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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Exploring Death and Dying:
the views of the Irish public

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Joan McCarthy

Mark Loughrey

Chapter One

Introduction and Background

1. Introduction

This report presents the findings of a research project undertaken on behalf of the Irish Hospice Foundation. Fieldwork for the research was conducted by MRBI, with all other aspects of the project managed by *Weafer and Associates Research & Consultancy Ltd*, in conjunction with the School of Nursing and Midwifery and the Faculty of Law, University College Cork (UCC), and the Faculty of Nursing and Midwifery, 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 is to explore what Irish people think about diverse end-of-life issues, including what they understand as autonomy in the context of care.

In essence, the Irish Hospice Foundation proposes to develop a framework of standards regarding dying, death and bereavement in acute and community hospitals and to provide resources to develop the capacity of hospitals to introduce these standards. The overall aim of the programme is to change the culture of care and organisation around dying, death and bereavement in Irish hospitals over the next five years. One of the key themes of the Irish Hospice Foundation's *Hospital Friendly Programme* is 'Patient Autonomy', which is concerned with ensuring a focus on issues of concern to a patient with the belief that a 'good death' in hospital is possible, and that an ethical framework is required to assist hospital staff in trying to take the needs and wishes of the dying person into account.

Issues Included in the Research

The specific issues addressed in the present research are detailed below and a copy of the questionnaire used in the survey is appended.

- Awareness of diverse 'end of life' terminology i.e., Advance Directive, Palliative Sedation, Post-Mortem, Physician assisted suicide, cardiopulmonary resuscitation, artificial hydration, Do Not Resuscitate Order, persistent vegetative state, living will, and euthanasia.

- How people with a terminal illness would like to be given information about their condition.

- Who Irish adults believe has the authority to make decisions about starting or stopping treatment if a person were in a coma or in the final stages of a terminal illness.

- Who Irish adults would like to have the authority to make a decision about starting or stopping treatment such as life support if they themselves were in a coma, and in the final stages of a terminal illness, and had not expressed any wishes as to how they would like to be treated.

- The percentage of people who have told anyone how they would like to be treated if they were terminally ill, either in person or written down in a living will.

- The attitudes of Irish adults to a number of statements related to death and dying.

- What concerns people have in relation to their own death and dying and the extent to which their general life experience, their religion, their education, their family, friends or colleagues, and television, newspapers, or the Internet has influenced these concerns.

2. Research Methodology

The questionnaire was designed by Dr. Joan McCarthy and Mr. Mark Loughrey of the School of Nursing and Midwifery, University College Cork (UCC), with the assistance of Mr. Mervyn Taylor and Ms. Orla Keegan of the Irish Hospice Foundation, and an advisory consortium of experts: Dr. Dolores Dooley and Dr. David Smith, Department of General Practice in the Royal College of Surgeons in Ireland (RCSI), Ms. Catherine O'Neill and Dr. Christina Quinlan, Faculty of Nursing and Midwifery, RCSI, and Dr. Mary Donnelly and Dr. Deirdre Madden, Faculty of Law, UCC. PCI Counselling Service, an initiative of PCI College, agreed to provide counselling or psychological support for any interviewees who requested support.

The questionnaire design phase was also informed by an extensive literature review[1] and qualitative research commissioned specifically for this project.[2] For comparative purposes, some questions were taken directly from similar surveys conducted in the UK and these will be referenced in the text.

[1] The main sources consulted in the course of the review that had a direct impact on questionnaire design included: Catt et al (2005a and b), Clancy et al. (2004), Drought et al. (2002), The Irish Council for Bioethics (2005 and 2007), Keating et al. (2005), McNamee and O'Keefe (2004), Oberle and Hughes (2001), O'Brien et al. (2001), O'Keefe (2001), O'Shea and McGee (2002), the SUPPORT Principal Investigators (1995), and Weafer Research Associates (2004 and 2007).

[2] Weafer Research Associates (2009) 'A Qualitative Study of Public Perceptions of End-of-life Issues'. Dublin: The Irish Hospice Foundation.

The Sampling Process

The research was conducted as part of the MRBI telephone Omnibus service, *Phonebus*, during September 2007[3]. A sample of 1,046 persons living in the Republic of Ireland[4] was initially contacted. For the purposes of this survey, only persons over the age of 18 years were subsequently asked to participate in the research, resulting in a valid sample of 967 persons. This number was further reduced to 667 adults when the content of the survey was disclosed to respondents (see overleaf).

Respondents were selected for interview through random digit dialling (RDD). This method of respondent selection ensures that ex-directory households are as likely to be selected for interview as listed households. In order to ensure the sample reflects the profile of the national population 15+ years in the Republic of Ireland, quota controls were imposed for region, by age within sex and social class within sex. Where any discrepancies occurred in the sample, the data was weighted to ensure the final sample was representative of the Irish adult population.

The sample was first stratified by a total of 15 broad regions, encompassing five different community types (cities; towns 10,000+; towns 5,000 – 10,000; towns 1,500 – 5,000; and rural <1,500) within the four standard areas of Dublin, Rest of Leinster, Munster and Connaught/Ulster. This ensured a representative territorial spread of the sample. Within each cell of the resulting matrix (region by community type), the appropriate number of primary sampling units (District Electoral Divisions – DEDs) were chosen using probability sampling procedures i.e., probability to size of population.

[3] Each Omnibus survey contains a number of sections on different topics.
[4] References to Ulster include areas within the Republic of Ireland only - Counties Donegal, Cavan and Monaghan.

The second stage of the sampling procedure involved the systematic sampling of individuals within each of the pre-selected DEDs. At each DED, the interviewer adhered to a quota control matrix based upon the known profile of Irish adults in each region in terms of age, within gender, and socio-economic profile. The quotas for age and sex were derived from the most recent CSO data.

It is generally accepted that a quota sample of 1,000 respondents allows for a margin of error between 2% and 3% at the 95% confidence interval. So, for example, reported percentage frequencies of 10% or 90% have a +/- 2% range, while percentage frequencies of 50% to 70% have a range of +/-3%. Determining the statistical significance of any relationship is therefore only possible on a question-by-question basis.

Interviewing was conducted using CATI (Computer Aided Telephone Interviewing) technology from 18th to the 27th September 2007.

3. Additional Measures to Protect Respondents' Right to Choose

Given the sensitivities surrounding the topic of death, a number of special measures were agreed in advance to protect the rights of respondents and the integrity of the research. Firstly, ethical approval was sought from the Clinical Research Ethics Committee of the Cork Teaching Hospitals[5]. Full approval was subsequently granted, subject to a number of amendments to the introduction of the survey and the provision of details of a professional counselling service, should respondents feel distressed by the questions.

[5] The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised to carry out the ethical review of clinical trials of investigational medicinal products.

Secondly, as already stated, all respondents were 18 years of age or over. Thirdly, the introduction to the survey specifically warned participants at the outset that the questionnaire may be distressing for anyone who may have been recently bereaved, suffering a potentially terminal illness, or related to or close to someone suffering from such an illness (See text overleaf). It was also made clear to participants that they had the right not to participate.

Fourthly, details of a counselling service, PCI Counselling, were given to anyone who felt in any way distressed by the questions. PCI Counselling Service, an initiative of PCI College, agreed to provide counselling or psychological support for any interviewees who requested support. In the event, five per cent of participants found the questions distressing. However, no one contacted the counselling service during the study period.

These special measures are summarised in the chart overleaf.

Steps Taken To Protect Respondents' Right To Choose

1. Ethical approval for survey from the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

2. All adults 18+ years.

3. Comprehensive Introduction to Survey.

> 'This survey is being undertaken on behalf of the Irish Hospice Foundation. Its primary purpose is to identify the concerns of the Irish public in relation to dying, death and bereavement. Please note that the survey may be distressing for anyone who may be recently bereaved, suffering a potentially distressing illness or related to, or close to someone suffering such an illness. You can be assured that everything you say will be treated with the strictest confidence and that your responses will be recorded anonymously. You have the right not to answer any individual question or, if you wish, not to participate in the survey at all. Finally, details of a professional counselling service will be given to you at the conclusion of the survey in case you wish to speak to anyone about the issues raised in the survey'.
>
> 'Are you happy to answer questions on this topic?'

4. PCI Counselling Service, an initiative of PCI College, agreed to provide counselling or psychological support for any interviewees who requested support.

4. Profile of Participants and Non-Participants

Approximately one third of the original sample contacted either did not qualify due to age restrictions[6] or decided that the topic was unsuitable for some reason. Participants were not asked to explain their reason(s) for not wanting to participate in the survey. However, it is important to note that their refusal was more than just a lack of time or unwillingness to participate in the survey, as all of them went on to answer other sections of the Omnibus survey.

The profile information in Table 1 overleaf indicates that the youngest and oldest age groups, members of the farming community, students and retired were most likely to refuse to participate in the research. Thus, for example, approximately four in ten (39%) of the youngest age group chose not to participate, compared with one quarter of those aged 34-54 years. To compensate for this under-representation of some groups and over-representation of others, the results were statistically weighted to ensure they represented the profile of Irish adults.

[6] Seventy-nine of the original sample were less than 18 years of age and were automatically eliminated from the research.

Table 1 Profile of Non-Participants 18+ years

	Total Number 18+ years	Number of Non Participants	Non Participants as % of Total
Total	967	285*	29
AGE			
18-24 years	119	46	39
25-34 years	215	58	27
34-44 years	188	48	25
45–55 years	171	41	24
55-64 years	132	40	30
65+ years	142	52	37
SEX			
Male	488	144	30
Female	479	141	29
REGION			
Dublin	260	67	26
Rest of Leinster	230	65	28
Munster	261	86	33
Connaught/ Ulster	215	67	31
SOCIAL CLASS			
AB	148	27	18
C1	286	79	28
C2	218	67	31
DE	240	80	33
F	75	32	43
EMPLOYMENT STATUS			
Working	621	164	26
Student	58	25	43
Housewife	74	20	27
Retired	171	61	36
Unemployed	42	14	33

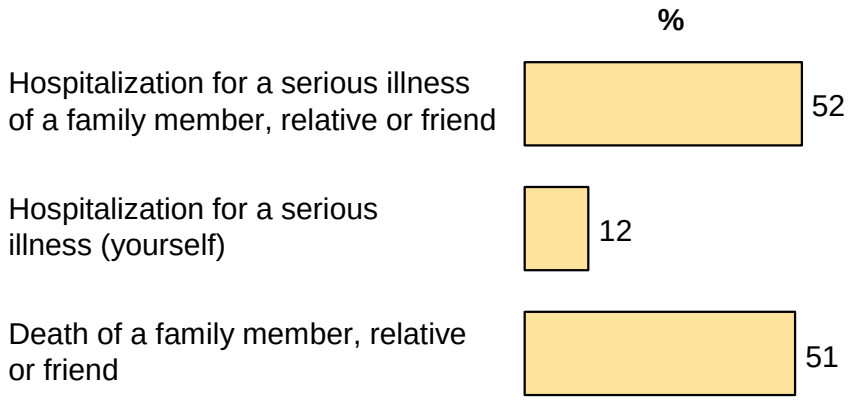
* Information was not available on 15 non-participants.

5. Experience of Hospitalisation and Bereavement

Just over one half (52%) of those who participated in the survey had experienced the hospitalisation for a serious illness of a family member, relative or friend in the last three years, with a similar proportion (51%) having experienced the death of a family member, relative or friend during the same time period. Just over one in ten (12%) participants had been hospitalised themselves for a serious illness in the last three years.

Experience of Hospital and Bereavement in Past Three Years

(Base: All Respondents, N = 667)



Q. Please indicate if you have encountered any of the following three experiences in the last three years or so.

6. Telephone Interviewing

Finally, a note on the use of telephone survey methodology as an appropriate means of interviewing the general public on sensitive topics, such as death and sexual abuse. In the past, such topics were either avoided completely or conducted using face-to-face methods. However, in recent years, telephone survey methodology has been used in a number of important surveys on sensitive topics. Two Irish studies by the Royal College of Surgeons, for instance, used this methodology quite effectively in their surveys of sexual abuse and violence in Ireland[7]. Similarly, a study entitled, *'Priorities and Preferences for end-of-life care in England, Wales and Scotland'* by Professor Irene J. Higginson (2002) of the Department of Palliative Care and Policy, King's College London is based on a national telephone survey. The Irish Hospice Foundation 2004 survey, '*A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying'* also used this methodology[8].

Apart from the enhanced access this method brings to survey research, due to the high penetration of telephones in Ireland, it is also recommended for the anonymity it affords respondents in answering relatively sensitive questions. The specific use of an Omnibus survey also facilitated the development of rapport between the interviewer and the respondent prior to asking the more sensitive end-of-life questions. The questions on Death and Dying comprised the final section of the Omnibus survey.

[7] McGee, H., Garavan, R., de Barra, M., Byrne, J, and Conroy, R. 2002 *Sexual Abuse and Violence in Ireland:* A National Study of Irish Experiences, Beliefs and Attitudes Concerning Sexual Violence (The SAVI Report). Dublin: Rape Crisis Centre.
Goode, H., McGee, H., and O'Boyle, C. 2003. *Time to Listen:* Confronting Child Sexual Abuse by Catholic Clergy in Ireland. Dublin: The Liffey Press.
[8] Weafer Research Associates/ MRBI (2004) '*A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying'*. Dublin: The Irish Hospice Foundation.

7. Structure of the Report

Following this introduction, the findings from the national survey are presented in Chapter Two. The appendices contain information on the questionnaire, charts, and more detailed tabular results. Whilst a separate qualitative study commissioned by the Irish Hospice Foundation to inform the present national survey will be referenced in the present report to add substance to the statistical data derived from the national survey, it is important to note that the present national survey stands alone as a unique and distinctive study. It is envisaged that Dr. Joan McCarthy and Mr. Mark Loughrey, of the School of Nursing and Midwifery, University College Cork, will publish more detailed analysis of the survey findings at a later date. Accordingly, the level of commentary in the present report is primarily descriptive.

Chapter Two

Research Findings

2.1 Deaths and Births in the Republic of Ireland

Since the turn of the century statistics collected by the Central Statistics Office indicate that approximately 30,000 people die each year in the Republic of Ireland. However, the CSO data below indicates that the number of deaths in Ireland is decreasing while the number of births is increasing (Table 2).

Table 2 Births and Deaths, Republic of Ireland (1950-2006)

Year	Births	Deaths
1950	63,565	37,741
1960	60,735	32,660
1970	64,284	33,686
1980	74,064	33,472
1990	53,044	31,370
2000	54,239	31,115
2001	57,882	29,812
2002	60,521	29,348
2003	61,517	28,823
2004	61,684	28,151
2005	61,042	27,441
2006	64,237	27,479

Source: CSO (www.cso.ie)

2.2 Awareness of Terminology Relating to End-of-Life

A list of 10 terms relating to end-of-life was read out to respondents and they were asked to indicate to what extent, if any, they knew about these terms[9]. As the following Table and Chart illustrate, the stated awareness levels for many of the terms is quite low. This finding is consistent with other studies conducted with the Irish public (Irish Council for Bioethics, 2005; Weafer Research Associates, 2004). The results of the Irish Council for Bioethics 2005 survey, for instance, found the Irish public's knowledge and awareness of various bioethical areas to be quite limited in most instances, with the majority claiming to know 'just a little or nothing' about end-of life issues.

More in-depth probing in the Irish Hospice Foundation's qualitative study (Weafer, J. 2004) also demonstrated a general lack of knowledge or understanding of end-of-life terminology or the different options open to people who are terminally ill. With the exception of euthanasia, most people who participated in this study were confused regarding the implications and procedures associated with terms such as 'Do Not Resuscitate' or 'Advanced Care Directives'.

Whilst the present study did not explore respondents' understanding of, or attitudes towards, these terms, the Irish Hospice Foundation's qualitative study, for instance, suggests that 'extra' morphine administered by a qualified medical person, with the implicit support of family members, was generally acceptable if the terminally ill person was suffering. Conversely, the suggestion of withdrawing feeding or hydration evoked more negative responses. A number of people spontaneously associated

[9] It is important to keep in mind that the level of understanding was not tested, just their stated awareness.

such actions with euthanasia and not something they would favour (Weafer, J. 2007).

The results from the present survey also shed more light on the findings of previous research. The 2004 Irish Hospice Foundation study, 'A *Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying',* for instance, found that only 14 per cent of Irish adults had written up an 'advance directive' or living will. When these terms were separated in the present survey, it is clear that more people are aware of the term 'Living Will' than 'Advance Directive'.

Table 3 Awareness of End-of-life Terminology

TERMINOLOGY	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%

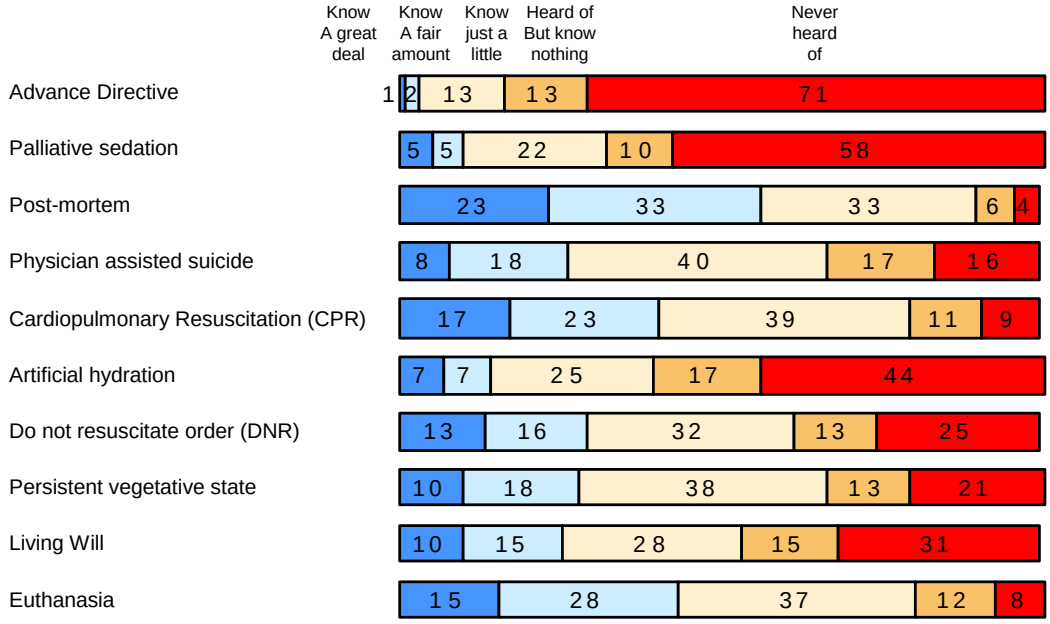
Note: The rows don't always add to 100% due to rounding and the exclusion of the small number of 'Don't Knows'.

Thus, whereas almost nine in ten (89%) of respondents claimed to know something about the term 'Post-mortem', seven in ten (71%) respondents had 'never heard of' the term 'Advance Directive'. Overall, the findings

indicate highest awareness levels for most of the terms are to be found amongst middle class respondents, people less than 65 years of age, females, and those with highest levels of formal education. A detailed analysis of awareness levels for each term by age, sex, province, employment status, and education is contained in Appendix B of this report.

Awareness of Terminology

(Base: All Respondents, N = 667)



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.

Some of the more salient findings for each of the terms are summarised overleaf.

Advance Directive:

Most people had never heard of the term 'Advance Directive', with more than eight in ten (81%) respondents stating they had either 'never heard' or 'Heard of but know nothing' of the term and only 16 per cent stating they knew something[10]. Those most likely to have heard something comprised those aged 34-55 years, female, residents in Connaught/Ulster, working, and belonging to the AB socio-economic group[11]. However, with the exception of social class, the differences are not particularly significant (Table Q2.1).

Palliative Sedation:

Somewhat higher proportions of respondents claimed to know something about Palliative Sedation. Highest awareness was found amongst 55-64 year olds, females, Dublin residents, ABC1 middle class, retired, and those with some Third Level or Professional qualification (Table Q.2.2).

[10] This combines the three categories, 'Know a great deal', 'Know a fair amount', and 'Know just a little'.

[11] Social class is typically measured in terms of eight different socio-economic groups. The defining characteristics of each group are as follows: **A** – professional/ very senior people in business/top level civil servants; **B** – middle management executives in large organisations, with appropriate qualifications. Principal officers in local government and civil servants. Top management or owners of small business concerns, educational and service establishments. **C1** – junior management; owners of small establishments; and all others in non-manual positions. **C2** – All skilled manual workers and those manual workers with responsibility for other people. **D** – All semi-skilled and unskilled manual workers. **E** – All those entirely dependent on the state long term through sickness, unemployment, old age or other reasons. **F1** – farmers with 50+ acres. **F2** – farmers with less than 50 acres and farm labourers. It is standard practice to combine these separate categories into three summary categories when analysing differences between different socio-economic groups as follows: ABC1, C2DE, and F.

Post-Mortem:

Awareness of the term Post-mortem was the highest amongst the ten terms tested, with only four per cent of all respondents stating they had never heard of the term and more than half claiming they 'knew a great deal' or 'a fair amount'. The groups most likely to know a great deal or a fair amount were 18-24 years, living in Connaught/Ulster, ABC1 middle class, students, and with a Third Level or Professional qualification (Table Q2.3).

Physician Assisted Suicide:

Approximately one quarter (26%) of respondents claimed to know 'a great deal' or 'a fair amount' about the term Physician Assisted Suicide. Those most likely to know 'a great deal or a fair amount' about the term were 45-54 years of age, ABC1 middle class, student or working, and with a Third Level or Professional qualification (Table Q.2.4).

Cardiopulmonary Resuscitation (CPR):

Four in ten respondents (40%) claimed to know a 'great deal' or a 'fair amount' about the term cardiopulmonary resuscitation. Above average awareness for this term was found amongst 18-24 year old, Dublin residents, AB professionals, students or working, and with a Third Level or Professional qualification (Table Q.2.5).

Artificial Hydration:

The term Artificial Hydration is not well known amongst the Irish public, with the majority stating they had 'never heard of' or 'heard of but know nothing' about the term. The groups most likely to know something about the term included 45-54 year olds, people living in Leinster or Dublin, middle class, employed, and with a Third Level or Professional degree (Table Q.2.6).

Do Not Resuscitate Order (DNR)

More than six in ten (61%) Irish adults claimed to know something about the term 'Do Not Resuscitate', with a further 13 per cent having heard of it but knowing nothing about it. The groups most likely to know something about DNR were less than 65 years of age, female, living in Leinster or Dublin, middle class, working outside the home, and with a Third Level or Professional qualification (Table Q.2.7).

Persistent Vegetative State

Two thirds (66%) of Irish adults claimed to know something about the term 'Persistent Vegetative State', with a further 13 per cent having heard of it but knowing nothing about it. The groups most likely to know something about this term were 34-54 years of age, living in Leinster or Dublin, middle class, working outside the home, and with a Third Level or Professional qualification (Table Q.2.8).

Living Will

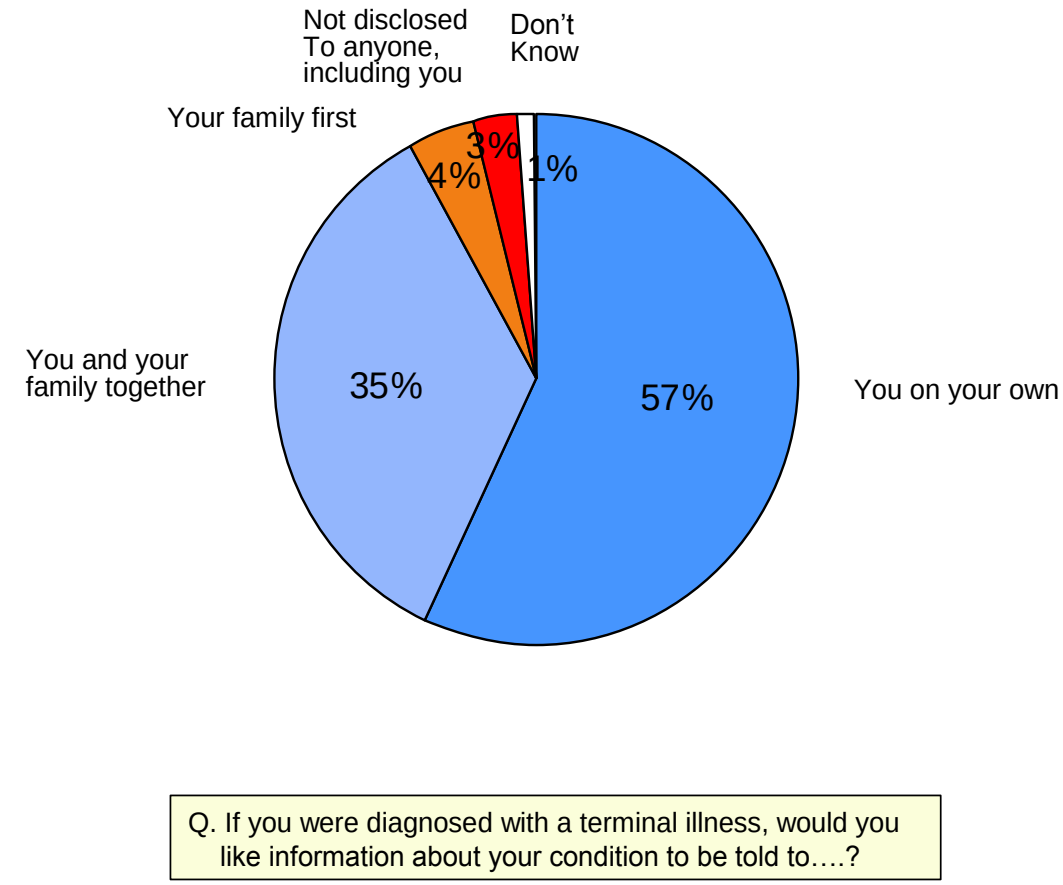
Just over half (53%) of Irish adults claimed to know something about the term 'Living Will', with a further 15 per cent having heard of it but knowing nothing about it. The groups most likely to know something about this term were 34-64 years of age, middle class, working outside the home, and with a Third Level or Professional qualification (Table Q.2.9).

Euthanasia

Eight in ten (80%) Irish adults claimed to know something about the term 'Euthanasia', with a further 12 per cent having heard of it but knowing nothing about it. The groups most likely to know something about this term were 25-64 years of age, living in Connaught/ Ulster, middle class, working outside the home, and with a Third Level or Professional qualification (Table Q.2.10).

2.3 Information on Terminal Illness

Most people would like to know if they were diagnosed with a terminal illness (Keating et al., 2005; Weafer Research Associates, 2007). When asked if they would like to hear the news on their own or with someone present, most respondents (57%) said they would prefer to be told on their own, followed by approximately one third (35%) who would prefer to be told in the presence of their families. Only three per cent would not like the information disclosed to anyone.



Interestingly, just over one in ten (11%) respondents over 65 years of age would prefer if the news was not disclosed to anyone, including themselves. Not surprisingly, given the negative correlation between age and formal education[12], a similar percentage of persons with primary or no formal education also opted for non-disclosure. Those most likely to want to hear the news on their own included males, members of the farming community, and those aged 45-64 years of age. Conversely, 25-34 year olds, females, housewives, and people living in Leinster are most likely to want to hear the news with their family present (Table Q3, Appendix B).

The qualitative phase of the research identified an interesting dilemma with regard to how much information, if any, should be given to people with terminal illness (Weafer 2007). 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…?'*
>
> *'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'.*

[12] Data from the 2002 Census of Population indicates that nearly half of those born in the 1930s left education after primary school, compared with 3 per cent of those born in the 1970s. Nearly one third of the younger generation were educated to third level compared with 12 per cent of the 1930s generation. Persons employed in farming, fishing, forestry, textiles, and building had the lowest formal education levels (www.cso.ie).

2.4 Decision-Making on Terminal Illness

Respondents were presented with two scenarios relating to a person in a coma who was in the final stages of a terminal illness. In the first case, they were asked who they think has the authority to make decisions about starting or stopping treatment, such as a life support machine. In the second instance, they were asked who they would most like to make decisions about starting or stopping treatment, such as life support, if they themselves were in a coma and had not expressed any wishes as to how they would like to be treated. In both scenarios, the family emerged as the preferred decision-maker, either alone or in conjunction with a doctor. This finding is in keeping with other research, such as The Irish Council for Bioethic's survey conducted in 2005, which found that 72% of respondents stated that they would prefer their next of kin to make healthcare decisions[13] on their behalf if they were incapable of doing so, with only 21% preferring to leave such decisions to their doctor (ICB 2005).

Whilst the responses to both questions evoked similar answers, the role of the doctor received somewhat higher mentions in the case of the more anonymous person in a coma, whereas the family was slightly more likely to be mentioned if they themselves were in a coma[14]. In general, younger respondents (18-34 years) and lower middle class respondents would prefer the decision to be made by their families, whereas males and older respondents (55+ years) tended to place more emphasis on the role of the doctor in making the decision (Table Q.4/5, Appendix B). When the views of those over 50 years of age are considered separately, people in their 50s

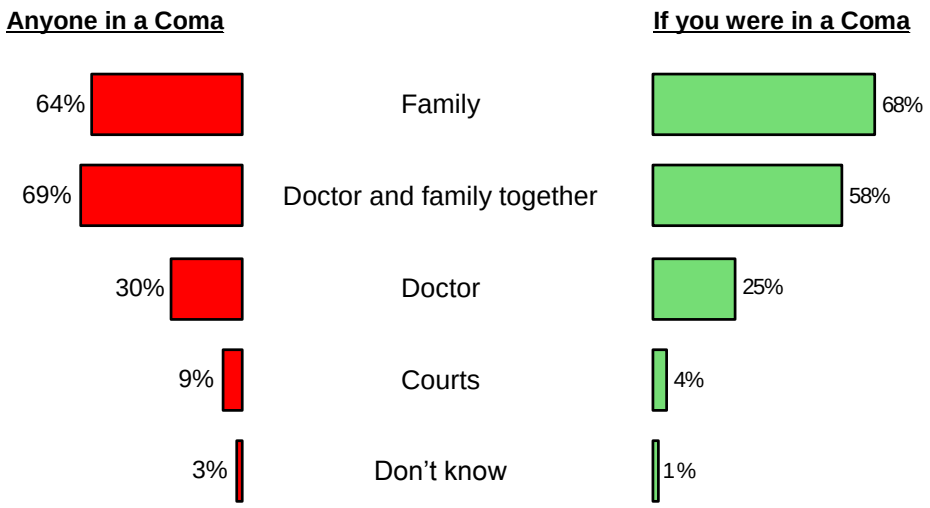
[13] The difference in wording and emphasis between the ICB and the IHF surveys should be noted. In the former case, the question related to health care (e.g., where to live, what medication to have), where as the IHF question focused on end-of-life decisions.

[14] Unlike the previous question, where respondents were asked to select one answer, this is a multiple response question in which respondents were asked to give an answer for each of the four different options.

tended to be somewhat more likely than those over 60 years to want their doctor to end their life in a terminal illness, 34% and 27%, respectively. Allowing for the differences in the age profiles, this latter finding is consistent with the results of a study of elderly patients in the UK by Catt et al (2005b), which found that people aged more than 75 years of age were less likely than younger participants (55-74 years) to want their doctor to help end their life in a terminal illness.

Making Decisions in the Final Stages of a Terminal Illness If Person in Coma

(Base: All Respondents, N = 667)



Q If, in Ireland today, a person were in a coma and in the final stages of a terminal illness, who, in your opinion, has the authority to make decisions about starting or stopping treatment such as a life support machine?

Q If you were in a coma and in the final stages of a terminal illness, and you had not expressed any wishes as to how you would like to be treated, who would you most like to make decisions about starting or stopping treatment such as life support?

The uncertainty as to who should make the decision to end life in a terminal illness was also apparent in the qualitative research phase of this project (Weafer, J. 2009). The qualitative study found that while most people would agree 'theoretically' with any measure that lessened the pain

and discomfort of terminally ill patients; in practice, they would be much more reluctant to give unrestricted approval for any 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. The best decision, they felt, is one that involves the patient, their family and medical team working together. Some verbatim comments illustrate their thoughts and feelings on this contentious issue.

> *'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 a person was in, approximately how much time he/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 or father. 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'.*
>
> '*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?'*

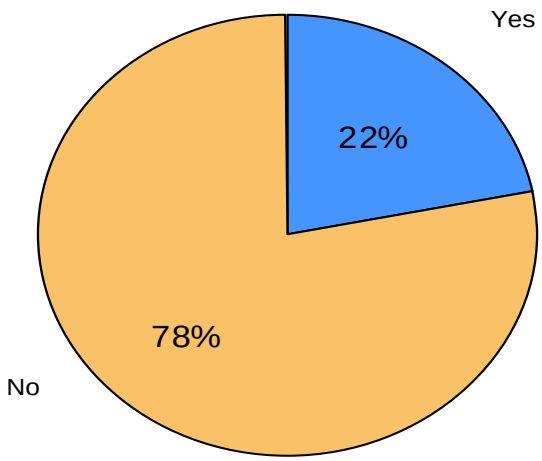
> *'If people are very sick, maybe put something into their medication to speed them on. Die today instead of next week but with no pain'.*

2.5 Informing Others How You Would Like to Be Treated

Just over one fifth (22%) of respondents have told someone how they would like to be treated if they were terminally ill and dying. Although not directly comparable, the Irish Hospice Foundation's 2004 survey, '*A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying*', found that 14 per cent of Irish adults have told someone where they would like to be treated if they became terminally ill (e.g., hospital, home, hospice); 21 per cent had told someone what they would like at their funeral; and 46 per cent had told someone whether they would like to be buried or cremated (Weafer Research Associates, 2004).

Ever Told Anyone how You Would Like To Be Treated If Terminally Ill?

(Base: All Respondents, N = 667)



Q. Have you told anyone, e.g., your doctor your family, how you would like to be treated if you were terminally ill and dying?

The percentage of respondents who had told someone how they would like to be treated if they were terminally ill was highest for 34-44 year olds, and to a lesser extent for females, residents of Dublin and Connaught/Ulster, middle class, persons employed outside the home, and those with a Third Level/ Professional degree. Members of the farming community were least likely to have told anyone (Table Q6, Appendix B).

2.6 A Living Will

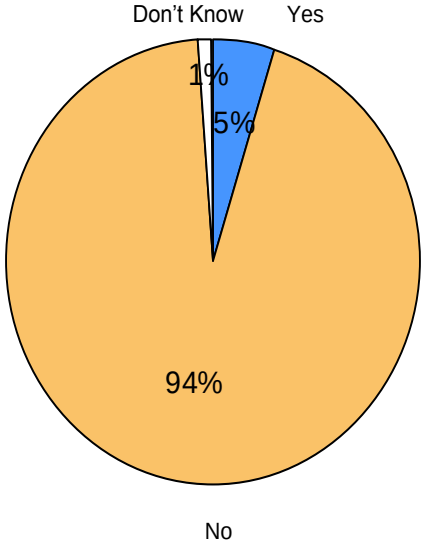
A very small percentage (5%) of respondents had ever written down, in the form of a living will, how they would like to be treated if they were terminally ill and dying[15]. This figure was lowest for members of the farming community (2%) and highest for persons with primary or no formal education (14%). Previous surveys on this topic suggest that the 5 per cent who have written a living will is relatively low. In 2004, for instance, 14% of a representative sample of the Irish public stated they had written an advance directive or living will (Weafer Research Associates, 2004) and 11%`of participants in The Irish Council for Bioethics consultation said they had 'actually written up an advance directive/ living will or any document concerning your future medical care'. However, should be exercised in making direct comparisons due to differences in wording and methodology[16].

[15] An explanation of what constitutes a Living Will was read to respondents in advance of this question.
[16] The wording and context of the questions differ across the three surveys. Furthermore, whilst both of the Irish Hospice Foundation studies are nationally representative studies, respondents to The Irish Council for Bioethics study were self-selecting.

Ever Written A Living Will?

(Base: All Respondents, N = 667)

A 'living will' is a written statement made by a competent adult relating to the type and extent of medical treatments he or she would or would not want to undergo in the future should he/she be unable to express consent or dissent at that time.



Q. Have you ever written down, in the form of a living will, how you would like to be treated if you were terminally ill and dying?

The qualitative phase of the research explored people's reluctance to leave instructions as to how they should be treated if they were terminally, with most people believing that 'you should not interfere with death' unless you have to. While the notion of advance care directives or living wills may sound rational and reasonable, some respondents wondered what would happen if something goes wrong and 'you change your mind'. Taking everything into account, the general consensus of the groups was that 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.

'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 chance 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'.

2.7 The Authority of a Living Will

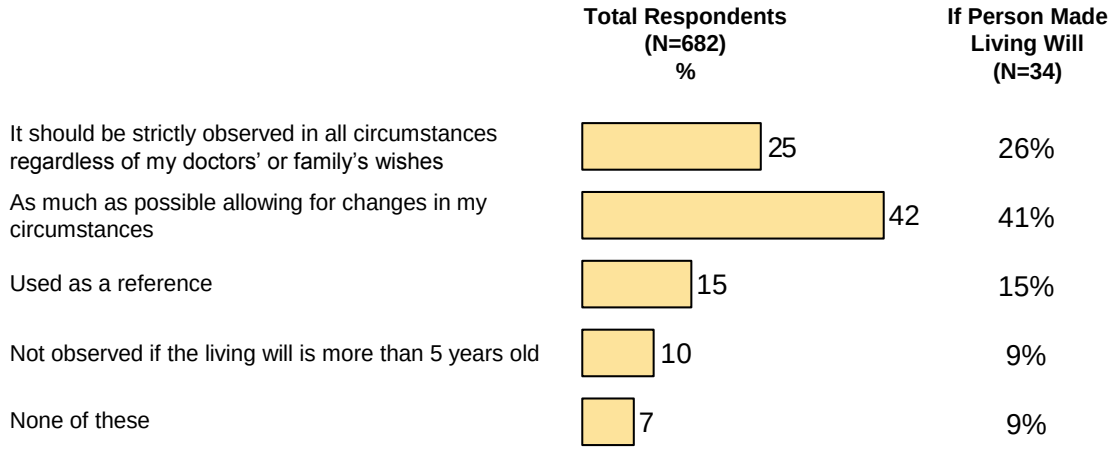
When asked to what extent they would like to be treated by a living will, supposing they had created one, respondents were quite divided in their opinions[17]. The largest group, comprising just over four in ten respondents (42%) would like the living will to be followed 'as much as possible allowing for changes' in their personal circumstances. The next largest group, comprising one quarter of all respondents, felt it should be 'strictly observed in all circumstances', regardless of the wishes of their doctor or family. Others indicated it should either be used as a reference or ignored if the living will was more than five years old.

The thirty-four respondents who have already made a living will responded in a similar fashion as the total group, with most people somewhat ambivalent about the status of an Advance Directive. Older respondents were most likely to want the living will to be strictly observed (Table Q8, Appendix B).

[17] A question in the ICB (2005) survey found that 39% of Irish adults 'strongly agreed' with the statement 'Advance Directives should be legally binding in all circumstances and take precedence over the wishes of a patient's next of kin and their doctor's advice'. Others were less sure of what the legal standing of an Advance Directive should be.

Authority Of a Living Will

(Base: All Respondents, N = 667)



Q. Supposing you have created a living will, to what extent would you like to be treated according to it?

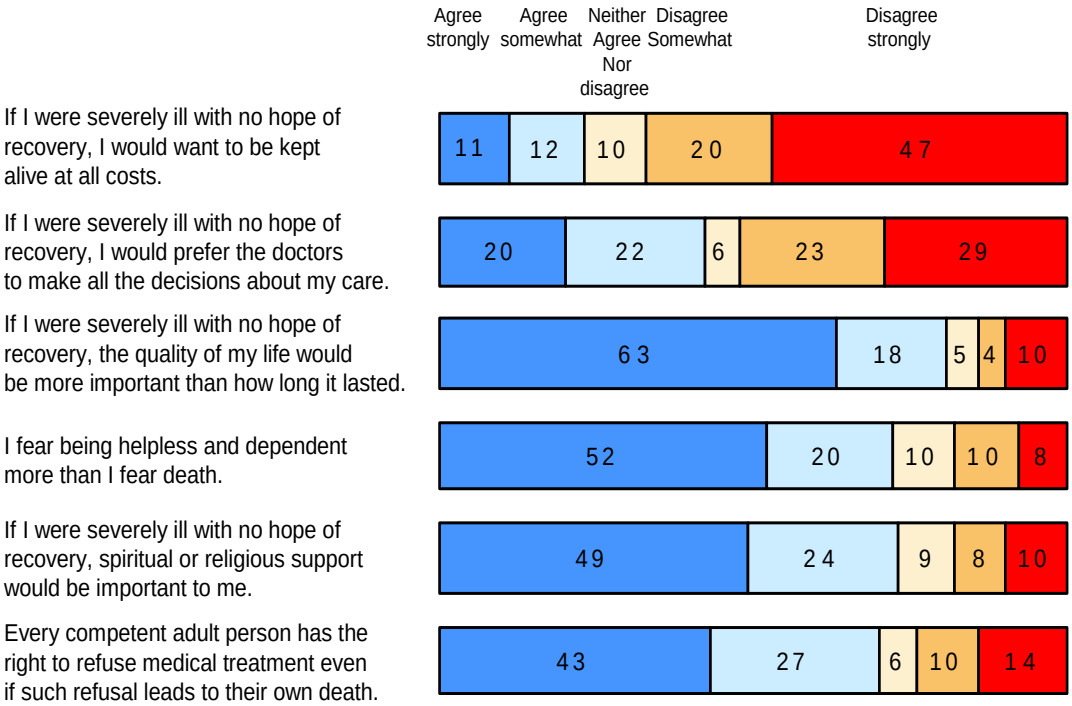
2.8 Attitudes Towards Diverse Aspects of Death and Dying

Respondents were read out a list of six statements relating to diverse aspects of death and dying, and asked to what extent, if any, they agreed or disagreed with them. In general, the majority of people felt that if they were severely ill with no hope of recovery, the quality of their life would be more important than how long it lasted, and that spiritual and religious support would be important to them. Furthermore, most respondents indicated that they feared being helpless and dependent more than they feared death, and that every competent person has the right to refuse medical treatment even if such refusal leads to their own death.

The ICB 2005 survey found more ambivalence towards the rights of people to make decisions regarding their death, with half of all adults interviewed agreeing with the statement, 'Terminally ill people are competent to make the decision to end their own lives'.

Attitudes Towards Death And Dying

(Base: All Respondents, N = 682)



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.

The groups most likely to agree with the different statements are:

Statements	**Above Average Agreement**
1. If I were severely ill with no hope of recovery, I would want to be kept alive at all costs.	18-34 years; 65+ years; Dublin; Leinster; working class; farmers; unemployed; low formal education.
2. If I were severely ill with no hope of recovery, I would prefer the doctors to make all the decisions about my care.	65+ years; male; working class; retired; low formal education.
3. If I were severely ill with no hope of recovery, the quality of my life would be more important than how long it lasted.	Less than 56 years of age; students; unemployed; Third Level/ Professional qualifications.
4. I fear being helpless and dependent more than I fear death.	25-55 years of age; middle class; students; unemployed; and Third Level educated non-degree.
5. If I were severely ill with no hope of recovery, spiritual or religious support would be important to me.	65+ years; Munster; students; housewives; retired; Third Level educated non-degree.
6. Every competent adult person has the right to refuse medical treatment even if such refusal leads to their own death.	Less than 56 years of age; female; Dublin; Connaught/Ulster; middle and working class; second level and Third Level qualification.

The possible relevance of religion to respondents' attitudes was also investigated by analysing the responses to these statements with two indicators of religious commitment – 'How important are your religious beliefs are to the way you live your life' and 'How often, if ever, do you ever go to Church?' In general, the more religious respondents tended to agree most with statements 1, 2 and 5, whilst the opposite was true for statement 6. Thus, the more religious respondents were most likely to say that if they were severely ill with no hope of recovery, they would want to be kept alive at all costs, to prefer the doctors to make all the decisions about their care, and that spiritual or religious support would be important to them. Conversely, the less religious were most likely to

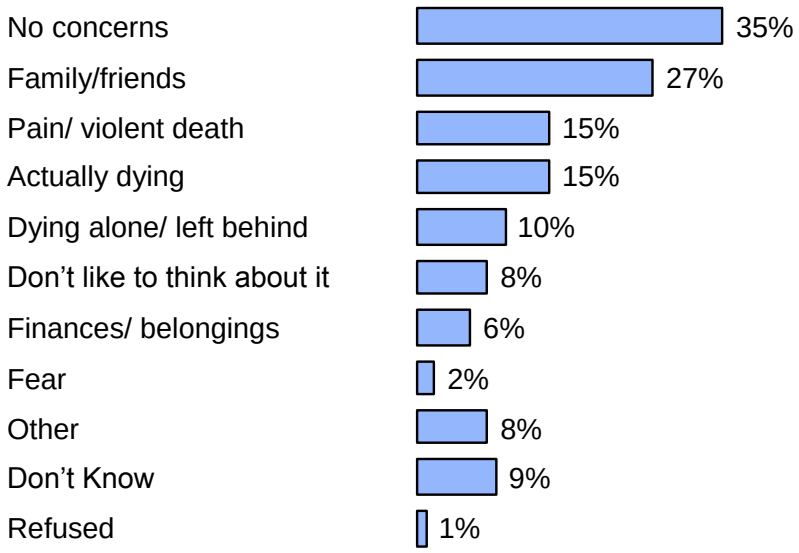
believe that 'Every competent adult person has the right to refuse medical treatment even if such refusal leads to their own death'. No significant differences emerged in terms of religious commitment to statements 3 and 4: 'If I were severely ill with no hope of recovery, the quality of my life would be more important than how long it lasted' and 'I fear being helpless and dependent more than I fear death'.

2.9 Concerns Relating To Their Own Death and Dying

Two thirds of respondents (65%) mentioned at least one concern they have in relation to their own death and dying. The top three concerns mentioned related to family/friends, pain/violent death, and actually dying[18].

Concerns People Have In Relation To Their Own Death And Dying

(Base: All Respondents, N = 667)



Q. What 3 concerns, if any, do you have in relation to your own dying and death?

[18] A similar, albeit more positively phrased question, was asked in the Irish Hospice Foundation's 2004 survey, '*A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying*, in which respondents were asked what three things they would consider to be most important about the care available to them if they were dying or in the last stages of a terminal illness. The most important aspects of care cited by respondents were: to be surrounded by people I love (68%), to be free from pain (55%), to be conscious and able to communicate (35%), to be at home (34%), to have medical and nursing support readily available (32%), to have spiritual support available (19%), and to be in private space (11%).

Most of the people who were concerned about the effect of their death on their family/friends highlighted the areas of financial security, and the sadness and upset that their family/friends would experience at their deaths. Others were more practical, citing their concern for their animals' welfare, and the conflict that would arise following the reading of the will.

No Concerns

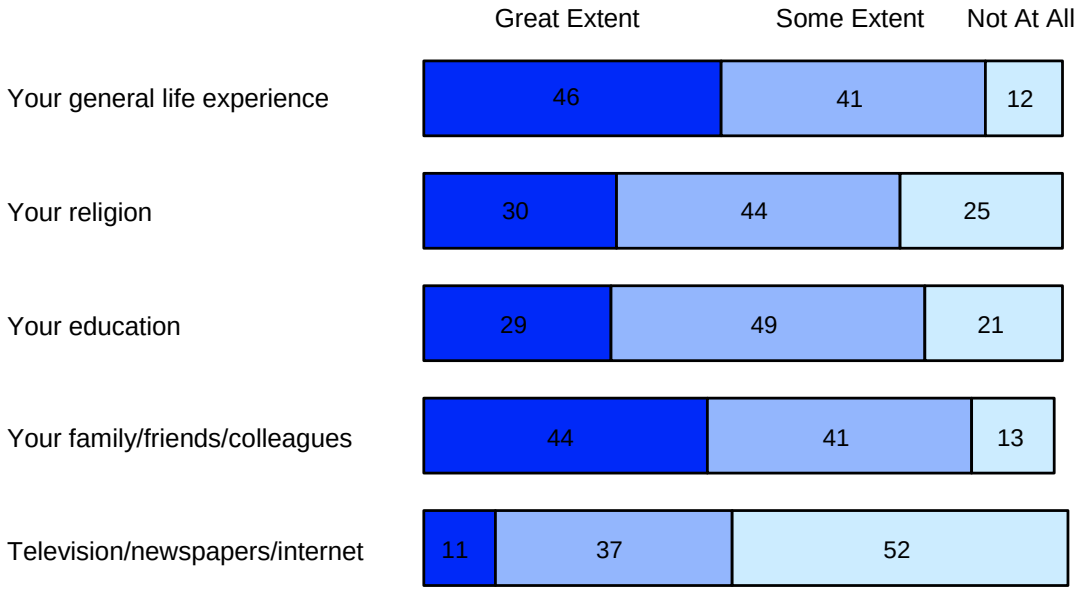
Just over one third of respondents (35%) claimed not to have any concerns about their own death and dying. This group comprised a wide range of individuals across the different social-demographic groups in Irish society. However, they were most likely to be 35-44 years of age, members of the farming community, unemployed, uncertain about the importance of religious values to the way they lived their lives, and with a post-graduate qualification.

2.10 Influence of Different Factors on Their Views of Death and Dying

The final question asked respondents to state what effect, if any, a number of different factors had on their concerns for death and dying. The greatest impact was perceived to come from their general life experience and their family/friends/colleagues. Conversely, television/newspapers/Internet was perceived to have the least influence[19]. Education and religion came somewhere in between these two extremes.

Influences On Attitudes Towards Death And Dying

(Base: All Respondents, N = 667)



Q. Thinking about these concerns, to what extent, if at all, do you believe '*Your general life experience'* has influenced your views about death and dying? Would it be to a great extent, to some extent, or not at all?

[19] Newspapers and television are more likely to be cited as sources of information on bioethical areas (ICB, 2005).

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