

Appendix 1 (as supplied by the authors): Study survey with FAMCARE questionnaire (adapted from Kristjanson LJ. Validity and reliability testing of the FAMCARE scale: measuring family satisfaction with advanced cancer care. *Soc Sci Med* 1993;36:693-701)



Palliative Symptom Management Clinic Care Survey

The purpose of this survey is to help improve the services provided by the Palliative Symptom Management Team located on the first floor of the cancer centre. Any information you give will be kept confidential. We are interested in your honest opinion; there is no right or wrong answer.

Please tell us a little about yourself:

1. Your age: _____ (in years)
2. Gender: Male OR Female
3. How are you related to the patient:
 Spouse
 Child
 Other (parent, sibling, friend) _____
4. Do any of YOUR children live at home: Yes No
5. What is your highest complete level of Education:
 Grade 8 (primary school)
 Grade 12 (high school)
 College or University
6. How often do you work:
 Do not work outside the home
 Part-time
 Full-time
 Retired

Please tell us a little about your loved one:

7. Age: _____ (in years)

8. Gender: Male OR Female

9. Cancer origin:

Gastrointestinal / bowels

Lung

Breast

Prostate

Other _____

10. Place of death:

Hospital

Home

Hospice

11. Thinking back on your loved ones journey, do you feel your loved one was referred to the symptom clinic:

Too early

Too late

At the right time

Think about the care your family member received then rate your level of satisfaction for each of the following:

	Very Dissatisfied	Dissatisfied	Undecided	Satisfied	Very Satisfied
12. The patient's pain relief	1	2	3	4	5
13. Information about the patient's prognosis	1	2	3	4	5
14. Answers from health professionals	1	2	3	4	5
15. Information given about side effects	1	2	3	4	5
16. Referrals to specialists	1	2	3	4	5
17. Availability of a hospital bed	1	2	3	4	5
18. Family conferences held to discuss the patient's illness	1	2	3	4	5



Think about the care your family member received then rate your level of satisfaction for each of the following:

	Very Dissatisfied	Dissatisfied	Undecided	Satisfied	Very Satisfied
19. Speed with which symptoms are treated	1	2	3	4	5
20. The palliative care team's attention to patient's description of symptoms	1	2	3	4	5
21. The way tests and treatments are performed	1	2	3	4	5
22. Availability of doctors to the family	1	2	3	4	5
23. Availability of nurses to the family	1	2	3	4	5
24. Coordination of care	1	2	3	4	5
25. Time required to make diagnosis	1	2	3	4	5
26. The way the family is included in treatments and care decisions	1	2	3	4	5
27. Information given about how to manage the patient's pain	1	2	3	4	5
28. Information given about the patient's tests	1	2	3	4	5
29. How thoroughly the palliative care team assesses the patient's symptoms	1	2	3	4	5
30. The way the tests and treatments are followed up by the palliative care team	1	2	3	4	5
31. Availability of the palliative care team to the patient	1	2	3	4	5

Think about the care your family member received then rate your level of satisfaction for each of the following:

	Very Dissatisfied	Dissatisfied	Undecided	Satisfied	Very Satisfied
32. Information about possible changes in your emotions	1	2	3	4	5
33. Timely referrals to social worker	1	2	3	4	5
34. Timely referral to dietician	1	2	3	4	5

Please use this space to add any other comments or suggestions you wish to share with the palliative care team...

Thank you for completing this questionnaire.