CHAPTER 7

SUPPORTING PATIENTS AT THEIR END-STAGE OF LIFE: A VOLUNTEER-PARTNERED COMMUNITY CAPACITY BUILDING APPROACH

Iris K. N. Chan
Jockey Club End-of-Life Community Care Project, The University of Hong Kong

Arnold T. T. Leung, Kimmy K. Y. Lam, Francis K. Y. Wong and Katy H. T. Poon
S.K.H. Holy Carpenter Church District Elderly Community Center, Hospice & Bereavement Service Division

Francis T. W. Fung
Jockey Club End-of-Life Community Care Project, Faculty of Social Sciences, The University of Hong Kong

Vivian W. Q. Lou
Department of Social Work & Social Administration, The University of Hong Kong

Service fragmentation and less-than-adequate available community supports for patients at the end-stage of their lives pose significant challenges to people who wish to receive end-of-life care (EoLC) at home. The S.K.H. Holy Carpenter Church District Elderly Community Center (HCCDECC) has a long-term mission to support community-dwelling patients at EoL. It has established a volunteer-partnered community capacity building EoLC model to provide person-centred and holistic care to home-dwelling patients who are facing life-limiting diseases, and their family members. The model features strategic partnerships between the HCCDECC service team and the Medical Palliative Medicine (MPM) Unit of Tuen Mun Hospital (TMH). Community care services are coordinated by case managers, and community support networks are built through resourcing and mobilising volunteers and community partners. A 3Ls (Loss–Love–Legacy) volunteer-partnered psychosocial–spiritual support” framework has been consolidated during the course of the project, with the aim of promoting quality of life (QoL) with dignity for patients at EoL and their family members. This chapter introduces the rationale, objectives, strategies and components of this service model, followed by preliminary findings on its effectiveness.

BACKGROUND

S.K.H. HOLY CARPENTER CHURCH

The motto of S.K.H. Holy Carpenter Church is "To serve, not to be served". To enact its motto, the S.K.H. Holy Carpenter Church has provided different kinds of social service in Hong Kong since 1954. The S.K.H. Holy Carpenter Church social service initiative currently has two units: the S.K.H. Holy Carpenter Church Community Centre and the S.K.H. Holy Carpenter Church District Elderly Community Centre (HCCDECC), which provide social services in the Hunghom, To Kwa Wan, Whampoa and Homantin areas. One of the core services of HCCDECC is bereavement care and death education through the Hospice and Bereavement Service Division (HBSD). This was established in 2004 and aims to serve EoL patients, their family members and bereaved persons of all ages, ethnicities, religious backgrounds and districts in Hong Kong. The HBSD is known for its work in developing death literacy among the general public through death education using various arts media (e.g. DEAtHFEST) and the PARACLETE – Care and Comfort Angels Project. This project offers funeral support and bereavement counselling by social workers and a trained volunteer team. Between 2014 and 2016, the S.K.H. Holy Carpenter Church expanded its service scope to EoL patients and family members through a pilot project on home-based hospice care, funded by the Li Ka Shing Foundation. Drawing from experiences and learnings in their pilot services, and building on their strengths in community engagement and networks with church groups, the HCCDECC HBSD expanded its efforts to promote QoL for EoL patients and their family members by introducing a new community-based EoLC support service to the New Territories West district as part of the JCECC Project.

CHALLENGES FACED BY HOME-DWELLING PATIENTS WITH LIFE-LIMITING DISEASES

Previous chapters have discussed the various challenges faced by community-dwelling people with life-limiting diseases and their family members. The lack of specialised community support services for these people, coupled with fragmented local medical and social supports, shrinking family size and increasing numbers of people living alone (or only with a spouse) make it difficult for many older people to remain living at home safely (and with high QoL) for as long as they wish whilst experiencing life-threatening diseases. Moreover, supporting elderly people to be cared for at home can place a heavy burden on family members, many of whom provide daily support. International studies report that multidisciplinary teams are best for supporting patients and families in achieving their choices regarding places to receive EoLC and to die (Leclerc et al., 2014). It has also been reported that a desirable EoL model that gives patients and their families QoL should not only rely on health professionals, but should also include the community as a whole (Kellehear, 2013; Stjernswärd, Foley & Ferris, 2007).

OBJECTIVES AND SIGNIFICANCE OF THE MODEL

In the JCECC Project, the HCCDECC HBSD developed the "Hospice in Family: Home Care Support Services" to serve community-dwelling EoL patients and their families in the Tuen Mun, Yuen Long and Tin Shui Wai districts. Of note, Tuen Mun and Yuen Long ranked 5th and 7th, respectively, as districts with the lowest median monthly domestic household income among 19 Hong Kong districts in 2016 (HKSAR Census and Statistics Department, 2017). Patients at their end-stage of life, who have a low family income, might face more difficulties in maintaining a good QoL while residing in the community. Despite such needs, at the time of this census there were no specialised EoL community support services within these districts. Establishing a new sub-base in the New Territories West, the HCCDECC HBSD strived to promote QoL of community-dwelling EoL patients in the district by developing a community-based EoLC support service, at the same time as raising public awareness and building up networks for this purpose.

The overarching objectives of the "Hospice in Family: Home Care Support Services" are to:

- Support patients and their families to live in the community with dignity and respect;
- Optimise QoL through care in physical, practical, psychological, medical, social and spiritual aspects;
- Enhance community support for patients and families; and
- Raise public awareness on death preparation and EoLC.

The concepts and theories underpinning the service model are discussed in the next section.

THE UNDERPINNING PRINCIPLES OF THE SERVICE MODEL

The volunteer-partnered community capacity building EoLC model was developed to guide the practice in the "Hospice in Family: Home Care Support Services". This model is underpinned by three principles, comprising community capacity building, coordinated and holistic care, and dignity preservation.

Community capacity building is a process that involves different levels of action, all of which are oriented to health promotion. These actions encompass, but are not limited to, building partnerships, collaborations and networks in the community and garnering resources (human and social capital) (Simmons, Reynolds & Swinburn, 2011). Demands for EoLC always outstrip the supply of professional services, and building community capacity offers a potentially sustainable way of meeting growing demand. Indeed, community capacity building has been recognised as an important way of enhancing the ability of the community to respond to and cope with issues related to death and dying, rather than relying solely on services provided by professionals (Mills, Rosenberg & McInerney, 2015). Although community engagement in EoLC is underdeveloped in Hong Kong, there is a pressing need to empower the community through education and volunteer participation and to establish partnerships between professional and non-professional groups in the provision of care.

Coordinated and holistic EoLC is important for ensuring patients receive consistent care across settings and timelines (National Institute for Health and Care Excellence [NICE], 2011). It requires seamless care provided by different professional groups working in interdisciplinary teams across settings. It also requires information sharing between service providers to ensure consistency of care and messages to patients and families (NICE, 2011). Care coordination for people at EoL takes a holistic approach, referring to coordination of the support services required to meet the multidimensional needs of individuals (Eldercare Workforce Alliance, 2016). When putting the constructs of coordinated multidisciplinary care into practice in Hong Kong, pivotal steps have been taken to develop an interface between medical and social services through strategic partnerships. This has taken a case management service coordination approach for individual patients. In the NICE guidelines for EoLC for adults (NICE, 2011), one of the quality measures of coordinated care is evidence of regular multidisciplinary case review meetings. Studies have found that these are linked to improved QoL, optimised patient function, reduced hospitalisations, improved care coordination and planning, and information sharing (Tuckett et al., 2014). The practice of interdisciplinary case conferences in palliative care (PC) is not new, as it has been practised for some time in many specialist PC settings in Hong Kong. However, cross-sectoral interdisciplinary case conferences (involving medical and community settings) are rare, despite having a high potential to strengthen care at the medical–social interface.

Preservation of dignity is central to the practice of PC and EoLC (Guo & Jacelon, 2014). According to Rodriguez-Prat, Monforte-Royo, Porta-Sales, Escribano & Balaguer (2016, p. 2), there are two broad perspectives on dignity:

» ***Intrinsic dignity***, which can be regarded as a human innate feature that is irrevocable; and

» ***Dynamic dignity***, which is “a personal quality that is related to people’s perception of themselves and of the context in which they live in”.

Based on this definition, dynamic dignity, to a certain extent, embodies a relational view of dignity, given that people’s perception of themselves can be influenced by how others see or treat them. Guo and Jacelon (2014) reviewed the meaning of dying with dignity in the literature, and concluded that dignity is a human right that encompasses the characteristics of autonomy and independence; symptom relief; being respected; being human and being self; having meaningful relationships; receiving dignified treatment and care; spiritual satisfaction; having privacy; and being in a calm environment. Some characteristics are specific to one form of dignity (e.g. intrinsic dignity [being human] and dynamic dignity [being respected, having privacy, spiritual satisfaction]). Moreover, characteristics identified with dynamic dignity are mostly relational, such as relating with oneself (e.g. being self, autonomy and independence); relating with one’s existential self (e.g. spiritual satisfaction); relating with others (e.g. meaningful relationship, being respected); and relating with care providers (e.g. symptom relief, dignified treatment received). As such, the characteristics of dignified death described by Guo and Jacelon (2014) provide insights into what relationships should be like in order to promote the dignity of patients approaching EoL.

The social dimension of dignity is described in the social dignity inventory in Chochinov’s dignity model (2002), while Ho et al. (2013) found that familial factors play an important role in patient dignity in the Chinese context. Ho et al. (2013) suggested that dignity conservation and spiritual care should go hand-in-hand, and interventions that promote acceptance of suffering, letting go, relationship reconciliation, meaning making, and building continuing bonds are particularly important for Chinese patients. In addition to these, studies examining a patient's sense of self at EoL also suggest that there is a temporal dimension in the sense of self or personhood. Kong, Fang & Lou (2016) examined how personhood could be conserved in older people dying in residential care homes in Hong Kong. They proposed that a person's sense of self should be explored in the "here-and-now", as well as in his/her history and in his/her preferred future, in order to know the integral self of the dying person. Carlander, Ternestedt, Sahlberg-Blom, Hellstrom & Sandberg (2011) studied self-identity (the existential question of "who am I?") of EoL patients. They found that in the face of impeding death, identity reconstruction variously took place in the patient's everyday life because of ongoing changes within self, as well as in relationships between patients and significant others, and with the community. These authors further emphasised that it is "important to let the past and the former identity, as well as the new, be a vital part of the present situation" (2011, p. 12). Drawing from these studies, it seems that an element of dignity-conserving work should be aimed at helping patients maintain or retain harmonious relationships with their systems, alongside interventions on symptom relief and respect of choices and autonomy. Consideration should also be given to the temporal dimension of these relationships, and their integration to achieve a sense of completion among patients.

THE IMPLEMENTATION OF THE VOLUNTEER-PARTNERED COMMUNITY CAPACITY BUILDING EoLC MODEL

Targeted service user. The service target population is elderly patients who are receiving PC services at the MPM Unit of TMH, and are in advanced stages of disease, such as chronic renal failure, heart failure and neurodegenerative diseases (motor neurone disease, multi-system atrophy, advanced Parkinsonism, etc.) or cancer. Priority is given to those who are financially disadvantaged or who lack social support. The service serves patients and their families in Yuen Long, Tuen Mun and Tin Shui Wai.

Team composition and respective roles. The model is actioned by two service teams: the MPM Unit of the TMH (called the MPM team hereafter) and the social care team of the HCCDECC (called the social care team hereafter). The MPM team involves a PC doctor, PC nurses, nurses from the palliative home care team and a medical social worker; whereas the social care team comprises two social workers, a nurse and volunteers. The MPM team is responsible for identifying suitable cases for referral, medical and nursing care, palliative home care nursing services and the formulation of Advance Care Planning (ACP) with patients. The medical social worker of the MPM team also works closely with the social care team to coordinate care. The social care team is responsible for providing and coordinating various psychosocial and community support services for patients, supporting them and their family members to prepare for death, including fulfilling last wishes, accompanying patients and family members through the last stage of their life, as well as funeral and bereavement support.

Service delivery features. Service delivery is characterised by three features: case conferences between health and social care teams; case management or case coordination; and volunteer-partnered care and support.

Monthly interdisciplinary case conferences. These are held between the MPM and social care teams to share updated information on patient progress. This facilitates collaborative and holistic assessment and care planning. The meetings also ensure consistency of the information provided by both teams to patients and family. Issues such as the patient's and family members' preferences on care, and their wishes, are also discussed in these meetings, ensuring that all agencies coordinate care in ways that are consistent with the patient's preferences. Moreover, the MPM team often provides medical and nursing advice to the social care team. Apart from case conferences, each team has one additional designated contact person for information sharing, which ensures continuity between meetings. The two teams collaboratively formulate discharge plans in an attempt to facilitate seamless care when patients are discharged to the community from the MPM Unit. However, collaboration is not only limited to these activities. The social care team also visits patients' homes for early identification of needs for intervention from the MPM team. This results in more timely support from the hospital (e.g. early bookings for consultation or visits by palliative home care nurses), and thereby facilitates better utilisation of hospital services.

Case management. This is provided by social workers and nurses in the HCCDECC social care team and focuses on care coordination for patients and their families. Case managers conduct holistic assessments for patients and family members, and they source and coordinate support services according to needs. An array of professional services is available to patients and families to optimise function and meet practical needs at home – ultimately to enhance QoL and dignity. These include physiotherapy, occupational therapy, dietetics, home-help and escort services. The team also arranges complementary therapies, such as aromatherapy and hypnotherapy, when it was assessed to be appropriate and desired by the patient and/or family members. Moreover, the team organises patient and caregiver mutual support groups and home visits between patients of the same diagnostic group and their caregivers to expand mutual support networks. In summary, case managers play a key role in care coordination, and they act as a bridge to link and mobilise support networks for patients and their families.

Volunteer-partnered care and support. This involves training volunteers to preserve dignity by focusing on the 3Ls (Loss–Love–Legacy). The social care team has trained over 30 volunteers each year to participate in this project. Volunteers receive 30 hours of training and 20 hours of internship before they are allowed to provide formal services. They are equipped with compassionate communication skills and knowledge about EoLC to help them play a companion role for patients and families. They are matched with specific patients and families, whom they follow across the course of disease till the bereavement stage. In 2017, a 3Ls framework of psychosocial–spiritual intervention gradually emerged from the empirical experience of the social care team. The 3Ls framework was also inspired by the concepts of dynamic dignity and sense of self, as discussed in the previous section. This framework guided the practices of both case managers and volunteers.

The 3Ls framework provides guidance on assessment and psychosocial–spiritual interventions with the aim of preserving the dignity and QoL of patients at EoL (see **Figure 7.1**). Central to this framework is the notion that the dignity of a patient approaching EoL is linked to his/her relationship with the divine, with self, with family and with other significant people in his/her social network. Dignity can be enhanced by harmonising and/or mending these relationships. Moreover, there is a temporal dimension on these relationships, reflecting the past, the present and the future. Within the context of impending death, the 3Ls framework proposes that the core "harmonising task" regarding past relationships is facing **loss**; for present relationships, it is the expression of **love**; and for the future, it is leaving a **legacy** to allow the formation of continuing bonds.

The temporal dimension (past, present, future) and the relationship-type dimension (self, family, social, spirituality) forms a 4x3 matrix, with each cell representing a core task in a specific time point (past, present, future). For instance, in the cell of "relationship with family in the past", when patients have indicated unresolved relationship issues with significant family members that has hampered patients from achieving feelings of completion and satisfaction, intervention strategies should seek to support patients to resolve conflicts with family members through creating chances for reconciliation, letting go or through family counselling. It should be noted that discussions about these relationships not only applies to patients, but also to caregivers, and both patients and family members can be engaged in this process. Our empirical experience with this framework suggests that helping patients come to terms with their values and thoughts regarding past relationships, and to have the chance to share these thoughts with family members, usually promotes harmony in relationships. Moreover, these discussions can lead to identification of important psychosocial aspects relevant to individual ACP.

RELATIONSHIP TYPE

TIME

	SELF	FAMILY	SOCIAL	SPIRITUALITY
Past (loss)	Mend the broken relationship with self	Mend the broken relationship with family	Mend the broken relationship with friends /relatives	Mend the broken relationship with the divine/sacred
	Interventions: Life review, recognising past contribution, self-forgiveness	*Interventions: Resolving conflicts in the past, restorating, family counselling*	*Interventions: Resolving conflicts or resuming contact with friends/relatives*	*Interventions: Facilitating the accepting and forgiving oneself for not following teaching or expectations from the divine, rejecting/ leaving the divine*
Present (love)	Consolidate love relationship with self	Consolidate love relationship with family	Consolidate love relationship with friends/relatives	Consolidate love relationship with the divine/sacred
	Interventions: Maintaining daily life habit, hobby, expression of self, wish fulfilment	*Interventions: Expression of love and forgiveness, family activities, cerebration of festival, wish fulfilment*	*Interventions: Organising gatherings/parties, cerebration of festival/anniversary, wish fulfilment*	*Interventions: Playing spiritual songs/music, reading spiritual books, arranging visits by spiritual leader/volunteers, attending religious gatherings, praying/ chanting/mediation, etc.*
Future (legacy)	Prepare death and separation in tangible context	Leave blessings to family	Leave blessings to friends/relatives	Explore belief in divine/sacred, explore belief in afterlife
	Interventions: Writing will, funeral planning, discussions on body/organ donation, discussions on AD	*Interventions: Sharing life-review book with family, leave blessings to family through words, photo, video and gifts, building continuing bonds*	*Interventions: Sharing life-review book with friends, leave blessings to friends through words, photo, video and gifts, building continuing bonds*	*Interventions: Reading spiritual books, arranging visits by spiritual leader/volunteers, planning for funeral, praying/chanting/ mediation*

Figure 7.1 3Ls (Loss–Love–Legacy) Volunteer-Partnered Psychosocial–Spiritual Intervention

Volunteers are trained to use the 3Ls framework, which equips them with values, knowledge and skills related to its application. They learn why the 3Ls are significant for service recipients, how to evaluate the needs of the service recipients using the 3Ls perspective and how to map these to their corresponding intervention choices. Case managers conduct initial patient assessments and identify aspects of the 3Ls framework that require intervention. Pre-visit briefings orient volunteers to patients' needs within the 3Ls framework so that volunteers can be coached to further explore relevant relationship aspects during their visits. The information gathered by volunteers is then shared with case managers to facilitate intervention planning. Given the level of engagement of some volunteers, this is sometimes conducted collaboratively by case managers and volunteers. For example, volunteers have actively engaged in producing life-review books, planning family gatherings and wish fulfilment activities, and sharing spiritual books and religious ornaments with patients who need the support. On the other hand, case managers might provide professional counselling when there are complicated relationship issues. To support partnerships and communication, a volunteer recording form has been developed, based on the 3Ls framework, to facilitate communication between volunteers and case managers in relation to their observations and interventions at each visit.

CARE MANAGER: VOLUNTEER-PARTNERED SERVICE DELIVERY PROCESS

The 3Ls framework features are interwoven in the assessment and service delivery process to ensure that person-centred and holistic care is offered to patients and their family members (considered as a unit) (see **Figure 7.2**). Upon receiving a referral from the MPM Unit of TMH, the social care team conducts a holistic assessment in which any practical support required by the patient and family members to maintain caregiving at home is given the highest priority. This remains a priority throughout the case manager's support service coordination.

Healthcare from the MPM team is ongoing, whereas support from the social care team is facilitated by monthly case conferences and close communication between the teams. Dignity cannot be promoted without appropriate healthcare and practical supports that work to maintain function and person–environment harmony. This is why healthcare and practical support are prerequisites in the service delivery pathway. Psychosocial and spiritual needs are the focus after any physical and practical concerns have been adequately addressed. Patients with complex needs (e.g. family conflicts, persistent intense emotional distress) and/or unstable conditions are mainly supported by case managers through counselling. However, those patients who are deemed to have lower psychosocial or emotional needs may be matched with volunteers, who will provide psychosocial care using the 3Ls framework in collaboration with case managers.

Periodic assessments of patients are conducted by case managers, who report the need for changes in care coordination when they arise. When patients are in their final weeks or days of life, they might be moved to another place of care. The MPM Unit and case manager work closely to facilitate as smooth a transition as possible to the new place of care. Spiritual support is also provided to enable patients to pass away with peace. Since the MPM Unit facilitates the completion of Advance Directives (AD) and/or Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders with patients and family members, the majority of these patients receive comfort care in hospital in their final days. At the same time, the social care team and volunteers provide companionship, and emotional and spiritual support to both patients and family members. Funeral assistance and bereavement care services are provided to bereaved family members by the social care team and volunteers upon the patient's death.

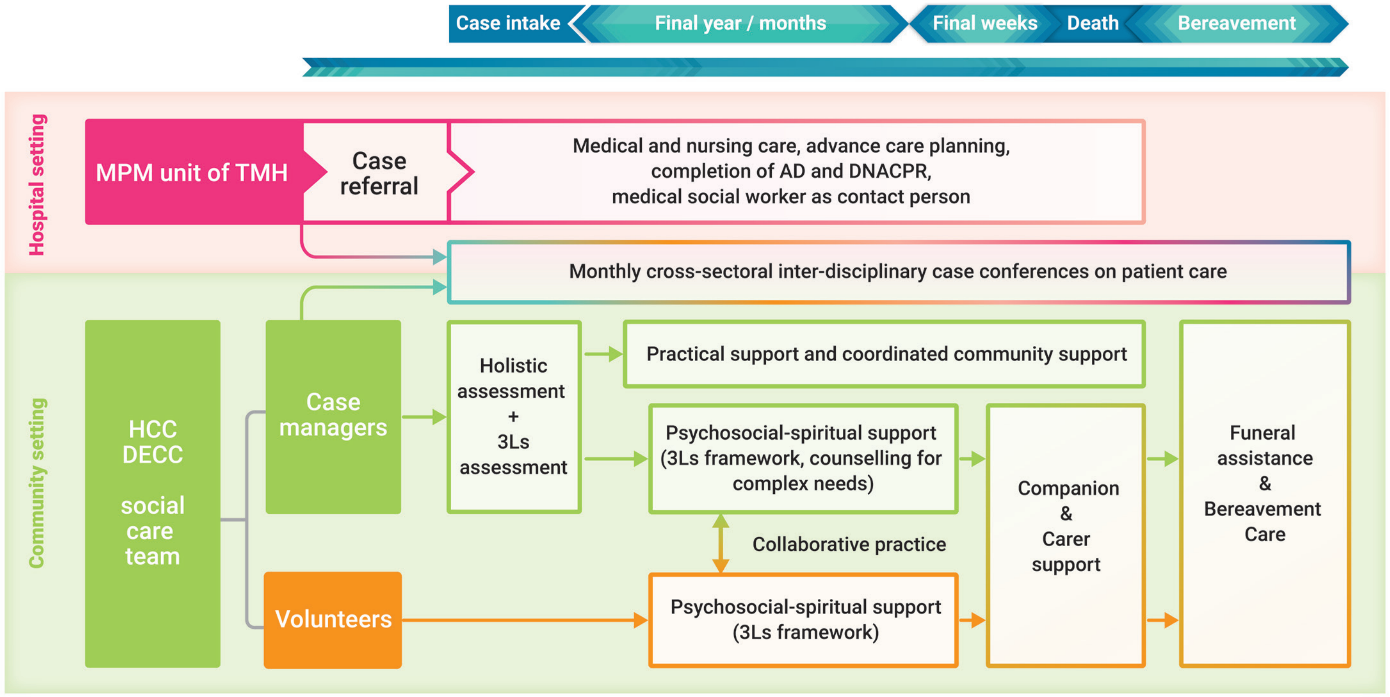

Figure 7.2 Service Delivery Pathway

BEST PRACTICES

The following two cases are used to illustrate good practices in health and social integrated care, and how the 3Ls framework has been applied to preserve dignity and enhance QoL.

CASE STUDY 1: PROMOTING SEAMLESS CARE BY SYNERGISTIC MEDICAL–SOCIAL PARTNERSHIP AND CARE COORDINATION

Mrs Lee, aged 65, was suffering from end-stage renal failure. She lived with her son, Peter. When Mrs Lee was admitted to the HCCDECC EoLC programme, she was still able to take care of herself, and could still manage to help with house chores when Peter went to work. The case manager and two volunteers visited the Lee family regularly. They usually accompanied Mrs Lee and Peter to Chinese restaurants and walked around the park with them in order to build up rapport with the family, as well as to strengthen family cohesion and understand their needs. Recently, however, volunteers found that Mrs Lee has become more reluctant to go out, unwilling to eat and feeling tired all the time. The case manager visited Mrs Lee and found that she was sleeping a lot, was worried about falling and was losing weight rapidly. In the meantime, Peter revealed that he felt physically and emotionally exhausted because Mrs Lee had lost motivation in helping with house chores and other activities which she once enjoyed.

Mrs Lee's case was discussed with the MPM team in the monthly case conference, and the MPM team arranged for the home care nurse to visit Mrs Lee. During this consultation, she also explained the deterioration expected in the end-stage renal failure to Peter, so that he could better understand his mother's seemingly "lazy behaviour". The social care team also immediately connected the family with community resources, such as the physiotherapist and the dietician, before the hospital provided its regular consultation. To help relieve Peter's caregiving stress, the social care team referred the family for home cleaning, hospital escort and personal care services. EoL-related issues were also discussed with the family, including Mrs Lee's wishes for her last days and her preferred funeral arrangements. Mrs Lee was a Christian and she wished to have her churchmates around, singing hymns and chatting with her in her final days. The social care team shared this information in the case conference. Acknowledging her wishes, the MPM team arranged a separate room in the MPM ward for Mrs Lee when she reached her final days, so that her son, her churchmates and the social care team could stay with her. To continue to promote Mrs Lee's dignity and autonomy till her very last moments, the social care team encouraged Mrs Lee to choose her favourite Christian songs to be played in her room. The team also prepared a booklet that contained the song lyrics, which could be shared with friends and churchmates during their visits. This meant that her friends were also more prepared to support Mrs Lee during her final days, in the way she wished.

CASE STUDY 2: PRESERVING DIGNITY THROUGH 3Ls INTERVENTIONS

Mr Wong, aged 60, had been suffering from motor neuron disease (MND) for a few years before he was admitted to the HCCDECC EoLC programme. Mr Wong lived with his wife and two daughters. Mrs Wong was really the only family caregiver as her two daughters seldom stayed at home during their busy working week. The case manager visited the family with two volunteers. They assessed the family's needs using the 3Ls framework.

During these visits, the social care team found many photos on the walls. Through talking about the photos, the team found that Mr Wong had been a busy businessman before he became too sick to work. While he was working, he had managed his time well, he had insisted on having dinner with the family every evening, and he had also arranged regular gatherings with his friends, or even his daughters' friends. The team and the family affirmed that Mr Wong had been a "responsible and respectable" person during his life, and Mrs Wong thanked Mr Wong for all his contribution to the family (Self – Past). The team also explored Mr Wong's current concerns, acknowledged his sadness and explored alternative ways to maintain his daily life activities (Self – Present). Mr Wong was asked about his thoughts on the preferred type of care at EoL and also his preferences for funeral arrangements (Self – Future).

Family conferences facilitated by the case managers allowed the whole family to talk about family relationships in the past. This highlighted that the Wong family had strong familial cohesion (Family – Past). The family was then encouraged to talk about their current life, which they all noted was "all about caregiving" (Family – Present). This was found to contribute to Mr Wong's sense of self-blame (seeing himself as a burden), and the family was helped to understand that Mrs Wong's commitment to care and Mr Wong's guilt feelings were actually alternative ways of expressing love and care. The social care team tried to engage the daughters in more caregiving in an effort to ensure that Mrs Wong had some personal time. With assistance from volunteers, the family collaboratively prepared a family life book to continue the love and joyful memories after Mr Wong's death, as well as to record Mr Wong's life wisdoms for posterity (Family – Future).

It was found that unplanned and unexpected visits from friends tended to interrupt the daily caregiving routine, but the family wanted to maintain connections with relative and friends. Thus, the case manager facilitated the family to set up a "visiting schedule" to ensure Mr and Mrs Wong could commit to a daily routine, as well as enjoy social activities. For instance, Wednesday and Friday mornings were scheduled for friends' visits, and some caregiving tasks were left to the afternoons (Social – Present). Volunteers also supported Mr Wong in approaching his old friends and re-engaging with them (Social – Past).

The social care team organised regular visits by the local vicar and church members (Spirituality – Present). With their support, Mr Wong learnt to forgive himself by prayers (Spirituality – Past). Although the social care team only supported Mr Wong for four months before his death, the whole team and the local church came together to support the Wong family at the funeral and in bereavement (Spirituality – Future).

OUTCOMES

Up to 31 March 2018, 58 patients who have received the "Hospice in Family: Home Care Support Services" have completed three assessments each (at service intake, one month and three months after service commencement) and 27 caregivers have completed the first two assessments (at service intake and at three months after service commencement). Twenty bereaved caregivers have also completed the bereavement assessment two months after the patient had passed away. A large number of patients could not complete all assessments because of unexpected early death or a deteriorating physical condition that rendered them unsuitable for assessment.

Of the 58 patients with full assessments, 28 (44.3%) were male. The group had a mean age of 75.8 (SD=11.2) years and they came from diverse diagnostic groups: 12 (20.7%) had cancer, 26 (44.8%) had renal diseases, 7 (12.1%) had chronic obstructive pulmonary disease, 6 (10.3%) had MND and 5 (8.6%) suffered from heart failure. Over half (56.7%) of them were living in the family home with other family members, 20.7% were living alone and 17.2% were living in residential elderly care homes with relatively poor familial support. Of the 27 caregivers who provided assessments, 8 (29.6%) were male. The caregivers had a mean age of 63.0 (SD=11.8) years, and they were mainly spouses (63%) or children (29.6%) of patients.

For evaluation purposes, the outcome indicators collected from patients and caregivers over time were divided into binary form (low- or high-needs) using a critical threshold set at the mean baseline score plus one standard deviation for each indicator (see Chapter 5). During analysis, the percentage of high-need patients and caregivers in each outcome indicator was compared between baseline (commencement) and the three-month service mark using paired t-tests.

It was found that the proportion of patients with high needs in physical symptoms at baseline increased slightly at the three-month follow-up, while the proportion at baseline with high needs in practical problems, anxiety and depression decreased at follow-up (see **Figure 7.3**). The proportion of caregivers reporting high strain at baseline reduced (but not significantly) at the three-month follow-up (see **Figure 7.4**), while caregivers who reported low levels of intimacy with patients at baseline showed a significant improvement at three months ($p<0.05$). In relation to bereaved caregivers (assessed at two months after the patient's death), 85% reported low risk of complicated grief.

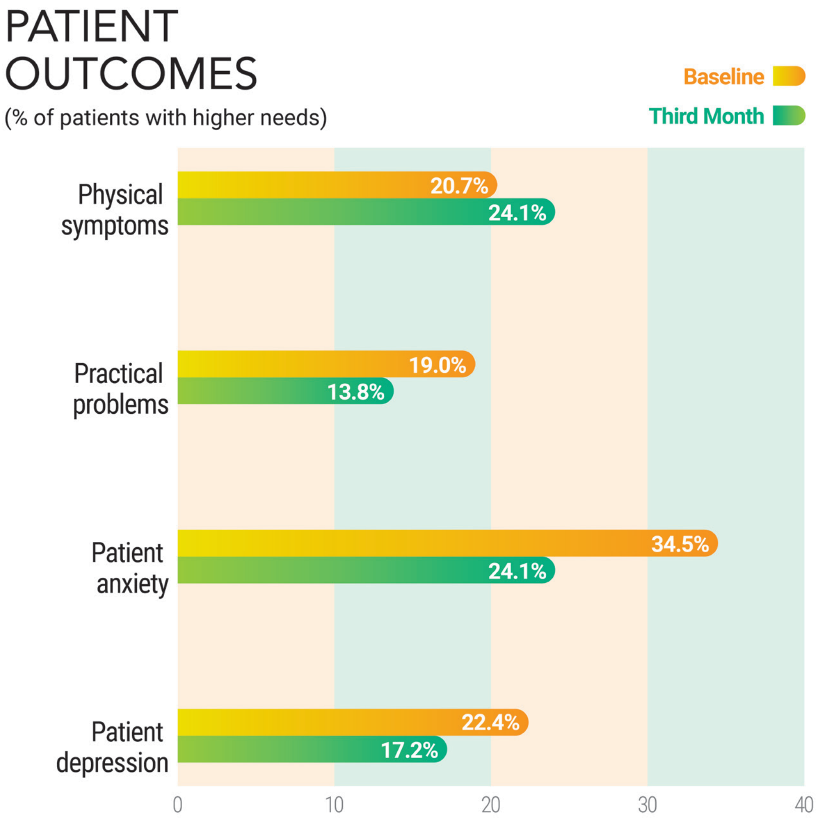

Figure 7.3 Changes in Patient Outcomes after Three Months of Service

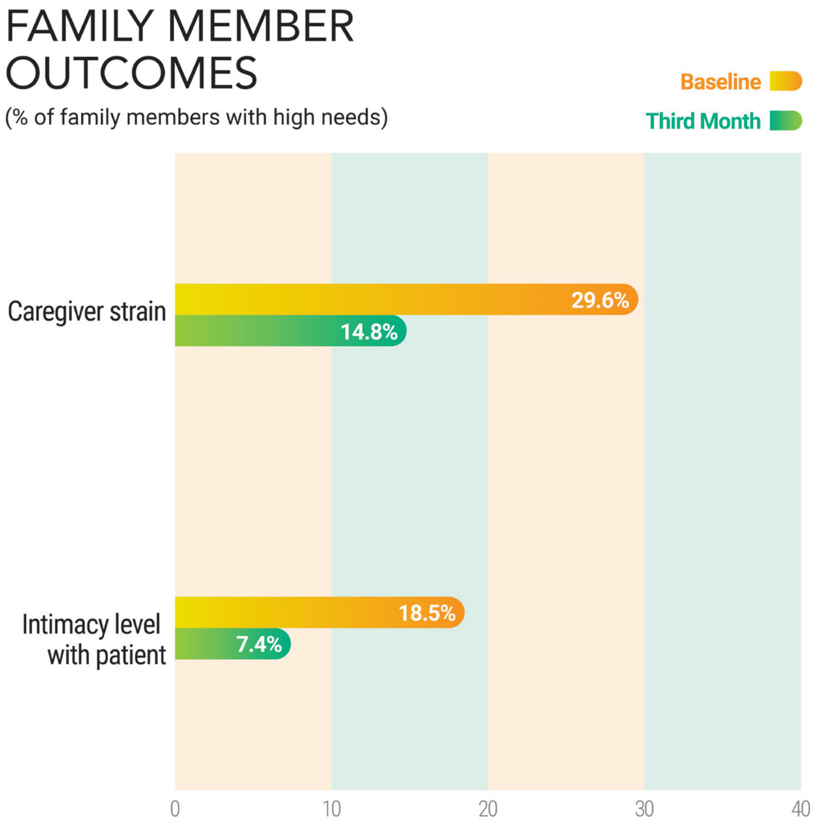

Figure 7.4 Changes in Family Members' Outcomes after Three Months of Service

By examining changes in patient and caregiver needs and concerns over their first three months receiving the “Hospice in Family: Home Care Support Services”, the service model demonstrated the potential to alleviate patients’ practical concerns and enhance their psychological well-being despite deteriorating physical conditions. Increasing physical symptoms are anticipated when patients are approaching death. However, over-time evaluations to date have shown relatively stable intensity of physical symptoms. Reduced caregiver strain over time also mirrors decreases in patients’ practical concerns. Given the considerable number of patients who were living alone or had relatively weak familial support, intensive practical support and support provided out-of-office hours may be indicated. These needs are challenging to meet with the current available levels of community support. Conserving dignity focused on relationship harmonisation, and the significant improvement in the level of intimacy between caregiver and patient provides preliminary evidence for its effectiveness.

We also examined the findings of a satisfaction survey regarding care coordination and conservation of dignity. All the surveyed patients (N=27) strongly agreed that the service “helped him/her live with dignity” and that “their wishes had been respected by the service team” (a score of 7 or above out of 10 was classed as high agreement). A newly added item on medical–social collaboration was administrated to 16 patients, and all of them agreed that “the cooperation between the hospital and the service team facilitated a stable and satisfactory care for the patient”. This provides early evidence to support the effectiveness of medical–social collaboration, which is a feature of the current service model. Since the service model has been gradually evolving during the project period, the chances are that more time will be required for the impacts of the evolved model to be fully reflected by the evaluation data.

LEARNINGS, REFLECTIONS AND SUMMARY

The volunteer-partnered community capacity building EoLC model is characterised by a medical–social strategic partnership between the MPM Unit of TMH and the HCCDECC HBSD. A community capacity approach to coordinating and providing care is facilitated by a partnership between case managers and volunteers. Key highlights and lessons from the implementation of this EoLC model to date are summarised next.

INNOVATIVE MODEL THAT FILLS A GAP

The model is the first of its kind in Hong Kong, and it fills a gap in the currently fragmented and inadequate support systems available to community-dwelling patients facing life-limited diseases and their families. The model is innovative and, as such, it contributes to international EoLC knowledge.

EFFECTIVE

The model has continually evolved since its inception two years ago, in response to feedback and observed need. Preliminary evaluation findings lend support to its effectiveness in enhancing the QoL of patients residing at home, as well as that of their families. The model also supports services that appear to preserve patients' dignity, underpin seamless care experiences, and promote patients' satisfaction.

CONSTRUCTIVE FRAMEWORK AND TEAM COMPOSITION

The model was built on three clearly defined, intertwined principles relevant to community, service and family. Enacting these principles at each of these levels has significant implications for interventions and good practices. The composition of the social care team was also appropriate, as team members could successfully engage with the three service delivery features. Good practices underscored the service delivery features of the model:

- Honouring patients' wishes and autonomy;
- Enabling seamless and coordinated care by collaboration between the MPM Unit and social care team;
- Mobilising the community support networks by the efforts of the social care team; and
- Enhancing patients' dignity by case managers and volunteers using the 3Ls framework to explore and promote harmonious relationships for patients (with themselves, with family members, with others, and with their religion).

Moreover, the partnership has been shown to facilitate sharing and better use of resources in meeting patient and family needs.

A BALANCE BETWEEN STANDARDISED AND STRUCTURED ASSESSMENT AND TAILORED INTERVENTION

The three guiding principles in the model encompass the universal needs of patients at EoL, and it provides a flexible framework that supports balancing standardised and structured assessments and tailored interventions. It has been applied to, and found suitable for, patients from a broad range of diagnostic groups.

There is always room for improvement, and further refinement of the model is anticipated. In order to further enhance service effectiveness, patients should be engaged in discussing issues related to ACP (e.g. wishes, care preferences, preferences regarding funeral arrangements, etc.) using the 3Ls framework as early as possible after commencing in the programme. It was noticed that discussions on these issues became challenging if left until the patient's condition started to deteriorate and their symptoms became more distressing. It was also observed that discussing care plans, wishes and preferences with only the patients (and not the family) may not lead to real actions. However, when family members were engaged in these discussions, the plans were more likely to be enacted with the help of family members. Therefore, family members should be engaged and included, as far as possible, during care planning. Communication tools and resource packages should be developed based on the 3Ls framework to assist volunteers and case managers to easily use the framework for assessment, communication and intervention. All in all, there is sound evidence that the volunteer-partnered community capacity building model could be further developed to benefit other patients and families in the future.

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