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Autonomy and paternalism at the end of life for elderly patients

Doctoral Thesis

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Summary

This Thesis critically examines the complex relationships between autonomy and paternalism for elderly patients approaching the end of life. It examines what is currently known about elderly patients' views on autonomy and how they may wish to exert it at the end of life and how the state as the main provider of care and protector and promotor of autonomy fulfils these obligations.

Populations across the world are aging. In England, almost 70% of people now die over the age of 75 years. Concomitantly, the patterns of death and dying are changing as a result with death most frequently preceded now by a prolonged period, often of many years, marked by physical, mental and social decline accompanied by increasing frailty and dependence on others. At the same time there are marked technological and societal changes which impact on attitudes and responses to death and dying in old age. The end of life phase is marked by a heightened risk of conflict between the autonomy of individuals and paternalism which, although almost always well intentioned, can inadvertently adversely impact on the autonomy of elderly patients. In England, rhetoric in health and social policy attaches great symbolism to the concept of choice including at the end of life giving it almost a status of 'primus inter pares' above all other concerns. This reflects the culture shift towards an individualistic, atomist view of the world and is based on a superficial understanding of the importance of autonomy construed as 'doing what I want, free from interference'. This thesis demonstrates that elderly patients view the importance of autonomy differently and as an enabler to make moral choices.

This thesis critically evaluates the role of the state, in England as a beneficent paternalist in protecting and promoting the autonomy of elderly people at the end of life. It shows that there has been too little evaluation of the desires and needs of the majority who die who are elderly. Moreover, that greater attention needs to be focussed on the risks of harm from well-intentioned policy initiatives.

A multidisciplinary, empirical approach is adopted to explore the meanings of autonomy for elderly patients approaching the end of life and critically appraise current national policy in this context. The Thesis draws on literature and analytical approaches from bioethics, philosophy, sociology, psychology and public health.

The Thesis concludes with words of caution and recommendations for all sectors of society on how to achieve better care while respecting the autonomy of elderly patients.

Streszczenie

Niniejsza praca doktorska poddaje krytycznej analizie złożone relacje między autonomią a paternalizmem w odniesieniu do starszych pacjentów zbliżających się do końca życia. W pracy analizuje się dostępne dane i materiały dotyczące poglądów starszych pacjentów na autonomię oraz tego, jak mogą pragnąć ją wykorzystać pod koniec życia, a także w jaki sposób państwo jako główny dostawca opieki i opiekuna oraz promotor autonomii wypełnia swoje zadanie.

Populacje na całym świecie się starzeją. W Anglii prawie 70% ludzi umiera w wieku powyżej 75 lat. Jednocześnie zmieniają się wzorce śmierci i umierania, co jest wynikiem znacznie przedłużającego się okresu poprzedzającego śmierć – często trwającego wiele lat – naznaczonego upadkiem fizycznym, psychicznym i społecznym, któremu towarzyszy rosnąca słabość i zależność od innych. Zachodzące obecnie ogromne zmiany technologiczne i społeczne wpływają na postawy i reakcje na śmierć jako taką oraz śmierć w starszym wieku. Faza końca życia charakteryzuje się podwyższonym ryzykiem konfliktu między autonomią jednostek a paternalizmem, który, choć prawie zawsze przejawiany w dobrych intencjach, może niekorzystnie wpłynąć na autonomię starszych pacjentów. W Anglii w retoryce stosowanej w polityce zdrowotnej i społecznej przywiązuje się wielką wagę do koncepcji wyboru, w tym szczególnie pod koniec życia, nadając jej prawie status „primus inter pares" ponad wszystkimi innymi kwestiami. Odzwierciedla to zmianę kultury w kierunku indywidualistycznego, atomistycznego spojrzenia na świat i opiera się na powierzchownym definiowaniu autonomii rozumianej jako „robienie tego, czego chcę, bez żadnych ograniczeń". Ta praca pokazuje, że starsi pacjenci postrzegają znaczenie autonomii w inny sposób – jako czynnik umożliwiający dokonywanie wyborów moralnych.

Niniejsza praca krytycznie ocenia rolę państwa w Anglii jako dobroczynnego paternalisty w ochronie i promowaniu autonomii osób starszych pod koniec życia. Pokazuje, że dokonano zbyt pobieżnej oceny pragnień i potrzeb większości umierających w podeszłym wieku. Ponadto zauważa, że należy zwrócić większą uwagę na ryzyko szkód płynące z inicjatyw ukierunkowanych politycznie.

Przyjęto podejście multidyscyplinarne, empiryczne, aby zbadać znaczenie autonomii dla starszych pacjentów zbliżających się do końca życia i krytycznie przeanalizować obecną politykę krajową w tym kontekście. Praca opiera się na literaturze i metodach analitycznych z takich dziedzin jak bioetyka, filozofia, socjologia, psychologia i zdrowie publiczne.

Praca kończy się słowami zalecającymi ostrożność i wskazówkami, jak osiągnąć wyższe standardy opieki przy jednoczesnym poszanowaniu autonomii starszych pacjentów, skierowanymi do wszystkich sektorów społeczeństwa.

Acknowledgments

I firstly wish to thank my Doctoral Supervisor Professor Jan Hartman for his supervision of the work for this thesis. It has been a long haul and he has been supportive throughout. He has posed provocative questions which I hope I have answered. I feel very privileged that I have been able to study for this Doctoral Thesis at the Jagiellonian University of Krakow.

I am grateful to my employer, Public Health England for funding me to undertake this doctoral thesis and giving me time as part of my continuous professional development to work on it. I thank colleagues at Public Health England especially Jon Templeton who has helped me balance a very busy work schedule and academic time to work on this thesis. I also thank the rest of the team in the National End of Life Intelligence Network and academic partners at the University of the West of England. Together we produce research and national publications which hopefully contribute to the improvement of Palliative and End of Life Care for people in England and beyond. The issues which I have explored in this thesis arise out questions which we encounter and debate in our daily routine work which is the epidemiological analysis of big data.

Finally, I wish to thank my family Rebecca, Beatrice, Ilaria and Grzegorz who have been supportive and patient during the long gestation period of this Doctoral Thesis and Zofia who helped me get the Thesis to the printers before ‘Godzina W’ on the 75th Anniversary of the Warsaw Uprising.

Statement of Authorship

The work presented in this doctoral thesis is my own original work.

I personally have formulated the questions, undertaken the literature reviews and undertaken the critical analyses. In Appendix 1, I have listed the Abstracts, which directly relate to the work undertaken for this Thesis which have been presented at the European Association of Palliative Care Conferences from 2012 to 2019. In Appendix 2, I have listed my peer review publications in Palliative and End of Life Care 2013-2019 which have provided knowledge and background for this doctoral thesis but are not direct outputs from this work.

Where I illustrate arguments in this Thesis, using data from research that I have conducted with my team in the National End of Life Care Intelligence Network or with the University of the West of England, I cite the sources of this data as I would with any other work I have referenced.

Dedication

I dedicate this Thesis to my dearly beloved and greatly missed parents

Christine and Stefan Verne

My parents were with me at the start of this work, encouraging me in the importance of it for them and all the other elderly people reaching life's last chapter – the term my father would have liked me to use instead of end of life. Both gave me permission and encouraged me to use everything I had learned from caring from them to help others.

This is the second doctoral Thesis my mother supported me with. The first was at the start of a life, driving me to endoscopy clinics and caring for my first child, so I could breastfeed in between clinical sessions. In this current Thesis, at the end of her life, she urged me on, from her bed and chair, through the prolonged frailty of her terminal illness, being the living exemplar of dying with grace and dignity. She expressed her autonomy through tiny gestures and words as her physical strength faded. She gave me the privilege of caring for her in my home during her 15 month terminal illness, during which we established a 'low tech hospital at home' with support from the GP, community nursing and social care, the local Hospice and Marie Curie nurses. So, when I analyse the issues of autonomy and paternalism at the end of life for elderly people I do so with the personal insight of having experienced and observed many of the issues.

My father, a combatant in the Warsaw Uprising died suddenly in the 72nd year since the Uprising. He died in my home, living life to the full, expressing his autonomy to the end.

Both my parents instilled in me the importance of service to others, the value of scientific rigour, as both were scientists, and courage and dignity in the face of adversity. From a very early age they took me to visit and sit with the dying. These visits were formative lessons in compassion for the dying and their families. I will be eternally grateful to my parents and I hope that this Thesis does justice to their memory and will be a force to improve care for other elderly people facing the last chapter of their lives.

I also dedicate this Thesis to Dr Jozef Felix, my Great-Uncle who graduated from the Medical Faculty of the University of Krakow in 1923 and died in 1986. He was a great inspiration to me first to train in medicine and secondly to strive to be a really compassionate doctor and listen carefully to the real concerns of patients and their families.

Abbreviations

Advance Care Plans (ACPs)

Advance Care Planning (ACP)

Advance Directive (AD)

Advance Directive to Refuse Treatment (ADRT)

Black and Minority Ethnic (BAME)

Cardiopulmonary Resuscitation (CPR)

Care Quality Commission (CQC)

Commissioning for Quality and Innovation' (CQUIN)

Clinical Commissioning Group (CCG)

Deprivation of Liberty Safeguards (DoLS)

Do Not Attempt Resuscitation (DNAR)

Department (Ministry) of Health and Social Care (DHSC)

The European Convention on Human Rights (EHCR)

End of Life (EOL)

European Commission on Human Rights (ECHR)

General Practitioner (GP)

Gold Standards Framework (GSF)

Human Rights Act 1998 (HRA 1998)

Integrated Care Pathways (ICPs)

Legal Power of Attorney for Health and Welfare (LPA).

Liverpool Care Pathway for the Care of the Dying Patient (LCP)

Leadership Alliance for the Care of Dying People (LACDP)

National Health Service (NHS)

National End of Life Care Intelligence Network (NeOLCIN)

National Institute of Clinical and Health Excellence (NICE)

Non- Government Organisations (NGOs)

General Medical Council (GMC)

Palliative and End of Life Care (P&EOLC)

Abbreviations continued.

Physician Assisted Suicide (PAS)

Supportive and Palliative Care Indicators Tool (SPICT ^{TM})

United Kingdom of Great Britain and Ireland (UK)

United States (US)

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Chapter 1 Introduction

1.1. The rationale for choosing the subject for this thesis

This thesis focuses on the relationship between the individual autonomy of elderly patients approaching the end of life and the state acting as a paternalist agent in protecting and promoting their rights.

The sufficient provision of palliative care is considered to be a global human rights issue [1-4]. The World Health Organisation (WHO) estimated in 2011 that 56 million adults died in that year, of which about 29 million adults needed palliative care at the end of life, of which at least 3 million failed to receive any care at all at the end of life [5]. In 2014 we published revised estimates of the proportion of the population, in high income countries, who could benefit from palliative care based on inclusion of no,-cancer diagnosis, multiple morbidity contributing to death and changing place of death. In a collaborative study with Murtagh et al, we estimated that between 69-82% of people who die could benefit from some form of palliative care to support their end of life care needs, although not necessarily specialist palliative care [6]. This type of care would include symptom relief, not only pain, but also breathlessness, terminal agitation and also support in the four other domains of psychological, social and spiritual/existential needs at the end of life. It was similar to the estimate of 75% by Gomez-Batiste et al based on chronic disease prevalence reflecting that almost everyone who does not have an ‘unexpected’ death, which we estimated to be about 25% of the population, may need at least some element of palliative care [6-8].Correct this reference to be 7,8.

The topic of autonomy at the end of life for elderly patients has been chosen because of the magnitude of the public health policy challenge in protecting and promoting the autonomy of one of the largest groups, numerically, in high income countries, who are at significant risk of being deprived of their autonomy and human rights [9, 10]. It is the elderly (aged 75 years and older) who comprise the majority of people who die in high income countries [9]. In England for example, in 2016, 68.2% (333, 590 people) of those who died were aged 75 years or older at death [11]. Indeed 194,715 (39.8%), four out of ten, people who died were aged 85 years or older at death [11]. The size of this group is rapidly growing because of demographic change, both due to increased life expectancy and the aging of the ‘baby boom’ population who were born after the Second World War [11-14]. Similar changes are seen in Poland, the population is aging but there are still very striking differences in life expectancy between males and females with just under half (46.7%) of men and almost three quarters of women (73.3%) of women dying aged 75 or older [15]. Yet, despite the size of the population affected and the diversity of ethical issues faced by elderly patients at the end of life and those who care for them, this subject has been underexplored in the bioethics, palliative care and gerontology literature and the concepts are poorly understood within public health and end of life care policy [16-18].

It is not simply that populations are aging but the number of younger people of working age who could help care for the elderly at the end of life is, in many countries, reducing. The relationship between the numbers elderly, who may need caring for, and the numbers of people of working age who could potentially care for them is described by the ‘dependency ratio’. Dependency ratios (ratio of people aged $\geq$65 years to people of working age) are, in general, increasing across high income countries, but across Europe there are difference. In Poland the dependency ratio is 20.1% (just over 5 people aged 65 years to every 1 person of working age), compared with the EU average of 29.9%. Dependency ratio is complex as it depends of age profile of the population, birth rate, life expectancy and inward and outward migration. However, the countries with the highest rates, such as Italy at 34.8%, have significant challenges in the workforce to care for the elderly [19, 20]. Across Europe the shortage of people to care for the elderly presents significant challenges to the protection and preservation of their autonomy as they approach the end of life.

Palliative and End of life care (P&EOLC) is recognised under international human rights’ legislation as a basic human right. Under Article 12 of the International Covenant on Economic, Social and Cultural Rights and Article 7 of the International Covenant on Civil and Political Rights, ‘all member countries of the United Nations are obliged to safeguard patients at the end of life against pain and suffering, allowing them to die with dignity. While the importance of human rights in P&EOLC has been widely discussed in the literature the focus on human rights has been almost exclusively a focus on relief of pain and other symptoms and the right to access symptom relieving medication such as opiates [2, 3, 5, 21-23]. Interpretations of the role of dignity of the dying patient as a human rights issue have been limited to a focus on ensuring patients die without suffering pain and other terminal symptoms. Access to P&EOLC has been advocated by international organisations as ‘a human right based on the right to the best attainable standard of physical and mental health’ [3]. The Lisbon Challenge was produced by the European Association for Palliative Care

(EAPC), the International Association for Hospice and Palliative Care (IAHPC) and Human Rights Watch (HRW) to promote better quality of and access to palliative care [3].

Elderly patients are extremely vulnerable as they approach the end of life because of physical and mental frailty and so P&EOLC for the elderly requires an acute awareness of this vulnerability and appropriate action to address a whole range of human rights' issues [10]. While the United Nations have recognised that elderly people need special attention to protect their human rights [10], there is no published literature to date on the specific human rights of elderly people at the end of life. This thesis will elucidate a broad range of aspects of human rights which require attention in the elderly, some of which differ from the needs of younger dying patients. Physical frailty alone reduces the individual's ability to take autonomous actions even in the most basic daily tasks and forces reliance on others for example professional and family carers [17, 18]. However, it is the high prevalence of loss of mental capacity in elderly patients due to dementia-like conditions which really impacts on their autonomy and leaves them especially vulnerable to potentially paternalistic decision making by others [24]. Alzheimer Europe published estimated prevalence rates of dementia in Europe for 2013 [25]. For Poland the estimated prevalence was 1.31% of the population (38,317,090), slightly lower than the EU average of 1.55%. In the UK, the prevalence is 1.65% of the population (62,796,099). In England, 22% of patients, on average 108,400 per annum, die with a diagnosis of Dementia, Alzheimer's or Senility mentioned on their death certificate indicating a severe degree of reduction of mental capacity [11]. This is likely to be an underestimate as the dementia must have been severe enough for the doctor writing the death certificate to mention it [26]. In a study of people with clinically diagnosed dementia only 63.6% had this recorded on their death certificate in 2013 [27]. Thus, applying this estimate to uplift our findings, perhaps as many as 170,440 people are dying in England every year with dementia which would equate to 34% of those who die. This compares with around 137, 000 deaths from cancer (as underlying cause) to which most of specialist palliative care expertise and resource is currently directed and about which most of the research in palliative care to-date has been published [11, 28, 29].

The first national End of Life Care Strategy was published in England in 2008, a decade ago [30]. It initiated a tranche of wide reaching policy initiative and actions including the establishment of: a National End of Life Care Intelligence Network (NEoLCIN), the team which I have led since 2010, to analyse and monitor trends in need and quality of care [31]; a National Social Marketing Programme, called 'Dying Matters', to raise awareness of, and behaviour change with respect to, planning for dying and death [32]; and a plethora of initiatives to improve the quality of care provided by the National Health Service [33]. Ensuring patients were give choice about their care, and involved in decision making with doctors about their care, was a key theme in the first national End of Life Care Strategy[30]. However, the emphasis on giving patients choice especially centred on choices about place of care and place of death. This was based on early, population based, survey work suggesting most people would prefer to die at home [30, 34, 35]. The national strategy was led by specialists in P&EOLC and based on the already successful model used to transform and improve the quality of cancer services in England. This involved having a national strategy, an intelligence function to monitor progress and local policy initiatives [30].

As I started the work for this thesis, the government's responses to the Independent Review into the Liverpool Care Pathway for the Care of the Dying Patient (LCP) were just underway [33,39]. The LCP had been widely adopted in the UK as national policy initiative to improve the quality of end of life care for patients in their hours of life [36, 37]. Indeed its use was promoted in the 2008 National End of Life Care Strategy [30]. It had also been widely adopted internationally [36, 38]. However, problems in its practical application in England by doctors working general hospital wards with elderly non-cancer patients, as opposed to palliative care specialists in specialist units with cancer patients emerged. These included: a 'tick box' approach to the process; failure to respect patients' autonomy and obtain informed consent from patients themselves or discuss care plans with relatives; deep sedation of patients and withheld or withdrawn hydration and nutrition [36, 39-41]. This inappropriate use of the LCP led to public out-cry and national media coverage first in 2009 and then 2012 with titles such as 'Sentenced to death on the NHS' [42-44]. The Government responded by commissioning Baroness Julia Neuberger to undertake an independent review into the LCP which was published in July 2013 [39]. The findings of the review and public vitriol shook the Specialist Palliative Care Community and opened up to public scrutiny the whole debate about the autonomy of the dying patient as exemplified by the cases described in Baroness Neuberger's review report called 'More Care: Less Pathway' [39]. The review stimulated a government-led, system wide, response and influenced the formulation of an updated national strategy – 'Ambitions for Palliative and End of Life Care - A Framework for Local Action 2015-2020', which was published in 2015 [33]. The emphasis on choice has been reduced in the Ambitions Framework in favour of terms like 'patient and family centred care'. However, as will be shown in this thesis, the emphasis on choice, especially with respect to place of death, in the implementation of national policy has barely diminished.

National policy on P&EOLC in England is supported by a range of legislation designed to promote and protect the autonomy of patients in general but some, especially the Human Rights Act 1998, the Mental Capacity Act 2005, the Equality Act 2010 and the Care Act 2014 have particular significance in End of Life Care [45-48].

The development of palliative care services of a country is dependent on government policy, investment, education in palliative care and implementation of palliative care programs based on local cultural, social, psychological and financial structural frameworks [49]. There is good evidence that during the decade since the publication of the first national strategy for EOLC that there have been significant improvements in care [11]. In 2010, the United Kingdom was in the highest category in a global mapping exercise of existing palliative care services amongst 40 other countries, where a comprehensive provision of palliative care at the end of life existed, supported by a national palliative care association and the involvement of multiple service providers [50]. In 2015, a study reported by the Economist Intelligence Unit showed that the United Kingdom ranked first in the 2015 'Quality of death Index' amongst 80 other countries researched on their quality of palliative care with a score of 93.9 [51]. Poland was ranked 26th with a score of 58.7. Both the UK and Poland have national strategies for developing infrastructure, training workers and promoting the concept of palliative care. However, a key differences between the UK and Poland was described in this report was the specificity of the vision, and the presence of clearly defined targets. The countries of the UK have action plans, known as national strategies or frameworks and monitoring mechanisms to drive the achievement of targets. In Poland milestones have been specified achieved but not yet specific targets [51].

This of course by no means translates into everything being perfect in England and one of the areas requiring significant further work is providing good end of life care for elderly patients [31]. Death has been described as a social justice issue and there are many areas of social injustice with respect to access to P&EOLC for elderly patients, especially with respect to the social care element of this [52].

If a single criticism could be levelled at P&EOLC policy and practice in England it would be that there has been little significant engagement of experts in the care of the elderly or of elderly people themselves despite the fact that the elderly account for the majority of people who die (Professor Malcolm Johnson unpublished report). However, there is hope for the future as a few publications are starting to explore the relationship between palliative care specialists and geriatricians [53-55].

Despite this ray of hope, to date there is a paucity of research, worldwide, but specifically in England on what good end of life care would look like for elderly patients and how they would like to exert their autonomy with respect to it [17]. This thesis reviews some of this evidence. It also reviews the current legislative, policy and regulatory frameworks in England intended to protect and promote the autonomy of elderly patients at the end of life. It explores specifically the role of the state as an agent of beneficent paternalism in protecting and promoting the elderly person's autonomy and identifies the benefits and risks of state paternalism.

I also selected this topic for the thesis because I am uniquely placed to undertake the interdisciplinary research which was necessary to explore the ethical questions. I have been working at a national level in England in P&EOLC policy for over 12 years and over 20 years in total in P&EOLC as a Public Health Specialist. I am national lead for P&EOLC at the national public health agency – Public Health England. As part of my responsibilities I direct the National End of Life Care Intelligence Network (NEoLCIN), established in 2010, to provide system wide support through statistical analysis, reports and interactive tools to inform national and local stakeholders about patterns of need, provision and outcome in end of life care [31, 56]. I have been a member of the National Steering Committees or governing boards for policy making in England since 2007. I also have a wide portfolio of research interests and collaborations in end of life care, which extend beyond epidemiological analysis of data. A list of my peer review publications and abstracts which have helped inform and contextualise the research for this thesis are presented in the Appendices.

From a personal and professional level I chose this topic because I knew it was under-researched and it gave me the opportunity for significant professional development, learning in a new but allied field to my own. I was also confident that the results would have important and immediate implications for policy and most importantly for elderly patients.

The simultaneous start of work on my thesis, with the opportunity to be closely associated with the analysis of went wrong with the LCP and the series of policy initiatives, national audits and other activity which followed, gave me a unique opportunity to critically analyse and reflect on what autonomy means for the dying elderly patient and how public health policy should respond to protect and promote it [41].

The thesis adopts an interdisciplinary approach to analyse the key facilitators and obstacles to protecting and promoting autonomy in elderly patients at the end of life. It draws on evidence from medicine, psychology, sociology, ethics, law and public health practice and policy. Similar interdisciplinary approaches have been used for example in the Hastings Centre Report by Zimmerman on Public Health Autonomy [57] and a Study of Assisted Suicide and the Right to die by Rosenfeld which looked at the interface of social science, public policy and medical ethics [58].

Most work in bioethics at the end of life focusses on end of life care decision making either for children or young adults on life support facilities or on questions related to withholding or withdrawing treatment or physician assisted suicide or euthanasia [59]. Very few papers address the extremely prevalent ethical challenges faced on a daily basis by millions of elderly people world-wide as they approach the end of life, each one of which would hardly register on a medical ethics ‘Richter’ scale, if such a thing existed. However, the enormous numbers of people affected and the cumulative nature of daily ethical challenges faced by elderly patients, their families and professionals are important from a public health perspective as they impact on the wellbeing of all concerned [60-68]. Guevara-Lopez et al. examined the values which clinicians recognised as important in the daily, small, ethical decisions to be made in end of life care and summarised them as: truth telling, justice and professional humility [66]. For the elderly patient decisions made by doctors and family members without involving the patient may affect the quality of their last days and hours of life. However, there is also good evidence that the decisions which affect the way people die impact also on the health and wellbeing of the family left behind [69, 70]. So, from a preventative, wellbeing perspective, good ethical decisions in end of life care for elderly patients are important to the population’s health and in England, may impact on over 1.5 million people every year [11]. Good ethical decisions at the end of life for elderly people also has resource implications for example, failure to respect an elderly patient’s wish not be admitted to hospital when they are dying leads to distress for the patient and family but also unnecessary hospital costs.

A key thread running through the thesis is the exploration of good end of life care as a human rights issue [3, 21, 23]. To this end a framework derived from the UK Human Rights Act

1998, which itself is derived from the European Convention on Human Rights, is used throughout this thesis as structure for the critical analysis of the evidence [45]. This is supplemented, where appropriate, by evaluation against other ethical principles.

1.2. The aims of the thesis and ethical issues to be explored

The aims of this thesis are to:

- Identify, through multi-disciplinary literature review, what is known about the way in which elderly patients wish to exert their autonomy as the end of life approaches and the most important factors from their perspective which can protect and promote their autonomy.
- Conduct a critical analysis of the current situation in England comparing what is important to elderly patients and the type of care they currently receive.
- To critically examine the role of the state, using England as the exemplar, in protecting and promoting the autonomy of elderly patients at the end of life especially using a human rights framework.

1.3. Structure of the thesis

The structure of the thesis is as follows:

Chapter 1. Introduction

This chapter describes the rationale for choosing the research topic described in this thesis. It highlights why it is not only a topic of national importance in England but for all industrialised countries. The chapter describes also the aims and outline of the chapters. It concludes with a very brief summary of outputs from the work presented in this thesis.

Chapter 2. Background

This chapter will expand on the rationale for focussing on end of life care for elderly patients, highlighting statistics on recent trends in age at death, causes of death in the elderly and place of death where care is provided. The chapter will also give a brief summary of the chronology of the development of Palliative and End of Life Care in England, policy and relevant legislation and compare and contrast this with Poland.

Chapter 3. The meaning of autonomy for elderly patients approaching the end of life

The desire to have autonomy in end of life care stems from people's interest in making significant decisions about their lives for themselves, and importantly, in coherence with their own values or conception of a good life, especially as their life approaches its end. This chapter critically appraises the published literature regarding what is known about elderly patients wishes as they approach the end of life, for care, death, dignity and how or indeed if they wish to exert their autonomy.

Chapter 4. The relationship between individual autonomy in elderly patients approaching the end of life and human rights

The chapter critically appraises, from the elderly patient’s perspective, whether policy and legislation, most specifically the Human Rights Act 1998, are helping to achieve their wishes. It elucidates some of the dilemmas encountered in evaluating the success of attempts to protect and promote the individual autonomy of elderly patients in P&EOLC when a human rights framework is used.

Chapter 5. Paternalism and the state – how does it use its powers to protect and promote the autonomy of elderly patients at the end of life?

This chapter describes and critically evaluates the role of the state as a paternalist agent in creating the environment within which elderly people are trying to exert their autonomy at the end of life. It use a broad definition of the state which refers to the civil government of a country including the services provided by the state [71]. This includes the three branches of the state: Legislative, Executive and Judiciary which cover the functions of the Government, Parliament, the Judiciary and the Public Sector. A framework suggested by Huxtable to analyse the state’s role based on ‘ the duty to respect life; the obligation to alleviate suffering and the need to respect patient autonomy’ [72] is supplemented by Articles from the Human

Rights Act 1998 [45]. The chapter examines whether the state's paternalist role is successful in protecting and promoting the autonomy of elderly patients and if so what form of paternalism is used.

Chapter 6. Beneficence, non-maleficence, justice and autonomy in state policy in Palliative and End of Life Care in England: the impact on elderly people

This chapter continues the theme of the state as a paternalist agent in protecting and promoting autonomy for elderly people at the end of life. It applies the Beauchamp and Childress four principles of bioethics [73]: beneficence, non-maleficence, justice and autonomy to a framework to critically appraise the state in England's approach to P&EOLC for elderly patients. The framework is used specifically to critique the extent to which national policy and legislation, which have supported the development and the delivery of P&EOLC in England, since the publication of the first national strategy in 2008, do so in a beneficent and just manner [30].

Chapter 7. Concluding Remarks

This chapter pulls together the threads from the proceeding chapters to summarise they key findings, draw conclusions and make recommendations for future work.

1.4. Outputs from the work presented in this thesis

The work towards this thesis has already influenced directly and indirectly a number of scientific publications and abstracts presented at International Conferences for example the European Association of Palliative Care (2015, 2016, 2017 and 2018). Findings from this research are used on an almost daily basis to promote debate about policy and its implementation and to guide new research. There is still a lot of work in progress to use the analyses and learning from this thesis to write both peer review articles and policy documents. In the list of peer review publications and abstracts accepted for conference presentation shown in the Appendices, those which derived directly from the work for this thesis are shown in Appendix 1.

Chapter 2. Background

2.1. Scope of this chapter

This background expands on the context within which the care of elderly patients approaching the end of life in England takes. The chapter defines terms which will be used in this thesis such as Palliative and End of Life Care, autonomy and paternalism. A brief introduction to the importance of autonomy for elderly people who are approaching the end of life is given and this is expanded upon in the Chapter 3. The chapter also defines and expands on the concept of paternalism, which will appear throughout the thesis.

This background described the epidemiology of P&EOLC for the elderly in England, but similar patterns are being seen certainly in Belgium where they have similar types of epidemiological analysis [74]. The epidemiological analysis gives an understanding of the magnitude and characteristics of the challenges in providing good P&EOLC for elderly people from a population perspective. The analyses are produced by my team, the National End of Life Care Intelligence Network (NEoLCIN), under my direction [75]. Demographic trends in age of death and causes of death are shown as well as data describing where elderly people are cared for and die at the end of life and temporal trends in this. The chapter highlights the importance of family as carers for elderly people and the sad predicament of those who have no-one to care for them.

In the second half of the background there is description of the key legislation and policy initiatives which have shaped the development of P&EOLC in England over the past decade and which I will critically appraise in this thesis for their impact on the autonomy of elderly people. While some of the detail, for example, policy and legislation is England specific, even this has generic relevance.

2.2. Definitions of Palliative and End of Life Care

This section defines both Palliative and End of Life Care. The definition of palliative care is international [76] and increasingly, in the European literature, the term supportive is used alongside palliative [77]. Professionals working in the care of people at the end of life also recognise both a type of practice and population groups, especially the elderly needing care which is out-with the definitions of specialist palliative care and provided by generalists and so the term end of life care is also becoming more widely used [78]. In line with current policy, in England, the phrase ‘Palliative and End of Life Care’ (P&EOLC) will be used to describe care using palliative principles and employed intentionally (as opposed to just normal care) to elderly patients in the groups defined within the end of life definition in section 2.2.2. It covers the spectrum of care from specialist to generalist end of life care.

2.2.1. Palliative Care

The World Health Organization (WHO) 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’ [5]. In palliative care, emphasis is placed on treating the whole person. Palliative care has been described from the perspective of the patient as:

- providing relief from pain and other distressing symptoms,
- affirming life and regards dying as a normal process,
- intending neither to hasten or postpone death,
- integrating both psychological and spiritual aspects of care,
- offering a support system to for patients to live as actively as possible until death. Indeed, palliative care aims to improve the quality of life and in some cases may even prolong it.

In addition palliative care helps and supports families during the phase of caring and before death and during bereavement.

Importantly palliative care is provided through the efforts of multi-disciplinary teams and by a range of health and social care staff [33]. Sometimes a distinction is made between specialist palliative care, led by doctors who have a specialisation in palliative medicine and specially trained nurses, and generalist palliative care which can be provided by doctors from any specialty and other health professionals. Most of the P&EOLC, if planned as such, that elderly patients receive, is provided by GPs (family doctors), geriatricians and a whole range of specialisations and ranks of hospital doctors. Community nursing services are also major providers of non-specialist P&EOLC care to elderly people living in their own homes or care homes [33].

2.2.2. End of Life of Life Care

The General Medical Council, for the purposes of their guidance for doctors on treatment and care towards the end of life have defined patients are ‘approaching the end of life’ when they are ‘likely to die within the next 12 months’ [79]. This includes ‘patients whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions,
- general frailty and co-existing conditions that mean they are expected to die within 12 months,
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition,
- life-threatening, acute, conditions caused by sudden catastrophic events’.

2.2.3. Supportive Care

Despite the definitions given above, many health professionals still regard palliative care as appropriate for patients only when all attempts to ‘cure’ the person have failed. In England, the term supportive can be used together with palliative care, as for example in the National Institute for Health and Clinical Excellence (NICE) Guidance. This helps to counteract a harsh distinction between ‘active treatment’ while a cure still seems possible and ‘palliative care’ when there is no hope of cure [80].

Indeed, it has been suggested that, when a patient is given a diagnosis of a life-threatening, illness, their care should have several strands:

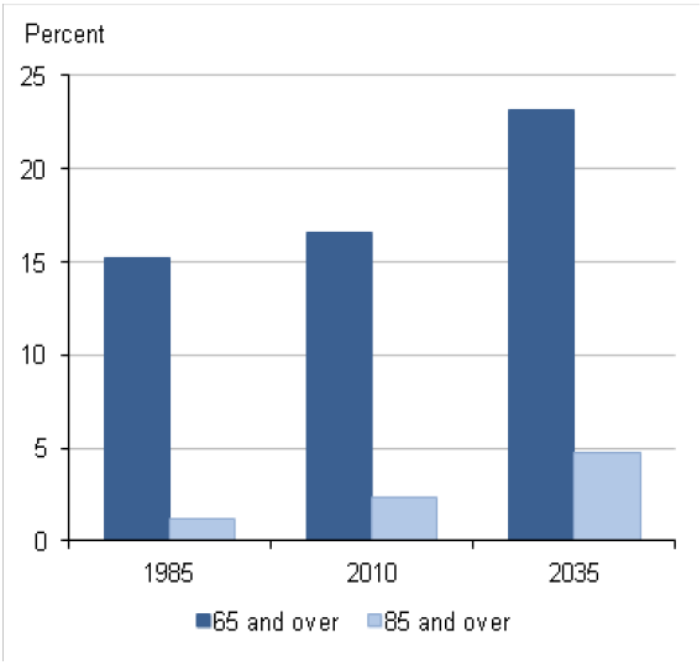
- Disease-directed therapy, which attempts to control the disorder itself.
- Care directed to the patient as a person, which covers more generic aspects of illness such as pain relief, rehabilitation, social and psychological support.
- Support for the family in caring for the patient and also bereavement support after the patient’s death [80].

Indeed, the definition of supportive care describes the type of care which many elderly people should receive as routine as the majority will have accumulated one or more condition which while not immediately life threatening increases their risk of death.

Sometimes, parallel planning is used in the same context, for example for liver disease in the 2nd Lancet Commission Report on Liver Disease [81].

2.3. Demographic change is driving the focus on the needs of the elderly for palliative and end of life care

The population of England, as across the industrialised world, is aging. Figure 1 below shows how the proportion of older people (≥65 and ≥85 years old) in the UK has changed and is projected to change up to 2035. Over the next two decades, the number of people aged 85 years and older in England will double and those aged 100 years and older will quadruple. The UK is now defined as an 'aged society' and by 2035 it will become a 'super-aged society' based on the proportion of the population aged 65 years and older [9, 82, 83].



Source: Office for National Statistics, National Records of Scotland, Northern Ireland Statistics and Research Agency

Figure 1. Percentage of older people in the UK 1985, 2010, 2035

The majority of people who die in England are aged 75 or older (68% in 2016) and this proportion has changed little over recent years [11]. However, rapid increases in life expectancy have meant that mortality and overall numbers of deaths temporarily reduced over the past two decades but they are both starting to rise rapidly and it is the elderly and very elderly who are contributing to a large projected rise in numbers of deaths.

Figure 2 shows the number of deaths in 2016 (490,791), the fall from 529,034 in1995 and the projected 26% increase in the number of deaths from 2016 to 2040 (616,479). Figure 3 shows how, over the past decade, the number of deaths in people aged 75-84 years has fallen, because of increased life-expectancy. For a period, older people appear to have achieved immortality, but in fact their age at death is just being postponed and so there are increasing numbers of people dying aged 85 years and older. The proportion of all deaths that occurred in those aged 85 years and older has increased from 35% in 2007 to 40% in 2016 while the proportion of people that died between 75 and 84 years has decreased from 32% in 2007 to 28% in 2016. Similar projections have been found by others [14]. Overall, the total number of deaths and proportion of total deaths in people aged 75 years and older has increased as a whole from 310,616 (66.4%) in 2006 to 333,590 (68.2%) in 2016 [11]. This will present many challenges for public health end of life policy in terms of care provision and ethical challenges [13, 14].

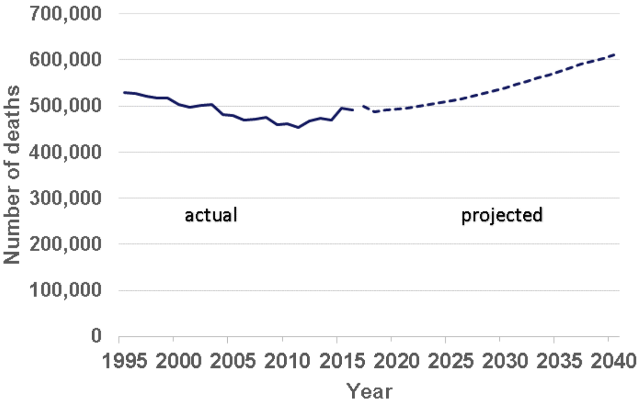


Figure 2. Actual and projected number of deaths in England 1995 to 2040

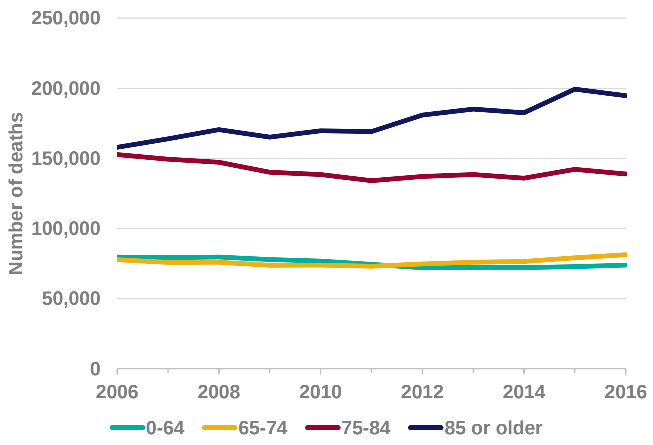


Figure 3. Number of deaths by age at death, England 2006-2016

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract Produced by National End of Life Care Intelligence Network

The age distribution of deaths projected for future years is shown in Figure 4. In 2040, 51% of all deaths (317,038 deaths) are projected to be in those aged 85 and older, compared to 40% of all deaths in 2016 (194,715 deaths). This means that the profiles of conditions that people live with and die from will change, probably with even more frailty and dementia and multi-morbidity. It will also affect the type of care which will be needed. This also would suggest that more care home places will be required as indicated by the projections produced by Etkind et al 2018 [62]. Interestingly, the difference in the age at death between males and females is projected to reduce, with females making up 55% of people dying aged 85 or older in 2040 compared to 62% in 2016. This narrowing of the age at death between males and females means that the number of elderly people living alone may reduce and care may need to focus more on frail couples than frail individuals. This will introduce a new dynamic into the concept of autonomy as it may be the shared priorities for autonomy of a couple, along the lines of ‘til death do us part’, rather than individual priorities of elderly people that health and social care will have to consider more frequently in the future [84, 85].

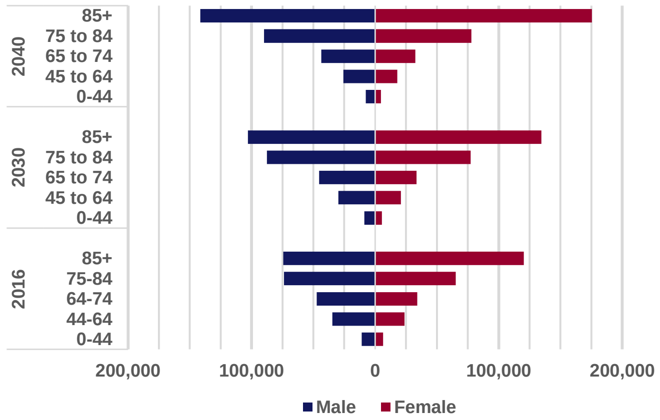


Figure 4 Current and projected number of deaths by age and sex, England 2016, 2030 and 2040

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract Produced by National End of Life Care Intelligence Network

The specific care needs of people toward the end of their life are influenced by their underlying illnesses. Some of the changing patterns of cause of death in the past decade are illustrated in Figure 5. There have been reductions in the number of people dying from stroke and heart disease, especially between 75 and 84 years of age and the number of people dying with dementia recorded as an underlying or contributory cause of death has increased considerably [11]. In some regions of England one in four people die with dementia [11]. The future is likely to see this trend continue, with even more people at the end of their life suffering from dementia due to the expected increase in the number of people dying in their late eighties or later.

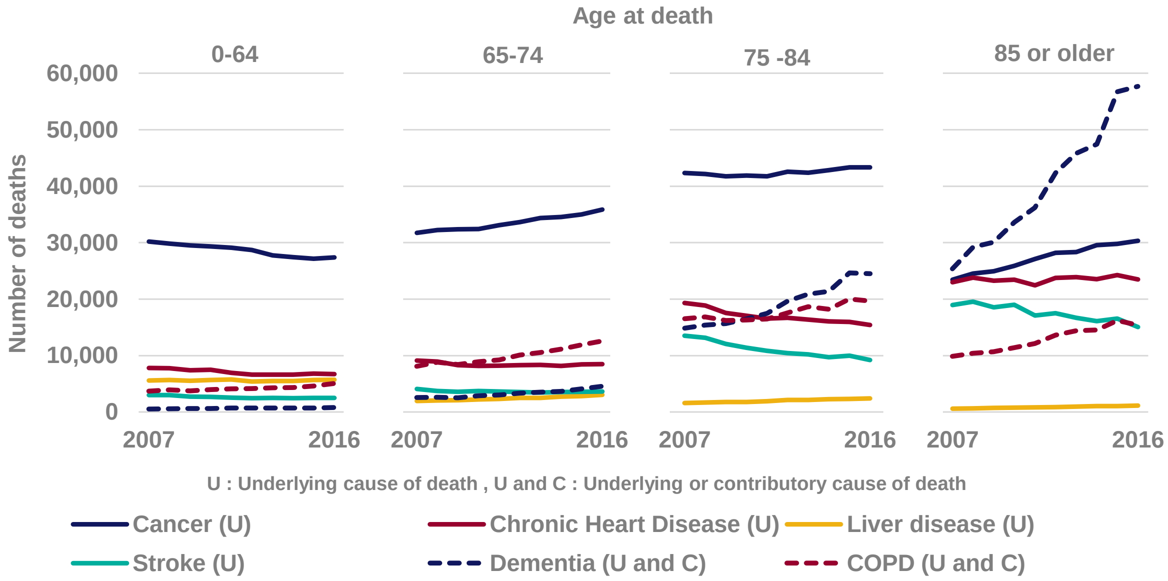


Figure 5 Number of deaths, selected causes of death by age at death, England 2007-2016

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract. Produced by National End of Life Care Intelligence Network

Place of care at the end of life and place of death are important to many people [86, 87]. However, more nuanced analysis shows that symptom control and being surrounded by loved ones and being treated with dignity is more important than place [16, 87-90]. Cause of death, age, socioeconomic status, type of residence before death (own home or care home) and social support such as whether they are married or have family to help care for them influence where patients die [87, 91-93]. However, often patients' wishes to stay at home are not respected because they have not previously discussed this with relatives and doctors and more importantly there is no documentation to evidence this. An increasing number of studies have shown that Advance Care Planning (ACP) increases the chances that patients will die in their preferred place [86, 94]. Although many elderly people would prefer to die in their own home, or a hospice, half of all deaths occur in hospital and very few ~2% (aged 85+ years), occur in a hospice. The NEOLCIN has been monitoring place of death at a national and local level as a proxy indicators of quality of care. Table 1 shows the number and percentage of deaths by place of death in 2007 and 2016. Over this period the proportion of deaths in hospital has fallen by 9.0%, from 55.9% to 46.9% while the proportion of deaths in care homes and at home have increased.

Table 1. The number and percentage of deaths by place of death, England 2007 and 2016

Place of death	2007		2016	
	Number of deaths	Percentage of deaths	Number of deaths	Percentage of deaths
Hospital	261,798	55.9%	229,095	46.9%
Home	91,757	19.6%	114,700	23.5%
Care Home	79,644	17.0%	106,641	21.8%
Hospice	24,644	5.3%	27,721	5.7%
Other Places	10,725	2.3%	10,779	2.2%

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract Produced by National End of Life Care Intelligence Network

Age affects place of death. People who die aged 75-84 have the highest proportion of their deaths in hospital. Those who die aged 85 years and older have the lowest (but still high) proportion of their deaths in hospital and the lowest chances of dying at home or in a hospice. They have the highest proportion of deaths in care homes as this is where many live. [11]. Yet care home is the least preferred place of death [95].

Tables 2a & 2b. Distribution of deaths by place of death and age at death, England 2016

Number of deaths	Hospital	Home	Care home	Hospice	Other Places	Total
All ages	229,095	114,700	106,641	27,721	10,779	488,936
0-64	33,712	25,122	2,148	7,725	5,295	74,002
65-74	39,995	24,611	6,960	8,156	1,622	81,344
75-84	70,126	33,089	25,979	7,795	1,886	138,875
85+	85,262	31,878	71,554	4,045	1,976	194,715

Percentage of deaths	Hospital	Home	Care home	Hospice	Other Places	Total
All ages	46.9	23.5	21.8	5.7	2.2	100.0
0-64	45.6	33.9	2.9	10.4	7.2	100.0
65-74	49.2	30.3	8.6	10.0	2.0	100.0
75-84	50.5	23.8	18.7	5.6	1.4	100.0
85+	43.8	16.4	36.7	2.1	1.0	100.0

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract Produced by National End of Life Care Intelligence Network

Cause of death also affects place of death, with a particularly high proportion of deaths from liver disease, stroke and chronic obstructive pulmonary disease occurring in hospital, a high proportion of deaths with dementia occurring in care homes and a dominance of cancer deaths in hospice. The distributions are shown in Tables 3a and 3b.

Tables 3a & 3b. Distribution of deaths by place and cause of death, England 2016

Number of deaths	Hospital	Home	Care home	Hospice	Other Places	Total
All	229,095	114,700	106,641	27,721	10,779	488,936
All cancers	49,801	42,018	18,943	23,898	2,236	136,896
Chronic Heart Disease	22,056	20,924	8,814	629	1,701	54,124
Liver disease	7,262	3,179	743	966	175	12,325
Stroke	18,968	3,249	7,770	241	215	30,443
Dementia*	27,111	8,566	50,410	649	801	87,537
Chronic obstructive pulmonary disease*	31,491	12,816	6,312	1,515	591	52,725

Percentage of deaths	Hospital	Home	Care home	Hospice	Other Places	Total
All	46.9	23.5	21.8	5.7	2.2	100
All cancers	36.4	30.7	13.8	17.5	1.6	100
Chronic Heart Disease	40.8	38.7	16.3	1.2	3.1	100
Liver disease	58.9	25.8	6.0	7.8	1.4	100
Stroke	62.3	10.7	25.5	0.8	0.7	100
Dementia*	31.0	9.8	57.6	0.7	0.9	100
Chronic obstructive pulmonary disease*	59.7	24.3	12.0	2.9	1.1	100

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract Produced by National End of Life Care Intelligence Network

Notes: Neonatal deaths excluded. Cause underlying cause of death except * which are deaths with “any mention” of the condition. These latter deaths may also be reported in another category

Over the past decade, just as the overall trend in place of death has been changing it has also for specific causes of death. These trends are shown in Figure 5.

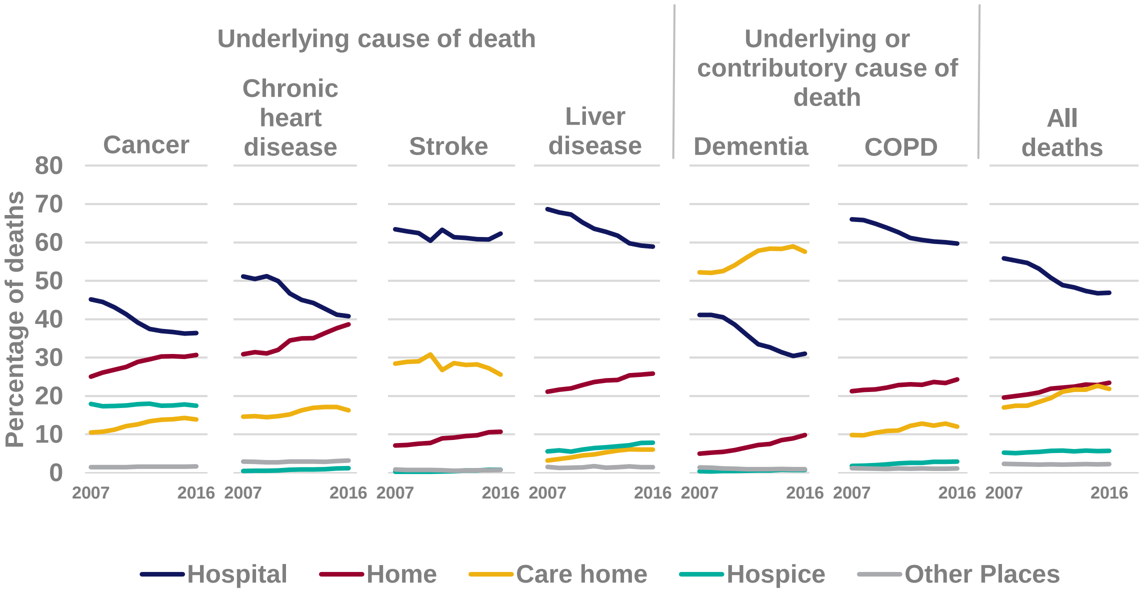
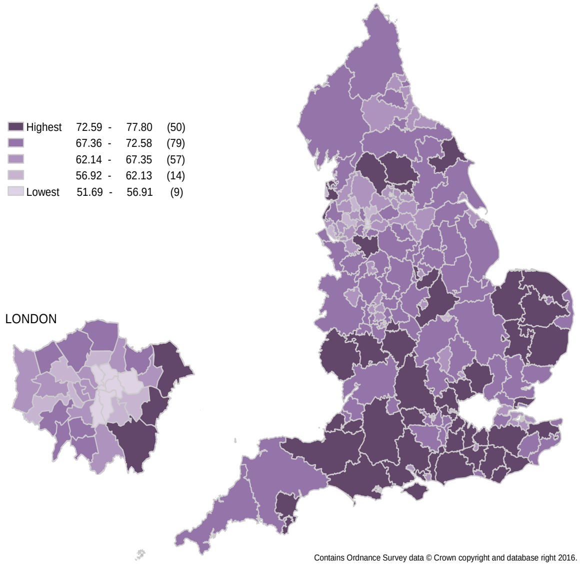


Figure 5. Trend Percentage of deaths in each place of death by selected cause of death, England 2007-2016

Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract linked to Hospital Episode Statistics. Produced by National End of Life Care Intelligence Network

The following maps taken from our Atlas of Variation in Palliative and End of Life Care show that the challenges of providing high quality P&EOLC to elderly people, across England, vary in magnitude and complexity [11]. For example, Map 1 shows that the proportion of the local Clinical Commissioning Group [(CCG), (local health administrative area (209 in England)] population dying aged 75 years and older varies from 52% to 78% i.e. from half to just over three-quarters of those who die. Some CCGs have more elderly people so their services need to be more tailored to the needs of the elderly. Map 2 shows data from the 2011 census on the proportions of elderly people aged 65 years and older who live alone in their own homes. This varies from 25% to 45% by Local Authority (local government area). Living alone increases with age and by the time people reach the age of 85 years, almost 60% of those in their own homes will be living alone. This not only presents challenges for care but may also lead to loneliness and depression and even a wish to hasten death [17, 96-103]. Map 3 shows the variation by CCG in proportion of all people who died aged 75 years and older in a care home (2015). The range was 10 - 43%. The number of care home places per 100 people alive and aged 75 years and over also varies geographically. The scatter plot in Figure 6 shows that while there appears to be what would seem to be an obvious relationship between availability of care home beds and people dying in care homes the R^2 value shows that the variation in availability of beds only accounts for around 30% of the variation seen in proportion of people who die in care homes. This indicates that other factors are important and these may include proximity of family members who can help to care, the local rate of Advance Care Planning (ACP), levels of home based social and health care and variation in causes of death among the elderly in different geographical areas.



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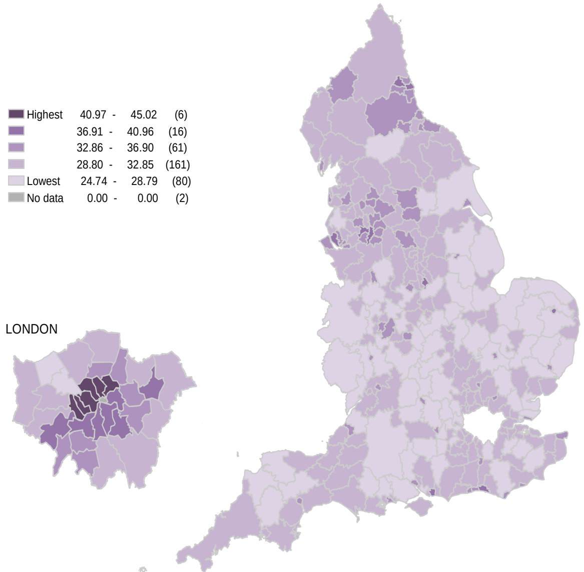
Map 1. Variation in the proportion of all people who died who were aged 75 years and older by Clinical Commissioning Group (2015)



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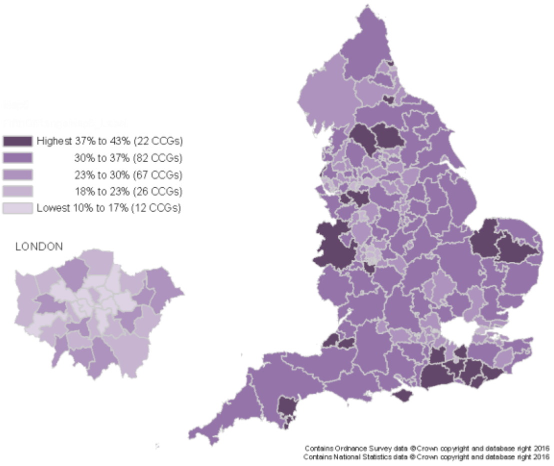
Map 2. Variation in the proportion of adults who are aged 65 years or older and who are living alone by Lower Tier Local Authority (2011)



Map 3. Variation by CCG in proportion of all people who died aged 75 years and older in a care home (2015) Range 10-43%

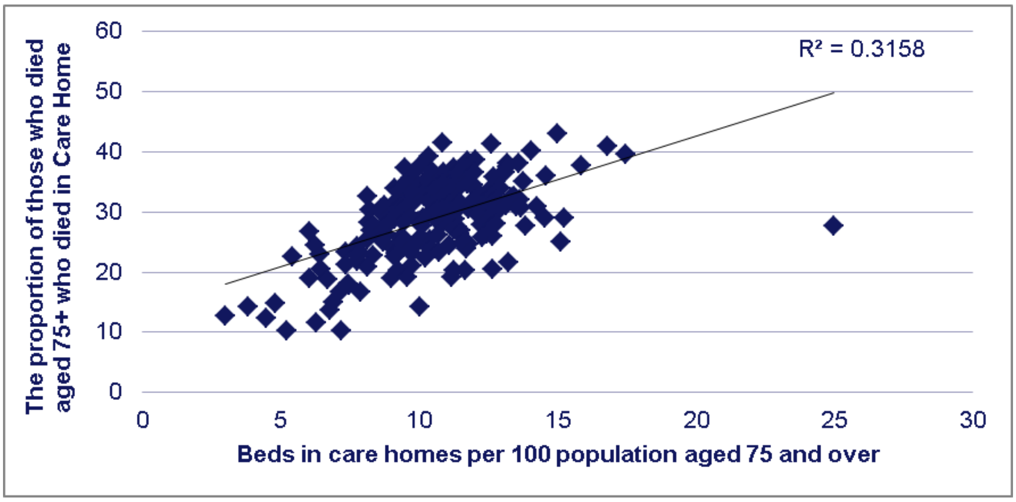
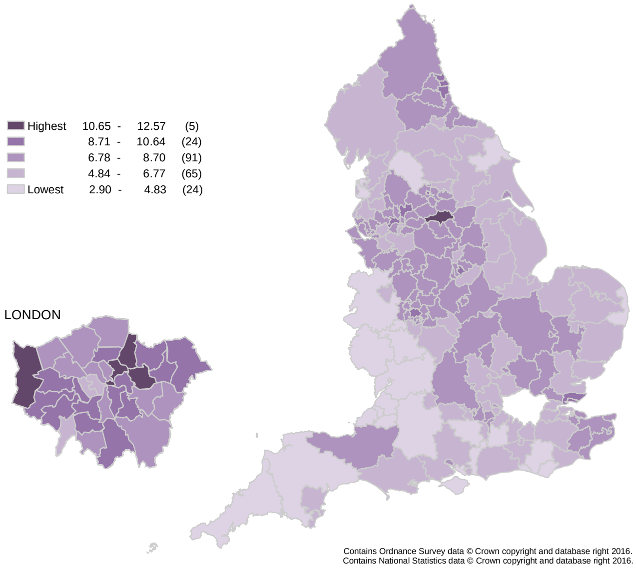


Figure 6. Variation in the relationship between proportion of people who died in a care home with number of care home beds per 100 people aged 75 years in the local population Clinical Commissioning Group (CCG) population in England.

Sources: Population; ONS Mid-Year Population estimates for CCGs; Deaths, ONS Mortality data; Care home beds; Care Quality Commission

Hospitals are important places of care towards the end of life for many patients even if they die in the community. Two thirds of people who died had a hospital admission in the final 90 days of their life and on average, 1 in 14 (6.9%) had three or more emergency hospital admissions during the last 90 days of life [11]. However, the risk of multiple admissions varies geographically as shown in Map 4. Many of the patients with multiple admissions are elderly and this primarily reflects inadequate arrangements to care for them in the community and absence of clear indications from patients, in ACP, as to whether they want these transfers. There is good evidence that multiple transfers between home/care home and hospital at the end of life is very distressing to patients and their families [104,105]. Older adults account for the majority of hospital deaths – 155,388 (67.8%) are aged 75 years and older at death and 85,262 (37.2%) are aged 85 years and older at death. The age profile of deaths in hospital reflects the age profile of deaths in the population 68% and 40% for people aged 75 years or 85 years and older respectively.



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Map 4. Variation in the proportion of people who have 3 or more emergency hospital admissions during the last 90 days of life by CCG (2015)

2.4. Why is autonomy important for elderly patients in end of life care?

The data presented above throw a light on some of the practical issues which may impinge on the autonomy of elderly patients needing P&EOLC. However, autonomy is not simply about arranging practical issues related to care [106]. Autonomy is important to people approaching the end of life for an optimal sense of psychological wellbeing, retaining identity and sentience as long as possible, as well as retaining at least some control over physical, social and spiritual matters where these are considered important to them [106-109]. The desire to have autonomy in end of life care stems from people's interest in making significant decisions about their lives for themselves, and importantly, in coherence with their own values or conception of a good life especially as their live closes [106, 110, 111]. Dignity and duty especially not to be a burden emerge as strong reasons for exerting autonomy in elderly people [106, 112-117]. These latter issues are important as they shift the raison d'être for having autonomy and decision making capacity from a simply egocentric focus to a potentially moral one which may take into account the impact of their decisions on other people [110]. Sometimes these two objectives are closely interwoven and sometimes autonomy can be used to further more prominently one or the other – the hedonist or the dutiful member of a family or society [107]. The feeling and reality of having control over what is happening is important for a sense of dignity and feeling of self-worth and efficacy [118]. From a medical point of view, importantly in end of life care, more people want to decide whether they do or do not have certain interventions or where they are cared for or die and who is present. Death is final, there are no rehearsals (usually) so many people want to die, in their own way, in a manner defined by them as so far as this is possible [119, 120]. Indeed, the most popular non-religious music played at funerals in England is Frank Sinatra's 'I did it my way' [121]. I will expand more on what is known empirically about the meaning and purpose of autonomy for elderly patients and policy makers' interpretation of autonomy at the end of life in Chapter 3 on autonomy. However, here I will expand a little on the extra complexities regarding end of life and autonomy in elderly patients.

As alluded to in the introduction, aging itself is often a long drawn out processes of declining autonomy produced by increasing physical frailty and sometimes gradual loss of mental capacity too [18]. Gradually the world for many elderly people shrinks as they are able to travel less away from the home, climb stairs, see to read or hear until even activities of daily living such as preparing meals, eating, going to the toilet or washing become difficult and they require support [18]. The autonomy to do physical things, including self-care, is lost as a process of aging and accumulation of disease processes results in sometimes steady, sometimes stepwise decline to death [99, 122]. Often the elderly patient experiences acute exacerbations associated with infections, or sudden worsening of morbidity already present, or the onset of new conditions [17, 104, 108]. Dependence on others to undertake activities of daily living increases so the elderly patient already have had to cede some of their autonomy to other people [19, 63, 123]. If they are fortunate to be a recipient in a true caring relationship, the way care is provided will maximise the elderly patient's autonomy [124]. As an elderly person becomes more frail they may need to move into a residential home which is better adapted to their physical ability and has non-nursing staff on site or a nursing home which has nursing staff [18]. There are very good descriptions in the literature about the acute and devastating feelings of loss of autonomy for the elderly person when this occurs and feelings of guilt in the family that they could not provide enough care to prevent it [17, 18, 113]. Of course for some elderly people the move is a positive choice as receiving help allows them to regain some autonomy or at least retain it when compared to being at home [125]. While the elderly person still has mental capacity they can exert their autonomy by expressing their likes and dislikes and asking for things to be done or not done and they can make plans for example what type of care they would prefer to receive if their physical state deteriorates further or they lose Mental Capacity to decide for themselves. In P&EOLC, the general term for this planning is Advance Care Planning (ACP), although there are many ways of doing this with different pros and cons which will be described in the chapter on autonomy [109]. Many elderly patients approaching the end of life have been experiencing a steady loss of autonomy for some time before they get close to death and this gives them time for reflection and decision making, if they chose to use it.

Most people fear a loss of Mental Capacity and being left in a state where everything must be done for us by others [126]. Dementia is common and may strike early when the person is still physically quite active or accompany physical decline. As describe in the introduction at least 22% of patients in England die with Dementia, Alzheimer’s disease or Senility mentioned somewhere on their death certificate and this is likely to be an under-estimate as it has to be severe enough for the doctor to mention it as contributing to death on the death certificate [11, 127]. Initially Mental Capacity will be fluctuating and guidance for doctors from the General Medical Council [79] is very clear, enshrined in the legislation of the Mental Health Act 2005 [46], that every effort must be made to involve patients in decision making. There should not be a blanket assumption of lack of Mental Capacity in a patient with a degenerative brain condition but for each decision large or very small the patients capacity to make it should be reviewed and every effort made to make it possible for them to participate using simple language, non-verbal cues or returning to the decision on another occasion [46, 79]. The best comprehensive summary of autonomy issues for patients with Dementia is the Nuffield Council for Bioethics Report on Ethics and Dementia [24].

2.5. Paternalism in end of life care

Paternalism if defined in a general sense ‘ is an action performed with the intent of promoting another’s good but occurring against the other’s will or without the other’s consent’ [128]. In the context of P&EOLC for elderly people, several players could have paternalistic roles: the state, in terms of policy initiatives, doctors and other health professional, institutions and family members [128-133]. As in the definition above, the intention of these potential paternalists is almost always to protect and promote the elderly patient’s good and wellbeing, however, in the complexities of P&EOLC, which require attention not simply to the management of medical problems but other domains of people’s wellbeing such as psychological, social spiritual and of course autonomy, it is easy for those caring for elderly patients to forget or unintentionally override the patient’s autonomy. There is a particular risk of this occurring, due to competing pressures which include; legal requirements, time and resources and in the case of family carers competing needs for autonomy and wellbeing [61, 65, 113, 134]. The following chapters will reveal how much of the state paternalism which is still occurring, despite multiple national policy initiatives to put the patient at the centre of shared decision making, is unintentional and can even be unconscious. The thesis identifies issues which merit further research and discussion in order to make further progress in moving attention to the autonomy of the elderly patient facing the end of life.

In the context of caring for elderly patients in the family context, where often role reversal occurs such that the younger generation take a parental role in providing both physical care and taking decisions the term parentalism has been coined to express paternal and maternal components of the caring role [134]. This expression possibly could also be applied to the state.

2.6. Palliative and End of Life Care is a Human Rights Issue – protection through legislation

A described in the introduction, P& EOLC is recognised under international human rights legislation as a basic human right. Under Article 12 of the International Covenant on Economic, Social and Cultural Rights and Article 7 of the International Covenant on Civil and Political Rights [2, 21].

In England, where a piece of primary legislation (new or changes to existing law) is termed an Act, it is an Act of Parliament which is a Bill approved by both the House of Commons and House of Lords and been given Royal Assent by the Monarch. Act is a specific term used for a codified set of rules and regulations passed in Parliament, it is a short hand for an act of the legislature, or a statute [135].

2.6.1. The Human Rights Act 1998

In 1998 the European Convention on Human Rights was incorporated into the UK Human Rights Act 1998 [45]. The HRA 1998 provides a set of minimum standards, which are enshrined in law for how the state should treat people. It guarantees these minimum standards in two ways:

- The HRA 1998 places a legal duty on public officials to uphold standards by respecting human rights in everything they do (section 6 of the HRA).
- All legislation including health and social care law has to be complaint with the HRA 1998 (section 3 HRA).

The implication for P& EOLC is that all relevant health and social care law should be written and implemented in a way that respects, protects and fulfils human rights right up to the end of life [45]. This section gives a brief overview of the legal framework relevant to P&EOLC for elderly patients.

The HRA 1998 requires all 'public authorities' to act in accordance with the rights and duties set out in the Act. Of relevance to the provision of P&EOLC for elderly patients these 'public authorities' include the National Health Service, outsourced NHS services provided by the charities for example Hospices, or Marie Curie Nurses, who provide care arranged for and/or paid for, even if only part paid by the NHS or local authorities, public and privately funded residential or nursing homes and domiciliary care arranged and/or paid for by a local authority or funded by the NHS. Public Officials are under a legal duty to act compatibly with the HRA 1998 [45]. The duty applies to all staff whether doctors or other frontline staff, senior managers or board level executive directors. They are required to observe the HRA 1998 in reaching decisions about individual patients and in relation to other aspects of NHS service or social care delivery [45]. Importantly in the context of end of life care for the elderly, the UK Human Rights Act 1998 allows a person to ask a court or tribunal to decide whether the acts or omissions of public officials have violated their human rights or are putting them at risk.

The HRA 1998 is a foundation law meaning that the Act is clarified and supported by other legislation derived from it, for example the Mental Capacity Act 2005, the Care Act 2014 and the Equality Act 2010 all of which are highly relevant to the promotion and protection of autonomy of elderly patients at the end of life [46-48]

2.6.2. The Mental Capacity Act 2005

This law was introduced to protect people who lack the mental capacity to make decisions for themselves [46]. It may apply to a substantial proportion of older people who are nearing the end of their life and who have dementia or who are losing mental capacity because of other aspects of their terminal illness. Having a diagnosis of dementia, per se, does not mean that a patient has no mental capacity. Indeed, the first of five principles of the Mental Capacity Act 2005 is that capacity should always be assumed [46]. A patient's diagnosis, behaviour or appearance should not lead people to presume that capacity is absent. In practice this means that for every decision, however small the patient's capacity at that moment to make the decision needs to be assessed especially as Mental Capacity can fluctuate and be influenced by drugs, infection, a sudden change of environment for example from care home to hospital and deterioration [24, 54, 104]. Moreover, the second principle is that a person's ability to make decisions must be optimised [79]. This means providing sufficient time to allow patients to make decisions and supporting them by using sign language, pictures or interpreters if necessary. The third principle, which is very relevant to end of life care, is that patients are entitled to make unwise decisions. Lack of Mental Capacity needs to be excluded and if not present then patients' unwise decisions, which may result in their earlier death must be accepted. Principle 4 states that decisions and actions made for people lacking capacity must be made in their best interests. The Mental Capacity Act is explained in many guidance documents, for example, the General Medical Council (GMC) Guidance on P&EOLC describes the processes which should be followed to ensure adherence [79]. Finally, the fifth principle which links very tightly to the ECHR and to patient autonomy is that decisions made for people lacking capacity should be also the least restrictive of their basic rights and freedoms [46].

2.6.3. The Care Act 2014

The Care Act 2014, sets out the duties of local authorities' (local government) duties in relation to assessing people's needs and their eligibility for publicly funded social care and support [48]. It states that 'all local authority-funded and/or arranged care and support services regulated by the Care Quality Commission (CQC) have a legal duty under the HRA 1998' [45,136]. This includes 'commissioned services provided under contract to a local authority and services obtained through local authority direct payments, if delivered by a regulated service provider' [48]. The Care Act 2014 is especially important for elderly patients being cared for at home or in a care home towards the end of life where they may need help with activities of daily living, not classified as healthcare needs. However, social care, unlike health care is 'means tested' so only people with very little income or savings receive free social care [48]. There are elements of the Care Act which are very autonomy promoting and which pay due attention to the needs of family carers with a view to prevention of morbidity caused by caring.

2.6.4. The Equality Act 2010

The Equality Act 2010 simplified and strengthened legislation into a discrimination law which protects individuals from unfair treatment and is designed to promote a fairer and more equal society. There ae nine protected characteristics defined under the legislation: age disability, gender assignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, pregnancy and maternity. Consideration must be given in the provision of and access to P&EOLC whether any groups are discriminated against in their opportunities to benefit from such services [47].

2.7. Recent policy developments in England

This section gives a very brief history of development of policy in P&EOLC in England since 2008. Details of specific initiatives are expanded upon in subsequent chapters and critically appraised.

The first hospice as we know it today, St Christopher's Hospice in London, was opened by Dame Cicely Saunders 52 years ago in London. Now there are over 200 Hospices providing in-patient, day care and outreach home care and many are members of the umbrella organisation 'Hospice UK' which represents their interests [32]. The Hospice movement plays an important role in influencing government policy regarding the care of the dying and bereaved.

However, since around 2,000 the Department (Ministry) of Health and Social Care and the National Health Service in England have been taking an increasing interest and leadership role in the development of strategy and provision for P&EOLC. In particular, recognising that the majority of P&EOLC care is provided outside hospices and by non-specialists in P&EOLC. In 2008, the first End of Life Care Strategy for England outlined a clear vision for improving access and quality of end of life care for all. The slogan was "How we care for the dying is an indicator of how we care for all sick and vulnerable people", which attempted to engender the concept of social solidarity although this theme was largely lost in the implementation of the strategy [30]. Choice, especially in terms of place of death was a key theme in this 2008 strategy, based on early research which suggested that this was important to people [30]. The theme of 'choice' in P&EOLC has gone on to dominate policy and thinking in the past decade. The End of Life Care Strategy established both the National End of Life Care Intelligence Network (NEOLCIN), which I run, and the Dying Matters Campaign [31]. The NEOLCIN was established to provide statistical analyses, reports and interactive tools to policy makers, providers and commissioners of care to inform decisions about how best to provide P&EOLC for local populations and to monitor and compare quality and progress [11, 137]. The 'Dying Matters' Campaign was initially established as a well-researched social marketing campaign designed to encourage people to talk about death and dying and plan for it and was heavily influenced by the focus on giving patients choice [32, 138]. There were also many other initiatives including the ill-fated Liverpool Care Pathway for the Care of the Dying Patients (LCP) [39] the programme in Acute Hospitals called the Transform Programme and Amber Care Bundle [139], and the 1% Campaign [140]. The first three of these initiatives aimed to improve the quality of P&EOLC, largely in hospitals and the latter was another approach to encourage patients to make and record choices during consultation with their family doctor.

The scandal surrounding the use of the LCP, which will be analysed in depth in subsequent chapters, prompted the LCP Review – published as More Care - Less Pathway [39]. The Government then ordered a system wide response to the reviews findings, establishing the Leadership Alliance for the Care of the Dying Person, then the Choice Review and finally the National Palliative and End of Life Care Partnership which produced the 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020' [33, 120, 141]. The Ambitions Framework is effectively the second national strategy document [141] and has set out six ambitions for end of life care:

- Each person is seen as an individual.
- Each person gets fair access to care.
- Maximising comfort and wellbeing.
- Care is coordinated.
- All staff are prepared to care.
- Each community is prepared to help [141].

The Secretary of State for Health also made a commitment to the population, on behalf of the government to ‘improve palliative and end of life care including greater respect for patients’ choices [142].

In addition, the National Institute for Health and Care Excellence (NICE) has produced evidence based guidance on the care of dying adults in the last days of life and a quality standard on care of dying adults in the last days of life, which in particular provides evidence based guidance on hydration [80, 143].

There have been a large number of other national and local initiatives, one of particular note has been the ‘Gold Standard Framework’ [144]. This is primarily focussed on P&EOLC in the community and offers assessment frameworks and training in primary care and care homes.

The past decade has witnessed significant progress in some areas of the strategy, for example, as shown above, the proportion of people dying in hospital decreased from 57.9% in 2004 to 46.9% in 2016 [11]. However, success has not been uniform in all aspects of strategy’s vision for high quality care for all, irrespective of age, diagnosis, gender, socio-economic deprivation, and ethnicity. There has, more recently, been a move away from choice in place of care and death towards more emphasis on fair access to end of life care. This includes tackling unwarranted variation in care due to where people live, their age, diagnosis, background or income. However, the mantra of choice is still very evident in local policy making [33].

2.8. Development of Palliative and End of Life Care in Poland

The modern day hospice and palliative care movement in Poland was officially recognised almost four decades ago in 1981. However, there were already a number of initiatives across Poland to improve the quality of care for the dying. Two models emerged, one which was based on hospice care at St Lazarus Hospice in Krakow and the other, a home care hospice model, founded by the team of the Hospitium Pallottinum in Gdansk. In four decades, Poland has developed a national network of over 400 palliative and hospice care teams. These are staffed and supported by several thousand paid employees and volunteers, who work in multidisciplinary teams to care for people at the end of life and their families [145].

Not only has the hospice and palliative care movement increased the quality of care but increased social awareness and ‘interpersonal solidarity’ towards the chronically ill and dying and their families through local and national publicity campaigns, for example, ‘Dying in a Human Way’. Key principles which have underpinned the development of P&EOLC in Poland have included: compassion, a focus on the dignity of the dying person and equality of access to care whatever the age, social status or religion of the patient. Christian principles have been a strong driving force behind the movement in Poland. From the outset, interdisciplinary care teams including: doctors, nurses, psychologists, social workers, priests and volunteers have been key to the services. Since 1993, the Ministry of Health and Social Welfare has supported the development of P&EOLC in Poland. This support has included provision of a legal framework to support the hospices and of volunteers. The Polish Hospice Forum, which is an umbrella association for government funded and non-governmental organisations providing care to very frail and terminal patients defines standards and represents the members in negotiations with central government. The Hospice Foundation has organised campaigns to raise awareness in the general population and developed volunteers as well as providing psychological support and other assistance for bereaved people [145].

While the hospice based origins and principles of compassion are similar between Poland and England, as will be demonstrated and critically appraised throughout this thesis, the development of national policy in P&EOLC in England has followed a medically dominated path, heavily influenced by a neoliberal approach to the importance of patients exerting choice in their care. This narrative of choice in P&EOLC has dominated and marginalised other discussions of social justice in access, dignity for the patient, social solidarity for the dying patients and their relatives and compassion. As described above, the UK scores highly in international comparisons of the development of P&EOLC because of its clear policies and mechanisms for monitoring. However, this thesis critically examines whether the P&EOLC is really serving the needs of elderly patients at the end of life.

Chapter 3. The meaning of autonomy for elderly patients approaching the end of life

3.1. Introduction

This chapter critically examines the meaning and significance of autonomy for elderly people who are approaching the end of life (EoL). It explores, through empiric analysis of an interdisciplinary literature review, the significance of autonomy to elderly people, in terms of their identity, role in society and how they wish to confront and approach death.

It is clear that elderly patients, possibly more than any other sector of society, have moral concerns regarding others [112, 113] and many see their identity and reason for being and even dying in relational terms with others, especially family members [62, 112-114, 146]. Many elderly people feel a strong sense of duty to family and wider society [90, 147-149]. The evidence suggests that most elderly people are acutely aware of the inevitability of death and their own diminishing autonomy due to increasing frailty as they approach death [16, 148, 150]. Yet, despite this, many do not feel a special need to plan for death [62, 148, 151]. This chapter therefore examines in which contexts and for what purposes elderly patients wish to exert their autonomy in their final chapter of life. In particular, the analysis presented in this chapter exposes the paucity of research about the views of elderly people regarding end of life care planning. From the little evidence available, it is clear that the current national policy drive to encourage everyone to make Advance Care Plans (ACPs), for their care at the end of life, has not been researched or evaluated adequately in elderly patients [62, 152, 153]. Moreover, it is also appears that specialists in Palliative and End of Life Care (P&EOLC) have, as yet, little understanding of the different needs, wishes and therefore suitable models of provision of end of life care for elderly people [53].

In the light of the understanding of the views of elderly patients with respect to their autonomy in the last chapter of life derived from the literature review, this chapter critically looks at P&EOLC policy in England, especially with its medicalised focus on choice, to evaluate to what extent it protects, promotes and supports autonomy as perceived by elderly patients. I will especially challenge the current zeitgeist in England that autonomy at the end of life is primarily about self-centred choices about what treatment to have or where to be cared for and die [33, 120, 142, 154, 155]. I will review whether the structures, processes and tools available in health and social care services are useful for elderly patients to protect and enhance their autonomy especially when they are at their most vulnerable.

3.2. Methods

This chapter presents a critical evaluation of empiric data from interdisciplinary literature reviews examining perspectives on autonomy in elderly people approaching the end of life. It will challenge the way in which autonomy is promoted in P&EOLC in England as an unbounded and independent characteristic of the individual to be used to simply exert choices about care [142]. It will show that as death approaches, especially as physical and mental capacity diminishes that the scope for autonomy also diminishes. However, the review will identify in which spheres of life it is important, and how elderly patients wish to manifest their autonomy. The chapter will then examine the extent to which national policy on P&EOLC in England protects and promotes the autonomy of specifically elderly patients at the end of life and examine ways in which their autonomy can be enhanced.

This Chapter will explore four key issues:

- The characteristics of autonomy for elderly people approaching the end of life as they perceive it.
- Elderly peoples' perspectives on what factors influence a good death.
- The wish to die.
- How well does national policy on P&EOLC support elderly people approaching the end of life to exert their autonomy?

3.3. The policy context and choice

Since the first national P&EOLC Strategy was published in England in 2008, patient choice has been at the heart of policy initiatives [30, 33, 120, 142]. Reflecting this emphasis on choice, there has been a great deal of emphasis in national policy on supporting patients to choose their place of care and death and make ACPs including very specifically Advance Directives to Refuse Treatment (ADRT). These latter may record, for example a Do Not Attempt Resuscitation (DNAR) wish or refusal of other treatments such as ventilation. This not only reflects early research which suggested that this was important, but these are also measurable proxies for quality of care using routine data sources [62, 86, 94, 120, 142, 154].

To support the emphasis on choice, Advance Care Planning (ACP) has been promoted as the way in which patients can exert their choices for P&EOLC either while they have mental capacity or more specifically through Advance Directives (ADs) or Legal Power of Attorney for Health and Welfare (LPA) if they should, in the future, lose mental capacity [32, 33].

Although the other spheres of wellbeing at the EOL such as social, psychological and spiritual are mentioned in national policy, they almost fade into the background, when policy is implemented, compared to the focus on choice related to the medical and physical aspects of dying [33].

Choice in how health care is received by the patient and involvement in decision making is also a very strong theme more widely throughout National Health Service (NHS) Policy in England. It is repeatedly mentioned in the NHS Constitution and the NHS website providing information about health and health care to the public is called 'NHS Choices' [155, 156]. The latest National Strategy for End of life Care – The Ambitions Framework still puts the patient at the centre of decision making but is a little more circumspect about the use of the word 'choice' [33] as there is now greater realisation that both patient and service provision factors may mean that the patient's choice cannot always be fulfilled. For example, a patient may hope to be cared for at home until death but may deteriorate and require hospital care for severe symptoms as they approach death, or local services may not be able to provide the type of care required at home to keep the patient safe and comfortable.

The policy of promoting choice has been implemented through the National Campaign 'Dying Matters' which has strongly promoted the importance of choice at the end of life, encouraging the public to talk about death and dying, make funeral plans and wills and think about ACP and discuss their wishes with family [32].

The 1% Campaign encourages GPs to identify patients likely to die within the next year and initiate discussions about choice in P&EOLC planning [140]. This could include placing the patient on an electronic P&EOLC register in the practice so that other doctors would know that ACP had been discussed and the details and then offer care accordingly [157]. Interestingly, although most P&EOLC practitioners are in favour of these electronic registers, they have been challenged as infringing human rights [60]

The Review of Choice in End of Life Care, commissioned by the Secretary of State for Health and Social Care for England, as a response to the Liverpool Care Pathway Inquiry contained the following words in the foreword:

‘...whilst dying is inevitable, and universal, that is the only certain thing about it. So much else is unpredictable. It is therefore vital to offer people choice and control over the things that are important to them at this point of maximum vulnerability in their lives.

Choices at the end of life affect us all. People have told us during this review that they want their end of life care to reflect their own individual views and preferences; as one person said, ‘this is about those unique things that make me, me.’ [120].

It is important to note that all these national initiatives in P&EOLC are strongly driven by specialists in palliative care [33]. Their training and experience is almost exclusively related to cancer and in particular younger adults with cancer. There is a notable absence of expertise or influence from Geriatricians, Gerontologists, Old Age Psychiatrists and other professionals with expertise in the care of the elderly in all the recent national policy making committees (Professor Malcolm Johnson, Personal Communication). This means that national policy continues to be produced without an adequate understanding of elderly people and patients and their views on how they wish to exert their autonomy [53].

3.4. Autonomy’s sphere of influence wanes for many elderly people approaching the end of life

The majority of people who die are elderly, aged 75 years or older at death (68.2%) [11]. While some, especially those who die suddenly in good health, will retain autonomy over a wide spectrum of their daily life until death, this accounts for about 15-25% of deaths in elderly people [158]. The vast majority, in the months or years preceding death, will have accumulated many co-morbidities and will have experienced a period of increased physical and or mental frailty which will have resulted in increasingly limited ability to exert full autonomy over their lives [12, 17, 18, 63, 159, 160]. Technology can help overcome some of the physical impediments to autonomy: hearing aids, vision aids, mechanised beds, electric wheelchairs, stair lifts, the internet, WhatsApp, all help the elderly person retain autonomy especially in relation to liberty to communicate with others, move about their home freely or to leave it and to have control over timings of their daily routines [17, 53, 161, 162]. Of course, the need for physical help from others could be considered simply as another form of aid to autonomy, with other people doing things for the elderly patient, for example, taking them out to the shops or, more intimately, like washing the patient, while the patient still retains a sense of autonomy [65]. In practice though it is unavoidable that there is a shift in the power relationships from the person receiving care to those providing it [65] as timings and modes of doing things depend on the carer even if those providing care may attempt to care in an autonomy enhancing way for the individual [17, 18, 134, 163, 164]. The elderly patient becomes dependent on the other person's goodwill, whether paid or not, to aid them in exerting their autonomy in the way which is congruent with their identity and dignity [63, 148, 152].

3.5. The relationship between Identity and Autonomy in elderly people

The exertion of autonomy is inextricably linked to self-identity whether autonomy is defined through liberal or utilitarian schools of thought [126, 134, 165]. This section will expand upon the spheres in which identity and autonomy are especially relevant to elderly people.

3.5.1. Societal constructs and elderly people's identity and feelings of self-worth

In societies where identity is defined by group membership, then it is threats to the safety of the group which are feared [166]. Indeed, in hunter gatherer, migratory communities, older adults were be left to die, as the tribe moved on, if they became too weak to keep up with the group, in order not to compromise the safety of the group [166]. In primitive agricultural communities, the elderly were often given a role as religious leaders or keepers of wisdom and oral history, when they no longer have strength for physical work [166]. These functions became important for greater stability of group functioning. However, even in classical times, respect for the elderly was not universal. The philosopher Juncus wrote 'that even to his friends and relatives an old man is an oppressive, painful, grievous and decrepit spectacle; in short an Iliad of woes' [167].

Today, one of the problems for dignity and of valued self-identity for elderly people is the perceived gulf between young and old in a society that values productivity and material wealth above other values [168]. In western society, the elderly have a less clearly defined role in terms of their place in society appearing to some people to become more consumers of societal support than contributors [168]. There is a prevalent negative stereotype of the elderly as dependent individuals who need costly and specialised services and who no longer lead 'real' i.e. productive lives and are simply an economic drain on society [168]. Many elderly people become isolated when they are no longer part of the economic workforce and see themselves or are made to feel obsolete and redundant [168, 169]. Debates also rage about the elderly having to use their hard saved investments to pay for their social care at the end of life, despite the promises of the Welfare State, during their working age, that the taxes they paid then would be used to care for them in old age [170]. This has the result that elderly people are made to feel not only that their past contribution to society is not valued but they have a future that is not wanted [169]. This can lead to some elderly people contemplating death as a release from their feeling of having no value and being a burden [99, 101, 171-173].

More optimistically, recent research, conducted with my colleagues, suggests that many elderly people are finding useful niches in society [174]. In a survey of >3,500 adults aged 45 years and older, we found that they are actually very busy, even some of the very elderly, looking after grandchildren, their own elderly relative or neighbours or doing volunteer work for other elderly or dying people [174]. Elderly people reported this gave them a sense of self-worth [174]. This type of work identifies ways in which even quite frail elderly people can make a contribution to others and restore self-esteem and maintain a sense of belonging and societal worth. Indeed, in Poland the potential for senior citizens to both volunteer had re-discover a sense of societal self-worth has been identified through the Governmental Programme “Social Activity of the Elderly” (ASOS). This has been developed through the Pomorska Szkoła Woluntariatu Opiekuńczego and through the programme ‘Pomaganie jest pięknie’, ‘Helping is Beautiful’ – Activation of Senior citizens through Care-Orientated Voluntary Activity [175].

However, perhaps dying and even death itself need to be given, or given back, a value in society so those who are dying feel also feel valued [168, 169, 176]. Most middle aged adults in England have not seen a dead body or seen a person die and therefore have little understanding of death and how they might value the elderly who are dying [169]. However, people who work as volunteers caring for the dying often describe transformational experiences which enrich their lives, but this is not widely known about in society [177]. At an individual level, there is a new field of psychological looking at ‘Meaning Centred Therapy’(MCT) aimed at giving people a sense of meaning and value to their life even as it is ebbing away, a similar approach is taken in ‘Dignity Therapy’ [176, 178]. This has been shown to be a useful form of therapy in managing anxiety about death.

3.5.2. Elderly patient or person approaching the end of life?

In England, despite the social origins of the Hospice movement under Dame Cicely Saunders, the current policy approach to P&EOLC, is very much is driven by a medical model in which the dying person tends to be viewed primarily as a patient. This contrasts with the more sociological model of dying in Poland where an individual's personhood is respected alongside their medical needs [179].

Dying involves a major re-negotiation of social identity [16, 65, 90, 180, 181]. There is, therefore, a risk, where the medical model of P&EOLC dominates, that an elderly person's social identity is constrained to 'I am an elderly patient' rather than 'I am an elderly person who may have health, social, psychological and spiritual needs' [18, 106, 118, 154, 181]. Elderly people approaching the end of life still want to be regarded as people not simply patients in a bed [17, 18]. Indeed the majority of elderly people will retain a fair degree of independent living until very close to the end of their life [18, 63, 65, 87, 113, 182].

Although P&EOLC describes itself as covering medical, psychological social and spiritual domains [76, 78, 80, 145, 183] the dominance of the medical model, to an extent, always seeks to medicalise and professionalise all the domains [154, 184]. There is a growing rhetoric that the dominance of end of life by the medical model should be reduced to enable elderly people to approach the end of their life as people, each with an identity, rather than labelled as patients [18, 106, 118, 154, 184]. Indeed, following this argument, probably the title of this thesis should have been autonomy and paternalism for elderly people approaching the end of life as opposed to patients.

3.5.3. The importance of family and social ties

Family are an important part of the identity of elderly people for those who have them and for those whose family stay in touch [113, 163]. Interdependence and responsibilities to each other remain until death [113] and indeed, in some senses, may continue after death [32, 35, 146]. For this reason consideration of family can heavily influence the elderly patient's autonomous decisions as they look towards death [35, 65, 113, 119, 177, 185]. Families, play a critical role in protecting and promoting the autonomy of elderly people at the end of life [61, 119, 147, 164]. It has been demonstrated that an elderly person with a supportive family is able to exert more autonomy both over a wider range of options and more forcefully because of backup by family than a similar elderly person without a supportive family [62, 87, 119, 164, 186, 187].

An elderly patient’s biography is an important determinant of who they are as a person approaching death [178, 188]. Personal history will influence their social position, level of education, financial resources and beliefs about what is important to them and what death means to them [181]. Biographical therapy is very useful for patients with dementia, who are losing their identity because it helps them to remember who they are and locate decision making within the context of their identity [24]. It has also been suggested to be a good way to help older people prepare for death and support their family by leaving memories [176]. Biographical therapy and Meaning Centred Therapy (MCT) may also help individuals struggling for meaning as they approach death [176]. Reconnecting through biographical work may help individuals to relocate their life and dying back within a family and societal context [176, 178].

3.5.4 Isolation, living alone and loneliness

Although family is significant to many elderly people’s identity, at the 2011 Census, only 56% of people aged 65 years or older were living in couples (married/civil/cohabiting) households [189]. The proportion of people aged 65 years and older living in single person households is 31% nationally however, the proportion varied across England from 11.4 % to 63.3% [11, 189].

Our own collaborative research has emphasised how isolated many elderly people may feel in terms of being able to ask others for help as illustrated in Tables 3.1.and 3.2. Of people aged 45 years and older 21% reported that they had no relatives or family to call on for help, 64% no neighbours and 53% no friends [174].

Table 3.1. Perceptions of who and how many people could be relied on for regular help if needed? An online survey of 3,590 adults age 45 years and older [174]

Number of people who they felt could counted on for regular help:	Relatives/family %	Neighbours %	Friends (who are not neighbours) %
None	21	64	53
1 person	33	14	13
2 persons	20	12	16
3 persons	11	3	6
4+ persons	15	7	12

A more in depth analysis revealed that 12% of those aged 45 years and older reported that they had no relative, friend or neighbour that they could count on for regular help if the need arose. A further 19% claimed there was one person. So just under one third feel that they have no one or only one person that they could count on for regular help. In contrast, 37% claimed there were two to four people they thought they could count on and 33% thought there were five or more people [174]. Examining age groups reveals an interesting difference with older respondents having potentially a slightly larger informal support network possibly because they have more children and grandchildren. Inevitably some will have moved closer to their family.

Table 3.2. Perceptions of how many people could be relied on for regular help if needed analysed by age group. An online survey of 3,590 Adults age 45 years and older [174]

	Proportion of people responding to various levels of perceived help which could be counted on (%)			
Perceived number of people they could count on	**45-69 years old (N=2021)**	**70-79 years old (N=1019)**	**80+ years old (N=550)**	**45 years and older (N=3,590)**
None	13	10	10	12
One person	20	15	17	19
Two to four persons	35	39	44	37
Five or more	32	36	30	33

Moreover, the higher proportions of older people reporting other people they feel they could reply on for help may reflect patterns of care they are already receiving or giving. Younger people may not yet have needed help or given it so believe that they could not ask for it. However, they may not have actually tested whether help would be forthcoming if they needed it. People of working age may also feel isolated from local networks due to the hours they spend working and distance from their homes.

The social capital that elderly people can rely on can have very practical implications for the range of choices open to elderly people. For example, with respect to place of care and death, if the elderly patient's autonomy to undertake activities of daily living is reduced and they are dependent on the help of others they may not be able to stay in their own home if this help is not available [62, 187]. Staying at home may not be a practical option if family or friends cannot provide at least some of the care [119, 190, 191]. Our and others' studies have shown that people are less likely to die at home if they do not live with a partner or spouse or have close family nearby and financial resources [93, 191, 192]. Our own work has shown that single people are less likely to die at home (20.7 vs 27.8%), in hospital (45.0 vs 49.7%) or in a hospice (4.1 vs 8.2%) and more likely to die in a care home (27.8 vs 12.6%) compared to those in a couple [193].

Living alone not only presents challenges but loneliness impacts on people's wellbeing especially at the end of their life [193, 194]. People living alone are more than twice as likely to report feeling lonely as those who live with other people (30.8% compared to 12.6%). Importantly, in relation to an elderly person's identity, high loneliness rating is associated with lower feelings of worth (10.5% vs. 1.1%) and feeling unhappy (18.8% compared to 5.6%) than low loneliness ratings [194]. People in rented or social housing felt higher levels of loneliness than those owning their home. 15.3% vs. 11.7% [194, 195]. As deprivation is associated with not owning one's own home, loneliness may affect elderly people from poorer backgrounds more than the affluent elderly [194-196]. Moreover, the affluent elderly have more resources to buy in care which may help alleviate loneliness [193-195].

Perhaps unsurprisingly, the presence of Long Term Limiting Illness (LTLI), which is a marker for chronic disease(s), which reduce autonomy, is associated with higher loneliness This is not surprising precisely because it is limiting in activities of daily living which are important for social contact [195]. The majority of elderly people approaching the end of life will have at least one LTLI [197].

Loneliness may even impact on an elder person’s desire to continue life and may even lead to premature death [99-101, 103, 196, 198, 199].

3.5.5. Religion, spirituality and identity at the end of life

Religion has traditionally been an important accompaniment to death, whether helping to prepare for it, reach acceptance, or to bear suffering [176, 178, 181, 200, 201]. Of course, religion does not always provide comfort, some people see terminal illness as a punishment for sins [200, 201]. However, there is good evidence that, in general, elderly patients who profess a faith die more peacefully than declared atheists [148, 201-203]. Rumbold suggests that spirituality is emerging and being used by individuals in England to assert their identity and autonomy at the end of life against the dominating expert discourse of medicine, formalised religion and secularism [204]. Defining religion, faith or spirituality, in England, is now complex [204, 205]. Spirituality is defined as ‘the way in which people understand their lives in view of their ultimate meaning and value’ [205]. The secularisation of society, that has weakened western religious institutions, has not necessarily led to a disappearance of faith in elderly people [206]. Moreover, some suggest it has led to a deregulation of religion [204]. As people express spirituality as a form of autonomy, and vice versa, they assert their right to choose what to believe from the dogma of institutionalised religion [168, 207]. Today, many elderly people have collected an eclectic selection of beliefs and practices drawn from many sources. Rather than being passive recipients of religious doctrine, people are exerting their autonomy to use their own interpretations of religion, explore other religions, or to blend aspects of what holds meaning for them to construct their own personal belief system in a syncretic fashion [207]. In England, even when people declare a religious affiliation they may not practice it in a predictable fashion. Some sociologists suggest that despite the decline of formal religion, there is an increasing interest and search for spiritual meaning as a reaction to a world driven by science and materialism and formal religions which try to enforce conformity rather than individual interpretations [207]. However, this plethora of interpretations of religions and spirituality where there are no longer any rules to follow or spiritual leaders to offer guidance may actually lead to anomie for individuals as death approaches.

Spirituality is starting to be acknowledged once again as an important complement to health care at least in P&EOLC after a long period of rejection (at least in England) [200, 208]. In the medical profession it is certainly being recognised by specialists in palliative care and psychologists as having an important role in reducing the fear of death and moving to acceptance [181]. In societies where religion continues to play a significant role there is more of a connection between religious belief and care and religious belief and the meaning of suffering and death [145, 181, 200, 208, 209].

In P&EOLC there are two models of approaching the question of spirituality at the end of life. The first identifies spirituality as a domain that needs addressing like medical symptoms and social problems which need professional help [33, 207]. This model regards it as important to identify and 'treat' a patient's or family's spiritual needs to achieve a good death or bereavement in a similar way to treating or managing their needs in the other domains of P&EOLC: physical, psychological and social [207]. In some respects this may make good sense as there is evidence that dealing with religious or spiritual angst may help with clinical problems [200, 201, 208]. If spiritual distress can be relieved pain control may be better [201, 210, 211].

The other model sees spirituality as key to identity and therefore critical to a patient making sense of everything that is happening as the patient approaches the end of life [201-203, 210-212]. In England, religion and spirituality is more important to elderly patients as they approach the end of life than it was to themselves at younger ages and to younger patients [148, 204, 212, 213]. This means that for elderly patients having the autonomy to express and practice spirituality or religion is very important on multiple levels at the end of life: existential and physical too [148, 181, 200, 201, 204, 210, 212].

3.5.6. Identity and dementia

Dementia, which is very prevalent among elderly patients at the end of life [11], causes one of the most challenging unresolved issues about the role of identity in decisions about end of life care [24, 70, 126, 165, 214, 215]. Is the patient with advanced dementia the same person as before the onset of disease [29, 126, 131, 153, 165, 180, 216]? Changes in behaviour, from nervous to placid and placid to aggressive, from sexually continent to licentious, as dementia takes hold throw the question of continuous and preserved identity into doubt [24, 126, 182, 217]. The pressing reason why the issue is important in dementia and P&EOLC is when considering to what extent wishes, discussed with relatives, written in Advance Directives, or invested in Legal Power of Attorneys, should be honoured in providing P&EOLC [24, 29, 126, 165, 215]. Indeed, the major reason for ACP is for the patient to communicate their wishes for care to others in the hopes that these wishes will be followed if, at some time in the future, they lose mental capacity, most probably due to dementia. This dilemma has been well explored by others [126, 165]. However, persistent uncertainty whether a patient with advanced dementia is the same person as before, strengthens argument to consider the 'best interests' for the patient as they are at the time of decision making [218, 219]. This is especially important when there is doubt, either in the minds of doctors or families, whether an AD should be followed [165]. Indeed, this is the way a court, in England, will make a decision for a patient who lacks mental capacity rather than using substituted decision making, in other words what the patient would have wanted had they not lost mental capacity. Previous wishes are taken into account in the overall assessment of best interests but do not dominate in the assessment [220, 221]. The dilemma posed when considering the validity of previous decisions in the patient with dementia also supports the option of appointing a Legal Power of Attorney for Health and Welfare (LPA) who will make decisions on behalf of the patient [222]. A similar situation is being considered in Poland, using the term 'health care agent' [219].

The dilemma faced by family members was exemplified in recent media of the case of a well-known national journalist who published on, and was vociferous about, voluntary euthanasia and withdrawal of life supporting treatments in the case of dementia [223]. She had also written about this with respect to herself, if she were to suffer dementia. Unfortunately, she now has dementia and her journalist colleagues are publically pushing her line that efforts should not be made to prolong her life, for example, not treating her with antibiotics if she got a chest infection. However, her son believes that because she appears to be placid and content in her dementia that withdrawing or foregoing life prolonging medications, at least at this stage, should not be contemplated. Indeed he believes that could his mother see herself now she too may not want to forego all treatments [223].

3.6. What influences a good death from the perspective of an elderly patient?

3.6.1 A historical perspective

In classical times, it was thought natural to die in one's 60s, but to die younger was seen as a harsh and unnatural fate [167]. Now, over two thirds of people in England die aged 75 years or older [11]. Indeed, today many older people, having lived a long and fulfilling life, do not fear death, prepare for it and reach a state of acceptance and waiting for its approach [17, 99-101, 113, 152, 171, 176, 190, 224].

Historically a good death was also considered to be one which was prepared for especially in terms of preparation for the soul [167, 181, 207]. People were also expected to put their affairs in order with respect to inheritance and pass on their wisdom to future generations [167, 178, 181, 207]. Family involvement was important [178, 207]. Sudden death was not wanted as this prevented preparation of the soul [204, 212]. Now, many elderly people often express a wish for a sudden death or death in their sleep [207]. They do not want to be conscious of their death and they do not wish their death to be 'messy' or troublesome for others, reflecting a recurrent theme of not wanting to be a burden [35, 99, 113, 148, 152, 160].

3.6.2. Control of symptoms and relief of suffering

Elderly patients, just as younger patients, fear the physical suffering associated with dying and wish to have this relieved [225, 226]. Pain is a universal symptom that all patients at all ages fear and want support with [227-229]. Having pain and symptoms well managed during a terminal illness was ranked higher in importance for patients than place of death [62, 152]. Among the elderly, patients with dementia need very careful assessment for pain as they cannot express their suffering [190, 214, 215]. Options for pain relief need to be carefully discussed with patients as, while they may not want to die in agony, they may also want to retain as much consciousness as possible and so opiates need to be titrated as in best practice palliative care [80]. Breathlessness is another very frightening and distressing symptom which is very common in elderly patients who may have chronic pulmonary obstructive airways disease, congestive cardiac failure and who often have pneumonia as a terminal condition [108, 230-232]. Breathlessness can be very distressing for the patient and watching family too [232] and many patients with breathlessness due to COPD would prefer to be cared for in hospital [192, 232]. The third common symptom in the triad of symptoms terminal patients experience is terminal agitation. There is evidence based guidance on the management of this [80, 230]. Less is known about the patients' views regarding terminal agitation, but this is also distressing to watch and understand from the family's point of view [230].

3.6.3. Preservation of self-control and dignity

Patients identify preservation of self-control as integral to high quality end-of life care and a good death [10, 16, 90, 106, 118, 178]. Retaining control underpins the concept of the various forms of ACP [233]. Despite this, it is striking how few elderly people make use of any form of ACP and it is not clear why not [234, 235]. It maybe that the current way in which ACP is presented is not focussing on what is important to elder people [235]. Self-control should extend not only to negative autonomy and refusal of treatments but positive autonomy regarding doing things to protect and promote an elderly person's privacy and dignity. However, most ACP only focusses on refusal of treatments [109, 153, 234, 235]. It is a great challenge for elderly people to maintain dignity and self-control over life when all self-care has to be performed by other people [10, 21, 63, 90]. For elderly patients even small concerns in terms of way they are addressed, preservation of their modesty and perhaps the gender of their carers can impact on their sense of retained dignity [17, 18].

3.6.4. The influence of religion and spirituality in a good death

If an elderly person adheres to a religion then following the customs and practices of their religion in preparation for death may be important to them. Different faiths have different perspectives on the end of life which may influence the elderly patient's perspective on a good death [236]. When death is near, Roman Catholicism encourages administration of 'Last Rights' (Anointing the sick, Penance and Viaticum. Suicide and voluntary euthanasia are prohibited but withdrawal of "extraordinary measures," even if death is anticipated (but not intended) to result is allowed [200]. Eastern religions, such as Buddhism and Hinduism, may consider that pain and enduring suffering are important for karma [200, 208]. For followers of these religions life support, and deep sedation may be considered unnatural and that they could interfere with a peaceful death or reincarnation [208]. In Christianity and the other Abrahamic religions many people may not want to have deep sedation so that they are able to prepare for death [204, 208, 212]. Some traditions in Judaism emphasize an obligation to sustain life above all else, even at great cost and in the context of suffering [201, 208, 237].

Views on religion and its relationship with end of life care decisions can be a source of conflict and misunderstanding between doctors and patients or their relatives and between patients and their family who are involved in decision making with them or on their behalf [65, 201, 203, 213, 237-239]. It is a very sensitive issue where the autonomy of elderly patients, with respect to not only religious practices, but also practical aspects of P&EOLC, may be overridden by well-intentioned others such as doctors and family acting paternalistically [213, 238, 239]. Often this paternalism is unconscious and unthinking.

3.6.5. The importance of place of death to a good death

Early in the development of national P&EOLC strategy in England, surveys of people's hopes and desires suggested that place of death was important, with most people hoping to die at home [30]. These were conducted in the healthy general population who were largely a long way from death [120]. A more nuanced survey of preference for place of death which gives granularity by age has shown that although home is the most frequent preference for place of death in all age groups the preference for home decreases with age and a preference for hospice increases, especially among people aged 75 years and older [160]. Older people have quite clear views of their own about preferences for place of death and the reasons underpinning these [95, 119, 147, 153, 160, 223, 240, 241]. For many elderly people who are still very independent, care homes are the last place that they would like to be cared for and die in. Some elderly people feel that when they start to loose independence they have to put all of their focus into maintaining it and trying to avoid institutionalisation in the form of care homes, which some consider life in a care home as a 'living death' [242]. However, many elderly patients accept a move to a care home as inevitable when they can no longer care for themselves and as they become increasingly frail and dependent on others [95, 160, 190, 243]. One of the reasons hypothesised for the preference for hospices as a place of death, is that elderly people do not want to be a burden to others when reaching older age [113, 244]. A preference for hospices as a place of care and death may also reflect the success of hospices in their marketing. Their charity shops are multiple on every high street and elderly people often shop there, donate goods to be sold or volunteer to work in the shops or hospices. Moreover, hospices are renowned for their good end of life care and could be viewed by elderly people as a safe and peaceful place to die as opposed to a busy hospital ward. The majority of elderly patients will have experienced an inpatient stay in hospital, at least two thirds are admitted to hospital in the last 90 days of life [12] so they know what care in hospital is like. If elderly people live alone they may fear death alone and under these circumstances a care home may not seem such a bad option [18].

However, despite the elderly being the age group with the highest preference (41%) to die in a hospice, they are the least likely group in the population to do so. Only 3% of people aged 75 years or older die in a hospice compared with 9-11% for other age groups [11, 160]. Moreover, the gap between preferences and actual place of death is widest for the 75 year olds and older wishing to die in hospice than for any permutation of age group and preference for place of death [160]. Death in care homes is more common than death at home among the elderly in some parts of England [245].

In England, volunteering to help in hospices or their fund raising shops and direct donation of money by the elderly is really altruistic as they have almost no chance of benefiting certainly as an inpatient or even through home care unless they have cancer. The support given to care homes by hospices, in England, is also still at a very low level and, as we have shown, largely related to training rather than outreach care [246].

3.6.6. Factors other than place of death important to a good death

Surveys that have sought to explore the importance of factors other than place of death. These surveys asked people to rank preferences to show what other things are important to a good death [54, 62, 130, 148, 160, 187, 247].

The importance of having loved ones close takes second place in importance after symptom management. Familiarity with surroundings and a calm and peaceful atmosphere ranks below these other factors [148, 152]. More recent research has revealed that a feeling of safety is important as death approaches, perhaps underpinning some of the other issues mentioned such as having trained professionals to advise and help [148, 152].

In recent research, not being a burden to others is increasingly featuring high in the rankings of things elderly patients consider as being important in a good death [54, 62, 63, 65, 113, 114, 116, 117, 148, 163, 190, 248-251]. This desire not to be a burden seems to transcend cultural, ethnic and religious differences [115, 117]. It even may lead people to consider that they may have a ‘duty to die’ [112].

Focussing on values, relationships and quality of life rather than material issues has been identified as a change which occurs naturally with aging but also on receipt of a terminal diagnosis [176, 252, 253].

3.6.7. Death anxiety and reaching a state of acceptance

Contemplation of death arouses anxiety in most people at some time in their life [181, 254]. Death, unlike most other life events, is unavoidable and irreversible. It is the finality of death that is, for many people, the most anxiety provoking. Psychologists describe death anxiety as a multidimensional construct with two main components: existential death anxiety (the fear of the unknown and annihilation) and practical anxiety (fear about the bodily process of dying) [181, 255]. On a practical level the fear of agonal suffering and loss of dignity are issues that professionals, especially palliative care specialists are trained to provide care for and therefore hope that these can be avoided or mitigated against [148, 254]. While death anxiety is normal, if heightened it can be debilitating, accompanied by depression and avoidance of action[181] . Avoidance of death is one of the most frequent coping strategies [176, 255]. In this state the individual remains anxious and also, as a result of avoidance, forgoes benefits which could be achieved for example, finding deeper meaning in life or better quality care [255]. If an individual experiences death anxiety it does not mean that they have not lived a good life or that they do not appreciate life. They are just afraid of losing it in the absence of a conviction of anything beyond or acceptance of the simple finality of death [176, 178, 256]. Research has shown that loving of life and having death anxiety are two separate factors and can exist independently [176]. The healthy response to facing death is acceptance and indeed many older people do not fear death, prepare for it and reach a state of acceptance, waiting for its approach [17]. Research suggests that younger people fear death more than older people but that fear reduces with increasing age [256]. A meta-analysis of 49 studies of fear of death [254] confirmed that the prevalence of fear of death plateaus over 60 years of age. Qualitative research has found that the very old do not fear death itself but rather the process of dying [254]. Acceptance does not necessarily mean that elderly patients formally plan for death, many do not plan while accepting its inevitability [235].

Sometimes it is difficult for younger generations to understand and accept that elderly patients await and accept death and do not appear to want to fight it. Older people describe their younger family not wanting to discuss the elderly patient’s own acceptance of imminent death [120]. This is clearly captured in the exert shown below from the famous poem ‘Do not go gentle into that good night’ by Welsh poet, Dylan Thomas, written to his dying father, in which he urges him to fight against, rather than accept, approaching death [257].

‘Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.’…….
And you, my father, there on the sad height,
Curse, bless me now with your fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light.’ (Dylan Thomas)

3.7. The wish to die.

3.7.1. Introduction

Some elderly people, and indeed it may be many, because the desire fluctuates, not only accept the approach of death but may experience a wish to die [101, 103, 152, 171, 258]. It is important to differentiate between the wish to hasten death (WTHD) and the wish not to prolong life (WNTPL) [103, 171-173, 227, 259, 260].

In this section I examine the empirical data on the wish to hasten death (WTHD) and suicide in elderly people to elucidate the lessons which can be learned for improving P&EOLC for elderly patients but also with respect to societal treatment of elderly people per se. This section will also highlight some of the reasons why people may chose an Advance Directive to Refuse Treatment (ADRT) and other ways of recording or enacting negative autonomy for example through Legal Power of Attorney (LPA). It is important to understand the reasons for people wishing to hasten death, or at least not prolong life, as P&EOLC may be able to alleviate some of the suffering that leads to this state of mind. Moreover, it is important to exclude mental health issues for example depression [172].

3.7.2. Factors underpinning the Wish to Hasten Death (WTHD)

Monforte-Royo et al. in 2010 undertook a review of clinical studies examining the circumstances under which patients, when faced with physical and /or psychological suffering, may have a WTHD [260]. The studies included were dominated by studies from the US and Belgium and the Netherlands where Physician Assisted Suicide (PAS) or voluntary euthanasia is legal. They found that the WTHD has a multi-factorial aetiology but importantly, for the elderly population group who are the focus for this thesis, that psychological, social and spiritual and existentialist factors are more important than physical factors for example pain [260]. Even in cancer patients, many of whom will experience terminal pain, in one study it was estimated that ‘17% of patients reported a strong WTHD because of depression, hopelessness and loss of meaning rather than pain’ [261]. Importantly, one study reviewed by Monforte-Royo et al., found that patients who had declared an interest in voluntary euthanasia or PAS were more likely to have symptoms of depression [260].

Some of the most relevant data for England is derived from the VOICES Survey of bereaved relatives [262]. Seale and Addington-Hall used two of the VOICES studies, asking recently bereaved relatives who had cared for a patient in the last year of life, whether their deceased relative has at some point ‘wished to die soon’. Of those surveyed, 24% said that their relative had expressed this wish and 3.6% said their bereaved relative had requested voluntary euthanasia despite it not being legal in England [262].

However, in expressions like this it is difficult to distinguish between an expressed wish and real intent. Interesting data comes from analysis of people applying to end their life under PAS law. In Oregon 1% of patients at the end of their life request PAS but only 0.1% actually continue to die as a result of PAS [260]. Several studies have found WTHD is common in patients with chronic disease or life threatening acute illness but the wish is fluctuating and unstable dependent on circumstances and mental state [118, 172, 260]. Moreover, the request to hasten death does not always represent a genuine desire to die, one systematic review suggested paradoxically that most patients requesting WTHD were really crying out for help to continue living [172, 260]. Phenomenological and qualitative studies are useful in examining why this occurs [263]. The expressed WTHD which were really cries for help were categorised as ‘existential yearnings for connectedness, care and respect’ [263]. A study in Belgium found some patients changed their WTHD after they felt that their concerns about suffering had been heard and were being attended to [264]. Feelings of isolation and lack of support triggered the WTHD request. This has implications and resonances for the many elderly people facing the end of life alone. As described above, in England, poorer elderly people are more likely to feel lonely and isolated and more affluent elderly can buy in this type of care so there could be an inequality issue with respect to WTHD [194, 196]

The introduction of human support, through nursing, has been shown to help to alleviate the WTHD [252]. Given this evidence, it is therefore important for doctors and other professionals caring for elderly people to assess potential mitigatable causes of WTHD. Emanuel in 1998 proposed a set of clinical guidelines for assessing patients who express a WTHD to make sure that reasons are identified that can be mitigated by management of physical symptoms or psychological symptoms such as depression. Similarly, that social needs are identified and addressed [265]. Unfortunately, very few studies have been conducted in elderly patients, the majority have been in cancer patients. However, one particularly interesting study by Schroepfer et al., in a group of 96 elderly patients with less than six months to live, developed a conceptual framework to describe the way they were considering death. This framework distinguished six ‘mind frames [266]. The first consisted of elderly patients who were neither ready for, nor accepted death. We see this group reflected in patients who simply do not want to talk about death or make advance care plans as discussed below [234, 235]. The second group felt they were not ready for death but did accept it as inevitable. Many elderly patients fall into this group and this may also explain the apparent resistance to ACP. The third group were elderly patients who felt both ready for death and accepted it as inevitable. The fourth group accepted death and wished that it would come quickly. The fifth group had considered a hastened death but had no plans and the sixth group said that they had a specific plan to hasten death [266]. This framework would be a very useful adjunct to end of life care assessment of elderly patients, as it would identify both the group who do not want to be involved, even though this makes their care difficult, and the groups (4 and 5) for whom attention should be focussed and who may need full and urgent assessments for more intensive holistic end of life care to see if any form of suffering can be reduced. This framework could act as a red flag system to identify patients at risk of suicide or with high levels of suffering.

This section has shown that the WTHD may appear to be a manifestation of the elderly patient's autonomy but actually may be a cry for help [263]. It is very important that doctors do not accept a patient's WTHD at face value without excluding potential treatable causes [171].

3.7.3. Are there lessons from understanding suicide in elderly people which can be used to improve end of life care?

Suicide is not a criminal offence in England [267, 268]. The WHO expects, as a result of an aging world population and the high rate of suicide in elderly people, for suicide to become the tenth commonest cause of death in the older population [269]. Interestingly from a sociological and cultural point of view, a systematic review of elderly suicide prevention found that rates are especially high in Asian Countries [269]. Worldwide, the highest rate of suicide in in people over 75 years and this affects a much greater number of older men than women [269]. In the US, men comprise 85% of those who commit suicide over the age of 65 years. Worldwide older people use more violent methods which have a higher chance of successfully ending their lives [269]. In the US firearms were used to commit suicide by 80% of older men and 40% of older women [270]. Studies of coroners' reports find physical health problem are common. In a study in 16 US states, suicide notes revealed inability to endure chronic or unremitting pain in 50% of those aged 65 years or older and 60% those aged years or older. The notes also revealed a loss of hope related to psychological and physical frailty, loss of independence, fear of being a burden on their loved ones or having to go into a nursing home [270]. These mirror the WTHD in other studies described above. Suicide was considered to be both an acceptable and rational response to suffering by more men than women [270]. The study also showed that around one in four elderly people who commit suicide had discussed this with their family [270]. This would provide an opportunity for families to raise concerns with health professionals.

In contrast with most of the rest of the world the suicide rate in people aged 75 years or older in the UK is falling. The suicide rate in men aged 75 years or older is 15.4 per 100,00 and for women 4.7 [271] which is a quarter of the rate in the late 1950s or 1960s. In contrast the suicide rate in South Korea for men aged 70 years or older was 192.1 per 100,000 in 2012 [272].

Reasons for these marked international differences in both rates of suicide in elderly people and trends have not been fully evaluated. Hypotheses include that in England, because of free health care (including all prescription medicines) and free social care for many, the financial pressures on elderly people are not so great as in other countries and people also feel less of a need to be a burden on their families because of state support. It may also be that primary care and community based health services are relatively comprehensive for elderly people and the holistic approach allows for management of physical symptoms such as pain and better recognition of depression and social isolation problems [269]. Other explanations for the fall in suicide rates in the elderly in the UK include better prescription of antidepressants and greater age equality in social and economic circumstances. Pickering, who set up a centre at Oxford University to develop the works of Emile Durkheim on suicide, attributed this fall to a theory that ‘we are much more concerned with older people and they are therefore less lonely and we are better at keeping them feel part of society [273]. This may be true, but I have demonstrated that there are still many elderly people who live alone and in isolation [193]. Moreover, loneliness among elderly people in England has been recognised to be so great a problem that a Minister for Loneliness was appointed to the UK Government in 2018 and a strategy to tackle the effects published in late 2018 [274].

There may also be cultural and religious differences which underpin the acceptability of suicide in the elderly between the East and the West. In the Jain religion from India, while not strictly suicide as an acute event, because they are against violence, it is an accepted practice for elderly people, following consultation with family and religious leaders, to retreat from contact and stop eating and drinking with the intention of dying [203].

Similarly to the WTHD studies, there are lessons from suicide studies for improving P&EOLC for elderly patients. The epidemiology of suicide in elderly patients gives us an important insight into interventions which are important for good P&EOLC to reduce patients feeling of need to end their life prematurely. One study in the US found that 70% of elderly people who committed suicide presented to primary care within a month of death which suggests that primary care was not very good at identifying them as at risk [270]. This US study did not focus much on depression and yet this is one of the biggest risk factors for suicide. In England we know that 20% of older people experience depression rising to 40% of those living in care homes [198]. Risk factors for depression and suicide in the general population of elderly people include social isolation, poverty and bereavement [273, 275]. Ageism may mean that people accept that depression is a natural feature of aging and may not seek help [275]. Lack of help seeking behaviour for depression in elderly patients is also a generational issue because mental health was previously not discussed openly and a diagnosis seen as stigmatising [275]. The Mental Health Strategy for England is trying to combat this myth and encourage patients and doctors to recognise the symptoms and seek treatments [275]. Epidemiological studies clearly show that worsening health especially the onset of terminal conditions, bereavement, social isolation and poverty contribute to depression in older people [275]. These should act as triggers for doctors, especially when observed in elderly patients with terminal conditions, to assess patients for depression. It has also been suggested that older men have unrealistic expectations and strategies in place to deal with the problems of aging especially if they are widowed, which places them more at risk [198, 276]. Moreover, men at high risk are less likely to seek help than women [198]. It is clear that the management of physical symptoms especially pain and recognition of depression are important to reduce the risk of suicide in the elderly [171]. However, it should be noted that the diagnosis of depression in elderly patients especially close to the end of life can be especially difficult as the somatic symptoms can overlap with physical causes of morbidity. Other sociological interventions to reduce the feelings of loneliness and lack of value or self-worth, for example through volunteer schemes to visit and support elderly patients living alone are also likely to be important [177]. Suicide prevention studies have revealed important differences in approach needed for elderly men and women. Suicide prevention strategies in the elderly both nationally and internationally have more success in women [269]. This finding might extrapolate to managing the WTHD in P&EOLC. Therefore attention need to be paid especially to the risk factors and potential interventions in men.

3.7.4. What do these findings mean for autonomy and elderly patients' wish for death at the end of life?

It is very clear from the results of these studies that physical, psychological and social suffering can lead elderly patients to a WTHD, to ask for PAS or voluntary euthanasia in countries where this is legal, and to commit suicide [99, 101, 172, 173, 260, 265, 269, 270, 276]. Given many of these factors can be ameliorated, the question arises whether a patient is exercising their autonomy freely when they are suffering as it is clear that many would take a different approach to death if their suffering could be reduced. I would argue that doctors and professionals have a duty to elucidate whether these forms of suffering are contributing to a patient's WTHD and treat those which are within their remit and refer for help from others as appropriate. This will be autonomy enhancing.

3.8. Avoidance, anomie, and acceptance in the face of death

3.8.1. Introduction

There is a clear need for more research to understand the priorities for P&EOLC and regarding death for elderly patients, so that policy and practice can be better adapted to their needs and wishes. [53, 83, 249, 277]. However, in the current climate in England, of absence of social norms – anomie – about death, elderly patients may not know for what purposes they should, or could, exert their autonomy. Avoidance of contemplation of death could worsen their feeling of anomie and anomie may lead people to avoid thinking about death as they do not know where to seek guidance. Indeed, anomie and avoidance of thinking about death may lead to a reinforcing cycle which prevents the patient from reaching acceptance. There is an accumulating evidence base that not knowing what to think or do about death or avoiding thinking and talking are major challenges for elderly patients and their family carers in trying to protect and promote their autonomy at the end of life [154, 207, 254].

The data from our own, academic partnership, research, illustrated in the Table 3.3 below, in over 3,500 people aged 45 years and older, illustrates the gap between thinking seriously about care and action [174]. We found that 37% (45-69 years), 30% (70-79years), 18% (80+ years) had not thought about care for themselves until the survey. These results show that age and proximity to death do increase the proportion of elderly thinking about their needs for care. However, still almost 1 in 5 people aged 80 years or older have not thought seriously about their future care. Moreover, the stated proportion for whom their next of kin know their wishes is just under a quarter for people aged 70-79 and still only 30% for people aged 80+. There is evidence from our survey of both avoidance of thinking and talking about P&EOLC planning and perhaps anomie reflected in the relatively low level of evidence of planning in terms of who would provide care [174].

Table 3.3. Responses to questions about end of life care planning analysed by age (%) [174]

	Age		
Questions about end of life care planning	**45-69 years** % response	**70-79 years** % response	**80+ Years** % response
I simply have not thought seriously about care for myself until this survey	37	30	18
I have put off thinking about it	14	10	10
I thought that the state would provide	10	8	6
I thought my partner or family would step in and help	9	17	15
I will have the finance to buy care	6	7	14
My next of kin/ relatives know my preference	13	23	30
None of these	10	5	6

It is not clear how anomie, absence of social norms, may lead to patients avoiding consideration of, discussion about and planning for death. No-one has explored whether it is the lack of knowing what is normal and the sense of security that would come with this that leads elderly people to avoid talking about death [207]. Indeed, it may be that today, in England, there are so many options related to care, dying, death and funerals compared to the more traditional patterns that elderly people would have observed for their parents' and grandparents that this leads to confusion and paralysis.

3.8.2. Avoidance of death

Of course it was always known that there are people who do not like to think about or talk about death, especially their own [16, 266]. In England, the 1% Campaign, encouraging GPs to identify patients they think are likely to die within a year and talk to them about End of Life Care Planning revealed that there are a significant number of patients who not only do not want to talk about death, but are offended and lose trust in their GP because of their belief that the GP's primary interest should be in prolonging life (personal communication Prof Andrzej Zbrozyna) [140].

There are both sociological and psychological explanations for the avoidance of death which are not necessarily independent [181, 255].

From a psychological point of view, denial or avoidance of death has been described as a protective psychological mechanism against the fear of death [278]. Terror management theory has been used to explain why people attempt to avoid death anxiety by focusing on other things such as cultural beliefs or self-esteem [278]. Wong and Oliver suggest that this response is unconscious and defensive and therefore may prevent the individual from achieving an optimal quality of their life [176]. In a practical way, patients may not benefit from interventions to enhance their quality of life and dying because they do not confront death and do not discuss the possibility and options for care with their doctor [176]. They may not live life to the full because they do not want to confront the limits to their life.

In recent years, much of the focus on the psychology of death has focused on death anxiety. The main effort has been not only to describe its foundations but to develop therapies to help people with death anxiety [176, 178, 279].

From a sociological point of view the main explanation of avoidance of death is the medicalisation of death. In his book, the Loneliness of the Dying (1985:8) Norbert Elias suggests that longer life expectancy is contributing to society's problems in facing and planning for death and the emotional problems they experience as a result of this [280]. He states that 'The attitude to dying and the image of death in our societies cannot be completely understood without reference to this relative security and predictability of individual life and the correspondingly increased life expectancy. Life grows longer, death further postponed. The sight of dying and dead people is no longer commonplace. It is easier in the normal course of life to forget death' [280].

Zygmunt Bauman (1998) also contributed to this debate suggesting that 'modern societies deny and defer death by turning the inevitable ending of life into a multitude of smaller 'non-ultimate' and potentially resolvable 'health hazards' and illnesses' [281]. In his model, mortality is 'deconstructed', which leads to 'endless defensive battles against aging and death' [281, 282]. This 'final medical battle with death' is confirmed by our own epidemiological studies of the final year of life for elderly people, showing multiple, emergency, hospital admissions [11, 281]. This is also found in other studies we have published on end of life care for people with chronic diseases which illustrate how people become used to treating, curing and managing their chronic, end stage illnesses and being brought back from the brink of death during repeated hospital admissions and treatments to prolong life [81, 187, 191, 239, 283-285].

Moreover, it has been suggested that one of the consequence of the medicalisation of dying and death has been a creeping public passivity in abdicating control for their end of life and so not preparing themselves to face the existentialist crises and anomie of approaching death [138, 207].

An alternative view point is that in today's individualistic culture, the stronger the idea of 'I' the greater the fear of death and of separation from life. This has been described by Tony Walter as the Achilles heel of individualism [207].

However, there are authors that challenge the discourse that elderly people do not think about and/or talk about death [174, 207]. Indeed the research already presented suggests that many older people are aware of the inevitability of death and there is some suggestion that it is in fact the younger generation who supress elderly patients attempts to broach the subject or older people who do not want to trouble them [138, 174]. Similarly, many doctors do not like talking about death so may change the subject when raised by the elderly patient [286]. It has been reported also that patients do not want to upset their doctor by talking about their death as it would seem like acknowledging the doctor's failure [130]. It may be that there has not been sufficient exploration of the contexts within which older people think or talk about or plan for death and this needs further exploration in order to give them greater opportunities to do so in a place and manner in which feel comfortable.

The question is does it matter if older people do not want to think about or talk about death? There are several reasons why it might be important. Firstly, some philosophers, religious practitioners and psychologists argue that that paradoxically, only by confronting death can we really enjoy a vital, authentic and meaningful life [279]. It requires reflection on the fragility and finiteness of life to appreciate life fully. Yalom, a psychologist, suggested that 'the idea of death has saved many lives' in the sense that reflection on, and acceptance of, death led to those lives really being lived 2008 [287]. Heidegger too suggested that contemplation of death gives freedom to live: 'If I take death into my life, acknowledge it, and face it squarely, I will free myself from the anxiety of death and the pettiness of life - and only then will I be free to become myself' [288].

Secondly, there is evidence from empirical studies that patients who do not want to confront death suffer more at the end [255, 279]. This has some obvious logic from a practical perspective as it means professional and families cannot provide care in a way to give the patient not only the best physical comfort but also psychological, social and spiritual comfort unless they know what is important to the elderly patient. These patients are more likely to die very distressed and '*Rage, rage against the dying of the light'* as Dylan Thomas had, perhaps inadvertently or even selfishly, wished his 'death accepting' father would do [257]. This poem clearly illustrates the dissonance and potential communication challenge between an older death accepting parent and their younger adult son who urges them to fight rather than accept death.

Thirdly, if elderly people avoid contemplation and discussion about death, they may not be aware of the possibilities for good quality care, at home or elsewhere and the opportunity to discuss and record their wishes for care.

3.8.3. The problem of anomie and death

Even if an individual wanted to face death and plan for death, it is difficult to know what one should do. The loss of community, tradition and religion, combined with the greater focus on individualism and privacy, have led to a loss of rituals and support and increased uncertainty in the face of death [207, 281, 282]. Anomie (normlessness) is exaggerated as death approaches because of the lack of experienced social norms. This, in itself, can cause distress as people search for guidance about how to prepare for death [207].With no paternalists, such as religious leaders to guide people as they approach death, and if they are faced with an inability to find meaning, many elderly people will experience an existentialist crisis, others are stoical in the face of death, others long for it as a release from suffering, or yet others feel life no longer has a purpose as they feel they have no function to contribute [99, 101, 172, 173, 227, 259, 260, 262, 288].

In the absence of other sources of meaning for a frail and declining life with loss of autonomy and in the presence of a national press narrative which talks about the burden of caring for elderly people, many elderly people do not want to be a burden [113]. An analysis of requests for Physician Assisted Suicide in the Netherlands reveals increasing numbers of elderly people requesting it in order not to feel a burden [289]. It is, cognisant of this risk, that in 2015 the Assisted Dying Bill was overwhelmingly rejected by MPs in Parliament after the Supreme Court in 2014 had stated it could not make rulings as this was a matter for parliament [290].

3.8.4. Acceptance of death

Kubler–Ross was the first psychologist to describe and categorise the human response to death [291]. She described the reactions as occurring sequentially: denial, anger, bargaining, depression and finally acceptance. Denial and bargaining were identified as defense mechanisms and anger and depression as negative emotional reactions [291]. Since her early work the sequential nature of the responses and whether they all happen in every individual has been challenged [292]. Interestingly an analysis of Kubler-Ross' works identifies the phrase 'dignity and peace' mentioned many times in the context of reaching acceptance [293]. Burnier, the author of the analysis comments on the co-opting by the pro-euthanasia movement of the word 'dignity', as for example in the 'Dignitas Clinic' in Switzerland or the pro-euthanasia lobby in England 'Dignity in Dying'. Burnier suggests that the term 'dignity' is almost lost now as a descriptor associated with acceptance of death [294]. Burnier also describes how the pro- euthanasia lobby are, more recently, starting to co-opt the word peace in their lexicon as well [293].

While most recent psychological research has focused on death anxiety and its potential management, there has also been some research on death acceptance [295].

Three types of death acceptance have been described:

- Neutral death acceptance: accepting death rationally as a part of life.
- Approach acceptance: accepting death as a gateway to a better afterlife.
- Escape acceptance: accepting death as a better alternative to a painful existence.

Approach acceptance has been defined as related to religious and spiritual beliefs [206]. Harding, Flannelly, Weaver and Costa (2005) showed that belief in God's existence and an after-life were negatively correlated with death anxiety and positively correlated with death acceptance [206]. Escape acceptance may lead to a WTHD in the face of suffering which is perceived to be unbearable and unmanageable [171]. In which case doctors have a responsibility to assess the treatment options rather than at face value accepting the patient's acceptance of death as the only option to escape suffering while still respecting their views [171, 265].

Cicirelli (2001) has further divided neutral acceptance into extinction, motivator and legacy [296]. A person may find a motivation for dying, for example, if a person believes that a cause is worth dying for then they may lose or overcome their fear of death. Elderly patients may reach this state of acceptance if they do not want to be a burden on their family as Hardwig suggested in his discussion of 'duty to die' [112]. Similarly, if people they feel that they can leave a legacy, which could be intellectual, offspring or money this may make acceptance of death easier [297]. I would argue that motivator and legacy reasons for overcoming the anxiety of death do not seem to be neutral as they are infused with meaning.

3.9. The disconnect between what elderly patients want and what they are encouraged by the state and health professionals to want

Given the anomie in relation to death, as described by Walter [207], where are elderly patients receiving their guidance from about a good death and preparation for it? Families have very little experience now of death and many middle aged and young adults have never seen a dead body [207]. Despite the news being full of stories about death in wars and disasters or deaths of celebrities, members of the public know little about what happens to ordinary elderly people and their families as death approaches [255].

In this normative vacuum, the urgings of palliative care professionals and national campaigns for elderly people to exert autonomy and die as they would wish is problematic when they really do not know what the realistic options are that are open to them [138]. The patients are facing possibly the most critical point in their lives are suddenly required by the 'experts' to express individuality – 'die as you have lived! If I were to do that it would be swinging on a trapeze to the music of Wagner's 'Flight of the Valkyries' but if I am fortunate to live until old age then that is an unlikely modus morendi. If a person has never thought about, let alone experienced, dying how do they know what they need? Does one suddenly become enlightened by becoming a dying person about what one needs? Certainly the onset of terminal disease focuses the mind but even so the options may not be clear and they could be swiftly reducing as death approaches [153, 216].

In a secular society, doctors and other professionals working in the field of death, such as undertakers and lawyers, are filling some of these gaps in terms of guiding people in what they should do as they approach death [32]. In England, the state, in benign paternalistic mode, through its Palliative and End of Life Care Strategies, decided to help people face up to death by commissioning a social marketing campaign 'Dying Matters' [30, 32]. The campaign's rationale was to promote autonomy by getting people to think and talk about death and dying so they could make plans which would protect and promote their autonomy. Indeed, Dying Matters suggests people should be in contact with doctors, lawyers and undertakers [32]. The 'Dying Matters' Campaign urges people to discuss wishes with family, make wills and funeral plans and undertake Advance Care Planning. It is very dominated by a financial model (wills and funerals) and medical model (Advance Care Planning) and the need to make 'Choices' [32]. As it is run by non-religious people, religion or spirituality, is barely mentioned, nor the social components for preparing for the end of life [138]. Chapter 6, on the role of the state, critiques whether these type of campaigns exacerbate anomie or in paternalistic fashion creates a new guide on dying.

Professional advice helps with the physical, psychological, sociological and financial side of approaching death but not always with the aspects of identity such as meaning of life and death although psychologists, philosophers and sociologists are increasingly recognising the importance of this [154, 176, 178, 207, 255, 279, 295].

Importantly, none of the policy initiatives and more specifically the advice being given to the public on planning for end of life has been subject to a rigorous ethical assessment and some of it is just superficial and some misleading. Even more important, none of it has been systematically assessed with reference to older people, who are the majority of people who die [138].

As already described above, National End of Life Care Policy in England, especially in the first, 2008, strategy was very influenced by population surveys which found that most people would prefer to die at home rather than in hospital. A death at home was considered, from a policy perspective, to be a good death because it fitted with the emphasis across the NHS of 'Choice' [30, 120, 156]. This was rapidly transferred into practical policy with a huge focus on choice of place of death to be recorded in End of Life Care Plans and monitoring of national and local administrative area performance through a Key Performance Indicator (KPI) - Death in Usual Place of Residence (DIUPR) [11].

In the haste to implement policy little care was taken to consider that these surveys had been conducted in healthy, predominantly younger members of the general public who were far away from death both in years but also experience and imagination. Thinking was also heavily influenced by a model of specialist palliative care in which the majority of patients who are supported are younger and die from cancer, many of whom do want to die at home and often have family to support them [138] as well as high levels of specialist palliative care input to facilitate this [28] .

Subsequent surveys and research have shown, as described above, that there is greater subtlety in people’s desires and these include other greater priorities such as pain and symptom relief, respect and dignity, calm surroundings, feeling safe, close family or friends present, and not being a burden to others [62, 87, 90, 114-117, 152, 160]. As described earlier, older people say they would prefer to die in hospices and least prefer to die in care homes [95, 160]. However, the results from the National Survey of Bereaved Relatives, the VOICES survey, has shown that for all locations where patients have died, more than three quarters of relatives consider that it was the right place including for those that died in hospital [258]. This perhaps reflects the unpredictable and changing needs of care as death approaches and that aspects of care are good and appropriate wherever a patient dies [153].

Another national source of information on options for P&EOLC is, aptly named and following the zeitgeist of choice, ‘NHS Choices’ – the nationally approved website for the National Health Service on health matters [155]. Other national charitable organisations who support older people such as Age Concern provide information which is more tailored to older people [298]. These may be more likely to reach their target.

There are fundamental problems with the zealous approach of policy makers to prioritising choice in place of care at end of life and place of death in campaigns and discussion about ACP. Choice is not really choice because there is an expectation it will be home [153, 234]. Some groups of patients, especially elderly with end stage COPD or CHD, feel safer in hospital especially when their most frightening end stage symptoms are difficulty breathing [61, 192]. For them a good death would be in hospital with nurses and doctors that they know and trust relieving their symptoms especially as the terminal phase is difficult to predict [299, 300]. Yet well-meaning professionals, influenced by national policy, in particular the indicators which regularly measure and compare proportion of people dying at home, may put pressure on these patients that home is the ‘norm’ and they should try harder for this option. This may be especially challenging for elderly patients who have no family or none close or willing to help care [147]. It may be very challenging for the family too, especially if the patient has dementia [24, 70, 182, 241]. For other patients their condition deteriorates and care would be no longer safe or effective if provided at home or in care homes [87, 119, 127]. Death is especially difficult to predict in frailty and the onset of complications and deterioration may result in a sudden change in the type of care needed by the patient [17]. Patients also change their mind in the face of increasing difficulty in coping or fear of being alone especially if they live alone [62, 103, 160, 216, 249]. Patients and their families may then be left with a sense of failure for not conforming to the new social norm [301].

Another popular source of information on death and dying are what have been described by as 'pathographies' [207]. These are published personal, usually autobiographical, descriptions of dying, caring for the dying or bereavement either in the media, books or self-help guides. This is not something new. In seventeenth century England, the Puritans also published death bed accounts [207]. However, they did not include realistic details of suffering or delirium but rather idealist descriptions that the person was conscious, confessing their faith, and reassuring all around them. Walter suggests that current day pathographies, like their puritan predecessors, are idealised to portray the deceased, or the carer and the whole process in a good light and in order to sell copies. Walter has proposed that pathographies would not be popular if they increased anxiety and fear of death so they 'always finish on a positive note reflecting acceptance and triumph in the face of death' [207].

An important difference between the Puritan accounts and modern pathographies is that the earlier form tended to follow the same model of an idealised death but the modern form describes more diversity [207]. Some modern ethicists, for example Hardwig, have attempted to revive the idea of a 'vade mecum' for dying as in his 'Art of dying in the early twenty first century'[297].

It has been suggested that despite the apparent diversity described by modern pathographies there is less diversity than would at first appear as the majority are written by middle-class, white females so they tend to be culturally and socially similar and reveal very little about the experiences of poor elderly people dying alone or those from Black and Minority Ethnic (BAME) Groups. Moreover, their authors, many of whom are already professional writers, produce professionalised accounts which tend to re-emphasise the medical model of death and dying with some positive, personalised, human elements superimposed. However, two recent books written about death by Americans, both from BAME groups, have been best-sellers [302, 303].

Some of the pathographies do describe the ordinariness of daily troubles and tribulations of dying for elderly patients. There are some insightful accounts of decline to death associated with dementia for example for the British author Iris Murdoch [304].

Ironically, those who want to push individualism and autonomy (in a superficial way) upon the dying are actually prescribing for them these accounts as norms and not actually promoting a wider concept of autonomy for example as a moral being.

Surprisingly, film may offer more instructive insights into facing and coping with dying and death. Some psychologists undertook an in depth analysis of the subject of death in films and identified many instructive scenes in terms of attitudes to, preparing for, coping with and accepting death while finding meaning in life in the face of suffering. They recommended that films could be both educational to the general population and used as teaching aids to students of thanatology [305].

3.10. What do elderly people approaching the end of life use their autonomy for?

3.10.1. Introduction

In older times dying had a set of mutual expectations and obligations for the dying and the supporters. Impending death was recognised and appropriate care was given, rituals undertaken, gifts exchanged, preparations made, reconciliation with family or God considered [166]. Being present at a death was also a learning experience for others about human frailty and the limits of human existence [207].

Today, the wishes of elderly patients range from not being given cardiopulmonary resuscitation (CPR) to finding someone to look after their dog [154, 207]. Indeed for many elderly people pets are their main companions and one of their greatest concerns as they approach their end of life is who will care for their pet. The Sue Ryder Survey, shows that ~ 30% of people mention wanting to be surrounded by personal possession and/or their pet(s) when they are dying [306]. Independence and dignity and consideration of family and others emerge as significant themes over which elderly people wish to exert their autonomy [35].

3.10.2. Independence and participation in decision making about themselves

Independence is very important to elderly people and most will use their autonomy to stay independent as long as possible [18, 35, 87, 113]. This is not a new concept Cicero said that ‘old age will be only respected if it fights for itself, maintains its rights, avoids dependence on anyone and asserts control over its own to its last breath’ [167]. The desire for independence and concurrently not to be a burden are widespread among the elderly approaching the end of life [113]. This desire for independence also applies to not wanting to move to a care home or die there [17, 18, 160]. Older adults report being unhappy with the low levels of participation in medical decision making that their doctors allow and want to participate more actively [307]. Many report that it is important to have a sense of control in decision making. However, not all patients want full control over medical decisions [130, 308] or indeed other decisions [307]. It is important for doctors to elucidate the level and type of control which each individual patient wants. The elderly differentiate between control over personal behaviour and those decisions which involve external players for example medical decisions [130]. Amongst this cohort of patients there is still acknowledgement that the doctor has greater knowledge and many elderly people therefore retain respect for their doctor’s ability to make medically important decisions [64, 72, 130, 309]. Moreover, they also come from a generation who were used to doctors making decisions for patients and they are less used to and sometimes thrown by the concept of shared decision making [17, 64]. Recent research has found that elderly patients prefer to delegate decision making challenging despite the recent focus on trying to promote patient choice [307]. It could, of course, be argued that delegation is a mode of exerting autonomy.

As elderly peoples’ autonomy to make larger decisions diminishes, small decisions are left, such as, what clothes to be dressed in, or whether to have milk or sugar in their tea [18]. These personal decisions are different to medical ones and almost every patient, as long as they have mental capacity, wants control over aspects of their life which affect their sense of identity and dignity [18, 90, 108, 134]. In trying to maintain the dignity of the elderly patient as a sentient, autonomous being, professional and family carers need to seek to find these aspects of daily life in which the elderly patient can make decisions [18, 63, 106, 118]. Fortunately, the (Social) Care Act places emphasis on this type of autonomy. This means that for professionals to truly protect and promote elderly patient’s autonomy they must understand and respect the dignity of the individual and aid them in their choices by fully explaining the disease (s), prognosis in so far as that is possible, and care options [48].

3.10.3. Obligations to family and others

There is good empirical evidence from a number of studies especially in elderly people that finds that they do not want to be a burden [113, 174]. Indeed, not being a burden may be their top priority [115]. In our panel survey of 3,590 adults aged 45 years and older respondents were asked: 'if you were judged at some point in the future as needing care for age related problems or were close to end of life, which of these would be your first choice for care and then your second, third and fourth choices?'[174]. Tables 3.4, 3.5 and 3.6 show some interesting results. Table 3.4 shows that that for the whole cohort only 48% would want care from their family as first choice but Table 3.5 shows that desiring care from the family increases with age to 56% in people aged 80 years or older. This may reflect a changing perspective that older people are much clearer about the type of help and who would be best placed/they would prefer to provide it the closer they become to needing help. Moreover, as shown in Table 3.6, when first, second and third choices of preferences for source of care are aggregated, almost three quarters of this cohort, in each age group, would want help from their family. It is interesting how few people would want to be cared for in a hospital, one in twenty or less as a first choice but still only around a quarter for first, second or third choice. Table 3.6 shows that less than a quarter of elderly people would chose having stranger volunteers care for them in their own home, despite being supported by professionals as one of their top three preferences.

Table 3.4. Preference for type of care should the need arise based on 3,590 respondents aged 45 years and older to the statements posed [174]

Statements regarding type of care preferred	**First choice** **%**	**First/second or third choice %**
Your family/a family member caring for you in either your home or their home supported by health professionals	48	72
Visiting carers provided by NHS/Social Services	17	62
Close friends caring for you in your home supported by health professionals	9	44
A care/nursing home	13	44
A hospital	5	25
Local people you know caring for you informally in your home supported by health professionals	5	30
A group of volunteers you may not know caring for you in your home supported by health professionals	4	22

Table 3.5. First choice preferences for types of care should the need arise based on 3,590 respondents to the statements posed and analysed by age group [174]

First choice responses to statements regarding type of care preferred	**45-69 years N=2021 %**	**70-79 years N=1019 %**	**80+ years N=550 %**
Your family/a family member caring for you in either your home or their home supported by health professionals	46	50	56
Visiting carers provided by NHS/Social Services	17	16	14
Close friends caring for you in your home supported by health professionals	9	7	7
A care/nursing home	14	12	13
A hospital	5	6	3
Local people you know caring for you informally in your home supported by health professionals	5	5	4
A group of volunteers you may not know caring for you in your home supported by health professionals	4	4	3

Table 3.6. Aggregate of first/second or third choice preferences for types of care should the need arise based on 3,590 respondents to the statements posed and analysed by age group [174]

Aggregate of first, second and third choice responses to statements regarding type of care preferred by age group	**45-69 years N=2021 %**	**70-79 years N=1013 %**	**80+ years N=550 %**
Your family/a family member caring for you in either your home or their home supported by health professionals	71	73	77
Visiting carers provided by NHS/Social Services	61	64	66
Close friends caring for you in your home supported by health professionals	45	41	41
A care/nursing home	44	43	46
A hospital	26	28	20
Local people you know caring for you informally in your home supported by health professionals	31	28	29
A group of volunteers you may not know caring for you in your home supported by health professionals	23	22	21

Those not putting their family as their first choice for care should it be needed were asked why. The majority did not want to be a burden on their family. It is interesting, as shown in Table 3.7, that the majority preferred the burden to fall elsewhere rather than on their own family.

Table 3.7. Reasons given for the family not being the first choice to ask for help based on 1,842 responses to statements [174]

Statements regarding reasons why family would not be first choice to ask for help.	% of responses N=1842
I don't want to be a burden to my family	54%
My family live too far away	24%
My family would not be capable of looking after me	14%
My family would probably prefer not to be involved	9%
We are not really compatible	5%
I have no family left	8%
Other	5%
Don't know	6%

In qualitative research, terminally ill cancer patients reported that being dependent was a major reason for feeling that they were a burden [116]. Older adults are concerned about burdening others with their care and may wish to limit their care so as not to be a burden. [116]. The distress associated with feeling a burden may lead to patients wanting to end their life prematurely [117]. It is important to exert caution in comparing the results of surveys undertaken in the United States with the situation in England because of the differences in funding and provision of health and social care. In the US, two thirds of people who are dying feel that they are a burden to their families financially, physically socially or emotionally [114, 116, 117]. The feeling of being a burden to the family is an important cause for anxiety and depression. Patients seek ways to reduce their own distress and that which they fear they are causing to others [114].

Concerns for family are central to the decisions that elderly patients make. There are many choices that elderly patients make with the hopes of reducing the burden on their loved ones. So a perceived sense of duty to family and perhaps more widely to society is a frequent motivator for elderly patients to exert autonomy [114]. Perceived duties to families may include: leaving a will, paying for their own funeral and planning it, making advance care plans or at least describing clearly to their family what they might want to happen to them under various permutations, signing up to be an organ donor, passing on family history or wise advice and behaving with dignity and courage in the face of death [114, 116]. From a financial perspective the concern about being a financial burden is much greater in the US than for example in England where all health and some social care is provided free to older people. Some elderly people may also prefer to make decisions independently so that their family are spared difficult decision making [310]. They may consider ACP will reduce the burden on family members of being asked to make decisions about their care. The problem is that they are not informed that it may reduce the burden if all goes according to plan but if not relatives may be left with pathological feelings of guilt and resultant psychological morbidity [69, 301].

The quality of family relationships between the elderly patient and spouse or adult children have a complex impact on the likelihood of the elderly patient undertaking Advance Care Planning (ACP). The better the relationships the more likely they are to undertake ACP [311].

Elderly people may take altruistic autonomous decisions, for example, registering for organ and tissue donation or to donate their body for medical student anatomy classes. Indeed this is one of the actions that Dying Matters urges people to consider [32].
In England, as migrants age, the melting pot of cultures, with diversity of ethnicity and religion contribute to diversity in the uses to which elderly people want to put their autonomy at the end of life [312]. For many elderly people from BAME family based care and reciprocal obligations across generations remain strong [312]. So across society, in England, we see a multitude of patterns of behaviour.

3.10.4. Dying with dignity

Dignity has been defined as the ‘quality or state of being worthy, honoured or esteemed [293]. Chochinov et al. 2002 found that 47% of patients in their last months of life experienced a feeling of loss of a sense of dignity [313]. By this they meant a lack of consideration, by others, of things that were important to them as a person. Dignity is, in this context, related to personhood and the personal values of the individual. If we say someone was not treated with dignity – what happens is a failure to recognise their personhood. Chochinov is the pioneer of ‘Dignity Therapy’ which is ‘designed to decrease suffering, enhance quality of life and protect and promote a sense of dignity’ [178, 188]. In Dignity Therapy patients are helped to review the most important components of their lives in order to restore, re-find or regain basic values such as: enjoyment, family, a sense of success, caring and being cared for and true friendship [314]. Dignity Therapy focusses on concerns in three areas of life: illness-related concerns, a dignity conserving repertoire, and a 'Social Dignity Inventory' [178]. The process and outcomes of Dignity Therapy can be useful to carers, both professional and family. For example, elderly patients can help their carers to respect their dignity by clearly communicating what is important to their personhood and dignity from small details like how they wished to be dressed, to their views on pain control or spirituality [188, 314].

A discussion of dying with dignity is complex because of different use of the word by conflicting schools of thought. One which says bearing suffering with grace portrays dignity and the other which says that suffering equals loss of dignity so to die with dignity is to die without suffering or at least to die to be released from suffering [90, 293, 315, 316]. There is a further interpretation of the word which is used in the context of how one individual treats another. Thus, the NHS Constitution states that patients have the right to be treated with respect and dignity in all their dealings with the NHS. In this context treating someone with dignity is to respect their personhood [156].

Aristotle suggested that 'The ideal man bears the accidents of life with dignity and grace, making the best of circumstances'[167]. Many elderly patients wish to adhere to this ideal [114, 314]. A major question is whether dignity can be maintained in the face of suffering, indeed pro-euthanasia or pro- physician assisted suicide organisations exploit people's fear of suffering equating it with a loss of dignity. They misappropriate even the word to entitle their campaigns such as 'Dignity in Dying' or the name of the famous clinic in Switzerland 'Dignitas', to propagate a thesis that dignity can only be obtained by escape from suffering through death [294, 317]. They consider a dignified death is one in which there is no suffering, loss of function or control. Again, Aristotle has thoughts on this subject 'Suffering becomes beautiful when anyone bears great calamities with cheerfulness, not through insensibility but through greatness of mind' [167]. I witnessed this in the death of my mother, somehow she truly became more beautiful, noble and dignified as she approached death despite her suffering.

3.10.5. Dying with courage

Closely aligned to dying with dignity is dying with courage. Indeed, Aristotle's quote cited above implies the importance of courage. The issue of enduring suffering with courage or at least accepting it to be awake and present at death is recognised both by philosophers and many religions: Christianity, Judaism, Islam, Buddhism and Hinduism [201, 318]. In history, it was important to show courage in the face of death and give courage to those around you [166, 211, 297]. In medieval times dying (of natural causes) with courage was considered important as a lesson to others who witnessed the death as described in the Ars Moriendi [319]. A courageous death was considered to be a good death [318]. Indeed, this was an ultimate expression of autonomy as a duty to others [318]. My father who was captured by the Germans, during the Warsaw Uprising, and put in front of a firing squad told me how they had been taught to be courageous in the face of death and to smile to give comfort to others around [320].

There is evidence, contrary to common belief, that there are elderly people who wish to face death with courage and therefore may chose not to have strong pain killers or sedation [318]. Doctors may be surprised at this approach but should understand how facing suffering and death with courage is important for religious and philosophical reasons for many elderly people.

3.10.6 Are there other things elderly people could use their autonomy for?

It has been suggested that the best way to conquer the fear of death is to make life meaningful and live it to the full despite the ever present shadow of death. Moreover, that developing an existential positive psychology can enhance wellbeing [255, 295]. Some people do this by following avenues which have the greatest significance for them. This may be things that give them pleasure or in a legacy sense that will help them leave something for others to remember them by or discovering or rediscovering a focus on moral values and principles [321, 322].

Personal values help to give meaning not only to life bit also suffering and death. Personal values are defined as “an enduring belief that a specific mode of conduct or end-state of existence is personally or socially preferable to an opposite or converse mode of conduct or end-state of existence” [176]. Thus, personal values are both emotionally and cognitively important in giving meaning to people’s lives and influencing their decsions [176, 181, 295]. Some people, approaching death, report that living according to their values increases their sense that their life, even if soon to be lost, is worth living [176]. There is evidence that when people receive a terminal diagnosis many focus more on moral values rather than material success [176, 181]. This happens also as a normal part of the aging process[176]. Many people confronting death try to increase the significance and meaning of their life. This may manifest itself through the way in which patients use their autonomy. Terminally ill patients have been observed to reappraise life and to refocus the importance they give to religious morality, self-control and preserving health, family and friendships whereas other things such as immediate gratification, ambition and material success became less important [323]. Fegg et al. 2005 found in a study of terminally ill cancer and neurology patients that the most important values were benevolence, self-direction and universalism whereas power, achievement and stimulation were less important [324]. The findings have been more widely observed in other palliative patients too [325].

The exact focus depends on what is important to the patient. Some elderly patients when confronted with a terminal diagnosis will adopt a more self-gratification approach and decide to blow their savings and fulfill their travel or other dreams [181]. Choices may be influenced by social and cultural determinants. For example, in elderly patients with end stage renal failure, it has been found that socioeconomic differences influence both the patients' attitude to costly acts of self-gratification and of course the financial resources to enable them to do so. It has been observed that more affluent patients may choose not to have dialysis but to travel and live to the full in their time left, while less affluent patients do not see these possibilities and chose dialysis. Notions of locus of control may also be important determinants of these choices. It has been reported that patients who do not re-prioritise as they approach death tend to have more spiritual and existential problems as well as lower quality of life [181].

Spirituality is defined as 'the way in which people understand their lives in view of their ultimate meaning and value' [205]. There is evidence that a terminal diagnosis causes some patients to give more importance to religious concerns. Patients may wish to use their autonomy to engage or re-engage with religion or spirituality. In a study of cancer patients asked about their spiritual and existential needs the authors found that 51% wanted help to overcome their fears, 42% to find hope, 40% to find the meaning of life and 39% to find spiritual help [326]. The desire for support was significantly more frequent among patients from BAME groups than those of white ethnicity. A study of terminally ill cancer patients found spiritual wellbeing reduced end of life despair including the wish to hasten death (WTHD), a sense of hopelessness and suicidal thoughts [171]. These findings emphasise the importance of exploring with patients whether they require more spiritual support, which is one of the domains of palliative care [171].

Meaning centered therapy (MCT) can improve spiritual wellbeing, quality of life, sense of dignity and meaning, depression, anxiety and WTHD [176, 261]. The aim is to try to help the patient find meaning in the face of existentialist crisis. It has been shown to be especially effective in treating despair and WTHD in patients who do not have depression [176].

Meaning centered therapy is based on meaning management theory. Wong et al. have described meaning management theory as a framework to understand death acceptance [176]. Meaning management theory is based on an approach called existentialist positive psychology [255]. It is closely related to Dignity Therapy [178]. The theory suggests that the best protection against the fear of death is to focus on meaning which can help the individual transform fears into courage and faith. It suggests it is more productive or effective to courageously and honestly confront death anxiety and at the same time pursue meaningful goals [321]. The therapy helps people to focus on something bigger than their individual life or death for example either a cultural world view or god. It helps individuals to look for meaning, create meaning and reconstruct meaning and even hope even in the face of suffering [178, 314, 321].

It could be argued that introducing meaning centred therapy when people are confronted with a terminal illness is almost too late and likely to only have a partial impact because of the short time frame involved. On the other hand, there is good evidence that the type of positive existentialist psychology meaning centred therapy is trying to develop, such as courageously and honestly confronting death, naturally develops with age, but of course not for every elderly person [296]. In England, most people will not have access to this type of therapy as there are too few psychologists and there are very few practitioners trained in this concept. It may be better to encourage a population-wide approach, perhaps through a public health campaign, to contemplate death and face it as described by Heidegger and many religions and therefore to consider planning for all aspects of old age and death as a responsibility earlier in life [181].

Patients may want to use their autonomy in specific ways to enhance the relationship with their doctor(s) as they approach the end of life [64, 130, 286, 315, 326]. There are clearly defined professional duties of doctors, outlined by the GMC but it could also be argued that patients, even elderly ones, approaching the end of life have responsibilities to treat the health care staff caring for them with mutual respect [79, 156, 326]. Indeed, such patient responsibilities are outlined in the NHS Constitution [156]. This could go further to perhaps also to help them undertake their jobs by making clear P&EOLC preferences [225, 249, 327]. It could even help doctors by initiating a discussion about ACP as doctors frequently do not like talking about death [64]. Alternatively dying patients who want to die may actively chose not compromise the values of others, for example by not asking doctors for assisted suicide [109].

Finally and controversially, some ethicists have taken the debate on moral duties a step further than most would consider and suggested that elderly people could have a duty to die [112, 297]. The debate is not new, Annie Besant (1847-1933), the essayist and reformer, who later became involved with the National Secular Society, considered it a duty to society to "die voluntarily and painlessly" when one reaches the point of becoming a 'burden' [328]. In more recent times, Hardwig, in particular, in his Hastings Review, discussed whether the elderly patient may perceive, as an altruistic consideration, a ‘duty to die’ in order not to be a burden on their family first and foremost [112]. Interestingly, after presenting the arguments for having a duty to die he suggests that this decision should not be taken ‘atomistically’ and paternalistically by the elderly patient but there should be shared decision making with the family [112]. This seems an invidious question to ask family members of a younger generation ‘am I too much of a burden to you so shall I end my life?’ However, this is not a subject confined to academics. As already mentioned, the VOICES survey in England showed that up to a quarter of dying patients tell their family that they want to die [258]. The desire of elderly, dying patients not to be a burden has been extensively described in elderly patients approaching the end of life [113, 114, 116, 117, 329]. For some this leads to a WTHD and even requests for VE or PAS [172, 173, 259, 260, 289]. Such examples cross my desk too, in my role as lead for P&EOLC for the National Public Health Service, I received email communication from a lady wishing to influence national policy in order to be able to die when she chose, so that she would not suffer indignities and also save money to the state.

3.11. Exertion of autonomy in End of Life Care Decision making

There is good evidence that older patients would like to participate more in medical decision making and that their family or healthcare providers ignore or neglect this [65, 130, 307]. However, putting aside loss of mental capacity, there are also personal characteristics which determine whether an elderly patient is more or less likely to be involved in End of Life Care Planning. Other factors such as the terminal disease impact on the patient, treatments themselves and fear may also impinge on decision making capacity and involvement [72, 153, 165, 216].

3.11.1. Personal characteristics and decision making for elderly patients at the end of life

National policy has urged people to ‘die as they have lived’ [120, 142] suggesting that the way in which to ensure this is by Advance Care Planning [33]. Ironically, urging people to make advance care plans is perhaps missing the point about the relationship between a person’s identity, decision making and the way they conduct their lives. It is therefore interesting that whether or not elderly patients chose to exert their autonomy in terms of decision making in end of life care in part reflects how they have approached the rest of their life. People tend to take a similar approach to making end-of life decisions as to other major life decision [310]. They prefer to ‘die as they have lived’ making their own decisions if that is what they always did or differing to others to make decisions if that was their preference [64]. There is evidence too that the relationship between the elderly patient and their family also influences the likelihood of them planning for death and communicating their own wishes in complex ways [233, 311].

These observations reflect the literature on general decision making which suggests that people tend to have a consistent and preferred manner of making decisions. This preferred mode of being involved or not in making decisions is partly determined by cognitive ability and other characteristics such as self-belief in efficacy [330]. In general, people who like to be independent in normal daily life taking their own decisions including being involved in medical decisions also prefer it in end of life decision making [331]. However, neither taking personal control over decision making or deference to others are blanket behaviours. While people may have general preferences, situational factors also impact on their preferences [331]. Elderly people will take into account not only their personal sense of efficacy but also the impact of their relationship with other players in the decision making process [332]. Elderly patients may like their doctor to take decisions for them, out of respect for their professional knowledge but retain personal and family decision making roles for themselves [64, 128]. In considering future loss of mental capacity, elderly people often distinguish between medical decisions which they would like their doctor to take and personal or social impact decisions that they would like their family to take [333]. Personal views on self-identity and sense of agency are predictive for a preference for independent or delegated decision making [330]. People who strongly value quality of life prefer deciding for themselves about factors that impact on their quality of life [331]. Indeed, people who value quality of life are more likely to choose to stop life-prolonging interventions if they believe that quality of life will be poor [334]. People who avoid thinking about death prefer to delegate decision making to others especially if they also want life-prolonging treatment [229]. They may or may not get what they hope for but, as in general there is a bias to life prolonging treatments in the absence of any clear documentation to the contrary, they are likely to be fortunate in having that wish fulfilled [331].

One of the most important choices elderly patients can make is in choosing surrogate decision-makers. In England this is only valid a person gives Lasting Power of Attorney to someone [32, 155]. In the US, people nominate surrogates on hospital admission [331]. In the current climate in England of patient focussed care and choice, some professionals are concerned that older adults who share or delegate decision making to families are relinquishing their right to make autonomous decisions [130]. However, older adults who share or delegate decision making do not necessarily consider that they are relinquishing autonomy, rather that they are taking an autonomous decision to place decision making in safe hands, chosen by them [64, 229]. They see their surrogates as enhancing and promoting their autonomy where there is a supportive relationship [310]. Not all models of autonomy are atomistic and relational models of autonomy acknowledge that people are interdependent so social dependencies may influence the choices that people make. Indeed surrogates are, almost always, people that older adults have a long term meaningful relationship e.g. spouse, sibling or adult child [335].

Affiliative beliefs, in other words belonging to a religious or other social group with strong decision making rules or hierarchy, may affect the way in which elderly patients wish to make their decisions [201]. However, in one study, the only belief linked with preferences at the end of life was wish not be a burden. People who would choose death rather than become a burden were more likely to want to make decisions independently and they often wished to stop life prolonging treatment if in living longer they would be a burden [114].

Consideration of the impact of being involved in decision making on surrogate decision makers may influence elderly patients’ choices of surrogates [113, 335]. An elderly person may choose a surrogate who, in their opinion, would best bear the psychological aspects of responsibility or they may decide not to have a surrogate at all or instead to appoint joint surrogates to try to prevent jealousies and conflict [149, 213, 336, 337]. However, family members who made decisions for patients who died describe this role as a very burden although some said that despite this they felt that they gained benefit from fulfilling their loved one's wishes [69, 239, 329, 337] [338]. Some elderly patients with insight may decide to spare their family from having to take difficult decsions [331]. In Terry et al.'s 1999 study asking participants about why they did or did not choose a surrogate decision maker, some people said they wanted to make decisions independently because they felt that a surrogate might be too emotional to stop treatment [339]. They also asked elderly people in their study to explain their choice to have their written preferences either followed or overridden by their surrogates in certain circumstances. Some older adults who wanted the option to have their written preferences to be overridden, thought that family's best interests should be included in decision making. Others trusted the surrogate's judgement over their own in medical situations [339].

Having a family whose members could potentially act as surrogates does not mean that the elderly patient feels comfortable to ask them. Despite having family, the elderly patient may people may still feel lonely or that they do not matter or there is a lack of trust and so do not involve family members in medical decision making [332, 335, 340].

One trend emerging in the research on involvement in medical decision making by elderly patients is that regardless of amount of information given to them patients in general had less desire to make decisions regarding the condition than expected. Many studies in elderly patients found that the patients would want the physicians involved to make the decisions [64, 128].

Distress has been described by elderly patients who feel they are being pressurised to make P&EOLC decisions [341]. This suggests that people who feel low agency prefer to defer decision making to others and will experience distress if pressurised to make decisions themselves [342].

In the exertion of autonomy the process of decision making is as important as the decision. Although end of life decisions may be made independently, the decision making process may be shared or delegated [343]. The implications of this are that healthcare providers should first establish how elderly people would like to make their decisions; level of information, inclusion of others. Also, in decisions, which are as important as those at the end of life, it is important for medical professionals to assure themselves that patients have had adequate information but perhaps not overburden the patient with information, especially if they have fluctuating or reduced mental capacity [79]. This may mean making decisions over a period of time and not at the first discussion. Given the range of things important to elderly patients and their frailty, greater diversity in approaches and methods for decision making is required [153, 226, 343].

3.11.2. Factors impacting adversely on autonomous decision making

It is very important for professional and family carers of elderly people approaching the end of life to be aware of the panoply of factors which may adversely influence how a patient choses or appears to be exerting their autonomy in decision making. Some of these factors have been discussed above in relation to WTHD and suicide in elderly patients [172, 227, 259, 260, 276] and requests for Physician Assisted Suicide or Voluntary Euthanasia [102, 173]. These include: pain and other severe symptoms, depression, loss of identity and feelings of usefulness, existentialist crises, spiritual or religious issues, anxiety about how care will be provided and by whom. Studies have shown, as illustrated above, in relation to WTHD, that resolution of these factors may enable a patient to make different autonomous choices [171]. Other factors can influence the elderly patient decision making capacity these include: the influence of medication, loss of or fluctuating mental capacity due to dementia like conditions [24, 79]. In elderly patients special care needs to be given to exclude concurrent infection especially urinary and chest as this often just presents as confusion or delirium [344].

The question is then under what state does anyone make truly autonomous choices especially as death approaches? For elderly people approaching end of life, almost all will have personal, medical and external factors which are causing duress and may lead to decisions that the patient would not make otherwise if not facing death. Doctors therefore have an absolute duty to elucidate these factors to give patients the maximum chance to make the autonomous decisions the best they can be approximating those they would make without duress [79].

3.12. Aids to exercising autonomy

This section explores the ways in which patients can express their autonomy to others, to aid decision making when they have mental capacity, and to try to ensure their wishes are respected if they lose mental capacity. It will evaluate whether tools used in Advance Care

Planning (ACP) such as Advance Directives (ADs) are really valid tools for enhancing and extending autonomy or whether their promotion to patients is not strictly honest given their limitations.

3.12.1. Advance Care Planning and Directives

Advance Care Planning (ACP) and Advance Directives (ADs) are actually processes and documents intended to extend a patients autonomy and thereby respect their wishes primarily regarding medical care for a time in the future in case they were to completely lose mental capacity [46, 221, 345]. However, because the discussions and decisions focus on whether or not to have life prolonging treatment, as this is all that is regarded to be important from a legal perspective, they have become strongly associated with the concept of end of life care planning. A patient with mental capacity has the right to refuse treatment, a person without mental capacity cannot. ACP and ADs were initially simply a tool to extend autonomy to a time when the patient may not have mental capacity. However, because protection of life is a legal duty, any document containing instructions not to give life prolonging treatments or to withdraw treatments under poor prognostic circumstances must be legally constituted [46]. These forms of AD are called, in England, an Advance Decision to Refuse Treatment (ADTR). An ADRT is described under the Mental Capacity Act 2005 [46]. People completing them have to be capable of understanding, retaining, weighing up and commentating or contributing to decisions. In order for it to be valid and applicable the refusal must have been made when the person had mental capacity. If it includes refusal for life sustaining treatment the ADRT must be written signed and witnessed and to include the statement ‘to apply even if my life is at risk’ [46, 155]. It is important to note that the type of choices predominantly recorded usually are of the negative autonomy type ‘I do not want’. Legally binding ADs are usually ADRTs and therefore do not express positive autonomy, unless one can say it is a positive form of autonomy to actively put in mechanisms to refuse treatment. ADRTs need to be used with caution especially as patients with mental capacity should be able to change their mind regarding decisions previously made [153, 216]. The treatment decisions made by the patients in legally valid ADTRs must be respected by doctors even if they disagree with the decision.[79]. If there is disagreement or the doctor feels morally compromised by the decision they must in the first instance involve colleagues. If the matter cannot be resolved it can be referred to the courts for a legal decision by the court of protection [79].

In Poland, the constitution and legislation give patients the right of self-determination. Patients must give consent to therapeutic interventions and can choose between equally effective treatments. Patients can also refuse treatments. It is illegal to give a patient with mental capacity a physical treatment against their will. The patient’s right to make autonomous decisions depends on three preconditions: patients must have mental capacity, they must be well informed and they can only approve or refuse treatment options that the physician has actually proposed [346].

Advance Care Planning (ACP) is usually presented as a way of ensuring patients’ wishes are respected with respect to Palliative and End of Life Care (P&EOLC) if mental capacity is lost at some time in the future [347]. It is clear from the above description though that ACP and even ADs not legally constituted are not legally binding a rather a record of discussion about wishes. In England ADs can also have a role, while the patient still has medical capacity, as an adjunct or tool to support exertion of individual autonomy. In terminal disease decline, possibly combined with the frailty of old age, there is not always a clear distinction between having or not having mental capacity as it may fluctuate as the end of life approaches not just day to day but even hour to hour [24]. Even for elderly patients who have mental capacity, when deterioration occurs, or crises develop, it may be very difficult for them to make their voice heard against those of members of their family or professionals [239, 311]. It is for this reason, not just in case of loss of mental capacity, that ACP is encouraged. Through national policy in England and public campaigns such as Dying Matters and the doctor targeted 1% campaign elderly people are encouraged to think about death and dying and at the first level talk to their family and doctor [32, 140]. The main focus is on discussing and recording the patient’s preference for place of death and care and this is the outcome most frequently cited in publications on the success of ACP and ADs [86, 94, 348] .

3.12.2 Concerns about Advance Care Planning and Advance Directives

The concepts underpinning ACP, ADs and ADRTs have been vigorously challenged by ethicists and clinicians [60, 109, 126, 153, 165, 216, 234, 345]. Where the purpose is to extend autonomy to a time in the future when the person has lost mental capacity, the arguments centre on the ability to decide what will be best for a future demented self and the impossibility of planning and deciding for future unknown scenarios. Where a wider view is taken, that ACP and ADs are used to express and record wishes of patients to support decision making even when they retain autonomy, there are concerns about the practical implementation of the processes.

The unresolvable question of whether a person who has lost mental capacity especially with dementia is the same person as they were before has dominated one aspect of the debate on validity of ACP, ADs and ADRT from an ethical point of view. The question is if they could make a decision in their current state would it be different to that which they made previously [59, 109, 126, 153, 165, 345]? It is a particular challenge for people given Legal Power of Attorney for Health and Welfare as they are expected to represent a person who has lost mental capacity's wishes yet cannot help being influenced by the current state of the person whom they represent as well as the impact of any decision on them personally. From the court's perspective, in England, decisions are made on 'best interests' under Parens Patriae Jurisdiction, so take into account the patient's current state and all other surrounding circumstances including, but not dominating, what is known about their previous wishes [131].

Another, linked issue, which also applies to elderly patients who maintain mental capacity is the problem of not being able to predict future events and circumstances and one's reaction to them. The very idea underpinning ACP and ADs is encapsulated in the word 'Advance', in other words ahead of some unspecified time in the future. However, the key problem is that future scenarios cannot be predicted and there is a complex interaction between changes in the patient's physical and psychological status, their needs for care, the family's ability to provide support and the possible need to transfer to a care home. Moreover, treatments cannot not be predicted or one's views on them when they are not required [66, 109, 152]. There is good evidence that elderly patient's views on what would be best for them change as their medical condition changes, dependence on others increases, they experience increased causes of suffering and death is more imminent [153, 165, 216, 234]. Many forms of discussing and recording ACP or ADs lack adequate capacity or function to allow changes and review [60, 151, 216].

There are other concerns, already described to an extent above, about the circumstances under which decisions are made, which lead to ADRT [153]. The patient may be under duress because of suffering in any of the four spheres: physical, psychological, social or spiritual and may feel compelled to make decisions which if these were ameliorated they would not make [334]. People really fear loss of autonomy especially in degenerative neurological conditions and dementia and their decision making to refuse future life extending treatment may be driven by fear of loss of dignity and by existentialist concerns [346].

There are also concerns about the influence other may have on decision making in any form of ACP including doctors and family. There is good evidence that doctors have unconscious biases with respect to care at the end of life influenced by their medical training, ethnicity and religious backgrounds. They may subconsciously put pressure on patients to make decisions in ways that support their own beliefs [349-351]. The role of doctors may vary country to country even in Europe and is influenced by the legislative and medical regulatory framework within which they work in terminal care as elegantly demonstrated by Weber et al. in a comparative analysis of doctors roles in decision making in advanced neurological disease in Germany, Poland and Sweden [346]. Family dynamics also play an important role which can be either supportive or unhelpful or in the worst situation ruthless and immoral in persuading elderly people to complete ADRTs against their wishes [149, 310, 311, 338, 345]. There is no question that sometimes family carers of people with dementia start to welcome the death of their loved one both to end the suffering of their loved one and their own caring burden [70]. Of course this does not mean that they would actively do anything to hasten the death, except perhaps more actively support proposals to withhold or withdraw life prolonging treatment.

In Poland, there is less emphasis on ACP and this helps to address some of these issues about the challenge of predicting both the medical trajectory and the patient's reaction to it. Doctors tend to treat the patient's immediate problems as they are now. They may of course respond to questions about prognosis during early stage disease however it would be less common to plan with the patient for future eventualities and document them [346]. Therapeutic decisions on life saving interventions would generally be made at the time when they are actually or highly likely to be required and at that point discussions are held, patient consent obtained and the decisions documented in the patient's medical notes. Currently neither Polish healthcare law nor clinical practice have provision for ACP or ADs. There are no legally assured routes for patients to influence their treatment in advance of losing mental capacity or ability to communicate in the future.

However, there is wide spread debate about '*pro futuro'* statements [352]. The feasibility for patients to legally appoint a surrogate decision-maker is being evaluated, by experts, but has not yet, to the best of my knowledge, entered the legislative process [219]. Under the proposals, the surrogate decision maker suggest use of a term such as medical power of attorney. Although, if there were no problems this would be a life-long designation, the person nominated can resign from the role. Moreover, if in the opinion of a doctor they were not fulfilling their obligations or their actions and decisions appeared to be contrary to the patient's best interests, the doctor should notify a relevant court of law whose would be able to revoke medical power-of-attorney status. Currently, a legal guardian can be assigned to an incapacitated adult patient only through a court ruling [219].

ACP and ADs may be useful in care homes for the elderly to for example reduce unwanted and unnecessary admissions to hospital [54]. However, there have been particular concerns about autonomy being overridden especially in care homes where Advance Directives are completed by staff with or without family members but without the elderly patient's involvement. For example, within the Gold Standards Framework there is a standard for 100% of residents of care homes to complete them [144]. This would mean that there could not be full autonomous decision making for all the residents as there is clear evidence that many patients lack mental capacity due to dementia [245] and not all patient want to discuss death or make plans [147]

Even if an Advance Directive has been completed there can be significant problems in accessing it across the health system, especially out of hours for Ambulance Services and Emergency Departments. The Electronic Palliative Care Co-ordination Systems (EPaCCS) systems overcome this making these records available across a local geography to all relevant parts of the health system but they are not uniformly available across England. We and others have shown that these are effective in realising patient choice of care and death and are very cost effective [157, 353]. However, concerns have been made about the sharing of data across organisations which some have suggested may even infringe human rights [60].

There are very specific concerns about ADRTs. ADRTs may include for example: 'Do Not Attempt Resuscitation' (DNAR), do not admit to hospital, not for antibiotics, not for ventilation. There is wide concern about ADRTs [153] these include:

- Poor communication with patients and family so they do not know what is recorded or understand the decisions that they are making.
- Failure to involve patients adequately in decisions about DNAR orders.

- DNAR decisions being made in ad hoc manners and with variation across different settings such as hospitals, care homes, GP practices.
- Unjustified DNAR decisions being made in some types of patients.
- Variation in the method of making and of recording decisions.
- People being subject to Cardiopulmonary Resuscitation (CPR) where there would be no benefit or contrary to their wishes.
- Doctors misinterpreting a DNAR to go beyond CPR and withholding other treatments which may be of benefit such as antibiotics.

Finally, the concept of ACP being solely an egoistic approach to try to control physical death has been challenged [354]. ACP in the UK focuses narrowly on issues such as place of care and death and refusal of life prolonging treatment issues like DNAR. Failure to widen the context to include how decisions impact on family and carers actually reduces the autonomy of the patient as a moral being if unaware of the benefits they can accrue to others [354].

3.12.3. Why is there low uptake of Advance care planning and Advance Directives?

Despite almost a decade of national policy encouraging people to make ACPs, including Dying Matters and the 1% Campaign [32, 140], very few people have completed any form of ACP or AD estimated as under five per cent in 2013 in England compared with around one third of people in the United States (US) [355]. A 2017 study reviewed 150 studies published between 2011 and 2016 looking at proportion of adults in the US who had completed ADs. Of the almost 800,000 people included 37% had completed some type of AD. People over 65 were significantly more likely to complete an AD than younger people 46% vs 32%. Interestingly the difference between healthy and sick was 33% vs 38% [355]. The comparison with the situation in England raises, as yet unanswered, questions as to whether the higher rates of AD completion in the US is a cultural, rights based difference or related to the insurance based provision of health care, or more pressure for completion of ADs on admission to hospital. Certainly Medicare try to incentive doctors to encourage their patients to complete ACP, by reimbursing them for counselling about ACP benefits. In 2016, Medicare stated they will pay physicians $86 for 30 minutes of ACP in a physician's office and $80 for the same service in a hospital. In both settings, Medicare will pay up to $75 for 30 additional minutes of consultation [356]. In the US based insurance system completion of an AD or ACP, especially for older patients, to ensure that they will get access to palliative care. Medicare may have a financial interest in promoting ACP. If a patient selects a palliative care option they have to relinquish their rights to all life prolonging treatments for example chemotherapy. In practice therefore, this means that the patient’s choice is not a completely free one as an ACP is the key to palliative care if they should need it [356].

In England, the question is why there is such a disparity between four out of five people thinking it’s a good idea to complete an AD and only a few percent actually doing so. One explanation may simply be preferential responding. People respond that they think it’s a good idea because that is what they think is the answer they should give especially is a question is presented as if this is the social norm. It could be that elderly people do not complete them because they are wiser and more reflective about end of life and its unexpected twists and turns, perhaps based on their life-time experience. Perhaps they understand that ADs can be problematic and not able to predict all scenarios. Or maybe they realise it does not matter as others will decide. Other postulated reasons why people are reluctant to make an AD include: they worry they will not receive other types of care if they sign a DNAR order and they are worried that they may not be able to change their mind [235]. There is also some surprising evidence that as people age they are more willing to have treatments, they may have rejected when they were younger, in order to prolong their life [234]. ADs assume that the future can be anticipated with accuracy and many people recognise that this is an illusion [234].

Perhaps policy makers, in England, need to accept that decisions need to be made in real time with all the information available at that time as in Poland.

Some people have suggested that even if elderly patients do not want to complete an AD they should appoint a health care proxy decision maker or LPA in England [153, 222, 350]. Indeed, this would fit well with the evidence that elderly people usually want to exert their autonomy in a relational manner and place great value on and trust in family decision making [35, 62, 311]. In England, as described earlier, the Power of Attorney must be a legally appointed to have decision making power. There is a registration fee of £82 in England and Wales for each lasting power of attorney registered if an individual does this themselves via the internet. If they use a lawyer to help then this would incur a fee to the lawyer. In England there are several potential barriers to elderly people doing so: firstly knowing about the role of lasting power of attorney, secondly completing the application on-line as not all elderly people are computer literate, thirdly the fee.

Some authors have suggested that given elderly patients actually have a variety of reasons for exerting their autonomy, not all related to medical decisions that the process of ACP should have much greater flexibility in both form and function to accommodate, understand and support the autonomy priorities of elderly patients [226].

3.13. Discussion

Evidence from studies on aging and frailty show that many, but not all, elderly patients start to lose autonomy for independent action usually months or years before death, sometime punctuated by a significant stepwise loss in autonomy for example: confined to a wheelchair, bed, or move to a care home or the progression of dementia [17, 18]. This means that for many elderly patients, the approach of death occurs on a trajectory of loss of autonomy [18, 283]. As I have described elsewhere, 'The 'Choice Funnel' of Life starts wide but ends up narrow' [283]. Elderly people often fight to retain as much autonomy and with this dignity as they can as death approaches [18]. Despite this reduction in physical capabilities, elderly patients retain or even strengthen their view of autonomy in a relational sense and value their identity as members of families and society [116]. Common themes expressed by elderly people are that they wish to have their dignity and identity as a person respected [113, 228, 313]. Many still fiercely wish to make decisions which will not result in or relieve the burden of caring for them on others [113]. Our own work showed more than half of people aged 45 years or older (54%) cite not wanting to be a burden on their family [174].

In contrast to younger generations, many elderly patients, still hold religious and spiritual beliefs [201]. Indeed it has been observed that with aging and especially the approach of death, religious, spiritual and existentialist concerns increase and other materialist concerns reduce [176]. This also influences the way in which elderly patients decide to exert their autonomy both from a moral and a practical view [202].

A clear dissonance is appearing between national policy initiatives urging people to make choices and record them [32, 33, 140] and the views of many elderly patients who seem reluctant to consign choices to paper and would prefer doctors or family members to make choices for them [64, 310, 335]. However, at a population level it still is not clear whether the majority hold this view. It is also clear that there is still real paucity of evidence about what elderly people think about end of life care planning and how, if they were to engage in it they would like to do this [331].

With respect to autonomy and P&EOLC, elderly patients are being encouraged to make plans and talk to family and professionals about what they would like to happen to them at the end of life for a time in the future when it may be difficult or impossible for them to express their wishes. National P&EOLC policy in England emphasises the importance of choice in a liberal, but not necessarily intended to be, interpretation of autonomy as simply being self-regarding [154] . The choices, which it suggests need to be made, are about place of care and death or withholding or withdrawal of treatment. The Dying Matters Campaign also suggests people should plan funeral arrangement or making wills [32]. National Policy does little to address the very issues central to elderly people as they approach the end of life and these are related to their identity, their dignity and family [62]. The empirical evidence is that elderly patients do not make end of life care decisions only on a self-regarding basis [114, 116, 117].

Liberal autonomy theory suggests that individuals are rational and independent beings who are "unencumbered" or "disengaged" from a social context [345]. Observation of real life challenges a liberal autonomy approach to making choices. Most elderly people are deeply interlinked with a community. At the first level they usually, but not always, have family, then wider circles of friends and neighbours and social groups. For those with few family or social contacts it is rarely a personal choice. The elderly and their supports are linked by reciprocal obligations, dependencies, shared traditions, and a network of institutions with whom they interact [18]. In most cases, elderly patients, because of frailty, are too dependent on others to be a self-sufficient and only self-regarding, atomistic decision makers as portrayed in the Choice Review [357]. Proponents of a communitarian approach challenge the concept that an individual can be considered to be independent of their community. Moreover, that the approach of liberal autonomy does not acknowledge the importance of communal values which in turn influence the way individuals make value-based decisions [59]. Thus, autonomy, in the context of end of life care, cannot mean simply a person's right to choose for herself based on personal interests alone. Elderly patients almost always need to consider the impact on others in their decision making, either because their help is needed, or because the decision will impact on them in some other way [116, 117]. The identity of elderly people and therefore the nature of their choices and even their capacity for choice, cannot be divorced from influences on their family and community [358]. The communitarian view of identity is "narrative" and based on the person’s biography, which in the case of elderly people can be long and rich, whose telos has been "intersubjective" [358].

It could be argued therefore that it is morally wrong, to urge the elderly patient, as a moral agent, to make decisions in an atomist way which is contrary to their natural state of being which is located in a community from which they derive their moral identity and sense of duty to others [112, 113, 297].

Liberals criticise the effects on individual's choices of social manipulation [350]. This is ironic and especially interesting in the context of P&EOLC policy in England. It could be argued that National policy, through the Dying Matters Campaign, has been trying to manipulate people into making choices, who would rather not, either because they do not want to think about death, or they think about it but still do not want to make choices [32]. There is good evidence that there are older adults who fall into both groups [220]. Not only a specific type of decision is being promoted but there is also an expectation of specifically what that decision might be. So care and death at home has been seen, for example, as the 'Gold Standard' [86]. Only very recently it has been recognised that it is unfair to present this to patients as the ideal especially for frail elderly and those with Chronic Obstructive Pulmonary disease and Heart Failure where terminal symptoms may be very frightening for patients and relatives and care in hospital may be more appropriate [192, 299, 359]. I am aware of multiple anecdotal reports of family members being persuaded to decide that their elderly relative should not have CPR by being given lurid reports of how terrible the procedure is for example breaking ribs and how distressing it is for staff to witness. While the rhetoric is that these should be informed choices they are presented in an emotionally loaded way to patients and families which may indeed be unethical [350, 360, 361].

Social marketing campaigns are supposed to produce individual and societal benefits [362]. There is an undercurrent, known to policy makers, although not made publically explicit, that the type of choices which are being promoted: place of care and death, DNAR and perhaps other aspects of ADRTs, has not only potential benefit for the patient and could be autonomy promoting, but also a societal benefit in terms of reducing costs, certainly in hospitals. This, while true and a valid utilitarian argument, could be misinterpreted by the public who could feel their autonomy and choices are being restricted, even in death, because of budget restrictions on state funded services. Social marketing campaigns should have an ethical framework underpinning them but there is no evidence that one was employed for the implementation of Dying Matters. Development of an ethical framework is very pressing given the risks of public misinterpretation or overzealous implementation [350].

End of life care policy in England, especially after the Choice Review, which responded to the Liverpool Care Pathway Inquiry Report (More Care, Less Pathway), has been very focussed on a concept of autonomy that could be defined by liberal philosophical theory, although in reality no theoretical basis has underpinned the thinking. As will be discussed in the Chapters on State Paternalism in fact the campaign to promote ACP is somewhat dishonest as care is not so universally good across the country that patients have real choices to make [11].

Indeed, Baroness Neuberger's Inquiry Report on the LCP was called 'More care, less pathway' not 'More choice, less pathway' and her conclusions related to better universal care and informed consent [39]. The informed consent somehow slipped into the lay and liberal language of choice when the government set up 'The Choice Review' committee to advise on how to respond to the Neuberger Review and the national Leadership Alliance for the Care of Dying People report 'One Chance to get it right' [39, 120, 363]. This was then converted within the zeitgeist of choice in the NHS, to a choice agenda for end of life care couching end of life care planning in phrases like 'so you can die as you have lived' [120]. The Dying Matters social marketing campaign, even though well intentioned, was already using the mantra of choice within their campaign materials seeking to empower and influence individual's behaviour and choices with respect to end of life care. Putting aside the risks of manipulation described above, the campaign approach fails on several counts related to priorities for autonomy for elderly people. Firstly, that when push comes to shove, access to and quality of care is more important to the individual than choice of place of death. Secondly, the patient's condition or ability of family members to provide care may deteriorate such that previous choices about place of care have to be abandoned to provide safe and effective care. Thirdly the type of care a person may be encouraged to decide upon may not be available in their local health administrative area. Fourthly, the choice agenda has failed to understand how elderly patients, who make up the majority of people who die, view their individual self not as an isolated being, making self-centred and selfish choices simply about what they want, but as part of a family and or social group and as part of wider society. For this reason personal relationships and how decisions made about wishes for end of life care need to be taken into account. The urging of people to make decisions about place of death and care as if this is the most important things ignores elderly patients' views about values or social justice or intergenerational justice [113, 116, 117].

Even more serious is that a campaign which suggests people should make clear where they would like to be cared for is deceitful especially to the elderly as their chances of their preferences being realised are slim [160].

Thinking about death and wanting death are common among elderly patients [258]. Many do not fear the shadow of death [296]. While some may wish to hasten death quite rationally because they are tired of life [100, 102] many may wish for it because of uncontrolled symptoms, depression, fear of being a burden or fear of death itself [227, 263]. Professional providers of care, especially doctors, have a duty to elucidate these potentially mitigatable causes and offer the patients interventions as appropriate [171]. There is perhaps not yet sufficient emphasis on identifying these factors within the general medical and even specialist P&EOLC services. Moreover, most health professionals have very limited time to discuss anything except the most pressing medical decisions. Only specialist palliative care professionals have more adequate time to spend with the patient [225]. Failure to resolve these issues may mean that the patient dies in torment and the family are left with feelings of guilt [69] .

Some argue that debates about how autonomy is exercised whether through independent or delegated decision making is irrelevant because often in the end when the patient is dying there is little in the way of choices to be made [364]. Firstly, because of the unpredictable nature of terminal illness and death itself and secondly that it is the doctors and health and social care teams who hold the power. These forces interact so that in the end, patients and families are forced into ‘choosing the inevitable’ [364].

There are multitudinous reasons why trying to choose a place of death may be frustrated by the twists and turns of fate. Between 15-25% of people will die suddenly, of an acute event such as a heart attack or stroke, and this could occur anywhere [158]. Sudden deterioration may precipitate an admission to hospital [54, 187, 277, 365]. Relatives or carers may not be able to manage care at home, care at home may be unsafe because of the risk of falls or other issues in the case of dementia [24, 104, 119]. Symptoms may need more specialist and intensive management than can be offered at home. On the other hand, elderly patients have a greater chance of achieving their wishes if they specify where they would prefer to receive most of their care at the end of life and plan for this too in a practical way [86]. The majority of patients spend most of their time during the last six months of life in the community and not in a hospital or hospice. However, our statistics show that even this varies by geographical area [137]. It is not clear whether this variation is due to variation in levels of community care, certainly variation in levels of care home beds will contribute [11] or patient choice or case mix. There is good evidence that expressing a wish to be cared for at home and not to be admitted to hospital as an emergency in an Advance Directive has a good chance of being realised [94]. However, this possibility should not be over promised as it can lead to pathological feelings of guilt in the families if it cannot be achieved [69, 329, 366].

The analysis presented here raises questions about the duties of elderly patients. These duties could be to the family and/or to their medical carers, over even wider society. However, even duty, if exerted in atomistic way, can become paternalistic. Therefore, even when the elderly patient is exerting their autonomy for its moral purpose they must remain vigilant not to become so egocentric about how they make moral decisions that they ignore the impact that their decision may have on others [112, 180].

If elderly patients are to make truly autonomous decisions when they choose surrogate decision makers, then they should be aware that: a) surrogate decision making is difficult for the surrogates and can be enormously stressful leaving the surrogates with feelings of guilt, b) surrogates preferences are not always the same as the patient would expect because obviously they are individuals who think differently [69, 213, 336, 367]. Holding shared values seems to enhance the chances of making similar decisions, so the sharing of values underpinning choices is important in asking a surrogate to play that role [367].

3.14. Conclusions

In conclusion, there is good evidence that the priorities for autonomy in elderly patients approaching the end of life are both very personal and frequently relational. National policy promotes choice, but largely within a medical model, which helps to make the job of doctors easier and possibly enables some of the patient’s wishes to be fulfilled. However, other aspects of care such as respecting the identity and dignity of the individual and their concerns for family and others receive less prominence and these need greater focus as they are the fundamental things which are important to elderly patients as they approach death.

Chapter 4. The relationship between individual autonomy in elderly patients approaching the end of life and human rights

4.1 Introduction

The European Convention on Human Rights (EHCR) and its derivative laws in individual countries, such as the Human Rights Act 1998 (HRA 1998) in the United Kingdom of Great Britain and Ireland (UK), were drawn up to protect the autonomy and dignity of the individual [45]. Aspects of autonomy appear under various Articles of the Human Rights Act 1998, for example the right to liberty (not to have one's liberty restricted) or the right to protection against inhuman or degrading treatment [45]. This chapter critically examines the relationship between the factors important to individual autonomy in elderly patients approaching the end of life and various dimensions of human rights as described by Articles of the HRA 1998. Chapter 6, looks at human rights and Palliative and End of Life Care (P&EOLC) from the other side of the coin by examining the role that the state plays as a beneficent paternalist adopting the doctrine of 'parens patriae' in ensuring that human rights are protected and respected in delivery of P&EOLC in England, especially for vulnerable elderly people with reduced or no capacity to make their own decisions.

Palliative and End of Life Care has, itself, been described as a human rights issue and this theme is being used to argue the case for improved P&EOLC across the world from countries from Armenia to Brazil with significant activity across Europe through the Lisbon Challenge [2, 3, 21-23, 315, 368-370]. The debate about what this means in practice tends to be dominated by a specialist palliative care perspective and a focus on cancer patients. Key topics identified are: access to medications to relive suffering, especially opiates, and to qualified staff to provide care as well as respecting the patient's autonomy with respect to choices. This latter is usually only defined in very medical terms and in predominantly in relation to the autonomy to refuse treatments [1, 2, 4, 21, 22, 315]. To date no-one has published on the theme of human rights and palliative care from the specific perspective of elderly patients approaching the end of life and their priorities for autonomy. The United Nations has, however, identified that the human rights of the elderly across the world are in general poorly respected and established a working group [10]. However, this does not look specifically at P&EOLC.

This chapter uses a framework based on Articles from the Human Rights Act 1998 in England [45] to evaluate to what extent the issues identified as important by elderly patients for exerting their autonomy at the end of life (EOL) fall under the aegis of human rights legislation. This is important because, if they are considered human rights, it elevates those issues above mere hopes and desires expressed by the patient, to placing legal obligations on state funded carers to protect and promote these aspects of autonomy [45]. This has policy implications because for frontline staff to fulfil their legal obligations they will have to be adequately aware of how the wishes of elderly people fall under the HRA 1998 legislation and what they are required to do to protect or fulfil the rights. This would mean publishing documentation giving greater clarity on the autonomy issues which are important to elderly patients, how they are seen as human rights and also providing more training to staff on this matter [368].

This chapter will explore how priorities for exerting autonomy in elderly people approaching the EOL identified in Chapter 3, map onto legislation including the HRA 1998 and other legislation derived from it. Moreover, there is an analysis of how this legislation currently protects and promotes these autonomy issues and similarly how policy and provision of care supports this. The autonomy themes identified from the research presented in Chapter 3 include: elderly peoples' relationship with death itself, desire not to suffer both physically and psychologically and specifically not to suffer through loss of dignity. Other aspects of autonomy such as liberty in particular freedom from constraint, freedom of religious views and expression and justice in terms of equal rights for elderly patients to access to good quality P&EOLC. I will also examine how the wish to hasten death (WTHD) may be considered as a human rights issue and how, in England, this is approached.

4.2. Methods

Key topics which emerged in Chapter 3 as priorities for autonomy in elderly people at the EOL have been matched against 'Articles' from the Human Rights Act 1998 [45, 368] to create a framework. This has been used to explore these issues using an interdisciplinary approach to synthesise the evidence from published literature, P&EOLC policy documents and other evidence sources such as the National End of Life Care Intelligence Network [137]. Table 4.1 summarises the framework.

Table 4.1. Framework to evaluate how the HRA 1998 protects and promotes elderly patients' autonomy at the end of life.

Questions of Autonomy	**Article of the HRA 1998**
How does the desire and right to have life protected and the desire to have it prolonged through medical intervention interface with the desire of some elderly patients to die?	Protection of Life (Article 2 HRA).
What are the types of suffering elderly people experience and what is the responsibility of others to mitigate this suffering? What are the risks for elderly patients of inhuman and degrading treatment and how can they and others mitigate against this? How does suffering influence the wish to hasten death amongst elderly patients?	Alleviation of suffering, protection against inhumane or degrading treatment (Article 3).
What is important to the identity of elderly patients approaching the end of life and how do they want to use their autonomy? (N.B. themes are identified in Chapter 3 but they are used in the analysis here)	The right to a private and family life, home and correspondence under which the right to autonomous choices is located (Article 8 HRA).
The elderly wish to conserve their liberty and through this autonomy as long as possible. Are there threats to the liberty of elderly patients approaching the end of life and what protections are in place to protect them?	The Right to Liberty (Article 5).
How important are the freedoms under Article 9 for elderly patients approaching the end of life and how are they protected and promoted?	The Right to freedom of thought, conscience and religion (Article 9).
Elderly patients wish to have fair and equal access to good quality care and not be discriminated against. Moreover, many see it as their right having paid taxes all their life and having lived most or all of their lives within the context of a welfare state with free access to health care and, until recent years, free social care.	The Right to enjoy all these human rights without discrimination (Article 14).

4.3. The Right to Life (Article 2 HRA) and the right to death - the interfaces between protection of life and alleviation of suffering and protection against inhumane or degrading treatment (Article 3 HRA)

4.3.1. The main areas of discussion

This section will first explore whether, in the context of elderly patients nearing the end of life Article 2 of the HRA1998 refers to the right not to be unjustly killed, or does it also include a right to be kept alive at all costs or even against a person's will if their decisions are considered to be unwise. It will then explore whether people have a right under the HRA 1998 to die in the face of intolerable suffering or even because they have simply become tired of life. This section will then explore how an individual's wish to hasten death (WTHD) must be weighed up against the needs of the community, especially the vulnerable elderly to protect life.

4.3.2 Protecting life

As will be seen throughout this thesis, there is great emphasis on protection of the right to life and clearly defined responsibilities assigned by the state to doctors, other health and social care professionals and the health and social care provider organisations who employ them. The elderly patient nearing the end of life may also be dependent on their family to alert health care workers on their behalf, especially if they have dementia, of deteriorations in their condition which may be reversible even if they are terminally ill [163, 182, 311].

There is a prima facie moral obligation not to kill all people but there are obligations to keep alive only some people [72]. There is a fundamental difference between allowing a natural death, which would only be averted by medical intervention and actively ending someone's life [72, 79, 267]. In England, there are no obligations to keep people alive who wish to die if they make this decision with full mental capacity and are fully informed that without specific interventions they will die [220, 371]. This also applies to patients who do not have mental capacity who made a previously valid Advance Directive (AD) including an Advance Decision to Refuse Treatment (ADRT) or appointed a Lasting Power of Attorney for Health and Welfare (LPA) [79, 371].

Many people consider that, in the end of life care context, Article 3 of the HRA 1998 - alleviation of suffering, protection against inhumane or degrading treatment - relates not only to the need for good provision of P&EOLC but also, to the issue of not prolonging life where suffering becomes so great that the patient feels it is intolerable, inhuman or degrading to continue living [294]. These views may be seen as in direct opposition by some people or on simply different ends of the same spectrum by others [372]. As will be demonstrated throughout this thesis Article 3 of the HRA is about much more than death as the answer to such suffering as there are many P&EOLC interventions to lessen a patients suffering which may change a patient's wish for death as the only way out of suffering [99, 101, 103, 171, 172, 227, 260, 315]. There are also worldwide strong arguments that alleviation of suffering could also be achieved through Physician Assisted Suicide (PAS) or Voluntary Euthanasia (VE) [294, 316, 373]. The counterargument to legalisation of assisted dying is the denial of choice to continue living if legislation were to result in imposing increased public pressure to opt for euthanasia rather than to be a burden on family, friends or the state [374]. This is especially relevant now in the UK, in the current political and media climate of public debate about the burden placed on the state and society of older people and particularly in terms of health and social care. However, cognisant of this, in the UK, protection of life of the vulnerable, who may feel pressurised to request termination of their life in order not to be a burden, has been given a higher priority by Parliament than accepting the lobbying of a minority for PAS. Therefore, the Parliamentary Bill to introduce assisted dying was rejected [290]. Moreover, the British Medical Association also opposes all forms of assisted dying on the basis that this could threaten the therapeutic relationship of trust between patient and doctor [375]. This is especially important in the wake of fears engendered by the Liverpool Care Pathway problems about patients being put on a 'pathway to death' without their consent [36, 39].

There is empirical evidence at a population level that good provision of P&EOLC reduces requests for PAS [172]. Indeed, when a Bill was recently put before the Government of Guernsey to introduce PAS, the Government responded not by introducing PAS but with an under taking to substantially increase resources for palliative care on the island [376].

I would argue also that, based on the evidence described in Chapter 3, regarding potentially ameliorable factors causing suffering which can lead a patient to a WTHD, there is a strong obligation on doctors and others to investigate and offer treatment or support where such factors are identified [172, 265]. These factors may be, for the patient, conscious or unconscious reasons for the WTHD including severe pain, depression, loneliness or spiritual distress and whose treatment or relief may lead to patients changing their mind [99, 100, 171, 172, 227, 259].

Equally importantly, Article 8 HRA - the right to a private and family life, home and correspondence, under which the right to autonomous choices is situated - should not translate to a right to be ‘allowed to rot’ [377]. In other words, doctors should not accept at face value a request to withdraw or withhold treatment without first excluding the type of factors identified as potential causes of a WTHD and ensuring that the patient really understands the consequences [171, 265]. Doctors must be very self-aware that in this process they do not force their own views in a paternalistic fashion [130, 349, 351]. In the same vein, there is also a strong obligation to provide comfort care which may be P&EOLC if this is what the patient desires [23]. There is also a prima facie responsibility not to allow a patient who has refused life prolonging treatment to be subjected to degrading or inhuman treatment for example denying them access to P&EOLC, on the assumption that the patient is rejecting all forms of care [21, 22, 79, 263, 315].

4.3.3. The wish not to prolong life

Most of the ethical debate around end of life care in England is not about interventions to prolong life. The discussions fall into two main groups: ending life prematurely and not delaying or postponing natural death. The former group include discussions about Voluntary Euthanasia (VE) and Physician Assisted Suicide (PAS) and could include, in an end of life care context, suicide [267]. The latter group includes: patient wishes not to be admitted to hospital if they deteriorate and withholding or withdrawing interventions or treatments to allow natural death to occur. These interventions may include cardiopulmonary resuscitation (CPR), surgery, chemotherapy, antibiotics, or artificial nutrition and hydration [79].

4.3.3.i Ending life prematurely

In England, where both VE and PAS are illegal, this is where most policy initiatives and legal debate about enhancing patient autonomy are focussed [289, 372, 378]. In England, both withdrawal and withholding artificial life sustaining treatment are legal if a patient with mental capacity requests it, or Legal Power of Attorney for Health and Welfare requests it on the behalf of the patient or if detailed through a legally constituted ADRT [79]. If a patient without mental capacity does not have a LPA or an ADRT the doctor must apply to the court of protection for a decision on withdrawal of treatment.

In Poland too, both VE and PAS are illegal with risk of imprisonment from 3 months to 5 years' [380]. The Medical Code of Ethics, in Articles 30 and 31, prohibits voluntary euthanasia or physician-assisted suicide [379]. In theory, the Medical Code of Ethics has provision which permits cessation treatment under certain conditions however, actual practice may be more complicated. For example, withdrawing artificial ventilation could be considered to be assisted suicide which would be illegal. There are similar challenges related to withdrawal of artificial hydration and nutrition which could be considered to be "passive assisted dying" [381].

The issues of the use of palliative sedation is also complicated in Poland. On the one hand patients are have the right to die in peace and dignity according to Article 20 of the Act on Patients' Rights. This includes "a right for medical services which provide alleviation of pain and other suffering" [383]. A Commissioner for Patients' Rights guarantees this right [382]. Palliative sedation or what is sometimes known as 'terminal sedation' can, as in England too, only be used to control symptoms in patients who are imminently dying [384]. The use of opioids and benzodiazepines when withdrawing of life-sustaining therapy could be considered to be illegal in Poland [379]. However, if a patient dying of respiratory failure, who does have mental capacity, refuses artificial respiratory support, they can be offered sedation [384]. Nevertheless, the use of opiates, especially in terminal respiratory disease, is challenging because opiates also suppress respiration. There is a risk that if the patient is sedated until their death the act is considered 'lethal analgesia' [379]. The ethical debate in these clinical scenarios centers on the principle of double effect which means that it is accepted that the use of opiates may contribute to but are not intended to cause the patient's death [381,385].

Voluntary Euthanasia (VE) is legal in several countries including Belgium and the Netherlands [378]. In VE, it is the doctors, who after a rigorous assessment process, end the life of the patient with a lethal injection. In Physician Assisted Suicide (PAS) the patient themselves takes a fatal oral dose of a drug like pentobarbital, prescribed by a doctor again after a rigorous assessment process, this is the practice in Switzerland [317]. Unlike VE, in PAS the patient is given the opportunity even at the final stage to not to proceed to death. Herein lies a subtle but important difference in autonomy and responsibility. In VE, the patient places the burden of taking their life on the doctor. In PAS, although the doctor is complicit by prescribing and providing the medication, it is the patient who takes their own life [267].

4.3.3.ii Not prolonging life

In England, PAS is not legal and elderly patients may have religious, moral or other reasons for not wanting to take their own life by suicide. However, they may also not want to have it artificially prolonged [258].

The Mental Capacity Act is designed to protect people who do not have mental capacity to make decisions for themselves from paternalistic decisions by others especially those resulting in withholding or withdrawal of treatment which is not in their best interests [221]. The Mental Health Act protects the interests of patients who have a serious psychiatric conditions which may impair their decision making [46, 221]. In contrast, the rights of people who do have mental capacity to refuse treatment and who do not have a severe enough Mental Illness to be sectioned under the Mental Health Act, are protected to allow them to make decisions to stop treatment or not initiate treatment which could be considered unwise by others and may or will result in their death [46, 221]. Doctors have to respect the patient's decision not to have their life artificially prolonged unless there is evidence that either they do not have mental capacity or have a severe mental illness [79].

Of course, the situation is rarely clear cut and an elderly patient may have fluctuating mental capacity due to dementia or depression which is very common in elderly patients, especially in care homes and especially in those approaching the end of life [159, 165, 216]. The General Medical Council gives clear guidance, to adhere to the Mental Capacity Act, on assessing patients under these conditions and this includes the assumption that the patient has capacity unless proved otherwise and attempts to maximise the patient's opportunities for being involved in decision making [79].

As described above, if a patient decides they do not want to have life prolonging intervention then they should be offered comfort care [79].

4.4. Alleviation of suffering, protection against inhuman or degrading treatment (Article 3 HRA)

Elderly people at the end of life, especially those with dementia, are extremely dependent on the goodwill and care of others [24, 386]. It is extremely difficult for them to protect themselves against inhuman or degrading treatment, which could, rarely, be through active abuse or more commonly through neglect [386-388]. There is a prima facie responsibility to protect everyone against inhuman or degrading treatment and especially the weak and vulnerable who cannot protect themselves [368]. Families and all public services employees have to be very alert and report any suspected breaches [48]. Public sector employees have a specific responsibility under the Care Act [48]. The preservation of dignity, in other words still being treated as 'a person worthy of value and respect', in the face of losing control to do things for themselves, is very important to elderly people [228]. Not being treated with dignity can be associated with inhuman or degrading treatment [39, 386].

Alleviation of physical and medical mental suffering is of course a responsibility of health care providers and clearly fall within the remit of P&EOLC. However, doctors can inadvertently go against patient wishes if these have not been made explicit. An example would be deep sedation until death which the doctors may consider to be relieving suffering but may not make entirely clear to the patients that they will no longer be conscious before death [351, 389, 390]. Full consent should be obtained from the patient or LPA [79]. Doctors may also go against patients' wishes inadvertently because of their own biases which may be influenced by their training, ethnicity or religious views [238, 349, 351].

Many argue that advance care planning, especially if it includes more positive details about how the patient would wish to be treated and the values which are important to the patient, helps to ensure that the patient's dignity can be maintained as much as possible [151, 347]. The consent process for medical interventions in England should help to protect against treatments that the patient would find degrading or cause them more suffering [79]. Similarly the strong NHS focus on Choice including 'no decision about me without me' should place the patient at the centre of decision making [155, 156].

Chapter 3 showed that elderly patients approaching the end of life experience a range of other types of suffering including social isolation, loneliness and fear of being a burden, as well as religious, spiritual or existentialist suffering [99, 113-117, 148, 153, 173, 193, 260]. While the social and spiritual domains of both suffering and need for care are well recognised in specialist palliative care at present these domains of suffering will largely be unmet for many elderly people [224, 270, 296, 321]. This is because the vast majority of elderly people are not cared for by specialists in P&EOLC and others doctors are often not trained in the recognition and even less the management of these spheres of suffering. Given that in some surveys fear of being a burden is ranked above other death related fears [113-117] and there is good evidence for spiritual/existentialist suffering [204, 255] and suffering related to loss of dignity and identity and all of these may worsen physical suffering [176, 178, 313, 314], there is a clear need for policy and training initiatives to focus on these issues.

4.5. The right to a private and family life, home and correspondence under which the right to autonomous choices (Article 8 HRA). The Right to freedom of thought, conscience and religion (Article 9 HRA)

It is under Articles 8 and 9 that the drivers for autonomy of elderly patients really come into force. As described in Chapter 3, elderly patients often see their own identity as part of a family and therefore it is important that health and care professional take into account the patient's wishes for treatment and care within the context of their family circumstances and family decision making processes [24, 113, 164, 310, 311]. Confidentiality is clearly a key element of an individual's privacy and the elderly patient has a right to confidentiality [79]. Sometimes observing this right to confidentiality can come into conflict with a family's need for information especially if the patient is losing mental capacity and the family are primary carers [24]. This is a complex area where both the law and GMC guidance is still not completely clear. Indeed the GMC recently launched a new consultation on patient confidentiality and consent to share information.

The right to elderly patient's autonomy to freedom of thought and expression needs to be respected as long as this does not cause harm to others [45]. Sometimes problematic expressions of thought need to be considered within the context of dementia [24]. As illustrated above many elderly patients express concerns related to their conscience and feeling of duty to others. These must be respected but duties and the autonomy of family members can inadvertently come into conflict in the complex dynamic of end of life care for elderly people [65, 113, 146, 163, 239, 311].

4.6. The right to liberty (Article 5)

The right to liberty is an absolute right under the HRA1998 [45]. This right is frequently compromised and limited by well-meaning others such as family members or doctors and particularly nursing homes, who wish to protect the patient from harm [24, 119, 163, 310, 311, 391-393]. Very frequently the patients are not aware of their rights and because of their frailty and the imbalance of power they acquiesce to limitations on their free movement in exchange for the benefits of being cared for [18]. If a patient being cared for, or living in, an institution (hospitals, care homes, hospices) has their liberty to move freely deprived, then that patient automatically has protection under the Law. Under the Law, there is a requirement that any restrictions to liberty are scrutinised by the Local Authority (Local Government Administration) [391, 392, 394]. Patients whose liberty is restricted by anxious relatives do not at present have protections to have their deprivation of liberty safeguarded through assessment by the Local Authority to check if it is justified. The right to liberty for elderly patients approaching the end of life is described briefly here. There is a fuller description, based on research I have undertaken, in Chapter 6, of the magnitude of this problem, to show the extent to which liberty is deprived in elderly people including those who are dying and the geographical inequity in the use of Deprivation of Liberty Safeguards.

For patients with mental capacity who are prevented from leaving hospital until care in the community is arranged but have no physical reason to stay in hospital this is a clear contravention of their liberty although no-one views it in this light, neither the doctor nor the patient. If the hospital deprives an elderly of their liberty by keeping them in a locked ward, for example, then the hospital must apply for a Deprivation of Liberty Safeguard Assessment from the Local Authority [392]. A similar situation arises when elderly patients move to care homes if their liberty will be restricted [392]. However, elderly people often accept transfer to a care home not realising that their liberty will then be restricted.

There are a small number of elderly patients who die every year in prison (~200), but this number is slowly increasing reflecting the growing elderly population in the country [395]. These do have their liberty restricted for the protection of others. Their needs were highlighted in a CQC report and attempts to improve the quality of end of life care for elderly people in prison are ongoing [28]. Much more advanced work has been undertaken in Poland to consider the end of life care needs of prisoners [145]. Similarly, a number of elderly patients die each year in Psychiatric Institutions. To date, little attention has been paid to their end of life care needs.

4.7 The right to enjoy all these human rights without discrimination (Article 14)

Elderly patients should be able to enjoy exercising their autonomy towards achieving the best possible end of life and end of life care for themselves regardless of who they are [45]. The identity of the patient should not make it more difficult to access their basic rights in terms of end of life care [368]. However, unfortunately across health and social care services there is evidence that not all groups in society have equal access to P& EOLC. The elderly are perhaps the largest group in society who are routinely discriminated against both consciously and unconsciously [12]. My team at the National End of Life Care Intelligence Network (NeOLCIN) and others have shown that for example, place of death is very different in elderly patients from younger patients [11, 12]. Within the group of elderly patients, those who are from more deprived backgrounds, from Black and Minority Ethnic Groups or who are most frail physically or mentally are less likely to access specialist palliative care services than those from more affluent, white backgrounds [312]. An even clearer differential access to specialist palliative and end of life NHS funding in nursing homes is based on disease groups [28]. Patients with cancer as a terminal diagnosis are more likely to access specialist palliative care services either within a hospice or hospital or at home than patients without a cancer diagnosis [11, 28]. Similarly, patients known to be terminal, are more likely to receive rapid funding decisions for NHS paid care to be transferred from hospital to a nursing home if they have cancer than dementia [245]. Patients with congestive cardiac failure or end stage respiratory disease form an intermediate group [245]. This has implications not only for quality of care but for who pays for care – the state or patient [28, 136]. The result is that elderly patients, especially those with dementia may have to remain on busy noisy hospital wards in their last hours and days rather than in the tranquillity of a nursing home [119, 127, 217, 241, 245]. If they are transferred to a nursing home they are more likely to have to fund the care themselves if they have dementia than if they have cancer as NHS approval for funding is less frequently given [24, 28, 127, 215]. Only the poorest elderly will have the care provided from the social care budget for free. The elderly patients or their families will have to pay for social care at home or the costs of a nursing home [136]. Levels of health and social care provision also varies across England by local government and health administration so elderly patients with exactly the same needs may get better or worse care depending on where they live as we have shown in our Atlas of Palliative and End of Life Care in England [11].

Patients with dementia and perhaps other co-morbidities such as cancer are especially disadvantaged with respect to pain and symptom control because of communication problems which make it difficult to assess symptoms and because of the low levels of support from specialist palliative care in nursing homes [24, 127, 190, 217, 246, 396, 397]. This means that patients with dementia may not have their symptoms controlled indeed they have been described as the most neglected pain patients [396]. NHS England produced guidance in 2018 for P&EOLC for patients with dementia [215].

While none of this may be deliberate discrimination based on any of these known characteristics of the patient, the result is the same which is that not all elderly patients get the same access to best quality end of life care [28, 245].

4.8. Discussion

From the perspective of the patient, this chapter shows that in many of the spheres in which they may want to exert their autonomy that they are afforded protection by the state in terms of legislation. The legislation, especially the HRA1998 places an obligation on all workers paid directly or indirectly by the state to protect and promote the autonomy of elderly people even if they are approaching the end of life [45]. This is reinforced through the professional guidance to doctors from the General Medical Council [79]. Indeed human rights legislation becomes even more cogent the more vulnerable the person becomes. There is a strong legal structure in England to protect life until its natural end and to protect individuals against degrading or inhuman treatment [45]. While the legislation is backed up by policy, it still has not succeeded in making these protections universal although there are continuous improvements [28, 386]. The Government Inspector and Regulator of Health and Social Care Services, which is known as the Care Quality Commission (CQC), has adopted a human rights informed approach to its work [398]. The HRA 1998 also gives elderly patients the right to alleviation of suffering. However, while this is an absolute right, does not include the relief of suffering by having their lives deliberately ended by others or with the help of others either doctors of family or others [267, 399]. All these acts are illegal in England. For supporters of PAS or VE this is an area of controversy [294]. Health and social care services still have more to do to ensure not only greater levels of basic palliative care provision to ensure all elderly patients have access, regardless of their medical conditions [28] or where they live [11] but also to start to address the other non-medical reasons for suffering which are often more prevalent that medical symptoms [172, 227]. This will need a substantial rethink as at present the model of care directed at relieving suffering is a very medical model. Doctors, nurses and social workers will need more training in issues such as spiritual and existentialist suffering and the other issues that elderly patients identify such as fear of being a burden if they are to be able to respond better to the range of suffering of elderly patients. Raising the profile of these non-medical sources of suffering will be important for the proper assessment of patients who express a WTHD both to protect their lives under Article 2 and alleviate their suffering under Article 3 of the HRA 1998 [227, 265].

Chapter 5 will describe in greater detail the state's role in implementing the HRA 1998 and the implications of this for the protection of autonomy and paternalism at the end of life in elderly patients.

Chapter 5. Paternalism and the state – how does it use its powers to protect and promote the autonomy of elderly patients at the end of life?

5.1 Introduction

This chapter critically examines the role of the state, in England, in protecting and promoting the autonomy of elderly patients at the end of life by an analysis of the impact of legislative and policy and service provision initiatives on this. I have used the framework suggested by Huxtable to analyse the state's role based on: the duty to respect life; the obligation to alleviate suffering and the need to respect patient autonomy [72]. These correspond to Article 2 (the right to life), Article 3 (the right to be free from inhuman or degrading treatment and Article 8 (the right to a private and family life, home and correspondence under which the right to autonomous choices is located) of the UK Human Rights Act 1998 (HRA 1998) [45]. The state has a responsibility to all its citizens to enjoy the protection of the HRA (1998), but the state really manifests its protective role with respect to the most vulnerable in society. The elderly dying patient is often extremely vulnerable and the HRA (1998) provides a safety net of protection surrounding the policy initiatives and care provision. I have expanded this framework, to include Article 8 (the right to liberty).

The analysis will also explore whether the state, which many sociological and political commentators would agree has a paternalistic role or is indeed a paternalistic agent [218, 400], exerts its functions with respect to improving end of life care for elderly patients in a libertarian paternalistic manner with respect to interventions to promote patient choice in Palliative and End of Life Care (P&EOLC) [129, 131, 237, 350, 395, 401]. The term parentalism may be more appropriate reflecting paternalistic decision making for the population and provision of services and a maternalist nurturing function to promote individual autonomy [402].

5.2. Definition of the State

In using the word state, in this thesis, I am referring to a collective term which refers to the civil government of a country including the services provided by the state [71]. This includes the three branches of the state: Legislative, Executive and Judiciary which cover the functions of the Government, Parliament, the Judiciary and the Public Sector. The Public Sector includes organisations which are directly funded by the government. This includes the National Health Service and Local (government) Authorities. It also includes, what are known as, ‘arms-length’ bodies, these are government organisations, where the employees are civil servants, as in government ministries, but the ‘arms-length’ bodies have some independence written into their contract with the government. An example of this is the National Public Health body: Public Health England (PHE) for whom I work. As a central government employee, with the title ‘Civil Servant’ I am bound by the civil service code of conduct with loyalty to the Crown but, working for PHE, I have the freedom and duty to speak the truth on matters of importance to the health of the nation. This wide definition is in line with a citation from the online Oxford Dictionary which is used to exemplify a wide definition of the State and its activities ‘The United Kingdom is unusual in the extent to which the state employs hospital consultants in state run hospitals’ [71]. Although the state, as in this example may refer to the United Kingdom or Great Britain, for the purposes of this thesis I will be referring to the state as it applies to England. This is because I work for Public Health England, the National Public Health organisation for England as its national lead for Palliative and End of Life Care and all my national work on P&EOLC is limited to the jurisdiction of England. Moreover, as a result of devolution of some powers to Scotland, Wales and Northern Ireland there are some differences in Law and Policy. For example, only in England is the state responsible for social care [136]. Therefore, in this chapter I will only be referring to law and policy and its implementation as it applies to England.

In this chapter I analyse the main national policy initiatives introduced during the decade since the publication of the first National Strategy for End of Life Care in England in 2008 and examine the impact these have had on the protection and promotion of autonomy of elderly patients at the end of life.

In England, historically and extending until the present time, a ‘parens patriae’ role was described first for the Monarchy and then for the State to care for the vulnerable [131, 218]. This concept will be woven into the narrative.

5.3. Methods

I have been uniquely placed during the decade since 2008, when the First National Strategy for End of life Care was published, having worked continuously as a Senior Civil Servant for the Department of Health and then from April 2013 as a Senior Civil Servant working for the National Public Health Body, Public Health England. Throughout this time my role has been to give advice on aspects of policy through my role as a Medical Public Health Consultant with expertise in Palliative and End of Life Care (P&EOLC) from a population perspective. In particular, since 2010 when I was asked to lead and establish the National End of Life Care Intelligence Network (NEoLCIN), I have been the main advisor on how data and intelligence can be used to support improvements in the quality of P&EOLC. Since its establishment in 2010, the work of the NEoLCIN has thrown up ethical dilemmas and these will be explored under the section on monitoring [75].

I was a member of the National Panel: The Leadership Alliance for the Care of Dying People (LACDP), which produced the report ‘One chance to get it right’, set up by the Secretary of State for Health and Social Care to provide him with advice on how the system should respond to the Report of the Enquiry into the Liverpool Care Pathway and I was also a member of the subsequent Choice Review Panel ‘What’s important to me: a review of choice in end of life care’ [141]. I continue to be a serving member of the National End of Life Care Board, hosted by the NHS, which determines national policy on P&EOLC and of the Ambitions Partnership which oversees the implementation of the 2015 national Framework for improving P&EOLC [33].

Key national policy initiatives in P&EOLC since 2008 have been identified. I have also identified other relevant policy initiatives in Health and Social Care which have a material impact on the autonomy of elderly patients at the End of Life (EoL). I have also examined the role of legislation as it pertains to the national policy on P&EOLC.

National policy, such as the National End of Life Care Strategy 2008 and the more recent Ambitions Framework, outline principles which are to be followed and the desired direction of travel [30, 33]. It is the role of the National Health Service (NHS) and other Public Bodies such as Public Health England (PHE) and the Care Quality Commission (CQC) to implement strategies at a national level, to drive these policies forward and to monitor their implementation [33]. Where relevant, I have identified these, what I will call, secondary policy initiatives and analysed their actual and/or potential impact on the autonomy of elderly patients at the end of life. There is a formal reporting mechanism on an annual basis to the Secretary of State for Health on progress in improving the quality of P&EOLC against the Ambitions Framework of actions identified in national policy [33].

The work described in this chapter uses the framework described in Table 5.1. below.

Table 5.1. The role of the state in protection and promotion of autonomy for elderly patients at the end of life through human rights

Ethical Principle	**Questions**
Protection of Life (Article 2).	Does the state have adequate systems in place to protect the Right to Life of elderly patients nearing the end of life?
Alleviation of suffering, protection against inhumane or degrading treatment (Article 3).	Does the state have adequate systems in place to protect elderly patients nearing the end of life against inhumane or degrading treatment?
The right to a private and family life, home and correspondence (Article 8). *Autonomy*	Does the state have adequate systems in place to protect and promote autonomous decisions of elderly patients nearing the end of life?
The Right to Liberty (Article 5). *Autonomy*	Does the state have adequate systems in place to protect the Right to Liberty of elderly patients nearing the end of life?
The Right to freedom of thought, conscience and religion (Article 9). *Autonomy*	Does the state have adequate systems in place to protect the Right of elderly patients nearing the end of life under Article 9?
The Right to enjoy all these human rights without discrimination (Article 14). *Justice*	Does the state have adequate systems in place to promote equality in access to good end of life care for elderly patients and to detect discrimination?

5.4. Protection of life

Perhaps the most important role of all states is to protect the life of its citizens and to protect them from harm [45, 290]. Through its ‘parens patriae’ role the state has a particular role in protecting the vulnerable and this includes the frail elderly who have lost mental capacity [131, 218]. The duty to respect life, stems from Judaeo-Christian teaching based on the idea that ‘life has a special worth’ and therefore ‘should not intentionally be brought to an end’ [403]. Elderly people approaching the end of life are particularly vulnerable because of their physical and sometimes also mental frailty. This makes elderly patients very dependent on the good will and physical help of others and often the decisions made by others on their behalf [52]. The elderly are therefore at particular risk of losing their life prematurely or becoming victims of neglect or maltreatment which leads to harm [388]. The state has special responsibilities to guard against this which it exercises through legislation and the role of the Care Quality Commission (CQC) which regulates and inspects health and social care providers, both publically and privately funded [28, 136].

In this section, I focus on the state’s role in protection of life in the sense of it not being prematurely terminated by a deliberate action.

Elderly patients are comprehensively protected under a number of pieces of legislation from having their life deliberately taken (murder) or carelessly taken through neglect or through abuse (manslaughter) [267, 290]. The House of Commons, in 2015, overwhelmingly rejected a Bill to permit Physician Assisted Suicide (PAS), also known as ‘assisted dying’ [290]. The main rationale for this was to protect elderly and other vulnerable people from being put under pressure not to be a burden and therefore ask for PAS. A secondary and equally important reason was to maintain public confidence in the therapeutic role of doctors and a relationship of trust between doctors and patients. This was strongly supported by the British Medical Association’s consultation with the public and doctors, which I contributed to [375].

Suicide is not illegal but there is clear criminal legislation and case law which makes aiding a suicide illegal [399]. For example, an appeal to the High Court and then Supreme Court made by Mrs Petty, a woman with a degenerative neurological condition, to test if her husband would be prosecuted for taking her to the Dignitas Clinic in Switzerland ruled that this would be aiding a suicide [267, 399]. However, more recently, updated guidelines from Director of Public Prosecutions suggests that compassionate assistance of suicide will not necessarily be prosecuted and that the role of family members would be judged on case by case basis [399].

Despite these guidelines, the policy is clear that "the police are responsible for investigating all cases of encouraging or assisting suicide". The police do this if they are informed about someone travelling overseas for an assisted death, or of a person providing assistance [399, 404]. Returning a person's dead body to England will also trigger a coroner's inquest as for all deaths of British Subjects abroad [405]. This will almost certain to lead to a criminal investigation. It is estimated that a person, usually with their family travels to the Dignitas Clinic from the UK every 8 days [406]. No family members have to date been prosecuted. However, a recent display of a public intent to fund raise to support a patient to travel to Dignitas was clearly judged to be crossing the line when sisters arranged and publicised a party to collect money for their mother to travel to the Dignitas Clinic. The police intervened and gave a caution but there were no prosecutions [404]. Some describe travel to Switzerland for PAS as a loop hole which the rich and better educated can exploit but it is still illegal and the relatives could face prosecution [406].

In contrast, the state, though its legislation, respects people's autonomy to make, what might be in other people's eyes, unwise decisions and refuse life prolonging or saving treatment. Under the Mental Capacity Act patients are free to refuse treatment even if this may lead to their death, if they have mental capacity and if they have had the consequences of their actions comprehensively explained [46].

Similarly, if a patient has lost mental capacity but has made a valid Advance Directive to Refuse Treatment (ADRT) or their chosen representative has Legal Power of Attorney for Welfare (LPA) and decides that treatment should be withheld or withdrawn, the doctor will respect this unless they are concerned that this does not act in the patients best interests [46, 79]. The General Medical Council (GMC) states that 'if after consultation with medical colleagues concerns persist then a request must be made to the Court of Protection for a judgement [221]. When courts are asked to make of judgement about withholding or withdrawing a treatment, they consider whether the proposed treatment plan is reasonable according to 'a responsible body of medical opinion'. Although the court will listen to the evidence from doctors, the patient's relatives and other interested parties and review any Advance Care Plans or Directives, the court makes its own assessment of what will be in the patient's best interests [79, 218].

This overview demonstrates the state's comprehensive approach to protecting the life of elderly people who are approaching its end from having it prematurely terminated without their consent and protecting them from duress or assistance to do so.

5.5. An obligation to alleviate suffering and the right to free from inhuman or degrading treatment (Article 3 HRA)

5.5.1. Degrading or inhuman treatment

In this section I bring together Huxtable's 'obligation to relieve suffering' together with Article 3 of the HRA 1998 'the right to be free from inhuman or degrading treatment' [72].

Examples of inhuman or degrading treatment in the context of EOLC for elderly patients include:

- dying in pain or with other severe symptoms untreated,
- not having one's dignity as a human being respected,
- having decisions made by others without one's consent,
- not giving food or water if these would be of benefit to the patient,
- intentional withdrawal of nutrition, water or medications when these would be a benefit,
- failure to keep a person clean and in sanitary conditions being left to lie in one's own faeces or urine as happened to many old people in the Mid Staffordshire Trust is inhuman and degrading [386].

All these situations have unfortunately been described in the context of P&EOLC for the elderly in England [39, 386].   Inhuman and degrading treatment is not limited to medical care it may also occur in social care which provides assistance with feeding washing and other personal issues to patients in the community or care homes. Having to rely on another person for every aspect of daily life can feel degrading unless they provide it with compassion [63, 113]. It could be argued that dying completely alone, unless sudden or what one specifically wants, is also inhuman [147]. Similarly, deprivation of liberty too is inhuman and degrading. This will be dealt with under Article 8.

It is for these reasons, as mentioned in the introduction to this thesis, that P&EOLC is recognised under International Human Rights Legislation as a basic human right. Under Article 12 of the International Covenant on Economic, Social and Cultural Rights and Article 7 of the International Covenant on Civil and Political Rights 'all member countries of the United Nations are obliged to safeguard patients at the end of life against pain and suffering, allowing them to die with dignity' [1-3, 21, 315, 368].

Since 2008, with the publication of the first National Strategy for End of Life Care, and with the most recent Ambitions Framework, England has had, through the work of the state, a panoply of interventions, in legislation, policy, monitoring, professional education and social marketing to try to improve end of life care to alleviate the suffering of the dying and to prevent inhuman and degrading treatment of the dying. Even the ill-fated Liverpool Care Pathway (LCP) was a serious attempt to alleviate suffering and protect against inhuman and degrading death in suffering. Unfortunately, unthinking, uncaring application of the LCP by poorly trained staff using it in a situation for which it was not designed and had not been tried and tested led to the opposite for a significant number of patients [39]. Interestingly the LCP had been enthusiastically adopted in other countries without these complications being reported [38]. Not only did Baroness Neuberger's report on her review of what went wrong identify the lack of consent, which contravened the patient's dignity, but she revealed significant concerns about the withdrawal of active treatment for patients believed to be within days or hours of death, some of whom recovered. There was a particular concern about with-holding hydration, not simply oral but as the GMC describes 'artificial' through intravenous routes [39, 79]. This had particularly distressed relatives who thought their loved ones were dying from lack of hydration and therefore receiving inhumane treatment, especially because the doctors had not explained anything about the dying process which can be prolonged over several days. Concerns about nutrition and hydration at the end of life have continued to be reported by families in a more recent study [230]. The belief which underpinned withdrawal or with-holding of artificial hydration and nutrition was that as the patient was dying it was a natural part of the process that the patient themselves withdrew from eating and drinking and moreover this was not required to be supplemented [39]. Furthermore, there were physiological concerns about 'water overload' if fluids were given intravenously at a time the kidneys were stopping functioning as part of the dying process which in turn could lead to patient discomfort and could be considered inhumane treatment [407].

Baroness Neuberger's report 'More Care: Less Pathway' followed fast on the heels of the first Francis Report on the inhumane treatment and terrible neglect of, particularly elderly patients in the Mid-Staffordshire Hospital [386]. Key features included patients not being given help with eating and drinking and being left for hours in their bed in their own excrement [386].

The government acted swiftly in the wake of 'More Care: Less Pathway' and the Francis Report to seek advice and to implement a wide range of policy to improve the quality of care especially of elderly patients in hospital {People, 2014 #228}.

Most recently there has been a report into the deaths of elderly patients in Gosport Memorial Hospital [408]. This has suggested that patients were put on end of life care treatment, especially opiate pumps at doses higher than normally recommended and may have died prematurely. A single handed doctor was making these decisions, with no discussion or oversight by anyone else. Again, as with the LCP there were no discussions with patients or their families [408].

In particular, since, the report 'More Care: Less Pathway', there has been a review of hydration and nutrition at the end of life and the GMC Guidance to doctors has been revised. The offer of food and drink by mouth is now considered 'part of basic care in the same way as is the offer of washing and pain relief'. Therefore, 'food and drink must always be offered to patients who are able to swallow without serious risk of choking or aspirating food or drink'. However, the GMC guidance also clarifies that patients can, if they have mental capacity refuse food and drink. Importantly although an Advance Decision to Refuse Treatment ADRT must be respected, an advance refusal of food and drink does not have the same legal status [79].

The issue of artificial hydration can present new challenges to elderly patients wishing to die at home and in care homes. New research suggests that subcutaneous slow infusions of saline can be used which are easier for non-specialist nurses to administer [409, 410, 411].

Patients at the End of Life can experience a range of physical, psychological, social, spiritual and existentialist suffering at the end of life. Specialists in Palliative Care are trained to assess and recognise suffering in all these domains [77]. National Policy in England since 2008 has made it clear that all these domains are equally important [33, 208]. Multi-disciplinary team (MDT) working is promoted in specialist palliative care to bring together experts to provide care or signpost to support across all these domains [33]. However, as demonstrated from our data very few elderly patients die in a hospice [11]. Some will die in hospital having seen a specialist palliative care team member and some dying in the community will have been seen and supported by an outreach specialist, however, our research on the level of specialist palliative care support and training to care homes found that in general it is poor [246]. Most end of life care for elderly patients will be given in the community by generalists: GPs and community nurses who may not have specific training in P&EOLC nor access to specialist MDTs. The provision of P&EOLC for the dying elderly in the community can be especially challenging for non-specialists and, because of their lack of training in P&EOLC, result in patients' suffering not being adequately recognised or treated. For example, the assessment and titration of pain relief in the elderly and especially in those with dementia is more difficult [217, 396, 412, 413]. NHS England recently released guidance on End of Life Care for people with dementia which describes this challenge among others [215].

The state has attempted to understand more about unmet need in terms of the suffering of patients at the end of life by funding the National Surveys of Bereaved People known as the VOICES surveys. These are the only national source of data which have given an insight into levels of suffering and its management in the general population at the end of life. They were conducted between 2011 and 2015 [258]. These surveys are conducted with random samples of bereaved relatives, who are recorded as informants on the death certificate, and sent about six months after the loss of their loved one. The structured questionnaire asks about the care in the last three months of the deceased's life. In this section I will describe insights given by these surveys on the relative's perception of care. The survey looks at whether the relative considers their loved one was treated with dignity and respect in the last three months, how well the care was coordinated in the last three months of life, how good was the pain relief in the last three months of life and the overall level of care in the last two days of life. When asked about overall quality of care 75% of bereaved relatives rated the care as outstanding, excellent or good but 10% rated it as poor. There were differences dependent on the location of their loved one's death, so 69% rated hospital care as outstanding excellent or good but this was significantly lower than in care homes (82%), hospice care (79%) or care at home (79%) [258]. This clearly illustrates that hospitals still need to improve the quality of P&EOLC [139]. It is interesting that care homes scored highest. Bereaved relatives also reported problems about the co-ordination of care with a third (33%) reporting problems of co-ordination between hospital services and GPs and community based service. While 86% of relatives said that they understood the information given to them by health professionals, an important minority (16%), reported insufficient time given by doctors for discussion and to answer questions. Importantly, 75% of bereaved relatives felt that their loved one's nutritional needs had been met in the last 48 hours of life. However, it is of concern that just over 1 in 10 (13%) felt that the patient had not received support to eat or receive nutrition. Similar results were reported for fluid intake. Of particular concern, because patients'number one priority is symptom relief, is the finding that pain control is not universally good in all locations. Bereaved relatives report better rates of pain control in hospital than at home. As might be expected, relatives reported that their love one's pain was relived "completely, all of the time" most frequently for patients in hospices (64%). However, worryingly, given national policy to encourage people to die at home if they choose so, pain was completely relived for only 1 in 5 (19%) of those who died at home and 8% did not have their pain relieved at all [258]. This is a serious issues given that patients are being encouraged to exert their choice to die at home and brings into question the morality of this if pain control cannot universally be guaranteed.

These data show that the majority of patients are being treated to at least meet some of their basic P&EOLC needs and suggest that national policy on end of life care is having an effect and reaching a wider range of patients than the traditional patient group served by specialist palliative care who are young cancer patients managed by Hospice or Hospital based palliative care specialist teams. However, but there is a worrying minority for whom care, even of the most basic nature such as nutrition and hydration is neglected. The levels of pain relief are also of concern. As the survey is representative of the general population these proportions translate into large numbers of patients for whom there are concerns about basic aspects of care such as nutrition and hydration and pain relief. The NHS needs to increase its efforts to make sure this does not occur. The Care Act has placed responsibilities on all public sector workers to raise concerns and act if a person's human rights are being violated. From a state perspective there is still scope for improvement especially in the hospital sector to alleviate suffering [139, 414].

5.5.2 Abuse

Elderly patients, especially those with dementia are particularly at risk of becoming victims of abuse [24, 387, 388]. Although abuse fortunately is rare, there have been some high profile cases of abuse of frail elderly people which includes inhuman and degrading treatment in institutions [388]. CQC inspections and the duty placed on public officials to report suspected abuse of elderly patients will help to prevent and identify this. Abuse of elderly patients is a criminal offense and has led to prosecutions [136].

5.6. The Right to Liberty (Article 5) for the elderly at the end of life

5.6.1. When are elderly patients at risk of Deprivation of Liberty?

The right to liberty is enshrined in the Human rights Act 1998 (HRA 1998, Article 5) [45]. A large proportion of elderly patients approaching the end of life will have dementia. In England 58% of people who die in care homes and 29% in hospital have dementia or senility recorded on their death certificate [75]. Although not all would have their liberty restricted this is a very large number of people potentially at risk if the processes are not used appropriately. There are significant ethical challenges also when patients with dementia would prefer to be cared for at home about the family's role in keeping them safe [182]. Moreover, 38% of people aged over 75 years die in a care home and these may have restrictive rules on movement even if the patient does not have dementia.

Dementia may lead to confusion, wandering and sometimes aggression or other inappropriate behaviour [214]. Other medical issues such as infection, fear and confusion can also lead to behaviour in elderly patients that well-meaning doctors and nurses or institutions believe may be a threat to their safety or others [24, 214, 215, 241]. This may result in the liberty of freedom of movement of the elderly patient being controlled. They may not be able to leave their room, institution (care home or hospital) or even their bed if they are restrained there [18, 24]. Often restriction of liberty, especially in care homes is more about convenience for the institution especially if staffing levels are inadequate and it is difficult to keep track of all the patients all the time [18]. Almost 40% (38%) of people aged 75 years or older, die in care homes and many are affected by institutional rules restricting liberty [11, 18]. Even if a patient has very little mobility, and in practice they are unlikely to wander, structures (locked doors) and processes (refusal to take them out) deprive them of their liberty and is a contravention of their human rights under Article 5. Lady Hayle, Deputy President of the Supreme Court, in a 2014 judgement on restrictions of liberty for care home residents said 'A gilded cage is a cage nevertheless' [415]. Her judgement has meant that every patient/person whose liberty is restricted by a hospital or care home must be referred for an independent assessment by the local authority to see if this is justified [393, 394]. The problem of deprivation of liberty in care homes is not unique to England, in Germany there was an interesting recent case where two elderly patients went missing from a care home and were found by the police at a nearby heavy metal concert having a good time but were forced to return back to the care home [416].

5.6.2. The legal framework

Restricting a person's freedom is a contravention of their Human Rights and can only be done within a legal framework. The Deprivation of Liberty Safeguards (DoLS) were introduced in 2009 as part of the Mental Health Act [393, 417]. A Deprivation of Liberty Safeguard can be applied to any adult over the age of 18 who may be a danger to themselves or others. It applies to people being cared for in care homes (residential or nursing) or hospitals or hospices. The Deprivation of Liberty Safeguards (DoLS) are a legal framework to ensure that individuals who lack the mental capacity to consent to care where it results in "deprivation of liberty" (by restricting an individual's freedom of choice or movement) have the arrangements independently assessed to give or refuse 'authorisation' by experts to ensure they are in the best interests of the individual concerned. A key element of the safeguards is that health and care providers must formally apply to their local authority (local government) with Adult Social Services Responsibilities (CASSR) and satisfy six different assessment criteria [392, 392].

The CASSR should be also acting as an advocate for the person for whom an application has been made and they should represent the person's best interests. DoLS are not designed to be a 'one-size- fits all'. Decisions made about a person's care under a DoLS application are supposed to be person centred, and as in other elements of the Mental Capacity Act, should be in the person's best interests. DoLS need to be reviewed after a year to check that the conditions for the DoLS still exist. This is important as the patient's condition may change over time and previous indications for deprivation of liberty may no longer be valid. Sometimes there may be more than one application made per person. This can occur if the patient moves for their care – for example they live in a care home and are transferred to hospital for care [393, 394].

Lady Hayle's Supreme Court Judgment of March 2014, in the case of "Cheshire West", clarified an "acid test" for what constitutes a deprivation of liberty [415]. The acid test states that an individual who lacks the capacity to consent to the arrangements for their care and is subject to continuous supervision and control and is not free to leave their care setting, is deprived of their liberty and should be the subject of a DoLS application (where they are in a care home or hospital setting) [415]. Recent case law has clarified that supervisory bodies also have a duty to monitor compliance with any conditions that are attached to a person's authorisation under a DoLS [393].

Lady Hayle's judgement has resulted in a massive increase in the number of applications because organisations became more aware that their previously restrictive practices on patients were imposed without consent or perhaps proper assessment and could be in breach of HRA 1998 (Article 5) [394].

The Care Quality Commission is responsible for monitoring the use of DoLS in hospitals and care homes and reporting to Parliament through their Annual Reports on how they are being implemented [136]. The focus of this report to Parliament is the protection of the human rights, dignity and wellbeing of people who are deprived of their liberty while receiving health and social care. The reports are derived from data collection on all DoLSs applied for which are published as summary tables by NHS Digital NHS Digital Annual Report of data derived from the Mental Capacity Act 2005, Deprivation of Liberty Safeguards (DoLS) data 2015-16 [394] and from the CQC's inspection and regulatory functions.

5.6.3. Potential harm caused by DoLS

In this section I explore the potential harm caused to elderly dying patients and their relatives by Deprivation of Liberty Safeguards (DoLS). As per other examples in this chapter, DoLS are intended to be beneficent, protecting people from harm but they have the potential for harmful consequences.

In 2016 I had already become aware of the terrible impact on grieving relatives of elderly patients dying with a DoLS orders in place. At that time, as the law stood, because their loved one had died, deprived of liberty by the state, it was similar to having died in prison or compulsorily detained in a psychiatric hospital and the death had to be referred to a coroner for an inquest. This meant very long delays before the body could be released and funerals could be conducted [418]. Moreover, there was also the trauma of the inquest process, with the death being investigated as if there were suspicious circumstances.

Of course, in the case of prisoners and psychiatric patients this legislation is to protect them from unwarranted deaths while deprived of their liberty by the state, so chimes with human rights legislation (Article 2 the Right to Life) and the procedural duties applied to public bodies under the HRA 1998 to investigate deaths of people under their care [45].

However, in the case of elderly patients with dementia, their deaths were expected (sooner or later) because of their extreme mental and physical frailty. The majority were in nursing homes. Fortunately, due to campaigning, by clinicians and peers in the House of Lords, the government responded and made provision in the Policing and Crime Act 2017 which introduced changes that the coroner no longer has to hold an automatic inquest for a person dying under a DoLS authorisation [268, 418]. Of course, if there are suspicious circumstances, for example neglect the coroner will undertake an inquest.

5.6.4. What is the magnitude of the problem?

In the section below, I describe much greater concerns numerically, about the large number of elderly patients who die from dementia like conditions in institutions (hospitals or care homes) and for whom the imposition of a DoLS may impact on the patient’s autonomy, dignity and wellbeing in end of life care (EOLC). These concerns are prompted by the numbers of DoLS being applied for and authorised, delays in the process, inexplicable regional variations not related to the numbers of cases of elderly people with dementia and the continuation of DoLS right up to death when it is probably apparent that the patient no longer requires one as they are dying.

In order to explore the wide potential impact of DoLS on autonomy, dignity and wellbeing at the EOL for elderly patients with dementia like conditions I have reviewed published and grey literature and statistics from the NHS Digital Annual Report of data derived from the Mental Capacity Act 2005, Deprivation of Liberty Safeguards (DoLS) data 2015-16 and its accompanying data sheets [394]. I have compared these data with data produced by my own team on potential numbers of elderly people at risk. The results of the analysis below provide justifiable concern about the autonomy and dignity of elderly patients dying in institutions especially with dementia.

In the financial year 2015-6, Local Authorities received 195,840 DoLS applications and 105,055 completed applications compared with 13,040 completed in the financial year2013-14, an eight-fold increase. This very large increase reflected care homes being increasingly aware of their legal obligations not to deprive people of their liberty without a DOLS assessment by the CASSR, care homes made 150,355 applications, acute hospitals 27,855 and hospices 715. The England rate for DoLS applications was 454 per 100,000 adults varying by region from 665 to 179 (3.7 fold). This variation cannot be explained by geographical variation of the potential need of the population or levels of elderly people living in care homes. My analysis found no apparent correlation between applications and age distribution of regions, prevalence of dementia or numbers of care home beds.

In total, 51% of applications cited dementia, 44% of 206,010 living with $\geq$1 DoLS were $\geq$85 years and when applied to the population this translated to 7.1% (7,073 people) of people $\geq$85 years who had an application made on their behalf. So, 7.1% of people aged 85 years or older have deprivation of their liberty acknowledged via a DOLS application. However, geographical variation in rates suggest that some local areas are more active than others. This probably means that the 7.1% is a significant underestimate of the very elderly whose liberty is deprived.

The datasheets and other information [394] show that large numbers of patients whose applications were rejected may have been deprived of their liberty, autonomy and dignity inappropriately and potentially illegally during prolonged periods, when their life expectancy is already short. It was found that 40% of authorisations took >3 months leaving a long period of lack of clarity about measures to restrict liberty for a patient at the end of their life. Alternatively some patients may not have been safe during this period while waiting an assessment. As with the number of applications being made, there is variability across the country in delays. According to a NHS Digital Report citing The Association of Adult Directors of Social Care (ADASS) budget survey 'Only 29% of directors who responded to the survey are fully confident of being able to deliver all of their statutory duties in this year (including for DoLS), falling to just 4% who think they can do so for next year' (Association of Directors of Adult Social Services, ADASS budget survey

2017) [394]. Some of this is related to the increased numbers of applications following the Supreme Court Ruling that not only clarified the definition of a DoLS but also widened the potential scope of its use.

Further evidence of delays this time on the part of the providers of care comes from the 'Right to Decide' Report which reports on complaints about DoLS made to the Local Government Ombudsman Local Government and Social Care Ombudsman (The Right to Decide: towards a greater understanding of mental capacity and deprivation of liberty, July 2017) [391].

Of the completed applications made 76,530 (73%) were granted. Of those which were not granted, 30% were not granted because the patient had already died (8,495) moreover, 29% of annual reviews also found the patient had died while on a DoLS. These data demonstrate that large numbers of elderly patients are dying while their liberty is deprived. The question is whether the DoLS was appropriate as death approached and whether there should be a process to revoke it if the patient's condition has deteriorated such that they are no longer a risk to themselves or others.

As described elsewhere, public bodies have procedural duties under the HRA1998 to prevent or investigate human rights abuses. Local Authorities are mandated to report applications and authorisations to the Care Quality Commission (CQC) which is responsible for monitoring the use of DoLS and reporting to Parliament. The CQC reported that only 82,621 authorisations were reported to them a significant mismatch with those recorded by NHS digital (CQC) (ref). The CQC report identified system-wide problems with training and implementation of DoLS [136].

This evaluation has shown that DoLS are being used frequently in elderly people with short life expectancies living in care homes.   The results which show unwarranted and inexplicable geographical variations in DoLS applications, approvals and waiting times raise concerns about justice. When combined with concerns raised by the CQC and Local Government Ombudsman these results raise alarm bells about issues of dignity and autonomy for elderly patients at the end of life whose liberty is deprived. It is recognised that the balance between paternalistic restriction of liberty and an individual' autonomy is not being entirely safeguarded [136].

Prior to moving to a care home elderly people are not explicitly told that there is a significant chance that their liberty will be restricted. So in agreeing to move, often under pressure from family and doctors, they are not consenting in a fully informed way.

A far less clear situation of deprivation of liberty occurs frequently in hospital when an elderly person, with mental capacity, wishes to return home but the medical staff will ‘not allow’ them to unless a suitable care package is arranged in the community. The doctors are paternalistically trying to protect the patient from what they perceive as a risk of harm and override the patient’s desire to take that risk. The concern often arises simply because it is difficult to quickly mobilise social and medical care to be able to support a frail elderly patient on discharge.

DoLS are a prime example of how paternalistic health and social care professionals can restrict the autonomy of elderly patients even if the autonomy is extremely limited and fluctuating by restricting their human rights. It also illustrates the state’s attempts to protect the right to liberty of elderly patients. It is recognised that the balance between paternalistic restriction of liberty and an individual’s autonomy is not being entirely safeguarded.

5.7. The Right to freedom of thought, conscience and religion (Article 9)

5.7.1. Introduction

There are two components to the right to freedom of thought, conscience and religion (Article 9). The right to believe what you want is an absolute right and cannot be restricted. The right to manifest your beliefs may be restricted to protect the rights of others or society [45, 368].

5.7.2. Religion and spirituality

National policy on end of life care, especially the Ambitions Framework, recognises the importance of religion and spirituality at the end of life [33]. Indeed these have been recognised as important to a person’s wellbeing at the end of life since the development of specialist palliative care [76]. However, the right to manifest a religion is a ‘qualified right’. This means it can be limited or restricted for example to protect the rights of others or to keep a person safe and balanced against the rights of others and the needs of society. Any restriction on this right must be lawful, for a legitimate reason and necessary.

When people are nearing the end of their life they may wish to observe practices for their belief. Elderly patients are far more likely to have a religion or faith than younger patients [201-203]. The legal duties on medical staff mean that they cannot interfere with a person's right to think or believe what they want and indeed medical staff may have a positive duty to secure a patient's enjoyment of these rights. This is especially true in P&EOLC and particularly for elderly patients who are more likely to hold religious views than younger people [202, 203]. Staff, especially in palliative care are trained in cultural awareness so that they can enable patients and families to follow religious traditions as the patient is dying and after death, for example in care of the body [78, 125]. For example staff could call for a religious leader to attend at the request of patient or family or arrange to lay a Hindu patient on the ground as death approaches. However, following the recurring theme of this thesis about individual autonomy, it is really important that staff do not make cultural or religious assumptions about how an elderly patient or their family may want to behave as each individual must be supported to exert their autonomy to practice their religion or spirituality in their own personal way. The NHS has produced some useful Guidance [208].

Spiritual and existentialist suffering can, understandably be great as death approaches and it is important that professional and family carers recognise this not only for its own sake and to seek help for the patient but also because it may exacerbate physical and psychological suffering too [99, 172, 199, 210]. There is some evidence that patients with no religion suffer more, in an existentialist sense as death approaches [201].

Physical suffering and death has a complex relationship because some religions teach that suffering is an important facet of life and leads to a better state of existence. Cutting suffering short by pain control, may interfere with progress towards liberating the soul, salvation or atonement in the afterlife in Christianity and Islam or Nirvana, the end of all suffering in Buddhism [200, 2001, 208]. Doctors and nurses need to be aware that not all patients wish for their suffering to be controlled with medication, or if they do not so much that they lose consciousness [200, 201, 238, 349].

While specialist palliative care practitioners are very familiar with the importance of the religious and spiritual domains of care, and the NHS has recently produced a literature review on the role of the healthcare chaplain [208], there is still much to do to raise the awareness of the importance of religion and spirituality among medical and nursing staff more generally.

For example, during my own experience as an inpatient, the Professor overseeing my care saw the Chaplain talking to me and shouted ‘why is he here, you are not dying’!

5.7.3. Freedom of thought and conscience

Article 9 of the HRA is not just about religion, there may be other issues of conscience and thought that are important to elderly patients approaching the end of life. Perhaps the most controversial is the wish to hasten death (WTHD) [99, 101, 171, 172]. The right to believe that there should, for example, be access to physician assisted suicide is an absolute right and cannot be restricted. However, the right to have this belief fulfilled, is restricted by law, to protect the rights perhaps of the individual, if they were under duress by others to end their life, and certainly of other vulnerable elderly people in society [399]. Similarly, people may believe that out of love or a sense of duty they should assist a loved one to end their life by committing suicide if they are suffering but assisting suicide is illegal and there are structures and processes in place as described above to prevent this [267].

5.8. Promotion and protection elderly patients’ autonomy

5.8.1. State policy and practice to promote autonomy at the end of life

In England, the Department of Health and Social Care has for several years promoted the importance of placing patients or, in the case of social care, clients, at the center of decision making [156]. Choice and informed consent has been an important feature for many years in both services (NHS Constitution and Care Act 2014) [48, 156]. It is an extremely strong thread throughout the NHS Constitution, slogans have been used such as “no decision about me without me” in the NHS Constitution [156]. The Mental Health Act and the Care Act have extensive references to enabling and supporting people to make choices about their care [46, 417] . The Mental Capacity Act, in particular, supports the concept of giving people with diminishing mental capacity maximum chances to exert their autonomy in decisions about care. Since 2008, with the publication of the first National Strategy for End of Life Care, choice has been promoted as important although in a libertarian paternalistic fashion focusing on issues primarily related to place of care at the end of life and place of death or negative autonomy such as writing Advance Directives to Refuse Treatments (ADRTs)

[30, 154, 350]. Choice continues as a thread through the Choice Review and into the current national policy, the Ambitions Framework, which to all intents and purposes is an updated national strategy [33, 39, 120]. The state has promoted the exertion of choice in P&EOLC through its nationally funded social marketing campaign called 'Dying Matters' [32, 138].

The libertarian paternalistic approach argues that it is legitimate to influence peoples' choices, in this case to exert their autonomy to make choices about their end of life care, if it increases their welfare without limiting their freedom of choice [350].

However, given the fact that more than two thirds of people who die are elderly, is very little research into what elderly people actually want and what autonomy means to them as they approach the end of life and indeed whether the type of choices being promoted to them are of interest [18, 78, 87, 88, 119]. The little research conducted, as reviewed in Chapter 3, suggests that they have more moral concerns and often wish to exert their autonomy in a way which causes least burden on others [113]. Moreover, elderly patients even though they know that death is approaching do not want to engage with end of life care planning [235].

For this reason, as well as others which will be explored in the next chapter in the section on non-maleficence, there are concerns as to whether the National Campaign 'Dying Matters' which aimed to be state funded instrument of beneficence to raise people's awareness of death and dying to enable them to take more control is really doing something useful or could cause harm [138]. Moreover, it will question whether the actions of the state fulfil the criteria for a libertarian approach in promoting so strongly the need to exert choice at the end of life [350].

The state through end of life care policy and focus on choice also places emphasis on the importance of Advance Care Planning (ACP), Advance Care Directives (ADs), Advance Directives to Refuse Treatment (ADRT), and appointment of Legal Power of Attorneys for Health and Welfare (LPA) [32, 33, 120, 154]. However, despite almost a decade of activity there is almost no increase in the uptake of any of these initiatives. The national policy makers should reflect on this. A clue may be, as mentioned above, that so little attention has been paid to the majority of people who die, who do not want to make these plans, although the reasons for this are not fully evaluated [235].

5.8.2. Evidence of increased autonomy being exercised at the end of life as a result of state policy and practice

Despite low levels of uptake of ACP, studies on the use of advance care planning tools which include Electronic Patient Palliative Care Systems for recording decisions have shown that they do support patient choice in both place of care and death, in their use makes preferences more likely to be fulfilled [94, 347].

National statistics, produced by my team, the NEoLCIN, and used by the state for monitoring the success of the national end of life care strategy, can only monitor proxy indicators of quality or patient autonomy and the key indicator is place of death. The graphs shown in the background, produced by the NEoLCIN, show a statistically significant reduction in deaths in hospital and a narrowing of the degree of variation across health administrative areas over the past decade [11]. Death in hospital is also reducing for all ages and for various conditions and across all ethnic groups [75]. In younger patients there is also a significant increase in deaths at home. In elderly people most of the out of hospital increase in place of death is occurring in care homes [75]. At a macro level of choice of place of death there is evidence that national policy supported by a panoply of local interventions is having an effect but there are clearly still injustices in the distribution of services. Policy appears to be enhancing patients autonomy if place of death reflects this. However, in elderly patients the falling death rate in hospital and rising death rate in care home may not reflect choice at all. It may reflect the patients' deteriorating circumstances and indeed loss of choice as more people move to care homes before death because they cannot manage in any other way [119]. Moreover, there is evidence of increasing numbers of elderly people being transferred from hospitals and even hospices to care homes, predominantly nursing homes, to die who previously lived in their own homes [245]. Despite these temporal trends, there is wide, statistically significant, geographical variation in proportions of people dying in hospital or elsewhere [11]. Some of this reflects the underlying difference in geography of the populations but importantly also levels of care provision and implementation of policy [11].

The near obsession with choice of place of care and death, especially as there is an attempt to establish a social norm that this will be not in hospital, has to be treated with caution as there are groups of patients who do want to die in hospital for example patients with chronic respiratory diseases and liver disease [81, 419]. Moreover, choices change and circumstances change as death approaches [153]. Furthermore, as described above, the VOICES survey of bereaved relatives show that more than three-quarters say the place of death was the correct one even if it was not the patient's original choice and this applied to hospital deaths too [258].

5.8.3. A proposed change to organ donation policy – is the state overriding individual autonomy?

An area of recent controversy, regarding autonomy at the end of life is the current government's recent proposal to change the law on organ transplantation. At present in England there is an 'opt-in' situation where people place themselves on a national register of potential donors. Recently the government has proposed a presumed consent model with the possibility of 'opt-out'[420]. The reason given is to increase the number of transplants as there is a shortage of organ donations.

Although at first glance it might not appear of relevance to elderly patients, in fact elderly people can still donate various organs and tissue and their body for medical student dissection [420]. There has been a very large increase in the number of elderly patients suffering chronic renal failure who could be eligible for renal replacement therapy, either dialysis or even transplantation. Interestingly in elderly patients dying from kidney disease there is a higher need for life saving organ transplantation among people from Black and Minority Ethnic (BAME) groups but lower donation rates of kidneys from BAME groups which is problematic because genetic matching is required. The presumed consent model is designed to redress this too.

The current organ donation system in England is claimed to be altruistic [420]. People need to register their desire to donate and can specify what they would like to donate. At present only around a third of people who say they would like to be an organ donor are actually on the national organ donor register. For people who are not on the register and who may be suitable donors and are in a state not compatible life, their relatives may be asked if organs can be used. Relatives can override a person's registered wish to be a donor and this happens relatively frequently [420].

There has been ethical debate about the legitimacy of a presumed consent model. Saunders argued that under a presumed consent policy "it would be morally legitimate to remove organs from individuals whose wishes concerning donation are not known because combining the concept of normative consent with Peter Singer's 'greater moral evil principle', it would be immoral for an individual to refuse consent to donate his or her organs" [421] . Others suggest that the introduction of presumed consent in fact a slippery slope of the government deciding to override individual autonomy and just enable anything or everything to be taken from our bodies after death [422]. The legal position is already in fact that we do not own or have rights over our body after death. A debate has also arisen suggesting that organ donors in heart-beating and non-heart-beating protocols are not actually dead when their organs are surgically removed. If this is the case , then how can people have a duty to consent to their lives being taken for their organs to be given. Many people who have been major supporters of organ donation as an altruist act threaten to withdraw their consent and opt out of donation should it be imposed through presumed consent legislation as they see it as a major assault on individual autonomy to decide about their own body [423]. In not all countries is altruism considered to be sufficient to encourage organ donation and incentives are used. This would seem to contravene the principles for libertarian paternalism since the presence of incentives will prevent the individual from having unbiased autonomy in choice [424, 425]. A presumed consent policy has also been criticised for undermining people's ability to act as moral beings and voluntarily chose to be altruistic. These critics see this as yet another case of state paternalism undermining the individual as a moral being and therefore diminishing the importance of the development of values such as altruism and solidarity [426, 427].

5.9. Discussion and conclusions

5.9.1. Discussion

This chapter has examined the paternalistic role of the state, working through its institutions, in promoting protecting and promoting the autonomy of elderly patients at the end of life.

It has demonstrated that through legislation, most notably, the Human Rights Act (1998) as a foundation law, and the legislation which has stemmed from it, that in England, there is a strong infrastructure to protect and promote autonomy and ensure it is implemented in P&EOLC and indeed all health and social care for elderly patients [45, 398]. This permeates every aspect of the way in which end of life care for elderly patients should be delivered [368]. There are obligations derived from the legislation on all staff members, specific policies on end of life care, regulation of doctors by the General Medical Council and regulation of providers of health and social care services by the Care Quality Commission [79, 398]. When autonomy of elderly patients is not respected this is, unfortunately, usually at the level of individual professionals and sometimes organisations [39, 386]. As described elsewhere, the route of this is usually lack of training, lack of awareness of legislation and policy, time pressures and inadequate resources [39, 41].

The state provides almost all of the healthcare for elderly people at the end of life [136, 400]. Very little is provided by the voluntary sector for example hospices in contrast to younger patients especially those with cancer [28]. Although the National Health Service is under great pressure, the pressures are even greater in social care, which is not universally free but means tested (dependent on income and savings). There is widespread debate about how the social care for elderly people at the end of life should be funded, in particular whether this should be funded by state especially in the final 6 months of life [170, 428]. This has very important implications for P&EOLC for elderly patients. It would be good if the planned policy on free social care for the last six months of life could be implemented to mirror the DS1500, a small state benefit given to carers of people who are dying [429]. The charity, Marie Curie, also provides advice on how other benefits can be accessed and fast tracked for terminally ill people [429].

The needs of the population for health and social care are changing rapidly because of the aging population and the complexity of caring for very frail elderly people with multiple morbidities [13, 14, 62]. There is a clear need for better recognition of these challenges at a state, professional and societal level [14, 53].

In England, the state is very clear that people with mental capacity can refuse treatment which could prolong their life [220]. Suicide is not illegal. However, it is illegal for anyone else to take a person’s life or assist them in suicide [267, 268]. An important differentiation is made between active killing and withdrawal or withholding of treatment at the patient’s request [79, 290].

The state is very concerned to protect the vulnerable and has weighed up the risks to many potentially vulnerable people against the requests of a few who request PAS and found in favour of protecting the many [290]. Maintaining confidence in the medical profession that they will not end the life of people prematurely has become very important following concerns regarding the LCP and most recently Gosport [36, 39, 375, 408, 430].

One of the clearest examples of beneficent paternalism is the repeated rejections of appeals for euthanasia or physician assisted suicide to be introduced [290]. The main argument supporting this is to protect the vulnerable including the elderly who might otherwise feel pressurised into requesting this in order not to be a burden. Another example is the Mental

Capacity Act which seeks to protect the rights of those who do not have the mental capacity to make their own decisions about care [220].

5.9.2. Conclusions

In conclusion, the state in England clearly intends to act as a beneficent paternalist with respect to protecting elderly patients at the end of life, especially through legislation. The implementation of and adherence to legislation to protect lives and protect against degrading and inhuman treatment is supported by a national infrastructure and policies. Several Articles of the HRA 1998 are both protective and promoting of the autonomy with the respect to at least some of the issues important to elderly patients approaching the EOL. The state, in England, has a libertarian paternalist approach to encouraging choice. There are of course many areas where care can be improved but there are structures and processes in place to identify and respond to these needs for improvement.

Chapter 6. Beneficence, non-maleficence, justice and autonomy in state policy in Palliative and End of Life Care in England: the impact on elderly people

6.1. Introduction

Since the pioneering ideas of Cyrus the Great, 550 B.C., ruler of Persia, most states, in governing and exercising their obligations, consider how they can promote the wellbeing of their citizens [431]. They often exercise this governance as beneficent paternalism [432]. Underpinning this beneficent approach is the idea that healthy and happy citizens will be good for the state in terms of economic wellbeing and peaceful social order [431]. There may also be more altruistic motives to a state's beneficence towards its citizens such as the protection of the vulnerable and weak as exemplified by the Human Rights Act 1998 in the UK [45]. The application of a human rights approach to Palliative and End of Life Care (P&EOLC) is now recognised internationally through the WHO and Lisbon Treaty and countries as far afield as Armenia, Spain and Brazil are describing their state's approaches to P&EOLC in human rights' terminology [2, 3, 21, 22, 315, 369, 370]. Beauchamp coins the phrase 'social beneficence' as applied to this type of state policy [432]. At the same time as promoting beneficence, the state wishes to avoid harm to its citizens. However, in implementing national policy, especially public health policy, there is always a risk that while the majority of people to whom it applies may benefit, some may be harmed [433, 434]. Avoiding maleficence by constant awareness of the 'primum non nocere' principle is fundamental in state policy [435]. Although harm to small numbers of people cannot be totally avoided, the risks of harm should be minimised by being well researched, understood, documented and mitigated against [434, 436-438]. In public health policy a utilitarian approach is adopted promoting the greatest possible balance of beneficial consequences and the least possible balance of bad consequences [360, 436, 437].

In general, states also have an obligation to ensure justice in terms of access to the services that they provide to their citizens. Beauchamp draws parallels between social beneficence and social justice and indeed describes how these are inextricably linked [432]. It is at the level of national policy and legislation that issues of distributive justice can be seen to play out. The extent to which national policy considers and attempts to address issues of justice, in Palliative and End of Life Care (P&EOLC) for elderly patients will be explored. In public health terms this could be called an equity audit as it explores the context of fairness in access to P&EOLC [52, 439].

This chapter examines the Beauchamp and Childress four principles of bioethics [73]: beneficence, non-maleficence, justice and autonomy as a framework to critically appraise the state in England's approach to P&EOLC for elderly patients. The role of the state in protecting and promoting the individual elderly patient's autonomy has been evaluated in the previous chapter. In this chapter, I take a more unusual approach to examining autonomy in the field of bioethics, but one recognised in political science by state autonomy theorists [401]. This is to examine whether the state itself is acting autonomously with respect to its policy, legislation and infrastructures for P&EOLC or whether it is responsive to its citizens [120].

6.2. Methods

In this chapter I have adopted as a framework for analysis the four principles of bioethics described by Beauchamp and Childress and operationalised for medical practice in the UK by Gillon [73, 110, 111]. These have been used to analyse the national policy and legislation which supports the delivery of P&EOLC in England and its implementation. I have critically reviewed national policy for P&EOLC and its implementation since the publication of the first national strategy for Palliative and End of Life Care in England in 2008 [30]. As there is ample evidence of the state's beneficent intentions with respect to legislation, policy, regulation and monitoring and P&EOLC, described in global rankings and in Chapter 5 [51], I will focus in this chapter particularly on non-maleficence.

Non-maleficence must remain a serious consideration for policy makers. It has been suggested by Seymour and Clarke that the impact of the media coverage surrounding the downfall of the Liverpool Care Pathway for the Care of the Dying Patient (LCP) was so far reaching that 'the sequence of events surrounding the Liverpool Care Pathway (LCP) brought to an end the era of 'unconditional regard for palliative care' [36, 39]. They also suggested that 'no longer could it be assumed that palliative care was universally welcomed' [36].

An analysis of the state's role in first promoting the LCP in national policy, then investigating and responding to the problems which were publicised by the media, provides the backdrop for considering the caution which should be exercise with respect to other selected national policy initiatives [39].

Thus, a number of policy initiatives are critically appraised with respect to the obligation of non-maleficence (primum non nocere), in other words, exploring whether the state instigated policies in P&EOLC have the potential to, or actually cause, harm to patients or relatives.

The section on justice primarily focuses on distributive justice as the state, like a good parent, should try to care for those people for whom it is responsible fairly. This does not mean necessarily equally as individuals may and certainly do have different levels of need for specialist or generic P&EOLC. Analyses of national data can give insights to distributive justice because as a group, the needs of elderly and very elderly patients will differ from younger patients because of greater prevalence of co-morbidity and frailty and different causes of death [11].

The Table 6.1 below summarises the framework for evaluation

Table 6.1 Framework for evaluating the state's role in P&EOLC with respect to beneficence, non-maleficence, justice and its own autonomy

Four principles of Bioethics described by Beauchamp and Childress [73]	**Questions to be evaluated**
Beneficence	The state, de facto, has a paternalist role in legislating and providing for and regulating end of life care for elderly patients - does this manifest itself as beneficent?
Non-maleficence	What evidence is there of measures to evaluate and prevent harm being caused to elderly patients at the end of life as a result of policy decisions?
Justice	Does the state have mechanisms in place to ensure justice with respect to the HRA (Article 14) and distributive justice in terms of fair and equal access to high P&EOLC?
Autonomy	Is the state acting in an autonomous fashion with respect to P&EOLC policy and its .implementation or is it listening to the views of the people affected and those of the non-governmental organisations which represent them?

6.3. State structures and functions to support a beneficent paternalist approach to Palliative and end of Life Care for Elderly Patients

There is good evidence that the state in England has a fairly comprehensive, policy driven, beneficent approach to the medical needs of the population for P&EOLC on the basis of international comparisons [5, 50, 51]. Moreover that the state is attempting to take a beneficent paternalistic approach in terms of investment and infrastructures to develop P&EOLC. The UK's position as top of the league table of countries in Palliative Care provision reflects the state's commitment and investment even though, as shown in our recently published Atlas of Variation in Palliative and End of Life Care for England, and as will be elucidated in this chapter, the coverage and quality still has room for improvement [11, 51]. Chapter 5 has demonstrated that the state in England has policies and structures in place to deliver P&EOLC from a human rights perspective, although there is still ample room for improvement.

6.3.1. National Strategies and infrastructure for leading and monitoring P&EOLC

Against the backdrop of generic protections of elderly patients' life and autonomy afforded by legislation, and described in Chapter 5, since 2008, the state has introduced a wide range of strategies, policies regulation and monitoring to try and ensure minimum standards for P&EOLC and to strive for universally good quality care for all patients, including the elderly [33]. Demonstrable examples include two National Strategies for P&EOLC published in 2008 and 2015 [30, 33] and the work of the NEoLCIN, monitoring indicators of performance [11]. A plethora of National Standards have been set as Guidance for commissioning of specialist end of life care and for professional practice [79, 80, 143, 365].

The state provides almost all of the healthcare for elderly people at the end of life [136, 400]. Very little P&EOLC is provided by the voluntary sector to elderly people, for example by hospices, in contrast to younger patients especially those with cancer [28]. Although the National Health Service is under great pressure, the pressures are even greater in social care, which is not universally free. Social care is funded through local government administrations whose budgets have been repeatedly reduced over the past few years against a rising need for care due to the aging population [136]. Each Local Authority decides how much of its budget to spend on social care and has different assessment thresholds for access to free care, for example paid places in nursing homes. This leads to substantial inequalities in the care elderly patients at the end of life can receive without payment. The differences are also stark in terms of care home (residential and nursing home) bed availability across the country [11, 245]. Most elderly people approaching the end of life will require both medical and social type care (help with washing, going to the toilet, feeding). This has prompted widespread debate about how the social care for elderly people at the end of life should be funded, in particular whether this should be funded by state especially in the final 6 months of life [170, 428]. This has very important implications for P&EOLC for elderly patients and their families as if social care is not free at the end of life this type of care must be paid for or provided by families. There is not yet an army of volunteers ready and trained to help fill the gap, indeed, our research suggests that there is not an as yet, a vast untapped reserve of people willing to do this kind of work as a volunteer [174]. It would be good if the planned policy on free social care for the last six months of life could be implemented to mirror the DS1500, a small state benefit given to carers of people who are dying [429]. Marie Curie Care, a national Charity also provides advice on how other state benefits can be accessed and fast tracked for terminally ill people [429].

However, despite the fact that most people who die are elderly, to date there has been a distinct lack of focus on the elderly in NHS P&EOLC planning, similarly by social services and the voluntary sector. For example, NHSE has only just produced guidance for End of Life Care for Dementia patients [215]. In contrast, the NEoLCIN, my team, recognised very early after its establishment the importance of P&EOLC for elderly people and among its first publications, in 2010, published a comprehensive report of health statistics on P&EOLC for Older Adults [12] and one on place of death for people with Dementia. Last year it produced a number of products on end of life care in care homes [13, 246] and the 2019 work programme is devoted to P&EOLC for older adults. The focus on understanding the priorities for P&EOLC in elderly patients and improving their access to it must remain a priority. It should be a target for England to become internationally recognised for its excellence in P&EOLC for elderly patients, which will mean a significant change in direction from the classic specialist P&EOLC model. All industrialised countries are facing the emerging challenges of greater numbers of frail elderly requiring P&EOLC [78] and many are looking at innovative solutions such as in Poland where volunteers play an increasing important role in supporting the elderly at the end of life [179].

So, the state rhetoric is strong and appears beneficent regarding ensuring everyone has access to good quality P&EOLC and this is supported by policy and monitoring. However, in practice the low level of focus on the P&EOLC needs of elderly patients is not in proportion to their need numerically or the complexity of their needs.

6.3.2. Legislative frameworks which support palliative and end of life care

A number of underpinning generic legislative initiatives by the state, demonstrate its benevolent paternalism or ‘parens patriae’ role and have protective implications for elderly patients nearing the end of life [131]. These include: the UK Human Rights Act 1998 (HRA 1998) and a number of pieces of legislation which stem from this such as the Mental Capacity Act, the Care Act and the Equalities Act [45-48]. These establish a comprehensive legal framework which should protect the human rights of elderly patients approaching the end of life [368]. Moreover, as described in Chapter 5, the responsibility for protecting human rights is placed on all public officials (paid by the public purse). This means that even professionals working in charitable institutions like hospices, which are part funded by the state, carry the same legal responsibility. They are under a legal duty to act compatibly with the HRA 1998 [45]. Importantly, also, in the context of end of life care for the elderly, the HRA 1998 allows a person to ask a court or tribunal to decide whether the acts or omissions of public officials have violated their human rights or are putting them at risk.

The Mental Capacity Act (MCA 2005) is a good example of state beneficence in terms of ensuring its ‘Parens Patriae’ role to protect the weak, in this case people without the mental capacity to make decisions for themselves [46]. Approximately 108,400 people die with dementia or a mental capacity reducing condition mentioned on their death certificate, this accounts for 22 % of all deaths [75]. The proportion of elderly people who die with these conditions recorded by location is: 58% of people who die in care homes, 29% in hospital, 12% at home and only 1% in hospices [11]. Based on these data the Mental Capacity Act 2005 may apply to a very high proportion of elderly people at the end of life. The fifth principle of the MCA 2005 which links very tightly to the HRA 1998 and to patient autonomy is that decisions made for people lacking capacity should be the least restrictive of their basic rights and freedoms [24]. As described elsewhere, unfortunately this fifth principle is not always applied and elderly patients at the end of life have their liberty restricted perhaps unjustifiably [391].

The last decade has seen a dramatic shift to making the patient and their family the centre of decision making at every stage, with a strong emphasis on patient choice and respect by the medical and social care professions for their choices [156, 159, 215, 440]. This could be argued to fulfil a beneficent paternalist state role in providing care but with due attention not simply to the views of civil society as a group but to each individual within society. Moreover, the state is ensuring through legislation that structures and procedures are in place to listen to patients, the public and carers. The Health and Social Care Act 2012 requires all organisations providing care to involve patients and the public in all aspects of services design and monitoring to ensure public, patient and carer voices are at the centre of health services [441].

The state is very concerned to protect the vulnerable and has weighed up the risks to many potential vulnerable people against the requests of a few who request PAS and found in favour of protecting the many [290]. In addition, maintaining confidence in the medical profession that they will not end the life of people prematurely has become very important following concerns regarding the LCP and most recently Gosport [36, 39, 375, 408, 430].

So, through a comprehensive set of legislation, the state in England also exerts it paternalist role in protecting the vulnerable, especially the elderly and those who have lost mental capacity at the end of life.

6.3.3. Regulation of health and social services

The state not only provides health services but also has structures to regulate and ensure the quality of these services. Since 2009-10 all healthcare providers, whether NHS, charitable or private sector, have been “registered” with the regulator, the Care Quality Commission (CQC) and assessed against national standards of quality and safety. Each year the CQC publishes its assessment of the performance of all organisations in the NHS and of care homes. Organisations failing to meet the standards will need to take urgent remedial action and could, in the last resort, lose their registration [136].

In 2016 the Care Quality Commission (CQC) prioritised end of life care as a theme in its inspection of hospitals [28]. The CQC also has a particular role in the regulation and monitoring of the use of Deprivation of Liberty Safeguards DoLS as described in Chapter 5 [136].

The state has a permissive relationship with the medical and nursing profession allowing the General Medical Council (GMC); and the Nursing and Midwifery Councils to licence and regulate their own professionals [442]. However, the way they do this is under scrutiny by the state. The findings of LCP review led to pressure on the GMC to tighten its guidance and regulation with respect to P&EOLC [39].

The state exerts its paternalist role by not only having an infrastructure in terms of policy and legislation to protect and promote elderly patients at the end of life but also has regulatory systems to check that this is being universally implemented. However, this is work in progress as universally high quality of P&EOLC has not yet been achieved in all institutions England [11, 28].

6.3.4. State funded social marketing to improve autonomy in P&EOLC for elderly patients

As described above, in England, the state has a legislative function to protect the rights of elderly people approaching the end of life, a policy and funding function, to provide health and social services and a regulatory function to check that these are safe and standards are maintained. It could be argued that the state has further functions in educating the population to enhance their autonomy and empower them to make the choices they are entitled to [432]. This would be an example of libertarian paternalism [350]. Indeed right to education, although not specifically of this type, is also defined in the Human Rights Act1998 (HRA) [45]. It could be argued that actually the state should actively try to encourage the public to take back control of a natural life event that is so personal to them especially in the light of the strong argument that, as a consequence of the medicalisation of dying and death, there has been a creeping public passivity and abdication of control for their end of life [121].

There are two rival perspectives on how to achieve a return of autonomy to the individual regarding dying and death. The prevailing 'current-paradigm' suggests that the ‘experts’, specialist palliative care clinicians, should have a prominent role in guiding the public in decisions relating to end of life care, including Advance Care Planning or whether to stay at home or move into a care institution and therefore the professionals should guide behaviour change programmes. The alternative perspective is that death and dying is a natural process and a more sociological approach should be taken, handing back more control to the people. If the latter approach is supported, a new paradigm is required to enable the locus of control to fundamentally shift to the public. Supporters of this paradigm shift consider that this will be a significant challenge as too much power and control currently lies with medical professionals [120, 154].

Governments, policy makers and public health specialists have moved on beyond simple campaigns providing information to the public, as they now recognise that provision of information alone does not result in significant behavioural change at a population level. Moreover, it often causes inequalities between the rich and poor or better educated and less well educated with the result of widening gaps in health behaviour, as it is often only the better educated and more financially able who are able to make best use of the information . Social marketing is now a preferred approach [443]. This uses marketing science for social good [443]. Marketing science seeks to segment the population into groups who behave more similarly with choices and actions [443]. In the marketing world messages to buy products can be more successfully targeted at specific population subgroups on the basis of a better understanding of their preferences and purchasing behaviour. In social marketing a similar approach is taken but with an underpinning ethical framework to enable messages about health or other socially desirable behaviour change to be more effectively targeted to different segments of the population having understood their triggers and barriers to change [362].

In 2008, the Department (Ministry) of Health and Social Care (DHSC) provided a very significant level of funding to a charitable organisation, the National Council for Palliative Care (NCPC) to establish an independent team to run an evidence based social marketing campaign to change the public's behaviour with respect to planning for end of life [138]. It could be argued that the state by adopting a social marketing approach to establish what the public want and then guide them to achieve it was acting as a benign, if libertarian paternalist [350]. The social marketing campaign was called 'Dying Matters'. The aim was to encourage people to take back control over death and dying, especially from the specialist palliative care view of end of life which is dominated by experience caring for young cancer patients [32].

As early as 2008, as the first National Strategy for Palliative and End of Life Care was published, early research suggested that the majority of people asked in questionnaires said that they would prefer to be cared for and die in their homes [30]. However, it was clear that there was a significant mismatch between the views of the general population and where people actually died, given the majority died in hospital. Research at that time, based on the healthy general population, suggested that very few people talked about death and their hopes or plans with those close to them or their doctors and therefore were unable to express their wishes in advance and have them respected [138]. The DHSC funded National End of Life Care Programme Team decided, after consultation with behaviour change experts from the National Social Marketing Centre, that a Social Marketing Campaign to encourage people to talk more freely and frequently about death and dying especially with their loved ones would lead to better planning and therefore better recognition and implementation of patients' autonomous choices. This was based on the premise that getting people to think and talk about death and dying leads also to action for example making Advance Care Plans, appointing a Legal Power of Attorney for Health and Welfare, making Wills and Funeral Plans [32]. The campaign achieved demonstrable success in increasing the number of people talking about death and dying but there is little evidence of change in behaviour [138]. The empirical data presented in the chapter on autonomy, which explores elderly patients' attitudes to planning for death suggests that many, despite being cognisant of their imminent death, do not want to plan, or at least not in the way professionals envisage this [160, 165, 235]. Indeed, this perhaps has been one of the flaws in the campaign that specialist palliative care professionals understand very little about elderly people and their end of life wishes. For example, a literature review of empiric studies noted older people's readiness to talk about death and dying contrary to belief amongst policy makers in England [148]. It is also clear that the priority for elderly people which concerns them most are the circumstances of their dying, in particular loss of control and pain relief, rather than place of death [247]. Even when specifically asked about dying at home, elderly patients anticipated that home would be their ideal place of care during dying but they recognised and expressed practical and moral problems which could arise. So elderly patients were not selfishly set on home being their place of death [160].

Unfortunately, as state funding reduced and then ceased the Dying Matters Campaign, which was established as an independent, social marketing campaign, shifted from an evidence based programme into what was termed a social movement. Funding was sought from people and organisations with an interest in death and dying and the independence of the leadership and steering committee was lost becoming more dominated by specialist palliative care professionals [138]. Campaign themes were more determined by 'good ideas' than evidence based research. However, the campaign was still hosted within a broad based charitable organisation interested in P&EOLC. In 2017 the host organisation merged with Hospice UK (an umbrella organisation representing the interests of Hospices) who have taken over the running of Dying Matters and the campaign is now firmly in the hands of specialist palliative care medical professionals [32]. A critique of this situation is given in the next section on non-maleficence to examine whether the intended benign libertarian paternalism really achieves what it intends.

6.4. The State and non- maleficence – primum non nocere

The maxim ‘primum non nocere’ is usually presented as an absolute [341, 361]. It is almost never the case though that an action, especially a clinical intervention or decision about the type or place of care is completely beneficial and without risk. Certainly, in clinical decision making, the risks of harm should be considered and taken into account and discussed with the patient or their LPA, before a joint decision is made, respecting the patient’s views on the level of risk they wish to take. A similar assessment could be applied to policy to weigh up the risks and benefits and communicate these clearly as well as the choices to be made [444].

In policy development sometimes the risks are not so easy to predict or decision makers get carried away with a focus on the potential benefits without adequately considering the risks. Systems should be put in place for the monitoring of the implementation of new policy including specific methods of detecting adverse incidents and effects [445]. After more than a decade involved in national policy and research related to end of life care, it is very clear to me that benefits and risks in policy making in P&EOLC, more than any other area I work in, are finely balanced. Moreover, for every good initiative, there is a significant potential for harm to occur to patients if doctors or hospitals are financially incentivised or measured against targets to encourage specific behaviour [36, 341]. Lessons must be learned from the Liverpool Care Pathway (LCP) implementation, which will be critically appraised below. It is clear that in order not to repeat the mistakes of the LCP national roll-out, all new policy initiatives in P&EOLC should undergo a full assessment of the potential benefits and risks including costs as well as an inequalities impact assessment (will it reduce health inequalities). There should also be ongoing monitoring after introduction of the policy to identify potential problems in practice [445].

Major policy innovations initiated by the state and covering an entire country are rare in P&EOLC. In the following sections section, I will present selected examples of national policies in England, where the risks of harm were not, or still are not, adequately predicted and so safeguards to mitigate them not put in place. I will give also one example of a battle which ensued and was won not on the primum non nocere principle but an economic one, illustrating how different tactics have to be employed sometimes in policy development in order to protect the population from harm.

6.5. The Liverpool Care Pathway for the Care of the Dying Patient (LCP)

6.5.1. What went wrong?

The Liverpool Care Pathway for the Care of the Dying Patient (LCP) was a tool developed in specialist palliative care, in a hospice setting, and then implemented widely across hospitals in England [36]. It was also enthusiastically taken up internationally [36, 38]. The LCP was designed to improve the quality of care of patients in the 'dying phase' (described as the last 48 hours of life in the original LCP documentation).

In 1997, a paper published by Professor John Ellershaw and colleagues, who developed the LCP, suggested that the LCP could be used to transfer key principles derived from hospice-based terminal care into general health care settings, such as hospitals and care homes [446]. Over the following ten years several studies were published which reported that the LCP improved the quality of care for dying patients [37]. This led to a slow uptake of the LCP in hospitals by specialist palliative care teams based in hospitals. In 2008, the National End of Life Care Strategy recommended the national implementation of the LCP '….[Hospitals are] strongly recommended to ensure that the LCP is adopted and its use audited in all locations where patients are likely to die' [30]. It is significant that this statement included the recommendation for auditing its use but unfortunately this aspect of the recommendation was not widely implemented and so problems were not detected by the health service.
By 2011, the LCP was endorsed in a number of national policy documents by organisations which pride themselves on providing evidence based guidance or guidelines. These included: the National Institute of Clinical and Health Excellence (NICE) Guidance on End of Life Care and the General Medical Council (GMC) Guidelines to doctors on the care of the dying patient [79, 80, 143]. The recommendations for widespread adoption of use in hospitals were supported by financial incentives through the Commissioning for Quality and Innovation (CQUIN) initiative [447]. When the national media discovered the CQUINs payments they found the idea of payment to hospitals to implement a pathway for dying abhorrent especially as there were already concerns that patients were dying prematurely [36].

The LCP was discontinued in 2014 following five years of negative media stories which culminated in an open letter to the Secretary of State for Health and an online petition demanding a Public Inquiry [36]. Baroness Julia Neuberger was appointed to conduct a national review, the results of which were published on 15 July 2013, in her report 'More Care, Less Pathway: a review of the Liverpool Care Pathway' [39]. The review findings shocked the whole P&EOLC establishment and prompted rapid and far reaching recommendations for change from a leadership group (The Leadership Alliance for the Care of Dying People (LACDP) formed from across all sectors of responsibility for P&EOLC [141]. I was a member of this group representing Public Health England. The media coverage also promoted public debate about what is 'good' or 'bad' practice in the care of the dying. Some practices in palliative care, for example deep sedation had not been heard about previously in the public domain and concerns were raised that this was being use without the patients' full understanding or consent [389]. Unfortunately, it has become clear recently that a maverick doctor at Gosport Memorial Hospital, who was working single handed, without peer support or review, still continued to use deep sedation to death without patient consent and probably a large number of patients died prematurely as a result [430].

The national implementation of the Liverpool Care Pathway (LCP) was an archetypal exemplar of the state intending to act as a beneficent paternalist identifying what it thought would be good for people and encouraging the widespread uptake of an intervention intended to improve P&EOLC. However, the state made a number of basic errors in its enthusiasm to see the LCP widely used [36, 39].

The evidence base for effectiveness of the LCP was weaker than assumed. Somehow the organisations, such as the GM and NICE, which pride themselves on providing evidence based practice accepted the evidence from observational studies rather than randomised controlled trials. Only after the LCP was stopped in England were two randomised controlled trials published which demonstrated that the weakness in use was due to the way doctors operationalised it and the supporting methods of implementation in hospitals not the pathway itself [36].

The Neuberger Review found that insufficient training and supervision of staff had been provided for the use of the LCP on the general wards of hospitals where P&EOLC practice and principles were less familiar. Most of the doctors implementing LCP had not been trained in palliative care or even adequately in the LCP's use [39]. Furthermore, the overall process for using the LCP in a clinical setting was changed for mass roll out reducing the chance to identify problems. Importantly, in the early days of the LCP use in specialist palliative care settings, both multidisciplinary review of patients on the pathway and exception reporting of problems were used as a safety net to ensure patient safety and wellbeing. During the mass roll out in general hospitals these critical safety features were dropped leaving junior doctors with inadequate training to use the LCP on their own without the need for consultation with seniors. This meant that identification of a person in a terminal phase was often made by a junior doctor not an experienced clinician and more importantly there was no senior multidisciplinary review to identify patients who were not actually terminal. In the elderly, recognising a true terminal phase can be difficult for the inexperienced doctor as their condition may deteriorate and then rapidly improve for example with the onset and treatment of an infection [344]. This lack of experience also led to patients being over sedated and hydration and some essential medicines may have been withheld or withdrawn inappropriately [39].

The LCP was a form of Integrated Care Pathway (ICP) which were very fashionable at the time of the LCP national roll out. At a system level, in the NHS, there was enthusiasm for ICPs which were seen as a way to standardise and raise the quality of care across the country in the NHS. Importantly, at this time there was a lot of concern about the so called 'post-code lottery' in quality of care whereby the standard of care a patient received might vary from hospital to hospital dependent on different doctors' practices. ICPs were seen as a way to standardise care no matter which hospital was treating the patient as well as generally improving outcomes and patient safety [448]. The enthusiasm for, and familiarity with, ICPs, which were being introduced across both medical and surgical disciplines, meant that the LCP was readily accepted by non-palliative care specialists who were using other ICPs. However, alarm bells were already being raised that ICPs may not be the panacea for improving medical practice across all conditions and all patient groups. It was noted that they were effective in standardising and improving practice for simple, predictable clinical problems but less so not where the patient's prognosis was uncertain. For example, ICPs were found to be useful in the acute management of stroke but not in rehabilitative care, where recovery pathways were more difficult to predict [448]. This observation has clear resonances in P&EOLC, especially for elderly patients where the prognosis is often difficult to determine [128, 449]. However, despite concerns being raised specifically by the specialist palliative care community these went unheeded [41]. Indeed concerns about the appropriateness of the LCP for elderly patients because of their unpredictable, fluctuating patterns of decline and recovery were among the earliest criticisms raised, including by geriatricians, but these were unfortunately ignored [389]. ICPs were also criticised for focussing just on disease management and ignoring the patient. Pinder et al. suggested that ICPs 'abstract the patient and reify the condition' and 'omit the plasticity of patients' personal circumstances and lived experience'[450]. Dr Katherine Sleeman writing in the BMJ echoed this sentiment about the use of the LCP in the palliative care setting [41]. This focus on the pathway rather than the patient was certainly also reflected the findings of Baroness Neuberger's Review [39].

At a system wide level, despite the 2008 national recommendation [30], there was no process to audit or identify problems of implementation early during the national roll out and to check that a tool used in specialist palliative care would be safe when used by generalists.

Importantly, when the alarm was raised by doctors, there was a failure to listen to concerns and to investigate them. Indeed the doctors raising initial concerns were dismissed as religious cranks with a pro-life agenda. The national newspapers picked up the professional concerns and public concerns. The first national story was published by the Daily Telegraph in 2009 and between 2010 and 2012 National Newspapers of all intellectual levels and with both left and right-wing readerships published stories [36]. Even in the face of mounting public and media concern, the specialist palliative care profession closed ranks and continued to promote the benefits of the LCP and failed to meet the mounting criticism with an open mind [36]. Perhaps if the national leaders of P&EOLC had responded quickly, and in a transparent fashion investigated the public's criticisms and concerns, the LCP might still be in use.

Finally, another policy initiative, payment of financial incentives which are used to encourage adoption of good medical practice, was adopted uncritically to encourage the use of the LCP. There was insufficient thought given to the potential perverse incentives which could be associated with financial payments to implement the LCP and potential public reaction to this [447]. At the time of the LCP and indeed still today, the Department of Health and Social Care and now NHS England have used financial incentives to encourage good medical practice under a system called 'Commissioning for Quality and Innovation' (CQUIN) [447]. The CQUIN associated with the LCP encouraged hospitals to put dying patients on the LCP.

The Department of Health and Social Care used the CQUIN framework to enable commissioners of health services to reward excellence by linking a very small proportion of the provider (hospital) income (0.5% of total contract value in 2009/100 conditional on achievement of locally agreed goals in quality improvement and innovation). CQUIN targets were set for 2011/2012 for the End of Life Care Program. It was intended that the number of patients identified to be on the end of life care pathway should increase gradually to 30% of all patients who die in hospital. After several years, the date had not been specified, hospitals would be expected to reach this target to receive payment [36].

Some hospitals, such as the internationally renowned Brompton Hospital in London, made the targets very ambitious such as: 95% of patients identified as end of life (last 48 hours) for expected deaths are offered a P&EOL care planning discussion, 80% of those offered a discussion have a plan, 98% who have an Advanced Care Plan (ACP) should have a record of a resuscitation decision stated clearly in the notes, 50% of patient who die in hospital (expected deaths) should die on the LCP. Looking at these ambitions with a knowledge of the statistics of the characteristics of patients who die in hospital, I would be skeptical that these targets could be achieve as not all patients identified as dying will have mental capacity so ensuring 95% are offered an end of life discussion would seem impossible especially if mental capacity was to be assessed properly to make these all important decisions. Even if families were having the discussions not all patients have families to participate. Of course the Brompton is a specialist hospital dealing with heart and lung diseases and cancer and so there patient group is different to the end of the population. Even so achieving 95% discussion rate amongst patients likely to die within 48 hours suggests that perhaps patient autonomy is being ridden over roughshod. Similarly, achieving 98% of those who have an ACP also have a resuscitation decision seems only possible with a paternalist steer from doctors to persuade patients to have a Do Not Attempt Resuscitation (DNAR) order. When completing Advance Directives to Refuse Treatment (ADRT), such as DNAR orders, palliative/ EOLC patients are presented with a description that Cardiopulmonary Resuscitation (CPR) is very unlikely to succeed, accompanied by a description of the brutality of the procedure: broken ribs, intubation etc. which results in patients who know they are dying rapidly acquiescing to a DNAR order being written in their notes [153, 341, 451].

The national media found both abhorrent and sensational the idea of payment to implement a pathway about which there were already concerns about premature deaths. In 2012, a national newspaper, the Daily Telegraph, published an article with the headline ‘ Hospitals paid millions to put patients on death pathway' and reported that half of all NHS hospitals had received, or were due to receive, financial awards for demonstrating use of the pathway [42]. The Telegraph suggested this was evidence of undue financial and bureaucratic influence on individual doctors’ practice. However, when doctors’ were surveyed about whether they thought that the LCP was used to ‘save money’ almost 60% s said that although they were not in favour of financial incentive being paid to hospitals for adoption of the LCP, 98% did not think that these financial incentives for the hospital influenced decisions by front line doctors to use the LCP [36]. CQUINS payments to hospitals for palliative care were officially ceased in 2014.

These failures not only led to unintended consequences and patients being harmed, but official abandonment of the LCP as a tool to improve the care of dying patients. Many doctors had found the LCP to be a useful tool to guide P&EOLC for terminal patients [452]. This was a classic situation of ‘throwing the baby out with the bath water’. If senior officials had responded earlier to concerns and investigated them, the LCP perhaps could have been improved for hospital use with additional safeguards, perhaps rebranded and still used to benefit dying patients. There was debate in the medical literature about the merits and risks of the LCP including titles such as the ‘The LCP villain or scapegoat’ as it was clear that there were elements which could improve patient care [40, 41, 453-455].

Indeed, the LCP Review Panel acknowledged the positive outcomes from use of the LCP as well as the negative. The report stated that ‘from the evidence received that: …where the LCP is used properly patients die a peaceful and dignified death’. However, the review panel also acknowledge the numerous examples of poor care [39].

Currow and Abernethy in a 2014 Lancet editorial were ferocious in their assessment ‘…the LCP was taken up by bureaucrats who did not understand the implications of widespread implementation of an initiative for which the net effects were poorly defined’. They also suggested that ‘a government, when introducing such initiatives, should properly assess them in rigorous trials of health services, preferably randomised; if this cannot be achieved then a formal prospective assessment of new interventions as they are implemented must be the minimum standard' [445].

6.5.2. Ongoing concerns

Key issues have emerged in the wake of the LCP problems about caution and considerations in the implementation of new policy initiatives in end of life care, especially about the primum non nocere principle. It is also clear that despite palliative care specialists being in general opposed to euthanasia and the LCP definitely not proposing this, that pro-life, anti-euthanasia groups through exploitation of media and public anxieties clearly impacted on the reputation of the LCP.

The fears of the general public about doctors' use of opiates to hasten death and withdrawal and withholding of hydration and nutrition have surfaced again following the publication of the Gosport Memorial Hospital Inquiry albeit it was looking at historical clinical practice [408, 430]. Interestingly, at the same time as the LCP was being actively promoted for use across the country, other 'tools' were recommended by the End of Life Care Programme for example the Gold Standards Framework (to improve end of life care in primary care) [144]. These have not come under the same level of scrutiny or criticism as the LCP.

6.6. The 1% Campaign

6.6.1. Introduction

The aim of the 1% Campaign was to encourage General Practitioners (GPs) (family doctors) to identify the 1% of the patients on their list who they thought might not live longer than a year and to try to engage the patients in Advance Care Planning (ACP). The 1% Campaign was launched with letters sent to all general practices [140]. The 1% was based on the fact that on average 1% of the population die each year [11]. GPs were encouraged to go through their practice lists and identify potential patients to be approached. Having gained the patient's consent (not always the case) the patient is flagged on the GPs practice electronic database and sometimes on a local area Electronic Palliative System [157]. Both systems allow extra observations to be recorded such as patients' preferences for place of care and death and ADRT and /or DNAR orders. The former can only be viewed by other GPS in the practice, the latter by health professionals across the local area including Ambulance crews and the local hospital [157]. The Campaign is advertised on the Dying Matters Website ‘Find Your 1%: supporting GPs in delivering quality end of life care’ [140].

There are a number of potential problems with the 1% Campaign. Firstly, this is unsound messaging from a statistical point of view as the proportion of people who die, while 1% for England as a whole, varies by local administration between 0.44 % in Haringey and 1.44% in Rother depending on the age distribution and other characteristics of the population [11]. Secondly, this is unsound messaging from a clinical point of view as none of the tools proposed for identifying patients who may die in the next year have been sufficiently well evaluated nor has the programme as a whole which is being implemented rather like a screening programme. It is very difficult to predict with any precision at all except for terminally ill cancer patients, which patients will die in the next year [153]. In the section after next, I describe a critical analysis of this. Finally, there are significant risks of unintended harm with this Campaign. If GPs, with lack of training or insensitivity, broach the subject of dying with the frail elderly who are surprised by their doctor wanting to discuss their future death rather than how they can control their diseases and symptoms this could cause significant mistrust. I know of one case where the patient refused to be seen by the GP again and her husband a retired doctor was furious about the impropriety of an unsolicited conversation to tell the patient that in the doctor’s opinion she might be dead within a year so would she like to start planning for death (Personal Communication Prof Andrzej Zbrozyna). Similar results of loss of Trust have been reported in the literature [286]. GPs have often been too direct in starting conversations without first trying to ascertain whether the patient wanted to discuss their future risk of dying which not all patients do (ref patient not wanting to discuss ACP). Moreover, if choice of place of care or death is encouraged and cannot be fulfilled this causes distress to patient and family [329].

Despite the outrage of the financial incentives linked to use of the LCP, financial incentives are still used to promote P&EOLC activities in primary care. This is paid primarily through the Primary Care Quality and Outcomes Framework (QOF) [456].

Until recently, among 29 QOF indicators for use in primary care, covering also other health issues such as asthma and diabetes, there were several which were directly or indirectly related to end of life care and could be used to gain points towards financial payments. A

Gold Standards Document, published in 2006, described how GPs could maximise their QOF points and therefore their payments. It was suggested that ‘This is an opportunity to be rewarded for some of the work you are already doing’ [457].

As with almost every indicator especially linked to payments this could attract perverse incentives [458] for example, to increase the number of people dying in their preferred place of care GPs could make sure that large numbers of elderly people living in care homes and at home complete advance care directives stating this is their preferred place of death (which might be true or encouraged) and then not admit them to hospital if they deteriorate but are not definitely dying. They would then die in their preferred place of residence. While it is unlikely that most doctors would deliberately do this, their judgement could be inadvertently coloured by an overzealous emphasis on dying in place of choice as compared with carefully assessing the patient’s needs to identify those who could and want to benefit from hospital care.

The Gold Standard Framework (GSF) which aimed to improve end of life care in the community through training of staff and encouraging use of ACPs had a target that ADs should be in place for all care home residents where their programme was adopted. This again raises concerns about paternalism overriding patient autonomy. I personally vociferously challenged this on the basis of 100% compliance cannot represent patient autonomy only to be countered by a challenge that I did not care about good quality of death for elderly people. This was characteristic of the fundamentalist zeal of many of the main proponents of the 1% Campaign and earlier of the LCP.

6.6.2. Are there ethical differences between offering a patient an unsolicited prognosis and giving them a prognosis when discussing the results of investigations or if they spontaneously ask for one?

Traditionally doctors have been considered to have two principle roles: diagnosis and cure of their patients. However, there are two other key roles that doctors perform: giving a prognosis and providing care when cure is not possible [403]. Many years ago, and still in some parts of the world, diagnoses were made and cures or care offered without telling the patient of their diagnosis or prognosis. Now, at least in England, the NHS Constitution and the GMC Guidance strongly recommend giving patient full information so they can participate in decision making [79, 156].

The interaction between the patient and doctor is important. Traditionally, the patient developed signs or symptoms and consulted the doctor to seek a diagnosis. It is implicit in this interaction that the patient wants to know what is wrong with them, although in reality they may not have thought through the consequences of what they will do with this knowledge [459]. The doctor has the obligation to use her skills or knowledge, and today the skills and knowledge of others and technology, to make the diagnosis [460]. Even in today's technologically driven world not every cluster of symptoms can be precisely diagnosed. So even in diagnosis there is sometimes uncertainty which should be communicated to the patient [79]. The doctor then has to provide a cure or treatment to try to prevent progression of the disease and this should be evidence based [460]. Indeed, today, while cures do exist much of medicine is devoted to the management of chronic disease rather than cure [461]. This fits well with the telos of medicine as saving and prolonging life and with Article 2 of the HRA 1998 – a duty to protect life [45]. For many simple diagnostic procedures, blood tests, x-rays even CT Scans, in England, there is no written consent process, so the patient's consent to have the test is assumed because the patient has accepted the doctor's recommendation. Written consent is used in interventional radiology or biopsies or other diagnostic operations because of the potential risks involved. What is less clear is whether the doctor is under obligation to provide a diagnosis [462]. This is assumed by the doctor, however, at the time of sending the patient for tests, doctors do not usually ask them whether they are sure that they want to know the result [462].

Of course once a diagnosis is made the question arises about communicating not only the diagnosis but a prognosis. It is clear that the doctor will convey the diagnosis. What about the prognosis? Is this something the patient asks for on hearing the diagnosis or the doctor gives unsolicited? For the doctor it is simple if the prognosis is good and they will probably volunteer this to encourage the patient. If the prognosis is poor, then how should the doctor communicate this [462]? We are familiar with the situation where the patient asks at the time of a serious diagnosis 'well doctor how long will I live?' The patient may also ask what the chances are of their condition being cured. Prognosis may appear to go hand in hand with diagnosis but it has different meanings and challenges. Firstly for the patient they may be thrust into confronting mortality and secondly for the doctor there are issues of uncertainty, and it is this uncertainty that should be conveyed especially when talking about risk of death [79]. Doctors working in specialties with high patient mortality for example hepatology (liver disease) are used to calculating prognostic indicators for consideration for transplantation or entry into clinical trials and then turning their attention to the patient in front of them, knowing that the patient may confound the poor results of prognostic tool and live longer than predicted or have a sudden complication and die earlier [81]. As will be seen elsewhere in the thesis, there is plenty of evidence that doctors do not like talking about death both because of the uncertainty of prognosis outside the terminal phase and also because it feels like accepting failure and they are afraid the patient may lose trust in them [286].

6.6.3. How does the 1% Campaign match up to the ethical criteria for screening programmes?

This section explores whether there are ethical differences between the traditional way of practicing medicine and the current policy initiative in England (1% Campaign) encouraging doctors to try to pro-actively identify patients in the last year of life, encourage them to think about ACP and put them on special registers. As described above in the section on the LCP, there have been QOF payments associated with the 1% Campaign. GPs received payment for having an End of Life Care Register and holding multi-disciplinary review meetings for the patients on this register [457]. GPs also receive payments, under QOF, for many other services such cancer screening or undertaking annual reviews of patients with asthma and diabetes. The P&EOLC QOF payment carried less risk that the LCP CQUIN because it was not attached to a specific P& intervention apart from putting patients on an EOL Register. This carries the risk of discussing death and ACP with patients who do not wish to. P&EOLC has a special status whereby patients' care should to tailored to their individual needs unlike some other conditions where practice should primarily adhere to evidence based guidelines [450].

In this section, I will compare and contrast the ethical dimensions of the 1% campaign with public health campaigns for example cancer screening programmes or health promotion campaigns and also with the normal practice of medicine in patient-doctor consultations. Although no national policy makers have called the 1% Campaign a screening programme, from my public health perspective it is being implemented like one, except without the rigorous evaluation which is required by the National Screening Committee before implementation of new programmes [463]. Table 6.1 below summarises an critical evaluation of features of the 1% Campaign, as if it were a screening programme, against the modified

Wilson and Jungner WHO Criteria for evaluating the suitability of a new screening programme [434].

Table 6.1. Evaluation of the 1% Campaign against the modified Wilson and Jungner 1968 WHO Criteria for introducing a screening programme [434]

Criteria	Evaluation
The condition is an important public health problem. There are large numbers of people are affected by it.	Around half a million people die each year in England and the number is rising [11]. This is a large health issue in terms of quality of life and a large health and social care service issue in terms of complexity and cost of provision. It has been estimated that at least one third of NHS costs are spent in the last year of life A further, approximately 2 million family members are affected by deaths per year [11].
The natural history is well understood.	Prognosis for cancer patients when they enter the terminal phase is quite well understood. The end of life trajectory for elderly patients is poorly understood and prognostication is difficult. There is often a prolonged terminal decline punctuated by acute exacerbations [419].
Intervention should be more efficacious when applied to screen detected disease than when applied to the stages of disease with which patients usually present. (Earlier diagnosis produces better outcomes than late ones).	Several studies suggest that earlier Advance Care Planning leads to better patient and family outcomes [149] and cost savings to health services [464, 465].

Table 6.1. continued. Evaluation of the 1% Campaign against the modified Wilson and Jungner 1968 WHO Criteria for introducing a screening programme [434]

Criteria	**Evaluation**
The risks of physical or psychological harm from the screening programme should be less than the benefits.	This element of the 1% Campaign has not been evaluated. There is very little data on harm related specifically to the Campaign although throughout this thesis I demonstrate the potential for harm, firstly in forcing discussion of death in those who are unwilling and also the harm for patients and relatives if choices cannot be fulfilled. Moreover, the benefits which are measured are largely limited to fulfilment of patient's place of care and death. There is little information on impact on quality of care, although we know from VOICES that pain control is less good at home [258]. Also there are a range of potential existentialist, spiritual and moral benefits which are currently not even under consideration as outcomes, which are discussed in the Chapter 3.
The methods of screening and intervention must be acceptable to patients and clinicians.	There is no information specifically related to the 1 % Campaign, however, there is lots of evidence that doctors do not like and do not feel comfortable or adequately trained to discuss death especially when this is not immediately clinically indicated [60, 286, 351]. There is no formal evaluation of patients' views either but there is anecdotal information that patients and families can be upset by the unexpected discussion of death and planning for it (Prof Zbrozyna personal communication) [286].

Table 6.1. continued. Evaluation of the 1% Campaign against the modified Wilson and Jungner 1968 WHO Criteria for introducing a screening programme [434]

Criteria	Evaluation
There is a good screening test.	There have been a number of small studies using prognostic tools. There has been no largescale evaluation of any of them with the rigour required for a national initiative [466]. In this 1% Campaign doctors just use their clinical judgement.
There should be sufficient resources to meet the increased demand which may be generated by screening without diverting them from perhaps more important aspects of care.	This criterium makes an important ethical point that programmes should not create expectations and need for services which cannot be fulfilled. So it is important that when a screening programme is established the services to manage to cases detected is adequate and moreover there should not be delays for the patients in accessing them [434]. Moreover, there is always a need at a population level to balance investment across many areas of health and social care. In the specific case of end of life care, I have demonstrated throughout this thesis that the quality and quantity of end of life care services for the elderly approaching the end of life across in England are variable [11]. Moreover, asking patients their wishes may create more demand for hospice services which cannot be fulfilled. There is moderately good evidence that good quality community services will save money compared to hospital costs so if investment were to be shifted this would be good use of health resources if quality of care, especially symptom control can be as good [465]. At present, reducing the wide variations in availability and quality of end of life care should be prioritised over promoting expectations of choice which cannot be guaranteed [33, 142].

Public Health practitioners are always looking for better ways of preventing disease or detecting it earlier than if a patient presents symptomatically. Many countries have national cancer screening programmes and there is a large ethics literature on the different obligations associated with inviting people who believe themselves to be healthy to undergo a screening test which is less than perfect compared with patients presenting symptomatically [434]. Most screening tests are not diagnostic tests therefore they have both false negative (e.g. fail to detect the cancer) and false positive results (e.g. a positive screening test result but no cancer). The ethics literature makes it very clear that people being invited for screening should have this explained to them so that they can give informed consent [467] and should not have undue pressure exerted to comply or other healthcare choices limited by not complying [350]. However, other obligations include having good services to manage the patients whose disease is detected by screening [434].

There are also programmes to identify people with risk factors for disease for example smokers, people drinking heavily, or obese people to give them advice on life-style changes, these too carry warnings about this libertarian paternalistic approach [350]. The consent issues about this are less clear than in screening as doctors may ask questions or just use their observation and make recommendations which are unsolicited by the patient [435, 438].

The National End of Life Care Strategy has introduced a completely new concept to the practice of medicine in the 1% Campaign – encouraging doctors to seeking out patients who in the doctor’s opinion are likely to die within a year and starting a conversation with them [140]. Some doctors are using prognostic tools as ‘screening’ tests to identify patients likely to die within a year. These range from the unscientific ‘surprise question’ which is would you, the doctor, be surprised if this patient was dead within a year, if not then you should consider discussing ACP with the patient [140, 468] to algorithms using data about the patient. The algorithms to predict prognosis are based on co-morbidity and functional status [466]. The former could be called the ‘eyeball test’, look at the patient and make a judgement. These ‘you are likely to die within the next year’ screening tools have not been subject to the rigorous demands of the evidence based practice found in screening where large pilot studies followed by randomised trials are the gold standard . There also has been no ethical framework, until the work in this thesis, to assess the soundness of the concept. The ‘screening tools’ and the 1% Campaign are being introduced by specialist palliative care enthusiasts who influence national policy just as the LCP was.

There is very little data on the:

- sensitivity (ability to detect those who will die in the next year);
- specificity (ability to detect those who do not die in the next year);
- positive predictive value (of those with a positive result what proportion would actually die within the next year).

At the NEoLCIN, we have developed crude indicator to assess the extent to which GPs are using this form of 'screening' which is the 'Variation in the ratio of GPs' use of palliative care/support registers to the number of all deaths (x 100) by Clinical Commissioning Group (CCG)' [11]. We have found that this varies by CCG (health administrative district) between 13-115%. In the majority of areas the ratio is very low only 12 (6%) of CCGs have above 75% whereas 90 (43%) have 33% or lower. The area with 115% has a higher number of patients on the register than the number that died in that year. In GP practices in London the indicator varies from 0.02 to 0.85 %. So for every 100 patients who die in London less than one person will be on a GP practice register. This indicates extremely low use of the GP registers in London [11]. Perhaps, this demonstrates that attempts to persuade GPs to identify those patients likely to die within a year have not worked and they feel reluctant to implement the initiative.

Up to this point the telos of medicine was largely based on hopes of curing or controlling disease, peppered with some conversations like 'if you don't stop smoking this will/may happen, or if you don't control your diabetes better you will end of blind or with your feet being amputated' or obesity will kill you [435, 438, 444]. It was based more on a partnership between doctor and patient through which the doctor was encouraging the patient to take control. Moreover, these warnings were laced with hope that, if the patient did as they were advised, they could stave off some evil like a premature death. However, in the 1% Campaign patients are being advised that the evil i.e. death cannot be staved off and they should simply prepare for it [140, 468].

The proponents of the 1% campaign could suggest a similarity to cancer screening programmes based on the idea that earlier diagnosis of an end of life phase for the patient, may have a better outcome, in terms of a better death and better outcomes for relatives too if the death is 'good' because it was planned for and health and social services were delivered as well as patient choice. Indeed, as described above, there is some evidence, from small studies, to support this but no randomised controlled trials [94, 347, 348, 464].

The 1% Campaign purpose is to give patients control by informing they may die soon, even if they were not contemplating this, and offering them advice on how to make and record choices [140]. There is no discussion in the Campaign material of other potential benefits like the patient changing their perspective on life when faced with death. Others would argue that this is very different from other unsolicited approaches for prevention and screening as these are all aimed at prolonging patients' lives and the 1% campaign is not. However, it is true that some patients, for example in cancer screening, will be detected with advanced symptomatic cancer and given not only an unexpected diagnosis but poor prognosis too as well as needing to undergo life changing surgery which impacts on their identity [469].

Prognosis outside the field of terminal cancer is notoriously difficult. It therefore could seem unethical to suggest to someone they may die within the next year if the prognostic testing at an individual level is poor [468].

A few methods are currently being trialled in England particularly for the identification of elderly patients approaching the end of life: Supportive and Palliative Care Indicators Tool (SPICT ^{TM}) and Gold Standards Framework (GSF) [144, 466, 470, 471]. There are some encouraging results from a study in Airedale in the North of England which uses a combination of GSF and SPICT tools to identify patients approaching the end of life in General Practice, place them on a register and offer them ACP and a 'Gold Line' single point of access telephone system for palliative care advice in and out of hours. This system achieved a 23% reduction in emergency admissions to hospital compared to baseline ($p<0.0001$). In terms of predictability 15% were on Gold Line for more than 12 months 4% were on the Gold Line for more than 24 months. In other words 85% of the patients registered for the Gold Line did die within a year and 96% within two years (Professor Bee Wee personal communication). Co-ordinate my care is an electronic patient record sharing system across London for patients to record their ACP which is then available to GPs, the Ambulance Service and Hospitals. An analysis of recent registrations revealed that 80% of patients had documented CPR decisions, 65% have treatment plans with documented ceilings - ADRTs. In terms of outcomes, 78% of patient died in their preferred place and there were fewer deaths in hospital: 19% versus a national average of 47%. However, these are selected patients and the denominator from which they were selected is not known (Professor Bee Wee personal communication).

Researchers are looking at the potential for using artificial intelligence to analyse patients' data in General Practice to identify elderly people who may have P&EOLC needs [472]. This will require ethical consideration if it moves into wide scale application.

The results of some of these studies look positive in terms of the usefulness of tools to identify patients who might be in the last year of life and enable them to exert their autonomy through ACP, if the most important outcomes are place of death and reduced hospital admissions. Of course these are measureable from routine data sources. The challenge is that data on others outcomes, which are important to the patient, such as being treated with dignity are not routinely collected. Moreover, none of these studies collect data on the patients who are upset by the process or who refuse to participate [473, 474]. How will we know if patients are delighted to be given this opportunity to face their forthcoming death early and whether they accrue benefits from this or whether harm is being caused. There are no mechanisms in place to monitor the effects on the patients. Of course there may also be a range of other benefits to patients, the first giving them improved access to palliative care [474]. There may be indirect benefits for the patient, which are never normally discussed in medical practice, resulting from confronting death, such as reappraisal of values, priorities, freedom to live even for a limited period. These potential benefits are discussed in more detail in Chapter 3.

In summary, the 1% Campaign is being implemented like a national screening program. However, in many aspects it lacks rigorous evaluation and there is good reason to believe that there are risks of harm as well as benefit but the balance between these is far from clear with no current plans to evaluate it. The 1% Campaign, is another example, like the LCP, of doctors perhaps uncritically adopting a new initiative designed with good intentions to improve P&EOLC, and which probably does have some good effects, but in practice, by implementing in an unthinking way may cause harm.

6.7. The Choice Agenda: disappointment, anger and guilt - the potential adverse consequences of raising false expectations

6.7.1. The risks of harm

The word choice has appeared frequently in National P&EOLC strategy with a strong association with an emphasis on home deaths [30, 33, 120, 142, 154]. National and local monitoring focuses on changes in and variations in place of death, especially through the national Key Performance Indicator (Death in Usual Place of Residence) [11].

However, as already seen, policy intended to do good can also cause harm. The concept of Choice, in P&EOLC policy in England, is used as a shorthand and proxy for autonomy but leads to a focus on place of care and death not the myriad of other things which are important to patients. In 2016, I had an abstract published as conference proceedings of the European Association of Palliative Care entitled ‘The ‘Choice Funnel’ of Life - Starts Wide but Ends up Narrow: Easy Conclusions from Big Numbers [283]. I will describe some of its findings here.

An inadvertent consequence of the emphasis on choice at the end of life, is that the patient may suffer great distress if their choices cannot be realised including disappointment and anger [59, 154, 283, 475]. Family carers and health professionals can also experience these emotions and family carers can also suffer long term high levels of guilt, depression and stress comparable with post-traumatic stress disorder. I explored this in an abstract accepted for presentation at the EAPC 2015 entitled “Linguistics and the burden of ‘guilt’ in bereaved relatives” and I also give a teaching session on the topic for the MSc in Palliative Care at King’s College London [301].

The reasons for unfulfilled choice include:

- Variability in levels of provision and preparedness of health services staff to recognise and provide end of life care to elderly patients especially in the community [11].
- Challenges of delivering adequate and safe services at home especially if the elderly patient lives alone with no family nearby to help [147, 190, 214, 476].
- Resource limitations [477, 458].
- Real practical difficulties in delivering choice at the end of life for example when a patient’s condition is deteriorating rapidly or unpredictably [62, 213].

Indeed, empirical research shows that choice changes and becomes constrained as death approaches [153]. Moreover, the VOICES survey of Bereaved Relatives showed that in the final assessment of P&EOLC, choice of place of death becomes far less important than quality of care received. The survey found that 74% of bereaved relatives they felt that hospital was the right place for their loved one to have died, despite only 3% saying that patients had wanted to die in hospital [258]. This clearly demonstrates firstly that there are significant medical challenges in fulfilling choices because the patient's medical condition may deteriorate or families may be unable to cope with providing care at home. In the end, hospital may be the correct place because professional medical care is available around the clock (24 hours). Elderly people also clearly express the desire not to burden family members and are aware of the practical and moral consequences of insisting on a home death so may wish to avoid this to spare their loved ones by accepting admission to hospital [113, 152].

Perhaps the worst example of giving a false impression of choice to elderly patients arises from the injustice of the mismatch of elderly patients' desire to die in hospices (41%) compared with only 3% of people aged 75 years who do so. Indeed, people aged 75 years and older at death are the least likely group in the population to die in a hospice. Among younger age groups between 9-11% die in a hospice [160]. The gap between preferences and actual place of death is widest for the 75 year olds and older wishing to die in a hospice than for any permutation of age group and preference for place of death [160]. This occurs because hospice policies give priority to young cancer patients and others with a more predictable terminal phase than the elderly. Indeed even of the patients aged 75 years and older who die in a hospice, 92% die from cancer. The CQC also highlighted these injustices [478]. The lack of transparency is iniquitous and could be exacerbated by Hospice UK running the Dying Matters Campaign as it will reinforce the public's view of Hospices as being the majority providers of end of life care, whereas they are in fact the minority or organisations who provide care for the dying.

The VOICES survey of bereaved relatives has also shown that pain is less likely to be fully controlled at home than in other locations (hospice, hospital care home) [258]. Which means promoting home as the best place to die may be depriving patients of better symptom control elsewhere.

The specialist palliative care movement's attempt to change the zeitgeist to one in which home is seen as the ideal place of death might disenfranchise and actually harm elderly patients who do not want this and cannot achieve it or who are left suffering as a result of inadequate P&EOLC at home [95, 119, 147]. Failing to understand the views of elderly patients could lead to them being even more marginalised from societal norms even in death [147].

Not all health professionals working in the field are uncritically supportive of the choice agenda. Research commissioned by my team from the University of the West of England to test the views of Opinion Leader in End of Life Care found more measured views (Professor Alan Tapp, personal communication, manuscript in preparation).

Some professionals believed that the word choice had become politicised as a neo-liberal policy that assumed a consumerism paradigm would work in the field of dying and death:

'Is it a neoliberal approach? A political diversion? Autonomy? Choice, choice, choice – that's all that's important – me, the individual, I must choose everything?' (*Health professional)*

As suggested above, there were concerns about the 'choice policy' that false choices were being offered in the context of scarce resources and funding cuts. They felt that the choice agenda was simply a smokescreen because the state could not in reality afford to honour these choices.

'The underlying assumption in public service is that choice leads to control and more control leads to better quality and better quality leads to better outcomes. That's kind of the logic of the argument and I think it is deeply problematic in the context of end of life care, because the concept of choice implies choosing between something.' (Clinician)

Other, considered choices unnecessary. In the workshop one participant argued that choices did not need to be created because most people in fact wanted similar things at the end of their lives:

'*[To be] pain free; having your conditions managed; surrounded by your loved ones; dignity; being in familiar surroundings (not specifically a particular location); being calm and peaceful.' (Academic specialist)*

Furthermore, the choice agenda was seen as ethically problematic if choices are offered that cannot be delivered upon*:*

'Are we falsely raising expectations about what can be achieved, and some of it can't be achieved? If we prompt somebody that they can die at home and we can't achieve it, sometimes that leaves the family with incredible feelings of guilt.' (Health professional)

It was also suggested there was the possibility that offering choices may be confusing:

'I think, personally, that choice is possibly the wrong word in the context of End of Life Care (EoLC), ...I don't think anyone has started from the place that this is about a binary choice of location or choosing different options. Actually what underlies it, I think in the context of EoLC, is the concept of control and preference. I know it's a slightly hackneyed comparison, but if we look at the analogy of birth and birth plans, for example, it's pretty well understood that's an opportunity to express preferences..[ ]... this idea that it's about expressing preferences, expressing wishes... I think the harsh word of 'choice' is unhelpful.' (Care sector professional)

There was another view that there has been political use of 'choice' as a cover-up to avoid the need to offer universal high quality care:

'Choice, I think is driven politically in particular and within end of life, I suppose people are short-cutting what that means. ... Choice, where do I want to die? – that's the shortcut that people see, not even where they want to be cared for, but right to that very end point. So it does seem to simplify what's actually a really complex set of things. I'm not particularly comfortable with the Choice Agenda as it's set out ... most people would say, I think, that they want high quality of care.' (NHS professional)

In multicultural England there was also concern that market ideology of consumer choice was at odds with a religious perspective on end of life:

'*X has indicated in a way where the choice agenda is coming from in terms of individuals choosing in neoliberal terms ideally from a market, but there have been many, many millions of humans on this planet who have seen dying in a very, very different way, primarily as a spiritual transition. I know some research that shows a number of religions may not be so comfortable with a choice and control agenda because they feel that dying is essentially in God's hands. ...I just want to flag up the question, whether this kind of neo-liberal, white, secular, post-Protestant agenda is actually not fully respecting a part of the society that we're in.'* (*Public health end of life expert)*

Palliative care specialists who were trained and experienced in advising patients about end of life care considered that guiding patients in their choices was an important part of their job. However, they had insight that there are potential problems. One clinician raised the example of the choice to die at home, and warned of the moral dilemmas that campaigns to encourage dying at home would create: the apparently natural wish to die at home may be at odds with the worry of being a burden to one's relatives, or the sense that relatives can't cope and the guilt associated with this, both of which have been reported [113, 301]. Another concern was that giving the impression that dying at home is morally a 'good thing', or the norm, may be very dangerous because quality of care might be less good at home as described above for pain relief [258]. Clinicians therefore felt they needed to guide discussions carefully and that the 'choice agenda' was best operationalised in the context of complex discussions about *preferences* led by a clinician, rather than being presented as a set of 'consumer choices' with people being left to make these on their own.

'For people who get older it's not about choice, it's about care (NHS, care home, wherever). We don't want to make choices, we want to know that all the local care homes are good. You don't want to make choices at that stage in life, you just want to be looked after.' (Academic Specialist in end of life studies)

In other recent work we have conducted on population views on volunteering to help elderly people at the end of life and receiving volunteer help, we have found that in general older people, recognise that when they will actually need help they will have to be grateful for any type of help they can get [479].

The comments fell into three groups:

- Elderly people would have no other choice than except the help of stranger volunteers if there was inadequate help from health and social care or from their own social network.
- The alternatives of not having such help do not look good.
- So, under these circumstances, the elderly people would be grateful and appreciative.

An illustrative quote was *"I don't think you get much choice do you. I mean what's going to happen otherwise! You could live in a mire or something in the end" (Male, 73, Suburban South West).*

This illustrates that elderly people understand that choice may not be the most important issue when they need and want to be cared for [479].

6.7.2. Current status of the Choice Agenda

In the development of the most recent policy documents, there has been clear recognition that unbounded choice, especially with respect to place of death, is not realistic largely because P&EOLC services are not uniformly of the same standard across England so choices cannot be guaranteed [11, 33, 62, 154, 258, 283]. In addition, there is concern that home/care home as a place of death is not suitable for all patients and national focus on this will cause the problems outlined above. The current national policy described in the Ambitions Framework is more circumspect [33]. In practice, change is being slowly translated into less rhetoric about choice at a national policy level. However, the idea of choice in P&EOLC had been so successfully communicated over the past few years that the word ‘choice’ is still widely used on the front line in the context of P&EOLC. There is still little recognition or quantification at a national level, of the adverse impact on patients and their families if it cannot be delivered [283, 329]. It is hoped that the more measured approach taken in the Ambitions Framework will help to reduce the adverse effects of an unrealistic focus of choice. This change in rhetoric will have to be matched in population based campaigns and one to one doctor-patient conversations.

A switch in emphasis from the national KPI monitoring place of death to the Clinical Commissioning Group Improvement Assessment Framework, new indicator on three or more admissions in the last 90 days of life should help [11]. This is described in more detail in the section below. The Care Act Guidance 2016, which focuses on social care provision, takes a more balanced approach placing a lot of importance on assessing needs of not just the person receiving care but also the family context and trying to prevent family members from themselves requiring care as a result of the burden of caring [48, 480].

6.8. The use of population data to drive improvements in P&EOLC for elderly patients at the end of life – risks and benefits

6.8.1. Introduction to the National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEOLCIN), which I set up in 2010 at the request of the National Clinical Director for Palliative and End of Life Care and mentioned in the 2008 National Strategy, is the main resource nationally for statistical analysis, reports and indicators, using routine data sources on end of life care [11, 75]. The NEOLCIN produces data and reports for national policy makers to inform policy development and monitor its impact on quality of care. The NEOLCIN also produces interactive data tools for use by local health service and local authority administrators and specially commissioned work for example an economic tool for end of life care, which recently won a prize as one of the best poster presentations at the European Association of Public Health Conference 2018 [465]. The team also produces specialist reports for example P&EOLC for Liver Disease [481], or P&EOLC in Care Homes [245].

However, as with almost every well intended action in P&EOLC there can be some risk of adverse effects. Place of death and variation in this by geodemographic and disease characteristics and trend over time can be easily measured and presented in sophisticated tools and reports. It is for this reason that a National Key Performance Indicator (KPI) – death in usual place of residence (DIUPR) (home or care home) was devised and has been used since 2011 to monitor progress nationally and locally in promoting choice in P&EOLC [11].

However, measuring and monitoring place of death (because it is easy) can lead to an excessive focus on place of death and too heavy a reliance on this, as a proxy for quality of P&EOLC or choice. It can reinforce the zeitgeist of the policy of choice of place of death as being the key choice one should make. Even more potentially problematic, as described above, is the risk of reinforcing the idea of death at home as the desirable and optimal social norm, when this actually may not be practical for all patients, especially the elderly [17, 119, 160, 245]. Indeed, as described the quality of care at home, especially in terms of symptom relief may be poorer [258]. At present, levels of service provision in the community are inadequate to deliver care for all the terminally ill patients who wish to die as home especially as care will never be 24 hours per day.

However, there is a dilemma, one which I face every day. We can only measure things accurately at a national level and with geographic, socioeconomic and disease based breakdowns for which we have large, nationally representative data sets. The NEoLCIN uses national, Office for National Statistics (ONS) mortality data and national hospital activity data (Hospital Episode Statistics, HES) [75, 137]. We do not have routine sources of nationally representative data on what really matters to patient about for example quality of care. The VOICES survey of bereaved relatives provided the best insight into what really mattered to patients but has been temporarily halted [258].

6.8.2. Performance Indicators

Soon after establishment of the NEoLCIN we were asked to identify a range of potential performance indicators to monitor the progress of implementation of national policy.

The first was a Key Performance Indicator on place of death, as described above, because it was a major focus of national policy to enable patients to die in their place of choice. Initially we were asked to measure the variation by local health administrations and trends at national and local level in death at home. In 2010 we recognised that many older people died in care homes which at the time we assumed had become their normal place of residence. So the DIUPR indicator was created which is the proportion of all deaths which occur in a private homes or care homes. This has been used in national monitoring since 2011. Historic data has shown a significant increase in DIUPR [11] with corresponding reduction in hospital deaths and almost no change in deaths in hospices. The KPI has been useful to mobilise action at a local level, investigate inequalities and not just geographical variation by health administrative areas but also by population demographics and medical causes of death [137]. The downside of this KPI is that it reinforces the focus on place of death as the proxy for expression of autonomy over other factors, particularly which are important to elderly patients. The trends look very different for people under and over 75 years with reducing hospital deaths being matched by an increase in home deaths for the under 75 year olds but an increase in care home deaths in the 75 year and old group [11, 137]. Recent analysis also has shown that in fact a summary statistic on death in care homes included not only people who live there before death but also elderly patients who lived at home, were admitted to hospital and then discharged to a care home where they died [147, 243, 245]. Therefore we now split the DIUPR to home and care home deaths for monitoring and show a separate indicator which we have called ‘temporary care home resident’s to measure the numbers and trends in patients admitted to care homes shortly before death [75]. Death in a care home may or may not be an expression of autonomous choice for elderly patients and may actually be a necessity based on their frailty and intensive level care required. There is some indication from the VOICES survey that some aspects of care may be better than at home, for example pain relief [258]. However, we have shown that levels of specialist palliative care input to care homes are still very inadequate and that the input is primarily linked to training of care home staff rather than actual medical advice from specialists [246].

In 2011 we were asked to develop other indicators based on admissions to hospital at the end of life. A senior official wanted an indicator based on very short admissions resulting in death (0-3 days) with the aim of reducing these. I argued on clinical grounds that it would be unsafe to try to reduce these as, within the first 72 hours following an emergency admission, patients were being assessed and treated and it was not always clear that they were dying. Moreover, in this period, doctors were usually trying to save lives. I had little success with clinical arguments but then I demonstrated that these short admissions accounted for only 25% of all admissions ending in death and because they were short there was not much scope to reduce total numbers of days in hospital. Reducing these admissions would lead to very little economic savings. In contrast half of all patients who died in hospital did so after an admission of ≥8 days. These longer admissions gave more opportunity for proper assessment of the patient’s clinical state and wishes so there was time to plan a discharge, back to home or care home to die, if this is what the patient wanted. Improving the speed of discharge home, for patients who wanted it and where safe care could be provided, could lead to very substantial financial savings from the perspective of hospitals and probably overall. The economic argument won the day although the indicator was never introduced for monitoring. The indicator on the proportion of patients dying in hospital after a stay of eight or more days was reconsidered in 2017 to become a national indicator as there is evidence of unwarranted geographical variation. However, an indicator measuring three or more admissions in the last 90 days of life was selected in preference [11].

Around this time we also explored the use of a specific ‘z’ code in the national hospital record data base which represented palliative care consultations. Initially we thought this would be an excellent way of monitoring how much palliative care was going on in hospitals and we thought we would be able to undertake analyses, for example, on which groups of patients were benefiting from palliative care input and how it changed their care, including length of stay in hospital. We found that the z code was not widely used by hospitals because it was not associated with a financial payment in contrast to recording codes for surgical consults. However, when we graphed the data for every hospital in the country we found three with exceptionally high levels. The highest we discovered was the infamous Mid Staffordshire Hospital where large numbers of patients were dying of neglect [386]. For several years officials had been looking at the hospital mortality data concerned that it was very high. The hospital may have adopted the use of z codes vigorously because predicted deaths, seen by a palliative care specialist, could be excluded from the mortality analysis. This would have the effect of making the hospital mortality rate look less bad. Having been presented with the information that perhaps z codes were being misused and there was no other positive incentive for their use, for example, financial payment, officials abandoned the use of z codes as an idea for monitoring. This was a prime example of a perverse incentive for coding related to P&EOLC.

The most recent indicator my team has developed is three or more emergency admissions in the last 90 days of life. This varies by health administrative district from 2.9-12.6% [11]. Repeated emergency admissions for patients approaching the end of life, if they are a result of failures of care in the community and against the patients' wishes are undesirable [104, 105, 284]. Moreover, they can be very distressing and disorientating to elderly patients. Acute hospital wards are often not very peaceful places for elderly patients to die [61, 139, 365]. In London where the highest rates are seen there are high rates of elderly people living alone, and a shortage of care home beds which may be contributing to the high repeated emergency admissions [11]. Although this indicator is being adopted for monitoring I am very cognisant that it too could lead to perverse incentives for example patients being inappropriately kept at home or care home when they could have benefited from hospital admission. The adoption of this measure will have to be carefully monitored for its beneficial effects and to ensure no adverse effects.

6.9. The Dying Matters Campaign

6.9.1. A scientifically based start with evaluation of efficacy

A brief introduction to Dying Matters as a potentially beneficent, autonomy enhancing intervention by the state was given above. In this section, I explore whether there is potential for harm related to the Dying Matters Campaign. I will consider whether the (then) national policy makers were acting as libertarian paternalists with respect to this policy initiative using ‘nudge’ strategies [350, 482]. Recently there has been increased interest in governments using ‘nudge’ tactics to change human behaviour [482]. There has been particular interest in public health campaigns and also the clinical context [350]. The use of ‘nudge’ approaches have been justified with respect to the framework of libertarian paternalism which considers that it is legitimate to influence peoples’ choices if it increases their welfare but without limiting their freedom of choice [350]. Ironically, the aim of Dying Matters is to nudge people to choose to make choices about their P&EOLC [32, 138]. The libertarian aspect defends people’s right to choose which is the rationale of the ‘Dying Matters’ campaign. However, the paternalistic component argues that the direction in which peoples’ action should be nudged is to increase their welfare. The problem is that in many programmes the definition of welfare, in other words what is good for the person, is determined by the paternalists who are running the programmes and not by the subject’s ex ante preferences [350, 482]. The paternalist could argue that people, ex ante, do not know what will increase their welfare so they need to be nudged by the experts. The Dying Matters Campaign, designed by palliative care experts is based on the idea that people do not know it is a good idea to talk about death with family members and professionals and to make plans such as Advance Directives or appoint Legal Power of Attorneys, write wills or plan their funeral. The Dying Matters Campaign tries to educate people to do this.

Behaviour Change methods, like nudge, can use a number of methods to influence choice: incentivising or dis-incentivising, ‘default rules’, ‘framing’ the choice, and priming. Incentivising is obvious and a good example of this are privileges associated with organ donation in Israel [424]. ‘Default rules’ mean that people tend to follow set choices, and they have to make an effort to choose not to. An example are ‘opt out’ organ donation schemes where by default people become potential organ donors unless they actively refuse [422]. Framing is the presentation of information. There is evidence that providing information which emphasises what the normal choice is will increase the subject’s chance of choosing this option. An example of this is seatbelt wearing [360, 437]. Finally, priming occurs when the environment changes subtly or by enhancing cues to action, for example, building stairs next to lifts to encourage more use of the stairs [360].

During the major Dying Matters Campaign week, which is held in May every year, people are incentivised to make a will, by certain companies doing this for free. There is perhaps a hope that since the Campaign is run by Hospice UK that as people make use of the free will service that they will include a legacy to Hospice UK. Indeed on their website close to the campaign banner there is a bubble saying ‘Donate’. So potentially the paternalists are not completely disinterested providers of help and advice. The Dying Matters Campaign has been trying to frame discussion of death and dying and planning as a normal phenomenon [32]. It could be argued that priming is occurring through a number of other initiatives for example the 1% Campaign in which GP’s ask people whether they would like to consider Advance Care Planning [140].

An assessment carried out by Professor Alan Tapp of the University of the West of England found that the initial form of the Dying Matters Campaign as a social marketing campaign aiming to get members of the public to talk about death and dying had been based on sound social marketing research which consisted of finding out what the public thought and wanted of end of life care and what message they would find encouraging to help them discuss it. Early evaluation suggested that the Campaign was a success in getting people to talk about death and dying [138]. The Dying Matters evaluation cited early survey evidence that one of their key objectives had been achieved, in that since their inception 70% of the British public were now ‘comfortable talking about death’ compared to 13% who felt uncomfortable doing this [483].

However, Professor Tapp questioned the hypothesis that talking necessarily leads to behaviour change. Indeed, the British Social Attitudes Survey findings [483] suggested that there has been little progress in encouraging more of the public to make plans for end of life and indeed levels of Advance Care Plans (ACPs) lodged with GPs remain very low. Only four per cent reported having a living will or ACP in 2009 and five per cent in 2013. The reasons underpinning this are unclear but some insight, especially for elderly patients who seem not to want to plan [213, 235] has been provided in Chapter 3. Perhaps the early research was not focussed on the right things. If behavioural outcomes in terms of increased numbers of Advance Care Plans (ACPs) were intended, then the programme has not achieved this. This could be because of the narrow focus on influencing behaviours rather than on the Campaign’s ability to enable greater social good [484]. The lack of impact on ACPs may mean that Dying Matters did not adequately look at the structural causes (e.g. the macro-environment) that may prevent individuals and communities from behaving in a way that contributes to the greater social good [485] for example a more open approach to death and dying not knowing how to make ACPs, or costs.

From an ethics perspective, focusing on personal autonomy, there is a deeper philosophical question about the true voluntary nature of behavioural change that the campaign is trying to achieve. The classic definition of social marketing is *‘the application of commercial marketing technologies to [...] programs designed to influence the voluntary behaviour of target audiences in order to improve their personal welfare and that of society of which they are a part’* [486].

The campaign is clear in its objectives to get people to talk about dying and make plans for death and dying. However, marketing campaigns achieve behavior change by presentation of material and strategies designed to ‘create involuntary physiological and psychological responses that are beyond the control of the individual’ [487] and that “nudge” the individual in a pre-specified direction to change their behavior [482]. Therefore, it is clear that marketing concepts, even if being used for social good rarely lead to truly voluntary behavior change [488]. The question is does this matter if a social good is achieved.

The International Social Marketing Association, European Social Marketing Association and Australian Association of Social Marketing (2014) incorporates a reference to ethical principles in its definition:

‘Social Marketing seeks to develop and integrate marketing concepts with other approaches to influence behaviours that benefit individuals and communities for the greater social good. Social Marketing practice is ***guided by ethical principles****. It seeks to integrate research, best practice, theory, audience and partnership insight, to inform the delivery of competition sensitive and segmented social change programmes that are effective, efficient, equitable and sustainable’* [486].

Ethical principles have at no time been described for the Dying Matters Campaign and there has never been an ethical strand to the campaigns design, implementation or oversight. This probably explains also why there has not been a clear exposition of the greater social good which it is trying to achieve.

6.9.2. Evolving potential conflicts of interest

As described above, the social marketing campaign migrated into, what was called by its host organisation, a social movement in which organisations signed up to be part of Dying Matters paying subscriptions and committing to activities especially during 'Dying Matters' week held annually in May. In the most recent period the funding ceased from NHS England. The Programme has now transferred to Hospice UK a charitable umbrella organisation for the Hospice Movement [32]. On the website "Hospice UK is the national voice of hospice care in the UK". This raises concerns about how independent the campaign or social movement can be from the aims of and promotion of Hospices. It is of concern that without a clear and transparent governance structure that a big charity promoting the work of Hospices should be leading this campaign if they cannot demonstrate benefit for all of the population the majority of whom will not be cared for by hospices. In contrast to the founding principles of the Campaign, there is no clarity about who is leading it, if there a steering group and if so who are the members, and where do they get their advice from. On the website there is simply a statement 'Dying Matters remains active within Hospice UK' [32]. On the Hospice UK Website it states that 'The mission of the Dying Matters Coalition is to support changing knowledge attitudes and behaviours towards death, dying and bereavement, and through this to make 'living and dying well' the norm'. This is followed immediately by a request for donations including 'leaving a legacy in your will' [32].

As described above, unethical practice which could emerge as part of the campaign could be provision of support with writing a Will, with embedded links inviting people to make donations or to leave a legacy to Hospice UK in their will.

The key risk is that the Dying Matters Campaign will now promote, even more, the beliefs of specialists in palliative care, about what they believe patients want and how care should be delivered. This belief is coloured by their clinical experience with young cancer patients in hospices and it has little in common with the wishes and needs of the majority of patients who are elderly. Moreover, as discussed above, promoting choice may be unethical when in fact there is no choice because services are not available or the patient’s condition or level of family support make their choice for care impossible.

Hospice UK have recently been commissioned to act as a catalyst for spreading implementation of choice commitments. Again, it will be very important to ensure that the message does not include simply promotion of the Hospice vision which does not have much overlap with the experience of elderly patients at the end of life.

6.9.3. Warnings from the past

While there are concerns about a specialist palliative care organisation running the Dying Matters Campaign, there could of course be dangers also in state running such a campaign if their motives were not transparent or at worse maleficent.

This chapter has already exposed the perverse incentives which can occur when targets and monitoring are used to try and improve care. It is really important that social marketing or mass behaviour change programmes aimed at improving the quality of end of life care for elderly patients and perhaps a societal good are based on sound ethical principles [486]. The spectre of encouraging choice in P&EOLC to save the state money is very real because the evidence suggests that if patients die at home there is likely to be cost savings to hospital based health services [458, 465].

An examples of an extreme social marketing campaign related to death and money saving can be found in the Nazi "T-4," or "euthanasia," program which encouraged parents and ordinary Germans to identify and handover their own children and others with disabilities to be killed [378]. Psychiatric Patients were also killed in hospitals [489]. Propaganda included posters telling the public how much handicapped people cost the state. The "T-4" program required the cooperation of many German doctors, who reviewed the medical files of patients in institutions to determine which handicapped or mentally ill individuals should be killed. The doctors also supervised the actual killings. While a ‘million miles’ away in terms of concept and time from current issues, the spectre must not be forgotten [378, 489].

On a completely different level, there is a particular concern today in England, given the enormous financial pressure on the NHS and Social Care that Social Marketing Campaigns to change behaviour with respect to P&EOLC in the Elderly could be used to encourage behaviour which reduces this pressure on the services, especially avoiding emergency admissions to hospital. As described above, there is also concern expressed by health professionals that the focus on choice of place of death is used to switch divert attention and responsibility to the patient for their choice and away from addressing the deficiencies in the NHS and social care which mean care is not universally good for all types of patients wherever they live in the country. Aiming to reduce health service costs is nothing new in Social Marketing Campaigns and indeed clearly stated for behaviour change campaigns to reduce smoking, alcohol and obesity and for early recognition of stroke through the FAST Campaign [490]. So could the Dying Matters campaign go one step further by encouraging certain types of behaviour rather than just getting people to talk This is in effect what the Dying Matters Campaign does and its slogan has changed in 2018 to 'What can you do' [32]. The state could have a special interest in promoting choice, if choice leads to achieve financial savings which it probably would do [458, 465]. Indeed, the literature review and EOLC Economic Tool commissioned by my team suggest that savings could be made to the health service (especially acute hospitals) if more patients died at home [465]. However, there is accumulating evidence that care as more patients die at home or in care home the costs and actual provision of care transfer from state provision to family and privately funded care from people's savings not through health insurance which few people have.

It is difficult for the state to separate a genuine desire to support people's autonomy with respect to dying from a knowledge that certain choices could reduce cost pressures on the NHS and possibly social care. One could argue, that from a societal, utilitarian, perspective that this is ethically permissible and that optimising the use of limited resources for health is a legitimate reason for a social marketing campaign as it enables limited health and social service resources to be used in a better way for other patients. This could fulfil the aim in the earlier definition of social marketing to improve personal welfare and that of society. Indeed such campaigns are already in place to encourage people to not use emergency hospital services unless absolutely necessary or to not expect a prescription for antibiotics every time they visit the doctor with minor infections to combat antibiotic resistance [155].

There is a risk that a Campaign which also explicitly argued for cost savings would play on the psyche of many older people who already express the wish not to be a burden, either on their families or on the state [113]. It could either lead to more elderly people expressing a wish to hasten death (WTHD) [99-101, 153, 171-173], or public and media outrage as seen with the financial incentives linked to the LCP [42]. Any suggestion that the campaign is about saving money could seriously backfire. As described above, the population is still very sensitised by the LCP scandal to concerns that peoples' life may not be prolonged in NHS care in order to save money [36, 42]. Our own qualitative and quantitative research work suggests that at least some older people are also angry at the proposition that state resources for health and social care are insufficient and so, other solutions, for example family care or care by volunteers may be needed to care for the elderly and dying [174]. These elderly people feel they paid their taxes throughout their entire working life with the expectation, if not even the promise, that the state would provide for their care in old age. Indeed, they will have seen a previous generation cared for by the state in their old age. However, even 20 years ago, life expectancy was much shorter and the number of elderly people needing care much lower.

The messaging for Campaigns such as dying Matters should be carefully researched and subject to ethics review. As discussed above, all new or modified P&EOLC interventions, require more rigorous scientific evaluation pre and post implementation [445].

6.10. Justice

6.10.1 Introduction

Justice is one of the four pillars of medical ethics described by Beauchamp and Childress and outlined for doctors by the GMC and the Medical Protection Society [73, 79, 491].

There are three elements to justice from a medical ethics perspective [491]:

- Legal justice - respect for the law.
- Rights based justice – respect for people's rights, such as prohibitions of discrimination.
- Distributive justice – fair distribution of limited healthcare resources.

In this section I will investigate the extent to which justice is being implemented in the care of elderly patients at the end of life.

In Chapter 5, I have explored the extent to which the Human Rights Act 1998 (HRA 1998) protects and promotes the autonomy of elderly people at the end of life. In this section I will return to the HRA 1998, to examine its impact on elderly patients at the end of life, to enjoy all the rights described under the articles without discrimination [45]. In the second part of this section I will critically examine distributive justice in end of life care.

I start from the premise that in England there is a National Health Service and Social Care is also governed by national legislation namely the Care Act 2014 [48]. Moreover, as described above the state is responsible for the quality of the care provided and ensuring that state funded providers of health and social do not contravene the HRA 1998 [136]. The health and social care regulator, the Care Quality Commission (CQC) launched a new policy ‘Human Rights Approach to the regulation of services in September 2014 [398].

6.10.2. Legal and rights based justice

Earlier in this chapter I explored the relevance of Articles 2,3,5,8,9 of the HRA 1998 to EOLC for elderly patients The right to enjoy all these human right without discrimination is protected under Article 14 of the HRA 1998.

Section 6 of the Human rights Act 1998 places a duty on public authorities to comply with human rights in everything that they do HRA (1998). This means that public authorities have legal responsibilities for respecting, protecting and fulfilling human rights. This applies to all services that the Care Quality Commission (CQC) register or inspect [398]. The CQC has a role to ensure that health and social care providers exert their positive duty to protect (right to life and freedom from inhuman or degrading treatment) and their negative duty to avoid interfering with peoples’ rights and fulfill their procedural duties for example to prevent or investigate human rights abuses [398]. The Equality Act specifies the protected characteristics [47].

The need to consider equality and ensure freedom from discrimination in end of life care is clearly stated in NHS England Specialist Level Palliative Care: Information for commissioners April 2016 [183]. In the introduction to this document there is a clear statement about the need to consider equality:

‘Promoting equality and addressing health inequalities are at the heart of NHS England’s values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it.

- Given regard to the need to reduce inequalities between individuals in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this might reduce health inequalities'.

The VOICES survey of bereaved relatives found some inequalities in reported quality of care by groups protected under the equalities act [258]. With respect to gender, overall quality of care for females was rated significantly higher than males with 44% of bereaved relatives rating the care as outstanding or excellent for females, compared with 39% for males. Fair or poor quality care were significantly higher for those living in the most deprived areas 29% compared with the least deprived 22% this may reflect both doctor paternalism and lower levels of empowerment for people from more deprived background. Interestingly, there is no age differences in experiences of fair or poor quality care. No data is available to compare experiences by ethnic group or other protected characteristics [258].

There have been several high profile reports on equality issues in P&EOLC, two published by my team. The first was a report on End of life Care for people aged 75 years or older [12], the second a report on Ethnicity and End of Life Care [312]. Both showed significant significantly poorer access to specialist palliative care services for both groups in society. The CQC has shown growing inequalities in access to health and social care [492] and published a report on access to and quality of EOLC for people from especially marginalised groups such as prisoners, and gypsy/travelers [492]. The CQC has also published a highly critical report comparing the quality of P&EOLC for cancer patients compared with non-cancer patients showing the very low levels of P&EOLC for non-cancer patients [478].

The theme of discrimination or at least failure to consider and address the needs of elderly patients needing P&EOLC flows throughout this thesis [13, 53, 54]. The thesis has critically appraised many aspects of the knowledge about elderly patients' wishes and quality of P&EOLC for elderly people. It demonstrates repeatedly that elderly patients have poorer access to both specialist and generalist palliative care than younger patients and specifically cancer or neurology patients [12, 53, 148, 249]. Usually policy makers are concerned with discrimination or neglect of minority groups with respect to public services but ironically in end of life care it is the majority (68.2%) of people who die, who are aged 75 years and older, that have poorer access.

6.10.3. Distributive Justice

In this section I will be critically appraise how well the state provides fair and equal access to end of life care for elderly patients. There is an overlap with the previous section. It is often not very clear where there is clear discrimination against elderly patients in terms of access to P&EOLC or whether they have poorer access because of poorer provision of the type of care they need for example P&EOLC in care homes, or whether they are discriminated against because of their diagnoses for example dementia, not simply because they are old [24, 119, 190, 215, 241, 396].

Much of non-specialist P&EOLC is provided within the National Health Service (NHS) and, in England, is free at the point of need, including all care and prescriptions for people over the age of 60 and those with chronic diseases. Charities, especially hospices, supplement the care provided by the NHS, especially specialist P&EOLC, but they tend to do so to selected patient groups. Although the hospices receive on average one third of their funding from the National Health Service, and this would be subject to a contract, in practice the local health services commissioners (administered by senior GPs) have limited power to determine how hospices function because they provide the minority of funding [493]. Hospices provide in-patient care, day care and care in people's homes. Social care is organised by local authorities (local government) providing some of it through their own care homes or social services and commissioning most of it from private providers [48]. Social care is means tested. If people have substantial income and savings, including their own home that they live in, they will have to pay for social care until they have less than £23,250 left. There is a lot of debate about what counts as social care and what as nursing care for frail elderly people and health and local government administrators mostly battle, occasionally work co-operatively, over who is responsible for the care of the elderly [136, 357, 365, 441]. The result is distributive injustice in community care in that the chances of an elderly patient having free NHS nursing care at home or having their care in a nursing home paid for by the NHS varies from local area to area in England for exactly the same degree of frailty [11, 136, 441]. Moreover, this is dramatically exacerbated by the variation in number of care home and nursing home beds per head of population aged over 75 years, shown by my team [245]. Injustices in access to what is called 'NHS Continuing Care' – NHS care in the community for the very frail also varies with diagnosis [136]. It has been widely reported that patients with a main diagnosis of dementia are less likely to be provided with continuing care than elderly patients with cancer or heart failure [478]. In 2011, estimates produced for the Dilnot Commission suggested that one in ten people would face future social care costs of more than £100,000 from the age of 65 [170]. The figures for how many people would face this level of costs today are not available. In 2011 the Alzheimer's Society reported that_'People with dementia face the highest costs of care of any group and have to pay the most towards their care' [170]. For this reason a government proposal to increase personal contributions for social care was described as 'The Dementia Tax'. These are clear examples of distributive injustice affecting elderly patients versus young and groups of elderly patients in particular, especially those with dementia.

NHS policy on Palliative and End of Life Care (P&EOLC), in Ambition 2 of the Ambitions Framework [33] tries to address these inequalities by stating clearly that services providing P&EOLC should 'Accept referrals based on need rather than disease label'.

The role of my team, the National End of Life Care Intelligence Network (NEoLCIN) is to provide information about the way P&EOLC is delivered across the state funded providers using routinely collected data. This function is different to the CQC who conduct inspections on the quality of the service. As we are a Public Health based organisation we are very interested in equality issue and justice in terms of fair access to care, for all, regardless of their personal characteristics but related to their level of health and social care need.

The NEoLCIN has published an Atlas of Variation in Palliative and End of life Care in England, which shows geographical variation in every indicator of end of life care within the Atlas. The Atlas shows how the specific examples described above are repeated across all aspects of access to end of life care [33]. Within the envelope of costs for health and social care there is no consistency in terms of distributive justice between geographical administrative areas or between the young and the old in terms of P&EOLC [28]. Reviews of local government administrative area business plans and Strategic Transformation Plans in the NHS show that not all of them give P&EOLC a high priority compared with other health services, some not even mentioning it as a priority [494, 495]. Half of the 150 local government Health and Wellbeing Strategies mentioned end of life care (52%) and only 4% prioritised it. None cited evidence for effective interventions. Of the 78 strategies which mentioned end of life care, 43 mentioned the importance of specific medical conditions, with ageing and dementia the most cited. This latter was positive, as aging is usually not mentioned at all [494]. The inequalities related to commissioning of specialist palliative care in England have been described by others too [493]. The End of Life Care Coalition also found variation in prioritisation across larger administrative, NHS, structures designed to transform health services [495]. Similar geographical and disease specific inequalities in access to elements of end of life care for the elderly are vividly illustrated in our suite of publications on end of life care in care homes [245, 246].

Quality of P&EOLC is also not equally distributed between places where people die, population groups and by causes of death. As described above, the VOICES survey 2016 showed lots of variation in quality of care as has the Care Quality Commission (CQC) [28, 258] .

For most settings, cancer patients had significantly better quality of care compared with those who died from cardiovascular disease or other causes [28]. Even just within lung disease there are differences in the P&EOLC of lung cancer patients and other lung disease patients [419, 496]. This reflects the dominant model of specialist palliative care and hospices focusing on cancer. An exception to cancer patients receiving the highest rated care by setting, was reported by bereaved relatives from hospital nurses, where quality of care was rated significantly higher for patients with cardiovascular disease (44%), than patients with cancer or other causes of death (both 40% rated excellent) [258].

Again, according to bereaved relatives, quality of care during the last three months of life was highest provided by hospice (76%) and lowest by urgent care including out-of-hours services (26%) [258]. The latest end of life care Audit by Royal College of Physicians Audit (2016) showed only 11% of NHS Trusts offered out-of-hours face to face access to palliative care service [497].

Assessing whether all the variation described above really represents true inequality in access to the actual type of P&EOLC needed by different patients is not always simple. At first glance it may appear that certain groups do not have fair access. For example, the NEoLCIN recently busted a myth that people from Black and Minority (BAME) Groups are less likely to die in Hospices. Certainly from a numerical point of view this appears to be true, the numbers of people from BAME groups dying in hospices is very low. However, given that the majority of patients who die in hospices die from cancer, it is important to take into account the numbers of people from BAME dying from cancer which are only a tiny fraction of those of white origin. This analysis showed that 17.8% of white people and 12.8%, 16.8%, 21.0% and 24.1% of people from Asian, Black, Chinese and mixed ethnic origins respectively died in a hospice [498]. However, despite this finding, a comprehensive literature review jointly published by our team from PHE, Marie Curie and King's College London showed strong evidence that people from BAME groups dying from non-cancer conditions may experience many challenges to get the same access to P&EOLC as the white population of England [312]. BAME ethnic origin, especially Asian, has been shown to be a risk factor for emergency admission to hospital in the terminal phase [187, 498].

When the equity of access to P&EOLC for elderly patients is considered, a first glance, the statistics show that, for example, only 5.6% of elderly patients aged 75-84 years at death die in a hospice and even fewer, 2.1% of people aged 85 years and older die in a hospice [11]. This compares with 10% of all ages up to 75 years. Of course some of this difference in deaths in hospices can be explained by different causes of death and the frailty of many elderly people which leads them to live in residential or nursing homes [11, 245]. It is clear that patients with dementia are less likely to get care from hospices or specialist palliative care teams [54, 119, 125, 147, 246, 277]. In our study of over 671,000 deaths in people aged 85 years and older who had been admitted at least once to hospital in their last year of life we found that 62% died in hospital [191]. The chance of dying in hospital was lower for those aged over 90 years and for those elderly people who lived in a care home. Having a mention of dementia on the death certificate was associated with an adjusted odds ratio of 0.34 (95% CI 0.34-0.35), so they were 66% less likely to die in hospital than those without a mention. Elderly people from poorer backgrounds were more likely to die in hospital than more affluent as were those with non-cancer causes of death. The chances of dying in hospital increased with the number of emergency admissions in the last year of life, 50% had at least two admissions but 24% had three of more [191]. The rate of repeat admissions close to death is higher than the general population [11]. Repeat admissions can be very distressing for elderly patients and their relatives [104] but hospital admission provides the opportunity to consider Advance Care Planning [499] however, this is unlikely to be undertaken by specialist palliative care physicians and underlines the need for others such a geriatricians to take a more active role in P&EOLC [53].

The question is whether this is injustice or whether in a situation of restricted resources Specialist Palliative Care services should be devoted to the most complex cases of cancer in younger patients and perhaps elderly patients can be well cared for by their own GPs or other clinicians.

It is clear from the study of the very elderly that even if they were not able to access specialist palliative care, the chances of dying in hospital is at least in part dependent on the quality of community services which, if adequate, may prevent unwarranted emergency admissions [365].

6.11. Is the state autonomous pursuing its own interests with respect to end of life care for the elderly?

6.11.1. Autonomy and the state

State autonomy theorists sometimes known as "New institutionalists" suggest that the state is ‘an entity that is impervious to external social and economic influence, and has interests of its own’[401]. It is argued that the state controls the means to get things changed and so individuals and groups in civil society are largely dependent on the state to achieve their goals. This leads to a situation where state officials may impose their own values and preferences on civil society because they hold power and determine strategy. This effect may result in ingrained behaviours towards the state, especially in the elderly population, even a long time after political changes have occurred, as has been seen in Russia [132]. This section explores these ideas with respect to P&EOLC for the elderly in England and shows that civil society has, over the past decade, had a significant impact on national P&EOLC policy which is written, funded and implemented by the state.

6.11.2. The impact of scandals on state action

‘There is no doubt that the occasional scandal does an enormous amount for a social service’. (Sir Keith Joseph, House of Commons, 12th July 1971) [500].

There have been a number (fortunately small) of high profile scandals regarding untimely death or degrading treatment and neglect of elderly patients resulting in death since 1969 [39, 386, 408, 430, 500]. On each occasion, bereaved relatives supported by the media has forced the state to hold enquiries or reviews which have led to far reaching changes to legislation, policy, practice and regulation with respect to the quality of P&EOLC for elderly patients [39,120,141,143]. These have resulted in paradigm shift towards a focus on the autonomy of the individual and those close to them at the end of life, with special protection for the vulnerable elderly. However, the policy initiatives, as shown above, are not yet always filtering down to the level of direct P&EOLC for the vulnerable elderly.

These examples, such as the commissioning of, and response, to Baroness Neuberger's report on the failures of the LCP demonstrate that the state is not impervious or autonomous of public concerns and will respond with changes. However, it takes considerable fight from members of the public and is probably only successful once a number of similar stories emerge and the media keep up high levels of interest [36]. Social media has made a significant difference to the speed and intensity with which public concerns can be raised enabling, for example, on-line petitions to rapidly accumulate large numbers of signatures and campaign groups to be formed. This was evident during the campaign against the LCP [36]. In the section below, as a case study, I describe how a small number of doctors and patients, supported, exploited or at least promoted by the media caused the state to 'volte face' over the LCP.

6.11.3. The Liverpool Care Pathway and public pressure for change

The Review into the LCP was a defining moment in the history of P&EOLC in England [36, 453]. Once the debate had reached the public domain, it opened up discussion about all aspects of end of life care, both benefits and harms, especially for the elderly [36, 453, 454].

This section explores how the media and public and a small group of doctors drew the state's attention to problems with the LCP. It shows how the advent of social media enabled bereaved relatives voices to be heard in a more public arena and be picked up and promulgated by main stream national print media. It shows how the state reacted and how changes were eventually implemented.

In September 2009, a letter critical of the LCP, signed by six doctors, was published in the Daily Telegraph. The doctors stated that ' …a tick box approach to the management of death is causing a national crisis in care (and) … a nationwide wave of discontent … as family and friends witness the denial of food and fluids to patients … (and) … that many deaths 'come about' as a result of terminal sedation' [501]. The authors included: an emeritus professor of geriatric medicine, a consultant in palliative medicine, an anaesthetist, and the Chairpersons of the Medical Ethics Alliance and 'Choose Life' (Christian 'pro-life' organisations) [501]. An accompanying editorial was also published and entitled 'Sentenced to death on the NHS: Patients with terminal illnesses are being made to die prematurely under an NHS scheme to help end their lives, leading doctors have warned' [44, 501]. A week earlier, a report from the Patient's Association had claimed that up to a million patients received poor NHS care. This story was covered widely in the media so in a sense the media and the public had been sensitised to stories about poor NHS care. It has been suggested that the six doctors used this heightened media and public interest in poor NHS care to publicise their concerns about the LCP. Their concerns were not completely unfounded as latter described by Baroness Neuberger's review [39]. Despite the relevant professional expertise of the authors, the senior policy makers in P&EOLC were dismissive of all their concerns based on a) their misquoting of the research on deep sedation and b) their religious pro-life affiliation. The state representatives found it easy to discredit the doctors as belonging to a marginal, religiously motivated, group [36].

However, the Daily Telegraph journalists were persistent as they thought they had uncovered a newsworthy story and published a series of follow-up articles [44]. An analysis of the responses published in the Daily Telegraph found that there were 431 individual comments in response to the original letter and the reports that followed [40]. The media coverage attracted the attention of concerned bereaved relatives who had perhaps previously perhaps not felt able to voice their concerns. They took advantage of the new public forums created by social media such as Facebook and Twitter [36]. Through these, the concerns of 'the people' 'res publica' could be publicised and it allowed them establish links as individuals and with organisations, including the media, who took up their cause. Their concerns were: they had not been told their relative was dying, lack of involvement in decision-making about end of life care for their relatives and poor quality of communication.

The public exposition of family members' concerns on social media gave the mainstream media more personal stories to construct articles around and these were published in a range of national newspapers reaching a wider national audience of different political persuasions and socioeconomic groups. For example, the Guardian Society, appealing to a more educated audience, published rhetorical 'think pieces' [502]. In contrast, the Daily Mail newspaper, which appeals to a more populist audience published 'shock, horror, scandal' type articles using terms such as 'Liverpool Killing Pathway' [503]. Between 2010–2012 most national newspapers published articles on the LCP, most were critical and some used shock tactics and emotive language to sell their stories [36, 40].

The professional supporters of the LCP either did not know how to, or were reluctant to, engage with the media so limited their responses to medical journals and the health care press, although some were active on Twitter. Perhaps senior policy makers' reluctance to have an open mind and say they would investigate concerns early made the situation worse as it appeared that the state and proponents of the LCP were closing ranks. If they had responded early and accepted that there were problems the story may have ended differently. Finally, an open letter to the Health Secretary (Minister) in the Daily Telegraph National Newspaper and an online petition by the organisation Change.org requesting a national enquiry resulted in one of the Health Ministers committing to ‘appoint an independent chair to review how end of life care is working and oversee the reviews into the LCP. … This review will also consider the value of locally set incentives, and whether they are leading to bad decisions or practice’ [43].

Key features of the media and public’s sustained demand for the state to investigate included: personal stories, sustained media activity, the recruitment of campaign groups and the use of the social media. As Seale found in an analysis of the media reporting of his work on end of life decisions and deep sedation, the media through discussion of wider end of life issues could raise public awareness and debate about end of life care beyond the narrow focus on euthanasia and assisted dying. He noted how stories which are likely to catch the public imagination and shock produce a ‘feeding frenzy’ of ‘pack journalism’ amongst the media [390].

The impact of the LCP media coverage lingers on. About three years ago I was invited to talk to a group of retired Trade Union Members about by work in P&EOLC, but I did not specifically mention the LCP. However, when it came to discussion time they repeatedly said things like ‘I don’t want to be put on that Liverpool thing’ or I think my wife was ‘Liverpooled when she was dying’. Even more recently, in the wake of media coverage of the Gosport Memorial Enquiry on opiate use in frail patients, bereaved relatives phoning into BBC programmes on the subject have mentioned Liverpool as a short hand for pathway to death [430].

In England, the public debate about end of life care is now dichotomous both tinged with suspicion and fear that their lives may be ended prematurely, largely in hospital, while at the same time maintaining an almost religious reverence for hospices and their work.

The independent review panel into the LCP made its recommendations to the state and also to NHS England, Department of Health, General Medical Council, Care Quality Commission, and NICE. In England, a rapid response was mounted and the ‘Leadership Alliance for the

Care of Dying People' was formed with representatives from 21 organisations involved in policy, delivery and regulation of P&EOLC as well as supporting patients and relatives [141]. These included those named and others, including Public Health England (which I represented) and charities. The terms of reference of the LACDP included '…to take collective action to secure improvements in the consistency of care given in England to everyone in the last few hours or days of life and their families' [141]. The LACP looked at and made recommendations for improving all components of a state wide approach to delivering high quality P&EOLC. All the organisations made pledges about what they would do. The work of the LACDP in England was followed by the Choice Review (2015) and the 2015 National Institute of Clinical and Health Excellence guideline on care of dying adults in the last 2 to 3 days of life [80, 120]. The findings of all of these influenced the structure and direction of the second national policy on P&EOLC, the 2015 'Ambitions Framework' [33].

The changes implemented following the LACDP's report were subsequently described as 'a step change in shared responsibility for end of life care …. doing the right clinical thing is no longer the sole responsibility of care providers. In addition, the role of contracting and resources is recognized through an explicit expectation that Commissioners of care will share the responsibility for effective end-of-life care, while previous training deficiencies are acknowledged through placing this responsibility also with Commissioners of education and training as well as the Medical and Nursing Royal Colleges' [504].

In 2016 the government published its commitment to the population in terms of delivering high quality P&EOLC [142].

6.11.4. The role of the Charitable Sector, Non-Government Organisations

In England, the modern Hospice Movement was founded by Dame (Dr) Cicely Saunders. Her husband Marian Bohusz - Szyszko, an artist, was a friend of my Great Uncle, who qualified in medicine from Krakow University, died in 1986 and to whom this thesis is dedicated.

Not only did Dame Cicely found the modern Hospice movement in England she was also instrumental in the history of medical ethics in the UK being a founder member of the London Medical Group which later became the Institute of Medical Ethics. Her talk 'The Nature and Management of Terminal Pain' was repeated many times as other ethics groups set up and was published in the LMG's 'Documentation in Medical Ethics' which was a precursor to the journal of Medical Ethics .

Dame Cicely was also influential in the beginnings of the Hospice movement in Poland [145]. The Hospice movement in Poland is also very strong in influencing national policy on P&EOLC.

In England, there is more than a decade of evidence of the impact on the direction and content of state policies and initiatives by Charitable, Non-Government Organisations (NGOs) and civil society organisations interested in P&EOLC [32, 140, 141]. It is now estimated that there are around 200 hospices in England providing inpatient beds, day center care, and home care, largely in peoples' homes [32]. Hospices also provide important training and support beyond the Hospice, for example for care homes in order to improve P&EOLC for elderly patients, as we and others have shown [125, 246]. Several multi-million pound turnover Charities such as Marie Curie, and Sue Ryder have specific interests in end of life care and political persuasion power as does Hospice UK. Several of them have formed The End of Life Care Coalition [505]. Over recent years large charities such as Age UK and Dementia UK have also taken and interest in end of life care, especially for elderly patients and campaigned at a political level. These NGOs not only represent the professional voice but more importantly patients, their family and the general population.

In End of Life Care, prior to a decade ago, the major developments in P&EOLC, were in specialist palliative care and occurred out-with the structure of the state. However, charities and representatives of hospices and specialist palliative care have played a 'center stage role' in guiding the development of national strategy as represented in on National End of Life Care Boards, the LACDP, Choice Review and hosting Parliamentary events [505].

These organisations have had a strong influence on successive government policies by requesting meetings with ministers, campaigning at Political Party Conferences, trying to influence Party Manifestos prior to elections and holding ministers to account for delivery of promises made in their manifestos [428]. The Charities have been represented in all major government advisory fora since the publication of the first National Strategy on End of Life Care in 2008 [30, 140,141].

The NGOs have been successful in forming and guiding national strategy and raising the importance of good P&EOLC with successive Secretaries of State for Health and Social Care. This led to mentions of P&EOLC in election manifestos across the political spectrum [428]. They campaigned especially hard for free social care for the last six months of life.

This was mentioned in the Coalition Manifesto however momentum was lost after the general election demonstrating that not all election promises to stakeholders come to fruition [428].

However, the potential downside of the predominance of the big NGOs, who have a specialist palliative care focus is that they perpetuate a model of care based around the hospice and care for cancer patients while the interests of the elderly are largely ignored. The discussion from NGOs representing the elderly is now focusing on how P&EOLC be delivered and at the same time democratised and de-medicalised so that a voice is given to the majority of people who die, who are the elderly and the families who care for them [154].

6.12. Discussion

This Chapter has examined the beneficent, paternalist role of the state in driving and delivering P&EOLC through the functions of the Government, Parliament, the Judiciary and the Public Sector. This is a clear example of intended social beneficence as described by Beauchamp, applied to national P&EOLC strategy [432]. The beneficent approach extends to the family carers too, by acknowledging the need to preventing morbidity in carers by provision of supportive services to them [506].

However, more importantly, the care of the dying is seen also through an altruistic lens, as one of the state’s obligations to care for the most vulnerable [142]. One of the clearest examples of beneficent paternalism is the repeated rejections of appeals for euthanasia or physician assisted suicide to be introduced [290]. The main argument supporting this is to protect the vulnerable including the elderly who might otherwise feel pressurised into requesting this in order not to be a burden. Another example is the Mental Capacity Act which seeks to protect the rights of those who do not have the mental capacity to make their own decisions about care [220].

While the state rhetoric, extensive policy initiatives and universal basic levels of provision in P&EOLC are undisputed and ranked the best in the world [51], there has not to date, apart from in the case of the Liverpool Care Pathway, been a critical assessment of the risk of harm associated with the various policy initiatives which have been implemented since 2008 [36, 39]. This thesis contains the first attempt to do so and also demonstrates the lack of structures to anticipate and monitor these risks of harm [445].

The chapter has also examined the state's paternalistic role in delivering beneficent justice as described by Beauchamp [432], particularly in the context of distributive justice and shown that there is still substantial work needed, firstly to understand the P&EOLC needs of elderly people and then appraise whether the current disparities in access to specialist palliative care services for the elderly [28], and those seen geographically [11], are true injustices. Indeed new ways of measuring quality of care are urgently needed to compare needs with actual quality of care, especially for older people. These should take into account their wishes and issues such as dignity and pain control.

There is still clear evidence of a lack of distributive justice in end of life care for elderly people, they are far less likely than other patients to benefit from hospice care or specialist palliative care and more likely to die in hospital [28]. Concerns about inequalities in access to care have focussed on very small minority groups but so far inadequately addressed the stark inequalities between those who die under the age of 75 years and those who die older than 75 years [12, 152, 190, 245, 249, 480]. Indeed, it is a strange situation that the majority of people who die (68%) have, in general, less good end of life care than a minority. This requires an important shift in attention of policy makers. My team's work also shows geographical inequities in access to care for elderly patients at the end of life, especially to care home places and this needs strategic attention to address [245].

The state, in England, provides almost all of the healthcare for elderly people at the end of life [136, 400] and much of the social care. Although the National Health Service is under great pressure, the pressures are even greater in social care, This leads to substantial inequalities in the care elderly patients at the end of life can receive without payment and may impact on need to be admitted to hospital for care as well as other markers of quality of care [11]. The stark differences in care home (residential and nursing home) bed availability across the country [11, 245] contributes further to injustices in the opportunities for safe care, for the elderly, at the end of life. The debate about funding social care for elderly people at the end of life continues and there are strong humanitarian, social justice as well as economic reasons to support funding by the state especially in the final 6 months of life [170, 428].

This chapter identifies several examples of inadvertent maleficence by the state with respect to P&EOLC which especially impacts on elderly people. These include, the LCP, CQINS, DOLS and the Choice agenda. These examples all represent either the effect of perverse incentives or of unpredicted outcomes of initiatives intended to promote better quality and safer care [60, 153, 361, 445, 454].

Individual patients, family and the media played a significant role in bringing concerns to the attention of the relevant authorities [36]. Action was taken and new procedures put in place and policies changed [33, 142]. These problems have heightened the states' awareness of the risk of inadvertent maleficence [445]. Now those of us who are responsible for advising on policy attempt to examine the likely consequences of any new change to policy, both positive and negative, for the patient and their relatives. However, there is still no formal structure for doing so. Ideally, all new policy initiatives in end of life care would be evaluated against an ethical framework which also insists on a strong evidence base for the implementation of interventions. The framework suggested by Currow, in his analysis of preventing another LCP situation, should be considered and adopted or modified and [445].

It is evident, especially in the wake of the independent review of the LCP [36] that in England, the state is not pursuing an entirely autonomous role with respect to the provision of end of life care for the elderly. It is not impervious to public pressure. Major charities, tenacious bereaved family members and the media have all had an influence on the way policy has changed over more than a decade [36, 495, 504].

Chapter 7. Concluding Remarks

This thesis has critically examined the relationship between individual autonomy and state paternalism at the end of life for elderly patients. In particular, it has examined what is known about the way in which elderly patients may differ in the way they wish to exert their autonomy when faced with approaching death and compares and contrasts this with younger patients. The thesis then critiques the paternalistic role of the state in protecting and promoting the autonomy of elderly patients at the end of life. The analysis of the role of the state focusses on the situation in England but the findings are of international relevance, not least because all industrialised countries are witnessing increases in life expectancy and the aging of the post-war baby boom generation leading to older ages at death and also increased numbers of people dying in advanced old age with significant levels of physical and psychological frailty. Most industrialised countries also have human rights legislation which may serve to protect vulnerable elderly people as they approach the end of life and promote their autonomy [3]. The strong focus on patient choice in medical decision making at the end of life seen in national policy making in England [142, 154] is seen also in other Anglo-Saxon countries such as the US [153] but the concept of Advance Care Planning is also now widely prevalent in Europe [3].

Most work in bioethics at the end of life, especially on autonomy, focusses on Palliative and End of Life Care (P&EOLC) decision making either for children or young adults on life - support, or on questions related to withholding or withdrawing treatment, or physician assisted suicide or euthanasia [59, 220]. Very few papers address, the everyday ethical challenges faced on a daily basis by millions of elderly people world-wide as they approach the end of life [18, 66, 507]. Although the ethical challenges for elderly people perhaps lack the drama of life and death decisions in the Intensive Care Unit, ethical challenges faced by elderly patients in exerting their autonomy and their interactions with their families and professionals are important from a public health perspective as they affect millions of people every year [248, 508]. The elderly are especially vulnerable as they approach the end of life due to the high probability of them experiencing physical and mental frailty with increasing dependence on others for care [17, 18]. Poor decisions and decision making may impact on wellbeing of the elderly patient and their family in all spheres of care: physical, psychological, social and spiritual [18]. Extremely poor care may extend to compromise their human rights [3, 10, 18]. The vulnerability of elderly patients and their dependence on the goodwill of others means that the number and cumulative nature of almost daily ethical dilemmas encountered in caring for elderly people at the end of life have a high probability of impinging on the psychological, spiritual and existentialist wellbeing of all involved especially families. The challenges of appropriately respecting patient autonomy are exacerbated by the finality of death. There are no second chances to get things right.

Taking a utilitarian, public health perspective, good ethical decisions in P&EOLC for elderly patients are important to the population's health. In England, P&EOLC decision making may impact on up to 1.7 million people (dying elderly patients and their close family) every year [11]. Elderly patients (≥75 years), who die comprise a significant population group (>333,500 per annum in England), and for every one elderly patient who dies a further, on average, four family or friends close to the deceased may be affected by providing care, involvement in care decisions and bereavement [11]. There is good evidence that the decisions which affect the way in which people die impacts on the health and wellbeing of the family left behind [163, 248]. Family carers are at significant risk of morbidity and even premature mortality as a result of their caring role [248, 508] . For this reason the families of dying patients are often referred to in specialist palliative care as hidden patients [248, 508]. These numbers of people affected, accounting for about ~3.5% of the population are highly significant in terms of public health action to promote wellbeing of the dying patient and family and prevent morbidity and mortality in family carers [509]. It is therefore also an important matter for state policy making.

In addition to the human cost of poor quality P&EOLC provision and decision making, if a distributive justice perspective is taken, making good ethical decisions at the end of life for elderly people may also have resource implications [465]. It is an unavoidable fact, but which adds further complexity to the public debate, that poor quality and especially unplanned care at the end of life costs the state more money [465]. For example, failure to respect an elderly patient's wish not be admitted to hospital when they are dying, which happens frequently, incurs additional health services costs compared with providing the care they want where they live, especially if they are already living in a nursing home [105, 465]. However, the introduction of a public discussion about finances and saving money through good P&EOLC may be misconstrued by the public as attempts by the state simply to save money. This is especially sensitive in the wake of the Liverpool Care Pathway (LCP) debacle, where there was media and public outrage that hospitals were paid to put patients on what some described as ‘a pathway to death’ [36, 42].

The thesis has shown that the elderly have a range of issues over which they wish to exert their autonomy as they approach the end of life ranging from wishes universally shared with all patients to have their physical symptoms relieved, but not at the cost of not being conscious at their death, through to very strong desires not to be a burden on others [113, 114, 116, 117, 190]. Preservation of dignity, identity and decision making even if this is through delegation to chosen individuals is also important [149, 313, 510]. The thesis shows that there is still relatively poor understanding of the desires of elderly people and that policy is not based on research or good understanding of this population group and of their needs. Of a more serious nature is the apparent disconnect between policy and the real choices for elderly patients to access good quality P&EOLC and the evidence that the elderly, as a group, have much poorer access to specialist P&EOLC.

The nature of the relationship between the state as a paternalist agent and the autonomy of elderly people approaching the end of life has been tested by critically appraising national policy and legislation in England. However, the findings of this thesis are of universal relevance and similar methodology could be used elsewhere. Although contextual issues may have to be considered, for example the observation of a very dependent relationship between elderly Russian people on what they regard as a paternalistic state [132]. In England some observers have also suggested a degree of dependency on the ‘Welfare State’, which for 70 years has provided, for free, everyone’s health and social care needs. It has been suggested that this may have led many elderly people to abrogate responsibility for planning for their care because they believe that the state, through doctors or social workers, will make decisions for them and provide appropriate care [64, 128, 207].

Although every country will have differences in the way P&EOLC is provided to elderly people, especially in the way health and social care services are funded and sophistication of national policy on P&EOLC, all industrialised countries are facing the same challenges which are to care for increasing numbers of elderly people with frailty and dying [9, 77]. Trend data published by my team, the National End of Life Care Intelligence Network (NEoLCIN) and others, show that, in England, the total numbers of deaths has risen significantly and is projected to undergo a dramatic increase over the next two-three decades and this is being driven by increasing numbers of deaths in elderly people [11, 13, 14].

Therefore the topic has practical relevance to policy makers and those charged with implementing policy across the industrialised world. It also has personal relevance to the current and future elderly as it highlights issues for individual reflection and action.

The UK was ranked top for provision of palliative care in the world in 2015, in an assessment conducted by Economist Intelligence Unit [51]. This thesis illustrates and critically appraises some of the factors which contribute to this ranking especially in terms of wide-ranging national policy on P&EOLC. However, the purpose of the thesis has been to drill down below these global high scores and critically appraise, the interplay between autonomy and paternalism for elderly patients, within the context of an internationally recognised, national system for P&EOLC. This has been done by combining critical analysis of published literature on the subject with evaluation of policy, legislation and empiric data from England. This thesis has demonstrated that the state, in England, has national policy, supported by legislation and regulation which is designed to provide good quality and safe P&EOLC within a human rights framework. However, it also shows that despite extensive policy initiatives and a legislative and regulatory framework, it does not always mange to meet the needs of elderly people at the end of life.

There has been, since 2008, a strong intention to promote and protect the autonomy of people at the end of life, including but not specifically the elderly, through the motet of choice [30, 33, 120, 142]. Empiric analysis of national data shows signs, using proxy indicators of quality such as place of death, that there have been improvements in P&EOLC for elderly patients with respect to choices over the most recent decade since the first national P&EOLC strategy was introduced (2008) [11]. Deaths in hospital in elderly patients, and specifically from dementia and other conditions of old age, have reduced statistically significantly over the past decade [11, 75]. This is considered to be a success in terms of national policy making and no doubt reflects better identification, planning and care provision for elderly people and perhaps also respecting their choices better [348]. In contrast, other indicators of quality, for example three or more emergency admissions in the last 90 days of life, which primarily involve elderly patients has risen over the past decade [11].

In an ideal world, all elderly patients will have universally good access to high quality, autonomy protecting and promoting, P&EOLC which is appropriate to their specific needs as an individual [3, 21, 53, 78]. At present, it is clear from quantitative evidence from my own team and analysis of the literature that there is still a long way to go to achieve this [11, 12, 28, 78, 148, 152, 245]. There are still injustices in which elderly patients get access to specialist P&EOLC, those with cancer are more likely to than their peers, but less likely to than younger cancer patients [28, 75]. More importantly, across P&EOLC services, there appears to be injustice between the P&EOLC that elderly patients receive compared with younger patients in general and especially cancer or neurology patients [28]. The latter groups will almost always have access to specialists in palliative care, in hospital, in hospices or at home whereas elderly patients will not [17]. Elderly people from BAME Groups and from very deprived backgrounds may have even less chance of accessing specialist P&EOLC [312]. Similarly, patients with dementia especially those living in nursing homes are also unlikely to receive specialist palliative care [190, 245]. Although the evidence clearly shows a difference in the chances of elderly people accessing specialist palliative care, caution must be applied in always labelling it as injustice. The reason is that there is insufficient known about the best models of P&EOLC for elderly people. Initiatives such as the Gold Standards Framework have shown good quality non-specialist P&EOLC can be delivered to elderly patients in care homes by training the nursing and auxiliary staff and having protocols and guidance in place [144, 246]. Similarly, GPs (family doctors) together with community nursing teams can provide excellent quality non-specialist P&EOLC to elderly patients in their homes [144].

Decisions made by the elderly patient and by others for them can have a significant impact on the quality of their last days and hours of life [86]. However, so also can a failure to make decisions at an earlier point and communicate them. Without this knowledge, doctors or family members may make decisions that contravene the previous wishes of the elderly patient [348]. Advance Care Planning (ACP) and Advance Directives (ADs) have been proposed as a way to increase the chances of patients dying in the way and where they prefer and there is some evidence that they can support this [94, 108, 348] . There are still many unresolved issues particularly relevant to the elderly, for example, the meaning of identity in patients with dementia [218, 346] and the validity of Advance Directives (ADs) in these patients [126, 165, 180, 182]. More specifically, whether their ADs should be respected or rather ‘best interest decisions’ should be made on their behalf assessing all the information available at the relevant moment in time as would be done in Poland [131, 346].

Advance Care Planning (ACP) and ADs are not simple solutions to protecting and extending autonomy especially when the patient losses autonomy [60, 109, 126, 153, 165]. There are also concerns that rigid adherence to ADs may actually not be autonomy respecting as circumstances change as death approaches [60, 109, 153, 165].

The thesis has shown, that providing technically competent medical care to dwindling, frail and dying elderly patients alone is insufficient if their personhood and other spheres of autonomy wellbeing such as psychological, social and religious/spiritual and those of family carers are not attended to. This is not to say that competent palliative care is not important, it is, because in studies looking at a hierarchy of priorities at the end of life, patients rank pain and symptom relief highest [190]. However, of course, it depends what questions are posed to the patients to rank and in several other studies it has been shown that dying, elderly patients, identify not being a burden on others as their highest priority [63, 113-115, 117, 172]. Indeed this concern may be so great as to cause a wish to hasten death (WTHD) sometimes framed as a 'duty to die' [112-115, 117, 148, 259, 313] and even requests for PAS or VE [102, 173, 289].

Given the evidence to-date from the literature, elderly people want their dignity to be respected and want to be involved in discussions about decisions but do not always want to undertake formal planning [106, 118, 130]. An overwhelming theme from the analysis is that elderly people value their autonomy but in a relational sense, as part of a family, friendship group or society [65, 113]. Many do not want to be a burden and fear of being a burden influences their choices [113]. While elderly patients want to be involved in decision making and often to share this with family members [149, 511] they do not always want to make the actual decisions about their care, often deferring the decision to others who they consider have a better grasp of the issues [64, 130, 213, 310, 511]. Perhaps this objectivity about how decisions should be made, cognisant and understanding the full facts at the time of the decision and taking into account the needs of others also underlies the reluctance of elderly people to complete ADs [213].

Perhaps elderly people see ADs like the 'Emperor's New Clothes' - a new fashion - distracting attention from the naked truth of uncertainty about future scenarios, limited health and social care resources and the type of decisions which will have to be taken as these unfold. This may explain the suggestion from the literature for their preference to leave decision making to the doctors or surrogates at the time the decision needs to be taken [130, 134, 315]. Further research is needed to understand why elderly patients, in England, appear to have little interest in in ACP [235].

The unpredictability of death in elderly people is one of the biggest challenges General Practitioners, Geriatricians and hospital doctors face when planning care for their elderly patients [299, 300, 466]. An audit we conducted showed that imminent death was only identified usually 48 hours before patients died in hospital (unpublished findings). Of course, having some indication of what the patient wants or would have wanted does help the doctors as well in making difficult decisions at a stressful time [130].

One of the important issues highlighted in this thesis, which tends to 'lurk in the shadows' and is not openly discussed, at least in England, is the wish to hasten death (WTHD) expressed by many elderly people [172]. The literature review, supported by empiric data from the national VOICES survey, has shown that the WTHD is not uncommon in elderly patients [172, 258]. This often results from a feeling of lack of autonomy in the face of suffering and feeling of being a burden as well as the high prevalence of unrecognised depression [114, 173, 254, 261]. Although the term is 'wish to hasten death', elderly patients more often actually 'wish for death to hasten', or in other words to come quickly. As shown in this thesis, only a small proportion of the elderly population actually consider taking active steps to bring death forward, towards them. It has also been shown that medical and social contributors to the patient's WTHD should be identified and interventions offered as these can reduce or reverse the WTHD [171]. Moreover, that WTHD may be expressed as a cry for help, thus WTHD should not just be accepted as an inevitable consequence of facing terminal illness and/or old age [171, 176, 178, 314].This issue is more widely acknowledged and openly discussed in Belgium and the Netherlands [173]. However, there are concerns that elderly patients may be requesting VE who in fact have modifiable risk factors.

Families play a critical role in protecting, promoting and enabling autonomy of elderly patients approaching the end of life. Indeed they make up for shortfalls in state provision of care and, for many elderly people, they are the preferred option for non-professional help over unknown volunteers [512]. The current emphasis in national policy to treat patient and family as a unit of care is a positive development especially given the evidence of elderly patients' approach to relational autonomy [33]. As there is considerable evidence of the physical and psychological burden of caring, autonomy of individuals in a family can come into invidious conflict. It is not always clear which individual's needs are greater or should be prioritised [65, 182, 506]. Paternalism can also be apparent in the family setting as can changes in roles of who exhibits paternalism in the family especially as younger adult generations take a greater role in decision making [213].

The thesis has touched on the extremely sad and also challenging, in terms of state provision of care, situation faced by the large numbers of elderly people who live alone, either with no family or abandoned by their family [96, 512]. The precise magnitude of the challenge and development of models of care for these, especially vulnerable, elderly patients needs to be mapped out to address their needs [13, 14, 28].

One way to consider autonomy of the individual at the end of life is in human rights terms [2]. The WHO has identified Palliative and End of Life Care as a human rights issue [21]. Many countries, in Europe, have a legislative framework incorporating principles from the European Convention on Human Rights (ECHR) which is applied to P&EOLC [315]. In England, the Human Rights Act 1998 (HRA 1998), derived from the ECHR, provides a legal basis for the protection and promotion of human rights with respect to P&EOLC and old age [45]. Moreover, human rights in P&EOLC are supported and enhanced by specific health and social care legislation and equality legislation which derive from this foundation Act. The legislation should impact on the quality of P&EOLC, especially the protection and promotion of the autonomy of elderly patients [46-48, 290]. Many Countries are adopting a human rights approach to P&EOLC [3, 4, 67, 315, 369, 398].

This thesis, has demonstrated the usefulness of using a framework of rights derived from the European Commission on Human Rights (ECHR) and outlined in the HRA 1998 to assess the extent to which autonomy of elderly people is being respected and protected at the end of life. This framework could be equally used in the same way for other groups for example people with learning disabilities or people from Black and Minority Ethnic Groups (BAME) or in other countries. The framework enables critical evaluation of the impact policy and practice on the autonomy of elderly patients at a macro (national) and micro (individual) level. It could just as easily be used to test the application of the human rights principles to P&EOLC at the meso-level in the interaction between doctors and patients, or between families, patients and doctors, or even looking at the role of institutions. I have already tested this utility outside the scope of this thesis.

The Human Rights Act 1998, and laws derived from it comprehensively provides a framework to protect and promote life and wellbeing in terms of freedom from suffering and degrading treatment [45]. Indeed, in England, protection of life, especially for the vulnerable is given priority by parliament over pressure to introduce Physician Assisted Suicide or Voluntary Euthanasia as solution to suffering [290]. For more than a decade, governments have proactively responded to the need to provide care for those with terminal suffering through its end of life care policies and stated commitments, although not very commitment has borne fruit [30, 33, 142, 428]. The HRA1998, also protects the liberty of elderly patients which, as I in this thesis, and others have shown, may be quite extensively restricted inappropriately [391-394]. Freedom of thought and religious practice, the latter which may be important to the elderly patients approaching the end of life is not just a human rights issue but an integral part of P&EOLC which is identified in policy [33, 208]. Justice in terms of fair access to P&EOLC for elderly patients still has a long way to go to bring it to a similar standard to that which many cancer patients receive [28]. To achieve this there will need to be firstly a change in understanding of the way P&EOLC needs to be provided for the type of conditions which elderly patients die from including frailty and dementia. There also needs to be a greater understanding of the hopes and wishes of elderly patients [62, 100, 296]. This change will require more engagement with experts in the care of elderly patients such as Geriatricians [24, 53, 150, 214, 249]. Undoubtedly, there will need to be investment in state services to raise the standards and availability of care universally across the country. Consideration should also be given to the role played by family carers alongside health professionals.

The analysis of legislation shows scope for wide protection of the autonomy of elderly patients who are approaching the end of life. However, critical analysis of implementation of legislation through policy initiatives in this thesis has revealed potential problems in its under-pinning rationales, especially the characteristics of, and all-pervading nature of, the focus on choice. A comparison of policy, with research evidence on autonomy related issues in P&EOLC in the elderly reveals at best a dissonance with the little evidence which exists on their views and at worst a lack of research evidence for the applicability of current policy to elderly patients. This comparison also reveals significant opportunities for doing things better and in a more autonomy respecting manner for elderly patients [153]. The importance of understanding the needs, wishes and behaviours of elderly people in order to design appropriate P&EOLC policy for them is highlighted in this thesis as also are some of the unanswered questions.

Paternalism, with respect the elderly patient approaching the end of life, may take several forms. At a population level, the state, in England, attempts to be a beneficent paternalist by caring for and protecting elderly people approaching the end of life and fulfilling its ‘parens patriae’ role to protect the most vulnerable who have no Mental Capacity [131, 400]. The state also functions as a liberal paternalist in promoting choice in P&EOLC [109, 129, 350]. At the level of patient care, paternalism either emerges from concerns about the safety of the elderly patient, as in deprivation of liberty or medical paternalism or it is unwitting in doctors or family members [128, 182, 392]. Awareness and education about where and when these care related forms of paternalism arise could be linked with prompts to help those caring to remember to consider the autonomy of the elderly patient. Similarly, shared decision making will help to reduce this type of paternalism from occurring and is what many elderly patients would like [55, 65].

The LCP Review, and the media coverage which led to it, exposed terrible examples of medical paternalism in the management of patients put on the pathway, without their or their families' knowledge, with withdrawal of treatment and sometimes deep sedation [36, 39]. Most of this arose because of overenthusiasm and uncritical implementation of the LCP in situations in general hospitals of poor training and lack of supervision of junior doctors [39]. However, despite a public review, abandonment of the LCP and policy reforms, the scandal has left a low level but pervasive mistrust of the motives of palliative care and fear that elderly people might be 'Liverpooled' in other words have their life ended prematurely by doctors either withdrawing nutrition and/or hydration or deeply sedating with opioids (personal communication at meeting with UNISON).

The General Medical Council, which registers all doctors in the UK and assesses their fitness to practice, reacted decisively and has very clear guidelines for doctors on the management of patients at the end of life to which doctors are expected to adhere to [79]. These place great emphasis on respect for the patient's autonomy and shared decision making [79]. They are very clear about the role of artificial nutrition and hydration and decision making around this. Similarly the National Institute for Health and Clinical Excellence (NICE) has produced evidence guidance on the care of patients in the last days and hours of life and standards against which the quality of care can be measured [80, 143]. The guidance is also very clear about P&EOLC for patients without Mental Capacity. Hopefully situations such as occurred with the LCP are now very rare, but historic scandals are still appearing for example in Gosport Hospital where a single handed GP gave high doses of opiates to patients and withdrew hydration without consent [408, 430].

The majority ~80% of elderly patients die in institutions (hospitals, care homes and hospices). Therefore it is very important that the institutions are autonomy and human rights protecting and promoting as medical institutions have a tendency to be paternalistic in their functioning [513]. The state tries to ensure that all the institutions providing health and social care are subject to the HRA 1998 and legislation deriving from it. The institutions are all subject to regulation and inspection by the Care Quality Commission which has adopted a human rights approach [398]. Institutions by their nature have to fulfil legal and other requirements and it is always challenging to individualise care. Hospices are the institutions where patients and their families are not only put centre stage in consideration but they also have high levels of staffing and conducive accommodation, moreover their ethos and raison d'être is to provide high quality end of life care. For hospitals and care homes caring for the dying is just part of their function although a relatively frequent one. One of my local hospitals has ~ 1,800 deaths per year so about 5 per day. Pressure on staff, privacy for patients and families in hospitals present real challenges for respecting patient dignity and autonomy and their resources are almost universally over stretched [104]. This could be a further argument for enabling more patients who do not want to die in hospital and/or do not stand to benefit from and admission to be cared for in the community [33]. Most of the focus is on improving the quality of care and choice but surveys show other things are important especially dignity [178, 313].

It is interesting that, from a public health perspective, that the nationwide campaigns to improve P&EOLC, the Dying Matters Campaign and the 1% Campaign looks very different to the usual public health population based campaigns. The Dying Matters Campaign, which started as a Social Marketing Campaign, urges people to take control of their death and dying by talking about what they would like and making plans, such as Advance Care Plans. The focus is on individuality, enhancing the autonomy of individuals and providing individualised care around their needs and wishes, rather than identifying an effective intervention and applying it to all those appropriate regardless of identity and preferences as it would for example if encouraging people to stop smoking [138, 360]. The 1% Campaign encourages GPs (family doctors) to identify patients in their last year of life and encourage them to discuss their wishes and to make plans [140]. The contrast is exposed in the section in Chapter 5 comparing the 1% Campaign against the Wilson and Jungner 1968 WHO Criteria for a screening programme [434]. Ironically 'choice' has been pushed as the therapeutic or preventative intervention in both Dying Matters and the 1% campaigns as the panacea for a good death [32, 138]. The implication is that the patient's choices, will lead to better end of life care. Indeed there is evidence that for example choice of place of death or care is more likely to be achieved if wishes are recorded [86, 94, 348] Of course, it has been with good intentions and is a nod towards the importance of autonomy and identity at the end of life. Moreover, there is truth in the concept that if the patient does not make it clear they want to die at home, or having other choices respected, their chances of doing so are very much reduced [120]. However, patient choice will not make the quality of end of life care better is it is currently variable in terms of levels of provision and basic things such a pain relief as demonstrated by our Atlas of Variation in Palliative and End of Life Care, the Global Atlas and the VOICES surveys of bereaved relatives in England on quality of care [5, 11, 258].

The concept of choice at the end of life is widely promoted in tones that sound neoliberal 'die as you have lived' but without any philosophical or ethical underpinning theory [120, 154]. In the diminishing world of possibilities for the elderly dying patient it seems at best disingenuous. Indeed, I presented this concept in 2016 at the European Association of Palliative Care conference under the title 'The 'Choice Funnel' of Life – starts wide but ends narrow. Easy conclusions from big numbers' [283].

The choice on offer is in fact moulded by the paternalistic policy makers based on what they believe patients want – choice in place of care and death – which also ideally should be home, and what they believe to be good for elderly patients - to refuse various types of intervention such as CPR [32]. There have been calls for a more critical look at end of life care outcomes, especially those which are important to the patient [35, 475]. Indeed, even from a human rights perspective it would be better to ensure universal access to competent doctors who can provide pain and symptom relief day and night whatever the location of the patient rather than putting the responsibility on the patient to choose a place of care like home where they may have a worse chance of good symptom relief [258]. Moreover, the choice of how to make choices is not really a choice with almost all policy and campaigning effort being directed towards encouraging people to complete written Advance Directives [33]. National Policy is based on experience with cancer patients and predominantly younger cancer patients not sufficiently on knowledge about what older patients want [16, 104, 150, 249].

Although much of specialist palliative clinical practice is evidence based [80, 143, 365], specialists in palliative care have sought to extend their practices to the generality of patients who differ in many ways from those they are used to caring for [36, 160]. Each major initiative, the LCP, Dying Matters and the 1% Campaign has lacked adequate trial evidence of their effectiveness when applied to an elderly population and/or a framework for evaluation of the roll out as recommended in the wake of the findings of the LCP Review [445]. In particular, the campaigns have not been fully informed by research specifically with older people, although they are the majority target audience, to gain an understanding of what elderly patients who are close to death want [138]. Rather like the problems encountered with the Liverpool Care Pathway (LCP), an initiative which seemed very good in a specialist palliative care setting for young cancer patients, many of whom would prefer to die at home or in a hospice, has been extrapolated into a national campaign. The population targeted is now is predominantly elderly, the majority of whom will deteriorate slowly and die in a far less predictable and very different to the way to cancer patients enter the terminal phase and die [7, 466, 470, 514]. Moreover, the majority of the target population are elderly and they are rarely afforded the luxury of having their case reviewed at multidisciplinary meetings with fast referral to specialist palliative care [54, 119, 190, 245, 246]. Also, unlike the majority of patients who die in hospices, who are young cancer patients, elderly patients, in reality, have virtually no chance of dying in a Hospice even if is the preferred place of death for the majority of elderly people [160].

The national campaigns in England are promoting a choice agenda which does not link with what is known from the published literature about the priorities of elderly patients, which are about dignity, not being a burden and feeling safe and supported or reassured in their fear of the dying process and supported in their loneliness both real and existentialist [34, 62, 114-116, 148, 160, 199, 249, 279, 295, 296, 313, 327]. Instead they are selling a choice which may actually not be achievable especially about place of care and place of death [34, 515]. As a starting point, health and social services need to be equally good in every part of the country to make offering choice a fair an honest proposition. My team have shown this is not the case [11]. For example, the death rate for elderly patients in hospital is very high in London and the number of care home beds per head of population aged 75 years and older is the lowest in the country and more elderly people live alone than outside London. Therefore, if patients are too frail to care for themselves at home, there is little extra option except to be admitted to hospital [11].

These campaigns may be even be causing harm by suggesting these choices exist as not only patients, but particularly relatives, may suffer significant psychological morbidity when choices cannot be achieved [69, 113, 301].

The campaigns are also trying to establish new (or a return to old) social norms where people plan for death and more people die at home. However, the reality of today cannot be airbrushed into a glowing haze of idealised death in previous generations. Firstly, in the past many people died suffering without any medical care and, before welfare states, they died in and from abject poverty. Secondly, the population today cannot suddenly become immune to the medicalisation of life and death and the lived example of people's increasing life expectancy and miraculous, medicine mediated, escapes from the jaws of death [207, 281, 402, 513]. Thirdly the pattern of decline and causes of death, for example dementia and frailty as major causes are very different from the past [17, 83, 166, 168]. Furthermore, because increasing the number of people dying at home may result in financial benefits to the health system [464] caution needs to be exercised by the state in promoting a social norm of dying at home. The campaign may back-fire and prompt public anger if perceived to be a cost saving measure. Moreover, although costs for the state funded services may be reduced these will be born elsewhere, primarily by the elderly people and their families. Furthermore, from a physical and mental health perspective caring for a dying elderly patient at home may not be in the best interests of many elderly patients and their families [114, 150, 160].

Rabbi Baroness Julia Neuberger, who chaired the LCP Inquiry, raised the 'issue of questions of conscience as being the real problem. Since the middle of the twentieth century we have had choices about how we die in the Western world. We can make choices about how hard to try to stay alive, whether to ask for pain control or be heroic or to ask for probably futile interventions' [39]. Old authorities, the church, tradition or duty which gave guidance on how to die and make end of life choices are being replaced by the authority of the individual self [207]. This approach is alright in commercial decisions, especially if one follows trends, there is information and other people's examples to follow. A mistake is not critical the product can be taken back, sold or given away. However, there are no rehearsals for death (usually) and today people face anomie regarding what they should think or do about death. Perhaps this is one of the reasons why elderly people do not appear to want to plan – they no longer have guides to follow [207].

In this consumer age, constraints are seen as undesirable because they limit choice. Yet constraint in activities and choices is a fact of life in P&EOLC especially for elderly patients. There are limits to the health and social services provided and there are constraints imposed by terminal conditions and their treatments and families' abilities to contribute to care [11, 24, 126, 136, 241, 299, 311]. P&EOLC policy makers are not transparent enough about resource limitations and even practical clinical problems that will limit choice in P&EOLC.

Lessons have not fully been learned from the LCP experience about harm which can be inadvertently caused by inadequately trialled and tested initiatives. Moreover, there is a risk that harm and will not be detected without an ongoing evaluation framework in place [36, 39, 40, 445].

Many of the findings of this thesis may appear strange to a Polish audience. The description of anomie with respect to death and dying encountered in England [207, 318] would probably be a rare occurrence in Poland, where the majority of elderly people still profess a Roman Catholic faith and traditional practices associated with dying and funerals are still widely followed by the majority of the population [145]. This means that for many elderly people in Poland, they would express and enact their autonomy within the bounds of a traditional and well defined context that they and everyone else was aware of. The idea that choices have to be forcefully stated, communicated and recorded regarding future care may also seem unusual as may a neoliberal approach to the patient’s wishes being considered almost in isolation from their family and community. In England, this focus on individual autonomy also seems to be at odds with the actual views of elderly patients who place great emphasis on their interdependence with, and duty towards, other family members [354]. In Poland the development of Palliative and Hospice Care has from its initiation had a strong underpinning of social solidarity [145]. In England, social solidarity was also a founding principle for Dame Cicely Saunders, the pioneer of the hospice and palliative care movement, but P&EOLC, while maintaining a rhetoric about the importance of non-medical issues has become increasingly medicalised [207].

In Poland, in contrast to England, attention the spiritual, psychological and social wellbeing of patients approaching the end of life is still on an equal footing with medical provision of care and do not have to be reinvented as pseudo medical activities as in England [145]. In England, the need to emphasise attention to the non-medical needs of patients reflects the secularisation and medicalisation of dying and death [207, 318]. Indeed, while multi-disciplinary care is practiced in Hospices in England, in the community at home or in care homes it will be largely left to the doctors to try and identify whether patients have needs in any of these spheres. In Poland multidisciplinary working is widely found in home care palliative care services [145].

There are many other dynamics which differ in the relationship between the state and leaders and experts in P&EOLC between Poland and England which may impact on the way policy has evolved. In England, while the Hospice Movement pioneered P&EOLC, it is the case that national policy is now largely determined by senior officials working for the state, although advised by specialists in palliative care, so generic state policies related to the provision of health and social care services have a strong impact on P&EOLC policies. In Poland, while the government has provided support since the 1993 founding by the ministry of Health and Social Welfare of the National Council of Palliative Care, the Hospice movement, under the Hospice Foundation still plays a leading role in policy development [145].

Perhaps one of the most interesting areas of contrast is the focus for national campaigns. In England, the ‘Dying Matters’ campaign has been aimed at encouraging individual to exert their autonomy with respect to dying and death, to talk about what they want and to make plans [32]. The major underpinning theme is the promotion of autonomy through the exertion of choices regarding the care wanted or hoped for. In contrast, social campaigns in Poland have had a more societal approach to promote solidarity with the frail elderly and dying. One aim is social education. Each year the Hospice Foundation conducts the national social campaign ‘Hospice is also Life’ which aims to reduce peoples’ fears and taboos about the role of hospice care and to educate the population about terminal care. In 2008 the Hospice Foundation ran the Campaign ‘Dying in a human Way’ These campaigns have achieved wide media coverage including documentaries and interviews on TV and radio and each year have addressed different topics such as communication with patients and their relatives as in ‘Bring the Truth in Time’ or opportunities for volunteering. These latter campaigns such as the 2011 ‘Volunteer at 50+’ emphasise the benefits to the volunteers themselves too with strap lines such as ‘how much you can gain by becoming a volunteer’. Other campaigns have also raised the profile of issues related to frailty and dying by encouraging volunteering. One example is the ‘Pomaganie jest pięknie!’ (Helping is Beautiful) – Activation of Senior Citizens through Care-Orientated Voluntary Service campaign organised by the Pomeranian School of Care-Orientated Voluntary Service (PSWO) [175]. This aimed to develop a voluntary service within long-term home care and at health and social care facilities, taking the objectives of good practice in the hospice voluntary service to these settings. This approach not only raises population awareness of the needs of the frail elderly but helps to find a practical solution to support overstretched health and social care services and provides older people who volunteer with a purpose in life [145]. The three year ‘I like to Help’ project helped to build a national network of voluntary service centres, unique across Europe. Elements of this initiative included a social campaign as well as training and education in schools. The volunteer centres developed co-operation with local schools, universities, the media and businesses. One of the most innovative, prize winning and unique in the world, campaigns has been to train volunteer prisoners to act as care assistants in hospices and care homes and the project has been implemented in over 30 facilities [145]. It is interesting to reflect whether these very different approaches reflect real cultural differences in the populations of Poland and England or whether it is more reflective of the personal views of those who have led the campaigns. In England the campaigns focus on individual needs, in Poland on societal solidarity.

This difference in emphasis may also underpin the difference in interest between the two countries in Advance Care Planning. The Polish Constitution and legislation protects patients' rights to self-determination and choice when it comes to medical decisions about their care and such decisions are made in full knowledge of the patient's situation in that moment [346]. In Poland there have been discussions about 'pro-futuro' statements and legally appointed surrogate decision makers, which indeed can already be appointed by a court in the case of a patient without mental capacity [219, 352]. It is yet to be what general interested there would be among the general population. In England, the level of uptake of Advance Care Planning and/or Legal Power of Attorneys is still very low and the elderly in particular do not seem interested in these formal approaches to planning for future, possibly unpredictable medical scenarios. As described in earlier chapters, perhaps this reflects their wisdom and life experience about the unpredictability of life and death and the difficulty in planning for this.

In Conclusion, elderly patients approaching the end of life have, in general, different medical, psychosocial, spiritual and existentialist care needs from the average patients cared for by specialists in palliative care [62, 63, 87, 115, 152, 307, 321]. However, at present there is too little known about their needs and how best to meet them in a way which will maximally promote their autonomy. National policy on P&EOLC in England and across the world needs to start addressing the issues for the majority of people who die who are elderly patients.

State provided health and social care services are already over stretched and as the elderly population grows are unlikely to be sufficient to provide all the care needed. Families, friends, neighbours and volunteers already contribute to care but the need for their contribution is likely to increase so the benefits and risks, to the autonomy and safety of elderly people, of greater input from non-professional care need to be better understood [163, 177, 311, 516].

There are many legal and regulatory structures in place in England to protect the human rights of elderly people in health and social care settings and this goes part way to protecting and promoting their autonomy [45-48, 441]. Nevertheless, it is clear that not only more training is required for health and social care staff but still greater focus needs to be placed on listening to elderly patients and their families and placing them at the centre of care decision making.

A campaign for doctors and the general population focussing on kindness, compassion, respect or ‘what can I do for you’ may be actually more autonomy respecting of individual elderly patients than trying to persuade the elderly people to make choices they do not want to make, in a way they do not want to, about issues which are not top of their priority list [67, 154, 184, 228, 517-519]. Indeed Poland provides a great example of this population based approach of solidarity for the dying [145]. Across the world national and local strategies are developing to build compassionate communities for P&EOLC this may produce better quality care for elderly patients especially those who live alone than any effort to persuade them to make Advance Care Plans [67, 68, 184, 370, 517, 518, 520-524].

Recommendations

This thesis has identified several areas for action to ensure better quality and autonomy protecting and promoting care for elderly patients. These fall into two groups: improving universally the quality of EOLC for elderly patients in all settings and to gain a better understanding of elderly patients' views about dying and death and how they want to approach it.

Better universal EOLC for elderly people

- Achieve a much better understanding of the medical and social care needs of elderly patients and ensure that services are universally improved across the country to deliver a model suitable for elderly patients by involving geriatricians and elderly patients.
- Use this enhanced knowledge to educate health professionals about end of life care for elderly patients and make it everyone's business not just specialist palliative care
- Quantify geographical variation and inequalities in access to care based on patient and disease characteristics in elderly patients.*
- Increase the understanding of how to care for the most vulnerable elderly patients who have no family of social network.*
- Explore the options for incentivising families and volunteers to support elderly people approaching the end of life as an adjunct to state provided services.*
- More training for doctors and nurses in human rights issues for example using the course devised by the Sue Ryder Charity with the British Institute of Human Rights [368].

Improve understanding of elderly patients' thoughts regarding dying and death

- Improve understanding of elderly patients' opinions regarding dying and death.*
- Undertake research to elucidate elderly patients understanding of, and opinions about, Advance Care Planning for P&EOLC including the role of surrogates both through Legal Power of Attorney and informal surrogates. Identify barriers and incentives to recording wishes or thoughts if elderly patients would like to do this including solutions not currently offered.*

*Work on these latter themes is already underway within my research group.

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Appendix 1

Abstracts presented at the European Association of Palliative Care conferences which directly derive from work undertaken for this doctoral thesis

2019

Verne, J., Ethics of Using Prognostic Tools to Screen General Practice Populations to Identify People Approaching the End of Life – A Comparison with the WHO Wilson and Jungner 1968 Criteria for Screening Programmes. (Poster)

2018

Published in Palliative Medicine, Volume 32 Issue 1_suppl, May 2018 (First Published April 20, 2018; pp. 3–330)

Verne, J., Pring, A., Bowtell, N., Living alone, in poverty and loneliness – challenges for pensioners wishing to be cared for and die at home in England. (Poster)

Verne, J., Pring, A., Bowtell, N., Dementia and End of Life Care - Implications of Deprivation of Liberty Safeguards in England. (Poster)

2016

Published in Palliative Medicine June 2016 vol. 30 no. 6 NP1-NP401 Online 11 May 2016, doi: 10.1177/0269216316646056

Verne, J., The ‘choice funnel’ of Life - starts wide but ends up narrow: easy conclusions from big numbers. Online 11 May 2016, (Poster)

2015
Verne, J., Linguistics and the burden of ‘guilt’ in bereaved relatives. (Poster)

2012
Verne, J., State Paternalism and Individual Autonomy in End of Life Care. (Poster)

Appendix 2

List of Peer Review Publications on End of Life Care March 2013- July 2019

Jul-19	Public Responses to Voluntary Community Care: Propositions for Old age and End of Life. A Tapp, C Nancarrow, Y Morey, S Warren, N Bowtell, J Verne. PLOS One. https://doi.org/10.1371/journal.pone.0218597
May-19	Urban and Rural differences in Geographical accessibility to inpatient Palliative and End-of-Life (PEoLC) facilities and Place of death: a national Population-based study in England, UK. Emeka Chukwusa; Julia Verne; Giovanna Polato; Ros Taylor; Irene Higginson; Wei Gao. International Journal of Health Geographics. 2019 May 6;18(1):8. doi: 10.1186/s12942-019-0172-1.
Apr-19	Socioeconomic position and use of health care in the last year of life: a systematic review and meta-analysis. J Davies, K Sleeman, J Leniz, R Wilson, I Higginson, J Verne, M Maddocks, F Murtagh. PLOS Medicine. Publication due 23/04/19
Feb-19	The role of service factors on variations in place of death: an observational study. Gao W, E Chukwusa, J Verne, P Yu, G Polato, I Higginson. Health Services and Delivery Research Volume: 7, Issue: 8, Published February 2019. https://doi.org/10.3310/hsdr07080
Nov-18	Factors associated with older people's emergency department attendance towards the end of life: A systematic review. Anna Bone, Catherine Evans, Simon Etkind, Katherine Sleeman, Barbara Gomes Da Silva, Melissa Aldridge, Jeff Keep, Julia Verne, Irene Higginson. European Journal of Public Health. https://doi.org/10.1093/eurpub/cky241
Nov-18	The Impact of Sociodemographic Factors and Emergency Admissions on the Place of Death of Gynecological Cancer Patients in England: An Analysis of a National Mortality-Hospital Episode Statistics-Linked Data Set. Sonali Kaushik, Luke Hounsome, Catherine Blinman, Robert Gornall, Julia Verne. International Journal of Gynecological Cancer: November 2018 - Volume 28 - Issue 9 - p 1714–1721 doi: 10.1097/IGC.0000000000001373
Nov-18	Gathering momentum for the way ahead: fifth report of the Lancet Standing Commission on Liver Disease in the UK. Roger Williams, Graeme Alexander, Richard Aspinall, Rachel Batterham, Neeraj Bhala, Nick Bosanquet, Katherine Severi, Anya Burton, Robyn Burton, Matthew E Cramp, Natalie Day, Anil Dhawan, John Dillon, Colin Drummond, Jessica Dyson, James Ferguson, Graham R Foster, Ian Gilmore, Jonny Greenberg, Clive Henn, Mark Hudson, Helen Jarvis, Deirdre Kelly, Jake Mann, Neil McDougall, Martin McKee, Kieran Moriarty, Joanne Morling, Philip Newsome, John O’Grady, Liz Rolfe, Peter Rice, Harry Rutter, Nick Sheron, Douglas Thorburn, Julia Verne, Jyotsna Vohra, John Wass, Andrew Yeoman. The Lancet. http://dx.doi.org/10.1016/S0140-6736(18)32561-3
Aug-18	Specialist palliative care providers’ perspectives on how to meet the service delivery challenges in adult care homes in England: a national survey. Alisha Newman, Gemma Allnatt, Nicola Bowtell, Kerry Archer-Dutton, Anita Hayes, Mirella Longo, Andy Pring, Amanda Read, Ros Taylor, Julia

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