

# Bereavement care provision in Europe: a survey by the EAPC Bereavement Care Taskforce

The Bereavement Care Taskforce of the EAPC has conducted a survey on bereavement care service provision in Europe. **Mai-Britt Guldin, Irene Murphy, Orla Keegan, Barbara Monroe, Maria Antonia Lacasta Reverte** and **Inger Benkel** report on the results. One of the key findings is that not all palliative care services seem to prioritise bereavement care as an integral part of their offer

**B**ereavement care is an aspect of palliative care that extends to caring for those who are important to the patient.<sup>1</sup> There is limited information about the range, type and extent of bereavement interventions available from palliative care services in Europe. National surveys of bereavement care provision within palliative care have been conducted in the UK,<sup>2</sup> Spain,<sup>3,4</sup> the USA<sup>5</sup> and Australia.<sup>6-8</sup> These surveys have shown that service provision varies in bereavement care delivery, needs assessment, the areas served, the disciplines involved in providing bereavement care, and the extent to which services interact with bereavement support in the community.<sup>2,8,9</sup>

Models of bereavement care have been presented in guidance on supportive and palliative care from the National Institute for Health and Care Excellence in the UK;<sup>10</sup> in evidence-based standards for bereavement care developed in Australia;<sup>11</sup> and in a 'public health approach' model focusing on needs assessment.<sup>12,13</sup> A tiered or layered approach to bereavement care has been advocated based on meta-analyses of clinical trials.<sup>14,15</sup>

Bereavement support has been divided into three components or levels based on need:<sup>10,11,14</sup>

- Bereavement care provided by family and friends or professionals but open to all (universal services)
- Bereavement care offered to groups at risk of complications (selective services)
- Targeted treatment provided by specialist mental health services when indicated; that is, to people showing symptoms indicative of complications (indicative services).

We do not know to what extent palliative care services in Europe use these models to inform and plan bereavement care.

## Methods

The European Association for Palliative Care (EAPC) Bereavement Care Taskforce, set up in 2013, has committee members with backgrounds in social work and psychology as well as clinical and research training. It conducted a survey of bereavement care service provision to describe the type, level and extent of care provided within palliative care settings in EAPC member countries.

In 2013, an online questionnaire informed by previous bereavement care surveys<sup>2,4,6,7</sup> was developed. A pilot was sent to a selection of bereavement co-ordinators and counsellors across Europe to test the comprehensibility

## Key points

- The Bereavement Care Taskforce of European Association for Palliative Care (EAPC) has surveyed bereavement support within palliative care services in EAPC member countries; of the 370 services that responded, 302 provide bereavement support.
- The prioritisation of bereavement support as a core part of care was not evident in all palliative care services, and a substantial minority (18%) offered no bereavement support at all.
- Services had few bereavement-specific roles; less than two thirds formally trained their staff; only a quarter conducted formal risk assessments; and only a third applied formal policies or guidelines.
- To optimise support for bereaved relatives, it seems timely for the EAPC and palliative care services in Europe to formalise the planning of bereavement care. The next step for the Taskforce is to develop an EAPC statement of best practice in this area.

**Table 1. Characteristics of responding palliative care services**

<b>Type of service (number of respondents to this question = 370)</b>	
Inpatient unit/hospice	220 (59%)
Home care service	188 (51%)
Hospital support service	99 (27%)
Day care service	55 (15%)
Other	43 (12%)
<b>Mean number of deaths per year in the service (number of respondents to this question = 367)</b>	
0–99 deaths per year	102 (28%)
100–199 deaths per year	86 (24%)
200–399 deaths per year	91 (25%)
400+ deaths per year	69 (19%)
Unknown	19 (5%)
<b>Years of existence of the service (number of respondents to this question = 366)</b>	
Less than 5 years	48 (13%)
5–10 years	97 (26%)
10–15 years	76 (21%)
15–20 years	52 (14%)
More than 20 years	93 (25%)
<b>How long has your palliative care service been delivering bereavement services? (number of respondents to this question = 296)</b>	
Less than 5 years	73 (25%)
5–10 years	88 (30%)
10–15 years	50 (17%)
15–20 years	40 (13%)
More than 20 years	45 (15%)
<b>Number of people receiving bereavement care in the service per year (number of respondents to this question = 294)</b>	
0–9	15 (5%)
10–99	141 (48%)
100–199	57 (19%)
200–299	21 (7%)
300–399	13 (4%)
400–500	14 (5%)
500+	12 (4%)
Unknown	21 (7%)
<b>Does your service offer bereavement support? (number of respondents to this question = 370)</b>	
Yes	302 (82%)
No	68 (18%)

and relevance of the questionnaire, and their feedback was incorporated into the final version. A letter with a link to the online questionnaire was distributed via the EAPC to 56 national palliative care associations in 32 countries in December 2013 and January 2014. The national associations were asked to send the link on to the directors of palliative care services in their respective countries. To boost response rates, reminders were sent to the national palliative care associations, as well as to the Taskforce's mailing lists of bereavement co-ordinators and counsellors.

The online questionnaire, available in English and Spanish, comprised 54 questions and six sections: background information; bereavement support activities; personnel; access and levels of care; community links and funding; resources and care model.

Data were handled and analysed using Excel 2007, SPSSv18 and Stata 13. Responses were cleaned, duplicates removed and missing data indicated as such. Numerical data were presented using descriptive statistics.

## Results

There were 370 responses from 25 countries (78% of countries responded). The questionnaire was most likely to have been completed by respondents in Italy (n=56), Spain (n=56) and the UK (n=53). Less than five responses were received from Belgium, Hungary, Iceland, Lithuania, Georgia, Greece, Poland, Slovakia, Latvia, Norway and Slovenia.

### Characteristics of services

Of the 370 responding palliative care services, 302 (82%) offered bereavement support, and most provided it free of charge. There were wide variations in terms of the type (inpatient, hospital or home-based) and size of palliative care services, as well as the number of years for which they had been offering bereavement support (see Table 1).

### Service provision

A wide range of bereavement support was provided, telephone support being the most common one (offered by 84% of the 302 services). There was a trend towards services being offered on the basis of need: 81% of services provided bereavement counselling but only to people with symptoms indicative of complicated grief (see Table 2).

**Table 2. Level and type of bereavement support provided**

Public health level	NICE level and/or component <sup>10</sup>	Type of bereavement support	Number of services offering that type of support (total number=302)
Universal (services offered to all)	1	Telephone support	254 (84%)
		Literature – adult grief	245 (81%)
		Literature – children’s grief	225 (74%)
		Information/education sessions on bereavement	196 (65%)
		Letters	179 (59%)
		Memorial services	170 (56%)
		Cards	149 (49%)
		Attend funeral	123 (41%)
		Anniversary cards	68 (22%)
Selective (services offered to selected groups, such as at-risk groups)	2	One-to-one support	237 (79%)
		Home visits	177 (59%)
		Referral to support groups run by other agency	176 (58%)
		Provide support group	169 (56%)
		Provide on-to-one volunteer support	135 (45%)
		Referral to one-to-one volunteer support provided by external agency	106 (35%)
Indicative (services offered to bereaved people with symptoms indicative of complicated grief)	3	Bereavement counselling	244 (81%)
		Psychological support/psychotherapy based on a manual	196 (65%)
		Referral to other counselling/psychotherapy	232 (77%)
		Referral to psychiatrist	192 (64%)

NICE = National Institute for Health and Care Excellence

### Staff and training

Nearly half of the 302 services (n=141, 47%) had someone co-ordinating bereavement care: 59 (20%) employed a full-time salaried care co-ordinator; 40 (13%) employed a part-time salaried co-ordinator; 20 (7%) devoted a few hours per week to co-ordination of care; and in six (2%), co-ordination was undertaken by volunteers. Around a quarter of services (n=72, 24%) employed staff with the sole purpose of providing bereavement care. Table 3 shows the professional backgrounds of those providing care and of those co-ordinating care.

Formal training of palliative care staff in bereavement care was available in 181 (60%) of the 302 services. In 85 of them, training duration was less than 16 hours.

### Guidelines and formal risk assessment

Of the 370 responding services, 132 (36%) said that recommendations or guidelines for bereavement care existed in their country.

Of the 302 services that offered bereavement support, 197 (66%) stated that this support was not based on any formal policies or guidelines; 122 (40%) were not aware of any guidelines in their country; and 98 (33%) said formal guidelines did inform their bereavement services design. A quarter of the 302 services (n=75, 25%) described using a formal risk assessment tool (see Table 4).<sup>16–20</sup>

### Discussion

This was the first survey to assess bereavement care provision in palliative care services across a range of European countries, and to the best of our knowledge it is the largest of its kind, globally. Responses came from 25 countries and 370 palliative care services, 82% of which (n=302) were offering bereavement support.

A comparison of our findings with those of surveys describing bereavement service provision in the USA,<sup>5</sup> Australia,<sup>6–8</sup> the UK<sup>2</sup> and Spain<sup>3,4</sup> shows many similarities. In all

studies including ours, bereavement care was considered an important part of palliative care and a range of support types were provided – information materials and telephone support generally being among the most common. In our survey, a high proportion of services offered support that can be categorised as ‘universal’ (that is, available to all), which is also in line with earlier studies.<sup>2,5,7,8</sup> Yet our survey also showed a tendency toward a tiered approach in some services.

As in earlier surveys,<sup>2,5,7,21</sup> the use of formal risk assessment was limited, occurring in only a quarter of services. Therefore it is not known whether services are appropriately targeting the groups that most need support, as is recommended in the literature.<sup>12,14,15</sup>

No earlier studies had looked at the use of national guidelines to inform the design of bereavement services, yet most of them had concluded that services needed evidence-based guidelines.<sup>2,5,7</sup> In our survey, only 33% of services said they used formal guidelines on bereavement care provision and 40% did not know of any such guidelines in their country.

We can only speculate as to why there is such a limited use of formal guidelines and risk assessment tools. The fact that assessment tools have not been extensively tested and validated may be one reason for this. Lacking the resources required to use such tools may be another. A further potential barrier may be that many do not find it acceptable to target bereavement support at certain groups only.<sup>21</sup>

In our survey as well as in an earlier study in the USA,<sup>5</sup> less than half the services employed bereavement co-ordinators. Meeting the needs of bereaved persons with complicated grief can be seen as a complex and specialised task; the lack of trained and specialist staff might affect the efficacy of services.<sup>22</sup>

The lack of national and local guidance on bereavement support is an important finding of our survey, as it suggests a reliance on intuition over evidence when responding to bereavement care needs in palliative care.

### Strengths and limitations

One of the strengths of this survey is the wide range of information obtained about bereavement care service provision, including the use of formal guidelines and risk assessment tools. However, there were a number of challenges in undertaking this survey that should be considered when

**Table 3. Who are the professionals providing care and care co-ordination?**

Profession	Providing bereavement care (n=302)	Providing care co-ordination (n=141)
Doctor	137 (45%)	6 (4%)
Psychologist	185 (61%)	48 (34%)
Social worker	128 (42%)	29 (20%)
Nurse	180 (60%)	22 (16%)
Pastoral care worker	125 (41%)	4 (3%)
Other mental health worker	18 (6%)	–
Counsellor	–	22 (16%)
Bereavement co-ordinator or counsellor	77 (25%)	–
Palliative care volunteer	69 (23%)	2 (1%)
Bereavement volunteer	70 (23%)	1 (0.5%)
Other	39 (13%)	7 (5%)

**Table 4. Risk assessment tools used by the 75 services stating that they perform a formal risk assessment (services may use more than one tool)**

Risk assessment tool	Number of services using the tool
Bereavement Risk Index <sup>16</sup>	32
Inventory of Complicated Grief <sup>17</sup>	29
Family Risk Index <sup>18</sup>	18
Adult Attitude to Grief Scale <sup>19</sup>	24
Prolonged Grief 13 <sup>20</sup>	7

62 further services said that they use local and non-standardised tools for risk assessment

interpreting the results. There were logistical issues identifying and contacting palliative care services in each country, as services are organised in different ways and co-ordinated to different degrees, thereby introducing a risk of selection bias. We have no information regarding the services who did not respond to the survey; services from Eastern Europe were under-represented; and services that do not offer bereavement care may have been less keen to reply. Consequently, the extent to which the findings can be generalised is uncertain. Responses were received from 78% of countries, and considerable effort was put

into securing a representative sample and satisfactory response rate. Nonetheless, we think that the findings are generalisable to services in western Europe, more than to those in eastern Europe.

Finally, it was a challenge to draft questions that would elicit detailed and precise information on bereavement support in culturally and linguistically diverse countries, and an information bias may have been introduced. None of the previous questionnaires we used to produce our own had had to deal with that issue. We made all the efforts we could to address potential language issues and tested the questionnaire with volunteer respondents in a range of countries, in order to ensure that it would capture the desired information.

Taking the above issues into consideration, caution was applied when deriving trends and patterns in service provision from the data.

## Conclusions

An overall picture of bereavement support in palliative care services in Europe has been presented. The findings reveal a range of support activities. However, the prioritisation of bereavement care as a core part of palliative care was not evident in all services, and a substantial minority (18%) offered no bereavement support at all. Services providing bereavement support had few bereavement-specific roles, and less than two thirds had formally trained staff.

There is considerable scope for increasing the use of formal tools and documents, as only a quarter of services conducted formal risk assessments, and only a third applied formal bereavement care guidelines.

The findings of this survey will be used to shape the next phase of the work of the Taskforce, which is to develop an EAPC statement of best practice in bereavement care. Given what we know about bereavement and bereaved families' need for professional help, a comprehensive approach seems to be indicated in order to strengthen preventive care, promote support in the community and secure treatment for complicated grief among at-risk groups. To optimise support for bereaved relatives, it seems timely for the EAPC and palliative care services in Europe to formalise the planning of bereavement care.

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## Declaration of interest

The authors declare that there are no conflicts of interest.