



Hearing the Voice of Bereaved Relatives

“Because of the support he received, my husband died well.
Because my husband died well, I live well.”

(Forum on End of Life, Dublin Castle, October 2013)

Report compiled on behalf of The Irish Hospice Foundation by Dr. Kathleen McLoughlin.

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Acknowledgements

The Irish Hospice Foundation would like to sincerely thank the 59 bereaved relatives who took the time to respond to this survey. We also thank the fourteen healthcare facilities that took the time to administer the survey to relatives in 2012-3.

Executive summary

It has been suggested that the quality of end-of-life care received by people in healthcare settings is reflective of the quality of healthcare for the whole society. This document highlights the key findings from a pilot of a new survey of bereaved relatives, developed as one element of a National End-of-Life Audit and Review System, with reference to standards for End-of-Life Care in Ireland published by the Health Information and Quality Authority (HIQA) and The Irish Hospice Foundation.

The findings suggest that generally most people found the care of their loved one to be acceptable and the majority of relatives were satisfied with the care received. However, there is clearly considerable room for improvement when the elements of care, as outlined in published standards, are examined in detail. The study highlights that considerably more can be done to improve direct communication with the patients regarding end-of-life care wishes and preferences, throughout the illness journey. In addition, there is need for greater access to single rooms for people at the end of life. Qualitative findings suggest that where improvements in care are necessary, a combination of factors requires attention, including the culture of care at department / organisational level and system-wide changes with regard to access to home support, nursing home provision and emergency department overcrowding.

An integrated mechanism to monitor progress against published standards is required for end-of-life care in Ireland. As part of this system, a survey of bereaved relatives is an important component. Consideration is also given to other international studies of this nature.

Introduction and background

High-quality end-of-life care can make a significant difference to the physical, psychological and spiritual outcomes for the bereaved. In turn, when care is poor, it can have a detrimental impact (1). The Office of the Ombudsman in Ireland recently published a thematic collection of complaints received regarding end-of-life care in acute hospitals(2). The complaints focused on the need for improvement with regard to communication, patient autonomy, access to specialist palliative care, support for families and friends, post-mortem examinations, returning the deceased person's belongings and management of complaints. These elements are all central features of the Irish Hospice Foundation's Quality Standards for End-of-Life-Care in Hospitals(3) and national standards mandated by the Health Information and Quality Authority(4,5) as part of their focus on improving the quality of care for people generally and at the end of life. Indeed, this focus is echoed internationally, and *"caring for older people and those approaching the end of their lives is rightly said to be a litmus test for health and social care and indeed a measure of our whole society"*.(6)

Measuring the quality of end-of-life care

In Ireland there is no nationally agreed system to measure the quality of end-of-life care. Continually involving service users in improving care delivery and developing systems for listening to and seeking their feedback is a central tenet of the HSE's Quality and Patient Safety Strategy(7) and national policy(8). The complexities associated with evaluating the quality of end-of-life care from a dying patient's perspective have been well documented internationally(9), and surveying the voice of bereaved relatives is considered a reasonable proxy(10) and an important component of a quality and risk approach(11).

Whilst a number of surveys of bereaved relatives have been developed in different jurisdictions(12,13), none of these have been tested in an Irish context and do not specifically align to existing national quality standards.

In 2008/9 the first National Audit of End-of-Life Care in Hospitals in Ireland was conducted. It reviewed a random sample of 1,000 patient deaths from the differing perspectives of

doctors, nurses and bereaved relatives. The Audit identified key factors that improve the quality of end-of-life care. The Audit also provided each hospital participating in the programme with baseline data on how they scored on these key factors. As a result, each hospital has been able to monitor its progress on improving these aspects of end-of-life care.

National End-of-Life Care Audit and Review System

In 2011 The Irish Hospice Foundation's Hospice Friendly Hospitals Programme established a Steering Committee to oversee the development of a survey of bereaved relatives, as one component of a new National End-of-Life Care Audit and Review System, building on that developed in 2008. The new system aims to support a process of continuous improvement in the care of persons at the end of life, including their families. This report highlights the main findings from that survey, with reference to published standards within each domain.

Method and response rate

The Survey of Bereaved Relatives¹ was sent to 120 relatives who were next-of-kin to people who had died in either acute hospital or residential care services for older people across 14 sites. Excluded were people under the age of 18, those who were flagged by clinical staff to be likely to be experiencing significant distress due to the bereavement or a subsequent known life event, and cases where a major investigation or complaint was pending. Contact with bereaved relatives was only made, initially by phone, when at least three months had passed since their family member had died. Following the consent of the bereaved relative by phone, an information letter, questionnaire and information leaflet outlining support available for bereaved relatives, was sent by post. One follow-up reminder letter was sent by post two weeks later. Those relatives who wished to participate opted-in by returning the questionnaire. Ethical approval was obtained from local HSE / University Research Ethics Committees before conducting this research in each participating region.

The questionnaire asked bereaved relatives to give information on and rate various elements of their experience of end-of-life care. Ratings were expressed on a scale of 1 to 10. The questionnaire also included a qualitative section, which invited participants to give feedback on areas for improvement and share their stories².

After the findings had been collated the results were presented to staff. Audit managers reported that it was the respondents' descriptions of their experiences and areas they felt needed improvement that made the most impact on healthcare staff. (In fact, audit managers reported that staff took little note of the statistics presented back from the surveys.) Some staff members were shocked by the negative experiences reported, sometimes expressing disbelief that such failings of care could occur. To avoid demoralising staff, the qualitative section of the survey was amended following the pilot, to ask specifically about both positive experiences and areas for improvement, utilising questions

¹ NB The development and testing of the Survey of Bereaved Relatives is described in detail elsewhere.

² Participants' feedback from the qualitative section of the survey is reproduced exactly as given, and may contain typographic and grammatical errors.'

advocated at national level by the HSE Consumer Affairs department, and thus avoiding a focus on negative experiences.

Response rate and demographics of respondents

Of the 14 sites that participated in the survey, 4 were acute hospitals and 10 were residential care services for older people. Of the 120 bereaved relatives who were invited to participate, 59 (49%) responded. 36 (61%) were recruited via an acute hospital and 23 (39%) from a residential care service for older people. Of the 59 participants 56% were female and 37% were the adult child of the person who had died (Table 1). 37% (22/59) described themselves as full-time carers of the deceased.

Table 1: Participant demographic gender details (N=59)

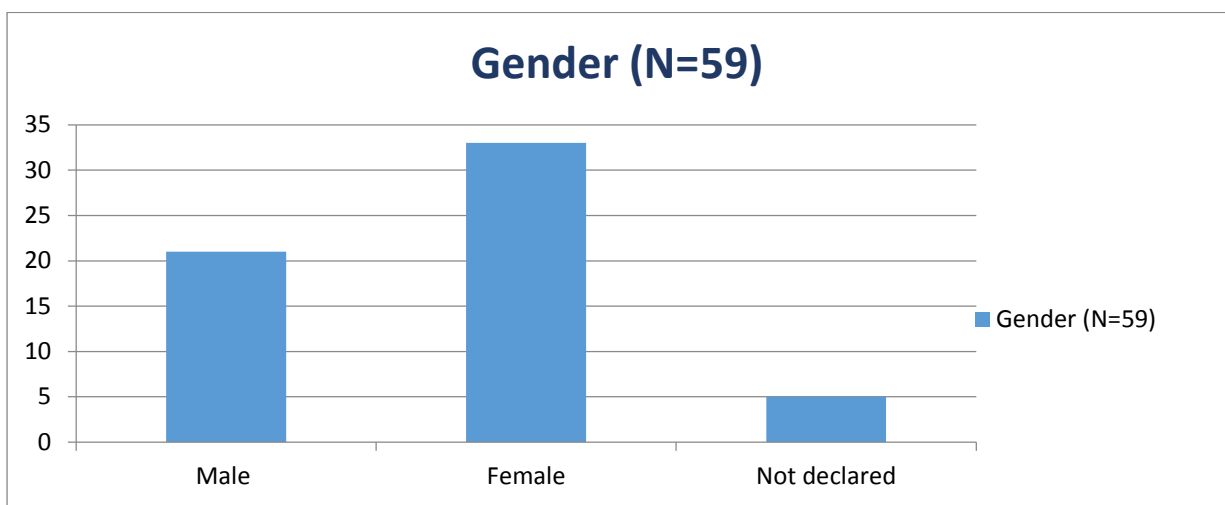


Table 2: Participant demographic age details (N=59)

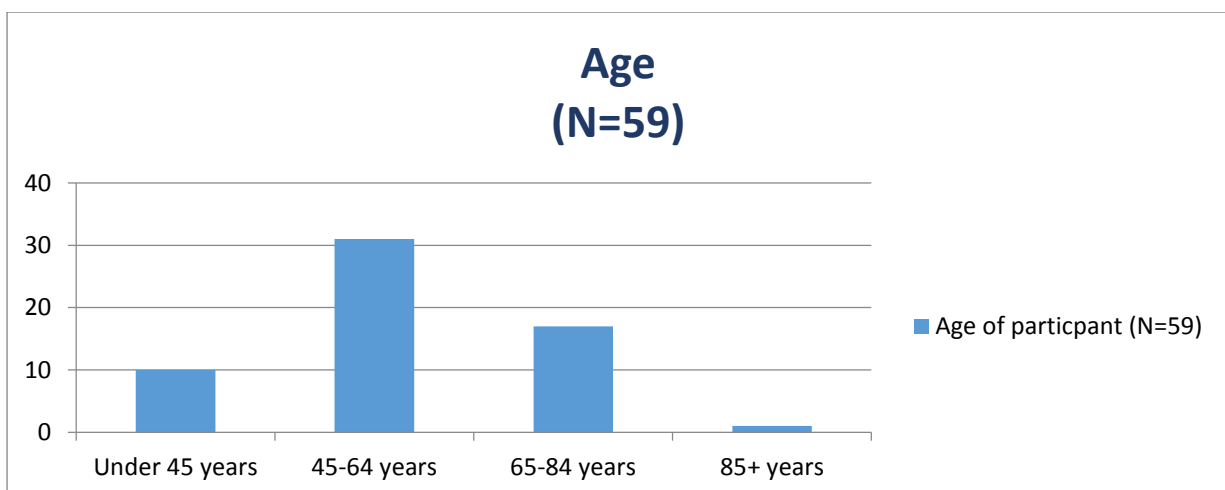
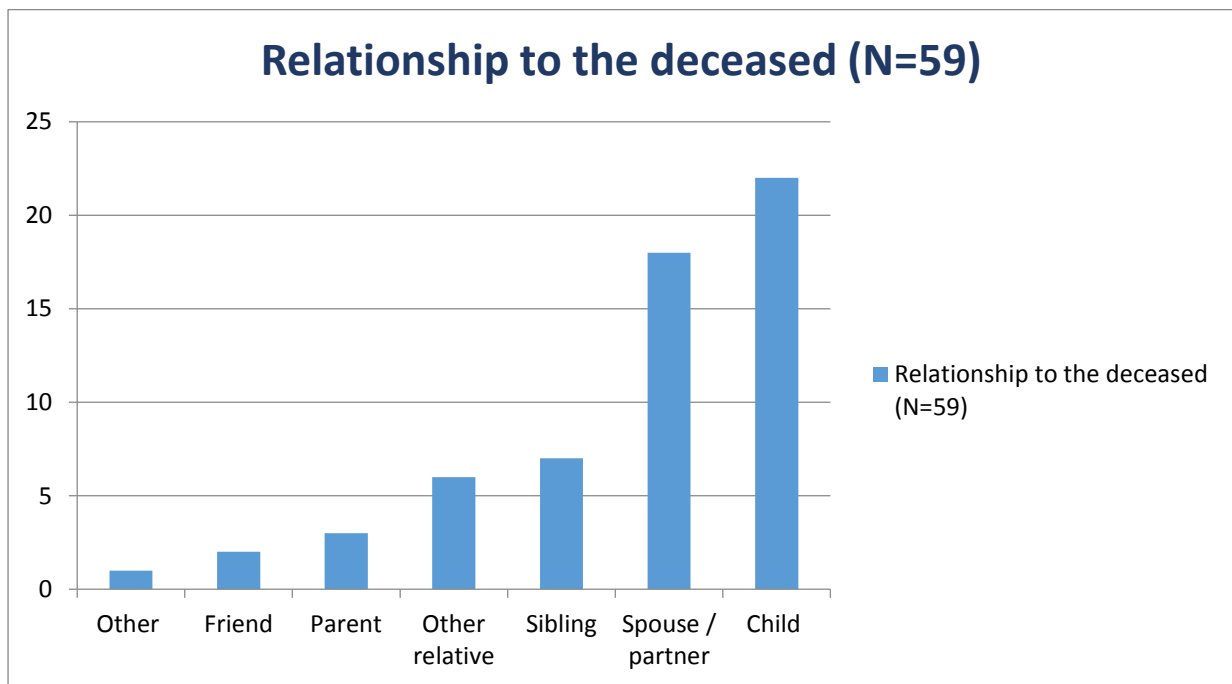


Table 3: Participant demographic relationship to the deceased (N=59)



Report findings

Time spent in hospital during the last six months of life

'A recent Scottish study shows that up to 30% of inpatients in (Scottish)hospital today will be dead within a year.' (16)

64% (38/59) of relatives responded that their loved one had spent time in an acute hospital during their last six months of life. The number of stays in hospital ranged from 1 to 10, with a mean of 2.2 visits to an acute setting in the six months prior to death. The median number of nights spent in hospital during this timeframe was 20, and ranged between 1 and 210 in this sample.

Expectation of death

'75% of deaths in hospital are expected' (16)

Bereaved relatives reported that in almost half of cases, the death of their loved one was expected (28/58 – 48%) and in most cases this was recognised by the person who was dying (76%), the healthcare staff (100%) and the respondent (100%). The person's death was considered to be unexpected by the relative in 52% of cases.

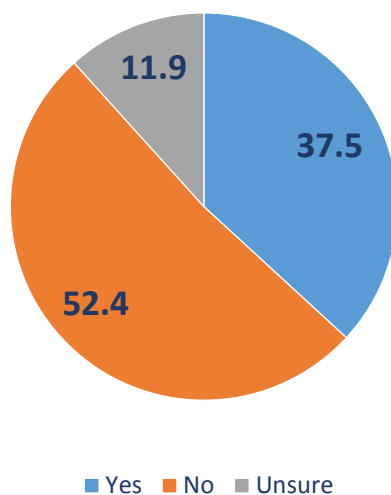
Discussions with healthcare professionals

*'Discussions are held with the patient on an on-going basis about his/her needs and preferences and the outcomes of these discussions are documented in the Healthcare Record' (Quality Standards of End-of-Life Care in Hospitals **Standard 3.3**)*

'The resident's wishes and choices regarding end-of-life care are discussed and documented, and, in as far as possible, implemented and reviewed regularly with the resident.' (HIQA Standards for Residential Care Settings for Older People 16.2)

Thirty-eight percent of relatives reported that the person who had died had discussed their wishes regarding end of life with a healthcare professional and 12% were unsure if a discussion between the dying person and a healthcare professional had taken place. This is shown in Figure 1. In contrast to this data, discussions with the family occurred in 62% of cases.

Figure 1: % of relatives reporting that a discussion had taken place between their relative and healthcare professionals regarding end of life wishes



For those where death was expected, a discussion between the person about their end-of-life care wishes and a healthcare professional was reported to have taken place in just 57%

of cases. In 91% of cases where death was expected, a discussion took place with the family.

In cases where the person's death was expected, and the person was mainly conscious during their last week of life, discussion regarding end-of-life care wishes took place between the healthcare professional and that person in 64% (7/11) of cases.

Communication with healthcare professionals was a common area where possible improvements were identified, as outlined in qualitative feedback from relatives. For example:

"While I am aware of how busy hospitals and wards are, especially at this time, I found it was up to me (family) to make inquiries as to how my mother's health was (daily). I feel the hospital should be more proactive in updating family on patient's condition. The opinions I have may not be the reason my mum was moved to a single room - but if it is right I feel the family should be informed of what is taking place. My mother was moved to a single room a few days before she died. I feel now having filled out question 4³ in the survey that my mother was moved to this room because the hospital felt she was dying. This was never said to us, to allow us time to plan our last days with our mum. I would like to take this opportunity to thank X hospital for the excellent care they showed to my mother over many years and many stays with you."

"Maybe more communication with family as we were unaware that relative was close to death in days before she died."

"One of the doctors could have been more sensitive answering questions especially when my wife was dying, more training might help."

³ Question 4 of the Survey for Relatives/Friends on End-of-Life Care v19 asks the following questions;

(4.1) Did your relative ever request a single room? 1 Yes. 2 No. 3 Not applicable since relative was already in a single room. 4 Not applicable since relative died in family home.

(4.2) Did you or your family ever request a single room? 1 Yes. 2 No. 3 Not applicable since relative already in a single room. 4 Not applicable since relative died in family home.

(4.3) Did your relative die in a single room? 1 Yes. 2 No. 3 Not applicable relative died in family home

(4.4) If relative did not die in a single room, why not? Tick more than one if appropriate 1 No single room available. 2 Relative not expected to die. 3 Relative did not want single room. 4 Other (please specify). 5 Not applicable because relative died in family home.

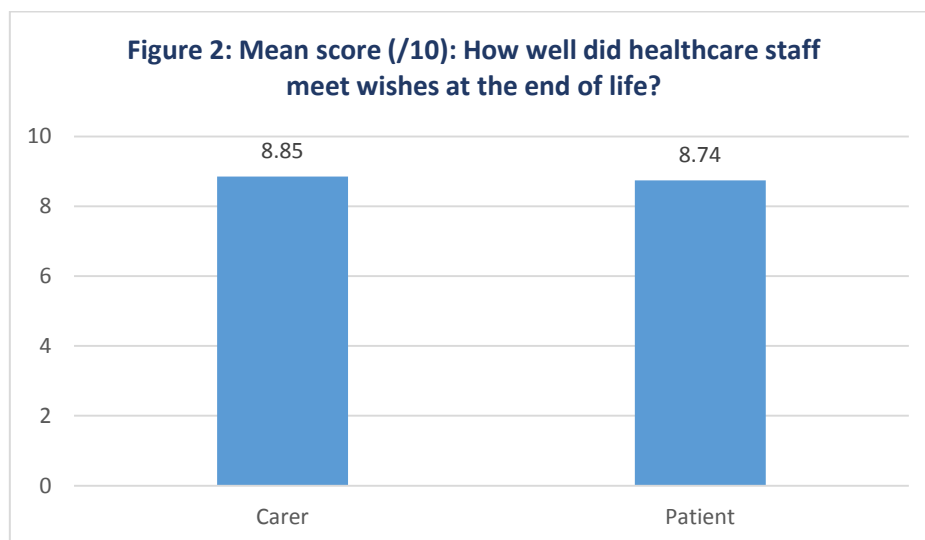
(4.5) If your relative died in a single room, how many hours / days during the last week did (s)he spend there? ___hours ___days. 1 Not applicable because relative died in family home.

Meeting wishes

'All communication between hospital staff and patients and/or family members is governed by the wishes of the patient.' (Quality Standards of End-of-Life Care in Hospitals **Standard 1.3**)

'The resident's palliative care needs are assessed, documented and regularly reviewed. The information derived from these assessments is explained to, and options discussed at regular intervals with the resident, his/her family or representative, in accordance with the resident's wishes.' (HIQA Standards for Residential Care Settings for Older People **16.1**)

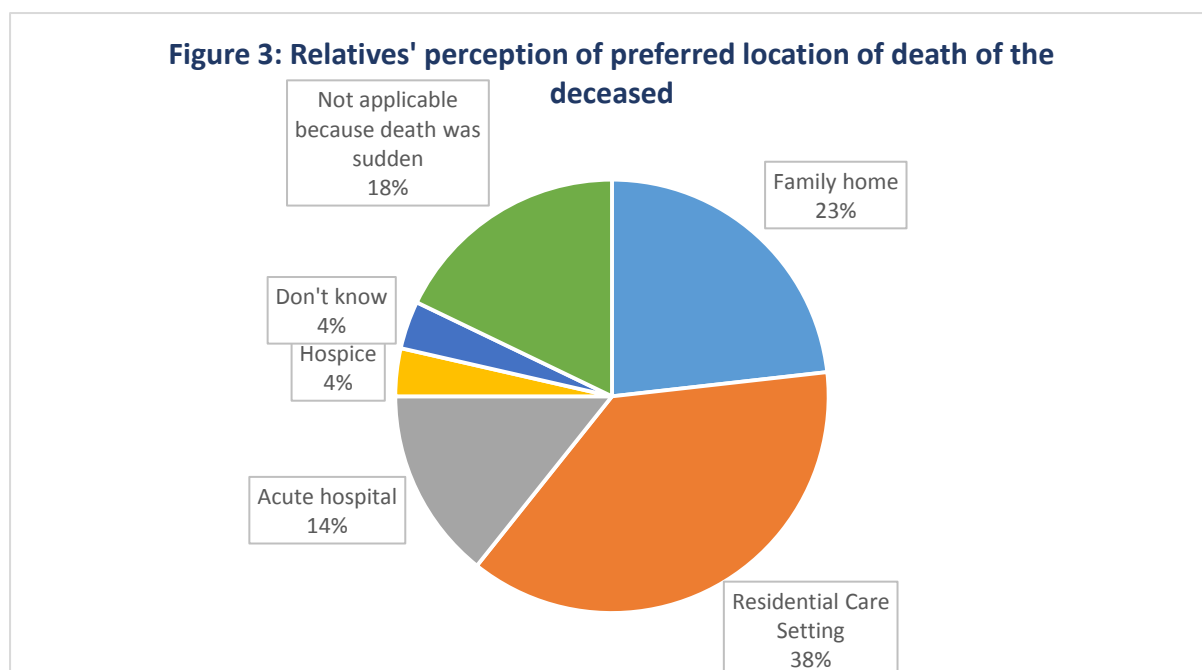
Relatives were asked to report, on a scale from 1-10, how well healthcare staff met their loved one's wishes in the last week of life. Scores ranged from 1 to 10, but generally relatives were happy with the way both their own and their relative's wishes were met at the end of life. The mean score was 8.7/10 (s.d. +/-2.1). Figure 2 compares this mean with the ratings relatives gave regarding whether their own wishes were met.



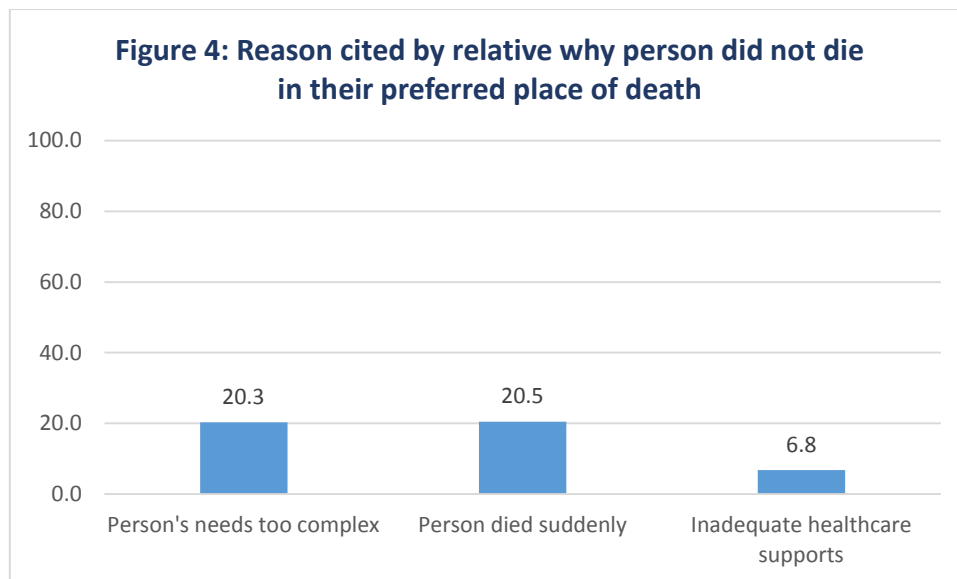
Preferred place of death

'74% people in Ireland want to die at home' (17).

The relatives of everyone who completed this survey died in an acute hospital or a residential care service for older people. As indicated in Figure 3, the majority of relatives reported that their loved one's preferred place of death was the family home or their residential care setting.



The main reasons cited by relatives for their loved one not dying in their preferred location were that the person died suddenly or that their needs were too complex (Figure 4).



None of the relatives reported that they were unwilling to support the person who may have wanted to die at home, and for those who died in hospital, no relative reported in this section that this was linked to issues associated with delayed discharge from the acute setting. However, one relative discussed how a lack of community care and nursing home beds resulted in months in an acute hospital for her 101 year old mother.

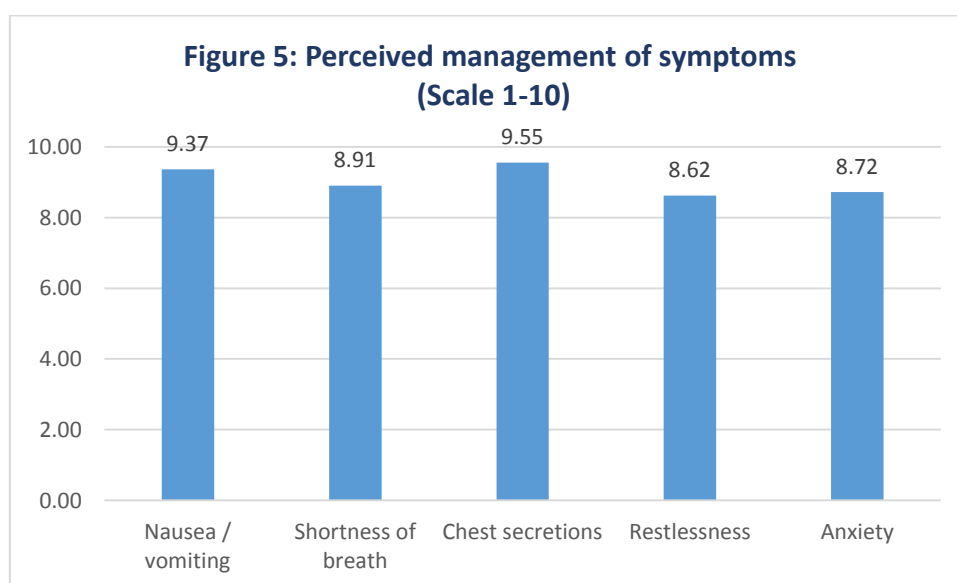
“Staff at x hospital were excellent to my mother but she did not need to be in the hospital most of the 5 months but we could not afford full time care which at nearly 102 years of age any mother then required. I want the HSE to have the fair deal applied to own home as well as nursing homes but although 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 hospital’s care”.

Pain and symptom management

*‘The patient’s experience and description of pain and symptoms, including verbal, non-verbal and behavioural expressions of discomfort and pain, are identified, regularly assessed and responded to promptly. There is on-going dialogue with the patient regarding his/her experience of pain, distress and other symptoms and the level of comfort obtained from different interventions.’ (Quality Standards of End-of-Life Care in Hospitals **Standard 3.4**)*

*‘Effective pain and symptom management is provided as a key component of end-of-life care and staff education in the hospital ... The hospital/department has Guidelines for use during initial assessments and reassessments that assist staff in identifying patients who are experiencing pain. There is documentation within the Healthcare Record of regular assessment, timely response, monitoring and review of pain and symptoms according to need and the patient’s expressed experience of the pain/symptom(s) and intervention measures.’ (Quality Standards of End-of-Life Care in Hospitals **Standard 1.9**)*

Pain was generally well managed; however, 13% of relatives perceived that their loved one was in pain all or most of the time during their last week of life. There was a high level of satisfaction around the perceived management of other common symptoms, with satisfaction ratings ranging from 8.62 to 9.55. This is illustrated in Figure 5.



Palliative care

*‘The patient is referred to specialist palliative care services as soon as patient needs, symptoms and other care factors indicate a need for such expertise.’ (Quality Standards of End-of-Life Care in Hospitals **Standard 1.9**)*

*‘In accordance with the resident’s assessed needs, referrals are made to specialist palliative care services so that an integrated multidisciplinary approach to end-of-life care is provided.’ (HIQA Standards for Residential Care Settings for Older People **16.3**)*

Although relatives were not asked about palliative care specifically, the need for improved access and availability to palliative care was mentioned in a number of the qualitative responses:

“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 for family to fill in might also help them identify areas which need attention.”

“On the morning relative fell ill at home. Palliative care was supposed to be in place and we have been given a number to ring from home. When we got in touch with palliative care team in the xxx [name of hospital/care home] we were told it was not set up yet. If it had not been for the care and support of [name] day ward mam would have died in A&E. Mam was taken directly to day ward as instructed, treated and died there. Palliative care team did not arrive til 6.30pm and mum had been there since 10 am that morning. We felt let down by pal care team on that day. [Name] ward dealt with mum so so well always.”

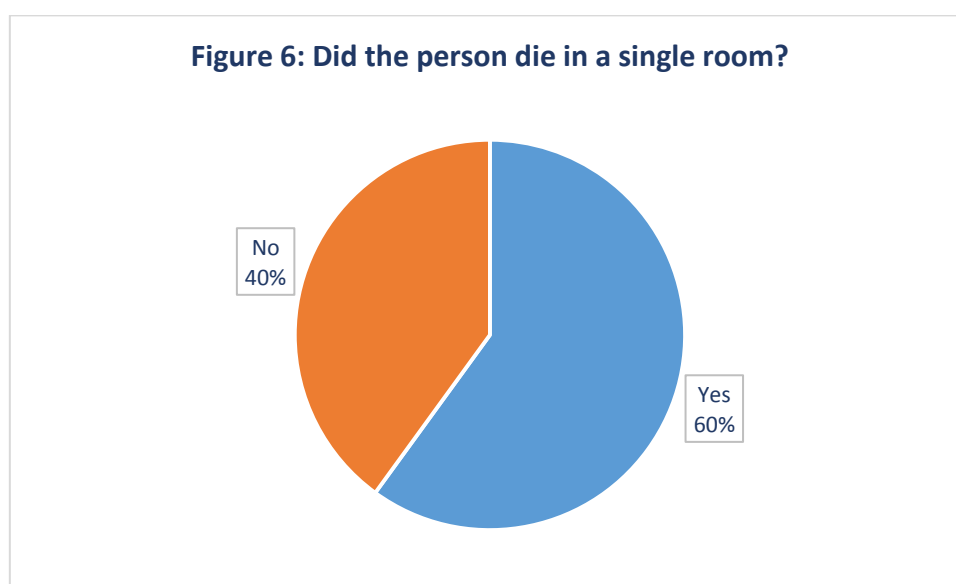
Dying in a single room

'End-of-life care patients are offered the choice of being accommodated in a single room.' (Quality Standards of End-of-Life Care in Hospitals **Standard 1.5**)

'The dying patient is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested.' (Quality Standards of End-of-Life Care in Hospitals **Standard 3.6**)

'Every effort is made to ensure that the resident's choice as to the place of death, including the option of a single room or returning home, is identified and respected.' (**HIQA Residential Care Standard 16.6**)

Relatives reported that 6 out of 10 people died in a single room (Figure 6).



For 36% of people who did not die in a single room, the reason cited by relatives was 'lack of availability'. In 27% of cases, a person was reported not to have had the opportunity die in a single room, as their death occurred suddenly. The lack of availability of single rooms was problematic for many patients, families and other patients at the time of death.

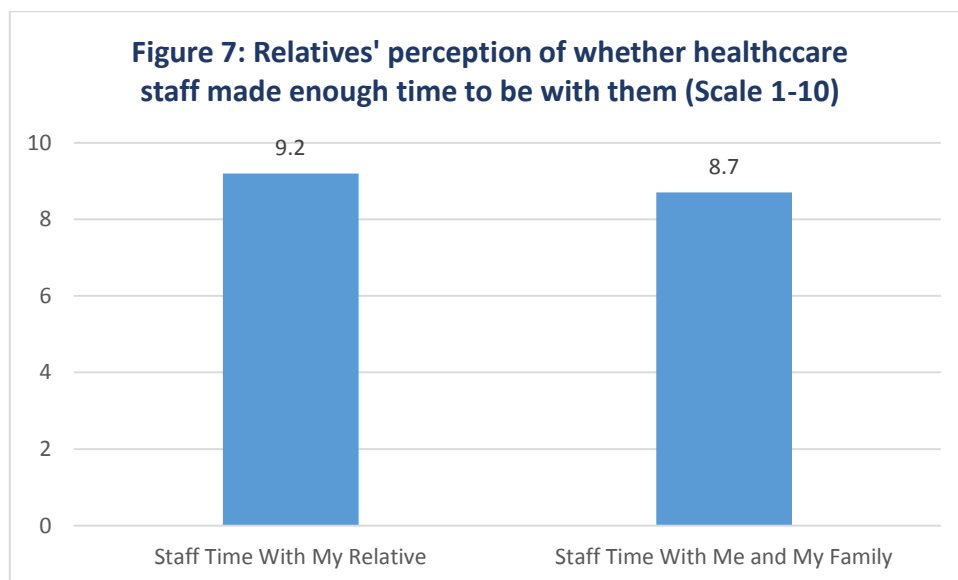
"She shared a room and the other occupant refused to leave her bed as she was ill. This caused a lot of difficulty. She herself was not mentally in a position to deal with my mother dying. Hence I believe that a private dying room is a vital necessity for

privacy and comfort. The occupant left the room upon my mother's death, so I believe she was upset too."

"Patient occupied a single room from the outset of the hospital stay - over 3 weeks - on one occasion he was told he was being moved to facilitate another patient that was infectious. This caused patient a high level of unnecessary anxiety and he wasn't moved. I was upset at patient being told this might happen as it was known he was dying from the time of his admittance to hospital and it caused unnecessary distress and anxiety."

Spending time with patients at end of life

In general, relatives rated the amount of time healthcare staff spent with them and their loved one positively, with mean satisfaction ratings of 8.7 and 9.2, respectively (Figure 7).



'The hospital facilitates family members with overnight rest and refreshment facilities.' (Quality Standards of End-of-Life Care in Hospitals **Standard 1.5**)

'When a death is believed to be imminent, the patient's family is informed and facilitated as far as possible and in accordance with the patient's wishes to spend as much time as they wish with the patient, including overnight stays if feasible.' (Quality Standards of End-of-Life Care in Hospitals **Standard 4.5**)

'The resident's family and friends are facilitated to be with the resident when he/she is very ill or dying and overnight facilities are available for their use. Upon the death of the resident, time and privacy are allowed for his/her family, friends and carers. An atmosphere of peace and calm is maintained at all times.' (**HIQA Standards for Residential Care Settings for Older People 16.7**)

Facilitating and supporting relatives

Two out of three relatives were offered the opportunity to stay overnight. In cases where the person's death was expected, 80% of relatives were offered overnight accommodation. Four relatives reported that overnight accommodation was not available in the facility where their loved one died. One relative said that there was a

"Lack of facilities for families to stay overnight - waiting room did not allow people to sleep and there was no natural light / windows."

Another advised that she would have liked

"To be told they could visit anytime and to be asked if they would like to stay overnight."

'The hospital provides assistance and supports to families in dealing with loss during the period approaching and following a death.' (Quality Standards of End-of-Life Care in Hospitals **Standard 1.13**)

'Families are offered timely bereavement supports before and after the death of a loved one which respond to their varied grief needs associated with their individual and cultural and spiritual experiences of dying and death.' (Quality Standards of End-of-Life Care in Hospitals **Standard 4.5**)

Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. This information may be offered on more than one occasion.' (Quality Standards of End-of-Life Care in Hospitals **Standard 1.13**)

'Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions.' (Quality Standards of End-of-Life Care in Hospitals **Standard 4.6**)

'Upon the death of a resident, his/her family or representatives are offered practical information (verbally and in writing) on what to do following the death and on understanding loss and bereavement. This includes information on how to access bereavement care services and how to register the death.' (**HIQA Standards for Residential Care Settings for Older People 16.10**)

Bereavement support

Only one in three relatives (32.7%) reported that they had been offered support by the healthcare facility since their loved one had died. Relatives reported a mean satisfaction rating with the support offered of 7.2 out of 10. One person said:

"I am not dissatisfied with the support given to relatives - but there wasn't any. Everyone is working hard caring for patients, a little more information on the patient's condition would be helpful."

Raising issues and concerns/Giving feedback

'Opportunities are provided by clinicians and nursing staff for family members to clarify issues and concerns about the patient's well-being, provided this is in keeping with the patient's wishes. Feedback from family members is acknowledged and noted in the Healthcare Record and complaints are dealt with promptly and sensitively.' (Quality Standards of End-of-Life Care in Hospitals **Standard 4.1**)

Just 16.7% of relatives were advised of opportunities for them to give feedback on the care of their loved one (apart from the survey they were completing).

Moment of death

'Particular attention is given to deploying staff to ensure that the patient is not left alone while dying, particularly if the patient's family are not present. The patient's family are advised as a matter of urgency when death may be imminent and are facilitated to be present with the patient, where this is not contrary to the patient's wish.' (Quality Standards of End-of-Life Care in Hospitals **Standard 3.6**)

Only one person died alone in this study. Two out of three people died with family present and just over half of people died with at least one member of the healthcare team in the room at that time.

Spiritual needs

'All supports and services consider and respond to individual, cultural and spiritual requirements.' (Quality Standards of End-of-Life Care in Hospitals **Standard 4.6**).

Relatives reported that spiritual needs of the person who had died were generally well met (mean = 9.1/10).

Satisfaction with care

Relatives were asked to rate overall how acceptable they found the care of their loved one, on a scale from 1-10. Scores ranged from 3 to 10 with a mean score 9.1/10 (s.d +/-1.6).

Some relatives took the opportunity to make positive comments regarding the care their relatives received, for example:

“My relative was 86 years old, she was given respect, kindness and dignity by all the staff at all times.”

“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.”

47% (28/59) of respondents stated that there were areas for improvement in the care received. In addition to the areas outlined within earlier sections of this report, these have been themed as follows:

Staffing levels and facilities

Many relatives stated that whilst the care was adequate, they were aware that services and staff were stretched in terms of capacity.

“The nurses were all very willing to help, but there were too many residents for the size of the nursing home.”

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

“The staff did their best but they didn't have the time as they were understaffed for the amount of patients they had under their care.”

Hygiene

Improvements in hospital hygiene were mentioned by three families, as they perceived poor hygiene (lack of infection control) as the probable cause of death of their relative/friend:

“Reduce the incidents of VRE and other super bugs in hospitals, as relative died as a result of contracting VRE, following what was a successful valve replacement operation.”

“Hygiene - patient went in for routine non-surgical procedure, contracted hospital bug and died unexpectedly after one week.”

Resigned to expected health system inadequacies

Some relatives seemed to be resigned to the fact that shortages in staff and the health system meant that care would not be high quality:

“My dad passed away 8 hours after he arrived at hospital. We were mostly left in the dark about the situation and were left on our own mostly. But hospital very busy (A&E) "hectic" so no-body is at fault. It's just how it is. Staff cared but were outnumbered in every way.”

“This was a sudden death. Patient had a stroke so could not communicate. Nurses had so much to do so they could not look after my mother the way they should have. We felt that a single room would have been wonderful but also felt that the nurses could not cope when she was in a 5-bedded room so did not want to put her in danger. Again, it was NOT the nurses' fault...but I believe it was the system. My relative's spiritual needs were fully met after they died. No young grandchildren were allowed EVER and my mother loved her grandchildren and greatgranddaughter so much. I feel she may have made progress if she had seen them. Also she should have been given more nursing care. No fault to the nurses, they did not have time. To end this survey, I would like to say that both the doctors and nurses did the best they could for my mother but her care was compromised by the system.”

The big little things

There were areas where attention to detail may have prevented distress for patients or their families:

“A member of staff could bring family members to the morgue. In our experience we were given a key to let ourselves in and I found it very disturbing to find my husband in a locked, dark place. It took us a few moments to find the light switch and when we did a spotlight came on on my husband's face before the main lights came on. My family and I were alone and very upset.”

“Lockers and wardrobes with locks are necessary as my sister’s nightwear was stolen. There was no social worker for the gynae oncology patients, including my sister.”

Patient stories

Some of the accounts given by respondents painted a moving and sometimes disturbing picture of their experiences, which encompassed both failings in care and moments of kindness and sensitivity from the caregivers:

“My sister was not provided emesis bowls when she was frequently vomiting - I had to go and find care staff to leave a few bowls / no offer of mouth care. The staff were extremely overworked and basic care like offering my sister help with washing was not done. My sister was short of breath on slight exertion and was not advised that she could use oxygen for relief. When my sister felt unwell and subsequently [cardiac(14)] arrested, a nurse held her hand and she was not alone. I am very grateful for that. The arrest team were very kind and the priest even told a few white lies to make my mother feel better (he said she received holy communion every day even though she didn't). The doctors held her hand and sat with her for about half an hour after my sister’s death.”

“More communication between medical staff to family and relative. Transferred from nursing home to acute hospital. Spent 2 days on a trolley in ED alone, frightened, we weren't informed. Had to listen to relative in pain and had to ask for pain relief constantly. The staff were very good, working under tremendous pressure. It's time for change. The family had to round the clock stay with relative to wet lips, see to oral hygiene and toileting needs. To think relative could have died alone in ED confused and frightened without family input and comfort, as a result of no communication. It is a shame and sad to think an animal would be treated better in a vet practice. Dignity!? I hope things will change soon.”

“A&E department (4 days before) did they read the patients’ medical files and history? It was recent. He was sent home after an overnight stay, catheterised and informed a BIT of a prostate problem. I felt that I should not have gone to A&E and I was furious when he was discharged as he was so ill and, on reflection, he was dying and it was offhand treatment from the nurse. I spoke with the consultants he was attending and I was informed no prostate issues. As a son of the deceased I would like to add I find it extremely concerning that my father was sent home from A&E on the morning of the [date?] with a "bit of a prostate problem" when his condition was much more serious. My father’s internal organs were failing and this was not diagnosed. I find it difficult to understand how this was missed as my father was in the process of dying. Please use this information as constructive feedback to improve the health services.”

“I believe [relative] would have a better chance of survival if there had been an earlier diagnosis. We made several visits to A&E and after knocking on the glass window were left waiting up to 20 mins before anyone even spoke to us, and then to be sent home several hours later with a prescription for antibiotics and pain killers once at 2am. I also believe the first scan at [hospital] was misread. My greatest distress was caused after [relative’s] first operation when I took her to [hospital] to see Mr [surgeon name] who performed the first operation and although she was vomiting and in severe pain [surgeon] sent her home after a 5 minute examination. Later that day because she was in severe pain and vomiting I rang the GP, [name], who suggested I take her back to [hospital]. [Relative] refused to go back to [names] hospital because of her terrible experiences there, then [GP] sent a text to [names] hospital, I took [relative] to A&E and she spent all weekend on a trolley from Friday evening until Monday morning. This was a terrible experience for X and all her family and friends. PS While I feel [relative]’s care was excellent from that point onward when she was finally admitted to a ward. I do feel that there should be a review of her care previously to prevent any other family from going through such a dreadful experience. I feel that [surgeon]’s behaviour was at least reckless in not ensuring [relative] got proper care at that time.”

Discussion

Measuring the quality of care is a vital step related to the ongoing development and implementation of standards regarding end-of-life care, and most importantly improving care for patients at the end of life. The survey of bereaved relatives developed in this study is centred in current standards for end-of-life care in Ireland and is a comprehensive, multi-domain instrument designed to assess the quality of care in the last week of life, from a bereaved relative's perspective.

The findings of this study indicate that whilst most bereaved relatives report being reasonably satisfied with the end-of-life care their loved one received, there remains significant room for improvement.

Of particular concern is that communication directly with the patient regarding their end of life wishes does not appear to be taking place on an ongoing regular basis, and that where communication does occur, it is most likely to take place with the family, as opposed to the patient. Whilst this may be appropriate in the event that a person dies suddenly, or where a person has a significant cognitive impairment, in the majority of cases, where a person's death is expected, there may have been a number of points during the person's interaction with the healthcare teams, in either acute or primary care settings, for these important conversations to take place. Resources such as *Think Ahead*⁴ and *Let Me Decide*⁵ are available to assist practitioners to frame such discussion and aid people to plan ahead. Training is available for healthcare professionals to empower them to lead these discussions through programmes such as *Final Journeys*⁶, *What Matters to Me*⁷ and Milford Care Centre's two-day *Advanced Communication Skills*⁸ Programme.

The lack of availability of single rooms is another key issue identified by relatives who completed this survey. Whilst the findings of this study suggest that the percentage of

⁴ Think Ahead is the 'flagship project' of the Forum on End of Life in Ireland. Think Ahead emphasises the need to talk to other people; particularly, as in the case of chronic or life-threatening illnesses, with your doctor. When you have thought about what you want and talked to others then it is time to tell key people what you want and to record your wishes on a Think Ahead Form.

⁵ 'Let Me Decide' is an easy-to-follow advance care directive by Professor William Molloy, Professor of Medicine and Chair of Gerontology and Rehabilitation in University College Cork.

⁶ Final Journeys is a one-day workshop developed by the Irish Hospice foundation which aims to improve end-of-life care by raising awareness and empowering staff to become more competent, confident and comfortable dealing with patients and families. It aims to enhance communication skill of hospital staff so they are better able to support people nearing end of life.

⁷ What Matters to me is a one day workshop developed by the Irish Hospice Foundation designed for staff working in community hospitals or long-term care settings. The course is similar to the on day Final Journeys course, with some adaption to reflect the longer-term nature of staff-patient/resident relationships within community hospitals or long-term care settings.

⁸ Advanced Communications Skills is for Senior Health Care Professionals; an evaluation of a 3 day evidenced based programme.

people dying in single rooms has increased since 2008/9 and while acknowledging that it may not be appropriate or preferred for everyone to die in a single room, it is clear that the allocation and availability of single rooms for people at the end of life requires further consideration within healthcare sites. The Irish Hospice Foundations Design and Dignity Grant Scheme is an important facilitator to enabling sites to upgrade accommodation and existing spaces and has demonstrated the transformations that can be achieved with thoughtful planning and financial investment.

The qualitative feedback from relatives highlights that, in the majority of cases, where improvement is required to ensure that people die with dignity and respect, it is underpinned by the need for a more considered culture of high quality care and attention to those within the healthcare system who are at their most vulnerable. Many respondents praised the healthcare staff and reported kindness and sensitivity. Even when failings in care were highlighted, respondents tended to blame this on the pressure on resources and still rated positively the staff members' efforts. However, there were accounts where issues highlighted could have been prevented by more consideration being given to the feelings and wishes of the person and/or their family. It is clear from some of the respondents' accounts that even seemingly minor failings in care or conversely small kindnesses can make a huge difference to both patients and family members. This emphasises the importance of continuing and supporting education and awareness programmes such as *Final Journeys*⁶ and *What Matters to Me*⁷ that encourage staff of all grades and disciplines to reflect on the culture of care within their ward and/or organisation and what would be important to them or a loved one, if they were receiving end-of-life care in this setting.

Other areas of quality improvement noted by relatives include the provision of support to enable people to die at home, if that is their wish, an increase in nursing home places with a reduced Fair Deal waiting time and improvements to the Emergency Department system, with particular reference to waiting times, staffing and maintaining the dignity of those who are at the end-of-life in this environment. These issues are somewhat out of the control of individual sites, and must remain an important area of focus for healthcare policy makers and planners at a regional and/or national level.

Obtaining feedback from relatives is considered an important component of a quality and risk system(10) and of particular usefulness, according to audit managers in this study, are the qualitative comments within these surveys that highlight the stories, both good and bad, behind the statistics. These comments are of major interest to healthcare staff and have the potential to drive quality improvement locally. In fact, audit managers reported that staff took little note of the statistics presented back from the surveys and honed in on the qualitative feedback from relatives, using this feedback to frame quality improvement. Relatives took considerable time to share their stories, many of which highlighted the importance of small things that had a considerable impact on their experience.

There was a tendency, upon feeding back the findings to teams, for staff to question the negative experiences: did they really happen, and can a person be believed? These experiences, whilst sometimes conflicting with quantitative data captured from healthcare staff, represent the truth for bereaved relatives. These are the stories that circulate amongst their friends and family and their community. It is this qualitative information that forms the story about that healthcare institution and about their loved ones' death.

The use of surveys of bereaved relatives is an important component of a quality system to measure and inform end of life quality improvement. In the UK, a National Bereavement Survey (VOICES) is conducted by the Office for National Statistics on behalf of the Department of Health. The aims of the survey are to assess the quality of care delivered on a quarterly basis for adults who died in all settings in England and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients. VOICES has been used successfully to assess the quality of end-of-life care to patients living with a range of conditions and across settings(15). The validity of the tool is well established and there is interest within the membership of the Hospice Friendly Hospitals Programme to test the system in an Irish context.

Conclusion

Ireland has two sets of well-developed, evidence-based standards for end-of-life care in the acute and community hospital settings: Hospice Friendly Hospitals Quality Standards for End-of-Life Care in Hospitals and the HIQA National Quality Standards for Residential Care Settings for Older People in Ireland.

These standards represent the best-practice standards which all healthcare facilities should aim to meet. The system needs a standardised mechanism to measure and monitor quality of care against these standards to inform local quality improvement plans, to identify geographical variation in the quality of end-of-life care and to identify areas for national practice and/or service development.

The National End of Life Care Audit and Review System aims to support healthcare settings in achieving the highest possible care of people at the end of life in Ireland, including their families. The Survey of Bereaved Relatives, with its baseline measures for aspects of end-of-life care, represents one part of the System.

One of the strengths of a survey such as this is that the baseline data provided by the quantitative element is complemented by the voice of service users - capturing the stories, both good and bad, behind the statistics. These reflections are insightful and may be an important motivator for staff to change and reflect on practice, with the active support of hospital management, within a health service that is fit for function. In fact, audit managers reported that during feedback sessions staff took little note of the statistics and honed in on the qualitative feedback from relatives, using this feedback to frame quality improvement.

Whilst these experiences are unique to each individual and often conflicting with the quantitative data, it is these stories that form the basis upon which a person may have a "good" or a "bad" bereavement and they should be given due attention. As highlighted by Doyle et al (14). *"Clinicians should resist side-lining patient experience as too subjective or mood orientated, divorced from "real" clinical work of measuring safety and effectiveness."*

There is increasing focus on the need for leadership in quality and safety in acute settings. The need to hear the patient and family voice as a feedback mechanism to support these improvements is critical.

This report provides direction for those who wish to improve delivery end of life care in all health care settings, using an audit and review mechanism.

References

1. Parkes, C. M. Determinants of outcome following bereavement. *OMEGA--J Death Dying*. 1975;6(4):303–23.
2. Office of the Ombudsman. A Good Death: A Reflection on Ombudsman’s Complaints about end of life care in Irish hospitals. [Internet]. Ireland: Office of the Ombudsman; 2014 p. 36. Available from: <http://static.rasset.ie/documents/news/a-good-death-report.pdf>
3. Hospice Friendly Hospitals IHF. Quality Standards for End-of-Life Care in Hospitals: Making end-of-life care central to hospital care. [Internet]. The Irish Hospice Foundation; 2010. Available from: http://hospicefoundation.ie/wp-content/uploads/2013/04/Quality_Standards_for_End_of_Life_Care_in_Hospitals.pdf
4. Health Information and Quality Authority. National Quality Standards for Residential Care Settings for Older People in Ireland. [Internet]. Health Information and Quality Authority; 2009. Available from: <http://www.hiqa.ie/publication/national-quality-standards-residential-care-settings-older-people-ireland>
5. Health Information and Quality Authority. National Standards for Safer Better Healthcare. [Internet]. Health Information and Quality Authority; 2012. Available from: <http://www.hiqa.ie/standards/health/safer-better-healthcare>
6. Statement on publication of the Mid Staffordshire NHS Foundation Trust Public Inquiry [Internet]. National Council for Palliative Care. 2013. Available from: <http://www.ncpc.org.uk/news/francis-report-%E2%80%93comment-ncpc>
7. Health Service Executive. Patient charter, You and Your Health Service [Internet]. Quality and Patient Safety Director’s Office. 2014. Available from: http://www.hse.ie/eng/about/Who/qualityandpatientsafety/About_QPS/
8. Department of Health and Children HSE, Health Services National Partnership Forum. National Strategy for Service User Involvement in the Irish Health Service 2008 - 2013 [Internet]. Department of Health; 2008. Available from: http://www.hse.ie/eng/services/publications/corporate/Your_Service,_Your_Say_Consumer_Affairs/Strategy/Service_User_Involvement.pdf
9. Chen, E. K. R C., Adelman, R., R. M. C., Warmington, M., M. S. S., Pillemer, K. Why is High-Quality Research on Palliative Care So Hard To Do? Barriers to Improved Research from a Survey of Palliative Care Researchers. *J Palliat Med*. 2014;17(7):782–7.
10. Mayland, C. R., W, E. M., Addington-Hall, J., C, T. F., Ellershaw, J. E. Assessing the Quality of Care for Dying Patients From the Bereaved Relatives’ Perspective: Further Validation of “Evaluating Care and Health Outcomes—for the Dying.” *J Pain Symptom Manage*. 2014;47(4):687–96.

11. Manary, M. P. B W, Staelin, R. G, S. W. The patient experience and health outcomes. *N Engl J Med.* 2013 Jan 17;201–3.
12. Addington-Hall, J. M. O, A. C. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *J Palliat Med.* 23(3):190–7.
13. Mayland, C.R. W, E.M.I., Ellershaw, J.E. How well do current instruments using bereaved relatives' views evaluate care for dying patients? *J Palliat Med.* 2008;22(2):133–44.
14. Cathal Doyle DB, Laura Lennox. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* [Internet]. 2013 Jan 3;3(1). Available from: <http://bmjopen.bmj.com/content/3/1/e001570.full>
15. Office for National Statistics (ONS). First national VOICES survey of bereaved people: key findings report [Internet]. United Kingdom: Department of Health; 2012 Jul p. 51. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216894/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf
16. The Irish Hospice Foundation. Hospice Friendly Hospitals: The case for continues investment. The Irish Hospice Foundation; 2014.
17. Weafer, J.A. Irish Attitudes to Death, Dying and Bereavement 2004-2014 [Internet]. Ireland: The Irish Hospice Foundation; 2014 Oct p. 38. Available from: <http://hospicefoundation.ie/wp-content/uploads/2014/12/Weafer-J-2014-Irish-attitudes-to-death-dying-bereavement-2004-2014.pdf>