End-of-Life Care in Ireland: ethical challenges and solutions

Submission to the Joint Committee on Health and Children

Dr. Joan McCarthy 24 October 2013

Contents

INTRODUCTION

1. In 21st century Ireland, we are witnessing a fundamental change in the way we die. With this change, has come a readjustment of the expectations of patients and families and a rethinking of the goals of medicine and the roles of health professionals.

2. Death in the past before medical advances: came sooner, often as a result of acute infection, childbirth, accident, the progression of an untreated disease. Death in the present amid advanced medical technologies: comes later, postponed and managed in intensive medical settings, and often follows one kind of medical decision or another. With medical technology we gain greater control over how and when we die. With greater control comes greater responsibility for the range of complex decisions medical technology makes available.

3. One of the goals of the Irish Health Service Executive Strategic Plan for 2008-13, is 'to develop the role of the "expert patient", especially those with long-term illnesses, in developing their own care plan and in looking after their own condition'.[1] Two of the related actions to achieve this goal are: the promotion of patients as 'partners with health professionals' and the education of staff on the 'importance of patient involvement in their care'.[2] This HSE strategic plan linking as it does, the notion of patient autonomy with the idea of individual participation in care planning and self-care, reflects the changes in the way in which illness is managed in the 21st century by health professionals and, increasingly, by patients themselves. It is directly relevant to one particularly vulnerable group of individuals: patients who are dying. However, while more than 4 out of every 10 people in Ireland die in acute care settings; end-of-life care is not seen as a core activity of hospitals, and it is not normally included in service plans for patients and families. Neither is its importance adequately reflected in hospital culture and organisation.

4. Currently Irish legislative and regulatory bodies are driving reform in relation to medical practices in end-of-life care. This is a long time coming and is to be welcomed. However, if the reforms envisaged in documents such as the National Consent Policy (2013) and the Assisted Decision Making Bill (2013) are to come about in the fullest sense; there has to be a cultural shift in healthcare institutions and practices as well as among the general public.

5. Similar reforms in the US for example, have been seen to be excessively driven by the law and some argue that there is a need for society more broadly to catch up.

The next decades should be, we believe, a time of education and soul-searching discussions in communities and at kitchen tables, as well as in health care settings. […] We must talk about what we dare not name, and look at what we dare not see. We shall never get end of life care 'right' because death is not a puzzle to be solved. Death is an inevitable aspect of the human condition.

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[1] Health Service Executive (2008), *National strategy for service user involvement in the Irish health service 2008-2013*, Department of Health and Children, Dublin, p.14.

[2] Ibid, p.6

But let us never forget: while death is inevitable, dying badly is not.[3]

6. We might live in an age of instant solutions but ethical problems in end-of-life care are not easy to resolve because they involve value-laden opinions and strong personal emotional responses. The increasing diversity of the Irish population and the need to respect different cultural values and religious perspectives also demand greater sensitivity, deeper understanding and more inclusive policies and practices. Ethics is increasingly everyone's business: we can't just leave ethics to the ethical 'experts'; nor can we assume that clinical expertise implies ethical expertise.

7. Given the current national and international focus on the processes of death and dying in healthcare settings, the Hospice Friendly Hospitals Programme (HfH) of the Irish Hospice Foundation has made and continues to make a timely contribution to what has been called a 'national conversation about death in Ireland'.[4] One of its many significant initiatives is the **Ethical Framework for End-of-Life Care**.[5]

ETHICAL FRAMEWORK FOR END-OF-LIFE CARE[6]

8. The **Ethical Framework**, consisting of 8 Modules of Learning, is a set of resources for health professionals, allied professionals, healthcare ethics and law lecturers and students, to support and enhance teaching and learning about the diverse ethical issues that arise in relation to death and dying.[7] It aims to foster and support ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals and healthcare settings. The outcome of a unique collaboration between University College Cork, the Royal College of Surgeons in Ireland and the Irish Hospice Foundation, it has contributions from ethicists, legal experts, theologians, sociologists and clinicians.

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[3] Murray, TH, Jennings, B., (2005) The quest to reform end of life care: rethinking assumptions and setting new directions, *Hastings Centre Report*, Nov-Dec; S52-7, p.57.

[4] Doyle, E. (2008) A National Conversation about Death, unpublished Thesis, University of Edinburgh, p.25.

[5] See Appendix 3 for authorship of the Framework and empirical research.

[6] The Ethical Framework is available (free) online at:
http://hospicefoundation.ie/publications/ethics/ It is also published by Cork University Press: *End-of-Life Care: Ethics and Law* (2011)

[7] The 8 Modules of Learning (combine ethics, laws and professional guidelines):
   1. Explaining Ethics
   2. The Ethics of Breaking Bad News
   3. Healthcare Decision-making and the Role of Rights
   4. Patient Autonomy in Law and Practice
   5. The Ethics of Pain Management
   6. The Ethics of Life Prolonging Treatments
   7. The Ethics of Confidentiality
   8. Ethical Governance in Clinical Care and Research

9. The Framework draws on a range of values and principles that have been identified as important considerations in end-of-life decision making by international experts in bioethics and by professional codes of conduct, policy documents and laws. One of its unique features is that is also informed by extensive national research - the first national survey of the general public with a focus on ethical issues that arise at the end of life[8]; and the first description and analysis of the ethical views and experiences of Irish health professionals.[9]

10. While this research indicates that the general public, patients, families and health professionals have many positive experiences in relation to end-of life care in Irish health care settings; the research also paints a picture of
    a. a general public that have little or no understanding of end-of-life treatment and care terminology and
    b. are not very comfortable with or informed about the processes of dying and death
    c. are confused about the role of families in relation to receiving information and making decisions for incompetent patients and many assume (incorrectly) that families have a right to make decisions about the medical treatment of their loved ones.
    d. This confusion can create difficulties for health professionals especially in situations of family conflict.
    e. On the one hand, there is general agreement that competent individuals have the right to refuse medical treatments even if this decision results in their death and
    f. most people also place emphasis on the quality of their life rather than on its length, and they fear being helpless and dependent more than they fear death.
    g. On the other hand, health professionals indicated that active medical interventions and treatments were continued long after some practitioners thought them beneficial.
    h. There was little or no documentation of patients' wishes in acute or community hospitals.
    i. Many deaths are managed in a moment-by-moment decision-making process embedded in uneasy communication between distressed relatives and under-resourced and over-stretched healthcare staff.
    (See **Appendix 1** for a more detailed description of these points)

TO ENSURE THAT PEOPLE DIE WELL IN IRELAND

11. What is certain is that if the notion of the 'expert patient' who is empowered to participate in decisions about their treatment and care, as envisaged in the HSE Strategic Plan, mentioned at the outset, is to be realized; **educational and**

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[8] See Weafer (2009), Weafer et al (2009) and McCarthy et al (2010). Given that the sample surveyed in Weafer et al (2009) (n = 667) was representative of the general population and that the study's findings are consistent with related research undertaken in Ireland, confidence can be placed in the representativeness of the survey results.

[9] See Quinlan and O'Neill (2009) for more information about their research involving 14 focus groups; 57 interviews; 102 written submissions with different health care staff in 15 hospitals (both acute and community) around Ireland.

support strategies need to be put in place to start and/or continue conversation and debate about the processes of death and dying in Irish healthcare settings e.g.

   a. the lack of familiarity with terms used in relation to end-of-life treatment and care places an onus on state agencies and healthcare organisations to ensure that basic information about end-of-life care is communicated in a meaningful way to the general public.

   b. there is an onus on professionals and hospitals to ensure that patients and their families are aware of the processes of decision making for competent and incompetent patients and the role that individuals and families might have in any deliberations and care plans.

   c. while legal challenges in relation to assisted suicide and euthanasia might capture the public imagination, clarity and understanding are also needed in relation to more routine but also complex and contested decisions and interventions such as starting, stopping and descalating treatment, sedation and pain management and the provision of nutrition and hydration.

   d. Patients do not always want what is right or reasonable to want. It is important to recognize the ethical work of health professionals and to acknowledge that it may come at a personal cost. There is a need for ethical leadership, moral teamwork and for ethically healthy organisations that encourage open, inclusive and respectful dialogue about ethical, professional and legal issues. In this way, nagging doubts and uncertainties can be expressed and shared, the personal cost of acting ethically is not unbearable and sight is not lost of the fundamental bond between professional and patient

12. In turn, further **research** into the relationships between patients, families and professionals and the ethical climate of healthcare organisations is needed e.g.

   a. The Irish population is racially, ethnically and culturally diverse. Considering that 3.9 of 4.2 million people supplied a religion in the 2006 Irish population census and that 87% of respondents in our research stated that spiritual and religious support at the end-of-life were important to them, the impact of religious belief on death-related attitudes in Ireland presents an important area for further research.

   b. There is need for research in relation to the disclosure needs and concerns of particular patient groups and their families such as individuals with intellectual disability or mental health problems who have also been diagnosed with serious or terminal illnesses.

SUGGESTED SOLUTIONS

A National Network of Clinical Ethics Committees

13. Providing formal ethics support for health professionals and allied staff in the everyday treatment and care of patients and their families by introducing Clinical Ethics Committees into Model 1-4 hospitals in Ireland would bring Ireland into line with international best practice. In Canada, Europe, the UK, US and Australia such multidisciplinary committees perform a threefold function:

   a. Ethics education for health professionals, hospital staff, patients and families
   b. Formulation and review of hospital policies
   c. Consultation to support staff with complex and difficult clinical cases.[10]

14. While every hospital would have its own Clinical Ethics Committee [at least 10 hospitals in Ireland already have some form of a Clinical Ethics Committee e.g. Beaumont and The Bons Secours]; each Committee would also be linked at local, regional and national levels with other Clinical Ethics Committees. The work of the Committees would also be supported by key experts in ethics, law and related disciplines working in third level institutes and universities. In turn the Committees would be linked with the educational and research programmes of the National End-of-Life Healthcare Ethics Observatory described below. It is envisaged that the economic cost of each hospital Committee would be minimal (largely administrative) while a small task force in the Department of Health and Children would be responsible for coordinating and supporting the Network at a regional and national level.
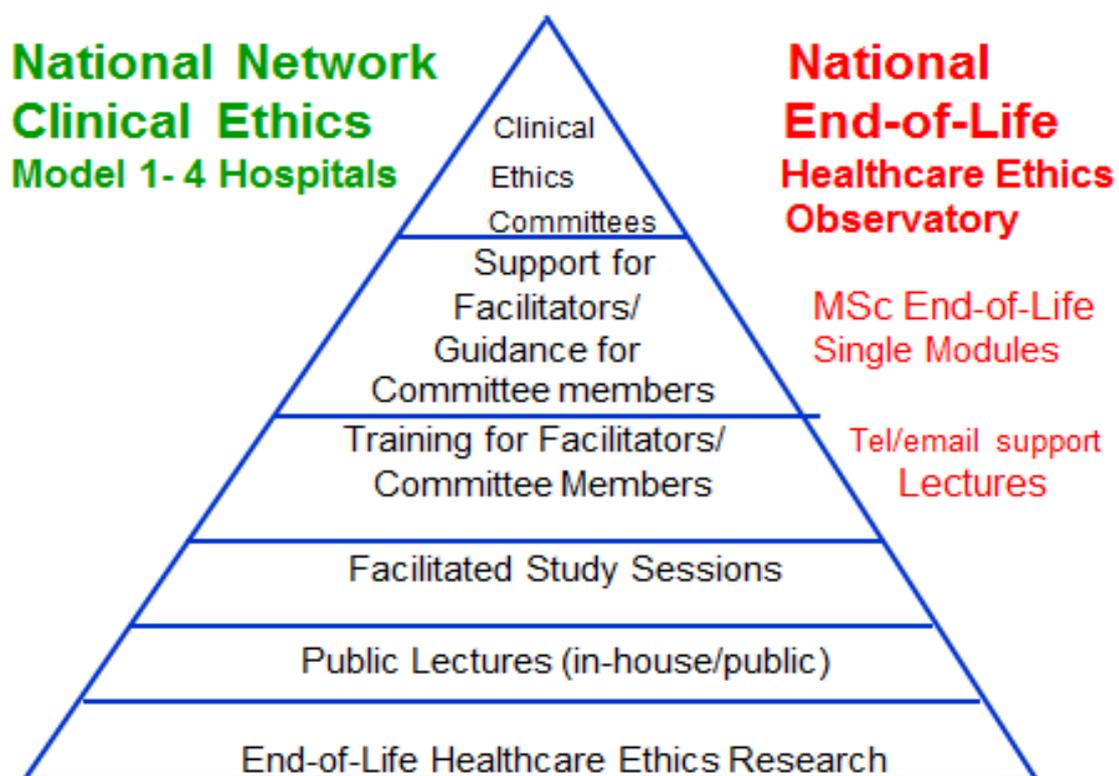
A National End-of-Life Healthcare Ethics Observatory

15. The Observatory would be the joint initiative of third level educators in ethics, law and related disciplines drawn from relevant institutes and universities in partnership with hospital education centres and professional bodies in Ireland. Given current economic constraints the Observatory might begin as a Virtual Observatory (supported by a network of suitably qualified individuals and housed in one or more third level institution) with a view to finding accommodation in the longer term in a large national or regional hospital. Building on the collaboration between UCC and RCSI that resulted in the development of the Ethical Framework, the work of the Observatory would include:

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[10] See Module 8, Ethical Framework for End-of-Life Care, for further explanation and analysis of Clinical Ethics Committees

a. Providing educational support to the general public in the form of lectures, workshops and dissemination of information through the social media.
b. Improving the training and continuous professional development of clinicians involved in caring for dying patients e.g. stand-alone modules, certificate and postgraduate programmes on end-of-life healthcare ethics.
c. Developing and updating the Ethical Framework and accompanying Study Sessions to ensure they are current, relevant and fit for purpose.
d. Initiating 4th level educational programmes (PhDs and clinical doctorates jointly supervised by academic and clinical experts) in clinical ethics and bioethics in Ireland for clinicians, ethicists, lawyers, chaplins etc.
e. Supporting the work of Clinical Ethics Committees with expert advice and educational interventions.
f. Undertaking evidence based ethics research e.g. to evaluate the effectiveness of interventions such as educational initiatives in improving ethical practice or the development of interventions to enable vulnerable populations to participate more fully in end-of-life decision-making.

16. The **National Network of Clinical Ethics Committees** and the **National End-of-Life Healthcare Ethics Observatory** would work together in educational and research initiatives that would contribute to improving the culture and organisation of death and dying in Ireland. Ultimately, they would positively impact on the care of all patients, service users, family members and staff working in healthcare. A visual representation of how the work of the two initiatives would overlap is provided below.

17. A number of the educational initiatives referred to above have already been developed e.g. an MSc in End-of-Life Healthcare Ethics was offered by UCC in 2011-2013.[11] Study Sessions that engage health professionals in the Modules of the Ethical Framework have been piloted with health professionals in Limerick.[12] Both of these initiatives have been very positively evaluated. The Framework itself has been very positively evaluated by the Irish national media and by international academic journals (See **Appendix 2**).

18. Moreover, where ethics support is a standard part of healthcare organisations, the evidence indicates that health professionals and hospital staff are:
- more self-aware of their own beliefs and values
- more sensitive to moral values at risk
- less paralysed by moral issues
- engage in more dialogue, less debate about the 'right' answer
- postpone judgement
- listen and feel heard
- more willing to engage in a process that will involve some degree of negotiation
- bring reasons for decisions out into the open – greater transparency

Leading to:
improved patient and family outcomes and less moral stress, desensitization and burnout.[13]

19. The success of these initiatives to date indicates what can be done with limited resources where individuals and groups commit themselves to making change happen. Clearly, given the evident success of the work of the Hospice Friendly Hospitals Programme, much more can be done with minimal cost but also the support of state agencies working together with regulatory bodies and third level institutions to enhance the quality of death and dying in Ireland.

20. This is also an opportunity for Ireland to take a leadership role internationally, in the development of educational and clinical strategies that foster and support ethically and legally sound clinical practices in end-of-life treatment and care in healthcare settings.

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[11] The Schools of Nursing and Midwifery, Medicine and Philosophy, UCC offered an MSc in End-of-Life Healthcare Ethics with exit routes for a Postgraduate Certificate/Diploma for health and allied professionals and the general public (2009-11). The RCSI offers an MSc in Healthcare Ethics and Law and some modules have a focus on end-of-life healthcare ethics.

[12] See C. McArthur, 'Pilot Study Evaluating the Effect of the Ethical Framework for End-of-Life Care Study Sessions, MSc End-of-Life Healthcare Ethics, UCC, 2013.

[13] Molewijk B, Zadelhoff E, Lendemeijer B, Widdershoven G. (2008) Implementing moral case deliberation in Dutch health care: improving moral competency of professionals and quality of care. *Bioethica Forum*, 1 (1) 57-65.

Conclusion

21. When the Liverpool Care Pathway was found to have contributed to poor care for dying patients and their families in the UK earlier this year, the reviewers called on the British government to ensure that 'guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever'.[14]

22. It has now become abundantly clear that care for the dying is a complex art that demands greater public understanding and involvement as well as greater organisational and professional sensitivity to individual patients and their families. Providing the tools for thinking about difficult ethical and legal issues that arise in relation to death and dying and fostering a range of ethical skills and competencies to ensure that decisions are arrived at in the most reasonable, sensitive and collaborative way possible must be part of any national strategy that is seriously interested in achieving any real progress in this area.

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[14] Independent Review of the Liverpool Care Pathway (2013) More Care, Less Pathway, A Review of the Liverpool Care Pathway. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf; page 11.

APPENDIX 1

EMPIRICAL RESEARCH ON ETHICAL ISSUES (2008-10)[15]

Experience and understanding of death

The Irish general public have little or no understanding of end-of-life treatment and care terminology. They are likelier to know more about euthanasia, assisted suicide and post mortems than they are to know about advance directives, palliative sedation, artificial hydration and CPR. Most people had never heard of the term 'Advance Directive', with more than eight in ten (84%) respondents to the Weafer et al (2009) survey stating they had either 'never heard' or 'heard of but know nothing' of the term.

Many people tend to link the withholding and withdrawing of artificial nutrition and hydration (ANH) as well as certain pain relief measures with the hastening of death and euthanasia. The majority of research participants were confused regarding the implications and procedures associated with a 'Do Not Resuscitate (DNR)' orders. This is consistent with earlier Irish research in this area.[16]
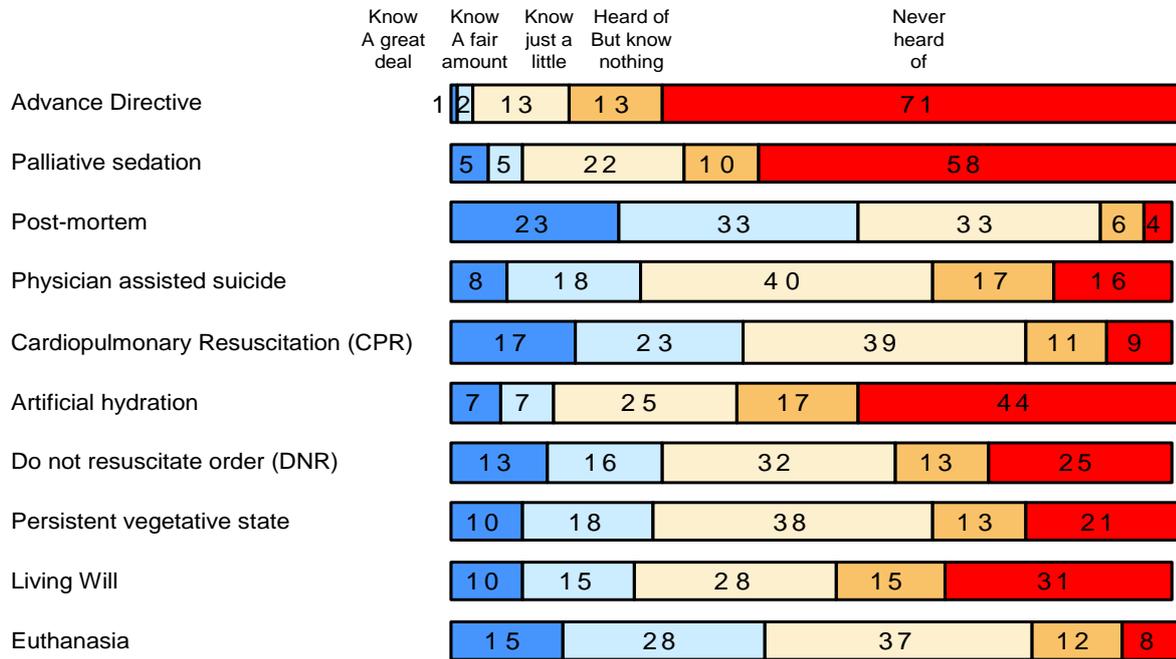
See Figure 1. Awareness of Terminology below.

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[15] See Appendix 3 and Reference List for authorship of the empirical research.

[16] Weafer, Research Associates and TNS/MRBI (2004) *A nationwide survey of public attitudes and experiences regarding death and dying,* The Irish Hospice Foundation/Health Services National Partnership Forum, Dublin.

Awareness of Terminology

(Base: All Respondents, N = 667)

	Know A great deal	Know A fair amount	Know just a little	Heard of But know nothing	Never heard of

Term	Know A great deal	Know A fair amount	Know just a little	Heard of But know nothing	Never heard of
Advance Directive	1	2	13	13	71
Palliative sedation	5	5	22	10	58
Post-mortem	23		33	33	6 / 4
Physician assisted suicide	8	18	40	17	16
Cardiopulmonary Resuscitation (CPR)	17	23	39	11	9
Artificial hydration	7	7	25	17	44
Do not resuscitate order (DNR)	13	16	32	13	25
Persistent vegetative state	10	18	38	13	21
Living Will	10	15	28	15	31
Euthanasia	15	28	37	12	8

Q. I am now going to read out a list of terms and would like you to tell me if you know a great deal, a fair amount, just a little, heard of but know nothing about or never heard of each term I read out.
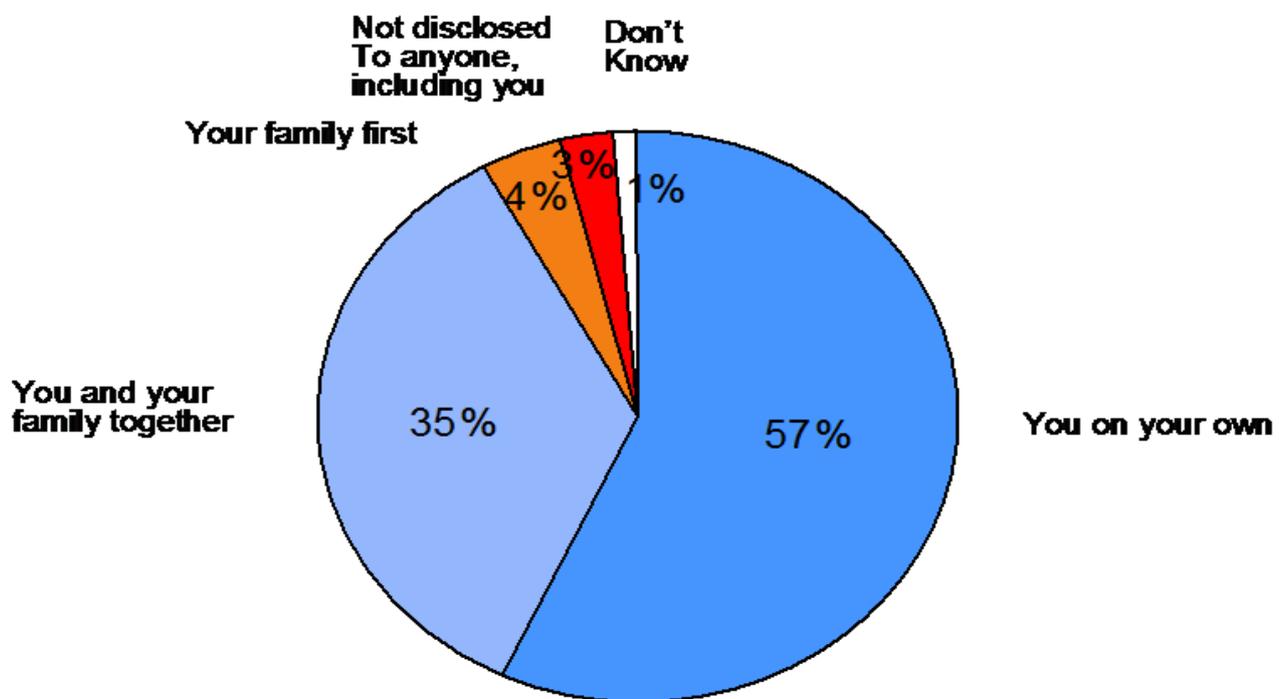
Figure 1.

Breaking Bad News

The findings of Weafer et al. (2009) confirm that most people, if seriously ill, would want to be told the truth about the diagnosis and the prognosis, either alone or in the presence of their families.

See Figure 2. Information of Terminal Illness

Information of Terminal Illness

(Base: All Respondents, N = 667)

Q. If you were diagnosed with a terminal illness, would you like information about your condition to be told to....?

That said, there remains a strong culture among relatives in Ireland of seeking to protect loved ones from bad news. Some adopt a 'gatekeeper' stance; filtering what they deem the patient should and should not be told. The Quinlan and O'Neill (2009) study found a culture wherein clinicians often liaised with a patient's family either

exclusively or prior to liaising with the patient. Their research with healthcare staff indicated that talking about death is difficult – even for those who work in healthcare and healthcare workers generally feel more at ease having end-of-life discussions with a patient's family rather than the patient. Where staff are anxious to talk with patients they may hindered by family members who are uncomfortable with open communication around death and dying.

Decision-making
Many Irish people, particularly older people, place a great deal of trust in their physician when decisions must be made about their care. In our research, most participants agreed that competent persons had the right to refuse medical treatment, but a sizable number also seemed unclear as to who has the authority to make decisions for incompetent patients.

The Irish general public as well as health professionals are confused about the role of families in making decisions for incompetent patients and many assume (incorrectly) that families have a right to make decisions about the medical treatment of their loved ones. This confusion can create difficulties for health professionals especially in situations of family conflict. While the Assisted Decision Making Bill (2013) and the National Consent Policy (2013) clarify who has the authority to make decisions and how those decisions might be made, the findings of our research underline the need to inform and educate the general public and health professionals about the process of decision making in relation to incompetent patients.

Findings of research with health professionals indicated that
- active medical interventions and treatments were continued long after some practitioners thought them appropriate and beneficial
- there was little or no documentation of patients' wishes

Lack of planning meant:
- many deaths are managed through a moment-by-moment, event by event decision-making process
- embedded in uneasy communication between distressed and grieving relatives and under-resourced and over-stretched healthcare staff. (Quinlan and O'Neill 2009 p.4)
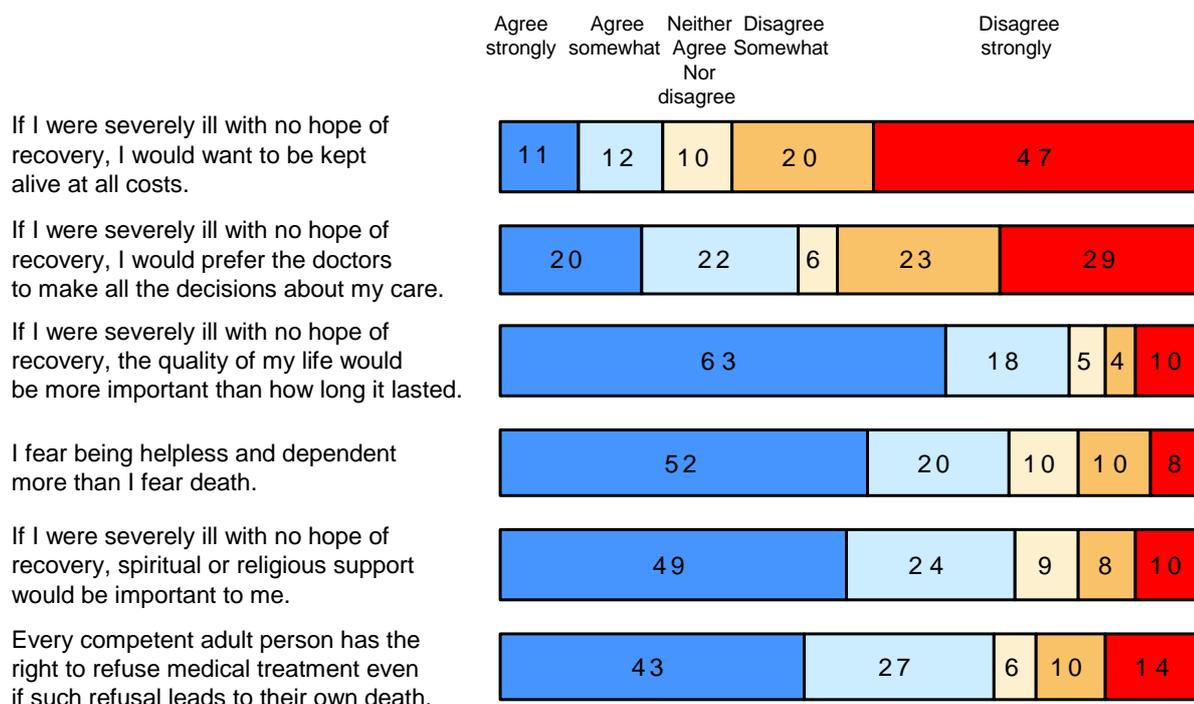

Attitudes towards death and dying
There is general agreement that competent individuals have the right to refuse medical treatments even if this decision results in their death. Most people also place emphasis on the quality of their life rather than on its length, and they fear being helpless and dependent more than they fear death.

See Figure 3. Attitudes Towards Death and Dying

Figure 3

Attitudes Towards Death And Dying

(Base: All Respondents, N = 682)

	Agree strongly	Agree somewhat	Neither Agree Nor disagree	Disagree Somewhat		Disagree strongly

If I were severely ill with no hope of recovery, I would want to be kept alive at all costs.
| 11 | 12 | 10 | 20 | 47 |

If I were severely ill with no hope of recovery, I would prefer the doctors to make all the decisions about my care.
| 20 | 22 | 6 | 23 | 29 |

If I were severely ill with no hope of recovery, the quality of my life would be more important than how long it lasted.
| 63 | 18 | 5 | 4 | 10 |

I fear being helpless and dependent more than I fear death.
| 52 | 20 | 10 | 10 | 8 |

If I were severely ill with no hope of recovery, spiritual or religious support would be important to me.
| 49 | 24 | 9 | 8 | 10 |

Every competent adult person has the right to refuse medical treatment even if such refusal leads to their own death.
| 43 | 27 | 6 | 10 | 14 |

> Q. I am now going to read out a list of statements and I would like you to tell me whether you agree strongly, agree somewhat, neither agree nor disagree, disagree somewhat or disagree strongly with each statement that I read out.

Spiritual/religious support

Spiritual and religious support at the end of life are considered very important by the majority of the general public (87%). Those who are religiously committed place a high value on life, reject the right to refuse treatments that might forestall death, respect medical authority and value spiritual support in their end-of-life care.

APPENDIX 2

Reviews of the Ethical Framework

Irish Times Editorial, 7 October 2010

Extract: How often does technology's availability lead to futile treatment, sometimes at immense discomfort to the patient? When is it appropriate to tell someone they are dying? How is a patient's autonomy respected? Is it ethical to withhold nutrition and hydration? … The framework performs a valuable public service in highlighting issues such as managing pain, confidentiality, governance in clinical care, breaking bad news, healthcare decision-making and life-prolonging treatments. In that regard, it should encourage open public debate and enable healthcare professionals to be collaborative, informed and confident in addressing these matters, however complex and contentious.

Mullock A (2012) *Medical Law Review*, 20(4): 655-7.

Extract: As an Irish endeavor, the framework aims to support ethically and legally sound clinical practice in this sector of medical care in Ireland (p.9). As the framework features bioethical principles and ideals which are internationally recognized, together with universally relevant clinical dilemmas, the book has much to commend it to those outside of Ireland.

Tschudin V. (2012) *Nursing Ethics*, 19(3): 443

Extract: The book is set within the practice and legal boundaries of Ireland, but its impact is surely way beyond the confines of this one country. The examples and cases used are drawn from practice and have relevance in almost any setting.

Danaher J, *European Journal of Health, Law* 20 (2013) 235-237

Extract:
The book has a number of strengths. First, its narrow focus on end-of-life care, and its specific target audience of healthcare professionals, make it a relatively unique contribution to the pedagogical literature in this area. Those of us who teach medical students and professionals dealing with the end-of-life will be hardpressed to find a book that is more appropriately pitched to them … Designed to encourage critical reflection on key ethical concepts and arguments, these case studies are drawn from real-life clinical reports and legal cases, and are consistently interesting and well-chosen.

APPENDIX 3

Biography of Presenter

Dr. Joan McCarthy, MA, PhD is a College Lecturer in Healthcare Ethics in the School of Nursing and Midwifery, UCC. She coordinates the MSc in End-of-Life Healthcare Ethics in the College of Medicine and Health, UCC and also contributes to the MSc in Healthcare Ethics in the Royal College of Surgeons in Ireland and the Medical University of Bahrain. She is a member of the Irish National Advisory Committee on Bioethics, the Ethics Committee of the Nursing and Midwifery Board of Ireland, the Editorial Board of *Nursing Ethics* and the International Centre of Nursing Ethics, Surrey UK. She has published widely on various topics in healthcare and nursing ethics. Her recent publications include *End-of-Life Care: Ethics and Law* (with M. Donnelly, D. Dooley, L. Campbell and D. Smith, 2012, Cork University Press) and *Nursing Ethics, Irish Cases and Concerns* (2nd edition with D. Dooley 2012, Gill and Macmillan). She has been involved in a number of national and international research projects and she was the principal investigator of a national multi-disciplinary project that led to the development of the Ethical Framework for End-of-Life Care.

Ethical Framework for End-of-Life Care

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