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National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9

Dying in Hospital in Ireland:
An Assessment of the Quality of Care in the Last Week of Life

National Audit Report 5
Final Synthesis Report

May 2010

THE IRISH HOSPICE FOUNDATION

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Poem

In the realm of the passing away
by Stephen Levine [1]

This is the realm of the passing away. All that
exists does not for long.
Whatever comes into this world never stops sliding
toward the edge of eternity.
Form arises from formlessness and passes back,
arising and dissolving in a few dance steps between
creation and destruction.
We are born passing away.
Seedlings and deadfall all face forward.
Earthworms eat what remains.
We sing not for that which dies but for that which
never dies.

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[1] Stephen Levine (1937 -), from his collection of poetry, Breaking the Drought: Visions of Grace. He is the author of several classic books in the field of conscious living and dying, including A Gradual Awakening, Who Dies?, Healing into Life and Death, and A Year to Live. He lives in New Mexico, USA.

Research Team

Research Team

Kieran McKeown
Social & Economic Research Consultant,
16 Hollybank Rd., Drumcondra, Dublin 9, Ireland.
Email: kmckeown@iol.ie

Trutz Haase
Social & Economic Consultant,
17 Templeogue Rd., Terenure, Dublin 6W, Ireland.
Email: thaase@iol.ie

Jonathan Pratschke
Lecturer in Economic Sociology and Research Methods,
Department of Sociology and Political Science, University of Salerno,
84084 Fisciano (SA), Italy.
Email: jpratschke@unisa.it

Shelagh Twomey
National Audit Manager, HFH Programme,
Irish Hospice Foundation, Morrison Chambers,
32 Nassau St., Dublin 2, Ireland.
Email: hfhshelagh.twomey@hse.ie

Helen Donovan
Standards Development Coordinator HFH Programme,
Irish Hospice Foundation, Morrison Chambers,
32 Nassau St., Dublin 2, Ireland.
Email: helen.donovan@hospice-foundation.ie

Feline Engling
Research Assistant,
Rua Actriz Palmira Bastos N°12 6°E,
1950–005 Lisboa, Portugal.
Email: feline.engling@gmail.com

Audit Reports

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Ownership & Confidentiality

This report is the joint property of the hospitals who contributed to the national audit of end-of-life care in 2008/9, and the Irish Hospice Foundation. Information about any individual hospital is confidential to that hospital.

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Foreword by Dr. Deirdre Madden, Chair, National Audit Sub-Committee

This is the first-ever National Audit of End-of-Life Care in Hospitals in Ireland. Its publication is a significant landmark for our health service because it clearly acknowledges that dying, death and bereavement are part of the core business of every hospital. It is a major achievement that so many acute and community hospitals participated in the audit, and this makes it a truly national audit with far-reaching implications for national policy and practice.

These are challenging times for hospitals and the audit is a tribute to the commitment of management and staff to improving the quality of their services. For that reason, I want to thank the nurses, doctors and hospital staff, who participated in the audit, and especially those who acted as audit managers in their hospital. My special thanks goes to those bereaved relatives whose participation ensured that, even if we did not hear the voice of the dying patient, we still heard the voice of someone near and dear to them; someone with a perspective that complements that of the care providers.

The end of life, like its beginning, is profoundly important and hospitals are increasingly the setting in which these precious moments in the life cycle take place. In an audit like this, it would be easy to lose sight of the fact that hospitals touch people at the most intimate moments in their lives and to over-emphasise the acknowledged methodological and technical challenges in carrying out an audit of this scale. The report remains firmly grounded in the reality that hospitals are meant to be places of hospitality whose simple essence is to care. This clarity and simplicity

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is also the hallmark of this report. Its simple style, and the clarity of its conclusions, disguise a depth of quantitative and qualitative analysis on which it is based.

The National Audit raises many questions about the way in which we organise and deliver our health services. It challenges us to consider difficult issues. Issues such as, the role of hospitality in hospitals; the tension between efficient use and compassionate conduct; the extent to which patient-centredness can be realised in highly systems-focused and task-driven facilities; the balance between care in the home and care in an institutional setting.

The picture that emerges from the National Audit is one where admissions to hospital are typically unplanned and uncoordinated and where there is great variability in the quality of care offered to patients with different conditions. At the same time, every effort is made to allow patients die in a single room despite resource constraints, and to facilitate relatives to be with the patient as much as possible right to the end.

The Report of the Commission on Patient Safety and Quality Assurance, which I chaired, stated that 'As patients we are entitled to expect to be treated by competent professionals who are appropriately skilled and up-to-date with developments in their field, in facilities that are fit for purpose and subject to regulatory oversight to ensure that appropriate standards are complied with'. The Quality Standards for End-of-Life Care, which accompany the publication of this report, address similar issues and stress the centrality of competence, compassion, communication and coordination.

As Chair of the National Audit Sub-Committee, I have heard a wide range of expert views on this report. These views are positive and complementary and, in light of that, I am happy to endorse this report as an excellent piece of work which meets the highest scientific standards. For that reason, I would like to thank Dr. Kieran McKeown

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and his research team for their work, and the staff of the HFH Programme who supported him throughout the entire process. The report sets a standard for future audits on end-of-life care which I hope will continue in the years to come.

Finally, I would like to emphasise that this report is just a means to an end, not an end in itself. The end is to improve the quality of care for patients who die in hospital. My hope is that each hospital will carefully consider the different ways suggested by the audit to improve the quality of their end-of-life care. The audit suggests that our services are as good as elsewhere but, in striving to be the best, I know we can do even better.

Deirdre Madden

Dr. Deirdre Madden, Chair,
National Audit Sub-Committee
National Steering Committee:
Hospice Friendly Hospitals Programme

Members of the National Audit Sub-Committee

Dr. Deirdre Madden (Chair)	Senior Lecturer	**Faculty of Law, University College Cork**
Mr. Michael Shannon	Area Director, Nursing & Midwifery Planning & Development	**Health Service Executive. Dublin Mid-Leinster**
Prof. Irene Higginson	Professor of Palliative Care & Policy	**King's College London**
Ms. Orla Keegan	Manager Education & Research	**Irish Hospice Foundation**
Prof. Charles Normand	Edward Kennedy Chair in Health Policy and Management	**Trinity College Dublin**
Ms. Lorna Peelo-Kilroe	National Practice Development Coordinator	**Health Service Executive**
Mr. James Conway	Assistant National Director, Palliative Care & Chronic Illness	**Health Service Executive**
Ms. Anne Marie Taylor	Public Interest Representative	
Dr. Kieran McKeown	Social & Economic Research Consultant	**Kieran McKeown Ltd**
Mrs. Jane McKenna	Public Interest Representative	**Laura Lynn Foundation**
Ms. Shelagh Twomey	Specialist Palliative Care Nurse	**Wexford General Hospital**
Mr. Mervyn Taylor	HFH Programme Manager	**Irish Hospice Foundation**

Mr. Eugene Murray	CEO	**Irish Hospice Foundation**
Mr. Erik Koornneef	Development Programme Manager	**Health Information and Quality Authority (HIQA)**
Ms. Mary Bowen	HFH Operations Manager	**Irish Hospice Foundation**
Ms. Barbara Fitzgerald	Director of Nursing	**Naas General Hospital**
Prof. Joanne Lynn,	Bureau Chief	**Department of Health, Washington DC**
Prof. Brendan McCormack	Professor of Nursing Research	**University of Ulster**
Prof. Cillian Twomey	Consultant Physician in Geriatric Medicine	**Cork University Hospital**
Dr. Pat Doorley	National Director of Population Health	**Health Service Executive**

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Acute Hospitals	Hospital Audit Managers
Cork University Hospital	Fionuala O'Gorman
Mid-Western Regional Hospital Limerick	Catherine Hand
Cavan General Hospital	Bridget Clarke
Monaghan General Hospital	Josephine O'Hagan
Our Lady of Lourdes Hospital, Drogheda	Mary McCrane
Our Lady's Hospital, Navan	Concepta Tallon
Louth County Hospital, Dundalk	Kathriona Campbell
Kerry General Hospital, Tralee	Richard Walsh
Wexford General Hospital	Bernard Finnegan
St. James's Hospital, Dublin 8	Paul Gallagher & Lucy Kielty
Sligo General Hospital, Sligo	Kate Bree
Mater Misericordiae University Hospital	Breda Doyle
Connolly Hospital	Catriona Higgins
Letterkenny General Hospital	Pauline McManus
St. Luke's Hospital, Rathgar	Wendy Fair
Portlaoise, Midland Regional Hospital	Emer McEvoy & Ann Sheerin
Beaumont Hospital	Mary Baggot
Waterford Regional Hospital	Cliona Rafter
South Tipperary General Hospital	Maria Barry
St. Luke's Hospital, Kilkenny	Debbie Kavanagh
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Nenagh, Mid-Western Regional Hospital	Mary Clifford
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Community Hospitals	Hospital Audit Managers
St. Joseph's Hospital, Trim	Frances Flynn
Royal Hospital Donnybrook	Anne Dooley
Bru Chaoimhin	Muthu Saba
Bellvilla	Niamh Curran
Meath Community Unit	Karen Rowlett
St. Mary's Phoenix Park	Michelle Russell
St John's Hospital, Sligo	Fran Butler
St. Mary's Castleblayney	Susan McGoldrick
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Breffni	Ann Gaffney
Virginia	Bernardine Lynch
Lisdaran	Bernie McManus
Sullivan Centre, Cavan	Martha Adams
Boyne View Drogheda	Lena Varghese
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HFH Pilot Study	**RCSI Pilot Study**
Cork University Hospital	Midland Regional, Mullingar
Mater M University Hospital	Naas General Hospital
St. Mary's Phoenix Park	St. John's Hospital, Sligo
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St. Mary's Castleblayney	
St. Columba's, Co. Kilkenny	

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Mervyn Taylor	Programme Manager
Shelagh Twomey	Deputy Programme Manager
Helen Donovan	Standards Development Coordinator
Mary Bowen	Operations Manager
Denise Connor	Project Development Coordinator
Róisín Clarke	Programme Administrator
Grace O'Sullivan	Programme Administrator & Development Support
Lorna Peelo-Kilroe	National Practice Development Coordinator End-of-Life Care (HSE & HFH Programme)
Paul Murray	Development Coordinator - Forum on End-of-Life
Joanne Carr	Development Coordinator
Amanda Manning	Development Coordinator
Fran McGovern	Development Coordinator
Bryan Nolan	Development Coordinator
Aoife O'Neill	Development Coordinator
Ruth Agar	Development Coordinator
Colette Cunningham	Development Coordinator
Mary Friel	Development Coordinator
Nuala Harmey	Development Support

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Prof. David Clark	Chair, Visiting Professor of Hospice Studies, TCD & UCD
Orla Keegan	Head of Education, Research & Bereavement Services, The Irish Hospice Foundation
Mervyn Taylor	Programme Manager, Hospice Friendly Hospitals Programme
Shelagh Twomey	Deputy Programme Manager, Hospice Friendly Hospitals Programme
Max Watson	Consultant in Palliative Medicine, Northern Ireland Hospice
Gail Birkbeck	The Atlantic Philanthropies (in attendance)

The HFH Programme is overseen by a National Steering Committee whose membership currently comprises:

Prof. Cillian Twomey	Consultant Physician in Geriatric Medicine at Cork University Hospital and St. Finbarr's Hospital, Cork
Denis Doherty	Chairman, The Irish Hospice Foundation
Eugene Murray	Chief Executive Officer, The Irish Hospice Foundation
James Conway	Assistant National Director, Palliative Care and Chronic Illness, Office of the CEO, Health Service Executive (HSE)
Professor David Clarke	Director, University of Glasgow, Scotland
Ann Coyle	Planning Specialist, Office of the Assistant National Director for Older People, Health Service Executive (HSE)
Sheila Dickson	First Vice-President, Irish Nurses and Midwives Organisation
Barbara Fitzgerald	Director of Nursing, Naas General Hospital
Geraldine Fitzpatrick	Principal Officer, Services for Older People & Palliative Care, Department of Health & Children
Orla Keegan	Head of Education, Research and Bereavement Services, The Irish Hospice Foundation
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Acknowledgements

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Dr. Doiminic Ó Brannagáin	Clinical Director, Louth Meath Hospital Group, Consultant Physician in Palliative Care Medicine, Health Service Executive, North East
Brenda Power	Broadcaster and Journalist
Ann Ryan	Inspector Manager, Health Information & Quality Authority (HIQ)

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Dr. Kieran McKeown, on behalf of the Research Team.

May 2010.

Executive Summary

The context of this report is set by the fact that most people die in a hospital or similar setting, outside the home. When you consider that most people are also born in hospital, and may spend some time there over the course of a lifetime, it becomes clear that hospitals are central to our passage into life and out of it, touching people at the most important and intimate moments of their lives. In this sense, the work of hospitals mirrors the cycle of life and the expectations of society about its role at each stage of the life cycle.

The report assesses the quality of care provided by Irish hospitals in the last week of life. The word 'hospital' shares a common linguistic root with words like hospice and hospitality. Hospitality – understood as being welcomed and cared for with kindness and attentiveness - is still what everyone seeks when they come to hospital, including patients and their families who are going through the journey of dying, death and bereavement. That is why the Hospice Friendly Hospitals Programme (2007-2012) commissioned this first ever national audit of end-of-life care in Irish hospitals.

This report contributes to the growing practice within the Irish hospital system of auditing performance against standards in order to ensure that every aspect of its work meets, and even exceeds, the highest standards of care and excellence. Given that end-of-life care standards did not exist at the time the audit – but have since been published as Quality Standards for End-of-Life Care in Hospitals[1] – it may be more appropriate to regard this report as a 'pre-audit' or 'baseline-audit'. It is Government policy, since February 2009, to introduce a mandatory licensing system whereby each hospital will only be allowed to practice if, on the basis of audited performance, it meets acceptable quality standards of service.

Approach to the Audit

Our starting point is the simple premise that the core 'outcome' of a hospital is care. This, in turn, is influenced by 'inputs' provided by the hospital through its staff and facilities. When a patient dies in hospital, the care outcome can be understood as having the following dimensions:

1. acceptability of the way patient died
2. quality of patient care

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[1] Hospice Friendly Hospitals Programme (2010).

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3. patient's symptom experience
4. patient's symptom management
5. support for patient's family.

Care inputs are the hospital's response at each stage of the patient's final journey. This journey begins with the patient's admission to hospital - although the end-of-life journey often begins well before the final admission to hospital - and involves numerous interactions with patient and family, ends with the patient's discharge at death, but may also involve subsequent support for the family after death. We define these inputs as having the following dimensions:

1. patient characteristics, including disease and cause of death
2. route of admission, including length of stay
3. physical environment, including single rooms and mortuary facilities
4. end-of-life care decisions
5. care practices such as team meetings
6. communication with patients and relatives
7. documentation in healthcare record
8. support for families before, during and after death
9. ward and hospital culture
10. hospital characteristics, including its size and governance on end-of-life care.

Within this framework, the audit answers a number of questions but three are central. The first is: how good are the care outcomes for patients who die in Irish hospitals compared to hospitals elsewhere? The second is: which care inputs have a significant and substantial influence on care outcomes? The third is: how can the findings be used to improve the quality of end-of-life care in Irish hospitals?

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Scope of Audit

In order to answer these questions, we collected data on a sample of 1,000 deaths from nurses, doctors and relatives who spent the most time with the patient during their last week of life. Each hospital completed the audit on a random sample of 50 deaths in the four month period between November 2008 and February 2009. As a proportion of total deaths in Ireland in 2008, the audit is a representative sample of 10% of acute hospital deaths and 29% of community hospital deaths.

The audit was completed in 24 acute hospitals which constitute three quarters of the acute hospital sector in Ireland in terms of number of patients (72%), deaths (71%), staff (73%), and bed-capacity (74%). In that sense, it is truly a national audit, and its findings are relevant to the entire acute hospital sector. The audit was also completed in 19 community hospitals which represents 20% of community hospital beds in the country; these hospitals tend to have a higher average number of beds (110) compared to the average community hospital (68).

Assessing Care Outcomes

Care outcomes are matters of judgement rather than matters of fact. For that reason, the judgements of nurses, doctors and relatives do not always agree on care outcomes for specific patients. Typically, doctors tend to give the highest ratings for care outcomes, relatives tend to give the lowest, with nurses holding an intermediate position. This is consistent with previous studies which compared these ‘proxy’ ratings to those of patients themselves; these studies show that doctors tend to under-estimate the negative aspects of care, relatives tend to over-estimate them, while nurses hold an intermediate position. In practice this means that, from the perspective of relatives, care outcomes are typically not as good as nurses and doctors believe.

We found that nurses, doctors and relatives give importance of different care outcomes reflecting, to some extent, their role and function during the patient’s final journey. For example, doctors give most importance to the patient’s symptom management; nurses tend to assess on all the care outcomes; relatives give most importance to the patient’s symptom experience and acceptability of the way patient died. Each of these judgements reflects the separate-but-connected ‘universes’ which inform those judgements.

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Overall, when these judgements are compared with studies from elsewhere, the quality of care for people who die in an Irish hospital compares favourably to other hospitals. Care tends to be generic rather than specific in the sense that it might be more appropriate to describe it as 'care at the end of life' rather than 'end-of-life care'. In short, dying in an Irish hospital is probably not very different to dying in a comparable hospital in the US, the UK, or France, the main countries for which we have comparative data.

Eighteen Ways to Improve Hospital Care at the End of Life

The overall results of the audit reflect well on the quality of care in Irish hospitals. This makes it easier to be constructively critical about Irish hospitals and to acknowledge the weaknesses which have been identified in this audit. For those who die in hospital, these weaknesses occur at every stage of the patient's journey from admission to discharge at death. The weaknesses identified in the audit are also opportunities to correct them. The analysis provides an overall map of how to locate these weaknesses within the system as well as more detailed 'local' guidance on the factors that keep them in place and could help to remove them. As such, the audit provides knowledge, to an approved scientific standard, about where the hospital system needs improvement in order to ensure that patients receive the best possible hospital care at the end of their lives.

The audit identified 18 separate influences on end-of-life care. Each influence was analysed separately and, for the sake of clarity will be presented separately, even though many of them are inter-connected in practice. In order to strengthen the link between these audit findings and implementation of the Quality Standards for End-of-Life Care in Hospitals, we present them thematically as 18 ways to improve end-of-life care under each of the four standards.

Standard 1. The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.

1.1 Put End-of-Life Objectives in the Hospital's Service Plan

The audit revealed that hospitals which have end-of-life objectives in their service or business plans have better care outcomes compared to those who do not. This provides solid grounds for recommending that all hospitals should have end-of-life objectives in their service plans. It also highlights the leadership role of hospital management in setting goals for end-of-life care and the practical impact this can have on clinical care.

1.2 Move from Emergency to Planned Admissions

Most patients who die in acute hospital are admitted through A&E, even though many would have been patients of the hospital already, with already-diagnosed conditions. Admissions through A&E have a negative impact on care outcomes; this is mainly perceived by nurses and doctors and underlines a perception from inside the hospital that A&E is not an appropriate route of admission for many patients. Improvements could be made to care outcomes, in cases which are not truly accidents or emergencies, by simply changing to a more planned and hospitable route of admission. Conversely, a more planned approach to discharge might also reduce unplanned and emergency admissions.

1.3 Improve the Hospital's Physical Environment and Usage of Single Rooms

Single rooms are consistently associated with better care outcomes. In addition, wards which lack dignity or which have poor environmental quality are associated with poorer outcomes. This is solid evidence that substantial improvements in care outcomes could be achieved by simply increasing the number and/or usage of single rooms for end-of-life care, and by improving the physical environment of multi-bedded wards.

1.4 Improve Documentation in the Healthcare Record

The audit revealed that the quality of patient documentation in the healthcare record is uneven. Documentation about selected aspects of care – notably diagnosis of dying, decisions about palliative care, wishes of relatives to be kept informed - had no effect on any of the care outcomes. Given that documentation is essential to supporting a consistent approach to patient care across the hospital team – and other studies have found it to be a good indicator of quality of care - this result merits further reflection on how healthcare records are maintained. Documentation is markedly better in some wards (oncology) and specialties (cancer) – both

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associated with better care outcomes – which suggests that it is more affected by work practices than by patient needs.

1.5 Ensure Sufficient Ward Staff

The ward environment can be a demanding place of work and staffing levels are of primary importance. Wards that have inadequate staffing levels have a significant negative effect on care outcomes. This is an issue that merits attention by hospital management, and requires detailed and transparent assessments of workloads taking into account ward type, work processes, and the composition of ward staff.

1.6 Improve Hospital Information Systems

The overall quality of information about various aspects of end-of-life care in Irish hospitals is poor. This draws attention to the need for a national minimum dataset on deaths in hospital – and other out-of-home places of care - so that the HSE can produce a more accurate national picture of deaths across the spectrum of care settings, and address any governance issues that might arise from the analysis of that data.

1.7 Facilitate Patients to Die at Home

The audit suggests that a substantial minority of patients (20-25%) could have died at home if appropriate supports were available. This issue merits further examination from the perspective of meeting patient needs and preferences.

Standard 2. The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

2.1 Develop Skills to Diagnose End-of-Life and Dying

The diagnosis that a person may be approaching the end of life or dying is recognised to be a clinical challenge and the audit confirms this since we could find no relationship between the diagnosis of dying and care outcomes. Given the importance of assessing patient needs through proper diagnosis, this result merits further training on this aspect of caring for patients at the end of life.

2.2 Improve End-of-Life Care Decision-Making

The extent to which end-of-life care decisions are taken about dying patients in Irish hospitals is significantly less compared to patients on the Liverpool Care Pathway (LCP) in English hospitals. The audit found that doctors and nurses were reluctant to make decisions to stop invasive treatments when patients were dying. Apart from the decision to move patients into a single room, which could be regarded as an end-of-life care decision, there was no relationship between end-of-life care decisions and care outcomes. This finding merits reflection and discussion on how decisions are made and implemented about patients in their last week.

2.3 Hold Team Meetings

Team meetings, especially between nurses and doctors, have a positive impact on symptom management and patient care. These meetings – including after death review meetings - are recommended good practice in end-of-life care settings, and should endeavour to involve patients and/or relatives, if that is their wish. However, the audit revealed that holding of team meetings seems to be less influenced by patient needs than by the work practices of different wards (being more frequent in oncology and geriatric wards) and specialties (being more frequent for cancer patients).

2.4 Provide Training in End-of-Life Care

Nurses who have done a formal training course on end-of-life or palliative care, since qualifying, generate better care outcomes compared to nurses who do not. This is a definitive endorsement of the value of training. Ideally, basic training on end-of-life issues should be provided for all professional, support and administrative staff who come in contact with patients and relatives; more intense training is needed for clinical staff in areas such as breaking bad news, end-of-life discussions, diagnosing dying, managing symptoms, understanding bereavement and loss, and dealing with death at a personal level.

2.5 Prepare Staff for the Death of Patients

Care outcomes are improved significantly when a nurse feels prepared for dealing with the death of a patient. While this may appear obvious, the fact that most hospital staff receive little or no preparation for different aspects of care at the end of life suggests that this insight is rarely acted upon. Feeling prepared for the death of a patient is enhanced by experience and training but it is also strongly associated with feeling comfortable talking about death and talking to people who have been recently bereaved. This is important because we know that hospital staff are broadly similar to the people of Ireland in that a majority of them are *not* very comfortable talking about dying, death and bereavement.

2.6 Build on the Experience of Staff

The audit found that a nurse's years of experience working in a hospital and ward has a positive effect on care outcomes. This result gives substance to the idea that a hospital's greatest resource is its staff but adds to it by showing that the resource improves as staff mature. The finding underlines the importance of retaining experienced nurses within the hospital and ward, and ensuring that they have a direct role in patient care. It is likely that the benefits of staff experience are mediated through ward managers who, by their example, set and maintain standards of clinical care that produce better outcomes. In addition, the finding invites hospitals to think creatively about the processes that need to be in place to help staff distil their years of experience into wells of experience by developing a more mature understanding of the simple essence of care.

Standard 3. The Patient

Each patient receives high quality end-of-life care that is appropriate to his / her needs and wishes.

3.1 Extend to All Patients the Quality of Care for Cancer Patients

The audit revealed that a hierarchy exists in the quality of dying in Irish hospitals, based on the patient's disease. The range, from best to worst, is: cancer, circulatory diseases, respiratory diseases, dementia/frailty. The quality of care in the specialty of cancer – which is not confined to patients in oncology wards but affects all cancer patients, the majority of whom are not in oncology wards - offers an example of how better end-of-life care can be provided in a hospital. It is true that the disease trajectory of cancer patients is more predictable than for other patients but the audit suggests that the reasons for their better outcomes are not specific to cancer, but attributable to other factors such as more planned admissions, greater likelihood of dying in a single room, better communication, more team meetings, and more support for families to stay overnight and be present at the moment of death. This finding also opens up the possibility that the cancer specialty could take a lead role in terms of improving the overall standard of end-of-life care across each hospital.

3.2 Improve the Quality of Communication with Patients

Care outcomes are influenced by the *quality* of discussion with patients and relatives, not by the *amount* of discussion. Equally significant is the fact that care outcomes are influenced more by the quality of discussion with relatives than with patients. This may be due to the way we measured communication which focused exclusively on verbal communication – the quality of discussion – since that may be less important than non-verbal communication as patients in their last week of life begin to show signs of withdrawing from the world and, in these circumstances, relatives usually become patient proxies. At the same time, the findings raise questions as to whether care and communication is as patient-centred as it could or should be. Whatever the reason, the audit provides grounds for suggesting that further reflection and discussion is merited about the way nurses and doctors communicate verbally and non-verbally with patients during their final weeks and days. The findings also provide grounds for suggesting that nurses and doctors – but possibly other hospital staff – may benefit from some basic training in communication skills.

3.3 Strengthen the Role of Specialist Palliative Care

Specialist palliative care is known to be effective and the audit suggests that its effectiveness is mediated through other variables which are known to have a positive and direct impact on care outcomes such as cancer, single rooms, team meetings, and support for families. The audit also identified a lack of clarity about the role of specialist palliative care services in acute hospitals and this points to a need to strengthen its role while also expanding that role to meet the needs of all patients who need it.

Standard 4. The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during and after the patient's death.

4.1 General Support for Families

The audit reveals that one of the strengths of the hospital system is its relationship with families, both in terms of the quality of communication and facilitating them to be with the patient as much as possible, including at the moment of death. This has a positive influence on care outcomes. It endorses and encourages the widespread practice in Irish hospitals of facilitating relatives to be with the patient during his/her final journey.

4.2 Support for Families Following Sudden Deaths

Just as cancer is associated with more positive care outcomes, sudden deaths are associated with more negative ones. Sudden deaths are more likely to result in a post-mortem and, understandably, this can be difficult for relatives since the sense of loss at death may be compounded by the shock of its suddenness, and by the fact that funeral arrangements may have to be delayed as a result of the post-mortem. The audit shows that a third of relatives do not seem to have been properly informed about the reasons for a post-mortem and were less than satisfied with the information provided by the hospital. In light of this, hospitals may wish to look at their systems for responding to the more intense needs of relatives in the event of a sudden death and/or post-mortem.

Concluding Comment

The quality of care for people who die in an Irish hospital compares favourably to other hospitals in the US, the UK, and France, the main countries for which we have comparative data. At the same time, the audit identified significant weaknesses in how the hospital system responds at each stage of the patient’s journey from admission through to death. These weaknesses also contain the seeds for improvement since the substantial variation in quality of care offered to patients and relatives at the end of life – not only between hospitals, specialties and wards but within them as well - demonstrates the scope for improvement that already exists, and that better and best are possible and within reach. The audit, along with the standards which have been developed for end-of-life care are offered by the HFH Programme to each hospital in order to support it to become a hospice friendly hospital. In this way, each hospital can become a more hospitable place to die, as the term hospice friendly hospital suggests.

Chapter 1

Introduction

Introduction

This report assesses the quality of care provided by Irish hospitals at the end of life. Its rationale is that, through greater understanding of the journey towards dying and death, hospitals will be able to respond with greater care and compassion to each person as s/he reaches this important threshold. The focus of the report is on hospitals because that is where a majority of people die. Dying, death and bereavement are important events for patients, families and friends and, for that reason, it is appropriate to inquire how, and how well, hospitals provide care for people at this stage of life. The purpose of the audit therefore is to shed light on this previously unexplored aspect of hospital care in Ireland.

We begin with a brief outline of how, over the past century, hospitals in Ireland, as elsewhere, have become central to the process of dying and death, a process that might be referred to as the 'hospitalisation of dying' (1.1). The Hospice Friendly Hospitals (HFH) Programme is itself a natural response to this development, because it encourages hospitals to see dying and death as a natural and integral part of their work, inviting them to adopt a hospice philosophy in order to create the conditions for patients to experience a good death. To explain the motives underlying the study we summarise the programme's core objectives in Section 1.2.

This report is an 'audit', and not just a 'baseline study', because it is designed to be part of a quality improvement process for each hospital. Given that audit is becoming an integral part of the way in which hospitals work – and will be a condition for the mandatory licensing system to be introduced in the next few years – we set out the rationale for this in the broader context of audit and quality assurance in hospitals (1.3). The concept of audit is closely aligned to the concept of standards, and the HFH programme offers both instruments to improve the quality of end-of-life care in hospitals. In light of that, we briefly summarise the scope and content of these end-of-life standards, since they provide the measuring stick against which the audit results will be judged (1.4). Finally, we briefly outline the overall structure of the report (1.5).

1.1 Role of Hospitals in Dying and Death

Most people die in a hospital or similar setting outside the home. In Ireland, at least half of all deaths occur in acute hospitals (48%) or hospices (4%); deaths at home still constitute a quarter of the total (25%), and a fifth die in long-stay facilities (20%); the remainder are deaths from suicide and traffic accidents (3%)[2]. When you consider that most people are also born in hospital, it becomes clear that hospitals are central to our passage into life and out of it, touching people at the most important and intimate moments of their lives. In this sense, the work of hospitals mirrors the life cycle and the expectations of society about its role at each stage of the cycle.

This was not always so, and just 120 years ago (in 1885) the vast majority of people in Ireland (85%) died at home. By 2005, however, that pattern had been completely reversed, with only 25% of people dying at home (see Figure 1.1). Other developed countries have followed the same path although, in many cases, the proportion dying at home is even smaller. In this respect, Ireland is in an intermediate position between those countries which have proportionately fewer deaths at home, such as England & Wales (19%) and the USA (21%), and those which have a higher proportion of deaths at home, such as France (28%), Switzerland (28%), Germany and the Netherlands (30%).[2]

The trend towards 'the hospitalisation of dying' looks set to continue, for a variety of reasons. There are demographic factors such as longer life-expectancy[3] accompanied by rising illness rates (sometimes referred to as morbidity), particularly among older age groups, which is resulting in high rates of hospitalisation for older people.[4] There are cultural reasons, sometimes referred to as the 'medicalisation of everyday life',[5] which predisposes individuals to think of life's difficulties – including dying[6] – as abnormal or pathological, and leads institutions such as hospitals to offer 'treatments' for these difficulties. This process can both over-value and over-burden hospitals and, in the case of dying, can create a disposition to see

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2 McKeown, Haase and Twomey, (2011a, Table 1.1b).

3 Walsh (2008); Whelan (2008).

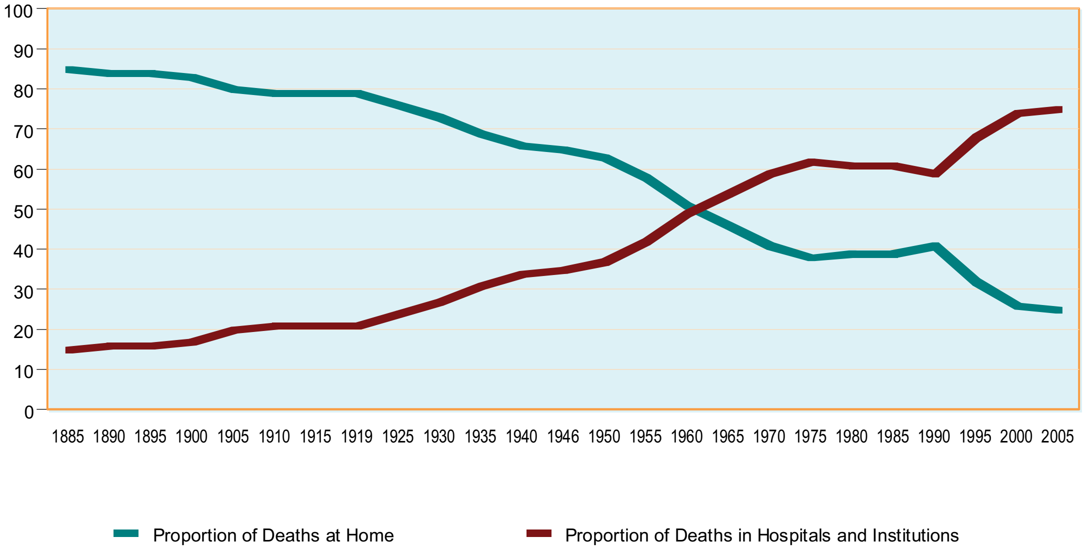
4 Armstrong (2008).

5 Szasz (2007); one of the earliest and most influential commentaries on the 'medicalisation of dying' was by Ivan Illich (1976).

6 The concept of 'medicalisation' has been used to throw light on the inappropriate use of medical concepts – such as patient, disease and treatment – to explain 'normal' life processes such as birth and death, as well as 'normal' life difficulties such as mental health problems, deviant behaviours, sexual functioning and orientation, drug dependency, etc. It is true that these situations may have a medical aspect – involving symptoms of physical dysfunction – but clearly there is no 'medical solution' to conditions such as dying, death and bereavement. These are inescapable parts of the human condition and, as the evolution of palliative medicine testifies, they call for a human response to ensure that unnecessary suffering - including physical pain, fear and loneliness – is relieved. It is clear that having a 'good death' – as defined in the UK end-of-life strategy – requires much more than medical treatment; the UK end-of-life strategy defines a good death as comprising: (i) being treated as an individual with dignity and respect (ii) being without pain and other symptoms (iii) being in familiar surroundings and (iv) being in the company of close family and/or friends (Department of Health, 2008:9).

dying as 'something to be resisted, postponed, or avoided'.[7] There may also be social reasons such as the decline in family size and other community supports, although the evidence suggests that families still care for older people, as in previous generations.[8]

Figure 1.1: Place of Death in Ireland, 1885-2005



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[7] Clark (2002).

[8] See Fahey and Field (2008: 57) for a summary of the evidence.

At the same time, there are also countervailing forces to the hospitalisation of dying, such as the expressed preferences of the majority of Irish people to die at home.[9] Indeed, the preference for dying at home would appear to be even stronger among doctors and nurses than among patients.[10] In addition, there is a growing realisation by hospitals and health services that a substantial proportion of patients who die in hospital could be cared for more appropriately at home, in a hospice, or in a nursing home.[11] In this audit we found that around a fifth of deaths could have occurred at home if there was enough support, according to the opinion of nurses, doctors and relatives (see 3.15 below).

The overall balance of forces affecting the hospitalisation of dying suggests that most people do not die at home because the majority of deaths follow a period of chronic illness related to conditions such as circulatory disease, cancer, respiratory disease or dementia/frailty. Long-term projections in England[12] – which already has a lower proportion of deaths at home (19%) compared to Ireland (25%) - suggest that only 10% of people will die at home in 2030,

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[9] In a national survey carried out in 2004, a clear majority of Irish people (67%) indicated that they would like to die at home with only a tenth preferring to die in a hospital (10%) or a hospice (10%) (Weafer and Associates, 2004: 10-11).

[10] As part of the audit, we surveyed 2,358 ward staff and 1,858 hospital staff and asked about their preferred place to die (McKeown, Haase and Twomey, 2010d). The results showed a much higher preference to die at home among both ward staff (81%) and hospital staff (77%); correspondingly, the proportion preferring to die in hospital (6%) is smaller than in the national population (10%). This is consistent with the results of a survey of 1,899 ICU doctors, nurses and patients in six European countries, who were asked where they would rather be if they had a terminal illness with only a short time to live; the results showed that more doctors and nurses would prefer to be at home or in a hospice and more patients and families preferred to be in an ICU (Sprung, Carmel, Sjokvist, et al., 2007). The same study also revealed that physicians provide more extensive treatment to seriously ill patients than they would choose for themselves, possibly indicating a public demand for life-prolonging interventions that may have little prospect of success.

[11] In Ireland, a random sample of 3,035 medical and surgical in-patients across 37 acute hospitals were reviewed between November 2006 and February 2007 by PA Consulting Group and Balance of Care Group (2007) for the HSE. The results of this study, though not focused on end-of-life, showed that 13% could have been treated outside an acute setting, 75% of elective survey patients were admitted earlier than necessary, 39% of day patients could have been treated in an alternative setting, and discharge planning was in evidence from the notes of 40% of patients. In response to this, the HSE introduced a Code of Practice for Integrated Discharge Planning in December 2008 with the overall purpose of reducing the average length of stay in hospitals to the OECD average. This code of practice provides a framework for care and case management and comprises a suite of national standards, recommended practices, forms, toolkits, key metrics and audit tools. In the UK, a recent study on end-of-life care by the National Audit Office (2008:7) reported: “Our detailed examination of patient records in one PCT [Primary Care Trust] found that 40 per cent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month. Alternative places of care for these patients identified by our work were equally split between home based alternatives (in the patient’s own home or a care home) and bed based care in a hospice. Local data suggest there was sufficient inpatient palliative care capacity to take many of the patients who died in hospital”.

[12] Gomes and Higginson (2008).

and this is part of the scenario on which the end-of-life strategy for England is based.[13]

1.2 The Hospice Friendly Hospitals (HFH) Programme

Given the importance of hospitals in our society, it is useful to remember that the word 'hospital' shares a common linguistic root with words like hospice, home, and especially hospitality. Hospitality – understood as welcoming and caring for another person with kindness and attentiveness – is still what everyone seeks when they come to hospital, including patients and their families who are going through the journey of dying, death and bereavement. Understanding the key role of hospitals in helping people to make this journey, and recovering the sense of hospitality at the heart of the hospital idea, is the *raison detre* for the Hospice Friendly Hospitals programme. It is also the reason why we carried out this audit of end-of-life care.

The HFH Programme is a five-year programme (2007-2012) designed to improve the quality of end-of-life care in acute and community hospitals in Ireland. It was initiated and developed by the Irish Hospice Foundation, in partnership with the HSE and supported by The Atlantic Philanthropies, the Dormant Accounts Fund and the Health Services National Partnership Forum. The overall vision of the programme is to promote a 'good death' by encouraging hospitals to adopt a hospice philosophy in caring for dying patients: 'The single most important outcome is the development of a widespread understanding of what constitutes a good death, how that is best achieved and how constraints in achieving it can be addressed'.[14]

The HFH programme acknowledges that hospitals have a mission to both cure patients wherever possible (the curative model) but also to care for patients whose condition is beyond cure (the palliative model). In the past, hospitals may have overlooked the palliative aspect of their care – even regarding death as a failure – and the programme invites a more balanced relationship to the end of life, where staff can 'live and work with dying'. This involves supporting patients through illness where death is the likely or inevitable outcome, such

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[13] Department of Health (2008: 26).

[14] Irish Hospice Foundation (2006), Grant Proposal to Atlantic Philanthropies, 19 July.

as when there is an advanced life-limiting or life-threatening disease, or when a diagnosis of dying has been made using specific clinical criteria. In effect, this involves the hospital adopting a more friendly attitude towards dying and death and becoming a 'hospice-friendly hospital' where end-of-life care is seen as 'everybody's business', and the organisational culture guarantees consistently high quality care.

The HFH programme has three aims:

- To develop comprehensive standards for all hospitals in relation to dying, death and bereavement
- To develop the capacity of acute and community hospitals to introduce and sustain these standards
- To change the overall culture in hospitals and institutions in relation to dying, death and bereavement.

The programme adopts a broad systems-approach to improving the organisation and culture of care within and across hospitals, and between hospital and community care. It does this by promoting the idea that end-of-life care is central to the mission and everyday business of the hospital, and affects all staff – clinical, administrative and support – who may have an involvement with dying, death and bereavement.

The activities of the programme are focused on four key themes: (i) integrated care (ii) communication (iii) design and dignity and (iv) patient autonomy. The focus of activities in the area of integrated care is to promote a more seamless, holistic, and user-friendly care for the dying person and his or her family. Activities in the area of communication aim to enhance the skills of staff to relate simply and warmly to patients while respecting their autonomy and their preferences. The focus of design and dignity is on providing peaceful and dignified surroundings which ensure the patient's dignity and privacy, and offer a sense of psychological and spiritual support. Activities in the realm of patient autonomy focus on the rights of patients and on the importance of an ethical framework which supports hospital staff to become more informed, confident and collaborative in addressing the ethical and legal challenges that arise in the treatment and care of dying patients and their families.

The rationale, or 'logic model', which informs the HFH Programme is based on the assumption that a set of programme inputs – focused on standards and capacity development through a range of activities under the four themes discussed above – will result in a set of outputs which are measurable against HFH standards for end-of-life care in hospital. These outputs are expected, in turn, to produce outcomes such as improved end-of-life experiences for patients and their families in the participating hospitals. This logic model (see Figure 1.2) informs the overall stated aim of the programme: "The Hospice Friendly Hospitals Programme aims to put hospice principles into hospital practice and to ensure that a systematic quality approach exists within the public health services to facilitate ... a good death when it is expected, or can be predicted, and supportive systems when death occurs unexpectedly".

The HFH Programme has two phases. Phase One (2007-2010) focuses on hospitals which responded to a call for expressions of interest in 2006. Phase Two (2010-2012), also based on expressions of interest, focuses on hospitals which are willing to prepare a development plan to implement the standards – The Quality Standards for End-of-Life Care in Hospitals[15] and the Design and Dignity Guidelines[16] – in light of the findings of this audit.

1.3 Rationale for the Audit

Clinical audit is normally defined as follows: "Clinical audit is a quality improvement process that seeks to improve the patient care and outcomes through systematic review of care against explicit criteria and the implementation of change. Aspects of the structures, processes and outcomes of care are selected and systematically evaluated against explicit criteria. Where indicated, changes are implemented at an individual team, or service level and further monitoring is used to confirm improvement in healthcare delivery".[17]

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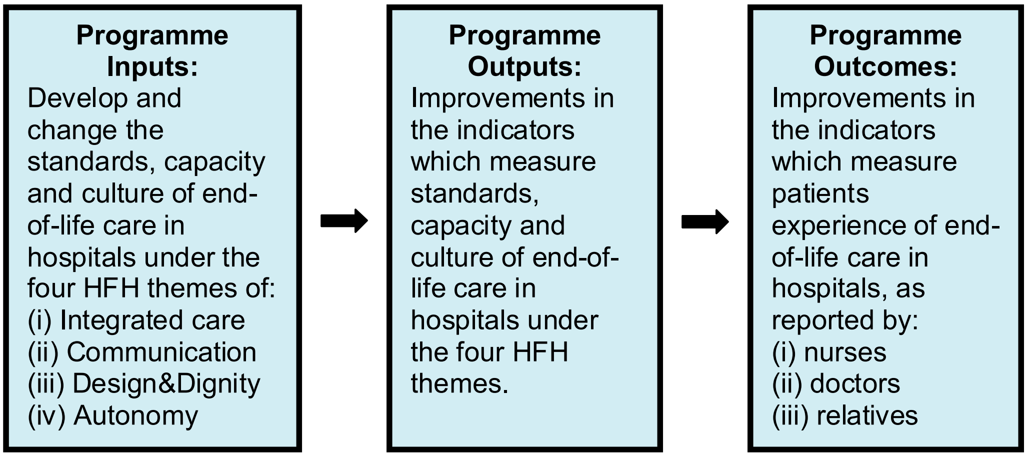
[15] Hospice Friendly Hospitals Programme (2010).

[16] Hospice Friendly Hospitals Programme (2007, 2008).

[17] Copeland, G. (2005: 3). This is the definition used in the UK's National Health Service (NHS), National Institute of Clinical Excellence (NICE), and the Healthcare Commission.

Figure 1.2: The Logic Model of HfH Programme



In Ireland, audit is set to become a central feature of the hospital system, given that it is Government policy since February 2009 to introduce a mandatory licensing system whereby hospitals will only be allowed to practice if, on the basis of audited performance, they meet acceptable standards of service. This policy is based on a recommendation by the Commission on Patient Safety and Quality Assurance[18] which outlines the rationale for audit as follows: "Clinical audit needs to be at the heart of clinical practice, and is something that all health practitioners should be engaged in. Clinical audit is about continuing evaluation and improvement by health professionals working towards delivery of safe, high quality care for patients. Clinical audit arguably constitutes the single most important method which any health care organisation can use to understand and ensure the quality of the service it provides. It is one of the principal methods used to monitor clinical quality and the results provided by clinical audit are a source of indispensable information to patients, the public, clinicians, and healthcare managers. It also provides a powerful mechanism for ongoing quality improvement highlighting incidences where standards are not met and identifying opportunities for improvement".[19]

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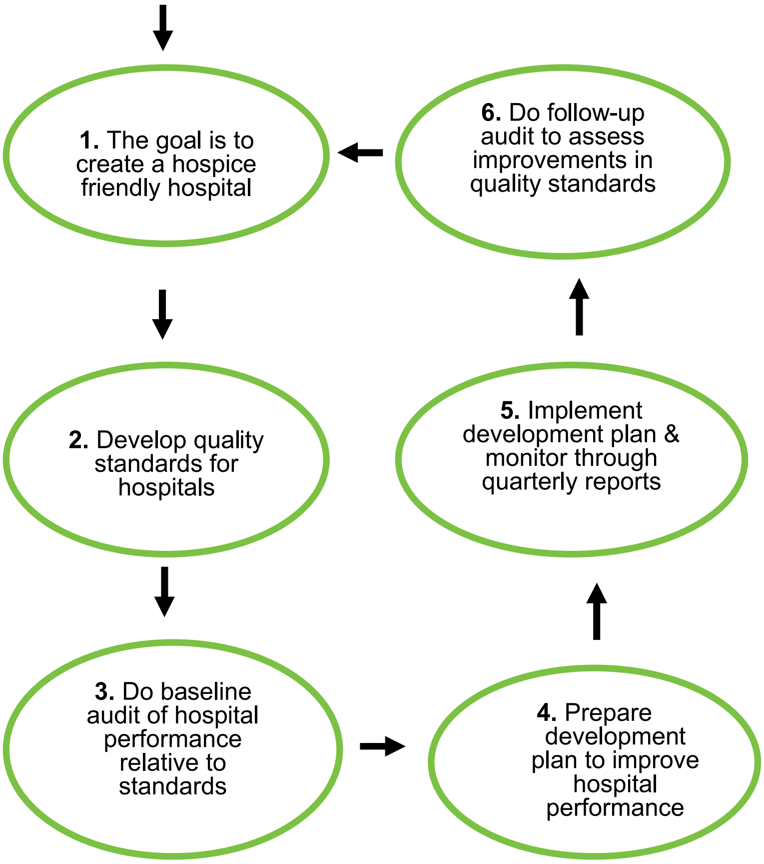
18 The key recommendations are that "there should be a mandatory licensing system in Ireland to cover both public and private healthcare providers. It must be an equitable and transparent system, with a review of licences every three years. It will apply to existing and new bodies, with time being given for compliance" (Commission on Patient Safety and Quality Assurance, 2008: 25). The Commission recommends further that: "All licensed healthcare facilities must demonstrate active participation in local and national clinical audit as appropriate to their services" (Ibid: 30).

19 Commission on Patient Safety and Quality Assurance (2008: 151).

In keeping with its focus on quality improvement, this audit is designed to assist each hospital to become a hospice-friendly hospital by meeting – and, if possible, exceeding – the Quality Standards for End-of-Life Care[20] and the Design and Dignity Guidelines.[21] The instrument for achieving this is a development plan which hospitals (those participating in Phase 2 of the HFH Programme) will prepare in light of the standards and audit, and an assessment of their needs and capacities. This process is graphically illustrated in Figure 1.3, and shows the logic which links the overall goal of becoming a hospice-friendly hospital to standards, baseline audit, development plan and follow-up audit.

Figure 1.3: Map of the Quality Improvement Process for End-of-Life Care



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[20] Hospice Friendly Hospitals Programme (2010).

[21] Hospice Friendly Hospitals Programme (2007, 2008).

1.4 Standards for End-of-Life Care

The Quality Standards for End-of-Life Care in Hospitals,[22] and the earlier Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End of Life Care,[23] were developed by the HFH Programme in consultation with staff in hospitals and other interested parties, including professional bodies, voluntary organisations and the general public (including bereaved relatives). These standards set out a shared vision for the type of end-of-life care that each hospital should aim to provide and that each patient and family can come to expect.

There are four quality standards covering hospital, staff, patient and family:

1. The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.
2. Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.
3. Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes.
4. Family members are provided with compassionate support and, subject to the patient's consent, given information before, during and after the patient's death.

Each standard is accompanied by criteria against which to judge if it has been met. The minimum dataset which we have prepared using this audit will contribute towards monitoring end-of-life care against these standards on a regular basis.

The standards are focused on hospitals, and the latter are also responsible for their implementation. However, it is envisaged that the standards will also facilitate and support end-of-life care in the home, in hospices and in long-stay settings such as nursing homes. The Health Information and Quality Authority (HIQA) has endorsed the development of these standards. HIQA has a number of statutory responsibilities under the Health Act 2007,

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[22] Hospice Friendly Hospitals Programme (2010).

[23] Hospice Friendly Hospitals Programme (2007, 2008).

including responsibility for setting standards in health and social services and monitoring healthcare quality. HIQA is currently developing the National Standards for Quality and Safety and these may include reference to the end-of-life care standards developed by the HFH programme. Implementation of HIQA's National Standards for Quality and Safety will be the first step in a 2-3 year programme that will culminate in a mandatory licensing system for public and private healthcare providers, as indicated above.

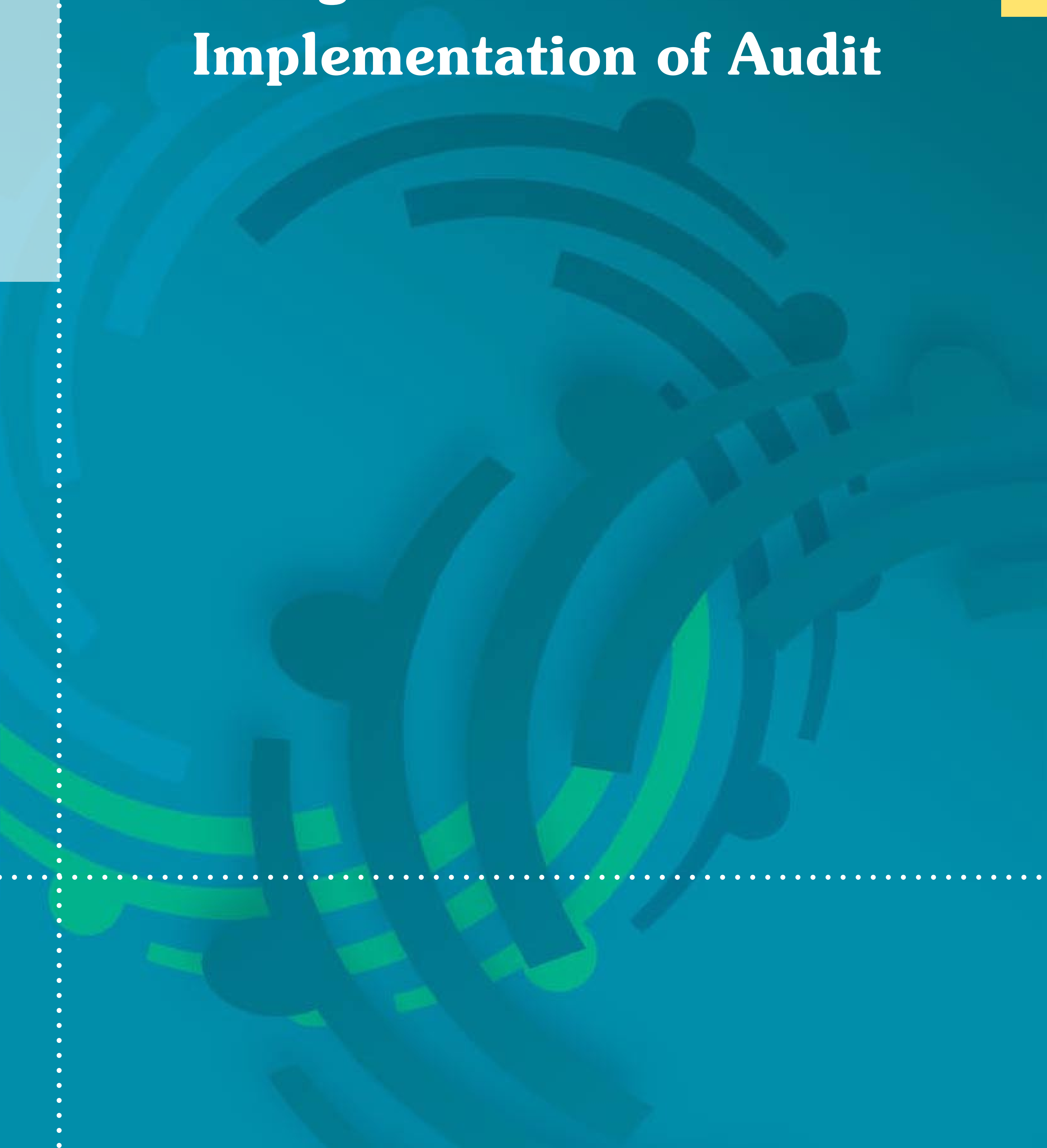
1.5 Structure of Report

The report contains five chapters as follows:

- Chapter 1: Introduction
- Chapter 2: Design and Implementation of Audit
- Chapter 3: What Influences the Quality of Hospital Care at End of Life?
- Chapter 4: Rating the Quality of Hospital Care at End of Life
- Chapter 5: Conclusions: Issues for Consideration and Action

Chapter 2

Design and Implementation of Audit



Design and Implementation of Audit

2 Design and Implementation of Audit

This is the first time that a national audit of end-of-life care has been undertaken in Ireland. For this reason, it was necessary to design the entire audit system from scratch, albeit with the benefit of previous research and drawing on the experience and expertise of those involved in the practice and policy of end-of-life care. Our starting point is the simple premise that the core 'outcome' of a hospital is care, and that this is influenced by a range of 'inputs' such as staff, care practices, facilities, etc.

The main challenge was to find an adequate and appropriate definition of 'care outcomes' for patients who die in hospital and to identify the range of potential 'care inputs' that may influence that care. Building on this perspective, we carried out an extensive review of the existing literature, including reviews of written standards for end-of-life care in hospital, with a view to identifying and specifying care inputs and outcomes.

We begin by defining 'care outcomes' (2.1) and 'care inputs' (2.2). Building on this, we describe the process by which this conceptual framework was implemented through a series of stages which involved designing questionnaires (2.3), coverage of the audit (2.4), obtaining ethical approval (2.5), sampling and data collection (2.6), dataset and response rates (2.7), and data analysis (2.8). We conclude this chapter by discussing the strengths and weaknesses of the audit (2.9).

2.1 Care Outcomes

The core outcome of a hospital is care. This is primarily care for the patient but also includes support for the patient's family. Hospital care has generic elements that are common to all patients, as well as elements which are specific to each, including the subjective experience of dying. With this in mind, we adopt a broad approach to defining 'care outcomes', which reflects the different dimensions of what it is like to die in a hospital, namely:

1. acceptability of the way the patient died[24]
2. quality of patient care[25]
3. patient's symptom experience[26]
4. symptom management[27]
5. support for patient's family[28]

Each of these dimensions has been used, either singly or in combination, in previous studies of care at the end of life. It is nevertheless useful to expand on the rationale which informs the selection of these care outcomes.

The first care outcome – the acceptability of the way the patient died – involves a global judgement about whether the patient had an 'acceptable' death. It is well recognised that a good or acceptable death is not easy to define, because it changes over time and place,[29] and

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24 This was measured by a question used in a study of 3,793 patients who died in 200 French hospitals in 2004; nurses were asked if the way the patient died was acceptable to them and their families (Ferrand, Jabre, Vincent-Genod, et al., 2008).

25 This was measured using a sub-scale from the Family Evaluation of Hospice Care (FEHC). The Family Evaluation of Hospice Care (FEHC) was developed by Joan Teno and Stephen Connor at Brown University in the US (Connor, Teno, Spence and Smith, 2005) based on a previously validated scale, Toolkit After-Death Bereaved Family Member Interview (Teno, Clarridge, Casey, Edgman-Levitan and Fowler, 2001). The FEHC was used in a survey of 116,974 relatives whose family members died in 819 hospices throughout the US (Rhodes, Mitchell, Miller, Connor, and Teno, 2008). The FEHC is available from, the National Hospice and Palliative Care Organisation (NHPCO), based in Virginia in the US at: http://www.nhpco.org/i4a/pages/Index.cfm?pageid=4397.

26 This was measured using a sub-scale from the Quality of Dying and Death Instrument (QODD) which was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001). It has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005). It is available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html.

27 The measurement of symptom management was based on five symptoms that are used as key indicators of end-of-life care in the Liverpool Care Pathway. The national audit of the Liverpool Care Pathway LCP was based on 3,893 patients in 115 hospitals who died between October and December 2008 (Marie Curie Palliative Care Institute Liverpool, 2009: 45-54).

28 This is also based on a sub-scale taken from the Family Evaluation of Hospice Care (FEHC).

29 A distinction has been made between the pre-modern, modern and post-modern definitions of a good death. According to this analysis, the good pre-modern death is to "die at peace with God and one's neighbour. ... Being free from physical pain, while desirable, was of secondary importance" (Walters, 2004: 405). A modern death, reflecting the rise of medical science, is "something to be prevented and its occurrence, eventually, a failure" (Ibid). A good post-modern death, reflecting individual autonomy and the palliative care movement, is a "death within our control" (Ibid: 406), either through controlling the time of one's death or controlling the symptoms which accompany it. Naturally, these three definitions are not confined to separate chronological periods in history but co-exist as different ways and

varies between individuals. It is also recognised that some patients may not have a good death even when care is good, although good care probably increases the chance of a good death.

The reality of good and bad deaths is recognised by hospital practitioners in Ireland[30] and is seen as a useful indicator of care at the end of life.[31] Taking these considerations into account, we measured a good death by asking those directly involved with the patient during the last week of life – nurses, doctors, and relatives – if the way the patient died was personally acceptable to them. This question is a simple, intuitive and empathic way of assessing a good death and allows each respondent to draw on their own experience and understanding of what constitutes a good death.

The second care outcome is patient care. As indicated, this outcome is widely used to assess the quality of care offered to patients who die in hospices. It comprises three simple questions: How well did staff manage the patient's symptoms? How well did staff communicate with the patient? How well did staff respect the patient's wishes?

The third and fourth care outcomes are about symptoms. There is general agreement that five symptoms are common at the end of life – pain, nausea, breathlessness, secretions and anxiety – and their management has been adopted as a key indicator of end-of-life care in the

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combinations in which people currently frame their understanding and acceptance of dying and death.

[30] A recent study concluded that: "The evidence of this research clearly establishes that there are good and bad deaths in Irish hospitals. The good deaths have a number of features in common: patient autonomy, the patient choosing what they want, articulating or communicating those choices, and those choices being respected and acted upon; the patient having access to all the resources and supports available; the patient having the support of palliative services, among them good pain and symptom management; and the establishment of good relationships between patient, family and practitioners. ... Bad deaths in hospital are often associated with inappropriate and, arguably, unethical active or aggressive treatments, investigations, resuscitations, and the administration of invasive, unwarranted, unnecessary and/or inefficacious procedures. Patients in Irish hospitals do not, as a rule, plan for their end-of-life experience. They do not anywhere or at anytime indicate in any way what it that they would want in terms of treatment or supports when they are dying. As a result of this, most deaths in hospital are managed through a moment-by-moment, event-by-event, decision-making process which is embedded in an oblique or certainly less than frank communication process which is negotiated between distressed and grieving relatives and under-resourced and commonly over-stretched carers and clinicians" (Quinlan and O'Neill, 2009: 3). This study was based on practitioners who manage end-of-life in hospitals in Ireland and comprised 102 written narratives, 57 interviews, and 14 focus groups with 104 practitioners (Ibid: 3).

[31] A previous study recommended "promoting the concept of a good death [since] the central tenet of palliative care is facilitation of a good death" (Keegan et al. 2009: ix). This study, based on a sample of 155 bereaved relatives, found that 84% of patients had a 'good death' (Ibid: vii).

Liverpool Care Pathway (LCP).[32] It is true that there are other symptoms associated with end of life and dying - fatigue, confusion, cognitive failure, ADL disability – but we decided to adopt the five LCP indicators of symptom management, based on the assessments of nurses and doctors. In addition, drawing on a scale to measure the quality of dying and death,[33] we asked nurses and relatives to rate patient's experience of the following: physical pain, ability to eat or drink, breathing problems, being comfortable and at ease, feeling afraid or anxious, showing signs of enjoyment, having the energy to do things, being able to control when to go to the toilet, being worried about causing strain to loved ones and maintaining dignity and self-respect.

The fifth and final outcome indicator is family support. This comprises just two questions from the scale used to measure patient care (above): How well did staff communicate with relatives? How well did staff give emotional support to relatives?

This approach to defining care outcomes for patients who die in hospital is consistent with what are generally regarded as the most important aspects of care at the end of life. In Ireland, a number of surveys have been undertaken on the most important things about care when dying, based on the general population, but also based on bereaved relatives and hospital

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[32] The Liverpool Care Pathway (LCP) is a multi-professional framework of care which is used during the dying phase and is based on standards of care found in the hospice environment. The goals of care are to ensure the physical comfort of the patient, psychosocial insight, spiritual care for patients and carers, as well as communication including information giving and receiving. This framework is one of three – the other two are Gold Standards Framework and Preferred Priorities for Care – that have been recommended by the UK Department of Health and by the UK National Institute for Health and Clinical Excellence (NICE). In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), based on a sample of 3,153 deaths between October 2006 and March 2007, one third of those diagnosed as dying (33%, 1,505) were placed on an end-of-life care pathway. For those not on a pathway, the "overall quality of care was less good than those who had such a pathway in place" (National Confidential Enquiry into Patient Outcome and Death, 2009: 91). However this study also drew attention to some limitations of care pathways: "While these [care pathways] may well be an aid to patient care by providing a common framework, good quality end of life care can equally well be provided by committed and compassionate individuals who are experienced in the care of the dying. Indeed consideration should be taken to prevent the act of dying becoming overly medicalised and process driven. Perhaps the greatest value of these care pathways may be in situations were health care professionals are less confident and experienced in providing end of life care" (National Confidential Enquiry into Patient Outcome and Death, 2009: 90).

[33] The experience of symptoms was measured using the Quality of Dying and Death Instrument. This was developed by, and is available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

staff. The findings of these surveys indicate that there is a substantial consensus that the two most important things about end-of-life care are to be free from pain and to be surrounded by loved ones.[34] Internationally, the aforementioned dimensions of care at the end of life are also recognised as indicators of a good death.[35]

These care outcomes are, in essence, matters of judgement rather than matters of fact. For that reason, we measured them using the judgements of nurses, doctors and relatives, as applied to each patient whose death is included in the audit. One might say that this is a democratic way of measuring care outcomes, since the judgement of nurses, doctors and relatives are given equal weight. However, the research design is also 'flawed' to the extent that it does not include the judgements of patients, an issue to which we will return at the end of this chapter.

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[34] **The key finding are:**

Most important things about care if dying or terminally ill	Ireland* (n=1000)%	Relatives** (n=461) %	Ward*** (n=2358) %	Hospital*** (n=1858) %
To be free from pain	55	57	57	47
To be surrounded by loved ones	68	20	27	30
To be conscious & communicate	35	6	6	7
To be at home	34	6	15	12
To have medical & nursing support	32	7	4	4
To have spiritual support	19	6	4	4
To be in a private space	11	6	5	8

*Weafer and Associates Research (2004).
**McKeown, Haase, and Twomey (2010c).
***McKeown, Haase, and Twomey (2010d).

[35] For example, the end-of-life strategy in the UK notes that "although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve: being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends" (Department of Health, 2008: 9).

2.2 Care Inputs

We define 'care inputs' as covering the hospital's response at each stage of the patient's journey. This journey begins with the patient's admission to hospital - although the end-of-life journey typically begins well before the final admission to hospital - and involves numerous interactions with patient and family, ends with the patient's discharge at death, but may also involve subsequent support for the family after death. In broad terms – and drawing on previous research on the determinants of end-of-life care – we define care inputs as comprising the following:

1. Patient characteristics, including disease and cause of death
2. Route of admission and length of stay
3. Physical environment, including single rooms and mortuary facilities
4. End-of-life care decisions
5. Care practices such as team meetings
6. Communication with patients and relatives
7. Documentation in healthcare records
8. Support for families before, during and after death
9. Ward and hospital culture
10. Hospital characteristics, including size and governance of end-of-life care

In the main, information on care inputs was supplied by one of the nurses who cared for the patient during the last week of life.

The selection of these care inputs was also informed by the understanding that a person's experience of hospital – as of other social settings, such as the home, school, work, etc. – is shaped by the individual's personal characteristics and by characteristics of the setting in which the experience takes place.[36] In the case of a patient in hospital, for example, this experience is influenced by personal characteristics such as the person's illness and how s/he relates to it, but also by different characteristics of the setting, such the route of admission, the physical surroundings, the quantity and quality of care received from nurses and doctors, the organisational culture of the ward and hospital, and the overall capacity and resources of the hospital.

This implies that the experience of being a patient in hospital is shaped by a number of overlapping and interacting influences. This could be described as a 'systems approach' since it acknowledges how the different elements and processes of the hospital system – including the patient – interact to produce the care outcomes. In statistical terms, these layers of influence are assigned to 'levels', which are nested hierarchically (individuals within wards, wards within hospitals, and hospitals within a national health system). Through the use of multilevel modelling, it is possible to separate each level of influence and to estimate the contribution of each factor to the overall patient experience (see Annex 6 for an introduction to multi-level modelling).

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[36] This approach to studying the patient's experience in hospital is similar to that found in other types of social research such as education (where student performance is seen as the outcome of student-level and classroom-level characteristics), or family well-being (where outcomes are determined by individual, family, and neighbourhood characteristics).

2.3 Questionnaire Design

Six questionnaires were designed to collect data on the domains described above. Wherever possible, standardised questions were used (drawing on the CSO,[37] HIPE[38] and national surveys[39]) and standardised scales were used to measure care outcomes. The six questionnaires, including a detailed guide to each question, is included in a separate manual.[40] These questionnaires generated over 200 variables, a full list of which is contained in Annex One of the Technical Appendix.

A core aspect of the study design is that the six questionnaires are linked by a common identification code. This generates an integrated database and permits maximum use to be made of the data collected. Every item of information on a patient is linked to corresponding information about the nurse, the doctor, the relative, the ward and the hospital.

The questionnaires were piloted in six hospitals (as indicated in the Acknowledgements) before being finalised. Figure 2.1 illustrates the interlinked nature of the questionnaires and the resulting dataset.

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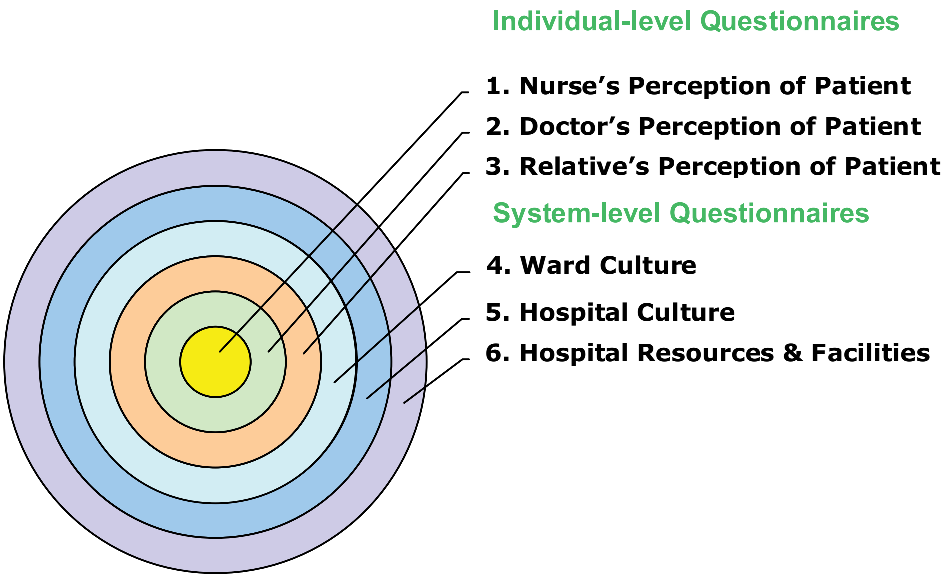
[37] All questions on the demographic characteristics of patients were taken from the questionnaire used by the Central Statistics Office (CSO) in the 2006 Census of Population.

[38] The HIPE system (Hospital In-Patient Enquiry), established in 1971, is a computer-based health information system designed to collect clinical and administrative data on discharges from, and deaths in, acute hospitals in Ireland. In 2006, 57 acute public hospitals in Ireland reported to HIPE. The ESRI has been responsible for managing, and reporting on the HIPE Scheme on behalf of the Department of Health and Children and the Health Service Executive since 1990. In 2006, HIPE captured 96.7% of activity in public hospitals.

[39] A series of questions in a national survey of attitudes to dying and death were used to measure the same attitudes of hospital staff (Weafer & Associates Research with TNS MRBI, 2004).

[40] McKeown (2008).

Figure 2.1: Questionnaires Used in National Audit of End-of-Life Care



2.4 Coverage of Audit

Given that this is a national audit of end-of-life care, it is appropriate to describe its coverage of the acute[41] and community[42] hospital sectors in Ireland. All of the main acute hospitals in the country (38) were invited to participate in the audit,[43] and 24 agreed to participate, equivalent to nearly two thirds (63%) of those invited. A total of 43 hospitals – 24 acute and 19 community – participated in the audit.

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[41] In this report, the acute sector is defined as the 38 hospitals in the HIPE system (Hospital In-Patient Enquiry) who have an accident and emergency department, excluding children's hospitals, orthopaedic hospitals and eye & ear hospitals.

[42] Note that there is no official definition of a 'community hospital' in Ireland, but the convention is to differentiate it from an 'acute hospital' if it does not have an accident and emergency department. Community hospitals are effectively long-stay institutions, but offer a higher level of medical support compared to nursing homes.

[43] Children's hospitals were not included in the invitation because the audit system is not suitable for assessing end-of-life care for children. Orthopaedic hospitals and eye & ear hospitals were also excluded because end-of-life care is not a normal or expected feature of these hospitals.

In geographical terms, as Figure 2.2 illustrates, the coverage of the audit is strongest in the eastern part of the country. Coverage is weaker in the west, with no participation by hospitals in Galway, Mayo or Roscommon (the former Western Health Board Region).

Turning to the community hospitals, Figure 2.2 shows a similar pattern, with a much higher level of participation in the east compared to the west. This is not a reflection of interest by community hospitals nationwide, since the audit was offered only to community hospitals in Phase 1 of the HFH Programme, and all but one accepted. In total, 19 community hospitals participated in the audit, equivalent to 12% of the 156 community hospitals in Ireland. In geographical terms, these hospitals are situated exclusively in the eastern part of the country – especially Dublin and the North East – with the exception of St. John's Community Hospital in Sligo.

From a sectoral perspective, the national audit covers a major part of the acute hospital sector in Ireland, as measured in terms of the number of patients (72%), deaths (71%), staff (73%) and bed-capacity (74%).[44] In this sense, it is truly a national audit, and its findings are relevant to the entire acute hospital sector.

Coverage of the community hospital sector is weaker, because the audit represents just 20% of all community hospital beds in Ireland, although these hospitals tend to be larger (averaging 110 beds each) compared to community hospitals more generally (averaging 68 beds each). Nevertheless, the findings of the audit are also likely to have direct relevance to end-of-life care in all community hospitals.

2.5 Ethical Approval

Hospitals were invited to participate in the audit, and the majority of the acute hospitals who agreed to participate required approval from their ethics committee, including:

1. St. James's Hospital
2. Beaumont Hospital

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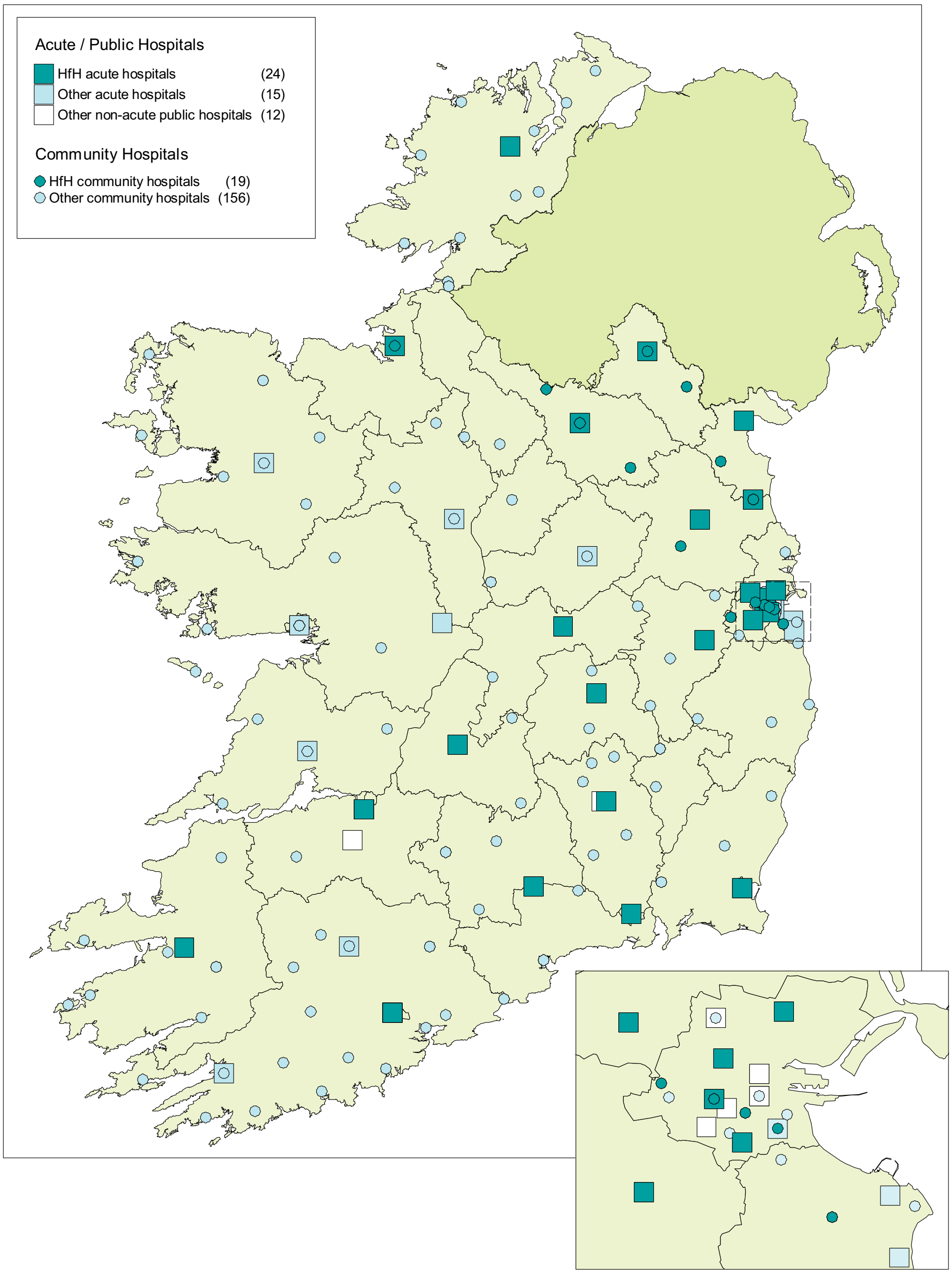
[44] McKeown, Haase and Twomey (2010a).

Design and Implementation of Audit

Figure 2.2: Hospitals in the HFH Audit



3. Cork University Hospital
4. Tallaght Hospital (AMNCH)
5. Mater Misericordiae University Hospital
6. Limerick Regional Hospital
7. Letterkenny General Hospital
8. Kerry General Hospital
9. Naas General Hospital
10. Nenagh General Hospital
11. Sligo General Hospital
12. St Luke's Hospital, Rathgar
13. HSE Dublin North East (covering Connolly Hospital and hospitals in Meath, Louth, Cavan and Monaghan)
14. HSE South East (covering hospitals in Wexford, Waterford, Kilkenny and Tipperary).

The process of obtaining ethical approval was a major undertaking because a separate application form was required for each committee, many committees required an oral presentation, and written clarification of specific issues was sought in many cases. This level of scrutiny gives confidence that the audit has been fully proofed against ethical objections. However, a nationally-coordinated procedure for ethical approval – which would give due recognition to the decisions of each ethics committee – would be preferable, as it is difficult to imagine how or why an audit could be judged ethical in one hospital and unethical in another.

2.6 Sampling and Data Collection

The audit required each hospital to ensure that the patient-related questionnaires for nurses (Q1), doctors (Q2) and relatives (Q3) were completed on a random sample of 50 deaths in the four month period between November 2008 and February 2009.[45] The quota for each month was broken down to reflect the proportion of deaths in the previous year in: (i) A&E (ii) ICU and (iii) other wards. The monthly quota was filled by taking all deaths from the beginning of the month until the monthly quota for each category was completed. This ensured that the sample was random and that the audit was manageable in terms of the number of questionnaires to be completed each month, an important consideration in larger hospitals. However, this procedure could not be followed in smaller hospitals and these were required to complete Questionnaires 1, 2 & 3 on every death from the start of the audit, because it was impossible for them to meet the quota of 50 deaths in a four-month period.

The sampling procedure for Questionnaires 1, 2 & 3 was based on a number of considerations. First, monthly variations in the number of deaths in Irish hospitals are relatively modest – no more than 15% above or below the mean for all hospitals in the HIPE system – so that no significant distortion arises from the selected four month audit period. Second, the risk of selection bias may be excluded because hospitals were given no discretion as to which death to include in the audit. In larger hospitals, all deaths from the beginning of each month were to be selected until the quota for that month was filled, whilst in smaller hospitals, all deaths were included in the audit period without exception. Third, the statistical analysis of data, especially the separation of patient-level and hospital-level data, requires roughly 25 individual-level observations per hospital; given an anticipated response rate of 50% to the survey of bereaved relatives (Questionnaire 3), this target could be met in most cases.

Questionnaires 1 & 2 were completed by the nurse and doctor who provided most care to the patient during the last week of life in hospital. Questionnaire 3 was completed by the patient's relative. A period of three months was allowed to pass between the death of the patient and contact being established with the relative, similar to the 'bereavement period' adopted in other surveys of bereaved relatives.[46] Prior to sending out the questionnaire, a designated member of staff in each hospital phoned the relatives to ask for their consent to send out the questionnaire. There were very few refusals and these were mostly from

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[45] In a small number of cases, local circumstances dictated minor changes to the audit period and resulted in the audit beginning earlier or finishing later than the agree audit period.

[46] Similar surveys are those which have used, as in this audit, the Quality of Dying and Death Scale (QODD), or the Family Evaluation of Hospice Care Scale (FEHC). The bereavement periods before contacting the family are as follows:

relatives who were dissatisfied with the experience of the hospital. As a consequence, the audit may underestimate the true range of responses among relatives. Nevertheless, given the relatively low refusal rate, the extent of this potential bias is probably not great. The materials sent to each relative included a letter of invitation for the survey, a questionnaire, a leaflet on bereavement and a stamped addressed envelope to return the completed questionnaire. A national help-line was set up to assist relatives who, on foot of being contacted by the hospital, may have felt a need for bereavement support. Only two phone calls were received.

Questionnaire 4, on the culture of care in each ward, was completed by a random sample of nurses and healthcare assistants in each of the wards where a patient died and whose death is included in the audit. Ten staff per ward participated, and these were weighted to reflect the number of nurses and healthcare assistants in each ward.

Questionnaire 5, on the culture of care in the hospital, was completed by a quota sample of 100 staff in each hospital with participation proportionate to five different staff categories, excluding nurses and health care assistants who completed Questionnaire 4.

The staff categories are:

1. Management (including CEO/GM, Director and Assistant Directors of Nursing) and administration (including reception and ward clerks)
2. Medical and dental (including consultant and non-consultant doctors)
3. Nursing specialists (not specific to a ward)

Name of study	Achieved sample	Bereavement period	Response rate
QODD: US Deaths in hospital & home (Curtis et al. 2002)	252	1-3 years	27%
QODD: US Deaths in ICU (Levy et al. 2005)	50	1 month	55%
QODD: US Deaths in ICU (Mularski et al. 2004)	38	4-12 months	38%
FEHC: US Deaths in hospice (Teno et al. 2007)	106,514	1-3 months	45%

In Ireland, one survey achieved a response rate of 57% (Keegan et al. 1999) while a more recent survey had a response rate of 32% (McCarthy and O'Boyle, 2010).

4. Health and social care (including allied health professionals such as radiographer, social worker, physiotherapist, occupational therapist, speech therapist)
5. General support staff (including porters, catering, household, security, mortuary)
6. Other patient care (including pastoral care, bereavement coordinator, end-of-life care coordinator, complaints officer, patient advice and liaison officer)

Questionnaire 6, on the hospital's resources and facilities for end-of-life care, was based on 2008 data, and was authorised by hospital management before being returned. This questionnaire posed a challenge for hospitals because many do not have information systems to retrieve data easily. As a result, gaps and inconsistencies were identified when the returns were cross-checked against centralised HSE data in FactFile, HealthStat, Health Intelligence, National Employment Monitoring Unit, Consultant Appointments Unit, Office of Consumer Affairs, HIPE, etc.

The coordination of data collection in each hospital was a major logistical exercise. In order to ensure that this was managed consistently across hospitals, a detailed set of guidelines for the completion of each questionnaire was prepared. In addition, each hospital appointed an audit manager to oversee the audit; these are listed in the Acknowledgements.

2.7 Dataset and Response Rates

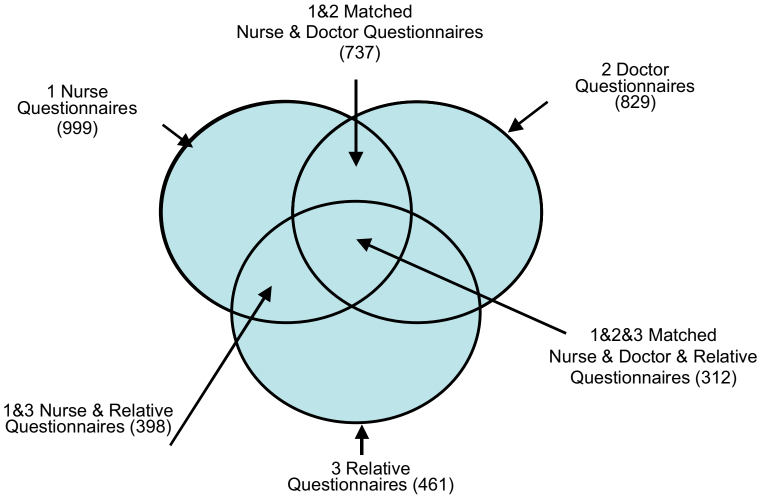
The dataset produced by the audit is summarised in Table 2.1, which also gives the response rate to each questionnaire. The total number of deaths in the audit is 999. This is the number of copies of Questionnaire 1 completed by nurses and is equivalent to a response rate of 84% (based on those hospitals which could have met the quota). Most of these deaths took place in acute hospitals (880, 88%) with the remainder (119, 12%) in community hospitals. As a proportion of total deaths in 2008, the audit is a representative sample of 10% of acute hospital deaths and 29% of community hospital deaths in Ireland. In sampling terms, this is a high sampling fraction and, other things being equal, provides a robust basis for drawing conclusions about the experience of dying in an Irish hospital.

Table 2.1: Dataset and Response Rates

Questionnaire	Dataset	Response Rate
1	999 deaths (nurse-based)	84%
2	737 deaths (doctor-based)	68%
3	461 deaths (relative-based)	46%
4	2,358 ward staff	83%
5	1,858 hospital staff	52%
6	24 acute & 19 community (hospital-based)	100%

Doctors completed Questionnaire 2 on 68% of the quota, yielding 737 valid questionnaires. In other words, of the 999 deaths in the audit, there are 737 deaths for which there is matching data from both nurses and doctors (Figure 2.3).

Figure 2.3: Nurse, Doctor, and Relative Questionnaires in Audit



The total number of copies of Questionnaire 3 returned by relatives was 461, equivalent to a response rate of 46%, and within the range found in similar surveys of relatives, both in Ireland[47] and elsewhere.[48] The response rate was somewhat higher where the patient died in

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[47] In Ireland, one survey achieved a response rate of 57% (Keegan et al., 1999) while a more recent survey had a response rate of 32% (McCarthy and O'Boyle, 2010).

[48] In the US, four studies which have used either the QODD or the FEHC, both used in the audit, had response rates of

a community hospital (52%) than in an acute hospital (45%). The 461 questionnaires returned by relatives had a corresponding match with a nurse's questionnaire in 86% of cases (398) and with a doctor's questionnaire in 68% of cases (312).

The returns by staff of Questionnaire 4 (83%) and Questionnaire 5 (64%) are high and represent one of the largest surveys in Ireland on staff attitudes to a range of end-of-life issues. The lower response rate to Questionnaire 5 is due to the fact that many community hospitals in the audit do not have 100 staff and therefore could not meet the quota.

2.8 Data Analysis

Data analysis involved a number of different stages and procedures. First, descriptive statistics – frequencies, means and cross-tabulations – were prepared for every variable in the audit. The results of this analysis are presented in the first four audit reports.[49] These reports, and the database on which they are based, are listed in Table 2.2. Each of these reports comprises a detailed commentary on the findings and a technical appendix with the tables of data. We draw freely on these reports to provide the descriptive context in this final synthesis report.

Table 2.2: Audit Reports

Report	Title	Data Source	Summary
1	Resources and Facilities for End-of-Life Care in Hospitals in Ireland	Questionnaire 6	Annex 1
2	Dying in Hospital in Ireland: Nurse and Doctor Perspectives	Questionnaires 1&2	Annex 2
3	Dying in Hospital in Ireland: Family Perspectives	Questionnaire 3	Annex 3
4	The Culture of End-of-Life Care in Hospitals in Ireland	Questionnaires 4&5	Annex 4
5	Dying in Hospital in Ireland: An Assessment of Quality of Care in the Last Week of Life	Questionnaires 1-6	-

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27% (Curtis et al., 2002), 38% (Mularski et al., 2004), 45% (Teno et al., 2007), and 55% (Levy et al., 2005).

[49] McKeown, Haase and Twomey (2010a, 2010b, 2010c, 2010d).

Second, regression analysis[50] was used to do a preliminary analysis of the influence of each care input on care outcomes. This was carried out in order to make a pre-selection of variables to meet the requirements of multi-level modelling.

Third, multilevel modelling[51] was used to analyse the influence of each care input on care outcomes. As explained in Annex 6, multilevel modelling is the most appropriate method for this type of analysis because, in addition to separating individual-level and system-level influences, it also controls for covariance between the care inputs. A total of 16 multilevel models were generated corresponding to the five outcomes and the different perspectives of nurses, doctors and relatives. These models are particularly important from a strategic perspective in establishing which care inputs are likely to have the largest effect across the entire care system. The results are summarised in the Technical Appendix (annex 7 and 8) and are analysed in Chapter Three[52].

Fourth, additional analysis was undertaken using ANOVA[53] to identify other potential factors associated with each of the care inputs included in the multilevel models. In this way, we can build up a more complete picture of the patterns of influence at work in determining care outcomes. The ANOVA results run to over 50 pages and, for reasons of space, are not reproduced in the Technical Appendix.

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50 Regression analysis is a method of explaining variability in a dependent variable using information from one or more independent variables. It is referred to as multiple regression analysis where there is more than one independent variable. The regression coefficient is the average amount the dependent variable increases when the independent variable increases by one unit and other independent variables are held constant. The fact that regression analysis holds constant the influence of other independent variables makes it a significantly more powerful statistical technique than correlation analysis.

51 Multi-level modelling is essentially an advanced form of multiple regression analysis (see Annex 6 of the Technical Appendix). The advantage of multilevel modelling in the context of this audit system is that it enables us to quantify the relative impact of patient-level factors and hospital-level factors on the quality of end-of-life care.

52 Not all of the effects included in the multilevel models are statistically-significant, which means that the influence measured by the coefficient (however large or small this may be) would not be significantly different from zero in at least 95 out of 100 samples, drawn at random from the population, like the present one. The definition of "significantly different" is a statistical one, and relates to the "normal distribution". In a normal distribution, 95 per cent of cases are within plus or minus 1.96 standard deviations of the mean. It is therefore possible to assess whether a coefficient is statistically-significant by comparing it to the associated "standard error". If the coefficient divided by the standard error is equal to or greater than 1.96, it is reasonable to conclude that the influence of the variable in question is statistically-significant. All statistically-significant results are highlighted in bold in Annex 7 and 8 below.

53 In general, the purpose of ANOVA (analysis of variance) is to test for statistically-significant differences between means. In this case, we analysed if there was a statistically-significant difference in the means of 60 separate variables associated with each of the care inputs.

Fifth, building on results from the previous steps, we rated the performance of each hospital. The benchmark chosen was the mean score for the top quartile (25%) of acute hospitals for each care outcome and care input. Using this benchmark, we then rated the performance of each hospital using a 'dashboard' comprising three categories which are colour-coded (green, amber, red), as described in Chapter Four below. Given that there are 24 acute hospitals, this means that the mean score is set by the top six acute hospitals for each care outcome and care input.

In the fifth and final chapter of the report, we draw conclusions and identify the main issues for consideration and action that arise from our analysis. This chapter situates the findings in a broader context of policy and practice in order to facilitate reflection within each hospital on its response and reaction to the audit findings.

2.9 Strengths and Weaknesses of the Audit

The main strength of the audit is that it covers many aspects of the patient's final journey in hospital, 'from admission to discharge', including detailed information about the care received as well as characteristics of the room, ward and hospital where the patient died. However, an acknowledged weakness of the audit – albeit one shared by most studies on end-of-life care – is that the patient's voice is missing.[54] This is a weakness, because the experience of dying in hospital is unique to each patient and, in its fullest sense, can only be understood through that experience.[55] Naturally, this understanding is impossible to ascertain once the patient has died and, even in circumstances where death is expected or sudden, it can be difficult to access the patient's direct experience.[56] Even where this possible, it raises questions about whether it is

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[54] In acknowledging that the audit is based on the mediated experiences of nurses, doctors and relatives, we also acknowledge that these experiences do not necessarily coincide with those of patients. The patient's experience in hospital, as one review has pointed out, "is such that no-one else can know how it works from one moment to the next, how the different aspects of the experience (the process of care, the manner in which it is delivered, the environment in which it occurs, the physical sense of place) come together, or what they mean for this particular person at this particular moment in their life" (Goodrich and Cornwell, 2008: 7).

[55] The uniqueness of the patient's experience is underlined by Daniel Gilbert as follows: "If we want to know how a person feels, we must begin by acknowledging the fact that there is only one observer stationed at the critical point of view … she is the only person who has even the slightest chance of describing 'the view from in here', which is why her claims serve as the gold standard against which all other measures are measured" (Gilbert, 2006).

[56] For example, one study conducted in the UK found that approximately two thirds of palliative care patients could not complete a brief survey (Hearn and Higginson, 1999). Another study found that a similar proportion of cancer

necessarily in the patient's best interests to do so.[57]

The fact that the audit relies on the judgements of nurses, doctors and relatives who were with the patient during the last week of life offers a practical solution to the natural complexity of assessing care outcomes when a patient dies. It also makes sure that if an outcome is assessed as positive by a nurse, doctor or relative, then it is registered as such in the audit. However, this approach also has its limitations, since the judgements of nurses, doctors and relatives about care outcomes often differ quite radically. For example, while all three groups agree about the acceptability of a patient's death in about two thirds of cases, for other outcome measures the level of agreement is less than half.

We are not in a position to overcome this limitation, but our analysis of this issue in Chapter Three offers an insight into the separate-but-connected 'universes' which inform the perspectives of nurses, doctors and relatives. Even with this limitation, nurses, doctors and relatives remain central to the assessment of care outcomes at end-of-life. At the same time, the audit highlights the need for a more 'objective' set of predictors of care outcomes which can provide a sound basis for inferring that good care has been achieved. This essentially coincides with what we refer to as the "minimum dataset" of predictors, which emerges from this audit (see Annex 12 of the Technical Appendix).

The audit draws strength and authority from its coverage of approximately three quarters of the acute hospital sector and 20% of the community hospital sector. It is based on a random sample of 1,000 deaths, representing about 10% of acute hospital deaths and 29% of community hospital deaths in Ireland. This is a robust basis for drawing conclusions about the experience of dying in an Irish hospital. However, the combination of acute and community hospitals within the same dataset, while adding strength in terms of coverage, may also be

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patients in a London hospital could not be interviewed (Addington-Hall et al., 1992).

[57] This does not imply that it is never appropriate to interview dying patients, since the experience of the Picker Institute (2005) is that when interviewers are trained and sensitive to bereavement issues both patients and family members are usually willing to participate in surveys of this type. A team of researchers recently observed that "some people facing death [however] may want to participate in research and should be allowed to do so. Ethics committees and clinical staff must balance understandable concern about non-maleficence with the right of people with advanced illness to participate in research. Despite the inherent difficulties, end of life research can be conducted with ethical and methodological rigour. Adequate psychological support must be provided for participants, researchers, and transcribers" (Kendall et al., 2007).

a source of difficulties, because community hospitals do not have emergency admissions, for example, which represent a major challenge for acute hospitals and a negative predictor of care outcomes.

One of the strengths of using statistical analysis to determine which care inputs exercise an influence on care outcomes is that this determination is carried out independently of any interpretation by respondents or researchers. It is true that, as researchers, we offer possible interpretations of the results but these results rely solely on the statistical technique of multilevel modelling, as explained in Annex 6. This adds to the robustness of the results because they identify significant non-random associations between care inputs and care outcomes which could not be generated through an interpretative process. Indeed, the results in Chapter Three frequently challenge some of the presumptions which respondents and researchers usually make about the care inputs which influence end-of-life care outcomes. This is the case, for example, with the findings on the influence of different aspects of end-of-life care (such as the diagnosis of dying, end-of-life care decisions, or referral to specialist palliative care), the importance of documentation, or the significance of communication with patients and relatives.

It is sometimes argued that the quality of care cannot be quantified. It is true that the essence of care cannot be directly measured, because this – like all concepts – is measurable only through indicators of the underlying reality which it represents.[58] Given that this is common to all forms of understanding, it is more appropriate to regard it as a limitation rather than a weakness, one that is not unique to this audit but common to many forms of scientific research.

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[58] This understanding of measurement reflects a philosophical perspective which recognises that the essential quality of experience is only accessible through its 'phenomenal' manifestations. This understanding is also reflected in the statistical term 'latent variable', a term used to refer to the underlying factor which influences various indicators and is thus measurable. The concept of care, and the associated concepts of life and death, lend themselves particularly to this understanding of measurement, while also engendering appropriate respect for the limitations of those measurements.

Design and Implementation of Audit

The approach adopted in this audit is primarily 'quantitative', and may thus be contrasted with more 'qualitative' methods such as critical incident analysis[59], focus groups,[60] case studies[61] or 'emotional touchpoints'.[62] All of these methods, when used carefully and creatively, can contribute to knowledge and understanding. Similarly, the fact that we quantify thousands of answers to the questions in our survey instruments does not detract from the qualitative content of those very questions. In this more restricted sense, it is misleading to suggest that quantitative and qualitative research represent mutually exclusive poles, and certainly misguided to suggest that one is superior to the other.

From the perspective of standards, it could be argued that a weakness of this audit is that it relies heavily on 'subjective', rather than 'objective' measures, and is therefore more akin to a self-audit than an independent-audit. This is true in the sense that our measurement of care outcomes is based on the 'subjective' judgements of nurses, doctors and relatives rather than on the 'objective' perspective of standards. In turn, this is due to the fact that the audit was

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[59] Critical incident analysis was used effectively in a study by Keegan et al. (1999). This study was based on 155 relatives of patients who died in St. James's Hospital, Dublin, between July 1996 and June 1997. Relatives were asked to describe "specific events which were meaningful to them and signified either positive or negative features of the care received" (Ibid: 53). This yielded nearly twice as many negative (568) as positive (297) incidents.

[60] This method was used in a study at Our Lady of Lourdes Hospital in Drogheda (Browne, O'Mahony and MacEochaidh, 2005).

[61] This method was used in a study of hospitals commissioned by the Hospice Friendly Hospitals Programme and involved collecting data on good and bad deaths in these hospitals using 102 written narratives, 57 interviews with hospital practitioners, and 14 focus with 104 practitioners (Quinlan and O'Neill, 2009).

[62] This method has been used in a number of care settings in Scotland as part of the Leadership in Compassionate Care Programme (Dewar, Mackay, Smith, Pullin and Tocher, 2009). The method involves asking the patient to speak about a number of different points, 'touchpoints', in the patient's journey. Emotional touchpoints might include coming into the hospital, going for tests, meal times, visiting times, night-time, talking with doctors and nurses, etc. A range of emotional words are printed on cards – such as numb, powerless, bewildered, happy, curious, hopeful and encouraged – and the patient is asked to select the emotion that matches the touchpoint and to elaborate on this. These different elements of the method are integrated as follows: "The patient or family member was invited to discuss their experiences of being in hospital. This was conducted in a private room on the ward. The touchpoints were laid out on a table and the patient was invited to select, from these touchpoints, those that they would like to talk about. They were also asked if there were other key moments that they would like to discuss. ... Taking each touchpoint in turn the storyteller was then asked to describe what happened and select from the emotional words those that best summed up for them how that experience felt. There were blank cards that could be used if the patient used an emotional word that is not in the pre-prepared collection of emotional words. They were then invited to say why they felt this way. If appropriate, they were also asked to discuss how things could have been different, particularly if the emotion identified was a negative one. Talking with patients about what they see as potential solutions to issues they have raised helps patients to co-design the service rather than being passive givers of information" (Ibid: 32). Following the interview, the story is written up and the patient is given an opportunity to read and adapt as wished. Significantly, the authors emphasise that 'there needs to be a strong connection between the story and action. The stories need to be linked with other evidence and put into the context of the culture so that meaningful learning and action can be facilitated' (Ibid: 34).

developed before the standards and, in this sense, it may be appropriate to refer to the report as a 'pre-audit' rather than an audit.[63] Nevertheless, the audit is informative about the actual standards which are currently shaping hospital care at the end of life, whilst simultaneously providing strong indications about whether they are in conformity with the normative standards in the Quality Standards for End-of-Life Care in Hospital[64] and the Design and Dignity Guidelines.[65]

A related issue in this context is that hospital staff tend to give consistently high ratings for all care outcomes, with staff at community hospitals providing the highest ratings. In acute hospitals, these ratings are consistently higher than those of relatives, which indicates that care outcomes may not be as good as nurses and doctors believe. In the absence of explicit standards about how to judge care outcomes and in the presence of implicit standards that are self-referential and based on limited comparativeinformation, staff members may be subject to a risk of positive bias. There may also be an 'audit effect', whereby staff provide overly-positive ratings for care outcomes as a result of a sense of pride in their work, due to a fear of negative consequences or out of organisational loyalty. While these effects – which cannot be excluded *a priori* – would limit the audit from the perspective of assessing conformity to normative standards, it does not affect the statistical analysis presented in the next chapter, which investigates the determinants of care outcomes. These relationships depend on the overall pattern of ratings rather than their absolute level, and are thus relatively robust to such broad forms of bias as those mentioned above.

The audit has arguably achieved its main goal: to analyse what factors influence hospital care at the end of life and to rate the performance of each hospital using those factors. As such, it provides essential information to assist hospitals in preparing development plans to implement the standards while also contributing to the establishment of a minimum dataset for ongoing monitoring of end-of-life care, based on the known determents of quality.

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63 The term 'pre-audit' is used in the report of the Commission on Patient Safety and Quality Assurance, to refer to "data collection with the explicit purpose of setting standards of best practice" (Commission on Patient Safety and Quality Assurance, 2008: 152). However, this audit is probably closer to its definition of clinical audit: "Clinical audit is a clinically-led quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and acting to improve care when standards are not met" (Commission on Patient Safety and Quality Assurance, 2008: 152).

64 Hospice Friendly Hospitals Programme (2010).

65 Hospice Friendly Hospitals Programme (2007, 2008).

Chapter 3

What Influences the Quality of Hospital Care at End of Life?

What Influences the Quality of Hospital Care at End of Life?

In order to improve the care provided by hospitals at the end of life, it is necessary to understand what influences that care. As we explained in Chapter Two, this can be achieved by using multilevel modelling to analyse and interpret[66] how the 'care outcomes' of those who die in hospital are influenced by the hospital's 'care inputs'. In this chapter we will report the results of that analysis.

Given the centrality of care outcomes to our analysis, we begin by describing how the five different care outcomes are connected to each other and, in that way, demonstrate the coherence and robustness of this approach (3.1). We have already observed that care outcomes are matters of judgement rather than matters of fact and, for that reason, we analyse the factors which influence nurses, doctors and relatives when they make these judgements (3.2).

This analysis is a stepping stone to the main theme of the chapter, which is to report on each care outcome and identify the care inputs which influence outcomes. We will describe the judgements of nurses, doctors and relatives in relation to each of the care outcomes, including an overall care outcome (3.3).

Our analysis will embrace a wide range of care inputs along the patient's journey from admission to discharge, and from this we can identify a small number of key statistically-significant influences on care outcomes. We will present an overview of these influences in Section 3.4, followed by a detailed description of each domain of influence, including the manner in which it affects care outcomes (3.5 to 3.14). We will then discuss the issue of whether some patients could have died at home; while this was not included in our statistical analysis of care outcomes, it is relevant to the issue of patient choice and meeting patient preferences (3.15). We will

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69 When interpreting the results of statistical models, there is an understandable tendency to move from the identification of statistically-significant effects to causal conclusions regarding the relationship between independent variables (care inputs) and dependent variables (care outcomes). It is important to stress that causal conclusions cannot be reached on exclusively statistical grounds. In the absence of experimental conditions, in order to conclude that a causal relationship exists between care inputs and care outcomes, it is necessary, at the very least, to show that the inputs preceded the outcomes, that the model is fully and correctly specified and that a plausible account of the underlying mechanism can be provided. Although all of the data used in the audit were collected at the same point in time, many of the care inputs (notably the patient's disease, route of admission, physical environment, staff readiness, hospital governance, etc.) clearly precede the patient's journey through the hospital and therefore precede the care outcomes. In these cases, to the extent that we are able to develop a plausible account of the intervening mechanisms, it is arguably acceptable to use 'causal language', whilst simultaneously stressing that causation in other cases (such as communication or team meetings) may operate in the opposite direction or even in a reciprocal fashion.

conclude the chapter by drawing attention to some of the key findings (3.16). The full results of the multilevel models are included in Annex 7 and 8 of the Technical Appendix.

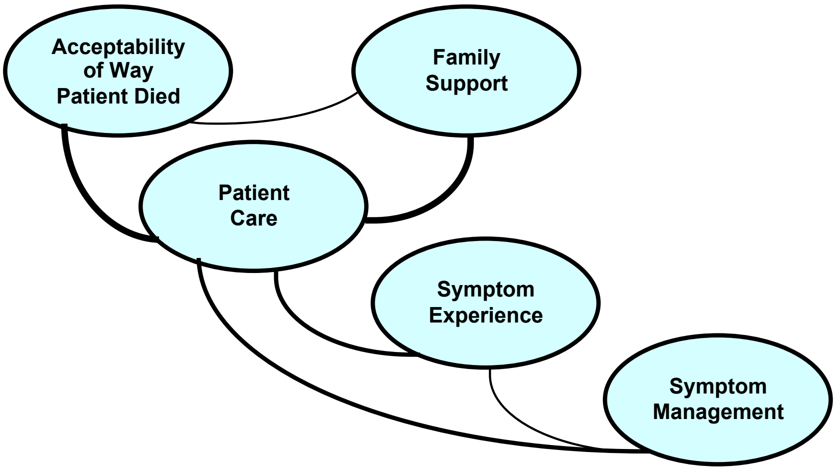
3.1 Connections Between Care Outcomes

We have seen in Chapter Two that there are five different kinds of care outcome:

1. acceptability of the way patient died
2. quality of patient care
3. patient's symptom experience
4. symptom management
5. support for family

Our hypothesis is that these five outcomes are different manifestations of the same underlying reality which we call 'outcomes of end-of-life care'. We tested this hypothesis and the results indicate that there is a statistically-significant association between each of the care outcomes, thereby suggesting that they are part of the same overall concept or 'latent variable' (so called when a variable cannot be directly observed or measured). This is illustrated in Figure 3.1 which, in turn, is based on the multilevel model results in Annex 7 and 8.

Figure 3.1: Statistically-Significant Connections Between Care Outcomes



The strength of the association between each of the care outcomes, all of which are statistically-significant, is highlighted by the width of the connecting lines. Attention is drawn in particular to the centrality of patient care which is strongly and consistently linked to all other care outcomes. This suggests that all of these care outcomes are part of the same underlying reality and, like a jigsaw, contribute to the one overall picture of end-of-life care outcomes. It also means that the concept of patient care comes closest to capturing the essence of end-of-life care, and is based on just three simple questions: How well did staff manage the patient's symptoms? How well did staff communicate with the patient? How well did staff respect the patient's wishes?

The importance of this result is that it provides a statistically robust foundation for the approach used in the audit to assess end-of-life care outcomes. That approach invited nurses, doctors, and relatives to assess end-of-life care on each of these five outcomes. This result gives us confidence that their assessment on any, and all, of the care outcomes is a reliable predictor of the overall quality of end-of-life care. In turn, we can have confidence that care inputs which have a statistically-significant influence on these care outcomes can be taken as predictors of the overall quality of care.

3.2 How Do Nurses, Doctors and Relatives Assess Care Outcomes?

We have already suggested that the measurement of outcomes, based on the judgement of nurses, doctors and relatives, might be regarded as democratic because it gives equal weight to their respective judgements. As a consequence of adopting this position, it is necessary to address two challenges. The first is whether any of these judgements correspond to the views of the patient on whose behalf they are made. The second is that the judgements of nurses, doctors and relatives about care outcomes differ frequently, which raises the issue of how to reconcile opposing views of the same subject.

The audit, as explained in Chapter Two, follows the procedure used in numerous previous studies, where the patient experience is examined through the eyes of nurses, doctors and relatives. Inevitably, these studies raise questions about the correspondence between the patient's actual experience and the patient's reported experience – sometimes referred to as 'patient-proxy agreement'.

A full meta-analysis[67] of these studies has not been undertaken, but some of the broad findings, of particular relevance to the audit, are worth noting:

1. there tends to be a 'moderate' level of agreement between the reports of patients and those of their relatives,[68] nurses and doctors.[69]
2. by comparison with patients, nurses and doctors tend to under-estimate symptoms[70] – and doctors tend to under-estimate more than nurses[71] – while relatives tend to over-estimate symptoms.[72] As a consequence of this, there is a general acknowledgement that patient symptoms such as pain may be under-diagnosed and under-treated by hospital staff.[73]
3. the reports of nurses and doctors tend to show less agreement with patients when there is severe pain,[74] while levels of agreement between patients and their relatives tend to decline when symptoms are highly subjective and not directly observable.[75]
4. nurses, doctors and other health professionals tend not use standardised procedures for assessing and recording pain,[76] and this is likely to militate against its accurate diagnosis and treatment.

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[67] Meta-analysis is a statistical technique for synthesising a number of individual quantitative studies. Results from these individual studies are entered into a database and this 'meta-data' is analysed using statistical methods similar to those used in primary data analysis. The result is an integrated review of findings that is more exact than a narrative review such as this. The appeal of meta-analysis is that, in effect, it combines all the research on one topic into one large study with many participants. The danger is that in amalgamating a large set of different studies, the construct definitions can sometimes become imprecise and the results may be difficult to interpret meaningfully. The term 'meta-analysis' was first used by Gene Glass in 1976 (Glass, 1976, 2000).

[68] Tang and McCorkle (2002); McPherson and Addington-Hall (2003); Teno (2005).

[69] Horton (2002); Hearn and Higginson (1999); Davoudi et al. (2008).

[70] Davoudi et al. (2008); Puntillo et al. (2003); Puntillo et al. (1997); Bondestam et al. (1987).

[71] Budischewski et al. (2006); Nekolaichuk et al. (1999).

[72] Tang and McCorkle (2002); McMillan and Moody (2003); Bondestam et al. (1987).

[73] Seland et al. (2005); Puntillo et al. (2003); Weiner et al. (1999); Grossman et al. (1991).

[74] Puntillo et al. (2006); Grossman et al. (1991).

[75] Tang and McCorkle (2002); McPherson and Addington-Hall (2003).

[76] Seland et al. (2005); Chanvej et al. (2004); Bruera et al. (2005).

In the audit, we found significant differences in the assessment of outcomes by nurses, doctors and relatives. As we will show in Section 3.3, these differences are consistent with the pattern found in previous studies, where doctors tend to under-estimate the negative aspects of care, relatives tend to over-estimate them, while nurses hold an intermediate position. In addition to comparing the mean scores for these three groups, we examined the extent of agreement[77] on individual cases between nurses, doctors and relatives (Table 3.1).

Table 3.1: Agreement Between Nurses, Doctors & Relatives on Care Outcomes

Care Outcomes	Nurses Doctors Relatives %	Nurses & Doctors %	Doctors & Relatives %	Nurses & Relatives %
Acceptability of death*	68	82	82	73
Quality of patient care*	19	39	39	35
Symptom experience*	NA**	NA**	NA**	67
Symptom management*	25	45	45	44
Support for family*	25	45	45	44

* Based on the subset of patients where responses are available for nurses, doctors and relatives.

** NA = Not Available because the data was collected from nurses and relatives only.

The results of this analysis show that the highest level of agreement is recorded for acceptability

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[77] In most studies, the level of agreement between evaluations of two observers is measured using Cohen's kappa. A value of 1 indicates perfect agreement, a value of -1 perfect disagreement, whilst a value of 0 indicates that agreement is no better than chance. For research purposes, there seems to be general agreement that kappa should be at least .60 or .70. However, the use of this statistic in the present context poses a number of difficulties, because it is sensitive to the number of cases. As a result, it is possible to have results where the kappa is low but the percent of cases where there is agreement is high. In view of this, we use a simpler measure of agreement – the percent of cases classified in the same way by nurses, doctors and relatives. In using this measure, we are aware that it is sensitive to the number of categories used. If, for example, we use a ten-point scale ranging from very bad to excellent, there are comparatively few identical ratings between nurses, doctors and relatives. If, however, we reduce the number of categories to four, as we have done in this study, the proportion of ratings which are in agreement will rise accordingly. Thus, the level of agreement has to be viewed in the context of the number categories and the distribution of ratings across these.

of the way the patient died; for all the other care outcomes, the level of agreement is below 50%.

In order to clarify this issue, and identify how the judgements of nurses, doctors and relatives differ, we can use the results of the multilevel models (presented in greater detail later in this chapter) to assess which care outcomes and inputs have the greatest influence on the assessments of nurses, doctors and relatives. The results show that there are substantial differences between nurses, doctors and relatives in the importance attached to care outcomes and care inputs. It should, however, be noted that the results shown are only a subset of the total influences included in the models and a more detailed analysis of the magnitude of each of these will be provided later in the chapter.

Beginning with care outcomes, doctors are more likely to assess care in terms of symptom management which is strongly associated with their assessment of patient care and this, in turn, is associated with their assessment of acceptability and family support. Nurses tend to assess on all care outcomes with the strongest associations between patient care, acceptability and family support. For relatives, symptom experience influences their assessment of patient care which, in turn, is strongly associated with their assessment of acceptability and family support.

Similarly, different patterns of assessment can also be seen with care inputs. Nurses give greater importance to all aspects of the physical environment where care is delivered, especially single rooms, compared to doctors or relatives. Nurses also give more importance to communication with patients and relatives compared to relatives or doctors. Similarly, nurses place more value on the involvement of relatives – such as staying overnight and being present at the moment of death – than relatives themselves, while this is not a consideration in the assessment of care outcomes by doctors. By contrast, doctors are influenced by whether the nurse has had training in end-of-life care and by whether there are end-of-life objectives in the hospital's service plan, unlike nurses and relatives. Overall, nurses take a much larger number of care inputs into account when assessing care outcomes compared to doctors or relatives, and relatives tend to be closer to nurses in the factors which influence their assessment of care outcomes.

These considerations highlight the different perspectives of nurses, doctors and relatives and, in some ways, offer an insight into the separate-but-connected 'universes' which inform those perspectives. Given that these perspectives are central to the care outcomes of patients at end of life - especially the assessments by nurses and doctors – the findings invite further reflection on how this may influence the practice of care, and whether the summary judgements of care outcomes in the audit are a true reflection of day-to-day practice.

By documenting these differences - and giving transparency to processes within hospitals that are normally implicit, unspoken, and difficult to pin down - it may be possible for hospital staff, through dialogue and reflection, to develop a more fluid and holistic perspective of care that is less partitioned by role and function than appears to be the case in the audit. The different patterns of assessment by nurses, doctors and relatives underlines why each is necessarily central in monitoring care. At the same time, these differences also highlight the need for a more 'objective' set of predictors of care outcomes which, when known to be present, can provide safe and scientific grounds for inferring that good care outcomes are also present. That effectively is the minimum dataset of predictors which has emerged from the audit (see Annex 12 in the Technical Appendix).

3.3 Care Outcomes

The assessment of care outcomes by nurses, doctors and relatives are summarised in Table 3.2 (full details are provided in Annex 9, 10 and 11 in the Technical Appendix). This includes an overall care outcome score based on: (i) acceptability of the way patient died (ii) quality of patient care (iii) symptom management and (iv) support for the family. Care outcomes can be measured using these four dimensions, comprising just 12 questions as indicated in the minimum dataset in Annex 12, excluding symptom experience.

The results in Table 3.2, expressed on a scale from 0 (the worst outcome) to 100 (the best outcome), indicate that the overall care outcome score is highest for doctors (80.4), followed by nurses (77.5), and relatives at a lower level (70.0). This is consistent with the pattern found in previous studies where doctors tend to under-estimate the negative aspects of care and relatives tend to over-estimate them. There is also a strong likelihood that the particularly low score of relatives for the overall acceptability of death is influenced by a confounding of the care aspects and the bereavement associated with the loss of a loved one.

Table 3.2: Rating of Care Outcomes by Nurses, Doctors & Relatives

Care Outcomes	Scale	Nurses	Doctors	Relatives
Overall care outcome	0 - 100	77.5	80.4	70.0
Acceptability of dying	0 - 100	70.9	80.7	66.5
Patient care	0 - 100	75.4	81.3	72.9
Symptom management	0 - 100	80.3	74.3	70.1
Family support	0 - 100	83.3	82.9	70.0

The scores of nurses and doctors are consistently high for all care outcomes. They are higher in community hospitals than acute hospitals with no discernible difference between teaching and other acute hospitals. For relatives, scores are generally lower – though still higher in community hospitals than acute hospitals – and the lowest score (66.5) is for the acceptability of dying. Relatives rate family support (70.1) much lower compared to nurses (83.3) and doctors (82.9). This overall pattern of scores indicates that, from the perspective of relatives, care outcomes are not as good as nurses and doctors believe and, as suggested, this may be influenced by bereavement associated with the loss of a loved one as much as the objective aspects of care.

The measurement of care outcomes is a useful end in itself – since it provides an assessment of care along these dimensions – but it is also a pre-requisite if we want to identify the set of care inputs that can positively affect end-of-life care, as we first have to define care outcomes in measurable terms. In the remainder of this section, we describe in more detail the findings for each care outcome before discussing the care inputs that have the greatest influence on care outcomes.

3.3.1 Symptom Management

The key symptoms that may occur for patients in the terminal or dying phase are pain, nausea, breathing difficulties, increased secretions, restlessness and anxiety[78]. If these symptoms are experienced all or most of the time, it seems reasonable to infer that the patient is uncomfortable and the symptoms are not being properly managed. Conversely, where symptoms are experienced none or only some of the time, it is plausible to conclude that the patient is relatively comfortable.

Using this standard, the results show that most patients are relatively comfortable during their last week of life, although nurses have a slightly less positive view than doctors in this respect. Most patients are relatively comfortable as far as pain (84-90%), nausea (94-95%), anxiety (87-89%), restlessness (83-85%) and secretions (80-83%) are concerned, but a smaller percentage are able to breathe comfortably (60-65%). Further analysis reveals that cancer patients are more likely to experience pain, those diagnosed with a respiratory disease are, understandably, more likely to have breathing difficulties, and patients diagnosed with frailty/dementia are least likely to experience anxiety possibly because this is more difficult to assess with these patients.

These results are broadly similar to the symptom management of patients on the Liverpool Care Pathway (LCP) in England, where 75% were assessed as comfortable in these symptom areas, falling to 62% in the case of bowel care.[79] If taken at face value, and with the exception of breathing difficulties, these results suggest that patients who die in Irish hospitals maintain a comparable level of comfort to those who die in English hospitals using the Liverpool Care Pathway (LCP).

Given the importance of pain in symptom management, it is noteworthy that the prevalence for pain ('all or most of the time') reported in the audit – 10% according to doctors, 15% according

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[78] Marie Curie Palliative Care Institute Liverpool (2009: 34); see also Klinkenberg, Willems, van der Wal and Deeg (2004).

[79] Marie Curie Palliative Care Institute Liverpool (2009: 40-42). This study is based on 3,893 patients in 115 English hospitals who died between October and December 2008. Note that the assessment of comfort in the LCP involved six assessments over a 24-hour period, one every four hours (Ibid: 67), and is clearly a much more in-depth assessment compared to the retrospective assessment of doctors and nurses used in this audit.

to nurses, 23% according to relatives – is lower than reported in a previous study in Ireland,[80] and lower than studies elsewhere of elderly patients in long-term care, where a common and validated assessment instrument was used and completed by nurses.[81] The broad consensus of these studies - in Europe,[82] the US,[83] and Canada[84] – is that about 50% of patients experience pain in the last week and that in roughly half of these cases, the experience of pain is a daily occurrence.

These results suggest at least three possibilities regarding Irish patients who die in acute and community hospitals: (i) their pain is correctly assessed and treated; (ii) their pain is under-

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[80] Keegan et al. (1999). This study, based on 155 relatives, found that during the last week, 64% of patients had pain (58% of it very distressing), 83% had trouble breathing (47% of it very distressing) and 50% had anxiety (61% of it very distressing) (Ibid: 19, Table 3.1).

[81] The instrument is referred to as the Minimum Data Set (MDS) and is part of the interRAI Long Term Care Facility Resident Assessment Instrument (interRAI LTCF). It is designed to assess the needs, strengths and preferences of those in long-term care settings (www.interrai.org). The MDS assessment combines a physical examination, patient history, observation, consultation with other caregivers and information abstracted from medical records. Where used, a full MDS assessment is performed within 7 days of admission to the facility, after 30 days, and quarterly thereafter. In the 1990s, the MDS instrument was obligatory for all nursing homes in the US, and several European countries have since tested and progressively introduced it into routine practice, including the Netherlands, Italy, Sweden, Norway, Finland and Denmark. Currently, the EU commission is funding an eight-country study to assess and validate the MDS for use in nursing homes in Europe, referred to as the SHELTER Study (www.shelter-elderly.eu). It includes Italy, Czech Republic, Germany, Finland, France, Israel, the Netherlands, Spain and the United Kingdom. The MDS assessment is filled out primarily by nurses who know the resident well. Pain is measured in terms of frequency (coded as no pain; less than daily pain; and daily pain in the last 7 days) and intensity (coded as no pain; mild pain; moderate pain; and severe pain). The validity and precision of the MDS for measuring pain has been established against the Visual Analogue Scale in a study involving 95 US nursing home residents (Fires et al., 2003). The definition of pain in the MDS is as follows: "Pain refers to any type of physical pain or discomfort of the body. Pain may be localized to one area, or be more generalized. It may be acute or chronic, continuous or intermittent (comes and goes), or occur at rest with movement. The pain experience is very subjective; pain is whatever the resident says it is" (Morris et al., 1995). Coding instructions are as follows: "Code for the highest level of pain present in the last seven days" (Ibid).

[82] Achterberg et al. (2010). This study, based on 10,015 residents in long-term care in Finland, Netherlands and Italy, found 49% had pain in the last week, leading the authors to conclude: "The prevalence of pain that we found is indeed alarming, especially because estimates do not show any improvement compared to earlier studies, despite increased attention to its assessment and treatment worldwide. The adoption of a common instrument such as the MDS [Minimum Data Set] allows, for the first time, to compare prevalence rates and to document clinical correlates of pain that are basically identical near the north pole as well as at the borders of Africa. A more widespread adoption of a tool such as the MDS instrument might represent a way to improve the situation, by cross-national benchmarking, and by the exchange of best practices. Implementation of verbal and non-verbal pain scales will help increase recognition of pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment" (See also Finne-Soveri et al., 2000).

[83] Sawyer et al. (2007). This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. Other studies, using different instruments, also indicate "a pain prevalence of 70-100% among cancer patients" (Lorenz et al., 2004: 2).

[84] Proctor and Hirdes (2001). This study, based on 3,195 nursing home residents in Ontario, Manitoba and Saskatchewan found that 50% had pain in the last week. See also Zyczkowska et al. (2007).

assessed and under-treated; or (iii) some combination of both depending on practices and protocols in each setting. None of these possibilities can be verified using the available data. Nevertheless, the divergence of views between relatives, nurses and doctors raises questions about the diagnosis and treatment of pain among patients who die in Irish hospitals.

In order to improve pain and symptom management generally, the audit results highlight four areas that are associated in a statistically-significant way with better outcomes: the route of admission (better when it is planned); the physical environment (better in a single room); staff readiness (better when staff feel prepared for the death of a patient and have experience and training); and end-of-life objectives in the hospital's service plan. Naturally, this is not a complete recipe for improving symptom management but, from the audit data, we know that these are the factors which contribute to better symptom management.

3.3.2 Symptom Experience

Symptom experience refers to the quality of life of a patient during their last week and is simultaneously a measure of the patient's experience of living and dying. One of the established instruments for measuring this – which was employed in the audit – is the Quality of Dying and Death Instrument (QODD).[85] This scale involved asking nurses and relatives to rate, on a 1-10 scale, how symptoms were experienced by the patient during the last week of life.

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[85] Developed by, and available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis, 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

The total QODD score, based on nurses assessment is 72.4 and falls within the range set by two US studies which yielded total QODD scores of 66.9 and 73.2.[86] This suggests that the quality of dying in Irish hospitals is not very different from that observed in US hospitals. The audit results indicate that the patient's symptom experience is influenced in a statistically-significant way by having a single room; by admissions which are planned rather than emergency; by staff readiness (notably staff with years of experience and feeling prepared for the death of a patient); and communication with the patient.

3.3.3 Patient Care

This care outcome was measured using the Family Evaluation of Hospice Care (FEHC) scale.[87] The results, when expressed using the original 10-point scale, are: 7.5 (according to nurses), 8.1 (according to doctors) and 7.3 (according to relatives). The main comparative data – albeit pertaining to hospices rather than hospitals – is provided by the US National Hospice and Palliative Care Organisation, which uses the FEHC to evaluate hospice performance. This indicates that the quality of care, as rated by relatives, averages 9.4 out of 10.[88] This does not

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[86] The main QODD-based studies, and their scores, are as follows:

Study	Sample	Completed by Relatives		Completed by Nurses		Completed by Doctors	
		M	SD	M	SD	M	SD
US Deaths in hospital and home (Curtis, et al, 2002)	252	67.4	15.1	-	-	-	-
US Deaths in ICU (Hodde, et al, 2004)	149	-	-	73.1	21.4	-	-
US Deaths in ICU (Levy, et al, 2005)	38	77.7	9.3	66.9	16.3	67.8* 82.5**	22.5* 17.3**
US Deaths in ICU (Mularski, et al, 2004)	38	60.0	14.0	-	-	-	-

Notes: *resident physicians or registrars. *attending physicians or primary doctor.

[87] Developed by, and available from, the National Hospice and Palliative Care Organisation (NHPCO), based in Virginia in the US at: http://www.nhpco.org/i4a/pages/Index.cfm?pageid=4397. The Family Evaluation of Hospice Care (FEHC) was developed by Joan Teno and Stephen Connor at Brown University in the US (Connor, Teno, Spence and Smith, 2005) based on a previously validated scale, the Toolkit After-Death Bereaved Family Member Interview (Teno, Clarridge, Casey, Edgman-Levitan and Fowler, 2001).

[88] Connor, Teno, Spence and Smith (2005: Table 3). This was based on a survey of 29,292 relatives whose family members died in 352 hospices in the US during 2004. Another much larger sample using the full Family Evaluation of Hospice Care (based on 116,974 relatives whose family members died in 819 hospices throughout the US) found that a high level of satisfaction with the quality of care was associated with four key processes of care: (i) being regularly

necessarily imply that the quality of care in Irish hospitals is below that offered by hospices since acute hospitals deal with a much wider spectrum of deaths from sudden to expected; this factor would need to be taken into account in any valid comparison.[89]

The audit results identify four areas that are consistently associated in a statistically-significant way with better patient care outcomes: when multidisciplinary team meetings to manage end-of-life care are held; when patients die from cancer; when the physical environment is pleasant and facilitates dignified personal care (especially in a single room); and when there is good communication (sensitive, honest, reassuring, and open to hearing the patient's concerns). These findings provide statistically-reliable guidance on how to improve patient care but, understandably, they do not exhaust all the possibilities because they are based only on the data collected.

3.3.4 Acceptability of the Way the Patient Died

This was measured using a question borrowed from a study of dying in French hospitals[90] which asked if the way the patient died was acceptable. The results reveal that the proportion of 'unacceptable' deaths in the audit was considerably higher in the assessment of relatives (21%) than nurses (13%) or doctors (3%). However, this is much lower than in French hospitals, where 58% of nurses found the deaths of their patients unacceptable to them or their family/friends.[91]

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informed by the hospice team about their loved one's condition (ii) the hospice team providing the right amount of emotional support to them (iii) the hospice team providing them with accurate information about the patient's medical treatment and (iv) identifying one nurse as being in charge of their loved one's care (Rhodes, Mitchell, Miller, Connor and Teno, 2008).

[89] One study, based on a sample of 40 respondents who had the experience of a relative dying of cancer in both a hospital and a hospice in England found that: "In comparison to hospital care, from the perspective of bereaved relatives, hospice in-patient care provided better pain control, better communication with patients and families, and better medical, nursing and personal care, which treated the patient with more dignity" (Addington-Hall and O'Callaghan, 2009: 190).

[90] Ferrand, Jabre, Vincent-Genod et al. (2008).

[91] Ferrand, Jabre, Vincent-Genod et al. (2008: Table 4). This study was based on 3,793 patients who died in 200 French hospitals in 2004. The 'yes/no' response format in the French study was converted to a 10-point scale to give comparability with the audit results.

Acceptability is a global assessment of the way the patient died and, as already indicated, it is strongly associated in a statistically-significant way with the overall quality of patient care, itself influenced by symptom management and experience. However it is a more distilled assessment than these. The audit results highlight four areas that have a statistically-significant association with more acceptable ways to die: the route of admission (more acceptable if planned rather than emergency); the physical environment (more acceptable if the patient dies in a single room); supporting relatives (by facilitating them to stay overnight and be present at the moment of death); and staff readiness (more acceptable where staff feel prepared for the death of a patient and have years of experience).

3.3.5 Family Support

Family support, like patient care, was also measured using a sub-scale from the Family Evaluation of Hospice Care (FEHC). The results, when expressed using the original 10-point scale, are: 8.3 (according to nurses), 8.3 (according to doctors, and 7.0 (according to relatives). As above, this is lower when compared to the experiences of relatives in US hospices (9.3) and is not unexpected given the wider spectrum of deaths that typically occur in acute hospitals.

The audit results reveal that family support has a statistically-significant association with planned admissions; multidisciplinary team meetings; good communication with relatives; and staff experience.

3.4 Overview of How Care Inputs Influence Care Outcomes

The results of our multilevel modelling reveal that eight sets of care inputs have a statistically-significant influence on care outcomes (see Annex 7 and 8). These are:

1. Disease and cause of death
2. Route of admission
3. Physical environment

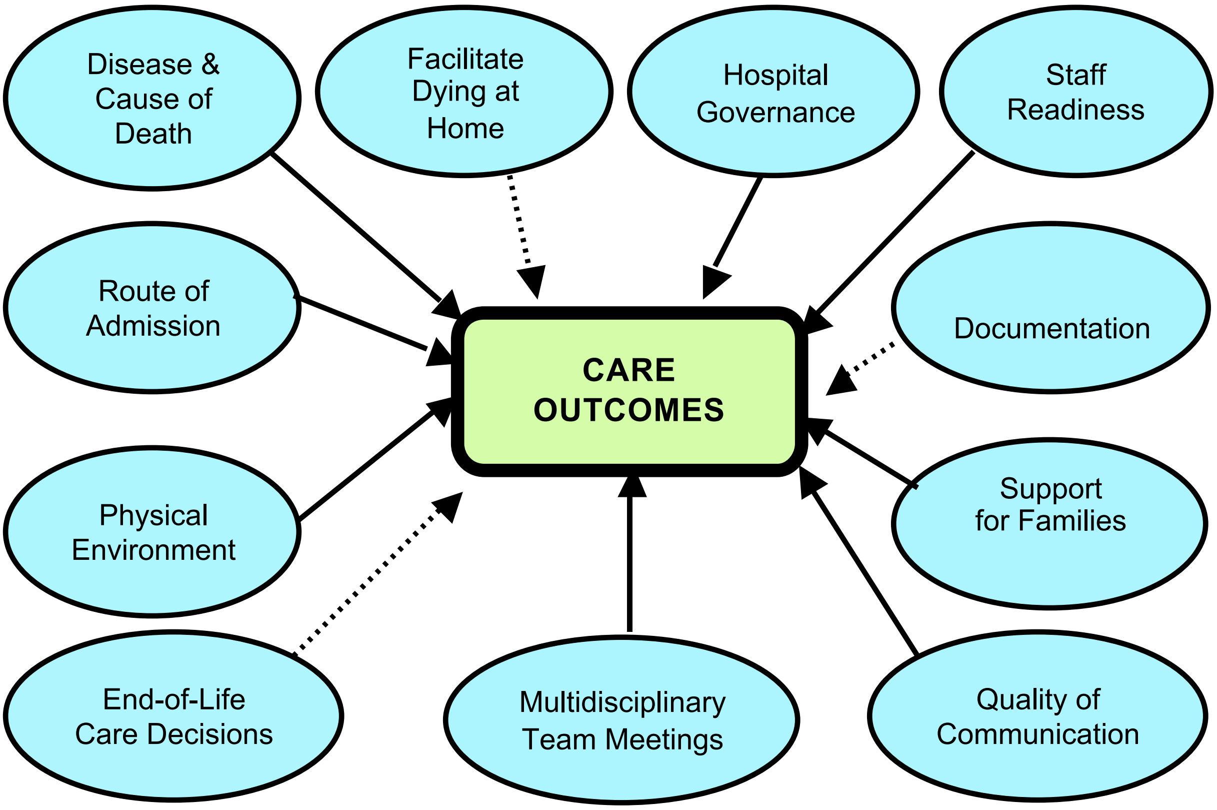
4. Multidisciplinary team working
5. Communication
6. Support for families
7. Staff readiness
8. Hospital governance

These are graphically illustrated in Figure 3.2 by the solid connecting lines between care inputs and care outcomes. In addition, we include two sets of care inputs which are known to be important for end-of-life care but which, in this analysis, showed no statistically-significant influence on care outcomes, once we control for the other factors included in the models. These, represented by the broken connecting lines, are:

9. end-of-life care decisions
10. documentation

The reasons why these two inputs appear not to have any statistically-significant influence on care outcomes are explored later in the chapter. We now discuss each influence, beginning with disease and cause of death.

Figure 3.2: Influences on Care Outcomes



3.5 Disease and Cause of Death

In Ireland, the three main causes of death are circulatory system diseases (35%), cancer (28%) and respiratory system diseases (13%).[92] These are also the three main causes of death among patients in the audit: circulatory[93] (31%), cancer (23%) and respiratory (19%). Our analysis revealed that disease has a statistically-significant influence on care outcomes at the end of life. Specifically, cancer is a positive predictor of care outcomes. Though not a disease, sudden deaths are a negative indicator of care outcomes.

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[92] Vital Statistics (2009: 49).

[93] Our definition of circulatory diseases includes heart, strokes and circulatory diseases, kidney diseases, liver diseases.

Significantly, the patient's personal characteristics (age, sex, marital status, religion, ethnicity, etc.) do not influence the quality of end-of-life care, although patients with private health insurance are perceived by their relatives to have a more positive symptom experience. In the remainder of this section we will discuss these influences on care outcomes. Each individual effect reported should be understood as being statistically-significant and subject to a ceteris paribus clause (all else being equal – i.e. controlling for the other variables included in the model).

3.5.1 Cancer Deaths

Patient care is best, in the assessment of doctors, for cancer patients (3.45% better for cancer patients compared to patients with circulatory diseases). The worst care, in the assessment of nurses, is for patients with dementia/frailty (5% worse compared to patients with circulatory diseases). Patients with respiratory diseases also receive lower scores from nurses in relation to patient care (3.16% lower than patients with circulatory diseases). In other words, the hierarchy of care, from the best to the worst descends from cancer to circulatory diseases, respiratory diseases and dementia/frailty.

The higher scores of cancer patients on care outcomes are attributable to the facts that, compared to other patients, they are statistically more likely to be planned admissions (though, like most patients, most are still unplanned), to die in a single room, to be the object of more team meetings and better communication, to have relatives who stay overnight and are present at the moment of death. All of these factors are statistically-significant influences on care outcomes. This contrasts with the end-of-life care received by dementia patients, who are more likely to die in a multi-occupancy room, where there is less and poorer communication and where relatives are less likely to be present at the moment of death.

It is clear from this that if all patients were offered the same standard of care that is currently available to cancer patients, then the quality of end-of-life care in hospitals could be improved significantly. This, in turn, suggests that those involved in cancer care may be in a position to offer leadership within hospitals to improve the overall standard of patient care at the end of life.

3.5.2 Sudden Deaths

The audit collected data according to whether the patient's death was expected or sudden, even though it is recognised that these are fluid categories since a death may be expected but its timing sudden, or sudden but is seen in retrospect as expected. Despite this, the distinction has substantial and statistically-significant consequences since sudden deaths are the strongest and most negative predictor of care outcomes. Nearly a quarter of all deaths in the audit (24%) are sudden or unexpected. The unexpected nature of these deaths has a negative impact on care outcomes because they are associated with worse symptom experiences according to both nurses (-4.46%) and relatives (-6.94%). As might be expected, sudden deaths are a particular shock for relatives, who give a much more negative appraisal of patient care when compared to other kinds of deaths (-14.57%), but it is again reasonable to suspect that this is at least partially coloured by a confounding of the evaluation of patient care and the unexpected loss of a loved one.

Further statistical analysis of sudden deaths reveals that these are much more likely to occur in A&E and ICU, and are negatively associated with all of the statistically-significant predictors of care outcomes. In addition, we know that sudden deaths are three times more likely to result in a post-mortem compared to other deaths; if the sudden death occurs in A&E, it is ten times more likely to result in a post-mortem compared to other deaths. These findings draw attention to the importance of supporting relatives, particularly when the sense of loss at death is compounded by the shock of its suddenness, and by the fact that funeral arrangements may have to be delayed as a result of the post-mortem.

3.5.3 Patient Characteristics

We collected a substantial amount of information on the personal characteristics of patients, including their age, gender, marital status, living alone or with a carer, nationality, religion and private health insurance. Private health insurance – itself an indicator of affluence relative to those who have a Medical Card only[94] – is the only 'personal' variable to have any statistically-

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[94] The Medical Card is an entitlement to receive certain health services free of charge, with eligibility predominantly

significant influence on care outcomes.

Specifically, patients with private health insurance are assessed (by relatives) as having a much more positive symptom experience (+8.37%) compared to patients without private health insurance. For nurses and doctors, private health insurance has no independent influence on the assessment of care outcomes although, as we will see later, it does seem to improve the quality of communication with relatives.

If we were to confine our attention to doctors' and nurses' responses, we would conclude that patient characteristics – with the exception of the type of disease – do not influence care outcomes. While this appears to indicate a substantial equality of care for patients, it is nevertheless striking that symptom experience, as reported by relatives, is much better for patients who have private health insurance.

This is an important issue, requiring further research, as this kind of distinction – which is linked with the structure of the health care system in Ireland – has the potential to create obstacles to the achievement of equality in end-of-life care.

3.6 Route of Admission

The audit measured the route of admission through two separate questions: one measured whether the admission was through A&E, outpatients, day services, or medical admissions, whilst the other registered whether the admission was emergency or elective. The results show that almost all A&E admissions are emergency admissions, so that these two questions actually measure the same thing: route of admission. Under this heading we also discuss the significance for care outcomes of patients who lived in a nursing home prior to admission.

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determined by income or age. In 2001, the Medical Card was made available to all persons aged 70 years and over, irrespective of their financial means. In 2009, this was restricted to those persons aged 70 years and over whose self-assessed income met the eligibility criteria. Given that the mean age of patients in the audit is 75 years (ranging from 18 to 100), it is likely that most patients have a Medical Card.

3.6.1 Admission through A&E

The majority of acute hospital patients in the audit were admitted through A&E (84%). This is considerably higher than the route of admission to a cross-section of UK hospitals (57%) in which patients died within 96 hours of admission.[95] All admissions to community hospitals are planned because they do not have an A&E department.

The results of our analysis reveal that emergency admissions through A&E – irrespective of the ward where they died in hospital - have a statistically-significant and negative impact on care outcomes, as assessed by doctors, nurses and relatives. The biggest impact is on the overall acceptability of death and results in patients admitted through A&E having a less acceptable death, when compared to other patients (by 5.63% according to nurses and 4.13% according to doctors). In addition, these patients have more negative experience of symptoms (-5.11% according to nurses) and poorer symptom management (-4.22% according to doctors). For relatives, emergency admissions are associated with a reduced sense of family support (-3.64% according to relatives).

Further analysis of the factors associated with emergency admissions suggests that three sets of influences may be at work. First, emergency admissions are understandably associated with trauma or accident – involving about 7% of deaths in acute hospitals in the audit – and with a number of negative predictors of care outcomes such as the following: (a) the ward area is poorer in terms of privacy and dignity; (b) team meetings are somewhat less likely; (c) staff communication with the patient and relatives is slightly poorer; (d) there is more frequently a request for a post-mortem. These factors influence the more negative ratings of nurses and doctors.

Second, community hospitals do not have admissions through A&E and appear to rate care outcomes consistently more highly than acute hospitals. This may have the effect of strengthening the negative association between A&E and care outcomes.

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[95] This study was carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), based on a sample of 3,153 deaths which occurred between October 2006 and March 2007. See National Confidential Enquiry into Patient Outcome and Death (2009: Table 3.2).

Third, cancer patients are less likely to be admitted through A&E, and therefore more likely to be planned admissions although the majority are still emergency admissions. Given that these patients also have consistently better care outcomes than other patients, this enhances the negative influence of A&E as a route of admission on outcomes. It is true that the disease trajectory of cancer patients is more predictable than other patients[96] but there would also appear to be a more planned approach to admissions in the cancer specialty, compared to others. This suggests that the practice within different specialties of relying on emergency rather than planned admissions may be a contributory factor in reducing care outcomes.

Overall, these results point to the statistically-significant impact that route of admission has on care outcomes. It is also significant that these impacts are mainly perceived by nurses and doctors (rather than relatives), as it highlights the clinical consequences and difficulties that are associated with A&E admissions. This suggests that improvements could be made in care outcomes for patients who die in acute hospitals by seeking to reduce the need for emergency admissions.

Naturally, A&E will remain the route of admission for accident and trauma cases and, for those who die in A&E or shortly thereafter, these deaths may be judged as 'unacceptable' – if unavoidable – by nurses, doctors and relatives. For others, however, the route of admission through A&E – particularly where the patient's condition is already well-known to the hospital – is a burden that may be avoidable and a more planned and hospitable route of admission could significantly improve care outcomes at the end of life. The extent to which this is possible will depend on the characteristics of each case; understandably, unplanned admissions may be inevitable if the patient suffers a sudden deterioration or an acute onset of infection. However a more planned approach to admissions also depends on improving the coordination of services between hospital and community, and having systems in

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[96] It is usual to distinguish three main end-of-life trajectories, each associated with different types of illness, functional decline and length of stay in hospital (Lunney, Lynn and Hogan, 2002; see also Department of Health, 2008: 46; Hospice Friendly Hospitals Programme, 2009). The first trajectory is usually associated with cancer and involves a relatively predictable decline over a shorter period. The second trajectory is usually associated with circulatory, organ and respiratory diseases with a more intermittent pattern of functional decline. The third trajectory is usually associated with frailty and dementia and a longer-term pattern of functional decline.

place – such as protocols and good lines of communication for fast-tracking patients - which enable a more planned and patient-centred response when emergencies arise.

3.6.2 Admission from Nursing Homes

Most patients who die in an acute hospital were living at home prior to their admission. However, the audit revealed that more than half (56%) of all admissions to community hospitals are from a nursing home. These are mainly elderly patients with dementia. Our analysis indicates that being transferred from a nursing home to a hospital had a benign influence on these patients. This is because their symptom management is significantly better than for other patients (by 6% according to doctors), while the acceptability of their death is much better than for other patents (by 10% according to relatives). This finding draws attention to the current limitations of nursing homes in meeting the end-of-life needs of older patients with dementia, and invites further analysis into the specific reasons why nursing homes are transferring residents at the end of life.

3.7 Physical Environment

Our analysis reveals that three aspects of the physical environment have a statistically-significant influence on care outcomes at the end of life. The first is whether the patient died in a single or multi-occupancy room, the second relates to the physical characteristics of the room or ward where the patient spent most of the last week of his or her life, and the third is the standard of the mortuary facility. We will describe each of these in turn.

3.7.1 Single Rooms

On average, about 15% of beds in acute and community hospitals are in single rooms,[97] which is below all standards for this type of hospital accommodation.[98] Despite this, a third of patients

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[97] This is similar to the proportion of 'side-rooms' in English hospitals which use the Liverpool Care Pathway (15%). See Marie Curie Palliative Care Institute Liverpool (2009: 23).

[98] In the US, 100% single rooms have now been adopted as the standard for all new hospital accommodation (Facility Guidelines Institute and the AIA Academy of Architecture for Health, 2006). In the UK, a minimum of 50% of single

(33%) spent most of their last week of life in a single room, and more than four in ten (44%) died in a single room.[99] This suggests that hospital staff try to allocate single rooms to patients in order to facilitate a more dignified death, itself indicating staff awareness about the importance of single rooms at the end of life. Nevertheless, given that nearly half of all patients who died in a shared room would have preferred a single room (45%), a significant degree of unmet need clearly remains.

Our analysis reveals that deaths in single rooms are associated in a statistically-significant way with substantially better care outcomes, when compared to multi-occupancy rooms. The acceptability of a patient's death is much higher in single rooms (by 6% according to nurses and 5% according to relatives). Symptom management is better in single rooms (by 4% according to doctors) and symptom experience is also much better (by 7% according to relatives).

Further statistical analysis throws light on which patients are most likely to die in a single room. Patients with a hospital infection are the most likely, by a factor of 10, to die in a single room. Cancer patients are also significantly more likely to die in a single room compared to patients in other diagnostic categories. For example, patients in oncology wards are nearly four times more likely to die in a single room, while cancer patients elsewhere in the hospital are nearly twice as likely to die in a single room. Patients with private health insurance are also more likely to die in a single room, although this factor is less influential than whether the patient has cancer or a hospital infection. The easier access to single rooms of patients with private health insurance may help to explain why they have higher scores than other patients in relation to symptom experience (according to relatives' assessments).

It is clear from this that single rooms have the capacity to substantially improve care outcomes

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rooms is now the standard (cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009: 278). In Ireland, a draft of the infection control building guidelines recommends that 100% of in-patient accommodation in newly built acute care hospitals should be single-patient rooms (cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009: 278). Significantly, the HIQA standard for residential care facilities for older people in Ireland requires that there must be 80% single rooms for "the newly built residential care setting, new extension or first time registration" (Health Information and Quality Authority, 2008: 45).

[99] This is lower than the 70% of patients who die in single rooms in hospitals in Northern Ireland. This estimate is taken from the audit of dying, death and bereavement in Northern Ireland. Most deaths were in the three areas of general medicine (40%), elderly care (20%) and general surgery (10%), where the proportion "cared for in a single room on more than 75% of occasions" is 65%, 75% and 80% respectively (Northern Ireland Health and Social Care Bereavement Network, 2009: 6, 28). From this it is a reasonable inference that around 70% of deaths are in single rooms.

at the end of life. Given constraints on space, this is a challenge for hospitals, but the measurable benefits of single rooms – involving improvements in the region of 4-7% – provide a clear incentive to find ways of overcoming these difficulties. Our analysis in Chapter Four suggests that, with the same proportion of single rooms, some hospitals are considerably more resourceful than others in facilitating patients to die in a single room.

3.7.2 Physical Characteristics of Room/Ward

The physical environment of the room and ward where the patient spent most of the last week of life was measured by asking nurses to rate it in terms of privacy (such as allowing conversations with family and staff), dignity (such as facilitating personal care with dignity; easy access to toilet, shower or bath; being able to choose company or be alone), environment (such as experiencing nature, daylight and quiet) and control (such as altering the temperature, light or air in the room or being able to turn on/off the TV). The results reveal, as might have been expected, that the poorest physical environments in hospital are A&E and ICU wards, with oncology wards receiving the highest ratings.

Our analysis reveals that the dignity aspect of a room or ward has a statistically-significant influence on care outcomes. However, it is interesting that this influence is only a significant predictor of nurses' assessments of care, not those of doctors or relatives, possibly because dignity affects the personal care of patients, which is undertaken by nurses and health care assistants rather than doctors or relatives. In the assessment of nurses, a percentage point increase in the dignity of a ward improves symptom management by 0.09%, patient care by 0.1%, and the acceptability of the patient's death by 0.14%.

The environment of the room or ward also has a significant influence on care outcomes. A percentage point improvement in the environment increases patient care by 0.80% for nurses and by 0.12% for doctors.

These findings are in line with other research on the physical environment of Irish hospitals,[100] as well as mirroring international research evidence which highlights how the physical characteristics of wards and rooms – and the hospital generally – impact on the outcomes of care.[101] Overall, our findings provide compelling evidence that certain aspects of the physical environment of Irish hospitals have a negative impact on care outcomes for patients who die there. Specifically, wards which lack dignity or which have poor environmental quality (as defined above) are associated with poorer outcomes.

Our measures of the physical environment are quite straightforward and, for that reason, the implications of these findings are also quite straightforward. In simple terms, the findings provide an assurance that facilitating patients to die in a single room and improving the dignity and environment of wards will have a statistically-significant and substantial impact across almost all care outcomes for patients at the end of life.

3.7.3 Mortuary Facilities

All acute, and most community, hospitals in the audit have a mortuary. The Design and Dignity Guidelines[102] identifies 21 facilities that should be available in a mortuary. Using this standard, we found teaching hospitals have more of the required facilities (75%) compared to other

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[100] A study was carried out on the physical environment of 20 Irish hospitals – all included in this audit – and led the authors to observe that: "Throughout the review, a general finding was that the lack of single rooms and use of multiple bed bays means that patients and relatives are not afforded the dignity that they deserve. Although generally the wards allowed for a degree of gender separation, this was not always the case with there being several examples of mixed gender wards and bed bays. It is recognised best practice to separate male and female patients into different wards, or areas. This is clearly to provide each with dignity, privacy and respect. Where this is not possible, it completely breaches privacy and dignity issues, which may become heightened where a person is nearing the end of life and may require more levels of personal support and intervention. The ward layouts did not tend to allow for any significant level of privacy for patients or visitors from an acoustic or visual perspective given that the main bed complement of the wards is based on multiple bed bays. This was particularly apparent in the older estate facilities where there were poor ward layouts and not enough space between each bed on the ward. ... Noise levels where often high in many of the wards visited. ... In general, there was a lack of quiet spaces, interview or relatives' rooms across all sites, preventing opportunities for confidential discussion and/or quiet reflection" (Tribal, 2007:13).

[101] This was highlighted in a recent review of research on the use of evidence-based design in health care settings: "Compared to 2004, the body of evidence has grown rapidly and substantially ... It is now widely recognised that well designed physical settings play an important role in making hospitals less risky and stressful, promoting more healing for patients, and providing better places for staff to work" (Ulrich, Zimring, Zhu et al., 2008; see also Keller and Kronick, 2008; Sadler, Keller and Rostenberg, 2009). The practical implications of this research for improving the design of existing and new hospital facilities are spelt out in Sadler, Keller and Rostenberg (2009).

[102] Hospice Friendly Hospitals Programme (2008: 32-34).

acute (38%) or community hospitals (29%).[103] Our analysis revealed that the quality of mortuary facilities, in the assessment of doctors, is inversely related to symptom management (-0.09%) and acceptability of the patient's death (-0.08%). This finding is counter-intuitive since one would expect the quality of mortuary facilities to have a direct rather than an inverse relationship to care outcomes. A possible explanation of the result is that, since the quality of mortuary facilities mirrors the different categories of hospital (teaching, other acute, and community), and since the larger teaching hospitals also have a larger and more complex spectrum deaths, this may be reflected in lower scores for symptom management for certain of those hospitals.

3.8 End-of-Life Care

End-of-life or palliative care aims to reduce and, if possible, eliminate suffering and improve the quality of living and dying of patients.[104] Where patients have been diagnosed as being beyond cure and entering the dying phase, hospital staff are expected to re-orient their care towards comfort and the control of symptoms. That is the clear guidance of the Irish Medical Council to its doctors: "Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain treatment which is futile or disproportionately burdensome".[105]

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[103] McKeown, Haase and Twomey, 2010a. These findings are broadly consistent with an independent architectural assessment of 20 hospitals (15 acute and 5 community) carried out in 2007 (Tribal, 2007:20-21). That assessment found mortuary facilities were deficient in terms of viewing rooms, waiting rooms, interview rooms, and rooms for preparing and storing bodies. At the same time, it also found that 'every effort was made' to accommodate different faiths and cultures. Its overall conclusion was that 'there were several examples where the mortuaries and post-mortem rooms were clearly no longer fit for function, for either viewing, body storage or for post-mortems. Conversely, there were one or two examples of some very good to excellent facilities'. A more recent review of mortuaries in Ireland concluded: 'The current operation of many mortuary services in the State is excellent; yet some others are running less optimally, with inexperienced or unqualified staff with no professional education programme in place; an excessive workload; some policy and SOPs [standard operating procedures] not being in place or up to date. … . Some mortuaries that have excellent facilities… . Others have good facilities. … A number of mortuaries are substandard. … Generally viewing facilities for relatives were not to a high standard and with small amendments to environment could be much improved. … Mortuaries and post-mortem examination facilities are of a variable standard throughout Ireland' (Willis, 2009:114)..

[104] Palliative care has been described as an "interdisciplinary speciality that focuses on improving quality of life for patients with advanced illness and for their families through pain and symptom management, communication and support for medical decisions concordant with goals of care, and assurance of safe transitions between care settings" (Morrison et al., 2008).

[105] Irish Medical Council, 2004:Paragraph 23.1. The Law Reform Commission considered this ethical guidance in the

What Influences the Quality of Hospital Care at End of Life?

The World Health Organisation has stated that "palliative care has the following characteristics: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications".[106]

In the audit we measured end-of-life care in terms of three sets of practices: (i) diagnosis of dying (ii) making decisions about appropriate treatment and care and (iii) using specialist palliative care. Our analysis found that these three aspects of end-of-life care had no statistically-significant influence on care outcomes. In the remainder of this section, we report on these findings in more detail.

3.8.1 Diagnosis of Dying

It is recognised by experts that assessing when the end-of-life journey begins, and specifically when dying begins, can be difficult and uncertain, except for specific conditions such as cancer, where relatively accurate prognosis is possible.[107] Indeed, it might even be questioned whether the concept of 'diagnosing dying' - building as it does on the analogy of diagnosing an illness – is helpful since it often involves a process of many diagnoses. For this and other reasons, the diagnosis of dying has been described as 'a clinical challenge'.[108]

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context of its report on advance care directives and made the following comment: "The Commission considers that this guidance deals correctly with a difficult ethical matter in a manner that is also consistent with existing criminal law on euthanasia" (Law Reform Commission, 2009: Paragraph 1.78, page 34).

[106] Available at http://www.who.int/cancer/palliative/en/. Accessed 18 March 2009.

[107] Lynn, Schall, Milne, Nolan and Kabcenell (2000); Lynn, Schuster and Kabcenell (2000).

[108] Marie Curie Palliative Care Institute Liverpool (2007: 10).

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In the UK strategy for end-of-life, one of the top ten 'quality markers' is to "institute effective mechanisms to identify those who are approaching the end of life".[109] In the US, the 'no surprise' question has been recommended for doctors and nurses as an aid to diagnosis: "Is this person sick enough that it would be no surprise if he or she died within the coming year (or the coming few months)?"[110] Commenting on this approach to diagnosis, its author observed: "This 'no surprise' question has worked well for targeting clinical improvement activities, though it has not been tested in regulatory, financing, or more formal service delivery innovations. Some patients identified in this way will die quickly and some will live a long time, but all are sick enough that they would benefit from comprehensive services tailored to advanced illness and the last part of life".[111]

In the audit we measured diagnosis of dying by asking nurses and doctors, after the patient had died: "Had the medical team diagnosed that this patient was dying?" The results indicate that a diagnosis of dying was made by the medical team in the vast majority of cases (86%), and this occurred 5-6 days before the patient's death. This rate of diagnosing death is high compared to a French study, which found that 50% of deaths were anticipated by nurses "for at least 3 days".[112] It is also high compared to a UK study where, within the sampling period, 50% of deaths were expected[113]. Similarly, the duration between diagnosis and death would appear to be longer in Ireland compared to England, where it averages 33 hours[114]. From this it would appear that deaths in Irish hospitals are anticipated more frequently than in French hospitals and earlier

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109 Department of Health (2009: 11). Similarly, the Australian palliative care standards notes that: "Health care providers need to be experienced and skilled in recognising when the terminal phase of the life limiting illness has begun. This is important in order to facilitate appropriate care for the patient, their caregiver/s and family" (Palliative Care Australia, 2008: 30).

110 Lynn (2004: 43).

111 Lynn (2004: 44).

112 Ferrand, Jabre, Vincent-Genod et al. (2008: 870, Table 2). This study was based on 3,793 patients who died in 200 French hospitals in 2004.

113 National Confidential Enquiry into Patient Outcome and Death (2009: Table 8.1). This study was based on a sample of 3,153 deaths which occurred between October 2006 and March 2007.

114 This is inferred from the audit of patients on the Liverpool Care Pathway (LCP), based on 3,893 patients in 155 hospitals who died between October and December 2008. Patients are placed on the LCP where there is a diagnosis of dying and the average length of time on LCP was 33 hours (Marie Curie Palliative Care Institute Liverpool (2009: 21; see also 2007: 5). The audit estimates that 21% of all deaths in those hospitals were on the LCP (Marie Curie Palliative Care Institute Liverpool, 2009: 24).

than in English hospitals, although the retrospective collection of this data may have influenced the results.

Our analysis suggests that the diagnosis of dying, or the duration between diagnosis and death, had no statistically-significant impact on care outcomes. This means that care outcomes were no different in cases where a diagnosis was made compared to cases where no diagnosis was made. It is possible that some of these deaths were 'diagnosed' retrospectively rather than prospectively. As a consequence, there could be no real impact on the care provided or on the subsequent outcomes. Another possible explanation is that there is substantial variation in the way hospitals, wards and individual staff understand the concept of diagnosing dying, and how to respond once a diagnosis is made, with the result that our data is inherently ambiguous. These explanations are simply hypotheses, which may operate in tandem with other mechanisms.

We undertook further analysis of the factors associated with a diagnosis of dying and found that this is more likely to occur when the patient dies in a single room, when team meetings about the patient are held, when specialist palliative care is provided, and when there is high quality communication with relatives (who are also allowed to stay overnight and be present at the moment of death). This suggests that the diagnosis of dying is part of a complex of other decisions about end of life and draws attention to the overall effectiveness of decision-making in producing care outcomes.

3.8.2 Decisions to Review Care

The need to review care and make appropriate decisions arises when a patient is no longer responding to active treatment, has a life-limiting illness which is deteriorating rapidly and where the patient is presenting signs of dying. In these circumstances, a decision may be required to switch from curative to palliative care. With this in mind, the audit asked nurses and doctors whether a range of decisions were made during the last week of life.

Doctors reported that the following decisions were made in about three quarters of cases: to review whether the aims of care were mainly curative or palliative, to optimise comfort, to stop non-essential medication and to talk about resuscitation. About three quarters of nurses also reported that decisions were taken to optimise comfort, talk about resuscitation and assess skin integrity. However, both nurses and doctors report that no decisions were taken in the majority of cases to stop antibiotics or invasive monitoring or to withhold treatment. In general, decisions about end-of-life care were more likely to be taken in oncology wards, involving cancer patients, where death is expected and, perhaps as a consequence of this, for patients in single rooms.

The extent to which end-of-life decisions are taken about dying patients in Irish hospitals is significantly lower that that observed in English hospitals,[115] especially those on the Liverpool Care Pathway (LCP) where, in the vast majority of cases, decisions were made to discontinue blood tests (91%), antibiotics (89%), IV fluids/medications (83%), not resuscitate (94%), and avoid inappropriate nursing interventions such as vital signs and blood sugar monitoring (75%).[116] None of the acute hospitals in the audit use the LCP, although it is used by some hospitals which are not included in the audit.[117] Similarly, although decisions to withhold or withdraw life support are taken more frequently in intensive care (53%) compared to other wards (47%), they are much less frequent compared to current practice in 17 European countries.[118]

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[115] In a study of 3,153 deaths across acute hospitals in the UK, discussions about treatment withdrawal were held with patients or relatives in 83% of cases (National Confidential Enquiry into Patient Outcome and Death, 2009: 89).

[116] This audit was based on 3,893 patients in 115 hospitals who died between October and December 2008 (Marie Curie Palliative Care Institute Liverpool, 2009: 36-37).

[117] The Liverpool Care Pathway (LCP) is a multi-professional framework of care which is used during the dying phase and is based on standards of care found in the hospice environment. The goals of care are to ensure the physical comfort of the patient, psychosocial insight, spiritual care for patients and carers, as well as communication including information giving and receiving. This framework is one of three – the other two are Gold Standards Framework and Preferred Priorities for Care – that have been recommended by the UK Department of Health and by the UK National Institute for Health and Clinical Excellence (NICE). In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), based on a sample of 3,153 deaths between October 2006 and March 2007, one third of those diagnosed as dying (33%, 1,505) were placed on an end-of-life care pathway. For those not on a pathway, the "overall quality of care was less good than those who had such a pathway in place" (National Confidential Enquiry into Patient Outcome and Death, 2009: 91). However, this study also drew attention to some limitations of care pathways: "While these [care pathways] may well be an aid to patient care by providing a common framework, good quality end of life care can equally well be provided by committed and compassionate individuals who are experienced in the care of the dying. Indeed consideration should be taken to prevent the act of dying becoming overly medicalised and process driven. Perhaps the greatest value of these care pathways may be in situations were health care professionals are less confident and experienced in providing end of life care" (National Confidential Enquiry into Patient Outcome and Death, 2009: 90).

[118] In the Ethicus study of 4,248 intensive care deaths in 17 European countries, both withholding and withdrawing life support – but not active life-ending procedures – occurred in 73% of patients (Sprung, Cohen, Sjokvist et al., 2003). The Mater Hospital contributed to the Ethicus study and its results were published separately to show that 70% of patients who died in ICU in 1999/2000 had a decision made to withhold or withdraw life-sustaining therapy, but only

Our analysis revealed that the number of end-of-life care decisions had no statistically-significant impact on care outcomes. We also found that the decision to 'review medication, route of administration, and stop non-essential medication' – which factor analysis identified as most strongly associated with all decisions – had no statistically-significant effect on care outcomes. This result means that the relationship between care outcomes and care decisions does not have a measurable, systematic impact, perhaps due to variability of the different approaches adopted in specific cases. Decisions are more likely to be made where the course of the illness poses specific problems, generating a certain confounding between symptoms and decisions.

We undertook further analysis of the factors associated with the decision to 'review medication, route of administration, and stop non-essential medication' and found that this is more likely to happen in oncology wards, with cancer patients and where specialist palliative care services are provided. The fact that cancer is already established as a statistically-significant predictor of positive care outcomes suggests that the effect of end-of-life care decisions may be mediated at least partially by different specialisms.

3.8.3 Specialist Palliative Care

The purpose of palliative care, as defined by the National Advisory Committee on Palliative Care, is "the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure. Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement".[119] A number of studies have documented how palliative care improves the quality of living and dying for patients with advanced disease.[120] The National Advisory Committee recommended that, in the acute hospital sector, "patients should be referred to the specialist palliative care team for advice on symptom control, psychosocial support and problems relating to quality of life. The function of the specialist palliative care team is to act as a role model, sharing its knowledge and skills with hospital teams, and not to

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72% of these decisions were documented (Collins, Phelan, Marsh and Spring, 2006: 317).

[119] National Advisory Committee on Palliative Care (2001: 20). This committee was set up by the Minister for Health and Children in 1999 and its report was published in 2001. This report, in turn, has been adopted as government policy. The committees recommendations on acute general hospitals are in Chapter Seven (pp. 57-70) of the report while the recommendations on community hospitals are in Chapter Eight (pp. 89-90).

[120] Casarett, Pickard, Bailey et al. (2008); Ferrand, Jabre, Vincent-Genod et al. (2008); Cohen, Boston, and Mount (2001); Stromgren, Sjogren, Goldschmidt et al. (2005).

de-skill members of the ward team by taking over care”.[121]

In Ireland, only a quarter of acute hospitals meet the government-approved standard of having a full specialist palliative care team.[122] In addition, specialist palliative care services are unevenly distributed between hospitals. This uneven distribution seems to reflect supply-led considerations – such as some hospitals seeking palliative care resources while others do not – rather than any objective measure of need such as the number of deaths. This, in turn, highlights the need for a more explicit resource allocation model for specialist palliative care services that is firmly needs-based, and reflects demand-led rather than supply-led considerations.

The audit reveals that a majority of patients did not receive specialist palliative care. The percentage receiving such care varies from 22% (according to doctors) to 32% (according to nurses), a substantial, ten percentage-point difference in opinion. In over a quarter of cases where patients did not receive specialist palliative care, nurses and doctors did not know if the patient would have benefited from it. This suggests that there may be some misunderstanding between – and within – nurses and doctors as to the precise role and function of specialist palliative care.

In comparative context, the proportion of patients in the audit who received specialist palliative care is higher compared to UK hospitals (19%)[123], and much higher compared to French hospitals where, according to one study, “only 12.1% had a palliative care consultation”.[124] The exception to this is patients in A&E and ICU, where the audit reveals that specialist palliative care services are consulted in only 3% and 6% of cases respectively.

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[121] National Advisory Committee on Palliative Care (2001: 81).

[122] McKeown, Haase and Twomey (2010a). This result is in line with a more comprehensive analysis of specialist palliative care teams in 38 acute hospitals carried out by the Irish Hospice Foundation (IHF), based on 2004 data. See Murray, Sweeney, Smyth and Connolly (2006), Murray (2008).

[123] In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), a sub-sample of deaths (1,478) was analysed and there was no involvement by a palliative care team in 81% of cases (National Confidential Enquiry into Patient Outcome and Death, 2009: 94). Commenting on this, the report states: “While the sample of patients included in this study may not be representative of all who were admitted with palliative intent, the paucity of input from palliative care teams may be indicative of the lack of co-ordinated end of life care in acute hospitals” (Ibid: 94-95).

[124] Ferrand, Jabre, Vincent-Genod et al. (2008: 870). This study was based on 3,793 patients who died in 200 French hospitals in 2004.

In the data analysis for this audit, the contribution from specialist palliative care services did not show a statistically-significant influence on care outcomes. This is surprising given that its benefits are well documented. The lack of statistical significance may be due to the absence of a shared understanding about the role of specialist palliative care within hospitals since, as the audit shows, nurses and doctors did not always know if the patient was in receipt of, or would have benefited from, a referral to the specialist palliative care service. In effect, this is a 'response error', and partly explains why the audit did not detect a statistically-significant effect on care outcomes. Nevertheless, it is still an important result because it suggests that there may be lack of clarity about the role of specialist palliative care services within hospitals. This lack of clarity may also have an organisational dimension, indicating the need for additional information and guidelines so that the service can play the role envisaged for it within acute hospitals by the National Advisory Committee on Palliative Care.[125]

Another explanation for this result is that the effects of specialist palliative care services are mediated through other variables which have a direct positive impact on care outcomes. For example, we carried out further analysis and found that two thirds of those who received specialist palliative care were cancer patients which we know to have better care outcomes than other patients[126]. Specialist palliative care is also more likely to be offered when the patient is in a single room, when team meetings are held, when relatives are facilitated to stay overnight and to be present at the moment of death. All of these variables are associated in a statistically-significant way with better care outcomes. In other words, the benefits of specialist palliative care - possibly because it frequently provides expert advice to doctors and nurses but does not manage their cases – is mediated through its effect on other care inputs and, in this sense, has an indirect rather than direct effect.

Overall, specialist palliative care is known to be effective and the audit suggests that its

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[125] This is especially the case with the recommendation that "patients should be referred to the specialist palliative care team for advice on symptom control, psychosocial support and problems relating to quality of life. The functions of the specialist palliative care team is to act as a role model, sharing its knowledge and skills with hospital teams, and not to de-skill members of the ward team by taking over care" (National Advisory Committee on Palliative Care, 2001: 81).

[126] It is increasingly recognised that the need for specialist palliative care arises for patients other than those with cancer. A recent report estimated that when the needs of patients with heart failure, dementia and chronic obstructive pulmonary disease are added to those with cancer, the estimated number of patients requiring specialist palliative care "would increase by at least 50%" (Health Service Executive and Irish Hospice Foundation, 2008: 2).

effectiveness may be mediated through other variables which are known to have a positive impact on care outcomes such as cancer patients, single rooms, team meetings, and support for families. This finding is consistent with the fact that specialist palliative care frequently provides expert advice to doctors and nurses but does not manage their cases. Nevertheless, the audit also identified a lack of clarity about the role of specialist palliative care services in acute hospitals and this points to the need to strengthen its role, while also expanding its role to meet the needs of all patients who need it.

3.9 Team Meetings

There are two types of meeting where hospital staff discuss the patient's needs and review the aims of care. The first, and most frequent, of these is a meeting of the medical and nursing staff who are involved with the patient. This type of meeting was held in nearly seven out of ten cases. The second is a multidisciplinary team meeting of all health care professionals involved with the patient; this was held in about four out of ten cases. These meetings are attended by the family in about two thirds of cases.

The audit suggests that there is considerable flexibility and informality around the holding of, and attendance at, team meetings, and there seems to be no standardised procedure for reporting the outcome of meetings to patients and relatives. This is suggested by the responses of doctors and nurses, including the fact that in up to a third of cases, respondents do not agree on whether a meeting actually took place. The fact that the frequency of team meetings varies by ward (being more frequent in oncology and geriatric wards) and diagnostic category (being more frequent for cancer patients) suggests that a team approach to patient care, where it exists, may be more influenced by the work practices of different disciplines and wards rather than by a standardised hospital-wide approach to planning the end-of-life care of patients.

Our analysis revealed that the first kind of meeting – comprising medical and nursing staff – has a statistically-significant influence on care outcomes, leading to substantial improvements in patient care and family support. The effect of this meeting is to improve patient care by 3.49% (where assessed by doctors) and 4.91% (where assessed by nurses). Nurses also give a higher rating for family support (by 2.68%) where this meeting has been held. The second type of meeting – involving all relevant health care professionals – also has a significant impact on care outcomes. In the assessment of nurses, these meetings improve symptom management by 5.22%.

These findings underline the substantial contribution (in the region of 4-5%) that team meetings can make to improving care outcomes, especially symptom management and patient care. In subsequent analysis, we found that these meetings tend to be associated with other statistically-significant predictors of care outcomes such as cancer, dying in a single room, and better communication with patients and relatives. This, in turn, illustrates the cumulative way in which care inputs combine to produce better care outcomes, especially for cancer patients. Conversely, team meetings are less likely in cases where negative predictors of outcomes are at work, such as when the patient dies suddenly, dies in A&E or a surgical ward, dies because of an accident or trauma, or dies within a week of admission. Nevertheless, given that three quarters of all deaths are not sudden, there is scope to ensure that the beneficial effects of team meetings are extended to many more patients who die in hospital.

3.10 Communication with Patients and Relatives

There is a substantial body of evidence that effective and empathic communication influences the quality of care and the quality of life of patients who are dying,[127] and even stronger grounds to believe that this is an area where end-of-life care could be improved within hospitals.[128] It is recognised that compassionate care involves more than attending to the patient's physical needs; it also involves a dialogue between patient and caregiver where communication is "human to human rather than clinician to patient. … In short, for healthcare professionals, compassion means seeing the person in the patient at all times and at all points of care".[129] For this reason, quality standards for end-of-life care tend to place great importance on discussing

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[127] Empathy has been described as "the key to a caring patient-doctor relationship – the art of medicine" (Janssen, Macleod and Walker, 2008: 390). Empathy has an affective component which, like sympathy, has the capacity to feel as the other person is thought to feel. However, unlike sympathy, empathy also has a cognitive component which is the capacity to reflect and understand why the other person feels as they do. The importance of empathy is underlined by the fact that it is associated with reduced symptoms and improved satisfaction for patients (Reynolds and Scott, 2000), and is a good predictor of clinical competence (Hojat, Gonnella, Nessa et al., 2002), diagnostic accuracy and patient compliance (Roter, Stewart, Putnam et al., 1997; Coulehan, Platt, Egener et al., 2001).

[128] Baker et al. (2000); Edmonds and Rogers (2003); Heyland et al. (2005); Hodges, London and Lundstedt (2006); Irvine (1993); Murphy et al. (2000); Pincombe, Brown and McCutcheon (2003).

[129] Cornwell and Goodrich (2009). According to Macleod and McPherson (2007: 1591): "The virtue of compassion is a trait combining an attitude of active regard for another's welfare with an imaginative awareness and emotional response of deep understanding, tenderness and discomfort at the other person's misfortune or suffering. It is expressed in acts of beneficence that attempt to prevent and alleviate the suffering of the other person".

and documenting the needs and preferences of patients and their relatives.[130]

The audit measured two aspects of communication between hospital staff and patients and relatives: (i) the amount of discussion and (ii) the quality of discussion. Beginning with the amount of discussion, the results indicate that hospital staff are much more likely to discuss end-of-life issues with relatives (96%) than with patients (55%). Where no discussion took place with patients, this was mainly because the patient was too ill (80%). It is noteworthy that some of the reasons which are commonly cited for hospital staff not discussing their patient's end-of-life issues – such as the patient did not want to talk about dying, relatives did not want the patient to be told, lack of privacy, hospital staff lacked experience in communication – were not frequently observed.

The quality of discussion between staff on the ward and patients and relatives was assessed by nurses according to whether this was experienced by patients and relatives as being sensitive, open, honest, reassuring, inclusive, involving the patient in decision-making and providing opportunities to ask questions and to talk about concerns and preferences. The results indicate that, where a discussion took place, the quality of communication with relatives (a mean of 8.5 out of 10) was significantly better than with patients (7.3 out of 10). Equally significant is the fact that there is little variation in ratings for different types communication, and little variation between hospitals, wards and type of diagnosis.

Our analysis reveals that care outcomes are influenced in a statistically-significant way by the quality of discussion with patients and relatives, not by the amount of discussion. Equally significant is the fact that care outcomes are influenced more by the quality of discussions with relatives than with patients themselves.

Beginning with patients, the quality of discussion had a small statistically-significant and positive impact on how nurses perceive both symptom experience and patient care; for each percentage point increase in the quality of discussion with patients, symptom experience

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[130] For example, two of the top ten quality markers in the UK end-of-life strategy are to "ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals' and 'ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment" (Department of Health, 2009: 11). In the Australian standards for palliative care, the need to assess and document the needs and preferences of patients and relatives is also explicitly noted (Palliative Care Australia, 2008: 24).

improved by 0.04% and patient care by 0.06%. In other words, if the quality of discussion with patients improves by 100%, symptom experience increases by 4% and patient care increases by 6%.

Turning to relatives, the results show a larger and more widespread statistically-significant impact on most care outcomes. For each percentage point increase in the quality of discussion, as assessed by nurses, symptom management improves by 0.15%, patient care by 0.12%, acceptability of the patient's death by 0.09% and family support by 0.08%. Relatives also experience an improvement in family support (of 0.05%) associated with the quality of discussion.

We undertook further analysis of the factors associated with the quality of discussion and found that it is associated with other indicators that have a statistically-significant influence on care outcomes. For example, team meetings improve discussions with patients but even more so with relatives. The preparedness of nurses for dealing with the death of a patient improves discussions with both patients and relatives. The quality of discussion is slightly better with cancer patients than other patients, but not their relatives. The privacy, dignity and environment of the ward improves discussion, but being in a single room is correlated with a better quality of discussion with relatives but not patients. To the extent that the allocation of a single room indicates that the patient may be approaching a more critical clinical stage, this finding should be interpreted with care.

The quality of discussion with relatives is also associated with facilitating their involvement through visiting at any time, staying overnight and being present at the moment of death. Beyond these variables, which we know to have a statistically-significant influence on care outcomes, our analysis suggests that the quality of discussion with patients and relatives is also associated with holding a ritual after the death (such as offers of sympathy, prayers, lit candles, silence, tea). Finally, the quality of discussion with relatives tends to be better when they have private health insurance, while discussion with patients tends to be worse when they have a hospital infection.

A number of aspects of these findings are particularly noteworthy. First, care outcomes are influenced by the quality of discussion with patients and relatives, not by whether a discussion took place. In other words, although discussion must take place as a necessary condition, the sufficient condition is that its quality determines the statistically-significant impact on care outcomes, at least as we have measure it. Second, the quality of discussion is a key consideration in how nurses – and to a lesser extent relatives – assess the outcomes of care. By contrast, doctors do not appear to be influenced by the quality of discussion with patients or relatives in assessing care outcomes. Third, the quality of discussion with relatives is consistently more influential on how nurses assess care outcomes compared to their discussions with patients. Fourth, the positive associations between quality of discussion and other statistically-significant influences on care outcomes – notably team meetings and staff preparedness – implies that improvements in any one of these is likely to strengthen the quality of discussion with patients and relatives.

The patterns of communication identified in the audit may be due to the way we have measured communication which focused exclusively on verbal communication – the quality of discussion – since that may be less important than non-verbal communication as patients in their last week begin to show signs of withdrawing from the world and from contact with those around them. Indeed, some patients may become somnolent, comatose or delirious and, in these circumstances, relatives usually become patient proxies. At the same time, previous research suggests other possible explanations for the patterns of communication identified: (i) there is a general tendency among health care professionals to speak with the families of older people rather than the older person[131] (ii) hospital practitioners have difficulty talking about dying and death[132] (iii) there is a fear that relatives have a power to complain which dying patients do not[133].

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[131] One study identified a tendency among health care professionals to 'speak with families of older people, as opposed to the older individuals themselves, regarding treatment and services' (McGlone and Fitzgerald, 2005:72).

[132] Quinlan and O'Neill, 2009:5, in their study of hospital practitioners, report that: 'The practice, in general, among clinicians in terms of communication around dying and death is to follow the patient's lead, to answer any direct questions. This means that clinicians seldom volunteer information. Also highlighted as problematic were euphemisms that are used by clinicians when talking to patients about dying and death. Consultants were said to be very cautions and deliberately oblique with the language they use with patients'.

[133] This possibility is opened up in the results of the audit of the Liverpool Care Pathway (LCP) – based on 3,893 patients in 115 hospitals who died between October and December 2008 – which shows that relatives are much more likely than patients to be aware of the patient's diagnosis (79% compared to 50%), to recognise that the patient is dying (76% compared to 40%); and to have had the patient's care plan explained (72% compared to 30%) (Marie Curie Palliative Care Institute Liverpool, 2009: 45-51). The commentary on the first round of the LCP audit seems to acknowledge and endorse, perhaps unwittingly, that this result may indicate greater importance being attached to the views of relatives over patients: 'This suggests that healthcare professionals are more comfortable in assessing

Whatever the reason, these findings suggest the need for some deeper reflection by nurses and doctors on whether the patterns of communication revealed by the audit are entirely consistent with a patient-centred approach, and the importance of protecting the patient's autonomy as far as possible. More generally, they invite reflection on how hospital staff empathise and interact with patients, especially those who are nearing the end of life, including the extent to which their relationships with patients are informed by compassion.[134]

3.11 Support for Families

The close relatives and friends of a patient can be important companions on the end-of-life journey, and these constitute the family of each patient. Their importance arises from the attachments that bind together family members and which, in all their variety, assume particular significance at the end of life.[135] From a care perspective, therefore, it makes sense to regard the

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the insight of carers which is encouraging as the Healthcare Commission Report 'Spotlight on Complaints' (2007) illustrates that many complaints arise from carers being unprepared for the patient's death' (Marie Curie Palliative Care Institute Liverpool, 2007:43).

[134] There are numerous ways of characterising styles of interaction depending on the underlying psychological theory. One of the most respected – and which underpins most behavioural and cognitive approaches – is attachment theory which explains a person's style of interaction by the way they 'attach' or connect with people, itself influenced by their early life experience of significant others, especially parents (Bowlby, 1979; Ainsworth, 1991). Depending on those formative experiences in early life, three main types of attachment and interaction style emerge: secure attachment, insecure-avoidant attachment, and insecure-anxious attachment. A secure style is where others are regarded as reliable and available and is associated with a warm, positive and reassuring style of interaction. An insecure-avoidant style is where others are regarded as uninterested or unavailable and is associated with an interaction style that is cold, competitive and controlled. An insecure-anxious style is where others are seen as unreliable or difficult and leads to an interaction style characterised by anxiety, stress and lack of confidence. The significance of this for doctors has been explored in a recent article on medical education: 'Attachment theory can provide valuable insight into situations where caring is paramount. In an institutional setting, patients are typically vulnerable and searching for security. Stresses to heighten a patient's vulnerability and need for attachment include their role as an ill person, the uncertainty of their well-being, the requirement placed upon them to trust strangers, their separation from loved and reliable people, and the novel context. ...... Clinicians need far more than a diagnosis in order to understand the perceptions, experiences, and resulting behavior of the person who is ill . .... . A doctor's experiences of care, his or her resulting attachment style, and the levels of support that colleagues and senior figures provide the doctor can make an important difference to the experiences and outcomes of a person under that doctor's care. .... A secure clinician is unlikely to become overwhelmed or controlling when faced with the clingy or anxious behavior typical of insecure-anxious patients.' (Janssen, Macleod and Walker, 2008:391-392).

[135] Attachment is a core concept in psychology to explain the quality of connection within families which, in turn, is used to explain the type of attachments and interactions which one typically has with others in the world (Bowlby, 1979; Ainsworth, 1991). Attachments are influenced by early life experiences of significant others, especially parents, and psychologists have distinguished three types of attachment: secure attachment, insecure-avoidant attachment, and insecure-anxious attachment. Naturally, the attachment style of patients and families will manifest at the end of life, and will be similar – both positively and negatively – to their previous attachment experiences.

patient, along with his/her family, as part of a single 'unit'. This is consistent with a palliative care approach to end-of-life care.

The audit reveals that hospitals offer a range of supports to enable relatives spend time with the patient, including the possibility to visit at any time (88%), refreshments (78%) and the ability to stay overnight in the hospital (67%). Few relatives (19%) are offered preferential parking and fewer still (15%) are offered information leaflets on dying, death and bereavement. These supports are more likely to be offered to cancer patients, to patients in single rooms and, understandably, to those where death is expected rather than sudden.

It is well known that the presence of family members at the time of death can be important for the dying patient, as much as for the relatives[136]. The audit revealed that relatives or friends were definitely present at two thirds of the deaths (65%), and possibly more, since there is no information in nearly a fifth of cases (18%). This is much higher compared to a study of dying in French hospitals where only a quarter had family or friends present.[137] Hospital staff were present at three quarters of the deaths (75%). Overall, someone was present – either family or staff – at the moment of death in three quarters of cases (75%) in the audit, but we do not know who, if anyone, was present in the remaining one quarter. In the French study cited above, no one was present at the patient's death in 16% of cases.[138]

In our analysis we found that two aspects of facilitating relatives – staying overnight and being present at the moment of death – had a statistically-significant influence on care outcomes. Specifically, when a relative is present at the moment of death, the acceptability of the death increases by 5% according to both relatives and nurses. Prior to the moment of death, when relatives stay overnight this has a beneficial impact on symptom management, which increases by 3.84%, as assessed by nurses.

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[136] A study, based on 178 patients who died in ICU, found that: "Nurses in our study perceived patients with family members or others present at the time of death and those without CPR performed in the 8 hrs before their death as having higher quality deaths" (Hodde, Engelberg, Treece, Steinberg and Curtis, 2004: 1652). More generally, in a survey of 1,000 adults aged 15+ in the Republic of Ireland, carried out in 2004, the largest proportion of respondents (68%) indicated that the most important thing about care when dying was to be surrounded by loved ones (Weafer and Associates, 2004: 23).

[137] Ferrand, Jabre, Vincent-Genod et al. (2008: Table 3).

[138] Ferrand, Jabre, Vincent-Genod et al. (2008:Table 3).

The likelihood of family members being present at the time of death, and being allowed to stay overnight, is associated with a number of other statistically-significant predictors of care outcomes. For example, it is more likely if the patient has cancer, is in a single room or where the privacy, dignity and environment of the ward is better, where team meetings have been held. As with other care inputs, this suggests that the determinants of care outcomes operate in a mutually-reinforcing manner which implies that improvements in one area are likely to have spill-over effects in others. This has implications for the quality improvement process, since it suggests that care inputs which have the greatest spill-over effects are likely, other things being equal, to have the biggest overall impact on quality improvement.

These findings confirm the importance of families in supporting hospitals to provide good care outcomes at the end of life. In this sense, the findings endorse and encourage the widespread practice in Irish hospitals of facilitating relatives to be with the patient during their final journey. Naturally, this may not be possible in the significant minority of cases where there is a sudden or traumatic death. Where it is possible, however, the observed effects on care outcomes are substantial.

3.12 Documentation in Healthcare Record

The healthcare record is an essential component of patient care because it supports a consistent approach across the entire hospital team. The HSE's standards for the management of healthcare records specify that: "all relevant communication with patients and families shall be documented in the relevant part of the healthcare record'[139] and 'the involvement of the patient in decisions about his or her care shall be documented in the record under 'patient wishes'".[140]

The audit found that key information about patients – such as the diagnosis of dying, the patient's wishes and worries, decisions about palliative care – are documented, at most,

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[139] HSE National Hospitals Office (2008: 30).

[140] HSE National Hospitals Office (2008: 31). The overall standard on the content of the healthcare record states: "The content of the healthcare record shall provide an accurate chronology of events and all significant consultations, assessments, observations, decisions, interventions and outcomes. The content of each record shall comply with clinical guidance provided by professional bodies and legal guidance provided by the Clinical Indemnity Scheme. This standard shall apply to both hardcopy and electronic documentation" (p. 20).

in only three quarters of cases. The uneven quality of documentation is further illustrated by the fact that, in a substantial minority of cases, the responses of nurses and doctors do not agree about whether a particular item of patient information was documented. From a comparative perspective, the practice of documenting medical decisions about end-of-life care in Irish hospitals tends to be less frequent than for patients on the Liverpool Care Pathway (LCP) in English hospitals, particularly in areas such as medication, blood tests, IV fluids and resuscitation – where over nine out of ten decisions are documented.[141] However, decisions regarding the non-medical aspects of LCP are less likely to be documented,[142] and may not be very different to practices in Irish hospitals.

The results of our analysis indicate that documentation about selected aspects of care – such as diagnosis of dying, decisions about palliative care, wishes of relatives to be kept informed - had no statistically-significant effect on any of the care outcomes. This contrasts with the results of a large French study which found that documentation is associated with improved end-of-life care.[143] This result arises because the quality of documentation makes no consistent difference to the quality of care outcomes, which suggests that documentation does not support a consistent quality approach to care across the hospital team. However, documentation may be said to have an indirect effect due to its association with other variables which we know to directly influence care outcomes. Specifically, documentation is more likely to occur in oncology wards and for cancer patients generally; it is also more likely to occur when there are team meetings, when the patient is in a single room, where relatives are facilitated to stay overnight and be present at the moment of death.

These findings underline the overall importance of documentation in the care process while

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[141] Marie Curie Palliative Care Institute Liverpool (2009: 34-37).

[142] For example, inappropriate nursing interventions such as vital signs and blood sugar monitoring are not documented in a quarter of cases (Marie Curie Palliative Care Institute Liverpool, 2009: 37). In the case of a patient's psychosocial and spiritual aspects of care – such as awareness of diagnosis, recognition of dying, religious and spiritual needs assessed – the extent of non-documentation is closer to a third (Marie Curie Palliative Care Institute Liverpool, 2009: 45-46); discussing the plan of care with the patient was not documented in half the cases compared to a quarter in the case of relatives (Marie Curie Palliative Care Institute Liverpool, 2009: 51). Equally, the extent to which the family were given information about hospital procedures or about bereavement is not documented in about half the cases. Adherence to hospital procedures for at the time of death and after ('last offices') is not documented in about half of all cases (Marie Curie Palliative Care Institute Liverpool, 2009: 56-58).

[143] One study – based on 3,793 patients who died in 200 French hospitals in 2004 – found that nurses were more likely to perceive a patient's death as acceptable if the patient's wishes about treatment were documented (Ferrand, Jabre, Vincent-Genod et al., 2008: Table 4).

simultaneously highlighting the considerable variability that exists between and within wards in how this is practiced. The fact that documentation is markedly better for cancer patients than for other patients – who also have better care outcomes - suggests that practice standards in each medical specialty have a marked influence. In addition, the fact that documentation is markedly better in oncology wards compared to other wards suggests that the quality of ward management may also be a contributory factor in the uneven quality of documentation.

3.13 Staff Readiness

By its nature, care depends on the qualities – personal as well as professional – of the person delivering the care. In the audit, we collected information on characteristics of nursing staff, in order to explore whether these can influence care outcomes. For practical and logistical reasons, we did not collect the same information from doctors and other hospital staff. To this extent, our analysis may be said to be limited. The analysis of nurse characteristics indicates that the following have a statistically-significant influence on care outcomes: nursing staff feel personally and professionally prepared for dealing with the death of a patient; number of years experience in the hospital and ward; formal training in end-of-life care. We will now outline how each of these factors impacts on care outcomes.

3.13.1 Nurse Prepared for Patient's Death

A survey of ward and hospital staff was undertaken as part of the audit, including the following two questions:

(i) How prepared do you feel, professionally, for dealing with the death of a patient?
(ii) How prepared do you feel, personally, for dealing with the death of a patient?

The responses obtained were rated on a 4-point scale from 'completely unprepared' to 'completely prepared'. Nine out of ten nurses and doctors rated themselves as 'reasonably' or 'completely' prepared for dealing with the death of a patient, with no difference between personal and professional preparedness when sampling error is taken into account.

Our analysis reveals that the preparedness of nurses (specifically those who completed the audit on patients) has a statistically-significant impact on care outcomes; the preparedness of other staff in the ward or hospital has no effect. Where nurses feel professionally prepared for dealing with the death of a patient, the patient's symptom experience improves (+4.14%), and there is also a more positive perception of this by relatives (+6.75%). In addition, nurses who feel personally prepared for dealing with the death of a patient are more likely to see the patient's death as acceptable (+4.42%).

Further analysis revealed that the preparedness of nurses for the death of a patient is mainly associated with the other nurse characteristics mentioned above: having formal training in end-of-life care and years of experience in the hospital and ward. This suggests that preparedness for the death of a patient is enhanced by both training and experience. It is also strongly associated with feeling comfortable talking about death and talking to people who have been recently bereaved. This underlines the personal as well as the professional aspect of care, especially in caring for dying patients, and the specific need to address the fears that hospital staff have about dying and death.[144]

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[144] The link between the fear of dying and death, and the quality of care offered to dying patients was articulated over 40 years ago by Elisabeth Kubler-Ross – herself a medical doctor - in her pioneering work on dying and death where she writes: 'When a patient is severely ill, he is often treated as a person with no right to an opinion. ... He may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine, or a tracheostomy. He may want one single person to stop for one single moment so that he can ask one single question – but he will get a dozen people round the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being. ... Is the reason for this increasingly mechanical, depersonalised approach our own defensiveness? Is this approach our own way to cope with and repress the anxieties that a terminally or critically ill patient evokes in us? Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending end, which is so frightening and disquieting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being, which would remind us once more of our lack of omnipotence, our own limitations and fallibility and, last but not least perhaps, our own mortality?' (Kubler-Ross, 2009:7-8). There is a large body of literature on the fear of dying and death - by philosophers, poets, spiritual teachers, etc. – and the pervasive influence it exercises not just on caring relationships but on the experience of a 'good life' and a 'good death'. The life and work of Socrates (469-399BC) is often cited as an example of this. When condemned to death for allegedly corrupting the youth of Athens, Socrates observed that he had no fear of dying since he had been practicing death all his life. He regarded death as no more than release and separation of the soul from the limitations of the body which is also the state of wisdom sought by the true philosopher; "If a man has trained himself throughout his life to live in a state as close as possible to death, would it not be ridiculous for him to be distressed when death comes to him? ... True philosophers make dying their profession" (Plato, 2003: 129). More contemporarily, the American cultural anthropologist Ernest Becker, under the influence of Kierkegaard (1983), has argued that human conditioning and culture is shaped by the need to deny death which, however, can be transcended through a process of self-realisation where the person "opens himself up to infinity ... links his secret inner self, his authentic talent, his deepest feelings of uniqueness to the very ground of creation" (Becker, 1974: 90). A core theme in these writings is the invitation provided by dying and death to reflect on the true

It is worth recalling, in this context, the results of survey data which indicate that a majority of nurses and hospital staff (just like a majority of the general public) are not very comfortable talking about dying and death, and are even less comfortable talking to a person who has been recently bereaved.[145] This may come as a surprise, given that those who work in wards and hospitals encounter dying and death more frequently in their work compared to the general public. If talking to a patient who is dying is just as difficult as talking to someone who has been bereaved recently, then it follows that many staff may feel uncomfortable about communicating with patients and relatives about end-of-life issues. This inference is consistent with another Irish study which found that hospital practitioners have difficulty talking openly, simply, and sensitively about dying and death.[146]

3.13.2 Nurse Years of Experience

On average, nurses have worked for 7.7 years in their current hospital, of which 5.2 years have been spent in the current ward. There is a substantial range in nurse's work experience, from under a year to over 20 years.

Our analysis reveals that years of experience – both in the hospital and ward – are associated in a statistically-significant way with improved care outcomes. Beginning with the hospital, the nurse's years of experience improves acceptability of the way the patient died, as assessed

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nature of the self, and the reality which is unaffected by it (see also, Ramana Maharshi, 1989:82).

[145] The key finding are:

Most important things about care if dying or terminally ill	Ireland* (n=1000)%	Ward*** (n=2358) %	Hospital*** (n=1858) %
Comfortable talking about death or dying	38	39	37
Comfortable talking to people recently bereaved	25	28	28

* Weafer and Associates Research (2004).

** McKeown, Haase, and Twomey (2010c).

*** McKeown, Haase, and Twomey (2010d).

[146] Quinlan and O'Neill (2009: 5).

by relatives (+3.69) and improves family support, as assessed by nurses (+0.91).[147] The patient's symptom experience is further improved, according to the responses of both nurses and relatives, with each additional year on the ward. For example, each year of work experience improves the patient's symptom experience by between 0.46% (in the assessment of nurses) and 1.34% (in the assessment of relatives). Years of experience are associated with feeling prepared for the death of a patient and with end-of-life training, and it is also the case that this will be associated with the nurse's age.

3.13.3 Nurse Training in End-of-Life Care

Nearly a quarter of nurses (23%) have completed a formal training course on end-of-life/ palliative care since qualifying. Where nurses have received this training, a statistically-significant improvement in symptom management as assessed by doctors of 5.92 percentage points is observed. This is a substantial impact, particularly as it is recorded by a different actor. We have already seen that end-of-life training is associated with nurses feeling more prepared for the death of a patient, having longer years of service in the hospital and ward, which directly improves care outcomes as perceived by nurses and relatives. Further analysis reveals that nurses who have participated in end-of-life training are also more likely to be ward managers and Irish nationals.

Overall, these findings suggest that experience and training combine to increase the preparedness of nurses to care for dying patients. It is significant that the effects of preparedness on care outcomes are visible not only to nurses, but also to doctors and relatives. Equally significant is the importance of nursing experience, which draws attention to the importance of retaining experienced nurses within the hospital and ward, and ensuring that they have a direct role in patient care, where they can have an impact on care outcomes and on their fellow staff members.

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[147] Note that these impacts cannot be expressed in percentage terms because the variable is expressed as a log rather than as a linear scale.

3.13.4 Non-National Nurses

Finally, our analysis produced the statistically-significant finding that non-national nurses are associated with higher levels of symptom management (+5.43%) and patient care (+5.41%). We analysed this result further and found that non-national nurses are not strongly associated with other statistically-significant predictors of care outcomes. However, they are nearly four times more likely than Irish nurses to work in a community hospital and these hospitals, in turn, tend to have higher ratings for all aspects of care, when compared with acute hospitals. Without additional information, perhaps including more qualitative research, it is difficult to advance further hypotheses regarding this effect.

It is interesting to note that up to a quarter of nurses in the audit (23%) were brought up outside Ireland, a much higher figure than in the Irish health services more generally, where 10% of staff are non-Irish.[148] The proportion of non-Irish ward staff – which includes health-care assistants as well as nurses – is higher still, at nearly a third (31%). The two main countries from which non-Irish ward staff originate are the Philippines and India, which is also the main source of non-Irish staff in the Irish health services generally.[149] Consistent with this, English is not the first language for nearly a quarter (24%) of ward staff.

3.14 Hospital Governance

Hospitals do not always recognise the enormous significance of their role for society as a whole in relation to dying, death and bereavement. Notwithstanding the fact that most people die outside the home in a hospital or similar setting, many hospitals do not regard end-of-life care as a core activity. The audit reveals that only nine of the 24 acute hospitals (38%) and only six of the 19 community hospitals (32%) had a service plan in 2008 which included specific objectives and targets for improving end-of-life care. This contrasts with the situation in Northern Ireland, where an audit of end-of-life care in hospitals and hospices revealed that the infrastructure of policies, procedures and guidelines for end-of-life care is considerably more developed compared to the Republic of Ireland.[150]

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[148] HSE and Department of Health (2009: 62).

[149] HSE and Department of Health (2009: 62).

[150] For example, the Northern Ireland audit revealed the percent (in brackets) of hospitals and hospices with written

Our analysis indicates that two aspects of hospital governance have a statistically-significant impact on care outcomes. The first is having end-of-life care objectives in the hospital's service plan, whilst the second is having sufficient ward staff. We will briefly discuss the significance of each of these characteristics.

3.14.1 End-of-Life Objectives in Service Plan

The analysis shows that hospitals which have end-of-life objectives in their service or business plans have statistically-significant better care outcomes. Specifically, the score for symptom management, as assessed by doctors, is 4.89 percentage points higher in hospitals which have end-of-life objectives in their service plan. This may be due to the fact that hospitals develop this aspect of their service plans when they have doctors who are more attuned to end-of-life issues. Equally, there may be an influence in the opposite direction, with the service plan raising awareness among doctors about the importance of symptom management at the end of life. It is also possible that other variables associated with the service plan may be at work, including organisational features and practices. This is an important result, because it shows the influence that hospital leadership can (at least potentially) exercise on end-of-life care.

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policies, procedures and guidelines on the following:
- Accessing translation services (94%)
- Do not attempt resuscitation (94%)
- Reporting cases to the coroner (91%)
- Cultural and religious practices (88%)
- Death certification (82%)
- Breaking bad news (77%)
- Care of the dying pathway (74%)
- Care plan for women who experience miscarriage, stillbirth or neonatal death (73%)
- Post-mortem processes (71%)
- Cremation (69%)
- Memorandum of understanding (68%)
- Information for relatives (62%)
- Burial by hospital, if no next-of-kin (61%)
- Advance directives (51%)
- Identification of the deceased (49%)
- Bereavement care (46%)
- Chaplaincy/spiritual care (46%)
- Sudden death protocols (42%)
- Care after death ('last offices') (over 80% for most items).

(Northern Ireland Health and Social Care Bereavement Network, 2009: 13-14). It is worth pointing out that, notwithstanding all these written policies, procedures and guidelines, only 42% of the hospital staff surveyed regarded written guidance/information as excellent or good (Ibid: 53).

3.14.2 Sufficient Staff on Ward

The survey of ward staff – comprising a sample of nurses and health-care assistants in each ward where an audited death took place – shows that more than half (56%) believe that staffing levels on their ward are not sufficient. This perception has a small statistically-significant but negative effect on care outcomes. Specifically, for each percentage point increase in the number of respondents who feel that staffing levels are insufficient, the acceptability of deaths on these wards (according to doctors) declines by 0.08%. This variable may be an indicator of objective staff shortages in some wards, or it may be indicate lower staff morale, or a combination of both. Given its significance for care outcomes, this issue clearly merits attention by hospital management.

3.15 Patient Choice: Could Patient Have Died at Home?

Whether a patient could have died at home, or would have preferred to die at home, has no distinct effect on care outcomes. Nevertheless, the question itself is important, not just in terms of meeting patient preferences but also in terms of the entire system of health services. The importance of dying at home is underlined by the fact, described in Chapter 1 above, that a majority of Irish people would prefer to die at home and even doctors and nurses have a stronger preference to die at home compared to patients. At least one study has shown that patients who die at home, and who die in the place they prefer, have a better quality of dying compared to those who do not.[151]

Dying at home is also relevant in the context of a growing realisation that many patients who are treated in acute hospitals in Ireland could be treated as well, and more cost-effectively, in

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[151] Curtis, Patrick, Engleberg, Norris, Asp and Byock (2002). This study, based on the Quality of Dying and Death (QODD) instrument completed by relatives on 252 patients who died at home or in hospital found that: "Decedents who died at home had a significantly higher QODD score than those dying in other settings (P=0.006). Decedents who died in the setting where the respondent told us they died in the setting where the respondent told us they wanted to die also had higher QODD scores that approached our definition of statistical significance (P=0.013)" (Curtis, Patrick, Engleberg, Norris, Asp and Byock, 2002: 25).

other settings.[152] We know from this audit that patients who die in Ireland's acute hospitals spend at least twice as long there before dying compared to other countries, such as the UK,[153] the US[154] and OECD countries,[155] and this inevitably raises questions about whether this reflects the case-mix of patients or, more likely,[156] the overall management of hospitals and health services generally. In line with this, the HSE's five-year development framework for palliative care services acknowledges the need for some "reorientation and reconfiguration of existing resources" within the sector.[157]

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152 In Ireland, a random sample of 3,035 medical and surgical in-patients across 37 acute hospitals were reviewed between November 2006 and February 2007 by PA Consulting Group and Balance of Care Group (2007) for the HSE. The results of this study, though not focused on end-of-life, showed that 13% could have been treated outside an acute setting, 75% of elective survey patients were admitted earlier than necessary, 39% of day patients could have been treated in an alternative setting, and discharge planning was in evidence from the notes of 40% of patients. In the UK, the National audit office found that "forty per cent of the 200 patients who died in hospital were found not to have had medical needs which required them to be in hospital at the point of admission, and could have been cared for elsewhere" (National Audit Office, 2008: 28). Significantly, the study also found that: "These patients used 1,500 bed days in acute hospitals. Assuming the cost of an inpatient day in an acute hospital to be £250 … this suggests that over the course of a year up to £4.5 million could be made available for end of life care in the community in Sheffield through more appropriate use of hospital care for people approaching the end of their life" (Ibid).

153 A study of 599 deaths in an acute hospital in the south west of England found that the average length of stay before death was 12 days (Abel, Rich, Griffin and Purdy, 2009: 3, Table 6). A study of 314 cancer deaths in Boston Lincolnshire between September 2006 and March 2007 found that the average length of stay before death was 16.6 days (Addicott and Dewar, 2008: Tables 4 and 7).

154 Martin, Nelson, Lloyd, and Nolan (2007: 6); see also Wennberg et al. (2004). This target was set following research published by Dartmouth Atlas which showed that length of stay in the last six months of life varied across the US from 4.87 to 19.67 days for the same diagnostic categories and independently of need and outcome albeit with significant variations in cost (Wennberg, Fisher, Stukel, Skinner, Sharp and Bronner, 2004). At the same time, setting targets for average lengths of stay, also needs to recognise that short lengths of stay combined with high occupancy levels can put pressure on the quality of care. A recent study of the factors enabling compassionate care in acute hospital settings noted that: "The factor that has arisen again and again in terms of producing stress and reducing compassion is the heightened bed occupancy within hospitals. As hospitals cope with increasing patient demand and higher levels of throughput, it becomes even more important to address humanity within the process, dealing compassionately with staff so that they in turn can do the same for patients. There is of course noting wrong per se with technically focused, rapid treatment, high-turnover, and short lengths of hospital stay – only a minority of patients would willingly prolong their stay in hospital – but it is important for compassion to be seen and valued as essential to the delivery of care, not an option or add-on" (Firth-Cozens and Cornwell, 2009: 12).

155 The OECD average length of stay is 6.3 days (OECD, 2007: 73).

156 In the introduction to the 2009 HSE National Service Plan, the CEO observed that: "There is no acceptable reason why people in Ireland should have to spend longer in an acute hospital than those in comparable countries for the same conditions and procedures. To address this issue and improve on our ability to deliver consistently high quality patient experiences, we will continue to modernise many front line services in keeping with our overall strategic direction as set out in our Corporate Plan 2008-2011. … Our focus on making services more easily available through enhanced community services is now widely accepted and, as a result of the continued commitment to community based care from Government, more new developments will be rolled out during 2009. We will also continue to integrate hospital and community based services so we can provide more seamless and streamlined services, support more direct clinical involvement in management and at the same time devolve more responsibility and authority locally within defined national parameters" (Health Services Executive, 2009: iv).

157 HSE Palliative Care Services – Five Year Development Framework 2009-2013 (2009). A review of evidence on the cost of end-of-life care concluded that "hospice care saves money at all levels of analysis when compared with the

In the audit, nearly a quarter of patients are described as being suitable to die at home by nurses (22%), doctors (22%) and relatives (24%).[158] However, when the assessments of nurses, doctors and relatives are compared on a case-by-case basis, we find that all three agree in only 29% of cases, while nurses and doctors agree in only 48% of cases. This suggests only a moderate level of agreement on how to assess the suitability of patients for dying at home, which is perhaps inevitable given the complexity of this evaluation.

It is possible that hospital staff could benefit from an agreed methodology for assessing the suitability of patients to die at home. This is mentioned in another Irish study, which found that assessments by nurses and doctors on the feasibility of dying at home were of limited value "not least because of the lack of standardisation and objectivity in the judgements of the doctors and nurses with respect to the feasibility of care at home with adequate nursing support".[159] Clearly, any measures to facilitate patients to die at home must first involve a proper assessment of their needs and preferences - including supports at home and in the community - using protocols that have been tried and tested elsewhere. In order to facilitate the planning of services, an assessment of the proportion of patients who could die at home would need to be carried out and peer reviewed, in order to establish the likely scale of alternative support services needed.[160]

We estimate that up €80 million could be made available for end-of-life care if 22% of patients

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alternatives. Sustained support for hospice care will ensure the integration of a cost-effective and desirable alternative in the health service" (Murray, 2009: 103). An exception to this is a recent study on the impact and costs of The Marie Curie 'Delivering Choice Programme' in Lincolnshire, England. This programme, whose aim is to develop services for people who choose to die at home, found that "the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients receiving palliative care in the last eight weeks of life ... As such, we can conclude that the findings presented here demonstrate that the programme has successfully achieved its objective while not incurring any additional costs on the health care system or indeed incurring any significant overall shifts in costs between the acute and community sectors" (Addicott and Dewar, 2008: 33).

[158] This is somewhat similar to another study where doctors and nurses assessed that 18% of patients who died in a hospice or hospital could have died at home (Tiernan, Connor, Kearney and Siorain, 2002).

[159] Tiernan, Connor, Kearney, and Siorain (2002: 234).

[160] Some of the alternative supports could include adequate nursing care, night sitting service, good symptom control, confident and committed general practitioners, access to specialist palliative care, effective co-ordination of care, financial support, and terminal care education.

died at home rather than in acute hospitals.[161] This is something worth investigating further, but would need to be done as part of a whole-system approach to end-of-life care and the creation of a network of services which support patients to die at home, in nursing homes, and in hospices, in accordance with their needs and preferences. The rationale for a whole-system approach is that "It is no good taking care out of hospitals if it leaves behind 'stranded costs' – both from staffing and infrastructure. If these are not removed from the system and savings passed back ... for maintaining the supply of other services, care closer to home will cost more than the current pattern of hospital-based care".[162]

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161 This calculation is based on a number of parameters. There were 11,412 deaths in the 38 acute hospitals in Ireland's HIPE system in 2007 (latest data available). The average cost of an inpatient day varies from €825 in a major regional hospital to €1,917 in a major teaching hospital, equivalent to an overall average of €1,371 per day (PA Consulting Group, 2007: 155). The audit reveals that 22% of deaths could have taken place at home, and the average length of stay for deaths in acute hospitals is 24 days. This results in the usage of 60,203 bed days by these patients. The cost of these bed days, in turn, is approximately €82.5 million. This is likely to over-estimate the resources that would be available if these patients died at home since, other things being equally, some of these patients are likely to spend at least some time in hospital.

162 Harvey, Liddell and McMahon (2009: 41). Significantly, these authors add: "At the moment, there is little firm evidence that care closer to home is cheaper than hospital-based care (although there may be some quality benefits). It would be useful if an authoritative study were undertaken to show how the benefits – including the reduction of costs in acute hospitals – could be derived. This would need to recognise that changes in the way care is delivered should be system-wide" (Harvey, Liddell and McMahon, 2009: 42). A recent study on the impact and costs of The Marie Curie 'Delivering Choice Programme' in Lincolnshire, England found that "the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients receiving palliative care in the last eight weeks of life ... As such, we can conclude that the findings presented here demonstrate that the programme has successfully achieved its objective while not incurring any additional costs on the health care system or indeed incurring any significant overall shifts in costs between the acute and community sectors" (Addicott and Dewar, 2008: 33). However, a review of evidence on the cost of hospice care concluded that: "hospice care saves money at all levels of analysis when compared with the alternatives. Sustained support for hospice care will ensure the integration of a cost-effective and desirable alternative in the health service" (Murray, 2009: 103).

3.16 Concluding Comments

This chapter described the factors which have a statistically-significant influence on the quality of care for patients who die in hospital, including the support offered to relatives. We tested over 200 variables and identified eight sets of influences on the quality of hospital care at the end of life. These influences are: the cause of death, the route of admission to hospital, the physical environment of the hospital, team meetings, quality of staff discussion with patients and relatives, support for families to be with the patient, staff preparedness for the death of a patient, and some aspects of hospital governance.

The knowledge that these influences are statistically-significant is valuable and provides reliable guidance on how hospitals could improve the quality of their care at the end of life. In Chapter 5 we will draw out the implications of these findings and highlight the alternative courses of action that are open to hospitals who wish to improve the quality of care at end of life.

It is also appropriate to draw attention to some of the factors which do not have a distinct or direct statistically-significant influence on care outcomes, but which may nevertheless be of substantive importance. For example, two factors generally thought to be important to hospital care at the end of life, which are incorporated in all existing standards – end-of-life care decisions and documentation in the healthcare record – were found to have no statistically-significant influence on care outcomes. This is a reminder that the audit provides insights into the standards and criteria which currently shape care in the Irish hospital system, including the judgements which nurses, doctors and relatives make about that care. Whether these are in conformity with normative standards, or whether they could be improved by introducing additional standards or criteria, is a separate issue

Two characteristics of patients have an influence on how they are cared for by the hospital: their disease and their possession of private health insurance. In relation to the former, there appears to be a 'hierarchy' of care outcomes, going from 'best' to 'worst': cancer, circulatory diseases, respiratory diseases and dementia/frailty. As far as private health insurance is concerned, this has a powerful impact on relatives' assessments of symptom management, which may be due to preferential access to single rooms, more or better attention from doctors, the possibility of exerting choice in relation to medical specialists, or other intervening factors.

What Influences the Quality of Hospital Care at End of Life?

Once we have controlled for other influences, care outcomes are not affected by hospital size, as measured by the number of beds, patients, staff, deaths, or the distinction between teaching and non-teaching, acute and community hospitals. This suggests that the volume-outcome relationship – whereby a higher volume of hospital activity is associated with better outcomes – does not seem to apply to care at the end of life.[163] As we have seen, this is because the influence of hospital characteristics on care outcomes is mediated by other, more specific attributes.

Similarly, the culture of care in the ward and hospital does not have an influence on care outcomes over and above the influence exercised by individual nurses and doctors and the caring culture which they embody. This finding highlights how a 'caring culture' is an internal reality within each individual – rather than an abstract external reality – and manifests itself through individual caring behaviours, and the actions and decisions of all hospital staff.[164] At the

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[163] Numerous studies have established a direct and positive relationship between volume and outcome, particularly in the area of cancer services, whereby a higher volume of cancer operations is associated with higher outcomes in terms of survival rates. It is generally assumed that the causal sequence is from volume to outcome based on the principle that 'practice makes perfect'; the reverse causal sequence from outcome to volume – whereby better outcomes lead to a higher volume of referrals and cases – is generally discounted. The volume-outcome relationship is stated as a core principle in A Strategy for Cancer Control in Ireland (National Cancer Forum, 2006:44-45): "There is clear evidence that people who have surgical treatment for many common cancers in centres with higher throughput, experience better quality of care and better survival rates. Services that take place in such centres are generally characterised by the following features:

- care is more specialised, thus increasing the likelihood of better survival
- there are higher caseloads of patients, increasing the experience and ability to sub-specialise of individual clinicians and clinical teams
- diagnosis and treatment planning is conducted by multidisciplinary teams
- care delivery is informed by evidence-based guidelines
- audit and other quality assurance programmes are in place
- there is participation in clinical trials and other forms of cancer research
- undergraduate and postgraduate teaching takes place".

[164] This finding is consistent with the findings of a recent review of research on organisational culture in healthcare which observed: "Notwithstanding the more or less rigorous investigations of academic researchers, an entire industry has been built on the idea that organisational culture and performance are indeed linked. ... There have been few empirical studies, and most of them are methodologically weak. ... Although the notion of organisational culture is now invoked frequently in the social science and popular management literature, it remains a contested concept, fraught with rival interpretations and eluding a consensual definition. This contestability, however, has not precluded culture change and management from becoming a familiar prescription in health system reform. Nowhere is this more apparent than in the UK health system" (Mannion, Davies and Marshall, 2005: 130, 197).

same time, some of the discrepancies which we have observed between stated values – such as patient-centred care, patient autonomy and patient equality – and actual practices – such as the marginal influence on care outcomes exercised by communication with the patient and the different outcomes for patients with different diseases - draw attention to the fact that much of what is called 'culture' is observable only through these discrepancies.[165]

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[165] As one review of studies on the influence of organisational culture in healthcare settings has observed, "the essence of an organisation's culture lies in its unspoken assumptions. These assumptions may be conceived as an organisational unconscious, of which artefacts and values are conscious manifestations. However one views the psychoanalytic metaphor, it is generally acknowledged that organisational cultures are like icebergs in that only the peak is visible above the surface ... The basic technique for examining the submerged culture is to look for discrepancies between espoused values and actual practices (artefacts). By exploring these faults in the fabric of organisational life, ... it is possible to bring an underlying pattern of assumptions to the surface" (Scott, Mannion, Davies and Marshall, 2003: 125).

Chapter 4

Rating the Quality of Care at End of Life in Hospital

4 Rating the Quality of Care at End of Life in Hospital

The purpose of the audit is to assist hospitals to meet, and if possible exceed, the Quality Standards for End-of-Life Care[166]. Given that these standards were not available when the audit was being carried out, it may be appropriate to refer to this report as a 'pre-audit' or 'baseline-audit' rather than an audit. Nevertheless, the audit is informative about the actual standards which are currently shaping hospital care at the end of life, while simultaneously providing strong indications about whether they are in conformity with these standards.

The chapter sets out a framework to assist hospitals in applying the results of the audit so that, in addition to assessing their performance against standards, they can also place their performance in the comparative context of other hospitals. This is because the results for each individual hospital have added significance in the context of corresponding results for other hospitals. In this way, the framework facilitates each hospital to identify the areas where its performance, relative to the benchmark set by all hospitals in the audit, merits improvement and the types of actions that might help it to meet the standards.

It is worth emphasising that a hospital's performance on each of the key variables – relative to other hospitals in the audit – is not an indication of whether it has met or exceeds the standards. Nor is it a 'league table' in any sense since each hospital's rating is likely to be different for each variable – indicating strengths in some areas and weaknesses in others – and there is no overall composite score. In other words, the performance rating system outlined in this chapter is simply a devise to facilitate a more practical action-oriented interpretation of the audit findings with a view to implementing the standards.

The process used to rate the performance of each hospital involved three relatively simple steps. The first step involved calculating, for each hospital, the mean score for each care outcome – as seen from the perspective of nurses, doctors and relatives – and for each care input associated

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[166] Hospice Friendly Hospitals Programme, 2010; note also that the Design and Dignity Guidelines are also part of the standards (Hospice Friendly Hospitals Programme, 2007, 2008).

with those outcomes (4.1). The second step involved setting the benchmark of performance based on the top 25% of scores for each variable (4.2). The third step involved rating each individual hospital[167] against this benchmark (4.3). Once the performance of each hospital and each category of hospital (teaching, other acute, community) has been rated, we provide an overview of performance across the hospital system (4.4) and situate it in the context of quality improvement (4.5). We conclude the chapter by re-emphasising that this performance rating system is just a means to an end, not an end in itself; its purpose is to assist each hospital in applying the results of the audit in order to meet and exceed the standards (4.6).

4.1 Calculating Performance Scores

The performance of each hospital is measured by its mean scores for each care outcome and associated inputs. These are summarised in Annex 9, 10 and 11 of the Technical Appendix. This can also be regarded as a minimum dataset for measuring the quality of hospital care at the end of life. The actual questions that make up this minimum dataset are detailed in Annex 12 of the Technical Appendix. Given that the original audit comprised more than 200 separate variables, which themselves are based on over 1,000 original data items derived from the six questionnaires, the reduction to a minimum dataset of just 36 statistically-significant items is a considerable achievement.

The scale in these tables, with few exceptions, ranges from 0 (the lowest or worst score) to 100 (the highest or best score). This means that they can be read as percentages, with higher scores indicating better performance.

4.2 Setting the Benchmark for Performance

Benchmarking is simply a process of making comparisons – between hospitals, wards, specialties, individual staff, etc. – for the purpose of providing an incentive to improve performance. In the context of the audit, our focus is on comparing hospitals and our purpose is to set benchmarks

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[167] In view of the small number of audited deaths in some community hospitals, and none in some of them, we decided to reduce community hospitals to four sub-groupings.

in such a way that hospitals are encouraged to compare themselves with the best scores, rather than with the average scores.

By definition, most hospitals will cluster around the mean value. This implies that a significant improvement in performance can only occur if hospitals compare themselves with those at the top, rather than those at the middle of the distribution of scores. The rationale for this is well-documented: "a major shift towards improved quality will only occur if health organisations in the middle of the range of performance are transformed, that is if the quality of care is brought up to the level of the exemplars, with those below the mean likewise making incremental improvements".[168]

Based on these considerations, we decided that the benchmark should be based on the mean score of the top quartile (25%) of acute hospitals for each care outcome and care input. This is because, of the hospitals included in the audit, 88% of deaths occur in acute hospitals. Given that there are 24 acute hospitals, this means that the mean score is set by the top six acute hospitals for each care outcome and care input.

4.3 Rating Performance Against the Benchmark

Having established the benchmark, we then rate the performance of each hospital using a 'dashboard' comprising three colour-coded categories (green, amber, red). These are summarised in Table 4.1. This dashboard allows the mean scores for care outcomes and inputs in each hospital to be colour-coded according to their performance, thereby allowing an instant interpretation of scores relative to the entire set of hospitals in the audit.

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[168] Parsley and Corrigan (1999: 158), Scally and Donaldson (1998). Consequently, best in class was adopted as the default target in the absence of any other. HSE's HealthStat system follows a similar procedure where "best in class was adopted as the default target in the absence of any other. This was calculated by taking the average of the top three performers in the group" (Turner, 2009: 183). HealthStat is HSE's information system for measuring and managing the performance of hospitals. The system contains 38 indicators or 'metrics' to measure the three themes of access (such as waiting times), integration (such as length of stay), and resources (such as staff absenteeism). Performance on each individual indicator and on each overall theme is visually displayed on a 'dashboard' using the three colours of the traffic light: (i) green means very good performance if within 15% of the target (ii) amber means average performance, room for improvement, if within 15%-35% of the target (iii) red means unsatisfactory, requiring urgent attention, if outside the target by 35% or more. In March 2009, data on 29 hospitals in the HealthStat system were published on the HSE website: http://www.hse.ie/eng/HealthStat/. Accessed on 3 April 2009. See Turner (2009).

Table 4.1: Performance Rating System for Hospitals

Colour	Criterion	Comment
Green	100% of benchmark	Good performance
Amber	80-99% of benchmark	Average performance; Room for significant improvement
Red	<80% of benchmark	Unsatisfactory performance; cause for major concern

This, in turn, allows us to read the pattern of results both column-wise (for individual hospitals and groups of hospitals), and row-wise (for each care outcome and care input). Taking this perspective, we will now make some general observations about the quality of care at end of life in Irish hospitals.

4.4 Overview of End-of-Life Care in Irish Hospitals

The results of the performance rating system in Annex 9, 10 and 11 provide a quick numerical overview of the quality of care at end of life in Irish hospitals. Six features, already alluded to in the analysis reported in Chapter Three, are of particular note.

First, hospital staff tend to give consistently high ratings for all care outcomes, with community hospitals having the highest ratings. By contrast, relatives give consistently lower ratings, especially in acute hospitals. For example, the ratings of nurses and doctors in acute hospitals indicate that there is no hospital in the red category for three care outcomes (overall care, patient care, family support). By contrast, the ratings of relatives place eight of these hospitals in the red category for overall care, five hospitals in the red category for patient care, and eight hospitals in the red category for family support.

In community hospitals, there is a much greater congruence between the views of nurses, doctors and relatives, although this masks certain disparities at the level of individual hospitals. Overall, it is clear from this that the care outcomes of hospitals, as perceived by relatives, are less satisfactory than for nurses and doctors.

Second, care outcomes tend to be rated very highly, which may be due (as we suggested in Chapter Two) to the absence of explicit standards for judging care outcomes and the presence of implicit standards that are self-referential and limited in scope, or indeed to a more general 'audit-effect' or 'response bias'.

Third, across the hospital system, we find that certain care inputs are more likely to be consistently in the red category. These merit particular attention, because of their capacity to negatively influence care outcomes. About two thirds of hospitals are in the red category for admissions through A&E, deaths in single rooms, nurses trained in end-of-life care, experience of nurses, sufficient staff on wards, and end-of-life goals in the hospital's service plan. These highlight known factors which are diminishing the capacity of hospitals to deliver quality care to patients at the end of life. In addition, the role of specialist palliative care merits attention.

Fourth, the general tendency to provide strongly positive assessments of care outcomes as well as inputs draws attention to the need for hospitals to focus on performances which are in the amber as well as the red category. This is because the compression of scores towards the top of the scale means that it can be difficult to accurately differentiate hospitals in terms of their performance. This is particularly the case for communication and feeling prepared for the death of a patient which have consistently high ratings but which may mask areas which require further reflection and action.

Fifth, it is clear that most hospital-level characteristics (apart from having end-of-life goals in the hospital's service plan and sufficient staff on wards) do not impact on care outcomes. This is also evident from the performance rating system where we see relatively little difference in the mean scores of teaching and other acute hospitals. An exception to this is the physical environment, which we discuss in the next point. There is also significant variation within each of these categories, as well as within community hospitals.

Sixth, the proportion of deaths in single rooms is significantly higher in teaching hospitals (55%) than in other acute hospitals (42%) and lowest in community hospitals (34%). Of potentially greater significance is the fact that the proportion of deaths in single rooms seems to be quite independent of the proportion of single rooms in each hospital, suggesting that hospital practices are also influential in determining the proportion of patients who die there. In addition, mortuary facilities are markedly better in teaching hospitals, having 75% of the facilities required by the Design and Dignity Guidelines[169], compared to 38% in other acute hospitals and 29% in community hospitals.

4.5 Setting Performance in the Context of Quality Improvement

The rationale for the audit, as explained in Chapter One, is to contribute to the process of quality improvement by meeting, and if possible exceeding, standards (see Figure 1.3 above). It is true that the substantive results are of considerable interest from a research perspective, but their main purpose is to motivate and support the improvement of end-of-life care in hospitals. One aspect of the quality improvement process is to assist each hospital to interpret the results of the study and to position itself in the broader context of hospitals more generally. This is because the results for each individual hospital have added significance in the context of comparison with the corresponding results for other hospitals.

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[169] Hospice Friendly Hospitals Programme (2007, 2008).

Rating the Quality of Care at End of Life in Hospital

In addition to comparing its performance with other groups of hospitals – the *actual* standards of performance in the hospital system – the quality improvement process requires each hospital to examine whether its performance is in conformity with *normative* standards in the Quality Standards for End-of-Life Care in Hospitals[170] and the Design and Dignity Guidelines[171]. These quality standards are the true benchmark against which the quality of care provided by a hospital at the end of life is to be judged.

The process of deliberating and reflecting on standards in light of the audit can lead to quality improvements if there is a development plan – or equivalent – to give practical expression to the actions which will be undertaken by the hospital to address the gaps identified. In order to maintain the focus on standards, each action needs to be set in the context of a specific standard – or set of standards – with detailed targets and timelines, possibly using a simple template such as outlined in Table 4.2.

Table 4.2: Possible Template for Development Plan to Implement Each Standard

Name & number of standard
Existing performance against standard, based on audit and other data
Targets to achieve the standard, including timeframe
Description of actions to achieve standard, including timeframe
Name of Responsible Lead for actions
Resources & supports needed to implement actions
Verifiable data to be used in reports on implementation
Explain how the action(s) are sustainable

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[170] Hospice Friendly Hospitals Programme (2010).

[171] Hospice Friendly Hospitals Programme (2007, 2008).

4.6 Concluding Comments

In this chapter we described the performance rating system as a way of simplifying the results of the audit and making them accessible to each hospital. This is because the results for each individual hospital have added significance in the context of corresponding results for other hospitals. The results of the audit, including the individual hospital reports, will provide each hospital with guidance on the range of actions that are most likely to have an impact on their quality of care, helping them to orient those actions towards the wider context of quality improvement and standards. These results will supplement the knowledge and expertise that is already available at local level about the changes that are needed.

It is worth emphasising that a hospital's performance on each key variable – relative to the benchmark set by all hospitals in the audit – is not an indication of whether it has met or exceeds the standards. Nor is it a 'league table' in any sense since each hospital's rating is likely to be different for each variable – indicating strengths in some areas and weaknesses in others – and there is no overall composite score. In other words, the performance rating system outlined in this chapter is simply a devise to facilitate a more practical action-oriented interpretation of the audit findings with a view to implementing the standards.

It is true that knowledge and information can make a valuable contribution to the quality improvement process – in health care as in other settings – but it is rarely the most important factor. Most of the challenges are human rather than technical and it is well recognised that quality improvement needs to be embedded in a motivation to change on the part of staff members, with the active support of hospital management.[172]

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[172] A recent review of the evidence on how to improve the care of patients in hospital noted that: "The ambition to improve patients' experience of care will be realised only with the willing cooperation and effort of all staff in direct contact with patients and if the wider organisation provides support and encouragement" (Goodrich and Cornwell, 2008: 44)

This points to the key role of hospital leadership in achieving standards and in mobilising hospital stakeholders to strive for excellence in a planned and coordinated way.[173]

In the next and final chapter of the report, we will draw out the implications of the audit findings and their substantive implications for improving the quality of hospital care at the end of life.

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[173] A recent review of the evidence on how to improve the care of patients in hospital also noted that: "Leadership for improvement at team and institutional levels is absolutely necessary. The actions, words and behaviours of leaders are critically important" (Goodrich and Cornwell, 2008: 44). Supporting this finding, the Healthcare Commission in the UK concluded that gross failures in service quality are "invariably associated with senior leaders failing to show interest in the experience of patients and staff and failing to focus systematically on service quality" (cited in Goodrich and Cornwell, 2008: 364). This understanding of quality improvement is also reinforced by a study of successful health care quality initiatives in leading hospitals in Europe and the US which found that: "The structural (planning and coordination) and cultural (framing and valuing) processes proved to be the most central dimensions of organising for quality and go hand in hand, in contrast to conventional quality approaches that emphasise one or the other" (Rand Health, 2009: 5; original study by Bate, Mendel and Robert, 2008). Other findings from this study show that: "Educational and learning processes, including learning from one's own mistakes, are critical to supporting continuous improvement and typically require integration across a variety of other processes to be effective. Health care organisations, including many of those in this study, are still searching for the keys to addressing the emotional processes of mobilising, inspiring, and building momentum ... The physical and technological aspects of quality need to be placed in perspective. Even the best technology will not add much to service ... if no one knows how to use it (learning), it is not perceived as important or useful (cultural), does not fit into existing work routines (structural), or rubs against vested interests and fear of change (political and emotional)" (Rand Health, 2009: 5). Of relevance here is the seven leadership points produced by the US Institute for Healthcare Improvement (Reinersten, Bisognano and Pugh, 2008).

Chapter 5

Conclusions: Issues for Consideration and Action

5 Conclusions: Issues for Consideration and Action

It is reasonable to ask, in light of the audit, how dying in an Irish hospital compares to dying in a hospital elsewhere. It is possible to answer this question as long as one remains mindful of the limitations of the audit (outlined in Section 2.8), and the even greater limitation of comparing measurements across countries. In this light, the audit suggests that the quality of care for people who die in Irish hospitals compares favourably with that reported elsewhere.

For example, the diagnosis of dying seems to be made more frequently here than in French hospitals and earlier than in English hospitals, although this finding is likely to have been affected by the fact that our data were collected retrospectively rather than prospectively.

Patients who die in Irish hospitals seem to be as comfortable as patients who die in English hospitals where the Liverpool Care Pathway (LCP) is used. Also, deaths are more likely to be rated as acceptable by nurses and doctors in Ireland compared to deaths in French hospitals. Beyond these inter-country comparisons, the quality of life of patients, and the quality of care offered to them and their relatives, are broadly comparable to that reported in other studies.

This overall finding reflects well on the quality of care in Irish hospitals and is consistent with other international comparisons[174]. This awareness makes it easier to be constructively critical about Irish hospitals and to acknowledge the weaknesses which have been identified in this audit. For those who die in hospital, these weaknesses occur at every stage of the patient's journey from admission to discharge at death. The weaknesses identified in the audit are also opportunities to correct them. The analysis provides an overall map of how to locate these weaknesses within the system as well as more detailed 'local' guidance on the factors that keep them in place and could help to remove them. In total, the audit identifies 18 different ways in which each hospital could improve its end-of-life care. As such, the audit provides knowledge, to

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[174] For example, in a study of palliative care (PC) in the EU, Ireland was placed second, after the UK, out of the EU-27. This was on the basis of resources (such as PC staff, beds, units, etc) and vitality (such as the number of activists and professionals involved in PC) (Martin-Moreno, Harris, Gorgojo, Clark, Normand, Centeno, 2008). More recently, Ireland was positioned 13th out of 33 European countries in the 2009 European Healthcare Consumer Survey Index (Bjornberg, Cebolla Garrofe and Lindlaid, 2009). This is up two positions on the previous year.

an approved scientific standard, about where the hospital system needs improvement in order to ensure that patients receive the best possible hospital care at the end of their lives.

In this final chapter, we will return to the areas of the hospital system where significant and substantial improvements are necessary and possible. These improvements will help to make hospitals more hospitable to patients, while being more friendly and less fearful towards the reality of dying, as the term 'hospice-friendly hospital' suggests.

5.1 Overview of Patient Journey through the Hospital System

We begin with the overall map of the patient's journey though the hospital system, as summarised in Figure 3.2 above. In constructing this map, we distinguish between 'care outcomes' which are essentially different aspects of the care provided in hospital, and 'care inputs' which are the things that determine the quality of this care. Given that the entire analysis is built around these two sets of concepts, it is important to explain them briefly (see Chapter Two for a fuller explanation).

The core outcome of a hospital is care and, for patients who die there, we define and measure care outcomes in relation to the following dimensions: (i) acceptability of the way the patient died, (ii) quality of patient care, (iii) symptom experience, (iv) symptom management and (iv) support for family. These outcomes are matters of judgement rather than matters of fact and we rely on the judgement of nurses, doctors and relatives to make those judgements. Care outcomes are influenced by 'care inputs', which may be defined as the hospital's responses at each stage of the patient's journey. We identified ten care inputs, generally acknowledged to be relevant and important when considering the care of patients who die in hospital. In the main, information on care inputs was supplied by nurses who cared for the patient during the last week of life.

The results of our analysis show that eight sets of care inputs have a statistically-significant influence on care outcomes. These are: (1) disease and cause of death (2) route of admission (3) physical environment (4) team meetings (5) quality of communication with patients and relatives (6) support for families (7) staff readiness (8) hospital governance. Two factors, generally thought to be important to hospital care at the end of life – end-of-life care decisions and documentation in the healthcare record – were not found to have a statistically-significant influence on care outcomes once we have controlled for the above factors, although subsequent analysis revealed that their impact may be indirect and mediated through the eight factors which have a direct and positive impact on care outcomes.

Before proceeding to draw out the implications of the audit findings, we address an issue which has been central throughout the audit – how do nurses, doctors and relatives assess the outcomes of care? - but which also seems central to understanding how hospitals work. Related to this, we also discuss the fact that the direct voice of the patient is missing from the audit.

5.2 How Do Nurses, Doctors and Relatives Assess Care Outcomes?

When we examine the differences between nurses, doctors and relatives in detail, we find that while they agree on the acceptability of the way patient died in about two thirds of cases, for other care outcomes, the level of agreement is less than half. When nurses, doctors and relatives assess care outcomes, each appears to take different factors into account, placing a different value on those factors. Beginning with care outcomes, doctors are more likely to assess care in terms of symptom management which is associated in a statistically-significant way with their assessment of patient care and with their assessment of acceptability and family support. Nurses tend to assess on all the care outcomes with the strongest statistically-significant associations between patient care, acceptability and family support. For relatives, symptom experience influences their assessment of patient care which, in turn, is strongly associated in a statistically-significant way with their assessment of acceptability and family support.

Similarly, different patterns of assessment can also be seen with care inputs. Nurses give greater importance to all aspects of the physical environment where care is delivered, especially single rooms, compared to doctors or relatives. Nurses also give more importance to communication compared to relatives or doctors. Similarly, nurses place more value on the involvement of relatives – such as staying overnight and being present at the moment of death – than relatives themselves, while this is not a consideration in the assessment of care outcomes by doctors. By contrast, the assessment of care outcomes by doctors is influenced by whether the nurse has had training in end-of-life care and by whether there are end-of-life objectives in the business plan, unlike nurses and relatives. Overall, nurses take a much larger number of care inputs into account when assessing care outcomes compared to doctors or relatives, and relatives tend to be closer to nurses in the factors which influence their assessment of care outcomes.

These considerations highlight the different perspectives of nurses, doctors and relatives and, in some ways, offer an insight into the separate-but-connected 'universes' which inform those perspectives. Given that these perspectives are central to the care outcomes of patients at end of life - especially the assessments of nurses and doctors – the findings invite further reflection on how this may influence the practice of care, and whether the summary judgements of care outcomes in the audit are a true reflection of day-to-day practice. By documenting these differences - and giving transparency to processes within hospitals that are normally implicit, unspoken, and difficult to pin-down - it may be possible for hospital staff, through dialogue and reflection, to develop a more fluid and holistic perspective of care that is less partitioned by role and function than appears to be the case in the audit.

5.3 Missing the Patient's Voice

An acknowledged weakness of the audit is that the patient's voice is missing. This can be justified in terms of the difficulties of collecting information from patients during their last week of life, and the fact that it has become accepted and acceptable to rely on 'proxies' – in this case nurses, doctors, and relatives – to provide an approximation of the patient's experience. This justification does not close the issue and the possibility remains that proxies, however well-meaning, may not truly reflect the views of patients.

The audit re-opens this question by recording that, of the eight influences on care outcomes, one of the least powerful is the quality of discussion with the patient. Not only do nurses rate the quality of discussion with relatives as being significantly better than with patients, both nurses and relatives see their discussions as exercising much greater influence on care outcomes than the corresponding discussions with patients. In the case of doctors, their assessments of care outcomes cannot be predicted on the basis of the quality of discussions with patients or relatives. As discussed above, this may be due to the way we have measured communication which focused exclusively on verbal communication – the quality of discussion – since that may be less important than non-verbal communication as patients in their last week begin to show signs of withdrawing from the world and from contact with those around them. Indeed, some patients may become somnolent, comatose or delirious and, in these circumstances, relatives usually become patient proxies. At the same time, previous research suggests other possible explanations for the patterns of communication identified: (i) there is a general tendency among health care professionals to speak with the families of older people rather than the older person; (ii) hospital practitioners have difficulty talking about dying and death; and (iii) there is a fear that relatives have a power to complain which dying patients do not. Whatever the reason, these findings raise questions about whether the approach taken in the audit may have missed something important about the patient's voice.

5.4 Eighteen Ways to Improve Hospital Care at the End of Life

The purpose of the audit is to assist hospitals to meet, and if possible exceed, the Quality Standards for End-of-Life Care[175]. Given that these standards were not available when the audit was being carried out, it may be appropriate to refer to this report as a 'pre-audit' or 'baseline-audit' rather than an audit. Nevertheless, the audit is informative about the actual standards which are currently shaping hospital care at the end of life, while simultaneously providing strong indications about whether they are in conformity with normative standards.

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[175] Hospice Friendly Hospitals Programme, 2010; note also that the Design and Dignity Guidelines are also part of the standards (Hospice Friendly Hospitals Programme, 2007, 2008).

Conclusions: Issues for Consideration and Action

In responding to the findings of the audit therefore, it is important to do so in the overall context of quality standards, since these represent the benchmark against which the quality of care is to be judged. Within that context, the influence of each care input should be examined, whether statistically-significant or not. For care inputs that are statistically-significant, the key considerations that should inform a hospital's response to each finding relate to the size of its influence on care outcomes and its association with other statistically-significant influences.

The audit identified 18 separate influences on end-of-life care. These are analysed separately in the report, even though many of them are inter-connected in practice. In order to strengthen the link between audit findings and implementation of the standards, we present them thematically as 18 ways to improve end-of-life care under each of the four standards.

Standard 1. The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.

1.1 Put End-of-Life Objectives in the Hospital's Service Plan

Most influences on care outcomes occur at different points of contact along the patient's final journey through the hospital system. This journey begins with the patient's disease and route of admission, encountering the hospital's physical environment, communication with staff including team meetings, the readiness of staff for dealing with patients who are dying and facilitating relatives to be with the patient. Given the importance of these points of personal contact, it is striking that care outcomes are also influenced by less personal contact with patients, notably the hospital's service or business plan and whether it contains end-of-life objectives. The precise links between the formal stance adopted by the hospital, on the one hand, and improvements in care outcomes are not clear, but are most likely mediated by medical staff. This statistically-significant finding underlines the role that hospital management can play, through its governance, in setting an agenda to improve care for patients who die in hospital.

1.2 Move from Emergency to Planned Admissions

The end-of-life journey of patients who die in acute hospitals takes place in a health system which, by and large, does not operate a planned approach to admissions. Most patients who die in acute hospital are admitted through A&E, even though many have conditions that were diagnosed by this or another hospital. This suggests that there is a discontinuity in the health system between primary and acute care on the one hand, and between different episodes of acute care on the other.

The audit shows that emergency admissions through A&E have a statistically-significant and negative impact on care outcomes as assessed by doctors, nurses and relatives. It is noteworthy that the negative association between care outcomes and A&E admissions are mainly perceived by nurses and doctors, suggesting that the trajectory of these unplanned admissions may create specific difficulties for these professionals.

Naturally, A&E will remain the route of admission for accident and trauma cases and, for those who die in A&E or shortly thereafter, these deaths may be judged to be ‘unacceptable’ – if unavoidable – by nurses, doctors and relatives. For others, however, the route of admission through A&E, particularly where the patient’s condition is already well-known to the hospital, is a burden that may be avoidable and a more planned and hospitable route of admission could significantly improve care outcomes at the end of life. The extent to which this is possible will depend on the characteristics of each case and some patients may experience a sudden deterioration such as an acute onset of infection or a new symptom that requires immediate hospitalisation. However a more planned approach to admissions also depends on improving the coordination of services between hospital and community, and having systems in place which enable a more planned and patient-centred response even when emergencies arise. Conversely, a more planned approach to discharge might also reduce unplanned and emergency admissions.

1.3 Improve the Hospital's Physical Environment and Usage of Single Rooms

The audit confirms the importance – already well established in Irish and international research – that single rooms and the ward environment generally, are important for improving care outcomes. Specifically, single rooms are consistently associated in a statistically-significant way with better care outcomes in the assessments of nurses, doctors and relatives. In addition, wards which lack dignity or which have poor environmental quality are associated with poorer outcomes. Team meeting are also more likely to be held when patients are in a single room.

The quality of staff communication with relatives is better when patients are in a single room and this also enables relatives to stay overnight and be present at the moment of death. However, it is worth noting that single rooms are not associated with any improvement in the quality of communication with patients.

These findings should be seen in the context that, on average, Irish hospitals have about 15% of their beds in single rooms but manage to ensure that more than four in ten deaths (44%) occur in a single room. This suggests that hospital staff try to facilitate a more dignified death in a single room, and some hospitals are better at this than others. This could also help to explain why, at this stage, a single room may make no further contribution to improving communication with the patient, as the patient's illness is likely to be at an advanced stage.

At the same time, it merits repeating that the proportion of single rooms in Irish hospitals falls below all standards for this type of hospital accommodation. The results of the audit provide solid statistical evidence that substantial improvements in care outcomes could be achieved by simply increasing the number of deaths that take place in a single room.

The substantial influence exercised by the hospital's physical environment on its care outcomes merits further consideration by management and staff. This is because the audit shows that they – as well as relatives – have a tendency to over-rate the quality of the physical environment by comparison with the ratings of independent healthcare consultants, and even compared to the staff ratings of hospital facilities in Northern Ireland. Conversely, they may under-estimate the negative aspects of the physical environment and its negative impact on care outcomes. In light of the known impact of dignity on care outcomes, it is noteworthy that nurses rated the dignity of multi-occupancy wards, where a majority of patients died, at 6.3 out of 10. These wards had, on average, five other patients, and a quarter of them were of mixed gender. This tendency to over-rate the physical environment of hospitals may be due to the fact that nurses – as well as relatives – rightly regard the quality of care as being more important than the quality of the physical environment, although it may also indicate a lack of awareness about what is possible and desirable in terms of evidence-based design in hospitals.

An important part of every large hospital is the mortuary. The Design and Dignity Guidelines identify 21 facilities that should be available in every mortuary but the audit results indicate that teaching hospitals have more of the required facilities (75%) compared to other acute (38%) or community hospitals (29%). The mortuary facilities that particularly require improvement, and which were also highlighted in a previous assessment, include viewing rooms, waiting rooms, interview rooms, and rooms for preparing and storing bodies. This is also consistent with a more recent review of mortuaries in Ireland.

1.4 Improve Documentation in the Healthcare Record

The audit suggests that key information about patients – such as the diagnosis of dying, patient's wishes and worries, decisions about palliative care – are documented in no more than three quarters of cases. The uneven quality of documentation is further illustrated by the fact that, in a substantial minority of cases, the responses of nurses and doctors do not agree about whether a particular item of patient information was documented.

From a comparative perspective, it would appear that the practice of documenting medical decisions about the end of life in Irish hospitals is less frequent than for patients in English hospitals on the Liverpool Care Pathway (LCP). These results suggest that existing practices for documenting discussions with patients and relatives, including their wishes and worries, may fall short of the HSE's standards for the management of healthcare records.

The results of our statistical analysis indicate that documentation about selected aspects of care – such as diagnosis of dying, decisions about palliative care, wishes of relatives to be kept informed - had no effect on any of the care outcomes. Given that documentation is essential to supporting a consistent approach to patient care across the hospital team – and is itself an indicator of quality of care – this result merits further reflection on how healthcare records are maintained.

The fact that documentation is markedly better for cancer patients than for other patients – who also have markedly better outcomes – suggests that practice standards in each medical specialty may have a substantial influence on the quality of documentation. Similarly, the fact that documentation is markedly better in oncology wards compared to other wards suggests that ward management may also be a contributory factor in the uneven quality of documentation. Overall, this finding suggests that documentation in each patient's healthcare record is an area requiring significant improvement in wards and hospitals.

1.5 Ensure Sufficient Ward Staff

The ward environment can be a demanding place of work and staffing levels are thus of primary importance. In the survey of ward staff, more than half (56%) indicated that staffing levels on their ward are inadequate. This indicator has a statistically-significant effect on care outcomes, and one that is detected by doctors in their assessment of the acceptability of the patient's death. Given its significance for care outcomes, this is an issue that merits attention by hospital management, requiring detailed and transparent assessments of workloads in relation to ward type, work processes and the composition of ward staff.

1.6 Improve Hospital Information Systems

The quality of information in any organisation is often a good indicator of what it values, based on the adage that "what gets measured gets done and what gets done gets valued". Applying this diagnostic procedure to hospitals suggests that death is not a priority for hospitals and for the HSE. For example, we found that the HSE collects relatively little data about deaths, while the different systems used by hospitals to record and retrieve information about deaths are rather weak. This was exemplified by the fact that many hospitals were unable to indicate the number of deaths referred to a coroner, the number of post-mortems and almost none were able to distinguish between a hospital post-mortem and a coroner's post-mortem. Equally, there were systemic weaknesses in recording the number of patients 'brought in dead' (BID) and some hospitals seemed to have difficulty distinguishing between those BIDs who are brought to the mortuary and those who are brought in for preparation by funeral directors.

Beyond the specific difficulties related to end-of-life data, the collection of other data for the audit (on matters such as patients, beds, staffing, etc.) was seriously challenged by the huge diversity of HSE databases and the fact that each tends to operate in isolation. Even the most elementary building block of an integrated information system – such as a unique identifier for each hospital – is missing, with the result that each hospital tends to be known by a slightly different name and/or acronym in each database.

The audit also encountered data difficulties in that the HSE classification of complaints to hospitals does not include the category 'end-of-life issues'. Complaints provide a valuable learning opportunity for a hospital, although it needs to be recognised that they are not an unambiguous indicator of quality. This is because complaints usually cover only a small proportion of patients and treatments within a given year (about 6% on average) and it is possible for patients to be satisfied with some aspects of a service and dissatisfied with others.[176] Complaints about end-of-life care face even greater difficulties because deceased patients cannot complain.

Overall the quality of information about end-of-life care in Irish hospitals is poor. This suggests

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[176] This was highlighted in a recent study of complaints to the National Health Service in Scotland which found that over 80% of those surveyed were satisfied with most aspects of the hospital care received but half of these (44%) were also dissatisfied with certain aspects of the service, especially waiting times (Craigforth, 2006: 19-21). Significantly, only 6% of those who expressed dissatisfaction proceeded to make a complaint and, for these, staff attitudes and behaviour were the single biggest source of complaint (Ibid: 42-44). This is not dissimilar to results of a survey, commissioned by the HSE's Office of Consumer Affairs, involving a random sample of 3,517 Irish people on their experience of public health and social care services in Ireland in 2007. A sub-sample of these (344, 10%) had experience of hospital services in the last year and reported high overall levels of satisfaction on dimensions such as: effective treatment by a trusted professional (78%), involvement in decisions and respect for own preferences (75%), clear and comprehensive information (80%), emotional support, empathy and respect (83%), easy to get around the hospital (74%). However there was a marked dip in satisfaction on dimensions such as cleanliness of hospital toilets (62%), contact with the hospital by phone (69%) and car-parking facilities (46%) (UCD and Lansdowne Market Research, 2007).

the need for a national minimum dataset on deaths in hospital – and other places of care – so that the HSE can produce a more accurate picture of deaths across the spectrum of care settings and address any governance issues that might arise from the analysis of that data.[177]

1.7 Facilitate Patients to Die at Home

The audit reveals that over a fifth of acute hospital patients (in the opinion of nurses and doctors) could have died at home if appropriate supports were available. This has significant implications in terms of meeting patient needs and preferences, and the associated costs.

In terms of preferences, it is known that a majority of Irish people would prefer to die at home and, interestingly, doctors and nurses have an even stronger preference to die at home. In addition, there is evidence that patients who die at home, and who die in the place they prefer, have a better quality of dying compared to those who do not.

Further consideration of this issue raised some doubts about the robustness of the assessments of nurses and doctors on who could have died at home, since they agree in less than half the cases, and the level of agreement falls to less than a third when the additional perspective of relatives is taken into account. While this does not undermine the importance of seeking to meet patient preferences to die at home where this is a realistic possibility, it suggests that hospital staff do not have an agreed methodology for making these assessments, leaving aside the additional question of whether there are adequate services to support this. Accordingly, any measures to facilitate patients to die at home must first involve a proper assessment of their needs and preferences - including supports at home and in the community - using protocols that have been tried and tested elsewhere. More generally, in order to facilitate the planning

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[177] For example, the audit revealed significant variation between hospitals in what happens to a patient's body after death such as the proportion of deaths that are referred to the coroner. While these referrals are understandably higher in A&E and ICU compared to other wards, there is also considerable variation between hospitals; some hospitals have 10% or less of deaths referred to a coroner while others have 20% and some have over 40%. This variation may be due to the differing profiles of deceased patients in each hospital, and there may also be some variation in the referral practices of A&E and ICU. The point is that, without proper data, this issue cannot be properly investigated. Similarly, hospital practices vary considerably with regard to 'brought in dead'. For example, in six acute hospitals bodies are brought in to be prepared by funeral directors but this does not happen in other hospitals. In July 2009, the HSE issued a Memorandum on Embalming at Hospitals Operated or Funded by the HSE which implements a number of recommendations from the Retained Organs Audit (Willis, 2009: 120-121).

of services, an assessment of the proportion of patients who could die at home would need to be carried out and peer reviewed, in order to establish the likely scale of alternative support services needed.

Standard 2. The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

2.1 Develop Skills to Diagnose End-of-Life and Dying

A surprising finding of the audit is that certain aspects of end-of-life care – notably diagnosis of dying, making decisions about appropriate treatment and care, and the use of specialist palliative care – do not have any statistically-significant influence on care outcomes when all other factors are taken into account. It is recognised that diagnosing when the end-of-life journey begins, and specifically when dying begins, can be difficult and uncertain. Nevertheless, nurses and doctors report that, in the vast majority of cases (86%), they had diagnosed dying 5-6 days before the patient's death, much more frequently than in French hospitals and earlier than in English hospitals.

One possible reason why the diagnosis of dying does not have an impact on care outcomes may be that that there is substantial variation in the diagnostic skills of hospital staff, which effectively means that some deaths were 'diagnosed' retrospectively rather than prospectively and, as a result, they had no impact on the care provided. Another possibility is that there is substantial variation in the way hospitals, wards and individual staff respond to a diagnosis of dying with the result that a diagnosis of dying has no systematic effect on care outcomes. Given the importance of assessing patient needs through proper diagnosis, this result merits further investigation by hospitals.

2.2 Improve End-of-Life Care Decision-Making

The audit revealed that the extent to which end-of-life decisions are taken about dying patients in Irish hospitals is significantly lower compared to patients dying in English hospitals, especially those on the Liverpool Care Pathway (LCP). Although decisions to withhold or withdraw life support are taken more frequently in intensive care (53%), compared to other wards (47%), they are much less frequent compared to the practice in 17 European countries. Our analysis reveals that end-of-life care decision-making – either the overall number of decisions or the specific decision to 'review medication, route of administration, and stop non-essential medication' – had no statistically-significant effect on care outcomes.

As with the diagnosis of dying, this finding suggests that there may not be a common approach to end-of-life decision-making. All standards for end-of-life care indicate that an effective approach requires making appropriate decisions when the patient is no longer responding to active treatment or has a life-limiting illness which has deteriorated recently and rapidly, or where the patient is presenting signs of dying. The audit suggests that, for whatever reasons, these decisions are not regularly being made in Irish hospitals and, where they are made, they seem to have little effect on care outcomes. This is a challenging finding because it suggests that while hospitals provide 'care at the end of life' they are not necessarily providing 'end-of-life care' because the care seems to lack an effective palliative care component.

2.3 Hold Team Meetings

The audit reveals that considerable flexibility and informality exists around the holding of, and attendance at team meetings in hospital, and there is clearly no standardised procedure for reporting the outcome of meetings to patients and relatives. This is suggested not just by the responses of doctors and nurses, but also by the fact that these responses disagree on whether the meeting actually took place in up to a third of cases.

Our analysis shows that team meetings have a statistically-significant impact on care outcomes, especially symptom management and patient care, but are also associated with other predictors of care outcomes such as a cancer diagnosis, dying in a single room and better communication with patients and relatives. Conversely, team meetings are less likely in cases where there are negative predictors of care outcomes such as sudden death, death in A&E or a surgical ward, due to accident or trauma, or within a week of admission. Given that three quarters of all deaths are not sudden, there is scope to ensure that the beneficial effects of team meetings are extended to more patients who die in hospital.

The fact that the frequency of team meetings varies by ward (being more frequent in oncology and geriatric wards) and diagnostic category (being more frequent for cancer patients) suggests that a team approach to patient care, where it exists, may be more influenced by the work practices of different disciplines and wards rather than by a hospital-wide approach to planning the end-of-life care of patients. While this underlines the diversity of practices, it also draws attention to the fact that these practices are not influenced by patient needs but by the work habits of different specialties and wards and could, therefore, be changed.

2.4 Provide Training in End-of-Life Care

Nurses who have received formal training on end-of-life or palliative care since qualifying can achieve better care outcomes than nurses who have not. This is a statistically-significant finding and a definitive endorsement of the value of training. We also know that training is strongly correlated with nurses feeling prepared for the death of a patient and feeling comfortable talking about death and to people who have recently been bereaved. This suggests that training may help nurses to relate more comfortably to the reality of dying and death and to their own fears about dying and death, which are inevitably projected onto patients and relatives. This finding provides encouragement to hospitals and staff that training is an investment that pays dividends in terms of improved care outcomes.

Ideally, basic training on end-of-life issues should be provided for all professional, support and administrative staff who come into contact with patients and relatives, with more intense training for clinical staff in areas such as breaking bad news, end-of-life discussions, diagnosing dying, managing symptoms, understanding bereavement and loss, and dealing with death at a personal level. In addition, end-of-life care is rarely mentioned in staff induction, unlike the practice in Northern Ireland where it is an integral element of induction, and this is something that needs to be addressed.

As with communication, one of the obstacles to training in end-of-life care is the belief by a majority of hospital staff – and the vast majority of nurses and doctors – that they are already well-prepared for dealing with the death of a patient, even though most staff have not had any training in this area. The fact that training in end-of-life care makes a statistically-significant difference to care outcomes, as the audit reveals, may help to dissolve resistance by inviting nurses, doctors and other hospital staff to be more open to the possibility that training could improve their practice and improve care outcomes for patients and relatives.

2.5 Prepare Staff for the Death of Patients

The fact that care outcomes are substantially better in a statistically-significant way when a nurse feels prepared for dealing with the death of a patient may appear obvious. However, the fact that most hospital staff receive little or no preparation for different aspects of care at the end of life suggests that, if obvious, this insight is rarely acted upon. The audit clearly draws attention to the importance of preparing hospital staff for the specific aspects of this care, and the absence of this preparation may help explain why hospitals seem to provide generic 'care at the end of life' rather than more specific 'end-of-life care'.

Feeling prepared for the death of a patient is enhanced by experience and training, but it is also strongly associated with feeling comfortable talking about death and talking to people who have been recently bereaved. This underlines the personal as well as the professional aspect of care, especially in caring for dying patients, and the specific need to address the fears that hospital staff have about dying and death.

The fear of dying and death is common, and most people experience it, at some stage and to some degree. It is widely recognised that this fear has an influence on how each person relates to, and is able to speak about, dying and death. Naturally, this fear affects healthcare professionals as much as other people, and this has been cited as one of the reasons why end-of-life care in hospitals is often less than satisfactory. The link between the fear of dying and death, and the quality of care offered to dying patients was articulated over 40 years ago by Elisabeth Kubler-Ross – herself a medical doctor – in her pioneering work on dying and death: "When a patient is severely ill, he is often treated as a person with no right to an opinion. ... He may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine, or a tracheostomy. He may want one single person to stop for one single moment so that he can ask one single question – but he will get a dozen people round the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being. ... Is the reason for this increasingly mechanical, depersonalised approach our own defensiveness? Is this approach our own way to cope with and repress the anxieties that a terminally or critically ill patient evokes in us? Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending end, which is so frightening and disquieting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being, which would remind us once more of our lack of omnipotence, our own limitations and fallibility and, last but not least perhaps, our own mortality?"[178]

We did not collect information on the preparedness of doctors – or other hospital staff – to care for dying patients, and we acknowledge that this gap should be addressed since we know that many doctors are not comfortable talking about dying and death and are even less comfortable talking to a person who has been recently bereaved.

2.6 Build on the Experience of Staff

The finding that a nurse's years of experience working in a hospital and ward has an independent effect on care outcomes is an important result. There is a common assumption that, over time, people get better at what they do, but this is far from inevitable and improvement requires more than the simple passage of time. The effect of experience identified in the audit may embody the simple process of growing older and wiser, itself a psychological and not just a chronological process. It may also embody a relationship with work and service whereby, through dedication and reflection, years of experience become wells of experience.

This finding gives substance to the idea that a hospital's greatest resource is its staff but adds to

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[178] Kubler-Ross (2009: 7-8).

it by showing that the resource improves as staff mature. It seems likely that the same processes apply to doctors and other hospital staff but, since we collected this data from nurses only, we are not in a position to confirm this. Nevertheless, the finding underlines the importance of retaining experienced nurses within the hospital and ward, and ensuring that they have a direct role in patient care. Ideally, the benefits of staff experience are mediated through ward managers who, by example, set and maintain standards of clinical care that produce better outcomes. In addition, the finding invites hospitals to think creatively about the processes that need to be in place to help staff distil their years of experience into a more mature understanding of the simple essence of care.

Standard 3. The Patient

Each patient receives high quality end-of-life care that is appropriate to his / her needs and wishes.

3.1 Extend to All Patients the Quality of Care for Cancer Patients

The fact that a patient's disease is a statistically-significant influence on his or her care outcomes at the end of life could be seen as a challenge to the equal treatment of patients. Indeed, as we have seen, the audit reveals that there is a 'hierarchy' in the quality of dying in hospital based on type of disease. The hierarchy of care, from the best to the worst descends from cancer to circulatory diseases, respiratory diseases and dementia/frailty.

This finding prompts the question as to why hospitals are able to offer better care to cancer patients than other patients. It is true that the end-of-life trajectory of cancer patients is more predictable compared to other patients, but the audit suggests that this is not the reason for their better care outcomes. Our analysis suggests that cancer patients have better care outcomes because their route of admission to hospital is more likely to be planned, team meetings are more frequent, patients are more likely to die in a single room, and relatives are more likely to be present at the moment of death.

Apart from patients who die suddenly, there seems to be no obvious reasons why these options could not be available to all other patients. This suggests that the quality of care in the specialty of cancer care – which is not confined to patients in oncology wards but affects all cancer patients, the majority of whom are not actually cared for in oncology wards - offers an example of how end-of-life care could be improved. This finding also opens up the possibility that this specialty could take a lead role in terms of improving end-of-life care across each hospital.

3.2 Improve the Quality of Communication with Patients

The audit reveals that communication with patients is one of the weakest influences on care outcomes though still statistically-significant. This is contrary to substantial research evidence that effective and empathic communication influences the quality of care and the quality of life of patients who are dying, but consistent with an even larger body of evidence that this is an area where end-of-life care could be improved within hospitals. Our finding may be due to the way we measured communication which focused exclusively on verbal communication – the quality of discussion – since that may be less important than non-verbal communication as patients in their last week begin to show signs of withdrawing from the world and from contact with those around them. Indeed, some patients may become somnolent, comatose or delirious and, in these circumstances, relatives usually become patient proxies. At the same time, previous research suggests other possible explanations for the patterns of communication identified: (i) there is a general tendency among health care professionals to speak with the families of older people rather than the older person; (ii) hospital practitioners have difficulty talking about dying and death; and (iii) there is a fear that relatives have a power to complain which dying patients do not.

Some of the more intriguing findings of the audit relate to communication with patients and relatives. When asked how well (on a 10-point scale) the staff team communicated with the patient, nurses rated this at the upper end of the scale (7.0) while doctors give even higher ratings (7.7). When a similar question was asked about communication with relatives, the rates were consistently higher than for patients, according to nurses (8.6) as well as doctors (8.8). In fact, the overall relationship with relatives (which we call family support) is consistently better, in the assessment of nurses and doctors, than their relationship with patients (which we call patient care).

Further statistical analysis showed that the acceptability of the patient's death for nurses is related to the quality of staff discussions with relatives (not patients). The quality of these discussions also influences nurses' assessments of patient care, but does not predict doctors' ratings of care outcomes. It is clear from this that, during the last week of life, discussions with relatives are more influential than discussions with patients. Additional analysis showed that the quality of discussions with patients is better when the nurse feels more prepared for dealing with the death of a patient, and this may be one of the keys for improving communication with patients, as well as addressing the apparent lack of balance in the triangular relationship between patients, nurses/doctors and relatives.

Overall, these findings invite reflection and discussion about how nurses and doctors – and hospital staff generally - communicate verbally and non-verbally with patients during their final weeks and days. The findings also provide evidence for suggesting that hospital staff may benefit from some basic training in communication skills. It is remarkable that this aspect of hospital care is often overlooked, and even more remarkable that nurses and doctors rate their communication skills so highly - and more highly than relatives experience them – given that communication is the weakest influences on care outcomes in the audit. This suggests that one of the obstacles to improving communication skills may be the belief that nurses and doctors do not need training since, paradoxically, they are not aware of problems in communicating with patients and relatives.

3.3 Strengthen the Role of Specialist Palliative Care

In Ireland, only a quarter of acute hospitals meet the government-approved standard of having a full specialist palliative care team.[179] In addition, specialist palliative care services are unevenly distributed between hospitals. This uneven distribution seems to reflect supply-led considerations – such as some hospitals seeking palliative care resources while others do not – rather than any objective measure of need such as the number of deaths. This, in turn, highlights the need for a more explicit resource allocation model for specialist palliative care services that is firmly needs-based, and reflects demand-led rather than supply-led considerations.

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[179] This result is in line with a more comprehensive analysis of specialist palliative care teams in 38 acute hospitals carried out by the Irish Hospice Foundation (IHF), based on 2004 data. See Murray, Sweeney, Smyth and Connolly (2006), Murray (2008).

The audit reveals that a majority of patients did not receive specialist palliative care. The proportion of patients who actually received such care varies from 22% according to doctors to 32% according to nurses, a substantial 10-percentage point difference of opinion. In over a quarter of cases where patients did not receive specialist palliative care, nurses and doctors did not know if the patient would have benefited from it. This suggests that there may be some misunderstanding between nurses and doctors as to what exactly the term specialist palliative care implies.

In a comparative context, the proportion of patients in the audit who received specialist palliative care is higher compared to UK hospitals (19%), and much higher compared to French hospitals where, according to one study, "only 12.1% had a palliative care consultation". Patients in A&E and ICU are an exception to this, as the audit reveals that specialist palliative care services are consulted in only 3-6% of cases respectively in these wards.

Overall, specialist palliative care is known to be effective and the audit suggests that its effectiveness is mediated through other variables which are known to have a direct positive impact on care outcomes such as cancer patients, single rooms, team meetings, and support for families. This finding is consistent with the fact that specialist palliative care frequently provides expert advice to doctors and nurses but does not manage their cases. Nevertheless, the audit also identified a lack of clarity about the role of specialist palliative care services in acute hospitals and this points to the need to strengthen its role to meet the expectations envisaged by the National Advisory Committee on Palliative Care. The audit also suggests expanding its role to meet the needs of all patients who need it.

Standard 4. The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during and after the patient's death.

4.1 General Support for Families

The audit reveals that one of the strengths of the hospital system is its relationship with families, both in terms of the quality of communication and facilitating them to be with the patient as much as possible, including at the moment of death. This has a statistically-significant and positive influence on care outcomes, consistent with other research which shows that the presence of family members at the time of death can be important for the dying patient as much as for the relatives. Hospitals offer a range of supports to assist relatives spend time with the patient including: the facility to visit at any time (88%), staying overnight in the hospital (67%) and the provision of snacks (78%). Relatives were present in at least two thirds of deaths (65%), and possibly more (there is no information in nearly a fifth of cases). This is much higher compared to a study of dying in French hospitals where only a quarter had family or friends present.

These findings confirm the importance of relatives in supporting the patient, and helping the hospital to provide good care at the end of life. In this sense, the findings endorse and encourage the widespread practice in Irish hospitals of supporting families to be with the patient during their final journey.

4.2 Support for Families Following Sudden Deaths

Just as cancer is correlated with more positive care outcomes, sudden deaths are correlated with more negative ones. In fact, the sudden onset of death is the strongest and most negative predictor of care outcomes. Sudden deaths are much more likely to occur in A&E and ICU, and are negatively associated with all of the statistically-significant predictors of positive care outcomes. In addition, sudden deaths are more likely to result in a post-mortem and, understandably, this can be difficult for relatives since the sense of loss at death may be compounded by the shock of its suddenness, and by the fact that funeral arrangements may have to be delayed as a result of the post-mortem..

The audit shows that whenever a post-mortem takes place, about two thirds of relatives were made aware of the reasons for it in a sensitive, timely and clear manner. However, a third of relatives do not seem to have been properly informed about the reasons for the post-mortem and were less than satisfied with the information provided by the hospital. In light of this, hospitals may wish to look at their systems for responding to the more intense needs of relatives in the event of a sudden death and/or post-mortem.

5.5 Concluding Comments

We began this chapter with the observation that, in many respects, the quality of care for patients who die in an Irish hospital compares favourably with the care provided by hospitals elsewhere. This care tends to be generic rather than specific in the sense that it might be more appropriate to describe it as 'care at the end of life' rather than 'end-of-life care'. At the same time, the audit has also shown that there are significant and substantial weaknesses in how the hospital system responds at each point of the patient's final journey from admission to death. By the same token, these weaknesses also contain the seeds of improvement and this chapter has suggested ways in which the care of patients could be improved.

It is worth recalling that this audit report forms part of a wider HFH programme, whose core aim is to improve the quality of care for people who die in Irish hospitals. The audit, along with the standards which have been developed for end-of-life care are offered to assist and resource each hospital to become a hospice friendly hospital. Knowledge and information can make a valuable contribution to improving the quality of end-of-life care. However, these are rarely the most important influences on quality improvement, in healthcare as in other settings. Most of the challenges in quality improvement are more human than technical and, although careful planning and coordination of actions are important, leadership is crucial at very level of the health service - in the HSE, in each hospital, in each specialty, in each ward; ultimately, these forms of leadership model a sense of service that imbue individual staff with an understanding and commitment to the essence of care.

The findings of the audit, and the issues raised in this final chapter, offer each hospital a menu of options that may assist them in playing a more caring, compassionate and comfortable role in society around dying, death and bereavement. The fact that there is substantial variation in the quality of care offered to patients and relatives at the end of life – not only between hospitals, specialties and wards but within them as well – demonstrates the scope for improvement that already exists and demonstrates what is possible for each hospital, specialty, ward and staff member. In this way, hospitals can become more hospitable places to die, and more friendly and less fearful towards dying and death, as the term hospice friendly hospital suggests.

Bibliography

Abel, J., Rich, A., Griffin, T., and Purdy, S.,2009. 'End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year', Palliative Medicine, 28 May.

Achterberg, WP., Gambassi, G., Finne-Soveri, H, Liperoti, R., Noro, A., Frijters, DHM., Cherubine, A., Dell'Aquila, G., and Ribbe, MW., 2009. 'Pain in European long-term care facilities: Cross-national study in Finland, Italy and the Netherlands', Pain, doi:10.1016/j.pain.2009.10.008.

Addicott, R., and Dewar, S., 2008. Improving choice at end of life: A descriptive analysis of the impact and costs of The Marie Curie Delivering Choice Programme in Lincolnshire, London: King's Fund. Available at www.kingsfund.org.ul/publications. Accessed on 14 October 2009.

Addington-Hall, JM., et al, 1992. 'Randomised Control Trial of effects of coordinating care for terminally ill caner patients', BMJ, Vol 305, pp.1317-1322.

Addington-Hall, J., and O'Callaghan, AC., 2009. '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 to hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire', Palliative Medicine, 23, pp.190-197.

Ainsworth, MDS., 1991. 'Attachments and other Affectional Bonds Across the Life Cycle', in Parkes, CM., Stevenson-Hindle, J., and Marris, P., (Editors), Attachment Across the Life Cycle, pp.33-51, New York: Tavistock/Routledge.

Angus, DC., Barnato, AE., Linde-Zwirble, WT., et al., 2004. 'Use of intensive care at the end of life in the United States: an epidemiologic study'. Crit Care Med, 32: 638-43.

Baker, R., Wu, A.W., Teno, J.M., Kreling, B., Damiano, A.M., Rubin, H.R., Roach, M.J., Wenger, N.S., Phillips, R.S., Desbiens, N.A., Connors, A.F., Jr., Knaus, W., & Lynn, J., 2000. 'Family satisfaction with end-of-life care in seriously ill hospitalized adults'. Journal of the American Geriatrics Society, 48(5 Suppl), S61-9.

Bate, P., Mendel, P., and Robert, G., 2008. Organizing for Quality: The Improvement Journeys of Leading Hospitals in Europe and the United States: Oxford: Radcliffe Publishing.

Bibliography

Bjornberg, A., Cebolla Garrofe, B., and Lindblad,A., 2009. European Healthcare Consumer Survey Index 2009: Report, Health Consumer Powerhouse. Available at www.healthpowerhouse.se. Accessed on 26 March 2010.

Bondestam, E., Hovgren, K., Gaston Johansson, F., Jern, S., Herlitz, J., and Holmberg, S., 1987. 'Pain assessment by patients and nurses in the early phase of acute myocardial infarction'. J Adv Nurs, Nov, 12(6):677-82.

Bowlby, J., 1979. The Making and Breaking of Affectional Bonds, London: Tavistock.

Bruera, E., Willey, JS., Ewert-Flannagan, PA., Cline, MK., Kaur, G, Shen, L., Zhang, T., and Palmer, JL., 2005. 'Pain intensity assessment by bedside nurses and palliative care consultants: a retrospective study'. Support Care Cancer, Apr, 13(4):228-31.

Budischewski, KM., de la Fuente, F., Nierhoff, CE., Mose, S., 2006. 'The burden of pain of inpatients undergoing radiotherapy – discrepancies in the ratings of physicians and nurses'. Onkologie, Oct, 29(10):431-5.

Casarett, D., Pickard, A., Bailey, FA., et al., 2008. 'Do palliative consultations improve patient outcomes?' Journal of American Geriatric Society, 56(4), 593-599.

Census 2006, 2007. Principal Demographic Results, March, Dublin: Stationery Office.

Chanvej, L., Petpichetchian, W., Kovitwanawong, N, Chaibandit, C., Vorakul, C., Khunthong, T., 2004. 'A chart audit of postoperative pain assessment and documentation: the first step to implement pain assessment as the fifth vital sign in a University Hospital in Thailand', J Med Assoc Thai, Dec, 87(12):1447-53.

Cohen, SR., Boston, P., and Mount, BM., 2001. 'Changes in quality of life following admission to palliative care units', Palliative Medicine, 15(5), 363-371.

Collins, N., Phelan, D., Marsh, B., and Sprung, CL., 2006. 'End-of-life care in the intensive care unit: the Irish Ethicus data', Critical Care and Resuscitation, Volume 8, Number 4, December, pp.315-320.

Bibliography

Commission on Patient Safety and Quality Assurance, 2008. Building a Culture of Patient Safety, July, Dublin: Stationery Office. Available at www.doh.ie

Connor, S. R., Teno, J., Spence, C., & Smith, N., 2005. 'Family evaluation of hospice care: results from voluntary submission of data via website'. Journal of Pain and Symptom Management, 30(1), 9-17.

Copeland, G., 2005. A Practical Handbook for Clinical Audit, March, Published at: http://www.evidence.nhs.uk

Cornwell, J., and Goodrich, J., 2009. 'Exploring how to enable compassionate care in hospital to improve patient experience', 21 April, www.nursing times.net.

Cornwell, J., 2009. 'Exploring how to improve patients' experience in hospital at both national and local levels', 6 July, www.nursing times.net.

Coulehan, J.L., Platt, F.W., Egener, B., et al., 2001. 'Words that help build empathy'. Annals of Internal Medicine, 135, 221–227.

Curtis, J. R., Patrick, D. L., Engelberg, R. A., Norris, K., Asp, C., & Byock, I., 2002. 'A measure of the quality of dying and death. Initial validation using after-death interviews with family members'. J Pain Symptom Manage, 24(1), 17-31.

Davoudi, N., Afsharzadeh, P., Mohammadalizadeh, S., and Haghdoost, AA., 2008. 'A comparison of patients' and nurses' assessment of pain intensity in patients with coronary artery disease', Int J Nurs Pract. October 14(5):347-56.

Department of Health, 2008. End of Life Care Strategy: Promoting high quality care for all adults at the end of life, July, January, London: Department of Health. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm. Accessed 30 May 2009.

Department of Health, 2009. End of Life Care Strategy: Quality Markers and measures for end of life care, June, January, London: Department of Health. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm. Accessed 30 May 2009.

Bibliography

Facility Guidelines Institute and the AIA Academy of Architecture for Health, 2006. Available at: http://www.fgiguidelines.org/guidelines.html. Accessed 20 March 2009.

Ferrand, E., Jabre, P., Vincent-Genod, C., et al, 2008. 'Circumstances of Death in Hospitalized Patients and Nurses' Perceptions', Arch Intern Med, 168(8), 28 April, 867-875.

Finne-Soveri, UH., Ljunggren, G., Schroll, M., Jonsson, P.V., Hjaltadottir, I., El Kholy, K., and Tilvis, RS., 2000. 'Pain and its association with disability in the institutional long-term care in four Nordic countries', Can J Aging 19, pp. S38–S49.

Firth-Cozens, J., and Cornwell, J., 2009. The Point of Care: Enabling compassionate care in acute hospital settings, April, London: The King's Fund. Available at: www.kingsfund.org.uk/publications.

Fries, BE., Simon, SE., Morris, JN., Flodstrom, C., and Bookstein, FL., 2001. 'Pain in U.S. nursing homes: validating a pain scale for the minimum data set', Gerontologist 41, pp. 73–179.

Edmonds, P., & Rogers, A., 2003. 'If only someone had told me . . .' A review of the care of patients dying in hospital'. Clinical Medicine, 3(2), 149-52.

Gilbert, D., 2006. Stumbling on Happiness, New York: Knopf.

Goodrich, J., and Cornwell, J., 2008. Seeing the Person in the Patient: The Point of Care review paper, November, London: The King's Fund. Available from: www.kingsfund.org.uk/publications Accessed on 8 September 2009.

Goodrich, J., 2009. 'Exploring the wide range of terminology used to describe care that is patient-centred'. Nursing Times.net, 19 May. Available at: http://www.nursingtimes.net/nursing-practice-clinical-research/acute-care/exploring-the-wide-range-of-terminology-used-to-describe-care-that-is-patient-centred/5001746.article. Accessed 24 August 2009.

Grossman, SA., Sheidler, VR., Swedeen, K., Mucenski, J., Piantadosi, S., 1991. 'Correlation of patient and caregiver ratings of cancer pain', J Pain Symptom Manage, Feb, 6(2):53-7.

Bibliography

Harvey, S., Liddell, A., and McMahon, L., 2009. Windmill 2009: NHS response to the financial storm, London: The King's Fund. Available from: www.kingsfund.org.uk/publications Accessed on 18 December 2009.

Health Service Executive and Irish Hospice Foundation, 2008. Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks, June, . Available at: http://www.hospice-foundation.ie and http://www.hse.ie Accessed on 8 June 2009.

HSE Audit of Palliative Care Service Provision, 2007, Dublin: Health Service Executive. Available at: http://www.hse.ie/eng/services/Publications/corporate/palframework.html Accessed on 5 October 2009.

HSE National Service Plan 2009, 2008. November. Dublin: Health Services Executive. Available at: http://www.hse.ie/eng/Publications/corporate/National_Service_Plan_2009.pdf Accessed on 5 October 2009.

HSE Palliative Care Services – Five Year Development Framework 2009-2013, 2009. Dublin: Health Service Executive. Available at: http://www.hse.ie/eng/services/Publications/corporate/palframework.html Accessed on 5 October 2009.

Hearn, J., and Higginson, IJ., - Palliative Care Audit Project Group, 1999. 'Development and validation of a core outcome measure for palliative care: The palliative care outcome scale', Quality in Health Care, Vol 8, pp.219-227.

Heyland, D.K., Groll, D., Rocker, G., Dodek, P., Gafni, A., Tranmer, J., Pichora, D., Lazar, N., Kutsogiannis, J., Shortt, S., & Lam, M., 2005. 'End-of-life care in acute care hospitals in Canada: a quality finish?' Journal of Palliative Care, 21(3), 142-50.

Hodges, M., London, M.R., & Lundstedt, J., 2006. 'Family-driven quality improvement in inpatient end-of-life care'. Journal for Healthcare Quality, 28(2), 20-6, 31.

Hodde, N. M., Engelberg, R. A., Treece, P. D., Steinberg, K. P., & Curtis, J. R., 2004. 'Factors associated with nurse assessment of the quality of dying and death in the intensive care unit'. Crit Care Med, 32(8), 1648-1653.

Hojat, M., Gonnella, J.S., Nasca, T.J., et al. 2002. 'Physician empathy: Definition, components,

Bibliography

measurement, and relationship to gender and specialty'. American Journal of Psychiatry, 159, 1563–1569.

Horton, R., 2002. 'Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting', Palliative Medicine, Nov, 16(6):488-94.

Hospice Friendly Hospitals Programme, 2010. Quality Standards for End-of-Life Care in Hospitals, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net.

Hospice Friendly Hospitals Programme, 2008. Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care, June, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net.

Hospice Friendly Hospitals Programme, 2007. Design and Dignity Baseline Review, November, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net.

Hospital In-Patient Enquiry, 2006. December, Dublin: Economic and Social Research Institute.

HSE National Hospitals Office, 2008. Code of Practice for Healthcare Records Management, October, Available at www.hse.ie Accessed on 16 October 2009.

Irish Life Tables No. 15, 2009. 29 January, Dublin: Central Statistics Office. Available at: http://www.cso.ie/releasespublications/documents/births_d_m/current/irishlife.pdf. Accessed 24 August 2009.

Irish Medical Council, 2004. A Guide to Ethical Conduct and Behaviour, Dublin: Irish Medical Council.

Irvine, B., 1993. 'Developments in palliative nursing in and out of the hospital setting'. British Journal of Nursing, 2(4), 218-20, 222-4.

Bibliography

Janssen, AL., Macleod, RD., and Walker, ST., 2008. 'Recognition, reflection, and role models: Critical elements in education about care in medicine', Palliative and Supportive Care (), 6, 389–395.

Keegan, O., McGee, H., Brady, T., Kunin, H., Hogan, M., O'Brien, S., and O'Siorain, 1999. Care for the Dying – Experiences and Challenges. A study of quality of health service care during the last year of life of patients at Saint James's Hospital, Dublin, from their relatives' perspective, February, Dublin: Royal College of Surgeons of Ireland and the Irish Hospital Foundation, and St. James's Hospital.

Keegan, O., McGee, H., Hogan, M., Kunin, H., O'Brien, S., & O'Siorain, L. 2001. 'Relatives views of health care in the last year of life'. International Journal of Palliative Nursing, 7(9), 449-456.

Keller, JA., and Kronick, K., 2008. 'Transforming care in children's hospitals through environmental design: Literature Review', in Evidence for Innovation: Transforming Children's Health Through the Physical Environment, Alexandra VA: National Association of Children's Hospitals and Associated Institutions, pp.18-47. Available at http://www.childrenshospitals.net Accessed on 26 May 2009.

Kendall, M., Harris, F., Boyd, K., Sheik, A., Murray, S., Brown, D., Mallinson, I., Kearney, N., and Woth, A., 2007. 'Key challenges and ways forward in researching the 'good death': qualitative in-depth interview and focus group study', BMJ, 334:521 (10 March).

Klinkenberg, M., Willems, DL., van del Wal, G., Degg, DJ., 2004. 'Symptom burden in the last week of life', Journal of Pain and Symptom Management, 27(1):5-13.

Kubler-Ross, E., 2009. On Death and Dying. What the Dying have to Teach Doctors, Nurses, Clergy, and their own Families. Fortieth Anniversary Edition, Oxon: Routledge.

Law Reform Commission, 2009. Bioethics: Advance Care Directives, Report, September, Dublin: Law Reform Commission,

Levy, CR., Ely, EW., Payne, K., Engelberg, RA., Patrick, DL., and Curtis, JR., 2005. 'Quality of Dying and Death in Two Medical ICUs', Chest, 127, 5, May, pp.1775-1783. Available from www.chestjournal.org

Bibliography

Lorenz K., Lynn, J., Morton, SC., Dy S., Mularski, R., Shugarman, L., Sun, V., Wilkinson, A., Maglione, M., Shekelle, PG., 2004. End-of-Life Care and Outcomes. Evidence Report/ Technology Assessment No. 110. (Prepared by the Southern California Evidence-based Practice Center, under Contract No. 290-02-0003.) AHRQ Publication No. 05-E004-2. Rockville, MD: Agency for Healthcare Research and Quality. December 2004. Available at www.ncbi.nlm.nih.gov

Lunney JR, Lynn J, Hogan C., 2002. 'Profiles of Older Medicare Decedents', J Am Geriatr Soc, Vol. 50, No. 6, pp. 1108-1112.

Lynn J., Schuster JL., Kabcenell A., 2000. Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians, RAND , 2000.

Lynn J., Schall M. W., Milne C., Nolan K. M., Kabcenell A., 2000. 'Quality improvements in end-of-life care: Insights from two collaboratives'. Journal of Quality Improvement 26: (5) 254-267.

Lynn J., 2004. Sick to Death and Not Going to Take it Anymore! Reforming Health Care for the Last Years of Life, California/Milbank Books on Health and the Public, University of California Press, Berkeley, CA: 2004.

Macleod, R., and McPherson, KM., 2007. 'Care and compassion: Part of person-centred rehabilitation, inappropriate response or a forgotten art?', Disability and Rehabilitation, Ocotber-November, 29(20-21):1589-1595.

Marie Curie Palliative Care Institute Liverpool, 2007. National Care of the Dying Audit – Hospitals (NCDAH): Generic Report, 2006/2007, December, Liverpool: Marie Curie Palliative Care Institute. Available from www.mcpcil.org.uk

Marie Curie Palliative Care Institute Liverpool, 2009. National Care of the Dying Audit – Hospitals (NCDAH): Round 2, Generic Report, 2008/2009, September, Liverpool: Marie Curie Palliative Care Institute. Available from www.mcpcil.org.uk

McCormack, B., and Wright, J., 2009. The Implementation of a Model of Person Centred Practice in Older Person Settings: Interim Report, July, Newtownabbey Co. Antrim: University of Ulster.

Bibliography

McCarthy, S., and O'Boyle, C., 2010. Family Views of End-of-Life Care in Acute and Community Hospitals, Dublin: Royal College of Surgeons of Ireland and the Irish Hospice Foundation.

McGlone, E., and Fitzgerald, F., 2005. Perceptions on Ageism in Health and Social Services in Ireland, Report No. 85, Dublin: National Council on Ageing and Older People.

McKeown, K., 2008. National Audit of End-of-Life Care in Hospitals in Ireland, The Manual, October, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010a. Resources and Facilities for End-of-Life Care in Irish Hospitals, National Audit Report 1, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010b. Dying in Hospital in Ireland: Nurse and Doctor Perspectives, National Audit Report 2, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010c. Dying in Hospital in Ireland: Family Perspectives, National Audit Report 3, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McKeown, K., Haase, T., and Twomey, S., 2010d. The Culture of End-of-Life Care in Hospital in Ireland, National Audit Report 4, May, Dublin: Irish Hospice Foundation. Available at http://www.hospicefriendlyhospitals.net

McPherson, GJ., and Addington-Hall, JM., 2003. 'Judging the quality of care at the end of life: can proxies provide reliable information?', Social Science and Medicine, 56, pp.95-109.

Martin-Moreno, J., Harris, M., Gorgojo, L., Clark, D., Normand, C., Centeno, C., 2008. Palliative Care in the European Union, Strassburg: European Parliament.

Martin, LA., Nelson, EC., Lloyd, RC., and Nolan, TW., 2007. Whole System Measures, Innovation Series 2007, Cambridge Massachusetts: Institute for Healthcare Improvement. Available at www.ihi.org.

Bibliography

Morris, JN., Murphy K., and Nonemaker, S., 1995. Long term care facility Resident Assessment Instrument (RAI) user's manual version 2.0, HCFA, Baltimore.

Morrison, RS., Penrod, JD., Cassel, JB., Caust-Ellenbogen, M., Litke, A., Spragens, L., Meier, DE., 2008. 'Cost Savings Associated with US Hospital Palliative Care Consultation Programs', Arch Intern Med, Volume 168, Number 16, 8 September.

Mularski, RA., Heine, CE., Osborne, ML., Ganzini, L., & Curtis, JR., 2005. 'Quality of dying in the ICU: ratings by family members'. Chest, 128(1), 280-287.

Mularski, RA., Curtis, JR., Osborne, ML.,, Engleberg, RA., and Ganzini, L., 2004. 'Agreement among family members in their assessment of the Quality of Dying and Death', Journal of Pain and Symptom Management, Vol 28, No 4, October, pp.3.6-315.

Mularski, RA., et al., 2007. 'A Systematic Review of Measures of End-of-Life Care and Its Outcomes', HSE: Health Services Research 42:5, October, 1848-1870.

Murphy, P., Kreling, B., Kathryn, E., Stevens, M., Lynn, J., & Dulac, J., 2000. 'Description of the SUPPORT intervention. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments'. Journal of the American Geriatrics Society, 48(5 Suppl), S154-61.

National Advisory Committee on Palliative Care, 2001. Report, Dublin: Department of Health & Children.

Nolan, A., 2007. 'Productive Ward: releasing time to care', Health Service Journal, 117, 6052, S1-S19.

National Audit Office, 2008. End of Life Care, Report by the Comptroller and Auditor General, November, London: The Stationery Office.

Northern Ireland Health and Social Care Bereavement Network, 2009. Northern Ireland Audit: Dying, Death and Bereavement, Policies, procedures and practices in hospital and hospice settings, Belfast: Department of Health, Social Services and Public Safety.

OECD, 2007. Health at a Glance 2007, November. Paris: OECD.

Bibliography

O'Keeffe, S. T., Noone, I., & Pillay, I., 2000. 'Telling the truth about cancer: views of elderly patients and their relatives'. Irish Medical Journal, 93(4), 104-105.

O'Mahony, S., McHenry, J., Blank, AE., Snow, D., Karakas, SE., Santoro, G., Selwyn, P. and Kvetan, V., 2009. 'Preliminary report on the integration of a palliative care team into an intensive care unit', Palliat Med OnlineFirst, 13 October, 0(00) 1-12.

PA Consulting Group, 2007. Acute Hospital Bed Capacity Review: A Preferred Health System in Ireland to 2020: Detailed Report, September, Dublin: Health Services Executive. Available at: http://www.hse.ie/eng/Publications/Hospitals/PA_Consulting_Acute_Hospital_Bed_Capacity_Review_2008.html. Accessed 20 March 2009

PA Consulting Group and Balance of Care Group, 2007. Acute Hospital Bed Review: A review of acute hospital bed use in hospitals in the Republic of Ireland with an Emergency Department, June, Dublin: Health Services Executive.

Palliative Care Australia, 2008. Standards for Providing Quality Palliative Care for all Australians, http://pallcare.org.au

Parsley, K., and Corrigan, P., 1999. Quality Improvement in Healthcare: Putting Evidence into Practice, Cheltenham, UK: Nelson Thornes Ltd.

Patrick, D. L., Engelberg, R. A., & Curtis, J. R., 2001. 'Evaluating the quality of dying and death'. J Pain Symptom Manage, 22(3), 717-726.

Picker Institute, 2005. A guide to the NHS patient survey programme, Oxford: Picker Institute. Available at: http://www.pickerinstitute.org/publications.html Accessed 3 August 2009.

Pincombe, J., Brown, M., & McCutcheon, H., 2003. 'No time for dying: a study of the care of dying patients in two acute care Australian hospitals'. Journal of Palliative Care, 19(2), 77-86.

Proctor, WR., and Hirdes, JP., 2001. 'Pain and cognitive status among nursing home residents in Canada', Pain Res Manage 6, pp. 119–125.

Bibliography

Puntillo, K., Miaskowski, C., Kehrle, K., Stannard, D., Gleeson, S., and Nye, P., 1997. 'Relationship between behavioural and physiological indicators of pain, critical care patients' self-reports of pain, and opioid administration', Crit Care Med. Jul, 25(7):1159-66.

Puntillo, K., Neighbor, M, O'Neill, N., and Nixon, R., 2003. 'Accuracy of emergency nurses in assessment of patients' pain', Pain Manag Nurs. Dec, 4(4):171-5.

Puntillo, K., Neighbor, M, Chan, GK., and Garbez, R., 2006. 'The influence of chief complaint on opioid use in the emergency department', J Opioid Manag. Jul-Aug, 2(4):228-35.

Quinlan, C., and O'Neill, C., 2009. Practitioners' Perspectives on patient Autonomy at End of Life, November, Dublin: Hospice Friendly Hospitals Programme.

Rhodes, RL., Mitchell, SL., Miller, SC., Connor, SR., and Teno, JM., 2008. 'Bereaved Family Members' Evaluation of Hospice Care: What Factors Influence Overall Satisfaciton with Services?', Journal of Pain and Symptom Management, Vol. 35, No. 4, April, pp.365-371.

Reinertsen,JL., Bisognano, M., Pugh, MD., 2008. Seven Leadership Leverage Points for Organization-Level Improvement in Health Care (Second Edition). IHI Innovation Series white paper. Cambridge, MA: Institute for Healthcare Improvement. Available on www.IHI.org.

Reynolds,W.J. & Scott, B., 2000. 'Do nurses and other professional helpers normally display much empathy?' Journal of Advanced Nursing, 31, 226–234.

Roter, D.L., Stewart, M., Putnam, S.M., et al., 1997. 'Communication patterns of primary care physicians', JAMA, 277, 350–356.

Sadler, BL., Keller, JA., and Rostenberg, B., 2009. Using Evidence-Based Environmental Design to Enhance Safety and Quality. Institute for Healthcare Improvement Innovation Series White Paper, Cambridge, Massachusetts: Institute for Healthcare Improvement. Available at www.IHI.org Accessed on 26 May 2009.

Sawyer, P., Lillis, P., Bodner, BS., and Allman, RM., 2007. 'Substantial daily pain among nursing home residents', J Am Med Dir Assoc 8, pp. 158–165.

Bibliography

Scally, G., and Donaldson, L., 1998. 'Clinical governance and the drive for quality improvement in the new NHS in England', 4 July, 317(7150): 61-65.

Seland, M., Kaasa, S., and Klepstad, P., 2005. 'Symptoms assessment in cancer patients on admission to hospital', Tidsskr Nor Laegeforen, Sep 22, 125(18):2500-3. [Article in Norwegian].

Sprung, CL., Cohen, SL., Sjokvist, P., et al., 2003. 'End-of-life practices in European intensive care units. The Ethicus study'. JAMA, 290: 790-7.

Sprung, CL., Carmel, S., Sjokvist, P., et al., 2007. 'Attitudes of European doctors, nurses, patients and families regarding end of life decisions'. The ETHICATT Study. Intensive Care Medicine, 33:104-110.

Stromgren, AS., Sjogren, P., Goldschmidt, D., et al., 2005. 'A longitudinal study of palliative care: patient-evaluated outcome and impact of attrition', Cancer, 103(8), 1747-1755.

Tang, ST., and Corkle, R., 2002. 'Use of family proxies in quality of life research for cancer patients at the end of life: A literature review', Cancer Invest, 20, pp.1086-1104.

Teno, JM., 2005. 'Measuring End-of-Life Outcomes retrospectively?', Journal of Palliative Medicine, Volume 8, Supplement 1, pp.S42-S49.

Teno, J. M., Clarridge, B., Casey, V., Edgman-Levitan, S., & Fowler, J., 2001. 'Validation of Toolkit After-Death Bereaved Family Member Interview', Journal of Pain & Symptom Management, 22(3), 752-758.

Tiernan, E., Connor, MO., Kearney, PM., and Siorain, L., 2002. 'A Prospective Study of Preferred Versus Actual Place of Death Among Patients Referred to a Palliative Care Home-care Service', Irish Medical Journal, Vol 95, Issue 8, September, pp.232-235.

Turner, M., 2009. 'HealthStat: measuring the performance of the Irish public health service', Journal of the Statistical and Social Inquiry Society of Ireland, Vol.38, 2008/09, pp.178-204.

Bibliography

UCD and Lansdowne Market Research, 2007. Insight 07: Health and Social Serivces in Ireland – A Survey of Consumer Satisfaction, Dublin: Health Services Executive. Available at http://www.hse.ie/eng/Publications/Your_Service,_Your_Say_Consumer_Affairs/Reports/Insight_07.pdf Accessed on 27 May 2009.

Ulrich, R., 2008. 'Design and Dignity: The Case for Renewing our Hospitals', Public Lecture in St. Ann's Church, Dawson St. Dublin, June. Available at http://www.hospicefriendlyhospitals.net

Ulrich, R., Zimring, C., Zhu X, et al, 2008. 'A review of the research literature on evidence-based health-care design', Health Environments Research and Design Journal, 1(3):61-125.

Vital Statistics, 2009. Annual Report for 2006, July, Dublin: Stationery Office.

Walters, G., 2004. 'Is there such a thing as a good death?', Palliative Medicine, 18:404-408.

Weafer & Associates Research with TNS MRBI, 2004. A nationwide survey of public attitudes and experiences regarding death and dying, November, Dublin: Hospice Friendly Hospitals Programme.

Weafer, J., McCarthy, J., and Loughrey, M, 2009. Exploring Death and Dying: The views of the Irish public, November, Dublin: Hospice Friendly Hospitals Programme.

Weafer, J., 2009. A Qualitative Study of Public Perceptions of End-of-Life Issues, September, Dublin: Hospice Friendly Hospitals Programme.

Wennberg, JE., Fisher, ES., Stukel, TA, Skinner, JS., Sharp, SM., and Bronner, KK., 2004. 'Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States', British Medical Journal, Volume 328, 13 March, pp.607-610.

Zyczkowska, J., Szczerbinska, K., Jantzi, MR., and Hirdes, JP., 2007. Pain among the oldest old in community and institutional settings, Pain 129, pp. 167–176.

Technical Appendix

Annex 1: Resources and Facilities for End-of-Life Care in Hospitals in Ireland - Summary of Report 1[180]

This report describes the resources and facilities for end-of-life care in the 24 acute and 19 community hospitals. All data pertains to 2008.

Coverage of Audit

Most people die in a hospital or similar setting, outside the home. In Ireland, at least half of all deaths occur in acute hospitals (48%) or hospices (4%); deaths at home still constitute a quarter of the total (25%), and a fifth die in long-stay facilities (20%); the remainder are deaths from suicide and traffic accidents (3%). The main focus of the audit is on patients who die in acute hospitals[181] but patients in one type of long-stay facility – community hospitals[182] – are also included. The 24 acute hospitals in the audit represent a major part of that sector in Ireland in terms of bed-capacity (74%), number of patients (72%), deaths (71%), and staff (73%). Coverage of the community hospital sector is less extensive, covering just 20% of bed-capacity although the average size of these hospitals in the audit (110 beds) is considerably higher than the average for all community hospitals (68 beds). In geographical terms, the audit has strongest coverage in the eastern part of the country. Weakest coverage is in the west with no participation from hospitals in Galway, Mayo or Roscommon - the former Western Health Board Region.

Data Limitations

The audit data supplied by many hospitals is limited because: (i) some data is missing; (ii) some data is inconsistent with published HSE data; and (iii) some data is at variance with the experience of HFH staff who work with individual hospitals. For example, there is missing data on: deaths (such as whether the death was referred to a coroner, whether a post-mortem was held, whether it was a hospital or coroner's post-mortem, and number of 'brought-in-dead'), patients (such as number of in-patients and day-patients with a Medical Card), staff (such as actual and WTE number of staff, turnover and absenteeism), specialist palliative care staff, and complaints especially complaints about end-of-life issues. Similarly, there are inconsistencies with published HSE data in areas such as: the proportion of deaths followed by a post-mortem, absenteeism, and number of complaints. Finally, there are significant variances between

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[180] McKeown, Haase, and Twomey, 2010a.

[181] In this report, the acute sector is defined as the 38 hospitals in the HIPE system which have A&E departments but excluding children's hospitals, orthopaedic hospitals, and eye & ear hospitals.

[182] There is no official definition of a 'community hospital' in Ireland but the convention is to differentiate it from an 'acute hospital' if it does not have an accident and emergency department. Community hospitals are effectively long-stay facilities but offer a higher level of medical support compared to the average nursing home.

hospital returns and the independent observations of healthcare experts in rating the quality of hospital and mortuary facilities[183].

Single rooms

Single rooms are increasingly seen as the standard of accommodation required in hospitals in order to control the spread of infection and cater for the preferences of patients and their families. In the audit, the proportion of single rooms in acute and community hospitals is 15%, similar to that in English hospitals[184]. However, this is far short of any of the standards – 100%[185], 80%[186], 50%[187] - that have been proposed for the proportion of single rooms in hospitals.

Bed occupancy rate

The average bed occupancy rate of hospitals in the audit is 93% for both the acute and community hospitals, and even higher for the larger hospitals. This rate is well above the OECD average of 75%[188], and is generally regarded as too high because it has the effect of causing overcrowding, reducing access for new patients, increasing the risk of infection, and threatening the quality of care of patients.

Place of death

The audit established that most deaths in acute hospitals take place in wards (68%), the remainder occurring in intensive care (20%) and A&E (12%). In the community sector, most deaths (85%) occurred in the community hospital where the patient lived, but 15% took place in acute hospitals.

Coroners and post-mortems

Over the past century, an increasing proportion of deaths have become the subject of post-mortems and inquests. In 1885, for example, only 2% of deaths in Ireland involved a post-mortem / inquiry but, 120 years later in 2005, nearly a fifth (18%) of all deaths were investigated by a coroner. The results of the audit reveal that 12% of all acute hospital deaths are referred to the coroner while over a fifth (21%) are followed by a post-mortem.

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183 Tribal, 2007.

184 In 155 English hospitals which use the Liverpool Care Pathway, the median number of beds was 478 and the median number of side-rooms was 74, which implies that 15% of beds are in single rooms (Marie Curie Palliative Care Institute Liverpool, 2009:23).

185 Facility Guidelines Institute and the AIA Academy of Architecture for Health, 2006. Available at: http://www.fgiguidelines.org/guidelines.html. Accessed 20 March 2009. In Ireland, a draft of the infection control building guidelines recommends that all 'new-builds' should have 100% single rooms (Cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278-9).

186 Health Information and Quality Authority, 2008:45

187 Cited in Fitzpatrick, Roche, Cunney and Humphreys, 2009:278

188 OECD, 2007.

Brought in dead

The concept of 'brought in dead' refers to patients who are pronounced dead outside the hospital. In the audit, as in the HIPE system, these deaths are additional to deaths which take place within the hospital. In acute hospitals, these deaths are equal to nearly a quarter (23%) of all deaths in the hospital. The majority of these were brought directly to the mortuary (71%), with the remainder brought to A&E (17%) and for preparation by funeral directors (121%).

Staffing

In acute hospitals, nurses are by far the largest category of staff (40%) with a nurse-to-doctor ratio of 3.4 compared to an OECD average of 2.9[189]. Nurses are also the largest staff category in community hospitals (41%) but 'other patient care', mainly comprising health care assistants, is also a large staff category (37%). Staff turnover is 15% in acute hospitals and 14% in community hospitals, higher than the national average of 10%. The rate of absenteeism is 6% in the acute sector and 5% in the community sector and is regarded as a significant problem by the management in both sectors. This rate of absenteeism is well above the national average – and the HSE target - of 3.5% although there are large variations across staff grades.

Standard of hospital facilities

Using the Design and Dignity Guidelines[190] as a standard, hospitals self-rated their facilities at 5.8 out of 10.0, with almost no difference between acute and community sectors. Facilities with a specific focus on end-of-life care received the same rating. This result is at variance with an independent observation of 15 acute and 5 community hospitals carried out for the HFH programme in 2007[191], which awarded the hospitals an average score of 3.6 out of 10.0. Despite their relatively high self-assessed scores, only one acute hospital and no community hospital, merits a 'green light' (equivalent to a score of 8.5 or higher).

Distribution of specialist palliative care services

A majority of acute hospitals in Ireland do not meet the government-approved standard of having a full specialist palliative care team. This result is in line with a more comprehensive analysis of specialist palliative care teams in 38 acute hospitals carried out by the Irish Hospice Foundation (IHF)[192]. Similarly, a majority of community hospitals do not have access to a specialist palliative care service. The audit was unable to discover any rationale behind the distribution of specialist care services in hospitals since it seems to bear no relationship to the number of deaths in each hospital.

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189 OECD, 2007.

190 Hospice Friendly Hospitals Programme, 2008:18.

191 Tribal, 2007.

192 Murray, Sweeney, Smyth and Connolly, 2006. See also Murray, 2008.

Complaints

All acute hospitals received complaints but more than half the community hospitals (10, 53%) reported no complaints. Complaints about end-of-life care seem to represent a relatively small proportion of total complaints in acute hospitals (2.7%), and this appears low by comparison with experience elsewhere[193].

Policies and procedures on end-of-life care

A third of acute hospitals (33%) - compared to less than two out of ten community hospitals (16%) - do not have written policies, procedures, objectives or targets on end-of-life care. This compares unfavourably with the infrastructure of written policies, procedures and guidelines for end-of-life care in hospitals in Northern Ireland[194].

Training for end-of-life care

End-of-life care rarely features in the induction of staff, unlike the practice in Northern Ireland where all staff are normally informed about the hospital's policies, procedures and guidelines for end-of-life care during their ward induction[195]. Despite this, hospitals provide a substantial amount of in-service training in end-of-life care, both acute (19, 79%) and community (10, 51%), broadly similar to that in English hospitals[196]. Significantly, the provision of end-of-life training in acute hospitals is not related to either the number of deaths – a proxy indicator of need for specialist palliative care services – or the existence of a full, partial, or no specialist palliative care team.

Supports for end-of-life care

Over half the acute hospitals (58%), but less than a fifth of community hospitals (16%), have a document outlining the supports that are available for staff involved in end-of-life care.

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193 For example, the Healthcare Commission for England & Wales (replaced by the Care Quality Commission in March 2009) received over 16,000 complaints for independent review between 2004 and 2006. Of these, 54% were complaints about hospitals involving the care received at the time death, compared with only 22% being about patient safety. Most families complained about quality of communication; for example receiving contradictory information from different staff members and not being prepared by staff for the patient's death (Cited in Mayor, 2007).

194 Northern Ireland Health and Social Care Bereavement Network, 2009:13-14.

195 Northern Ireland Health and Social Care Bereavement Network, 2009:14.

196 In 155 English hospitals which use the Liverpool Care Pathway, continuing education and training for care of the dying is provided for medical staff (74%), nursing staff (84%) and non-qualified clinical staff (58%) (Marie Curie Palliative Care Institute Liverpool, 2009:28).

Standard of mortuary facilities

Using the Design and Dignity Guidelines[197] as the standard, the audit found that acute hospitals had 45% of the recommended facilities for mortuaries compared to 40% in community hospitals. These findings are consistent with two previous assessments of mortuaries in Ireland[198].

Bereavement services and facilities

The majority of acute (14, 58%) and community (16, 84%) hospitals do not have a bereavement service. However, hospitals which have a bereavement service also tend to have reasonably good facilities to deliver that service.

Conclusions and issues for consideration

These findings raise a number of issues which merit further consideration by each individual hospital and their staff, and the HSE generally. In the final section of the report, we outline these issues in detail in order to facilitate discussion, reflection and a considered response.

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197 Hospice Friendly Hospitals Programme, 2008:18.

198 Tribal, 2007:20; Willis, 2009:114.

Annex 2: Dying in Hospital in Ireland: Nurse and Doctor Perspectives - Summary of Report 2[199]

This report describes the experiences, as perceived by nurses and doctors, of 999 patients who died in hospitals in Ireland in 2008/9. Nearly nine out of ten of these patients died in acute hospitals - the remainder in community hospitals - and this constitutes a representative sample of 10% of annual deaths in those acute hospitals. These acute hospitals, in turn, represent three quarters of the acute sector in Ireland[200], so it is a reasonable inference that the report is broadly representative of the care offered at the end of life by acute hospitals in Ireland. Coverage of the community hospital sector is less extensive, covering just 20% of bed-capacity, and is therefore less representative. Throughout the report we use comparative data, wherever possible, to assess how the experience of dying in an Irish hospital compares to hospitals elsewhere.

Patient Characteristics

Patients are mainly 65 years and over and were admitted to hospital through Accident and Emergency Departments (A&E). The average length of stay in acute hospitals (24 days) is well above the national average[201], and well above international standards for patients who die in acute hospital[202]. The three main causes of death reflect the national pattern in terms of their order of priority: circulatory system diseases (31%), cancer (23%), and respiratory system diseases (19%).

Ward and Room Characteristics

Less than half of all patients (44%) died in a single room, significantly less than the proportion of patients who die in single rooms in Northern Ireland (70%)[203]. In acute hospitals, these patients spent five days in a single room before death, compared to 3 days in a community

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[199] McKeown, Haase, and Twomey, 2010b.

[200] The 24 acute hospitals in the audit represent a major part of that sector in Ireland in terms of bed-capacity (74%), number of patients (72%), deaths (71%), and staff (73%); see McKeown, Haase and Twomey, 2010a.

[201] The national average for acute in-patients aged 65 and over is 11.5 days (Hospital In-Patient Enquiry, 2006:Table 3.9). In the HSE's 2009 National Service Plan, the target for average length of stay in acute hospitals is 5.9 days (HSE National Service Plan 2009, 2008:71).

[202] For example, the OECD average length of stay is 6.3 days (OECD, 2007:73). In the US, the average length of stay in the last six months of life varies from 4.87 to 19.67 days for the same diagnostic categories and independently of need and outcome (Wennberg, Fisher, Stukel, Skinner, Sharp, and Bronner, 2004). In the UK, the average length of stay before death is usually well below 20 weeks. (Abel, Rich, Griffin and Purdy, 2009; and Addicott and Dewar, 2008).

[203] This estimate is taken from the audit of dying, death and bereavement in Northern Ireland. Most deaths were in the three areas of general medicine (40%), elderly care (20%) and general surgery (10%) where the proportion 'cared for in a single room on more than 75% of occasions' is 65%, 75% and 80% respectively (Northern Ireland Health and Social Care Bereavement Network, 2009:6 and 28). From this it is a reasonable inference that around 70% of deaths are in single rooms.

hospital. Conversely, most patients died in multi-occupancy rooms and, in the acute sector, over a quarter (28%) of these are mixed gender. The room where patients died was rated at 5.7 out of 10 in terms of dignity, privacy, environment and control, and appears higher compared to the staff ratings of hospital facilities in Northern Ireland.

Assessment of Patient

The vast majority of patients (86%) were diagnosed as dying about 5-6 days before their death. This suggests that deaths in Irish hospitals are anticipated more frequently than in French hospitals[204] and earlier than in English hospitals[205]. About a fifth of patients could have died at home, in the opinion of nurses and doctors, if appropriate supports were available. Studies in the UK suggest that a similar pattern over-using acute hospitals for patients at the end of life[206].

Team Meetings about Patient

Two types of meetings - usually involving medical and nursing staff only, but sometimes involving the full multidisciplinary team of all health care professionals – are held to discuss the care of the patient in about seven out of ten cases. Significantly no meetings are held in nearly a third of cases. The responses of nurses and doctors agree, in about six out of ten cases only, that these meetings actually took place, which suggests that they are relatively informal and probably not documented in many cases. Meetings are more likely in community hospitals and, within acute hospitals, were more likely for patients with cancer and those in single rooms. The family attended these meetings in about two thirds of cases but where they did not, only half were told about their outcome.

Communication with Patients and Relatives

Hospital staff are much more likely to discuss end-of-life issues with relatives (96%) than with patients (55%). Equally, discussions with relatives are more likely to be documented (83%) compared to discussions with patients (76%). The quality of communication with relatives was assessed, using a 10-point scale, as being significantly better (8.5) compared to communication with patients (7.3). These findings are consistent with another Irish study which identified a tendency among health care professionals to 'speak with families of older people, as opposed to the older individuals themselves, regarding treatment and services'[207]. This pattern of

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204 Ferrand, Jabre, Vincent-Genod, et al, 2008:870 and Table 2. This study was based on 3,793 patients who died in 200 French hospitals in 2004.

205 This is inferred from the audit of patients on the Liverpool Care Pathway (LCP), based on 3,893 patients in 155 hospitals who died between October and December 2008. Patients are placed on the LCP where there is a diagnosis of dying and the average length of time on LCP was 33 hours (Marie Curie Palliative Care Institute Liverpool, 2009:21; see also 2007:5). The audit estimates that 21% of all deaths in those hospitals were on the LCP (Marie Curie Palliative Care Institute Liverpool, 2009:24).

206 Abel, Rich, Griffin and Purdy, 2009; National Audit Office, 2008.

207 McGlone and Fitzgerald, 2005:72.

communication is also similar to that found among English patients on the Liverpool Care Pathway (LCP)[208].

Meeting the Wishes of Patients and Relatives

Relatives expressed wishes more frequently than patients (88% compared to 32%) but also expressed a larger number of wishes (4.4 compared to 1.3). Although the wishes of patients were more likely to be documented (62% compared to 43%) the actual number of relatives' wishes which were documented would necessarily be much greater compared to patients. In the assessment of nurses, using a 10-point scale, the hospital was significantly more likely to meet the wishes and worries of relatives (8.3) compared to patients (6.8).

Palliative Care Decisions about Patient

Nurses and doctors make about six end-of-life decisions for each patient. However, in a third of cases, the responses of nurses and doctors do not agree[209] on whether a decision was made, or on whether that decision was documented. Even when a patient has been diagnosed as dying, there seems to be a reluctance by nurses and doctors to make a decision to stop invasive monitoring, stop antibiotics, withhold or withdraw treatment. This contrasts with the LCP practice in English hospitals where, in the vast majority of cases, decisions are made to discontinue blood tests (91%), antibiotics (89%), IV fluids / medications (83%), do not resuscitate (94%) and inappropriate nursing interventions such as vital signs and blood sugar monitoring (75%)[210]. Similarly, decisions to withhold or withdraw life support are taken much less frequently in Irish hospitals compared to other European countries[211].

Quality of Palliative Care

Nurses and doctors have markedly different perceptions of the 5-6 key symptoms that many patients experience in the last days and hours of life such as pain, nausea, breathing

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[208] The results of a national audit of patients on the Liverpool Care Pathway LCP – based on 3,893 patients in 115 hospitals who died between October and December 2008 – showed that patients were less likely to be aware of their diagnosis (50%, compared to 79% of relatives), to recognise that they were dying (40%, compared to 76% of relatives), or to have their care plan explained to them (30%, compared to 72% of relatives). (Marie Curie Palliative Care Institute Liverpool, 2009:45-54).

[209] Note that the measurement of agreement is sensitive to the number of response categories for each question and the level of agreement tends to fall as the number of response categories increases. For example, questions with 10 response categories will show a much lower level of agreement than questions with four or two response categories. In view of that, we measured agreement using either two or four response categories, depending on the question (See Section 14.5 in the Technical Appendix).

[210] Marie Curie Palliative Care Institute Liverpool, 2009.

[211] Decisions to withhold and withdraw treatment were taken in less than half of all cases (47%) but more frequently in intensive care (53%). This is significantly lower than in the Ethicus study of 4,248 intensive care deaths in 17 European countries where both withholding and withdrawing life support – but not active life-ending procedures – occurred in 73% of patients (Sprung, Cohen, Sjokvist, et al., 2003). The Mater Hospital contributed to the Ethicus study and its results were published separately to show that 70% of patients who died in ICU in 1999/2000 had a decision made to withhold or withdraw life-sustaining therapy, but only 72% of these decisions were documented (Collins, Phelan, Marsh and Spring, 2006:317).

difficulties, increased secretions, restlessness, and anxiety. Agreement is low between the responses of nurses and doctors on the frequency (50% agreement) and management (42% agreement) of these symptoms. This raises a question about the true quality of palliative care, and whether in fact patients are being kept comfortable and free of pain in the last week of life. Bearing this question in mind, nurses and doctors estimate that 80-90% of patients are kept relatively comfortable during the last week of life. In the national audit of patients on the LCP in English hospitals, about 75% were assessed as comfortable in these symptom areas[212].

Specialist Palliative Care Services

A majority of patients did not receive specialist palliative care. The proportion of patients who actually received it varies from 22% according to doctors to 32% according to nurses, which is a substantial 10-percentage point difference of opinion. This suggests that there may be some misunderstanding between – and within – nurses and doctors as to what exactly is specialist palliative care. Leaving aside these differences, the proportion of patients who received specialist palliative care is slightly higher compared to UK hospitals (19%)[213], but much higher compared to French hospitals where, according to one study, 'only 12.1% had a palliative care consultation'[214].

Quality of Life

The quality of living and dying in Irish hospitals, measured using the Quality of Dying and Death Instrument (QODD)[215], is reasonably good compared to similar studies in the US[216]. Relationship well-being is stronger than personal well-being, both physical and psychological, , possibly because many hospitals facilitate relatives to spend time with the patient in the last days. Some of the physical challenges facing dying patients are indicated by the high prevalence of those who, for most or all of the time, do not have the energy to do things (87%), show little or no sign of enjoyment (65%), and have breathing difficulties (31%). At the same time, patients appear to be greatly comforted by aspects of their relationship such as spending

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[212] Marie Curie Palliative Care Institute Liverpool, 2009:40-42.

[213] In a UK study carried out by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), a sub-sample of deaths (1,478) was analysed and there was no involvement by a palliative care team in 81% of cases (National Confidential Enquiry into Patient Outcome and Death, 2009:94). Commenting on this, the report states: 'While the sample of patients included in this study may not be representative of all who were admitted with palliative intent, the paucity of input from palliative care teams may be indicative of the lack of co-ordinated end of life care in acute hospitals' (Ibid:94-95).

[214] Ferrand, Jabre, Vincent-Genod, et al, 2008:870. This study was based on 3,793 patients who died in 200 French hospitals in 2004.

[215] Developed by, and available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

[216] Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004.

most or all of the time with children (79%) and friends (78%), or simply knowing that loved ones are there (88%).

Quality of Care

Quality of care was measured using a sub-scale from the Family Evaluation of Hospice Care (FEHC)[217]. As with palliative care, the responses of nurses and doctors do not always agree on what constitutes good quality of care for a patient (only 44% agreement), or what constitutes an acceptable death (only 40% agreement). Despite that, both rate the quality of care given to patients at over 8 out of 10, somewhat lower than the scores normally given by relatives for hospice care in the US, the main source of comparative data on the FEHC scale[218]. Both nurses and doctors gave their lowest rating for communication with the patient and their highest for communication with relatives. A minority of deaths are regarded as unacceptable (13% according to nurses and 5% according to doctors), a low figure by comparison with a French study where 58% of nurses found the deaths of their patients unacceptable[219].

Moment of Death and After

Relatives or friends are often present at the moment of death (65%), much higher than in a recent French study (24%)[220]. Hospital staff were present at three quarters of the deaths. However there is no evidence of anyone being present at a quarter of all deaths. The main ritual immediately following death is for hospital staff to offer sympathy (91%) and tea (87%) to the family; prayers are frequently said (81%), candles are usually lit (69%), and there is a moment of silence in over half the cases (53%).

Staff offered information and advice about moving the body to the mortuary (73%) and collecting the patient's personal belongings (73%), but were less likely to inform relatives about mortuary access and viewing times (39%), how the deceased patient may be taken home (43%), arranging the funeral (48%), or how to register the death (20%). The personal

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[217] Developed by, and available from, the National Hospice and Palliative Care Organisation (NHPCO), based in Virginia in the US at: http://www.nhpco.org/i4a/pages/Index.cfm?pageid=4397. The Family Evaluation of Hospice Care (FEHC) was developed by Joan Teno and Stephen Connor at Brown University in the US (Connor, Teno, Spence and Smith, 2005) based on a previously validated scale, Toolkit After-Death Bereaved Family Member Interview (Teno, Clarridge, Casey, Edgman-Levitan and Fowler, 2001).

[218] Connor, Teno, Spence and Smith, 2005:Table 3. This was based on a survey of 29,292 relatives whose family members died in 352 hospices in the US during 2004. Another, much larger sample using the full Family Evaluation of Hospice Care – based on 116,974 relatives whose family members died in 819 hospices throughout the US - found that a high level of satisfaction with the quality of care was associated with four key processes of care: (i) being regularly informed by the hospice team about their loved one's condition (ii) the hospice team providing the right amount of emotional support to them (iii) the hospice team providing them with accurate information about the patient's medical treatment and (iv) identifying one nurse as being in charge of their loved one's care (Rhodes, Mitchell, Miller, Connor, and Teno, 2008).

[219] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 4.

[220] Ferrand, Jabre, Vincent-Genod, et al, 2008:Table 3.

belongings of patients are usually handed over in a bag supplied by the patient or relative (43%), or in a hand-over bag supplied by the hospital (21%), but plastic bags are used in a significant minority of cases (21%).

Less than a third GPs are known to have been informed about the patient's death (32%), similar to the pattern found in English hospitals[221]. Most nurses were unable to state if the patient's death had been certified or if a death certificate had been issued by the hospital.

Reviewing Deaths and Supporting Staff

A ward-level review of the patient's death takes place in half of all cases (51%), and these seem to mainly involve an informal discussion with peers; a formal review facilitated by a senior member of ward staff is relatively rare (13%). A significant minority of staff felt very upset at the death of a patient (21%) but few of these (15%) are known to have had an opportunity to talk about how this affected them. This suggests a relatively low level of support for staff, similar to the situation in Northern Ireland[222].

Conclusions and issues for consideration

These findings raise a number of issues which merit further consideration by each individual hospital and their staff, and the HSE generally. In the final section of the report, we outline these issues in detail in order to facilitate discussion and reflection.

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[221] Marie Curie Palliative Care Institute Liverpool, 2009:52.

[222] This emerges from an audit of dying, death and bereavement in Northern Ireland hospitals and hospices, which included a survey of 1,632 hospital staff. According to this survey, relatively few staff perceive that supports are in place for: case review / critical incident analysis (27%), de-briefing following traumatic situations with either peers (21%), or the multi-professional team (14%). (Northern Ireland Health and Social Care Bereavement Network, 2009:55).

Annex 3: Dying in Hospital in Ireland: Family Perspectives – Summary of Report 3[223]

This report describes the experiences, as perceived by family members, of 461 patients who died in hospitals in Ireland in 2008/9. Nearly nine out of ten (87%) of these patients died in acute hospitals, the remainder in community hospitals. This sample constitutes 5% of annual deaths in these acute hospitals[224] and 14% of annual deaths in these community hospitals[225]. The response rate to the survey is 46% which is within the range found in similar surveys of relatives, both in Ireland[226] and elsewhere[227].

It is recognised that the patient's experience is not the same as that reported by the relative, or indeed by the nurse or doctor. Nevertheless, given the frailty of patients during their last week of life, the accepted and acceptable method of study is to rely on reports about the patient from family and friends, since there is considerable evidence that these reports tend to be a reasonable approximation of the patient's experience[228].

Characteristics of Relatives

Two thirds of relatives are female (65%) with an average age of 57. A majority are either the child (41%) or partner (24%) of the patient. This profile is broadly similar to two other studies

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[223] McKeown, Haase, and Twomey, 2010c.

[224] The 24 acute hospitals in the audit represent a major part of that sector in Ireland in terms of bed-capacity (74%), number of patients (72%), deaths (71%), and staff (73%). See McKeown, Haase, and Twomey, 2010a.

[225] The 19 community hospitals in the audit constitute 12% of the 156 community hospitals in Ireland, equivalent to just 20% of all community hospital beds in Ireland although these hospitals tend to be larger (averaging 110 beds each) compared to community hospitals generally (averaging 68 beds each). See McKeown, Haase, and Twomey, 2010a.

[226] In Ireland, one survey achieved a response rate of 57% (Keegan, et al, 1999) while a more recent survey had a response rate of 32% (McCarthy and O'Boyle, 2010).

[227] In the US, four studies which have used either the QODD or the FEHC, both used in the audit, had response rates of 27% (Curtis, et al, 2002), 38% (Mularski, et al, 2004), 45% (Teno, et al, 2007), and 55% (Levy, et al, 2005).

[228] Three substantial reviews (Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003; Teno, 2005) have examined the extent of agreement between direct patient reports and the reports of their relatives, referred to as 'patient-proxy agreement'. The first review examined 25 patient-proxy studies and concluded that 'this review highlights that the majority of terminal cancer patients and their family caregivers agreed at least moderately well (0.60) on the patients' QOL. Family caregivers can act as a reliable alternative source of data for terminal cancer patients who are no longer able to speak for themselves. The bias introduced by the use of family respondents is generally of a modest magnitude. When discrepancies existed, without exception, family caregivers held a more negative view of patients' QOL than did patients. The degree of agreement between patients' and family caregivers' assessments varies as a function of the dimensions of QOL being measured. Caregivers were least reliable in evaluating the aspects of QOL that lack observable clues and require subjective judgments, as well as psychological reactions and social/spiritual concerns of patients. Family caregivers were best able to assess physical and functional aspects. As patients' health deteriorates, family caregivers become less effective in assessing and reporting patient QOL.' (Tang and McCorkle, 2002:1101). The second review examined 23 studies and concluded: 'This review provides encouraging evidence for the use of proxies at the end of life, for some aspects of the patient's experience, most notably for service provision and evaluation, and for symptoms that are more observable in nature. However, care must be taken when using proxies to report on aspects of the patient's experience that are more subjective, such as pain and affective states' (McPherson and Addington-Hall, 2003:106). The third review, while acknowledging the need for care in the use of proxy data, concluded that: 'It is important to recognise that bereaved families' perceptions of the quality of care delivered to them during the final illness of loved ones are important indicators of the quality of care' (Teno, 2005:S-47). Overall, these reviews suggest that relatives are a reasonably good proxy for the experiences of patients.

of bereaved relatives in Ireland[229]. In terms of attitudes, respondents are positive about the quality of end-of-life care in Irish hospitals. They regard 'being free from pain' as by far the most important thing about care when dying, which contrasts to the findings of a national survey which rated the presence of loved ones as the most important thing about care when dying[230]. Significantly, relatives rated the least important things about dying as: to be in a private space (6% compared to 11% in national survey), to have spiritual support (6% compared to 19% in national survey), and to be at home (6% compared to 34% in national survey).

Characteristics of Patients

There is no significant difference between the patients on whom relatives completed Questionnaire 3 (461) – on which this report is based - and the larger sample of patients on whom nurses completed Questionnaire 1 (999), on which Report Two[231] is based. Both samples are virtually identical in terms of gender, age, marital status, living alone, nationality, ethnicity, religion, public / private status, route of admission to and length of stay in hospital, expected / sudden deaths, and primary diagnosis. This means that we can have confidence that the sample is broadly representative of the entire population of patients and relatives. In summary form, these patients are generally 65 years and over and were admitted to hospital through Accident and Emergency Departments (A&E). They are mainly public patients with average length of stay in acute hospitals of 24 days. The three main causes of death reflect the national pattern in terms of their order of priority: circulatory system diseases (31%), cancer (23%), and respiratory system diseases (19%).

Characteristics of Ward

About 15% of beds in acute and community hospitals are in single rooms[232]. Despite this, nearly half the patients (48%) died in a single room, which is lower than the 70% of patients who die in single rooms in hospitals in Northern Ireland[233]; the remainder (52%) in a shared room with at least five other patients, some of them mixed-gender rooms. On a 10-point scale, relatives gave a higher rating to the room where the patient died rated (6.2) compared to nurses (5.7) and hospital management (5.8), and much higher than independent healthcare consultants (3.6)[234]. In terms of organisation, nine out of ten relatives believe the ward where the patient

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[229] Keegan, et al, 1999; McCarthy and O'Boyle, 2010.

[230] Weafer & Associates Research, 2004.

[231] McKeown, Haase and Twomey, 2010b.

[232] McKeown, Haase and Twomey, 2010a.

[233] This estimate is taken from the audit of dying, death and bereavement in Northern Ireland. Most deaths were in the three areas of general medicine (40%), elderly care (20%) and general surgery (10%) where the proportion 'cared for in a single room on more than 75% of occasions' is 65%, 75% and 80% respectively (Northern Ireland Health and Social Care Bereavement Network, 2009:6 and 28). From this it is a reasonable inference that around 70% of deaths are in single rooms.

[234] Tribal, 2007.

died was either very well organised (54%) or relatively well organised (35%). However, one third (33%) believed the ward's end-of-life care was either average, poor or very poor.

Preferences for dying in a single room

Nearly half of all patients who died in a shared room would have preferred a single room (45%). This suggests that there is a substantial unmet preference for patients to die in a single room which, given the high proportion of patients who did not express a preference, could range from 24-40% of all deaths.

Preferences for dying at home

Just over a tenth of patients indicated to relatives (14%), during the last week of life, that they would like to die at home. In the assessment of relatives, nearly a quarter of all patients (24%) could have died at home if there was enough support, similar to the overall assessments made by nurses (22%) and doctors (22%)[235]. However a case-by-case comparison of these assessments indicates that relatives, nurses and doctors agree in only 29% of cases, while nurses and doctors agree in only 48% of cases. This suggests that each has a different approach to making these assessments. Further analysis reveals that relatives are more likely to assess a patient as suitable to die at home when they rate the responsiveness of staff to requests as average or poor, and when the quality of end-of-life care on the ward, and in Irish hospitals generally, is rated as average or poor.

Quality of staff

Relatives gave high ratings for the quality of all staff – nursing, medical, other - in both acute and community hospitals. Over eight out of ten relatives (83%) rated the responsiveness of staff - the way staff responded to requests - as good or very good. Nearly nine out of ten relatives rated the quality of staff - what do you think of the quality of staff - as good or very good. However, a quarter of relatives felt there was not enough nursing and medical staff in acute hospitals, and this may be due to their experience that staff do not have – and are not given – enough time to be with patients and relatives. Nevertheless, these results paint a positive picture of staff quality and responsiveness, and are consistent with other findings

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[235] McKeown, Haase and Twomey, 2010b.

which show relatively high levels of satisfaction among people who have direct experience of Irish hospitals[236].

Quality of life

The quality of life of patients during their last week is simultaneously a measure of their living and dying. It is therefore an important indicator of a hospital's end-of-life care, since quality of life is as intrinsically valuable as life itself. Reflecting this, it is the preference of the majority of Irish people that, if they were ill with no hope of recovery, the quality of life would be more important than how long it lasted[237]. Overall, the quality of living and dying in Irish hospitals, as measured by the Quality of Dying and Death Instrument (QODD)[238], is comparable to that found in other QODD-based studies of hospital deaths[239]. During their last week of life, patients are more challenged by their physical and psychological symptoms, but their relationship well-being seems to be a major source of comfort and support, consistent with the findings of an other QODD study[240].

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236 In 2007, HSE's Office of Consumer Affairs commissioned a study, comprising a random sample of 3,517 Irish people, on experiences of public health and social care services. A sub-sample of these (344, 10%) had experience of hospital services in the last year and reported high overall levels of satisfaction on dimensions such as: effective treatment by a trusted professional (78%), involvement in decisions and respect for own preferences (75%), clear and comprehensive information (80%), emotional support, empathy and respect (83%), easy to get around the hospital (74%). However there was a marked dip in satisfaction on dimensions such as cleanliness of hospital toilets (62%), contact with the hospital by phone (69%), and car-parking facilities (46%) (UCD and Lansdowne Market Research, 2007). Similarly, a majority of people (75%) who had someone close die in an Irish hospital in the past two years or so reported that end-of-life care in Irish hospitals was good or very good (Weafer & Associates Research, 2004: Figure 15, page 19).

237 This is based on a national survey of 667 adults who were interviewed by telephone in September 2007. In response to the statement - if I were ill with no hope of recovery, the quality of my life would be more important than how long it lasted - 63% agreed strongly and 18% agreed somewhat (Weafer, McCarthy and Loughrey, 2009:35).

238 Developed by, and available from, the University of Washington End of Life Care Research Program at: http://depts.washington.edu/eolcare/instruments/index.html. The Quality of Dying and Death Instrument (QODD) was developed by Donald Patrick, Ruth Engleberg and Randall Curtis (Patrick, Engleberg and Curtis 2001) and has been used in four studies (Curtis, Patrick, Engleberg, Norris, Asp, and Byock, 2002; Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004; Mularski, Heine, Osborne, Ganzini, and Curtis, 2005; Levy, Ely, Payne, Engelberg, Patrick and Curtis, 2005).

239 The main QODD-based studies, and their scores, are as follows:

Study	Sample	Completed by Relatives		Completed by Nurses		Completed by Doctors	
		M	SD	M	SD	M	SD
US Deaths in hospital and home (Curtis, et al, 2002)	252	67.4	15.1	-	-	-	-
US Deaths in ICU (Hodde, et al, 2004)	149	-	-	73.1	21.4	-	-
US Deaths in ICU (Levy, et al, 2005)	38	77.7	9.3	66.9	16.3	67.8* 82.5**	22.5* 17.3**
US Deaths in ICU (Mularski, et al, 2004)	38	60.0	14.0	-	-	-	-

Notes: *resident physicians or registrars. *attending physicians or primary doctor.

240 Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004. This study, based on 178 patients who died in ICU, found that: 'Nurses in our study perceived patients with family members or others present at the time of death and those without CPR performed in the 8 hrs before their death as having higher quality deaths' (Hodde, Engelberg, Treece, Steinberg, and Curtis, 2004:1652).

Compared to nurses, relatives report that patients have more frequent negative experiences of some physical and psychological symptoms such as being in pain, uncomfortable, anxious, or worried. The prevalence of pain among patients, for all or most of the time during the last week of life, varies significantly between relatives (34%), nurses (16%) and doctors (11%). Significantly, all of these ratings suggest a lower level of pain compared to previous studies in Ireland[241] and to studies of elderly patients in long-term care in Europe[242], the US[243], and Canada[244].

The patient's quality of life seems to improve in line with staff responsiveness to requests, and the perceived quality of end-of-life care in the ward and hospital. Conversely, it seems to decrease in line with the patient's pain and anxiety, while the number of treatment decisions made by hospital staff, and the receipt of specialist palliative care does not seem to have any direct effect on QODD scores.

Quality of care

The quality of care for patients who die in Irish hospital appears reasonably good, reflected in the fact that a substantial majority of relatives (78%) rate it as 'good or very good'. This however is lower than the corresponding ratings by nurses (91%) and doctors (95%) indicating that, from the perspective of relatives, the quality of care is not as good as nurses and doctors believe.

The concept of 'quality of care' is far from clear-cut, and the different perceptions of relatives, nurses and doctors are underlined by the fact that there is only 30% agreement between them. The fact that communication with patients is consistently assessed by relatives, nurses and doctors as the weakest aspect of care is a challenging finding. Equally challenging is the

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[241] Keegan et al, 1999. This study, based on 155 relatives, found that during the last week, 64% of patients had pain (58% of it very distressing), 83% had trouble breathing (47% of it very distressing), and 50% had anxiety (61% of it very distressing) (Ibid:19, Table 3.1).

[242] Achterberg, et al, 2010. This study, based on 10,015 residents in long-term care in Finland, Netherlands and Italy, found 49% had pain in the last week, leading the authors to conclude: 'The prevalence of pain that we found is indeed alarming, especially because estimates do not show any improvement compared to earlier studies, despite increased attention to its assessment and treatment worldwide. The adoption of a common instrument such as the MDS [Minimum Data Set] allows, for the first time, to compare prevalence rates and to document clinical correlates of pain that are basically identical near the north pole as well as at the borders of Africa. A more widespread adoption of a tool such as the MDS instrument might represent a way to improve the situation, by cross-national benchmarking, and by the exchange of best practices. Implementation of verbal and non-verbal pain scales will help increase recognition of pain, but not necessarily lead to quantitative and qualitatively better (pharmacological) treatment' See also Finne-Soveri, et al, 2000.

[243] Sawyer, et al, 2007. This study, based on 27,628 Alabama nursing home residents found 45% had pain in the last week. Other studies, using different instruments, also indicate 'a pain prevalence of 70-100% among cancer patients' (Lorenz, et al, 2004:2).

[244] Proctor and Hirdes, 2001. This study, based on 3195 nursing home residents in Ontario, Manitoba and Saskatchewan found 50% had pain in the last week. See also Zyczkowska, et al, 2007.

fact that there is least agreement (10%) in their three assessments on this aspect of care. Relatives perceive the quality of care to be better when staff are responsive to requests, when relatives perceive that end-of-life care in the ward and hospital is good or very good, and when patients are free from pain and anxiety.

An Acceptable Death

The rate of unacceptable deaths in Irish hospitals is not inconsiderable (21%) and, although much lower compared to French hospitals (58%), it is significantly higher compared to the assessments of nurses (13%) or doctors (3%). This is an important finding given that an acceptable death would appear to be a good indicator of a 'good death' which is one of the core outcomes of the HFH programme, as articulated in the original grant proposal: 'The single most important outcome is the development of a widespread understanding of what constitutes a good death, how that is best achieved and how constraints in achieving it can be addressed'[245].

Post-Mortems

Just under a tenth of all deaths (9%) were followed by a post-mortem, all of them in acute hospitals. This suggests that the sample of relatives under-estimates the true extent of post-mortems since about a fifth of all acute hospital deaths are followed by a post-mortem[246]. Whenever a post-mortem took place, about two thirds of relatives were made aware of the reasons for it in a sensitive, timely, and clear manner. However a third of relatives do not seem to have been properly informed about the reasons for the post-mortem, and were less than satisfied with the information provided by the hospital.

Conclusions and issues for consideration

These findings raise a number of issues which merit further consideration by each individual hospital and their staff, and the HSE generally. In the final section of the report, we outline these issues in detail in order to facilitate discussion, reflection and a considered response.

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245 Irish Hospice Foundation, 2006, Grant Proposal to Atlantic Philanthropies, 19 July.

246 McKeown, Haase, and Twomey, 2010a.

Annex 4: The Culture of End-of-Life Care in Hospitals in Ireland - Summary of Report 4[247]

This report describes the attitudes of hospital staff to a range of end-of-life issues. These attitudes manifest some aspects of the hospital's culture about end-of-life care because they touch on underlying beliefs and values about dying and the care of patients who die in hospital. The report is based on two datasets derived from a survey of: (i) 2,358 ward staff with a response rate of 83%; and (ii) 1,858 hospital staff with a response rate of 64%.

Respondent Characteristics

The vast majority of respondents are female (81%), consistent with the overall gender profile of HSE staff which is 80% female[248]. Nearly a quarter (23%) of all staff were brought up outside Ireland – especially the Philippines and India – which is much higher than in the Irish health services generally where 10% of staff are non-Irish[249]. As a result, English is not the first language for nearly a quarter (24%) of ward staff.

Feeling Comfortable Talking About Dying and Death

Nearly four out of ten staff, in both the ward (39%) and hospital (37%), are very or completely comfortable with talking about death and dying, similar to the proportion in the national population (38%)[250]. However staff are markedly less comfortable – by 10 percentage points - with talking to people who have been bereaved recently, just as in the national population. Within wards, nurse managers are the most comfortable and nurses are the least comfortable.

Preferred Place to Die

There is a much higher preference to die at home among both ward staff (81%) and hospital staff (77%) compared to the national population (67%)[251]. Correspondingly, the proportion preferring to die in hospital (6%) is smaller than in the national population (10%). This finding is consistent with other studies which show that doctors and nurses have a stronger preference to die at home compared to patients[252].

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[247] McKeown, Haase, and Twomey, 2010d.

[248] HSE and Department of Health 2009: Table B3, p.61.

[249] HSE and Department of Health 2009:62.

[250] Based on a survey of 1,000 adults aged 15+ in the Republic of Ireland, carried out in 2004 (Weafer and Associates Research, 2004).

[251] Based on a survey of 1,000 adults aged 15+ in the Republic of Ireland, carried out in 2004 (Weafer and Associates Research, 2004).

[252] Sprung, Carmel, Sjokvist, et, al., 2007.

Quality of End-of-Life Care in Irish Hospitals

A majority of hospital staff (63%) rate the end-of-life care in Irish hospitals as good or excellent, but significantly lower compared to the general population who have had direct experience of end-of-life care in hospital in the past two years (75%)[253].

Most and Least Important Things About Dying

The two most important things about care when dying, according to staff, are: to be free from pain (86%) and to be surrounded by loved ones (87%). These are also the two most important things about care when dying in the national population. The three least important things for staff about care when dying are: spiritual support (13% compared to 19% in the general population), medical and nursing support (19% compared to 32% in general population), and a private space (25% compared to 11% in the general population).

Physical Environment of Ward

Ward staff rated their ward, on a 1-10 scale, at 4.7 in acute hospitals and 6.4 in community hospitals. These ratings were highest in oncology wards (6.1), and lowest in A&E (2.9). The two highest ratings are for dignity (6.6) and privacy (5.8) while the lowest are for environment (4.8) and control (3.7). This pattern of results is at variance with an independent observation of 15 acute and 5 community hospitals – all included in this audit - which gave an overall score of 3.6 out of 10 for the physical environment of these hospitals[254].

Bed Occupancy

The survey revealed that nearly eight out in ten ward staff (79%) believe that the bed occupancy rate in their ward is high or very high, and this perception is much stronger in acute than in community hospitals. This is consistent with the first audit report which indicated an overall bed occupancy rate of 93% for both the acute and community hospitals. Ireland has the fourth highest bed-occupancy rate in the OECD where the average is 75%[255].

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[253] Weafer & Associates Research, 2004: Figures 12 and 15, pages 16 and 19. This suggests that people's experience of hospitals tends to be quite positive and, perhaps more significantly, tends to be more positive among those who speak from direct experience of hospital services. This is consistent with a study in 2007 by HSE's Office of Consumer Affairs, comprising a random sample of 3,517 Irish people, on experiences of public health and social care services. A sub-sample of these (344, 10%) had experience of hospital services in the last year and reported high overall levels of satisfaction on dimensions such as: effective treatment by a trusted professional (78%), involvement in decisions and respect for own preferences (75%), clear and comprehensive information (80%), emotional support, empathy and respect (83%), easy to get around the hospital (74%). However there was a marked dip in satisfaction on dimensions such as cleanliness of hospital toilets (62%), contact with the hospital by phone (69%), and car-parking facilities (46%) (UCD and Lansdowne Market Research, 2007)

[254] Tribal, 2007.

[255] OECD, 2007.

Patient turnover

The survey revealed that nearly six in ten ward staff (58%) believe patient turnover is high or very high, and much higher in acute than community hospitals. Given that patient turnover is determined by the average length of stay, this needs to be seen in the context that average length of stay is slightly higher in Ireland's acute hospitals (6.7 days) compared to the OECD average (6.3 days)[256]; in addition, the average length of stay of patients who die in acute hospitals in Ireland (24 days) is high by comparison with the UK[257] and the US[258].

Patient Dependency

Nearly three quarters of ward staff (74%) believe that patient dependency in the ward is high or very high, with little difference between acute than community hospitals.

Patient Deaths

For a majority of ward staff (85%), deaths occur relatively infrequently at about every two weeks or less. Deaths are more frequent in acute than in community hospitals.

Staff Sufficiency

More than half the ward staff (56%), especially in acute hospitals, believe there is not sufficient staff on the ward.

Staff Turnover

Staff turnover is perceived to be low. This is consistent with the relatively low annual turnover of staff in acute (15%) and community (14%) hospitals[259] and in Ireland generally[260].

Working Environment

More than eight out of ten staff (81%) believe their workplace is good or very good. The highest rated aspects of the ward, on a scale from 1-10, are the standard of care (8.7), ward management (8.1), and staff relationships (7.9). End-of-life care was given a lower rating (7.3) along with ward facilities (7.9).

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[256] OECD, 2007:73. In the HSE's 2009 National Service Plan, the target average length of stay in acute hospitals is 5.9 days (HSE National Service Plan 2009, 2008:71).

[257] A study of 599 deaths in an acute hospital in the south west of England found that the average length of stay before death was 12 days (Abel, Rich, Griffin, and Purdy, 2009:3 and Table 6). A study of 314 cancer deaths in Boston Lincolnshire between September 2006 and March 2007 found that the average length of stay before death was 16.6 days (Addicott and Dewar, 2008:Tables 4 and 7).

[258] The Institute for Healthcare Improvement has adopted 7.24 days as an indicator of an efficient length of stay during the last six months of life (Martin, Nelson, Lloyd, and Nolan, 2007:6; see also Wennberg, et al, 2004). This target was set following research published by Dartmouth Atlas which showed that length of stay in the last six months of life varied across the US from 4.87 to 19.67 days for the same diagnostic categories and independently of need and outcome albeit with significant variations in cost (Wennberg, Fisher, Stukel, Skinner, Sharp, and Bronner, 2004).

[259] McKeown, Haase and Twomey, 2010a.

[260] Bergin, 2009:24

Work satisfaction

Overall work satisfaction is high, consistent with the results of a national survey on job satisfaction in Ireland which found 'over 90 per cent of respondents agreeing or strongly agreeing that 'in general' they are satisfied with their job'[261]. Hospital staff are twice as likely to be dissatisfied with their work (11%) compared to ward staff (5%). At the level of wards, the highest proportion of dissatisfied staff (16%) are to be found in A&E and the lowest in oncology (0%). Dissatisfaction with work is twice as high in acute hospitals (12%) as in community hospitals (6%). Doctors are the most dissatisfied group of hospital staff (15%) while the least dissatisfied are those involved in other patient care such as pastoral care, bereavement, and end-of-life care (4%).

Quality of End-of-Life Care

On a scale from 1-10, ward staff rate the quality of end-of-life care on their ward at 8.1, higher for community hospitals (8.7) than for acute hospitals (8.0). These scores are high and show relatively little variability.

Acceptability of Way Patients Die in Hospital

The vast majority of ward staff (90%) and hospital staff (87%) regard deaths in the ward and hospital as acceptable to them. Deaths are perceived to be more acceptable in community hospitals than in acute hospitals. Within wards, the highest rates of unacceptable deaths are to be found in A&E (26%) and the lowest in oncology (3%).

Education, Training and Preparedness for End-of-Life Care

The survey asked ward and hospital staff to rate 11 statements about the hospital's education, training and other supports for end-of-life care. Seven items were rated consistently below the mid-point (5) and can therefore be regarded as less than adequate while the other four statements scored are just above the mid-point and might be regarded as minimally adequate. Nevertheless, the vast majority of ward staff feel prepared for the death of a patient, both professionally (92%) and personally (90%).

Supports for Staff Very Upset After a patient's Death

Over half the ward staff (51%) felt very upset after a patient's death during the past year; this suggest a higher rate of upset compared to nurses who completed the audit on deceased patients where only 21% reported feeling very upset after a patient's death. The vast majority of ward and hospital staff can rely on the support of colleagues, their manager, and in-house counselling if they felt very upset at the death of a patient.

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[261] O'Connell and Russell, 2007:62. This study also found that job satisfaction tends to be higher among managers, professionals and technical staff and lower among sales staff and operatives while those in part-time work tend to be marginally more satisfied than those in full-time work.

Hospital Priorities

Staff rated the priority given to 13 different activities in the hospital. Most activities received broadly similar priority, averaging 7 out of 10. The highest priority is for active treatment of the patient and the lowest is for carrying out innovative research. End-of-life care, though not the top priority, is perceived to receive a substantial amount of attention, according to ward staff (7.6) and hospital staff (7.4).

Religious Ethos

The majority of ward staff (65%) and hospital staff (72%) perceive their hospital to be fairly religious. Staff in community hospitals are twice as likely to perceive their hospital as very religious compared staff in acute hospitals. Very few staff describe their hospital as non-religious.

Conclusions and issues for consideration

The purpose of this report is to describe some aspects of hospital culture with a view to examining what impact it might have the outcomes of end-of-life care, bearing in mind that much of what is called 'culture' remains in the realm of the unconscious in the form of unspoken assumptions[262]. The ultimate test of the impact of these variables will depend on the statistical analysis in the fifth audit report. Nevertheless, the aspects of hospital culture described in this report are also of intrinsic interest, and we raise a number of issues in the final section of the report which merit further attention and reflection.

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[262] Scott, Mannion, Davies and Marshall, 2003:125.

Annex 5: Variable Definitions

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Patient Domain					
Nurses Perception: Symptoms	1	scaled	nurses perception: symptoms	N1A_Symptoms	q1f2 (Part A)
Doctors Perception: Symptoms	1	scaled	doctors perception: symptoms	D1A_Symptoms	q2f2 (Part A) (q2b2)
Relatives Perception: Symptoms	1	scaled	relatives perception: symptoms	R1A_Symptoms	q3f2 (Part A) (q3c,1,2,3,4,5)
Nurses Perception: Symptom Management	1	scaled	nurses perception: symptom management	N1B_SymptMgm	q1f2 (Part B)
Doctors Perception: Symptom Management	1	scaled	doctors perception: symptom management	D1B_SymptMgm	q2f2 (Part B) (q2b2)
Nurses Perception: QODD Experience	1	scaled	nurses perception: QODD experience	N1C_QODDExp	q1h (items1-10)
Relatives Perception: QODD Experience	1	scaled	relatives perception: QODD experience	R1C_QODDExp	q3h (items1-10) q3c (1-8,10,14)
Nurses Perception: Patient Care	1	scaled	nurses perception: patient care	N2_PatCare	q1j1,2,4
Doctors Perception: Patient Care	1	scaled	doctors perception: patient care	D2_PatCare	q2j1,2,4 (q2d1,3,4)
Relatives Perception: Patient Care	1	scaled	relatives perception: patient care	R2_PatCare	q3j1,2,4 (q3c1,3,4)
Nurses Perception: Acceptability of Dying	1	scaled	nurses perception: acceptability of dying	N3_AccDeath	q1j8.1
Doctors Perception: Acceptability of Dying	1	scaled	doctors perception: acceptability of dying	D3_AccDeath	q2j8.1 (q2d6.1)
Relatives Perception: Acceptability of Dying	1	scaled	relatives perception: acceptability of dying	R3_AccDeath	q3j8.1 (q3d6)
Nurses Perception: Family Support	1	scaled	nurses perception: family support	N4_FamSupp	q1j3,5
Doctors Perception: Family Support	1	scaled	doctors perception: family support	D4_FamSupp	q2j3,5 (q2d2,5)
Relatives Perception: Family Support	1	scaled	relatives perception: family support	R4_FamSupp	q3j3,5 (q3c2,5)
Age	1	scaled	years	V1.1.1s_age	q1a2
Gender is Female	1	yes/no	dummy variable - reference category is male	V1.1.2d_gen	gender (q1a1)
Ethnicity is non-Irish	1	yes/no	dummy variable - reference category is Irish	V1.1.3d_eth	q1a19
Living alone prior to Hospital Admission	1	yes/no	dummy variable - reference category is all others	V1.1.4d_lal	q1a8
Marital status - not Married	1	yes/no	dummy variable - reference category is married	V1.1.5d_mar	q1a17
Religion not Roman Catholic	1	yes/no	dummy variable - reference category is Roman Catholic	V1.1.6d_rel	q1a20

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Private Healthcare	1	yes/no	dummy variable - reference category is public healthcare	V1.2.1d_gmc	q1a16
Primary Diagnosis (Cancer)	1	yes/no	1/5 dummy variable - reference category is heart and circulatory	V1.3.1d1_can	primDC (q1a11.1)
Primary Diagnosis (Lung & Breathing)	1	yes/no	3/5 dummy variable - reference category is heart and circulatory	V1.3.1d3_bre	primDC (q1a11.1)
Primary Diagnosis (Frailty & Dementia)	1	yes/no	4/5 dummy variable - reference category is heart and circulatory	V1.3.1d4_dem	primDC (q1a11.1)
Primary Diagnosis (Other)	1	yes/no	5/5 dummy variable - reference category is heart and circulatory	V1.3.1d5_oth	primDC (q1a11.1)
Trauma or Accident	1	yes/no	dummy variable - reference category is no trauma/accident	V1.3.2d_tra	q1a12
Sudden Death	1	yes/no	dummy variable - reference category is expected death	V1.3.3d_sud	expect (q1a13)
Dementia	1	yes/no	dummy variable - reference category is no dementia	V1.3.4d_dem	q1a14
Hospital Acquired Infection	1	yes/no	dummy variable - reference category is none	V1.3.5d_inf	q1b5.1.1
Place of Living prior to Admission is Nursing Home	1	yes/no	2/3 dummy variable - reference category is home	V1.4.1d2_nur	q1a7
Place of Living prior to Admission is other	1	yes/no	3/3 dummy variable - reference category is home	V1.4.1d3_oth	q1a7
Admission Route to Hospital is not A & E	1	yes/no	dummy variable - reference category is A & E	V1.4.2d_adm	q1a5
Elective Admission	1	yes/no	dummy variable - reference category is emergency	V1.4.3d_eme	q1a6
Length of Hospital Stay	1	scaled	days	V1.4.4s_sta	q1a3
Care Domain					
Patient Died in Single Room	1	yes/no	dummy variable - reference category is multi-occupancy room	V2.1.1d_sin	room (q1b4.1)
Up to One Week Spent in Single Room by Patients who Died there	1	yes/no	2/3 dummy variable - reference category is not in single room	V2.1.2d1_dsr	q1b5.2.1
Over One Week Spent in Single Room by Patients who Died there	1	yes/no	3/3 dummy variable - reference category is not in single room	V2.1.2d8_dsr	q1b5.2.1
Multi-occupancy Room is Mixed Gender Room	1	yes/no	dummy variable - reference category is male only, female only or single room	V2.1.3d_mix	q1b6.3
Nurses Perceptions of Room: Privacy	1	scaled	10 point scale	V2.1.4s_pri	q1b7cat1 (items 1,2,3)
Nurses Perceptions of Room: Dignity	1	scaled	10 point scale	V2.1.5s_dig	q1b7cat2 (items 4,5,6)
Nurses Perceptions of Room: Environment	1	scaled	10 point scale	V2.1.6s_env	q1b7cat3 (items 7-10)
Nurses Perceptions of Room: Control	1	scaled	10 point scale	V2.1.7s_ctr	q1b7cat4 (items 11-15)
Nurses Perceptions of Room: Quality of Room	1	scaled	10 point scale	V2.1.8s_tot	q1b7 (items 1-15)

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Diagnosis of Dying (Nurses)	1	yes/no	dummy variable - reference category is not diagnosed dying	V2.2.1d_dyi	q1c1
Length of Awareness from Diagnosis to Death (Nurses)	1	scaled	days (log transformed)	V2.2.2s_awa	q1c3
Multi-disciplinary Team Meeting	1	yes/no	dummy variable - reference category is no multi-disciplinary meeting	V2.2.3d_mdm	q1c5.1
Medical & Nursing Team Review Meeting	1	yes/no	dummy variable - reference category is no nursing team meeting	V2.2.4d_ntm	q1c5.2
Staff Communicated with Patient about Situation & Prognosis	1	yes/no	dummy variable - reference category is no communication	V2.3.1d_cpat	q1d1.1
Staff Communication with Patient was Documented	1	yes/no	dummy variable - reference category is not documented	V2.3.2d_cpatd	q1d1.2
Quality of Discussion with Patient	1	scaled	10 point scale	V2.3.3s_qdp	q1d5
Staff Communicated with Relatives about Patient's Situation & Prognosis	1	yes/no	dummy variable - reference category is no communication	V2.3.4d_crel	q1e1.1
Staff Communication with Relatives was Documented	1	yes/no	dummy variable - reference category is not documented	V2.3.5d_creld	q1e1.2
Quality of Discussion with Relatives	1	scaled	10 point scale	V2.3.6s_qdr	q1e6
Hospital Response to Patient's Wishes	1	scaled	10 point scale	V2.3.7s_act	q1d7
Relatives were Offered Opportunity to Stay Overnight	1	yes/no	dummy variable - reference category is could not stay overnight	V2.4.1d_ovn	q1e9.1
Relatives were Free to Visit at Any Time	1	yes/no	dummy variable - reference category is not visit any time	V2.4.2d_any	q1e9.3
Number of Treatment Decisions	1	scaled	sum of decisions	V2.5.1_dec	q1f (items 1-11)
Decision to Review Care in Last Week	1	yes/no	dummy variable - reference category is no review	V2.5.2_rev	q1f1.3.1
Use of Specialist Palliative Care	1	yes/no	dummy variable - reference category is no SPC	V2.5.2d_spc	q1g2
Relatives Present at Moment of Death	1	yes/no	dummy variable - reference category is not present	V2.6.1d_rel	q1j6.1
Staff Present at Moment of Death	1	yes/no	dummy variable - reference category is not present	V2.6.2d_hst	q1j6.2
PM Requested	1	yes/no	dummy variable - reference category is not requested	V2.7.1d_pmr	q1a15.1.1, q1a15.2.1
PM Carried Out	1	yes/no	dummy variable - reference category is no PM	V2.7.2d_pmd	q1a15.1.2, q1a15.2.2
Time Given After Death	1	yes/no	dummy variable - reference category is no time after death	V2.8.1s_tad	q1k1 (Part A)
Culture Domain					
Years Working in Hospital	1	scaled	years	V3.1.1s_yhosp	q1n2 (q1(2)a2)
Years Working on Ward	1	scaled	years	V3.1.2s_yward	q1n3 (q1(2)a3)

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Nurse Country of Origin not Ireland	1	yes/no	dummy variable - reference category is Ireland	V3.1.3d_nnat	q1n4 (q1(2)a4)
Nurse's Age	1	scaled	years	V3.1.4s_nage	q1n6 (q1(2)a6)
Nurse First Language not English	1	yes/no	dummy variable - reference category is English	V3.1.5d_neng	q1n7 (q1(2)a7)
Comfortable Talking About Death	1	scaled	5 point scale	V3.1.6s_ctd	q1o1 (q1(2)b1)
Comfortable Talking to Relative	1	scaled	5 point scale	V3.1.7s_ctr	q1o2 (q1(2)b2)
Professionally Prepared for Death	1	scaled	4 point scale	V3.1.8s_ctd	q1s3 (q1(2)f3)
Personally Prepared for Death	1	scaled	4 point scale	V3.1.9s_ctr	q1s4 (q1(2)f4)
Formal EoLCare Training	1	yes/no	dummy variable - reference category is no EoL training	V3.1.10d_EoLt	q1s1 (q1(2)f1)
Private Healthcare	1	yes/no	dummy variable - reference category is public healthcare	W1.2.1d_gmc	V1.2.1d_gmc (q1a16)
Ward Domain					
Primary Diagnosis (Cancer)	2	scaled	% of L1 patients with cancer	W1.3.1d1_can	V1.3.1d1_can
Primary Diagnosis (Lung & Breathing)	2	scaled	% of L1 patients with breathing difficulties	W1.3.1d3_bre	V1.3.1d3_bre
Primary Diagnosis (Frailty & Dementia)	2	scaled	% of L1 patients with dementia	W1.3.1d4_dem	V1.3.1d4_dem
Primary Diagnosis (Other)	2	scaled	% of L1 patients with other diagnosis	W1.3.1d5_oth	V1.3.1d5_oth
Sudden Death	2	scaled	% of L1 patients with sudden death	W1.3.3d_sud	V1.3.3d_sud
Years Working in Hospital	2	scaled	mean years (L1)	W3.1.1s_yhosp	mean V3.1.1s_yhosp
Years Working on Ward	2	scaled	mean years (L1)	W3.1.2s_yward	mean V3.1.2s_yward
Nurse Country of Origin not Ireland	2	yes/no	dummy variable - reference category is Ireland	W3.1.3d_nnat	V3.1.3d_nnat
Nurse First Language not English	2	yes/no	dummy variable - reference category is English	W3.1.5d_neng	V3.1.5d_neng
High Bed Occupancy Rates	2	scaled	% nurses stating high bed occupancy rates	W3.4c1	q4c1 (4, 5)
High Patient Turnover Rates	2	scaled	% nurses stating high patient turnover rates	W3.4c2	q4c2 (4, 5)
High Patient Dependency Rates	2	scaled	% nurses stating high patient dependency rates	W3.4c3	q4c3 (4, 5)
High Staff Turnover Rates	2	scaled	% nurses stating high staff turnover rates	W3.4c4	q4c4 (4, 5)
Not Enough Nursing Staff	2	scaled	% nurses stating not enough nursing staff	W3.4c5	q4c5 (1, 2)
High Frequency of Death	2	scaled	% nurses stating patient dies nearly every day or week	W3.4c6	q4c6 (1, 2)

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Room Privacy	2	scaled	mean of 10 point scales	W3.4c7priv	mean q4c7cat1 (q4c7.1 to q4c7.3)
Room Dignity	2	scaled	mean of 10 point scales	W3.4c7dign	mean q4c7cat2 (q4c7.4 to q4c7.6)
Room Environment	2	scaled	mean of 10 point scales	W3.4c7envi	mean q4c7cat3 (q4c7.7 to q4c7.10)
Room Control	2	scaled	mean of 10 point scales	W3.4c7cont	mean q4c7cat4 (q4c7.11 to q4c7.15)
Working Conditions	2	scaled	mean of first factor scores	W3.4d8	mean FAC1_1 (q4d1 to q4d7.1)
Formal Training Course	2	scaled	% nurses having EoL training	W3.4f1	q4f1
Professional Preparedness	2	scaled	% nurses professionally prepared to deal with death of patient	W3.4f3	q4f3 (3, 4)
Personal Preparedness	2	scaled	% nurses personally prepared to deal with death of patient	W3.4f4	q4f4 (3, 4)
Hospital Domain					
A & E	3	scaled	% L1 patients in A & E	Hwardgrp1	wardgrp, 1 (q1a9)
Intensive Care	3	scaled	% L1 patients in Intensive Care	Hwardgrp2	wardgrp, 2 (q1a9)
Surgical	3	scaled	% L1 patients in Surgical	Hwardgrp3	wardgrp, 3 (q1a9)
Medical	3	scaled	% L1 patients in Medical	Hwardgrp4	wardgrp, 4 (q1a9)
Oncology	3	scaled	% L1 patients in Oncology	Hwardgrp5	wardgrp, 5 (q1a9)
Geriatric	3	scaled	% L1 patients in Geriatric	Hwardgrp6	wardgrp, 6 (q1a9)
Other Ward	3	scaled	% L1 patients in Other Ward	Hwardgrp7	wardgrp, 7 (q1a9)
Single Room	3	scaled	% L1 patients dying in single room	Hroom	room (q1b4.1)
Gender is Female	3	scaled	% L1 female patients	Hgender	gender (q1a1)
Age	3	scaled	mean age (L1)	Hage	mean q1a2
Length of Stay in Hospital	3	scaled	mean stay (L1)	Hstay	mean q1a3
Nurses Perception: Mean Symptoms	3	scaled	nurses Perception: mean symptoms (L1)	HN1A_Symptoms	mean N1A_Symptoms
Doctors Perception: Mean Symptoms	3	scaled	doctors Perception: mean symptoms (L1)	HD1A_Symptoms	mean D1A_Symptoms
Relatives Perception: Mean Symptoms	3	scaled	relatives Perception: mean symptoms (L1)	HR1A_Symptoms	mean R1A_Symptoms

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Nurses Perception: Mean Symptom Management	3	scaled	nurses Perception: mean symptom management (L1)	HN1B_SymptMgm	mean N1B_SymptMgm
Doctors Perception: Mean Symptom Management	3	scaled	doctors Perception: mean symptom management (L1)	HD1B_SymptMgm	mean D1B_SymptMgm
Nurses Perception: Mean QODD Experience	3	scaled	nurses Perception: mean QODD experience (L1)	HN1C_QODDExp	mean N1C_QODDExp
Relatives Perception: Mean QODD Experience	3	scaled	relatives Perception: mean QODD experience (L1)	HR1C_QODDExp	mean R1C_QODDExp
Nurses Perception: Mean Patient Care	3	scaled	nurses Perception: mean patient care (L1)	HN2_PatCare	mean N2_PatCare
Doctors Perception: Mean Patient Care	3	scaled	doctors Perception: mean patient care (L1)	HD2_PatCare	mean D2_PatCare
Relatives Perception: Mean Patient Care	3	scaled	relatives Perception: mean patient care (L1)	HR2_PatCare	mean R2_PatCare
Nurses Perception: Mean Acceptability of Dying	3	scaled	nurses Perception: mean acceptable death (L1)	HN3_AccDeath	mean N3_AccDeath
Doctors Perception: Mean Acceptability of Dying	3	scaled	doctors Perception: mean acceptable death (L1)	HD3_AccDeath	mean D3_AccDeath
Relatives Perception: Mean Acceptability of Dying	3	scaled	relatives Perception: mean acceptable death (L1)	HR3_AccDeath	mean R3_AccDeath
Nurses Perception: Mean Family Support	3	scaled	nurses Perception: mean family support (L1)	HN4_FamSupp	mean N4_FamSupp
Doctors Perception: Mean Family Support	3	scaled	doctors Perception: mean family support (L1)	HD4_FamSupp	mean D4_FamSupp
Relatives Perception: Mean Family Support	3	scaled	relatives Perception: mean family support (L1)	HR4_FamSupp	mean R4_FamSupp
Private Healthcare	3	scaled	% of L1 patients with private healthcare	H1.2.1d_gmc	V1.2.1d_gmc
Primary Diagnosis (Cancer)	3	scaled	% of L1 patients with cancer	H1.3.1d1_can	V1.3.1d1_can
Primary Diagnosis (Lung & Breathing)	3	scaled	% of L1 patients with breathing difficulties	H1.3.1d3_bre	V1.3.1d3_bre
Primary Diagnosis (Frailty & Dementia)	3	scaled	% of L1 patients with dementia	H1.3.1d4_dem	V1.3.1d4_dem
Primary Diagnosis (Other)	3	scaled	% of L1 patients with other diagnosis	H1.3.1d5_oth	V1.3.1d5_oth
Sudden Death	3	scaled	% of L1 patients with sudden death	H1.3.3d_sud	V1.3.3d_sud
Admission Route to Hospital is not A & E	3	scaled	% of L1 patients not admitted through A & E	H1.4.2d_adm	V1.4.2d_adm
Elective Admission	3	scaled	% of L1 patients without emergency admission	H1.4.3d_eme	V1.4.3d_eme
Patient Died in Single Room	3	scaled	% of L1 patients who died in single room	H2.1.1d_sin	V2.1.1d_sin
Nurses Perceptions of Room: Dignity	3	scaled	mean dignity (L1)	H2.1.5s_dig	mean V2.1.5s_dig
Length of Awareness from Diagnosis to Death (Nurses)	3	scaled	mean awareness (L1)	H2.2.2s_awa	mean V2.2.2s_awa

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Multidisciplinary Team Meeting	3	scaled	% L1 patients were MDM took place	H2.2.3d_mdm	V2.2.3d_mdm
Medical & Nursing Team Review Meeting	3	scaled	% L1 patients NTM took place	H2.2.4d_ntm	V2.2.4d_ntm
Staff Communication with Patient was Documented	3	scaled	% L1 patients where communication was documented	H2.3.2d_cpatd	V2.3.2d_cpatd
Quality of Discussion with Patient	3	scaled	mean quality (L1)	H2.3.3s_qdp	mean V2.3.3s_qdp
Staff Communicated with Relatives	3	scaled	% L1 patients were communication with relatives took place	H2.3.4d_crel	V2.3.4d_crel
Quality of Discussion with Relatives	3	scaled	mean quality (L1)	H2.3.6s_qdr	mean V2.3.6s_qdr
Response to Patient's Wishes	3	scaled	mean response (L1)	H2.3.7s_act	mean V2.3.7s_act
Relatives were offered Opportunity to Stay Overnight	3	scaled	% L1 patients where relatives could stay overnight	H2.4.1d_ovn	V2.4.1d_ovn
Relatives were Free to Visit at Any Time	3	scaled	% L1 patients where relatives could visit any time	H2.4.2d_any	V2.4.2d_any
Stop non-essential Medication	3	scaled	% L1 patients were non-essential medication was stopped	H2.5.2_rev	V2.5.2_rev
Use of Specialist Palliative Care	3	scaled	% L1 patients received SPC	H2.5.2d_spc	V2.5.2d_spc
Relatives present at Moment of Death	3	scaled	% L1 patients with relatives present	H2.6.1d_rel	V2.6.1d_rel
PM Request	3	scaled	% L1 patients with PM request	H2.7.1d_pmr	V2.7.1d_pmr
Years Working in Hospital	3	scaled	mean years (L1)	H3.1.1s_yhosp	mean V3.1.1s_yhosp
Years Working on Ward	3	scaled	mean years (L1)	H3.1.2s_yward	mean V3.1.2s_yward
Nurse Country of Origin not Ireland	3	scaled	% L1 nurses not from Ireland	H3.1.3d_nnat	V3.1.3d_nnat
First Language not English	3	scaled	% L1 nurses were first language is not English	H3.1.5d_neng	V3.1.5d_neng
Professionally Prepared for Death	3	scaled	mean professionally prepared (L1)	H3.1.8s_ctd	mean V3.1.8s_ctd
Personally Prepared for Death	3	scaled	mean personally prepared (L1)	H3.1.9s_ctr	mean V3.1.9s_ctr
Formal EoLCare Training	3	scaled	% L1 nurses with EoL training	H3.1.10d_EoLt	V3.1.10d_EoLt
Teaching Hospital	3	yes/no	dummy variable	hfhid3_1	HfHID3, 1
Regional Hospital	3	yes/no	dummy variable	hfhid3_2	HfHID3, 2
Other Acute Hospital	3	yes/no	dummy variable	hfhid3_3	HfHID3, 3
Community Hospital	3	yes/no	dummy variable	hfhid3_4	HfHID3, 4

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Comfortable Talking about Death	3	scaled	% nurses comfortable to talk about death	H3.4b1	q4b1 (4, 5)
Comfortable Talking to Recently Bereaved	3	scaled	% nurses comfortable talking to bereaved	H3.4b2	q4b2 (4, 5)
High Bed Occupancy Rate	3	scaled	% nurses stating high bed occupancy rates	H3.4c1	q4c1 (4, 5)
High Patient Turnover Rate	3	scaled	% nurses stating high patient turnover rates	H3.4c2	q4c2 (4, 5)
High Patient Dependency Rate	3	scaled	% nurses stating high patient dependency rates	H3.4c3	q4c3 (4, 5)
High Staff Turnover Rate	3	scaled	% nurses stating high staff turnover rates	H3.4c4	q4c4 (4, 5)
Not Enough Nursing Staff	3	scaled	% nurses stating not enough nursing staff	H3.4c5	q4c5 (1, 2)
High Frequency of Death	3	scaled	% nurses stating patient dies nearly every day or week	H3.4c6	q4c6 (1, 2)
Room Privacy	3	scaled	mean of 10 point scales	H3.4c7cat1	mean q4c7cat1 (q4c7.1 to q4c7.3)
Room Dignity	3	scaled	mean of 10 point scales	H3.4c7cat2	mean q4c7cat2 (q4c7.4 to q4c7.6)
Room Environment	3	scaled	mean of 10 point scales	H3.4c7cat3	mean q4c7cat3 (q4c7.7 to q4c7.10)
Room Control	3	scaled	mean of 10 point scales	H3.4c7cat4	mean q4c7cat4 (q4c7.11 to q4c7.15)
Place to Work	3	scaled	mean of 10 point scale	H3.4d1	mean q4d1
Staff Relations	3	scaled	mean of 10 point scale	H3.4d2	mean q4d2
Well Equipped	3	scaled	mean of 10 point scale	H3.4d3	mean q4d3
Standard of Care	3	scaled	mean of 10 point scale	H3.4d4	mean q4d4
Place to Deliver Care	3	scaled	mean of 10 point scale	H3.4d5	mean q4d5
Ward Management	3	scaled	mean of 10 point scale	H3.4d6	mean q4d6
Overall Quality of Care	3	scaled	mean of 10 point scale	H3.4e17	mean q4e17
Formal Training Course	3	scaled	% nurses having EoL training	H3.4f1	q4f1
Professional Preparedness	3	scaled	% nurses professionally prepared to deal with death of patient	H3.4f3	q4f3 (3, 4)
Personal Preparedness	3	scaled	% nurses personally prepared to deal with death of patient	H3.4f4	q4f4 (3, 4)
Education and Training	3	scaled	mean of 10 point scales	H3.4h12	mean q4h12 (q4h items 1-11)

Domain - Concept	L	Categories	Description	Variable Name	Source Variable(s)
Hospital Priorities	3	scaled	mean of 10 point scales	H3.4j15	mean q4j15 (q4j items 1-13)
Hospital Very Religious	3	scaled	% nurses state very religious	H3.4j14	q4j14 (3)
Comfortable Talking About Death	3	scaled	% non-nursing staff comfortable talking about death	H3.5b1	q5b1 (4, 5)
Comfortable Talking to Recently Bereaved	3	scaled	% non-nursing staff comfortable talking to recently bereaved	H3.5b2	q5b2 (4, 5)
Overall Work Satisfaction	3	scaled	mean of 10 point scale	H3.5c1	mean q5c1
Acceptable to Staff Member	3	scaled	mean of 10 point scale	H3.5d1.1	mean q5d1.1
Acceptable to Family Member	3	scaled	mean of 10 point scale	H3.5d1.2	mean q5d1.2
Formal Training Course	3	scaled	% non-nursing staff having EoL training	H3.5e1	q5e1
Professional Preparedness	3	scaled	% non-nursing staff professionally prepared to deal with death of patient	H3.5e3	q5e3 (3, 4)
Personal Preparedness	3	scaled	% non-nursing staff personally prepared to deal with death of patient	H3.5e4	q5e4 (3, 4)
Education and Training	3	scaled	mean of 10 point scales	H3.5g12	mean q5g12 (q5g items 1-11)
Hospital Priorities	3	scaled	mean of 10 point scales	H3.5h15	mean q5h15 (q5h 1-13)
Hospital Very Religious	3	scaled	% non-nursing staff state very religious	H3.5h14	q5h14 (3)
Proportion of Single Beds	3	scaled	scale variable (%)	H4.1	q6a2
Average Bed Occupancy Rate	3	scaled	scale variable (%)	H4.2	q6a3
WTE Palliative Care Staff per 100 Deaths	3	scaled	scale variable	H4.3	q6e2
Consultant Palliative Medicine Hours per Death	3	scaled	scale variable	H4.4	q6e2, 1
Total Complaints per 1000 Patients	3	scaled	scale variable	H4.5	q6g1, HSE
EoL Policy - Document	3	yes/no	dummy variable	H4.6	q6h1
EoL Policy - Objective	3	yes/no	dummy variable	H4.7	q6h2
EoL Policy - Memo	3	yes/no	dummy variable	H4.8	q6h3.1
EoL Policy - Co-ordinator	3	yes/no	dummy variable	H4.9	q6h3.2
EoL Staff Support Document	3	yes/no	dummy variable	H4.10	q6j2
Mortuary Facility Score	3	scaled	scale variable (%)	H4.11	q6k2

Annex 6: Introduction to Multilevel Modelling

6.1 Multilevel Models: Reading the Results of the Statistical Models

This study was designed with the ward-based organisational structure of the hospital in mind. This hierarchical structure – which groups together particular kinds of patients within wards, and wards within hospitals – is associated with a well-known set of methodological issues related to the construction and estimation of statistical models. In the first place, data with a nested, multi-level structure present problems for traditional techniques, which generally assume that each individual observation is independent of the others and drawn from a single population.[263] By definition, contextual influences are shared by a group of nurses, patients or doctors, by virtue of their shared environment. Secondly, it has been demonstrated that nested data structures offer considerable opportunities for investigating the effects of contextual influences by using multilevel models.

Our starting point is thus the hypothesis that ward-level or hospital-level effects can have an impact on the experience of end-of-life care. The influence of such higher-order factors may be due to management style, organisational culture, geographical location, hospital or ward type, resources, facilities, the diffusion of certain behaviours or practices within wards and so on. By using appropriate statistical techniques, we can ascertain whether these higher-level effects strengthen or weaken end-of-life care or interact with individual-level variables, such as length of experience or participation in training courses, to influence patient care in specific ways.

As far as data considerations are concerned, there are two basic ways of gathering information on the ward or hospital context: by measuring contextual factors at the aggregate level (ward or hospital), perhaps by interviewing a representative or by using existing administrative data; second, by computing averages or other summary measures using individual-level data. In the present study, we use both techniques to develop a set of robust and powerful ward-level and hospital-level explanatory variables. These are used, in conjunction with individual-level data collected from nurses, doctors and relatives, to develop a rich representation of the experience of end-of-life care in Irish hospitals.

Although multilevel modelling techniques have received considerable attention from educational researchers, epidemiologists, geographers and many other researchers, it should be remembered that contextual effects are typically not the most important influences at work in

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[263] Cf. Jones, 1991; Goldstein, 1995; Kreft and de Leeuw, 1998. This bias affects the estimates produced by many statistical models (in particular, the identification of statistically-significant effects) because the information gathered from people who work or receive care within the same hospital or ward context is not “independent”, at least in statistical terms.

any given situation. On the contrary, published models reveal that these effects often have quite a circumscribed role in relation to a range of phenomena. The growing popularity of multilevel models is due to their ability to quantify these effects, however small they may be, to reveal the existence of compositional effects, to provide unbiased estimates of individual effects and to incorporate more complex structures (such as growth curves, multiple outcomes etc.).

Given the flexibility and complexity of multilevel models, an incremental, structured approach was adopted, proceeding from (a) the careful conceptualisation of key aspects of the hospital and ward contexts to (b) the specification of relatively simple models and (c) the development of more complex models on the basis of the results of the preliminary analysis. This logical progression was repeated for each type of respondent (nurses, doctors, relatives) and each outcome variable, with a view to understanding how the different parameters in the models changed as model specification was altered.

All models presented here were estimated using the software package MLwiN v. 2.10, and were specified as three-level linear regression equations with varying ("random") level two and level three intercepts. The level two (ward) and level three (hospital) estimates for the intercepts can be divided into an overall estimate (or "grand mean") and a "residual" for each ward or hospital. The residual expresses the distance between that ward or hospital and the aforementioned average, and thus provides a level-specific measure of variability. If individual-level explanatory variables are included in the model, the level two and level three residuals (referred to now as "adjusted residuals") express the variations in outcomes between wards and hospitals, after controlling for their composition.

6.2 Multilevel Models of end-of-life care

For each of the six dependent variables (Symptoms, Symptom Management, Experience of Symptoms, Patient Care, Acceptability of Death and Family Support), and for each respondent for whom we have data (nurse, doctor, relative) we report estimates for the following models: (1) the 'variance components' model with no explanatory variables, (2) the 'variance components' model with only individual-level explanatory variables, (3) the 'variance components' model with only ward-level explanatory variables, (4) the 'variance components' model with only hospital-level explanatory variables, (5) the 'variance components' model with individual-level, ward-level and hospital-level explanatory variables.

A fifth set of models was also estimated, including "random slopes" as well as "random intercepts", but significant slope variation was found in only one case. In order to ensure comparability between models, therefore, we concentrate on the five 'variance components' models described above, which are presented in Annex 3.

The specification of the multilevel models was developed in incremental fashion, starting with the results of bivariate linear regression models and progressing to more complex models. The sensitivity of the results to the inclusion or removal of key variables was tested with a view to identifying spurious results and achieving a robust model. By inspecting the results, it was possible to develop a common structure for each outcome variable in order to facilitate comparison between the three potential respondents. As a result, the coefficients obtained from models based on a given outcome, using nurses', doctors' and relatives' responses, can be directly compared.

6.3 Interpreting the results of the multilevel models

All of the outcome variables are measured on a "percentage" scale which ranges from 0 to 100, and the same is true for most of the continuous, individual-level explanatory variables. Dichotomous variables, by contrast, assume the values 0 and 1, and are used here to measure the influence of characteristics such as gender. Multinomial explanatory variables with more than two categories (marital status, for example) were transformed into a set of dichotomous variables before being included in the statistical models. Each of these dichotomous variables expresses the contrast between one of the possible outcome categories and a "reference category" (which is automatically excluded).

Variables with a "natural scale", such as length of experience (years) or length of stay (days), were not transformed to the 0-100 scale, even where further transformations were applied (natural log, for example). Where ward-level or hospital-level variables were constructed by aggregating individual-level responses, the resulting variable is measured either as the (mean) percentage or as the percentage of cases that belong to a given category (percentage non-national, for example).

When interpreting the results of the statistical models, therefore, it is necessary to take the measurement scale of the explanatory variables into account. In broad terms, the following guidelines should be followed:

For continuous variables measured as percentages, effects should be interpreted as follows: "for each percentage point increase in the explanatory variable, holding all other explanatory variables constant at their mean, the outcome variable increases by x percentage points" (where x is the coefficient for the explanatory variable in question). This interpretation applies not only to individual-level influences, but also to ward-level and hospital-level explanatory variables, to the extent that these capture either an average percentage value or the percentage of cases belonging to a given category.

For continuous variables measured in their original units, effects should be interpreted as follows: "for each unit increase in the explanatory variable, holding all other explanatory variables constant at their mean, the outcome variable increases by x percentage points" (where x is the coefficient for the explanatory variable in question). This interpretation applies not only to individual-level influences, but also to ward-level and hospital-level explanatory variables where these indicate an average value (average length of stay, average years of experience) [264].

For single dichotomous variables, effects should be interpreted as follows: "holding other explanatory variables constant at their mean, the outcome variable is x percentage points higher in group A than in group B (where the dummy variable is coded 1 for group A and 0 for group B)" (and where x is the coefficient for the dichotomous variable in question). This interpretation applies not only to individual-level influences, but also to ward-level and hospital-level explanatory variables to the extent that these are coded as dichotomous measures.

For multiple "dummy" variables that relate to a single classification, effects should be interpreted as follows: "holding other explanatory variables constant at their mean, the outcome variable is x percentage points higher in group A than in group B (where the dummy variable is coded 1 for group A and where group B is the "reference" category)" (and where x is the coefficient for a dummy variable that forms part of a set). This interpretation applies not only to individual-level influences, but also to ward-level and hospital-level explanatory variables, to the extent that these form part of a set of dummy variables relating to a given classification.

Not all of the effects included in the multilevel models are statistically significant, which means that the influence measured by the coefficient (however large or small this may be) would not be significantly different from zero in at least 95 out of 100 samples, drawn at random from the population, like the present one. The definition of "significantly different" is a statistical one, and relates to the "normal distribution". In a normal distribution, 95 per cent of cases are within plus or minus 1.96 standard deviations of the mean. It is therefore possible to assess whether a coefficient is statistically significant by comparing it to the associated "standard error". If the coefficient divided by the standard error is equal to or greater than 1.96, it is reasonable to conclude that the influence of the variable in question is statistically significant.

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[264] Note, however, that transformed continuous variables are not directly interpretable in this way.

6.4 Assessing the adequacy of the multilevel models

The statistical significance of a whole set of explanatory variables is evaluated, during model construction, using what is referred to as the "deviance statistic"[265]. By contrast, the explanatory power of the model is evaluated at the end of this process by assessing the reduction in the variance of the residuals as we move from the simplest to the most complex model (from Model 1 to Model 5).

Model 1 merely partitions the variance between the three levels, and provides an initial indication of how the scores for the outcome variable fluctuate at individual, ward and hospital level. Model 5 includes individual-level, ward-level and hospital-level explanatory variables (where these are statistically significant), and thus has the greatest potential to "explain" the outcome.

The tables containing the results of the multilevel models indicate the percentage of the residual variance that is explained by the final model, comparing the variance of the residuals at each level with the estimate obtained from the baseline model (Model 1). In many cases, the introduction of individual-level explanatory variables has the effect of reducing the variance of the ward-level and/or hospital-level residuals. This is due to "composition effects", i.e. inter-ward or inter-hospital differences that are due to the kinds of individual cases that are typically found within them, rather than being attributable to specific, contextual factors.

In certain cases, the introduction of individual-level explanatory variables has the effect of increasing the variance of the level two or level three residuals. This is a similar situation to that described above, but implies that the composition of the wards or hospitals conceals the differences that exist between them, rather than over-emphasising them.

In this context, it is important to bear in mind that the capacity of a statistical model to explain the variance of an outcome variable depends on a number of different factors, not just the specification of the model or the quality of the data. Certain kinds of phenomena are highly predictable, whilst others are more contingent in nature. This often has to do with how the variables have been constructed and operationalised, as well as with how the study itself has been designed. The number of symptoms experienced by a patient, for example, is only weakly related to the broad pathology that he or she suffers from (circulatory illness, cancer, etc.), the length of stay and so on, as it depends on a number of quite contingent, specific factors. Other variables, such as feeling supported, are more strongly related to features of the ward and hospital, and can therefore be more easily predicted.

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265 When comparing two different (nested) models, the difference in the deviance statistic is chi-square distributed with degrees of freedom equal to the number of parameters that differ between the models.

Annex 7: Results from the Multilevel Models

Nurses Perception: Symptoms

	Model 1		***Model 2***		***Model 3***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***54.38***	*1.15*	***39.46***	*2.46*	***54.47***	*1.05*	***39.19***	*2.46*
Private health insurance			-1.31	2.23			-1.25	2.22
Primary diagnosis cancer *			**8.79**	2.35			**8.63**	2.34
Primary diagnosis breathing *			**8.93**	2.30			**8.62**	2.30
Primary diagnosis dementia *			-5.37	3.23			-5.55	3.22
Primary diagnosis other *			**6.10**	2.28			**6.27**	2.27
Death was unexpected			**-8.27**	2.14			**-5.50**	2.52
Hospital stay in days (log)			**1.64**	0.41			**1.47**	0.41
Death in single room			2.49	1.68			2.36	1.68
Communication with patient			**7.76**	1.64			**7.66**	1.64
Relatives stayed overnight			**5.67**	1.85			**5.46**	1.84
Use specialist palliative care			**7.91**	1.99			**7.77**	1.98
Nurse is non-national			**4.18**	1.87			**3.98**	1.87
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
% patients with cancer					**0.15**	0.03		
% patients with breathing diff.					**0.11**	0.04		
% of unexpected deaths					**-0.24**	0.03	**-0.08**	0.04
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
level 1 residuals	**678.21**	34.58	**598.47**	29.73	**671.15**	33.47	**597.44**	29.64
level 2 residuals	**90.11**	26.89	4.23	14.32	12.45	17.15	2.29	14.01
level 3 residuals	5.57	10.38	9.40	7.60	10.31	8.77	9.77	7.60
Model assessment								
deviance statistic	9454		9242		9366		9238	
degrees of freedom	4		16		7		17	
N	999		999		999		999	
% variance explained (L1)			11.76		1.04		11.91	
% variance explained (L2)			95.31		86.18		97.46	
% variance explained (L3)			-68.76		-85.10		-75.40	

* Reference Group: Circulatory Illnesses

Doctors Perception: Symptoms

	Model 1		***Model 2***		***Model 3***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***49.19***	*1.37*	***42.59***	*3.11*	***49.36***	*1.21*	***42.25***	*3.10*
Private health insurance			-2.33	2.88			-2.28	2.86
Primary diagnosis cancer *			**10.65**	3.02			**10.57**	3.01
Primary diagnosis breathing *			3.69	2.93			3.36	2.92
Primary diagnosis dementia *			-2.34	4.07			-2.53	4.05
Primary diagnosis other *			0.94	2.91			1.31	2.91
Death was unexpected			**-10.07**	2.74			**-6.45**	3.15
Hospital stay in days (log)			**1.91**	0.52			**1.74**	0.52
Death in single room			3.04	2.20			2.93	2.19
Communication with patient			-0.77	2.06			-0.92	2.06
Relatives stayed overnight			**4.69**	2.39			4.44	2.38
Use specialist palliative care			**5.53**	2.50			**5.38**	2.49
Nurse is non-national			0.22	2.33			-0.21	2.32
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
% patients with cancer					**0.16**	0.04		
% patients with breathing diff.					**-0.27**	0.04	**-0.12**	0.05
% of unexpected deaths								
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
level 1 residuals	**696.12**	43.36	**645.75**	39.58	**689.62**	42.29	**644.46**	39.45
level 2 residuals	**184.64**	41.87	**91.67**	29.96	**97.62**	31.90	**86.17**	29.26
level 3 residuals	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Model assessment								
deviance statistic	7040		6933		6981		6928	
degrees of freedom	4		16		6		17	
N	736		736		736		736	
% variance explained (L1)			7.24		0.93		7.42	
% variance explained (L2)			50.35		47.13		53.33	
% variance explained (L3)								

* Reference Group: Circulatory Illnesses

Relatives Perception: Symptoms

	Model 1		***Model 2***				***Model 5***	
Parameter	**VCM**		**L1 variables**				**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Intercept	***70.04***	*1.19*	***66.25***	*3.49*			***65.96***	*3.51*
Private health insurance			**5.93**	2.80			**5.82**	2.80
Primary diagnosis cancer *			1.71	3.05			1.73	3.05
Primary diagnosis breathing *			2.07	3.08			1.99	3.08
Primary diagnosis dementia *			-6.09	4.78			-6.27	4.78
Primary diagnosis other *			-0.23	3.20			-0.10	3.20
Death was unexpected			-3.66	3.02			-2.26	3.58
Hospital stay in days (log)			**-1.42**	0.60			**-1.48**	0.61
Death in single room			-2.54	2.24			-2.55	2.24
Communication with patient			0.13	2.19			0.10	2.19
Relatives stayed overnight			4.50	2.61			4.43	2.61
Use specialist palliative care			3.51	2.59			3.49	2.59
Nurse is non-national			0.50	2.46			0.49	2.46
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
% patients with cancer							-0.04	0.06
% patients with breathing diff.								
% of unexpected deaths								
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**398.83**	36.23	**383.27**	34.58			**381.93**	34.60
level 2 residuals	58.63	30.59	45.77	26.23			46.72	26.40
level 3 residuals	0.113	10.2	0	0			0.00	0.00
Model assessment								
deviance statistic	3580		3556				3555	
degrees of freedom	4		16				17	
N	400		400				400	
% variance explained (L1)			3.90				4.24	
% variance explained (L2)			21.93				20.31	
% variance explained (L3)			100.00				100.00	

* Reference Group: Circulatory Illnesses

Nurses Perception: Symptom Management

	Model 1		***Model 2***				***Model 5***	
Parameter	**VCM**		**L1 variables**				**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Intercept	***80.36***	*0.76*	***74.55***	*1.78*			***74.54***	*1.79*
Number of symptoms			**-0.06**	0.03			**-0.06**	0.03
Was in a nursing home before			-0.61	1.56			-0.67	1.57
Was living elsewhere before			3.12	2.55			3.13	2.55
Elective admission			1.21	1.58			1.16	1.59
Death in single room			0.73	1.44			0.75	1.44
Dignity of room			**0.09**	0.03			**0.09**	0.03
Multidisciplinary team meeting			**5.22**	1.32			**5.22**	1.32
Communication with patient			-2.45	1.30			-2.47	1.31
Quality of talk with relatives			**0.15**	0.02			**0.15**	0.02
Relatives stayed overnight			**3.79**	1.50			**3.84**	1.51
Nurse is non-national			**5.43**	1.52			**5.43**	1.52
Nurse trained in EoL care			-1.29	1.49			-1.28	1.49
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
EoL goals in business plan							0.76	1.40
Mortuary facilities							-0.01	0.03
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**355.12**	20.28	**299.70**	17.10			**300.04**	17.10
level 2 residuals	19.54	12.63	15.26	9.77			14.70	9.71
level 3 residuals	0.68	4.63	0.00	0.00			0.00	0.00
Model assessment								
deviance statistic	7026		6886				6886	
degrees of freedom	4		16				18	
N	802		802				802	
% variance explained (L1)			15.61				15.51	
% variance explained (L2)			21.90				24.77	
% variance explained (L3)			100.00				100.00	

Doctors Perception: Symptom Management

	Model 1		*Model 2*		*Model 4*		*Model 5*	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***74.67***	*1.27*	***66.77***	*2.34*	***73.61***	*2.25*	***64.83***	*2.38*
Number of symptoms			0.02	0.03			0.01	0.03
Was in a nursing home before			**6.05**	1.88			**5.49**	1.88
Was living elsewhere before			**6.63**	3.02			**6.47**	3.00
Elective admission			**4.15**	1.94			**4.22**	1.87
Death in single room			**4.19**	1.73			**4.21**	1.71
Dignity of room			**-0.07**	0.03			**-0.06**	0.03
Multidisciplinary team meeting			3.02	1.60			2.90	1.59
Communication with patient			0.19	1.55			0.18	1.54
Quality of talk with relatives			0.03	0.03			0.02	0.03
Relatives stayed overnight			-1.51	1.80			-1.28	1.80
Nurse is non-national			1.31	1.80			1.47	1.78
Nurse trained in EoL care			**5.96**	1.76			**5.92**	1.75
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Regional Hospital					**-2.40**	3.37		
Other Acute Hospital					**-3.99**	2.73		
Community Hospital					**6.96**	3.18		
EoL goals in business plan					**4.67**	1.69	**4.89**	2.01
Mortuary facilities					**-0.12**	0.04	**-0.09**	0.04
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
level 1 residuals	**300.71**	21.77	**286.71**	20.58	304.87	21.71	**287.96**	20.58
level 2 residuals	30.18	16.75	18.93	14.52	21.79	14.11	18.53	14.29
level 3 residuals	**25.90**	13.06	**21.00**	10.98	0.00	0.00	8.88	7.56
Model assessment								
deviance statistic	4890		4847		4862		4838	
degrees of freedom	4		16		9		18	
N	564		564		564		564	
% variance explained (L1)			4.66		-1.38		4.24	
% variance explained (L2)			37.28		27.80		38.60	
% variance explained (L3)			18.92		100.00		65.71	

Nurses Perception: Experience of Symptoms (QODDExp)

	Model 1		***Model 2***		***Model 3***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***63.06***	*0.74*	***60.77***	*1.15*	*62.88*	*0.70*	***60.65***	*1.12*
Number of symptoms			-0.21	0.02			-0.21	0.02
Private health insurance			0.08	1.67			0.23	1.66
Death was unexpected			**-4.32**	1.47			**-4.46**	1.46
Not admitted through A & E			**5.57**	1.41			**5.11**	1.41
Death in single room			1.32	1.26			1.81	1.26
Quality of talk with patient			**0.04**	0.02			**0.04**	0.02
Professionally prep. for death			**4.32**	1.35			**4.14**	1.34
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Avg. years of experience					**0.57**	0.24	**0.46**	0.23
% nurses see insuff. staffing					**-0.05**	0.02	**-0.06**	0.02
Avg. room environment					**0.10**	0.04		
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
level 1 residuals	**358.29**	18.13	**322.61**	16.31	**355.05**	17.92	**321.27**	16.20
level 2 residuals	**32.20**	12.32	**27.33**	10.89	**27.00**	10.89	**24.86**	10.53
level 3 residuals	0.82	4.32	0.65	3.81	0.00	0.00	0.01	3.50
Model assessment								
deviance statistic	8786		8677		8765		8666	
degrees of freedom	4		11		7		13	
N	999		999		999		999	
% variance explained (L1)			9.96		0.90		10.33	
% variance explained (L2)			15.12		16.15		22.80	
% variance explained (L3)			20.73		100.00		98.78	

Relatives Perception: Experience of Symptoms (QODDExp)

	Model 1		***Model 2***		***Model 3***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***57.19***	*1.43*	***52.05***	*2.16*			***52.22***	*2.08*
Number of symptoms			**-0.61**	0.05			**-0.59**	0.05
Private health insurance			**8.67**	3.09			**8.37**	3.03
Death was unexpected			**-6.76**	3.01			**-6.94**	2.97
Not admitted through A & E			-1.11	2.60			-1.55	2.58
Death in single room			**7.17**	2.36			**7.66**	2.30
Quality of talk with patient			-0.01	0.03			0.00	0.03
Professionally prep. for death			**7.12**	2.58			**6.75**	2.53
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Avg. years of experience							**1.34**	0.41
% nurses see insuff. staffing							**-0.09**	0.04
Avg. room environment								
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**667.91**	59.31	**468.94**	42.25			**473.93**	41.91
level 2 residuals	42.95	42.78	53.60	31.76			26.01	27.84
level 3 residuals	1.44	14.78	0.00	0.00			0.00	0.00
Model assessment								
deviance statistic	3761		3635				3620	
degrees of freedom	4		11				13	
N	400		400				400	
% variance explained (L1)			29.79				29.04	
% variance explained (L2)			-24.80				39.44	
% variance explained (L3)			100.00				100.00	

Nurses Perception: Patient Care

	Model 1		***Model 2***		***Model 3***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***75.80***	*0.89*	***72.17***	*1.49*	***75.43***	*0.74*	***72.16***	*1.47*
Number of symptoms			**-0.12**	0.02			**-0.12**	0.02
Primary diagnosis cancer *			-0.54	1.55			-0.77	1.55
Primary diagnosis breathing *			**-3.10**	1.58			**-3.16**	1.57
Primary diagnosis dementia *			**-4.30**	2.17			**-5.01**	2.19
Primary diagnosis other *			0.74	1.56			0.65	1.56
Death was unexpected			-2.06	1.38			-1.68	1.39
Dignity of room			**0.11**	0.02			**0.10**	0.02
Medical/nursing team meeting			**4.92**	1.25			**4.91**	1.25
Quality of talk with patient			**0.06**	0.02			**0.06**	0.02
Quality of talk with relatives			**0.12**	0.02			**0.12**	0.02
Nurse is non-national			**5.66**	1.30			**5.41**	1.30
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Avg. room privacy					**0.15**	0.07		
Avg. room dignity					**-0.16**	0.08		
Avg. room environment					**0.20**	0.06	**0.08**	0.04
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
level 1 residuals	**323.58**	16.35	**264.57**	13.37	**319.83**	16.12	**263.50**	13.31
level 2 residuals	**20.45**	10.28	**18.62**	8.59	**20.04**	10.02	**19.20**	8.61
level 3 residuals	10.56	6.37	5.03	4.28	3.44	4.33	3.59	3.88
Model assessment								
deviance statistic	8681		8479		8658		8473.63	
degrees of freedom	4		15		7		16	
N	999		999		999		999	
% variance explained (L1)			18.24		1.16		18.57	
% variance explained (L2)			8.95		2.00		6.11	
% variance explained (L3)			52.37		67.42		66.00	

* Reference Group: Circulatory Illnesses

Doctors Perception: Patient Care

	Model 1		***Model 2***				***Model 5***	
Parameter	**VCM**		**L1 variables**				**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Intercept	***81.55***	*0.87*	***78.87***	*1.69*			***78.78***	*1.65*
Number of symptoms			**-0.08**	0.02			**-0.09**	0.02
Primary diagnosis cancer *			**3.70**	1.68			**3.45**	1.67
Primary diagnosis breathing *			-0.07	1.71			-0.13	1.71
Primary diagnosis dementia *			-2.83	2.36			-3.53	2.36
Primary diagnosis other *			-1.80	1.71			-1.94	1.71
Death was unexpected			0.42	1.51			0.83	1.51
Dignity of room			**-0.06**	0.02			**-0.07**	0.02
Medical/nursing team meeting			**3.64**	1.36			**3.49**	1.36
Quality of talk with patient			-0.02	0.02			-0.02	0.02
Quality of talk with relatives			0.02	0.02			0.02	0.02
Nurse is non-national			-0.22	1.39			-0.57	1.39
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Avg. room privacy								
Avg. room dignity								
Avg. room environment							**0.12**	0.06
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**242.25**	14.68	**227.19**	13.81			**227.65**	13.79
level 2 residuals	14.80	9.65	15.69	9.34			13.50	9.01
level 3 residuals	9.73	6.09	12.79	6.81			9.29	5.74
Model assessment								
deviance statistic	6186		6148				6139.54	
degrees of freedom	4		15				16	
N	736		736				736	
% variance explained (L1)			6.22				6.03	
% variance explained (L2)			-6.01				8.78	
% variance explained (L3)			-31.45				4.52	

* Reference Group: Circulatory Illnesses

Relatives Perception: Patient Care

	Model 1		***Model 2***				***Model 5***	
Parameter	**VCM**		**L1 variables**				**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Intercept	***72.89***	*1.34*	***81.95***	*3.47*			***81.72***	*3.50*
Number of symptoms			**-0.34**	0.06			**-0.34**	0.06
Primary diagnosis cancer *			-2.99	3.38			-2.86	3.39
Primary diagnosis breathing *			-5.53	3.73			-5.32	3.75
Primary diagnosis dementia *			2.45	5.69			2.94	5.77
Primary diagnosis other *			-5.88	3.85			-5.66	3.88
Death was unexpected			**-14.40**	3.36			**-14.57**	3.37
Dignity of room			0.00	0.05			0.01	0.05
Medical/nursing team meeting			-3.41	3.07			-3.25	3.09
Quality of talk with patient			-0.04	0.04			-0.04	0.04
Quality of talk with relatives			**0.09**	0.04			**0.09**	0.04
Nurse is non-national			-4.26	2.95			-4.03	2.98
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Avg. room privacy								
Avg. room dignity								
Avg. room environment							-0.04	0.08
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**718.76**	50.82	**618.17**	43.71			**617.75**	43.91
level 2 residuals	0	0	0	0			**0.00**	0.00
level 3 residuals	0	0	0	0			0.00	0.00
Model assessment								
deviance statistic	3766		3706				3705.59	
degrees of freedom	4		15				16	
N	400		400				400	
% variance explained (L1)			13.99				14.05	
% variance explained (L2)								
% variance explained (L3)								

Nurses Perception: Acceptability of Dying

	Model 1		***Model 2***		***Model 4***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	*71.53*	*1.30*	***62.67***	*2.41*			***63.41***	*2.41*
Number of symptoms			-0.03	0.03			-0.04	0.03
Patient Care			**0.74**	0.05			**0.74**	0.05
Was in a nursing home before			2.27	2.12			2.39	2.07
Was living elsewhere before			-3.23	3.44			-3.16	3.42
Elective admission			**6.02**	2.14			**5.63**	2.14
Death in single room			**5.63**	1.93			**5.67**	1.93
Dignity of room			**0.15**	0.04			**0.14**	0.04
Quality of talk with relatives			**0.09**	0.03			**0.09**	0.03
Use specialist palliative care			-2.82	1.97			-3.27	1.90
Relatives present at death			**5.07**	1.87			**5.00**	1.85
Nurse years of service (log)			1.92	1.00			1.85	1.00
Personally prepared for death			4.79	2.94			**4.42**	1.98
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Mortuary facilities							-0.03	0.04
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**886.57**	46.60	**580.65**	30.46			**580.55**	30.46
level 2 residuals	54.20	29.24	**35.62**	17.73			**36.09**	17.79
level 3 residuals	12.80	13.45	0.00	0.00			0.00	0.00
Model assessment								
deviance statistic	9029		8626				8627	
degrees of freedom	4		16				17	
N	932		932				932	
% variance explained (L1)			34.51				34.52	
% variance explained (L2)			34.28				33.41	
% variance explained (L3)			100.00				100.00	

Doctors Perception: Acceptability of Dying

	Model 1		*Model 2*		*Model 4*		*Model 5*	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***81.44***	*1.41*	***80.41***	*1.75*	***79.40***	*2.99*	***80.43***	*1.71*
Number of symptoms			0.03	0.03			0.03	0.03
Patient Care			**0.82**	0.05			**0.81**	0.05
Was in a nursing home before			-0.36	1.87			-0.68	1.86
Was living elsewhere before			-2.69	3.16			-2.84	3.14
Elective admission			**4.44**	1.86			**4.13**	1.83
Death in single room			2.91	1.72			3.13	1.70
Dignity of room			-0.01	0.03			-0.01	0.03
Quality of talk with relatives			0.01	0.02			0.01	0.02
Use specialist palliative care			**-3.40**	1.71			**-3.53**	1.70
Relatives present at death			-1.19	1.65			-1.13	1.64
Nurse years of service (log)			-0.20	0.90			-0.28	0.90
Personally prepared for death			1.78	1.80			1.88	1.79
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Regional Hospital					**-0.79**	4.70		
Other Acute Hospital					**0.40**	3.72		
Community Hospital					**9.63**	4.40		
Mortuary facilities					**-0.14**	0.06	**-0.08**	0.03
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
level 1 residuals	**509.06**	29.34	**339.36**	19.48	**505.96**	29.08	**337.90**	19.37
level 2 residuals	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
level 3 residuals	**33.03**	15.52	3.17	4.83	1.70	9.37	0.98	4.10
Model assessment								
deviance statistic	5766		5490		5749		5484	
degrees of freedom	4		16		8		17	
N	633		633		633		633	
% variance explained (L1)			33.34		0.61		33.62	
% variance explained (L2)								
% variance explained (L3)			90.40		94.85		97.03	

Relatives Perception: Acceptability of Dying

	Model 1		***Model 2***		***Model 4***		***Model 5***	
Parameter	**VCM**		**L1 variables**		**L2 variables**		**L1+L2 variables**	
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*	*coeff.*	*std. err.*
Intercept	***66.57***	*1.93*	***58.53***	*2.78*			***58.53***	*2.79*
Number of symptoms			**-0.11**	0.06			**-0.11**	0.06
Patient Care			**0.93**	0.04			**0.93**	0.04
Was in a nursing home before			**9.93**	2.94			**9.93**	2.95
Was living elsewhere before			4.95	4.66			4.95	4.67
Elective admission			-2.99	2.66			-3.00	2.69
Death in single room			**5.09**	2.59			**5.09**	2.59
Dignity of room			-0.04	0.05			-0.04	0.05
Quality of talk with relatives			0.04	0.04			0.04	0.04
Use specialist palliative care			2.20	2.50			2.20	2.50
Relatives present at death			4.98	2.64			4.98	2.65
Nurse years of service (log)			**3.69**	1.31			**3.69**	1.31
Personally prepared for death			-0.67	2.74			-0.67	2.76
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
Mortuary facilities							0.00	0.05
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*			*coeff.*	*std. err.*
level 1 residuals	**1228.4**	113.45	**464.50**	34.20			**464.50**	34.20
level 2 residuals	53.07	73.96	0.00	0.00			0.00	0.00
level 3 residuals	0.00	0.00	0.00	0.00			0.00	0.00
Model assessment								
deviance statistic	3687		3313				3313	
degrees of freedom	4		16				17	
N	369		369				369	
% variance explained (L1)			62.19				62.19	
% variance explained (L2)			100.00				100.00	
% variance explained (L3)								

Nurses Perception: Family Support

	Model 1		***Model 2***					
Parameter	**VCM**		**L1 variables**					
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Intercept	***83.67***	*0.80*	***81.47***	*0.83*				
Number of symptoms			-0.02	0.02				
Patient Care			**0.63**	0.03				
Acceptability of dying			**0.04**	0.02				
Not admitted through A & E			-0.01	0.94				
Medical/nursing team meeting			**2.68**	0.93				
Quality of talk with patient			**-0.07**	0.01				
Quality of talk with relatives			**0.08**	0.01				
Nurse years of service (log)			**0.91**	0.48				
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
level 1 residuals	**314.14**	15.79	**147.24**	6.93				
level 2 residuals	14.02	9.19	0.00	0.00				
level 3 residuals	7.11	5.08	0.78	1.41				
Model assessment								
deviance statistic	8633		7302					
degrees of freedom	4		12					
N	932		932					
% variance explained (L1)			53.13					
% variance explained (L2)			100.00					
% variance explained (L3)			89.03					

Doctors Perception: Family Support

	Model 1		***Model 2***					
Parameter	**VCM**		**L1 variables**					
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Intercept	***83.18***	*0.81*	***82.77***	*0.84*				
Number of symptoms			0.02	0.02				
Patient Care			**0.65**	0.03				
Acceptability of dying			**0.10**	0.02				
Not admitted through A & E			0.64	0.99				
Medical/nursing team meeting			1.07	0.98				
Quality of talk with patient			-0.01	0.01				
Quality of talk with relatives			0.01	0.01				
Nurse years of service (log)			0.31	0.51				
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
level 1 residuals	**263.35**	15.65	**115.57**	6.50				
level 2 residuals	0.21	8.12	0.00	0.00				
level 3 residuals	7.96	5.15	0.00	0.00				
Model assessment								
deviance statistic	6207		4803					
degrees of freedom	4		12					
N	736		633					
% variance explained (L1)			56.12					
% variance explained (L2)			100.00					
% variance explained (L3)			100.00					

Relatives Perception: Family Support

	Model 1		***Model 2***					
Parameter	**VCM**		**L1 variables**					
Level 1 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Intercept	***70.10***	*1.46*	***70.55***	*1.48*				
Number of symptoms			0.02	0.04				
Patient Care			**0.85**	0.04				
Acceptability of dying			**0.10**	0.03				
Not admitted through A & E			**3.64**	1.59				
Medical/nursing team meeting			-1.92	1.69				
Quality of talk with patient			-0.03	0.02				
Quality of talk with relatives			**0.05**	0.02				
Nurse years of service (log)			0.97	0.81				
Level 2 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Level 3 effects	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
Variances	*coeff.*	*std. err.*	*coeff.*	*std. err.*				
level 1 residuals	**856.36**	60.55	**185.77**	14.11				
level 2 residuals	0	0	0	0				
level 3 residuals	0	0	1.04	3.77				
Model assessment								
deviance statistic	3836		2977					
degrees of freedom	4		12					
N	400		369					
% variance explained (L1)			78.31					
% variance explained (L2)								
% variance explained (L3)								

Annex 8: Multilevel Model Results in Comparison

	Domain		Symptoms		
	Variable	**Variable label**	**Nurse**	**Doctor**	**Relative**
	Intercept		39.19	42.25	65.96
	Perceptions				
	Sx1A_Symptoms	Number of symptoms			
	Sx2_PatCare	Quality of patient care			
	Sx3_AccDeath	Acceptability of death			
	Patient				
L1	V1.2.1d_gmc	Patient has private health insurance	-1.25	-2.28	5.82
L1	V1.3.1d1_can	Primary diagnosis cancer (ref. circ. illness)	8.63	10.57	1.73
L1	V1.3.1d3_bre	Primary diagnosis breathing (ref. circ. illness)	8.62	3.36	1.99
L1	V1.3.1d4_dem	Primary diagnosis dementia (ref. circ. illness)	-5.55	-2.53	-6.27
L1	V1.3.1d5_oth	Primary diagnosis other (ref. circ. illness)	6.27	1.31	-0.10
L1	V1.3.3d_sud	Death was unexpected	-5.50	-6.45	-2.26
L2	W1.3.3d_sud	% of unexpected deaths in ward	-0.08	-0.12	-0.04
L1	V1.4.1d2_nur	Was in a nursing home prior to admission			
L1	V1.4.1d3_oth	Was living elsewhere prior to admission			
L1	V1.4.3d_eme	Admission was not emergency (i.e. elective)			
L1	V1.4.2d_adm	Admission was not A&E			
L1	LV1.4.4s_sta	Log of hospital stay in days	1.47	1.74	-1.48
	Care				
L1	V2.1.1d_sin	Patient died in a single room	2.36	2.93	-2.55
L1	SV2.1.5s_dig	Nurse's perception of room (dignity)			
L2	W3.4c7dign	Mean score for perception of room (dignity)			
L2	W3.4c7envi	Nurse's perception of room (environment)			
L1	V2.2.3d_mdm	Multidisciplinary team meeting on aims			
L1	V2.2.4d_ntm	Medical and nursing team review meeting			
L1	V2.3.1d_cpat	Staff informed patient of prognosis	7.66	-0.92	0.10
L1	SV2.3.3s_qdp	Quality of discussions with patient			
L1	SV2.3.6s_qdr	Quality of discussions with relative			
L1	V2.4.1d_ovn	Relatives could stay overnight	5.46	4.44	4.43
L1	V2.5.2d_spc	Patient received specialist palliative care	7.77	5.38	3.49
L1	V2.6.1d_rel	Relatives present at the moment of death			
L1	V3.1.3d_nnat	Nurse is non-national	3.98	-0.21	0.49
	Culture				
L1	V3.1.8d_prop	Nurse feels professionally prepared for death			
L1	V3.1.9d_perp	Nurse feels personally prepared for death			
L1	V3.1.10d_EoLt	Nurse has received formal end-of-life care			
L3	H4.7	Hospital sets end-of-life policy objectives			
	Organisation				
L1	LV3.1.1s_yhosp	Years that nurse has worked in hospital (log)			
L2	W3.1.2s_yward	Mean years of staff experience in ward			
L2	W3.4c5	% of nurses who see staffing as insufficient			
L3	H4.11	Quality of hospital mortuary facility			
	Variance expl. (L1)	Variance explained (level 1)	11.91	7.42	4.24
	Variance expl. (L2)	Variance explained (level 2)	97.46	53.33	20.31
	Variance expl. (L3)	Variance explained (level 3)	-75.40	-	100.00
L1	Sx1A_Symptoms	Symptoms			
L1	Sx1B_SymptMgm	Symptom Management			
L1	Sx1C_QODDExp	QODD Experience			
L1	Sx2_PatCare	Patient Care			
L1	Sx3_AccDeath	Acceptable Death			
	Total variance				
	Residuals				
	Variance expl. (L1)	Variance explained (level 1)			

continued

Domain	*Symptom Management*		*Symptom Experience*		*Patient Care*		
Variable	**Nurse**	**Doctor**	**Nurse**	**Relative**	**Nurse**	**Doctor**	**Relative**
Intercept	**74.55**	**64.83**	**60.65**	**52.22**	**72.16**	**78.78**	**81.72**
Perceptions							
Sx1A_Symptoms	**-0.06**	0.01	-0.21	**-0.59**	**-0.12**	**-0.09**	**-0.34**
Sx2_PatCare							
Sx3_AccDeath							
Patient							
V1.2.1d_gmc			0.23	**8.37**			
V1.3.1d1_can					-0.77	**3.45**	-2.86
V1.3.1d3_bre					**-3.16**	-0.13	-5.32
V1.3.1d4_dem					**-5.01**	-3.53	2.94
V1.3.1d5_oth					0.65	-1.94	-5.66
V1.3.3d_sud			**-4.46**	**-6.94**	-1.68	0.83	**-14.57**
W1.3.3d_sud							
V1.4.1d2_nur	-0.67	**5.49**					
V1.4.1d3_oth	3.13	**6.47**					
V1.4.3d_eme	1.16	**4.22**					
V1.4.2d_adm			**5.11**	-1.55			
LV1.4.4s_sta							
Care							
V2.1.1d_sin	0.75	**4.21**	1.81	**7.66**			
SV2.1.5s_dig	**0.09**	**-0.06**			**0.10**	**-0.07**	0.01
W3.4c7dign							
W3.4c7envi					**0.08**	**0.12**	-0.04
V2.2.3d_mdm	**5.22**	2.90					
V2.2.4d_ntm					**4.91**	**3.49**	-3.25
V2.3.1d_cpat	-2.47	0.18					
SV2.3.3s_qdp			**0.04**	0.00	**0.06**	-0.02	-0.04
SV2.3.6s_qdr	**0.15**	0.02			**0.12**	0.02	**0.09**
V2.4.1d_ovn	**3.84**	-1.28					
V2.5.2d_spc							
V2.6.1d_rel							
V3.1.3d_nnat	**5.43**	1.47			**5.41**	-0.57	-4.03
Culture							
V3.1.8d_prop			**4.14**	**6.75**			
V3.1.9d_perp							
V3.1.10d_EoLt	-1.28	**5.92**					
H4.7	0.76	**4.89**					
Organisation							
LV3.1.1s_yhosp							
W3.1.2s_yward			**0.46**	**1.34**			
W3.4c5			**-0.06**	**-0.09**			
H4.11	-0.01	**-0.09**					
Variance expl. (L1)	15.51	4.24	10.33	29.04	18.57	6.03	14.05
Variance expl. (L2)	24.77	38.60	22.80	39.44	6.11	8.78	-
Variance expl. (L3)	100.00	65.71	98.78	100.00	66.00	4.52	-
Sx1A_Symptoms	**-0.06**	0.01	-0.22	**-0.59**	-0.03	**-0.05**	0.04
Sx1B_SymptMgm			**0.44**		**0.30**	**0.44**	
Sx1C_QODDExp					**0.24**		**0.66**
Sx2_PatCare							
Sx3_AccDeath							
Total variance	355.12	300.71	358.29	667.91	323.58	242.25	718.76
Residuals	300.04	287.96	274.50	473.93	206.62	162.86	365.95
Variance expl. (L1)	15.51	4.24	23.39	29.04	36.15	32.77	49.09

continued

Domain		***Acceptability of Death***			***Family Support***	
Variable	**Nurse**	**Doctor**	**Relative**	**Nurse**	**Doctor**	**Relative**
Intercept	**63.41**	**80.43**	**58.53**	**81.47**	**82.77**	**70.55**
Perceptions						
Sx1A_Symptoms	-0.04	0.03	-0.11	-0.02	0.02	0.02
Sx2_PatCare	**0.74**	**0.81**	**0.93**	**0.63**	**0.65**	**0.85**
Sx3_AccDeath				**0.04**	**0.10**	**0.10**
Patient						
V1.2.1d_gmc						
V1.3.1d1_can						
V1.3.1d3_bre						
V1.3.1d4_dem						
V1.3.1d5_oth						
V1.3.3d_sud						
W1.3.3d_sud						
V1.4.1d2_nur	2.39	-0.68	**9.93**			
V1.4.1d3_oth	-3.16	-2.84	4.95			
V1.4.3d_eme	**5.63**	**4.13**	-3.00			
V1.4.2d_adm				-0.01	0.64	**3.64**
LV1.4.4s_sta						
Care						
V2.1.1d_sin	**5.67**	3.13	**5.09**			
SV2.1.5s_dig	**0.14**	-0.01	-0.04			
W3.4c7dign						
W3.4c7envi						
V2.2.3d_mdm						
V2.2.4d_ntm				**2.68**	1.07	-1.92
V2.3.1d_cpat						
SV2.3.3s_qdp				**-0.07**	-0.01	-0.03
SV2.3.6s_qdr	**0.09**	0.01	0.04	**0.08**	0.01	**0.05**
V2.4.1d_ovn						
V2.5.2d_spc	-3.27	**-3.53**	2.20			
V2.6.1d_rel	**5.00**	-1.13	4.98			
V3.1.3d_nnat						
Culture						
V3.1.8d_prop						
V3.1.9d_perp	**4.42**	1.88	-0.67			
V3.1.10d_EoLt						
H4.7						
Organisation						
LV3.1.1s_yhosp	1.85	-0.28	**3.69**	**0.91**	0.31	0.97
W3.1.2s_yward						
W3.4c5						
H4.11	-0.03	**-0.08**	0.00			
Variance expl. (L1)	34.52	33.62	62.19	53.13	56.12	78.31
Variance expl. (L2)	33.41	-	100.00	100.00	100.00	-
Variance expl. (L3)	100.00	97.03	-	89.03	100.00	-
Sx1A_Symptoms	0.04	-0.01	-0.03	0.00	0.02	0.02
Sx1B_SymptMgm	**0.18**	**0.13**		**0.07**	0.04	
Sx1C_QODDExp	**0.26**		**0.23**	-0.01		0.00
Sx2_PatCare	**0.49**	**0.73**	**0.80**	**0.58**	**0.62**	**0.85**
Sx3_AccDeath				**0.04**	**0.12**	**0.10**
Total variance	886.57	509.06	1228.36	314.14	263.35	856.36
Residuals	552.10	286.43	446.88	153.45	118.86	185.77

Annex 9: Hospital Performance Rating - Means

Hospital Performance Indicator	Scale	Teaching Hospitals (mean)	Other Acute Hospitals (mean)	All Acute Hospitals (mean)	Community Hospitals (mean)	All HfH Hospitals (mean)
Nurses Perception						
Overall care outcome	0 - 100	77.5	76.1	76.5	84.7	**77.5**
Acceptability of dying	0 - 100	69.7	68.9	69.1	83.3	**70.9**
Patient care	0 - 100	76.3	74.0	74.6	81.6	**75.4**
Symptom management	0 - 100	80.1	79.5	79.7	84.1	**80.3**
Family support	0 - 100	83.5	82.1	82.5	89.6	**83.3**
Doctors Perception						
Overall care outcome	0 - 100	77.0	80.4	79.5	86.0	**80.4**
Acceptability of dying	0 - 100	75.5	81.0	79.5	89.7	**80.7**
Patient care	0 - 100	77.5	81.7	80.6	85.8	**81.3**
Symptom management	0 - 100	71.6	72.7	72.4	84.1	**74.3**
Family support	0 - 100	80.6	83.2	82.5	85.8	**82.9**
Relatives Perception						
Overall care outcome	0 - 100	68.1	69.0	68.8	76.7	**70.0**
Acceptability of dying	0 - 100	64.5	65.5	65.3	73.7	**66.5**
Patient care	0 - 100	72.3	72.3	72.3	76.5	**72.9**
Family support	0 - 100	66.0	69.2	68.5	79.6	**70.1**
Route of admission:						
Not admitted through A&E	0 - 100	17.7	16.1	16.5	100.0	**26.4**
Elective admission	0 - 100	10.5	12.0	11.6	100.0	**22.1**
Physical environment:						
Death in single room	0 - 100	55.0	42.3	45.5	33.6	**44.0**
Dignity of room	0 - 10	6.9	7.1	7.1	7.6	**7.1**
Environment of room	0 - 10	5.1	5.6	5.5	6.8	**5.6**
Mortuary facilities	0 - 100	75.2	37.6	45.4	29.1	**38.2**
End-of-life care:						
Diagnosis of dying	0 - 100	86.8	85.6	85.9	76.5	**84.8**
Decision to review care in last week	0 - 100	65.0	68.6	67.7	77.3	**68.9**
Use of specialist palliative care	0 - 100	34.1	33.3	33.5	19.3	**31.8**
Team working:						
Medical and nursing team meeting	0 - 100	70.5	68.0	68.6	75.6	**69.5**
Multidisciplinary team meeting	0 - 100	48.2	42.4	43.9	55.5	**45.2**
Communication:						
Quality of discussion with patients	0 - 10	7.3	7.1	7.2	8.1	**7.3**
Quality of discussion with relatives	0 - 10	8.6	8.4	8.5	8.9	**8.5**
Facilitating relatives:						
Relatives stayed overnight	0 - 100	62.3	71.7	69.3	66.4	**69.0**
Relatives visited at any time	0 - 100	88.6	88.0	88.2	89.9	**88.4**
Relatives present at death	0 - 100	62.7	68.2	66.8	51.3	**65.0**
Healthcare record:						
Diagnosis of dying	0 - 100	77.3	76.1	76.4	63.0	**74.8**
Relatives told if condition worsens	0 - 100	33.2	34.2	34.0	48.7	**35.7**
Decision to review care in last week	0 - 100	59.1	53.2	54.7	60.5	**55.4**
Staff readiness:						
Nurse prepared for patient□s death	1 - 5	3.3	3.2	3.2	3.3	**3.2**
Nurse trained in end-of-life care	0 - 100	19.5	22.3	21.6	31.9	**22.8**
Nurse years of service in hospital	0 - 15	6.5	8.1	7.7	10.7	**8.1**
Hospital governance:						
End-of-life goals in business plan	0 / 1	2 / 5	7 / 19	9 / 24	1 / 4	**10 / 28**
Sufficiency of staff on ward	0 - 100	42.6	42.2	42.4	54.5	**44.4**

Annex 10: Hospital Performance Rating – Numbers

Hospital Performance Indicator	Teaching Hospitals (rating)			Other Acute Hospitals (rating)			All Acute Hospitals (rating)			Community Hospitals (rating)			All HfH Hospitals (rating)		
Nurses Perception															
Overall care outcome	1	4	0	2	17	0	3	21	0	4	0	0	**7**	**21**	**0**
Acceptability of dying	0	5	0	3	15	1	3	20	1	4	0	0	**7**	**20**	**1**
Patient care	2	3	0	1	18	0	3	21	0	2	2	0	**5**	**23**	**0**
Symptom management	0	5	0	1	18	0	1	23	0	1	3	0	**2**	**26**	**0**
Family support	0	5	0	3	16	0	3	21	0	3	1	0	**6**	**22**	**0**
Doctors Perception															
Overall care outcome	0	5	0	2	17	0	2	22	0	3	1	0	**5**	**23**	**0**
Acceptability of dying	0	4	1	3	13	3	3	17	4	2	2	0	**5**	**19**	**4**
Patient care	0	5	0	3	16	0	3	21	0	2	2	0	**5**	**23**	**0**
Symptom management	1	4	0	3	14	2	4	18	2	4	0	0	**8**	**18**	**2**
Family support	0	5	0	3	16	0	3	21	0	1	3	0	**4**	**24**	**0**
Relatives Perception															
Overall care outcome	1	2	2	1	12	6	2	14	8	2	1	1	**4**	**15**	**9**
Acceptability of dying	1	1	3	2	6	11	3	7	14	2	1	1	**5**	**8**	**15**
Patient care	1	3	1	1	14	4	2	17	5	2	1	1	**4**	**18**	**6**
Family support	0	3	2	2	11	6	2	14	8	2	2	0	**4**	**16**	**8**
Route of admission:															
Not admitted through A&E	0	0	5	2	2	15	2	2	20	4	0	0	**6**	**2**	**20**
Elective admission	0	0	5	4	1	14	4	1	19	4	0	0	**8**	**1**	**19**
Physical environment:															
Death in single room	1	1	3	1	4	14	2	5	17	0	0	4	**2**	**5**	**21**
Dignity of room	0	4	1	2	11	6	2	15	7	0	4	0	**2**	**19**	**7**
Environment of room	0	1	4	1	11	7	1	12	11	2	2	0	**3**	**14**	**11**
Mortuary facilities	2	2	1	1	4	14	3	6	15	0	0	4	**3**	**6**	**19**
End-of-life care:															
Diagnosis of dying	1	4	0	2	17	0	3	21	0	0	2	2	**3**	**23**	**2**
Decision to review care in last week	0	4	1	3	11	5	3	15	6	2	1	1	**5**	**16**	**7**
Use of specialist palliative care	1	0	4	1	2	16	2	2	20	0	0	4	**2**	**2**	**24**
Team working:															
Medical and nursing team meeting	0	4	1	2	13	4	2	17	5	2	1	1	**4**	**18**	**6**
Multidisciplinary team meeting	1	2	2	1	9	9	2	11	11	3	0	1	**5**	**11**	**12**
Communication:															
Quality of discussion with patients	0	4	1	2	11	6	2	15	7	2	2	0	**4**	**17**	**7**
Quality of discussion with relatives	1	4	0	2	17	0	3	21	0	3	1	0	**6**	**22**	**0**
Facilitating relatives:															
Relatives stayed overnight	1	0	4	2	13	4	3	13	8	0	1	3	**3**	**14**	**11**
Relatives visited at any time	0	5	0	2	17	0	2	22	0	0	4	0	**2**	**26**	**0**
Relatives present at death	1	1	3	2	14	3	3	15	6	0	0	4	**3**	**15**	**10**
Healthcare record:															
Diagnosis of dying	1	3	1	1	14	4	2	17	5	0	2	2	**2**	**19**	**7**
Relatives told if condition worsens	0	2	3	2	6	11	2	8	14	2	2	0	**4**	**10**	**14**
Decision to review care in last week	1	3	1	1	9	9	2	12	10	1	2	1	**3**	**14**	**11**
Staff readiness:															
Nurse prepared for patient's death	0	5	0	3	16	0	3	21	0	1	3	0	**4**	**24**	**0**
Nurse trained in end-of-life care	0	1	4	1	6	12	1	7	16	2	1	1	**3**	**8**	**17**
Nurse years of service in hospital	0	0	5	2	5	12	2	5	17	2	1	1	**4**	**6**	**18**
Hospital governance:															
End-of-life goals in business plan	2	0	3	7	0	12	9	0	15	3	0	1	**12**	**0**	**16**
Sufficiency of staff on ward	0	0	5	3	6	10	3	6	15	2	0	2	**5**	**6**	**17**

Annex 11: Individual Hospital Ratings

Hospital ID	Scale	1	10	12	17	21	2	3	4	5	6
Nurses Perception		Teaching Hospital					Other Acute Hospital				
Overall care outcome	0 - 100	72.8	78.6	77.7	77.5	81.4	75.0	71.1	78.4	78.5	79.4
Acceptability of dying	0 - 100	63.1	72.8	65.2	70.0	75.6	67.5	71.9	61.4	69.3	73.5
Patient care	0 - 100	70.8	76.7	79.2	76.0	80.3	73.1	63.9	80.9	76.8	78.6
Symptom management	0 - 100	78.0	79.1	78.4	82.2	82.4	83.4	78.2	78.6	82.8	83.8
Family support	0 - 100	78.8	85.4	85.7	82.3	86.2	77.7	73.1	88.6	84.4	83.7
Doctors Perception											
Overall care outcome	0 - 100	74.1	76.2	79.2	78.1	78.4	70.8	87.1	84.5	82.5	88.0
Acceptability of dying	0 - 100	74.5	79.3	71.3	74.8	75.8	63.9	91.5	93.3	84.0	88.3
Patient care	0 - 100	73.6	75.0	80.1	79.6	82.4	73.7	87.0	86.2	83.4	88.1
Symptom management	0 - 100	71.6	66.9	79.7	72.8	71.0	70.7	79.4	73.5	73.4	82.2
Family support	0 - 100	75.7	81.0	86.0	81.7	80.6	75.0	88.5	83.6	85.8	91.5
Relatives Perception											
Overall care outcome	0 - 100	56.4	66.0	74.6	71.9	87.7	70.5	100.0	68.2	65.2	75.0
Acceptability of dying	0 - 100	50.3	66.0	67.9	66.1	95.6	68.4	100.0	59.7	58.5	61.1
Patient care	0 - 100	61.7	68.3	83.0	76.2	87.4	74.1	100.0	68.5	70.8	75.3
Family support	0 - 100	54.6	63.9	72.2	71.0	80.0	69.4	100.0	76.4	66.2	85.2
Route of admission:											
Admission not through A&E	0 - 100	19.1	27.1	6.1	16.0	16.7	6.8	31.6	15.0	8.7	9.3
Elective admission	0 - 100	10.6	14.6	9.1	4.0	14.3	0.0	5.3	30.0	21.7	4.7
Physical environment:											
Death in single rooms	0 - 100	48.9	54.2	45.5	54.0	71.4	52.3	57.9	20.0	41.3	25.6
Dignity of room	0 - 10	6.8	6.9	6.6	6.3	7.9	7.3	7.5	7.5	6.2	6.3
Environment of room	0 - 10	4.6	5.0	4.7	4.6	6.5	4.7	6.0	5.2	4.7	4.4
Mortuary facilities	0 - 100	85.7	71.4	47.6	71.4	100.0	71.4	42.9	9.5	14.3	19.1
End-of-life care:											
Diagnosis of dying	0 - 100	85.1	87.5	75.8	88.0	95.2	81.8	84.2	95.0	91.3	81.4
Decision to review care in last week	0 - 100	66.0	64.6	72.7	54.0	71.4	65.9	84.2	70.0	71.7	60.5
Use of specialist palliative care	0 - 100	27.7	27.1	24.2	32.0	59.5	27.3	26.3	30.0	32.6	18.6
Team working:											
Medical and nursing team meeting	0 - 100	59.6	72.9	75.8	76.0	69.0	68.2	68.4	70.0	69.6	65.1
Multidisciplinary team meeting	0 - 100	38.3	56.3	60.6	42.0	47.6	34.1	31.6	55.0	43.5	51.2
Communication:											
Quality of discussion with patients	0 - 10	6.0	7.0	7.8	6.9	8.1	7.2	5.0	6.5	7.8	7.9
Quality of discussion with relatives	0 - 10	8.1	8.6	8.9	8.8	8.9	8.5	7.9	8.2	8.8	8.0
Facilitating relatives:											
Relatives stayed overnight	0 - 100	57.4	58.3	42.4	62.0	88.1	70.5	78.9	75.0	73.9	60.5
Relatives visited at any time	0 - 100	91.5	87.5	81.8	90.0	90.5	86.4	89.5	95.0	87.0	83.7
Relatives present at death	0 - 100	48.9	58.3	60.6	66.0	81.0	72.7	73.7	65.0	78.3	67.4
Healthcare record:											
Diagnosis of dying	0 - 100	72.3	79.2	63.6	78.0	90.5	75.0	78.9	80.0	80.4	74.4
Relatives told if condition worsens	0 - 100	25.5	33.3	27.3	40.0	38.1	29.5	47.4	25.0	47.8	41.9
Decision to review care in last week	0 - 100	59.6	62.5	66.7	48.0	61.9	50.0	63.2	45.0	65.2	48.8
Staff readiness:											
Nurse prepared for patient's death	1 - 5	3.2	3.3	3.2	3.4	3.2	3.3	2.9	3.3	3.2	3.2
Nurse trained in end-of-life care	0 - 100	14.9	29.2	15.2	26.0	9.5	31.8	10.5	10.0	23.9	14.0
Nurse years of service in hospital	0 - 15	7.2	7.0	5.1	7.0	5.2	8.4	5.7	12.4	5.5	7.6
Hospital governance:											
End-of-life goals in business plan	0 / 1	1.0	0.0	1.0	0.0	0.0	0.0	1.0	0.0	1.0	1.0
Sufficiency of staff on ward	0 - 100	29.2	47.8	45.6	40.9	46.4	36.2	53.7	46.4	16.7	37.2

continued

7	8	9	11	13	14	15	16	18	19	20	22	23	24	55	56	71	72
Other Acute Hospital (continued)														Community Hospitals			
75.2	77.7	75.7	71.4	76.1	76.1	74.3	80.7	67.0	81.9	77.2	71.2	78.2	78.7	84.1	81.8	89.8	82.6
71.6	69.0	71.0	67.6	69.4	62.5	67.9	79.6	54.0	77.8	66.7	61.7	67.4	79.0	82.5	81.8	87.7	81.3
72.3	75.8	76.9	66.7	75.1	76.5	74.1	72.4	64.8	77.0	78.2	64.3	78.2	75.9	82.0	78.4	87.4	78.0
76.8	79.4	72.7	74.1	79.1	83.3	73.9	83.2	69.9	88.0	80.5	78.3	80.9	76.6	83.8	79.2	88.1	84.0
79.0	86.9	80.6	77.2	81.4	83.2	81.5	87.0	74.1	85.0	82.9	82.6	86.8	83.5	89.7	85.5	95.2	87.2
82.5	74.1	73.9	83.4	80.8	82.5	80.1	79.9	84.3	73.5	79.6	79.2	81.0	73.0	84.5	88.6	85.7	86.1
82.1	75.5	74.4	83.8	83.3	80.8	92.6	77.1	88.9	68.7	85.2	80.9	80.7	66.7	87.5	98.4	87.7	90.8
84.0	75.1	74.8	81.0	83.0	84.1	77.8	79.9	85.2	75.5	79.0	83.8	83.3	75.8	85.5	86.7	85.9	85.2
75.8	68.9	57.7	76.1	73.4	80.4	72.5	68.1	75.3	69.1	68.7	60.3	74.5	64.5	82.3	96.0	79.3	80.6
84.5	75.8	80.0	88.4	80.6	82.9	81.0	85.7	86.3	77.8	80.6	86.3	82.5	80.0	85.2	81.7	88.0	87.7
69.6	71.4	77.4	73.2	70.7	68.7	65.2	81.6	62.8	70.1	52.0	49.1	65.1	75.7	65.6	78.8	88.6	89.4
69.3	64.4	76.2	72.2	66.7	64.8	66.7	86.9	59.1	68.9	36.1	33.3	60.8	77.2	59.7	85.2	81.5	88.9
69.0	73.7	77.3	74.1	74.6	71.4	64.2	82.8	66.1	75.4	65.9	60.7	71.5	78.0	66.7	74.8	89.2	88.5
70.4	74.7	79.2	71.7	70.2	69.8	64.8	75.3	61.5	65.7	57.8	53.3	62.1	74.9	69.4	77.8	93.6	90.7
6.7	8.0	41.7	35.1	25.7	16.2	66.7	3.7	10.2	7.7	57.7	4.5	6.1	17.9	100.0	100.0	100.0	100.0
11.1	6.0	12.5	21.6	11.4	13.5	22.2	3.7	10.2	7.7	15.4	13.6	14.3	17.9	100.0	100.0	100.0	100.0
33.3	34.0	33.3	62.2	57.1	40.5	100.0	51.9	40.8	56.4	26.9	36.4	28.6	48.7	14.7	52.2	30.0	43.8
7.3	6.4	6.3	7.2	7.1	7.2	9.1	8.3	6.5	7.7	6.5	7.8	7.5	8.1	8.1	7.4	7.5	7.2
6.1	5.1	5.4	5.5	6.4	5.6	8.7	5.7	4.7	6.7	6.4	6.7	5.9	6.4	7.0	6.4	7.2	6.4
28.6	19.1	52.4	9.5	28.6	42.9	66.7	38.1	33.3	.	42.9	52.4	71.4	71.4	38.1	23.8	37.3	24.2
86.7	88.0	83.3	78.4	82.9	91.9	100.0	88.9	79.6	87.2	84.6	77.3	83.7	92.3	82.4	69.6	83.3	68.8
77.8	62.0	75.0	64.9	57.1	83.8	88.9	74.1	61.2	69.2	65.4	59.1	65.3	74.4	82.4	73.9	93.3	59.4
33.3	34.0	29.2	40.5	31.4	35.1	88.9	22.2	28.6	53.8	46.2	18.2	34.7	35.9	17.6	21.7	16.7	21.9
73.3	66.0	70.8	67.6	71.4	75.7	66.7	48.1	53.1	79.5	61.5	59.1	69.4	82.1	82.4	60.9	80.0	75.0
53.3	28.0	41.7	35.1	54.3	51.4	55.6	22.2	24.5	56.4	46.2	36.4	46.9	48.7	67.6	26.1	56.7	62.5
5.9	7.8	9.2	6.9	8.0	7.4	8.3	5.7	6.0	7.7	7.6	6.3	7.4	6.8	8.4	8.7	8.0	7.5
7.6	8.6	8.6	8.2	8.5	8.4	8.3	9.0	8.0	9.0	8.1	8.4	8.8	8.7	8.9	9.1	9.1	8.5
71.1	74.0	70.8	56.8	80.0	86.5	100.0	77.8	61.2	74.4	69.2	68.2	67.3	76.9	76.5	60.9	60.0	65.6
88.9	92.0	100.0	83.8	82.9	94.6	100.0	88.9	81.6	87.2	84.6	81.8	89.8	89.7	85.3	87.0	93.3	93.8
66.7	60.0	70.8	54.1	62.9	81.1	66.7	74.1	63.3	71.8	65.4	45.5	73.5	74.4	50.0	56.5	56.7	43.8
77.8	74.0	66.7	67.6	68.6	81.1	88.9	77.8	67.3	84.6	84.6	72.7	73.5	84.6	76.5	39.1	80.0	50.0
24.4	36.0	33.3	40.5	25.7	29.7	0.0	40.7	24.5	43.6	42.3	31.8	34.7	30.8	50.0	39.1	60.0	43.8
48.9	54.0	62.5	48.6	40.0	64.9	77.8	59.3	46.9	56.4	46.2	31.8	53.1	61.5	61.8	56.5	73.3	50.0
3.3	3.1	3.3	3.1	3.1	3.2	3.4	3.4	3.2	3.2	3.4	3.3	3.3	3.1	3.4	3.3	3.3	3.3
24.4	30.0	16.7	16.2	22.9	10.8	44.4	22.2	16.3	28.2	30.8	31.8	28.6	15.4	20.6	39.1	30.0	40.6
15.1	10.0	9.0	7.0	5.5	7.1	5.4	7.5	6.5	5.5	9.0	9.7	8.7	8.0	9.8	14.4	7.1	11.9
0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	1.0	0.0	1.0	0.0	1.0	0.0	0.0	1.0	n/a	n/a
13.3	31.3	57.1	45.8	49.1	55.2	64.3	47.1	26.0	40.9	56.0	61.1	52.2	65.4	69.4	34.0	64.7	38.1

Annex 12: Minimum Dataset to Monitor End-of-Life care

Hospital Performance Indicator	**Scale**	**Question**
Overall care outcome	1-10	Mean of Indicators (1)+(2)+(3)+(4)
Acceptability of dying (1)	1-10	Do you feel the way this patient died in hospital would be acceptable for you? [Scale: definitely not acceptable (1) to very acceptable (10)]
Patient care (2)	1-10	▪ How well do you think the hospital team communicated with the patient about his or her situation and the likely prognosis? ▪ How well do you think the hospital team provided end-of-life care that respected the patient's wishes? ▪ How well do you think the hospital team managed the patient's symptoms, such as pain, to a level that was acceptable to him or her? [Scale: not well (1) to very well (10)]
Symptom management (3)	1-10	If the patient had this symptom at any time during their last week of life, how well it was managed by the hospital team to keep the patient comfortable? ▪ Pain ▪ Nausea and / or vomiting ▪ Breathing difficulties ▪ Increased secretions ▪ Restlessness or agitation ▪ Anxiety or fear [Scale: very badly (1) to excellent (10)]
Family support (4)	1-10	▪ How well do you think the hospital team communicated with the relatives or friends about the patient's illness and the likely prognosis? ▪ How well do you think the hospital team gave emotional support for the family or friends of the patient? [Scale: not well (1) to very well (10)]
Disease and cause of death:		
Disease		Which of these illnesses describes the patient's primary disease or illness at their last admission to hospital? [5 categories: cancer, circulatory, respiratory, frailty/dementia, other]
Sudden deaths	Y / N	Was the patient's death sudden? [2 categories: sudden and expected]
Route of admission:		
Admission not through A&E	Y / N	If the patient died in an acute hospital, was the patient admitted through A&E? [2 categories: A&E and outpatient/day services/medical admission]
Elective admission	Y / N	If the patient died in an acute hospital, was the admission elective? [2 categories: elective and emergency]
Physical environment:		
Death in single rooms	Y / N	Did the patient die in a single? [2 categories: single room and multi-occupancy room]
Dignity of room/ward	1-10	Tell what you think objectively about the type of room the patient spent most of the time during their last week of life in terms of the following: ▪ Patients have dignity when getting personal care ▪ Patients can have easy access to toilet, and shower or bath ▪ Patients can choose company, or to be alone [Scale: very poor (1) to excellent (10)]
Environment of room/ward	1-10	Tell what you think objectively about the type of room the patient spent most of the time during their last week of life in terms of the following: ▪ Patients can see nature ▪ Patients can see natural daylight ▪ Patients can experience quiet ▪ Patients can listen to TV or radio without disturbing others [Scale: very poor (1) to excellent (10)]

Hospital Performance Indicator	Scale	Question
Mortuary facilities	1-100	Does the mortuary have any of these: ■ An outer entrance with protection from the weather ■ An inner reception area ■ A waiting room that can hold more than one family ■ More than one waiting room ■ A waiting room that has hot and cold drinks ■ A waiting room that has toilets nearby ■ A viewing room that can hold several relatives at the same time ■ A viewing room that can be adapted to the needs of different faiths and cultures ■ A viewing room that can be adapted for baby or child deaths ■ A viewing room that has suitable furniture for relatives to stay overnight if they want ■ A viewing room where people can wash their hands ■ A viewing room that has toilets nearby ■ More than one viewing room ■ A multi-faith room ■ A meeting or interview room ■ A preparatory room for ritual washing of the body or preparation of the body for viewing ■ A storage area for extra furniture or storage of religious symbols of different faiths ■ Access to a mortuary garden ■ The route from the hospital to the mortuary is covered ■ Enough car parking at the mortuary ■ Good access and exit routes for cars to stop congestion between arriving and departing groups [Scale: hospital with no mortuary facilities (1) to all mortuary facilities (100)]
End-of-Life care:		
Diagnosis of dying	Y / N	Had the medical team diagnosed that this patient was dying?
Decision to review care in last week	Y / N	At any time during the patient's last week of life, was there a decision to review medication, route of administration, and/or stop non-essential medication?
Use of specialist palliative care	Y / N	Did the patient get any contribution from a specialist palliative care service after admission to hospital?
Team meetings:		
Medical and nursing team meeting	Y / N	If the staff generally knew that the patient was dying, did the medical and nursing staff have a meeting to talk about and review the aims of care for this patient?
Multidisciplinary team meeting	Y / N	If the staff generally knew that the patient was dying, did the multidisciplinary team (all health care professionals involved in the care of the patient) have a meeting to talk about and review the aims of care for this patient?

Hospital Performance Indicator	Scale	Question
Communication:		
Quality of discussion with patient	1-10	If there was a discussion with the patient, tell us what you think the patient felt about that discussion by rating these statements: ▪ The discussion was sensitive to the patient's needs and understanding of his or her situation ▪ The discussion was open and honest ▪ The discussion was reassuring for the patient ▪ The patient had an opportunity to talk about their concerns ▪ The patient had an opportunity to talk about their preferences ▪ The patient had an opportunity to ask questions ▪ The patient was involved in making decisions about his or her care [Scale: poor (1) to excellent (10)]
Quality of discussion with relative	1-10	If there was a discussion with the relative, tell us what you think the relative felt about that discussion by rating these statements: ▪ The discussion was sensitive to the needs of relatives and their understanding of the patient's situation ▪ The discussion was open and honest ▪ The discussion was reassuring for relatives ▪ The relatives had an opportunity to talk about their worries ▪ The relatives had an opportunity to talk about their preferences ▪ The relatives had an opportunity to ask questions ▪ The relatives were appropriately involved in decisions about the patient's care [Scale: poor (1) to excellent (10)]
Support for families:		
Relatives stayed overnight	Y / N	Did any relatives stay overnight in the hospital?
Relatives visited at any time	Y / N	Were relatives free to visit at any time?
Relatives present at death	Y / N	Who was with the patient at the moment of their death? ▪ Relatives or friends ▪ Hospital staff
Documentation:		
Diagnosis of dying	Y / N	Was it documented in the patient's hospital chart that the medical team had diagnosed that this patient was dying?
Relatives told if condition worsens	Y / N	Was it documented in the patient's hospital chart that relatives wanted to be told if the patient's condition deteriorated?
Decision to review care in last week	Y / N	Was it documented in the patient's hospital chart that there was a decision, during the patient's last week of life, to review medication, route of administration, and stop non-essential medication?
Staff readiness:		
Nurse prepared for patient's death	1-10	How prepared do you feel for dealing with the death of a patient? [Scale: completely unprepared (1) to completely prepared (10)]
Nurse years of service in hospital	years	▪ How long have you been working in this hospital? ▪ How long have you been working in this ward?
Nurse trained in end-of-life care	Y / N	Since qualifying, have you gone on a formal training course on end-of-life care or palliative care?
Hospital governance:		
End-of-life goals in service plan	Y / N	In the hospital's current service plan, are there specific objectives or targets for improving its end-of-life care?
Sufficiency of staff on ward	Y / N	In your opinion, are there enough nursing staff in this ward?