



# Association for Palliative Medicine

## **FAMCARE 2021**

### **Bereaved relatives' satisfaction with specialist palliative care services: A service evaluation by the Association for Palliative Medicine of Great Britain and Ireland (APM)**

Prepared by Dr Jaya Kane

Clinical Quality Committee

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## 1. FAMCARE Background

FAMCARE is an annual audit run by the Association for Palliative Medicine (APM) and has been running since 2013. It consists of a survey (FAMCARE 2 tool) which is sent out to recently bereaved relatives or a designated main carer.

This survey was developed by Prof Aoun who has given permission for its use by the APM. The survey consists of 17 questions which cover several different aspects of care which the patient received. It is completed by the main carer 4-6 weeks after the death of the patient and upon completion, is returned to the APM for analysis.

Participating services are either a hospital-based palliative care team, hospice inpatient unit or a home care team specialising in providing end of life care. Participating services receive individual feedback (including their own data) and also comparable (anonymous) data from other services.

### 1.1 The Project Lead

Though all the returned surveys are analysed by the APM, who is also responsible for creating the annual audit report, each service must have an assigned 'Project Lead'. This Project Lead must be a member of the APM and is responsible for obtaining local clinical governance approval. The National Research Ethics Committee has deemed that the project constitutes a service evaluation and so there is no need to obtain local research ethics committee approval. The Information Commissioner's Office has suggested that it is legitimate to use carers' contact details in this situation.

The 'Project Lead' is also responsible for requesting freepost envelopes from the APM and is required to set up a local mechanism for dealing with any queries, carer distress and carer complaints that may arise from the audit.

### 1.2 Methodology

Surveys were sent out from the 1<sup>st</sup> of August 2021 to the 29<sup>th</sup> of September 2021 and covered deaths between the 1<sup>st</sup> of June to the 30<sup>th</sup> of August 2021.

Services were sent a FAMCARE overview, a Project Lead checklist, a covering letter (to send to relatives), the FAMCARE 2 tool survey (to send to the relatives) a spreadsheet (used to record deaths in the service and number of surveys sent), a GDPR privacy notice and freepost envelopes.

### 1.3 General Data Protection Regulations (GDPR) Compliancy

In 2020, the APM worked closely with the compliance team Crimson Crab Ltd to ensure the service is following the rules and regulations to be fully compliant with the updated EU General Data Protection Regulations (GDPR). Relatives now receive a GDPR privacy notice along with other documents. The FAMCARE page (on the APM's website) includes clear information on GDPR and importantly, there is a link to the legitimate interest test conducted for the processing of personal data by end-of-life care providers to enable their participation in the FAMCARE survey carried out by the APM.

### 1.4 COVID-19

Since the COVID-19 pandemic began in 2020, many patient facing services have been faced with restrictions. Being GDPR compliant has allowed us to continue despite the limitations posed by the pandemic. Unfortunately, the FAMCARE tool cannot be amended so specific data could not be collected on COVID-19, including whether the deaths were related/caused by it - unless the relative mentioned it in the blank comments box.

## 2. FAMCARE Objectives

The aim of FAMCARE is to evaluate the care offered to patients and their relatives from specialist palliative care services. We hope the results provide outputs which enable services to identify areas for service improvement to enhance the experience of care for dying persons and their relatives.

FAMCARE is the only validated nationally run SPC audit which can be used to benchmark services against others, evidence appraisals, and to support the need for service development.

### 3. Participation of Services and Surveys Returned

For FAMCARE 2021 the APM received a total of **1363** returned surveys from bereaved relatives.

Table 1.

FAMCARE 2021		
Service	No. of services	Total surveys returned
HS	5	87
IU	30	494
HC	28	782
<b>Total</b>	<b>63</b>	<b>1363</b>

FAMCARE 2020		
Service	No. of services	Total surveys returned
HS	7	85
IU	22	382
HC	22	677
<b>Total</b>	<b>51</b>	<b>1144</b>

FAMCARE 2019		
Service	No. of services	Total surveys returned
HS	5	107
IU	29	547
HC	23	577
<b>Total</b>	<b>57</b>	<b>1231</b>

FAMCARE 2018		
Service	No. of services	Total surveys returned
HS	6	128
IU	26	538
HC	22	521
<b>Total</b>	<b>54</b>	<b>1187</b>

FAMCARE 2017		
Service	No. of services	Total surveys returned
HS	12	208
IU	31	718
HC	29	742
<b>Total</b>	<b>72</b>	<b>1668</b>

KEY

- \* Hospital support teams - **HS**
- \* Specialist Palliative Care Inpatient Unit - **IU**
- \* Home care teams – **HC**

In 2021 almost 20% more surveys were analysed compared to 2020. More services also participated in 2021 (63, compared to 51 in 2020). However there continued to be a fall in participating hospital support teams, but a rise in participating in-patient units and home care teams. For hospital teams, this may have been due to the continuation of the National Audit of Care at the End of Life (NACEL).

The increased participation from other services may be as a result of increased advertising for FAMCARE done through the APM. Alternatively, perhaps as we have begun learning to live with/manage COVID-19 better, more services wish to assess their performance.

#### 4. Sampling and Response Rates

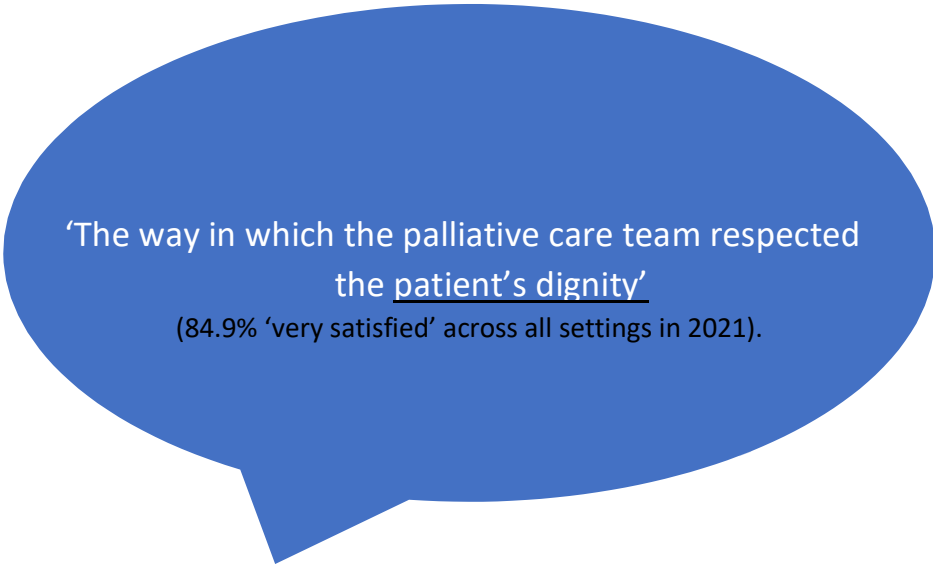
Table 2.

<b>FAMCARE 2021</b>		
<b>Type of Service</b>	<b>Sampling Rate</b>	<b>Response Rate</b>
Hospice Inpatient Unit (IU)	69.5%	34%
Home Care Team (HC)	69.3%	33.8%
Hospital Support Team (HS)	63.2%	33%

<b>FAMCARE 2020</b>		
<b>Type of Service</b>	<b>Sampling Rate</b>	<b>Response Rate</b>
Hospice Inpatient Unit (IU)	81.8%	42.9%
Home Care Team (HC)	68.7%	31.3%
Hospital Support Team (HS)	59.0%	26.2%
<b>FAMCARE 2019</b>		
<b>Type of Service</b>	<b>Sampling Rate</b>	<b>Response Rate</b>
Hospice Inpatient Unit (IU)	77.1%	39.0%
Home Care Team (HC)	61.5%	36.3%
Hospital Support Team (HS)	66.5%	32.3%

Table 2 shows the sampling rate (number of questionnaires posted divided by number of patient deaths) and the response rate (number of questionnaires returned divided by number of questionnaires posted) for FAMCARE 2021, 2020 and 2019.

## 5. Results and discussion



'The way in which the palliative care team respected  
the patient's dignity'  
(84.9% 'very satisfied' across all settings in 2021).

This question (4) received the highest percentage of 'very satisfied' responses from relatives across all 3 settings - the same as in 2020 and in 2019.

Overall the percentage of 'very dissatisfied' responses was low.

- For the hospice home care team, the highest percentage of 'very dissatisfied' responses (6%) came from question 12 - 'the doctor's attention to the patient's symptoms'.
- For the hospice inpatient unit, the highest percentage of 'very dissatisfied' responses (5.3%) came from questions 1 and 8. 'The patient's comfort', and 'the way in which the patient's physical needs for comfort were met'.
- For the hospital support team, the highest percentage of 'very dissatisfied' responses (4.6%) came from questions 5 and 12. 'Meeting with the palliative care team to discuss the patient's condition and plan of care', and 'the doctor's attention to the patient's symptoms'.

For question 2 (the way in which the patient's condition and likely progress had been explained by the palliative care team) the hospital support team received no 'dissatisfied' or 'very dissatisfied' responses.

Thankfully FAMCARE 2021 saw an increase in the number of services participating and total surveys returned compared to FAMCARE 2020 (see table 1). However, the response rate has remained poor across all services (see table 2.) One solution may be to digitalise the FAMCARE survey, allowing easier participation for relatives and perhaps more time efficient analysis of information received. This would be a complex and costly change to undergo, but will however be explored within the relevant committees.

Since 2020, the APM took a proactive approach in responding to negative comments. The majority of these were directed at the quality of the care received as opposed to issues with completing the survey. Though the APM is not responsible for any care provided we felt it was necessary for the relevant service providers to be made aware of concerns raised by relatives, in a prompt manner. Since 2020, if the NOK had provided their contact details, the APM contacted them to seek permission to further contact the service provider. Once permission was sought, the APM forwarded the comments to the project lead of that service. For FAMCARE 2021, 5 negative responses were handled in this manner (compared to 8 in 2020). All comments were regarding the quality of care received.

## 6. Results

Table 3.

Aspect of care	Degree of satisfaction	Setting			
		All settings n=63	Hospice inpatient n=30	Hospice home care n=28	Hospital support team n=5
1. The patient's comfort	Very satisfied	70.2	80.6	64.5	63.2
	Satisfied	17.3	12.6	19.6	24.1
	Neither satisfied or dissatisfied	2.4	0.8	3.7	0.0
	Dissatisfied	2.0	0.6	2.6	4.6
	Very dissatisfied	4.7	5.3	4.6	2.3
	Not relevant	3.4	0.2	5.1	5.7
2. The way in which the patient's condition and likely progress had been explained by the palliative care team	Very satisfied	64.9	70.6	61.1	66.7
	Satisfied	18.5	16.4	19.9	17.2
	Neither satisfied or dissatisfied	5.1	5.5	4.9	5.7
	Dissatisfied	2.3	1.2	3.3	0.0
	Very dissatisfied	4.0	3.8	4.5	0.0
Not relevant	5.1	2.4	6.3	10.3	
3. Information given about side effects of treatment	Very satisfied	44.9	46.2	45.4	33.3
	Satisfied	18.6	17.6	19.2	19.5
	Neither satisfied or dissatisfied	7.4	7.3	7.4	8.0
	Dissatisfied	2.1	1.6	2.3	2.3
	Very dissatisfied	3.5	3.4	3.6	3.4
Not relevant	23.5	23.9	22.1	33.3	
4. The way in which the palliative care team respected the patient's dignity	Very satisfied	84.9	88.3	83.2	80.5
	Satisfied	6.1	5.1	6.3	10.3
	Neither satisfied or dissatisfied	1.8	1.2	1.9	3.4
	Dissatisfied	0.9	0.8	0.9	1.1
	Very dissatisfied	3.8	4.3	3.8	1.1
Not relevant	2.6	0.4	3.8	3.4	



Aspect of care	Degree of satisfaction	Setting			
		All settings n (n=63)	Hospice inpatient n (n=30)	Hospice home care n (n=28)	Hospital support team n (n=5)
5.Meeting with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	60.0	63.6	58.1	57.5
	Satisfied	16.8	15.0	18.0	16.1
	Neither satisfied or dissatisfied	5.4	5.5	5.1	6.9
	Dissatisfied	2.6	1.6	3.1	3.4
	Very dissatisfied	4.3	4.5	4.1	4.6
	Not relevant	11.0	9.9	11.6	11.5
6. Speed with which symptoms were treated	Very satisfied	60.8	67.8	57.3	52.9
	Satisfied	19.4	17.4	20.6	19.5
	Neither satisfied or dissatisfied	4.4	2.8	4.6	11.5
	Dissatisfied	1.8	1.0	2.0	4.6
	Very dissatisfied	4.9	4.5	5.6	1.1
	Not relevant	8.7	6.5	9.8	10.3
7. Palliative care team's attention to the patient's description of symptoms	Very satisfied	62.6	65.0	62.3	51.7
	Satisfied	15.0	15.4	15.2	11.5
	Neither satisfied or dissatisfied	3.3	1.6	4.3	3.4
	Dissatisfied	1.0	0.4	1.5	0.0
	Very dissatisfied	3.8	4.0	3.8	2.3
	Not relevant	14.2	13.6	12.8	31.0
8.The way in which the patient's physical needs for comfort were met	Very satisfied	71.8	78.5	68.2	66.7
	Satisfied	14.8	12.3	16.1	17.2
	Neither satisfied or dissatisfied	3.2	2.4	3.3	5.7
	Dissatisfied	0.9	0.4	1.2	1.1
	Very dissatisfied	5.2	5.3	5.4	3.4
	Not relevant	4.1	1.0	5.9	5.7
9. Availability of the palliative care team to the family	Very satisfied	70.0	75.3	67.5	62.1
	Satisfied	14.6	14.8	14.3	16.1
	Neither satisfied or dissatisfied	4.2	2.0	4.9	10.3
	Dissatisfied	3.2	2.0	3.7	5.7
	Very dissatisfied	4.5	4.3	5.0	1.1
	Not relevant	3.5	1.6	4.6	4.6

Aspect of care	Degree of satisfaction	Setting			
		All settings (%) (n=63)	Hospice inpatient (%) (n=30)	Hospice home care (%) (n=28)	Hospital support team (%) (n=5)
10.Emotional support provided to family members by the palliative care team	Very satisfied	64.6	69.6	62.0	59.8
	Satisfied	15.8	14.6	16.4	17.2
	Neither satisfied or dissatisfied	5.5	4.7	5.6	9.2
	Dissatisfied	2.3	1.6	2.7	3.4
	Very dissatisfied	4.6	4.3	5.1	2.3
	Not relevant	7.1	5.3	8.2	8.0
11.The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	53.0	54.5	54.3	33.3
	Satisfied	9.8	10.7	9.3	8.0
	Neither satisfied or dissatisfied	3.6	1.8	4.3	6.9
	Dissatisfied	1.2	0.4	1.8	0.0
	Very dissatisfied	4.2	3.2	5.0	2.3
	Not relevant	28.2	29.4	25.2	49.4
12.The doctor's attention to the patient's symptoms	Very satisfied	53.4	71.3	41.9	55.2
	Satisfied	15.7	16.2	14.8	20.7
	Neither satisfied or dissatisfied	4.8	2.2	6.4	5.7
	Dissatisfied	2.5	1.6	3.3	0.0
	Very dissatisfied	5.4	4.5	6.0	4.6
	Not relevant	18.2	4.3	27.5	13.8
13.The way the family was included in treatment and care decisions	Very satisfied	64.1	65.8	63.8	57.5
	Satisfied	16.0	16.8	15.1	19.5
	Neither satisfied or dissatisfied	4.1	3.0	4.7	4.6
	Dissatisfied	2.5	2.0	2.8	2.3
	Very dissatisfied	3.5	3.4	3.7	2.3
	Not relevant	9.8	8.9	9.8	13.8

Aspect of care	Degree of satisfaction	Setting			
		All settings (%) (n=63)	Hospice inpatient (%) (n=30)	Hospice home care (%) (n=28)	Hospital support team (%) (n=5)
14.Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	54.1	48.4	59.2	40.2
	Satisfied	16.7	16.2	18.2	6.9
	Neither satisfied or dissatisfied	4.7	2.8	5.4	9.2
	Dissatisfied	2.4	1.6	2.9	2.3
	Very dissatisfied	3.4	3.2	3.8	1.1
	Not relevant	18.6	27.7	10.5	40.2
15.How effectively the palliative care team managed the patient's symptoms	Very satisfied	68.1	74.1	64.6	66.3
	Satisfied	17.3	16.8	17.0	22.1
	Neither satisfied or dissatisfied	2.7	1.4	3.6	2.3
	Dissatisfied	1.5	0.6	2.3	0.0
	Very dissatisfied	4.8	4.7	5.1	2.3
	Not relevant	5.6	2.4	7.4	7.0
16.The palliative care team's response to changes in the patient's care needs	Very satisfied	70.0	76.5	67.0	59.8
	Satisfied	14.2	12.8	14.5	19.5
	Neither satisfied or dissatisfied	2.6	1.6	3.1	4.6
	Dissatisfied	2.6	0.6	4.1	0.0
	Very dissatisfied	4.5	4.7	4.6	2.3
	Not relevant	6.2	3.8	6.8	13.8
17.Emotional support provided to the patient by the palliative care team	Very satisfied	64.0	70.4	60.6	57.5
	Satisfied	15.0	14.6	15.9	10.3
	Neither satisfied or dissatisfied	4.2	2.4	5.4	3.4
	Dissatisfied	1.8	1.2	2.2	1.1
	Very dissatisfied	4.8	4.0	5.5	3.4
	Not relevant	10.2	7.3	10.5	24.1