THE NATIONAL END OF LIFE CARE AUDIT AND REVIEW SYSTEM

Some findings relevant to dementia

Dr. Kathleen McLoughlin
Irish Hospice Foundation
In 2011 a Project Advisory Group was established to advise and support the development of a National End of Life Care Audit and Review System.

The system was piloted in 2012/2013 and has been used by healthcare staff to review the deaths of more than 140 people in Ireland, in all settings where people die (i.e. acute hospitals, residential care services, hospices and home).

The system enables staff and bereaved relatives to review and reflect upon end of life care across eight, evidence based domains.
The aim of the pilot was to test the audit and review system, with a view to documenting the pilot process and experiences and identifying emerging issues to be considered in advance of national implementation.
MIXED METHOD APPROACH

- Comparison of data from 130 staff reviews, 59 bereaved relatives and 23 independent assessments of care;

- Observation of audit and review meetings with staff;

- Questionnaires examining the experience of audit facilitators;

- Cognitive testing of the tools with healthcare staff using the QAS;

- Focus groups and one-to-one interviews with audit managers and facilitators.
EXPERIENCE
57% patients died in a single room

84% of patients were in at least some pain during the last week of life. In most cases staff and relatives considered it quite well managed (8/10)

76% of healthcare staff said that they didn't discuss end of life care preferences with the person. In 81% of cases it's discussed with the family.

Specialist palliative care were involved in the care of 27% deaths. Not everyone needs SPC but on review staff identified 20.3% who could have benefited from SPC.
Overall, in 30.7% of deaths reviewed, the person had a diagnosis of dementia.

- Acute Hospital: 7
- HSE Community Hospital: 76
- Nursing Home: 65
- ID Services: 50

% deaths reviewed with dementia
So, does it make a difference if you have dementia?
YOU MIGHT BE LESS LIKELY TO DIE IN A SINGLE ROOM...

% of people dying in a single room

Statistically Significant Difference

Dementia: 44.7%
No Dementia: 68.3%
YOU MIGHT BE A LITTLE BIT MORE LIKELY TO BE IN PAIN BUT IT MIGHT BE BETTER MANAGED

In pain some / all of the time in last week of life

<table>
<thead>
<tr>
<th></th>
<th>Dementia</th>
<th>No Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>In pain some / all of the time</td>
<td>59</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>8.6</td>
<td>8.3</td>
</tr>
</tbody>
</table>
YOU PROBABLY HAVEN’T DISCUSSED YOUR EOLC PREFERENCES PERSONALLY

8% of people like me will be asked about our end of life care preferences

40% of people like me will be asked about our end of life care preferences

I have dementia

I don’t have dementia
YOU MIGHT BE LESS LIKELY TO BE REFERRED TO SPECIALIST PALLIATIVE CARE

23% of people with dementia were referred to SPC

49% of people with no dementia were referred to SPC

In hindsight, 19% of those with dementia not referred would have benefited.

In hindsight, 26% of those with dementia not referred would have benefited.
OVERALL...IMAGINE THIS PERSON WAS YOU?

WOULD IT BE ACCEPTABLE TO BE CARED FOR IN THIS WAY IN THE LAST WEEK OF LIFE?

<table>
<thead>
<tr>
<th></th>
<th>Staff</th>
<th>Relative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rating</td>
<td>8.3</td>
<td>9.1</td>
</tr>
</tbody>
</table>
“Just keep doing what you are doing - the care and attention received was excellent, considered, respectful and dignified.
Initiating discussions
Supporting those who want to engage
Display resources
Honesty
Assessment of capacity
Agreeing status re: DNAR etc
Electronic communication
OOH Services
Listen to family and patient
Look after yourself
1 IN 4 RELATIVES OFFERED SUGGESTIONS FOR IMPROVEMENT...

**Improvements**

- Single Rooms
- Communication
- The big little things
- The System
- Stretched to capacity

---

1 IN 4 RELATIVES OFFERED SUGGESTIONS FOR IMPROVEMENT...
From mine and my family's experience with our relative's death we were impressed and very happy with staff. It is important to state that we had built up a very good relationship with all staff over the years while our relative was in the nursing home. She received great care throughout and also while she was dying RIP.

Just keep doing what you are doing - the care and attention received was excellent, considered, respectful and dignified.

There are always ways of improving, but we the family, were pleased our father died with dignity and respect and are grateful to the people who cared for him.
One of the doctors could have been more sensitive answering questions especially when my wife was dying, more training might help.

Insufficient bathroom facilities to care for patients. Fortunately, their needs were met by the most caring staff. I bless them daily.

When staff know their patient is dying a pain management team and palliative care team should be provided without family having to demand it. And this should be discussed with the family as early as possible so a plan of action is already in place (where possible). Also a survey from the nursing home for family to fill in might also help them identify areas which needs attention.
Check hospital re: medications as mistakes were made. Take more heed to patient and family as regards needs. More control of medication and feeding. Waited for feeding cup for my dad for 6 weeks and he still did not get it. Would be nice to have a place of rest and not have to go to funeral home so staff family and friends could visit. Staff were brilliant at the end.

The nurses were all very willing to help, but there were too many residents for the size of the nursing home.
She shared a room and the other occupant refused to leave her bed as she was ill. This caused a lot of difficulty. She herself was not mentally in a position to deal with my mother dying. Hence I believe that a private dying room is a vital necessity for privacy and comfort. The occupant left the room upon my mothers death, so I believe she was upset too.
Staff at x hospital were excellent to my mother but she did not need to be in the hospital most of the 5 months but we could not afford full time care which at nearly 102 years of age any mother then required. I want the HSE to have the fair deal applied to own home as well as nursing homes but although we had fair deal approval my mother died after a chest infection while waiting on a place. I got a call this month from x CNU to say they had a place - 4 months after she had died. I am very upset that my mother had to spend her last days in hospital as she was not very ill but as I was the only carer at 75 years I could not do full time care with an 84 year old husband. However I was grateful for the hospitals care.
"patient experience is consistently positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and outcome measures...clinicians should resist side-lining patient experience as too subjective or mood orientated, divorced from "real" clinical work of measuring safety and effectiveness".

A strange, horrible business, but I suppose good enough for Shakespeare’s day.

(Queen Victoria)
The system appears to be feasible and recognised as useful, particularly by healthcare teams providing end of life care in hospitals and in residential care settings.

A modified tool is required to review deaths in the home and hospice.

Areas were identified where the validity of the tool could be improved through changes in language and the provision of additional definitions.

Internal consistency of the tool could be improved if consideration is given to a separate tool for the review of sudden deaths.

The qualitative feedback from bereaved relatives was considered powerful by healthcare staff and is potentially the biggest driver of quality improvement.

The pilot findings have contributed to the development of v20.0 of the National End of Life Audit and Review System, that is now being tested.
YOU CAN GET INVOLVED...

HF Residential Care Services for Older People Initiative

Emer Meighan Development Support Officer

Hospice Friendly Hospitals Programme
32 Nassau St
Dublin 2
Ireland

Telephone: +353 1 679 0040
Direct Dial: +353 1 673 0068

Email: emer.meighan@hospicefoundation.ie
Website: www.hospicefriendlyhospitals.net
REFERENCES & ACKNOWLEDGEMENTS


HFH (2010). National Quality Standards for End of Life Care in Hospitals. Published by The Irish Hospice Foundation.


HIQA (2008). Residential Care Standards for Older People.

Thank you to:
- The Audit and Review Consultative Committee
- The organisations who engaged in the testing of the system
- The staff who gave their time to attend the audit and review meetings
- The audit managers challenged with the task of bringing everyone together
- The relatives who shared their experiences openly