



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)

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The service evaluation was undertaken in August to September 2016 (re deaths June to August 2016) by 59 specialist palliative care services in England, i.e. 29 hospice inpatient units, 22 home care teams, and 8 hospital support teams. One thousand two hundred and thirty three questionnaires were returned, with 601 relating to deaths in hospice inpatient units, 530 relating to deaths at home (with input from a home care team), and 102 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).

TYPE OF SERVICE	SAMPLING RATE	RESPONSE RATE
Hospice inpatient unit (n =29)	Median 80% (range 33-100%)	Median 49%
Home care team (n=22)	Median 70% (range 24-100%)	Median 43%
Hospital support team (n= 8)	Median 49% (range 33-88%)	Median 26%

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 1.97% (range 0.65 – 3.49 %), and lower than 2015 median percentage of 3.65% (range 2.01 – 5.29 %). The highest level of dissatisfaction in 2016 was for the item “The doctors’ attention to the patient’s symptoms”. In 2015 it was for the item “speed with which symptoms were treated”.

For carers of patients that died in a hospice, the median percentage of “dissatisfied” / “very dissatisfied” responses was 1.22% (range 0.5 – 2.16%), with the highest levels of dissatisfaction being for the item “Meetings with the palliative care team to discuss the patients condition and plan of care”.

The median percentage of “dissatisfied” / “very dissatisfied” responses from carers of patients that died under the care of a home care team was 2.04% (range 0.75 – 4.91%), compared with 3.29% (range 2.12 – 4.94%) in 2015, with the highest levels of dissatisfaction being for the item “The doctors attention to the patient’s symptoms”. For carers of patients that died in a hospital, the median percentage of “dissatisfied” / “very dissatisfied” responses was 6.10% (range 0.00 – 12.75%), with the highest levels of dissatisfaction being for the item “The patient’s comfort”.

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 a letter from a relative who was distressed by the survey which he had received only a few weeks after the death of his spouse. We have amended the guidance to reinforce the need to leave a gap between bereavement and sending out the survey. The chair of the PSC has written a response explaining our actions and expressing our concern.

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1233)	Hospice inpatient (n=601)	Hospice home care (n=530)	Hospital support team (n=102)
The patient's comfort	Very satisfied	69.18%	77.87%	63.40%	48.04%
	Satisfied	20.03%	16.47%	23.21%	24.51%
	Neither satisfied or dissatisfied	2.35%	1.50%	2.64%	5.88%
	Dissatisfied	1.54%	0.67%	2.26%	2.94%
	Very dissatisfied	2.35%	1.00%	1.89%	12.75%
	Not relevant	4.54%	2.50%	6.60%	5.88%
The way in which the patient's condition and likely progress has been explained by the palliative care team	Very satisfied	62.45%	68.55%	58.30%	48.04%
	Satisfied	23.03%	21.46%	23.58%	29.41%
	Neither satisfied or dissatisfied	4.79%	3.83%	5.85%	4.90%
	Dissatisfied	2.68%	2.00%	3.58%	1.96%
	Very dissatisfied	2.51%	2.00%	1.70%	9.80%
	Not relevant	4.54%	2.16%	6.98%	5.88%
Information given about side effects of treatment	Very satisfied	44.85%	47.59%	44.15%	32.35%
	Satisfied	23.20%	23.46%	23.58%	19.61%
	Neither satisfied or dissatisfied	9.25%	8.82%	9.25%	11.76%
	Dissatisfied	2.51%	1.83%	3.21%	2.94%
	Very dissatisfied	2.19%	1.50%	1.51%	9.80%
	Not relevant	18.00%	16.81%	18.30%	23.53%
The way in which the palliative care team respected the patient's dignity	Very satisfied	81.51%	87.19%	79.25%	59.80%
	Satisfied	10.30%	8.15%	11.13%	18.63%
	Neither satisfied or dissatisfied	1.95%	0.83%	3.02%	2.94%
	Dissatisfied	0.65%	0.17%	0.75%	2.94%
	Very dissatisfied	1.46%	1.16%	0.94%	5.88%
	Not relevant	4.14%	2.50%	4.91%	9.80%
Meetings with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	58.88%	62.56%	57.36%	45.10%
	Satisfied	22.06%	22.30%	21.13%	25.49%
	Neither satisfied or dissatisfied	5.84%	4.83%	6.79%	6.86%
	Dissatisfied	1.95%	2.16%	1.70%	1.96%
	Very dissatisfied	2.84%	1.83%	2.26%	11.76%
	Not relevant	8.43%	6.32%	10.75%	8.82%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1233)	Hospice inpatient (n=601)	Hospice home care (n=530)	Hospital support team (n=102)
Speed with which symptoms were treated	Very satisfied	59.69%	65.72%	56.98%	38.24%
	Satisfied	22.63%	20.80%	23.58%	28.43%
	Neither satisfied or dissatisfied	4.79%	3.83%	4.91%	9.80%
	Dissatisfied	2.19%	1.33%	2.83%	3.92%
	Very dissatisfied	2.03%	1.00%	2.08%	7.84%
	Not relevant	8.68%	7.32%	9.62%	11.76%
Palliative care team's attention to the patient's description of symptoms	Very satisfied	60.10%	65.89%	57.92%	37.25%
	Satisfied	21.25%	19.63%	23.21%	20.59%
	Neither satisfied or dissatisfied	4.79%	3.66%	4.91%	10.78%
	Dissatisfied	1.05%	0.33%	1.89%	0.98%
	Very dissatisfied	1.62%	1.16%	0.75%	8.82%
	Not relevant	11.19%	9.32%	11.32%	21.57%
The way in which the patient's physical needs for comfort were met	Very satisfied	71.86%	79.87%	66.79%	50.98%
	Satisfied	16.95%	14.14%	19.25%	21.57%
	Neither satisfied or dissatisfied	2.76%	1.50%	3.58%	5.88%
	Dissatisfied	1.78%	1.16%	1.89%	4.90%
	Very dissatisfied	1.62%	0.83%	0.94%	9.80%
	Not relevant	5.03%	2.50%	7.55%	6.86%
Availability of the palliative care team to the family	Very satisfied	63.99%	68.72%	62.83%	42.16%
	Satisfied	22.22%	21.13%	22.64%	26.47%
	Neither satisfied or dissatisfied	4.30%	3.49%	5.09%	4.90%
	Dissatisfied	2.27%	1.66%	2.64%	3.92%
	Very dissatisfied	2.27%	1.33%	1.51%	11.76%
	Not relevant	4.95%	3.66%	5.28%	10.78%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1233)	Hospice inpatient (n=601)	Hospice home care (n=530)	Hospital support team (n=102)
Emotional support provided to family members by the palliative care team	Very satisfied	62.61%	70.88%	56.42%	46.08%
	Satisfied	19.55%	18.47%	21.51%	15.69%
	Neither satisfied or dissatisfied	6.24%	3.83%	7.74%	12.75%
	Dissatisfied	1.70%	1.33%	2.08%	1.96%
	Very dissatisfied	2.68%	1.50%	2.26%	11.76%
	Not relevant	7.22%	3.99%	10.00%	11.76%
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	52.47%	57.90%	51.13%	27.45%
	Satisfied	15.25%	15.97%	15.28%	10.78%
	Neither satisfied or dissatisfied	5.11%	3.83%	5.47%	10.78%
	Dissatisfied	1.46%	0.83%	2.08%	1.96%
	Very dissatisfied	1.54%	0.83%	1.13%	7.84%
	Not relevant	24.17%	20.63%	24.91%	41.18%
The doctors attention to the patient's symptoms	Very satisfied	59.61%	70.22%	50.57%	44.12%
	Satisfied	19.63%	17.97%	19.81%	28.43%
	Neither satisfied or dissatisfied	6.16%	5.16%	7.36%	5.88%
	Dissatisfied	2.03%	0.67%	3.58%	1.96%
	Very dissatisfied	3.49%	1.50%	4.91%	7.84%
	Not relevant	9.08%	4.49%	13.77%	11.76%
The way the family was included in treatment and care decisions	Very satisfied	61.88%	65.89%	60.19%	47.06%
	Satisfied	21.57%	20.13%	22.64%	24.51%
	Neither satisfied or dissatisfied	5.68%	5.32%	5.28%	9.80%
	Dissatisfied	1.54%	1.33%	1.70%	1.96%
	Very dissatisfied	2.60%	2.16%	1.89%	8.82%
	Not relevant	6.65%	5.16%	8.11%	7.84%
	Missing	0.08%			

Aspect of care	Degree of satisfaction	Setting			
		All settings (n=1233)	Hospice inpatient (n=601)	Hospice home care (n=530)	Hospital support team (n=102)
Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	51.42%	52.91%	60.30%	28.43%
	Satisfied	22.38%	20.13%	22.68%	22.55%
	Neither satisfied or dissatisfied	5.68%	5.49%	5.29%	9.80%
	Dissatisfied	2.11%	1.50%	1.70%	0.98%
	Very dissatisfied	2.27%	1.33%	1.89%	10.78%
	Not relevant	16.06%	18.64%	8.13%	27.45%
	Missing	0.08%			
How effectively the palliative care team managed the patient's symptoms	Very satisfied	62.53%	69.88%	54.25%	44.12%
	Satisfied	21.98%	20.80%	24.95%	22.55%
	Neither satisfied or dissatisfied	4.70%	2.66%	5.10%	9.80%
	Dissatisfied	1.38%	1.00%	3.02%	0.98%
	Very dissatisfied	2.27%	1.00%	1.70%	12.75%
	Not relevant	7.06%	4.66%	10.96%	9.80%
	Missing	0.08%			
The palliative care team's response to changes in the patient's care needs	Very satisfied	65.45%	73.21%	57.84%	47.06%
	Satisfied	19.06%	16.81%	23.25%	21.57%
	Neither satisfied or dissatisfied	4.79%	3.16%	6.05%	8.82%
	Dissatisfied	1.30%	0.50%	1.89%	2.94%
	Very dissatisfied	1.95%	0.83%	1.70%	9.80%
	Not relevant	7.38%	5.49%	9.26%	9.80%
	Missing	0.08%			
Emotional support provided to the patient by the palliative care team	Very satisfied	62.45%	71.21%	60.30%	37.25%
	Satisfied	20.44%	15.81%	21.17%	26.47%
	Neither satisfied or dissatisfied	5.27%	3.66%	5.86%	10.78%
	Dissatisfied	1.14%	0.83%	1.89%	0.00%
	Very dissatisfied	2.19%	1.66%	1.70%	10.78%
	Not relevant	8.43%	6.82%	9.07%	14.71%
	Missing	0.08%			