FAMCARE and FAMCARE-2 Guidelines

Prepared by:
Crystal Beaumont BSc, Cheryl Nekolaichuk PhD, RPsych
Palliative and End-of-Life Institute
Health Services Centre, Grey Nuns Hospital
Rom DC-416, 190 Youville Drive West
Edmonton, AB T6L 0A3

Version 1.0 July 2012
Updated: 15-Aug-2012
Table of Contents

1. Background ..............................................................................................................
2. Versions ....................................................................................................................
3. Translations ..............................................................................................................
4. How to Administer ....................................................................................................
5. How to Interpret ........................................................................................................
6. How to Report ...........................................................................................................
7. How to Implement ....................................................................................................
8. FAQs .........................................................................................................................
9. Summary ..................................................................................................................

References ....................................................................................................................

Appendix A: Versions of the FAMCARE Tool ...............................................................
Appendix B: Demographic Information .........................................................................
1. **Background**

The FAMCARE Scale is a tool used to measure family satisfaction with advanced cancer care. It measures 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. The FAMCARE Scale is a validated instrument and it is used in such places as North America, Australia and Europe.

2. **Versions**

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).

In 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, because 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. It refers more to a team approach to palliative care, rather than focusing on doctors and nurses only. FAMCARE-2 makes reference to more symptoms than pain alone and offers more response options. Both the FAMCARE and FAMCARE-2 were developed for advanced cancer care and may need to be modified for care of other illnesses such as end stage organ failure and neurodegenerative diseases.
The FAMCARE was originally piloted on the palliative care unit at St. Michael’s Hospital, Lethbridge, in April 2010 and then piloted on the tertiary palliative care unit at the Grey Nuns Community Hospital, Edmonton, in August, 2010. In June, 2012, the Edmonton Zone Palliative Care Program (EZPCP) adopted the FAMCARE-2 for use on the tertiary palliative care unit and hospice sites in Edmonton. The Covenant Health palliative care units in Lethbridge and Medicine Hat have also adopted the FAMCARE-2 as of June, 2012.

3. Translations

FAMCARE is available in English, Turkish (Can et al., 2011), and Marathi (Duraisamy, unpublished).1 FAMCARE-2 is available in English and Swedish (Klarare, unpublished).2 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.

4. How to Administer

The FAMCARE/FAMCARE-2 was originally developed for administration to family members while a patient is receiving palliative care services. However, it can be administered to family caregivers while the patient is still alive or after the patient is deceased. Completion of the FAMCARE/FAMCARE-2 can be done by interview (Hwang et al., 2003, p. 321) or self-completion (Carter et al., 2011, p. 567). Many scales such as the FAMCARE are sent in the 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 palliative care sites, the 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.

5. 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.”

In the EZPCP and Covenant Health palliative care sites, a section has been added at the end of the tool for family caregivers to include comments. If a family caregiver is very dissatisfied and if contact information is available, then it would be important to 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 the structure of the organization administering care.

6. **How to Report**

Reporting of the FAMCARE/FAMCARE-2 helps with care planning, care evaluation, and multi- and inter-disciplinary team work. Discussing FAMCARE/FAMCARE-2 items with family caregivers 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 scale 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 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 audit purposes, a summary of FAMCARE/FAMCARE-2 responses from several family caregivers can be reported. These data are de-identified at the point of data entry and before reports are generated.

For research purposes, FAMCARE/FAMCARE-2 data are presented at an aggregate level. Family caregiver names and organizations are not identifiable, and findings are published for wide dissemination.

7. **How to Implement**

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:

- Good communication
- A proactive approach that involves all members of the team
- 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)
- Access to evidence based recommendations and scientific papers

---

4 Adapted from [http://pos-pal.org/How-to-implement.php](http://pos-pal.org/How-to-implement.php)
Staff members are sometimes reluctant to use the FAMCARE/FAMCARE-2 as it deals with some sensitive issues after a patient is deceased, but it is important for future patient care to collect these responses.

There is no universal consensus regarding the best time frame to send the FAMCARE/FAMCARE-2 to family members after a patient’s death, but a time frame of three to four months is generally recommended.

In a recent review of family satisfaction surveys (Beaumont & Nekolaichuk, unpublished), the time frame for contacting family members varied from one month to 10 months, with a median of 2.3 months. Of those studies involving the FAMCARE/FAMCARE-2, only one study distributed the FAMCARE survey to family caregivers one month after a patient’s death (Ringdal et al., 2002, p. 53; Ringdal et al., 2003, p. 167).

8. Frequently Asked Questions

i. How is the main family caregiver for the patient identified?

There may be several ways to identify the main family caregiver. 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).

ii. When is the main family caregiver identified?

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.

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 from the monthly bereavement lists that are generated for each site.

iii. 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.

iv. 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 caregivers. 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.

v. **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).

vi. **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. It is up to each organization to choose which is the most economical method and easiest to set up.

vii. **What demographics are normally collected with the FAMCARE/FAMCARE-2?**

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

- Age of the family caregiver
- Gender of the family caregiver
- Marital status of the family caregiver
- Ethnicity of the family caregiver
- Educational level of the family caregiver
- Occupation of the family caregiver
- Employment status of the family caregiver
- Income of the family caregiver
- Relationship to the patient
- Religious Affiliation
- Number of dependents at home
- Age of the patient
- Gender of the patient
- Patient diagnosis

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

viii. **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.
ix. **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 forms 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).

x. **Does clinical practice have to change to use the FAMCARE/FAMCARE-2?**

You do not need to alter your practice to use the FAMCARE/FAMCARE-2. It can be incorporated into clinical routines to help focus on issues relevant to family satisfaction with service of advanced cancer patients.

xi. **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?**

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 on the original FAMCARE. You may need to contact the family caregiver. The FAMCARE-2 does include an additional option of “not relevant to my situation”.

xii. **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).

xiii. **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 bring it forth in discussion to create a possibility for change to occur.

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

(Ringdal et al., 2002, p. 58). See Tables 2a and 2b in Appendix B for other demographic relationships and references.
Let staff and family members know that completing the FAMCARE/FAMCARE-2 survey may improve the care given to future patients. It can advance services and support; it can aid in obtaining information on new developments, priorities and requirements; and it may help target resources on issues of concern. It assists in demonstrating to staff and family members that there is a commitment to their opinions and provides an opportunity for unhappy family members to vent about their situation.

xv. **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.

xvi. **Whom should I contact to address any questions?**

In the EZPCP, you may contact [____________] with any further questions. You may also contact Dr. Samar Aoun at S.Aoun@curtin.edu.au for additional information about the development of the FAMCARE-2.

xvii. **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 reference to the authors who developed this revised version (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.

9. **Summary**

The FAMCARE/FAMCARE-2 tool measures family satisfaction with advanced cancer care. The FAMCARE comes in several variations and it is up to the individual team to decide which will best work for their program. It is a helpful scale to guide in future care changes that may need to be implemented to make care the best possible.
References


Appendix A:

Versions of the FAMCARE Tool
**Figure 1: Original FAMCARE Questions**

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

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

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Research Studies\textsuperscript{1,2}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of family member</td>
<td>1 (FAMCARE 2), 2 (translated original form), 3 (FAMCARE and FAMCARE 6), 6, 7, 9, 10, 11 (FAMCARE C19), 12, 13, 14</td>
</tr>
<tr>
<td>Age of patient</td>
<td>9, 10, 11 (FAMCARE C19), 13, 14, 15</td>
</tr>
<tr>
<td>Age in Range</td>
<td>1, 3, 9, 10</td>
</tr>
<tr>
<td>Specific Age given</td>
<td>2, 6, 7, 11, 12 (assumption), 13, 14, 15</td>
</tr>
<tr>
<td>Gender of family member</td>
<td>1 (FAMCARE 2), 2 (translated original form), 3 (FAMCARE and FAMCARE 6), 6, 7, 9, 10, 11 (FAMCARE C19), 12, 13, 14</td>
</tr>
<tr>
<td>Gender of patient</td>
<td>10, 11 (FAMCARE C19), 13, 14, 15</td>
</tr>
<tr>
<td>Marital status of family member</td>
<td>2 (translated original form), 3 (FAMCARE and FAMCARE 6), 10, 11 (FAMCARE C19), 12</td>
</tr>
<tr>
<td>Marital status of patient</td>
<td>9, 11 (FAMCARE C19), 15</td>
</tr>
<tr>
<td>Ethnicity of family member</td>
<td>1 (FAMCARE 2), 6, 7, 9, 10, 12</td>
</tr>
<tr>
<td>Ethnicity of patient</td>
<td>15</td>
</tr>
<tr>
<td>Educational level of family member</td>
<td>2 (translated original form), 6, 9, 10, 12, 13, 14</td>
</tr>
<tr>
<td>Educational level of patient</td>
<td>13, 14</td>
</tr>
<tr>
<td>Occupation of family member</td>
<td>2 (translated original form), 6, 9, 10, 13, 14</td>
</tr>
<tr>
<td>Employment status of family member</td>
<td>2 (translated original form), 3 (FAMCARE and FAMCARE 6), 6, 7, 12</td>
</tr>
<tr>
<td>Employment status of patient</td>
<td>2 (translated original form)</td>
</tr>
<tr>
<td>Income of family member</td>
<td>2 (translated original form), 9, 10</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>6, 7, 9, 10, 12, 13, 14, 15</td>
</tr>
<tr>
<td>Patient Diagnosis</td>
<td>2 (translated original form), 9, 10, 11 (FAMCARE C19), 13, 14</td>
</tr>
<tr>
<td>Length of time since diagnosis</td>
<td>10, 12</td>
</tr>
<tr>
<td>Length of time to patient death</td>
<td>13</td>
</tr>
<tr>
<td>Type of disease treatment(s)</td>
<td>2 (translated original form)</td>
</tr>
<tr>
<td>Patient ECOG performance status</td>
<td>2 (translated original form), 11 (FAMCARE C19)</td>
</tr>
<tr>
<td>Religious Affiliation</td>
<td>9, 10, 12</td>
</tr>
<tr>
<td>Involvement in religious activities</td>
<td>6</td>
</tr>
<tr>
<td>Area of residence</td>
<td>3 (FAMCARE and FAMCARE 6), 10, 15</td>
</tr>
<tr>
<td>Participated in a support group</td>
<td>6</td>
</tr>
<tr>
<td>Number of dependents at home</td>
<td>6, 13, 14</td>
</tr>
<tr>
<td>Living proximity to patient</td>
<td>6</td>
</tr>
<tr>
<td>Frequency of team member visits</td>
<td>12</td>
</tr>
<tr>
<td>Length of time receiving care from home hospice service</td>
<td>12</td>
</tr>
<tr>
<td>Other sources of support available</td>
<td>12</td>
</tr>
<tr>
<td>Location of patient death</td>
<td>13, 14</td>
</tr>
</tbody>
</table>

\textsuperscript{1} references from original FAMCARE tool, unless specified otherwise
\textsuperscript{2} see numbered reference list on pp. 21-22
Table 1b: Demographics Included in Quality Improvement Studies

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Quality Improvement Studies¹,²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of family member</td>
<td>4</td>
</tr>
<tr>
<td>Age of patient</td>
<td>4, 5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Age in Range</td>
<td>4</td>
</tr>
<tr>
<td>Specific Age given</td>
<td>5</td>
</tr>
<tr>
<td>Gender of family member</td>
<td>4</td>
</tr>
<tr>
<td>Gender of patient</td>
<td>4, 5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Marital status of family member</td>
<td>4</td>
</tr>
<tr>
<td>Marital status of patient</td>
<td>4</td>
</tr>
<tr>
<td>Ethnicity of patient</td>
<td>5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Educational level of family member</td>
<td>4</td>
</tr>
<tr>
<td>Educational level of patient</td>
<td>4</td>
</tr>
<tr>
<td>Patient Diagnosis</td>
<td>4, 5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Patient ESAS performance status</td>
<td>4</td>
</tr>
<tr>
<td>Patient PPS</td>
<td>5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Patient insurance status</td>
<td>5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>5 (FAMCARE not named)</td>
</tr>
<tr>
<td>Location of patient death</td>
<td>4</td>
</tr>
<tr>
<td>Site of Clinical Care (inpatient unit, consultation care, home support, long-term care)</td>
<td>8</td>
</tr>
</tbody>
</table>

¹ references from original FAMCARE tool, unless specified otherwise
² see numbered reference list on pp. 22-23
Table 2a: Relationships between demographics and family caregiver satisfaction, based on research studies

<table>
<thead>
<tr>
<th>Relationship Themes</th>
<th>Research Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Those with higher education rated higher care satisfaction</td>
<td>9</td>
</tr>
<tr>
<td>Those with less education are more satisfied than those who are more educated</td>
<td>12, 13</td>
</tr>
<tr>
<td><strong>Ethnic Background</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian family members rate care higher, while non-Caucasian rate care lower</td>
<td>9</td>
</tr>
<tr>
<td>Those who did not identify with a particular ethnic origin had a higher average satisfaction score than those who did identify with a specific cultural background</td>
<td>1</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Family members of older patients (over 50) rate care more positively than family members of younger patients</td>
<td>9, 12</td>
</tr>
<tr>
<td>Elderly tend to record greater levels of satisfaction</td>
<td>2, 12, 13</td>
</tr>
<tr>
<td>Satisfaction with information giving and availability of care and total satisfaction increased as the age of the caregiver increased (this one is more specific than the above statement)</td>
<td>2</td>
</tr>
<tr>
<td>Participants aged 50 and older had a higher average satisfaction score than those less than 50.</td>
<td>1</td>
</tr>
<tr>
<td>Satisfaction scores higher among younger families.</td>
<td>10</td>
</tr>
<tr>
<td><strong>Gender and Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Woman were more satisfied than men</td>
<td>12, 13</td>
</tr>
<tr>
<td>Satisfaction with information giving was low in male and unmarried caregivers of the cancer patients</td>
<td>2</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
</tr>
<tr>
<td>Those with less income were more satisfied than those with higher incomes</td>
<td>12</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
</tr>
<tr>
<td>Children of the deceased were the least satisfied group followed by the spouses of the deceased</td>
<td>13</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>The respondents related to patients with breast cancer or cancer of the female genitals had a lower score on the FAMCARE</td>
<td>13</td>
</tr>
<tr>
<td>Caregivers of metastatic cancer patients reported significantly lower satisfaction with the availability of the doctor.</td>
<td>2</td>
</tr>
<tr>
<td>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.</td>
<td>10</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>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</td>
<td>13</td>
</tr>
<tr>
<td><strong>Location of Death</strong></td>
<td></td>
</tr>
<tr>
<td>Respondents related to those who died at home scored significantly higher on FAMCARE than those who died in a hospital or nursing home</td>
<td>13</td>
</tr>
</tbody>
</table>
**Table 2a (cont’d)**

<table>
<thead>
<tr>
<th>Relationship Themes(^1)</th>
<th>Research Studies(^2,(^3)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant associations were found between FIN unmet needs scale and FAMCARE</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Saskatchewan family members scored higher than Manitoba in satisfaction scores. Alberta family members scored higher than Manitoba in satisfaction scores.</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Relatives other than the patient’s spouse reported a greater discrepancy between care expectations and care perceptions than did spouses.</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>No significant differences were found between responses of family members of the GPCU and responses of family members of NHCU patients.</td>
<td>15</td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) Some are statistically significant, while some are trends
\(^2\) References from original FAMCARE tool, unless specified otherwise
\(^3\) See numbered reference list on pp. 22-23
Table 2b: Relationships between demographics and family caregiver satisfaction, based on quality improvement studies

<table>
<thead>
<tr>
<th>Relationship Themes</th>
<th>Quality Improvement Studies(^\text{2,3})</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Site of Clinical Care</strong></td>
<td></td>
</tr>
<tr>
<td>PCU received the highest rating for availability of care and LTC the highest rating for psychosocial care</td>
<td>8</td>
</tr>
<tr>
<td>Overall, physical care was most satisfactory in the PCU, less satisfactory in LTC, least satisfactory in consultation care</td>
<td>8</td>
</tr>
<tr>
<td>Highest satisfaction to be found in LTC, less in PCU and least in consultative care</td>
<td>8</td>
</tr>
<tr>
<td>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</td>
<td>8</td>
</tr>
</tbody>
</table>

\(^{1}\)some are statistically significant, while some are trends

\(^{2}\)references from original FAMCARE tool, unless specified otherwise

\(^{3}\)see numbered reference list on pp. 22-23
References


