

EVALUATION REPORT on COMMUNITY PALLIATIVE CARE SUPPORT PROJECT



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**Evaluation Report on
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ACKNOWLEDGEMENTS

Palliative care is an approach of care that values life with dignity and love from the moment it begins to the moment it ends. People suffering from serious illnesses with life-limiting condition always encounter various uncomfortable symptoms, pain and emotional distress. Palliative care, in turn, optimises the quality of life by investigating anticipation, prevention and reduction to the related physical and psychosocial distresses. The mission of Community Palliative Care Support Project (CPCS), launched by Endless Care Services of Tung Wah Group of Hospitals (TWGHs), is to promote dying with dignity and peace which has already become a service trend worldwide.

CPCS was at first a 2-year project implemented in 2014 with the support from Li Ka Sing Foundation, aiming at providing palliative care to terminally-ill cancer patients in community. It was then funded by TWGHs' Board of Directors since 2016, and has been continuously supporting patients and their family members who suffer from end-stage illnesses by rendering holistic care to relieve physical and psychosocial pain at home setting. The service team consists of an experienced registered nurse and a registered social worker in delivering inter-disciplinary service and case management. Nursing consultation, home care support and advice are delivered via home visits, phone or video-conferencing contacts and volunteer visits. In addition to providing subsidies to ease the financial stress of patients, oral supplements and other purchased services, including centre-based physiotherapy training, home-based occupational assessment and dietitian consultation are also arranged to meet cases' needs in a timely manner, while saving waiting time at public medical sector. To reduce death anxiety, anticipatory grief and life regret, counselling service, wish fulfilment and life review services are offered, assisting the patients and their family members to achieve life completeness and encouraging them to pass on life wisdom and invaluable memory.

CPCS commissioned The Nethersole School of Nursing, Faculty of Medicine of The Chinese University of Hong Kong (CUHK) to study the effectiveness of the service, and simultaneously to raise public concern on the needs of patients and family in community palliative care service, as well as to provide a platform for related frontline healthcare workers to exchange professional knowledge and experience. The research results show that CPCS is effective in relieving physical and emotional distress for patients and family when facing terminal illness. Communication among the patients, family members and medical practitioners is largely improved or enhanced through service investigation resulting in better disease management. Death is inevitable, but living with dignity and grace especially at the end stage of life is no doubt the ultimate wish of all human beings.

Apart from our heartfelt thanks to our Board of Directors for the funding support to the research study, we would like to express our greatest appreciation to Dr. Chan Yue-lai, Helen and her research team from the CUHK for their unrivalled research efforts. Last but not least, we would like to thank all the interviewees for their keen participation and feedback in this study.

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EXECUTIVE SUMMARY

Background: Community-based palliative care has been advocated to improve the continuity of care between hospital and home care and support care in place for patients with life-limiting conditions and their family members. This study aims to evaluate the effects of a community palliative care support project guided by a medical-social collaboration model on the symptom experience of patients with advanced disease and the caregiving experience of their family members.

Methods: A mixed-method approach was adopted, including a prospective cohort study and individual qualitative interviews. The Integrated Palliative Care Outcome Scale was used for monthly assessment to monitor their condition. Wilcoxon signed-rank test was employed to examine changes in the outcomes over time. The interviews were audiotaped for qualitative content analysis.

Results: Forty-eight patients, with a predominance of cancer diagnoses, enrolled in the project. They reported anxiety, hardly feeling at peace, and neither receiving information as wanted nor being able to share their feeling with family/friends as more overwhelming than physical symptoms. Improvements were noted in emotional symptoms and concerns about communication/practical issues amongst patients at follow up, but changes in caregiving experience were not obvious amongst their family members. Three themes about recommendations for the project services were identified from the qualitative data, namely, maintaining sustainability of the service, strengthening the communication between care sectors and providing additional support for rehabilitation.

Conclusions: The findings demonstrate the positive effects of this community-based palliative care support project in meeting the complex care needs of patients with advanced diseases. Improvements were noted in their emotional and information needs despite their deteriorating health conditions. Meanwhile, greater efforts should be devoted to supporting their family members throughout the disease journey. Another noteworthy point is that non-cancer patients were underrepresented in the study sample. Further work is needed to strengthen the medical-social partnership to support end-of-life care in place albeit health deterioration.



1. BACKGROUND

1.1. Palliative care

Palliative care refers to a holistic approach to optimise the quality of life of people with life-limiting conditions, including non-cancer diagnoses, and their families (Worldwide Hospice Palliative Care Alliance, 2020). Palliative care highlights the importance of comprehensive assessment in physical, psychological, social and spiritual aspects, and multidisciplinary support throughout the illness process. Hence, palliative care has been advocated to be an integral part of health care services (World Health Organisation, 2014).

1.2. Need for palliative care services worldwide

The number of people with palliative care needs is high. Chronic progressive diseases in high-income countries accounted for nearly 75% of all deaths (Etkind et al., 2017). Approximately more than 56 million people per year are in need of palliative care worldwide (Worldwide Hospice Palliative Care Alliance, 2020). The service need is expected to grow given the increasing morbidity and mortality trend of chronic diseases.

1.3. Importance of community palliative care

Integrating palliative care into primary health care has received growing awareness to ensure wider access and improve continuity of care between acute and home care (Mitchell et al., 2017; World Health Organization, 2018). This kind of community palliative care aims to provide continuous support on symptom control and psychosocial needs of the community-dwelling group. Thus, unnecessary hospitalisation as well as alleviating caregiving burden amongst family members will be reduced (Dudley et al., 2018). Given its significance, community palliative care services have been developed in many countries, such as France, Germany, Belgium, Malaysia, Zimbabwe and Taiwan (Maetens et al., 2017; Worldwide Hospice Palliative Care Alliance, 2020). Statistics show that the availability of community palliative care for people with non-cancer diagnoses varied greatly from 10% – 15% in lower- to middle-income countries to 81% in the higher-income countries. More attention towards addressing the palliative care needs of the non-cancer group in the community is warranted.

1.4. Community palliative care services in Hong Kong

Palliative care service has been established in Hong Kong for nearly four decades (Lam, 2019). Then, the palliative care service was centrally coordinated by the Hospital Authority, which has governed all the public healthcare services in Hong Kong since the 1990s. Although the public healthcare sector has provided a wide spectrum of palliative care, including inpatient, outpatient and community, the focus was predominantly on the hospital setting and cancer patients (Lee et al., 2019). Statistics showed that over 90% of deaths in the older population and patients with advanced diseases occur in in-patient setting and one-third of them spent the last month of life in hospitals (Hospital Authority, 2017). In 2017, the Hospital Authority recognised the limited development of community palliative care when planning a strategic service framework for palliative care to guide future development. One of the directions for strategic development focused on enhancing palliative care in the community for cancer and non-cancer patients (Hospital Authority, 2017).

1.5. Service and research gaps

Various non-government organisations launched several initiatives in recent years to deliver community palliative care in Hong Kong (Lam, 2019). However, their effects have rarely been studied systematically. Moreover, published works on community palliative care mainly focused on the effects of the services on healthcare utilisation and cost in local context, with limited attention paid towards patients' outcomes (Lustbader et al., 2017; Yosick et al., 2019). Therefore, this study evaluates the effects of a community palliative care project on patients and their family members in Hong Kong. As relevant services in the local community are relatively new compared with those in other regions, research into this area provides important insights to health professionals, health care administrators and policymakers for future development.



2. DESCRIPTION OF PROJECT

This section provides an overview of the Community Palliative Care Support Project developed by Endless Care Services, Tung Wah Group of Hospitals.

2.1. Target population

The service is for community-dwelling adult patients identified with palliative care needs with their attending doctors agreeing to the surprise question “I would not be surprised if this patient died in the next 12 months.” Patients aged under 18 years or who were mentally incompetent to provide consent to join the project were excluded. An adult family member who provided direct care to the patient was also invited if he or she is able to communicate in Cantonese.

2.2. Recruitment

All healthcare professionals in public or private healthcare services or general practitioners were welcomed to make referrals. Self-approached patients who were diagnosed with end-stage of illnesses were also accepted.

2.3. Scope of service

The service aims to provide tailored home-based palliative care support to patients with advanced disease and their family members in the community. The key components resembled those identified in the literature or other overseas community palliative care programmes (Bone et al., 2016; Oosterveld-Vlug et al., 2019; Yosick et al., 2019). The key components included comprehensive assessment using a standardised assessment tool, advice on non-pharmacological strategies for symptom management, medication review, counselling, advance care planning, and care coordination subject to individual needs. These components were delivered through a case management approach.

2.4. Staff capacity

Similar to a community palliative care programme in the United States (Yosick et al., 2019), a medical-social collaboration model was adopted to facilitate interdisciplinary partnership. The nurse and the social worker have specialised training and previous experience in palliative care.

2.5. Logistic

Upon receiving a referral, a programme team member contacted the patient through phone for eligibility screening and to schedule home visits within a week. During the first visit, the team conducted a comprehensive assessment to identify the palliative care needs of the patient and family carer, and offer advice on care management and psychosocial support. Then, the team reviewed the progress in the subsequent visits or through phone follow-up calls. The team also liaised with the hospital healthcare teams if any urgent medical follow-up or medical investigation was needed. The team provided support to the patients until they died, or withdrew from the programme. Bereavement counselling would be provided according to the need of patients' family members. During the COVID-19 pandemic, professional consultation had been provided continuously through tele-conferencing when home visits were not possible.



3. METHODS OF EVALUATION

This section identifies the aim and objectives of the evaluation and describes the evaluative method, including study design, outcome assessment, qualitative interviews and procedures for data collection and analysis.

3.1. Aim and objectives

This study aims to evaluate the effects of the Community Palliative Care Support Project offered by Endless Care Services, Tung Wah Group of Hospitals. The objectives are as follows: (1) identify the needs of patients and family caregivers who are facing life-limiting conditions; (2) examine the effects of the project on symptom experiences, including physical and psychosocial aspects, over six months; and (3) explore the experiences of care recipients with the project, including patients and their family members.

3.2. Study design

A sequential mixed-method approach was adopted, including a prospective cohort study conducted between October 2019 and December 2020 and individual semi-structured qualitative interviews. By using a mixed-method approach, the qualitative data would be complementary to enable a deeper understanding of the evaluation results generated based on the quantitative data (Creswell, 2014).

3.3. Assessment of patients' symptom experience

The Chinese version of the Integrated Palliative Care Outcome Scale (IPOS, Appendix A) was used to assess the physical and emotional symptoms, communication and practical issues experienced by the patients. This scale is a valid and reliable patient-reported outcome measure (PROM) for assessing the severity of symptoms and concerns caused by advanced illness (Murtagh et al., 2019). Patients were asked to rate 13 physical symptoms, four emotional symptoms, and three items about communication or practical problems over the past week on a five-point Likert scale, from 0 (not at all) to 5 (overwhelming). A higher score suggests a higher level of distress.

3.4. Assessment of family members' experience

The Cantonese short version of the Zarit Burden Interview (ZBI, Appendix B) (J. Y. Tang et al., 2016) was used to measure the caregiving burden. Family members were asked to rate the frequency of 12 items on a Likert scale, from 0 (never) to 4 (very frequently). This tool is valid and reliable and is widely used for measuring caregiving stress worldwide.

In addition, the Chinese version of the Caregiver Inventory (CGI, Appendix C) was used to measure the caregiving self-efficacy of family caregivers (Leung et al., 2017). The 18 items cover three aspects, namely care of the care recipients, managing information and self-care, and managing emotional interaction with the care recipient. Family members were asked to rate their level of confidence from 1 to 9, where a higher score indicates a higher level of confidence in handling the concerned aspect.

3.5. Qualitative interview

A purposive sample of family members with different demographic characteristics were invited to individual semi-structured interviews. The purpose of the interviews was to understand their experience with the services provided in the project.

3.6. Data collection

Ethical approval for this study was obtained from the Survey and Behavioural Ethics Committee of The Chinese University of Hong Kong. Participation in the evaluation study was on voluntary basis. Participants can withdraw from the study at any time without influence on the care they received from the project. All data were coded and accessible to the principal investigator only to ensure participants' privacy. Qualitative interviews were conducted by a social worker with experience in palliative care but not involved in this project delivery. All interviews were audiotaped with participants' consent to facilitate analysis.

3.7. Data analysis

SPSS version 26.0 (IBM Corp., Armonk, NY) was used for statistical analysis. Descriptive statistics were used to present the demographic and the IPOS scores. Wilcoxon signed-rank test was applied to examine the changes in the IPOS subscale scores between two consecutive time points. A p value < 0.05 is considered statistically significant. Qualitative content analysis was performed to identify themes in the qualitative data (Graneheim & Lundman, 2004).



4. EVALUATION RESULTS

4.1. Recruitment

A total of 79 patients were referred to the project within the study time frame. The research team successfully reached 67 patients through phone (84.8%). Four (6.0%) patients or their family members declined the project. Fifteen (22.4%) died before the first home visit. Eventually, 48 patients were enrolled in the project. The participation rate in this study is higher than those reported by other community-based palliative care programmes, thereby suggesting the local societal needs for this kind of service (Yosick et al., 2019).

Amongst the five patients who withdrew from the study, the major reasons of withdrawal were difficulties in speaking or listening ($n = 2$) and a feeling of stress ($n = 1$). The remainders did not provide a reason for their withdrawal ($n = 2$). The total number of home visits ranged from 1 to 7, with nearly two-thirds (60.4%) receiving at least three home visits.

4.2. Participant characteristics

Table 1 shows the demographic and clinical characteristics of the patients. Of the 48 patients enrolled in the project, their age ranged from 28 to 94, with a mean of 63.8 years. Slightly more than half of them (54.2%) were younger than 65 years, and 24 participants (50%) were male. Except for two patients diagnosed with end-stage renal failure, the chief diagnosis was cancer, mainly lung ($n = 9$), colorectal ($n = 5$), liver ($n = 5$) and breast ($n = 4$) cancer. None of the participants attended palliative care day care centre services, and 20 (41.7%) received hospital palliative nursing outreach services.

Fourteen family members participated in the evaluation study. Of them, six also attended the individual interview to share their experiences regarding the project. The qualitative findings were complementary for explaining the quantitative results.

4.3. Symptom experience at baseline

At the baseline (Table 2), a considerable proportion of participants reported feeling anxious (79.2%), could not feel at peace (79.1%), could neither receive information as wanted (79.1%) nor share their feelings with family/friends (72.9%), and perceived practical matters as being unaddressed (77.1%). The ratings showed that these emotional symptoms and communication/practical issues were more overwhelming than the physical symptoms.

These findings were consistent with those using the same measurement tool in the United Kingdom (Murtagh et al., 2019). Patients with life-limiting conditions often perceived a lack of informational support for advance care planning as the disease progresses and were unclear about the legitimacy of their concerns (Hudson et al., 2019; Seow & Bainbridge, 2018). This is likely because dysfunctional communication (such as avoidance, denial and protective buffering) that prevents reciprocal disclosure of feelings and thoughts was common between cancer patients and their families (Traa et al., 2015). The cultural taboo of discussing issues related to death in Chinese community also hinder the communication between patients, family members and healthcare providers on end-of-life care.

Table 1. Patients' characteristics

	<i>n (%)</i> ^a
Mean age (SD)	63.8 (15.1)
Sex	
Male	24 (50.0)
Female	24 (50.0)
Marital status	
Single	13 (27.1)
Married	22 (45.8)
Widowed	9 (18.8)
Divorced	4 (8.3)
Living status	
Living alone	10 (20.8)
Living with maid only	5 (10.4)
Living with family	32 (66.7)
Care home	1 (2.1)
Chief diagnosis	
Cancer	46 (95.8)
Chronic renal failure	2 (4.2)
Self-care ability	
Independent	19 (39.6)
Need assistance	25 (52.1)
Bed bound	4 (8.3)
Experience of using hospital palliative care services	
Inpatient care	30 (62.5)
Day care	0
Home care	20 (41.7)

Footnote: ^anumber (percent), unless specified

Table 2. Symptom experience at baseline

	Prevalence	Rating ^a				
		Not at all (0)	Slight (1)	Moderate (2)	Severe (3)	Overwhelming / All the time (4)
<i>Physical symptoms</i>						
• Pain	52.1	25.0	22.9	25.0	18.8	8.3
• Shortness of breath	25.0	41.7	33.3	14.6	6.3	4.2
• Weakness / Lack of energy	70.8	8.3	20.8	39.6	31.3	0
• Nausea	33.3	37.5	29.2	25.0	8.3	0
• Vomiting	14.6	75.0	10.4	12.5	2.1	0
• Poor appetite	45.8	27.1	27.1	25.0	18.8	2.1
• Constipation	10.4	79.2	10.4	6.3	4.2	0
• Sore/dry mouth	37.5	37.5	25.0	35.4	2.1	0
• Drowsiness	27.1	47.9	25.0	18.8	8.3	0
• Poor mobility	64.6	16.7	18.8	29.2	27.1	8.3
• Insomnia	36.4	54.5	9.1	30.3	6.1	0
• Oedema	12.1	72.7	15.2	3.0	6.1	3.0
• Dizziness	6.0	75.8	18.2	3.0	3.0	0
<i>Emotional symptoms</i>						
• Patient anxiety	79.2	10.4	10.4	37.5	31.3	10.4
• Family anxiety	68.8	18.8	12.5	29.2	22.9	16.7
• Depression	60.4	20.8	18.8	27.1	25.0	8.3
	Prevalence	Always (0)	Most of the time (1)	Sometimes (2)	Occasionally (3)	Not at all (4)
• Feeling at peace	79.1	8.3	12.5	35.4	35.4	8.3
<i>Communication /Practical issues</i>						
• Sharing feelings	72.9	4.2	22.9	25.0	39.6	8.3
• Information	79.1	2.1	18.8	22.9	45.8	10.4
• Practical matters	77.1	2.1	20.8	52.1	20.8	4.2

Footnote: Prevalence was defined as rating on the item at 2 or above; ^aLower score better experience

4.4. Changes of symptom experience over time

Figures 1 and 2 show the IPOS total scores and subscale scores over time. A decreasing trend in the overall and all subscale mean scores was observed, suggesting improvement in various aspects amongst the patients. Figures 3 – 5 depict the patterns of specific physical symptoms, emotional symptoms and communication/practical issues, respectively.

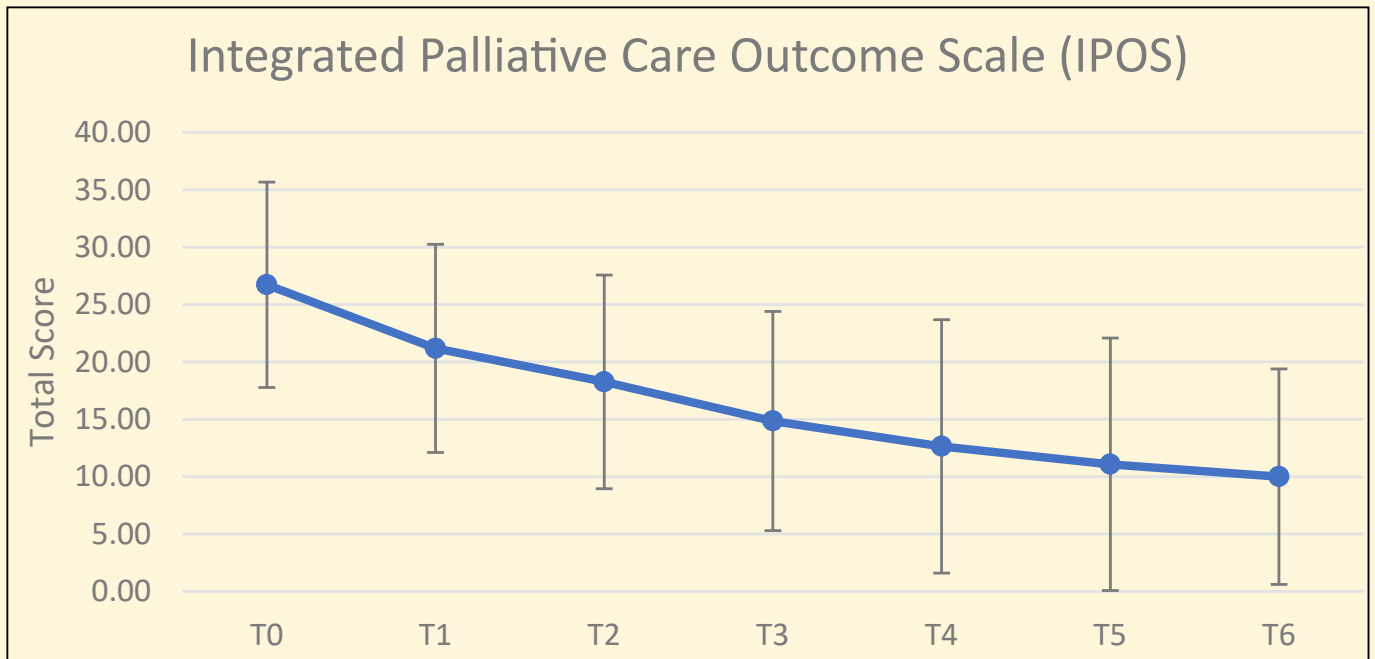


Figure 1. Changes in IPOS total scores over time

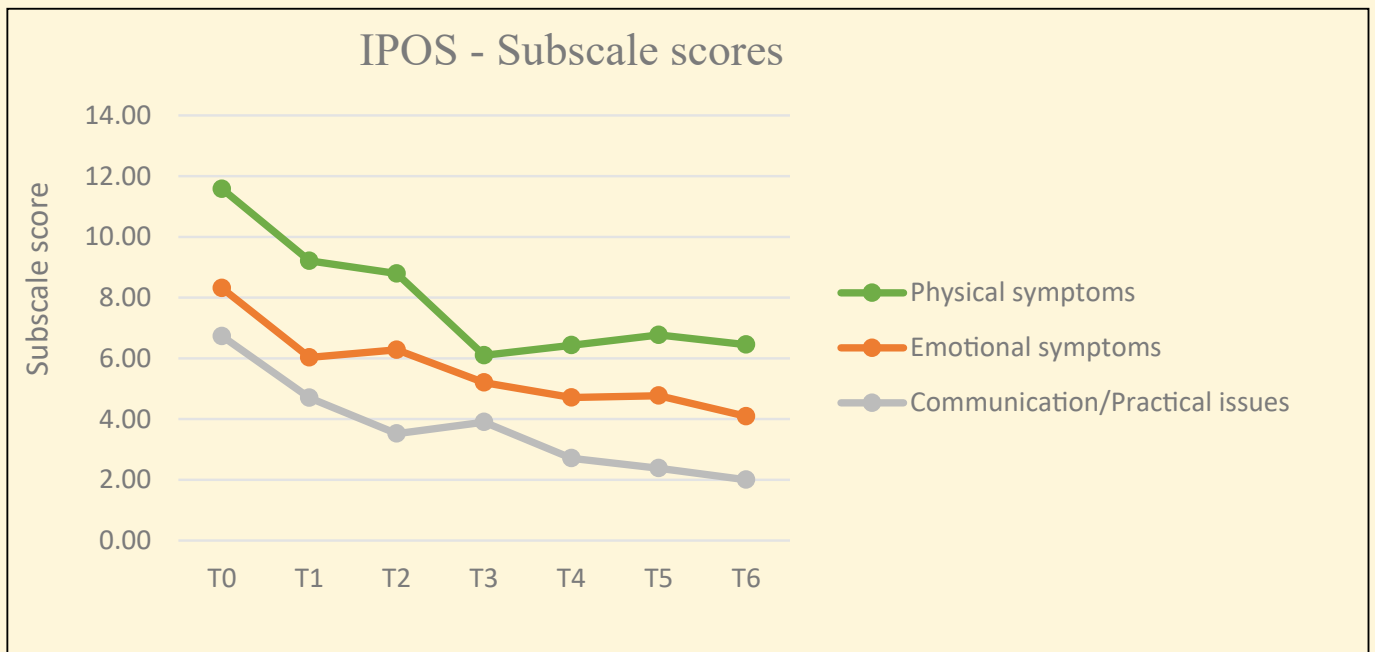


Figure 2. Changes in IPOS subscale scores over time

4.4.1. Physical symptoms

The three most distressing physical symptoms at baseline were weakness/lack of energy (70.8%), poor mobility (64.6%), and pain (52.1%). As shown in Figure 3, the mean scores of all physical symptoms are generally decreasing over the service delivery time, except for pain, sore/dry mouth and drowsiness. A more evident reduction was noted in nausea and vomiting.

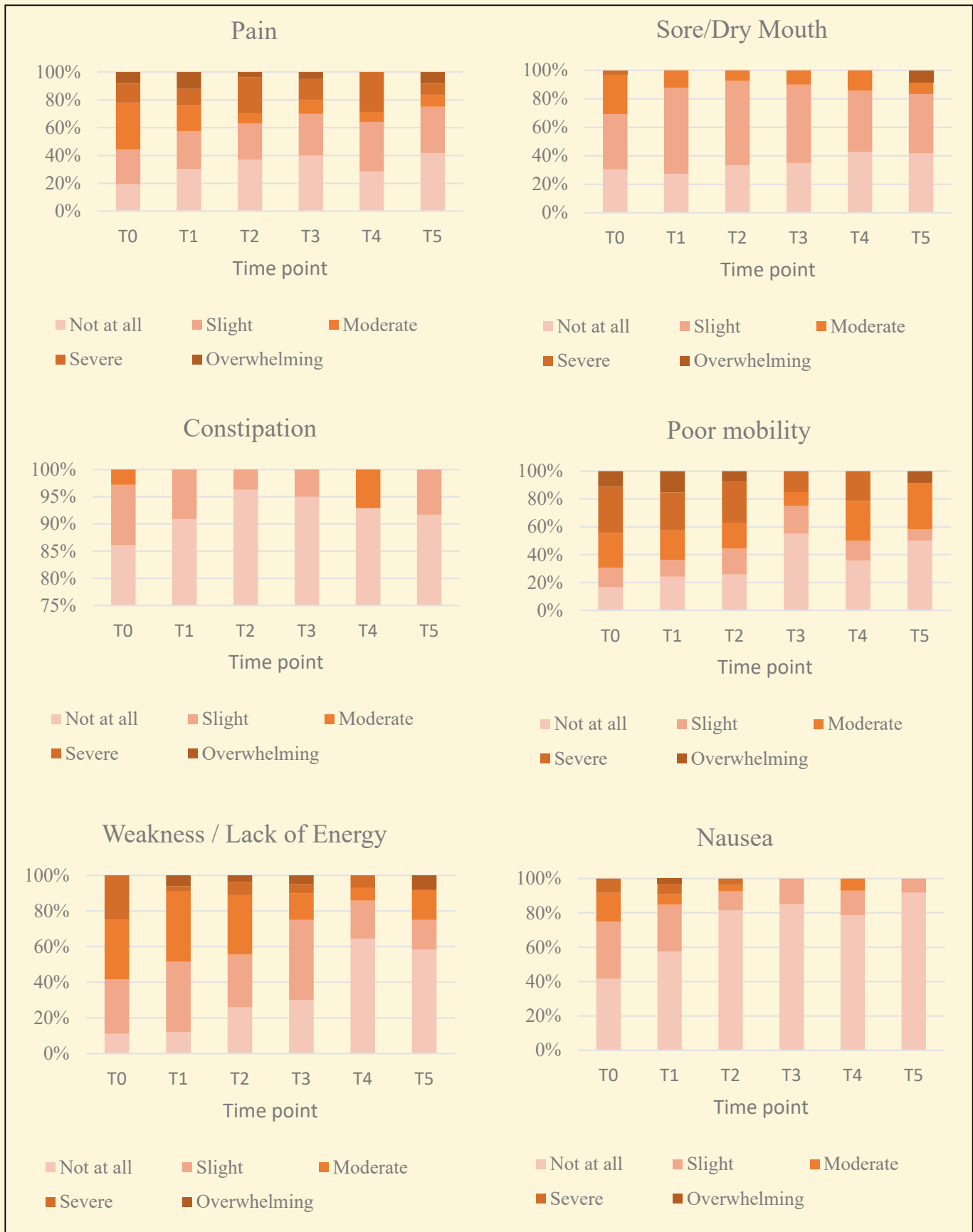


Figure 3. IPOS – Changes in severity of physical symptoms over time

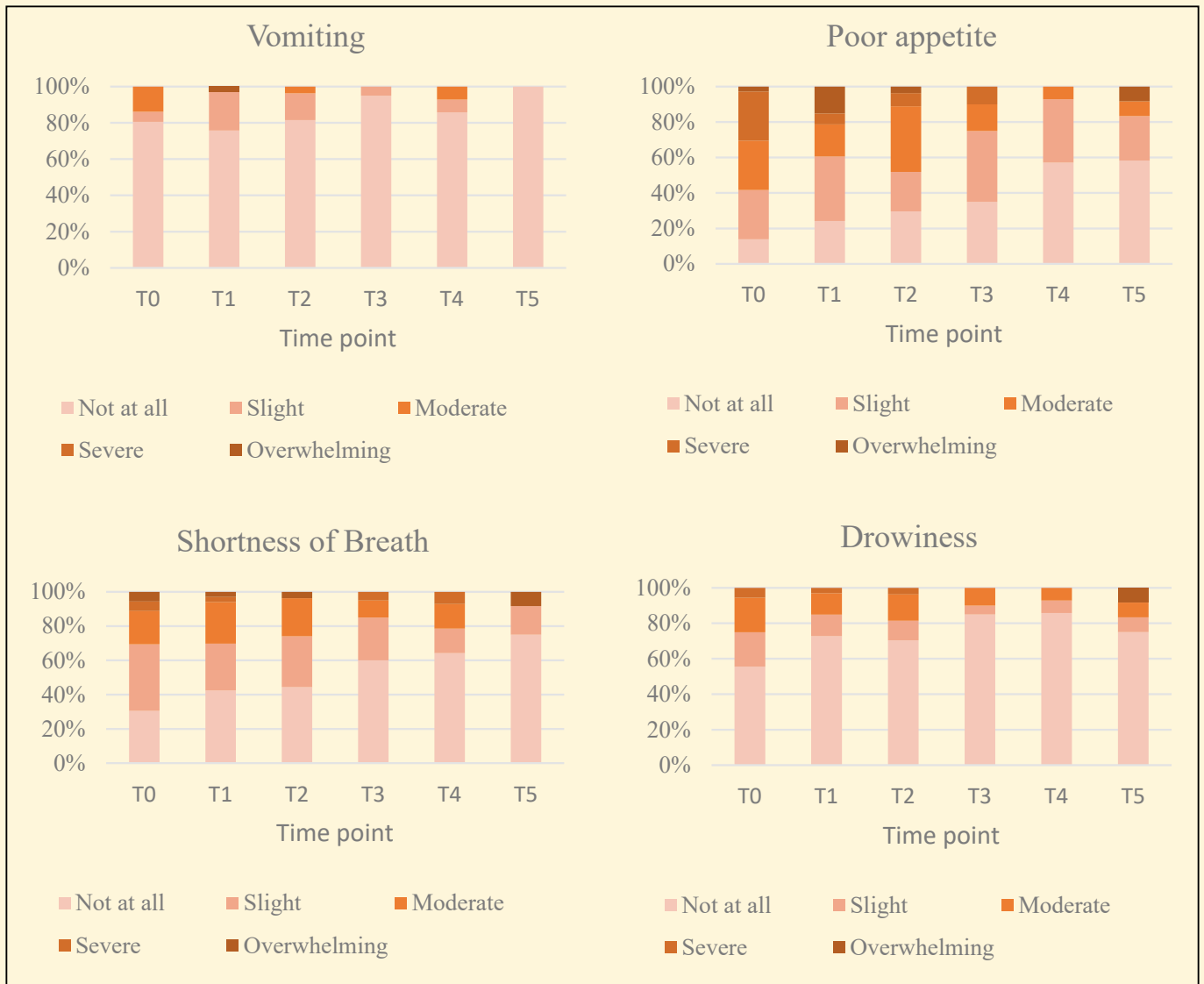


Figure 3. IPOS – Changes in severity of physical symptoms over time (Cont'd)

4.4.2. Emotional symptoms

As shown in Figure 4, the prevalence of anxiety and depressive mood markedly reduced over time. Over half of them reported that they always or most of the time could experience a sense of peacefulness at the third visits. The findings suggested that the emotional distress could be relieved through the regular visits and contacts provided in the project.

4.4.3. Communication and practical issues

Figure 5 shows the proportion of patients who reported that they were always or most of the time able to share their feelings and having their information needs being met increased gradually over time. During the interview, several family members noted that they learnt much information through the project. One of them told that she did not search for information about end-of-life care initially as she was not ready to accept the poor prognosis of her father. Through this project, she was able to learn information according to individual pace, *“I know there are some public talks on these issues but I am not ready to take it. This project is useful because I learnt something which I was not aware of previously either because the doctor did not mention [that] or I did not ask during medical consultation.”* (F1, daughter)

The quantitative findings also showed that most of the patients reported that their practical matters were resolved or mostly addressed following several visits. Similarly, many family members appreciated the practical advices given by the social worker and the nurse in the project. One of them recalled that, “They are very patience...teaching us how to give medication or call ambulance directly. In particular, my mum could not tolerate the pain when sitting [due to colorectal cancer], they suggest letting her to sit on a swimming ring. They sent me a lot of information on the internet about how and where to buy a suitable ring.” (F2, son). Another lady who took care of her son also shared that, “They gave us a medication reminder clock. I am old and forgetful, and so I often missed the medication. The clock alerted me to give medication on schedule.” (F3, mother).

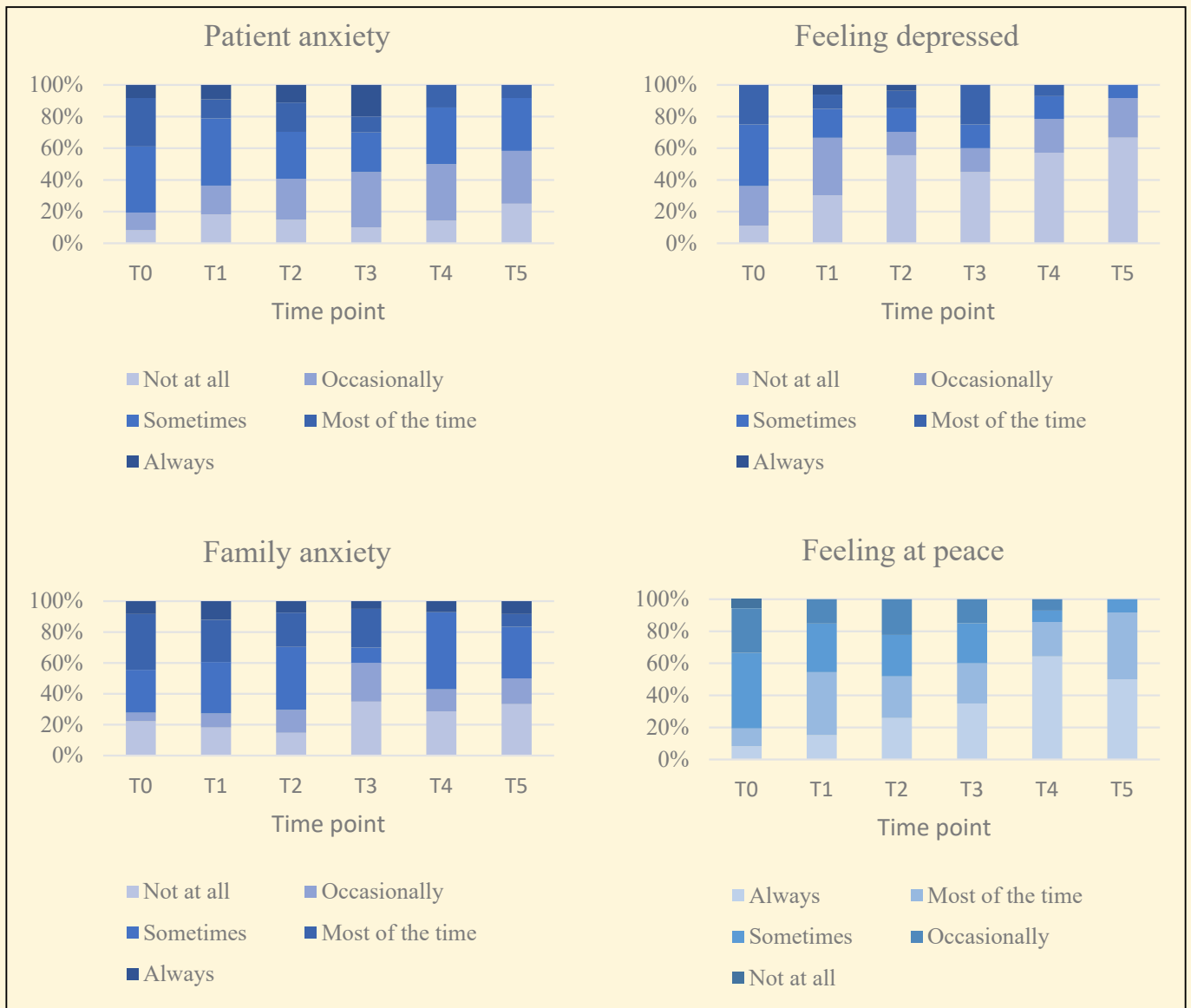


Figure 4. IPOS – Changes in severity of emotional symptoms over time



Figure 5. IPOS – Changes in severity of communication/practical issues over time

Many family members also shared that the project provided various tools or products, for example, incontinence pad, nutritional milk, and taxi voucher, that facilitate them to provide home care support to patients more effectively.

4.4.4. Pairwise comparison of IPOS subscale score

Table 3 shows the pairwise changes in the IPOS subscale scores. The findings showed that improvement in emotional symptoms at the 1-month follow up was statistically significant ($p < 0.001$), with a moderate effect size ($r = 0.44$). Improvements in communication/practical issues were also significant at the 1-month follow up ($p < 0.001$) and 2-month follow-up ($p = 0.005$), with a moderate effect size of 0.42 and 0.37, respectively. The non-significant results in the subsequent months noted in this study might be related to the small sample size and their progressive health deterioration.

Table 3. Pairwise comparison in IPOS subscale scores

Domains	Time points	<i>n</i>	Median	Z	<i>p</i> value	Effect size, <i>r</i>
Physical symptoms	T0	48	10.50	/	/	/
	T1	33	8.00	-1.517	0.129	0.19
	T2	29	6.00	-0.855	0.392	0.11
	T3	20	5.00	-1.037	0.300	0.16
	T4	14	6.50	-0.664	0.507	0.13
	T5	13	7.00	-0.535	0.592	0.10
	T6	6	2.50	-0.707	0.480	0.20
Emotional symptoms	T0	48	8.00	/	/	/
	T1	33	6.00	-3.609	<0.001	0.44
	T2	29	7.00	-0.512	0.609	0.07
	T3	20	6.00	-0.202	0.840	0.03
	T4	14	5.00	0.000	1.000	0
	T5	13	4.00	-0.343	0.732	0.07
	T6	6	3.00	-1.134	0.257	0.33
Communication / Practical issues	T0	48	7.00	/	/	/
	T1	33	4.00	-3.408	0.001	0.42
	T2	29	3.00	-2.784	0.005	0.37
	T3	20	3.00	-0.539	0.590	0.09
	T4	14	2.50	-0.997	0.319	0.19
	T5	13	1.00	-1.283	0.199	0.25
	T6	6	1.00	-1.414	0.157	0.41

Footnote: Wilcoxon signed-rank test; IPOS, International Palliative Outcome Scale; *n*, number of observations

4.5. Caregiving burden

Based on the ZBI total scores and subscale scores (Table 4), the family members in this project reported high levels of caregiving burden (21.50±10.75 out of 48), particularly for role strain and negative emotion. The scores are even higher than a local study about family caregiving burden for people with dementia (Total score: 19.1±8.8; Role strain: 1.48±0.89; Negative emotion: 1.46±1.15; Self-criticism: 1.74±0.86) (J. Y. Tang et al., 2016). The differences between the two studies suggested that care for people with an advanced health condition could be more stressful than those with dementia. Only the subscale score of self-criticism slightly decreased at 1-month follow up, but the changes were not statistically significant.

The quantitative findings are consistent with the qualitative data. A man who took care of his mother shared that he felt helpless before joining the project. He told that, “*I am glad to have this project guiding me through the process...Not everyone knows how to handle the patient’s problems. Also, the project team is very patience. You know, older persons do not like to share their thoughts, but the words of the nurse and the social worker are soothing. I can see the warmth of their kindness when they talked to my mum.*” (F2, son)

Table 4. Scores of Cantonese short version of the ZBI

Items	Baseline	Follow up	<i>p</i>
	Mean (SD)	Mean (SD)	
Mean ZBI Total score^a	21.50 (10.75)	21.33 (13.47)	0.173
Role strain^b	1.88 (1.25)	1.86 (1.17)	0.207
1. Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	2.36 (1.34)	2.83 (1.17)	
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	1.86 (1.66)	2.00 (1.67)	
4. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	1.57 (1.34)	1.00 (1.27)	
7. Do you feel that you do not have as much privacy as you would like because of your relative?	1.36 (1.60)	1.33 (1.51)	
8. Do you feel that your social life has suffered because you are caring for your relative?	2.14 (1.70)	2.00 (1.41)	
9. Do you feel that you have lost control of your life since your relative's illness?	2.00 (1.52)	2.00 (1.67)	
Negative emotion^b	1.79 (1.11)	1.89 (1.33)	0.071
3. Do you feel angry when you are around your relative?	1.57 (1.28)	1.67 (1.63)	
5. Do you feel strained when you are around your relative?	2.14 (1.51)	1.83 (1.60)	
10. Do you feel uncertain about what to do about your relative?	1.64 (1.45)	2.17 (1.60)	
Self-criticism^b	1.81 (0.85)	1.50 (1.34)	0.500
11. Do you feel you should be doing more for your relative?	1.64 (1.15)	1.33 (1.21)	
12. Do you feel you could do a better job in caring for your relative?	1.64 (1.15)	1.67 (1.51)	

Footnote: ZBI, Zarit Burden Interview; Higher score higher level of burden; ^aRange 0 – 47; ^bRange 0 – 4.

4.6. Caregiving self-efficacy

The mean subscale scores of the CGI for the “Care of the care recipient”, “Managing information and self-care”, and “Managing emotional interaction with care recipient”, reported by family members in this project are 6.00±1.88, 5.42±1.61 and 5.68±2.33 out of 9, respectively, at baseline (Table 5). All these scores are lower than the local study of caregivers of patients with palliative care needs in a hospital setting (Care of the care recipient: 7.07±1.39; Managing information and self-care: 6.38±1.51; Managing emotional interaction with care recipient: 6.46±1.72) (Leung et al., 2017). The differences between the two studies might reveal that family caregivers perceived a lower level of self-efficacy when providing care to patients at home. Following the project, their perceived self-efficacy in caregiving generally improved at 1-month follow up, but all these changes were not statistically significant.

During the interview, one lady bore the major role in taking care of her father because her brother could not help much. She became a full time caregiver that impeded her working or having a social life. During

the pandemic, she was particularly stressed as she worried that her father would be left unattended if she got sick. She stated that “*I was not dare to delegate any task to my brother. Once I sought his help to send father home but he just asked him to go home himself. We often have quarrels over the care.*” (F1, daughter) She found it difficult to share her feelings with others, and so, she greatly valued the chance provided by the project for her to ventilate her feelings. Another lady (F3, mother) who took care of her daughter also appreciated the emotional support provided by the project team through regular phone calls over the last year.

Table 5. Scores of Chinese version of the CGI

Items	Baseline	Follow up	<i>p</i>
	Mean (SD)	Mean (SD)	
Care of the care recipient	6.00 (1.88)	7.29 (1.03)	0.075
2. Listening and learning from the person as to how to care better for him/her	5.71 (2.13)	7.17 (1.47)	
5. Maintaining hope	6.21 (2.42)	5.67 (1.97)	
6. Being able to notice the “good moments” in caregiving when they occur	5.79 (2.39)	7.33 (1.03)	
7. Allowing the person to have and express his or her own feelings	5.50 (2.31)	7.17 (1.94)	
9. Continuing to take care of myself (e.g.: exercise, diet, sleep)	5.71 (2.27)	7.67 (1.37)	
18. Assisting and encouraging the person in following through with all treatments	6.36 (2.27)	7.67 (1.21)	
21. Maintaining a close relationship with the person I’m caring for	6.71 (2.56)	8.33 (0.82)	
Managing information and self-care	5.42 (1.61)	5.90 (0.95)	0.461
1. Coping with information overload	5.00 (2.18)	5.33 (0.82)	
3. Letting go of things I can’t control	5.71 (1.82)	6.00 (0.89)	
4. Expressing negative feelings about the illness	4.07 (2.56)	4.67 (2.25)	
14. Understanding medical information from doctors, nurses, or other sources	6.00 (2.04)	6.83 (0.98)	
15. Seeking support for myself	5.64 (2.31)	5.83 (1.33)	
16. Dealing with feelings of helplessness	4.71 (2.43)	5.67 (1.03)	
19. Asking physician and nurses questions	6.79 (2.23)	7.00 (1.67)	
Managing emotional interaction with care recipient	5.68 (2.33)	7.00 (1.54)	0.246
8. Assisting the person with activities such as feeding, washing, dressing, or toileting	5.86 (2.57)	7.67 (1.21)	
10. Talking openly and honestly with the person	7.00 (1.90)	5.64 (2.71)	
13. Providing emotional support for the person I’m caring for	6.00 (2.66)	6.50 (1.87)	
17. Dealing with the person expressing negative feelings toward me when they occur	5.21 (2.42)	6.83 (1.72)	

Footnote: Higher score higher level of self-efficacy in caregiving; Range 1 – 9.

4.7. Suggestions for improvement

From the qualitative findings, three suggestions for improving the community palliative care were identified.

4.7.1. Maintaining sustainability of the service

Generally, all family members appreciated that the project fills in the service gap to provide additional support to them at home and expected that the project could be sustained as part of regular healthcare service. One family member expressed her concern when she learnt that the project would end soon. She shared, *“My father’s condition continued to progress. I do not know that this project will cease. This is worrisome. I am not sure if I can manage the care at home myself. I wonder where I can seek similar help further.”* (F1, daughter)

4.7.2. Strengthening the communication between care sectors

The collaboration amongst various care sectors appears as a cornerstone to enhance the quality of care in the community. A family member highlighted the importance of maintaining direct communication between the hospital and the project team to enhance the continuity of care. *“It would be good if the project team can have access to the medical record and talk to the hospital team directly. Sometimes, I am afraid I might have conveyed the wrong message.”* (F3, mother) To empower and encourage the patients and their family members to communicate with medical staff on disease management was another aspect that the team had emphasized during the service delivery.

4.7.3. Providing additional support for rehabilitation

As the family members generally noticed that the health conditions of their sick relatives were worsening, they wished to have more cross-disciplinary support to maintain their physical functioning. Several family members appreciated the dietary advice from the project nurse and social worker, but they hope to have a dietician to offer more advices on how to prepare appropriate food or meals to increase the nutritional uptake through diet. Another family member expected inputs from physiotherapist to improve the patient’s strength and muscle endurance. He stated that, *“She [the patient] now cannot move well. It would be good to have some care assistants to come over to teach her some simple exercise to delay the deterioration.”* (F4, husband) Due to limited financial resources, the service could only offer centre-based physiotherapy. This expectation raises concern on promoting home-based rehabilitation training in order to maximize the patients’ mobility even at the late stage of life.



5. DISCUSSION AND CONCLUSION

5.1. Summary of findings

This study provides empirical evidence on the positive effects of this community-based palliative care support project using a medical-social collaboration model in primary health care in a Chinese community. Improvements were noted in symptom burden amongst patients with advanced diseases and caregiving self-efficacy amongst the family members. This observation echoed those of previous studies which demonstrated that the effects of short-term community palliative care support lasted between 8 and 12 weeks (Chan et al., 2014; Gao et al., 2020; Wong et al., 2016).

The less prominent results in the subsequent months noted in this study might be related to the patients' progressive health deterioration. The patients were generally weak and had a higher mortality rate compared with participants in other studies (Chan et al., 2014; Gao et al., 2020; Wong et al., 2016). Hence, their psycho-spiritual distress and physical problems might elevate along the illness trajectory, from the stable to unstable and deteriorating phases (Mather et al., 2018).

5.2. Support for caring in place

The findings of this study revealed the immediate societal needs of strengthening community palliative care in Hong Kong to promote care in place among people with advanced progressive health condition. The existing outreach community palliative care services might have alleviated the physical symptoms arising from the life-limiting condition. However, additional attention should be given to address the psychosocial and spiritual needs experienced by patients in face of the finite of life. Particularly, open communication and active listening should be promoted to enable the patients to share their concerns and empower them to express their views about their own care plan and wish. Previous studies showed that advance care planning that enables patients to articulate their personal values and care preferences could reduce anxiety and depressive symptoms amongst patients with cancer (Bernacki et al., 2019; S. T.Tang et al., 2019). Besides, information needs are recommended in an international expert consensus workshop as one of the key outcomes for evaluating the quality of palliative care, in addition to the quality of life and pain control (de Wolf-Linder et al., 2019).

5.3. Support for family members

Moreover, greater efforts should be devoted to supporting family members of patients with life-limiting conditions. This study unveils that the family members reported a higher level of caregiving burden and a lower level of caregiving self-efficacy than in other local studies. Compared with those involved in caregiving for sick relatives with chronic diseases, the health conditions of patients in this project, mostly with advanced cancer, deteriorated apparently within a short period of time. Thus, their family members have less time to adapt to the caregiving roles and tasks. This finding echoes with a recent study in the UK which reported that family support needs increased dramatically from the unstable phase to the deteriorating phase (Mather et al., 2018).

5.4. Importance of person-focused care

Person-focused care, including emotional support, providing reassurance and space for sharing personal worries, and an integrated team were highlighted from the perspectives of patients and family members as essential elements of community palliative care (Bone et al., 2016; Oosterveld-Vlug et al., 2019; Seow & Bainbridge, 2018). The European Intersectorial and Multidisciplinary Palliative Care Research Training (EURO IMPACT) team has stressed the importance of person-centred care in responding to psychosocial and information needs (van Vliet et al., 2015). This research result also echoes with the international studies in addressing the necessity of person-focused care by identifying the cases' needs via individual case assessment.

5.5. Lack of awareness towards the palliative care needs amongst non-cancer patients

One noteworthy point is that non-cancer patients are underrepresented in this project. Unlike other studies that focused on a specific non-cancer condition or that were supported by a particular palliative care team (Chan et al., 2014; Wong et al., 2016), enrolment to this project was reliant on referral across care settings in the region. Clinicians' hesitancy on prognostication has been identified as the major barrier for equitable access to palliative care amongst patients with non-cancer diagnoses (Zheng et al., 2013). The referral pattern of this study reveals that medical practitioners and healthcare providers might have overlooked the complex care needs of non-cancer patients and their family members. Evidence shows that their symptom burden were comparable to those of patients with advanced cancer (Etkind et al., 2017; Quinn et al., 2021; Zheng et al., 2013). The impacts on psycho-socio-spiritual wellbeing brought by the diseases can be equally overwhelming even though these non-cancer diagnoses seem less threatening or the treatment might seem ordinary. The World Health Organization (2014) has urged healthcare providers and policy makers to develop heightened awareness towards the palliative care needs of patients with advanced non-malignant conditions. Thus, professional and public education should be strengthened to enhance awareness and sensitivity toward the palliative care needs of patients, irrespective of diagnoses.

5.6. Study limitations

We acknowledge several study limitations. First, we did not conduct a controlled trial for ethical concern because the programme itself is a service improvement initiative. Ascertaining the causal relationship between the intervention and the outcomes would be difficult. Second, the sample size was small. Study enrolment and willingness for receiving home visits were negatively affected because the study period clashed with the period of social movement locally and the infection control measures during the COVID-19 pandemic globally. Third, the participants were predominantly patients diagnosed with cancer, and the study

generalisability to non-cancer patients could not yet be confirmed. Fourth, the data were only based on a PROM and we were unable to access the patients' hospital records. We did not use additional measurement to minimise the response burden because the patients were generally frail. Moreover, we could not preclude the possibility that the patients might have provided socially desirable responses. Data about healthcare utilisation were obtained from the self-report of patients or their family members.

REFERENCES

- Bernacki, R., Paladino, J., Neville, B., Hutchings, M., Kavanagh, J., Geerse, O., Lakin, J., Sanders, J., Miller, K., Lipsitz, S., Gawande, A., & Block, S. (2019). Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial. *JAMA Internal Medicine*, *179*(6), 751–759.
- Bone, A. E., Morgan, M., Maddocks, M., Sleeman, K. E., Wright, J., Taherzadeh, S., Ellis-Smith, C., Higginson, I. J., & Evans, C. J. (2016). Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders. *Age and Ageing*, *45*, 863–873.
- Chan, C. W. H., Chui, Y. Y., Chair, S. Y., Sham, M. M. K., Lo, R. S. K., Ng, C. S. M., Chan, H. Y. L., & Lai, D. C. Y. (2014). The evaluation of a palliative care programme for people suffering from life-limiting diseases. *Journal of Clinical Nursing*, *23*(1–2), 113–123.
- Creswell, J. W. (2014). *Research design : qualitative, quantitative, and mixed methods approaches* (Fourth ed). Los Angeles, Calif. : SAGE.
- de Wolf-Linder, S., Dawkins, M., Wicks, F., Pask, S., Eagar, K., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2019). Which outcome domains are important in palliative care and when? An international expert consensus workshop, using the nominal group technique. *Palliative Medicine*, *33*(8), 1058–1068.
- Dudley, N., Chapman, S., & Spetz, J. (2018). Community-Based Palliative Care Leader Perspectives on Staffing, Recruitment, and Training. *Journal of Hospice and Palliative Nursing*, *20*(2), 146–152.
- Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, *15*(1), 1–10.
- Gao, W., Wilson, R., Hepgul, N., Yi, D., Evans, C., Bajwah, S., Crosby, V., Wilcock, A., Lindsay, F., Byrne, A., Young, C., Groves, K., Smith, C., Burman, R., Chaudhuri, K. R., Silber, E., & Higginson, I. J. (2020). Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions: A Randomized Clinical Trial. *JAMA Network Open*, *3*(8), e2015061.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research : concepts , procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*, 105–112.
- Hospital Authority. (2017). *Strategic Service Framework for Palliative Care*. Hong Kong.
- Hudson, B. F., Best, S., Stone, P., & Noble, T. (2019). Impact of informational and relational continuity for people with palliative care needs: A mixed methods rapid review. *BMJ Open*, *9*(5).
- Lam, W. M. (2019). Palliative Care in Hong Kong - Past, Present and Future. *The Hong Kong Practitioner*, *41*(2), 39–46.
- Lee, V. H. F., Lam, T. C., Jing, H. M., Liu, F., Zhang, Y. S., Huang, J. J., & Lee, A. W. M. (2019). Integrative Palliative Cancer Care in Hong Kong: An Overview and an Example from the East. *Clinical Oncology*, *31*(8), 589–594.

- Leung, D. Y. P., Chan, H. Y. L., Chan, C. W. H., Kwan, J. S. K., Yau, S. Z. M., Chiu, P. K. C., Lo, S. K., & Lee, L. L. Y. (2017). Psychometric Properties of the Caregiver Inventory for Measuring Caregiving Self-Efficacy of Caregivers of Patients with Palliative Care Needs. *Neuropsychiatry (London)*, 7, 872–879.
- Lustbader, D., Mudra, M., Romano, C., Lukoski, E., Chang, A., Mittelberger, J., Scherr, T., & Cooper, D. (2017). The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization. *Journal of Palliative Medicine*, 20(1), 23–28.
- Maetens, A., Beernaert, K., Deliens, L., Aubry, R., Radbruch, L., & Cohen, J. (2017). Policy Measures to Support Palliative Care at Home: A Cross-Country Case Comparison in Three European Countries. *Journal of Pain and Symptom Management*, 54(4), 523-529.e5.
- Mather, H., Guo, P., Firth, A., Davies, J. M., Sykes, N., Landon, A., & Murtagh, F. E. M. (2018). Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients. *Palliative Medicine*, 32(2), 404–412.
- Mitchell, G., Gomez-Batiste, X., & Murray, S. (2017). Implementing a palliative care approach in the community and all settings of care. In *Building integrated palliative care programs and services* (pp. 123–136).
- Murtagh, F. E. M., Ramsenthaler, C., Firth, A., Groeneveld, E. I., Lovell, N., Simon, S. T., Denzel, J., Guo, P., Bernhardt, F., Schildmann, E., vanOorschot, B., Hodiament, F., Streitwieser, S., Higginson, I. J., & Bausewein, C. (2019). A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). *Palliative Medicine*, 33(8), 1045–1057.
- Oosterveld-Vlug, M. G., Custers, B., Hofstede, J., Donker, G. A., Rijken, P. M., Korevaar, J. C., & Francke, A. L. (2019). What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC Palliative Care*, 18(1), 1–10.
- Quinn, K. L., Wegier, P., Stukel, T. A., Huang, A., Bell, C. M., & Tanuseputro, P. (2021). Comparison of Palliative Care Delivery in the Last Year of Life Between Adults With Terminal Noncancer Illness or Cancer. *JAMA Network Open*, 4(3), e210677.
- Seow, H., & Bainbridge, D. (2018). A Review of the Essential Components of Quality Palliative Care in the Home. *Journal of Palliative Medicine*, 21(S1), S37–S44.
- Tang, J. Y., Ho, A. H., Luo, H., Wong, G. H., Lau, B. H., Lum, T. Y., & Cheung, K. S. (2016). Validating a Cantonese short version of the Zarit Burden Interview (CZBI-Short) for dementia caregivers. *Aging and Mental Health*, 20(9), 996–1001.
- Tang, S. T., Chen, J. S., Wen, F. H., Chou, W. C., Chang, J. W. C., Hsieh, C. H., & Chen, C. H. (2019). Advance care planning improves psychological symptoms but not quality of life and preferred end-of-life care of patients with cancer. *JNCCN Journal of the National Comprehensive Cancer Network*, 17(4), 311–320.
- Traa, M. J., DeVries, J., Bodenmann, G., & den Oudsten, B. L. (2015). Dyadic coping and relationship functioning in couples coping with cancer: A systematic review. *British Journal of Health Psychology*, 20(1), 85–114.

- van Vliet, L. M., Harding, R., Bausewein, C., Payne, S., & Higginson, I. J. (2015). How should we manage information needs, family anxiety, depression, and breathlessness for those affected by advanced disease: Development of a Clinical decision support tool using a Delphi design. *BMC Medicine*, *13*(1).
- Wong, F. K. Y., Ng, A. Y. M., Lee, P. H., Lam, P. T., Ng, J. S. C., & Ng, N. H. Y. (2016). Effects of a transitional palliative care model on patients with end-stage heart failure: A randomised controlled trial. *Heart*, *102*(14), 1100–1108.
- World Health Organisation. (2014). Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course. *Journal of Pain & Palliative Care Pharmacotherapy*, *28*(2), 130–134.
- World Health Organization. (2018). *Integrating palliative care and symptom relief into primary health care: care: a WHO guide for planners, implementers and managers*. Geneva, World Health Organization.
- Worldwide Hospice Palliative Care Alliance. (2020). *Global Atlas of Palliative Care* (2nd ed.).
- Yosick, L., Crook, R. E., Gatto, M., Maxwell, T. L., Duncan, I., Ahmed, T., & Mackenzie, A. (2019). Effects of a Population Health Community-Based Palliative Care Program on Cost and Utilization. *Journal of Palliative Medicine*, *22*(9), 1075–1081.
- Zheng, L., Finucane, A. M., Oxenham, D., McLoughlin, P., McCutcheon, H., & Murray, S. A. (2013). How good is primary care at identifying patients who need palliative care? a mixed methods study. *European Journal of Palliative Care*, *20*(5), 216–222.

Appendix A. Integrated Palliative Care Outcome Scale (IPOS)

紓緩照顧綜合結果量表

Q.1 過去一週內患者遇到的主要問題或憂慮有哪些？

- 1.1
- 1.2
- 1.3

Q.2 以下列表是一些您可能經歷過的症狀，對於每項症狀，請選出一個最合適的答案(在空格內加剔)，以形容該症狀在過去一星期內對您有多大的影響。

	一點都沒有	有輕微影響	有中度影響	有較大影響	有非常大的影響
2.1 痛	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.2 氣促	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.3 虛弱	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.4 反胃或作悶	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.5 嘔吐	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.6 無胃口	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.7 便秘	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.8 口腔痛或口乾	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.9 昏昏欲睡	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.10 行動不便	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.11 失眠	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.12 水腫	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.13 頭暈	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

過去一週內，如果您有一些以上未提及的其他症狀，請把這些症狀填到左下方括弧，並在每項症狀選出一個最合適的答案，以形容該症狀在過去一星期內對您有多大的影響。

	一點都沒有	有輕微影響	有中度影響	有較大影響	有非常大的影響
2.14 []	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.15 []	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.16 []	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	完全沒有	很少	有時	經常	總是
Q.3 您有否擔心自己的病情或治療？	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q.4 您的家人或朋友有否為您感到焦慮或擔心？	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q.5 您有否感到抑鬱？(例如：覺得情緒低落、絕望)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	總是	經常	有時	很少	完全沒有
Q.6 您有否感到心靈平安?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	總是/ 沒有此 需要	經常	有時	很少	完全沒有
Q.7 您能與家人或朋友盡情分享您的感受嗎?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q.8 您有多經常充分地得到您想要的資訊? (例如獲得您所需要的資料或訊息)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	困難得到 處理/ 沒有困難	困難 大部份 得到處理	困難部份 得到處理	困難絕少 得到處理	困難未能 得到處理
Q.9 病情所導致的任何實際生活困難是否已得到處理? (例如: 經濟或私人問題)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix B. Cantonese short version of the Zarit Burden Interview (ZBI)

以下句子描述了人們照顧其他人時的感受。在每句句子後，請指示你多久會有這樣的感覺：從不、很少、間中、經常、非常頻密。

	從不 (0)	很少 (1)	間中 (2)	經常 (3)	非常頻密 (4)
1. 你有冇覺得因為照顧病患者用咗你好多時間所以冇時間留俾自己?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. 你有冇覺得照顧病患者同你嘅家庭或者工作上嘅責任有衝突?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. 你有冇覺得您响病患者身邊嘅時候您會覺得悶?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. 你有冇覺得照顧病患者令你同你嘅屋企人或者朋友之間嘅關係帶嚟負面影響?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. 你有冇覺得你响病患者身邊嘅時候你會覺得緊張或者有壓力?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. 你有冇覺得因為照顧病患者而令到自己身體差咗?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. 你有冇覺得因為照顧病患者而令到自己無晒私隱?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. 你有冇覺得因為照顧病患者而犧牲咗自己嘅社交生活?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. 你有冇覺得病患者自從病咗之後令到你對自己嘅生活失去控制?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. 你有冇覺得唔肯定要點照顧病患者?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. 你有冇覺得你應該為病患者做得更多?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. 你有冇覺得你响照顧病患者方面可以做得更加好?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix C. Chinese version of the Caregiver Inventory (CGI)

	分數 (1 - 完全沒有信心 9 - 有十足的信心)
1. 應付泛濫的資訊	
2. 聆聽我正照顧的人並從中學習如何更好地照顧他/她	
3. 放下我不能掌控的事	
4. 表達對病患的負面感覺	
5. 保持希望	
6. 能夠察覺在照顧時出現的「美好時刻」	
7. 容許我正照顧的人擁有及表達他/她自己的感覺	
8. 協助我正照顧的人活動，例如餵食、清洗、穿衣或如廁	
9. 持續地照顧自己（例如：運動、飲食、睡眠）	
10. 坦誠地與當事人交談	
11. 提供情緒支援予我正照顧的人	
12. 理解從醫生、護士或其他來源所得的醫療資訊	
13. 為自己尋求支援	
14. 處理無助感	
15. 應付我正照顧的人向我表達負面情緒的狀況	
16. 協助和鼓勵我正照顧的人遵循所有治療	
17. 向醫生和護士提出問題詢問	
18. 與被我正照顧的人保持緊密的關係	

ENDLESS CARE SERVICES

TUNG WAH GROUP OF HOSPITALS

The Endless Care Services under Elderly Services of Tung Wah Group of Hospitals, was established in 2009. It offers a wide range of services including plan-ahead funeral arrangement, bereavement counselling, community palliative care support, as well as life and death education.

Service Objectives:

- To encourage the elderly to live a positive, fulfilling life upon entering the late stage, and by planning ahead for the funeral arrangements, so as to relieve the stress of the elders as well as the caregivers in facing the end of life;
- To break the taboo about death in the community and facilitate members of the public to review and reflect on their lives so as to promote the message “Cherish Life and Positive Living”.

Scope of Services:

1. Plan Ahead Funeral Arrangement

To facilitate the elders and their caregivers to plan ahead for the funeral arrangement, and to promote the message “Cherish Life and Positive Living” in the community through various innovative and immersive activities.

2. Funeral Care Service

To provide the childless elderly singleton and elderly couples with pre-funeral service and handle their funerals according to their will after they pass away.

3. “My Present for You” Video Shooting Service for the Elderly

Through the production of videos for their beloved ones, the elderly can review their pasts while mutual-appreciation of the achievements they have made can be facilitated.

4. Be-with Bereavement Support Service

To offer companionship for the bereaved, assisting them in handling the funeral affairs and providing bereavement counselling to ease their grief.

5. Community Palliative Care Support Project

To offer case management, nursing care, counselling service and home visits to the terminally-ill patients and their caregivers, also to provide community education talks and professional training to frontline staff on palliative care.

THE CHINESE UNIVERSITY OF HONG KONG

FACULTY OF MEDICINE

THE NETHERSOLE SCHOOL OF NURSING

The Nethersole School of Nursing, formerly the Department of Nursing (hereafter referred to as “School” in this paper), was established under the Faculty of Medicine at The Chinese University of Hong Kong (CUHK) in 1991. The School is the first university department of nursing in Hong Kong. The primary focus of the School is on high-quality nursing education and research so that nurses can become major contributors to improving population health and facilitating nursing development in Hong Kong. With the generous support of the Executive Committee of the Alice Ho Miu Ling Nethersole Hospital and the United Christian Medical Service, the School has further invigorated its commitment to pursuing excellence in nursing education, research and practice under the name of “The Nethersole School of Nursing” since 1 January 2002. In addition to nursing education, the School has provided gerontology education since 2012, in response to the needs of Hong Kong’s rapidly aging population. Undergraduate and postgraduate qualifications from the School enhance career progression of graduates locally, regionally and internationally. According to the QS World University Rankings 2019 – Nursing, the School ranks No. 1 in Hong Kong, No. 2 in Asia and No. 26 in the world.

Mission

To excel in teaching, research, and promotion of the highest standards of nursing and gerontology practice

Motto

To serve the community with compassion

Objectives

- To offer high-quality undergraduate and postgraduate education in nursing and gerontology that meets the changing needs of the profession and the health needs of the society
- To foster lifelong learning and to provide a foundation for continuing education
- To advance the art and science of nursing
- To promote the highest standards of nursing and aged care through scholarship, research, and innovative practice
- To increase nursing and gerontology knowledge through research

SPECIAL THANKS & PARTICIPATING PARTIES

We would like to express our greatest gratitude to the involved service recipients, the research team and staff members. Thank you very much for their contribution and active participation. We would also like to thank the project team of the Jockey Club End-of-life Community Care (JCECC) and Dr. Doris Leung for allowing us to use the Chinese version of the IPOS and the CGI, respectively, in the present project.

Publisher: Endless Care Services, Tung Wah Group of Hospitals

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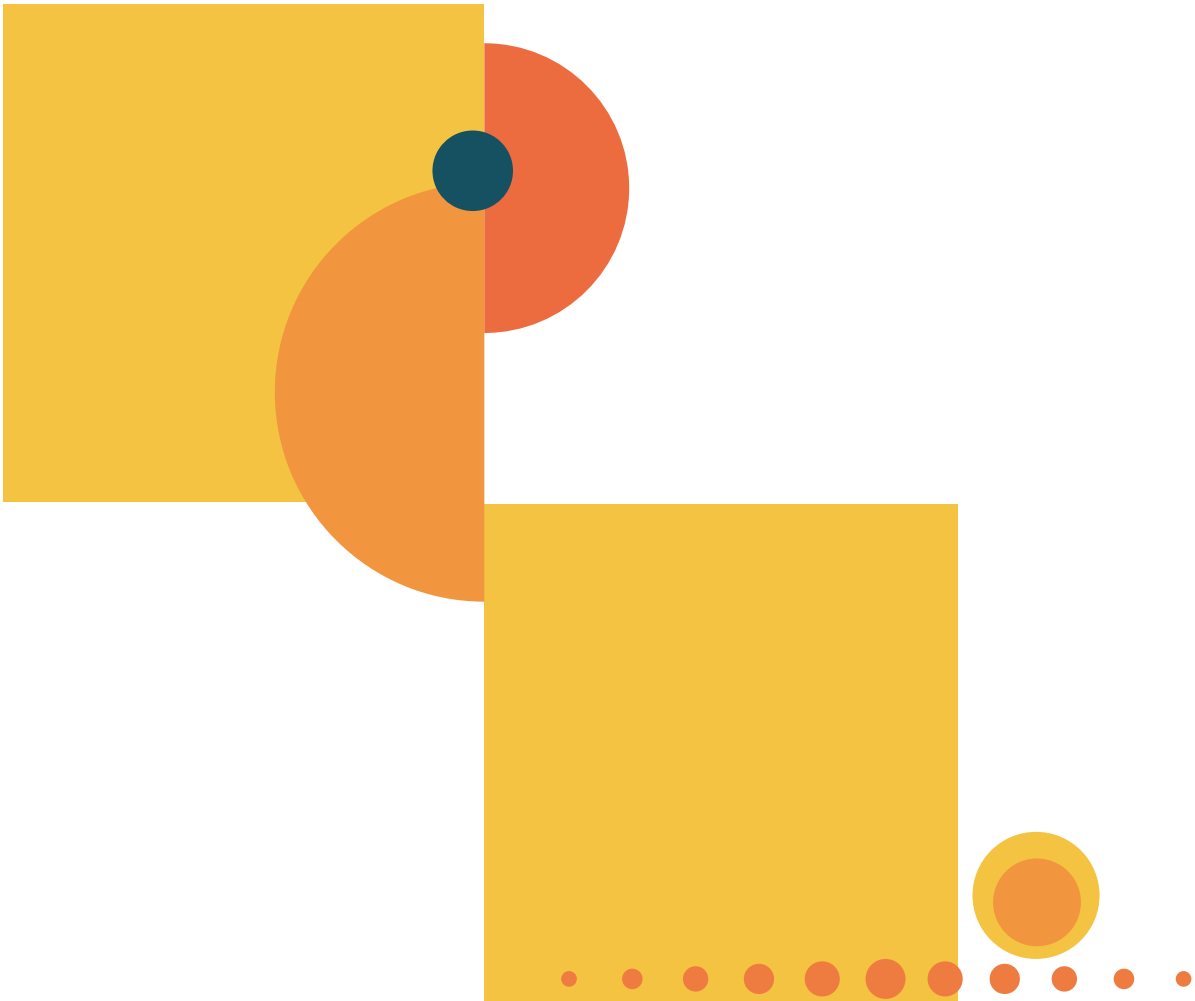
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Evaluation Report on Community Palliative Care Support Project
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ISBN 978-988-79311-3-3

Designed by Jerry Leung
Printed by New Artway Printing Production Limited

First published in August 2021 by
Endless Care Services
Tung Wah Group of Hospitals
Rm 319-321, 3/F, Kwun Tong Community Centre
17 Tsui Ping Road, Kwun Tong
Kowloon, Hong Kong
<https://ecs.tungwahcsd.org/>



ISBN 978-988-79311-3-3



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