

**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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Professional Standards Committee, APM

The service evaluation was undertaken in August / September 2014 by 38 specialist palliative care services in England, i.e. 16 hospice inpatient units, 10 home care teams, and 12 hospital support teams. Eight hundred and six questionnaires were returned, with 369 relating to deaths in hospice inpatient units, 145 relating to deaths at home (with input from a home care team), and 292 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 = 16)	Median 78% (range: 41 – 100%)	Median 61% (range: 52 – 86%)
Home care team (n = 10)	Median 75% (range: 43 – 100%)	Median 44% (range: 0 – 60%)
Hospital support team (n = 12)	Median 48% (range: 34 – 100%)	Median 36% (range: 19 – 47%)

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 4.5 % (range 1.5 – 6.5 %), with the highest level of dissatisfaction being for the item “the doctors attention to the patient’s symptoms”. For carers of patients that died in a hospice, the median percentage of “dissatisfied” / “very dissatisfied” responses was 1.5 % (range 0.5 – 2.5 %), with the highest levels of dissatisfaction being for the items “speed with which symptoms were treated”, “the doctors attention to the patient’s symptoms”, and “the palliative care team’s response to changes in the patient’s care needs”.

The median percentage of “dissatisfied” / “very dissatisfied” responses from carers of patients that died under the care of a home care team was 5.5% (range 2.5 – 8 %), 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 7 % (range 2.5 – 11.5 %), 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 two indirect (from the services) complaints, and no direct complaints (from the carers), about the service evaluation.

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 806)	Hospice inpatient (n = 369)	Hospice home care (n = 145)	Hospital support team (n = 292)
The patient's comfort	Very satisfied	552 (68.5%)	296 (80.0%)	89 (61.5%)	167 (57.0%)
	Satisfied	178 (22.0%)	51 (14.0%)	40 (27.5%)	87 (30.0%)
	Neither satisfied or dissatisfied	21 (3.0%)	5 (1.5%)	5 (3.5%)	11 (4.0%)
	Dissatisfied	16 (2.0%)	3 (1.0%)	1 (0.5%)	12 (4.0%)
	Very dissatisfied	9 (1.0%)	0 (0.0%)	3 (2.0%)	6 (2.0%)
	Not relevant	29 (3.5%)	13 (3.5%)	7 (5.0%)	9 (3.0%)
	No response	1 (0.0%)	1 (0.0%)	0 (0.0%)	0 (0.0%)
The way in which the patient's condition and likely progress has been explained by the palliative care team	Very satisfied	494 (61.0%)	257 (69.5%)	76 (52.5%)	161 (55.0%)
	Satisfied	190 (23.5%)	71 (19.0%)	44 (30.5%)	75 (25.5%)
	Neither satisfied or dissatisfied	43 (5.5%)	14 (4.0%)	9 (6.0%)	20 (7.0%)
	Dissatisfied	18 (2.5%)	4 (1.0%)	2 (1.5%)	12 (4.0%)
	Very dissatisfied	19 (2.5%)	3 (1.0%)	6 (4.0%)	10 (3.5%)
	Not relevant	42 (5.0%)	20 (5.5%)	8 (5.5%)	14 (5.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Information given about side effects of treatment	Very satisfied	334 (41.5%)	166 (45.0%)	63 (43.5%)	105 (36.0%)
	Satisfied	209 (26.0%)	85 (23.0%)	39 (27.0%)	85 (29.0%)
	Neither satisfied or dissatisfied	70 (8.5%)	30 (8.0%)	15 (10.0%)	25 (8.5%)
	Dissatisfied	20 (2.5%)	4 (1.0%)	3 (2.0%)	13 (4.5%)
	Very dissatisfied	23 (3.0%)	3 (1.0%)	8 (5.5%)	12 (4.0%)
	Not relevant	150 (18.5%)	81 (22.0%)	17 (12.0%)	52 (18.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
The way in which the palliative care team respected the patient's dignity	Very satisfied	637 (79.0%)	319 (86.5%)	112 (77.0%)	206 (70.5%)
	Satisfied	118 (15.0%)	34 (9.0%)	23 (16.0%)	61 (21.0%)
	Neither satisfied or dissatisfied	13 (1.5%)	4 (1.0%)	2 (1.0%)	7 (2.5%)
	Dissatisfied	2 (0.0%)	0 (0.0%)	0 (0.0%)	2 (0.5%)
	Very dissatisfied	12 (1.5%)	2 (0.5%)	4 (3.0%)	6 (2.0%)
	Not relevant	24 (3.0%)	10 (3.0%)	4 (3.0%)	10 (3.5%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 806)	Hospice inpatient (n = 369)	Hospice home care (n = 145)	Hospital support team (n = 292)
Meetings with the palliative care team to discuss the patient's condition and plan of care	Very satisfied	482 (60.0%)	243 (66.0%)	82 (56.5%)	157 (54.0%)
	Satisfied	198 (24.5%)	85 (23.0%)	34 (23.5%)	79 (27.0%)
	Neither satisfied or dissatisfied	32 (4.0%)	9 (2.5%)	10 (7.0%)	13 (4.5%)
	Dissatisfied	19 (2.5%)	2 (0.5%)	4 (3.0%)	13 (4.5%)
	Very dissatisfied	18 (2.0%)	3 (1.0%)	6 (4.0%)	9 (3.0%)
	Not relevant	56 (7.0%)	26 (7.0%)	9 (6.0%)	21 (7.0%)
	No response	1 (0.0%)	1 (0.0%)	0 (0.0%)	0 (0.0%)
Speed with which symptoms were treated	Very satisfied	464 (57.5%)	242 (65.5%)	78 (53.5%)	144 (49.5%)
	Satisfied	198 (24.5%)	81 (22.0%)	34 (23.5%)	83 (28.5%)
	Neither satisfied or dissatisfied	37 (5.0%)	10 (2.5%)	13 (9.0%)	14 (4.5%)
	Dissatisfied	34 (4.0%)	6 (1.5%)	5 (3.5%)	23 (8.0%)
	Very dissatisfied	18 (2.0%)	3 (1.0%)	5 (3.5%)	10 (3.5%)
	Not relevant	55 (7.0%)	27 (7.5%)	10 (7.0%)	18 (6.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Palliative care team's attention to the patient's description of symptoms	Very satisfied	463 (57.5%)	244 (66.0%)	78 (54.0%)	141 (48.0%)
	Satisfied	188 (23.5%)	67 (18.0%)	40 (27.5%)	81 (28.0%)
	Neither satisfied or dissatisfied	48 (6.0%)	11 (3.0%)	10 (7.0%)	27 (9.0%)
	Dissatisfied	8 (1.0%)	2 (0.5%)	1 (0.5%)	5 (2.0%)
	Very dissatisfied	14 (1.5%)	2 (0.5%)	4 (3.0%)	8 (3.0%)
	Not relevant	85 (10.5%)	43 (12.0%)	12 (8.0%)	30 (10.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
The way in which the patient's physical needs for comfort were met	Very satisfied	565 (70.0%)	297 (80.5%)	92 (63.5%)	176 (60.0%)
	Satisfied	158 (19.5%)	52 (14.0%)	33 (23.0%)	73 (25.0%)
	Neither satisfied or dissatisfied	28 (3.5%)	5 (1.5%)	8 (5.5%)	15 (5.0%)
	Dissatisfied	18 (2.0%)	5 (1.5%)	2 (1.0%)	11 (4.0%)
	Very dissatisfied	14 (2.0%)	1 (0.0%)	5 (3.5%)	8 (3.0%)
	Not relevant	23 (3.0%)	9 (2.5%)	5 (3.5%)	9 (3.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 806)	Hospice inpatient (n = 369)	Hospice home care (n = 145)	Hospital support team (n = 292)
Availability of the palliative care team to the family	Very satisfied	498 (61.5%)	257 (69.5%)	83 (57.0%)	158 (54.0%)
	Satisfied	194 (24.0%)	85 (23.0%)	39 (27.0%)	70 (24.0%)
	Neither satisfied or dissatisfied	47 (6.0%)	12 (3.0%)	10 (7.0%)	25 (8.5%)
	Dissatisfied	24 (3.0%)	3 (1.0%)	4 (3.0%)	17 (6.0%)
	Very dissatisfied	15 (2.0%)	2 (0.5%)	4 (3.0%)	9 (3.0%)
	Not relevant	28 (3.5%)	10 (3.0%)	5 (3.0%)	13 (4.5%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Emotional support provided to family members by the palliative care team	Very satisfied	491 (61.0%)	258 (70.0%)	84 (58.0%)	149 (51.0%)
	Satisfied	172 (21.5%)	68 (18.5%)	36 (25.0%)	68 (23.5%)
	Neither satisfied or dissatisfied	57 (7.0%)	20 (5.5%)	10 (7.0%)	27 (9.0%)
	Dissatisfied	19 (2.5%)	1 (0.0%)	2 (1.0%)	16 (5.5%)
	Very dissatisfied	15 (2.0%)	2 (1.0%)	6 (4.0%)	7 (2.5%)
	Not relevant	51 (6.0%)	19 (5.0%)	7 (5.0%)	25 (8.5%)
	No response	1 (0.0%)	1 (0.0%)	0 (0.0%)	0 (0.0%)
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	Very satisfied	417 (52.0%)	226 (61.0%)	72 (50.0%)	119 (41.0%)
	Satisfied	150 (18.5%)	58 (16.0%)	37 (25.5%)	55 (19.0%)
	Neither satisfied or dissatisfied	31 (4.0%)	12 (3.0%)	7 (5.0%)	12 (4.0%)
	Dissatisfied	17 (2.0%)	4 (1.0%)	1 (0.5%)	12 (4.0%)
	Very dissatisfied	13 (1.5%)	4 (1.0%)	3 (2.0%)	6 (2.0%)
	Not relevant	178 (22.0%)	65 (18.0%)	25 (17.0%)	88 (30.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
The doctors attention to the patient's symptoms	Very satisfied	488 (60.5%)	268 (72.5%)	75 (52.0%)	145 (50.0%)
	Satisfied	167 (20.5%)	57 (15.5%)	34 (23.0%)	76 (26.0%)
	Neither satisfied or dissatisfied	49 (6.0%)	15 (4.0%)	10 (7.0%)	24 (8.0%)
	Dissatisfied	28 (3.5%)	6 (1.5%)	7 (5.0%)	15 (5.0%)
	Very dissatisfied	22 (3.0%)	3 (1.0%)	4 (3.0%)	15 (5.0%)
	Not relevant	52 (6.5%)	20 (5.5%)	15 (10.0%)	17 (6.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 806)	Hospice inpatient (n = 369)	Hospice home care (n = 145)	Hospital support team (n = 292)
The way the family was included in treatment and care decisions	Very satisfied	478 (59.5%)	241 (65.5%)	83 (57.0%)	154 (52.5%)
	Satisfied	199 (24.5%)	89 (24.0%)	31 (21.5%)	79 (27.0%)
	Neither satisfied or dissatisfied	39 (5.0%)	11 (3.0%)	15 (10.0%)	13 (4.5%)
	Dissatisfied	21 (2.5%)	3 (1.0%)	4 (3.0%)	14 (5.0%)
	Very dissatisfied	20 (2.5%)	2 (0.5%)	5 (3.5%)	13 (4.5%)
	Not relevant	49 (6.0%)	23 (6.0%)	7 (5.0%)	19 (6.5%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Information given about how to manage the patient's symptoms (e.g. pain, constipation)	Very satisfied	407 (50.5%)	203 (55.0%)	78 (54.0%)	126 (43.0%)
	Satisfied	197 (24.5%)	87 (24.0%)	39 (27.0%)	71 (24.5%)
	Neither satisfied or dissatisfied	58 (7.0%)	14 (4.0%)	12 (8.5%)	32 (11.0%)
	Dissatisfied	10 (1.5%)	2 (0.5%)	2 (1.5%)	6 (2.0%)
	Very dissatisfied	18 (2.0%)	3 (0.5%)	6 (4.0%)	9 (3.0%)
	Not relevant	115 (14.5%)	59 (16.0%)	8 (5.0%)	48 (16.5%)
	No response	1 (0.0%)	1 (0.0%)	0 (0.0%)	0 (0.0%)
How effectively the palliative care team managed the patient's symptoms	Very satisfied	491 (61.0%)	253 (68.5%)	85 (58.5%)	153 (52.5%)
	Satisfied	196 (24.0%)	77 (21.0%)	36 (25.0%)	83 (28.5%)
	Neither satisfied or dissatisfied	43 (5.5%)	13 (3.5%)	10 (7.0%)	20 (7.0%)
	Dissatisfied	16 (2.0%)	4 (1.0%)	1 (0.5%)	11 (3.5%)
	Very dissatisfied	19 (2.5%)	4 (1.0%)	6 (4.0%)	9 (3.0%)
	Not relevant	41 (5.0%)	18 (5.0%)	7 (5.0%)	16 (5.5%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
The palliative care team's response to changes in the patient's care needs	Very satisfied	517 (64.0%)	271 (73.5%)	89 (61.0%)	157 (53.5%)
	Satisfied	175 (22.0%)	65 (17.5%)	34 (23.5%)	76 (26.0%)
	Neither satisfied or dissatisfied	33 (4.0%)	9 (2.5%)	7 (5.0%)	17 (6.0%)
	Dissatisfied	18 (2.0%)	5 (1.5%)	3 (2.0%)	10 (3.5%)
	Very dissatisfied	18 (2.0%)	3 (1.0%)	5 (3.5%)	10 (3.5%)
	Not relevant	45 (6.0%)	16 (4.0%)	7 (5.0%)	22 (7.5%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Aspect of care	Degree of satisfaction	Setting			
		All settings (n = 806)	Hospice inpatient (n = 369)	Hospice home care (n = 145)	Hospital support team (n = 292)
Emotional support provided to the patient by the palliative care team	Very satisfied	481 (59.5%)	255 (69.0%)	83 (57.0%)	143 (49.0%)
	Satisfied	176 (22.0%)	70 (19.0%)	37 (25.5%)	69 (24.0%)
	Neither satisfied or dissatisfied	54 (6.5%)	17 (4.5%)	10 (7.0%)	27 (9.0%)
	Dissatisfied	17 (2.0%)	2 (0.5%)	3 (2.0%)	12 (4.0%)
	Very dissatisfied	14 (2.0%)	3 (1.0%)	5 (3.5%)	6 (2.0%)
	Not relevant	64 (8.0%)	22 (6.0%)	7 (5.0%)	35 (12.0%)
	No response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Table 2