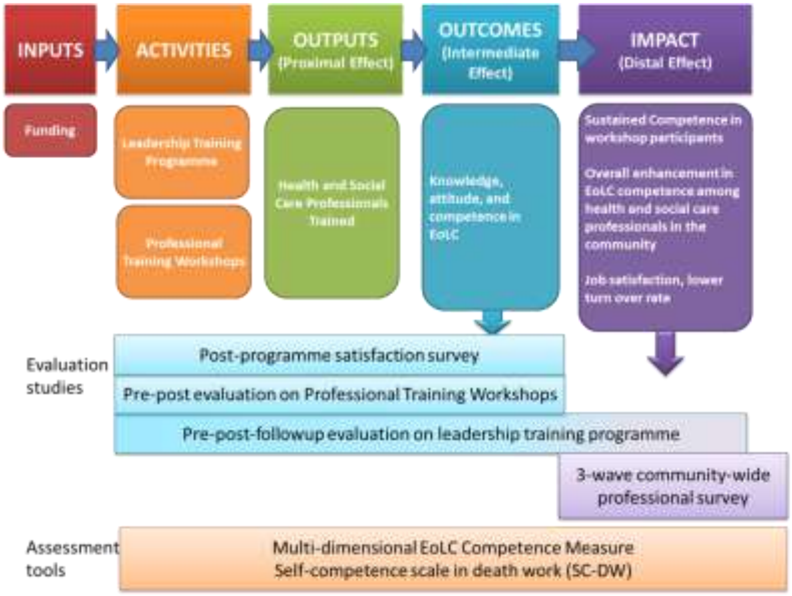

**Figure 2.1** Evaluation framework on professional capacity building programme

Evaluation on the outcomes and impacts of the Professional Capacity Building Programme was carried out through three studies as showed in **Figure 2.1**. The expected outcomes of the programme are enhanced EoLC competences, knowledge and attitude of health and social care professionals, whereas impacts concern with sustained competences in workshop participants, and the extended impacts of the programme on EoLC competences among health and social care professionals in Hong Kong at large. Pre-post or pre-post-followup evaluation was conducted among programme participants to assess the outcomes and impacts, whereas a 3-wave community-wide professional survey across the project period is employed to evaluate the extended impacts of the programme on health and social care professionals in Hong Kong. A multi-dimensional EoLC Competence measure was developed by the research team to assess 7 domains of EoLC competences in all studies involving professionals, each item in this measurement assess respondent's self-perceived specific EoLC competence on a 10-point Likert scale, with 1=totally incompetent to 10=very competent. Apart from this, the Self-competence scale in Death Work (SC-DW)[1] was also used. These two measurements assess professionals' competences on overarching knowledge and values in EoLC, communication skills, symptom management, EoL decision making, (evidence-based) psychosocial care, bereavement care, and self-care. In particular, the domain of overarching knowledge and values in EoLC is further composed by two sub-domains, with one sub-domain refers to the understanding EoLC in general, and another involves knowing and utilising community EoLC, which is a specific focus in the JCECC Project. In family caregiver seminars, only post-programme satisfaction survey was conducted.

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[1] Chan, W. C. H., Tin, A. F., & Wong, K. L. Y. (2015). Coping with existential and emotional challenges: Development and validation of the self-competence in death work scale. *Journal of Pain and Symptom Management, 50* (1), 99-105

### 2.1.3 Findings from Professional Training Workshops

894 professionals who were predominantly social workers (53.7%) and nurses (19%) participated in the professional workshops were assessed on their EoLC competences before and after training. They came from various service settings, for example elderly long-term-care residential setting (13.1%), long-term-care community setting (16.4%), hospitals (15.8%), hospice (5.4%), and other social service settings (24.1%). The bar chart below showed the changes in each EoLC competence domain of these professionals (**Figure 2.1**). Significant improvements were reported on all measured EoLC domains, and the overall competence levels increased by 23.4% (**Figure 2.1**). These supported the effectiveness of the professional workshops in enhancing the multi-dimensional competences of participants. Moreover, 966 participants responded to the post-programme satisfaction survey. On a 6-point Likert scale (from '*Strongly disagree*' to '*Strongly agree*'), 24.8% strongly agreed and 61% agreed that they were satisfied with the workshops suggesting a generally high satisfaction rate.

**Figure 2.1** Competence level before and after professional training (N=894)

### 2.1.4 Findings from Leadership Training Programmes

#### 2.1.4.1 Quantitative findings

The 47 leaders came from a variety of service settings including elderly long-term-care residential setting (27.7%), long-term-care community setting (17%), hospitals (6.4%), hospice (14.9%), and other social service settings which support elderly and persons with intellectual disabilities suffering from chronic illnesses (25.5%). The participants were predominantly social workers (74.5%), and a few nurses (8.5%) and physicians (6.4%). The mean number of years working in the field of EoLC was (4.15 ± 5.32) years. It was observed that the 2017 batch of leaders were on general more experienced than those in the 2016 batch (2.30 vs 5.93, $p<.05$).

Pre-post follow-up assessments were conducted on leaders. Upon completion of the programme (post-training), 32 leaders who underwent assessment showed significant improvements in all competence domains and leadership skills (**Figure 2.2** and **Figure 2.3**). The overall competence level and leadership skills improved by 31.6% and 47.5% respectively.

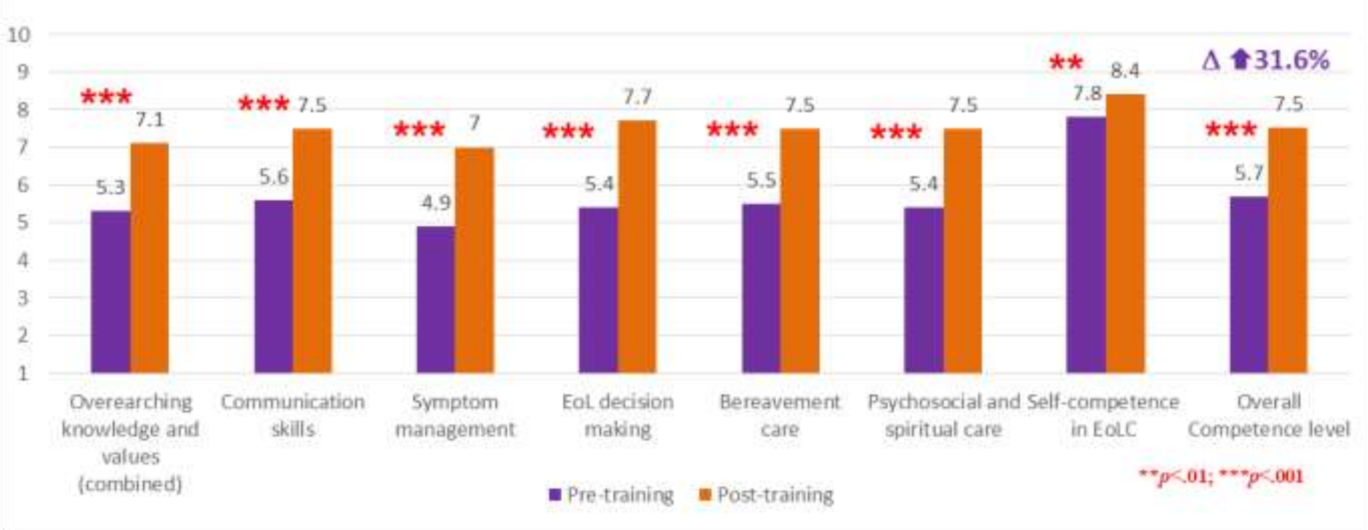

**Figure 2.2** Pre-post differences in EoLC Competences among 2016 and 2017 leadership programme participants (N=32)

**Figure 2.3** Pre-post differences in leadership skills among 2016 and 2017 leadership programme participants (N=32)

A follow-up assessment was conducted half a year after completion of the leadership programmes, with 28 participants assessed. The significant improvements in all competence domains and leadership skills upon completion of training were able to be sustained at half year after the completion of the programme (**Figure 2.4** and **2.5)**. The overall EoLC competence level and leadership skills increased by 36.2% and 50.5% respectively when compared between pre-programme and half a year after completion of the programme.

**Figure 2.4** Changes in EoLC competences between pre-training, post-training, and half-year follow-up among 2016 & 2017 leadership programme participants (N=23)

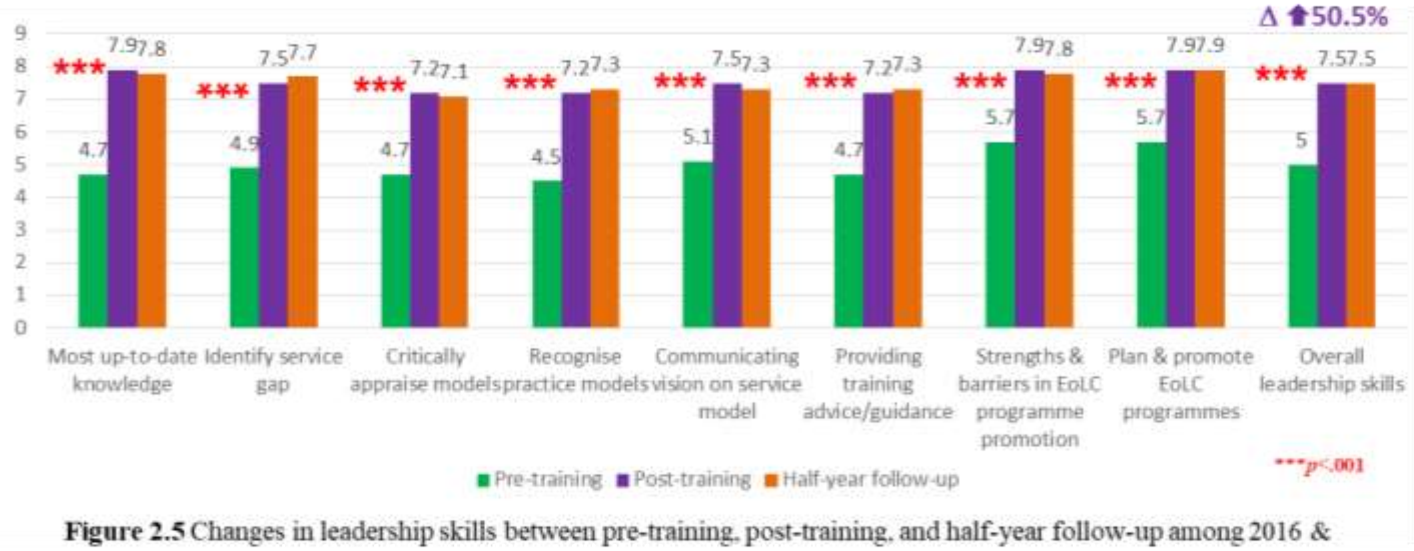

**Figure 2.5** Changes in leadership skills between pre-training, post-training, and half-year follow-up among 2016 & 2017 leadership programme participants (N=23)

### 2.1.4.2 Qualitative findings

Apart from objective evaluation, focus group has been conducted with the leaders in the 2017 programme (n=20). Interviewed leaders indicated that the programme had benefitted them in the following approaches:

**(a) Good variety of course content which broadened participant's horizons, cultivated new perspectives, and provided a more holistic view on EoL issues**

> *“但是這個課程包括的範疇很廣闊，擴闊了我的眼界讓我看到不同的角度”*
>
> *“所以我都諗就係頭先我哋大家都幾一致嘅就係個多角度去睇，或者喺唔同嘅地域啦，本地呀、宗教呀、文化，啲個嘅闊面係有嘅，即係個目標係達到嘅。”*
>
> *“我幾鍾意啲 overseas professors 啲啲 sharing，咁我覺得可能一嚟就可能真係唔認識啲個地方啦，其實可能佢只係 present 咗一少忽嘅嘅啫，但係因為唔識呀嘛。所以你就會覺得，都聽到一啲即係呀都幾特別嘅嘢呀”*
>
> *“我最欣賞的是課程提到 social work profession 在 ACP 當中的角色、如何去定位等等，令我發覺自己一直做的工作原來比較雜亂無章。但是課程就令到我的想法法可以有連貫性，能看得清哪方面有不足，或者哪方面沒有想過整體理念的關連性”*

**(b) Facilitated reflection on one's own practice and the service gap**

> *“我覺得整個課程讓我反思自己的服務對象，佢對 end of life care 的需要是什麼...以致我可以如何在我(提供的)服務上可以做得更好，或者如何可以在討論中或者在過程中可以讓他們參與更多”*
>
> *“係反而見到自己嘅不足多咗，即係個情況係見到自己不足多咗，更加要喺呢個 service 裏面點樣行多兩步。即係個感覺係要再要有啲氣力再行多幾步先喺個 service 上面可以完滿一啲，或者喺個業界可以做多少少嘢。”*
>
> *“課堂以外我都會問我的同事在 deliver service 的時候有什麼想法，他們覺得如何能夠真正幫助 clients。當我實行的時候又會採納不同同事的意見。當我之後在課程中跟 professor 交流的時候，我都會轉述同事的意見、他們認為要留意的事項等等’’*

### (c) Useful lecture notes which provided condensed knowledge and informed latest international development

> *“咁所以我諗正正本身你做緊前線嘅時候你未必好多時間去嗰啲 literature review 呀，academic 嘅嘢，咁我都係想 fill 返呢個 gap 同埋睇返啲最新呀外國嘅 trend 呀即係點……我諗最重要都係點樣 apply 喺 local context 囉有時我哋去學呢啲嘢。咁所以我覺得好好，其實即係都幫我執返個大囊啦，咁同埋實際上有啲我覺得都可以 modify 喺我工作上去用嘅”*

> *“就算我自己想在某方面了解得深入一點，我覺得已經決定了方向，我可以再參考有關的資料，再研究得深入一點，我覺得課程在這方面的確幫助頗大”*

> *“我幾 appreciate 呢就係啲有 lecture notes 嘅。係，咁呢就我會 go through 嗰啲 lecture notes，咁總有啲嘢呢就同自己個工作係有啲關係，咁我先至會睇比較 related 嗰啲下。佢啲好雞精嘅 lecture notes 呢…”*

### (d) Mutual support and networking for leaders

> *“因為例如我有印象就係我哋一開始到而家都係同一 group 嘅同學啦，咁係其實好好嘅，因為都好 friend 同埋有 comment 呀有 insight 呀咁樣嘅。”*

> *“另外我覺得同學之間的 sharing 都很有幫助，因為其實大家都是在各自的範疇工作，課程能讓大家日後可以有持續的交流”*

## 2.1.5 Findings from Survey with Health and Social Care Professionals

### 2.1.5.1 Objectives

Though the training offered by the JCECC Project cannot reach all health care and social care professionals in Hong Kong, it is hoped that the participants will bring a ripple effect to their colleagues after joining the training, for instances, sharing what they learnt from the workshops with their colleagues. Thus, a 3-wave community-wide professional survey has been conducted across the project period with 500 participants per wave as target, and a 12-month interval between each wave. The objective of the survey is to evaluate the extended impact of the professional capacity building programme on health and social care professionals in Hong Kong. We focused on their attitudes towards EoLC, EoLC competences, job satisfaction and meaningfulness, job stress and turn-over rate. In additional, we explored professionals’ satisfaction towards the JCECC programme in the 2018 wave of survey.

### 2.1.5.2 Methodology and Participants

The first survey was held between April-June 2016, the second between April-June 2017, and the third wave was launched in April 2018 and data collection was completed in early July 2018. Data was collected mainly through online survey. Health and social care professionals, particularly physicians, nurses, and social workers, were recruited mainly through relevant professional bodies and academic and research institutions including the *Hong Kong Geriatrics Society*, *the Hong Kong Palliative Medicine Society*, *the Federation of Medical Societies of Hong Kong*, *the Association of Hong Kong Nursing Staff*, *the Hong Kong Social Workers' General Union*, *the Hong Kong Social Workers Association*, *CUHK Alumni Affairs Office*, *the HKU Development & Alumni Affairs Office*, *the Centre of Behavioral Health*, *the Centre on Ageing*, and the mailing list and Facebook fan page of the JCECC Project. Invitation letters have also been sent to physicians working in family clinics, and specialties related to cardiology, nephrology, and emergency medicine. Totally, 515, 532 and 523 health and social care professionals completed the surveys in the 2016, 2017 and 2018 waves respectively. The distributions of professions of participants in the three waves were similar (**Table 2.1**) ($p<.05$). As expected, social workers/counselors, nurses, and physicians were the three predominant groups in our sample in all three waves.

**Table 2.1** Professions of participants in 2016, 2017, 2018 waves of professional survey

| | 2016 wave | 2017 wave | 2018 wave |
|---|---|---|---|
| N | 515 | 532 | 523 |
| Social workers/counselors | 174 (34.7%) | 193 (36.3%) | 126 (26%) |
| Nurses | 172 (34.3%) | 165 (31%) | 222 (45.9%) |
| Physicians | 110 (21.9%) | 109 (20.5%) | 98 (20.2%) |
| Others [a] | 46 (9.2%) | 65 (12.2%) | 38 (7.9%) |

*Note.* [a] This include occupational therapist, physiotherapist, chaplain or other religious workers, and trainers.

Professionals in the three waves have slightly different backgrounds (**Table 2.2**). In the 2018 wave, higher proportions of participants from hospitals and elderly long-term care settings (LTC) as compared to the 2016 and 2017 wave was observed while those came from other social services has slightly risen compared to 2017 wave. Participants in 2018 wave were also more experienced in EoLC as shown by their longer years in EoLC experience. Moreover, participants in 2018 were more likely to have joined JCECC training workshop(s) as compared to their counterparts in 2016. Given that all three waves employed the same recruitment strategies, these discrepancies might reflect that the professional survey has increasingly caught the attention of professionals who are relevant to EoLC. Moreover, an increasing number of participants have joined training under JCECC, which also reflects the increasing impact of JCECC in the field of EoLC professionals.

**Table 2.2** Demographics of 2016, 2017, 2018 waves of professional survey

| | 2016 wave | 2017 wave | 2018 wave |
|---|---|---|---|
| No. of participants | 512 | 531 | 522 |
| **Gender (Male)**** | 133 (26%) | 184 (34.7%) | 132 (25.2%) |
| **Age** | | | |
| 20-39 | 231 (45.1%) | 220 (41.4%) | 207 (39.7%) |
| 40-59 | 233 (45.5%) | 265 (49.9%) | 272 (52.1%) |
| 60 or above | 48 (9.4%) | 46 (8.7%) | 43 (8.2%) |
| **Service Setting***** | | | |
| Hospice | 14 (3.1%) | 30 (6.4%) | 15 (3.3%) |
| Hospital | 165 (36.6%) | 176 (37.5%) | 249 (55.3%) |
| Private practice | 30 (6.7%) | 19 (4.1%) | 23 (5.1%) |
| Elderly LTC | 122 (27.1%) | 180 (38.4%) | 88 (19.6%) |
| Other social services | 120 (26.6%) | 64 (13.6%) | 75 (16.7%) |
| **Involvements in EoLC** | | | |
| None | 109 (21.4%) | 85 (16%) | 86 (16.4%) |
| Small proportion (1/3) | 265 (52%) | 273 (51.4%) | 252 (48.2%) |
| Substantial proportion (between 1/3 and 2/3 of practice) | 88 (17.3%) | 109 (20.5%) | 120 (22.9%) |
| Most of the practice (more than 2/3 of practice) | 48 (9.4%) | 63 (11.9%) | 65 (12.4%) |
| **Experience in working with EoL patients and their family members (Years)** | 4.25 (1.01) | 5.87 (8.547) | 6.29 (9.763) |
| **Have joined training under the JCECC Project ***** | 90 (17.6%) | 150 (28.5%) | 170 (32.5%) |

*Notes.* $\chi^2$ test was adopted to test the group difference: **$p$<.01; ***$p$<.001.

Additional analysis was conducted to explore the relationship between EoLC competence levels and background characteristics of participants. Findings suggested significant but mild positive correlation between levels of involvement in EoLC and all competence domains (range of correlation: .09 - .28), between experience in EoLC and all competence domains (range of correlation: .1 - .23). Respondents who have previously joined training under JCECC also showed stronger EoLC competence, except for symptom management. These reflect that both practice experiences and training can affect the levels of competences in EoLC.

As expected, staff in different service settings which are not specialised in palliative care or EoLC also reported certain involvements in EoLC (**Figure 2.3**). Staff of these service settings might have various training needs in EoLC as well.

**Table 2.3** Involvements in EoLC by service settings (3 waves aggregated)

| | Hospice | Hospital | Private clinics | LTC Community | LTC Residential | Other social services |
|---|---|---|---|---|---|---|
| None | 0 (0%) | 63 (10.7%) | 21 (29.2%) | 23 (12.2%) | 9 (4.5%) | 85 (32.8%) |
| Small proportion | 22 (37.3%) | 463 (78.5%) | 47 (65.3%) | 161 (85.2%) | 169 (84.1%) | 147 (56.8%) |
| Substantial to most | 37 (62.7%) | 64 (10.8%) | 4 (5.6%) | 5 (2.6%) | 23 (11.4%) | 27 (10.4%) |

### 2.1.5.3 Key findings

Changes in attitude towards EoLC across years

Attitude was assessed by 12 items, each was measured with a 10-point Likert scale, with 1 being totally disagree and 10 being totally agree. A series of one-way ANOVA was conducted to determine statistically significant difference among the three waves. No significant difference was found. Subsequently, responses were categorised into two groups with 6/7 fixed as a cut-off score which stands for high agreement with an attitude. **Table 2.4** shows the distribution of high agreement group on each item across years and the results on an aggregated sample from all three waves. It can be concluded that most professionals identified with the core values in EoLC even at baseline (2016 waves). For examples, over 95% of all professionals surveyed in the three waves of surveys highly agreed that EoLC is a worthwhile experience, and only 4% thought that EoLC means giving up on life. Professionals viewed EoLC a family-based holistic care that not only care about the medical care of patients, but also emphasized family involvement and psychosocial care for both patients and family provided that over 95% of them strongly agreed with the relevant items.

**Table 2.4** Attitude towards EoLC professional survey participants by year and aggregated

| | **2016 wave** | **2017 wave** | **2018 wave** | **Three waves aggregated** |
|---|---|---|---|---|
| | **% of high agreement**[a] | **% of high agreement**[a] | **% of high agreement**[a] | **% of high agreement**[a] |
| Caring for family is important part of EoLC | 97.5% | 98.5% | 97.9% | 98% |
| Psychosocial support for patients & family is important part of EoLC | 97.9% | 97.9% | 97.5% | 97.8% |
| Family should be involved in process of EoLC | 96.1% | 96.1% | 96.7% | 96.3% |
| Important to tell patients & family what to expect after prognosis | 95.1% | 97.4% | 96.2% | 96.2% |
| Community support is important part in EoLC | 95.5% | 95.5% | 96.4% | 95.8% |
| Giving care to advanced illness patients is worthwhile experience | 94.4% | 97.2% | 94.1% | 95.2% |
| Important to tell patients & family truth about incurable prognosis | 94.7% | 95.9% | 93.5% | 94.7% |
| Patients with advanced illness and family should be key decision makers in EoLC | 90.9% | 91.4% | 93.3% | 91.8% |
| Willing to discuss EoLC with patients & families | 89.5% | 92.3% | 90.4% | 90.8% |
| For patients & family, receiving EoLC in the community is a better arrangement | 81.4% | 82.7% | 81.8% | 82% |
| Current community resources is sufficient in supporting patients & family *(Negative item)* | 10.1% | 9.4% | 9.9% | 9.8% |
| EOL implies giving up on life *(Negative item)* | 4.1% | 3.6% | 4.4% | 4% |

*Note.* [a] scores equal to or high than 7 are considered "high agreement".

Notwithstanding, while 95.8% strongly agreed that community support is important part in EoLC, only 9.8% strongly agreed that there is sufficient community support for EoL patients and family.

This suggested high unmet needs for community EoLC perceived among the professionals. Related to this is that although 82% strongly agreed that receiving EoLC in the community is a better arrangement for patients and family, the % of agreement was lower than other EoLC values. Probably, the perceived inadequacy of community support has contributed to the lower agreement on this item. On the other hand, although around 18% of all professionals from three waves expressed no involvement in EoLC in their practice, around 90% of our subjects expressed strong willingness to discuss EoLC with patients and families. These findings revealed that professionals were generally motivated to support EoL patients and the families.

### Changes in competence level across years

**Figure 2.6** shows the means of each competence domain by wave of study and also the aggregated means of all three waves. With one-way ANOVA, statistical significant effect of time was showed in the levels of EoL decision making (*F* [2,1550] =10.103, $p<0.01$) and community EoLC support (*F* [2,1547] =4.402, $p<0.05$). Post hoc tests revealed statistical significance in symptom management between 2016 & 2018 ($p<.05$), EoL decision making between 2016 & 2017 ($p<0.05$) and between 2016 & 2018 ($p<0.05$), and community EoLC support between 2016 & 2017 ($p<.001$) and between 2016 & 2018 ($p<.001$). In another word, the competence level on symptom management has been steadily increasing from 2016 to 2018, while the competence levels of Eol decision making and community EoL support both shared the trend of increase from the first wave and then levelled off from 2017 to 2018. Indeed, the overall EoLC competence shared the same pattern that it significantly improved in 2017 and then levelled off between 2017 and 2018, with a 3.1% overall increase from 2016 to 2018 (**Figure 2.6**).

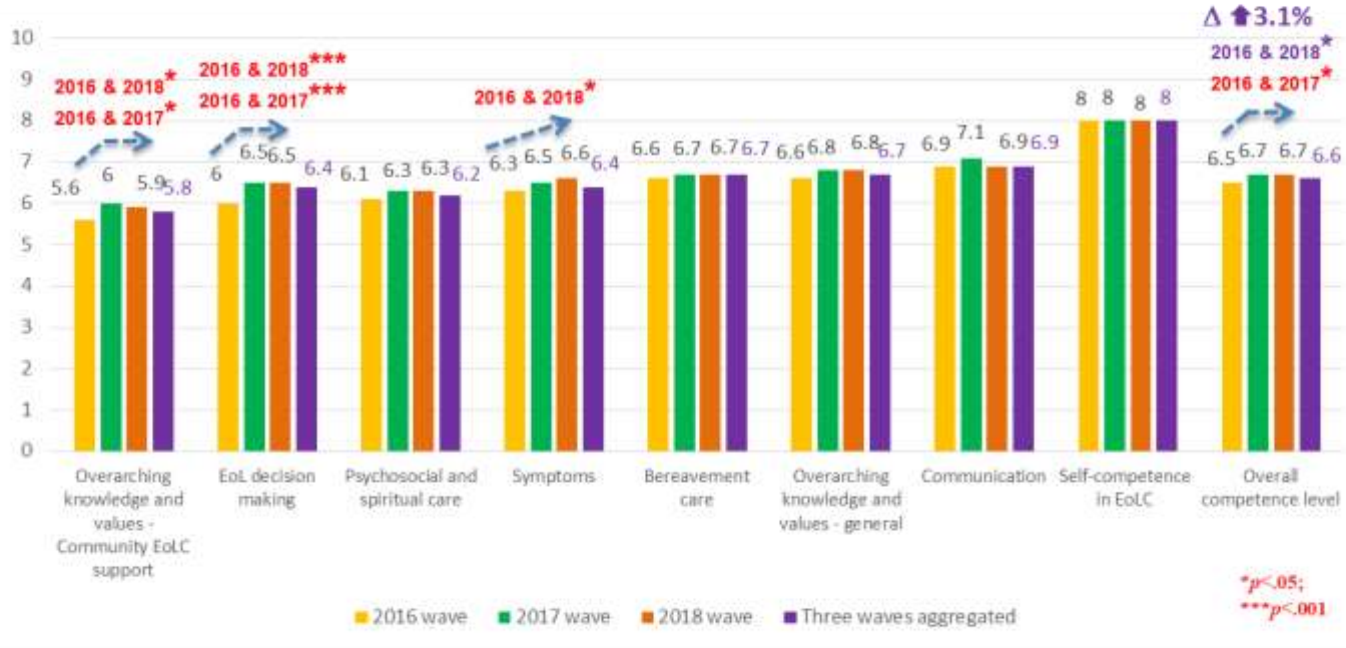

**Figure 2.6** EoLC competence levels of participants in professional survey by waves and aggregated

### Comparing competence level across domains

Comparing the competence levels across different domains with the aggregated means (**Figure 2.6**), it was found that the competency of "community EoLC support", which is a sub-domain under the "Overarching knowledge and values" and focuses on mobilising and collaborating with community services to provide support to EoL patients and their family members, was rated by professionals as the least competent (mean [SD]=5.8[2.26]). Other three competence domains which were rated below 6.5 over 10 included "psychosocial and spiritual care", "symptom management", and EoL decision making. This provided a direction for training topics in need by professionals in Phase II.

### Changes in job satisfaction, meaningfulness, stress and turn-over rates across years

ANOVA and Chi-square test were conducted to compare the job satisfaction, meaningfulness, stress, and turn-over rates among three waves of participants (**Table 2.5**). In particular, we selected participants who indicated at least some involvement in EoLC in their duties for this analysis in order to obtain more context-relevant results (**Table 2.5**). The findings suggested no significant differences among the three waves.

**Table 2.5** Comparison on turnover rates, job stress, job satisfaction and meaningfulness between three waves of participants who have some involvement in EoLC

| | 2016 wave | 2017 wave | 2018 wave | Δ between 2016 & 2018 |
|---|---|---|---|---|
| N | 400 | 441 | 436 | |
| **Changed job over the last 12 months (Yes)** | 59 (14.8%) | 72 (16.3%) | 51 (11.7%) | ⬇20.9% |
| **Reasons for changing job**[a] | | | | |
| Salary | 3 (5.1%) | 3 (4.5%) | 6 (14%) | |
| Development/Promotion | 13 (22%) | 19 (28.4%) | 10 (23.3%) | |
| Stress & burnout | 18 (30.5%) | 13 (19.4%) | 10 (23.3%) | |
| Personal reasons | 19 (32.2%) | 28 (41.8%) | 17 (39.5%) | |
| **Overall job stress level (1-10) (mean [SD])** | 6.07 (2.226) | 6.20 (2.091) | 6.09 (2.220) | ⬆0.4% |
| **Overall job satisfaction level (1-10) (mean [SD])** | 7.09 (1.791) | 7.09 (1.784) | 6.97 (1.869) | ⬇1.7% |
| **Overall job meaningfulness (1-10) (mean [SD])** | 7.9 (1.61) | 8 (1.57) | 8 (1.53) | ⬆1.8% |

*Note.* [a] Calculated with missing

### Relationship between job satisfaction, meaningfulness, stress and competences

A supplementary analysis was conducted to explore the relationship between job satisfaction, stress, and meaningfulness with competences in EoLC controlling for participants' involvement in EoLC work. It was found that for those who were involved in EoLC (minor to high involvement), higher competence in EoLC were significantly correlated with higher levels of job satisfaction and meaningfulness, but lower level of job stress (**Table 2.6**). These results suggest that enhancing EoLC competences among these health and social care professionals who work with EoL patients could improve their job satisfaction and meaningfulness while lowering job stress, resulting in a more competent and stable workforce in the field of EoLC.

**Table 2.6** Correlations between EoLC competences and job stress, satisfaction, & meaningfulness (*r*)

| | Job stress | Job Satisfaction | Job Meaningfulness |
|---|---|---|---|
| Basic values and knowledge in EoLC | $-.18^{***}$ | $.28^{***}$ | $.28^{***}$ |
| Communication skills | $-.15^{***}$ | $.34^{***}$ | $.33^{***}$ |
| Symptom management | $-.11^{***}$ | $.26^{***}$ | $.26^{***}$ |
| Psychosocial and spiritual care | $-.15^{***}$ | $.29^{***}$ | $.27^{***}$ |
| EoL Decision making | $-.16^{***}$ | $.28^{***}$ | $.27^{***}$ |
| Bereavement care | $-.12^{***}$ | $.31^{***}$ | $.29^{***}$ |
| Community EoLC | $-.13^{***}$ | $.25^{***}$ | $.19^{***}$ |
| Self-care | $-.25^{***}$ | $.35^{***}$ | $.38^{***}$ |

*Notes.* $^{**}p<.01$; $^{***}p<.001$. Sample which had minor to high level of involvement in EoLC work was selected.

### Satisfaction towards the JCECC Project

In the 2018 wave, satisfaction towards the JCECC Project was assessed. Among 523 professionals surveyed, 299 (57.2%) have heard of the JCECC Project. When asked the channels of knowing the JCECC Project, information in workplace (52.2%), participation in the JCECC project activities (35%), project promotion emails (29%), and friends (20%) were the 4 most common sources which participants were notified of the Project (**Figure 2.7**). It is note-worthy that apart from direct promotion, there was a considerable portion heard about the project through word-of-mouth (friends), which provided support to our assumption that the news about the project could have been spread to non-participants through rippling effect. Moreover, the electronic social media such as Facebook was found to catch the attention of some participants as well.

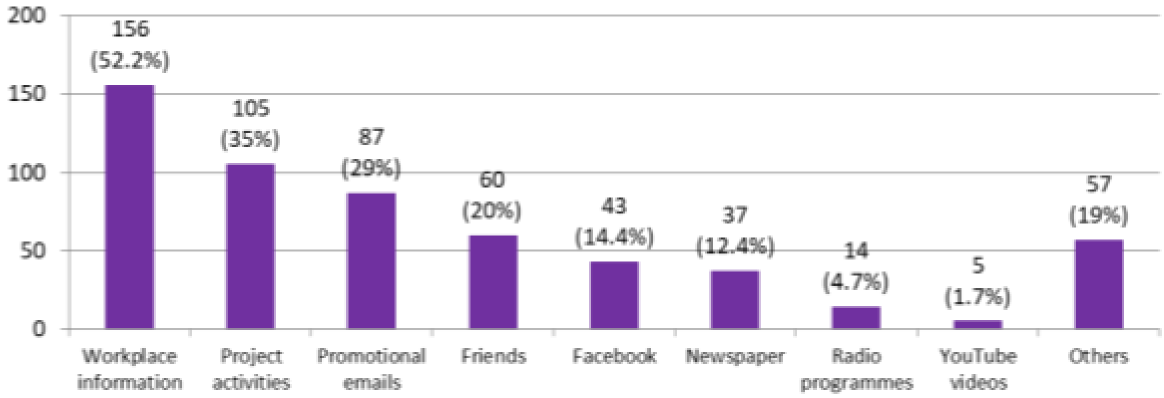

**Figure 2.7** Channels of knowing the JCECC Project [Allow multiple options] (N=299)

Participants who have heard about the Project were further asked their satisfaction with the Project education initiatives. Each item is assessed on a 10-point Likert scale, from 1=totally dissatisfied/totally disagree to 10=highly satisfied/strongly agree. If scores equal to 7 or above is classified as “highly satisfied/strongly agree”, 78% were highly satisfied with the JCECC Project as a whole (**Figure 2.8**). Furthermore, 80% and 73% strongly agreed that the Project has enhanced professional capacities in providing EoLC, and that the Project has raised public awareness on EoLC respectively. It should be noted that among these 299 participants, only 170 (57%) had personally participated in the training workshops of JCECC before. Again, the high proportions of satisfied responses particularly on the professional training activities might reflect the rippling effect of the educational initiatives of the Project.

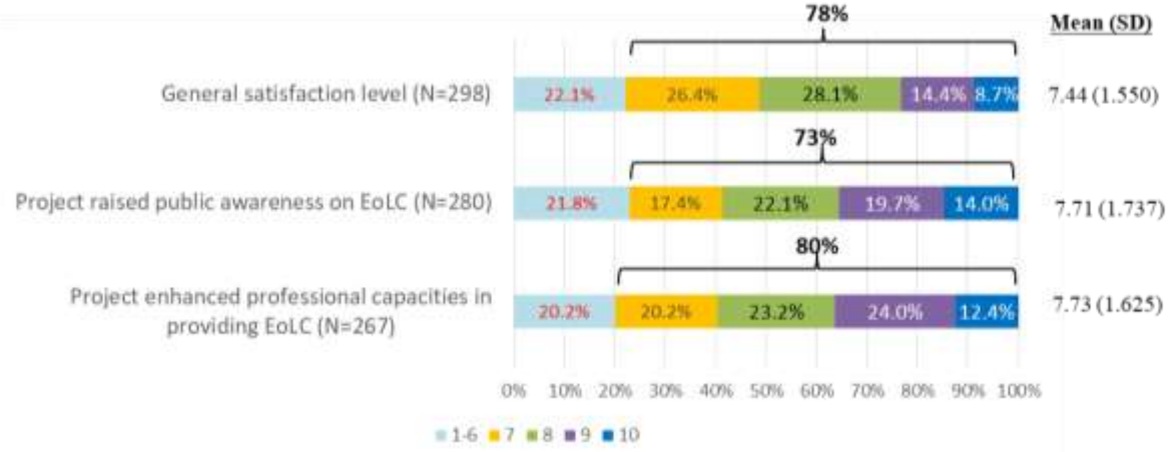

**Figure 2.8** Satisfaction with JCECC Project education initiatives

Preferred education format

In order to design training programmes with formats which meet the needs of various professions, further analysis was conducted on the preferred types and formats of training among the three waves of surveyed professionals. Professionals generally preferred workshops, short-term courses, and lectures/seminars more than retreats and longer term courses (**Figure 2.9**). Probably, the first three types require lower time commitment which made them more suitable for many healthcare and social care professionals with busy and tight work schedules. Moreover, there were significant differences in the preferred types of programmes between professions. Workshops, which imply practice-based training but are likely to be short-term, were most preferred by social workers. Nurses showed preference for all workshops, short-term courses, and lectures/seminars. However, they showed the highest preference for short-term course among all choices, and also among all professions. Regarding doctors, they preferred workshops or lecture/seminars. They were also the group which had the highest proportion of votes to lectures/seminars, which imply more knowledge-based of training, among all professions.

Regarding format of training, face-to-face training was the most popular choice for all professions, although doctors showed a particularly lower votes compared to other professions (**Figure 2.10**). Online learning and multimedia case demonstrations were also welcomed by over one-third of the participants. Among 76 participants who suggested other means of education, considerable number of them (42%) suggested trainings which are practice-based including experiential learning, clinical supervision, attachment programme, role-plays and case discussion. Around one-fourth suggested online platforms such as Webinar, Podcast, and well established e-learning platform specific for EoLC. When preferred day was analysed by professions, nurses and social workers were more likely to prefer weekdays than doctors and other professions, while doctors preferred weekends more (**Figure 2.11**). Furthermore, it was found that for all professions, except weekends evening was less preferred, each of other options (morning, afternoon and evening) was preferred by around one-third of the professions.

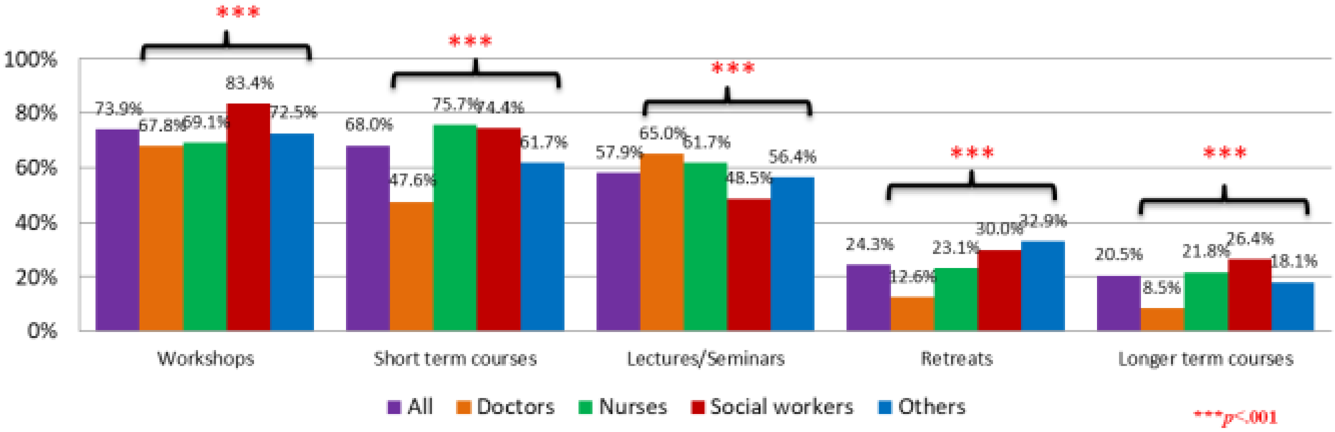

**Figure 2.9** Preferred types of professional education programmes by professions and all [Multiple options] (N=1570)

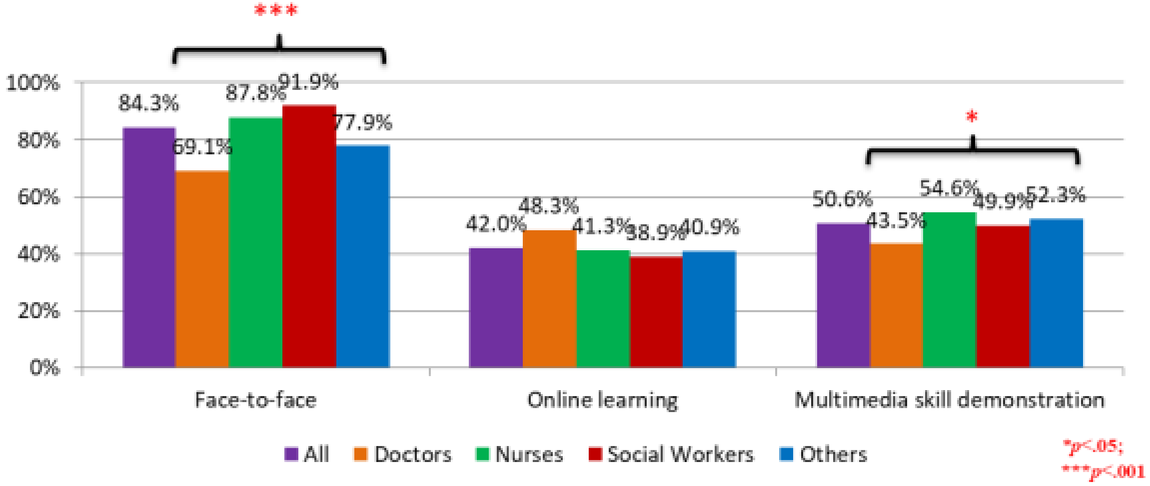

**Figure 2.10** Preferred formats of professional education programmes by profession and all [Multiple options] (N=1570)

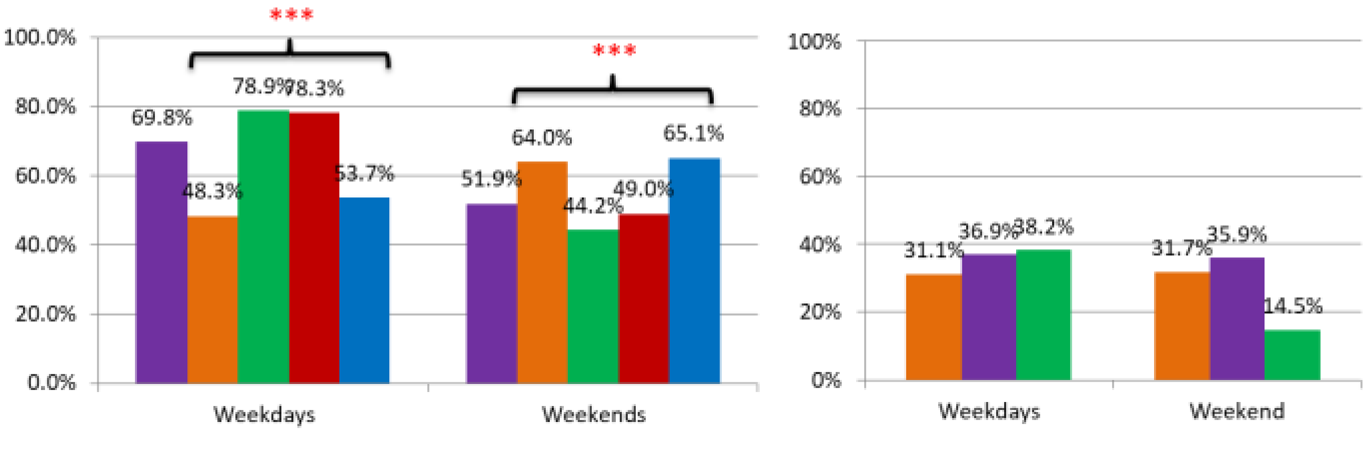

**Figure 2.11** Preferred day and time for education programmes (N=1570)

### 2.1.6 Comparing competence levels across samples

**Figure 2.12** shows the comparison of the post-programme competence levels among leaders and professional workshop participants, and surveyed health and social care professionals in 2018. First, the surveyed professionals reported lowest mean competence levels across most domains when compared to programme participants. Although surveyed professionals reported higher competence in EoL decision making than their counterparts in 2016, there was clearly room for further improvement in EoLC competences, for example in psychosocial and spiritual care, among health and social care professionals in the community. Second, trained leaders had comparable pre-training sense of EoLC competences to participants of professional workshops, but they ended up with the highest sense of competences and the competences maintained at the same height after completion of the programme.

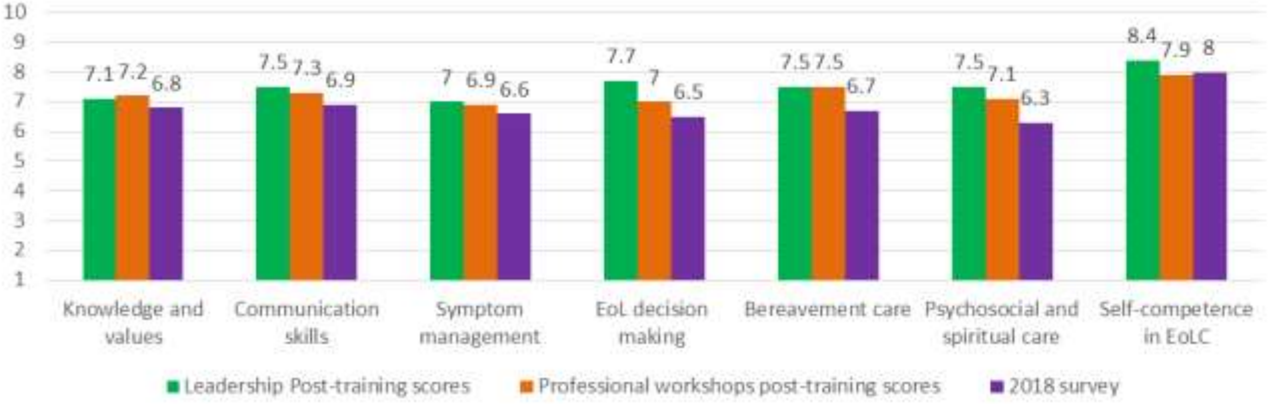

**Figure 2.12** Comparison of EoLC competence levels between leaders, workshop participants and 2018 survey participants

### 2.1.7 Key Performance Achievements

The overall output in the Professional Capacity Building Programme has over-achieved its target by 157% (**Table 2.7**).

**Table 2.7** Outputs of Professional Capacity Building Programme in the Community

| | Pledged output for 3 years | Actual output up to December 31, 2018 | Achievements |
|---|---|---|---|
| Leadership Training Programme | 40 | 47 | 118% achieved |
| Professionals | 850 | 1,570 | 185% achieved |
| Caregivers | 395 | 404 | 102% achieved |
| **Total** | **1,285** | **2,021** | **157% achieved** |

The results from the four studies on professionals suggested that the outcomes on professionals who participated in the JCECC capacity building programme remarkably exceeded the standard set in our key performance indicators (**Table 2.8**). Apparently, achievements regarding extended rippling impacts emerged particularly on EoLC competences and turn-over rate, but it was not apparent in job meaningfulness, job-satisfaction and stress. Overall, the rippling effect was partially supported by our results.

**Table 2.8** Key performance indicator achievements in professional capacity building programme

| | Key Performance Indicators | Performance of Professional capacity building programme in community [2] | Achievements[3] |
|---|---|---|---|
| 1 | Health care professional of different levels will have a 10% increase in sense of competence in EoLC | **Pre-post training change in EoLC competences among professional workshop participants (p.11)**<br>• Participants reported a 23.4% increase in overall EoLC competences upon completion of the programme | 234% achieved |
| | | **Pre-post training change in EoLC competences and leadership skills leadership training participants (p.12)**<br>• Leaders reported a 31.6% increase in EoLC competences and 47.5% increase in leadership skills upon programme completion. The overall increase was 40%. | 400% achieved |
| | | **Change in EoLC competences among healthcare and social care professionals in the professional surveys between 2016 and 2018 (p.19)**<br>• Surveyed professionals in 2018 showed a 3.1% increase in overall EoLC competences when compared to participants in 2016. Significant improvements were found on domains of EoL decision making, symptom management and community EoLC support, which increase by 8%, 5% and 5% respectively. | 31 % achieved |
| | | **Average:[4]** | 222% achieved |
| 2 | A 5% reduction in lower turnover rate and stress. With a more competent and stable team, patients as well as their family members in future will be benefited from the project indirectly | **Change in turn-over rate among healthcare and social care professionals in the professional surveys between 2016 and 2018 (p.20)**<br>• There was a 20.9% decrease in turnover rate when comparing the 2016 and 2018 waves. | 418% achieved |
| | | **Change in job stress among healthcare and social care professionals in the professional surveys between 2016 and 2018 (p.20)**<br>• The reported job stress increased by 0.4% between 2016 and 2018. | Not achieved (-8%) |
| | | **Average: [4]** | 205% achieved |

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[2] All % changes were calculated by the formula: (new values – old values)/old values.
[3] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes
[4] Assuming all indicators involved share the same weight.

### 2.1.8 Lessons Learned and Future Plan

#### 2.1.8.1 The programme was effective for participating professionals

The leadership programmes and professional training workshops were effective respective to their objectives. Leaders showed significant improvements not only on all EoLC competences but also leadership skills necessary in driving future development in EoLC (40% increase in competences). The enhanced competences maintained for 6 months and longer upon completion of programme. Referring to the comparison of EoLC competence levels among leaders, workshop participants and surveyed participants, it showed that the tailor-made leadership training programme was successful in providing more advanced level of knowledge and skills to professionals to equip them as future leaders. Likewise, participants of professional training workshops consistently reported significant improvements in self-perceived EoLC competences after training (23.4% increase in competences). Additionally, the favorable results from satisfaction surveys reflected the course contents met the needs of participants. Satisfaction items in the professional survey also showed that 80% of the respondents strongly agreed the JCECC capacity building programme helped enhance professionals’ competences. Our experience suggested that the development of the professional training programme based on the 7-domain competence framework was on the right track, and the competence framework also helped identify training needs among health and social care professionals in the community.

#### 2.1.8.2 Augmenting the rippling effect with the use of multi-modal education programmes

The revelations of leaders and the satisfaction survey with professionals in wider community suggested that rippling effects of the capacity building programme has been taking place. Participants of the JCECC capacity building programmes have spread the news of the Project to non-participants, which helped raise their awareness on EoLC as well as the Project *per sue*. The rippling effects on EoLC competence was emerging as seen from our professional survey (a 3.1% increase in competences between 2016 and 2018). Among the seven domains of EoLC competences assessed (with the “Overarching knowledge and values” domain consists of two sub-domains) in the professional survey, six areas showed positive direction of changes despite not all were statistically significant. In particular, mild but significant improvements regarding community EoLC, symptom management and end of life decision making were observed. Given that the rippling effects are indirect ones, the ceiling effect and relatively mild changes among professionals in community are fairly understandable. One possible explanation for the observed differentiated effects on different competence domains is that the rippling effects have been more effective on domains that were new to many professionals. Indeed, the three domains which showed significant improvements were three of the four domains which scored the lowest at baseline (2016 wave). Probably, direct training might be indispensable to promote further improvements in domains that professionals already had some basic understanding. Related is that our survey showed that healthcare and social care professionals are largely receptive to EoLC values and talking with patients and families about EoL issues. They are ready to learn more about

EoLC and be involved in providing support to patients and families facing EoL issues. The question remains: how to further strengthen the rippling effects and engage more professionals?

The exploration on preferred types and formats of education programmes provided helpful insights to this question. It is known that many professionals faced challenges in scheduling time for regular face-to-face training, and professionals tended to choose programmes of shorter term. Given that online learning was welcomed by more than one-third of the professionals in our survey, it could be assumed that developing online learning course could attract a considerable number of professionals who are otherwise difficult to engage through face-to-face training. However, there are limitations for online training, for examples, it could be less interactive and limit the opportunities for practice-level of learning. Furthermore, professionals' preference for practice-level learning (e.g. case demonstration) through multi-media was not as high as face-to-face training. It follows that for professionals who require practicum training, face-to-face training programme should be offered.

These findings shed light on the importance for training programmes to be able to offer both knowledge and practice experience, with consideration on the time commitment and flexibility. One solution is to develop multimodal programmes which make good use of online learning to deliver knowledge, while provide practicum training face-to-face. To promote knowledge acquisition through online learning, more interactive learning elements such as discussion forum and knowledge quizzes should also be embedded to the online learning platform. The goals of a multimodal programme are multi-folded: (1) to allow self-paced learning with online platform to reach out to professionals, (2) to optimize training effectiveness by fully utilising face-to-face training time for practicum training, (3) to promote continual learning through online networking even after completion of the course. It is believed that by extending our direct training to more professionals, rippling effect will be reinforced as well, as manifested as improvement in the attitude, knowledge and skills of other health and social care professionals in the field.

#### 2.1.8.3 The need for a level-differentiated standardised curriculum in EoLC

Most of the professional training workshops conducted in the past three years were competence domain-specific training designed for targets who have basic understanding on EoLC. However, we found that a considerable number of workshop participants had only limited understanding on basic values and knowledge on EoLC (a competence level below 6). The lack of solid foundation in EoLC might hamper their application of more advanced skills learned from our workshops. Moreover, as showed in the professional survey, professionals come across EoL patients and their families in various service settings. Although many professionals are not specialised in EoLC, they have to be equipped with necessary knowledge and skills in EoLC in order to provide high quality support to their clients with EoL issues regardless of settings. Hence, a course which spans all core domains is paramount to provide more comprehensive knowledge base for health and social care professionals, so that they can further build their competences in specific care domains based on a stronger knowledge foundation in EoLC. A standardised foundation course for professional which covers basic knowledge in all competence domains has been developed and delivered twice in the past three years with favorable responses from participants. This was just the first step towards building a structured curriculum in EoLC.

As proposed in the Strategic Framework for Palliative care by Hospital Authority, a three-level shared care model between non-palliative care specialists and palliative care specialists is considered appropriate in supporting EoL patients and families with various levels of EoLC needs[5]. It follows that differentiated curriculum for various levels of specialty in EoLC should be developed. In the phase II Project, courses of various levels should be established, such that basic course should cater the training needs of all healthcare and social care professionals, while more advanced-level course should be delivered to participants with high involvement in EoLC. In return, they will be expected to master the skills in providing specialised EoL psychosocial care to patients and families with complex needs after completing the advanced course.

#### 2.1.8.4 Identifying the training needs and optimizing training effects

Reviewing the findings from all the training programmes, the post-training competence levels of various domains were capped below 8 (out of 10) except for self-competences. On the other hand, professional survey informed relatively higher training needs regarding community EoLC, symptom management, EoL decision making, and psychosocial-spiritual care as compared to other competence domains. These four domains, one is related to basic knowledge in EoLC (community EoLC), and three are practice-related.

However, it is inappropriate to consider the seven competences as totally independent entities. The competences are inter-dependent as manifested in our professional survey. Through conducting case conferences with NGO partners in the past three years, our experience informed us that improving communication skills is fundamental to the upskilling of aforementioned competencies. The vital role of effective communication skills cannot be overlooked. Its importance was further supported by our professional survey which showed that communication skills were intertwined with the remaining competency domains, and that it was also associated with higher job satisfaction and sense of meaningfulness.

Concluding from the discussion above, we believed that there are still rooms for improvements in all competence domains, but the sequence of delivering training on seven competences could be reshuffled to optimise the training effects. For all professionals, basic knowledge and values, particularly on community EoLC, should be a prerequisite to strengthen professional’s positive attitude towards EoLC in community settings. The basic values should then be followed by topics on self-reflection and self-care. Although professionals showed relatively high self-competence in

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[5] Hospital Authority (2017). Hospital Authority Strategic Service Framework for Palliative Care (p.63) Retrieved on May 18, 2018 from http://www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf

death work in our findings, this part is fundamental as it facilitates professionals to reflect on their readiness in engaging in EoLC. It should be followed by practice domains. Communication skills should be the first domain to be introduced as communication skills penetrate into all remaining four practice domains. The domains of symptom management, psychosocial-spiritual care, EoL decision making, and bereavement care should then be delivered in relation to the communication skills. Particularly, more effort should be made to offer progressive trainings on physical symptom, psychosocial-spiritual care, and EoL decision making, starting from the basics and proceed to more advanced levels, given the relatively limited knowledge and skills on these domains among professionals. Regarding bereavement care, professionals should be helped to review their understanding on the topic, and they might be more ready to receive advanced training for this topic.

## 2.2 Professional Capacity Building in the Residential Care Homes for the Elderly (RCHEs)

### 2.2.1 Programme descriptions

This section reports the evaluation on an innovative initiative of the Hong Kong Association of Gerontology (HKAG) to provide culturally appropriate training on end-of-life care for staff in residential care homes for the elderly (RCHEs). Between 2016 and 2018, through the JCECC Project, the HKAG implemented EoLC in 36 RCHEs under 18 NGOs in the Kowloon East, Kowloon Central and Kowloon West districts. Adopting the concept and practice of District Based End of Life Care Professional Support to RCHE in the practice of Palliative and End of Life Care in RCHEs, two of the overarching goals of HKAG programme are to:

- develop a culturally congruent, locally applicable and evidence-based end-of-life (EoL) care model for improving outcomes in care for the terminally ill elders in RCHEs
- Serve 36 subvented RCHEs on delivering the EoL care services and test out the district-based model

To this end, capacity building of RCHEs in EoL care was therefore implemented. A structured training programme has been designed to target all staff of RCHEs, with two streams of education tailored to professional and non-professional staff (frontline staff). This training programme was developed on the premise that healthcare workers (both professional and non-professional) can provide quality EoLC if education and on-site coaching is provided. Core elements of the training programme for all staff include symptom control, ACP and Advance Directives (AD), legal and ethical concern in decision-making at EoL, psychosocial and spiritual care, grief and bereavement. Additional training was provided for professional staff to assess and manage symptoms. Training was delivered using multipronged approaches such as lectures, workshops, skill demonstrations and on-site coaching. Moreover, supportive attitudes and an empathic culture are essential for delivering quality EoLC, and therefore mindset-changing experiential workshops were provided to all staff in each RCHE before EoLC services are commenced. Continuous support has also been provided to RCHEs. Ongoing on-site coaching has been provided in the participating RCHEs throughout the EoLC service implementation period in order to support staff in putting what they have learnt into practice. This was actioned by a nurse and a social worker from the JCECC Project team designated to each care setting, who “walk along” with staff in their journey towards delivering quality EoLC.

Between 2016 and 2018, the HKAG has delivered 840 sessions of lecture training and talks to benefit more than 2,000 managerial staff, professional staff and front line staff in RCHEs. More than 7,400 professional consultations, 1,300 on-site support session, and around 240 on-site coaching sessions have been provided to RCHE staff.

### 2.2.2 Evaluation Framework

The evaluation of the capacity building programmes in the RCHEs was conducted through a mixed-methods study which consists of three core studies: (1) benchmarking of provision of palliative and EoLC in RCHEs, (2) evaluation on the EoLC knowledge and readiness in EoLC provision among trained RCHEs staff, and (3) qualitative studies (focus group and in-depth interviews) with RCHEs staff regarding their experiences with the training and EoLC implementation in their RCHEs (**Figure 2.13**).

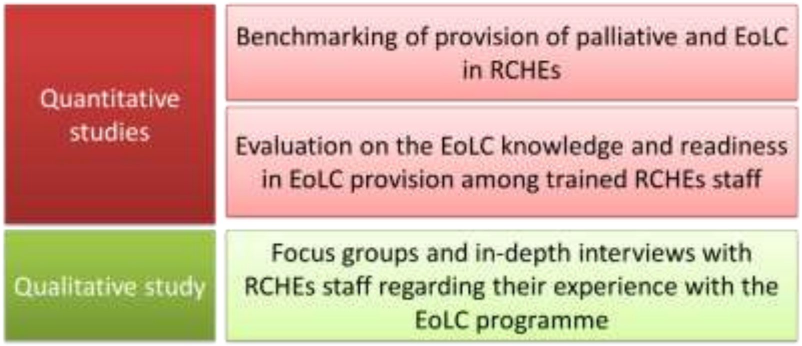

**Figure 2.13** Evaluation framework of the capacity building programmes in the RCHEs

Regarding benchmarking, level of palliative and EoL care provision in RCHEs were assessed by an assessment tool developed by HKAG. The instrument consists of items on the background information of the RCHE and 30 items on EoL care divided into three parts, namely, palliative care (16 items), EoL care (7 items), and postmortem care (7 items). The assessments were conducted by 1 to 2 assessors through on-site document review. Each item of the assessment is rated by assessor with scale ranged from 0, 1a, 1b, 2, to N/A, according to the degree of provision of EoL cares. In order to compare the difference in the level of the care provision in RCHEs after the programme, repeated assessments were conducted for three times: at baseline before the programme ($T_0$), one year ($T_1$) and two years ($T_2$) after RCHEs joined the programme. Same assessment tool is used for $T_0$, $T_1$ and $T_2$.

To assess RCHEs staff's readiness in delivering EoL care after joining the programme, a 16-item validated questionnaire[6] was used to capture changes. The questionnaire comprises three aspects, namely willingness, capability and resilience. Each staff was asked to complete the questionnaire at the first activity of the programme as baseline ($T_0$), as well as one ($T_1$) and two years ($T_2$) after joining the programme for comparison. Same assessment tool was used in $T_0$, $T_1$ and $T_2$. To assess the effectiveness of the training programme in enhancing staff's knowledge, each staff was asked to complete a set of questions on their knowledge regarding the training topics before ($T_0$) and

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[6] Chan, H. Y. L., Chun, G. K. M., Man, C. W., & Leung, E. M. F. (2018). Staff preparedness for providing palliative and end-of-life care in long-term care homes: Instrument development and validation. Geriatrics and Gerontology International, 18(5), 745–749.

after ($T_1$) joining the training session, as well as one year after the training session ($T_2$). Same assessment tool is used in $T_0$, $T_1$ and $T_2$.

In order to collect qualitative data regarding RCHEs staff's experience with the HKAG programme, between June 2017 and April 2018, the HKU research team conducted focus groups and in-depth interviews with staff of 16 RCHEs which completed training provided by HKAG. Managerial staff (superintendent, vice superintendent), professional staff (social workers, nurses), and frontline staff (personal care worker, health worker) were the target participants in this study. Focus groups were arranged for managerial staff and professional staff separately, and in-depth interviews were conducted with frontline staff. Random sampling was adopted to randomly select 3 RCHEs from which frontline staff were recruited to participate in in-depth interviews. The HKU research team facilitated the focus groups and in-depth interviews with semi-structured interview guidelines.

### 2.2.3 Findings from benchmarking of provision of palliative and EoLC in RCHEs

$T_0$ and $T_1$ data were collected from 32 RCHEs for comparisons (**Table 2.9**). The proportion of '0' decreased and the proportion of '2' increased notably across the three categories of the assessment. For the 'EOL care' category, the proportion of 'N/A' also notably dropped. As a whole, the improvement was the most salient in the 'EOL care' category, followed by the 'palliative care' category.

For $T_0$, $T_1$ and $T_2$ comparisons, data from 11 RCHEs were gathered (**Table 2.10**). The proportion of '0' kept decreasing and the proportion of '2' kept increasing as shown in $T_0$-$T_1$ and $T_1$-$T_2$ comparisons. According to the results of the pre-post comparisons, in general, the proportion of '2' increased and the proportion of '0' decreased at $T_1$, indicating improvement in the provision of EOL care one year after the implementation of the project. And the positive effects could be sustained over two years. The figures imply that the project was effective in improving the provision of EOL care at nursing home level.

**Table 2.9** Level of palliative and EOL care provision in RCHEs ($T_0$-$T_1$ comparisons)

| | **Palliative care** | | | **EOL care** | | | **Postmortem care** | | | **Total** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | $T_0$ % | $T_1$ % | **% Diff** | $T_0$ % | $T_1$ % | **% Diff** | $T_0$ % | $T_1$ % | **% Diff** | $T_0$ % | $T_1$ % | **% Diff** |
| **0** | 33.3 | 2.7 | **-30.6** | 38.8 | 3.6 | **-35.3** | 11.2 | 2.7 | **-8.5** | 29.4 | 2.9 | **-26.5** |
| **1a** | 5.1 | 3.3 | **-1.8** | 0.0 | 5.8 | **+5.8** | 1.8 | 2.7 | **+0.9** | 3.1 | 3.8 | **+0.6** |
| **1b** | 9.4 | 10.4 | **+1.0** | 5.8 | 4.9 | **-0.9** | 6.7 | 6.7 | **0.0** | 7.9 | 8.2 | **+0.3** |
| **2** | 51.6 | 82.0 | **+30.4** | 19.6 | 65.6 | **+46.0** | 56.7 | 64.7 | **+8.0** | 45.3 | 74.1 | **+28.8** |
| **N/A** | 0.6 | 1.6 | **+1.0** | 35.7 | 20.1 | **-15.6** | 23.7 | 23.2 | **-0.4** | 14.2 | 11.0 | **-3.2** |

Number of RCHEs = 32
% Diff = % of $T_1$ – % of $T_0$
0 = Neither had written guidelines/policies/procedures/mechanisms nor execution and documentation
1a = Had written guidelines/policies/procedures/mechanisms but no execution or documentation
1b = No written guidelines/policies/procedures/mechanisms but had execution and documentation
2 = Had both written guidelines/policies/procedures/mechanisms and execution and documentation

**Table 2.10** Level of palliative and EOL care provision in RCHEs ($T_0$-$T_1$-$T_2$ comparisons)

| | **Palliative, EOL and Postmortem care** | | | | | |
|---|---|---|---|---|---|---|
| | $T_0$ % | $T_1$ % | $T_2$ % | **$T_0$-$T_1$ % Diff** | **$T_1$-$T_2$ % Diff** | **$T_0$-$T_2$ % Diff** |
| **0** | 29.7 | 4.8 | 4.5 | **-24.8** | **-0.3** | **-25.2** |
| **1a** | 3.0 | 3.0 | 2.4 | **0.0** | **-0.6** | **-0.6** |
| **1b** | 5.2 | 1.5 | 2.1 | **-3.6** | **+0.6** | **-3.1** |
| **2** | 46.4 | 82.1 | 83.3 | **+35.8** | **+1.2** | **+36.9** |
| **N/A** | 15.8 | 8.5 | 7.6 | **-7.3** | **-0.9** | **-8.2** |

Number of RCHEs = 11
$T_0$-$T_1$ Diff = % of $T_1$ – % of $T_0$
$T_1$-$T_2$ % Diff = % of $T_2$ – % of $T_1$
$T_0$-$T_2$ % Diff = % of $T_2$ – % of $T_0$
0 = Neither had written guidelines/policies/procedures/mechanisms nor execution and documentation
1a = Had written guidelines/policies/procedures/mechanisms but no execution or documentation
1b = No written guidelines/policies/procedures/mechanisms but had execution and documentation
2 = Had both written guidelines/policies/procedures/mechanisms and execution and documentation

### 2.2.4 Findings from quantitative evaluation on staff's preparedness to EoLC delivery and knowledge in EoLC

Staff preparedness data were collected from 1003 professional and frontline staff from 33 RCHEs for $T_0$-$T_1$ comparisons (**Table 2.11**). Paired-samples *t* tests showed that the mean scores of willingness, competence and resilience significantly increased across professional and frontline staff at $T_1$. The increases for level of competence were the most obvious. Data were also collected from 209 professional and frontline staff from 9 RCHEs to compare their preparedness to deliver EOL care in $T_0$, $T_1$ and $T_2$ (**Table 2.12**). Paired-samples *t* tests showed that the mean scores of willingness, competence and resilience of professional and frontline staff were still significantly much higher at $T_2$ compared $T_0$. As one of the key performance indicator, the HKAG programme was found to enhance the competences of all ranks of RCHEs staff by 12.2% by the time of two years after programme started (**Table 2.12**).

Results showed that staff preparedness to EOL care delivery improved one year after the implementation of the project. And the positive effects could be sustained over two years. The figures implied that the project could better-equip staff in terms of willingness, competence and resilience in delivery EOL care at nursing home level.

**Table 2.11** Level of staff preparedness to EOL care delivery ($T_0$-$T_1$ comparisons)

| | $T_0$ Mean (*SD*) | $T_1$ Mean (*SD*) | Mean Diff | Δ between $T_0$ and $T_1$ |
|---|---|---|---|---|
| **Professional staff** | | | | |
| Willingness (*n*=342) | 3.56 (.57) | 3.66 (.52) | .096** | ⬆2.8% |
| Competence (*n*=344) | 3.11 (.58) | 3.47 (.49) | .361*** | ⬆11.6% |
| Resilience (*n*=344) | 3.68 (.53) | 3.82 (.47) | .137*** | ⬆3.8% |
| **Frontline staff** | | | | |
| Willingness (*n*=651) | 3.20 (.64) | 3.31 (.60) | .106*** | ⬆3.4% |
| Competence (*n*=643) | 2.84 (.67) | 3.07 (.56) | .229*** | ⬆8.1% |
| Resilience (*n*=659) | 3.48 (.65) | 3.63 (.58) | .153*** | ⬆4.3% |
| **All staff** | | | | |
| Willingness (*n*=993) | 3.29 (.68) | 3.30 (.67) | .102*** | ⬆0.3% |
| Competence (*n*=987) | 2.90 (.70) | 3.24 (.58) | .275*** | ⬆11.7% |
| Resilience (*n*=1003) | 3.51 (.66) | 3.75 (.55) | .148*** | ⬆6.8% |

Number of RCHEs = 33

Mean Diff = $T_1$ Mean – $T_0$ Mean

Items were rated from ‘1 completely disagree’, ‘2 disagree’, ‘3 neutral’, ‘4 agree’ to ‘5 completely agree’

*$p < .05$ by paired-samples *t* test

**$p < .01$ by paired-samples *t* test

***$p < .001$ by paired-samples *t* test

**Table 2.12** Level of staff preparedness to EOL care delivery ($T_0$-$T_1$-$T_2$ comparisons)

| | $T_0$ Mean (*SD*) | $T_1$ Mean (*SD*) | $T_2$ Mean (*SD*) | $T_0$-$T_1$ Mean Diff | $T_1$-$T_2$ Mean Diff | $T_0$-$T_2$ Mean Diff | Δ between $T_0$ and $T_2$ |
|---|---|---|---|---|---|---|---|
| **Professional staff** | | | | | | | |
| Willingness (*n*=76) | 3.56 (.67) | 3.62 (.56) | 3.72 (.53) | .058 | .105 | .163* | ⬆4.5% |
| Competence (*n*=76) | 3.16 (.71) | 3.44 (.58) | 3.49 (.46) | .279** | .048 | .327*** | ⬆10.4% |
| Resilience (*n*=76) | 3.70 (.59) | 3.79 (.51) | 3.83 (.48) | .083 | .048 | .132 | ⬆3.5% |
| **Frontline staff** | | | | | | | |
| Willingness (*n*=128) | 3.15 (.63) | 3.31 (.60) | 3.47 (.61) | .154** | .155* | .310*** | ⬆10.2% |
| Competence (*n*=132) | 2.81 (.73) | 3.16 (.52) | 3.19 (.64) | .348*** | .026 | .363*** | ⬆13.5% |
| Resilience (*n*=133) | 3.44 (.74) | 3.68 (.60) | 3.66 (.63) | .241*** | -.026 | .217** | ⬆6.4% |
| **All staff** | | | | | | | |
| Willingness (*n*=204) | 3.30 (.67) | 3.42 (.60) | 3.56 (.59) | .118** | .137** | .255*** | ⬆7.9% |
| Competence (*n*=208) | 2.94 (.74) | 3.26 (.56) | 3.30 (.60) | .322*** | .340 | .350*** | ⬆12.2% |
| Resilience (*n*=209) | 3.54 (.70) | 3.72 (.57) | 3.72 (.58) | .183*** | .001 | .186** | ⬆5.1% |

Number of RCHEs = 9

$T_0$-$T_1$ Mean Diff = $T_1$ Mean – $T_0$ Mean

$T_1$-$T_2$ Mean Diff = $T_2$ Mean – $T_1$ Mean

$T_0$-$T_2$ Mean Diff = $T_2$ Mean – $T_0$ Mean

Items were rated from ‘1 completely disagree’, ‘2 disagree’, ‘3 neutral’, ‘4 agree’ to ‘5 completely agree’

*$p < .05$ by paired-samples *t* test

**$p < .01$ by paired-samples *t* test

***$p < .001$ by paired-samples *t* test

Staff knowledge data were collected from 1447 professional and frontline staff from 36 RCHEs for $T_0$-$T_1$ comparisons (**Table 2.13**). Paired-samples *t* tests showed that the mean total score of all training topics at $T_1$ was significantly higher than those at $T_0$. In particular, the professional staff achieved the greatest improvement in the topics ‘末期病患者不適徵狀處理(I)’ (+40.8%) and ‘末期病患者不適徵狀處理(II)’ (+42.2%), while the frontline staff have the most obvious improvement in the topic ‘與末期病患者及其家屬之溝通技巧’ (+40.8%).

Data were also collected from 438 professional and frontline staff from 23 RCHEs to compare their level of knowledge towards EOL care in $T_0$, $T_1$ and $T_2$ (**Table 2.14**). Paired-samples *t* tests showed that although most of the staff showed retention of knowledge received in the training, there are fall backs in certain topics. For professional staff, in the topics ‘末期病患者不適徵狀處理(I)’ (-8.9%) a significant drop in the level of knowledge is noted. As for similar topics like ‘末期病患者不適徵狀處理(II)’ (-2.4%) and ‘瀕死期徵狀評估及護理’ (-3.55%) a decrease in knowledge is also noted. For frontline staff, for the topic ‘預設圓願照顧計劃及照顧家屬心社靈需要’ (-0.36%) , a slight decrease in knowledge level is also noted.

Results showed that the knowledge level of RCHE staff requires consolidation and reinforcement after one year especially in the care of residents in late stage illnesses and in the final days. Reinforcement can be achieved by on site coaching and further training programs.

**Table 2.13** Level of staff knowledge towards EoLC ($T_0$-$T_1$ comparisons)

| | $T_0$ Mean (*SD*) | $T_1$ Mean (*SD*) | Mean Diff |
|---|---|---|---|
| **Professional staff** | | | |
| 臨終照顧倫理與法律議題 (*n*=595) | 2.70 (.83) | 3.53 (.67) | .830*** |
| 末期病患者不適徵狀處理(I) (*n*=550) | 2.61 (1.03) | 3.68 (.62) | 1.065*** |
| 末期病患者不適徵狀處理(II) (*n*=522) | 2.48 (.87) | 3.53 (.59) | 1.046*** |
| 瀕死期徵狀評估及護理 (*n*=485) | 2.86 (.88) | 3.80 (.48) | .942*** |
| 心理社交及靈性需要照顧 (*n*=505) | 3.15 (.93) | 3.65 (.65) | .495*** |
| 預設圓願照顧計劃及照顧家屬心社靈需要 (*n*=525) | 2.76 (.77) | 3.55 (.71) | .790*** |
| 哀傷輔導及處理 (*n*=478) | 3.35 (.71) | 3.77 (.50) | .425*** |
| **Frontline staff** | | | |
| 臨終照顧倫理與法律議題 (*n*=852) | 2.52 (.78) | 3.42 (.73) | .900*** |
| 末期病患者不適及臨終徵狀處理 (*n*=778) | 2.72 (.81) | 3.64 (.70) | .916*** |
| 預設圓願照顧計劃及照顧家屬心社靈需要 (*n*=746) | 2.75 (.69) | 3.54 (.67) | .792*** |
| 與末期病患者及其家屬之溝通技巧 (*n*=783) | 1.61 (.81) | 3.16 (1.10) | 1.544*** |

Number of RCHEs = 36
Mean Diff = $T_1$ Mean – $T_0$ Mean
****p* < .001 by paired-samples *t* test

**Table 2.14** Level of staff knowledge towards EoLC ($T_0$-$T_1$-$T_2$ comparisons)

| | **$T_0$ Mean (*SD*)** | **$T_1$ Mean (*SD*)** | **$T_2$ Mean (*SD*)** | **$T_0$-$T_1$ Mean Diff** | **$T_1$-$T_2$ Mean Diff** | **$T_0$-$T_2$ Mean Diff** |
|---|---|---|---|---|---|---|
| **Professional staff** | | | | | | |
| 臨終照顧倫理與法律議 (*n*=182) | 2.76 (.81) | 3.53 (.67) | 3.01 (.85) | .775*** | -.522*** | .253** |
| 末期病患者不適徵狀處理(I) (*n*=158) | 2.69 (.98) | 3.80 (.46) | 2.47 (1.02) | 1.108*** | -1.323*** | -.215* |
| 末期病患者不適徵狀處理(II) (*n*=152) | 2.57 (.85) | 3.70 (.50) | 2.51 (.80) | 1.132*** | -1.191*** | -.059 |
| 瀕死期徵狀評估及護理 (*n*=145) | 2.92 (.85) | 3.86 (.43) | 2.82 (.93) | .945*** | -1.041*** | -.097 |
| 心理社交及靈性需要照顧 (*n*=150) | 3.25 (.90) | 3.74 (.57) | 3.45 (.71) | .487*** | -.287*** | .200* |
| 預設圓顾照顧計劃及照顧家屬心社靈需要 (*n*=144) | 2.72 (.80) | 3.60 (.67) | 2.94 (.67) | .882*** | -.653*** | .229** |
| 哀傷輔導及處理 (*n*=156) | 3.44 (.64) | 3.78 (.46) | 3.38 (.72) | .346*** | -.397*** | -.051 |
| **Frontline staff** | | | | | | |
| 臨終照顧倫理與法律議題 (*n*=252) | 2.66 (.78) | 3.54 (.63) | 2.82 (.82) | .881*** | -.726*** | .155* |
| 末期病患者不適及臨終徵狀處理 (*n*=256) | 2.75 (.74) | 3.71 (.62) | 2.78 (.80) | .965*** | -.938*** | .027 |
| 預設圓顾照顧計劃及照顧家屬心社靈需要 (*n*=236) | 2.76 (.72) | 3.49 (.66) | 2.75 (.67) | .725*** | -.733*** | -.008 |
| 與末期病患者及其家屬之溝通技巧 (*n*=236) | 1.56 (.85) | 3.19 (.06) | 1.57 (.74) | 1.631*** | -1.623*** | .008 |

Number of RCHEs = 23
$T_0$-$T_1$ Mean Diff = $T_1$ Mean – $T_0$ Mean
$T_1$-$T_2$ Mean Diff = $T_2$ Mean – $T_1$ Mean
$T_0$-$T_2$ Mean Diff = $T_2$ Mean – $T_0$ Mean
**p* < .05 by paired-samples *t* test
***p* < .01 by paired-samples *t* test
****p* < .001 by paired-samples *t* test

### 2.2.5 Findings from qualitative study

One focus group with managerial staff, one focus group with professional staff, and 6 in-depth interviews with frontline staff were conducted. These staff have stayed in the programme for more than a year. In the following, comments from the interviewed RCHE staff are summarised.

### Perceived positive impacts of the HKAG capacity building programme

From the discourse of interviewed RCHE staff, the impacts of the HKAG progamme, including the training and the continuous clinical support, were evident on several levels:

(a) On the RCHE staff level, interviewed RCHE staff generally agreed that the HKAG training programme had successfully promoted empathy and EoL values identification among RCHE staff, which in turn enhanced staff's commitment in providing quality care to residents in EoL. Moreover, staff agreed that the training enhanced the knowledge of staff regarding EoLC, facilitated the internalization of the importance of holistic care in EoL, and raised the awareness on the importance of psychosocial-spiritual needs of residents in EoL. In addition, staff who identified strongly with the goals of the programme expressed promoted sense of meaning in their work.

*“對於即係一啲生命教育嗰個諗法呢，即係因為同事之間點樣去睇呢一樣嘢都直接可以影響到點樣照顧個老人家咁樣嘅。可以做到感同身受囉。”* (Professional staff)

*“點樣陪佢走完最後一程，因為基本上醫療上已經無嘢可以做，唯有等佢……紓緩下佢嘅痛楚，咁就喺佢社交，或者喺佢 family 方面，睇下點樣可以盡量幫到佢囉，同埋作為照顧者就點樣可以令佢有尊嚴啲，幫輕佢嘅痛苦，解除痛苦就無可能㗎啦，大家都知道，咁都講得幾 detail 嗰陣時我記得”* (Frontline staff)

*“學識唔只係表面上嘅照顧，因為我哋點樣對老人家扶抱吖，點照顧佢。同埋我學識仲有一樣嘢，原來心靈上，或者佢精神上都好重要。”* (Frontline staff)

*“同埋我覺得佢個涵蓋面係 comprehensive。除咗係講價值觀、理念，實務技巧佢有。佢亦都教同事處理一啲臨終病人既癥狀，或者係評估佢哋一啲的情況既嘢，佢哋都有教。”* (Superintendent)

*“後尾到到佢覺得自己差啦，係佢自己話想參加呢個 programme 嘅，咁見住佢慢慢、慢慢差，其實自己都唔開心嘅，但係起碼我好好彩可以…即係佢走嗰日我可以喺度，我又返工，我可以陪到佢，咁就……好似……即係自己好似完整，complete 咗自己個 mission 咁樣，即係我真係陪你走咗啦，你好舒服咁樣走。”* (Frontline staff)

*“講個人反省。呢樣嘢好緊要，我要讚吓佢哋有一啲 workshop 帶到出嚟，係透過一啲情景遊戲，或者假設嘅遊戲。”* (Superintendent)

(b) On the patient and family caregiver level, interviewed staff, particularly front line staff who had participated in the programme for a longer period, perceived that the programme had reduced hospitalisation of residents in their end of life, had helped dying residents to achieve dignified end of life, increased quality family time between residents and caregivers, and reduced the risk of complicated grief of family caregivers.

*“果一次嘅安排就係佢啲家人同埋親屬都有過黎見佢最後一面咁樣。可能個婆婆未必爭大眼見到，但係佢可能都感受到，所以佢有一下係個血氧都幾好。咁果個樣都幾靚嘅。佢個屋企人反應啦，都話好安祥，所以呢個計劃都幾好。都可以幫到屋企人，可以幫到離開嘅婆婆舒服安祥咁樣。屋企人亦都話好多謝有呢個安排咁。”*(Frontline staff)

*“但係 so far 因為安寧頌…入咗安寧頌呢個 scheme 嘅關係啦，無乜必要我哋都唔會俾佢入院，咁有醫生俾啲退燒藥呀，即係盡 量可以我哋看到嘅都看，我覺得呢個係好成功嘅。佢嗰年入面真係無乜唔係需要話一定要入院啦”* (Frontline staff)

*“同埋屋企人來講，平時有咩同個長者講唔到嘅，都可以喺房最後嗰刻大家……表達俾佢知。如果平時一間房幾張床，隔離有院友都唔方便。醫院都係同一樣道理，起碼佢有佢哋嘅私隱。”* (Frontline staff)

*“對屋企人佢哋好開心，佢哋後尾有寫返 thank you card 俾我哋嘅，即係佢話覺得呢一年賺咗，可以……因為佢多咗時間陪伯伯，佢最開心嘅就係，佢可以每日放工都嚟到，唔使好似醫院咁限時限刻，咁其實我諗呢個對屋企人……即係佢可以放下啲悲傷，其實都係一個好好嘅過渡期。”* (Frontline staff)

(c) On the organisational level, interviewed staff observed certain changes in the atmosphere or culture of the RCHE that they were working in. For instance, staff’s awareness on resident’s autonomy was raised after joining the HKAG programme. Moreover, they observed that staff had become more proactive in engaging frail residents and family members in discussing AD and their wishes. Some suggested that RCHE staff-family communication had been strengthened while others observed enhanced teamwork after the introduction of the programme.

*“即係其實係呢個計劃係好嘅，同埋因為增加咗院友嘅自主性呀，以前可能真係佢覺得都係喺度等呀，或者各樣嘢啦。但一啲清醒嘅院友呢，即係佢可以好自主咁樣去決定自己即係將來嗰個照顧啦，或者有啲咩心願我要達成啦其實係可以做到呢一樣嘢囉。”* (Professional staff)

*“同埋定期嘅個案回顧啦，咁亦都可以加深咗同屋企人嗰個聯繫啦，同埋定期 check 返即係院友嗰個情況呢，其實亦都可以即係令到個個 party 嘅部門…對返呢一個長者會留意多咗嘅，同埋都認識深咗囉。”* (Professional staff)

> *"但係而家 so far 我哋做咗咁多個，其實大家都覺得係舒服嘅，即係對個長者係舒服嘅，咁我覺得大家都……同埋好合作㗎其實大家都，即係當有 case 嘅時候，譬如有啲 case 走啦，佢哋都會走入嚟，譬如 say byebye 呀咁囉，所以我覺得其實都好。"*(Frontline staff)

> *"而家呢我哋直情喺，即係老人家喺係仲係 sound mind 啦，佢係可以決定嘅時候呢，我哋盡快同佢做 AD 呀。"*(Professional staff)

(d) Regarding the collaboration with HKAG team, interviewed RCHE staff generally perceived strong support from the HKAG EOL team regarding nursing care and communication with family members of residents. This kind of support was usually described by the interviewed staff as "extra help".

> *"佢哋(安寧頌團隊)同院舍溝通上，同家屬方面都有幫助。因為好多時佢哋打電話同家屬傾，佢哋會同家屬傾，佢都會幫到我哋D嘢。"* (Frontline staff)

> *"上次有個經驗話我知…計劃個姑娘，真係好犀利，經驗都好豐富，無論係計時間計得好好，或者護理方面都做得好好。所以我地配合起上黎都比較輕鬆"* (Frontline staff)

## Perceived challenges in the implementation of EoLC in RCHEs

Notwithstanding the benefits the programme brought, interviewed staff perceived various challenges for them to implement EoLC in RCHEs. Below are two core challenges that they mentioned.

(a) Interviewed staff, particularly frontline and professional staff, expressed needs for more practical skills training and personal coaching in order to foster their confidence in providing direct care to EoL residents in the nursing home setting.

> *"譬如你話…譬如我哋負責嘅姑娘佢嚟到，佢講就會即係 practical 過我去聽書，聽嗰啲知識囉"* (Frontline staff)

> *"實用嘅。但技巧可能比較欠乏，所以要講多少少啦。可以喺呢方面再加強啲囉，即係你話個人培訓嗰度。係啦，呢方面要提供多啲 support"* (Frontline staff)

(b) Staff from different ranks had different views on the handling of critical situations. While there was no mention on the role of each party in decision making when handling critical situation, for instance whether to send residents to hospital or not, frontline staff believed that residents would stay in the RCHEs once they were enrolled to the service, whereas professional staff and managerial staff perceived that making this decision is still a challenge to them, and they need a concrete guideline to follow in handling these critical situations.

> *"不過可能有時候即係要決定呢個院，參加咗安寧在院舍計劃嘅院友，當佢有啲唔舒服嘅時候啦，可能我哋要諗佢係咪真係要去送院呢，我哋會諗多一層囉。即係因為同埋安寧頌嗰啲姑娘都又俾咗…係咪即係需要送院或者入安寧頌房……俾咗啲指引我哋嘅。即係如果有五個 point 佢仲咗三個嘅，咁可能佢就係需要入呢個安寧頌房喇咁樣。即係喺送院同唔送院之間我哋會諗多咗一層嘢囉，係喇。"*(Professional staff)

> *"如果佢 Join 咗安寧頌，已經話會喺院舍度離世，或者等到佢最後一刻先送院，咁反而我哋個要做嘅下一步係清晰咗好多。咁相對地係方便咗我哋嘅護理工作囉"*
> (Frontline staff)

> *"同事都會有啲咁既擔心。變咗係果個過程個困難呢，好 critical 就係，我哋成個團隊啲同事，我覺得要 clinical、或者 professional staff，其實要拉頭纜。佢哋要行前去，好準確 judge 到個老人家啲狀況，去穩定軍心。要帶領啲前線同事點去處理"*
> (Superintendent)

It should be noted that these interviews were conducted between mid-2017 and April 2018 so that it might fall short of presenting the latest scenarios of the programme implementation at the Project end. Indeed, these findings were discussed with HKAG shortly after the completion of interviews. It was noted that HKAG had also been developing new strategies in helping RCHEs with the identified challenges.

### 2.2.6 Key Performance Achievements

**Table 2.15** and **Table 2.16** show the beneficiaries and key performance achievements of HKAG capacity building programme in RCHEs. Overall, the results suggested that the capacity building programme had achieved the targeted performance.

**Table 2.15** Outputs of HKAG capacity building programme in RCHEs

| | Actual output up to Dec 31, 2018 | Achievements |
|---|---|---|
| **Number of participated homes** | 36 | 100% achieved |
| **Number of professional and frontline staff trained** | 2256 | 113.9% achieved |

**Table 2.16** Key performance achievements of HKAG capacity building programme in RCHEs

| | Key Performance Indicators | Performance of HKAG capacity building programme in RCHEs [7] | Achievements[8] |
|---|---|---|---|
| 1 | Health care professional of different levels will have a 10% increase in sense of competence in EoLC | **Changes in EoLC competences between programme start and two years after programme implementation among all RCHE staff (p.34)**<br>• RCHE staff participating in the HKAG programme reported a 12.2% increase in competence two years after enrolled in the programme | 122% achieved |

### 2.2.7 Lessons Learned and Future Plan

The current findings supported the effectiveness of HKAG programme in improving the RCHEs' performance in palliative care, EoLC and postmortem care provision. Moreover, RCHEs staff who had received EoLC training in the HKAG programme reported significantly increased willingness, competence, and resilience to deliver EoLC at nursing home level. These improvements were evident a year after joining the HKAG programme, and were maintained over two years after joining the programme. Evaluation on EoLC knowledge gained also suggested that the training was effective in improving RCHE staff's understanding on EoLC. However, continuous support including boosting sessions or clinical coaching might be needed to maintain the knowledge acquisition among staff. The results from the focus groups and in-depth interviews concurred with the quantitative findings that RCHEs staff perceived benefits brought about by the HKAG programme on various levels – on staff (enhanced knowledge, competences and values in EoLC), on patients and families (increased quality family time and reduced hospitalisation), and on the RCHEs as a whole (integration of EoLC values in elder care, enhanced respect for residents' autonomy, improved communication on elder care and with family members). Overall, they found the programme meaningful but they expressed needs for more clinical coaching and practical skills

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[7] All % changes were calculated by the formula: (new values – old values)/old values.

[8] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

training in order to provide direct care to dying residents and handle crisis more confidently. New measures to reinforce knowledge and skills acquisition are needed.

Informed by the phase I evaluation, the future plan of the HKAG capacity building programme in the next 3 years are summarised below:

- Extending the EoLC service to 12 more RCHEs, altogether 48 RCHEs;
- Establishing a validated quality standard to develop an accreditation tool on quality of EoLC in RCHEs;
- The tailored EoLC training programmes had been effective and gained high regard from RCHE staff. The training programmes will be offered to RCHEs that newly joined the programme; and
- Developing and delivering advanced EoLC training programmes for staff participating in the programme.

# 3. RESIDENTS AND FAMILIES IN RESIDENTIAL CARE HOMES FOR THE ELDERLY

## 3.1 Programme Descriptions

The background of the HKAG EoLC programme in the RCHEs has been introduced in Chapter 2. The HKAG programme is primarily a capacity building programme with an aim to upskill RCHEs staff to provide EoLC. Apart from the two goals mentioned in Chapter 2, the HKAG programme also aims to improve the quality of life and reduce medical service utilisation of frail residents in the RCHEs who are facing the end of life. This chapter reports the evaluation findings on the effectiveness of the HKAG programme in achieving this goal.

In order to reach this goal, the HKAG established a District-based Professional support team (EoL Team) which formed by EoL Team Nurse and Social Worker to support EoLC implementation in RCHEs. The EoL Team provided regular visits to RCHEs, provide coaching to RCHE staff and assisted them to follow a standardized EoLC protocol that was developed by HKAG to guide the EoLC service in RCHE. Concretely, one EoL Team Nurse was designed to serve 4 RCHEs, whereas one EoL Team Social Worker served 12 RCHEs. They provide assessment and counseling to residents and their family members, and enhance community with the medical team, and support front line and professional staff of RCHEs in delivery of palliative and EoL care.

Moreover, a comfortable EoLC Room furnished with home-like environment and necessary medical equipment was prepared in each RCHE. Apart from routine care provided according to protocol, individualized care of residents in final days, supported by EoL nurse, private Geriatricians and private night nurse 24 hours a day was also provided to RCHEs. The EoL Team did not provide service on their own, they collaborated with the RCHE staff, and the CGATs and the parent medical team in hospitals. The project co-operated with the respective regional hospitals and six CGATs of the Hospital Authority in Kowloon East Cluster, Kowloon Central Cluster and Kowloon West Cluster to provide professional medical support to the residents in participating RCHEs.

Apart from EoLC, the HKAG programme also promoted Advance Directives (AD) and Advance Care Planning (ACP) in the RCHEs. They promoted AD to residents with a sound mind, and promoted discussion of ACP to family members of residents with advanced dementia. Starting from the 3rd year of the programme, the EoL service was extended to elderly participants with life limiting conditions who might benefit from early identification and early engagement in ACP. This change was made because it was found that family members usually need much time to reach a consensus on the EoLC choice of residents. These participants were in “engagement stage” but not yet in EoLC services.

By the end of December 2018, the HKAG programme has served 384 residents, including those admitted to EoLC and those in the “engagement stage”. The programme has also benefited more than 2,000 family members. The EoL Team has conducted more than 1,100 visits for ACP, above 5,000 times of visits for symptom management, more than 4,800 sessions of counselling, and more than 2,800 times of psychosocial support to family members.

## 3.2 Evaluation Framework

In order to evaluate the patients and family caregivers’ outcomes and impacts in the HKAG EoLC programme in RCHEs, a quantitative study was used. **Figure 3.1** showed the study design of the evaluation.

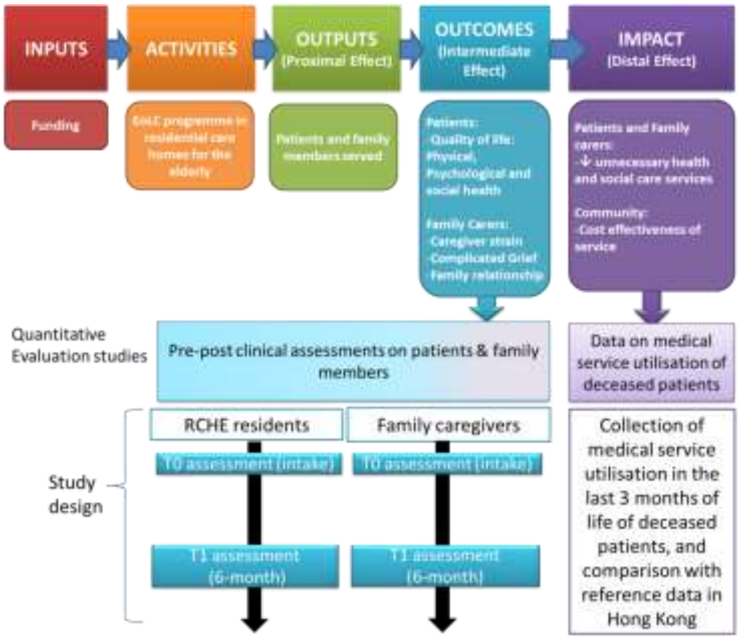

**Figure 3.1** Evaluation framework on RCHE residents and family caregivers enrolled to the HKAG end-of-life care programme in RCHEs

### 3.2.1 Outcomes

Two different packages of clinical assessment tools were designed for residents with dementia and those without dementia respectively. For residents with dementia, Symptom management at the end-of-life in dementia scale (SM-EOLD)[9] was used to measure symptoms, while Bedford Alzheime's Nursing Severity-Subscale (BANS-S)[10] was used to assess residents' severity of dementia. For residents without dementia, symptom severity was measured with Edmonton Symptom Assessment Scale (ESAS)[11] while functional level was assessed with the Barthel Index[12]. For evaluation purpose, the HKU research team collected two time points of data, with the first one being service intake ($T_0$) and the second one after receiving service for 6 months ($T_1$). A 6-month interval was chosen because the functional assessments (i.e. BANS-S and BI) were conducted at a half-year interval, so that data on all assessments would be available only at a half-year interval. It should be noted that physical function is not considered an outcome indicator but a control variable instead. It serves to reflect the impacts of course of disease on the residents across time. The EoLC aims to reduce distressing symptoms but it is unrealistic to expect the interventions will improve physical function among a group of severely dependent older adults who are dying. Regarding family members, the modified Chinese version caregiver strain inventory (C-M-CSI) was adopted. Assessment time points were at service intake ($T_0$) and after 6 months of service ($T_1$). **Table 3.1** showed an overview of the assessment tools.

**Table 3.1** Measurements used in the evaluation of HKAG EoLC in RCHEs

| | Residents with dementia | Residents without dementia |
|---|---|---|
| **Outcome on residents** | **Symptom Management at the End-of-Life in Dementia Scale (SM-EOLD) [0-45]**<br>• Higher scores the better the symptoms are being controlled | **Edmonton Symptom Assessment Scale (ESAS) [0-80]**<br>• Lower scores fewer symptoms |
| **Control variable** | **Bedford Alzheimer's Nursing Severity-Subscale (BANS-S) [7-28]**<br>• Higher scores poorer the function | **Barthel Index (BI) [0-100]**<br>• 0-2 Totally dependent; 21-60 Severely dependent; 61-90 moderately dependent; 91-99 Slightly dependent; 100 Totally independent |
| | **Family caregivers** | |
| **Outcome on caregivers** | **C-M-CSI [0-26]**<br>Higher scores more caregiving stress | |

### 3.2.2 Impacts

In order to evaluate the impacts, the medical service utilisation of deceased residents in HKAG programme in their last 3 months of life was compared to that of deceased end-of-life patients in 2015 in Hong Kong collected from the Hospital Authority. The originality of HA data will be further explained in Chapter 4 (**section 4.2**). Specifically, the number of hospital beddays and A&E admission were compared. It is believed that the programme would reduce hospital admission of EoL residents.

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[9] Volicer, L., Hurley, A. C., & Blasi, Z. V. (2001). Scales for Evaluation of End-of-Life Care in Dementia. Alzheimer Diseases and Associated Disorders, 15 (4), 194-200.

[10] Volicer, L., Hurley, A. C., Lathi, D. C., Kowall, N. W. (1994). Measurement of severity in advanced Alzheimer's disease. Journal of Gerontology, 49, M223-M226.

[11] Bruera, E., Kuehn, N., Miller, M., Selmser, P., & Macmillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. Journal of Palliative Care, 7, 6–9.

[12] Mahoney, F. I., & Barthel, D. (1965). Functional evaluation: the Barthel Index. Maryland State Medical Journal, 14, 56-61.

## 3.3 The Sample

### 3.3.1 Demographics

Between 2016 July and 2018 December, data on 158 cases admitted to the HKAG EoLC programme were submitted to HKU. These participants were enrolled to the EoLC services of the programme (not engagement stage), and were recruited from 33 different RCHEs. The number of participant(s) recruited by each of these RCHEs ranged between 1 to 18. **Table 3.2** summarised the demographics of the participants and their family caregiver.

**Table 3.2**. Demographics of RCHE residents and family caregivers in HKAG EoLC programme

| | **Freq. (%)/Mean (SD)** |
|---|---|
| **Residents (participants)** | 158 |
| **Age** | 90.3 (8.15) |
| **Gender (Male)** | 32 (20.3%) |
| **Religion** | |
| No religion | 74 (46.8%) |
| Christian | 32 (20.3%) |
| Catholics | 16 (10.1%) |
| Daoist | 10 (6.3%) |
| Buddhists | 16 (10.1%) |
| Traditional Chinese folks | 17 (10.8%) |
| **Education** | |
| Illiterate | 69 (43.7%) |
| Have received education | 38 (24.1%) |
| Primary school | 21 (13.3%) |
| Secondary school | 14 (8.9%) |
| Tertiary education or above | 1 (0.6%) |
| **Marital Status (8 missings)** | |
| Widowed | 110 (69.6%) |
| Married | 31 (19.6%) |
| Single | 8 (5.1%) |
| **Financial source (Major) (17 missings)** | |
| Family support | 39 (24.7%) |
| Pension | 3 (1.9%) |
| Savings | 1 (0.6%) |
| Old age allowance | 19 (12%) |
| Disability allowance | 12 (7.6%) |
| CSSA | 67 (42.4%) |
| **Dementia (Yes)** | 131 (82.9%) |
| **Family Caregivers** | 158 |
| **Age (58 missing)** | 57.13 (12) |
| **Gender (Male)** | 16 (23.2%) |
| **Frequency of visiting the resident per week (10 missings)** | 3.14 (2.419) |
| **Relationship with the resident (5 missings)** | |
| Adult child | 111 (70.3%) |

| | |
|---|---|
| Relatives (Mostly niece/nephew/adopted child etc.) | 20 (12.7%) |
| Spouse | 9 (5.7%) |
| Daughter/Son-in-law | 8 (5.1%) |
| Grandchild | 3 (1.9%) |
| Sibling | 1 (0.6%) |
| Friend | 1 (0.6%) |

Overall, the mean age of 158 residents was 90.3 (8.15) years-old, with majority of them being female (79.7%), and over two-thirds are widowed. Regarding major source of finance, over 40% were relying on CSSA, followed by receiving family financial support (24.7%), old age allowance (12%), and disability allowance (7.6%). Not surprisingly, majority (82.9%) of these residents were suffering from dementia.

There are considerable amount of missing data regarding the age of family caregivers. Nonetheless, the relationship of these caregivers with the participant suggested that over 70% were adult child of the elderly participants. It is legitimate to assume that majority of these caregivers are in their middle age. The mean frequency of visit by the caregivers is 3.14 (2.419) times per week. Indeed, among the 148 responses, only 13 (8.8%) replied none regarding their frequency of visit per week, while all other family members visited the participant at least once in a week.

### 3.3.2 Disease groups

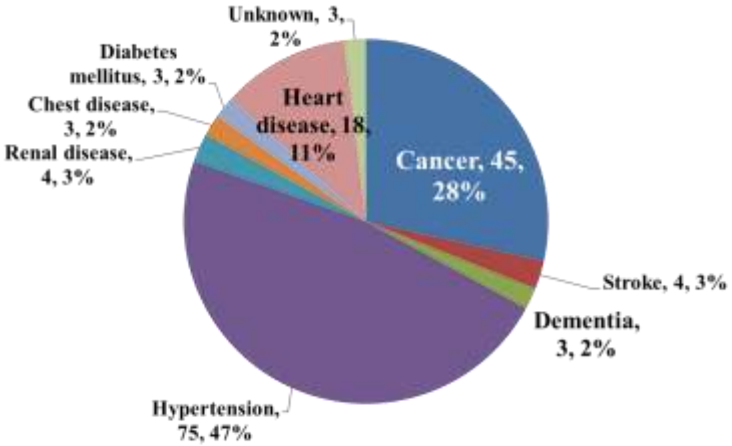

**Figure 3.2**. Major diagnosis (N=158)

Hypertension (N=75, 47%) was the most common major diagnosis received by the residents, followed by cancer (N=45, 28%) and heart diseases (N=18, 11%) (**Figure 3.2**). Majority of the residents were suffering from comorbidities, among them, 130 (82.3%) were diagnosed with 3 diseases, 19 (12%) with 2 diseases, and only 6 (3.8%) reported single major diagnosis. Those who died (N=86) also had hypertension as major diagnosis (47.7%), followed by cancer (33.7%), and heart disease (11.6%). The disease distribution was similar among residents who have already passed away and those who were still alive by December 31, 2018.

### 3.3.3 Service duration

Up to December 31, 2018, 86 residents have passed away, the mean service duration was 4.99 (5.646) months. When all participants are considered, the mean service duration up to December 31, 2018 for all 158 participants was 6.79 (6.350) months[13]. The range of service duration was between 0.07 and 28.33 months.

### 3.3.4 Assessment completion rate

Among participants with dementia (N=131), 60 (45.8%) were able to complete both the intake assessment ($T_0$) the assessment after 6 months ($T_1$). Regarding participants without dementia (N=27), only 13 (48.1%) were able to complete the assessment after 6 months ($T_1$), either fully completed or partially completed.

## 3.4 Key findings

### 3.4.1 Baseline results

In order to understand the conditions of residents by the time of programme admission, the baseline results of all participants were shown in **Table 3.3**. Not surprisingly, the baseline results on BI and BANSS both suggested that the participants were severely dependent**.** Regarding baseline symptom severity, the findings on ESAS and SMEOLD suggested that the admitted residents did face certain degree of distressing symptoms. When it comes to family caregivers, they were found to report relatively low caregiver strain (mean=2.98) when compared to their counterpart in the community (mean=12.28, in section 4.3.5). Although these caregivers had frequent contact with the residents (around 3 days per week), due to the fact that most physical care and IADL support were provided by RCHEs staff, certain items in the C-M-CSI might have become irrelevant to this group of caregivers.

**Table 3.3**. Baseline results of RCHE residents and their family caregivers

| | N | Freq. (%)/Mean (SD) |
|---|---|---|
| BI(0-100) | 26 | 35.77 (29.110) |
| ESAS (0-80) | 25 | 20.88 (14.669) |
| BANSS (7-28) | 131 | 22.13 (2.952) |
| SMEOLD (0-45) | 102 | 40.47 (6.424) |
| Caregiver strain Index (0-26) | 153 | 2.98 (3.716) |

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[13] Service duration for deceased duration was calculated by death date – case start date, whereas the formula for active cases is Dec 31, 2018 – case start date.

### 3.4.2 Changes in residents with dementia

**Figure 3.3** shows the changes in symptoms and physical functions of residents with dementia between service intake and after 6 months of service. Although 60 residents have received two times of assessments, due to missing data, the total number of cases varies across indicators. The findings suggested that residents with dementia experienced a significant improvement in overall symptom score by 8% as measured with SMEOLD ($p<.01$). When individual symptoms were examined, residents showed significant improvements in shortness of breath, depression, and agitation ($p<.05$ to $p<.01$). There were also marginally significant improvements in calmness, anxiety and resistiveness to care. Regarding objective physical function assessed with BANSS, there was no significant change observed. Residents' functional performance remained poor (22.56/28 at 6 months) but almost the same as baseline (22.62).

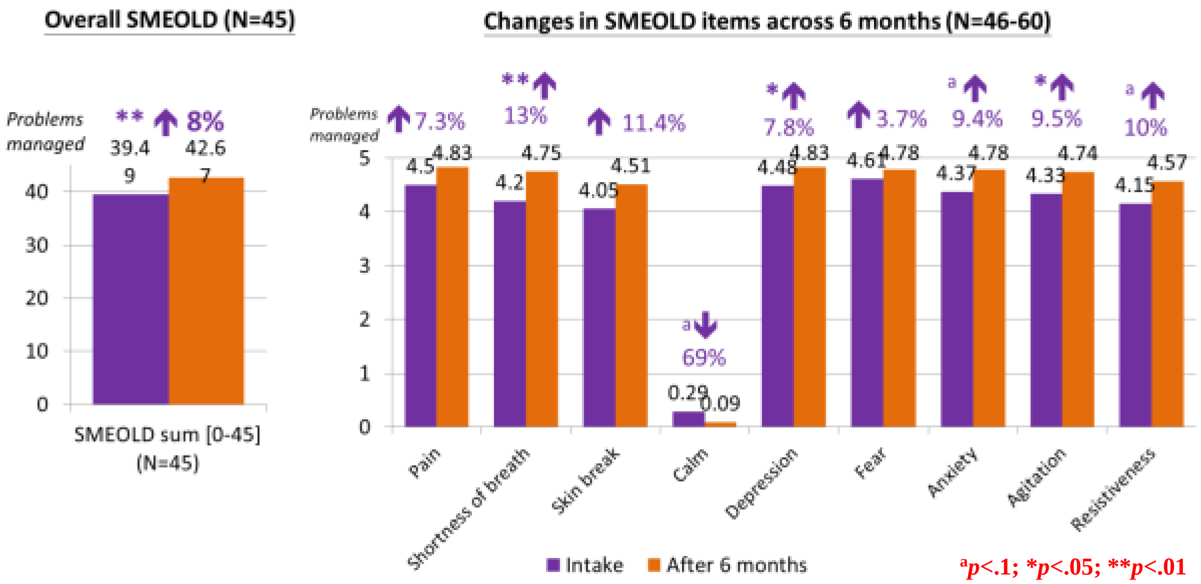

**Figure. 3.3** Changes in outcomes among RCHE residents who were suffering from dementia after 6 months

### 3.4.3 Changes in participants without dementia

**Figure 3.4** shows the changes in symptoms and physical functions of residents without dementia. The findings suggested that, after 6 months in service, residents without dementia reported a significant reduction in overall symptom score by 47% as measured with ESAS (*p*<.05). When individual symptoms were examined, residents showed significant reduction in pain and sadness (*p*<.05). Regarding objective physical function assessed with BI, there was also a significant reduction after 6 months, suggesting residents' physical function deteriorated significantly. These findings suggested that while these residents were approaching death and experiencing significant deterioration in their functional performance, their distressing symptoms, particularly pain and sadness, were successfully controlled under the services of the HKAG programme.

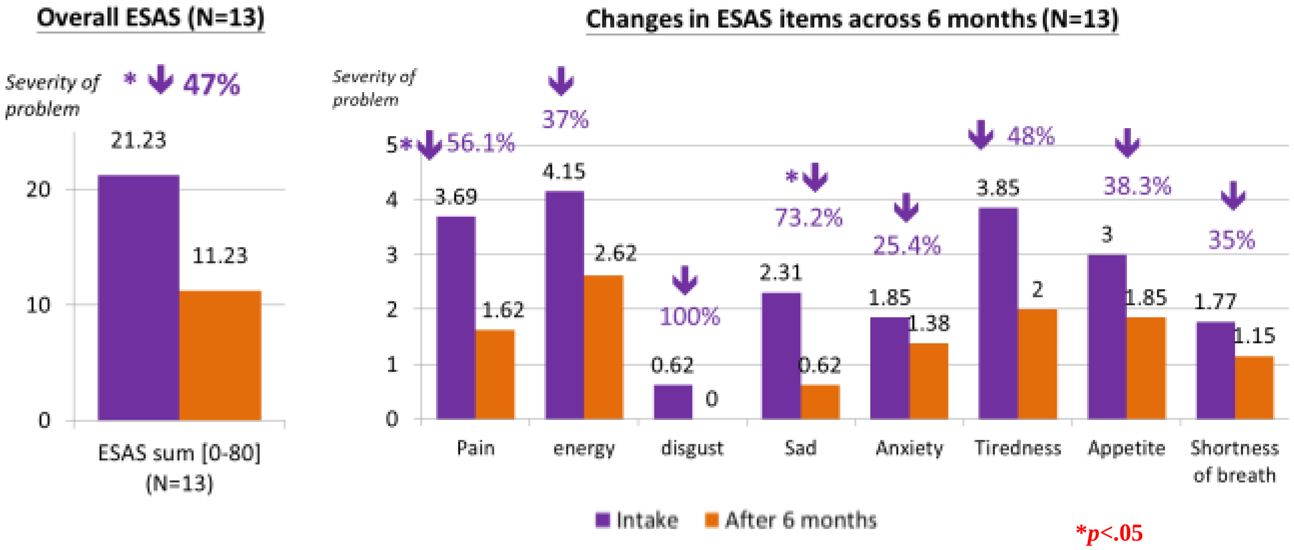

**Figure. 3.4** Changes in outcomes after 6 months among RCHE residents who were not suffering from dementia

### 3.4.4 Changes in family caregivers

For family caregivers, 57 of them completed both intake assessment and $T_1$ assessment upon 6 months in service. Caregivers experience marginally significant reduction in their caregiver strain (*p*=.055) **(Figure 3.5)**. A 14.2% of reduction in caregiver strain was recorded.

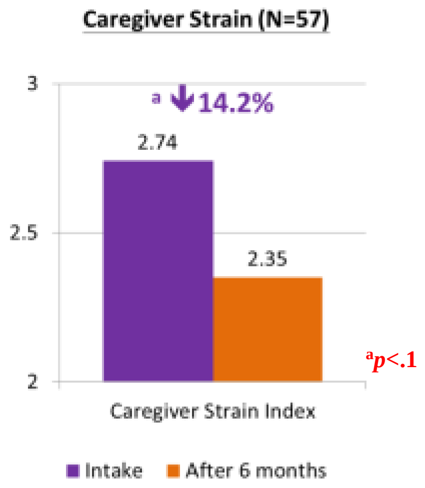

**Figure. 3.5** Changes in caregiver strain after 6 months

### 3.4.5 Impacts

Up to December 31, 2018, 37 deceased residents had retrievable data on medical service utilisation in the last 3 months of life. A comparison of their medical service utilisation with CDM sample suggested that deceased residents in the HKAG programme had 13.25 fewer hospital beddays and 0.33 fewer A&E attendances **(Figure 3.6)**.

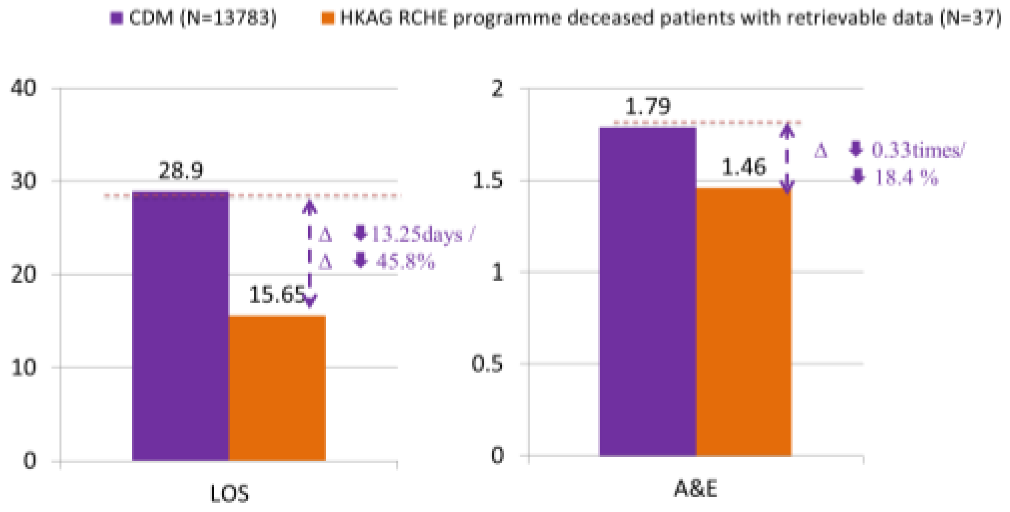

**Figure. 3.6** Comparison on medical service utilisation in the last 3 months of life between deceased residents in HKAG programme and the CDM sample

Further to the findings above, medical cost saved among these 37 deceased patients was estimated with the following equation [14]:

$$\boldsymbol{Medical\ cost\ saved\ by\ 37\ deceased\ patients\ in\ the\ HKAG\ EoLC\ programme\ in\ RCHEs}$$
$$= cost\ saved\ from\ reduced\ LOS\ (acute\ \&\ convalesce)$$
$$+\ cost\ saved\ from\ reduced\ A\&E\ attendance$$
$$= (13.25 \times 4{,}950 + 0.33 \times 1{,}390) \times 37$$
$$= \mathbf{52,696,493}$$

**Table 3.4** further shows the estimated total medical cost saved by the HKAG programme by extrapolating the medical cost saved to all 384 participants served by the programme. The potential medical cost saved if the services were provided to all RCHE residents with EoL issues who may choose to receive EoLC, was also estimated. The estimated medical cost saved by all 384 RCHE residents in the HKAG programme was 25.4 million (HKD 25,361,741). The programme might save HKD 449 million medical cost if made territory-wide.

**Table 3.4** Estimated medical cost saved by the HKAG EoLC programme in RCHEs

| | **(A)** | **(B)** | **(C)** |
|---|---|---|---|
| | **Medical cost saved per participant in the HKAG EoLC programme in RCHEs** | **Projected medical cost saved by the programme**<br>• *Extrapolating the findings from 37 patients to all 384 patients in the programmes* | **Potential medical cost saved if the programme was provided in Hong Kong territory-wide**<br>*Assumptions:*<br>• *46,000 deaths/year in 2016*<br>• *30,000 deaths among older adults caused by cancer or chronic diseases*<br>• *21,000 (70% of above) requires EOL care per WHO* [15]<br>• *17,000 (>80%) choose EOL care per JCECC public survey*<br>• *6,800 (40%) were elderly home EOL patients* |
| **Formula** | 52,696,493/37 | (A)×384 | (A) ×6,800 |
| **Estimated cost saved** | HK$ 66,046 | HK$ 25,361,741<br>25.4 million | HK$ 449,112,800<br>449 million |

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[14] The medical cost saved by the 221 deceased patients was estimated by the differences in LOS, A&E attendance, and ICU beddays between the 221 deceased JCECC service users and the CDM sample multiplied by cost per patient day in acute & convalesce ward, cost per A&E attendance, and cost per patient day in ICU. The costs for acute & convalesce ward and A&E attendance stated in HA Annual Report 2017-2018 were taken as references (http://www.ha.org.hk/ho/corpcomm/AR201718/eBook/en/index.html#p=212), whereas the charge on intensive care unit (ICU) per day for non-eligible person in 2018, which is 24,400, was assumed to be the cost of ICU per patient day (http://www.ha.org.hk/visitor/fees_and_charges.asp?lang=ENG).

[15] World Health Organization (2014). Global atlas of palliative care at the end-of-life. London: Worldwide Palliative Care Alliance.

## 3.5 Key Performance Achievements

As mentioned previously, the HKAG programme has reached 384 residents with EOL issues (**Table 3.5**). The number of elderly beneficiaries did not meet the target because it was found that much time was generally needed by family members to agree on the decision to participate in the EoL service. Often, the chance to receive EoLC service was missed as the condition of the resident further deteriorated. To tackle this challenge, the programme has extended the service to elderly participants with life limiting conditions who might benefited from early identification and communication on ACP. Regarding key performance indicator achievements, the HKAG programme were able to achieve all of the key performance indicators (KPIs) (**Table 3.6**). Indeed, the outcomes greatly exceeded the target set in the key performance indicators, which had been set at a relatively conservative level at the beginning of phase I Project. In phase II Project, the target in KPIs can be adjusted to gauge a meaningful level of achievements.

**Table 3.5** Outputs of HKAG EoLC programme in RCHEs

| | Actual output up to Dec 31, 2018 | Achievements |
|---|---|---|
| **Number of participating elderly** | 384 | 86.5% achieved |

**Table 3.6** Key performance indicator achievements of HKAG EoLC programme in RCHEs

| | Key Performance Indicators | Performance of HKAG EoLC programme in RCHEs[16] | Achievements[17] |
|---|---|---|---|
| 1 | A 5% increase in quality of life of patients | **Changes in symptoms of residents between service intake and 6 months after service**<br>• Residents with dementia showed 8% improvements in symptoms (p.49) while residents without dementia showed 47% improvements in symptoms (p.50). With a consideration that residents with dementia constituted 80% of HKAG programme participants, weighting factors of 0.8 and 0.2 were applied to the changes in residents with dementia and those without respectively. The weighted average obtained is 15.8%. | 316% achieved |
| 2 | A 5% increase in quality of life of family caregivers | **Reduction in family caregiver strain between service intake and 6 months after service**<br>• Family caregivers reported 14.2% of reduction in caregiver strain after 6 months in service (p.51) | 284% achieved |
| 3 | Reduction of 2 days of hospitalisation as well as 5% A&E admission in the last 3 months for patients receiving the services. | **The reduction in hospital service utilisation in the last 3 months of life compared to CDM data**<br>• Deceased residents in the HKAG programme showed a reduction of 13.25 (45.8% reduced) hospital beddays and 18.4% reduction in A&E admission in the last 3 months of life (p.51) | 345% achieved |

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[16] All % changes were calculated by the formula: (new values – old values)/old values.

[17] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

## 3.6 Learnings and Implications

### 3.6.1 Effective in promoting quality of life of RCHE residents facing EoL issues

The findings proved that the HKAG EoLC progamme in RCHEs was effective in improving the quality of life of residents with EoL issues. From the findings on both residents with dementia and those with a sound mind, significant improvements were reported in both physical distresses and certain psychological symptoms such as sadness and anxiety (8% reduction among residents with dementia, and 47% reduction among residents with normal cognitive ability). The sample size of non-demented residents might be too small to allow broad generalization of the findings, however, given that these residents provided direct responses to the assessments, the results generated from them have the advantage of being objective. It did provide strong support to the efficacy of service in relieving both physical and psychological distresses of the residents in face of significant deterioration in physical function. Regarding family caregivers, findings suggested a desirable change in their caregiver strain as measured by the Chinese modified caregiver strain index (C-M-CSI). The change was marginally significant. The irrelevant items in C-M-CSI in the caregiving context for family caregivers in RCHEs might have limited the sensitivity of the measurement.

### 3.6.2 Effective in reducing unnecessary medical service utilisation

The HKAG programme was also found to be effective in reducing unnecessary medical service utilisation of residents in their last 3 months of life. A reduction of 13.25 beddays in acute and convalesce wards, and 0.33 times of A&E admission per patient were recorded. When extrapolating this to all 384 residents in the HKAG programme, the programme was estimated to have reduced the use of hospital beds by 5088 days, and A&E by 126.7 times, while the involved medical cost reduced would be 25.4 million. It was estimated that the programme would save HKD 449 million medical cost if made territory-wide. One limitation in using the CDM data to compare with the findings from HKAG programme should be noted. As we were unable to identify RCHE residents from the CDM sample, the CDM data involves both patients residing in the community and those from RCHEs, with a high possibility that the former being more representative. Nonetheless, the finding of reduced hospitalisation echoed with the observations of RCHE staff who were interviewed in our qualitative study (**Chapter 2**).

### 3.6.3 Future plan

Similar to the future plan mentioned in **Section 2.2.7**, the HKAG programme would be extended to 12 more RCHEs, althougther 48 RCHEs in order to benefit more RCHEs and their residents. They will also pilot the implementation of Distict-based EOL care operation model to support EoLC in RCHEs in the same district. Moreover, HKAG will engage Hospital Authority to develop an agreed communication flow and collaboration model with medical teams and CGATs from hospital in order to provide seamless care to residents in end of life.

However, since the HKAG EoLC programme in RCHEs is a complex intervention that involve multiple parties providing different aspects of support during the service period (e.g. HKAG team, RCHEs staff, and CGATs), a mixed-method research was suggested in order to investigate the outcomes, process, and impacts of the programme more thoughtfully. In phase II project, the following advancements in evaluation framework on HKAG programme were recommended to improve the rigor of the evaluation:

1. Aligning core outcome measures and time frame on collecting medical service utilisation data between the community-based EoLC programmes and the HKAG programme to allow meaningful comparison;
2. Collecting service records to understand service delivery process, allow exploration of effective service components, and estimate the professional input per case;
3. Conducting satisfaction survey with residents and family caregivers;
4. Conducting in-depth interviews with residents and family caregivers to solicit in-depth information on service experiences.

# 4. PATIENTS & FAMILIES IN THE COMMUNITY

## 4.1 Programme Descriptions

Four NGO partners in the JCECC project, including St James' Settlement (SJS), Haven of Hope Christian Service (HOH), Hong Kong Society for Rehabilitation (HKSR), and S.K.H. Holy Carpenter Church District Elderly Community Centre (HCCDECC), developed four discrete innovative community-based end-of-life care (EoLC) models. These models of care serve patients aged at least 60 years of age, who have been diagnosed with an incurable disease, and who have a prognosis of six months or less. The common features of all service models are the strong medical social collaboration where each NGO collaborates with one or more public hospital(s) in serving the patients and their family members, and an emphasis on psycho-social care, family care, and respect for choice and autonomy. The common care components and service components specific to each service model were summarized in **Table 4.1.** In short, there are six common foci for all four models: (1) Practical support, (2) symptom management, (3) psychosocial-spiritual care, (4) Family communication, (5) end-of-life decision making, and (6) bereavement care. Further details on the service components in each service model will be elaborated in the by programme section **(section 4.6).**

**Table 4.1** NGO Innovative community EoLC service models

| | SJS | HOH | HKSR | HCCDECC |
|---|---|---|---|---|
| Programme | Cheering@Home End-of-Life Care Services | Hospice at Home | "Life Rainbow" End-of-Life Care Services | "Hospice in Family" Home Care Support Services |
| Service Model | Family capacity building model | Enhanced community-based health care model | Non-cancer patient capacity building mode | Community capacity building model |
| Common care components | Practical support, symptom management, psycho-social spiritual care, communication, end-of-life decision making, bereavement care | | | |
| Special interventions | • Family approach<br>• Cheering activities with an objective to bring happiness, bliss and joy to patients and caregivers at home | • strong nursing support and personal care in home environment<br>• strong focus on advance care planning | • EoLC for non-cancer patients at home<br>• Empowering patients and family in symptom self-management skills | • Volunteer as life companion closely supported by case manager<br>• Regular case conference with palliative care team |

## 4.2 Evaluation Framework

There are three overarching objectives of this evaluation:

1) To evaluate the effectiveness of the four service models as a whole, in terms of outcomes and longer-term impacts;
2) To identify effective intervention components by evaluating individual model;
3) To consolidate a unified community EoLC model based on the evidence generated from the evaluation.

To achieve these objectives, a common evaluation framework has been developed and applied across the four models (**Figure 4.1**). Two levels of evaluation were carried out: outcome assessment and impact assessment. Outcomes are immediate effects of the service models on patients and family caregivers. On the other hand, impacts are the distal effects of the services. It is expected that the service models will help reduce unnecessary medical service utilisation of patients and thus affect the cost in medical care in the long run. To capture outcomes which may otherwise be missed in a purely quantitative approach, mixed-methods study design was adopted in this evaluation. Patients and caregivers were selected with systematic sampling method for in-depth interview.

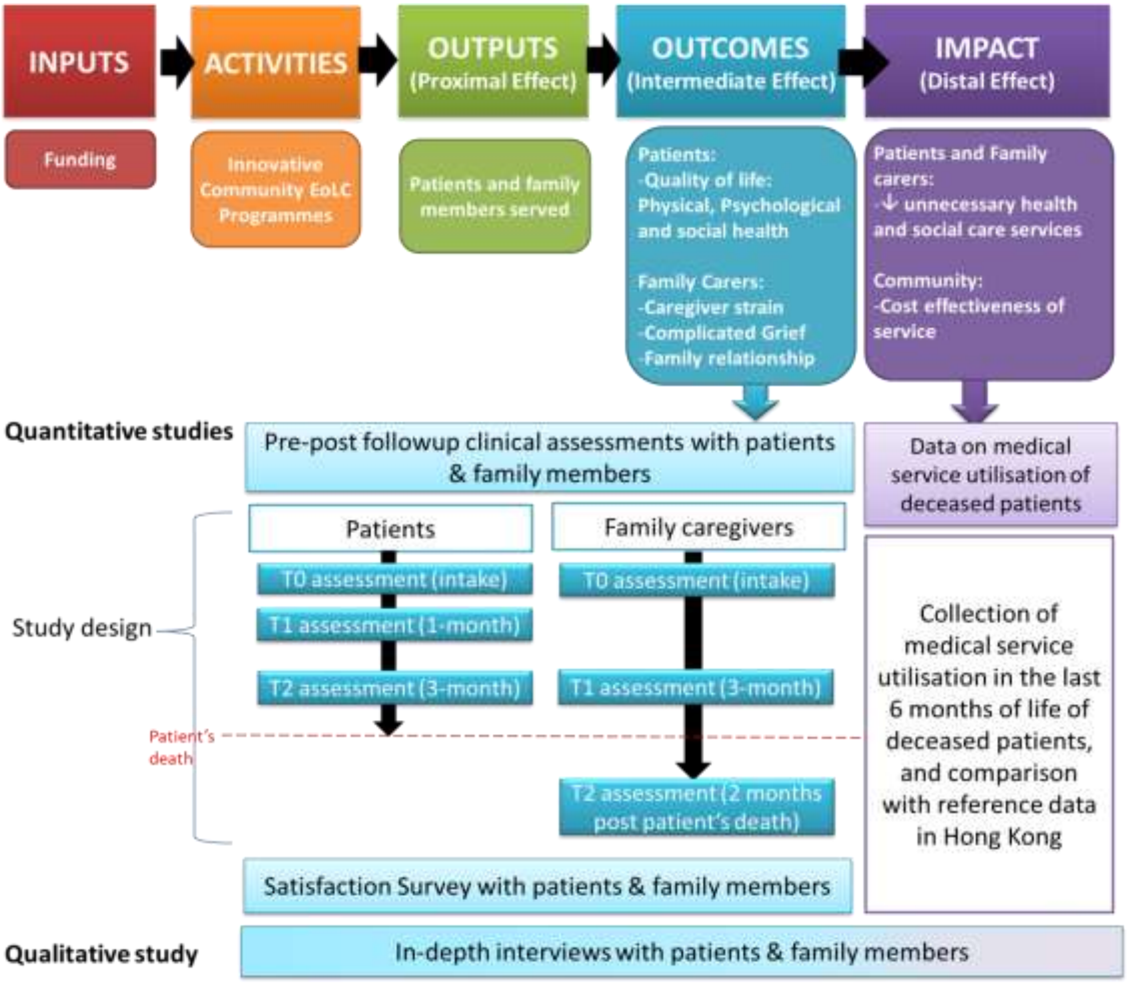

**Figure 4.1** Evaluation framework on the NGO community EoLC models

### 4.2.1 Outcomes

There are two levels of outcomes: objective outcomes and subjective outcomes.

*Objective outcomes* were assessed with a pre-post-followup clinical assessment conducted on patients and caregivers using standardised measurements. Quality of life of patients, and caregiver strains, family relationship, and grief of family caregivers were assessed. The Integrated Palliative Care Outcomes Scale (IPOS) was used to measure the physical symptoms, emotion, practical concerns, perceived family anxiety, barriers in sharing feelings with family members, and information needs of patients. Regarding family members, the Chinese modified Caregiver strain Index (C-M-CSI)[18], a single item on perceived intimacy with patient, and the Chinese Inventory of Complicated Grief (ICG)[19] were used to measure the expected direct outcomes on caregivers. Moreover, as a generic outcome on caregivers, the holistic well-being of caregiver was assessed using the 4-item integrated-body-mind-spirit scale. This scale measures caregivers' self-perceived physical health, emotional health, life satisfaction, and spiritual health. Apart from these outcomes, demographic information of patients and family caregivers were collected at baseline. In addition, caregiving conditions including the number of hours per week that caregivers provided care to patients, caregiver's satisfaction towards support from other family members on caregiving, and caregiver's perceived financial strain were collected as control variables. Both patients and family members were assessed at three time points. For patients, at service intake ($T_0$), 1 month after service ($T_1$), and 3 months after service ($T_2$). For family members, at service intake ($T_0$), 3 months after service ($T_1$), and 2 months after patient's death ($T_2$). **Table 4.2** maps the service foci with the respective objective outcome assessments. It should be noted that only five foci could be mapped with the items in the objective outcome assessment, while end-of-life decision making was assessed with an item in subjective assessment.

**Table 4.2**. Service foci and corresponding objective outcome assessments

| Service foci | Objective Outcome Assessments | |
|---|---|---|
| | Patients | Family caregivers |
| **Practical support** | Practical concerns (IPOS)<br>Information needs (IPOS) | Caregiver Strain Index (C-M-CSI) |
| **Symptom management** | Physical symptoms (IPOS) | -- |
| **Psycho-social spiritual care** | Depression (IPOS)<br>Anxiety (IPOS)<br>Not at peace (IPOS) | Family anxiety (IPOS)<br>Integrated body-mind-spiritual wellbeing (IBMS) |
| **Family communication** | Sharing of feelings (IPOS) | Intimacy with patient |
| **End-of-life decision making** | *Single-item on satisfaction with discussion on care plan in the subjective outcome* | |
| **Bereavement care** | -- | Inventory of Complicated Grief (ICG) |

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[18] Chan, 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

[19] 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.

*Subjective outcomes* refer to satisfaction of patients and family members towards services and their experiences with the services. Satisfaction surveys and in-depth interviews with patients and family members were conducted independently by the HKU research team through phone and face-to-face interviews respectively. All patients and family members were invited to participate to satisfaction survey with the help of NGO partners. Patient survey was conducted 3 months after service, while family members were interviewed 2 months after patient's death. In each of the three years, two patients and two bereaved family members were recruited from each NGO partner by systematic random sampling for in-depth interviews. The interview periods for patients and family members were the same as for satisfaction surveys (i.e. 3 months after service for patients, and 2 months after patient's death for family members).

### 4.2.1 Impacts

In order to evaluate the impacts, the medical service utilisation of deceased patients in the JCECC Community EoLC services was compared to that of deceased end-of-life patients in 2015 in Hong Kong who had a principal diagnosis of cancer, COPD, congestive heart failure, end-stage renal diseases, motor neuron disease, and Parkinson's disease, recorded in the 24 months prior to death. These data were retrieved from the Central Panel on Administrative Assessment of External Data (CPAA) of Hospital Authority in a clinical data mining (CDM)[20]. **Figure 4.2** plots the mean LOS, A&E admission, and ICU beddays by month in the last year of life of these patients. It shows that medical service utilisation in the last year of life gradually increase in the first 6 months, then substantial rise starts since the last 6 months in terms of hospital length of stay and A&E admission, with the most prominent rise in length of stay in the last two months of life. With the introduction of NGO community EoLC services, it is expected that there would be an impact on the medical service utilisation of patients in their last 6 months of life.

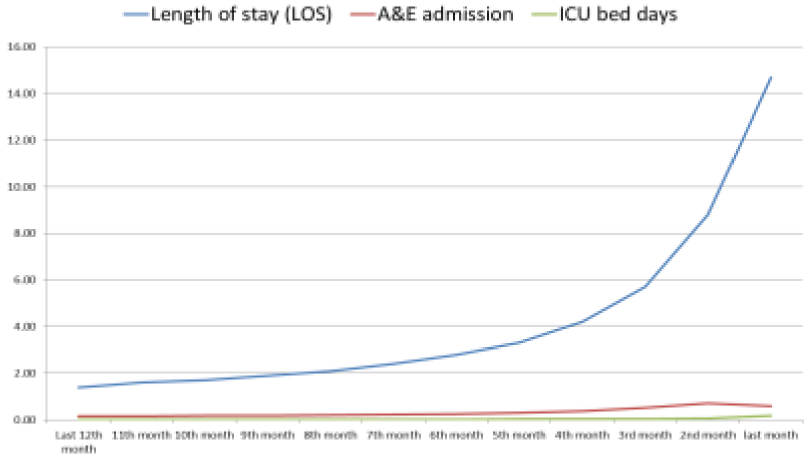

**Figure 4.2** Medical services utilisation in the last year of life of elderly EoL patients (aged 60 or above) who passed away in 2015 (N=13,783)

Retrospective report on deceased patients' medical service utilisation in the last 6 months of life provided by bereaved caregivers were used to compare to the findings derived from the

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[20] The use of Hospital Authority administrative data on deceased patients for the purpose in this Project has been approved by Hospital Authority.

CDM on data from HA. Different from other NGO partners, the HCCDECC retrieved these data from their hospital partner directly. These medical service utilisation data include length of stay, number of A&E admission, and number of ICU bed days in the last 6 months of life.

## 4.3 Service Users

### 4.3.1 Response rates and attrition

Data collection period ended on December 31, 2018. The four NGOs have admitted 777 patients up to Dec 31, 2018 (**Figure 4.3**). Among these patients, 614 (79%) have participated in the intake assessment, 409 (52.6%) and 285 (36.7%) respectively have completed $T_1$ and $T_2$ assessments. Overall, 268 (34.5%) patients have completed all assessments. For the remaining 509 patients who had only partial assessments, the core reasons for attrition were patient's death before assessment (N=198, 38.9%), patient's condition was unsuitable for assessment (N=99, 19.4%), patient's refusal (N=61, 12%), and failure to arrange assessment on time (N=50, 9.8%). In addition, 15 patients were assessed only at $T_0$ and $T_2$, and were included in the final analysis as well. This constituted a final sample of 283 patients for evaluation of outcomes on patients. One hundred and twenty (15.4%) patients also participated in the satisfaction survey. High attrition rates have been consistently reported in EoLC studies with a follow-up element. The response rates and reasons of attrition in the current study were comparable to other EoLC studies conducted around the world [21,22].

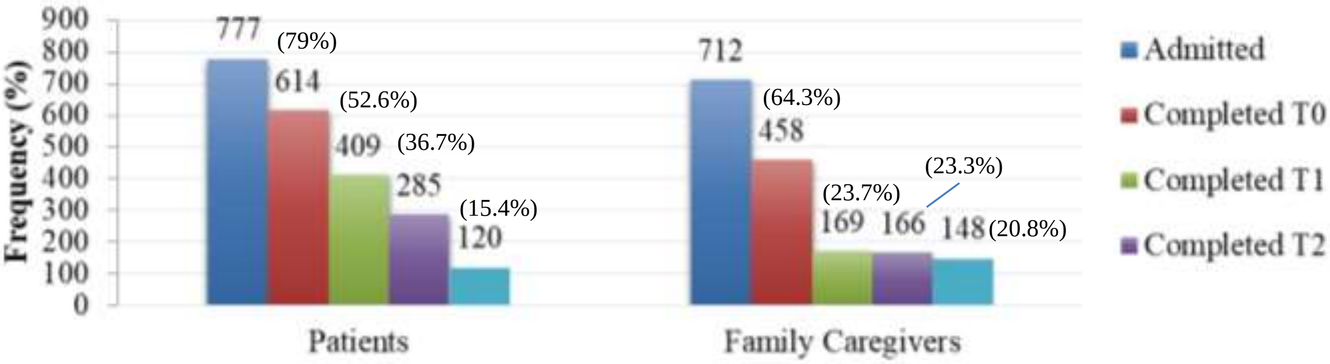

**Figure 4.3** Assessment conducted up to December 31, 2018

The primary family caregivers of the patients were invited to participate in the assessment. A family caregiver was identified from 712 cases. Among these 712 family caregivers, 458 (N=64.3%) participated in the intake assessment, and 169 (23.7%) completed $T_1$ assessment. However, only 164 (23%) completed both $T_0$ and $T_1$. The response rate at $T_1$ showed further improvement as compared to the 21.9% in June 2018. Caregivers failed to complete $T_0$ and/or $T_1$ assessment (N=547) mainly because patient passed away before $T_1$ assessment (N=186, 34%), followed by caregiver's refusal (N=106, 19.4%) and failure to arrange assessment

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[21] Hui, D., Glitza, I., Chisholm, G., Yennu, S., & Bruera, E. (2013). Attrition rates, reasons, and predictive factors in supportive care and palliative oncology clinical trials. *Cancer, 119*(5), 1098-1105. DOI: 10.1002/cncr.27854

[22] Bouça-Machado, R., Rosário, M., Alarcão, J., Correia-Guedes, L., Abreu, D., & Ferreira, J. J. (2017). Clinical trials in palliative care: a systematic review of their methodological characteristics and of the quality of their reporting. *BMC Palliative Care, 16*(10). Doi: 10.1186/s12904-016-0181-9

(N=105, 19.2%). Among all 482 bereaved caregivers[23], 166 (34.2%) and 148 (30.7%) caregivers participated in the $T_2$ assessment and satisfaction survey respectively. This set of data was used to evaluate the outcome of the family caregiver as well as outcome of patients if the latter did not have the mental capacity to respond to the assessment.

### 4.3.2 Basic information on all admitted patients

Up to December, 2018, 520 (70%) patients passed away and only 11 (1.4%)[24] patients dropped out. The remaining 246 cases (31.7%) were alive by the time of Project end. The deceased patients received a mean of 4.87 (5.381) (Mean [SD]) months of service before death, but the duration is longer for the deceased patients who have completed full assessments (N=138), which is 9.62 (5.689) (Mean [SD]) months. On the other hand, the active patients up to December 31, 2018 have stayed in the service for 14.69 (9.502) (Mean [SD]) months on average. Information on patients' gender and diagnosis were collected from all 777 admitted patients. Male outnumbered female in the patient sample (53.3% vs. 46.7%), and this proportion was compatible to the percentage of male (around 53%) among the deaths in the age group of 65 or above in both 2015 and 2016 [25] [26]. Cancer patients constituted the biggest group (50.7%), followed by renal disease (18.5%) and chronic obstructive pulmonary disease (COPD) (13%) **(Figure 4.4)**. Patients were predominantly referred by HA Hospitals (78.8%) followed by social service units (14.5%) and self-approach (6.7%) (**Figure 4.5**). The mean interval between referral and service admission was 4.56 (10.654) (Mean [SD]) days.

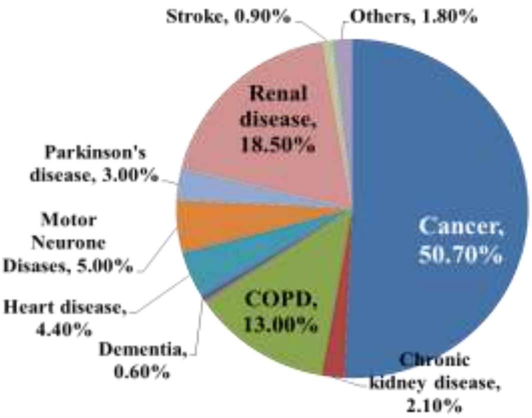

**Figure 4.4** Diagnosis of all admitted patients (N=777)

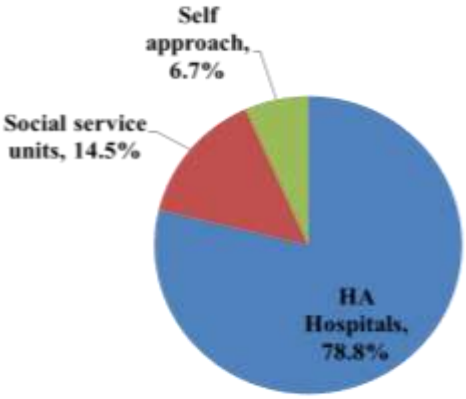

**Figure 4.5** Sources of referral of all admitted patients (N=777)

### 4.3.3 Demographics of patients who participated in the evaluation

As mentioned, 614 of 777 patients participated in at least one assessment. These patients had a mean age of 75.43 (12.38) (Mean [SD]) years old, 53.3% diagnosed with cancer, 16.1% with

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[23] Includes only cases that the patient passed away by Dec 31, 2018 and there is an identified family caregiver

[24] Four cases with incomplete data were mistaken as dropout cases in the previous interim report in July

[25] Department of Health. (2016). *Tables on Health Status and Health Services 2015*. Retrieved from https://www.chp.gov.hk/en/statistics/data/10/27/340.html#top

[26] Department of Health. (2017). *Number of deaths by leading causes of death by sex by age in 2016*. Retrieved from https://www.chp.gov.hk/en/statistics/data/10/27/340.html#top

renal disease, and 11.7% with COPD. This sub-group shared a similar disease group distribution to the whole sample. Slightly less than one-tenth (9.1%) reported no family caregiver, while others were cared by adult children (41.3%), spouse (35.9%), and other relatives (10.8%). Other basic demographics of patients are shown in **Table 4.3.**

**Table 4.3** Basic demographics of patients in all NGO models (with intake assessment)

| | **Freq. (%)** |
|---|---|
| N | 614 |
| **Education** | |
| No schooling/kindergarten | 139 (22.6%) |
| Primary school | 208 (33.9%) |
| Secondary school | 175 (28.5%) |
| Tertiary education | 69 (11.2%) |
| Others | 8 (1.3%) |
| **Marital status** | |
| Married/cohabitating | 356 (58%) |
| Widowed | 165 (26.9%) |
| Single | 43 (7%) |
| Separated/divorced | 41 (6.7%) |
| Others | 3 (0.5%) |
| **Religion** | |
| No religion | 246 (40.1%) |
| Chinese Traditional belief | 156 (25.4%) |
| Christian | 106 (17.3%) |
| Buddhist | 43 (7%) |
| Catholic | 35 (5.7%) |
| Others | 24 (3.9%) |
| **Relationship with primary caregiver** [a] | |
| Spouse | 231 (37.6%) |
| Adult child | 214 (34.9%) |
| Relatives (e.g. siblings, daught/son-in-law) | 59 (9.6%) |
| Domestic helper | 41 (6.7%) |
| No caregivers | 28 (4.6%) |
| Staff of residential care home | 14 (2.3%) |
| Parents | 5 (0.8%) |
| Friends | 5 (0.8%) |

*Notes.* [a] *Paid caregivers were not invited to assessment.*

The socio-economic statuses of patients were compared to the elderly population in Hong Kong **(Table 4.4)**. Our sample shared similar living arrangement, average domestic household size, and types of housing with the elderly population in general. However, comparatively, our patients reported a significantly lower household income. The differences were significant even the median monthly household income were adjusted for family size. Moreover, there were higher proportions of CSSA and disability allowance recipients among the patients in the JCECC services when compared to the elderly population in general in Hong Kong.

**Table 4.4** Comparison of socio-economic statuses of JCECC patients with elderly population in Hong Kong

| | **JCECC Participants** | **2016 Thematic report on older adults [27]** |
|---|---|---|
| **Living Arrangement** | **Freq. (%)** | **Freq. (%)** |
| N | 614 | 1,163,153 |
| Living Alone | 14% | 13.1% |
| Other living arrangements in the community | 80.5% | 78.7% |
| Living in non-domestic household | 4.4% | 8.1% |
| Average domestic household size (N=569) | 2.9 | 2.7 |
| **Housing of those living in domestic households** | **Freq. (%)** | **Freq. (%)** |
| N | 603 | 1,068,758 |
| Public housing | 39.6% | 36.7% |
| Non-public housing | 58.6% | 63.3% |
| **Median monthly domestic household income (HKD)** | **median** | **median** |
| All households (N=282) [a] [b]*** | 9,000 | 15,500 [c] |
| 1-person household (N=34) [b]* | 3,500 | 5,650 |
| 2-person household (N=81) [b]** | 6,000 | 9,780 |
| 3-person household[a] (N=73) *** | 10,000 | 23,000 |
| **Financial Assistance (N=483)** | **Freq. (%)** | **Freq. (%)** |
| CSSA Scheme (Yes)*** | 17.2% | 8.1% [d] |
| Disability Allowance (Yes) *** | 18.4% | 3.4% [e] |

*Note.* ** *p*<.01; *** *p*<.001; represents significant difference between the sample and the reference data from the general public in Hong Kong by binominal test; a Only included patients who provided both information on family income and household size, including patients who resided in RCHEs. [b] Figures were calculated after removal of "zero income" responses. It was speculated that household income was misinterpreted as "personal income" or the respondents had no idea in those cases. [c] This is the median monthly domestic household income of all households with older adult(s) in Hong Kong in 2016. [d] This figure was estimated by dividing the number of old age cases in CSSA in January 2018[28] by the total number of population age 60 or above in end-2017. [e] This figure was estimated by dividing the number of recipients aged 70 or above receiving normal or higher disability allowance in 2016-17[29] by the total number of population aged 70 or above in end-2017[30]

### 4.3.4 Demographics of family caregivers who participated in the evaluation

Among 458 family caregivers who completed intake assessment, 106 (23.2%) were male. They were either patient's spouse or adult child (43.4% and 42.6%). The mean age of these caregivers was 56.88 (18.18) (Mean [SD]) years old. **Table 4.5** shows other basic information of family caregivers. Notably, these caregivers have been providing 57 hours of care per week on average, with caregivers who had a full-time job provided on average 33.82 hours of care per week (around 5 hours per day), while non-working caregivers provided 74.27 hours of care per week (10.6 hours per day). Although they were providing long hours of care to patients, over 70% reported good support from other family members in caregiving to patient. Regarding their own health conditions, half of these caregivers reported diagnosis of chronic illnesses.

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[27] Census and Statistics Department (2018a). 2016 Thematic Report: older persons. Government of Hong Kong special Administrative Region.

[28] Social Welfare Department. (2018). *Statistics and figures on social security.* Retrieved from https://www.swd.gov.hk/en/index/site_pubsvc/page_socsecu/sub_statistics/

[29] HKSAR Government. (2018). *Number of recipients aged 70 or above under the normal disability allowance and higher disability allowance from the 2012-13 to 2016-17 financial years.* Retrieved from http://gia.info.gov.hk/general/201801/10/P2018011000454_275784_1_1515561543445.pdf

[30] Census and Statistics Department. (2018*). Population Estimates*. Retrieved from http://www.censtatd.gov.hk/hkstat/sub/sp150.jsp?ID=0&productType=8&tableID=002

**Table 4.5** Basic demographics of family caregivers in all NGO models (with intake assessment)

| | **Freq. (%)** |
|---|---|
| N | 458 |
| **Relationship with patient** | |
| Spouse | 199 (43.4%) |
| Adult child | 195 (42.6%) |
| Relatives (e.g. grandchild, child-in-law, siblings) | 61 (13.4%) |
| Parent | 5 (1.1%) |
| Others | 1 (0.2%) |
| **Education** | |
| No schooling/kindergarten | 26 (5.7%) |
| Primary school | 82 (17.9%) |
| Secondary school | 146 (31.9%) |
| Tertiary education | 139 (30.3%) |
| Others | 2 (0.4%) |
| **Marital status** | |
| Married/cohabitating | 339 (74%) |
| Single | 97 (21.2%) |
| Separated/divorced | 13 (2.8%) |
| Widowed | 7 (1.5%) |
| Others | 1 (0.2%) |
| **Religion** | |
| No religion | 172 (37.6%) |
| Chinese Traditional belief | 96 (21%) |
| Christian | 83 (18.1%) |
| Buddhist | 44 (9.6%) |
| Catholic | 39 (8.5%) |
| Others (e.g. Daoism, Muslim) | 7 (1.4%) |
| **Employment Status** | |
| Retired/Not working/Home maker | 245 (53.5%) |
| Full-time employed | 143 (31.2%) |
| Part-time employed | 46 (10%) |
| On leave/unemployed | 17 (3.7%) |
| **Whether the caregiver was diagnosed with any chronic illness(es) (Y)** | 237 (51.7%) |
| **Co-residing with patient (N)** | 131 (28.6%) |
| **For caregivers who are not residing with patient, number of days visiting patient per week (N=127)** | 4.44 (2.28) |
| **Time needed to take care of patient per week (hours) [baseline]** | 57 (55.55) |
| **How satisfied you are with the support you receive from your family members in your role as a caregiver? [baseline]** | |
| Dissatisfied – very dissatisfied | 26 (5.7%) |
| Average | 88 (19.2%) |
| Satisfied – very satisfied | 330 (72.1%) |
| **Whether the caregiver has received any financial allowance? (N=355)(Y)** [a] | 235 (66.2%) |
| CSSA | 27 (7.6%) |
| Disability allowance | 21 (5.9%) |
| Old age living allowance | 24 (6.8%) |
| Old age allowance | 50 (14.1%) |
| **Perceived financial strain (N=349)** [a] | |
| Slightly difficult - No difficulties | 267 (76.5%) |
| Moderately difficult | 49 (14%) |
| Very difficult - Extremely difficult | 33 (9.5%) |

*Note.* [a] *Not all family caregivers answered the questions relating to finance.*

### 4.3.5 Baseline assessment

In order to understand the baseline conditions of patients and their family caregivers, the results from baseline assessment are presented in this section. Since there are no official cut-offs in most outcome indicators, review on research studies which employed these measurements with descriptive findings presented in the journal articles were conducted. Five studies from UK [31,32], Germany[33], and Italy [34] involving the use of IPOS/POS on end-of-life patients in hospital or community settings were identified. Means of individual IPOS item were calculated based on the pooled means from these seven articles. Regarding C-M-CSI, the mean published in the scale author's study was used as reference. These aggregated means are presented in **Table 4.6** as references.

**Table 4.6** Baseline assessment results of patients and family caregivers and reference on mean scores derived from literature

| | **JCECC service users baseline results** | | **Reference derived from literature** | |
|---|---|---|---|---|
| | N | Mean (SD) | Number of sample involved | Mean |
| **Patient Outcomes** | | | | |
| IPOS- physical symptoms [0-40] | 579 | 10.52 (5.960) | -- | -- |
| IPOS- pain [0-4] | 602 | 1.2 (1.126) | 450 | 1.54 |
| IPOS- anxiety [0-4] | 576 | 1.2 (1.137) | 349 | 1.55 |
| IPOS- depression [0-4] | 576 | .92 (.972) | 202 | 1.48 |
| IPOS- not at peace [0-4] | 589 | 1.24 (1.041) | 120 | 1.10 |
| IPOS- barriers in sharing feelings with friends/family [0-4] | 570 | 1.91 (1.179) | 349 | 0.80 |
| IPOS- practical concerns [0-4] | 605 | 1.15 (1.157) | 450 | 0.69 |
| IPOS- information needs [0-4] | 277 | 1.91 (1.239) | 450 | 0.45 |
| **Family caregiver Outcomes** | | | | |
| IPOS- family anxiety [0-4] | 594 | 1.85 (1.107) | 349 | 2.23 |
| C-M-CSI [0-26] | 443 | 12.28 (6.367) | 223 | 13.1 |
| IBMS [4-40] | 447 | 25.4 (6.854) | -- | -- |
| Intimacy with patient [0-4] | 458 | 3.23 (.746) | -- | -- |

A comparison between the baseline results and the reference suggested that patients in the JCECC community EoLC services reported less pain, and emotional distress (depression and anxiety) when compared to their overseas counterparts. On the contrary, they reported substantially higher level of barriers in sharing feelings, practical concerns and information needs than their oversea counterparts. Note-worthily, barriers in sharing feelings and

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[31] Saleem, T. Z., Higginson, I. J., Chaudhuri, K. R., Martin, A., Burman, R., & Leigh, P. N. (2012). Symptom prevalence, severity and palliative care needs assessment using the palliative outcome scale: A cross-sectional study of patients with Parkinson's disease and related neurological conditions. Palliative Medicine, 27(8), 722-731.

[32] Malik, F. A., Gysels, M., Higginson, I. J. (2013). Living with breathelessness: A survey of caregivers of breathless patients with lung cancer or heart failure. Palliative Medicine, 27(7), 647-656.

[33] Hermann, K., Engeser, P., Szecsenyi, J., & Miksch, A. (2012). Palliative patients cared for at home by PAMINO-trained and other GPs - health-related quality of life as measured by QLQ-C15-PAL and POS. BMC palliative care, 11, 13. doi:10.1186/1472-684X-11-13

[34] Costantini, M., Rabitti, E., Beccaro, M., Fusco, F., Peruselli, C., La Ciura, P., … Higginson, I. J. (2016). Validity, reliability and responsiveness to change of the Italian palliative care outcome scale: a multicenter study of advanced cancer patients. BMC palliative care, 15, 23. doi:10.1186/s12904-016-0095-6

information needs are both related to communication. These might reflect the suppressed needs under the Chinese virtue of sharing only good news but not suffer.

An assessment tool is helpful to clinical practice when it offers clinically meaningful results. Indeed, literature has suggested that Chinese patients tended to report less emotional symptoms than their counterparts in foreign countries [35], and some scholars have attributed these discrepancies to the challenges faced by Chinese patients in articulating their emotion with words, or propensity to somatise psychological symptoms [36]. In view of these cultural differences, clinically meaningful cut-off scores for these indicators might have to be derived from empirical data collected in the local context.

It was noticed that the item on information needs (IPOS) had exceptionally high number of missing. NGO partners suggested that some patients indicated no needs for information, but there was no answer option for such response. Due to the large number of missing values, this item was discarded in the subsequent analysis to avoid biases.

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[35] Sham, M. M. K., Chan, K. S., Tse, D. M. W., & Lo, R. S. K. (2006). Impact of palliative care on the quality of life of the dying. In Death, Dying and Bereavement: A Hong Kong Chinese Experience, in Chan C. L. W. & Chow A. Y. M . (Eds.) (pp. 139-150). Hong Kong: Hong Kong University Press.

[36] Zhou, X., Dere, J., Zhu, X., Yao, S., Chentsova-Dutton, Y. E., & Ryder, A. G. (2011). Anxiety symptom presentations in Han Chinese and Euro-Canadian outpatients: is distress always somatized in China? Journal of Affective Disorders, 135 (1-3), 111-114.

## 4.4 Findings on All Models

### 4.4.1 Quantitative studies

#### 4.4.1.1 Objective Outcomes

**Figure 4.6** summarises the 3-month changes in the quality of life of 283 patients in terms of physical symptoms, psychosocial-spiritual distress, as well as practical concerns. Due to missing data, the total number of patients varies for each indicator. Results showed that patients experienced significantly reduced problems in all these realms (*p*<.05 to *p*<.001). For physical symptoms, the overall severity level reduced by 18% (*p*<.001). When individual symptoms were examined, seven of the ten assessed symptoms showed significant improvements, including pain, shortness of breath, weakness/fatigue, poor appetite, nausea, vomiting, and poor mobility. While constipation, sore or dry mouth, and drowsiness remained stable. Patients reported significant reduction in depression and anxiety (*p*<.001), spiritual distress (not at peace) (*p*<.001), and barriers in sharing feelings with family or friends (*p*<.01). Moreover, practical problems reduced by half after 3 months in service (*p*<.001).

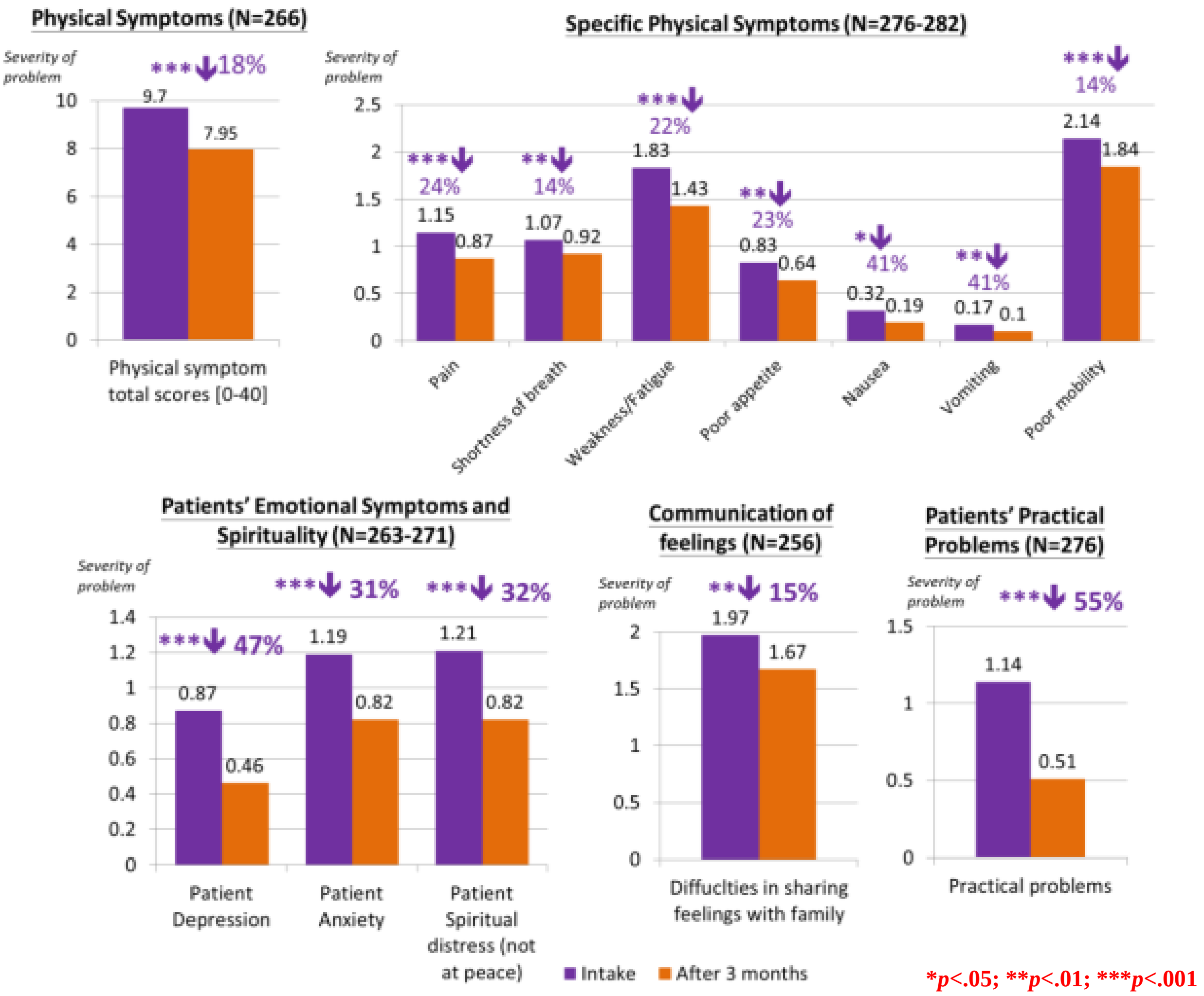

**Figure 4.6** Changes in patients after 3 months

In **Figure 4.7**, 265 patients reported the anxiety level of their family members at both baseline and 3rd month in service, whereas 164 caregivers have completed both baseline and 3rd month assessments. Findings showed significantly reduced family anxiety and caregiver's self-reported caregiver strain at the third month. There were marginally significant improvements in the body-mind-spiritual wellbeing of caregivers, and intimacy with patient ($p<0.1$). Regarding other control variables, no changes in the caregiving hours and satisfaction with support from other family members on caregiving were reported at the third month. After patient's death, 89.8% of the 166 assessed bereaved family members had low risk of complicated grief, which represented a reduction of high risk population by 26.6% when compared to the reference (13.9%) reported among a Chinese population[37].

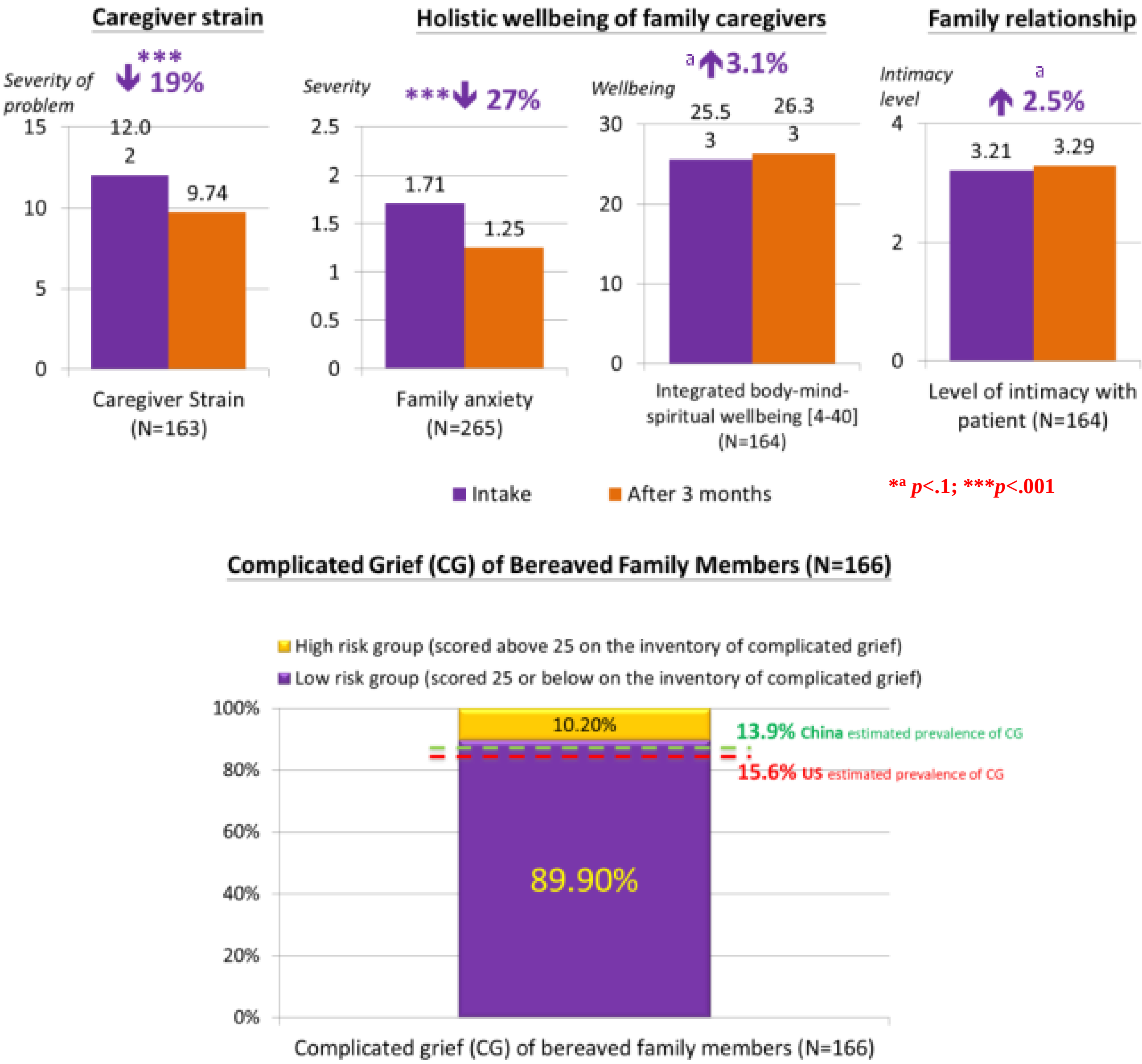

**Figure 4.7** Changes in family caregivers after 3 months and complicated grief in bereaved family members

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[37] Li, Jie & Prigerson, Holly. (2016). Assessment and associated features of prolonged grief disorder among Chinese bereaved individuals. *Comprehensive Psychiatry, 66*, 9-16. 10.1016/j.comppsych.2015.12.001.

### 4.4.1.2 Subjective Outcomes

Patients (N=120) were asked to rate their levels of satisfaction on a 1-10 Likert scale (**Figure 4.8**). Adopting the cut-off score of 6/7 as an indication of high satisfaction as shown in the hospital authority patient satisfaction survey, patients were generally highly satisfied with the services they received. All of the items asked had more than 85 % of score higher than 6. The three items which obtained the highest mean rating were: volunteer service provided, service team respected the patient's needs and social work services met patient's needs. Greater rooms for improvement were observed in symptom management.

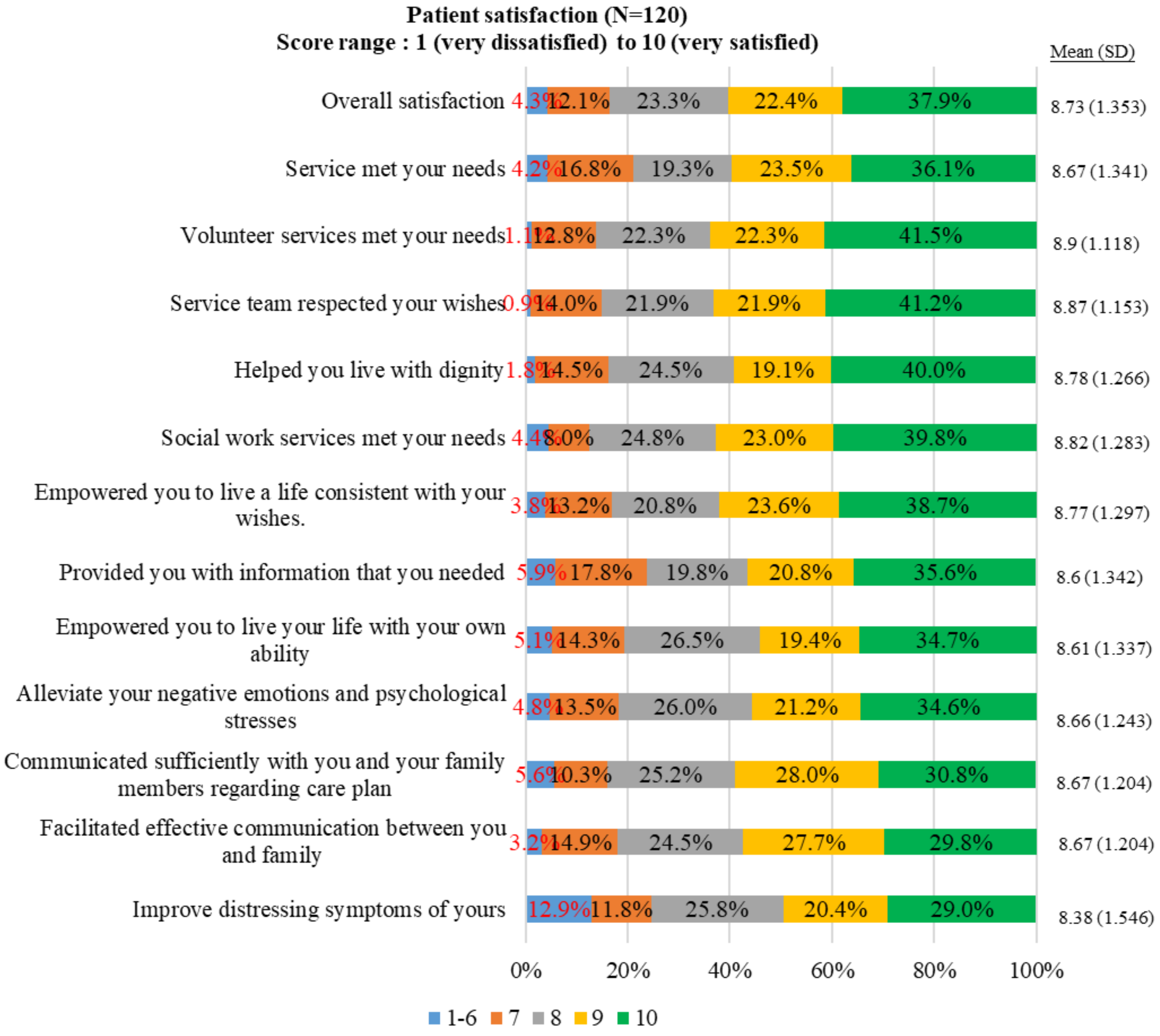

**Figure 4.8** Patient satisfaction survey of all NGOs

For caregivers (N=148), adopting the cut-off score of 6/7 as an indication of high satisfaction as shown in the hospital authority patient satisfaction survey, similar result was obtained in the overall satisfaction rate among caregivers when compared to one done on patients. Moreover, satisfied responses contributed to 85% of the response for all indicators (**Figure 4.9**). Similar to patients, caregivers were particularly contented with the service team in respecting their wishes, as well as volunteer and social workers' support (three items with highest mean scores). Just like patients, caregivers also expressed relatively lower satisfaction on physical symptom management.

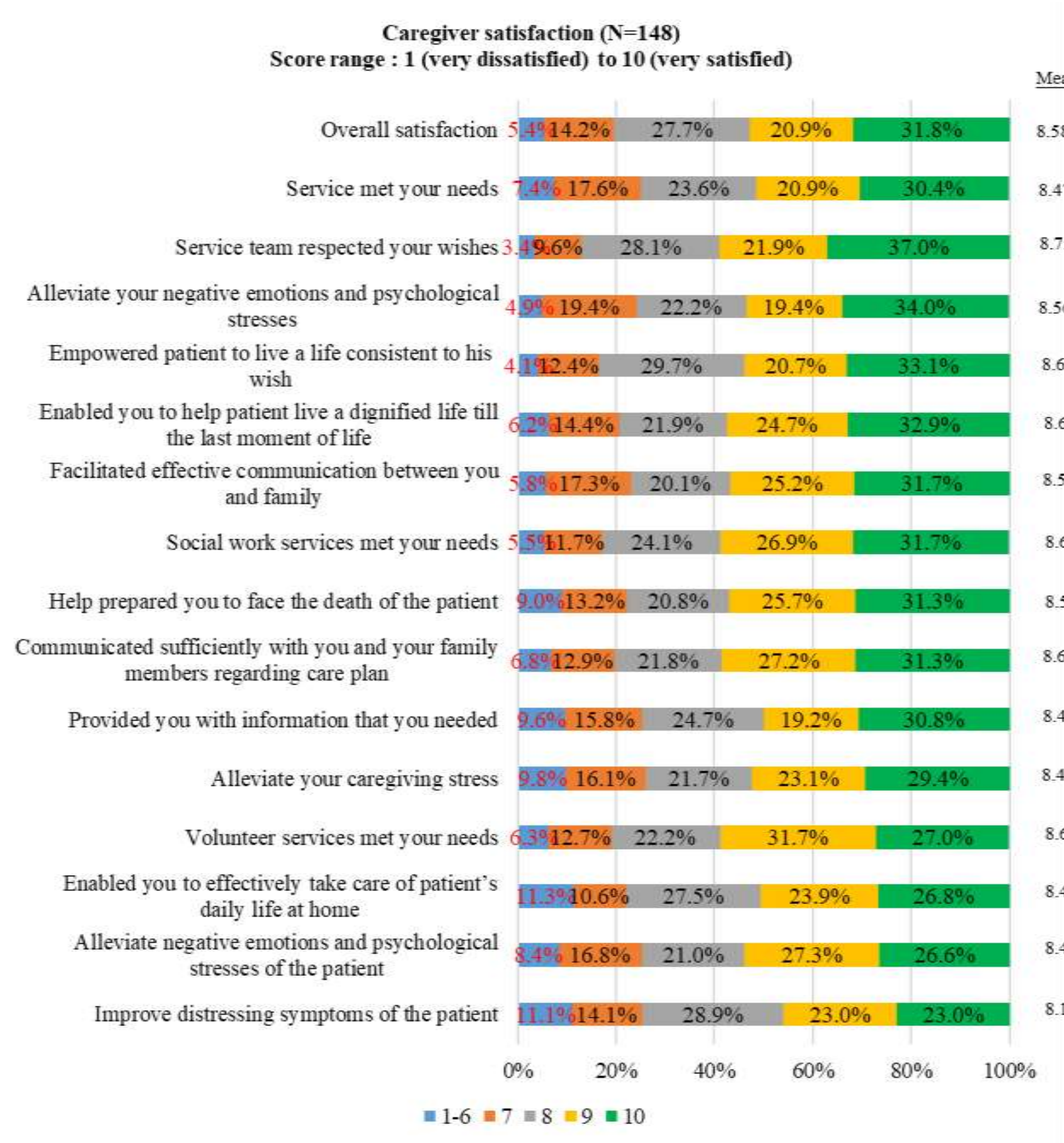

**Figure 4.9** Caregiver satisfaction survey of all NGOs

### 4.4.1.3 Impacts

Medical service utilisation data was retrievable from a total of 227 deceased patients from all service models (43.7% of all deceased patients in four models). Six cases were found to have stayed in hospital for 150 or more days (i.e. 5 months) in the last 6 months of life. Since these patients were exposed to limited community support services provided by the NGO partners, they were excluded from the final analysis. Subsequently, 221 cases were included in the analysis, and the mean length of stay in hospital (i.e. hospital beddays), A&E attendance, and ICU beddays were calculated. **Figure 4.10** presents the comparison between the data of JCECC patients and the CDM. The finding suggested that deceased patients in the JCECC community EoLC services reported 4.87 hospital beddays, 0.32 times of A&E attendance, and 0.08 ICU beddays fewer than EoL patients in general.

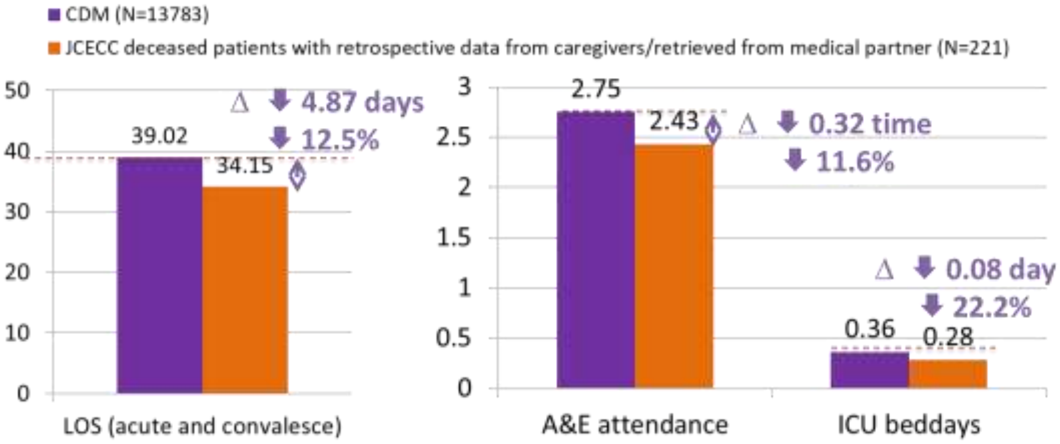

**Figure 4.10** Comparison between deceased patients in the JCECC community EoLC services and CDM sample on medical service utilisation in the last 6 months of life

Further to the findings above, medical cost saved among these 221 deceased patients in the JCECC service was estimated with the following equation [38]:

$$
\begin{aligned}
&\boldsymbol{Medical\ cost\ saved\ by\ 221\ deceased\ patients\ in\ the\ JCECC\ Community\ EoLC\ service}\\
&= cost\ saved\ from\ reduced\ LOS\ (acute\ \&\ convalesce)\\
&+ cost\ saved\ from\ reduced\ A\&E\ attendance\\
&+ cost\ saved\ from\ reduced\ ICU\ beddays\\
&= (4.87 \times 4{,}950 + 0.32 \times 1{,}390 + 0.08 \times 24{,}400) \times 221\\
&= \mathbf{5,857,163}
\end{aligned}
$$

**Table 4.7** further shows the estimated total medical cost saved by the four service models by extrapolating the medical cost saved to all 777 participants. Besides, the potential medical cost saved if the services were made territory-wide was estimated. The estimated medical cost saved

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[38] The medical cost saved by the 221 deceased patients was estimated by the differences in LOS, A&E attendance, and ICU beddays between the 221 deceased JCECC service users and the CDM sample multiplied by cost per patient day in acute & convalesce ward, cost per A&E attendance, and cost per patient day in ICU. The costs for acute & convalesce ward and A&E attendance stated in HA Annual Report 2017-2018 were taken as references (http://www.ha.org.hk/ho/corpcomm/AR201718/eBook/en/index.html#p=212), whereas the charge on intensive care unit (ICU) per day for non-eligible person in 2018, which is 24,400, was assumed to be the cost of ICU per patient day (http://www.ha.org.hk/visitor/fees_and_charges.asp?lang=ENG).

by 777 patients in the JCECC community EoLC services was 20.6 million (HKD 20,592,831). It was estimated that the services would save HKD 270 million medical cost if made territory-wide.

**Table 4.7** Estimated medical cost saved by the JCECC community EoLC services

| | **(A)** | **(B)** | **(C)** |
|---|---|---|---|
| | **Estimated medical cost saved per patient in the JCECC community EoLC services** | **Projected medical cost saved by the JCECC community EoLC models**<br>• *Extrapolating the findings from 221 patients to all 777 patients in the services* | **Potential medical cost saved if the EoLC services were implemented in Hong Kong territory-wide**<br>*Assumptions:*<br>• *46,000 deaths/year in 2016*<br>• *30,000 deaths among older adults caused by cancer or chronic diseases*<br>• *21,000 (70% of above) requires EOL care per WHO* [39]<br>• *17,000 (>80%) choose EOL care per JCECC public survey*<br>• *10,200 (60%) were non-elderly home EOL patients* |
| **Formula** | 587,163/221 | (A)×777 | (A) ×10,200 |
| **Estimated cost saved** | HK$ 26,503 | HK$ 20,592,831<br>20.6 million | HK$ 270,330,600<br>270 million |

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[39] World Health Organization (2014). Global atlas of palliative care at the end-of-life. London: Worldwide Palliative Care Alliance.

### 4.4.1.4 Exploration of influential factors on the changes in outcomes

Extra analyses were conducted to explore if any of the personal characteristics of the patients and caregivers would affect the effectiveness of the service. **Table 4.8** showed the findings with patients. Results suggested that the effectiveness of the services did not affect by the background of patients, including their age, gender, disease, education, living conditions, and relationship with caregivers.

**Table 4.8.** Factors related to the changes in outcomes of patients (N=258)

| | **IPOS** | **Physical symptoms** | **Anxiety** | **Depression** | **Peace** | **Sharing of feelings** | **Patient's practical problems** | **Perceived family anxiety** |
|---|---|---|---|---|---|---|---|---|
| Intercept | 1.223 | -.264 | .728 | .429 | .416 | .131 | .189 | -.371 |
| [Disease=cancer] | .342 | .025 | -.030 | -.043 | .258 | .040 | -.231 | -.126 |
| [Disease =COPD] | -.351 | -.104 | -.216 | -.211 | -.286 | -.227 | -.267 | -.367 |
| [Disease=renal disease] | -.676 | .320 | -.117 | .162 | .024 | .268 | -.330 | .015 |
| [Disease =others] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Marital = others] | -.012 | -.330 | -.373 | -.372 | -.044 | .066 | -.050 | -.110 |
| [Marital = married/partnered] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [CG Relationship=parents] | | 1.070 | .922 | -.815 | -.050 | .023 | -.604 | **1.725*** |
| [CG Relationship=spouse] | -.333 | -.026 | .064 | -.119 | .007 | .150 | **.497*** | .236 |
| [CG Relationship=children] | -1.048 | -.077 | .276 | .008 | -.022 | .226 | -.005 | .265 |
| [CG Relationship=other family member] | -.618 | -.059 | .057 | .060 | -.235 | -.065 | .511 | .196 |
| [CG Relationship=others] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Religious=No] | .195 | .240 | -.083 | .118 | .028 | .079 | .025 | -.028 |
| [Religious=Yes] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Living condition=alone] | -.645 | .097 | .182 | -.095 | .172 | .033 | .284 | .053 |
| [Living condition=with others] | -.741 | -.165 | -.299 | -.262 | .089 | -.333 | .105 | -.182 |
| [Living condition=in group] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Education=none] | -.181 | .255 | -.443 | .201 | .176 | -.162 | .031 | -.292 |
| [Education=primary school] | .502 | .312 | -.354 | .179 | .006 | -.233 | .299 | -.180 |
| [Education=middle school] | .654 | .375 | -.421 | .159 | -.114 | -.076 | .097 | -.181 |
| [Education=university/college and above] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Gender=male] | .126 | -.196 | -.258 | -.033 | -.027 | .266 | -.128 | -.194 |
| [Gender=female] | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| Age | -.006 | .003 | .001 | -.002 | -.008 | -.001 | -.005 | .010 |

Note: all the changes were estimated by standardised residuals for each measure. a. This parameter is set to zero because it is redundant. * $p < .05$

Regarding caregivers, the findings showed that the service could reduce caregiver strain and reduce caregivers' grief severity following bereavement, regardless of their gender, employment, marital states, education level, and the disease of the patients whom they provide care **(Table 4.9)**. However, the service was more beneficial for younger caregivers. Moreover, the bereavement care of the service models was found to be less effective for caregivers who were parents of the patients.

**Table 4.9.** Factors related to the changes in outcomes of caregivers

| | **Completers for $T_0$ & $T_1$, N = 154** | | | **Completers for $T_0$ & $T_2$, N = 133** |
|---|---|---|---|---|
| | **Caregiver strain** | **Holistic wellbeing (IBMS)** | **Intimacy with patients** | **Complicated grief** |
| Intercept | .419 | 0.221 | -0.649 | 14.334 |
| [Gender=male] | .318 | 0.020 | 0.202 | 0.749 |
| [Gender=female] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Disease=cancer] | -.095 | 0.035 | 0.013 | -5.642 |
| [Disease =COPD] | .047 | 0.202 | 0.361 | -1.542 |
| [Disease=renal disease] | .310 | -0.415 | 0.404 | -6.395 |
| [Disease =others] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Education=none] | -.074 | 0.093 | -0.534 | 1.027 |
| [Education=primary school] | -.096 | 0.088 | -0.148 | -3.895 |
| [Education=middle school] | -.056 | -0.098 | -0.053 | -3.519 |
| [Education=university/college and above] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [fully employed=No] | .352 | 0.069 | 0.319 | 1.580 |
| [fully employed=Yes] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Marital = others] | .118 | -0.219 | -0.094 | 4.764 |
| [Marital = married/partnered] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [CG Relationship=parents] | .502 | 0.020 | 0.019 | **13.437*** |
| [CG Relationship=spouse] | .168 | 0.050 | 0.329 | 7.199 |
| [CG Relationship=children] | -.097 | 0.109 | 0.043 | 5.194 |
| [CG Relationship=other family member] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| [Religious=No] | .123 | -0.165 | -0.132 | 0.651 |
| [Religious=Yes] | $0^a$ | $0^a$ | $0^a$ | $0^a$ |
| Age | **-.019*** | -0.002 | 0.005 | **-0.143*** |

#### 4.4.1.5 Exploration of mechanism of changes

Further cross-lagged analyses were conducted to investigate the mechanism of changes in the service interventions. First, within the patient's system, the relationship among physical symptoms (physical dimension), emotional symptoms (psychological dimension) and perceived barriers in sharing feelings (social dimension) was examined **(Figure 4.11)**. Findings suggested that the presence of more severe physical symptoms led to increase of emotional symptoms and perceived barriers in sharing feelings with family and friends afterwards. This highlighted physical symptom severity as a risk factor for deteriorating emotional wellbeing and sharing of feelings, and pinpointed the importance of symptom management which could promote better psychosocial wellbeing of patients in terms of emotions and willingness to express it.

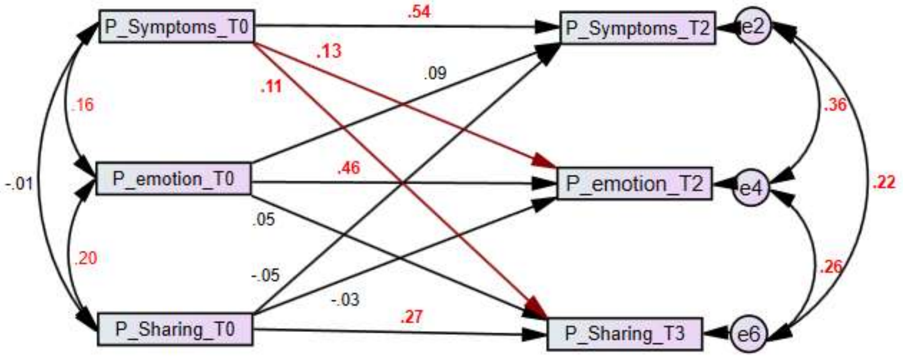

**Figure 4.11.** Cross-lagged analysis for the relationship among physical, emotional symptoms and intention to share with family at baseline and 3-month follow-up

Secondly, within the caregiver's system, it was found that their perceived family support on caregiving affect the changes in their holistic wellbeing (**Figure 4.12**). And their holistic wellbeing was directly and negatively related to the severity of symptoms of complicated grief two months after patient's death. The finding suggested higher level of satisfaction towards family support on caregiving helped reduced the degree of deterioration in holistic wellbeing of caregivers afterwards.

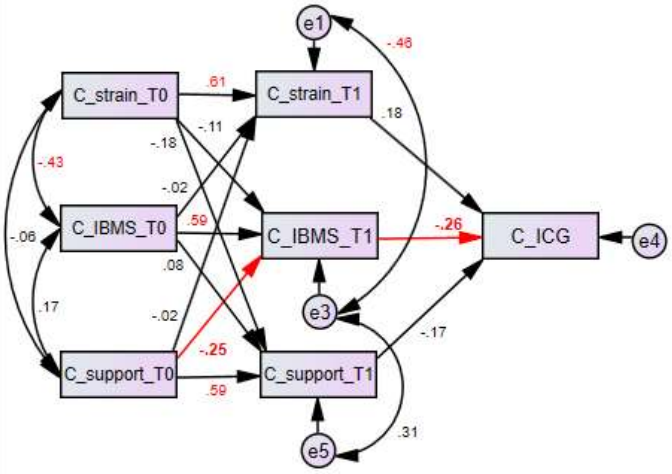

**Figure 4.12.** Cross-lagged analysis for the relationship among physical, emotional symptoms and intention to share with family at baseline and 3-month follow-up

Thirdly, the dyadic influence between patients’ physical and emotional health and family caregivers’ caregiving strain was also explored. Results showed that it was patients’ emotional symptoms rather than physical symptoms that led to increased caregiver strain (**Figure 4.13**). Moreover, when caregivers had poorer holistic wellbeing, it led to an increase in perceived barrier to share feelings by patients **(Figure 4.14)**.

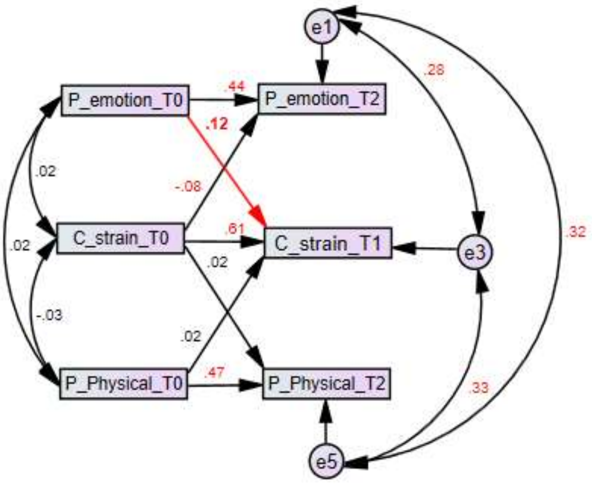

**Figure 4.13** Cross-lagged analysis for the relationship of patients’ physical and emotional symptoms with caregiver strain at baseline and 3-month follow-up

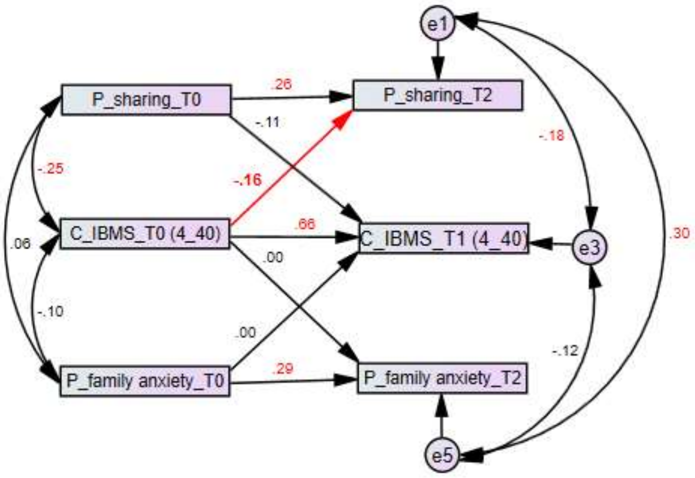

**Figure 4.14.** Cross-lagged analysis for the relationship of caregiver’ holistic-well-being, with patients’ perceived family anxiety, intention to share at baseline and 3-month follow-up

These findings highlighted the importance of relieving physical symptoms as severity of physical distress could lead to deterioration of emotional symptoms and willingness to share it. Moreover, the emotional distress of patients was also a risk factor for increasing the caregiver strain. It also suggested caregivers’ perception on familial support made a difference on their wellbeing. Besides, the analysis revealed that patient’s sharing of feelings was affected by both intrapersonal (physical symptoms) and interpersonal factor (caregiver’s wellbeing). This sheds light on possible strategies to enhance open communication through symptom management as well as preparing the caregivers.

## 4.4.2 Qualitative study

### 4.4.2.1. Participants

A total of 23 in-depth interviews were conducted in this 3-year project. Ten and 13 of patients and caregivers were interviewed respectively to explore their experience and views in receiving the JCECC community EoLC servicse. The profile of patients and caregivers interviewed are summarised below (**Table 4.10** and **Table 4.11**). The recruited patient sample presented a range of diagnosed diseases. Similarly, recruited caregivers shown diversity in their relationship with patient, and the disease types of patients who were being taken care.

**Table 4.10** Profile of patients in in-depth interviews [a]

| | NGO | Gender | Diagnosed disease |
|---|---|---|---|
| **Patient 1** | HCCDECC | Male | Renal Disease |
| **Patient 2** | HCCDECC | Female | Myelofibrosis |
| **Patient 3** | HCCDECC | Female | Multiple system atrophy |
| **Patient 4** | SJS | Female | Cancer |
| **Patient 5** | SJS | Male | Heart Failure |
| **Patient 6** | SJS | Male | Cancer |
| **Patient 7** | HKSR | Female | COPD |
| **Patient 8** | HKSR | Female | COPD |
| **Patient 9** | HKSR | Male | Renal Disease |
| **Patient 10** | HKSR | Male | Parkinson’s disease |

*Note.* [a] All patients drawn from the Heaven of Hope sample by systematic sampling were too frail to join the interviews.

**Table 4.11** Profile of family caregivers in in-depth interviews

| | NGO | Gender | Relationship with patient | Diagnosed disease of patient |
|---|---|---|---|---|
| **Caregiver 1** | HCCDECC | Female | Wife | Renal Disease |
| **Caregiver 2** | HCCDECC | Male | Son | Motor Neuron Disease |
| **Caregiver 3** | HCCDECC | Male | Son | Renal Disease |
| **Caregiver 4** | SJS | Female | Daughter-in-law | Cancer |
| **Caregiver 5** | SJS | Female | Daughter | Cancer |
| **Caregiver 6** | SJS | Female | Wife | Cancer |
| **Caregiver 7** | HOH | Female | Neighbor | Cancer |
| **Caregiver 8** | HOH | Male | Husband | Cancer |
| **Caregiver 9** | HOH | Female | Daughter | Cancer |
| **Caregiver 10** | HKSR | Female | Wife | Parkinson’s disease |
| **Caregiver 11** | HKSR | Female | Sister | Renal Disease |
| **Caregiver 12** | HKSR | Female | Wife | Cancer |
| **Caregiver 13** | HKSR | Female | Daughter | Parkinson’s disease |

### 4.4.2.2. Findings

After analysing the participant's disclosure on receiving the service, three service delivery features which promoted service satisfaction emerged. Moreover, service components which were favored by patients and caregivers and how these services had affected them would be explored after discussing service delivery features.

***Identified helpful service delivery features***

1. Proactive and timely support

One of the most frequently mentioned features was how workers **actively approached patients and caregivers to provide timely service to meet their imminent needs in end of life**. From participants' revelation, they described that the waiting time for the service was short; workers actively paid close attention to their needs in different stages, offered helps proactively in times of crisis, and even think ahead for them which were helpful in preparing them for future. Moreover, it was found that when caregivers expressed that they got timely support from workers at times of crisis, and/or the workers had prepared them for the possible changes along the disease trajectory of patient, they also tended to report lower grief and better adjustment after patients died.

> *好快, 半個鍾頭內, 真係半個鍾頭內嘅 (in receiving the call form case workers after referral) (Caregiver)*

> *係，**照到我……唔係講明燈，佢直情係攞咗盞燈照住我行嘅**，我跟得佢行，佢去邊度我就跟，根本都唔使我出力，我又唔使出口水，又唔使講嘢，我……我就係跟到佢尾，佢叫我跟佢去邊度，就去邊度，因為要我身份證，要簽字呀嘛，所以我必需要跟佢。*(Caregiver)

> *後來，**後來醫院嗰度咩嚟，收尾我就打電話俾 XX 囉同埋 XX(workers' names)，佢兩個好快十零分鐘就趕到，好快，真係好快。我挨住我老公嗰度個身上哭，佢兩個就在後面拍住我。我都唔知佢幾時咁快就到。後來，佢一直幫我哋辦我老公個後事，一直跟到尾…***(Caregiver)

> ***姐係岩岩係最徬徨嘅時候佢就幫手啦。**咁佢亦都解釋得好清楚, 姐係話其實好多人遇到呢 D 危急嘅病嘅時候都要面對好多唔同嘅困難呀……咁我地本來都去左個 D 醫療個 D 鋪頭個到睇下,買一張咁嘅床係點樣。咁但係咁多款又唔知買 D 咩, 咁呀 XX(worker's name)就話我地其實可以借一張比你嘅。 咁我地就覺得好好囉。因為我地都姐係又價值不比啦個 D 床, 咁姐係如果可以借一張咁就可以試下佢係咪幫到佢呀, 或者岩唔岩呀, 又可以快 D 呀, 唔洗我地好急咁樣, 姐係買 D 乜野返黎。*
> (Caregiver)

> *由第一日見 XX (workers’ names)嘅時候佢地都好多跟進呀,* ***咁佢地問嘅問題呀又或者係提點嘅野都好適時囉,*** *姐係話比如話有無諗過家務助理,或者係護士呀,又或者係其實呢 D 癌症病人會經過唔同嘅階段呀,咁佢地又上黎我地屋企又幫手睇下如果遲少少要坐電椅又點樣,如果要推個時要點行入廁所又過唔過到呀,張床姐係入唔入到呀,好仔細囉佢地嘅服務。* ***我地都無諗過嘅野佢地都有幫我地。*** (Caregiver)

> *(社工教我)摸吓哥哥(the patient)呀，同佢按摩呀，傾計呀，掃吓佢個頭，佢會 feel 到，雖然佢答你唔到，佢會 feel 到，咁我一路跟佢做，咁我都做晒，都冇遺憾。因我都冇掂我哥哥咁多年，因為佢有菌嘛，同埋一向佢知我唔掂佢埋面，唔拖佢隻手嘅，但由嗰刹那，我都同佢按摩呀，拖住佢隻手，摸吓佢塊面，見到佢有 D 淚水，可能自己心理上啦，安慰自己啦，好似有 D 淚光咁，可能自己安慰自己，佢(社工)教我，我覺得好開心囉！* (Caregiver – describing the scenario of saying goodbye to the patient)

<u>2. Individualized care which based on needs</u>

The second key feature identified from the interviews was the individualized support which target on patients and caregivers’ needs. It was found that the services received by the interviewed patients and caregivers were not totally the same. In cases which suggested highly satisfying service experience, it was found that workers would explore the wish and unmet needs of patients and caregivers, and offered assistance accordingly instead of providing standardised service. This was reflected by the detailed description and appreciation of interviewed patients and caregivers towards services which they thought really helped them. For instance, when workers found that the patient felt life meaningless, they would find out what the patient enjoyed and arrange those activities in order to help the patient maintain an active life. In another case, the patient wanted to leave a legacy to his family, and workers engaged the patient in making a life review book for the patient’s children. Workers also arranged volunteer support to make outdoor activities possible for families which have been socially isolated due to caregiving, and arranged separated support to caregivers who perceived high caregiving stress. Below are some of the example quotes:

> *講真,* ***我覺得伯伯(Patient)嘅尊嚴真係好好囉*** *，點解咁講因為我哋從來，我又好啦，X 姑娘(worker)嗰邊好啦，* ***都係跟隨住伯伯嘅意願嘅，一路到佢好後期都好啦，佢堅持到最後嗰一刻留係屋企到最後我哋都係夾定嘅*** *……雖然未必真係 keep 到佢最後果點留係屋企走，但係起碼佢真係堅持到最後一刻，我冇拒絕佢，我冇拒絕佢，寧養嗰邊都冇拒絕佢，好啊你要留到聽日嘅話你聽日真係要入院喎，即係姑娘都係咁樣同佢講。就唔會話真係迫佢，唔得啊，你個 case 唔可以再拖啦，佢冇咁樣同佢講，所以我覺得佢已經係好有尊嚴地離開。係啦所以如果你講尊嚴而方面我覺得好好。 (Caregiver)*

> *其實真係將心比己，真係而家個生活好平淡加嗎。**姐係佢(患病家屬)可以做到嘅野已經唔係好多，有一樣野人地黎到呢到同佢，佢仲覺得自己係有能力喎，你話幾勁呀。姐係捉棋贏左係咪好開心呀？**(Caregiver)*

> *…我已經完咗我嘅責任，我已經87啦，你比我食多幾多年啊，我已經完咗我嘅責任，唔使咩架啦，**呢本書就係同我寫我嘅經歷(A life review book developed by patient with the help of workers)，我依家就咁講呢就係咁嘅經歷。我就話個仔一本啦，由佢哋自己去睇下啦，已經完成我責任啦。**(Patient)*

> *去濕地公園。因為早一年呢，16年呀，佢(Patient)個妹妹呢帶左仔女番黎，黎到我地呢度就佢地有去濕地公園，當時我就唔係好想同佢地去，咁就即係驚住照顧唔到，咁後尾X姑娘呢就聽見我咁講，佢就，佢就話咁你係咪想去呀問我先生，**我話我都未去過，我話好呀，如果係呢不如帶埋佢去行下啦。咁X姑娘同埋哥日好似三個義工，四個連埋我地就好似七個人，佢地五個好似，我地兩個，計埋七個，咁樣就好開心真係，我先生嗰日，佢番黎仲成日講住啦**(Caregiver)*

> *唉，我都唔識講呀。姐係咁，最好就去老人院啦，佢又唔肯去咁呀。但係呢呀X姑娘(worker)都同我講，佢話同我搵個義工，幫我有時搞下衛生，減輕我個壓力。 (Caregiver)*

> *自從X姑娘(worker)接左手啦, 佢都幫我d細路哥搵左好既資源去照顧兩個細路哥做作業, 唔洗增加咁大我壓力啦, 分擔我個壓力丫麻. 第二呢, 佢又搵d社工經常上黎探啦, 有時我都可以休息下啦麻, 我都有我既野做下, 其實照顧老人家, 我而家有抑鬱症架, 照顧咁多年, 你話慢性者喎, 十零年照顧落黎, 你話你一個正常人都有病啦, 係咪?(Caregiver)*

In certain interviewed cases, we found that patients and caregivers could not clearly recall the specific services that they had received, or they merely mentioned "workers visited and talked to us". This might imply a failure to identify and deliver services which targeted on specific needs of patients and/or caregivers. All in all, these findings shed light on the vital role of meeting individualised needs of patients in end of life and their family members through need-based care.

### 3. Therapeutic relationship through caring and respectful attitude

Another most frequently mentioned helpful service feature was the caring and respectful attitude of the workers. It can be seen that a trusting relationship was easily built between workers and families with such good attitude. Patients and caregivers interviewed were thankful for the patience of the workers, their listening to their needs, attention paid to what the patients liked or disliked, and being thoughtfulness in follow-up, and some suggested the service and readiness of response often exceeded their expectations. Service would be extended to caregivers who were in needs even after the patients passed away. Some described the care from service team made them experience the warmth in human relationships, hope, and not just being viewed as a patient but a person.

> *其實XX(worker's name)好熱心, XX(worker's name)開始打俾我一路都同我跟進，問我佢個情況，伯伯個情況係點樣，我講咗俾佢聽，佢哋服務都好積極，所以我都覺得XX(Worker's name)嗰邊真係做得唔錯。對於一個癌症嘅病人真係做得唔錯。(Caregiver)*

> *點會有咁好服務提供畀我呢, 好似中咗六合...六合彩呀, 我媽咪(Patient)咁樣講, 因為我地呢平時都係, 即係點講, 我朋友又唔係好多, 所以乜野都係自己去去去解決嘅, 同埋我個人呢, 你見我好似好健談, 但我個人其實係好內歛㗎, 我係唔鍾意求人, 乜嘢都係自己去承擔, 自己去...做得到嘅我自己走去做...所以呢我媽咪就係話, 唉有呢個XX (worker's name) 提供嘅呢個服務呢, 係幫到我哋好多, 令到我媽咪下佢都好開心, 從呢到就睇到, 唔係我剩係地家屬呢可以得到一個嘅支持啦, 同埋呢, 個心會定落嚟啦, 連病患者都感覺到係有人關心佢, 咁樣啦。(Caregiver)*

> *佢哋既愛心啦，就係佢哋係會好⋯好忍耐啊、好有耐性啊，同埋好啊⋯睇到你嗰個情況點樣，佢都會盡量去將佢哋嗰個專業既知識咁樣話比佢聽點做點做。我覺得呢樣嘢嗯係好難得因為如果你無呢個愛心呢，咁係做唔到呢樣嘢出嚟。⋯信任先最重要架嘛。佢哋係做得到呢樣嘢。即係你係好陌生架嘛，你嚟嗰陣時。咁但係你好難去打開個話匣，又要你相信，唔係有啲人，渾渾噩噩咁又係好難架嘛，咁佢又要覺得漸漸你會帶動咗佢嗰個人嗰種情緒上嚟嘞，咁你咪變咗舒服好多囉。大家都舒服啲囉。所以我覺得佢哋最難得既就係有個耐性，同埋有個愛心。(Caregiver)*

> *其實佢都知道側跟有好多人可以幫佢(Patient)，因為去到最後期嘅時候連樓下XX 會姑娘都上埋黎睇佢嘅，但係就佢唔係好接受，可能因為真係去到佢最後階段你先至見，就無XX(Worker)嗰邊咁照顧，我見到佢嘅反應就係每一次XX 會啲姑娘過去，佢就話得啦我自己有打算，唔使講啦，推咗佢，但係嗰邊，即係XX(Worker)嗰邊佢就會一路都同人講我邊度辛苦啊，我邊度唔舒服啊，你叫我咁樣啊好啦我會。(Caregiver)*

> *係呀，即係估唔到⋯⋯我覺得即係依家我有呢個病，依家後期呢個病，原來咁多唔識嗰啲人嚟主動關心自己，你話係咪好開心，好滿足呀？⋯⋯即係你唔使話好似晚期孤伶伶呀，無人理你，剩係屋企人呀咁，咁起碼有外來啲社工，咁多人嚟關心你，你唔開心呀？(Patient)*

> *佢通常嚟講就係同佢嗯...勸解吓佢囉。同埋嗯...佢會當佢一個老人家咁架。當佢一個老人家咁同佢傾偈囉，即係話嗯...你啲孫又點啊？你有冇諗過邊...諗吓嗯同啲孫去邊度食吓嘢、玩吓咁樣。即會將嗰個話題帶開咗，就唔係淨係講佢病情嗰啲。咁等佢就可以唔駛咁集中喺佢自己身體裏邊啲嘢囉。(Caregiver)*

### *Identified helpful service components*

The aforementioned features are the most prominent aspects that were valued by respondents as identified in the interviews. Next, from our data, we identified several recurrent themes pertinent to concrete service components perceived as helpful by the interviewees. These service components identified from the discourse of interviewees shed light on the mechanism on how positive outcomes were made possible with the services. Noteworthily, traces of the above identified service features were also found intertwined in the practice of these service components.

<u>1. Gap-filling practical support to enable EoLC in community</u>

A core element recommended by the interviewed respondents was the timely practical support provided to them that made home care possible, reduced their frustration, and improved quality of life at home. To many interviewed respondents, the first home care experience was usually frustrating due to lack of practical resources and knowledge or information on home care. A considerable of them were referred to the JCECC community EoLC services to support them after they were discharged home from the hospital. Some of the respondents described workers as resourceful that they could utilise existing social resources to coordinate and organise different kinds of support from community to help them, including the lending of wheelchair, walking aids, specialized bed, and information on other community resources available. Even though some respondents revealed that they might not need the practical support at the moment, being informed of the available support seemed to enhance their sense of security.

> *幾乎日日、日日在屋企扶住佢，呢個 XX 同埋 XX (workers' names)，佢兩個(Wrokers)都推咗兩部車嚟，輪椅呀，佢推咗一部嗰啲老人啲輪椅，我都推咗佢(Pateint)去四次飲茶，因為我老公生前好鍾意飲茶，我都推佢去過呢個XX(restaurant name)嗰度飲咗四次茶，就靠佢部車仔推到。 (Caregiver)*

> *咁佢本來就唔係係我屋企住嘅，但係因為佢咁大病，咁就要搬過黎……咁我地本來都去左嗰啲醫療 鋪頭到睇下，買一張咁嘅床係點樣。咁但係咁多款又唔知買咩，咁呀 XX(Social worker)就話我地其實可以借一張比你嘅。 咁我地就覺得好好囉。因為我地都姐係又價值不非嗰啲床，咁姐係如果可以借一張咁就可以試下佢係咪幫到佢呀，或者岩唔岩呀，又可以快 D 呀，唔洗我地好急咁樣，姐係買啲乜野返黎。咁佢地都好好配合囉…其實屋企本來唔係特別有個位比呀奶奶黎住囉。(Caregiver)*

> *姐係預計到有呢D佢地(Worker)都有姐係好清楚介紹佢地有咩係可以幫到我地,如果佢地未必幫到嘅,咁例如我一個人未必應付到咁多樣野啦,咁佢地都會姐係幫我揾D資料。(Caregiver)*

> *都係嫁,呢個都係,佢地都有幫助到囉。姐係話呀,比如如果佢需要D照料嘅時候有D乜野resources啦。姐係比如可能呀,我都諗過會唔會係可能有人送飯呀,又或者護士係你屋企呀,或者係去探嘅時候嘅幫手呀,呢D其他嘅resources佢地都比到我地姐係令到我地有得選擇。姐係都會話返比你聽係好實質嘅提點。(Caregiver)*

2. Caregiving or self-management education and support

Another helpful intervention raised by the case was the supplementary caregiver skill training/advice obtained from workers. Respondents suggested that case workers provided complementary caregiving advice that strengthened the skills and confidence of families in providing basic care, like changing napkins or cleaning patient's body. Moreover, some cases reflected that nurses might provide some advice to them in relieving patient's pain symptoms, or in which aspects should families pay specific attention in assessing patient's conditions. Caregivers also received education from workers regarding the expected care needs on patients in the future. Respondents suggested that there support were very useful in promoting continuous care to patients at home. Besides, some cases might also receive transitional service when awaiting the referred service from public hospitals. Some cases had received speech therapy, dietitian service during the waiting period of receiving their service in public hospitals. This could ensure that they could still receive some basic support before referral. In addition to this, some service partners might also invite their cases to join their health talk that are related to the patient's symptoms.

> *搬先生去廁所, 佢其實啱啱開始佢都唔想既, 佢著尿片都唔習慣啦, 啱啱開始嗰時候, 但係慢慢無辦法, 著尿片有時自己失禁, 日日都失禁啦, 係我去幫佢換尿片啦, 換尿片都要講方法要講技巧要講架……嗰D, 啱開始係醫院教, 後尾X姑娘(worker's name)都有教。 (Caregiver)*

> *又唔記得攞出來問(醫生), 而家出咗門啦(離開了醫生房), 三五分鍾就出去, 咁呢一點呢, 我就覺得係好好, 因為上門教我地, 除咗教我, 同埋話俾我媽咪知, 真係如果你又咩唔舒服呀, 點樣舒緩呀, 你可以自己做呢個動作呀, 或者係點樣樣…咩姿勢呢, 就可以減輕你嘅痛楚呀, 咁又教我啲嘢, 咁係呢到我就覺得真係幾好… (Caregiver)*

> *佢幫我……即係起碼土幫我……佢嗰邊有咩免費嗰啲……嗱，好似佢帶嗰個物理治療師呀嗰啲上嚟呀，咁教你做下啲運動。(Patient)*

> *咁係既，或者佢…佢都好…個佢真係唔想擺個樣比你睇，佢係樣樣嘢要你照顧既。即後期真係冇辦法嘞，佢真係照唔到嘞，咁佢先至要咩，睇即係…個過程係睇到……嗰啲姑娘已經提我…我係贊成佢哋同嗰啲病者家屬講啲…嗯…有啲咩佢要留意啊，去到某個情況你又要做呢樣，做嗰樣嘢，睇得…即係你到時到候你會知道點做嘛。因…你唔係你等唔到嘛，佢突然間會咁既？你以為佢突然間會…但係佢唔係既，佢係已經又去到另一個情況吖嘛，即巨嗰個情況一路向下架嘛。但係你唔知道佢，你以為佢今日係咁啫，聽日又會好番架。*(Caregiver)

### 3. Psycho-social-spiritual support which improve patient's emotion and their outlook to future

Respondents reported that after joining the service, the most notable change is the improvement in emotion. From respondents' revelation, it can be seen that patient's emotion could be improved by engaging different kinds of social activities with case workers or volunteers. Caseworkers would also design some activities that may be previously enjoyed by patients. It could help them to create a sense of normality, to encourage them to join the activities that they previously spent time in. Home visits by case workers and volunteers, as well as joining some social activities organised by service partners could also lighten up the mood of patients, as they could feel like they were still connected with the community and felt less isolated socially.

> *係啊，久唔久搭兩句，咁佢哋係好開心既。咁同埋有時呢，佢上去，佢送啲小禮物比佢，送啲盆栽仔啊，送咭比佢呢，佢老人家開心。其實每次佢哋上嚟呢，媽媽都係開心既。係好正面既，即係…譬如有，嗰日佢負面情緒都好，佢都嗯…都開心番。*(Caregiver)

> *講到嗰啲社工上去屋企咁樣。即佢哋每次上去同媽媽傾完偈呢，其實媽媽都好開心架。個心情開朗既。...我由得佢哋坐埋，同佢一齊咁傾既，我就有時行開吓，咁啊睇吓手機。*(Caregiver)

> *咁有一日呢, XX (Worker)打電話, 我就話我媽咪入院喇, 佢話 YY(Volunteer)好似返左黎...如果係咁我搵一日 YY(Volunteer) 同我黎探你媽咪, 我話好呀, 果次入醫院, 其實果幾日呢, 我媽咪已經係唔係太清醒, 講唔到野喇, 你同佢講野, 佢一係岌下頭, 即係唔會講野既, 都冇乜笑容架喇, 因為痛丫麻, ... 果日 YY(Volunteer)同 XX (Worker)黎, "伯母, 呢個咩黎架?" 媽咪個樣好開心, 睇到佢就, 佢就呢 ... YY(Volunteer)攞左 2 個, 一個係我媽咪做陶瓷, 一個係 YY(Volunteer)做陶瓷, 俾佢睇, 佢好開心, 即係探左佢一輪啦, 幾好丫 ...總之盡量安慰下佢啦講 D 野, 即係令佢, 令我媽咪開心咁樣, 之後呢, 都唔係好耐,就話, "伯母, 我下一次再黎探你吓, 我今日我地今日而家就走喇, 下一次我再黎探你", 我媽咪話, "好呀", 我第一次見佢*

> *個樣呢, 係好開心好開心, 即係喺醫院咁耐時間, 第一次見佢個笑容呢係燦爛既, 即係平時我媽咪好靚架。*(Caregiver)

### 4. Connected with family members through relationship-enhancing activities at the end of life

Some respondents reflected that arguments and dissatisfaction often occurred in home-bases family caregiving, as providing care at home was a source of stress to family members. Therefore, maintaining a harmonious and supportive relationship within family could be a challenge for them. Respondents expressed that they often felt more connected with other family members while joining the family activities organised by caseworkers. It was observed in the interviews that most of the last wishes of patients were often family-related, like having a good and enjoyable time with family. Workers would design some family activities that could be joined by both family and patient. Patents and family could become more connected with each other in this kind of activities. Their memories could also become a reminiscence to the whole family and patients. For patients seeking for family reconciliation, worker also played a role in arranging family activities to improve their family relationship with each other. Caregivers who had experience like this reflected that patients could leave the world peacefully by completing the wish of being accepted by his family again.

> *同佢地一齊去迪欣湖囉…係呀，幾開心呀我地成家,個義工特登煲啲果汁俾我地飲喎。佢一個義工同埋 XX (workers' names) 囉, 即係好有 Feel 囉嗰次，嗰次就一家同埋阿囡囡去玩下影下相咁樣，好似創造左 D 回憶出黎係呀，回憶同埋呢可能有啲野會記住囉。(Caregiver)*

> *開心啲啦，佢見到陌生人都會好啲囉。咁唔係你成日兩個，見嚟見去就…你冇咗嗰種衝擊啊嘛。個人始終…你否如去瞓吓覺啦，開睇吓電視啦咁樣。有人嚟係會好啲。對佢嚟講，對個病者嚟講係好啲既。咁同埋呢喺我個個學識嚟講，有人同佢傾偈啊，咁我都可以聽吓佢講既嘢啊，咁佢平時，佢唔會同我講啲嘢，我都喺嗰段時間都聽到佢點樣去表達佢個心中既諗法囉。*(Caregiver)

> *XX (workers' names) 就問咗我媽咪(想去邊度玩), 佢就諗咗一諗…有一次去老人中心話去慈山寺, 當時係嗰間老人中心呢, 係果 d 旅遊巴, 即係我媽咪係坐輪椅咁就唔方便嘅, 咁所以就唔附合資格參加佢呢個行程囉, 咁所以就冇去到, 咁我又唔知有咩途經, 可以去果度, 我都冇再深入去打聽啦, 因為又冇時間啦, 第二個我又唔識上網, 我屋企有冇電腦果 d, 我又唔識果 d 手機, 咁同 XX (workers' names) 講啦, XX (workers' names) 就話, 好好好, 到時安排你地去慈山寺, 即係…果次呢我地真係去咗慈山寺, 我媽咪好開心, 因為你知個環境係冇特別嘅車, 係好難去到個地方架嘛 。所以果日我媽咪好開心, 嗰個環境又好寧靜啦, 呀... 同埋環境又好啦, 空氣又好啦, 好多綠色嘅樹木呀, 我 阿媽咪係好滿意好滿意, (Caregiver)*

> *好彩又影咗家庭照，最開心呢樣嘢！本來計劃仲在生，諗住重有咩可以帶佢玩，點知講都講唔到。我諗住 X 姑娘(social worker)帶佢去燒嘢食。(Caregiver)*

Indeed, two areas of support which had received far less attention from respondents. The first one was discussion on end-of-life care preferences. Patients and caregivers rarely mentioned advanced care planning when they were asked what the service team had done with them. Upon researchers' asking specifically on EoLC planning, in some cases, patients and/or caregivers mentioned that they had already discussed DNACPR or advanced directives with the medical team in hospital prior to the admission to the service. In a few cases, they mentioned discussions on care arrangement when health conditions deteriorate, such as hiring a domestic helper or moving to RCHEs, as well as funeral planning. It seemed that the advanced care planning process was not explicit to most of the interviewed cases, particularly for cases not served by HOH. However, relevant discussions indeed took place in many interviewed cases from all service models. Therefore, there are reasons to assume that the advance care planning process was not conducted individually, but carried out in parallel with other interventions in a less structured way.

Secondly, for models which provided no nursing care, physical symptom management was rarely mentioned. We found that some cases considered that physical care was not part of the support provided by our service partners, and hence many of them had never sought for any advice on this aspect. In other cases, nurses in the service teams could only answer some general enquiries aroused in the care process. It might worth considering that in the future, further support on the physical care part can be offered without duplicating the medical support of cases received from the hospitals. We did identify other service gaps which had been repeatedly mentioned by interviewed participants, such as transportation and respite services. These are gaps which might be difficult to fulfill through the current models, but worth developing in future community-based EoLC services. We also found that all service models provided services not only to patients, but also to caregivers directly, while a part of services targeted on both. Hence, all service models could be considered family-based.

To conclude, four helpful service components have been identified from the indepth interviews. These are practical support, education and support related to caregiving at home and symptom management, psychosocial support to both patients and caregivers, and enhancement of family relationship. These components can be largely categorised into **Physical, psychosocial and practical support**. The service components *per sue* were crucial, but even more vital were the three service delivering features – proactive and timely, individualized and need-based, and caring and respectful attitude – which made the service person-centered and dignity-conserving. Moreover, these services target not only on patients, but caregivers or the whole family as well.

## 4.5 Key Performance Achievements

The outputs in the community EoLC services was calculated by counting the number of cases admitted (**Table 4.12**). It exceeded the pledged output in 3 years.

**Table 4.12** Outputs of JCECC community EoLC services

| | Pledged output for 4 NGOs in 3 years | Actual output up to Dec 31, 2018 | Achievements |
|---|---|---|---|
| **Cases** | 690 | 777 | 112.6% achieved |

The results from the combined sample were able to achieve most of the key performance indicators (KPIs). The only item with lower than 100% achievement was intimacy between patients and family caregivers. Yet, 50% achievement was recorded. The evidence corresponds to the KIP achievement was mapped in the **Table 4.13** below:

**Table 4.13** Key performance indicator achievements of JCECC community EoLC services

| | Key Performance Indicators | Performance of all NGO models[40] | Achievements[41] |
|---|---|---|---|
| **1** | A 5% increase in quality of life of patients *(reduced physical and emotional symptoms, wishes are respected, sense of security [practical], better family relationship [sharing feelings])* | • 18% reduction in physical symptoms (p.67) | 361% achieved |
| | | • 47% reduction in depression (p.67) | 943% achieved |
| | | • 31% reduction in anxiety (p.67) | 622% achieved |
| | | • 55% reduction in practical problems (p.67) | 1105% achieved |
| | | • 15% reduction in the barriers of sharing feelings (p.67) | 305% achieved |
| | | • 98.7% agreed that the service team respected your wish (subjective outcome) (p.69) | 132% achieved (75% as target) |
| | | Average: [42] | 578% achieved |
| **2** | A 5% increase in quality of life of family caregivers *(reduced caregiver burden, better family relationship)* | • 19% reduction in caregiving strain (p.68) | 379% achieved |
| | | • 27% reduction in family anxiety (p.68) | 538% achieved |
| | | • 2.5% increase in intimacy (p.68) | 50% achieved |
| | | Average: [42] | 322% achieved |
| **3** | Family members will have reduced regrets in bereavement process | • 26.6% of reduced risk for complicated grief when compared to the reference data from another Chinese sample (p.68) | Target achieved |
| **4** | Patients and family members have an overall satisfaction towards the EoLC of 75% or above. | • Patients have an overall satisfaction towards the service of 96% (p.69) | 128% achieved (75% as target) |
| | | • Caregivers have an overall satisfaction towards the service of 95% (p.70) | 126% achieved (75% as target) |
| **5** | Reduction of 2 days of hospitalisation as well as 5% A&E admission in the last six months for patients | • Deceased patients in the JCECC community EoLC services showed a reduction of 4.87 days of hospitalisation,11.6% reduction in A&E admission in the last 6 months of life relative to EoL patients in CDM study. (p.71) | Achieved. |

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[40] All % changes were calculated by the formula: (new values – old values)/old values.

[41] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

[42] Assuming all indicators involved share the same weight.

## 4.6 Findings by Service Models

### 4.6.1 St James' Settlement

#### 4.6.1.1 Service components

St James' Settlement (SJS) aims to provide alternatives to advanced illness patients and their family members by supporting them to live with informed choice to stay at home with dignity. The key features/service components include:

- A family-based approach: individual and family counselling
- Augmenting enjoyment in life: Recruit volunteers and cheering practitioners to bring fun and happiness to patients and their families, and to create memories for them to move on.
- Intensive tangible support to enable patients stay at home
- Collaborate with hospital palliative care services and community in home care to provide seamless support to patients and their families.

Patients, who live on Hong Kong Island, with a life-threatening illness, mostly cancer, and a life expectancy of around six months are the major target beneficiaries. Their family members are secondary target. 210 patients and 630 family members are expected to be served in 3 years. Priorities are given to those on CSSA, or with household income lower than median income, or patients are not eligible to receive services from Enhanced Home Care Team. **Table 4.14** summarises the components of SJS model by service foci.

**Table 4.14** Service components of SJS model

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Equipment Loan<br>· Escort<br>· Home environment modification<br>· Intensive support by care officers | · Referrals to occupational therapists | · Cheering activities<br>· Legacy<br>· Wish fulfilment<br>· Individual counselling | · Family counseling<br>· Family activities | · Care plan discussion<br>· Funeral planning | · Bereavement support<br>· Funeral support |

#### 4.6.1.2 Service users

Between January 2016 and December 31, 2018, St James' Settlement has admitted a total of 205 cases. Among these cases, 189 (92.2%) completed assessment at intake ($T_0$), and 65 (31.7%) of these cases have completed both intake ($T_0$) and 3-month assessment ($T_2$). Only from one case, no family caregiver could be identified for clinical assessment. Among the remaining 204 cases in which at least one family caregiver could be identified, 182 (89.2%) took part in the intake assessment ($T_0$), and 44 (21.6%) completed 3-month assessment ($T_1$) as well. In addition, 71 (34.8%) bereaved caregivers completed the bereavement assessment two months after patient's death ($T_2$). Data from the 189 patients and 182 caregivers with intake assessment will be used to understand the profile of service users of SJS. However, only patients and caregivers with both intake ($T_0$) and 3-month assessment ($T_2$ for patients, and $T_1$ for caregivers) will be included in the analysis of changes in outcome indicators.

Among all 205 patients, majority (82%) had cancer as major diagnosis, the remaining were chronic kidney disease (8%), renal disease (5%), heart failure (1%), motor neuron disease (1%), and chronic lower respiratory diseases (1%) (**Figure 4.15**). Regarding sources of referral, 85% were referred by public hospitals, followed by social service units (14%), and self-approach (1%) (**Figure 4.16**). By December 31, 2018, 163 (79.5%) patients have already passed away. The mean service duration of these deceased patients was 4.57 (5.638) (Mean [SD]) months. Patients who were alive (N=42) have stayed in service for 11.94 (10.149) (Mean [SD]) months on average. When all cases considered, the average service duration was 6.08 (7.405) (Mean [SD]) months.

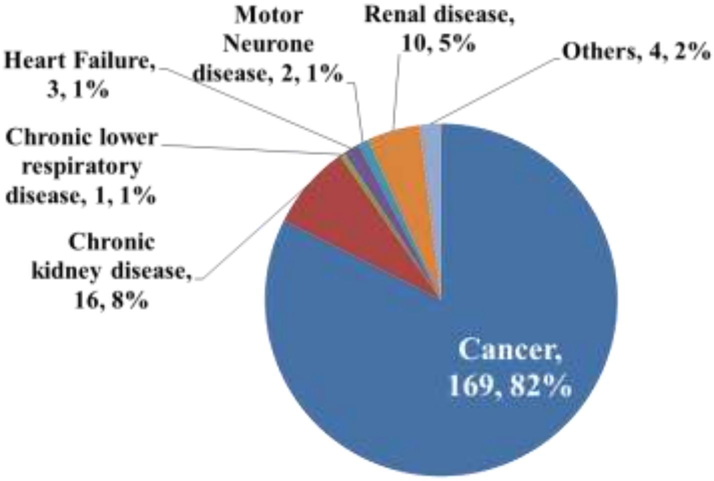


**Figure 4.15** Diagnosis of all admitted patients in SJS programme (N=205)

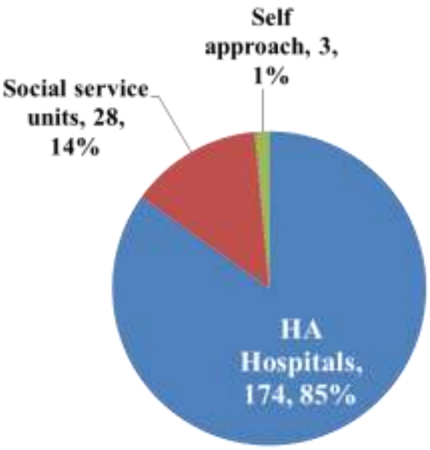


**Figure 4.16** Sources of referral of all admitted patients in SJS programme (N=205)

Demographic data were collected from patients who have completed intake assessment (N=189) (**Table 4.15**). These patients had a mean age of 76.46 (11.95) (Mean [SD]) years old, 82% diagnosed with cancer, 8.5% with chronic kidney disease, and 4.8% with 43% with renal disease, which is of similar distribution to the whole sample. Patients were mainly cared by spouse (38.1%), adult children (38.1%), and other relatives (12.7%). All of them were residing in the community, with around one-tenth were living alone. Among one-hundred and eighty-one patients who provided information on their financial sources, not many were receiving CSSA (8.3%), but a considerable portion of them (30.9%) were living on disability allowance.

**Table 4.15** Basic demographics of patients (with intake assessment) of SJS model

| | **Freq. (%)** |
|---|---|
| N | 189 |
| **Education** | |
| No schooling/kindergarten | 45 (23.8%) |
| Primary school | 49 (25.9%) |
| Secondary school | 66 (35%) |
| Tertiary education | 22 (11.6%) |
| Others | 5 (2.6%) |
| **Marital status** | |
| Married/cohabitating | 109 (57.7%) |
| Widowed | 58 (30.7%) |
| Single | 11 (5.8%) |
| Separated/divorced | 10 (5.3%) |
| **Religion** | |
| Chinese Traditional belief | 71 (37.6%) |
| No religion | 47 (24.9%) |
| Christian | 27 (14.3%) |
| Buddhist | 15 (7.9%) |
| Catholic | 15 (7.9%) |
| Others | 13 (6.8%) |
| **Relationship with primary caregiver** [a] | |
| Spouse | 72 (38.1%) |
| Adult child | 72 (38.1%) |
| Relatives (e.g. siblings, daughter/son-in-law, other relatives) | 24 (12.7%) |
| Domestic helper | 10 (5.3%) |
| Parents | 1 (0.5%) |
| Friends | 1 (0.5%) |
| No caregivers | 1 (0.5%) |
| **Living arrangement** | |
| Living Alone | 19 (10.1%) |
| Other living arrangements in the community | 168 (89%) |
| Average domestic household size (N=183) | 2.87 (1.34) |
| **Housing of those living in domestic households (N=189)** | |
| Public housing | 65 (34%) |
| Non-public housing | 114 (60%) |
| Others | 2 (1.1%) |
| **Financial Assistance (N=181)** | |
| CSSA Scheme (Yes) | 15 (8.3%) |
| Disability Allowance (Yes) | 56 (30.9%) |

*Notes.* [a] *Paid caregivers were not invited to assessment.*

Among the 182 caregivers who received assessment at intake, the mean age was 56.54 (16.27) (Mean [SD]) years old, and 51 (28%) were male. They were highly involved in caregiving, although a majority received support from other family members (80% satisfied with support from family). **Table 4.16** shows the demographic information of these caregivers.

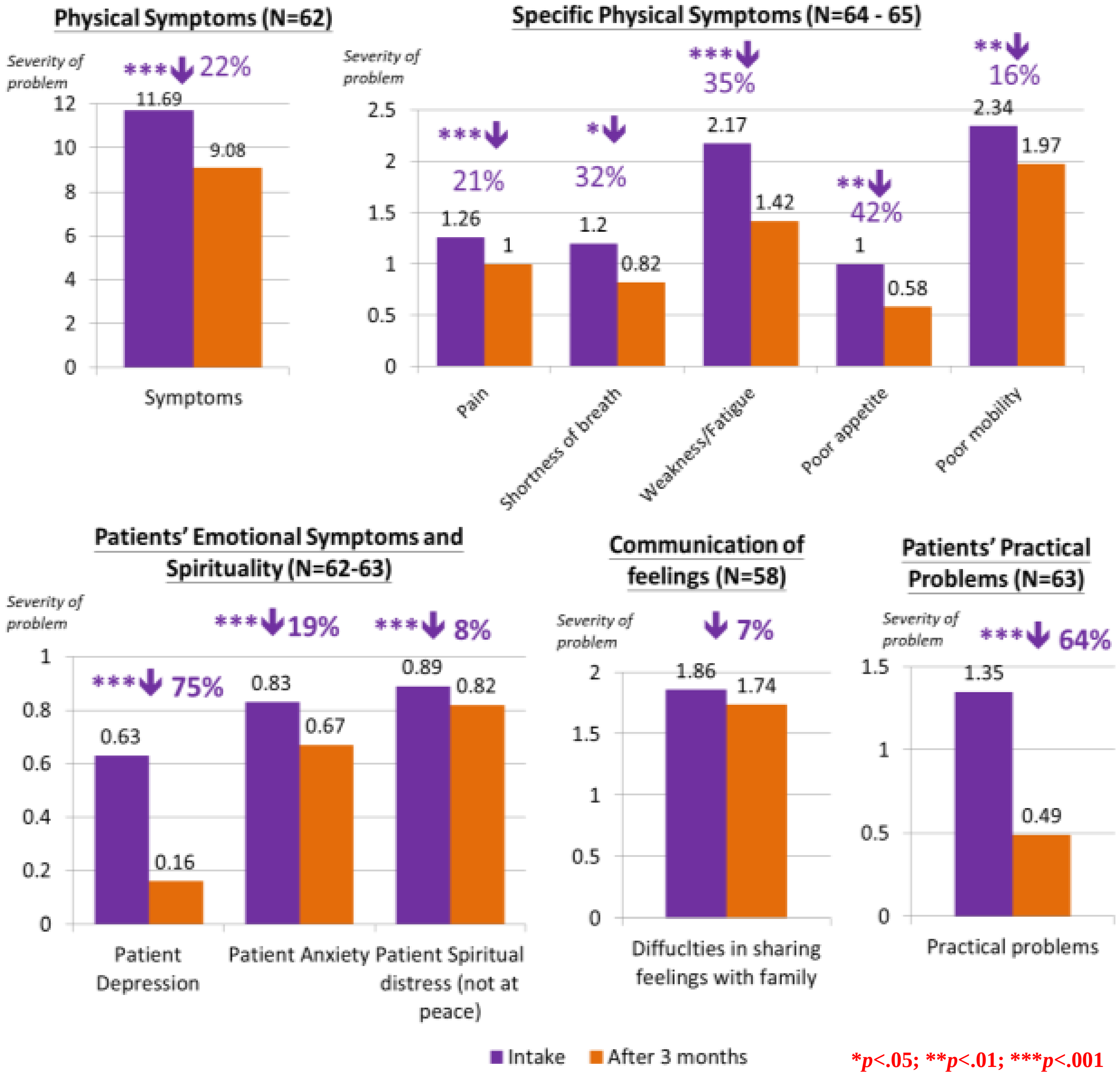
**Table 4.16** Basic demographics of family caregivers (with intake assessment) of SJS model

| | Freq. (%) |
|---|---|
| N | 182 |
| **Relationship with patient** | |
| Spouse | 79 (43.4%) |
| Adult child | 75 (41.2%) |
| Relatives (e.g. grandchild, child-in-law, siblings) | 26 (14.3%) |
| **Education** | |
| No schooling/kindergarten | 8 (4.4%) |
| Primary school | 30 (16.5%) |
| Secondary school | 92 (50.5%) |
| Tertiary education | 50 (27.5%) |
| Others | 1 (0.5%) |
| **Marital status** | |
| Married/cohabitating | 132 (72.5%) |
| Single | 41 (22.5%) |
| Separated/divorced | 6 (3.3%) |
| Widowed | 1 (0.5%) |
| Others | 1 (0.5%) |
| **Religion** | |
| No religion | 60 (33%) |
| Chinese Traditional belief | 44 (24.2%) |
| Christian | 25 (13.7%) |
| Catholic | 21 (11.5%) |
| Buddhist | 16 (8.8%) |
| Others (e.g. Daoism, Muslim) | 15 (8.2%) |
| **Employment Status** | |
| Retired/Not working | 60 (33%) |
| Full-time employed | 59 (32.4%) |
| Home maker | 37 (20.3%) |
| Part-time employed | 16 (8.8%) |
| On leave/unemployed | 9 (4.9%) |
| Others | 1 (0.5%) |
| **Whether the caregiver was diagnosed with any chronic illness(es) (Y)** | 107 (58.8%) |
| **Co-residing with patient (N)** | 37 (20.3%) |
| **For caregivers who are not residing with patient, number of days visiting patient per week (N=34)** | 4.68 (2.333) |
| **Time needed to take care of patient per week (hours) [baseline] (N=181)** | 59.17 (56.006) |
| **How satisfied you are with the support you receive from your family members in your role as a caregiver? [baseline]** | |
| Dissatisfied – very dissatisfied | 3 (1.6%) |
| Average | 26 (14.3%) |
| Satisfied – very satisfied | 148 (81.3%) |
| **Whether the caregiver has received any financial allowance? (N=160)(Y)** [a] | 46 (28.7%) |
| CSSA | 8 (5%) |
| Disability allowance | 7 (4.4%) |
| Old age living allowance | 9 (5.6%) |
| Old age allowance | 21 (13.1%) |
| **Perceived financial strain (N=159)** [a] | |
| Slightly difficult - No difficulties | 127 (79.9%) |
| Moderately difficult | 18 (11.3%) |
| Very difficult - Extremely difficult | 14 (8.8%) |

*Note.* [a] *Not all family caregivers answered the questions relating to finance.*

### 4.6.1.3 Objective outcomes

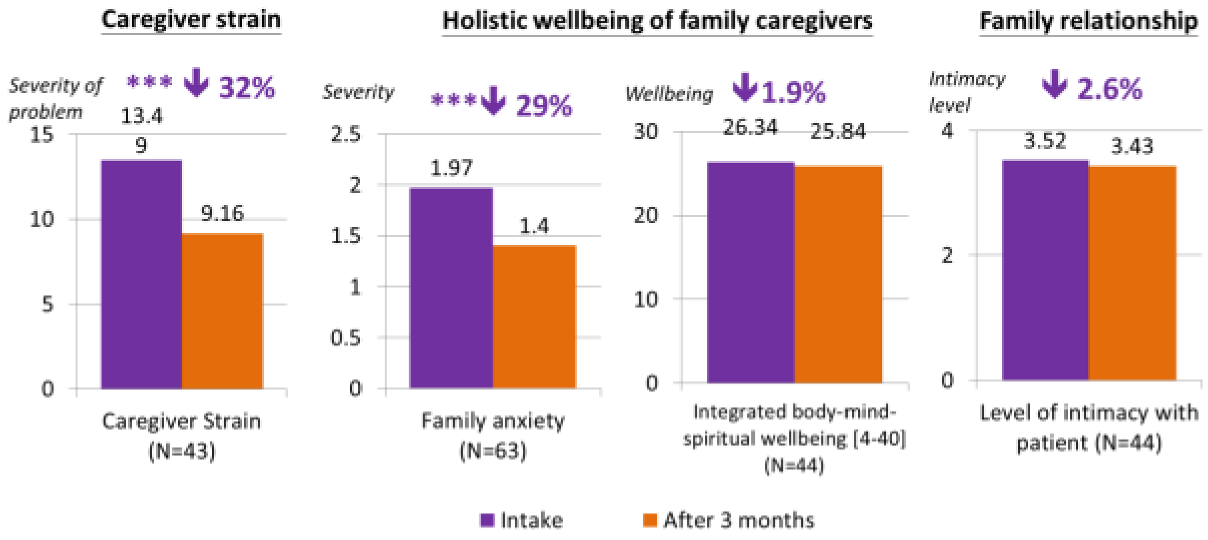
**Figure 4.17** summarised the 3-month changes in physical symptoms, psychosocial-spiritual distress, as well as practical concerns of 65 patients. Results showed that patients experienced significantly reduced problems in all these realms except barriers in sharing feelings (*p*<.05 to *p*<.001). For physical symptoms, the overall severity level reduced by 22% (*p*<.001), with five of the ten assessed symptoms all showed significant improvements, including pain, shortness of breath, weakness/fatigue, poor appetite, and poor mobility. Patients reported significant reduction in depression and anxiety (*p*<.001), spiritual distress (not at peace) (*p*<.001), and barriers in sharing feelings with family or friends (*p*<.01). Moreover, practical problems reduced by over 60% after 3 months in service (*p*<.001).



***p*<.05; ***p*<.01; ****p*<.001**

**Figure 4.17** Changes in objective outcomes of patients in SJS programme after 3 months

In **Figure 4.18**, 63 patients reported the anxiety level of their family members at both baseline and 3rd month in service, whereas 44 caregivers have completed both baseline and 3rd month assessments. Findings showed significantly reduced family anxiety and caregiver's self-reported caregiver strain at the third month ($p$<.001). There were no significant changes in the body-mind-spiritual wellbeing of caregivers and intimacy with patient. Regarding other control variables, no changes in the caregiving hours and satisfaction with support from other family members on caregiving were reported at the third month. After patient's death, 94.4% of the 71 assessed bereaved family members had low risk of complicated grief, which represented a 59.7% reduction of high risk population when compared to the reference (13.9%) reported among a Chinese population[43].



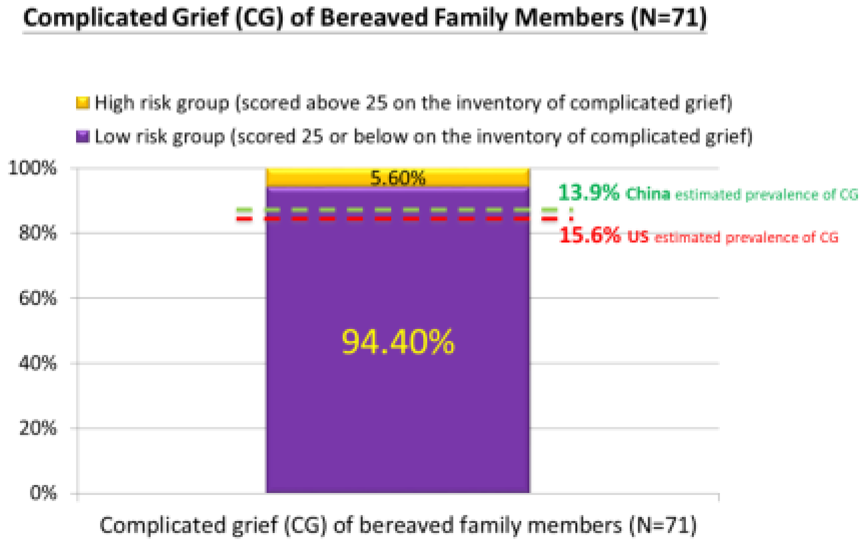


**Figure 4.18** Changes in family caregivers after 3 months in SJS programme and complicated grief in bereaved family members

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[43] Li, Jie & Prigerson, Holly. (2016). Assessment and associated features of prolonged grief disorder among Chinese bereaved individuals. *Comprehensive Psychiatry, 66*, 9-16. 10.1016/j.comppsych.2015.12.001.

### 4.6.1.4 Subjective outcomes

A total of 30 patients completed the satisfaction survey **(Figure 4.19)**. A cut-off score of 6/7 was adopted as an indication of high satisfaction. None of the patients gave score below 7 in the overall satisfaction rate to this project, as well as of the service in meeting their needs. Moreover, participants also showed great satisfaction to volunteer services, and they rated highly that the service helped him/her live with dignity and respected his/her wish (mean >8.9). Compared with all other items, an area which might need more improvement could be "improving distressing symptoms of patients" (mean=8.4).

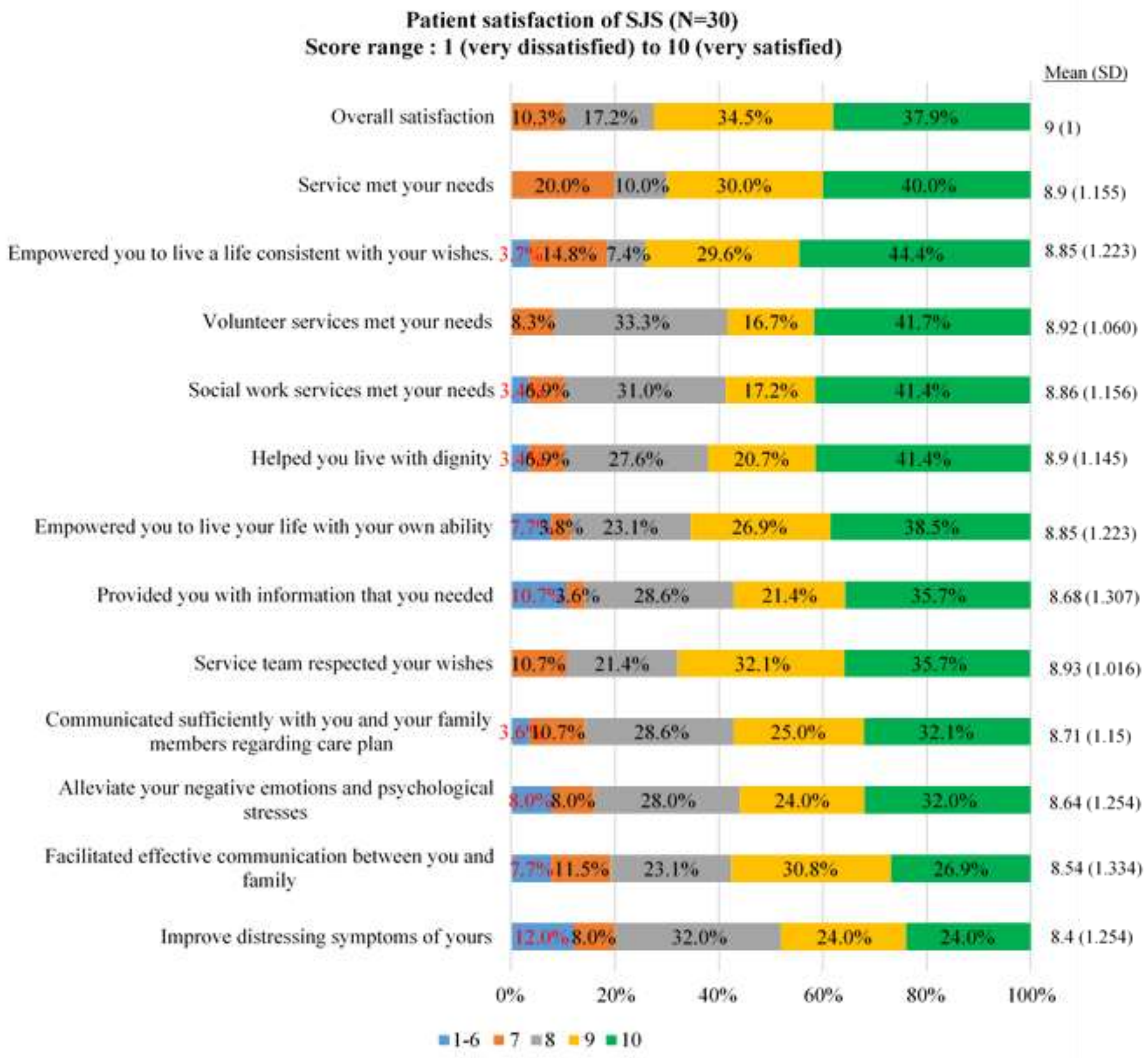

**Figure 4.19** Patient satisfaction survey of SJS

A total of 57 caregivers responded to the satisfaction survey (**Figure 4.20**). A cut-off score of 6/7 was adopted as an indication of high satisfaction. On the overall satisfaction to this project, a majority of the responses was scored 7 and higher. In addition, caregivers showed great satisfaction to the service team in respecting their wishes, and they were particularly satisfied with the volunteers and social workers' interventions (mean >8.7). Areas which might need to be improved include managing the physical symptoms of the patients (mean= 8.15), and alleviating the negative emotions and psychological stresses of the patients (mean= 8.37).

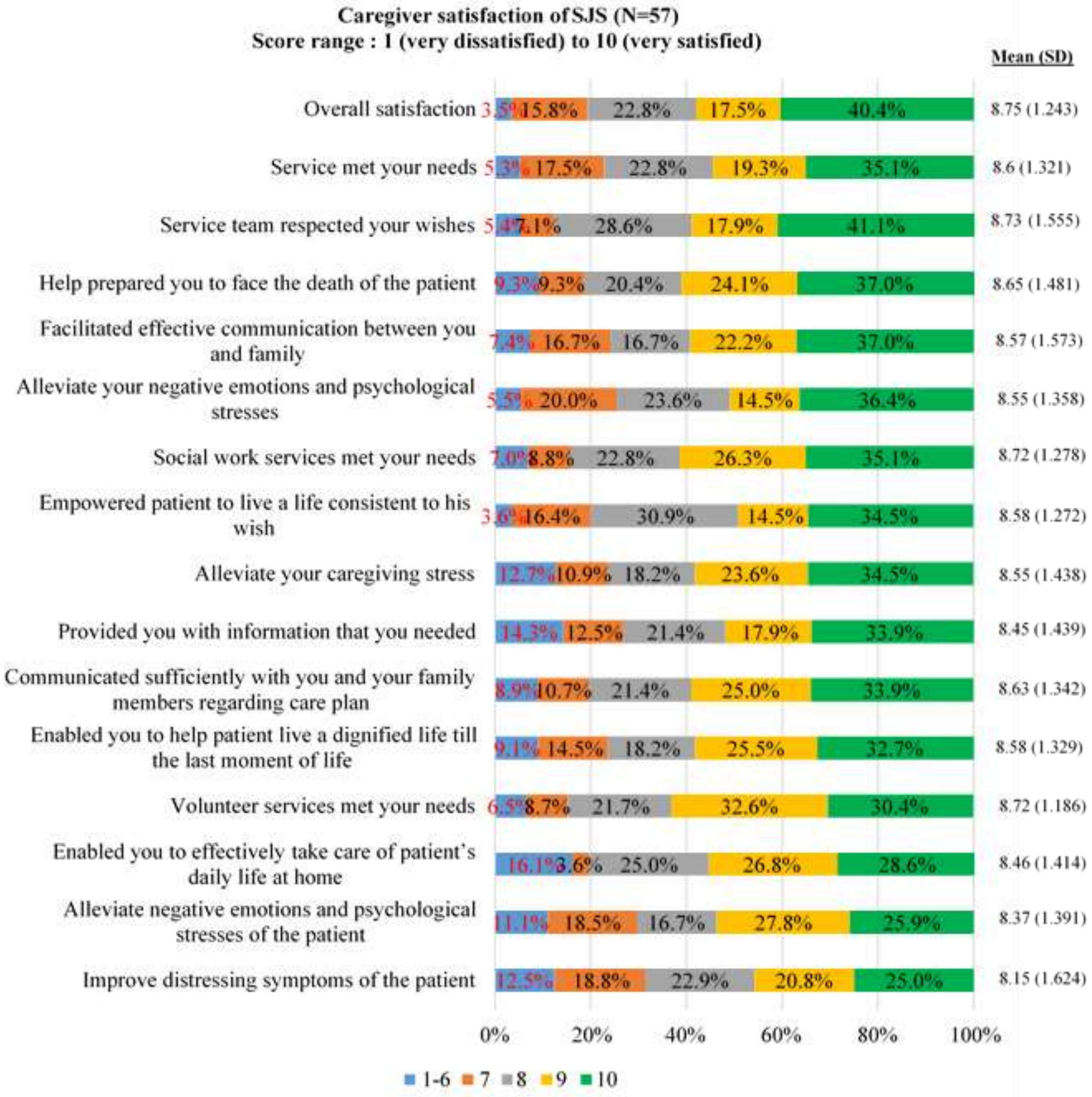

**Figure 4.20** Caregiver satisfaction survey of SJS

### 4.6.1.5 Impacts

Medical service utilisation data was retrievable from 65 deceased patients from the SJS service model (40% of all deceased patients in SJS service). Two cases were found to have stayed in hospital for 150 or more days (i.e. 5 months) in the last 6 months of life. Since these patients were exposed to limited community support services provided by SJS, they were excluded from the final analysis. Subsequently, 63 cases were included in the analysis, and the mean length of stay in hospital (i.e. hospital beddays), A&E attendance, and ICU beddays were calculated. **Figure 4.21** shows the comparison between the data of SJS patients and the CDM. The finding suggested that deceased patients in the SJS model reported 4.9 hospital beddays, 1.23 times of A&E attendance, and 0.07 ICU beddays fewer than end-of-life patients in general.

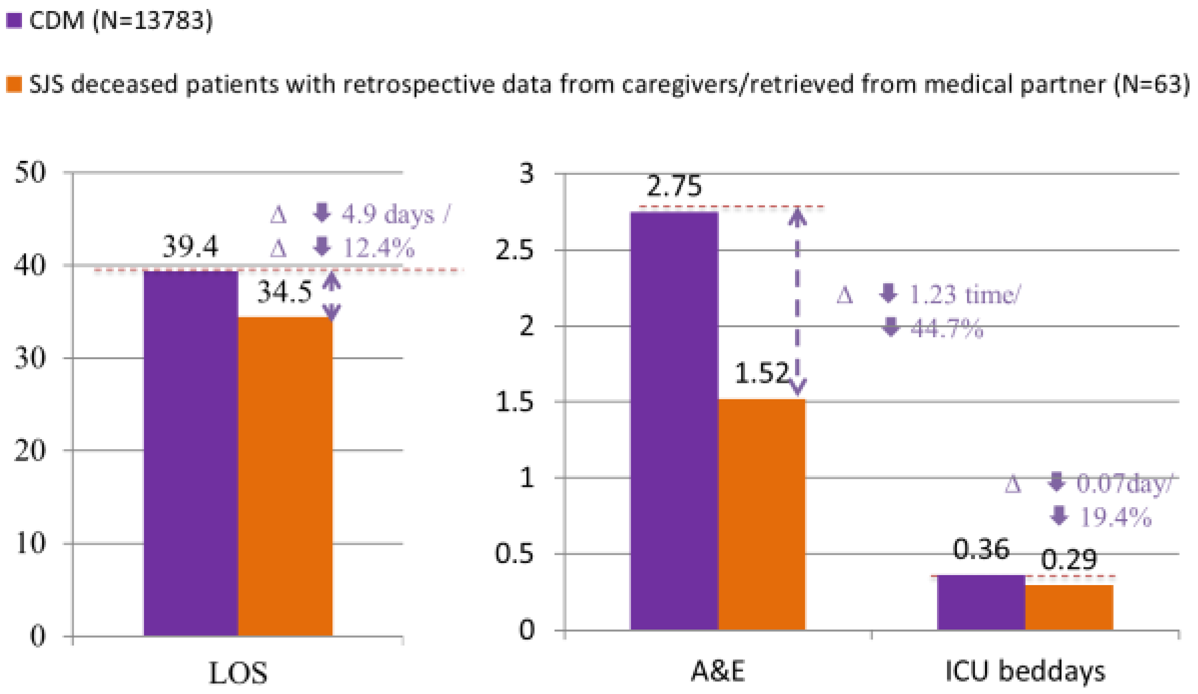

**Figure 4.21** Comparison on medical service utilisation in the last 6 months of life between deceased patients in SJS model and the CDM sample

### 4.6.1.6 Key Performance Indicators Achievement

Key performance indicators (KPIs) had been developed to measure the achievement of targets of each project components. The first column of the Table 4.17 shows the relevant KPIs for EoLC service models. Relevant outcome/Impact indicators are included in the column "performance of SJS service model" for corresponding KPI. The achievements of the target specified in the KPIs were calculated by dividing the % changes obtained from the evaluation by the target % change specified in the KPIs.

**Table 4.17** Key performance indicators achievement of SJS model

| | Key Performance Indicators | Performance of SJS service model[44] | Achievements[45] |
|---|---|---|---|
| **1** | A 5% increase in quality of life of patients *(reduced physical and emotional symptoms, wishes are respected, sense of security [practical], better family relationship [sharing feelings])* | • 22% reduction in physical symptoms (p.92) | 447% achieved |
| | | • 75% reduction in depression (p.92) | 1492% achieved |
| | | • 19% reduction in anxiety (p.92) | 386% achieved |
| | | • 64% reduction in practical problems (p.92) | 1274% achieved |
| | | • 6% reduction in the barriers in sharing feelings (p.92) | 129% achieved |
| | | • 100% agreed that the service team respected your wish (p.94) | 133% achieved |
| | | Average: [46] | 643.4% achieved |
| **2** | A 5% increase in quality of life of family caregivers *(reduced caregiver burden, better family relationship)* | • 132% reduction in caregiving strain (p.93) | 642% achieved |
| | | • 29% reduction in family anxiety (p.93) | 579% achieved |
| | | • 2.6% reduction in intimacy (p.93) | Not achieved (-51%) |
| | | Average: [46] | 390% achieved |
| **3** | Family members will have reduced regrets in bereavement process | • 59.7% of reduced risk for complicated grief when compared to the reference data from another Chinese sample (5.6% in SJS model Vs. 13.9% in another Chinese sample) (p.93) | Target achieved |
| **4** | Patients and family members have an overall satisfaction towards the EoLC of 75% or above. | • Patients have an overall satisfaction towards the service of 100% (p.94) | 133% achieved |
| | | • Caregivers have an overall satisfaction towards the service of 96.5% (p.95) | 129% achieved |
| **5** | Reduction of 2 days of hospitalisation as well as 5% A&E admission in the last six months for patients | • Patients in SJS model showed a reduction of 4.97 days of hospitalisation (including acute ward and ICU) as well as 44.7% reduction in A&E admission in the last 6 months of life when compared to that for EoL patients derived from CDM study. (p.96) | Achieved. |

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[44] All % changes were calculated by the formula: (new values – old values)/old values.

[45] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

[46] Assuming all indicators involved share the same weight.

### 4.6.1.7 Analysis

The findings from objective outcomes suggested that SJS model was effective in helping patients and families with symptom relief, improving emotion reactions of patients, improving patients' spiritual wellbeing, reducing practical concerns and caregiver strains. These changes were all statistically significant. Moreover, bereaved family members showed low risk of complicated grief as well. Note worthily, patients reported significantly improved physical symptoms even though intervention of SJS model focused primarily on psychosocial and practical facets. It should be noted that symptom relief was also provided by the palliative care teams collaborating with SJS. This improvement could be considered as an aggregated impact of such collaboration. Particularly, in the in-depth interviews with patients of SJS, there was evidence that cheerup activities helped distracted patients from their physical distress. There was evidence to believe that the joy brought to the families through cheerup activities had exerted a positive secondary impact on the patients' perception on his or her physical functions. Subjective outcomes confirmed that the service had helped patients and caregivers to live with dignity and consistent with their wishes, and they were particularly satisfied with volunteer services, who were the backbone for cheerup activities.

However, the improvements in patient's barriers in sharing feelings and the intimacy between patient and caregivers were not as prominent as expected. Subjective outcomes also reflected that service users were less satisfied with family communication aspect when compared to other psychosocial-spiritual-practical support. However, patients in the SJS model have reported particularly high physical symptoms at baseline when compared to other models (SJS 12.67 (5.897), HCCDECC 11.95 (6.067), HOH 8.86 (4.464), HKSR 7.42 (4.624), *F*(3, 566)=30.336, *p*<.001). In our previous cross-lagged analysis, physical symptom severity was found to lead to higher barriers in sharing feelings with family and friends. This might partly explain the sustained barriers in sharing of feelings among SJS patients who were affected by more severe physical distresses. Moreover, the high intimacy level at baseline weakened the sensitivity of our intimacy measurement towards further positive changes which is known as ceiling effect. Despite these confounding factors, in order to promote family communication in face of the barriers posted by patient's physical distresses, family engagement could be strengthened in the process of arranging cheerup activities, given that cheering activities might be able to distract patients from physical distress and are more ready for more family communication.

Regarding impacts, based on 69 sample (40% of all deceased patients in the programme), the current results on medical service utilisation suggested that the SJS model had high potential to reduce unnecessary utilisation of medical services during patients' last 6 months of life. These findings suggested that the service components of SJS model targeting on practical needs, symptom management, psychosocial-spiritual care, and bereavement care have been particularly effective. **Table 4.18** summarises the outcomes by service foci, with effect sizes (*ES*) on the changes specified for each outcome indicator.

**Table 4.18** Relatively effective service components in the SJS model (shaded area) and the effect sizes for each outcome indicator which showed significant changes

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| • Equipment Loan<br>• Escort<br>• Home environment modification<br>• Intensive support by care officers | • Referrals to occupational therapists (Could be the results of symptom relief of medical partner coupled with secondary effects of psychosocial care) | • Cheering activities<br>• Legacy<br>• Wish fulfilment<br>• Individual counselling | • Family counseling<br>• Family activities | • Care plan discussion<br>• Funeral planning | • Bereavement support<br>• Funeral support |
| ⬇practical concerns ***(*ES*=-0.79)<br>⬇caregiver strain ***(*ES*=-0.8) | ⬇physical symptoms*** (*ES*=-0.51) | ⬇depression***(*ES*= -0.38)<br>⬇anxiety*** (*ES*=-0.16)<br>⬇not at peace*** (*ES*=-0.07)<br>⬇family anxiety*** (*ES*=-0.54)<br>Caregiver IBMS unchanged | No significant changes in barriers in sharing feelings and family intimacy | 96.4% patients and 91.1% caregivers satisfied that care plan was sufficiently discussed | 59.7%reduced risk for complicated grief |

## 4.6.2 Haven of Hope Christian Service

### 4.6.2.1 Service components

Haven of Hope (HOH) aims to provide quality home care with intensive medical and nursing support to patients with terminal cancer/ other chronic irreversible illnesses of limited life expectancy so as to delay or avoid unnecessary admissions to hospitals. Service features include:

- Case management model—nurse as case manager
- Communication – regular reviews and discussion on advance care plan with patients and family
- Medical back up by palliative medicine specialist

Patients aged 60 or above, with terminal cancer/ other chronic irreversible illnesses, of middle to low income families, staying at home and with expected life span usually not more than 6 months are considered as target beneficiaries of the service. Family will also be included. Target clientele can be extended to service users of day care centres and residential care homes for the elderly under Haven of Hope Christian Service. **Table 4.20** summarized the intervention components of HOH model by service foci.

**Table 4.20** Service components of HOH model

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Escort and transportation<br>· Personal care<br>· Respite services | · Home visits by nurses and symptom management<br>· Telemedicine<br>· Rehabilitation therapies | · Emotion care<br>· Spiritual care by Chaplin<br>· ACP discussion which covers wish and unfinished business | · ACP discussion | · ACP review | · Bereavement support |

### 4.6.2.2 Service users

Between January 2016 and December 31, 2018, Haven of Hope Christian Service (HOH) has admitted a total of 196 cases. Among these cases, 153 (78.1%) completed assessment at intake ($T_0$), and 56 (28.6%) of these cases have completed both intake ($T_0$) and 3-month assessment ($T_2$). Only from 7 cases, no family caregiver could be identified for clinical assessment. Among the remaining 189 cases in which at least one family caregiver could be identified, 102 (54%) took part in the intake assessment ($T_0$), and 41 (21.7%) completed 3-month assessment ($T_1$) as well. In addition, 36 (25.2%) bereaved caregivers completed the bereavement assessment two months after patient's death (143 deaths) ($T_2$). Data from 153 patients and 102 caregivers with intake assessment will be used to understand the profile of service users of HOH. However, only patients and caregivers with both intake ($T_0$) and 3-month assessment ($T_2$ for patients, and T1 form caregivers) will be included in the analysis of changes in outcome indicators.

Among all 196 patients, majority (90.3%) had cancer as major diagnosis, the remaining were renal disease (3.6%), heart failure (2.6%), dementia (1.5%), Parkinson's disease (1%), and chronic lower respiratory diseases (1%) (**Figure 4.22**). Fifty-five percent of the cases were referred by public hospitals, followed by self-approach (24%), and social service units (20.9%) (**Figure 4.23**). By December 31, 2018, 143 (73%) patients have already passed away. The mean service duration of these deceased patients was 3.39 (4.18) (Mean [SD]) months. Patients who were alive (N=53) have stayed in service for 13.38 (11.35) (Mean [SD]) months on average. When all cases considered, the average service duration was 5.56 (7.43) (Mean [SD]) months.

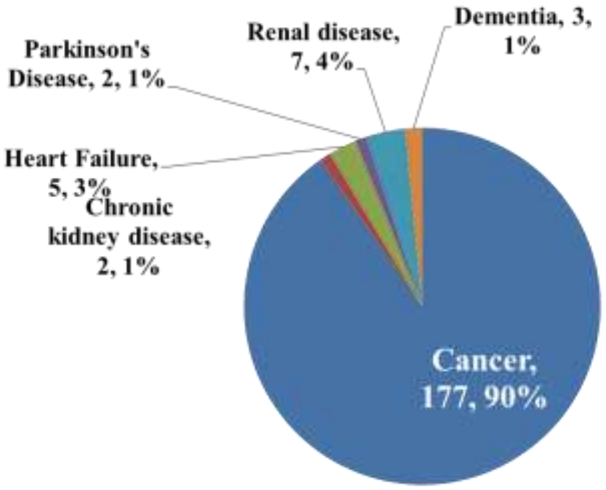


**Figure 4.22** Diagnosis of all admitted patients in HOH programme (N=196)

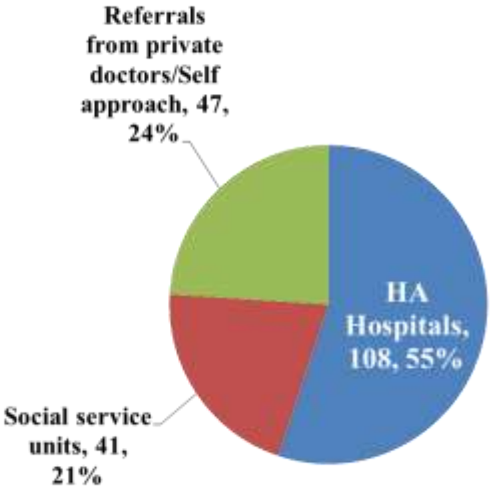


**Figure 4.23** Sources of referral of all admitted patients in HOH programme (N=196)

Demographic data were collected from patients who have completed intake assessment (N=153) (**Table 4.21**). These patients had a mean age of 76.12 (11.012) (Mean [SD]) years old, and the proportions of disease groups resemble the one composing the full same (e.g. 90.2% diagnosed with cancer). Patients were mainly cared by spouse (38.1%), adult children (38.1%), and other relatives (12.7%). Over 95% were residing in the community (3.9% residing in RCHEs), with around 17% were living alone. Among 107 patients who provided information on their financial sources, not many were receiving disability allowance (6.5%) but one-fourth was receiving CSSA (25.2%).

**Table 4.21** Basic demographics of patients (with intake assessment) of HOH model

| | **Freq. (%)** |
|---|---|
| N | 153 |
| **Education** | |
| No schooling/kindergarten | 42 (27.5%) |
| Primary school | 38 (24.8%) |
| Secondary school | 34 (22.2%) |
| Tertiary education | 30 (19.6%) |
| Others | 1 (0.7%) |
| **Marital status** | |
| Married/cohabitating | 86 (56.2%) |
| Widowed | 43 (28.1%) |
| Single | 12 (7.8%) |
| Separated/divorced | 11 (7.2%) |
| **Religion** | |
| No religion | 58 (37.9%) |
| Christian | 42 (27.5%) |
| Chinese Traditional belief | 29 (19%) |
| Buddhist | 12 (7.8%) |
| Catholic | 8 (5.2%) |
| Others | 4 (2.6%) |
| **Relationship with primary caregiver** [a] | |
| Adult child | 70(45.8%) |
| Spouse | 46 (30.1%) |
| Relatives (e.g. siblings, daughter/son-in-law, other relatives) | 17 (11.1%) |
| Domestic helper | 9 (5.9%) |
| No caregivers | 3 (2%) |
| Others (e.g. Friends, RCHE staff, others) | 6 (3.9%) |
| **Living arrangement** | |
| Living Alone | 26 (17%) |
| Other living arrangements in the community | 121 (79%) |
| RCHEs | 6 (3.9%) |
| Average domestic household size (N=142) | 2.75 |
| **Housing of those living in domestic households (N=145)** | |
| Public housing | 53 (35%) |
| Non-public housing | 82 (54%) |
| Others | 10 (6.5%) |
| **Financial Assistance (N=107)** | |
| CSSA Scheme (Yes) | 27 (25.2%) |
| Disability Allowance (Yes) | 7 (6.5%) |

*Notes.* [a] *Paid caregivers were not invited to assessment.*

The mean age of 102 assessed caregivers was 56.54 (16.27) years old, and 51 (28%) were male. Over half of these caregivers were adult children of patients, and actually half of these caregivers were not living with the patients **(Table 4.22)**. However, the mean caregiving hours per week was still considerably high (around 50 hours per week). Over 30% felt that the support from other family members was “less than satisfied”.

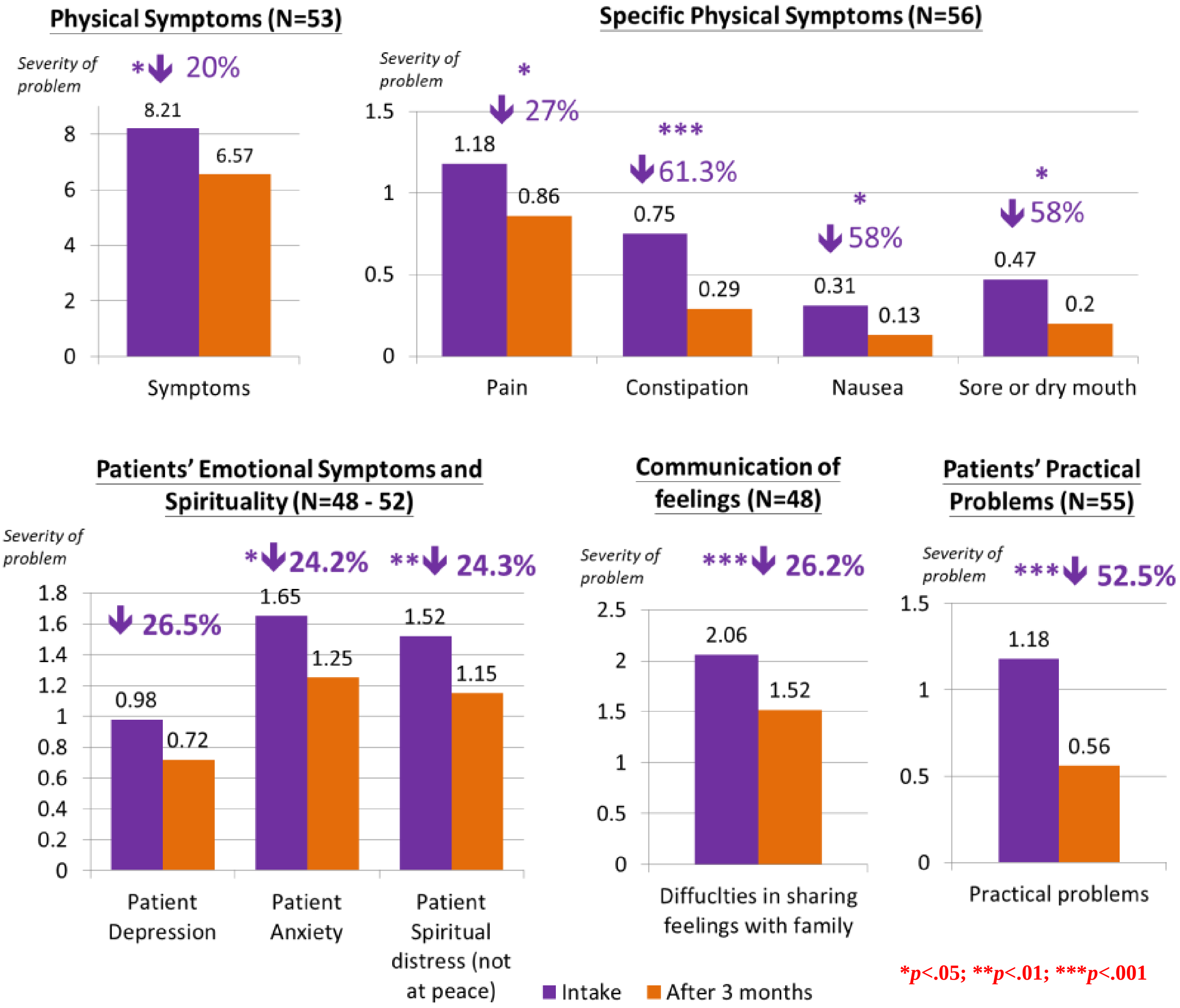
**Table 4.22** Basic demographics of family caregivers (with intake assessment) of HOH model

| | **Freq. (%)** |
|---|---|
| N | 102 |
| **Relationship with patient** | |
| Adult child | 57 (55.9%) |
| Spouse | 28 (27.5%) |
| Relatives (e.g. grandchild, siblings, child-in-law, other relatives) | 17 (16.6%) |
| **Education** | |
| No schooling/kindergarten | 5 (4.9%) |
| Primary school | 8 (7.8%) |
| Secondary school | 28 (27.5%) |
| Tertiary education | 60 (58.8%) |
| **Marital status** | |
| Married/cohabitating | 68 (66.7%) |
| Single | 27 (26.5%) |
| Separated/divorced | 4 (3.9%) |
| Widowed | 3 (2.9%) |
| **Religion** | |
| No religion | 40 (39.2%) |
| Christian | 33 (32.4%) |
| Chinese Traditional belief | 12 (11.8%) |
| Catholic | 8 (7.8%) |
| Buddhist | 5 (4.9%) |
| Others (e.g. Daoism, Muslim) | 2 (2%) |
| **Employment Status** | |
| Full-time employed | 35 (34.3%) |
| Retired/Not working | 22 (21.6%) |
| Home maker | 19 (18.6%) |
| Part-time employed | 14 (13.7%) |
| On leave/unemployed | 9 (8.9%) |
| Others | 3 (2.9%) |
| **Whether the caregiver was diagnosed with any chronic illness(es) (Y)** | 38 (37.3%) |
| **Co-residing with patient (No)** | 52 (51%) |
| **For caregivers who are not residing with patient, number of days visiting patient per week (N=50)** | 4.1 (2.21) |
| **Time needed to take care of patient per week (hours) [baseline] (N=102)** | 49.82 (52.923) |
| **How satisfied you are with the support you receive from your family members in your role as a caregiver? [baseline]** | |
| Dissatisfied – very dissatisfied | 7 (6.9%) |
| Average | 28 (27.5%) |
| Satisfied – very satisfied | 64 (62.7%) |
| **Whether the caregiver has received any financial allowance? (N=73)(Y) [a]** | 16 (21.9%) |
| CSSA | 7 (9.6%) |
| Disability allowance | 2 (2.7%) |
| Old age living allowance | 2 (2.7%) |
| Old age allowance | 5 (6.8%) |
| **Perceived financial strain (N=69) [a]** | |
| Slightly difficult - No difficulties | 51 (73.9%) |
| Moderately difficult | 12 (17.4%) |
| Very difficult - Extremely difficult | 6 (8.7%) |

*Note.* [a] *Not all family caregivers answered the questions relating to finance.*

### 4.6.2.3 Objective outcomes

**Figure 4.24** summarises the 3-month changes in physical symptoms, psychosocial-spiritual distress, as well as practical concerns of 56 patients. Results showed that patients experienced significantly reduced problems in all these realms except depression ($p<.05$ to $p<.001$). For physical symptoms, the overall severity level reduced by 20% ($p<.001$), with four of the ten assessed symptoms showed significant improvements, including pain, constipation, nausea, and sore or dry mouth. Patients reported significant reduction in anxiety ($p<.05$), spiritual distress (not at peace) ($p<.01$), and barriers in sharing feelings with family or friends ($p<.001$). Moreover, practical problems reduced by half after 3 months in service ($p<.001$).



*$p<.05$; **$p<.01$; ***$p<.001$

**Figure 4.24** Changes in objective outcomes of patients in HOH programme after 3 months

In **Figure 4.25**, 50 patients reported the anxiety level of their family members at both baseline and 3rd month in service, whereas 44 caregivers have completed both baseline and 3rd month assessments. Findings showed significantly reduced family anxiety (by 27%) and caregiver's strain (by 13%) at the third month (*p*<.001). There were no significant changes in the body-mind-spiritual wellbeing of caregivers, but a marginally significant improvement in the intimacy between caregivers and patients. Regarding other control variables, no changes in the caregiving hours and satisfaction with support from other family members on caregiving were reported at the third month. After patient's death, 13.9% of the 36 assessed bereaved family members had low risk of complicated grief. This prevalence of high risk group was the same as the reference (13.9%) reported among a Chinese population[47].

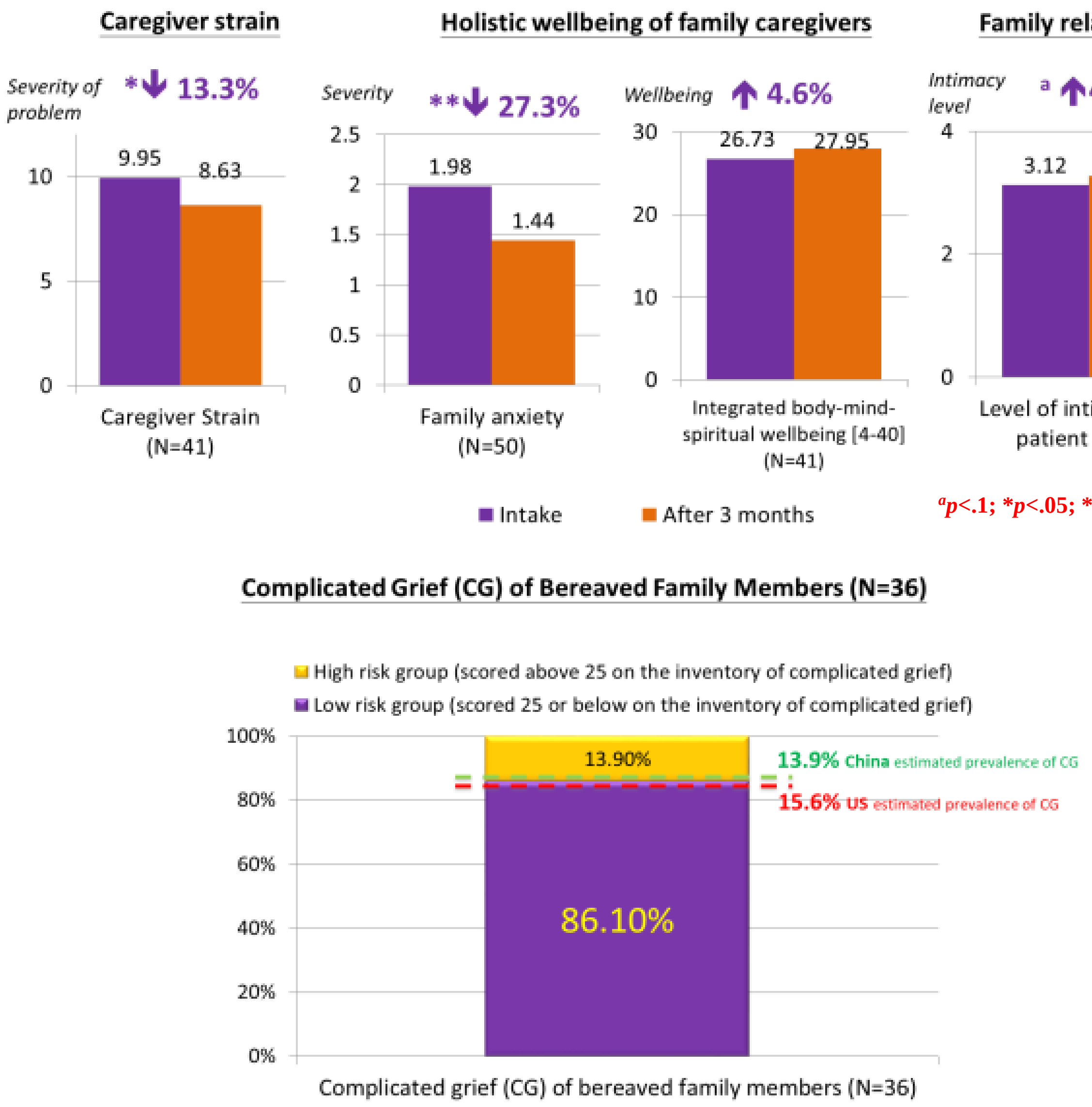


**Figure 4.25** Changes in family caregivers after 3 months in HOH programme and complicated grief in bereaved family members

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[47] Li, Jie & Prigerson, Holly. (2016). Assessment and associated features of prolonged grief disorder among Chinese bereaved individuals. *Comprehensive Psychiatry, 66*, 9-16. 10.1016/j.comppsych.2015.12.001.

### 4.6.2.4 Subjective outcomes

A total of 10 patients completed the satisfaction survey **(Figure 4.26)**. Partly because of physical weakness of many patients in the HOH model, a relatively low response rate among patients was noticed. A cut-off score of 6/7 was adopted as as an indication of high satisfaction. The results revealed that none of the patients gave score below 7 in the overall satisfaction rate to this project, as well as the service in meeting their needs and how the service respected their wishes. Moreover, participants also showed great satisfaction in terms of the volunteer service and social work service (mean ≥8.9). Areas that might have rooms for improvement included alleviation the negative physical symptoms, empowering patients to live a life with their own ability, and providing information that was needed (mean <8.5).

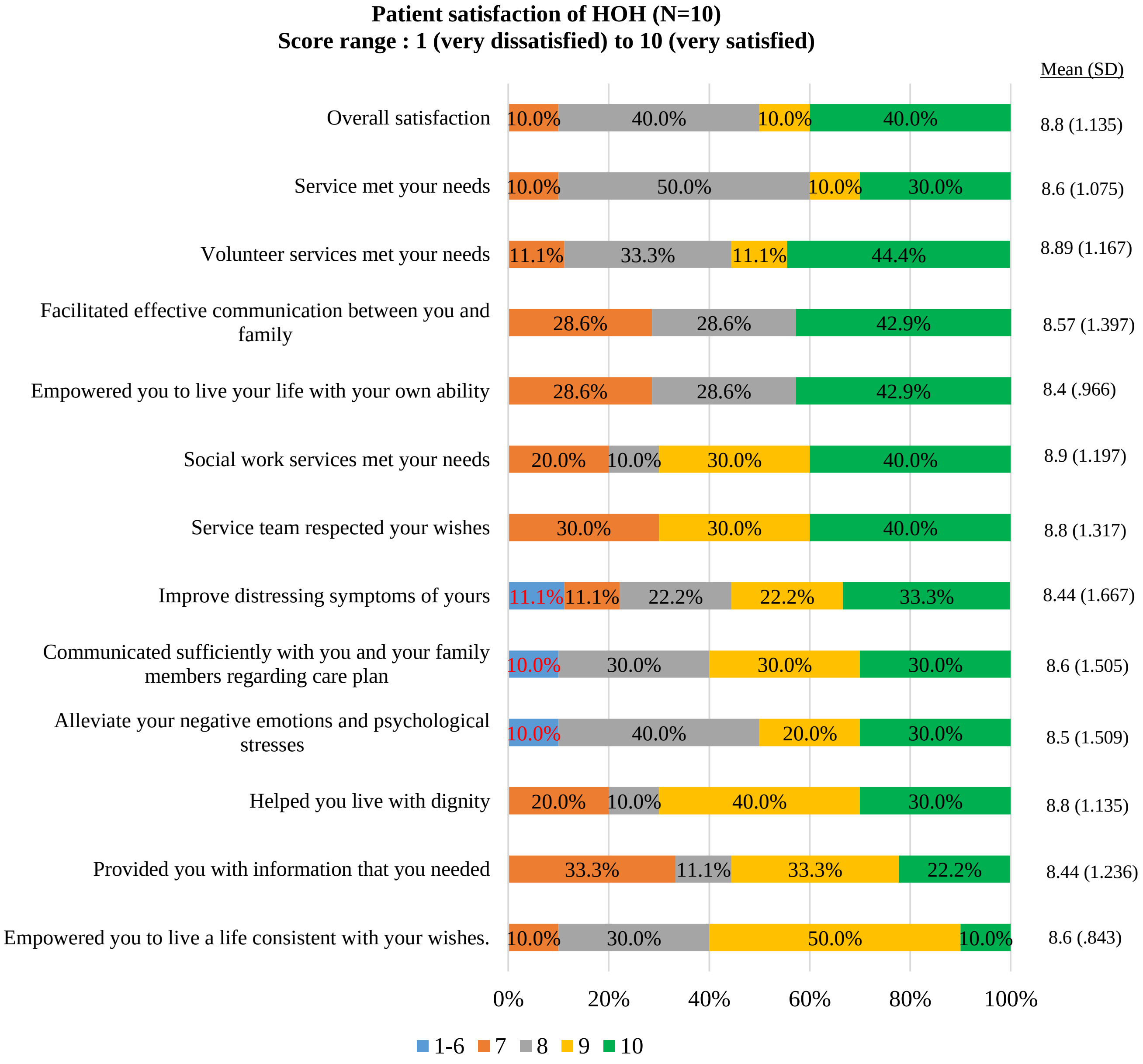

**Figure 4.26** Patient satisfaction survey of HOH

A total of 49 caregivers responded to the satisfaction survey **(Figure 4.27).** A cut-off score of 6/7 was adopted as an indication of high satisfaction. On the overall satisfaction to this project, nearly 90 % of the responses was higher than 6. Caregivers were most satisfied that the service team respected their wishes, and that the service empowered patient to live a life consistent to his/her wish (mean>8.5). The one item which was rated the lowest was that the service met the caregivers' needs. It might imply these caregivers had certain needs or expectations which were not met by the current scope of service components, given that their satisfaction levels on all other service components were higher

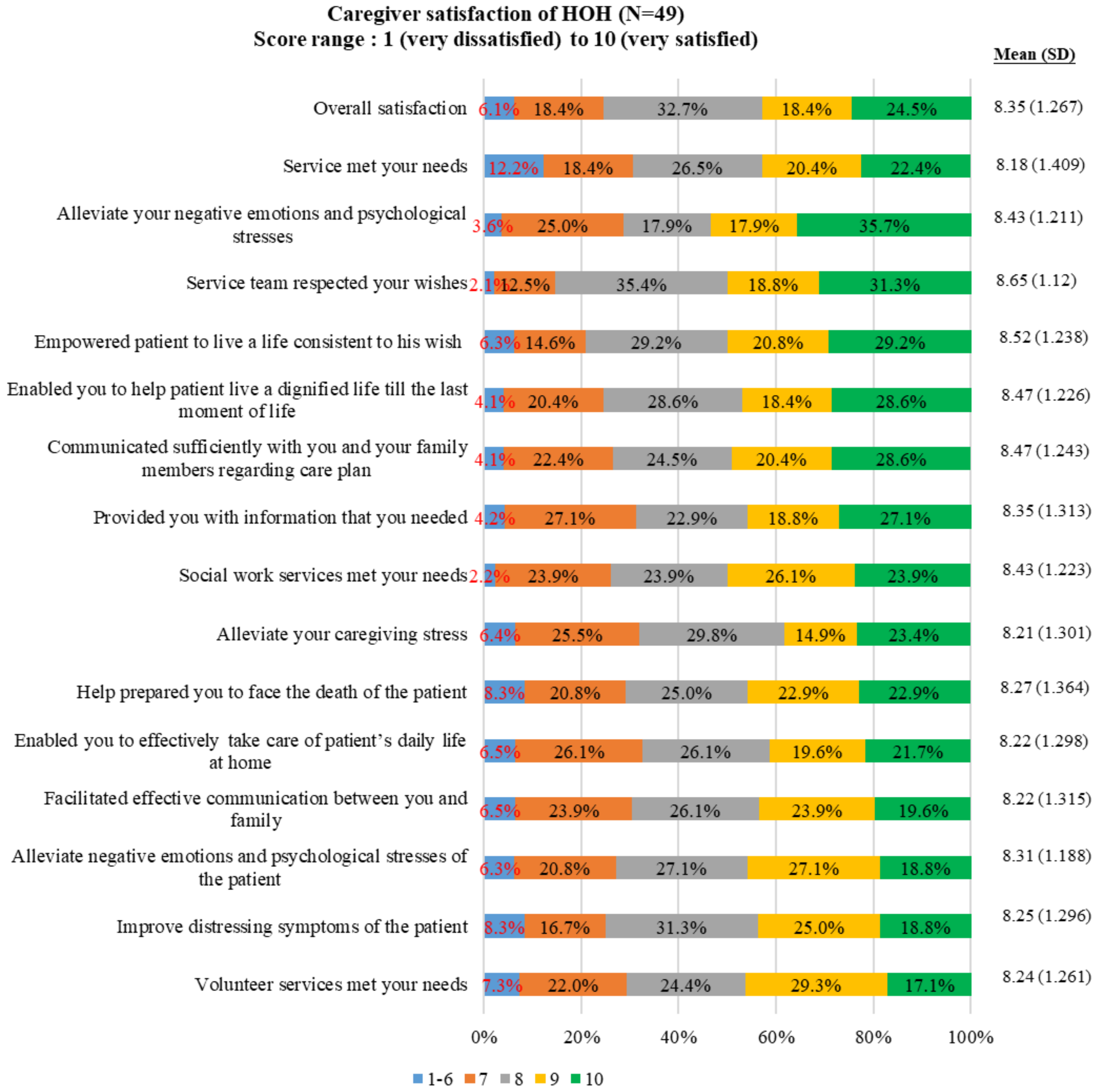

**Figure 4.27** Caregiver satisfaction survey of HOH

### 4.6.2.5 Impacts

Medical service utilisation data was retrievable from 30 deceased patients from the HOH service model (21% of all deceased patients in HOH service). The mean length of stay in hospital (i.e. hospital beddays), A&E attendance, and ICU beddays were calculated based on these 30 patients. **Figure 4.28** shown the comparison between the data of these 30 patients and the CDM. The finding suggested that deceased patients in the HOH service model had 22.2 hospital beddays, 1.54 times of A&E attendance, and 0.36 ICU beddays fewer than end-of-life patients in general. Despite the relatively small sample size, this finding provided initial evidence to support the effectiveness of the HOH model in reducing the unnecessary utilisation of medical services among EoL patients.

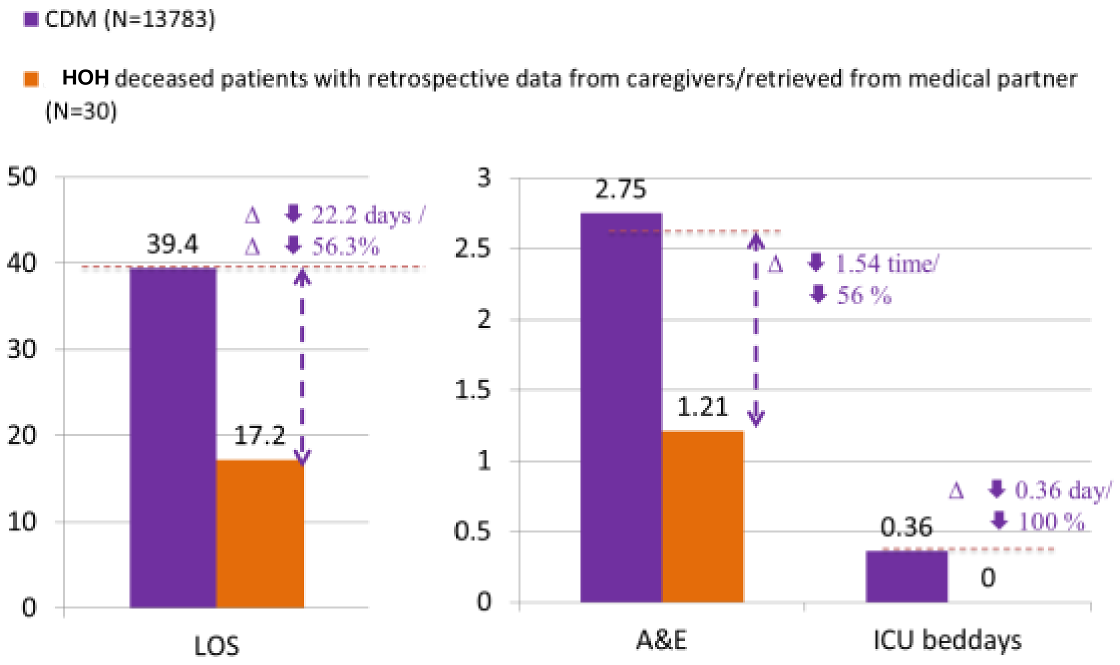

**Figure 4.28** Comparison on medical service utilisation in the last 6 months of life between deceased patients in HOH model and the CDM sample

### 4.6.2.6 Key Performance Indicators Achievement

Key performance indicators (KPIs) had been developed to measure the achievement of targets of each project components. The first column of the **Table 4.23** shows the relevant KPIs for EoLC service models. Relevant outcome/Impact indicators are included in the column "performance of HOH service model" for corresponding KPI. The achievements of the target specified in the KPIs were calculated by dividing the % changes obtained from the evaluation by the target % change specified in the KPIs.

**Table 4.23** Key performance indicators achievement of HOH model

| | Key Performance Indicators | Performance of HOH service model [48] | Achievements [49] |
|---|---|---|---|
| **1** | A 5% increase in quality of life of patients *(reduced physical and emotional symptoms, wishes are respected, sense of security [practical], better family relationship [sharing feelings])* | • 20% reduction in physical symptoms (p.105) | 400% achieved |
| | | • 27% reduction in depression (p.105) | 531% achieved |
| | | • 24% reduction in anxiety (p.105) | 485% achieved |
| | | • 53% reduction in practical problems (p.105) | 1051% achieved |
| | | • 26% reduction in the barriers in communication of feelings (p.105) | 524% achieved |
| | | • 100% agreed that the service team respected your wish (p.107) | 133% achieved |
| | | Average: [50] | 521% achieved |
| **2** | A 5% increase in quality of life of family caregivers *(reduced caregiver burden, better family relationship)* | • 13% reduction in caregiving strain (p.106) | 265% achieved |
| | | • 27% reduction in family anxiety (p.106) | 546% achieved |
| | | • 4.8% increase in intimacy (p.106) | 96.2% achieved |
| | | Average: [50] | 302% achieved |
| **3** | Family members will have reduced regrets in bereavement process | • Prevalence of high risk group the same as the reference data from another Chinese sample (13.9% in HOH model Vs. 13.9% in another Chinese sample) (p.109) | Target not met |
| **4** | Patients and family members have an overall satisfaction towards the EoLC of 75% or above. | • Patients have an overall satisfaction towards the service of 100% (p.107) | 133% achieved |
| | | • Caregivers have an overall satisfaction towards the service of 93.9% (p.108) | 125% achieved |
| **5** | Reduction of 2 days of hospitalisation as well as 5% A&E admission in the last six months for patients | • Deceased patients in the HOH model showed a reduction of 22.2 days of hospitalisation as well as 56% reduction in A&E admission in the last 6 months of life when compared to EoL patients derived from CDM study. (p.109) | Achieved. |

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[48] All % changes were calculated by the formula: (new values – old values)/old values.

[49] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

[50] Assuming all indicators involved share the same weight.

### 4.6.2.7 Analysis

The findings from objective outcomes proved that the HOH model was effective in resolving practical concerns of patients as well as reducing caregiver’s strain, relieving patients’ distressing physical symptoms, reducing patients’ emotional and spiritual distresses including anxiety, not at peace, as well as family members’ anxiety. The results also suggested that the HOH model was effective in facilitating communication and sharing of feelings between patients and family caregivers. Indeed, even though the family intimacy was high in the baseline, a marginally significant improvement was detected in the third month. The consistent positive effects on communication could be attributed to the effectiveness of advance care planning which emphasize family engagement in decision making process with the patients. Compatible bereavement risk with the existing literature was reported by the bereaved family. Subjective outcomes confirmed that the service had helped patients and caregivers to live with dignity and consistent with their wishes. However, while interviewed patients perceived that service met their needs, a lower proportion of caregivers reported the same. This might suggest caregivers experienced certain needs which were yet to be fulfilled by the current scope of support provided in the HOH model. Regarding impacts, based on the data of 30 deceased patients, HOH model was found to have drastically reduced the medical service utilisation in the last 6 months of life of deceased patients. This might be attributable to the strong nursing care and medical advice provided by the HOH team which had enabled patients to manage their symptoms and have more confidence to stay home. Regarding areas for improvement, the findings suggested that there might be rooms for improvement in bereavement care. Probably bereavement care which span across pre-death (anticipatory grief) period to post-death period could be strengthened in the HOH model. Based on the outcomes, it was inferred that the intervention components of HOH service model specific for practical needs, symptom management, psychosocial-spiritual care, family communication, and end-of-life decision making have been particularly effective **(Table 4.24)**. **Table 4.24** summarised the outcomes by service foci, with effect sizes (*ES*) on the changes specified for each outcome indicator.

**Table 4.24** Relatively effective service components in the HOH model (shaded area) and the effect sizes for each outcome indicator which showed significant changes

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Escort and transportation<br>· Personal care<br>· Respite services | · Home visits by nurses and symptom management<br>· Telemedicine<br>· Rehabilitation therapies | · Emotion care<br>· Spiritual care by Chaplin | · ACP discussion<br>· ACP review | | Bereavement support |
| ⬇practical concerns ***(*ES*=-0.65)<br>⬇caregiver strain ** (*ES*=-0.23) | ⬇physical symptoms* (*ES*=-0.36) | ⬇anxiety** (*ES*=-0.44)<br>⬇not at peace** (*ES*=-0.44)<br>⬇in family anxiety** (*ES*=-0.63)<br>Depression and caregiver IBMS no significant changes. | ⬇barriers in sharing feelings*** (*ES*=-0.61)<br>Family intimacy showed marginally significant changes | 90% patients and 95.9% caregivers were satisfied that the care plan was sufficiently discussed | No observed reduction of risk for complicated grief. |

## 4.6.3 The Hong Kong Society for Rehabilitation

### 4.6.3.1 Service components

The organisation mainly serves the patients with late-stage non-cancer chronic diseases. It establishes collaboration with medical and healthcare professionals from the Department of Medicine and Allied Health Departments of Pamela Youde Eastern Nethersole Hospital (PYNEH). Key service features include:

- Emphasize on patients and caregivers' empowerment
- Applies "Transdisciplinary Approach", which social workers, nurse, professional and community volunteers work together to provide comprehensive care
- Build capacity of executive members and volunteers of Patient Self-Help Organisations

Patients with specific late-stage chronic diseases including chronic obstructive pulmonary disease (COPD), end-stage renal failure, Parkinson's disease and motor neuron disease, and heart failure, residing in the community and their family members. Service priority will be given to the elderly who are singleton, or living with elderly spouse, or having limited social support, though the service is not limited to the most deprived group. **Table 4.25** summarized the intervention components of HKSR model by service foci.

**Table 4.25** Service components of HKSR model

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Equipment consultation<br>· Service referral | · Symptom self-management education<br>· Health behaviour action plan<br>· Caregiving skills training | · Joyful activities<br>· Legacy<br>· Wish fulfilment | · Positive death education | · Care preference discussion | · Bereavement support |

### 4.6.3.2 Service users

Between January 2016 and December 31, 2018, The Hong Kong Society for Rehabilitation (HKSR) has admitted a total of 179 cases. Among these cases, 124 (69.3%) completed assessment at intake ($T_0$), and 74 (41.3%) of these cases have completed both intake ($T_0$) and 3-month assessment ($T_2$). From 6 cases, no family caregiver could be identified for clinical assessment. Among the remaining 173 cases in which at least one family caregiver could be identified, 93 (53.8%) took part in the intake assessment ($T_0$), and 36 (20.8%) completed 3-month assessment ($T_1$) as well. In addition, 17 (21.8%) bereaved caregivers completed the bereavement assessment two months after patient's death (78 deceased patients with identified family caregiver) ($T_2$). Data from the 124 patients and 93 caregivers with intake assessment will be used to understand the profile of service users of HKSR. However, only patients and caregivers with both intake ($T_0$) and 3-month assessment ($T_2$ for patients, and $T_1$ for caregivers) will be included in the analysis of changes in outcome indicators.

Except two cancer patients, HKSR's sample composed of varieties of non-cancer patients. Among all 179 patients, 46% had COPD as major diagnosis, followed by renal disease (29%), Parkinson's disease (10.6%), heart failure (6.7%), motor neuron disease (5%), stroke (1.1%), and dementia (0.6%) (**Figure 4.29**). Three-fourths (76%) of the cases were referred by public hospitals, followed by social service units (23%), and self-approach (1%) (**Figure 4.30**). By December 31, 2018, 79 (44.1%) patients have already passed away. The mean service duration of these deceased patients was 5.67 (5.995) (Mean [SD]) months. Patients who were alive (N=100) have stayed in service for 17.11 (8.347) (Mean [SD]) months on average. When all cases considered, the average service duration was 11.5 (9.258) months (Mean [SD]).

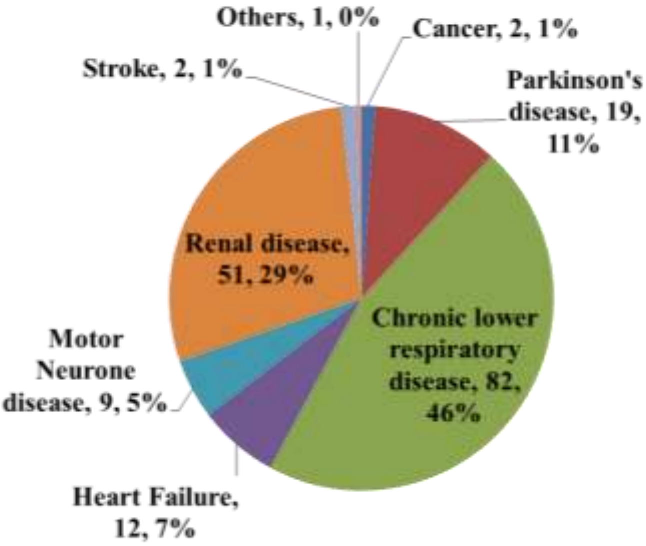

**Figure 4.29** Diagnosis of all admitted patients in HKSR programme (N=179)

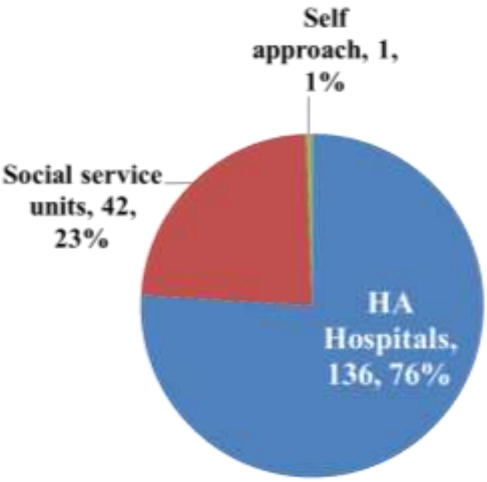

**Figure 4.30** Sources of referral of all admitted patients in HKSR programme (N=179)

Demographic data were collected from patients who have completed intake assessment (N=124) (**Table 4.26**). These patients had a mean age of 75.16 (10.598) (Mean [SD]) years old, more male (67.7% vs. 32.3% of female), with COPD patients being the largest group (48%), followed by renal disease (21%), Parkinson's disease (12.9%) and other non-cancer diseases. The distribution was similar to the whole sample of HKSR. Half of the patients were cared by spouse (52.4%), and around one-third by adult children (32.3%), and other relatives (8.9%). Over 95% or the patients were residing in the community, while the remaining 5 were living in RCHEs. Fifty-five patients answered questions relating to their finance. Among them, only around one-tenth were receiving CSSA (12.7%) and/or disability allowance (10.9%).

**Table 4.26** Basic demographics of patients (with intake assessment) of HKSR model

| | **Freq. (%)** |
|---|---|
| N | 124 |
| **Education** | |
| No schooling/kindergarten | 11 (8.9%) |
| Primary school | 66 (53.2%) |
| Secondary school | 37 (29.8%) |
| Tertiary education | 10 (8.1%) |
| **Marital status** | |
| Married/cohabitating | 86 (69.4%) |
| Widowed | 23 (18.5%) |
| Single | 6 (4.8%) |
| Separated/divorced | 7 (5.6%) |
| **Religion** | |
| Christian | 13 (10.5%) |
| Catholic | 6 (4.8%) |
| Buddhist | 6 (4.8%) |
| Chinese Traditional belief | 33 (26.6%) |
| No religion | 65 (52.4%) |
| Others (e.g. Muslim) | 1 (0.8) |
| **Relationship with primary caregiver** [a] | |
| Spouse | 65 (52.4%) |
| Adult child | 40 (32.3%) |
| Relatives (e.g. siblings, daughter/son-in-law, other relatives) | 12 (10.97%) |
| Domestic helper | 5 (4%) |
| Friends | 1 (0.8%) |
| No caregivers | 1 (0.8%) |
| **Living arrangement** | |
| Living Alone | 13 (10.5%) |
| Other living arrangements in the community | 106 (85.5%) |
| RCHEs | 5 (4%) |
| Average domestic household size (N=119) | 3.06 |
| **Housing of those living in domestic households (N=119)** | |
| Public housing | 55 (46.2%) |
| Non-public housing | 63 (52.9%) |
| Others | 1 (0.8%) |
| **Financial Assistance (N=55)** | |
| CSSA Scheme (Yes) | 7 ( 12.7%) |
| Disability Allowance (Yes) | 6 (10.9%) |

*Notes.* [a] *Paid caregivers were not invited to assessment.*

The mean age of 93 assessed caregivers was 59.86 (16.812) (Mean [SD]) years old, and 15 (16.1%) were male. Over half of these caregivers were spouse of patients, followed by adult children (32.3%) **(Table 4.27)**. Three-fourths were living with the patients, and around two-thirds were not working. The mean caregiving hours per week was as high as 56 hours. Nevertheless, three-fourths were satisfied with the support from family members on caregiving.

**Table 4.27** Basic demographics of family caregivers (with intake assessment) of HKSR model

| | **Freq. (%)** |
|---|---|
| N | 93 |
| **Relationship with patient** | |
| Spouse | 53 (57%) |
| Adult child | 30 (32.3%) |
| Relatives (e.g. grandchild, child-in-law, siblings) | 14 (15.1%) |
| **Education** | |
| No schooling/kindergarten | 8 (8.6%) |
| Primary school | 26 (28%) |
| Secondary school | 45 (48.4%) |
| Tertiary education | 14 (15.1%) |
| **Marital status** | |
| Married/cohabitating | 79 (84.9%) |
| Widowed | 2 (2.2%) |
| Single | 11 (11.8%) |
| Separated/divorced | 1 (1.1%) |
| **Religion** | |
| Christian | 12 (12.9%) |
| Catholic | 6 (6.5%) |
| Buddhist | 10 (10.8%) |
| Others (e.g. Daoism, Muslim) | 2 (2.2%) |
| Chinese Traditional belief | 26 (28%) |
| No religion | 37 (39.8%) |
| **Employment Status** | |
| Full-time employed | 26 (28%) |
| Part-time employed | 7 (7.5%) |
| Home maker | 22 (23.7%) |
| On leave/unemployed | 4 (4.3%) |
| Retired/Not working | 34 (36.5%) |
| **Whether the caregiver was diagnosed with any chronic illness(es) (Y)** | 56 (60.2%) |
| **Co-residing with patient (No)** | 25 (26.9%) |
| **For caregivers who are not residing with patient, number of days visiting patient per week (N=24)** | 3.75 (2.172) |
| **Time needed to take care of patient per week (hours) [baseline]** | 56.41 (52.547) |
| **How satisfied you are with the support you receive from your family members in your role as a caregiver? [baseline]** | |
| Dissatisfied – very dissatisfied | 5 (5.4%) |
| Average | 17 (18.3%) |
| Satisfied – very satisfied | 69 (74.2%) |
| **Whether the caregiver has received any financial allowance? (N=49)(Y)** [a] | 27 (55.1%) |
| CSSA | 3 (6.1%) |
| Disability allowance | 4 (8.2%) |
| Old age living allowance | 8 (16.3%) |
| Old age allowance | 15 (30.6%) |
| **Perceived financial strain (N=49)** [a] | |
| Slightly difficult - No difficulties | 40 (81.6%) |
| Moderately difficult | 4 (8.2%) |
| Very difficult - Extremely difficult | 5 (10.2%) |

*Note.* [a] *Not all family caregivers answered the questions relating to finance.*

### 4.6.3.3 Objective outcomes

**Figure 4.31** summarises the 3-month changes in physical symptoms, psychosocial-spiritual distress, as well as practical concerns of 74 patients. Results showed that patients experienced significantly reduced problems in all these realms except barriers in sharing feelings (*p*<.05 to *p*<.001). For physical symptoms, the overall severity level reduced by 23% (*p*<.01), with three out of ten assessed symptoms showed significant improvements, including pain, weakness/fatigue, and nausea. Reduction in shortness of breath was marginally significant. Patients reported significant reduction in depression (by 72%) and anxiety (by 55.3%) (*p*<.001), spiritual distress (by 68.3%) (not at peace) (*p*<.001), and barriers in sharing feelings with family or friends (by 31.2%) (*p*<.001). Moreover, practical problems reduced by over 60% after 3 months in service (*p*<.001).

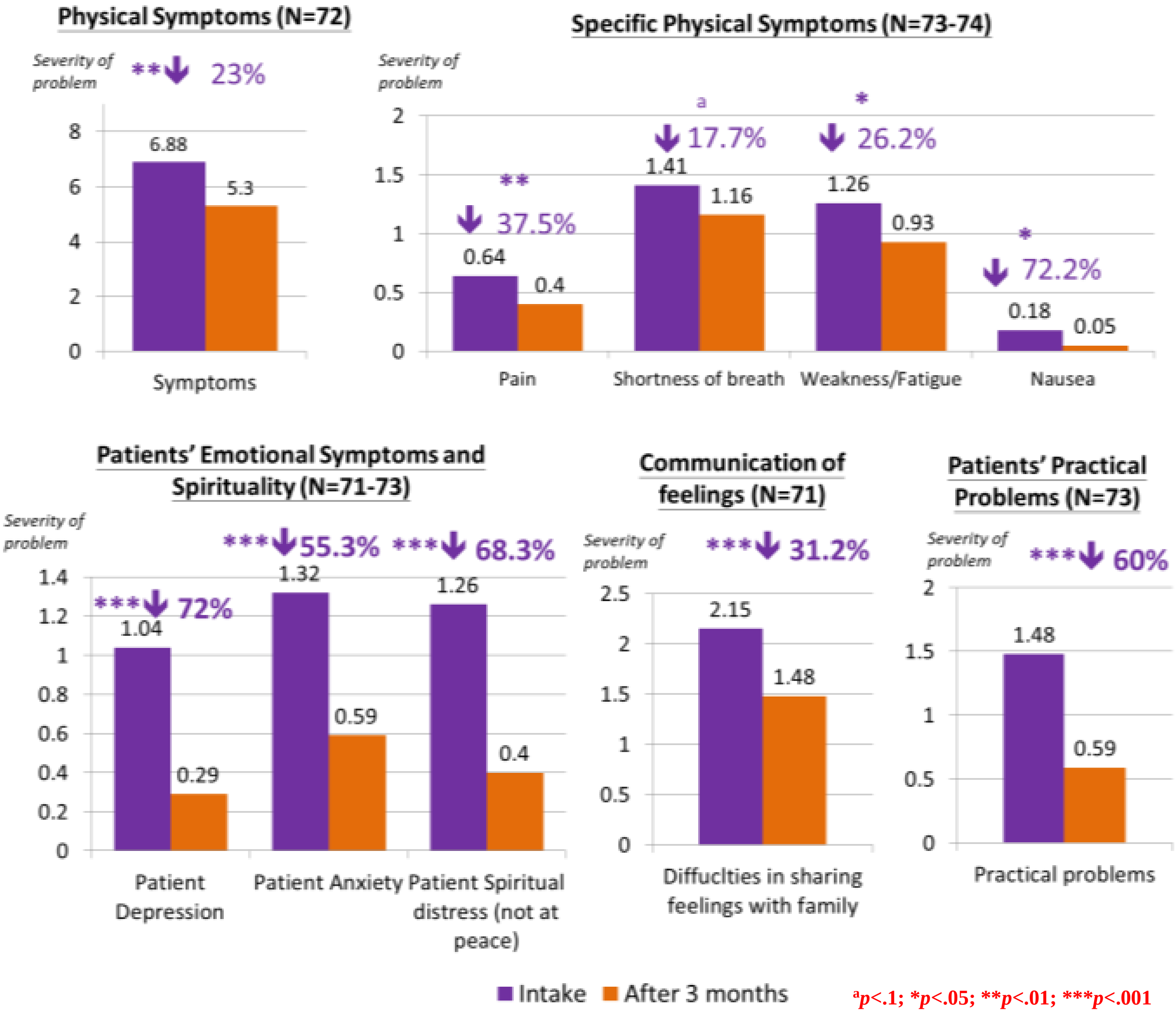

**Figure 4.31** Changes in objective outcomes of patients in HKSR programme after 3 months

In **Figure 4.32**, 72 patients reported the anxiety level of their family members at both baseline and 3rd month in service, whereas 44 caregivers have completed both baseline and 3rd month assessments. Findings showed significantly reduced family anxiety (*p*<.001) and improved body-mind-spiritual wellbeing of caregivers (*p*<.05) at the third month. However, there were no significant changes in the caregiver strain and intimacy with patient. Regarding other control variables, no changes in the caregiving hours and satisfaction with support from other family members on caregiving were reported at the third month. After patient's death, 17 bereaved family members were assessed their risk for complicated grief. All assessed caregivers were identified as low risk. This represented an absolute reduction of 13.9% of high risk population when compared to the reference (13.9%) reported among a Chinese population[51].

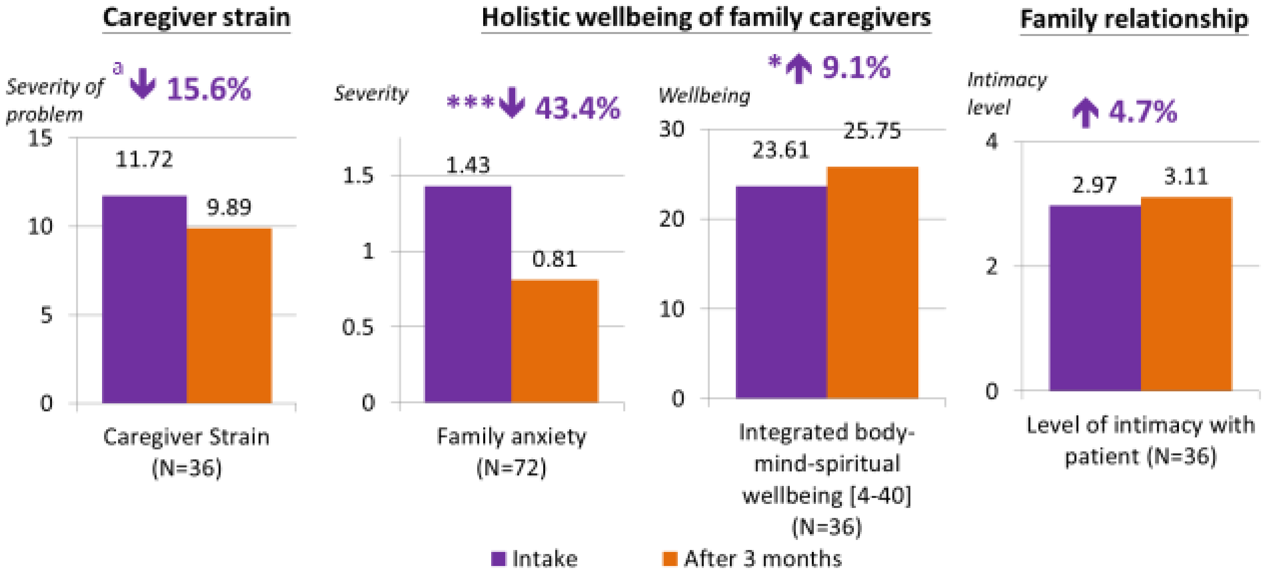

**Figure 4.32** Changes in family caregivers after 3 months in HKSR programme and complicated grief in bereaved family members

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[51] Li, Jie & Prigerson, Holly. (2016). Assessment and associated features of prolonged grief disorder among Chinese bereaved individuals. *Comprehensive Psychiatry, 66*, 9-16. 10.1016/j.comppsych.2015.12.001.

### 4.6.3.4 Subjective outcomes

A total of 34 participants completed the survey. A cut-off score of 6/7 was adopted as an indication of high satisfaction. The result of the satisfaction survey showed that more than 80 % the patients gave score over 7 in the overall satisfaction of this project **(Figure 4.33)**. The most satisfying areas regarded by the patients included the volunteer services, social work services, and the facilitation of communication between patient and family (mean≥9). Indeed, the mean scores of all items were above 8.5 which suggested that patients were largely satisfied with all aspects of the service.

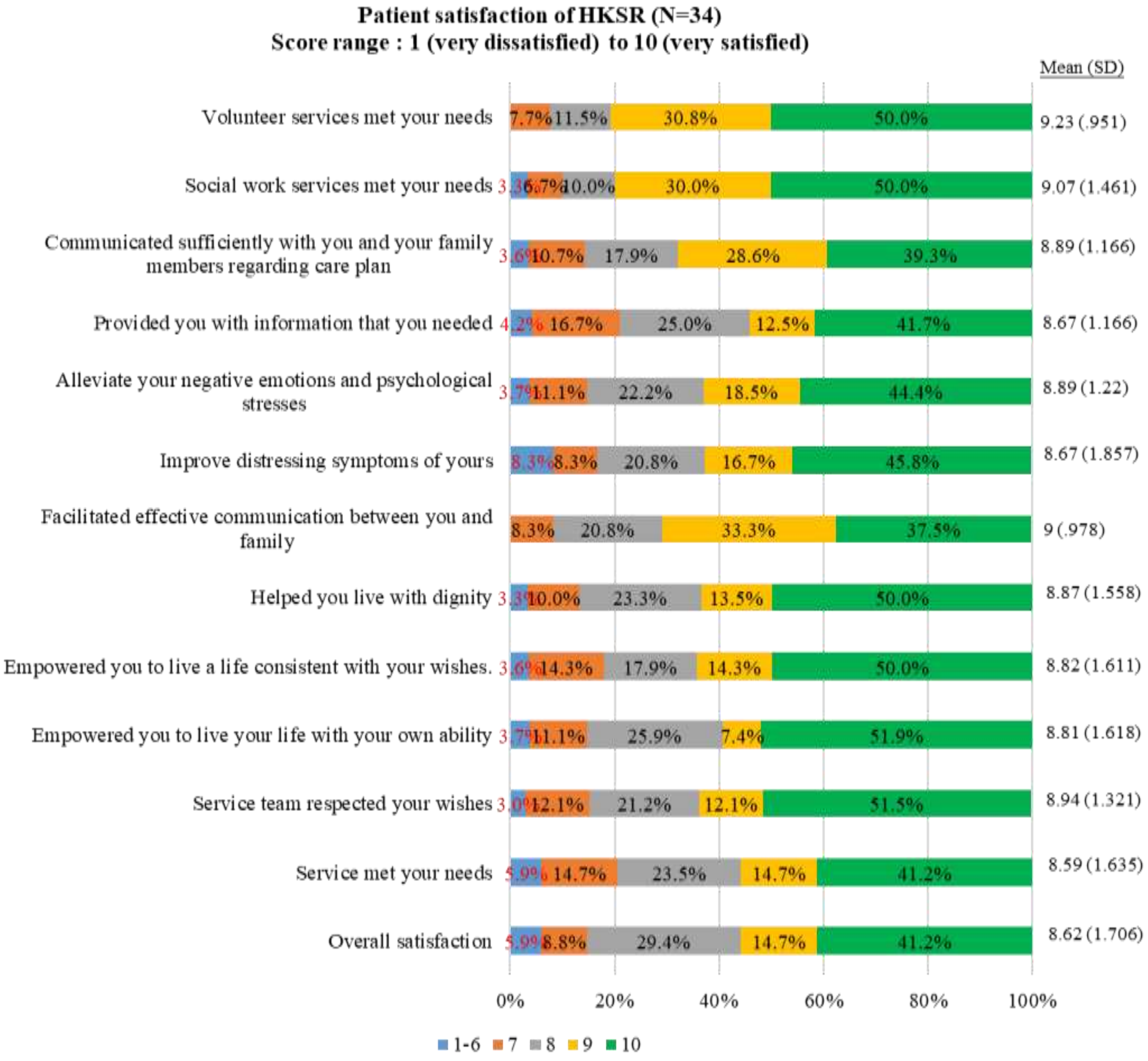

**Figure 4.33** Patient satisfaction survey of HKSR

A total of 13 caregivers completed the survey. A cut-off score of 6/7 was adopted as an indication of high satisfaction. Among the surveyed caregivers, nearly 90% of them gave score higher than 7 in the overall satisfaction of this project **(Figure 4.34)**. Caregivers were particularly satisfied with the volunteer services, facilitation of communication between them and the patients, and that the service enabled them to help patient live a dignified life till the last moment of life (mean≥9.2). Although caregivers were least satisfied with symptom relief, the mean score was still above 8.5 for the item.

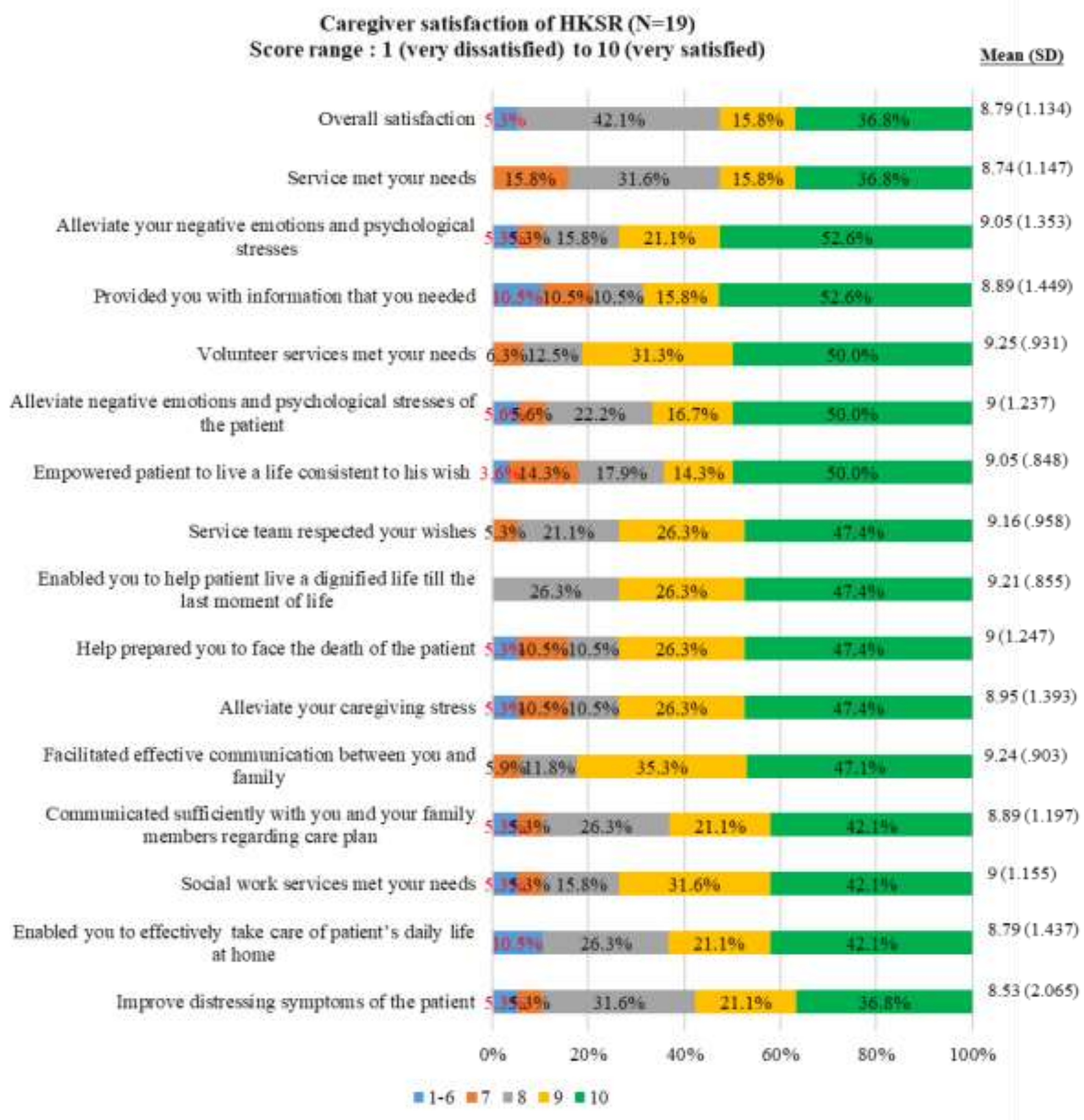

**Figure 4.34** Caregiver satisfaction survey of HKSR

### 4.6.3.5 Impacts

Medical service utilisation data was retrievable from 17 deceased patients from the HKSR model (21% of all deceased patients in HKSR service). The mean length of stay in hospital (i.e. hospital beddays), A&E attendance, and ICU beddays of these 17 cases were calculated. **Figure 4.35** shows the comparison between the data of these patients and the CDM. The finding suggested that in the last 6 months of life, deceased patients in the 17 deceased patients in the HKSR service model had 8.1 hospital beddays in acute or convalesce ward less than EoL patients in general, but 0.07 ICU beddays and 1.23 times of A&E attendance more than end-of-life patients in general. When the LOS was calculated regardless of type of wards, these 17 patients still enjoyed 6.32 more days in the community during the last 6 months when compared to EoL patients in general. Upon further examination, it was found that 12 of these deceased patients have not been admitted to ICU, but the remaining 5 patients have been admitted to ICU for treatments on reversible clinical conditions, and the admissions were not in the final month of life. However, given the small sample size, the generalization of the current findings should be handled with caution.

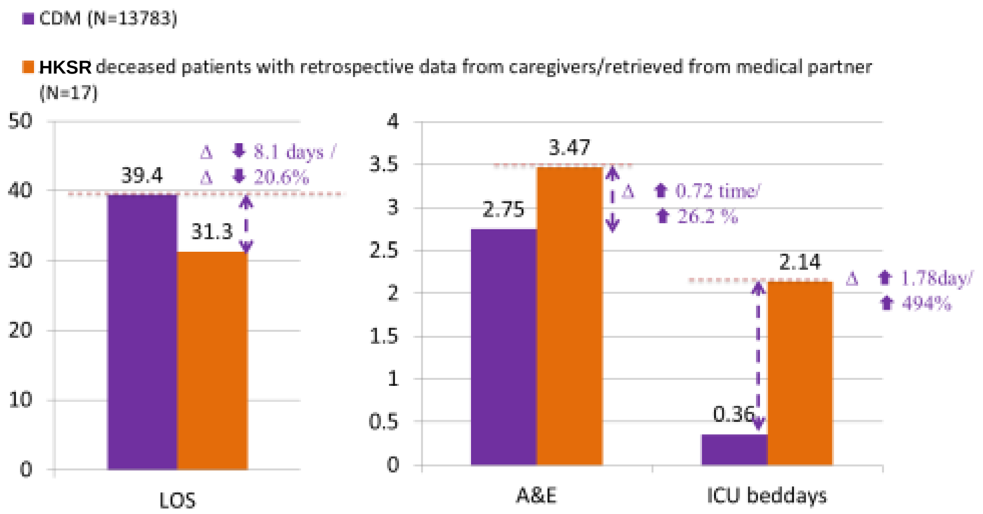

**Figure 4.35** Comparison on medical service utilisation in the last 6 months of life between deceased patients in HKSR model and the CDM sample

### 4.6.3.6 Key Performance Indicators Achievement

Key performance indicators (KPIs) had been developed to measure the achievement of targets of each project components. The first column of the **Table 4.28** shows the relevant KPIs for EoLC service models. Relevant outcome/Impact indicators are included in the column “performance of HKSR service model” for corresponding KPI. The achievements of the target specified in the KPIs were calculated by dividing the % changes obtained from the evaluation by the target % change specified in the KPIs.

**Table 4.28** Key performance indicators achievement of HKSR model

| | **Key Performance Indicators** | **Performance of HKSR service model** [52] | **Achievements**[53] |
|---|---|---|---|
| **1** | A 5% increase in quality of life of patients *(reduced physical and emotional symptoms, wishes are respected, sense of security [practical], better family relationship [sharing feelings])* | • 23% reduction in physical symptoms (p.116) | 473% achieved |
| | | • 72% reduction in depression (p.116) | 1447% achieved |
| | | • 55% reduction in anxiety (p.116) | 1106% achieved |
| | | • 60% reduction in practical problems (p.116) | 1204% achieved |
| | | • 31% reduction in the barriers in communication of feelings (p.116) | 627% achieved |
| | | • 97% agreed that the service team respected your wish (p.117) | 129% achieved |
| | | Average: [54] | 831% achieved |
| **2** | A 5% increase in quality of life of family caregivers *(reduced caregiver burden, better family relationship)* | • 15.6% reduction in caregiving strain (p.117) | 313% achieved |
| | | • 43.4% reduction in family anxiety (p.117) | 874% achieved |
| | | • 4.7% increase in intimacy (p.117) | 93.5% achieved |
| | | Average: [54] | 427% achieved |
| **3** | Family members will have reduced regrets in bereavement process | • 100% of reduced risk for complicated grief when compared to the reference data from another Chinese sample (0% in HKSR model Vs. 13.9% in another Chinese sample) (p.117) | Target achieved |
| **4** | Patients and family members have an overall satisfaction towards the EoLC of 75% or above. | • Patients have an overall satisfaction towards the service of 94.1% (p.118) | 126% achieved |
| | | • Caregivers have an overall satisfaction towards the service of 94.7% (p.119) | 126% achieved |
| **5** | Reduction of 2 days of hospitalisation as well as 5% A&E admission in the last six months for patients | • Patients in HKSR service model showed a reduction of 6.23 days of hospitalisation but 26.2% increase in A&E admission in the last 6 months of life when compared to EoL patients derived from CDM study. (p.120) | Partially achieved. |

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[52] All % changes were calculated by the formula: (new values – old values)/old values.

[53] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

[54] Assuming all indicators involved share the same weight.

#### 4.6.3.7 Analysis

The HKSR model is effective in helping non-cancer end-of-life patients and their family members with relieving physical symptoms, improving emotion reactions of patients and family members, promoting the sharing of feelings, reducing practical needs, promoting holistic wellbeing of caregivers, and reducing risk of complicated grief. There was desirable direction of changes in intimacy and caregiver strains, but the changes not yet reach statistical significance. Subjective outcomes suggested that patients and family caregivers both highly appreciated the help on facilitating family communication. Regarding impacts, the findings suggested that the 17 HKSR deceased patients were able to stay in the community for 6.32 days during the last 6 months of life when compared to EoL patients in general. However, the findings also suggested that these 17 patients had longer stay in ICU compared to EoL patients in general largely because of treating reversible clinical conditions. However, given the small sample size of retrievable data on medical service utilisation among HKSR patient, generalisation of this finding requires caution.

It should be noted that HKSR has been collaborating with non-palliative care units in the hospital. The prominent reduction showed in patients’ physical symptoms provided strong evidence to support the effectiveness of the symptom self-management strategies of HKSR model. Similarly, the joyful activities, legacy and wish fulfillment activities had showed their efficacy to improve the psychosocial-spiritual wellbeing of both patients and caregivers. However, it was found that although caregivers reported improved holistic wellbeing, caregivers strain and family intimacy didn’t show significant reduction as expected. One possible explanation was that the HKSR model might have put more focus on caregiving skill training, and this in turn promoted the subjective well-being of caregivers and subsequently better adaptation in bereavement stage, but had comparatively less impact on improving family intimacy. Moreover, since the caregivers in HKSR model were older, over 60% were also suffering from chronic disease(s), and they had looked after the patients with chronic diseases for a long period of time, the chronic strain coupled with old age were less likely to be relieved drastically, particularly in face of deteriorating health of patients and long hours of caregiving. The maintenance of low level of strain could also be considered a good sign in such situation.

Based on the outcomes, it was suggested that the intervention components of HKSR service model have been effective for all service foci **(Table 4.29)**. **Table 4.29** summarised the outcomes by service foci, with effect sizes (*ES*) on the changes specified for each outcome indicator.

**Table 4.29** Relatively effective service components in the HKSR model (shaded area) and the effect sizes for each outcome indicator which showed significant changes

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Equipment consultation<br>· Service referral | · Symptom self-management education<br>· Health behaviour action plan<br>· Caregiving skills training | · Joyful activities<br>· Legacy<br>· Wish fulfilment | · Positive death education | · Care preference discussion | · Bereavement support<br>· Positive death education |
| ⬇practical concerns ***(*ES*=-0.99)<br>No significant changes in caregiver strain | ⬇physical symptoms** (*ES*=-0.40) | ⬇depression***(*ES*=-1.05)<br>⬇anxiety*** (*ES*=-0.95)<br>⬇not at peace*** (*ES*=-1.09)<br>⬇family anxiety*** (*ES*=-0.75)<br>⬆Caregiver IBMS * (*ES*=0.28) | ⬇barriers in sharing feelings*** (*ES*=-0.60)<br>No significant changes in family intimacy | 96.4% patients and 94.6% caregivers satisfied that care plan was sufficiently discussed | 100%reduced risk for complicated grief |

## **4.6.4** S K H Holy Carpenter Church District Elderly Community Centre

### 4.6.4.1 Service components

The HCCDECC model aims to treat EoL patients with dignity and respect, without pain, in familiar surrounds and in the company of his/her loved ones and family members. The model collaborated with the Tuen Mun Hospital Medical Palliative Medicine unit to provide holistic care to both cancer and non-cancer EoL patients and their families. Key service features include:

- Train up community volunteers to enhance social support to community-dwelling EoL patients and their families
- Help patients fulfil his/her final wishes and enhance family communication and relationship through family reunion activities

End of life patients and family members from New Territories West cluster of the Hospital Authority. 180 patients and 180 family members within 3 years. Priority will be given to those patients who are deprived or lack of social support. **Table 4.30** summarised the intervention components of HCCDECC model by service foci.

**Table 4.30** Service components of HCCDECC model

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Equipment Loan<br>· Escort<br>· Personal Care referral | · Health consultation over phone<br>· Alternative therapies | · Legacy<br>· Wish fulfilment<br>· Life review assisted by volunteers | · Volunteer social visits<br>· Family reconciliation | · Funeral planning<br>· Communication on care preference | · Bereavement support<br>· Funeral support |

### 4.6.4.2 Service users

Between January 2016 and December 31, 2018, the S K H Holy Carpenter Church District Elderly Community Care (HCCDECC) has admitted a total of 197 cases. Among these cases, 148 (75.1%) completed assessment at intake ($T_0$), and 86 (43.7%) of these cases have completed both intake ($T_0$) and 3-month assessment ($T_2$). A family caregiver was identified from 145 cases. Among these family caregivers, 81 (55.9%) took part in the intake assessment ($T_0$), and 43 (29.7%) completed 3-month assessment ($T_1$) as well. In addition, 42 (40.8%) bereaved caregivers completed the bereavement assessment two months after patient's death (There are 103 deceased patients with identified bereaved family member) ($T_2$). The largest available sample size will be adopted to understand the profile of service users of HCCDECC, but only patients with both intake ($T_0$) and 3-month assessment ($T_2$), and caregivers with both intake ($T_0$) and 3-month assessment ($T_1$) will be included in the analysis of changes in outcome indicators.

The HCCDECC served both patients with cancer and those with non-cancer diagnosis. The distribution of diagnosis types was quite diversified. The largest group was renal disease (39%), followed by cancer (23%), then motor neurone disease (14%) and COPD (8%). Patients with other non-cancer organ failure diseases including stroke, dementia, parkinson's disease, and heart failure constituted around 15% of the sample (**Figure 4.36**). Virtually all cases were referred by public hospitals (98%) because the HCCDECC team has been collaborating with TMH closely (**Figure 4.37**). By December 31, 2018, 135 (68.5%) patients have already passed away. The mean service duration of these deceased patients was 6.34 (5.403) (Mean[SD]) months. Patients who were alive (N=62) have stayed in service for 14.80 (9.199) (Mean[SD]) months on average. When all cases considered, the average service duration was 9 (7.863) (Mean[SD]) months.

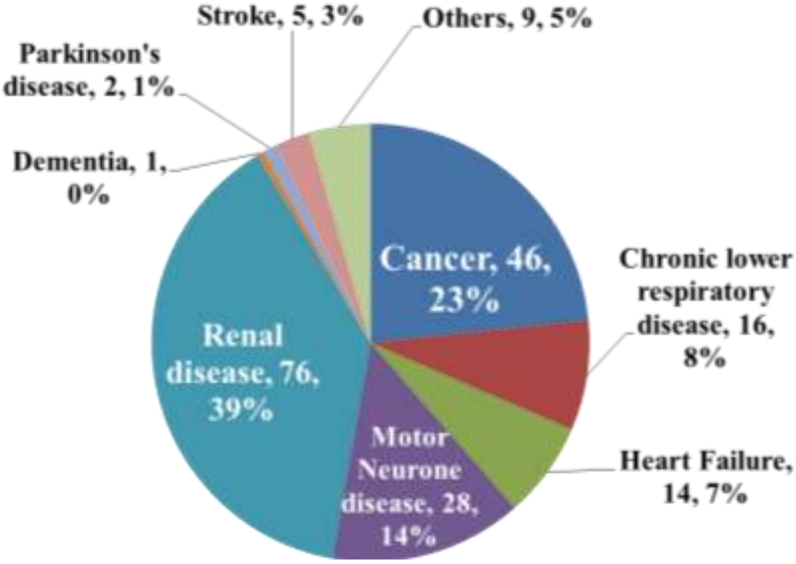


**Figure 4.36** Diagnosis of all admitted patients in HCCDECC programme(N=197)

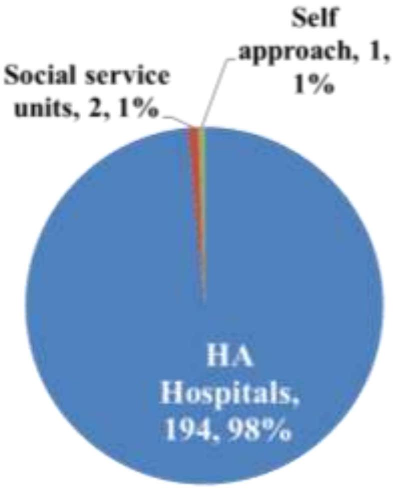


**Figure 4.37** Sources of referral of all admitted patients in HCCDECC programme (N=197)

Demographic data were collected from 148 patients. These patients had a mean age of 73.6 (15.268) years old, and around 40% were renal diseases patients, followed by cancer (22.3%) and motor neuron disease (16.2%). Patients were cared by spouse (32.4%), adult children (21.6%), and domestic helpers (11.5%) (**Table 4.31**). Notably, a considerable of them (15.5%) had no caregivers, or they were residing in a RCHE (8.1%). Slightly below one-fifth of these patients were living alone in the community. Among 138 patients who provided financial information, 24.6% were receiving CSSA and 14.5% were living on disability allowance. Overall, these patients were characterised with weaker familial support and financial disadvantages.

**Table 4.31** Basic demographics of patients (with intake assessment) of HCCDECC model

| | **Freq. (%)** |
|---|---|
| N | 148 |
| **Education** | |
| No schooling/kindergarten | 41 (27.7%) |
| Primary school | 55 (37.2%) |
| Secondary school | 38 (25.7%) |
| Tertiary education | 7 (4.7%) |
| Others | 2 (1.4%) |
| **Marital status** | |
| Single | 14 (9.5%) |
| Married/cohabitating | 75 (50.7%) |
| Separated/divorced | 13 (8.8%) |
| Widowed | 41 (27.7%) |
| Others | 1 (0.7%) |
| **Religion** | |
| Christian | 24 (16.2%) |
| Catholic | 6 (4.1%) |
| Buddhist | 10 (6.8%) |
| Chinese Traditional belief | 23 (15.5%) |
| No religion | 76 (51.4%) |
| Others (e.g. Daoism, others) | 6 (4.1%) |
| **Relationship with primary caregiver** [a] | |
| Spouse | 48 (32.4%) |
| Adult child | 32 (21.6%) |
| Relatives (e.g. siblings, daughter/son-in-law, other relatives) | 9 (6.3%) |
| Domestic helper | 17 (11.5%) |
| No caregivers | 23 (15.5%) |
| RCHEs staff | 12 (8.1%) |
| **Living arrangement** | |
| Living Alone | 28 (18.9%) |
| Other living arrangements in the community | 101 (68.2%) |
| RCHEs | 16 (10.8%) |
| Average domestic household size (N=125) | 2.98 (1.668) |
| **Housing of those living in domestic households (N=132)** | |
| Public housing | 70 (54%) |
| Non-public housing | 58 (45%) |
| **Financial Assistance (N=138)** | |
| CSSA Scheme (Yes) | 34 (24.6%) |
| Disability Allowance (Yes) | 20 (14.5%) |

*Notes.* [a] *Paid caregivers were not invited to assessment.*

Eighty-one caregivers were assessed at intake. Their mean age was 55.61 (13.651) years old, and 19 (23.5%) were male. They were predominantly spouse (48.1%) or adult children (40.7%) of the patients **(Table 4.32)**. Three-fourth of them were living with the patients, and the mean number of caregiving hours per week was as high as 61.83 hours. Around 40% felt that the support from other family members was "less than satisfied".

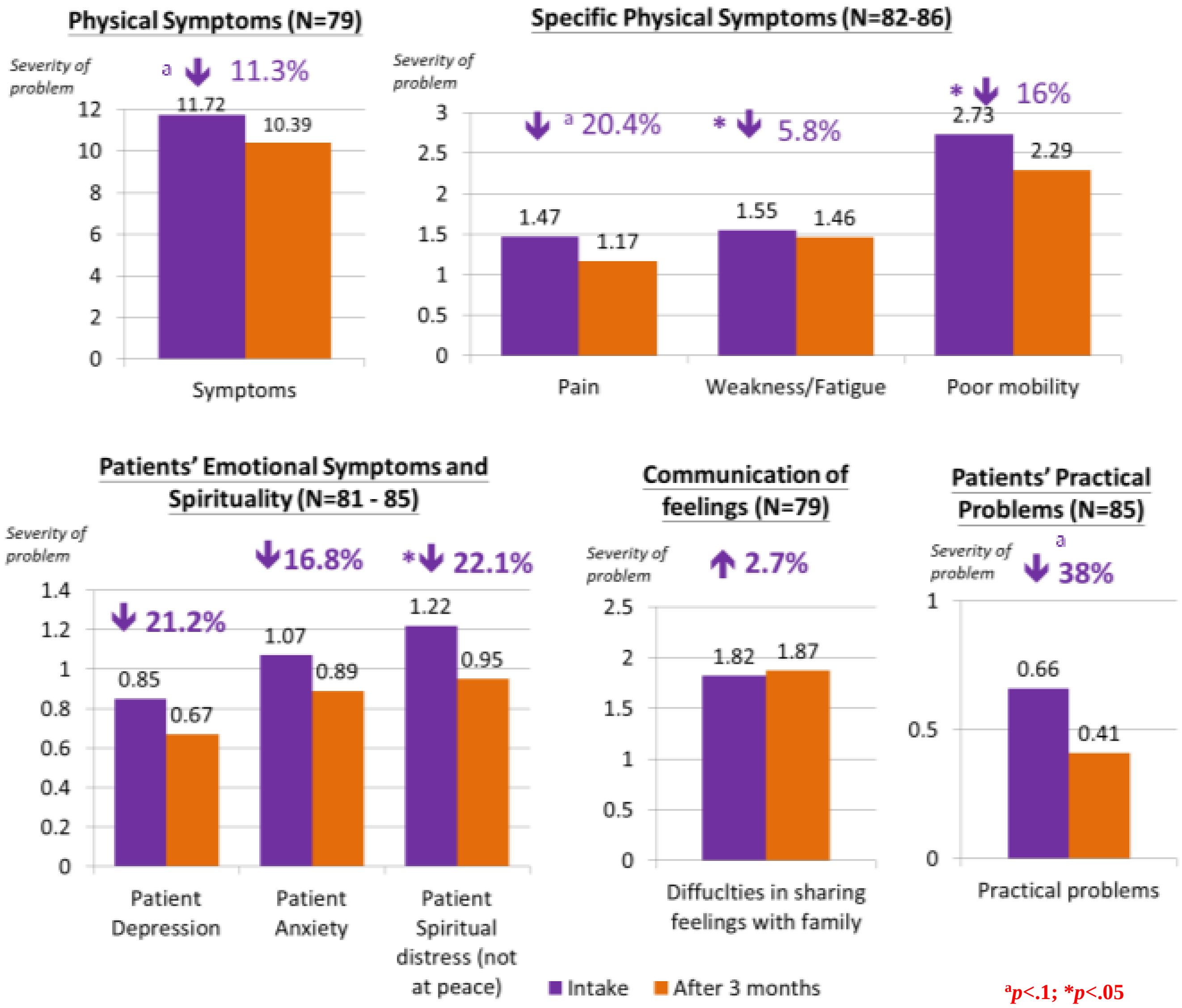
**Table 4.32** Basic demographics of family caregivers (with intake assessment) in HCCDECC model

| | **Freq. (%)** |
|---|---|
| N | 81 |
| **Relationship with patient** | |
| Spouse | 39 (48.1%) |
| Adult child | 33 (40.7%) |
| Relatives (e.g. grandchild, child-in-law, siblings) | 9 (11.1%) |
| **Education** | |
| No schooling/kindergarten | 5 (6.2%) |
| Primary school | 18 (22.2%) |
| Secondary school | 42 (51.9%) |
| Tertiary education | 15 (18.5%) |
| **Marital status** | |
| Single | 18 (22.2%) |
| Married/cohabitating | 60 (74.1%) |
| Separated/divorced | 2 (2.5%) |
| Widowed | 1 (1.2%) |
| **Religion** | |
| No religion | 35 (43.2%) |
| Chinese Traditional belief | 14 (17.3%) |
| Christian | 13 (16%) |
| Buddhist | 13 (16%) |
| Catholic | 4 (4.9%) |
| Others (e.g. Daoism, Muslim) | 1 (1.2%) |
| **Employment Status** | |
| Full-time employed | 23 (28.4%) |
| Part-time employed | 9 (11.1%) |
| Home maker | 22 (27.2%) |
| On leave/unemployed | 2 (2.5%) |
| Retired/Not working | 22 (27.2%) |
| Others | 3 (3.7%) |
| **Whether the caregiver was diagnosed with any chronic illness(es) (Y)** | 36 (44.4%) |
| **Co-residing with patient (No)** | 19 (23.5%) |
| **For caregivers who are not residing with patient, number of days visiting patient per week (N=19)** | 5.79 (2.07) |
| **Time needed to take care of patient per week (hours) [baseline]** | 61.83 (60.971) |
| **How satisfied you are with the support you receive from your family members in your role as a caregiver? [baseline]** | |
| Dissatisfied – very dissatisfied | 11 (13.6%) |
| Average | 17 (21%) |
| Satisfied – very satisfied | 49 (60.5%) |
| **Whether the caregiver has received any financial allowance? (N=73)(Y)** [a] | 31 (42.5%) |
| CSSA | 9 (12.3%) |
| Disability allowance | 8 (11%) |
| Old age living allowance | 5 (6.8%) |
| Old age allowance | 9 (12.3%) |
| **Perceived financial strain (N=72)** [a] | |
| Slightly difficult - No difficulties | 49 (68.1%) |
| Moderately difficult | 15 (20.8%) |
| Very difficult - Extremely difficult | 8 (11.1%) |

*Note.* [a] *Not all family caregivers answered the questions relating to finance.*

### 4.6.4.3 Objective outcomes

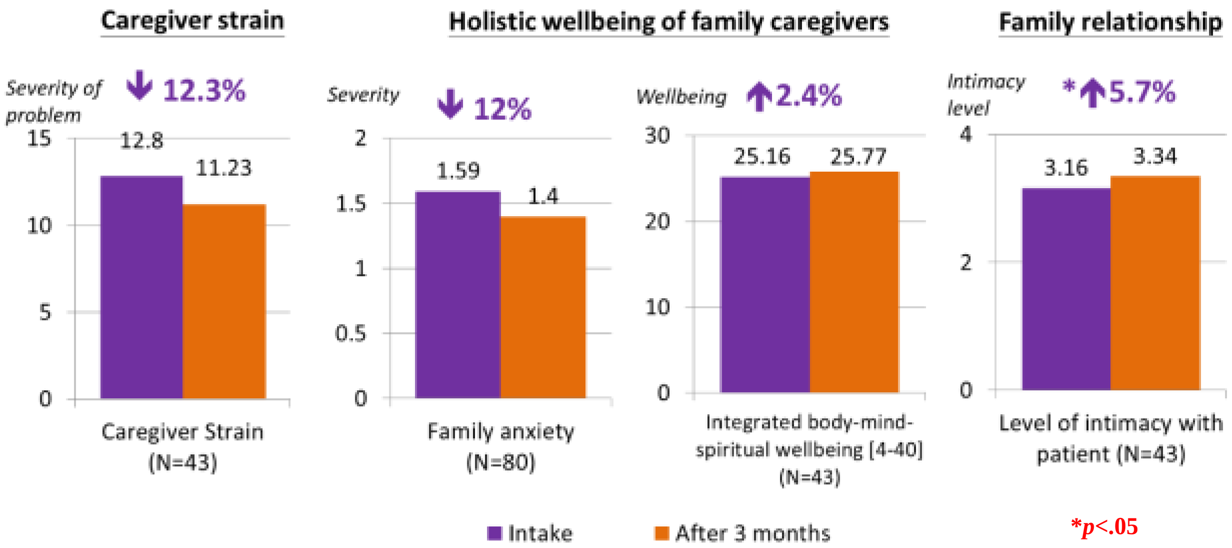
**Figure 4.38** summarises the 3-month changes in physical symptoms, psychosocial-spiritual distress, as well as practical concerns of 86 patients. Results showed that patients experienced significantly reduced spiritual distress (not at peace) (*p*<.05). For physical symptoms, the overall severity level reduced by 22% but it was marginally significant. Two of the ten assessed symptoms showed significant improvements, including weakness/fatigue and poor mobility. There were trends of reduction in patients' depression and anxiety, though the differences were not statistically significant. Barriers in sharing feelings remained more or less the same. For practical problems, there was a marginally significant reduction at the third month.



$^{a}p<.1$; $^{*}p<.05$

**Figure 4.38** Changes in objective outcomes of patients in HCCDECC programme after 3 months

In **Figure 4.39**, 80 patients reported the anxiety level of their family members at both baseline and 3rd month in service, whereas 43 caregivers have completed both baseline and 3rd month assessments. Findings showed significantly improved family intimacy at the 3rd month ($p<.05$). However, although improving trends were observed in caregiver strain, family anxiety and body-mind-spiritual wellbeing of caregivers, the differences were not statistically significant. After patient's death, 81% of the 42 assessed bereaved family members had low risk of complicated grief. The proportion of high risk for complicated grief was compatible but slightly higher than the reference (13.9%) reported among a Chinese population[55].



Complicated Grief (CG) of Bereaved Family Members (N=42)

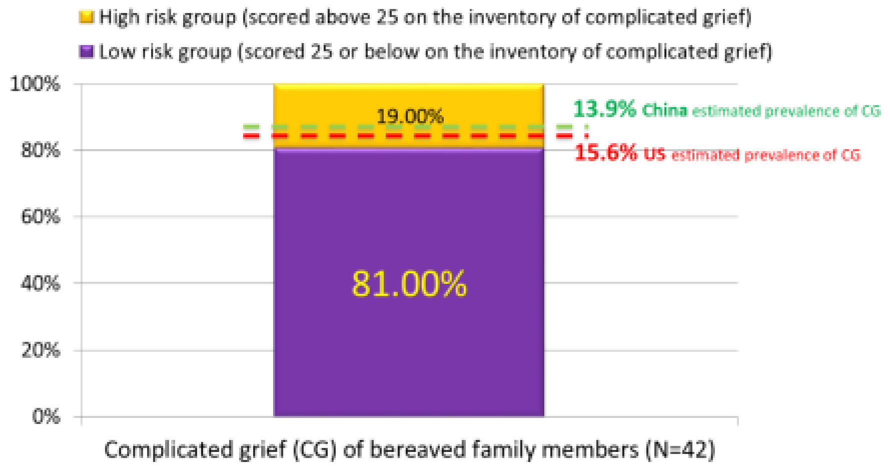


**Figure 4.39** Changes in family caregivers after 3 months in HCCDECC programme and complicated grief in bereaved family members

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[55] Li, Jie & Prigerson, Holly. (2016). Assessment and associated features of prolonged grief disorder among Chinese bereaved individuals. *Comprehensive Psychiatry, 66*, 9-16. 10.1016/j.comppsych.2015.12.001.

#### 4.6.4.4 Subjective outcomes

A total of 46 participants completed the survey. A cut-off score of 6/7 was adopted as an indication of high satisfaction. The result of the satisfaction survey showed that more than 85 % the patients gave score over 7 in the overall satisfaction of this project **(Figure 4.40)**. The most satisfying areas regarded by the patients was the service team respected your wishes, the volunteer services, and that the service empowered the patient to live a life consistent with his/her wishes (mean≥8.66). Areas which might have more rooms for improvements included empowering the patient to live with his/her own ability, and improving distressing symptoms (mean<8.5).

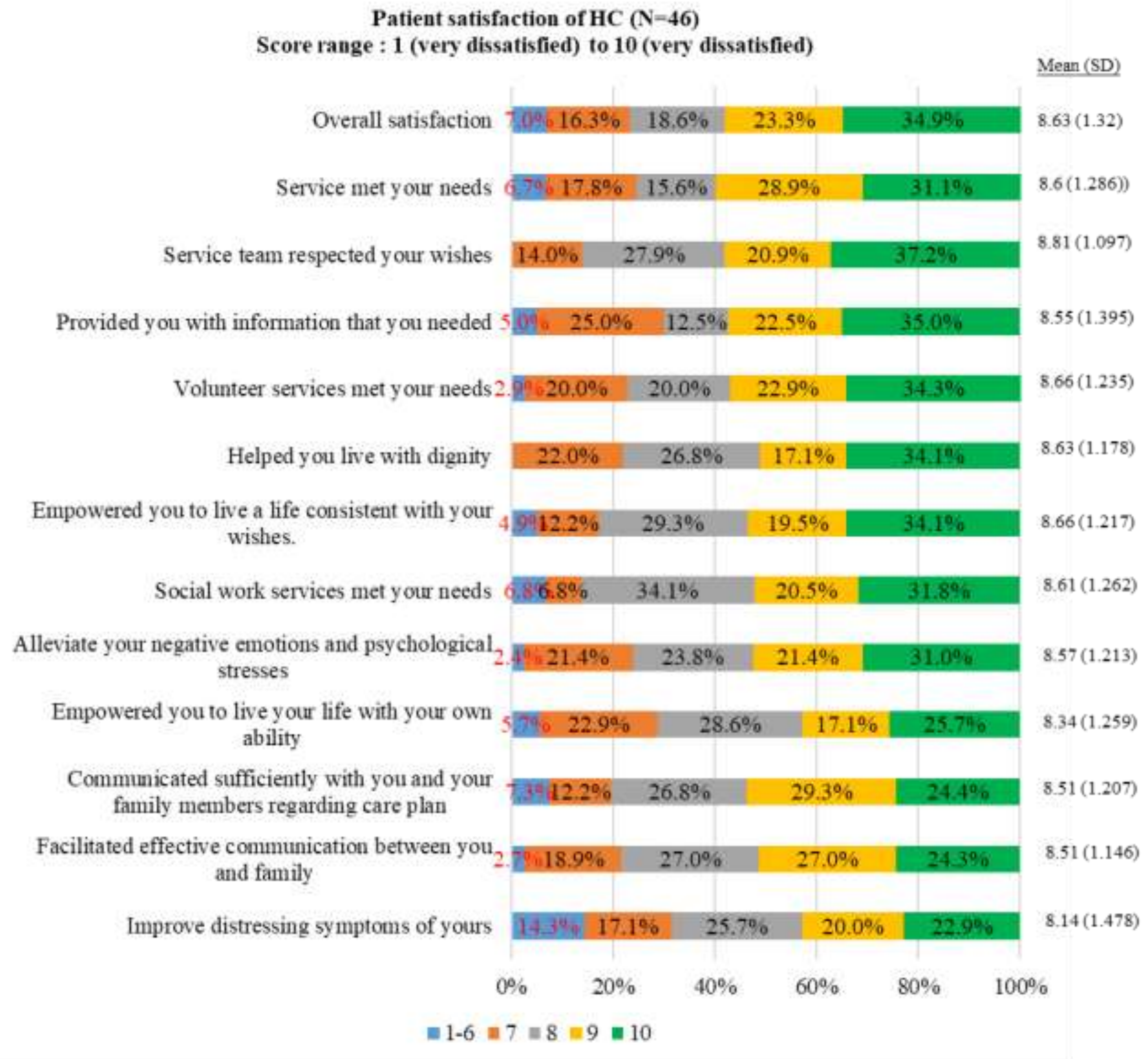

**Figure 4.40** Patient satisfaction survey of HCCDECC

A total of 23 caregivers completed the survey. A cut-off score of 6/7 was adopted as an indication of high satisfaction. Among the surveyed caregivers, around 80% of them gave score higher than 7 in the overall satisfaction of this project **(Figure 4.41)**. Moreover, caregivers were most satisfied that the service team respected their wishes (mean=8.7). It should be noted that the area with the largest rooms for improvement was symptom relief for patient (mean=7.7).

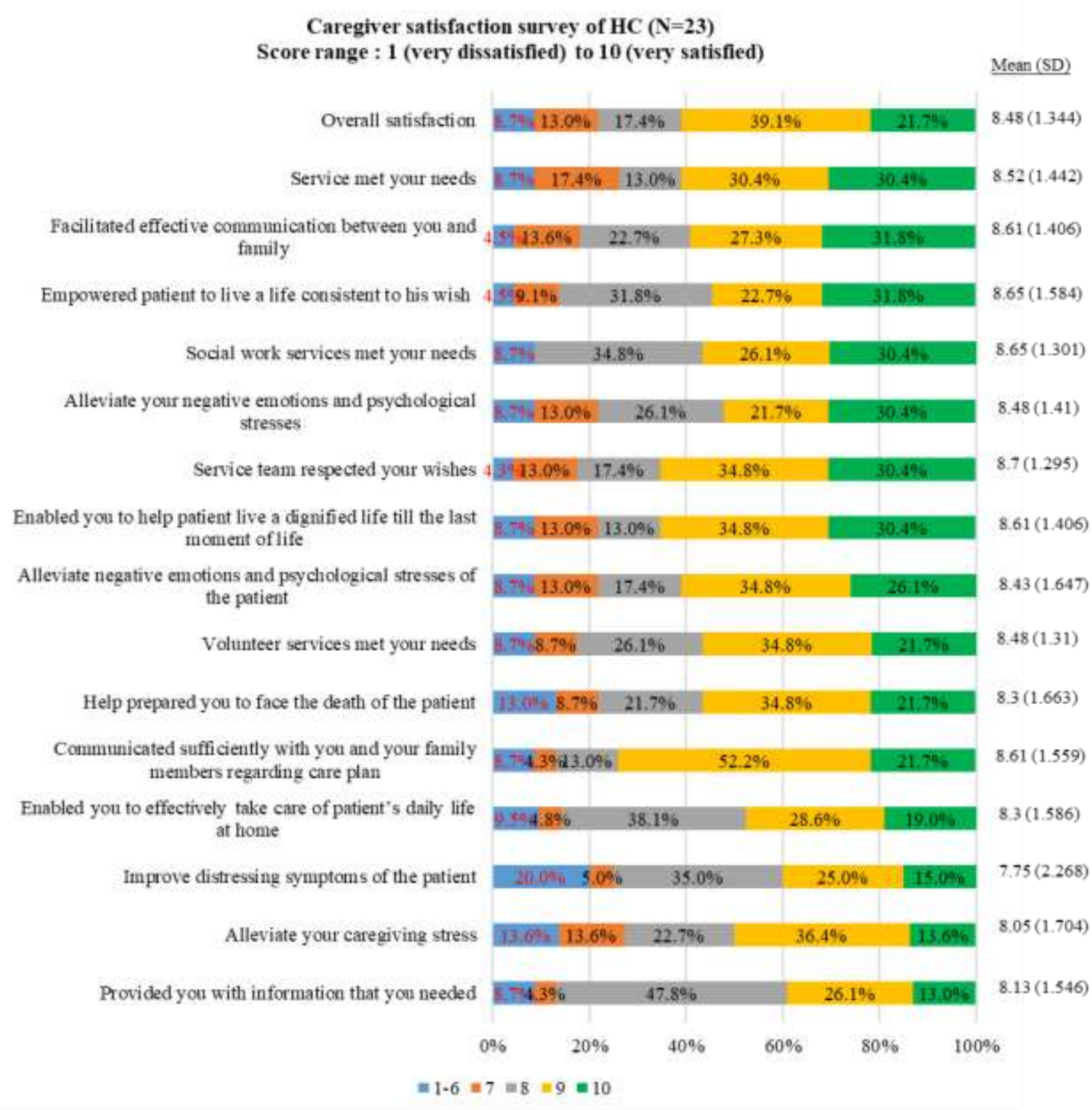

**Figure 4.41** Caregiver satisfaction survey of HCCDECC

### 4.6.4.5 Impacts

Medical service utilisation data was retrieved from 115 deceased patients from the HCCDECC model. Four cases were found to have stayed in hospital for 150 or more days (i.e. 5 months) in the last 6 months of life. Since these patients were exposed to limited community support services provided by HCCDECC, they were excluded from the final analysis. Subsequently, 111 cases were included in the analysis, and the mean length of stay in hospital (i.e. hospital beddays), A&E attendance, and ICU beddays at the last 6 months of life were calculated. **Figure 4.42** shows the comparison between the data of these 111 patients and the CDM. The finding suggested that deceased patients in the HCCDECC service model had 0.1 hospital beddays and 0.33 ICU beddays fewer than end-of-life patients in general. However, their mean A&E attendance outnumbered the reference data by 0.35 times.

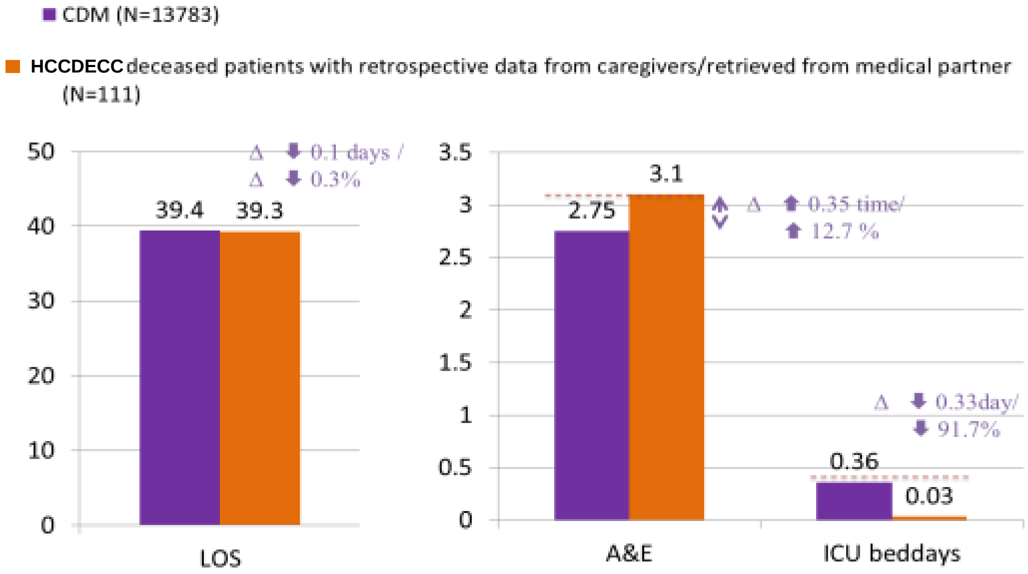

**Figure 4.42** Comparison on medical service utilisation in the last 6 months of life between deceased patients in HCCDECC model and the CDM sample

### 4.6.4.6 Key Performance Indicators Achievement

Key performance indicators (KPIs) had been developed to measure the achievement of targets of each project components. The first column of the **Table 4.33** shows the relevant KPIs for EoLC service models. Relevant outcome/Impact indicators are included in the column "performance of HCCDECC service model" for corresponding KPI. The achievements of the target specified in the KPIs were calculated by dividing the % changes obtained from the evaluation by the target % change specified in the KPIs.

**Table 4.33** Key performance indicators achievement of HCCDECC model

| | **Key Performance Indicators** | **Performance of HCCDECC service model**[56] | **Achievements**[57] |
|---|---|---|---|
| **1** | A 5% increase in quality of life of patients *(reduced physical and emotional symptoms, wishes are respected, sense of security [practical], better family relationship [sharing feelings])* | • 11% reduction in physical symptoms (p.128) | 227% achieved |
| | | • 21% reduction in depression (p.128) | 422% achieved |
| | | • 17% reduction in anxiety (p.128) | 345% achieved |
| | | • 37% reduction in practical problems (p. 128) | 750% achieved |
| | | • 3% increase in the barriers in sharing feelings (p.128) | not achieved (-55.5%) |
| | | • 100% agreed that the service team respected your wish (p. 130) | 133% achieved |
| | | Average: [58] | 298% achieved |
| **2** | A 5% increase in quality of life of family caregivers *(reduced caregiver burden, better family relationship)* | • 12% reduction in caregiving strain (p.129) | 244% achieved |
| | | • 12% reduction in family anxiety (p.129) | 236% achieved |
| | | • 5.9% increase in intimacy (p.129) | 118% achieved |
| | | Average: [58] | 199% achieved |
| **3** | Family members will have reduced regrets in bereavement process | • The proportion of high risk group was 19% for the HCCDECC caregivers, which was higher than the reference data from another Chinese sample (13.9%) (p.129) | Not achieved |
| **4** | Patients and family members have an overall satisfaction towards the EoLC of 75% or above. | • Patients have an overall satisfaction towards the service of 93% (p.130) | 124% achieved |
| | | • Caregivers have an overall satisfaction towards the service of 91.3% (p.131) | 122% achieved |
| **5** | Reduction of 2 days of hospitalisation as well as 5% A&E admission in the last six months for patients | • Patients in HCCDECC model showed a reduction of 0.43 days of hospitalisation in the last 6 months of life when compared to EoL patients derived from CDM study. However, the A&E attendance among the HCCDECC patients outnumbered that of CDM sample by 12.7%. (p.132) | Partially achieved. |

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[56] All % changes were calculated by the formula: (new values – old values)/old values.

[57] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

[58] Assuming all indicators involved share the same weight.

#### 4.6.4.7 Analysis

The HCCDECC model is effective in helping patients and families with improving intimacy between patients and family members, and reducing spiritual distress of patients. Desirable direction of changes in emotions of patients and family members, and caregiver strains were observed, which are marginally significant. Subjective outcomes were generally positive. Patients and caregivers both thought they their wishes were respected by the service team, while patients were particularly satisfied with the volunteer services. Regarding impacts, although HCCDECC deceased patients showed a slightly higher mean A&E attendance in the last 6 months of life when compared to EoL patients in general, there was a slight reduction in total length of stay, both in acute and convalesce wards as well as ICU.

With a further examination on HCCDECC outcomes, the level of physical symptoms of patients actually showed a reducing trend at the 3rd month of service, but not significant. While the role of team nurse was to provide health consultation to patients, it is believed that more could have been done to enhance symptom relief in the HCCDECC model. One of the possibilities is to strengthen the education role of the team nurse to support patients and family caregivers to manage symptoms at home.

On the other hand, the HC model emphasizes on the use of volunteer-assisted psychosocial intervention which put more focus on spiritual wellbeing (the 3L model). Such intervention seemed to be particularly effective in bringing patients and caregivers together and creating more chance for communication between patients and caregivers which resulted in improved familial intimacy, and patient’s reduced spiritual distress. However, corresponding improvements in patient’s sharing of feelings did not happen. Our previous cross-lagged analysis, physical symptom severity was found to lead to higher barriers in sharing feelings with family and friends, and more severe emotional distresses. This might also imply strengthening symptom management in the HCCDECC model could possibly support the improvement in patient’s willingness to share their feelings as well as further enhance the improvements in patients’ emotions. Similarly, bereavement care is another area which can be further strengthened.

Based on the outcomes, it was suggested that the intervention components of HCCDECC programme have been effective for spiritual care as well as facilitating family communication **(Table 4.34)**. **Table 4.34** summarised the outcomes by service foci, with effect sizes (*ES*) on the changes specified for each outcome indicator.

**Table 4.34** Relatively effective service components in the HCCDECC model (shaded area) and the effect sizes for each outcome indicator which showed significant changes

| Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|
| · Equipment Loan<br>· Escort<br>· Personal Care referral | · Health consultation over phone<br>· Alternative therapies | · Legacy<br>· Wish fulfilment<br>· Life review assisted by volunteers | · Volunteer social visits<br>· Family reconciliation | · Funeral planning<br>· Communication on care preference | · Bereavement support<br>· Funeral support |
| Marginally significant reduction in practical concerns, no significant changes in caregiver strain. | Marginally significant reduction in physical symptoms. | ⬇not at peace* (*ES*=-0.27)<br>No significant changes in patients' depression, anxiety, and caregivers IBMS and anxiety. | ⬆Family intimacy* (*ES*=0.29)<br>No significant changes in barriers in sharing feelings | 91.3% patients and 92.7% caregivers satisfied that care plan was sufficiently discussed | No observed reduction of risk for complicated grief. |

## 4.7 Summary on the findings

### 4.7.1 Effective in promoting quality of life of patients and family caregivers

The findings from objective outcomes proved that the community EoLC service models were effective in improving the quality of life of both patients facing end of life and their family caregivers (**Table 4.35**). The services remarkably relieved patients' physical symptoms and the practical problems that affected them. Psychologically, the services reduced various psychological symptoms of patients including depression, anxiety, and spiritual distress. In terms of family communication, the services encouraged patients' sharing of feelings with family and friends. For family caregivers, they reported significantly reduced caregiver strain and anxiety. There was also an improving trend in the holistic wellbeing and family intimacy reported by caregivers. The services also effectively reduced the risk for complicated grief of bereaved family caregivers. Regarding end-of-life decision making, over 90% of the interviewed patients and caregivers were highly satisfied with the help from the services in facilitating the discussion of care plan with both the patients and family caregivers.

**Table 4.35** Summary on the changes in patients and caregivers of the JCECC NGO community EoLC services after 3 months

| | Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|---|
| **Patients** | ⬇practical concerns ***<br>(*ES*=-0.62) | ⬇physical symptoms***<br>(*ES*=-0.31) | ⬇depression***<br>(*ES*=-0.50)<br>⬇anxiety***<br>(*ES*=-0.35)<br>⬇not at peace***<br>(*ES*=-0.44) | ⬇barriers in sharing feelings***<br>(*ES*=-0.25) | 94.4% patients satisfied that care plan was sufficiently discussed | |
| **Caregivers** | ⬇caregiver strain***<br>(*ES*=-0.37) | | ⬇family anxiety***<br>(*ES*=-0.43)<br>Marginally significant increase in caregiver IBMS | Marginally significant increase in family intimacy | 93.2% caregivers satisfied that care plan was sufficiently discussed | 27.6% reduced risk for complicated grief |

### 4.7.2 Effective in promoting dignity of patients and family caregivers

The evaluation findings confirmed that the JCECC community EoLC services could promote dignity of patients and family caregivers. In the satisfaction surveys with patients and family caregivers, 99% patients (N=120) thought that their wishes were respected by the service team, and 98% thought that the service helped them live with dignity. Views of family caregivers also concurred with patients' opinions, such that at least 95% of the surveyed family caregivers (N=148) thought that the service models empowered patient to live a life consistent to his/her wish, and that patient's dignity was maintained till the last moment of life.

### 4.7.3 Effective in reducing unnecessary medical service utilisation

Findings on impacts suggested that the service models reduced unnecessary medical service utilisation of patients in their last 6 months of life. A reduction of 4.87 beddays in acute and convalesce wards, 0.32 times of A&E admission, and 0.08 ICU beddays per patient were recorded. When extrapolating this to 777 patients in four models, the services were estimated to have reduced the use of hospital beds by 3784 days, ICU beds by 62 days, and A&E by 248.6 times, while the involved medical cost reduced would be 20.6 million.

These not only enabled patients to spend more time in a familiar place that they preferred during their last journey in life, but also freed the hospital services to other needy patients. It was estimated that the services would save HKD 270 million medical cost if made territory-wide.

### 4.7.4 Flexible service to meet diversified care needs

Further analysis on relationship between personal characteristics of patients and their changes in outcomes confirmed that patients from diversified background all benefited from the service models to the same extent. Given that patients' needs are prone to be affected by their diagnosis, available familial support, and living conditions etc., these findings suggested that the model designs allowed flexibility for services to be tailored to meet the diversified needs of patients regardless of their disease types and various socio-economic factors. Regarding family caregivers, the services were found to be more effective to younger caregivers when compared to their older counterparts.

Not surprisingly, older caregivers usually face more challenges to provide intensive care to terminally ill family members when compared to younger caregivers. The first challenge they first might be their own health condition. Among the older caregivers in our sample who aged 60 or above, 74% reported at least one diagnosed chronic illness, and they provided on average 72 hours of care per week. The caregiving process could be exhaustive to them and they could be easily isolated from the community due to long hours of caregiving. This group of caregivers should be given more caregiving support. Since our findings found that the perceived familial support on caregiving could be a protective factor against deterioration of holistic wellbeing of caregivers, interventions should also engage other family members to support the caregiving of primary caregivers. Apart from these, there was a minority of parent caregiver (N=5) in our sample which consisted of an old-old parent taking care of young-old son/daughter with terminal illness. This situation has put caregivers in high risk for complicated grief as reflected by our findings. This group of caregiver might require more support to prepare them for the patient's death and specialised bereavement care after the patient passed away.

### 4.7.5 Mechanism of changes

The current findings suggested that physical symptom severity could lead to deterioration of emotional symptoms and patients' willingness to share their emotions. In other word, physical symptom is a risk factor for deteriorating emotional and social wellbeing. On the other hand, in the caregiver's system, the findings showed that caregivers' perception on familial support made a difference on their holistic wellbeing. Besides, rather than caregiver strain, it was the caregiver's holistic wellbeing that affected caregivers' adaptation in bereavement stage. There were also dyadic effects between patients and caregivers. It was found that patients' willingness to share feelings was affected not only by intrapersonal factor (physical symptoms as previously suggested), but also caregiver's holistic wellbeing which is an interpersonal factor. Oppositely, it was the patient's emotional wellbeing but not physical symptoms which led to changes in caregiver strain. All in all, the implications on practice are as follows:

1. Symptom management has to be implemented alongside psychosocial spiritual care to support each other in our service models;
2. Psychosocial-spiritual support for patients should be emphasized which not only for the patient's sake but also for reducing caregiver's strain;
3. Initiative to engage family members in caregiving apart from the primary caregiver should be strengthened to promote the well-being of primary caregivers;
4. Measures for reducing caregiving burden might not be adequate for promoting personal well-being of caregivers and thus better adjustment after patient's death, psychosocial-spiritual support which are extended to caregivers is recommended.
5. Patient and caregivers' wellbeing are inter-dependent, this is imperative to adopt a family-based approach in our service models.

### 4.7.6 Effective features of service delivery

Three service delivery features which led to satisfying and dignified experiences of patients and family caregivers were identified from the in-depth interviews. These were (1) timely and proactive support, (2) individualized interventions which target on the patients and caregivers' needs, and (3) caring and respectful attitude of workers. Since our patients are facing life-limiting illnesses and their conditions change along the disease trajectory, timeliness of interventions is vital to support the patients and caregivers through the end of life process. Moreover, we found that timely support during critical moments (e.g. patient's condition suddenly deteriorates; patient discharged home from hospital, saying goodbye to patients etc.) helped caregivers adapt better at the bereavement stage. Concerning the focus of interventions, patients and caregivers' revelation suggested that rather than the type or frequency of services, targeted interventions addressing the expressed needs of them promoted their service satisfaction. Lastly, the caring and respectful attitude of workers was found to be therapeutic *per sue*. It helped the building of a trustful relationship between the families and the workers. These features should be further strengthened in the integrated model to allow services to be delivered in a right time, to the right persons, and in a way which is consistent to the patients and caregivers' wishes.

### 4.7.7 Distinguishing effective service components

The four community end-of-life care models which include the non-cancer patient capacity building model, family capacity building model, community capacity building model and enhanced community-based health care model, are complex interventions with several interacting care components offered by different level of staff. As analysed, they share a few common components but also have their unique elements, resulting at different level of impacts on the differentiated outcomes. The ultimate goal of this project is to develop a comprehensive and holistic community-based end-of-life care model for Hong Kong. Thus through analysing and synthesising the available data of the evaluation of the four different models, a preliminary integrated model is germinated.

The four models share six foci of attention, namely practical support, symptoms management, psycho-social spiritual care, communication, end-of-life decision making and bereavement care. These foci have also been used in presenting the findings on effectiveness of each model. The four models have different intervention components for each focus which are summarized in **Table 4.36**.

**Table 4.36**: Intervention components of each focus area by each NGO

| NGOs | Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|---|
| SJS | · Equipment Loan<br>· Escort<br>· Home environment modification<br>· Intensive support by care officers | · Referrals to occupational therapists | · Cheering activities<br>· Legacy<br>· Wish fulfilment<br>· Individual counselling | · Family counseling<br>· Family activities | · Care plan discussion<br>· Funeral planning | · Bereavement support<br>· Funeral support |
| SASHCC | · Escort and transportation<br>· Personal care | · Home visits by nurses and symptom management<br>· Telemedicine<br>· Respite services | · Emotion care<br>· Spiritual care by Chaplin<br>· ACP discussion which covers wish and unfinished business | · ACP discussion | · ACP review | · Bereavement support |
| HKSR | · Equipment consultation<br>· Service referral | · Symptom self-management education<br>· Health behaviour action plan<br>· Caregiving skills training | · Joyful activities<br>· Legacy<br>· Wish fulfilment | · Positive death education | · Care preference discussion | · Bereavement support |
| HCCDE CC | · Equipment Loan<br>· Escort<br>· Personal Care referral | · Health consultation over phone<br>· Alternative therapies | · Legacy<br>· Wish fulfilment<br>· Life review assisted by volunteers | · Volunteer social visits<br>· Family reconciliation | · Funeral planning<br>· Communication on care preference | · Bereavement support<br>· Funeral support |

Outcomes evaluation on each service model suggested that each model had its strengths.

All models reported reduction in practical concerns, further examination on the significance and effect sizes of the changes, it was found that SJS, HOH and HKSR showed large effect sizes on the improvement in this regard. Deductively, the intensive and timely intervention by the care officers in SJS model in supporting the patients’ family during the transitions, and respite care as well as visits by nurses and personal care workers by SASHCC are postulated to the effective intervention in this aspect. Regarding HKSR, in-depth interviews with their patients and caregivers always showed that patients and caregivers found the service team resourceful in terms of searching for available community support and providing information which facilitate their caregiving process in a timely manner. The use of this empowerment model might have led to the great reduction of practical concerns among patients.

Related is that SJS and HOH models were found to be the only model which significantly reduced caregiver strain. In particular, SJS model reported a large effect size in the reduction of caregiver strain. It is speculated that the intensive tangible support by the care officers, timely equipment loan at the time of hospital discharge which target on practical problems also greatly reduced the caregivers' stress at the same time. The use of respite service and personal care worker's visit by HOH might also have helped relieve the stress of caregivers, but probably the intensity of the visits and the fact that not all cases would be provided with respite service have limited the coverage of its impact on caregivers.

Regarding symptom management, indeed all models showed positive direction of changes in this regard. In particular, SJS, HOH, and HKSR showed improvements which are statistically significant with moderate effect sizes. These findings suggested that the nursing care, telemedicine, rehabilitation therapies of HOH model, and the symptom self-management education as well as caregiving skills training of HKSR have been effective in relieving physical symptoms of patients. Interestingly, SJS model relied mostly on psychosocial care, while referrals for OT/PT for symptom management were not frequently reported. Yet, SJS model reported the largest effect size in the improvement of physical symptoms. It was speculated that the cheerup activities of SJS, which deliberately explored the interest of patients and engaged them in activities that they preferred, had augmented the effects of symptom management of hospital partners by enhancing patients' subjective feelings on their physical conditions. Indeed, in in-depth interviews with SJS patients and caregivers, one of the patients described that he forgot his pain when he focused on the activities that he liked. The current findings also pinpointed the vital role of psychosocial care in supporting the changes in physical conditions.

When it comes to psycho-social spiritual care, joyful activities were offered by HKSR and SJS, and the improvements in patients' depression and anxiety of the two organisations were found to be higher than the other. Regarding spiritual care, legacy and wish fulfillment were common activities that all models adopted and these found to be effective in promoting peace among patients of all models. Particularly, HCCDECC trained volunteers to conduct life review with patients, while chaplains provided spiritual care in the HOH model. Our findings suggested that their patients reported significant improvements in spiritual wellbeing after these interventions. Related was the holistic wellbeing of caregivers. HKSR was the only model which showed significant improvements in caregivers' holistic wellbeing. Upon further comparison between models, HKSR was the only model which emphasized training caregiving skills for caregivers through empowerment approach, and it was a separated service component targeted on caregivers. This direct service for caregivers might have exerted greater impacts on caregivers' overall wellbeing when combined with other indirect services which targeted on patients.

Regarding family communication, HOH and HKSR models showed significant improvements in patients' sharing of emotions with family and friends. It suggested that the positive death education of HKSR and ACP facilitation of HOH successfully encouraged patients to share their feelings with other, and these changes were also supported by improvements in patients' physical symptoms and caregivers' holistic wellbeing as suggested in previous discussion. Family intimacy, which is a relational aspect in caregiver support, was significantly improved only in the HCCDECC model. Probably, the volunteer-assisted psychosocial care and family reconciliation activities in the HCCDECC model helped bridge patients and caregivers together which eventually enhanced relationship intimacy.

The current evaluation framework did not include objective outcome indicators on end-of-life decision making while the subjective outcome indicator might not be able to inform the true efficacy of model in this regard. However, the qualitative finding suggested that ACP discussions were reported more concretely by the interviewed caregivers of the HOH model. In view of these, more components should be added to this service area in the future integrated model.

While all models provided bereavement support (and some provided funeral support as well), SJS and HKSR showed better outcomes on reducing risk of complicated grief in bereaved family caregivers. There was not sufficient evidence to explain the differentiation between models in this regard. However, given that bereavement adjustment was pertinent to the holistic well-being of caregivers before patient's death, it was legitimate to believe that enhancing caregiver-targeted psychosocial-spiritual support is needed for those who were at risks for grief.

Lastly, in our previous analysis on medical service utilisation by service model, SJS and HOH showed better efficacy in reducing hospitalisation. The higher involvement of home visit by care officers of SJS, and nurse visits offered by HOH were suggested to be the determining factor for reduction of unnecessary hospitalisation.

**Table 4.37** summarises the identified effective service components in each service model. The shaded cells indicated effective service components. These components should be integrated into the integrated model.

**Table 4.37** Identified effective components specific to individual model

| | Practical Needs | Symptom Management | Psycho-social Spiritual Care | Family Communication | End-of-Life Decision Making | Bereavement Care |
|---|---|---|---|---|---|---|
| **SJS** | • **Equipment Loan**<br>• **Escort**<br>• **Intensive support by care officers**<br>⬇practical concerns ***(*ES*=-0.79)<br>⬇caregiver strain ***(*ES*=-0.8) | • **Cheerup activities** (It was reported that OT referrals have been under-used)<br>⬇physical symptoms*** (*ES*=-0.51) | • **Cheerup activities**<br>• **Legacy**<br>• **Wish fulfilment**<br>• **Individual counseling**<br>⬇depression*** (*ES*=-0.38)<br>⬇anxiety*** (*ES*=-0.16)<br>⬇not at peace*** (*ES*=-0.07)<br>⬇family anxiety*** (*ES*=-0.54)<br>Caregiver IBMS unchanged | • **Family counseling**<br>• **Family activities**<br>No significant changes in barriers in sharing feelings and family intimacy | • **Care plan discussion**<br>• **Funeral planning**<br>96.4% patients and 91.1% caregivers satisfied that care plan was sufficiently discussed | • **Bereavement support**<br>• **Funeral support**<br>59.7%reduced risk for complicated grief |
| **HOH** | • **Escort and transportation**<br>• **Personal care**<br>• **Respite services**<br>⬇practical concerns ***(*ES*=-0.65)<br>⬇caregiver strain ** (*ES*=-0.23) | • **Home visits by nurses and symptom management**<br>• **Telemedicine**<br>⬇physical symptoms* (*ES*=-0.36) | • **Emotion care**<br>• **Spiritual care by Chaplin**<br>• **ACP discussion which covers wish and unfinished business**<br>⬇anxiety** (*ES*=-0.44)<br>⬇not at peace** (*ES*=-0.44)<br>⬇in family anxiety** (*ES*=-0.63)<br>Depression and caregiver IBMS no significant changes. | • **ACP discussion**<br>⬇barriers in sharing feelings*** (*ES*=-0.61)<br>Family intimacy showed marginally significant changes | • **ACP review**<br>90% patients and 95.9% caregivers were satisfied that the care plan was sufficiently discussed | • **Bereavement support**<br>Compatible risk for complicated grief with literature |
| **HKSR** | • **Equipment consultation**<br>• **Service referral**<br>⬇practical concerns ***(*ES*=-0.99)<br>No significant changes in caregiver strain | • **Symptom self-management education**<br>• **Health behaviour action plan**<br>• **Caregiving skills training**<br>⬇physical symptoms** (*ES*=-0.40) | • **Joyful activities**<br>• **Legacy**<br>• **Wish fulfilment**<br>⬇depression*** (*ES*=-1.05)<br>⬇anxiety*** (*ES*=-0.95)<br>⬇not at peace*** (*ES*=-1.09)<br>⬇family anxiety*** (*ES*=-0.75)<br>⬆Caregiver IBMS * (*ES*=0.28) | • **Positive death education**<br>⬇barriers in sharing feelings*** (*ES*=-0.60)<br>No significant changes in family intimacy | • **Care preference discussions**<br>96.4% patients and 94.6% caregivers satisfied that care plan was sufficiently discussed | • **Bereavement support**<br>100% reduced risk for complicated grief |
| **HCCDECC** | • **Equipment Loan**<br>• **Escort**<br>• **Personal Care referral**<br>Marginally significant reduction in practical concerns, no significant changes in caregiver strain. | • **Health consultation over phone**<br>• **Alternative therapies**<br>Marginally significant reduction in physical symptoms. | • **Legacy**<br>• **Wish fulfilment**<br>• **Life review assisted by volunteers**<br>⬇not at peace* (*ES*=-0.27)<br>No significant changes in patients' depression, anxiety, and caregivers IBMS and anxiety. | • **Volunteer social visits**<br>• **Family reconciliation**<br>⬆Family intimacy* (*ES*=0.29)<br>No significant changes in barriers in sharing feelings | • **Funeral planning**<br>• **Communication on care preference**<br>91.3% patients and 92.7% caregivers satisfied that care plan was sufficiently discussed | • **Bereavement support**<br>• **Funeral support**<br>Compatible risk for complicated grief with literature |

## 4.8 The Integrated Model – Integrated Community End-of-Life Care Support Team (ICEST)

With the evidence from the evaluation on the service models in the first 3 years, an integrated model called ICEST is consolidated. The ultimate goals of the development of ICEST are to establish a viable and effective reference service model in community-based EoLC to improve the quality of life of community-dwelling EoL patients and their family members, respect their choices of care, and reduce unnecessary hospital admissions by providing holistic EoLC. The ICEST embraces the following core features:

1. A unified and standardised model of care;
2. Provision of need-based targeted interventions facilitated by standardised assessment tools and evidence-based practice guidelines; and
3. Establishment of partnerships with existing services;
4. Rigorous evidence-based development on the effectiveness, efficiency and cost-effectiveness of the care model.

### 4.8.1 A unified and standardised model of care

With the pieces of information from analysis on effective service components, the effective service features, and the analysis on mechanism of changes, a standardised model of care was proposed with the following advancements from the phase I models:

- Adoption of three board service domains, namely physical care, practical care, and psychosocial-spiritual care (the 3-Ps) to communicate the service components in the service model;
- Integration of identified effective service components in an unified framework;
- Strengthening service components targeting on caregivers; and
- Strengthening service components in end-of-life decision making.

The core services provided by ICESTs are outline in **Table 4.38**. Standardised manpower and required personnel are also proposed for the ICEST. Each ICEST will be implemented by a multi-disciplinary team which consists of a nurse (N), social workers (SW), and care workers (CW). Trained volunteers (V) are also an integral part of the team. This team composition is essential in delivering the 3-Ps interventions of the ICEST.

**Table 4.38** A proposed 3-Ps framework on service components

<table>
<tr><th>Care domains</th><th>Patient</th><th>Caregivers</th></tr>
<tr><td><b>Physical care</b></td><td>- Symptom self-management education</td><td>- Caregiving skills training</td></tr>
<tr><td rowspan="5"><b>Psychosocial-spiritual care</b></td><td colspan="2"><b>Psychological:</b><br>- Individual and family counseling<br>- Cheering activities/Joyful activities</td></tr>
<tr><td colspan="2"><b>Spiritual:</b><br>- Religious engagement<br>- Life review<br>- Wish fulfilment</td></tr>
<tr><td colspan="2"><b>Social:</b><br>- Volunteer social support<br>- Family reconciliation</td></tr>
<tr><td colspan="2"><b>Eol decision making:</b><br>- Preparation for ACP discussion/ACP discussion<br>- Positive death education<br>- Funeral planning</td></tr>
<tr><td></td><td><b>Bereavement care</b><br>- Bereavement support<br>- Funeral support</td></tr>
<tr><td><b>Practical care</b></td><td>- Equipment loan<br>- Escort<br>- Personal care referral<br>- Intensive support by care officer</td><td>- Respite services<br>- Patient sitting service<br>- Provision of information on relevant resources</td></tr>
</table>

### 4.8.2 Developing need-based targeted interventions facilitated by standardised assessment

Timely and proactive interventions and need-based care have been found to be successful factors leading to satisfying experience with EoLC in our models. Indeed, need-based approach interventions have gained growing attention in palliative care in the last few decades. It has been noticed that EoL patients experience diversified disease trajectories which in turns affect their levels of needs for palliative care in the course of disease [59,60,61]. As such, the World Health Organization (WHO) has advocated for integration of palliative care into all levels of healthcare system to provide different levels of palliative and EoLC care for EoL patients with varied levels of EoLC needs[62]. Not all EoL patients need the same type and intensity of services, and given the limited life expectancies of patients, it is paramount for ICESTs to be able to identify the needs of patients and families and provide targeted interventions accordingly in a timely manner. This will also help optimize the cost-effectiveness of interventions.

To facilitate need-based and targeted interventions, a *stepped care model* is proposed for ICEST model with continuous assessment of the needs of the patients and families with a need-

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[59] Irish Association for Palliative Care. (2018). What is palliative care. In.
Johnson III, R. J. (2018). A research study review of effectiveness of treatments for psychiatric conditions common to end-stage cancer patients: needs assessment for future research and an impassioned plea. BMC Psychiatry, 18(1). doi: 10.1186/s12888-018-1651-9

[60] McCallum, M. e. a. (2018). Developing a palliative care competency framework for health professionals and volunteers: the Nova Scotian Experience. Journal of Palliative Medicine, 21(7), 947-955.

[61] Palliative CAre Australia. (2005). A guide to palliative care service development: A population based approach.

[62] World Health Assembly. (2014). Strengthening of palliative care as a component of comprehensive care throughout the life course. http://apps.who.int/gb/ebwha/pdf_files/wha67/a67_r19-en.pdf

stratifying assessment tool. Services of the ICESTs will be delivered based on a standardised need-stratifying assessment tool on the three aforementioned care domains (3-P assessment). Baseline results of the assessment tool used in phase I project was used to provide evidence to facilitate decision on the threshold values to differentiate various levels of needs in different care domains. The general rule is to add 1 standard deviation to the mean score obtained in each outcome indicator at baseline. To increase the sensitivity of the screening, a slightly lower threshold was selected in certain indicators. A score equal or higher than the threshold indicates a high need in that outcome indicator. **Table 4.39** summarized the proposed threshold for each outcome indicator. Using the proposed thresholds, the high need group in each indicator range between 18.5% (caregiver strain) to 61% (patient's information needs). It should be noted that there would be more outcome measures in the ICEST model after enhancement of the evaluation framework.

**Table 4.39** Mean scores in outcome indicators at baseline and respective threshold levels

| | JCECC service users baseline results | | Proposed threshold level for high needs | % of high need group |
|---|---|---|---|---|
| | N | Mean (SD) | | |
| **Patient Outcomes** | | | | |
| IPOS- physical symptoms [0-40] | 579 | 10.52 (5.960) | Any item ≥ 3 | 311 (53.7%) |
| IPOS- depression [0-4] | 576 | .92 (.972) | ≥ 2 | 154 (26.7%) |
| IPOS- anxiety [0-4] | 576 | 1.2 (1.137) | ≥ 2 | 228 (39.6%) |
| IPOS- not at peace [0-4] | 589 | 1.24 (1.041) | ≥ 2 | 217 (36.8%) |
| IPOS- practical concerns [0-4] | 605 | 1.15 (1.157) | ≥ 2 | 255 (42.1%) |
| IPOS- information needs [0-4] | 277 | 1.91 (1.239) | ≥ 2 | 169 (61%) |
| **Family caregiver Outcomes** | | | | |
| IPOS- family anxiety [0-4] | 594 | 1.85 (1.107) | ≥ 3 | 170 (28.6%) |
| C-M-CSI [0-26] | 443 | 12.28 (6.367) | ≥ 19 | 82 (18.5%) |

By using a need-stratifying assessment tool, when the need is assessed to be lower than the threshold, care of lower intensity should be provided by professional staff in the ICESTs or by volunteers, whereas for those with indicated needs (i.e. high level of needs), they will be provided with more intensive care delivered by different care professionals in the ICESTs. **Figure 4.43** outlines the idea of the need-based care. The stepped care model will not only promote the provision of right care at the right time, but also facilitate efficient allocation of resources through targeted interventions on only indicated needs with clear targeted outcomes.

To take one step further to enhance the evidence-basis of the interventions in ICEST model, recommendations on evidence-based interventions would be drafted to provide guidance on interventions regarding each care domain and its sub-domains.

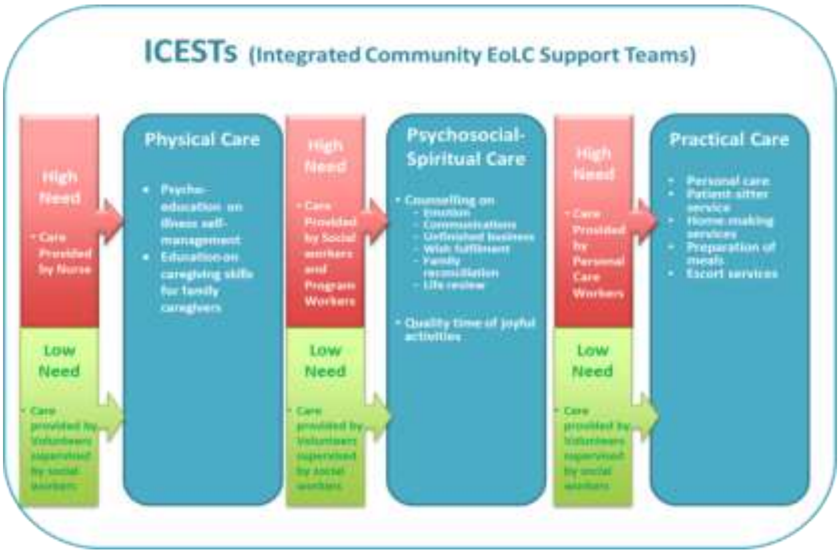

**Figure 4.43** Stepped care model in ICESTs

### 4.8.3 Integration with existing services for end-of-life care

Our integrated model is not only integrating the four NGOs' models but also integrating with other existing social and health care services. In line with the strategic service framework for palliative care published by Hospital Authority, there is growing support of developing palliative care or end-of-life care in the community. HA is committed to enhance medical-social collaboration to support palliative care in the community. As shown in **Figure 4.44**, the ICEST is proposed to be piloted in a shared care model with existing health care services provided by HA such as Community nurse services and CGATs, and social care services provided by SWD including EHCCS, IDSP, and CVVS. It is proposed to develop a sustainable medical-social interface with HA in terms of identification of suitable case, case referral, and shared care across care settings. After receiving case referrals from HA, care will be delivered by the ICESTs based on a standardised need-stratification tool as proposed in last section. If the patients meet the criteria of other existing community service, shared care will be provided collaboratively. The service teams are expected to fill the gap of existing services.

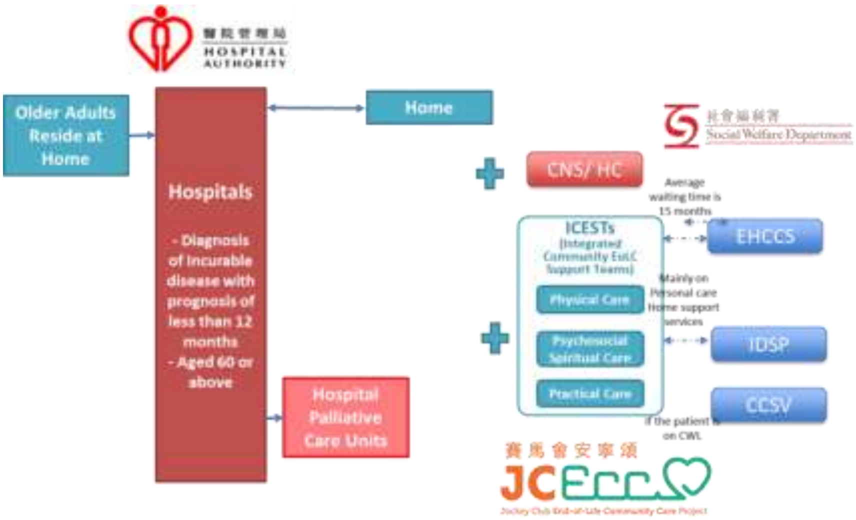

**Figure 4.44** Collaboration between ICESTs and existing services

### 4.8.4 Rigorous evidence-based development on the effectiveness, efficiency and cost-effectiveness of the care model

The evaluation framework adopted in the first 3 years was able to capture the outcomes and impacts of service models. In order to enhance the rigor of evaluation on the ICESTs, the existing evaluation framework will be continued to be adopted with some refinements. These advancements include:

1. Strengthening the alignment between outcome measures and service components, and adding outcome indicators to specific service components in ICESTs such as advance care planning, social support, and caregivers' emotional support.
2. Conducting cost-benefit analysis through Social return on investment (SROI).
3. Calculation of cost per case

# 5. VOLUNTEERS

## 5.1 Programme Descriptions

The EoLC (End-of-Life Care) volunteer programmes of NGO partners have been evolving in the past 3 years of the project. NGO partners have different role functions prescribed to their volunteers who served in their community-based EoLC programmes, and thus they developed different training contents and structure for their volunteer programme in the first two years of the Project (**Table 5.1**). By studying the recruitment process, identifying the common themes in the training programmes, challenges faced and needs of volunteers of NGO partners, coupled with literature review on necessary EoLC volunteer competences, a standardised screening tool and volunteer core course were developed in second year, and implemented in the third year.

**Table 5.1** Volunteer Programmes of 4 NGO partners

| | **St. James Settlement** | **Hope of Heaven Christian Services** | **S.K.H. Holy Carpenter Community Centre** | **The Hong Kong Society for Rehabilitation** |
|---|---|---|---|---|
| **Name of the Service** | The "Cheering @ Home" programme | The "Hospice Based Home Care" programme | The "Hospice in Family Home Care Support Service" programme | The "LET Go – Life Rainbow" programme |
| **Local training (hours)** | 6 | 6 | 18 + 20 hours internship | 6 |
| **Mission** | Enjoy valuable and wonderful time at the EoL stage | Explore the meaning of life | Improve quality of life | Safeguard the dignity |
| **Role of volunteers** | Bring joy to the EoL elderly patients and their family members through home entertainment | Provide spiritual care and support EoL elderly patients and their family members' emotional and social needs | Be a companion to the EoL elderly patients and their family members, and helping them to hold positive beliefs towards life | Support EoL elderly patients and their family members' emotional and social needs |

A volunteer screening tool was specifically developed to facilitate standardised procedure in recruitment and screening to identify appropriate candidates and was implemented along with the volunteer core course. The volunteer core course consisted of 4-session lectures (16 hours) delivered by the HKU project team followed by 2-6 sessions provided separately by individual NGO which amount to 8 to 18 extra training hours. The core course aims to provide a knowledge and skill base necessary for EoLC volunteers with emphases on communication skills and role boundary, while NGO sessions focused on specific area relevant to the special roles of volunteers in their service programme.

The first centralized volunteer core course was conducted in January 2018. It involve 3 stages: (1) recruitment and screening, (2) training, (3) continuous support and management. Recruitment was carried out collaboratively between the HKU Project team and the NGO partners, with the HKU Project team coordinating a centralized system for registration, while NGO partners responsible for screening. All applicants were asked to complete the screening tool at the time of application, and NGO assessed the suitability of the applicants using the screening tool as well as face-to-face interview process. All applicants must complete at least 80% of the training course, including both the HKU centralized core course and NGO extended courses, before they can join the NGO EoLC programme to provide formal services.

## 5.2 Evaluation Framework

A pre-post-followup study using quantitative structured questionnaire was designed to capture the outcomes and impacts of the volunteer training programme in the year of 2016 and refined in the year of 2018 for the core training courses evaluation. The refined evaluation framework was shown in **Figure 5.1**. All volunteers would be assessed before training ($T_0$), right after training ($T_1$), and 6 months after completion of training ($T_2$). The outcomes measured include knowledge, attitude, and competence in EoLC and will be assessed with a multi-dimensional EoLC competence measure developed by the Project team. Impacts include life satisfaction measured with Flourish scale, quality of life measured with body-mind-spiritual health scale, changes in caring behavior, and sustained EoLC knowledge and skills 6 months after training.

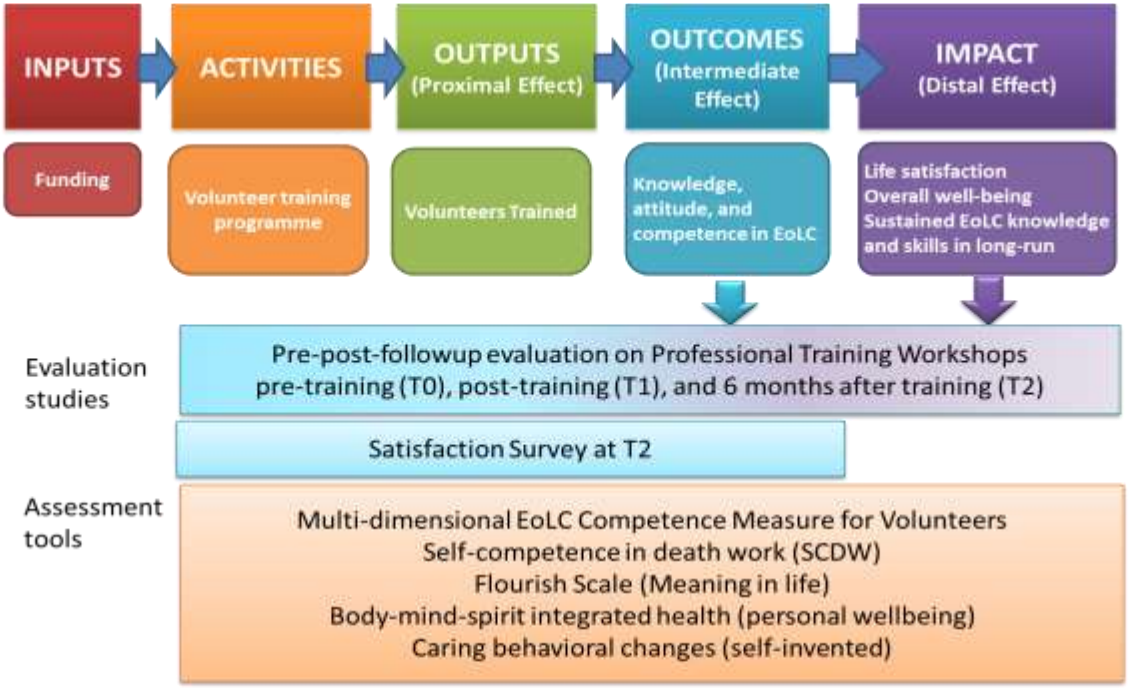

**Figure 5.1** Evaluation framework on volunteers

## 5.3 Characteristics of Volunteers

In the first three years (2016-2018) of JCECC project in Phase I, totally 278 applicants enrolled in the End-of-Life training courses held by Specific NGO (2016-2017) or by HKU (2018), Among these enrolled applicants, 201 of them successfully completed 80% of the course (completion rate 72.3%), and 194 completed the pre-post training evaluation. Table 4.2 (left side) showed the demographics information and their experience with volunteering of these volunteers who joined EoL care training courses from 2016 to 2018 in JCECC project.

For the core course training conducted in January 2018, between December 2017 and January 2018, over 150 applications were received for the volunteer core course, after the first round of screening based on their screening results, 121 applicants were selected by NGOs for further screening interviews. Eventually, 91 volunteers were enrolled in the core course training in the University of Hong Kong, and eighty-two of these volunteers successfully completed the training in 2018 (completion rate 90.1%). Meanwhile, 80 of these volunteer who successfully completed the core training courses completed the pre-post training evaluation. **Table 5.2** showed the demographics information of these volunteers, and their experience with volunteering.

**Table 5.2** Demographics of volunteers who successfully completed EoL training courses

| | Training in three years | | | | | 2018 core training courses | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Freq | % | Mean | SD | N | Freq | % | Mean | SD |
| **Gender (Male)** | 200* | 54 | 28.0 | | | 81* | 24 | 30.0 | | |
| **Age** | | | | | | | | | | |
| 18-29 | | 28 | 14.6 | | | | 11 | 13.8 | | |
| 30-39 | | 15 | 7.8 | | | | 8 | 10.0 | | |
| 40-49 | | 32 | 16.7 | | | | 14 | 17.5 | | |
| 50-59 | | 64 | 33.3 | | | | 26 | 32.5 | | |
| 60-69 | | 46 | 24.0 | | | | 18 | 22.5 | | |
| 70-79 | | 7 | 3.6 | | | | 3 | 3.8 | | |
| **Education** | | | | | | | | | | |
| Primary | | 6 | 3.1 | | | | 2 | 2.5 | | |
| Junior secondary | | 17 | 8.8 | | | | 5 | 6.3 | | |
| Senior secondary | | 59 | 30.6 | | | | 18 | 22.5 | | |
| Tertiary | | 110 | 57.0 | | | | 55 | 68.8 | | |
| **Employment status** | | | | | | | | | | |
| Full-time | | 49 | 25.3 | | | | 27 | 33.7 | | |
| Part-time | | 34 | 17.6 | | | | 14 | 17.4 | | |
| Retired | | 54 | 28.0 | | | | 19 | 23.8 | | |
| Not working | | 56 | 29.0 | | | | 20 | 25.9 | | |
| **Marital status** (Married) | | 97 | 51.3 | | | | 37 | 41.8 | | |
| **Religion** | | | | | | | | | | |
| Christian | | 82 | 43.6 | | | | 32 | 42.1 | | |
| Catholic | | 20 | 10.6 | | | | 8 | 10.5 | | |
| Buddhism | | 17 | 9.0 | | | | 10 | 13.2 | | |
| Traditional Chinese beliefs | | 5 | 2.6 | | | | 2 | 2.6 | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| No Religion | 64 | 34.0 | | | 24 | 31.6 | | |
| **Work hours per week (among those employed) (N=31)** | | | 32.24 | 16.47 | | | 33.32 | 16.34 |
| **Have received training/education on EoLC (yes)** | 34 | 17.9 | | | 19 | 24.7 | | |
| **Have received training/education on bereavement care (yes)** | 48 | 25.3 | | | 23 | 29.9 | | |
| **Have bereavement experience in past 2 years (yes)** | 83 | 42.3 | | | 31 | 38.3 | | |
| **EoL experience of family/friends (yes)** | 63 | 32.3 | | | 46 | 59.7 | | |
| **EoL experience - Relationship with this person** | | | | | | | | |
| Close family members | 25 | 36.8 | | | 15 | 46.9 | | |
| Friends | 32 | 47.1 | | | 17 | 53.1 | | |
| Others | 11 | 16.2 | | | -- | -- | | |
| **Intimacy of the relationship with the patient (1-5)** | | | 3.32 | .88 | -- | -- | | |
| **PHQ** (0-6) | | | .28 | .60 | | | .25 | .54 |
| **PSS** (0-56) | | | 22.34 | 7.27 | | | 27.32 | 4.56 |
| **Overcommitted** (0-4) | | | 1.28 | .74 | | | 1.02 | .61 |
| **Flexible Personality** (1-5) | | | 3.26 | .74 | | | 3.33 | .79 |

*Note: the demographic information of one person was missing due to uncompleted information provided.

The findings suggested that applicants who successfully completed EoL care training in Phase I was a diversified group with varieties in age, education, employment status, as well as experience in volunteer activities. Nearly one third of these volunteers were male, about 72.5%-74% of them were aged between 40 and 79, more than half of them had received high education in colleges or universities, about half of them were married and had Christian or Catholic religion. Meanwhile, about half of these volunteers were retired or not working currently, ranging from homemakers with less education to highly educated professionals, from no volunteer experience to more than 4 years of volunteer experience. The diversity has implication not only on the design of the education programme to meet the needs of volunteers with different backgrounds, but also on later volunteer management and task allocation by NGO partners.

## 5.4 Outcomes and Impacts

As the evaluation framework was refined in the year of 2018 for evaluating the training effects for core training courses, which was slightly different from the original framework used for the training in the year of 2016 and 2017, we will report the outcomes and impacts for the training in 2016 and 2017, and for the training in 2018, respectively.

### 5.4.1 Outcomes and Impacts for NGO-based training courses (2016-2017)

Pre-training ($T_0$) evaluation and 6 months follow-up ($T_2$) evaluation have been completed by volunteers. As volunteers had been trained by different NGO partners and with different training content, we only report the general findings for the training effects in these two years. Findings suggested that improvements were found in most aspects of EoL competence from $T_0$ to $T_2$, i.e. self-care, communication skills, being accompanying, bereavement care, and emotional support, however, none of these improvements were statistically significant **(Figure 5.2)**.

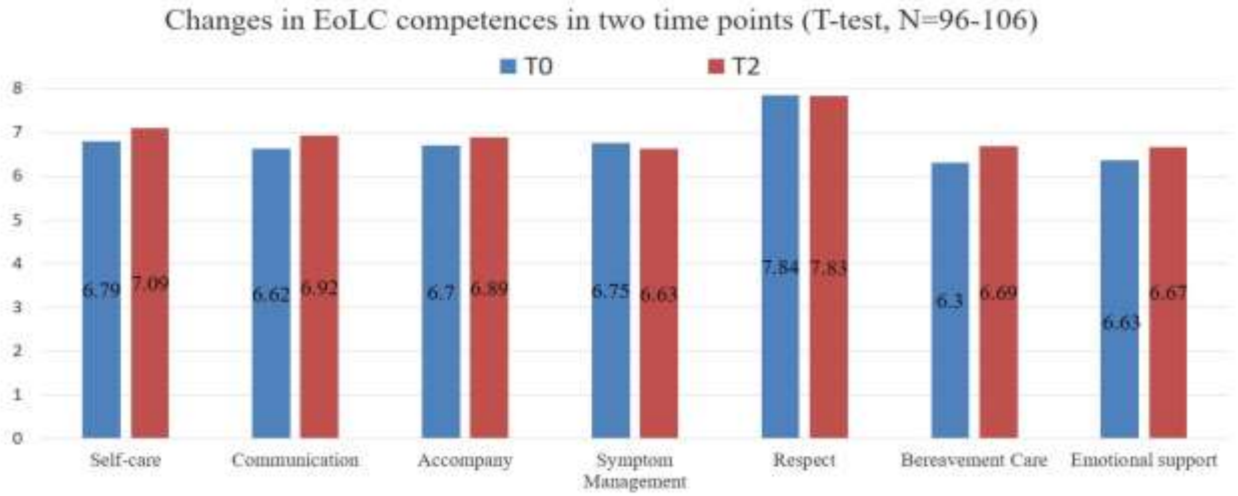

**Figure 5.2** Changes in EoLC competences in volunteers for NGOs training courses (*t*-test, 1-10)

Regarding the death work competence measured by self-competence in death work scale, significant improvements were found in total score of death work competence and subscale of emotional competence of death work (**Figure 5.3**).

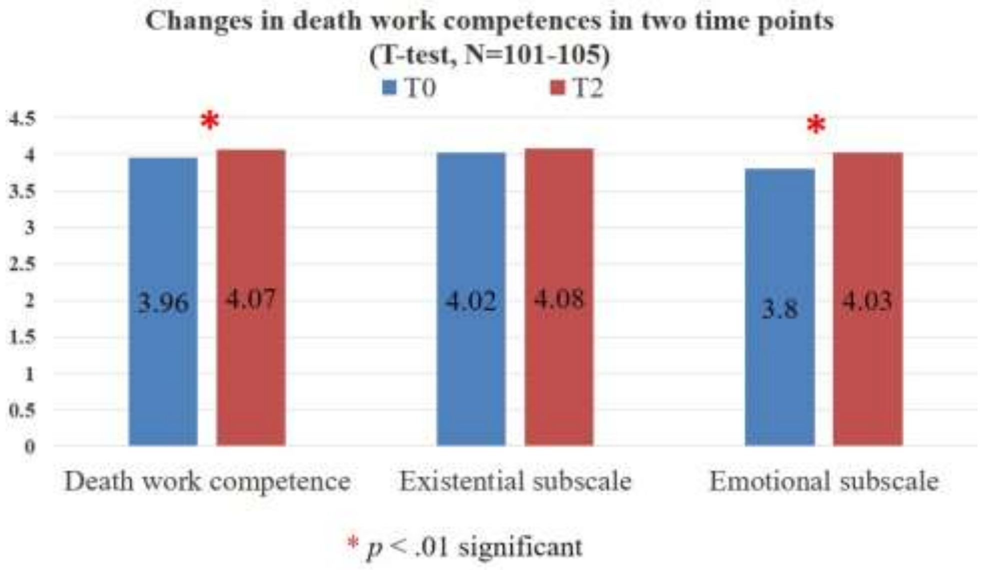

**Figure 5.3** Changes in death work competences in volunteers for NGOs training courses (*t*-test, 1-5)

Regarding impacts, meaning in life and body-mind-spiritual health were measured (**Figure 5.4**). It was found that despite the highly emotionally demanding nature of EoL volunteer work, no adverse effects were found in volunteers' meaning of life and BMS health from pre-training ($T_0$) to up to 6 months post-training ($T_2$).

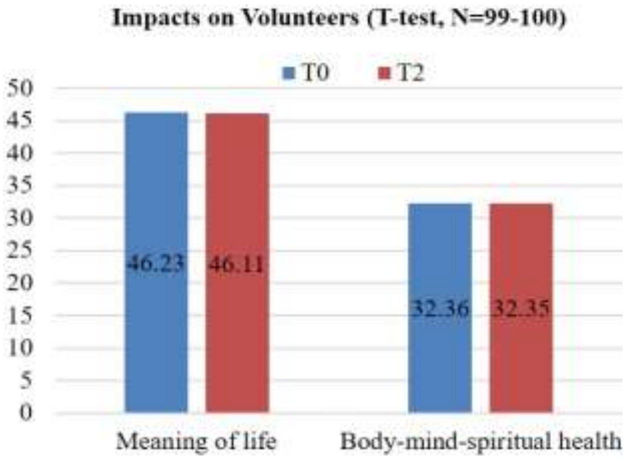

**Figure 5.4** Impacts on Volunteers for NGOs training courses (*t*-test)

### 5.4.2 Outcomes and Impacts for core training courses (2018)

Post training ($T_1$) evaluation has been completed by volunteers, but follow-up ($T_2$) evaluation will only be conducted in July – August, 2018. Findings suggested that significant improvements were found in every aspects of EoL competences from $T_0$ to $T_1$, and the improvements were maintained at T2 (6 months after training). Knowledge on EoLC increased from 6.33 to 7.84 (out of 10). Regarding competences, volunteers reported significantly improved competences in all 6 EoLC competences namely basic EoLC values and knowledge, communication skills, symptom management, EoL decision making, bereavement care, and psychosocial care (**Figure 5.5**).

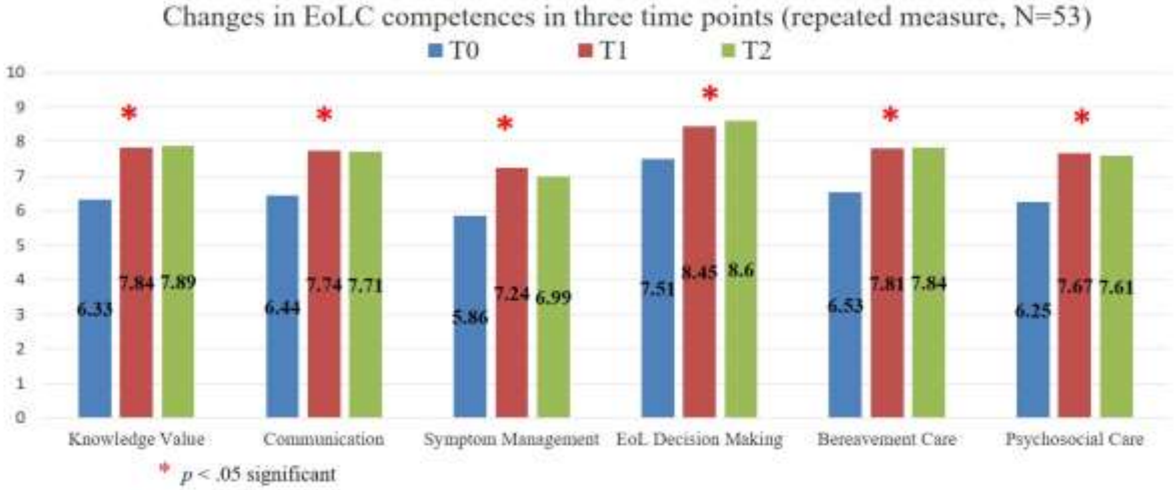

**Figure 5.5** Changes in EoLC competences in volunteers for core training courses (Repeated factor analysis, 1-10)

Regarding the death work competence measured by self-competence in death work scale, significant improvements were found in total score of death work competence and subscale of emotional competence of death work **(Figure 5.6**).

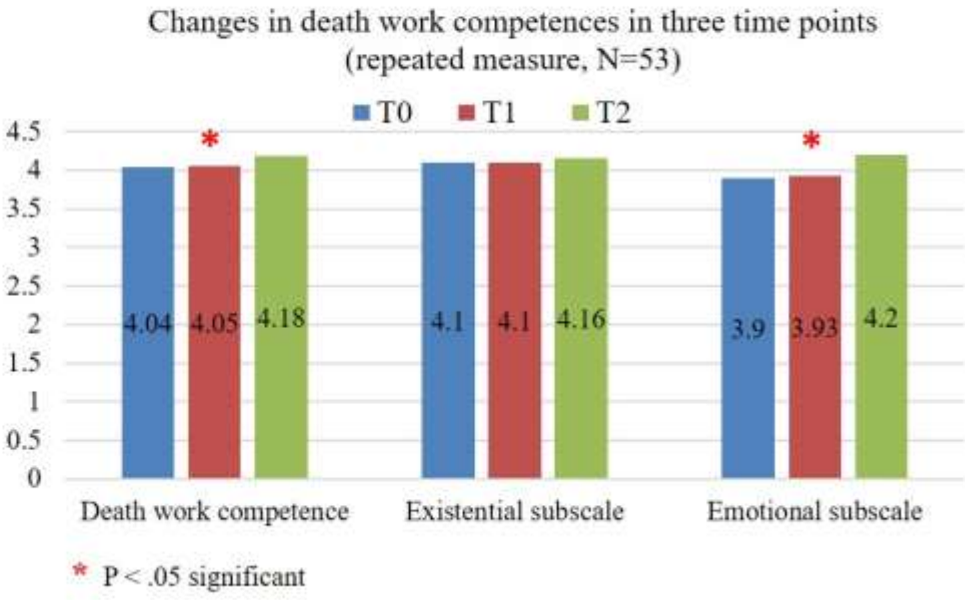

**Figure 5.6** Changes in death work competences in volunteers for core training courses (Repeated factor analysis, 1-5)

Regarding impacts, meaning in life (by Flourish scale) and quality of life (Body-mind-spiritual health scale) were measured (**Figure 5.7**). It was found that despite the highly emotionally demanding nature of EoL volunteer work, no adverse effects were found in volunteers' meaning of life, BMS health, and spiritual health from pre-training ($T_0$) to up to 6 months post-training ($T_2$). Meanwhile, significant improvement was found for the aspect of self-care from pre-training ($T_0$) to post-training ($T_1$), and maintained up to 6 months post-training ($T_2$).

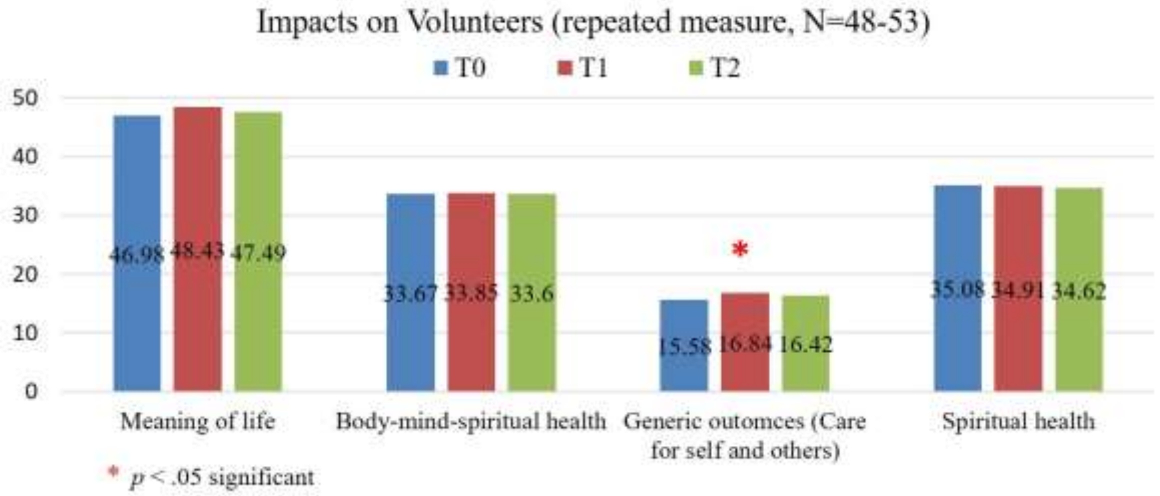

**Figure 5.7** Impacts on Volunteers for core training courses (Repeated factor analysis)

### 5.4.3 Outcomes and impacts from volunteer focus group interview

Two volunteer focus group interviews were conducted in September 2018 on a sample of 17 volunteers who had joined after they completed volunteer core training courses and were supervised by social workers in specific NGOs. The interviews aimed to provide a better picture of volunteer contribution, and also allow more in-depth analysis on the relationship between volunteer involvement and the impacts on patients, family members, as well as volunteers themselves. The questions asked were about the impacts of volunteer training programmes, their experience in providing EoLC volunteer service, their feedback on the received support and coordination from the NGO, and their comments on the content of volunteer training courses. The findings of the interviews were showing below:

1) The positive outcomes and impacts of the volunteer training courses were reported including the improvement in EoLC knowledge and knowledge in symptom management, the enhancement of communication skills, self-reflection, and self-care awareness, and the change of attitude which in turn leads to good preparation for participating in EoLC volunteer service.

2) Most of the volunteer admitted they had positive influences on the patients and their families. Their activities were mainly home visit or phone visit, outing, and escort. Some of volunteers reported to have experience in providing funeral support and bereavement care to families in bereavement. The volunteers identified the importance of their roles in providing emotional and psychosocial support to the patients and their families and the companionship, and they also

emphasized the importance of listening and empathy when communicating with patients and their families.

3) Challenges were reported for providing EoLC service, such as starting the first home visit, having not enough EoLC information for patients and their familes, and the emotional distress they met when the patients they cared for passed away.

4) The support and coordination from NGOs were highly appreciated by the volunteers. They stressed the important roles of NGOs in doing briefing and debriefing, giving promote responses and feedback, providing updated information of EoLC knowledge and skills, providing emotional support, and offering effective coordination and mentorship when volunteers facing challenges in relationships with other volunteers or the patients and their families.

5) The content of core training courses were also highly appreciated by volunteers especially for the EoLC knowledge and communication skills trained in the course. They found these knowledge and skills were not only helpful in strengthening their competences in providing EoLC service, but also important in enhancing their confidence when communicating with te patients and their families. But one difficulty was reported by the volunteer that they found the knowledges were easily forgotten when the training courses finished. Therefore, they hope there could be a method to help them easily access to these knowledge and information even after the courses ended.

## 5.5 Key Performance Achievements

While there is no pre-defined output standard for volunteer capacity building programme under the HKU Project team, the key performance indicators regarding volunteers have been largely achieved (**Table 5.3**). Particularly regarding the enhancement of EoLC competences level as well as meaning in life.

**Table 5.3** Key performance indicator achievements in volunteer capacity building programme

| | Key Performance Indicators | Performance of JCECC volunteer capacity building programme [63] | Achievements[64] |
|---|---|---|---|
| 1 | Volunteers will have a 10% increase in sense of competence in EoLC | **Change in EoLC competences among volunteers upon completion of centralised training**<br>• 18% increase in EoLC competences was detected among volunteers upon completion of training. | 180% achieved. |
| 2 | Volunteers will have a higher meaning in life and quality of life after participating the care | **Change in meaning of life among volunteers as measured by Flourish scale upon completion of centralised training**<br>• Significant but mild improvement of 3% was detected in meaning of life | Achieved. |

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[63] All % changes were calculated by the formula: (new values – old values)/old values.

[64] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

| | | | |
|---|---|---|---|
| | | **Change in quality of life as measured by the body-mind-spiritual health scale upon completion of centralised training**<br>• Slight improvement of 1.2% in quality of life upon completion of volunteer training | Achieved. |

For other output in Phase I of JCECC project, a volunteer coordinator manual “義工組織”, which was developed by organising the experience of volunteer recruitment, the use of screening tool, and the contents in core training programme, was published in June 2018.

## 5.6 Lessons Learned and Future Plan

By summarizing the outcomes and impacts shown above, some lessons were learned: 1) Standardised and centralised core training courses (2018) and NGO-based training courses (2016-2017) were effective in enhancing EoLC competences among volunteers, however, the core training courses were more effective than NGO-based courses no matter in improving volunteers’ EoLC competences or in protecting volunteers from negative impacts on emotion and health during they providing EoLC service. 2) Volunteer screening tool, which was developed for core training courses, helped facilitate selection of suitable volunteers. 3) Continuous support, effective management strategies, and further training are required to maintain training effects on EoLC competences and sustaining motivation.

Therefore, the high number of applications to the core course, the feedback of participating volunteers and NGO partners, and the outcome and impact evaluation on the volunteer core training courses supported the effectiveness of the interventions. Based on these successful experiences, the Project team came up with the following plan for further developing the volunteer competence programme:

### 5.6.1 Enhancing the volunteer core training courses

The centralized 4-session volunteer core training courses developed in the 1st phase covers a comprehensive knowledge base in EoLC competences for volunteers. With the help of the volunteer manual produced in the first phase project, this course will be further enhanced and run as the basic course for volunteers recruited for EoLC services in both home setting and RCHEs.

### 5.6.2 Developing volunteer elective training courses

In order to strengthen volunteers’ skills in selected EoLC domains, provide them with continuous support, and prepare them to provide an expanded scope of services in the model of Integrated Community End-of-Life Care Support Teams (ICESTs), the volunteer elective training courses will be developed. These course will include but are not limited to training on (i) basic physical care for patients, (ii) practical care for patients and caregivers, (iii) communication with family and cohesiveness, and (iv) bereavement care for families.

### 5.6.3 Developing training courses for volunteer leaders

In order to build a sustainable volunteer infrastructure and motivate active participation to support the growth of community-based EoLC, a specialised course will be developed for identified potential volunteer leaders in the NGO Community-based EoLC programmes. The course aims at cultivating leadership among potential volunteer leaders, who may share the responsibilities in recruiting, supporting and mentoring other new volunteers with an aim to ensure the quality of volunteer services. Potential volunteer leaders will be identified by NGOs through a structured screening procedure which will be collaboratively designed with NGOs.

### 5.6.4 Building (IV) E-learning materials for volunteers and volunteer coordinators

In order to respond to the volunteers' need described in the findings from volunteer focus group interviews, the existing information pages on EoLC volunteers will be upgraded to include e-Learning materials and resources used in the training of volunteers and volunteer coordinators. The materials will be accessible online even after the project ends.

### 5.6.5 Developing a new Volunteer Manual for volunteer management

Specialised workshops on theories and effective practices in volunteer management will be developed for potential/existing EoLC volunteer coordinators. The evidence and learning from the evaluation on EoLC volunteer practices in the JCECC Project will shape the volunteer management strategies to be taught in the workshop. In particular, the volunteer management strategies will be used to develop the second volume of volunteer coordinator. While the first volunteer coordinator manual focuses on volunteer recruitment, screening, and training, which are the beginning stages of volunteer programme development, the second volume will focus on evidence-based strategies in continuous support, volunteer retention and management in the EoLC context.

### 5.6.6 Organising Volunteer Appreciation Event

A volunteer appreciation event will be organised where all new and old volunteers participating in the JCECC Project will be invited to celebrate for their contribution and achievements together.

# 6. COMMUNITY STAKEHOLDERS

## 6.1 Background and Objectives

The first satisfaction survey on community stakeholders of the JCECC community-based EoLC programmes has been conducted between March and April in 2018. Survey participants were community partners including service agencies which have referred clients to the JCECC community-based EoLC programme and the RCHEs and CGATs which have participated in the HKAG district-based EoLC programmes. This survey aims at exploring the satisfaction level and views of these community partners regarding the overall contribution and effectiveness of this services.

## 6.2 Methodology

A cross-sectional, self-administered online/paper form survey was used. Participants were recruited from service agencies that previously referred patients to the JCECC Community-based EoLC programmes run by the 4 NGOs and HKAG. These agencies included medical service units, community social service units, and residential care homes for the elderly (RCHEs). Staff who has referred patients to the JCECC community EoLC programme(s), or staff who has provided service to patients and/or family in collaboration with JCECC project were recruited to join the survey. All referrers have been invited.

## 6.3 Participants

158 completed questionnaires were received after sending out 224 of invitations. The response rate was 70.54%. **(Table 6.1)** The average number of patients served or referred to the JCECC project is 7.17 (SD=8.411).

**Table 6.1** Demographic information of participants in stakeholder survey

| | Percentage |
|---|---|
| **Gender (Male)** | 18.47% |
| **Age** [65] | |
| 20-39 | 44.6% |
| 40-59 | 53.5% |
| 60 and above | 0.6% |
| **Profession** [66] | |
| Nurse | 45.5% |

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[65] 1.3% of participants missed reporting their age.

[66] 0.5 % of participants missed reporting their profession.

| | |
|---|---|
| Social Worker | 22.2% |
| Doctor | 11.4% |
| Others [67] | 10.8% |
| Health Worker | 6.0% |
| Program Worker | 2.4% |
| Educator/ Trainer | 1.2% |
| **Work unit [68]** | |
| Social Service Setting (Elderly Setting) | 54.1% |
| Medical Setting (Non-Hospice Ward) | 15.9% |
| Medical Setting (Hospice Ward) | 13.4% |
| Community Geriatric Assessment Team (CGAT) | 2.6% |
| Social Service Setting (Rehabilitation Service) | 1.9% |
| Social Service Setting (Family Service) | 0.7% |
| Others [69] | 10.8% |

## 6.4 Key Findings

### 6.4.1 Overall satisfaction rate

The mean score on the satisfaction level in working with JCECC NGO community-based EoLC service teams is 8.06 out of 10 (SD= 1.355), with 88.1% participants gave a score of 7 or above in this item (**Figure 6.1**). On a scale of 1 to 10, over 90% of participants rated 7 or above on the overall satisfaction level of this service programme and the mean score is 8.19 (SD=1.249) (**Figure 6.1**). Regarding recommendation, 89.8 % of participants said that they were likely and very likely to recommend this service programme to other organisations.

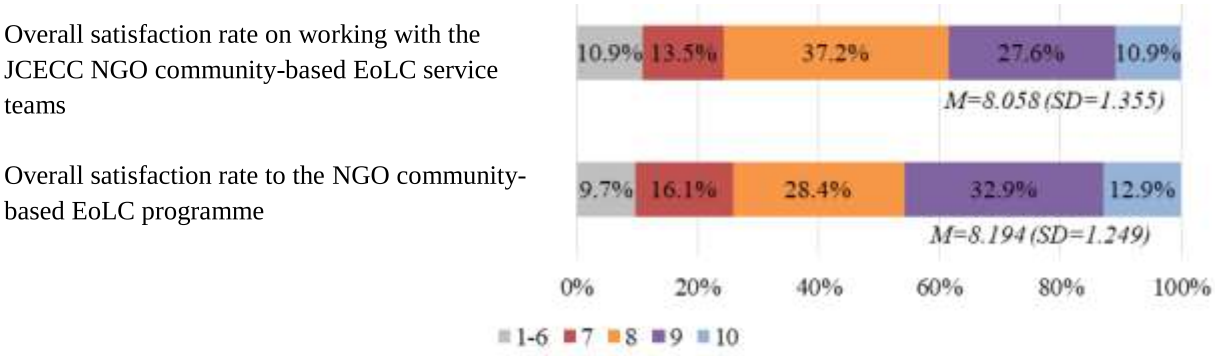

**Figure 6.1** Overall satisfaction rates of community stakeholders towards the JCECC NGO community-based EoLC service teams and the Programme

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[67] Other occupations include aromatherapist, physiotherapist, occupational therapist, expressive art therapist, dietitian etc.
[68] 0.6 % of participants missed reporting their work unit.
[69] Other work units include agency providing out-patient escort service, patient resource center and other non-governmental organisations.

### 6.4.2 Attainment of service objectives

More than 80 % of participants rated 7 or above on the 4 objectives of the NGO community-based EoLC service programme as listed in **Figure 6.2.**

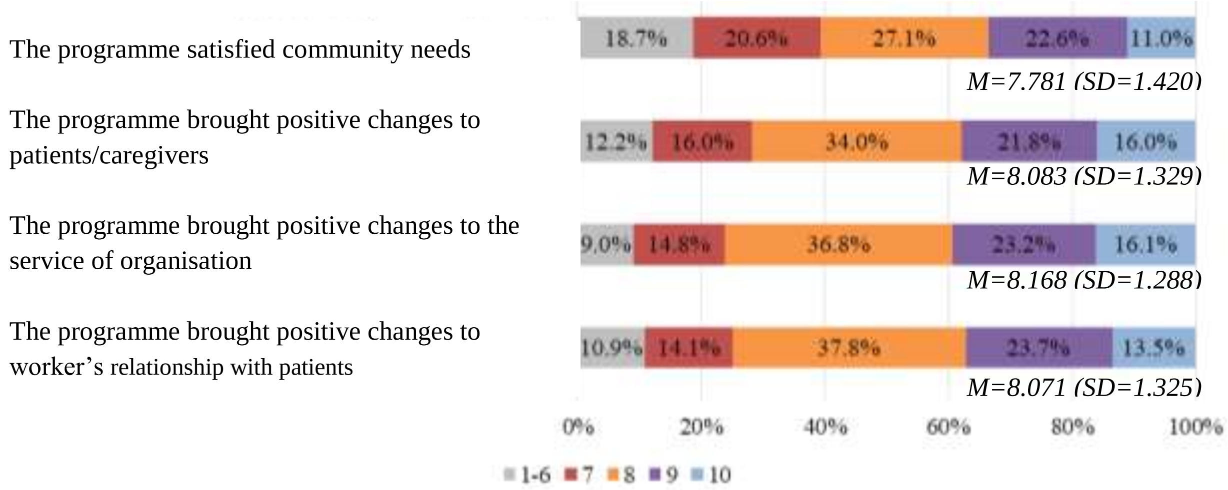


**Figure 6.2** Community stakeholders' rating on the level of attainment of service objectives by the NGO programmes

Qualitative comments suggested that participants highly appreciate the tailor-made, flexible and timely service provided by the NGO programmes which brought about the following two biggest contributions:

(a) bridged the unmet gaps in current end-of-life care service, helped reduce the number of unnecessary hospital admission and relived the pain suffered by patients. The NGO programme provided a more holistic care in the community, which allowed more patients to consider different end-of-life care choices and more willing to stay in community to receive end-of-life care service.

- ○ *"病人及家屬的崩緊放鬆了，有一些病人的病情也有改善。"*
- ○ *"填補醫院舒緩治療團體對社區服務病人的不足，此計劃最大的貢獻是解決了很多病人在社區面對的問題, 令病人能安心在家中休養, 減少病人因照顧上的問題而不能出院的機會, 從而增加醫院病床的流動性."*
- ○ *"可以讓院友免除後期出入醫院之苦"*

(b) Improved relationship and trust among patients, caregivers and medical staff, and helped facilitate open communication on the topics related to EoLC and death.

- *“令醫護人員和病人之間更能建立信任的關係. 每當病人有社區服務的需要求助於醫護人員, 透過貴機構的幫助解決病人的疑難, 病人更能相信醫護人員, 聆聽醫護的建議”*
- *“Filled up the service gap between the clinical team and patient and carer. It was because there is lack of time / contact to discuss with patient and carer on the issue of end of life care especially in the late stage period. Less conflict was noted between clinical team and patient and carer in discussing end of life care after fulfillng the wishes of patient and carer.”*
- *“令服務使用者有更多自決的空間和較正面談論死亡”*
- *“家人表現更信任院舍的護理安排,員工接受培訓後能更體會安寧在院舍計劃的背後理念,擔憂從而減少”*

Finally, most of the comments mentioned their hope of transforming the current service of this project into a routine one, and extend the service to other residential care homes for elderly, and even to the public hospitals.

- *“如果能繼續保留此計劃, 定能讓更多病人受惠”*
- *“期望計劃可持續營運下去”*
- *“冀能於全港各區域增加同類服務”*

## 6.5 Lessons Learned and Future Plan

The community stakeholder survey provided additional evidence on the effectiveness of the community-based EoLC programmes from the perspective of collaborating community partners. The findings from this survey echo with the findings from the evaluation on patients and caregivers that the programmes helped improve quality of life of patients and caregivers. More importantly, the responses reflected that the services filled the existing service gaps in the community for EoL patients and even promoted communication between patients and family members with the community partners, which have implications on the continuity and coordination of care across care settings, and thus satisfaction of patients and caregivers towards the overall care experience in the community. To further strengthen the coordination of care among different service providers, engagement activities, such as training, sharing platforms, or further opinion surveys, targeting on these community partners can be considered in future.

# 7. GENERAL PUBLIC

## 7.1 Programme Descriptions

The knowledge and skill transfer programme targets on the general public with an aim to raise the public awareness and knowledge on EoLC. In the past three years, the HKU Project team has organised altogether 48 public seminars and forums on various topics related to EoLC, benefiting more than 7,300 general public. A mini-movie “My Little Story with Mom” featuring a story on EoLC was produced by the team, and a Premiere was held in late 2017 with over 1,000 participants. The extended impacts of the mini-movie reaching the general public was facilitated by wide media coverage of the Mini-movie in YouTube Channel, movie trailer, Facebook page, and Newspaper coverages. Under the collaboration with other project partners, 15 episodes of RTHK Radio programme were delivered, and 19 issues of newspaper column in Ming Pao on EoLC topics were published with around 2,700,000 readers. Two International Conferences have been organised in the past two years. The second conference was held in June 2018, with 3 renowned international experts in EoLC as keynote speakers, and over 450 participants from 10 different countries. Apart from these, a set of communication card game for facilitating conversations related to EoLC has been developed in both English and Chinese. More than 1000 sets have been distributed to the public and both local and international professionals in the mini-movie premiere, various public education activities, and the international conference.

## 7.2 Pledged Deliverables

### 7.2.1 Inauguration Ceremony

Inauguration Ceremony were held to launch the Project. The ceremony was held on January 6, 2016, with officiating guests including Professor Peter Mathieson, Vice-Chancellor of the University of Hong Kong (“HKU”), Mr. Li Ka Cheung, Steward of The Hong Kong Jockey Club (“HKJC”) and Mr. Ko Wing-man, Secretary for Food and Health Bureau, HKSAR. A symposium and a press conference were held after the Launch Ceremony. 330 participants from NGOs, healthcare organisations, tertiary institutions, parents, families and individuals who were interested in JCECC Project attended the ceremony.

### 7.2.2 Public Seminars

48 public seminars and forums on various topics based on the themes of end-of-life care were held during the project period, benefiting more than 7,300 general public. Renowned local, regional and overseas speakers were invited to speak in the seminars and forums, which included Professor

Ilora Finlay from United Kingdom, Professor Chantal Chao from Taiwan, Professor Danai Papadatou from Greece, David Kissane from Australia, etc.

### 7.2.3 International Conferences

Two international conferences were held to create wisdom-sharing platforms for local and overseas academics, experts, as well as professionals and other stakeholders including caregivers and parents, families and other interested individuals, to share the latest research and best practices to support patients and families.

The Conference on Collaboration in Creating Compassionate Holistic End-of-Life Care for the Future was held on March 8 to 9, 2017 and attract about 390 participants. It comprised three keynotes (‘Building Community Capacity for End-of-Life Care: A Public Health Approach’ by Professor Allan Kellehear from University of Bradford, United Kingdom; ‘Optimizing Holistic End-of-Life Care: A Multidimensional Approach’ by Ms Shirley Otis-Green from Coalition for Compassionate Care of California, USA and ‘Compassionate Healing: Dancing with the Patients and the Caregivers at End Stage of Life’ by Professor Tang Lili from Beijing Institute for Cancer Research, China). The Conference also included a pre-conference workshop, two parallel seminars, oral and poster presentations sessions.

The international conference 2018, titled Innovation and Impact: The Review and Vision of Community End-of-Life Care was held on June 20 to 21, 2018. It provided a platform for local and international practitioners, educators and researchers exchanging inspiring practice and research wisdom as well as establishing partnership.  450 participants attended the Conference. It comprised three keynotes (‘Palliative and Healthcare Environment: Global Community Based Palliative Care Development - A Progress Report and Way Forward’ by Dr Stephen Connor from Worldwide Hospice Palliative Care Alliance, USA; ‘Building Human Capacity in Palliative Care: Local, National and International Experiences’ by Professor Irene Higginson from King’s College London, United Kingdom and ‘Community Engagement in End-of-Life Care’ by Dr Wang Ying Wei from Tzu Chi University/ Tzu Chi General Hospital, Taiwan). The Conference also included three pre-conference workshops, parallel oral and poster presentations, invited seminars and symposia and post-conference activities/visits.

### 7.2.4 Mini-movie Premiere and Seminars

In 2017, the Project produced a mini-movie titled “My Little Story with Mom”, aimed to advocate the importance of family communication in end-of-life care. The movie featured celebrities included Ms. Susan Shaw and Miss Catherine Chau. A mini-movie premiere was held in late 2017 at HKU Grand Hall with over 1000 participants. The movie and the premiere received a very positive response and its extended impacts was facilitated by a wide media coverage included YouTube, Facebook page and newspaper coverage. To further advocate the theme, four community screening and seminars of the mini-movie were held in 2018 at local cinemas, with a total of around 400 participants.

### 7.2.5 Press Conference

Besides the press conference on the introduction of the JCECC Project at the beginning of the Project in January 2016, a press conference on Community-wide Survey on End-of-Life Care in Hong Kong 2016 were also held on November 1, 2016. The evaluation result and achievement of the Project was announced during the time. NGO partners and cases, including family members and volunteers were invited to share their feedback and impression of the Project. Over 10 presses from newspapers, radio channels and online medias participated in the press conference.

### 7.2.6 Videos

11 videos were produced to promote the project, raise public awareness on end-of-life care and serve as self-learning materials of the online platform **(Table 7.1)**.

**Table 7.1** Videos produced for the promotion of the JCECC Project

| No. | Category | Topic | Publication Month |
|---|---|---|---|
| 1 | Project Video | JCECC Project Introduction Video | March 2016 |
| 2 | | JCECC Project Highlight | January 2018 |
| 3 | Video Story | 心安 ・ 家寧 | July 2016 |
| 4 | | 承伴 ・ 諾行 | April 2017 |
| 5 | | 擁抱晚晴 心靈關顧 | September 2017 |
| 6 | | 有您幫助的堅持 | November 2017 |
| 7 | | 醫社無縫 | December 2018 |
| 8 | | 樂聚.回憶 | December 2018 |
| 9 | E-learning Video | Basic Principles for Someone Experiencing Loss and Grieving | June 2016 |
| 10 | | An Overview of the Different Phases of a Life-threatening Illness | June 2016 |
| 11 | | Applying Logotherapy in End-of-Life and Bereavement Care | September 2016 |

### 7.2.7 Radio Programme

Collaborated with the Radio Television Hong Kong (“RTHK”), the Project held 15 episodes of radio programme at RTHK “Healthpedia (精靈一點)” in 2016 and 2017 covering a varieties of themes of end-of-life care (**Table 7.2**). All project partners made contributions by providing speakers for the programme.

**Table 7.2** Radio programmes held by the JCECC Project teams

| No. | Category | Topic | Date |
|---|---|---|---|
| 1 | Radio Programme | 「精靈一點」社區臨終護理 | March 23, 2016 |
| 2 | | 「精靈一點」締造豐盛晚年生活 | March 30, 2016 |
| 3 | | 「精靈一點」給照顧者的話 | April 6, 2016 |
| 4 | | 「精靈一點」院舍安寧服務 | April 13, 2016 |
| 5 | | 「精靈一點」在家安寧服務 | April 20, 2016 |
| 6 | | 「精靈一點」安寧醫療服務的專業培訓 | April 27, 2016 |
| 7 | | 「精靈一點」醫院定屋企好？ | September 15, 2017 |
| 8 | | 「精靈一點」有病、無痛 － 徵狀處理 | September 22, 2017 |
| 9 | | 「精靈一點」食得是福 － 健康飲食 | September 29, 2017 |
| 10 | | 「精靈一點」照顧易啲啲 – 起居照顧 | October 6, 2017 |
| 11 | | 「精靈一點」開心秘笈 | October 13, 2017 |
| 12 | | 「精靈一點」 － 言「揀」意賅 | October 20, 2017 |
| 13 | | 「精靈一點」 － 安樂窩 | October 27, 2017 |
| 14 | | 「精靈一點」 － 自己話事: 預設醫療指示 | November 3, 2017 |
| 15 | | 「精靈一點」 － 醫社無縫 | November 10, 2017 |

### 7.2.8 Newspaper Column

Collaborated with Ming Pao, the project produced 19 issues of newspaper columns on different topics of end-of-life care (**Table 7.3**). Around 2,700,000 readers were reached. All project partners provided rich content to the columns, with different case stories from the patients and families, different expert advices and useful tips from health and social care professional from HKU, CUHK and NGO partners.

**Table 7.3** Newspaper Columns produced under the JCECC Project

| No. | Category | Topic | Date |
|---|---|---|---|
| 1 | Newspaper Column | 延長生命? 四處走走? 不帶遺憾? 最後一程有得揀 | September 19, 2016 |
| 2 | | 一家人 不能盡在不言中 溝通化除誤解 促進關係 | October 3, 2016 |
| 3 | | 我: 不用救 安詳去 簽妥「預設指示」 生死兩相安 | October 17, 2016 |
| 4 | | 老人院友 也可自決最後旅程 | October 31, 2016 |
| 5 | | 安寧照顧 走進家中 心理醫護多方面支援 | November 14, 2016 |
| 6 | | 義工同行 安在家終 | November 28, 2016 |
| 7 | | 樂而忘病 死都要玩 | December 12, 2016 |
| 8 | | 肺病唔順氣 還須心藥醫 | December 26, 2016 |
| 9 | | 對話，是最佳晚期治療 | January 9, 2017 |
| 10 | | 獲關懷支援 心安便是家 | January 23, 2017 |
| 11 | | 家級紓緩院舍 開「告別」派對 | February 20, 2017 |
| 12 | | 最後日子 放下「三不」重拾愛 | March 6, 2017 |
| 13 | | 食完麵見多幾面 街坊笑聲解病愁 | March 20, 2017 |
| 14 | | 大限到，點解唔話我知 | April 3, 2017 |
| 15 | | 迎生命終章 短遊也盡興 | April 17, 2017 |
| 16 | | 腦退化不懂吞嚥陷兩難 | May 1, 2017 |
| 17 | | 誰說又老又病就無用? | May 15, 2017 |
| 18 | | 「送死」之後 照顧者需減壓? | May 29, 2017 |
| 19 | | 久病牀前無賢妻? 老人照顧老人谷到爆! | June 12, 2017 |

### 7.2.9 "Cradle to Grave" Gamecards

The "Cradle to Grave" Gamecard was designed by the Project team and was disseminated starting from late 2017. The card acted as a tool to enhance patients and family members' communication on end-of-life care. Over a thousand of copies were disseminated to the public and healthcare professionals. The general feedback is very positive and a number of NGOs often use the cards as a tool for communicating with the case clients.

### 7.2.10 Project Website and APP

A project website (jcecc.hk) was created to promote the Project, especially to consolidate the experience in the project's activities and achievements and to form an online platform to various stakeholders including healthcare professionals, patients, families, peers and general public. Employing both textual and multimedia elements, the web-based knowledge hub encouraged self-learning and disseminated end-of-life care contents. The project website attracted about 250,000 view times during the project period. In 2017, the Project also developed an APP called "安寧遊". It is an APP to facilitate patients and family members to travel safely and easily with specific advices regarding end-of-life care.

### 7.2.11 Publications and Newsletters

Four bilingual newsletters and e-newsletters (安寧 · 誌) were published to promote the project, highlight its development and the related activities being organised. Over 90,000 readers were reached, including but not limited to HKU staff, students, alumni, district councillors, stakeholders in the third sector and other recipients in our database.

Three Chinese publications ("心安家寧系列：安寧概念篇, 義工組織篇, 放鬆練習篇") and an English academic publication ("Innovation • Impact: The foundation of community-based end-of-life care in Hong Kong") were also published in June 2018 and April 2019 respectively, which aims to disseminated variety of end-of-life care knowledge and provide evidence-based references of the Project to the public and professionals.

## 7.3 Evaluation Framework

Two studies were used to assess the outcomes and impacts of the knowledge and skill transfer programme (**Figure 7.1**). Regarding outcomes, participants of public talks, seminars, and international conferences were invited to a post-programme satisfaction survey which measured their level of satisfaction towards the appropriateness of the topics and contents of the programme. When it comes to impacts, a 3-wave community-wide public survey was designed to capture the knowledge, attitude and preferences towards EoLC among general public. These surveys were carried out in form of telephone survey of 20-30 minutes administered by the Social Science Research Centre (SSRC), the University of Hong Kong. A target of 1,500 respondents who are Hong Kong residents aged 18 or above was set for each wave. The three surveys were separated by a 15-month interval. The first wave was conducted between January - March in 2016, and the second wave was carried out between April – May in 2017 respectively. The third wave was conducted between July – September 2018. Comparison between the three waves will be reported.

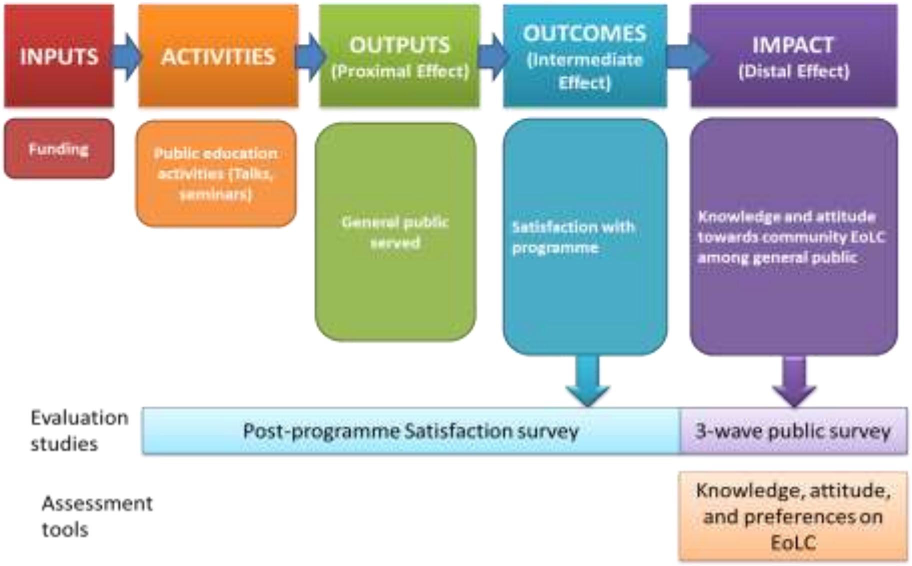


**Figure 7.1** Evaluation framework on knowledge and skill transfer programme

## 7.4 Outcomes

692 participants in the skills and knowledge transfer programmes respondeded to the post-programme satisfaction survey. On a 5-Likert scale (from ‘Strongly disagree’ to ‘Strongly agree’), 43.4% strongly agreed and 53% agreed that they were satisfied with the workshops, suggesting a very high satisfaction rate. 45.5% strongly agreed and 51% agreed programmes were inspiring. 61.4% strongly agreed and 35.9% agreed the speakers at the programmes were knowledgeable. 36.6% of respondents strongly agreed and 52.4% agreed that the events increased their knowledge in EoLC. These results supported the effectiveness of the skills and knowledge transfer programme in inspiring the general public on EoLC issues, and in transferring skills and knowledge from experts to the public.

## 7.5 Impacts

### 7.5.1 The sample

1,600, 1,515 and 1523 respondents were surveyed in the 2016, 2017 and 2018 survey, with a response rates of 62%, 57% and 79.7% respectively. In all 3 waves, similar gender ratios and education level were observed, with around one-third were male, and approximately 8 in ten have attained secondary school education or above (**Table 7.4**). However, respondents in 2018 sample were older compared to 2016 and 2017, with a higher portion of respondents age 61 and above (43.4% in 2018, 40.7% in 2017 and 33.9% in 2016).

**Table 7.4** Demographics of respondents in three waves

| | 2016 wave | 2017 wave | 2018 wave |
|---|---|---|---|
| Gender (Male) | 38.9% | 37.1% | 36.6% |
| Age *** | | | |
| 18-40 | 22.6% | 19% | 17.7% |
| 41-60 | 43% | 39.9% | 39% |
| 61 and above | 33.9% | 40.7% | 43.3% |
| Education attainment | | | |
| No formal education - kindergarten | 3.6% | 3.2% | 3.8% |
| Primary school education | 15.9% | 17.6% | 17.6% |
| Secondary school education | 41.9% | 42.5% | 43.9% |
| Tertiary education or above | 38.6% | 36.7% | 35.3% |

*Note.* ****p*<.001 for comparing group difference; the 2018 wave respondents were found to be older compared to 2016 and 2017 wave suggested by *Chi*-square test.

## 7.5.2 Key Findings

### 7.5.2.1 Knowledge on EoLC

Knoweldge on EoLC-related terms

**Figure 7.2** shows the differences on the percentage of respondents who have heard about different terms related to EoLC in 2016, 2017 and 2018 waves. The findings from all 3 years were presented to show the trend of changes, and the chi-square tests were conducted to explore the changes between 2016 and 2017, between 2017 and 2018, and between 2016 and 2018 respective. The changes in different professional terms showed differentiated trends as below:

*Steady improvement across years:*

- the percentage for having heard of end-of-life care “安寧照顧” showed significant and steady increase in each year, across 2016, 2017 and 2018 (30% in 2016 vs. 34.5% in 2017 vs. 39% in 2018), which resulted in an increase of 30% between 2016 and 2018 (*p*<.001).

*Delayed improvement occurred in second year:*

- Regarding Palliative care “紓緩治療”, the proportion which have heard of the term remained unchanged between 2016 and 2017, but significantly increased between 2017 and 2018, resulted in a significant increase by 21.3% between 2016 and 2018 (37.6% (2016) vs. 45.6% (2018), *p*<.001).

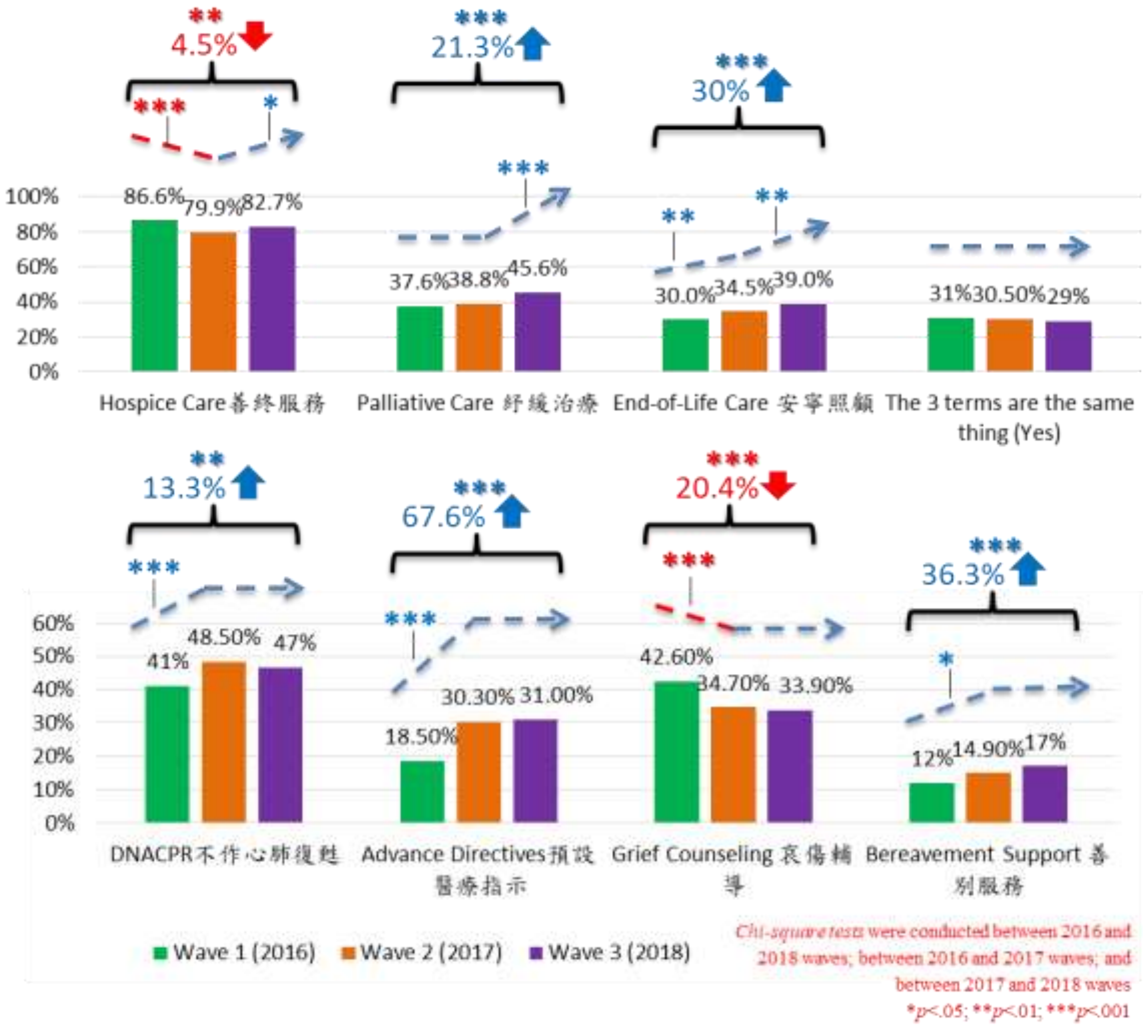
*Significantly improved in first year and levelled off:*

- Moreover, the percentage for having heard of the following professional term experienced a drastic increase from 2016 to 2017 (*p*<.05 to *p*<.001), but levelled off between 2017 and 2018: AD “預設醫療指示” (18.5% (2016) - 30.3% (2017), 31% (2018)), “DNACPR 不作心肺復甦術” (41.2% (2016) - 48.5% (2017) – 47% (2018)), and Hospice Care/Services “善終服務”

(12% (2016) – 14.9% (2017), 17% (2018)). These results in significant increase by 67.6% in the awareness on AD (*p*<.001), 13.3% increase in DNACPR (*p*<.01), and 36.3% increase in bereavement support (*p*<.001).

*Overall reduction*

- Hospice care "善終服務", an older term for EoLC, and Grief Counselling "哀傷輔導", showed significant reduction in the percentages of respondents who have heard of them. The percentages of hearing the term reduced significantly for Hospice care in the first year, and it bounced back somehow in the second year, but an overall significant reduction by 4.5% was recorded between 2016 and 2018 (86.6% (2016) vs. 82.7% (2018), *p*<.01). Regarding Grief Counselling, it experienced a significant reduction in the percentage of reports on having heard of it in the first year, and then levelled off in the second year, resulting in an overall reduction of 20.4% between 2016 and 2018 (42.6% (2016) vs. 33.9% (2018), *p*<.001).



*Chi-square tests* were conducted between 2016 and 2018 waves; between 2016 and 2017 waves; and between 2017 and 2018 waves
*$p$<.05; **$p$<.01; ***$p$<.001

**Figure 7.2** Percentages of respondents who have heard about different terms related to EoLC in 2016, 2017 and 2018 waves of public survey

The overall awareness on all these terms related to EoLC increased by 10.4% in 2018 wave when compared to 2016 wave[70]. The majority of public (approximately 69% in 2016, 69.5% in 2017 and 71% in 2018) think that the three terms, Hospice, Palliative Care and End-of-Life Care are different. It can be inferred that the awareness on the service difference is relatively high.

### Knowledge on service components in EoLC

Survey respondents were asked an open-ended question "What are the service components in EoLC?". The five most frequent responses in 2016, 2017, and 2018 surveys suggested that respondents perceive a holistic approach of EoLC which encompasses physical-psychosocial-spiritual care. This pattern was more evident in 2017 and 2018 (**Table 7.5**). When comparing the differences between three waves, it was found that the "Don't know" responses were the most frequent response, however, it dropped significantly from 38.7% in 2016 to 34.1% in 2017 and 30.8% in 2018 ($p$<.001), equivalent to a reduction of ignorance by 20.4% across three years. This may imply an increase in awareness on EoLC components.

**Table 7.5** Comparison of top 5 responses towards "What are the service components in EoLC?" in 2016, 2017 and 2018 waves of public survey

| | Top 5 responses in 2016 (N=1,600) | Top 5 responses in 2017 (N=1,515) | Top 5 responses in 2018 (N=1,523) |
|---|---|---|---|
| 1st | Don't know (38.7%) | Don't know (34.1%) | Don't know (30.8%) |
| 2nd | Psycho-counselling 心理輔導 (29.1%) | Psycho-counselling 心理輔導 (27.3%) | Medical care & support 醫療護理/支援 (27.9%) |
| 3rd | Spiritual Care 心靈關顧 (14.7%) | Medical care & support 醫療護理/支援 (25.8%) | Psycho-counselling 心理輔導 (25%) |
| 4th | Hospitalisation 住院 (10.8%) | Spiritual Care 心靈關顧 (22%) | Homecare services 家居照顧 (22.1%) |
| 5th | Homecare services 家居照顧 (10.6%) | Pain/Symptom relief 疼痛/徵狀紓緩 (17%) | Spiritual Care 心靈關顧 (21.3%) |

When the changes in the frequency of various responses towards this question were explored, significant increase in the frequency across years were found on "spiritual care", "pain and symptom management", and "medical care and support" ($p$<.001) **(Figure 7.3)**. However, there was significant reduction in the frequency of "psychosocial support and counselling" ($p$<.01). Yet, 25% respondents mentioned this component in 2018. Apart from that, respondents also mentioned service settings. It was found that respondents became less likely to mention hospitalisation in 2018 and 2017 as compared to 2016 ($p$<.001), at the same time, they became more likely to mention home care services (10.6% (2016) vs. 15.4% (2017) vs. 22.1% (2018), $p$<.001). Residential care home service has also been mentioned but in a relatively low frequency. These findings suggested that the public has significantly increased awareness on home care services as one part of EoLC.

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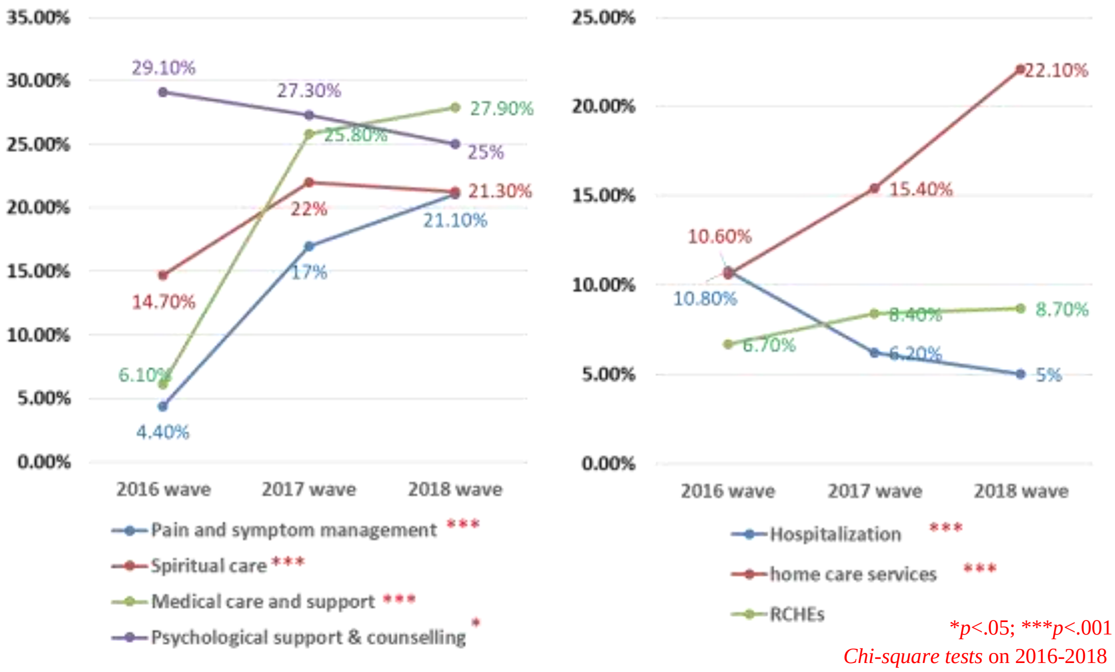
[70] This was calculated by comparing the changes in % of the total number of positive response (have heard of the term) on all 7 EoLC related terms between 2016 and 2018.



*p<.05; ***p<.001
*Chi-square tests* on 2016-2018

**Figure 7.3** Changes in the frequency of various responses towards "What are the important components in EoLC?" across 2016, 2017 and 2018 waves

## Knowledge of Advance Care Planning

**Figure 7.4** shows the general knowledge of Advance care Planning in the 2018 wave of the public survey. The question was being newly added to the 2018 wave in order to tab on the general public knowledge and attitude of Advance Care Planning in general. The percentage of hearing Advance Care planning (ACP) is 8%. In this 8%, 44 % of those who have heard of ACP know what it is and only 12% of them have made Advance Care plan themselves.

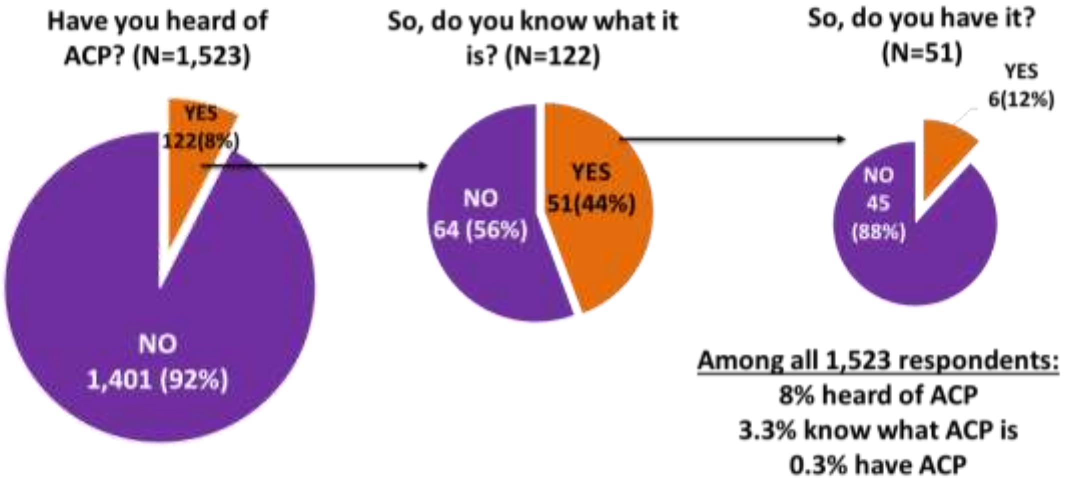


**Figure 7.4** Percentage of respondents' knowledge of Advance Care planning in 2018 wave of public survey

#### 7.5.2.2 Attitudes towards EoLC

Perceived effectiveness of EoLC

Respondents were asked if they think their quality of life would be improved by receiving EoLC if they were in the last 6 months of life. Responses in the three waves suggested that seven in ten people believed in the effectiveness of EoLC (**Figure 7.5**). Moreover, the percentage of positive response remained more or less the same between the first and second year, but significant increase was observed in 2018, which results in an overall increase of 5.4% of support towards the effectiveness of EoLC. In other words, the public has become more positive towards the effectiveness of EoLC across the 3-year Project.

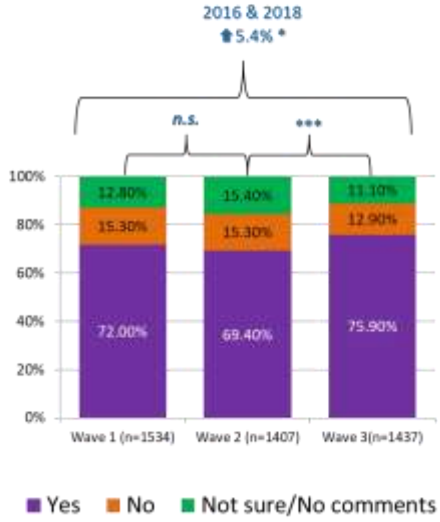
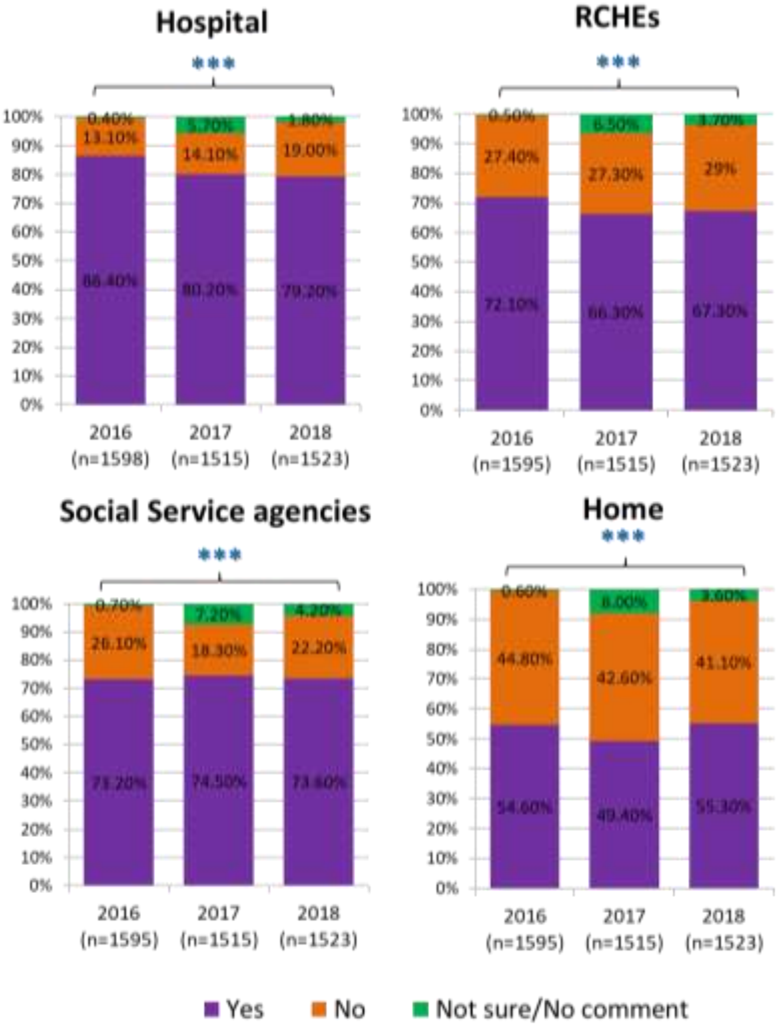


**Figure 7.5** Public perception on effectiveness of EoLC between 2016, 2017 and 2018 waves of public

Preferences on EoLC places

The Preferences on place of care in EoL were compared between three waves (**Figure 7.6** ). In this question, respondents could choose more than one place (hospital, RCHEs, home, and social service agencies). While all three waves are presented here, *Chi-square tests* were conducted to compare 2016 and 2018 waves to explore any overall changes across three years.

An overview on these findings suggested that in all 3 waves, hospital was still the most popular choice (86.4% in 2016, 80.2% in 2017, 79.2% in 2018). However, at least around half of the respondents showed their preference for EoLC in two community settings, including social service agencies (73.2% in 2016, 74.5% in 2017, 73.6% in 2018), and domestic home (54.6% in 2016, 49.4% in 2017, 55.3% in 2018). Around 6 to 7 out of 10 of the respondents expressed preference for RCHEs (72.1% in 2016, 66.3% in 2017, 67.3% in 2018) as well. These provided support for the importance of developing community-based EoLC to expand care choices for the public. Although there were significant differences found on the preference for each setting between 2016 and 2018 by *Chi-square* tests (*p*<.001), the pattern of changes varied across settings as identified by multiple comparisons between dichotomized variables of these settings.



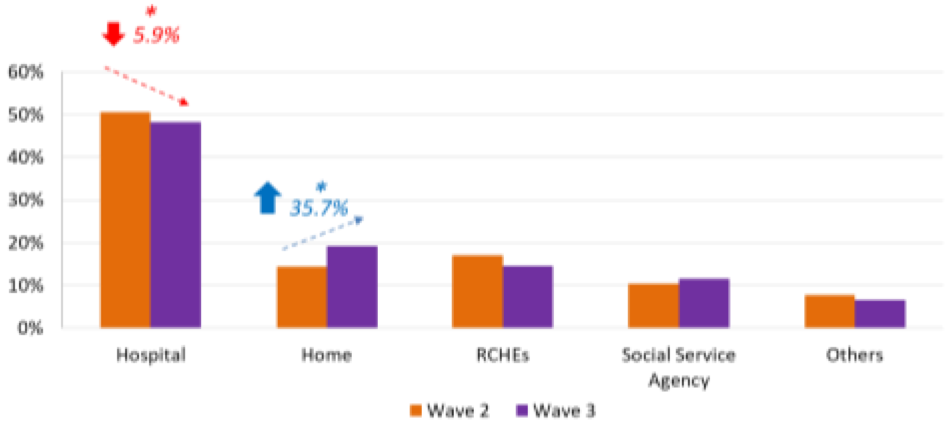
****p*<.001
*Chi-square tests* on
2016 and 2018

**Figure 7.6** Preferred place of care in EoL in 2016, 2017 and 2018 public survey

- For hospital, the significant changes rested on the proliferation of the "No" and "Not sure" responses, while significant reduction in "Yes" responses. This means that the public has become less likely to opt for hospital for EoLC or they started to question this option.
- For RCHEs, the significant differences came from significantly reduced percentage of "Yes" response coupled with increase in "Not sure" response. No significant changes in the percentage of "No" response. This may imply that there were more people who had doubts over this option, but not necessarily rejected this option.
- Regarding social service agencies and home setting, the significant differences were caused by the reduced percentage of "No" along with an increase in "Not sure" response, but no significant change in "Yes" response. In other words, the support gained by these community settings remained stable, but for others who did not show support, they became less likely to explicitly reject these options, they expressed doubts instead.

One common features of the changes in all four settings is the significant increase in the proportions of “Not sure/no comment” response. The emerging proportions of response of “Not sure/No comment” might imply needs for more education and information on the available choices of EoLC in these settings in order to facilitate informed choices. Overall, the support reduced by 8.3% and 6.7% for hospital and RCHEs in 2018, whereas there were 0.5% and 1.3% increase in the support for social service agencies and home by 2018.

In 2017 and 2018 waves, respondents were also asked to choose one most suitable place for providing EoLC (**Figure 7.7**). Despite hospital was still the most popular option, it was found that the support for hospital significantly reduced by 5.9% (*p*<.05) while those who opted for home significantly increased by 35.7% (*p*<.05).



**p*<.05

**Figure 7.7** Most suitable place for providing EoLC in 2017 and 2018 waves of public survey

### Preferences on places of death

When it comes to places of death, again, although hospital remains the most frequently chosen place constituting 55% in previous two waves, the percentage in the 2018 wave decreased to around 51% followed by home, which accounted for 24% in 2016, 21% in 2017 and 22% in 2018 respectively (**Figure 7.8**). However, these changes were insignificant. Apart from these two options, other responses were quite scattered, except for “No preference/Don’t know” which showed a significant increase in percentage in 2017 and 2018 as compared to 2016 (*p*<.001). Elderly/nursing homes and hospice/specialised EoLC settings were two of the remaining smaller groups. While only a small number of respondents chose elderly/nursing homes across all waves, there was a significant increase in the option of hospice and specialised EoLC settings across years. The percentage increased from 1% in 2016, to 2% in 2017 and 5% in 2018 (*p*<.001). The emerging preference for hospice/specialised EoLC setting might reflect increased receptivity of the public towards hospice and EoL services.

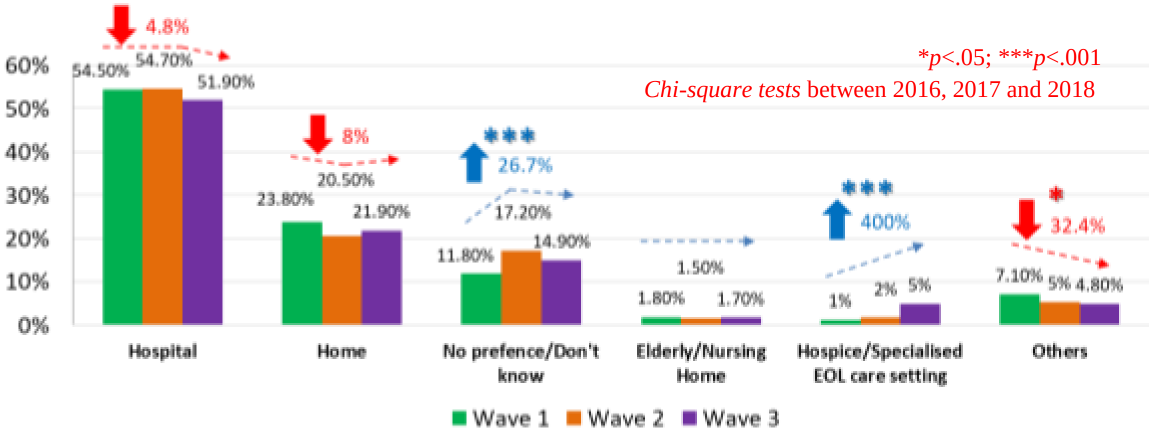


**Figure 7.8** Most suitable place for death in 2016, 2017, 2018 waves of public survey

Attitude towards community EoLC

In 2016, 2017 and 2018 surveys, the large majority verbalized their positive attitude (support) towards community EoLC (**Figure 7.9**). In all waves, above 80% respondents expressed support towards building EoLC facilities near home, and three-fourths supported neighbor to receive EoLC at home, while slightly below 60% of all respondents supported neighbor to choose to die at home. *Chi-square tests* were conducted to compare the changes in percentage of "support" response between 2016 and 2018. It was found that the proportion of respondents who supported building EoLC facilities near home significantly increased in 2018 when compared to 2016 ($p<.001$). But there was no time effect on the other two items. Over three years, the support towards building EoLC facilities near home and that neighbor receive EoLC at home increased by 6.5% and 0.3% respectively.

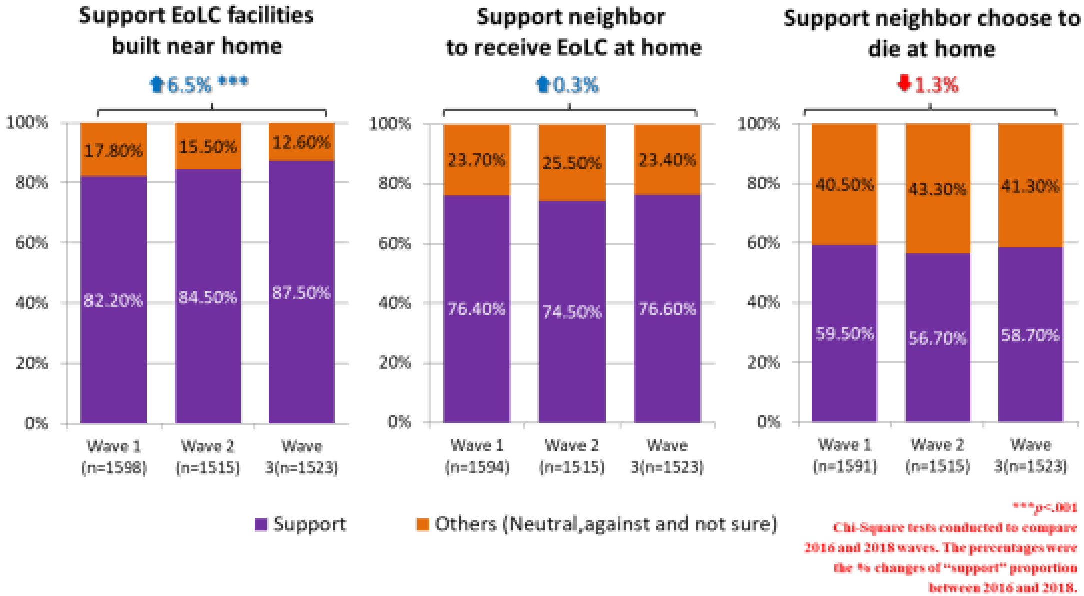


**Figure 7.9** Attitudes towards community EoLC in 2016, 2017, and 2018

## Perceived important components in community EoLC

In the 2018 survey, new items about attitude regarding service components in community EoLC were added. Respondents were asked how helpful three types of care services would be for patients receiving EoLC in the community. These three types of services are “physical care and symptom relief service”, “emotional and psychological care”, and “practice support services”. They were also asked to choose one of these three types of care that they believed to be most important and helpful. Findings suggested that the public perceived practical support as most helpful, followed by emotional and psychological care, and finally physical care and symptom relief (**Figure 7.10**). The difference was statistically significant (*p*<.001). It is understandable that practical support is paramount when a patient with advanced illness has to stay at home. The high ratings on emotional and psychological care once again points out psychosocial care cannot be neglected in promoting quality of life of EoL patients. Concerning the relatively low perceived helpfulness on physical care and symptom relief, this might reflect a low confidence on the effectiveness of symptom relief in advanced illness. Given the advances in symptom management in palliative care and EoLC, more education could be provided to the public to allow the development of a more optimistic view.

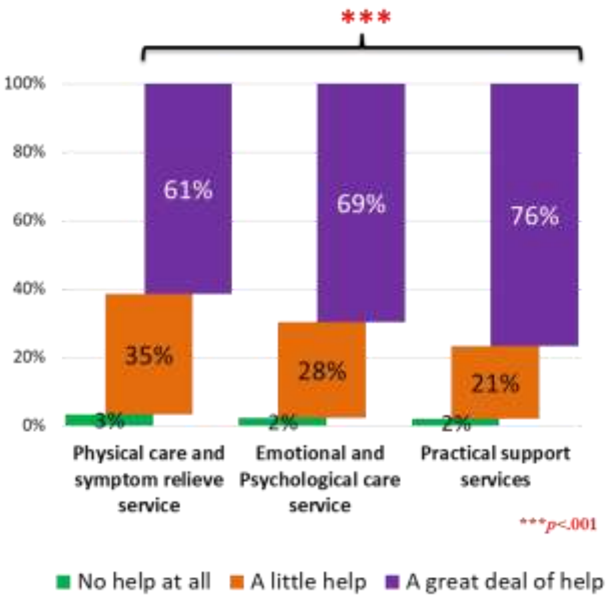


**Figure 7.10** Perceived helpfulness of physical care, emotional care, and personal care to EoL patients in community

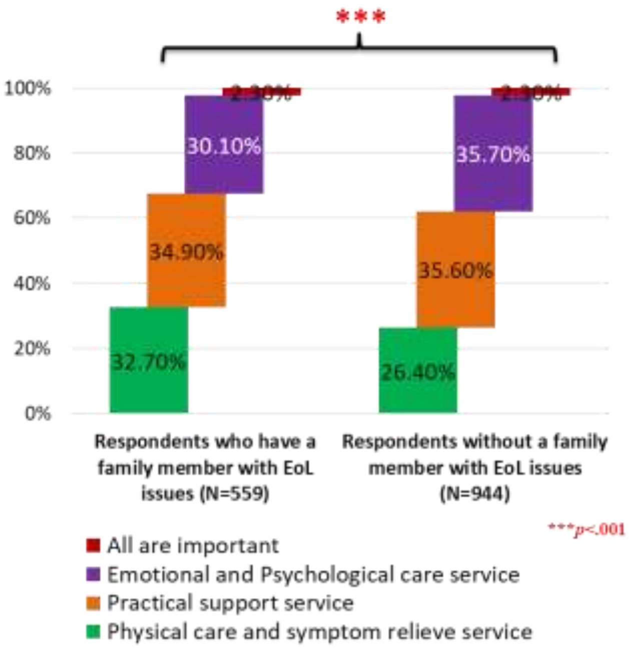


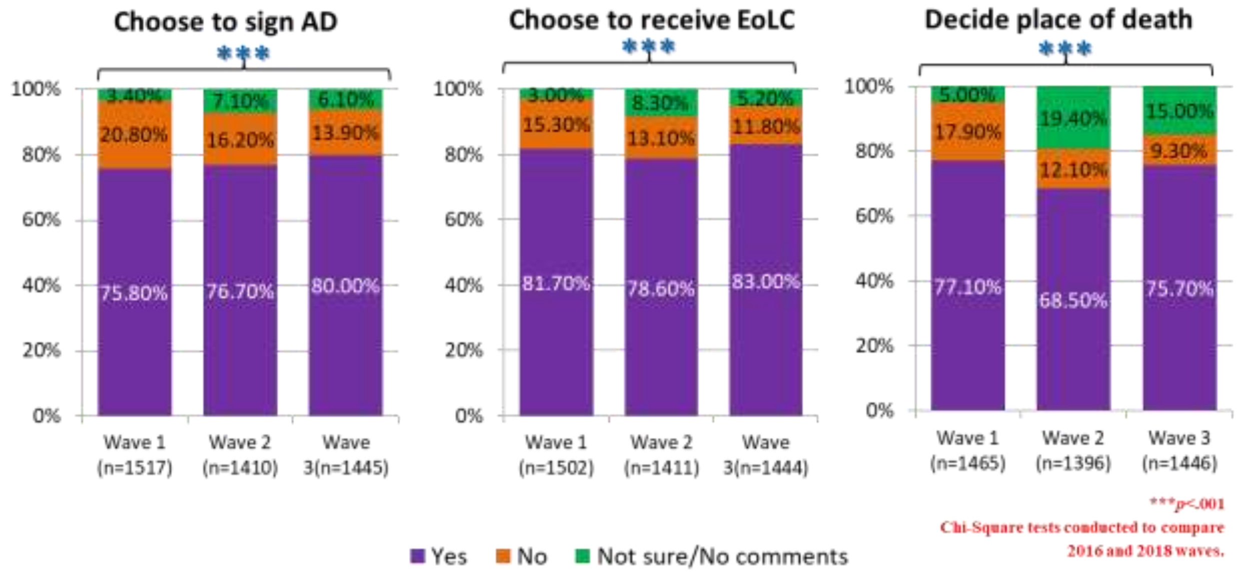
**Figure 7.11** Perceived most helpful care component in community EoLC

When asked to choose the most important care, all three types of care obtained similar percentage of votes (**Figure 7.11**). These findings suggested that all three types of services might be equally important but should be provided according to the indicated needs of service users. Interestingly, respondents who have a family member with EoL issues were more likely to attach highest importance to physical care and symptom relief than their counterpart who have no such experience. Our findings from EoLC service evaluation proved that symptom relief plays a vital role in promoting emotional wellbeing of patients. The real life experience of taking care of a family member with EoL issues might have led these respondents to put more focus on symptom relief.

### 7.5.2.3 Motivation to take action related to EoLC

#### EOL decision making

In 2016, 2017 and 2018, the large majority of participants verbalized their willingness towards using advance directives or receiving EoLC, and deciding place of death (**Figure 7.12**). Seven out of ten surveyed respondents would sign AD, decide to receive EoLC and decide on his/her preferred place of death, if they only have 6 months left to live. When the changes across years are examined, *Chi-square tests* suggested there were significant differences across years. In fact, the comparisons between any two years were found to be statistical significant for all three items. For simplicity, only the results on the comparison between 2016 and 2018 are presented here. It was observed that there was a gradual but consistent reduction on the proportion of respondents who refused to use AD, receive EoLC, and decide place of death from 2016 wave to 2018 wave. However, not all refusal proportion switched to support, but expressed uncertainty. For instance, for "choosing to sign AD", the proportions of "support" and "Not sure/No comments" both increased across years, while proportion of refusal reduced consistently, with the support group being the biggest group in all years. There was a significantly reduced resistance towards AD among the public. The proportions of "support" for other two items (choose to receive EoLC and decide place of death) underwent inconsistent changes across years but remained the biggest group. Along with the reduction of "refusal" proportion, more people were complementing the



***$p<.001$
Chi-Square tests conducted to compare 2016 and 2018 waves.

**Figure 7.12** Comparison on EOL decision making between 2016 wave, 2017 wave and 2018 wave of public survey options (not sure) in later two waves. The trend of change is encouraging. It also demonstrates that improving awareness and knowledge on EoLC can possibly reduce the public's resistance towards AD and EoLC. The proportions of respondents who refused to sign AD, receive EoLC, and decide place of death reduced by 33.2%, 22.9%, and 48% between 2016 and 2018. At the same time, the "support" proportion for signing AD and receiving EoLC increased by 5.5% and 1.6% between 2016 and 2018.

### Engaging family members in EoL decision making

Apart from self-determination in making decisions related to EoL, majority of the survey participants also verbalized their willingness to discuss one's EoLC decision and arrangement with family members (**Figure 7.13**). Again, seven out of ten respondents would communicate with family members about signing an AD, and around 6 out of ten respondents would talk to family members about receiving EoLC and their preferred place of death. *Chi-square tests* were conducted to explore the changes between 2016 and 2018. The results proved that there were significant changes between 2016 and 2018. Similar to the findings from the public's willingness to have an AD in previous paragraph, consistent reduction in the proportions that against engaging family members in the discussing were found between 2016 and 2018 for all three items. Simultaneously, the proportion that supported discussion with family members showed consistent increase across years. More prominent increases were observed between 2017 and 2018. Overall, the % of support towards discussing AD with family, discussing about receiving EoLC with family, and discussing with family about place of death increased by 8.3%, 11%, and 10.4% respectively between 2016 and 2018. This reflected on one hand, the important role of family members in EoL decision making given that at least around two-thirds of the respondents opted to discuss this topic with family members in all waves, on the other hand, more people become opened to discuss EoL decisions with family members.

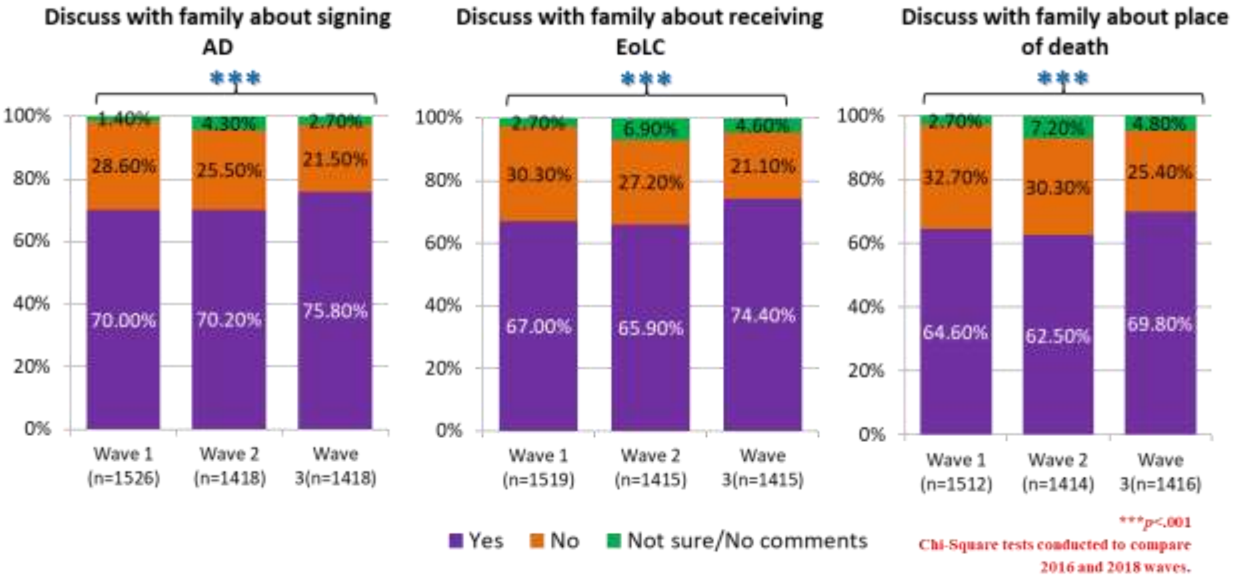


**Figure 7.13** Comparison on attitude towards engaging family members in EoLC between 2016 wave and 2017 waves of public survey

An extra question regarding perceived difficulties in talking about EoLC and related treatment decisions was added in the 2018 survey (**Figure 7.14**). About half of the respondents perceived no difficulties in talking about EoL decisions with family members. In other words, they are ready to talk about this topic with family members. For others who expressed challenges, the first two most frequently mentioned difficulties are related to family members, particularly emotions and different views of family members. Some respondents found it difficult to initiate the topic. These showed that death and dying is still a taboo subject towards many of our respondents, if not all. Only around 5% of the respondents thought there is no need to discuss EoL with family members. Because most reported challenges were family-related, promotion of ACP and discussion of EoL issues might have to emphasize the role of family's participation and support instead of solely focusing on patient's self-determination. Moreover, education might work best if a family approach, which engages not only the elderly people but also their family members, is adopted. Alternatively, education activities targeting on different groups, such as youngsters, the middle-aged, and elderly people, with consideration of their possible roles in the context of EoLC, can be developed to bring tailored messages to different audience with an aim to facilitate more open discussion on EoL issues in families.

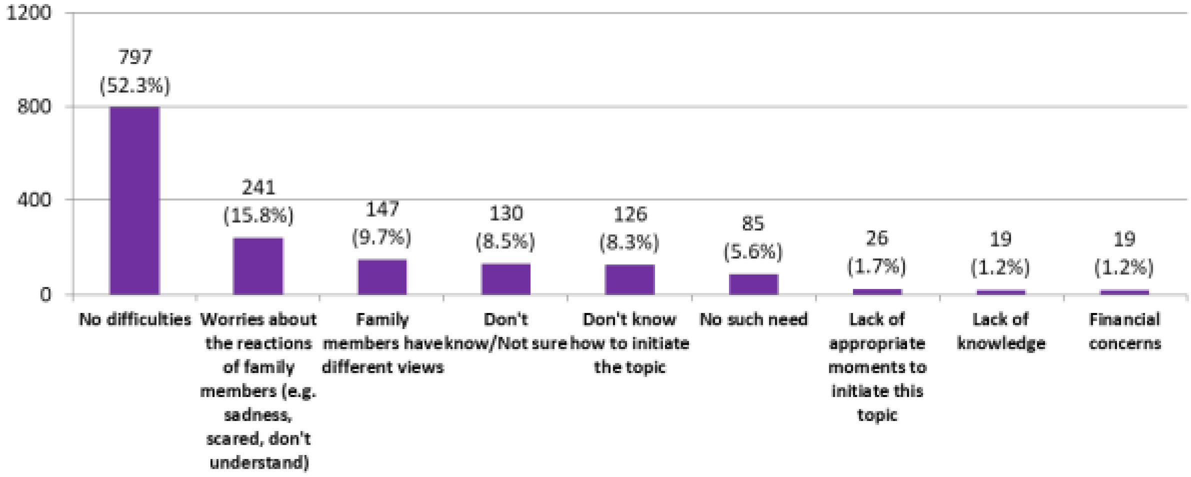
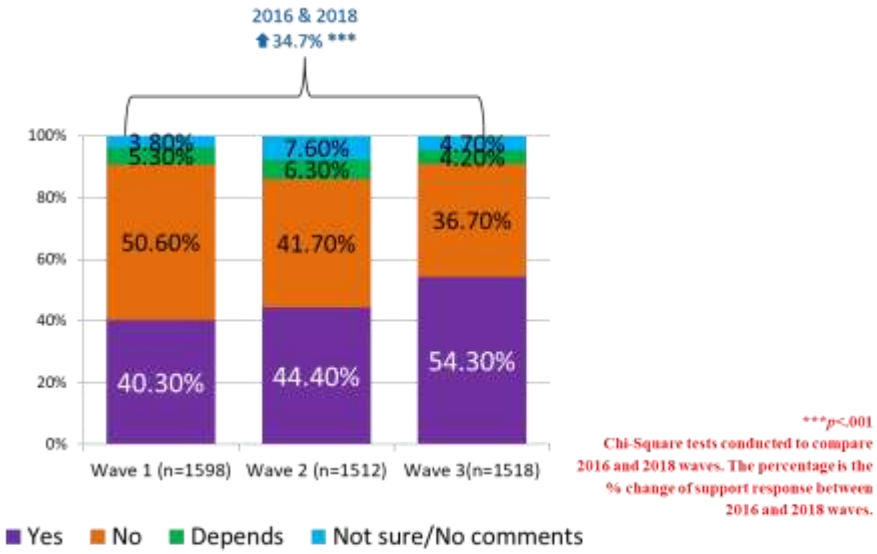


**Figure 7.14** Perceived difficulties in talking about EoLC and EoL treatment decisions [Multiple options] (N=1523)

## Intention to learn more about EoLC

Lastly, respondents were asked if they would join any educational activities and seminars related to the subject of EoLC in future. Findings showed that in 2016, half of the respondents were not planning to join any EoLC education activities in future (**Figure 7.15**). Those who were planning to do so amounted to 40%. The percentages of respondents who said they would join EoLC educational activities in future increased significantly across years (40.3% (2016) vs. 44.4% (2017) vs. 54.3% (2018)), whereas those who said "No" reduced significantly at the same time (50.6% (2016) vs. 41.7% (2017) vs. 36.7% (2018)). Chi-square tests were conducted and findings suggested that there was significant change between any two years. The overall increase of the "Yes" response from 2016 to 2018 was 34.7%. These results reflected increased interest of the public in the subject of EoLC, and higher motivation to learn more about the topic.



***$p$<.001
Chi-Square tests conducted to compare 2016 and 2018 waves. The percentage is the % change of support response between 2016 and 2018 waves.

**Figure 7.15** Expressed intention to participate in EoLC education activities in future in 2016, 2017, and 2018 waves of public survey

## 7.6 Key Performance Achievements

The overall output in the Knowledge and Skill Transfer has over-achieved its target by 616% (**Table 7.6**).

**Table 7.6** Outputs of Knowledge and Skill Transfer

| | Pledged output for 3 years | Actual output up to Dec 30, 2018 | Achievements |
|---|---|---|---|
| Inaugural/Closing | 300 | 330 | 110% achieved |
| International Conference | 600 | 840 | 140% achieved |
| Seminar/Forum/Alternative Intervention Workshop | 6,000 | 7357 | 123% achieved |
| Multimedia | 120,000 | 283,404 | 236% achieved |
| Publications | 90,000 | 91,736 | 102% achieved |
| Media Coverage | 750,000 | 5, 576, 059 | 743% achieved |
| **Total** | **966,900** | **5, 959, 726** | **616% achieved** |

The key performance indicator regarding knowledge and skill transfer concerns with improved public attitude towards community-based EoLC, was partially achieved as reflected in our public surveys (**Table 7.7**).

**Table 7.7** Key performance indicator achievements in knowledge and skill transfer

| | Key Performance Indicators | Performance of JCECC Knowledge and Skill Transfer [71] | Achievements[72] |
|---|---|---|---|
| 1 | The public attitude towards EoLC in the community will be improved by 5%, making a more caring community | **Changes in the percentages of support of the general public towards providing EoLC in social service agencies or at home, having EoLC facilities built near home, and neighbour receiving EoLC at home across three years from 2016 to 2018**<br>• There was an increase of support for providing EoLC in social service agencies and at home by 0.5% and 1.3% respectively (p.176), while support for building EoLC facilities near home and that neighbour receive EoLC at home increased by 6.5% and 0.3% (p.177). The average increase among these four indicators is 2.2%. | 44% achieved |

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[71] All % changes were calculated by the formula: (new values – old values)/old values.

[72] KPI achievements were calculated by: % changes in the KPI obtained/targeted % changes

## 7.7 Lessons Learned and Future Plan

In three waves of public survey, the knowledge of terms towards EoLC was enhanced, in particular, the awareness towards the term “End of life care” increased steadily across years and showed a promising increase by 30%. The knowledge towards other EoLC-related terms and EoLC service components were also enhanced, and people has become more aware of the home care components of EoLC as well. Contradictory to this, there was an extremely low awareness on ACP among the public as reflected in the 2018 survey.

Regarding attitude, a clear insight we gained was that the majority hold positive attitude towards community-based end-of-life care. They expressed preference for having more choices of care in the community, with at least half of them supported provision of EoLC in community settings like social service agencies and at home, as well as residential care setting. Moreover, over 80% supported EoLC facilities to be built near home and the proportion who supported the idea showed significant increase across years as well. Our findings suggested that the support for having EoLC in hospital dropped significantly in 2018, although the proportion of people who expressed uncertainty on their preferences for EoLC in the community remained low across 3 years, it showed significant increase, which might suggest more information and discussion on place of care might be needed for general public. The public also preferred a holistic EoLC which emphasizes both medical care and psychosocial spiritual care, and the public also showed increasing confidence on the effectiveness of EoLC across years. Regarding important components in community EoLC, the public attached high importance to three types of care: (1) physical care and symptom relief, (2) emotional and psychological care, and (3) practical support. This view also supports the 3Ps (Physical, Psychosocial, and Practical care) service framework in the proposed ICEST model. It is high time that our community develops high quality and holistic EoLC to provide more choices of care to the public so that the preferences of more people could be respected.

Last but not least, with the enhancement of knowledge and improvement of attitude comes with an increase in positive action. The proliferation of general willingness towards self-determining EOL decision making was the best evidence where over 80% of the public in 2018 expressed they were determined to have AD and receive EoLC. It was found that the proportion of the public who against signing AD and receiving EoLC reduced remarkably in the past 3 years. Moreover, around two-thirds of respondents in all waves were ready to engage family members in the discussion of EoLC issues, and the proportion that supported discussion with family members showed consistent increase in the past 3 years. The public also showed increased motivation to join education activities on the subject of EoLC. In light of these, further public education should create momentum in the community to promote more in-depth discussion on EoLC issues among the public and families. Comparison between the findings from 2016, 2017 and 2018 provided further directions for future development in public education on EoLC:

### 7.7.1 Increased knowledge on EoLC in general public

With the effort of the Knowledge and Skill Transfer of the JCECC Project, the awareness on the new term “安寧照顧” steadily increased from 2016 to 2018. The awareness on palliative care showed improvements only between 2017 and 2018. Probably, the publishing of palliative care strategic framework by Hospital Authority in the same year also helped raised the public’s awareness as well. Various education activities and talks on EoL decision making which involves education on AD and related terms have been held by various project partners in the past three years. Our findings also showed that the public reported increased knowledge on AD and DNACPR. However, a ceiling effect was observed between 2017 and 2018. Despite the increased awareness on various EoLC-related terms in the past 3 years, the fact that less than half of the public had heard of virtually all these terms suggests rooms for further improvement in the public knowledge of EoLC. Moreover, the public still had very limited knowledge on ACP, which is one important part in communication on EoL decisions. Related is that we found a proliferation of “Not sure” responses in 2017 and 2018 as compared to 2016 on most items related to preference on EoLC places. The difficulties in making a firm decision might suggest more information on EoLC in various settings is needed by the public in order to make more “informed decision”. Entering Phase 2 of the Project, public education activities should keep focusing on these terms to increase their exposure to the general public, try to rekindle the awareness of some older terms such as Grief counselling and bereavement support, and educate the public about EoLC available in the community and how to access to these services.

### 7.7.2 Not only information, but also family communication and psychosocial care

The public showed increased willingness to discuss and communicated about AD, receiving EoLC, and place of death, and they also showed increasing acceptance towards talking about these topics with family members. The increasing trajectory we observed for these items from 2016 and 2018 are promising. However, even with the change of attitude and improved awareness, there are still discrepancies between the improved of awareness and the behavior, so public education activities introducing teachable moments through indirect communication such as using the stories of others and alternative activities that the general public are familiar with but EoL messages subtly incorporated in it, could engage the public into the discussion of the EoL topics. Indeed, the knowledge and skill transfer programme of the HKU project team has been gearing towards this direction since the second year of the project. For instance, the Mini-movie and communication card games produced in 2017. The findings of three waves also underscored the importance of psychosocial care and family communication in EoLC in the Hong Kong context. Psychosocial care and family communication are two intertwined components in EoLC which could substantially influence the care experience of patients and family members. These two care domains have been emphasized in our professional training programme, the same should also apply to the general public.

# 8. CONCLUSIONS

The evidence gathered on the outcomes during the past three years showed that the Project components of the JCECC Project have been effective and achieved the expected outcomes on multiple levels of target users encompassing health and social care professionals, patients and families, volunteers, community stakeholders, as well as the general public. Emerging distal impacts of different project components have also been observed, suggesting that the strategies adopted by the Project were on the right track.

The Professional Capacity Building Programme in the community successfully promoted the end-of-life care competences of health and social care professionals participated in the workshops. Leadership training programme enhanced not only EoLC competences but also motivation of future leaders to continue to promote EoLC in the community. Similarly, the Capacity Building Programme in RCHEs had succeeded in helping RCHEs to integrate EoLC in the elder care, and successfully upskilled RCHE staff in providing EoLC in the care homes. These efforts subsequently led to significant improvements in symptoms and reduction of utilisation of medical services of dying residents. The community-wide survey on healthcare and social care professionals regarding EoLC suggested improvements in professionals’ confidence in symptom management, community EoLC, and end-of-life decision making across years. Healthcare and social care professionals in general had become more aware of and knew more about EoLC, and these helped prepare them for provision of EoLC.

Regarding patients and family members in the community, the community-based EoLC services provided by four NGO partners were able to alleviate physical symptoms, emotional distress, practical problems, and medical service utilisation of patients, and reduce caregivers’ stress and anxiety at the same time. Feedback from community partners corroborated the findings on patients and caregivers, and it even reflected that the service facilitated trust and communication between patients, family members and the community partners. Community participation is indispensable in EoLC. The standardised volunteer core training course developed by integrating the training of each service model was proved to be effective in enhancing EoLC competences of volunteers. Volunteers reported greater sense of meaning in life as well. Various public education activities have been delivered to the general public through various means and different social media, and the general public has showed significantly improved knowledge on the more recent terms related to EoLC (e.g. EoLC, palliative care, AD, DNACPR etc.) across years. The survey with general public reflected that the majority (>70%) hold positive attitude towards community EoLC.

We found emerging evidence on the positive impacts of the Project on all service user groups, yet, this is just a start. There is much more can be and have to be done to transmit the knowledge and skills of EoLC to health and social care professionals of various care settings and of different levels of specialty, to support more EoL patients in the community, by strengthening the collaboration of other community partners to foster seamless care, to nurture volunteers with effective management strategies to sustain a pool of competent volunteers, and to systematically engage the public in more in-depth discussions on the issues of EoLC.

To keep that momentum going, future plans on the coming three years have been proposed and outlined in **Figure 8.1**. It is believed that even greater changes could be actualized with the advanced strategies.

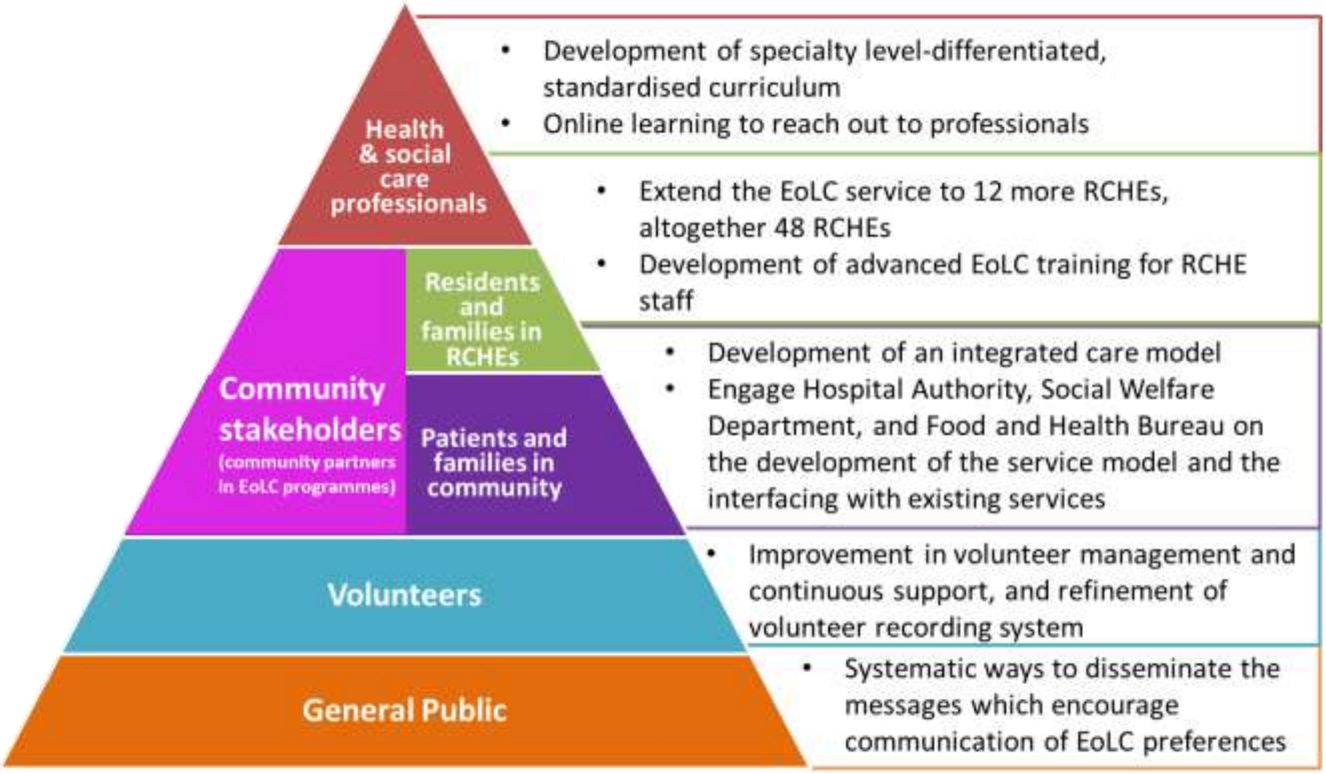

**Figure 8.1** Summary on the future plans between 2019 - 2021

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