

**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)**

Dr Andrew Davies & Dr Amy Proffitt

Professional Standards Committee, APM

The service evaluation was undertaken in August to September 2015 (re deaths June to August 2015) by 52 specialist palliative care services in England, i.e. 27 hospice inpatient units, 15 home care teams, and 10 hospital support teams. One thousand three hundred and fifty five questionnaires were returned, with 601 relating to deaths in hospice inpatient units, 439 relating to deaths at home (with input from a home care team), and 315 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 = 27)	Median 89% (range: 56 – 100%)	Median 54% (range: 25-80%)
Home care team (n = 15)	Median 64% (range: 31 – 100%)	Median 49% (range: 33-100%)
Hospital support team (n = 10)	Median 70% (range: 27 – 89%)	Median 45% (range: 24-57%)

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 3.65% (range 2.01 – 5.29 %), with the highest level of dissatisfaction being 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 2.53% (range 1.52 – 3.71%), with the highest levels of dissatisfaction being for the item “the doctors attention to the patient’s symptoms”.

The median percentage of “dissatisfied” / “very dissatisfied” responses from carers of patients that died under the care of a home care team was 3.29% (range 2.12 – 4.94%), with the highest levels of dissatisfaction being for the item “speed with which symptoms were treated”. For carers of patients that died in a hospital, the median percentage of “dissatisfied” / “very dissatisfied” responses was 5.41% (range 2.55 – 9.56%), with the highest levels of dissatisfaction being for the item “speed with which symptoms were treated”.

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 complaints (from the carers) about the service evaluation.

It should be noted that the service evaluation takes up a significant amount of secretariat time (i.e. 70 hours during the period September 2014 and August 2015). The APM Executive Committee has discussed charging units / members a nominal fee to cover the administration costs of future service evaluations.

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 1355)	Hospice inpatient (n = 601)	Hospice home care (n = 439)	Hospital support team (n = 315)
The patient's comfort	Very satisfied	67.06%	75.89%	63.53%	55.10%
	Satisfied	24.22%	19.39%	26.35%	30.57%
	Neither satisfied or dissatisfied	2.46%	1.35%	2.12%	5.10%
	Dissatisfied	1.79%	1.18%	2.35%	2.23%
	Very dissatisfied	1.12%	0.34%	1.65%	1.91%
	Not relevant	3.35%	1.85%	4.00%	5.10%
The way in which the patient's condition and likely progress has been explained by the palliative care team	Very satisfied	59.76%	66.10%	55.76%	52.23%
	Satisfied	26.15%	23.44%	27.53%	29.94%
	Neither satisfied or dissatisfied	4.47%	4.22%	5.18%	4.14%
	Dissatisfied	1.86%	2.02%	1.65%	1.91%
	Very dissatisfied	1.71%	0.84%	1.41%	3.82%
	Not relevant	6.04%	3.37%	8.47%	7.96%
Information given about side effects of treatment	Very satisfied	40.83%	45.36%	38.12%	34.39%
	Satisfied	27.57%	23.10%	31.06%	31.85%
	Neither satisfied or dissatisfied	10.66%	9.61%	10.35%	13.38%
	Dissatisfied	1.86%	2.36%	1.65%	1.27%
	Very dissatisfied	1.34%	0.84%	1.41%	2.23%
	Not relevant	17.66%	18.72%	17.41%	16.56%
The way in which the palliative care team respected the patient's dignity	Very satisfied	79.51%	85.50%	78.59%	69.75%
	Satisfied	13.86%	10.46%	14.35%	19.43%
	Neither satisfied or dissatisfied	1.79%	1.01%	1.41%	3.82%
	Dissatisfied	0.97%	0.84%	0.47%	1.91%
	Very dissatisfied	1.04%	0.67%	1.65%	0.64%
	Not relevant	2.83%	1.52%	3.53%	4.46%
Meetings with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	59.39%	63.91%	59.06%	50.96%
	Satisfied	24.74%	22.43%	23.53%	30.89%
	Neither satisfied or dissatisfied	4.99%	4.55%	5.65%	5.10%
	Dissatisfied	1.64%	1.18%	1.18%	3.18%
	Very dissatisfied	2.01%	1.35%	2.12%	2.87%
	Not relevant	7.23%	6.58%	8.47%	7.01%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 1355)	Hospice inpatient (n = 601)	Hospice home care (n = 439)	Hospital support team (n = 315)
Speed with which symptoms were treated	Very satisfied	58.20%	65.77%	55.06%	47.45%
	Satisfied	24.81%	22.26%	27.06%	27.07%
	Neither satisfied or dissatisfied	4.77%	4.72%	3.76%	6.37%
	Dissatisfied	2.76%	1.85%	2.82%	4.46%
	Very dissatisfied	2.53%	1.35%	2.12%	5.10%
	Not relevant	6.86%	4.05%	8.94%	9.55%
Palliative care team's attention to the patient's description of symptoms	Very satisfied	57.30%	64.76%	56.94%	42.99%
	Satisfied	23.92%	21.75%	26.35%	25.16%
	Neither satisfied or dissatisfied	4.47%	2.53%	3.76%	9.24%
	Dissatisfied	1.79%	1.35%	1.65%	2.87%
	Very dissatisfied	0.97%	0.67%	0.94%	1.27%
	Not relevant	11.55%	8.94%	10.35%	18.47%
The way in which the patient's physical needs for comfort were met	Very satisfied	66.54%	77.23%	59.29%	55.73%
	Satisfied	19.60%	15.85%	18.82%	28.03%
	Neither satisfied or dissatisfied	3.43%	2.70%	2.59%	6.05%
	Dissatisfied	1.42%	1.18%	1.18%	2.23%
	Very dissatisfied	2.01%	1.35%	2.12%	2.87%
	Not relevant	7.00%	1.69%	16.00%	5.10%
Availability of the palliative care team to the family	Very satisfied	63.34%	69.65%	64.24%	49.68%
	Satisfied	23.92%	20.91%	23.06%	31.21%
	Neither satisfied or dissatisfied	4.55%	3.71%	4.00%	7.01%
	Dissatisfied	1.19%	1.01%	0.71%	2.23%
	Very dissatisfied	2.61%	1.35%	2.82%	4.46%
	Not relevant	4.32%	3.20%	5.18%	5.41%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 1355)	Hospice inpatient (n = 601)	Hospice home care (n = 439)	Hospital support team (n = 315)
Emotional support provided to family members by the palliative care team	Very satisfied	63.71%	71.84%	57.88%	55.73%
	Satisfied	20.19%	16.53%	24.94%	21.02%
	Neither satisfied or dissatisfied	5.66%	4.55%	4.00%	10.19%
	Dissatisfied	1.49%	1.85%	0.71%	1.91%
	Very dissatisfied	2.24%	1.18%	3.06%	2.87%
	Not relevant	6.71%	4.05%	9.41%	8.28%
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	50.22%	59.70%	43.76%	40.45%
	Satisfied	16.32%	16.36%	15.29%	17.83%
	Neither satisfied or dissatisfied	4.17%	4.55%	2.59%	5.73%
	Dissatisfied	1.19%	0.67%	0.94%	2.55%
	Very dissatisfied	1.42%	0.67%	1.65%	2.23%
	Not relevant	26.68%	18.04%	35.76%	31.21%
The doctors attention to the patient's symptoms	Very satisfied	59.17%	70.66%	47.76%	52.55%
	Satisfied	21.24%	17.37%	21.88%	27.71%
	Neither satisfied or dissatisfied	5.74%	4.38%	6.35%	7.64%
	Dissatisfied	2.01%	2.36%	1.41%	2.23%
	Very dissatisfied	1.94%	1.35%	1.65%	3.18%
	Not relevant	9.91%	3.88%	20.94%	6.69%
The way the family was included in treatment and care decisions	Very satisfied	62.97%	68.13%	59.06%	57.96%
	Satisfied	21.24%	18.38%	25.41%	21.34%
	Neither satisfied or dissatisfied	4.47%	4.22%	4.71%	4.78%
	Dissatisfied	2.09%	1.52%	0.47%	5.41%
	Very dissatisfied	1.94%	1.35%	1.65%	3.18%
	Not relevant	7.23%	6.24%	8.71%	7.32%

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 1355)	Hospice inpatient (n = 601)	Hospice home care (n = 439)	Hospital support team (n = 315)
Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	49.40%	54.30%	49.88%	39.17%
	Satisfied	23.62%	19.06%	28.24%	26.11%
	Neither satisfied or dissatisfied	5.89%	4.72%	6.59%	7.32%
	Dissatisfied	2.24%	2.19%	1.41%	3.50%
	Very dissatisfied	1.64%	0.51%	1.88%	3.18%
	Not relevant	17.21%	19.22%	12.00%	20.70%
How effectively the palliative care team managed the patient's symptoms	Very satisfied	62.37%	71.50%	57.88%	50.64%
	Satisfied	24.89%	20.24%	29.41%	28.03%
	Neither satisfied or dissatisfied	4.10%	3.71%	1.88%	7.96%
	Dissatisfied	1.64%	1.01%	2.12%	2.23%
	Very dissatisfied	1.86%	0.84%	2.12%	3.18%
	Not relevant	5.14%	2.70%	6.59%	7.96%
The palliative care team's response to changes in the patient's care needs	Very satisfied	64.61%	72.85%	61.65%	52.87%
	Satisfied	21.24%	16.69%	24.94%	24.84%
	Neither satisfied or dissatisfied	4.32%	3.88%	3.53%	6.37%
	Dissatisfied	1.79%	1.35%	0.94%	3.82%
	Very dissatisfied	2.09%	1.01%	2.12%	3.82%
	Not relevant	5.96%	4.22%	6.82%	8.28%
Emotional support provided to the patient by the palliative care team	Very satisfied	62.37%	71.84%	59.76%	47.45%
	Satisfied	20.57%	14.84%	25.18%	25.48%
	Neither satisfied or dissatisfied	5.74%	4.89%	4.71%	8.92%
	Dissatisfied	1.71%	1.52%	1.41%	2.55%
	Very dissatisfied	2.09%	0.84%	2.59%	3.50%
	Not relevant	7.53%	6.07%	6.35%	12.10%

Table 2