



Association for Palliative Medicine

FAMCARE 2019

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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Introduction

The service evaluation ran from the beginning of August to the end of September 2019 and relates to patients who died between 1st June 2019 and 31st August 2019.

57 specialist palliative care services in the UK and Ireland took part: 29 hospice inpatient units, 23 home care teams and 5 hospital support teams. A total of 1231 surveys were returned, with 547 relating to deaths in hospice inpatient units, 577 relating to community palliative care services and 107 relating to deaths in hospitals (with input from a hospital support team).

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).

Table 1

TYPE OF SERVICE	SAMPLING RATE	RESPONSE RATE
Hospice inpatient unit (n = 29)	77.1	39.0%
Home care team (n = 23)	61.5	36.3%
Hospital support team (n = 5)	66.5	32.3%

Results

The response rates for the hospice inpatient unit, home care team and hospital support teams last year were 44.9%, 37.5% and 59.9% respectively; higher than the rates seen this year. The greatest difference is seen in response rates from the hospital support team, however the number of surveys returned has remained low for the second year in a row (107 in 2019, compared to 128 in 2018 and 208 in 2017).

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). Overall percentages of 'very satisfied' responses appear similar, with the range being 47.2%-84.5% (47.1-83.1% in 2018).

Overall percentages of 'dissatisfied' / 'very dissatisfied' responses appear to have reduced with the range now 0.73-4.79 (1.2 - 5.1% in 2018). The highest level of dissatisfaction in 2019 was 'emotional support provided to family members by the palliative care team' - the same as in 2018 (4.8% and 5.1% in 2018).

Discussion

There were slightly more services taking part in 2019 than 2018 (57 vs. 52) but fewer than in 2017 (72). This pattern was also seen last year and was predicted in consequence of the 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 second time and some teams may have chosen to postpone taking part in FAMCARE as well.

Results from the hospital support teams continue to be the least satisfied when compared to the other services, however only a small number of units have participated which may have affected the results. It will be important to review results again next year to see if this trend continues and it may be beneficial to compare results with NACEL.

Difficulties encountered during the data collection process included the length of time for relatives to return surveys. Steps may need to be considered to improve this but bearing in mind that response rates from all services has remained low.

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1231)	Hospice inpatient (n=547)	Hospice home care (n=577)	Hospital support team (n=107)
The patient's comfort	Very satisfied	72.7%	84.6%	64.1%	49.5%
	Satisfied	16.7%	9.7%	20.8%	29.9%
	Neither satisfied or dissatisfied	3.2%	1.5%	4.5%	4.7%
	Dissatisfied	1.8%	1.1%	1.7%	5.6%
	Very dissatisfied	3.8%	2.7%	4.0%	8.4%
	Not relevant	2.6%	0.4%	4.9%	1.9%
The way in which the patient's condition and likely progress has been explained by the palliative care team	Very satisfied	65.8%	72.8%	61.5%	53.3%
	Satisfied	19.4%	16.3%	21.1%	26.2%
	Neither satisfied or dissatisfied	4.5%	4.2%	4.3%	6.5%
	Dissatisfied	2.4%	1.3%	2.4%	7.5%
	Very dissatisfied	4.0%	2.7%	5.2%	3.7%
	Not relevant	4.0%	2.7%	5.4%	2.8%
Information given about side effects of treatment	Very satisfied	47.2%	50.8%	46.3%	33.6%
	Satisfied	18.3%	16.5%	20.5%	15.9%
	Neither satisfied or dissatisfied	7.7%	6.4%	7.8%	14.0%
	Dissatisfied	2.5%	2.4%	1.9%	6.5%
	Very dissatisfied	3.3%	2.7%	3.6%	4.7%
	Not relevant	21.0%	21.2%	19.9%	25.2%
The way in which the palliative care team respected the patient's dignity	Very satisfied	84.5%	89.6%	82.0%	72.0%
	Satisfied	7.8%	5.3%	9.2%	13.1%
	Neither satisfied or dissatisfied	1.7%	0.9%	2.3%	2.8%
	Dissatisfied	0.7%	0.2%	0.7%	3.7%
	Very dissatisfied	3.7%	3.1%	3.6%	6.5%
	Not relevant	1.6%	0.9%	2.3%	1.9%
Meetings with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	66.5%	70.4%	64.6%	56.1%
	Satisfied	15.0%	14.1%	14.9%	19.6%
	Neither satisfied or dissatisfied	4.8%	4.8%	4.9%	4.7%
	Dissatisfied	2.6%	2.6%	1.7%	7.5%
	Very dissatisfied	4.6%	2.9%	5.7%	6.5%
	Not relevant	6.7%	5.3%	8.1%	5.6%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1231)	Hospice inpatient (n=547)	Hospice home care (n=577)	Hospital support team (n=107)
Speed with which symptoms were treated	Very satisfied	65.2%	74.0%	60.1%	47.7%
	Satisfied	16.9%	14.3%	18.0%	24.3%
	Neither satisfied or dissatisfied	4.1%	2.2%	5.5%	5.6%
	Dissatisfied	2.3%	1.5%	2.4%	5.6%
	Very dissatisfied	4.4%	3.5%	4.2%	10.3%
	Not relevant	7.2%	4.6%	9.7%	6.5%
Palliative care team's attention to the patient's description of symptoms	Very satisfied	64.6%	71.5%	62.6%	40.2%
	Satisfied	15.2%	12.6%	16.3%	22.4%
	Neither satisfied or dissatisfied	3.1%	1.6%	3.8%	6.5%
	Dissatisfied	1.2%	0.9%	1.0%	3.7%
	Very dissatisfied	3.6%	3.5%	3.5%	4.7%
	Not relevant	12.4%	9.9%	12.8%	22.4%
The way in which the patient's physical needs for comfort were met	Very satisfied	73.8%	83.4%	67.9%	56.1%
	Satisfied	13.5%	11.0%	13.9%	24.3%
	Neither satisfied or dissatisfied	2.3%	1.1%	3.1%	3.7%
	Dissatisfied	1.7%	0.9%	1.9%	4.7%
	Very dissatisfied	3.7%	3.1%	3.5%	8.4%
	Not relevant	5.0%	0.6%	9.7%	2.8%
Availability of the palliative care team to the family	Very satisfied	69.2%	75.3%	67.8%	45.8%
	Satisfied	16.9%	15.7%	17.0%	22.4%
	Neither satisfied or dissatisfied	4.7%	4.2%	4.3%	9.4%
	Dissatisfied	2.4%	1.3%	2.4%	7.5%
	Very dissatisfied	4.3%	2.6%	4.9%	10.3%
	Not relevant	2.5%	0.9%	3.6%	4.7%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1231)	Hospice inpatient (n=547)	Hospice home care (n=577)	Hospital support team (n=107)
Emotional support provided to family members by the palliative care team	Very satisfied	66.3%	76.6%	61.2%	41.1%
	Satisfied	15.6%	12.8%	18.2%	15.9%
	Neither satisfied or dissatisfied	5.9%	3.7%	7.1%	10.3%
	Dissatisfied	2.0%	1.1%	6.2%	4.7%
	Very dissatisfied	4.8%	3.5%	2.3%	10.3%
	Not relevant	5.5%	2.4%	5.0%	17.8%
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	53.6%	60.9%	62.0%	25.2%
	Satisfied	9.3%	8.4%	9.4%	14.0%
	Neither satisfied or dissatisfied	3.3%	3.0%	3.0%	8.4%
	Dissatisfied	1.4%	1.1%	30.9%	1.9%
	Very dissatisfied	3.3%	2.6%	1.6%	6.5%
	Not relevant	29.2%	25.0%	3.3%	43.9%
The doctors' attention to the patient's symptoms	Very satisfied	61.9%	78.1%	48.0%	54.2%
	Satisfied	14.4%	11.3%	16.5%	18.7%
	Neither satisfied or dissatisfied	4.7%	2.7%	5.4%	11.2%
	Dissatisfied	2.3%	1.3%	2.4%	5.6%
	Very dissatisfied	4.0%	3.1%	4.9%	3.7%
	Not relevant	12.8%	3.5%	22.9%	6.5%
The way the family was included in treatment and care decisions	Very satisfied	68.7%	72.4%	68.1%	53.3%
	Satisfied	14.9%	13.9%	13.9%	25.2%
	Neither satisfied or dissatisfied	4.2%	3.3%	4.0%	10.3%
	Dissatisfied	1.6%	1.3%	1.7%	2.8%
	Very dissatisfied	4.1%	3.5%	4.9%	3.7%
	Not relevant	6.4%	5.7%	7.5%	4.7%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1231)	Hospice inpatient (n=547)	Hospice home care (n=577)	Hospital support team (n=107)
Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	57.2%	56.7%	61.7%	35.5%
	Satisfied	15.7%	14.3%	16.8%	16.8%
	Neither satisfied or dissatisfied	4.4%	3.3%	4.7%	8.4%
	Dissatisfied	2.5%	2.0%	2.4%	5.6%
	Very dissatisfied	3.9%	3.3%	4.2%	5.6%
	Not relevant	16.3%	20.5%	10.2%	28.0%
How effectively the palliative care team managed the patient's symptoms	Very satisfied	70.4%	78.4%	66.7%	48.6%
	Satisfied	15.8%	12.8%	16.3%	29.0%
	Neither satisfied or dissatisfied	3.3%	2.7%	4.0%	2.8%
	Dissatisfied	1.9%	1.3%	1.6%	6.5%
	Very dissatisfied	3.7%	2.9%	4.0%	6.5%
	Not relevant	4.9%	1.8%	7.5%	6.5%
The palliative care team's response to changes in the patient's care needs	Very satisfied	71.1%	78.2%	68.1%	50.5%
	Satisfied	13.5%	11.2%	13.9%	23.4%
	Neither satisfied or dissatisfied	2.5%	2.4%	2.8%	1.9%
	Dissatisfied	2.2%	1.1%	2.6%	5.6%
	Very dissatisfied	4.2%	3.5%	4.2%	8.4%
	Not relevant	6.5%	3.7%	8.5%	10.3%
Emotional support provided to the patient by the palliative care team	Very satisfied	67.3%	76.0%	63.6%	43.0%
	Satisfied	13.1%	9.7%	16.0%	15.0%
	Neither satisfied or dissatisfied	4.8%	3.7%	5.4%	7.5%
	Dissatisfied	2.0%	1.7%	1.9%	4.7%
	Very dissatisfied	4.1%	3.0%	4.3%	9.4%
	Not relevant	8.6%	6.0%	8.8%	20.6%