



FAMCARE and FAMCARE-2 Guidelines for Use

Developed by the Edmonton Zone Palliative Care Program

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1. 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. The tool was subsequently piloted on the tertiary palliative care unit (TPCU) at the Grey Nuns Community Hospital, Edmonton, in August, 2010, for a one-month trial period. It was implemented on the TPCU in January, 2011, as part of routine clinical practice.

In June, 2012, the Edmonton Zone Palliative Care Program Council adopted the FAMCARE-2 for use on the TPCU (Grey Nuns Community Hospital) and hospice sites in Edmonton. The Covenant Health palliative care units in Lethbridge and Medicine Hat will be adopting the FAMCARE-2 in January 2013.

This document was developed to support the implementation of the FAMCARE/FAMCARE-2 in the EZPCP and Covenant Health, by providing an evidence-based overview of the tools.

2. Background

The FAMCARE Scale is used to measure family satisfaction with care of patients with advanced cancer. The tool was originally developed for use on inpatient units, measuring different areas of care such as availability of care, physical patient care, psychosocial care and information giving. The original scale is a "20 item Likert-type scale measuring the degree to which family members are content with the health care provider behaviors directed toward the patient and themselves" (Kristjanson, 1993, p. 696). The FAMCARE Scale can be given to family members while a patient is receiving palliative care or at some point after a patient's death. Validity evidence for the tool has been gathered in a number of different settings, including inpatient units, outpatient cancer clinics and home care. It is used in such places as North America, Australia and Europe.

3. <u>Versions</u>

There are currently two main versions of the FAMCARE Scale: FAMCARE and FAMCARE-2. FAMCARE has 20 questions, whereas FAMCARE-2 has 17 questions (see Appendix A). The 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.

For the FAMCARE-2, "items now refer to services delivered by palliative care teams rather than a doctor or a nurse, and items refer to symptom management rather than pain management alone. Four of the original items that refer to care by a doctor or a nurse were combined into two, and three other questions were added: family responses about their emotional wellbeing; access to practical care assistance; and an ability to comment on their perceptions about the way the care team attended to the patient's need for dignity. A new response option was also added for all 17 questions in the FAMCARE-2 version: 'Not relevant to my situation'" (Aoun et al., 2010, p. 675).

There are other versions available as well:

- FAMCARE-6 which was developed as a "short instrument suitable for computerized administration in the clinical setting" (Carter, 2011, p. 565) (see Appendix A)
- FAMCARE-C19 which omitted the item "time required to make a diagnosis," as "Ringdal and colleagues found this item to be poorly associated with the other FAMCARE items in their validation study" (Lo, Burman, Hales, et al, 2009, p. 3184)
- other adapted scales for family members (Fernandes et al., 2010).

There have also been versions created for the patients:

- FAMCARE-P13 (Lo, Burman, Hales, et al, 2009)
- FAMCARE-P16 (Lo, Burman, Rodin, et al, 2009)
- an unnamed version (Follwell et al., 2009)

Should I use the FAMCARE or FAMCARE-2?

The FAMCARE-2 is shorter and more concise than the FAMCARE. FAMCARE-2 refers more to a team approach to palliative care, rather than focusing on doctors (primarily) and nurses. FAMCARE-2 makes reference to more symptoms than pain alone and offers more response options. The FAMCARE was specifically developed for care of patients with advanced cancer, while the FAMCARE-2 was extended for use in palliative care settings. Further validity evidence is needed for the use of either tool in specific palliative conditions, such as end stage organ failure and neurodegenerative diseases.

4. Translations

FAMCARE is available in English, Turkish (Can et al., 2011), and Marathi (Duraisamy, unpublished). FAMCARE-2 is available in English and Swedish (Klarare, unpublished). A formal translation process (e.g. forward and back translation) was used for these translations. Translations into German, Swedish, Dutch (Aoun, personal communication) and Arabic (Klarare, personal communication) are currently in progress. The availability of translated versions allows the scales to be used in different places around the world.

5. How to Administer

The FAMCARE and FAMCARE-2 tools were originally developed for administration to family members while a patient received palliative care services. However, either tool can be administered to family caregivers while the patient is still alive or after the patient is deceased. Family members can complete either tool in an interview setting (Hwang et al., 2003, p. 321) or independently (Carter et al., 2011, p. 567). Many scales such as the FAMCARE are sent in the

http://www.asco.org/ascov2/Meetings/Abstracts?&vmview=abst_detail_view&confID=74&abstractID=53 500.

http://www.stockholmssjukhem.se/Documents/SPN/Translating%20and%20Culturally%20Adapting%20the%20FAMCARE-2%20scale%20for%20use%20in%20Sweden%20Back-translation%20Relevance-%20Anna%20Klarare.pdf.

¹Retrieved from

²Retrieved from

mail and returned by the family caregiver once completed (Ringdal et al., 2002, p. 55). Informal training can be given to staff on how to administer the scale.

In the EZPCP and Covenant Health in-patient palliative care sites, the FAMCARE/FAMCARE-2 is mailed to family caregivers approximately one to two months after a patient's death. Completed surveys are returned by mail to the palliative care sites.

6. How to Interpret

Each FAMCARE/FAMCARE-2 item is a five-point Likert-scale with the following responses: very satisfied, satisfied, undecided, dissatisfied and very dissatisfied. Family caregivers may decide that a question is not applicable and/or they may choose not to answer some questions. In the FAMCARE-2, family members can select an additional option, "not relevant to my situation." The formal scoring system of the FAMCARE/FAMCARE-2 can be either using percent (satisfied or dissatisfied) or the mean score for each item depending how you are summarizing the information.

In the EZPCP and Covenant Health palliative care sites, an additional section has been added for family caregivers to provide comments (see Appendix A). If a family caregiver is very dissatisfied and if contact information is available, then it would be important for a staff member to contact the family caregiver to go over the issues experienced. It is important to receive this valuable information so changes can be made to how patients and their families receive care.

7. How to Report³

Reporting of the FAMCARE/FAMCARE-2 helps with care planning, care evaluation, and multiand inter-disciplinary team work. Follow up with family caregivers who provide contact information aids in future patient care. Accurate reporting in a format that is accessible and clear is, therefore, important.

There are some general principles that aid reporting of the FAMCARE/FAMCARE-2 scale to team members, such as:

- Avoiding the use of jargon
- Reporting back promptly
- Reporting briefly and accurately
- Being able to describe concrete examples of how reported information is influencing
 patient care as determined by family caregivers (when administered while a patient
 is still alive) and how information can be used to improve future care (when
 administered after a patient's death).

Different strategies can be used to help report the FAMCARE/FAMCARE-2 responses in a meaningful way to different audiences. This may involve using Excel databases visually depicting responses that have been collected. For clinical reporting in team meetings, it is useful to explain when the FAMCARE/FAMCARE-2 data were collected, any changes that have been

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³ Adapted from http://pos-pal.org/How-to-report.php"

noticed and the meaning of these changes to future patient care. Establishing regular FAMCARE/FAMCARE-2 review dates within clinical meetings can be helpful.

For quality assurance purposes, a summary of FAMCARE/FAMCARE-2 responses from multiple family caregivers can be reported. Personal identifiers are removed at the point of data entry and before reports are generated.

For research purposes, FAMCARE/FAMCARE-2 findings are presented at an aggregate level, removing personal identifiers, such as family caregiver names. Findings are published for wide dissemination.

8. How to Implement⁴

Clinicians are generally willing to use the FAMCARE/FAMCARE-2. However, there can be barriers to implementation or wider and sustained use. Implementation can be aided by:

- maintenance of confidentiality (of personal identifiers)
- aggregate reporting
- good communication on reasons the tool is useful
- a proactive approach that informs all team members about the implementation and rationale for use of the tool
- ensuring that the FAMCARE/FAMCARE-2 adds value to the work of individuals within the organization (for example, sharing how the FAMCARE/FAMCARE-2 contributes to future patient care)
- providing evidence-based recommendations and scientific papers that support why the tool should be implemented

There is no universal consensus regarding the best time frame to distribute the FAMCARE/FAMCARE-2 to family members after a patient's death. In a recent literature review of family caregiver satisfaction tools (Beaumont & Nekolaichuk, unpublished), the minimum time frame was approximately three months (mean = 3.504 months; median = 3 months), with a minimum range of one to 10 months.

9. Frequently Asked Questions

9.1 How and when is the main family caregiver for the patient identified?

There may be several ways to identify the main family caregiver, such as the "primary person responsible for the care of the patient" (Can et al., 2011, p. 1321), the closest family member (Ringdal et al., 2002, p. 54) or "the individual who is most involved in or affected by the patient's illness" (Hwang et al., 2003, p.320). The following is an example of a comprehensive definition: "the individual identified by the patient as the person most involved in the care of the patient. The relationship with the patient could be biological, legal, or functional" (Medigovich et al., 1999, p. 50).

If the FAMCARE/FAMCARE-2 is administered before a patient's death, then the patient can identify the family caregiver. Some patients may wish to identify several caregivers.

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⁴ Adapted from"http://pos-pal.org/How-to-implement.php"

If the FAMCARE/FAMCARE-2 is administered after a patient's death, then the staff members might identify the family caregivers, based on their interactions with families prior to the patient's death.

In the EZPCP, family caregivers may be identified after a patient's death from the monthly bereavement lists that are generated by each site (e.g. TPCU). Family caregivers may also be identified at the time of a patient's admission to a palliative care service (e.g. Hospice Palliative Care Unit, Edmonton General Hospital).

9.2 How many family caregivers are contacted after the patient is deceased to complete the FAMCARE/FACMARE-2 survey? Will there be more than one respondent for each patient?

Your team may choose to contact several family caregivers in hopes of receiving at least one response back. This will have to be taken into account and noted when gathering response rates for a report.

9.3 How are family caregivers contacted about the FAMCARE/FAMCARE-2 scale?

At a reasonable time after the patient's death, the FAMCARE/FAMCARE-2 may be mailed to the main family caregiver(s). Sometimes, teams choose to send the FAMCARE/FAMCARE-2 form with a bereavement package. Teams may also choose to obtain consent from family members before a patient's death (Ringdal et al., 2003, p. 168) or follow up with a phone call before they mail out the FAMCARE/FAMCARE-2 to family members.

9.4 How often are assessments done before death?

FAMCARE/FAMCARE-2 surveys can be completed while the patient is still alive. Assessments can be given, for example, every second month until death (Ringdal et al., 2003, p. 168).

9.5 What is the best way to administer the FAMCARE/FAMCARE-2?

There are a variety of ways to administer the FAMCARE/FAMCARE-2, such as face-to-face interviews (Hwang et al., 2003, p. 321), phone interviews (Rodriguez et al., 2010, p. 169), mail/self-report (Ringdal et al., 2002, p. 55), and computerized surveys (Carter et al., 2011, p. 565). Another option would be to develop and administer the survey online.

9.6 What demographics are potentially collected with the FAMCARE/FAMCARE-2?

In a recent literature review of the family caregiver satisfaction tools (Beaumont & Nekolaichuk, unpublished), the following demographics had been collected with the FAMCARE/FAMCARE-2:

Family Caregiver

- Age
- Gender
- Marital status
- Ethnicity
- Educational level

- Occupation
- Employment status
- Income
- Relationship to the patient
- Religious affiliation
- Number of dependents at home

Patient

- Age
- Gender
- Diagnosis
- Religious affiliation

A summary of the demographics and corresponding references appear in the Appendix B (see Tables 1a and 1b).

These demographics are not currently being collected in the EZPCP, but other programs have collected them.

9.7 What are the relationships between family caregiver satisfaction and patient demographics?

Family caregiver satisfaction responses have been associated with specific patient demographics, such as age, gender and education. The elderly tended to record greater levels of satisfaction (Can et al., 2011, p. 1328), women were more satisfied than men (Ringdal et al., 2002, p. 58) and those with less education were more satisfied than those with more education (Ringdal et al., 2002, p. 58). See Tables 2a and 2b in Appendix B for other demographic relationships and references.

9.8 What other types of family satisfaction tools have been used in palliative care?

Other family caregiver satisfaction tools have been used to capture family member satisfaction with palliative care. Some of these tools are:

- Satisfaction Scale for Family Members Receiving Inpatient Palliative Care (Sat-Fam-IPC; Morita & Chihara, 2002)
- Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C; Shin et al., 2011)
- Family Inventory of Needs (FIN; Kristjanson et al., 1995)
- Problems and Needs in Palliative Care (PNPC-sv; Osse et al., 2007)
- CANHELP questionnaire (Heyland et al., 2010)
- Views of Informal Carers Evaluation of Services (VOICES; Addington-Hall et al., 1998).

9.9 Does clinical practice have to change to use the FAMCARE/FAMCARE-2?

No, clinical practice does not have to change in order to use the FAMCARE/FAMCARE-2. The tool can be incorporated into clinical practice to help focus on issues relevant to family satisfaction with service of advanced cancer patients.

9.10 How do I know if a family caregiver responds to an item "undecided" if s/he is actually undecided or the question was not applicable to their situation?

For the FAMCARE tool, you will not be able to tell if the response is "undecided" or "not applicable," unless further information is acquired or if there are comments from the family caregiver. If the family caregiver has provided contact information, then you could contact the individual to clarify these items.

For the FAMCARE-2, there is an additional option of "not relevant to my situation".

9.11 What do I do if the patient was only in the place of care for a short while and not all questions are applicable?

Please note in your report that some of the patients only stayed a short duration. Any comments made can be analyzed to determine any similarities and differences between the patients who stayed a short time compared with the patients who stayed a longer time (only applicable for those patients who can be identified, but most of the time this is not possible).

9.12 How do I go about following up a family caregiver's negative response on the FAMCARE/FAMCARE-2?

Family caregivers with negative responses or serious concerns on the FAMCARE/FAMCARE-2 form should be contacted if their contact information is available. Try to find out what went wrong and at the next team meeting (which varies from site to site but may be monthly, quarterly, etc.) bring it forth in discussion to create a possibility for change to occur.

9.13 How do I communicate the importance of FAMCARE/FAMCARE-2 to family caregivers and staff?

Let staff and family members know that completing the FAMCARE/FAMCARE-2 survey may improve the care given to future patients. The feedback will be used to advance services and support. Through the tool, the organization can obtain information on new developments, priorities and requirements, and help target resources on issues of concern. The systematic use of a family caregiver satisfaction tool demonstrates to staff and family members that family members' opinions are important. The survey also provides the opportunity for family members to share their experiences, whether satisfactory or unsatisfactory.

9.14 What publications are available on the FAMCARE/FAMCARE-2?

Please see the references at the end of these guidelines and the tables in Appendix B. This list provides a summary of key publications, but is not an exhaustive list.

9.15 Are there any copyright issues to be aware of?

The FAMCARE can be used freely and can be found on the internet. The FAMCARE-2 can be used with the appropriate acknowledgement of the instrument developers and reference citation (Aoun et al., 2010). As a courtesy, you can contact Dr. Samar Aoun at S.Aoun@curtin.edu.au to inform her that the tool will be used at a specific site.

<u>Summary</u>

The FAMCARE/FAMCARE-2 tool is one measure of family caregiver satisfaction of palliative care services. The FAMCARE-2 provides a broader interdisciplinary focus than the FAMCARE, Ultimately, it is up to the individual team or program to decide which version will best work in their setting(s).. The systematic use of this scale in clinical practice can help guide future care planning to optimize patient care.

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Appendix A:

Versions of the FAMCARE Tool

Figure 1: Original FAMCARE Questions

Instructions
Think about the care that your family member has received. Please answer the questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), or very dissatisfied (VD). Not Applicable (NA). Please circle the letters below that best match your experience.

How satisfied are you with:

How sa	tisfied are you with:						
1	The patient's pain relief	VS	S	U	D	VD	NA
2	Information provided about the patient's prognosis	VS	S	U	D	VD	NA
3	Answers from health professionals	VS	S	U	D	VD	NA
4	Information given about side effects	VS	S	U	D	VD	NA
5	Referrals to specialists	VS	S	U	D	VD	NA
6	Availability of a hospital bed	VS	S	U	D	VD	NA
7	Family conferences held to discuss the patient's illness	VS	S	U	D	VD	NA
8	Speed with which symptoms are treated	VS	S	U	D	VD	NA
9	Doctor's attention to patient's description of symptoms	VS	S	U	D	VD	NA
10	The way tests and treatments are performed	VS	S	U	D	VD	NA
11	Availability of doctors to the family	VS	S	U	D	VD	NA
12	Availability of nurses to the family	VS	S	U	D	VD	NA
13	Coordination of care	VS	S	U	D	VD	NA
14	Time required to make a diagnosis	VS	S	U	D	VD	NA
15	The way the family is included in treatment and care decisions	VS	S	U	D	VD	NA
16	Information given about how to manage the patient's pain	VS	S	U	D	VD	NA
17	Information given about the patient's tests	VS	S	U	D	VD	NA
18	How thorough the doctor assesses the patient's symptoms	VS	S	U	D	VD	NA
19	The way tests and treatments are followed up by the doctor	VS	S	U	D	VD	NA
20	Availability of the doctor to the patient	VS	S	U	D	VD	NA

Additional comments:			
Please provide your contact ir	formation if you have any questic	ons and would like us to contact you:	:
Name:			
Contact Information:			

Figure 2: FAMCARE-2 Questions

Think about the care that your family member has received on our Palliative Care Unit. Please answer the questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), very dissatisfied (VD), or not applicable (NA). Please circle the letters below that best match your experience. You may choose not to respond to some items. Patient" refers to your loved one who was cared for on the Palliative Care Unit. "Family" refers to you and others important to the patient.

How satisfied are you with:

1	The patient's comfort	VS	s	U	D	VD	NA
2	The way in which the patient's condition and likely progress have been explained by the palliative care team	VS	S	U	D	VD	NA
3	Information given about the side effects of treatment	VS	S	U	D	VD	NA
4	The way in which the palliative care team respects the patient's dignity	VS	s	U	D	VD	NA
5	Meetings with the palliative care team to discuss the patient's condition and plan of care	VS	s	U	D	VD	NA
6	Speed with which symptoms are treated	VS	S	U	D	VD	NA
7	Palliative care teams' attention to the patient's description of symptoms	VS	s	U	D	VD	NA
8	The way in which the patient's physical needs for comfort are met	vs	s	U	D	VD	NA
9	Availability of the palliative care teams to the family	VS	s	U	D	VD	NA
10	Emotional support provided to family members by the palliative care team	VS	s	U	D	VD	NA
11	The practical assistance provided by the palliative care team (e.g., bathing, home care, respite)	VS	s	U	D	VD	NA
12	The doctor's attention to the patient's symptoms	vs	s	U	D	VD	NA
13	The way the family is included in treatment and care decisions	VS	s	U	D	VD	NA
14	Information given about how to manage the patient's symptoms (e.g., pain, constipation)	VS	s	U	D	VD	NA
15	How effectively the palliative care team manages the patient's symptoms	VS	S	U	D	VD	NA
16	The palliative care team's response to changes in the patient's care needs	VS	S	U	D	VD	NA
17	Emotional support provided to the patient by the palliative care team	VS	S	U	D	VD	NA

Date:	

Confidential Comments:	
Please provide your contact information if you have any questions and would like us to contact you:	
Contact Name:	
Contact Phone Number:	
Date:	

For further information about the Edmonton Zone Palliative Care Program, please visit our website at www.palliative.org or call (780) 735-7834

Figure 3: FAMCARE-6 Questions

How satisfied are you with:

- 1. Answers from health professionals
- 2. Information given about side effects
- 3. Speed with which symptoms are treated
- 4. Availability of doctors to the family
- 5. Time required to make a diagnosis
- 6. Availability of the doctor to the patient

Appendix B:

Demographic Information

Table 1a: Demographics Included in Research Articles

Demographics	Research Studie	es ¹			
	FAMCARE	FAMCARE	FAMCARE	FAMCARE	FAMCARE
	original	translated	2	6	C19
		original			
Age of family member	3, 6, 7, 9, 10,	2	1	3	12
	11, 13, 14, 15				
Age of patient	9, 10, 11, 14,				12
	15, 16				
Age in Range	3, 9, 10, 11		1	3	
Specific Age given	6, 7, 13, 14,	2			12
	15, 16				
Gender of family member	3, 6, 7, 9, 10,	2	1	3	12
	11, 13, 14, 15				
Gender of patient	10, 11, 14, 15,				12
	16				
Marital status of family member	3, 10, 11, 13	2		3	12
Marital status of patient	9, 10, 16				12
Ethnicity of family member	6, 7, 9, 10, 11,		1		
Fall of the of continue	13				
Ethnicity of patient	10, 16				
Educational level of family member	6, 9, 10, 11,	2			
	13, 14, 15				
Educational level of patient	10, 14, 15				
Occupation of family member	6, 9, 10, 11,	2			
O	14, 15				
Occupation of patient	10	2		2	
Employment status of family member	3, 6, 7, 13	2		3	
Employment status of patient	0.10.11	2			
Income of family member	9, 10, 11	2			
Income of patient	10				
Relationship to patient	6, 7, 9, 10, 11,				
Patient Diagnosis	13, 14, 15, 16 9, 11, 14, 15	2			12
Length of time since diagnosis	11, 13	2			12
Length of time to patient death	14				
Type of disease treatment(s)	14	2			
Patient ECOG performance status		2			12
Religious Affiliation of family member	9, 10, 11, 13				14
Religious Affiliation of patient	10				
Involvement in religious activities	6				
Area of residence	3, 11, 16			3	
Participated in a support group	6			, ,	
Number of dependents at home	6, 14, 15				
Living proximity to patient	6				
Frequency of team member visits	13				
Length of time receiving care from home	13				
hospice service	13				
Other sources of support available	13				
Location of patient death	14, 14				
Location of patient death	14, 14				

¹ see numbered reference list on pp. 23-24

Table 1b: Demographics Included in Quality Improvement Studies

Demographics	Quality Improvement Studies ¹		
	FAMCARE original	FAMCARE Other	
Age of family member	4		
Age of patient	4	5	
Age in Range	4		
Specific Age given		5	
Gender of family member	4		
Gender of patient	4	5	
Marital status of family member	4		
Marital status of patient	4		
Ethnicity of patient		5	
Educational level of family member	4		
Educational level of patient	4		
Patient Diagnosis	4	5	
Patient ESAS performance status	4		
Patient PPS		5	
Patient insurance status		5	
Living arrangements		5	
Location of patient death	4		
Site of Clinical Care (inpatient unit, consultation care, home support, long-term care)		8	

¹ see numbered reference list on pp. 23-24

Table 2a: Relationships between demographics and family caregiver satisfaction, based on research studies

Relationship Themes ¹	Research Studies ²		
	FAMCARE FAMCARE		FAMCARE 2
	original	translated original	
Education			
Those with higher education rated higher care satisfaction	9		
Those with less education are more satisfied than those who are more	13, 14		
educated			
Ethnic Background			
Caucasian family members rate care higher, while non-Caucasian rate	9		
care lower			
Those who did not identify with a particular ethnic origin had a higher			1
average satisfaction score than those who did identify with a specific			
cultural background			
Age	•		
Family members of older patients (over 50) rate care more positively	9, 13		
than family members of younger patients	ĺ		
Elderly tend to record greater levels of satisfaction	13, 14	2	
Satisfaction with information giving and availability of care and total	,	2	
satisfaction increased as the age of the caregiver increased (this one is			
more specific than the above statement)			
Participants aged 50 and older had a higher average satisfaction score			1
than those less than 50.			
Satisfaction scores higher among younger families.	11		
Gender and Marital Status	L		L
Woman were more satisfied than men	13, 14		
Satisfaction with information giving was low in male and unmarried	,	2	
caregivers of the cancer patients		_	
Income	L		L
Those with less income were more satisfied than those with higher	13		
incomes			
Relationship to patient			
Children of the deceased were the least satisfied group followed by the	14		
spouses of the deceased			
Diagnosis	L		L
	14		
		2	
		_	
•	11		
Treatment	<u> </u>		
	14	1	
The respondents related to patients with breast cancer or cancer of the female genitals had a lower score on the FAMCARE Caregivers of metastatic cancer patients reported significantly lower satisfaction with the availability of the doctor. The mean care perception scores for those diagnosed longer than 2 years was higher than for those who had been diagnosed for less than 2 years. Treatment Respondents related to patients who had been included in the intervention for more than 100 days were somewhat more satisfied than those with a shorter inclusion	11	2	

Table 2a: continued

Tubic 24. continued			
Relationship Themes ¹	Research Studies ²		
	FAMCARE original	FAMCARE translated original	FAMCARE 2
Location of Death			
Respondents related to those who died at home scored significantly higher on FAMCARE than those who died in a hospital or nursing home	14		
Other			
Significant associations were found between FIN unmet needs scale and FAMCARE	7		
Saskatchewan family members scored higher than Manitoba in satisfaction scores. Alberta family members scored higher than Manitoba in satisfaction scores.	11		
Relatives other than the patient's spouse reported a greater discrepancy between care expectations and care perceptions than did spouses.	11		
No significant differences were found between responses of family members of the GPCU and responses of family members of NHCU patients.	16		

¹some are statistically significant, while some are trends ² see numbered reference list on pp. 23-24

Table 2b: Relationships between demographics and family caregiver satisfaction, based on quality improvement studies

Relationship Themes ¹	Quality Improvement Studies ²
Site of Clinical Care	FAMCARE Other
PCU received the highest rating for availability of care and LTC the highest rating for psychosocial care	8
Overall, physical care was most satisfactory in the PCU, less satisfactory in LTC, least satisfactory in consultation care	8
Highest satisfaction to be found in LTC, less in PCU and least in consultative care	8
Satisfaction with the following was found to be highest in the PCU: information regarding side effects of treatment, attention provided to symptoms, availability of a physician and information about tests being performed	8

¹some are statistically significant, while some are trends ² see numbered reference list on pp. 23-24

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