

Family satisfaction with the St. Michael's Palliative Care Unit, Lethbridge: What can we learn from implementing FAMCARE & FAMCARE-2?

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Introduction: In response to Accreditation Canada's recommendation, Covenant Health and the Edmonton Zone Palliative Care Program (EZPCP) have adopted the FAMCARE/FAMCARE-2 as a measure of family caregiver satisfaction of palliative care services. In Covenant Health, the palliative care unit at St. Michael's Hospital, Lethbridge, was the original pilot site in Alberta for the implementation of the FAMCARE in April 2010.

Background: The two main versions of the FAMCARE Scale are: FAMCARE and FAMCARE-2. FAMCARE has 20 questions, whereas FAMCARE-2 has 17 questions. FAMCARE-2 was developed for use in diverse palliative care settings, including acute care, hospice and home care, with both advanced cancer and non-cancer populations. FAMCARE-2 refers more to a team approach to palliative care, rather than focusing on doctors (primarily) and nurses, FAMCARE-2 makes reference to symptom management rather than pain management, and offers more response options.

Aim: The aim of this study was to describe and evaluate family caregiver satisfaction with tertiary palliative care and hospice services in the Lethbridge palliative care unit between April, 2010 and March, 2014..

Method: The FAMCARE tool (April 2010-March 2013) and FAMCARE-2 tool (April 2013-present) was mailed to the identified closest relative of the patient approx. 1 month after the patient's death. Since that time, there have been 571 deaths on the unit & 245 forms have been returned. The estimated response rate is 43% based on the assumption that the survey was mailed to the closest relative of every patient that dies on the unit. The tools instruct recipients to think about the care that their family member received and to answer the questions as being very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), very dissatisfied (VD), or not applicable (N/A). Each item is rated on a five point Likert scale, ranging from 1 (very satisfied) to 5 (very dissatisfied).

FAMCARE Results:

- 17/20 items were rated as S or VS by >75% of participants
- D or VD replies for each question never exceeded 4%
- 3 items with the lowest frequencies of positive responses :
- Q5 (referral to specialists, 63%)
- Q14 (time required to make a diagnosis, 70.3%)
- Q17 (information given about the patient's tests, 72%)
- For all 3 items, >19% of respondents left item blank or wrote N/A, & <1.5% were dissatisfied (i.e. D & VD combined)
- Average subscale scores ranged from 1.3 (availability of care) to 1.5 (physical patient care)

FAMCARE-2 Results:

- Overall, frequencies of satisfied (S or VS) responses for all 17 FAMCARE-2 items were higher than for FAMCARE
- All items were rated as S or VS by >75% of participants
- 3 items with the lowest frequencies of positive responses:
- Q11 (practical assistance, 78.5%)

- Q3 (information about side effects, 78.6%)
- Q5 (meetings with palliative care team, 83.9%)
- Average subscale scores ranged from 1.3 (physical symptoms and comfort, family support, patient psychological care) to 1.4 (provision of information)

Discussion & Conclusions:

- The reported level of family satisfaction is high, despite the generally high level of symptom and psychosocial distress in patients admitted
- The FAMCARE/FAMCARE-2 tool may be capturing health experiences prior to the patient being in the unit
- The results also point us towards areas in which we can improve
- Results show that the FAMCARE-2 questions are generally more applicable than the questions in the FAMCARE survey
- There is generally a higher level of N/A and blank responses for the FAMCARE compared to the FAMCARE-2; this is related to the applicability of the questions
- In the future, qualitative data will be analyzed to gain further insights into areas of improvement