CHAPTER 9

IMPROVING QUALITY OF LIFE FOR PATIENTS AND FAMILIES WITH LATE-STAGE NON-MALIGNANT CHRONIC DISEASES: A HOLISTIC INTEGRATED COMMUNITY-BASED MODEL

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Although the leading cause of death in Hong Kong is cancer, non-cancer deaths comprise two-thirds of the total causes of death (HKSAR Department of Health, 2017). There is a significant disparity in access to palliative care (PC), however, as approximately only 1.5% non-cancer patients receive it, compared with 80% cancer patients (Lau, Tse, Lam & Lam, 2008; Lau et al., 2010). To fill this service gap, the “JCECC: Life Rainbow – End-of-life Care Service” was launched by the Hong Kong Society for Rehabilitation (HKSR) on 1 January 2016, funded by the Hong Kong Jockey Club Charities Trust in partnership with the Hong Kong East Cluster of the Hospital Authority. This chapter describes the processes entailed in establishing the service, the components and the evaluation to date.

BACKGROUND

END-OF-LIFE CHALLENGES FOR PEOPLE WITH ADVANCED CHRONIC ILLNESS

People with non-cancer terminal conditions can suffer from organ failure, decreased mobility and functioning in daily living and other debilitating physical, psychological and spiritual conditions. These all significantly undermine their quality of life (QoL). People with organ failure are more likely to experience variable health trajectories and functional incapacities than people with any other health condition. Moreover, they develop long-term progressive limitations punctuated by intermittent serious episodes (Bostwick et al., 2017; Murray, Kendall, Boyd & Sheikh, 2005). In their last six months of life, non-cancer patients are likely to report distressing symptoms such as dyspnoea, oedema, pain and fatigue. They generally have higher rates of intensive care unit admissions, outpatient clinic attendances and ward admissions, as well as longer lengths of stay in hospital than patients with cancer (Lau et al., 2008; Lau et al., 2010).

LACK OF DEATH PREPARATION AND ADVANCE CARE PLANNING

The rate of physical deterioration of people nearing end-of-life (EoL) can be variable and unpredictable. Many patients with advanced illness and their family members are influenced by death denial and death taboo. Repeated hospital admissions may give family members unrealistic expectations of recovery and longevity. When death comes, it is often regarded as being too soon and many families are unprepared for it (Murray et al., 2005). Because of limited access to end-of-life care (EoLC) support, for many non-cancer patients there is often very little Advance Care Planning (ACP) discussions or access to appropriate documentation. Discussion of the desire, or not, for resuscitation (Do Not Resuscitate [DNR]) is often only initiated when patients have a few days left to live. One study found that only 11.5% non-cancer patients were involved in ACP discussions, compared with 40.8% cancer patients. It also found and that ACP discussions were first documented within three days before death for 26.9% patients with chronic obstructive pulmonary disease (COPD) and 35.7% patients with chronic heart failure (Lau et al., 2008; Lau et al., 2010). Moreover, family members have indicated that they view discussion of ACP, or withdrawal of renal dialysis or other active interventions, as gestures of the hospital giving up on the patients. Families often react emotionally in these situations, and this emotion can block opportunities for death preparations. This also puts pressure on healthcare professionals when they attempt to initiate discussions on ACP.

JCECC: LIFE RAINBOW – END-OF-LIFE CARE SERVICE

PROJECT OBJECTIVES

The Life Rainbow project is a multidisciplinary home-based empowerment programme that adopts a holistic, integrative service model to enhance QoL for late-stage chronic disease sufferers residing in the community. A collaborative approach is adopted, aiming at fostering care partnership between hospital staff, family members, patients' self-help groups and volunteers in supporting patients and their families.

THE SERVICE MODEL

A "LET Go: Community Palliative Care Model for Chronic Patients" model (Leung & Chan, 2011) was developed for this project (see **Figure 9.1**). This is a culturally specific, family oriented holistic care model, which is strength-based and person-centred. The model comprises four themes, represented by the acronym LET Go, showing how the QoL of late-stage chronic patients and their families can be enhanced through holistic community-based service of palliative care.

Living fully despite illness — holistic care

Empowering family — capacity building

Transforming loss — person-centred

Going in peace and harmony — family-oriented

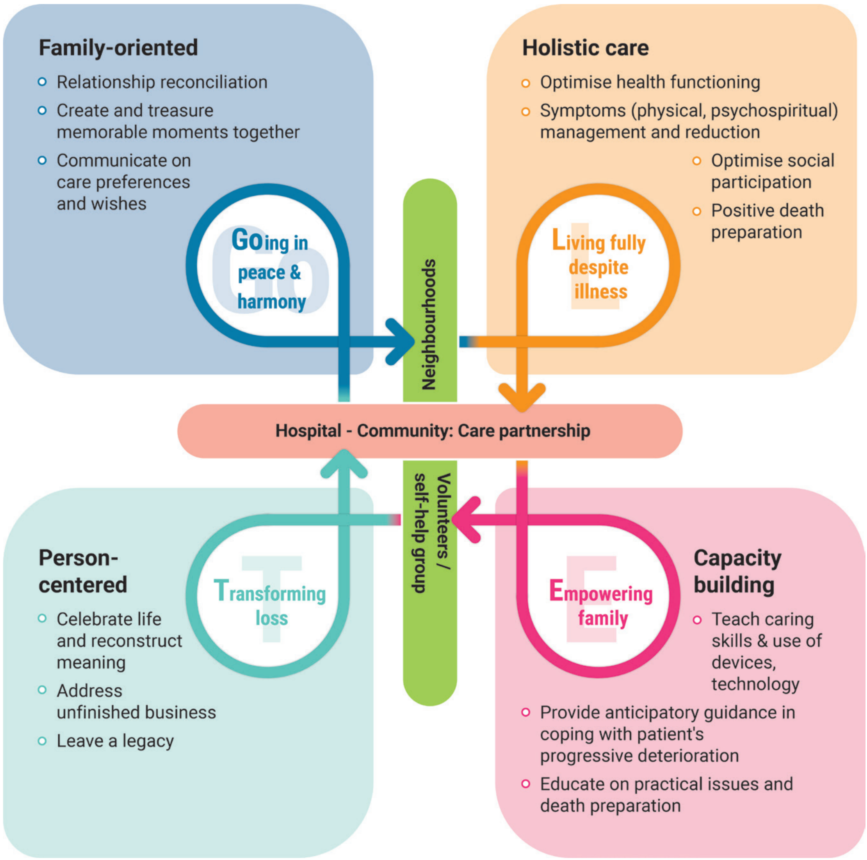

Figure 9.1 LET GO: Community PC Model for Chronic Patients and their Families

SERVICE TARGETS AND RECRUITMENT

Patients targeted for this project include those with COPD, renal failure, heart failure or neurological diseases. Patients are identified by medical teams in the Hong Kong East Cluster of the Hospital Authority (HA). These doctors and nurses select patients based on their negative responses to the question, “would I be surprised if this patient died in the next six months?” The specific selection criteria for inclusion in the project are dependent on four selected disease groups:

1. End-stage COPD
    - Stage IV: Very severe COPD
    - FEV1 (forced expired volume in one second)/FVC (forced vital capacity) <70%; FEV1 <30% or FEV1 <50% predicted plus chronic respiratory failure
2. End-stage kidney diseases
    - Stage V: Kidney failure
    - Glomerular filtration rate (GFR) <15 ml/min/1.73 m^2
    - Accepting peritoneal dialysis
3. End-stage heart disease
    - Based on clinical condition and decision by healthcare workers
4. End-stage neurological diseases (e.g. motor neuron disease and Parkinson’s disease)
    - Based on clinical condition and decision by healthcare workers

DEMOGRAPHY OF PATIENTS AND FAMILIES

During the first two years of the project, a total of 126 patients and 121 caregivers were treated. Patient disease typology and demographic data are reported in **Tables 9.1** and **9.2**.

Table 9.1 ***Disease Classification of Patients Included in Life Rainbow (N=126)***

	FREQUENCY (%)
COPD	61 (48.4)
Renal failure	33 (26.2)
Heart failure	4 (3.2)
Neurological diseases (e.g. motor neuron disease, Parkinson’s disease)	22 (17.5)
Others (e.g. cancer, dementia, stroke)	6 (4.8)

Table 9.2 *Patient's General Demographics (N=89)*

	FREQUENCY (%)/MEAN (SD)
Gender (male)	61 (68.5)
Age (mean)	75.9 (10.9)
Marital status	
Married/cohabitating	63 (70.8)
Widowed	15 (16.9)
Separated/divorced	6 (6.7)
Single	3 (3.4)
Others	2 (2.2)
Relationship of primary caregiver with patient	
Spouse	46 (51.7)
Child	28 (31.5)
Domestic helper	5 (5.6)
Sibling	3 (3.4)
Relative	3 (3.4)
Others (including friends)	3 (3.4)
Parent	1 (1.1)
Friend	1 (1.1)
Living arrangement	
Living with family only	50 (56.2)
Living with a domestic helper and family	19 (21.3)
Living alone	8 (9.0)
Living with a domestic helper only	7 (7.9)
Residential care homes for the elderly (RCHEs)	5 (5.6)

THE SERVICE PATHWAY

The Life Rainbow service pathway is divided into four phases: (1) assessment, (2) active intervention, (3) maintenance and (4) dying and bereavement support (see **Figure 9.2**). The Life Rainbow model adopts a multidisciplinary team approach, including social workers, nurses, professional volunteers who have medical training background, and community volunteers. Social workers serve as case managers to conduct assessments, interventions and who monitor and coordinate services throughout the case journey. The nurses and professional volunteers are responsible for providing symptom management education to empower patients and caregivers to cope with late-stage symptoms, as well as optimise physical functioning and well-being. The community volunteers are crucial as they provide practical and emotional support to patients and family, as well as assisting in case monitoring during the maintenance phase.

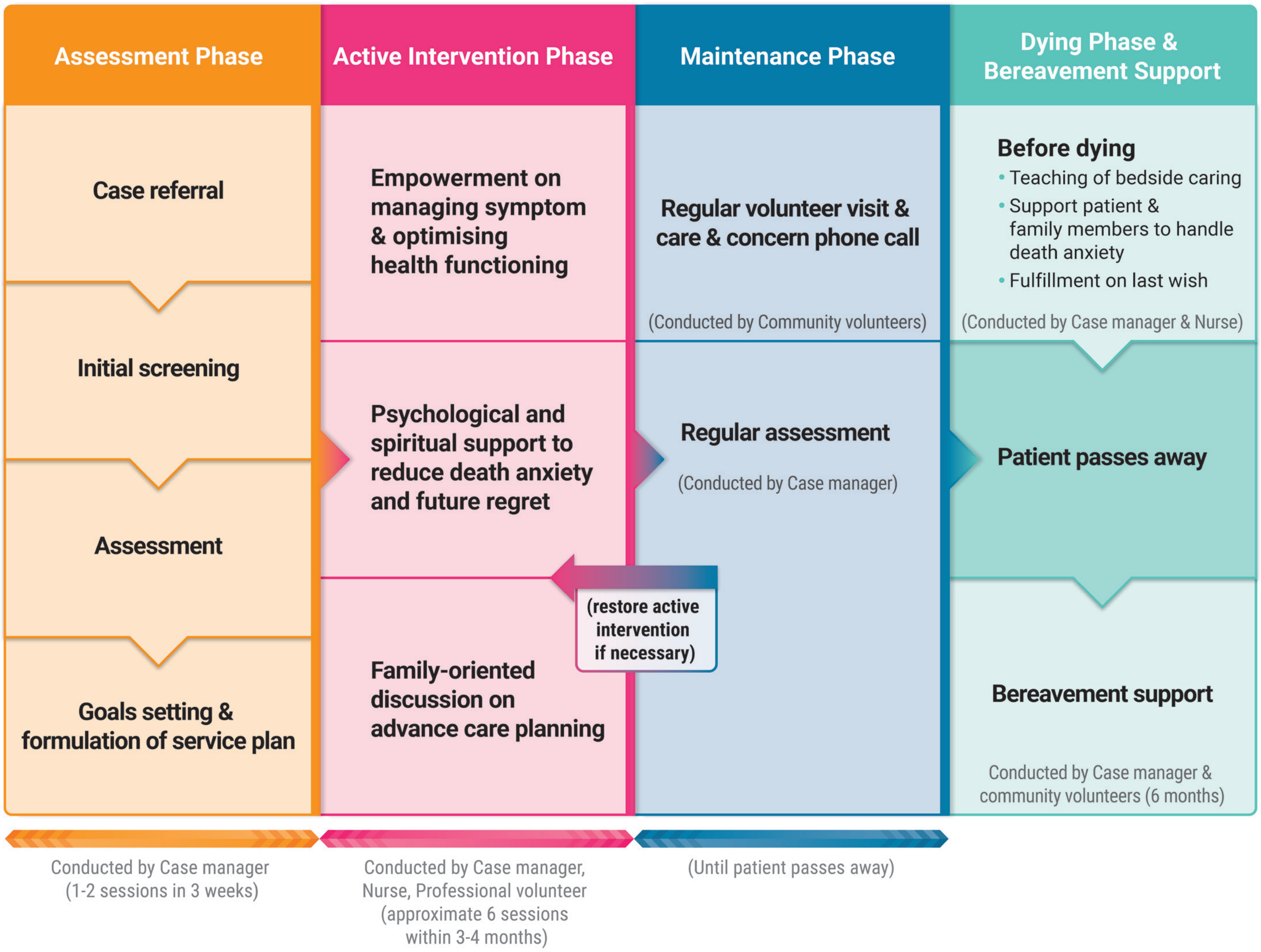

Figure 9.2 Service Pathway of the "JCECC: Life Rainbow – End-of-Life Care Service"

ASSESSMENT PHASE

Comprehensive assessment is conducted to understand the patient's physical and psychological health, social and economic circumstances, preparation for readiness for death, and other issues. After the assessment, personalised goals and service plans are established with patients and family members, aiming to improve QoL.

ACTIVE INTERVENTION PHASE

The active intervention phase comprises three components: Empowerment on managing symptom & optimising health functioning; psychological and spiritual support to reduce death anxiety and future regrets; and family-oriented discussion on ACP.

Empowerment on managing symptoms & optimising health functioning. For people with end-stage chronic illness, physical symptoms are generally their primary source of burden. The Life Rainbow model emphasises empowering patients and caregivers to improve their capacity to manage symptoms. Disease education is provided to patients and families, enabling them to understand the disease trajectory and the common symptoms of their illness. By using a "symptom management logbook", patients and caregivers are taught to record important vital signs (e.g. blood pressure, body temperature, pulse, degree of blood oxygen saturation, etc.) and the specific symptoms with which they struggle most days. Patients regularly give scores to assess the severity of each symptom, using the Integrated Palliative Care Outcome Scale (IPOS) (see Chapter 5). These health records are useful for patients and families as well as for healthcare staff to monitor the progression of illness and be better prepared for impending physical deterioration. To relieve symptoms, self-management techniques and care skills are demonstrated by the nurses and professional volunteers. Patients and caregivers learn and practice how to regularly manage specific physical symptoms using simple and practical non-pharmaceutical methods. Educational booklets, posters and videos of symptom management skills are also provided to patients and caregivers. **Table 9.3** outlines common symptoms and management approaches.

Table 9.3 *Examples of Common Symptoms for End-Stage Chronic Patients and the Management Techniques*

MAJOR SYMPTOMS	SYMPTOM MANAGEMENT TECHNIQUES
Dyspnoea/ shortness of breath	Postural drainage
	Pursed-lip breathing
	Diaphragmatic breathing
	Airflow simulation
	Exercise
Weakness or lack of energy	Rearrangement of daily activities
	Distraction with personal hobbies or interesting activities
	Relaxation breathing
	Exercise
Pain	Cold/heat pack
	Relaxation exercise
	Meditation
	Massage
	Regular exercise
Oedema	Positioning
	Massage
	Restriction in water and sodium intake
	Exercise
Poor mobility	Exercise
	Proper transfer and lifting skills
	Use of proper walking aids

Moreover, the project has adopted many of the Integrative Body–Mind–Spirit (IBMS) techniques, which promote inherent strengths and the potential of patients to live well with their physical concerns. Patients are encouraged to accept their physical limitations, focus on finding meaning in their everyday lives, as well as living in the here-and-now (Lee, Ng, Leung & Chan, 2009). IBMS aims to empower patients to regain an equilibrium within their condition, instead of eliminating the problems. IBMS exercises such as Clapping Qi-Gong (拍手功), Pulling Qi-Gong (拉氣功), Shi-Qiao Shou (十巧手), Swinging hand Qi-Gong (甩手功), Backing Patting (拍背功) and Calf Stimulation (踢腿功) are taught to patients and caregivers, and they are encouraged to do daily practice.

Patients are also invited to formulate a personal action plan of health behaviour to improve their physical well-being. For example, for a patient with end-stage COPD suffering from dyspnoea, he/she might establish an action plan of “Practice three-minute pursed-lip breathing twice a day in the coming week”. For a patient with end-stage kidney disease significantly affected by fatigue, he/she might establish an action plan of “Practice one-minute Swing hand Qi-Gong three times a week in the coming month”. The case manager and caregivers help to monitor and review the implementation of the action plans. This emphasises the patient’s ability and responsibility throughout the illness, which in turn increases the patient’s self-control and self-efficacy.

CASE STUDY: MR CHENG

Mr Cheng, who was 81 years old and suffering from late-stage COPD, was frequently admitted to hospital due to dyspnoea. He had little understanding of COPD and had little confidence in controlling his dyspnoea. He lived in constant anxiety, out of fear of sudden shortness of breath attacks. He rested in bed most of the time to prevent dyspnoea, and he described himself as “a useless person who is living in a lonely jail”.

After being admitted to the project, Mr Cheng was educated in the prognosis of COPD and shortness of breath management. During home visits, professional volunteers helped Mr Cheng review and improve his breathing techniques in the use of inhalers and home oxygen. Moreover, he was educated in taking simple steps to tackle sudden attacks of shortness of breath. Mr Cheng was taught breathing exercises and IBMS techniques for relaxation, as well as lung functioning training, and these techniques were practised at each home visit. Mr Cheng also learnt to record his vital signs and measure the severity of his dyspnoea by scoring every day on a COPD self-management log book. These records provided a good reference for him to monitor changes in his illness. Once he had his self-monitoring plan in place, a case manager helped Mr Cheng set up an action plan to improve his skills in managing shortness of breath. He planned to practice pursed-lip breathing and diaphragmatic breathing every morning and evening. The case manager and community volunteers assisted in monitoring his implementation of the action plan. Finally, Mr Cheng successfully developed the habit of doing daily breathing exercises, which were effective in decreasing his dyspnoea.

The project helped Mr Cheng to gain confidence in coping with shortness of breath. He felt that he had a better sense of control of his illness, and he became more relieved and less anxious. With the help of community volunteers, he took walks in the park near his home every other week. He enjoyed going out very much and felt less lonely with companionship from volunteers.

Psychological and spiritual support to reduce death anxiety and future regrets. Approaching EoL can induce intense frustration and disappointment for patients and carers. To facilitate patients in regaining and maintaining motivation and hope in their lives, both patients and caregivers are taught self-care and stress management skills, such as meditation, relaxation breathing, muscle relaxation exercises, mindfulness exercises, etc. Tailored therapeutic interventions (e.g. expressive art therapy and life review, etc.) are also provided by professional staff to help patients incorporate the experience of loss into self-integration, self-appreciation and positive death preparation.

Chinese people pay a lot of attention to family relationships and rituals. The project focuses on enhancing families' intimacy and connection. Case workers facilitate open discussion of fulfilment of unfinished business and life wishes among patients and family members. They are encouraged to express their appreciation, love, gratitude and forgiveness to each other through verbal, symbolic or metaphorical ways. The creation of treasurable family moments helps them capture loving memories that can reduce the feeling of after-death regrets.

CASE STUDY: DANIEL

Daniel was 58 years old with end-stage renal failure. He lived with his 90-year-old mother, and had one sister. Having dealt with drug addiction, Daniel had been in and out of prison throughout his troubled life. His sister was disappointed for his unruly behaviour and she had refused to see him for many years. Yet, she promised to take care of Daniel after his diagnosis because her mother begged her to do so.

During a home visit, the social worker facilitated Daniel to conduct a life review. Daniel's sister recalled that Daniel always protected her from being bullied by other children. She also remembered her brother always carried her on his back from school to home. During the process, they realised they used to be very close. Daniel described his life as messy and chaotic. He felt he had wasted most of his time on drugs. He was regretful and sorry for disappointing his family. Surprisingly, Daniel said his happiest stage of life was this EoL stage because of the reunion with his sister. He was very grateful that his sister was willing to accept him again. Daniel's sister was very touched by his confession.

Later, the social worker suggested Daniel express his gratitude to his sister by giving her a present. Daniel knew his sister likes Japanese food and therefore decided to make sushi for her. The social worker helped him videotape the sushi-making process. The video became a memorable legacy from Daniel to his sister. The social worker also helped arrange a family photoshoot for Daniel and his family. It was full of laughter and the family had an enjoyable time. A week after, Daniel died with a smile on his face.

Family-oriented discussion on ACP. Project case workers help patients and families work on communication and reach agreement on ACP. Project staff provide anticipatory guidance in coping with a patient's progressive deterioration, and this helps them understand the pros and cons of common life-sustaining treatments (LSTs), such as cardiopulmonary resuscitation (CPR), mechanical ventilation, etc. An ACP workbook, videos, game cards and other relevant materials are used to facilitate discussions.

CASE STUDY: PUI-YING

Pui-Ying, an 85-year-old lady who was suffering from COPD, lived alone after her husband had moved into an elderly care home two years previously. Pui-Ying was a determined person. When discussing ACP, she explained clearly her three wishes: (1) she did not want to have CPR and LSTs when she was in an irreversible life-limiting situation; (2) she wanted to have sea burial after her death; and (3) she wanted to visit her husband every day if possible.

With the help of the social worker, a family meeting was conducted to discuss the pros and cons of Pui-Ying's care plan. The family all agreed to help Pui-Ying fulfil her wishes. First, accompanied and witnessed by her son, Pui-Ying signed an Advance Directive (AD) in the hospital with her doctor, to refuse unnecessary resuscitation during EoL. She felt good and relieved after signing it because her choice was being respected. Second, a professional volunteer (retired nurse) visited her regularly to advise her on symptom management to help her maintain her physical ability for as long as possible so that she could visit her husband.

The discussion of ACP helped Pui-Ying live her life actively, according to her own preferences. She said it helped her regenerate flexibility in life, instead of focusing only on her physical disabilities.

MAINTENANCE PHASE

Life expectancy of late-stage chronic patients is unpredictable. After the active intervention phase, community volunteers provide intensive support in regularly monitoring patients' conditions. The Life Rainbow project has a team of community volunteers, composed of patient volunteers and volunteers who are ex-caregivers (e.g. family member of patients who have passed away). With personal experience in surviving illnesses themselves or walking with their sick family members through their EoL journey, these people are more empathetic and compassionate in understanding the needs of others and can easily build rapport with the project service users. Each community volunteer must attend a 12-hour PC volunteer training course. After training, they are paired up to provide home visits for patients and families who are in the maintenance phase. Playing the role of peer supporter, community volunteers accompany patients in doing exercises, support their IBMS practices, take them on outings, play games and engage with them in other joyful activities. Community volunteers also provide practical support to patients such as escorting them to hospital for medical follow-ups and doing grocery shopping. Apart from home visits, every project participant receives at least one caring telephone call from the community volunteer team.

Case workers and community volunteers keep in close communication and are kept updated on the changing conditions of their patients. Re-assessment of patient needs is conducted by the case worker every three months. Active interventions are reactivated if necessary, according to the changing condition of patients and changing needs of their caregivers.

CASE STUDY: MR SIT

Mr Sit, who was 78 years old, suffered from end-stage Parkinson's disease, was outgoing and enjoyed meeting new people. However, he was wheelchair-bound and had not been able to meet up with his old friends at a tea house since the disease had become so advanced. "I used to go to the tea house every morning, and my favourite seat and pot of tea would be waiting for me. Everyone there knew me and enjoyed listening to my stories." Mr Sit's wife had had a stroke, and their son needed to work, so neither could accompany Mr Sit on his outings.

Mr Leung was the volunteer who had been matched with Mr Sit, and tasked to visit him regularly. He had done this once every two weeks to play card games with him. After each session came the real highlight of the day – a trip to the tea house. The two would spend time trading jokes and stories. Mr Leung was not a patient with Parkinson's disease himself, but his late wife had been, and he understood the difficulties in coping with the illness. Mr Sit agreed: "He really understands what I am going through." Mr Leung said, "Being a volunteer benefits me too, not just the people I help, as here I feel I can do something worthwhile and be recognised for it."

DYING PHASE AND BEREAVEMENT SUPPORT

When patients enter the dying phase, project staff, including the nurses and case managers, actively support the patients, as well as their family members. Many of the families are stressed and helpless when they see their loved ones dying. At this time, many medical decisions must be made. Project staff provide emotional support to patients and families to help them fulfil their final wishes and to assist them in reaching mutual understanding and agreement on medical treatment. Bedside caring techniques (such as massage, comfort touching, comfort talking) are taught to family members so that they can provide psychological comfort and support to dying patients. It is very important at this stage to acknowledge family members for their contribution, love and caring for their loved ones.

CASE STUDY: JESS AND HER MOTHER

More than a decade ago, Jess left her job to become a full-time caregiver for her mother, who was diagnosed with renal disease. Losing a loved one is never easy, and it was hard for Jess to watch her mother suffer in the final stage of her disease. In the final days, Jess's mother had been in a coma. With support from the project, she was able to obtain assistance from a social worker and a nurse. After evaluating the mother's health, the nurse taught Jess some bedside skills, such as hand massage, face cleaning, etc. For Jess, it was crucial to feel connected with her mother through physical contact and bedside caring. The social worker also provided mental health support to Jess, recognising the love and effort she put in in taking care of her mother. The social worker told Jess that when a person dies, the sense of hearing is the last to go. For that reason, the social worker encouraged Jess to talk to her mother on a daily basis, for instance saying "thank you", "do not worry", "I will take good care of myself" and to tell her she loves her. Jess's mother had one last wish, which was to see her four-year-old grandchild who lived overseas. With coordination between the social worker and the hospital, a quiet corner was arranged for the family to say goodbye to the dying mother. In the end, Jess's mother passed away peacefully with her family by her side. Afterwards, Jess said that she had offered the best care for her mother and she had no regrets.

This phase of the project aims to provide bereavement support to surviving family members so that they can suffer from less complicated grief and travel a normal bereavement pathway. Bereavement support is provided to family members for about six months after patients have died. Case workers and community volunteers support families with funeral arrangements, if necessary, and case managers keep regular contact with family members to assess their bereavement progress after the funeral. In fact, many caregivers have been so devoted in caring for their loved ones (often for years) that they have neglected their own physical and psychological well-being. Case managers will match surviving family members with group work services of chronic illness management and psychosocial support provided by the Hong Kong Society for Rehabilitation – Community Rehabilitation Network (CRN) according to their needs. They are invited to join different mutual support groups, volunteer groups or caregiver group to re-establish social connections and for peer support. Meanwhile, community volunteers provide emotional support by care telephone calls, accompanying them on outings and doing things they enjoy. If there are surviving family members who have complicated grief and are at high bereavement risk, they will be referred to agencies that specialise in providing bereavement counselling.

CASE STUDY: MONICA

Monica was a full-time caregiver for her mother, who had been diagnosed with renal failure 10 years earlier. As the only daughter in the family, she was appointed as the main carer by her four older brothers. After her mother died, Monica felt empty and purposeless. She claimed that: "All my life was for her over all these years, now I seem to have nothing after she has gone." Monica was invited by the case manager to join a bereavement support group and to build up social networks with other peers. They would meet regularly for different organised social activities. She also attended some therapeutic groups, such as mindfulness experiential groups, organised by the Community Rehabilitation Network (CRN) to try to recognise her own emotions, to understand different meanings of physical symptoms and to take good care of herself. After several months, Monica felt more released from her grief and has joined the Life Rainbow project as a volunteer.

OUTCOMES

Data from 126 cases were analysed from the first two years of the pilot project (to 31 December 2017). The findings indicated that after one month of engagement with the Life Rainbow project, patients showed significant improvement in physical symptoms (shortness of breath, weakness/lack of energy, poor appetite, drowsiness and poor mobility), psychosocial well-being (depression, anxiety and not feeling at peace), family communication (family anxiety and being unable to share feelings with friends and family), as well as other practical concerns (practical difficulties and unmet information needs). After three months of engagement, the results remained positive and patients showed significant improvement in all these areas. They also reported that alleviation of physical symptoms was more significant in the first month than in the third month, while psychological symptoms as well as family communication were significantly improved from the second to third month of project engagement. In addition, medical utilisation in terms of hospital bed days were reduced significantly (t (43) = –2.281, p=0.028) after three months of engagement with the project.

Regarding caregivers, it was reported that family anxiety reduced significantly after receiving support from the project, while caregiving strain, as well as IBMS of the caregivers, remained stable. In the bereavement stage, the Inventory of Complicated Grief (ICG) scored 13 out of 76, with all family members in the low grief group (0–25). It was noted, however, that the number of days in the last month for caregivers being sick was significantly higher than in previous stages.

PROJECT EXPERIENCE HIGHLIGHTS AND CONCLUSION

The first insight from the JCECC: Life Rainbow project is that this multidisciplinary, holistic, community-based approach to providing EoLC is effective for relieving symptoms and improving psychosocial–spiritual well-being for late-stage chronic disease patients. It suggests that this approach is promising for meeting the estimated huge demand for local community-based PC. By adopting non-pharmaceutical approaches, such as IBMS and self-management, with collaboration of medical staff and professional and neighbourhood volunteers, the Life Rainbow project could provide support to patients and their families to more effectively improve the quality of EoLC at a lower cost.

The second insight from the project is that death preparation and discussion about ACP for non-cancer patients should occur as early as possible, even at the point of early diagnosis of a disease. In the JCECC: Life Rainbow project, case managers and nurses usually initiate these discussions during the first few sessions, when providing anticipatory guidance to patients and family members about coping with the patient's progressive deterioration. Content of discussion is comprehensive, including life review, future planning, death preparation, wish fulfilment and preferred treatment options. The project found that most patients and family members are willing to discuss this openly, using a step-by-step community-based ACP approach. To date, 90% of the Life Rainbow project cases have completed ACP discussion and formulated their plans. Among those service participants who have passed away, approximately 90% of them were reported to have signed a DNR statement in hospital during their final days. Early ACP discussion is crucial to help patients and families become more competent to face increasing physical deterioration and ultimate death.

Another lesson from the project is that caregiver support should be strengthened. In the project, caregivers are very involved in the interventions (determining what they should be and delivering them if possible). They are empowered and supported to take care of their patients, and to try to meet the patient's needs and wishes. However, there is not enough emphasis on addressing caregivers' own holistic needs, including their physical health, their needs to improve emotional competence and opportunities for more social participation. It is reported that more than 50% of the caregivers in this project have different kinds of chronic health conditions, but they also claim that because of the caregiver role, they are "always busy" and do not have time to take care of their own health. They occasionally miss their own medical appointments because of the caring demands placed on them. In view of this, the future service model should include raising awareness of caring for the caregivers and providing viable support for them, which match their busy daily schedules and are sustainable in the long term. Possible strategies include forming support groups for caregivers and organising workshops to improve their wellness and increase their readiness to face the death of their loved one. During the bereavement phase, it is important to provide ongoing support to caregivers, not only with funeral arrangements, but in other areas such as arranging companionship from peer supporters, organising short-term bereavement workshops and encouraging caregivers who have chronic health conditions to learn how to better manage their own health.

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