



# Association for Palliative Medicine

## BEREAVED RELATIVES SATISFACTION WITH THE END-OF-LIFE CARE PROVIDED BY SPECIALIST PALLIATIVE CARE SERVICES: A SERVICE EVALUATION BY THE ASSOCIATION FOR PALLIATIVE MEDICINE OF GREAT BRITAIN AND IRELAND (APM)

Prepared by Dr Amy Proffitt on behalf of the  
Professional Standards Committee, APM

The service evaluation was undertaken in August / October 2017 by 72 specialist palliative care services in England, i.e. 31 hospice inpatient units, 29 home care teams, and 12 hospital support teams. One thousand six hundred and sixty-eight surveys were returned, with 719 relating to deaths in hospice inpatient units, 742 relating to deaths at home (with input from a home care team), and 208 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).

<b>TYPE OF SERVICE</b>	<b>SAMPLING RATE</b>	<b>RESPONSE RATE</b>
Hospice inpatient unit (n = 31)	Median 89.2%	Median 43.13%
Home care team (n = 29)	Median 69%	Median 44.33%
Hospital support team (n = 12)	Median 65.4%	Median 12.48%

**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). Indeed, the overall median percentage of “dissatisfied” / “very dissatisfied” responses was only 2.46 % (range 0.66 – 3.78 %), with the highest level of dissatisfaction being for the item “the emotional support provided to the family members by the palliative care team”. For carers of patients that died in a hospice, the median percentage of “dissatisfied” / “very dissatisfied” responses was 1.84 % (range 0.5 – 3.5 %), with the highest levels of dissatisfaction being for the “the emotional support provided to the family members by the palliative care team”.

The median percentage of “dissatisfied” / “very dissatisfied” responses from carers of patients that died under the care of a home care team was 2.26% (range 1 – 3/58 %), with the highest levels of dissatisfaction being for the item “The way in which the patient’s condition and prognosis has been explained by the palliative care team ”. For carers of patients that died in a hospital, the median percentage of “dissatisfied” / “very dissatisfied” responses was 2.45 % (range 0.97 – 4.0%), with the highest levels of dissatisfaction being for the item “the emotional support provided to the family members by the palliative care team”.

In addition to the aforementioned quantitative data, a number of carers provided additional (qualitative) feedback on their experiences; this feedback was overwhelmingly positive in nature.

The APM received no direct complaints (from the carers), about the service evaluation. The APM are currently evaluating the on-going running of this service evaluation

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1668)	Hospice inpatient (n=718)	Hospice home care (n=742)	Hospital support team (n=208)
The patient's comfort	Very satisfied	69.89%	79.83%	65.03%	73.43%
	Satisfied	17.82%	13.00%	20.42%	15.87%
	Neither satisfied or dissatisfied	3.18%	1.50%	3.40%	3.24%
	Dissatisfied	1.80%	1%	1.89%	1.62%
	Very dissatisfied	2.58%	1.83%	2.46%	2.27%
	Not relevant	4.62%	2.83%	6.81%	3.56%
The way in which the patient's condition and likely progress has been explained by the palliative care team	Very satisfied	62.03%	70.22%	59.43%	63.97%
	Satisfied	21.00%	17.80%	23.40%	19.96%
	Neither satisfied or dissatisfied	5.76%	4.66%	3.58%	6.58%
	Dissatisfied	3.12%	2.50%	3.58%	2.91%
	Very dissatisfied	2.22%	1.66%	2.26%	2.16%
	Not relevant	5.88%	3.16%	7.74%	4.42%
Information given about side effects of treatment	Very satisfied	44.39%	48.75%	46.23%	43.78%
	Satisfied	22.02%	19.87%	23.40%	20.86%
	Neither satisfied or dissatisfied	8.70%	7.68%	8.68%	8.43%
	Dissatisfied	3.72%	3.17%	3.40%	3.78%
	Very dissatisfied	1.86%	1.84%	1.51%	1.95%
	Not relevant	19.14%	18.70%	16.79%	21.19%
The way in which the palliative care team respected the patient's dignity	Very satisfied	79.24%	84.00%	80.38%	78.94%
	Satisfied	10.68%	8.83%	9.62%	11.23%
	Neither satisfied or dissatisfied	2.58%	1.50%	3.02%	2.48%
	Dissatisfied	0.66%	0.67%	1%	0.97%
	Very dissatisfied	1.92%	1.33%	1.32%	1.94%
	Not relevant	4.86%	3.67%	5.28%	4.43%
Meetings with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	59.15%	64.94%	59.62%	60.11%
	Satisfied	19.92%	18.03%	20.57%	19.03%
	Neither satisfied or dissatisfied	5.34%	4.51%	6.60%	4.76%
	Dissatisfied	2.40%	2%	1.32%	2.81%
	Very dissatisfied	3.48%	2.84%	2.64%	3.68%
	Not relevant	9.60%	7.68%	9.25%	9.62%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1668)	Hospice inpatient (n=718)	Hospice home care (n=742)	Hospital support team (n=208)
Speed with which symptoms were treated	Very satisfied	60.05%	70.38%	57.74%	62.89%
	Satisfied	19.50%	16.47%	20%	19.20%
	Neither satisfied or dissatisfied	5.70%	3.16%	6.79%	4.31%
	Dissatisfied	2.76%	1.50%	2.83%	2.80%
	Very dissatisfied	3.42%	2.83%	3.21%	3.67%
	Not relevant	8.58%	5.66%	9.43%	7.12%
Palliative care team's attention to the patient's description of symptoms	Very satisfied	59.03%	66.22%	60.57%	58.96%
	Satisfied	19.62%	17.47%	19.43%	18.47%
	Neither satisfied or dissatisfied	5.28%	3.49%	6.60%	4.54%
	Dissatisfied	1.74%	0.67%	2.08%	1.40%
	Very dissatisfied	2.76%	2.50%	1.51%	3.13%
	Not relevant	11.52%	9.65%	9.81%	13.50%
The way in which the patient's physical needs for comfort were met	Very satisfied	71.15%	80.20%	69.06%	73.54%
	Satisfied	15.42%	12.65%	15.09%	15.23%
	Neither satisfied or dissatisfied	3.54%	1.33%	4.34%	2.81%
	Dissatisfied	1.50%	0.83%	2.08%	1.40%
	Very dissatisfied	2.88%	2.16%	2.08%	2.81%
	Not relevant	5.46%	2.83%	7.36%	4.21%
Availability of the palliative care team to the family	Very satisfied	61.49%	70.83%	60.94%	63.24%
	Satisfied	21.42%	17.67%	20.75%	20.65%
	Neither satisfied or dissatisfied	6.06%	3.67%	6.42%	6.27%
	Dissatisfied	2.52%	1.17%	3.02%	2.05%
	Very dissatisfied	3.00%	2.50%	3.02%	2.49%
	Not relevant	5.40%	4.17%	5.85%	5.30%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1668)	Hospice inpatient (n=718)	Hospice home care (n=742)	Hospital support team (n=208)
Emotional support provided to family members by the palliative care team	Very satisfied	62.15%	72.50%	59.25%	65.19%
	Satisfied	18.84%	14.00%	21.13%	16.86%
	Neither satisfied or dissatisfied	6.42%	5.67%	5.47%	7.03%
	Dissatisfied	1.56%	0.50%	1.89%	1.51%
	Very dissatisfied	3.78%	3.50%	3.02%	4%
	Not relevant	7.14%	3.83%	9.25%	5.41%
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	53.33%	60.40%	54.72%	52.43%
	Satisfied	13.32%	13.81%	12.26%	13.70%
	Neither satisfied or dissatisfied	4.86%	3.49%	4.72%	4.53%
	Dissatisfied	1.50%	0.83%	1.51%	1.51%
	Very dissatisfied	2.58%	2.33%	3.02%	2.27%
	Not relevant	24.3%	19.13%	23.77%	25.57%
The doctors attention to the patient's symptoms	Very satisfied	58.85%	70.88%	50.75%	64.08%
	Satisfied	20.28%	16.64%	20.57%	20.50%
	Neither satisfied or dissatisfied	6.00%	3.66%	7.74%	4.64%
	Dissatisfied	2.22%	0.83%	2.45%	1.83%
	Very dissatisfied	2.76%	2.33%	3.21%	2.37%
	Not relevant	9.90%	5.66%	15.28%	6.58%
The way the family was included in treatment and care decisions	Very satisfied	60.59%	66.56%	60.94%	61.58%
	Satisfied	20.16%	18.23%	20.57%	19.70%
	Neither satisfied or dissatisfied	5.28%	4.18%	5.66%	4.98%
	Dissatisfied	2.16%	1.67%	1.70%	2.38%
	Very dissatisfied	3.30%	3.18%	2.26%	3.90%
	Not relevant	8.34%	6.19%	8.87%	7.47%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1668)	Hospice inpatient (n=718)	Hospice home care (n=742)	Hospital support team (n=208)
Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	51.29%	54.91%	56.60%	48.11%
	Satisfied	19.50%	16.64%	21.70%	17.26%
	Neither satisfied or dissatisfied	6.30%	5.49%	6.98%	6.15%
	Dissatisfied	1.98%	1.16%	2.08%	1.83%
	Very dissatisfied	2.76%	2.66%	1.89%	2.91%
	Not relevant	18.18%	19.13%	10.75%	23.73%
How effectively the palliative care team managed the patient's symptoms	Very satisfied	63.11%	71.55%	60.57%	65.59%
	Satisfied	20.40%	17.47%	20.75%	19.74%
	Neither satisfied or dissatisfied	4.08%	2.50%	4.91%	3.88%
	Dissatisfied	2.58%	1.33%	3.40%	2.05%
	Very dissatisfied	2.82%	2.66%	1.89%	3.13%
	Not relevant	7.02%	4.49%	8.49%	5.61%
The palliative care team's response to changes in the patient's care needs	Very satisfied	63.59%	73.04%	61.70%	65.48%
	Satisfied	18.78%	15.81%	18.87%	18.66%
	Neither satisfied or dissatisfied	3.84%	1.83%	5.09%	2.91%
	Dissatisfied	1.98%	1.33%	1.89%	2.16%
	Very dissatisfied	2.88%	2.16%	2.26%	2.91%
	Not relevant	8.94%	5.82%	10.19%	7.87%
Emotional support provided to the patient by the palliative care team	Very satisfied	62.87%	71.05%	62.08%	63.75%
	Satisfied	17.22%	14.14%	18.30%	16.07%
	Neither satisfied or dissatisfied	6.00%	4.66%	6.60%	5.72%
	Dissatisfied	1.68%	1%	1.32%	2.05%
	Very dissatisfied	2.82%	1.83%	3.02%	2.48%
	Not relevant	9.42%	7.32%	8.68%	9.92%