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THE EFFECT OF SIMULTANEOUS IMPLEMENTATION OF AN ADVANCE CARE PLANNING PROGRAM AND A PALLIATIVE CARE INITIATIVE ON END OF LIFE CARE IN LONG TERM CARE.

BY

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Declaration

This thesis is submitted to University College Cork in accordance with the requirements for the degree of Doctor of Philosophy (PhD) in the Faculty of Medicine.

I declare that this thesis is a record of my own work and it has not been submitted for any other academic award. Where the work of others has been used to augment this thesis, it has been fully acknowledged and referenced accordingly.

Signed: _____ Date: _____

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Abstract

Introduction

International research suggests care at the end of life in long term care is suboptimal, but quality improvement initiatives incorporating advance care planning have shown promising results. Little is known about the care given at this time of life, in this environment, in Ireland, where advance care directives are not yet part of the Irish culture. The objectives of this thesis were to examine the effect of implementation of as advance care planning program combined with a palliative care educational initiative on end of life care in the long term care setting in Ireland.

Methods

A study was carried out to examine healthcare professionals' attitudes and knowledge of advance care directive, end of life care and decision making for older adults with diminished decision making capacity in Ireland, Canada and the United Kingdom. The baseline educational needs of Irish nursing home staff was explored and the data used to create a palliative care educational initiative tailored to the needs of staff. An existing advance care planning program (Let Me Decide) was modified for use in an Irish long term care setting. The effect of systematically implementing both these programs simultaneously on end of life care was examined through a before and after feasibility study.

Results

Attitudes to and knowledge of advance care directives was good amongst healthcare professionals in Ireland compared with the UK and Canada, but knowledge of the legal situation for medical decision making for a person with diminished capacity was lacking, as was knowledge of the successful outcome for cardiopulmonary resuscitation. End of life care education was suboptimal but improved subsequent to the study program intiation. The challenges faced in advance care planning and implementing an associated educational program found lack of time and staff pressures to be key factors. The program resulted in a substantial rise in the proportion of decedents with a plan for end of life care

and a marked shift in the timing of care conversations from the last weeks and days of life, to a median time almost 6 months before death. The proportion of long term care residents included in care planning decisions improved from 5.5% to 27%. Bereaved relatives commended the end of life care received by their loved ones, they rated the quality of their loved ones dying experience highly and highlights practices of good end of life care that could be disseminated elsewhere. In addition the prescribing practices in the last 3 months of life were examined. Though there was evidence of deprescribing in over half of decedents this tended to only happen close to death, when anticipatory prescribing for end of life symptoms also took place, albeit to a greater extent in the after period of the study. The study findings were sustained when re-examined in 2017.

Conclusions

Advance care planning with residents (or their family) was not part of the culture of end of life care in Ireland, and decisions on resuscitation or hospitalisation tended to occur with family when imminent death of nursing home residents was recognised. The advance care planning program introduced in this project was acceptable, feasibility and its impact sustainable in the onger term. Palliative care training was suboptimal in long term care in Ireland but staff were keen to engage with education and the study intiaitive improved the prevalence of trained staff in the study sites. Additionally, the end of life care provided in nursing homes in Ireland is rated highly by bereaved relatives.

Chapter 1: Introduction

1 Introduction

This research is multifaceted and explores the intertwining domains of advance care directives, advance care planning, palliative care, and their relationship with end of life care in a long-term care setting in Ireland.

This chapter will define and explore the evolution of advance care directives, advance care planning, palliative care and end of life care. Subsequently, it will discuss the challenges in providing end of life care for older people in the long-term care setting in Ireland, with a focus on medical decision making for end of life, particularly for those lacking capacity.

This chapter concludes with a description of the rationale and objectives of this thesis and an outline of the subsequent chapters.

1.1 Medical Decision Making at the end of life in those lacking capacity

Amongst long term care residents there is a high prevalence of conditions such as dementia which may limit or negate a person's capacity to make medical decisions on their own behalf. The legal situation in Ireland (and Canada) regarding medical decision making for someone with diminished capacity is outlined in detail in Chapter 3, and discussed further in Chapter 4. Essentially, if healthcare decisions need to be made for an individual, and they lack the capacity to decide for themselves, then someone else will have to take on the task. Legislation differs from country to country as to who and how a person might be nominated to act as proxy decision maker. Regardless, the decision will need to be made, and the process and challenges are discussed in Chapter 4. Ultimately there are two positions which need to be considered; whether the person's wishes are known, or not.

Capacity is not "black or white" but a spectrum of grey, and though a person may ultimately lack capacity to make a decision, they may still retain the ability to express their viewpoint to some extent; clearly this needs to be considered heavily in any decision-making process. In other situations, the person may lack any means of communicating their thoughts. In the latter scenario, they may, in

the past, have expressed their thoughts related to the decision at hand; these views equally carry weight. Often their thoughts on the issue were not expressed, so two common means of making decisions on their behalf would be taking either a "substituted judgement" or a "best interests" approach.

Taking a substituted judgement approach, the proxy decision-maker guesses what the person might choose were they still able, taking cognisance of their knowledge of the individual: what was important to them, their beliefs, their values, their worldview. But at best, it is just a guess. Even in situations where a proxy decision maker knows the person intimately, and has discussed care choices with them, research shows significant discrepancies between what the person wants, and what their proxy thinks they would want.(1, 2)

A best interests approach is relatively self-explanatory, but to be able to appreciate what is in a person's best interest one must have an understanding of the decision that is being made and be able to weigh the different options. If a decision with regard to cardiopulmonary resuscitation (CPR) is to be made, it is important to understand why the decision is being made; to understand the underlying health of the patient and their prognosis – dementia for example is often not perceived by family as a life limiting illness; to understand why cardiac or pulmonary arrest might happen and to what extent the cause of an arrest might be treatable or reversible if CPR attempts were successful in restoring circulation; to understand what CPR entails and how successful or unsuccessful CPR attempts are likely to be for the given patient and in a given scenario.(3) This is a lot to consider. It is a lot to be educated on. Cardiopulmonary resuscitation is an area that is often misrepresented in the media and on television, important information sources, leading to much misunderstanding on CPR amongst the general public (and many healthcare professionals).(4, 5)

When CPR decisions need to be made in a crisis situation, lack of time for clarification, education and reflection may impede the decisions being made, irrespective of whether a best-interests or substituted judgement approach is used. The value of advance care planning is readily apparent.

1.2 Advance Care Directives

1.2.1 Definition of Advance Care Planning and Advance Care Directives

Advance care planning has been defined by Singer as "a process whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care".(6) It explores the individual's goals, values and beliefs and how these inform their preferences for future healthcare. Singer goes on to state that "physicians can play an important role by informing patients about advance care planning directing them to appropriate resources, counselling them as they engage in advance care planning and helping them to tailor advance directives to their prognosis".(6) In truth this role does not need to be solely that of the physician but rather any health care professional with the relevant knowledge and skills to educate and guide an individual on the issues pertaining to the decisions being made.

One potential outcome of advance care planning is an advance care directive. An advance care directive is a legally binding document records the care, including life-sustaining treatments, that person would or would not wish to receive, if they become incapacitated to make, or communicate care decisions in the future. Of note, an advance care directive is only *valid* if made *voluntarily*, by a *competent* informed person and is *used or acted upon* if the person subsequently loses capacity and the situation envisioned in the directive occurs. Depending on the jurisdiction, advance care directives can be legally binding, such is the case in Ireland. It is important to note, that an advance care directive requesting something illegal, (such as euthanasia, which is illegal in most countries), is in itself invalid and not legally binding. Another potential output of advance care planning is an advance care plan, which is a less formal, non-legally binding, record of an individual's wishes.

Whilst a competent, informed person has the right to refuse treatment even if this may lead to their death, they do not have the same right to demand treatment. Requests for treatment are likely to be upheld though, if appropriate, feasible and non-futile.

Although “advance healthcare decision” is the term used in Irish legislation, “advance care directive: is the term chosen for use in this thesis as it is the term most often used in international literature. The original term coined was “living will”. Although these terms are sometimes used synonymously, there are differences in that a living will is essentially a limited form of an advance care directive. A living will allows for documentation of an individual’s wishes regarding life-sustaining measures, whereas an advance care directive also contains the option of designating a proxy decision maker. There are many other terms used to describe similar entities such as; “advance healthcare decision”, “advance directive”, “advance decision”, “instructional directive”, “advance treatment directive” and “advance statement”.

1.2.2 **Evolution of Advance Care Directives**

Advance care directives did not evolve in a vacuum. At their core is the concept of self-determination, which existed in medical law long before the Nuremburg Code of 1947 and the Declaration of Helsinki (1964 -2004). In 1914 in the famous case of *Schloendorff v. Society of New York Hospital,* Justice Benjamin Cardozo stated that:

> “Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.”

Despite this case essentially establishing the principle of *informed consent*, the practice at the time in providing information to patients, of truth-telling, was very much coloured by the longstanding authoritarian and paternalistic model of beneficence which persisted in medicine into the late nineteenth century. Autonomy was viewed as a danger to the health of most patients essentially since Hippocratic times.(7) The Hippocratic Corpus advised physicians of the wisdom of:

> "concealing most things from the patient, while you are attending him;….turning his attention away from what is being done to him; … revealing nothing of the patient's future or present condition".(7)

In his book *Medical Ethics* published in 1794, Thomas Percival recognised the patient's right to the truth, but this conflicted with his paternalistic recommendations for benevolent deception, which he considered morally justified when used in the best interests of the patient.(8) He advised that:

> "as misapprehension may magnify real evils, or create imaginary ones, no discussion concerning the nature of the case should be entered into before the patients, either with the house surgeon, the pupils of the hospitals, or any medical visitor."(9)

In 1883, Austin Flint predicted that Percival's paternalistic principles,

> "lasting as they had for almost 100 years", would "probably continue to be the guide of the great mass of intelligent medical men through the centuries to come."(10)

Faden in 1986, observed how remarkably accurate Flint's statement turned out to be.(7)

It could be argued that it was only in the late twentieth century that an increasing respect for patient autonomy began to replace the paternalistic attitudes that had prevailed for centuries before. A study by Oken in 1961 of 219 US physicians, found 90% of them would not disclose a diagnosis of cancer to patients.(11) Only 16 years later, in 1977, a subsequent survey of 264 medical staff found a complete reversal of attitudes, with 97% of respondents stating they would disclose a cancer diagnosis.(12) However, Novack also found that physicians seemingly still based their decision on emotionally laden personal convictions.(12)

The rationale for advance care directives is best appreciated after considering, not only the fall of paternalism, but also the dramatic changes that occurred in

medicine in the few decades before Chicago based civil rights lawyer, Luis Kutner first described the concept of a Living Will in 1969.

When Luis Kutner was born in 1908, the average life expectancy for a man was just 49.5 years.(13) European life expectancy had already risen from an average of 30-40 years of age, which had remained stagnant between the 1500's and the early 1800's. Improvements in sanitation, access to clean drinking water, better nutrition, and the discovery of immunisation all likely contributed to this improved longevity. By the time Luis Kutner conceived the Living Will in 1969, male life expectancy was 67 years and he had witnessed incredible medical advances.(13)

New treatments had been found for once fatal diseases such as diabetes. Banting and Best discovered insulin in 1921; purified animal insulin became widely available in 1923, changing the previously short lives of diabetics. By the 1960's insulin was manufactured synthetically.

From 1846, to have surgery no longer meant dulling the pain of the scalpel with alcohol or biting on a stick.(14) Ether's use in anaesthesia since 1842, Pagés pioneering use of epidural anaesthesia in 1921,(15) advances in intubation equipment in the 1930's and Emerson's invention of a mechanical anaesthetic ventilator in 1949 transformed surgery and no doubt helped progress surgical fairytales such as Hans Christian Jacobaeus first laparoscopic surgery in 1910, and innovations such as the first human kidney transplant in 1954, lung transplant in 1963, Barnard's first human heart transplant in 1967 in Cape Town South Africa and the first successful liver transplant the following year. (16-21)

In the 1900's the top causes of death in the United States (U.S.) were influenza, pneumonia, tuberculosis and gastrointestinal infections, together accounting for 539 deaths per 100,000 population.(22) In 1927, use of vaccination for tuberculosis and tetanus joined the previously discovered vaccines for pertussis (1926), diphtheria (1923), rabies (1882), anthrax (1881), cholera (1879) and smallpox (1796). The discovery of penicillin by Alexander Fleming in 1928, which became available for therapeutic use during World War II in 1942, was

truly revolutionary. Antibiotics (and antiseptics) changed the face of human mortality; no longer were the leading causes of death infection related. By the 1960's the top two causes of death; heart disease and cancer, accounted for similar figures (518 deaths/100,000 population).(22) Why people died, had changed.

With the discovery of new therapeutic modalities came new responsibilities. The introduction of haemodialysis in 1943, and invention of Scribner's dialysis shunt in 1960 (which facilitated repeated vascular access for haemodialysis), meant a new treatment for end stage renal failure (ESRF).(23, 24) At that time, ESRF killed 100,000 people in the U.S. annually. Unfortunately, dialysis machines were still essentially an experimental tool and at a cost of $15,000 per patient per year, access was extremely limited. A means of deciding who received treatment was required. Shana Alexander in her 1962 article in LIFE magazine, 'Medical miracle and a moral burden on a small committee: They decide who lives, who dies', described the difficult deliberations on dialysis candidates by the "Admissions and Policies Committee of the Seattle Artificial Kidney Centre at Swedish Hospital" in Seattle.(25) They became known as the "Life or Death committee" as they decided "which one patient out of 50 shall be permitted to hook up to Seattle's life-giving machines and which shall be denied." Her article prompted serious public debate, contributing to advancements in bioethics (the term forged in 1970 for this new discipline). By 1979, Tom Beauchamp and James Childress had described the four principles of biomedical ethics: autonomy, beneficence, non-maleficence and justice; bringing "order and coherence" through a "systematic analysis of the moral principles that should apply to biomedicine" (p vii).(26)

Some medical advances were directed at prolonging life at the point it would previously have ended. Claude Beck designed a cardiac defibrillator, which was built by James Rand, and used it to perform the first successful human open chest (internal) cardiac defibrillation, on a 14 year old boy, in 1947.(27) Six years later, in 1953, Stephenson published the outcome of 1200 patients with cardiac arrest: though 56% (n=672) had their hearts restarted with thoracotomy, internal cardiac massage and internal defibrillation, many died

soon afterward. Of the 672 resuscitated patients; 563 died within 24 hours, 63 within a week and a further 20 died some short time later, meaning long term survival occurred in only 2% (n=26).(28) Not all innovations were as complex. Zoll showed success with external defibrillation after applying the defibrillator to the closed human chest wall in 1955, thus negating the need for thoracotomy.(29) Though Friedrich Maass described the first successful human closed-chest cardiac massage in 1892,(30) it was not until 1958 that Knickerbocker, Jude and Kouwenhoven rediscovered external chest compressions.(31) In the same year, Gordan, Elam and Safar described mouth-to-mouth resuscitation in a series of eloquent experiments, showing expired air to be adequate for artificial ventilation.(32-35) These components of modern day cardiopulmonary resuscitation (CPR): mouth-to-mouth respiration, external chest compression and defibrillation, finally came together and there followed widespread education and training in the technique.

When Kouwenhoven, Jude and Knickerbocker first described modern day CPR in JAMA in 1960, they reported an "over-all permanent survival rate of 70%" in 20 patients, most of whom had cardiopulmonary arrest during surgery or in the perioperative period.(31) Most of the patients described in this article would be expected to survive CPR by modern day standards and prognostication. They stated "anyone, anywhere can now initiate cardiac resuscitative procedures. All that is needed are two hands." The following year, they published again in JAMA, on the application of CPR in 118 patients.(36) Success had diminished in applying the technique to a broader cohort of patients. Only 24% survived to hospital discharge. By 1983, CPR success rates had declined to 14%.(32) In this study, none of the patients with pneumonia survived (n=58/294).(37)

Since 1983, significant but subtle improvements in CPR outcome have been shown; following an in-hospital cardiac or respiratory arrest, overall survival is approximately 17.5%, and the rate of severe neurological disability post CPR remains static, at approximately 10%. (38-40) It has been suggested that the improvements in survival may have resulted from better quality CPR or post resuscitation care, new techniques or earlier recognition and treatment.(40)

Equally though, the improvements could be explained by a more judicious use of CPR; knowing when to use it, and when not to.

Though cardiopulmonary resuscitation has the potential to save life, it is not a harmless intervention, a fact recognized as early as 1961.(36) Rib and sternal fractures are not uncommon, but aortic, splenic or hepatic laceration and rupture, haemothorax, pneumothorax, left ventricular contusion and even pulmonary bone marrow embolism have all been described.(41)

The chance of surviving a cardiac arrest with CPR is affected by many factors (table 1). Witnessed cardiac arrests, with a shockable rhythm, which occur in a hospital setting have more favourable survival statistics. Unsurprisingly advancing age and the comorbidities that come with it, have a detrimental effect on survival.

A recent meta-analysis by Van de Glind et al, found for patients aged 70 years or older with an out-of-hospital cardiac arrest, the pooled overall survival to discharge was only 4.1% (95% confidence interval (CI) 3.0-5.6%).(42) For patients with heart failure (median age 74 years), the odds ratio (OR) for survival to discharge, after witnessed out-of-hospital cardiac arrest was only 0.04 (95% CI 0.03-0.31).(43) Nursing home residency when compared with cardiac arrest of older people outside the nursing home was also associated with poorer outcomes: Deasy et al reported an OR of 0.26 (95% CI 0.11-0.6) after adjusting for factors such as; what year the arrest took place, gender, whether the arrest was witnessed, whether bystander CPR took place and the Emergency Response Service (EMS) response time.(44) Given all these issues, it is not surprising that in 1992, Saunders stated: “If the expected outcome is death, a procedure less dignified and peaceful could hardly be devised”

Table 1.1: Factors associated with cardiac arrest outcome with CPR

<table>
<tr><th>Worse Survival Rates</th><th>Better Survival Rates</th></tr>
<tr><td colspan="2">Pre-arrest Factors</td></tr>
<tr><td>Older age [42, 44]
<table>
<tr><td rowspan="2">Age (years)</td><td colspan="2">Survival to Hospital discharge</td></tr>
<tr><td>Shockable rhythm</td><td>Non-shockable rhythm</td></tr>
<tr><td>65-79</td><td>17%</td><td>1%</td></tr>
<tr><td>80-89</td><td>10%</td><td>1%</td></tr>
<tr><td>90-99</td><td>4%</td><td>0.5%</td></tr>
</table>
Higher Charlson Comorbidity Index (CCI)[45]
<table>
<tr><td rowspan="2">CCI</td><td colspan="2">Survival to hospital discharge</td></tr>
<tr><td>OR</td><td>95% CI</td></tr>
<tr><td>1</td><td>0.87</td><td>0.76-1.00</td></tr>
<tr><td>2</td><td>0.80</td><td>0.68-0.94</td></tr>
<tr><td>3</td><td>0.62</td><td>0.50-0.78</td></tr>
<tr><td>≥4</td><td>0.53</td><td>0.41-0.68</td></tr>
</table>
- Malignancy [46]
- Cardiac failure [43]
- Pneumonia
- Dementia [46]
- Traumatic aetiology [47]
- Nursing home resident [42, 44, 48-50]</td><td>Myocardial Infarction
Urban setting [51]</td></tr>
<tr><td colspan="2">Peri-arrest Factors</td></tr>
<tr><td>- Out of Hospital Arrest
- Unwitnessed Arrest
- Non-shockable rhythm (Pulseless electrical activity, asystole)
- Longer interval between cardiac arrest and CPR commencing
- Longer interval between cardiac arrest and first shock in shockable rhythms
- Longer duration of CPR [52]
- Less adrenaline given [47]</td><td>- In-hospital Arrest
- Witnessed Arrest [53]
- Shockable rhythm (Pulseless ventricular tachycardia, ventricular fibrillation) [40]
- Quick initiation of CPR [54]
- Quick delivery of shock in shockable rhythm [55]
- Quick delivery of adrenaline in non-shockable rhythms [56]</td></tr>
<tr><td colspan="2">Post-arrest Factors</td></tr>
<tr><td>Slow to regain consciousness [57]</td><td>Quick to regain consciousness</td></tr>
</table>

In the 1960's, it became the default to initiate CPR when hearts stopped beating or lungs stopped breathing, irrespective of whether it was an acute remediable situation, or the natural end to a long-lived chronic and irreversible disease process. Rarely were patients consulted on what their wishes might be. The lines narrating a normal death, the natural act of dying, became blurred. How people died had changed. CPR had become "an essential rite of passage for dying in the modern hospital".(37)

Where people died had changed. For example, in Ireland in 1885, 85% of people died at home, in their own beds, surrounded by those who knew them. Death was a natural part of life. But increasingly, the Dying were brought to hospital; and when modern medical interventions were defeated, in hushed tones, death was hidden, and seen as a failure. By the 1960's only about 50% of Irish deaths occurred at home, current figures show only about 25% of people die there.(58) (figure 1.1)

Ivan Illich was one of the first to describe this "medicalisation of death" in his book *Medical nemesis* in 1976:

> "when all suffering is "hospitalized" and homes become inhospitable to birth, sickness, and death; – when suffering, mourning, and healing outside the patient role are labeled a form of deviance."(59) (p20)

It was in this environment that Luis Kutner devised the living will, that the "Society for the Right to Die" was born, and the milieu from which the modern palliative care movement emerged, and changed the face of dying.

People were concerned about being given treatment against their wishes, about being kept alive indefinitely and artificially through unwanted medical treatment or being subjected to futile interventions at the end of their days. If their minds could no longer speak for them, they wanted some semblance of control over what happened to their bodies. Luis Kutner, a prominent Chicago human rights lawyer, was a co-founder of Amnesty International and a proponent of world *habeus corpus*. He was prompted to act, after watching a friend die a slow, painful death from injuries inflicted during a violent

robbery.(60) He recognised a person's right to refuse treatment, even if this shortened their life. He acknowledged "a patient may not be subjected to treatment without their consent" and that where it is not possible to obtain consent, that a physician must apply *ordinary means* in order to preserve life. He argued that people should be allowed to state, under what circumstances they would not want life-sustaining treatments and that such an advance statement, if made by a competent person, should be respected were they ever to lose the capability of making healthcare decisions.(61) He is quoted as saying:

> "People do not want to accept the notion of death being final, and doctors, for differing reasons, have become obsessed with denying it. But where there is the possibility of continuing a life without value, when heroic measures will keep someone alive without any hope of restoring that life, it is barbaric, cruel, and costly to do so."(62)

Though some treatments may have been initiated to save life, at some point, their continued application transforms them into "heroic measures" keeping "someone alive without any hope of restoring that life." To distinguish whether an intervention is saving life or prolonging death at any given time can be incredibly complex, if not impossible. Physicians had professional difficulty in stopping life sustaining treatments. Trained since Hippocratic times to firstly do no harm, *primum non nocere,* to maintain life whenever and however possible; doctors feared the consequences of terminating life sustaining measures. To do so was interpreted almost as a form of euthanasia. To try to discontinue a treatment once started proved contentious and several influential courtroom battles ensued.

Karen Quinlan was a 22-year-old woman, in a persistent vegetative state subsequent to an overdose of diazepam and alcohol whilst on a "crash diet". In 1976, her father made a court appeal to have "all extraordinary medical treatment" discontinued for her.(63) Her doctors refused to turn off her ventilator, partly from fear of criminal liability, but also as it went against their medical code of ethics.(64) The court in its deliberation made reference to the

reasoning of Pope Pius XII on this subject, as expressed to a conference of anaesthesiologists, in November 1957. With much forethought, Pope Pius XII stated that *"no one has a moral obligation to sustain life by use of "extraordinary means";* but what constituted "extraordinary" or "ordinary means" prompted much debate (and still does).(65) Pope Pius XII considered ordinary means to be those that "do not involve any grave burden for oneself or another" and that extraordinary treatments could licitly be withdrawn or withheld. Interventions which were excessively costly, dangerous, painful, difficult or unusual when weighed against anticipated benefits were interpreted to be "extraordinary".(66)(p286) The court ruled that Karen Quinlan could be removed from her ventilator. She lived for another nine years, sustained by tube feeding, until ultimately she died from respiratory failure due to pneumonia.(67)

Another landmark legal case was that of Ms. Nancy Cruzan. She was diagnosed as being in a persistent vegetative state aged 25 years old, after being resuscitated following a road traffic accident in 1983. Her family applied to the trial court in 1988 to have her feeding tube removed. The court allowed its removal, but the decision was reversed by the Supreme Court of Missouri when Ms. Cruzan's guardian ad litem appealed the initial decision. The Missouri Supreme Court refused removal of the tube based on the lack of "clear and convincing evidence" that this was Ms. Cruzan's wish. There was another appeal to the Supreme Court of the United States in 1989 and they ruled that the feeding tube should be removed based on evidence that she had expressed a wish that "she would not wish to continue her life unless she could live at least halfway normally."

Some legal cases attempted to introduce religiosity into decision making, but arguments based on religious teachings are fraught with difficulty as within each faith there will be varying degrees of expression and belief between people, indeed the same person may have diverse ethos at different stages of their lives. An example of such a case using a religious claim was that of Terri Schiavo.

Terri Schiavo was a twenty-seven-year-old woman, who was resuscitated from a hypokalemia induced cardiac arrest in 1990, but resulting severe hypoxic brain injury led to her being in a persistent vegetative state. Unsurprisingly she did not have an advance care directive or a nominated health care proxy, so under Florida law, the health-care-surrogacy statute designated her husband as her health care proxy. He applied to the Florida courts in 1998 to have her feeding tube removed. He believed she would not want to be kept alive by artificial means, if there was no hope of recovery. Her parents did not agree with this decision, arguing that it would go against her Catholic faith. There followed a seven-year battle of highly publicized litigation which ultimately concluded in her feeding tube being withdrawn, and her death within a few days.(68)

These and many other legal cases bookmarked the history of legislation for advance care directives. Outside of the US, other cases tested the same waters as those of Karen Quinlan, Nancy Cruzan and Terry Schiavo. Two notable cases include *Airedale NHS Trust v Bland(69)* in the United Kingdom and *Re a Ward of Court (withholding medical treatment) No 2 (1996) 2 IR 79(70)* in Ireland.

Airedale NHS Trust v Bland involved a 17-year old Hillsborough football stadium disaster victim, Tony Bland, who was in a persistent vegetative state as a result permanent brain damage caused by injuries sustained during a crush of people at the 1989 FA Cup semi-final. He was unable to communicate, but could breathe independently and his nutrition and hydration was maintained artificially by means of a nasogastric tube. His medical team with the support of his parents and family, applied to the court to withdraw his artificial nutrition and hydration. Mr. Bland lacked medical decision-making capacity, so the House of Lords in applying the “best interests” standard agreed not to prolong his life through artificial hydration and nutrition, as there was no treatment that would confer any benefit to him. They declared that the feeding tube could legally be removed.

The Irish case of *Re a Ward of Court No 2 (1996) 2 IR 79* bore many similarities to that of *Airedale NHS Trust v Bland* in the United Kingdom. Whilst undergoing

a minor gynaecological procedure under general anaesthetic, the Ward, a 46-year old lady, had a series of three cardiac arrests. The resulting anoxic brain injury left her in a near persistent vegetative state for over 24 years, with artificial hydration and nutrition being provided to her through a percutaneous endoscopic gastrostomy (PEG) tube. Her mother applied to the court for direction on her proper care and treatment and whether medical treatment should be withdrawn. Judge Lynch found that although the Irish State "had an interest in preserving life, this interest was not absolute in the sense that life must be preserved and prolonged at all costs and no matter what the circumstances." The High Court judged the artificial hydration and nutrition to be a medical treatment and taking the view of a "prudent, good and loving parent" that it would be in the Ward's best interest that it be withdrawn allowing her to die with such palliative treatment as might be necessary to ensure a peaceful death. The case was appealed to the Supreme Court who upheld the decision of the High Court and made indirect reference to advance care directives and that "where the person has had the foresight to provide for future eventualities" that these their wishes should be respected.

1.2.3 **International Advance Care Directive Legislation**

The California Natural Death Act was signed into law in 1976 making California the first U.S state to legislate for advance directives. It acknowledged that "modern medical technology has made possible artificial prolongation of human life beyond natural limits" and was the first legislation to affirm an individual's right to have some control over the dying process, that:

> "Adult persons have the fundamental right to control the decision relating to the rendering of their own medical care, including the decision to have life sustaining procedures withheld or withdrawn in instances of a terminal condition."

In 1991, the Patient Self Determination Act (1990) was enacted giving federal level support to advance care directives in the United States. It requires all government funded institutes to inform hospitalised patients of their legal right to make healthcare decisions and to complete an advance care directive (ACD),

and that the presence of an advance care directive should be recorded in their medical notes. By 1992, all 50 states in the U.S. had legislation for advance care directives.

Though America was the first country to have specific legislation for advance care directives, provision existed since 1957 in Austria through the Federal Hospital Law Act (Bundeskrankenanstaltengesetz) for a person to register in their medical notes an advance refusal of treatment, in case of future incapacity. Despite this 1950's allowance, specific legislation for advance care directives only came into force in Austria in 2006 (Bundesgesetz über Patientenverfügungen). (71)

Legislation relating to advance directives has been in place in several European countries for decades; e.g. Finland enacted the *Act on the Status and Rights of Patients* in 1992; advance care directives were covered by the *Medical Treatment Contracts Act* of 1994 in the Netherlands and Hungary's new Health Act validated in 1998; Denmark in the same year introduced legislation in the *Law on Patients' Legal Status (No. 482, 1998),* and Belgium and Spain gave legal status to advance care directives in 2002.(72) Advance care directives have a legal basis in the United Kingdom (UK) since 2009 when the *Mental Capacity Act, 2005* came into effect. Ireland lacked a legislative framework for ACDs until the *Assisted Decision-Making (Capacity) Act* was signed into law by the Irish Government in 2015. As of October 2018, this Act has not yet come into effect. Regardless, it has long been expected that a validly constructed ACD would be upheld in Ireland, if challenged.(73, 74)

Alongside legislation for advance care directives came legal frameworks for the appointment of a proxy or surrogate decision maker to act on one's behalf. In some jurisdictions, this came under the umbrella of expanding existing legislation on Powers of Attorney to include healthcare decisions. This is the case now in Ireland, except that an enduring power of attorney does not extend to refusing life-saving treatment. Assignment of a proxy decision-maker has been incorporated into much of the advance care decision's legislation

internationally including the US *Patient Self Determination Act (1990)* and the *Uniform Health-Care Decisions Act (1993)*.

Since their inception, there has been an explosion of various advance care directives formats and some expansion in the use of advance care directives, though overall there remains a paucity of individual's completing advance care directives let alone appointing proxy decision makers. In the absence of an advance care directive or appointed surrogate decision maker, many jurisdictions have resolved the issue of who decides legally for a person that has lost capacity, by designating a hierarchy of surrogate decision makers.(75) This can lead to confusion in countries lacking such a hierarchy or where designation rank differs between countries.

A more detailed account of the relevant legislation on advance care directives and medical decision making for those lacking capacity is found in chapters three and four of this thesis.

There is a myriad of reasons why individuals choose not to complete an advance care directive even when aware of their existence and knowledgeable in their purpose and potential advantages. Evidence suggests some older adults do not wish to document their wishes for end of life care in a legally binding document, instead preferring to record their wishes in a less formal format either verbally or in writing such as in the form of an advance care plan. Trying to bridge this gap has led to the development of advance care planning, a term which began to emerge in medical literature in the late 1990's.

1.3 Advance Care Planning

1.3.1 **Definition of Advance Care Planning**

A recently published paper sought to define advance care planning using a consensus definition from a multidisciplinary Delphi panel.(76) Agreeing on a definition was challenged by concerns as to whether the definition should focus on written or verbal directives, patient values compared with treatment preferences and current shared decision making versus future medical decisions. The definition reached was*:*

"Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."(76)

1.3.2 **Evolution of Advance Care Planning**

Over time there has been an evolution of advance decision making which has to a large extent moved away from formal legally binding advance care directives towards less legalistic advance care planning processes as it became increasingly apparent the importance of the role of communication around end of life decisions and knowledge of the thoughts, values, beliefs and worldview that informed a person's decision making.

A review by Sabatino describes this transition from a "transactional" approach focusing on the nuances of the legally binding documentation of advance decisions and appointment of surrogate decisions makers, to a "communications" approach which places greater emphasis on the process of determining a person's wishes rather than the completion of the advance care directive form itself.(77)

Sabatino also describes some of the common issues with advance care directives, many of which pertain equally to the process of advance care planning: poor completion rates; poor understanding of what decisions a person may face in the future; poor understanding of the advance care directive forms and poor guidance provided by the forms themselves; a person's potential change in preferences and goals over time; poor proxy understanding of the donor's wishes; poor knowledge of the existence of a completed advance care directive; and lack of certainty that a completed advance care directive will affect the patient's care.(77)

Just as people may vary in the extent to which they wish to control decision-making, they may vary in the extent to which they wish to involve their loved

ones or their doctor in the role of proxy decision-makers. Equally, if they were to lose capacity, some people would prefer for decisions to be made using a substituted judgement approach, whilst others would opt for what is felt to be in their best interests – or a combined approach.(78) These are useful things to explore, but again people will vary in the extent to which they will want to. Nonetheless, it is a beneficial exercise to merely initiate discussion of end of life care with a person if they are willing.

1.4 Advance Care Directives and Advance Care Planning Research

A search of Pubmed using the term 'advance * directive* OR "living will"' from 1980 to 1990 yielded just 328 citations. Much of the literature in this decade focused on the use of advance care directives, describing their introduction and new legislation, healthcare professional's attitudes on their use, and difficulties in their implementation (79-82). Some articles described the ethical and legal deliberations in situations where no advance care directive has been completed and medical decisions must be made for individuals lacking capacity, others discussed the role and potential short-fallings of decision making by surrogates in such situations. Many articles in this time-frame discussed advance care directives in the same breath as euthanasia and often linked them with issues of religious beliefs.

A Pubmed search using the same search term for subsequent decades demonstrates the explosion in literature on the topic: a search from 1990-2000 produced 2563 citations, many concentrating on the attitudes and experience of various population groups in using advance directives, the barriers and facilitators to their completion and practical issues such as measuring an individual's capacity to complete an advance care directive and compliance with the directive itself. The same search for 2000-2010 generated 2761 articles and a diversification of subject matters relating to advance care planning which has continued in the 1444 journal articles found on searching Pubmed from 2010 to 2015.

Despite widespread public, governmental, legal and healthcare professional's support of advance decision-making and/or appointment of surrogate decision makers, few people actually complete advance care directives or even communicate their wishes for end of life care with others.

A systematic review of studies published between 2011 and 2016 in the United States estimated the prevalence of adult Americans with completed advance care directives to be 36.7%.(83) A Canadian study found a written advance directive prevalence of 51.7% in community dwelling adults over 65 years of age, and a 67.8% prevalence of the sample population having discussed their wishes with family.(84) Advance directive prevalence in community dwelling adults in Southern Australia has been estimated at 12-14%; similar proportions had completed a Medical Power of Attorney (11%) or an Enduring Power of Guardianship (13%), and greater proportions had completed Enduring Power of Attorney (22%).(85, 86) Another Australian study of 300 people presenting to the Emergency Department of three Victorian hospitals in 2011 found 0% of community dwelling individuals had an ACD, compared with 26.6% of nursing home residents.(87) Elsewhere estimated completion rates are even lower; 11% of German nursing home residents, and only 5% of the general public in Ireland. (88, 89)

Whilst the premise of the living will is extremely appealing, its simplicity is overstated. It can be appreciated that there is clear merit and desire to respect a dying person's wishes, which is the ultimate goal of advance care planning, however there are many barriers that must be overcome in order to achieve this. These stumbling blocks are discussed.

1.4.1 **Individuals characteristics**

Those with higher levels of education and better cognition have been found to be more likely to have completed an ACD or Power of Attorney (POA).(90) Greater age has also been found to facilitate completion, as has residing in a nursing home (OR = 2.15 (95%-CI = 1.26–3.66) for living in a nursing home vs community for POA completion).(91, 92) ACD prevalence for nursing homes residents ranges from 18-70%.(90) For those with dementia who died,

completion rates have been found to be similar to those who were cognitively intact (67.6% (95%-CI = 58.6–76.7; *n* = 69) vs 69.0% (95%-CI = 65.6–72.4))(91) Race has been found to be a factor in several studies, with non-Whites being less likely to complete an ACD.(93, 94) A cohort of Canadian patients with malignancy found 55% of 193 patients had completed an ACD in 2016; patient age as well as higher income and having been referred to palliative care services were all significantly associated with completion of ACDs.(95) Unsurprisingly, personal situations also have an impact; people who had experienced the death of a close family member or friend appear more likely to complete an ACD, as do people who have cared for a dying person (OR 1.36, 95% CI 1.04-1.76) or been involved in life support decisions.(92)

1.4.2 **Awareness and knowledge of advance care planning**

It is intuitive that someone who has never heard of advance directives will be unlikely to have completed one. Nonetheless, a New York study of 200 hospitalised patients in 2008 found 11% of those who stated they had an ACD also stated they had never heard of them!(96) The authors didn't comment on the cognitive status of this subgroup. Overall, in this study 25% of participants had never heard of ACDs.

Awareness of ACDs is generally high though. A German study, in 2003, of adult cancer patients (n=100), healthy controls (n=100) and medical staff (n=100) found good awareness of advance care planning, but poorer patient knowledge of the possibility of appointing a proxy decision maker (29-43%). They found a high intention to complete an advance care directive (50-81%) which was associated with deteriorating health, but poor realization of this intent in that only 18-19% of patients and 10% of medical staff had actually written an advance care directive.(97) Education on ACDs has been shown to improve short term awareness of ACDs, but education alone is insufficient to stimulate ACD completion.(98, 99)

1.4.3 **Willingness to consider end of life issues: willing, ready and able**

A Canadian study of the community dwelling general population in 2010 found 43.6% of respondents had already completed a written advance care directive,

a further 42.1% planned to complete one, however 14.3% of those surveyed had no intention of completing one.(92) Given that ACD completion rates rose from 47% to 72% amongst decedents in the US between 2000 and 2010, clearly people in the US are willing to complete ACDs.(100)But willingness does not necessarily equate to readiness. What are the factors that translate willingness into a completed interpretable advance care plan?

Older people, both those with dementia and those who are cognitively intact, are often prompted to complete an advance care plan in reaction to a medical, living situation or financial issue experienced by a friend or family member or personal illness.(101-103) In a study by Hirschman et al of people with dementia, though most advanced care planning was reactionary, a smaller proportion was found to be active, in an attempt to "put their affairs in order".(101)

A study by Fried et al used focus groups of older adults and caregivers, to explore advance care planning as a health behavior using various constructs to explain why people choose to engage or not in the advance care planning process.(104) The results revealed four key themes: 1) variable readiness to participate in ACP using the Transtheoretical Model's concept of "stages of change"(105), 2) wide range of benefits of and barriers to participating in ACP, 3) participant's use of a variety of processes to increase their readiness for ACP participation and the broader spectrum of behaviours associated with planning for future declines in health, and 4) the influence of experiences with loved ones on perceptions of susceptibility and engagement in ACP.(104) They found a motivational factor for caregivers to complete their own advance care plan included their experience with the end of life care, or need to be involved in decision-making, for a dying loved one.

Prochaska describes the stages of change a person may go through in changing their health related behavior using the Transtheoretical Model, these included *precontemplation* (no intention to take action in the next 6 months), *contemplation* (intends to take action in the next 6 months), *preparation* (intends to take action and has taken some steps in this direction), *action* (has

made a change), *maintenance* (continued change over time) and *termination* (able to self-maintain change).(106, 107) Using the Stages of Change model, assessing a person's readiness to engage in advance care planning allows a more tailored approach to facilitate advance care plan completion.(107) Interventional studies using this approach have been successful in improving advance care directive completion rates.(108) Using this approach also allows efforts and time to be diverted to people who are more prepared to engage in advance care planning, and to plant the seeds of contemplation in those who are not yet ready.

Just as willingness does not always equate to readiness, being ready does not always equate to being able. Ultimately one of the commonest reasons a person may lose the capacity to make medical decisions is through diseases such as dementia. Of a cohort of people with mild to moderate dementia (Mini Mental State Examination (MMSE) >11), 91.7% of them wished to be involved in dementia treatment decisions (though only 40% were deemed to have the capacity to make such decisions and only 29% of their caregivers judged that the patient would want to be involved in deciding).(109) Despite the desire to be involved, there may be avoidance of advance care planning, procrastination, even for people with dementia. Dementia is often not appreciated as a life limiting condition. Of 48 patients with mild to moderate dementia, 48-67% lacked insight into their cognitive problems, diagnosis or prognosis for further cognitive deterioration.(109)People with dementia may deny the diagnosis itself or - because of the disease - may lack insight into its potential consequences for decision making in the future, therefore not appreciating the particular relevance and importance of advance care planning for them.(101, 109)

Capacity is not dichotomous, but more like a spectrum of decision-making ability. Even healthcare professionals who routinely assess patient capacity as part of their daily work only agree to a moderate extent on the capacity of people with mild to moderate dementia to make medical treatment decisions.(109) Furthermore, such experienced healthcare professionals may be uneasy about the formal nature of capacity assessment with regard to

drawing up a legally binding advance care directive or registering a Power of Attorney. Capacity is discussed in more detail in Chapter 4.

1.4.4 **Willingness to discuss end of life issues and with whom**

It is not sufficient to have capacity and to be willing to complete advance care planning, one needs to appreciate one's preferences and - as part of the process - to be willing to consider one's own mortality.

There is an assumption that older people don't want to talk about death and dying. This is most often not the case.(110) Evidence from Ireland would suggest this was certainly the case in the past, but that the older people of modern Ireland differ, and are more welcoming of engagement in discussion of cardiopulmonary resuscitation at least.(111)

A study by Cotter et al in Galway found older stable hospital inpatients to be very receptive to discussion of resuscitation, 94% felt it was a good idea in 2007, with only 5-8% finding discussion of the topic upsetting.(111) The study compared a survey of older hospital inpatients from Dublin in 1992 with a Galway cohort in 2007. There were significant changes in Irish society in this time-frame and this study found almost a reversal of attitudes to CPR in older in-patients. In their current state of health, only 3% wanted CPR in 1992 compared with 81% in 2007. A patient's likelihood of not wanting CPR increased with age, (OR 2.77 (95% CI 1.25–6.13), for those aged 75–84 years and OR 15.19 (4.26–54.15), for those aged 85 years or more compared with those aged 65–74 years). Importantly 69% (1992) to 58% (2007) were agreeable to a doctor making a unilateral decision not to resuscitate if their prognosis was very poor. This study was limited by exclusion of patients with life limiting illness and those with impaired cognition (Mental Test Score <8/10 or MMSE <23/30) or communication, whose preferences may have differed from the patient's included in the study. The study was limited by not knowing the participant's perception of the likelihood of success with CPR, this information could have added to the findings. Previous studies have found an accurate understanding of the limitations of CPR significantly affects the resuscitation choices made by people.(112)

An Irish study of haemodialysis patients found them to be comfortable talking about death, but not necessarily with their family. Most wanted life-prolonging treatment, that pain and other symptoms would be controlled, their comfort maintained and that they would have spiritual peace at the end of life.(113)

Decision control preferences describe *how* a person wishes to make treatment decisions, to what extent they want to contribute to the process and the ultimate decision. Preferences range from some people wanting an entirely autonomous mode, to others wanting to delegate decision-making entirely to others.(114) The commonly used Control Preferences Scale was designed and validated by Degner et al (115, 116) and using text and cartoons depicted on five cards, a patient can designate the extent to which they want to control decisions. This scale was further modified by Nolan et al in collaboration with Degner to depict how a person would want others to decide for them if they were to lose capacity to decide for themselves.(117) The modified scale judges the extent to which the person would want decisions to be made using substituted judgement compared with an approach based on what would be in their best interests. A further addition to the tool was to allow a person to weigh the input they would assign to their doctor versus their loved ones.

Nolan et al validated the scale on a group of patients who had been recently diagnosed with life limiting conditions which had a 2-year mortality of at least 50%, such as amyotropic lateral sclerosis, advanced heart failure (non-transplantable) or advanced non-resectable lung cancer.(117) The study revealed the intricacies of medical decision making in scenarios of capacity and incapacity. It found that most people while still competent to make their own decisions wanted a shared decision making approach, placing greater importance on the role of their doctor (52%) than their family (44%). Only 34% wanted to make decisions autonomously of their doctor (50% independently of their family), and fewer preferred to delegate decisions to others (15% to their doctor and 7% to their loved ones). For this study's participants, imagining how they would want decisions made for them if they were unconscious, shifted importance away from the patient's previously expressed wishes (substituted judgement) towards decisions being made by

others that took the participant's best interests into consideration. Study participants placed greater importance on their loved ones' input into an ultimately shared decision with their doctor. The key message from the study was that the complexity of this area means one style of decision making will not fit all. Similar desires for a collaborative approach to decision-making have been found by other researchers.(118)

Though many older people welcome discussion of end of life issues, and may be content to express their preferences, some are more content to leave the ultimate decision making to their family or to healthcare professionals, trusting them to act in their best interests.(117, 119) Research shows that people who prefer to leave decision-making to others, are just as likely to complete an advance care directive as those who want to make decisions for themselves.(120) Understanding a person's decision-making preferences may be important to support them in advance care planning.

1.4.5 **Willingness to make end of life decisions: for death or for dying**

"The widespread and deeply held desire not to be dead" thwarts end of life decision making. (121) Death is inevitable. What happens after one's death is far more controllable though than the vastly less predictable circumstances of *how* one dies. Older people are more likely to have made plans for the Death rather than the Dying; funeral plans and Wills are frequently made even among those who are not prepared to make decisions for the end of life care.(122-124) Funerals and Wills are some of the controllable aspect of death, the parts that can be easily organized, and funerals are the public face of death. The act of dying has become hidden in modern Western civilization such that it is denatured and people struggle to cope with this foreign visitor.(125)People who have little experience of bearing witness to the Dying in their last days, weeks and hours, will likely have more difficulty in trying to plan for what is unfamiliar to them.

1.4.6 **The hypothetical future or the current existence**

A systematic review by Auriemma et al evaluating the stability of end-of-life care preferences over time, and with changes in health, found the majority of

patient's preferences are stable (71%).(126) There appeared to be greater stability in inpatient and seriously ill outpatient populations than in older adults without serious illnesses ($p<0.002$). Preferences to decline life sustaining treatments tended to be more stable than those wishing for such treatments, and higher levels of education and people who had completed advance care plans or advance care directives also had more stable preferences.

1.4.7 Willingness to document end of life related wishes or appoint a proxy decision maker

A study by Singer et al. found that patients purpose for completing an ACD was not just about preparing for potential incapacity, but more so about preparing for death and dying.(127) They perceived its role as an exercise of control but also an attempt to relieve the burden of decision making for their loved ones. They also found it to be a social process linked with both the doctor-patient and the family relationship.(127) Desires to relieve family of the burden of decision making was found to be an incentive to advance care planning in other studies also.(122) Additional prompts include receiving a diagnosis where recovery was remote or where the chances of losing capacity were more certain.(122) In a study by Piers et al, the lack of family or surrogate decision makers was another motivator to complete advance care plans.(123)

1.4.8 Proxy decision makers

Where a potential proxy decision maker exists, and is appointed, it is obviously important that they are empowered to make end of life decisions for their loved one **with** the knowledge, or at least a sense, of what their loved one would have wanted. Clearly discussion of end of life issues as part of the advance care planning process is beneficial and improves the likelihood of having a more accurate understanding of the person's expressed wishes.

A systematic review by Shalowitz et al found that the accuracy of proxy decision makers in predicting the patient's treatment wishes was correct only 68% of the time.(2) In a randomised controlled trial, even having access to a patient's advance care directive instructions had minimal impact on the decisions made by proxies.(128)

Family as proxy decision makers tend to use a best interests approach (57%) rather than using substituted judgement (43%).(129) Even when using a substituted judgement standard, this was not viewed as distinct from best interests, rather the two approaches are blended. The omission of discussion with the patient/donor is not the only reason for a best interests approach being taken, other factors include the need for family consensus, the patient having unrealistic expectations, and the need to encompass quality of life and healthcare professionals' views in the decision.(129)

There is also a need for proxy decision makers, and patients themselves to have an understanding of life sustaining treatments and how they relate to the individual. This takes time and diminishes the quality of decisions on treatment and interventions made in times of crisis, which is one of the rationales for advance care planning.

1.4.9 **Use of advance care directive forms**

A disincentive to completing an advance care directive, at least in the United States, includes poor readability of advance care directives particularly state mandated directives. Most advance care directive use complicated language, beyond a 12th grade reading level, despite the Institute of Medicine recommending a 6th grade level readability for documents related to health.(130-132)

It's not just patients who may have trouble understanding advance care directives. Healthcare professionals and patient's family may also have difficulty extrapolating what the patient's intended wishes were.(133) There is low concordance between patient discussed wishes and the interpretation of those wishes by a proxy decision maker or physician.(134) The terminology used in advance care directives is open to interpretation. Even the language used in what appear to be very specific and well-constructed directives can become ambiguous when trying to apply a patient's directive to the healthcare scenarios it intended to control. Furthermore, directives which are too specific ultimately may be too restrictive to apply to the situations that arise. (135, 136)

Compliance with advance care directives has also been raised as an issue.(137, 138) A systematic review by Brinkman-Stoppelenburg et al found that Do Not Resuscitate (DNR) orders reduced cardiopulmonary support efforts and hospitalization.(139) They found that Do Not Hospitalise (DNH) orders reduced the number of hospitalisations and increased the use of hospice care and that advance care directives increased out-of-hospital care. Studies performed in hospitalized populations did not find an association with the medical treatment received and advance care directive use.(139) Complex advance care planning intervention on the other hand were associated with an increased frequency of out of hospital and out of-ICU (intensive care unit) care, increased compliance with patient's end of life wishes as well as greater satisfaction with care.(139) Population based studies often assume that the presence of an advance directive implies that individuals want to limit life sustaining treatment. This is not always the case as advance directives are equally applicable for people who wish to document their wishes for intensive care. Studies at individual level in contrast to population based studies have found poor compliance with advance directives and not exclusively because of difficulty with the validity or interpretability of the directive.(140)

A systematic review by Houben et al found 55 randomised controlled trials of advance care planning interventions and found more complex advance care planning interventions focusing on advance directives, that also included end of life care discussions increased the likelihood of advance care directive completion and that end of life care discussions in turn improved compliance with patient preferences for care.(141) Actively engaging people in discussion of end of life care seems to be more important than just passively providing information and hoping the conversations and subsequent documentation of wishes will happen.(142)

Much of the research to date has focused on the use of advance care planning in the long term care setting where it has been found that a systematic approach to advance care planning has the potential to improve completion rates in long term care residents.(143, 144) Advance care planning and initiatives to support long term care residents are increasingly recognized and promoted as

important measures in providing quality care in this setting. Advance care planning is included as a prompt in the Gold Standards Framework in the United Kingdom and in the National Standards for Residential Care Settings for Older People in Ireland set out by HIQA (Health Information and Quality Authority).(145, 146) The latter have responsibility for inspecting the quality of care provided in all residential long term care settings in Ireland, all of whom must register with the authority since the Health Act of 2007.(146)

1.5 Long Term Care

Much of the research to date on advance care planning has involved long term care residents, but research must be interpreted knowing that the term "long term care" can mean different things in different places. It can include both formal and informal care. Long term care is sometime taken in this thesis to mean long term residential care, but others use the term to also encompass a range of services provided in a person's own home. Long term care particularly in the United Kingdom includes services from local authority social and community health services, day care, and home care services, each with the aim of helping an older person to maintain their ability to function and to live at home. Of course, even the types of facilities which provide residential long term care can also be identified by a variety of names other than "nursing home", and provide varying levels of care: in the UK they are typically known as residential care homes or nursing homes; in the United states they include assisted living facilities, personal care facilities, residential continuing care facilities. In this thesis, "long term care" it is taken to be synonymous with the type of care typically provided in a nursing home.

Though many long term care facilities in Ireland are modern and purpose built, a large number of long term care units, particularly public facilities, began life as workhouses and evolved gradually over the years into places of care for older people. The historical roots of long term care facilities in Ireland were far removed from places that promoted autonomy, rather they were places of last resort that typically stripped people of free choice. With multi-occupancy rooms and "Nightingale" wards they were not designed to facilitate the privacy sought

after in providing high quality end of life care. Infrastructurally, this can be very challenging or impossible to change. To understand their role in caring for those older people who are no longer in a position to live independently in their own homes, it is useful to examine the evolution of nursing homes in Ireland, an evolution which has some common ground with that of palliative care.

The Poor Law Act in providing "poor relief", essentially, though unintentionally, imposed on English society the first legal responsibility to provide care for older people through the workhouse system. Sir G Nicholls, an English Poor Law overseer, criticised the old Poor Law workhouse as "the resort of the idle and profligate", but stated the *new* English Poor Law of 1834 was designed such that a well-regulated workhouse would answer two conditions:

> *"No person in actual want will reject the relief proffered therein, and a person not in actual want will not submit to the restraints by which the relief is accompanied. Workhouse relief will be more repugnant than labour to persons able to work, whilst to those who are disabled as well as indigent the workhouse will be a welcome refuge " (147)*

Ireland's economic structures differed from England, and the extent and prevalence of poverty in Ireland was far greater. Dr. Whately, the Anglican archbishop of Dublin, as part of the *Royal Commission of Inquiry into the Conditions of the Poorest Classes in Ireland* (1833-1836), reported that the sheer scale of poverty in Ireland was such that almost 2.4 million people would need to be housed in workhouses if the English Poor Laws were applied in Ireland. Several workhouses already existed since the early 1700's being authorised by law from 1703 as places "for employing and maintaining the poor, punishing vagabonds and providing for and educating foundling children". Workhouses came to also provide "asylum for lunatics and idiots", "retreat for incurables from the hospitals and convalescents from fever" and as a "house of refuge for the infirm and sick poor". Their infirmaries were mainly occupied by "the bedridden and feeble who, though not acutely ill, nevertheless required nursing care."(148)

Nicholls, who oversaw the enforcement of the Act in Ireland devised a Poor Law system that differed from England. Whilst every destitute person in England had the legal right to poor relief, this was not the case with the Irish Poor Law Act of 1838. These differences, combined with the level and nature of destitution in Ireland, the intermittent famines experienced in the 1800's, and the Great Irish famine of 1845-1848, meant that the workhouses were inhabited by the sick, starving and dying. The workhouse gained exceptional stigma along with an unanticipated role in caring for these people and the elderly.

Under Poor Law provision, Ireland was divided into 130 "unions" (ultimately 163 by the end of the famine), comprised a city or market town and surrounding hinterland. The union's workhouse, located centrally in the town, provided relief for the unemployed and destitute of the area, usually with a workhouse infirmary attached. A Board of Guardians had overall responsibility for the union, and the 1832 Act also allowed then to provide fever hospitals in association with the workhouses. The expansion of fever hospitals was prompted in part by an outbreak of Cholera; the first case of the ensuing epidemic was diagnosed by the famous physician William Stokes in 1832.

The Medical Charities (Dispensary) Act of 1851 stipulated that each district have its own dispensary to provide free medicines and treatment for the poor, the cost of which was borne by the Boards of Guardians.(149) The dispensaries were often co-located at the workhouse. From 1856 the fever hospitals were allowed to admit paupers as well as those with "Fever". The 1862 Poor Law (Amendment) Act officially opened the workhouse hospitals to non-paupers though - in the absence of alternative hospitals in most locations - they had already been attending prior to this. In 1863 the workhouse doctors also became Registrars of births and deaths enabling the collection of accurate statistics and facilitating vaccination of children against disease such as smallpox.(150) These two acts effectively secured Ireland with one of the most advanced health services in Europe at that time.

Before the non-contributory state pension was introduced in 1909, poorer older people who could no longer care for themselves or be supported by family to live at home, often had no choice but to be admitted to the workhouse or "County Home", as many of them came to be known after the Poor Law Reform Act (1906). In the late 1800's about 75% of those living in the workhouses comprised of the elderly and infirm.(149) Around this time, the provision of care to those residing in the workhouses that remained under state control, was allocated to various religious orders. The order's nuns, often qualified nurses, had been allowed to provide care in the workhouses since 1861, firstly in the hospital of the Limerick Union Workhouse, which ultimately became St. Camillus's Hospital; a unit which now provides stroke care, rehabilitation as well as long term care for older people.(151) In Limerick, the workhouse in Newcastle also evolved over time to become a site for older person rehabilitation and long term care: St. Ita's Hospital.(151)

Ultimately with the abolition of the majority of Boards of Guardians under the Local Government (Temporary Provisions) Act, 1923, the role of the workhouses changed.(150) During the Irish Civil war, many workhouses became military hospitals or bases. In the early 1920's many were bombed or destroyed for this reason. From 1922 onwards, the workhouses that remained were generally either closed, or turned into acute County or District *Hospitals* (e.g. Naas General Hospital, St. Finbarr's Hospital in Cork), Fever Hospitals, or residential County *Homes* for the elderly and infirm. Many of the latter have remained in the public Irish Health Service, several as "geriatric hospitals" providing long term care residence and also having rehabilitation facilities on site.

In 1966, there were 36 of these long term care facilities providing care for 8,057 older patients. Though the numbers have since declined with the closure of some of these facilities, those geriatric long-stay units that remain are an important contributor to the estimated 30,000 long term care beds in Ireland.(152) Since the Health Act 2007, the Health Information and Quality Authority (HIQA) have responsibility for the registration and inspection of all

long term care centres for older people. On their website, www.hiqa.ie, they publish information on these centres and their inspection reports.

There are 125 public (HSE managed) nursing homes providing care for 6555 older people in Ireland, 47 (38%) of them evolved from a workhouse, but together these provide 3025 beds which represents almost half (46%) of the public nursing home beds in the State. Of the 125 public long term care facilities, 25 (20%) of them are in counties Cork or Kerry with registered beds for a total of 1384 residents.(153, 154) Of these 25 HSE long term care facilities several are newly built modern premises, but 14 (715 beds) of them are either in the existing workhouse building (e.g. St. Columbanus Home Killarney, St. Finbarr's Hospital Cork, and the Community Hospitals in Clonakilty, Fermoy, Kinsale, Midleton) or in new buildings on the old workhouse site (e.g. the Community Hospitals in Listowel, Kenmare, Millstreet, Skibbereen, and in Macroom, Bandon, Bantry and Dunmanway where the original buildings were burnt in 1921 in the Irish civil war).(149) The mentality of the "County Home" as being a place of last resort exists still, with admission to a nursing home - particularly those with historical links to the workhouse - being seen as something to be avoided, at all costs, by most older Irish people, even as death approaches.

Evolution of long term care in Cork: the case of St. Finbarr's Hospital

The Cork Union Workhouse, was purpose built on the Douglas Road, and attached to an infirmary. In 1898, the Cork Union Workhouse became known as the Cork District Hospital.(155)(p31) With the abolition of the Poor Law system in 1923, it was taken over to be used as an acute hospital. It ultimately became St. Finbarr's Hospital, which was one of the main acute hospitals and clinical medicine teaching facilities in Cork City until 1978, when it's role changed with the opening of Cork University Hospital. An inspection by the British Medical Council in 1961 reported that the hospital "retains the essential structure of a large workhouse infirmary of the last century", a report which also identified the need for a new regional teaching hospital and contributed to the establishment of Cork University Hospital.(155)p59-61

At that time St Finbarr's Hospital was perceived by the general public in a similar light; to still have the "whiff of the old poorhouse it had once been , a place offering rude shelter to the destitute and the dying who had nowhere else to go".(156) During the last and largest polio epidemic in Western Europe in 1956, St. Finbarr's also served as a fever hospital and was "regarded with terror by people in Cork" who "crossed the road outside to avoid walking close to its walls for fear of infection".(156) St. Finbarr's Hospital campus now provides nearly 100 long-term care beds for older people, and houses a variety of other facilities, including the Munster blood transfusion service.

Though workhouses evolved into nursing homes, they were still associated with their origins, as places of accommodation for the destitute, not as places of care for older people. Despite the passing years, the stigma of the workhouse or "poorhouse" remained and many older Cork people in need of long term care perceived St. Finbarr's hospital (and other community hospitals that had been workhouses in former lifetimes) as a place of last resort, and would refuse to be admitted there even into the last decade.

Residential long-term care for older people in Ireland is provided in a variety of settings:

- Public (HSE) Geriatric Hospitals like those outlined above where long term care is offered alongside more specialised services such as rehabilitation or stroke care e.g. St. Finbarr's hospital in Cork City, St. Camillus Hospital in Limerick. Together with acute geriatric departments, these units form part of Specialised Geriatric departments either on the same site as an acute hospital e.g. in St. James Hospital in Dublin, or off-site like at St. Finbarr's Hospital in Cork which is linked with the geriatric departments in Cork University Hospital and the Mercy University Hospital.
- Public (HSE) Geriatric Community Hospitals, some of which were workhouse in former lifetimes as detailed above before becoming county hospitals, district hospitals or county homes before ultimately becoming places for long term care e.g. e.g. St. Columbanus/Killarney Community

Hospital, Co. Kerry. Many more were purpose built such as the newer modern buildings at Farranlea or Ballincollig Community Nursing Units in Cork.

- Private Voluntary Nursing Homes such as St. Luke's Nursing Home in Cork which had its origins in the religious sector
- Private nursing homes such as Haven Bay Care Centre, a purpose built private nursing home, also one of the study sites described later in this thesis
- Some Psychiatric hospitals also have attached long term care units for older people with chronic psychiatric conditions, an example being Mount Alvernia in Mallow, Co. Cork.

Parallel to the evolution of workhouses into long term care facilities and hospitals, there were two additional relevant elements to the history of hospital and residential healthcare development in Ireland; the Voluntary Hospital or Charitable Infirmary sector and the evolution of modern day Hospices.

Ireland was virtually devoid of hospitals from the time Henry VIII suppressed monastic hospitals in the "Reformation", until the end of the 17th century when the more fortunate and wealthy in Irish society established the first voluntary hospitals, to attend to the recognised plight of the sick poor in society. Prior to this the ill – who had the means - were managed at home, and that is where the majority of them died. Even with the development of hospitals in Ireland, it was clear that they "retained only such cases as were found susceptible of treatment" which left the sick poor especially without institutional care.(157)

1.6 Palliative Care and End of Life Care

1.6.1 **Evolution of Palliative Care**

The word "hospice" comes from the Latin *hospes* meaning guest or stranger. In the 4th century "hospice" referred to a house of hospitality for pilgrims. By the middle ages hospices had become places of shelter for the poor, elderly, ill, wounded and dying.(158) The concept of hospice as we know it today began to emerge in 17th century. Mme Jeanne Garnier, a young woman whose husband

and two children had died at only 24 years of age, joined other women with similar experiences of loss in 1842, and formed *L'Association des Dames du Calvaire*.(159, 160) Together they opened the first hospice specifically for the dying in 1843, in France, this was followed by six more, including one in New York.

In Ireland, during the cholera outbreak in 1832, a series of temporary hospitals were set up in Dublin and Cork by the Religious Sisters of Charity, an order founded by Cork born Mother Mary Aikenhead. A Cork Physician, Dr. Patrick Murphy was so impressed by the care they provided to his father and sister on their deathbeds, that he donated what remained of his estate to the Sisters of Charity on the condition that within two years of his death, they established a hospital or room for patients with incurable diseases such as cancer.(161) Thus St. Patrick's Hospital for Incurables - (now Marymount University Hospital and Hospice) opened to its first patient in 1870.(162) After this, the Sisters of Charity opened Our Lady's Hospice for the Dying in Dublin in 1879, followed by St. Joseph's Hospice in London in 1905 and later others in England, Scotland and Australia, all of which exist to this day as modern palliative care units.(162)

In the mid 19th century death was considered a natural part of life, most often occurring in a person's home. Over the century that followed there was rapid growth in the number of hospitals and nursing homes and increasingly, this was where people died.

Despite the premise that the two early Irish hospices (St. Patrick's Hospital for the Incurables in Cork and Our Lady's Hospice in Dublin) would admit terminal cancer patients, the majority of deaths in these institutes were due to advanced tuberculosis, at least until the late 1940's, when following the discovery of streptomysin, the proportion of those dying from tuberculosis was overtaken by those dying from cancer, for the first time.(163)

By the 1950s concerns were growing about care at the end of life. The National Health Service in the United Kingdom was in its infancy having been established in 1948, but its focus was very much on acute medical and rehabilitation care. It's founder, Aneurin Bevan was chairman of the Cottage Hospital Management

Committee (1929-1930). His speech in the House of Commons during the reading of the NHS Bill in 1946 is often quoted: "I would rather be kept alive in the efficient if cold altruism of a large hospital than expire in a gush of warm sympathy in a small one". This mentality can be understood given the incredible advances in medical achievements of that era, but it was also a time where people were less likely to die from infection; instead living long enough to develop the chronic diseases and disability that increase with age.

To quote Ivan Illich's 1976 book *Medical nemesis:*

> "the limits of effective medical treatment apply not only to conditions that have long been recognized as sickness—rheumatism, appendicitis, heart failure, degenerative disease, and many infectious diseases—but even more drastically to those that have only recently generated demands for medical care. Old age, for example, which has been variously considered a doubtful privilege or a pitiful ending but never a disease, has recently been put under doctor's orders. The demand for old-age care has increased, not just because there are more old people who survive, but also because there are more people who state their claim that their old age should be cured ….. Old age has been medicalized at precisely the historical moment when it has become a more common occurrence for demographic reasons;" (59)(p34)

With advances in medicine, and an increasing emphasis on cure and rehabilitation, death came to be seen as a failure, and those beyond cure began to be neglected. The dying became less welcome in hospitals. The religious orders who set up the early hospices saw the unmet needs of the dying and devoted themselves to caring for them, particularly the dying poor, with what resources and few beds they had. The religious orders made no distinction between the needs of those dying from cancer or those dying from non-malignant conditions, and "accepted a measure of suffering", by modern standards the care was unsophisticated.(164)

Around the same time as Luis Kutner was proposing the Living Will in the 1960s, a separate but equally important movement was also changing the face of dying; the modern Palliative Care movement.

All too often, those with life limiting conditions and their families were told, "there is nothing more that can be done". Dame Cicely Saunders a trained nurse, social worker and physician refused to accept this, or the inadequate care offered those dying in hospitals. Believing "there is so much more to be done", her vision and work led to the birth of the "modern hospice" movement. She opened the first "modern" hospice, St. Christopher's Hospice in 1967 founding it on the principle of combining expert pain and symptom control with holistic care, research and education. Her new and bold approach to care for the dying was both inspirational and revolutionising.

Cancer has a disease trajectory that is often predictable and in the 1960s and 1970s when Dame Cecily Saunders pioneered palliative care, it is not surprising that care focused on the needs of those with terminal malignancy. In those days, more often than not, cancer was incurable and the needs of the terminal cancer patients were often neglected, sometimes leaving people suffering intractable pain, nausea, dyspnoea or other distressing symptoms.(165, 166) These individuals were often young, active contributors to the economy, in the prime of their lives and their deaths were perhaps seen to be not as timely as deaths in older people might have been perceived. It is not hard to imagine how the hospice and palliative care movement, which aimed to improve the dying experience, was so easily accepted for those dying of cancer, particularly as pain management was much less well developed then (for any illness) compared with today.

The modern hospice movement developed in response to the needs of terminally ill cancer patients. Palliative care is not limited to cancer care though, it has a role in all life-limiting illnesses and in all settings. Nowadays, it is agreed that access to specialist palliative care be based on need, not diagnosis. This is reflected in Irish policy documents and in changing practices.(167-169) A recent national audit of end-of-life care in Irish acute and

community hospitals found favourable comparisons with care in hospitals in the US, UK and France, but also found that significant weaknesses exist, consequently, quality standards for end-of-life care in hospitals were published.(58, 170) They add to other international strategies, frameworks and initiatives such as the Gold Standards Framework and the Liverpool Care Pathway for the dying in the UK, in endeavouring to improve end-of-life care in the general palliative care setting.(145, 171, 172)

1.6.2 **Definition of Palliative Care**

Palliative care is more easily defined in many ways than end of life care. The World Health Organisation defines Palliative Care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.(173)

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness

Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or

radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."(173)

In Ireland, Palliative care services are structured in three ascending levels of specialisation: Level 1- Palliative Care Approach, Level 2- General Palliative Care and Level 3- Specialist Palliative Care as defined in the report of the Irish National Advisory Committee on Palliative Care. (167)

> **"Palliative Care Approach:** Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel."
>
> **"General Palliative Care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings."
>
> **"Specialist Palliative Care:** Specialist palliative care services are those whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary care services."

Only a small proportion of Irish deaths are in hospice (6%).(174) This may in part be due to the considerable paucity of specialist palliative care hospice beds delivering level 3 (Specialist palliative) care. There were 153 in-patient hospice beds reported in 2007, the same report estimated a deficit of 390 hospice beds

for the country. There are an additional 187 palliative care support beds which provide level 2 (General) palliative care.(175)

Historically specialist palliative care services in Ireland (and elsewhere) has focused predominantly on the care of patients with advanced cancer.(176) The Irish public still perceive palliative care in this light, and in terms of specialist care provision rather than including general palliative care which is the source of much palliative care in this country. Specialist palliative care provision is changing as this specialty evolves to become more inclusive of those with needs due to non-malignant life limiting illnesses. The National Advisory Committee on Palliative Care laid out the framework for such an expansion in 2001.(167) Palliative care's extension into the realm of non-malignant disease began with motor neurone disease, in the 1970s and early 1980's. The skills and ethos of palliative care developed in treating cancer patients were equally relevant in motor neurone disease (and many other neurodegenerative diseases). A life limiting illness with a predictable trajectory, motor neurone disease tends to afflict adults from 20-50 years, robbing them of their body's functions but not their minds. Aiding people with this disease, to die well, obtained public support and funding. It was not always as easy to garner support in moving beyond cancer care, to expand services to those dying with AIDs in the 1980's.(177)Brogan and George highlighted four areas that challenged in AIDS palliation that differed from cancer care, similar arguments could be made for other non-malignant life limiting conditions:

1. new symptoms may warrant investigation even in end stage disease as easily treated conditions often presented atypically - this is also true in older people especially those with dementia
2. distressing symptoms sometimes were best controlled by targeting treatment at the underlying condition – which may also be the case in exacerbations of end stage heart failure or COPD or symptoms experienced in advanced Parkinson's disease
3. For symptomatic reasons, drugs used for prophylaxis needed to be continued to the end of life – this could hold true for drugs such as antianginals in those with end stage cardiac disease

4. Combination therapies placed a heavy symptomatic burden on the patient with HIV

More recently palliative care services have extended to include referrals for people with other non-malignant life limiting conditions such as COPD, heart failure, Parkinson's disease or dementia.(169) Of the approximately 30,000 deaths each year in Ireland, about 80% are estimated to die from conditions likely to have palliative care needs.(176) At present only about 15% of patients seen by Specialist Palliative Care services have a non-malignant diagnosis.(178) Change takes time.

Importantly, only a proportion of patients (25.8%) referred to Irish Specialist Palliative Care services ultimately die in a hospice.(178) A Cork based study found 9.1% of such referred patients died in a nursing home, but that most people who avail of specialist palliative care services die in hospital (39.3%) or at home (25.8%).(178)

1.6.3 **End of life care**

Defining end of life care is in some ways more complex, and the language used to describe it equally so.(179) Whilst most medical practitioners in Ireland and the United Kingdom will know the difference between general and specialist palliative care, this terminology may be less familiar to those in other parts of the World. "Terminal care", "care of the dying", "end of life care", "palliative care", are terms seen and used interchangeably by the public, but these are not synonymous. They have specific albeit variable meaning depending on context, discipline, culture, location and time of their use.

1.6.4 **Differences in meaning of terminology**

The inconsistencies in terminology's definition may be confusing, for example in the past in the United Kingdom, "end of life" care was taken to mean care when death was imminent, a short period of usually days to weeks, latterly most national bodies in the United Kingdom have adopted the definition as care in the last year of life, a similar definition to that generally used in Canada and the United States.

The Irish Health Service Executive National Clinical Program for Palliative Care differs and chooses a much shorter timeframe for its definition:

> *"End of life care is the term used to describe care that is provided during the period when death is imminent, and life expectancy is limited to a short number of hours or days. The term has been used to describe the last 12 months of life. The clinical program does not use the term in this way."(180)*

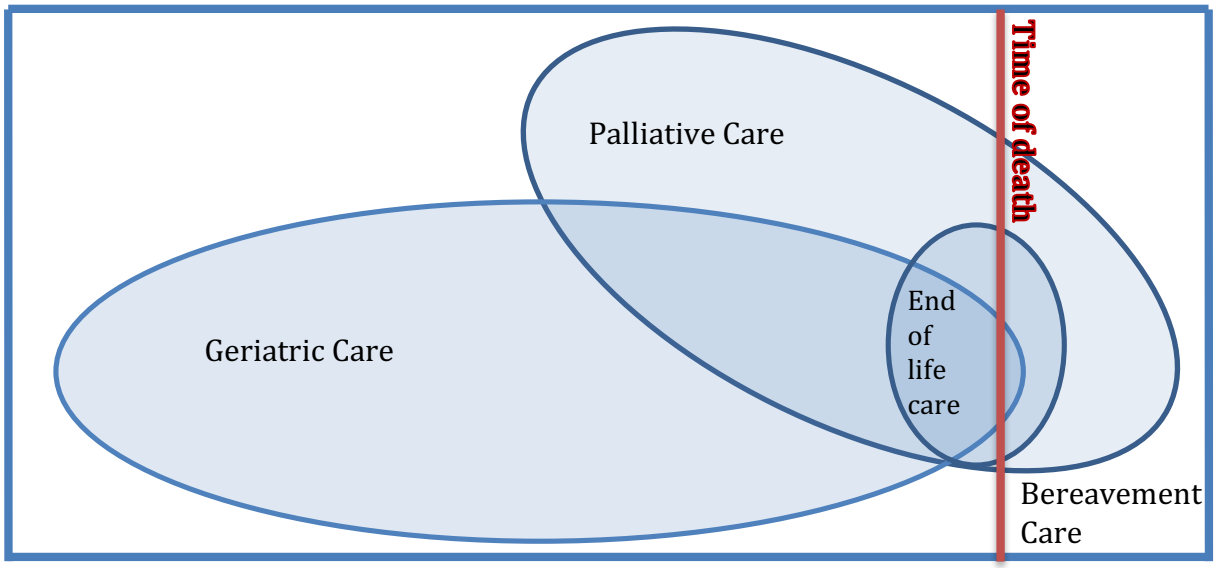
The Australian viewpoint is similar to the Irish timeframe.(181)

For the purposes of this theses, end of life care denotes that care given in the days (and sometimes weeks) immediately surrounding the time of death when it becomes apparent that the person is "actively" dying, that their death is imminent and potentially unavoidable. It also includes the care given to their families, both before and after their loved one's demise.

But, at what point on the continuum does care become end of life care? The trajectories of decline that are typical of various conditions differ, for example the decline seen in cancer is often quite sudden whereas that of heart failure and chronic obstructive pulmonary disease (COPD) is more gradual, marked with periods of acute deterioration with full or partial recovery, but any of which could result in death. For people with severe heart failure (NYHA class IV) which causes dyspnoea at rest, 30-70% of them will die each year, but 5-30% of these deaths will be sudden, some feel such a diagnosis is worse than cancer given the duration of symptoms.(182-184) The more typical trajectory seen for frailty and dementia can be even more gradual, like the downward slope of a bumpy hill. It can be very difficult to pinpoint a time when "care" ends and "end of life care" begins.

It is clear that there is considerable overlap between "palliative care" and "end of life care". A third and important overlapping entity for older people at least, is Geriatric Medicine which focuses on the holistic care of the older person, but also includes that care given up to and beyond death.

Figure 1: Schematic of care for older people with life limiting condition (including old age and frailty) and their family



1.6.5 **The beginning of the end**

The National Council for Hospice and Specialist Palliative Care Services (1997) described the signs and symptoms of approaching death in their document *Changing Gear- Guidelines for Managing the Last Days of Life in Adults.* (185) These signs included:

- profound weakness such that a person spends more time in bed or needs assistance with all their care needs;
- that a person may be drowsier or have reduced cognition;
- that they may be more disorientated in time and place, have difficulty concentrating or be poorly co-operative;
- that their appearance may become gaunt;
- that their oral intake may be reduced or that they may be less able to swallow medication.

This may be a useful guide in cancer patients and younger people for whom these signs may indicate that death will be soon. However, the frail or those with dementia may exhibit such signs for months or even years before their ultimate demise. There is a high prevalence of dementia amongst nursing home residence, estimated between 50 and 92% (186) for whom incontinence,

confusion and agitation may be present long before death. For nursing home residents, their path to death is often a slow declining one, peppered with several acute, potentially fatal, but also potentially reversible illnesses such as pneumonia or urosepsis.

A study of nursing home residents in the Netherlands highlighted the difficulty of prognostication, residents were eligible for inclusion if their treating physician expected to them to die soon, within 6 weeks, the study found that 1 in 10 patients recovered from their "terminal phase".(187) The study which excluded residents with sudden unexpected death, found the median survival for those who died was only 3 days, 83% were dead within 7 days, indicating that most residents were only identified as being in the terminal phases at a very late stage in their illness.(187)

A Norwegian study similarly found death was identified as being imminent in only 61% of nursing home residents, 85% of whom were dead within 7 days.(188) In this study the presence of fatigue (99%), drowsiness (98%) and reduced appetite (95%) were the most common symptoms seen on the day the resident was recognised as being imminently dying.(188) The presence of fatigue (OR 1.8, 95% CI 1.16-2.85,) and decreased appetite (OR 1.2, 95% CI 1.06-1.41) were associated with recognising imminent death.(188)

Studies looking at the symptoms experienced by nursing home decedents found different profiles in those who died due to malignancy compared with those who died from other life limiting conditions.(187, 189) Nausea (13.3% vs 1.3%, p=0.001), vomiting (11.7% vs 1.3 %, p=0.002), anorexia (17.3% vs 26.7%, p=0.13) and extreme tiredness (26.7% vs 3.2%, p<0.001) appear to be more common in cancer than dementia patients, but taking very little oral fluid (49.4% vs 21.7%, p<0.001) or food (32.7% vs 21.7%, p=0.14), dysphagia (12.2% vs 5%, p=0.14), or subcoma (10.3% vs 0%, p=0.007) were more common in dementia than cancer patients.(187)

For all residents, symptoms such as pain, dyspnoea, anxiety, fatigue, drowsiness, dry mouth, anorexia and dysphagia become more prevalent as death approaches, but for those with dementia in particular, challenging

behaviour becomes an increasing issue. (186, 188, 190) Maddocks et al found the prevalence of confusion was only 34% in a hospice population but 81% in nursing homes where challenging behaviour prevalence was as high as 67%.(191) Specialist palliative care may not be as well experienced in dealing with the symptoms that may present at end of life in dementia, in particular challenging behaviour.

This is an example of how the learning from specialist palliative care may not be entirely transferrable, without modification, from care of patients with more predictable disease such as terminal cancer and motor neurone disease onto care of people dying from life limiting diseases such as dementia.

It is possible that the palliative care movement would not have been as successful in its endeavours had its initial focus been on the care of the dying with advanced dementia in long term care. These individuals are often hidden from and sometimes neglected by the society to which they have long since paid their dues, but to whom they have come to be seen as a burden. They might not have been such a wise first target for the modern-day hospice movement, but were and are equally deserving of high quality care at the end of life.

1.6.6 **End of Life Care in Long Term Care**

> *Valuing life, and letting life go, are not exclusive. In combination they can be profoundly life affirming" Sheldon Ekland-Olson.(192)*

Generically long term care in Ireland originated in workhouses, places that were not designed or intended to provide care for older people at the end of their lives. They evolved over time as places of residence for older people, when they could no longer live independently in their own homes. Rather than trying to mimic a place of private residence, nursing homes tended to recreate a more hospital-like environment. Unsurprisingly, for the most part, they took a medical model of care such that care focused on protecting the resident, fixing and curing, rather than promoting their autonomy and independence. Taking a medical model of care meant that the emphasis was on rehabilitation and maintaining function, and neglected preparation for inevitable death as it drew

ever closer. To quote the opening chapter of *End of life in care homes: A palliative care approach*:

> *"the philosophy of many of these settings does not necessarily incorporate preparing residents for death or training carers in terminal care or even how to handle chronic conditions."*(193)

Just as death had become hidden in hospitals, it was hidden in the majority of long term care residences. Rather than embracing it as the natural end to a resident's life, a cloak of concealment was placed around the deceased who passed unseen and unacknowledged from the premises. Unacknowledged at least from the other resident's perspective who were denied the opportunity of marking the person's death as they would have in the community outside of long term care residence.

A report by Townsend in the UK in 1962 described the removal of those who were dying to a separate location away from others and that when they died nothing was said, the death was not acknowledged, other residents were denied the opportunity to visit the body, to even say goodbye. This practice persists today. He commented that nursing homes failed to "create a substitute community or a network of social relationships which could sustain a sense of individual purpose or pride". (194)

Modern day research finds it still to be the case that nursing homes fail to recreate the private everyday lifestyle they experienced in their own homes despite more homelike environments.(195, 196) This situation will hopefully change as evidence of the factors that influence the sense of home in nursing homes emerges.(196)

Ireland still has one of the youngest populations in Europe. In the next 30 years though, life expectancy in Ireland is predicted to reach 86.5 years for men and 88.2 years for women. The Irish population aged over 65 years is set to double to 1.4 million (5% of this group reside in long term care) but increases will be even more dramatic in those aged over 85 years, of whom 21% currently reside in long term care.(197, 198) This growth in the older Irish population is

anticipated to place increased demands on the long term care sector. At present, there are approximately 30,000 long term care beds in Ireland. The Economic and Social Research Institute (ESRI) predicted in 2009 that each year over the next decade, approximately 1000 extra (new) long term care beds would need to be sourced to meet this rising accommodation demand, provided the proportion of older people needing long term care remained static at 5%.(197) This rising need for long term care beds is not uniquely an Irish phenomenon, similar challenges present for example in Canada.(199) Increasingly it is in long term care where people spend their last months and years and increasingly where they will die. Thus, it is obviously essential that long term care facilities are enabled to provide the highest quality of end of life care.

The proportion of those aged 65 years and over who died in "residential aged care facilities" in the last decade (2000-2010) varied widely geographically from 3% in Korea to 38% in Iceland and New Zealand.(200) About 25% of the 30,000 deaths in Ireland each year take place in long term care.(174) The growth in the proportion of deaths occurring in long term care is a trend which has been seen worldwide in the United States of America (USA)(201) the United Kingdom (UK)(202, 203), Australia and elsewhere.(204) Considering rising life expectancy, the growing older population and societal changes in Ireland, this trend is likely to continue.

Unfortunately, there is evidence that the end of life care provided in long term care facilities is suboptimal and that the family of nursing home decedents are dissatisfied with the end of life care given to their loved ones.(205-208) Cartwright et al (2006) found although family of nursing home decedents might have been satisfied overall with their loved ones' end of life care, they had concerns about staff's communication, insufficient monitoring of their loved one and lack of knowledge of symptom management amongst staff.(190) Bereaved family also identified deficits in nursing home staff's communication as an issue in a study by Thompson et al.(209)

A study by Reynolds et al found a high prevalence of symptoms at end of life in nursing home decedents: pain (86%), problems with personal cleanliness

(81%), dyspnoea (75%), incontinence (59%), fatigue (52%), low mood (44%), anxiety (31%) and loneliness (21%).(210) Hanson et al also found a high prevalence of pain (47%), dyspnoea (48%), problems with cleanliness 990%) and reduced oral intake (72%).(211) Sandvik et al found moderate to severe pain (60%), sleep disturbance (50%), anxiety (44%), dyspnoea (44%) and depression (33%) were commonly observed symptoms at the time of recognition of imminent death.(188)Hendriks et al found that for residents with dementia despite agitation being the commonest symptom (57-71%) it became less of an issue in the last week of life (35%) in contrast the prevalence of pain (47-68%) and dyspnoea (16-26%) rose in the last week of life (78% and 52% respectively).(212)

Oliver et al found half of all family of deceased nursing home residents described situations where their expectations for care were not met.(213) Themes that emerged were around lack of preparation or information, lack of collaboration between nursing home staff and between them and hospice staff, inadequate communication, and issues with resident's care in particular their pain management.(213)

In addition, a cohort of long term care residents' transfer to hospital in their dying days and end up dying in acute hospitals. This population remains understudied. Houttekier et al found death in long term care was more likely with increasing age but that in 2003 in Brussels, 23.8% of long term care residents ultimately died in hospital.(214) Whilst figures for Ireland are unknown, slightly more than 20% of US, 23% in the UK and 25% of French nursing home residents die in hospital each year.(215-217)

Temkin-Grenner et al found that US nursing home residents who died in hospital were likely to be younger (27.98% of those under 65 years vs 17.7% of those aged 85 years or over), male (22.44% male vs 19.3% female), Black or Hispanic (28.05% and 27.15% respectively compared with 19.49% whites), and more likely to be "short term" rather than "long term" nursing home residents (25.39% short-term vs 17.35% long term). They also found that those with cancer or Alzheimer's disease were less likely to die in hospital than residents

without those conditions (15.24% vs 20.44% for cancer and 14.41% vs 20.68% for Alzheimer's respectively) and that residents with a Do Not Resuscitate order were less likely to die in hospital (13.97% vs 30.28%) as were those with a Do Not Hospitalise order (4.57% vs 20.49%). Patients who received hospice care in their last 30 days grew from 1 in 5 in 2003 to 1 in 3 (31.1%) by 2007. This group were also less likely to die in hospital (2.34% vs 26.78%). They reported that each year between 2003 and 2007, one third of nursing home residents were hospitalised in the last 30 days of their lives and that the cost of these hospitalisations in 2007 alone was $1.6 billion.(215)

It is interesting that in a Belgian study of all deaths of people with palliative care needs in 2008, (n=44,229) the proportion of people who normally reside at home but died in hospital was >60% (and 9% of them died in a nursing home if they had been living alone), whereas the proportion of nursing home residents with similar needs who died in hospital was only 16%.(218) Similar results were found in an Amsterdam based longitudinal study.(219)

Nursing homes are clearly not hospitals, and are therefore not expected to provide care that should be delivered in a hospital setting. Though many transfers of nursing home residents to hospital are appropriate and necessary, a US based study by Saliba et al judged 40% of nursing home residents' admissions to hospital to be inappropriate, a figure which rose to 45% when resident's preferences (e.g. from an advance care directive) were taken into consideration.(220) Using robust assessment methods to gauge the appropriateness and unavoidability of transfer, they estimated 21% of transfers were the result of poor quality of care in the nursing home.(220) A US study published 10 years later found up to 67% of nursing home resident hospitalisations to be potentially avoidable.(221)

This US based study was published in 2000, a more recent UK based study published in 2013 found only 6.7% of admissions of patients with palliative care needs in 2010 were potentially avoidable, most of these were admitted to hospital "out of hours".(222) Consistent with these results, in 2013 a Scandinavian study reported 0.38 hospital referrals per nursing home bed per

year of which 78.6% (n = 282), 7.8% of those admitted died (n=22), and only 7% (n=20) of the admissions were deemed inappropriate. The study noted that the referral rate in the study municipality was lower than the 0.60 referral per bed per year found in neighbouring areas.(223) Regardless the personal cost for residents inappropriately transferred is important, and additionally the study estimated a cost of €6198 per admission (€123,960 per year). However, as more than 92% of those admitted were discharged back to the nursing home, it is also important that focusing on small numbers of inappropriate transfers doesn't deprive the vast majority of appropriate transient care in hospital.

Evidence suggests that long term care residents transferred to hospital are treated similarly to an age matched cohort regardless of the presence of an advance care directive, in terms of the urgency with which they are assessed, number of investigations and interventions in the Emergency Department and admission rates.(87) This suggests that once a patient arrives in the hospital's Emergency Department, wheels are set in motion that tend not to distinguish between patients with and without advance care plans.

There is evidence that nursing home residents who transfer to hospital have worse outcomes than older community dwelling adults.(224) A UK study by Ahearn et al found 33.9% of nursing home residents died in hospital after admission compared with 15.7% of community dwelling adults over 70 years.(224) They also died sooner than their community dwelling counterparts with a median time from admission to death of 5 days compared with 11 days.(224) Of the nursing home residents who survived to discharge, 41.5% of them were either readmitted to hospital or had died by 6 weeks.(224)

But why do nursing home residents end up being transferred inappropriately to hospital?

Three themes emerged in an English study that explored how paramedics make decisions on whether to transfer nursing home residents to hospital when they are nearing the end of their lives.(225) Paramedics found it hard to identify nursing home resident's wishes (something that advance care planning should ameliorate). Paramedics tended to use a best interest reasoning process for

patients lacking capacity, weighing the risks and benefits of transfer to hospital for that resident.(225) However, a third emergent theme was the negotiation that then frequently transpired, where paramedics came under pressure if their decisions were at odds with the preferences of others such as nursing staff or the resident's family.(225)

A New Zealand based study by Gott et al delved into general palliative care professional's views on the 'appropriateness' of patients with palliative care needs being transferred to hospital at the end of life.(226) They mostly framed 'appropriateness' in relation to their own understanding of a good death happening in a familiar place surrounded by familiar faces, though cultural differences were also apparent.(226) They identified several reasons for 'potentially avoidable' admissions, such as family not coping with the patient's care needs - though this may be less of an issue for nursing home residents - the "'rescue culture' of modern medicine" and "financing and availability of community services and practice within aged residential care" are pertinent to a long term care population.(226)

An English study by Seymour et al reported that lack of support from GPs, other agencies and community resources - particularly out of hours - was a barrier to providing quality end of life care, identified by nursing home staff.(217) Other factors included reluctance by GPs to prescribe appropriate medication, the cost of syringe drivers and lack of information about available support and training.(217)

Is it possible to avoid unnecessary or inappropriate transfer of nursing home resident at the end of life? A systematic review by Dwyer et al found potential modifiable factors that could influence burdensome (inappropriate or unwanted) transfer of long term care residents to hospital.(227) Patients with certain diseases including chronic obstructive pulmonary disease (COPD), congestive cardia failure (CCF), diabetes and indwelling devices were found to be more likely to be hospitalised.(227) For COPD and CCF unexpected hospitalisation is not uncommon as their disease trajectory is peppered with unpredictable acute exacerbations which may be difficult to manage in a

nursing home setting, particularly out of hours when staffing levels are reduced and access to on call physician services may be reduced. Patients with advance care plans were less likely to be transferred to hospital.(227) Gozalo et al also found the presence of a written advance care directive, Do Not resuscitate order or Do not Hospitalise order reduced the risk of a burdensome transfer among 469,411 US nursing home residents with advanced cognitive impairment.(228) Dwyer et al found that long term care facilities with poorer staff to patient ratios, and those that were "for profit" had higher transfer rates.(227)

Why do long term care residents die in hospital? What is hoped to be achieved by such moves? Reasons might include the hope of better end of life care provision; that hospital staff and resources might be better equipped to meet the resident's needs; it may be simply more convenient for nursing home staff given that end of life care can be time consuming and exhausting; it may be an attempt to maintain facility mortality statistics or fear of litigation for not having done "everything possible" to maintain the resident's life, irrespective of what their wishes might have been.

What can be done to prevent inappropriate transfer to hospital: advance care planning, and empowering long term care staff to provide high quality end of life care?

Nursing home and Emergency department staff believe that family often influence the decision to transfer a nursing home resident to hospital or not.(229) Stephens et al found four main drivers influencing family's sense of crisis at a change in their loved one's condition, these included: insecurities with the nursing home care; families being unprepared for the resident's death; lack of advance care planning and lack of communication and agreement with regard to the goals of care.(229) Other studies have also found advance care planning to reduce terminal hospitalisation rates for nursing home residents.(139, 230-233) Similarly studies of nursing homes with increased palliative care provision show reduced terminal hospitalisation rates.(234) Interventions to improve the quality of end of life care for long term care residents, such as the Gold Standards Framework in Care Homes in the UK have

also shown reductions in terminal hospitalisation of residents.(235) This is key, as it is important to have an understanding of what is to be reasonably expected of transferring a resident at the end of life, to an acute hospital. In Ireland, such a transfer to hospital in the current climate means a high likelihood of significant time spent on an Emergency Department trolley.

There is evidence that nursing homes with staff who have better palliative care knowledge are more likely to have documented that a resident has been assessed to be likely to die within the next 6 months.(236) Such nursing homes are less likely to use restraints, tube feeding, have residents hospitalised in the last 30 days of life and less likely to have residents who die in hospital.(236, 237)

It would appear then that advance care planning and improving communication, palliative care knowledge and end of life care skills are potentially beneficial in a nursing home population in improving end of life care. There are many challenges in implementing any of these elements in this setting, not least the poor culture of advance care planning in Ireland.

1.7 Conceptual Framework

As discussed there is evidence of suboptimal end of life care in the long term care setting internationally, but also research suggesting that there is the potential to improve end of life care outcomes through increased advance care planning and augmenting the palliative care capacity of long term care staff.

1.7.1 **Theoretical underpinning**

Published international research contributed to the conceptual framework of this thesis' research in some key ways. Based on published research it would appear that:

- If consistent with international research, it was anticipated that end of life care in long term care in Ireland would be suboptimal, that there would be unmet palliative care needs for residents at the end of life and that relatives would perceive there to be inadequacies in this care:

- Primarily it is general practitioners, nursing staff and care workers who deliver general palliative care and end of life care for most people dying in the long term care setting in Ireland. International research suggests that the resources, skills and knowledge to provide such end of life care to a high standard is often lacking.(217, 238, 239) Internationally many people dying in long term care have unmet palliative care needs (210, 240) and bereaved carers are often dissatisfied with their relatives' end of life care.(241, 242)
- A recent Irish audit of end of life care in acute and community hospitals (many community hospitals provide long term care) found that although we compare favourably with hospitals in the US, UK and France, significant weaknesses exist, and consequently Irish quality standards for end of life care in hospitals were published.(58, 170)

- If consistent with international research it was expected that long term care staff would have suboptimal knowledge and skills in providing palliative and specifically end of life care and would also therefore have educational needs in this area.
- It was hypothesised that an educational program in palliative care, focusing on end of life care, would improve staff knowledge and confidence in providing high quality end of life care.(243)
    - Two Cochrane systematic reviews found poor evidence to support the use of end of life care pathways or interventions to improve palliative care for older people in long term care.(244, 245) The paucity of supporting evidence for the latter, was primarily due to a lack of randomised controlled trials, quasi-experimental or controlled before and after studies; most research in this area is descriptive or qualitative.(245) The review did identify a study that suggested a complex palliative care intervention incorporating a palliative care educational program may improve end of life care and improve documentation of advance care plans(246)

- It was expected that at baseline few residents in long term care in Ireland would have completed advance care directives or advance care plans.
    - In the United States of America where advance care directives are more established legislatively, about 70% of those who die have an advance care directive, but Irish knowledge of advance care directives and issues relating to end of life care, is poor.(248)(89) In a recent nationwide survey, 71% had never heard of an advance care directive, and only 5% claimed to have drafted one.(89) Advance care directives are not yet part of Irish culture.
    - In the absence of advance care plans it was anticipated that most end of life decision making would take place when the resident had become critically unwell and would likely be made without the input of the resident.
- It was anticipated that similar to other countries, a considerable proportion of long term care residents would transfer to hospital in their last few days and weeks of their lives and likely often die there, some having transferred inappropriately or even when clearly dying.(215-217) The proportion of terminal transfers in Ireland was unknown.
- There is evidence that ACDs and advance care planning can improve satisfaction with end of life care.(247)
    - It was hypothesised that use of advance care directives, advance care planning or end of life care planning i.e. the Let Me Decide intervention would improve
        - Knowledge of residents' wishes
        - Improve anticipatory planning for end of life care
        - Prevent inappropriate transfers to hospital
        - Reduce the incidence of long term care residents dying in hospital when their care needs could have met in the long term care setting

At the outset of this research it was noted that many initiatives to improve end of life care in long term care, such as the Gold Standards Framework in Care

Homes (145) in the UK, contained a prompt for advance care planning, but didn't use specific advance care planning programs, such as "Preferred Priorities for Care" (248), "Respecting Patient Choices"(249), "Think Ahead" or the "Let Me Decide" program. There is little published on the use of such initiatives in Ireland, and nothing on advance care directive implementation in Irish long term care. Researchers elsewhere have looked specifically at initiatives such as Gold Standards Framework in Care Homes or the use of advance care directives in long term care but investigating the effects of using a combined end of life care educational initiative and a specific systematic advance care directive/advance care planning program such as "Let Me Decide", is relatively novel. (250, 251)

Systematic reviews of advance care directives have focused on advance care directive completion rates and surrogate decision maker accuracy, rather than on the effects on the quality of end of life care; the latter was the subject of an ongoing Cochrane review.(2, 245, 252-254) A protocol for this review was published with Cochrane by Houttekier et al in 2012, but was subsequently withdrawn without results being published.(255, 256)

The outcomes measured in studies in this area have tended to be at an organisational rather than a patient level. For example, although studies measured whether pain was assessed, few looked at whether pain was treated satisfactorily. There is also a dearth of information on the cost effectiveness of advance care directives, (257, 258) and even more so palliative care initiatives.

If a combined advance care planning and palliative care educational initiative proved successful to improve the dying experience in long term care, this program could be disseminated broadly to improve end of life care and the quality of dying elsewhere.

1.8 Research aim and objectives

The overall aim of this thesis is to investigate the feasibility of systematically implementing an advance care planning program in a long term care setting in Ireland combined with a palliative care educational initiative tailored to the

needs of each research site, and its effect on the death and dying experience of residents.

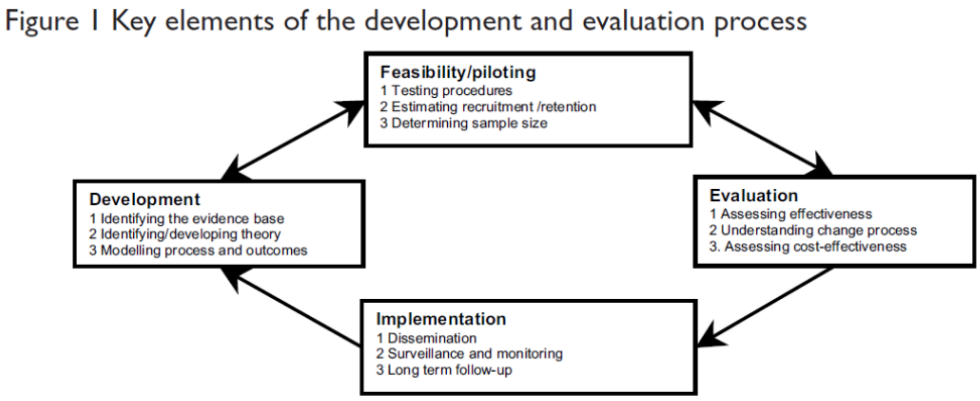
In particular the objectives are:

1. To explore Irish healthcare professionals' knowledge, skills and attitudes of advance care planning, end of life care and medical decisions making for older adults, particularly those with diminished cognition.
2. To examine the changes that would be required to adapt an existing advance care planning program such as the "Let Me Decide" program for use in an Irish long term care setting. This program was developed for use in Canada by Professor William Molloy and will be described in Chapter 3.
3. To investigate the palliative care educational needs of long term care staff, their confidence in delivering end of life care and their experience, attitudes and perceived barriers to advance care planning.
4. To analyse the effect of providing training in general palliative care and advance care planning alongside the systematic implementation of the Irish adapted "Let Me Decide" program on:
    a. Long term care staff educational needs, knowledge, attitudes and confidence in delivering end of life care and advance care planning.
    b. The dying experience and end of life care provided to dying long term care residents before and after implementation of the complete program.
    c. The feasibility and acceptability of advance care planning in an Irish long term care setting where there is not yet a culture of advance care planning but where there is a high prevalence of impaired cognition and frailty.
    d. The challenges that may be encountered in introducing the initiative and embedding it in the care culture of the long term care organisations

1.9 Rationale for the study design

Ideally a randomised controlled trial would be used to evaluate the program used in this study, however this complex intervention was still in the feasibility and piloting stage of development at the outset of the research described in this thesis. Therefore, this is a feasibility study of a complex intervention for the simultaneous implementation of an advance care planning program and a palliative care education initiative in the long term care setting in Ireland. A before-after study design was used across the study sites and a stepped wedge cluster randomisation approach was taken. The intervention development followed the Medical Research Council's framework for complex interventions.(259) Stage 1 involved performing a detailed literature review and establishing baseline practice and knowledge and then adaptation of an existing advance care planning program, "Let Me Decide" for use in Ireland. Stage 2 of the intervention development was the feasibility testing.

Figure 1.2 Key elements of the development and evaluation process from the Medical Research Councils framework for complex interventions



This feasibility testing was needed for several reasons. Firstly, there was not a clear evidence base from Ireland as to how acceptable advance care planning would be in the long term care setting.

Based on a study finding that only 5% of the Irish general population had drafted an advance care directive or advance care plan,(89) the limited existing evidence suggested that there would be a low prevalence of these documents amongst long term care residents in Ireland compared with other countries.

There was no Irish evidence on what the likely uptake of advance care planning in the long term care population would be. It was also likely that the intervention and outcome measurement methodology may change over the course of the study as it became more refined.

Secondly, the proposed advance care planning intervention needed to be adapted and modified for use in Ireland. This required exploration of current practice in Ireland in relation to advance care planning, and exploration of the education and training needs in long term care. These results are presented in chapters 2, 4 and 5.

Thirdly although the Let Me Decide program was established elsewhere, the palliative care part of the intervention had not been tested Stage 3, the randomised controlled trial resulting from this study, is underway, and will be introduced briefly at the end of the thesis.

1.10 Ethical Approval

Ethical approval for this project has been granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

1.11 Outline of Chapters

Chapter 2 presents results on the views and knowledge of healthcare professionals on advance care directives and on medical decision making for those without capacity and without an advance care directive based on a large three country survey. It describes healthcare professionals' confidence, training and attitudes on palliative care and more specifically end of life care and medical decision making for those lacking capacity at a time when death approaches.

Chapter 3 describes the development of the Let Me Decide advance care planning program and associated advance care directive for use in an Irish long-term care setting. This adaptation of the Let Me Decide program was necessary due to significant differences in legislation between Ireland and Canada, where the program originated. This chapter also describes the implementation

strategy for the program, in addition to the logistical, practical and change management issues encountered.

Chapter 4 presents the ethical challenges experienced in implementing the Let Me Decide program in three long term care facilities in Ireland.

Chapter 5 describes the educational needs, knowledge and attitudes of the healthcare staff in the pilot long term care nursing homes, comparing results of staff questionnaires completed before implementation of the program and subsequent to its establishment in the nursing homes. This chapter also describes the general palliative care educational program developed taking staff's educational needs into consideration, and outlines how this educational program was delivered.

Chapter 6 presents a review of the literature specifically around outcome measures for quality of end of life and quality of dying, and presents the justification for the final choice of outcome tool used in the study described in chapters 7 and 8.

Chapter 7 reports on the changes that occurred in care planning for end of life care, the location of death and hospitalisation rates in the pilot homes with introduction of the Let Me Decide program and the palliative care educational iniative. It also examines the feasibility and acceptability of end of life care planning in long term care where there is a high prevalence of cognitive impairment amongst residents.

Chapter 8 outlines the death experienced by residents during the study period and the quality of dying, from the perspective of the deceased resident's family. This chapter goes on to examine for differences between the period before and after implementation of the Let Me Decide advance care planning program and accompanying palliative care educational intervention.

Chapter 9 describes the use of medication at end of life in the pilot study nursing homes before and after the program's initiation.

Chapter 10 concludes this thesis by summarising the results of the feasibility study and its implications for end of life care in the long-term care setting in Ireland. It also specifically explores “death anxiety” and other important influencers on change management and delivery strategies to aid broader, sustainable use of the program in a general setting, outside the context of a research study.

Chapter Two:
Baseline knowledge and attitudes on advance care directives, training and confidence in providing palliative care and end of life treatment choices

Research from this chapter has been published:

McGlade C, Timmons S, Coffey A, Weathers E, Pope G, Goggin C, Molloy W. The influence of healthcare professional's confidence and training in palliative care on treatment choices at the end-of-life. *Irish Journal of Medical Science* 2012; 181(S7), S292. Poster Presentation at the Irish Gerontological Society 62nd Annual and Scientific Meeting 2012.

McGlade C, Molloy W, Timmons S. Who would doctors wish to make end of life decisions for them in the event of mental incapacity? *Irish Journal of Medical Science* 2011 180(S10): S359. Poster Presentation at the Irish Gerontological Society 61st Annual and Scientific Meeting 2011.

McGlade C, Molloy W, Timmons S. Awareness and Perceptions of Advance Care Directives Amongst Healthcare Professionals. *Irish Journal of Medical Science* 2011 180(S10): S359-36. Poster Presentation at the Irish Gerontological Society 61st Annual and Scientific Meeting 2011.

Related work taking data from the nursing cohort has been published as:

Coffey A, McCarthy G, Weathers E, Friedman MI, Gallo K, Ehrenfeld M, Itzhaki M, Chan S, Li WH, Poletti P, Zanotti R, Molloy DW, **McGlade C**, Fitzpatrick J.J. Nurses' preferred end-of-life treatment choices in five countries. *International nursing review*. 2013 Sep 1; 60(3):313-9.

Coffey A, McCarthy G, Weathers E, Friedman MI, Gallo K, Ehrenfeld M, Chan S, Li WH, Poletti P, Zanotti R, Molloy DW, **McGlade C**, Fitzpatrick JJ, Itzhaki M. Nurses' knowledge of advance directives and perceived confidence in end-of-life care: a cross-sectional study in five countries. *Int J Nurs Pract.* 2016 Jun;22(3):247-57.

2 Baseline: knowledge and attitudes on advance care directives, training and confidence in providing palliative care and end of life treatment choices

This chapter presents data from a study of healthcare professionals in Ireland, Canada and the UK. The first section of this chapter focuses on their knowledge and attitudes on advance care directives and medical decision making for those lacking capacity. The first section also reports the personal advance care directive completion rates of these healthcare professionals.

The second section of this chapter describes further results from the same study but focuses on the palliative care and end of life care training and confidence of this cohort of healthcare professionals; the end of life care choices they would make in a hypothetical scenario; and the factors that might influence their decisions in the scenario of an older patient with diminished decision-making capacity.

2.1 Advance Care Directive Completion and Medical Decision Making for those lacking Capacity: Healthcare Professionals' Perspectives

2.1.1 Introduction

In recent decades, medical advances have progressed the treatment of many diseases once considered fatal, sustaining life where death may once have been certain. However, such prolongation of life is not always appropriate, in a patient's best interests, or indeed what the patient would have wanted. Medical paternalism has been replaced with a growing respect for patient autonomy and involvement in medical decisions. Unfortunately such involvement, is not always possible e.g. through diminished decision-making capacity. This, combined with the fear of unwelcome treatment has prompted the evolution of advance care directives. An advance care directive, also known as a 'Living will', is a statement about the type and extent of treatment an individual would want in the event they become unable to make their own healthcare decisions.

Specific legislation relating to advance care directives has existed in many parts of the world for decades.(260) In the United States, where all 50 states have enacted advance care directive legislation, about 70% of all those who die have an advance care directive.(100, 261) This high prevalence of advance care directives may be due to promotion of advance care planning from the *Patient Self Determination Act (1991)* that requires all government funded institutes to inform hospitalised patients of their legal right to make healthcare decisions and complete an advance care directive. In Western Canada the *Personal Directives Act* came into effect in 1997. There is less experience with advance care directives in the United Kingdom (UK) where they only have a legal basis since 2009 when the *Mental Capacity Act, 2005* came into effect. Ireland lacked a legislative framework for advance care directives until the *Assisted Decision-Making (Capacity) Act* was enacted in 2015. This Act has not yet come into full effect. Regardless, it has long been expected that a valid advance care directive would be upheld, if challenged.(73, 262)

Long anticipated legislation, recent Irish publications and the legal validity for advance care directives in the UK have made advance care directives topical in Ireland.(260, 263) Despite this, advance care directives are not yet part of Irish culture where only 5% of people claim to have drafted one.(89) A nationwide survey of the Irish public (n=667) showed poor awareness of advance care directives (84% knew nothing of them) and "living wills" (only 25% of respondents claimed to know much about them).(89) Knowledge of responsibility for healthcare decisions in the event of mental incapacity was equally poor. The majority of those surveyed mistakenly believed that in the absence of an advance care directive or Wardship of Court, families would have legal authority to make treatment decisions for incompetent patients, which is not legally the case in Ireland.(89, 264)

It is important for healthcare professionals (HCPs) to understand this area as many are involved in care planning and decision-making for those with diminished capacity. In some countries, such as Ireland, healthcare professionals may have responsibility for such decisions. Yet, little is known of

healthcare professionals knowledge, attitudes or perceptions of advance care directives or medical decision-making for legally incompetent older adults.

This study aimed to assess healthcare professionals' knowledge and perceptions of advance care directives and medical decision-making for people with diminished capacity in Ireland, a country where advance care directive legislation has not yet been applied, and countries with existing advance care directive legislation such as the UK or Canada, where advance care directives are embedded as part of the care culture. The study also describes personal advance care directive completion rates amongst participants.

2.1.2 **Methods**

A comparative, descriptive survey design was used to assess participants' knowledge and perceptions of advance care directives and medical decision making for people with diminished capacity in Ireland, Canada and the United Kingdom.

Participants

The following disciplines were included: registered medical practitioners including both consultant and non-consultant hospital doctors, general practitioners, registered nurses and midwives, and allied healthcare professionals (AHPs). Senior medical, nursing and midwifery students who were in their final or penultimate years were also invited to participate. The study sample was recruited using convenience sampling of attendees of local and international clinical and educational meetings and conferences in Ireland, Canada and the United Kingdom.

Ethics

Ethical approval was received from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. This study was conducted in adherence with the Declaration of Helsinki (1975). Completion of the survey implied consent. Data collection maintained respondents anonymity and non-respondents were non-identifiable. This was of particular importance for the students.

Procedure

Prior to survey completion, participants received an explanation of advance care directives (ACDs) either in verbal or written format which is described in figure 2.1. Data were collected using a modified version of a survey instrument developed by Molloy *et al*, which has been used in previous international research. (265) The content validity of the modified survey was evaluated by two consultant geriatricians (one a medical professor, the other an academic senior lecturer), a nursing academic senior lecturer, and a specialist registrar. All had considerable experience in geriatric and general internal medicine, end-of-life care and instrument development.

Figure 2.1: Description of Advance Care Directives

Figure 2.1: What is an Advance Care Directive?

Advance Care Directives are sometimes called *living wills* or *advance directives.*

An advance care directive is a written statement regarding your wishes for future healthcare. An advance care directive can be made by anyone who has the capacity (i.e.is "compos mentis") to do so. An advance care directive is then **only** used if at some point in the future the person becomes incapable of making health care decisions for themselves (e.g. through dementia or stroke). In an advance care directive you have the option of nominating a *proxy* to make decisions on your behalf in the event of you becoming incompetent to.

Advance care directives can cover areas such as Cardiopulmonary Resuscitation (CPR), PEG (percutaneous endoscopic gastrostomy) or NG (nasogastric) tube feeding, life sustaining treatments, organ donation etc. They can be used to specify what you would or would not want in your current state, and in what states (eg permanent vegetative state, end stage dementia etc) you might not want certain treatments (specified by you) such as CPR.

Basic demographic details such as gender, age, occupation, years in practice and the proportion of their work involving older people were recorded. Participants were also asked whether they already had completed a will or an advance care directive for themselves. Their views on advance care directives, end-of-life

care and medical decision-making for an older adult with diminished mental capacity were sought. For questions of attitude, participants were asked to rate their agreement or disagreement with statements using a Likert scale: 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree or 5 = strongly agree.

Data Collection and Analysis

Data were analysed using IBM SPSS Statistics (version 20, SPSS Inc). Descriptive statistics were used to report the results. Median values were reported with their interquartile range (IQR). For non-parametric continuous data the Mann-Whitney U test or Kruskal-Wallis test was used, as appropriate, to compare groups. *Post hoc* Bonferroni adjusted Mann-Whitney tests reported at a 0.0167 level of significance were used to compare results between countries. Multivariate logistic regression analysis was conducted to examine for associations between respondents' age and country of origin with ACD completion.

Previous studies of the general population in Canada and Ireland estimated advance care directive completion rates of 19-44% and 5% respectively.(89, 92) If healthcare professionals' advance care directive completion rates were similar to the general population in Canada and Ireland, at approximately 30% and 5% respectively, a sample size of n=28 would be needed to detect a difference in proportions of this magnitude with 80% power, at an alpha significance level of 0.05.

Unless otherwise stated, results were reported after responses were re-categorised as follows; "strongly disagree" and "disagree" responses were combined to form the category "disagree"; "strongly agree" and "agree" were combined to form the category "agree"; "neutral" responses were not re-categorised. Differences in categorical variable responses were tested using the Chi Square test, at 0.05 level of significance. As some results were more meaningfully reported for healthcare professionals rather than students, subgroup analysis was performed looking at healthcare professionals alone. Results labelled as "HCP" only include healthcare professionals and exclude students.

2.1.3 **Results**

Completed surveys were returned by 959 respondents; their demographic profile is summarised in Table 2.1. The median age was 33 years and females represented 69% of the group. Respondents had a median of 14 years of clinical experience. There were 293 doctors (31%), 356 nurses (37%), 42 nursing students (4%), 208 medical students (22%), and 46 allied healthcare professionals (AHPs) (5%). There were 107 (11%) respondents surveyed in Canada, 95 (10%) in the UK and 757 (79%) in Ireland.

Differences between groups

The age of healthcare professionals and years of experience were significantly different between countries. Canadians were older than respondents from Ireland (U = 8453, r = -0.39, p < 0.001) or the UK (U = 769, r =-0.70, p < 0.001) and had more years of clinical experience than healthcare professionals in Ireland (U = 13484, r = -0.30, p < 0.001) or the UK (U = *1371,* r = -0.60, p <0.001). The difference in age and clinical experience between Irish and UK respondents was less marked ((U = 15392, r = -0.19, p <0.001) and (U = 14029, r = -0.22, p <0.001) respectively).

Knowledge and Experience of Advance Care Directives

Table 2.2 depicts respondents' knowledge and experience of advance care directives. The majority (80%, n=764) of respondents knew about advance care directives prior to being surveyed. Not surprisingly, the lowest level of awareness was amongst the student group. However, student awareness (69%, n=173) compared favourably with that of qualified healthcare professionals (84%, n=591). Knowledge of advance care directives was greatest in those countries with established legislation for advance care directives, and was best in the UK where legislation was introduced relatively recently. In the UK, 96%, (n=87) of qualified healthcare professionals had prior awareness of advance care directives, compared with 85% (n=88) in Canada, and 82% (n=416) in Ireland.

Although prior knowledge of advance care directives was high, experience with advance care directives in practice was less marked.

Table 2.1. Demographic profile of respondents*

	Total (n=959)	**Canada** (n=107)	**Ireland** (n=757)	**UK** (n=95)	
Age in years, *median (IQR)*					**H Statistic**
Total group	33 (24-47)	55 (30-82)	31 (18-75)	32 (26-62)	
HCP	40 (31-51)	55 (47-61)	39 (31-49)	33 (26-39)	H(3)=115.75,
Student	19 (19-22)	30 (n=1)	19 (18-42)	24 (23-24)**	p<0.0001
Gender, n (%)					**χ^2 Statistic**
Male	287 (31%)	47 (44%)	203 (27%)	37 (39%)	X^2= 15.44,
Female	635 (69%)	57 (53%)	520 (69%)	58 (61%)	p<0.0001
Occupation, n (%)					
Doctor	293 (31%)	62 (58%)	165 (22%)	66 (70%)	
Nurse	356 (37%)	34 (32%)	309 (41%)	13 (14%)	
AHP	4 (5%)	5 (5%)	28 (4%)	13 (13%)	
Student	250 (26%)	1 (1%)	246 (32%)	3 (3%)	
HCPs Years of Experience, median (IQR)* **					**H Statistic**
	14 (7-25)	28 (18-33)	14 (7-25)	7 (2-13)	H(3)=90.9, p<0.0001
HCPs Proportion of work involving older people, n (%) * **					
<20%	75 (11%)	12 (11%)	61 (12%)	2 (2%)	
21-40%	94 (13%)	26 (25%)	65 (13%)	3 (3%)	
41-60%	131 (19%)	25 (24%)	93 (18%)	13 (14%)	
61-80%	132 (19%)	12 (11%)	95 (19%)	25 (27%)	
>81%	240 (36%)	24 (23%)	167 (33%)	49 (53%)	

* Percentages may not equal 100% due to some missing or non-applicable data in individual categories.

** N=3 for this group

*** HCP group, this excludes students

Table 2.2: Knowledge and Experience of ACDs in different groups

	Total N (%)	**Canada** N(%)	**Ireland** N(%)	**UK** N(%)
Proportion with prior knowledge of ACDs n (%)				
Total HCPs	591/703 (84)	88/104 (85)	416/508 (82)	87/91 (96)
Doctor	262/293 (89)	54/62 (87)	142/165 (86)	66/66 (100)
Nurse	282/352 (80)	27/33 (82)	243/307 (79)	12/12 (100)
AHPs	38/46 (83)	4/5 (80)	25/28 (89)	9/13 (69)
Students	173/250 (69)	1/1 (100)	169/246 (67)	3/3 (100)
Total group	764/953 (80)	89/105 (85)	585/754 (78)	90/94 (96)
Proportion of HCPs with "any previous experience of ACDs", n (%)				
Total HCPs	151/698 (38)	58/102 (57)	50/506 (30)	59/90 (66)
Doctor	151/289 (52)	40/59 (68)	65/164 (40	46/66 (70)
Nurse	92/351 (26)	14/34 (41)	68/306 (22)	10/11 (91)
AHP	20/46 (43)	2/5 (40)	15/28 (54)	3/13 (23)
Proportion of HCPs who had previously dealt with a patient with an ACD n (%)				
Total HCPs	249/699 (26)	61/103 (59)	125/505 (25)	59/91 (65)
Doctor	143/292 (49)	40/61 (66)	55/165 (33)	48/66 (73)
Nurse	81/350 (23)	16/33 (49)	57/305 (19)	8/12 (67)
AHP	16/46 (35)	2/5 (40)	11/28 (39)	3/13 (23)
If respondent had no ACD, would they complete one for themselves, n (%)				
Total HCPs	536/638 (84)	66/72 (92)	412/479 (86)	58/87 (67)
Doctor	208/265 (78)	38/43 (88)	129/160 (81)	41/62 (66)
Nurse	287/321 (89)	24/24 (100)	254/285 (89)	9/12 (75)
AHP	36/42 (86)	2/2 (100)	26/27 (96)	8/13 (62)
Students	192/246 (78)	1/1 (100)	190/242 (79)	1/3 (33)
Proportion of respondents who have a will n (% of that country's respondents)				
Total HCPs	324/698 (46)	74/102 (73)	216/505 (43)	26/91 (28)
Doctor	141/288 (49)	49/60 (82)	71/162 (44)	21/66 (32)
Nurse	151/353 (43)	20/34 (59)	127/307 (41)	4/12 (33)
AHP	17/45 (38)	¾ (75)	13/28 (46)	1/13 (8)
Students	9/249 (4)	1/1 (100)	8/245 (3)	0/3 (0)
Proportion of respondents who have an ACD, n (% of that country's respondents)				
Total HCPs	44/696 (6)	27/101 (27)	14/504 (3)	3/91 (3)
Doctor	21/290 (7)	16/59 (27)	2/165 (1)	3/66 (5)
Nurse	19/349 (5)	8/33 (24)	11/304 (4)	0/12 (0)
AHP	3/45 (7)	2/5 (40)	1/27 (4)	0/13 (0)
Students	0 (0)	0 (0)	0 (0)	0 (0)
"Total HCP" figures include respondents who failed to give their profession				

More respondents had engaged with patients with an advance care directive in the UK or Canada, where 65% (n=59) and 59% (n=61) of healthcare professionals had experienced patients with advance care directives respectively. In contrast, only 25% (n=125) of the Irish healthcare professional group had such familiarity.

Regardless of previous knowledge or experience of advance care directives, the majority (83%, n=772) of those surveyed reported that they would complete an advance care directive for themselves. Despite this keenness to complete one, very few had actually done so. No students had completed an advance care directive. Most of the healthcare professionals who had an advance care directive were in Canada (n=27) where 27% (95% confidence interval (95%CI): 18-36%) of respondents had one. Advance care directive completion rates for healthcare professionals were only 3% in the UK and Ireland (UK: n=3, 3%, 95% CI: -0.5 – 6.5%) (Ireland: n=14, 3%, 95% CI: 1.5-4.5%).

Table 2.3: Respondents with a completed Advance Care Directive by country

Respondents who had already completed an Advance Care Directive for themselves (n)						
	n /total (%)		OR (95% CI)	P value	Age adjusted OR (95% CI)	P value
Ireland	14/749	(3%)	1.00		1.00	
UK	3/94	(3.2%)	1.83 (0.51 – 6.55)	0.352	2.27 (0.61 – 8.37)	0.22
Canada	27/102	(26.5%)	19.83 (9.58 – 41.03)	<0.0001	6.79 (3.06 – 15.05)	<0.0001

Views on Advance Care Directives

The vast majority of participants, (91%, n=869) agreed that advance care directives are a good idea, 7% were neutral (n=69) and 2% disagreed (n=15). This opinion differed little between countries and neither gender (91% males vs 92% females), occupation (91% doctors, 93% nurses, 90% students, 89% AHP) nor student status appeared to affect the result.

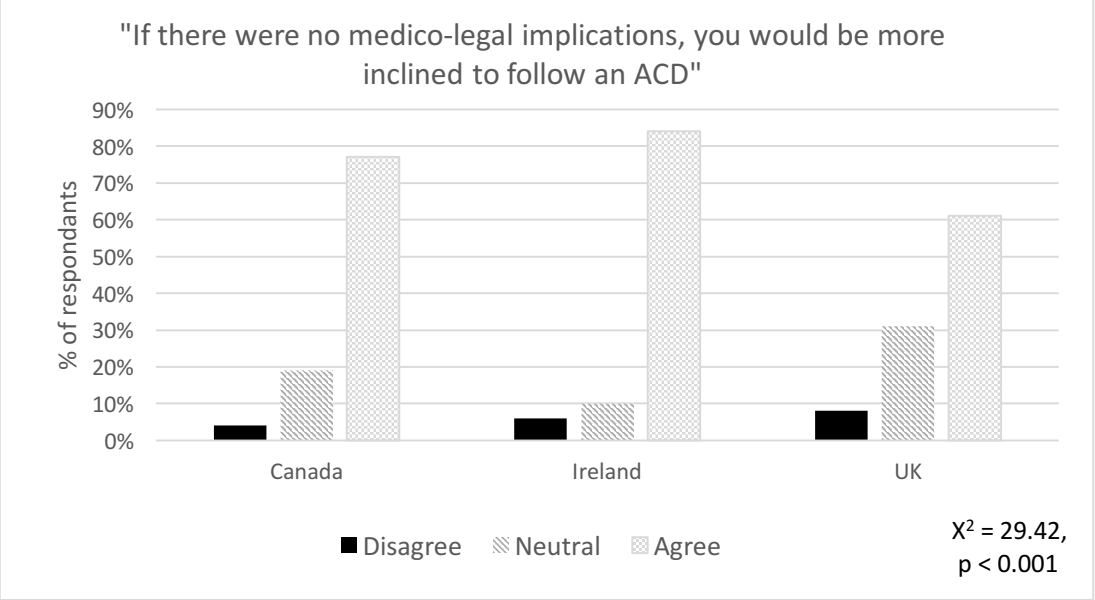
Most respondents (74%) would recommend people to complete an advance care directive, however the degree of certainty in this recommendation differed between countries (see Table 2.4). Canadians appeared most certain of their convictions, whilst those in the UK were most uncertain. Neither age, occupation, nor gender appeared to affect the result.

Table 2.4. Respondents agreement with the statement: "Would you recommend people to complete an advance care directive"

		Disagree % (n)	**Neutral % (n)**	**Agree % (n)**	
Total Group	(n = 950)	3.6% (34)	22% (210)	74% (706)	
Students	(n = 249)	3.6% (9)	24% (59)	73% (181)	
HCP	(n = 701)	4% (25)	22% (151)	75% (525)	
Canada	(n = 103)	1% (1)	8% (8)	91% (94)	$\chi^2 = 30.7$, $p<0.0001$*
Ireland	(n = 752)	4% (27)	22% (167)	74% (558)	
UK	(n = 95)	6% (6)	37% (35)	57% (54)	
* Fisher exact test result rather than Pearson Chi Square test result quoted					

Most healthcare professionals (79%, n=549) felt comfortable following an advance care directive but this comfort was more evident in Canada (93%, n = 95), compared with the UK (78%, n=72) or Ireland (76%, n=382). The highest prevalence of HCPs who felt uncomfortable following an advance care directive was in Ireland (7% (n=36) vs 3% (n=3) in the UK and 1% (n=1) in Canada). The fear of medicolegal implications for following an advance care directive may have been one of the factors impacting these figures (see Figure 2.2). Although only 6% (n=40) of all HCPs felt uncomfortable following an ACD, 68% (n=27) of them agreed they would be more inclined to follow one were there no medicolegal implications for doing so.

Figure 2.2 Respondent's agreement with the statement: "If there were no medico-legal implications, you would be more inclined to follow an ACD"



Attitudes on Compliance with Advance Care Directives

Most respondents (66%, n=615) felt that if they made an advance care directive, that a doctor would follow it. Doctors and medical students more than other disciplines, felt that a doctor would follow an advance care directive (nurses, nursing students and AHP 75%, n=370 vs 55%, n=238 respectively).

Were respondents no longer capable of making medical decisions for themselves and had no advance care directive, only 32% (n=311) felt they would get the type of treatment they would have wanted. There were concerns in over half of respondents (53%, n=506) that they would get treatment inconsistent with their wishes. Some 25% (n=243) felt they would be treated too aggressively, while 7% felt they would not be treated aggressively enough.

Most respondents, 88% (n=848) were happy to act as a proxy for a friend, if asked to do so, a role that respondents in the UK (95%, n=90) appeared to be more comfortable with than those in Ireland (89%, n=674) or Canada (79%, n=84).

Decision-makers in the event of incapacity

Many respondents (61%, n=581) believed that if they lost capacity, their family would have difficulty making decisions on their behalf. Yet, they were comfortable with their family making a "directive" expressing what the family wished for their care (62%, n=587). The majority thought the use of an advance care directive alone (86%, n=802) or an advance care directive in conjunction with a proxy decision maker (90%, n=836) would result in treatment choices that would be most consistent with what they would want. Most felt that without an advance care directive, their family (80%, n=750) or preferably their family and doctor together (84%, n=796), would make treatment choices consistent with the respondent's wishes. Only half of respondents agreed (n=462) that their doctor acting alone, without consulting their family, would make choices consistent with the respondent's wishes. As a group, doctors and medical students differed from nurses, nursing students and allied health professionals in this regard, as they seemed more likely to consider that doctors would act well in making decisions on their behalf (61% doctors and medical students vs 37% of nurses, nursing students and AHPs)

Legality of medical decision making for those lacking capacity

Participants (using free text responses) were asked to reply to the following statement: "if you were to become mentally incapable and you had no advance directive, who legally, can make healthcare decisions for you?" They were also asked who they felt should make such decisions. Healthcare professionals were more likely than students to correctly identify who had legal responsibility (40%, n=277 of HCPs vs 9%, n=23 of students; $\chi^2 = 77.6$, $p<0.001$). The proportion of HCPs correctly identifying who legally makes these decisions differed between countries (highest in Canada, lowest in Ireland) and between disciplines (highest for doctors and lowest for nurses). The results are presented in Table 2.5 and take into consideration what is legal in each country.

When asked who should make medical decisions for those lacking the ability to do so, the majority of respondents (74%, n=688) wanted their families to have the ultimate decision. Canadians were more likely to want their family to make decisions on their behalf (88% (n=87) vs 72% (n=601) in the UK or Ireland). UK

doctors differed from all other disciplines in each country; they were the only group where the majority (59%, n=38 of 64) felt their doctor rather than their family should make decisions on their behalf, compared with an average of only 18% in other groups (range 5-25%).

Table 2.5 Proportion of HCPs correctly identifying the legal medical decision makers for people lacking capacity

HCPs correctly identifying legal medical decision makers for an incapacitated adult				
	Total % (n)	Canada % (n)	Ireland % (n)	UK % (n)
All HCPs	40% (277)*	88% (89)	25% (128)	67% (60)
Doctors	55% (156)	86% (50)	35% (56)	77% (50)
Nurses	28% (97)	88% (30)	21% (63)	31% (4)
AHP	42% (19)	100% (9)	25% (9)	50% (6)
* 5 HCPs failed to give their occupation				

2.1.4 **Discussion**

This study presents the findings of a questionnaire surveying the perceptions and understanding of healthcare professionals in three countries. It found a high level of awareness of advance care directives among healthcare professionals (83%) and students (69%) and an overwhelmingly positive attitude to them. This is consistent with the findings of other research.(79, 266-269) Healthcare professionals in countries with advance care directive legislation (Canada and the UK) had greater knowledge and experience of advance care directives than Ireland. Awareness in the Irish cohort compares well however with other countries without established legislation e.g. Korea, where only 40% of physicians and 56% of nurses were familiar with advance care directives.(270) It is nevertheless disappointing that nearly one in five healthcare professionals were unfamiliar with advance care directives. That knowledge of advance care directives was greatest in UK respondents may relate to the recent introduction of legislation there - making it topical - but equally could be influenced by the higher proportion of UK respondents being involved in care of older people, for whom end-of-life care planning is more commonplace.

It is intuitive that healthcare professionals working in Canada or the UK had more experience of caring for patients with an advance care directive. A survey of UK Geriatricians (n=811), found 56% had cared for a patient with an advance care directive, which is comparable with the 65% of UK respondents in our study.(271) A 2010 Canadian population based study (mean age 50 years, n=1,184) reported that 43.6% of the general public had completed an advance care directive,(92) though only 19.3% of attendees (over 70 years old, n=280) of an urban Canadian Emergency Department had done so.(272) A national survey of the Irish public (n=667) found only 5% claimed to have drafted a living will.(89) Given these figures it is not surprising that 60% of Canadian, but only 25% of Irish respondents, had encountered patients with advance care directives, despite many Irish HCPs having trained or worked abroad.

Many barriers to advance care directive completion have been described. Lack of awareness of advance care directives is an obvious and common reason for people not to have one.(273, 274) Many patients feel that it is the responsibility of healthcare professionals to introduce conversations about end-of-life care and preferences for care. Other barriers to advance care directive completion include time constraints, reluctance and low confidence amongst some healthcare professionals to have advance care planning discussions and the differing views amongst healthcare professionals as to whose responsibility it should be to complete them with the patient. (275-277) Whilst 74% of this study group would recommend advance care directives to people, it is likely that few of them will initiate the process. In addition, if healthcare professionals do not see the value in completing an advance care directive or advance care plan for themselves, this potentially reduces the likelihood of them completing one with their patients.

Advance care directive completion rates of 10-35% have been found amongst healthcare professionals, which is similar to the completion rates described for their patients or their respective country's general population. (97, 269, 278-280) In this study, completion rates among healthcare professionals were higher in countries with more advance care directive experience (Canada: 27% vs UK: 3% vs Ireland: 3%) and highest in Canada, where legislation exists

longest. The healthcare professionals' advance care directive completion rates in this study are reflective (albeit slightly lower) of the completion rates of each country's general population. Recent Canadian studies have found approximately 40-45% of the general public, of a similar age to the Canadian participants in this study, have completed an advance care directive.(92) The maturity of Canadian respondents may account for some of the discrepancy in advance care directive completion rates seen, but after adjusting for age the difference persists. Also reports on healthcare workforce demographics suggest the Canadian healthcare workforce is older than that in the UK or Ireland, which may partly explain the older Canadian healthcare professionals in this study. Only about 23% of doctors registered with the Irish Medical Council were over 55 years.(281)

This appears to be the first study to report advance care directive completion rates amongst Canadian, UK and Irish healthcare professionals. The Canadian and UK samples are small, with an excess of UK respondents involved in care of older people, so results for these countries may be less generalizable. The Irish sample however was broad and inclusive of many medical and nursing specialties, both hospital and community based and in this sense is likely a more representative cohort.

Whilst convenience sampling facilitated access to respondents with diverse professional backgrounds and varying levels of experience, it may have contributed to the inequity in age, gender and other demographic features found producing potential selection bias. The sampling technique also made a response rate impossible to calculate for the group as a whole. Whilst completion rates in this study were reflective of the completion rates in each of the respective countries general population, a sample of n=1506 would have been needed to detect the difference between the observed Irish respondent's completion rate (3%) and that of the general Irish population (5%) with a power of 80% at an alpha significance level of 0.05. Though the study was underpowered to detect some of the differences found, the results are suggestive and nonetheless.

All healthcare professionals should know who has the legal authority to make medical decisions for patients unable to do so for themselves through diminished capacity. Unfortunately misinformation abounds and only 40% of healthcare professionals in this sample could correctly identify the legal decision-maker. Irish respondents were poorest in this regard. This might be explained by confusion arising from differences in legislation between Ireland, the UK, the United States and elsewhere. Legislation on who has the authority to make healthcare decisions for people with diminished capacity differs between countries. Overlooking such differences may contribute to misunderstanding amongst the general public, for whom the internet and television are an important source of healthcare information.(4, 282, 283) Equally, healthcare professionals must be cognisant of legislative differences between their own country and that which may be presented by foreign TV, the internet and print media.

Legislation such as the *Patient Self Determination Act (1991)* in the United States may impact on advance care directive completion. Use of the "*Surprise Question: Would I be surprised if this patient died in the next 6-12 months*" to screen for patients who may benefit most from advance care planning, might also encourage completion. Public education campaigns that use posters, leaflets or TV adverts, in isolation have not significantly increased completion rates, but if combined with dialogue between patients and their healthcare providers, this approach positively impacted on completion rates. (253) A recent systematic review identified various techniques to facilitate such dialogue; the use of hypothetical questions was found to be particularly useful. (284) Key to any efforts to improve engagement with advance care planning however, is patient and healthcare professional awareness and willingness to engage and spend time in a process that both perceive to be useful and meaningful. This is especially so for healthcare professionals as they are more often the ones to prompt discussion and in doing so, increase the likelihood of advance care plan completion. (285, 286)

2.1.5 **Conclusion**

This study explored knowledge and perceptions of advance care directives and medical decision making in older adults with diminished capacity. It appears to be the first study to report personal advance care directive completion rates amongst healthcare professionals in Ireland. Though the majority of respondents would recommend their patients to complete an advance care directive, few had completed one for themselves.

This study differs from previous research by asking healthcare professionals their views, after conceptualising themselves as the patient with diminished capacity for whom end of life care decisions have to be made. In the event of incapacity, most respondents (86%) felt an advance care directive would result in treatment consistent with their wishes and that a doctor would follow their directive. In the absence of an advance care directive, over half of respondents thought they would get care incongruent with their wishes and that their family would have difficulty making decisions on their behalf. Despite this, 80% felt their family would make good treatment decisions for them, particularly if they consulted with the doctor. When asked specifically who should have legal authority to make treatment decisions for them, in the absence of an advance care directive, most (74%) requested their family. Clear educational needs were found for healthcare professionals in the legal aspects of medical decision making for adults with diminished capacity.

This study showed high awareness and a positive attitude to ACDs, and a belief in the benefits of their use. Future research needs to focus on how best to translate these motivating factors into action, to overcome the barriers to advance care planning, such as time and environmental constraints, perhaps by targeting patient populations most likely to engage with and gain from completion of an advance care plan, especially those likely to have stable treatment preferences over time. (126, 287)

2.2 The influence of healthcare professional's confidence and training in palliative care on end of life treatment choices

2.2.1 Introduction

Knowledge of palliative care and confidence in the core skills involved is important for all healthcare providers, but sadly these are areas where deficiencies have been reported.(167, 212, 288-292) In Ireland (and elsewhere) many people feel uncomfortable discussing or dealing with end-of-life issues, this may also be true for healthcare providers.(293) The training and experience healthcare providers have in palliative care and end-of-life care varies widely and is likely to affect how they interact with the dying and their families.(294-296)

Providing end-of-life care can be challenging for healthcare providers for a myriad of reasons. One area where difficulties arise for some, is in making critical treatment decisions for patients who face life threatening illness and have lost the ability to decide for themselves e.g. through dementia. For any specific patient situation, the care choices healthcare professionals would make are broad; some focus on maintaining comfort; whereas others will do all that is medically possible to save life.(265, 297) Though immeasurable factors contribute to the disparity in approaches to care, it is important to be aware of at least some of the factors that may influence healthcare professional's choices.

There were several objectives of this part of the study:

1. to examine healthcare professional's level of comfort in providing care to people (and their families) at the end of life in Ireland.

2. to assess whether healthcare professionals in Ireland feel they have adequate training and experience in end-of-life care.

3. to explore the treatment decisions healthcare professionals would make in a hypothetical scenario (see figure 2.3 below).

4. to explore the factors which might influence treatment choices.

2.2.2 **Methods**

The methods for this part of the study are the same as those described in section 2.1.2, but the results presented represent the Irish cohort only. The questionnaire described in section 2.1.2, included an additional section on respondents' comfort in dealing with dying patients and their families, confidence in treating symptoms, adjusting medications, and satisfaction with training and experience in end-of-life care. It also explored their preferred treatment approach for life threatening illness in advanced dementia using a hypothetical scenario (see figure 2.3) and what factors might influence these choices. Content validity was evaluated in the same way as in section 2.1.2.

Figure 2.3 Hypothetical Scenario on which treatment decisions were based

Mr Murphy is an 84 year old man who you were asked to see as an emergency. He has been living in a nursing home for a month. He has suffered from Alzheimer's disease for seven years and now he is moderately demented. He does not recognise his children but smiles at his wife. He needs help getting in and out of bed and walks with help. He has urinary incontinence and occasional incontinence of faeces. He is vomiting bright red blood and his blood pressure is low (BP 80/40mmHg). Unless he is treated he will most likely die. His family are not available and there is no advance care directive in his medical notes.

Please choose from one of the following treatment options:

Palliative:	Leave him in the nursing home and keep him comfortable
Limited:	Transfer to hospital for blood transfusion but no surgery or endoscopy
Surgery:	Blood transfusion, endoscopy and surgery if necessary
Intensive:	Blood transfusions, endoscopy and surgery, intensive care, ventilator, and everything a modern hospital has to offer to maintain life if necessary

2.2.3 **Statistical Considerations**

In addition to the statistical considerations in section 2.1.2, odds ratios were calculated for factors affecting outcomes. Kendall's tau, τ was used to test correlation for non-parametric data. Binomial logistic regressions were performed to examine for associations between variables (age, years of experience, gender, occupation, proportion of work involving older people, satisfaction with training and experience in care of the dying) and whether respondents felt comfortable caring for the dying and whether they were satisfied with the adequacy of their training in end of life care. For each binomial logistic regression analysis, Likert type responses were recoded: "strongly disagree" and "disagree" were combined to form the code "disagree"; "strongly agree" and "agree" were combined and coded as "agree"; "neutral" responses were then excluded.

2.2.4 **Results**

The respondents' demographic details are the same as those presented for Irish respondents in section 2.1.3 above. The group consisted of 72% females. There were fewer female doctors and medical students (45% and 53% respectively) compared with nurses and nursing students (94% and 100% respectively).

The majority of respondents identified themselves as Roman Catholic: 87% of Nurses, 78% of Students, 75% of Doctors and 54% of Allied Healthcare Professionals. Nurses worked across a range of areas: 63% in General Nursing, 11% in Public Health, 11% in Psychiatry, 5% in Intellectual Disability services and 4% as Midwives. Most doctors worked in a hospital environment (59%), 37% worked in General Practice, and a minority worked in a Hospice setting (3%) or as Old Age Psychiatrists (3%). Hospital doctors represented a range of specialties and levels of seniority, but most worked in internal medicine specialties. Of medical students 37% were graduate entrants with prior qualifications in Science (63%), Pharmacy (13%), Law (7%), Engineering (6%), Business (4%) or other healthcare related specialties (6%). Rotations in Geriatric Medicine or Palliative Medicine had been completed by 22% and 14% of Medical Students respectively.

Respondent's degree of comfort in providing end of life care

As presented in table 2.6, the majority of Irish healthcare professionals (80%) felt comfortable in dealing with patients at the end of life. Not unexpectedly students were less comfortable with the dying; only 48% were comfortable. Despite being relatively comfortable in dealing with dying patients, most students (66%), many allied healthcare professionals (41%), and about a third of nurses and doctors found dealing with such patients more difficult than managing other patient groups.

Table 2.6 Respondents' comfort and confidence in end of life care

	Total	Agree		Neutral		Disagree	
	n	n	%	n	%	n	%
Respondent feels comfortable dealing with patients at the end of life							
Total HCPs	507/511	407	80%	0	8%	58	11%
Doctor	165/165	129	78%	14	9%	22	13%
Nurse	306/309	250	82%	25	8%	31	10%
AHPs	27/28	21	78%	3	11%	3	11%
Students	243/246	117	48%	73	30%	53	22%
Respondent finds it harder dealing with patients at end of life than other patients							
Total HCPs	504/511	171	34%	66	13%	266	53%
Doctor	165/165	55	33%	25	15%	85	52%
Nurse	303/309	103	34%	39	13%	161	53%
AHP	27/28	11	41%	1	4%	15	56%
Students	243/246	161	66%	33	14%	49	20%
Respondent feels comfortable dealing with a patient's family at the end of life							
Total HCPs	506/511	392	77%	55	11%	59	12%
Doctor	164/165	128	78%	16	10%	20	12%
Nurse	306/309	237	78%	35	11%	34	11%
AHP	27/28	20	74%	4	15%	3	11%
Students	241/246	66	27%	65	27%	110	46%
Respondent feels comfortable dealing with bereaved families							
Total HCPs	503/511	365	73%	65	13%	71	14%
Doctor	163/165	114	70%	18	11%	31	19%
Nurse	305/309	225	74%	44	14%	36	12%
AHP	26/28	20	77%	3	12%	2	12%
Students	243/246	58	24%	66	27%	119	49%

Healthcare professionals were similarly comfortable dealing with a patient's loved ones at, or after, the patient's death (77% at end of life, and 73% in bereavement). Students appeared to be less prepared in interacting with patients' families at these times than with the dying patient themselves; only 27% were comfortable with families as their loved one was dying and just 24% were comfortable with bereaved family members.

Degree of confidence in managing patients' symptoms at the end of life

Consistent with allied healthcare professionals' roles and students' inexperience, these groups lacked confidence in managing symptoms at the end of life (table 2.7). Less than 75% of nurses and only 66% of doctors felt confident in managing end of life symptoms. As prescribers, doctors have a role in ceasing medication; 80% were comfortable in stopping preventative medications such as bisphosphonates as a patient's death approached. Compared with doctors, nurses appeared less likely to be comfortable stopping preventative medications (OR 0.51, 95% CI 0.33 to 0.81, p=0.004). There was no significant difference between hospital doctors and general practitioners responses.

Table 2.7 Respondents' confidence in symptom and medication management at end of life

	Total	Agree		Neutral		Disagree	
	n	n	%	n	%	n	%
Respondent feels confident managing patient's symptoms at the end of life							
Total HCPs	501/511	349	70%	76	15%	76	15%
Doctor	165/165	109	66%	30	18%	26	16%
Nurse	305/309	225	74%	38	13%	42	14%
AHP	23/28	10	44%	6	26%	7	30%
Students	54/246	20	38%	18	33%	16	30%
Respondent feels comfortable stopping preventative medications at the end of life							
Total HCPs	493/511	349	71%	75	15%	69	14%
Doctor	162/165	130	80%	13	8%	19	12%
Nurse	305/309	206	68%	55	18%	44	14%
AHP	18/28	8	45%	6	33%	4	22%
Students	55/246	15	27%	22	40%	18	33%

Healthcare professionals who felt comfortable caring for dying patients were far more likely to also feel confident managing symptoms at the end of life (OR 58.39, 95% CI 23.77, 143.42, p <0.0001) and stopping preventative medications (OR 6.71, 95% CI 3.46, 12.995, p<0.001).

Satisfaction with training and experience in end of life care

Respondents' satisfaction with their training and level of experience in end of life care is presented in table 2.8. Healthcare professionals who deemed their training in end of life care to be adequate were over four times as likely to also be comfortable dealing with the dying (RR 4.72, 95% CI 2.37-9.41, p<0.0001) and over nine times as likely to be confident dealing with end of life symptoms (RR 9.38, 95% CI 4.03-21.81, p<0.0001). Respondents judging their personal experience in providing end of life care to be adequate, also appeared to be linked with greater comfort in managing the dying (OR 27.37, 95% CI 11.81-63.42, p<0.0001) and their symptoms (OR 66.5, 95% CI 27.08-163.30, p<0.0001).

Table 2.8 Satisfaction with training and experience in end of life care

	Total	Agree		Neutral		Disagree	
	n	n	%	n	%	n	%
Proportion who feel they have adequate training in end of life care							
Total HCPs	506/511	241	48%	91	18%	174	34%
Doctor	165/165	76	46%	30	18%	59	36%
Nurse	306/309	150	49%	52	17%	104	34%
AHP	27/28	11	41%	7	26%	9	33%
Students	55/191	15	27%	12	22%	28	51%
Proportion who feel they have adequate experience in end of life care							
Total HCPs	507/511	292		75		131	
Doctor	165/165	88	53%	30	18%	47	29%
Nurse	306/309	191	62%	40	13%	75	25%
AHP	27/28	13	48%	5	19%	9	33%
Students	55/246	8	15%	9	16%	38	69%

Examining healthcare professionals (students excluded), a binary logistic regression analysis of potential predictors of feeling comfortable in providing end of life care was performed including the variables: age, gender, occupation,

proportion of patients who are older, and satisfaction with adequacy of end of life training, and confidence in managing symptoms and stopping medications at end of life. Regression results are shown in table 2.9.

A further binary logistic regression analysis of the potential predictors of healthcare professionals' satisfaction in their end of life care training included the variables: age, gender, occupation and the proportion of their patients who are older. The results of the analysis are presented in table 2.10, and suggest that age, female gender and having greater proportions of older patients were linked with greater satisfaction in training – perhaps because they were more proactive in obtaining this training ($p<0.01$).

Table 2.9 Binary logistic regression analysis of potential predictors of healthcare professionals' comfort in providing end of life care to patients.

Variable	B(SE)	95% CI for Odds Ratio (OR)			P
		Lower	OR	Upper	value
Confident in managing symptoms	4.08 (0.90)	10.19	59.27	344.77	<0.001
Adequate end of life care training	1.90 (0.94)	1.07	6.71	41.91	0.042
Confident in stopping medications	1.05 (0.83)	0.56	2.85	14.46	0.207
Gender (male v female)	0.03 (0.88)	0.18	1.03	5.83	0.971
Age	0.88 (0.91)	0.41	2.40	14.15	0.334
Proportion of patients who are older					0.327
<20%	1.13 (1.14)	0.33	3.11	29.02	0.320
21-40%	-1.29 (1.14)	0.03	0.28	2.60	0.260
41-60%	-0.05 (1.27)	0.08	0.95	11.51	0.967
61-80%	-0.05 (1.27)	0.13	0.96	7.12	0.971
>81%	-0.04 (1.02)	0.57	0.82	1.20	0.308
Note: R^2= 0.579 (Hosmer and Lemeshow), 0.323 (Cox & Snell R Square), 0.659 (Nagelkerke R square), Model χ^2 (12) 96.25, p<0.001					

Table 2.10 Binary logistic regression analysis of potential predictors of healthcare professionals' satisfaction in the adequacy of their end of life care training.

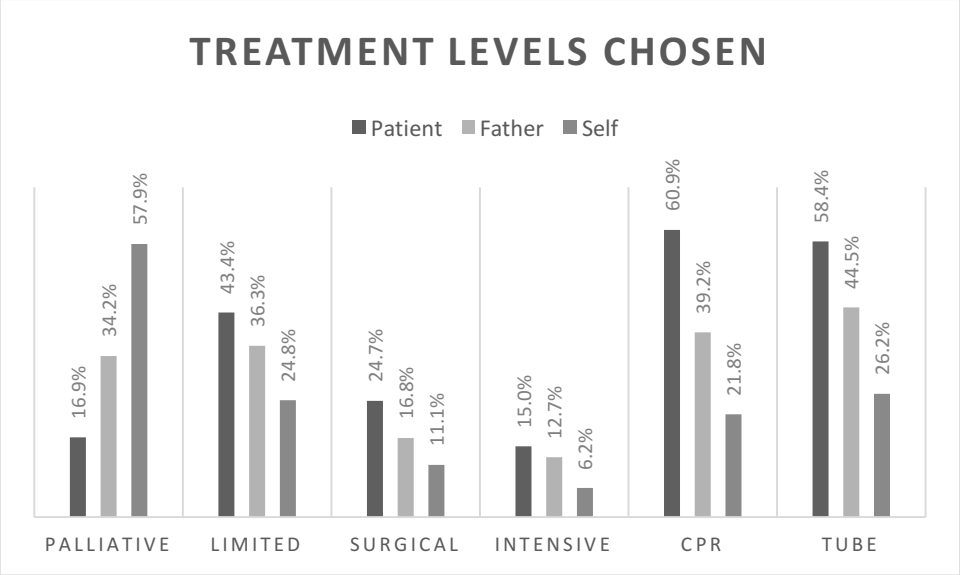
Variable	B(SE)	95% CI for Odds Ratio (OR)			P value
		Lower	OR	Upper	
Age	1.13 (0.37)	1.49	3.10	6.44	0.002
Gender (M vs F)	-0.67 (0.34)	0.68	0.80	0.93	0.004
Occupation (compared with AHPs)					0.87
Doctor	0.24 (0.61)	0.39	1.27	4.13	0.70
Nurse	0.08 (0.58)	0.35	1.09	3.39	0.89
Proportion of older patients (compared with <20% older)					<0.001
21-40%	1.31 (0.47)	1.46	3.70	9.37	0.006
41-60%	1.51 (0.44)	1.91	4.54	10.76	0.001
61-80%	1.72 (0.45)	2.34	5.60	13.41	<0.001
81-100%	2.16 (0.42)	3.81	8.66	19.73	<0.001

Note: R^2= 0.12 (Hosmer and Lemeshow), 0.15 (Cox & Snell R Square), 0.21 (Nagelkerke R square), Model χ^2 (9) 58.92, p<0.001
AHP =Allied Healthcare Professionals, M = Male, F = Female
Linearity of the logit assumption for age was not met, Age-LogAge p = 0.004

Decision making for patients with diminished decision-making capacity

Respondents were asked what treatment they would choose for a patient with moderate to severe Alzheimer's dementia in an emergency scenario described in figure 2.3. They were then asked how they would treat the same person if it were the respondent's father (i.e. their father was the person with dementia in the scenario) and subsequently what treatment they would want if they themselves were the person with dementia in the scenario. With each sequential situation, the level of treatment tended to become less intense. These results are presented in Figure 2.4.

Figure 2.4: Treatment levels chosen for the person with dementia described in the vignette based on whether deciding was the respondent's patient, their father or themselves, and whether they would initiate CPR or enteral feeding



Respondents who felt they had adequate experience in end of life care (45% vs 65%, χ^2 =16.59, OR = 2.25 (95% CI: 1.52 – 3.33), p<0.001), who felt their training in end of life care was adequate (47% vs 58%, χ^2 = 5.42, OR = 1.57 (95% CI: 1.07 – 2.29), p = 0.02) or who felt comfortable dealing with dying patients (55% vs 78%, χ^2 = 19.66, OR 2.91 (95% CI: 1.79 – 4.72), p<0.001) were less likely to choose to perform CPR on the patient in the scenario. Additionally, respondents were less likely to choose to perform CPR on the patient if they had correctly estimated the patient's likely survival with CPR (34% vs 62%, χ^2 =15.04, OR 0.32 (95% CI: 0.17 – 0.57), p<0.001.

When comparing treatment choices made for the patient with those made for their father (as the patient) most respondents choose the same (n=423/722, 58.6% for total group, AHP: n=20/26, 76.9%, doctor: n=95/153, 62.1%, nurses: n=180/301, 59.8%, Students: n=124/234, 53%) or a lower level of treatment (n=224/722, 31% for total group, Doctors: n=52/153, 34%, Nurses: n=93/301, 30.9%, Students: n=70/234, 29.9%, AHP: n=5/26, 19.2%) though a small proportion chose a higher level of treatment (n=75/722, 10.4% for total group, Students: n=40/234, 17.1%, Nurses: n=28/301, 9.3%, Doctors: n=6/153, 3.9%, AHP: n=1/26, 3.8%). These results are presented in Table 2.11.

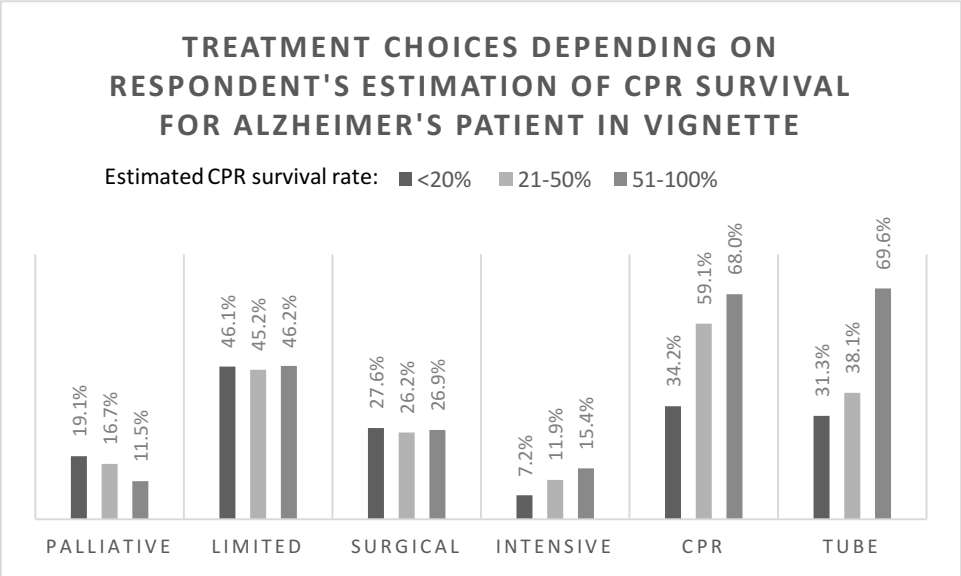
When comparing treatment choices made for the patient with what respondents would choose for themselves were they the person in the scenario, the majority chose a lower level of care for themselves (Total group: n=378/710, 25.7%, Doctors: n=84/151, 55.6%, Students: 127/232, 54.7%, Nurses: n=157/302, 52%, AHP: n=10/25, 40%). Only 4.1% of respondents would give themselves more aggressive treatment than the patient were they in the same scenario (n=29/710, AHP: 0/25, 0%, Doctors: 1/151, 0.7%, nurses: n=10/302, 3.2%, Students: n=18/232, 7.8%).

Table 2.11: Treatment choices depending on occupation and patient scenario

	Palliative		**Limited**		**Surgical**		**Intensive**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
For Patient Scenario								
Total, n=722	122	16.9%	314	43.5%	177	24.5%	109	15.1%
Doctor, n=153	20	13.1%	76	49.7%	44	28.8%	13	8.5%
Nurse, n=301	61	20.3%	150	49.8%	66	21.9%	24	8%
Student, n=234	27	11.5%	73	31.2%	64	27.4%	70	30%
AHP, n=26	12	46.2%	11	42.3%	2	7.7%	1	3.8%
For Father as patient in scenario								
Total, n=722	247	34.2%	261	36.1%	123	17%	91	12.6%
Doctor, n=153	51	33.3%	69	45.1%	22	14.4%	11	7.2%
Nurse, n=301	120	39.9%	114	37.9%	48	15.9%	19	6.3%
Student, n=234	58	24.8%	63	26.9%	52	22.2%	61	26.1%
AHP, n=26	14	53.6%	12	46.2%	0	0%	0	0%
For self as patient in scenario								
Total, n=710	410	57.7%	175	24.6%	81	11.4%	44	6.2%
Doctor, n=151	91	60.3%	36	23.8%	17	11.3%	7	4.6%
Nurse, n=302	187	61.9%	81	26.8%	25	8.3%	9	3%
Student, n=232	111	47.8%	54	23.3%	39	16.8%	28	12.1%
AHP, n=25	21	84%	4	16%	0	0%	0	0%

For those who chose an intensive level of treatment for the patient, 48.6% (n = 53/109) continued to choose this level of care for their father, and 27.8% (n=30/108) for themselves. For those who chose a surgical level of care for the patient, 45.8% (n=81/177) maintained this level of care for their father and 33.5% (n=59/176) for themselves. For those who chose a limited level of care for the patient, 58.6% (n=184/314) maintained this level of treatment for their father (as the patient) and 33.3% (n=103/309) for themselves. In contrast 86% (105/122) of those who chose a palliative approach for the patient also chose this level of care for their father, and 94.9% (n=111/117) for themselves.

Figure 2.5: Treatment choices depending on respondents' estimation of CPR survival for the patient with Alzheimer's disease in the vignette



In this study 90.1% of doctors, 55.5% of nurses and 50% of Allied Healthcare professionals estimated CPR survival to be <20% for the patient with Alzheimer's Disease described in the vignette in Figure 2.3.

Respondents were asked to judge to what extent a number of factors may have influenced the treatment decisions they made when choosing for the patient in the scenario. The results are presented in Table 2.12. It would appear that the use of hospital resources was of least concern. Respondents for the most part did not feel their own religious beliefs influenced their decision making. Markers of the patient's frailty and the severity of their dementia appeared to

influence respondent's decision making, particularly doctors, who marked these factors as more influential than did nurses, allied healthcare professionals or students. Students ranked the influence of previous experience of similar situations lower than doctors, nurses and allied healthcare professionals – which probably reflects their clinical inexperience and younger age exposing them to fewer related life (or death) events. Students ranked the fear of legal action higher than other occupations (mean students= 3.47 vs nurses = 3.41, doctors = 3.22, AHP = 2.91).

Students were most likely to deem the duty to preserve life as influencing their decision making. Of all respondents, those who agreed that their duty of care to preserve life influenced their decision were more likely to choose more aggressive treatment (49.1%, n=241/491) for the patient than those who deemed their duty to preserve life not to have influenced their treatment choices (16.7%, n=13/78, χ^2=27.27, OR = 4.82, 95% CI 2.59 – 8.97, p<0.001).

Table 2.12 Respondents' assessment of factors influence on decision making

Variable (n)	Mean	Median	Disagree/ strongly disagree	Neutral	Agree/ strongly agree
Hospital resource use concern (702)	2.12	2	67%	19%	14%
Own religious beliefs (707)	2.32	2	56%	23%	21%
Urinary incontinence (708)	2.83	3	41%	29%	31%
Likely time on A+E trolley (707)	2.9	3	39%	26%	35%
Faecal incontinence (706)	2.94	3	37%	28%	35%
Inability to walk unaided (704)	2.98	3	36%	26%	38%
Duration in nursing home (702)	3.08	3	33%	26%	41%
Similar experience with family (714)	3.13	3	32%	23%	45%
Fear of legal action (712)	3.37	4	27%	19%	54%
Experience of similar situations (715)	3.43	4	22%	19%	59%
Family being uncontactable (701)	3.44	4	24%	20%	56%
Inability to recognise family (707)	3.45	4	23%	20%	57%
Uncertainty of patient outcome (702)	3.5	4	16%	24%	60%
Patient's age (706)	3.52	4	21%	19%	60%
Level of confusion (706)	3.57	4	19%	17%	64%
Duration of confusion (706)	3.63	4	18%	17%	65%
Not knowing patient's wishes (694)	3.8	4	13%	18%	69%
Duty to preserve life (704)	3.88	4	12%	17%	71%

Results of univariate analysis for each of the potential influencers dichotomised as either agree or disagree (neutral responses were omitted as described in the methodology) were compared with regard to how likely respondents were to choose more aggressive care (surgical or intensive levels of care combined) over less aggressive levels (limited or palliative levels of combined). The results of these analysis are presented in table 2.13.

Table 2.13 Influence of various factors on respondents' choosing more aggressive levels of care for hypothetical patient in scenario

Variable (n)	χ^2	Odds Ratio*	95% Confidence Interval	P value
Duty to preserve life (569)	28.62	4.82 †	2.59 – 8.97	<0.001
Fear of legal action (566)	9.84	1.80 †	1.24 - 2.60	0.002
Family being uncontactable (547)	4.99	1.54 ^	1.05 – 2.26	0.026
Not knowing patient's wishes (558)	0.70	1.23	0.76 – 1.98	0.404
Uncertainty of patient outcome (519)	0.75	1.21	0.79 – 1.86	0.387
Hospital resource use concern (557)	0.02	1.03	0.66 - 1.61	0.88
Inability to walk unaided (507)	0.62	0.87	0.61 – 1.24	0.429
Own religious beliefs (534)	0.64	0.95	0.65 - 1.40	0.80
Adequate EOL care training (444)	0.47	0.87	0.58 – 1.30	0.49
Adequate EOL care experience (456)	0.60	0.85	0.57 – 1.28	0.440
Patient's age (558)	2.48	0.73	0.50 – 1.08	0.116
Urinary incontinence (493)	4.44	0.68	0.47 – 0.97	0.035
Faecal incontinence (495)	6.80	0.62 †	0.43 – 0.89	0.009
Confident dealing with EOL Pts (613)	6.55	0.58 †	0.38 – 0.88	0.011
Likely time on A+E trolley (508)	10.23	0.55 †	0.39 - 0.80	0.001
Duration in nursing home (509)	11.52	0.54 †	0.37 – 0.77	0.001
Inability to recognise family (557)	10.86	0.54 †	0.37 – 0.78	0.001
Similar experience with family (539)	20.25	0.45 †	0.31 – 0.64	<0.001
Level of confusion (576)	17.52	0.43 †	0.29 – 0.65	<0.001
Duration of confusion (574)	18.72	0.42 †	0.28 – 0.62	<0.001
Experience of similar situations (564)	25.59	0.38 †	0.26 – 0.56	<0.001

EOL = End of life, Pts = patients
* = Odds Ratio for choosing a more aggressive level of care (surgical or intensive care level) over a less aggressive level (palliative or limited care level)
† = p-value significance <0.02,
^ = p-value significance <0.05

2.2.5 **Discussion**

This study found that the majority of healthcare professionals and senior nursing and medical students are comfortable engaging with dying patients and their families, though a considerable number still find dealing with the Dying more difficult than other patient groups. In contrast to healthcare professionals, senior medical and nursing students were relatively unprepared for interacting with the dying person's family. This may relate to their younger age and relative "life experience", but equally it could identify gaps in their education syllabus.

A 2005 survey of medical school curriculum found that although all five medical schools in Ireland dedicated time to teaching palliative care, in two schools this amounted to a day or less and for the most part teaching was through didactic lectures rather than experiential.(298) Though four of the medical schools offer rotations in palliative medicine, uptake was low.(298) Undergraduate teaching in palliative care is likely to have evolved and broadened in content and modality since, as suggested by a recent systematic review of worldwide palliative care teaching in medical schools.(299) This is supported by an Irish study of a recently introduced self-selected module in Palliative care in University College Cork.(300)

Just as student education may need to be addressed, so too may healthcare professionals'. Only about half of nurses and doctors felt satisfied with their training or experience in end of life care; fewer allied health professionals and only about a quarter of medical and nursing students felt their training was sufficient. Though this is the first study to examine Irish undergraduates and healthcare professionals (other than GPs) perception of the adequacy of their end of life training, similar inadequacies in both university and postgraduate level end of life training have been identified by studies from other countries.(290, 301-307) An Irish study of GP trainees identified comparable deficiencies in palliative care training.(308) Reasons for healthcare workers not gaining adequate training in this area need to be explored and addressed to facilitate their learning and continuing professional development.

Knowledge of palliative care and confidence in the core skills involved are important for all healthcare professionals, as almost all in clinical practice will care for dying patients or their relatives at some point in their careers. Our study showed a significant relationship between increasing age and proportions of older patients and respondents' satisfaction with their training in end of life care and furthermore that satisfaction in end of life care training and experience was linked with increased confidence in caring for the dying and their symptoms. It may be that healthcare professionals who are regularly dealing with dying patients are more inclined to seek out training in palliative care in an effort to maintain and improve their skills.

There have been changes to incorporate increased palliative care training into the undergraduate curriculum of medical and nursing students and postgraduate healthcare professionals.(300, 309) The duration of education seems to be important as shown in a UK based study of medical students undertaking palliative care training.(310, 311) There is much evidence that training in palliative care particularly experiential training that includes working in a palliative care setting or with staff skilled in providing end of life care improves knowledge, confidence and communication skills in end of life care.(311-313) The importance of practical and experiential learning has also been highlighted in Irish research of GP trainees.(308)

A word of caution though: this study did not explore respondents' knowledge or skills in end of life care. Comfort in providing care tells little of the standard of that care; a person with poor skills may be unaware of their paucity but remain confident in their abilities. The "arrogance-ignorance paradox" may apply.(314) Research has shown that with advancing years of experience healthcare professionals confidence increases despite their level of knowledge remaining much the same.(315, 316) This is thought due to many healthcare professionals learning their end of life care skills by trial and error or from their peers (who are also likely to have learned by trial and error or from their peers).(315) Measuring competence - either perceived or achieved – in palliative care provision is fraught with difficulty; a systematic review by Frey et al identified no single validated competence assessment tool.(317)

The factors contributing to the comfort healthcare professionals have in caring for their dying patients are myriad, but important. In our study, experience of similar scenarios either with respondents' own families or in their work seemed to be associated with less aggressive treatments choices. Knowledge of CPR, confidence in providing care for the dying, and satisfaction with experience and training in end-of-life care appear to influence treatment choices, particularly those in relation to cardiopulmonary resuscitation. The importance of practical experience in decision making is borne out in research.(318) Older healthcare professionals seem to be less pessimistic about end of life care, and in younger non-Hispanic healthcare professionals pessimism appears to reduce over time.(319) A recent Norwegian study of newly qualified doctors working in long term care described how this experience impacted on their end of life communication and decision-making skills; they veered towards a more collaborative and often a less "heroic" approach than that usually experienced by them in their hospital rotations in managing dying frail older patients.(320)

A US study by Daly et al exploring the influencing factors for physicians and family surrogates in real life intensive care patients' decision making found the only consistent influencer was physician expectations for survival and future cognitive status, and not patient, physician or family characteristics, values or preferences for care or priorities for treatment (comfort vs survival).(321)

In a recent study looking at the effect of personality and religious beliefs on healthcare professionals' decision making on end of life issues, the fear of litigation was also identified as a factor, more so for doctors.(322)

With regard to the representativeness of the study sample, the Irish Medical Council's Workforce Intelligence Report 2016 and Health Service Executive publications on workforce, found a similar proportion of female doctors (41%) and doctors aged 55 years and over (23%) to that found in this study (45% and 20% respectively), and the average age of 42.4 years for doctors and 44.8 years for nurses in our study, compares with the national average of 40.7 years for doctors and 43.7 years for nurses.(323). This study's sample included

healthcare staff across a number of disciplines, including a minority of surgical staff. The sampling methodology may have introduced representation bias, as respondents were self-selecting to attend some of the conferences, lectures and educational symposia sampled in this study due to an interest in end of life care or advance care planning. Therefore those working in medicine, geriatric care and palliative care may have been overrepresented. This makes the results even more important perhaps, as these groups represent those healthcare workers most likely to encounter patients near or at end of life.

Chapter Three:
Let Me Decide Program; background, development and implementation challenges

3 The Let Me Decide Program

The Let Me Decide (LMD) advance care planning program was developed by Professor Willie Molloy in Ontario, Canada in 1990. The first version of the accompanying book was published in 1992. This book serves as an educational resource for those who wish to complete the associated Let Me Decide advance care directive. Over a million copies of the book have been sold. The first Irish edition of the book was printed in 2011.

The Let Me Decide advance care directive has been used extensively. Research citing its usage in several countries has been published, and it has been successfully employed in a number of settings and populations: community dwelling older people and veterans, and in long term care.(144, 233, 324, 325) It was used in one of the few randomised controlled trials of advance care directives in long term care.(144) The results of this randomised controlled trial were published in *JAMA* in 2000 and according to Google Scholar, this work has been cited by at least 419 journal articles (correct as of 9th June 2017).

The editorial accompanying the *JAMA* article, raised two key concerns with the study; firstly that the study did not collect data on symptom control or the quality of life of residents in the study homes, and secondly that it was not possible to know if the reduction in hospitalisations seen was not at the cost of reduced quality of end of life care and was, in truth, reflective of the residents' expressed wishes. (326) Previous trials of the Let Me Decide advance care directive in long term care showed that a majority of residents completing the directive chose to remain in their respective long term care residences at the end of life.

3.1 Background

3.1.1 Advance care directive legislation: Canada and Ireland

Comparison of advance care directive legislation in Canada and Ireland

At the outset of this research, competent Irish people, like those in Canada had the right to control healthcare decisions for themselves, and the same right to refuse treatment, even if this led to their death. Though small nuances of

difference in the advance care directive legislation existed between Canadian provinces, the law on advance care directives had been well established there for many years. Ireland, conversely, lacked any legislation for advance care directives and a dearth of Irish case law relating to their use contributed to a lack of clarity regarding the validity and applicability of advance care directives.(327) It was expected though that, if challenged, a validly created advance care directive would have been upheld in Ireland.(73, 74)

In 2008, the Irish Law Reform Commission recommended there be a statutory framework on advance care directives in its *Consultation Paper Bioethics: Advance Care Directives 2008.* (328) Their subsequent report in 2009 advised this framework be incorporated into the anticipated Irish Mental Capacity Act, and outlined a proposal for how such a framework might operate.*(263)*

Irish law, under the Powers of Attorney Act 1996, allowed for a competent adult (the donor) to register a Power of Attorney, appointing whom should act on the donor's behalf in the event the donor lost the capacity to manage their own affairs. Whilst this Act conferred on the nominated Attorney the right to make decisions connected with property, finance or personal care - those rights did not extend to healthcare decisions; and certainly not to those regarding life sustaining treatment. The Law Reform Commission in their 2009 report suggested an extension to the Power of Attorney Act 1996 to allow a person to stipulate that their nominated Attorney could make healthcare decisions including whether (or not) the donor would be resuscitated. The report recommended that this power should only extend to decisions on life threatening illnesses if the donor had expressly indicated this level of authority.

When Dáil Éireann presented the Assisted Decision-Making (Capacity) Bill 2013 in July 2013, this recommendation was included, but only in part. It proposed the Power of Attorney could include healthcare decisions, but did not permit the attorney to refuse life sustaining treatment.(329)

Ultimately, during the course of this research, the Assisted Decision-Making (Capacity) Act 2015 was signed into law by the Irish President on 30 December 2015.(330) This replaced the previous legislation: the Marriage of Lunatics Act

1811 and the Lunacy Regulation (Ireland) Act 1871.(331) When it is commenced, the 2015 Act will allow for a person to create an advance healthcare directive and to appoint a "designated healthcare representative" who would have the "power to consent to or refuse treatment, up to and including life sustaining treatment, based on the known will and preferences of the directive-maker" (p91, section 88. (1) (b) (ii)). Canadian legislation similarly allows an adult with capacity, to create an advance care directive under the *Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A* and/or the appointment of a proxy medical decision maker, a Power of Attorney for Personal Care, under the *Substitute Decision Act, 1992, S.O. 1992, c. 30*

This raises the question of what would happen in the absence of an advance care directive or appointed proxy decision maker, for an adult lacking capacity with regard to medical decision making.

3.1.2 Medical decision making in the older adult with diminished capacity

Medical decision making for older adults with diminished capacity in Ireland

As the 2015 Act has not yet been commenced, the legal situation in Ireland remains as it was at the beginning of this research. Once commenced, this Act will abolish the existing Wardship or Ward of Court system as designated within the meaning of the Lunacy Regulation (Ireland) Act 1871. This is the current legal mechanism for medical decision making for adults lacking capacity. The system is not inexpensive and "in the main considered to be cumbersome and is not often utilized."(332)

In July 2016 there were approximately 2600 Wards of Court in Ireland.(333) The alternative, which is more commonplace in Ireland, is that the person lacking capacity is not a registered Ward of Court and in this scenario, the legal authority for treatment decisions then rests with the lead clinician treating the individual. The Irish Medical Council advises that where possible the clinician consults with the family of the person lacking capacity about the treatment choices their loved one would have wanted. (334) Where there is disagreement

between the clinician and the family on treatment, the Medical Council advises the clinician to seek a second opinion.(334)

The legality of this approach was questionable as until the 2015 Act there was no formal provision in Irish law (except under Wardship) for a person to give or refuse consent on behalf of an incompetent adult. Case law helped address this issue to some extent, in relation to healthcare decisions; in 1996, a High Court decision by Judge Lynch, in Re a Ward of Court, recommended the physician make medical decisions. Although this has since become the standard practice, the general population, and indeed many Irish healthcare professionals as seen in Chapter 2, still have a poor understanding of the roles and clinical responsibilities in making medical decisions for those lacking capacity.(335, 336) This is no doubt fed by "the widespread false belief that family members and carers may make valid decisions on behalf of people who do not have legal capacity" acknowledged in the Law Reform Commission Consultation Paper on Law and the Elderly in 2003, which led them to advise the law on consent to medical treatment would need to be addressed.(337)

Medical decision making for older adults with diminished capacity in Canada

Legal clarity regarding medical decision making for the older adult lacking capacity is of longer duration in Canada. In Ontario, the *Health Care Consent Act, 1996* addressed this through the appointment of a "substitute decision maker". The Act describes who may be appointed and the process for making decisions to optimise respect for the person lacking capacity's wishes; or where their wishes are unknown dictates that decisions be made in their best interests in the least intrusive or restrictive fashion.

If the individual had not appointed a substitute decision maker, the highest-ranking person according to the hierarchy set out in the Canadian Act would then become the legal substitute decision maker. The hierarchy of decision makers is:

a) The person's Guardian of the person, if they have authority for healthcare decisions (court appointed by the Superior Court of Ontario)

b) The person's Attorney for personal care, if the Power of Attorney confers authority for healthcare decisions
c) A Representative appointed by the Consent and Capacity Board, (anyone can apply to the Board to be appointed)
d) The person's spouse, common-law spouse or partner
e) The person's child (if aged over 16 years) or parent
f) The person's parent with right of access in custodial cases,
g) The person's sibling
h) Any other relative by blood, marriage or adoption
i) The Office of the Public Guardian and Trustee (the person of last resort)

3.2 Development of the Let Me Decide Program for Ireland

3.2.1 The research site managers' feedback and steering group

The steering group was composed of the researchers and senior nursing staff from each of the proposed pilot study sites for the piloting of the Let Me Decide program, and several other long term care residences, the steering group met regularly in the early stages of the project. This group was formed for a variety of reasons; it served as a means of gaining insight, information and buy in from the key stakeholders within the management structures of each study site. The group also served the important purpose of allowing two-way feedback between the researcher(s) and the study site staff, which facilitated modification of the Let Me Decide program material taking account of their feedback. In addition, the group had the important function of solidifying a feasible and practical standardised design for delivery of the study's complex intervention across sites. In this regard, the group assisted in the development and formalisation of a study protocol that was sensitive to local contexts, both organisational and logistical, on how the advance care planning program, palliative care educational program and its associated training would be implemented in the study sites.

The study protocol was based on the original Canadian study protocol, but took account of the legal situation in Ireland at the time, and practical issues in its application within each of the study sites. The protocol was devised by

consensus through regular meetings and feedback from both the senior nurse managers and from their staff "on the ground". The finalised protocol is in Appendix 2.

In addition, this group advised on various edits of the advance care directive form, which had to be modified due to the differing legal scenarios between Canada and Ireland.

3.2.2 **The supplementary educational material**

Despite the Let Me Decide book, being written in plain English, being only 57 pages long, and approximately A5 size (14cm x 22cm), it proved too much for the majority of residents to tackle, even those who were physically reasonably well and cognitively intact. Their adult children read it with interest and absorbed it with ease, but felt for the most part, it was aimed at a younger audience than their elderly parents. Alternative simpler educational tools were developed. The book was synopsized to eight A4 pages. This was too much to maintain the concentration of many residents. It was shortened to four A4 pages, but again even this brief booklet was excessive for a cohort of residents. Finally, a two-sided laminated A4 page with the key educational elements in large print was devised, not to be used independently, but as an educational tool or prompt to supplement conversation and discussion with the nursing staff facilitating advance care planning with the resident. Later relevant illustrations were added. Staff feedback was that this approach worked best for most residents.

3.2.3 **The Let Me Decide Advance Care Directive form:**

The original Canadian form contained five parts:

1. **Introduction:** which named the person completing it, and contained an explanation of the purpose of the document

2. **Personal Statement:** this part allowed the individual to stipulate what they would deem to be an "unacceptable condition". This part also contained a

section on whether they would agree (or not) to blood transfusion, organ donation or cremation.

3. **The Health Care Chart**: this section outlined the wishes of the individual with regard to cardiopulmonary resuscitation (CPR) if they arrested, tube feeding and the level of care they would wish to receive ("palliative", "limited", "surgical" or "intensive") in the event of life threatening illness in two scenarios;

Firstly "Reversible/Acceptable": what they would want if the illness was reversible and their condition at the onset of illness was acceptable to them and

Secondly "Irreversible/Intolerable": what they would want if they had an irreversible life threatening illness, or their condition was unacceptable or intolerable to them at the onset of the life threatening illness, as defined in their personal statement in section 2 of the ACD.

4**. Definitions**: This defined what was meant by each of the terms used in the document, importantly it defined what was meant by the four levels of care ("palliative", "limited", "surgical" and "intensive") from section 3 of the ACD, what it meant if they chose to have or not have CPR, what types of feeding they might want (or not).

5. **Signature section**: this section contained the relevant signatures of the donor (the person completing the directive), and witnesses. It also allowed the donor to name a "proxy" decision-maker.

Although it was first envisioned that the Canadian Let Me Decide ACD form could be used in this Irish study, it became apparent that an Irish version relevant to the long term care population in the study sites would need to be created. Therefore, the form evolved both before, during and indeed after completion of this research project.

Revisions of the Let Me Decide ACD form: Legislative reasons

Firstly, the form was changed to account for legislative differences between Ireland and Canada in 2011 as outlined above. In particular, the Canadian form allowed for the legal appointment of a proxy decision maker and in the absence

of this designation, the hierarchy of substitute decision makers would be applied for someone lacking capacity. In Ireland, healthcare decisions made by relatives or proxies have no legal basis in Ireland, and it is the physician who has ultimate responsibility as described above.

Over the course of the project, as more information became available on what was proposed in the forthcoming Assisted Decision Making Bill, the form was adjusted to remain in line with the anticipated Bill. Ultimately the form was changed again so that with the passing of the new Act in December 2015, the form would remain consistent with legislation.

In addition, it was realised that interpretation of the form's validity, by those external to the study could be difficult due to an absence on the form of any account of the person's cognition or capacity at the time of completing the Let Me Decide advance care directive. Thus, a section containing their *Mini Mental State Examination* score (MMSE)(338, 339) and *Screening Instrument to Assess Competency to Complete an Advance Directive* (SIACAD) score was added, along with the date these scores were achieved.(340)

Revisions of the Let Me Decide ACD form subsequent to staff feedback

Secondly, the form was altered to accommodate feedback from nursing staff who were using it with residents in the three long term care pilot study sites. Staff found that cognitively intact older people had difficulty and reluctance in hypothesising future situations; they preferred to base care decisions on their wishes for the present, their present selves and present situation. This is in line with several studies which found particularly for the oldest old, that they prefer to "live in the moment" and have trouble dealing with the complexities and uncertainty of what circumstances might arise in the future. (341-345) This led to the "health care chart" section of the form changing to become firstly "in my CURRENT state of health/functioning if I became seriously ill I would choose….." which was followed by an optional part where the person could define: "if my state of health/functioning became IRREVERSIBLY WORSE and my quality of life became UNACCEPTABLE to me, AND I became seriously ill, I would

choose…..", and then describe in their personal statement section what would be unacceptable to them and in what circumstances these choices would apply.

3.2.4 The need for an additional means of care planning for those with diminished capacity to complete an ACD.

Advance care directives are legally binding documents (where legislation exists) and in Ireland can only be completed by a competent adult for their own healthcare wishes. In the absence of an advance care directive, there is no legal basis for a family member to make healthcare decisions for someone lacking capacity. It is the physician's responsibility, but with advice that they should consult with the family with regard to the person's wishes. The process for a person lacking capacity is described in more detail in section 4.2.1.

This meant the development of a separate non-legally binding form to document the outcome of end of life care planning discussions for those with diminished capacity or those who did not want to commit to a legally binding advance care directive document. There was much controversy amongst the group as to what this document should be called, for most of the project it was referred to as the *End of life Decisions Care Plan for Person Lacking Capacity* (EoLCP) though it has been renamed as the *End of life Decisions Care Plan for Person With Diminished Capacity* (EoLCP). Some of the study site Let Me Decide nursing facilitators chose to document verbatim the discussions with the resident, so as to best capture the resident's wishes.

Chapter Four: Challenges in Implementing the Let Me Decide Advance Care Planning Program in Long Term Care

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4 Challenges in Implementing the Let Me Decide Advance Care Planning Program in Long Term Care

4.1 Abstract

Background: A high prevalence of cognitive impairment and frailty complicates the feasibility of advance care planning in the long-term-care population.

Research aim: To identify challenges in implementing the 'Let Me Decide' advance care planning program in long-term-care

Research design: This feasibility study had two phases: (i) staff education on advance care planning and (ii) structured advance care planning by staff with residents and families.

Participants and research context: long-term-care residents in two nursing homes and one community hospital

Ethical considerations: The local research ethics committee granted ethical approval.

Findings: Following implementation, over 50% of all residents had completed some form of end of life care plan. Of the 70 residents who died in the post-implementation period, 14% had no care plan, 10% (with capacity) completed an advance care directive and lacking such capacity, 76% had an end of life care plan completed for them by the medical team, following discussions with the resident (if able) and family.

The considerable logistical challenge of releasing staff for training triggered development of an e-learning program to facilitate training.

Discussion: The challenges encountered were largely concerned with preserving residents' autonomy, avoiding harm and suboptimal or crisis decision-making, and ensuring residents were treated fairly through optimization of finite resources.

Conclusions: Although it may be too late for many long-term-care residents to complete their own advance care directive, the *'Let Me Decide'* program includes a feasible and acceptable option for structured end of life care planning for residents with variable capacity to complete an advance care directive, involving discussion with the resident (to the extent they were able) and their family. While end of life care planning was time-consuming to deliver, nursing staff were willing to overcome this and take ownership of the program, once the benefits in improved communication and enhanced peace of mind among all parties involved, became apparent in practice.

4.2 Background

Advance care planning (ACP) is a process of communication between an individual, their healthcare providers, and often close family, to explore the individual's goals, values and beliefs and how these inform their preferences for future healthcare. One potential outcome of ACP is an advance care directive (ACD). An ACD is only *valid* if made *voluntarily*, by a *competent* informed person. It records what care, including life-sustaining treatments, that person would or would not wish to receive, if they become incapacitated to make, or communicate care decisions in the future; which is the only situation an ACD would be *used or acted upon.* Depending on the jurisdiction, ACDs can be legally binding. Another potential ACP output is an advance care plan, which is a less formal, non-legally binding, record of an individual's wishes.

ACP empowers people to direct the care they wish to receive at the end of life. Research suggests that most older adults do not want life-sustaining interventions at the end of life, but would accept interventions to keep them comfortable.(137, 346, 347) Studies including two recent systematic reviews found positive effects of ACP and ACDs on the quality of end of life care, including increased concordance between preferences for and delivered care.(137, 139, 141, 348) Additional ACP benefits include better preparation for dying, relief of anxiety, avoidance of prolongation of dying, and strengthening of personal relationships.(233, 349-351)

ACP may also help family prepare for potential difficulties in bereavement. In an Australian randomised controlled trial (RCT) involving older inpatients, a patient-centred ACP improved end of life care, patient and family satisfaction with care, and reduced stress, anxiety and depression in surviving relatives.(247)

With advancing age, an increasing proportion of older people come to reside in long-term-care (LTC) residences.(198) Ultimately it is where 15-25% of people die and where most LTC residents choose to die.(200, 352, 353) Cognitive impairment is highly prevalent (50-89%) in LTC residents.(340, 354) An English National Audit Office Report suggested about half of LTC residents who died in hospital could have died in LTC or at home, frail older people were most vulnerable to hospitalisation.(355) Several studies indicate ACP may help prevent avoidable hospitalisation of LTC residents.(144, 228, 233) An Australian controlled study utilising the Let Me Decide (LMD) ACD found that ACP, alongside a hospital-in-the-home scheme, decreased hospital admission and mortality of LTC residents.(233)

Whilst ACP strives to extend a person's autonomy to a time when they can no longer make decisions for themselves and evidence suggests many positive effects, research also identifies issues that proponents of ACP need to address, such as patient procrastination(356) and change of mind.(126) These challenges arising in relation to ACP often have an ethical dimension and they may differ depending on the healthcare setting, patient population and prevalence of cognitive impairment. We consider these in the Discussion section in relation to the particular challenges that we identified in implementing the LMD program in the LTC setting in Ireland.

4.2.1 **The 'Let Me Decide' program**

The LMD program offers a structured approach to end of life care planning in the LTC setting for both residents with and without capacity to complete an ACD,(357) and has been successfully implemented in LTC facilities in Canada.(144) A recent review of studies on ACP programs in LTC, classed the

LMD program as dementia-friendly based on criteria in the Dementia Policy Lens Toolkit.(358)

Table 1 lists key elements of the LMD program, including the use of a specially developed tool (*Screening Instrument to Assess Competency to Complete an Advance Directive (SIACAD)*) to assess a resident's capacity to understand the implications of choices made in completing a LMD ACD.(340)

Figure 4.1 Key features of the *'Let Me Decide'* Program for use in LTC settings.

- The resident's cognition is assessed using the *Standardised Mini Mental State Examination* (SMMSE).(339)
- Includes structured education of residents and families about ACP/end of life care planning
- The resident's capacity to complete the LMD-ACD is assessed using the *(SIACAD).(340)*
- The LMD-ACD form includes a menu of healthcare options that the resident is asked to choose for two different situations: (i) in their current state of health, if they became seriously ill and required life-saving treatment and (ii) if their state of health/level of functioning had become unacceptable to them and was irreversible, and they became seriously ill requiring life-saving treatment.
- When completing the LMD-ACD form, a person can make a *'Personal Statement'* indicating which irreversible states of health/levels of functioning would be unacceptable to them.
- Healthcare choices relate to three different areas: (i) Cardiopulmonary Resuscitation (CPR) or No CPR; (ii) Basic Feeding or Tube Feeding; and (iii) Level of treatment: Palliative-Comfort Care or Limited Care or Surgical Care or Intensive Care. Explanations of each of these terms is included in the LMD program's educational material.
- Residents are encouraged to include a close family member/friend in the ACP process.

- The individual may nominate a surrogate decision-maker (healthcare proxy) whom they would like to be consulted in the event they lose capacity.
- The LMD program ensures that ACDs are made voluntarily, without coercion or undue influence.
- For a resident who lacks capacity to complete an ACD:
  - if interested, any resident, wherever possible may engage in ACP to the extent that their cognition will allow. They are encouraged to include a close family member or friend in care planning discussions.
  - any expressed views in relation to their EoL care preferences are documented.
  - for residents who lack capacity and are unable to express views on EoL care e.g. because of advanced dementia, the family/next-of-kin is approached to see if they would like to engage with nursing and medical staff in discussing EoL care for their relative
  - these discussions will help inform the completion of an '*End of life Decisions Care Plan for Person Lacking Capacity'* by the doctor and senior nurse.

For residents lacking capacity to make an advance care plan, an *End of life Decisions Care Plan for Person Lacking Capacity* (EoLCP) was created. It is not legally binding and was completed by the healthcare professional in a collaborative fashion with the resident (to the extent they were able to engage in the process) and their family, taking into consideration any views expressed currently or historically by the individual in relation to end of life care; what their family believe would have been the person's wishes; and the views of the family and healthcare professionals on what care is in the person's best interest and most consistent with their values and worldview. Every attempt was made to complete an EoLCP reflecting the wishes of the individual, with their assent.

4.3 Methods

The LMD program was implemented in two nursing homes and one community hospital, totalling 290 beds. The study received ethical approval from the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

Each resident and/or family member, who voluntarily engaged in the LMD end of life care planning process, was given a verbal and written explanation of the study and assurance in relation to withdrawal of their consent, confidentiality, quality of care, and the risks of participation in the study. The information and assurances given are listed in Table 2.

Figure 4.2 Information and assurances given to residents (and/or their family) voluntarily engaging in the *'Let Me Decide'* process, regarding issues of consent and confidentiality.

- You are <u>not</u> required to engage in the *'Let Me Decide'* advance care planning (ACP) process, it is completely voluntary
- Your decision to engage in the ACP process will not affect the quality or amount of healthcare that you receive
- There will be no risks involved by your participation
- You can decide at any stage that you no longer wish to proceed
- If you decide to proceed, you are under no obligation to complete an ACD form at the end of the ACP process; you may choose to document your wishes in a less formal way (like in the form of a 'letter')
- At any time, you can change your mind about any of the decisions you have made in your ACD, or you can withdraw your ACD completely.
- Your ACD will only be used if, in the future, you are unable to make healthcare decisions or communicate these to others; if you are still able to think straight and communicate your wishes, you will be asked about your treatment preferences at that time.
- If you agree to your medical records being reviewed as part of this feasibility study, please sign the consent form after you are satisfied that you have enough relevant information.

- Any information collected as part of this feasibility study will be treated as strictly confidential.

The study had two phases.

4.3.1 Phase 1 – Pre-implementation survey and education of healthcare staff

Almost 30 senior nurses from participating sites completed two half-day workshops on ACP and the use of LMD including ethical, legal and practical considerations. Staff in the study sites, were surveyed before and after implementation on their palliative care and ACP knowledge, their perceived and experienced barriers to ACP, and their educational needs and confidence in delivering end of life care and ACP. Findings from the pre-implementation survey were used to refine the palliative care educational component of this program. Two half-day workshops covering the principles of palliative care, communication skills, bereavement and symptom assessment and management, were delivered to nurses and healthcare assistants.

4.3.2 Phase 2 – Delivery of ACP by staff to residents and families

Senior nurses involved in delivering ACP to residents/families were provided with the necessary documentation and resources. The first step in the LMD ACP process assesses cognition using the SMMSE, to measure the likelihood the resident has sufficient capacity to engage with ACP.(340) In the second step, nurses educated willing residents/families regarding ACP and LMD. Following this, the resident's capacity to complete the LMD ACD was assessed using the SIACAD tool.(340)

Staff were supported by the research team on an ongoing basis. During monthly feedback meetings, any issues arising during implementation were discussed and changes were made to the program to address the needs identified.

4.4 Findings

4.4.1 Diminishing capacity of residents to complete ACDs

Following implementation of the LMD ACP program, more than 50% of residents in each of the three study sites had some form of end of life care plan in place. Of the 70 residents who died in the post-implementation period, 14% had no care plan, 10% (with capacity) completed their own ACD; and lacking such capacity, 76% had EoLCPs completed for them by the medical team, following discussions with the resident (if able) and family.

From our audit of residents' completed ACDs, the majority choose (i) "No CPR"; (ii) "Basic feeding" (rather than "Tube feeding"); and (iii) either "Comfort/Palliative Care" or "Limited Care" (rather than "Surgical Care" or "Intensive Care"). Nursing staff reported that, in general, families were keen to be involved in the end of life care planning process, and that families of residents lacking capacity to complete an ACD, consistently asked for low levels of intervention at the end of life.

Legislative differences between Ireland and Canada necessitated alteration of the original LMD program for this study. In the original intervention, residents lacking capacity to complete an ACD, had a proxy (court appointed guardians, attorneys for personal care, family members or guardians) complete one for them. In Ireland however, the process of decision-making was dictated by the situation that prevailed at the time of the study (2013-2014) where the authority for treatment decisions for individuals lacking capacity was vested in the lead clinician. Policies such as the National Consent Policy (2014) and Irish Medical Council guidance explicitly encourage clinicians to consult with family of those lacking capacity, about the treatment and care of their loved ones, but how, precisely, this might be done was not clear.(334, 359)

The LMD program tried to address this issue. Where a resident lacks capacity to complete an ACD, this does not diminish the importance of their opinions and therefore any expressed views on end of life care were documented. Residents were encouraged to involve family in end of life care discussions. Capacity,

while traditionally seen as dichotomous, is increasingly recognized as being a more dimensional and inclusionary concept, not "black and white", but a spectrum of ability to engage in decision-making which may vary depending on the complexity of the decision being made. Assent refers to the approval of a decision by a person lacking capacity to manipulate information relevant to that decision.(360) As cognition decreases, so too does this ability to use information, leading to gradually reducing participation in the decision-making process and increasing reliance on others to contribute. In these situations, we strove to obtain assent, but a point came for many people e.g. those with advanced dementia, where the ability to assent or even contribute to decision-making became impossible and in these situations the entirety of decisions was made by others. Discussion ensued pertaining to the end of life care that would be of benefit to that individual, and their known preferences, beliefs and values. The LMD program encouraged discussion of end of life care issues and using a combination of a substituted judgment and best interests approach, allowed for plans to be formulated with information, time and consideration, rather than being made in a crisis situation.

4.4.2 **Communication difficulties with residents**

Hearing and other communication impairments presented important barriers to ACP. For many frail residents, the ability to concentrate during the ACP education process was limited to short time periods. Staff feedback on these issues led to the development of synopsized versions of the LMD educational material. Through further feedback, laminated cue cards were developed to provide visual imagery to facilitate delivery of educational material in bite-sized chunks.

4.4.3 **Staff training, confidence, availability and ownership**

The pre-implementation survey of nursing and medical staff (n=83) had a 51% response rate; over 50% of respondents had no palliative care training and only 40% felt confident discussing end of life issues with residents/families. Lack of staff education, lack of available education programs in the healthcare system, and a perception that residents/families may feel uncomfortable discussing end

of life care were identified as important obstacles. Directors of Nursing in each study site stated to release several staff at once for a full-day workshop would be difficult, so training was delivered over two half-days and an online learning module was developed to facilitate future training.

With introduction of the LMD program, nurse's role in ACP became far more substantial. They become the main drivers for the process. A small number of nurses, having attended the ACP workshops, were reluctant to take ownership of delivering ACP, seeing it as a role for management. To overcome this, live ACP demonstrations, with a sample of residents and families, were conducted for small groups of nurses.

4.4.4 **Time to deliver ACP to residents/families**

The pre-implementation staff survey found lack of knowledge about ACDs among residents and families and insufficient time for educating them, to be key expected barriers to ACP. Just as there were challenges in allocating time for staff training, feedback during implementation, identified lack of time to deliver ACP as the biggest challenge encountered, and that protected time would be needed to engage in ACP effectively. For residents lacking capacity to participate in ACP, the whole process was sometimes slowed down by family members having to consult with each other and achieve consensus on their understanding of what the resident might want (the question of *which family member* should be involved sometimes caused tension).

Senior nurses encountered difficulty in finding the appropriate time to introduce ACP to residents/families. When approaching residents who had been in LTC for longer periods, they were often suspicious as to what was prompting conversation around end of life care e.g. "is there something you know, that you're not telling me?" Routinely offering educational literature about the LMD program to all new residents/families on admission helped to address this.

4.4.5 **Non-recognition of ACD/EoLCP documentation**

In this study, there were isolated incidences of failure of out-of-hours doctors and ambulance staff to recognise the validity of signed ACD/EoLCP forms presented to them. Despite forms indicating 'no transfer if at all possible', they decided to hospitalise rapidly deteriorating residents. This could have related to lack of knowledge about the nature of the forms, or difficulty in establishing the validity of care decisions. Documents from the pre-implementation period often included no information on who was involved in the decision-making process or what the resident's decision-making capacity was at the time. This was important if a resident with capacity was excluded from discussions or, where the resident was involved, what their level of understanding had been. Where plans were made in collaboration with family, it was difficult to establish on what basis decisions were made e.g. whether representing the resident's previously expressed wishes or made using another approach. All these factors may have impacted on staff external to the study sites' interpretation of the care decisions made. The key challenges identified during implementation are shown in Table 3.

Figure 4.3 Key challenges identified in implementing advance care planning in long-term-care.

1. Diminishing capacity of residents to complete ACDs
Only 10% of residents had capacity to complete ACDs and the majority of residents with varying levels of capacity were more or less involved (with family members and health professionals) in EoLCPs for their care.

2. Communication difficulties with residents
Hearing and other communication impairments in LTC residents presented obstacles to ACP.

3. Staff training, confidence, availability and ownership
Over half of the staff surveyed had no palliative care training, lacked confidence in discussing EoL issues with residents and families. Staff release for the program

was difficult and some staff were reluctant to engage with it seeing ACP as a management role.

4. **Time to deliver ACP to residents/families**
Staff reported the lack of adequate time to deliver ACP and education to residents/families in a measured and inclusive way.

5. Non-recognition of ACD/EoLCP documentation by allied health professionals
Occasionally, out-of-hours doctors, ambulance staff, and hospital A&E staff did not recognise the validity of signed ACD/EoLCP forms.

4.5 Discussion

The challenges that we met and responded to in implementing the LMD program were fundamentally ethical in nature and were largely concerned with preserving the autonomy of residents, avoiding harm and ensuring that they were treated fairly. We address these issues in turn.

4.5.1 Preserving Autonomy

The standard view of an autonomous person in healthcare, is of someone with a sound understanding of the reasonable risks and benefits associated with their treatment and care, who can make decisions on the basis of their own beliefs and values, without the undue influence of others.(361)

The first and second challenges we encountered, related to the diminishing capacity of the majority of residents and the communication difficulties for some residents in understanding and completing ACDs, which clearly meant that many of these individuals did not fit with the standard view. This prompted us firstly to develop alternative means of involving residents in decision-making, thereby, preserving their autonomy. As outlined in the previous section, we developed an alternative communication process involving residents' loved ones and carers in the documentation of an end of life care plan rather than an ACD.

Secondly, we adapted our materials and the timing of their delivery so that residents with hearing or other impairments could more easily understand the information provided. In the course of adapting the decision-making and communication processes we were conscious that we were in uncharted ethical and legal waters in Ireland and, though guided by national policies and best practice elsewhere, we were mindful that any kind of surrogate decision-making is fraught with difficulties. Since our study was completed, the Assisted Decision Making (Capacity) Act 2015 gives legal force to a range of supported decision making processes as well as Advance Healthcare Directives in Ireland and it is anticipated that it will be supported by a Code of Practice for health professionals. The challenges that we met with in our study provide added rationale for the need for such formal and transparent protocols to ensure that the autonomy of individuals in healthcare settings is preserved and promoted. They also flag ethical quandaries that may persist however well crafted legislation on capacity and ACP may be.

A 2012 systematic review of four studies found limited evidence for the effectiveness of ACP in people with cognitive impairment in improving documentation of patient preferences for care or reducing hospitalisation rates.(362) Three of the four studies reported the deployment of formal processes of capacity assessment, and determined that up to 36% of participants only, were judged to have capacity. Whilst it may be reasonable to use a functional capacity assessment as a pre-requisite for the completion of a legally binding ACD, to use it as a requirement to engage in ACP means it will be too late for the majority of LTC residents to discuss their wishes. An overemphasis on autonomy sets the bar too high and undermines patient care by denying residents still able to express their opinions, of the professional guidance needed to make informed decisions. To do so diminishes their autonomy.

The new Assisted Decision-Making (Capacity) Act 2015 mentioned above, does not require any threshold conditions (such as the SMMSE or the SIACAD capacity test used in this study) for the completion of an ACD. Instead, it

provides mechanism for others, such as family members to assist in ACP completion.

Certainly our study underlines the importance of ascertaining people's wishes early on in dementia, before their ability to consider future care is compromised. It begs the question though; what is the best approach for those with diminished capacity, i.e. the majority of residents in our study? People with advanced dementia may lose the ability to express their views in any way, in these circumstances others will have to decide for them. Nevertheless people, whose dementia has not progressed to this extent, may still retain an ability to express their views and such views should not be dismissed, nor were they in this study. Yet, there remains concern about the actual level of involvement of family members; how consistent the EolCP was with the previous or current wishes of the resident and, finally, what happens if the reported wishes of the resident were at odds with what the lead clinician believed was in their clinical interests, though in practice, this was not encountered in this study.

Though family may be in a position to relay the previously expressed wishes of people with dementia prior to loss of capacity, the validity of surrogate decision-making has been challenged. The preferences of people with dementia and their loved ones may differ.(363) A review by Shalowitz found surrogates predicted patient's treatment preferences with only 68% accuracy.(2) A RCT of out-patients and their self-designated surrogates in the USA, found that having access to a patient's instructional ACD had little or no impact on the decisions made by surrogates in different illness scenarios.(128) Likewise, preferences for end of life decisions are often in flux, necessitating periodic reassessment, (364) particularly challenging in those with progressive cognitive impairment.

There are other issues with surrogate decision-making. The misperception that dementia is not a life-limiting illness may influence decisions made on behalf of the individual with dementia.(3) Lack of knowledge and understanding of the person with dementia's comorbidities, prognosis, or the likelihood for them, of a successful outcome with various life sustaining treatments may equally impact on decisions made. It is essential that decisions be based on fact and not

perception. A study by Diem et al examining survival rates following CPR on the then popular medical TV shows *ER, Chicago Hope* and *Rescue 911* found between 1994 and 1995, 77% were successfully resuscitated with at least 37% surviving to discharge, a depiction at odds with reality.(4) Portanova et al repeated this study in 2010 and 2011, coding CPR survival rates from medical TV shows *Grey's Anatomy* and *House*.(5) They found little had changed; 71.9% survived CPR to be discharged, and ACP discussions happened only twice. A study by Groarke et al found 70% doctors, 24% nurses and 0% of the public correctly estimated survival to discharge following in-hospital CPR attempts.(264) Many respondents, including some healthcare professionals, vastly overestimated the utility of CPR. The general public's expectations of CPR mirrored that portrayed on television; that 40-80% would survive to discharge post CPR. A study by Murphy et al found the proportion of older adults opting for CPR almost halved on learning the probability of survival.(112) This highlights the importance not only of patients and their family, but also healthcare professionals being adequately informed and the importance of educational and communication strategies between patients, their nominated proxies and healthcare professionals, regarding care preferences.

4.5.2 **Avoiding harm**

One of the tenets of biomedical ethics is to "do no harm" and there was an initial fear amongst staff in this study that discussing ACP would be upsetting to residents or their families.(365) Cited deterrents for doctors also included communication difficulties and anxiety that ACP discussions might deprive their patients of hope or cause distress.(247, 366) The latter may be unfounded.(111, 367) An Irish study found that 94% of older hospitalized patients thought it a good idea for doctors to discuss CPR with patients, only 5% found discussing CPR upsetting, but anecdotally most of them still valued the discussion.(111) Staff reported similar findings in our study, stating any distress was more their own fear of end of life conversations rather than that of the residents. Staff reported their own anxiety quickly dissipated with use of the LMD program.

Moving to reside in LTC represents a major life event, which may prompt consideration of one's own mortality and presents an opportune time to discuss end of life care. Central to the older person's ability to discuss end of life care, is their acceptance of being in a care home, the extent to which they believed they could influence decision-making within their everyday lives and the involvement of family members in making decisions.(343) In completing an ACD, there is a desire amongst patients for the doctor to initiate the discussion.(368) But the challenge is, when to initiate discussion.(369) Introducing the LMD program to residents who had been in LTC for a considerable time, initially raised suspicions in some, as to why the topic was being addressed. This and other factors lead all of the study sites, to move towards introducing the LMD program to new residents early on and once the resident had "settled in" to LTC, inviting them to consider their care wishes.

Our findings were consistent with a recent Australian study of the quality of ACP policy and practice in LTC facilities, which concluded that a systematic approach to ACP implementation is required to maintain best practice.(370) Having a structured ACP program in place can be a powerful tool for LTC staff in initiating difficult conversations about end of life care with residents/families, and can offer a framework for discussion. While it is useful for nurses to follow a structured ACP process, it is important to avoid it becoming a "tick box" exercise. A person-centred approach more readily encourages residents' meaningful participation.(371)

One of the key targets identified by Billings in delivering effective ACP is developing systems to ensure residents' ACDs are quickly locatable, up-to-date, and easily transferable between different care settings.(372) For someone to go through the process of planning future care only for documentation to be ambiguous or irretrievable is indefensible. The LMD program incorporates standardized procedures and documentation, clarifying the validity of decisions made, and consistency in documentation storage ensures speedy retrieval.

Finally, healthcare professionals, in particular those in the emergency services, need to be educated about ACDs and the harm that can ensue as well as the

ethical and legal implications of failing to respect a patient's recorded wishes. Variations in ACD legislation across different countries may lead to uncertainty about 'what is legally binding' and make staff wary of following ACDs.(373) Staff from all disciplines need to be confident in observing a person's autonomy and supported so they do not fear criticism in following an ACD, particularly one requesting active treatment *not be* given.(136)

Many differences exist between countries with regard to the cultural aspects of discussing death, LTC population profiles, public and professional awareness of ACDs and ACD legislation, including how it defines the decision-maker in situations of varying capacity. Thus some of this study's findings may not be applicable across all jurisdictions.

4.5.3 **Distributive Justice**

In healthcare, distributive justice involves the fair or equitable distribution of finite resources. Time is the key resource in successful ACP implementation. Effective ACP may involve lengthy discussions with residents/families and requires healthcare staff to be knowledgeable and confident in their ability to deliver ACP in a sensitive, patient and supportive way. Lack of continuity and time for educating and discussing treatment decisions are frequently cited barriers to ACP by both doctors and nurses.(368, 374, 375) Challenges reported in our study included the bottleneck in the ACP process presented by the labour-intensive nature of educating residents, lack of time and practical experience. Time taken for ACP with one resident is time taken from other areas of care of all residents. Nevertheless, time should be allocated in an equitable way so that those who are most disadvantaged and in greatest need, can benefit. Access to treatment and care, while constrained by the availability of resources, should not be restricted on the basis of age, disability, psychological or intellectual impairment.(376)

Problems such as the allocation of staff time among residents with varying needs could be minimised by the appointment of an ACP facilitator with specialist training. In addition, the development of a blended online learning program (including face-to-face simulation-based training) may help

standardise and facilitate convenient delivery of a comprehensive ACP education for LTC staff, thus promoting confidence and ensuring that both staff and residents are comfortable with and understand the process of planning for the future. In the UK, a qualitative study of professionals' experiences of ACP in dementia identified a lack of 'ownership' of the process, with no single group considering assessment of capacity as their responsibility.(136) This highlights a need for greater clarity regarding the roles and responsibilities of different professional groups, as we found in our study, and suggests that specialist skills may be required to deliver the more complex aspects of ACP.

If ACP can be time consuming, it is this time taken for education and discussion that make ACP care choices so much more valuable than those made when a health crisis has occurred. Decisions made in a crisis situation are likely to be strongly influenced by the crisis itself. This is just as applicable for the patient, as it is for their family. Key factors in decision-making include prognosis, risk-benefit analysis of the proposed interventions, symptom burden, temporal pattern of illness, patient's age, life stage and goals of care.(377) Understanding these issues can take time, but correcting misconceptions can strongly influence treatment choices made.(112)

On the basis of challenges identified in this study, key recommendations for ACP implementation are summarised in Table 4.

Figure 4.4 Recommendations for implementing a program of advance care planning in the long-term-care setting

- Deliver a comprehensive ACP education package to LTC staff
- Implement a comprehensive policy on ACP, tailored to each nursing home's individual requirements
- Provide a structured ACP process for staff to follow
- Clarify who is responsible for different aspects of the ACP process
- Provide staff member(s) with specialist training to act as ACP facilitators and provide protected time for engagement in ACP
- Provide appropriate educational material for residents/families

(culturally-sensitive, appropriate literacy level, large print versions, bite-sized chunks of information)

- Include education of GPs as part of program implementation
- Promote open communication between nursing staff, residents, families and doctors
- Design systems within the nursing home so that ACD/ACP forms are accessible and all staff are aware of their existence and content
- Provide information to out-of-hours doctors, emergency ambulance services, and local hospital emergency departments on the ACP program
- Promote communication and collaboration between LTC staff, GPs (including out-of-hours), emergency ambulance services and specialist palliative care doctors
- Ensure ACD/ACP forms are easily interpretable by different groups of HCPs
- Ensure procedures are in place for LTC staff to access advice from specialist palliative care services outside of traditional hours
- Design systems for seamless transfer of ACP information between different healthcare settings
- Implement quality assurance systems in place in the nursing home
- Allow time for embedding.

4.6 Conclusion

Despite the challenges encountered, staff reported that the LMD program improved their ability to engage in difficult conversations around death and dying with both residents and families. Over 50% of residents in each of the three LTC facilities had a plan for end of life care in place, as did 86% overall of residents who died (suggesting that staff may prioritise ACP for sicker residents). With the support of management, staff willingly overcame challenges and took ownership of the LMD program, once the beneficial effects of their efforts became apparent in practice for the longer term.

In short, the LMD program offered a systematic approach to structured end of life care planning in LTC for both residents with and without capacity to complete their own ACD. Implementation is an iterative process, whereby changes are made, observed and then modified to meet the needs of staff, residents and families. Embedding the LMD program in LTC requires time. While ACP in LTC can be challenging and laborious, it can open lines of communication and enhance peace of mind for all involved, while promoting residents' autonomy. In essence, the benefits far outweigh the challenges to implementation. As few studies have investigated these benefits in suitably powered RCTs(378)

future validation of ACP programs such as LMD should incorporate qualitative as well as more quantitative outcomes measures.

Chapter Five: Palliative Care Education in Long Term Care

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5 Palliative Care Education in Long Term Care

5.1 Palliative care and end-of-life care planning knowledge, attitudes, and self-perceived educational needs and barriers: long term care healthcare staff opinion

5.1.1 Abstract

Background

Rising life expectancy, a growing older population and societal trends, have led to increasing numbers of older people residing and ultimately dying in long term care. Research has found those dying in long term care have unmet palliative care needs and there is suboptimal palliative care education amongst long term care staff. It is essential therefore that long term care staff be knowledgeable, skilled and supported in providing high quality end of life (EoL) care. Education is optimised if staff's training needs are considered. This study aimed to assess these needs and the impact of a general palliative care educational program on staff perceptions and confidence in providing EoL care for residents in three long term care facilities

Methods:

In this quantitative descriptive study, long term care staff completed detailed questionnaires before, and after delivery of a palliative care educational program tailored to the educational needs identified by staff, which included advance care planning (ACP) training.

Results:

There were 179 completed questionnaires. Before the program, at least 43% had some PC training, this improved post intervention to at least 68%, which 92% of attendees found useful. Though they had many common learning needs, more nurses sought training on pain and symptom management, while healthcare assistants wanted symptom assessment, recognising dying and addressing patient's emotional needs. Staff with training showed improved knowledge, reported greater confidence in discussing EoL issues and dealing with bereaved families, and more engagement in advance care planning (ACP).

Nurses with training were more confident and knowledgeable in using a syringe driver. There were differences in perceived barriers to ACP for staff engaged in ACP and those who were not. Delivering education was challenging particularly with difficulty releasing staff to attend.

Conclusions:

The tailored palliative care training was well received and had a beneficial effect. PC education was associated with greater knowledge and confidence in providing end-of-life care and a trend to greater engagement with ACP in those who also received this training as part of the study's educational initiative.

5.1.2 **Introduction**

There have been major changes in recent decades in where, how and at what stage of life people can expect to die. People are living longer than ever before and can anticipate life into their 80's in many developed countries. In the next 30 years, life expectancy in Ireland is predicted to reach 86.5 years for men and 88.2 years for women.(198) Currently, 4.5% of the Irish population aged over 65 years, resides in long-term care.(379) In the next 30 years, this age group is predicted to double, with those aged over 85 years trebling (of whom 21% are long term care residents).(198) With advancing age, accumulating co-morbidities and an increasing prevalence of life-limiting conditions, the likelihood of admission to long term care rises (174, 200, 202, 203, 210, 214, 380-383) Increasingly it is in long term care where older people live out their last days and ultimately where they will die.(200, 214)

The "medicalization of death" has contributed to the growth seen worldwide in the proportion of deaths occurring in long term care including United States of America (USA)(210) the United Kingdom (UK)(202, 203) Japan and Australia.(380-383) In 1885, 85% of Irish deaths occurred at home, by 2010 only 26% died there.(384) An equal proportion (25%) die in long term care.(174) Similar figures are reported worldwide.(200)A 20% increase in the proportion of deaths in long term care is predicted by 2030, when only 1 in 10 UK deaths are expected to occur at home, a trend that is set to continue.(383) Considering rising life expectancy, a growing older population and societal

changes, this trend is likely to continue. It is therefore essential that long term care staff are knowledgeable, competent, confident and supported in providing high quality palliative care to older patients.(217)

Unfortunately there is evidence of unmet palliative care needs in those dying in long term care (201, 211, 240) and that bereaved carers are often dissatisfied with their relatives' end-of-life (EoL) care.(241) People dying in long term care often have distressing symptoms, which may go unrecognised and undertreated.(261) They experience similar symptoms to people dying elsewhere, the commonest being; fatigue, pain, dyspnea, constipation, anorexia, confusion and incontinence.(385, 386) The resources, skills and knowledge to adequately manage these symptoms and to provide a high standard of EoL care are sometimes lacking in long term care.(217, 238, 239, 387)

Primarily, it is general practitioners, nursing staff and care workers who deliver general palliative and end-of-life care for most people dying in the community or long term care. Long term care staff have been found to have suboptimal palliative care training and fewer educational opportunities than in acute care.(217, 239, 291, 294, 302, 387-392) Staff's considerable educational needs have been described in several studies and they particularly request teaching on symptom management, communication skills and bereavement care.(239, 294, 389, 391, 393-395) Evidence suggests training that incorporates the educational needs, existing skills and knowledge of participants works best.(396, 397) Palliative care education has been associated with improved EoL care and support for long term care residents and their family, reduced death anxiety, improved staff attitudes to death and dying and capacity for EoL care discussions with patients and their family. (235, 397-402)

This study aimed to identify the palliative care learning needs of long term care staff from mixed settings and assess the effect of delivering a tailored education program on staff's confidence in and knowledge of palliative care and their capacity to engage in an element of care requiring good communication skills and confidence in handling EoL issues: advance care planning.

5.1.3 **Methods**

This study used a descriptive survey design, which recruited nursing and healthcare staff from three geriatric long term care facilities in Southern Ireland which included; a public community long term care hospital, a voluntary, and a private nursing home. These sites were part of a larger study investigating the effects in long term care of an advance care planning (ACP) program using the 'Let Me Decide' advance care directive (ACD), and accompanying palliative care education for staff (see below). In total, these sites had 288 long term care residents and employed 122 Nurses and 182 Healthcare Assistants (HCA). Staff were surveyed between September 2012 and February 2013, before implementation of the ACP program and palliative care training in late February 2013. Those surveyed formed the "Before" group. Staff were surveyed again in May 2014 once education and the program became embedded in the care culture of each site; this formed the "After" group. Each site's senior management and nursing staff fully supported the program.

Distribution

Questionnaires, with an explanatory cover letter, were distributed to all staff at each site. Completed questionnaires were returned to a sealed collection box or by post using pre-paid, pre-addressed envelopes to maintain respondent's anonymity. Reminders to encourage staff response were given verbally and once in writing.

Questionnaire

The semi-structured questionnaire contained a mixture of closed and open-ended questions and items rated using a Likert-type scale. It's eight sections included; demographic details; perceived palliative care educational needs; barriers/facilitators to education; educational format; views on ACDs; and barriers/facilitators to ACP in an older long term care population. These sections were taken with permission from a survey developed by Molloy et al.(403) Following a literature review, two consultant geriatricians in collaboration with senior nursing colleagues (all with palliative care experience), expanded and developed the questionnaire's palliative care section

further, to include staff's understanding, knowledge and confidence in palliative care.

Palliative Care Education

The study's palliative care education was refined based on the learning needs and knowledge gaps identified by the questionnaire and a literature review. The syllabus also benefited from the core skills and educational areas defined in Irish Health Service Executive Palliative Care Competence Framework which was gratefully shared with the study group as a nearly finalised draft.(404) The palliative care competence framework was developed by the National Clinical Program for Palliative Care. A multiagency, multidisciplinary working group collaboratively developed the framework which describes the core competencies expected for a variety of disciplines. The education comprised of six modules delivered on one full-day or two half-days depending on site preference, repeated as often as needed. Staff from each site were free to attend training in any of the other sites. The first three modules; principles of palliative care; communication; loss grief and bereavement were for both nurses and HCAs who attended together. The second three modules intended for nurses only covered: optimising comfort and quality of life; ACP; and related ethical and legal considerations.

Advance Care Planning Education

In each site, a cohort of staff also received training in ACP using the 'Let Me Decide' program. This included EoL care planning for those with diminished capacity to complete an ACD. The program developed by Molloy et al was researched in Canada and Australia.(144, 233, 405) Due to legislation differences, the program was modified for use in an Irish long term care setting as described in chapter 3. Barriers to ACP were compared for staff with ACP training who had and had not engaged in care planning with residents or their families.

Data Analysis

Data were analysed using SPSS software (version 20) with a 2-sided type 1 error rate of 0.05. Descriptive statistics were used. Categorical variables were

compared using the chi-square test. Additionally, a stepwise logistic regression analysis was performed to identify factors associated with having confidence to discuss end-of-life issues with residents or their families (dichotomised as confident or not) once "After" respondents who indicated they had completed the "before" survey were excluded.

5.1.4 **Results**

In total 179 completed surveys were returned. Most "before" respondents (87%) were nurses, whereas "after" respondents were split between nurses (48%) and HCAs (52%), despite any discipline being eligible to complete it. Nursing response rates "before" were 61% (n=74/122), and 36% "after" (n= 44/122), HCA's response rates rose from only 2% (n= 4/182) "before" to 26% (n= 48/182) "after". The majority of staff were female and had high levels of professional experience; their demographics are summarised in *table 5.1*.

Table 5.1. Characteristics of respondents

Characteristic	**Before**		**After**	
	%	**n**	**%**	**n**
Participants		86		93
Female	98.5%	(67/68)	90%	(84/93)
Age, years	Mean =44.8 (SD=10.47, Range=23-64)		Mean = 43.1 (SD=11.88, Range=21-63)	
Age 20-29 years	7%	(6)	18%	(16)
Age 30-39 years	27%	(23)	22%	(20)
Age 40-49 years	29%	(25)	21%	(19)
Age 50+ years	36%	(31)	39%	(35)
Occupation				
Nurse	87%	(74/85)	48%	(45/93)
Healthcare assistant	5%	(4/85)	52%	(48/93)
Other [a]	8%	(7/85)	0%	(0/93)
Years Experience	Mean= 20.2 years (SD=10.0, Range=0-43)		Mean =17 years (SD=11.7, Range=1-41)	
Long-Term Care Facility Type				
Private nursing home	22%	(19)	58%	(49)
Public nursing home	32%	(27)	18%	(15)
Community hospital	46%	(39)	24%	(20)

[a] = Doctor n = 3, Administrator n = 2, Physiotherapist n = 1, Occupational therapist n = 1

Palliative Care Education

Many staff reported having received little or no palliative care training before this study *(table 5.2)*. Staff's level of palliative care training varied widely, ranging from some who had attended day courses to a minority with training to diploma level (1%). Very few respondents ("before": n=4, "after": n=2) had worked in a specialised palliative care environment, and then only briefly (range 6 months (n=3) to 2 years (n=1). Overall, at least 43% (n=34) had some training in the "before" period, which improved post intervention to at least 68% (n=63). Only 20% (n=18) of "after" respondents had attended the palliative care training provided in the study; half of these were nurses. Of training attendees, 92% (n=11 of 12 who answered) found it useful.

Table 5.2: Respondent's self-reported palliative care training experience before and after the palliative care education program

	Before		**After**					
			Total		**Nurses**		**HCAs**	
Characteristic	n	%	n	%	n	%	n	%
Respondents	80		93		45		48	
Palliative Care Training Level								
Diploma	1	(1%)	1	(1%)	1	(2%)		
Certificate	4	(5%)	9	(10%)	6	(13%)	3	(6%)
~ Week long course	16	(20%)	7	(8%)	4	(9%)	3	(6%)
Day course	5	(6%)	13	(14%)	6	(13%)	7	(15%)
Other	8	(10%)	33	(36%)	12	(27%)	21	(44%)
Training Summary								
Some Palliative Care Training	34	(43%)	63	(68%)	29	(64%)	34	(71%)
No Palliative Care Training	9	(11%)	18	(19%)	10	(22%)	8	(17%)
Didn't answer	37	(46%)	12	(13%)	6	(13%)	6	(13%)

Concept of Palliative Care

Participants were asked to define "palliative care", 76 responses were received from the "before" period and 70 from the "after" period. Most staff interpreted "palliative care" as EoL care (n=90, 62%), that encompasses symptom management (n=73, 50%), using a holistic approach that aims to improve quality of life (n=25, 17%) and maintain patient comfort (n=40, 27%). Nurses were significantly more likely than HCAs to view palliative care in terms of

symptom management (n=60/103 nurses vs n=10/32 HCAs, χ^2 =7.13, p=0.008). While most respondents (n=120) framed the target of care as the patient, 25% (30 of 120) also included their family. Nurses were significantly more likely to include family than HCAs (n=26/105 nurses vs n=2/32 HCAs, χ^2= 5.357, p=0.021). Some staff saw palliative care as a specialised area (n=4, all from "before"), some included the multidisciplinary team (n=5), others palliative care's role in a "natural" death (n=2), in living well until death (n=6) and promoting patient autonomy (n=4, all from "after").

Palliative Care education needs

Staff identified their learning needs from 36 listed topics (or suggested other needs) and then ranked these subjects' importance. Using free text, they could also suggest other learning needs they might have. Each topic was acknowledged as a learning need by at least half of staff (*table 5.3)*. Even for staff with higher levels of training, i.e. diploma or certificate, most topics remained important. Irrespective of prior training, occupation or time (before or after), some topics were ranked highly by the majority:

- understanding and managing the emotional needs of the dying person and their family;
- the physiological impact of life-threatening illnesses;
- pain assessment.

Topics deemed more important by nurses than HCAs were:

- the pharmacological and non-pharmacological management of pain
- the management of a "death rattle" and respiratory symptoms and
- the ethical, religious, and legal issues of end-of-life care.

Whereas more HCAs than nurses wanted teaching on

- the diagnosis of death and
- the physical changes as it approaches.

Table 5.3. Staff self-reported palliative care education needs

Educational topics	% of respondent group identifying each topic as a learning need				
	Nurses			HCAs	Total
	Total	Before	After		
Pharmacological management of pain	93 ^	91 ^	95 ^	65 *	83 ^
Non-pharmacological pain management	88 ^	87 ^	90 ^	65 *	81 ^
Pain and symptoms assessment	85 ^	87 ^	83 ^	74 ^	81 ^
Advance directives and power of attorney	84 ^	84 ^	85 ^	70	80 ^
Understanding the emotional needs of the dying person	84 ^	87 ^	80	78 ^	75
Managing the emotional impact on families as death nears	83 ^	84 ^	83 ^	74 ^	82 ^
Understanding life-threatening illness' physiological impact	83 ^	79	88 ^	76 ^	83 ^
Ethical, religious, & legal aspects of dying	83 ^	81 ^	85 ^	65 *	77
Respiratory secretion/ "death rattle" management	83 ^	84 ^	80	72	79 ^
Management of grief & bereavement	81	81 ^	80	70	79 ^
Staff stress management	80	79	80	70	78
Individual/family crisis management	79	78	80	65 *	75
Individual/family stress management	79	79	78	70	76
Confusion & agitation assessment & management	79	78	80	74 ^	77
Stages of dying	79	79	78	78 ^	82 ^
Culture and death	78	76	80	70	75
Determining mental competency	78	76	80	67	75
Dyspnoea assessment and management	78	78	78	65 *	72
Primary roles of the palliative care team ^	77	76	78	76 ^	78
Understanding personal autonomy	75	72	80	76 ^	75
Individual/family support services	75	75	76 *	72	75
Family counselling	74	72	78	65 *	72
Nausea assessment and management	74	72	78	67	72
Communication & history-taking skills	73	71	78	70	72
Physical changes as death approaches	73	68 *	83 ^	78 ^	76
Individual/family spiritual needs	73	72	76 *	72	74
Impaired swallow assessment & management	72 *	69	78	72	71 *
Dehydration assessment & management	72 *	68 *	78	76 ^	73
Loss of appetite/weight/taste assessment and management	72 *	68 *	78	67	71 *
Sleep disorder assessment & management	71 *	69	73 *	57 *	66 *
Fatigue management	70 *	63 *	80	67	69 *
Nutrition as death approaches	70 *	68 *	73 *	67	72
Diagnosing dying	67 *	66 *	68 *	74 ^	68 *
Maintaining mobility/preventing complications of immobility	62 *	56 *	73 *	70	64 *
Incontinence assessment & management	59 *	56 *	73 *	70	64 *
Maintaining self-care (e.g. mouth care)	40 *	49 *	71 *	70	61 *

Staff Confidence in End-of-Life care

Staff confidence in EoL care issues is presented in Table 5.4.

Table 5.4: Staff self-reported confidence in End-of-Life Care

Respondent Group	Unconfident		Neutral		Confident	
	%	n	%	n	%	n
Q 1. How confident do you feel discussing end-of-life issues with a resident or their family?						
Before						
Total	**43%**	(32/75)	**16%**	(12/75)	**41%**	(31/75)
Nurses	**42%**	(27/65)	**15%**	(10/65)	**43%**	(28/65)
HCAs		(1)		(2)		
After						
Total	**31%**	(29/88)	**22%**	(20/88)	**42%**	(39/88)
Nurses	**29%**	(12/42)	**24%**	(10/42)	**48%**	(20/42)
HCAs	**37%**	(17/46)	**22%**	(10/46)	**41%**	(19/46)
Nurses						
With PC training	**19%**	(10/54)	**13%**	(7/54)	**69%**	(37/54)
Without PC training	**55%**	(27/49)	**24%**	(12/49)	**20%**	(10/49)
Q 2. How confident do you feel dealing with bereavement issues with a resident's family?						
Before						
Total	**32%**	(24/76)	**21%**	(16/76)	**47%**	(36/76)
Nurses	**27%**	(18/66)	**23%**	(15/66)	**50%**	(33/66)
HCAs		(2)		(1)		
After						
Total	**34%**	(30/88)	**18%**	(16/88)	**48%**	(42/88)
Nurses	**31%**	(13/42)	**19%**	(8/42)	**50%**	(21/42)
HCAs	**37%**	(17/46)	**17%**	(8/46)	**47%**	(21/46)
Nurses						
With PC training	**15%**	(8/53)	**15%**	(8/53)	**70%**	(37/53)
Without PC training	**42%**	(21/50)	**28%**	(14/50)	**30%**	(15/50)
Q 3. How confident do you feel setting up and using a syringe driver to deliver medications to a person at the end of life? [a]						
Before	**34%**	(27)	**15%**	(11)	**46%**	(36)
After	**29%**	(13)	**16%**	(7)	**49%**	(22)
Nurses with PC training	**22%**	(12/54)	**15%**	(8/54)	**63%**	(34/54)
Nurses without PC training	**44%**	(22/50)	**16%**	(8/50)	**40%**	(20/50)

[a] only nurses and doctors are included in this part of the analysis on syringe drivers, as non-clinical staff and HCAs would not be expected to have this skill

The topics cited least often across both disciplines were:

- Assessment and Management of Incontinence
- Assessment and Management of Sleep Disorders
- Maintaining Mobility/Preventing Complications of Immobility

  Maintaining Self-Care Activities (e.g. Mouth care)

Logistic regression analysis (including the predictive variables; having had any palliative care training, occupation, years of experience, type of long term care facility, and time-period) showed having prior palliative care training was the only variable predictive of a respondent having confidence to discuss EoL issues with residents or families (odds ratio (OR) = 8.08 (95% confidence interval (CI) 3.329-19.612), $p<0.001$), the other variables were not significant.

Syringe driver

Respondents were asked when they would use a syringe driver; they indicated its purpose at the EoL (before: n=25/69, after: n=19/57) to provide medication for symptom management (before: n=43/69, after: n=39/57), when swallowing was difficult (before: n=32/69, after: n=24/57) or when oral or stat doses given *pro re nata* (PRN, "when necessary") were no longer working (before: n=13/69, after: n=6/57). It was considered a delivery route that gave constant symptom relief (before: n=10/69 after: 10/57) avoiding the need for repeated injections (before: n=11/69, after: 6/57). Pain was the commonest symptom mentioned (before: n=31/43, after 28/39), followed by nausea (before: n=14/43, after: 8/39). There was a sense amongst some, that the syringe driver was a panacea for comfort irrespective of what it contained or the dosage; that it was more potent than any oral treatment.

Whether a syringe driver shortened or prolonged a person's life produced mixed views; 29% (n=35/122) believed it shortened life, but many believed it depended on the person and their condition. Responses were analogous irrespective of palliative care training (with: 28% (n=20/96) vs without: 31% (n=14/45)), or time-period ("before": 29% (n=19/65) vs "after": 28% (n=16/57)). Other staff qualified their responses by saying they didn't know, or that it didn't matter, as the priority and purpose of using a syringe driver was to maintain patient comfort and provide a better quality of dying experience.

Nurses and doctors were asked to name up to 5 medications deliverable through a syringe driver and their indication for use (*table 5.5)*. All indications given were correct, but some listed medications are unavailable in Ireland (e.g. diamorphine) or not formulated for syringe driver administration (e.g. DF118,

cyclimorph™, oromorph™). Most suggested midazolam's use for agitation; but few linked it with relieving dyspnoea and a minority in treating seizures; morphine was predominantly seen for its analgesic effects. Knowledge was lacking on which drugs can be combined in a syringe driver (*table 5.6)* and on diluents.

Table 5.5. Medication proposed for use in a syringe driver

Medication	**Before (n=69)**		**After (n=41)**	
	n	%	n	%
Morphine	66	95%	41	100%
Midazolam	50	72%	35	85%
Hyoscine	62	90%	33	80%
Cyclizine	28	41%	20	49%
Metoclopromide	26	38%	20	49%
Levomepromazine	15	22%	6	15%
Haloperidol	14	20%	7	17%
Cyclimorph™	5[a]	7%	5 [a]	12%
Diamorphine	4[b]	6%		
Prochlorperazine	4	6%	3	7%
Saline	3	4%		
Hydromorphine	2	3%		
Oxycodone	1	1%	2	5%
Isolated medications	Dexamethasone, DF118™ [a] , Insulin [a] , Noradrenaline [a] Pethidine, Oromorph™, had 1 response each (1% each)		Dexamethasone [a] , Insulin, Ondansetron and Diazepam had 1 response each (2% each)	

[a] = response of one respondent without palliative care training

[b] = response of four respondents without palliative care training

Figure 5.1: Responders ability to name medications used in a syringe driver

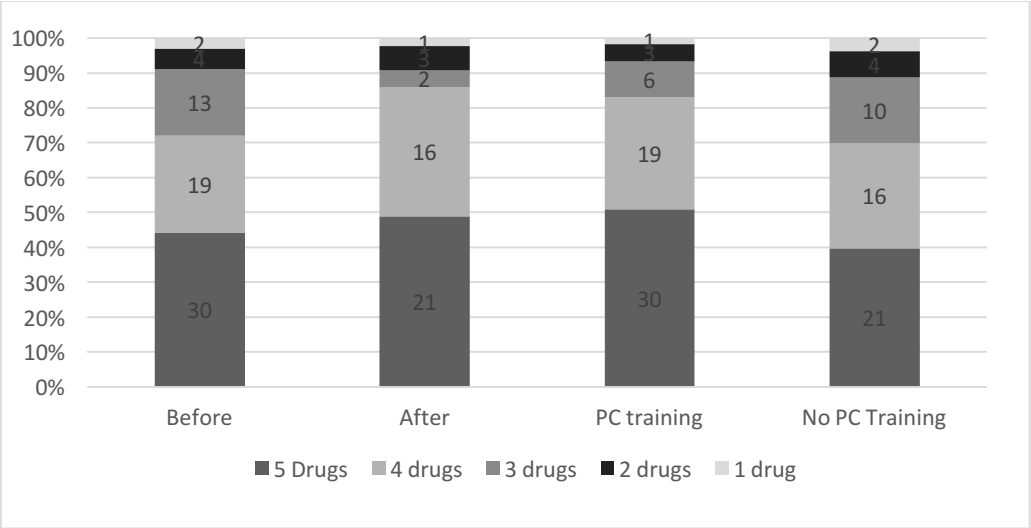


Table 5.6. Knowledge of drugs that can be combined in a syringe driver

Drug Combination	Survey period	Can be combined		Cannot be combined		Unsure	No response
		%	n	%	n	n	n
Cyclizine and Morphine	Before	54%	(39/72)	7%	(5/72)	18	10
	After	69%	(31/45)	0%	(0/45)	6	8
	With PC training	68%	(41/60)	2%	(1/60)	11	7
	No PC training	54%	(27/50)	8%	(4/50)	12	7
Cyclizine and metoclopro-mide	Before	8%	(6/72)	35%	(25/72)	22	19
	After	4%	(2/45)	53%	(24/45)	10	9
	With PC training	8%	(5/60)	42%	(25/60)	20	10
	No PC training	6%	(3/50)	44%	(22/50)	11	14
Morphine and metoclopro-mide	Before	47%	(34/72)	4%	(3/72)	21	14
	After	69%	(31/45)	0%	(0/45)	10	4
	With PC training	60%	(36/60)	2%	(1/60)	16	7
	No PC training	52%	(26/50)	4%	(2/50)	13	9

Note: only nurses and doctors are included in this analysis, as other staff would not be expected to have this knowledge

Referral to Specialist Palliative Care Services:

Awareness of how to access specialist palliative care services was good. The reasons cited for referral included; advice and help on symptom management (pain, agitation, nausea), particularly if proving difficult, advice on analgesia, need for equipment (syringe driver), and support for the resident and their family.

Advance Care Directives and Medical Decision-Making for those with Advanced Dementia

Staff were asked their opinion on advance care directives and advance care planning by asking them to rate to what extent they would agree with a series of statements. This section of the survey was taken from the previous survey used by Molloy et al described above. Staff responses are presented in Table 5.7.

When asked "who makes medical decisions for someone with advanced dementia?"; 50% responded correctly, but 23% (39% HCAs, 16% nurses) believed the family are responsible, which was not the current legal situation in Ireland. Time period, discipline and training in palliative care did not appear to influence the result. Only a minority (5%) included the patient in the decision-making process.

Previous staff ACD experience improved from only 32% of nurses before (n=8/25, of whom 5 had completed an ACD with a resident) to 52% nurses (n=23/44) and 2 HCAs "after". This section of the questionnaire had a poor response rate in some groups ("before" nurses 34%, n=25/74, and "after" HCAs 21%, n=10/48 who may not have seen this as their role).

Of "after" respondents, 23 nurses and 2 HCAs had received 'Let Me Decide' ACP training and 86% (n=22/25) found it useful. Despite 73% (n=11/15 who answered) of them feeling moderately to very confident in conducting ACP with residents, only a third (n=7) had engaged in ACP. One additional nurse was also doing ACP after being trained by an experienced colleague.

On a scale of 1-5 (easy-difficult) on how it was to get families involved in care planning for a resident, "after" staff indicated it was somewhat easy with family

of residents with capacity (mean of 2.64, SD 0.86), but a little easier with family of residents lacking capacity (mean 2.8, SD 1.08). All except one of those active in conducting ACP had completed palliative care training, almost all (n=11/13, 2 non-response, 1 neutral) felt confident in dealing with EoL issues with residents and bereavement issues with their families (n=9/13, 2 non-response, 2 neutral).

Barriers' to completing advance care directives

Barriers to ACD completion were measured using a 33-item questionnaire. The barriers most frequently cited (by over 80% of the sample) were: the lack of knowledge of ACDs in residents/their families and finding sufficient time for education; people's hearing or communication impairment; those needing more time; insufficient education about ACDs throughout the healthcare system and the public; and conflicting opinions within a family (table 5.8).

Factors influencing the format of education delivery

Participants in the "before" period provided information on their preferred learning formats. Several factors were important influences on staff attending education: its location (66%, n=57), timing (38%, n=33), attending during time-off (23%, n=20), loss of pay for attending (16%, n=14), and the teaching format (9%, n=8). Free text responses qualified these areas further.

Location: Most respondents wanted training locally either in the workplace or nearby due to competing domestic commitments, convenience, travel time and cost and parking issues. They asked that training be open to staff from other sites so they could gain knowledge "from other people's experiences in other nursing homes or healthcare facilities".

Cost: The personal cost in terms of time, travel and parking was emphasised. Some staff sought training (n=4) or their attendance (n=7) be paid for by the employer. One respondent highlighted the potential cost to employers for locum staff to cover absences due to training.

Timing: It was clear from responses that any education would be in competition with both domestic and work-related obligations; childcare issues, spousal work patterns, and the need for "work-life" balance were cited.

> "domestic commitments would prevent long distance travel"
> "I need my days off for me"
> "if it is considered as work or paid workshop and is calculated along within 40 hour week. I'm married, have 2 small kids and my time off is important to me as much as my work. There has to be a balance I'd say."
> "if it was incorporated as part of my working week. Would find it hard to come in when off duty"

Table 5.7. Staff attitudes on advance care planning and advance care directives

Question	Period	Response, %				
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Every competent person has the right to accept or refuse medical treatment	Before	-	-	-	69	31
	After	1	1	2	27	69
Every competent person can complete an ACD	Before	-	-	3	39	59
	After	1	2	1	31	65
ACDs are a way of getting rid of old people	Before	83	18	-	-	-
	After	76	20	3	1	-
HCPs are the best people to make health decisions for patients	Before	9	48	27	13	3
	After	9	36	27	16	12
A patients family are the best people to make health care decisions when a patient no longer can and has no ACD	Before	8	33	28	28	3
	After	7	34	27	23	10
There is a need for patients to become more involved in their health care decisions	Before	3	-	-	45	52
	After	4	2	3	42	48
If people are allowed to make their own health care decisions, they will usually make the wrong decision	Before	35	54	8	2	2
	After	32	54	11	3	-
People who complete ACDs should be allowed to leave instructions which others may feel are not in their best interest	Before	5	14	13	55	14
	After	4	18	13	45	20
ACDs can make the decision-making process for HCP easier, by letting them know the patients and family's wishes	Before	2	-	2	45	52
	After	-	3	1	47	48
Every competent person should be required to complete an ACD	Before	3	23	25	34	15
	After	2	11	19	34	34
ACDs can contribute to a better patient/HCP relationship	Before	-	3	12	48	37
	After	-	3	17	41	40
ACDs are a step on the road to legalised euthanasia	Before	49	38	13	-	2

	After	38	32	21	8	2
The elderly should be allowed to request intensive care treatment	Before	-	3	22	52	23
	After	1	5	12	50	32
ACDs are a positive step towards greater patient autonomy	Before	-	2	5	62	32
	After	-	-	14	56	30
HCPs should be required to follow ACDs	Before	-	3	2	67	27
	After	-	3	9	43	45

Abbreviations: ACD = advance care plan, HCP = Healthcare professionals

Table 5.8. Staff perceived and experienced barriers to advance care directive use and advance care planning

Question: In your work do you encounter any of the following potential barriers to the use of advance care directives?						
Barriers		**Identified barriers**				
		Before		**After**		**% Change**
		Total	**n1**	**Total**	**n1,n2**	
		%	n1[a]	%	(n1, n2)[a]	
1.	Finding sufficient time to educate patients /residents about ACDs or having ACP discussions?	96	(4/5)	83	(8, 8)	-13
2.	Elderly people with hearing/other communication impairments/who need more time?	91	(4/5)	91	(8, 10)	0
3.	Conflicting opinions among family members when filling out ACDs?	86	(4/5)	90	(7, 9)	4
4.	Insufficient education for the general public about ACDs?	100	(5/5)	80	(7,10)	-20
5.	Families who have not been previously educated about ACDs?	100	(5/5)	80	(7, 9)	-20
6.	People who do not want to learn about ACDs?	48	(1/5)	78	(7, 9)	30
7.	Lack of education programs about ACDs throughout the healthcare system?	87	(3/5)	86	(6, 11)	-1
8.	Assessing the patient/resident/clients competence to complete an ACD?	64	(2/5)	68	(6, 4)	4
9.	People who cannot understand the concept of ACDs?	73	(1/5)	73	(5, 7)	0
10.	Patients/Residents/Clients being influenced too much by family's opinions when filling out ACDs?	73	(3/5)	72	(5,8)	-1
11.	Staff lack of education about the ACDs/ ACP?	91	(4/5)	74	(5, 8)	-17
12.	Patient/Resident/Client's lack of education?	70	(3/5)	72	(5, 7)	2
13.	Lack of education about ACDs in acute hospitals?	73	(3/5)	68	(5, 8)	-5
14.	Old age i.e. older people have more difficulty completing ACDs?	57	(2/5)	60	(5, 7)	3
15.	Poor communication with residents/patients and families about ACDs?	55	(1/5)	56	(5, 5)	1

16.	Resident / their family don't feel comfortable to discuss ACP?	86	(3/5)	79	(4, 10)	-7
17.	Accommodating the different education needs of patients?	70	(1/5)	76	(4, 8)	6
18.	Staff lack of comfort in discussing ACP?	73	(3/5)	61	(4, 6)	-12
19.	Finding a private area to discuss ACP?	36	(2/5)	50	(4, 4)	14
20.	A person's youth, i.e. young people have more problems completing ACDs?	33	(0/5)	46	(3, 2)	13
21.	Lack of education, i.e. lower educated people have more problems completing ACDs?	68	(3/5)	44	(3, 5)	-24
22.	Lack of medical knowledge with regard to disease, prognosis, treatment options or EoL issues?	50	(1/5)	44	(3, 2)	-6
23.	Different language or need to translate when completing ACDs?	35	(0/5)	42	(3, 2)	7
24.	The area where ACDs are completed is too noisy?	32	(2/5)	36	(3, 4)	4
25.	Doctors who do not support ACDs?	14	(1/5)	36	(3, 5)	22
26.	The lack of educational aids, e.g. books, videos?	74	(4/5)	62	(2, 8)	-12
27.	Patients ignoring family members' opinions when filling out ACDs?	60	(2/5)	50	(2, 5)	-10
28.	Cultural differences in attitudes and values around life and death?	46	(0/5)	50	(2, 6)	4
29.	Too much conflicting education on ACDs?	46	(1/5)	45	(2, 4)	-1
30.	Nurses who do not support ACDs?	18	(0/5)	35	(2, 4)	17
31.	Other staff, e.g. administrators, who do not support ACDs?	5	(1/5)	21	(2, 1)	16
32.	Low socio-economic status?	33	(2/5)	15	(1, 1)	-18
33.	Gender?	9	(0/5)	16	(0, 0)	7

[a] n1= responses of staff who had completed ACPs with residents (n=5 before, n=8 after), n2 = responses of staff with ACP training who had not completed an ACP/ACD with residents (n=13)

Some specifically wanted training incorporated into their working week, others wanted it to be outside their working hours; "in my own time", at "weekends or evening", or needed it on specific days, whilst others wanted flexibility. Some requested full or half day sessions, others preferred shorter teaching repeated over a longer timeframe. Staff acknowledged competing agendas would necessitate employer's involvement, so that staff would be released to attend, and locums potentially employed to cover absent staff's duties:

> "at work, there is always lack of time in attending these workshops due to staff shortages, rather than giving out dinners".

Format: Staff's preferred format varied. Most wanted a combination of approaches which included: "handouts" (56%, n=49), lectures (54%, n=47), group discussions (53%, n=46), case based teaching sessions (38%, n=33), "self-directed learning packages e.g. videos, manuals" (25%, n=22), seminars (23%, n=20). Others suggested practical workshops, one proposed online training. One person was very clear on what they did not want:

> "please not group discussions, please not role-play, etc., would appreciate a certificate of attendance".

5.1.5 **Discussion**

Research from other countries found 25-46% of long term care staff have received palliative care education and this study confirms similarly low levels in a diverse Irish cohort.(291, 406, 407) One other Irish study found comparable results, but only examined staff from public long term care settings. Our study broadened inclusion to voluntary and private long term care staff and gave detail of their training which for the most-part consisted of one to several day courses, though a few had completed certificate or even diploma level training.(294)

Our study showed that the prevalence of palliative care education rose to at least 68% after the program's implementation despite staff turn-over. Far more staff received training than the few "after" respondent attendees. Issues with staff turnover have been found in other studies.(408, 409) One study found long

term care staff turnover rates of 16-72% over 18 months.(250) Similar to a Northern Irish study, our study found the culture of EoL care changed in the involved sites post intervention, the positive effects persisted despite staff turnover, "the seeds had been sown" in recognising palliative care as a core competency and the importance of PC education for all staff.(287, 407).

Inadequate palliative care training was highlighted as far back as 1967 for nurses and 1980 for doctors in the UK.(410, 411) Nurses role in palliative care is pivotal, but a 1986 UK study, found their training included a mean of only 9.8 hours of palliative care teaching(412) and many nursing students felt inadequately prepared to provide terminal care.(413) US medical undergraduate curriculums also paid limited attention to palliative care from the 1970s until about 2000 when the situation improved. By then almost all nursing and medical training contained some palliative care education albeit with an average of only 8-20 hours teaching.(414-416) By 2006, the duration for undergraduate nurses had improved to 45 hours (mean) and over 96% of courses incorporated communication with terminally ill patients in their teaching methods.(417) The lack of prior palliative care education in our study is unsurprising as many staff would have completed undergraduate training prior to 2000.

Providing and maintaining long term care staff education is hampered by many competing barriers; difficulty releasing staff due to shortages, competing duties, lack of time, training costs, accessing night workers and even domestic issues such as childcare or spousal work patterns. Some of these barriers were also identified in a study by Potter et al.(418) Previous research found long term care staff wanted "hands-on" applied education (13.9%) more often than short topic related sessions (6.5%) or lectures (7.7%).(291) Our study cohort was more open to these formats but preferences varied. Moreover, this study's staff presented potential solutions to training feasibility issues and need for flexibility in the form of a blended learning approach; mixing shorter face-to-face teaching with online material accessible at a time most suited to the individual. Compared with traditional learning, an online course in PC (totaling 96 hours) significantly increased participating primary care physician's

palliative care knowledge, improved overall quality of life for their patients with advanced cancer, reduced pain and the severity of their symptoms, and their families' anxiety.(419) Even a half day course in palliative care has shown appreciable improvements in symptom management, levels of support offered to families, improved communication and team cooperation.(398) We have since developed an online training program, which is currently being trialled.

Like others, we found overlapping and divergent training needs and slightly differing understanding of palliative care for HCAs and nurses, in keeping with their roles.(239, 294, 391) Long term care staff deemed education in communication and the assessment and management of family psychosocial and bereavement needs as important, whilst nurses had additional needs around pain and symptom management.(395, 403) HCAs are nurses "eyes and ears" and will likely spend more time with the patient, which may explain our cohort seeking education on recognising the signs of dying, and understanding and managing the emotional needs of the dying and their families.

Lack of education and training and a perceived reluctance of the patient or family are commonly cited barriers to initiating conversations on EoL care found in a recent review by Travers et al.(420). Our study also found these to be important in addition to finding sufficient time and the impact of resident communication or cognitive impairments but in contrast found cultural differences and prognostication difficulties to be amongst the least important barriers. Our study found that though lack of education was amongst the more commonly experienced barriers; staff's lack of education was notable but so too was education of residents, their families, the public and health system in general. Travers review focused on acute hospital doctors and nurses so barriers may differ in long term care.

Our study's findings suggested the perceived barriers to ACP may differ from those actually experienced by staff actively engaged in the process, though clearly small numbers of the latter limit the findings. With regard to older people's comfort in discussing EoL care, over 75% of participants perceived this as a barrier but only half of those engaged in ACP, who stated: "it was our

discomfort that prevented it to begin with, not theirs, now the conversations are much easier". Subsequent focus groups found the 'Let Me Decide' ACP process strengthened relationships, and normalised the topic of death, which was no longer seen as taboo.(287)

Clearly, palliative care training is important for all staff caring for the dying. The training provided in this study was open to any staff wishing to attend. It is unclear, however, why a considerable proportion of those who had received ACP training had failed to apply their skills by not yet engaging in ACP with residents. A study by Albers et al in 2014 found nurses with more palliative care education wanted to be involved in EoL medical decision making.(421) In our study, those who engaged in ACP appeared more likely to have palliative care education. But it could be that those with an interest and inherent capacity to engage in difficult conversations about death and dying with residents are also more drawn to obtain further palliative care education. If it were possible to distinguish staff with an interest in "upskilling" and an aptitude to apply their learned skills in becoming "champions" of palliative care in their workplace; the valuable resources of time, cost and effort for extra training could be focused on staff most likely to benefit. Neither education alone, nor the sharing of information through palliative care link nurses/champions will likely be sufficient to create changes in the culture of EoL care within a long term care organisation. Change management frameworks suggest there needs to be a commitment to change and quality improvement in EoL care established within the workplace, particularly with senior management.(422) Moreover, if the link nurse/champion is to implement change, these individuals also need qualities of good leadership, vision for what EoL care should look like within their organisation and the capacity to plan, communicate and drive that vision to fruition.

The study has a number of limitations. Nurse's response rate of 61% is good for this survey type but may introduce bias if respondents differed from non-responders. Maintaining staff's anonymity, prevented pairing of individual staff responses from "before" with "after", though assigning predetermined random numbers to each staff member could have ameliorated this issue. In addition,

the findings are limited by the paucity of HCAs in the “before” period, which meant design of the palliative care education without information about HCA’s specific needs and only used those cited in a literature review. That HCAs represented over half (52%) of respondents in the “after” period may be due to their inclusion in the educational program and a greater appreciation of their role, something which other research has found when education was delivered to nurses and HCAs together.(423)

5.1.6 **Conclusions**

This study found deficits in palliative care knowledge, diverse views and learning needs in long term care staff working with older patients whose low levels of training improved with an education program. Palliative care education was associated with greater knowledge and confidence in providing EoL and a trend to greater engagement with ACP in those who also received this training as part of the study’s educational initiative.

Chapter Six: What constitutes a “Good Death” and the Holy Grail of its measurement

6 What constitutes a “Good Death” and the Holy Grail of its measurement

Defining types of deaths in terms of their being sudden or gradual, expected or unexpected is not difficult in comparison with delineating what constitutes a “good death” or a “bad” one. The “good death” is highly variable, based on individual preferences, and finding a means of measuring it accurately is as elusive as the Holy Grail.

Most people in the Western world have only a limited experience of death. Some may never have been with a dying person in their final days or seen someone die. Indeed, many healthcare professionals may have only limited exposure to caring for dying patients.

There are several aspects of the end of life experience that could be measured, including:

- the quality of life,
- the quality of life at the end of life
- the quality of end of life care and
- the quality of dying and death

and though similar, there are subtle but important differences between each of these overlapping entities. The concept of what constitutes each of these entities is complex though, and difficult to define. In addition, each of these entities contain both objective and subjective elements making accurate, meaningful and comparable measurement tenuous.

6.1 Quality of Life – Older People

The vastness of the components of quality of life has meant that in recent years efforts have been made to identify the domains that are important to various sub-populations such as older people, people at the end of life or people with specific symptoms or diseases, across various settings (such as community, hospital or long term care).

Bowling et al undertook a survey of adults over age 65 years on their quality of life using the vehicle of the Office for National Statistics Omnibus Survey in Great Britain. Published in 2002, the study found that community dwelling older adults identify several domains as important to their quality of life:

- Social comparisons and expectations
- Personality and psychological characteristics – self-efficacy and optimism
- Health and functional status – physical functioning, health status, longstanding illness
- Social capital (personal and external) - social activities, social contacts, social support, pets, frequency of loneliness, increase in loneliness, quality and safety.(424)

6.2 Quality of Life - Long Term Care

When older people move to reside in long term care their priorities for quality of life appear to change. Kane et al described eleven important domains to older people in this setting: autonomy, individuality, dignity, privacy, enjoyment, meaningful activity, relationships, security, comfort, spiritual well-being and functional competence. Autonomy, especially having a sense of control over one's environment, privacy, as well as maintaining personal identity, seem to become more important as a person moves to residential care.(425, 426)

Older people who have become more dependent and less physically or mentally well, identify important domains to their quality of life to be:

- Sense of self – perceptions of own and others' frailties and strengths, appearance, personal possessions and privacy
- Care environment – autonomy, control, choice, independence and staff/resident relationships
- Relationships – social interaction, relationships with other residents and relationships with family
- Activities – meaningful activities, organised activities and religious activity.(427)

Cahill et al examined whether the perceptions of quality of life differed for nursing home residents with varying levels of cognitive impairment.(428) The study found four important themes: social contact; attachment; pleasurable activities and affect, but as reflected in the study's title "I hate having nobody here. I'd like to know where they all are", the absence of social contact and the quest for human connection became more important as cognitive function diminished.(428)

6.3 Quality of Life – at End of Life

It is reasonable to expect that as a person draws closer to the end of their days that the ingredients for quality of life will evolve further and will be more inclusive of elements important for a 'good death'. Establishing what is important at this time of life is challenged by the uniqueness of each older person's life experiences, situation and worldview, but also by the absence of awareness or acceptance for some older people that their demise is evermore imminent. In truth, it can also be challenging for the researcher to know that a study participant's demise is indeed imminent.

Mularski et al identified several domains as important in quality of life at the end of life for people of all ages across many care settings through a systematic review published in 2007:

- Life completion
- Relationships with the healthcare system – this domain includes the person's participation and sense of control over decision making, their being kept informed and treated as a person
- Preparation or anticipatory concerns
- Symptom impact
- Connectedness and affective social support (429)

Steinhauser et al explored the components felt to be important for a "good death" through focus groups with healthcare professionals, seriously ill patients with life limiting illness and recently bereaved family; they found the themes identified by respondents were:

- Pain and symptom management
- Clear decision making (which included patient control of circumstances and decisions not being made in a crisis situation when "emotional reserves were already low")
- Preparation for death (which included finalising plans for after death and knowing what to expect and preparing for that)
- (Life) Completion
- Contributing to others
- Affirmation of the whole person (430)

Steinhauser et al went on to survey 1462 people (seriously ill patients, recently bereaved family, physicians and other healthcare professionals) in 1999 to determine the factors felt to be important at the end of life. The respondents were asked to rate 44 attributes of the "experience at the end of life" based on the themes that emerged in the first study.(430, 431) The results of these studies were then used to develop a tool (QUAL-E) to measure the "quality of life at the end of life". A limitation of this tool however is that it was developed on what was perceived to be important for a "good death", not what constituted "quality of life at the end of life".(432) Another issue in applying the QUAL-E tool to older people in long term care is that the tool was developed based on the opinions of predominantly community dwelling people and though their ages ranged from 26 to 77 years, the mean age was only 47 years.

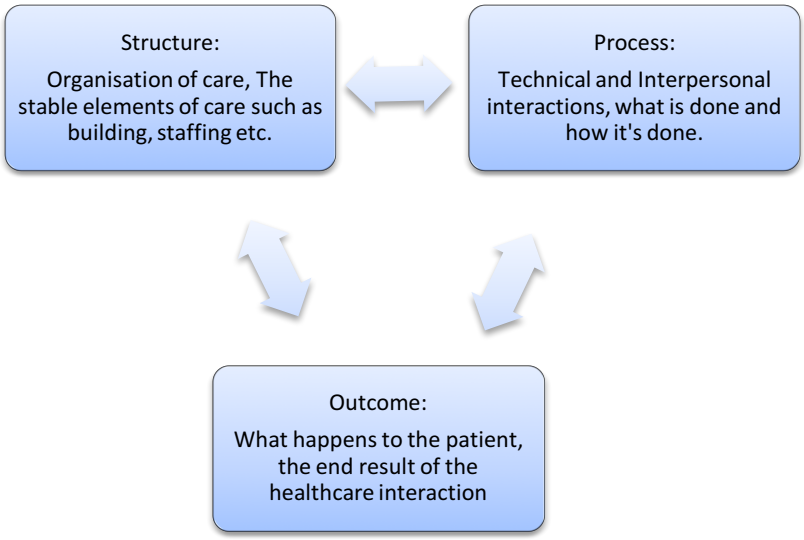
Some see the quality of dying as synonymous with the quality of life when dying.(433) It is important though to distinguish between "quality of life at the end of life", "quality of care at the end of life" and a "good death" in assessing the end of life experience.(434) Lack of such clarity in defining what is being measured leads to confusion and detracts from the usefulness and applicability of tools developed to measure the broad area of the end of life experience.

6.4 Quality of Care – End of Life Care

When the evaluation of the quality of care is examined, Donabedian's conceptual framework is often cited.(435) Donabedian was a pioneer in the

area of quality of care, he tamed a difficult to define concept by putting a structure on it, which guides measurement.

Figure 6.1 Schematic of Donabedian model



Since Donabedian's work in the 1960's, many have used the Donabedian model, and some have applied it to the quality of end of life care.(434, 436) Often however, the distinction between the *quality of end of life care* and the *quality of dying* were not delineated, adding ambiguity and lack of clarity as to what was being evaluated. Stewart et al clearly distinguished these two related domains and developed the concept further as it applies to the end of life experience.(434) Stewart added 'patient factors' to Donabedian's model. The outcomes of care in Stewart's model were subdivided into

1. "Satisfaction with health care" and
2. "Quality and length of life".

"Quality and length of life" was further subdivided into the

1. *quality of life of the patient*, *their loved ones*, the
2. *quality of dying*
3. *length of life*.

Length of life

In exploring the domain of "length of life" in general patients wish for life to extend as long as possible, provided the quality of life they experience is acceptable to them.(437).

Quality of dying

Patrick et al identified the quality of dying as the "experience of preparing for, facing and experiencing death itself" and defined the quality of dying and death as "the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died as reported by others."(436) A problem with this definition is that it requires that the patient's preferences be known and obtainable - this may not be possible for example in patients with advanced dementia whose wishes are either unknown or for whom the continued validity of historically expressed wishes might be questionable. Where an advance care plan exists, it may not be available to decision makers in a timely way; for example, a study of extended care facility residents transferred to emergency departments found only 28% of residents had a DNR order transported with them, despite 68% having a DNR order. In addition, examining the quality of death and dying as defined by Patrick et al, there might not be agreement between a surrogate's assessment of the death and how the death was experienced by the deceased person - which is ultimately an unknown experience given that the dead cannot report on it.

In a study by Cahill et al guidelines for the end of life care of people with dementia were developed based on a literature review and interviews with bereaved spouses of people with dementia who had died in long term care in the Republic of Ireland and Northern Ireland. The guidelines focused on five key areas:

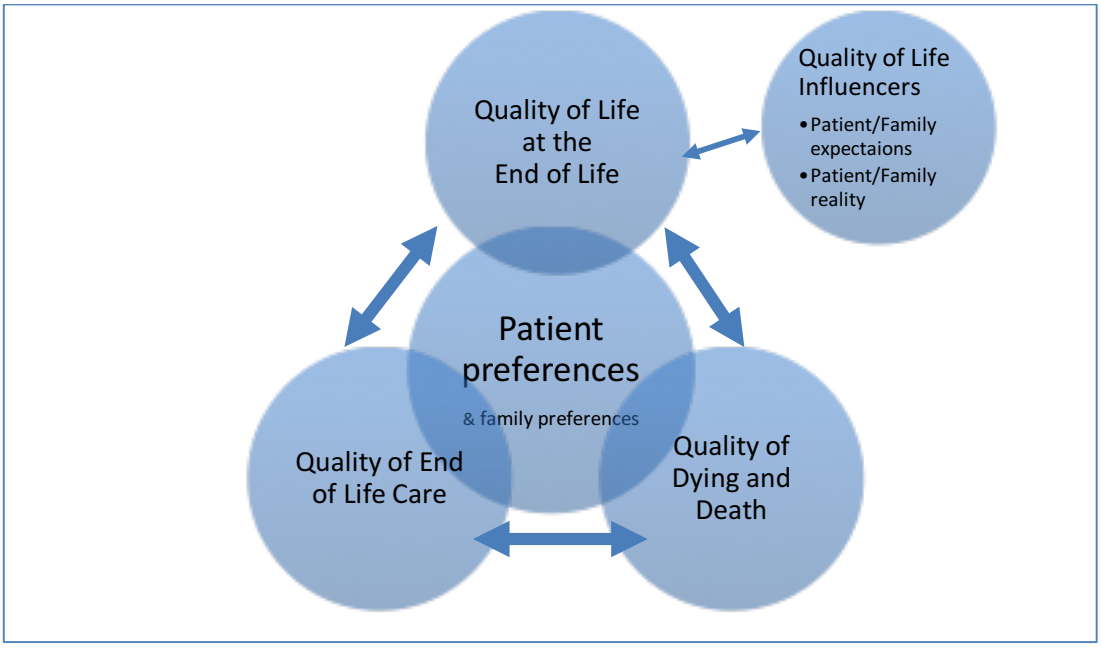
1. Person centred care underpinned by a knowledge of the dying person's life history
2. Good personal-care based on ongoing assessment and attention to detail
3. Staff-training in the needs of people with dementia at the end of life
4. A partnership approach with the nursing home fully integrated into local healthcare systems.

5. A shared approach to care with trusting relationships between the spouse and the nursing home and the spouse's involvement in and support with decision making.(438)

These guidelines take a person centred approach to the area of end of life care.

Taking the line that the priorities set out by patients and their families are the centre of the concept of a "good death" an alternative model could be proposed (figure 6.2)

Figure 6.2 Alternative model of measuring a "good death"



6.5 A "Good Death" in Long Term Care

It is important to resist forcing the end of life experience into the mould of the ideal "good death". Cottrell describes this "Western revivalist good death" as

> "*a peaceful and dignified death, free from pain and other distressing physical symptoms. Death is timely. It occurs in old age and follows a predictable course. It occurs at home, with the dying individual surrounded by family members. The dying individual is aware of and accepts their impending death, has made appropriate legal and financial preparations, and, ideally, has planned their dying experience through an advance directive"* (439)

Goldsteen et al in an analysis of 13 patients (mean age 65 years, range 39 – 83 years) with cancer and less than three months expected life, found that key categories of normative expectations of a good death, as part of the current Western cultural framework, included:

- an awareness and acceptance of death;
- open communication;
- living one's life to the end;
- taking care of final responsibilities and
- dealing with emotions adequately.(440)

These domains may not be universally equivalent as cultural and individual predilections may create alternative hierarchies of importance.

The Western revivalist good death is the ideal that is embraced by the Hospice philosophy. It promotes patient autonomy; but when a patient's ideal differs, it should not denote that their non-normative preferences equate to a "bad death". Equally the "good death" has become the "managed death", the "controlled death",(441) but people look for varying levels of control over their dying process, and not all elements of a person's death are controllable. Deaths in long term care are often from life limiting illness with unpredictable trajectories such as COPD or heart failure where any exacerbation or decompensation event could be terminal, but equally might be survivable. Death may occur suddenly, unexpectedly. This lack of predictability can impede "control" and can confuse the treatment decision making processes. Where the decedent has advanced dementia, it may preclude awareness of impending death or the ability to plan for dying (in the absence of previously made advance care plans). Indeed, it may preclude the recognition of the patient's impending death for healthcare professionals caring for that person. This does not mean that a "good death" cannot be achieved in these scenarios, it means alternative "ideals" of a "good death" exist and need to be explored.

Many have tried to qualify what constitutes a good death and common themes have emerged. A concept analysis review of the attributes of a good death found

pain and symptom management, awareness of death, maintaining the patient's dignity, the presence and support of family and good communication to be key elements.(442)

A limitation of most research to date, on what constitutes a good death is based on the perceptions of community dwelling, cognitively intact individuals, so it is difficult to know how this conceptualisation applies to those who are resident in long term care, particularly those with cognitive impairment or indeed advanced dementia. In the course of this research, bereaved relatives of long term care residents were asked to rate their loved one's quality of life in the last week of their life. Two dichotomous leitmotifs became apparent for decedents with dementia. Relatives tended to frame their viewpoint either by comparing their relative's quality of life with their own personal quality of life, or they framed it based on how content they perceived their relative to be. The important domains at the end of life and of a good death, reflect the lens through which they are perceived and the focus will differ depending on whose perspective is being examined: the dying person, their family or the healthcare professionals caring for them.(443, 444) This lens is likely coloured by culture, the stage of the patient's life limiting illness, their age, the imminence and acceptance of their demise and the psychological or emotional state of the perceiver.

A recent study by Mulqueen et al found that long term care residents with dementia and a MMSE ≥18 emphasised comfort and peace, privacy, family presence, familiar staff and surroundings as important for good end of life care.(445) Residents also valued good communication, being kept informed, involved and included (not isolated or left alone), that there would be continuity of care and that staff would "know" them, indicating that the preservation of personal identity remained important right up to the end of life. The study acknowledged residents' individuality and that a generic approach would not suffice.(445) The study also examined long term care nurses' views on the priorities for end of life care. Their focus differed from residents in that nurses targeted pain and symptom management, whereas patients had a more holistic sense of "comfort and peace". Nurses prioritised knowing a person's

wishes in advance, whereas residents valued inclusion and ongoing communication.

It is important that priorities for end of life care do not become a "tick-box" exercise, that there is continuous person-centred review of individualised priorities for care according to contemporaneous rather than historical wishes to the extent that this remains possible.

Nurses in the study by Mulqueen et al did not fully appreciate that residents viewed as important, not just having familiar faces, but also having familiar things around them.(445) If a person can no longer live and die in their own homes, then the place where they reside should become their home or at least as home-like as possible. Emerging literature links the sense of "feeling at home" in a nursing home with residents' quality of life and that "home" is more than just a place but rather a location representing familiarity, comfort and safety where one can be with loved ones.(446, 447) There is some commonality between the qualities that identify the sense of "home" and those deemed important in quality of life and care at the end of life. Cooney grouped these dimensions of "home" into three groups: "(1) a place of retreat, safety and relaxation, freedom and independence; (2) a place of privacy, self-expression, familiarity, identity and continuity; and (3) the centre of family life, togetherness, belonging and connectedness.(446) Creating a sense of home is important for long term care residents in adapting to the transition from their own home to the nursing home, important for the quality of their dying and links with the desire that 25-87% of people want to die at home.(448) An Irish survey found 67% of people would prefer to die at home, however this study was based on results of a random digit dialling phone survey of adults, of whom only 13% were aged 65 years or more.(293)

Most international studies looking at preferred place of death also tend to ask this question of community dwelling adults, often exploring the views of adults of all ages. It is quite possible that with advancing age and illness, declining independence and changes in people's social environment, that people's preference for place of care at the end of life, and preferred place of death (in a

realistic as opposed to aspirational sense) will change. Research has shown that a considerable proportion of people do change their opinion on preferred place of care and place for death over time, but a systematic review by Gomes et al found overall for 80% of people, their preferences remain stable over time.(126, 449-451) Masson described the paradoxical tensions that can exist for people in constructing the "good death" and used the term "flexible realism" to describe the changing preferences for the ideal death that may occur with people's changing reality as life limiting illness progresses and death approaches.(452)

There are few studies that look at the preferences of long term care residents for place of death. A Japanese study by Miyahara et al found 51% of long term care residents preferred to die in long term care rather than elsewhere.(453) Another Japanese study found only 16 of 86 residents (19%) were asked their preference, of whom 2 could not decide, 2 preferred to be transferred to hospital and 12 wanted to stay in the nursing home to die.(454) A United States based study by Hays et al found that about two thirds of continuing care retirement community residents' preferred place to die was on the care campus, either in their own residential unit or in the facility associated nursing home.(353) Only 5% of the group wished to die in hospital. The preferences for place of death of 89% of respondents was conditional on various factors such as the type, amount and duration of care, illness associated symptoms, their family concerns and cost implications.(353) These study participants were independently living older people, albeit living in a place of care. A Chinese study of 1600 cognitively intact nursing home residents found 35% would prefer to die in their nursing home.(455) These differences suggest culture has an impact on decisions made on preferred place of death.

The quality of dying and death has been expressed as an evaluation of the dying experience as a whole, according to one's expectations and values.(434) A systematic review by Hales et al found the construct of the quality of dying and death to be of a multidimensional nature though subjectively determined and outlined seven broad domains:

- physical experience,
- psychological experience,
- social experience,
- spiritual or existential experience,
- the nature of health care,
- life closure and
- death preparation and the circumstances of death.(456)

The review highlighted notable factors influencing what is perceived to be important for a good death, e.g. culture, where self-determination and control is desirable in some cultures, but not in others. The review did not take account of the family perspective though.

There are many factors that contribute to a "good death" but they are highly personal and often very subjective and difficult to quantify. Measuring how a person died is as unique as how they came into the world and the distinct meandering course of their individual life. No two deaths are the same. The ultimate question in measuring the quality of how someone dies would be to ask them "how good was that death for you?" but given the dead can't speak, no one can know the true answer and those left behind can only surmise. The perceptions of bereaved family, friends and those who cared for the decedent are coloured by a myriad of factors such as their emotional state and stage of grief.(457)

Emanuel and Emanuel produced a useful framework for a good death in 1998.(458) They described the dying experience as having four critical components: 1) the fixed characteristics of the patient such as their age, ethnicity, diagnosis and prognosis, 2) modifiable dimensions of the patient's experience for example their symptoms burden, psychological state, social relationships and supports, hopes and expectations, spiritual and existential beliefs, 3) the care-system interventions potentially available such as pain management, advance care planning, spiritual advisor supports, and 4) the overall outcome – the overall experience of the dying process. Though now almost twenty years old, the framework is still a valid and helpful tool in

conceptualising the elements of a good death and in framing a means of measuring it.

If one is assessing whether a person's death could have been "better", the distinction between what is modifiable and what remains fixed is important in any attempt to measure the overall dying experience. A study by Payne et al in 1996 found patient and hospice staff's perceptions of a good death differed.(459) Many of the features of a "good death" described by patients were uncontrollable: dying in one's sleep or dying suddenly, though other features were potentially modifiable: being pain free, dying quietly and with dignity. Staff tended to view a good death in terms of the adequacy of symptom control, family involvement, peacefulness and lack of distress – all potentially controllable elements – and they viewed a "bad death" as one with uncontrolled symptoms, lack of acceptance and being young – uncontrollable elements.(459)

The "good death" has become the "well managed death".(439, 441) Whilst patient control and respect for autonomy have been identified as features of a good death, it needs to be acknowledged that not all components of how a death is experienced can be controlled, modified or managed, nor do all patients wish for control or place the same value on autonomy as healthcare professionals might.

Ultimately there are a number of measurable outcomes that are of broad value in the care of the dying. For example, freedom from pain and other distressing symptoms is consistently ranked as an important goal of quality end of life care and a good death by patients, family and healthcare professionals. The assessment of pain is therefore clearly important and is a key performance indicator and goal of quality end of life care, however assessment is only part of the issue. Though pain assessment may have occurred, it is no guarantee that pain has been adequately managed, and similarly for other common symptoms experienced at the end of life such as dyspnoea, anxiety, lethargy and respiratory secretions or "death rattle".

It has been suggested that in managing physical symptoms the attention given to the patient to relieve physical distress may alleviate non-physical suffering

caused by unmet emotional, social and spiritual needs to promote a more holistic and improved quality of dying.(460)

Another key outcome measure in end of life care is that of control and involvement in decision making. Research has shown that terminally ill patients vary widely in the extent to which they want their expressed preferences to control decisions made about their future care, if their decision-making capacity is lost. Most prefer a shared decision making approach, taken between their loved ones and their physicians.(78) This is echoed in the results presented in chapter 2.

In deciding what outcome measures of the end of life experience to use in this study, a literature review was undertaken. Several systematic reviews were identified. A systematic review of 928 articles by Teno et al identified 293 outcome measures from literature published between 1967 and 2000; of these they recommended 35 measures based on the study selection criteria across the spectrum of end of life domains.(461) Teno et al reported several measures useful at the end of life, but not always specific to this period of life e.g. the Barthel index as a measure of function.

A systematic review by Mularski et al in 2007 built on Teno's review and aimed to identify psychometrically sound measures of outcomes in end of life care and organised the identified measures into 10 major domains.(429) Of 24,423 citations, they extracted 200 articles describing 261 measures, of which they accepted 99 for further examination; only 8 of these measures were used in more than two studies. Overall, they found that most measures were not developed or tested in a rigorous fashion. Of all the measures examined they recommended three for use:

- Quality of Life at End of Life (QUAL-E)
- Palliative Care Outcome Scale (POS)
- Quality of Dying and Death (QODD).

A systematic review by Albers et al in 2010 identified the QUAL-E and QODD instruments as having the best overall measurement properties of all 29

instruments identified for use in palliative care patients, additionally they recommended the McGill Quality of Life instrument.(462, 463) The QODD was also identified in a systematic review by Hales et al in 2010 as the most widely used, validated and best suited measure to capture in a general and individual sense, the domains important in the quality of dying and death.(464)

6.5.1 **Quality of Life at End of Life (QUAL-E)(432)**

The QUAL-E instrument was developed by Steinhauser, Bosworth, Clipp, McNeilly, Christakis, Parker and Tulsy, a North Carolina (U.S) multidisciplinary group, with backgrounds in Geriatric care, Medicine, Primary Care and Palliative Care, in 2002. They were driven to develop the instrument as they found most existing instruments at the time had been developed for cancer patients or for terminal patients who have acknowledged their dying. In an attempt to create a valid instrument to assess the quality of life at the end of life of patients with a variety of life limiting diseases, in a range of care settings, who may or may not have acknowledged the terminal nature of their condition, they used an inductive approach. The instrument was based on the accounts of seriously ill patients, recently bereaved relatives, or healthcare professionals on what attributes were important to them for a good death.(430, 431) This process led to the creation of a 54 item instrument covering 6 domains.

Item reduction was informed by patients (n = 200) with stage IV cancer, congestive cardiac failure with an ejection fraction ≤ 20%, chronic obstructive pulmonary disease with forced expiratory volume in 1 second (FEV1) of ≤ 1 litre, and dialysis dependent end stage renal disease patients. Exploratory factor analysis reduced the instrument to 24 items and revealed five distinct domains:

1. life completion
2. relationships with the healthcare system
3. preparation/anticipatory concerns
4. symptom impact
5. connectedness and affective social support

On review of the QUAL-E questionnaire, it was felt that the focus was more on quality of life than the quality of care or the dying process, and that residents

with significant cognitive impairment may have difficulty engaging with the instrument. It was therefore decided not to use this instrument for the study presented in Chapter 7 of this thesis, as it was expected a substantial proportion of long term care residents would have significant cognitive impairment.

6.5.2 **Palliative Care Outcome Scale (POS)(465, 466)**

The Palliative Care Outcome Scale was developed by Hearn and Higginson. Their aim was to construct an outcome measure for use in the study of patients with advanced cancer and their families. It was developed using data from other outcome measures reviewed, and then refined by a multidisciplinary collaboration of healthcare professionals, patients and local palliative care researchers. The Palliative Care Outcome Scale assesses physical, psychological, emotional and spiritual domains as well as information communication and supports. Since 1999 it has been further refined and has been used in studies assessing predominantly patients with cancer, but also studies of patients with HIV/AIDS, neurological conditions such as multiple sclerosis or motor neurone disease, chronic kidney disease (n=1), heart failure (n=1) and COPD (n=1) and in several countries including the UK, Germany and Africa.(466-469) It can be used by the patient's carers to assess the patient.

It was decided not to use this outcome scale as it was designed for use in a cancer population and though it has been applied in a long term care setting, including for patients with dementia, its usefulness in the more advanced stages of dementia has been questioned.(470)

A study by Brandt et al used the Palliative Care Outcome Scale in a nursing home setting in the Netherlands in patients both with and without dementia, they found a high proportion of "non-scores" for the patients with dementia.(470) Responses were designated as "non-scores" if the respondent was unable to answer the question for the resident being assessed. Valid responses for each of the ten items in the Palliative Care Outcome Scale were achieved in between 29.4% and 92% of assessments, however for five of the ten questions "non-score" responses were obtained for over 40% of residents.(470)

For this reason it was decided not to use the Palliative Care Outcome Scale in the study described in Chapter 7 of this thesis.

6.5.3 **Quality of Dying and Death (QODD)**

The Quality of Dying and Death instrument was developed by Patrick, Engelberg and Curtis based on concepts derived from literature review, qualitative studies of people with and without life limiting illnesses (including people with cancer, dementia, end stage COPD or AIDS and nursing home residents) taking consideration of existing instruments and desirable properties for a measurement tool.(436) The conceptual model they developed for the instrument encompassed 6 domains, containing 31 items which were then incorporated into a questionnaire.

The QODD questionnaire's validity and reliability were tested in an after death interview study of relatives of decedents in 1996 and 1997 in Missoula county in Montana.(471) Through this after death interview study the instrument was refined further. Over 50% of respondents found four items to be "not applicable", this led to item reduction to 27 items. The Cronbach's alpha for the QODD total score was 0.89.(471) The study reported higher QODD scores for people who died in their preferred place of death, who had better symptom management (as measured by a retrospectively applied Memorial Symptom Assessment Scale), who had discussed their preferences for end of life care and who reported that healthcare professionals listened to their relative (and their family) and provided good care.(471) (472)

A systematic review by Van Soest-Poortvliet et al, reviewed articles published between 1988 and 2010 for instruments to measure the quality of dying and the quality of care when dying in long term care.(433) The review distinguished between these two concepts and found 11 instruments that met their inclusion criteria for further review:

- End-of-Life in Dementia Comfort Assessment in Dying (EOLD-CAD),(473)
- End-of- Life in Dementia Symptom Management (EOLD-SM),(473)

- End-of-Life in Dementia Satisfaction With Care (EOLD-SWC),(473)
- Family Assessment of Treatment at the End-of-Life Short version (FATE-S),(474)
- Family Perception of Care Scale (FPCS),(475)
- Family Perception of Physician-Family Caregiver Communication (FPPFC),(476)
- Minimum Data Set-Palliative Care (MDS-PC),(477)
- Mini-Suffering State Examination (MSSE),(478)
- Palliative Care Outcome Scale (POS),(465)
- Quality of Dying in Long-Term Care (QOD-LTC) (479)and
- Toolkit of Instruments to Measure End-of-Life Care (TIME)(480)

They used a classification system described by Stewart et al to organise the constructs measured in each of the tools reviewed. Van Soest-Poortvliet et al's review found that while some of these instruments measured purely the construct of quality (process or structure) of end of life care (FPPFC and EOLD-SWC), or a quality of dying construct (EOLD-SM, EOLD-CAD), most measured a combination of these, some also with the addition of patient characteristics.(433) This review excluded the QODD measure as they stated it had only "been tested with respondents who were cognitively able to participate". The original QODD validation study included 3% of decedents whose cause of death was dementia and included nursing home residents (24.2% of decedents) or other residential care settings for older people (8.4%).(471) It is likely far more decedents had dementia than the 3% identified from their death certificate, as dementia as a cause of death or contributing factor is widely acknowledged as being underreported on death certificates.(481-484)

On examining each of the instruments identified in this systematic review, none of them on face value appeared superior to the QODD instrument in addressing the domains being investigated in this thesis study. An additional reason for choosing the QODD instrument was that it was also the instrument used in the National Audit of End of Life Care in Hospitals in Ireland, 2008/2009, so it was

felt potentially useful to be able to compare results with those of the national audit.(58, 384)

6.6 Measuring the Dying Experience: deciding on methodology

In attempting to measure the dying experience various approaches can be taken. An account of the death can be recorded either prospectively or retrospectively or both. The account of the death can be made from the perspective of the patient themselves, their family or from the healthcare professional who have cared for them in their last days. The assessment of the dying experience could focus on one domain such as symptom management or could take a more global approach. In measuring the end of life experience, a decision needs to be made as to which tool (or tools) to use to measure these domain(s) ensuring that the tools are valid for the population and setting of interest; in this case a population of older adults with a high prevalence of dementia, in a long term care setting.

6.6.1 **Prospective or Retrospective**

Though rich knowledge of the personal experience of dying may be gleaned from taking a prospective assessment approach, there are challenges. In measuring the dying experience, it is simple to diagnose death, but less straightforward to prognosticate that a person is nearing death. Clearly some people will die suddenly which will negate attempts to measure their dying experience prospectively. Some patients will be too ill to participate in assessments or engage in interviews as death draws near. (465, 485-487) In addition the high prevalence of dementia amongst nursing home residents may hinder collection of reliable accurate prospective reports. Some people particularly the frail or those with dementia, may be dying for months before their demise, and may have many “false alarms” along the way. There may not be a clearly defined period of “dying”.

For the purposes of the studies described in Chapters 7 and 8, it was decided to take a retrospective assessment approach as it is clearly identifiable when

someone has died. This was married with a contemporaneously account from the resident's medical notes.

6.6.2 **Patient, Family or Healthcare Professional's account of dying**

On exploring the experiences of people at the end of life Higginson et al wrote "by the time it is certain that individuals qualify for the study, they are no longer available for comment".(457) Clearly the patient's account of the dying experience is the most important, but obtaining it, particularly in the setting in this study, is fraught with practical difficulties, including the intrusiveness of measurements at this time of life.(436)

Retrospective accounts from surrogates such as family or close friends is a tried and tested method of gaining information on a person's death, but at best it is a guess of the decedent's experience, coloured by that of the relative. Bereaved relatives have a tendency to overestimate the severity of symptoms compared with patients' assessment of symptoms experienced before death, especially for pain, depression, anxiety and distress.(457, 488) Agreement between patient and proxy accounts tend to be better for more objective, obvious or visible elements and less so for subjective aspects such as emotional states.(489)

Though clearly the deceased cannot be interviewed after death, it is likely that were this possible, their recollection of subjective symptoms such as pain is likely to change over time. If the example of labour pain is taken, a study by Waldenström and Schytt of women 2 months, 1 year and 5 years after childbirth found that for most of 1383 women surveyed, the memory of labour pain declined over this period, but not for women with a negative overall childbirth experience.(490)

Any inaccuracy in the bereaved relatives' portrayal, rather than detracting, adds to overall picture of the death. It is the relative who lives on with the experience of that death. Furthermore, the World Health Organisation's definition of palliative care includes family in the unit of care, so their perspective is an important ingredient in the account of the death. Their perceptions are potentially influenced by many factors though, including caregiver burden or

distress, the proxy's own levels of anxiety or depression and the time the proxy spent with the deceased.(457, 491, 492)

6.6.3 **Timing of measurement of the end of life experience**

In taking a retrospective or after death approach in measuring the patient end of life experience from the perspective of a proxy, their grief is a major consideration. This may impact on the timing of after death interviews.

Most studies have chosen an empirical period of waiting one to six months after the death before interviewing bereaved relatives.(493) Some chose this time period based on the findings of a 1970s study which found widow's tearfulness declined considerably between one and three months after their spouse's death.(494) Earlier assessments are feasible and reasonable. A study by Casarette and Crowley found there was no difference in the distress, or the response rates of family responding to surveys on the death of their loved one whether surveyed 2 weeks or 6 weeks after the death, and distress rates were low.(495) Another rationale for choosing three to nine months is that Cartwright et al. found a greater refusal rate at three months (62%) compared with at nine months (48%) after the death, but a higher likelihood of relatives being uncontactable at nine months through having moved address.(496) This study was based on small numbers (n=13) however which may limit the findings. A more recent study of bereaved family (n=22), found that 86% felt comfortable to be interviewed within 5 months of the death and 43% were content to be interviewed within weeks of the death.(497) Respondents in this study hinted at potential therapeutic benefit from talking about their experiences earlier in bereavement, but that ultimately bereaved family should be allowed to decide the best timing for themselves.(497)

Concerns have been raised on how proxy's perceptions of the dying experience change with time and grief. McPherson et al examined bereaved relatives for changes with the passage of time in their perceptions of the decedent's pain, anxiety and depression in the last week (or month) of life.(498) They found greater consistency for ratings of anxiety than for pain or depression. In

addition, the study revealed some of the complexity of the cognitive processes behind proxies judgement of their relative's dying experience.(498, 499)

A large US based study (n=1532) published in 2016 found bereaved family member responses to be stable when interviewed between three and nine months after the death of the patient.(500) Therefore this time period of three to nine months after the residents' death for assessment was that chosen to be used in the study described in Chapter 7.

6.7 Study Design: Meeting the Implementation Challenges of the Let Me Decide Program

For this feasibility study, an uncontrolled before and after study design was chosen for reasons outlined in chapter section 1.9. Although superior to observational studies, uncontrolled before and after studies have significant limitations and as a quasi-experimental study design, there are intrinsic weaknesses.

Changes observed in the sample group attributed to the intervention may be confounded by natural changes taking place in the population from which the sample is drawn, for reasons specific to that population but not attributable to the intervention, or by changes that are happening across the population for reasons unrelated to the intervention.(501) For example in my study the results found may have been confounded by campaigns such as the *Hospice friendly hospitals* initiative, which were raising the profile of palliative care outside of the hospice setting with the goal of improving end of life care in Ireland. The Hawthorne effect also called the observer effect may impact on the interpretation of uncontrolled before and after study's results. The Hawthorne Effect was first described in 1939 by Roethlisberger and Dickson following research into worker productivity in the 1920's and 30's in the Western Electrical Company's Hawthorne Works in Chicago. Roethlisberger stated

> *"if a human being is being experimented upon, he is likely to know it. Therefore, his attitudes toward the experiment and toward the*

experimenters become very important factors in determining his responses to the situation".

Though originally used in the context of worker productivity, its scope has broadened and it is often used in healthcare research to describe the non-specific beneficial effect on staff performance of taking part in research.(502) The Hawthorn effect describes improvements that occur just because of the involvement in research, thus improvements attributed to the intervention may be overestimated.(503)

The "before" period of the study described in Chapters 7 and 8 was measured retrospectively. The deaths in the "before" period occurred before the long term care staff were aware of the research project and so the assessment of this period was unbiased by the Hawthorn effect and as true a representation as could be gleaned within the described limitations of the assessment tools used. The Hawthorn effect may have biased the assessments of the quality of care and the quality of death and dying in the "after" period of the study.

Chapter Seven: Changes in end of life care planning with implementation of the study intervention

7 Changes in end of life care planning with implementation of the study intervention

7.1 Introduction

There is evidence of unmet palliative care needs for those dying in long term care and dissatisfaction amongst their family with regard to the end of life care their loved one received.(206, 261, 504, 505) Thus it is often assumed that end-of-life care in long term care is suboptimal. The most frequently cited evidence is now nearly twenty years old. Much may have changed in the interim with the expansion of palliative care and hospice programs and multiple wide scale quality improvement initiatives in end of life care.(506-508) Limited research is conflicting as to whether the inadequacies in end of life care have changed in recent decades.(291)(502)(509)

As discussed in chapter 6, the qualities of a "good death" that patients rate as important, include pain and symptom control, the avoidance of inappropriate prolongation of dying, clear decision making, having a sense of control, being prepared for death, life completion, relieving burden on others and strengthening relationships with loved ones.(430, 510) Nursing home residents with dementia additionally value comfort, the presence of family, familiar staff and surroundings.(445) Advance care planning is not just a means of planning for future incapacity. It can match some of these listed elements of a "good death". In clarifying decisions, it reduces decisional uncertainty, enhances patient control over end of life care, and has a role in their preparation for death.(511) In understanding and respecting people's wishes, advance care planning may reduce burdensome hospitalisations and unwelcome treatment at the end of life and avoid prolonged dying, though evidence is incongruent.(100, 139, 512, 513) Patients perceive advance care planning as a social process and beyond augmented communication with loved ones. Patients feel it strengthens relationships with family and reduces burden on them.(127) Other cited advantages of advance care planning include improved family satisfaction with end of life care given to their loved ones, and reduced stress, anxiety and depression in those bereaved.(139, 247, 513, 514)

Worldwide, a dominant focus of research on advance care planning has been advance care directive or advance care plan completion rates. Most of the published studies are based in the United States, where advance care directives are a recognised component of end of life care and legislation has existed to support their use for over 25 years.(139) The prevalence of advance care planning in the United States has risen since the *Patient Self Determination Act 1990* was introduced in 1991.(100) A recent review found a 36.7 % prevalence of advance care directives amongst adults in the United States, where 71% of decedents and 19% of long term care residents have an advance care directive, while 73% in long term care have a Do Not Resuscitate order.(83, 228, 514)

The prevalence of advance care directives elsewhere, outside the United States, is lower.(86, 88, 515-519) Amongst community dwelling adults in Ireland, the prevalence is estimated at only 5%.(89, 520) In Ireland though approximately 5% of adults over 65 years old reside in long term care, 25% of all deaths occur there; the prevalence, feasibility, practicalities or process of advance care planning among Irish long term care residents is unknown.(152, 197, 520)

A particular challenge faced in planning for end-of-life care in the long-term care setting is the high prevalence of frailty and cognitive impairment with many residents already in the advanced stages of dementia such that their contribution to care planning discussions may be limited, if not impossible. (521-526) Planning for end of life care in advance of a medical crisis forcing decisions brings the laudable advantage of time: time to understand diagnoses and prognosis, time to appreciate the common acute medical problems that can present in long term care residents, time to consider treatment goals and the preferred level of care and in what circumstances hospitalisation would be undesirable, time to educate on life sustaining treatments and the realistic achievability of successful outcomes. In the absence of time and preparation, crisis decision making, often by surrogates, prevails.(137, 527, 528)

Though some research has looked at compliance with the wishes expressed in advance care directives or advance care plans, few have looked at the effects of advance care planning on the quality of end of life care received.(137, 139)

Where such research exists, much has focused on quality metrics such as hospitalisation rates and duration of stay, death in hospital, use of emergency departments, intensive care units or hospice.(139, 512, 529) Little research has examined the effect an advance care planning program would have on the dying experience at an individual level in the long term care setting.

The aim of this study was to establish baseline end of life decision making practices in long term care in Ireland and to assess the feasibility and acceptability of a systematically implemented advance care planning program in this setting. In addition, the study examined whether such a program, combined with a palliative care educational initiative, would affect the quality of dying experienced by long term care residents, the location of their deaths, their involvement in decision making for end of life care and the timing of such decisions. We explored to what extent end of life care planning could be facilitated for those with diminished capacity to complete an advance care directive.

7.2 Methods

7.2.1 **Study design:**

This study used a quasi-experimental uncontrolled before and after study design to explore the effect of a complex intervention comprising an advance care planning and palliative care educational initiative on the end of life experience of long term care residents.

7.2.2 **Intervention:**

The advance care planning program

Let Me Decide is an established advance care planning program which was developed in Canada by Molloy.(530) It has been successfully implemented in a variety of settings in Canada and in the long term care setting in Australia.(144, 233, 324, 405, 531) The program provides a structured approach to advance care planning for people with capacity to complete the associated advance care directive, and also a means of documenting end of life care plans for those with diminished capacity. The Dementia Policy Lens toolkit found Let Me Decide to

be dementia friendly.(358) Due to legislative differences between Canada, Australia and Ireland, the program was adapted for use in the Irish long term care setting.

Training on the use of the Let Me Decide (LMD-ACP) program was provided to staff in each of the study sites. Nursing staff from participating units completed two half-day workshops on the LMD-ACP program with a focus on the ethical, legal and practical aspects of advance care planning with long term care residents and their families. Live advance care planning demonstrations were held with a sample of residents and their families for nursing staff engaging in advance care planning at each site.

A detailed LMD-ACP implementation manual including an advance care directive or advance care plan completion policy, structured forms, documentation templates, educational resources for residents and families as well as communication and decisional aids for residents, was given to each facility. Monthly feedback meetings offered support to senior nursing staff participating in advance care planning discussions and addressed any implementation issues arising.

The palliative care education intervention

As described in chapter 5, a separate palliative care educational program was delivered over two half-days sessions to staff in each study site. The syllabus for this program was based on the educational needs identified by each site's staff verbally and through questionnaire and was guided by the Irish Health Service Executive Palliative Care Competence Framework.(404) Some of the sites found it easier to facilitate staff attendance if both half day sessions were combined and delivered over a single day.

The first half-day session, attended by nurses and healthcare assistants together, focused on the palliative care approach, communication at end-of-life, grief, care in the last week of life and bereavement. The second half-day session, for nursing staff only, educated on symptom assessment and management, the recognition of residents who would benefit from timely specialist palliative care referral and ethical issues related to end of life. The aim of this education was to

enhance staff skills to provide holistic, patient-centered care, using the principles of palliative care, to ensure high quality end of life care for residents.

7.2.3 **Setting:**

The program was implemented in three long-term care facilities in southern Ireland. These sites included one private and one voluntary nursing home and a publically funded geriatric long term care community hospital. The number of beds in these long term care facilities ranged from 286 to 304 beds in total. The bed numbers varied over the study period, due to units either expanding their premises, or closing beds to improve the space available for residents.

7.2.4 **Participants:**

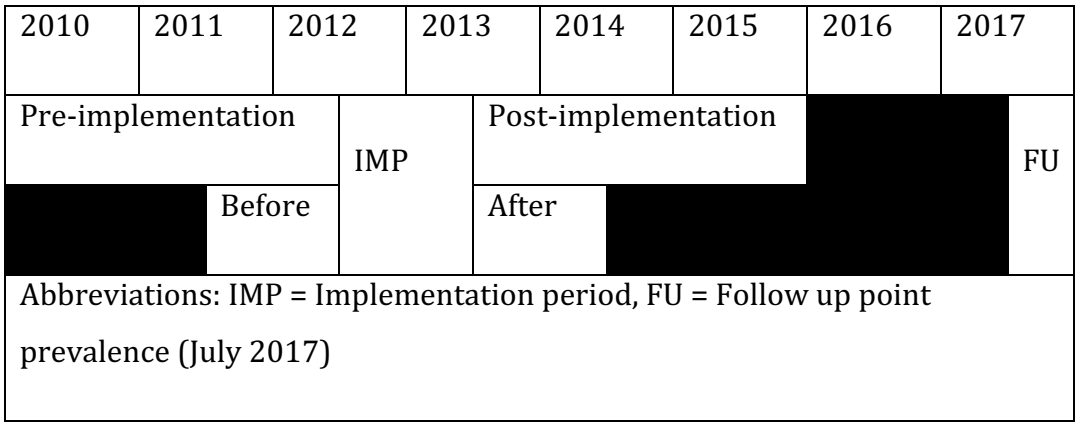
All adult long-term residents of these facilities were eligible for inclusion. Existing residents in each site were approached and informed of the study by staff trained in advance care planning. All new residents during the study period were introduced to the study shortly after admission, and approached again with regard to becoming involved after a "settling in" period. The process of recruitment, obtaining consent, education of residents and their families and assessment of residents' capacity to complete an advance care directive has been described previously in detail.(532, 533) The means by which residents with diminished cognition were involved to the greatest extent has also been described elsewhere.(533)

7.2.5 **Variables:**

Demographic details for residents in each site were collected including the residents' cognitive and functional ability. These variables are measured every three months as part of all registered residential care settings requirements as stipulated by the Health Information and Quality Authority (HIQA).(154) The number and location of residents' deaths each year, residents' acute care hospitalisations and length of hospital stay were recorded. This data was collected in all facilities for 30 months before and again for 30 months after an implementation period of one year. These time periods are referred to as the "pre-implementation", "post implementation" and "implementation" periods

respectively (see figure 1). Data collected during the implementation period itself was not included in the analysis as this was a time when the facilities were being educated and trained in the advance care planning intervention's use, were improving their skills and capacity to deliver advance care planning, which was becoming embedded in the culture of care in each site. Point prevalence of end of life care plans was collected once more in July 2017 to establish the longer-term sustainability of the program.

Figure 7.1 Details of study period categorisation



All residents who died in the period immediately before, and in the first year after the implementation period, were studied in more detail. These periods are referred to as the "before" and "after" periods respectively (figure 1). For these residents, it was recorded whether they had an advance care directive, advance care plan, an end of life care plan (EOLCP) or orders such as a Do Not Resuscitate (DNR) order or a Do Not Hospitalise (DNH) order. To qualify as an EOLCP, there needed to be some element other than a DNR and or a DNH order, such as the level or approach to care they wished for. There was a spectrum of resident involvement in EOLCP completion. Some cognitively intact residents preferred to complete an EOLCP in preference to a legally binding advance care directive. EOLCPs were also a means for residents with diminished capacity to document their wishes and for family in collaboration with healthcare providers to document previously expressed wishes or plans for care for residents who had lost the capacity to be involved in care planning e.g. through advanced dementia.

The interval between the documentation of residents' plans for their end of life care and their ultimate demise was calculated, as was their overall length of stay in the long term care residence. It was recorded whether documents on end of life decisions contained information as to the resident's capacity to complete an advance care plan; whom was involved in making the end of life care decisions; and whether the resident was included. This information was retrieved from the resident's medical notes and any end of life care plans documented.

Once three months had elapsed from the time of a resident's death, the facility's director of nursing wrote to the resident's family, offering sympathy for their recent bereavement, and informing them of the study, and its purpose. Allowing three months before contacting relatives is in line with previous similar surveys which had an average response rate of about 50%.(170, 496, 497) The investigator then contacted the relative inviting them to participate in the study. Once informed consent was obtained, a questionnaire assessing the patient's dying experience was administered either by phone or by post as per the relative's preference. Reminder letters were sent to those who agreed to accept the questionnaire by post, but who had not returned it. The questionnaire used questions from the "Quality of Dying and Death" (last seven days version) instrument (QODD), a validated assessment tool; in addition to bespoke questions similar to those used in the Irish National Audit of End of Life Care in Hospitals in Ireland.(384, 436) Any additional comments made during phone interview or in the margins of the questionnaire were recorded. Symptom management, family satisfaction with care and communication, and family perception of the quality of the resident's life at the end of life and the quality of death were examined through the questionnaire. The responses for the before period were compared with those obtained in the after period. Permission was also obtained to examine the resident's clinical notes. To reduce discrepancy from using a single data source, details of residents' end of life care was also extrapolated from their medical and nursing notes including: details of symptoms and their management, evidence of compliance with residents wishes, location of death and whether the death was expected or not.

Healthcare utilisation costs were also estimated and results from this element of the study have been published.(532) This data is not presented here as though I personally collected almost all of the data, I did not perform the economical analysis.

7.2.6 **Bias:**

To avoid investigator bias in conducting the interviews with relatives of deceased residents, the interviewer was blinded to whether the deceased resident had an end of life care plan or not. All chart reviews as to whether the resident or their family had participated in advance care planning were conducted after the relative completed the questionnaire and questions pertaining to advance care planning completion were left to close to the end of the questionnaire. In addition, all relevant information given by the relative other than that covered by the questionnaire were recorded.

To reduce the Hawthorn effect introducing bias from staff knowingly being observed for research purposes in the quality of end of life care, a before and after study design was used. The deaths of those residents included in the pre-implementation period (which included the "before" sample) occurred prior to the study sites becoming involved in the project, and a period of a year was left from the time of initiation of the study intervention and beginning to collect post implementation data (including that from the "after" sample). In using historical data from the before period, each site essentially acted as its own control.

7.2.7 **Study Size:**

The prevalence of long term care residents with advance care plans, or other care plans related to end of life such as Do Not Resuscitate orders or Do Not Hospitalise orders in Ireland is unknown, but it has been estimated that 5% of an Irish community dwelling adult population would have an advance care directive.(89) International research has found variable advance care directive completion rates amongst nursing home residents; 11% to 21% have advance care directives in Germany, 17.5% in Belgium but up to 71% of US nursing home decedents have a Do Not Resuscitate order.(88, 143, 351, 534)

If 5% of Irish nursing home residents have an advance care directive, and anticipating a rise in advance care directive prevalence to 50% a sample size of n=19 in each group would be needed to achieve a 90% power to detect this pre-post difference in prevalence of advance care directives with a certainty of 95%.

It was found that about 50% of residents who died in the "before" period had some form of care plan for end of life care, and it was felt that an increase to 75% would be meaningful. In order to achieve a 90% power to detect the difference in prevalence of any end of life care plan between the before and after periods, with a certainty of 95%, it was estimated that 77 deaths would be required in each group. In total for the three study sites, there was a mean of 87 deaths annually.

7.2.8 **Statistical methods:**

For continuous, normally distributed data, means were compared using t-testing. Categorical data was compared using Chi-squared testing, and non-parametric variables were compared using Mann Whitney U testing where appropriate.

7.2.9 **Ethics:**

The Clinical Research Ethics Committee of the Cork Teaching Hospitals granted ethical approval for this study, which was conducted in adherence with the Declaration of Helsinki (1975).

7.3 Results

In the pre-implementation 30 month phase, the total number of residents ranged from 286 to 288. Resident numbers ranged from 297 to 305 between the beginning and the end of the post implementation 30 month phase.

Presented in Table 7.1 are the residents' characteristics. These were similar across the three study sites, though there were significantly fewer females in Site 3 (χ^2/df = 3.93, p=0.0197). Site 2 was urban whereas the other sites were more remote from their nearest city; despite this all sites were within 35 km of an acute hospital.

Table 7.1 Characteristics of residents of each long-term care site

Characteristic	Site 1	Site 2	Site 3	Total
Numbers of beds, n	61 - 79	120 - 128	105-98	286-305
Age, median (IQR) years	84 (78-90)	84 (78-91)	83 (77-90)	84 (78-90)
Female Gender, %	77%	71%	59%	68%
MMSE, median (IQR)	16 (5-22)	28 (23-30)*	15 (8-20)**	17 (8-24)
MTS, median score	NA	5 (1-8)	6 (3-9)	6 (2-8)
Barthel Index, median	8 (2-13)	7 (2-12)	6 (2-12)	7 (2-12)
Length of stay, median (IQR) days	1014 (456-1843)	793 (325-1486)	654 (192-1211)^^	782 (304-1528)
Access to SPC service	Yes	Yes	Yes	
Visiting Consultant Geriatrician	No	Yes	Yes	
Distance to nearest acute hospital	26 km	6.7 km	33 km	

MMSE = Mini Mental State Examination Score (out of 30), MTS = Mental Test Score (out of 10), IQR = Interquartile range, km = kilometres, SPC = Specialist Palliative Care
*N=5, **N=6, ^^ one outlier of 12291 days was removed

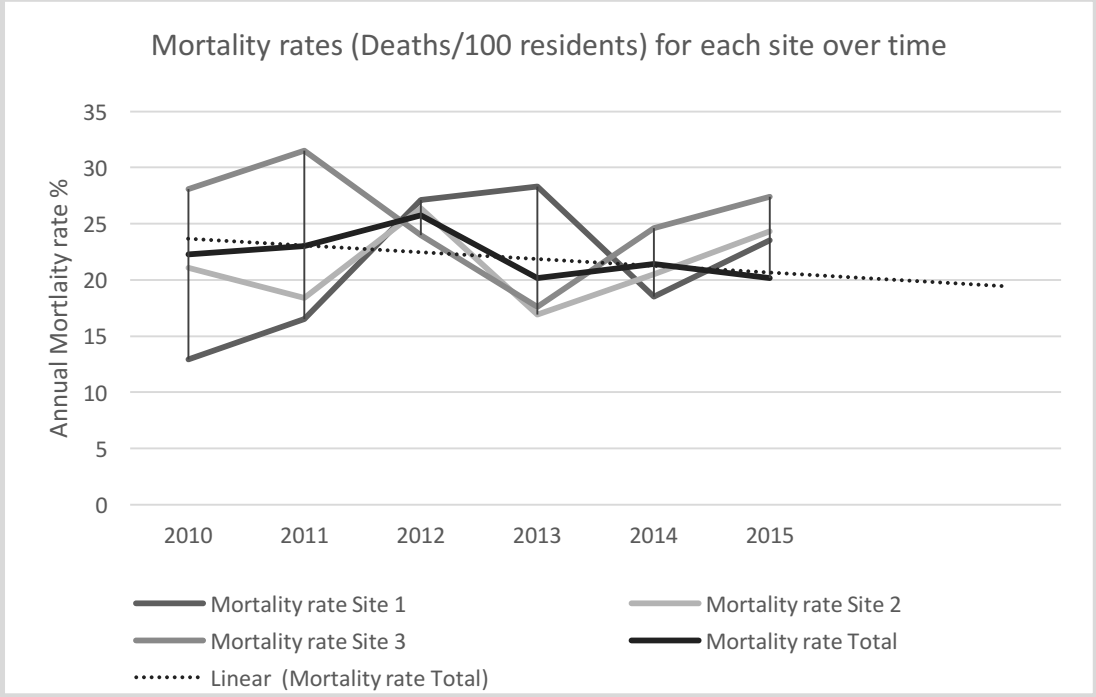
The odds of a resident dying in the nursing home rather than in hospital were slightly higher in the post-implementation period but this difference was not significant (OR = 1.176, 95% CI: 0.598 – 2.313, p =0.637). In the pre-implementation period 9.2 % of deaths occurred in hospital, compared with 7.9% of deaths in the post-implementation period (n=20/198 pre vs 17/215 post, χ^2= 0.222, p=0.637). Details of resident beds, deaths and the location of deaths for each of the study sites are presented in Table 7.2. At baseline, there were very few deaths in hospital in one of the sites (Site 3), this site was the most remote from the nearest acute hospital. In one of the other sites (site @2) there appeared to be a consistent trend over time towards fewer residents dying in hospital, where 19% of all deaths were in hospital in 2010 compared with only 2% in 2015.

Table 7.2 Mortality Rates and Proportion of deaths in hospital over time

	Year					
	2010	**2011**	**2012**	**2013**	**2014**	**2015**
Beds						
Site 1	61	66	70	71	75	78
Site 2	120	120	120	128	128	128
Site 3	105	98	98	98	98	98
Total	286	284	288	297	301	304
All deaths						
Site 1	9	13	26	28	17	24
Site 2	32	27	43	26	33	41
Site 3	41	45	31	21	32	37
Total	82	85	100	75	82	102
Deaths/available beds/year						
Site 1	0.13	0.17	0.27	0.28	0.19	0.24
Site 2	0.21	0.18	0.26	0.17	0.21	0.24
Site 3	0.28	0.32	0.24	0.18	0.25	0.27
Total	0.22	0.23	0.26	0.20	0.21	0.25
Deaths in hospital n, (%)						
Site 1	1 (11%)	2 (15%)	1 (4%)	5 (12%)	2 (12%)	3 (13%)
Site 2	6 (19%)	3 (11%)	4 (9%)	2 (8%)	4 (12%)	1 (2%)
Site 3	2 (5%)	3 (7%)	0 (0%)	1 (5%)	0 (0%)	2 (5%)
Total	9 (11%)	8 (9%)	5 (5%)	8 (11%)	6 (7%)	6 (6%)

Mortality rates were not significantly different between the 30 month pre-implementation and post-implementation periods (26% vs 25% respectively, χ^2= 0.115, p=0.735).

Figure 7.2 Mortality rates per site over time



To understand in more detail the impact of the study initiative on decision making and end of life care, those residents who died in the before and after periods were analysed in more detail.

Before implementation of the LMD-ACP program, only 51% of decedents had any type of plan made for end of life care compared with 89% after the program was introduced. Of the plans made for end of life care, the majority in the before period related to resuscitation (DNR) and or hospitalisation (DNH) only (n = 48 of 64 plans, 75%), whereas in the after period most were either advance care directives (n = 11 of 62, 18%) or EOLCPs dealing with more than just resuscitation or hospitalisation (n = 31 of 62, 50%). Only one decedent (1%) in the before period had an advance care directive.

The timing of care discussion and decision-making changed following implementation of the LMD-ACP program. Prior to the program being introduced - even for residents with the potential capacity to discuss end of life care - often it was not until the resident had deteriorated, was dying and no longer able to engage in these discussions that end of life care was then broached with their family.

Table 7.3: Care planning for end of life care in the Before and After periods

	Decedents		
	Before	**After**	
Resident beds	286-288	297-305	
Decedents, n	126*	70	
Gender, Male %	45%	28%	p = 0.021
Age at death, mean (SD)	85.4 (8.5)	85.7 (7.4)	p = 0.82
MMSE, mean (95%CI)	10.6 (6.7, 14.4)	12.4 (8.3,16.6)	p = 0.51
CCI, median (IQR)	7 (6, 9)	7 (5, 8)	p = 0.41
ACDs, n (%)	1 (1%)	11 (16%)	p < 0.0001
EOLCP, n (%)	15 (12%)	31 (44%)	p < 0.0001
DNR only, n (%)	8 (6%)	2 (2%)	p = 0.29
DNH only, n (%)	6 (5%)	0	p = 0.064
DNR and DNH, n (%)	34 (27%)	17 (24%)	p = 0.68
Verbal wishes	0 -	1 (1%)	p = 0.18
Any plan for EOL care	64 (51%)	62 (89%)	p < 0.0001
Length of stay, median (IQR)	840 days (215, 1828)	1001 days (437, 1849)	p = 0.18 U = 3835
Time from admission to plan for EOL care completion, median (IQR)	530 days (101, 1703)	742 days (208, 1414)	p = 0.53 U = 191
Time from plan for EOL care completion to death, median (IQR)	36 days (5.5, 95)	170.5 days (42.5, 436)	p < 0.0001 U = 953 r = 0.413
Time from plan for EOL care completion to diagnosing dying, median (IQR)	1 day (0 to 86)	159 days (45 to 441)	p < 0.0001 U = 498, r = -0.479

*The excess of decedents in the before period resulted from it being slightly longer than the after period to better establish the baseline characteristics of the sample population
CCI = Charlson Comorbidity Index, MMSE = Mini Mental State Examination, DNR = Do Not Resuscitate order, DNH = Do Not Hospitalise order, EOLCP = End of Life Care Plan i.e. plan that contains more than just order on resuscitation or hospitalisation, ACD = Advance care directive or Advance care plan, EOL = End of Life

In the before period, when care planning did occur, in over 90% of cases this took place between residents' doctors and family, with nursing staff taking less of a role. There was a tendency to leave end of life care discussions until patients were close to the end of their lives. The median time between documentation of end of life care decisions and the resident dying was only 36 days (IQR = 5.5 – 95 days). Decisions were made in the last week in 30% of cases (n=19 of 64 decisions) and in the last month of life in 48%. When the timing between decision making and the person being "diagnosed" as dying was examined, the differences seen were even more stark. Of decedents for whom decision timing was known, 50% (n=22/44) of decedents in the before period - but only 6% (n=3/51) in the after period had decisions for their end of life care made either on the day that death was recognised as imminent (n=13/44 before, n= 1/51 after) or in the days following (n=9/44 before, n= 2/51 after). Additionally, 7% (n=3/44) of before and 10% (n=5/51) of after decedents had decisions made in their last fortnight before dying was diagnosed.

Figure 7.3 Days between completion of end of life care plans and death

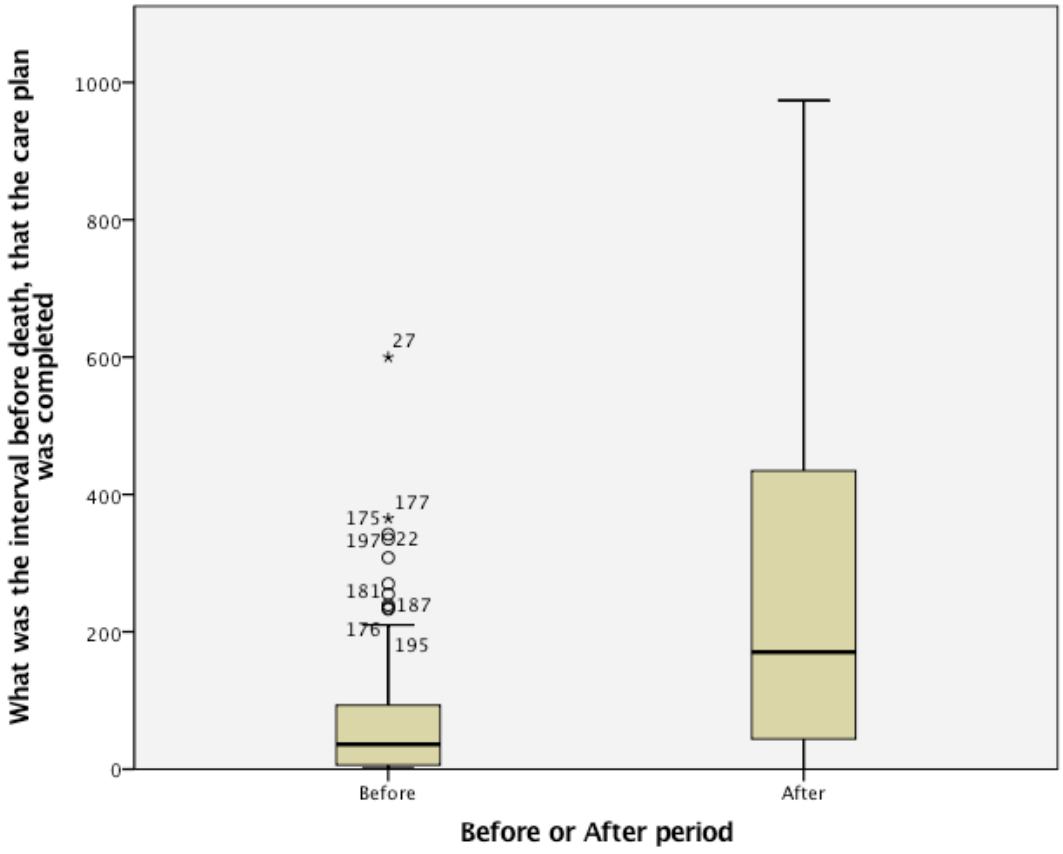
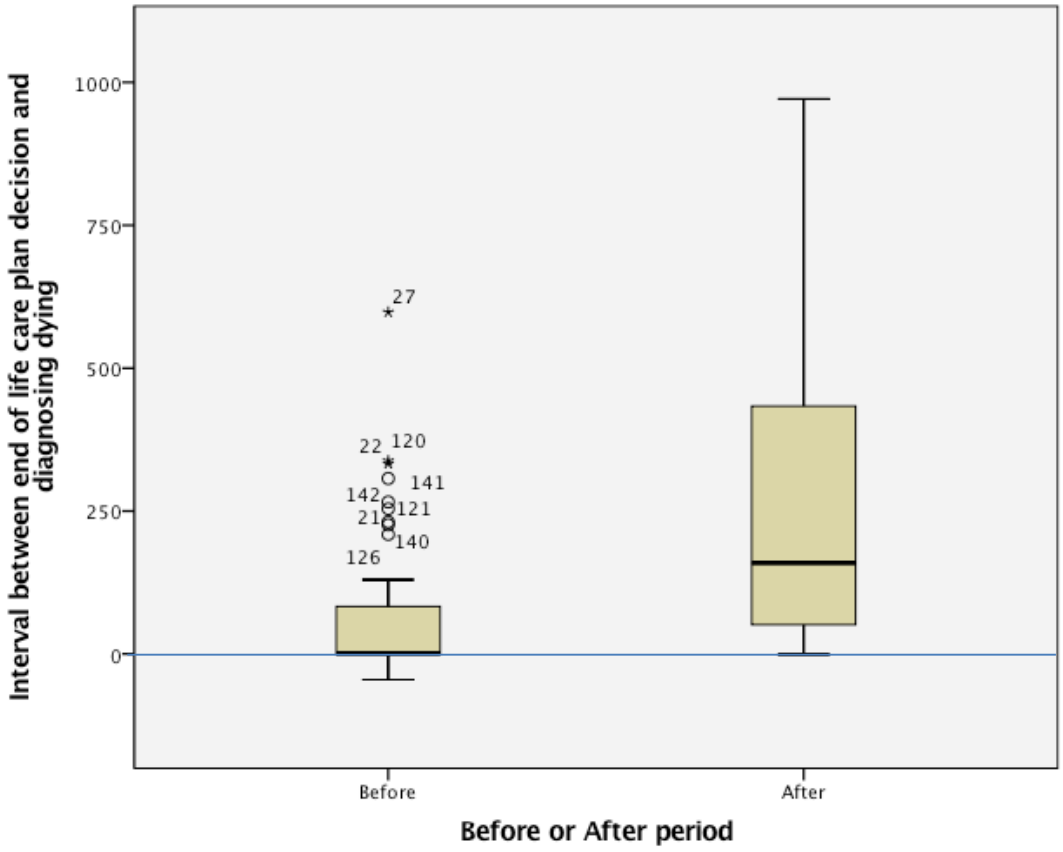


Figure 7.4 Days between completion of end of life care plans and diagnosing dying



The trend towards earlier decision making for end of life care aligned to more involvement of residents themselves in the care planning process. This was despite a high prevalence of cognitive impairment and dementia. Only seven residents (5.5%) who died in the before period were involved in planning for their own end of life care. This proportion rose significantly to 27% (n = 19) after implementation ($\chi^2 = 18.23$, $p < 0.0001$). Residents tended to decide earlier for themselves in the after period; the median interval between residents' decisions and death in the before period was 42 days (IQR 24.5 to 73.5 days) compared with 101 days (IQR 34 to 230 days) in the after period ($U = 39.5$, $p = 0.119$). For the rest of decedents, decisions for their end of life care was made by others – mostly their families, with variable input from the resident according to their ability.

Table 7.4 Resident cognition and involvement in decisions on end of life care

	Resident involvement in end of life care decisions					
	Involved in decision		Not involved in decision		No decision made	
Cognition	Before	After	Before	After	Before	After
MMSE ≥ 25 MTS 9 or 10	7 (6%)	19 (31%)	6 (5%)	1* (2%)	5 (4%)	0
MMSE 21-24 MTS 8	0	0	3 (3%)	1 (2%)	4 (3%)	0
MMSE 16-20 MTS 6-7	0	0	8 (7%)	8 (13%)	8 (7%)	1 (2%)
MMSE 11-15 MTS 4-5	0	0	9 (8%)	2 (3%)	7 (6%)	2 (3%)
MMSE ≤ 10 MTS ≤ 3	0	0	31 (27%)	23 (38%)	27 (23%)	4 (7%)

Due to missing information, n=115 for before period, n=61 for after period

* care plan was not clear on the resident's involvement in care planning (MMSE 28), but at the time of care plan documentation, the patient had become "very weak".

There is a high prevalence of cognitive impairment in long term care, thus many of the residents might not have been capable of involvement in decision making, e.g. through having end stage dementia. Using documented cognitive test scores as a crude estimate of residents' potential for involvement in end of life care planning, it was speculated that an additional five residents in the before period should have had the capacity to be involved in their care plan (MMSE ≥ 25, or MTS ≥ 9, n = 5/64, 8%), and three residents probably would have been capable of meaningful involvement (MMSE 21 to 24, or MTS of 8/10, n = 3 of 64, 5%) in the few weeks prior to their deaths. Decedents' cognitive test scores and their related involvement in decision making is presented in Table 7.4 Clearly some

residents with lower scores may also have been capable of involvement. Other undocumented circumstances may have precluded resident involvement in care planning, or there may have been instances when residents' involvement wasn't clearly documented.

Prior to implementation of the Let Me Decide program the documentation of care decisions often made it difficult if not impossible to determine whether and to what extent residents were involved in planning their own end of life care. The residents' cognitive abilities were not readily identifiable on the forms used, meaning it was a challenge to establish whether or not they were included in the process and if excluded, why this was the case and whether this was appropriate or not.

The patient who completed the advance care directive in the before period devolved end of life decision making to the doctor and was open to whatever treatment the doctor deemed appropriate, but did not want resuscitation. A palliative level of care was preferred by all of the residents with an EOLCP in the before period and in 28 of 31 EOLCPs in the after period, and in the other three a limited level of care was requested. In the after period, of those with advance care directives, nine residents requested a palliative level of care, one a limited level and one a more intensive level, this last resident died in hospital.

Combining decedents from the before and after periods, of those without a care plan, nine (13%) died in hospital compared with six (5%) of the decedents with a care plan (9 of 70 without plan vs 6 of 126 with a plan: $\chi 2 = 4.173$, OR 0.34, 95% CI 0.115 - 0.996, $p = 0.049$). Notably hospitalisation was compliant with the residents' plans in three of the six cases and the others were transferred to hospital for conditions that were difficult to manage in the nursing home in order to achieve greater comfort for the residents.

Point prevalence study and sustainability of program over time

The characteristics of the residents of each of the study sites at the time of the point prevalence survey in July 2017 did not differ significantly from the baseline characteristics presented in table 7.1. The point prevalence results are

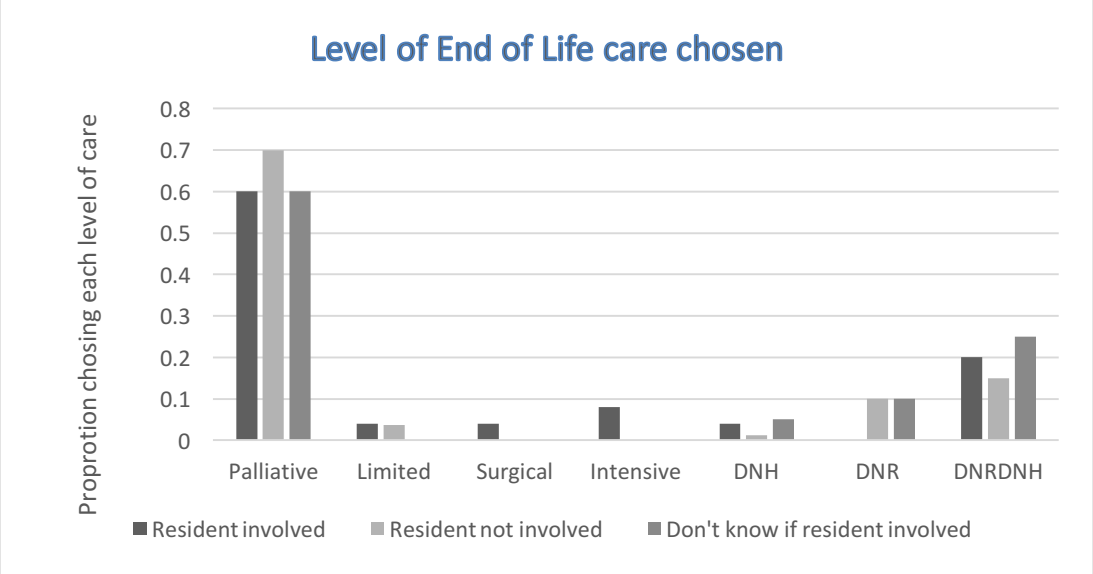
presented in table 7. 5 and show the sustainability of the program in the longer term, long after the researchers' presence in the study sites had diminished.

Table 7.5 Point prevalence of end of life care planning for residents in July 2017

	Total	**Site 1**	**Site 2**	**Site 3**
Residents, n	291	79	127	85
Any plan for end of life care, n (%)	213 (73%) 95% CI 68%, 78%	53 (67%)	113 (89%)	47 (55%)
ACD, n (%)	61 (21%)	15 (19%)	25 (20%)	21 (25%)
EOLCP, n (%)	142 (49%)	36 (46%)	80 (63%)	26 (31%)
DNRDNH, n (%)	8 (3%)	0	8 (6%)	0
DNR only, n (%)	2 (1%)	2 (3%)	0	0
DNH only, n (%)	0	0	0	0
Documented that resident involved in plan, n (%)	98 (46%)	28 (53%)	44 (39%)	26 (55%)
ACD = Advance Care Directive, EOLCP = End of Life Care Plan, DNR = Do Not Resuscitate, DNH = Do Not Hospitalise, DNRDNH = Do Not Resuscitate or Hospitalise order				

There were 291 residents in the three study sites in July 2017. Of these, 213 (73%) residents had a plan for end of life care, of whom 46% (n=98) residents were documented as making the decision on end of life care. Thirty-one of these residents (32%) chose a palliative approach to their care if they were to develop a life-threatening illness in their current state of health, 36 (37%) a limited approach, 7 (7%) chose a surgical approach and 8 (8%) chose an intensive approach, while 11 (11%) had wishes that were specifically relating to just resuscitation or hospitalisation.

Figure 7.5 Level of end of life care chosen by residents compared with others



Of the 51 residents who did not choose a palliative approach to care, 35 stated they wanted a palliative approach if their health was unacceptable to them and they defined what would be unacceptable. Five (5%) of the 98 residents who were involved in decision making for their own end of life care wanted to leave these decisions to others, but 4 of the 5 stated they did not want CPR. Anecdotally many residents had difficulty imagining a future state that would make them choose differently than their contemporaneous choice for care.

Only eleven of the 114 residents not involved in decision making had an MMSE greater than 18 or an MTS over 7. For most of the 114 residents who weren't involved in care planning, it was because attempts had been made to include them but their cognition, mental health or frailty precluded them from engaging in the conversations, or some residents opted for decisions to be made through consultation with nominated family instead. Often in these situations the resident had previously expressed wishes on their end of life care and plans were based on these wishes where known.

Figure 7.6 Kaplan-Meier survival curve for time from admission to end of life care plan completion for each resident depending on time period of admission

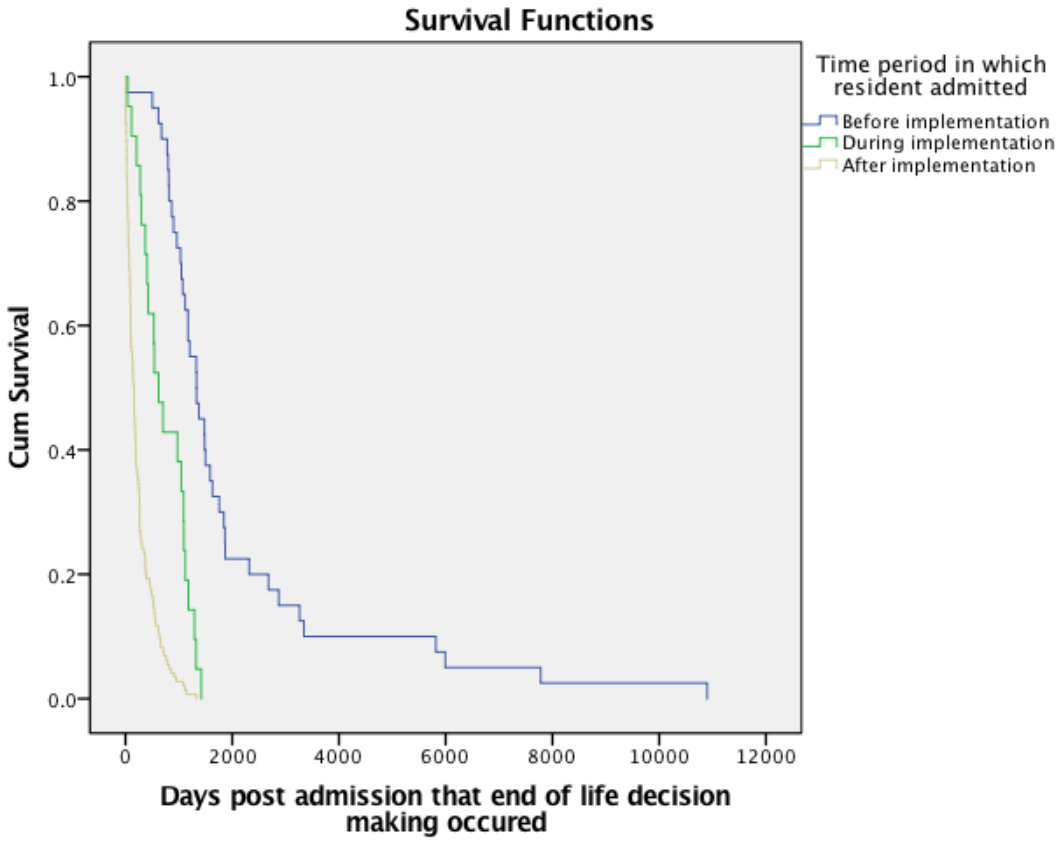


Table 7.6 Prevalence and timing of residents' end of life care plans in 2017

	Time period in which July 2017 residents were admitted						
	Pre Implementation		**During Implementation**		**Post Implementation**		
	%	n	%	n	%	n	
Plan for EOL care	78%	40/51	84%	21/25	69%	145/210	
Days since admission median (IQR)	2491 (2190, 2895)		1597 (1537, 1735)		551 (2014, 855)		H=170.4, p<0.0001
Median days to decision (IQR)	1544 (1043, 2480)		975 (390, 1309)		161 (57, 369)		H=124.3, p<0.0001
Kaplan-Meier survival median days from admission to care plan (95% CI)	1330 (1065, 1595)		622 (360, 884)		157 (120, 194)		Log-rank = 116.2 Breslow = 84.53, p<0.0001
Proportion of residents involved in their care plan	37%	15/41	48%	10/21	48%	69/145	

Of the 291 residents, 210 (72%) were admitted after implementation of the LMD-ACP program, 69% (n = 145) of whom had an end of life care plan. Examining just the residents admitted after LMD-ACP implementation found the prevalence of residents with end of life care plans differed between sites. Some sites appeared to be more successful in planning for end of life care than others, the results are presented in Table 7.6.

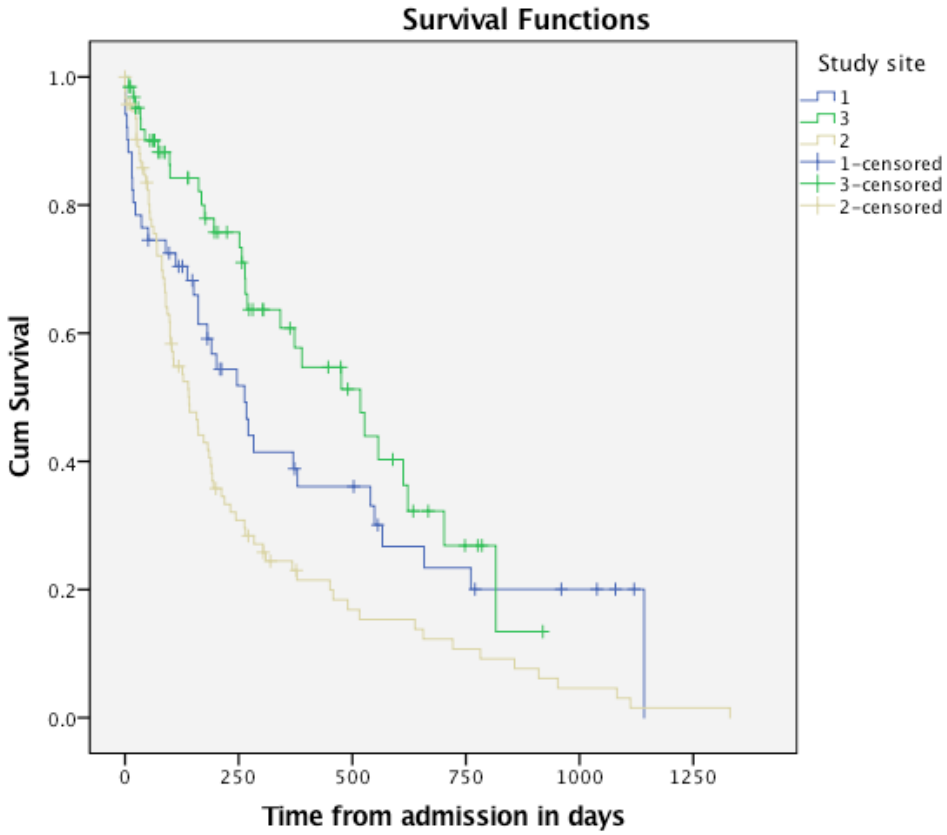
Table 7.7 Characteristics of residents admitted after LMD-ACP implementation

	Site 2	**Site 1**	**Site 3**	
Residents admitted post July 2013, n	95	51	64	
Residents with end of life care plan, n (%)	82 (86%)	35 (69%)	29 (45%)	
Resident documented involvement in plan,	35 (43%)	19 (54%)	15 (52%)	
Median length of stay, days (IQR)	592 (251 to 924)	556 (212 to 960)	431 (119 to 796)	KWCHI = 6.126, P=0.047
Median days from admission to care plan completion (IQR)	126 (56.5 to 264)	161 (16 to 283)	257 (86 to 497)	KW CHI 4.737, P=0.09
Kaplan Meier median survival time from admission to care plan in days (95% CI)	141 (92 to 190)	263 (170 to 356)	518 (339 to 697)	p < 0.001*

*Log rank = 18.102

While there may be many reasons for the difference in prevalence found between sites, the timing of care plan completion appeared to be important and when explored it was found that the sites with the highest prevalence of plans, also had the shortest interval between admission and care plan completion. The resulting Kaplan-Meier survival curve is shown in figure 7.4.

Figure 7.4 Kaplan-Meier survival curve for time from admission to end of life care plan completion for each study site's residents admitted after implementation of the LMD-ACP program



Quality of death and dying

Residents' families were overall very satisfied with the way in which their relative died and there was little difference between the before and after periods or between decedents with plans for care compared with those without. Respondents were asked to rate the quality of their relatives' death using a scale of 1 to 10, where 1 represented "terrible" and 10 represented "almost perfect". They rated very highly the quality of how their loved one died (median 10, IQR 8-10), only 9 of 130 (7%) gave a score of 5 or less, whereas 96 of 130 (74%) gave a score of 9 or 10. Of those who scored less than 9, 22 (65%) were from the "before" period compared with 12 from the "after" period (35%), 13 (38%) had no care plan for end of life care, 14 (41%) had either a DNR or a DNH order, while 7 (21%) had an EOLCP. There was also a non-significant tendency for patient involvement in decision making to result in family giving a higher

rating on the quality of the death (score of 9 or 10) (OR = 5.56, χ^2 = 3.087, p = 0.079). For residents who were involved in care planning, only 1 of the 13 (8%) had relatives who rated their death as less than 9, whereas 19 of the 60 (32%) relatives whose loved one wasn't involved in care planning rated their death as less than 9.

Where residents' family indicated that the family were involved in care planning they were almost twice as likely to rate highly the quality of how their relative died (Odds ratio of scoring 9 or 10 on quality of death = 1.99, 95% CI 0.80 to 4.95, p=0.137). When the quality of death was rated more poorly by relatives (a score of <9) there was also a trend towards later rather than earlier decision making (OR = 1.778 for decisions made in the last month vs more than 3 months before the death, 95% CI 0.52 to 6.03, p = 0.356).

In addition, relatives were asked what they felt went well and what they felt could have gone better in relation to their loved ones' deaths. Many complements of the care were received. For the most part, staff having more time to spend with each resident and communication were the areas identified as being most in need of improvement. These comments, good and bad, were fed back in an anonymised fashion to staff in the nursing homes.

Several areas of good practice were highlighted by bereaved relatives, particularly around being able to visit freely and the acknowledgement of the death by staff. One site had an open visiting policy which was very welcomed by family – one son wrote of how his routine was to take breakfast with his father every morning and read the newspaper together.

The rituals around the time of death were praised by others – one site have the practice of offering to use one of the sitting rooms to "lay out" the deceased resident reminiscent of the Irish practice of "waking" the person in their home - this was valued by family. One commented that it allowed the other residents to recognise the death and to say their farewells. Another custom of this site was for staff to form a "guard of honour" as the deceased resident left the home – through the front door. In winter this was sometimes a candle lit affair. Families praised the home for these efforts and found them comforting.

Table 7.8: Characteristics of respondents to Quality of Dying and Death Questionnaire

	Before	After	P value	Plan for End of Life Care		P value
				Known	Not Known	
Decedents, n	126	70		126	70	
QODD respondents, n (% response rate)	85 (68%)	51 (73%)	0.43	95 (75%)	41(59%)	0.014
From Before period, n (%)				47 (49%)	38 (93%)	<0.0001
Deceased Relative had care plan for end of life, n (%)	46 (54%)	48 (69%)	<0.0001			
Respondent was spouse, n (%)	7 (8%)	5 (10%)	0.81	8 (9%)	4 (10%)	0.81
Respondent was a son/daughter, n (%)	45 (54%)	37 (73%)	0.05	61 (66%)	18 (45%)	0.022
Respondent was a sibling, n (%)	8 (10%)	2 (4%)	0.21	4 (4%)	6 (15%)	0.033
Respondent another relation of decedent, n (5%)	23 (28%)	8 (16%)	0.098	19 (21%)	12 (30%)	0.24
Female respondent, n (%)	43 (51%)	34 (67%)	0.05	59 (63%)	18 (44%)	0.042
Respondent age in years, mean (SD)	58 (10.6)	60 (12.2)		59 (11.2)	59 (12.3)	
Spent time with decedent in last week, n (%)	83 (98%)	50 (98%)	0.91	93 (98%)	40 (96%)	0.91
Present at death, n (%)	47 (55%)	37 (73%)	0.04^	63 (68%)	21 (51%)	0.068
Not present at death, but death was sudden, n (%)	8 (21%)	3 (25%)		7 (23%)	4 (24%)	
Someone present at death, n (%)	67 (79%)	49 (96%)	0.02^^	81 (85%)	28 (78%)	
Respondent expected the death, n (%)	69 (82%)	40 (78%)		75 (80%)	28 (78%)	
Respondent prepared for the death, n (%)	62 (75%)	38 (73%)		71 (76%)	24 (69%)	
^ OR = 1.88 (95% CI 1.04, 3.41), p = 0.04 **^^** OR = 2.06 (95% CI 1.11, 3.82), p = 0.02						

Table 7.9 Relatives perceptions on decedents' dying experience

	Before n (%)	After n (%)	Plan for End of Life Care	
			Known n (%)	Not Known n (%)
Staff response to queries/requests				
Good/very good	83 (98%)	49 (92%)	92 (97%)	33 (92%)
Quality of care				
Good/very good	83 (98%)	49 (92%)	92 (97%)	35 (97%)
In Pain				
None/Little of the time	47 (63%)	29 (81%)	54 (62%)	18 (58%)
Most/All of the time	2 (3%)	3 (6%)	4 (5%)	1 (3%)
Able to breath comfortably				
None/Little of the time	6 (7%)	4 (8%)	6 (7%)	4 (11%)
Most/All of the time	59 (70%)	39 (80%)	70 (76%)	24 (67%)
Comfortable				
None/Little of the time	8 (10%)	2 (4%)	6 (6%)	4 (11%)
Most/All of the time	57 (70%)	36 (73%)	65 (71%)	23 (66%)
Anxiety				
None/Little of the time	65 (78%)	31 (69%)	65 (74%)	27 (77%)
Most/All of the time	1 (1%)	2 (4%)	2 (2%)	1 (3%)
Signs of enjoyment in the last week, e.g. smile or laughing				
None/Little of the time	47 (57%)	27 (56%)	50 (55%)	19 (54%)
Most/All of the time	10 (12%)	5 (10%)	12 (13%)	3 (9%)
Resident was treated with dignity and their self-respect was maintained:				
None/Little of the time	5 (6%)	0	2 (2%)	3 (9%)
Most/All of the time	77 (92%)	49 (98%)	90 (97%)	31 (89%)
Decedent felt a strain on loved ones				
None/Little of the time	65 (84%)	37 (80%)	74 (84%)	23 (77%)
Most/All of the time	2 (3%)	2 (4%)	2 (2%)	2 (7%)

Continued	Before n (%)	After n (%)	Plan for End of Life Care	
			Known n (%)	Not Known n (%)
Decedent said "goodbyes"	21 (27%)	22 (49%)	33 (36%)	9 (25%)
Resident had funeral plans	24 (30%)	20 (40%)	31 (33%)	11 (31%)
As far as respondent knew, end of life care decisions were discussed with				
Resident	8 (10%)	9 (18%)	14 (15%)	2 (6%)
Respondent or Resident's family	51 (67%)	34 (77%)	69 (83%)	11 (34%)
Would have liked more information on dying or what to do afterward	18 (22%)	10 (20%)	19 (21%)	9 (25%)
How well staff communicated with resident, median (IQR)^	9.5 (8-10)	10 (8-10)	9 (8-10)	9 (8-10)
How well staff communicated with respondent/family, median (IQR)^	10 (9-10)	10 (9-10)	10 (8.5-10)	10 (8.3-10)
Extent that care given respected decedents wishes, median (IQR)^	10 (9-10)	10 (8.3- 10)	10 (9-10)	10 (9-10)
Quality of life in last week, median (IQR)^^	8 (3-10)	7 (4-9.8)	6.5 (2.8-9)*	8 (4.5-10)
Overall quality of how the resident died, scale 1-10, median (IQR)^^	10 (8-10)	10 (9-10)	10 (9-10)	9 (8-10)

*many of the respondents qualified that they judged the quality of life as low because of the effects of dementia, rather than the effect of the care or being in the nursing home

^likert scale used, 1-10, 1=very poorly, 10 = excellent

^^ likert scale used, 1-10, 1 = terrible, 10 = almost perfect

7.4 Discussion

Feasibility, acceptability and sustainability of the program,

This study showed that the systematic implementation of an advance care planning program is both feasible for staff, acceptable to residents and their families and sustainable in the longer term in the long term care setting in Ireland. This is despite a high prevalence of dementia in nursing homes and staff turnover with time. Though time consuming, staff saw the benefit of advance care planning and continued to perceive it as a useful endeavour.(287) Advance care plan completion remained prevalent over 5 years after implementation started and with time showed a move to greater and earlier involvement of residents in decision making.

Baseline end of life decision making practices in long term care in Ireland: timing and resident involvement

One of the key differences that became apparent after the introduction of the Let Me Decide advance care planning program was the change in the way in which end of life care decisions were made, a shift in timing of decision making and the implications of this.

After implementation of the LMD-ACP program, end of life care planning took place far earlier; only 6% of end of life care plans were made in the last week of life compared with 30% before introduction of the advance care planning program ($p = 0.0025$). The median interval between making decisions on end of life care and diagnosing dying for decedents in the before period was only 1 day, whereas in the after period this gap increased to a median of 159 days ($p < 0.0001$)

The program changed end of life decision making from family directed decisions made at a time of a health-related crisis or when death was imminent, to a process that took place months in advance of death with time for education, consideration, discussion and most importantly inclusion of the resident.

Lamberg et al found 83.8% of nursing home decedents with advanced dementia had a DNH order at the time of death, but similar to this study a large proportion (40.3%) of the orders were written in the last 30 days of life.(535) With regard to the timing of end of life decisions, Billings and Bernacki warned

of the Goldilocks phenomenon that they need to be timed not too early, not too late, but just right.(528) Too early and residents have difficulty hypothesising potential future situations, and consequently may need to change their decisions. Few of the residents in this thesis study met Billings et al's description of being too early, few residents (or their families) changed the decisions made in the first instance. Most residents made their choices based on their current status, and chose a palliative approach to care with a preference to opt out of hospitalisation. Too late and like at baseline, before the Let Me Decide program was introduced, fewer residents are included in decision making because of declining capacity, increasing frailty or being too ill.

Similar to this study's finding at baseline, of a lack of inclusion of residents in decision making, a Norwegian study found nearly half of residents to be competent or partly competent, but that there was an almost non-existent attention to their opinions.(537) There was a preference instead to discuss treatment with their relatives, few of whom considered the residents' autonomy or potential involvement in discussions on their own care.(536) Introduction of the Let Me Decide program in this thesis study seemed to change this dynamic.

Nursing home residents' ability to consent - and subsequently their preferences not always being recognised - was highlighted as an issue in a systematic review of end of life expectations and experiences among nursing home patients and their family.(537) This review also highlighted the difficulty and distress experienced by family when they became proxy decision makers, particularly when guidance from healthcare professionals was lacking.(537-539)

A German study of adults over 75 years, found the most commonly cited reason for not having an advance care directive or Power of Attorney was participants trust that their relatives (59.4%) or physicians (44.8%) would make the right decisions for them when the time came.(91) Other studies have had similar findings of older peoples' faith in the decision making capabilities of their family or healthcare providers.(538, 540, 541) Though we didn't explore reasons for

not having an advance care directive in this study, we did encounter several directives where at least some of the decision making was explicitly left in the trust of the treating physician or the family. Another common reason for people not completing an advance care directive was that they did not want to concern themselves with this topic.(91, 538) This too was encountered in documentation of the end of life care planning in this study.

Effect of program on the quality of the dying experience

There is a perception from published research that the end of life care provided in nursing homes is poor. The findings of this study do not support that view. The vast majority of relatives, over 90%, commended the care their loved one received at the end of their lives. A study by the Irish Hospice Foundation published in 2014 also found that relatives' perception (n=59) of the care received by their loved ones who died in nursing homes in Ireland was good (35%) or excellent with no room for improvement (54%).(520) As with all studies of this nature, causality cannot be proven, however it does not appear that the combination of palliative care education and an advance care planning program used in this study had any detrimental effect on the care of the dying.

A systematic review of advance care planning found that symptom management and satisfaction with care were less commonly focused on than the main outcomes measured: choice of treatment and place of care at the end of life.(139) In this thesis' study for the most part symptoms were managed well, and over two thirds of those dying were described by family as being comfortable most or all of the time. Given that one third were not mostly comfortable shows clear room for improvement in symptom management.

The control of symptoms, being pain free and comfortable is consistently ranked as one of the most important measures of a "good death". Despite evidence of unmet palliative care needs for some residents, their families were still very satisfied with the way in which they died, the care given and felt it reflected the wishes of the decedent. This discrepancy between the control of

symptoms and the overall quality of the death was also observed by Caprio et al.(460) It raises the question of why and how symptom management is viewed and conceptualised differently than the quality of care or the quality of the death. It may be that there is an acceptance of or perhaps an expectation of some degree of discomfort or suffering as death approaches.(542) It may also be that for patients who have chronic pain (e.g. from severe arthritis) or dyspnoea (e.g. from advanced chronic obstructive airways disease) that these symptoms are somewhat ignored or tolerated as they have become part of the day to day reality of the person.

The need for decision making as death draws near is common. A US based study found that 42.5% (95% CI 39.9-44.5) of adults over 60 years who died needed decisions made about treatment in their final days, of these, 70.3% (95% CI 67.3 to 73.2) had lost decision-making capacity.(137) Loss of decision making capacity was more likely in nursing home residents (adjusted odds ratio, 1.36; 95% CI, 1.17 to 1.58; P<0.001.(137) In this thesis study, for residents who were not involved in decision making, there was a tendency for their relatives to perceive the quality of dying less positively. This may be linked to the burden that may come from making decisions for a loved one.(536)Without knowledge of a decedent's wishes there may be a fear or anxiety for the proxy decision maker that the care chosen was too aggressive or not aggressive enough.

Location of deaths

This study found a non-significant trend towards fewer residents dying in hospital without a change in mortality rates. Following introduction of the program, hospital deaths fell from 9.2% to 7.9% though one site already had very few hospital deaths (0 to 7% per year) and one of the site's hospital deaths dropped from 19% in 2010 to 2% in 2015. Decedents with a care plan were less likely to die in hospital, and when they did die in hospital this was in line with their expressed wishes in half of cases.

Internationally studies report that nursing home residents die in hospital in between 19-25% of cases in Canada, 8-43% in the UK and 20% in the US.(543-545)(537)(251)(216) A study based on 2.5 million US nursing home residents'

deaths found lower proportions of hospital deaths for residents with advance care plans (14% vs 30%), DNH orders (4.6% vs 20.5%) or dementia (14.4% vs 20.7%).(215) Gozalo et al reported a similar proportion of 15% of US nursing home residents with dementia dying in hospital.(228) In the UK, introduction of the Gold Standards Framework reduced hospital deaths for nursing home residents from 43% to 21% over a 7 year period.(536) Another UK study found similar results to our study whereby implementation of the Gold Standards Framework reduced nursing home residents' hospital deaths from a baseline of 15% to 8% after the framework was put into practice.(250)

Data up until now for long term care resident deaths in hospital in Ireland have been largely unknown and this study suggests a low prevalence of deaths in hospital but that such deaths are usually appropriate for the patients' condition or wishes. Extrapolating results from a local study in Cork and combining with HIPE (Hospital In-Patient enquiry) data estimated 10% of nursing home residents ultimately die in hospital, which indicates our results are likely generalizable at least to this area of Ireland.(546)

Limitations:

There were several limitations to this study, firstly the uncontrolled non-randomised nature of the design may have introduced confounding due to other contemporary efforts in Ireland to improve palliative care, so care needs to be taken in interpreting the results. Secondly, measuring the quality of the end of life experience of the resident from family members' perspective may be inaccurate or coloured by elements such as the relatives' relationship with the decedent, their emotional state or perspective at the time of the death or of the survey.(457, 488)Research has shown better agreement between decedents' assessment pre-death and relatives' retrospective views for objective measures, and less agreement for subjective outcomes such as symptoms.(444, 498) Also, research has shown that while there are global attributes of a good death, patients and family may define and weigh these differently.(547, 548)

Generalisability:

The nature of dying is very unique as are relatives' perceptions of their loved ones' deaths. Given the diversity of human nature and experience and the impossibility of measuring all characteristics and variables that may have influenced the responses to the questionnaire it is not feasible to extrapolate the results to all situations.

This study's population was predominantly white, Christian and older, so the results of this study might not be generalizable to populations in other countries or to nursing home residents of different faith or cultural background for whom values and beliefs may differ. The high prevalence of cognitive impairment in our study population is in line with international research on long term care residents, particularly in Europe, where long term care models are similar. In this study 84% of residents had a MMSE <25 and/or a mental test score <9, some of the other 16% of the study sample may also have had mild dementia, many of whom were unacknowledged as having cognitive impairment.

In French nursing homes, it's estimated 70% of residents have dementia, 67% in Sweden, 52% in Germany, though in China a prevalence of dementia of only 37% has been recorded. In addition, there is a significant level of undiagnosed dementia amongst nursing home residents. A Canadian study found 11.6% of nursing home residents had undiagnosed dementia, whilst a Scottish study found a prevalence of 32%.(521-526, 549) In Ireland Cahill et al found only 32% of nursing home residents had a clinical diagnosis of dementia, though 89% were cognitively impaired with 69% of residents having moderate to severe impairment.(550)

The sites chosen for this study include both public and private facilities, urban and non-urban and larger as well as smaller long term care residences which adds to the generalisability of the results found.

The results presented suggest that the systematic approach used in implementing the Let Me Decide program contributed to greater and clearer documentation of end of life care decisions and inclusion of residents in these decisions. This likely facilitated interpretation of the validity of the documented

care decisions. The program was accepted by residents and feasible for staff even within the time constraints of their work environment. Several of the study sites moved to introducing the program shortly after admission and revisiting advance care planning once a resident had "settled in" to the home. The results suggest that this approach led to a greater uptake of planning for end of life care and inclusion of residents at a time when they remained capable of participating. Further research is needed to explore the best timing of end of life care planning in this setting to achieve the best possible outcomes for residents, their families and long term care staff.

Chapter Eight:
Medication use at end of life in long term care in Ireland

8 Medication use at the end of life in long term care in Ireland

8.1 Introduction

Good prescribing at the end of life involves the avoidance of inappropriate medications and polypharmacy, yet the number of medications taken in the last year of life has been found to increase by about 50%.(551) Polypharmacy increases the risks of drug interactions, adverse events, and potentially reduces quality of life and survival.(552-556) The increase in polypharmacy as death approaches is predominantly due to the addition of symptom relieving medications without rationalisation of preventive medications, many of which may no longer be indicated or beneficial, or may indeed be potentially detrimental to the health of the patient.(551) Such rationalisation of prescribing, considered within the individual clinical context, is the essence of deprescribing.(557)

Research addresses the issue of when to start preventive medications but rarely explores when such medications should be stopped. Discontinuation of preventive treatments of uncertain benefit is most pertinent to older people particularly those with limited life expectancy where changes in drug absorption and metabolism, renal and hepatic function increase the risk of adverse effects further. The decision to stop medications can be difficult. There may be uncertainty about the patient's prognosis or dying trajectory, about the potential adverse effects of stopping a medication or the activeness of the disease targeted by the preventive medication being considered for discontinuation.(556) Furthermore there is a paucity of clear deprescribing guidelines.(558, 559)

The addition of medication for symptom relief includes medication for incident symptoms but also - as per best practice guidelines - the prescription of anticipatory medications.(560-562) Anticipatory prescribing is where medications needed to manage common end of life symptoms are prescribed in advance of being required. It is recommended that anticipatory prescribing for a dying person would include analgesia for pain, an anxiolytic for anxiety, an

anti-secretory medication for respiratory secretions, sometimes known as the death rattle, and antiemetic medications for nausea or vomiting.(560, 561)

There are four stages in anticipatory prescribing: deciding to prescribe, prescribing, dispensing and administering the medicines. (563, 564) Though the need for medications may be anticipated by nursing home staff, it is the general practitioner or out of hours general practitioner service who complete the prescription and oftentimes the request for anticipatory medication prescription must be negotiated carefully by nurses with the attending doctor, who in many instances may not know the patient.(564)

Anticipatory prescribing at the end of life has become more common in an attempt to empower nurses to quickly relieve a dying patient's suffering without having to wait the attendance of medical "call out" personnel and also to avoid the need for hospitalisation.(565) Approximately 25% of Irish deaths occur in a long term care, but it is unknown to what extent anticipatory prescribing practices take place in this setting.

The aim of this paper was to investigate the prevalence and adequacy of medication rationalisation, prescribing practices including anticipatory prescribing and medication administration at end of life for older people residing in a long term care setting in Ireland.

8.2 Methods

8.2.1 **Study design**

This study was a retrospective observational cohort study of prescribing practices at end of life in three long term care settings in Southern Ireland.

8.2.2 **Study population**

Advance care planning using the Let Me Decide program and a palliative care educational initiative tailored to each of three study sites was implemented through a series of educational workshops from September 2012 to July 2013. This complex intervention has been described in detail in section 7.2.2. The palliative care education included a module on symptom assessment and

management both pharmacological and non-pharmacological. The advance care planning program allowed description of the aggressiveness level of care desired for the resident.

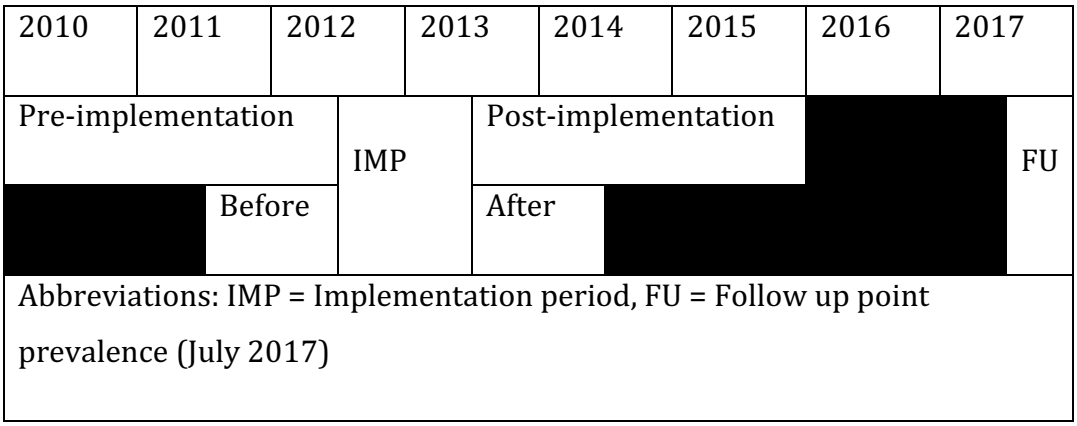
The study sites characteristics have also been described in chapter 7. All long term care residents of the study sites, aged 65 years of age or older, who died in the periods before and after implementation of the advance care planning and palliative care educational program as outlined in figure 7.1 were eligible for inclusion in data collection.

8.2.3 **Study outcome measures**

Once three months had elapsed from the death, members of the family were contacted as outlined in section 7.2.5 and the timeline is presented in figure 8.1. Family were asked for permission to access the decedent's clinical notes and with their consent, the family member completed a questionnaire as described in section 7.2.5. The questionnaire used questions from the "Quality of Dying and Death" (last seven days version) instrument (QODD), a validated assessment tool; in addition to bespoke questions similar to those used in the Irish National Audit of End of Life Care in Hospitals in Ireland.(384, 436) Part of this questionnaire addressed the symptom burden experienced by the deceased resident in their last week of life, as perceived by their bereaved relative. Symptom prevalence and management was also assessed from examination of the clinical notes of decedents in the before and after periods. Alongside analysis of symptoms a retrospective detailed review of medications prescribed, deprescribed, administered and omitted or refused took place.

The diagnosis of dying was defined as the date where anticipated death was documented in the patient's notes or where an end of life care pathway was started. This was evident in one of the sites. It was not related to the Liverpool Care pathway but rather a care pathway prompting assessment that the elements of good end of life care were in place.(172)

Figure 8.1 Details of study period categorisation



The interval between prescription of medications and death was calculated. Particular attention was paid to the changes in medications prescribed in the last 3 months of life. Data on the medications prescribed and given were obtained from the prescription record in each patient's notes. Data was anonymised.

Preventive medications included: lipid lowering agents, antihypertensives, antiplatelets, ACE inhibitors, ARB, calcium channel blockers, beta blockers, anti-osteoporosis medications, calcium Vitamin D supplements

Symptom relieving medications included: analgesics, antipyretics, anxiolytics, antipyschotics, antisecretory medications, antiemetics and laxatives.

Some medications were both preventive and symptom relieving, these included: loop diuretics, beta blockers, calcium channel blockers, antiarrhythmics, anticonvulsants.

Polypharmacy was defined as the prescription of ≥ 4 regular medications and excessive polypharmacy as ≥ 10 regular medications. It was accepted that using this definition somewhat underestimated the true problem, as in addition to regular medications, residents were also prescribed PRN medications which if administered, added to their pill burden.

Regular medications were those taken on a regular basis for an unfixed period of time, e.g. this excluded short courses of antibiotics or steroids. Food

supplements were also excluded as regular medications, but supplements in tablet form such as folic acid or iron were included as regular medications. Pro Re Nata (PRN) medications included those that were prescribed to be taken only when needed. The prescription initiation date was taken to be the date when that drug was initiated rather than the date the dose was last changed where this was applicable. In some instances, administration of the drug was omitted as death approached, often due to the patient being too drowsy to take oral medication or due to the development of dysphagia in this context. A record was made of how long before death this type of omission of regular medications began.

The date of rationalisation of medications was taken as the earliest date in the last three months of life where there appeared to be an effort to discontinue potentially unnecessary medications. In some cases, medications were discontinued on a phased basis, where this occurred it was the earliest date with evidence of rationalisation of medications that was taken for analysis purposes.

Prescription of prophylactic medications for end of life care was deemed to be satisfactory when there was prescription of an opioid analgesic, an antiemetic, an anxiolytic and an anti-secretory agent. It was deemed to be partly satisfactory if one or more of these agents was prescribed. Ideally these drugs would have been prescribed in a parenteral form, preferably subcutaneous rather than intramuscular.

The intervals between rationalisation of medications, prescription of prophylactic medications for end of life care and the diagnosis of dying and the time of death were calculated and compared.

Symptoms were judged to be present based on the relative's judgement (from the questionnaire), documentation in the clinical notes or the dispensing of relevant medications, e.g. the administration of antiemetics indicated the presence of nausea or vomiting.

Sudden deaths were those which were unexpected and happened quickly without an identifiable preceding acute deterioration e.g. somebody dying in their sleep.

8.2.4 Efforts to address bias

The risk of selection bias was minimised by including all deaths within each of the study sites for inclusion in the study. Recall bias with regard to the prescription and administration of drugs and the presence of symptoms was minimised by examining individual decedents prescription records rather than relying on doctor's or nurse's recollection, and also by comparing the findings from the prospectively recorded clinical notes with relative's responses from the questionnaire.

8.2.5 Statistical analysis

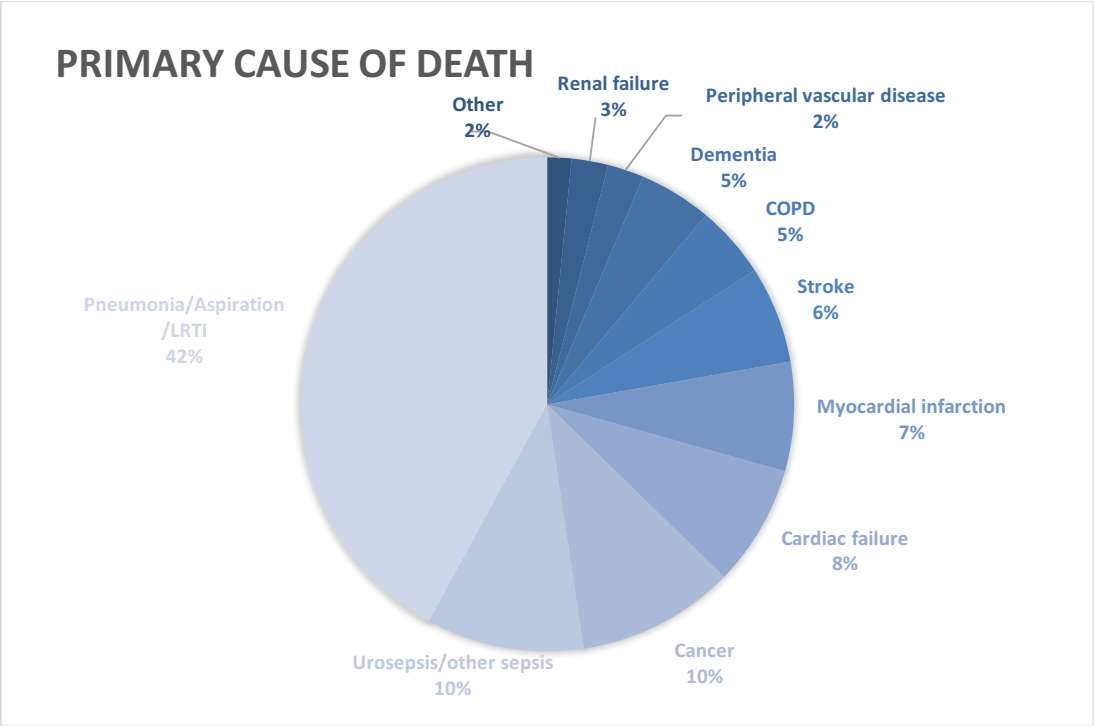
All data was analysed using SPSS V.24 (IBM SPSS Statistics, IBM Corporation, Chicago, IL).

Descriptive statistics were used. For continuous, normally distributed data, means were compared using t-testing. Categorical data was compared using Chi-squared testing, and non-parametric variables were compared using Mann Whitney U or Kruskal Wallis testing as appropriate. Related sample non-parametric data was compared using the Wilcoxin signed-rank test.

8.3 Results

There was a total of 196 deaths during the two observational periods. Relatives completed the questionnaire for 136/196 (69%) of deceased residents. Clinical notes were obtainable in 191/196 (97%) of cases, unobtainable notes were all from the before period. Of the 196 deaths, 36 (18%) were residents of site 1, 71 (36%) of site 2 and 89 (45%) of site 3. Sudden death represented 10% (n=19/191) of dying trajectories overall. Dying was diagnosed, or recognised, in the documentation of 84% (n = 161/191) of residents overall, and 94% (n = 161/172) of decedents who did not die suddenly. The primary causes of death are depicted in Figure 8.2 and decedents characteristics are found in table 8.1.

Figure 8.2 Primary cause of death of decedents



Of the 196 decedents, 9% (n = 18) died in an acute hospital, all others died in the nursing home, 9 of these deaths were in the before period representing 7% of before deaths, and 9 were in the after period representing 13% of after deaths. The reason for the discrepancy in the proportion of deaths in an acute hospital between the before and after period was likely that site 3 contributed a greater proportion of the observed deaths in the before period and this site, this site was the most remote from an acute hospital, and also had the lowest rates of hospitalised deaths.

Overall Prescribing and Polypharmacy

Prescription details were available for 188 of the 196 decedents (96%). The number of regular oral/transdermal/rectal medications prescribed fell from a median of 7 (IQR 5 to 10, range 0 to18) at 3 months before death, to a median of 5 medications (IQR 2 to 8, range 0 to 16) by the time of death. There was no significant difference between the before and after groups (table 8.2).

Table 8.1 Deceased residents' characteristics in the before and after periods

	Decedents			
	Total	**Before**	**After**	
Resident beds	286 – 305	286-288	297-305	
Decedents, n	196*	126*	70	
Died in hospital, n (%)	18	9 (7%)	9 (13%)	
Gender, Male % (n)	39% (77)	45% (57)	29% (20)	p = 0.021
Age at death, mean (SD)	85.5 (8.2)	85.4 (8.5)	85.7 (7.4)	p = 0.82
CCI, median (IQR)	7 (6, 9)	7 (6, 9)	7 (5, 8)	p = 0.41
Length of stay, median (IQR)	950 days (277, 1826)	840 days (215, 1828)	1001 days (437, 1849)	U = 3835 p = 0.18
Sudden deaths	10% (19)	11% (14)	7% (5)	p = 0.37
Dying Dx (excluding sudden deaths)	94% (162)	93% (99)	97% (63)	p = 0.23
Dying Dx and seen by SPC, % (n)	25% (41/162) 95% CI 18% - 32%	26% (26/99) 95% CI 17% - 35%	24% (15/63) 95% CI 13% - 35%	P = 0.73
Interval from dx dying to death, median (IQR)	3 days (1, 7) range 0 - 124	4 days (1, 8) range 0 – 94	3 days (1, 5) range 0 – 124	U = 2492 p = 0.28
Documented diagnoses				
Dementia	116 (61%)	85 (70%)	31 (44%)	
Undocumented dementia	54 (28%)	24 (20%)	30 (43%)	
Stroke disease	55 (28%)	37 (31%)	18 (26%)	
Cancer	50 (26%)	33 (27%)	17 (24%)	
COPD	47 (25%)	27 (22%)	20 (29%)	
Cardiac failure	64 (34%)	37 (31%)	27 (39%)	
Diabetes	32 (17%)	18 (15%)	14 (20%)	
Chronic Kidney Disease	25 (13%)	17 (14%)	5 (7%)	

*The clinical notes for 5 decedents in the before period were unobtainable

CCI = Charlson Comorbidity Index, EOL = End of Life, Dx = diagnosing

The number of regular medications prescribed at 3 months before death and at death was compared for those who were diagnosed as dying, those who were not recognised as actively dying and those who died suddenly.

- For those who were diagnosed as dying (n = 159):
    - the median number of regular medications fell significantly from 7 (IQR 5 to 10, range 0 to 18) to 5 (IQR 2 to 8, range 0 to 16) (T = 21, z = -7.53, p <0.001, r = -0.42). At an individual level, the median difference was a reduction of 1 prescribed regular medication over this timeframe (IQR -4, 0, range -15 to +3).
- For those who were not recognised as dying (n = 10):
    - there was no change; the median remained at 5 regular medications (IQR = 2 to 9, and range 1 to 12 at both times).
- For those who died suddenly (n= 19):
    - at 3 months before death the median number of regular medications prescribed was comparable with residents who were diagnosed as dying and unsurprisingly, did not change before death (median 7, IQR 5 to 9.5, at 3 months before death (range 3-14) and at death (range 3 to 13)).
- The difference between these 3 groups was not significant at 3 months before death (H (2) = 1.992, p = 0.37), but they did differ significantly at the time of death (H(2) = 8.113, p = 0.017) reflecting the reduction in medications seen in those who were diagnosed as dying.

For residents who were diagnosed as dying, there was a significant rise in the number of PRN medications as death approached. The median number of PRN medications prescribed rose form 4 (IQR 2,5) at 3 months before death to 6 (IQR 4.25, 8) at the time of death (T = 3, z = -10.13, r = 0.8, p <0.001). This rise in the number of PRN medications prescribed counteracted the fall in number of regular medications prescribed such that the total number of medications (both regular and PRN) was the same with a median of 11 medications prescribed at both 3 months before death (IQR 8, 13) and at death (IQR 8, 14). At an individual level, there was a median of one more medication prescribed at death compared with at 3 months before death. Either way polypharmacy was

highly prevalent as shown in table 8.2 for regularly prescribed medications. If the total number of medications (both PRN and regular) is considered, at 3 months before death 95% of residents were on ≥ 4 medications, and 58% were on ≥ 10 medications. At death, 97.5% of residents were on a total of ≥ 4 medications, while 65% were on ≥ 10 medications.

Medication review and rationalisation

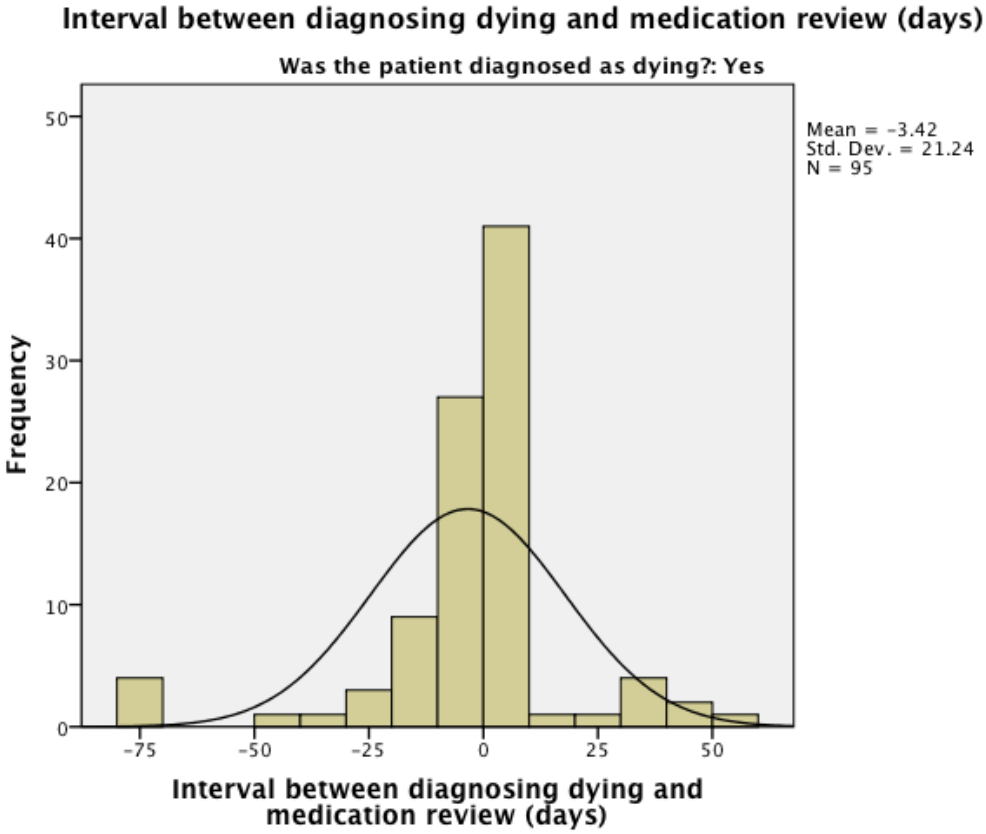
Though polypharmacy was problematic there was evidence of medication review in 56% of decedents (n = 107/191) overall; 26% (n=5/19) of those who died suddenly, 27% (n = 3/11) of those who were not recognised as dying, but 62% (n = 99/159) of those who were recognised as dying. Medication review tended to happen in the last week or two of life though (median 8 days before death, IQR 3, 19), and often only occurred when dying had been recognised (median interval between diagnosing dying and medication review = 0 days, IQR -7, 1) or the resident became too dysphagic, or too unwell to take oral medications (median interval between medication review and medications omissions = 7 days, IQR 1, 18). In 48% (n= 46/96) of all decedents, medication review happened before the resident was recognised as dying, 24% (n = 23/96) of medication reviews took place over a week before dying was recognised, 28% (n=27/96) took place at the time of diagnosing dying or the subsequent 24 hours, and 43% (n = 41/96) in the week after a dying trajectory was acknowledged. Thus only 9% (n = 9/96) of decedents had their medications reviewed more than a week after dying was recognised.

Table 8.2 Characteristics of decedents who were recognised as actively dying

	Total	**Before**	**After**	
Diagnosed as dying, n (%)	162*/191 (85%)	99/121** (82%)	63/70 (90%)	P = 0.13
Interval between dx dying & death, median (IQR)	3 days (1, 7) range 0 to 124	4 days (1, 8) range 0 to 94	3 days (1.25, 5) range 0 to 124	U = 2469 p = 0.37
Regular medications 3/12 pre-death, median (IQR)	7 (5,10) range 0 to 18	7 (5, 10) range 0 to 18	7 (5, 10) range 0 to 14	U= 2959 p = 0.78
Regular medications at death, median (IQR)	5 (2, 8) range 0 to 16	5 (2, 8) range 0 to 16	4 (2, 7) range 0 to 16	U = 2998 p = 0.89
On ≥ 4 regular medications 3/12 pre-death, % (n)	**86%** (n=147/160) 95% CI 80.6% - 91.4%	**88%** (n=86/98) 95% CI 81.5% - 94.4%	**82%** (n=51/62) 95% CI 72.4% - 91.6%	P = 0.33
On ≥ 4 regular medications at death, % (n)	**60%** (n=96/160) 95% CI 52.4% - 67.6%	**58%** (n=57/98) 95% CI 48.2% - 67.8%	**63%** (n=39/62) 95% CI 51% - 75%	P = 0.55
On ≥ 10 regular medications 3/12 pre-death, % (n)	**28%** (n=44/160) 95% CI 21% - 35%	**27%** (n=26/98) 95% CI 18.2% - 35.8%	**29%** (n=18/62) 95% CI 17.7% - 40.3%	P = 0.73
On ≥ 10 regular medications at death, % (n)	**12%** (n=19/160) 95% CI 7% - 17%	**13%** (n=13/98) 95% CI 6% - 19.7%	**10%** (n=6/62) 95% CI 3% - 17.5%	P = 0.49
PRN medications 3/12 before death, median (IQR)	4 (2,5) range 0 to 10	4 (2,5) range 0 to 7	3 (2,4) range 0 to 10	U = 2866 p = 0.54
PRN medications at death, median (IQR)	6 (4.25, 8) range 1 to 12	6 (5, 8) range 1 to 12	6 (4, 8) range 1 to 12	U = 2845 P = 0.50
Evidence medication review before death, % (n)	62% (n = 99/159) 95% CI 54% to 70%	62% (n = 60/97) 95% CI 52% to 72%	63% (n = 39/62) 95% CI 51% to 75%	P = 0.9
Interval between medication review and death, median (IQR)	8 days (3,18) range 0 to 86	9 days (3, 18) range 0 to 78	7 days (3, 20) range 0 to 86	U = 1161 p = 0.95
Interval between dx dying and medication review, median (IQR)	0 days (-7, 1) 47% pre dying dx 24% >7 days pre dying dx	0 days (-6.25 to 2) 41% before dying dx 19% >7 days pre dying dx	-1 days (-9 to 1) 57% before dying dx 32% >7 days pre dying dx	U = 914 p = 0.23
Interval between dx of dying and medication omissions, median (IQR)	2 days (0, 5) range -25 to 119	3 days (1, 6.5) range -5 to 94	1 day (0, 3.5) range -25 to 119	U = 1889 **p=0.005**

Interval between medication omissions and death, median (IQR)	0 days (0, 3) range = 0 to 27	0 days (0, 1) range = 0 to 7	2 days (0, 4) range 0 to 27	U = 1926 **p <0.001**
*prescription chart missing for 2 decedents **5 clinical notes missing				

Figure 8.3 Interval between medication review and recognising resident dying



Medication omission as death approached

A large proportion of decedents, 97% (n = 186/191), started to have regularly prescribed oral medications omitted because they were too drowsy to take them, had developed new dysphagia or simply because they refused or were too unwell. In 60% (n = 115/191) of decedents such omission of drugs only started on the day they died, but for 24% (n = 46/191) omission began 3 days or more before death. A decedent being unable to take medications by mouth may be an important prognostic sign that death may be imminent. Of those who were diagnosed as dying in 73% (n=107/146) omission of medications came after diagnosis of dying, in 12% (n=18/146) it came on the day dying was diagnosed and in 14% (n=20/146) it came in the week before that diagnosis and may have been one of the prompts that death was approaching.

Prescribed medications and their review: what was stopped, what was continued

The regular medications most commonly prescribed at 3 months before the end of life were:

- antidepressants, 59%
- proton pump inhibitors (PPIs) 55%
- laxatives 50%
- antiplatelets 47%
    - aspirin represented the most commonly prescribed antiplatelet
- regular oral Benzodiazepines 37%
- diuretics 37%
    - loop diuretics represented 70% of diuretics prescribed
- regular Paracetamol 36%
- regular opioids, excluding those via syringe driver 34%
- inhaled Bronchodilators 28%
- cholinesterase inhibitors or memantine 25%
- antipsychotics 24%
- beta blockers 24%
- ACE inhibitors or Angiotensin receptor blockers 23%
- anticonvulsants 18%
- statins 17%

The most common newly prescribed regular medications in the last 3 months of life were:

- Regular opioids started in 19%
    - Oral opioids started in 12%
    - Transdermal opioids started in 7%
- Diuretics started in 8% (loop diuretics n=13/15)
- Laxatives started in 7%
- Antidepressants started in 5%
- Antipyschotics started in 5%
- Inhaled bronchodilators started in 4%

Proportionally, the most commonly discontinued regular medications in the last 3 months of life were:

- Bisphosphonates (88%, n=7/8)
- Thiazides (77%, n = 10/13)
- Regular antiemetics (62%, n=8/13)
- 5α reductase inhibitors (58%, n= 7/12)
- Regular oral opioids (58%, n= 22/38)
- Regular antipsychotics (51%, n=28/55)
- Alpha blockers (50%, n = 11/22)
- Anticoagulants
    - Low molecular weight heparin (50%, n = 1/2)
    - Direct oral anticoagulant (50%, n= 2/4)
    - Warfarin (44%, n=8/18)
- Beta blockers (46%, n=23/50)
- Topical NSAIDS (46%, n= 5/11)
- Thyroxine (46%, n=10/22)
- Antihistamines (44%, n=11/25)
- Statins (44%, n=14/32)
- Antidepressants (42%, n=51/122)

Of all patients regularly prescribed drugs, the ones most commonly still being prescribed at the time of death were:

- Laxatives 42% of all decedents
- Proton Pump Inhibitors 41% of all decedents
- Antidepressants 37% of all decedents
- Regular Oral/transdermal opioids 34% of all decedents
- Regular Paracetamol 32% of all decedents
- Regular benzodiazepines 31% (excludes patients receiving benzodiazepines via syringe driver) of all decedents
- Antiplatelets 30% of all decedents
- Diuretics 28% of all decedents

Table 8.3 Medication started, stopped and continued in decedents' last 3 months

	Proportion of all decedents prescribed this medication						Proportion of all prescriptions in last 3 months	
	At 3 months pre-death		Newly in their last 3 months		At time of death		Stopped	Not stopped
	%	n	%	n	%	n	%	%
Antidepressant	59	112	5	10	37	71	42	58
Proton Pump Inhibitor	55	105	4	7	41	79	29	71
Laxative	50	95	7	14	43	81	26	74
Antiplatelets (total)	47	89	2	3	30	57	38	62
Aspirin	36	69	0	0	22	42	39	61
Clopidogrel/ Dipyridamole	10	20	2	3	8	15	35	65
Benzodiazepine	37	71	3	5	31	60	21	79
Diuretics total)	37	71	8	15	28	53	38	62
Loop diuretic	29	55	7	13	25	47	31	69
Thiazide	6	12	1	1	2	3	77	23
K sparing	2	4	1	1	2	3	40	60
Paracetamol	36	68	4	7	32	62	17	83
Opioids total	34	64	19	36	34	64	36	64
Transdermal opioids	26	49	7	13	25	48	23	77
Oral opioids	8	15	12	23	8	16	58	42
Bronchodilator (inhaled)	28	54	4	8	26	49	21	79
Steroid inhaled	9	18	1	1	9	18	5	95
Steroid oral (>14/7)	8	16	0	0	7	14	13	88
Cholinesterase Inhibitor/Memantine	25	48	2	3	17	32	37	63
Antipsychotic	24	46	5	9	14	27	51	49
Beta blocker	24	46	2	4	14	27	46	54
ACE inhibitor or ARB	23	43	2	4	17	32	32	68
Statin/Cholesterol lowering agent	17	32	0	0	9	18	44	56
Warfarin	9	18	0	0	5	10	44	56
LMWH	2	4	0	0	1	2	50	50
Direct Oral Anticoagulant	1	2	0	0	1	1	50	50
Digoxin	7	13	2	4	5	10	41	59
Alpha blocker	12	22	0	0	6	11	50	50
Amlodipine/ Lercanidipine	6	12	0	0	4	7	42	58
Other cardiac drugs	8	15	1	1	6	11	31	69
Anticonvulsant	18	34	2	3	13	25	32	68

Parkinson's treatment	6	11	0	0	4	8	27	73
Bisphosphonate	4	8	0	0	1	1	88	13
Calcium/Vitamin D	16	30	0	0	10	19	37	63
Iron supplement	15	29	0	0	9	17	41	59
Folic acid supplement	13	24	0	0	8	15	38	63
Diabetic medication	12	22	1	2	9	18	25	75
Antihistamine	11	21	2	4	7	14	44	56
Thyroxine	11	21	1	1	6	12	45	55
5A reductase inhibitor	6	12	0	0	3	5	58	42
Anticholinergic (bladder)	3	6	0	0	2	4	33	67
GnRH/LHRH agonist	2	4	0	0	2	3	25	75
Prophylactic antibiotic	5	10	0	0	3	6	40	60
NSAID po (top)	5	9	1	2	3	6	45	55
Antiemetic	4	8	3	5	3	5	62	38
Other	19	37	3	6	15	28	35	65

Additionally 61 decedents were on a total of 100 dietary supplements or drinks.

Prescription of PRN parenteral anticipatory medications for end of life care

Residents who were diagnosed as dying were significantly more likely than those who were not recognised as dying, to be prescribed PRN parenteral:

- Benzodiazepine (OR = 6.9 (95% CI 2.0, 23.7) $\chi^2 = 13.70$, p = 0.002)
- Opioids (OR = 16.4 (95% CI 5.8, 46.1) $\chi^2 = 40.79$, p <0.0001)
- Antisecretory (OR = 10.0 (95% CI 4.0, 25.2) $\chi^2 = 30.48$, p <0.0001)
- Antiemetic (OR = 2.7 (95% CI 1.2, 6.0) $\chi^2 = 6.06$, p = 0.015)

Residents who were diagnosed as dying in the after period were more likely than those in the before period to be prescribed PRN parenteral benzodiazepines (significantly) and opioids (not statistically significantly), but less likely to be prescribed an antiemetic or an antisecretory (not statistically significant).

- Benzodiazepine (OR = 2.1 (95% CI 1.1, 3.9) $\chi^2 = 4.84$, **p = 0.03**)
- Opioids (OR = 1.2 (95% CI 0.5, 2.4) $\chi^2 = 0.16$, p = 0.69)
- Antisecretory (OR = 0.7 (95% CI 0.3, 1.5) $\chi^2 = 0.69$, p = 0.41)
- Antiemetic (OR = 0.6 (95% CI 0.3, 1.1) $\chi^2 = 2.49$, p = 0.12)

For decedents who were recognised as dying and prescribed parenteral PRN medications, the likelihood of receiving an antiemetic in the after period was significantly higher than in the before period, and though there was a trend for other parenteral PRN medications to also be given more often, the differences were not statistically significant.

- Opioids (OR 1.4 (95% CI 0.7, 3.0), $\chi^2 = 0.90$, p = 0.34)
- Benzodiazepines (OR 1.3 (95% CI 0.5, 3.5), $\chi^2 = 0.27$, p = 0.60)
- Antisecretory (OR 1.9 (95% CI 0.9, 4.2), $\chi^2 = 2.53$, p = 0.11)
- Antiemetic (OR 3.2 (95% CI 1.4, 7.4), $\chi^2 = 7.46$, p = 0.007)

The proportion of residents who were recognised as dying and received such medications through a continuous subcutaneous infusion in their dying days rose from 74% (n=72/97) in the before period to 83% (n=52/62) in the after period, this difference was non significant though.

Table 8.4 Characteristics of anticipatory prescribing in all decedents

		Sudden death		Non Sudden death				
				Dying not recognised		Dying recognised		
		%	n (of 18)	%	n (of 11)	%	n (of 159)	
PRN parenteral opioids, % (n)		**0%**	(0)	**46%**	(5)	**77%**	(123)	**p <0.0001**
PRN parenteral benzodiazepines, % (n)		**6%**	(1)	**18%**	(2)	**47%**	(75)	**p = 0.002**
PRN parenteral antisecretory, % (n)		**6%**	(1)	**55%**	(6)	**76%**	(121)	**p <0.0001**
PRN parenteral antiemetic, % (n)		**28%**	(5)	**73%**	(8)	**69%**	(109)	**p = 0.015**
Of these parenteral anticipatory medications, number prescribed, %	**0 medications**	**63%**	(12)	**9%**	(1)	**12%**	(19)	
	1 medication	**28%**	(5)	**27%**	(3)	**5%**	(10)	
	2 medications	**6%**	(1)	**36%**	(4)	**13%**	(18)	
	3 medications	**0%**	(0)	**18%**	(2)	**40%**	(66)	
	4 medications	**0%**	(0)	**9%**	(1)	**31%**	(46)	
Number of these parenteral anticipatory medications prescribed, median (IQR)		0	(0, 1)	2	(1, 3)	3	(2, 4)	H(2) =38.8 **p <0.001**
Interval between parenteral anticipatory medications prescribed and death, median (IQR)		4 days before death, 140 days before death, others >3/12 before death		On day of death, 3 days, 39 days and 47 days before (each n=1), others >3/12 before death		73% in last week Median = 3 days (IQR 1,9) Range (0 to 162 days)		

Table 8.5 Characteristics of anticipatory prescribing for decedents who were recognised as dying

		Total decedents recognised as dying						
		Total		Before		After		
		%	n (of 159)	%	n (of 97)	%	n (of 62)	
PRN parenteral opioids, % (n)		**77%**	(123)	**76%**	(74)	**79%**	(49)	p = 0.69
Prescribed PRN parenteral opioids given		60%	(74/123)	57%	(42/74)	65%	(32/49)	p = 0.34
PRN parenteral benzodiazepines, % (n)		**47%**	(75)	**40%**	(39)	**58%**	(36)	**p = 0.03**
Prescribed PRN parenteral benzodiazepines given		69%	(52/75)	66%	(26/39)	72%	(26/36)	p = 0.60
PRN parenteral antisecretory, % (n)		**76%**	(121)	**78%**	(76)	**73%**	(45)	p = 0.41
Prescribed PRN parenteral antisecretory given		62%	(75/121)	57%	(43/76)	71%	(32/45)	p = 0.11
PRN parenteral antiemetic, % (n)		**69%**	(109)	**73%**	(71)	**61%**	(38)	p = 0.15
Prescribed PRN parenteral antiemetics given		53%	(58/109)	44%	(31/71)	71%	(27/38)	**p = 0.009**
Of these parenteral anticipatory medications, number prescribed, %	**0 medication**	**12%**	(19)	**11%**	(11)	**13%**	(8)	
	1 medication	**6%**	(10)	**7%**	(7)	**5%**	(3)	
	2 medications	**11%**	(18)	**12%**	(12)	**10%**	(6)	
	3 medications	**42%**	(66)	**40%**	(39)	**44%**	(27)	
	4 medications	**29%**	(46)	**29%**	(28)	**29%**	(18)	
Number of these parenteral anticipatory medications prescribed, median (IQR)		3	(2, 4)	3	(2, 4)	3	(2, 4)	U = 3015 P = 0.92
Interval between parenteral anticipatory medications prescribed and death, median (IQR)		3 days (1, 9) range 0 to 192		3 days (1, 9) range 0 to 97		3 days (1, 12) range 0 to 162		U = 1853 P = 0.97
Interval between diagnosing death and anticipatory medications prescribed, median (IQR)		0 days (0,1) range -146 to 50		0 (0, 1) range -96 to 50		0 (-1, 1) range -146 to 25		U = 1516 P = 0.47
Interval between oral anticipatory medications prescribed and death		19.5 days (8, 62.5) range 0 to 255		11 days (4.5, 38.5) range 0 to 99		42 days (14, 120) range 1 to 255		U = 327 **P = 0.002**

Table 8.6 Association of pain and treatment

	Symptom Frequency according to relatives account					
	None/A little of the time		**Some of the time**		**Good bit/Most/All of time**	
	%	**n**	**%**	**n**	**%**	**n**
Pain present	61%	75/122	30%	36/122	9%	11/122
Paracetamol prescribed	93%	70/75	83%	30/36	91%	10/11
PRN Paracetamol doses given	Median 1 dose (IQR 0, 7)		Median 0 doses (IQR 0, 2)		Median 0 doses (IQR 0, 1.5)	
PRN oral opioid prescribed	32%	24/75	53%	19/36	64%	7/11
Decedents who received PRN oral opioid doses in last week, median doses given (IQR)	54%	13/24	47%	9/19	86%	6/7
	Median 1.5 doses (IQR 0, 3.25)		Median 0 doses (IQR 0, 4.5)		Median 2 doses (IQR 2.5, 3.75)	
PRN parenteral opioid prescribed	79%	59/75	64%	23/36	64%	7/11
Proportion with PRN parenteral opioid prescribed who received doses in last week of life	60%	34/59	70%	16/23	100%	7/7
	Median 1 dose (IQR 0, 2)		Median 2 doses (IQR 0, 3.5)		Median 2 doses (IQR 1.5, 4.5)	
*n=122/196 relatives responded on presence of pain, n=14/196 relatives didn't know if decedent had pain,						

Table 8.7 Association of dyspnoea and treatment

	Symptom Frequency according to relatives account					
	None/A little of the time		**Some of the time**		**Good bit/Most/All of time**	
	%	**n**	**%**	**n**	**%**	**n**
Able to breath easily	1%	10/129	11%	14/129	81%	105/129
PRN oral opioid prescribed	50%	5/10	43%	6/14	57%	60/105
PRN oral opioid given in last week, median doses	40%	2/5	50%	3/6	42%	25/60
	5 doses given to 2 people		15 doses given to 3 people		Median 3 doses (IQR 2,6)	
PRN parenteral opioid prescribed	80%	8/10	71%	10/14	91%	96/105
Proportion with PRN parenteral opioid prescribed who received doses in last week of life	75%	6/8	70%	7/10	49%	47/96
	Median 1 dose (IQR 0.75, 1.25)		Median 1.5 dose (IQR 0.25,2)		Median 0 doses (IQR 0,2)	
PRN parenteral benzodiazepine prescribed	40%	4/10	43%	6/14	48%	50/105
Proportion with PRN parenteral benzodiazepine prescribed who received doses in last week of life	50%	2/4	50%	3/6	62%	31/50
	2 given 1 dose each		9 doses given to 3 people		Median 3 doses (IQR 1, 4.5)	
PRN parenteral antisecretory prescribed	80%	8/10	71%	10/14	70%	73/105
Proportion with PRN parenteral antisecretory prescribed who received doses in last week of life	50%	4/8	70%	7/10	64%	47/73
	7 doses given to 4 people		24 doses given to 7 people		Median 2 doses (IQR 1,4)	

8.4 Discussion

One of the key findings of this study was the high prevalence of polypharmacy (≥ 4 medications) in Irish nursing home residents at the end of life, where 95% of residents were on a total of 4 or more medications, which rose to 97.5% at the time of death. In addition, excessive polypharmacy (≥ 10 medications in total) was found in 58% of residents at 3 months before death and 65% at the time of death. When PRN medications were excluded, polypharmacy of regular medications remained very prevalent at 86% of residents at 3 months before death and 60% at the time of death. Excessive polypharmacy of regular medications was found in 28% of residents at 3 months before death falling to 12% at death. Though the median number of regular medications fell from 7 medications at 3 months before death to 5 at the time of death, this was offset by a rise in the median number of PRN medications prescribed from 4 medications to 6 as death approached.

A nationwide Swedish study of all decedents over 65 years of age who died between 2007 and 2013, also found that polypharmacy became increasingly prevalent as death approached.(566) In the year before death the proportion of Swedish decedents prescribed ≥ 10 medications rose from 30.3% to 47.2%.(566) Similar trends were described in an Australian study of long term care residents in their last year of life.(567)

The degree of polypharmacy found in our study is comparable with the results of the SHELTER study of 4,156 nursing home residents across 8 European countries.(568) The SHELTER study found excessive polypharmacy varied from 8.8% in Israel to 56.7% in Finland. Ireland was not included in the study cohort. Neither were any studies of Irish nursing home resident polypharmacy found. In an Irish longitudinal study of mostly community dwelling older patients admitted to acute hospital, polypharmacy was found in 79% and excessive polypharmacy in 24%.(569) A retrospective study of prescribing in community dwelling patients with dementia in Northern Ireland found polypharmacy in 82% (n = 4393)(570)

There is an established association between polypharmacy in older people and potentially inappropriate prescribing.(571, 572) Potentially inappropriate prescribing is common; prevalence is over a third of the Irish population over 70 years and is estimated to have an associated cost of over €6 million in Northern Ireland and €45.6 million in the Republic of Ireland.(572, 573) The largest contributor to this cost was inappropriate prescription of proton pump inhibitors, drugs which was prescribed for 55% and 41% of the cohort in our study at 3 months before death and at death respectively.

Systematic review has found a high prevalence of inappropriate prescribing in nursing home residents ranging from 18.5% to 82.5%, but with a median of 35.1% based on use of Beers criteria of 2003 or 61.1% when STOPP criteria were applied.(574) In a Belgian study of potentially inappropriate prescriptions (PIP) and potential prescribing omissions (PPO) in nursing home residents, prescription of benzodiazepines (46.7%) and omission of vitamin D (51.5%) were the most commonly encountered.(575) A Canadian study of nursing home residents with advanced dementia found 86.3% had received at least one medication of questionable benefit in their last year of life, the most common being anti-dementia drugs (63.6%) and lipid lowering agents (47.8%).(576) Lipid lowering drugs were also commonly, but potentially inappropriately, prescribed in a Swedish study of older people with dementia.(577) A systematic review of preventive medication use in patients with limited life expectancy similarly found statins to be frequently prescribed in addition to antiplatelet agents, angiotensin converting enzyme inhibitors and angiotensin receptor blockers, calcium channel blockers and anti-osteoporosis medications.(555) Pyschotropics are also commonly used.(578)

While our study didn't screen for PIPs or PPOs, there was evidence of medication review and deprescribing in over half of decedents. Though bisphosphonates were not commonly prescribed (4%), the majority were stopped before death (88%), and of the medications listed above 32-44% were discontinued before death (statins 44%, antiplatelets 38%, ACE inhibitors or ARBs 32%, calcium channel blockers 42% antipsychotics 51%, acetylcholinesterase inhibitors/memantine 37% stopped).

It is suggested that attempts to reconcile life expectancy, comorbidity, care goals and patient preferences should be made and that part of this process should include the deprescription of medications with questionable benefit for the patient.(554) Yet, there is a lack of clarity around deprescribing for older patients with multiple comordities, particularly for general practitioners who have conflicting opinions on stopping commonly prescribed preventive medications such as statins, dipyridamole or bisphosphonates.(579) This is despite evidence that supports a lack of adverse effects in statin discontinuation in such patients, and potential beneficial effects including an improved quality of life.(580) Decreasing the use of antihypertensive medications amongst nursing home residents equally did not have adverse effects on systolic blood pressure, and possibly reduced hospitalisation.(581)

Some recent publications may help add clarity in the area of deprescribing in frail older adults with limited life expectancy where symptom control is becoming more of a priority than prevention of disease progression.(582, 583) A useful screening tool to target medications for deprescribing in frail older adults that has been developed is the STOPPFrail tool which builds on the original STOPP tool for use in this specific population.(582, 584, 585) The NORGEP-NH is another tool, developed through a Delphi consensus methodology, which has been used to support deprescribing in a similar population but specifically those in nursing home care.(583)

An Australian/New Zealand study of geriatricians found the most important reported influencers for deprescribing were severity of cognitive impairment and functional dependency, limited life expectancy and pill burden.(586) These are all common issues in older frail nursing home residents. Despite reflecting the opinions of 930 physicians, the findings of the study were limited by a response rate of only 14.4% and for the most part it is general practitioners who deprescribe in most nursing home settings in Ireland.(586) Despite a pharmacist driven intervention making recommendations on the appropriateness of medications and recommended medications that could be deprescribed, 64% of the recommendations resulted in no action.(587)

While deprescribing is important so too is anticipatory prescribing of medications needed for symptom control in the face of death. In our study, it appeared the recognition of imminent death (in days) was the main driver for both deprescribing and anticipatory prescribing practices. A Dutch study found a high incidence of pain (47-68%), agitation (57-71%) and dyspnoea (up to 52%) in a nursing home cohort, and similar to our study that symptom management only intensified as death was imminent.(212)

Singer et al found that the prevalence of symptoms such as pain at end of life rose in the US between 1998 and 2010 despite increased hospice use and a greater focus on the quality of end of life care.(292)Under treatment of pain with opioids in people with dementia is a finding of a recent systematic review.(588) Pain management in people with dementia living in long term care has been a recent focus of research attention, and quality improvement initiatives are emerging.(589, 590) An Icelandic study found the frequency of pain (51%), agitation (36%) and respiratory tract secretions (36%) were treated with appropriate medications but that dosing of opioids left room for improvement and there was potential to improve control of agitation and secretions through better use of benzodiazepines and anticholinergic medications.(591) Worldwide the use of opioids and paracetamol (both scheduled and PRN) in the long term care population have increased over time.(592) It has been suggested that research is needed to explore whether this had led to appropriate pain management and effective PRN medication use for long term care residents.(592)

A Scottish study found though 54% of long term care residents had anticipatory medications prescribed, only 15% of prescriptions were adequate to meet national recommended levels.(593) They recommended interventions to increase the availability of anticipatory medications to manage common end of life symptoms.(593) This is inherently important alongside palliative care education if nursing staff in long term care are to be empowered to provide high quality end of life care that optimises symptom management. Wilson and Seymour describe how important interdisciplinary communication is to the process of anticipatory prescribing and end of life care.(594)

For nurses, anticipatory medications act as a safety net giving nurses some control over being able to manage patients' uncontrolled symptoms in a timely fashion as death draws near without having to wait for a General Practitioner or out of hours cooperative doctor having the time to assess and prescribe relief for a patient's distressing symptoms.(595) Whilst nurses may believe they initiate anticipatory prescribing through "careful negotiation" with the General Practitioner, it is ultimately the General Practitioner who controls whether or not medication is prescribed in anticipation of potential emergence of the common symptoms that occur at the end of life.(595) Not having anticipatory medications prescribed and thus being powerless to manage distressing symptoms adequately is distressing and emotionally draining for nurses. (596)

Research needs to explore the barriers to anticipatory prescribing for end of life that exist for General Practitioners for practical, existential or other reasons.

Strengths and Limitations of the study

One of the strengths of this study is the response rate of 69% for relatives responding to the questionnaire, this is high a high response rate for this type of survey, and greater than the 46% response rate from the National Audit on End of Life Care in Hospitals in Ireland conducted in 2008/9.(58) That such a large proportion of relatives responded makes the results more generalizable, though it does not eliminate responder bias – however it could be argued than non-responders who though negatively about their loved ones death are just as likely to respond as those who had a positive experience.

Another strength of the study is its inclusion of both rural and urban, private and public, and nursing homes of varying size and distance from acute hospital services. The resident population in the nursing home study sites are representative of nursing home residents elsewhere in Ireland, where it tends to be frail dependent older people who move to reside there. Nursing home residents' characteristics may differ in other countries where different models of long term care exist.

One of the study's main limiting factors is that it is underpowered to detect some of the differences found particularly in relation to anticipatory prescribing which would appear to have improved following the study intervention of advance care planning and palliative care education for nursing home staff. A larger study powered to detect such differences is needed to explore these findings further.

Chapter Nine: Conclusions

9 Conclusions

The research presented in this thesis covers a broad range of areas pertinent to end of life care planning and the use of advance care directives or advance care plans in the long term care setting in Ireland.

Healthcare professionals' attitudes, knowledge and experience of advance care directives

The data presented in chapter 2 shows that there is a good awareness of advance care planning and advance care directives amongst healthcare professionals in Ireland, but less practical experience of their completion or implementation. Consistent with international studies, the healthcare professionals surveyed had a positive impression of advance care directives.(266-269) In this Irish study, of the healthcare professionals sampled, most would recommend the use of advance care plans to their patients, and stated they would complete a personal advance care directive (86%), but despite this keenness, almost no healthcare professionals (3%) had one. This study appears to be the first to report on the personal advance care directive completion rates among healthcare professionals in Ireland.

Regardless of any lack of experience of patients with advance care directives or advance care plans, healthcare professionals for the most part (76% of respondents), would feel comfortable in following one presented by a patient. The fear of medicolegal implications appeared to be an important source of discomfort in following (or not following) a directive.

While it was shown that respect for older peoples' autonomy was valued, there was a poor awareness of the legal status of medical decision making for older people who lose decision making ability. Though doctors in Ireland were more knowledgeable than nurses in this regard, sadly almost 2 out of 3 doctors and 3 out of 4 nurses were unable to correctly identify the legal decision-maker for a person lacking decision-making capacity without an advance care directive. Since this study was completed, there has been an extensive educational campaign for healthcare professionals in Ireland, ahead of the commencement

of the Irish *Assisted Decision Making (Capacity) Act* 2015. It would be beneficial to examine whether this has led to an improved awareness amongst healthcare professionals on the legislative practicalities and responsibilities in medical decision-making for adults with diminished capacity.

The study presented in Chapter 2 was novel in that it pushed respondents to conceptualise their responses as though they themselves were the patient lacking decision-making capacity. Most respondents (66%) thought that if they had a personal advance care directive, their doctor would follow it, but that in the absence of such a directive, some had concerns that they would receive care inconsistent with their wishes. If lacking capacity and in the absence of a directive, 62% felt their family would have difficulty making decisions on end of life care on their behalf, but 84% of respondents thought that their family and doctor in collaboration would make treatment choices consistent with the respondent's wishes. Almost two thirds of respondents were comfortable with the notion of a collaborative approach by family and physician in making treatment decisions in these circumstances. These findings support the methodological approach taken in end of life care planning discussed subsequently in chapters 4 and 7.

Healthcare professionals' opinions on care and decision making at end of life

The second part of Chapter 2 presented further results from this cohort of healthcare professionals in Ireland which found that only about half of doctors and nurses surveyed felt their training or experience in end of life care was adequate. Despite this, the majority of those surveyed felt comfortable caring for the dying (80%) and their families (77%). There seemed to be a relationship between a healthcare professionals' satisfaction in their end of life care training and their comfort in caring for the dying, confidence in managing their symptoms or stopping preventive medications as death approached.

All of these factors together with an accurate appreciation of the likelihood of attempted CPR success, appeared to influence the aggressiveness of healthcare professionals' treatment choices for the end of life care of a patient lacking

decision-making capacity (as presented in a scenario of a life threatening illness).

Doctors were better able in general to estimate CPR success rates than other healthcare disciplines. The aggressiveness of care chosen for a patient with dementia, frailty and a life threatening emergency seemed to be influenced most by the respondents' sense of duty to preserve life, the fear of legal action, the lack of availability of the patient's family, lack of knowledge of the patient's wishes and difficulty in prognostication. Interestingly, healthcare professionals tended to choose sequentially lower levels of care for their patients, their parent and themselves (if imagining themselves or their parent as the patient in the given scenario).

That only half of respondents were satisfied with their training in end of life care is concerning. A 2005 study of Irish undergraduate medical school coverage of palliative care in their curriculum left room for improvement and similar deficiencies in palliative care training have also been reported for Irish GP trainees.(298, 308, 597) The results presented in the second part of chapter 2 added to the evidence of dissatisfaction in end of life training for a broader cohort of healthcare professionals in Ireland. Identifying the barriers and facilitators for Irish healthcare professionals to improve the adequacy of their training in end of life care is important.

It was hypothesised that healthcare professionals who regularly care for dying patients may be more inclined to seek out training in palliative care to maintain or improve their skills. The research presented in Chapter 5 showed there was a lack of palliative care education also amongst staff working in the long term care setting in Ireland, but they displayed a distinct keenness for training in this area. The general palliative care educational initiative which was developed and tailored to the self-perceived needs of long term care staff was well received and contributed to an improvement in the prevalence of palliative care training in staff in the "after" period compared with that present before the educational initiative was offered.

In this pilot study, staff of the involved sites were keen to avail of training in palliative care and advance care planning. The delivery of this training was not without challenges though, as presented in chapter 4 and 5. Not least of the difficulties faced was that of the release of staff to attend training, and release of the same staff if training was delivered at separate intervals. To overcome this particular difficulty, an online educational program for advance care planning and the use of the Let Me Decide advance care directive was developed by a multidisciplinary team including the researcher, specialist palliative care experts in addition to academics and clinicians in both gerontology, nursing and ethics. This online program is available in both a short certificate level course (through the Let Me Decide website, www.letmedecide.ie) and a more in-depth version (MH6016, a 5 credit module) through University College Cork.

Timing of introduction of end of life care planning

The issue of the most appropriate time to introduce care planning for end of life care is likely one subject to individual variation and preferences, however as shown in Chapter 4 and 7 there was a scepticism and suspicion aroused in many longer term residents when the topic of end of life care was broached without a prompt. The study sites' approach to initiating advance care planning with residents and their families evolved over the study period, and moved by preference and practicality to introduction of the program at the time of admission and addressing advance care planning itself, once the resident had "settled in" to the nursing home. The move to earlier care planning also seemed to result in higher completion rates amongst residents of the sites that embraced this earlier approach to the greatest extent.

Feasibility of end of life care planning in advance of death in long term care

The purpose of the research presented in chapter 7 was to assess the feasibility and acceptability of implementing a complex intervention comprising an advance care planning program with a tailored palliative care education initiative in the long term care setting in Ireland. The results presented in Chapter 7 showed that end of life care planning in advance of death was very feasible in the long term care setting when a systematic approach to care planning was taken. There was a significant and meaningful increase in the

completion of care plans, at a far earlier stage in long term care residents' lives than was previously the case. Implementation of the study intervention shifted the timing of end of life care discussions from a time close to death, where discussions happened predominantly with residents' family to the exclusion of the residents themselves. Instead discussions came to occur many months in advance of residents' decline in health or crisis health events. The advance care planning program very much encompassed and promoted residents' rights to make decisions on their own behalf (where able), in addition to this objective, the systematic implementation and the shift in the timing of decisions to an earlier point in residents' lives, resulted in a far greater inclusion of residents in the decision making process.

After the introduction of the study intervention, there was also a significant increase in plans for care which noticeably focused not only on wishes around resuscitation and hospitalisation, but also included the focus of care, and the acceptability of various levels of aggressiveness of treatment. Such inclusion of residents in care planning occurred despite a high prevalence of cognitive impairment, dementia and frailty in the study sites. The prevalence of care planning for end of life and inclusion of residents themselves in the process was maintained long after the before and after study observation periods as outlined in Chapters 7 and 8 were completed. In July 2017, the point prevalence study showed 73% of residents of the study sites had a care plan for end of life care. Of all residents, 21% had an advance care directive, 49% had comprehensive end of life care plans and in total 46% of residents were involved in their own end of life care planning and consistently they opted for lower levels of aggressiveness in treatment. This demonstrates the sustainability of the intervention and its effects in the longer term.

The feasibility study gleaned important information on the intervention's implementation and effects, which has been used to guide a more thorough evaluation through a multi-centre randomised controlled trial funded by a project grant from the Health Research Board of Ireland; this is now well underway.

Measuring the quality of end of life care and the dying experience

One of the issues encountered in this study was in the measurement of the quality of end of life care and the dying experience. It was hypothesised based on previously published international research, that end of life care in long term care in Ireland would be suboptimal and that the advance care planning program and palliative educational initiative would improve end of life care and the residents' dying experience. The reality as perceived by deceased residents' family or close friends, was that the care provided at baseline was far superior to that expected based on findings from the medical literature. Relatives' high praise for the end of life care provided and their positive impressions of the quality of dying left little room for improvement.

Bereaved relatives preferring to frame their recollection of their loved ones' death in a positive light may have affected scores on end of life care and quality of dying. Bereaved relatives also might not have experienced many deaths, and thus have a limited ability to compare a "good death" with a "bad one". However, these biases are also likely to have been an issue for any of the previously published research on the quality of end of life care in nursing homes.

It is plausible that there was no change in the quality of care or quality of dying experienced in the time after the intervention, compared with before its implementation. It is also possible that the lack of change related to the Quality of Dying and Death tool (QODD) used to evaluate the dying experience of residents demonstrating a ceiling effect on some of the questionnaire items, such as the quality of the death as perceived by the decedents' relatives.

Regardless of these issues, as outlined in Chapter 7 (table 7.8), there appeared to be a (non-significant) tendency towards somewhat better comfort, pain and dyspnoea management for residents who died in the after period, and also for those with end of life care plans compared to those without. Relatives of decedents who had care plans for end of life care also felt their relative seemed to worry less about being a strain on their family and those with care plans had

also more often said their "goodbyes". There was a significantly greater likelihood that family were present at residents' deaths in the after period.

Though the National Audit of End of Life Care in Hospitals in Ireland in 2008/9, included some long term care hospitals, the results were not presented based on the type of care site (acute vs long term care).(384) Regardless, the findings detailed in Chapter 7 on symptom management appear to be broadly in line with, or indeed better than, the findings of the national audit which found bereaved relatives reported pain "all or most of the time" for 23% of decedents. As presented in Chapter 7 (table 7.8), our cohort had pain "all or most of the time" in only about 5% of cases. These results are also better than those found in other studies of long term care decedents.(211) The national audit found family were present at the time of death in 65% of cases, Chapter 8 results found this proportion rose significantly from 55% in the before period to 73% in the after period (p=0.04). In the national audit 86% of patients were diagnosed as dying, generally 5-6 days before the patient died. This is similar to results presented in Chapter 8 – that 84% overall were diagnosed as dying, a median of 3 days (IQR 1, 7) before death. Both the national audit and the results presented in chapter 8 are better than those found in a French study (50% diagnosed as dying) and an audit of the Liverpool Care Pathway in the UK which found the average diagnosis of death occurred 33 hours before death.(598, 599)

Polypharmacy, Prescribing and Deprescribing at End of Life

Polypharmacy was highly prevalent in both before and after periods with 98% of residents on ≥ 4 medications in total (both regular and PRN) at the time of death and 65% on ≥ 10 medications, this was despite evidence of medication rationalisation and deprescribing in 56% of residents as presented in Chapter 8.

When dying was diagnosed, the likelihood of medication review was greater (62% compared with 27% of those not recognised as dying and 26% who died suddenly). Such medication review tended to happen in the last week or two of life however and at death there remained a high prevalence of prescriptions for preventive medication of dubious benefit for the patient. Hopefully practices around prescribing for people in long-term care will improve in the coming

years, and tools like the STOPP-Frail tool (intervention study currently ongoing) may be useful in this regard. Regardless anticipatory prescribing for parenteral PRN medications was significantly better for residents recognised as being in their dying days and there was a greater tendency for such anticipatory prescribing of opioids (non-significant) and benzodiazepines (significant) in the after period. Residents prescribed such anticipatory medication, were possibly more likely to receive them, but the differences seen were non-significant and a larger study powered to detect such differences is needed to explore these findings further.

It is possible that the palliative care educational initiative may have reduced the fear of administering opioids and benzodiazepines in the management of symptoms. Future research may need to focus on the impact that healthcare professionals' anxiety levels about death and dying may have on their capacity to not only deliver high quality empathic end of life care, but also to engage in advance care planning and to put the learning from palliative care education into practice.

9.1 Thanatophobia

The concept of thanatophobia or death anxiety is of considerable importance in the context of research on advance care planning and end of life care.

Thanatophobia, the fear of death, is derived from the Greek mythological character of *Thanatos,* the personification of death. The word was first coined by Sigmund Freud in 1915 in his essay collection: *Thought for the time on War and Death.* The two essays: *Our Attitude Towards Death* and *The Disillusionment of the War* were written with the aim of helping general civilians to understand the mental distress they were experiencing, the disillusionment and altered attitude to death provoked by the incredible loss of life seen in the first months of World War I. Thanatophobia has been used interchangeably with the term "death anxiety" which Farley defined as "a feeling of dread, apprehension or solicitude (anxiety) when one thinks of the process of dying or ceasing to 'be'".(600)

Lehto and Stein identified six attributes of death anxiety: emotion, cognitive, experiential, developmental, sociocultural shaping, and source of motivation.(601) In their review they also identified three categories of antecedents that may precipitate death anxiety: stressful environments such as war or the experience of unpredictable circumstances, diagnosis of life-threatening illness or the experience of a life-threatening event, and experiences with death and dying.(601)

Langs stated that "both clinical and psychological evidence indicate that death anxiety is, in all likelihood, the single most powerful unconscious psychodynamic dynamism in present day emotional life". He described three types of death anxiety: 1) *Predatory death anxiety;* "the conscious and unconscious dread of being annihilated", the fear of being harmed 2) *Predator death anxiety*; the fear "of the consequences of harming or annihilating others", the fear of doing harm and 3) *Existential death anxiety;* the fear of the "personal prospect of death and dying".*(602)*

Becker hypothesised that as a person develops *mortality salience* or an awareness of the inevitability of death, through fear, they will try to suppress thoughts of death and use denial as a coping mechanism.(603) Schumaker speculated that Western society's efforts to protect themselves from death by concealing the sick, elderly, and dying from view, only heighten death anxiety by making it an unusual phenomenon detached from the natural order of events.(604) Heidegger, philosophised that it is only in accepting death's inescapable nature, in no longer denying mortality, that the angst of death could be cleared.(605)

Chapter 7 described some of the rituals around acceptance and acknowledgement of residents' deaths in the study sites that were valued by bereaved relatives. The effect of such rituals described (like "waking" the decedent in a common living area) should be explored from the perspective of surviving residents.

Psychologist Erik Erikson theorised that as one grows older, a stage of *ego integrity* is reached when a person comes to terms with their life and accepts it,

finds meaning and purpose in their existence, which in turn leads to a reduction in death anxiety.(606) Those who do not reach this level, instead perceiving their lives negatively, perhaps as a series of failures or missed opportunities, are conversely more likely to fear death. Firestone argued however that as life becomes more meaningful and valued, that death anxiety increases because the emotional investment in one's existence has grown too.(607) With advancing age comes a realisation that there is less time left to live,(608) and so older people tend to shift their focus from knowledge gaining goals to emotional and social goals.(609) The wish for more time in life beyond what is expected, seems to be more pressing for those aged between 75 and 84 years and becomes less of an issue above this age as the ubiquitous nature of death draws closer.(608) Circelli linked higher death anxiety with an incongruence between desired and expected time left living, influenced by the person's health and perceived purpose in life.(608)

Senescence, or growing old, is defined by Comfort as *the inevitable and irreversible age related process of loss of viability and increase in vulnerability*.(610) Advancing age is associated with restriction of social networks and changes in physical condition that pose risks for older people; an increased burden of disease and problems related to its chronicity; reduced mobility; declining independence; and the increased likelihood of admission to long term care or need for health service assistance at home.(611, 612) To age, without such troubles, would likely increase the anticipatory fear of death, to quote philosopher Leon Kass: "Would not the fear and loathing of death increase, in the absence of its antecedent harbringers?"(613) Fortner and Neimeyer found that death anxiety was highest in the middle-aged, falling as one entered later adulthood before stabilising in old age, and that older people with high death anxiety related to physical and psychological problems and lower ego integrity.(614)

Many factors have been proposed to influence death anxiety. The evidence for variables such as religiosity, gender and self-esteem are conflicting, with some studies finding positive and others inverse relationships with death anxiety levels.(615) There are also differences in response to death anxiety;

Hirschberger found that gender appeared to play a role; males tended to withdraw emotion and compassion, whilst females demonstrated increasingly compassionate responses.(616)

Several scales have been used to assess death anxiety including the Frommelt Attitude Toward Care of the Dying Scale (FATCOD) (617), the Death Anxiety Inventory (618), the Multidimensional Fear of Death Scale (619), the Collett-Lester Fear of Death of Self Scale (620), and the Templer Death Anxiety Scale (DAS)(621) amongst others.

A study by Sinoff et al, examined the relationship between death anxiety in older in-patients from an acute geriatric ward (mean age 81 +/- 4.71 years) and that of their adult children (mean age 52 +/- 6.41 years).(622) Interestingly, using Templer's Death Anxiety Scale (DAS), they found higher death anxiety levels in the adult children than in their older parents (mean score: 6.9 +/- 3.3 compared with 4.0 +/- 1.4, $p<0.01$). Adult children vastly overestimated their parent's death anxiety level (mean 8.1/15, $p<0.001$) compared with their parent's true score (mean 4.0/15).(615) The older person's anxiety predominantly related to fear of the dying process, e.g. fear of a painful death (100%), rather than death ceasing their existence. Their children assumed death anxiety in their parents, and that it related to both fear of the dying process and of being dead, similar to their own anxieties, i.e. they appeared to extrapolate their own beliefs and anxiety about death onto their parents. This has clear implications for the pragmatism of family involvement in medical decision making in an unbiased way on behalf of their parents. Schafer described the older person's understanding of the finite nature of life, whereas their children's wishes are for continuing existence.(623) The findings presented in Chapter 2 for healthcare professionals making different, less aggressive treatment decisions for themselves than their parent for the imagined scenario, fits with Schafer's ideology.

Death anxiety may be precipitated by experience of illness, loss and death, so is of particular relevance to healthcare workers for whom death is omnipresent despite advances in medicine and greater longevity.

Death anxiety may interfere with a healthcare professional's ability to empathise with the dying and may affect the quality end of life care they provide.(402, 624) Doctors and nurses with higher death anxiety levels are more uncomfortable with care of the dying.(402, 625) Social workers with higher death anxiety levels have been found to be less likely to disclose information about advance care directives with patients -conversely healthcare professionals who are more accepting of death are more willing to discuss advance care directives with patients, or collaborate with colleagues in relation to them.(626, 627)

Indeed, death anxiety may lead to avoidance behaviours being initiated consciously or subconsciously, by healthcare professionals, who may distance themselves from dying patients and their families as a coping mechanism, in order to maintain their own well-being. Research has shown interventions can significantly reduce healthcare workers levels of death anxiety, improve their existential well-being, reduce their use of avoidance mechanisms relating to death and more importantly lead to improved helping relationship skills and self-perceived psycho-existential support they provided to their dying patients and the patient's families.(628)

A study by Melo and Oliver examined the relationship between death anxiety and staff burnout, they found an educational intervention aimed at lowering death anxiety had a positive effect in this regard and also reduced staff burnout, improved well-being and professional satisfaction and the quality of their relationships with patients and patient's families.(629)

A Greek study of renal nurses using the Death Attitude Profile-Revised (DAP-R) assessment scale, found those with palliative care education did not have a fear of death and had less difficulty talking about death and dying.(401) It had been found that for healthcare professionals greater age and longer work experience related to more positive attitudes towards death and less death anxiety.(402) This is similar to the findings outlined in Chapter 2 that healthcare professionals who had greater satisfaction in their training in end of life care, were more comfortable in dealing with dying patients. In Chapter 5, it was

found amongst staff in the long term care pilot sites that palliative care education was associated with greater staff knowledge and confidence in providing end of life care, and a trend to greater staff engagement with advance care planning in those who also received this training as part of the study's educational initiative. Future research could focus on whether death anxiety is a contributory factor.

A review by Peters et al found multiple studies supporting the notion that palliative care and/or communication training, reduced death anxiety and led to more positive attitudes of nurses towards care of the dying and greater comfort in discussing death related concerns with patients and their families.(402) The palliative care educational initiative described in chapter 4 and 5 included a session on communication skills which was attended by both nurses and healthcare attendants. Future research could assess whether this education reduced death anxiety amongst participants. Education in end of life care incorporating the use of simulation teaching has also been shown to improve medical and nursing students attitudes towards care of the dying and help prepare them for their future roles in this regard.(630, 631) Such training may equally be useful for long term care staff, particularly in smaller nursing homes, where annual exposure to dying residents would be more limited. The results outlined in Chapter 4.4.3 demonstrate that staff also found simulation training to be useful in the form of "live advance care planning demonstrations".

Clearly the aetiologies of death anxiety are complex and highly individual for each person, and many variables will likely be unmodifiable by simple education measures. Some healthcare professionals may have more of an aptitude for care of the dying and communicating end of life issues, than others. This researcher hypothesises that healthcare professionals with lower death anxiety levels may have greater aptitude in this area. It would make sense that, if this is the case, tools to evaluate thanatophobia could identify healthcare workers who could be nurtured more readily to become champions for palliative care, good end of life communication and motivators for positive change in the end of life care culture in their place of work. Additionally, such tools might help to recognise healthcare workers who might benefit from

addressing issues of death anxiety to ensure these don't impact on their ability to deliver high quality empathic end of life care. Further research is warranted to explore this.

A recently published study by Carmack et al reported the reliability and validity of the Communication Apprehension About Death scale.(632) This may prove a promising tool in distinguishing which healthcare workers might be more comfortable in engaging in potentially difficult end of life care planning discussions and act as champions for good palliative care. It may also help target which staff members are more likely to benefit from advance care planning and palliative care training in terms of their likelihood and aptitude for the practical application of such education.

Whilst many staff were trained in the use of Let Me Decide, few put their training into action as discussed in Chapter 4. There may have been several potential aetiologies for this reluctance to initiate discussions on end of life care planning. There may have been insufficient "buy in" from nursing home management, which prohibited newly trained staff in changing the practical culture of the home in terms of end of life care. There may have been issues with staff retention and turnover such that trained staff "moved on", or competing tasks occupied trained staff's time. Staff shortages may also have been an impacting factor. Equally, some of the trained staff may not have felt comfortable in having end of life care discussions with residents and/or their families, because of death anxiety or thanatophobia.

Research has borne out time and again that older people wish for their voices to be heard and appreciate the opportunity to discuss end of life care.(110) There are many barriers to advance care planning including reluctance of family members to discuss death related matters and hesitancy on the part of medical professionals in initiating the conversation as seen in the initial days of the intervention described in this thesis. Families often try to protect their loved ones from upsetting conversations or even to accept their older relative's inevitable mortality.(110) Death anxiety plays an important role for healthcare

professionals also, but so too do practical issues such as time pressures and constraints.(633)

End of life care issues are not flippant topics or easily dropped into a conversation without some precipitant. In this research, as outlined in the results of Chapters 4 and 5, the trigger of admission to nursing home became the catalyst to instigate thought, education and conversation on advance care planning.

Despite even very old age, there remains uncertainty about the dying trajectory which can be far more difficult to forecast in a frail older adult with multiple comorbidities than it is for someone dying of malignancy.(634) This uncertainty can be a barrier to advance care planning, as evidenced in the results in Chapter 2, where healthcare workers and students stated difficulty in prognosticating outcomes for a patient impacted on their cognitive processes in deciding on treatment. Such uncertainty about the future might also have been a reason why 5% of residents described in Chapter 7, opted to nominate others to make end of life care decisions for them, if the need to make such decisions arose in the future.

In the young old, a study by Moore in 1999 found a cited disadvantage to advance care directives was that there may be uncertainty with regard to potential for recovery if life sustaining treatments are stopped.(635) Stewart described staff's difficulty with the uncertainty of how an advance care directive might relate to unforeseen medical circumstances,(636) e.g. "some terrific bleed" that might leave staff with "no choice other than sending (the long term care resident) to hospital".(637) Despite seeing the benefits of making plans for future healthcare, many older people prefer to "live for today" and a minority prefer to postpone advance care planning until they are even older, or until they are in worse health, though they acknowledge this carries the risk of leaving it too late.(122, 345, 638) It appears that for older people death anxiety relates less to death (being dead), but the act of dying, the process itself and what that may bring, e.g. pain, being on one's own.(341, 615)

This may explain why it appears to be more difficult for older people to bring themselves to plan for the dying process with advance care planning, and easier to plan for a funeral or what happens after death with their estate in the form of a will. Perhaps it has to do with control. As we age evidence suggests an acceptance that death is inevitable, there can be no control over whether we will die or not. It will eventually happen to every human. So as the adage goes "don't worry about what you can't control". However how one dies has many variables, and as such may be more difficult to contemplate, certainly more difficult to truly have control over but in the oldest old, this appears to be less of an issue, in that there is perhaps more acceptance, with a realisation that "*you can't really plan the end of your life can you?"*.(344)

In a wonderfully refreshing study by Fleming et al, the oldest old (age range 95 - 101 years, mean age 97.5 +/- 1.5 years) there was still awareness of the complexity of uncertainty, difficulty hypothesising for a situation they have not yet experienced, and a reluctance to plan for hypothetical situations with regard to decision making in the event of a life threatening illness; however for the most part, they were quite prepared to die, with most expressing the sentiment that they took each day as it came, and that they were long ready, and waiting to die.(344)

> *"When I look back in my family, my parents. They were alive, then they were dead, but it all went off as usual. Nothing really dramatic or anything (…) Why should it be any different for me?"(344)*

> *"I'm not frightened to die, if that's what you mean. No, not at all. I mean there isn't any other future."* (344)

A study of patients with advanced cancer found those with a Do Not Resuscitate order had better quality of life as death drew near, and they suggested that the presence of a Do Not Resuscitate order led to this improved quality of life.(639) There are alternative explanations however. It may be that those who have lower levels of death anxiety, those who are more accepting of the inevitability of death and those who are more prepared mentally for death, are also those who are more likely to complete a Do Not Resuscitate order, and that it is this

mental predisposition rather than the presence of a Do Not Resuscitate order that leads to better quality of life.

9.2 Incorporating end of life care into long term care setting

In introducing the complex intervention that has been the focus of this research, the importance of a framework of change management cannot be overemphasised. There are many models for change management; one of the most widely used being that described by John P. Kotter in 1996.(640) The framework for changing the end of life care culture in the study sites involved in the research presented in this thesis mirrored Kotter's eight-stage process in creating major change within an organisation:

1. Establishing a sense of urgency
2. Forming a powerful guiding coalition
3. Developing a vision and strategy
4. Communicating the vision
5. Empowering others to act on the action
6. Generating short term wins
7. Consolidating gains and producing more change
8. Anchoring new approaches in the culture

The sense of urgency for change and improvement in the end of life care provided in the study sites was potentially driven by external influences such as HIQA's publication of the *National Quality Standards for Residential Care Settings for Older People in Ireland* in 2009 and HIQA's regular auditing of elements of end of life care provided in long term residential care facilities in Ireland. Another potential external driver may have been the changes, not long before the study initiative began, which led to all deaths in Irish nursing home becoming reportable to the Coroner.

From the outset, there were also internal influencers such as staff's palpable and keen sense of the need to improve end of life care and decision making, with a vision for how improved care might look, informed by the results of baseline "before" study results. Using an action research methodology, a

collaborative approach was taken to developing and refining the study interventions as detailed in Chapters 3 and 5; this was facilitated by the research site managers' feedback and steering group as described in Chapter 3.

There was investment from senior management in each of the study sites and a strong coalition developed between senior staff and the researchers in terms of driving the changes in practice "from the top". Through seeking out the opinions of frontline staff, there was genuine engagement with staff around their expressed educational needs rather than imposing "expert" generated needs from a literature search. Such staff participation is empowering to them, encouraged engagement with an initiative that was built on their views and as such is an important component of organisational development.(641) At the end of the palliative care educational sessions some of the positive findings from the "before" survey of bereaved relatives was fed back to participants. "What went well" in each site in their provision of end of life care, was commended to acknowledge the good work done by staff – a "short term win" - but feedback on the negative findings on "what did not go so well" was also given, so the driver for further change and a map for quality improvement was laid down.

The changes in the culture of end of life care seen over the course of this research project were both feasible and sustainable. There was a natural evolution and incorporation of the advance care planning and palliative care initiative in this study, into the day to day care environment and practices of the study sites. All study sites moved, by choice, to introducing the Let Me Decide program to residents at the time of their arrival. This move essentially began the process of integrating end of life care into the overall care of the resident, right from the time of admittance, rather than just from the time dying is recognized.

"You can't always get what you want

But if you try sometimes

You just might find

You just might find

You get what you need"

— Mick Jagger / Keith Richards, Let it Bleed, 1969

10: Bibliography

10 Bibliography

1. Sulmasy DP, Terry PB, Weisman CS, Miller DJ, Stallings RY, Vettese MA, et al. The accuracy of substituted judgments in patients with terminal diagnoses. Annals of internal medicine. 1998;128(8):621-9.
2. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: A systematic review. Archives of internal medicine. 2006;166(5):493-7.
3. Dempsey D. Advance care planning for people with dementia: benefits and challenges. International journal of palliative nursing. 2013;19(5):227-34.
4. Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary Resuscitation on Television — Miracles and Misinformation. New Engl J Med. 1996;334(24):1578-82.
5. Portanova J, Irvine K, Yi JY, Enguidanos S. It isn't like this on TV: Revisiting CPR survival rates depicted on popular TV shows. Resuscitation. 2015;96:148-50.
6. Singer PA, Robertson G, Roy DJ. Bioethics for clinicians: 6. Advance care planning. CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne. 1996;155(12):1689-92.
7. Faden RR, Beauchamp TL. A history and theory of informed consent: Oxford University Press; 1986.
8. Sokol DK. How the doctor's nose has shortened over time; a historical overview of the truth-telling debate in the doctor-patient relationship. Journal of the Royal Society of Medicine. 2006;99(12):632-6.
9. Percival T. Medical ethics: Cambridge University Press; 2014.
10. Flint A. Medical ethics and etiquette: D. Appleton and Company; 1883.
11. Oken D. What to tell cancer patients: a study of medical attitudes. JAMA : the journal of the American Medical Association. 1961;175(13):1120-8.
12. Novack D, Plumer R, Smith R, Ochitill H, Morrow G, Bennett J. Changes in physicians' attitudes toward telling the cancer patient. JAMA : the journal of the American Medical Association. 1979;241(9):897-900.
13. Anderson RN, DeTurk PB. United States life tables, 1999. National vital statistics reports. Hyattsville, Maryland, United States.; 2002. Contract No.: 6.
14. Bigelow HJ. Insensibility during Surgical Operations Produced by Inhalation. The Boston Medical and Surgical Journal. 1846;35(16):309-17.
15. Pagés F. Anestesia metamerica: Imprenta de Julio Cosano; 1921.
16. Robinson DH, Toledo AH. Historical development of modern anesthesia. 2012(1521-0553 (Electronic)).
17. Barnard C. The operation. A human cardiac transplant: an interim report of a successful operation performed at Groote Schuur Hospital, Cape Town. South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde. 1967;41(48).
18. Hardy JD, Webb WR, Dalton ML, Walker GR. Lung homotransplantation in man: report of the initial case. JAMA : the journal of the American Medical Association. 1963;186(12):1065-74.
19. Merrill JP, Murray JE, Harrison JH, Guild WR. Successful homotransplantation of the human kidney between identical twins. J Am Med Assoc. 1956;160(4):277-82.
20. Calne R, Williams R, Dawson J, Ansell I, Evans D, Flute P, et al. Liver Transplantation in Man—II, a Report of two Orthotopic Liver Transplants in Adult Recipients. British medical journal. 1968;4(5630):540-6.
21. Hatzinger M, Kwon St Fau - Langbein S, Langbein S Fau - Kamp S, Kamp S Fau - Hacker A, Hacker A Fau - Alken P, Alken P. Hans Christian Jacobaeus: Inventor of human laparoscopy and thoracoscopy. (0892-7790 (Print)).
22. Jones DS, Podolsky SH, Greene JA. The Burden of Disease and the Changing Task of Medicine. New Engl J Med. 2012;366(25):2333-8.

23. Kolff WJ, Berk HTJ, Welle NM, van der Ley AJW, van Dijk EC, van Noordwijk J. The Artificial Kidney: a dialyser with a great area. Acta Medica Scandinavica. 1944;117(2):121-34.
24. Quinton W, Dillard D, Scribner BH. CANNULATION OF BLOOD VESSELS FOR PROLONGED HEMODIALYSIS. ASAIO Journal. 1960;6(1):104-13.
25. Alexander S. They decide who lives, who dies. 1962.
26. Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 1979.
27. Beck CS, Pritchard WH, Feil HS. Ventricular fibrillation of long duration abolished by electric shock. J Am Med Assoc. 1947;135(15):985-6.
28. Stephenson Jr HE, Reid LC, Hinton JW. Some common denominators in 1200 cases of cardiac arrest. Annals of surgery. 1953;137(5):731.
29. Zoll PM, Linenthal AJ, Gibson W, Paul MH, Norman LR. Termination of ventricular fibrillation in man by externally applied electric countershock. New Engl J Med. 1956;254(16):727-32.
30. Maass F. Die methode der wiederbelebung bei herztod nach chloroformeinathmung. Berl Klin Wochenschr. 1892;12(3):265-8.
31. Kouwenhoven WB, Jude JR, Knickerbocker GG. Closed-chest cardiac massage. JAMA : the journal of the American Medical Association. 1960;173:1064-7.
32. Safar P, Mc MM. Mouth-to-airway emergency artificial respiration. J Am Med Assoc. 1958;166(12):1459-60.
33. Safar P, Escarraga LA, Elam JO. A comparison of the mouth-to-mouth and mouth-to-airway methods of artificial respiration with the chest-pressure arm-lift methods. The New England journal of medicine. 1958;258(14):671-7.
34. Gordon AS, Frye CW, Gittelson L, Sadove MS, Beattie EJ, Jr. Mouth-to-mouth versus manual artificial respiration for children and adults. J Am Med Assoc. 1958;167(3):320-8.
35. Elam JO, Greene DG, Brown ES, Clements JA. Oxygen and carbon dioxide exchange and energy cost of expired air resuscitation. J Am Med Assoc. 1958;167(3):328-34.
36. Jude JR, Kouwenhoven WB, Knickerbocker GG. Cardiac arrest. Report of application of external cardiac massage on 118 patients. JAMA : the journal of the American Medical Association. 1961;178:1063-70.
37. Bedell SE, Delbanco TL, Cook EF, Epstein FH. Survival after cardiopulmonary resuscitation in the hospital. The New England journal of medicine. 1983;309(10):569-76.
38. Abbo ED, Yuen TC, Buhrmester L, Geocadin R, Volandes AE, Siddique J, et al. Cardiopulmonary Resuscitation Outcomes in Hospitalized Community-Dwelling Individuals and Nursing Home Residents Based on Activities of Daily Living. Journal of the American Geriatrics Society. 2013;61(1):34-9.
39. Nadkarni VM, Larkin G, Peberdy M, et al. First documented rhythm and clinical outcome from in-hospital cardiac arrest among children and adults. JAMA : the journal of the American Medical Association. 2006;295(1):50-7.
40. Girotra S, Nallamothu BK, Spertus JA, Li Y, Krumholz HM, Chan PS. Trends in Survival after In-Hospital Cardiac Arrest. New Engl J Med. 2012;367(20):1912-20.
41. Hoke RS, Chamberlain D. Skeletal chest injuries secondary to cardiopulmonary resuscitation. Resuscitation. 2004;63(3):327-38.
42. van de Glind EM, van Munster BC, van de Wetering FT, van Delden JJ, Scholten RJ, Hooft L. Pre-arrest predictors of survival after resuscitation from out-of-hospital cardiac arrest in the elderly a systematic review. BMC geriatrics. 2013;13(1):68.
43. Fabbri A, Marchesini G, Spada M, Iervese T, Dente M, Galvani M, et al. Monitoring intervention programmes for out-of-hospital cardiac arrest in a mixed urban and rural setting. Resuscitation. 2006;71(2):180-7.

44. Deasy C, Bray J, Smith K, Harriss L, Bernard S, Cameron P, et al. Out-of-hospital cardiac arrests in the older age groups in Melbourne, Australia. Resuscitation. 2011;82(4):398-403.
45. Andrew E, Nehme Z, Bernard S, Smith K. The influence of comorbidity on survival and long-term outcomes after out-of-hospital cardiac arrest. Resuscitation. 2017;110:42-7.
46. Terman SW, Shields TA, Hume B, Silbergleit R. The influence of age and chronic medical conditions on neurological outcomes in out of hospital cardiac arrest. Resuscitation. 2015;89:169-76.
47. Xue J-k, Leng Q-y, Gao Y-z, Chen S-q, Li Z-p, Li H-p, et al. Factors influencing outcomes after cardiopulmonary resuscitation in emergency department. World Journal of Emergency Medicine. 2013;4(3):183-9.
48. Applebaum GE, King JE, Finucane TE. The outcome of CPR initiated in nursing homes. Journal of the American Geriatrics Society. 1990;38.
49. Iwami T, Hiraide A, Nakanishi N, Hayashi Y, Nishiuchi T, Uejima T. Outcome and characteristics of out-of-hospital cardiac arrest according to location of arrest: A report from a large-scale, population-based study in Osaka, Japan. Resuscitation. 2006;69.
50. Kim C, Becker L, Eisenberg MS. Out-of-hospital cardiac arrest in octogenarians and nonagenarians. Archives of internal medicine. 2000;160.
51. Masterson S, Wright P, O'Donnell C, Vellinga A, Murphy AW, Hennelly D, et al. Urban and rural differences in out-of-hospital cardiac arrest in Ireland. Resuscitation. 2015;91:42-7.
52. Reynolds JC, Grunau BE, Rittenberger JC, Sawyer KN, Kurz MC, Callaway CW. Association Between Duration of Resuscitation and Favorable Outcome After Out-of-Hospital Cardiac Arrest. Circulation. 2016;134(25):2084.
53. Brady WJ, Gurka KK, Mehring B, Peberdy MA, O'Connor RE. In-hospital cardiac arrest: impact of monitoring and witnessed event on patient survival and neurologic status at hospital discharge. Resuscitation. 2011;82(7):845-52.
54. Rajan S, Wissenberg M, Folke F, Hansen SM, Gerds TA, Kragholm K, et al. Association of Bystander Cardiopulmonary Resuscitation and Survival According to Ambulance Response Times After Out-of-Hospital Cardiac Arrest. Circulation. 2016;134:2095-104.
55. Link MS, Atkins DL, Passman RS, Halperin HR, Samson RA, White RD, et al. Part 6: Electrical Therapies. Circulation. 2010;122:S706-S19.
56. Khera R, Chan PS, Donnino M, Girotra S. Hospital Variation in Time to Epinephrine for Nonshockable In-Hospital Cardiac Arrest. Circulation. 2016;134:2105-14.
57. Temple A, Porter R. Predicting neurological outcome and survival after cardiac arrest. Continuing Education in Anaesthesia, Critical Care & Pain. 2012.
58. McKeown K, Haase T, Pratschke J, Twomey S, Donovan H, Engling F. Dying in Hospital in Ireland: An assessment of the Quality of Care in the last week of life, Report 5, Final Synthesis Report. Dublin: Irish Hospice Foundation; 2010.
59. Illich I. Medical nemesis. New York: Pantheon. 1976;30.
60. Saxon W. Luis Kutner, Lawyer WHo Fought For Human Rights, Is Dead at 84. The New York times. 1993 04/03/1993.
61. Kutner L. Due process of euthanasia: the living will, a proposal. Ind LJ. 1968;44:539-54.
62. The 'Living Will' gains acceptance. The New York times. 1984 20/09/1984.
63. Re Quinlan. New Jersey Supreme COurt; 1976.
64. Law Reform Commission. Report, Bioethics: Advance Care Directives,. Dublin: Law Reform Commission,; 2009.
65. Pope Pius XII. 'The Prolongation of Life' (November 24, 1957). The Pope Speaks. 1958;4(4):395-6.

66. Pellegrino ED. Decisions at the end of life: The use and abuse of the concept of futility. The dignity of the dying person Vaticano: Libreria Editrice Vaticano. 2000:95.
67. Styker J. The New York times. 1996 March 31 1996.
68. Quill TE. Terri Schiavo — A Tragedy Compounded. New Engl J Med. 2005;352(16):1630-3.
69. KINKEL LKO, CHIEVELEY LGO, LOWRY L, BROWNE-WILKINSON L, MUSTILL L. Airedale NHS Trust v Bland. House of Lords; 1993.
70. In the matter of A Ward of Court (withholding medical treatment) (No. 2) High Court; 1996.
71. Bundesgesetz über Patientenverfügungen., (2006).
72. Alzheimer Europe Report (01/2006): The use of advance directives by people with dementia. Luxembourg: Alzheimer Europe; 2006.
73. Mills S. Clinical Practice and the Law. 2nd ed. Haywards Heath: Tottel Publishing; 2007.
74. Madden D. Medicine, Ethics and Law. 1 ed. Dublin: Butterworths; 2002.
75. Pope TM. Legal fundamentals of surrogate decision making. Chest. 2012;141(4):1074-81.
76. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. Journal of pain and symptom management. 2017.
77. Sabatino CP. The evolution of health care advance planning law and policy. The Milbank quarterly. 2010;88(2):211-39.
78. Sulmasy DP, Hughes MT, Thompson RE, Astrow AB, Terry PB, Kub J, et al. How would terminally ill patients have others make decisions for them in the event of decisional incapacity? A longitudinal study. Journal of the American Geriatrics Society. 2007;55(12):1981-8.
79. Davidson KW, Hackler C, Caradine DR, McCord RS. Physicians' attitudes on advance directives. JAMA : the journal of the American Medical Association. 1989;262(17):2415-9.
80. Iserson KV, Rouse F. Prehospital DNR orders. The Hastings Center report. 1989;19(6):17; discussion -9.
81. Zweibel NR, Cassel CK. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. The Gerontologist. 1989;29(5):615-21.
82. Emanuel LL, Emanuel EJ. The Medical Directive. A new comprehensive advance care document. JAMA : the journal of the American Medical Association. 1989;261(22):3288-93.
83. Yadav KN, Gabler NB, Cooney E, Kent S, Kim J, Herbst N, et al. Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care. Health Aff (Millwood). 2017;36(7):1244-51.
84. Bravo G, Dubois M-F, Cohen C, Wildeman S, Graham J, Painter K, et al. Are Canadians Providing Advance Directives about Health Care and Research Participation in the Event of Decisional Incapacity? The Canadian Journal of Psychiatry. 2011;56(4):209-18.
85. Bradley SL, Woodman RJ, Tieman JJ, Phillips PA. Use of advance directives by South Australians: results from the Health Omnibus Survey Spring 2012. The Medical journal of Australia. 2014;201(8):467-9.
86. White B, Tilse C, Wilson J, Rosenman L, Strub T, Feeney R, et al. Prevalence and predictors of advance directives in Australia. Internal medicine journal. 2014;44(10):975-80.
87. Street M, Ottmann G, Johnstone MJ, Considine J, Livingston PM. Advance care planning for older people in Australia presenting to the emergency department from the

community or residential aged care facilities. Health & social care in the community. 2015;23(5):513-22.
88. Sommer S, Marckmann G, Pentzek M, Wegscheider K, Abholz HH, in der Schmitten J. Advance directives in nursing homes: prevalence, validity, significance, and nursing staff adherence. Deutsches Arzteblatt international. 2012;109(37):577-83.
89. McCarthy J, Weafer J, Loughrey M. Irish views on death and dying: a national survey. Journal of medical ethics. 2010;36(8):454-8.
90. Hirschman KB, Abbott KM, Hanlon AL, Prvu Bettger J, Naylor MD. What factors are associated with having an advance directive among older adults who are new to long term care services? Journal of the American Medical Directors Association. 2012;13(1):82 e7-11.
91. Luck T, Rodriguez FS, Wiese B, van der Leeden C, Heser K, Bickel H, et al. Advance directives and power of attorney for health care in the oldest-old - results of the AgeQualiDe study. BMC geriatrics. 2017;17(1):85.
92. Wilson DM, Houttekier D, Kunju SA, Birch S, Cohen J, MacLeod R, et al. A Population-Based Study on Advance Directive Completion and Completion Intention among Citizens of the Western Canadian Province of Alberta. Journal of palliative care. 2013;29(1):5-12.
93. Taylor DM, Ugoni AM, Cameron PA, McNeil JJ. Advance directives and emergency department patients: ownership rates and perceptions of use. Internal medicine journal. 2003;33(12):586-92.
94. High DM. Advance directives and the elderly: a study of intervention strategies to increase use. The Gerontologist. 1993;33(3):342-9.
95. McDonald JC, du Manoir JM, Kevork N, Le LW, Zimmermann C. Advance directives in patients with advanced cancer receiving active treatment: attitudes, prevalence, and barriers. Supportive Care Cancer. 2017;25(2):523-31.
96. Alano GJ, Pekmezaris R, Tai JY, Hussain MJ, Jeune J, Louis B, et al. Factors influencing older adults to complete advance directives. Palliative Supportive Care. 2010;8(3):267-75.
97. Sahm S, Will R, Hommel G. Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff. Journal of medical ethics. 2005;31(8):437-40.
98. Yamada R, Galecki AT, Goold SD, Hogikyan RV. A multimedia intervention on cardiopulmonary resuscitation and advance directives. Journal of general internal medicine. 1999;14(9):559-63.
99. Ramsaroop SD, Reid MC, Adelman RD. Completing an advance directive in the primary care setting: what do we need for success? Journal of the American Geriatrics Society. 2007;55(2):277-83.
100. Silveira MJ, Wiitala W, Piette J. Advance directive completion by elderly americans: A decade of change. Journal of the American Geriatrics Society. 2014;62(4):706-10.
101. Hirschman KB, Kapo JM, Karlawish JH. Identifying the factors that facilitate or hinder advance planning by persons with dementia. Alzheimer disease and associated disorders. 2008;22(3):293-8.
102. Mansell D, Kazis L, Glantz L, Heeren T. Roles of physicians, attorneys, and illness experience in advance directives. Southern medical journal. 1999;92(2):197-203.
103. Carr D, Khodyakov D. End-of-life health care planning among young-old adults: an assessment of psychosocial influences. J Gerontol B Psychol Sci Soc Sci. 2007;62(2):S135-41.
104. Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding advance care planning as a process of health behavior change. Journal of the American Geriatrics Society. 2009;57(9):1547-55.

105. Prochaska JO, Velicer WF, DiClemente CC, Fava J. Measuring processes of change: applications to the cessation of smoking. Journal of consulting and clinical psychology. 1988;56(4):520-8.
106. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. Am J Health Promot. 1997;12(1):38-48.
107. Westley C, Briggs LA. Using the stages of change model to improve communication about advance care planning. Nursing forum. 2004;39(3):5-12.
108. Pearlman RA, Starks H, Cain KC, Cole WG. Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. Archives of internal medicine. 2005;165(6):667-74.
109. Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JH. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? The Gerontologist. 2005;45(3):381-8.
110. Sharp T, Moran E, Kuhn I, Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: A systematic literature review and narrative synthesis. Br J Gen Pract. 2013;63(615):e657-e68.
111. Cotter PE, Simon M, Quinn C, O'Keeffe ST. Changing attitudes to cardiopulmonary resuscitation in older people: a 15-year follow-up study. Age and ageing. 2009;38(2):200-5.
112. Murphy DJ, Burrows D, Santilli S, Kemp AW, Tenner S, Kreling B, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. The New England journal of medicine. 1994;330(8):545-9.
113. Collins M, Lehane E. Perspectives on death, dying and advance care planning from patients receiving haemodialysis. J Ren Care. 2013;39(1):5-11.
114. Ekdahl AW, Andersson L, Friedrichsen M. "They do what they think is the best for me." Frail elderly patients' preferences for participation in their care during hospitalization. Patient education and counseling. 2010;80(2):233-40.
115. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? Journal of clinical epidemiology. 1992;45(9):941-50.
116. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres. 1997;29(3):21-43.
117. Nolan MT, Hughes M, Narendra DP, Sood JR, Terry PB, Astrow AB, et al. When patients lack capacity: the roles that patients with terminal diagnoses would choose for their physicians and loved ones in making medical decisions. Journal of pain and symptom management. 2005;30(4):342-53.
118. Singh JA, Sloan JA, Atherton PJ, Smith T, Hack TF, Huschka MM, et al. Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. The American journal of managed care. 2010;16(9):688-96.
119. Ekdahl AW, Andersson L, Wirehn AB, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. BMC geriatrics. 2011;11:46.
120. Chiu C, Feuz MA, McMahan RD, Miao Y, Sudore RL. "Doctor, Make My Decisions": Decision Control Preferences, Advance Care Planning, and Satisfaction With Communication Among Diverse Older Adults. Journal of pain and symptom management. 2016;51(1):33-40.
121. Finucane TE. How gravely ill becomes dying: a key to end-of-life care. JAMA : the journal of the American Medical Association. 1999;282(17):1670-2.
122. Samsi K, Manthorpe J. 'I live for today': a qualitative study investigating older people's attitudes to advance planning. Health & social care in the community. 2011;19(1):52-9.

123. Piers RD, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, et al. Advance Care Planning in terminally ill and frail older persons. Patient education and counseling. 2011.
124. Malcomson H, Bisbee S. Perspectives of healthy elders on advance care planning. Journal of the American Academy of Nurse Practitioners. 2009;21(1):18-23.
125. Ariès P. Western attitudes toward death: from the Middle Ages to the present: JHU Press; 1975.
126. Auriemma CL, Nguyen CA, Bronheim R, Kent S, Nadiger S, Pardo D, et al. Stability of end-of-life preferences: a systematic review of the evidence. JAMA internal medicine. 2014;174(7):1085-92.
127. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. Archives of internal medicine. 1998;158(8):879-84.
128. Ditto PH, Danks JH, Smucker WD, Bookwala J, Coppola KM, Dresser R, et al. Advance directives as acts of communication: A randomized controlled trial. Archives of internal medicine. 2001;161(3):421-30.
129. Hirschman KB, Kapo JM, Karlawish JH. Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person? The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry. 2006;14(8):659-67.
130. Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in translation: the unintended consequences of advance directive law on clinical care. Annals of internal medicine. 2011;154(2):121-8.
131. Mueller LA, Reid KI, Mueller PS. Readability of state-sponsored advance directive forms in the United States: a cross sectional study. BMC medical ethics. 2010;11:6.
132. Nielsen-Bohlman L, Panzer A, Hamlin B, Kindig D. Institute of Medicine. Health literacy: a prescription to end confusion. Committee on Health Literacy, Board on Neuroscience and Behavioral Health. Washington, DC: National Academies Press; 2004.
133. Nauck F, Becker M, King C, Radbruch L, Voltz R, Jaspers B. To what extent are the wishes of a signatory reflected in their advance directive: a qualitative analysis. BMC medical ethics. 2014;15:52.
134. Fischer GS, Tulsky JA, Rose MR, Siminoff LA, Arnold RM. Patient knowledge and physician predictions of treatment preferences after discussion of advance directives. Journal of general internal medicine. 1998;13(7):447-54.
135. Kossman DA. Prevalence, views, and impact of advance directives among older adults. Journal of gerontological nursing. 2014;40(7):44-50.
136. Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. Palliative medicine. 2013;27(5):401-8.
137. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. New Engl J Med. 2010;362(13):1211-8.
138. Cosgriff JA, Pisani M, Bradley EH, O'Leary JR, Fried TR. The association between treatment preferences and trajectories of care at the end-of-life. Journal of general internal medicine. 2007;22(11):1566-71.
139. Brinkman-Stoppelenburg A, Rietjens JAC, Van Der Heide A. The effects of advance care planning on end-of-life care: A systematic review. Palliative medicine. 2014;28(8):1000-25.
140. Hartog CS, Peschel I, Schwarzkopf D, Curtis JR, Westermann I, Kabisch B, et al. Are written advance directives helpful to guide end-of-life therapy in the intensive care unit? A retrospective matched-cohort study. Journal of critical care. 2014;29(1):128-33.

141. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: A systematic review and meta-analysis. Journal of the American Medical Directors Association. 2014;15(7):477-89.
142. Abba K, Byrne P, Horton S, Lloyd-Williams M. Interventions to encourage discussion of end-of-life preferences between members of the general population and the people closest to them-a systematic literature review. BMC palliative care. 2013;12(1):40.
143. In der Schmitten J, Lex K, Mellert C, Rotharmel S, Wegscheider K, Marckmann G. Implementing an advance care planning program in German nursing homes: results of an inter-regionally controlled intervention trial. Deutsches Arzteblatt international. 2014;111(4):50-7.
144. Molloy DW, Guyatt GH, Russo R, Goeree R, O'Brien BJ, Bedard M, et al. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. JAMA : the journal of the American Medical Association. 2000;283(11):1437-44.
145. Gold Standards Framework. http://www.goldstandardsframework.org.uk/ [Available from: http://www.goldstandardsframework.org.uk/.
146. Health Information and Quality Authority. National Standards for Residential Care Settings for Older People in Ireland. Dublin: Health Information and Quality Authority; 2016.
147. Nicholls G, MacKay T. A history of the English poor law: In connection with the state of the country and the condition of the people,. London: New York: P.S. King and son; 1898
148. Government of Ireland. The Care of the Aged: Report of an Inter-Departmental Committee on the Care of the Aged, 1968. . Dublin; 1968.
149. Higginbotham P. The Workhouse in Ireland. 2008.
150. Donnelly B. http://historyofmedicineinireland.blogspot.ie/2015/03/the-historical-development-of-irish.html2015.
151. Grace P. Medicine and Doctors in Limerick. 2008.
152. Health Do. Health in Ireland, Key Trends 2016. In: Health Do, editor. Dublin: Government Publications; 2016.
153. Executive HS. Nursing Home Support Scheme, Cost of Care in Public Nursing Homes http://www.hse.ie/eng/services/list/4/olderpeople/nhss/costofcareHSE.pdf Health Service Executive, http://www.hse.ie/; 2016 [
154. Health Information and Quality Authority. http://www.hiqa.ie/ [
155. O'Sullivan DJ. The Cork school of medicine: a history: UCC Medical Alumni Association, University College Cork; 2007.
156. Cockburn P. The Broken Boy: Random House; 2010.
157. Ltd HT. Oispidéil na hÉireann Ireland's Hospitals 1930-1955. Dublin: Parkgate Printing Works, ; 1956.
158. Porter R. The Cambridge illustrated history of medicine: Cambridge University Press; 2001.
159. Saunders C. Foreword. In: Derek DOyle GH, Nathan Cherny, Kenneth Calman, editor. Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press; 2005.
160. Garnier MMJ. Paris: https://www.jeanne-garnier.org/jeanne-garnier/dhier-a-aujourdhui/; [
161. O'Brien T, Clark D. A national plan for palliative care - the Irish experience. In: Ling J, O'Siorain L, editors. Palliative Care in Ireland. Berkshire: McGraw-Hill Education (UK); 2005. p. 3.
162. Tony O'Brien, David Clark. A national plan for palliative care-the Irish experience. In: Julie Ling LOS, editor. Palliative Care in Ireland. Facing Death. Berkshire: Open University Press; 2005.

163. Humphreys C. Tuberculosis, poverty and the first 'hospices' in Ireland. Eur J Palliative Care. 2003;10(4):164-7.
164. David Clark, Jane Seymour. History and Development. In: Clark D, editor. Reflections on Palliative Care. Facing Death. Buckingham: Open University Press; 1999.
165. Glaser BG, Strauss AL. Awareness of dying: Transaction Publishers; 1966.
166. McIntosh J. Communication and awareness in a cancer ward. 1977.
167. Department of Health and Children. Report of the National Advisory Committee on Palliative Care. Dublin: Department of Health and Children; 2001.
168. Health Information and Quality Authority. National Quality Standards for Residential Care Settings for Older People in Ireland,. Dublin2010.
169. Health Service Executive and Irish Hospice Foundation. Palliative Care For All-Integrating Palliative Care into Disease Management Frameworks, Report of the Extending Access Study. Dublin: Health Service Executive and Irish Hospice Foundation,; 2008.
170. Hospice Friendly Hospitals. Quality Standards for End-of-Life Care in Hospitals. Dublin: Irish Hospice Foundation,; 2010.
171. Department of Health. End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life. London: Department of Health; 2008.
172. Ellershaw J, WIlkinson S. Care of the Dying: Pathway to Excellence. Oxford: Oxford University Press; 2003.
173. Organisation WH. WHO Definition of Palliative Care Geneva: http://www.who.int/cancer/palliative/definition/en/; 2010 [
174. McKeown K. Enabling more people to die at home: making the case for quality indicators as drivers for change on place of care and place of death in Ireland. 2014. Report No.: 0956659098.
175. Ryan K, Guerin S, O'Brien N, Nixon E, Cooney F, Fitzpatrick S, et al. National Palliative Care Support Beds Review Subgroup. Report of the First National Palliative Care Support Bed Review. Dublin: Health Service Executive; 2014.
176. Kane PM, Daveson BA, Ryan K, McQuillan R, Higginson IJ, Murtagh FE, et al. The need for palliative care in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of nonmalignant conditions. Journal of pain and symptom management. 2015;49(4):726-33 e1.
177. Gabi Brogan, Rob George. HIV/Aids. In: Julia M. Addington-Hall, Irene J. Higginson, editors. Palliative Care for Non-Cancer Patients. Oxford: Oxford University Press; 2001. p. 137-8.
178. O'Leary MJ, O'Brien AC, Murphy M, Crowley CM, Leahy HM, McCarthy JM, et al. Place of care: from referral to specialist palliative care until death. BMJ Supportive & Palliative Care. 2014.
179. Praill D. Who are we here for? Palliative medicine. 2000;14(2):91-2.
180. National Clinical Programme for Palliative Care. Glossary of Terms. In: Clinical Strategy and Programmes Division HSE, editor. Dublin: Health Service Executive; 2014.
181. Harris P. Guidelines for a palliative approach in residential aged care. 2006.
182. Hockley JM, Dunlop R, Davies RJ. Survey of distressing symptoms in dying patients and their families in hospital and the response to a symptom control team. Br Med J (Clin Res Ed). 1988;296(6638):1715-7.
183. Califf RM, Adams, K.F. McKenna, W.J., Gheorghiade, M., Uretsky, B.F., McNulty, S.E., Darius, H., Schulman, K., Zannad, F., Handberg, T.E., Harrell, F.E., Wheeler, W., Soler, S.J., Swedberg, K.,. A randomised controlled trial of epoprostenol therapy for severe congestive heart failure: The Flolan International Randomised Survival Trial, (FIRST). American heart journal. 1997;134:44-54.

184. Group CTS. Effects of enalapril on mortality in severe congestive heart failure. Results of the Cooperative North Scandinavian Enalapril Survival Study (CONSENSUS). New Engl J Med. 1987;316:1429-35.
185. Higginson I, Sen-Gupta G, Dunlop D. Changing gear: guidelines for managing the last days of life in adults. The research evidence London: National Council for Hospice and Palliative Care Services. 1997.
186. Estabrooks CA, Hoben M, Poss JW, Chamberlain SA, Thompson GN, Silvius JL, et al. Dying in a Nursing Home: Treatable Symptom Burden and its Link to Modifiable Features of Work Context. Journal of the American Medical Directors Association. 2015;16(6):515-20.
187. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: A nationwide observational study in the netherlands. Archives of internal medicine. 2005;165(3):314-20.
188. Sandvik RK, Selbaek G, Bergh S, Aarsland D, Husebo BS. Signs of Imminent Dying and Change in Symptom Intensity During Pharmacological Treatment in Dying Nursing Home Patients: A Prospective Trajectory Study. Journal of the American Medical Directors Association. 2016;17(9):821-7.
189. Duncan JG, Forbes-Thompson S, Bott MJ. Unmet symptom management needs of nursing home residents with cancer. Cancer nursing. 2008;31(4):265-73.
190. Cartwright JC, Hickman S, Perrin N, Tilden V. Symptom Experiences of Residents Dying in Assisted Living. Journal of the American Medical Directors Association. 2006;7(4):219-23.
191. Maddocks I, Abbey J, Pickhaver A, Parker D, DeBellis A, Beck K. Palliative Care in Nursing Homes. . Adelaide: Commonwealth Department of Health and Family Services. ; 1996.
192. Ekland-Olson S. Life and Death Decisions: The Quest for Morality and Justice in Human Societies: Routledge; 2014.
193. Katz JS, Peace S. End of life in care homes: a palliative care approach: Oxford University Press; 2003.
194. Townsend P. The Last Refuge. London: Routledge and Kegan Paul; 1962.
195. Hauge S, Kristin H. The nursing home as a home: a field study of residents' daily life in the common living rooms. Journal of clinical nursing. 2008;17(4):460-7.
196. Rijnaard M, van Hoof J, Janssen B, Verbeek H, Pocornie W, Eijkelenboom A, et al. The factors influencing the sense of home in nursing homes: a systematic review from the perspective of residents. Journal of aging research. 2016;2016.
197. Layte R, Barry M, Bennett K, Brick A, Morgenroth E, Normand C, et al. Projecting the Impact of Demographic Change on the Demand for and Delivery of Helath Care in Ireland. Dublin: The Economic and Social Research Institute; 2009.
198. Central Statistics Office. Population and Labour Force Projections 2011-2041. Dublin: Central Statistics Office; 2008.
199. Smetanin P, Kobak P, Briante C, Stiff D, Sherman G, Ahmad S. Rising tide: the impact of dementia on Canadian society. Toronto, ON: Alzheimer Society of Canada. 2010.
200. Broad JB, Gott M, Kim H, Boyd M, Chen H, Connolly MJ. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Public Health. 2013;58(2):257-67.
201. Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in nursing homes. Journal of palliative medicine. 2002;5(6):895-901.
202. Cartwright A. Changes in life and care in the year before death 1969-1987. Journal of public health medicine. 1991;13(2):81-7.

203. Ahmad S, O'Mahony MS. Where older people die: A retrospective population-based study. QJM Mon J Assoc Phys. 2005;98(12):865-70.
204. Hunt R, Maddocks I. Terminal Care in South Australia: historical aspects and equity issues. In: Clark D, Hockley J, Ahmedzai S, editors. Facing Death - New Themes in Palliative Care. Buckingham: Open University Press. p. 101-5.
205. Oliver DP, Porock D, Zweig S. End-of-life care in U.S. nursing homes: A review of the evidence. Journal of the American Medical Directors Association. 2004;5(3):147-55.
206. Parker-Oliver D, Porock D, Zweig S. End-of-Life Care in U.S. Nursing Homes: A Review of the Evidence. Journal of the American Medical Directors Association. 2005;5.
207. Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. International psychogeriatrics / IPA. 2005;17(1):31-40.
208. van der Steen JT, Gijsberts MJ, Muller MT, Deliens L, Volicer L. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. International psychogeriatrics / IPA. 2009;21(2):321-9.
209. Thompson GN, McClement SE, Menec VH, Chochinov HM. Understanding bereaved family members' dissatisfaction with end-of-life care in nursing homes. Journal of gerontological nursing. 2012;38(10):49-60.
210. Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in nursing homes. Journal of palliative medicine. 2002;5(6):895-901.
211. Hanson LC, Eckert JK, Dobbs D, Williams CS, Caprio AJ, Sloane PD, et al. Symptom experience of dying long-term care residents. Journal of the American Geriatrics Society. 2008;56(1):91-8.
212. Hendriks SA, Smalbrugge M, Galindo-Garre F, Hertogh CMPM, van der Steen JT. From Admission to Death: Prevalence and Course of Pain, Agitation, and Shortness of Breath, and Treatment of These Symptoms in Nursing Home Residents With Dementia. Journal of the American Medical Directors Association. 2015;16(6):475-81.
213. Oliver DP, Washington K, Kruse RL, Albright DL, Lewis A, Demiris G. Hospice Family Members' Perceptions of and Experiences With End-of-Life Care in the Nursing Home. Journal of the American Medical Directors Association. 2014;15(10):744-50.
214. Houttekier D, Cohen J, Bilsen J, Deboosere P, Verduyckt P, Deliens L. Determinants of the Place of Death in the Brussels Metropolitan Region. Journal of pain and symptom management. 2009;37(6):996-1005.
215. Temkin-Greener H, Zheng NT, Xing J, Mukamel DB. Site of death among nursing home residents in the united states: Changing patterns, 2003-2007. Journal of the American Medical Directors Association. 2013;14(10):741-8.
216. Morin L, Johnell K, Aubry R. Variation in the place of death among nursing home residents in France. Age and ageing. 2015;44(3):415-21.
217. Seymour JE, Kumar A, Froggatt K. Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. Palliative medicine. 2011;25(2):125-38.
218. Houttekier D, Cohen J, Pepersack T, Deliens L. Dying in hospital: A study of incidence and factors related to hospital death using death certificate data. European journal of public health. 2013;24(5):751-6.
219. Kaspers PJ, Pasman HRW, Onwuteaka-Philipsen BD, Deeg DJH. Changes over a decade in end-of-life care and transfers during the last 3 months of life: A repeated survey among proxies of deceased older people. Palliative medicine. 2013;27(6):544-52.
220. Saliba D, Kington R, Buchanan J, Bell R, Wang M, Lee M, et al. Appropriateness of the Decision to Transfer Nursing Facility Residents to the Hospital. Journal of the American Geriatrics Society. 2000;48(2):154-63.

221. Ouslander JG, Lamb G, Perloe M, Givens JH, Kluge L, Rutland T, et al. Potentially avoidable hospitalizations of nursing home residents: Frequency, causes, and costs. Journal of the American Geriatrics Society. 2010;58(4):627-35.
222. Gott M, Gardiner C, Ingleton C, Cobb M, Noble B, Bennett MI, et al. What is the extent of potentially avoidable admissions amongst hospital inpatients with palliative care needs? BMC palliative care. 2013;12(1).
223. Vossius CE, Ydstebo AE, Testad I, Luras H. Referrals from nursing home to hospital: reasons, appropriateness and costs. Scandinavian journal of public health. 2013;41(4):366-73.
224. Ahearn DJ, Jackson TB, McIlmoyle J, Weatherburn AJ. Improving end of life care for nursing home residents: An analysis of hospital mortality and readmission rates. Postgraduate medical journal. 2010;86(1013):131-5.
225. Murphy-Jones G, Timmons S. Paramedics' experiences of end-of-life care decision making with regard to nursing home residents: an exploration of influential issues and factors. Emergency medicine journal : EMJ. 2016.
226. Gott M, Frey R, Robinson J, Boyd M, O'Callaghan A, Richards N, et al. The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers. Palliative medicine. 2013;27(8):747-56.
227. Dwyer R, Stoelwinder J, Gabbe B, Lowthian J. Unplanned Transfer to Emergency Departments for Frail Elderly Residents of Aged Care Facilities: A Review of Patient and Organizational Factors. Journal of the American Medical Directors Association. 2015;16(7):551-62.
228. Gozalo P, Teno JM, Mitchell SL, Skinner J, Bynum J, Tyler D, et al. End-of-life transitions among nursing home residents with cognitive issues. The New England journal of medicine. 2011;365(13):1212-21.
229. Stephens C, Halifax E, Bui N, Lee SJ, Harrington C, Shim J, et al. Provider Perspectives on the Influence of Family on Nursing Home Resident Transfers to the Emergency Department: Crises at the End of Life. Current gerontology and geriatrics research. 2015;2015:893062.
230. Krishnan P, Williams H, Maharaj I. Patterns of end-of-life care: Place of death and terminal hospitalization among long-term-care residents. J Hospice Palliative Nurs. 2015;17(2):133-42.
231. Baron K, Hodgson A, Walshe C. Evaluation of an advance care planning education programme for nursing homes: A Longitudinal study. Nurse education today. 2015;35(5):689-95.
232. Nicholas LH, Bynum JP, Iwashyna TJ, Weir DR, Langa KM. Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. Health Aff (Millwood). 2014;33(4):667-74.
233. Caplan GA, Meller A, Squires B, Chan S, Willett W. Advance care planning and hospital in the nursing home. Age and ageing. 2006;35(6):581-5.
234. Levy C, Morris M, Kramer A. Improving end-of-life outcomes in nursing homes by targeting residents at high-risk of mortality for palliative care: Program description and evaluation. Journal of palliative medicine. 2008;11(2):217-25.
235. Badger F, Clifford C, Hewison A, Thomas K. An evaluation of the implementation of a programme to improve end-of-life care in nursing homes. Palliative medicine. 2009;23(6):502-11.
236. Miller SC, Lima JC, Thompson SA. End-of-life care in nursing homes with greater versus less palliative care knowledge and practice. Journal of palliative medicine. 2015;18(6):527-34.

237. Zheng NT, Mukamel DB, Friedman B, Caprio TV, Temkin-Greener H. The effect of hospice on hospitalizations of nursing home residents. Journal of the American Medical Directors Association. 2015;16(2):155-9.
238. Hall S, Goddard C, Stewart F, Higginson IJ. Implementing a quality improvement programme in palliative care in care homes: A qualitative study. BMC geriatrics. 2011;11.
239. Whittaker E, George Kernohan W, Hasson F, Howard V, McLaughlin D. The palliative care education needs of nursing home staff. Nurse education today. 2006;26(6):501-10.
240. Torvik K, Kaasa S, Kirkevold Ø, Rustøen T. Pain in patients living in Norwegian nursing homes. Palliative medicine. 2009;23(1):8-16.
241. Wetle T, Shield R, Teno J, Miller SC, Welch L. Family perspectives on end-of-life care experiences in nursing homes. The Gerontologist. 2005;45(5):642-50.
242. Oliver DP, Porock D, Zweig S. End-of-Life Care in U.S. Nursing Homes: A Review of the Evidence. Journal of the American Medical Directors Association.5(3):147-55.
243. Froggatt KA, Wilson D, Justice C, MacAdam M, Leibovici K, Kinch J, et al. End-of-life care in long-term care settings for older people: a literature review. International journal of older people nursing. 2006;1(1):45-50.
244. Chan R. WJ. End-of-life care pathways for improving outcomes in caring for the dying (Review). Cochrane Database Syst Rev [Internet]. 2011; (1). Available from: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008006.pub2/pdf.
245. Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. Cochrane Database Syst Rev. 2011(3):CD007132.
246. Hanson LC, Reynolds KS, Henderson M, Pickard CG. A quality improvement intervention to increase palliative care in nursing homes. Journal of palliative medicine. 2005;8(3):576-84.
247. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010;340:c1345.
248. NHS National End of Life Care Programme. Preferred Priorities for Care. [Available from: http://www.endoflifecareforadults.nhs.uk/eolc/ppc.htm.
249. Respecting Patient Choices. [Available from: http://www.respectingpatientchoices.org.au/.
250. Hockley J, Watson J, Oxenham D, Murray SA. The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. Palliative medicine. 2010;24(8):828-38.
251. Hockley J, Watson J, Murray S. The Midlothian 'Gold Standards Framework in Care Homes' project. University of Edinburgh. 2008.
252. Durbin CR, Fish AF, Bachman JA, Smith KV. Systematic review of educational interventions for improving advance directive completion. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau. 2010;42(3):234-41.
253. Tamayo-Velázquez M-I, Simón-Lorda P, Villegas-Portero R, Higueras-Callejón C, García-Gutiérrez J-F, Martínez-Pecino F, et al. Interventions to promote the use of advance directives: An overview of systematic reviews. Patient education and counseling. 2010;80(1):10-20.
254. Patel RV, Sinuff T, Cook DJ. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. Journal of critical care. 2004;19(1):1-9.
255. Houttekier D, Cohen J, Cools F, Deliens L. Advance care planning for end-of-life care. Cochrane Database Syst Rev. 2012(2).

256. Houttekier D, Cohen J, Cools F, Deliens L. Advance care planning for end-of-life care. Cochrane Database Syst Rev. 2016(1).
257. Emanuel EJ, Emanuel LL. The economics of dying: The illusion of cost savings at the end of life. New Engl J Med. 1994;330(8):540.
258. Taylor JS, Heyland DK, Taylor SJ. How advance directives affect hospital resource use. Systematic review of the literature. Canadian family physician Medecin de famille canadien. 1999;45:2408-13.
259. Craig P DP, Macintyre S, Michie S, Nazareth I, Petticrew M. . Developing and evaluating complex interventions: new guidance. London: Medical Research Council; 2008.
260. The Irish Council for Bioethics. Is it time for Advance Healthcare Directives. Dublin; 2007. Report No.: 978-1-904890-25-6.
261. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al. Family perspectives on end-of-life care at the last place of care. JAMA : the journal of the American Medical Association. 2004;291(1):88-93.
262. Madden D. Medicine, Ethics & the Law. 1st ed. Haywards Heath: Tottel Publishing; 2002.
263. Law Reform Commission. Report Bioethics: Advance Care Directives (LRC 94-2009). Dublin: Law Reform Commission; 2009.
264. Groarke J, Gallagher J, McGovern R. Conflicting perspectives compromising discussions on cardiopulmonary resuscitation. Irish medical journal. 2010;103(8):233-5.
265. Alemayehu E, Molloy DW, Guyatt GH, Singer J, Penington G, Basile J, et al. Variability in physicians' decisions on caring for chronically ill elderly patients: an international study. CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne. 1991;144(9):1133-8.
266. Periyakoil VS, Neri E, Fong A, Kraemer H. Do Unto Others: Doctors' Personal End-of-Life Resuscitation Preferences and Their Attitudes toward Advance Directives. PloS one. 2014;9(5):e98246.
267. Coleman AME. Physician Attitudes Toward Advanced Directives: A Literature Review of Variables Impacting on Physicians Attitude Toward Advance Directives. American Journal of Hospice and Palliative Medicine. 2013;30(7):696-706.
268. Bond CJ, Lowton K. Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study. Age and ageing. 2011;40(4):450-6.
269. Brunetti LL, Carperos SD, Westlund RE. Physicians' attitudes towards living wills and cardiopulmonary resuscitation. Journal of general internal medicine. 1991;6(4):323-9.
270. Lee J, Kim KH. Perspectives of korean patients, families, physicians and nurses on advance directives. Asian nursing research. 2010;4(4):185-93.
271. Schiff R, Sacares P, Snook J, Rajkumar C, Bulpitt CJ. Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians. Age and ageing. 2006;35(2):116-21.
272. Gina KGG, Fukushima E, Abu-Laban RB, Sweet DD. Prevalence of advance directives among elderly patients attending an urban Canadian emergency department. Cjem. 2012;14(2):90-6.
273. Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. American journal of preventive medicine. 2014;46(1):65-70.
274. Johnson RW, Zhao Y, Kristin Newby L, Granger CB, Granger BB. Reasons for noncompletion of advance directives in a cardiac intensive care unit. Am J Crit Care. 2012;21(5):311-20.
275. Boddy J, Chenoweth L, McLennan V, Daly M. It's just too hard! Australian health care practitioner perspectives on barriers to advance care planning. Aust J Prim Health. 2013;19(1):38-45.

276. Putman-Casdorph H, Drenning C, Richards S, Messenger K. Advance directives: evaluation of nurses' knowledge, attitude, confidence, and experience. Journal of nursing care quality. 2009;24(3):250-6.
277. Yee A, Seow YY, Tan SH, Goh C, Qu L, Lee G. What do renal health-care professionals in Singapore think of advance care planning for patients with end-stage renal disease? Nephrology (Carlton). 2011;16(2):232-8.
278. Go RS, Hammes BA, Lee JA, Mathiason MA. Advance directives among health care professionals at a community-based cancer center. Mayo Clinic proceedings. 2007;82(12):1487-90.
279. Lester PE, Sykora A, Wolf-Klein GP, Pekmezaris R, Auerbach C, Feuerman M. Do geriatricians practice what they preach?: Geriatricians' personal establishment of advance directives. Gerontol Geriatr Educ. 2009;30(1):61-74.
280. Orlander JD. Use of Advance Directives by Health Care Workers and Their Families. Southern medical journal. 1999;92(5):481-4.
281. Irish Medical Council. Medical Workforce Intelligence Report. Dublin, available at https://www.medicalcouncil.ie/News-and-Publications/Reports/Medical-Workforce-Intelligence-Report-2015.html: Irish Medical Council, ; 2015.
282. Flynn KE, Smith MA, Freese J. When Do Older Adults Turn to the Internet for Health Information? Findings from the Wisconsin Longitudinal Study. Journal of general internal medicine. 2006;21(12):1295-301.
283. Schwartz KL, Roe T, Northrup J, Meza J, Seifeldin R, Neale AV. Family medicine patients' use of the Internet for health information: a MetroNet study. The Journal of the American Board of Family Medicine. 2006;19(1):39-45.
284. Parry R, Land V, Seymour J. How to communicate with patients about future illness progression and end of life: a systematic review. BMJ Supportive & Palliative Care. 2014;4(4):331-41.
285. Gordon NP, Shade SB. ADvance directives are more likely among seniors asked about end-of-life care preferences. Archives of internal medicine. 1999;159(7):701-4.
286. Musa I, Seymour J, Narayanasamy MJ, Wada T, Conroy S. A survey of older peoples' attitudes towards advance care planning. Age and ageing. 2015;44(3):371-6.
287. Cornally N, McGlade C, Weathers E, Daly E, Fitzgerald C, O'Caoimh R, et al. Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staff perspectives. BMC palliative care. 2015;14:55.
288. Charlton R, Currie A. A UK perspective on worldwide inadequacies in palliative care training: a short postgraduate course is proposed. The American journal of hospice & palliative care. 2008;25(1):63-71.
289. Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. Palliative medicine. 2002;16(6):457-64.
290. Schmit JM, Meyer LE, Duff JM, Dai Y, Zou F, Close JL. Perspectives on death and dying: a study of resident comfort with End-of-life care. BMC medical education. 2016;16(1):297.
291. Frey R, Boyd M, Foster S, Robinson J, Gott M. Necessary but not yet sufficient: a survey of aged residential care staff perceptions of palliative care communication, education and delivery. Bmj Supportive & Palliative Care. 2016;6(4):465-73.
292. Singer AE, Meeker D, Teno JM, Lynn J, Lunney JR, Lorenz KA. Symptom trends in the last year of life from 1998 to 2010: a cohort study. Annals of internal medicine. 2015;162(3):175-83.
293. Weafer J. A nationwide survey of public attitudes and experiences regarding death and dying. . Dublin: The Irish Hospice Foundation supported by the Health Services National Partnership Forum; 2004.

294. McDonnell MM, McGuigan E, McElhinney J, McTeggart M, McClure D. An analysis of the palliative care education needs of RGNs and HCAs in nursing homes in Ireland. International journal of palliative nursing. 2009;15(9):446, 8-55.
295. Shipman C, Addington-Hall J, Barclay S, Briggs J, Cox I, Daniels L, et al. Educational opportunities in palliative care: what do general practitioners want? Palliative medicine. 2001;15(3):191-6.
296. van de Geer J, Groot M, Andela R, Leget C, Prins J, Vissers K, et al. Training hospital staff on spiritual care in palliative care influences patient-reported outcomes: Results of a quasi-experimental study. Palliative medicine. 2017;31(8):743-53.
297. Lever JA, Molloy DW, Eisenmann M, McMurdo ME, Finucane P, Guyatt GH, et al. Variability in nurses' decisions about the care of chronically ill elderly patients: an international study. Humane medicine. 1992;8(2):138-44.
298. Dowling S, Broomfield D. Undergraduate teaching in palliative care in Irish medical schools: a questionnaire survey. Medical education. 2003;37(5):455-7.
299. Fitzpatrick D, Heah R, Patten S, Ward H. Palliative Care in Undergraduate Medical Education—How Far Have We Come? American Journal of Hospice and Palliative Medicine®. 2017;34(8):762-73.
300. Sweeney C, Lynch G, Khashan A, Maher B, Murphy M, O'brien T. The impact of a medical undergraduate student-selected module in palliative care. BMJ supportive & palliative care. 2014;4(1):92-7.
301. Frey R, Gott M, Raphael D, O'Callaghan A, Robinson J, Boyd M, et al. Clinical staff perceptions of palliative care-related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting. BMJ Support Palliat Care. 2014;4(4):381-9.
302. Brazil K, Brink P, Kaasalainen S, Kelly ML, McAiney C. Knowledge and perceived competence among nurses caring for the dying in long-term care homes. International journal of palliative nursing. 2012;18(2):77-83.
303. Henderson A, Rowe J, Watson K, Hitchen-Holmes D. Graduating nurses' self-efficacy in palliative care practice: An exploratory study. Nurse education today. 2016;39:141-6.
304. Al Qadire M. Nurses' knowledge about palliative care: A cross-sectional survey. J Hospice Palliative Nurs. 2014;16(1):23-30.
305. Weil J, Gold M, McIver S, Rotstein L, Philip J. Australian resident doctors want more palliative medicine education: a survey of attitudes and perceived needs. Internal medicine journal. 2012;42(7):828-30.
306. Charlton R, Smith G. Perceived skills in palliative medicine of newly qualified doctors in the UK. Journal of palliative care. 2000;16(4):27.
307. Head BA, Schapmire TJ, Earnshaw L, Chenault J, Pfeifer M, Sawning S, et al. Improving medical graduates' training in palliative care: advancing education and practice. Advances in medical education and practice. 2016;7:99.
308. Dowling S, Leary A, Broomfield D. Education in palliative care: a questionnaire survey of Irish general practitioner trainees. Education for Primary Care. 2005;16(1):42-50.
309. Nakazawa Y, Yamamoto R, Kato M, Miyashita M, Kizawa Y, Morita T. Improved knowledge of and difficulties in palliative care among physicians during 2008 and 2015 in Japan: Association with a nationwide palliative care education program. Cancer. 2018;124(3):626-35.
310. Mason SR, Ellershaw JE. Undergraduate training in palliative medicine: is more necessarily better? Palliative medicine. 2010;24(3):306-9.
311. Peh TY, Yang GM, Krishna LKR, Yee ACP. Do Doctors Gain More Confidence from a Longer Palliative Medicine Posting? Journal of palliative medicine. 2017;20(2):141-6.

312. Price S, Schofield S. How do junior doctors in the UK learn to provide end of life care: a qualitative evaluation of postgraduate education. BMC palliative care. 2015;14(1):45.
313. Vergo MT, Sachs S, MacMartin MA, Kirkland KB, Cullinan AM, Stephens LA. Acceptability and impact of a required palliative care rotation with prerotation and postrotation observed simulated clinical experience during internal medicine residency training on primary palliative communication skills. Journal of palliative medicine. 2017;20(5):542-7.
314. von Gunten CF. Arrogance ignorance paradox. Journal of palliative medicine. 2005;8(5):898-9.
315. Emanuel L, Ferris F, von Gunten C, Von Roenn J. EPECO: Education in palliative and endoflife care for oncology.© The EPEC Project,™ Chicago. IL; 2005.
316. von Gunten CF. Interventions to manage symptoms at the end of life. Journal of palliative medicine. 2005;8 Suppl 1:S88-94.
317. Frey R, Gott M, Banfield R, Campbell T. What questionnaires exist to measure the perceived competence of generalists in palliative care provision? A critical literature review. BMJ Support Palliat Care. 2011;1(1):19-32.
318. Pulsford D, Jackson G, O'Brien T, Yates S, Duxbury J. Classroom-based and distance learning education and training courses in end-of-life care for health and social care staff: a systematic review. Palliative medicine. 2013;27(3):221-35.
319. Long AC, Downey L, Engelberg RA, Ford DW, Back AL, Curtis JR. Physicians' and Nurse Practitioners' Level of Pessimism About End-of-Life Care During Training: Does It Change Over Time? Journal of pain and symptom management. 2016;51(5):890-7. e1.
320. Fosse A, Ruths S, Malterud K, Schaufel MA. Doctors' learning experiences in end-of-life care - a focus group study from nursing homes. BMC Med Educ. 2017;17(1):27.
321. Daly BJ, Douglas SL, O'Toole E, Rowbottom J, Hoffer A, Lipson AR, et al. Complexity Analysis of Decision-Making in the Critically Ill. Journal of intensive care medicine. 2016:0885066616678394.
322. Ntantana A, Matamis D, Savvidou S, Marmanidou K, Giannakou M, Gouva M, et al. The impact of healthcare professionals' personality and religious beliefs on the decisions to forego life sustaining treatments: an observational, multicentre, cross-sectional study in Greek intensive care units. BMJ open. 2017;7(7):e013916.
323. Executive HS. Our People Our Workforce. http://www.hse.ie/eng/staff/Resources/Our-Workforce/Our-People-Our-Workforce-December-2016-.pdf); 2016.
324. Molloy DW, Guyatt GH. A comprehensive health care directive in a home for the aged. CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne. 1991;145(4):307-11.
325. Meller AE, Caplan GA. Let someone else decide?: Development of an advance care planning service for nursing home residents with advanced dementia. Dementia. 2009;8(3):391-405.
326. Teno JM. Advance directives for nursing home residents: achieving compassionate, competent, cost-effective care. JAMA : the journal of the American Medical Association. 2000;283(11):1481-2.
327. McGlade C, Molloy D, Timmons S. Decision-Making in Incompetent Older Adults: Clinical, Social and Legal Issues. Medico-Legal Journal of Ireland. 2011;17(2):70-5.
328. Law Reform Commission. Consultation Paper, Bioethics: Advance Care Directives (LRC CP 51 - 2008),. Dublin; 2008.
329. Houses of the Oireachtas. Assisted Decision-Making (Capacity) Bill 2013 as initiated and Explanatory Memorandum

http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/document1.htm: http://www.oireachtas.ie/; 2013 [
330. Assisted Decision-Making (Capacity) Act 2015 (No. 64), Houses of the Oireachtas(2015).
331. Department of Justice and Equality. Assisted Decision-Making (Capacity) Act 2015 http://www.justice.ie/en/JELR/Pages/Assisted_Decision-Making_(Capacity)_Act_20152016 [Available from: http://www.justice.ie/en/JELR/Pages/Assisted_Decision-Making_(Capacity)_Act_2015.
332. Bioethics. TICf. Is it Time for Advance Healthcare Directives? Opinion,. Dublin2007.
333. An tSéirbhís Chúirteanna na hÉireann - The Courts Service of Ireland. Courts Service Annual Report. Dublin: The Courts Service,; 2016.
334. Irish Medical Council. Guide to Professional Conduct and Ethics for Registered Medical Practitioners. 7th ed. Dublin2009.
335. In the matter of a Ward of Court (withhoding medical treatment) (no. 2) 2 I.R. 79,. High Court; 1996.
336. Sheikh A. Older People: Consent, Do Not Resuscitate Orders and Medical Research. In: O'Dell E, editor. Older People in Modern Ireland: Essays on Law and Policy. Dublin: First Law; 2006. p. 222.
337. Commission TLR. Consultation Paper on Law and the Elderly (LRC CP 23-2003). 2003.
338. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975;12(3):189-98.
339. Molloy DW, Alemayehu E, Roberts R. Reliability of a Standardized Mini-Mental State Examination compared with the traditional Mini-Mental State Examination. The American journal of psychiatry. 1991;148(1):102-5.
340. Molloy DW, Silberfeld M, Darzins P, Guyatt GH, Singer PA, Rush B, et al. Measuring capacity to complete an advance directive. Journal of the American Geriatrics Society. 1996;44(6):660-4.
341. Hallberg IR. Death and dying from old people's point of view. A literature review. Aging clinical and experimental research. 2004;16(2):87-103.
342. Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. International psychogeriatrics / IPA. 2013;25(12):2011-21.
343. Mathie E, Goodman C, Crang C, Froggatt K, Iliffe S, Manthorpe J, et al. An uncertain future: the unchanging views of care home residents about living and dying. Palliative medicine. 2012;26(5):734-43.
344. Fleming J, Farquhar M, Brayne C, Barclay S. Death and the Oldest Old: Attitudes and Preferences for End-of-Life Care--Qualitative Research within a Population-Based Cohort Study. PloS one. 2016;11(4):e0150686.
345. Carrese JA, Mullaney JL, Faden RR, Finucane TE. Planning for death but not serious future illness: qualitative study of housebound elderly patients. BMJ : British Medical Journal. 2002;325(7356):125-.
346. Resnick B, Andrews C. End-of-life treatment preferences among older adults: a nurse practitioner initiated intervention. Journal of the American Academy of Nurse Practitioners. 2002;14(11):517-22.
347. Silvester W, Parslow RA, Lewis VJ, Fullam RS, Sjanta R, Jackson L, et al. Development and evaluation of an aged care specific Advance Care Plan. BMJ Support Palliat Care. 2013;3(2):188-95.

348. Morrison RS, Chichin E, Carter J, Burack O, Lantz M, Meier DE. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. Journal of the American Geriatrics Society. 2005;53(2):290-4.
349. UK Department of Health. End of Life Care Strategy:Promoting high quality care for adults at the end of their life. http://www.dh.gov.uk/; 2008.
350. Hertogh CM. Advance care planning and the relevance of a palliative care approach in dementia. Age and ageing. 2006;35(6):553-5.
351. Vandervoort A, Houttekier D, Vander Stichele R, van der Steen JT, Van den Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. PloS one. 2014;9(3):e91130.
352. McKeown K, Haase T, Twomey S. Resources and Facilities for End-of-Life Care in Hospitals in Ireland. Report 1. Dublin: Irish Hospice Foundation; 2010.
353. Hays JC, Galanos AN, Palmer TA, McQuoid DR, Flint EP. Preference for Place of Death in a Continuing Care Retirement Community. The Gerontologist. 2001;41(1):123-8.
354. Cahill S, Diaz-Ponce AM, Coen RF, Walsh C. The underdetection of cognitive impairment in nursing homes in the Dublin area. The need for on-going cognitive assessment. Age and ageing. 2010;39(1):128-31.
355. National Audit Office Report. . End of life care. http://www.nao.org.uk/ 2008.
356. Sachs GA, Stocking CB, Miles SH. Empowerment of the older patient? A randomized, controlled trial to increase discussion and use of advance directives. Journal of the American Geriatrics Society. 1992;40(3):269-73.
357. Molloy D. Let Me Decide. First Edition ed. Waterford, Ireland.: Newgrange press Ltd. ; 2011.
358. Wickson-Griffiths A, Kaasalainen S, Ploeg J, McAiney C. A review of advance care planning programs in long-term care homes: are they dementia friendly? Nurs Res Pract. 2014;2014:875897.
359. Health Service Executive National Consent Advisory Group. National Consent Policy. http://www.hse.ie/ Health Service Executive,; 2014.
360. Molinari V, McCollough LB, Workman R, Coverdale J. Geriatric assent. The Journal of clinical ethics. 2004;15(3):261-8.
361. Beauchamp TL, Childress JF. Principles of biomedical ethics: Oxford university press; 2001.
362. Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and ageing. 2012;41(2):263-9.
363. Dening KH, Jones L, Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. Palliative medicine. 2013;27(5):409-17.
364. Wittink MN, Morales KH, Meoni LA, Ford DE, Wang NY, Klag MJ, et al. Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins Precursors Study. Archives of internal medicine. 2008;168(19):2125-30.
365. Cornally N MC, Weathers E, Daly E, Fitzgerald C, O'Caoimh R, Coffey A, Molloy DW. Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: A user's perspective. Submitted BMC Palliative Care 2015, in press.
366. De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, et al. Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. Scandinavian Journal of Primary Health Care. 2013;31(4):215-26.

367. Finucane TE, Beamer BA, Roca RP, Kawas CH. Establishing advance medical directives with demented patients: a pilot study. The Journal of clinical ethics. 1993;4(1):51-4.
368. Spoelhof GD, Elliott B. Implementing advance directives in office practice. Am Fam Physician. 2012;85(5):461-6.
369. Seymour J, Almack K, Kennedy S. Implementing advance care planning: a qualitative study of community nurses' views and experiences. BMC palliative care. 2010;9:4.
370. Silvester W, Fullam RS, Parslow RA, Lewis VJ, Sjanta R, Jackson L, et al. Quality of advance care planning policy and practice in residential aged care facilities in Australia. BMJ Support Palliat Care. 2013;3(3):349-57.
371. Jeong SY, Higgins I, McMillan M. The essentials of Advance Care Planning for end-of-life care for older people. Journal of clinical nursing. 2010;19(3-4):389-97.
372. Billings JA. The need for safeguards in advance care planning. Journal of general internal medicine. 2012;27(5):595-600.
373. Sampson EL, Burns A. Planning a personalised future with dementia: 'the misleading simplicity of advance directives'. Palliative medicine. 2013;27(5):387-8.
374. Ryan D, Jezewski MA. Knowledge, Attitudes, Experiences, and Confidence of Nurses in Completing Advance Directives: A Systematic Synthesis of Three Studies. Journal of Nursing Research. 2012;20(2):131-41.
375. Molloy DW, Bedard M, Guyatt GH, Patterson C, North J, Jubelius R, et al. Attitudes training issues and barriers for community nurses implementing an advance directive program. Perspectives. 1997;21(1):2-8.
376. Syrett K. Health Care Resource Allocation Issues in Dementia. In: Foster C, Herring, J., Doron, I.,, editor. The Law and Ethics of Dementia. Oregon: Oxford and Portland; 2014. p. 421-33.
377. Weissman DE. Decision making at a time of crisis near the end of life. JAMA : the journal of the American Medical Association. 2004;292(14):1738-43.
378. Weathers E, O'Caoimh R, Cornally N, Fitzgerald C, Kearns T, Coffey A, et al. Advance care planning: a systematic review of randomised controlled trials conducted with older adults. Maturitas.
379. Maev-Ann Wren CK, Brendan Walsh, Adele Bergin, James Eighan, Aoife Brick, Sheelah Connolly, Dorothy Watson, Joanne Banks PROJECTIONS OF DEMAND FOR HEALTHCARE IN IRELAND, 2015-2030: FIRST REPORT FROM THE HIPPOCRATES MODEL. ESRI, Whitaker Square, Sir John Rogerson's Quay, Dublin 2:

Economic and Social Research Institute

; 2017.
380. Hunt R MI. Terminal care in South Australia: historiacal aspects and equity issues. . In: Clark D HJ, Ahmedzai S, editor. Facing Death- New Themes in Palliative Care Buckingham: Open University Press; 1997. p. 101-5.
381. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ : British Medical Journal. 2002;324(7342):905-7.
382. Yang L, Sakamoto N, Marui E. A study of home deaths in Japan from 1951 to 2002. BMC palliative care. 2006;5:2.
383. Gomes B, Higginson IJ. Where people die (1974-2030): Past trends, future projections and implications for care. Palliative medicine. 2008;22(1):33-41.
384. McKeown K. National Audit of End-of-Life Care in Hospitals in Ireland 2008/9 & 2011/12 The Manual. Dublin: Hospice Friendly Hospitals; 2008.

385. Kristjanson LJ, Walton J, Toye C. End-of-life challenges in residential aged care facilities: a case for a palliative approach to care. International journal of palliative nursing. 2005;11(3):127-9.
386. Ersek M, Carpenter JG. Geriatric palliative care in long-term care settings with a focus on nursing homes. Journal of palliative medicine. 2013;16(10):1180-7.
387. Brazil K, Bédard M, Krueger P, Taniguchi A, Kelley ML, McAiney C, et al. Barriers to providing palliative care in long-term care facilities. Canadian Family Physician. 2006;52(4):472-3.
388. Ersek M, Kraybill BM, Hansberry J. Assessing the educational needs and concerns of nursing home staff regarding end-of-life care. Journal of gerontological nursing. 2000;26(10):16-26.
389. Lee J, Cheng J, Au KM, Yeung F, Leung MT, Ng J, et al. Improving the quality of end-of-life care in long-term care institutions. Journal of palliative medicine. 2013;16(10):1268-74.
390. Watson J, Hockley J, Dewar B. Barriers to implementing an integrated care pathway for the last days of life in nursing homes. International journal of palliative nursing. 2006;12(5):234-40.
391. Whittaker E, George Kernohan W, Hasson F, Howard V, McLaughlin D. Palliative care in nursing homes: exploring care assistants' knowledge. International journal of older people nursing. 2007;2(1):36-44.
392. Kaasalainen S, Brazil K, Ploeg J, Martin LS. Nurses perceptions around providing palliative care for long-term care residents with dementia. Journal of palliative care. 2007;23(3):173-80.
393. Katz J, Sidell M, Komaromy C. Death in homes: bereavement needs of residents, relatives and staff. International journal of palliative nursing. 2000;6(6):274-9.
394. Brazil K, Vohra JU. Identifying educational needs in end-of-life care for staff and families of residents in care facilities. International journal of palliative nursing. 2005;11(9):475-80.
395. Ersek M, Kraybill BM, Hansberry J. Investigating the educational needs of licensed nursing staff and certified nursing assistants in nursing homes regarding end-of-life care. American Journal of Hospice and Palliative Medicine. 1999;16(4):573-82.
396. Wlodkowski RJ. Strategies to enhance adult motivation to learn. In: Galbraith MW, editor. Adult learning methods. Malabar: Krieger Publishing; 1990. p. 97-118.
397. Froggatt K. Evaluating a palliative care education project in nursing homes. International journal of palliative nursing. 2000;6(3):140-6.
398. Friedrichsen M, Heedman PA, Åstradsson E, Jakobsson M, Milberg A. Does a half-day course about palliative care matter? A quantitative and qualitative evaluation among health care practitioners. Journal of palliative medicine. 2013;16(5):496-501.
399. Letizia M, Jones T. An educational intervention for nurse practitioners providing palliative care in nursing homes. J Hospice Palliative Nurs. 2012;14(5):351-7.
400. Silverdale N, Katz J. The impact of a distance learning death and dying course: an analysis of student self-reported changes. Nurse education today. 2005;25(7):509-18.
401. Zyga S, Malliarou M, Lavdaniti M, Athanasopoulou M, Sarafis P. Greek renal nurses' attitudes towards death. J Ren Care. 2011;37(2):101-7.
402. Peters L, Cant R, Payne S, O'Connor M, McDermott F, Hood K, et al. How death anxiety impacts nurses' caring for patients at the end of life: a review of literature. Open Nurs J. 2013;7:14-21.
403. Patterson C, Molloy W, Jubelius R, Guyatt GH, Bédard M. Provisional educational needs of health care providers in palliative care in three nursing homes in Ontario. Journal of palliative care. 1997;13(3):13-7.

404. Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, et al. Palliative care competence framework 2014: Health Service Executive (HSE); 2014.
405. Molloy DW, Russo R, Pedlar D, Bedard M. Implementation of advance directives among community-dwelling veterans. The Gerontologist. 2000;40(2):213-7.
406. Eriksson G, Bergstedt TW, Melin-Johansson C. The need for palliative care education, support, and reflection among rural nurses and other staff: A quantitative study. Palliative Supportive Care. 2015;13(2):265-74.
407. Curry C, Middleton H, Brown B. Palliative care training. Nursing older people. 2009;21(9):18-23.
408. Avis M, Jackson JG, Cox K, Miskella C. Evaluation of a project providing community palliative care support to nursing homes. Health Soc Care Community. 1999;7(1):32-8.
409. Zimmerman S, Sloane PD, Hanson L, Mitchell CM, Shy A. Staff perceptions of end-of-life care in long-term care. Journal of the American Medical Directors Association. 2003;4(1):23-6.
410. Quint JC. The nurse and the dying patient: Macmillan; 1967.
411. Wilkes E. Report of the Working Group on Terminal Care of the Standing Sub-Committee on Cancer. London: Her Majesty's Stationary Office. 1980.
412. Field D, Kitson C. Formal teaching about death and dying in UK nursing schools. Nurse education today. 1986;6(6):270-6.
413. Doyle D. Education and training in palliative care. Journal of palliative care. 1987;2(2):5-7.
414. Dickinson GE. Teaching end-of-life issues in US medical schools: 1975 to 2005. The American journal of hospice & palliative care. 2006;23(3):197-204.
415. Dickinson GE, Field D. Teaching end-of-life issues: current status in United Kingdom and United States medical schools. The American journal of hospice & palliative care. 2002;19(3):181-6.
416. Lloyd-Williams M, Field D. Are undergraduate nurses taught palliative care during their training? Nurse education today. 2002;22(7):589-92.
417. Dickinson GE, Clark D, Sque M. Palliative care and end of life issues in UK pre-registration, undergraduate nursing programmes. Nurse education today. 2008;28(2):163-70.
418. Potter G, Pesut B, Hooper BP, Erbacker L. Team-based education in a palliative approach for rural nurses and unlicensed care providers. J Contin Educ Nurs. 2015;46(6):279-88.
419. Pelayo-Alvarez M, Perez-Hoyos S, Agra-Varela Y. Clinical Effectiveness of Online Training in Palliative Care of Primary Care Physicians. Journal of palliative medicine. 2013;16(10):1188-96.
420. Travers A, Taylor V. What are the barriers to initiating end-of-life conversations with patients in the last year of life? International journal of palliative nursing. 2016;22(9):454-62.
421. Albers G, Francke AL, de Veer AJ, Bilsen J, Onwuteaka-Philipsen BD. Attitudes of nursing staff towards involvement in medical end-of-life decisions: a national survey study. Patient education and counseling. 2014;94(1):4-9.
422. Kotter JP. Leading change: Harvard Business Press; 1996.
423. Pesut B, Potter G, Stajduhar K, Sawatzky R, McLeod B, Drabot K. Palliative approach education for rural nurses and health-care workers: A mixed-method study. International journal of palliative nursing. 2015;21(3):142-51.
424. Bowling A, Banister D, Sutton S, Evans O, Windsor J. A multidimensional model of the quality of life in older age. Aging & mental health. 2002;6(4):355-71.

425. Kane RA, Kling KC, Bershadsky B, Kane RL, Giles K, Degenholtz HB, et al. Quality of life measures for nursing home residents. The journals of gerontology Series A, Biological sciences and medical sciences. 2003;58(3):240-8.
426. Reed J, Cook, G., Burridge, C.,. Loss and change. In: Hockley J, Clark, D.,, editor. Facing Death: Palliative Care for Older People in Care Homes. Buckingham: Open University Press; 2002.
427. Tester S, Hubbard, G., Downs, M., MacDonald, C., Murphy, J.,. Frailty and institutional life. Walker A, Hagan Hennessy, C.,, editor. Berkshire: Open University Press; 2004.
428. Cahill S, Diaz-Ponce AM. 'I hate having nobody here. I'd like to know where they all are': Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? Aging & mental health. 2011;15(5):562-72.
429. Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, et al. A systematic review of measures of end-of-life care and its outcomes. Health Serv Res. 2007;42(5):1848-70.
430. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Annals of internal medicine. 2000;132(10):825-32.
431. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. JAMA: The Journal of the American Medical Association. 2000;284(19):2476-82.
432. Steinhauser KE, Bosworth HB, Clipp EC, McNeilly M, Christakis NA, Parker J, et al. Initial assessment of a new instrument to measure quality of life at the end of life. Journal of palliative medicine. 2002;5(6):829-41.
433. Van Soest-Poortvliet MC, Van Der Steen JT, Zimmerman S, Cohen LW, Munn J, Achterberg WP, et al. Measuring the quality of dying and quality of care when dying in long-term care settings: A qualitative content analysis of available instruments. Journal of pain and symptom management. 2011;42(6):852-63.
434. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. Journal of pain and symptom management. 1999;17(2):93-108.
435. Donabedian A. Evaluating the quality of medical care. The Milbank memorial fund quarterly. 1966;44(3):166-206.
436. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. Journal of pain and symptom management. 2001;22(3):717-26.
437. Patrick DL, Danis M, Southerland LI, Hong G. Quality of life following intensive care. Journal of general internal medicine. 1988;3(3):218-23.
438. Cahill S, Doran D, Watson M. Guidelines for nursing homes delivering end-of-life care to residents with dementia across the island of Ireland. Quality in Ageing and Older Adults. 2012;13(1):60-71.
439. Cottrell L, Duggleby W. The good death: An integrative literature review. Palliative Supportive Care. 2016;14(6):686-712.
440. Goldsteen M, Houtepen R, Proot IM, Abu-Saad HH, Spreeuwenberg C, Widdershoven G. What is a good death? Terminally ill patients dealing with normative expectations around death and dying. Patient education and counseling. 2006;64(1-3):378-86.
441. Kellehear A. A social history of dying. Cambridge. 2007;21:36.
442. Granda-Cameron C, Houldin A. Concept Analysis of Good Death in Terminally Ill Patients. American Journal of Hospice and Palliative Medicine. 2012.

443. Addington-Hall J, Kalra L. Who should measure quality of life? BMJ. 2001;322(7299):1417-20.
444. Teno JM. Measuring end-of-life care outcomes retrospectively. Journal of palliative medicine. 2005;8 Suppl 1:S42-9.
445. Mulqueen K, Coffey A. Preferences of residents with dementia for end of life care. Nursing older people. 2017;29(2):26-30.
446. Cooney A. 'Finding home': a grounded theory on how older people 'find home' in long-term care settings. International journal of older people nursing. 2012;7(3):188-99.
447. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. Palliative medicine. 2004;18(5):460-7.
448. Higginson IJ, Sarmento VP, Calanzani N, Benalia H, Gomes B. Dying at home--is it better: a narrative appraisal of the state of the science. Palliative medicine. 2013;27(10):918-24.
449. Townsend J, Frank A, Fermont D, Dyer S, Karran O, Walgrove A, et al. Terminal cancer care and patients' preference for place of death: a prospective study. Bmj. 1990;301(6749):415-7.
450. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? Palliative medicine. 1994;8(3):183-96.
451. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC palliative care. 2013;12:7.
452. Masson JD. Non-professional perceptions of 'good death': a study of the views of hospice care patients and relatives of deceased hospice care patients. Mortality. 2002;7(2):191-209.
453. Miyahara S. A study of dying in a special nursing home for the elderly. Japanese Journal of Primary Care. 1999;22:41-8.
454. Takezako Y, Tamiya N, Kajii E. The nursing home versus the hospital as the place of dying for nursing home residents in Japan. Health Policy. 2007;81(2):280-8.
455. Chu LW, Luk JK, Hui E, Chiu PK, Chan CS, Kwan F, et al. Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong. Journal of the American Medical Directors Association. 2011;12(2):143-52.
456. Hales S, Zimmermann C, Rodin G. The quality of dying and death. Archives of internal medicine. 2008;168(9):912-8.
457. Addington-Hall J, McPherson C. After-death interviews with surrogates/bereaved family members: some issues of validity. Journal of pain and symptom management. 2001;22(3):784-90.
458. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet. 1998;351 Suppl 2:SII21-9.
459. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. Palliative medicine. 1996;10(4):307-12.
460. Caprio AJ, Hanson LC, Munn JC, Williams CS, Dobbs D, Sloane PD, et al. Pain, dyspnea, and the quality of dying in long-term care. Journal of the American Geriatrics Society. 2008;56(4):683-8.
461. Teno J. Time: Toolkit of Instruments to Measure End-of-Life Care Center for Gerontology and Health Care Research, Brown Medical School. Available at http://www.chcr.brown.edu/pcoc/toolkit.htm2005 [
462. Albers G, Echteld MA, de Vet HC, Onwuteaka-Philipsen BD, van der Linden MH, Deliens L. Evaluation of quality-of-life measures for use in palliative care: a systematic review. Palliative medicine. 2010;24(1):17-37.
463. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. Palliative medicine. 1995;9(3):207-19.

464. Hales S, Zimmermann C, Rodin G. Review: the quality of dying and death: a systematic review of measures. Palliative medicine. 2010;24(2):127-44.
465. Hearn J, Higginson I. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Quality and Safety in Health Care. 1999;8(4):219-27.
466. Bausewein C, Fegg M, Radbruch L, Nauck F, von Mackensen S, Borasio GD, et al. Validation and clinical application of the german version of the palliative care outcome scale. Journal of pain and symptom management. 2005;30(1):51-62.
467. Bausewein C, Le Grice C, Simon S, Higginson I, Prisma. The use of two common palliative outcome measures in clinical care and research: a systematic review of POS and STAS. Palliative medicine. 2011;25(4):304-13.
468. Higginson IJ, Hart S, Silber E, Burman R, Edmonds P. Symptom prevalence and severity in people severely affected by multiple sclerosis. Journal of palliative care. 2006;22(3):158.
469. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. Health and quality of life outcomes. 2010;8(1):10.
470. Brandt HE, Deliens L, van der Steen JT, Ooms ME, Ribbe MW, van der Wal G. The last days of life of nursing home patients with and without dementia assessed with the palliative care outcome scale. Palliative medicine. 2005;19(4):334-42.
471. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. Journal of pain and symptom management. 2002;24(1):17-31.
472. Portenoy RK, Thaler HT, Kornblith AB, Lepore JM, Friedlander-Klar H, Kiyasu E, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer. 1994;30(9):1326-36.
473. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of End-of-Life Care in Dementia. Alzheimer disease and associated disorders. 2001;15(4):194-200.
474. Casarett D, Pickard A, Bailey FA, Ritchie CS, Furman CD, Rosenfeld K, et al. A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. Journal of palliative medicine. 2008;11(1):68-75.
475. Vohra JU, Brazil K, Hanna S, Abelson J. Family perceptions of end-of-life care in long-term care facilities. Journal of palliative care. 2004;20(4):297-302.
476. Biola H, Sloane PD, Williams CS, Daaleman TP, Williams SW, Zimmerman S. Physician communication with family caregivers of long-term care residents at the end of life. Journal of the American Geriatrics Society. 2007;55(6):846-56.
477. Steel K, Ljunggren G, Topinková E, Morris JN, Vitale C, Parzuchowski J, et al. The RAI-PC: An assessment instrument for palliative care in all settings. American Journal of Hospice and Palliative Medicine. 2003;20(3):211-9.
478. Aminoff BZ, Purits E, Noy S, Adunsky A. Measuring the suffering of end-stage dementia: reliability and validity of the Mini-Suffering State Examination. Archives of gerontology and geriatrics. 2004;38(2):123-30.
479. Munn JC, Zimmerman S, Hanson LC, Williams CS, Sloane PD, Clipp EC, et al. Measuring the quality of dying in long-term care. Journal of the American Geriatrics Society. 2007;55(9):1371-9.
480. Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J. Validation of Toolkit After-Death Bereaved Family Member Interview. Journal of pain and symptom management. 2001;22(3):752-8.
481. Martyn CN, Pippard EC. Usefulness of mortality data in determining the geography and time trends of dementia. Journal of Epidemiology & Community Health. 1988;42(2):134-7.

482. Ganguli M, Rodriguez EG. Reporting of dementia on death certificates: a community study. Journal of the American Geriatrics Society. 1999;47(7):842-9.
483. Raiford K, Anton-Johnson S, Haycox Z, Nolan K, Schaffer A, Caimano C, et al. CERAD: VII. Accuracy of reporting dementia on death certificates of patients with Alzheimer's disease. Neurology. 1994.
484. Romero JP, Benito-León J, Louis ED, Bermejo-Pareja F. Under reporting of dementia deaths on death certificates: a systematic review of population-based cohort studies. Journal of Alzheimer's Disease. 2014;41(1):213-21.
485. Wenger NS, Oye RK, Bellamy PE, Lynn J, Phillips RS, Desbiens NA, et al. Prior capacity of patients lacking decision making ability early in hospitalization: implications for advance directive administration. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Journal of general internal medicine. 1994;9(10):539-43.
486. Drought TS, Koenig BA. "Choice" in end-of-life decision making: Researching fact or fiction? The Gerontologist. 2002;42(SPEC. ISS. 3):114-28.
487. Addington-Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM, et al. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. BMJ. 1992;305(6865):1317-22.
488. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Social Science & Medicine. 2003;56(1):95-109.
489. Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. Journal of clinical epidemiology. 1992;45(7):743-60.
490. Waldenström U, Schytt E. A longitudinal study of women's memory of labour pain—from 2 months to 5 years after the birth. BJOG: An International Journal of Obstetrics & Gynaecology. 2009;116(4):577-83.
491. Clipp EC, George LK. Patients with cancer and their spouse caregivers. Perceptions of the illness experience. Cancer. 1992;69(4):1074-9.
492. Rothman ML, Hedrick SC, Bulcroft KA, Hickam DH, Rubenstein LZ. The validity of proxy-generated scores as measures of patient health status. Medical care. 1991;29(2):115-24.
493. Lendon JP, Ahluwalia SC, Walling AM, Lorenz KA, Oluwatola OA, Price RA, et al. Measuring experience with end-of-life care: a systematic literature review. Journal of pain and symptom management. 2015;49(5):904-15. e3.
494. Parkes CM. Bereavement: Studies of Grief in Adult Life. 1972.
495. Casarett DJ, Crowley R, Hirschman KB. Surveys to assess satisfaction with end-of-life care: does timing matter? Journal of pain and symptom management. 2003;25(2):128-32.
496. Cartwright A, Hockey L, Anderson JL. Life before death. Life before death. 1973.
497. Bentley B, O'Connor M. Conducting research interviews with bereaved family carers: when do we ask? Journal of palliative medicine. 2015;18(3):241-5.
498. McPherson CJ, Addington-Hall JM. How do proxies' perceptions of patients' pain, anxiety, and depression change during the bereavement period? Journal of palliative care. 2004;20(1):12-9.
499. McPherson CJ, Addington-Hall JM. Evaluating palliative care: bereaved family members' evaluations of patients' pain, anxiety and depression. Journal of pain and symptom management. 2004;28(2):104-14.
500. DiBiasio EL, Clark MA, Gozalo PL, Spence C, Casarett DJ, Teno JM. Timing of Survey Administration After Hospice Patient Death: Stability of Bereaved Respondents. Journal of pain and symptom management. 2015;50(1):17-27.

501. Cook TD. 8: Campbell, DT (1979). Quasi-experimentation: Design and analysis issues for field settings. Chicago: Rand McNally.
502. Moser C.A. K, G., . Survey Methods in Social Investigation. 2nd ed. Gower: Aldershot; 1979.
503. Grimshaw J, Campbell M, Eccles M, Steen N. Experimental and quasi-experimental designs for evaluating guideline implementation strategies. Family practice. 2000;17(90001):11-6.
504. Ersek M, Wilson SA. The challenges and opportunities in providing end-of-life care in nursing homes. Journal of palliative medicine. 2003;6(1):45-57.
505. Livingston G, Pitfield C, Morris J, Manela M, Lewis-Holmes E, Jacobs H. Care at the end of life for people with dementia living in a care home: A qualitative study of staff experience and attitudes. International journal of geriatric psychiatry. 2012;27(6):643-50.
506. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. Journal of pain and symptom management. 2013;45(6):1094-106.
507. Connor SR. Development of hospice and palliative care in the United States. OMEGA-Journal of Death and Dying. 2008;56(1):89-99.
508. Shaw K, Clifford C, Thomas K, Meehan H. Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. Palliative medicine. 2010;24(3):317-29.
509. Fleming J, Calloway R, Perrels A, Farquhar M, Barclay S, Brayne C, et al. Dying comfortably in very old age with or without dementia in different care settings - A representative "older old" population study. BMC geriatrics. 2017;17(1).
510. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA : the journal of the American Medical Association. 1999;281(2):163-8.
511. Brazil K, Carter G, Cardwell C, Clarke M, Hudson P, Froggatt K, et al. Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. Palliative medicine. 2018;32(3):603-12.
512. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance care planning and the quality of end-of-life care in older adults. Journal of the American Geriatrics Society. 2013;61(2):209-14.
513. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. Journal of Clinical Oncology. 2010;28(7):1203.
514. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end-of-life care: a national study. Journal of the American Geriatrics Society. 2007;55(2):189-94.
515. De Gendt C, Bilsen J, Stichele RV, Deliens L. Advance care planning and dying in nursing homes in Flanders, Belgium: A nationwide survey. Journal of pain and symptom management. 2013;45(2):223-34.
516. de la Rica Escuín ML. Need for palliative care in institutionalised residents with advanced progressive chronic diseases and a limited life expectancy. Med Paliativa. 2016;23(4):183-91.
517. Vandervoort A, Houttekier D, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. Advance care planning and physician orders in nursing home residents with dementia: a nationwide retrospective study among professional caregivers and relatives. Journal of pain and symptom management. 2014;47(2):245-56.
518. Diestre Ortín G, González Sequero V, Collell Domènech N, Pérez López F, Hernando Robles P. Advance care planning and severe chronic diseases. Revista Espanola de Geriatria y Gerontologia. 2013;48(5):228-31.

519. Lo YT, Wang JJ, Liu LF, Wang CN. Prevalence and related factors of do-not-resuscitate directives among nursing home residents in Taiwan. Journal of the American Medical Directors Association. 2010;11(6):436-42.
520. Weafer J. Irish attitudes to death, dying and bereavement 2004-2014. 2014.
521. Morin L, Aubry R. End-of-life care for nursing home residents with dementia. Medecine Palliative. 2015;14(3):191-202.
522. Björk S, Juthberg C, Lindkvist M, Wimo A, Sandman PO, Winblad B, et al. Exploring the prevalence and variance of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; A cross-sectional study. BMC geriatrics. 2016;16(1).
523. Hoffmann F, Kaduszkiewicz H, Glaeske G, van den Bussche H, Koller D. Prevalence of dementia in nursing home and community-dwelling older adults in Germany. Aging clinical and experimental research. 2014;26(5):555-9.
524. Bartfay E, Bartfay WJ, Gorey KM. Prevalence and correlates of potentially undetected dementia among residents of institutional care facilities in Ontario, Canada, 2009-2011. International journal of geriatric psychiatry. 2013;28(10):1086-94.
525. Lithgow S, Jackson GA, Browne D. Estimating the prevalence of dementia: Cognitive screening in Glasgow nursing homes. International journal of geriatric psychiatry. 2012;27(8):785-91.
526. Guo M, Gao L, Zhang G, Li Y, Xu S, Wang Z, et al. Prevalence of dementia and mild cognitive impairment in the elderly living in nursing and veteran care homes in Xi'an, China. Journal of the Neurological Sciences. 2012;312(1-2):39-44.
527. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. Annals of internal medicine. 2010;153(4):256-61.
528. Billings JA, Bernacki R. Strategic targeting of advance care planning interventions: the Goldilocks phenomenon. JAMA internal medicine. 2014;174(4):620-4.
529. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2003;21(6):1133-8.
530. Molloy W. Let Me Decide: Document to Ensure That Your Health Care Wishes are Carried Out in the Event of Incapacity or Crisis. Canada: Peguin Books Ltd; 1993.
531. Patterson C, Molloy DW, Guyatt GH, Bedard M, North J, Hassard J, et al. Systematic implementation of an advance health care directive in the community. Canadian journal of nursing administration. 1997;10(2):96-108.
532. O'Sullivan R, Murphy A, O'Caoimh R, Cornally N, Svendrovski A, Daly B, et al. Economic (gross cost) analysis of systematically implementing a programme of advance care planning in three Irish nursing homes. BMC research notes. 2016;9(1):237.
533. McGlade C, Daly E, McCarthy J, Cornally N, Weathers E, O'Caoimh R, et al. Challenges in implementing an advance care planning programme in long-term care. Nursing ethics. 2017;24(1):87-99.
534. Teno JM, Gozalo P, Mitchell SL, Bynum JP, Dosa D, Mor V. Terminal hospitalizations of nursing home residents: does facility increasing the rate of do not resuscitate orders reduce them? Journal of pain and symptom management. 2011;41(6):1040-7.
535. Lamberg JL, Person CJ, Kiely DK, Mitchell SL. Decisions to hospitalize nursing home residents dying with advanced dementia. Journal of the American Geriatrics Society. 2005;53(8):1396-401.
536. Dreyer A, Forde R, Nortvedt P. Autonomy at the end of life: Life-prolonging treatment in nursing homes-relatives' role in the decision-making process. Journal of medical ethics. 2009;35(11):672-7.

537. Fosse A, Schaufel MA, Ruths S, Malterud K. End-of-life expectations and experiences among nursing home patients and their relatives--a synthesis of qualitative studies. Patient education and counseling. 2014;97(1):3-9.
538. Bollig G, Gjengedal E, Rosland JH. They know! - Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. Palliative medicine. 2015;30(5):456-70.
539. van Eechoud IJ, Piers RD, Van Camp S, Grypdonck M, Van Den Noortgate NJ, Deveugele M, et al. Perspectives of Family Members on Planning End-of-Life Care for Terminally Ill and Frail Older People. Journal of pain and symptom management. 2014;47(5):876-86.
540. Gjerberg E, Lillemoen L, Forde R, Pedersen R. End-of-life care communications and shared decision-making in Norwegian nursing homes - Experiences and perspectives of patients and relatives. BMC geriatrics. 2015;15(1).
541. Mignani V, Ingravallo F, Mariani E, Chattat R. Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: a systematic review and thematic synthesis. Clinical interventions in aging. 2017;12:475-84.
542. Sharma RK, Khosla N, Tulsky JA, Carrese JA. Traditional expectations versus US realities: first- and second-generation Asian Indian perspectives on end-of-life care. Journal of general internal medicine. 2012;27(3):311-7.
543. McGregor MJ, Tate RB, Ronald LA, McGrail KM. Variation in site of death among nursing home residents in British Columbia, Canada. Journal of palliative medicine. 2007;10(5):1128-36.
544. Menec VH, Nowicki S, Blandford A, Veselyuk D. Hospitalizations at the end of life among long-term care residents. J Gerontol Ser A Biol Sci Med Sci. 2009;64(3):395-402.
545. Hockley J, Kinley J. A practice development initiative supporting care home staff deliver high quality end-of-life care. International journal of palliative nursing. 2016;22(10):474-81.
546. Martin R MM, Coveney S, O'Byrne K, Healy L, O'Regan N, McGlade C, Clare J, Timmons S. . Appropriateness of Nursing Home Transfers to Acute Hospital. Irish Journal of Medical Sciences. 2012;181(Supplement 7):S294.
547. Lee GL, Woo IMH, Goh C. Understanding the concept of a good death among bereaved family caregivers of cancer patients in Singapore. Palliative Supportive Care. 2013;11(1):37-46.
548. Meier EA, Gallegos JV, Montross-Thomas LP, Depp CA, Irwin SA, Jeste DV. Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. American Journal of Geriatric Psychiatry. 2016;24(4):261-71.
549. Cheng ST, Lam LCW, Chow PK. Under-recognition of dementia in long-term care homes in Hong Kong. Aging Ment Health. 2012;16(4):516-20.
550. Cahill S, Diaz-Ponce AM, Coen RF, Walsh C. The underdetection of cognitive impairment in nursing homes in the Dublin area. The need for on-going cognitive assessment. Age and ageing. 2009;39(1):128-31.
551. Currow DC, Stevenson JP, Abernethy AP, Plummer J, Shelby-James TM. Prescribing in palliative care as death approaches. Journal of the American Geriatrics Society. 2007;55(4):590-5.
552. Garfinkel D, Zur-Gil S, Ben-Israel H. The war against polypharmacy: a new cost-effective geriatric-palliative approach for improving drug therapy in disabled elderly people. IMAJ-RAMAT GAN-. 2007;9(6):430.
553. Garfinkel D, Mangin D. Feasibility study of a systematic approach for discontinuation of multiple medications in older adults: addressing polypharmacy. Archives of internal medicine. 2010;170(18):1648-54.

554. Scott IA, Gray LC, Martin JH, Pillans PI, Mitchell CA. Deciding when to stop: towards evidence-based deprescribing of drugs in older populations. BMJ Evidence-Based Medicine. 2013;18(4):121-4.
555. Poudel A, Yates P, Rowett D, Nissen LM. Use of Preventive Medication in Patients With Limited Life Expectancy: A Systematic Review. Journal of pain and symptom management. 2017;53(6):1097-110.e1.
556. Payne RA, Abel GA, Avery AJ, Mercer SW, Roland MO. Is polypharmacy always hazardous? A retrospective cohort analysis using linked electronic health records from primary and secondary care. British journal of clinical pharmacology. 2014;77(6):1073-82.
557. Alldred DP. Deprescribing: a brave new word? International Journal of Pharmacy Practice. 2014;22(1):2-3.
558. Narayan SW, Nishtala PS. Discontinuation of Preventive Medicines in Older People with Limited Life Expectancy: A Systematic Review. Drugs & Aging. 2017;34(10):767-76.
559. Maddison AR, Fisher J, Johnston G. Preventive medication use among persons with limited life expectancy. Prog Palliative Care. 2011;19(1):15-21.
560. Wilcock A. Pre-emptive prescribing in the community. Palliative Care Formulary (PCF4). 2011.
561. Scotland N. Scottish Palliative Care Guidelines http://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/Anticipatory-Prescribing.aspx: NHS Scotland; 2014 [
562. Ruegger J, Hodgkinson S, Field-Smith A, Ahmedzai SH. Care of adults in the last days of life: summary of NICE guidance. BMJ: British Medical Journal (Online). 2015;351.
563. Wilson E, Seymour J, Morbey H, Payne S, Brown J, Seale C. Anticipatory prescribing in end-of-life care. Nursing times. 2014;110(44):16-7.
564. Faull C, Windridge K, Ockleford E, Hudson M. Anticipatory prescribing in terminal care at home: what challenges do community health professionals encounter? BMJ Supportive & Palliative Care. 2013;3(1):91-7.
565. Wilson E, Morbey H, Brown J, Payne S, Seale C, Seymour J. Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community and in nursing homes. Palliative medicine. 2015;29(1):60-70.
566. Morin L, Vetrano DL, Rizzuto D, Calderón-Larrañaga A, Fastbom J, Johnell K. Choosing Wisely? Measuring the Burden of Medications in Older Adults near the End of Life: Nationwide, Longitudinal Cohort Study. American Journal of Medicine. 2017;130(8):927-36.e9.
567. van der Meer HG, Taxis K, Pont LG. Changes in prescribing symptomatic and preventive medications in the last year of life in older nursing home residents. Front Pharmacol. 2018;8(JAN).
568. Onder G, for the SP, Liperoti R, for the SP, Fialova D, for the SP, et al. Polypharmacy in Nursing Home in Europe: Results From the SHELTER Study. The Journals of Gerontology: Series A. 2012;67A(6):698-704.
569. Walsh KA, O'Regan NA, Byrne S, Browne J, Meagher DJ, Timmons S. Patterns of psychotropic prescribing and polypharmacy in older hospitalized patients in Ireland: the influence of dementia on prescribing. International psychogeriatrics / IPA. 2016:1-14.
570. Barry HE, Cooper JA, Ryan C, Passmore AP, Robinson AL, Molloy GJ, et al. Potentially inappropriate prescribing among people with dementia in primary care: a retrospective cross-sectional study using the enhanced prescribing database. Journal of Alzheimer's Disease. 2016;52(4):1503-13.
571. Gallagher P, Lang PO, Cherubini A, Topinková E, Cruz-Jentoft A, Montero Errasquín B, et al. Prevalence of potentially inappropriate prescribing in an acutely ill population of older patients admitted to six European hospitals. European Journal of Clinical Pharmacology. 2011;67(11):1175-88.

572. Cahir C, Fahey T, Teeling M, Teljeur C, Feely J, Bennett K. Potentially inappropriate prescribing and cost outcomes for older people: A national population study. British journal of clinical pharmacology. 2010;69(5):543-52.
573. Bradley MC, Fahey T, Cahir C, Bennett K, O'Reilly D, Parsons C, et al. Potentially inappropriate prescribing and cost outcomes for older people: a cross-sectional study using the Northern Ireland Enhanced Prescribing Database. European journal of clinical pharmacology. 2012;68(10):1425-33.
574. Storms H, Marquet K, Aertgeerts B, Claes N. Prevalence of inappropriate medication use in residential long-term care facilities for the elderly: A systematic review. Eur J Gen Pract. 2017;23(1):69-77.
575. Anrys PMS, Strauven GC, Foulon V, Degryse JM, Henrard S, Spinewine A. Potentially Inappropriate Prescribing in Belgian Nursing Homes: Prevalence and Associated Factors. Journal of the American Medical Directors Association. 2018.
576. Matlow JN, Bronskill SE, Gruneir A, Bell CM, Stall NM, Herrmann N, et al. Use of Medications of Questionable Benefit at the End of Life in Nursing Home Residents with Advanced Dementia. Journal of the American Geriatrics Society. 2017;65(7):1535-42.
577. Morin L, Vetrano DL, Grande G, Fratiglioni L, Fastbom J, Johnell K. Use of Medications of Questionable Benefit During the Last Year of Life of Older Adults With Dementia. Journal of the American Medical Directors Association. 2017;18(6):551.e1-.e7.
578. Heppenstall CP, Broad JB, Boyd M, Hikaka J, Zhang X, Kennedy J, et al. Medication use and potentially inappropriate medications in those with limited prognosis living in residential aged care. Australas J Ageing. 2016;35(2):E18-E24.
579. Ailabouni NJ, Nishtala PS, Mangin D, Tordoff JM. General practitioners' insight into deprescribing for the multimorbid older individual: A qualitative study. International Journal of Clinical Practice. 2016;70(3):261-76.
580. Kutner JS, Blatchford PJ, Taylor DH, Jr., Ritchie CS, Bull JH, Fairclough DL, et al. Safety and benefit of discontinuing statin therapy in the setting of advanced, life-limiting illness: a randomized clinical trial. JAMA internal medicine. 2015;175(5):691-700.
581. Gulla C, Flo E, Kjome RLS, Husebo BS. Deprescribing antihypertensive treatment in nursing home patients and the effect on blood pressure. Journal of Geriatric Cardiology. 2018;15(4):275-83.
582. Lavan AH, Gallagher P, Parsons C, O'Mahony D. STOPPFrail (Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy): consensus validation. Age and ageing. 2017;46(4):600-7.
583. Nyborg G, Straand J, Klovning A, Brekke M. The Norwegian General Practice–Nursing Home criteria (NORGEP-NH) for potentially inappropriate medication use: A web-based Delphi study. Scandinavian journal of primary health care. 2015;33(2):134-41.
584. Lavan AH, Gallagher P, O'Mahony D. Inter-rater reliability of STOPPFrail [Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy] criteria amongst 12 physicians. European journal of clinical pharmacology. 2018;74(3):331-8.
585. O'Mahony D, O'Sullivan D, Byrne S, O'Connor MN, Ryan C, Gallagher P. STOPP/START criteria for potentially inappropriate prescribing in older people: Version 2. Age and ageing. 2015;44(2):213-8.
586. Ní Chróinín D, Ní Chróinín C, Beveridge A. Factors influencing deprescribing habits among geriatricians. Age and ageing. 2015;44(4):704-8.
587. Pruskowski J, Handler SM. The DE-PHARM project: A pharmacistdriven deprescribing initiative in a nursing facility. Consult Pharm. 2017;32(8):468-78.
588. Griffioen C, Willems EG, Husebo BS, Achterberg WP. Prevalence of the use of opioids for treatment of pain in persons with a cognitive impairment compared with cognitively intact persons: A systematic review. Current Alzheimer Research. 2017;14(5):512-22.

589. Petyaeva A, Kajander M, Lawrence V, Clifton L, Thomas AJ, Ballard C, et al. Feasibility of a staff training and support programme to improve pain assessment and management in people with dementia living in care homes. International journal of geriatric psychiatry. 2018;33(1):221-31.
590. Corbett A, Nunez KM, Smeaton E, Testad I, Thomas AJ, Closs SJ, et al. The landscape of pain management in people with dementia living in care homes: a mixed methods study. International journal of geriatric psychiatry. 2016;31(12):1354-70.
591. Hálfdánardóttir SI, Ólafsdóttir KL, Siguroardóttir V. Frequency of symptoms and drug treatment among dying patients in the last 24 hours of life at Landspitali-The National University Hospital of Iceland and in nursing homes. Laeknabladid. 2017;103(5):223-8.
592. La Frenais FL, Bedder R, Vickerstaff V, Stone P, Sampson EL. Temporal Trends in Analgesic Use in Long-Term Care Facilities: A Systematic Review of International Prescribing. Journal of the American Geriatrics Society. 2018;66(2):376-82.
593. Finucane AM, McArthur D, Stevenson B, Gardner H, Murray SA. Anticipatory prescribing at the end of life in Lothian care homes. British journal of community nursing. 2014;19(11):544-7.
594. Wilson E, Seymour J. The importance of interdisciplinary communication in the process of anticipatory prescribing. International journal of palliative nursing. 2017;23(3):129-35.
595. Bowers B, Redsell SA. A qualitative study of community nurses' decision-making around the anticipatory prescribing of end-of-life medications. Journal of advanced nursing. 2017;73(10):2385-94.
596. Sandgren A, Thulesius H, Petersson K, Fridlund B. "Doing Good Care"—a study of palliative home nursing care. International journal of Qualitative Studies on Health and Well-being. 2007;2(4):227-35.
597. Dowling S, Broomfield D. Ireland, the UK and Europe: a review of undergraduate medical education in palliative care. Irish medical journal. 2002;95(7):215-6.
598. Ferrand E, Jabre P, Vincent-Genod C, Aubry R, Badet M, Badia P, et al. Circumstances of Death in Hospitalized Patients and Nurses' Perceptions: French Multicenter Mort-a-l'Hôpital Survey. Archives of internal medicine. 2008;168(8):867-75.
599. Liverpool MCPCI. National Care of the Dying Audit–Hospitals: Generic Report 2008/2009. 2009.
600. Farley G. Death anxiety and death education: a brief analysis of the key issues. In: Foyle L, Hostad J, editors. Delivering Cancer and Palliative Care Education. Oxford: Radcliffe; 2004. p. 73-84.
601. Lehto RH, Stein KF. Death anxiety: an analysis of an evolving concept. Research and theory for nursing practice. 2009;23(1):23-41.
602. Langs R. Death Anxiety and the Emotion-Processing Mind. Psychoanalytic Psychology. 2004;21(1):31-53.
603. Becker E. The denial of death,. New York: The Free Press; 1973.
604. Schumaker JF, Barraclough RA, Vagg LM. Death anxiety in Malaysian and Australian university students. J Soc Psychol. 1988;128(1):41-7.
605. Heidegger M. Being and time: A translation of Sein und Zeit: Suny Press; 1996.
606. Erikson EH. Identity and the life cycle: Selected papers. Psychological issues. 1959.
607. Firestone RW. Individual defenses against death anxiety. Death studies. 1993;17(6):497-515.
608. Cicirelli VG. Fear of death in mid-old age. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2006;61(2):P75-P81.
609. Carstensen LL, Isaacowitz DM, Charles ST. Taking time seriously: A theory of socioemotional selectivity. American psychologist. 1999;54(3):165.
610. Comfort A. The Biology of Senescence. New York: Elsevier; 1979.

611. Cicirelli VG. Older adults' views on death: Springer Publishing Company; 2006.
612. Fiori KL, Smith J, Antonucci TC. Social network types among older adults: A multidimensional approach. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2007;62(6):P322-P30.
613. Kass LR. Mortality and morality: the virtues of finitude. Toward a more natural science. New York: The Free Press; 1988.
614. V. Fortner RAN, Barry. Death anxiety in older adults: A quantitative review. Death studies. 1999;23(5):387-411.
615. Sinoff G. Thanatophobia (Death Anxiety) in the Elderly: The Problem of the Child's Inability to Assess Their Own Parent's Death Anxiety State. Frontiers in Medicine. 2017;4:11.
616. Hirschberger G, Florian V, Mikulincer M. Fear and compassion: A terror management analysis of emotional reactions to physical disability. Rehabilitation psychology. 2005;50(3):246.
617. Frommelt KH. The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. The American journal of hospice & palliative care. 1991;8(5):37-43.
618. Tomas-Sabado J, Gomez-Benito J, Limonero JT. The Death Anxiety Inventory: a revision. Psychological reports. 2005;97(3):793-6.
619. Neimeyer RA, Moore MK. Validity and reliability of the Multidimensional Fear of Death Scale. 1994.
620. Lester D, Abdel-Khalek A. The Collett-Lester fear of death scale: A correction. Death studies. 2003;27(1):81-5.
621. Templer DI. The construction and validation of a Death Anxiety Scale. J Gen Psychol. 1970;82(2d Half):165-77.
622. Sinoff G, Iosipovici A, Almog R, Barnett-Greens O. Children of the elderly are inapt in assessing death anxiety in their own parents. International journal of geriatric psychiatry. 2008;23(11):1207-8.
623. Schafer A. Research on Elderly Subjects. Aging: Decisions at the end of life: Springer; 2001. p. 171-205.
624. Dunn KS, Otten C, Stephens E. Nursing experience and the care of dying patients. Oncology nursing forum. 2005;32(1):97-104.
625. Kvale J, Berg L, Groff JY, Lange G. Factors associated with residents' attitudes toward dying patients. Family medicine. 1999;31(10):691-6.
626. Peck MR. Personal death anxiety and communication about advance directives among oncology social workers. Journal of social work in end-of-life & palliative care. 2009;5(1-2):49-60.
627. Black K. Health care professionals' death attitudes, experiences, and advance directive communication behavior. Death studies. 2007;31(6):563-72.
628. Melo CG, Billings J. Including personal development in palliative care education to address death anxiety. International journal of palliative nursing. 2017;23(1):36-45.
629. Melo CG, Oliver D. Can addressing death anxiety reduce health care workers' burnout and improve patient care? Journal of palliative care. 2011;27(4):287-95.
630. Dame L, Hoebeke R. Effects of a simulation exercise on nursing students' end-of-life care attitudes. J Nurs Educ. 2016;55(12):701-5.
631. Lewis C, Reid J, McLernon Z, Ingham R, Traynor M. The impact of a simulated intervention on attitudes of undergraduate nursing and medical students towards end of life care provision. BMC palliative care. 2016;15(1).
632. Carmack HJ, Degroot JM. Development and Validation of the Communication Apprehension about Death Scale. Omega (United States). 2016;74(2):239-59.

633. Hickman SE, Unroe KT, Ersek MT, Buente B, Nazir A, Sachs GA. An Interim Analysis of an Advance Care Planning Intervention in the Nursing Home Setting. Journal of the American Geriatrics Society. 2016;64(11):2385-92.
634. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA : the journal of the American Medical Association. 2003;289(18):2387-92.
635. Moore CD, Sherman SR. Factors that influence elders' decisions to formulate advance directives. Journal of Gerontological Social Work. 1999;31(1-2):21-39.
636. Michael N, O'Callaghan C, Sayers E. Managing 'shades of grey': a focus group study exploring community-dwellers' views on advance care planning in older people. BMC palliative care. 2017;16:2.
637. Stewart F, Goddard C, Schiff R, Hall S. Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. Age and ageing. 2011;40(3):330-5.
638. Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life: the views of older people about advance care statements. Soc Sci Med. 2004;59(1):57-68.
639. Garrido MM, Balboni TA, Maciejewski PK, Bao Y, Prigerson HG. Quality of Life and Cost of Care at the End of Life: The Role of Advance Directives. Journal of pain and symptom management. 2014.
640. Kotter JP. Why transformation efforts fail. The Journal of Product Innovation Management. 1996;2(13):170.
641. Noblet AJ, LaMontagne AD. The challenges of developing, implementing, and evaluating interventions. The Oxford handbook of organizational well being2009.

11 Appendices

Appendix 1: Questionnaire used to collect data presented in Chapter 2

11.1 Appendix 1: Questionnaire used to collect data presented in Chapter 2

Advance Directive Survey **Date: _____/_____/_____**

Age: _____ Gender: M / F
Occupation (circle): Doctor, Nurse, OT, Physio, Social Worker, Student, Other

_____
How many years are you in practice? _____years
What type of practice are you in? (circle) solo, group, hospital, other

_____
How much of your work involves older people? (circle) <20% / 21-40% / 41-60% / 61-80% / >81%
What is your area of specialty eg, general practice, geriatrics?_____

Do you have a will? Yes □ No □
Before today did you know what an advance directive was? Yes □ No □
Have you any previous experience of Advance Directives? Yes □ No □
Have you ever dealt with a patient who had an Advance Directive? Yes □ No □
Do you have an Advance Directive? Yes □ No □
If you don't have an Advance Directive would you complete one? Yes □ No □
If a friend or relative asked you to be a proxy for an Advance Directive, would you? Yes □ No □

Please let us know how you feel about Advance Directives.....	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Advance Directives are a good idea	1	2	3	4	5
You would recommend to people to fill out an Advance Directive	1	2	3	4	5
If you were presented with a patient's Advance Directive, you would feel comfortable following it	1	2	3	4	5
If there were no medico-legal implications, you would be more inclined to follow an Advance Directive	1	2	3	4	5
A doctor would follow your wishes from an Advance Directive	1	2	3	4	5

If you were to become incapable do you think	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Your family would find it difficult to make decisions for you	1	2	3	4	5
Your family should be allowed to make a "directive", expressing the wishes of the family with regards your care	1	2	3	4	5
You would receive treatment that's not consistent with your wishes	1	2	3	4	5
You would receive treatment that is too aggressive	1	2	3	4	5
You would receive treatment that is not aggressive enough	1	2	3	4	5
Your doctor would follow your wishes from an Advance Directive	1	2	3	4	5

If today, you were to become mentally incapable and you had no advance directive, who, legally can make healthcare decisions for you? -

_____

If you were to become incapable, who do you think should make healthcare decisions for you?____

_____

_____

Imagine that you have become mentally incapable and healthcare choices have to be made for you. To what extent do you believe each of the following would make choices for you, that were consistent with what you would have wanted for yourself?

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Your doctor	1	2	3	4	5
Your family	1	2	3	4	5
Your family and doctor together	1	2	3	4	5
A living will stating your treatment choices	1	2	3	4	5
A living will and a proxy (someone nominated by you to act on your behalf)	1	2	3	4	5

When do you think is the best time to complete an advance directive?

Now while in good health Yes □ No □

When older but still capable mentally Yes □ No □

With regard to yourself to what extent are the following true	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
You feel comfortable dealing with patients at the end of life (last few weeks or months of life)	1	2	3	4	5
You find it harder dealing with patients at the end of life compared to other patients	1	2	3	4	5
You feel confident managing patients symptoms at the end of life	1	2	3	4	5
You feel comfortable stopping preventative medications at the end of	1	2	3	4	5

life e.g. calcium supplements, bisphosphonates etc.					
You feel comfortable dealing with relatives of patients at the end of life	1	2	3	4	5
You feel comfortable dealing with bereaved family of patients who have died	1	2	3	4	5
You have adequate training in care at the end of life	1	2	3	4	5
You have adequate experience in care at the end of life	1	2	3	4	5

A positive advance directive is one in which specific treatments are requested to be given, eg organ transplants, experimental treatments etc. Do you think advance directives should include such requests? Yes □ No □

A negative advance directive is one in which specific treatments are refused, eg CPR, blood transfusions, mechanical ventilation etc. Do you think advance directives should include such requests?

Yes □ No □

Mr Murphy is an 84 year old man who you were asked to see as an emergency. He has been living in the nursing home for a month. He has suffered from Alzheimer's disease for seven years and now he is moderately demented. He does not recognise his children but smiles at his wife. He needs help getting in and out of bed and walks with help. He has urinary incontinence and occasional incontinence of faeces.

He is vomiting bright red blood and his blood pressure is very low (BP 80/40). Unless he is treated he will most likely die. His family are not available and there is no advance directive in the medical notes.

Please choose from one of the following treatment options: (circle) 1, 2, 3, 4

1. **Palliative:** Leave him in the nursing home and keep him comfortable
2. **Limited:** Transfer to hospital for blood transfusion but no surgery or endoscopy
3. **Surgery:** Blood transfusion, endoscopy and surgery if necessary
4. **Intensive:** Blood transfusions, endoscopy and surgery, intensive care, ventilator, and everything a modern hospital has to offer to maintain life if necessary

If his heart stops will you try to revive him with cardiopulmonary resuscitation (CPR)?

Yes □ No □

If he recovered and was unable to swallow himself would you use tube feeding?

Yes □ No □

Now imagine Mr Murphy (as described above) were your father and you are not the doctor.....

Please choose from one of the following treatment options: (circle) 1, 2, 3, 4

1. **Palliative:** Leave him in the nursing home and keep him comfortable
2. **Limited:** Transfer to hospital for blood transfusion but no surgery or endoscopy
3. **Surgery:** Blood transfusion, endoscopy and surgery if necessary
4. **Intensive:** Blood transfusions, endoscopy and surgery, intensive care, etc. as above

If his heart stops will you try to revive him with cardiopulmonary resuscitation (CPR)?

Yes □ No □

If he recovered and was unable to swallow would you use tube feeding?

Yes □ No □

Now consider that YOU are in the same situation as Mr Murphy (with dementia as above).

What treatment would you want for yourself? (circle) 1, 2, 3, 4

1. **Palliative:** Leave me in the nursing home and keep me comfortable
2. **Limited:** Transfer me to hospital for blood transfusion but no surgery or endoscopy
3. **Surgery:** Blood transfusion, endoscopy and surgery if necessary
4. **Intensive:** Blood transfusions, endoscopy and surgery, intensive care, etc. as above

If your heart stops do you want to receive cardiopulmonary resuscitation (CPR)?

Yes □ No □

If you recovered and were unable to swallow would you want tube feeding?

Yes □ No □

Overall what percentage of people survive CPR (i.e. live to be discharged from hospital)? <20% □ 21-50% □ 51-75% □ 76-100% □

When you acted as the doctor to what extent do you think the following factors influenced your decision?

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Patient's Age	1	2	3	4	5
Level of confusion	1	2	3	4	5
Duration of confusion	1	2	3	4	5
Duration of Nursing home stay	1	2	3	4	5
Incontinence of Urine	1	2	3	4	5
Incontinence of Faeces	1	2	3	4	5
Inability to recognise Family	1	2	3	4	5
Inability to walk without help	1	2	3	4	5
Patient's family being uncontactable	1	2	3	4	5
Lack of knowledge of patients current or prior wishes	1	2	3	4	5
Duty of care to preserve life as a doctor	1	2	3	4	5
Fear of legal action	1	2	3	4	5
Likelihood of prolonged time on a trolley in Accident & Emergency	1	2	3	4	5
Concern over conserving scarce hospital resources	1	2	3	4	5
Your own religious beliefs	1	2	3	4	5

Your own personal experience with a family member or friend	1	2	3	4	5
Your experience of dealing with families in similar situations	1	2	3	4	5
Uncertainty of patient's acute outcome	1	2	3	4	5
Other factors, comment:					

Which of the following conditions, <u>if they were irreversible</u>, would you consider unacceptable? In this state, you would want <u>no CPR, no tube feeding,</u> and a palliative approach for a life threatening illness?

1. **Persistent Vegetative State (permanent coma, unable to move, communicate or feed)** **Yes** □ **No** □
2. **Unable to recognise family** **Yes** □ **No** □
3. **Unable to communicate with family (or others)** **Yes** □ **No** □
4. **Unable to wash or dress oneself** **Yes** □ **No** □
5. **Unable to move both arms and legs** **Yes** □ **No** □
6. **Unable to walk even with help** **Yes** □ **No** □
7. **Blindness** **Yes** □ **No** □
8. **Deafness** **Yes** □ **No** □
9. **Unable to take food by mouth (can't swallow)** **Yes** □ **No** □

Comments on any question asked or any aspect of this survey topic

_____
_____
_____
_____

Appendix 2:
Local implementation protocol for study site advance care planning

11.2 Local implementation protocol for study site advance care planning

ADVANCE CARE DIRECTIVE POLICY (PILOT)

INTRODUCTION:
XXXX home is committed to providing residents with choice and options. Advance Care Directives (or "Advance Healthcare Decisions" as they are called in the proposed Advance Healthcare Decisions Bill 2012) provide people an opportunity to document their choices about the type of care they wish to receive in the event of incapacity. They also allow a person to designate another individual to be consulted or to be involved in decisions regarding care on their behalf.

Incapacity to make an advance healthcare directive is defined in the Advance Healthcare Decisions Bill 2012 Section 4 (draft June 2012) as follows:

> ..... a person shall lack the capacity to make an advance healthcare decision or any decision in respect of treatment if at the material time, he or she is unable—
>
> i. to understand the information relevant to the decision,
> ii. to retain that information,
> iii. to use or weigh that information as part of the process of making the decision, or
> iv. to communicate his or her decision (whether by talking, using sign language or any other means) or, if the decision requires the act of a third party to be implemented, to communicate by any means with that third party.

POLICY:
An Advance Care Directive will be offered to all residents and families.
The completion of an Advance Care Directive is voluntary.

PURPOSE:

1. <u>For a resident who has the capacity to make healthcare decisions:</u>
    a. To determine and <u>record the wishes of the resident</u> with regard to their future healthcare so that their wishes are known, should they become unable to make healthcare decisions in the future.
    b. To support the resident in <u>designating a person to be consulted</u>, if in the future, the resident becomes unable to make their own healthcare decisions and such decisions have to be made. Under the proposed Advance Healthcare Decisions Bill 2012 and its proposed extension of the Powers of Attorney Act 1996, this designated person could furthermore be appointed as an attorney with the power to make certain specified healthcare decisions on the resident's behalf.
2. <u>For a resident who has lost the capacity to make healthcare decisions:</u>

a. To support families to record any wishes or views their relative may have expressed in relation to future healthcare at a time, in the past, when they still had decision-making capacity.
b. To facilitate families through consultation with a healthcare professional, to determine and record what they think their relative would have wanted in relation to future healthcare, and should this not be possible, to record what the family's views are.

PROCEDURE:

On admission, the CNM 1 will determine if the resident has completed an Advance Care Directive (or Advance Healthcare Decision, both are referred to as ACD).

A. For residents who have completed an ACD prior to admission to XXXX home which is not a "Let me decide" (LMD) directive

1. The CNM 1 will arrange a meeting with the doctor, the resident and any other relevant people e.g. family members.
2. The doctor will assess whether the resident understands the ACD they completed.
   a) Provided the resident understood the ACD and has the capacity to do so, any changes desired may be made to the existing ACD at this stage.
   b) The resident will be offered the opportunity to complete a LMD directive instead. If they wish to do this, the procedure in section B will be followed.
   c) For residents who no longer understand the ACD they previously completed, and no longer have the capacity to make healthcare decisions, no changes will be made to the ACD unless there is a compelling legal reason to do so.
3. The doctor will document the meeting, its outcome and any care plan agreed upon in the resident's medical notes.
4. The CNM1 will document the discussion and outcome in the multidisciplinary notes.
5. The current and valid ACD will be filed in the front of the Care file with 2 copies attached.

B. For residents who have not completed an ACD prior to admission to XXXX home

The CNM1 will provide information to the resident and/or their family about advance care planning and ACDs and for the purposes of education will make the "Let Me Decide" booklet available to them.

1. For residents who are not interested in advance care planning or completing an ACD, this will be documented in the front of the Care Plan by the CNM1.
   a) They will be offered the opportunity to complete an ACD again on an annual basis, after a serious illness or transfer to hospital unless they state otherwise.

2. For residents who are interested in advance care planning and/or completing an ACD using "Let MeDecide" (LMD), the CNM1 will arrange to meet with the resident (and/or their family according to the resident's wishes).

a) The CNM1 will do a cognitive screen using the Standardised Mini Mental State Exam (sMMSE) which will be filed in the resident's medical care file.
    i. Residents who score <10 on the sMMSE will be deemed to lack capacity to complete LMD unless there are reasons to suspect otherwise e.g. they have speech disturbance making it difficult for them to express themsleves.
    ii. Residents who score 10 to 20 on the sMMSE will be interviewed further by the CNM 1 prior to education on advance care planning to assess whether they are likely to understand what is involved.
    iii. Residents who score >20 will be educated on LMD.
b) After education, all residents who wish to complete the LMD directive will need to have their capacity assessed using the SIACAD questionnaire which will be filed in the resident's care file.
    i. Residents with SIACAD scores < 10 will be deemed to lack capacity to complete the LMD directive
    ii. Residents with SIACAD scores of 10-15 will be re-educated on LMD. The SIACAD will be re-administered. If their score is ≤15, they will be assessed by their doctor prior to completing the LMD directive.
    iii. Residents with SIACAD scores > 15 will be deemed capable of completing the LMD directive.
c) The CNM 1 will arrange a meeting with the doctor, the resident and any other relevant people e.g. family members, to discuss the advance care plan and ACD and to answer any questions or clarify any issues for them.
d) The doctor will assess whether the resident understands the ACD they wish to complete.
e) The doctor will document the meeting, its outcome and any care plan agreed upon in the resident's medical notes.
f) The CNM1 will document the discussion and outcome in the multidisciplinary notes.
g) The ACD will be filed in the front of the Care plan with 3 copies attached. The original will always remain in the care file.
h) The resident will be offered a copy of their ACD.

3. <u>For residents who have not completed an ACD and are deemed to lack capacity</u> to complete one. Any care decisions will be discussed with the next-of-kin/significant other.
    a) Once it has been confirmed by the doctor that the resident lacks capacity to make care decisions, the CNM 1 will provide information on care planning on end-of-life issues to the family/"next-of-kin".
    b) If it is felt that the resident would be able to express their own views on end-of-life care, these should be explored and documented, even if the resident lack capacity to make care decisions. Any expressed views should be taken into account when making decisions in the best interests of the resident.
    c) If the family are interested in providing input into the resident's end of life care plan, they will be given a copy of the "Let Me Decide" booklet and a meeting will be arranged with the CNM 1 and any

other relevant person such as the doctor. It will be made clear to the family that currently the legal responsibility for making healthcare decisions for their relative rests with their treating doctor. A discussion will take place to ascertain:

i. if the resident ever expressed wishes with regard to end-of-life care
ii. if not, what they think the resident would want were they still able to decide for themselves
iii. if they can't answer i) or ii) what the family's wishes are in relation to care

d) This discussion will be documented in the resident's care file by the CNM 1.
e) If the doctor was not at this meeting, the information from this meeting will be provided to him/her so that together a "care plan for end-of-life decisions for people lacking decision making capacity" (EOL decisions care plan) can be completed. This care plan should be discussed with the family.
f) If an EOL decisions care plan is completed, this will be filed at the front of the resident's care file with 3 copies attached. The original will always remain in the care file.

4. For residents who are Wards of Court the CNM 1 will contact the appropriate office to determine if the designated decision-maker will make a plan with regard to end-of-life care on the resident's behalf.
5. If the resident has an ACD or an EOL decisions care plan, a white circular sticker will be attached to the spine of the residents care file.
6. If the resident is transferred to hospital:
   a) Send a copy of the ACD or EOL decisions care plan attached to the Transfer Letter and make a note of it on the Transfer sheet
   b) Photocopy the ACD or EOL decisions care plan and replace the one which was sent with the resident to the hospital.
7. If the resident is discharged to another facility or home, send the original ACD or EOL decisions care plan with the resident. The copies of the ACD or EOL decisions care plan will be retained in the resident's file.
8. All directives will be reviewed and updated:
   a) Annually
   b) After a significant change in health or after a serious illness
   c) Anytime the resident (with capacity) wishes.

   For families who were initially not interested in being involved in advance care planning for the resident, they will be offered the opportunity again as outlined in 8.a) and 8.b).

Appendix 3: Questionnaire used to collect Chapter 5 data

11.3 Appendix 3: Questionnaire used to collect Chapter 5 data

Advance Care Directives and Advance Care Planning

Questionnaire for Long-term Care Staff on
Attitudes, Barriers and Palliative Care Learning Needs

You may have already filled in certain sections of this questionnaire as part of an earlier staff survey we carried out in 2012/ 2013. However, we would be very grateful if you could complete these sections again as we would like to see if there have been any changes in the meantime.

Please indicate if you filled in our questionnaire in the past: YES NO

Section A: Demographic Information

Please complete the following:

1. What is your gender?(Circle) Male Female
2. What is your age? ☐
3. What is your current job?

   □ Registered Nurse □ Physician

   □ Clinical Nurse Specialist □ Healthcare Assistant

   □ Clinical Nurse Manager Other: _____

4. How long have you been working in your profession? ☐ Years
5. In which **health care setting** do you currently work? *(Please circle)*

   Community Hospital Private Nursing Home Public Nursing Home

   Other *(Please specify):* _____

SECTION B: Advance Care Planning & Advance Care Directives Attitudes

Please circle your response:

1. **Every competent person has the right to accept or refuse medical treatment.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

2. **Every competent person can complete an advance care directive.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

3. **Advance care directives are a way of getting rid of old people.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

4. **Health care professionals are the best people to make health care decisions for patients.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

5. **A patients' family are the best people to make health care decisions when a patient no longer can and has no advance care directive**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

6. **There is a need for patients to be more involved in their health care decisions.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

7. **If people are allowed to make their own health care decisions, they will usually make the wrong decisions.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

8. **People who complete advance care directives should be allowed to leave instructions which others may feel are not in the person's own best interest.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

9. **Advance care directives can make the decision-making process for health care professionals easier by letting them know the patient's and family's wishes.**
   Strongly Disagree Disagree Neutral Agree Strongly Agree

10. **Every competent person should be required to complete an advance care directive.**
    Strongly Disagree Disagree Neutral Agree Strongly Agree

11. **Advance care directives can contribute to a better patient/health care professional relationship.**
    Strongly Disagree Disagree Neutral Agree Strongly Agree

12. **Advance care directives are a step on the road to legalised euthanasia.**
    Strongly Disagree Disagree Neutral Agree Strongly Agree

13. **The elderly should be allowed to request intensive care treatment.**
    Strongly Disagree Disagree Neutral Agree Strongly Agree

14. **Advance care directives are a positive step towards greater patient autonomy.**
    Strongly Disagree Disagree Neutral Agree Strongly Agree

15. **Health care providers should be required to follow advance care directives.**
    Strongly Disagree Disagree Neutral Agree Strongly Agree

Section C:
Learning Needs Questionnaire For Palliative Care (LNQFPC)

1. Did you attend any Palliative Care Educational Workshops given by Dr. Ciara McGlade?

□ **NO**
□ **YES all sessions**
□ **YES some sessions only**

If you answered 'YES' then please answer Q 2, if 'NO' then go to Q 3

2. How useful did you find this Palliative Care training?

Very useful Quite useful A little useful Not useful

3. Have you had any other training in Palliative Care? **YES** **NO**

If you answered 'YES' then please answer Q 4-7, if 'NO' then go to Q 8

4. Describe any further training in Palliative Care you have had: eg courses attended, duration and where, certificate, diploma, masters etc.:

_____
_____
_____

5. Did you undertake the ***'Final Journeys'*** Palliative Care training? **YES** **NO**

6. Did you ever work exclusively in specialist palliative care? **YES** **NO**

If 'YES': For how long did you work in Specialist Palliative Care? ☐ Years

8. What is Palliative Care?

_____
_____

9. Who makes medical decisions for someone with advanced dementia?

_____
_____

10. What are the signs that a person may be dying?

_____
_____

11. How do you go about referring to Specialist Palliative Care Services if a patient is in need of this?

_____
_____

12. Why might you refer a resident to Specialist Palliative Care Services?

_____
_____

Below is a list of topics relating to delivering end-of-life palliative care in long-term care.
If you think further information on a topic will assist you in providing better end-of-life palliative care to your residents, please circle **"YES"**.
Circle **"NO"** if the topic is not a learning need for you.

EDUCATIONAL TOPICS	Is this a learning need?		Please rate importance of topic		
			Very important	Important	Less important
1. Advance Directives, Power of Attorney, and Living Wills	Yes	No			
2. Determining a person's mental Competency	Yes	No			
3. Understanding Personal Autonomy	Yes	No			
4. Primary Roles of the Palliative Care Team	Yes	No			
5. Understanding the Physiological Impact of Life-Threatening Illnesses	Yes	No			
6. Stages of the Dying Process	Yes	No			
7. Physical Changes as Death Approaches	Yes	No			
8. Diagnosing Dying	Yes	No			
9. Pain and Symptoms Assessment	Yes	No			
10. Assessment and Management of Nausea	Yes	No			
11. Assessment and Management of Incontinence	Yes	No			
12. Assessment and Management of Loss of Appetite/Weight/Taste	Yes	No			
13. Assessment and Management of Dyspnoea	Yes	No			
14. Assessment and Management of Impaired Swallowing	Yes	No			
15. Assessment and Management of Confusion and Agitation	Yes	No			
16. Assessment and Management of Dehydration	Yes	No			
17. Management of Fatigue	Yes	No			
18. Management of "death rattle" or respiratory secretions	Yes	No			
19. Pharmacological Management of Pain and opioids (e.g. morphine)	Yes	No			
20. Non-Pharmacological Management of Pain (e.g. biofeedback)	Yes	No			
21. Assessment and Management of Sleep Disorders	Yes	No			
22. Maintaining Mobility/Preventing Complications of Immobility	Yes	No			
23. Maintaining Self-Care Activities (e.g. mouth care)	Yes	No			
24. Management of the Nutrition as Death Approaches	Yes	No			
25. Understanding the Emotional Needs of the Dying Person	Yes	No			
26. Managing the Emotional Impact on Families as Death nears	Yes	No			
27. Stress Management for the Individual and Family	Yes	No			
28. Crisis Management for the Individual and Family	Yes	No			
29. Management of Grief and Bereavement	Yes	No			
30. Spiritual Needs of the Individual and Family	Yes	No			
31. Ethical, Religious, and Legal Implications of Dying	Yes	No			
32. Culture and Death	Yes	No			
33. Counselling the Family	Yes	No			
34. Stress Management for Staff	Yes	No			
35. Developing Communication and History-Taking Skills	Yes	No			
36. Support Services for the Family and the Individual	Yes	No			
37. Other:	Yes	No			

13. How confident do you feel discussing end of life issues with a resident or their family? (circle answer)

Not at all confident **A little unconfident** **Neutral** **Confident** **Very confident**

14. How confident do you feel dealing with bereavement issues with a resident's family? (circle answer)

Not at all confident **A little unconfident** **Neutral** **Confident** **Very confident**

15. How confident do you feel setting up and using a syringe driver to deliver medications to a person at the end of life? *(circle answer)*

Not at all confident **A little unconfident** **Neutral** **Confident** **Very confident**

16. Name 5 drugs that you commonly used in a syringe driver at the end of life and for what symptoms you use them.

1. Drug: _____ used for _____
2. Drug: _____ used for _____
3. Drug: _____ used for _____
4. Drug: _____ used for _____
5. Drug: _____ used for _____

17. What do you most commonly use to dilute the medications in a syringe driver? Please circle:

Water for injection **Saline** **Not sure**

18. Does it matter which you use to dilute?

Yes **No** **Not Sure**

Comment:

_____

_____

19. Which of the following can be used in combination in a syringe driver?

Cyclizine and morphine	Yes	No	Not Sure
Cyclizine and metoclopromide	Yes	No	Not Sure
Morphine and metoclopromide	Yes	No	Not Sure

20. When would you use a syringe driver?

_____

_____

_____

21. Do you think a syringe driver shortens or prolongs a person's life? Please comment.

_____

_____

_____

22. What do you think about syringe drivers?

_____

_____

_____

Section D: Advance Care Planning

1. How have you learned about advance care directives? (Please specify).

   Workshops *Magazines* *Books* *Lectures Articles*

   Other (Please specify): _____

2. Do you have previous experience with advance care directives? (Circle) **Yes** **No**

3. Did you attend a *'Let Me Decide'* Advance Care Planning workshop/study day?

   □ **NO**
   □ **YES all sessions**
   □ **YES some sessions only**

   *If **'YES'** then please answer the next question, if **'NO'** then please proceed to Q 5*

4. How useful did you find this Advance Care Planning training?

   Very useful Quite useful A little useful Not very useful

5. Have you completed advance care directives with patients? (Circle) **Yes** **No**

   *If **'YES'** then please answer Section E, if **'NO'** then please proceed to Section F*

Section E: Implementation of the '*Let Me Decide*' Programme

Please answer the questions below if you have been involved in delivering advance care planning to residents in your long-term care setting

1. How would you rate the level of support received from UCC Study personnel during the implementation of the *'Let Me Decide'* Programme?

   Excellent Very good Quite good Adequate Inadequate

2. Did you have enough opportunity to meet with UCC Study personnel? **YES** **NO**

3. Did you have enough opportunity to give feedback to Study personnel? **YES** **NO**

4. How *confident* do you feel about going through the *'Let Me Decide'* process with a resident who has capacity to complete their own advance care directive?

   Very confident Moderately Adequately Not at all

5. How *confident* do you feel about going through the *'Let Me Decide'* process for a resident who lacks capacity to complete the *'Let Me Decide'* advance care directive?

   Very confident Moderately Adequately Not at all

4. How useful did you find the '*Let Me Decide*' Process for your ***Competent Residents***?

Very useful Quite useful A little useful Not very useful

5. How useful did you find the '*Let Me Decide*' Process for ***Residents who lack capacity*** *and for their families?*

Very useful Quite useful A little useful Not very useful

6. How easy/ difficult did you find the process of **getting families involved** in the care planning process for your ***Competent Residents*** (where applicable)?

1	2	3	4	5
Easy				Difficult

7. How easy/ difficult did you find the process of **getting families involved** in the care planning process for your ***Residents lacking capacity***?

1	2	3	4	5
Easy				Difficult

8. What was **good** about the *Let Me Decide* Advance Care Planning Process?

_____

_____

9. What **specific difficulties** did you encounter in implementing *'Let Me Decide'* in your work setting?

_____

_____

10. What, in your opinion, could make the '*Let Me Decide'* process **more user-friendly** in the long-term care setting?

_____

_____

11. Overall, how would you rate the usefulness of the *'Let Me Decide'* Advance Care Planning programme to you in your practice?

Very useful	Quite useful	A little useful	Not very useful

12. Do you have any additional comments?

_____

_____

SECTION F: BARRIERS TO IMPLEMENTING ADVANCE CARE DIRECTIVES

Please complete this questionnaire if you are a qualified nurse.

This instrument measures barriers to implementing advance care directive programs in different health care sectors. It is used to define obstacles and needs that must be addressed in policies, education and in the implementation itself.

Here is a list of barriers to advance care directive use. For each statement, please identify if the item is a barrier to directive completion where you work by circling Yes or No.

- **If No, continue to the next question.**
- **If Yes, please score the importance of this item as a barrier, by choosing a number from 1-5 on this 5 point scale.**
    1. **Least Importance**
    2. **Somewhat Important**
    3. **Important**
    4. **Very Important**
    5. **Most Importance**

	In your work do you encounter the following?	N=No Y=Yes	Least Level of Importance Most
1	Differences in attitudes and values around life and death in different cultures?	**N Y**	**1 2 3 4 5**
2	Differences in language or translating when completing advance care directives?	**N Y**	**1 2 3 4 5**
3	Gender?	**N Y**	**1 2 3 4 5**
4	Old age i.e. older people have more difficulty completing advance care directives?	**N Y**	**1 2 3 4 5**
5	Low socio-economic status, i.e. poor people have more problems completing advance care directives?	**N Y**	**1 2 3 4 5**
6	Lack of education, i.e. lower educated people have more problems completing advance care directives?	**N Y**	**1 2 3 4 5**
7	A person's youth, i.e. young people have more problems completing advance care directives?	**N Y**	**1 2 3 4 5**
8	Finding sufficient time to educate patients/residents/clients about advance care directives have advance care planning discussions?	**N Y**	**1 2 3 4 5**
9	With elderly people with hearing or other communication impairments or who need more time?	**N Y**	**1 2 3 4 5**
10	Patient/Resident/Client's lack of education?	**N Y**	**1 2 3 4 5**
11	Staff lack of education about the advance care directives/ advance care planning?	**N Y**	**1 2 3 4 5**
12	The lack of educational aids, such as books and videos?	**N Y**	**1 2 3 4 5**
13	Accommodating the different education needs of clients/residents/patients?	**N Y**	**1 2 3 4 5**
14	People who do not want to learn about advance care directives?	**N Y**	**1 2 3 4 5**
15	The lack of education about advance care directives in acute hospitals?	**N Y**	**1 2 3 4 5**
16	The lack of education programs about advance care directives throughout the healthcare system?	**N Y**	**1 2 3 4 5**

	In your work do you encounter any of the following?	N=No Y=Yes	**Least**	**Level of Importance**			Most
17	Insufficient education for the general public about advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
18	Families who have not been previously educated about advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
19	Too much conflicting education on advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
20	Patients/Residents/Clients being influenced too much by family members' opinions when filling out advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
21	Conflicting opinions among family members when filling out advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
22	Patients/Residents/Clients ignoring family members' opinions when filling out advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
23	Nurses who do not support advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
24	Doctors who do not support advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
25	Other staff, i.e. administrators, social workers, OT's Physiotherapists who do not support advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
26	Poor communication with residents/patients and families about advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
27	Finding a private area to discuss advance care planning?	**N Y**	**1**	**2**	**3**	**4**	**5**
28	Because the area where directives are completed is too noisy?	**N Y**	**1**	**2**	**3**	**4**	**5**
29	People who are not able to understand the concept of advance care directives?	**N Y**	**1**	**2**	**3**	**4**	**5**
30	Assessing the patient/resident/clients competence to complete an advance care directive?	**N Y**	**1**	**2**	**3**	**4**	**5**
31	Resident / their family don't feel comfortable to discuss advance care planning?	**N Y**	**1**	**2**	**3**	**4**	**5**
32	Staff lack of comfort in discussing advance care planning?	**N Y**	**1**	**2**	**3**	**4**	**5**
33	Staff lack of medical knowledge with regard to disease, prognosis, treatment options or end-of-life issues?	**N Y**	**1**	**2**	**3**	**4**	**5**
34	Other barriers not mentioned						

For more information please contact:
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Thank-you for your time

Appendix 4: Data collection sheet for Chapter 7

11.4 Appendix 4: Data collection sheet for Chapter 7

QODD: Quality of Dying and Death Questionnaire (seven day version)

Section A:

A.1	What is your relationship to the person who died?	I am his or her.....							
		Husband or wife	Partner	Child	Brother	Sister	Other relative	Friend	Other

A.2	Are you male or female?	Male	Female

A.3	How old are you?	years

A.4	Did you get to spend time with your relative or friend in their last week?	Yes	No

A.5	Were you with your relative or friend when they died?	Yes	No

Section B: Experience of where your relative or friend died

B.1	In what kind of room, did your relative or friend die?	Single room	Shared room	Don't know
B.2	In what kind of room do you think your relative or friend would have liked to have died?	Single room	Shared room	Don't know

B.3	Did the type of room where your relative or friend died affect the quality of how he or she died?	Not at all	Mildly	Moderately	A lot	Extremely

Please rate the following with regard to where your relative or friend spent most of their time in their last week of life		Very poor	Poor	Average	Good	Very Good	Don't know
B.4	The space where you could talk privately with staff						
B.5	The space where you could talk privately with your relative or friend						
B.6	You could stay as long as your relative or friend wanted you to						
B.7	How did staff respond to your queries or requests						
B.8	What did you think of the quality of care provided by the staff						

Section C: Quality of life in the last week

The following questions are about your relative or friends experience during their last week of their life.
Please answer each question even if they were unconscious for some or all of the time.
Some of the questions relate to problems such as a person's ability to eat or drink, control going to the toilet or their ability to communicate. For some people such as people with advanced dementia, these may have been problems for many months, if this was the case for your relative or friend, please indicate when they last would have had no problem in that area.

C.1a	**Did your relative or friend have physical pain?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.1b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.2a	**Was your relative or friend able to eat or drink?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.2b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.3a	**Was your relative or friend able to breathe comfortably?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.3b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.4a	**Did your relative or friend seem comfortable and at ease?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.4b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.5a	**Did your relative or friend seem anxious or afraid?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.5b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.6a	**Did your relative or friend smile, laugh or show signs of enjoyment in their last week?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.6b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.7a	**Did your relative or friend seem to have the energy to do most of the things that they wanted to do?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.7b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.8a	**Was your relative or friend able to physically control when they went to the toilet?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.8b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.9a	**Was your relative or friend's dignity and self respect maintained?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.9b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.10a	**Was your relative or friend helped to spend time with their family in the way they wanted to?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.10b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.11a	**Was your relative or friend helped to spend time alone in the way they wanted to?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.11b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10				10 = Almost perfect		Don't know

C.12a	**Did your relative or friend seem worried about causing strain to his or her loved ones?**	**None of the time**	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**	**Don't know**
C.12b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10					10 = Almost perfect	Don't know

C.13a	**Did your relative or friend have his or her loved ones around them in the last week of life?**	**Yes**	**No**	**Don't know**
C.13b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10	10 = Almost perfect	Don't know

C.14a	**Did your relative or friend say goodbye to their loved ones?**	**Yes**	**No**	**Don't know**
C.14b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10	10 = Almost perfect	Don't know

C.15a	**Did your relative or friend seem to have meaning and purpose in their life?**	**Yes**	**No**	**Don't know**
C.15b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10	10 = Almost perfect	Don't know

C.16a	**Did your relative or friend have any money worries, such as the cost of care?**	**Yes**	**No**	**Don't know**
C.16b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10	10 = Almost perfect	Don't know

C.17a	**Did your relative or friend have one or more visits from a religious or spiritual advisor such as a priest?**	**Yes**	**No**	**Didn't want these visits**	**Don't know**
C.17b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10		10 = Almost perfect	Don't know

C.18a	**Was anyone there at the moment of your relative or friends death?**	**Yes**	**No**	**Don't know**
C.18b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10 = Almost perfect		Don't know

C.19a	**In the moment before your relative or friend died, were they**	**Alert**	**Semi-conscious but able to speak**	**Unconscious**	**Don't know**
C.19b	How would you rate this part of their dying?	1 = Terrible 1 2 3 4 5 6 7 8 9 10 = Almost perfect			Don't know

C.20	**Overall how would you rate relative or friends quality of life during their last week?**	**1 = Terrible** 1 2 3 4 5 6 7 8 9 10 **10 = Almost perfect**	**Don't know**

C.21	**Had your relative or friend made funeral plans?**	**Yes**	**No**	**Don't know**

C.22	**How well did staff (doctors and nurses) communicate with your relative or friends about their illness?**	**1 =Very Poorly** 1 2 3 4 5 6 7 8 9 10 **10 = Excellent**	**Don't know**

C.23	**How well did staff communicate with you and your relative or friends family about his or her illness and death?**	**1 =Very Poorly** 1 2 3 4 5 6 7 8 9 10 **10 = Excellent**	**Don't know**

C.24	**How well did staff provide end of life care that respected your relative or friends wishes?**	**1 =Very Poorly** 1 2 3 4 5 6 7 8 9 10 **10 = Excellent**	**Don't know**

C.25	**Did your relative or friend discuss their wishes for end of life care with their doctor or other staff?**	**Yes**	**No**	**Don't know**

C.26	**If no, did the doctor or staff looking after your relative or friend ask what end of life care your relative or friend would have wanted?**	**Yes**	**No**	**Don't know**

C.27	**Were you expecting your relative or friends death?**	**Yes**	**No**	**Don't know**

C.28	**Did you feel prepared for your relative or friends death?**	**Yes**	**No**	**Don't know**

C.29	**Would you have liked more information on what to expect as someone is dying or what to do afterwards?**	**Yes**	**No**	**Don't know**

C.30	**Overall how would you rate the quality of your relative or friends death?**	**1 = Terrible** 1 2 3 4 5 6 7 8 9 10 **10 = Almost perfect**		**Don't know**

Section D: Comments on the care of your relative or friend

F.1 **What went well in the care of your relative or friend during their last week of life?**

F.2 **What did not go so well in the care of your relative or friend during their last week of life?**

F.3 **Are there any other comments you would like to add?**