CHAPTER 6

HAVEN OF HOPE CHRISTIAN SERVICE: "HOSPICE AT HOME" PROGRAMME

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The Jockey Club End-of-Life Community Care (JCECC) Project has been a systematic attempt to pilot and evaluate different forms of community-based palliative care (PC). It has partnered with the Haven of Hope Christian Service (HOHCS) to develop the JCECC "Hospice at Home" Programme. The goal of this programme is to develop and pilot a model to provide high-quality, holistic home care for people with life-limiting illness in Hong Kong. It places a special emphasis on Advance Care Planning (ACP) and provision of spiritual care through an interdisciplinary care team, in addition to medical and nursing care at home. This chapter describes the features of the "Hospice at Home" services, and the use of interdisciplinary teams in addressing different needs of people at end of life (EoL). It also provides case studies on how people have benefitted from the programme

BACKGROUND

THE NEED FOR HOLISTIC HOME CARE SUPPORT TO PREVENT "REVOLVING DOOR SYNDROME"

Studies have shown that most patients at EoL (including physically frail patients) reside at home, and would prefer to stay at home for as long as possible if medical and nursing support were available (Woo, Kwok & Tse, 2018). Yet, these patients are routinely sent to public hospital Accident & Emergency (A&E) Departments when physical symptoms cannot be effectively managed. They are also highly likely to be discharged quickly due to the shortage of hospital beds. Given the limited availability of palliative home care provided by public hospitals and the shortage of private palliative home care in Hong Kong, many terminal patients in the community are deprived of essential support and thus often experience repeated A&E visits, resulting in the "revolving door syndrome". The huge need for quality and holistic (integrated body, mind and spirit) end-of-life care (EoLC) for patients who wish to stay at home, as well as the need for support for their families, is beyond doubt (Leung & Chan, 2015; Woo et al., 2018).

THE NEED FOR ACP TO RESPECT PATIENTS' WISHES

The objective of ACP is to prepare patients (and patient surrogates) to work with clinicians in making the best possible in-the-moment medical decisions when the patient is at the EoL (Sudore et al., 2017). There is considerable research that has shown that ACP can benefit patients and families on many different levels (see **Table 6.1**).

Table 6.1 ***Benefits of ACP on Different Levels***

CATEGORY	BENEFITS
Quality of care	» ACP is associated with improved quality of care at the EoL, including less in-hospital death and increased use of hospice (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014) » ACP improves patient and family satisfaction towards care (Detering, Hancock, Reade & Silvester, 2010)
Respect for patient's EoL wishes and consensus on care goals	» The patient's EoL wishes are more likely to be known and followed (Detering et al., 2010) » ACP interventions increase the completion of Advance Directives (AD) (Houben, Spruit, Groenen, Wouters & Janssen, 2014) » ACP helps maintain concordance between patient's preferences for care and delivered care (Houben et al., 2014)
Spiritual needs	» Enables deeper discussions and consideration of spiritual or existential issues, allows reflection on meaning and priorities, and encourages resilience and realistic hope (Watson, 2010)
Psychosocial needs of family members	» Family members had significantly less stress, anxiety and depression (Detering et al., 2010)

Despite the numerous benefits of ACP, the rates of completion of ACPs and ADs remain low in Hong Kong (Au et al., 2017; Chu, 2012). The relational aspect of ACP can be particularly challenging to the Hong Kong Chinese population. In Hong Kong, it has been observed that a shared decision-making model is preferred by Chinese PC patients (Chan, Tse & Wong, 2015). Lam & Lam (2013)'s research showed that a significant proportion of people with cancer wanted to involve their family in decision-making regarding their current (36%) or future (47%) healthcare. Family members thus have the potential to become either a motivator or barrier to ACP. Some patients may worry that their family members might be placed under undue stress and sadness if they are involved in the EoLC decision-making process. Indeed, disagreement is often observed among family members during the ACP process. The concept of respecting patient autonomy, which underlies both the philosophy of both ACP and AD, is not indigenous to the Hong Kong Chinese population. Traditional Chinese family values largely centre on the importance of filial piety and collective decision-making, which can hinder truth-telling, open and honest discussion of the patient's poor prognosis, and the patient's own wishes in the ACP process (Ho et al., 2015).

In addition to these relational barriers, completing an ACP is not routine practice in the Hong Kong healthcare system. As a result, many dying patients are unable to communicate their treatment preferences because they are incapacitated when the decision is required. Without a proper system for encouraging the timely completion of an ACP, patients who become incapacitated in the later course of the illness trajectory often have to undergo operations and medical procedures that they never wanted. Examples of such violations of a patient's care wishes include terminal cancer patients receiving cardiopulmonary resuscitation (CPR) against their will when they were dying, advanced dementia patients being fed through tubes and people with devastating strokes being kept alive with repeated courses of "big gun" antibiotics. Such interventions could be avoided if patients had been empowered to complete an ACP when they were still able to communicate their wishes.

THE NEED FOR SPIRITUAL CARE AT EoL

Spirituality can be defined as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (Puchalski et al., 2009, p. 887). Spiritual needs have been recognised as part of holistic PC needs (World Health Organization, 2018). In order to understand the spiritual needs of Hong Kong Chinese patients facing EoL, an assessment of the holistic well-being and spiritual needs in Chinese patients receiving the JCECC "Hospice at Home" services was conducted using a cross-sectional study design. A total of 120 patients with life-limiting illnesses were admitted to the programme between January 2016 and December 2017. They were evaluated with the Holistic Well-Being Scale (HWBS) (Chan, Chan et al., 2014). Thirty-five (29.2%) patients expressed symptoms of emotional vulnerability and 28 (23.3%) expressed loss of meaning and hope. Spiritual distress in patients with advanced illness is a distinct entity, and it was not found to be correlated with age, sex, the number of physical symptoms, functional status or social/financial status. This suggests that a considerable percentage of patients at EoL may be distressed by spiritual crisis, and routine provision of spiritual care is essential for them (Wong & Chen, 2018).

Besides helping patients to feel more at peace and lower their existential distress, good spiritual care can also positively influence PC in other domains. The UK's National End of Life Programme proposed that conversations about spiritual needs can be a way to lead to discussions about ACP (National Health Service, 2010). This can be greatly beneficial to patients and families. By respecting the Chinese culture, integration of Eastern and Western concepts of spirituality will be advantageous to Hong Kong people at EoL, and their families (Chan, Chan, Tin, Chow & Chan, 2006; Chan, Wong & Chan, 2014). Spiritual care therefore has the potential to help with the ACP process in some Hong Kong Chinese patients, who may otherwise find it difficult to talk about their wishes in a culture that is not used to speaking about individual autonomy.

OVERVIEW OF THE JCECC "HOSPICE AT HOME" PROGRAMME

Background of Haven of Hope Christian Service. To pursue its mission of Christian ministry through holistic care, the HOHCS commissioned the services of the Sister Annie Skau Holistic Care Centre (SASHCC) in Tseung Kwan O in 2006. This Centre was purposely designed for holistic EoLC of cancer and non-cancer patients, and to date it has served over 2,000 patients. Of its 100 inpatient beds, 15–20 beds are designated as Relief and Charity Service (RCS) beds to serve the poor and sick. The Home Care Nursing Service is an extension of the inpatient and day care service, and it commenced operation on 1 April 2008. Apart from providing nursing care during home visits, the Home Care Nursing Service also provides intake assessment, telephone follow-up and counselling to patients and their family members.

Programme objectives. The HOHCS launched the JCECC "Hospice at Home" programme in January 2016 as a way of developing a comprehensive community-based palliative support team to assist people with life-limiting illnesses to remain in their community, if so desired. The programme adopted a holistic approach for total person care through an interdisciplinary team offering medical, nursing and rehabilitation, as well as personal and psychosocial–spiritual care. The programme aims to:

1. Provide intensive and holistic EoLC support to patients with terminal cancer or other chronic irreversible illnesses who, with supporting family members or caregivers, opt to spend more time at home rather than be admitted to hospital;
2. Reduce hospital stay while enhancing the quality of life (QoL) of both patients and their families through the provision of quality EoL home care;
3. Respect patients' autonomy through facilitating ACP; and
4. Promote spiritual well-being through holistic interventions.

Target groups and sources of referrals. The target clients of the programme are people with life-limiting illnesses that are advanced, progressive and incurable, which will lead to general frailty and comorbid conditions. Their health conditions are expected to deteriorate in the short term, and death is anticipated within 6–12 months. Between January 2016 and August 2018, a total of 178 patients and 528 family members were served by the programme. The key collaborating units that referred patients to the programme were the Clinical Oncology Departments in Queen Elizabeth Hospital and Pamela Youde Nethersole Eastern Hospital. The majority of referrals (88%) were patients suffering from cancer. The remainder of the life-limiting diseases included neurodegenerative, end-stage renal failure, chronic heart failure and chronic obstructive pulmonary disease. All patients were elderly (45%, 86% and 99% were above 80, 70 and 60 years of age, respectively).

CORE SERVICE COMPONENTS

The "Hospice at Home" programme takes the needs and wishes of patients into consideration to enable them to go home, stay home and avoid the "revolving door syndrome". To achieve this, the following service components are established as part of the programme.

A team of PC specialists. The PC physicians in the team provide strong medical support to patients, and the PC nurse specialists empower family members to assist with nursing patients at their EoL. This is the only team in the JCECC Project with PC physicians who can collaborate with the Clinical Oncology Units in public hospitals as a clinical partner.

Respite support. The SASHCC has reserved two inpatient beds for respite services provided in the programme, as well as Specialist Out-Patient Clinic (SOPC) sessions for patients in the programme. Respite support can reduce unnecessary hospital admissions because timely symptom management can be handled in the SASHCC. Moreover, respite care for patients can help family members who need to travel or attend to their own health issues. Within nine months of offering the respite service, 17 patients received respite services, totalling 130 bed days.

Telemedicine. Relevant technological support enables doctors to provide timely medical consultations for patients at home to minimise AED attendance, clinic consultations and unnecessary hospital admissions.

Transportation. Many patients have difficulties travelling to and from hospital, especially if they are frail, use a wheelchair or require oxygen equipment. HOHCS offers transportation and escort services to these patients to enable them to travel to and from the hospital or clinic, despite suffering from deteriorating medical conditions.

Strong psychosocial–spiritual care, rehabilitation support and practical assistance. The chaplains, together with the social workers and trained volunteers, form a strong team offering psychosocial, spiritual and bereavement support to patients and their families. Physiotherapists and trained health workers offer rehabilitation training and non-pharmacological interventions to patients. In addition to rehabilitation training, health workers also provide practical assistance, such as bathing, to frail patients at home. Without this assistance, patients may have to stay in hospital or be admitted to institutions.

SERVICE DELIVERY FEATURES

The “Hospice at Home” programme has three core service delivery features embedded in it: the adoption of an interdisciplinary team approach, an emphasis on ACP, and specialised spiritual care at EoL. These three features are inter-related and are supported by the service components mentioned earlier.

Adoption of interdisciplinary team approach to care. The interdisciplinary “Hospice at Home” service team involves a PC physician and nurses, a social worker, a chaplain, a physiotherapist, health workers and volunteers. The team operated in a collaborative approach according to the Palliative Care Competence Framework developed by the Palliative Care Competence Framework Steering Group of the Health Service Executive (2014). This framework emphasises the respective roles and responsibilities of each profession in an interdisciplinary team. It also recognises the merit of interprofessional collaborations in enabling truly holistic assessment and interventions in addressing the multidimensional needs of patients facing life-limiting diseases, as well as the needs of their family members (Palliative Care Competence Framework Steering Group, 2014). The respective roles of the team members in the “Hospice at Home” service team are summarised in **Table 6.2**.

Table 6.2 *Roles of Team Members in the Interdisciplinary "Hospice at Home" Care Team*

TEAM MEMBERS	ROLES AND RESPONSIBILITIES
Palliative care nurse	» Designated nurse for each family to support the patient throughout the last journey through home visits and telephone consultations » Provide comprehensive assessment, symptom management and referral to other supportive services, and to develop care plans » Perform nursing procedures in the home, e.g. care of malignant wound, tubes and drains » Skills transfer through educating healthcare professionals and family/ caregivers on PC nursing skills
Social worker	» Assist patients and family in making EoLC decisions based on their preferences » Support patients and families who experience fear, anger, anxiety and sadness » Provide bereavement support and family counselling to resolve conflicts and differences in values » Train volunteers to support people with life-limiting illness » Manage liaison and referral to other community resources and services
Chaplain	» Support for spiritual and existential concerns raised by patients and families » Explore the ultimate meaning and value of life with the patients
Physiotherapist	» Maintain physical function, independence and physical comfort of patients » Prescribe and provide equipment to improve mobility, e.g. wheelchairs, frames and walking sticks » Teach caregivers how to assist patients with mobility issues » Assist with the management of physical symptoms, e.g. pain relief techniques, breathlessness with breath control techniques, oedema management and fatigue management, and include bandaging, advice, exercises and massage
Health worker	» Offer practical assistance in the home » Assist in the patient's transportation to and from appointments
Volunteer	» Offer care and support to the patients and caregivers based on their individual needs, which may include emotional support and companionship, social outings and activities, practical assistance in the home, transport to and from appointments, and respite visits to allow caregivers to take a break
Palliative care physician	» Provide specialist medical PC, and work in collaboration with other members of the PC team and referring partners » Mode of service: doctor home visit, consultation by telemedicine, respite care for patient in hospice setting » Participate in professional education and knowledge exchange

It is not simple for many people with life-limiting illnesses to attain a good QoL while living in the community because they may experience a variety of needs that can vary in complexity and severity during the illness trajectory. In terms of medical care needs, many people with life-limiting illnesses have to cope with multiple physical symptoms whose management routinely depends on care provided by different healthcare specialists and experts in the hospital system. To enable patients to remain at home without experiencing the "revolving door syndrome", the PC specialists in the "Hospice at Home" service team provide intensive support for symptom management at home. During the service period of the programme (the first 32 months), the doctors in the team provided 488 visits and 233 telemedicine consultations. Nurses and other healthcare workers are also key members of the outreach team, providing 3,935 visits to patients' homes in the service period (approximately 22 visits per patient). Social workers and volunteers made 796 visits, and the team provided 1,218 counselling sessions to patients and families (approximately seven counselling session per family). A total of 488 palliative rehabilitation visits were made by physiotherapists and trained healthcare workers. Such strong home care support to assist in managing physical symptoms contributed to many patient's ability to stay in the community in their EoL.

Emphasis on ACP as part of psychosocial–spiritual care. ACP can be documented in the form of an ACP record or AD. Patient's wishes regarding EoLC decisions should be respected, and family members should also be involved in the process of discussion in order to reduce the burden on family caregivers of having to make difficult decisions at a time of crisis.

ACP is an integral part in the "Hospice at Home" service and consists of five steps (see **Figure 6.1**).

Step 1 involves introducing the topic of EoLC decision-making. This usually starts with exploring the patient's understanding about the disease and its prognosis, and their concerns regarding the future care needs and health deterioration. At this stage, the interdisciplinary team has to identify and remove barriers that may hinder the patient's participation in ACP, such as distressing symptoms, fear, misunderstanding, lack of knowledge on EoL-related decisions and unfavourable prior related experiences.

Step 2 identifies the key family member who can participate in the ACP discussion. This family member should understand and show respect towards the patient's wishes, be able to make decisions under stress and be accessible to the healthcare team. It is common for this family member to serve as a contact person for liaising with other family members and arriving collectively at a decision, instead of acting as the only decision-maker on behalf of the patient. Thus, it is important for this contact person to be able to communicate and engage with other key family members.

Step 3 explores the patient's values and beliefs regarding QoL, preferences and goals of care. The care team often explores these areas by asking "what would be important to you?" This question usually leads to a discussion of accomplishments in life, last wishes, funeral arrangements and goals of care in EoL. This also has implications for psychosocial–spiritual interventions for the care team.

In Step 4, the care team clarifies care and treatment priorities with the patient. Information on various life-sustaining treatments (LSTs), the concept of PC and natural death are sensitively provided to support patients to make informed decisions. Patient's preferences are reviewed in time of changes in health status, advancing illness and changes of care setting.

Finally, in Step 5, after the patient has indicated his/her priorities of care and treatments, the discussion is documented in the patient's medical record. An ACP record form has been developed by the "Hospice at Home" programme as a means of communicating with the referring medical team. Patients are also encouraged to document their wishes and preferences using the ACP record form or AD, and patients are reminded that ACP decisions can be changed at any time. It should be noted that completion of the ACP record form is voluntary, and consensus from family members is sought before the patient signs the form. Patients who have completed the ACP record form are encouraged to communicate their preferences with their doctor in hospital with the help of the ACP record form.

Figure 6.1 Five-Step Approach to ACP in the "Hospice at Home" Programme

Strengthened spiritual care at the EoL. Although the HOHCS has a mission of providing Christian ministry, its spiritual care is tailored for people from diverse spiritual backgrounds. The "Hospice at Home" programme has served many non-religious patients (about 40% up to December 2017), as well as patients who are Chinese Folk believers, Christians, Buddhists, Catholics and Muslims, among others.

Many spiritual care methods are applicable to patients from a wide range of belief systems. Life review is one of the most popular ways to promote spiritual well-being of patients at EoL (Wang et al., 2017). Death education programmes have also been found to be useful through a pilot project of open discussions about death and reflections on the worries and issues related to death among persons with chronic illness (Leung et al., 2015). In addition, the "Hospice at Home" programme adopted an integrative body–mind–spirit intervention based on a holistic bio–psychosocial–spiritual framework in its service to patients from all religious backgrounds (Chan & Dickens, 2015).

In the interdisciplinary team in the "Hospice at Home" programme, the resident chaplain or spiritual worker is also responsible for spiritual care. Other healthcare workers on the team (including doctors, nurses and social workers) play essential roles in connecting patients with the chaplain or spiritual workers, and to help obtain a well-rounded spiritual history in their interactions with the patient. During the process of taking a spiritual history, the physician or healthcare workers may identify beliefs, values, spiritual issues and stresses of patients and family members, and may also identify and assess their potential spiritual resources and strengths. Such information is routinely shared with other members of the interdisciplinary team during case conferences to help the team formulate a holistic treatment plan for patients. During the process of spiritual care/intervention, different modalities of therapy can be used to relieve distress and ensure holistic well-being, as applicable to the individual needs of the patient and caregiver (Puchalski et al., 2009).

CASE STUDIES

The following case stories illustrate how the "Hospice at Home" programme has enabled people with life-limiting illness to spend their last days at home with quality.

CASE STUDY 1: HOLISTIC CARE PROVIDED BY THE INTERDISCIPLINARY TEAM

Amy was a retired surgical nurse with previous experience of taking care of advanced cancer patients. She was diagnosed with terminal inoperable liver cancer, with life expectancy of weeks. With her professional training and experience, she had solid knowledge and full understanding of her own prognosis. She was admitted to the "Hospice at Home" programme where she received holistic support provided by the interdisciplinary team throughout the last phase of her life's journey:

Symptom management and respite care. Amy was suffering from the symptoms of liver failure including severe bilateral leg oedema, constipation and fatigue. The physiotherapist and the home care nurses offered oedema management to relieve her symptoms. However, as the disease progressed, she was admitted to an inpatient bed in the Centre for respite care to administer infusion of albumin to lessen the leg oedema, and to provide dietary advice and medications to ease the constipation. As the liver was failing, she had increasing difficulty in travelling to and from the clinic. Visits at her home and the use of telemedicine helped to reduce the need for her to travel for consultation.

ACP and family engagement. The team social worker discussed the goals of care with Amy and her family, and their preference was to promote comfort and to avoid CPR. Amy enjoyed good family relationships and thus her priority was to spend as much time with her family as possible and to stay at home until the very last moment. However, although she was prepared for a sudden death, she did not opt for home death as she did not want to scare her grandson, who was a toddler. The ACP record and an AD documenting her medical decision regarding EoLC were signed. Amy's preference was honoured. She was admitted to inpatient PC when her condition could no long be managed at home.

Psycho-spiritual support. Counselling and psycho–spiritual support were offered through engaging Amy in activities sucah as life review, planting and drawing.

Amy was very grateful to the "Hospice at Home" programme, as seen from her participation in the programme's video sharing her personal story in choosing to stay at home for as long as possible (http://foss.hku.hk/jcecc/en/madam-chans-story/). The filming took place at her home and she passed away four days after the video interview.

Amy's case shows that physical needs are not the only areas being focused on in the "Hospice at Home" programme. ACP and psycho–spiritual support were also offered to Amy and her family to provide holistic EoLC.

CASE STUDY 2: RESPECTING PATIENT'S EoLC CHOICES THROUGH FAMILY ENGAGEMENT IN ACP, AND BY CONFLICT RESOLUTION

Angela was a 60-year-old single lady, born and raised in Hong Kong. She was diagnosed with breast carcinoma in spring 2016 while she was working as a missionary in the rural area of a developing country. Angela was highly educated, rational and decisive. When she learnt that her cancer was metastatic, she opted for natural therapy instead of formal oncology treatments with chemotherapy and radiotherapy. Later, when told that her cancer had become incurable, she planned to optimise QoL and minimise physical suffering. Angela was well aware of her diagnosis and prognosis, and she could face death positively as her faith gave her strength. Angela's case shed light on how faith can influence ACP preferences and how the "Hospice at Home" programme team helped a family to resolve conflict over the patient's treatment decisions.

Despite Angela's preference for a palliative approach to her illness, her siblings insisted that she seek active treatment. Angela was the fourth child and she had six brothers and sisters. It was difficult to fight against the traditional Chinese culture of making decisions as a family, not as individuals. As a result, Angela returned to Hong Kong to live with her sister Betty and finally began palliative chemotherapy as per the request of her siblings. Angela privately told the "Hospice at Home" care team that she agreed to palliative chemotherapy against her wishes only because that was what her siblings wanted for her. Angela was worried that her siblings could not accept the prognosis of her terminal illness, and that Betty was suffering from caregiver stress.

Angela's symptoms improved significantly after several weeks of palliative chemotherapy and hormonal therapy. Her siblings, now convinced that they made the right decision about Angela's treatment choice, pushed Angela to seek active treatment again. A month later, many new symptoms emerged. This time, Angela insisted that she had fulfilled the wish of her siblings for a trial of palliative chemotherapy and refused to receive another line of chemotherapy. She said she would not want "to prolong her life by spending money", and would rather give the money to charity or save it for future use in quality PC.

The team understood that Angela's and her sibling's views on treatment goals were in conflict. In subsequent home visits, the interdisciplinary PC team focused on facilitating communications between Angela, Betty and the other siblings. The team helped them to vocalise their respective reasons for prioritising different treatment options. The team also worked on helping family members understand the importance of respecting an EoL patient's autonomy and spiritual needs. Eventually, the family members decided to respect Angela's decision to prioritise enjoying quality time with her loved ones instead of prolonging life. Feeling that her wishes had been honoured by her siblings, Angela achieved a sense of spiritual peace and expressed her wish to pass away comfortably and with dignity. She opted not to attempt CPR if she had a cardiac arrest and planned for admission to a PC centre in her last days of life.

In the subsequent home visits, Angela focused more on enjoying her favourite foods and meeting with loved ones. She scheduled weekly gatherings with her family and friends to relive happy memories. She also prayed every day for the poor and needy people in developing countries, which gave her meaning and peace. She passed away peacefully a few months later with no more chemotherapy or invasive interventions.

OUTCOMES

The outcomes of the "Hospice at Home" programme were evaluated by the common evaluation framework adopted across all service models under the JCECC Project and also by the organisation-specific service records. Patients' and family caregivers' outcomes, the utilisation of medical services predominantly in hospital admissions, and the uptake of ACP and use of LST before death are presented in this section.

PATIENTS' PSYCHOSOCIAL–SPIRITUAL OUTCOMES AND CAREGIVERS' OUTCOMES

Between 1 January 2016 and 31 March 2018, 32 patients were admitted to the programme and completed all three periods of assessment (at service intake, one month after service commencement and at three months after service commencement). Of these patients, 28 (87.5%) were cancer patients, while the rest suffered with dementia, heart failure, Parkinson's disease or renal disease. The mean age of these patients was 78.9 (SD = 9.59) years. During the same time period, 19 family caregivers, mostly adult children (73.7%) and spouses (10.5%) of patients, completed the first two assessments (at service intake and at three months after service commencement). Twenty-four bereaved family caregivers completed bereavement assessment two months after the patient's death.

Patients' outcomes were measured with the Integrated Palliative Care Outcomes Scale (IPOS), and family caregivers' outcomes were measured as the perceived level of intimacy with the patient. These scores were divided into low and high-need groups, using a critical threshold set at the mean baseline score plus one standard deviation, for each outcome indicator (see Chapter 5). The percentage of high-needs patients and caregivers in each outcome indicator was compared between baseline (service intake) and three months after service commencement. Paired t-tests were applied to examine if changes as a result of the intervention were significant.

The preliminary findings showed that at the third month of service, the proportions of high-need patients had reduced when compared to the time of service intake (high needs included practical problems, anxiety, not being at peace, perceived family anxiety and barriers in sharing feelings with family members). Paired t-tests showed that improvements in practical problems, perceived family anxiety, and sharing feelings with family members were significant ($p<0.05$) (see **Figure 6.2**). At the same time, caregivers reported significantly higher sense of intimacy after three months of service ($p<0.05$). The majority (83.3%) of bereaved caregivers reported a low risk of complicated grief. These findings showed that the "Hospice at Home" programme was particularly effective in facilitating family relationships, communicating and reducing family's anxiety. This could be attributed to the active engagement of family members in the ACP process. The intensive home care support, transportation and respite services provided in the programme was also found to be highly effective in helping patients cope with practical problems when staying at home. Overall, patients' psycho–spiritual well-being showed an improving trend, while physical symptoms remained low.

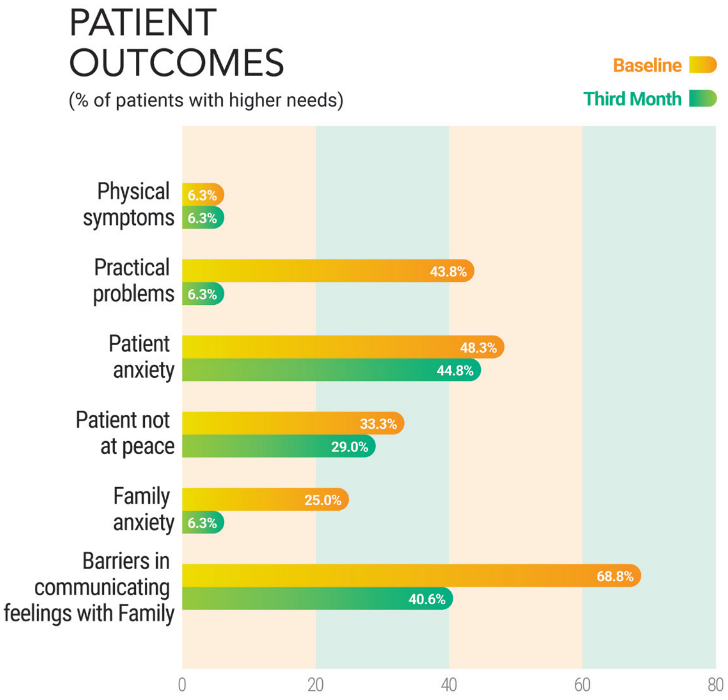

Figure 6.2 Outcomes for Patients

UPTAKE OF ACP AND LST AT EoL

Among the 130 patients who passed away between January 2016 and August 2018, 107 (82.3%) signed an ACP record or AD refusing LSTs. Among all deceased patients, the majority (N=124, 95.4%) died without receiving CPR. Significantly fewer patients received CPR in the group that had undergone an ACP compared to the non-ACP group (1% versus 17.4%).

LENGTH OF STAY IN THE LAST HOSPITAL ADMISSION

The mean length of stay (LOS) in the last hospital admission before death among “Hospice at Home” programme participants was compared to data of a local study on cancer patients receiving PC in a public hospital (Lam, 2018). For patients in the “Hospice at Home” programme, the mean LOS in the last hospital admission was seven days, which is a significant reduction when compared to the findings of 18.4 days from Lam’s study (62% deduction, $p<0.05$). This finding suggested that the “Hospice at Home” programme could successfully enable patients with advanced cancer to stay in the community for longer (Chen, 2018).

LESSONS LEARNT AND CONCLUSIONS

The “Hospice at Home” programme service model has been found to be successful in achieving its objectives in providing holistic EoLC in the community. Its unique service features were key to the programme’s success, comprising a well-rounded interdisciplinary team providing intensive services in the community, dedication to providing high-quality spiritual care and including ACP as a routine service element for people with life-limiting illness. Evaluation of patient outcomes has shown that by facilitating ACP discussions between patients and family members, the programme’s service users have better family communications and fewer days in hospital during their final admission, which means that patients can spend more time in the community with their loved ones.

Most importantly, promoting the completion of ACP in the programme has allowed patients’ wishes and EoLC preferences to be honoured by their families and healthcare service providers. The two case stories in this chapter demonstrated the potential for such a service model to provide holistic EoLC by an interdisciplinary team working closely in the community. This was achieved by the programme’s interdisciplinary team of professionals possessing complementary skills that allowed holistic care to be provided and the patient’s needs to be met in different domains (including spiritual needs). The programme can serve as a blueprint for PC service development in Hong Kong to expand quality spiritual care at EoL, to promote the completion of ACP and to help patients spend more time in the community instead of being trapped in the “revolving door syndrome”.

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