

Marie Curie end of life care: exploratory analysis from the first National Bereavement Survey (Voices)

The Office for National Statistics (ONS) conducts annual surveys of bereaved relatives (the VOICES survey), which assess the quality of care delivered to people in the last three months of their lives. Marie Curie commissioned the ONS to carry out analysis on data from the survey published in 2012 to establish whether people who receive Marie Curie nursing have a different care experience to those who do not.

The analysis showed that the bereaved relatives of people who received care from Marie Curie Nurses report a considerably higher overall quality of care than others who spent time at home at the end of their lives. Three-quarters of respondents whose relatives received care from a Marie Curie Nurse reported complete pain relief at home some or all of the time, compared to 44% of those who did not receive our care. Significantly, bereaved relatives of Marie Curie patients were more likely to state that they had enough choice in where they died.

The following reports were compiled by the ONS for Marie Curie.

Note: It is important to point out that people who receive care from Marie Curie Nurses tend to receive care from a range of other providers and from a greater range of services than other people at the end of their lives. The results of Marie Curie's own 2013 user survey support the ONS findings. 98% of respondents rated their overall experience of the Marie Curie Nursing Service as good (12%) or very good (87%).



Report 1

Marie Curie and end of life care: exploratory analysis from the first National Bereavement Survey (VOICES)

Comparison group

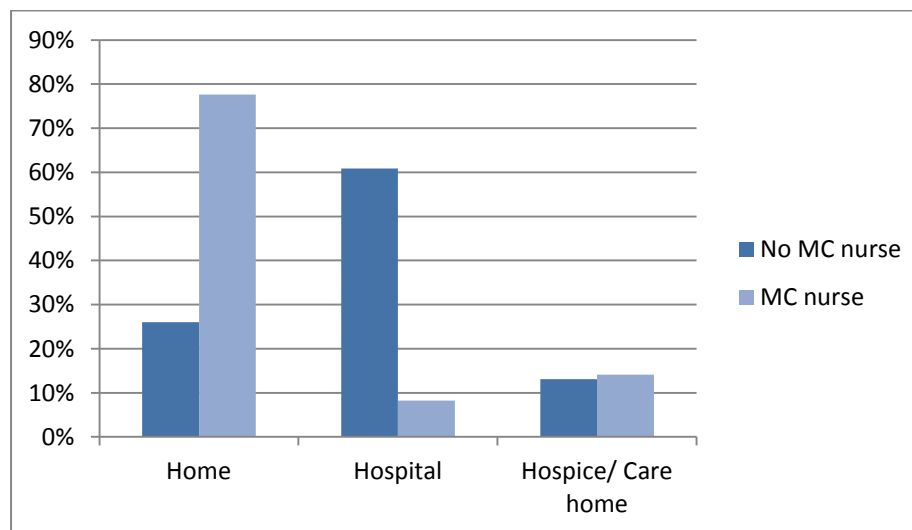
For the purpose of this exploratory analysis the control group consisted of those patients who spent some time at home in the last three months of life who did not receive any help from a Marie Curie nurse.

Sample characteristics: Of the 12,339 people that spent some time at home in the last three months of life, 6.3 per cent received help from a Marie Curie nurse.

Most patients who received help from a Marie Curie nurse had cancer as the underlying cause of death (80.2 per cent), 12.8 per cent of these patients were classified under the 'other' cause of death group and the remaining 7.0 per cent had cardiovascular disease as the underlying cause of death.

Figure 1 shows that patients who had help from a Marie Curie nurse were more likely to die at home (77.7 per cent) than in a hospital (8.3 per cent). This is in contrast to patients who did not receive help from a Marie Curie nurse who were more likely to die in hospital (60.9 per cent) than at home (26.0 per cent).

Figure 1: Place of death of patients by whether help at home received from a Marie Curie nurse



Advisory note: The following factors should be considered when interpreting these data. The National Bereavement Survey (VOICES) was not designed to split the data by type of help received at home (e.g Marie Curie nurse) and this group has been defined *post hoc* by determining patients who spent some time at home in the last three months of life and who received help from a Marie Curie nurse.

Many patients who received help from a Marie Curie nurse also received help from one or more of the other services listed in question three (Table 1). For example, 74.1 per cent of people that received help from a Marie Curie nurse also received help from a Macmillan

nurse, hospice home care nurse or specialist. In fact only 1.6 per cent of patients received help at home from a Marie Curie nurse alone. This therefore makes it hard to attribute any findings to a single service provided.

Table 1: Other services from which Marie Curie patients received help at home

Service	Percentage of Marie Curie patients receiving help from this service (%)
District or community nurse	91.6
Macmillan nurse, hospice nurse or specialist	74.1
Any other nurse at home	11.1
Home care worker, home care aide or home help	48.2
Social worker/ support worker	16.9
Counsellor	2.4
Religious leader	17.0
Meals-on-wheels or other home delivered meals	2.8
Hospice at home	22.8
Occupational therapist (OT)	20.0
Rapid response team	22.7
Something else	4.3

The structure of the VOICES-SF questionnaire allows respondents to only answer those questions which are of relevance for them, which reduces the number of questions where numbers are sufficient for analysis. Therefore, a limited number of responses are given below. Due to the small numbers, these should be regarded as exploratory analyses and should be followed up with combined years of data which would provide more robust findings.

Table 2: Overall quality of care across all settings by whether patient received help at home from a Marie Curie nurse

percentage [Confidence intervals]

	Number	Outstanding/ Excellent	Good	Fair	Poor
No Marie Curie nurse	10,981	39.3	33.8	15.9	11.0
[Confidence intervals]		[38.4, 40.3]	[32.9, 34.7]	[15.2, 16.6]	[10.4, 11.6]
Marie Curie nurse	756	66.6	24.9	5.9	2.6
[Confidence intervals]		[63.1, 69.9]	[21.9, 28.1]	[4.4, 7.9]	[1.6, 4.0]

Respondents of patients who received help from a Marie Curie nurse were more likely to rate the overall quality of care as outstanding or excellent compared with those who did not

receive help from this service, and were much less likely to rate the overall quality of care as poor (Table 2).

Table 3: Co-ordination of care while patient was at home

percentage [Confidence intervals]

	Number	Yes, definitely	Yes, to some extent	No, did not work well together
No Marie Curie nurse	7,463	43.0	42.8	14.3
[Confidence intervals]		[41.8, 44.1]	[41.7, 43.9]	[13.5, 15.1]
Marie Curie nurse	765	63.6	31.0	5.4
[Confidence intervals]		[60.1, 67.0]	[27.8, 34.4]	[4.0, 7.3]

Respondents of patients who received help from a Marie Curie nurse were more likely to rate the co-ordination of care, whilst the patient was at home, as definitely working well together (63.6 per cent) compared with those who did not receive help from a Marie Curie nurse (43.0 per cent). Only 5.4 per cent of respondents in the 'Marie Curie nurse' group reported the services did not work well together, compared with 14.3 per cent in the 'No Marie Curie nurse' group (Table 3).

Table 4: Help and support for carer/family when patient was at home

percentage [Confidence intervals]

	Number	Yes, as much support as wanted	Yes, some support but not as much as wanted	No, although tried to get more help	No, but we did not ask for more help
No Marie Curie nurse	9,650	48.7	20.0	16.0	15.4
[Confidence intervals]		[47.7, 49.7]	[19.2, 20.8]	[15.2, 16.7]	[14.7, 16.1]
Marie Curie nurse	768	72.8	18.9	6.4	2.0
[Confidence intervals]		[69.5, 75.9]	[16.2, 21.8]	[4.8, 8.4]	[1.2, 3.3]

More respondents of patients who had received help from a Marie Curie nurse felt they had been given as much help as they had needed when caring for the patient (72.8 per cent) compared with respondents of patients who did not receive help from a Marie Curie nurse (48.7 per cent). Nearly ten per cent more respondents in the 'No Marie Curie nurse' group felt they did not get enough support, despite trying to get more, than the 'Marie Curie nurse' group (Table 4).

More patients who received help from a Marie Curie nurse expressed a preference as to where they would like to die (75.1 per cent) compared with those who did not receive help from a Marie Curie nurse (37.3 per cent). Of those that expressed a preference as to where they would like to die, 90.9 per cent in the 'Marie Curie nurse' group and 76.5 per cent in the 'No Marie Curie nurse' group said they would like to die at home. The fact that nearly twice as many people who received help from a Marie Curie nurse said where they wanted to die

may help explain the findings in Figure 1 which found that these patients were more likely to die at home.

In addition, respondents of patients who received help from a Marie Curie nurse were more likely to say the patient had enough choice about where they died (86.2 per cent), compared with those who did not receive help from a Marie Curie nurse (51.5 per cent) (Table 5).

Table 5: Patient had enough choice about where they died

percentage [Confidence intervals]

	Number	Yes	No	Not sure
No Marie Curie nurse	7,716	51.5	22.9	25.6
[Confidence intervals]		[50.4, 52.6]	[21.9, 23.8]	[24.7, 26.6]
Marie Curie nurse	735	86.2	5.4	8.4
[Confidence intervals]		[83.4, 88.5]	[4.0, 7.4]	[6.6, 10.7]

Background note:

Confidence intervals provide a measure of the variability, error or uncertainty surrounding a value. They are especially important when using findings from a sample rather than the whole population and are calculated around the estimated value to give a range in which the true value for the population is likely to fall. The width of the confidence interval depends to a large extent on the sample size and so larger studies tend to give more precise estimates of effects (and hence have narrower confidence intervals) than smaller studies. Thus, wide confidence intervals show greater uncertainty and narrow ones show greater confidence in the estimated value. A confidence interval may be reported for any level of confidence but most commonly is reported at the 95 per cent level. This can be taken to mean that there is only a 5 per cent chance that the true population value lies outside the confidence interval.

Confidence intervals are also used to guide interpretation of the data when comparing change over time, examining differences between geographical areas or between certain groups, such as sex or age. As a general rule and for the same measure, if the confidence interval around one value overlaps with the interval around another, we cannot say with certainty that there is more than a chance difference between the two values. For example, for a value of 45.3 at time 1 with a 95% confidence interval of 42.1 - 48.5 and a value of 47.5 at time 2 with a 95% per cent confidence interval of 44.2 - 50.8, the intervals overlap and so we could not say with certainty that there had been a [significant] change over time. Confidence intervals should therefore be taken into consideration when making comparisons between figures.

Report 2

Marie Curie and end of life care: additional exploratory analysis from the first National Bereavement Survey (VOICES)

Comparison group

For the purpose of this exploratory analysis the control group consisted of those patients who spent some time at home in the last three months of life who did not receive any help from a Marie Curie nurse.

Table 1: Other services from which patients who spent some time at home in the last three months received help at home by whether or not patient received help from a Marie Curie nurse.

percentage [Confidence intervals]

Service	Percentage of non-Marie Curie patients receiving help from this service (%)	Percentage of Marie Curie patients receiving help from this service (%)
District or community nurse	49.6 [48.7 ; 50.5]	91.6 [89.4 ; 93.4]
Macmillan nurse, hospice nurse or specialist	23.2 [22.4 ; 24.0]	74.1 [70.9 ; 77.0]
Any other nurse at home	4.4 [4.0 ; 4.8]	11.1 [9.1 ; 13.5]
Home care worker, home care aide or home help	31.8 [30.9 ; 32.6]	48.2 [44.7 ; 51.8]
Social worker/ support worker	13.4 [12.8 ; 14.1]	16.9 [14.4 ; 19.7]
Religious leader	6.8 [6.4 ; 7.3]	17.0 [14.5 ; 19.9]
Meals-on-wheels or other home delivered meals	6.2 [5.7 ; 6.6]	2.8 [1.8 ; 4.1]
Hospice at home	3.5 [3.2 ; 3.9]	22.8 [20.0 ; 25.9]
Occupational therapist (OT)	11.0 [10.5 ; 11.6]	20.0 [17.3 ; 23.0]
Rapid response team	8.9 [8.4 ; 9.5]	22.7 [19.8 ; 25.7]
Something else ¹	11.1 [10.5 ; 11.7]	6.4 [4.8 ; 8.3]
Total number in each group	11,559	778

¹ 'Counsellor' has been included with 'Something else' due to small numbers.

Source: Office for National Statistics

With the exception of 'Meals-on-wheels or other home delivered meals' and the response option 'Something else', patients who had help from a Marie Curie nurse were more likely to have additional help from all of the other services compared with patients who did not receive help from a Marie Curie nurse.

Even when co-varying for cancer as the cause of death, these figures remained significant (Table 2).

Table 2: Odds ratios for services from which patient received help at home in the last three months by whether or not help received from a Marie Curie nurse

Service	Odds ratio	Adjusted odds ratio ¹
District or community nurse	11.1**	8.3**
Macmillan nurse, hospice nurse or specialist	9.5**	6.0**
Any other nurse at home	2.7**	2.9**
Home care worker, home care aide or home help	2.0**	2.6**
Social worker/ support worker	1.3**	1.7**
Religious leader	2.8**	2.4**
Meals-on-wheels or other home delivered meals	0.4**	0.6*
Hospice at home	8.1**	4.9**
Occupational therapist (OT)	2.0**	1.9**
Rapid response team	3.0**	2.8**
Something else ²	0.5**	0.6**

** Significant at the 0.01 level

*Significant at the 0.05 level

¹Adjusted odds ratios when controlling for cancer as the cause of death.

² 'Counsellor' has been included with 'Something else' due to small numbers.

Source: Office for National Statistics

Table 3: How well pain was relieved at home by whether patient received help at home from a Marie Curie nurse.

percentage [Confidence intervals]

	Number	Completely, all the time	Completely, some of the time	Partially/ Not at all
No Marie Curie nurse	7,721	15.2	28.9	55.9
[Confidence intervals]		[14.5, 16.1]	[27.9, 29.9]	[54.8, 57.0]
Marie Curie nurse	673	34.4	40.7	24.9
[Confidence intervals]		[30.9, 38.1]	[37.0, 44.5]	[21.7, 28.3]

Source: Office for National Statistics

Respondents of patients who received help from a Marie Curie nurse were more likely to say that the pain of the patient was relieved completely, all of the time (34.4%) or completely, some of the time (40.7%) compared with patients who did not receive help from a Marie Curie nurse (15.2% and 28.9% respectively) (Table 3).

Table 4: Enough help in the last two days by whether patient received help at home from a Marie Curie nurse.

percentage [Confidence intervals]

	Number	Strongly agree	Agree	Neither agree or disagree	Disagree/ Strongly disagree
Personal care needs					
No Marie Curie nurse	9,856	38.7	37.2	9.1	15.1
[Confidence intervals]		[37.7, 39.6]	[36.2, 38.1]	[8.6, 9.7]	[14.4, 15.8]
Marie Curie nurse	733	54.5	35.3	4.7	5.6
[Confidence intervals]		[50.9, 58.1]	[31.9, 38.8]	[3.3, 6.5]	[4.1, 7.5]
Nursing care					
No Marie Curie nurse	9,874	40.6	35.6	9.4	14.4
[Confidence intervals]		[39.6, 41.6]	[34.6, 36.5]	[8.9, 10.0]	[13.7, 15.2]
Marie Curie nurse	738	55.4	34.1	4.7	5.8
[Confidence intervals]		[51.8, 59.0]	[30.8, 37.7]	[3.4, 6.4]	[4.3, 7.8]

Source: Office for National Statistics

More respondents of patients who received help from a Marie Curie nurse strongly agreed that the patient had enough help with personal care needs in their last two days of life (54.5%) compared with patients who did not receive help from a Marie Curie nurse (38.7%). This was also true for nursing care in the last two days of life (55.4% compared with 40.6%).

Table 5: Support for patient in last two days of life by whether patient received help at home from a Marie Curie nurse.

percentage [Confidence intervals]

	Number	Excellent	Good	Fair	Poor
Spiritual support					
No Marie Curie nurse	4,655	36.9	28.9	13.3	20.9
[Confidence intervals]		[35.5, 38.3]	[27.6, 30.2]	[12.4, 14.3]	[19.8, 22.1]
Marie Curie nurse	381	49.9	29.1	12.5	8.6
[Confidence intervals]		[44.9, 54.9]	[24.7, 33.9]	[9.5, 16.2]	[6.1, 11.9]
Emotional support					
No Marie Curie nurse	7,466	37.7	30.5	14.9	16.9
[Confidence intervals]		[36.6, 38.8]	[29.5, 31.6]	[14.1, 15.7]	[16.0, 17.8]
Marie Curie nurse	641	55.5	31.1	8.7	4.7
[Confidence intervals]		[51.6, 59.3]	[27.6, 34.8]	[6.7, 11.2]	[3.3, 6.8]

Source: Office for National Statistics

Respondents of patients who received help from a Marie Curie nurse were more likely to rate the spiritual support and emotional support that the patient received in their last two days of life as excellent (49.9% and 55.5% respectively) compared with patients who did not receive help at home from a Marie Curie nurse (36.9% and 37.7% respectively).

Table 6: Preferred place of death and actual place of death by whether patient received help at home from a Marie Curie nurse

percentage [Confidence intervals]

Preferred place of death	Actual place of death				
	Number	Home	Hospital	Care Home	Hospice
Home					
No Marie Curie nurse	3,824	47.3	42.9	4.2	5.6
[Confidence intervals]		[45.7, 48.9]	[41.3, 44.5]	[3.7, 4.9]	[4.9, 6.4]
Marie Curie nurse	547	88.8	4.0	2.3	4.9
[Confidence intervals]		[85.9, 91.2]	[2.6, 6.1]	<i>[1.3, 4.0]</i>	[3.4, 7.0]

Percentages calculated from fewer than 20 counts are shown in italics.

Source: Office for National Statistics

Respondents of patients who received help from a Marie Curie nurse were more likely to die in their preferred place of death if this was at home compared with patients who did not receive help from a Marie Curie nurse (88.8% compared with 47.3%).

Multivariate analysis

Multivariate analysis was carried out for each of the tables in this document, and those in the previous analysis, to examine the relationship between the care a patient received whilst at home and whether or not a patient received help from a Marie Curie nurse, whilst co-varying for cancer as the cause of death.

Table 7: Odds ratios for differences between those who received help at home from a Marie Curie nurse and those that did not receive help from a Marie Curie nurse

Question	Odds ratio	Adjusted odds ratio ¹
Outstanding or excellent care across all settings in the last three months of life	3.1**	2.4**
Co-ordination of care definitely worked well while patient was at home	2.3**	2.1**
Help and support for carer/family was received as much as family wanted while patient was at home	2.8**	2.4**
Patient had enough choice about where they died	5.9**	4.5**
Pain was relieved completely, all of the time while patient was at home	2.9**	2.4**
Strongly agree that enough help with personal care needs was received in the last two days of life	1.9**	1.5**
Strongly agree that enough help with nursing needs was received in the last two days of life	1.8**	1.4**
Excellent spiritual support was given in the last two days of life	1.7**	1.4**
Excellent emotional support was given in the last two days of life	2.1**	1.7**

** Significant at the 0.01 level

*Significant at the 0.05 level

¹Adjusted odds ratios when controlling for cancer as the cause of death.

As can be seen from table 7, when controlling for cancer as the cause of death, significant differences at the P<0.01 level remained for each of the tables previously created which compared the experiences of patients who received help at home in the last three months from a Marie Curie nurse and those patients who did not receive help from a Marie Curie nurse.

Background note:

Confidence intervals provide a measure of the variability, error or uncertainty surrounding a value. They are especially important when using findings from a sample rather than the whole population and are calculated around the estimated value to give a range in which the true value for the population is likely to fall. The width of the confidence interval depends to a large extent on the sample size and so larger studies tend to give more precise estimates of effects (and hence have narrower confidence intervals) than smaller studies. Thus, wide confidence intervals show greater uncertainty and narrow ones show greater confidence in

the estimated value. A confidence interval may be reported for any level of confidence but most commonly is reported at the 95 per cent level. This can be taken to mean that there is only a 5 per cent chance that the true population value lies outside the confidence interval. Confidence intervals are also used to guide interpretation of the data when comparing change over time, examining differences between geographical areas or between certain groups, such as sex or age. As a general rule and for the same measure, if the confidence interval around one value overlaps with the interval around another, we cannot say with certainty that there is more than a chance difference between the two values. For example, for a value of 45.3 at time 1 with a 95% confidence interval of 42.1 – 48.5 and a value of 47.5 at time 2 with a 95% per cent confidence interval of 44.2 – 50.8, the intervals overlap and so we could not say with certainty that there had been a [significant] change over time. Confidence intervals should therefore be taken into consideration when making comparisons between figures.