

Perspectives and Experience of Patient Autonomy at End of Life

A Qualitative Study with Patients, Families and Friends



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St. Francis Hospice



The Irish Hospice Foundation

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Friends

Report of a Pilot Study Conducted in Beaumont
Hospital and St. Francis Hospice



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**Perspectives and Experiences of Patient Autonomy at End of Life:
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A pilot study

This research project was a pilot study designed to explore the methodological possibilities and issues in conducting a major study of experiences of patient autonomy in end of life care from the perspectives of patients, family members and friends.

The pilot study was carried out in St. Francis Hospice and in Beaumont Hospital, Dublin. Data gathering for the study was conducted at these two sites over a five month period. The participants in the pilot study were patients, family members and friends.

The objectives of the study were as follows.

- This study explored the feasibility of establishing a major qualitative study on the perspectives and experiences of patients, family members and friends with regard to patient autonomy at end of life;
- The pilot study was designed to provide a blue print which would facilitate the development of an appropriate methodological approach for such a qualitative study;
- The pilot study was designed to highlight the problems and difficulties in studying the perspectives and experiences of patients, their family members and friends, so that those problems and difficulties could be circumvented in the major study.

The pilot research project follows on from the research carried out by Quinlan (2009) and Quinlan and O'Neill (2009) for the Ethical Framework in End of Life Care (McCarthy et al 2011). The Ethical Framework for End-of-life Care is part of a national programme, The Hospice Friendly Hospitals Programme (HfH) of the Irish Hospice Foundation. This national programme was developed in order to improve the culture of care and organisation in end of life experiences in Irish hospitals.

Patient autonomy is a key issue in ethics in contemporary healthcare. The word autonomy comes from the Greek 'auto', meaning self, 'nomos', meaning law, and 'autonomos' meaning the right to self govern. Autonomy is one of four key principles in bioethics (Childress, 1990; O'Neill, 2002; Rendtorff, 2008), the other three key principles being non-maleficence, beneficence and justice. 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. Patient autonomy, as defined in this study, is the capacity of the patient to express their wishes and then have those wishes heard and acted upon. In the background research carried out for the Ethical Framework in End of Life Care there was a particular focus on patient autonomy. This particular focus on patient autonomy was a response to calls for such a focus in the literature on end of life care. This pilot study is a development from the research conducted for The Ethical Framework for End of Life Care.

Rationale for the Study

The background research carried out for the Ethical Framework in End of Life Care highlighted the fact that research around end of life experiences tends to be conducted with healthcare professionals rather than with patients, family members and friends (Quinlan 2009). In order to make some attempt to fill that gap, this pilot study was proposed. The hope was that the pilot study would provide a blueprint which would guide the design and development of an appropriate methodology for use in a major research project which would explore and examine experiences of patient autonomy of dying patients, drawing on testimony from the patients themselves, family members and friends.

Ethical Implications: There are particular sensitivities in researching dying and death with patients, family members and friends, and this fact has been well documented (see Quinlan 2009, and Quinlan and O’Neill 2009). These sensitivities in large part explain the lack of research with these populations. As explained above, it is the lack of research in this area that prompted this pilot study; the hope being that the pilot study when completed would provide a rationale for as well as a blueprint for a substantial study of experiences of patient autonomy in end of life care from the perspectives of patients, family members and friends. The intention of the researchers in undertaking this pilot study was to carry out an ethically sound study which would pave the way for a substantial research project.

The key ethical considerations in the pilot study were that the participants in the study would freely and knowingly participate in the study, that they would suffer no ill effects from their participation and that the data they provided to the study would be used to explore the feasibility of a major study and used to highlight any ethical and methodological issues in such a study. The hope being that a major study on patient autonomy in end of life experiences, from the perspectives of those living the experiences could and would be established. Substantial efforts were made throughout the fieldwork for the research to ensure that the ethical issues that did arise were dealt with properly and thoroughly. The researchers who undertook the pilot study are very experienced and highly skilled. All have considerable experience in end-of-life research. Ethical approval for the study was granted by the Research Ethics Committees of both Beaumont Hospital and St. Francis Hospice.

Literature Review

There has been a substantial amount of research activity on the topics of end of life experiences and experiences of end of life care, in this country and elsewhere. However, the literature review undertaken by Quinlan (2009), for the ethical framework for end of life care (McCarthy et al 2011), showed that relatively little research has been undertaken with patients at end of life and their families. Little has changed since that work was published. The literature review carried out by Quinlan (2009), showed that the focus generally in the literature is not on the perspectives of patients, but on the perspectives of clinicians and researchers (see also Spichiger;

2008). In addition to this, much of the literature was shown to focus on attitudes to death, on death anxiety and fear of death. The research published in this field is largely quantitative; much of it conducted using a survey methodology, experimental design and/or attitude measurement scales.

While this pilot study focuses on exploring experiences of patient autonomy in end of life care, with patients, their family members and friends, the researchers undertaking the study are cognisant of the difficulties posed by this approach. Research on dying and death tends to be conducted post-bereavement, with relatives of the person who has died. The tendency for research on dying and death to be conducted post-bereavement provides another signal of the sensitivities involved in engaging in research around dying and death with patients who are dying and their families.

When patients are dying, often strenuous efforts are made by the patients themselves and by their family members and friends to protect the dying patient and to protect each other. The determination of patients and their families and friends to protect each other throughout end-of-life experiences including, and arguably particularly, end-of-life experiences in institutional care settings, is evident in the literature (Leichten Tritt and Rettig; 2002, Meeker and Jezewski; 2005, Quinlan and O'Neill; 2009, Cohen Fineberg et al. 2011, Ayotte et al. 2012). This determination to protect the patient in such circumstances is even stronger when the patient is a child or a young person (Hinds et al 2007). This instinct to protect patients at end of life is admirable and in terms of the human experience of dying and death it is of the utmost importance. However, as Hinds et al (2007), explained we do need to study end of life experiences if we are to improve our ability to prevent or diminish suffering in dying patients and their families.

One of the issues in exploring through research experiences of dying and death is the fundamental reluctance of people to engage in conversations about dying and death. This issue was highlighted in an Israeli study, carried out by Leichten Tritt and Rettig (2002), which outlined in detail the reluctance of people generally to discuss dying and death and end of life issues and experiences. These researchers detailed and explained the different family communication strategies that they uncovered in their research, among them the use of anecdotes, private codes, taking space or distance in

a conversation, jokes, sarcastic comments, silence, self-disclosure, and avoidance, all of which were used to manage conversations around dying and death. The authors of this study concluded that these communication strategies were designed to do one of three things; promote communication; block communication; or shift communication to other topics.

In blocking conversations, for example, participants would avoid questions or issues and/or avoid using particular words. They would make private signs to some members of the family and they would take space from the conversation, diverting the conversation. In an endeavour to protect one another they would skip questions. They would privately indicate the need to skip over or avoid an issue. They would interrupt and effectively silence a speaker, and they would stop conversations for short breaks, going in and out of the room in which the conversation was being held on a variety of pretexts and excuses. In some families there was one family member who was clearly the ‘protector’ in that family. The authors said that this role had clearly been given to this person by the other family members, and this person had clearly accepted this role. The protector in the family always ensured that conversations were kept at a low level of emotional intensity.

Communication generally is critically important in end of life experiences. In their nationwide (in Ireland) qualitative study of practitioner perspectives on patient autonomy, Quinlan and O’Neill (2009), found that patients at end of life are often excluded from conversations and communications regarding their end of life experiences. The research carried out by Quinlan and O’Neill (2009) uncovered many reasons why this is the case. One substantial reason, as detailed above, is the strong desire in families to protect the family member who is the patient. Clinicians too, the researchers found, could be over-protective of patients. Such over-protectiveness can render clinicians unwilling to signal to a patient their impending death. The often oblique styles of communication used by some clinicians, and the reactive mode of communication frequently used, where clinicians respond to questions but do not initiate discussions of, in particular, (sensitive) issues, was also highlighted as an issue in the research.

In their research into communication in family conferences, Cohen Fineberg et al (2011), concluded that there are substantial benefits to all of the interested parties being present together at the conference, i.e. patients, family members and clinicians and other care professionals. The ‘simultaneous presence’ of all meant, the researchers found, that all involved in patient case were essentially ‘on the same page’. All had a shared knowledge and understanding of the patient’s illness, care options, decisions, wishes and needs and this, they found, was particularly valued by family members. In their study, a meta analysis focused on family perspectives in end of life care, Ayotte et al. (2012), found that ‘open and frequent communication among the patients, family members, and healthcare providers emerged as essential to satisfaction of all participants at the end of life’.

Patient autonomy is a very complex concept. An issue in patient autonomy, as highlighted by Quinlan (2009), is the fact that patients in hospital have a compromised autonomy, due to the fact that they are patients in an institution and under the legal and ethical care of the institution. As patients in care settings are under the care of their carers, and their carers have a legal, ethical and moral responsibility for them, patients cannot act entirely autonomously. They cannot do what they want to do, when they want to do it, how they want to do it. They are obliged to follow some direction, and they are obliged to fit themselves into the necessarily structured and ordered life of the care setting. In addition, as Quinlan (2009) explained, a patient’s willingness and capacity to assert their autonomy, along with their mental state, their degree of competency and their physical condition, are all key to determining the degree of autonomy desired and the degree of autonomy allowed.

As well as the necessary organisational and situational constraints on patient autonomy, Quinlan and O’Neill (2009), found that patient autonomy was in fact only one value of a number of values that were important to patients at end of life. Highlighted in the study was the respect that patients tend to have for other patients and their needs, the concern of patients for their families, and respect and deference patients tend to show to nurses and doctors. These values, it was said, would bring patients sometimes to suppress their own needs and wishes. Also highlighted in the study was the issue of many, if not most, patients in an Irish context coming primarily from cultures which were community-based, cultures where familial ties were very

strong and very fundamental to the fabric of daily life. Such cultures were said to be based on and built around collective rather than individual values. These collective values were, it was said, quite in opposition to autonomy and expressions of autonomy. In fact, one participant in the research conducted by Quinlan and O'Neill (2009), suggested that autonomy was generally not a part of the consciousness of everyday life in Ireland to anything like the same extent as it is in the 'post modern situations within which some people live'.

In her review of the literature on patient autonomy (2009), Quinlan highlighted as useful two published biographical studies of end of life experiences. Both of these biographical studies provided substantial accounts of the experiences of the two individuals about whom they had been written, Michael Wilson, a middle aged man at the end of his life, and Lucy Grealy, a young woman whose life experience, including her end of life experience, had been shaped by her diagnosis. In her exploration of the stories of Michael Wilson and Lucy Grealy, Quinlan (2009), explained that these stories provide very substantial and very useful insight into the phenomenon of end of life for people living through such experiences.

What was clear from these two narratives, Quinlan (2009) explained, was that despite the fact that Michael Wilson and Lucy Grealy, the people at the centre of the narratives, were patients, it was not their medical care that wholly absorbed them. These two individuals were in fact very substantially concerned with their experiences of living. Both had very profound concerns that actually had little to do with their clinical conditions or their clinical care, and little to do with the clinical settings in which they were obliged to spend substantial amounts of time. These biographical accounts are very useful records of two end of life experiences. Above all, for the purposes of this pilot study and the proposed subsequent major study, the documented experiences of both Lucy Grealy and Michael Wilson clearly demonstrate the limitations of studies of end of life experiences which exclude the perspectives of the patients themselves.

While the two biographical studies do provide great insight into the experiences of the individuals whose lives and end of life experiences the biographies were written to explore and in part explain, they are limited from the perspective of the social

sciences. Both are biographical studies; neither one is a scientific study. Neither one was conducted using a scientific research methodology; neither was situated within theoretical frameworks. There is an established need for social scientific explorations of the end of life experiences of people in clinical settings.

This pilot study is a social scientific exploration of patient autonomy in end of life care from the perspectives of patients, family members and friends. The hope for this pilot study is that it will provide a template for a substantial research project which will help to some degree in meeting the need for research around the experiences of patients, family members and friends.

Patient autonomy in theory and in hospital practice is a multi-faceted phenomenon. As explained above, Quinlan (2009) suggested that patients in hospital have a compromised autonomy, necessarily so as they accommodate the organisation of the care setting within which they find themselves. It is also clear, from the evidence of the two autobiographies detailed above, that patients have very many concerns and motivations which have little or nothing to do with the medical practices to which they are subject. While this is the case, the literature review undertaken by Quinlan (2009) shows that in hospital practice, conceptions of patient autonomy, practices around patient autonomy, and expressions of patient autonomy are often reduced to patient involvement in medical decision-making. The experiences, wishes and expectations of the people who are patients are not taken into account. It is the experiences, wishes and expectation of patients in relation to medical decision-making that is the focus. This was clearly demonstrated recently in a debate conducted in 2011 in the journal the *Archives of Internal Medicine*.

This debate was launched by Billings (2011) who, in an article on patient autonomy and physician responsibility in end of life care, wrote that excessive deference to an unreflective concept of patient autonomy could, inadvertently, compromise patient autonomy by placing too much responsibility for medical decisions on patients or their surrogate decision makers rather than on their physicians. Such practices, Billings states, can harm patients by depriving them of the expert, professional advice they need and deserve when making important decisions about their health care. Clearly Billings made an important point and he highlighted a critical issue in this

article. It is indeed an abdication of responsibility to privilege the bioethical principle of patient autonomy above the duty of care of the clinician in relation to medical decision making; a case of one bioethical principle trumping another, or all of the other bioethical principles, patient autonomy over justice; and beneficence; and even non-maleficence.

In a response to Billings (2011), Goldberg and Meier (2011) used the metaphor of ‘a swinging pendulum’ to illustrate and explain the balance between physician responsibility and patient autonomy. Once again, the focus of Goldberg and Meier (2011), as with Billings (2011), was on patient autonomy in medical decision making. Conflating patient autonomy with patient self-determination in medical decision making, Goldberg and Meier (2011) began by explaining why patient autonomy is currently centre stage in medical bioethics (among the reasons outlined are the range and complexity of treatments available, and the likely positive and negative effects of the different treatments; they also point to relatively high levels of education of patients, family members and friends) and they concluded by stating that medical care providers must include patients and their surrogates in the (medical) decision-making process by soliciting, through dialogue, individual patients’ values and goals and then providing as much as possible medical treatment that matches these values and goals. The authors state that such dialogues are at the heart of the art of medicine.

While patient autonomy is, as Goldberg and Meier (2011) state, ‘centre stage’ in medical bioethics, and patient autonomy should be facilitated by means of dialogue with patients, family members and friends, Dreyer et al (2012), found that the relatives who participated in their study had little knowledge about the end of life and few of them understood the concept of patient autonomy. This finding is important. It is important in the context of research on patient autonomy and it is particularly important in the context of patient autonomy in medical decision-making. If patients, their family members and friends don’t know very much about dying and death, if they don’t understand the bioethical concept patient autonomy, then there are substantial issues yet to be considered in relation to research on patient autonomy, and research on patient autonomy in end of life experiences.

It is important to note that while Dreyer et al (2012) found in their study that few of the participants, all of them relatives of patients at end of life, understood the concept patient autonomy, Quinlan and O'Neill (2009), found in their study '*Practitioners' Perspectives on Patient Autonomy at End of Life*' that some of the practitioners who participated in their study found the task of defining and describing patient autonomy to be quite challenging. The research showed that although some practitioners were very knowledgeable about patient autonomy and were 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, were slow to outline a definition of patient autonomy, and slow too to describe practices around it.

An editorial published in the BMJ in 2003 prompted much of the reflection engaged in by Quinlan and O'Neill in their 2009 study; the findings of that study, in turn, prompted this pilot study. In the BMJ editorial Clark (2003), stated that 'the "needs" of the dying patient tend to be defined and filtered through the views of family and healthcare professionals'. There is a great need, Clark wrote, for research with patients at end-of-life and their families, in terms of their experiences of end-of-life, both in terms of the meaning for them of their end-of-life experience and in terms of their experiences of end-of-life care. So while there are very substantial sensitivities and very substantial ethical issues in conducting research with patients, family members and friends around end of life experiences and experiences of end of life care, there are very real and very substantial reasons why such research should be carried out.

Patient-centred death, and advocacy for this, is a fundamental objective now in end of life care. In the BMJ Editorial, Clark (2003), called for patient-centred death and a divesting of authority in dying and death away from doctors and families and an investing of authority to patients. This is an important perspective on patient autonomy. Patients' concepts of a good death, Clark (2003) suggested, should guide efforts to make deaths better. The editorial called for research into the ways in which patients see death, the meaning and the experience of end of life for dying people; and it recommended the use of novel qualitative methods in such research, such as ethnography, phenomenology and textual analysis. As stated earlier, patient autonomy is a complex concept. Patient autonomy in end of life care even more complex. There

are issues around communication and there are issues around decision-making. There is the human need and the legal, ethical and moral obligation to protect the dying patient. There is the human need of the person dying to live life to the end and, in the end, to die as they wish to die.

These are among the key issues of concern for the researchers in undertaking this pilot study. The researchers hope that through the exploratory work of this pilot study, they will find an appropriate approach and an appropriate research methodology for a substantial study of the end of life experiences of patients, their families and friends.

Research Methodology

A case study methodology was used in the research and this case study methodology was operationalised using a two-step approach in the two study sites, Beaumont Hospital, Dublin, and St Francis Hospice, Raheny, Dublin. Three data collection methods were used in the study, observations and formal interviews were carried out and narratives were gathered. In the first place, the researcher who undertook the fieldwork for the pilot study engaged in observations at multi-disciplinary team meetings in Beaumont Hospital and St Francis Hospice. Subsequently, the researcher carried out a series of interviews with patients and family members. A relatively small sample was engaged in the study. In total six patient cases, three on each site, were used; the proposal for the pilot study stated that a relatively small sample would be used, it was envisaged that there would be a maximum number of 6 patient cases, three on each site.

A social network approach was taken to the research and an attempt was made to construct a triad for each patient case; each triad was to consist of the patient, a family member and a friend of the patient. In the field, however, due to the difficulties that emerged in terms of securing participants for the study, cases were developed opportunistically and the number of participants in each interview and their relation to each other varied. In the end however, and as proposed, six interviews were carried out. The interviewees were sourced using a judgemental or purposive sampling method; the researcher maintained a presence in the field and through informal conversations and with the support of Dr. Regina McQuillan, Consultant in Palliative

Medicine and a member of the research team, the researcher established contact with potential participants. The key inclusion criterion for the sample was that the participants be, at the time of the study, participating in an end-of-life experience (their own or the experience of a family member or friend).

There is in medical practice a clinical challenge in determining when death will occur. For this reason in this pilot study the concept of 'no surprise', as developed by Lynn (2004) was used. Lynn used the following question: 'is this person sick enough that it would be no surprise if s/he died within the coming year?' In the approach taken to this research, this concept of 'no surprise' was used with clinicians at both sites in developing the sample of participants. As family members and friends were included in the sample, it was difficult before the fieldwork was completed to predict accurately the final number of participants. In the end, the final number of participants was eleven.

The following paragraphs detail the six interviews conducted:

1. The first interview was conducted with a female patient and her husband in St Francis Hospice, this patient was at the time of interview an out-patient of the hospice. The patient and her husband were both retired nurses and they were very happy to contribute in any way they could to knowledge in health sciences and healthcare, and so they were happy to participate in the research project.
2. The second interview was conducted with a patient in Beaumont Hospital and with his wife and their daughter. This was, in the end, the only triad accomplished in the fieldwork and this triad was flawed in relation to the design of the pilot project in that it consisted of a patient and two family members rather than a patient, a family member and a friend. Each of these three participants was very appreciative of the care the patient had received and continued to receive in the hospital. They were happy to engage in the research if their contributions were deemed to be of value to the research.
3. The third interview was conducted with a patient in St Francis Hospice. This patient was a day-care patient in St Francis Hospice. The researcher had

attended the day-care gatherings at the hospice and had participated in the activities there for many weeks. Over the course of those weeks this patient and the researcher had had many informal conversations. Suddenly, one day, in the middle of one of these conversations, the patient very quickly asked the researcher what she wanted, and if she wanted to interview him, the patient. Then this patient, very quickly and without waiting for a response from the researcher, volunteered to participate in an interview. Taken by surprise, the researcher agreed and interviewed the patient. At the start of the fieldwork in the hospice, senior staff at the day-care centre there had gone through a list of patients attending day-care with a view to identifying patients who could potentially participate in the study and, unfortunately, this patient was deemed by them not to be a suitable research participant. As it turned out, the experience of the interview caused the patient some anxiety and distress and the researcher was asked by the staff of the day-care centre to meet with the patient to allay his fears. This she did.

This experience highlights again the sensitivities in end-of-life research and the essential need in fieldwork on end-of-life issues with patients, their family members and friends to progress slowly and to double-check with supervisors and managers, even after immersion in the field, before actually commencing any data gathering exercise with any individual patient, family member or friend. It is essential that the data gathering exercise proposed meets with the approval of and is acceptable to the clinicians in charge. Fortunately, in this case, the patient needed only the reassurances of the researcher of the confidential nature of the research. Subsequently the researcher, as a frequent participant over the time period of the fieldwork in the activities of the day-care service in the hospice, had many conversations with this patient about his life experiences as well as his end of life experiences. While these conversations did help to inform the researcher about end of life experiences and end of life issues from the perspective of the person/patient undergoing that experience, the conversations were not officially recorded. While they did inform the researcher and the researcher's perspective on end of life care, they were not a part of the formal data gathering exercises conducted for the research project.

4. The fourth interview was carried out with a patient in Beaumont Hospital and his daughter. This patient appeared to be still working through his diagnosis and he was concerned about and to some degree disbelieving of both his diagnosis and his prognosis. Both he and his daughter were happy to participate in the research. Both had great appreciation for the work of clinicians and others engaged in end of life care, although, as the patient himself said, he couldn't understand why anyone would choose to work in the field.

5. The fifth interview was carried out with a female patient alone in Beaumont Hospital. This patient seemed very troubled, or, to be more accurate, very hurt by her diagnosis. She seemed alone in this pain. Although she talked about her very supportive family, and about the very professional and supportive manner of the clinical staff, thoughts of her impending death were very painful for her and she appeared to be responding to this pain defensively. Throughout the brief interview conducted she assumed an indifference, a forced cheerfulness and a briskness. This response on the part of this patient mirrored responses the researcher had observed in informal conversation throughout the fieldwork with day-care patients at St Francis Hospice. This public presentation of self is clearly a substantial part of the experience and the struggle of living with a terminal diagnosis. It is also perhaps a feature of the presentation of self of the patient with a terminal diagnosis to an individual who is not unwell, who is not living with a terminal diagnosis.

6. The sixth interview was carried out with an in-patient at St Francis Hospice and his wife. This patient was very open. He appreciated the hospice, his room in the hospice and the service provided for him by the hospice. In particular he appreciated the respite the hospice provided for his wife in assuming, as it did, a part of the burden of the care that he required. The patient's wife was also very open to both the research and the researcher, and she too was very appreciative of the hospice and the support and care the hospice was providing for her husband, herself and their family.

These are the participants in the pilot study and these are the circumstances of their participation. Throughout the engagement with the participants in the study, the researcher reflected on the ethics of this engagement. The researcher frequently felt inadequate when faced with the pain of some of the participants in the pilot study and she frequently questioned the value of the research, in light of the experiences of those patients, in light of their pain and the depth of that pain. Such questioning should not be used to obstruct end of life research with patients, their family members and friends. Rather it should be used to further and deepen critical engagements with proposed methodologies and practices in fieldwork in relation to studies of end of life experiences from the perspectives of those living through the experiences. Such experiences should be used to open up dialogue about dying and death, used to draw more and more people into discussions on dying and death, and through these discussions, such experiences can be used to promote understanding and disseminate knowledge. In this study, these experiences, and the reflections prompted by them, were used to inform the development of an appropriate research methodology for a substantial study in this field.

In relation to research methodologies for studies of end of life experiences, it is important to note that over the five months during which the fieldwork was carried out, not one in-patient presented in the acute hospital setting who was suitable for inclusion in the sample of patients used in the study. While engaged in the fieldwork in the hospital the researcher attended weekly staff meetings in Oncology and in Palliative Care. Over the five months of the fieldwork for the study the researcher circulated two formal (written) research up-dates to staff at these meetings. This was done primarily to inform staff about the research and about the progress of the research. It was also done to raise the profile of the research among the staff in the hospital in the hope of securing the necessary participants for the study. In the end, none of the study participants from the acute hospital setting were in-patients in the hospital.

The primary reasons why none of the research participants were in-patients in the hospital are, in the first place, the general busyness of the acute hospital and, in the second place, the eventfulness of the lives of in-patients in an acute hospital. Patients in acute hospitals who are in need of end of life care tend to be very busy people.

They tend to be in hospital for a range of treatments and/or tests, and such patients are frequently and often rapidly moved from one acute hospital to another or from the acute hospital to a different care centre. The schedules of in-patients in acute hospitals tend to be full and their schedules tend to change suddenly and without warning. For example, one in-patient in the acute hospital had agreed to participate in the study, but when the researcher arrived at the appointed time for the interview, the patient had been taken away for a scan and nobody was sure when, or even if, the patient would return. In this particular case, the researcher and the clinical team concluded that it would not be appropriate to engage the participant in a research interview following a medical intervention. This patient left the hospital shortly after the medical intervention and so did not participate in the research.

In addition to these sudden changes in the treatment circumstances of in-hospital patients who are at end of life, such patients are often too ill to participate in research. Of the other patients in the acute hospital who were deemed by staff there to be potential participants in the research, one was suddenly transferred to another acute hospital; one was experiencing 'a new event'; one was suddenly 'actively dying'; and one was, as the clinician said, 'transitioning at the moment'. There were patients who were just out of ICU, patients with cognition issues, patients who were 'too vague', patients who were in crisis, patients 'with too many issues', and patients who were 'just too sick'.

In the end, in the acute hospital setting, three patients participated in the study. The researcher engaged all three participants and their relatives on the day oncology ward of that hospital. Each of the three patients came into the hospital for chemotherapy and while they were waiting to have this therapy, they participated in the research project. They were not admitted to the hospital. They were patients on the day oncology ward. The day oncology ward was a good setting for the fieldwork. There were many patients there who fitted the inclusion criteria for participation in the study, and the patients there had time to participate in the study. They had time while they were receiving chemotherapy or time while they were waiting to receive chemotherapy. They were in a settled treatment mode. There were no sudden changes in their treatment plans, no sudden decisions were made to move them from the day oncology ward to other treatment locations or other care settings.

An ethical issue arose in relation to the research conducted on the day oncology ward. The issue concerned those patients on the day oncology ward who were not invited to participate in the study. The fact that a study was being conducted, and the fact that some patients were not invited to participate in the study seemed, the researcher perceived, to be a cause of some slight concern to these patients. In fact, the researcher felt that every patient on the day oncology ward was weighing the possible implications for them and their diagnoses and prognoses, of whether they were or were not invited to participate in the study. A simple explanation of the study, in the form of a flyer circulated to everyone on the ward, emphasising the fact that the study was a pilot study exploring experiences of patient autonomy (with an explanation of the concept of patient autonomy) for which no more than three interviews were to be conducted at the site, would have forestalled any concern. This experience again highlights again the sensitivities that exist in conducting research in end of life care. To avoid such situations researchers should develop protocols designed to protect patients who in the course of fieldwork may become aware that research is being conducted while not understanding, if they have not been invited to participate in the study, why this is the case.

Apart from this issue, the use of the day oncology ward to source participants for the pilot study worked well. The three interviews conducted on the ward were carried out and completed quickly and efficiently. It became clear to the researcher that this approach to research with acute hospital patients who are at end of life was a good approach in terms of sourcing participants for the research and in terms of engaging such patients in acute hospitals in the fieldwork of a research project.

The researcher spent one day on the day oncology ward and she managed in that day to carry out and complete the field work for the acute hospital. The researcher was able to do this with the support of the hospital and the support of the staff on the day oncology ward, and particularly with the support of the nursing staff on the day oncology ward. While the staff on the day oncology ward were very supportive, the researcher experienced a phenomenon on the day oncology ward that she came to conceptualise as 'screening out'. 'Screening out' is the capacity that some nurses on the day oncology ward used to avoid unwanted interruptions. Using a practice of

‘screening out’, some nurses were able to ignore individuals on the ward who were not the focus of their attention, and those who did not bring themselves to their attention. Through this process of ‘screening out’ these nurses were able, in effect, to not see these people.

While on the day oncology ward, the researcher found that if she did not assertively insert herself into the workflow of the ward, she was ignored by some members of the nursing staff on the ward. If the researcher wanted to attract the attention of some of the nurses on the day oncology ward, she had to very insistently catch their attention. If she did not do this, she would not come to their attention and the work of the day oncology ward would flow on around her. The staff would carry on around her without appearing to see her or notice her, without acknowledging her presence or her needs. From these observations of the practice of screening out in action, the conclusion the researcher drew was that in the general busyness of the acute hospital setting, assertiveness on the part of the patient or the person, family member or friend, accompanying the patient is sometimes essential in terms of securing attention. Securing the attention of the staff is the first essential step in securing care.

An interview schedule was designed for the interviews conducted in this pilot study and each of the interviews conducted in the field was guided by that interview schedule (see Appendix One). As each interview was conducted, as well as engaging with the issues outlined in the interview schedule, participants were asked to recount a narrative, a story, or more than one narrative if they wished. These narratives were stories which illustrated for them their experiences of exercising patient autonomy and the manner in which that exercise of patient autonomy was received and responded to by care staff of the institution and by the institution itself. Each of the interviews was electronically recorded and the recorded interviews were transcribed. The transcripts of the interviews were subsequently analysed using a thematic approach (Corbin and Strauss; 2008).

In addition to the interviews, the team meetings that the researcher attended in both St Francis Hospice and Beaumont Hospital provided the researcher with insight into the complex care issues that arise for patients at end of life, patients who are being cared for in both acute hospital and hospice settings. The insights gained from the

experience of attending these meetings, as well as the analysis of the interviews, are detailed in the following section on data analysis.

Data Analysis

The analysis of data presented here provides an in-depth understanding of the data gathered in the fieldwork conducted for the study and it provides a summary of the key issues to emerge from the analysis of that data. As stated, the data from the observations conducted at team meetings in the acute hospital and the hospice are presented first. These are followed by a presentation of the analysis of the interview data and the narratives gathered.

Observations of team meetings

The team meetings in both institutions, Beaumont Hospital and St Francis Hospice, were attended by representations of all of the professionals working with patients in those institutions. Medical consultants attended, social workers attended, physiotherapists attended, nurses attended, chaplains attended, and so on. Typically there would be eight to twelve members of staff in attendance at the team meetings in St Francis Hospice, and up to twenty-five members of staff in attendance at the meetings at Beaumont Hospital.

At the meetings in both institutions patient cases were discussed, information was shared in relation to patient cases and important decisions were made, decisions in relation to treatments possible, decisions in relation to when to end treatment, decisions in relation to whether or not the patient should stay in the acute hospital or the hospice or be transferred out of it. In some cases the patient was sent home, in some cases the patient was sent to an acute hospital or to hospice care, or the patient was sent to some other care centre such as a nursing home.

In discussing each case, the family circumstances of the patient would be shared with the team and the relative strengths and weaknesses of the family would be considered in relation to their capacity to cope with the patient's illness; any particular needs that the patient might have, social, psychological, spiritual and other were considered, and decisions around the supports that would be put in place for the patient were made on

foot of those discussions and in response to the patient's particular needs and circumstances. Each team was able to provide a very broad range of treatments and supports for patients.

The teams discussed different patients and their illnesses. The complexity of the work of supporting seriously ill and dying patients was very evident in the discussions. Also evident in the discussions was the complexity of every life lived. The teams talked about the ideas and conceptions that patients had in relation to their own illnesses and in relation to their care, and the ways in which these ideas and conceptions shaped their healthcare experiences. For example, they talked about the distrust of medics that some patients exhibited. They talked of some patients 'having no faith in western medicine' and they talked of other patients 'having too much faith in western medicine'.

There were issues in dealing with patients who were under eighteen years of age, and issues in dealing with children. The sadness and the tragedy of the lives and deaths of the patients were evident in the discussions. One team talked, for example, about a nineteen-year-old who wouldn't be going to the party that he desperately wanted to go to and had been planning to go to, because he was going to die. They talked about the young mother who might miss her child's first communion, because she was going to die. They talked about the old man who had become upset and depressed over the death of another patient; they had been close and the old man had sometimes sat with the patient and fixed his pillows for him.

The teams discussed family members who, in attempts to protect themselves, distanced themselves from the experience of dying and death. There were family members who left the country in order to distance themselves, family members who went abroad on one pretext or another. The private nature of grief in some families was discussed. The barriers raised by some families were discussed. Politeness was one of those barriers. The teams talked of attempting to pierce through that politeness. They talked of families 'circling the wagons' to protect themselves and each other in their end of life experiences.

Both teams, in the hospice and the hospital, talked about pain, pain management and pain control. They talked about combinations of factors. They talked about patients having difficulty standing up, walking, sitting down, lying down. They talked about patients who were 'in the bed' and patients who were 'out of the bed'. They talked about shortness of breath. They talked about symptom care and terminal care. They talked about degrees of cognition and degrees of impairment. Prognoses were discussed in terms of weeks and months, patients were said to have short months or long weeks to live, some had short weeks or long days, some patients had just short days. Nausea, vomiting and intractable vomiting were frequently discussed. So too were renal functions, bowel obstructions and diarrhea. Some patients were said to fluctuate between constipation and diarrhea.

There were patients who were said to be losing function. Some were weakening slowly, some weakening rapidly. The fears that some patients had about losing ability were discussed. There was talk of some patients collapsing. There was talk sometimes of collapsing body parts. There were mood swings, mood dips and depressions. There was loneliness and generalised anxiety. There was fear and terror. There were discussions about anger, discussions about fear and stress, discussions about confusion and agitation, and discussions about delirium. The teams talked of delusions and mental illnesses. They talked about aggression, about the violent responses of some patients to terminal diagnoses and prognoses.

There were communication issues, there were cross cultural issues, and there were language barriers. The responsibility that the consultant carried to explain to patients the consequences of the different treatment options open to them was evident all the time. The consultant had to communicate the different options and the possible consequences of those options to the patient. The question often was about how much the patient understood. Some patients, it was said, understood the options in an abstract sense. They did not understand the options in terms of the real, lived, embodied, physical, psychological, social and emotional reality of those consequences. The difference between these two understandings led sometimes, it was said, to patients 'making wrong decisions'.

The communication between the consultant and the seriously ill and dying patient was described by one consultant as 'a dance'. Through this 'dance' the consultant tried to communicate with the patient, tried to ascertain how much the patient wanted to know, how much the patient could bear to know, how much knowledge the patient could cope with. In this way the consultant tried to establish how much the patient understood. It was clear from these discussions among participants in the team meetings that sometimes terminally ill patients don't want to think about dying and death and they don't want other people to talk about such things.

The questions typically asked by the teams in relation to each patient were as follows:

- how much does s/he know?
- How much does s/he want to know?
- How much does s/he want other people to know?
- How much does s/he want difficult family members to know?

The teams talked of complex family relationships and they talked of complex family circumstances. Some families had more than one family member who was ill in hospital; there were patients in some families other than the dying patient. Some families coped with other illnesses, illnesses apart from the illness or illnesses of the dying patient. There were tensions in some families and estrangements in others. There were different personalities in families and personality disorders in some families. There was 'dark stuff' in some families. In some families there was a lack of transparency, in others there were secrets. In some families there were manipulations. In others there were deceptions and dishonesties.

Some patients were said to be disoriented. Some were said to be distressed. Different patients were said to have different coping mechanisms, some patients were planning trips to Lourdes; others were drinking to excess. Some patients were very frail, others were very fatigued. Some patients were very stoical; sometimes this stoicism evidenced illness denial, even death denial. In one meeting the team talked about a patient as 'being closed', this patient, they said, was so closed she even closed her eyes when she spoke. The team concluded that this patient 'did not feel the need to communicate every move and shift in her emotions'; there were a lot of things, it was

said, about which she did not feel the need to communicate. It was noted that the patient ‘opened up’ in gardening, in participating in the gardening project at the hospice.

The teams in both research settings were very open to the researcher who carried out the fieldwork and very open to the research. The members of both teams were keen to help the researcher and keen to support the work of the research as much as they possibly could. The observations conducted at the team meetings gave the researcher insight into the work of clinicians and other healthcare professionals caring for and responsible for patients at end of life. The depth and level of the care provided for patients emerged as a key theme from the observations. Very evident in the data was the weight of responsibility that healthcare workers bear in relation to their patients. Also very evident was the advocacy role that healthcare workers frequently and readily assume on the part of their patients.

The data gathered in the observations provided the researcher with an understanding of the experience of serious illness for those patients who are seriously ill and dying. The observations also provided the researcher with an acute awareness of the physical, psychological and emotional impact of serious illness on the dying individual. The data gathered helped the researcher develop an understanding of the social complexity of each patient case. It is this perspective that provides, in part, the justification required for a substantial study based upon this pilot study. It is this experience which essentially provides a substantial element of the rationale for a major study of the experiences of end of life and of end of life care for patients, their family members and their friends, developed through an appropriate methodological approach.

There was one very upsetting and very challenging experience for the researcher during the course of the fieldwork. One day, as she participated as an observer in a team meeting in the acute hospital, the clinical team discussed the case of a patient who happened to be a friend of the researcher’s. The researcher did know that her friend was seriously ill and a patient in the hospital. She did not know, or did not fully comprehend, the seriousness of the friend’s illness. It became clear to the researcher very quickly at this team meeting that her friend was in fact close to death. The shock of hearing this was profound. The experience of hearing a friend discussed as a case,

in the terms used by clinicians when discussing a case, was shocking. The researcher gave no indication at the team meeting that there was anything different or unusual about her participation that day. She did discuss the experience after the meeting with a palliative care consultant, the consultant who is a member of the research team. The experience underlines once again the particular sensitivities in researching end of life experiences.

The observations that the researcher carried out in the field, and the detailed patient cases that she had access to, as they were described and discussed at the team meetings, gave the researcher a deep understanding of the impact on patients and their families of a terminal diagnosis, and the calamitous experience that this is for those patients and their families. Throughout the fieldwork conducted for the study, the researcher observed closed, muted, family gatherings. She noted, at the two research sites, both young and old patients with impending death clearly etched on their faces. The researcher frequently noted closed expressions of resignation on the faces of the companions, family members and/or friends, of those patients. There seemed to be a sense about them of their not knowing what to do; a sense of them coming to terms with the fact that there was, in fact, nothing that they could do.

From patients themselves, particularly patients in day-care in the hospice, the researcher experienced many withdrawals and rebuffs, all of them very subtle and all of them always within the realms of kindness and invariably quite amiable. These rebuffs and subtle withdrawals signalled to the researcher, as they were designed to do, that she didn't know and couldn't know what it was to experience dying, what it was to be dying, what it was to be facing death. Everywhere, the researcher noted, there was pain, physical pain, psychological pain and emotional pain. There was loneliness, grief and regret. Sometimes all of the loneliness and pain was accompanied by a sense of an injustice, a sense of unfairness, a sense of being cheated, in a most unforgiveable manner, out of life.

In addition to the pain and suffering and the injustice, there was a sense of aloneness for many of the patients. This sense of aloneness was relieved for most, if not all, in the camaraderie of other patients. It was relieved for them in the company of other people on the same or on a similar journey. There clearly was some solace to be found

in the company of other people experiencing similar distresses and traumas, similar pains. There was some comfort to be had from the company of other people also confronting a certain and imminent death.

All of this evidence of profound existential pain led again to the researcher questioning, on occasion, the value of the research. While engaged in the fieldwork for the study, the researcher often thought that the clinicians and care staff who were immersed in the field, through their daily work in the field, would be much better placed to give expression to the experiences of dying patients and their families and friends than a social scientist who was, in a sense, simply visiting. In the final analysis the researcher concluded that this is not the case.

The fact is that the clinicians and careworkers are so immersed in the field, so practiced at the work, they are inoculated in a way from the shock and the horror experienced by every new patient, and by their family and friends, at a terminal diagnosis. In fact, the practiced ease of the clinicians and the careworkers in the field provided yet another conundrum for the researcher, the social scientist in that field; and that is how does the social scientist, who is not a carer and has no caring duties or responsibilities, establish themselves in such a field as a responsible professional with a valid and valuable role, indeed a critical role in that field. This is an issue that needs to be fully addressed if this pilot study is to be developed into a substantial study on experiences and expressions of patient autonomy in end of life experiences and end of life care.

The Interviews

As explained above, in total six interviews were conducted with a total of eleven participants. Three interviews were conducted in Beaumont Hospital and three interviews were conducted in St. Francis Hospice. The following paragraphs detail the key themes to emerge from the analysis of the interview data. The key themes were:

1. Patient Autonomy;
2. The lived experience of the dying body;
3. The centrality of family at end of life;
4. Standards of care in hospital and hospice care settings;

5. The reliance of patients and families on expert clinical care;
6. The expectations of patients of kind and respectful treatment in care;
7. The role of the researcher in end of life care;
8. The need for support for the researcher in end of life research.

In relation to experiences of patient autonomy, that is the patient being able to express their wishes and then having those wishes heard and acted upon, one of the patient's interviewed recounted the following narrative:

'Well, I wanted to go home. I wanted to go home and I said I can stay with my sister and she could look after me. No, he said, I'm so sorry, you can't go home. Cos he said we have to check the bloods every day, You know, the bloods go down and then they go up. He couldn't, but he let me go another week after that.'

Another said:

'Oh yeah you could approach them. No matter what he wanted, the nurses kept popping in and out, pleasant and in good form. They'd get him pain killers, get him what he wanted. When he had nausea, they were holding his head. And no matter what time I was here, not one of them ever said to me, you shouldn't be here.'

The patients who participated in the interviews talked about the embodied knowledge an ill person has. They talked of knowing themselves, within themselves, how ill they were. For example, one patient spoke of the family needing to know, needing to be told how ill the patient is. This participant said that,

'the patient already knows, because, with the body, there is so much change'.

In this patient's experience, his body had undergone so many changes that he knew that he was dying. He said that, when things get to this stage, when the patient feels in their body that they are dying, the patient's concern is entirely for their family, as he said:

'concern for their suffering in relation to your dying.'

One of the patient's interviewed outlined the following narrative:

'And then there is another story, my son, my son is living in Cork. I saw him one day passing by the ward and I said to myself, what's he doing here, he should be working. And then I saw my two daughters after that and the three of them were crying. So that time they gave me about two weeks to live, and I didn't care, it didn't mean anything to me. I was so ill. But I picked up again. They call me the miracle woman.'

Family was central to each person's experience in this study. Each of the participants was accompanied on their journey towards death by family members and, for all of them, their primary concern was for those family members. Interestingly, none of the participants in the study had friends accompanying them on the journey. If they had had friends accompanying them, those friends could have been included in the research, in order to form the triads initially proposed for the interviews. None of the participants in the research either mentioned or alluded to close friends during the interviews. It would seem from this evidence that frequently, in Ireland, the intimacy of dying is played out in family circles rather than in friendship circles.

In relation to the caring nature of all staff in an acute hospital, one interviewee said:

'But I remember one morning I was very low, and I just couldn't.... I cried. I cried for two hours. I lay down and I covered my head. And the lady that was cleaning, she came over to me, and..... she was brilliant. And that passed.'

One of the patients interviewed said:

'When I was sick I got VIP treatment... When I was upstairs, the staff were up and down to me to see how I was, ringing up to see how I was. They were all fantastic. Even the day I came in, the doctor heard that there was a man in here with my name, and he came straight up to see if it was me. He came straight up. They are all fantastic, every one of them.'

One of the patients described his experience as a patient in the hospice as follows:

I was starting to get depressed and I was never depressed a day in me life. I went home and I just got a dose of depression and I don't know how anyone could stick depression day in and day out. Cos I got this dose of

depression and nothing was right and nothing was wrong. Then I got the option of coming in here and I thought that that was the best option, to come in here, to a place that knew what it was all about, the hospice.'

His wife interjected – **'He was crying all the time.'**

'I think you know yourself; the first few days in a hospice are strange, very strange. I started to realise then that there are people in here in the very same position as I am; different area but in the same class as I am. So that helped me settle down, relax. It's only in the past few days that I've started to go out, and the likes of the doctor pushing me to go out more. I think that that's fantastic, pushing me to go out more. They work on your inner strength, if you have any inner strength. You get to go out then and then you're doing things that you didn't think you were able to do. They encourage you to tackle them. That's what I found about coming in. They've given me strength to go out and meet people. I wouldn't go outside the front door. They make you strong. I think I was in denial, about what I had. I hadn't come to terms with it yet. The minute anyone mentioned how are you feeling, I started crying. The nurses here are having a bit of a laugh with you and when I go for a cigarette, I can have a chat with the other people in the room. I seem to have become more friendlier, since I've come into the hospice.'

This patient's wife spoke of finding a big difference between hospital and hospice care. She said:

'There's a big difference (here in the hospice) towards a hospital. I took him home one day from Beaumont Hospital. I wouldn't leave him in it. The nurse said bring him in I'll have a bed for him. She didn't have a bed, she had a chair. I wouldn't leave him in it.'

While this evidence highlights the difference between the hospice and the hospital setting, as well as the resource constraints of the acute hospital setting, other participants had more positive experiences to report. One participant said:

'For me anyway, the day Daddy came in, the amount of people that was around him, trying to help him. That was helpful. There was a time when it used to frighten the life out of us.'

Another said:

'That was when he was with that team. Now the team were brilliant. Then we had him home. And then he had a scan, and they discovered it on his liver. And then he started chemo and here, I have to say, they were brilliant. They just..... The nurses, doctors, everyone, they're great.'

Another said:

‘And then we were at home and he took this very very severe pain. And I rang here and they said don’t bring him to casualty, bring him straight up to the ward and when we got up here, there was doctors and nurses all around him trying to help him.’

The participants talked about their reliance on professional help. One said:

It’s all about expert help. There’s no way you could manage on your own, it’s such a worrying time.

One patient spoke of the value of good humour, emotionally and physically. He said of the hospice:

‘To have people around you who are laughing and joking, that’s a great help when you’re feeling down. You get drawn into it. You’re not left out. There’s people in here, the nurses, and if it wasn’t really important what they were talking about they’d bring you into their conversation. If it was real important what they were talking about, they’d go outside to talk about it. They’d bring you into their conversation and you could have a laugh and a joke about it. That all helps. It helps with the building up of your own body.’

One of the participants clearly illustrated the value she placed on being able to help the medical service, being able to make a contribution to knowledge in this field. In outlining this narrative, she also demonstrates how her autonomy as a patient was respected. She said:

‘There was that time that you could see my liver and my spleen, my stomach was so distended, and I saw every student from UCD, they came in to see it, because they had never seen it before.’ (her husband interjected- ‘She was so thin. She went down to under 7 stone’). ‘I was in good form, and they used to come in two at a time, and they would ask did I mind, ever so professional they were, and they would ask did I mind, and they would have a little chat at the end of the bed, and I overheard them say, muscle wasting, very very thin, but in great form. I must have seen thirty of them. It made me feel a little bit special. I don’t think they see that too often. It was a help to the students, it was, cos they were very pleased about it. I remember one day two of them came. I got a lot of nose bleeds when I was very down. I could get a nose bleed and have it all day. Drip drip. I say no, I couldn’t see you today. That was fine. They came back tomorrow and I did see them then. I didn’t like that part of it now, the nose bleeds.’

It was clear from the interviews conducted that the participants in the study greatly appreciated the care and kindness they received from the staff, clinicians and others caring for them in both the acute hospital and in the hospice. As well as appreciating the expert clinical care provided for them, the participants valued the kindness, good humour and humanity of the professionals caring for them and they outlined and illustrated such experiences in the interviews.

The data gathered in the interviews seem to indicate that patients at end of life have an embodied knowledge about the state of their physical health. This unique perspective that each individual has on their own physical condition, and on their physical condition as it deteriorates, provides each with a unique insight into the state of their ill health. It seems likely from this then that dying patients do know that they are dying.

In relation to embodied knowledge, and indeed the shared knowledge between the physician and patient, one consultant said during the course of the fieldwork that it is possible to know something on one level, and not know it at all on other levels. Sometimes patients can be in denial over their condition. Sometimes they can interpret their experience of ill health as an episodic phenomenon, from which they will recover, and which may or may not recur, rather than evidence of a terminal condition.

Concern for family, for loved ones, was an overriding concern for most of the participants. One participant outlined a concern regarding the need for clear communication with family members regarding the health status of the patient. Most of the participants expressed gratitude for the support the healthcare facility provided for family members.

The profound crisis that serious ill health produces in the lives of patients and their families was clearly evident in the data gathered in the interviews. The vulnerability of seriously ill patients was evident in the data, as was the need they have for expert treatment as well as kind and respectful treatment. There was some evidence that the service provided for seriously ill patients in the acute care setting can sometimes be less than it should be. This demonstrates the necessity of all professionals engaging in

continuous critical examination of the standard of healthcare provided to patients. Professionals working in healthcare have to ensure that the standard of care provided is reasonable, acceptable and continuously updated, developed and improved.

The difficulty that the researcher had in inserting herself into the flow of the busy acute hospital and ensuring that her needs were heard and dealt with, documented above, can be read as a metaphor for the difficulty that the seriously ill patient, their family members and friends, may have in ensuring that they are heard and responded to appropriately. The pilot study shows that sometimes busy professionals focus on the tasks in hand and they screen out anything that might distract them from the tasks in hand. The facility to screen out in the context of a busy healthcare service should be critically examined and the implications of this practice for vulnerable people and vulnerable patients should be explored, analysed, explained, highlighted and challenged. The practice of 'screening out' by staff working in healthcare settings should be formally acknowledged and actively discouraged.

The interviews conducted with the patients were very useful and very interesting. They highlighted many important issues in relation to experiences of care at end of life, and in relation to experiences of end of life care. Above all, and from a research methodology perspective, these interviews highlighted the length of time needed with research participants in order to allow them to focus on, to reflect on, and to communicate to the researcher the experiences on which the research and the researcher are focused. This is particularly the case when the focus of the research is on a concept and an experience as complex as patient autonomy in end of life care. It is even more so the case when, as detailed earlier, patients, family members and friends often have little knowledge about the end of life and few of them understand the concept of patient autonomy.

Perhaps the most important finding of the analysis of the interview data is that, in fact, patients at end of life have little interest in so abstract a concept as patient autonomy. Despite the best efforts of the researcher to focus the interviews on the concept and the experience of patient autonomy in end of life care, it was clear that the patients really wanted to talk about their life experiences, and within that, their end of life experiences. The research shows that patients at end of life are comfortable talking

about their life experiences and they are both happy to talk about and happy to explain their life experiences. It is their life experiences, and their end of life experiences, that pre-occupy them. In attempting to examine end of life care from the perspectives of those experiencing end of life, either their own dying and death or the dying and death of a loved one, it would be useful to draw on this willingness of patients and their family members to talk about, to analyse and explain their own life experiences, and within those experiences, their end of life experiences.

The sensitivity of the issues explored in the interviews never ceased to be a critical issue throughout all of the interviews conducted. The need for support for participants in the interviews never ceased to be an issue throughout the research. The need for support for the researcher, although not an issue in this pilot study, would be a substantial issue in any major study undertaken. The researcher would ideally need to debrief with a senior member of the team once a week, at a scheduled meeting. At this meeting the researcher would talk about how s/he felt about the research, about how s/he experienced the research in the field, about any issues arising from the research, for the researcher personally, for the participants in the research, and for the other stakeholders in the research, and about any research issues arising from the development of the study and the roll-out of the fieldwork.

Conclusions and Recommendations

This pilot study highlighted many issues in relation to engaging in research with patients and families experiencing dying and death.

The pilot study provides a good template and guide for social scientists and other researchers in terms of what they can expect when working as researchers in an acute hospital setting and in a hospice setting with patients who are experiencing end of life, their family members and friends.

Given all of the issues that the researcher encountered while conducting the fieldwork for the research the key recommendation arising from this pilot study is that a major research project be developed.

The recommendation is that this research project be developed at St Francis Hospice.

This recommendation emerges from the issues and difficulties that arose in this pilot study in relation to engaging patients in acute hospitals, and in particular in engaging patients in acute hospitals in the kind of in-depth research required for the proposed study on end of life experiences in care settings.

The recommendation is that a major biographical research project be developed at St Francis Hospice in order to study patient experiences at end of life and in end of life care. The pilot study showed that patients are happy in a research context to talk about and to reflect on their life experiences, and within that, their end of life experiences.

The abstract concept 'patient autonomy' had little or no meaning or relevance for the patients and family members who participated in the research.

As this is the case, the recommendation is that the focus of the major study be more broadly on the life experiences of patients, with their end of life experiences being one aspect of their life experiences, and with patient autonomy being explored if it is articulated by participants in the study as an issue or a theme in their end of life experience.

The recommendation is for a major study on end of life care sited at St Francis Hospice to be developed using an innovative research methodology.

An innovative research methodology is essential for such a study given the requirement for in-depth research on the topic, given the sensitivity of the topic, and given the issues highlighted in this pilot study in terms of engaging in research with patients facing imminent death.

The innovative research methodology recommended for the major study is biographical research.

This biographical project should become one of the activities offered in the hospice to patients, both day care and residential patients. Presented as an activity in the hospice,

patients will be able to engage with the biographical research project, if they choose to do so, for a couple of hours, a couple of days, a couple of months or even for a number of months. Over the period of their engagement with the biographical research project, participants will produce a biographical document that they can keep and give to their loved ones, (see Chochinov's Dignity Therapy, Chochinov et al. 2012). The work of producing the biographical document will be therapeutic for the patient, and the interaction between the researcher and the patient in the course of working together to produce the biographical document will provide the data for the research project.

The biographical research project at St Francis Hospice should be modelled on the art project and the gardening project in the hospice. The biographical research project will be managed, operationalised and administered by a doctoral candidate or a post-doctoral researcher. The doctoral candidate or the post-doctoral researcher will be supported in operationalising the project by hospice volunteers.

It is in this way, in this instance, that the researcher, a social scientist, will be able to establish themselves in the care setting as a responsible professional, who is not a carer and has no caring duties or responsibilities, as a responsible professional with a valid and valuable role, indeed a critical role in that field.

The doctoral candidate or post doctoral researcher will work for two years on the biographical research project. It is envisaged that it will take six months to set the project up, one year to carry out the fieldwork for the study, the biographical research project, and six months to write up and begin to disseminate the findings of the study.

The data gathering for the project will be carried out using a wide range of methods and drawing on a wide variety of sources, including narratives, images, artefacts, focus groups and interviews. All of the data will be gathered through the biographical research project.

One of the products of the biographical research project will be an art installation at St Francis Hospice. This art installation will document the biographical research project.

The art installation will be comprised of patient biographies which will be documented using photography, video footage and a large collage generated from different and innovative media including photographs, post cards, theatre programmes, cinema tickets, newspaper clippings, ball gowns, wedding dresses, baptismal clothes, and so on. These materials will be used to document the biographies, the lives and the life experiences including the end of life experiences of participants in the study.

The biographical research project will document the lives of patients, and within their life experiences, their end of life experiences, their dying and death.

In this biographical research project, dying and death will properly be represented as a part of life.

The findings of the study will be used to develop our understanding of experiences of dying and death and to critically examine end of life care. The findings will be used to create blue prints for changing and improving end of life care.

A number of academic outputs will be produced from the study, including one major report and a number of journal articles. The knowledge developed from the biographical research project about the end of life experiences of patients and their families will be disseminated widely.

This pilot study was conducted in order to explore the methodological issues in developing a research methodology for a substantial study of patient autonomy in end of life experiences from the perspectives of patients and their families.

Following the research, the proposal is for a biographical research project focused on the life experiences of patients, their families and friends, and within their life experiences, their end of life experiences. Their experiences of patient autonomy will be explored and examined if and when and how patient autonomy is articulated by the participants as an issue in end of life care.

The biographical research project proposed should, when it is completed, provide substantial insight into the experiences of dying and death from the perspectives of those living through such experiences.

The objectives of the pilot study and the means by which these objectives were accomplished are detailed below.

- This study explored the feasibility of establishing a major qualitative study on the perspectives and experiences of patients, their families and friends with regard to patient autonomy at end of life;

This objective has been accomplished. The research carried out for the pilot project clearly showed that the participating patients and their family members had little interest in the concept or the experience of patient autonomy. They were interested in, and happy to talk about, the patients' life experiences and within those experiences, their end of life experiences. The recommendation on foot of the pilot study is for a major biographical research study on end of life care. The study is to be sited at St Francis Hospice. The biographical research project at St Francis Hospice will be presented as one of the activities of the hospice, along with the art project and the gardening project, and patients may engage with the project as they wish. The focus of the biographical research project will be on the life experiences, and the end of life experiences, of the participating patients, family members and friends.

- The study served as a pilot study for the develop an appropriate methodological approach for such a qualitative study;

This objective has been accomplished. An appropriate methodology for the study has been outlined. The methodology proposed is a biographical research method.

- The study was designed to highlight the problems and difficulties in such a qualitative study with a view to providing solutions to those problems and difficulties.

This objective has been accomplished. Very many issues were highlighted in the course of this pilot study in terms of conducting a major qualitative study on end of

life care. The issues highlighted in this pilot study will inform the development of the biographical research project at St Francis Hospice. The findings of the pilot study will be broadly disseminated, in conference papers and in journal articles, and will consequently be made available to all researchers interested in studying end of life care from the perspectives of patients, their family members and their friends.

Gantt Chart Outlining Timeframe for Biographical Research Project

		Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug
Year One	Set up												
	Engage with patients												
Year Two	Engage with patients												
	Conclude work with patients												
	Complete write up of project												

The table below details the resources required for the biographical research project.

Resources Required for Biographical Research Project	
Resources	Funding
Post-doctoral Researcher / Doctoral Candidate	Salary x two years / PhD Bursary
Room facility at the hospice	Provided by the hospice
Art and craft tools and resources	Provided by the hospice
Digital film and photographic resources	Provided by the hospice
Support of volunteer workers	Provided by the hospice
Dissemination budget	One art installation at St Francis Hospice, one major report, four conferences, and a number of journal articles.

Bibliography

- Ayotte, J., Derderian, L., Fiorini, J., Osgood, R., Jackson, J., Shay, J.T., and White, P., (2012), Family Perspectives on End-of-Life Care: A Metasynthesis', *Journal of Hospice and Palliative Nursing*, Vol. 14, No. 4, 303-311.
- Billings, J.A., (2011), On Patient Autonomy and Physician Responsibility in End-of-Life Care, *Archives of Internal Medicine*, 171(9), 849-853.
- Chochinov H.M., Cann, B., Cullihall, K., Kristjanson, L., Harlos, M., McClement, S.E., Hack, T.F., and Hassard, T. (2012), 'Dignity therapy: A feasibility study of elders in long-term care', *Palliative and Supportive Care*, ol. 10, pp. 3 – 15.
- Clark, J. (2003). Patient Centred Death. *BMJ: British Medical Journal*, 327(7408), 174-175
- Cohen Fineberg, I., Kawashima, M., and Asch, S.M., (2011), Communication with Families Facing Life-Threatening Illness: A Research-Based Model for Family Conferences, *Journal of Palliative Medicine*, Vol. 14, No. 4, 421-427.
- Corbin J., and Strauss, A., (2008) 'Basics of qualitative research: Techniques and procedures for developing grounded theory', (3rd. ed.), Thousand Oaks, CA., Sage
- Dreyer, A., Forde, R., and Nortvedt, P, (2009) 'Autonomy at the end of life: life-prolonging treatment in nursing homes-relatives' role in the decision-making process', *Journal of Medical Ethics*, 35, 672-677.
- Goldberg, G.R., and Meier, D.E., (2011), A Swinging Pendulum: Striking a Balance between Physician Responsibility and Patient Autonomy, *Archives of Internal Medicine*, Vol. 171, No.9, 854,
- Hinds, P.S., Burghen, E.A., and Pritchard, M., (2007), 'Conducting end-of-life studies in pediatric oncology', *Western Journal of Nursing Research*, June, Vol. 29, Iss. 4, 448-65.Lynn

- Kukla, R. (2005). *Conscientious Autonomy: Displacing Decisions in Health Care*. The Hastings Centre Report, Vol. 35, Iss. 2, 34-44
- Leichten Tritt, R.D., & Rettig, K.D. (2002). Family Beliefs about End-of-Life Decisions: An interpersonal perspective. *Death Studies*, 26(77), 567-594.
- Lynn, J., (2004), *'Sick to death and not going to take it anymore!'*, University of California Press, Berkeley, CA.
- McCarthy J., Donnelly, M., Dooley, D., Campbell, L., Smith, D., O'Neill, C., Quinlan, C., and Weafer, J., (2009) *'The Complete Ethical Framework for End of Life Care'*, <http://www.hospicefriendlyhospitals.net/ethical-framework/>
- Meeker, M.A., & Jezewski, M.A. (2005). Family Decision Making at End of Life. *Palliative and Supportive Care*, 3(2), 131-142.
- Quinlan, C., (2009), *'Patient Autonomy at the End of Life: Literature Review'*, The Irish Hospice Foundation, The Irish Hospice Foundation, <http://www.hospicefriendlyhospitals.net/resources-and-courses/itemlist/category/16-resources-an-ethical-approach>
- Quinlan, C., and O'Neill, C., (2009), *'Practitioners' Perspectives on Patient Autonomy at End of Life'*, The Irish Hospice Foundation, http://www.hospicefriendlyhospitals.net/media/k2/attachments/Practitioners_Perspectives_2009_Quinlan_ONeill.pdf
- Spichiger, E. (2008). *'Living with Terminal Illness: Patient and family experiences of hospital end-of-life care'* International Journal of Palliative Nursing, 14(5), 220-228.

Appendix One

Interview Schedule

(interviews were audio taped)

Please talk about your hospital experience.

Please outline a narrative that for you illustrates your experience.

Please talk about your experiences in expressing yourself, your cares and your needs.

Please outline and explain any issues or concerns you have on that topic.

Please outline any thoughts or ideas you have in terms of how the experience of patients might be improved or enhanced.

Please express any thoughts or ideas you have in terms of how patient autonomy at end-of-life might be enhanced.

Please outline and explain any barriers or obstacles you have witnessed or experienced in relation to patient autonomy at end-of-life.

Would you please recount a narrative (a story) which for you illustrates your experience of patient autonomy in hospital/hospice care?