A cross-sectional study on the attitudes and perceptions of outpatients towards palliative care at the Hong Kong Queen Mary Hospital Hospice Centre

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**Background:** Palliative care aims to improve the quality of life for patients and their families, by helping them to cope with problems associated with illness. It targets four aspects of health: physical, psychological, social, and spiritual. Most of the current literature on palliative care is limited to the perspectives of health professionals. This study aims to investigate the views of outpatients receiving palliative care at the Hong Kong Queen Mary Hospital Hospice Centre (HKQMHHC), which offers palliative care services to cancer patients.

**Methods:** This observational cross-sectional study was performed with the completion of a single paper-based original questionnaire over 18 afternoon clinic sessions on Thursdays and Fridays from December 2017 to February 2018 at the HKQMHHC. The questionnaire was designed to examine patients' perspectives; in particular, the Edmonton Symptom Assessment Scale (ESAS) was used to assess their symptoms. Descriptive and univariate analyses were performed.

**Results:** One hundred patients attending HKQMHHC were included in the study. The study revealed that all the mean scores for aspects of care offered at the centre were above 8, on a scale of 0–10 with 0 being extremely inadequate and 10 being extremely adequate. Each respondent was able to identify an average of 1.82 of the 4 aspects of palliative care. Eighty-seven percent of respondents perceived the physical aspect of this care to be of the highest priority. A negative correlation (P<0.05) was found between the extent of symptoms experienced by the patient and their satisfaction towards the services offered.

**Conclusions:** Patients generally held very positive attitudes, reflecting that the services sufficiently met their needs. However, owing to their rather limited knowledge, this may have restricted their perspectives to a largely superficial level, as many discerned palliative care to be simply targeting physical health with medical consultations. Considering the implications of the results, the addition of accessibility and education components to Hong Kong's current system of palliative care is crucial in the betterment of such services for patients. There should also be increased local coverage of palliative care services to facilitate convenience of access. With reference to the World Health Organisation (WHO) palliative care model, the inclusion of a continued spectrum of services, such as physical and mental health activities and psychosocial counselling, should be reinforced throughout the progression of disease so as to better help patients to cope with illness. The discovery of the relationship between extent of symptoms experienced and patients’ satisfaction towards
services provided is a new direction for further study.

**Keywords:** Attitudes; cross-sectional studies; palliative care; patients; perceptions

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### Introduction

**Background/rationale**

According to the World Health Organisation (WHO), palliative care is an approach in medicine that aims to improve the quality of life and care for patients and their families, by helping them to cope with problems associated with life-threatening illness (1). This is achieved by means such as the management of suffering, of pain, as well as of physical, psychosocial, and spiritual health (1). Being multi-disciplinary in nature, palliative care offers a range of services including inpatient, outpatient and home support care. It also involves a multitude of professionals including physicians, physiotherapists, nurse specialists, and social workers, all of whom work together to provide a support system for the patient (2).

Having been recognised as a specialty in Hong Kong since 1998, palliative care has since expanded in the public health sector (2). The city has a unique approach by integrating clinical oncology and palliative care to form a combined specialty, which is supported by the European Society for Medical Oncology (ESMO) program of Designated Centre of Integrated Oncology and Palliative Care (3). Although additional training and resources are needed to face the high demand, such a concept facilitates the seamless incorporation of palliative care for cancer patients. At present, the Department of Clinical Oncology at the Queen Mary Hospital is listed as one of the three ESMO-accredited centres in Hong Kong (4).

The Hong Kong Queen Mary Hospital Hospice Centre (HKQMHHC) runs as part of the Li Ka Shing Foundation “Heart of Gold” Hospice Service Programme (5). This hospice centre is dedicated to offering outpatient palliative care services to cancer patients and represents the Hong Kong West Cluster region (6). Having opened in October 2007, it has developed with a wide range of services including medical consultation, activities for physical and mental development, education seminars, general counselling, and family grief counselling (5).

The importance of palliative care cannot be underestimated. Evidence on patient outcomes suggests that for a population of adults with advanced cancer, early palliative care may improve health-related quality of life slightly and alleviate symptom intensity (7).

Despite Hong Kong’s rapid advancements in palliative care, there are still challenges that need to be addressed, as well as major gaps in the knowledge and understanding of this field locally. Palliative care is still looked upon as luxury and non-essential by both the public and the government, making the process of obtaining more resources for expansion and development a difficult one (2). Additionally, current palliative care services are largely limited to cancer patients (6). Finally, most literature on palliative care is often limited to the perspectives of health officials and professionals, and there is a need to explore the perception from the perspective of patients.

In the Hospital Authority’s “Strategic Service Framework for Palliative Care” recently published, one of the major framework strategies for adult palliative care is to “Enhance palliative care in the ambulatory and community settings to support patients and reduce unnecessary hospitalisation” (6). Hence, in order to appraise palliative care services currently being offered in Hong Kong, it is crucial to consider the views of receiving patients.

**Objectives**

This study aims to investigate the perspectives of patients receiving palliative care services at the Hong Kong West Cluster Queen Mary Hospital Hospice Centre. Patients receive outpatient services there and are mainly ambulatory.

The primary objective of the study is to examine patient views towards palliative care. In specific, their attitudes on and perceptions of current services and their parameters will be observed. Their knowledge on the definitions of palliative care will be assessed. In looking at their beliefs, their views on the development and progression of care will be noted. We will also focus on whether these services
adequately meet patients’ priorities and needs.

We hypothesize that patients’ understanding of palliative care will largely be limited. Given the extensive development on such care in Hong Kong, we predict that the levels of satisfaction in services and care will be high. Furthermore, we foresee a negative relationship between the number and severity of symptoms experienced as well as patient satisfaction.

The outcome of the study is to gain a better understanding of the nature of palliative care services offered in a local setting as seen from the perspective of patients. Such information is used to evaluate the current quality of palliative care services and whether the system required any improvement. Ultimately, this culminates in an overall analysis that may be used for future evaluation and development of palliative care in this specific region in Hong Kong.

Methods

Participants and setting

The present analysis was performed as an observational cross-sectional study. There were no comparison groups allocated, no medical products used, nor any interventions assigned.

Only patients fulfilling these inclusion criteria were included: (I) receiving palliative care services in an outpatient setting at HKQMHHC; (II) able to read, comprehend, and complete the questionnaire having given informed consent. Patients were excluded if they were under 18 years of age, if they were receiving terminal care and physically or mentally incapable to conduct the questionnaire study; and/or if they would be following up at centres and/or clusters for palliative care services other than at the HKQMHHC.

Patients were identified by their attendance at the outpatient clinic at HKQMHHC at the specified time period as stated below. After being approached and assessed for eligibility, they were then informed of the study and asked for informed consent for participation.

Study design

Supplementary details the English and Chinese versions of the questionnaire. The questionnaire consists of 29 questions divided into the following four sections: (A) patients’ backgrounds; (B) knowledge and perceptions of palliative care; (C) objective assessment of symptoms; and (D) attitudes, beliefs, and future direction.

(A) Patients’ backgrounds

Patients’ basic demographic characteristics including age and sex, as well as their experience with palliative care such as duration and frequency of visits to the hospice centre, were documented.

(B) Knowledge and perceptions of palliative care

Their knowledge was assessed by their understanding of which aspects of health palliative care targets. Regarding patient perceptions, they were asked when they thought palliative care should be initiated, as well as whether they believed palliative care was sufficient in Hong Kong.

(C) Objective assessment of symptoms

The Edmonton Symptom Assessment Scale (ESAS) was used to objectively assess patient symptoms (8). It assesses nine symptoms common in cancer patients including pain and nausea; the severity is rated from 0 to 10 on a numerical scale, with 0 being absence of symptom and 10 being that it is of the worst possible severity. This assessment tool was selected for its simplicity, convenience and usage in palliative care patients (9).

(D) Attitudes, beliefs, and future direction

Finally, their attitudes towards the various services offered at the HKQMHHC were evaluated on a scale of 0 to 10 with 0 being extremely inadequate and 10 being extremely adequate. Their priorities of services based on their needs and experiences were also recorded. Open-ended questions such as “What additional services or improvements would you like to see for palliative care at this hospice centre?” were asked to determine how development of palliative care may be shaped in the future.

Data collection

The study was conducted in form of a patient questionnaire. The period of data collection took place over 18 afternoon clinic sessions of Thursdays and Fridays from December 2017 to February 2018 at the HKQMHHC, which is under the Department of Clinical Oncology, Queen Mary Hospital.

Participation in the study consisted of the completion of a single paper-based questionnaire survey. No follow-up was necessary. The questionnaire was distributed to patients
and fulfilled either independently or with the assistance
of the investigators, depending on the patient’s personal
preference. Assistance by investigators denoted that the
investigator would read the questions aloud without any
additional interpretation, and mark down the patients’
verbal answers.

Data analysis
All completed questionnaires were included in analysis for
the study. Data was prospectively collected and inputted into
a standardised database, with statistical analysis performed
with SPSS (all data will be prospectively collected and input
into the IBM SPSS Statistics software package (version 23.0,
SPSS < INC, Chicago, IL, USA). Univariate analysis was
also conducted, and the distribution, proportion and central
tendencies were presented. Correlation was performed with
Pearson’s coefficient. Qualitative data was examined with
content analysis.

Ethical considerations
The study protocol was approved by the Institutional
Review Board of the University of Hong Kong/Hospital
Authority Hong Kong West Cluster. The IRB reference
number is UV17-437. No personal data was collected,
and patients’ status of anonymity was maintained. Only
authorised persons have access to the data, and the dataset
will be destroyed after 2 years.

Results
Patient demographics

Figure 1 shows a flow chart of the participant selection
process in this study. The sample size was 100 participants
with a response rate of 52.6%.

The most common cancer types were colorectal (25%),
lung (20%) and breast (9%) cancers. These trends are
consistent with the pattern of most common cancers in
Hong Kong (10). Fifty-one percent respondents had been
diagnosed with cancer for more than 5 years; 30% had
been diagnosed within 1 to 3 years. Slightly more than half
(51%) did not have concomitant medical illnesses, reflecting
previous good health (Table 1).

Sixty percent of respondents had received palliative
care at the HKQMHHC for less than 2 years, while 19%
had done so for more than 5 years. A majority (89%) had
regular follow-ups between once every month and once
every 3 months, suggesting that this is the usual follow-up
frequency at HKQMHHC. Eighty-three percent indicated
that the time taken for the referral process to the clinic
was within 3 months. In Figure 2 regarding respondents’
participation in various services offered, the two most
common were medical consultation (97%) and counselling services (58%). The rest of the services had less attendance: physical and mental development (16%), family grief counselling services (14%), education seminars (12%), other activities including Tai Chi classes and music therapy (4%).

**Patients’ knowledge and perceptions**

Upon asking respondents which needs they believed palliative care addresses, each respondent answered an average of 1.82 out of the 4 aspects (i.e., physical, psychological, social, and spiritual). Half were able to recognise two or more aspects of palliative care (Figure 3).

Eighty-seven percent of respondents were able to identify physical needs as a component of palliative care, followed by 51% for psychological needs. Social needs and spiritual needs were only picked by 20% and 24% respectively.

The majority of respondents (88%) first heard of palliative care through doctor referral; only 9% had heard about it from family and friends, and 2% from the internet and media. Forty-nine respondents believed that palliative care should be initiated immediately after diagnosis, followed by 21% who believed that it should be started at the terminal stage of illness (Figure 4).

Nearly half the respondents believed that palliative care

<table>
<thead>
<tr>
<th>Table 1 Sample demographics (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics</td>
</tr>
<tr>
<td>Age, median [range], years</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Highest education level</td>
</tr>
<tr>
<td>Less than primary</td>
</tr>
<tr>
<td>Primary</td>
</tr>
<tr>
<td>Secondary</td>
</tr>
<tr>
<td>Tertiary or above</td>
</tr>
<tr>
<td>Missing data</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Chinese</td>
</tr>
<tr>
<td>Others: Caucasian-Chinese</td>
</tr>
<tr>
<td>Religious Belief</td>
</tr>
<tr>
<td>No religion</td>
</tr>
<tr>
<td>Christianity</td>
</tr>
<tr>
<td>Catholicism</td>
</tr>
<tr>
<td>Buddhism</td>
</tr>
<tr>
<td>Others: Islam, Chinese Folk Religion</td>
</tr>
<tr>
<td>Oncological unit attended (patients may be more than one)</td>
</tr>
<tr>
<td>Queen Mary Hospital</td>
</tr>
<tr>
<td>Ruttonjee Hospital</td>
</tr>
<tr>
<td>Tung Wah Hospital</td>
</tr>
<tr>
<td>Pamela Youde Nethersole Eastern Hospital</td>
</tr>
<tr>
<td>Tuen Mun Hospital</td>
</tr>
<tr>
<td>Hong Kong Sanatorium &amp; Hospital</td>
</tr>
<tr>
<td>St. Paul Hospital</td>
</tr>
<tr>
<td>Private Clinics</td>
</tr>
<tr>
<td>Ongoing oncological treatment?</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Missing data</td>
</tr>
</tbody>
</table>

Figure 2 Participation in various services offered by HKQMHHC. HKQMHHC, Hong Kong Queen Mary Hospital Hospice Centre.
is sufficient in Hong Kong, while 38% felt that it is not. Table 2 summarises their reasons for this inadequacy.

**Objective assessment of patients’ symptoms**

Based on the ESAS, respondents were asked to score various symptoms experienced in the past 24 hours from 0 to 10, with 0 being no symptom experienced and 10 being most severe. Table 3 shows the average score and score distribution for each symptom. The average score for tiredness was the highest (2.80), followed by poor feeling of wellbeing (2.49), and poor appetite (2.27).

**Patients’ attitudes, beliefs, and future directions**

As shown in Table 4, respondents were asked how adequately various aspects of palliative care met their needs on a scale from 0 (extremely inadequate) to 10 (extremely adequate) to reflect their attitudes. Overall, the mean scores for all aspects were over 8. In particular, the aspects of “Staff and healthcare professionals in palliative care” and “Environment and atmosphere of the hospice centre” scored the highest with averages of 8.87 and 8.86, respectively; “Location and convenience of access” had the poorest result. Furthermore, 83% respondents agreed that there is an adequate range of services offered at HKQMHHC.

Table 5 illustrates the features most enjoyed by respondents; the most common responses were the staff

### Table 3 Mean, median, and interquartile ranges of scores of symptoms (n=100)

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Median</th>
<th>Interquartile range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>2.01</td>
<td>2.81</td>
<td>0.00</td>
<td>4.00</td>
</tr>
<tr>
<td>Tired</td>
<td>2.80</td>
<td>2.92</td>
<td>2.00</td>
<td>5.00</td>
</tr>
<tr>
<td>Nauseated</td>
<td>0.560</td>
<td>1.65</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Depressed</td>
<td>1.10</td>
<td>2.20</td>
<td>0.00</td>
<td>1.03</td>
</tr>
<tr>
<td>Anxious</td>
<td>1.27</td>
<td>2.55</td>
<td>0.00</td>
<td>1.07</td>
</tr>
<tr>
<td>Drowsy</td>
<td>0.62</td>
<td>1.55</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Appetite</td>
<td>2.27</td>
<td>2.69</td>
<td>1.50</td>
<td>4.00</td>
</tr>
<tr>
<td>Poor feeling of wellbeing</td>
<td>2.49</td>
<td>2.45</td>
<td>2.00</td>
<td>4.00</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1.34</td>
<td>2.34</td>
<td>0.00</td>
<td>2.25</td>
</tr>
</tbody>
</table>

### Table 2 Reasons for why palliative care is inadequate in Hong Kong

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Frequency (n=41)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient education and promotion on palliative care</td>
<td>8</td>
</tr>
<tr>
<td>Insufficient number of hospice centres</td>
<td>6</td>
</tr>
<tr>
<td>Insufficient resources at hospice centres</td>
<td>3</td>
</tr>
<tr>
<td>Insufficient variety of palliative care services</td>
<td>3</td>
</tr>
<tr>
<td>Long waiting hours</td>
<td>1</td>
</tr>
<tr>
<td>Insufficient patient contact with healthcare professionals</td>
<td>1</td>
</tr>
<tr>
<td>No comment</td>
<td>19</td>
</tr>
</tbody>
</table>
members and their counselling, the positive atmosphere and environment of the centre, and the quality of medical consultations. When asked for suggestions for improvement, 65% expressed that there were no further areas of improvement needed; the suggestions are shown in Table 6.

The services offered at HKQMHHC can be expressed as 7 different categories; respondents were asked to prioritise these categories. Figure 5 illustrated the categories which the patient placed as rank one. Majority (85%) placed ‘Medical consultation/symptom control’ as their first priority, followed by ‘Psychosocial counselling’ (9%). Other services were considered less important. Regarding respondents’ preferred form of palliative care service, majority (80%) favoured outpatient services, followed by inpatient (11%) and home visits (9%).

Correlation between symptom intensity and satisfaction for services

In examining possible correlations between factors that were assessed as shown in Table 7, a negative association with a Pearson correlation coefficient of −0.197 (P<0.05) was found between the overall extent of symptoms experienced by patients (i.e., the number and severity of symptoms experienced) and their satisfaction towards services provided.

Discussion

This analysis in a cohort of outpatients receiving palliative

Table 4 Ratings of aspects of care at HKQMHHC

<table>
<thead>
<tr>
<th>Aspects of care by HKQMHHC</th>
<th>Mean score (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative outpatient service</td>
<td>8.61 (8.38–8.38)</td>
</tr>
<tr>
<td>Staff and healthcare professionals in palliative care</td>
<td>8.87 (8.66–9.08)</td>
</tr>
<tr>
<td>Frequency and interval of follow-up arrangements</td>
<td>8.21 (7.90–8.52)</td>
</tr>
<tr>
<td>Location and convenience of access</td>
<td>8.09 (7.75–8.43)</td>
</tr>
<tr>
<td>Resources and facilities at the hospice centre</td>
<td>8.46 (8.18–8.74)</td>
</tr>
<tr>
<td>Environment and atmosphere of the hospice centre</td>
<td>8.66 (8.66–9.06)</td>
</tr>
</tbody>
</table>

HKQMHHC, Hong Kong Queen Mary Hospital Hospice Centre.

Table 5 Features of palliative care most enjoyed

<table>
<thead>
<tr>
<th>Features of palliative care</th>
<th>Frequency (n=104)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff members and their patient counselling</td>
<td>28</td>
</tr>
<tr>
<td>Atmosphere and environment</td>
<td>23</td>
</tr>
<tr>
<td>Medical consultations</td>
<td>16</td>
</tr>
<tr>
<td>Course and facilities</td>
<td>5</td>
</tr>
<tr>
<td>Home visiting</td>
<td>1</td>
</tr>
<tr>
<td>Short waiting time</td>
<td>1</td>
</tr>
<tr>
<td>All features (did not specify)</td>
<td>4</td>
</tr>
<tr>
<td>No comment</td>
<td>26</td>
</tr>
</tbody>
</table>

Table 6 Suggestions for improvement

<table>
<thead>
<tr>
<th>Suggestions</th>
<th>Frequency (n=107)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce waiting time</td>
<td>7</td>
</tr>
<tr>
<td>Expand and improve the facilities of the centre</td>
<td>5</td>
</tr>
<tr>
<td>Increase the number of staff members available</td>
<td>5</td>
</tr>
<tr>
<td>Improve the quality of the medical consultations</td>
<td>5</td>
</tr>
<tr>
<td>Expand variety of current courses (excluding medical consultations)</td>
<td>4</td>
</tr>
<tr>
<td>Improve counselling services</td>
<td>3</td>
</tr>
<tr>
<td>Increase frequency of follow-up sessions</td>
<td>2</td>
</tr>
<tr>
<td>Provide allied health services</td>
<td>2</td>
</tr>
<tr>
<td>Decrease frequency of follow-up sessions</td>
<td>1</td>
</tr>
<tr>
<td>Provide transportation arrangement to the centre</td>
<td>1</td>
</tr>
<tr>
<td>Provide traditional Chinese medicine services</td>
<td>1</td>
</tr>
<tr>
<td>Increase promotion of palliative care</td>
<td>1</td>
</tr>
<tr>
<td>No suggestions for improvement</td>
<td>70</td>
</tr>
</tbody>
</table>

§ denotes that some respondents had multiple comments.

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care at the HKQMHHC suggested that while patients held generally positive attitudes and perceptions of palliative care, their rather limited knowledge of this topic may have potentially restricted their perspectives to a largely superficial level as most viewed palliative care to be simply targeting physical health with medical consultations. As such, the addition of components such as accessibility and education to Hong Kong’s current system of palliative care are crucial in the betterment of such services for patients.

Patient perceptions towards palliative care

Patients’ attitudes, as shown by their rating of the components of palliative care at HKQMHHC, were extremely positive. All mean scores were over 8, indicating that patients were generally very satisfied. Even the lowest-scoring category, “Location and convenience of access”, had a score of 8.09, with realistic suggestions for improvement concerning increasing the number of hospice centres around Hong Kong and arranging alternative transportation for patients. In interviews, many patients noted the high quality of staff and peaceful, soothing environment; indirectly, such positive aspects may also have favourable effects on patients’ psychosocial state, particularly for those under stress from their health. Furthermore, a striking majority of patients were satisfied with the range of services offered, and half expressed no further improvements needed, which suggests that patients’ needs are met.

Regarding patient perceptions of palliative care, there was a majority of 87% of respondents who identified physical needs as a component of palliative care, indicating that there is great priority placed on bettering patients’ physical wellbeing. On the other hand, only 20% and 24% selected social and spiritual needs respectively, this suggests that there may be lesser priority placed on the latter two aspects, perhaps owing to a lack of awareness on these often-underrated parts of palliative care.

Patients’ knowledge and expectations

The demographics and experiences of this population sample may be linked to their attitudes and perceptions. The large majority of respondents remarked that they had only found out about palliative care from their oncologist who had informed them that the next follow-up session would be at HKQMHHC. During this referral process, there may also have been insufficient explanations to patients on palliative care. These factors could have largely set the tone for patients to view this palliative care centre as a place for regularly monitoring their physical health instead of as one to help cope with all aspects of illness, not just physical. Furthermore, most respondents had already finished their active treatments and were in a stable condition. As such, most did not have active symptoms according to the ESAS, further supporting the idea that their visits to HKQMHHC were purely seen as standard follow-up procedure.

Diversity of palliative services

While there was a high participation rate for medical consultations and counselling services, there were smaller turnouts for other non-medical palliative care services, such as educational and spiritual talks, art workshops, and group outings. As many respondents were of relatively stable health, there may have been less urgency for them...
to learn about or tend to other aspects of health that palliative care includes. For those who were aware of such services, their non-participation may have been due to several reasons: some respondents expressed they already had adequate social support, some could not participate due to work obligations or inconvenience of time and location. Therefore, of the diverse range of services that HKQMHHC, medical consultation and counselling services had the most participation; it is noted the latter is often initiated by staff at the clinic.

**Patients’ symptom intensity**

From the ESAS, there was only a small number of patients who had experienced each symptom. As such, the effect of palliative care on symptom management was difficult to determine given the small sample size. There are multiple potential reasons for this phenomenon: (I) patients may already be in a stable state of health, thereby improvements in symptoms from palliative care services may be negligent; (II) palliative care aims to improve illness in the long run; as the ESAS only assesses symptoms active in the past 24 hours, any changes in patient symptoms may not be seen in such a short time period. Nevertheless, external literature has demonstrated vastly improved outcomes associated with outpatient palliative care not only in physical outcomes but also in psychosocial symptoms and quality of life (11-13).

**Palliative care service model**

The Strategic Service Framework for Palliative Care recently published in 2018 by the Hospital Authority points out four key directions for future development in Hong Kong, which are primarily in line with this study’s results (6). One of the directions is to “Enhance palliative care in the ambulatory and community settings to support patients and reduce unnecessary hospitalization” (6). Given respondents’ attitudes and suggestions for improvement of waiting times and location, progress in this area could greatly target their concerns, especially through expansion of palliative care support to elderly homes and community centres by NGOs and other support groups. Another direction is to “Strengthen performance monitoring for continuous quality improvement” (6), which has been demonstrated by this very study in examining patient perspectives; this may be further expanded to include patients from other clusters for a more well-rounded view. Finally, the generally positive attitudes that patients hold towards HKQMHHC largely support the remaining two directions of the framework, which are to “Enhance governance by developing cluster-based services with the collaboration of medical and oncology palliative care specialists” as well as to “Promote collaboration between palliative care and non-palliative care specialists through shared care model according to patients’ needs” (6). Since patients feel positively about the services currently being offered, this may be a favourable sign for palliative care to be expanded to various hospitals in different clusters, as well as non-oncological patients. Such care could also be integrated at the early stages of illness which is in line with patients’ desires for earlier initiation of palliative care.

**Correlation between symptom intensity and satisfaction for services**

Additionally, the newfound discovery of the relationship between extent of symptoms experienced and patients’ satisfaction towards services provided is a new direction for future study. These two components are crucial aspects to consider for patient care and can be further explored, such as whether satisfaction of services provided may causally improve their symptoms experienced. If there is a causal relationship present, this may support policies with greater emphasis on the provision of high-quality services for symptom alleviation in order to achieve a better clinical outcome.

**Future directions for palliative care in Hong Kong**

The findings from this study have reflected a need for patients to explore other aspects of palliative care apart from simply physical needs. From interviewing the outpatients at HKQMHHC, many reflected their wishes to expand the horizons of palliative care; specifically, of the patients who felt that palliative care was inadequate in Hong Kong, the most common reason given was “Inadequate education and promotion”. As well, accessibility to palliative care services is currently quite limited as they are only offered to oncological patients. Therefore, the components of education and accessibility are proposed as additions to the current model of palliative care in Hong Kong as illustrated in Figure 6.

Considering the WHO model of palliative care, the following specific improvements are suggested to further enhance palliative care; their positions in the model are shown in Figure 7:

- More comprehensive and accessible promotion and
education within the greater community, via means such as social media;

- Increased coverage of palliative care centres, such as more outpatient satellite clinics in each cluster to facilitate convenience of access to patients;
- Continued spectrum of services aside from medical consultation, such as psychosocial counselling, health education discussions, and group therapy activities.

**Study strengths and limitations**

One of the greatest strengths of this study was the collection of both objective and subjective feedback from individual patients through the questionnaire survey, which allowed more comprehensive review of patients’ perspectives. Additionally, this topic has not been explored sufficiently for this population and setting, and so the study's findings may prove to be useful for future health developments in Hong Kong.

Retrospectively, there were multiple limitations to the study. Selection bias was potentially introduced by the location and the specific time periods of data collection. Data collection took place during the 18 afternoon clinic sessions on Thursdays and Fridays at the HKQMHHC. The limited time periods at only one of the eight clinics offering palliative care may not accurately reflect the views of the entire population of patients in Hong Kong. In the future, both outpatients and inpatients may be considered for participation to reflect the different types of patients receiving palliative care. More diverse time periods at multiple centres offering such care could be used for data collection. Additionally, there may have been potential recall and reporting biases by participants. Although it was clarified that this study was performed independently to the clinic, patients may not have been accurately reflected their perspectives, regardless of whether this was intentional or not, such as understating or omitting complaints about the centre's palliative care services. Furthermore, some patients had limited understanding of their own medical history, which may have resulted in further inaccuracies in the data. To improve, investigators may consider cross-checking each participant’s electronic patient record to ascertain basic patient profile.

**Conclusions**

In conclusion, this study has shown that a great majority of outpatients currently receiving palliative care perceive the physical aspect of care, including medical consultations, to be the most important; they also have highly positive attitudes towards the services experienced. Patients’ lack of comprehensive understanding towards the definition and goals of palliative care may be attributed to the lack of promotional and educational activities through accessible means such as social media. As such, the newly proposed palliative care model has incorporated the aspects of accessibility and education, as well as the early introduction of comprehensive care such as psychosocial counselling and physical and mental activities, as essential parts of palliative care.
care to better help patients cope with illness.

Acknowledgments

We would like to acknowledge the Department of Clinical Oncology, Queen Mary Hospital, for their kind permission to conduct the study in the Queen Mary Hospital Hospice Centre. We also acknowledge the staff from the Queen Mary Hospital Hospice Centre for their kind assistance during the data collection process at the centre. We acknowledge Mr. John Fong for his assistance in statistical data processing. Last but not least, we extend thanks to Dr. Michael Ni, Dr. Felix Cheung and Mr. Eric Chen from the School of Public Health for their advice and support.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study protocol was approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster. The IRB reference number is UV17-437.

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Supplement A: Questionnaire (English version)

Questionnaire on the Attitudes and Perceptions of Outpatients Towards Palliative Care at the Hong Kong Queen Mary Hospital Hospice Centre

A. Patient Background
   i. Demographics
      1. What is your age? ___________ years

      2. What is your sex?
         □ Male
         □ Female

      3. What is your highest level of education?
         □ Primary school
         □ Secondary school
         □ Tertiary school
         □ Prefer not to disclose

      4. What is your ethnicity?
         □ Chinese
         □ Pakistani
         □ Indonesian
         □ Nepalese
         □ Filipino
         □ Thai
         □ White
         □ Other (please specify): ___________
         □ Indian
         □ Prefer not to disclose

      5. What is your religion?
         □ No religion
         □ Buddhism
         □ Christianity
         □ Other (please specify): ___________
         □ Catholicism
         □ Prefer not to disclose

      6. Which hospital do you normally attend for oncological (cancer-related) services?
         ______________________________________

      7. Are you currently receiving active cancer therapy (e.g. chemotherapy, radiation therapy)?
         □ Yes
         If so, what type of therapy are you receiving? ___________
         □ No
ii. Experience with Palliative Care

1. What cancer type have you been diagnosed with?

2. How long have you been diagnosed with this type of cancer?
   - [ ] 0 to <1 years
   - [ ] 1 to <2 years
   - [ ] 2 to <3 years
   - [ ] 3 to <4 years
   - [ ] 4 to <5 years
   - [ ] 5+ years

3. What other medical conditions have you been diagnosed with, if any?

4. How long have you been receiving palliative care at the Queen Mary Hospital Hospice Centre?
   - [ ] 0 to <1 years
   - [ ] 1 to <2 years
   - [ ] 2 to <3 years
   - [ ] 3 to <4 years
   - [ ] 4 to <5 years
   - [ ] 5+ years

5. How often do you visit this hospice centre to receive palliative care treatment?
   - [ ] More than once a week
   - [ ] Once a week
   - [ ] Once every two weeks
   - [ ] Once a month
   - [ ] Less than once a month

6. What palliative care services have you received at this hospice centre? Please tick all that apply.
   - [ ] Medical Consultation
   - [ ] Activities for physical and mental development
   - [ ] Education seminars
   - [ ] Counselling
   - [ ] Family grief counselling
   - [ ] Others (please specify): ________________________________

7. Have you received prior palliative care services at other hospice centres?
   - [ ] Yes, at ___________________________ for _______ months
   - [ ] No
8. How long did the referral process take, from the first referral made to the first appointment at this hospice centre?
   - < 1 month
   - 1 to < 3 months
   - 3 to < 6 months
   - 6+ months

B. Knowledge and Perceptions of Palliative Care
   1. Based on your understanding, which of the following should palliative care address?
      Please tick all that apply.
      - Physical needs
      - Psychological needs
      - Social needs
      - Spiritual needs

   2. How did you first hear of palliative care?
      - Medical referral
      - Family and/or friends
      - Internet/ Media
      - Others (please specify): ____________________________

   3. When do you feel that cancer patients should start receiving palliative care?
      - Immediately after diagnosis
      - After the start of treatment or therapy
      - At the terminal stage of illness
      - At any time the patient desires

   4. Do you feel that palliative care is sufficient in Hong Kong?
      - Yes
      - No
      Please briefly explain your answer: ________________________
      ________________________
C. Objective Assessment of Symptoms

*Based on the Edmonton Symptom Assessment System*

1. Please circle the number that best describes the symptoms in the last 24 hours:

   (i) No pain
       0 1 2 3 4 5 6 7 8 9 10  Worst possible pain

   (ii) Not tired
        0 1 2 3 4 5 6 7 8 9 10  Worst possible tiredness

   (iii) Not nauseated
          0 1 2 3 4 5 6 7 8 9 10  Worst possible nausea

   (iv) Not depressed
       0 1 2 3 4 5 6 7 8 9 10  Worst possible depression

   (v) Not anxious
       0 1 2 3 4 5 6 7 8 9 10  Worst possible anxiety

   (vi) Not drowsy
       0 1 2 3 4 5 6 7 8 9 10  Worst possible drowsiness

   (vii) Best appetite
         0 1 2 3 4 5 6 7 8 9 10  Worst possible appetite

   (viii) Best feeling of wellbeing
          0 1 2 3 4 5 6 7 8 9 10  Worst possible feeling of wellbeing

   (ix) No shortness of breath
        0 1 2 3 4 5 6 7 8 9 10  Worst possible shortness of breath

   (x) Others: No problem
        0 1 2 3 4 5 6 7 8 9 10  Worst possible problem

        Please describe:
2. How has palliative care improved your symptoms, with 1 being no change at all and 10 being complete improvement of symptoms (please select N/A if you have not experienced this symptom)?

(i) Pain

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(ii) Tiredness

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(iii) Nausea

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(v) Anxiety

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(vi) Drowsiness

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(viii) Feeling of wellbeing

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(ix) Shortness of breath

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(x) Others (please specify): ____________________________

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D. Attitudes, Beliefs and Future Direction

1. On a scale of 1-10, with 1 being extremely inadequate and 10 being extremely adequate, how do you feel the following aspects are in terms of adequacy to your needs?

   (i) Palliative outpatient service
       0 1 2 3 4 5 6 7 8 9 10

   (ii) Staff and healthcare professionals in palliative care
        0 1 2 3 4 5 6 7 8 9 10

   (iii) Frequency and interval of follow-up arrangements
        0 1 2 3 4 5 6 7 8 9 10

   (iv) Location and convenience of access
        0 1 2 3 4 5 6 7 8 9 10

   (v) Resources and facilities at the hospice centre
        0 1 2 3 4 5 6 7 8 9 10

   (vi) Environment and atmosphere of the hospice centre
        0 1 2 3 4 5 6 7 8 9 10

2. How involved have your family and friends been during your experience with palliative care?

   Not involved at all  0 1 2 3 4 5 6 7 8 9 10 Extremely involved

3. Do you feel that that there is an adequate range of services offered at this hospice centre?
   ☐ Yes
   ☐ No
4. What do you enjoy most about the palliative care services offered at this hospice centre?

________________________________________________________________________

5. What additional services or improvements would you like to see for palliative care at this hospice centre?

________________________________________________________________________

6. Please rank from 1 to 7 (1 being the most important, 7 being the least important) the importance of the following service to you:

   ____ Medical consultation/symptom control
   ____ Group therapy activities e.g. art therapy
   ____ Health education/talks
   ____ Psychosocial counselling
   ____ Family grief counselling
   ____ Nursing advice to patients and carers
   ____ Spiritual/religious services

7. Please rank from 1 to 4 (1 being the most important, 4 being the least important) the importance of the following needs to you:

   ____ Physical (including pain and symptom relief)
   ____ Psychological (including stress and anxiety)
   ____ Social
   ____ Spiritual

8. What type of palliative care services would you most prefer to receive?

   [ ] Outpatient
   [ ] Inpatient
   [ ] Home visits

End of questionnaire, thank you for your time!
香港瑪麗醫院寧養中心門診部病人對紓緩治療的態度與認知的統計研究問卷

甲. 受訪者背景及經歷

1. 請問您的年齡是什麼？
   ○ 写入您的歲數

2. 性別：
   ○ 男
   ○ 女

3. 您的教育程度是：
   ○ 小學程度
   ○ 中學程度
   ○ 高等教育程度
   ○ 不願意透露

4. 您的種族是：
   ○ 中國人
   ○ 巴基斯坦人
   ○ 印尼人
   ○ 馬爾代夫人
   ○ 菲律賓人
   ○ 泰國人
   ○ 白人
   ○ 印度人
   ○ 其他 (請註明)：

5. 您的宗教背景是：
   ○ 無宗教信仰
   ○ 基督教
   ○ 天主教
   ○ 佛教
   ○ 其他 (請註明)：

6. 您平時會前往哪間醫院的癌症治療中心接受治療？
   写入您的醫院名稱

7. 您是否正接受癌症主動或干預性治療（例如：化療、電療等）？
   ○ 是
   請註明治療種類：
   ○ 否
ii. 有關舒緩治療的經歷
1. 請問您被確診哪一種癌症？

2. 您是何時被確診這種癌症？

   □ 少於 1 年
   □ 1 至少於 2 年
   □ 2 至少於 3 年
   □ 3 至少於 4 年
   □ 4 至少於 5 年
   □ 超過 5 年

3. 您有沒有同時被確診患上其他疾病？如有，請註明。

4. 您在香港瑪麗醫院寧養中心接受了舒緩治療多久？

   □ 少於 1 年
   □ 1 至少於 3 個月
   □ 3 至少於 6 個月
   □ 6 個月至少於 1 年
   □ 超過 1 年

5. 您有多常前往這家寧養中心接受治療？

   □ 每週超過 1 次
   □ 每周 1 次
   □ 每兩週 1 次
   □ 每月 1 次
   □ 每 1 至 2 個月 1 次
   □ 每 2 個月 1 次
   □ 每 3 個月 1 次
   □ 每 6 個月 1 次
   □ 每年 1 次
   □ 少於每年 1 次

6. 您在這家寧養中心接受了什麼服務（可選多項）？

   □ 醫學諮詢／治療
   □ 發展身心活動
   □ 教學講座
   □ 心理輔導
   □ 親屬心理輔導
   □ 其他 (請註明): ___________________________
7. 您之前有沒有在其他地方接受過舒緩治療？

□ 有
在：________________________
多久：______月

□ 沒有

8. 您的個案轉介過程（由初次轉介起直至首次前往療養中心應診）需時多久？

□ 少於1個月
□ 1至3個月
□ 3至6個月
□ 超過6個月

乙. 有關舒緩治療的知識及看法

1. 根據您的理解，舒緩治療應該針對（可選多項）：

□ 身體及生理問題
□ 心理問題
□ 社會問題
□ 心靈問題

2. 請問您是從甚麼途徑認識舒緩治療？

□ 醫護人員轉介
□ 家人或朋友介紹
□ 網上或媒體
□ 其他（請註明）：________________________

3. 您認為癌症病人應該何時開始接受舒緩治療？

□ 在確診癌症後
□ 在開始接受任何治療時
□ 在病人癌症末期時
□ 按照病人意願的任何時候

4. 您認為香港的舒緩治療服務是否足夠？

□ 足夠
□ 不足夠

請簡單解釋：__________________________________________

__________________________________________
丙. 症狀評估
根據 Edmonton Symptom Assessment System

1. 請圈出您認為最貼合您最近 24 小時各方面症狀的選擇：

(i) 沒有痛楚  0  1  2  3  4  5  6  7  8  9  10  最強烈痛楚
(ii) 沒有疲累感  0  1  2  3  4  5  6  7  8  9  10  最嚴重疲累感
(iii) 沒有噁心  0  1  2  3  4  5  6  7  8  9  10  最嚴重噁心
(iv) 沒有憂鬱  0  1  2  3  4  5  6  7  8  9  10  最嚴重憂鬱
(v) 沒有緊張  0  1  2  3  4  5  6  7  8  9  10  最強烈緊張
(vi) 沒有頭暈  0  1  2  3  4  5  6  7  8  9  10  最強烈頭暈
(vii) 最佳胃口  0  1  2  3  4  5  6  7  8  9  10  最差胃口
(viii) 最佳生活質量的滿足感  0  1  2  3  4  5  6  7  8  9  10  最差生活質量的滿足感
(ix) 沒有呼吸困難  0  1  2  3  4  5  6  7  8  9  10  最嚴重呼吸困難
(x) 其他  沒有  0  1  2  3  4  5  6  7  8  9  10  最嚴重

請註明：
2. 請問舒緩治療能多大程度減輕您在以下症狀？（0 為最無效，10 為最有效，如果你並沒有出現該症狀，請選擇不適用）

(i) 痛楚
  不適用 0 1 2 3 4 5 6 7 8 9 10

(ii) 疲累感
  不適用 0 1 2 3 4 5 6 7 8 9 10

(iii) 噁心
  不適用 0 1 2 3 4 5 6 7 8 9 10

(iv) 憂鬱
  不適用 0 1 2 3 4 5 6 7 8 9 10

(v) 緊張
  不適用 0 1 2 3 4 5 6 7 8 9 10

(vi) 頭暈
  不適用 0 1 2 3 4 5 6 7 8 9 10

(vii) 胃口
  不適用 0 1 2 3 4 5 6 7 8 9 10

(viii) 生活質素的滿足感
  不適用 0 1 2 3 4 5 6 7 8 9 10

(ix) 呼吸困難
  不適用 0 1 2 3 4 5 6 7 8 9 10

(x) 其他 (請註明): __________________________
  不適用 0 1 2 3 4 5 6 7 8 9 10
丁．對於舒緩治療的態度、看法及未來發展方向

1. 由0至10，請您圈出能滿足您需要的數字（0為非常不滿意，10為非常滿意）。

(i) 養營中心門診服務
    0  1  2  3  4  5  6  7  8  9  10

(ii) 舒緩治療的醫護人員服務水平
    0  1  2  3  4  5  6  7  8  9  10

(iii) 覆診安排及頻密程度
    0  1  2  3  4  5  6  7  8  9  10

(iv) 養營中心的位置及便利程度
    0  1  2  3  4  5  6  7  8  9  10

(v) 養營中心內的設施及資源度
    0  1  2  3  4  5  6  7  8  9  10

(vi) 養營中心的環境及氣氛
    0  1  2  3  4  5  6  7  8  9  10

2. 在您的舒緩治療過程中，您的親人和朋友有多大程度參與其中？

沒有參與    0  1  2  3  4  5  6  7  8  9  10    總有參與

3. 您覺得養營中心所提供的服務種類足夠嗎？
   □足夠
   □不足夠

4. 您最滿意那一項由此中心提供的舒緩治療服務？
5. 作為舒緩治療服務的一部分，您認為此靈養中心有甚麼服務可以增添或改善的？

6. 請就以下七項舒緩治療服務的重要性排出先後次序（1 為最重要，7 為最次要）
   
   ____ 醫療諮詢及症狀管理
   ____ 小組療法活動（例如：藝術治療、音樂治療）
   ____ 健康教育及講座
   ____ 心理輔導
   ____ 家屬心理輔導
   ____ 病者及照顧病者之護理諮詢
   ____ 心靈或宗教服務

7. 請就您以下四方面需求的重要性排出先後次序？（1 為最重要，4 為最次要）

   ____ 身體及生理需要（痛楚及症狀緩解）
   ____ 心理需要（壓力及情緒緩解）
   ____ 社交需要
   ____ 心靈需要

8. 請問您最想選擇以下哪一種形式的舒緩治療服務？
   □ 童養中心門診服務
   □ 住院服務
   □ 家居探訪服務

問卷完，多謝您的參與!