



# Association for Palliative Medicine

## FAMCARE 2018

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

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Professional Standards Committee, APM

The service evaluation ran from the beginning of August to end of September 2018 and relates to patients who died between 1<sup>st</sup> June 2018 and 31<sup>st</sup> August 2018.

54 specialist palliative care services in the UK and Ireland took part, 26 hospice inpatient units, 22 home care teams, and 6 hospital support teams. They included three services from Northern Ireland, two from Co Limerick and one London based private hospital service. A total of 1187 surveys were returned, with 538 relating to deaths in hospice inpatient units, 521 relating to community palliative care services, and 208 relating to deaths in hospitals (with input from a hospital support team). There were less services taking part in 2018 than 2017 (52 vrs 72) which was predicted in consequence of the new General Data Protection Regulation (GDPR) and concerns about sending surveys to bereaved relatives. In addition, for hospital teams, the National Audit of Care at the End of Life (NACEL) was being run for the first time and some teams will have chosen to postpone taking part in FAMCARE as well.

Table 1 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).

<b>TYPE OF SERVICE</b>	<b>SAMPLING RATE</b>	<b>RESPONSE RATE</b>
Hospice inpatient unit (n = 26)	80.3%	44.9%
Home care team (n = 22)	59.6%	37.5%
Hospital support team (n = 6)	38.7%	59.9%

**Table 1**

In general, most bereaved carers were satisfied with the end-of-life care provided to their family member by the specialist palliative care service (Table 2). However, overall percentages of “dissatisfied” / “very dissatisfied” responses appear to have increased with the range now 1.2 - 5.1% (0.66 – 3.78% in 2017). The biggest change is in the hospital support team (HST) responses which are less satisfied than in 2017. There were only 6 HST services this year with 128 responses compared to 208 in 2017 and it may be that the smaller numbers have been affected by some negative responses/experiences. It will be important to review again next year to see if this trend continues.

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1187)	Hospice inpatient (n=538)	Hospice home care (n=521)	Hospital support team (n=128)
The patient's comfort	Very satisfied	72.3%	79.9%	67.9%	57.8%
	Satisfied	16.0%	12.1%	18.4%	22.7%
	Neither satisfied or dissatisfied	3.5%	1.9%	4.6%	6.3%
	Dissatisfied	2.5%	0.9%	2.9%	6.3%
	Very dissatisfied	2.4%	2.4%	3.3%	7.0%
	Not relevant	2.5%	2.8%	2.9%	0.0%
The way in which the patient's condition and likely progress has been explained by the palliative care team	Very satisfied	65.5%	69.9%	63.1%	56.3%
	Satisfied	20.0%	17.5%	21.3%	25.0%
	Neither satisfied or dissatisfied	3.6%	3.0%	4.2%	3.9%
	Dissatisfied	2.9%	2.0%	3.3%	5.5%
	Very dissatisfied	3.6%	2.8%	4.0%	5.5%
	Not relevant	4.4%	4.8%	4.0%	3.9%
Information given about side effects of treatment	Very satisfied	47.1%	49.4%	47.2%	36.7%
	Satisfied	21.2%	19.0%	23.2%	22.7%
	Neither satisfied or dissatisfied	7.2%	5.8%	9.2%	5.5%
	Dissatisfied	2.9%	1.9%	3.3%	5.5%
	Very dissatisfied	3.8%	3.3%	3.6%	6.3%
	Not relevant	17.8%	20.6%	13.4%	23.4%
The way in which the palliative care team respected the patient's dignity	Very satisfied	83.1%	85.7%	81.8%	77.3%
	Satisfied	8.3%	7.2%	9.2%	9.4%
	Neither satisfied or dissatisfied	1.9%	0.9%	2.1%	4.7%
	Dissatisfied	1.2%	0.4%	1.3%	3.9%
	Very dissatisfied	2.5%	2.4%	2.3%	3.9%
	Not relevant	3.0%	3.3%	3.3%	0.8%
Meetings with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	62.3%	67.1%	60.5%	49.2%
	Satisfied	18.4%	15.6%	18.8%	28.1%
	Neither satisfied or dissatisfied	4.8%	3.9%	6.0%	3.9%
	Dissatisfied	2.4%	2.2%	2.3%	3.9%
	Very dissatisfied	4.0%	3.2%	3.5%	9.4%
	Not relevant	8.2%	8.0%	9.0%	5.5%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1187)	Hospice inpatient (n=538)	Hospice home care (n=521)	Hospital support team (n=128)
		Speed with which symptoms were treated	Very satisfied	61.4%	67.8%
	Satisfied	20.0%	17.5%	21.1%	25.8%
	Neither satisfied or dissatisfied	5.20%	3.0%	5.8%	12.5%
	Dissatisfied	2.8%	1.5%	3.5%	5.5%
	Very dissatisfied	4.1%	4.3%	3.3%	7.0%
	Not relevant	6.5%	5.9%	7.3%	5.5%
Palliative care team's attention to the patient's description of symptoms	Very satisfied	60.9%	64.5%	62.8%	38.3%
	Satisfied	19.3%	17.7%	20.0%	23.4%
	Neither satisfied or dissatisfied	3.4%	2.2%	3.3%	8.6%
	Dissatisfied	1.5%	0.7%	1.5%	4.7%
	Very dissatisfied	3.5%	3.2%	3.1%	6.3%
	Not relevant	11.5%	11.7%	9.4%	18.8%
The way in which the patient's physical needs for comfort were met	Very satisfied	73.0%	79.6%	70.6%	55.5%
	Satisfied	14.9%	11.3%	16.3%	24.2%
	Neither satisfied or dissatisfied	3.4%	1.9%	3.8%	7.8%
	Dissatisfied	1.8%	0.7%	2.1%	4.7%
	Very dissatisfied	3.6%	3.5%	3.3%	5.5%
	Not relevant	3.3%	3.0%	3.8%	2.3%
Availability of the palliative care team to the family	Very satisfied	64.5%	69.5%	64.3%	44.5%
	Satisfied	20.5%	19.1%	19.6%	29.7%
	Neither satisfied or dissatisfied	5.0%	4.1%	4.2%	11.7%
	Dissatisfied	2.0%	1.1%	3.3%	0.8%
	Very dissatisfied	4.8%	3.3%	4.6%	11.7%
	Not relevant	3.2%	2.8%	4.0%	1.6%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1187)	Hospice inpatient (n=538)	Hospice home care (n=521)	Hospital support team (n=128)
Emotional support provided to family members by the palliative care team	Very satisfied	63.2%	67.7%	61.0%	53.1%
	Satisfied	18.2%	17.5%	18.4%	20.3%
	Neither satisfied or dissatisfied	5.7%	4.5%	5.8%	10.9%
	Dissatisfied	2.6%	1.3%	4.0%	2.3%
	Very dissatisfied	5.1%	3.9%	5.2%	10.2%
	Not relevant	5.1%	5.2%	5.6%	3.1%
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	52.5%	59.1%	52.0%	26.6%
	Satisfied	12.0%	10.0%	14.4%	10.2%
	Neither satisfied or dissatisfied	3.5%	3.2%	3.8%	3.1%
	Dissatisfied	1.3%	0.6%	2.1%	1.6%
	Very dissatisfied	3.7%	3.0%	3.6%	7.0%
	Not relevant	27.0%	24.2%	24.0%	51.6%
The doctors attention to the patient's symptoms	Very satisfied	61.4%	73.8%	51.6%	49.2%
	Satisfied	17.4%	13.2%	20.3%	22.7%
	Neither satisfied or dissatisfied	5.8%	3.2%	7.1%	11.7%
	Dissatisfied	2.5%	1.1%	3.6%	3.9%
	Very dissatisfied	4.7%	3.9%	5.2%	6.3%
	Not relevant	8.2%	4.8%	12.1%	6.3%
The way the family was included in treatment and care decisions	Very satisfied	65.8%	70.4%	64.5%	51.6%
	Satisfied	17.9%	14.7%	19.4%	25.0%
	Neither satisfied or dissatisfied	4.1%	4.1%	4.0%	4.7%
	Dissatisfied	1.6%	1.9%	1.0%	3.1%
	Very dissatisfied	4.5%	3.2%	5.0%	7.8%
	Not relevant	6.1%	5.8%	6.1%	7.8%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1187)	Hospice inpatient (n=538)	Hospice home care (n=521)	Hospital support team (n=128)
Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	55.3%	55.9%	60.1%	33.6%
	Satisfied	18.5%	16.5%	20.3%	19.5%
	Neither satisfied or dissatisfied	5.7%	5.0%	5.0%	11.7%
	Dissatisfied	1.6%	1.1%	1.2%	5.5%
	Very dissatisfied	3.7%	2.2%	4.6%	6.3%
	Not relevant	15.1%	19.1%	8.8%	23.4%
How effectively the palliative care team managed the patient's symptoms	Very satisfied	66.9%	72.5%	64.9%	51.6%
	Satisfied	18.3%	17.1%	18.2%	23.4%
	Neither satisfied or dissatisfied	4.5%	3.2%	4.8%	8.6%
	Dissatisfied	1.6%	0.7%	2.1%	3.1%
	Very dissatisfied	3.8%	3.2%	3.6%	7.0%
	Not relevant	5.0%	3.3%	6.3%	6.3%
The palliative care team's response to changes in the patient's care needs	Very satisfied	66.8%	72.9%	65.1%	48.4%
	Satisfied	17.0%	13.0%	18.8%	26.6%
	Neither satisfied or dissatisfied	3.8%	3.9%	3.3%	5.5%
	Dissatisfied	1.8%	0.7%	2.3%	3.9%
	Very dissatisfied	4.0%	3.3%	3.6%	7.8%
	Not relevant	6.7%	6.1%	6.9%	7.8%
Emotional support provided to the patient by the palliative care team	Very satisfied	64.0%	70.1%	62.0%	46.9%
	Satisfied	15.7%	11.9%	18.8%	18.8%
	Neither satisfied or dissatisfied	5.5%	3.7%	5.6%	12.5%
	Dissatisfied	1.9%	1.1%	2.5%	2.3%
	Very dissatisfied	4.3%	3.5%	4.2%	7.8%
	Not relevant	8.7%	9.7%	6.9%	11.7%