

Title	Conversations with the Irish public about death and dying
Authors	McCarthy, Joan;Loughrey, Mark;Weafer, John;Dooley, Dolores
Publication date	2009-12
Original Citation	McCarthy, J., Loughrey, M., Weafer, J. and Dooley, D. (2009) 'Conversations with the Irish public about death and dying', Studies: An Irish Quarterly Review, 98(392), pp. 457-472.
Type of publication	Article (non peer-reviewed)
Link to publisher's version	http://www.jstor.org/stable/25660709, http:// www.studiesirishreview.ie/
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Download date	2025-05-31 21:56:59
Item downloaded from	https://hdl.handle.net/10468/3011



University College Cork, Ireland Coláiste na hOllscoile Corcaigh

Conversations with the Irish public about death and dying

Joan McCarthy, Mark Loughrey, John Weafer, Dolores Dooley

Introduction

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' (¹p.14).

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'. The document defines 'involvement' as: A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing polices, in planning, developing and delivering services and in taking action to achieve change. (p.6)

This HSE strategic plan linking as it does, the notion of patient autonomy with the idea of individual participation in care planning and selfcare, 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. Writing about the recent death of the Irish author and broadcaster, Nuala O'Faoláin, Terence Cosgrave's editorial in the *Irish Medical Times* points out that: [*If] Nuala O'Faoláin has taught us anything, it is that we should put the person who is experiencing the trauma of terminal illness at the forefront* [...] *Their interests should be paramount and we should not let ideology blind us to their wishes - and* their rights [...] Doctors know if they treat any patient long enough, it will [...] end in failure. But the failure to keep a patient alive forever is acceptable – that is the nature of life. An undignified death – and needless suffering – is a much more catastrophic failure, and one that should be consigned to history.²

Cosgrave's editorial is of interest, not just because it underlines the inescapability of death but, also, because it focuses on the obligations of health professionals to accompany the dying well. Murray and Jennings³ support this commitment to addressing the issue, not of death, but of dying badly. They suggest that end-of-life-care reform in the United States has, in the past, been excessively driven by the law and it is time to turn the lens on the need for culture to catch up. They note: *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. But let us never forget: while death is inevitable, dying badly is not. (p.57)

Commentators on dying and death, such as Cosgrave and Murray and Jennings, would agree that we have witnessed a basic 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. The diversity of individual values and cultural differences tells us that an agreed consensus on what makes for a good dying may not be within our easy reach. However, if there is no universal agreement about what a 'good death' consists of, there is, fortunately, some consensus as to the core features of the care that needs to be provided to those who are dying and their families and loved ones. Drawing on long-established ethical principles, the UK General Medical Council, for example, articulates good end-of-life care as that which 'helps patients with life-limiting conditions to live as well as possible until they die, and to die with dignity' ⁴(p.4). In addition, several policy documents from around the world focus on a range of conditions for a good death such as the need for health professionals: to have good communication skills; to recognise, support and enable the unique values, priorities and individuality of patients;

to engage with patients and/or their families in relation to decisions about starting and stopping life prolonging treatments; to provide pain relief and comfort care to the end. 5-8

Given the current national and international attention to the process of death and dying in healthcare settings, the Hospice Friendly Hospitals Programme (HfH) of the Irish Hospice Foundation makes a timely contribution to what has been called a 'national conversation about death in Ireland' ⁹(p.25). Through the implementation of a range of initiatives involving wide public consultation, empirical research and educational initiatives, the HfH aims to develop comprehensive standards for regional and community hospitals in relation to end-of-life care and to develop the capacity of these hospitals to meet and exceed these standards. The study, this article reports on, is one of the measures undertaken to achieve the HfH's aims and it provides some basic information about the level of public understanding of, and concerns about, dying and death. The study's findings ultimately contributed to the development of a national survey on death and dying - the results of which are reported elsewhere.¹⁰

Methodology

The study sought to elicit public opinion on death and dying via a focus group methodology. Two focus groups, drawn from the adult general public, were convened in Dublin and Sligo in June 2007. Each of the participants had had someone close to them die after an illness in an Irish hospital within the previous five years. None of the participants were, themselves, diagnosed with or currently undergoing treatment for any life-threatening illness. Furthermore, no participant worked with terminally ill people or in a hospital, hospice, or nursing home. The focus group in Dublin consisted of middle class individuals aged between 30 and 45, whilst the Sligo group consisted of working class and farming individuals aged between 50 and 70 years. Each focus group consisted of four men and four women. The groups addressed three broad issues. Firstly, they discussed the subject of dying and death in general and, more specifically, what circumstances constitute a 'good death'. Secondly, participants were asked to give their views on patient autonomy and decision making in relation to end of life and, finally, participants were asked about their experiences in relation to the dying and death of their loved ones in Irish hospitals.

Findings: Conversations about death and dying well

Although most of the participants had spoken of death at some stage, most felt that there were appropriate times for discussing death, such as when a close family member or friend dies. *I don't think it* (death) *is a topic that is discussed much – it is too morbid. You know what is going to happen to you, but you don't want to talk about it.*

In reasoning as to why death was not discussed more readily many felt that it would be almost tempting fate to discuss the subject too lightly or out of context. Equally, the circumstances had to be right before anyone would consider discussing their own death or that of a relative, particularly in the presence of an older or ill person. A consensus emerged that older people (and to a lesser extent the terminally ill), are more likely to discuss different aspects of death and to attend funerals but, even then, it depends on the person concerned. *It's a life-stage thing. When you are younger, you keep away from funerals. As you get on, you realise it touches most people and you get more relaxed with it. My mother is 82 and she says she is ready now. She is not sick and I can't understand how she can say it.*

A number of people indicated they had felt quite awkward in the presence of friends who had been diagnosed with a serious or terminal illness. *I had a close friend who was dying from cancer and I purposely didn't visit her; I just phoned her from time to time. What do you say? How do I talk about something normal when I know what she is facing into? I just wanted to totally avoid how she felt and I don't think I am untypical.*

Others said that some close friends had not spoken to them following bereavement because they didn't seem to know what to say. Only on rare occasions had a dying person discussed their final days. We don't discuss the circumstances unless we really have to. If someone has cancer, we don't discuss what to do in the final stages; how to plan it. I feel you would have to be pushed into it; you wouldn't sit down and discuss it over the dinner table. The person would need to be very close to the end; it's as if it won't ever happen, and yet it does.

Generally when people did, specifically, speak about their own death it was in order to indicate funeral preferences, such as, whether they would

like to be buried or cremated; or how they would like to be cared for if they went 'ga ga'. The perceived lack of dignity associated with dementia was spontaneously mentioned as a real fear by a number of participants.

Good deaths were perceived to be those that occurred painlessly, quickly and peacefully (such as in one's sleep), in one's own home (albeit with medical support), surrounded by one's family, with both dignity and emotional reassurance and with control over the time and circumstance of the death. Some participants expressed a wish that the natural life cycle be adhered to with regards to their own dying – meaning that the death occur when they are old, with families reared, and all affairs in order. One participant took a more light hearted view - describing a good death as one which included a pint of Guinness in one hand and a model in the other! Some of the narratives that illustrate participants' views on what constitutes a good death are listed here: My father told everyone he was dying and to get everything ready. Twenty-four hours later, he was dead. We discovered afterwards that he had cancer but he was in control to the end. He had had enough and he simply turned off his clock. It depends on the illness but ideally, to die at home; otherwise, with the best available professional medical care. Time to make plans and to talk to your family.

Your children all grown up and independent [...]. According to the natural cycle – you get old and die and not have to bury your children. Dignity is huge with me. My mother was a very active woman, but she had a stroke and died without being able to do things for herself or say how she would like to be treated.

While few of those in attendance admitted to having seriously considered their own deaths, some did express personal fears. In a minority of cases, some individuals said they feared death itself and the uncertainty of what happens when you are buried: *I am really scared of dying and I just hate the part where they put the coffin into the ground. I have told my sister, I don't want that to happen to me. I don't know what is going to happen; when you are gone, you are gone; that's it. Close your eyes and everything goes black, just like going to sleep, but forever.*

Others were more concerned with the implications of their death for their loved ones: *I am very fearful. My fear is that I would die young and*

leave my children. Both my parents died young and when you see a parent die young and they are the centre of your universe, it has a lasting effect.

The most pervasive fear expressed by a number of participants was that they would lose their dignity and control as a result of a debilitating illness. Some felt that such an illness would impose an unnecessary burden on their families.

Patient autonomy

When the discussion progressed onto the topic of patient autonomy, participants demonstrated a general lack of knowledge or understanding of the different options open to people who are terminally ill. With the possible exception of euthanasia (which was most often associated with the killing of old people) the majority were confused regarding the implications and procedures associated with a 'Do Not Resuscitate (DNR)' order or the meaning of an 'Advanced Care Directive'. Participants also expressed some unease concerning decision-making that might end life prematurely. 'Extra' morphine administered by a medical person, with the implicit support of family members, was generally regarded as acceptable: *Definitely morphine – let them go out happy.*

However, the idea of withdrawing feeding or hydration evoked quite negative responses. A number of people spontaneously mentioned that this sounded like euthanasia and not something they would favour: *It would be terrible to watch a person who was not given water or liquids; it would have to be uncomfortable and lead to suffering; Oh no.*

Even in situations where the patient had indicated his/her wishes in advance, or where the person was clearly in pain, a number of people would be very reluctant to interfere with the 'natural' process of dying. For most, the primary motivation is a desire to do the best they can by their loved ones, or at least not to do anything wrong, and an acknowledgement that others (medical and religious personnel) know more than they do about dying. Uncertainty was compounded by 'true stories' of people who had recovered from prolonged periods of unconsciousness when some family members had wanted to stop life support machines: *Life is very precious. I remember when a businesswoman in this town was on a life support machine. One half of the family wanted to turn it off and one of her sons*

had to get a solicitor to stop them and she is living today. That was a decision that could have been made very wrong by the family.

Thus, while most people would theoretically agree with any measure that lessened the pain and discomfort of terminally ill patients; in practice, they would be much more reluctant to give general approval for any form of treatment that would end life prematurely. If such approval were given, they felt this might lead to the introduction of more general euthanasia in future, or to mistakes being made due to the increasing pressures on hospital staff. It may also have the opposite effect and lead to less pain relief being administered as doctors, patients and families become more conscious of litigation and what they can and cannot do. The best decision, they felt, is one that involves the patient, their family and medical team. However, when a patient is unable to make a clear decision for themselves, most people would prefer if the ultimate decision was made in accordance with best medical practice - without the family being asked to make that decision. The medical profession have an oath to prolong life as long as they can. The ultimate decision can only be made by the person themselves to say I don't want any more treatment. When a person is not capable or conscious, I think you have to listen to the medical profession. They have the knowledge and have seen thousands of people dying. Who can decide if a person is to live or die. Everyone backs away from decisions. Who are we to make decisions like that; who is capable and who has the right? Years ago, we looked to the person with most medical expertise and knowledge – our GP, and he would tell us how much pain she was in, approximately how much time she had left, and all of that. He didn't say he was going to give extra morphine and put any of us in a situation by asking 'Can I?' You just relied on him. Now there is so much information and teams of doctors involved that you don't know who is the lead consultant and if they really know your mother. You would worry about giving that automatic right to anyone. You like to feel you are more than a number but [...].

One possible explanation for the reluctance of some to make a formal decision themselves emerged as the fear that the wrong decision could be made to end life. Some participants felt that people should not be placed in a position where they would have to make that decision alone, or, to

make a decision that might conflict with other family members. Conversely, other participants would be prepared to follow the instructions of their loved ones, or, to make a decision that would lessen pain, even if it leads to an untimely death: *I don't believe in euthanasia or anything but if they were on morphine and it quickened their demise and it was pain free, why not?*

My family knows that if I were ever in a serious car accident, I do not want to be put on life support and I don't want them to feel guilty if they have to turn off the machine. It is really up to the person themselves if they expressed it to the family when they were competent to do so. You owe it to the person to respect any decision, like 'Do Not Resuscitate', if they made it when they were fully conscious and competent. The doctor might want the bed and switch you off too soon!

Some disagreement arose in relation to the fundamental question of whether people should be told if they have a terminal illness and how much information they should be given. The majority view was that a patient should always be told if they asked, but otherwise, not necessarily: *Only if they ask. Most people just know and not everyone wants to know how many days they have to live. It's ok to think it, but another thing to be told.*

Some participants said that people should be told 'bad news' only if they think they can take it, while others felt that patients should never be told, as it may lead to a loss of hope and ultimately life: *It would kill my mother if she knew she was going to die.*

However, when it came to themselves, most participants felt they would like to know. I would personally prefer to know first and to make the decision what information to impart to others and only information I wanted them to know. I don't think it is my wife's responsibility to be told that I am going to die and then up to her to tell me. Honesty is the best policy. My father was told he had treatable cancer and we were told the opposite. You can imagine the situation that put us in.

No one in the focus groups was familiar with the notion of an Advanced Care Directive or Living Will. When explained, some thought that they were a good idea whilst others feared what would happen if they changed their mind about what they had written in the directive. All in all, participants were of the opinion that it was 'safer' to trust in their own ability to make decisions or to rely on their loved ones to make decisions on their behalf. Younger participants were the most reluctant to consider Advanced Care Directives. It would depend. You might say shoot me if I get paralysed in a car accident but there are a lot of paralysed people who don't want to die. The reason I wouldn't like to make a Living Will is that none of us can be sure how we would feel in circumstances where we can't communicate and there is even an absolutely tiny change you could make it through. I wouldn't like to linger but I would also be reluctant to write it down. You never know and better not to tempt fate. Trust people close to you to make the right decision.

The importance of religious beliefs was mentioned by a number of participants; with most people believing that belief in the afterlife helps people to die (this belief was less prevalent among younger participants). In one instance, one man who witnessed the painful death of one of his sisters wondered if she had really died in pain or if, as suggested by a priest, she had been given the grace from God to withstand all pain: *We might think she is in horrendous pain but maybe not; maybe she had inner peace when she died.* He was very reluctant to consider any form of pain relief that might speed up the death process: *Irish people have great faith and it gets them through. You meet old people and as far as they are concerned they will meet their parents and siblings when they die. They know there is something there when they die, whereas our generation wonders if there is anything there. Older people are 110% sure they are going to a better place.*

Most people felt that, if conflict arose between medical staff and an adult patient as a result of the patient's religious beliefs (such as refusing to have a blood transfusion), then the patient's wishes should be respected. However, in the case of a child, then the best medical practices should prevail.

Experiences and perceptions of death

Participants recounted different personal experiences of death; some being positive and others much less so. In some cases, the care given to different people in the same institution was judged as terrible by some and excellent by others. Everyone spoke emotively of the death of a loved one and,

regardless of when the death occurred, recalled the circumstances with strong feeling. On the basis of their experiences, they suggested that end of life could be improved by:

- 1. A private space for terminally ill people and their families.
- 2. An appropriate space that creates the right mood, with soft lights.
- 3. Nurses who focus on care rather than medical treatment, like the care provided by palliative care nurses and older nurses who were trained in 'different times'.
- 4. A spokesperson within each hospital with a responsibility to liaise with patients and their families.
- 5. Information from doctors to keep people informed of 'what's happening', although not necessarily all the information given to every patient or members of their families.
- 6. Control of pain, within limits.

My father witnessed two people dying in the ward and he was terribly upset and kept saying, "That man is after dying". The following evening, another man died and my father was aware of all that. It's very tough on other people in the ward when a person is dying; they can't sleep and visitors are brought in at all hours. You definitely need a private room in a hospital. It's much more peaceful at home with palliative care. It is terrible to see a person dying and their families trying to grieve in an open ward. It is terrible for everyone – the patient, their family, and other patients in the ward. A cousin of mine died in a way she shouldn't have. I spent six months watching her die and it was horrendous. This woman was very religious, but she had a horrible death. Her bodily functions closed in slowly and the pain just got worse and worse. She was well into her 80s, but the doctors just wouldn't let her go. They kept filling her up with drugs. I don't know why they were keeping her alive, because it was awful for her. She seemed to be in awful pain and crying a lot of the time. I think the professionals kept her alive for their own knowledge.

When asked what type of care and choices they would wish for themselves if they were dying from a terminal illness, the participants emphasised many of the same features they had associated with a 'good death' generally: an appropriate private space, free from pain; comfortable; to die with dignity; and to be surrounded by family members. The principal difference between what they would wish for themselves and their loved ones related to the level of information and choice they would like. Many participants opted for greater control and information than they had afforded to their loved ones. Whereas they would like to protect their dying relatives from too much bad news, they did not feel this was appropriate for themselves. However, they were generally unwilling to consider planning for situations where they would be unable to make decisions, at least not until the final days before their expected demise: *You would not want to make a decision like that 40 years before you died; it would be good to have the option but only when you are diagnosed with a terminal illness.*

Discussion

The primary purpose of this study was to explore the public perception and understanding of certain issues in relation to death and dying in Ireland with a view to designing a questionnaire for a national survey. Because of the qualitative nature of the study, and the use of just two focus groups, the findings cannot be considered representative of public opinion as a whole, nor are they comprehensive or conclusive. On the other hand, the results of the conversations in the two focus groups offer insight into the experiences, perceptions and concerns of some Irish people and they lend support to the findings of existing national and international studies of peoples' experiences of death and dying in healthcare settings.

Previous studies in the UK¹¹ and Ireland¹² indicate that there is little discussion in general about death and dying. What is clear from our study is, not so much the level of discussion that occurs, but rather, the context in which such discussion occurs. For the study's participants, death discussions were unlikely to occur in the supermarket queue or at the water cooler. Rather they were reserved for very particular places and times. It is somewhat paradoxical that the participants indicated that they tended to avoid discussing death with older/ill adults – whilst at the same time acknowledging that it is the old and the ill who can speak most fluently about death. The avoidance of talk related to death with those who are actually dying is a recurring theme in Irish death-related literature.

A study conducted with relatives of those who had been terminally ill at St James' Hospital in Dublin found that, in very few instances, relatives or those who were actually dying, discussed death.¹³ However, avoidance of death related discussions is not peculiar to the general public. O'Shea *et al*¹⁴ demonstrated how health care professionals, who are charged with caring for the dying, may also avoid the topic of death. Of this phenomenon Elias notes; *There is a peculiar embarrassment felt by the living in the presence of dying people. They often do not know what to say. The range of words available for use in this situation is relatively narrow. Feelings of embarrassment hold words back. For the dying this can be a bitter experience. While still alive, they are already deserted*¹⁵(p.23)

Of those participants who did speak specifically about their own deaths, it was mostly in order to indicate practicalities, such as funeral preferences. This is in keeping with previous Irish research on the topic, where almost 50% of research participants had indicated whether they wanted to be buried or cremated. ¹⁶

In spite of the fact that all of the focus group participants had experienced the hospitalization for serious illness and/or death of a loved one, they were not familiar with end-of-life treatment and care terminology and they did not have a clear understanding of the clinical treatment and care processes that are provided to patients in the dying stages. Another study too confirms that there is a good deal of confusion in this area.¹⁷ Of particular significance in our study is that some participants tended 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, and, at least one participant seemed to view suffering as having a redemptive quality that might be lost if the patient were wholly pain-free. It is not surprising that the general public should be somewhat confused in relation to the role of ANH given the current tension between the positions of the Irish courts and the health professional bodies in relation to it.^{18.19}

In 1995, the Irish Supreme Court made a judgement that ANH was a form of medical treatment that could, legally, be withdrawn from a patient who was in a persistent vegetative state because it was considered to be ineffective and burdensome to her.²⁰ Responding to the court decision,

the Irish Medical Council stated that 'Access to nutrition and hydration remain one of the basic needs of human beings, and all reasonable and practical efforts should be made to maintain both'²¹(p.34). The Irish Nursing Board subsequently adopted the position of the Irish Medical Council. Such confusion, as well as the seeming lack of understanding, of what actually happens in the management of pain and suffering in end-of-life care, lends weight to the need for a wider public engagement and debate on these issues.

Whilst consensus on the key elements of a 'good death' is not settled, some similarities are emerging in studies which elicit public perceptions of a 'good death'. The findings in this study, for example, are consistent with those of Steinhauser *et al*²² who found that some of the overarching themes concerning a good death were pain/symptom control ('to pass on without suffering'), adequate decision making ('to make plans and to talk to your family'), adequate preparation for death ('he had enough and he simply turned off his clock') and a sense of completion ('your children all grown up according to the natural cycle').

Finally, while many English speaking countries around the world accept the notion of patient autonomy as a cornerstone of healthcare ethics, when it comes to choices in medical care and end-of-life decisions, our study indicates that Irish people place considerable trust in health professionals in relation to informing patients that they are dying and decision-making on behalf of incompetent patients. The rationale as to why many of the study participants seemed happy to rely on the authority of clinicians in a number of circumstances is uncertain. It may be related to their general reluctance to talk about death and dying, or, their lack of knowledge and understanding of the clinical management of dying patients, or, their religious beliefs and a traditional trust in the medical profession to 'do the right thing'. On a positive note, it may also indicate that health professionals working in this country have earned the trust that is invested in them.

What is certain is that if the notion of the 'expert patient' who develops their own care plan and looks after their own condition as envisaged in the HSE Strategic Plan, mentioned at the outset, is to be realized; educational 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. Moreover, further research into the relationship between patients and professionals and the role that the notion of patient autonomy might have, specifically in an Irish context, needs to be undertaken to ensure that the policies that are put in place genuinely address the needs of the patients, families and professionals they are meant to support and serve.

Dr. Joan McCarthy has a PhD in philosophy and lectures in healthcare ethics in the School of Nursing and Midwifery, University College Cork. She has published widely in the area of healthcare and nursing ethics and her recent publications include, *Nursing Ethics: Irish Cases and Concerns (2005)* and *Dennett and Ricoeur on the Narrative Self (2007)*. She is the lead investigator of the research project, *Ethical Framework for Endof-Life Care*, an educational resource funded by the Irish Hospice Foundation, which is intended to improve the culture of care and organization regarding dying, death and bereavement in Irish hospitals.

John A. Weafer is an independent social researcher with more than 27 years experience in conducting research. During this time, he has carried out a number of research studies on dying and patients' experiences of cancer, as well as disability advocacy and homelessness. He is currently commencing an ethnographic study of the lived experience of Irish diocesan priests. In addition to directorships in Irish Marketing Surveys and AGB Adelaide, he was director of the Irish Episcopal Conference's research unit in Maynooth College, where he still teaches research and community studies on a part-time basis.

Mark Loughrey is a registered general nurse. His speciality area is intensive and critical care nursing. Since completing a Masters Degree in Nursing at University College Cork he has been employed in post-graduate research on various projects including the Hospice Friendly Hospital Project. He is currently working as a research nurse on various studies concerning nutrition and health in the Department of Epidemiology and Public Health at University College Cork. Dr. Dolores Dooley retired from the Philosophy Department in University College Cork in 2005. She is a part-time lecturer at the Royal College of Surgeons in Ireland for the MSc in Healthcare Ethics and Law and she is Chairperson of the Irish Council for Bioethics. She is an author of ethics modules for the *Ethical Framework for End-of-Life Care*, for the Irish Hospice Foundation. Her publications include a study of the 19th century Irish Philosopher, William Thompson, *Equality in Community* (1996); *Ethics of New Reproductive Technologies* (2003); and Nursing Ethics: Irish Cases and Concerns (2005).

Notes

- ¹ Health Service Executive (2008), *National strategy for service user involvement in the Irish health service 2008-2013*, Department of Health and Children, Dublin.
- ² Cosgrave, T. (2008), "O'Faoláin opens new debate", *Irish Medical Times,* available at: http://www.imt.ie/opinion/2008/04/ofaolain_opens_new_debate.html, (accessed 1 November 2009).
- 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.
- ⁴ UK General Medical Council (2009), End of Life Treatment and Care: Good Practice in Decision-Making – a Draft for Consultation, available at: http://www.gmc-uk.org/CONSULTATION_DRAFT_ GUIDANCE.pdf_ snapshot.pdf, (accessed 1 November 2009).
- ⁵ Cassel, C.K., Foley, K.M. (1999), Principles for Care of Patients at the End of Life: An Emerging Consensus among the Specialties of Medicine, Milbank Memorial Fund, New York.
- ⁶ National Consensus Project for Quality Palliative Care (2009), *Clinical practice guidelines for quality palliative care, 2nd edition*, National Consensus Project for Quality Palliative Care, Pittsburgh, PA., available at: http://www.nationalconsensusproject.org/guideline.pdf (accessed 1 November 2009).
- ⁷ College and Association of Registered Nurses of Alberta (2005), *Position statement on hospice palliative care,* CARNA, Edmonton: available at: http://www.nurses.ab.ca/Carna-Admin/Uploads/Hospice%20 Palliative%20Care.pdf (accessed 1st November 2009).

- ⁸ German National Ethics Council (2006), *Self determination and care at the end of life*, Nationaler Ethikrat, Berlin.
- ⁹ Doyle, E. (2008), *A National Conversation about Death*, unpublished Thesis, University of Edinburgh.
- ¹⁰ Weafer, J, McCarthy, J & Loughrey, M (2009), A nationwide survey of public attitudes and experiences regarding death and dying, Irish Hospice Foundation, Dublin.
- ¹¹ Wallace, J (2003), Public awareness of palliative care: Report of the findings of the first national survey in Scotland into public knowledge and understanding of palliative care, Scottish Partnership for Palliative Care, Edinburgh.
- ¹² 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.
- ¹³ Keegan, O, McGee, H, Brady, T et al. (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 St. James's Hospital, Dublin, from their relatives' perspective, Health Services Research Centre, Irish Hospice Foundation and Palliative Care Service, St. James's Hospital, Dublin.
- ¹⁴ O'Shea, E, Murphy, K, Larkin, P *et al* (2008), *End of life care for older people in acute and long stay care settings in Ireland*, Hospice Friendly Hospitals Programme/National Council on Ageing and Older People, Dublin.
- ¹⁵ Elias, N. (1985), *The Loneliness of the Dying*, Basil Blackwell Ltd., Oxford.
- ¹⁶ Weafer, Research Associates and TNS/MRBI (2004), op. cit.
- ¹⁷ Weafer, J, McCarthy, J & Loughrey, M (2009), op. cit.
- ¹⁸ Dooley, D., McCarthy, J. (2005), *Nursing Ethics, Irish Cases and Concerns*, chapter 13, Gill and Macmillan, Dublin.
- ¹⁹ Madden, D. (2002) *Medicine, Ethics and the Law,* Butterworths, Dublin.
- ²⁰ *Re a Ward of Court,* [1996] 2 IR 79.
- ²¹ A Guide to Ethical Conduct and Behaviour Sixth Ed (2004), Medical Council, Dublin.
- ²² Steinhauser, KE, Clipp, EC, McNeilly, M *et al* (2000), "In search of a good death: Observations of patients, families, and providers", Annals of Internal Medicine, 132, 825-832.

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Politics in Ireland: Convergence and Divergence in a Two-Polity Island, by Maura Adshead and Jonathan Tonge; Basingstoke: Palgrave Macmillan, 2009; pp.273; (Comparative Government and Politics)

At a time when the importance of politics, in directly affecting the lives of individuals throughout the world, becomes ever more obvious, any attempt to deepen our understanding of political processes, especially those that produced the (now so-called) Celtic Tiger in the Republic and the (so-called) Peace Process in Northern Ireland is welcomed.

The decision to provide a book which brings together Northern Ireland and the Republic in one place appears, on the face of it, a sensible one. The two polities share an island and a history. And they are both moving to what might internationally be recognised as normal politics – the Republic is rejecting the clerical dominance of many aspects of society, and, perhaps, moving towards a more normal, ideologically-based, party system. Meanwhile, Northern Ireland, though still suffering from an institutionally reinforced sectarian party politics, now has a degree of selfgovernment that allows some room for debate on policy issues not related to its constitutional position. But the two places are also so different that one wonders what advantage is gained by comparing them.

The political systems are so different that not much can be learnt by comparing the two. One has normal parliamentary government; the other is a strange hybrid of federalism, consociationalism and, in some areas of government, dictatorship (direct rule). They hardly share a culture (political or otherwise), despite both places being influenced by Westminster politics and British popular culture. Economically, where one was backward, the other was progressive. This was then reversed – though there has been some convergence. The Republic has (now limited) control over economic policy; whereas the North has virtually none. Even the nationalism of the North was different to that of the South. Where Sinn Féin triumphed in