THE SHIFTING SANDS
OF BEREAVEMENT CARE
IN PALLIATIVE CARE

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Today’s journey
• What do we mean when we say bereavement care?
• Where does bereavement care fit in palliative care?
• What do we know about bereavement and bereavement services?
• What happens in St. Francis Hospice Dublin?
• What about the future?

Dame Cicely Saunders
• Founder of the modern hospice movement
• Vision for palliative care - care of the dying; research and education
• Care of family and friends – not just the patient
• Care in bereavement, not just during the illness

Impact of bereavement

Emotional
Spiritual

Social

Psychological

Physical

CONTEXT

Bereavement Needs Assessment
Assessment requires engagement with the family and discussions throughout the patient journey and should not be left to the last days of patients’ lives. Bereavement services also need to be in place, as assessment is not a standalone activity but part of a process aiming to match support to need.

(Reif et al; 2010: 5)
Bereavement Care as part of Palliative Care

Mulvihill, 2014

Palliative Care Bereavement Services

What model of service should be provided?
How do we identify those at most vulnerable or "at risk"?

- Family as the unit of care – includes children, adults, groups, vulnerable adults
- Increasing family complexity – blended families
- More people working
- Increased migration

What is the evidence?

Convergences from the research

- Of some of the theories
- Value of social support
- Need for information
- Risk BUT also resilience
- Context, role including caregiving
- Social variables including socioeconomic
- Not everyone needs counselling


Section 12: Services for Families and Carers, including bereavement care

"Hard to tell from here. Could be buzzards. Could be grief counsellors."

Cheaney, T.
“Whilst there have been some significant developments in bereavement care, the impact of these is as yet largely unknown and there is no tool to enable the quality of services offered to be checked or assessed with any degree of objectivity”

(Cruse Bereavement Care & Bereavement Services Association, 2014:4)

Value of in-depth assessment

- Assessment can clarify concerns and in itself be helpful to those being assessed, as it offers them opportunities to discuss their situation.
- Assessment facilitates objective decision making about the type and level of bereavement service that may be needed.

(Wilson et al, 2016: 6-7)

Go around and see what is being done and then see how your own circumstances can produce another version

The vision has to stay the same
The delivery needs to change

St. Francis Hospice Dublin

Raheny
In-patient unit: 19 beds
Community Palliative Care Team
Hospice Day Care

Blanchardstown
In-patient unit: 24 beds
Community Palliative Care Team
Hospice Day Care
A case for change in Hospice

- Population increase - Rising level of need
- Increasing vulnerability and complexity
- Increasing need for proactive rather than reactive care
- A role in the much needed integration of health and social care
- The requirement to do more with less
- Constrained and uncertain funding

"As the environment of care again threatens to fail too many and too often, hospices will need to unite in their thinking and develop a strong voice individually and collectively."

Dame Clare Tickell
"People who have been bereaved can experience social isolation because people don’t know what to say or how to act towards them, and it is therefore important to develop community capacity to support people who have been bereaved."

To Absent Friends...a people’s festival of story telling and remembrance 2015.

Public health approach to palliative care

"...it is important to look not only at data from clinical encounters, but at bereavement as it is lived out in everyday life."

Rumbold and Aoun in Absent Friends 2015.

- Links with community
- Networks, not just provider
- Rituals of remembrance and memorialisation build solidarity

Public health approach to palliative care

"Need to think about populations as well as individuals. That is what professional responsibility is"

Dame Barbara Monroe

Public Health Model

Perspective for Planning

<table>
<thead>
<tr>
<th>Palliative care services</th>
<th>Palliative care approach everywhere</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist services</td>
<td>Actions in all settings of health care</td>
</tr>
<tr>
<td>Institutional approach</td>
<td>Community approach</td>
</tr>
<tr>
<td>Services approach</td>
<td>Population approach</td>
</tr>
<tr>
<td>Individual service</td>
<td>Systems approach</td>
</tr>
</tbody>
</table>

Gomez-Batiste et al., 2017.

"Dying is not a technical glitch of the human operating system; it’s a feature. It’s the only prediction we can make at birth that we can bank on. Everyone will die, and it’s very likely somebody we love will die before we do. And yet the bereaved are often treated like those to whom something unnatural or disgraceful has happened. People avoid them, don’t invite them out, fall silent when they enter the room. The grieving are often isolated when they most need community."

Luscombe 2017

What is our vision?

- Sustainability
- Evidence based
- Range of responses to need
- Develop partnerships and networks

"When illness, death and grief strike people want to feel that they are part of a kind and compassionate nation"

Taoiseach Enda Kenny
Concluding points

- Bereavement care in palliative care involves support before, during and after death.
- We need to value the role of bereavement support in palliative care.
- Each palliative care service should have a range of responses to bereavement care.
- We need to develop standards based on evidence.
- We must develop networks and links with the communities we are based in - integration.

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