Practitioners’ Perspectives on Patient Autonomy at End of Life

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Table of Contents

Executive Summary 3

Chapter One – Introduction 6
  Methodology 6
  Data Collection Methods 9

Chapter Two – Literature Review 11

Chapter Three – Research Methodology 17
  Data Collection Methods 18
  Process of Gaining Ethical Approval 18
  Qualitative Research in a Medical World: yet more challenges 21
  Fieldwork 23
  Narratives of Good and Bad Deaths 25

Chapter Four – Data Analysis 27
  Theme One: Good and Bad Deaths 27
  Theme Two: Active and Palliative Treatments 36
  Theme Three: Patient Autonomy and Other Values 46
  Theme Four: Power, the Personal, Space and Time 66
  Theme Five: Communication 74

Chapter Five – Conclusions 85
  Good and Bad Deaths 85
  Active and Palliative Treatments 87
  Patient Autonomy and Other Values 89
  Power, the Personal, Place, Space and Time 92
  Communication 94
  Summary 97

Bibliography 100

Appendices 106
Executive Summary

This research was undertaken in order to provide qualitative data on practitioner’s perspectives on patient autonomy in end of life situations in hospital settings in Ireland. The research is part of a larger project entitled ‘An Ethical Framework for End-of-Life Care’ The latter aims to identify the key ethical issues that arise in relation to death, dying and bereavement and to develop a set of educational resources to deepen public and professional understanding of experiences of death, dying and bereavement and to enhance the experience of dying in diverse health care settings in Ireland.

The research explores patient autonomy from the perspective of practitioners managing end-of-life experiences in hospital settings throughout Ireland. The data required for the project was qualitative data. The timescale for the project was one year. A case study methodology was utilised. Three different data collection methods were used to gather data. To begin, narrative submissions were invited, via e-mail, from practitioners. These were to be brief narratives of experiences and concerns regarding patient autonomy at end of life; 102 written narratives in total were gathered. Interviews were conducted with doctors and nurses engaged with patients at end of life, 57 interviews in total. Fourteen focus groups were conducted. Each focus group was comprised of eight to twelve practitioners, 104 practitioners in total participated in the focus groups. The fieldwork for the research took place from April 15th 2008 until July 17th 2008.

In all, five key themes emerged from the research. The themes are as follows: a theme of good and bad deaths; a theme of active and palliative treatments; a theme of patient autonomy and other values; a theme of power, the personal, place, space and time; and a theme of communication. The evidence of this research clearly establishes that there are good and bad deaths in Irish hospitals. The good deaths have a number of features in common: patient autonomy, the patient choosing what they want, articulating or communicating those choices, and those choices being respected and acted upon; the patient having access to all the resources and supports available; the patient having the
support of palliative services, among them good pain and symptom management; and the establishment of good relationships between patient, family and practitioners. According to the research, bad deaths in hospital are often associated with inappropriate and, arguably, unethical active or aggressive treatments, investigations, resuscitations, and the administration of invasive, unwarranted, unnecessary and/or inefficacious procedures. Patients in Irish hospitals do not, as a rule, plan for their end-of-life experience. They do not anywhere or at anytime indicate in any way what it is that they would want in terms of treatment or supports when they are dying. As a result of this most deaths in hospital are managed through a moment-by-moment event-by-event decision-making process which is embedded in an oblique or certainly a less than frank communication process which is negotiated between distressed and grieving relatives and under-resourced and commonly over-stretched carers and clinicians.

Patient autonomy as practiced in Irish hospitals is a negotiation, negotiated individually with each patient. So the practice is unique in each patient case. One of the most problematic areas in terms of patient autonomy, as highlighted in the research, is the case of the autonomy of older patients. Another issue is the paternalism in the way in which clinicians sometimes care for patients in hospital. There is also a problem in terms of the autonomy of children in hospital who are dying, and an issue sometimes of collusion between families and clinicians in the exclusion of patients of all ages from the knowledge, awareness, understanding and management of their condition.

The issue of power within the hospital setting was a central issue, as was the inadequacy of the space that is the hospital as it is currently designed and organised in terms of supporting patients at end of life. The emotional needs of the dying were said by the participants to be generally overlooked in the hustle and bustle of the busy hospitals. The spiritual care and support of patients was substantially under-resourced in most of the hospitals. The inadequacies of the space that is hospital space in terms of providing a place for dying patients and their relatives was highlighted over and over again in the research.
The research clearly established that many patients hold other values to be more important than patient autonomy. Many patients will cede their autonomy to other family members. Many patients will cede their autonomy to clinicians. There are many patients whose autonomy at end of life is diminished because they are not aware of their diagnosis. They don’t know that they are dying and so don’t put their affairs in order; they don’t have the conversations with friends and relatives that they might have if they knew they were dying. There is evidence in the research of some patients being entirely oriented towards collectives, towards community and family, and not at all oriented towards the self, the individual self, or towards personal autonomy.

The final and the most substantive theme of the research was this theme of communication. At issue within patient autonomy at end of life is the right of the patient to make known their wishes for their end-of-life experience, and for those wishes to be heard and acted upon. The practice in general among clinicians in terms of communication around dying and death is to follow the patient’s lead, to answer any direct questions. This means that clinicians seldom volunteer information. Also highlighted as problematic were the euphemisms that are used by clinicians when talking to patients about dying and death. Consultants were said to be very cautious and deliberately oblique with the language they use with patients.

A key issue in communication around dying and death is the inability of many patients at end of life to engage in any kind of communication. In one hospital the use of touch was actively employed as a means of communicating with patients who could not communicate through other channels. Another key issue is the refusal of some families to allow clinicians communicate with their hospitalised relative about a terminal diagnosis or prognosis. This means in some cases patient’s under-report pain. It also means that patient’s who need it, do not receive palliative care. It means too that patients are denied the opportunity, arguably the right, to prepare for death.

The recommendations of the research centre on education and practice development around patient autonomy in hospital end-of-life care.
Chapter One

Introduction

This research was undertaken in order to provide qualitative data on practitioner’s perspectives on patient autonomy in end of life situations in hospital settings in Ireland. The research is part of a larger project entitled ‘An Ethical Framework for End-of-Life Care’. That project is part of the five-year Hospice Friendly Hospitals Programme, (HfHP), an initiative of the Irish Hospice Foundation in partnership with the HSE and Atlantic Philanthropies.

The overall project aims to identify the key ethical issues that arise in relation to death, dying and bereavement, and to develop a set of educational resources to deepen public and professional understanding of experiences of death, dying and bereavement and to enhance the experience of dying in diverse health care settings in Ireland. The following paragraph which comes from the Hospice Friendly Hospital’s Programme’s (HfHP) website describes the work.

“The concept of ‘a good death’ is now widely recognised in the international literature and there is increasing awareness that the needs and wishes of the dying person and not just of their family need to be taken into account. To underpin the concept of ‘a good death’ hospitals need to identify the rights and responsibilities of patients, clinicians and families and provide a means for addressing advocacy issues. The patient’s right to choose how and where they are treated is likely to become more of an issue as service users become increasingly more informed and assertive and end-of-life care is addressed by legislative frameworks.”

The qualitative research presented here explores patient autonomy from the perspective of practitioners managing end-of-life experiences in hospital settings throughout Ireland.

Methodology

The data required for the project was qualitative data. The timescale for the project was one year. For the research a case study methodology was utilised. This methodology was deemed to be the most appropriate methodology for this research because of the geographic scope of the project, the project was a nation-wide study; and because the
Hospice Friendly Hospitals initiative had deployed Development Co-ordinators to facilitate the development of ‘hospice friendly hospitals’, in hospitals in key geographic locations throughout Ireland. This network of Hospice Friendly Hospital Co-ordinators, and the hospitals within which they were at work, were used through the case study methodology.

A case study methodology allows for specific cases which are representative of the phenomenon under investigation to be examined in detail. The number of cases selected for examination is dependent upon the data requirements of the study and the time available for the study. According to Cresswell (1998, p.37, see also Yin, 1994 and 2003), in case study methodology:

- the ‘case’ to be studied is identified;
- the case is a bounded system, bounded by time and place; (in this research the cases might be said to be bounded by place)
- varied and many sources of information are used in data collection in order to provide as complete a picture as possible of the phenomenon.

In this research project, the case study methodology was utilised by identifying the cases to be included in the research, by gathering extensive data on each of the cases, and by analysing the data. The cases included in the research were selected on the basis of geographic area. The geographic scope of the research was narrowed, as stated above, to the areas within which there were networks of hospitals participating in the Hospice Friendly Hospital Project. There were in all, at the time, nine geographic networks. They are listed below.

**Acute Hospitals**
- South Eastern Region
- South Western Region
- North Eastern Region
- North Western Region
- Dublin Central
- Eastern Region

**Community Hospitals**
- Dublin Central and South
West – Sligo
North-East Community Hospitals

Each of these networks had a dedicated HfHP Development Co-ordinator. The Development Co-ordinators enabled the connection with each of the hospitals chosen for inclusion in the case study, and they helped facilitate the case study of their area. From the networks outlined above nine cases were delineated for the study. The cases are detailed in the figure below.

![Figure 1: A model of the nine cases](image-url)
Data Collection Methods

Three different data collection methods were used to gather data. To begin, narrative submissions were invited, via e-mail, from practitioners. These were to be brief narratives of experiences and concerns regarding patient autonomy at end-of-life. Despite extensive communication with the hospitals included in the research, with the Development Coordinators, and with key members of staff within the hospitals, the response to the appeal for written narratives was poor. Narrative interviews were conducted at each site with doctors and nurses engaged with patients at end-of-life. Four interviews in each hospital were planned and organised. A decision was taken to interview, in addition, any practitioner who indicated during the fieldwork that they wished to be interviewed. In total, 57 interviews were conducted. Finally, fourteen focus groups were conducted, one for each of the cases, except one. In one case, the staff of two small community hospitals came together in one focus group. Each focus group was comprised of eight to twelve practitioners, 104 practitioners in total participated in the focus groups. In light of the poor response to the invitation for written narratives, it was decided to invite written narratives on experiences of good and bad deaths from each of the participants in each of the focus groups at the end of each focus group. This means of gathering that data proved to be very successful and finally 102 written narratives were gathered. Outline schedules for the data collection methods are detailed in Appendix 3. A more comprehensive synopsis of the data collection methods is provided in the Methodology section of this report.

In all, five key themes emerged from the research. The themes are as follows: a theme of good and bad deaths; a theme of active and palliative treatments; a theme of patient autonomy and other values; a theme of power, the personal, place, space and time; and a theme of communication. Taken together, the themes that emerged from the data gathered yielded a comprehensive qualitative insight into practitioner’s perspectives on patient autonomy at end of life in hospital care settings throughout Ireland. These insights have been used to inform the larger project, the aim of which was the development of an
ethical framework to, as stated above, deepen public and professional understanding and enhance the experience of dying in diverse health care settings in Ireland.
Chapter Two

Literature Review

This qualitative research project is about practitioner’s perspectives on patient autonomy at end of life. A brief literature review is presented here in order to provide a theoretical framework for the project. The focus of this research is the degree to which the autonomy of patients at end of life is recognized and respected. A simple definition of patient autonomy is that patient autonomy is the right of patients to express their needs and wishes, and for those needs and wishes to be heard and acted upon. Autonomy was clearly established in the review as a problematic concept both theoretically and practically. Highlighted in the review is the problem of people being compelled to make autonomous decisions at the critical and what may often be traumatic time at the end of their lives. Further complications can arise from the availability of the medical and technological capacity to prolong life, and the perceived moral obligation to do so. Moral distress can be caused to professionals through carrying out actions on patients that the patients may not need, may not benefit from, and may not perhaps want.

In Ireland although most people would prefer to die at home, official statistics (O’Shea et al, 2002), have established that less than 36% do, the rest die in hospitals or other care settings. In relation to dying in hospital, the great majority of Irish people, over 80% of those surveyed (Weafer and Associates for the Irish Hospice Foundation (IHF), 2004), believe that there is a need for improvement in the hospital care provided in Ireland for people who are dying or who are terminally ill. The most important things about care at end of life were said by those surveyed to be as follows: to be surrounded by loved ones, to be free from pain, to be conscious and able to communicate, to be at home, to have medical and nursing support available, to have spiritual support available, and to have a private space (Weafer and Associates Nationwide Survey on Death and Dying for the IHF, 2004).

In relation to the notion of a good death, Steinhauser et al (2000) in their study found that physicians’ discussions of a good death differed greatly from those of other groups, such
as patients and recently bereaved family members. Following their analysis, Steinhauser et al (2000) concluded:

‘that the biomedical aspects of end-of-life care are crucial but merely provide a point of departure toward a good death. When physical symptoms are properly palliated, patients and families may have the opportunity to address the critical psychosocial and spiritual issues they face at the end of life’.

For some authors the issue in relation to experiences and expressions of care at end of life was autonomy versus (medical) paternalism (Richter et al, 2001; McHaffie et al, 2001; Wyatt, 2001; Myers, 2004). A major issue around end-of-life care in hospital settings is the focus and emphasis in hospital on the medical care of patients. This focus and emphasis precludes much focus on the cultural, social, emotional and spiritual circumstances, rituals and practices of patients. The focus on medical care precludes the development of a holistic approach to caring for patients in hospital, even patients at end of life in hospital. Elias held (1985), that it is possible that the social aspects of people’s lives, their capacity to relate to and with the other people in their lives, their relations to and with the other people in their lives, have in fact, special importance, for people who are dying. Yet Elias writes (1985, p.84), that people, clinicians, family members and friends, seem to tell themselves that there is nothing more that they can do when a person is dying, they shrug their shoulders he writes, and regretfully walk away. Elias suggested that doctors in particular ‘often seem to watch with a shudder’ how an illness or disease can take hold in sick and dying people and proceed without any possibility of control or containment to destroy them entirely. In her work Schermer (2002), explores patient autonomy in ethical theory and hospital practice. In practice Schermer writes that in medical ethics, autonomy has had a one-sided interpretation; that is the right to self-determination with regard to medical decisions (2002, p.182). The focus in hospital practice in terms of patient autonomy on medical decisions she writes, excludes every other issue and aspect of patient autonomy.

The experiences of dying patients within hospitals have been to some degree represented in the literature. In their work, Glaser and Strauss (1986), and Elias (1985), refer to the experience of dying in care settings as the rational institutionalisation of the dying (see
also Howarth, 2007). In the literature the removal of the dying from the community to institutions has been widely critiqued (Glaser and Strauss: 1968, Ariès: 1981, Elias: 1985, Illich: 1976). The removal has, it is said, removed death from view; it has distanced members of the community and society generally from death; it has sanitised death while providing for the social death of the dying patient before, and sometimes long before, the physical death. For Illich (1976, p.207-208), the institutionalization of dying means that technical death has won a victory over dying, mechanical death has conquered and destroyed all other deaths. Bradbury (1999, p.182), writes:

‘even the calmest and most expected death involves at least five institutions and is likely to lead to the employment of six or seven different kinds of deathworker. More complicated deaths – those which happen unexpectedly or in suspicious circumstances – will cause the employment of yet more deathworkers’.

The sociologist Talcott Parsons developed the concept of the ‘sick role’ to detail and describe the ‘correct’ role play of the person who has accepted that s/he is ill, and has surrendered their responsibility for their own care to their clinicians. Parson’s ‘sick role’, according to Frank (1995, p.15), ‘articulated the modernist requirement that ill persons delegate responsibility for their health to physicians’. Frank refers to the surrender of oneself as a ‘narrative surrender’ in that the patient agrees to follow the prescriptions of the physician and agrees, tacitly, to tell her/his story to the physician in medical terms. He highlights the ‘asymmetry’ (2002) or power imbalance of the doctor / patient relationship and the frequently non-dialogical (2002, p.16) nature of their engagements or encounters. In terms of contemporary practice, or post-modernity, Frank refers to lay familiarity with medical terms and techniques as one postmodern aspect of contemporary experiences of ill-health. Frank writes of post modern patients as demanding and claiming voices, insisting on speaking for themselves, making their wishes known and having these wishes observed.

Kübler Ross (1973), studied and wrote extensively on the importance of communication and dialogue between physicians and patients, in particular she wrote of the importance of such communication in end-of-life experiences. In 1973 Kübler Ross wrote (1973, p.32), that in communicating bad news with the patient, the clinician’s task is not ‘how
do I tell my patient?’ but ‘how do I share this knowledge with my patient?’ Kübler Ross wrote that the key to this type of communication is in the manner of the communication: the place of the communication; the empathy; the support; the feeling on the part of the patient of not being abandoned; the sense that they should have, that there are treatment possibilities. All of this, she insisted, should be conveyed in such communications. A glimpse of hope, according to Kübler Ross (1973, p.32), even in the most critical cases, helps patients to come to terms with their situations, with serious and terminal prognoses. It is all of this, she wrote, which facilitates people in living until they die, in accepting their mortality, and in the end, their own death.

Truth-telling according to Kirklin (2007), is essential in terms of respect for patient autonomy. Arguing to the contrary Murtagh and Thorns (2006), in a study of 101 patients found that ‘because there is increased risk of harm through delivery of information discordant with the patient’s own preferences’, it is vital to truly understand patient preferences in terms of information and involvement in decision-making towards the end of life (see also Kelly, p.2007). In 2009, Weafer, McCarthy and Loughrey, in a nationwide poll in Ireland, funded by the H/HP, found that only 3% of respondents would not want a terminal diagnosis disclosed. The survey also established that 59% of respondents believe that decisions around medical futility and withdrawal of treatment should be made by doctors and families together. In terms of treatment decision-making in situations of medical futility, Lofmark and Nilstun (2002), a in a survey of 750 articles published between 1980 and 2000, found that most of the authors concluded that judgements about medical futility should be made by physicians. However the survey, which was carried out on literature published over a time period of twenty years, found that over time (throughout that twenty years), more and more articles recommended that patients should be involved with clinicians in joint decision-making (see also Rodriguez and Young, 2006, and Mahindra, 2007).

The special needs of children at end of life are a consistent theme in the literature (see Quinn et al. (2005) for a Palliative Care Needs Assessment for Children in Ireland, see also www.sunshinehome.ie). The autonomy of the child in relation to their own imminent
death is considered in the literature to be extremely problematic (Vince and Petrus, 2006). At issue are the areas of withdrawal of treatment (McHaffie, 2001; Cremer et al, 2007; Jaing et al, 2007), and refusal of treatment (Van der Heide et al, 1998; Boyle et al, 2005). These issues are not by any means unique to children but deemed to be more complex with children, complicated as they are by the age of the child, the child’s understanding of their condition, the child’s maturity and relative degree of autonomy, and the wishes of relatives and guardians. Despite calls for palliative and hospice care for children, a recent study of 1127 deaths occurring in hospital in the UK (Ramnarayan, 2007), concluded that a ‘greater proportion of hospitalised children are dying in an ICU environment’.

In terms of decision-making, in their comprehensive review of bioethical practices in end-of-life decision making Drought and Koenig (2002), found shared decision-making between patients and healthcare professionals to be illusory. They found that patients often resist advance care planning and they found that patients often hold other values to be more important than autonomy. Weafer, McCarthy and Loughrey (2009) found that 70% of respondents had never heard of advance directives. The role of advance care directives has been formalised in the UK in legislation recently enacted (Mental Capacity Act, October 2007). The situation in Ireland is quite different. In 2007 The Irish Council for Bioethics made recommendations on Advance Healthcare Directives. The Council stated that the role of an advance directive is to ‘stimulate reflection, communication and exploration of fears and possibilities with physician and family’. Among the reasons put forward in the document to explain the lack of uptake in Ireland of advance directives is what was termed as ‘a generalised reluctance to face death’.

As can be seen, patient autonomy at end of life is a very complex concept. The complexity of the situation is compounded contemporarily by pharmacological and technological advances in healthcare and by the high numbers of deaths now occurring in care settings. In such settings bio-medical models of patient care have traditionally been the focus. Critiques of such models suggest that they tend to be paternalistic and narrow, allowing little or no scope for the social, psychological and spiritual aspects of patients’
end-of-life experiences. The literature clearly demonstrates that simple models of patient autonomy are inadequate. Patients often hold other values to be more important than autonomy. In addition, although people generally favour truth-telling and joint doctor/family decision-making practices at end of life, in practice truth-telling and shared decision-making between patients and healthcare professionals is rare (Drought and Koenig, 2002). This qualitative study is designed to explore practitioner’s perspectives on patient autonomy at end of life in acute and community care settings throughout Ireland.
Chapter Three
Research Methodology

As detailed in Chapter One, this qualitative research project explored patient autonomy from the perspective of practitioners managing end-of-life experiences in hospital. A case study methodology was utilised. The cases included in the research were selected on the basis of geographic area. The geographic scope of the research was narrowed to the areas within which there are networks of hospitals participating in the *Hospice Friendly Hospital Programme*. There are in all nine geographic networks. They are listed below.

**Acute Hospitals**
- South Eastern Region
- South Western Region
- North Eastern Region
- North Western Region
- Dublin Central
- Eastern Region

**Community Hospitals**
- Dublin Central and South
- West – Sligo
- North-East Community Hospitals

The HfH Development Co-ordinators enabled the connection with each of the hospitals chosen for inclusion in the case study and they each helped in various ways to facilitate the case study in the hospital(s) in their area. From the networks above, nine cases were delineated for the study. Each of the cases was drawn from one geographic area and each is comprised of two or more hospitals. In all, fifteen hospitals nationally participated in the research. To begin with, a specially devised information sheet and participant consent form was distributed in each of the fifteen hospitals. Practitioners from the hospitals were
invited to participate in the research. Both of these forms have been included in the Appendices 1 and 2.  

**Data Collection Methods**

As stated, three different data collection methods were used. Narrative submissions were invited from practitioners. These were brief narratives or stories describing personal experiences of dying and death, both good and bad experiences. Secondly in-depth interviews were conducted. Four interviews were planned and organised for each hospital. In addition to these four interviews, it was decided to interview any other practitioner who indicated during the fieldwork that they wished to be interviewed. Finally, a series of fourteen focus groups were conducted, one for each hospital except for two community hospitals, where the staff of both were combined into one focus group. The focus groups were comprised of eight to twelve practitioners. As detailed in Chapter One, because of the poor response to the initial invitations for written narratives, a decision was taken to invite written narratives, on experiences of good and bad deaths, from each of the participants in each of the focus groups. Outline schedules for the data collection methods are detailed in the Appendix 3.

The research, while comprehensive, was quite simple. The participants in the research were all practitioners, all of them working with dying patients. There was no engagement with patients or with patient records. There was no contact with sick or dying people. Yet the process of gaining ethical approval for the research was complex and protracted.

**The Process of Gaining Ethical Approval**

In the first place an application for ethical approval for the research was submitted to the Research Ethics Committee of the home institution where the researchers worked. The application was submitted October 26th 2007, both an electronic and hard copy. Ethical

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1 These forms were adapted to suit the particular requirements of two research ethics committees. The adapted forms have not been included in the appendices of this report.
approval for the research was granted at the end of January 2008. In the meantime, all but one of the fifteen hospitals included in the study had its own research ethics apparatus. Each of the Dublin acute hospitals included in the study had its own Research Ethics Committee. One of the Dublin community hospitals had a Research Ethics Committee; the other accepted the ethical approval of the home institute. In the provinces, each area had its own Research Ethics Committee operated through the Health Services Executive (HSE) for that region. However, each of the Research Ethics Committees operated its own idiosyncratic system, each with different requirements and expectations.

Apart from the home institute research ethics application, the researchers made applications to nine other Research Ethics Committees. Each of the committees had its own individual and unique application form. Each of the committees had its own practice in relation to applications for ethical approval. Four of the committees, for example, required that the researchers appoint to the research team a local hospital consultant as Principal Investigator (PI) on the research project. Two of the hospitals requested that the researchers meet with the Research Ethics Committee (REC), following the formal application. One of these two committees required that the local hospital consultant appointed as PI also attend the meeting. One of the RECs requested written letters of permission from hospital managers permitting the research in their hospitals to be submitted with the application form.

The responses to the applications for ethical approval for the research were entirely unique. Each REC raised its own unique issues. None of the committees raised the same issue or issues. One of the RECs wanted a unique design for the Participant Consent form. One of the RECs wanted all written correspondence with respondents to be on local hospital headed paper. Only two of the RECs ethically approved the research without asking for any amendment. The process of seeking ethical approval was not difficult. The study proposed was a simple study of practitioner’s perspectives. Yet the process was protracted, time-consuming and laborious.
### Table 1: The Research Ethics Committees and their requirements

<table>
<thead>
<tr>
<th>Institution</th>
<th>Method</th>
<th>Requirements</th>
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<tbody>
<tr>
<td>Home Institute</td>
<td>Application Form</td>
<td>Meetings with REC Convener</td>
<td>REC contacted some hospitals independently of the researchers</td>
<td></td>
</tr>
<tr>
<td>Dublin Acute Hospital</td>
<td>Application Form</td>
<td>Meeting with the REC – CQ and CON PI required to attend</td>
<td>All correspondence through local consultant</td>
<td></td>
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<tr>
<td>Dublin Acute Hospital</td>
<td>Application Form</td>
<td>Local Consultant Appointed as PI</td>
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<td>Dublin Acute Hospital</td>
<td>Application Form</td>
<td>Local Consultant Appointed as PI</td>
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<tr>
<td>Dublin Community</td>
<td>Application to REC</td>
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<tr>
<td>Dublin Community</td>
<td>Accepted RCSI Approval</td>
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<tr>
<td>North Western Region</td>
<td>Application Form</td>
<td>Correspondence with REC convenor</td>
<td></td>
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<tr>
<td>North Eastern Region</td>
<td>Application Form</td>
<td>Researcher was required to be available by phone during REC meeting</td>
<td>Letters from hospital mgrs (4) submitted with application</td>
<td></td>
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<tr>
<td>South Eastern Region</td>
<td>Application Form</td>
<td>Correspondence with REC convenor</td>
<td></td>
<td></td>
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<tr>
<td>South Western Region</td>
<td>Application Form</td>
<td>PI – Local Consultant</td>
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In all cases, the application form used by the RECs was designed for the approval of clinical trials. As such, most of the form was irrelevant. Some of the on-line application forms were difficult in terms of formatting. Formatting moved and changed, boxes moved and frequently vanished entirely from the page. One of the RECs would correspond only with the PI, the local hospital consultant. This meant obviously, more work for the consultant. It also meant a time delay for the research.

One of the RECs, when it received a response from the researchers to ethical issues raised by the REC, sent the response of the researchers and the application for ethical approval...
for consideration to a different member of the REC. This meant that the application and the response to the issues were viewed by ‘fresh eyes’. Those fresh eyes raised fresh issues. Sending the correspondence to a different member of the REC meant that there was no developing dialogue. New issues were raised rather than old or original issues being resolved.

One of the RECs highlighted and demanded changes with regard to issues other than ethical issues. The administrative support of the RECs and their convenors appeared on occasion to be quite inadequate. Sometimes REC meetings were postponed. Sometimes meetings with RECs were delayed. Formal correspondence with RECs was frequently protracted and slow. Our experience mirrors the experience of many including the experiences of Smith et al, (2004), as detailed in their reflection on the challenges in seeking ethical approval for national studies in Ireland. Our experience suggests that there have been few if any changes in Ireland since 2004 with regard to the challenges in seeking ethical approval for national studies.

Qualitative Research in a Medical World: yet more challenges

Elias (1985), in his reflection on medical sociology in the context to death and dying discussed the importance in medicine of treating the person within whom all organs are integrated, the integrating person, rather than treating his or her organs in isolation. He writes of the ‘rational institutionalisation of the dying’, highlighting the work of Glaser and Strauss (1968), where the dying person receives the most advanced scientifically based medical treatment, and is managed within the rules and structures of a work setting, an institution. Institutions tend to be bureaucratic with internal struggles over power and control. In such places it is frequently responsibilities that signal and signify status. Into such settings come dying persons at their most critical existential moment. With regard to the clinical care for dying people Elias, over twenty years ago, asked:

‘What does one do if dying people would rather die at home than in hospital, and one knows that they will die more quickly at home? But perhaps that is just what they want. It is
perhaps not yet quite superfluous to say that care for people sometimes lags behind the care for their organs’.

Over twenty years later we ask, what has changed? The call in the BMJ editorial (2003: 174-175), was for qualitative research with sick and dying people.

‘We don’t have good data on how people die (as opposed to what they die of), but there is a strong impression that many die badly….. What does it “mean” for patients to say they wish to die with dignity, or quietly, or suddenly? What is the meaning of the desire for death? Does suffering have any meaning? How do these notions vary across cultures, time, and space?... And how do we access dying patients’ perspectives? Research in palliative care settings is notoriously difficult; it is ripe for innovation, such as the use of advance consent and novel qualitative methods’.

As we have shown, the obstacles RECs present to research, even relatively simple and relatively risk-free research projects, are substantial. The obstacles RECs pose to researchers undertaking projects with sick and dying people, sick and dying children are formidable; the barriers to the use of ‘innovative and different methods’ with such populations are significant. We do need to know, as the BMJ Editorial pointed out, the meaning of suffering, the meaning of death and dying, the needs and wishes at end of life of people from non-Western cultures, patients with dementias and non-malignant conditions. We need to know more about the experiences of suffering and the meaning of death and dying for terminally ill children and the needs and wishes of dying children. It is the work of the qualitative researcher to explore such subjects. However, the issues for the qualitative researcher working in a traditionally positivistic research environment are manifold. Central issues in research such as those of reliability and validity are conceptualized differently within a positivistic framework and within constructivist, subjectivist and interpretivist frameworks (Crotty, 1998). Perhaps for qualitative researchers the term rigor is more adequate. Rigor can be articulated in terms of the consistency, dependability and adequacy of a study.

Outlined in this synopsis of the methodology used in this qualitative study are some of the issues for qualitative researchers in researching death and dying. The issues in the Irish context are not unique. Some of the difficulties for qualitative researchers in presenting their work for ethical and other approvals have been discussed. Noted, with
Kendall et al, (2007), are the societal taboos around death and dying that permeate too the world of research. It is worth noting the number of television and radio documentaries which explore with sick and dying people the experience of suffering and dying. It is worth noting the utility of such documentaries, as well as the interest that many sick and dying people have in participating in them. And yet it is almost impossible for social scientists, despite long years of training and experience, to engage such a population in a research project. There is a need for ethics committees and clinicians, as Kendall et al, (2007) state, to balance concerns about non-maleficence with the autonomy of people to participate in research if they wish. There is a need for ethics committees and clinicians to reflect on the traditional impulse in medicine towards paternalism and control and the impact of these on the development of knowledge and our understanding of the needs and desires of very ill people. For social scientists working from a predominantly qualitative perspective within a medical field there is the challenge of working on critically important research using new, or at least new in that context, methods and methodologies. There are too, as detailed here, the challenges and frustrations of seeking approval for research projects the designs of which do not fit with the philosophical, epistemological and indeed ontological frameworks of the proposed approvers.

Fieldwork

The fieldwork for the research took place from April 15th 2008 until July 17th 2008. In that time all fifteen hospitals participating in the research were visited. In that time, fourteen focus groups were conducted, comprised of 104 participants; 57 one-to-one in-depth interviews were conducted; and 102 written narratives, stories of good and bad deaths were recorded. The participants in the study were primarily nurses and doctors. In addition, social workers, pastoral care workers, health-care assistants participated, as did one physiotherapist, one occupational therapist and one mortician. The table below details the exact numbers of participants from each profession.
Table 2: Participants in the Research

<table>
<thead>
<tr>
<th>Profession</th>
<th>Interviews</th>
<th>Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>31</td>
<td>70</td>
</tr>
<tr>
<td>Directors of Nursing</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Assistant Directors of Nursing</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Doctors</td>
<td>16 (four of whom worked in Palliative Care)</td>
<td>3 (two of whom worked in Palliative Care)</td>
</tr>
<tr>
<td>Social Workers</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Pastoral Care Workers</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Health-Care Assistants</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Morticians</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
<td><strong>104</strong></td>
</tr>
</tbody>
</table>

The participants, although extremely busy with their own work, made time for the research and were enthusiastic in their participation in the research. Some of the participants came to their places of work on days off to participate in the research, and some of the participants travelled from one place of work to another in order to participate in the research. Refreshments for each of the participants were provided on site by the participating hospital.

As stated above, in addition to the interviews and focus groups, written narratives were invited from each of the participants. Initially in the design of the fieldwork it was anticipated that the narratives would be the first element of the fieldwork. Written narratives were invited from clinicians at each of the hospitals through the use of e-mail communication and posters but the response was poor. In the end, written narratives were invited at the end of each focus group from each participant in the focus groups. This method proved to be very successful. By the end of the focus groups, each participant was immersed in the topic and prepared to write one, or sometimes two, narratives of good and bad deaths. These narratives proved extremely useful. Below is an example of the written narratives (102 stories of good and bad deaths) received.
No problems were encountered during the fieldwork, with the research, the data collection methods, or the participants in the research. One participant withdrew from the research. The Research Officer wrote formally to this participant clarifying again the aim of the research and inviting the participant to further correspondence regarding the research, if the participant was interested in such correspondence. There was no further correspondence. The researchers had decided to conduct four interviews in each hospital, and more if more participants presented for interview. In one hospital, seven clinicians presented for interview and each was interviewed. Every participant in the research and every facilitator of the research expressed a profound interest in the research and support for the aim of the research and the aims of the Hospice Friendly Hospitals Programme. In each hospital, the research was facilitated by the Hospice Friendly Hospitals Coordinator, by the management and staff of the hospital and the research ethics apparatus of that hospital. Although the study was nationwide and involved 15 separate hospitals, the fieldwork was completed in a timely, efficient and effective manner. Transcripts of
each of the interviews and focus groups were sent to each participant for comment. Three
participants commented on their transcripts. The comments received pertained primarily
to confidentiality issues, and there was one minor amendment to a transcript. A
substantial amount of data was gathered through the fieldwork. Data analysis was
facilitated through the use of a computerised data analysis package, Atlas ti. The data was
analysed thematically. The main findings of the data are detailed in the following chapter.
Chapter Four
Data Analysis

In this chapter the analysis is presented of the data gathered through the three data collection methods, written narratives, one-to-one interviews and focus groups. The data was managed and analysed using the data analysis package Atlas ti. Through the analysis five main themes in total emerged. The five themes are as follows: good and bad deaths; active and palliative treatment; patient autonomy and other values; power, the personal, place, space and time; and communication. Each of these themes is presented in the following pages. The themes are presented in order of the emphasis given to them in the fieldwork for the research by the participants in the research: the theme of good and bad deaths is presented first, and the most substantial theme, the theme of communication, is presented last. The direct quotes included in the chapter are, for confidentiality purposes, not assigned to any data stream, the 102 written narratives, the 57 one-to-one in-depth interviews, and the 14 focus groups, any particular site of the research (any of the 15 hospitals that participated in the research), or any of the nine cases developed within the case-study methodology developed for the research.

End of life comes slowly or it comes suddenly. In slow end-of-life experiences there is time for practitioners to work with a patient, to develop a relationship, to develop a dialogue, verbal or non-verbal, to get to know a patient, to develop an understanding of what the patient wants and how the patient wishes live their end of life. This is not the way in the case of a sudden death. In such a case there is little or no time for practitioners to get to know a patient and what they might want for their end of life experience. End of life experiences vary, they vary from patient to patient and from care setting to care setting.

Theme One: Good and Bad Deaths

There are many different kinds of deaths in hospital. Some deaths are sudden, such as deaths as a result of road traffic accidents and some deaths are slower. The slower deaths
can, given the time allowed, be managed by clinicians and indeed a complex practice has developed around many of these deaths, deaths such as cancer deaths. In relation to hospital end-of-life experiences, it appears from this qualitative research that some clinical teams have developed a great deal of expertise around practice with dying and death, and this is because some clinical teams deal all the time with patients who are dying. Other clinical teams have less experience with dying patients and as a result have developed less expertise in terms of practice around appropriately and properly managing end-of-life experiences.

The issues around end-of-life experiences in hospital, as evidenced in the research, tend to be issues of where the end-of-life experience should take place, in the hospital, in a local hospice or at home; the management of pain and symptoms is an issue; the degree of autonomy allowed the patient is an issue. There are issues around communication, and these are dealt with later in this chapter. There are issues around how much the patient wants to know, and how much the patient knows, in relation to their diagnosis and prognosis. One clinician said: ‘a terminal diagnosis is a lot to take on board’. As has been evidenced in the literature review, there is a big taboo in society generally about death and dying, and many of the participants in the research talked of patients and their relations not wanting to talk about death and dying. They said that some patients cling to life and to hope, even though they are very weak and probably know in their hearts that they are close to dying. It is, the practitioners generally agreed, very difficult for people to accept that they are dying. Patients hope invariably that some treatment, surgery, or chemotherapy or something else is going to work. Medical training is about preserving life and one of the consultants who participated in the research said that a lot of doctors see a patient who is not going to survive as a failure on their part, even though the patient would not survive no matter what. This issue was highlighted by very many of the participants. The consultant went on to say that the focus in hospital is generally on ‘fixing’ people and when they can’t be fixed many doctors believe that it is difficult then to help them, those patients who cannot be fixed.
In relation to good and bad deaths, there were the narratives of good and bad deaths and there were the practitioner’s perspectives on the good and bad deaths. Hospitals are caring for older people who are quite ill, ill with more than one medical/health problem. The situation in hospitals caring for older people at the end of their lives is that people are living longer, they’re presenting at more advanced ages for surgery, but they’re also presenting with more co-morbidities, so they are sicker when they are operated on and so their prognosis following surgery wouldn’t be as good as it would be if they were younger. Children with serious illness are surviving into late childhood, into their teenage years, into early adult life. They are surviving because surgery has improved, medicines have improved as well. One of the implications of them surviving is that they are more and more aware of their conditions, their prognoses. As they mature the need for them to be autonomous and to be empowered to make autonomous decisions becomes more and more imperative.

There were very many cases in the data of patients, young and old, who wished to be at home, to live their end-of-life experience at home and to die at home.

‘We had this lady in Geriatrics who was quite a heavy care burden, if you understand, she was - she couldn’t do much for herself. So we had organised what’s called a level 1 care bed in a hospital for her and thought that she would go there for her end of life but it was very much not what the patient wanted even though, from a practical point of view, it would have been the most practical thing - she would have had full-time nursing care and full-time medical care in the hospital. But it was not what she wanted, she wanted to go home and we discussed that with her family and her daughter understood then that she was taking on the burden and she said “this is what my mother wants, she wants to come home for her last dying days” so that’s eventually what happened to that patient. She went home and she died at home. So I guess that was a time where, you know, we looked at it from a medical point of view - from a practical point of view was one issue but then the patient herself wished to be at home, that’s what she wanted so that’s what happened’.

There were very many cases in the data of heroic families, relatives and friends making extraordinary efforts to ensure that their family member or friend could be at home. There were cases of patients who represented very heavy care burdens who were taken home by their families to be cared for at home. There were cases too of families
renovating houses so that sick and dying relatives could be accommodated at home. There were also many cases in the data of families who could not for many and varied reasons care for their relative at home. For many, the families were geographically scattered. For many families the care burden was too much, and the level of care and expertise in care required could not be provided at home. There were many patients who would have had to have been alone at home all day or for very substantial portions of each day, and this would not have worked from a care perspective. One practitioner detailed, in terms of patient autonomy and some of the limits to it, the narrative below:

‘I think there are issues with dementia in Geriatrics because we had a lady with Alzheimer’s and at times she was perfectly lucid and then at times she didn’t know where she was. She was in the hospital in (named city) where I was but she was actually coming from (named city), that was her home place and that’s where she wanted to be, but her daughter was in (named city). So in effect she was kind of being kept in (named city) against her will because she wished to go back to (named city) and that’s where she wanted to be, she wanted to live in her own house. And at times when she was good, that would have been fine, she was perfectly capable of making decisions and she would have been fine living in (named city) by herself. But the other times when she was bad she would never have managed. So I guess in that case when she was lucid her wishes were that she wanted to go home and be at home, but she couldn’t, she had to be in (named city) with the daughter - near the daughter - so in that case I suppose her autonomy wasn’t respected, but with reasons behind it, I mean she wasn’t really able’.

There were many cases in the data of patients who had no home, and had few or no friends or relatives who were cared for in hospital until their death. There were cases highlighted in the data of some older people who were living their end-of-life experiences in hospital and had chosen or were choosing to refuse hydration and nutrition as a way of hastening their end of life. One of those narratives is detailed below:

‘She was 97 years of age and she just really and truly just pined to be at home, all she wanted was just to be at home and she totally took charge of her own destiny. She just said no way she’d take any more intervention, she had a lot of complications with her heart and everything, her mobility was very down and that’s why she couldn’t look after herself at home, her family were all abroad - America. She was on medication for her heart, she refused it point blank, we had doctor intervention, we spoke to consultants, we spoke to her, we reassured her - no, nothing would do. She stopped all intervention, wouldn’t take medication, she had a temperature at one stage and no way would she take the antibiotic. And another
thing then she just stopped drinking and stopped eating and we tried to encourage her with little Forticremes and she’d take the tip of the spoon literally. And the same with drinks, we used to give her these high protein drinks and the sips, you know, the Fortisips, and literally she’d sip it and it would still be three quarters full at the end of the day and no way, subcutaneous drips, no way, she wouldn’t have it. And she said “just leave me alone, I want to die, I know what I’m doing”.

Another case was recounted as follows:

‘We have one lady here now at present who is approaching the end of her life. She’s 92 years of age. She’s had a serious, a devastating CVA, and the current wish that we are getting from her is that we discontinue her PEG feeding. It is something that we will have to, as a team, discuss with her, her family and with the medical staff about continuing the PEG feeding which we probably will do because we’re not getting a direct order from the patient to stop feeding. Where somebody will tell you that they do not want to eat or drink, which I have seen, generally the consequences of that decision will be fully explored with the person. You will have the nursing input, you will have medical input - both from the geriatric side and from old age psychiatry - and the full implications of their lack of dietary intake will be explored with that person. It’s not something you see very often but it is something you see. So concerns I would have about autonomy at end of life, you have to wonder is the wish that’s being expressed by somebody for it to be all over, is this because they’re depressed? Are you addressing those issues? Is it because they’re in pain? There again, best nursing practice is that you would make sure that the person is as pain free as is humanly possible. Or is it just that they feel themselves that their life is winding down and that they’re moving into a new phase of their life? The act of dying can take days, weeks, months and sometimes years’.

The pressure on resources, even when people are dying was evident. The pressure for beds, they need the bed for the next patient, and even when a patient is dying, staff are coming to the ward and asking if the patient has gone to the mortuary. As one participant said:

‘they needed the bed and, you know, the sister said “no, the patient is very, very sick and I want to give her son time” and she died and I’d say she wasn’t cold and they were coming in “can you get the patient down to the Mortuary because we need the room, we need the bed for theatre” and she (the Sister) just told them to get out of the unit’.
The pressure on resources effects different people in their end-of-life experiences differently. In the case of one young man, the palliative nurse described the experience as follows:

‘...just the demands on the service I suppose in that like one of - a young lad that I’m seeing at the moment, 26, with metastatic malignant melanoma, he was only diagnosed last July. And he’s deteriorated so much, he’s been in hospital the last 5 weeks and I’d say his time will be short and from the outset he came in and thought he was only staying a few days and just wanted to go home but he needed a scan to be done and it took 2 weeks for that to be reported and then the 2 weeks were up and it still wasn’t reported. It wasn’t reported until the 3rd week. Then because of the result of that scan he needed radiotherapy to ribs because he had new rib mets. Then by the time that was done he needed a pump to be put in but he had to wait for a theatre slot, there was a delay with that. He finally got that in and now he’s got further metastatic disease so he’s waiting to see the Radiotherapy Team regarding more radiotherapy to his neck. And this is somebody that, if things in the service could be done quicker, then he may not like - I suppose he’s 5 weeks in and I see him being in all of this week and maybe next week. And I know every time we aim for home a new problem pops up but initially I kind of felt that he could have gone home for say 7-10 days but there was just a delay with things. It’s just I suppose the services in an acute hospital.....if his scans could have been reported quicker and if he could have got a theatre slot quicker and, you know, he may have - he may or may not - but I suppose we see that sometimes with patient, but it’s a busy acute hospital, nothing can be done about that but sometimes you just feel that if services could be done quicker ...they’re just so busy, every service is so busy. But if things could be done quicker you could see somebody like him - like somebody might say 5 weeks isn’t too much but if he’s only got another few to live it’s a long ..... time for him. And we come across that a lot’.

Another participant who was a chaplain said:

‘I had a situation recently in one of the wards where because of the staff shortages in a particular ward there was a lady who was a big age, she was into her 90s, she had been dying for a few weeks and she died and the staff didn’t call me or didn’t call any chaplain. Now the lady died on her own, she was probably sent to the Mortuary I assume and sent from the hospital then to the Undertakers and she had no next of kin, so I would have spoken to the Ward Manager about it afterwards and he pointed out that because of the staff shortages they simply couldn’t have time to – it was a lot easier on the staff to send the deceased out of the ward. I felt, in some respect, her spiritual autonomy had been compromised by that action. She was quite a religious woman, I mean I stress that, and I don’t blame the staff either I mean they were under a ferocious pressure trying to get beds, it was a lot faster to ship out the woman as fast as possible’.
And the pressure on resources is the same with dying children. Below is an end-of-life narrative detailed by one practitioner:

‘I have been put in a situation where a service was promised for a dying child to go home into the community, and when we got the child home it was withdrawn before they even came to meet the child. And it’s a Friday and you’re thinking “oh my God, I have this child at home who hasn’t got very long to live, what are we going to do?”’. Luckily for the child one of the nursing staff on the ward had agreed to help mind him, the public health nurse was a paediatric nurse and on the Monday I got a phone call from our consultant who covers the weekends to say that the child was worse. And I went in and he was dying, he was actively dying and I had to come back here to get some things and then go back out to the house and do what should have been done in the community. And the dilemma for me was that it had been promised, you know, they said they would take this on because otherwise we wouldn’t have offered. And he died peacefully at home and the parents were very, very happy and they never did know that he had been refused the support that had originally been offered to him’.

The challenge in terms of lack of resources is often overcome solely through the goodwill of practitioners and the willingness of practitioners to work over and above the call of duty. Where resources are strained or even unavailable, in hospital and in the community, practitioners will step into the breach and improvise and pull together and somehow make things work.

‘I remember one child who had been here for quite a long time, a baby. The hope was that he would have a transplant, and then things went into reverse and that wasn’t clearly going to be a possibility. And the family decided they would like to take him home to die. It was so difficult to get the necessary supports in place and it really was a case of people’s goodwill and a lot of people, you know, pulling together to sort it out. But I must say I remember feeling this was a real cobbled together arrangement. But he went home and they had him home that night, he hadn’t been home for a long time and the next day they decided that really he was making strange at home because he hadn’t been there and that the hospital was much more his home. And they rang and said could they bring him back to the hospital but it was for that reason they thought - it wasn’t because the cobbled arrangement hadn’t worked, thankfully. So the ward immediately had him back and I think he lived for another day or two but they were really happy that - well it was nice that they were able to get the choice’.

The issue of availability of resources in the community influences patients and their decision to be at home and their capacity to be at home. In some cases families want to
bring patients back to the hospital because they feel, or the patient feels, that the patient is safe in hospital and they don’t feel that the patient is as safe at home. Where there are symptoms and pain to be managed often families prefer to be in hospital where the expertise to manage such experiences is available, or more readily available. One practitioner detailed the following narrative:

‘A couple of years ago now when I was in Palliative Medicine in another centre, adult Palliative Medicine, we came across a gentleman who was referred to us after he had attempted to commit suicide and he had thrown himself into the local river, was referred to us then. The reason that he had tried to commit suicide was that he had a diagnosis of cancer which he’d lived with well for about eight years at this stage but was developing increasing pain and he was worried that if his pain was so bad at this stage and not controlled, how bad was it going to be when he was closer to death and it was really his fear about symptoms, you know, not being controlled. So he was able to relay all this to us, we then got his pain under control, relatively easily I suppose, it’s what we do every day, and we were able to reassure him that his pain would never have to be out of control as it had been and thereby his suicidal ideation completely resolved’.

One of the practitioners defined a good death as follows:

‘A good death is one which allows the patient to choose what they want. While there are very few deaths in the oncology day ward, it is good to know what patients are referred in a timely manner to end-of-life services. One of our patients had been coming to us for chemo, was at the hospice but continued to come for palliative chemo. All services had been put in place. Family members had been well informed early on. A good relationship between patient, family and staff in both establishments was in progress. The patient died in the hospice with good symptom control with family around. The family sent a card describing the final days and hours as peaceful’.

So for this participant the elements of a good death are patient autonomy, in this case the patient choosing what they want and those choices being respected; the patient having access to all the resources and supports available; the patient having palliative treatment and good pain and symptom management; the establishment of good relationships between patient, family and practitioners. In this good death scenario, the patient knows that death is imminent, so too does the patient’s family. There are difficulties in prognosticating death and patients can suddenly and unexpectedly deteriorate, and
patients can sometimes have a last-minute intervention, a medical intervention, which can extend their lives and improve their medical condition. This difficulty in prognosticating death poses problems for many clinicians in communicating about dying and death with patients. Many clinicians would be very reluctant to initiate a conversation about dying with a patient. Clearly if open communication around dying and death is one element of a good death, as defined above, difficulties around prognostication and communication have substantial implications for good and bad deaths.

While there were many examples in the data of good deaths, there were too many examples in the data of bad deaths. The bad deaths detailed in the data very often occurred as a result of poor pain and symptom management. Very often too they were as a result of inappropriate and, arguably, unethical active treatment. Below is a death narrative recounted by one of the practitioners:

‘So we had a situation recently where we had a man who had theatre one night and didn’t do well immediately post-operatively. He didn’t have a wife; his wife had died 10 years before that leaving a very young family with him. These were all teenagers, well very early 20s, but they didn’t have any extended family. They were like lost chickens really, there wasn’t anybody and they really didn’t know what was going on. And there was an extremely - an excellent CNM2 on duty that day and the patient was very, very sick. Basically the man had - his brain, his pupils were fixed and dilated, he was still bleeding and we could see the man really wasn’t - he was dead really apart from turning off the machine. But the consultant, regardless of anybody’s views, decided to bring him back to theatre in that situation, and I felt that the dignity of that patient was totally - the family had to wait another 24 hours for something that had actually taken place. They weren’t given any information by the medical side, they kept saying - in fact afterwards, they came and said the only people that were honest with them were the nurses because they asked the nurse in charge what did she think and she told them “your father is going to die” and they said that was the only time they got anybody that would actually tell them what was going on. It was like as if their father was just taken out of their control and they were just bystanders, they were just watching the situation. But because I think there wasn’t anybody there to support from an adult - even though they were adults, they were -they were young adults. So that was one situation which was very difficult for the staff to deal with. That happened two weeks ago… The consultant couldn’t understand what had gone wrong with the operation. As far as he was concerned it went well but the patient carried on bleeding and he tried everything to get to the root cause of it and in the end on the second day, that evening, he decided he’s taking him back. But at that stage this man really was dead. He took the patient back to surgery to try and find out what went wrong’.
Below is another narrative recounted by a practitioner:

‘I’m on the resuscitation team, when we arrived at the scene, you know, the first thing I could see, God, this is such an unethical resuscitation, if it was my relative in the bed I’d be so upset. It was an 84 year old gentleman that was admitted that night by a medical registrar that had not consulted with her consultant, and had not consulted with the anesthetic consultant, to review this patient. He was an 84 year old gentleman with end stage chronic obstructive airway disease that was on maximum medical treatment and home oxygen. So, I mean, the sort of thing we're talking about - resuscitation, that's why often patients and relatives are not explained to properly, or talking about will they benefit from their heart being shocked or will they benefit from being put on a life support machine? Now, this gentleman would not have benefited from that because he would never come off of the life support machine, research would have shown with end stage COPD. The poor little gentleman was very skeletal and he had a pigeon chest as well. You know, and the first thing I could say - I arrived at the scene the same time as the anesthetist and the medical registrar that called the rest of us there - and I said, this gentleman is for resuscitation, is he? And yes - and we were going through with it, and all his ribs were cracking as we were doing the procedure. And I said, God, this is very unethical, has this been discussed with the gentleman or relatives? And the registrar said, “No” and the anesthetist just chimed in as well, he said, “This is quite unethical.” And she just was continuing leading on, and she just said, “Oh well, we won't compress as much on the chest compressions, we'll do it gentler.” But the thing with resuscitation, you either do it properly or you don't do it at all. There are no half measures; we don't act out the role. He died; once the resuscitation was called off he died. He wasn't going to survive resuscitation’.

Theme Two: Active and Palliative Treatment

Another of the major themes to emerge from the analysis was the theme of active treatment. In this theme, the issues explored are the circumstances of active treatment, the ethical issues attendant upon and the decisions around active treatment, the dilemmas posed by proposing to move or moving from active to palliative treatment; the aggressive treatment of patients at end of life and the question of whether with such treatments it is a life or a death that is being prolonged. Decisions around the ending of active treatment are complex and they are complicated by the medical imperative to preserve life. They are complicated by the need that patients have to cling to life, and the wish that they sometimes have to hasten death; and they are complicated by the wishes of relations.
Decisions around the ending of active treatment are also complicated by the cultural and religious beliefs of some patients. Decisions around moving to palliative care are complicated by the availability of the service, whether or not it is available, and decisions around the acceptability of such a move to palliative care, to the patient’s consultant. Palliative care has been a recognised medical specialism in Ireland since 1995 and since 1987 in the UK. Both of these countries, the UK first and then Ireland, are at the top of a global league of nations, (Wright et al., 2008; Clark and Wright, 2007), within which palliative care is available. Despite this, the palliative service is very patchy is some areas and not available at all at some times. One participant said:

‘I find on the ward that Palliative Care isn’t brought in soon enough. I do feel that, especially with pain management because it’s something I feel very strongly about, I still find that sometimes teams are resistant to involve the Palliative Care for pain control. I don’t know why, I just feel there’s some resistance. I do think they were often very slow to involve Palliative Care’.

Another participant said:

‘In my experience I’ve seen too many patients who have been left too long before Palliative are called in’.

One of the participants in the study talked of palliation as a slow steady process, even when death is imminent. This participant said that there is a whole spectrum of issues that palliation and end-of-life care covers. This participant said that palliative carers would be highly trained in exploring with patients their desires for their condition at death; that there are very many options for palliative care; that palliative care is a provision for dying, that palliative care is not necessarily for the dying, although patients do die; that pain management is one aspect of that and that pain is relative, and physical pain is only one aspect of it. This participant expressed disillusion that the involvement of palliative care is sometimes so late. As well as a lack of knowledge or understanding of palliative medicine on the part of many medical teams evidenced in the research, there was evidence in the research of a lack of understanding on the part of many patients of palliative medicine and the role of palliative care. One practitioner said:
‘Some patients sort of - they just balk at the idea of the hospice I suppose, just the whole idea of it. They might not - they just see that death is more an immediate thing maybe when you talk to them about it. Some patients occasionally would be just quite adamant they just don’t want anything until they really need it, as it were. They think they need it towards the end of the line, we would prefer to get things organised earlier on, so that the patient is more familiar with the system, as it were, or people at the hospice or whatever and just the way things are done’.

Another participant said:

‘Maybe it’s a bit of denial or something that they don’t think it’s going to happen to them yet or they don’t need it yet. Maybe people just perceive that hospice is just end of the line, going there right before they die or when their pain is so severe that they need something done about it’.

Clearly if the elements of a good death call for good pain and symptom management, the provision of syringe drivers, the management of nausea and vomiting, and the establishment of good relationships between patients, families and practitioners, then the earlier palliative care can become involved with the patient the better. If the medical team resists or opposes engaging palliative care, if the patient or the patient’s family resists or opposes engaging palliative care, or if palliative care service is not available, the end of life experience in question will take place without the service. If a substantial part of the expertise of a palliative care team is symptom and pain management, then clearly the absence of such expertise can only have a detrimental effect on the end-of-life experience.

Practice around the active treatment of many patients was questioned by many of the practitioners who participated in the research. The varied practice in terms of active and palliative treatment from team to team was highlighted by many participants in the research and questioned too by many. One participant detailed the following narrative:

‘We have a gentleman at the moment who is ventilated up in ICU, he was undiagnosed when he was admitted a year ago, and was then duly diagnosed with Motor Neurone Disease. He’s ventilated and sedated, you know, and I suppose if things had been, you know, reviewed at the time or maybe, you know, initially when he was diagnosed, well he certainly wouldn’t have been put on the ventilator. But
now that we’re there, you know, he’s trying to die and just can’t die. That ventilator is keeping him alive up there. He took a turn on Friday and now is on his second syringe driver and the wishes of his wife are that he wouldn’t suffer any more, you know. This is very difficult I suppose from our perspective and also from the perspective of a patient being nursed in ICU. You know ICU is very curative and proactive. So that’s a huge dilemma, a huge ethical dilemma really for that patient. And at Christmas, when he was able to talk, when he got septic and they took blood, he clearly said “I don’t want anything else ...” you know. But now unfortunately, things are not moving on that quickly for him. He is very much palliative. Certainly my role as the Clinical Nurse Specialist would be to support patients and families in these decisions. Initially when patients are admitted to the hospital, certainly if they’re under the Medical Team and they’ve got a lot of co-morbidities or secondary cancers, that decision is normally made on admission, whether this patient would be resuscitated, with their consent, if they can give it. If not, it would be the next of kin. The problem arises when patients are admitted under the Surgical Team’.

Many participants in the research questioned the degree to which patients and families understood clearly what it was that they are consenting too when they consent to active or aggressive treatments. One participant described the experience of a patient who is on ventilation as follows:

‘They might be end stage COPD, and they’re on continuous oxygen nebulizers and not able to do any kind of movement and then when they come in to ICU, they’re ventilated and end up with a tracheotomy and maybe full care at that stage. And then down the road often they die from an infection’.

One of the participants in the research recounted the following experience:

‘I have a very recent experience that upset me greatly and that I’m still trying to have conversations with the individuals concerned and it was for a patient whom I happened to come across on their admission to the hospital four days previously. So I knew their history very well. They had had palliative radiotherapy for CA of the lung, a gentleman in his early 80s, and he had a chest infection on admission to hospital. I met up with the family about three days later when I took a report from a colleague at 5 pm in the evening, to hear that the patient’s condition had deteriorated. His oxygen saturations had dropped. He was on the medical unit and had been transferred to the high care unit and he was disimproving. I asked what the plan of care was for him and I was told that the family wanted him to have every possible chance. The consultant was not on duty that day. There was someone acting for him until 5 pm in the evening and as far as they were aware, the gentleman was
to be resuscitated. I asked had the fact that he had a chest infection as well as CA of the lung, (he knew what was wrong with him), been discussed with the patient and I was told no, because the family wanted him to have every chance. Before I got to the end of that report the emergency bleep went off and it was for this patient. When I got to the unit the patient was intubated. I asked the nurses about it. They said yes the family wanted - the doctor had discussed it with the family and they did want resuscitation measures taken if anything happened. They knew that their father was getting worse. The father himself had expressed that he didn’t want tubes or anything like that, so I was very annoyed really. I couldn’t understand how it had gotten to this stage. It hadn’t been discussed, you know, that a chest infection with CA of the lung and what the outcome of that could be for the patient. I came back to the office and I rang the consultant because it was then after 5 o’clock. He wasn’t very nice to me on the phone. I asked if he realised that this patient was as ill as he was, if he realised that he had been ill that morning, and did he now know that he was intubated, and whether the follow-up care been discussed with the family. He more or less said to me well just because the patient has a diagnosis of CA, it doesn’t say they don’t get the same chance as everyone else and that you can have approximately - with lung cancer the survival rate is poor but you could get about a year quality of life. I asked him what quality of life the gentleman had now and what was the likelihood that he would ever come off the ventilator. Anyway he, the consultant, came in to see the patient and to see the family. The family was spoken to on the corridor, even though I tried to get them into a private room. There is a relatives’ room here and they could have had the discussion there. He spoke to them collectively in the corridor, and then he spoke to them individually. The anesthetist was not happy with the situation at all. We have a protocol in the hospital whereby, which makes it even more difficult, we no longer care for patients who are ventilated. We ventilate them but we are not allowed to keep them. We have to transfer them out and I was saying to myself well if I go the phone looking for a bed for a patient ventilated with a diagnosis of CA of the lung who has been resuscitated, they are going to say “well we can’t take that patient, we need our beds for whatever”. I asked about transferring the patient. What was I going to do now? Would I look for a bed to transfer this patient to because we couldn’t, we weren’t allowed to keep him under protocol in the hospital, no. Anyway later on that evening, about an hour later, the patient arrested again. On this occasion he died. I tried to discuss it with the consultant and he said, well it was a good idea to do it in the first instance, it gave the family an additional hour. He had taken the family in to see the relative, to see what it looked like, to see what the future would be for the family and for the relative, what resuscitation meant, to enable them to come to their decision. I’ve tried to discuss it, he’s avoiding me. You know, it’s not right…. aside from the fact that the staff were saying to me the gentleman himself on admission to the High Care Unit said that he did not want any tubes. I just thought it couldn’t have been more wrong, much worse for all concerned’.
There was a great deal of evidence in the data of practitioners differing over treatment options, and a great deal of discussion of patients having indicated a wish for this kind of treatment or that kind of treatment, but nothing is formalised. In the absence of formal, written, documentation it is very difficult to establish in fact what it is that any patient wants or would want, or indicated that they did want. The patient’s family can be anxious about the patient. They can worry the staff about pain relief, about other kinds of interventions, about transfers to acute hospitals. The families are motivated by concern for the patient and loved one. Families generally have little or no nursing or medical knowledge or training. They read patients symptoms with lay eyes and make lay judgements about what it is that they see. They can urge aggressive treatment for a patient who is in fact at the end of their life or who has been judged palliative by the practitioners. They can urge a transfer to an acute hospital for a patient and then that patient may end their life on a trolley on a corridor in an acute hospital. The practitioners must obviously take on board the concerns of the families and relations as the families and relations must obviously listen to the opinions and the advice of the practitioners. Families want the very best for their family member. Of course they want them to live as long as they can. There is a propensity too, documented in the literature, of patients and families remaining ‘unconvinced of the inevitability of death and focus(ing) on each episode as a unique event’ (Drought and Koenig, 2002). Drought and Koenig (2002) found in their work shared decision-making between patients and healthcare professionals to be illusory and they found that patients often resist advance care planning. One of the participants presented a potential perspective of a patient and the decisions a patient might make and some of the motivations for making those decisions as follows:

‘If I have a heart attack in the morning, how do I want to go? Do I want to be dragged into a ward, resuscitated, put on drugs?” …doctors will do the business to save your life, but each one of us has a different way. We want to be treated with respect. We don’t want to be stuck somewhere, you know, in a ward with 9 or 10 people, our lives ebbing away. I’ve seen it happen, where nurses are run off their feet….. I don’t want to be left hanging somewhere with people running backwards and forwards, you know, keeping me alive at any cost’.
In relation to the lack of knowledge and understanding among most patients and families about active treatments participants in the research talked about PEG feeding, about ‘subcut fluids’ about DNR (Do Not Resuscitate) orders, about ‘defibbing’ and ‘shocking hearts back to life’. They talked about the desirability often of keeping patients comfortable, keeping them in the surroundings they are familiar with, as opposed to transferring patients out of their familiar surroundings to the hustle and bustle, the briskness, the strangeness of an acute facility. Practitioners discussed Do Not Resuscitate orders. They talked about some patients being reconciled to the end of their lives and some patients not being in that position. They talked about some patients being very explicit that they did not want to be resuscitated, and they talked about some patients who were very clear that they did want to be resuscitated. The key issue in terms of patient autonomy is that the patient has indicated or has perhaps explicitly stated what it is that they want. The important thing is that these wishes are acted upon. The widespread practice that was encountered in this research was of not documenting patients’ wishes. This has the most serious implications for patient autonomy. In general the practitioners who participated in the research were seeking more clarification, were seeking adequate documentation. The general consensus was that further clarification and documentation would lend more preparation in many end-of-life experiences. Such preparation, it was felt, would provide for more peaceful, more dignified, more autonomous deaths. One practitioner said:

‘Sometimes their wishes may not be respected. You might like have a patient and you might know the patient quite well and know that they probably want conservative treatment or palliative care. The families might want this done or want them transferred to (named acute hospital). The next thing they’re getting bloods and x-rays and the whole lot done and know in your heart and soul, this is not what this patient wants’.

According to Kukla (2005), the principle of autonomy, despite official equal status with the principles of beneficence and justice, is now receiving a disproportionate share of attention. It is the cardinal principle. In practice, however, in terms of medical decision-making this research found that sometimes the family makes the decisions and sometimes the practitioners make the decisions, seldom the patient. One practitioner said:
‘I think sometimes what will happen is, sometimes there is push from the family side - for aggressive management at the end. Even though the patient is not keen to go for that, family members may be pressurizing to do aggressive things to show the patient, or I don’t know maybe somebody else, maybe the other relatives or somebody to show that they are very much interested in them’.

Families and family members can be motivated by guilt and less worthy instincts, as well as by love or concern. The research shows that the fact is that the focus can readily shift from the patient and what the patient wants or needs to what is perceived by others to be in the best interests of the patient. As the focus with regard to patient care at end of life is prone to move from patient to family, there is clearly a need for a more assertive statement of the rights of patients to autonomy, to the opportunity to express their own desires and needs and for those expressed desires and needs to be acted upon, in conjunction with the family but contrary to the family if necessary. While most clinicians readily asserted the patients right to a voice in their own care and decision-making, it was clear that in practice, families can be very powerful. One consultant who participated in the study said:

‘Even if the clinician thinks that this patient should not be resuscitated, invariably we have to discuss with the family and then only everybody will be happy …… like the other staff members …… and once the family is okay then …… everybody’s happy. Everybody’s okay. That is the way’.

Another participant said:

‘People need to be educated, that sometimes a person’s life is over and that it is not appropriate to resuscitate them. They need to understand that the person is at the end of their life, that their life is over, and that that is how life is’.

One participant outlined the value of explaining to families the meaning of active treatment. This participant said:

‘Patients and relatives usually, but yes, sometimes it’s just with the patients’ relatives because the patient isn’t able to make that decision, you describe what happens and everyone has seen television, when you describe what happens in the event of a cardiac arrest. When we can say that someone’s prognosis is poor and they are not going to survive a week or two anyway and, you know, putting them through resuscitation at the last moments of life is really not fair. When you explain that it becomes very clear to the family that this is not in the patient’s best interest. And they are much happier then to sit with them peacefully’.
Another participant gave another view of DNR orders in practice. This participant said:

‘Now the decision to make those (DNR orders) is usually taken in conjunction with the family of the patient and the medical team; a ‘not for resuscitation’ order documented on the patient means that in the event of cardiac arrest they are not for resuscitation. It’s very specific. In practice sometimes it just means that the patient is parked in a corner and nobody ever looks at them again, that’s the difficulty. Should they deteriorate the DNR order means that they are not for Intensive Care transfer. It doesn’t mean that they’re not for the normal standard management that’s available. I find that’s a difficulty, but once the order is issued it is like nobody bothers going near the patient again. So it’s a very difficult order to make, however ...’.

Participants emphasized the fact too that a DNR status can be changed very quickly to a Full Resuss status and that it frequently is, when patients suddenly improve. One participant said:

‘We had a lady last week which was ‘Not for Resuss’ and this week she is ‘For Full Resuss’ because her condition has greatly improved. Last week she was so unwell and she had such a long history, this week she’s so much better, she’s ready to go to (named acute hospital) for a Coronary Artery Bypass Graft, that’s as good as her condition has got. It was discussed with her and her family and ...she’s a ‘Full Resuss’ status now’.

Clinicians daily weigh the cost/benefits of treatments. One participant spoke about a patient as follows:

‘it was moderately non-invasive but not entirely non-invasive forms of treatment to prolong his life, which after a certain point the longer it went on the more uncomfortable you would naturally feel, because you’re prolonging something that really isn’t benefiting him. Although, I would say that he had some very good days when he received those treatments, but at the expense of what he went through to get them’.

Participants agreed that in general people want to go home to die, but that not everyone does want that. As detailed above, some people want to die in hospice care or in hospital close to home. The participants said that patients prefer not to have a tube in their throat when they’re dying. The participants said that there are cases where patients decide to withdraw treatment and that is not a problem, as long as the patient clearly understands the implications of withdrawing treatment. Patients may lose some time through the withdrawal of treatment, the practitioners said, but they may gain in quality of life. They
may, having withdrawn treatment, be able to go home and be able to have their end-of-life experience at home. One participant told the following story:

‘I’m thinking of a lady that had metastatic disease, had brain disease, and we were asked to see her up on one of the medical wards and I suppose from the very first day that my colleague met her, and then I met her the following day, all she wanted to do was go home. But I suppose she was newly diagnosed with the brain disease, would have had a lung primary and she was having radiotherapy when she developed the brain mets, they sent a consult and they felt the best treatment was to give her the radiotherapy to the brain and I suppose her condition was weak so the doctors and nursing staff felt that she wouldn’t manage to come in and out each day as an Out-Patient even though she was living close by to the hospital, that it would be better for her to have her treatment as an in-patient and for discharge after that. Half way through the treatment she was fed up being in hospital, was very close to her family, and her sons and daughters used to come in and stay with her all day and the husband and she just wanted to get home and kept expressing her wishes each day “when can I go home?” and “I want to go home”. But I suppose the Medical Team felt that it would be best for her to complete the treatment before she went home and then we could see as the treatment was continuing that her condition was getting a bit weaker so I suppose people were questioning the benefit of having this treatment. So she completed her treatment and did get her wish and got home but was only home for a number of days before she died. So I suppose it’s very rare that that situation would happen but I suppose, looking back on it, I kind of felt maybe the whole team should have listened more to the patient and maybe the decision should have been made maybe to stop the treatment and let her go home earlier’.

In terms of the withdrawal of treatment, there was a great deal of evidence of changing practice. One participant said:

‘We’ve recently had a death on the ward where the way that the patient was cared for was significantly different. I think that we’re on a very sharp learning curve here from where we were at 20 years ago to 10 years ago to now. Before we would have been hydrating people virtually up to the minute they took their last breath and now that’s changed and practitioners are standing back and they are examining what we’re doing. They are saying on one hand “okay we’re going to pump a load of Hyoscine into this person to try and dry up their secretions, but at the same time we keep them hydrated and we’re going to pump a load of fluids into them. At least people are starting to say “stop”. We recently had a lady on the ward who was 13 days without fluids. Now we all had a problem with that because we were saying “the withdrawal of fluids, is this actively euthanasing this person?” It wasn’t, that person had a urinary output up to the day she died. She didn’t need the fluids, she was comfortable. Her family had a positive experience because they were happy that their mother died comfortably. They thought that she was going to be dreadfully uncomfortable, she wasn’t. We gave her whatever she needed to make her
comfortable. The only thing we didn’t do was we didn’t give fluids and she didn’t need them.’

Participants highlighted a particular difficulty with patients particularly elderly patients and particularly if they are confused, coming from nursing homes, from long-stay institutions into an acute facility. Sometimes, participants said, a patient arrives from a long-stay facility and they are clearly dying, and they wondered what would prompt staff of a long-stay facility to move a clearly dying patient into an acute setting. The participants talked about doctors from *Doctors on Call* overriding established medical-care decisions. These doctors may want the patient transferred to an acute setting, they may want full intervention. This can be against the patient’s wishes, the wishes of the family and against the wishes of the doctors and nurses caring for the patient.

In sum, the findings of the research in relation to active treatment indicate that there is a need for education around palliative care and what it is and what it can accomplish. There is need too for a degree of education around active treatment and what can happen to a patient at end of life in hospital subjected to active treatment. The influence of families, the pressure that can be brought to bear on patients calls for critical reflection. The willingness to move patients out of long stay facilities into acute hospitals and all that goes with that, the hurry and bustle, the general busyness, the anonymity and so on emphasizes the need for substantial critique.

**Theme Three: Patient Autonomy and Other Values**

The issues in patient autonomy and respect for patient autonomy in hospital care settings are manifold. At the centre of the issues is the fact that the patient by definition has surrendered a degree of autonomy by becoming a patient. A patient in hospital is by definition under the care of a team of clinicians, under the expert care of that team of clinicians. The degree of autonomy allowed the patient is often dependent upon the patient and the degree of autonomy they demand or the degree of autonomy they are capable of demanding. Very often patients in hospital care settings are incommunicative,
they can be drowsy, they can be confused, they can be unconscious, they can be comatose, they can be in a state of dementia, they can be intubated and ventilated. There can be other competency issues at play. There are different challenges in terms of patient autonomy for children who are patients in hospital, and there are different challenges for adults with intellectual disabilities who are cared for in long-term care settings. Communication can be difficult with some patients and there can be challenges for staff in the hospitals to establish communication with some patients and to establish through that interaction the degree of comprehension that exists for those patients. Clearly this has implications for patient autonomy. The evidence of this qualitative research emphasizes the role of the patient, their willingness and capacity to assert their autonomy, along with their mental state or degree of competency and their physical condition, in determining the degree of autonomy they are allowed. This evidences the value of advance planning or directives, where patients before they become in any way or to any degree incompetent, write out their wishes and their instructions for their care should their competency become impaired. These advance directives then can be accepted by clinicians as patient input or direction in terms of care from even the least competent of patients.

‘I actually think that we should start bringing in Living Wills, I really do because by the time it comes to the end of their lives, most of our patients don’t have a say because they’re either confused or they’re not compos mentis. You will try and listen to the ones that are and if you can make it possible you will make it possible but I do think we should bring in some sort of Living Will.’

One practitioner gave the following insight into end-of-life communication from the perspective of the ICU.

‘I suppose working in the Intensive Care Unit it is a very difficult situation from the point of view of patient autonomy because we don’t have very much interaction with the patient until they come into us and most of the time then they’re unconscious, they have an ET tube in their mouth so it’s very hard to know what exactly the patient would have liked, unless they have been in and out before which sometimes you do, you have patients who have been in and out of the unit before and you’ve managed, you know, you get to know them and you kind of get to know their wishes. Not always directly because, as I said, a lot of people in Ireland don’t discuss or
think about end-of-life decisions, I haven’t really had any experience where people have made a decision beforehand’.

This insight evidences the unwillingness of people to think about or discuss end-of-life issues. This ICU practitioner had never had any experience of patients having made any kind of an advance end-of-life decision.

One participant said:

‘There’s the ongoing concern about consent and about resuscitation status in relation to situations, and I suppose the problem is that if it’s not documented, then the resuscitation goes through and that is legally their duty to do so. But unfortunately sometimes families are asked themselves to take that responsibility on board and they find that they’re not in a position - they don’t feel they’re competent enough or comfortable enough to make that decision. So what they do is they would always take advice of the doctor and they would say “Look, we will do whatever you say.” So they’d actually throw back that responsibility to the consultant and that can put the consultant in a very awkward situation’.

The participants felt, many of them, that they needed to be more engaged in considering the patient and what the patient might want and what the patient’s wishes might be. Some of the participants felt that they often - particularly in a critical care setting - look at and search for what relatives’ concerns might be and what they think the patient wants. It was said to be a challenge for clinicians in that they often see patients when they are very ill and sometimes incapable of making their own decisions or, as one participant said, ‘we think or we perceive that they’re not able to make their own decisions’. So it’s about training and education and encouraging clinicians to listen to patients more, to look at their fears, concerns and emotional needs and to be able to discuss possible outcomes with them, and to try to ensure that any wishes they express be taken on board. A written document, drawn up by the patient, would provide input from the patient with regard to active or aggressive treatment in the event of the patient being incapable at the time of the intervention of giving their consent. Many of the practitioners expressed the view that advance directives would make for clearer communication generally, that the patient would be aware of their condition, their diagnosis and their prognosis, and that this then
would allow the clinical team to be clearer in their communications with patients and more open in their engagement generally with patients and in particular with patients at end of life. The problem is that often difficult decisions around active or aggressive treatment are not discussed with patients before they become so ill that they are incapable of participating in such a discussion. When a decision needs to be made for such a patient the clinicians consult the patient’s next-of-kin, the patient’s family, and somehow a decision must be made either by the family, or the clinician, or both. The decision then is made without input from the patient but often with the clinical team relying on the patient’s next-of-kin or family for some insight into what the patient’s wishes would be.

One of the most striking experiences of the fieldwork for this research was the challenge of defining and describing patient autonomy to very many of the practitioners. While some practitioners were very knowledgeable about patient autonomy and very descriptive in terms of practices around patient autonomy, a number of the practitioners who participated in the research were not knowledgeable about the concept. They were slow to outline a definition of it, and slow too to describe practices around it. Many of the nurses who participated in the research spoke very readily of being patient advocates, the nurses would be advocates for patients, with other members of the clinical team and with the patient’s family. This role of patient advocate that some nurses assume, and have been explicitly trained to assume, is very useful in terms of patient autonomy in care settings. One nurse said:

‘my role as Clinical Nurse Specialist is to support the patient in whatever decision that they might make, whether it’s for assent to control or for more active treatment or, you know, to withhold on all treatments’.

The reluctance or inability to engage with the concept of patient autonomy, evident in much of the fieldwork for this research, evidences more than anything the need for a programme of training and education around patient autonomy and the need for the new ethical framework on patient autonomy at end of life.

In terms of defining patient autonomy, the following exchange is a typical example of the dialogue that developed in the focus groups when the practitioners were asked to define and outline patient autonomy. The practitioners said:
‘I suppose it’s the right and the ability of the patient to make a choice’.

‘it’s the choice of what kind of treatment the patient is going to receive and the degree of treatment, if it’s going to be just like minimal or more aggressive’.

‘I suppose it’s more the patients’ right to make choices around that and, you know, that we would be respectful to the patient’s wishes …’.

‘… that we would take their wishes into consideration and act on them at all times …’.

‘It’s to do with, maybe not just the treatment, but things like patients’ family involvement and special particular requests that the patient might have as to whether we can, you know, the balance between whether we can have whatever the patient wants from a practical point of view’.

The power of the family, and the challenge the family can pose to patient autonomy in hospital care settings was very evident. This challenge was discussed in every encounter throughout the fieldwork. The family was said to play a major role in taking away autonomy from patients. The family was said not to want patients to hear bad news. Many families assume the right to tell clinicians what they can and cannot tell patients in terms of diagnosis and prognosis. As one participant said, it’s very hard for a patient to be autonomous if they don’t know what is wrong with them or what is happening to them or what is likely to happen to them. One practitioner said:

‘If the patient himself or herself doesn’t wish to know say the severity of his or her condition then he or she wouldn’t know exactly what’s happening, so in short, it’s the family members who will be making the decisions then’.

As the quote above evidences, communicating bad news in hospital care settings is fraught with difficulties and complications. In fact, perhaps the biggest challenge to patient autonomy in hospital settings is the challenge of breaking bad news. The evidence of the qualitative research suggests that in very many cases the patient is not told the diagnosis and so is not aware of their condition. This is frequently because the family insists that the patient not be told, and the hospital staff respect the wishes of the family.
This issue of communicating bad news, and practices around that, is dealt with in more detail later in this report in the section on Communication. One nurse said:

‘I did have the experience of a gentleman, you know, I got a referral to say that he was, you know, quite anxious and, you know, he needed to speak to somebody. He wasn’t really consenting to his treatment and, you know, I went to see him and his biggest thing was that he said he had got no information from the team as to what the treatment was, why he was getting it or what his outcome was going to be. Now he did say to me “I understand it’s not going to be good news but I’d rather know”. I think if people know good or bad they’ll find a way to deal with that or they’ll find a way to cope with that, it mightn’t be the best way but I suppose then you can come in and try and offer some support with that. But for that man, at that time, he just felt “I don’t know what they’re talking about” and at the same time he had a sense, he knew it wasn’t going to be good, “but just tell me so I can get on with it”, so those sorts of things. I think just people being fully aware at all times of what’s going on. I suppose that they feel that their wishes are respected, that we’re not running off and ringing the family to say well “they’ve said no but we really think ...”, you know, and I would always feel that - I would always go and see a patient first and say to them “listen, is it okay if I call such and such?”, if they say “no”, that’s fine, that’s their decision and the team mightn’t like that or, you know, a lot of people don’t like that but that’s - I feel that they should know that their wishes were respected. And then, you know, I suppose just the amount of dignity they have around that as well’.

A consultant said:

‘We’ve seen lots of examples of patient autonomy and that usually comes - the main areas that we see that is in terms of information disclosure so it’s a patient saying “I want to know” or “I don’t want to know” and, as a Palliative Physician, where that can become an issue then is typically when the family have a different view on it. So that’s maybe the most common and the most obvious point of patient autonomy. Then other areas would obviously be around treatment, choosing to have or not have treatment, choosing place of care where we feel the patient is well able to go home and they say they’re staying in the hospital and vice versa. I suppose there’s the whole idea of just empowering people at a stage when they’re becoming ever more dependent to try and retain some autonomy for patients at that point and to get other family members and professionals to see that, that although the person in the bed or in the chair or standing in front of you is less well and is maybe less able to walk or to think or to speak that, you know, we still need to look for what they can be autonomous about and help them with that’.

A nurse said:
'They (the patients) do make requests about wanting to stop treatment or wanting to go on with treatment and generally I think they are heard, yes. I mean very rarely there might be sometimes where you can sort of see that it’s, I mean I’m a nurse, I’m not an oncologist, but probably even that the doctors might be thinking the same thing that what’s the point of this as far as that you don’t think the chemo is doing any good, that it might be nearly doing more harm than good and the patient still really wants to have it because they feel so desperate or whatever it is that they feel like, that it is going to help them. I wouldn’t say that they’d be given chemo because it’s worthless, when they shouldn’t be having it, but there might be an instance of something that is not going to harm them but you’ll still give it to them. So I think in that way the patient’s autonomy is respected, you know, but obviously you can’t be giving patients a thing that’s going to harm them but I think that might very occasionally happen that it’s not going to harm them but it might not be doing them any good, put it that way. Certainly if patients say “that’s enough, I don’t want any more” that is definitely respected. And of course if there’s a situation where you might think, generally people - medical, nursing, might think that they should keep going ahead, you would try and encourage and educate. I can’t really think of many instances where people do just say “that’s it, I don’t want any more”, it seems to be more a joint decision really’.

Patients do ask for further treatments, for chemotherapy and so on, and where possible these requests are met. They are not met where the treatment would occasion damage or harm to the patient. Neither are they met where there is an issue of justice, where giving the treatment to one patient who will not benefit or is unlikely to benefit, in the opinion of the clinicians, when giving that treatment would deprive another patient of the treatment when that patient might in the opinions of the clinicians benefit from the treatment. It seems that giving such a treatment sometimes fosters a glimmer of hope within patients and sometimes that glimmer of hope can be life-sustaining, so where the treatment per se is not benefitting the patient, the experience of being given the treatment may be of benefit. In terms of justice one consultant said:

‘I think it’s probably number one if you look at the ‘classic four’, [autonomy, nonmaleficence, beneficence and justice], it’s probably number one of those but sometimes, having said that, it gets outweighed, patient justice frequently comes into it. There are resource issues for us that we can’t, you know, the patient who says “well I want this chemotherapy which has a 5 per cent chance of giving me another 2 months” and that treatment costs €12,000 for every 3 weeks, there is a patient justice issue if we spend that money then where are we taking the money from? So there are - patient autonomy has to be respected and encouraged but it’s not an absolute, it shouldn’t be an absolute. And I don’t think there is one thing that will
That consultant spoke of patient autonomy as being a process, a gradual process. This implies that patient autonomy is a negotiation between clinicians and patients, and of course families, an ongoing negotiation and a negotiation which is unique to each patient and each case. In fact this is probably close to the actual practice of patient autonomy as described throughout this qualitative research. The research shows patient autonomy to be an experience which is negotiated between the patient and the clinicians and as such the experience of autonomy for each patient is unique.

In terms of patient requests for further or on-going treatments one practitioner said:

‘Where patients make treatment decisions, where they say “look I’ve had enough of chemotherapy, I don’t want it” or they say “well, you’re telling me that there’s only a 5 per cent chance this will work but I really, really want to try it nonetheless”. We’ve a patient who went home last Friday again, it was a busy day, she has a particular problem that we’ve been investigating. Now we know it’s from her disease, but we haven’t be able to actually pin that down and there was a further test which might help us pin that down but it won’t help us change her treatment at all and therefore we’ve decided not to do that test and she said on Friday she wants that test done. She phoned in yesterday and she’s now - we have her booked in for Friday of this week, she’s coming in to have an invasive investigation done, which we think isn’t to her advantage, but she’s very clear that she wants to have it done. And I think it will be to her advantage in that it may put her mind at rest a little bit, so again, I think her call is maybe not the right decision but we’re going with it because it’s not outlandish and it’s not ultimately harmful to her to do this so we’re supporting that’.

One of the most critical areas in patient autonomy is in terms of the autonomy of older patients, and the degree of autonomy allowed patients in care settings appears to diminish with age. One practitioner said:

‘I think the most obvious place where patient autonomy falls down is with ageism. If somebody is 30 or 40 or 50 we are much more likely to pay heed to what they’re saying and involve them. If somebody is 70 or 80 or 90 we’re much less likely to so as a sweeping statement I think patient autonomy tends to decrease with age and I don’t think there’s a good reason for that but I think that is the practice of what happens’.
One of the participants described very clearly the journey into the ‘sick role’ for people or persons who become patients, and in particular older people who become patients, and the loss of self and the loss of identity and the loss of autonomy that is a part of that particular journey.

‘You know, I mean, they’re coming from their own environment whether they’re in their own home or in their own community and they have their own lifestyle and they do things their own way at their own time and they have their meals at a certain time and they feel free to do that in their own environment or in their own house, so they come into a hospital where they have literally let go of that routine that they are used to and fall into our routine, so as a result therefore there is control of their own lifestyle that is now taken from them to a degree because it’s important to have the structures that are in place here to give them the care that they need. I find that especially, you know, people maybe elderly people living on their own who have a very strict routine of their own and then completely come out of their own environment, to be sharing a room with five other people, to be eating meals at times they don’t usually, to wake up at a time they don’t usually wake up and to be interacting with people who they’re not used to or whatever and trying to take a lot of outside stimulation in on their own lives that they’re not used to and then they feel as if, what can I do now, you know, so they have no control over anything and then their illness then itself can also change their lifestyle and their routine of their lifestyle and the way they live and whatever it may be. So sometimes, you know, you need to give them back something so that they can feel that they can have ownership of their life again’.

There is paternalism too in the care provided by clinicians for patients. One practitioner said:

‘I’ve yet to remember when a patient had full, you know, control over what they exactly wanted. We feel we’re doing what’s best for the patient and we do, we do what’s best, but I don’t know whether we question enough by asking the patient “is this what you want”. So I think as yet patients haven’t got great control over end-of-life decisions’.

Participants in the research described patients as having no autonomy in the end, no autonomy at the end of their lives. Participants described patients being cared for physically and medically yet having their emotional needs ignored. Participants also gave some insights into the experience of being cared for at end of life within an institution where as one participant said the patient may feel that they do not have the freedom to make a request. Patients are conscious of other patients and do not want to infringe in any
way on their comfort. Patients generally have a great deal of respect for the nurses and are often in awe of the doctors and they won’t interfere in anyway in their work or in their duties or in their regimes of care. A patient may want the lights off or the TV off or the radio off. They might want to get up, get dressed, and go for a short walk. Patients generally tend not to give expression to these wishes, particularly if they feel the clinicians are busy or preoccupied. Patients know very well, the participants in the research said, that they are not in their own homes and that they are not free to act autonomously as they would if they were in their own homes. The participants expressed the wish and desire to be able to give people the confidence to ask for the things they want or to control their environments more and to control their own deaths if they want to do that. One participant said: ‘If they don’t want a load of Morphine and they’re getting it, to say “no”. Or they want more and they’re not getting it, not to be afraid to say it.’

It is not always possible to adhere to patients’ expressed wishes, even where there is a strong focus on patient autonomy, in particular where there are practical issues: a patient may wish to die at home, that might not be possible, medically and in terms of the home support available; the patient might want to die in the hospital, that might not be possible, there may be pressure on resources; a patient might want to go to a particular hospice to die, that might not be possible, there might not be a bed available in that hospice for the patient. Clinicians, out of medical necessity, will act in the patient’s best interests, when the patient is unable to express their wishes for their medical treatment. Clinicians will advocate or advise a particular treatment path for patients, even where patients have expressly stated that they do not want the treatment or they want the treatment withdrawn. A competent patient can decide to decline the treatment.

The consultant was said to lead the care of each patient within hospital and as such the consultant was said to be responsible, ultimately, for ensuring that patient autonomy was respected, as well as everything else.

‘The consultant is the person that leads the whole care and I think they need to be again informed about patient autonomy. I don’t know how much training they get on patient autonomy and how that’s achieved, but in practice patient autonomy is achieved through delivering information to the patient, that’s my opinion, and ensuring the patient knows where they’re going with the treatments, knows what
the outcomes of the treatment are, knows when treatments aren’t going to work, knows when, end of life is imminent...’.

Participants in the research expressed concerns that expressions of anger, anger at diagnoses and prognoses, and expressions of ignorance around the efficacy of particular treatments, might be taken as expressions of autonomy on the part of patients. These participants felt that there was a need for a great deal of training around patient autonomy for practitioners working with patients at end of life in order to ensure that such critical errors of judgements did not occur.

Particularly problematic is patient autonomy and respect for patient autonomy for children who are ill in hospital. In terms of patient autonomy for children, participants said that parents would be very involved, necessarily, in any discussions. The participants felt that children, as they get older, need more and more of a say in their treatment and in their medical decisions. Some participants felt that with very very young children there would be concerns about autonomy. While other participants felt that the challenge was with older children. One participant said:

‘A child who is on the cusp of having their own autonomy, you’re looking at teenagers, and we see children here from premature babies up to 18, 19 and sometimes 20. We see children with intellectual disabilities as well and the whole role of autonomy for somebody with an intellectual disability and the challenges that poses, in terms of can they be autonomous? Are they allowed be autonomous? Whether that is from their parents’ side of things or from the medical point of view or the child’s own abilities. That’s a huge challenge’.

Participants discussed the maturity of children who are seriously ill and who perhaps have spent long periods of time in hospital.

‘Because if a child is hospitalised you would find that they would have different, very much mature understandings of the whole workings of a hospital and many children, I know from recent experience, would be fairly familiarised with the whole concept of death’.

The issue of collusion, clinicians colluding with families in not telling patients bad news, was highlighted in particular by clinicians from the children’s hospital. Clearly this issue was an issue that had been given much thought among those clinicians and they readily expressed their concerns in terms of what they termed collusion between clinicians and
families in concealing diagnoses and prognoses. The issue of collusion was an issue more so in terms of the child patient’s autonomy than the adult patient’s autonomy. One participant said:

‘I suspect that in real terms, in terms of, you know, whether treatment continues or doesn’t continue, some children have the autonomy or are given that by their parents to some extent, particularly the older teenagers, but some aren’t. We’ve had parents who just absolutely point blank refuse to tell their child what’s happening and, you know, there’s I suppose collusion - there’s a huge amount of collusion, you know, you don’t tell them, they haven’t asked so I’m not going to tell them. So where is the autonomy there for that child’?

Another participant said:

‘I think we see a fair amount of collusion here where, you know, parents don’t want to tell their child their diagnosis for example. They might be going to have surgery for something, like say a central line so they can have chemotherapy, and the parents don’t want to tell the child that they’re going to theatre for a particular procedure. And because they don’t want to be seen as being bad perhaps, you know, there’s lot of various different reasons, there’s a huge amount of that sort of not telling them information. The parents have the information but maybe are not passing it on in a way that the children understand. And I would say that on a day-to-day basis very many of us see that, we see it in oncology a fair amount as well where they’re not actually told their true prognosis or what’s happening to them because the parents themselves don’t want to go there. But I mean some of them would be 14, 15, 16 year old children who don’t have that much autonomy therefore in terms of whether they can have treatment or no treatment or whether they continue with treatment’.

In terms of children’s autonomy one participant said:

‘I think the challenging ones for us are where the children aren’t, particularly older children who can understand, really told the full facts of what’s going on. In a way the parents, or the medical team, may want to protect them but, you know, you cannot really make a decision if you don’t really know how it affects you and I do think that happens here, that children are given a certain amount of information but not the whole facts. And you sometimes wonder if they had all the facts what choices would they make, if any, would they be different? And in that way I would sense that they don’t really have that amount of autonomy when it comes to that actual end decision because it is the parents that will make the decision until they are of an age where they can and at that stage they are probably in an adult hospital where they can make that decision themselves’.

Another participant said:
‘I suppose the whole issue in relation to the older adolescent child who isn’t told their diagnosis, is that really they do have a right to know, and that would be a concern definitely, even if a parent isn’t able to tell their child that, and a lot of parents might prevent the doctor from telling them anything and it’s not really fair, I think, when it’s an older child that they should be told. Children react differently when they’re told. Some will totally act like they were never told even though they were and that’s fair enough, but at least they’re given the opportunity to be told and that it’s honest, they’re given their prognosis and they can cope with it and deal with it whatever way they like, but they do have a right to be told. When parents request that they’re not told, it’s extremely difficult. Palliative care like at its simplest form is about quality of life. So when a child’s life is cut very short, you have only a short time to do what they want. They need to know. That an older child wouldn’t be told, that would be a huge concern’.

A sick child in a family is as much at the mercy of the family dynamics as any sick person within a family. Sometimes the dynamics are good and sometimes they are not so good. Where the not so good family dynamics interfere with the care of the child the clinicians may need to intervene and facilitate a resolution, as they intervene in any such family. Such interventions are often unwelcome and as such they can be difficult and challenging for the clinicians as well as the families. All of this goes to further the complexity of the situation of the patient in hospital and expressions and experiences of patient autonomy and practices around patient autonomy in hospital care settings. In addition to this, most patients wish to end their lives in their own homes and often the extent to which this can be accomplished is dependent on the level and degree of family support. There was a great deal of evidence in the data of families and individual family members interfering with expressions of patient autonomy in particular where a patient declines a treatment or a patient has clearly indicated that they would like treatment withdrawn. Families and individual family members sometimes find it difficult to let go, to allow the dying patient to die. There was a great deal of evidence in the data of clinicians establishing the patient’s care options, particularly on admission to hospital or at end of life within hospital, with families and family members rather than through discussion with the patients themselves. There was also evidence in the data of treatments being imposed on patients, sometimes without the patients being fully informed of the outcome, without the issues being fully explored with them, in terms of whether the treatment is going to benefit them, whether the treatment is going to prolong life, or whether the treatment is going to improve quality of life. There is evidence in the data of
elderly patients, people in their nineties, being admitted to acute hospitals and then going automatically onto a ‘treadmill’ of treatments and interventions which will not and cannot make the patient better, because the patient is at the end of their lives. The treatments may prolong the patient’s life, or may not; the treatments, because of their aggressive nature, may in fact shorten the patient’s life. Admission to an acute hospital automatically generates a battery of tests and interventions that often, for patients at the end of their lives, can become a treadmill with possible detrimental rather than advantageous consequences. One participant described the patient admitted to an acute hospital as a spectator, a spectator who is there because they have to be, not because they chose to be, a spectator to whom things happen, things they don’t have a choice about because someone else has deemed it necessary that these things happen to them.

The emphasis in the long term care facility for adults with intellectual disabilities was on quality of life. Patient autonomy was respected and was constantly the focus of the carers and clinicians within the hospital. The willingness of the senior management of the hospital to take risks with individual patients in order to enhance their autonomy and support their wishes shaped the experience of the facility for those living there. One of the clinicians in that facility reported the case of one of the patients who was terminally ill. This patient knew her prognosis, she had been given that by the doctor and she decided herself that she did not want to go to an acute hospital, she did not want to have surgery. The doctor advised the patient and the patient’s family, but respected the patient’s wishes. The woman who had an intellectual disability stayed in the long term care facility in which she had lived her life and she died there. That was her choice. Another participant said of another patient in this long-term care facility:

‘In my recent experience, while spending some time with a service user who was actually diagnosed with a terminal illness I sat with her and asked her if she had any wishes she would like us to look after and her wish was to visit Lourdes. She actually had been to Lourdes before but she felt herself that she just had the need to go to Lourdes again and she just felt that her condition was deteriorating. So while I was talking to her I documented what she was saying and her wish was granted. Another concern that this same person actually had was that she would visit her parents’ grave and this was a huge wish for her because she herself felt “well I want to know where I’m going to be buried” and that was looked after. So they were just two very simple - simple to us, we were well able to fulfill that duty - and to her it was a huge issue’.
One of the participants said of the respect that there was for patient autonomy within the care setting:

‘I can’t think of any situation whereby you have a patient who is totally orientated, without any cognitive impairment, who were able to make decisions for themselves and had those decisions overridden. I can’t remember any examples of that, you know, and obviously if a patient decides what they want to do and they are capable of making the decision in relation to that, that’s their choice. And if not, then we would discuss it with their next of kin and try to get a consensus on that but I can’t remember any incidences where people’s actual wishes were overridden’.

Another participant said:

‘When we actually know the wishes of the patient, when the patient is well enough to tell us what they would really like at the end of their life, we can really act. But when we don’t, when a patient comes into us very ill and we really don’t know their wishes and suddenly they become more seriously ill, we really don’t know if we’re doing everything according to their wishes. It could be according to the family’s wishes but it mightn’t be exactly according to their wishes. So we’re doing a piece of work at the moment, it’s all around the Hospice Friendly Hospital Programme on end-of-life issues, where we actually get to know the wishes of the patient when they’re not very, very ill. And what we’re doing is we’re doing a life story and, you know, documenting the wishes and then putting that in the care plan. Now we’re starting it so that we will know exactly what they want us to do, if for example they become seriously ill and would they like to be transferred to an acute hospital? Would they like to stay here with us’?

Patient autonomy is an extremely important value and in particular respect for patient autonomy in hospital settings is vital. It is vital because patients tend to become spectators to their own lives when they are admitted to hospital. They tend to lose their personal identities and those identities tend to become submerged in their new identities as patients. Patient autonomy is a fundamental right, as the Hospice Friendly Hospitals definition states: patients have the right to express their wishes in terms of their care and to have those wishes acted upon. It became however apparent through the research that patients often rate more highly values other than their own autonomy. One participant said:

‘…in our culture especially the rural culture in which we mainly - where most of patients come from - autonomy is not part of the consciousness of everyday life to
anything like the same extent as it is in, you know, post-modern kind of situations where people have moved on. We’re still very community based and family ties and the fabric of, you know, even the new type of families and so on is still very strong. And I think it needs to be worked out what does autonomy signify in this context…’

Often patients will allow other people to speak for them, and this may be an expression of their autonomy. It may be their wish that this person speak for them. They may appreciate the concern that this person has for them; they may be concerned about the loss they will be to that person when they do die. They may be trying to provide what comfort they can to that person or those people. One participant said:

‘I can think of an example a few weeks ago where this man just used to do the answering for his wife and, you know, like he did respect her decisions but he kind of - she had a brain tumour and he kind of used to answer the question before you’d get a chance to hear her answer and when we were offering her - her balance was very unsteady and we were offering her a place in the hospice and he said “no, no she can go home, we’ll manage at home”. And, you know, I suppose he was just not ready to let her go to the hospice and really keen to take her home and she went along with that but I felt that deep down, you know, if he was more open to the idea she’d have been more open to it as well because she was fearful that if she was at home the dogs would knock her over and that, you know, or that she’d be for periods on her own in the house - things like that’.

Many participants evidenced the fact that patients would regularly and readily defer to the nurse or the doctor, ‘whatever you think Nurse’ or ‘whatever you say Doctor’ were everyday elements of the dialogue between patients and clinicians throughout all of the hospitals visited for the research. The participants said again and again that patients will not complain. One of the consultants interviewed for the research said that:

‘There is almost a patient acquiescence in the final moments of their lives and it’s unusual to find a patient who is particularly demanding of us. They don’t want to make a bother; they don’t want to make a fuss’.

One participant said that they, the clinicians, would hold meetings about patients with patient families. The clinicians said that the patients would be given the option of taking part in the meeting and while some would, many would not. Those who did not want to attend the meeting were usually men who would let their wives decide what was right,
‘their wives are usually in charge’ and the patient would say ‘whatever the wife decides is absolutely fine by me’. The team would discuss the decision later with the patient.

It often happens that a patient will expressly not want to go home at the end of their lives, because they don’t want to be a burden to those at home or because they want to preserve the memories of them well and fit and strong in the home for the members of their family, and they would like to confine the memory of them ill and dying to the hospital or other institutional care setting in which they have chosen to live their end of life. This research clearly shows that very often patients will put the wishes of their families before their own wishes. This can be viewed as an expression of patient autonomy or as an abdication of patient autonomy. One narrative detailed the end of life of a man called John Joe, who did not want to die at home as he lived with his brother who was also unmarried and he felt that his dying at home might be too much for his brother to deal with. The narrative is detailed below:

‘On John Joe’s last visit following endless transfusion John Joe states he is ‘having no more of it’. He is now happier than he has been for some time, as he is in a ‘long stay’ palliative bed in the district hospital. His brother does not have to worry any more. His pain is managed. He is comfortable with where he is with his condition and is more content that the “burden of care is removed from the brother”. I heard on the radio yesterday of his death’.

The research clearly shows that people value life and they will in fact cling to life, and no matter how comfortable carers and clinicians try to make their end-of-life experiences, or how much respect is shown by clinicians and carers for their autonomy at end of life, some patients will deny that they are at the end of life, reject the end of life experience provided for them, and cling to life. Nobody wants to die. Patients at end of life cling to hope, hope that there will be another intervention, that this intervention will work, that there are other treatments and other options. Clinicians who participated in this study could remember very few if any patients in years of practice who rejected the offer of potentially life saving surgery, even when the surgery would occasion them great trauma and the odds of the surgery being successful were very clearly not in their favour. One participant said: ‘we’d find a lot of the patients are keen for further chemo, they see stopping chemo as losing hope’. Another participant said: ‘when the patient comes into
hospital the expectation is we’re going to make them better and get them home again and that’s what everybody wants no matter what age they are, that’s what they want, they don’t come in to hospital to die, they come in to get better’. Another participant found especially difficult patients, and the parents of patients, who were ‘being unrealistic, really unrealistic and unnaturally hopeful against all odds’. This participant said that we’ve become more technologically dependent and there are more treatments now than ever before and as a consequence perhaps, the public has a huge expectation that everything can be cured. One of the consultants who participated in this research said that it was wrong to give a patient a terminal diagnosis, certainly wrong to give such a diagnosis directly. This clinician said that patients need hope and that when all hope is removed there is a strong possibility that the patient will give up and die immediately.

Sometimes patients hold other values to be more important than medical care. This is true and again evidenced in this research in terms of Jehovah Witnesses and their refusal of blood transfusions. There was a case in this qualitative research of a Jehovah Witness refusing transfusions in a provincial hospital and subsequently dying from blood loss. There was a case reported in this research of a baby born to a Jehovah Witness being made a ward of court so that the hospital could legally administer blood to the baby, against the expressed wishes of the baby’s mother. In terms of other values, there is too the fact of patients, children and adults, who will under-report pain in order to protect their parents and families and relations, in order to spare them more distress. There is, as was seen above, the focus of the medics on curing and fixing patients, sometimes to the extent that other values are ignored completely. One nurse spoke of her consultant as follows:

‘I think he really, really goes in there thinking I’m not going to pull out on this patient until the very, very end and I know I’ve done absolutely everything that I could do. And that’s where the problem is, doing everything he can do is losing sight of the obvious, you know? The last patient I had to sit him down and say “listen, just sit back and look at this patient, just look. Do you really think this man is going to survive?” and then he had to say “yes, we’ll stop”…’

Then there are the patients whose autonomy at end of life is diminished because they don’t want to know that they are dying. There are parents who don’t want to know that
their child is dying, and so can never have an open discussion around end of life with the child. There are children, adult children of dying parents, who are so devastated by the possibility of the loss of their parent they can never confront that death or even the possibility of it. They can never discuss it, or even articulate it. There are too the patients who are dying, who know they are dying but who can’t or won’t articulate it. One participant said:

‘Eventually I think ultimately they always know. I was going to say I think it can take people a while to - I mean it can take parents a while to come to terms with what they’re hearing. And sometimes they never come to terms with it, some parents just don’t. And I don’t think you can make parents do what they don’t want to do. No. There are just some parents who just never get into that place where they understand. They don’t want to know - don’t want to go there and, you know, I suppose maybe it’s a self protective mechanism for them. But you can’t make people do what they don’t want to do. And I don’t think we try. We try and guide them along the way but, you know, if they come to a blank wall, they come to a blank wall’.

In relation to the deaths of children, one nurse said:

‘we also are morally and ethically bound to do what’s right for the child and, you know, we cannot extend life just for the sake of it or because the parent doesn’t want to give up, so we have to find a way of working together and that can be difficult. There’s no easy solution, there’s no quick fix, it takes time and sometimes parents never come to terms with the situation and they may be very angry and, you know, channel that anger at the nurse at the bed space or at other people as well. But I suppose the reality is, and it’s not me being harsh because I don’t think I am harsh, you know, the reality is that medicine cannot cure or the surgeon can’t cure, there are conditions that cannot - we cannot – fix, but we can allow people to live their life as well as they can, you know, and some people do more living in a shorter space of time, that it’s how well you live that life that you have’.

Some patients use not knowing as a defense mechanism; as one participant said: if a patient doesn’t want to know then information should not be forced upon that patient; some people use denial as a coping mechanism.

There is the value of privacy. Sometimes patients don’t want to talk about their end-of-life or impending death because they don’t want to feel that they are being counseled or analysed in terms of the manner in which they are engaging with that experience. There are patients who have little or no experience is discussing their thoughts or their feelings,
and little or no desire to do so. It was clear from the research that very many people and patients do not want to talk openly about death because they are trying to protect other people; because it is for them a privacy issue; or it is a personal, parental or family issue. Many of the participants felt that culturally, the whole country would make a big leap forward if we could and did talk openly about death.

Below is an end-of-life narrative detailing the experience of one family throughout the death of their son.

‘So this child had cancer that wasn’t treatable and his disease had progressed and he was in a lot of pain and he was protecting his parents and there was social issues, like the parents were separated and that and the boy would have been about 8/9, and if he had pain it would cause upset and stress to the parents. So he would under report his pain and then also the Dad had a real issue with the drugs we were giving him and felt we were inducing his death by giving him drugs for pain, rather than the fact that like it’s the disease that’s causing the pain and we have to keep him comfortable. He felt - what he felt and probably it was his own difficulty in coming to terms what was happening, was that we were killing him. Bringing it on somehow, with the drugs we were making it happen sooner and he would barter and try and get the drugs reduced, and you had to negotiate increases in medication with the Dad in particular, you know, and if he’d agree to let you put in drugs that the child needed for his comfort, that was a bonus which, you know, isn’t really right do you know? And that that child probably did suffer unduly. And like another aspect of that particular case is that child could have died at home but because of the parental discord I suppose and it wasn’t possible because of so much stress in the house and I suppose the parents were coming to terms with the situation themselves and there was a lot of anger. And the Dad was quite a big man and intimidating and from a home care point of view, they didn’t feel safe to a certain degree and it was the personalities like and I kind of feel that child, he wanted to die at home and it was his parents, you know. He just couldn’t, and it probably wasn’t hugely positive and I think we are very good at involving parents here and like everything is explained to them, but sometimes maybe it’s a bit too much for them and sometimes you would see that, parents are so confused as to what the right thing to do, that sometimes you just need someone clinical that is saying this is the right thing to do, don’t get bogged down about the drugs, you know that way? That it’s okay just to be a Mum or a Dad’.

There are a lot of issues highlighted in the above narrative. There is the anger and confusion over the impending death. There is the bewilderment in terms of medical treatment and which course of action is the best course of action. There is the need to be at the centre of that complex network of care that is the experience of hospital care. And
there is the absolute need to cede some autonomy to the clinical experts in order to be able to play the role that needs to be played, the role of the Mum or the Dad or the son or the daughter, the dying patient or the dying patient’s parent or loved one.

There was evidence in the research of other values in terms of palliative care. Where some participants evidenced great support for and interest in palliative care, others evidenced the opposite. There was evidence in the research of a misunderstanding of palliative care. One participant said: ‘palliative care has such negative connotations, I think, among the majority of people, that people are very reluctant to introduce it early’.

One nurse said: ‘I have a consultant at the moment who doesn’t believe in referring to palliative care’. In addition to palliative care at end of life, there are issues around spiritual care at end of life. Sometimes the data evidenced, that a patient who when compos mentis has rejected spiritual support, will receive it at the request of family or relations when they are no longer compos mentis. One participant outlined a situation where a priest was called to the bedside of a dying patient who was not Catholic. One of the priests who participated in the research talked about hospital culture and how within that culture certain things happen at certain times. He said that the culture generally dictates that if a patient is dying, the priest should be called.

There was also some small evidence in the research of concerns around elder abuse, in the family home, concerns around property rights and the vulnerability of elderly people to manipulation and exploitation in terms of assets and property. This was exceptional; three participants in the research highlighted one case each of such abuse. On the contrary, in general the issues raised in the research in terms of family were issues of familial concern, of loss and great grief.

**Theme Four: Power, the Personal, Place, Space and Time**

This theme is the theme of power, the personal, place, space and time. Within this theme the issues raised throughout the research in terms of each of these aspects of end-of-life experiences within hospital care settings in Ireland is explored. In terms of power, for many participants the doctor, registrar or consultant was deemed to have all of the power.
Many participants too highlighted the power at times of families. There are times the participants believed when the consultant must, legally and ethically make the decisions in terms of patient care. There are also occasions when families defer decisions to consultants when consultants would prefer if the families would or could take responsibility for the decisions, and themselves make the decisions. Overall it was generally felt that the consultants held most of the power. One participant said:

‘I work in the Cardiac Intensive Care and the consultants would have quite a large say in when life ends basically. You know, we’ve had patients for weeks and weeks and on mega drugs just to keep them alive and everybody around them can see this patient is not going to pull through and the dignity, – I won’t go into it – but, you know, their dignity is very much compromised and we almost have to sit the consultant down and say “enough is enough here, you know, where do we stop?”’.

There was, as outlined earlier, evidence of bad deaths. Below is one of the narratives of a bad death:

‘Patient transferred from (name of hospital). Underwent surgery. Poor post-operative period. Required major interventions with drugs and machinery. Remained on the unit for five weeks, became increasingly ill, remained ventilated, developed more complications. Family at bedside daily, tired, distressed, hopeful/hopeless. Expressed wish to let their loved one die. Some discussion with consultant. Refused to stop treatment. Two weeks later, following more discussions regarding interventions, consultant agreed to end treatment. Patient died within 24 hours, but physically bore no resemblance to their loved one. Was emaciated, jaundiced. I feel patient/family autonomy completely over-ridden by consultant’.

It was generally agreed that it is the doctor, the registrar or consultant, who decided whether or not to discuss the situation fully with the patient, whether or not to discuss fully end-of-life issues. Ultimately, it was this doctor who decided, and sometimes alone and with or without consultation, what it was that the patient actually wants. It was this doctor who would decide whether or not to refer the patient to palliative care. A pronounced reluctance on the part of some consultants to refer patients to palliative care was evident in much of the research.

The family of the patient was deemed too, as stated above, to be very powerful. Families were said by participants in the research to be often reluctant to engage with the palliative care services, as one respondent said: ‘because they have this notion unfortunately that
palliative tends to lead to a death immediately’. Sometimes, even when the doctor is quick to refer a patient to palliative care, the patient or the patient’s family can be reluctant and may refuse the referral. One participant said:

‘very occasionally, but still probably once a month, we would have patients who we end up not seeing the palliative service because that’s not acceptable to the family and there’s been backwards autonomy in the first place, I mean that the autonomy has been given to the family, the family decides whether or not the patient is seen by Palliative Care. It should never arise as the issue in the first place but it happens and typically it’s somebody who is frail, they can’t come into the clinic to see us without the support of their family and the family say “well you’ve got to guarantee me you won’t tell them that they have cancer otherwise I’m not bringing them in”. That’s very, very rare but we do have it. We had a case last week and the family just said “well sorry, we’re not bringing them in then if that’s what you’re going to do” so’.

The power struggle that can develop within hospitals over the care of patients was illustrated again by the participant who said:

‘There is a patient who is at home who I know from the referring physician, and even from talking to the family, that this patient is very unwell, needs the type of palliative support that we can offer and our community teams can offer but this patient went home and the doctor whose care they were under here in ….(name of hospital)… agreed not to tell them their diagnosis. They are now at home, the family isn’t telling the diagnosis and the patient isn’t being allowed access Palliative Care because we, the palliative service, will not agree to not telling them the diagnosis. We’re not saying that we have to tell them, but we’re saying that if the patient asks us why this has happened over the last two months that we will explain that to them in their own speed and in a gentle way. So I think that’s somebody whose autonomy isn’t being recognised and it’s someone who is cognitively intact’.

One nurse, representing generally practice in her hospital said:

‘So I say to the patient “you’ve been in hospital a long time, you’ve had a lot of scans and blood tests done, do you feel you know what’s going on? Do you feel you know enough or would you like to know more?” ….. and 8 or 9 times out of 10 the patient will say I want to know. And in a situation where the family is uncomfortable with that we would invite them to be present for that conversation, but I would never, ever undertake with the family not to tell the patient. And so your second question was - oh how does the Palliative Care Team become involved where we’re not? This frequently arises where a patient, where again, the families
will say “it’s great that you’re coming to see dad but don’t tell him you’re Palliative Care and don’t tell him he has cancer and don’t tell him he’s sick” and we would sort of understand that but again we would explain that we will go at the patient’s speed and the patient doesn’t need to know but the patient also has the right to know if they choose’.

As detailed in the previous section, patients in hospital care settings frequently do not benefit from palliative care services, even when such services are available, because some doctors, patients and patient families do not understand palliative care and the benefits that can accrue from a palliative service to patients who are in pain or / and who are at the end of their life. The research clearly established that there are different cultures in different hospitals and among different teams within different specialisms within hospitals. The power clinicians generally were acknowledged to have within the patient-clinician relationship is the power of expert power. The clinicians readily acknowledged that patients would acquiesce to them, patients would quickly and readily defer to their directions and their advice: ‘whatever you say Nurse’, ‘what you think Doctor’. Some of the participants spoke of the patients viewing the doctor as an authority figure. They said that patients won’t question a doctor, but they might question the nurse. They said that older people in particular, would never question the doctor: ‘they just do whatever they tell them to do, because the doctor knows best’. Many of the nurses acknowledged that generally within hospital there is a culture of ‘doing whatever the nurse tells you to do’.

In terms of medical paternalism, one participant said:

‘The fact that there should be equal power and control or authority just doesn’t happen. There’s an imbalance in power and authority and the autonomy or the respect for the individual gets lost. It doesn’t really matter what is wrong with the person, it doesn’t matter whether they have an illness or whether they have dementia or whether they are compos mentis or not. The reality is that that control and power is often taken away from them anyway by virtue of the culture that we’re in, the culture that holds that “medical people know best”’.

That being said, it was however generally felt by the participants in the research that such paternalism was old fashioned, and some participants felt that such paternalism was no longer an issue in hospital practice. In general, participants felt that medical practices are changing. One participant said that practice has ‘moved from the sort of autocratic model of medicine maybe even up to ten years ago that would’ve been the way, the doctor
knows best and the doctor decides’. This participant said that currently within medical practice a team approach was advocated, with the patient very much a member of the team.

The participants talked about patients at the end of their lives knowing that they are very unwell, feeling that they are very unwell but often perhaps not wanting, being either unwilling or unable or both, to discuss that. One participant spoke of the paternalistic dynamic of many Irish families where the urge is to take charge and protect the family member, even from the truth or the fact or reality of their own experience, their own end-of-life experience. The participants said that some families want to take charge and to make all of the decisions for the patient. The participants said that the families were, through that, taking the patients’ autonomy away from them. The families, they said, don’t see that, they see themselves as being kind. The special place of the family in end-of-life experiences was highlighted by one participant who said that precedence was given to family members:

‘even if it’s the first cousin who visits twice a year, if that’s biologically the next of kin that’s who we give priority to, rather than the friend who drops in four days a week, we don’t give them really much precedence at all’.

It is important too to say that families differ, they don’t all react in the same way. While some families will respect the advice of the clinicians and the views of the sick and dying family member, some will not. Some families are able to accept the impending death of a family member, and some, for a variety of often complex reasons, are not.

In general the hospitals were said by the participants in the research to be ill-equipped for the work of supporting patients through end-of-life experiences. Some of the hospitals were said to be old. One block in one hospital in which the fieldwork for the research took place was 131 years old. The hospitals were said to lack basic facilities such as private rooms. The general constraints of the every day experience of hospital wards were said to actually oppose the observance of patient autonomy. The apparently constant pressure for beds and bed spaces within hospital, the noise and general hustle and bustle, the numbers of patients were factors. Other factors included the needs of each individual
patient, the needs of visitors to the wards, the presence on wards of often very distressed patients and relatives, the lack of privacy on the wards, the number of beds on the ward, the proximity of the beds, the use of curtains around beds, and the anxious or even fraught whispered conversations around patient beds. In general, the research found that in not one of each of the hospitals in the study was it possible to provide a private small side room to dying patients, due primarily to the imperatives of infection control, MRSA, C difficile and other infections. There is little or no space in the hospitals in which to have a private conversation. There is no appropriate space in the hospitals in which to deliver bad news. The less than ideal environment that is the hospital environment was highlighted and discussed by practically all of the participants. There is no space for families within an acute hospital, no space within which to have a private conversation, no space within which to grieve, no space or place within which to have a private cup of coffee or tea. There was, one participant said, no space to die in, in an acute hospital. One of the participants said:

‘I feel that the dehumanising of the person starts the minute they walk in the front door of the hospital. They’re in an alien environment, their given a gown, so straight away you strip people of their identity in terms of just their clothing – that’s the start, so straight away they’re losing their ability, I suppose, to protect their autonomy, to speak up for themselves’.

One of the participants said that the whole culture of hospital lends itself to dealing with the family as opposed to dealing with the patient. Another participant said:

‘Once you put your foot in the door of the hospital as a patient you lose that power, that power you have as an individual. A hospital is an institution and it has to tick, it has to keep going, staff come and go, there’s rotas, there’s crises, there’s personalities, there’s conflict, there’s tension. People who are dying usually want to go home and they want to die at home. The journey they have had with cancer – could have involved a number of hospitals - and then they end up let’s say in this facility here. My experience of working here for nearly 2 years is that, and I’m sure it’s no different to any other institution or hospital, a lot of stuff gets lost, the emotional stuff doesn’t get dealt with. That could be because of a combination of family dynamics and ward dynamics and hospital dynamics. So my experience is that people lose an awful lot of autonomy and I’ve seen a lot of people die who have been totally disempowered and they die very, very - and people have good deaths I’m sure as well - but it’s kind of sad’.
The different spaces within the hospitals too were seen as presenting staff and dying patients with many and varied issues. Patients die in A and E (Accident and Emergency) and that environment is generally not conducive to privacy and expressions and experiences of patient autonomy. Patients die in ICU (Intensive Care Units), where generally family, relations and loved ones and their relationship with the dying patient and the dying patient’s personal experience of his/her end of life are all secondary to the dynamics of clinical care in the unit, the focus of which is on the aggressive preservation of life. Patients die on trolleys in hospital corridors. Patients die in strange beds in strange environments, environments into which frequently they have just recently been moved, environments which are inevitably staffed by clinicians who are strangers to the dying patients. Some patients die slowly and the institution and the staff of the institution have time to get to know the patient, and the patient’s family, and their needs. Sometimes patients die relatively quickly or very quickly and there is little time for the staff to get to know the patient and their family and their needs and wishes. There are staffing constraints which can mean that the staff available are overly busy and stretched to their limits practically all of the time. The palliative care team supporting one of the hospitals was said to be ‘stretched, stretched, stretched covering two counties’; the service was not available to the hospital on weekends.

Time constraints have a particularly negative impact on patient autonomy. Due to the general busyness, the emotional needs of patients dying in hospitals are frequently overlooked. One participant said: ‘we are very busy with the practical and the physiological elements of it….we’ve a lot more to learn, to widen our remit in dealing with the whole emotions together’. Patients were said to become ‘fragmented’ when they entered hospital. They were said to have been taken out of the places to which they felt they belonged; they were said to have to ‘surrender up’ much of what they’ve known and much of who they are. They were said to become part of the work-flow of the hospital. They were said to become sometimes disconnected from space and place and they were said to sometimes find it difficult to re-connect with themselves and with their feelings. There was a great deal of evidence throughout the research that spiritual support for
patients in hospital is radically underfunded. Chaplains who resigned were not being replaced, because of the recruitment embargo. Some community hospitals were paying for their pastoral service themselves through fundraising, through small grants from the Irish Cancer Society and the Irish Hospice Foundation, and from the proceeds of raffles and the profits from the hospital tuck-shop. This research showed that patients at end-of-life and their families are not properly cared for in such circumstances. One participant said that if there was not enough staff there would not be enough time, and if there was not enough time there would be poor, if any, communication. Poor communication, this participant said, would mean that patients and their families ‘would sometimes have this feeling of non-acceptance of what happened, simply because they were not properly prepared as to what to expect’. There is also the pace at which a patient and her/his family can digest and understand bad news and then make decisions, and that pace is substantially slower than the pace at which clinicians can and do process information. One participant said:

‘In my experience, sometimes people who are given a very difficult diagnosis, a very poor prognosis, are expected to make a decision there and then to get out of the hospital, because there is nothing more that we can do for you. I think this is a challenge in terms of patient autonomy. They’re just coming to terms with what they’ve been told. This is what is going on. You haven’t got long left to live and we have to move you on. And that is such a devastating place for the person and the family. Then they are told; we’ve done all we can. Patient autonomy doesn’t really come into it. That’s again because of the pressures of working in an acute hospital. Doctors see patients waiting on beds and the people in bed management are under pressure to get people moving. You know it sometimes is forgotten as well. The impact psychologically on someone who has been given a very poor prognosis. They are trying to come to terms with that. And they are being given information about hospice care, hospice home care, and they are dealing with change-of-life circumstances’.

Another participant said:

‘I think that is another area that we are lacking in, an opportunity for discussion, in terms of any kind of a death, whether it be an old person or a young person. And to be very realistic, I think if anything its gotten worse, there is more pressure for beds. I know that this sounds terrible, horrendous, but you’re getting phone calls, has the patient gone to the mortuary yet? …now it’s like a conveyor belt. It can be very very frustrating, and for this family. It is their last time to be in the hospital, to be on the ward. You’re trying to help them. To answer any questions they might have. They have arrangements to make and so on. And you’re getting phone calls at the same
time, about the bed. And the staff then have to wash the bed and to try and take up somebody else, another patient, straight away’.

It was, one participant said, ‘the tyranny of the immediate’. Another participant said: ‘the urgent things get done; but people seldom die urgently’. Hospitals were said to be becoming very outcome-focused, with the emphasis on short lengths of stay and discharge, a mindset which it was said doesn’t actually help in an acute setting in the care of somebody who is dying. The physical space within the hospitals was, another participant said, ‘disrespectful to people’ failing to meet their needs and wishes. One participant said of the hospital experience of end of life, of dying, that it was actually designed to support the living and not the dying. This participant said:

‘I think that …. the dying experience in many cases is for the living, it’s geared to the living and not to the dying, you know, it’s about protecting, you know, minding the family and trying to do the family’s wishes and not about actually focusing on the person that’s actually dying’.

In summary, the power of clinicians and families, the physical environment, staffing levels, time constraints, infection control were the substantive issues.

Theme Five: Communication

The final theme to emerge from the qualitative research is this theme of communication. This theme of communication was the most substantive theme to emerge from the qualitative research. This theme was coded for 402 times in the analysis of the data which means that this issue of communication in end of life experiences in hospital settings was discussed highlighted and problematised much more by the practitioners who participated in this research than any of the other themes which emerged from the analysis. The fundamental issue in terms of patient autonomy at end of life is that the patient be facilitated in expressing their wishes and that those issues are heard by practitioners and clinicians and families and acted upon. Clearly patient autonomy is first and foremost a communication issue. Clearly too, as is evidenced by this research, there are serious issues and problems in terms of practice around communication with patients at end-of-life. These issues are explored in the following paragraphs.
What was clear from the analysis was that some hospital teams and specialisms are much better at communication in end of life experiences, much more practiced, much more at ease. This is because some areas of hospital care and some specialisms deal with dying and death all of the time. In particular, oncology teams are in general very practiced in communicating at end of life. One consultant who participated in the research said:

‘We’re talking about pancreatic cancer, only about 5 or 10% are fit for surgery and the surgery has a 25% morbidity and somewhere around 5-7% mortality so it’s something we approach with them and we talk to them straight up. We have to. One patient in 20 is not going to come through the operation. They may come through the operation but they may never wake up or never get out of hospital and, you know, we approach that very early on’.

Oncology teams tend to be multi-disciplinary, consultant-led teams. They are practiced with dealing with patients and with families and the teams have learned through experience, practice and reflection to place the patient at the centre of care and the centre of communication, while including the family and encouraging the family through communication towards awareness, knowledge and acceptance. One participant said:

‘We meet them in the Oncology Clinic and usually the Medical Team are very good at sitting down with the patient and explaining to them what their diagnosis is, what stage their illness is at and what their plan of care is from there and what treatments they are offering and if it’s radiotherapy or chemotherapy they can explain that in detail to the patient, empower them, give them time to listen, take in the information, answer any questions they have, they usually give them a contact number of the Oncology Liaison Nurse so that they can contact her when they’ve made a decision on whether they want the treatment or not and they’d also explain our role and get us involved if they felt the patient was palliative and needed Palliative Care.’

Another participant said:

‘Here in Oncology we deal with patients of all ages who have cancer and my experiences here has been that people tend to be quite autonomous at the end, they are given their options - how far they want to take their chemo, how far they want to take the radiotherapy and the patient tends to get the information and they go away and they come back to Out-Patients to say if they want to proceed.’

Such teams have patient-centered agendas rather than relative-centered agendas. The advantage that oncology teams generally have over other hospital end-of-life experiences
is time. In general, oncology teams have time to get to know patients and their families. The other advantage oncology teams have is a number of treatment options, surgery, chemotherapy and radiation. Finally the team can focus on pain management and comfort measures. Such options offer hope to patients and families given even in the bleakest diagnoses and prognoses. A hospital team that can communicate end-of-life issues within a framework of hope always has an advantage. Some of the participants in the research spoke of the danger of patients losing hope, and dying very suddenly and very quickly after that. As a result, there is little very direct communication around dying and death. One consultant said:

‘You can never say to a person you’re dying because if you do, they will die’.

Another consultant said:

‘we cannot tell the patient that (that they are going to die) but I think at the end of the day they will realise that because, for example a cancer patient - a metastatic cancer patient, when they become terminally ill, they know their clinical condition, as the condition progresses, they know that they are going to be going down and down, so they know because of their physical condition as such….Their bodily experience will make them to understand that they are going down and down. I know that nobody will tell straight away that “okay so you are dying”, nobody will say that so at the end of the day we will tell you are very sick and I think there are things which we are doing to make you comfortable. When they use this type of tone, I think that most of the patients understand that …’.

Participants in the research said that they would regularly respond to a question with a question. A patient might ask, “how am I doing?” the clinician will respond, “how do you think you’re doing?” A patient might say “I don’t think I’m doing so well”, the clinician will respond “why do you think that?” Participants spoke of the euphemisms that are used you’re going downhill, you’re not that well, it’s taking you a bit longer now to pull back this time. Some participants acknowledged that patients seeking information are often ‘passed from pillar to post around the hospital as practitioner after practitioner evades the question’. Practitioners too are careful with the words they use, as one participant said:

‘The general medical consultants are the pits. They’ll go around it, they’ll say “… there’s inflammation there…”, the terms that can be used to describe a tumour or a malignant tumour are unreal “… you have a bit of inflammation, you have a shadow” and I mean “a
“bit of inflammation” if you wanted to believe it was nothing, then you can believe it’s nothing. So the general medical consultants are very bad and I would imagine surgeons aren’t much better’.

Another participant describing communication said:

‘is it a lump or a bump, a malignancy, a non-malignancy. People play around with these words. Sometimes the terms are played around with, they come in for an investigation, and now it turns out its malignant, and sometimes it’s the choice of words that are used, and the patient may still not know. The doctor may say something like; well it’s going to be more difficult than we originally thought. It is important that it is said to the patient, and it is important too that what is said is documented. The people on the next shift know then what words what terms have been used and there will be no misinterpretation’.

One participant spoke of a case where a man was dying, his wife was told that he was deteriorating and when the participant spoke to the wife she found that the wife didn’t know what the word deteriorating meant.

Information given to patients around end-of-life issues tends to be very guarded, with the information giver constantly trying to second-guess how the information is being received. One participant said that the real problem is the lack of infrastructure providing support to both the giver and receiver of information before during and after the exchange of information encounter. Some participants said that if a patient asked a very direct question, for example “am I dying”, that they would respond to the question honestly. The question however would have to be posed by the patient and the question would have to be very direct to elicit a direct answer. In addition to this, bad news is often communicated to patients and families on hospital corridors; another indication of the inadequacy of hospital spaces, and another deterrent to open honest clear communication.

The experience of all the participants is that some patients do not want to know, or perhaps they know but they do not want to acknowledge that they are dying. It may be that such an acknowledgement might perhaps force them into conversations and other verbal communications that emotionally they are unprepared or/and unable to undertake. One participant talked about being a messenger from the dead person to their family:

‘they haven’t got the ability to tell them themselves so they use us as messengers, so after the death has happened, I say: “I want to let you know that your father said to me that he
wanted you to know that he was okay about this and that he was able to deal with it and he was happy enough, that this was the reality”, because it’s very hard for a father to tell his son that he’s going to die, so they use us as messengers’.

The participants agreed that practitioners should and would only communicate about dying and death with patients to the degree that patients were prepared to engage in such communications. There was also an acknowledgement of the different needs of different patients, with some patients wanting very direct communication and some wanting no communication at all. One participant said: ‘… you have to be sure in whatever way you deliver bad news that you don’t deliver it in a bad way or in a hurtful way and you always assess the person, how well they are going to be able to take it …’. Other participants spoke about patients being in shock after having heard bad news. They said that the shock can be so substantial that the news actually doesn’t sink in at all, that patients after they’ve been given bad news can behave as if they haven’t because they haven’t actually taken in the communication, haven’t really understood the communication or the implications of the communication. They said that sometimes patients shut-down and can’t or won’t hear the bad news, because of the shock the news occasions them. Nurses interpreting bad news communications from consultants to patients will repeat the bad news over and over again, and they will give the bad news using different terms and different expressions, and they will request that another family member be present when the bad news is delivered, all in order to ensure that the communication they are giving is ultimately received by the patient. And even when they have done all of that, they will check again to see if the bad news has been heard and understood.

The other issue in such communications is the issue of the capacity of staff to talk about dying and death with a patient who is dying. There was a great deal of evidence in the data of practitioners, many of them advanced in years and very experienced in terms of practice, who could not discuss dying and death with a dying patient without being themselves overwhelmed with emotion. So these practitioners actively avoided such encounters, such conversations, such communication experiences. One participant said:

‘we’re inclined to kind of shy away from the subject and, you know, maybe when you’re having a chat with a patient and kind of pick your proper moment, maybe to get them to
open up, and maybe if you opened up the discussion and see if they pick up on it or that, you know. At least then you might get an idea of what they want and what their wishes are. And like if they had a particular wish, you could ask them then like have they discussed it with their next of kin and - or if they haven’t, you know, you could ask them, “Would you like - would they like you to facilitate talking to their next of kin?” You know, just to kind of maybe initiate the whole thing but I suppose we are inclined not to do that, you know. We’re inclined to - it’s not the nicest thing to talk about, so I suppose you’ll find something else to talk about first, you know’.

Participants in the research spoke of many patients not being fully aware that they were dying, and so not being in a position to plan for their end of life experience, or plan for their affairs after their death. One participant said:

‘a lot of the time people are nearly scared to say to people - to a person, you know, that - to tell them that they’re actually dying. It’s very hard to say to somebody, you know, that, you know, “You’re near the end of your life and is anything you want doing or how would you like your final days to be”’?

One participant in the research wrote the following end-of-life narrative for the research:

‘My friend died this year. She died from cancer. She had surgery and chemo. She thought she was going to get well, but after some weeks she developed pain and was admitted and died after three weeks. She refused morphine pump. She never spoke of dying to anyone. She had a lot of pain and I never knew what to say each time I visited her. I could see her fading away and she would say I feel so weak. The day before she died she did accept the morphine pump. She died very peacefully the following night. The loss, so little time, no time to talk about what she wanted’.

The other issue is the capacity, physical or intellectual, of patients to communicate. There are many patients in hospital who have advanced dementia or certainly a good deal of confusion. One participant said: ‘so to have a coherent discussion and understand what the patient actually wants is quite difficult; in a lot of certain situations it’s not possible’.

One participant who worked with adults with intellectual disabilities spoke of providing patients with massage and aromatherapy. This participant said:

‘That even in very, very, very late stages, where words fail, muscles speak. So the person can communicate their wishes to you at all stages. Right from the very early stages when they’re quite well, right up until the very, very end stage where you can do massage or Reiki Healing or aromatherapy, whatever. You will sense it. If the muscle tenses you know this person doesn’t want this or they don’t - and you will know exactly what that person wants. A great deal of communication goes on through touch, when you’re working on a certain area or using a certain pressure
you may feel the body relaxing. Well they are telling me then that they like this and this is okay and to continue in this way. Or if a muscle tenses, you know, okay you ease off a little bit here and maybe move somewhere else or just, you know moderate the pressure you’re using. So in that respect, I feel that where words fail, muscles speak’.

There was evidence too in this theme, of ageism. This was evident in relation to patient autonomy where with elderly patients control was readily passed by clinicians from the patient to the family. One participant said:

‘I’d say with some people - again maybe with elderly people maybe something is held back, they don’t know exactly how bad it is. The decision is probably made with their family that it’s best for them not to know which I guess is a bit paternalistic at times but it very much depends on the patient and their mindset and how they would be able to cope with information or how much they would want to know. And the families are probably the people who know them best’.

In some cases in fact, rather than ageism, it seems the issue is one of lack of preparedness. One participant said:

‘In practice I suppose in Geriatrics we deal with a lot of dementia and also because the vast majority of the families would have the patients’ best interests at heart anyway so they’re thinking about their mother or their grandmother and what would be best for her. And I think basically everyone is working towards the same end, they’re trying to say where the patient would be best placed, would they be better at home or would they be better in a nursing home - things like that, that’s generally what the decision comes back to. And at end of life do they want to die at home or would they prefer to die in the hospital or be in a nursing home to die’?

This participant went on to say:

‘In Oncology I guess a lot of patients know that their situation is not a sudden death, in that they know what’s coming so they tend to be involved with the Palliative Care Services and those decisions are thought about beforehand’.

An oncology nurse who participated in the research said that there was a lot of misinformation given and a great deal of collusion with the parents of sick children. This participant said:

‘I think we see a fair amount of collusion here where, you know, parents don’t want to tell their children their diagnosis for example. They might be going to have surgery for something, like say a central line so they can have chemotherapy, and
the parents don’t want to tell the child that they’re going to theatre for a particular procedure. And because they don’t want to be seen as being bad perhaps, you know, there’s lot of various different reasons, there’s a huge amount of that sort of not telling them information. The parents have the information but maybe are not passing it on in a way that the children understand. And I would say that on a day-to-day basis very many of us see that, we see it in oncology a fair amount as well where they’re not actually told their true prognosis or what’s happening to them because the parents themselves don’t want to go there. But I mean some of them would be 14, 15, 16 year old children who don’t have that much autonomy therefore in terms of whether they can have treatment or no treatment or whether they continue with treatment’.

There was evidence, as highlighted earlier in this report, that patients and indeed some clinicians, do not understand palliative care. There is a communication issue in this in terms of clearly explaining palliative care and the various capacities of it. There was a great deal of evidence in the data of patients refusing palliative care because, as one participant said, they think that if they are being offered palliative care that it really is the end of the road for them, that the clinicians have given up hope for them entirely.

Frequently when people reach the end of their lives they want to hold on for one most important occasion or event, a daughter’s wedding, or the birth of a baby, for example. There was detailed in the course of the research one such case of a patient who refused palliative care because she wanted to make it to her daughter’s wedding, and she felt she would be stronger for longer without palliative care. This is clearly a communication issue. This patient did not understand palliative care and palliative care was not properly communicated to this patient.

Another area of neglect in terms of communication with patients at end of life is the area of communicating the realities of active, aggressive or invasive treatments. As one participant said:

‘a lot of these people are non-medical, so they - you have to be kind of careful with the terminology used as well. Like they even mightn’t understand what invasive is or aggressive is, you know. Do you know, some of them might have spent very little time in a hospital’.

Another participant said:
‘I was here about maybe six/seven years ago in my early days here, and I’m thinking of a patient who had a cardiac arrest, a sudden cardiac arrest, and he was resuscitated and brought back. And I met him and I just had had a chat with him after and I says, “How did you feel about what happened to you?” And he felt that – he says “I wish they hadn’t done what they did.” I said “Why?” He says “Well they brought me back and I didn’t want to go back.” And I said, “Could you actually explain that to me?” And he explained to me about how he felt when he was dying and how he felt a sense of contentment and that he felt that he was being pulled back. And he asked the doctors “Why did you do that?” and he said well they said “We had no choice but to resuscitate you”. And he said “Did you ever ask me what I wanted beforehand?” and they said “No.” He said “Well you should have”, because he had in his own mind thought of it but nobody asked him the question and he didn’t know when it was right to bring it up or not’.

Another area of communication is the area of interpretation. Sometime the nurse might interpret for the patient precisely what it was that the doctor said. Sometimes a patient will not question a doctor but they might question a nurse. Nurses play a large role in interpreting the communications of doctors for patients. It would perhaps be useful for doctors themselves to clarify for their patients their pronouncements, diagnoses, prognoses, advice and directions. One participant said: ‘some consultants are very informative and give patients all the information and spend time with them, and others don’t’.

Many of the practitioners who participated in the research discussed the model of ‘The Twelve Aspects of Daily Living’ sometimes used to interview and assess all patients on admission to hospital. One participant described the encounter as follows: ‘mobility, skin integrity, social behaviors and one of the questions is on dying and it’s never asked. It’s always skipped’. So practice varies from consultant to consultant, from clinical team to clinical team and from hospital to hospital.

The issue of advance directives as a means of communication arose. One participant said:

‘I do think that decisions like end-of-life decisions or treatment decisions, it’s too far on in their, in the situation, you know. They’re acutely ill. They’re not able to make decisions, that’s when often they’re talked about. They’re not talked about early enough, you know, and when is the appropriate time but I do think we miss opportunities of discussing, you know. Patients’ preference or patients’ management, you know, often you do hear patients
“well if I go into ...” or we all say it “if I go into hospital, please don’t ventilate me” or “please don’t do this ...” but that’s not documented or that’s when the patients is well. So I suppose it’s when is the right time to discuss this with the patient”?

One participant said:

‘in Intensive Care various cases over the years of people who have been in and out of the unit, maybe have a chronic respiratory problem where they’ve decided that “okay if this happens again I don’t want to be resuscitated, you know, I don’t want to be ventilated” and there would have been certainly - I would have experienced occasions when this would have happened, their specific wishes are and would have been respected. I think sometimes it takes a while like it might have taken a few admissions where the patient has been in and out of the unit a few times to build up that rapport with the medical staff as well to actually document it. I think that’s a big part of it as well. If there’s nothing documented patients have to be resuscitated. Even when the patient makes these wishes known to medical staff they are not always documented. The medical staff might not always be in agreement with them. So if the patient comes in in an emergency situation through A&E and up to the unit they will actually be resuscitated and sometimes it’s just because it’s not documented anywhere’.

So sometimes even when patients have given an oral advance directive, because it is not written down it is ignored. There was a great deal of evidence of reluctance on the part of consultants to write down and formalise DNRs (do not resuscitate orders).

Participants in the research talked about moving away from a medical model of care to a more holistic approach but they generally felt that the constraints of working on a ward mitigated against such a change. One participant said:

‘Sometimes we don’t have the luxury to have the time to be able to communicate as effectively as we might like to and especially in the acute hospital setting, you know, I suppose working in a hospice environment and then come to the hospital environment where in the hospice it’s seen as a priority that you make time to actually be able to spend the time to talk to patients about their options, about where things are so that they can feel empowered to be able to, because patient autonomy is actually, it’s a burden sometimes if they’re not actually given enough information and enough support in making decisions and in the hospital environment you’re on a ward, you’re on a corridor, you’re running in and out, you’re getting bleeped all the time’.

Evidence from the research indicates that there is a clear and substantial need for a great deal of practice development in terms of communication around end-of-life issues and at end of life. There would be more positive experiences in terms of patient autonomy at end of life if there was
more honesty and openness in communication, despite the struggle such honesty sometimes represents for many practitioners. One participant said:

‘One doctor did come in, the wife had asked to see him and he came down. He examined her husband then he spoke to her and her son and he said “….in my opinion death is imminent”. Now I have never heard that before in my life but I witnessed it and it was the relief on that woman’s face, because now she knew her husband was dying and she could start a sort of a grieving process. It was probably one of the most powerful things I’ve ever heard said in a clinical situation but it was so clear and it was the clarity of it that made it so powerful’.
Chapter Five

Conclusions

This research was undertaken in order to provide qualitative data on practitioner’s perspectives on patient autonomy in end of life situations in hospital settings in Ireland. The data provided by the research was comprehensive. The data shows a clear need for practice development with practitioners around patient autonomy at end of life. The main issues that need to be addressed are issues of communication between practitioners and patients around end of life, and communication in terms of encouraging and supporting appropriate experiences and expressions of patient autonomy at end of life. The other issues to emerge from the data are issues related to each of the five key themes of the research, themes of good and bad deaths; active and palliative treatments; patient autonomy and other values; the theme of power, the personal place, space and time; and the theme of communication. The main conclusions in terms of each of these themes are detailed in the following paragraphs.

Good and Bad Deaths

The evidence of this research clearly establishes that there are good and bad deaths in Irish hospitals. The good deaths have a number of features in common: patient autonomy, the patient choosing what they want, articulating or communicating those choices, and those choices being respected and acted upon; the patient having access to all the resources and supports available; the patient having the support of palliative services, among them good pain and symptom management; and the establishment of good relationships between patient, family and practitioners. There are of course different kinds of deaths, and some deaths, deaths that take some time, are obviously more manageable in terms of the kinds of care and support that can be put in place for the dying patient. In good deaths the patient generally knows that death is imminent, and so too does the patient’s family. In some good deaths, the dying patient does not want to know that they are dying, and although the practitioners generally believed that people who are dying know through their bodily experience that they are dying, they may not wish, for a variety of reasons, to openly acknowledge this or to discuss this, or to engage
in any conversation about this. Such an acknowledgement might be too emotional for them or for the people close to them; such an acknowledgement might expose them to intrusions on their privacy, and so on. There are deaths in hospital in Ireland around which there has been a great deal of practice development. Such deaths or end-of-life experiences have hospital teams attending them with many years of practice development in caring for patients experiencing such deaths.

For older people who have reached the end of their life, often the issue in terms of patient autonomy is where they will live out the end of their lives. There was evidence of older people hastening their deaths because they cannot live the end of their lives in the place of their own choosing. Most patients want to die at home. Sometimes, because of the often very substantial care needs of patients, this is not possible. Sometimes, the patient’s family will not or can not undertake the care of the patient at home. On occasion a patient will want to die in hospital or in hospice, to remove the burden of care from those at home, or to preserve for the family good memories of them being strong and well at home.

The resources available to practitioners frequently dictate whether a death will be a good death or a bad death. The constant and relentless pressure on resources in hospital was seen to have a very negative impact on some deaths and end-of-life experiences, pressure for beds occasioning staff to be prompted to move bodies to mortuaries and grieving families off wards inappropriately quickly. The pressure on resources too rendered services slower to dying patients. This means that sometimes dying patients spend precious time, days and weeks, in hospital beds waiting for services, instead of spending that time where they wish to be, at home with family and friends. The pressure on resources puts extraordinary strain on clinicians caring for patients at end of life, strain over and above the strain they experience in caring for dying patients, in treating them medically, in fighting to try to keep them alive, in struggling to communicate on very sensitive issues with them. Bad deaths in hospital are often associated with inappropriate and, arguably, unethical active or aggressive treatments, investigations, resuscitations, and the administration of invasive, unwarranted, unnecessary and/or inefficacious procedures.
Active and Palliative Treatment

The issues in this theme were the issues of active or aggressive treatment of patients at end of life and the availability of palliative care for patients at end of life. The research showed that frequently within hospitals in Ireland there are inappropriate and, arguably, unethical active treatments provided to patients or acted upon patients. The evidence of the research shows that sometimes inexperienced staff make incorrect judgements around active treatment, moving patients who are dying from long-stay facilities to acute hospitals; instigating PEG feeding, or ventilation; engaging in resuscitation. The evidence of the research shows that sometimes experienced consultants and surgeons make questionable decisions around active treatment. All of these decisions and activities contribute to bad deaths in hospitals. In experiencing a bad death patients are left to die on corridors in strange acute facilities. Patients are obstructed from dying through ventilation and other inappropriate treatments. Deaths are unnecessarily prolonged by some treatments. Many of the narratives gathered for the research evidence the dreadful circumstances of the deaths of many patients in hospital in Ireland who have been aggressively treated or subjected inappropriately to active treatment in their end-of-life experience.

As stated in the preceding chapter, palliative care has been a recognised medical specialism in Ireland since 1995 and Ireland is ranked in second place globally (second to the UK) in terms of the provision of palliative care services. Despite this, the palliative service is very patchy is some areas and not available at all at some times. In addition to this, many medical and surgical teams have been shown in this research to be slow, or very slow, or just too slow, in calling palliative care for their patients. The participants in the research who had expertise in palliative care were concerned that palliative care and the range of services available through palliative care were not fully understood by many clinicians. Many patients and patient families did not understand the role of palliative care either. This lack of understanding means that an entire care specialism dedicated to the support of patients at end of life is, although available, frequently not availed of. So

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2 As detailed in the methodology section of this report, of the sixteen doctors who participated in the study, four were palliative care consultants. A number of palliative care nurses also participated in the research.
patients die in more pain than is necessary, and the physical pain is only one the many kinds of pain a palliative service can ease. Patients die experiencing more sickness than is necessary. Patients die in less comfort than is necessary.

The research clearly shows that patient families will act as patient advocates in hospital, but patient families usually don’t have any knowledge or understanding of active or palliative treatment. In general, as many of the participants in the research highlighted, patient families want the clinicians ‘to do everything’ for their family member, but they really have no idea of what ‘doing everything’ involves. This wish on the part of patient families does sometimes lead to the inappropriate aggressive treatment of patients at end of life, and it does lead to bad deaths in hospital. Many of the clinicians spoke of the work in communication and education that is required from clinicians to move families towards an appropriate view of their relative’s condition and towards a view of the appropriate care required by their relative at end of life. Such exercises in communication and education require expert clinical knowledge on the part of the clinician, as well as expertise in communication. Such exercises also require moral courage and confidence in order for the clinicians to engage families in such conversations about death. Clearly the pressure on hospital resources, detailed to some degree in the preceding chapter, diminishes the possibility of such developmental exercises and the time needed to engage in ‘death talk’ (Somerville, 2001). This is only one of the ways in which resource constraints in hospitals contribute to bad deaths.

A most serious issue which the research highlighted is the lack of formal (written) records in terms of treatment plans for patients at end of life. There is evidence in the research of consultants being unwilling to record in writing DNR orders. The research establishes that there is a profound lack of formal (written) records of patient wishes for their end-of-life experience. The problem is that nobody, patients or clinicians or people generally, wants to talk about dying and death. There is a generalised reluctance in Irish society, documented by the Irish Council for Bioethics (see Literature Review), to engage with the topic. This means that patients in Irish hospitals do not, as a rule, plan for their end-of-life experience. They do not anywhere or at anytime indicate in any way what it is that they would want in terms of treatment or supports when they are dying. As a result of
this most deaths in hospital are managed through a moment-by-moment event-by-event decision-making process which is embedded in an oblique or certainly a less than frank communication process which is negotiated between distressed and grieving relatives and under-resourced and commonly over-stretched carers and clinicians. The outcome is often a bad death.

**Patient Autonomy and Other Values**

The research showed that many clinicians could not readily define patient autonomy and were slow to describe practices around patient autonomy, while it was acknowledged in the research that patients, by virtue of the fact that they are patients, surrender degrees of their autonomy. The research adopted the Hospice Friendly Hospitals simple definition of patient autonomy. That is that the patient is facilitated in expressing their wishes for their end-of-life experience and those wishes are heard and acted upon. One of the critical issues to emerge from this research is that frequently patients at end of life in hospital are too ill, and often unconscious or have other competency issues, and are incapable at that stage of indicating their wishes for their end-of-life experience. In such situations, clinicians refer to patient families for decisions around end-of-life care. In many cases the families are reluctant to make those decisions and they refer the decisions back to the clinicians. This is a reflection of the expert power of clinicians and the respect that the general population has for that expertise. Some of the clinicians who participated in the research indicated that they would prefer if the families would not do this, but would assume the responsibility for such decisions themselves. This evidences again the utility of advance planning, advance directives or living wills.

The research shows that clinicians felt that generally they needed to be more engaged with patients in terms of supporting patient autonomy. There was an acknowledgment in the research of the propensity of clinicians often to engage with patient families first and foremost even in the context of a competent patient. This propensity was evident too and highlighted in Schermer’s (2002) work on patient autonomy in hospital settings. Schermer found in her work a preoccupation with medical decision-making. This was very evident in this research. The broad range of patient and individual needs and wishes
at end of life were felt by many of the participants in the research to be beyond the focus of many clinicians. Patient care at end of life in Irish hospitals, the evidence suggests, focuses still on the medical care of patients.

The power of the family in decision-making in terms of patient care was highlighted throughout the research. The willingness of families to prevent or obstruct patient autonomy was detailed over and over again. The participants discussed the propensity of families often to refuse to allow the communication of a terminal diagnosis to patients. This means that many terminally ill patients are never given their diagnosis or prognosis by the clinicians caring for them. So such information about patients can be available, and available to a substantial number of people, without the information ever being communicated to the patient themselves. The family is motivated by a paternalistic concern. This concern can lead to patient’s under-reporting pain, because they don’t realise how ill they are. The concern can also lead to patients being excluded from palliative care, because the relatives insist on the patient not knowing their diagnosis while the palliative care service, although not insisting that the patient know, will insist on responding sensitively but honestly to the patient and their questions. This insistence regularly leads to families refusing to allow their relative access to the palliative care service.

Patient autonomy as practiced in Irish hospitals is a negotiation, negotiated individually with each patient, and so the practice is unique in each patient case. One of the most problematic areas in terms of patient autonomy, as highlighted in the research, is the case of the autonomy of older patients. Some participants in the research felt that the voices of patients in their 30s 40s, 50s and 60s were heard much more readily in hospital than the voices of patients in their 70s, 80s and 90s. There is definitely an ageism issue.

There is paternalism too in the way in which clinicians care for patients in hospital. In addition to this there is an awareness on the part of patients that they are not in their own homes, that they are being cared for in an institution, and that it is in everyone’s best interest that they acquiesce (a term used by one of the consultants who participated in the
research to describe the manner in which patients at end of life tend to engage with the hospital to the institution and the institution’s ways and means.

In addition to the problems of ageism in patient autonomy, there is a problem in terms of the autonomy of children in hospital who are at end of life. Some clinicians felt that the autonomy of younger children was not respected, in general in terms of the inappropriate application of active or aggressive treatment. This issue was an issue too for older children. Another issue was the unwillingness of some parents to communicate or to allow the communication of a terminal diagnosis to children. As with adults, this leads to children under-reporting pain, and it leads to very ill children being excluded from the support of a palliative care service. The participants felt that there was an issue of collusion between families and clinicians in the exclusion of patients of all ages from the knowledge, awareness, understanding and management of their condition.

The research clearly established that many patients hold other values to be more important than patient autonomy. Many patients will readily and happily allow another person, usually a family member, to speak for them, to negotiate for them, to advocate for them. Many practitioners indicated that husbands generally declined invitations to attend case conferences at which they would be represented by their wives. There is a great deal of evidence in the research of patients, among them child patients, under-reporting pain, illness and distress, in order to avoid distressing their families and friends. The evidence of the research shows that patients generally value greatly the work and expertise of the clinicians, and will constantly defer to the clinicians. Sometimes patients hold other values to be more important than medical care. Among such patients are practicing Jehovah’s Witnesses who, for religious reasons, will refuse life-saving medical intervention. There is the focus of some physicians on treating, curing and fixing patients and this sometimes diminishes patient autonomy. There are many patients whose autonomy at end of life is diminished because they are not aware of their diagnosis. They don’t know that they are dying and so don’t put their affairs in order; they don’t have the conversations with friends and relatives that they might have if they knew they were dying.
It is worth mentioning again that one of the participants in the research spoke of some patients in Irish hospitals as being entirely oriented towards collectives, towards community and family, and not at all oriented towards the self, the individual self, or towards personal autonomy in any kind of post-modern sense. Frank (1995, 2002) considered in his work, the work of modernist sociologist Talcott Parson’s ‘sick role’, referred to as ‘a core social expectation’ of ‘surrendering oneself to the care of a physician’. Parson’s ‘sick role’, according to Frank (1995, p.15), ‘articulated the modernist requirement that ill persons delegate responsibility for their health to physicians’. There was a great deal of evidence in the research of patients surrendering to the sick role, and acquiescing to clinicians.

**Power, the Personal, Place, Space and Time**

In this theme, the issue of power within the hospital setting was a main issue, as was the inadequacy of the space that is the hospital as it is currently designed and organised in terms of supporting patients at end of life. Power in hospitals was generally acknowledged by the clinicians participating in the research to be held by them, the clinicians. This power was the power of expert power for the most part, although there was some evidence of a residual medical paternalistic power in the view that some patients, generally older patients, hold of doctors as being authority figures. The general deference of patients of all ages and from all cultures and walks-of-life to clinicians, doctors and nurses, was highlighted over and over again in the data. There is paternalism too in many Irish families and this paternalism encourages families to take charge of the care, medical and social, of hospitalised family members. This paternalism facilitates some families in assuming control of information relating to the diagnosis and prognosis of the patient, often with serious consequences for patient autonomy. When information is withheld from a patient regarding their condition, they frequently do not realise how ill they are, or that they are dying, or that death is imminent. This means that many people at end of life do not put their affairs in order. It means that many people at end of life under-report pain and suffering, because they do not realise how ill they are. It means that seriously ill patients, patients suffering extreme pain are excluded from the palliative care service if it is available because the palliative care service, while not forcing information
on patients will respond openly and honestly though sensitively to patient questions. This unwillingness on the part of palliative services to collude with relatives in concealing diagnoses and prognoses from patients’ means that many families flatly refuse to allow the service provide support to their family member.

Participants in the research spoke of the loss of power experienced by the person as they become a patient in a hospital. They spoke of stripping the patient of their identity as they are stripped of their clothes and dressed in hospital gowns. Patients were said to become ‘fragmented’ in hospital. They were said to lose so much of themselves, their identities, their sense of who they are, as they become a part of the work-flow of the hospital. They spoke of the routines and rotas and staff shifts and changes and cleaning routines and feeding routines as all contributing to the disempowerment of patients. Many participants felt that the entire culture of hospital tended towards dealing with families much more than dealing with patients. All of this may be a factor in the propensity, documented in this research, of patients to acquiesce to doctors and nurses and hospital regimens. In any case, the implications of all of this for patient autonomy are profound.

The personal was a constant theme throughout the fieldwork and in this theme the clinicians who participated in the research detailed fully and clearly the sadness and the despair sometimes in experiences of dying and death which they had witnessed or of which they have been a part. The emotional needs of the dying were said by the participants to be generally overlooked in the hustle and bustle of the busy hospitals. The spiritual care and support of patients is substantially under-resourced in most of the hospitals, with one or two pastoral care workers caring for entire hospital populations and their families and friends. Pastoral care workers who resign are not being replaced, due to the embargo on recruitment. Some hospitals were fund-raising, running raffles and using the profits form the hospital shop, to provide pastoral services to their patients. The time constraints on staff were said to impact too on the grief of relatives and friends, as frequently, because of staff shortages, clinicians do not have enough time to spend with relatives and friends preparing them for what is inevitably to come. As a result of this, patients and their families and friends would sometimes have a feeling of disbelief and non-acceptance of what happens when the person they’re caring for dies.
The inadequacies of the space that is hospital space in terms of providing a place for
dying patients and their relatives was highlighted over and over again in the research, and
it was a substantial issue in each of the fifteen hospitals nationally that participated in the
study. The hospitals were said to have no private spaces or rooms for dying patients.
Contemporarily, this is primarily because of the need for isolation spaces within hospitals
for infection control purposes, the control of infections such as MRSA and C difficile.
Patients die on crowded wards. They die against a background of loud televisions and
radios, of life going on all around them, sometimes loud and disruptive, sometimes
argumentative, often oblivious. Families and friends are given bad news on corridors and
in hallways. Grieving relatives fill up hospitals spaces already full with the drama of
hospital activity. In general there is no space within Irish hospitals within which to hold a
private conversation, within which to grieve, within which to come to terms with bad or
even dreadful, appalling, unimaginable news.

**Communication**

The final and the most substantive theme of the research was this theme of
communication. Clearly, as stated in this report, at issue within patient autonomy at end
of life is the right of the patient to make known their wishes for their end-of-life
experience, and for those wishes to be heard and acted upon. Therefore the entire
question of patient autonomy at end of life is a question of communication. Some clinical
teams are better at communicating around dying and death than others, and this is
because some clinical teams, generally oncology teams, have a great deal more
experience in such communication, and within some clinical teams a great deal of
practice development has taken place in terms of communication around dying and death.
Other clinicians and clinical teams had developed little or no practice around
communication in terms of dying and death, indeed some clinicians, many of them very
mature and advanced in terms of clinical experience, had no skills whatever in terms of
communicating around dying and death. Even in terms of the model of ‘The Twelve
Aspects of Daily Living’ used to interview and assess patients on admission to hospital,
the one question within the model which is never asked is the question on dying. It is
never asked.
The practice in general in hospitals in terms of communication around dying and death is to follow the patient’s lead, to answer any direct questions. This means that clinicians seldom volunteer information, the patient must ask for the information. Frequently communication practice among clinicians communicating with patients around dying and death involves clinicians responding to patient probes or questions with another question. For instance the patient might say something like, ‘I’m not as well as I was’. To this a clinician would respond ‘why do you say that?’ A patient might ask ‘how am I doing?’ to this a clinician would typically respond, ‘how do you think you’re doing?’ In this way, slowing and indirectly, a conversation will unfold between a clinician and a patient. This research has established that patients in hospital lose their identities, their sense of self, and much of their personal power. Also evidenced in this research is the acknowledgement of the clinicians who participated in the research of the deference that patients pay to clinicians, and the propensity of patients in hospital to acquiesce to physician power. The research has also detailed and explained the inevitability of hospitalised patients rapidly becoming part of hospital workflows. Given all of this, and the time needed for such conversations, it seems likely that it would be perhaps an exceptional patient who would lead and direct such a conversation.

The participants in the research also highlighted the euphemisms that are used by clinicians when talking to patients about dying and death. Patients might be told that they are going downhill, that they are not that well, that it’s taking them a bit longer now to pull back this time, or that it’s going to be a little more difficult than was originally thought. Consultants were said to be very cautious and deliberately oblique with the language they use with patients. Information given to patients around end-of-life issues tends to be very guarded, with the information giver constantly trying to second-guess how the information is being received. Consultants would typically talk to patients about inflammations and shadows when describing a tumour, even a malignant tumour. They would talk to patients about lumps and bumps and about whether the lump or bump was a malignancy or a non-malignancy. There is the difficulty too of patients and families simply not understanding the clinicians. There was one case reported in the research of the wife of a man who was dying being told that her husband was deteriorating, when the
woman did not know what the word deteriorating meant. Patients and their relatives often
don’t know what consultants are talking about, and frequently they do not have the
courage or capacity to question them. Nurses have a substantial role in communication in
hospitals, not least in terms of interpreting the communications of consultants for
patients. Patients seeking information were said to be often passed from pillar to post
around the hospital as practitioner after practitioner evades the question. In practice,
direct questions about dying and death from patients at end of life in hospital are very
rare, direct replies from clinicians even rarer.

Another major issue in terms of communication with patients at end of life is the capacity
of many patients at end of life to engage in any kind of communication. Many patients
because of their clinical condition would not be able to communicate verbally or in
writing. Many patients would not be compos mentis and so would not have the capacity
to engage in any decision-making. The clinicians working with adults with intellectual
disabilities gave some unique insights to the study of communication with apparently
incommunicative patients. One CNS (Clinical Nurse Specialist) working with such
patients said ‘that, even at the very very late stages, where words fail, muscles speak’.
For this clinician, working with touch was a fruitful means of engaging in communication
with patients who could not communicate verbally or in writing.

One other issue is that of the refusal of many families to allow communication with their
hospitalised relative about a terminal diagnosis or prognosis. This refusal to communicate
was considered by many of the participants in the research to be one of the most
substantial communication issues in dying and death in Irish hospitals. The consequences
of such barriers to communication have been explored in the paragraphs above. The final
communication issue was the communication of the reality of active treatment at end of
life to the relatives of patients at end of life. The participants in the research said that it
was a fact that when families fully understood the reality of active treatment, in general
they would not sanction it, and would instead be content to sit with their relative and to
work to support any comfort measures that could be given to their relative at that point.
There are clearly substantial issues in terms of communication around dying and death with patients in hospital in Ireland. There is also, a clear need for substantial practice development in terms of communication with patients and families of patients in hospital at end of life.

**Summary**

This qualitative study of practitioner’s perspectives on patient autonomy at end of life was carried out with the practitioners of fifteen hospitals nationwide. In all, 104 practitioners participated in the fourteen focus groups conducted; 57 practitioners participated in one-to-one in-depth interviews; and 102 practitioners submitted written narratives of good and bad deaths to the research. The data gathered was substantial and it was qualitative. As such, the data provides a comprehensive and in-depth view of the perspectives of practitioners on patient autonomy at end of life. The research is a small part of a large project entitled ‘An Ethical Framework for End-of-Life Care’; the latter aims to identify the key ethical issues that arise in relation to death, dying and bereavement and to develop a set of educational resources to deepen public and professional understanding of experiences of death, dying and bereavement and to enhance the experience of dying in diverse health care settings in Ireland.

The hope for this qualitative study is that it will make some contribution to the development of that ethical framework.

The table below provides a map of the key themes to emerge from the research, the key issues in those themes, and the key conclusions drawn for each theme.
Table 2: Key Themes and Issues and Main Conclusions

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Key Issues</th>
<th>Main Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good and Bad Deaths</td>
<td>There are very many good deaths, and there are very many bad deaths in hospitals in Ireland</td>
<td>A need for practice development in terms of patient-centred deaths, drawing on oncology and palliative care teams as role models</td>
</tr>
<tr>
<td>Active and Palliative</td>
<td>The active or aggressive treatment of patients at end of life</td>
<td>Need for a process within clinical teams to highlight judgement errors.</td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td>Need for practice development around communicating the realities and limitations of active treatment to patients and families.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A need for education around palliative care, the ethics and practice of palliative care, for clinicians, for patients and for families. Need for an educational/communications programme around the services available within that care specialism and the value of those services to patients at end of life.</td>
</tr>
<tr>
<td>Patient Autonomy and</td>
<td>Inability of many practitioners to define patient autonomy and to describe practice around patient autonomy – no set standard in terms of patient autonomy, each case negotiated individually</td>
<td>A need for training and development for practitioners around patient autonomy.</td>
</tr>
<tr>
<td>Other Values</td>
<td></td>
<td>A need for patient-centred care</td>
</tr>
<tr>
<td></td>
<td>Propensity in hospital culture to privilege families over patients</td>
<td>A need for practice development around patient autonomy at end of life – using palliative care practice as role model</td>
</tr>
<tr>
<td></td>
<td>Issues of medical and familial paternalism</td>
<td></td>
</tr>
<tr>
<td><strong>Patient autonomy issues for children and adults with intellectual disabilities and mental illness in hospital</strong></td>
<td>A need for practice development around patient autonomy at end of life – using palliative care practice as role model</td>
<td></td>
</tr>
<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>The other values of patients, autonomy as a principle of post modernity, majority of Irish patients displaying modernist characteristics, the focus on collectives, the family, relationships, the community</td>
<td>A deepening of public understanding of, and public debate around, an appropriate model of patient autonomy</td>
<td></td>
</tr>
</tbody>
</table>

| **Power, the Personal, Place, Space and Time** | **The power of consultants and families** | Need for public awareness campaign around patient autonomy. |
| --- | --- | A need for the development of hospice friendly hospitals. |
| **The powerlessness of patients** | The role of the institution that is the hospital in the disempowerment of patients | |

| **Communication** | **Patient autonomy is a communication issue** | There is in practice generally very poor communication around end of life and end-of-life issues and care |
| --- | --- | A need for practice development around communication with all practitioners and all patients at end of life. |
Bibliography


Rodriguez, K.L. and Young, A.J. (2006). *Perceptions of patients on the utility or futility of end-of-life treatment*. Journal of Medical Ethics, 32(8), 444-449


Appendix One
Participant Information Sheet
Qualitative Research – Ethical Death

This project is part of a broader project entitled ‘An Ethical Framework for a Good Death’. The broad project is designed to identify the key ethical issues that arise in relation to death, dying and bereavement and to design and develop an ethical framework to deepen public and professional understanding and enhance the experience of dying in diverse health care settings in Ireland. The project is part of the five-year Hospice Friendly Hospitals Programme launched by President Mary McAleese in May of this year. The Programme is an initiative of the Irish Hospice Foundation in partnership with the HSE and Atlantic Philanthropies. This element of the research project is a qualitative exploration of practitioner’s perspectives on patient autonomy in end-of-life experiences in acute and community care settings in Ireland.

The aim of this project is to explore patient autonomy at end-of-life from the perspective of healthcare practitioners.

The objectives of the project are as follows:

- To facilitate care professionals in articulating their perspective on patient autonomy at end-of-life within their care settings
- To examine any ethical challenges that the practitioners’ have or have encountered in relation to patient autonomy.
- To explore the impact that engaging with these ethically challenging situations has on the professionals caring for dying patients
- To identify the barriers, if any, that prevent professionals from facilitating the needs and wishes of dying patients
- To ascertain the support needs that health professionals might have in relation to protecting and promoting patient autonomy
- To critically analyse such experiences with a view to informing an ethical framework for a good death.

The study will provide qualitative data on the perspectives of professionals who care for dying patients in their current practice and on their support needs in relation to protecting and promoting patient autonomy.

This qualitative research is being carried out by Catherine O’Neill, Lecturer in Ethics in the College of Surgeons (RCSI) and Dr. Christina Quinlan, the Research Officer dedicated to this qualitative element of the research.

The research is being carried out using a case study methodology. Seven cases in all have been developed and they are detailed in the chart below. The research is important research. Your support of the research and your participation in it will help to ensure this outcome. Thank you for taking the time to read this information leaflet.

Catherine O’Neill and Dr. Christina Quinlan, Royal College of Surgeons, Ireland
Appendix Two

Participant Consent Form
Qualitative Research – Ethical Death

Please tick the appropriate answer:

I confirm that I have read and understood the Information Leaflet dated ________ attached and that I have had ample opportunity to ask questions all of which have been answered satisfactorily.  Yes □ No □

I understand that my participation in this study is entirely voluntary and that I may withdraw at any time, without giving reason. Yes □ No □

I understand that my identity will remain confidential at all times. Yes □ No □

I have been given a copy of the Information Leaflet and this Consent Form for my own records. Yes □ No □

FUTURE USE OF ANONYMOUS DATA:
I agree that I will not restrict the use to which the results of this study may be put, I give my approval that coded DATA concerning my perspective may be stored or electronically processed for the purpose of scientific research and may be used in related and other studies in the future. (This would be subject to approval by an independent body which safeguards the rights of people in medical research.) Yes □ No □

Participant ________________________ ______________________
Signature and dated Name in block capitals

To be completed by the Principal Investigator or her nominee:

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study and I have invited her/him to ask questions on any aspect of the study that concerns them.

_________________________ ________________________ ____________________________
Signature Name in block capitals Role in Research Date

4 copies to be made, 1 for participant, 1 for PI, 1 for Research Officer, 1 for Research Record
Appendix Three

Data Collection Methods

Invited Submissions

A one-page summary of the qualitative research will be sent to practitioners at each site within each of the cases. They will be invited to respond with narratives of their experiences and/or concerns relating to patient autonomy at end of life.

Narrative Interview Schedule  (interviews will be audio taped)

Interviewees will be asked to recount narratives of patient autonomy which give expression to their experiences and concerns regarding patient autonomy at end of life.

Interviewees will be asked to outline an example of where patient autonomy was recognised and respected.

Interviewees will be asked to outline an example of where patient autonomy was neither recognised nor respected.

Interviewees will be asked to recount narratives of practice on patient autonomy, and any issues or concerns they have on that topic.

Interviewees will be asked to give expression to any thoughts or ideas they have in terms of how patient autonomy at end of life might be enhanced. They will be asked to outline barriers or obstacles in practice to patient autonomy at end of life.

Focus Group Schedule (focus groups will be audio taped)

The will be a short introduction to the study.

Participants will be facilitated in focusing on the following topics:

- Your understanding of patient autonomy
- Your experience of patient autonomy
- What happens in practice?
- What are the issues, challenges and concerns around present practice?
- What could be done to enhance patient autonomy in practice settings?