


Agreeing a framework to guide the development of bereavement care in palliative care in Europe – A Delphi study

EAPC Bereavement Care Task Force

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Aims of Task Force

- Develop a baseline description of current bereavement care in palliative care services in Europe based in a survey within the EAPC membership countries. Guldin, M et al (2015) Bereavement care provision in Europe: survey by EAPC bereavement taskforce. *EJPC*, 4, 185-189
- Perform a Delphi study to formulate recommendations for bereavement care principles, structures, processes and delivery based on current practice and evidence.
- Via the Delphi study establish a consensus on recommendations.

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Method in Delphi Study

Round 1: Literature review; Drawing up concepts, dimensions and statements
 Expert Advisory Group: Prof Henk Schut, Prof Samar Aoun, Mr John Birrell; Dr Susan Cadell; Dr Linda Machin


Round 2: Consensus rating by expert panel in EAPC membership countries

Round 3: Statements with moderate agreement revised. Consensus rating with revised statements by expert panel

Round 4: Statements divided into "essential" and "desirable". Review by Expert Advisory Group for external validation

Round 5: Final statements prepared


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Delphi panel and criteria

- Panel – EAPC survey respondents, nominated experts
- Items with $\geq 80\%$ strongly agree/ agree consensus and a median of 5 = 'essential'
- Items with 75%-80% strongly agree/agree consensus and a median $> 4 < 5$ = 'desirable'
- Items with $< 75\%$ agreement were discarded

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Results

- In total, 411 emails were distributed by EAPC head office to the identified expert panel in EAPC membership countries.
- Response rates in Delphi Round 2 were 87 (23%)
- Response rates in Delphi Round 3 were 69 (79%)

Results: Dimension 1: Definition statements about grief and bereavement

	S. Agree (3)	Agree (4)	Neither (3)	Disagree (2)	S. Disagree (1)	Median	Combined SA + A
1. DEFINITION STATEMENTS ABOUT GRIEF/BEREAVEMENT							
Grief/bereavement is a natural reaction that allows the person to adapt to the loss and the new reality.	72%	28%	0%	0%	0%	5	100%
Grief/bereavement is an individual process that allows the person to adapt to the loss and the new reality.	75%	25%	0	0	0	5	100%
Grief/bereavement manifests in a number of ways: cognitive, affective, physiological, social, economic and behavioural.	78%	20%	2%	0	0	5	98%
Grief/bereavement occurs within a relational, familial, social, spiritual and cultural context.	69%	28%	3%	0%	0%	5	97%
Grief/bereavement is influenced by customs and beliefs.	62%	30%	8%	0	0	5	92%

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Results: Dimension 2: Statements about bereavement care

2. STATEMENTS ABOUT BEREAVEMENT CARE						
Supportive families, social networks and communities are considered to be an important foundation for bereavement support/ reducing risk	59%	40%	1%	0%	0%	95%
Bereavement care should be provided according to need.	57%	38%	5%	0	0	95%
A small proportion of bereaved people experience severe difficulties and develop health problems during bereavement	53%	38%	3%	1%	0%	95%
Bereavement care should be managed with extra care for those identified 'at risk'.	60%	31%	6%	2%	0%	91%
Bereavement care should be managed with therapeutic care for people with complications	53%	36%	7%	5%	0%	89%
Basic bereavement care recognises that all bereaved people should have access to verbal and written information about the grief experience and about bereavement services.	51%	36%	11%	1%	0%	87%
Most bereaved individuals adjust to life after the loss without severe emotional, psychological or physical problems	38	40	6	2	1	90%
Bereavement care reflects a multidisciplinary approach to assessment, support and treatment	45%	45%	7%	2%	1%	90%
Bereavement care refers to all services provided to support family members during palliative care and after the death.	43%	42%	7%	7%	1%	85%
It is not appropriate to offer specialist bereavement interventions to all bereaved people.	44%	33%	9%	10%	3%	77%

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Results: Dimension 3: Policies and governance

3. POLICIES AND GOVERNANCE: THE PROVISION OF BEREAVEMENT CARE IN PALLIATIVE CARE						
Service providers ensure that bereaved people are informed about the bereavement care available to them, to help them make necessary decisions & plan their own need for support	67%	59%	2%	0%	0%	96%
Bereavement care should continuously develop with reference to theories and research findings	51%	45%	6%	0%	0%	90%
Palliative care services should play a role in advocating for national bereavement care policies and guidelines	44	38	5	0	0	94%
All clinical staff providing bereavement care must avail of supervision	52%	42%	6%	0%	0%	90%
Palliative care services should ensure resources are available for bereavement care provision	51%	41%	7%	1%	0	92%
Palliative care services should promote the development of core national bereavement competencies for staff	41	36	6	1	0	90%
Palliative care professionals involved in bereavement care share a role in educating others about bereavement care	47%	44%	8%	1%	0%	91%
Palliative care services should tailor bereavement activities	46	38	7	1	0	91%
Palliative care services should support national standards for bereavement care	45%	45%	10%	0%	0%	90%
Development of formal clinical guidelines for bereavement care is recommended in palliative care services	44%	42%	13%	1%	0%	87%
In countries where volunteers provide bereavement care, palliative care services should promote the development of core national competencies FOR VOLUNTEERS	38	37	11	1	0	82%
Palliative care services should have their own formal policy outlining the bereavement care approach used in the service	44%	34%	11%	3	1	81%
A professional within the palliative care team with appropriate competence and experience should be appointed bereavement coordinator	46%	32%	12%	6%	0%	80%

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Results: Dimension 4: Assessment and decision-making

4. ASSESSMENT AND DECISION-MAKING IN BEREAVEMENT CARE IN PALLIATIVE CARE						
Bereavement support should give people information about grief/loss to facilitate appropriate help-seeking, if needed.	52%	46%	2%	0%	0%	90%
Bereavement care services should ensure that all professionals within the palliative care service are aware of available bereavement supports for families	51%	39%	5%	1%	1	90%
Bereavement care services should ensure that all professionals within the palliative care service are familiar with access/referral routes	51%	39%	7%	1%	0%	90%
Bereavement support should include support to prepare families for the loss.	52%	39%	6%	1%	0%	90%
Bereavement care services should educate staff to recognise bereavement care needs.	49%	46%	5%	0%	0%	90%
Assessment of bereavement care needs should aim to identify existing or potential mental health issues.	49%	40%	4	0	0	94%
Assessment of bereavement care should aim to identify the level of bereavement care needs.	49%	46%	5%	0%	0%	90%
Bereavement support should include helping families to understand when death is imminent.	49%	39%	6%	2%	1	87%
Assessment of bereavement care should be based on clinical guidelines for bereavement care.	49%	45%	14%	1%	0%	88%
Bereavement care services should clearly outline clinical roles and responsibilities within the palliative care team.	35	30	10	1	0	84%
From first referral to palliative care, consideration of future bereavement needs should begin.	41%	43%	13%	2%	1%	82%
Assessment of bereavement care should be continuous throughout the illness trajectory.	39%	40%	11%	6%	1%	82%
Assessment of bereavement care should include post death review by palliative care team members.	41%	40%	13%	2%	0%	81%

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Results: Dimension 5: Competencies, education and training

5. COMPETENCIES, EDUCATION AND TRAINING FOR BEREAVEMENT CARE IN PALLIATIVE CARE						
All clinical and non-clinical staff working within palliative care services receive basic education on loss, grief and self-care.	66%	31%	3%	0%	0%	97%
Palliative care professionals should be able to identify resilience and risk factors which might influence grief reactions.	54%	43%	3%	0%	0%	97%
Staff should understand the defined contributions of different professional roles in bereavement care.	53%	43%	5%	0%	0%	96%
Professionals and volunteers providing bereavement care should be adequately trained and have knowledge about evidence based intervention.	58%	33%	7%	1%	0%	91%
Palliative care staff have a role in educating other health and community staff in aspects of bereavement care.	43%	44%	14%	0%	0%	87%
Education and/or training should be to a demonstrated level of quality and/or accreditation.	40%	47%	13%	1%	0%	87%

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Results: Dimension 6: Integration with wider health care/community

6. INTEGRATING BEREAVEMENT CARE INTO WIDER HEALTH SERVICES AND COMMUNITY						
Bereavement care services within palliative care settings should be able to recognise when bereaved people are in need of care that lies outside the setting of palliative care i.e. specialist mental health services like psychologists or psychiatrists	66%	29%	6%	0%	0%	95%
Bereavement care services within palliative care settings should inform people about different care pathways and options available to them locally and nationally, e.g., on-line, telephone, voluntary group or professional care.	38%	55%	7%	0%	0%	93%
Bereavement care services within palliative care settings should ensure that referring agents such as general practitioners are informed and updated about different levels of need and available levels of bereavement care.	44%	45%	10%	1%	0%	89%
Bereavement care services within palliative care settings should develop partnerships with other bereavement care providers in the healthcare system and in the community.	40%	45%	15%	0%	0%	85%
Bereavement care services within palliative care settings should share and exchange common evidence-based standards for practice with other healthcare providers.	33%	49%	17%	0%	0%	82%

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Conclusion

- A final EAPC bereavement care guidance in palliative care has been developed
- 78 statements within six dimensions
- 26 recommendations exceeded 80% agreement with a median of 5 = essential
- 52 recommendations exceeded 80% agreement with a median of 4 = desirable

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Discussion

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