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MEDIA DISCOURSES ON AUTONOMY IN DYING AND DEATH

Christina Quinlan

Introduction

THIS PAPER IS A SYNOPSIS of a research project designed to examine the representations of particular experiences of dying and death as represented in media consumed in Ireland. This media research is a small part of a large study commissioned by the Hospice Friendly Hospitals Programme, through the Irish Hospice Foundation. The large study, undertaken by a team of researchers from University College Cork and the Royal College of Surgeons Ireland, was tasked with the development of an ethical framework for health-care practitioners on patient autonomy in end-of-life care. Patient autonomy at end-of-life is the degree of autonomy or control dying patients, in hospitals and other care settings, have over their end of life experiences. The aim of this media research was to identify and analyse the ways in which different media deal with end-of-life issues in relation to patient autonomy.

Each year in Ireland there are approximately 30,000 deaths and two-thirds of those deaths occur in hospital, 40 per cent of them in acute hospitals (Hospice Friendly Hospitals Programme website). This is despite the fact that research conducted in Ireland has established that most people would prefer to die at home (O'Shea et al., 2002). Death in Ireland, as in other developed wealthy societies, occurs mainly in organised professional settings. For this reason, the general public is usually at one remove from the processes of dying and death, and knowledge of what happens at the end of life is often formed through assimilation of various media images and reports. In relation to media reporting of dying and death, it is the case that most end of life experiences are not considered newsworthy, and so, except for death notices, are not reported in the media. Only tragic or unusual or remarkable end of life experiences and deaths tend to be reported in the media in any great detail. The focus of this media research is on representations of dying and death in the media, and on media representations of particular experiences of dying and death.

Methodology

The methodology used in the media analysis was case study (see Cresswell, 1998). Two different case studies were developed. The first case study was a mixed-media analysis, where experiences of death represented in a range of media were examined. In the second case study, eight separate end-of-life scenarios were developed. Each of these eight cases was designed specifically to explore and inform a particular ethical issue in dying and death in contemporary clinical practice.

The Mixed Media Case

In the first case, the mixed media case, the media selected included films, books, TV documentaries and radio interviews. The media sources used were the television archive of RTÉ, used in particular for the *Prime Time* programme on the Leas Cross Nursing Home; *The Hospice*, by Yellow Asylum Films, a four-part series on life and death in St Francis Hospice, in Raheny, Dublin; the BBC TV documentary *How to Have a Good Death* presented by Esther Rantzen; and four films – *The Death of Mr Lazarescu* (Romania, 2007), *The Diving Bell and the Butterfly* (France, 2008), *The Sea Inside* (Spain, winner of the 2005 Academy Award for Best Foreign Film), *The Savages* (US, 2008). Three RTÉ radio interviews were also included: the first was an interview Marian Finucane conducted with Nuala O’Faolain (*The Marian Finucane Show*: RTÉ Radio 1, 12 April 2008), where they discussed O’Faolain’s terminal diagnosis and impending death; the other two interviews were both conducted by Ryan Tubridy during his weekday radio programme on RTE Radio 1, one with a man whose wife had suffered a miscarriage (Wednesday, 10 October 2007), the other with two mothers of young children who had died from inoperable brain tumours (Monday, 2 February, 2008).

A public talk by Professor Regina McQuillan, Professor of Palliative Medicine, Beaumont Hospital, was included; it was given to a public audience in the Peacock Theatre, 16 October 2007, in conjunction with Marina Carr’s play *Woman and Scarecrow*. Joan Didion’s biography *The Year of Magical Thinking* was included. Finally two photographic exhibitions were studied: the award winning photographic essay by Australian photographer Kate Geraghty on the end-of-life assisted suicide experience of cancer patient John Elliot, *My name is John Elliot and I am about to die with my head held high* (see the *Sydney Morning Herald*: www.smh.com.au, see also *Irish Times*, 30 November 2007); and the photographic project of German photographer Walter Schels and his partner Beate Lakotta, *Life Before Death* (*Observer* 13 April 2008).

The Eight ‘Cases’

The team of researchers from the Royal College of Surgeon’s Ireland and University College Cork working on the Ethical Framework project in collaboration decided on the ‘cases’/scenarios to be included. The end-of-life experiences selected for inclusion were chosen because each represented a particularly pertinent case in terms of dying and death in contemporary healthcare ethics in Ireland; the overall purpose of the research into patient autonomy was, as stated above, to contribute to the development of an ethical framework for practitioners working with patients at end of life.

For data for the second case study, the eight cases, a sample of articles dealing with relevant issues from both Irish and UK newspapers were selected for analysis. A media database, Lexis-Nexis, was also used to develop the sample of articles. For each of the eight ‘cases’ 20 articles were selected from Irish newspapers and from UK newspapers sold in Ireland. This sampling procedure provided a total of 280 newspaper articles.

The cases are outlined below. Each was comprised of one or more different/related end-of-life experiences. The constraints of the journal article format, and in particular word count, preclude a detailed exploration here of the eight cases but this is available in the report of the research, from which this article is drawn (Quinlan, 2009).

- 1 *Persistent Vegetative State (PVS)*: This scenario encompassed three different cases, the 1995 Ward of Court case, the Tony Bland case and the Terri Schiavo case. Each of these three people ended their lives in a persistent vegetative state. In each case, the end-of-life experience was determined by the courts.
- 2 *Assisted Suicide*: This scenario encompassed the case of Rosemary Toole Gilhoolley, the case of Martin Barry and other assisted suicide cases. Each of the end-of-life experiences considered in this case was an experience of assisted suicide.
- 3 *Medical Futility*: The Charlotte Wyatt case. In the case of baby Charlotte Wyatt, Charlotte's parents petitioned the courts to compel medics to continue treating their baby daughter. The medics testified that the case was medically futile.
- 4 *Withdrawal of Treatment*: The 'Ms. K' Jehovah Witness case and other Jehovah Witness cases. Each end-of-life experience examined in the case involved either the refusal or withdrawal of treatment.
- 5 *Right-to-Die*: The Diane Petty case, the Ronald Lindsey case and the Ms B case. In this case, each of the end-of-life experiences examined was a right-to-die experience.
- 6 *The Leas Cross Nursing Home saga*: The Leas Cross Nursing Home was a private nursing home in Swords in North County Dublin. It opened in the late 1990s and closed in August 2005 shortly after RTÉ's Prime Time documentary. The Prime Time documentary, with the use of a hidden camera, exposed abuses of elderly residents in the nursing home. A subsequent investigation by the State (www.hse.ie) found that there was 'institutional abuse' and the home was quickly closed down.
- 7 *The Organ Retention case*: This case involved the retention by hospitals of the organs of children who died in the hospital, without the knowledge or permission of next-of-kin. Some of the organs were kept for research purposes and some were sold to pharmaceutical companies (Madden Report: 2006).
- 8 *The Evelyn Joel case*: Mrs Evelyn Joel, who had multiple sclerosis, died a few days after she had been taken to hospital by ambulance from her daughter's home in Wexford. Mrs Joel's condition on removal to hospital was described in the media as critical; she was reported to have been malnourished, dehydrated, and unkempt. Mrs Joel's daughter and son-in-law were subsequently charged with her manslaughter.

Findings of the Mixed Media Case

Three major themes emerged from the analysis of the mixed-media case: the first theme to emerge was that of mediated representations of good and bad deaths; the second theme to emerge was one of culture and society, and the implications for culture and society of the death and dying experiences represented in the media; the final theme to emerge was that of the plight of the individual. In the following paragraphs each of these themes is explored.

Theme One - Mediated Representations of Good and Bad Deaths

The stories told in the media were stories of people caught up sometimes suddenly and always tragically in experiences of severe illness and/or death. The articles examined detailed in general the story of one death or, at most, two deaths. Almost all of the deaths were unwelcome, two were not. The two deaths that were not unwelcome

were both assisted suicides: Dr John Elliot's death which occurred in the Dignitas Clinic in Switzerland; and Ramon Sampedro's death, assisted by a friend, following a failed 30-year legal battle in Spain to win the right to end his life. The unwelcome deaths were represented as dreadful even cataclysmic events. They were sudden in some cases. They were tragic when they were untimely, as when children or young people died. The deaths as they were represented in the media were experienced differently by the (lay) individuals at the centre of the experience, the dying individuals and their families and friends, and the (professional) individuals managing the experiences within institutions. For the professionals, the deaths were represented as regular and routine everyday experiences.

Within the media representations there were good deaths and there were bad deaths. Professor Regina McQuillan in her talk in the Peacock Theatre (16 October 2007), discussed the notion of 'the good death'. She said a good death was dependent on where you die and how you die. In the best circumstances she said, a good death happened at home. As well as good and bad deaths there were scandalous deaths. Among the scandalous death were those deaths and end-of-life experiences reported on in the RTÉ Leas Cross Nursing Home documentary. Among the deaths narrated in the documentary was the death of Dorothy Black an older resident who had died in the Nursing Home 'by medical misadventure'. A report in the *Irish Mirror* newspaper (5 July 2005), reported that the inquest into Dorothy Black's death heard how the 73-year-old 'was left to develop bedsores the size of melons which penetrated to the bone. She died of blood poisoning and complications caused by the bedsores'.

The analysis clearly showed that good deaths happened at home, at the end of a long fulfilled life, among loved ones. Bad deaths happened at the end of short lives. Bad deaths occurred in institutions which were uncaring or even cruel and neglectful. In addition to the oppositions represented in the media of good deaths and bad deaths, there were stories of individuals versus institutions, and there were the very great differences between the experiences of dying and death as they were experienced by lay people, as opposed to how they were experienced by clinicians and other healthcare professionals.

Theme Two – Culture and Society

A peculiarly Irish attitude to death was evident in the articles. It was evident in particular in stories from other, different, cultures. Issues of identity and belonging are often, according to Woodward (1997), signified through difference. The Irish attitude to death and dying was, for example, evident in McQuillan's assertion (Peacock Theatre: 16 October 2007), that 'there is a frankness about death in the UK and the US that is absent in Ireland'. 'We are not', she said, 'so open about death here'. The Catholic nature of much of Irish spirituality was evident. It was evident in the response of one mother to the terminal cancer in her young daughter Rachel (Tubridy Show, 4 February 2008). She spoke of trips to Lourdes, to Medjugorje, to Rome for a meeting with the Pope, in search of a miracle that would save her daughter's life.

The multicultural nature of Irish society was also evident. It was evident in McQuillan's discussion of Irish Travellers and their experience of hospice. McQuillan said that Irish Travellers, unlike Irish people generally, did not like to die at

home (Peacock Theatre, 16 October 2007). She talked about how Travellers would traditionally leave a place where one of their community died. She detailed how they would burn all of the person's belongings, even burn the dead person's trailer. She said that in the history of the Irish hospice only two Travellers had died in a hospice, both in 1999, with none since. She quoted one Traveller as saying: 'Now that we know what kind of place it is, we wouldn't want anyone to go there. It's a place without hope, and Travellers can't live without hope.'

Irish society is now a multicultural multi-ethnic society. While the Traveller response to death and dying evidences the need for an understanding and awareness around different cultural needs in terms of death and dying, the increasingly multicultural nature of Irish society emphasises this need.

The RTÉ *Prime Time Leas Cross* Nursing Home documentary evidenced different and sometimes opposing familial, professional, and legal cultures. One of the people particularly profiled in the documentary was Peter McKenna (see also *Irish Times*: 18 June 2007). Peter McKenna had Down Syndrome and Alzheimer's disease. He was 60 years old. He was moved from his home in St Michael's House where he had lived for 23 years, to the Leas Cross Nursing Home. He was moved against the express wishes of his family. In response to the opposition of Peter's family to the move, St Michael's House applied successfully to the courts to have Peter, who was a ward of court, moved. Peter died 13 days after the move; the cause of death was recorded as septicaemia. The RTE TV documentary evidences one of the most pronounced discourses in the Irish media, that of uncaring and often cruel institutions, and the plight of individuals being cared for within them.

In relation to this theme of individual biography, Rantzen opened the BBC documentary *How to Have a Good Death* with a reflection on the death in hospital in 2000 of her husband Desmond Wilcox. Rantzen talked in the documentary about how the hospital intruded into that experience of death, about how she could not get close to her husband because of the medical team about him, about how she could not hold him as he died because that would have interrupted the smooth running of the organisation and the work routines and patterns of the institution. Communication was one of the key issues highlighted again and again in the media in relation to hospitalised end-of-life experiences. This issue of communication was examined by Rantzen. Rantzen talks of people dying in pain, she talks of poor communication from medical staff. The lay people who feature in the documentary talk about the dependency that patients in hospitals have on medical staff for information regarding their condition(s). One woman said:

Nobody really explained to us what was going to happen.

No one of the medical staff ever discussed with us, any of us, the fact that death was a possible outcome.

You need the medical staff to be honest, to tell the truth.

Doctors and Nurses are trying to cure people. So death is seen as a failure.

The theme of emotion was a difficult theme, in particular for clinicians working with patients at end-of-life. One of the doctors who participated in the BBC documentary said that he had always conducted his engagement with sick and dying people with a focus on avoiding emotionality, avoiding tears. The doctor said: 'I used to judge

how I gave them bad news in terms of whether or not they cried. I now know that tears and crying is an appropriate response to devastating news.'

With regard to the clinical care for dying people Elias (1985), more than 20 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.

According to Rantzen, the cultural societal taboo around death is such that doctors don't know what patients want, because nobody talks about it. The suggestion in the documentary is that because we keep death out of sight and out of mind, the processes of death are strange to us and quite frightening. This experience of death as strange and frightening is evident throughout the media analysed for this project. It is evident in reactions to the photographic work of both Kate Geraghty (see, for example, *Irish Times* 30 November 2007) and Walter Schels (see Wellcome Collection, www.guardian.co.uk), work which appears generally to be viewed at best as extraordinary, at worst as intrusive, and almost always as ethically problematic.

Figure 1



'My name is John Elliot and I am about to die with my head held high',
photographer Kate Geraghty, *Sydney Morning Herald* newspaper.

Theme Three - Individual Biography

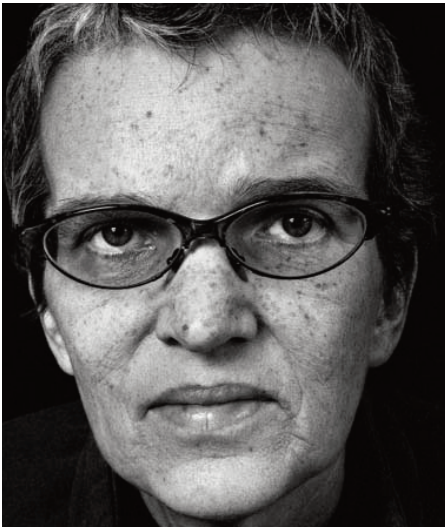
The final theme to emerge from the mixed media analysis was the theme of individual biography. Perhaps this theme is related to the rise of individualism in society generally, or perhaps it is related to the profoundly individual existential moment the experience of death and dying presents for all of us. For sociologists, the individual and the experience of the individual in relation to society are key, the study of the individual in society, the individual biography lived out against a backdrop of history. We are all historically situated. Our experience is ours in part because of who we as individuals are, and it is in part ours through our historical positioning, our situating within social structures. The sociologist C Wright Mills (1959) developed the concept of the sociological imagination which he used to describe the process of linking individual biographies with history, with social institutions and structures.

The sociological imagination is very useful in this theme of individual biography, and the end-of-life experiences of individuals in institutional settings. Elias in his reflection on medical sociology in the context of death and dying (1985) 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.

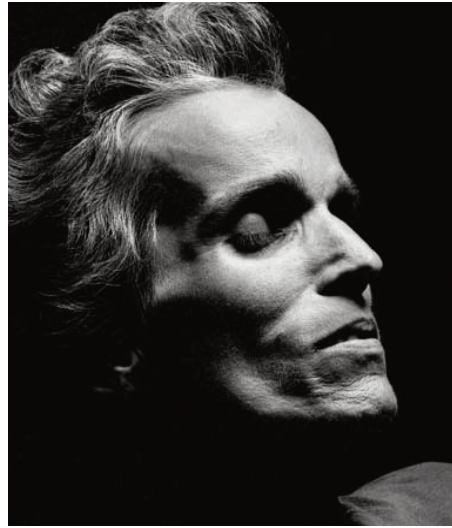
On the morning of Saturday, 12 April 2008, Nuala O'Faolain, a well-known Irish feminist, writer and journalist was interviewed by RTÉ journalist Marian Finucane, O'Faolain's old and close friend, on the latter's weekend radio show. The focus of the interview was the terminal diagnosis O'Faolain had just received, and her thoughts, feelings and beliefs regarding her own impending death. O'Faolain had been diagnosed with cancer six weeks earlier. O'Faolain explained how she had been walking in New York City, where she was living. She felt that there was something wrong with one of her legs and so she went into the Accident and Emergency (A&E) department of a local hospital. She described the chaos of that A&E. She said that the doctor who had examined her passed by her in the busy unit and he said to her, casually in passing, that she had two brain tumours. He also said that her brain tumours were secondaries, and that they (the medical team) needed to see where they (the tumours) were from. This was the first indication that O'Faolain had had that she was seriously ill. This was how her diagnosis of cancer was communicated to her. She said the same doctor later passed back and said to her, again casually and in passing, 'yes, the x-rays show that you have lung tumours'. 'In the middle of A&E?' Finucane asked. 'Yes,' replied O'Faolain, 'that was New York.' O'Faolain died in the Blackrock Hospice in Dublin on 5 May 2008, less than four weeks after the radio interview. O'Faolain's diagnostic experience clearly illustrates the gulf that lies between patients and healthcare professionals in experiences of dying and death.

The opposition found throughout the analysis was the opposition between routinised end-of-life experiences in hospitals, and the experiences of people caught up

Figure 2



Roswitha Pacholleck before death



Roswitha Pacholleck after death

Photographs: Walter Schels and Beate Lakotta/Wellcome Collection

in what is for them extraordinary, unique and often tragic end-of-life experiences. This hospitalised experience of dying and death is very different from the hospice experience of dying and death, as described in much of the media examined. It is different, for example, from the hospice experience of death presented by Rantzen in the TV documentary *How to Have a Good Death*; it is different from the hospice experience of death as presented in *The Hospice*, the documentary broadcast on RTÉ television; and it is different from the hospice end-of-life experience of Roswitha Pacholleck as depicted in the *Life Before Death* photographic project.

‘It’s absurd really. It’s only now that I have cancer that, for the first time ever, I really want to live,’ Roswitha told me on one of my visits, a few weeks after she had been admitted to the hospice. ‘They’re really good people here,’ she said. ‘I enjoy every day that I’m still here. Before this my life wasn’t a happy one.’ But she didn’t blame anyone. Not even herself. She had made peace with everyone, she said. She appreciated the respect and compassion she experienced in the hospice. ‘I know in my mind that I am going to die, but who knows? There may still be a miracle.’

In much of the media analysed for this study, the hospice experience of death and dying was presented as oppositional to experiences of death and dying in hospital. Hospital care tends to be critical care, focused on curing patients. Hospice care is palliative, focused on supporting patients through end-of-life experiences. In fact, the difference between the hospice experience of death and the end of life experience generally provided for in hospitals, as detailed in the media analysed, was substan-

tial, with hospitals tending to privilege institutional imperatives, medicine and technologies, and the hospice privileging the human and the personal in the experience.

Analysis of the Eight Cases

The main theme to emerge from the analysis of the eight cases was again that of private troubles being public issues. While we suffer end-of-life experiences individually and within family and friendship circles, each of these experiences is experienced within and through the structures provided within society for such experiences. In this way, the experiences are patterned, shared, and communal. In the following pages a brief synopsis of the analysis of each of the eight cases is presented (see Quinlan, 2009 for details of each of the cases and the detailed analysis).

Persistent Vegetative State cases: The three cases examined here are the cases of the 1995 Ward of Court, the Terri Schiavo case, and the case of Tony Bland. In each of the three cases, families or family members petitioned the courts to have feeding withdrawn so that the patient would die. The families were united in these requests in the case of the Ward of Court, and in the case of Tony Bland. Terri Schiavo's family were, as reported in the newspapers, divided and in opposition in respect of the request for the withdrawal of feeding. In the Ward of Court case, the only Irish case of these three cases, the issue as it was reported in the media was the decision of the Irish Supreme Court that a woman in a semi-persistent vegetative state could (legally) have food and hydration withdrawn. In 1995 the mother of the so-called '1995 Ward of Court' fought the case to the Supreme Court to win for her daughter the right to die.

Assisted Suicide Cases: The three cases selected for inclusion here were the cases of Martin Barry, Rosemary Toole Gilhooley, and Dr. Paddy Leahy. Martin Barry was 33 years old in 2005 when he travelled to the organisation Dignitas in Switzerland with a friend to end his life. He suffered from MS. He was interviewed on the Marian Finucane Show on RTÉ radio, and the interview was broadcast a second time on radio after his death. Most of the negative reaction to Martin Barry came from the Multiple Sclerosis (MS) Society of Ireland. Mr Barry was reported by the *Irish Independent* (11 May 2005), to be the fourth Irish person to have committed suicide with right-to-die groups since 2001. The same article reported that over 700 Britons were at that time registered with Dignitas. Rosemary Toole Gilhooley, at 48 years old, according to the *Irish Mirror* (5 November 2007), committed suicide in 2002 after a long battle with depression. The Rev George Exoo was with her when she died. Called Dr Death in the headline of that newspaper article, Exoo was accused of assisting in Toole Gilhooley's suicide. Dr Paddy Leahy died at home in his own home at 81 years of age. Prior to his death he had travelled to Thailand where the media reported he planned his own death through assisted suicide. Writing in the *Irish Times* in 2006 (16 May 2006), Pdraig O'Morain wrote that Dr Paddy Leahy was the only Irish doctor to declare publicly that he had helped people to die who were undergoing great pain and suffering from a terminal illness (see also *Irish Times* 18 December 1998).

The Case of Charlotte Wyatt: In this case, the hospital caring for baby Charlotte Wyatt petitioned the courts for permission to withdraw treatment. Withdrawing

treatment would mean that the baby would die. Charlotte's parents fought the hospital to the High Court. The court ruled that, given the weight of medical evidence, Charlotte should be removed from life support and allowed to die. In general, the newspaper headlines around this case suggested the hopelessness of the case:

'Doctors: we let "hopeless" babies die' (*Sunday Times* 18 June 2006), 'Charlotte Wyatt case: severely ill baby ought to be allowed to die, judge tells parents' 'Baby Charlotte is to be let die, rules UK court' (*Irish Times* 8 October 2004), (*Independent UK*: 8 October 2004).¹

Charlotte Wyatt was removed from life support, but she did not die. A very different headline appeared in the *Guardian* (24 November 2006), 'Parents of disabled newborns to be given a message of hope, not doom'.

The author of this article, journalist Jane Campbell, opened the article by stating that some people believe 'severe disability to be a fate worse than death'. She went on to dispute another journalist's claim that 'few would think this (Charlotte Wyatt's life) a life well saved'. The language (words and phrases) used in the article, for example, 'what is a tolerable life', 'the genocide of the less than perfect', evidences the heated debate around this case conducted in the media.

Withdrawal of Treatment Cases: the Ms B case, the Diane Petty case, the Ronald Lindsey Case, the 'Ms K' Jehovah's Witness case and other Jehovah's Witness cases: Ms B was the first person in Britain in full control of their mental faculties to have asked for and won the right to have medical treatment withdrawn when such an action would result in her death. Ms B had to go to court to establish her autonomy, her right to refuse medical treatment, because her wishes were contrary to the wishes and advice of her medical team. Ms B was reported to have died peacefully in her sleep after having been taken off the ventilator at her request, a month after she won her case (*Irish Times*, 30 April 2002). Ms K was a 24-year-old woman from the Democratic Republic of Congo who gave birth in the Coombe maternity hospital in Dublin. She said on admission to hospital that she was Roman Catholic and later, when in need of a blood transfusion, said she was a Jehovah's Witness, and could not, consequently, receive a blood transfusion. The hospital went to the High Court to secure an order allowing it to transfuse Ms K. The High Court granted the order. Ms K sued the hospital (*Irish Times* 5 October 2007, see also *Irish Sun* 14 December 2007). Ms K, in a counter claim, contended that the administration of the transfusion was a breach of her rights under the European Convention on Human Rights and that she was entitled to refuse such treatment. The *Irish Times* (5 May 2008), reported the judgement in the case of Fitzpatrick & Anor vs. K & Anor (the Ms K case).

The issue of patient autonomy, as evidenced in these newspaper articles, appears to be very contested in the tussles between Irish culture and other cultures, between the culture and ethic of care of Irish hospitals and the staff of those hospitals, and from a more mainstream Irish perspective, the often apparently strange and irrational choices and decisions of patients from other cultures. It seems from this analysis that

¹ Capitalisation, where used throughout this report, is copied directly from the referenced newspaper articles.

while the view of the Chair of the Medical Council's Ethics Committee is that patients, and their advocates, have the right to refuse treatment, the courts in Ireland, while referencing the need to respect patient autonomy, take leave to interpret that right.

The Case of the Leas Cross Nursing Home: The Leas Cross Nursing Home in Swords in North County Dublin opened in the late 1990's and closed in August 2005 shortly after RTÉ's *Prime Time* documentary. The documentary exposed abuses of elderly residents in the nursing home. The Leas Cross Nursing Home saga, which followed on foot of the documentary, produced tens of thousands of references in all of the databases considered for this research. Among some of the headings of newspaper articles were the following:

'Revealed: "appalling" care homes' (*Sunday Times*, 28 August 2006), 'Report calls Irish nursing homes "filthy and a danger' (*Daily Mail*, 26 October 2006), 'Get 'em out: health chiefs to tale elderly from house of horrors' (*Irish Mirror*, 21 June 2005), 'Horror home death probe: Inquiry into abuse at Leas Cross' (*Irish Mirror*, 5 July 2005), 'Inquiry ordered into deaths at scandal-hit nursing home' (*Irish Independent*, 5 July 2005), 'Steady rise in deaths unreported' (*Irish Independent*, 20 October 2005), 'Leas Cross Nursing Home paid ERU 5m by health services' (*Irish Times*, 28 December 2006), 'Report finds lower rate of survival of transfers to Leas Cross' (*Irish Times*, 19 October 2006), and finally 'A society that's caring less' (*Irish Times*, 04 June 2005).

In this institution patients were poorly treated or mistreated. In some cases the treatment the patients received hastened their deaths. The institution was represented throughout as neglectful and uncaring, and even callous and cruel. There were abuses of patients' rights; the right of patients to autonomy was rendered insignificant amidst the criminally low standards of care that prevailed in the institution.

The Organ Retention Scandal: The fact that organs were retained without the knowledge and permission of next-of-kin became public knowledge in Ireland in 1999. According to the Madden Report (2006), the views of clinicians and families regarding the practice of organ retention were irreconcilable. Doctors did not tell families because they felt the families were upset enough by the death of a family member. Families felt they should have and could have been told, because the worst had already happened to them, the worst being the death of their loved one. These experiences, as represented in the newspaper articles, again highlight a clear distinction between the shocking unique and individual experience of death and dying in hospital for the individuals, patients, families and friends, at the centre of the experience, and the routine everydayness of the experience for the hospitals' institutional structures and organisations, the work experience around hospitalised/institutionalised death and dying, and the experience of death and dying for clinicians and other hospital workers. A key theme to emerge in this case, a theme which was evidenced in other cases, was that of communication, the lack of communication between the hospitals and clinicians and the parents, families, and next-of-kin.

The Case of Ms Evelyn Joel: The final case studied for the research was that of Ms Evelyn Joel. The newspaper articles for this case were taken from the *Sun*, the *Irish Examiner*, and the *Irish Times*. According to the *Irish Sun* newspaper (29 March 2006),

Cops investigating the horror death of skin-and-bone granny Evelyn Joel handed a file to the Director of Public Prosecutions yesterday. Criminal charges could now follow in the “neglect” case that appalled the nation. Bedridden Evelyn, 58, died a week after being admitted to Wexford General Hospital on New Year’s Day. Gardai have spent three months investigating her death. The multiple sclerosis sufferer, who lived with her daughter Eleanor in Enniscorthy, Co Wexford, wasted away to little more than a skeleton. Confined to her bed since last September, she had become severely malnourished and dehydrated – weighing just 4st when she died. She was found covered in maggots and excrement in her bed.

The Health Services Executive (HSE) established an investigation into the case of Evelyn Joel. The investigation was to review the scope range and level of services provided to her from January 2004 to January 2006 (*Irish Times*, 24 July 2006). In 2007, Evelyn Joel’s daughter Eleanor Joel and her partner John Costin were charged with manslaughter and reckless endangerment in relation to the death of Ms Evelyn Joel (*Irish Times*, 11 January 2007, 29 March 2007, 18 April 2007, 07 November 2007). They both denied the charge. While Evelyn Joel’s relations were charged with criminal neglect, the evidence suggests that throughout her end-of-life experience, in an exercise of personal autonomy, she refused help, refused to engage with professionals charged with helping her, and refused to engage with professional services specifically designed for that purpose. This case raises the very complex questions around patient autonomy and the capacity of patients for autonomous decision making.

Conclusion

This media analysis was undertaken to identify and analyse the ways in which different media deal with end-of-life issues in relation to patient autonomy. A case study methodology was utilised in the research and the cases selected for inclusion in the research were selected because they informed particular and pertinent issues in contemporary healthcare ethics.

This analysis of different media and the ways in which they deal with end-of-life issues in relation to patient autonomy has shown patient autonomy to be a very fragile phenomenon. In hospital settings it has been shown to be secondary to institutional, medical and technical imperatives. In the hospitals involved in the organ retention scandal patient autonomy was entirely irrelevant; it was irrelevant too in the suffering experienced by patients in the Leas Cross Nursing Home. The capacity for institutions to override expressions of patient autonomy was demonstrated in the media reporting on the Ms B Jehovah Witness case and the Charlotte Wyatt case; while the potential complexity of patient autonomy was demonstrated in the media reporting the case of Evelyn Joel.

A major issue to emerge from the media analysis is that of the gulf between the understandings and experiences of the public generally of dying and death, and those

of clinicians and other healthcare professionals. This gulf is as a result primarily of the institutionalisation of dying in Irish and other western societies, and the removal of dying and death from everyday life. The narratives recounted in the newspapers signified above all the cultural chasm in experiences of dying and death between hospital and medical culture and the lives of ordinary people. The hospital end-of-life experience described in the media is in opposition to the hospice experience of end-of-life care: where in hospital the medical, technical and institutional take precedence, in hospice it is the personal that takes precedence.

In Ireland, ethical issues and dilemmas in hospitals are currently, regularly and frequently, referred to the courts for judgement and resolution. Each case is heard individually in different courts by different judges, and each case must be argued on its own merits. The obligation for clinical teams is the preservation of life. For patients, the issue is often the challenge to be heard, the capacity to express, by some means, autonomous wishes and to have those wishes acted upon. As evidenced by this media analysis, patient autonomy is a very fragile right, guarded, and subject always to representation and interpretation, within institutions and by medical and legal professionals, as well as by the media.

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Dr. Christina Quinlan's background is in social research; her PhD was a critical ethnography of women's experiences of prison in Ireland.

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- In addition, selected media were used in this research. They are referenced throughout the article