CHAPTER 8

FAMILY-ORIENTED CARE MODEL IN COMMUNITY-BASED END-OF-LIFE CARE

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The whole family is affected when a family member has an advanced illness. While family members provide invaluable support for the person with the illness, they also face stresses that deserve special care and attention. Family members of patients are thus sometimes referred to as "second patients" (Laryionava et al., 2018). One of the influences of Confucianism is filial piety, which is a central tenant of many Chinese families (Feng, 2017). The role of caring for the aged and sick has traditionally been undertaken by Chinese families (rather than by external agencies) using an informal network of shared family support. However, with recent demographic and socio-economic changes in Chinese society, as well as increased ease of geographical mobility, Chinese family care for aged and infirm members is weakening. For instance, the average domestic household size in Hong Kong dropped from 4.2 in 1976 to 3.3 in 1996 and to 2.8 in 2016. Moreover, the per-household ratio of non-employed members to employed members is 0.9 in 2016 (HKSAR Census and Statistics Department, 2017). This means that there are fewer family members available and/or willing to undertake caring responsibilities for family members dealing with advanced illness.

St James' Settlement joined the Jockey Club End-of-Life Community Care (JCECC) Project as a service provider in 2016. This organisation has extensive experience in caring for older and/or terminally ill people, and conducting innovative life and death education in the community. Adopting the framework and philosophy of Broaden-and-Build theory (Fredrickson, 2004) and Dying Role theory (Emanuel, Bennett & Richardson, 2007), St James' Settlement developed the Cheering@Home programme to serve families caring for people who have a prognosis of living less than six months.

In this chapter, the experiences faced by families of persons with advanced illnesses are outlined. The two foundation theories that inform the Cheering@Home intervention model are explored, followed by an introduction to the model itself. To link theories and practice, two cases are presented, and preliminary outcomes of families who have received Cheering@Home interventions from St James' Settlement since 2016 are reported. Insights into, and learnings from, the St James' Settlement model are presented at the end of the chapter.

BACKGROUND

THE PHENOMENON OBSERVED IN FAMILIES FACING END-OF-LIFE ISSUES

Conspiracy of silence. Having to talk about a poor prognosis and impending death is dreadful in any situation, but particularly so for Chinese families. There tends to be a conspiracy of silence, which is usually based on good, albeit misguided, intentions to protect others from distressing news. Yoshida et al. (2013) found that Chinese family members frequently assume a dominant role in medical decision-making, as well as disclosing information about a poor prognosis to ill family members. It is also common for Chinese adult children in Hong Kong to request that the medical team do not disclose the diagnosis or prognosis to aged parents, even if the latter are mentally competent. Not knowing the diagnosis or prognosis of an advanced illness can block communication between ill people and the family members, particularly in resolving unfinished business or making end-of-life care (EoLC) plans. These opportunities are lost if patients become mentally incompetent with the progression of their illness, and this situation usually leads to life-long regrets of family members.

Sometimes, patients gain awareness of their deterioration as their condition worsens. As described by Glaser and Strauss (1965), there are four types of awareness of dying in a family. First is closed awareness, which happens when the patient is the only one who does not know that he/she is going to die. The second is suspicion awareness, which occurs when the patient suspects that he/she has a terminal condition but cannot get information from others. The third category is mutual pretence, when both patient and family are aware of the imminent death but do not communicate about it. The last category is open awareness, when patient and family acknowledge impending death and communicate about it. Having open awareness can prevent mistrust developing between patients and family. This engages family participation at an earlier stage to reduce regrets about lost opportunities, as well as improving the patient–family relationship. This also allows EoLC decisions to be made in advance.

Illness as the focus. When advanced illness is acknowledged, managing the person suffering from it becomes the focus in most families. However, family members mostly focus on the medical treatment (either curative or palliative) or health-related diet and other remedial activities. As shared by a patient, "Even though I am a patient (bing ren, 病人, literally means a person with illness), I am still a person, and illness is just a small part of me. Don't pay all the attention to the illness, but treat me as a person!" EoLC should encompass holistic care for patients and family to address their multidimensional needs. These are not restricted to physical needs, but also include emotional, spiritual, family, social, economic and ethical needs, which emerge in a progressive process intertwined with crises (Gómez-Batiste et al., 2017, p. 227). To do this requires consistent and often substantial amounts of care, which should not only be person-centred, integrated and comprehensive, but also be delivered promptly based on appropriate holistic assessments.

Blameless guilt. Bennett (2018) coined the term "blameless guilt" perceived by caregivers of persons with advanced illness. This guilt may be groundless, and yet is commonly found among family caregivers. Filial piety is a valued attribute of Chinese family life, which also establishes an expected standard of care required from caregivers. If family members cannot care for patients at this standard, guilt may well result. Not being able to meet care expectations may occur if there are competing expectations with other duties (such as employment or other family commitments). As compensation, family members often offer financial resources for patients to seek miracle cures or they may seek expensive institutional care for their loved one. These actions sometimes produce in patients a sense of being a burden, which can affect their emotional state and quality of life (QoL). At times, caregivers may even suffer anxieties about visiting patients, which can be further complicated by a sense of indebtedness (Hennings, Froggatt & Payne, 2013). The discomfort, or even avoidance, of visiting family members with advanced illness, can waste golden opportunities to share quality time with them. Moreover, the guilt may continue even after the death of the loved one.

Unfinished family business. When patients and family members are aware that time is not on their side and there is unfinished business that requires resolution, problematic relationship issues may surface. Although it may be the wish of the dying person and family members to address relationship issues and resolve unfinished business, they may also worry about the outcomes of such discussions. These could be clouded by grief, avoidance of acknowledging and recognising the looming life-ending situation, and/or limited emotional and physical energy to pursue issues to completion. The patient's energy can be diminished by practical issues such as their illness, the effects of treatment or fatigue, while family members' energies can be drained by grief, guilt, the burden of unspoken issues or practical tasks of caring. Recognising this is particularly important in Chinese families who treasure wish completion, and finding ways to help them address unresolved issues must be identified (Chow, Chow, Wan, Wong & Cheung, 2011).

Exline, Prince-Paul, Root, Peereboom & Worthington (2012) focused on the study of forgiveness communication at the end of life (EoL). She found that communication of forgiveness is not as common as communication of love, gratitude or farewell. She suggested that in unresolved situations, lack of forgiveness is correlated with higher depressive symptoms in family members. Cohen, Auslander, Dror & Breuer (2016) found that involvement of patients and family members in existential tasks, such as life review, spirituality, multigenerational family relationships and preparation for death, was positively correlated with a sense of self-benefit for family members. Moreover, contrary to logical thinking, functional caregiving was not considered as a stressor. It is found to be positively, although weakly, correlated with a sense of self-benefit of family members.

When facing an EoL situation, family conflicts are often magnified, and can result in poorer bereavement adjustment (Kramer, Kavanaugh, Trentham-Dietz, Walsh & Yonler, 2010–2011). A family-centred holistic approach that addresses unfinished business and existential concerns will therefore be beneficial to the grieving family in the long term.

Figure 8.1 illustrates the phenomenon faced by patients and family when facing ramifications of advanced illness. Although the illness is primarily a medical issue, it also manifests in multidimensional needs for patients and their families. Family-based care that is individualised and holistic is an appropriate approach to assist families in coming to terms with approaching EoL of a loved one. Families of persons with advanced illness need a platform that allows trustful and open communications when they wish to engage in them. The objectives are to communicate care preferences and planning; address unfinished business; and exchange apologies, forgiveness and gratitude. These components need to be addressed in the design of care interventions.

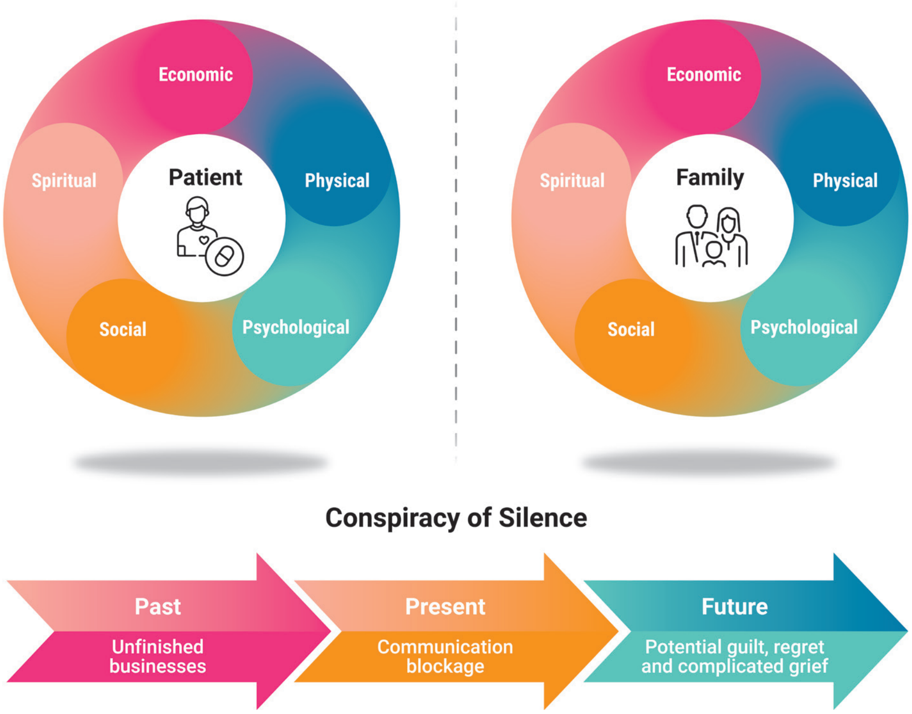

Figure 8.1 The Needs of Persons with Advanced Illness and their Families

INSIGHTS FROM THEORIES

There are two theories related to EoLC that have provided insights into the design of the St James' Settlement intervention for EoLC for patients and families. The Dying Role theory (Emanuel et al., 2007) is aligned with conclusions drawn from observations from clinical work, and the Broaden-and-Build theory of positive emotions (Fredrickson, 2004) provides an innovative approach to addressing the challenges faced by families with persons with advanced illnesses.

THE DYING ROLE THEORY

Parsons (1951) introduced the medico-sociological concept of the "Sick Role", which suggests that the person with illness has two rights (exempt from usual social roles and not being blamed for their condition) and two obligations (try to get well and seek appropriate help). Persons with advanced illness sometimes also adopt this sick role but become frustrated because no matter how much effort they make to fulfil the two obligations, it is in vain. Emanuel et al. (2007) proposed a new role theory – the 'Dying Role' – to help persons with advanced illness negotiate final life tasks. Specifically, they proposed three types of task of the 'Dying Role': practical tasks, relationship tasks and personal tasks. Practical tasks include the handling of financial legacy, organising EoL planning, caring for dependents and arranging last goodbyes. Relationship tasks recognise the coexistence with other roles, emphasise the teaching nature of the dying role, passing the mantle to others, and placing a legacy capstone. A reciprocal relationship task is permission-giving, where the patient permits family members to live fully and happily after their death, and family members allow the patient to die. Personal tasks relate to the patient adjusting to loss, reaching closure, handling existential tasks and preparing last rites of passage. This is also considered as the patient's final growth phase.

The 'Dying Role' theory offers a clear conceptualisation of tasks to be carried out for, and by, the patient at the EoL. It also addresses the holistic nature of EoLC, in particular not skewing care towards the patient's physical needs. Relationship tasks embrace the importance of addressing and resolving unfinished business, and provide a clear and relevant contour of what to address within the family. Moreover, the personal task addresses the existential concerns that are commonly observed among persons with advanced illness. The promotion of communication, in particular the reciprocal relationship tasks of permission-giving, should reduce some of the blameless guilt experienced by family members.

THE BROADEN-AND-BUILD THEORY

While there has traditionally been a focus on distress and negative emotions in psychological studies, there is growing attention towards positive emotions. Fredrickson (2004) proposed the Broaden-and-Build Theory, which suggests that positive emotions broaden the momentary thought–action repertoire of the individual, and builds his/her resources as a consequence. Positive emotions, in Fredrickson's conceptualisation, are not restricted to joy, but also include interest, contentment and sense of love. Joy urges the individual to play, which can push their creative limits. Similarly, interest urges the individual to explore and expand particular perspectives. Contentment urges the individual to sit back and savour their current life condition. Finally, love is said to be the combination of these three positive emotions that supports the individual in experiencing a safe and pleasant relationship with those around him/her, and to positively journey towards EoL. The urges to play, explore and savour should then expand into the habitual modes of thinking and positive actions. Positive emotions are found to undo any lingering negative emotions, fuelling psychological resiliency, improving psychological and physical well-being, and building personal resources.

Advanced illness is usually linked with negative emotions. A negative emotion such as depression has a downward spiral effect, which restricts one's thinking, incurring pessimism and resulting in even worse moods. Thus, when facing EoL, investing in positive emotions for the patient and family such as joy, contentment, interest and love might prevent this downward negative mood spiral, and offer the family a better thought–action repertoire and resources in facing this life challenge.

MODEL OF INTERVENTION – CHEERING@HOME

The theories outlined earlier enrich the design of EoLC with two dimensions. The Dying Role theory proposes a task-based perspective with clear suggestions of appropriate focus of care. The Broaden-and-Build theory offers an alternative angle to viewing the phenomenon of family–patient relationships during EoL. Instead of focusing on the distress in the family, there should be an equal, if not more, focus on the positive emotions of the family. The Cheering@Home intervention model was developed from these theories.

As shown in **Figure 8.2**, the goal of the intervention is to improve the QoL of patients and family members as EoL approaches. Through bringing awareness, and experience, of positive emotions to the family and the patient, thinking–action choices are expected to be broadened, and emotional resources are built or strengthened. At the same time, multidimensional tasks, as suggested by the Dying Role theory, are addressed, which should hopefully reduce the negative impact from the illness.

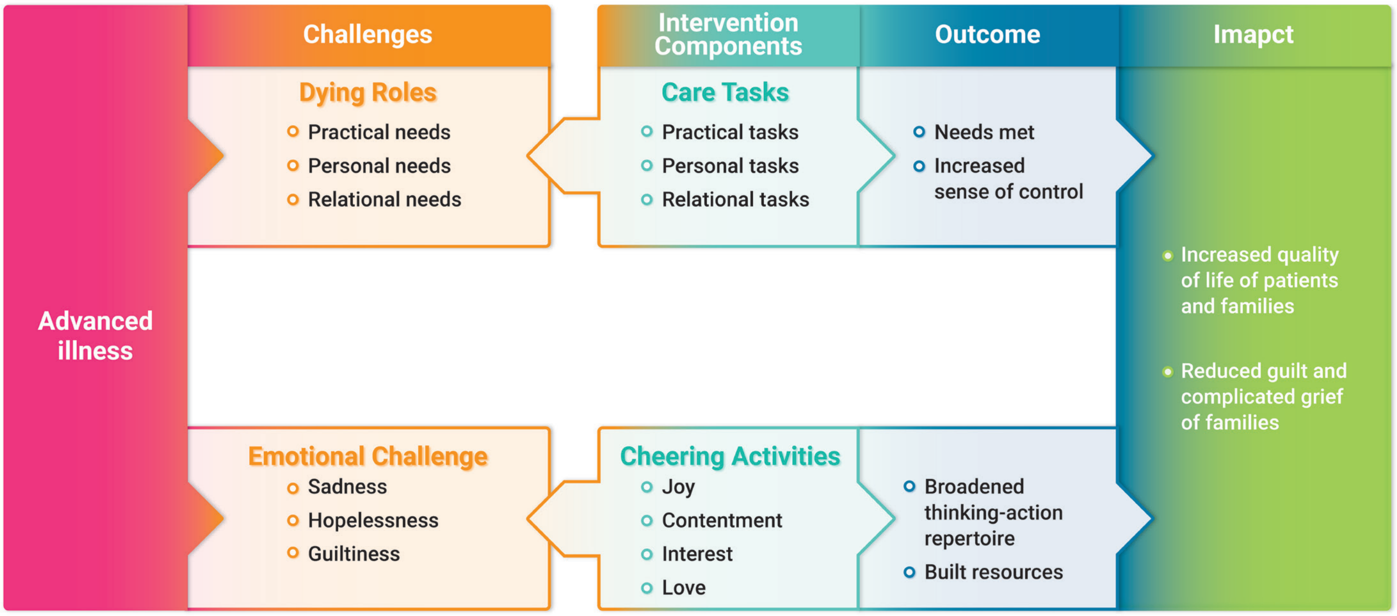

Figure 8.2 Mechanism of Change of the Cheering@Home Intervention

The Cheering@Home intervention has three features. First, related to the content of care, it adopts a holistic and family-centred approach and uses the Dying Role as a framework for organising required caring tasks. Second, which is related to the process of care, individualised and continuous assessment is carried out to ensure appropriate care is provided at the right time by the right care providers. Third, which is related to the philosophy, the intervention emphasises the importance of positive emotions. The process and components of care are outlined in **Figure 8.3**.

A referral to the Cheering@Home intervention can be received at any point of the illness trajectory. Ideally, it coincides with the start of palliative care (PC), when the prognosis of life expectancy is around six months. As part of the process of a new organisation (St James' Settlement) approaching the patient and family, the focus must be on engagement and rapport-building. Thus in the first phase, cheering-up activities, as well as practical help such as escort, daily care and equipment loan, are the focus. Cheering-up activities, including chess games, calligraphy, artwork, physical exercises, massage, group games, singing, beauty sessions, reading or cooking, are provided for the family, depending on their preference. Volunteers who are experienced in these activities are trained to lead these activities. A comprehensive assessment is done by professionals at the same time to ensure that there are strategies to meet the patient's and family's multidimensional needs.

After trust has been established and the family has been placed in a Broaden-and-Build framework, the interventions move to more intensive emotional topics such as supportive counselling to address the adjustment to loss. When the patient and family are ready, family communication and unfinished businesses are explored and addressed. The family is helped in developing legacy capstones or discussing sensitive topics such as financial legacy and EoLC planning.

When the patient is approaching the final days of life, the intervention enters the integrated care priorities (ICP) mode, where more focus is put on medical supports or funeral arrangements. The patient can choose the preferred place of death, and the team negotiates with the medical team to support these wishes. Appropriate bereavement counselling is also offered after the death of the patient to those family members who have indicated the need.

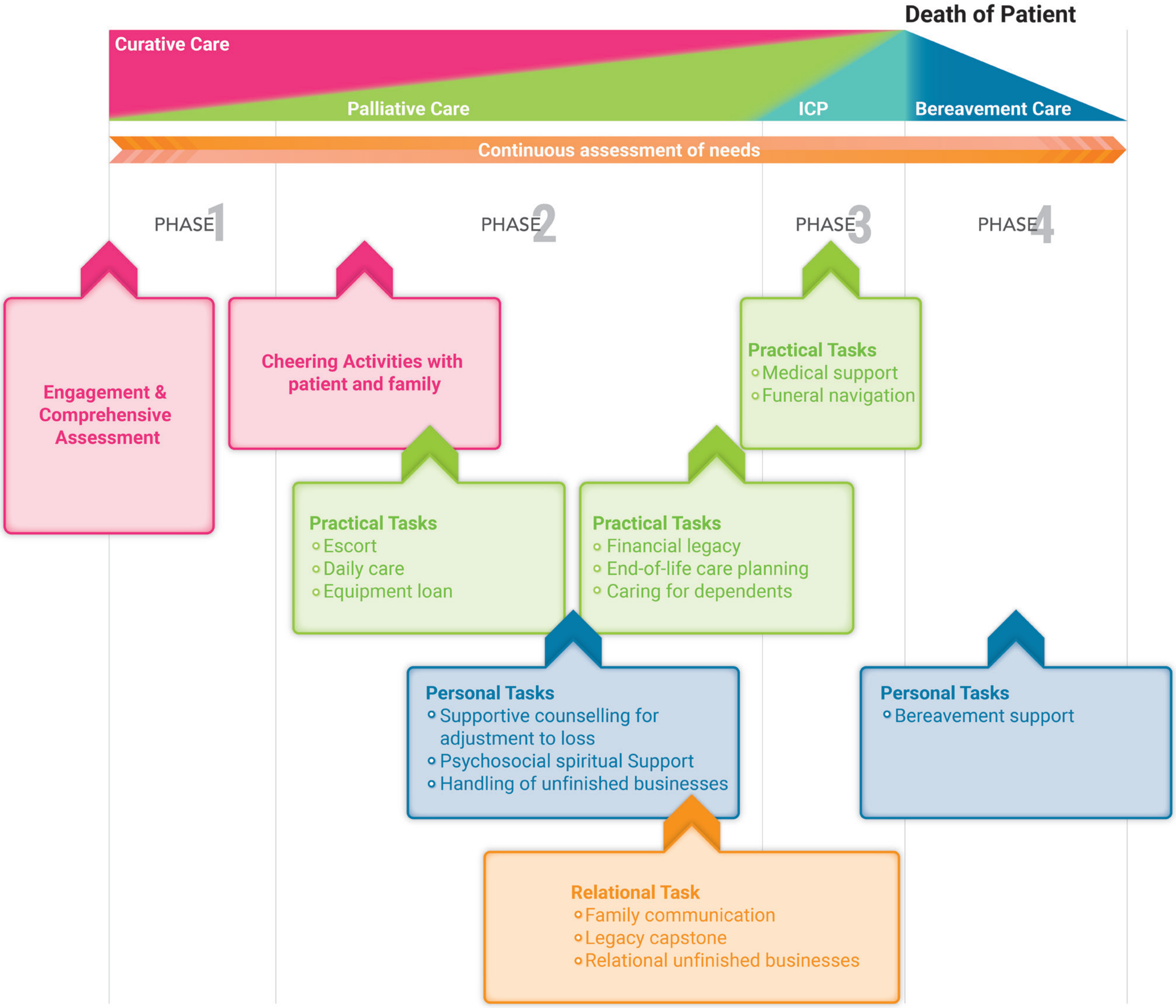

Figure 8.3
The Process and Component of the Cheering@Home Intervention Model

To encompass the Broaden-and-Build theory, the Cheering@Home EoLC team has developed the CHEER model to support patients and their families in eliciting positive emotions. The five core objectives of the project are embedded as an acronym of the name of the project "CHEER" (**Figure 8.4**).

Figure 8.4 Core Objectives of the Cheering@Home EoLC Programme

CASE ILLUSTRATIONS

The key component of this project is to use activities that elicit positive emotions for the family in building strength to face the challenges of illness. The following cases of Uncle Wong and Uncle Fai illustrate this.

CASE STUDY 1: UNCLE WONG

Uncle Wong was 89 years old and diagnosed with heart failure and dementia. Since his diagnosis, the family had arranged three different domestic workers to take care of him. Despite this, Uncle Wong had fallen several times at home. His daughter, Miss Wong, finally decided to take early retirement to be a full-time caregiver for him. Miss Wong was vigilant all the time because she was worried that her father might get injured by a fall. "I was woken up by a huge 'bang' one night and discovered that my father got hurt and was lying on the ground". These concerns made it difficult for Miss Wong to rest well at night. She rapidly lost weight and developed acid reflux since taking up the caregiving role. Moreover, the daily life of the Wong family was only focused on caregiving.

The Wong family was referred to "Cheering@Home End-of-Life Care Services" for psychosocial support. The case worker noticed that Miss Wong was very anxious about the future and always focused on Uncle Wong's illness. Moreover, taking a physical focus on pain and suffering made Uncle Wong question his existential issue, and he found life boring and meaningless. Therefore, after thorough assessment, the Cheering@Home case worker attempted to support the Wong family in accomplishing relationship and personal tasks as suggested in the Dying Role model. Different family activities were arranged to engage the Wong family in creating happy moments and to instil hope, which were the missing pieces in the caregiving journey. Borrowing from the Broaden-and-Build theory, "cheer-up" activities were arranged for Uncle Wong to strengthen his psychological resilience to face his sufferings.

Uncle Wong enjoyed spending time playing chess with volunteers. Those moments became something for him to look forward to. "I focus on the game and forget the discomfort", said Uncle Wong. The joy and positive emotion brought by chess games broadened Uncle Wong's capacity to manage his pain. Moreover, Miss Wong was amazed at her father's abilities and creativities. "Since my father was diagnosed with dementia, we seldom chat or enjoy any leisure activities. I only noticed his decline in health and abilities. Now it seems that his situation is not as poor as I thought." Cheering-up activities have facilitated Miss Wong and Uncle Wong to seek positive emotions together, to create special memories and to express love, appreciation and concern. "In the past, we were very quiet at home, but now we are actively thinking of new ideas, planning for outings and activities such as going out for meals, visiting Béthanie, having a party with the neighbours, etc."

The interventions also have practical implications. Miss Wong could be temporarily relieved from her routine caregiving tasks during the volunteers' visits. This enabled her to take a break to go shopping, have afternoon tea and/or just relax. Having this time to refresh and recharge helped Miss Wong to regain her energy and enthusiasm to continue her caregiving work for her father.

CASE STUDY 2: UNCLE FAI

Uncle Fai was 80 years old and diagnosed with prostate cancer. He lacked energy and had a severe hearing impairment. Being single and living alone, Uncle Fai was mainly cared by his younger sister (in her 60s) who lived some distance away. Her brother's deteriorating condition made the sister feel compelled to visit him more often, despite the long travelling distance. However, Uncle Fai refused more frequent visits by his sister because he wanted to rely on himself. They started to quarrel over minor issues. They were both worried about the future and how Uncle Fai would be cared for, although neither of them dared to talk about it.

Unfortunately, Uncle Fai slipped and fell one day, and he was sent to hospital. The family was then referred to the "Cheering@Home End-of-Life Care Services" for community support. The sister revealed her preference to move Uncle Fai to a private elderly home closer to her, so that she could visit him more often, but Uncle Fai resisted because of the financial burden on the family and the loss of his freedom. The Cheering@Home case worker realised that the family was caught in the dilemma of rationalising competing needs in practical (e.g. a feasible care plan), relationship (e.g. caregiver wish for a closer connection with patient) and personal tasks (e.g. patient hope for autonomy), and the avoidance of addressing the situation to find a solution.

In view of these concerns, the worker engaged Uncle Fai and his sister in discussing care plans in a family interview. By acknowledging the mutual care between the two parties and the common goal on finding a care arrangement that could provide better care to Uncle Fai, the worker encouraged both parties to honestly share their concerns and needs. She provided information on different care choices. As both Uncle Fai and his younger sister were prone to irritability, the worker helped both parties to objectively evaluate the pros and cons of care decisions separately at first, and then to discuss together the practicality and affordability of each choice. Gradually, Uncle Fai came to recognise the love of his sister behind her suggestion to move closer to her into a care home, while the sister improved her respect and appreciation towards Uncle Fai's self-reliance. This mutual understanding decreased the conflict, and a consensus was reached such that Uncle Fai was moved to an affordable elderly home near his sister's home. "We often had a quarrel on care planning in the past so we learnt to avoid this topic, but now we settled it peacefully", said Uncle Fai.

This arrangement fulfilled both their practical and relationship needs. Since most caregiving tasks were supported by the care home staff, the siblings could enjoy more time together for leisure. The sister's family visited Uncle Fai frequently. They went to Chinese restaurants for family time, chatted about interesting topics that may seem to be ordinary in others' eyes, but which were cheering for them all. Uncle Fai passed away one month after moving into the elderly care home, but he had spent wonderful times with family without losing dignity in the last stage of his life.

OUTCOMES

Of the patients and family caregivers who have been served by the Cheering@Home programme to date (between January 2016 and December 2017), 38 (27.1%) patients and 31 (22.3%) caregivers completed all assessments before the patient's death, and 51 (36.7%) caregivers completed bereavement assessments after death.

Patients were mostly in the old–old and oldest–old age cohorts, with a mean age of 78.9 years (SD=11.3), and 36.8% were male. There was an overall short mean length of care (5.7 months, SD=6.5) provided for the patients enrolled in the programme. Of these, 29.2% died within one month of referral. This underlines the need for timely and targeted interventions because EoL can approach very quickly. The majority of the patients enrolled in the Cheering@Home programme had been diagnosed with cancer (N=31, 81.6%), and the remaining patients suffered from heart failure (2.6%), motor neuron disease (2.6%), renal disease (2.6%), chronic kidney disease (2.6%) and a range of other individual conditions (7.9%).

There was an even gender distribution of primary caregivers (14 were male, 45.2%), and caregivers were predominantly adult children (N=17, 54.8%) or the spouse (N=12, 38.7%). The spouses were also approaching, or already in, old age (mean=60.8 years, SD=11.8).

Chapter 5 described outcome indicators and how the needs of patients and families were grouped. In summary, a threshold level was set for each outcome indicator at mean score plus one standard deviation. The proportions of high-need groups in all outcome indicators of patients and caregivers were compared between time of service intake and the third month of service, which signifies the period of active interventions.

Findings for patients supported the effectiveness of cheering activities in reducing negative emotions of patients. There was evidence of clear reduction in the proportion of patients with high needs in psychological (the proportion experiencing anxiety and depression), and spiritual areas (the proportion not-at-peace; see **Figure 8.5**). Moreover, cheering-up interventions incorporated into practical tasks appeared to be effective, as manifested by the significant reduction in reported practical problems of personal care. There was also a clear decrease in the number of patients who perceived anxiety in their family members. It may be that the alleviation of patients' practical problems might have a secondary impact on how these patients perceived family members' anxiety, through mediation activities to reduce familial distress. It is of note that despite the main focus of the Cheering@Home EoLC team on providing psychosocial-based supports, improvement in patients' physical symptoms were also observed. There are a couple of possible explanations for this finding. First, a considerable number of patients receiving the Cheering@Home intervention were also receiving specialised support from PC units. Thus, the improved physical symptoms might reflect the effectiveness of this symptom management approach. Second, patients who had developed capacity via the Broaden-and-Build model might have developed a more positive sense of self, not only in terms of emotional resilience, but also with improved subjective perceptions of their physical symptoms.

Nevertheless, over half the patients still reported difficulties in sharing feelings with family members after the months of the Cheering@Home intervention. This potentially correlates with the high proportion of caregivers who reported a reduced level of intimacy with patients (**Figure 8.6**). Conversely, the proportion of caregivers who reported high caregiver strain was halved. An explanation for this could be that while caregivers may have been relieved from stressful caring tasks because of their active involvement with the Cheering@Home intervention, their level of engagement in the care process may have been reduced to the point to be insufficient in supporting meaningful emotional exchanges with their ill loved one. Nevertheless, 94.1% of bereaved caregivers reported low risk of complicated grief, which suggested many of them were appropriately prepared to face the death of their family member.

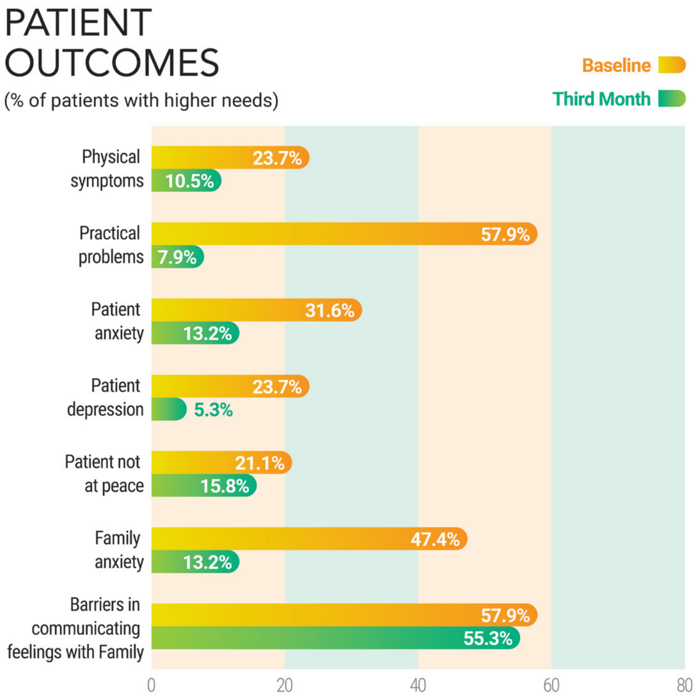

Figure 8.5 Comparison of Patient's Outcomes at Service Intake and after Three Months of Receiving the Cheering@Home Intervention

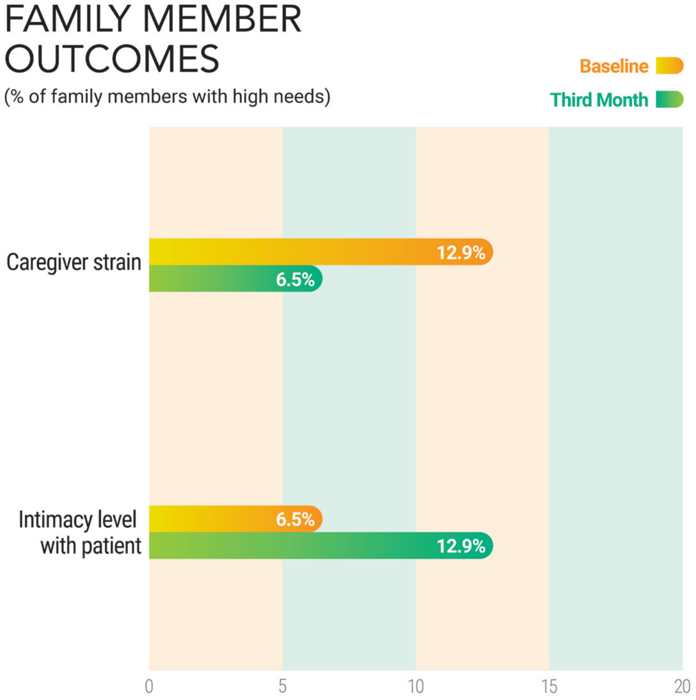

Figure 8.6 Comparison of Caregivers' Outcomes at Service Intake and after Three Months of Receiving the Cheering@Home Intervention

INSIGHTS AND FUTURE DIRECTIONS

As the Cheering@Home model of care intervention is grounded in Western theories and clinical observations, its applicability to a Chinese community requires critical examination. The two years of local Hong Kong practice offers practical insights that are not covered by the theories. These insights were gathered through clinical supervision meetings and are elaborated in the following section.

ENGAGEMENT OF FAMILY IN THE PROCESS OF CARE

The model adopts the family as the unit of care. In practice, some family members in Hong Kong are too busy with work and other commitments, and thus might not always be available to participate in the intervention. In the early stage of rolling out the Cheering@Home intervention, while some family members highly appreciated the care provided to the patient, they depended heavily on the worker to care for the patient, without joining the sessions. Consequently, the patients established strong relationships with workers and this created an unexpected tension with the family members. Although family members disengaged themselves from the patient because the Cheering@Home intervention services took care of the patients, they experienced immense guilt for not being as caring as the worker was to the patient. After identifying this outcome, the team put more effort into engaging family members in the patient's care and reducing the care that the intervention team gave the patient. Furthermore, any positive change in patients were attributed to the family members' engagement, in order to empower their participation.

The use of recreational cheering activities was a useful mechanism to engage the family, as they found it non-stressful and threatening to join in with the activities. While participating in recreational activities with the patient, some family members recalled and shared good memories they had had as families, specifically with the patient. This sharing helped to build family cohesiveness. When family members were more relaxed, the thorny topics of Advanced Care Planning (ACP) and even funeral planning could be approached and shared more naturally.

INTERESTING ACTIVITIES

When family members offered choices of a range of recreational activities to the patient, they demonstrated a sense of respect, which gave patients, even at the end-stage of life, autonomy to choose how they spent their time. While some patients preferred to participate in activities enjoyed in the past, some chose new activities. Enjoying new experiences with family members enriched patients' QoL. On top of the broaden-and-build effect of participating in interesting activities, patients were being distracted from their symptoms and the distress these caused. Patients had few complaints of symptoms when they were involved in interesting recreational activities and did not show signs of fatigue. This phenomenon is a good reflection of the impact of the Cheering@Home intervention on improving patients' and their families' QoL.

HOLISTIC CARE

The Dying Role model places practical tasks as one of its features, which refers initially to those preparing for impending death (such as determining financial legacy or EoL planning). However, although patients are facing certain death, they are still living. In this sense, there are equal, if not more, practical tasks that need to be considered related to daily life (such as being escorted to appointments, household chores, meal preparation, daily care). These tasks place great pressure on family caregivers if they are not provided with sufficient support, which in turn affects their psychosocial well-being. Patients might perceive themselves as a burden to the family and they desire a hastened death to reduce this burden. Appropriate care is therefore holistic, covering not just medical and psychosocial, but also the practical aspect of care. Providing appropriate assistance in completing practical tasks can reduce psychological and physical distress for both patient and caregiver. Moreover, reducing the demands of completing practical caring tasks on the family caregiver offers opportunity to spend more quality time with the patient.

PSYCHOLOGICAL AND PHYSICAL RESPITE CARE

Family caregivers also noted the importance of respite care. Some were torn between completing other duties (such as attending school functions of their children) and caring tasks, or between care for themselves (such as having a medical consultation of their own) and the care for the patient. Time-off from caring duties to take care of other responsibilities and to have time for themselves is essential for maintaining a balanced life. One family member shared, “This caring task is 24/7 without a break. It is the most difficult and tiring work one can have.” The presence of the care worker to take care of the patient, for even a short while, therefore offers physical and psychological respite for family caregivers, which could improve their QoL.

MEDICAL AND SOCIAL COLLABORATION

Most patients' needs are multifaceted and no single person or team of people is likely to comprehensively meet all those needs. Strong, respectful collaborations between medical teams and community social care teams is required to meet the complex needs of patients and families. Consequently, the hospital medical care team who referred the patient to the community social care team should maintain regular communication through case conferences and joint interviews. The medical team should also offer an emergency consultation number to the community social care team so that they can be called upon should any changes in the patient's condition is identified. This collaboration also facilitates a seamless discharge from hospital to community.

The collaboration should be within and between disciplines. There are existing community resources for practical care to support terminally ill patients and families, such as Integrated Home Care Services, Enhanced Home and Community Care Services, and Day Respite Service for Elderly Persons. The community social care team should explore available existing support services and ensure that patients and families are aware of possible care options. The waiting lists for these services in some Hong Kong districts are relatively long and, in this instance, an interim care plan should be provided by the social care team.

TIMELY INTERVENTION

The majority of patients in the pilot programme, especially those with cancer, demonstrated progressive deterioration in health and function over time. Timely intervention is therefore essential for ensuring patients and families receive the care they need, when they need it. During the Cheering@Home pilot period, some patients died within a week of the referral being made. By focusing on timely provision of patient- and family-centred care, the Cheering@Home team was able to offer care within three days after receiving a referral.

The team made another important observation regarding changed health status over time. On referral, some patients were in a poor health state, often associated with confusion. Unexpectedly, they became clear mentally and they were able to communicate freely with their family. While thinking that this may have reflected general improvement or even a cure, the patients often died within hours. In Chinese culture, this experience is called *hui guang fan zhao* (迴光返照, literally meaning "backlighting"). In Western medical literature, there is a similar concept called terminal lucidity (Nahm, Greyson, Kelly & Haraldsson, 2012). The team now pays extraordinary attention to sudden improvement in cognition of dying patients, in order to provide timely care during what is often a limited time window.

SUMMARY

The family-oriented Cheering@Home care model for families of persons with advanced illness is founded on clinical observations and Western theories. It has been trialled in Hong Kong over the past two years. The preliminary results indicate the intervention is promising, although the model requires ongoing amendments. One change is that due to the unavailability of some family members, the intervention may be offered to the patient only. Extra effort must be made to engage and involve family members. Another change is that the multidimensional needs of patients and families requires multidisciplinary teams, and strong collaboration within and between sectors to provide the appropriate care. Communication between teams, instead of working in silos, will increase the effectiveness and efficiency of care. A third change is that the intervention must address basic practical needs to improve QoL. When patients and families are facing a multitude of often overwhelming practical demands, psychosocial counselling alone will not reduce this distress. Practical support such as home and/or respite care will provide the foundation for delivering emotional support. Moreover, continuous assessment of patient and family needs is required throughout the illness journey. It was noted that creating positive emotions, such as joy, interest, contentment and love, through activities provides a foundation for discussing serious topics. Finally, the patient's condition can change quickly and unexpectedly, and timely intervention is therefore critical to programme success.

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