

**A Qualitative Study of Public Perceptions of
End-of-Life Issues**

By

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Chapter One

Introduction and Background

1.1 Introduction

This report presents the main findings from a qualitative research project undertaken on behalf of the Irish Hospice Foundation, in conjunction with the School of Nursing and Midwifery and the Department of Law, University College Cork (UCC), and the School of Nursing and the Department of General Practice in the Royal College of Surgeons in Ireland (RCSI). The present research is part of a larger study into the development of an *Ethical Framework for End-of-Life Care* and its primary purpose was to explore what Irish people think about diverse end of life issues, including what they understand as autonomy in the context of care. More specifically, the research focused on the following issues:

Part I: General Attitudes to End of Life Issues

- General attitudes to death and dying.
- What comes to mind when people think of a ‘good death’.
- What factors they feel might contribute to a person having a good or a bad death.
- What concerns or fears, if any, they have regarding end of life for themselves and others.

Part II: Patient Autonomy

- If they feel people can have choices about how they die and what measures should be put in place to protect and promote patient choice in this regard.
- What types of things can be controlled for and who should have the ultimate decision-making role.
- Their views and understanding of DNR, Advanced Care Directives, Euthanasia etc.

Part III: Experiences and Perceptions of Death

- Their views and experiences of people dying in Irish hospitals.
- If they think that their loved ones endured any kind of pain or suffering that could have been avoided or better controlled.
- If they believe the expressed needs, wishes and preferences of people dying in Irish hospitals are respected.
- What type of care and choices they would wish for themselves if they were dying from a terminal illness.

A comprehensive topic guide was designed in consultation with UCC, RCSI and the Irish Hospice Foundation, a copy of which is appended to this report. In particular, the topic guide was informed by an early draft of the national survey questionnaire compiled by the School of Nursing and Midwifery (UCC). In addition to these substantive issues, the research also sought to test the format of some questions that were subsequently used in a national survey of Irish adults.

1.2 Research Approach

The present report is based on the findings from two focus groups¹, the participants of which shared the following characteristics:

- Everyone had someone close to them who had died after an illness in an Irish hospital in the past 5 years or so.
- No one had a terminal illness or was currently undergoing treatment for any life-threatening illness.
- No one worked with terminally people or in any hospital, hospice, or nursing home.

Dublin	Sligo
30-45 years	50-70 years
Mixed gender	Mixed gender
Middle class (BC1C2)	Working class/ farmer (C2DEF)

The groups were held on Monday 25th and Wednesday 27th June 2007 in Dublin and Sligo, respectively.

¹ As is the case with most qualitative research, and particularly with the present study of only two focus groups, its primary purpose is to explore and understand issues rather than to produce any statistically representative measurement.

Chapter Two

General Attitudes to End of Life Issues

2.1 General End of Life Issues

Although most of the respondents had spoken of death at some stage, it is clear that 'end of life' is not a water-cooler or after-dinner moment. Most people felt that there are appropriate times for discussing death, such as when a close family member or friend dies, but that it would be almost tempting fate to discuss it too lightly or out of context. Equally, the circumstances have 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. The older you are, the more likely you are to discuss different aspects of death and to attend funerals but even then, it depends on the person concerned.

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. Others said that some close friends had not spoken to them following bereavement because they didn't seem to know what to say. Apart from the rare occasions when a person had discussed their final days, the most people spoke about death was whether they like to be cremated or buried; 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 respondents.

Some verbatim quotes illustrate the range of opinions expressed by the group participants:

'I don't think it (death) is a topic that is discussed much – it is too morbid'.

'If someone has a bereavement in the family, they do talk about it'.

'You know what is going to happen to you but you don't want to talk about it'.

'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'.

'When one of your relatives dies, it brings it closer to home. Irish people and especially men are not good saying how they feel about it'.

'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'.

'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'.

'People who are dying have come to terms with death and can speak of death in ways that others can't'.

'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'.

2.2 Features of a 'Good' Death

The principal features of a 'good death' were perceived to include the following:

- Fast and peaceful/ To die in your sleep (although this may be more painful for your family).
- To have your family with you when you die.
- To have control over the time and circumstances of your death.
- Cared for at home, with adequate medical support.
- No pain or suffering involved.
- To die with dignity and all that entails.
- Your children to be reared and independent.
- When you are old; in accordance with the natural life-cycle.
- With enough time to get your affairs in order.
- Emotional reassurance for the dying person.
- To stay alive as long as possible.
- To have time to do what you always wanted to do.
- With a pint of Guinness in one hand and a model (female) in the other!

'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 allow the person to pass on without suffering'.

'Time to make plans and to talk to your family'.

'Quick and peaceful – not a slow illness... give yourself a day to die'.

'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'.

2.3 Personal Fears and Concerns

While few of those in attendance admitted to having seriously considered their 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 put into the ground.

'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 respondents was that they would lose their dignity and control as a result of Alzheimer's or other debilitating illness, such as a stroke. Others felt that a lingering illness would impose an unnecessary burden on their families.

Another fear that emerged during the discussion on decision-making was that the wrong decision would be made to end life and that people should not be placed in a position where they would have to make that decision alone or in conflict with other family members.

Chapter Three

Patient Autonomy

3.1 Patient Autonomy

The discussion on patient autonomy 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 of group participants were confused regarding the implications and procedures associated with a ‘*Do Not Resuscitate*’ order or the meaning of *Advanced Care Directives*. It also led to some unease and questioning about any decision-making that might end life prematurely. While ‘extra’ morphine administered by a medical person, with the implicit support of family members, was generally regarded as acceptable, 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’.

‘Definitely morphine – let them go out happy’.

‘Does morphine give you a dignified death? What is a dignified death?’

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) know more than they do about the dying process. The 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.

‘It is very difficult making decisions. You try to make the right decisions but’.

'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 can't 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 and without their being asked to make a formal 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 ...'.

'You would be nervous making medical decisions. The medical profession would prolong life as long as they could and administer the proper treatment. I would be nervous that I might be doing the wrong thing. I don't know what they know'.

Conversely, others would be prepared to follow the instructions of their loved ones or to make a decision that would lessen pain, even if it lead 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?'

'If people are very sick, maybe put something into their medication to speed them on. Die today instead of next week but with no pain'.

'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'.

'My mother is 99 and if she asked for DNR, there is no way I would allow doctors to resuscitate her, even for medical reasons. That's her wish and let her go gracefully'.

'The doctor might want the bed and switch you off too soon!'

Some disagreement also 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. Some respondents 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. However, when it came to themselves, most respondents 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'.

'If a person doesn't ask...?'

'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'.

'I think you would know yourself, without being told'.

'It would kill my mother if she knew she was going to die'.

'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'.

3.2 Advanced Care Directives

No one had heard of Advanced Care Directives but when explained, the discussion generally reflected the overall tone of the focus groups i.e., don't interfere with death unless you have to. While they sound like a good idea for some people, what if something goes wrong and you change your mind? Taking everything into account, it is probably 'safer' to trust in your own ability to make decisions or to rely on your loved ones to make decisions on your behalf. Younger respondents were most reluctant to consider Advanced Care Directives or a Living Will.

'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'.

'What happens if you change your mind and you can't communicate that and you see the big needle coming at you....!'

'It takes away the personal touch. Better to talk it over with your family and not shut them out'.

'I am unsure about a Living Will. Better to let what happens, happen'.

'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'.

'You just don't know what is going to happen. You might get another 6 months! Obviously, you would have to place your trust in your husband and family but I believe in destiny – what's going to happen will happen and we have no control over it'.

'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'.

3.3 Religious Beliefs

The importance of religious beliefs was mentioned by a number of respondents, with most people believing that belief in the afterlife helps people to die, although this belief is less strong among younger people. 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. 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’.

‘We might think she is in horrendous pain but maybe not; maybe she had inner peace when she died’

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.

Chapter Four

Experiences and Perceptions of Death

4.1 Introduction

Not surprisingly, the respondents have had different 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 to be terrible by some and excellent by others. Everyone spoke emotively of the death of a loved one. Regardless of when the death of a loved one took place, they recalled the circumstances with strong feeling. On the basis of their experiences, they suggested that end of life could be improved by:

- A private space for terminally ill people and their families.
- An appropriate space that creates the right mood, with soft lights.
- 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’.
- A spokesperson within each hospital with a responsibility to liaise with patients and their families.
- 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.
- 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 has to be a room. Hospitals would stick you anywhere, in a little cubbyhole’.

‘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'.

4.2 What Type of Care They Would Like?

Not surprisingly perhaps, when asked what type of care and choices they would wish for themselves if they were dying from a terminal illness, the respondents 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 respondents 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.'

Key Findings

1. There is a time and context for discussing death and it is clearly not a 'water cooler' moment. Most people would discuss death following the death of someone they know but not on a social or casual basis.

2. Everyone could recall some occasion when the death of a loved one had affected their lives and their views of death. In some cases, their views were shaped in childhood and had persisted into adulthood. In other cases, respondents were most affected by the death of a parent.

3. When asked what they would regard as a 'good death', the following features were highlighted:
 - Fast and peaceful/ To die in your sleep.
 - To have your family with you when you die.
 - To have control over the time and circumstances of your death.
 - Cared for at home, with adequate medical support.
 - No pain or suffering involved.
 - To die with dignity and all that entails.
 - Your children to be reared and independent.
 - When you are old; in accordance with the natural life-cycle.
 - With enough time to get your affairs in order.
 - Emotional reassurance for the dying person.
 - To stay alive as long as possible.
 - To have time to do what you always wanted to do.
 - With a pint of Guinness in one hand and a model in the other!

4. Most people are reluctant to interfere with, or speed up, the dying process. Some reasons for this reluctance include:
 - An overriding desire to do the best they can for the dying person.
 - Life is precious and 'you never know'.
 - The fear of making a mistake.
 - A reluctance to take responsibility for anyone's death.
 - Religious beliefs.
 - Traditional trust in the medical profession to 'do the right thing'.

5. Attitudes towards the development of a standardised protocol were somewhat ambivalent due to a number of factors:

- The present system works well enough.
- Protocols may diminish patient or family choice and make the decision-making less personal.
- Trust in the medical profession.
- Possibly lead to less care due to litigation and accountability.
- Too many rules and regulations already.
- Suggestion of euthanasia.

6. Most respondents have a very low level of understanding of key care concepts, such as DNR and Advanced Care Directives. Giving a dying patient 'extra' morphine is the most acceptable form of 'assistance' and ideally, this should be done by medical staff without burdening family members.

7. In general, respondents would like more control over their own deaths than for their loved ones. This is largely due to a perceived need to protect the sick person from unwanted stress. However, although they would like to have more control over their final days, few would be willing to formalise their instructions too far in advance.

8. When asked what type of care and choices they would wish for themselves if they were dying from a terminal illness, the respondents emphasised many of the same features they had associated with a good death: an appropriate private space, free from pain; comfortable; to die with dignity; and to be surrounded by family. Above all else, if they had to die in hospital, they would like an appropriate private space to be made available for themselves and their families, regardless of whether they are conscious or unconscious.