

Supplement A: Questionnaire (English version)

Document: Questionnaire (Eng)

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
 Indonesian
 Filipino
 White
 Indian
 Pakistani
 Nepalese
 Thai
 Other (please specify): _____
 Prefer not to disclose

5. What is your religion?
 No religion
 Christianity
 Catholicism
 Buddhism
 Other (please specify): _____
 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?

- | | |
|--|--|
| <input type="checkbox"/> 0 to <1 years | <input type="checkbox"/> 3 to <4 years |
| <input type="checkbox"/> 1 to <2 years | <input type="checkbox"/> 4 to <5 years |
| <input type="checkbox"/> 2 to <3 years | <input type="checkbox"/> 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?

- | | |
|--|--|
| <input type="checkbox"/> 0 to <1 years | <input type="checkbox"/> 3 to <4 years |
| <input type="checkbox"/> 1 to <2 years | <input type="checkbox"/> 4 to <5 years |
| <input type="checkbox"/> 2 to <3 years | <input type="checkbox"/> 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

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (ii) Tiredness

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (iii) Nausea

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (iv) Depression

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (v) Anxiety

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (vi) Drowsiness

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (vii) Appetite

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (viii) Feeling of wellbeing

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (ix) Shortness of breath

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----
- (x) Others (please specify): _____

N/A	0	1	2	3	4	5	6	7	8	9	10
-----	---	---	---	---	---	---	---	---	---	---	----

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

i. 背景

1. 請問您的年齡是什麼？ _____ 歲
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
 印尼人
 菲律賓人
 白人
 印度人
 巴基斯坦人
 尼泊爾人
 泰國人
 其他 (請註明): _____
 不願意透露
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): _____
 不願意透露
6. 您平時會前往哪間醫院的癌症治療中心接受治療？

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. 有關紓緩治療的經歷

1. 請問您被確診哪一種癌症？

2. 您是何時被確診這種癌症？

- | | |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> 少於 1 年 | <input type="checkbox"/> 3 至少於 4 年 |
| <input type="checkbox"/> 1 至少於 2 年 | <input type="checkbox"/> 4 至少於 5 年 |
| <input type="checkbox"/> 2 至少於 3 年 | <input type="checkbox"/> 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紓緩治療多久？

- | | |
|--------------------------------------|------------------------------------|
| <input type="checkbox"/> 少於 1 年 | <input type="checkbox"/> 2 至少於 3 年 |
| <input type="checkbox"/> 1 至少於 3 個月 | <input type="checkbox"/> 3 至少於 4 年 |
| <input type="checkbox"/> 3 至少於 6 個月 | <input type="checkbox"/> 4 至少於 5 年 |
| <input type="checkbox"/> 6 個月至少於 1 年 | <input type="checkbox"/> 超過 5 年 |
| <input type="checkbox"/> 1 至少於 2 年 | |

5. 您有多常前往這家寧養中心接受治療？

- | | |
|---|-------------------------------------|
| <input type="checkbox"/> 每週超過 1 次 | <input type="checkbox"/> 每 2 個月 1 次 |
| <input type="checkbox"/> 每週 1 次 | <input type="checkbox"/> 每 3 個月 1 次 |
| <input type="checkbox"/> 每兩週 1 次 | <input type="checkbox"/> 每 6 個月 1 次 |
| <input type="checkbox"/> 每月 1 次 | <input type="checkbox"/> 每年 1 次 |
| <input type="checkbox"/> 每 1 至 2 個月 1 次 | <input type="checkbox"/> 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紓緩治療？

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寧養中心應診）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. 有關紓緩治療的知識及看法

1. 根據您的理解，紓緩治療應該針對（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紓緩治療？

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紓緩治療？

在確診癌症後

在開始接受任何治療時

在踏入癌症末期時

按照病人意願的任何時候

4. 您認為香港的紓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
素的滿足感 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 最差生活質
素的滿足感 |
| (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. 請問紓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. 對於紓緩治療的態度、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程度（0 為非常不滿意，10 為非常滿意）。

(i) 寧養中心門診服務

0 1 2 3 4 5 6 7 8 9 10

(ii) 紓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) 寧養中心的位置及便利程度

0 1 2 3 4 5 6 7 8 9 10

(v) 寧養中心內的設施及資源度

0 1 2 3 4 5 6 7 8 9 10

(vi) 寧養中心的環境及氣氛

0 1 2 3 4 5 6 7 8 9 10

2. 在您的紓緩治療過程中，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. 您覺得寧養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紓緩治療服務？

5. 作為紓緩治療服務的一部分，您認為此寧養中心有甚麼服務可以增添或改善的？

6. 請就以下七項紓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
- _____ 病者及照顧病者的護理諮詢
- _____ 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（痛楚及症狀紓緩）
- _____ 心理需要（壓力及情緒紓緩）
- _____ 社交需要
- _____ 心靈需要

8. 請問您最想選擇以下哪一種形式的紓緩治療服務？

- 寧養中心門診服務
- 住院服務
- 家居探訪服務

問卷完，多謝您的參與!