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Use of mobile app 'SUPPORT+' to enhance community palliative care in advanced cancer patients: a randomized controlled trial

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Study Sites:

- Queen Mary Hospital
- Pamela Youde Nethersole Eastern Hospital
- Princess Margaret Hospital
- Queen Elizabeth Hospital
- Tuen Mun Hospital
- Haven of Hope Hospital

Description:

This is the original IRB-approved study protocol, outlining the design of a multi-centre randomized controlled trial evaluating the SUPPORT+ mobile application for advanced cancer patients in Hong Kong.

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Title:

Use of mobile app “SUPPORT+” to enhance community palliative care in advanced cancer patients: a randomized controlled trial

Introduction:

Patients with advanced cancer often experience multiple physical and psychological symptoms because of progressing disease or anticancer treatment. A systematic review included 40 studies showed that patients with advanced cancer had a high prevalence of chronic symptoms.¹ Over 50% of patients with advanced cancer experienced one of the following symptoms, including fatigue, pain, lack of energy, weakness, and loss of appetite. The top two symptoms experienced were fatigue (74%) and chronic pain (71%). Often, patients reported these symptoms only when they become severe. Moreover, patients with advanced cancer, especially in their last year of life, tend to have high utilisation of hospital services such as emergency room (A&E) attendances and hospitalizations. Acute hospitalizations are always stressful to patients and their families if the goal of palliation is unmet and put major burden on the healthcare system.

In Hong Kong, near 90% of the oncology services are provided by public cancer centres of the Hospital Authority, which is highly efficient but unfortunately, resources are tight. Palliative care is not just about end-of-life or in-patient hospice care.² Most of the patients with advanced cancer, before their last period of time, are often ambulatory and taken care in the community. Both patients and their families wish to stay in the community as long as possible before admitted for hospice care. However, routine symptom monitoring for patients with cancer is not performed outside hospitals in Hong Kong. Symptoms usually happen in between clinic visits. There is hindrance for the health care team and the patients to effectively communicate about the uncontrolled symptoms, and the response of the health care team to symptom crisis is not fast enough. Unplanned admission or A&E visit before scheduled clinic reassessment is common.³ Therefore, there is an urgent need for an efficient system to improve symptom monitoring and provide timely clinical support in advanced cancer patients in the community to alleviate their sufferings.

Development of palliative care services has been regarded as one of the top priorities in the healthcare policy agenda worldwide, as well as locally in Hong Kong. According to the latest published “Hong Kong Cancer Strategy”, enhancing palliative care support for advanced cancer patients is one of the main missions.⁴ The Hospital Authority also published "Strategic Service Framework for Palliative Care" in 2017.⁵ It sets "enhance palliative care in the ambulatory and community settings to support patients and reduce unnecessary hospitalization" as one of the four main goals in palliative care in Hong Kong. It is important to provide ambulatory and community palliative care support to patients and their families/carers to facilitate care in place and reduce unnecessary

hospitalization.

Self-management is defined as ‘the person’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition’.⁶ Self-management has also been described as a participatory process where patients and clinicians develop strategies together to equip patients with the skills and knowledge to manage the impact of the condition, monitor their disease and make effective use of support services outside of the clinical setting.⁷ The ultimate goal is to enable and empower patients to achieve their own goals of care throughout the illness trajectory.⁸ Self-management focuses five core skills including problem-solving, decision making, resource utilisation, communication with health care professionals, and action planning or goal setting.⁹

There is an increasing acceptance of integrating self-management into palliative care in cancer care.^{10,11} Their integration can support patients with advanced cancer and their family caregivers across the care trajectory positively. Previous reviews supported routine and timely use of self-management strategies in palliative setting can reduce physical and psychological burden, improve physical functioning, enhance knowledge of care options, facilitate goal-setting and decision-making, maximize quality of life and reduce caregiver stress.^{12,13,14,15} There are various delivery modes of self-management interventions, including by nurses in person or by telephone, self-guided and eHealth, including web-based and mobile applications.^{16,17} Furthermore, eHealth interventions are increasing used in cancer management. It can enable patients to be actively engaged in healthcare, improve health outcomes, and lead to positive behavioural change.^{18,19}

Recently, systemic use of patient-reported outcome (PRO) measures, defined as the unfiltered and direct reporting of a given symptom by a patient without amendment or interpretation by a physician or anyone else, is considered as the gold standard for capturing symptoms or monitoring health-related quality of life (HRQoL) in cancer patients.²⁰ With greater internet connectivity and increasing availability of handheld and wearable electronic devices, electronic patient-reported outcomes (ePRO) have emerged as a feasible option for improving the quality of assessment, and they are expected to be an integral part of high-quality cancer care. Several ePRO systems have been developed and used in the oncology field in other countries.^{21,22,23,24} These ePRO systems can enhance patient care by flagging important symptoms, prompting clinicians to intensify symptoms management, and enhancing patient-clinician communication. A randomized controlled trial of a web-based symptom reporting system, by sending emails between nurses and patients who were on chemotherapy, compared with usual care performed in Memorial Sloan Kettering Cancer Centre (New York, USA) showed their PRO system helped improving quality of life, less hospitalization, less

emergency room admission, longer overall survival (1 year survival: 75% vs. 69%, $p=0.05$) and longer quality-adjusted survival (mean: 8.7 vs. 8.0 months, $p=0.004$).²⁵ Another multi-centre, randomized controlled trial on real time remote symptom monitoring in Europe (eSMART) demonstrated their system could reduce psychological distress and symptoms in patients with non-metastatic cancer who were on chemotherapy.²⁶ Besides using on patients receiving chemotherapy, a recently published systematic review on using ePRO system in palliative care demonstrated a few successful cases and revealed active studies on digital palliative cancer care interventions, highlighting significant room for research.²⁷

Hong Kong has one of the highest smart phone penetration rates in the World. Overall penetration rate was 92.1% in 2020.²⁸ Even among elderly population (age >65), 68.1% owns a smartphone. Hence, using smartphone as a platform to facilitate symptom monitoring is potentially feasible.

SUPPORT+ (“家支援”) is a mobile application initiative developed by the University of Hong Kong’s LKS Faculty of Medicine Department of Clinical Oncology. It was developed in collaboration with oncologists, palliative care specialists, nurses and community leaders to provide support for patients with advanced cancer and their caregivers or families to bring their care home. It was developed to support patients with advanced cancer to have an active role to self-manage their symptoms and improve their well-being. SUPPORT+ mobile app acts an additional support for cancer patients and their carers to help them equip their knowledge on cancer and palliative care, capture patients’ symptoms accurately and in real-time, and a step-care principle to deal with their symptoms by themselves with additional support from palliative care nurses. It aims to improve patients’ health-related quality of life and self-confidence in managing their illness, avoid AED visits or hospitalizations, and enhance communication between patients/ carers with HCPs. Details about SUPPORT+ app are in Appendix 1. More information about SUPPORT+ can be found in the link: <https://support-plus.med.hku.hk/index.php?lang=TC>

This study will evaluate the benefits of the ePRO system SUPPORT+ for adults with advanced cancer through a carefully designed randomized controlled trial (RCT) that will be conducted in six oncology/ palliative care centres under the Hospital Authority.

a) Aims and Hypotheses to be Tested:

This is a multi-centre, randomized controlled trial. This trial aims to evaluate the potential benefits of a remote monitoring system SUPPORT+ in advanced cancer patients. The hypothesis is that addition of SUPPORT+ (weekly online symptom reporting for 18 weeks) to usual care would lead to improvement or less deterioration in HRQoL and performance status, better self-efficacy (self-care),

reductions in symptom burden, AED visits and acute hospitalizations due to uncontrolled symptoms in advanced cancer patients in the community.

Primary outcome:

The main objective is to determine whether the addition of the ePRO system SUPPORT+ intervention can lead to improvement or maintenance in HRQoL compared with usual care. It is measured by the change in HRQoL from baseline to week 18, measured via the EQ-5D-5L.²⁹ The EQ-5D-5L questionnaire is a five-item general measure evaluating patients regarding the following dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

Secondary outcomes:

To evaluate the impacts of SUPPORT+ intervention compared with usual care, secondary outcomes include

- Change in performance status (ECOG) from baseline to week 18
- Frequency of emergency room visits
- Frequency and days of hospitalizations due to uncontrolled symptoms
- Symptom management (including both physical and emotional functioning) using Integrated Palliative Care Outcome Scale (IPOS) scale³⁰
- Self-efficacy, which is the patient's confidence and ability to manage symptoms, measured by "Self-Efficacy for Managing Chronic Disease 6-Item Scale"^{31,32}

b) Plan of Investigation:

[For advanced medical research, please state clearly how the study will focus on clinical studies and apply advanced technologies to facilitate the translation of knowledge generated from health and health services or infectious diseases studies into clinical practice and to inform health policies.]

[For study addressing thematic priorities under Implementation Science, please state clearly the proposed framework(s) / model(s) to be adopted and the pre-set criteria to evaluate/assess the barriers and facilitators of implementation outcomes.]

[For Seed Grant application (i.e. grant ceiling is HK\$500,000), please state clearly the pre-set criteria to enable scale-up to a larger project and/or enhance the efficacy/effectiveness of existing practice.]

This study is a multi-centre, 1:1 allocation prospective randomised two-arm parallel group design. Participants will be randomised to two groups: the intervention group (SUPPORT+ plus usual care) or

the control group (usual care). Participants will include advanced cancer patients who have follow-up in palliative care clinic in the Department of Clinical Oncology at Queen Mary Hospital, Pamela Youde Nethersole Eastern Hospital, Princess Margaret Hospital, Queen Elizabeth Hospital, Tuen Mun Hospital and the Division of Palliative Medicine at Tuen Mun Hospital.

(i) Subjects (with justification on the sample size)

Inclusion criteria:

1. Aged ≥ 18 years old at time of consent
2. A diagnosis of advanced malignancy (inoperable)
3. Follow-up in palliative care clinic in Department of Clinical Oncology at Queen Mary Hospital, Pamela Youde Nethersole Eastern Hospital, Princess Margaret Hospital, Queen Elizabeth Hospital, Tuen Mun Hospital and the Division of Palliative Medicine at Tuen Mun Hospital
4. Smartphone owners
5. Taken care in the community
6. No severe cognitive dysfunction
7. Agree to receive notifications from the SUPPORT+ app on their smartphone
8. Suffer from at least one symptom related to their advanced cancer
9. Valid consent is obtained with permission to review their medical records

Exclusion criteria:

1. Those on treatment for their cancer in radical intent
2. Short life expectancy of less than 3 months (ECOG ≥ 3)

Sample size calculation:

The primary endpoint is the change in EQ-5D-5L score from baseline to week 18. Comparison on the changes of the score between the two groups: intervention group (SUPPORT+ added on usual care) and the usual care group. The hypothesis is that the SUPPORT+ group will significantly surpass the usual care group in terms of the HRQoL changes from baseline to week 18. In other words, the HRQoL will either be improved or deteriorated less in the intervention group compared with that of the usual care group.

Taking the EQ-5D minimal important difference (MID) estimate of 0.11 for advanced cancer and standard deviation of 0.2, sample size of 157 per group will be necessary to achieve 90% power to detect difference of greater than MID at 5% significance.³³ Assuming around 20% dropout rate, enrolment of 394 participants is planned. The sample size calculation also accounts for the

stratification (see Methods).

(ii) Methods

Patients with advanced cancer having follow-up in palliative care clinic are enrolled in a prospective, randomized two-arm parallel group study over 18 weeks.

Physicians from each centre will identify the eligible patients. The research assistant will then approach the eligible patients in the waiting area after consultation. After explanation of the study and participant's rights, eligible patients will sign the consent form. Consenting patients are randomly assigned 1:1 to two groups: intervention group (SUPPORT+ added to usual care) or usual care group, stratified by (1) aged ≥ 65 years vs. < 65 years; (2) patients with chronic pain on opioids vs. not on opioids in random permuted blocks (variable block sizes: 8, 10, 15); (3) app user (patient vs. caregiver). Stratification is used in the randomization process, as we expect age and use of opioids have major influences on our study outcomes. According to the Hong Kong Cancer Register, around 50% of the cancer patients were diagnosed at age ≥ 65 . from the literature, around 53% of cancer patients had chronic pain that required long-term opioids. Since older adults have different physical functions and have different social background compared with the younger adults, as well as they are usually not so tech-friendly and may need carers support in using the app, we stratify aged ≥ 65 years old during randomisation. For patients who use opioids, they usually have more severe symptoms and may have more psychological stress.

Random assignment of clinicians is not possible because of the established team structures; therefore, staff saw patients in both arms.

Procedures

Baseline assessment

After signing consent, baseline information of each participant including age, gender, social background (marital status, occupation, and educational level), co-morbid conditions, baseline performance status, type of cancer and sites of metastasis, primary carer, medications used, average number of hospital admission in the past three months, number of AED visits in the past 3 months, experience and knowledge on palliative care, and health literacy will be collected at the initial visit. The SUPPORT+ app will be installed on the patient's smartphone. Android based and IOS based apps are both available.

Interventions

(A) Usual care group

Patients with advanced cancer have medical consultations in palliative care clinic and discuss on their care plan with symptom control. During follow-up, patients are regularly assessed by palliative care physicians for any symptoms and medications are prescribed till next clinic visit. Patients can use the SUPPORT+ app to read the educational materials only. The educational materials are the same as in the app for public to download.

(B) Intervention group (SUPPORT+ added on usual care)

Participants in the intervention arm also receive same care as the usual care group. In addition, they can use the full function of the app. They need to report their symptoms weekly and can contact their palliative care nurses directly on the app during the 18-week study period. The app interface is designed to collect the common symptoms according to the Integrated Palliative care Outcome Scale (IPOS).³⁰ The IPOS is a brief measure of palliative care problems and assessment of patient's QoL. It has proven to be an important and relevant tool in improving the practice of palliative care (See Appendix 2). The IPOS a valid and reliable outcome measure, both in patient self-report, carer-report and staff proxy-report versions, allowing maximum flexibility for clinical use. It has ten questions (17 items) which assess the following dimensions in advanced illness: physical, emotional, psychological, spiritual and provision of information and support. Five response options (score 0-4) are provided for each question, and only one response is allowed. An item scored 3 means severe and scored 4 means overwhelmingly.

Every week, an email or app-alert will be sent to the participants to record their symptoms on the mobile app. After reporting the weekly symptom diary on the SUPPORT+ app, participants will receive links on self-management according to their reported symptoms. The symptom record will also be sent to the palliative care nurse at real time. When reported symptom score reaches 3 or above, oncology or palliative care nurses will be alerted. During office hours, nurses will contact the participants and see what actions to take in response to the alerts within one working day. The medical advice includes adjustment on medication, tips on self-management, advancing medical appointments, referring to AED or hospitalization, etc. During non-office hours, patients are encouraged to seek for medical opinion in cases of emergency. A report tracking participants' symptoms will be reviewed by the attending oncologist/ palliative care physician at each clinic visit.

Besides reporting on the weekly symptom diary, participants can use the "Consult Nurse" in the mobile app to communicate with the palliative care nurses during office hour.

Both groups can continue to use the SUPPORT+ mobile app after the 18-week study period.

The management flow of the two groups is summarised in Figure 1.

Outcome measures:

All participants have assessment at three time-points: baseline assessment (week 0), week 9, and week 18. During each time point, participants will meet our research coordinator and complete a questionnaire on HRQoL, self-efficacy and ECOG performance status. Assessment will also be done by our research coordinator on performance scale, experience on advanced care planning, AED visits and hospitalizations.

Primary outcome:

(1) Health-related quality of life (HRQoL)

The primary outcome is the change in HRQoL measured by EQ-5D-5L utility score.²⁹ The EQ-5D-5L questionnaire is a reliable, validated and preferred measure of HRQoL in patients with advanced cancer.^{34,35,36,37,38} It measures five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with five levels each. It produces a EQ-5D-5L utility score between -0.865 (for the worst possible health state) and 1 (for the perfect health state), based on Hong Kong EQ-5D-5L value set.³⁹ Lower scores represent worse HRQoL. The EQ-VAS is also used to measure self-rated health. It is a vertical 100-point response scale, from 0 (worst health you can image) to 100 (best health you can image). This scale has been validated in advanced cancer patients with reliability of 0.75-0.89.^{40,41,42} A cumulative effect of the intervention was anticipated, and hence, a timepoint of 18 weeks (end of study) is selected as the primary endpoint, with 9 weeks being secondary endpoint.

Extensive research has shown EQ-5D-5L to be valid, reliable, and responsive in a wide range of conditions and populations, including patients with advanced cancer.^{43 44} There are systematic reviews demonstrating the validity and reliability of EQ-5D-5L in measuring HRQoL in patients with cancer. Moreover, EQ-5D-5L is frequently used in different oncology studies to measure HRQoL. According to the National Institute for Health and Care Excellence (NICE) guidelines, the EQ-5D is a recommended tool for estimating quality-adjusted life years (QALYs) using utility values for evaluating cost-effectiveness analyses of the intervention programs.⁴⁵

Secondary outcomes:

(1) Changes in performance status

The performance status is measured by Eastern Cooperative Oncology Group (ECOG) performance status (PS) scale. This is a widely used scale to assess the functional status and self-care of a patient. ECOG PS scale uses 5 points score (0 denoting perfect health and 5 death) to assess PS and is considered simple tool to use in daily clinical practice.⁴⁶

(2) Frequency of emergency room (AED) visits

The total number of AED visits during the study period can be counted by reviewing the medical records in the Clinical Management System (CMS) under Hospital Authority. Reasons of AED visit are recorded and analysed.

(3) Frequency and days of hospitalizations due to uncontrolled symptoms

The total number of admissions and total number of days of hospitalizations during the study period can be counted by reviewing the medical records. Reasons of hospitalizations are recorded and analysed.

(4) Self-efficacy

Self-efficacy is the confidence level that the patient can manage his own symptoms. It is measured by “Self-Efficacy for Managing Chronic Disease 6-Item Scale”, which is a validated, brief and effective tool that directly measures the self-efficacy for chronic diseases.^{31,32} This 6-item scale covers domains that are common across many chronic diseases such as symptom control, role function, emotional function and communication with physicians. Each item is rated on a 1 ‘not at all confident’ to 10 ‘totally confident’ scale. The score is the mean of the items, with the score range 1–10. A higher score indicates higher self-efficacy or more confidence in managing chronic disease. The change in self-efficacy from baseline to end-of-study (Week 18) is measured. This tool was translated into different languages including Chinese. The Chinese version was validated and published in 2013, with good reproducibility (ICC = 0.78; 95% CI, 0.70–0.84), and the reliability was good (Cronbach’s alpha = 0.88).³²

End of study assessment (week 18)

At the end of the study (Week 18), patients will have the end-of-study assessment. Assessment includes HRQoL, ECOG performance status and self-efficacy for managing chronic disease. The frequency of AED visits in the past 3 months, hospitalisations (frequency and number of days in the past 3 months) will be reviewed in the Computer Medical Record of the participants.

(iii) Study design

This is a multi-centre, 1:1 allocation prospective randomised controlled trial with two-arm parallel group design.

(iv) Data processing and analysis

Clinical and patient demographics are investigated by descriptive analyses for the entire study population. Categorical variables are calculated in counts and percentages while continuous variables are calculated by means and standard deviations.

For the analysis of primary outcome, EQ-5D-5L utility scores for participants in each study arm are calculated at 18 weeks and compared with baseline scores, excluding those who have not completed any postbaseline EQ-5D questionnaire. The proportion of patients in each arm who experience improved and non-improved scores from baseline to end-of-study are compared using Fisher's exact test. Mean score changes of EQ-5D-5L utility scores and EQ-VAS scores from baseline to end-of-study are compared using independent t-test. A multivariable linear regression model is performed with change of EQ-5D-5L utility score and EQ-VAS score as the dependent variable. Mean score changes of symptom management scores, self-efficacy scores, and knowledge on palliative care scores from baseline to end-of-study are compared.

Separate multivariable linear regression models are performed with the changes of ECOG PS, symptom management scores (IPOS) and self-efficacy score from baseline to end-of-study follow-up as dependent variables.

For AED visits and hospitalizations due to uncontrolled symptoms, cumulative incidence functions are calculated with death treated as a competing event. Competing risk regression is used to model treatment effects.

Intention-to-treat analysis are performed as main analysis, while complete-case analysis are performed as sensitivity analysis. There are potential biases of lost to follow-up, regardless of intervention or control group, following the health deterioration among patients with advanced cancer. To account for sample attrition, the revised proposal will perform imputation to the missing outcome data in the follow-up assessment through 'last value carrying forward' approach and 'multiple imputation'. Two-sided P-values of less than 0.05 are considered to indicate statistical significance.

To account for the subject heterogeneity, subgroup analysis, including age (<65 vs. \geq 65 years

old) and whether use of opioid, will be performed. We will also test the heterogeneity of effect size across subgroups using p-interaction.

Analyses will be performed by using SPSS / R software.

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Use of mobile app “SUPPORT+” to enhance community palliative care in advanced cancer patients: a randomized controlled trial

Background

Cancer is one of the most prevalent non-communicable diseases in Hong Kong due to the growing aging population. Cancer incidence in Hong Kong has increased by about 35% compared to a decade earlier, at an average rate of 3.1% per annum.¹ The annual number of new cancer cases in Hong Kong hit a historical high of 35,082 in 2016 and it is projected to increase by approximately 35% to over 42,000 by 2030. Cancer is also the leading cause of death in Hong Kong. It accounted for more than 30% of all deaths. Over the past decade, the number of cancer deaths rose at an average rate of 1.5% per year.

Patients approaching end of life, especially in their last year of life, tend to have high utilisation of hospital services such as emergency room attendances and hospitalizations. Acute hospitalizations are not only a stressor to patients and their families/ carers if the goal of palliation is unmet, but puts a major burden on the healthcare system.

Development of palliative care services has been regarded as one of the top priorities in the healthcare policy agenda worldwide, as well as locally in Hong Kong. According to the latest published “Hong Kong Cancer Strategy”, enhancing palliative care support for cancer patients approaching end-of-life is one of the main missions.² It emphasizes on the urge of collaboration among different specialties along the care continuum from hospital to community setting to facilitate care in the place. The Hospital Authority also published “Strategic Service Framework for Palliative Care” in 2017.³ It sets “enhance palliative care in the ambulatory and community settings to support patients and reduce unnecessary hospitalization” as one of the four main goals in palliative care in Hong Kong. It is important to provide ambulatory and community palliative care support to patients and their families/ carers to facilitate care in place and reduce unnecessary hospitalization. The emphasis is on enhancing day care, home care, support to residential care homes, and community partnership.

Moreover, in the “Government policy measures to promote smart elderly care services” published in 2017, development of gerontechnology, combination of elderly services and innovate technology, is noted to be of utmost importance in order to improve quality of life of elderlies and enhance their social function. The use of communication technologies can facilitate contact between elderlies and families/ carers and health care professionals, thereby strengthening the social connection of the elderlies.

Introduction to SUPPORT+

SUPPORT+ mobile application is a mobile application initiative developed by the University of Hong Kong's LKS Faculty of Medicine Department of Clinical Oncology. It is developed in collaboration with oncologists, palliative care specialists, nurses and community leaders to provide support for patients with advanced cancer and their caregivers or families to bring their care home. It was developed to support patients with advanced cancer to have an active role to self-manage their symptoms and improve their well-being. SUPPORT+ mobile app acts an additional support for cancer patients and their carers to help them equip their knowledge on cancer and palliative care, symptom monitoring and a step-care principle to deal with their symptoms by themselves with additional support from palliative care nurses. (This is to supplement Appendix 1: SUPPORT+ Information sheet)

The website of SUPPORT+: <https://support-plus.med.hku.hk/index.php?lang=TC>

SUPPORT+ App download link: <https://onelink.to/be45gg>

SUPPORT+ has three main modules:

1. Equip Yourself: Education Materials

All users (both control group and intervention group) can access educational materials related to cancer information, palliative care and end-of-life care to elevate their knowledge on palliative care. This information can be accessed both via the mobile app or the web platform.

Importantly, there are educational materials on end-of-life care and advance care planning. Information on end-of-life planning including will setting, burial, bereavement care, legal procedures and regulations related to "dying-in-place" will also be provided. If patients or families have wishes to "dying-in-place", they can also contact palliative care nurses through the apps for nurse consultation. Information about advance care planning (ACP), advance directive (AD), "Do not attempt cardiopulmonary resuscitation" (DNACPR), will setting, public and private hospices are available for patients or caregivers to follow step-by-step.

2. Symptom Diary

The symptom diary is a monitoring tool of the patient's symptoms to ensure that any changes to the patient's physical or mental wellbeing are being monitored closely and can be addressed promptly. It also allows for tracking of the symptoms over periods of time to monitor any potential deterioration to the patient's condition.

Every week, an in-app notification will be sent to remind the patients in the intervention group to record their symptoms on the mobile app. They need to answer a series of questions in relation to their physical health, pain score and mental wellbeing. The questions were developed based on the Integrated Palliative care Outcome Scale (IPOS). IPOS includes both physical symptoms and psychological concerns commonly experienced by cancer patients. Questions on physical symptoms and mental wellbeing are scored from 0 to 4 and pain score is scored from 1-10.

After the patients answer the weekly symptom diary, the system will respond and give self-management advice and words of encouragement to the patients according to their reported symptoms. For example, if patient reports "nausea and vomiting", the system will give advice to patient on how to manage this discomfort. Moreover, when the patients report symptoms scored 3

or above, palliative care nurses will contact the patients within one office day during working hours and advise on what actions the patients need to take.

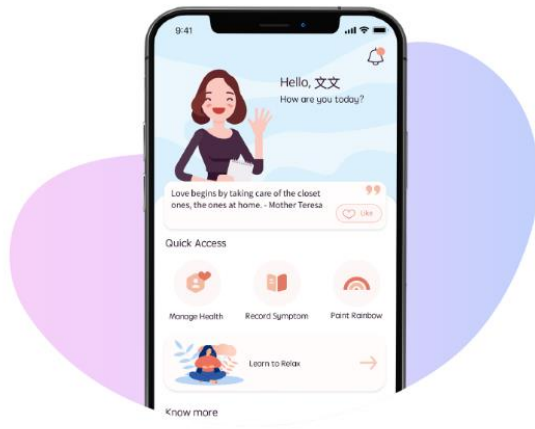
3. Contact Nurse

The “Contact Nurse” function is an instant messaging function that enables for text messages, voice messages and photos to be sent between patients/caregivers and their designated nurses during office hours to seek assistance. This function works in conjunction with the symptom diary to provide a way for patients to promptly notify their healthcare team of any changes to their condition so that it can be addressed rapidly.

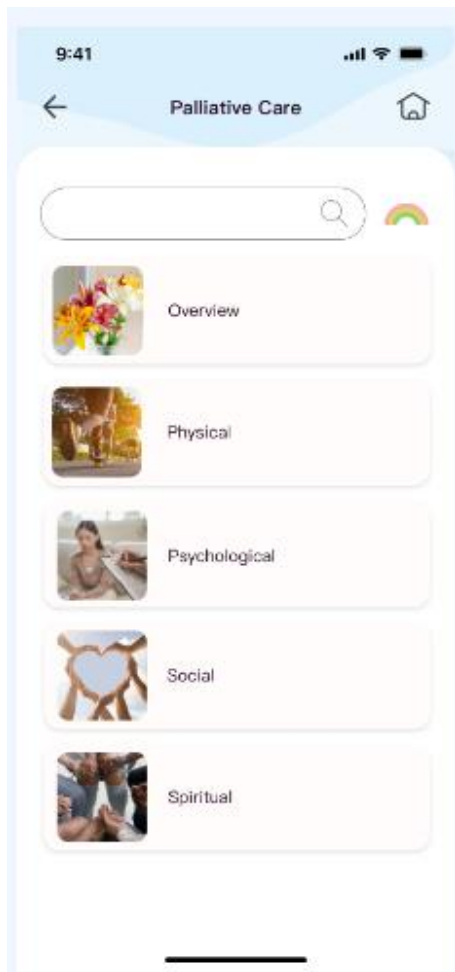
In our study, the control group can access the first function (Educational materials) while the intervention group can use all three functions.

Below are illustrations of the mobile application to demonstrate the overall workflow and features:

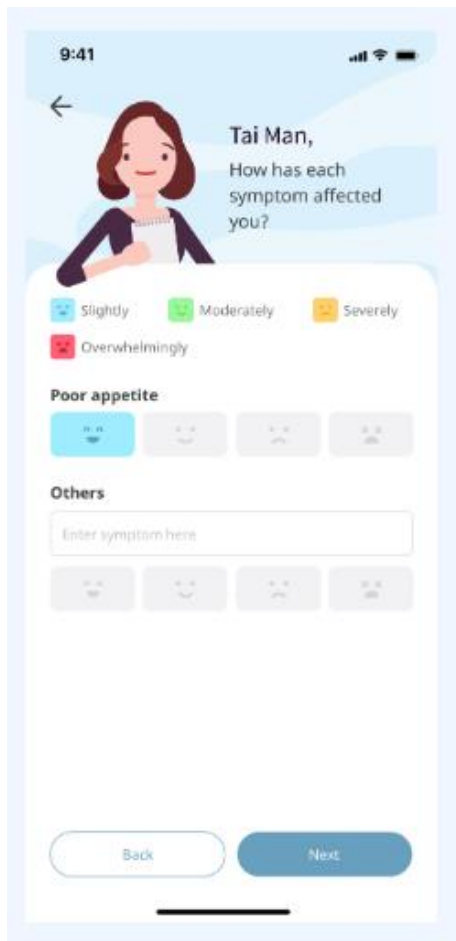
Homepage



1. Equip yourself: educational materials



2. Symptom Diary



9:41

←

Tai Man,
How has each
symptom affected
you?

Slightly Moderately Severely
Overwhelmingly

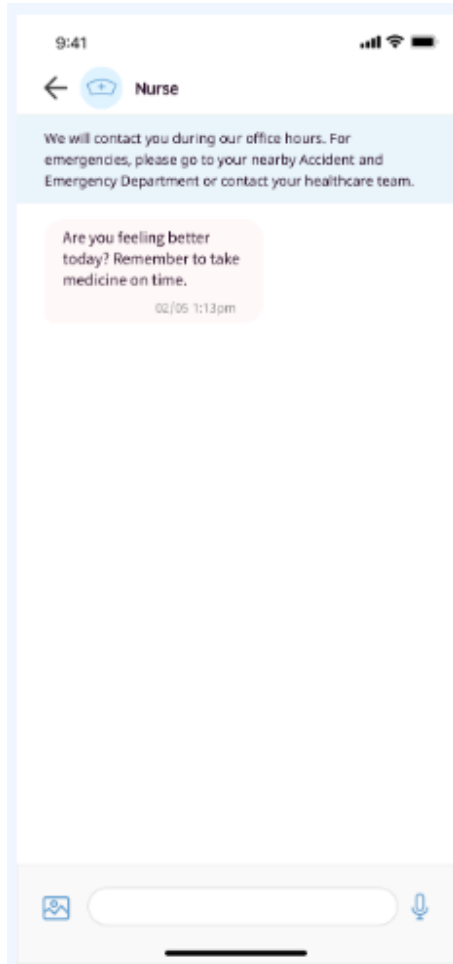
Poor appetite

Others

Enter symptom here

Back Next

3. Contact Nurse



¹ Hong Kong Cancer Registry [Overview of HK Cancer Stat 2019.pdf \(ha.org.hk\)](https://www.ha.org.hk/overview-of-hk-cancer-stat-2019.pdf)

² Hong Kong Cancer Strategy 2019, available at https://www.chp.gov.hk/files/pdf/aw_report_web.pdf

³ Strategic Service Framework for Palliative Care" available at https://www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf

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IPOS Questionnaire

Department of Clinical Oncology, The University of Hong Kong

IPOS Patient Version (Week 0, 9, 18) – in app questionnaire

Q1. What have been your main problems or concerns over the past week?

1.
2.
3.

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past week.

	Not at all	Slightly	Moderately	Severely	Over-whelmingly
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Please list any <u>other</u> symptoms not mentioned above, and tick <u>one box</u> to show how they have <u>affected</u> you <u>over the past week</u>.					
1.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
2.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
3.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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IPOS Questionnaire

Department of Clinical Oncology, The University of Hong Kong

Over the past week:

	<i>Not at all</i>	<i>Occasionally</i>	<i>Sometimes</i>	<i>Most of the time</i>	<i>Always</i>
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	<i>Always</i>	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Not at all</i>
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	<i>Problems addressed / No problems</i>	<i>Problems mostly addressed</i>	<i>Problems partly addressed</i>	<i>Problems hardly addressed</i>	<i>Problems not addressed</i>
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	<i>On my own</i>	<i>With help from a friend or relative</i>		<i>With help from a member of staff</i>	
Q10. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are worried about any of the issues raised on this questionnaire, then please speak to your doctor or nurse.

--- END ---