

The Influence of Hospital Policies and Culture on Do-Not-Resuscitate Decision-Making at the End of Life: A Sociological and Ethical Analysis



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Declaration

This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text. It is not substantially the same as any that I have submitted, or, is being concurrently submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution. I further state that no substantial part of my dissertation has already been submitted, or, is being concurrently submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University of similar institution. This thesis, at 76,945 words, does not exceed the prescribed word limit of 80,000 words exclude figures, photographs, tables, appendices and bibliography.

Elizabeth W. Dzeng

8 July 2015

“In Ethiopia, and even in Nairobi, people assumed that all illness – even a trivial or imagined one – was fatal; they expected death. The news to convey in Africa was that you’d kept death at bay. Those things that you couldn’t do, and those diseases you couldn’t reverse, were left unspoken. It was understood...”

In America, my initial impression was that death or the possibility of it always seemed to come as a surprise, as if we took it for granted that we were immortal, and that death was just an option.”

*“Cutting for Stone”
Abraham Verghese*

“How little do doctors understand the hells through which we put patients.”

“[We] had trained for years to actively engage with death, to grapple with it, like Jacob with the angel, and, in so doing, to confront the meaning of a life. We had assumed an onerous yoke, that of mortal responsibility. Our patients’ lives and identities may be in our hands, yet death always wins. Even if you are perfect, the world isn’t. The secret is to know that the deck is stacked, that you will lose, that your hands or judgment will slip, and yet still struggle to win for your patients. You can’t ever reach perfection, but you can believe in an asymptote towards which you are ceaselessly striving.”

*“When Breath Becomes Air”
Paul Kalanithi*

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Abstract

The aim of this thesis is to explore how institutional cultures and policies relating to patient autonomy influence physicians' clinical and ethical approaches to do-not-resuscitate (DNR) decision-making at the end of life. I explore this in the context of the evolution of the American medical profession that shifted medical decision-making power from paternalism to patient autonomy. Decades ago, the "doctor knows best" attitude prevailed. Since then, the pendulum has swung towards honouring patient autonomy. This thesis explores the implications of these changes and considers the tensions between the principle of beneficence and patient autonomy.

I conducted 58 semi-structured in-depth interviews with internal medicine physicians, sampled by years of experience and medical subspecialty. These interviews were conducted at three academic medical centres in the United States (University of Washington, Johns Hopkins, Columbia New York Presbyterian) and one in the United Kingdom (Addenbrooke's Hospital). It emerged during the research process that two of these four hospitals had policies that prioritised patient autonomy whereas the other two hospitals had policies that prioritised making decisions in the patient's best interest. The main focus of this dissertation is on the United States, where three of the hospital sites are located. The UK serves as an additional site as there are no hospitals in the United States that permit unilateral physician decision-making in the way that the UK allowed at the time of the study.

The focus on autonomy in American medicine today highlights the importance of freedom and choice to make one's own decision. However, to truly honour patient autonomy, the patient or surrogate must have an adequate understanding of his situation and choices. Although the shift away from paternalism was a necessary positive step, I argue that the way in which autonomy is practiced reflects a reductionist notion of autonomy that disempowers rather than empowers patients, as patients are asked to make choices without the understanding or guidance necessary to make informed choices.

Particularly at hospitals where autonomy is prioritised over other ethical principles such as best interest, trainee physicians equate autonomy with giving a menu of choices. They are uncomfortable giving a recommendation based on clinical knowledge as they worry that would be infringing upon patient autonomy. However, trainee physicians feel ethically compromised and experience significant moral distress when they are asked to provide therapies that they perceive to be futile.

Despite that, doctors are still power brokers in the physician patient relationship and are able to manipulate conversations in other ways to sway patients towards a decision that they believe is in the patient's best interest. Through a Habermasian approach, I explore how trainee communication practices of using purposefully graphic descriptions of resuscitation to discourage that choice are pathologic and disempowering. Physicians are fully inculcated in their respect for autonomy but unintentionally resort to strategic forms of communication because they feel constrained to resist recommendations in the name of autonomy. Rather than focusing on an ideology of autonomy, the American medical system needs to move towards practices that embrace a more nuanced and empathetic form of autonomy that fosters a more open form of communication that allows for co-creation of consensus between doctors and patients.

Table of Contents

Declaration.....	3
Acknowledgements.....	5
Abstract.....	8
Table of Contents.....	10
List of Figures.....	14
List of Tables.....	15
List of Abbreviations.....	16
Chapter 1: Introduction.....	17
1.1: Introduction of the Thesis.....	17
1.2: Structure of the dissertation.....	23
Chapter 2: The Changing Role of the American Medical Profession from the 1950s to the Present.....	30
2.1: Introduction.....	30
2.2: The Rise and Fall of the Profession of Medicine.....	32
2.3: Consumerisation’s Contribution to Sociological Changes in the Medical Profession.....	35
2.4: Deprofessionalisation of the Medical Profession.....	37
2.5: Loss of Knowledge Monopoly.....	38
2.6: Proletarianisation of the Medical Profession.....	39
2.7: Erosion of Public Trust in Physicians.....	41
2.8: Conclusion.....	44
Chapter 3: End of Life Care in the United States.....	47
3.1: Introduction.....	47
3.2: Dying a “Good Death”	49
3.3: Structural Constraints to Dying a Good Death.....	50
3.4: CPR at the End of Life.....	53
3.5: Futile Resuscitation at the End of Life.....	54
3.6: US and UK Differences in Resuscitation Practices.....	57
3.6.1: British Policy Regarding End of Life Decision-Making.....	60
3.6.2: Implications for Clinical Practice and in Particular ICU Triage.....	61
3.6.3: Palliative Care in the US and UK	62
3.6.4: Decision-Making Following the Loss of Patient Capacity.....	63
3.6.5: Existing Literature Addressing US-UK End of Life Issues.....	64
3.7: Conclusion.....	65
Chapter 4: Methods.....	67
4.1: The Interaction of Sociology, Bioethics, and Medicine.....	67

4.2: Constructionism as my Epistemology and Interpretivism as my Theoretical Position.....	70
4.2.1: Symbolic Interactionism.....	71
4.2.2: Critical Theory.....	72
4.3: Methodology.....	74
4.3.1: Analytical Approach During Interviews.....	75
4.3.2: Insider Research and Auto-Ethnography.....	76
4.4: Methods and Study Design.....	77
4.4.1: Pilot Interviews.....	77
4.4.2: Hospital Sample.....	78
4.4.3: Initial Hypotheses.....	81
4.4.4: Evolution of My Hypotheses During the Study.....	82
4.4.5: Institutional Changes During the Course of the Project.....	84
4.4.6: Ethical Considerations.....	85
4.4.7: Physician Sample.....	86
4.4.8: Interview Guide and Interview Process.....	88
4.4.9: Data Management.....	90
4.5: Analysis.....	91
4.5.1: Coding of Transcripts.....	91
4.5.2: Second Coder.....	93
4.5.3: Synthesis of Data Following Coding.....	94
4.5.4: Member Checking and Ethnographic Validation.....	96
4.6: Reflexivity, Self and my Research.....	98
4.7: Conclusion.....	101

Chapter 5: Influence of Institutional Culture and Policies on Do-Not-Resuscitate Decision Making at the End of Life.....102

5.1: Balancing the Ethical Principles of Autonomy and Beneficence.....	102
5.2: Demographic Characteristics of Study Participants.....	105
5.3: Institutions Prioritise Patient Autonomy or Patients' Best Interest.....	105
5.4: Experienced Physicians at All Sites were Willing to Recommend Against CPR when Resuscitation was Unlikely to Work.....	108
5.5: Inexperienced Physicians at Autonomy Focused Hospitals Felt Obligated to Offer Choice of CPR Without Explicit Recommendations Even if Success was Unlikely.....	109
5.6: Perceived Conflict Between Physicians and Patients.....	112
5.7: Conclusion.....	116

Chapter 6: Principlism in Practice: Moving Beyond an Ethics of Choice.....121

6.1: Introduction.....	121
6.2: Sociological Trends in Patient Autonomy and Decision-Making.....	122
6.2.1: The Shift Towards Autonomy as a Consequence of the Social Transformation of Physicians.....	122
6.2.2: The Rise of Autonomy and its Challenges to Beneficence.....	123

6.2.3: Models of Decision-Making.....	125
6.2.4: Debates Surrounding the Principlist Approach.....	127
6.3: An Ethics of Choice?.....	128
6.3.1: Respect for Autonomy Misconstrued as Giving Choice.....	128
6.3.2: Autonomy or False Choice?.....	130
6.3.3: Ethical Challenges in Surrogate’s Substituted Judgement.....	131
6.3.4: Why Having Choice Isn’t Always Better.....	137
6.3.5: Issues of Time.....	138
6.3.6: Time to Shift the Focus From the Outcome to the Process?.....	139
6.4: Understandings of Autonomy.....	143
6.4.1: Patient Understanding of Illness as a Challenge to Fulfilling Autonomy.....	143
6.4.2: Prognostication and Truth Telling in Autonomy.....	144
6.4.3: Balancing Principles	146
Section 6.4.3.1: Conflicts or Harmony Between Autonomy and Beneficence.....	146
Section 6.4.3.2: Balancing Justice.....	150
6.4.4: Self-Surveillance Magnifies the Effect of Policies and Litigation.....	152
6.4.5: The Importance of the Hidden Curriculum in Moulding Local Normative Ethical Beliefs.....	156
6.4.6: Critiques of Autonomy in Practice.....	158
6.5: Conclusion.....	160

**Chapter 7: Moral Distress and Alienation in US Physician Trainees Regarding
Futile End of Life Care.....165**

7.1: Introduction.....	165
7.2: Futility.....	167
7.3: Site-Specific Variations in Futility Policies and Practices.....	169
7.4: Themes of “Torture” and “Suffering”.....	171
7.5: Perceived Powerlessness.....	172
7.6: Dehumanisation and Rationalisation.....	174
7.7 : Moral Distress.....	174
7.8: Can Moral Distress Lead to Declines in Empathy and Burnout?.....	176
7.9: A Crisis of Alienation in Medical Education.....	178
7.10: Academic Medical Centre Hierarchy.....	180
7.11: Coping Mechanisms Against Moral Distress.....	181
7.12: Conclusion.....	185

Chapter 8: Communication Pathologies in End of Life Care.....188

8.1: Manipulation versus Persuasion.....	188
8.2: Empirical Findings Demonstrating Manipulative Communications.....	191
8.3: Communication Pathologies from the Perspective of Habermas’ Theory of Communicative Action.....	197

8.3.1: Communication Pathologies in End of Life Conversations – Relating Back to the Interview Data.....	201
8.3.2: Micro-Actions Reflecting Macro-Sociological Changes.....	204
8.3.3: Critique of the Literature on the Applications of Habermas to Medicine and a Proposed New Direction.....	206
8.3.4: The Unintended Consequences of Individual Actions Producing the Structure of Wayward Autonomy.....	210
8.3.5: Problems with Applying Habermas’ Theory of Communicative Action to End of Life Conversations.....	213
8.4: Language and Framing.....	214
8.5: Conclusion: Autonomy, Ideology, and Emancipation.....	223
Chapter 9: Conclusion.....	227
9.1: Summary of the Thesis.....	227
9.2: Policy Implications.....	232
9.3: Limitations.....	237
9.3.1: Self-reflexivity as a Researcher.....	237
9.3.2: Limitations on the Methodology.....	239
9.3.3: Limitations Related to Hospital Sampling.....	241
9.4: Changes in Institutional Culture and Policy During the Study.....	243
9.5: Future Directions.....	245
9.5.1: Further Descriptive Studies Needed to Determine Generalisability of Results.....	245
9.5.2: Potential Future Interventions: Communication Pathologies and Culture Change.....	247
9.6: Closing Thoughts.....	248
Appendices.....	251
Appendix A. NHS East of England’s DNACPR Flowsheet for DNACPR Decision Making.....	251
Appendix B. DNR Forms for Columbia New York Presbyterian Hospital.....	252
Appendix C. DNACPR Form for NHS East of England and Addenbrooke’s Hospital.....	258
Appendix D. Sample DNACPR Form from Addenbrooke’s Hospital.....	259
Appendix E. Consent Forms for the US and UK.....	260
Appendix F. Participant Information Sheets for the US and UK.....	267
Appendix G. Recruitment Email for the US and UK.....	272
Appendix H. Initial Interview Guide.....	274
Appendix I. Final Working Code Book.....	277
Appendix J. Initial Codebook.....	282
Appendix K. Sample Transcript with Hand Coding.....	285
Appendix L. Sample Excel Spreadsheet.....	286
Appendix M. Final Codebook.....	287
References.....	302

List of Figures

Figure 1.1: How Institutional Policies and Cultures Influence Physician Trainees' Attitudes and Communication Practices.....	24
Figure 5.1: Differences in Physicians' Willingness to Make Recommendations.....	112
Figure 8.1: Communicative and Strategic Action.....	199
Figure 8.2: Mishler's Voices of Medicine and the Lifeworld.....	200

List of Tables

Table 4.1: Hospital Characteristics and DNR Policies.....	79
Table 5.1: Demographic Characteristics of Study Participants.....	105
Table 5.2: Selective Illustrative Quotations of Institutional Ethical Priorities.....	107
Table 5.3: Selective Illustrative Quotations of Experienced Physicians' Willingness to Recommend.....	108
Table 5.4: Selective Illustrative Quotations of Inexperienced Physicians' Willingness to Make Recommendations.....	110
Table 5.5: Selective Illustrative Quotations Describing Degree of Conflict Between Physicians and Patients Regarding DNR Decisions.....	114

List of Abbreviations

CMT	Core Medical Trainee (UK)
CPR	Cardiopummonary Resuscitation
DNR	Do Not Resuscitate. Variations on this include DNACPR (Do Not Attempt CPR) and DNAR (Do Not Attempt Resuscitation)
FY	Foundation Year (FY)
ICU	Intensive Care Unit
PBE	<i>Principle of Biomedical Ethics</i> (Beauchamp and Childress 2013)
PGY	Post Graduate Year (US)
SpR	Specialist Registrar (UK)
UW	University of Washington
UK	United Kingdom
US	United States of America

Chapter 1: Introduction

Section 1.1: Introduction of the Thesis

There has been increasing recognition in the United States that Americans are neither dying well nor the way that they want to. Recent publications highlighting challenges in end of life care such as the Institute of Medicine's report on *Dying in America* and Atul Gawande's book, *Being Mortal*, among others, demonstrate the urgent need to better align medical care at the end of life with patient and societal preferences (Gawande 2014; Institute of Medicine 2014). The majority of Americans who have indicated end of life preferences choose to focus on alleviating suffering and pain, and prefer to die comfortably at home rather than with aggressive care in the hospital (Bernstein 2014).

Despite that, the medical system is programmed to a default setting of aggressive care for the terminally ill. Intensive care unit (ICU) use in the last month of life increased from 24% to 29% from 2000 to 2009 (Teno et al. 2013). Beyond issues of quality of care and honouring patient preferences, this has significant economic implications. It is problematic that the \$170 billion that Medicare spends on the last six months of life is not helping us die well (Pasternak 2013). Neither physicians nor patients are satisfied with their society's overall approach to dying, and yet both seem powerless to enact substantive change.

A particularly compelling reason to explore this issue in the United States is the intersection of three trends: 1) The aging of the population and in particular of the baby boomers, many of whom will be facing end of life issues over the next 15-20 years. In the 2010 census, those aged 85 to 94 were the fastest growing age group, at more than 5 million people (United States Census Bureau 2012). 2) The increasing use of advanced technologies at the end of life, the consequent ethical imperative to use these technologies, and the consequent prolongation of the dying process (Livingstone 2015); and 3) The unsustainable growth in health care expenditures in the face of uncertain economic times in the US. End of life medical care constitutes 10 to 12% of the total

health care budget and 27-30% of the Medicare budget (Halpern and Emanuel 2012). Costs in the last month of life constitute 40% of cost in the last year of life.

The aim of this thesis is to explore how institutional cultures and policies relating to patient autonomy influence physicians' clinical and ethical approaches to do-not-resuscitate (DNR) decision-making at the end of life. I explore this in the context of the evolution of the American medical profession where medical decision-making has shifted from paternalism to patient autonomy. Decades ago, the "doctor knows best" attitude prevailed. Since then, the pendulum has swung towards honouring patient autonomy. This thesis explores the implications of these changes and considers the tensions between the principle of beneficence (best interest)¹ and patient autonomy.

From 7 March, 2013 to 8 January 2014, I conducted 58 semi-structured in-depth interviews with internal medicine physicians, sampled by years of experience and medical subspecialty. My epistemologic foundations are rooted in constructivism, while my theoretical perspectives incorporate the interpretivist perspective of symbolic interactionism, followed by critical theory in the latter half of the thesis. Included in the study were physicians between one and 45 years of experience in general medical disciplines as well as medical subspecialties (i.e. palliative care, pulmonary and critical care medicine). During the interview process, patterns emerged differentiating attitudes and beliefs of more experienced and less experienced physicians, so subsequent analysis of the project further partitioned participants into stage of training².

¹ In this thesis, I will use beneficence and best interest interchangeably

² In the US, medical training following medical school begins with residency where they are called "residents" (of which the first year is called "internship"). Internal medicine residency is three years long. Following residency, physicians may either choose to go into practice as an attending general internist or hospitalist, or they continue with a subspecialty fellowship that typically lasts between 3-4 years. A colloquial term frequently used to describe physician trainees is "house staff." Years following training in the US are referred to as "Post Graduate Year" (PGY), as in PGY-1 for interns, PGY-2 and PGY-3 for residents, and PGY-4 for fellows, and so forth. In the UK, following medical school, trainees participate in Foundation Training (F1, F2) for two years. Following Foundation Training, physicians can choose specialty training where they are a "Specialist Trainee (ST)" or "Specialist Registrar". The first period of specialist training includes "Core Medical Training (CMT)." In the US, senior physicians (i.e. medical team leaders) are called attending physicians. The UK equivalent is the consultant. In the US, a subspecialty team consultation physician is called a consultant.

In this thesis, I have primarily been interested in the attitudes and beliefs of doctors, and their perceptions of care delivered and its effect on them. As such, semi-structured interviews are the ideal methodology to explore these issues. In Chapter 8, I discuss communication pathologies that arise from physician trainees' manipulation and framing in these conversations. For this section, I can only base my hypotheses on physician reports rather than actual practices. However, the prevalence of these descriptions in the interviews as well as my own experiences on the wards suggest that these practices do indeed occur at some frequency. Future studies would be helpful to further explore and confirm these practices.

These interviews were conducted at three academic medical centres in the United States (University of Washington (UW), Johns Hopkins, Columbia New York Presbyterian) and one in the United Kingdom (Addenbrooke's Hospital). It emerged during the research process that two of these four hospitals had policies and cultures that prioritised patient autonomy whereas the other two hospitals had policies and cultures that prioritised making decisions in the patient's best interest. The original intent of this study was to compare US and UK practices, but it became apparent during my interviews at UW that local cultures played a key role. As such, the focus of my thesis shifted from a comparative analysis to its current form. The main focus of this dissertation is the United States, where three of the hospital sites are located. The UK serves as an additional site as there were no hospitals in the United States that permit unilateral physician decision-making in the way that the UK allowed during the time of my study.

The shifts towards autonomy occurred due to criticism of physician paternalism. The traditional attitudes of paternalism have given way to patient autonomy and an emphasis on individual choice to make decisions over one's body. Best interest decision-making reflects an understanding that there may be other factors that are important to prioritise beyond autonomy. Although best interest decision-making is far from paternalistic, comparing hospitals that prioritise autonomy versus best interest shines a light onto how

this shift from paternalism to autonomy has affected physician attitudes, behaviors, and communication strategies regarding DNR decision-making.

It is important to first discuss the distinction between beneficence (best interest decision-making) and paternalism, which can sometimes be a fine line. Although it is possible to be both beneficent and paternalistic, acting with beneficence does not imply that one is being paternalistic. Beneficence is characterised as acts that benefit others, or acting in one's best interest. Definitions of paternalism are varied. Beauchamp and Childress's definition of paternalism is when someone *overrides* an individual's wishes against their will, defended by a claim that the person would be better off or protected from harm through the paternalistic act (Beauchamp and Childress 2013). Acts of paternalism may also include purposeful deception such as failure to disclose a bad diagnosis or purposeful omission of critical elements of informed consent in order to skew the decision towards a particular treatment plan.

Variations on this definition include somewhat "softer" definitions including Allen Buchanan's where, "paternalism is usually characterised as interference with a person's liberty of action, where the alleged justification of the interference is that it is for the good of the person whose liberty of action is thus restricted (Buchanan 1978)." Gerald Dworkin's definition of paternalism is similar to that of Buchanan, where this interference is justified by "reasons referring exclusively to the welfare, good, happiness, needs, interests, or values of the person being coerced (Dworkin 1988)."

The specific example I use to explore these sociological and medical issues is the perceived *de facto* requirement to offer cardiopulmonary resuscitation (CPR) to terminal patients with little likelihood of survival. This one critical decision of resuscitation status has significant downstream effects, as well as consequences on the overall aggressiveness of care and overtreatment at the end of life. Although a DNR decision is but one small component of a goals of care conversation, focusing on this particular conversation allowed me to hone in on a discrete decision that serves as an exemplar of the challenges we face in end of life decision-making.

A DNR order is implemented when it would not be appropriate or desired to perform CPR and other life-sustaining measures when the heart stops. This procedure was first established in 1960 to restart the heart following certain cardiac arrhythmias such as ventricular tachycardia and was very effective in doing so (Cooper, Cooper, and Cooper 2006). Since then, its scope has been expanded to become the default in hospital for anyone who dies, despite the fact that its efficacy is extremely limited in most medical conditions. For most patients, CPR is entirely ineffective, as it does nothing to correct the underlying conditions, which caused the patient to die, such as terminal metastatic cancer.

Resuscitation is not harmless, as it requires cracking ribs to adequately pump the heart, insertion of invasive lines, placing a tube down the throat to ventilate the lungs, and electric shocks to the heart to attempt to restart it. It also means that the last moments of the patient's life are spent receiving an aggressive and possibly futile treatment surrounded by medical staff rather than in peace surrounded by loved ones. Many physicians believe that performing resuscitation when it is unlikely to work causes harm and suffering.

It is important to clarify the specific clinical scenarios in which a DNR order would be appropriate that I focus on in this thesis. I am primarily interested in decisions surrounding patients who are imminently dying or who have no chance of meaningful survival to discharge (Taylor, Gustin, and Wells-digregorio 2010). Some might describe this scenario as one where resuscitation would be futile, which I define further in Chapter 3. Based on physiologic parameters, co-morbidities, and typical standards of reasonable modern medical care in the US and UK, the patients population I focus on has an extremely low likelihood of meaningful survival following CPR and some have a zero chance of survival as they may be imminently dying. By focusing on this population, I seek to avoid value-based arguments surrounding the degree to which a life is worth living. The purpose of this thesis is not to engage in these philosophical, theological, and personal debates. The goal of my thesis was to explore physicians' perceptions and reactions to cases they felt to be significant and that adhered to their understanding of the

above parameters. I interviewed internal medicine physicians who engage in a wide variety of subspecialties. These physicians see patients with a broad array of medical pathologies. It would have limited the scope of responses and eligible respondents to limit the patient population to a specific disease type.

The focus on autonomy in American medicine today highlights the importance of freedom and choice to make one's own decision. However, to truly honour patient autonomy, the patient or surrogate must have an adequate understanding of their situation and choices. Although the shift away from paternalism was a necessary positive step, I argue that the way in which autonomy is practised reflects a reductionist notion of autonomy that disempowers rather than empowers patients, as patients are asked to make choices without the understanding or guidance necessary to make informed choices.

Particularly at hospitals where autonomy is prioritised over other ethical principles such as best interest, trainee physicians equated autonomy with neutrally giving a menu of choices. They are uncomfortable giving a recommendation based on clinical knowledge as they worry that would infringe upon patient autonomy. However, trainee physicians feel ethically compromised and experience significant moral distress when they are asked to provide therapies that they perceive to be futile. An important finding in this study was that inexperienced physicians (i.e. physician trainees) were more affected by their institutions' cultural and policy leaning than experienced physicians. Experienced physicians, regardless of where they were based, generally appeared to have a more nuanced understand of autonomy to mean more than merely giving choice, and seemed more comfortable giving recommendations.

Despite this discomfort, doctors are still power brokers in the physician patient relationship and are able to manipulate conversations in other ways to sway patients towards a decision that they believe is in the patient's best interest. Use of language and framing during these conversations can be used strategically in ways that hinder open communications, but the inevitability of framing must also be recognised. Through a Habermasian approach, I explore how trainee communication practices of using

purposefully graphic descriptions of resuscitation to discourage that choice are pathologic and disempowering to the patient. Central to this problem, are also issues of colonisation of the lifeworld by the system, not only from the patient's perspective, but also colonisation of the doctor's own lifeworld during medical training.

Physicians are fully inculcated in their respect for autonomy but unintentionally resort to strategic forms of communication because they feel constrained to resist recommendations in the name of autonomy. Rather than focusing on an ideology of autonomy, the American medical system needs to move towards practices that embrace a more nuanced and compassionate form of autonomy that fosters a more open form of communication that allows for co-creation of consensus between doctors and patients.

These communication pathologies are harmful because they may result in treatments that are neither in the patient's best interest nor consistent with their goals and values. Furthermore, my interviews demonstrate that situations where US trainees are asked to provide therapies and resuscitation that they perceive to be futile, causes significant moral distress, which may contribute to alienation, burnout and decreased empathy.

Section 1.2: Structure of the dissertation

This thesis highlights the importance of local institutional policies and cultures on physician trainees' conceptualisation of ethical principles. This in turn influenced trainees' willingness to make recommendations regarding resuscitation at the end of life, which subsequently influences the way they communicate their recommendations. The interviews revealed that less experienced physicians were more likely to be influenced by these factors than experienced physicians. The conceptual framework below summarises my hypotheses of how institutional policies and cultures influence physician trainees' attitudes and communication practices.

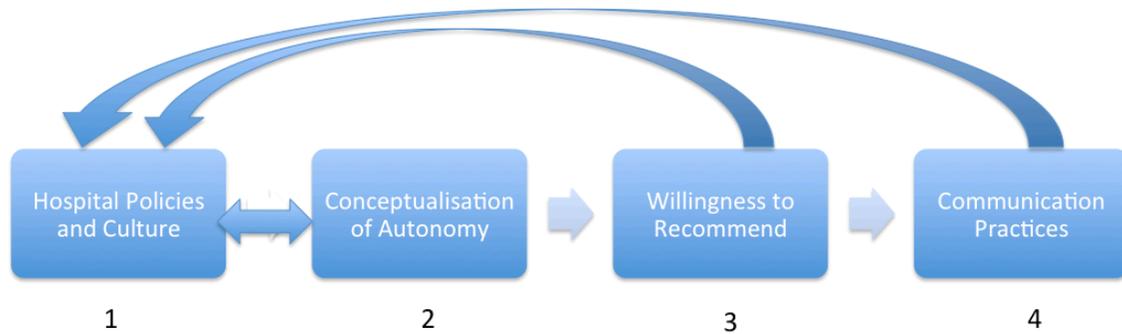


Figure 1.1: How institutional policies and cultures influence physician trainees’ attitudes and communication practices. Hospital Policies and Culture (step 1) influences how physicians conceptualise autonomy (step 2), which then influences their willingness to make recommendations regarding DNR decisions (step 3) and hence their communication practices surrounding DNR decision-making (step 4). However, this is not completely linear, as the actions and behaviours influenced by steps 2, 3, and 4 all contribute to and/or reinforce the existing hospital policies and culture.

In this introduction (**Chapter 1**), I outline my research question and the scope of the study. I then summarise the structure of the PhD and follow by introducing the conceptual framework that forms the structural backbone of the dissertation.

In **Chapter 2** of this thesis, I set the stage for how autonomy became the dominant discourse in the doctor patient relationship by describing the sociological transformation of the physician from the 1950s to the present, particularly in the United States. As a consequence of the deprofessionalisation, consumerisation, loss of trust and loss of knowledge monopoly, the American medical profession experienced a change in its power relations with patients. This contributed to the shifts from paternalism to autonomy in the physician patient relationship. **Chapter 3** hones in on the effect of this shift on the example of end of life decision-making, and specifically the decision to institute a DNR order.

Chapter 4 describes my methodological approach. I use Michael Crotty’s framework for conceptualizing methods, which focuses sequentially on Epistemology -> Theoretical perspective -> Methodology -> Methods. I outline how my constructivist perspective naturally leads to an interpretivist approach rooted in symbolic interactionism followed

by a critical theory approach. The methods I employ, which I describe in detail, are semi-structured in-depth interviews.

In **Chapter 5**, I describe how a hospital's prioritisation of autonomy versus best interest as reflected in institutional culture and policy appeared to influence the way that physician trainees conceptualised patient autonomy. This may have influenced the degree of choice and recommendations they were willing to offer regarding DNR decision-making. Trainees at hospitals where policies and culture prioritised autonomy-focused approaches appeared to have an unreflective deference to autonomy and felt compelled to offer the choice of resuscitation neutrally in all situations regardless of whether they believed resuscitation to be clinically appropriate.

In contrast, trainees at hospitals where policies and culture prioritised best interest-focused approaches appeared to feel more comfortable recommending against resuscitation in situations where survival was unlikely. Similarly, experienced physicians at all sites, did not exclusively allow their actions to be prescribed by policies and institutional culture, and were willing to make recommendations against resuscitation if they believed it would be futile. A paper based on this chapter was recently published in the *Journal of the American Medical Association (JAMA) Internal Medicine* (Dzeng, Colaianni, Roland, Chander, et al. 2015).

Building upon the dichotomy set forth in Chapter 5 between hospitals that prioritise autonomy versus those that prioritise best interest, in **Chapter 6**, I focus on the ethics portion of the conceptual framework. I elucidate how a hospital's prioritisation of best interest or autonomy influences a physicians' conceptualisation of ethical principles and how they balance autonomy and beneficence.

The ethical foundations of autonomy were initially grounded in rigorous moral reasoning and an adaptation to increasing societal prioritisation of patient choice. However, due to the time constraints, workflow, culture and structure of American medicine (particularly at hospitals which have a culture of prioritising autonomy), autonomy has been reduced to mean unlimited patient choice, rather than one of several

ethical principle that need to be considered in order to guide moral behavior. In essence, there has been a failure to transfer the theories of principlism³ to practice on the wards.

American medical trainees working over 80 hours a week do not have the time and space in their daily routine to develop conceptions of autonomy that are thoughtful and reflexive. As a result they distil the four principles, and especially that of autonomy into an unreflexive requirement to provide choice and are unwilling to take on the responsibility of making clinically informed treatment recommendation. They over-interpret resuscitation policies to mean that they must give a menu choices, and by doing so allow themselves to be shackled by their interpretation of autonomy.

This reductionist understanding of autonomy as the dominant discourse in American medicine, harms patients and runs counter to the original intentions of principlism. These self-imposed cultural constraints upon physician behavior reflect an overall over-interpretation of hospital policies, which are in part due to deprofessionalisation and perceived loss of power of the American physician described in Chapter 2.

Ironically, trainees' reductionist interpretation of autonomy may actually exacerbate their own moral distress, as they feel obligated to offer choice of treatments that they feel would not benefit the patient. **Chapter 7** describes the moral distress physician trainees experience when they feel obligated to provide treatments at the end of life that they believe to be futile. Some trainees developed detached and dehumanising attitudes towards patients as a coping mechanism, which may contribute to a loss of empathy. A major theoretical aspect of this moral distress is the concept of alienation and how that might hinder the physician trainee's ability to find meaning in their work, which has wide array of consequences from decreased empathy to burnout. A modified version of this chapter is under review ("revise and resubmitted") at the *Journal of General Internal Medicine*.

³ Principlism, which characterizes medical ethics in terms of the four principles of autonomy, nonmaleficence, justice and beneficence, is the predominant way of conceptualising ethics in American medical schools and hospitals (Beauchamp and Childress 2013). Principlism as a strategy to address ethical dilemmas examines the ethical dilemma through each of the four lenses and attempts to find the solution that best addresses all four principles. Conflicts between principles frequently occur, which is seen as a limitation of principlism. I will discuss principlism in more detail in Section 6.2.2

Chapter 8 exposes communication pathologies that may occur between physician trainees and patients/surrogates in end of life discussions by bringing together Habermas' Theory of Communicative Action and behavioural economic approaches to framing.

Because medical trainees at autonomy dominant hospitals feel uncomfortable making recommendations, but feel that patients sometimes choose the wrong intervention resulting in harmful overly aggressive treatment measures and futile resuscitation, they instead frame conversations in deceptive ways in order to manipulate patients and surrogates into choosing the “correct” treatment. These trainees frequently used graphic descriptions of CPR, such as breaking ribs and electrocuting the heart, to discourage patients/surrogates from choosing resuscitation.

This framing reflects what Jürgen Habermas describes as concealed strategic action in his Theory of Communicative Action, where speech is instrumentalised for purposes contingently related to what is said. In contrast to communicative action, which is oriented towards understanding and consensus, this strategic action is used to maintain dominance. I hypothesise that medicine's focus on patient autonomy constrains younger physicians from believing they can make recommendations. They instead revert to manipulative means to convince while continuing to give a “neutral” choice.

I then discuss the ways these graphic descriptions of resuscitation relate to ethical and practical debates surrounding the use of framing in conversations regarding resuscitation. I describe trainees' understanding, perception, and use of framing. I draw upon Kahneman and Tversky's research on heuristics to demonstrate how framing influences decision-making. I then discuss the inevitability of framing and argue that it is not only ethical to use framing, but it would be unethical not to frame, as either positive or negative framing is inevitable.

In this chapter, I also explore how these micro-sociological actions between individual actors reflect the macro-sociological changes I discussed in Chapter 2. Although there has undoubtedly been a shift of power from the physician to patient over the past several decades, physicians are still dominant in the relationship. They choose when to give

choice, and they are able through language to frame conversations in manipulative ways to shape decisions. And yet, these younger doctors often feel powerless to provide care that is in the patient's best interest. It is due to these perceived constraints that they revert to manipulative rather than persuasive means to come to a consensus.

These unintended actions not only contribute to trainee moral distress described in Chapter 7, but also harm patients and run counter to the rhetoric of patient empowerment and patient-centred care in modern medicine. These communication pathologies further create additional conflict between doctor and patient. Doctors perceive patients as being "demanding" and "difficult" without realizing their own role in creating situations where consensus is constrained. Antony Giddens' Structuration Theory is then used to elucidate this relationship between physicians' reflexive interpretation of their situation, their consequent actions, and the unintended consequences of their action on the overall structure in which they then operate.

I conclude my thesis in **Chapter 9** with a discussion of how the medical profession might improve how autonomy is conceptualised and enacted in medical interactions. Institutional cultures and policies might influence how physician trainees develop their professional attitudes towards autonomy and their willingness to make recommendations regarding the decision to implement a DNR order. A blind focus on autonomy might inadvertently undermine patient care by depriving patients and surrogates of the professional guidance needed to make critical end of life decisions. My research suggests that policies and cultures that are focused on autonomy may have inadvertently become a mechanism of social control that constrains physicians' ethical reasoning towards a reductionist understanding of autonomy merely as offering choice.

A Habermasian analysis of these communication pathologies allows us to better understand how this frequently employed strategy of graphic descriptions disempowers patients by depriving them of the ability to act as an equal partner in co-creating consensus regarding their end of life decisions. Understanding these pathologies facilitates the creation of future medical educational interventions that can raise awareness of, and modify these communication patterns.

There is a need to recalibrate the way physicians conceptualise and operationalise autonomy, as well as a need to keep physicians engaged with the lifeworld throughout their training. By fostering a culture in medicine where physicians do not forget their own lifeworld experiences, we can maintain the mutual trust, empathy and understanding to establish more open communications. A way to overcome communication pathologies is to embrace an emancipatory approach by encouraging awareness and self-understanding regarding these communication pathologies and physicians' roles in perpetuating them.

Another possible intervention is to establish policies that focus more on trust and care rather than merely choice. Policies that are more flexible and focused on best interest decision-making may allow physicians more room for self-reflection and consideration. This liberty to provide their clinical judgement and expertise to make recommendations in a patient's best interest rather than through a misinterpreted dogma of autonomy might improve patient care and provider satisfaction. In addition, this empirical data suggests that a best interest approach (i.e. informed assent) may improve the ways in which doctors and patients and surrogates can come together to co-create consensus on end of life decisions.

To summarise, the aim of this thesis is to explore how institutional cultures and policies surrounding patient autonomy influence physicians' clinical and ethical approaches to do-not-resuscitate (DNR) decision-making at the end of life. What follows in the next chapter is a sociological discussion of the transformation of the American physician from the mid-twentieth century to the present.

Chapter 2: The Changing Role of the American Medical Profession from the 1950s to the Present

I begin this chapter with an introduction to the history of the modern American medical profession, describing its rise to power in the first half of the twentieth century. I will then describe how the consumerisation and bureaucratisation of the medical profession led to deprofessionalisation and proletarianisation. These arguments set forth by sociologists in the 1970s and 80s, portended a fall of physician authority and the consequences it has had on power relationships in the physician-patient interaction. Simultaneously, a gradual erosion of public trust, as well as physicians' loss of knowledge monopoly through emerging technologies such as the Internet, further signaled a decline in authority. I conclude by arguing that this loss of physician authority allowed for a shift towards increased patient decision-making and choice.

Section 2.1: Introduction

The practices and norms of the American medical system today that I will describe in this thesis must be understood in light of the sociological processes that gave rise them. The current relationship between physicians, patients, and the medical industrial complex arose from a power struggle between these entities over the past several decades, culminating in the triumph of medical consumerisation and bureaucratisation (Starr 1982). These larger macro-sociological shifts that I will describe in this chapter have significant consequences on the micro-sociological interactions between doctors and patients, which I will elucidate in subsequent chapters.

From the 1950s onwards, sociologists became increasingly interested the sociology of the medical profession. *The Social System* (Parsons 1951) and in particular, his elucidation of the doctor patient relationship and the sick role, is often taken as the beginning of the detailed sociological scrutiny of the medical profession. Parsons emphasises the role of the physician and more generally the role of the professions in American society as a

special and highly privileged occupation. *The Social System's* publication began a protracted debate about the sick role and more generally opened up a considerable debate about the medical profession in the North America. This gradually enlarged into a consideration of the capitalist transformation of the American health care system.

Eliot Friedson, John McKinlay, Marie Haug, and others exchanged heated arguments about the rise and fall of the medical profession and its implications for care. Their discussions foreshadowed the effects of technologies, consumerisation, and other social forces on the physician's ability to maintain power in the health care system and in individual patient interactions. During that time, physicians were less aware of the developments that impacted their profession and did not adapt their behaviors and attitudes to these changing tides (Wolinsky 1988). Based upon my interview evidence, I will later argue that that is no longer the case, and physicians are very much aware of these social changes and its impact on their profession and practice.

An understanding the historical sociological context of the medical profession and how that shapes the physician-patient interaction helps provide context into how deeply ingrained societal and individual factors affect the behavior of doctors and patients. One example of the influence of social changes on the medical profession has been the prioritisation of choice and patient autonomy over clinical judgement in the United States. The erosion of trust in physicians has weakened the ability of the profession to legitimately claim that efforts to decrease patient autonomy are not for self-interested purposes. This becomes particularly relevant in conversations at the end of life, where decisions often have to be made within the constraints of critical illness, lack of patient capacity, emotional trauma, and limited prognostic information. A nuanced understanding of how choice and autonomy are prioritised will help contribute to understanding how physicians and patients may better work together to best serve patient interests at the end of life.

Section 2.2: The Rise and Fall of the Profession of Medicine

Prior to the publication of the Flexner Report in 1910, medical educational standards in America were non-existent and there was significant variation in the quality of medical training. This ranged from commercial medical colleges to the newly established Johns Hopkins School of Medicine, which established medicine as a highly rigorous, graduate level discipline. The Flexner Report investigated every medical school in the US and found that standards at most schools were deplorable and corrupted. The nascent profession realized that, it would never be respected “until it sloughed off its coarse and common elements (Starr 1982).” Medical authority was conferred when the American Medical Association (AMA) was “granted broad, monopolist-like powers over the health care industry, in exchange for its promise to provide quality medical care and eliminate the sad state of affairs described by Flexner (Wolinsky 1988). This control of theoretical knowledge including the development of specialized training and education, testing through formal exams and exclusion of individuals from the professional organisation through admission criteria, further differentiated a profession from merely being an occupation (Millerson 1964).

The rise of medical professional domination occurred during the “golden age” of medicine, which spanned the 1940s to 1950s. McKinlay defined this “golden age” as a time when physicians were maximally influential and strongly supported by the state, through almost unlimited third-party reimbursement, maintenance of legitimacy and exclusivity through state licensing and regulations, and significant state support of the training of new physicians (McKinlay and Marceau 2002). This was the time when physicians consolidated their power and became elevated in society from a status and authority standpoint (Starr 1982; Wright and Perry 2010). With this came significant autonomy and self-regulation, as it was established that their exclusive knowledge to define and treat disease entitled them to be the sole purveyors of medical authority (Clarke 1981; Freidson 1972; Parsons 1951). This power instilled a stronger sense of professionalism and ideal commitment to dedicating their lives to serve the people (Wright and Perry 2010).

Talcott Parsons was among the first to contemplate the role of illness and physicians in society where he defined the “sick role” (Parsons 1951). He classified sickness as a form of social deviance, whereby the sick person was exempted from social obligations and responsibility for her condition. The expectation was that sickness was a socially undesirable position and thus it was the sick person’s responsibility to get better as quickly as possible. This was to be accomplished by seeking the care of a physician and cooperating with him to get well. This consequently placed the physician in a powerful role of defining who was exempted as a socially acceptable deviant. Physicians were in turn obligated to do everything within reason to help his patient, focusing solely on the welfare of the patient rather than on maximisation of profits.

Parsons wrote *The Social System* during the “golden age” of medicine, where physicians were at the peak of their power, authority, and social status. His theories thus reflect the normative beliefs of the time, that a “deference to medical authority by the sick patient was necessary for the doctor-patient relationship to function effectively (Goodyear-Smith and Buetow 2001).” According to Parsons, “the prestige of the physician’s scientific training, his reputation for technical competence, gives authority to his approval, a basis for the acceptance of his interpretations (Parsons 1951).” The physician was at that time, the epitome of the dominant professional, defined by control over not only the content of his own work, but also that of the health care sector as a whole (Timmermans and Oh 2010). Parson’s description of the doctor role portrayed physicians as universally altruistic and competent. This assumption has been one that has been questioned for potentially ignoring the reality that physicians and patients might have conflicting interests (Turner 1987).

Michel Foucault discussed the relationship between knowledge and power in his book, *Birth of the Clinic* (Foucault 1973). He defined the “clinical gaze” as the changing medical approach to the body and disease, as well as a broader implication of medical power. Clinical examinations and technological innovations such as the stethoscope, allowed physicians to closely observe patients and pinpoint much more precisely than

had previously been possible where the problem was likely to be located. This created a completely new way of looking at a body and reflected not only a revolutionary advance in knowledge about the body, but also access to scientific knowledge, which bolstered physicians' influence and prestige (Turner 1987). Arguably, a physician's knowledge could be used to consolidate power and control over people by differentiating norms and deviations, which allowed populations to internalize notions of pathology and deviance. Physicians were important gatekeepers of definitions of normal and abnormal.

Eliot Friedson's arguments about professional dominance challenged Parsons' normative claims of patient deference to physicians (Freidson 1972; Light and Levine 1988). Friedson's theory reflected the changing perception in society of the unchallenged status of physicians. He suggested that professional dominance resulted from professional autonomy and control over the work of others in its domain, such as nurses, midwives and pharmacists. This included subordinating other health care occupations beneath them, limiting associated professions to a specific sub-area such as dentistry and chiropractics, and excluding competing occupations such as homeopathy by challenging their knowledge base (Turner 1987). Strategies to ensure exclusivity also included creating a rigorous set of barriers for admission into the profession and restricting access to medical training to those with similar and desirable backgrounds as a form of social closure (i.e. white, upper class male) (Navarro 1976). The dominance of the biomedical model also allowed medical professionals to extend their control into other spheres of life through the medicalisation of social problems such as drug use, gambling, homosexuality and crime (Freidson 1970).

Further reflecting the skepticism of physician authority, in *Limits to Medicine*, Ivan Illich explored the concept of over medicalisation and iatrogenesis (Illich 1974). His three categories of iatrogenesis included clinical, social, and structural iatrogenesis. Clinical iatrogenesis was defined as the side effects of medical technology and therapies on the individual, whereas social iatrogenesis described the increasing reliance of society on medical interpretations and the treatment of natural processes. Structural iatrogenesis described the medical profession's power to reduce the individual's ability to cope with

the normal process of body changes. Sickness, pain, and death, which were integral aspects of the human journey, were now seen as things to be controlled and treated. Individuals no longer took responsibility for their health problems and society encouraged people to become consumers of medical therapies.

Section 2.3: Consumerisation's Contribution to Sociological Changes in the Medical Profession

Just as the American state was instrumental in creating the “golden age” of medicine, they were just as powerful in expropriating it. A gradual shift of the state's allegiance from the medical profession towards the corporation created a new age of corporate dominance. Former President George Bush especially “emphasised individual responsibility in making decisions about health care and paying for it, as well as the positive role of the private market place (Mckinlay and Marceau 2002).” At the core of this transformation was the broader movement towards the neo-liberal values of individualism and the supremacy of competitive market forces in the 1980s (Wright and Perry 2010). This laid the foundation for an emphasis on the autonomous patient consumer, who was encouraged to demand the right to choose their treatments as one would choose products at Tesco. Given that Americans do not have a nationalised health care system and oftentimes have to pay out of pocket, these effects of consumerisation are especially prominent.

Medical authority can be “defined as the right to influence and direct behavior (Haug and Lavin 1979).” Consumerism's “focus on purchasers' (patients') rights and seller's (physician's) obligations,” directly challenges the traditional authority relationships of physicians as set out by Parsons and critiqued by Friedson (Haug and Lavin 1979). The emphasis on individual choice in the US has made it particularly difficult for physicians to exert authority in the clinical setting. Rather than being driven by a clinical assessment of the patient's needs, the doctor's path of least resistance is to keep the entitled customer happy by giving them what they wanted (Sanders 2004). The threat of a second opinion,

increasingly weighs on physicians' minds. Oftentimes choices are made to give patients what they want for fear that if they did not, the patient would choose a different doctor.

However, there is growing evidence that this focus on satisfaction in the US is misguided and possibly even detrimental. One American study demonstrated that higher patient satisfaction was associated with higher health care and prescription drug expenditures, greater inpatient use, as well as increased mortality (Fenton et al. 2012). Despite this, patient satisfaction has essentially been enshrined as the metric for optimal care, as the Department of Health and Human Services have recently decided to base 30% of hospitals' Medicare reimbursement on patient satisfaction survey scores (Robbins 2015). As a result, hospitals can be punished for patient satisfactions that are completely divorced from quality medical care such as a quadruple bypass patient complaining of mistreatment because he did not get enough pastrami on his sandwich (a high salt food item not recommended for a post-bypass cardiac patient). This focus on choice and satisfaction might detract from care that is actually needed.

The medical industrial complex, comprised of corporations such as pharmaceuticals and insurance companies, has been a primary contributor in this move towards consumerisation. One strategy is direct to consumer marketing of drugs, essentially bypassing the physician as the powerful gatekeeper of drugs. Pharmaceutical spending on direct to consumer advertising increased by 330% between 1996 to 2005 where they spent \$29.0 billion (Donohue, Cevasco, and Rosenthal 2007). These effects have generally been "at the margin of clinical appropriateness" with questionable implications on quality of care (Timmermans and Oh 2010).

Aggressive marketing has been used to significantly downplay dangerous side effects and even broaden disease definitions, essentially changing patterns of diagnosis and disease classification. This has been particularly prevalent in psychiatry where the mantra might be: "before you sell a drug, you have to sell the disease (Lane 2008)." One example is the transition of shyness from a personality trait to a social anxiety disorder that must be

pharmacologically intervened upon and the explosion of antidepressant use in people without diagnoses of depression (Lane 2008; Spielmans and Parry 2009).

Section 2.4: Deprofessionalisation of the Medical Profession

Two counterarguments to Freidson's professional dominance thesis were the theories of proletarianisation and deprofessionalisation. Durkheim and Weber defined a profession as one where altruistic values were institutionalized and its members were officially committed to community welfare and personal service rather than economic or personal reward (Turner 1987). The sociological definition of a profession often involves the possession of esoteric knowledge and freedom from lay control (Katz 2002). A more idealist interpretation of the medical profession from a Parsonian perspective emphasises the ethical nature of the profession, its commitment to serving the person and its basis in technical knowledge. Departure from this ideal, such as a business orientation towards the client, signified occupational change and deprofessionalisation.

Sociologists have argued for decades that the medical profession was undergoing deprofessionalisation, defined as a loss of "their unique qualities, particularly their monopoly over knowledge, public belief in the service ethos, and expectations of work autonomy and authority over the client (Haug 1973)." It has been suggested that the loss of the ideals associated with this "noble" profession of medicine may have paved the way towards practices that succumbed to the temptations of financial incentives. For example, lucrative reimbursements for chemotherapy and infusions, increasingly trump unbiased clinical decision-making (Smith and Hillner 2010, 2011). The consumerisation of medicine legitimized the "individual pursuit of financial self interest," at the risk of corrupting the profession's fundamental dedication to altruism and commitment to serving the patient's best interests (Freidson 2001; Timmermans and Oh 2010).

Despite the changes to medical practice including the possible loss of professional autonomy and status, medical training and practice continues to be emotionally, intellectually, and physically grueling. Young physicians are now less willing to fully

commit to the professional standards and ideologies of their predecessors. One commentator described the changes in the culture of medicine as follows, “you had a family, which your wife took care of, but your career came first,” to one where medicine is a job rather than a calling (Smith 2008). The drive towards specialisation reflects a prioritisation on financial compensation and lifestyle (Dorsey, Jarjoura, and Rutecki 2003; Richtel 2004; Smith 2005).

Section 2.5: Loss of Knowledge Monopoly

The rapid rise of information technologies has contributed to the erosion of authority bestowed upon the physician as the sole keeper of medical knowledge. Marie Haug foreshadowed the effect of computer technologies in challenging the profession’s “knowledge monopoly”, hypothesising that “changes in control over esoteric knowledge, as its storage and retrieval are computerized, present a potential threat to the eroding monopoly (Haug 1976).” This narrowing of the “competence gap” between doctors and patients would only increase as society becomes more egalitarian and educated and as greater volumes of information become available.

An abundance of information easily accessible online creates an illusion of knowledge and entitlement whereby patients may feel empowered to demand treatments and question medical opinion (Haug and Lavin 1979). Internet technologies have accelerated this to the point that much information is universally available and gives a false impression that self-diagnosis and treatment are possible. The Internet has also encouraged consumerisation of doctor shopping, through easily accessible physician directories and websites where consumers can rate and comment on a particular physician’s care. Online support groups also contribute to knowledge empowerment and higher standards of accountability.

Another important change is the explosion of new medical knowledge from technology driven research, which has made it impossible for a single individual to have detailed expertise in all areas of medicine (McKinlay and Arches 1985). The dependence on

technology transfers power from the physician as the owner of the means of production, to the capitalist who sells the technology. Technology has fundamentally changed the way physicians are trained, how they think and use information, and how they interact with their patients. Given the extent of medical knowledge, it is impossible for doctors to be experts in every disease. Instead, many physicians rely heavily on the Internet and technologies such as the iPhone for medical knowledge. This explosion of medical information is redefining the boundaries between lay and medical knowledge in some areas such as rare diseases, where at times the patient may know more about their disease than the physician, having done a significant amount of research on the internet.

Section 2.6: Proletarianisation of the Medical Profession

McKinlay and Arches were the first to propose the theory of proletarianisation of physicians, which they later relabeled corporatisation (possibly after realizing that physician proletarianisation was perhaps an inaccurate exaggeration as well as to distance the term from Marxism). They adapted the concept of proletarianisation from Harry Braverman's analysis of the changing nature of class structures and the decline in income, political power and status of the middle class in part due to changing technologies (Braverman 1974). They define proletarianisation as "the process by which an occupational category is divested of control over certain prerogatives relating to the location, content and essentiality of its stated activities and is thereby subordinated to the broader requirements of production under advanced capitalism (McKinlay and Arches 1985)."

This involved a loss of control over at least one of the following: the criteria for entrance, the content of training, autonomy regarding the conditions and terms of work, remunerations for labor, and the objects, tools, and means of labor. Some may argue that the proletarianisation thesis is an exaggerated view of the physician professions' loss of authority, as they still retain significant status and autonomy in comparison to the workers described in Braverman's book. Despite that, if we examine the profession over

the course of the last few decades, there are clear trends towards loss of authority due to increasing bureaucratization, corporatization, and consumerisation.

During the “golden age” of medicine in the US, most physicians tended to be self-employed fee-for-service businesses where they directed their own work and compensation. Today, this has been increasingly replaced by bureaucratisation and a medical industrial complex centred around large urban-based centres such as university academic centres, for-profit hospitals, and health maintenance organisations. Physicians have slowly been displaced down to middle management by administrators, retaining only narrow control of the technical and financial aspects of care (McKinlay and Stoeckle 1988). Furthermore, physicians frequently perceive themselves to be participating in “assembly-line medicine,” where seeing see one patient every ten minutes is not uncommon. John Stoeckle described it as, “working on the factory floor with an M.D. degree (Stoeckle 1987).”

The movement towards evidence based medicine (EBM), which sought to create consistent standards of quality of care, further supports the proletarianisation thesis. The drive towards standardisation as well as increasing evidence of widely inconsistent practice variations which have significant economic implications, created a preoccupation with evidence-based guidelines (Timmermans and Kolker 2004). Standardised trials, and particularly the randomised controlled trial, created the impression of scientific objectivity and thus helped elevate its apparent legitimacy and rigour.

Despite this attempt at regulation, physicians do not seem to follow their own guidelines. While sociologists have argued that this reflects the “resiliency of professional autonomy,” physicians themselves have attributed this to other more practical factors such as a lack of awareness, inertia of previous practices, outcome expectancy, and lack of belief in efficacy (Cabana et al. 1999; Timmermans and Oh 2010). EBM also reflects the tremendous growth of publications, which have become overwhelming and unmanageable under traditional forms of knowledge retention and diagnostic thinking.

Trends towards standardisation as an attempt to improve quality and conformity have found their way into many aspects of the physician's workflow. One of the risks of standardisation and EBM is a growing overemphasis on algorithmic rules rather than individualized patient centred care and clinical expertise (Greenhalgh, Howick, and Maskrey 2014). A large percentage of hospitals in the US and UK for example have adopted the EPIC system, a physician ordering system and electronic medical record, where templates and checkboxes are the structure for all electronic notes.

Rather than free text writing, this computer system encourages physician to fill in blanks and tick checkboxes of symptoms. One can choose a specific type of note (i.e. "chest pain note") that automatically populates a standard template. Keyword shortcuts that completely populate sections of the note further promote both efficiency at the expense of depersonalised, unnuanced care. A new generation of physicians will be trained not in the nuanced skill of crafting a differential diagnosis, but instead be prompted by a computer program to think in a series of symptoms that must be checked off.

Similarly, electronic order sets on the physician ordering system (i.e. standardised chest pain order set including serial troponins, EKG, oxygen, morphine, aspirin, etc.) mean that the diagnostic process becomes further devoid of critical thinking and personalised care. These trends in turn further encourage bureaucratisation and managerial overstep into the clinical realm. The shift away from the more intellectually engaging aspects of medical diagnostic thinking towards mechanical algorithms alienates physicians from meaningful and independent work (Sayers 2011).

Section 2.7: Erosion of Public Trust in Physicians

According to Freidson, the medical profession was able to claim (whether deserved or not) reliable authority and its special status, through its "extraordinary trustworthiness," bestowed upon them by their ethicality and knowledgeable skill (Freidson 1970). Haug stated that the profession's knowledge monopoly, coupled with their claims of public service, legitimated the "professional's authority and institutionalises client obligations to

trust the professional (Haug 1976).” Wolinsky further argues that loss of dominance was due to neither deprofessionalisation nor proletarianisation, but instead a public perception that the profession had lost their trust and adapted a self-interested, combative stance (Wolinsky 1988).

He urged medical professionals to return to Parson’s notion of a fiduciary agency and a “significantly greater stewardship of the limited resources available.” He warned of the consequences of the “benign neglect of maintaining the public’s imputation of medicine’s original avowed promise (Wolinsky 1988, 1993).” In particular, he cited a need to take responsibility for the allocation and consumption of resources, a commitment to the public good, and awareness of the negative image of excessive financial rewards. Suspicions that physicians act on financial incentives, sometimes over patient interests, have further contributed to distrust. His warnings ring particularly true today, with an increasing awareness amongst physicians of the need to take responsibility for controlling costs and limiting overuse of low value treatments.

The erosion of public trust in institution of medicine in the US has become increasingly evident. A recent study showed that only 34% of Americans stated they had great confidence in the leaders of the medical profession, in comparison to 73% in 1966 (Blendon et al. 2014). However, in this same study, they found that trust in physicians’ integrity remained high in 69% of respondents. The degree of public trust in physicians in the US ranks near the bottom of the 29 industrialized countries surveyed – only 58% of respondents believed they could trust their doctors, whereas 76% of British respondents felt they could trust their doctors.

Scandals, widely publicized malpractice suits and reports highlighting physician conflicts of interests may also contributed to mistrust, especially amongst African Americans. These situations demonstrate lapses in ethical behavior and circumstances where the physician prioritises his own benefit to the harm of others. Prior to the development of research ethics codes, this often took the form of unethical medical experimentation. Examples include the medical profession’s involvement in unethical research studies

such as the Tuskegee syphilis experiment, where researchers knowingly failed to treat syphilis patients despite known efficacy of penicillin. The Johns Hopkins Hospital in particular was responsible for taking cancerous cells from a poor African-American woman, Henrietta Lacks, without her permission for research purposes (Skloot 2011). Her cervical cancer cells became the first and most prolific immortal cell line (HeLa cells) used in biological research. Indeed, myths are abound at Johns Hopkins Hospital, where there is significant distrust amongst the predominantly low income African American East Baltimore population. A common parental warning is not to get too close to Hopkins because the doctors would “snatch you up and experiment on you.”

More recently, as market forces and financial conflicts of interest became more prevalent, lapses of professionalism often involved doctors performing unnecessary procedures for financial gain. For example, a Baltimore cardiologist with close relationships to Abbott Laboratories, was found to have inserted 585 unnecessary stents produced by Abbott Labs. A victim of this scandal described this betrayal of trust: “I was really shocked...I’m from a generation where doctors are thought very highly of (Harris 2010).” This erosion of trust has thus been “both a consequence and an accelerant for patient consumerism (Timmermans and Oh 2010).” This in turn has contributed to the changes in patient health behaviors, including interest in complimentary and alternative medications (CAM) and solicitation of second opinions.

These issues have not been confined to the US. Political interference and local mismanagement in the UK have created similar scandals. Although the cause of these scandals were less due to sinister motives and more to managerial incompetence, they still achieved similar effects of decreasing trust in the medical profession. One widely publicized scandal was the Mid-Staffordshire NHS Hospital Trust scandal, where poor care and infrastructure resulted in mortality rates in emergency care between 27-45% higher than expected (Smith 2009). While this particular scandal in part stemmed from the Trust’s prioritisation on NHS metrics (i.e. prioritizing patients with minor illnesses over seriously ill patients in order to prevent breaching the NHS’s four hour A&E wait

time target), reflecting the control of bureaucracy in medical care, this scandal reflected poorly on the physician profession as a whole.

Media portrayals of the medical profession throughout the past few decades reflect and influence popular beliefs and perceptions of professionalism, which consequently effect attitudes of trust. TV doctors in the 1960s and 1970s were father figures, garnering great respect through their sagacious, authoritative confidence. Television doctors such as *Ben Casey* (1961-1965), *Marcus Welby, MD* (1969-1976), and *Dr. Kildare* (1961-1966) not only had impeccable bedside manner but also dispensed wise life lessons. The introspective, respectful child prodigy portrayed in *Doogie Howser, MD* (1989-1993) stands in stark contrast to the misanthropic, self serving Dr. House, in *House, MD* (2004-2012). The popularity of these shows both mirror societal beliefs and strongly influences popular attitudes. Unrealistic depictions run the risk of adversely affecting public perception of medical professionals.

Section 2.8: Conclusion

The words of journalist, Katy Butler describing her dying mother's disillusionment encapsulates the changing perception of the modern physician:

“She was no longer a trusting and deferential patient...She no longer saw doctors...as healers or her fiduciaries. They were now skilled technicians with their own agendas. But I couldn't help feeling that something precious – our old faith in a doctor's calling, perhaps, or in a healing that is more than a financial transaction or a reflexive fixing of broken parts – had been lost (Butler 2010).”

Her single sentence describing physicians as simultaneously “skilled technicians” and with their “own agenda” encapsulates the contradictory dilemma of physicians who are perceived to be powerless yet completely powerful. This quotation reveals an interesting tension between the prevailing sociological interpretation of the evolution of the

American medical profession in the 20th century that I described in this chapter and the perception of physician responsibility for challenges in end of life care.

She describes physicians as “technicians,” which highlights the proletarianisation of physicians where they merely perform a task without control over the overall means of production. This reflects consumerisation and the co-option of the health care industry by the managerial class, which dictates the way care is administered. To illustrate, a recent article in the *New York Times* illustrates how financial incentives set by insurance providers and powerful nursing home and health care industries make it very difficult for a patient to actually die at home (Bernstein 2014). Oftentimes, physicians themselves are unable to advocate for patients in the face of economic and business oriented demands.

However, she simultaneously describes physicians as no longer healers, but having “their own agenda,” which implies that physicians do have the power and intention to go against a patient’s wishes and skew treatment decisions towards the most profitable choice. Because of this perceived conflict of interest, the medical profession had betrayed her mother’s trust.

Many reports in the US seeking to understand root causes contributing to problems in end of life care focus on economic factors that incentivise aggressive treatments. As this chapter outlines, there are many more complex sociological interactions that influence health care practices beyond economic factors (Smith and Hillner 2010). As such, I have focused my study on physicians at academic medical centres because they are more sheltered from the business and economic incentives that drive the medical system. Although the institutions in which they work are still guided by productivity measures and profit, academic physicians are likely to be less directly tied to a need for profit as say, a private oncologist who owns his own infusion centre.

Physician trainees especially, are even less likely to be motivated by the business and financial incentives. From my own observations and first hand knowledge of the US residency training system, economic pressures may be transmitted to house staff via

pressures to discharge or admit a certain number of patients as well as instructions on discharge planning led by social workers, but beyond that there are few intrinsic financial pressures. Discussions of financial motivations during patient care planning are more likely to come from hospital administrators and social workers than the physician trainees themselves. Furthermore, trainees are inexperienced having just completed medical school, and are thus an interesting subject of analysis as they are easily impressionable and adapt quickly to the particular routine and culture of their institution. Exploration of trainees' attitudes and beliefs thus reflect the institution's medical education and culture laid onto a relatively blank slate.

By focusing my study on academic physicians, and especially trainee physicians, I was able to strip away the factor of financial influences to expose a sociologically oriented pathology in the doctor patient relationship. This is not to say that we should not concern ourselves with the potential that physicians may be motivated to provide unnecessary or harmful care due to financial means, but that we must also explore alternative causations which also influence care and be perceptive of institutional and structural constraints that influence physician behavior.

Circling back to Katy Butler's quote, my thesis hones in on the consequences of the shift in medical power described in this chapter on end of life care. In the next chapter, I will begin to link these broader changes to the specifics of DNR decision-making at the end of life. As Sarah Palin's death panel scare in 2009 demonstrated⁴, the subject of choice and self-determination in death and dying is an echo chamber of an individual's deepest fears and insecurities. Given the intensely personal and emotional aspect of death and dying, exploring the influence of changing social attitudes on end of life care can be particularly illustrative.

⁴ During the 2009 US presidential campaign, Sarah Palin set off a political firestorm by falsely claiming that a bill that would have paid physicians for providing voluntary advanced care planning counseling to Medicare patients, would created "death panels" where doctors and government bureaucrats would decide whether Americans would be worthy of medical care (Palin 2009). The subsequent media frenzy made many false claims including ones where elderly grandmothers would be told how to "end their life sooner (Richert 2009)."

Chapter 3: End of Life Care in the US and UK

In this chapter, I begin with a general overview of what it means to die a “good death” and how dying in America in reality is far from the ideal of a dignified, peaceful death at home. This is in part due to structural constraints in the health care system that drives care towards more aggressive measures. I then follow with a brief history and epidemiology of CPR at the end of life, as well as a discussion of futile care. Finally, I discuss some of the differences in end of life decision-making and resuscitation practices between the US and UK, including differences in ICU triage, decisions when the patient has lost capacity. I additionally discuss significant media events, which demonstrate public mindset and controversy regarding death and dying in the UK.

Section 3.1: Introduction

The social changes in the medical profession that I described in the previous chapter had a significant impact on how ethical priorities have shifted over the past few decades and the way health care is delivered. In part as a consequence of the physician profession’s loss power, societal demands prevailed resulting in a shift away from physician paternalism towards patient autonomy (Gillon 2003). The social forces I described in the last chapter such as a general decreased deference to authority and a loss of knowledge monopoly due to the rise of internet technologies contribute to a desire for greater say in one’s own treatments.

This has affected both the willingness to which physician are willing to act unilaterally to implement a DNR order and the extent to which society is willing to accept physicians’ unilateral decision regarding DNR orders (Marsh and Staver 1991). Influential books such as *The Silent World of Doctor and Patient* by Jay Katz, written in 1984, exposed the physician profession’s unwillingness to permit patient participation in decision-making. He attributed this professional dominance to a “time-honoured professional belief in the virtue of silence, based on the ancient notions of a need for faith, reassurance, and hope,”

justifying physicians' trust by the faith that physicians would act in their patients' best interest (Katz 2002).

As a result, the primary ethical obligation of physicians shifted away from the duty to first do no harm and the obligation to act in the patient's best interest, towards the dominance of patient autonomy. Today, physicians' attitudes are markedly changed from decades past, having fully embraced (at least on the surface), the importance of respecting autonomy. It has become professionally and ethically unacceptable to act paternalistically, for example by withholding a diagnosis of cancer for fear of emotional distress. This shift was obvious as early as the late 1970s, as one paper demonstrated a complete reversal of attitudes from 1961 where 90% of physicians respondents indicated a preference for not disclosing a cancer diagnosis to patients to 97% in 1977 who indicated a preference for diagnostic disclosure (Novack et al. 1979).

However, this autonomy has created additional challenges and unintended negative consequences that are increasingly recognised. Perhaps most troubling are situations where physicians are asked to perform treatments at the end of life that they believe to be futile, such as resuscitation following cardiac arrest in a dying patient. Futile treatments not only are not in a patients' best interest, but also can be harmful and deny a patient of a "good death." Concerns about low value care and overly aggressive treatments at the end of life have further encouraged the need for discussion.

This chapter focuses on the United States since the focus of this thesis is on the American health care system and the influence of local institutional cultures, with the UK as a fourth site that at the time of the study allowed unilateral physician decision-making. Later in this chapter, I briefly describe the climate of end of life care in the UK to add context to the UK example.

Section 3.2: Dying a “Good Death”

Dying a “good death” has become increasingly elusive. It is defined by the Institute of Medicine as, one that is “free from avoidable distress and suffering for the patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Emanuel and Emanuel 1998). One study determined that factors considered most important at the end of life by patients, families, and care providers were pain and symptom management, physician communication, preparation for death and a sense of completion of life (Steinhauser et al. 2000). Although the majority of Americans want to die comfortably at home (Institute of Medicine 2014), the medical system is programmed to a default setting of aggressive care for the terminally ill where most die in the hospital or ICU (California Health Care Foundation 2012; Teno et al. 2013).

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was a major multi-centre study conducted from 1989 to 1994, which described many shortcomings in the care of dying patients and showed that these preferences are not met. They found that only 47% of physicians knew when their patients preferred to avoid CPR. Thirty eight percent of patients who died spent at least ten days in the ICU and 46% of DNR orders were written within two days of death, even though 79% had DNR request elsewhere (SUPPORT Principal Investigators 1995).

Follow up studies from the SUPPORT data also showed that nearly 50% of patients reported pain, including 15% who reported extremely severe or moderately severe pain at least half of the time and nearly 15% of those with pain were dissatisfied with its control (Desbiens et al. 1996). A subgroup analysis also showed that in a sample of 479 patients, 391 preferred to die at home, but 216 of them ultimately died in a hospital. A recent UK study showed that while 70% of individuals would prefer to die at home, more than half take place in the hospital (Wise 2012). Epidemiologic evidence demonstrates that despite an interest by patients in dying painlessly at home, measures that are consistent with less aggressive care, in practice it is difficult to accomplish.

Section 3.3: Structural Constraints to Dying a Good Death

Patients are not getting the care that they want at the end of life; their prevailing concerns are being treated too aggressively rather than not enough (Jacoby 2012). Structural constraints such as malpractice lawsuits, financial incentives to pursue aggressive care, medical culture, laws and hospital policies steer clinical practices in a way that go against both patient and physician interests (Gawande 2014; Kaufman 2006). The allure of new technologies in combination with patients' fear of death results in ever escalating interventions where the goal of health is forgotten for the sake of longevity (Elster 2013).

Choice and patient autonomy appear to be a priority at the end of life, but sometimes this choice is an illusion (Drought and Koenig 2002). Theresa Drought and Barbara Koenig argue that the idealised discourse of patient choice is flawed due to problems of prognostication and shared decision-making. They further describe that patients actually hold other values to be more important than autonomy, thus forcing a choice upon them when other factors may be more important to them.

Sharon Kaufman describes how dying in the hospital is deeply embedded in the “politics and economic organisation of medical care, the logic of hospital routine, [and] the values and language associated with individualism” (Kaufman 2006: 19). She argues that these individual decisions are not actually decisions, but instead determined by the structural pattern of the hospital system, which forces particular decisions upon both physicians and patients while claiming a false illusion of choice. This hospital mandated choice makes the decision even more anguishing as the decision to “choose death” is couched as a positive right, but instead becomes emotionally overwhelming and constrained.

Both physicians and patients are concerned about overly aggressive care, and yet both parties find themselves swept away by the currents onto this path. Most American hospitals have medical futility policies, and major medical organisations such as the AMA and the American College of Physicians (ACP) have policies that encourage adaption of policies that permit withholding futile treatment (Council on Ethical and

Judicial Affairs 1999; Snyder 2012). Although some do not, the majority of American hospitals have policies that typically give the physician the authority to discontinue life-sustaining treatments if they are non-beneficial.

Despite this, many physicians feel uncomfortable making decisions that go against a family's wishes based on futility and feel they would not be supported by their institution to making decisions to withhold non-beneficial care "...the unwillingness to refuse life support was not based on the belief that physicians *ought* to provide such treatment but rather that refusal to treat would subject the hospitals to unwanted litigation and adverse publicity" (Schneiderman and Manning 1997). *De facto* practices bind physicians to administering non-beneficial treatments and offering CPR regardless of clinical situation and *de jure* policies.

This tension between what doctors feel required to do and what they believe is right, is emotionally and ethically burdensome and has been known to contribute to burnout in the medical field. Practitioners can experience a high level of "moral distress" regarding treatments they perceive might be overly aggressive and contributes to a feeling of powerlessness regarding treatment decisions (Hefferman and Heilig 1999). This issue of moral distress amongst physician trainees regarding the obligation to provide treatments perceived to be futile and not in the patient's best interest will be discussed in depth in Chapter 7.

One strategy American physicians have employed to circumvent taking part in ethically compromising situations while also maintaining themselves within the system, is the concept of a "limited code" or "slow code" (in the US, resuscitations are called "codes"). This is a deliberate decision not to attempt aggressively bringing a futile patient back to life when the patient is "full code" (Muller 1992). Although this practice is ethically questionable and is explicitly not permitted by some hospital policies, I have seen this practised on multiple occasions throughout both medical school and residency. It is also discussed in the medical literature as a practice that is not uncommon. The perceived

need to underhandedly defy these rules emphasises the problematic nature of these structural constraints.

Most American doctors do not want this aggressive treatment for themselves if they were in that situation. This is particularly telling since doctors will at some point in their life become a very well informed patient. An essay by Dr. Ken Murray was widely circulated and acclaimed as an eloquent verbalisation of the sentiments of many American physicians (Murray 2012). He described that because most medical professionals have seen the consequences of futile care, they are most emphatic about not wanting that type of death for themselves. They understand that overly aggressive care creates unnecessary pain and suffering that goes against most dying people's wishes.

Reflecting this sentiment, a recent study demonstrated that 88.3% of physicians would choose a DNR order if they were terminally ill (Periyakoil et al. 2014). Perhaps more telling is another study comparing physician versus non-physician Medicare beneficiaries' utilisation of resources at the end of life. Interestingly, there was no difference found in physicians' likelihood of utilizing the hospital, likelihood of dying in the hospital, difference in mean ICU days, proportion using hospice, difference in mean number of days in hospice, nor any difference in utilisation of health care resources in the last month of life (Fischer et al. 2015). So although physicians state that they would prefer less aggressive care at the end of life, evidence shows that they are not any less likely to use aggressive care than non-physicians. There are many possible interpretations of these results and more research will need to be done to elucidate the cause of this surprising discrepancy⁵.

⁵ During a conversation with one of the authors of this study (Alex K. Smith) at the conference where this study was presented (Society of General Internal Medicine Annual Meeting, 2015), he said that he suspected that these physician deaths reflected an older generational attitude towards dying. These physicians, who were all over the age of 65, practised during the earlier era of medicine that I described in the previous chapter prior to the changes in autonomy, technology, and corporatisation. The degree to which this might be the case would be dependent on when these physicians stopped practicing. As I discuss later in this thesis, older physicians in my study were very much aware of the social and technological changes in end of life care. An alternative hypothesis is that these results reflect the default of aggressive care in American medicine, where even those who are most medically savvy and aware of their preference cannot save themselves from overly aggressive care at the end of life.

Section 3.4: CPR at the End of Life

CPR is a medical procedure where rhythmic closed chest cardiac massage is performed on a patient who has experienced clinical death due to cardiac arrest. Additional components of Advanced Cardiac Life Support (ACLS) include defibrillation of the heart to restore a viable cardiac rhythm, placement of invasive central venous lines into large vessels and delivery of powerful pharmacologic agents to elevate blood pressures, increase heart rates, and stabilise cardiac rhythms. A large scale study of 433,985 elderly patients showed that 18.3% of patients receiving CPR survived to discharge (Ehlenbach et al. 2009). A meta-analysis of 49 studies showed an overall rate of immediate survival of 40.7% and survival to discharge was 13.4% (Ebell et al. 1998). A more recent UK study found that survival to discharge after in-hospital cardiac arrest was 14.6% (Findlay 2012).

CPR is effective in attempting reversal of sudden, unexpected death in certain conditions such as ventricular arrhythmias. It is not indicated when the patient has a terminal irreversible illness, and was not meant to be used in this way. In the first CPR guidelines written in 1974 by the National Conference on Cardiopulmonary Resuscitation and Emergency Cardiac Care, there was also no mention of discussion with the patient or family when CPR was contraindicated (Faber-Langendoen 1991). Guidelines changed as expectations of autonomy and individual decision-making increased. The default option now assumed that resuscitation should be instituted in all instances of cardiac or respiratory arrest regardless of pre-arrest diagnosis. There was also a shift in the US in the authority to pursue resuscitation lying unilaterally with the physician, to a discussion that now occurs between the doctor and patient/surrogate.

Non-beneficial CPR is one example of overtreatment and overly aggressive care at the end of life. This can have significant downstream effects and implications for cost containment and utilisation of resources. Multiple large-scale studies have shown that

survival to discharge after CPR is highly dependent upon the comorbidities and condition that led to the cardiac arrest. Survival to discharge is zero amongst patients with stroke, sepsis, or metastatic cancer (Larkin et al. 2010; University of Washington 2013).

One argument supporting universal CPR is that the patient is already terminal and that any desperate attempts to preserve life is worthwhile. If the patient is going to die anyways, it does not hurt to try as the alternative is certain death. However, some argue that there are fates worse than death, such as situations where one is not dead but permanently in an unconscious state unable to be weaned off life support (Kitzinger and Kitzinger 2013). There are also significant risks to CPR though that should not be discounted, including the possible preference of passing in a dignified and non-traumatic manner. CPR can be an emotionally difficult and traumatic experience for family members and prevents loved ones from being with the patient in his last moments. Harmful side effects of CPR include rib fractures, traumatic central line insertion, hypoxic brain injury and internal organ damage. Even if a terminal patient survives the initial CPR effort, there is rarely meaningful prolongation of life and survival without intensive care life support is unlikely. Pain and suffering could be increased.

Section 3.5: Futile Resuscitation at the End of Life

Some argue that patients should be divided into three categories: 1) consider CPR as a plausible option, 2) Recommend against CPR, and 3) Do not offer CPR (Blinderman, *et al.* 2012). The third group of patients are those in whom resuscitation would not work. The term “futility” is highly controversial, and some argue that the term should not be used since there are negative implications to the term, but if defined correctly, I believe it is an appropriate term to use to describe this scenario.

Lawrence Schneidermann’s general definition of medical futility is as follows: “Medical futility means any effort to provide a benefit to a patient that is highly likely to fail and whose rare exceptions cannot be systematically produced (Schneiderman 1993).” They then further provide a quantitative definition of futility, that a treatment is futile if it has

not worked in the last 100 cases. Mark Ebell has attempted to achieve a less arbitrary basis for determining quantitative futility, which are based on “the number of consecutive failures of an intervention...to calculate the probability of success for the next attempted treatment (Ebell 1995).” Alternatively, he also proposes using quality-adjusted life years to balance burdens and benefits of a treatment to ultimately determine the probability of success beneath which a treatment would be futile.

One must emphasise that futility does not refer to a patient’s circumstance, but rather a particular treatment applied to a particular person at a particular time. In other words, a person is never futile; providing care is never futile but rather there may be treatments that are futile. They also emphasise that arguments against the notion of futility often abstract care down to the “mechanistic or biologically fragmented level. As long as medicine can achieve a physiological effect on any *part* of the body, such as lungs or heart or kidneys, they argue, then that treatments such as attempted CPR are not futile (Schneiderman 1990).” They counter that the goals of medicine are not to keep a body and its individual organ systems functioning, but to maintain a person.

Many physicians believe that there is a certain point beyond which resuscitation and other life-prolonging intensive care interventions should not be offered. One paper suggests that DNR should not be offered to patients where the probability of surviving to hospital discharge after CPR is less than 3% (Murphy and Finucane 1993). This includes patients with advanced, progressive, ultimately lethal chronic diseases such as bedbound patients with metastatic cancer, Child’s Class C Cirrhosis, dementia in a long term care facility, unsuccessful out of hospital CPR, and acute near fatal illness without improvement after three days in the ICU. The burden and cost of perceived futile care in the intensive care setting is high (Huynh et al. 2013).

One study found that during a three month period at five American ICUs, 8.6% of patients were perceived as receiving futile treatment, receiving 464 days of treatment perceived to be futile in the critical care setting, accounting for 6.7% of all assessed patient days. 84 of the 123 patients perceived as receiving futile treatments died before

discharge. The cost of futile treatment was estimated at \$2.6 million. One study found that 15.7% of patients in the ICU who died received CPR prior to death (Hart et al. 2015). Given that 22.4% of deaths in America occur in the ICU, this is a fairly large proportion of patients (Angus et al. 2004).

DNR orders are an important step in framing overall aggressiveness of care in the inpatient setting. A study of 627 advanced cancer patients reported that only 31.2% of patients had end of life discussions (Zhang et al. 2009). Those who had end of life conversations revealed a mean cost of care of \$1876 compared with \$2917 for those who did not. Furthermore, those who had higher costs reported worse quality of death in their final week. There have been several editorials by prominent physician experts invoking cost containment as a motivation for limiting DNR in elderly patients where the likelihood of discharge from the hospital is unlikely (Emanuel 1996; Halpern and Emanuel 2012; Murphy and Finucane 1993). Arguments to instituting such a policy include protecting patients from overtreatment, operationalising the concept of futility, reflecting upon the majority opinion of marginally beneficial life sustaining care, and protecting professionals from burnout (Murphy and Finucane 1993).

There has been increasing interest in the variation across hospitals regarding DNR orders, advanced care planning, and end of life care in general (Goodman et al. 2011). These variations of concern because a DNR orders and health care decisions should be a personal decision based on patient factors, rather than physician behavior and institutional culture. One study showed that there was considerable association between use of DNR orders and hospital characteristics, even after accounting for variations in patient characteristics (Zingmond and Wenger 2012). In particular, the odds of having an early DNR order written was significantly lower in for profit hospitals, larger hospitals, and in academic institutions. Rates of DNR order use varied ten fold across counties. Another study demonstrated wide variations in the proportion of patients admitted with treatment limitations (range <1.0-20.9%), the proportion who received CPR (3.8-92.4%), new forms of life support (6.0-84.2%), and in survivors, new treatment limitations

established (1.9-57.3%) (Hart et al. 2015). This variation could not be consistently explained by measurable centre level characteristics.

Other studies have highlighted the influence of advanced care planning norms and its influence on end of life ICU use. Amber Barnato has performed mixed methods studies demonstrating different cultures of high intensity institutions and low intensity institutions influence the way practitioners conceptualise a patient's medical situation and interpret medical findings in different ways (Barnato et al. 2012). These affect their patterns of decision-making regarding initiation, continuation, and withdraw of life sustaining therapies and contribute to institutional variations in end of life ICU care practices (Barnato et al. 2014).

Section 3.6: US and UK Differences in Resuscitation Practices

The UK serves as an ideal “control” site that had a greater emphasis on best interest decision-making than permitted in most US hospitals, due to the cultural similarities between these two developed Western nations of common origins. Despite these commonalities, the two health systems have very different historic roots and contrasting political philosophies. A simplified historical account of the NHS⁶ points to the collective ethos of the UK which has long been present and was strengthened following the devastation of World War II, where the British people felt a need to ensure equitable and just distribution of resources regardless of the ability to pay. Individuals were willing to accept the sacrifices inherent in the welfare state in order to create a more just and equitable society. The NHS was borne out of this principle. In contrast, the US has developed a market-based, consumer driven health care system that embodies traditional American ideals of individual freedom and choice. As such, the drive towards patient autonomy over physician paternalism developed over the past few decades in the US, whereas the UK is only now beginning to see similar shifts (Borgstrom and Walter 2015).

⁶ I recognise this does not do justice to the richness of British public health history, but a detailed analysis of the history of the NHS is beyond the scope of this thesis.

Both the US and UK have experienced varying levels of dissatisfaction with their health care systems and calls to reform. Ironically, both countries are seeking to improve their systems by moving closer towards each other. In the US, despite backlash against “socialised medicine,” many proposed initiatives have sought to increase regulation and distribution of quality care although resistance from the American right have made this politically challenging to implement. Obama’s Affordable Care Act was a step towards increasing access to care. Recent health and social care reforms have moved the NHS towards a more competitive marketised system, emphasizing patient choice. End of life care controversies in the UK signal a further shift towards a prioritisation of choice and autonomy more similar to US sentiments.

A UK court case last year illustrates some of the challenges surrounding DNR orders and societal shift in mentality. A patient’s family took doctors to court claiming that doctors at the Addenbrooke’s Hospital (one of the sites in this study) “badgered” Janet Tracey, a 63-year-old woman into agreeing to a DNR order and ultimately instituted it without the family’s permission (Judd 2012). She had fractured her neck in a car accident shortly after she was diagnosed with terminal lung cancer. The controversy surrounding the incident spotlights two questions: Is there a legal duty to inform and consult patients on DNR decisions? And should patients have the right to demand resuscitation, whatever the medical circumstance?

The courts initially decided the case should not go forward to judicial review, thus reaffirming that the decision to pursue CPR should be based on the doctor’s clinical assessment of what is in the best interest of the patient. Subsequently, the case went to a higher court, which overturned the decision stating that the hospital had violated her rights by not consulting her or her family before a DNR order was instituted. According to Dave Tracey’s (the husband) lawyers, his focus was not that patients should have the right to demand resuscitation, but rather that patients had the right to know how DNR decisions were made, and to be consulted about them.

This controversy cast light on the practice that physicians could (and should) refrain from discussing DNR decisions with patient if it would cause significant distress. Distress is an

important consideration and unfortunately not something that US physicians are permitted to invoke as a reason for not discussing resuscitation with their patients. However, this also creates a convenient “out” for physicians who do not want to discuss these decisions with patients for other reasons such as physician discomfort and a perceived lack of time to have these discussions. The judgement emphasises that patients have a legal right to be consulted and informed of decisions to withhold resuscitation; “distress is no longer a sufficient reason not to inform and consult with a patient. There must now be convincing reasons to displace this right (Meikle 2014).”

A joint statement from the British Medical Association, the Resuscitation Council UK, and the Royal College of Nursing was published in October, 2014, which clarified the guidance in the UK surrounding DNR decision-making (British Medical Association, Resuscitation Council UK, and Royal College of Nursing 2014). It states that CPR should not be attempted if death is inevitable, and that decisions not to attempt CPR if there is no realistic prospect of success does not require patient consent, though the presumption should be in favour of informing the patient. The report emphasises that physicians are under no obligation to offer or deliver inappropriate treatments such as resuscitation that would not work. If there is a disagreement between the provider and the patient about a DNR order, a second opinion should be offered.

Around the same time, another national controversy took hold in the UK surrounding the Liverpool Care Pathway (LCP), a gold standard pathway intended to replicate best practice standards for care of the dying found in many hospice centres within the hospital setting (Neuberger 2013). This included assessments of whether any further medications and tests would be beneficial and should be continued, whether fluids should be given, and a focus on ensuring patient comfort such as pain relief and aggressive symptom management. This pathway was created to help terminal patients die with dignity, but controversy ensued fuelled by media campaigns, with concerns that people were placed on the LCP without consent or their family’s knowledge and that the pathway hastened death. This ultimately led to the phasing out of this pathway (Dzeng 2013b).

Although this attention highlighted important concerns regarding informed consent and disclosure, unfortunately public outcry was fuelled by misleading reports from newspapers such as the *Daily Mail*, misconstruing facts about the LCP (National Health Service 2012). One of the concerns of the LCP was that it encouraged a tick box approach to end of life care, which can miss the original intention of each step (i.e. nurses preventing family members from giving comfort feeds because the pathway says that fluids are not necessary) and deindividualises this very personal process. These controversies highlight the growing demand for patient choice and informed consent in end of life decision-making.

Section 3.6.1: British Policy Regarding End of Life Decision-Making

The changes delineated in the previous section are changing policies and possibly practices in the UK. Because these changes occurred after my study, in this thesis, I will primarily describe UK practices during the period of my study prior to the changes prompted by the Tracey case. During the time of my study, patients were permitted to refuse but not demand additional treatment in the UK. CPR could be withheld without discussion with the patient/surrogate if it is deemed medically appropriate. The GMC's recommendations for treatment and care at the end of life illustrate the relative authority of physicians to make clinically informed decisions:

If the...doctor considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment...if you judge that CPR should not be attempted...you must carefully consider whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made... While some patients may want to be told, others may find discussion about interventions that would not be clinically appropriate burdensome and of little or no value... If, after discussion, you still consider that CPR would not be clinically appropriate, you are not obliged to agree to attempt it in the circumstances envisaged.

(UK General Medical Council 2010)

The GMC assume a level of trust that the British people have for the medical establishment that simply does not exist in the US. A leading physician was quoted in *The Guardian*, “If the decision is purely made because CPR is not going to work, the General Medical Council and the resuscitation guidelines are quite clear that we don't need to discuss with patients – why discuss it with a patient who is ill and frightened if you are not going to do it anyway? (Boseley 2012)” One could imagine the uproar and outrage this sort of comment would illicit in the US, where patients appear more suspicious and distrustful of a physician’s motivations.

Section 3.6.2: Implications for Clinical Practice and in Particular ICU Triage⁷

These differences in the way DNR decisions are made have significant implications for the management of patients who experience cardiac arrest and have no chance of survival or meaningful recovery. There are inevitably situations in both countries where patients in whom a DNR order would be appropriate, but had not been addressed prior to an in-hospital cardiac arrest. In the US, this scenario often results in the code team trying to resuscitate the patient while calls are frantically made to try to locate the surrogate and attempts are made to elicit an immediate decision to accept a DNR order so that resuscitation attempts can be stopped. Either the resuscitation proves unsuccessful or vital life signs are regained and the patient is sent to the ICU for further management. The ICU does not have the power to refuse such admissions, and both culture and legal climate are such that that scenario would not cross anyone’s mind. Frequently the patient eventually dies in the ICU.

In the UK, physicians, including ST3s and above, have the authority to end or withhold a futile resuscitation. Furthermore, the physicians in the ICU have the authority to refuse a patient’s transfer to the ICU if they decide it would be an inappropriate transfer. This

⁷ ICU triage in the US is the process of determining whether a patient should go to the ICU. At some institutions, including Columbia, this is comprised of a team of senior residents and an attending physician. Decisions are made based on bed availability, patient’s condition and prognosis. Although DNR status should not necessarily play a role in ICU triage decisions, from my experience practicing at Columbia, at least at this particular institution, in practice they did influence decisions.

includes patients who have no chance of survival, such as a patient in whom vital signs were regained during resuscitation, but the chance of meaningful survival is nil. In this scenario, the medical team would attempt to get a hold of the family and inform them that the patient had a cardiac arrest and was on life support but would not survive. They would maintain life support to allow the patient's loved ones to see him, and then they would terminally extubate the patient.

Section 3.6.3: Palliative Care in the US and UK

Medical cultures and societal culture surrounding death and dying also differ between the US and UK. Due to the leadership of Dame Cicely Saunders, generally regarded as the founder of the modern hospice movement, as well as of others, the UK has a strong tradition of palliative care. The NHS has integrated palliative care into the fabric of the health care support system in England, where services are escalated gradually as patients approach the end of life in tandem with treatment regardless of its intent (i.e. curative or palliative).

Despite this authority, there is evidence that UK physicians could do a better job of determining who would be appropriate for a DNR order. A study by the National Confidential Enquiry into Patient Outcome and Deaths (NCEPOD) showed that the UK also has problems with properly determining cases where a DNR would be appropriate (Findlay 2012). Only 44 of the 526 patients had DNR decisions recorded in the notes. The research team felt that an additional 89 patients who had not had a resuscitation decision should have also been DNR.

In contrast, the US Medicare system requires that patients choose between palliative care and treatment with a curative intent. In order to qualify for palliative care services, the patient must have a life expectancy of less than 6 months and must withdraw from curative treatment. This policy creates dire misunderstandings that are structurally ingrained, as people then assume that palliative care means end of life rather than symptom palliation throughout the course of a serious illness. Forcing patients to choose

between curative and palliative care encourages overly aggressive care and inadequate palliation as patients are often not ready to give up hope of a cure at a time when they would very much benefit from palliative care services. A landmark study was published shortly before I started my PhD studies in the UK demonstrating that early palliative care in metastatic non small cell lung cancer patients significantly improves quality of life and mood (Temel et al. 2010). This was hailed as a new, significant finding in the US but I was struck in the UK that people approached this study with confusion, as early palliative care was the norm and its findings appeared obvious to most.

Section 3.6.4: Decision-Making Following the Loss of Patient Capacity

Ideally, physicians should engage in discussions directly with patients regarding end of life and DNR decisions. Unfortunately, reality is far from ideal. In American and British hospitals, patients have often lost the capacity to engage in these discussions by the time they are brought up by the medical team or family. As such, necessary focuses of this discussion are the decisions made by surrogates rather than that of the patient. The question of how to best respect patient autonomy when the patient has lost capacity is one that the US and UK have addressed in different ways. British policy has enshrined in the Mental Capacity Act of 2005 best interest decision-making as the standard for patients who lack capacity (Mental Capacity Act 2005). As such, families and surrogates in the UK have no legal authority to decision-making in the UK, although physicians are encouraged to take into consideration families' preferences.

In contrast, in the US, autonomy is transferred from the patient to the surrogates when capacity is lost. The surrogates' substituted judgement is the accepted approach for decision-making in incapacitated patients in the US. The surrogate should make decisions based on what they believe the patient would have wanted, rather than on what the surrogate desires. There is a great deal of controversy surrounding substituted judgement with many critics arguing that substituted judgement places unreasonable expectations that cannot be fulfilled onto the surrogate.

Surrogates often have not had conversations with their loved one as to their goals and values, and are thus unable to truly make decisions based on the patient's wishes. Studies have shown that surrogates' predictions of patients' preferences are no better than chance, although many patients also wish their surrogates to make decisions on their behalf, including overruling them if there is a conflict (Drought and Koenig 2002). Even if they are aware of the patient's wishes, oftentimes other factors such as emotions, guilt, and an inability to let go cloud decision-making. The distinction between patient autonomy and substituted judgement of surrogates as a proxy for patient autonomy has important ethical implications that impact upon moral distress and care. There has been much ethical debate in the US regarding how best to make decisions for patients without capacity (Phillips and Wendler 2014; Sulmasy and Snyder 2014; Sulmasy and Sulmasy 2015).

Similar to situations experienced on the wards, most respondents assumed that the patient no longer had capacity when DNR decisions were being made amongst patients in whom survival would be unlikely. As such, most US physicians assumed that surrogates would be making the decision while in the UK most physicians assumed that a best interest decision would be made by the physicians in consultation with the patient's family. Although in interviews, themes of surrogate decision-making emerged in various circumstances, it was not specifically within the scope of the thesis to discern the differences in decision-making between patients and surrogates. It is also outside the scope of this thesis to engage in an ethical or legal debate between substituted judgement versus best interest decision-making.

Section 3.6.5: Existing Literature Addressing US-UK End of Life Issues

Literature on US-UK comparisons of DNR decision-making is limited. There have been some editorial papers discussing these differences. Many acknowledge the similarities between the UK system and proposals in the US to limit CPR in patients who would not benefit (Bishop et al. 2010a; Perkins, Pitcher, and Soar 2012). Prior empiric evidence

includes a qualitative study by Michelle Mello of 34 physicians and nurses in the US and UK eliciting their beliefs on DNR practices (Mello and Jenkinson 1998).

This latter study concluded that American doctors believed that they were legally obligated to discuss this decision with patients and provide futile care if requested. British physicians felt less obligated to do so, but felt a greater moral obligation to do so. Based upon my preliminary conversations with American physicians, legal requirements and standards of practices have changed where there has been an even greater shift towards autonomous patient decision-making over the past couple decades. Mello's article, written in 1994, likely reflects these earlier times where the transition was only becoming apparent.

Section 3.7: Conclusion

In order to fully understand the challenges we face in end of life care, it is important to have a historical sociological understanding of the forces that led us to where we are today. A particularly telling study demonstrated that physicians generally lacked awareness of the systemic and clinician related barriers to goals of care discussions (You et al. 2015). They primarily attributed barriers to primarily family and patient factors such as difficulty accepting a poor prognosis, difficulty understanding potential complications and limitations of life-sustaining care, and patients' inability to make goals of care decisions. This is particularly illustrative of the impulse to attribute problems to parties other than oneself, but also the tendency to ignore the less obvious influence of systems constraints.

Understanding and addressing how social trends affect end of life decision-making is critical to our ability to improve quality of care and the overall experience of death and dying. A fundamental aim of this thesis is to draw attention to structural factors and inadvertent mental biases that drive overly aggressive care at the end of life. This thesis will explore how institutional cultures and policies, as a consequence of shifting priorities on autonomy changed how doctors give choice and make recommendations, and the

unintended consequences of this mentality on communication practices and framing. In the next chapter, I will discuss methods employed in this thesis.

Chapter 4: Methods

In this chapter, I will discuss the methodological aspects of my thesis. I begin with a discussion of the interdisciplinary differences between sociology, medicine and bioethics that affect the epistemology and methodologies of studying ethical dilemmas in the real world setting. I then describe the methods and analytical strategies employed. The first half of this chapter relates to the theoretical framework and epistemological stance. I outline how my constructivist perspective naturally leads to theoretical perspectives rooted in symbolic interactionism, followed by critical theory. The second part of this chapter then details the exact methods I used in this study. Finally, I end with a broader discussion on reflexivity and self-reflexivity in research.

Section 4.1: The Interaction of Sociology, Bioethics, and Medicine

In my thesis, I employ ethical arguments from the existing medical ethical literature to derive normative claims on the appropriate balance between autonomy and the other principles. I employed the descriptive methods of sociology to understand how this ethical reasoning takes place in the context of medical practice. With my sociological theoretical foundations in symbolic interactionism predominantly in Chapters 5 and 6 followed by the critical theory of Habermas in Chapter 8, I have used these data to develop a framework on how physicians conceptualise and enact the ethical principles of autonomy and beneficence. Using a sociological framework helps hone in on the critical importance of social context, shaped by culture and policy, on individual physicians' normative ethical thinking and behavior. The way in which clinicians understand ethics has implications on the choices they offer to patients, communication strategies, and the subsequent interactions forged by their communication practices.

Rather than focusing on disciplinary boundaries and constrain myself to pre-existing disciplinary conception of the way the world works and what strategies we employ to understand it, I have sought instead to find the best epistemologies and methods to answer the research question. The goal of my thesis was to understand how institutional

cultures and policies influenced the way physicians conceptualised autonomy. This required combining the traditions sociology, medical ethics and clinical medicine.

There is a precedent for interactions amongst these disciplines, though these interactions have sometimes been fraught with conflict and tensions. My own experience and conversations with researchers operating within this interdisciplinary space betray a “negative solidarity” where over-defensiveness and dissatisfied compromises by the non-dominant discipline prevail (Hedgecoe 2004; Vries et al. 2006). Philosophers and social scientists may look down upon each other over the normative/descriptive divide (Herrera, 2008), where “philosophers who do medical ethics tell us social scientists: ‘You can’t get an *ought* from an *is*,’ and we social scientists respond, ‘You can’t get an *ought* from an *ought* (De Vries 2010)!” Medical sociologists bristle at the ways in which physician researchers have imposed positivist epistemologies onto “qualitative research,” demanding measures of validity and generalizability that do not make sense in qualitatively oriented interpretive frameworks (Barbour 2003).

Despite these tensions, researchers have increasingly recognized the necessity for integration between medicine, sociology, and bioethics (Hedgecoe 2004). Bioethicists speak of the “empirical turn” in bioethics (Borry, Schotsmans, and Dierickx 2005). Along with it, there is a growing realisation that an empirically informed bioethics is necessary to maintain relevance. Adam Hedgecoe asserts that the “significant differences between ethics as presented in bioethics, and the way in which ethical reasoning takes place in the clinic...isolates bioethics from practice, undermines the validity of its claims, and reduces its contribution to policy debates (Hedgecoe 2004).” As such, more integration of empirical methods is critical to bioethics’ ability to maintain relevance and authority in present day bioethical debates (Herrera 2008).

Philosophers examine moral dilemmas from a normative perspective where *a priori* truths guide moral behavior. Although sociologists should not assume that an ‘ought’ can be derived from ‘is’ - that because something *is* done in a certain way does not mean it *should* be done that way, they can instead explore how ethical practices are enacted in

real life. Sociological research demonstrates that in practice, people do consider the way things *ought* to be; that cannot be separated from the way things are currently already done. But, Hedgecoe argues, this division of labor between philosophers who explore ethical justification and sociologists who explore ethical understanding is an untenable division that does not reflect moral reality (Hedgecoe 2004).

The strengths of empirical bioethics is its ability to combine the philosophically normative with the sociologically descriptive to understand how *facts* and *values* interact and are influenced by each other in practice (Ives and Draper 2009). Utilizing sociology's empirical methodologies allow medical ethics to address critiques such as the following:

“The justificatory apparatus of traditional bioethics: ... (2) disregards the extent to which moral concepts and norms derive their meaning and their force from the social and cultural surroundings in which they are embedded; (3) neglects the way in which moral problems are generated and framed by the practices, structures, and institutions within which they arise; and (4) ignores the means by which social and cultural ideologies, and the power relationships they entrench, can both perpetuate moral inertia and effect moral change (Hoffmaster 2001).”

Hedgecoe argues for a “critical bioethics” approach which seeks to incorporate social science research into philosophical thinking (Hedgecoe 2004). Much of his critique centres around the origins of bioethics in moral philosophy where deductive arguments determine moral norms that are prescriptive by virtue of their rational justification. By justifying theories in terms of their rationality rather than by its applied practices, it ignores the gaps between the theory and practice of ethics. Because of ethics' focus on establishing universal principles and concerns of moral relativism, it attempts to transcend culture and imply that solutions are applicable in all cultural and social contexts. However, critical bioethics must be more than descriptive. It must be willing to maintain a critical stance with regards to its empirical findings. To fail to do so would resign it to a conservative bystander, “propping up, rather than challenging unsavory systems and practices (Hedgecoe 2004).”

Section 4.2: Constructionism as my Epistemology and Interpretivism as my Theoretical Position

Michael Crotty, in his book, *The Foundations of Social Research*, outlines the four elements he regards as sequentially necessary to properly position one's research (Crotty 1998). He describes them as epistemology -> theoretical perspective -> methodology -> methods, which are necessary to justify the ultimate methods that are most appropriate for the research question. Reflection upon one's theoretical framework is critical prior to the initiation of any research study because it fundamentally influences the way we as a researcher perceives the world and analyse and synthesise the data that comes out of it. Epistemology, a theory of knowledge exploring how we know what we know, is integral to providing the philosophical grounding for how we generate and legitimate the knowledge we seek. Theoretical perspective characterises the philosophical stance that informs one's methodology, "thus providing a context for the process and grounding its logic and criteria (Crotty 1998)."

The goals of my qualitative inquiry are to describe the underlying phenomena behind physicians' ethical understanding, develop a deeper conceptual understanding and framework, and elucidate hypotheses that may drive future work. As such, the most appropriate epistemology with which I have explored my qualitative inquiry is constructionism. This philosophical stance acknowledges that there is no particular objective truth that is universal, but rather that truth is constructed through our engagement with the realities of the world (Holstein and Gubrium 2008). Meaning is constructed by different subjects in different ways, rather than discovered somewhere in the real world. As such, there may be several interpretations to the same phenomena, co-constructed by subject and object and dependent upon the culture within which they are situated.

Section 4.2.1: Symbolic Interactionism

The theoretical perspectives employed in this thesis are interpretivist symbolic interactionism and critical theory. Symbolic interactionist approaches will factor most prominently in Chapters 5 and 6, whereas critical theory will be the predominant approach in Chapter 8. I will first briefly describe symbolic interactionism here, and address critical theory the following section.

The ideas inherent in the symbolic interactionism approach were first proposed and developed by Charles Horton Cooley, John Dewey, and George Herbert Mead. Herbert Blumer, drawing particularly on Mead, later coined the term symbolic interactionism, which rests on three defining premises:

- 1) People act towards things on the basis of the meanings that the things have for them
- 2) The meaning of things is derived from the social interaction that one has with one's peers
- 3) These meanings are modified through an interpretative process used by the person in dealing with the things he encounters.

(Blumer 1969)

Symbolic interactionism, in the tradition of interpretivism, hones in on the centrality of meaning. It focuses on the source of that meaning to the actor and the consequent influence that meaning has on the actor's interpretation of the world and her actions. Meaning is not intrinsic to the object nor does it arise within the subject herself, but arises from the social interactions between the subject and object. It is also dependent on the ways that the subject sees others act towards the object. An actor's development of meaning is not a passive process but a process of interpretation where meanings are used and revised through self-interaction and interaction with others. As such, symbolic interactionism accounts for how individuals "shape and control their conduct by taking

into account the expectations of others with whom he acts...[by studying] the margins where collective behavior and individual conduct overlap (Becker et al. 1961: 19-20).”

In Chapters 5 and 6, I describe how a hospital’s institutional culture and policies influence how physician trainees conceptualise the ethical principles of autonomy and beneficence, which then influences their prioritisation on choice in end of life decisions and their willingness to make recommendations. The symbolic interactionist approach in these chapters highlights the importance of understanding how meaning is constructed by physicians in relation to ethical decision-making at the end of life. Their meanings of autonomy are constructed from their interpretation of the hospitals’ culture and policies as reflected by the actions and attitudes of their peers and superior. Their interpretations of ethical principles do not necessarily reflect theoretical understandings of autonomy, but rather the local cultures’ interpretation of these policies. Their interpretation then influences the way they offer choice and recommendations in end of life conversations, which then in turn influences how other physician trainees interpret and act.

Section 4.2.2: Critical Theory

Jürgen Habermas, a Second Generation Frankfurt School critical theorist whose work I will engage with primarily in Chapter 8. He describes three non-reducible “knowledge-constitutive interests” - the technical, the practical, and the emancipatory (Bernstein 1985: 8). The last approach, the emancipatory approach, is the one most aligned with my research. The *technical* encompasses the positivist empirical-analytic approach, whereas the *practical* describes the historical-hermeneutic sciences, which are governed by a practical interest in understanding human behavior by interpreting the reasons people have for their activity. The *emancipatory* approach, or the critical theory approach, dialectically incorporates the empirical and hermeneutic disciplines to derive a framework aimed at facilitating emancipatory self-reflection. The goals are to achieve freedom from domination through a heightened understanding of the subject’s life circumstances and rational autonomy of action (Giddens 1985: 127).

Through this self-reflection, “individuals can become aware of forces which have exerted a hitherto unacknowledged influence over them (Held 1980: 318).” Habermas’ critical theory is firmly rooted in language. Dominance derives its power from the ability to systematically distort communications, but emancipation rises from the transcendence of these structures of communication to establish an alternative ideal speech situation (Crotty 1998: 143). A major focus of Habermas’ critical theory is a critique of ideology, which systematically examines power relations that are embedded in the communicative process and the social systems that allow ideology to appear natural.

A critical theory approach is most relevant in this thesis because as I will discuss further in later chapters, the lines between who is dominating and who is powerless are blurred. Traditionally, medical sociology has attributed power to the physician. The evolution of modern medicine has seen a welcomed shift of power from the doctor to the patient in order to empower patients to make decisions. However, these dichotomies of power and the powerless are rarely so simple.

Shifting power in the form of autonomy from the physician to the patient may have resulted in forced choice and false choice that is as disempowering as not having had choice at all. Despite this loss of power, physicians still remain the dominant player in the physician patient relationship, but as I demonstrate later in this thesis, physician trainees often feel powerless to act in a patient’s best interest. This can be both distressing for the physician as well as harmful to the patient. This is why an emancipatory approach is appropriate. Both doctors and patient feel powerless, but self-awareness and self-emancipation in both parties have the potential to promote true empowerment.

Symbolic interactionism, the main theoretical perspective using the interpretivist perspective used in Chapters 4 and 5, helps clarify how physicians’ interpretation of autonomy, rather than theoretical ethical principles defined in the ethical literature, is critical to the way they consequently act. I shift gears slightly in Chapter 8 where the theoretical perspective is instead critical theory. Critical theory allows us to consider the steps necessary to free oneself of the dominance of ideology and interpreted meaning

described in Chapters 5 and 6 by examining systematically distorted communication pathologies and the emancipatory alternatives of ideal speech types that we can instead strive towards. The dual focus on both empirical bioethics and critical theory work well as both methodologies have a strong commitment and tradition of reuniting theory and practice (Giddens 1985; Hedgecoe 2004).

Section 4.3: Methodology

Methodology describes the process and design underlying the particular choice of methods, thus linking the choice of methods to the desired outcome (Crotty 1998). Methods then describe the specific techniques and procedures used to gather and analyse data. In this section I will outline my methodology (approaches derived from grounded theory), which provides the context for Section 4, which describes my methods (interviews).

Blumer is critical of the more traditional forms of social scientific research, which focus on “adhering to scientific protocol, engaging in replication, testing hypotheses, and using operational procedures (Blumer 1969: 32).” They neither account for alternative empirical situations not circumscribed by the hypothesis, nor do they empirically validate the initial premises, data, relations, interpretations, and concepts. Rather than taking their evidence from the empirical social world, researchers sometimes instead resort to “*a priori* theoretical schemes, to sets of unverified concepts, and to canonised protocols of research procedure,” which force research to “serve their character and bend the empirical world to their premises (Blumer 1969: 33).”

He instead calls for a need to for direct examination of the empirical social world; to meticulously examine whether one’s premises, questions, data and interpretations are actually legitimate. The methods that naturally arises from symbolic interactionism is thus participant observation, in-depth unstructured interviews, and ethnography. All of these research methods seek to describe the ways that ordinary social actors understand and construct their world. Mead argues that to genuinely understand the attitudes of a

community, the researcher must take the role of others by adopting the standpoint of others (Crotty 1998: 74):

“The situation must be seen as the actor sees it, the meaning of objects and acts must be determined in terms of the actor’s meaning, and the organisation of a course of action must be understood as the actor organises it. The role of the actor in the situation would have to be taken by the observer in order to see the social world from his perspective (Psathas 1973: 6-7).”

Section 4.3.1: Analytical Approach During Interviews

A multitude of labels and approaches arose from qualitative approaches that derive from Glaser and Strauss’s Grounded Theory approach, all of which are united by the primacy given to data rather than preconceived hypotheses (Glaser and Strauss 1967). Truly grounded theory is nearly impossible in today’s research environment (i.e. grant funding requirements), as few are able to come into research with a complete blank slate. As an insider physician, this is clearly not possible for myself. Although I do not employ the specific strategies proposed by Glaser and Strauss such as coding specific to grounded theory, memo writing and coming into the research process with a complete blank slate without a prior literature review, the qualitative approach I use is one variation derived from grounded theory. Elements of grounded theory that I adapted into my own research included the integration of data collection and analysis, as well as the intimate relationship between theory and research. Although I had done a narrative review of the literature and my research was grounded in my own past experiences on the wards, my intent was to use the data to generate hypotheses and not test preconceived logically deduced hypotheses.

A narrative review of the literature, rather than a systematic review, best suited for this qualitative approach. The goals of my literature review were to examine a range of ideas across a diverse territory to broadly examine sociological thought from a historical perspective. Similar to grounded theory, subsequent analysis occurred throughout the

process of data collection through a constant comparative method, and nascent hypotheses were subsequently integrated into the interview guide to be tested, adapted, and refined. During the data collection and analysis process, I advanced and refined the hypotheses generated and circled back to the literature to further position them amongst the backdrop of existing bioethical debates and sociological theory. In the next section on hospital sample, I will describe in more specific detail how this occurred in my project.

As many prominent theorists have emphasised (Blumer 1969; Giddens 1985; Scambler 2001; Wacquant 1992) theory cannot be divorced from empirical research. Also important is the need to consider both the micro and macro aspects of sociological interactions (Scambler and Britten 2001; Wacquant 1992: 3). I have sought to remain true to this spirit in this thesis by considering how the macro-sociological changes in the medical profession may have affected micro-interactions between physicians and patients as well as how physicians perceive themselves and their actions.

Section 4.3.2: Insider Research and Auto-Ethnography

I have a uniquely privileged perspective as a researcher studying my own profession. In this sense, I have been participating in an auto-ethnographic study for my entire academic career, having been socialised originally into the profession through medical school, experienced the very issues of moral distress and ethical challenges I describe in this thesis, and continued to practice clinically during my graduate studies. As such, I inherently inhabit the actor's world and perspective in which I am interested in as an object of study. I am thus absolved to some extent of one of the primary challenges encountered in interpretative research, namely that the researcher "does not have a firsthand acquaintance with the sphere of social life that he proposes to study...His position is almost always that of an outsider; as such he is markedly limited in simple knowledge of what takes place in the given sphere of life (Blumer 1969: 35)." As a result of that, the researcher will tend to form his own views, beliefs, and judgements of the group.

As an insider, I face a different problem of bias, which might be focusing too much on my own views, beliefs and judgements, which may not only not be the views of others, or reflect general views of physicians who inhabit a culturally different social world, but will act as a lens through which I see the world. I discuss these issues and reflexivity in more detail in section 4.6 of this chapter. As such, in order to obtain the views of a diversity of physicians, the method that I choose was in-depth interviews. This allowed me to build upon my pre-existing auto-ethnographic foundation to query and understand a broader range of perspectives across the diverse physician population. The inclusion of several different hospital sites allowed me to explore the influence of local cultures on physician's understanding of ethical issues at the end of life.

Section 4.4: Methods and Study Design

Through semi-structured in-depth interviews and to a lesser extent, ethnography and auto-ethnography, I investigated physicians' views regarding the influence of institutional culture and policies on physicians' attitudes towards choice and autonomy in the DNR decision-making process. This study was exploratory in nature, intended to deepen conceptual understanding of underlying phenomena that drive physician attitudes and behavior.

My qualitative approach is grounded in a framework that acknowledges that multiple perspectives are intrinsic to the research process, and the particular importance of the perspective that the researchers bring to the fieldwork and analysis (Barbour 2001; Golafshani 2003; Mays and Pope 2000). Throughout the analyses, I drew upon my own clinical experiences in a reflexive manner, reflecting upon how it might both inform and potentially bias my interpretation of the interview data.

Section 4.4.1: Pilot Interviews

Prior to beginning my interviews, I had the opportunity to conduct a small number of un-recorded informal preliminary interviews with four senior consultants at Addenbrooke's

Hospital and two attendings at Columbia (palliative care director and ethics director) regarding DNR decision practices. Through these dialogues, I had the valuable opportunity to learn more about UK practices and perceived norms which have informed the design of this study. The initial hypotheses and study design were largely based on my conclusions from these initial pilot interviews. In addition, I obtained an honorary passport to shadow physicians (geriatrics, general medicine, chest medicine) on the wards at Addenbrooke's to gain a better sense of practices and norms in the UK.

Section 4.4.2: Hospital Sample

I purposively sampled three large academic medical centres with well-established residency and fellowship teaching programs in urban cities in the US (Columbia New York Presbyterian Hospital, Johns Hopkins Hospital, and the University of Washington (UW)) and one in the UK (Addenbrooke's Hospital) based on expected differences in hospital culture and variations in hospital policies. Columbia and Hopkins' policies and culture reflect prioritisation of patient autonomy, whereas UW and Addenbrookes' policies and culture prioritised beneficence-based decision-making. This was evident in the policies of each hospital which are summarised in this table:

Table 4.1: Hospital Characteristics and DNR Policies

Hospital	Geographic Location	Ethical basis of decision-making	Policy
Columbia	North-East, USA	Autonomy-focused	<p>“Consistent with the Hospital’s mission, “We Put Patient’s First, [Hospital A] protects patients’ rights, and the rights of those authorised to make health care decisions on behalf of the patients, to be fully informed about their health care in order to make treatment decisions. New York Public Health Law Article 29-CC, the Family Health Care Decisions Act (FHCDA), protect patients...who are unable to make their own decisions by granting medical decision-making authority to the patient’s family members or designated surrogate (New York Presbyterian Hospital 2010). (Hospital policy)</p> <p>Physicians must obtain consent from patient or surrogate before entering a DNR order “even if the physician concludes that administration of cardiopulmonary resuscitation would be ‘medically futile.’ (Spitzer 2003)” (New York State policy)</p>
Johns Hopkins	Mid-Atlantic, USA	Autonomy-focused	<p>DNR orders are implemented with consent of the patient or surrogate. ”It is the attending’s responsibility to advise the patient or family that considerations can be given to withholding resuscitation. The patient or surrogate shall be assured that the choice to provide, limit, or withhold resuscitation is free from coercion. When a DNR order is in effect and the patient or surrogate raises new concerns about the existing DNR order, it shall be rescinded by the attending physician until steps can be taken to resolve the problem. Physicians are not obligated to provide treatment that is considered medically ineffective or futile” but an ethics consult must be called...(Hospital policy)</p>
UW	Pacific North-West, USA	Best Interest-focused	<p>“A DNAR order may be written for a patient when the patient has expressed her preference that resuscitation not be attempted, or the attending physician has made a determination of futility according to the procedures described below...The attending physician bears ultimate responsibility for a DNAR Order, although in most cases the decision represents a consensus of all those involved in the patient’s care” (Hospital policy)</p>

Addenbrooke's	East of England, United Kingdom	Best Interest-focused	<p>“A DNACPR decision should only be made after appropriate consultation and consideration of all aspects of the patient’s condition. Decisions must be taken in the best interests of the patient, following assessment that should include likely clinical outcome and the patient’s known or ascertainable wishes...The overall decision for a patient’s resuscitation status rests with the consultant in charge of the patient (Hospital policy).” (See Appendix A)</p> <p>“If the...doctor considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment (UK General Medical Council 2010)” (UK national policy)</p>
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Insights into these institutional cultures also came from ethnographic and auto-ethnographic observations. My experience as a medical student at Johns Hopkins, a resident at Columbia, and a physician observer at Addenbrooke's helped confirm that these policies reflected the culture of the institutions. As I describe in Section 4.4.4, it was the differences between interview responses at Hopkins and my own experience as a resident at Columbia that compelled me to change my research question from a US/UK comparison to one exploring local institutional cultures.

DNR forms can also be a telling reflection of the legal and structural differences in resuscitation decision-making between the two countries. I have included DNR forms for the Columbia New York Presbyterian Hospital and the Addenbrooke's Hospital in Appendix B and C at the end of this thesis. Columbia’s forms reflect draconian New York State legislation well known to be one of the most restrictive in the nation in terms of prioritizing patient autonomy (Iseron 2010). It is a six-paged document that requires multiple signatures by the patient, the attending physician, a physician witness, and a general witness. The language is formal, comprehensive and reads like a legal document.

In contrast, Addenbrooke’s form does not require the patient’s signature and wording is minimal. As an American physician, a surprising aspect of the DNACPR form to me were the laxity of reasons for initiating a DNR order seen on completed forms on the wards. One form seen on the wards included “futility” on multiple occasions, as well as “multiple falls” and “osteoporosis.” (See Appendix D) Furthermore, many forms had

written “ward staff” in response to the question of whom the decision has been discussed with.

Section 4.4.3: Initial Hypothesis

Reflecting a grounded theory influenced approach, the research question and hypotheses flowing from them evolved as the study progressed, reflecting the emergence of unexpected themes and patterns in the initial interview data. My initial intention in interviewing physicians at Hopkins and Addenbrooke's, was to explore differences between the US and UK and to contrast physician practices and beliefs that I hypothesised were due to cultural and policy differences between these two countries. Specifically, I was interested in whether US and UK doctors believed that they acted in patients' best interest regarding resuscitation practices.

Reflecting this, my initial research questions were as follows:

What is the degree of difference in the obligation US and UK doctors feel to implement CPR against their judgement of what they believe is in the patient's best interest?

How do these choices reflect individual and societal attitudes, beliefs and values? What are the social and political factors underlying this decision. Why might they differ between the two countries?

My initial hypothesis for the project following the pilot interviews but prior to my interviews was the following:

Given that American physicians are both legally and *de facto* in practice required to discuss DNR decisions with patients and must get their consent before implementing one, I hypothesized that the vast majority of US physicians would inform a patient that a DNR is being considered and that the decision making authority lies with the patient. In contrast, responses would be more varied in UK physicians. I believed that US physicians

experience a greater discordance between what they think is in the best interest of the patient and what they would feel obligated to do. I surmised that US and UK physicians might have similar beliefs on what is clinically appropriate care for a terminal patient, but moral obligations may differ.

Section 4.4.4: Evolution of My Hypotheses During the Study

My hypotheses and research question evolved significantly during the course of the study as I interviewed more respondents and evaluated their responses in the context of the overall study. During my interviews at Hopkins, I was struck by the differences between physician responses and my own views, which were shaped by my experiences as a house staff at Columbia. I wondered whether these differences reflected my own unique views that were different from doctors in general, or whether they reflected overall differences in physician attitudes between Hopkins and Columbia. As such, I chose to then broaden my study to include physicians at Columbia to gain further insight into this evolving theoretical framework.

It appeared from my own experiences and confirmed during interviews that Columbia appeared to be more extreme on the spectrum of respect for patient autonomy compared to Hopkins. Based upon my experiences as a resident, where New York laws were often cited and discussed during rounds and informal conversations as a reason why DNR decisions were carried out in a certain manner, as well as similar sentiments expressed during interviews, I hypothesised that institutional policies might have some influence on the differences I observed between Hopkins and Columbia. At this point, I spoke to several attendings at Columbia who were able to direct me to the specific written document (Spitzer 2003).

In light of these local institutional differences, my supervisors and I discussed the need to follow up by exploring a hospital that was on the other side of the spectrum, closer in nature to Addenbrooke's and the UK, but located within the US. I decided subsequently to choose UW, a hospital geographically located in the Pacific North West of the United

States, because I hypothesised they might have a different culture from the East coast due to their known differences in norms regarding the end of life, such as the Death with Dignity movement in the Pacific North West, informed the selection of hospitals ("Death with Dignity Act, 2008). Furthermore, there were significant differences in the intensity of end of life care usage (Goodman et al. 2011).

The "eureka" moment for this project occurred during my two days of interviewing at UW, where I was very excited to note the distinct differences in attitudes, beliefs, and communication practices of UW physician trainees. It was here that I began to realise that the influence of local cultures might be as important as national differences. It was striking to recall how Columbia and Hopkins physicians remarked that obviously the US could never be like the UK since Americans prioritised autonomy so much, and then to hear respondents at UW describe how it was important to balance best interest and autonomy.

My hypothesis at this point was that each of these four hospitals was located on a spectrum of decision-making, ranging from autonomy focused (Columbia), intermediate (Hopkins), shared decision-making (UW), paternalistic (Addenbrookes). I hypothesised that while experienced physicians at all sites thought it was appropriate and important to make recommendations regarding resuscitation where appropriate, that inexperienced physicians had views which varied by their institutional setting. Trainees' comfort regarding making recommendations in a patient's best interest appeared to lie on a spectrum of decision-making from autonomy to shared decision-making to paternalism. There also appeared to be differences in the degree of conflict perceived between the doctor and patient which varied by institutional setting.

Subsequent to my interviews at UW, I had the opportunity to interview additional respondents at both Hopkins and Addenbrooke's, where my questions sought to hone in on further exploring some of the patterns and differences that emerged during the UW interviews. These subsequent interviews did indeed help confirm some of the findings from my previous interviews. During the course of my interviews, further reading also

helped broaden my theoretical understanding of the issues relevant to my developing hypotheses and position my research in the existing literature, such as Hafferty's writing on the hidden curriculum and medical papers describing variations in institutional norms in end of life care (Barnato et al. 2014; Hafferty and Franks 1994).

Following completion of the interviews, I began having doubts as to whether a shared decision-making focused approach was accurate, since the specific issues I focused on was whether physicians felt comfortable making recommendations grounded in beneficence. UW's policy of considering whether resuscitation would benefit the patient rather than offering all options regardless of clinical benefit perhaps reflected clinical judgement rather than a shared decision-making approach.

As such, I decided that a more appropriate approach was a dichotomous categorisation into autonomy focused (Columbia and Hopkins) versus best interest focused institutions (UW and Addenbrookes). I then hypothesised that while experienced physicians at all institutions felt comfortable making recommendations against resuscitation when appropriate, trainees at autonomy focused institutions were more likely to feel constrained by a reductionist understanding of autonomy to mean offering choice regardless of whether resuscitation would be clinically appropriate. In contrast, trainees at best interest focused institutions were more likely to have developed a more nuanced understanding of autonomy and like experienced physicians, felt more comfortable offering recommendations where appropriate.

Section 4.4.5: Institutional Changes During the Course of the Project

As is the case with any project that spans several years, changes have occurred on a local and national level that may have affected respondent's experiences and attitudes. I have already described in the previous chapter, national shifts in the conversation surrounding dying in the US and UK including the Janet Tracey court case. Institutional changes have also occurred at Johns Hopkins and Addenbrooke's.

At Hopkins, Tom Smith was recruited to start the Program in Palliative Care in October, 2011, the same month I began my PhD and the year prior to initiating interviews. Prior to his arrival, there was essentially no palliative care presence at Hopkins, but through his leadership, the program is flourishing. Palliative care consults began upon his arrival and a six-bed inpatient palliative care unit was subsequently opened in March, 2013. This had the effect of changing the culture towards greater awareness of end of life issues and utilisation of palliative care services at Hopkins. Simultaneously, changes were occurring at a state level, where on July 1, 2013, a new Maryland law mandated that hospitals must document patient's decisions about CPR and other life-sustaining treatments with a Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form. This was primarily required in patients being transferred to another health care facility such as a nursing home or rehabilitation facility.

At Addenbrooke's, a new initiative was piloted, trialed and subsequently rolled out called the Universal Form of Treatment Options (UFTO) which sought to replace the DNAR form with a more comprehensive form that addressed treatment options beyond just resuscitation (Fritz et al. 2013). Several of the respondents took part in educational initiatives relating to the UFTO roll out or may have been in one of the trial arms that implemented the UFTO. Following the roll out of the UFTO hospital wide, all physicians were exposed to the UFTO and discussions surrounding the UFTO. Initiatives to improve end of life care at both these hospitals may have contributed to an increased awareness, discussion, reflection, and possibly altered practices regarding palliative care and end of life issues. I will discuss this in more detail in my conclusion in Section 9.3.4.

Section 4.4.6: Ethical Considerations

Informed consent was obtained from all interviewees and interview data were anonymised during transcription. Please see Appendix E and F for the informed consent form and participant information sheet. The study was approved by the Johns Hopkins University Institutional Review Board and the UK National Health Service (NHS) National Research Ethics Service. Prior to initiating interviews, potential risks included

emotional distress and anxiety, though this was never an issue during interviews. Potential concerns were that the respondents' answers might affect their evaluation or be relayed to their superiors. None of these concerns materialised. Participants were told before the interviews that it would be confidential and that the interviewer had no affiliation with their residency program. During the interviews, they did not seem hesitant or concerned about discussing their training or superiors in an anonymised manner.

Privacy and confidentiality was protected at every stage of the research including data collection, analysis, and reporting. Interviews took place in private settings. Interview data was de-identified via a coding system that protects participant confidentiality. A single electronic master document in my private possession correlates the interview code with the identity of the respondent as well as their demographic information including their institution, years of experience, and contact information. Consent forms were signed and stored in a secured location separate from the interview data.

Section 4.4.7: Physician Sample

I recruited and interviewed fifty-eight internal medicine physicians (including internal medicine subspecialties) in person, with the exception of two interviews that were conducted via Skype. Interviews took place between March 7, 2013 through January 8, 2014. Participants were eligible if they were full time physicians at the selected institutions who were routinely involved in DNR conversations with patients at the end of life. They were purposively sampled by stage of training, years of experience, and medical subspecialty to provide a wide range of perspectives and contribute to understanding emerging patterns and themes. I specifically sought out categories of participants in order to yield a diverse and approximately equal number of participants in each category.

Determination of whether a candidate was an appropriate respondent was purposive in that selection occurred either prior to recruitment (in cases of referrals from respondents) or after the person expressed interest. For example, if I found out later that the person was

not an internal medicine physician, I politely declined. When I found that I had enough respondents who were, for example, less experienced, I focused recruitment instead on recruiting more experienced respondents. As this was a qualitative exploratory study intended to deepen conceptual understanding of phenomena and generate hypotheses, with a sampling strategy that was opportunistic, the intention was not to generalise to the totality of the medical profession. Physicians were excluded if they had not been practicing in the US or UK for the majority of their clinical career.

Recruitment occurred through group e-mail advertisements, individual solicitations, and referrals from respondents. Given this, there were no refusals, but only non-responses. We do not know anything about the reasons why people did not engage. Please see Appendix G for the recruitment e-mail. Given that my networks within the physician community were not as strong in the UK, I sought key networkers such as division heads, senior consultants, and program directors, asking them to send e-mails to their physician employees on my behalf and allowing me to briefly recruit for my study prior to meetings such as morning grounds or didactic lectures. Snowball sampling was subsequently used where participants recommended other colleagues who might be amenable to participation, whom I then subsequently vetted for appropriateness. Given the challenges of recruiting physician trainees, eventually I also included a £10-15 coffee gift card incentive in the UK.

Recruitment at Hopkins and Columbia was relatively easy, as I had established networks of physician colleagues, as well as a familiarity with the structure of each hospital's training programs. I began by targeting a wide variety of physicians of various levels of experiences and subspecialties. I also targeted "key informants" who were known palliative care or ethics experts and leaders, who could give an overall perspective of the hospital's culture, attitudes and practices regarding end of life care.

Recruitment of house staff posed different challenges given how busy they were⁸. In order to maximise responses, I logged onto the resident scheduling system (amion.com) and searched for house staff who were on less time consuming rotations such as vacation, research, and outpatient. I sent each of them personal e-mails and also offered a \$5 coffee gift card as an incentive. This strategy worked well and I had no trouble finding enough interested participants. Response bias may be a concern raised regarding sampling technique. As this was a qualitative exploratory study intended to deepen conceptual understanding of phenomena and generate hypotheses, with a sampling strategy was opportunistic, the intention was not to generalise to the totality of the medical profession.

Participant recruitment at UW was slightly different, and as such, may have resulted in a slightly different demographic, which I note as a limitation in the limitations section within the conclusion of this thesis. A key informant, who leads the palliative care program at that institution, assisted me with the recruitment of participants at his hospital. Given that he was doing me a tremendous favor and that without him, I would not have been able to feasibly recruit their physicians myself, I was not able to apply the same degree of diversity of subspecialty as I was at the other institutions. As such, there was a preponderance of pulmonary and critical care physicians.

Section 4.4.8: Interview Guide and Interview Process

Based upon my initial research question of interest, literature reviews, initial pilot interviews, participant observation on the wards at Addenbrooke's hospital, and my own auto-ethnographic experiences at Columbia and Hopkins, I developed an interview guide, which went through multiple iterations and refinements with peer review by mentors and supervisors and preliminary pilot testing (Appendix H). The interview guide used across all sites provided thematic continuity.

⁸ House staff in the US are restricted to working 80 hours a week, averaged over four weeks, which in actuality means that they are working more than 80 hours a week. Oftentimes, house staff do not log in all the hours worked beyond 80 hours in order to keep with work hour regulations. These are significantly longer hours than that typically worked by an attending physician.

Prior to the start of the interview, I again summarised the purpose of the interviews, which was to better understand physician attitudes and practices regarding DNR decision-making at the end of life. I provided them with a participant information sheet and had them read over and sign the consent form. They agreed to have the interview audio recorded. I then pushed the record button, placed the recorder on the table between myself and the respondent, and then began the interviews by asking the first question on the interview guide.

Although there was an interview guide, the semi-structured in-depth interview format was open ended, encouraging participants to explore those aspects they considered most relevant. Interviews lasted between 45 and 120 minutes and were audiotaped and transcribed verbatim. General themes began emerging very early on within the first five interviews at each site.

Subsequently, if there were particular comments that appeared to disconfirm hypotheses, I would question the respondent further to clarify their response. Frequently, their additional response would be helpful to clarify either their alternative position or alignment with the hypothesis. For example, at UW, I would ask some respondents whether they were familiar with Informed Assent⁹, to which some would frequently respond “no” and that they’ve never heard of it. I would then question them further and see that their clinical practices reflected Informed Assent even though they were not familiar with the actual term. Disconfirming cases were recognised and analysed in light of their effect on the emerging hypotheses.

As I described earlier, as themes and patterns emerged during the interviews, I had opportunities to reflect upon them and further refine my hypotheses in between interviews. Interview guide questions were adapted throughout the entire process to further hone in on emerging patterns. Hypotheses and themes developed became the subject of questions in subsequent interviews to further confirm the trustworthiness of the

⁹ I will discuss Informed Assent in Chapter 5. Informed Assent is where the clinician does not insist that the decision ultimately be made by the patient or family member, and explicitly recommends against CPR when clearly not indicated (Curtis and Burt 2007b).

data. I have included in Appendix I my final “working” interview guide which has been left in its working stage of additional questions that I left as notes to potentially ask, and which by the end of the interviews, I only loosely followed. Questions during interviews did not rigidly follow the interview guide and were conversational in nature. I asked follow up questions based upon the flow of the conversation. At the end of the interviews, I would review my interview guide in order to be thorough and ask questions that had not come up already during the interview.

Section 4.4.9: Data Management

Interviews were recorded using a Sony ICD-PX312 digital flash voice recorder. Audio files (MP3 format) were transferred to my password-protected personal Macbook Air laptop that is essentially always either in my possession or locked in my home. After audio files were transferred to my computer, they were immediately erased from the voice recorder.

Given a lack of funding and the need to cover the majority of transcription costs out of my own pocket, it was financially impossible for me to rely on expensive professional transcription services typically used by universities. Instead, I was able to find a transcriptionist via the internet service elance.com. I placed an advertisement seeking a transcriptionist for transcription of health interview data. Transcriptionists were first required to sign a confidentiality and non-disclosure agreement prior to initiating the first interview.

Transcriptions were done by “Get Your Typing Done” transcription services (Deborah Huyton) based in Manchester, England for \$25 USD (£16.25 GBP) per audio hour. Audio files and Microsoft word files were exchanged electronically via Dropbox. Segments of the interview that were inaudible to her were noted on the transcript with red highlighting and a time stamp. I listened to the audio recording in that section and was able to transcribe those relevant sections.

Section 4.5: Analysis

In this section, I will describe the analytical process that led me from the raw data to the hypotheses generated in this thesis.

Section 4.5.1: Coding of Transcripts

The hypotheses generation process I described in Section 4.4.4 occurred during and between my interviews, which were all completed prior to them being coded. During the interviewing phase, I continued to take notes on my evolving ideas and analysis after each interview day. Hypotheses were tested and refined continuously during the course of the interviews, where I asked questions in subsequent interviews to determine whether they were consistent with the evolving hypothesis. The final hypothesis described in Section 4.4.4 is the hypothesis I went into the coding process with and review and coding of the interview data did not result in any changes to the hypothesis during the coding process itself.

De-identified and transcribed interviews were printed on A4 sheets of paper. All interviews were read over once without any coding in order to re-familiarise myself with all the data, to get a sense of the larger picture, and to develop an initial codebook of themes and patterns that I saw emerging from my initial read of the interviews. This initial codebook has been included as Appendix J.

I then went back through all the interviews a second time for more in depth coding. Using coloured pens on the printed transcripts, I went through line-by-line and circled sections of the transcript that had a particular theme attached to it. I used the initial codebook as a foundation for coding, and added additional codes as they arose during interviews. Some codes also included sub-codes, which were related to the overarching code. For example, the code “Death” had multiple sub-codes such as “Death Fearing”, “Death Unexpected, and “Death Denial”. I have included a sample coded transcript page as Appendix K.

Four excel spreadsheets were created for each level of experience (i.e. senior attending, junior attending, fellow, and resident) with four sub-pages on each spreadsheet (Hopkins, Columbia, UW, and Addenbrooke's). Each page listed a code in the first column, the sub-code if applicable in the second column, the relevant quote in the third column, and the corresponding interview and line number in the fourth column. For example, this segment, "I guess you're asking me about my ideal world, but I'll just say that I feel now there's no room for clinical judgement. We have to put the entire, you know, menu out there." Would be categorised under "Choice Offering" which is a sub-code of "Choice." All codes and sub-codes are listed in alphabetical order and quotes were listed sequentially by interview number and line number. A screen shot of a sample excel spreadsheet is included as Appendix L.

Given that thinking and reflection of my hypotheses and analysis occurred throughout the course of my interviews, as well as the importance of analysing quotations in context rather than assuming meanings of isolated segments in a reductive manner, the most formative analysis occurred through close reading of full transcripts in light of the overall context of the interview and in relation to one another. Coding provided several useful functions. Firstly, as a means of organising my data into manageable sections so that when I wanted to compare directly responses surrounding a particular theme, I could easily identify and compare responses from all eight subgroups (hospital and level of experience). I was able to use the themes and codes to help confirm my final hypothesis, as I could go to a particular code that was relevant to my hypothesis.

For example, in the choice category, different understandings and insights regarding "choice false" would elucidate important differences between trainees at autonomy versus best interest focused institutions. Similarly, "choice of choice" was a theme that arose amongst trainees at best interest focused institutions, demonstrating a greater awareness of the need to tailor choice to the patient's preferences. "Choice offering" occurred in autonomy focused trainees as something they felt compelled to do, whereas it arose in best interest focused trainees as a reflective critique of offering choices that were not in a patient's best interest.

In addition, coding and categorisation helped highlight differences between subgroups that were not initially obvious during interviews. For example, it became clear during coding that moral distress was a theme that arose frequently amongst trainees in the US, but occurred less frequently amongst UK junior doctors and among experienced physicians in both countries. I should note that the nature of my study makes the number of times a particular theme occurs an unreliable measure, since it may only reflect whether it was discussed in the unstructured interview rather than whether there was actually less moral distress in particular subgroups. Thirdly, the coding was a necessary step in the process of double coding, which I describe in the next section.

Section 4.5.2: Second Coder

“Double coding” is required as a quality standard for publication of qualitative research in medical journals to help mitigate potential bias and to improve validity. As such, I recruited Alessa Colaianni, to be my second coder. At the time of the study, she was a third year medical student at Johns Hopkins taking a year away from medical school to pursue an MPhil in Cambridge in the History and Philosophy of Science.

She was an ideal candidate, as she had experience on the wards as a medical student at Hopkins as well as familiarity with the UK during her year here. In addition, she had a research interest in this area, having written papers about the hidden curriculum, the ethics of slow code, and an ethical paper on Nazi doctors, and had interdisciplinary experience and knowledge in the social science and ethics of medicine (Colaianni 2012). Alessa was compensated both with modest amounts of cash, as well as co-authorship on manuscripts derived from this study. Files were shared with Alessa through Dropbox, as well as Google Docs.

She double coded twelve of the 58 interviews (20%). I selected a wide range of interviews to be double coded including those that I found to be particularly rich with insights and those which I wanted to get alternative thoughts on interpretation. The first

time we met, I had already read through all the interviews and developed the initial codebook, which I gave her access to. We met two to three times prior to giving her the first transcript to discuss the project, my overall vision of the project, and to explain to her the coding process. I asked her to follow the identical process I did with printing the interviews and circling quotes and relating them to themes prior to our meeting.

We then met either in Baltimore or Cambridge depending on where we both were, to discuss each interview individually. We first discussed our overall impression of the interview, its implications on the overall data set and hypotheses, and particular features that supported or did not support the emerging themes and patterns. We then went line by line through the transcript discussing the codes that we had categorised quotes in prior to meeting in order to come to a consensus on coding.

Most often, we either had both written the same codes down. If there was disagreement, there was a discussion on whether it would be an appropriate code to put down. Discrepancies were usually due to omission rather than disagreement, and there was rarely overt disagreement after discussion. If new codes or sub-codes came up in the interviews, we would discuss the need for a new code, distinguish why this particular code differed from pre-existing codes, and agree upon a definition for the code, which we would then write in the code book (See Appendix M for final code book).

Following our meeting, I would then input the hand written codes into the excel spreadsheet as described in the previous section. Simultaneously to the process of double coding, I also continued to analyse additional transcripts using the same process. After completing all the double coding on 20% of the interviews, I went through the remaining interviews in the same manner until they were all completed.

Section 4.5.3: Synthesis of Data Following Coding

Analysis of the data occurred on a holistic level during the iterative readings of the transcripts and the coding process. The hypotheses generated in this study began to

develop during the interviews and during iterative readings of the transcripts as a whole. This sort of sociological and ethical analysis is best achieved through this more holistic analysis rather than the disjointed and taken out of context quotations coding develops. There were less new insights that occurred during the micro-coding level of analysis than during the stage where I analysed the complete transcripts and quotes *in situ*. It is also important to note that my coding not only took note of what respondents said, but my interpretation of what they said both in the context of that specific interview as well as its implications as a whole. A known challenge in qualitative research is the problem of primacy and recency bias (Suzuki et al. 2007). Reading through all the transcripts all at once following the completion of the interviews gave me the opportunity to assess all the interviews as a whole in light of my most recent thinking, which helped minimise this bias.

The coding process was subsequently useful as a confirming mechanism as well as an organisational tool. The division of quotations into codes out of context was useful for grouping types of quotes for direct comparison with each other and amongst different categories in the study. It made it possible to more easily discern patterns amongst institutions and amongst different levels of experience. Grouping quotations into codes was also useful for the writing up process. For example, if I wanted to write a section on “torture,” I could go to the excel spreadsheet and compare all the quotes where the theme “torture” occurred. I could compare whether or not they occurred more frequently amongst different groups (i.e. frequently in trainees and rarely in experienced physicians), and the nature of the quotation.

In deciding which quotations to use, I choose quotes that best illustrated the particular point I wanted to make. In order to avoid bias, I attempted to select quotes from a diversity of respondents and take into account the degree of variation and different perspectives. I did find that some respondents were selected more frequently than others. This may have been because in those particular interviews, I spent more time talking about that particular theme and thus had more material. Other times, a particular

respondent had particularly eloquent or informative descriptions or had the strength of response that I was looking for.

Some medical researchers may believe that counting the number of times a particular word or theme arises is informative. This qualitative study was not designed to make quantitative conclusions and it would be misleading to attempt to do so. This was a semi-structured interview, which meant that the interview guide served only as a guide and the questions asked in the interview emerged from themes that the respondent raises, which were further explored in subsequent questions. As such, expressing a percentage would be misleading because the number of times something is said can be influenced by whether I asked more questions on the particular topic of interest.

Section 4.5.4: Member Checking and Ethnographic Validation

In addition to the 58 formal semi-structured interviews, I have also had substantial informal interactions with physician colleagues in both the UK and US, which helped inform and to some extent to validate my research. Extensive feedback and discussion on my project occurred during informal one on one conversations as well as in larger groups through invited presentations at both Cambridge, Hopkins and beyond. This included presentations at academic conferences such as the Society of General Internal Medicine Annual Meeting as well as the Johns Hopkins General Internal Medicine Fellowship's Research In Progress seminars, which I presented at bi-annually.

In addition, I presented my research several times to various physician groups at Addenbrooke's hospital. Because the subjects of my study were my professional colleagues, comments from my academic physician colleagues were valuable both from the perspective of professional feedback as well as their own personal experiences and beliefs on these issues. These discussions in essence served as member checking and opportunities to test my hypotheses in a more general, informal manner.

Informal conversations with my physician colleagues about my research provided insights that were not captured in the interview data. As such, I do not formally report these as results in my thesis. Nonetheless, they were very important. For example, when I talked to my colleagues on the East Coast about my British experience, a frequent response would be, “We could never have a system like the UK. People in the US care too much about individual choice to allow doctors to constrain choice.” It was thus tremendously striking to later hear UW physicians endorsing limited choice as a means to providing beneficence based care. The insight that UW physicians had views more similar to their British colleagues than their American East Coast colleagues was one that arose from these informal interactions, which I then used the formal interview data to test and validate.

From a more ethnographic/auto-ethnographic perspective, I continued to practice medicine approximately 20% of the year at Johns Hopkins on the medicine consult service, hospitalist service, and in outpatient clinics. These served not only as opportunities to stay engaged in clinical medicine, but also as ways to be reflexive about my own clinical practice and how I engaged in shared decision making with my patients. From decisions to transfuse blood to end of life discussions, I found myself changing my own practices to reflect best practices learned through my research.

I reflected upon the things that I was doing that contradicted the best practices I preached in my research and dissected the structural aspects of care in practice that made theory more difficult to apply in practice. I also spent some time as a guest observer in Hopkins ethics committee meetings and ethics consultations, which further informed my study. In the UK, I was able to get an honorary passport to be an observer on the wards at Addenbrooke's Hospital. This was an opportunity for participant observation of differences between clinical practices between the US and UK.

Section 4.6: Reflexivity, Self and my Research

Pierre Bourdieu was one of the greatest advocates of reflexivity¹⁰ and relational thinking, emphasizing that epistemic reflexivity was a requirement for the praxis of sociology (Wacquant 1992: 38). He called for cognizance towards the “sociologist’s knowledge of himself and his position in the social world.” He describes the biases inherent in the sociologists’ position in the *academic* field, the intellectual space within which they operate and its consequent field of power, defined by their differences and distance from other competing fields. He reminds us of the need to constantly “scrutinise and neutralise in the very act of construction of the object, the collective scientific unconscious embedded in theories, problems and categories of scholarly judgement (Wacquant 1992: 40).” What is required is a dialogical public debate and mutual critique between the researcher, his subjects, and complementary scientific fields. In this next section, I will describe how I have sought to accomplish this during the research process.

In this regard, my own “lifeworld” experience was a total immersive experience, which reflected not only research reflexivity but also epistemic reflexivity. The very process of moving to Cambridge to do my PhD, and its inherent geographical and physical separation from the world of American medicine, required substantial epistemic adjustment and self-reflexivity. As a physician, I too had been inculcated throughout my entire academic life in the knowledge and epistemologies of medicine and positivist sciences. To an extent, my professional sense of self was infused with taken for granted assumptions embedded in the hidden and explicit curricula of medical training as well as institutional teachings to aspire to the qualities of the ideal doctor. I felt like a distinct outsider in the social scientific world, disoriented by conversations where name dropping seemed to be an oddly essential element (Who the heck were Foucault, Heidegger, and

¹⁰ Reflexivity attends to recognition that “a researcher’s background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions (Malterud 2001).” Reflexive awareness allows the researcher to understand the context of her knowledge production and how her perspective and position shapes her research at each step of the research process.

Sartre?) and insulting “doctor bashing” critiques from anthropology and sociology were commonplace. This forced me to be reflexive about what I see now as my original intellectual narrowness.

I not only realised how much of my intellectual identity was moulded by my medical training, but also that the entire discourse of medicine has influenced the way I think and perceive the world in realms completely beyond medicine. I remember thinking to myself initially that conversations about illness as a social construction and skepticism about what I believed were established truths were somewhat of a waste of time. There was no time when a hypovolemic patient was exsanguinating from an upper GI bleed to question whether the bleed was a social construction!

Throughout these past four years, as I became more exposed and open to unraveling the epistemic assumptions into which I had been socialised during my medical training, I realised I’ve “gone native.” I believe that my way of thinking now is more akin to that of a sociologist than a physician and at times I have to be careful during conversations with physician colleagues that I don’t inadvertently insult them by speaking too critically on the dominance of the physician profession. Going back to the wards always bears an element of culture shock for me now, where I need to transition my mindset from being a critical intellectual to a professional technician doing each medical task as they come along.

Straddling these two worlds not only academically, but also in real life and geographically, has allowed me to approach Bourdieu’s definition of epistemic and intellectual reflexivity. Working in the medical field full time for seven years and part time for four gives me the insider’s perspective and knowledge, but the four years of work in sociology has given me the distance to be critical from alternative, if not an outsider’s perspective. The insider perspective was critical to the success of my PhD project. It helped me establish rapport and trust with the physician participants. In particular, belonging to the Hopkins Medicine and Columbia New York Presbyterian communities as a current fellow and former resident were essential in establishing trust

and connections. I am familiar with the language, culture, and knowledge of medicine, which greatly facilitated communication and understanding during the interviews.

My position in the UK was also unique, as I was a partial insider being a medic, but one from a very different system. Although many aspects of medical practice in the UK were similar to the US, there were also striking differences that brought additional insights and perspectives to my understanding of the US medical system. For example, I was struck upon arriving to the UK by the frequent use of the term “patient’s best interest.” This was a term I had rarely, if ever, heard on the wards in the US. The omission of this term, which now seems so obvious to our goals as a physician, was a cause for professional introspective. This difference was so notable that it became the basis for this thesis.

Those who come from a predominantly objectivist mindset tend to see “insider” research as a fatal limitation; the bias and subjectivity that arises from this situation is said to invalidate its findings (Ellingson and Ellis 2008). The counterargument is that the perspective and position of the researcher is inextricable from the type of research she produces, even when using positivist methods. Andrew Curtis argued that subjectivity is ingrained in the scientific method, as the first few steps involve forming hypotheses and collecting data to substantiate or refute each hypothesis (Curtis 2012). Given that a hypothesis is a conjecture derived from but unproven by known natural laws, the influence of the scientists’ prior experiences and reasoning inevitably influence these initial steps. One study found that a geologist’s academic or professional background and experience influenced their interpretation of a scientific finding and their hypothesised geological model (Bond et al. 2012).

Ignoring the inherent nature of subjectivity in the objective sciences causes researchers to become vulnerable and blind to potential errors in their findings. Foucault argues that this subjectivity/objectivity debate instead reflects power/knowledge dynamics. Claims to objectivity do not actually result in objectivity, but instead reflect the power and authority of the dominant group’s ability to exert their particular perspective over others. The authority to judge knowledge as objective, and thus inherently more valuable, ensures

that knowledge (and thus power) remains in the status quo above the reportedly less objective group (Ellingson and Ellis 2008).

The interpretivist framework highlights the importance of acknowledging the researcher's lens to enhance one's research as well as ensure trustworthiness. Indeed, to not recognise the influence of the researcher's lens on research in general, is to ignore an important aspect of the data produced. Interpretivists recognise that there are multiple perspectives to the world that are co-created and constructed in everyday life as well as in the research process. The researcher operates as the instrument, bringing her own lens to the interpretation (Golafshani 2003). Reflexivity and understanding of how my own lens both informs and potentially biases the interpretation of the data is essential to the process.

Section 4.7: Conclusion

In this chapter, I described the epistemology and theoretical perspectives that informed my methodology and methods. My constructivist perspective led naturally to an interpretivists understanding of my data rooted in symbolic interactionism. This perspective was primarily used in Chapters 5 and 6. Subsequently in Chapter 8, I use Habermas' Theory of Communicative Action, which is rooted in critical theory, to explain communication pathologies in end of life communications. I then described my methods of semi-structured in-depth interviews in detail and concluded with a discussion of reflexivity and my position as a researcher. In the following chapter, I begin describing the empirical findings of my study.

Chapter 5: Influence of Institutional Culture and Policies on Do-Not-Resuscitate Decision-Making at the End of Life¹¹

In this chapter, I focus primarily on the hypothesis that trainees at autonomy versus best interest focused institutions have different conceptions of autonomy, which subsequently influences their willingness to make recommendations. I also describe differences between trainee physicians and experienced physicians, who for the most part generally have a less reductionist understanding of autonomy, similar to trainees at best interest focused institutions. In the subsequent chapter on ethical thinking, I elaborate further on the ways physician trainees conceptualize autonomy.

Section 5.1: Balancing the Ethical Principles of Autonomy and Beneficence

Although beneficence, the obligation to act in the patient's best interest, traditionally embodied the primary obligation of health care professionals, due to the social shifts I described in Chapters 2 and 3, this has given way to the primacy of patient autonomy (Beauchamp and Childress 2013; Gillon 2003; Schneiderman et al. 1990; Starr 1982). Controversy exists regarding whether the decision to pursue a Do-Not-Resuscitate (DNR) order should be grounded in an ethic of patient autonomy or in the obligation to act in the patient's best interest (beneficence).

Some worry that the pendulum has swung too far towards autonomy, replacing concerns of paternalism, where a person's preferences are intentionally overridden, with simplistic understandings of autonomy that "abandon patients to their autonomy" (Loewy 2005). This is problematic in situations where patients are overwhelmed by, do not want to, or are not able to choose from the menu of different options. The philosophical foundations

¹¹ This chapter is based on a manuscript published this year in JAMA Internal Medicine (Dzeng, Colaianni, Roland, Chander, et al. 2015). As with the thesis as a whole, this was a completely independent endeavour from start to finish. Alessa Colaianni's role as second coder is delineated in the Methods section and other co-authors provided editing suggestions and mentorship.

of autonomy according to Kant where autonomy meant the freedom to reason rather than the freedom to do whatever one wanted, bears only a hollow resemblance to its original intention in some situations described by my respondents. This may result in patients choosing treatments that are neither in their best interest nor consistent with their goals and values.

Some practitioners believe that in order to respect autonomy, they must present patients with all possible options and refrain from expressing recommendations (Quill & Brody, 1996). This stands in contrast to the guidance of the majority of professional organisations, which state that futile therapies should not be offered and recommendations consistent with the patient's goals and values should be addressed in a resuscitation status discussion in order to honour patient autonomy (Allen et al. 2012; Council on Ethical and Judicial Affairs 1991). The American Thoracic Society recently released a policy statement reaffirming that clinicians should not provide futile interventions (Bosslet et al. 2015). The definition of futility is controversial with no single definition being universally accepted. One definition describes futility as an inability to regain consciousness or survive outside the ICU setting (Schneiderman et al. 1990). Navigating the balance between beneficence and autonomy can be especially fraught at the end of life and in particular regarding resuscitation decisions.

Studies have shown that survival to discharge after CPR is highly unlikely in certain conditions such as sepsis or metastatic cancer, and is near zero when irreversible dying is imminent (Ebell et al. 1998; Taylor et al. 2010). Offering CPR when not clinically indicated can cause harm (Botti, Orfali, and Iyengar 2009; Workman 2011). On the other hand, leaving such decisions completely in the hands of physicians may lead to biased decision-making partially based on unconscious factors (i.e. patient race, age, socioeconomic status) as I discussed in Chapter 3 (Kelly and May 1982). Some have argued that DNR¹² decisions should be tailored to three distinct patient populations: 1)

¹² There are variations in the exact terminology used to describe this order including DNAR (do not attempt resuscitation) and DNACPR (do not attempt CPR). I have used DNR throughout this thesis for the sake of consistency, even though the four institutions studied used different terms. It is interesting to note that the two autonomy focused institutions use DNR, whereas the University of

consider CPR as a plausible option, 2) recommend against CPR, or 3) do not offer CPR to those imminently dying or who have no chance of surviving to discharge (Blinderman et al. 2012). This framework embraces the notion that providing clear recommendations is a part of a physician's duty to act with beneficence and empowers rather than hinders the patient's ability to make an informed, autonomous decision.

The concept of "informed assent" operationalises this best interest framework, where the clinician does not insist that the decision ultimately be made by the patient or family member, and explicitly recommends against CPR when clearly not indicated (Curtis and Burt 2007a). National and local policies differ between and within the United States and United Kingdom. Whereas broadly American institutions tend to prioritise autonomy and individual choice, British institutions promote best-interest decision-making guided primarily by the physician, who has the unilateral authority to withhold CPR where deemed appropriate (Bishop et al. 2010b; Mello and Jenkinson 1998; NHS 2011).

Studies have shown that institutional cultures surrounding advanced care planning contribute to variation in care provided by hospitals in end of life ICU care (Barnato et al. 2012, 2014; Quill et al. 2014; Wunsch and Harrison 2005). Others have demonstrated considerable variation in use of DNR orders and withdrawal of life sustaining therapies, even after accounting for variations in patient characteristics (Quill et al., 2014; Zingmond & Wenger, 2012).

Section 5.2: Demographic Characteristics of Study Participants

Thirteen to sixteen physicians participated at each site, with approximately equal numbers of attendings, fellows and residents¹³ at each site interviewed. Years of experience ranged from one to forty-five years of experience. Demographic characteristics, level of experience, and subspecialty within internal medicine (if applicable) are described in Table 5.1 below.

Washington uses DNAR and the UK uses DNACPR. Terminology is important and can influence decision-making (Venneman et al. 2008). These institutions enshrined in their terms a recognition that these would be *attempts* at resuscitation and not solely resuscitation.

¹³ See Introduction for explanation of UK medical ranking equivalents

Table 5.1: Demographic Characteristics of Study Participants

	Columbia (n=13)	Hopkins (n=16)	UW (n=13)	Addenbrooke's (n=16)
Years of Experience ¹⁴ Range	2-45	1-42	2-40	2-34
Male:Female	6:7	11:5	6:7	11:5
Professional Status				
Attending or Consultant	6 (46%)	9 (56%)	5 (38%)	9 (56%)
Fellow or ST	3 (23%)	3 (19%)	4 (31%)	4 (25%)
Resident or FY/CMT ¹⁵	4 (31%)	4 (25%)	4 (31%)	3 (19%)
Internal Medicine Subspecialty				
General Internal Medicine	5 (38%)	10 (62%)	5 (38%)	4 (25%)
Pulmonary/Critical Care	6 (46%)	2 (12%)	6 (46%)	4 (25%)
Palliative Care	1 (8%)	2 (12%)	1 (8%)	1 (6%)
Geriatrics	0 (0%)	0 (0%)	0 (0%)	3 (19%)
Oncology	0 (0%)	1 (6%)	1 (8%)	4 (25%)
Cardiology	1 (8%)	1 (6%)	0 (0%)	0 (0%)
Neurology	0 (0%)	0 (0%)	1 (8%)	0 (0%)

Section 5.3: Institutions Prioritise Patient Autonomy or Patients' Best Interest

At each hospital, physicians' ethical attitudes towards DNR decision-making reflected its hospital's policy position regarding its prioritisation of autonomy versus best interest (See Table 4.1). In general, physicians at Columbia and Hopkins, whose policies prioritised autonomy, felt that patient autonomy rose above other ethical principles. In contrast, at hospitals whose policies emphasised best-interest decision-making, UW and Addenbrooke's, physicians were more likely to feel that they had the ability to make clinical recommendations that respected both autonomy and the patient's best interest, or prioritised best interest as a whole. Most physicians at UW felt comfortable using the informed assent approach when appropriate. I recognise that these categorisations are a blunt instrument that do not reflect the richness and variation that is inherent to the social world. Nonetheless, what I hope to convey with this dichotomy are that broad

¹⁴ Years of postgraduate medical experience (i.e. after medical school graduation)

¹⁵ FY=Foundation Year Trainee, CMT=Core Medical Trainee, ST=Specialist Trainee

characteristics appeared to emerge which seemed to influence physicians' ethical thinking and behaviour.

Physicians in the UK have the unilateral authority to determine resuscitation status, which must first be determined clinically (please see Appendix H). Similarly, UW's DNR policy begins with a "determination of futility" prior to the section on eliciting "patient preferences." In this section, the policy indicates the likelihood of successful resuscitation is extremely low with pre-existing conditions such as metastatic cancer and sepsis, and emphasises that "there is consensus that CPR would not be effective or even if successful would not be beneficial to the patient. There are some patients in whom CPR should not be attempted (University of Washington 2013)." This language emphasises the importance of the physician's clinical judgement in determining DNR status. Trainees were generally not aware of their hospitals' DNR policies but appeared more aware of the culture of their institution regarding these policies rather than the policies themselves. The vast majority were unfamiliar with the details as they had never read the policy. Table 5.2 below describes select illustrative quotations from interview respondents that demonstrate institutions' ethical priorities that focus on either autonomy or best interest.

Table 5.2: Selective Illustrative Quotations of Institutional Ethical Priorities¹⁶

Columbia – Autonomy focused approach	Hopkins – Autonomy focused approach	UW – Best Interest focused approach	Addenbrooke’s – Best Interest focused approach
<p>“I think we face [futile CPR] a lot. I think if that’s what they want, that’s what they want. I think it’s a fair thing...if they want it after understanding all of those things, then that’s what they want. I think to some extent, that it’s not our job to dictate what exactly what you should do...it’s their decision. It’s their life, their body, they should choose whatever they want to be done with it. (PGY-3: 10)”</p>	<p>“I’m afraid autonomy pretty much drives the system, whether or not we think it should or not. Hospital policy says the patient is in the driver’s seat. Autonomy is the principle that rises to the top. (Attending: 3)”</p> <p>“House staff are thoroughly inculcated in the concept of the patient. DNR decisions are just kind of the tip of the iceberg. I often see them taking overwhelmed families and giving them a long list of therapies to approve or disapprove...I don’t know where [medical students] get it, you know...There’s multiple ethical principles but somehow the autonomy becomes the only one that enters into these discussions (Attending: 4).”</p>	<p>“Ideally I like for patient best interest and patient autonomy to line up. To get to a place where if the patient understands that they may understand that what we’re recommending is probably best interest...same with intubation sometimes. It’s not in the patient’s best interest, we shouldn’t be offering it. I think it’s a fine line trying to table out which way to go. (PGY-6: 8)”</p>	<p>“I feel a personal, clinical, legal responsibility to do the best for my patients so to offer them the best possible care but not to offer them treatments for which they’re, they are unlikely to benefit. (Consultant: 1)”</p> <p>“Best interest decision-making, we’re mandate by The Mental Capacity Act¹⁷ to take into account family’s views. So it would be absolutely impossible not to.” (Consultant: 5)</p>

¹⁶ I have chosen to present my quotations slightly differently in this chapter than I will in subsequent chapters. I have done this in order to emphasise the dichotomy of differing attitudes amongst respondents which appear to differ between institutions that prioritised best interest versus those that prioritised autonomy.

¹⁷ The Mental Capacity Act of 2005 is a law that mandates best interest decision-making in patients who lack capacity(Mental Capacity Act 2005)

Section 5.4: Experienced Physicians at All Sites were Willing to Recommend Against CPR when Resuscitation was Unlikely to Work

Experienced physicians at all sites generally felt comfortable engaging in best interest decision-making and when clinically appropriate, either not offer or make explicit recommendations against offering resuscitation. Table 5.3 below describes selective illustrative quotes demonstrating experienced physicians’ willingness to make recommendations against resuscitation when clinically appropriate.

Table 5.3: Selective Illustrative Quotations of Experienced Physicians’ Willingness to Recommend

Columbia – Autonomy focused approach	Hopkins – Autonomy focused approach	UW – Best Interest focused approach	Addenbrooke’s – Best Interest focused approach
“If the patient gets worse, you’re going to hear me recommend DNR because I’m not too sure that doing chest compressions will actually save this person’s life. (Attending: 2)”	“I will tell the family that there is nothing more to offer and when they die we’re not going to do CPR to bring them back to a condition that is worse than they were moments ago. (Attending: 7)”	“I tend to be a bit more directive and I say that in my experience the chance of your loved one being able to leave the hospital...if they’ve come to the point of requiring resuscitation is very small. (Attending: 1)”	“I will say, our plan is that we wouldn’t be active at that stage to try and re-start your heart and many of them say, well thank goodness for that. (Consultant: 2)”

Respondents stated that they would discuss with the patient or surrogate the situation from a goal of care perspective and either recommend against resuscitation, or focus on comfort care without explicitly mentioning resuscitation. Many of them expressed the belief that failure to give recommendations should be seen as a derogation of responsibility. As one attending at Hopkins stated:

“I would recommend the following and the patient decides. I think that’s autonomy. I think to say, ‘you could be resuscitated or not, what would you like to do?’ seems to me to be an abdication of responsibility to the patient in the name of autonomy. As the patient reminds me often, ‘You’re the doctor, how do I know?’ (Hopkins, Attending in Oncology: 2)”

Experienced physicians at hospitals that prioritised autonomy, recognised the primacy of autonomy at their institution, but believed that that did not mean that they should offer futile treatments that would not serve the best interest of their patients. They remained committed to what they believed was ethically the right thing to do, finding ways to balance autonomy and the law and making unilateral clinical decisions when they felt they were appropriate. This quote from a senior physician at Columbia demonstrated this balance:

“I have to do it because I cannot break the law. You do your best and try to minimise the amount of ethical or moral compromise by limiting the attempted resuscitation as much as possible... When it comes to a procedure that I know far better than the patient or the family, to question whether it is appropriate for me not to exercise my judgement, I think would be wrong. It is just the opposite. I would call it being a responsible doctor and exercising good judgement... My primary responsibility is to the patient, and if a family is asking me to do something that clearly is harmful to the patient, I will explain to them patiently why I don't think [it's right.] I am not going to let somebody suffer because of it (Columbia, Attending in Pulmonary Medicine: 1).”

Several respondents acknowledged a great degree of variation amongst physicians in terms of skill, attitudes, and practices, although many also expressed that their views were relatively mainstream.

Section 5.5: Inexperienced Physicians at Autonomy Focused Hospitals Felt Obligated to Offer Choice of CPR Without Explicit Recommendations Even if Success was Unlikely

Although hospital policies primarily dictated whether patient preferences should be honoured, and none of the hospitals required physicians to offer the choice of resuscitation if it was unlikely to work, trainees at hospitals where policies reflected autonomy focused approaches often interpreted policies to mean that they were obligated to offer a choice of resuscitation in all cases regardless of likelihood of survival, and that

they should not provide clinical recommendations (See Table 5.4 below, columns 1 and 2).

Table 5.4: Selective Illustrative Quotations of Inexperienced Physicians’ Willingness to Make Recommendations

Columbia– Autonomy focused approach	Hopkins – Autonomy focused approach	UW – Best Interest focused approach	Addenbrooke’s– Best Interest focused approach
<p>“I feel it’s more of moral burden for me, to say this person needs to be a DNR and I’m going to make then a DNR. I don’t necessarily know if I have the right, to make that decision for that patient. Again, I’m torn. I know that these decisions often mean, that yes, we’re going to spend x, y, and z time doing a potentially useless thing on this person and causing pain. I just don’t know. With my level of training and where I am, I don’t think I’ll feel comfortable doing that. (PGY-5: 8)”</p> <p>“These two attendings were wonderful... They don’t ask the patients and families, they sort of tell them. “You’re 90 years old, this would not be good for you. We would not do that. It would be a horrible experience, we would not want to do that to you.” Usually, in that format that they say it, the family members are like, “Okay, yeah, of course.” It was a completely different experience. It was really nice to see that. I remember having a</p>	<p>“The idea is not transfer of the right to make medical decisions to me, it’s to their loved one. And the reason for that is because they presumably know them better than I do, so you know. I try to give you as much information to make an informed decision, but it’s still [their decision]. So I do still subscribe to autonomy, I think more than perhaps [even if] I really don’t think this is in the patient’s best interests. (PGY-4: 12)”</p> <p>“There was family discord...that wanted to do everything and it doesn’t seem like the patient’s wishes but I think in those circumstances that I wish I could just say, you know: I think it’s not really medically indicated and we’ll make sure that she’s comfortable. (PGY-2: 15)”</p>	<p>“I feel strongly about our responsibilities for a recommendation and I think I do that more now than before. (PGY-3: 11)”</p> <p>“We don’t necessarily need them to pick from a list of options. It’s within the bounds of our responsibility to offer what our expert opinion is. (PGY-3: 10)”</p> <p>“And so if it’s one of those scenarios and we’ve already sort of decided that the patient wouldn’t benefit from a resuscitation...we will try and give as much information as we can before we finally say this is from our perspective what’s going on, and this is why we think your family member would not benefit from a resuscitation. (PGY-3: 11)”</p> <p>“I came in to residency with the mind-set that it’s just two options and you just choose one. You know you present them very equally and you leave it completely up to the family and you kind of leave your own opinion on the back</p>	<p>“And then explaining why we would feel that resuscitation wasn’t going to be in their best interests and why we thought it wasn’t going to be successful. That’s usually what I would say. (Jr Clinical Fellow in Oncology: 15)”</p> <p>“So I don’t pose it as a kind of [choice], it would be unusual for me to say, I don’t know what to do what do you think? It would be this is what I think tell me what you’re thinking, I’ll then think about it, we’ll discuss it I would recommend I would say I think this is best. (Geriatrics SpR (ST5): 10)”</p> <p>“I’d probably give it as a recommendation. I think if you tell a patient that’s what we’re going to do and it’s not open for discussion it results in agitation and annoyance. If you give it to them as a choice they’ll very rarely make a decision because they haven’t got the knowledge, the resources and it’s a very difficult decision to make. If you make a recommendation and</p>

<p>discussion with my co-residents after that. We were thinking, we were just saying that we don't know if we could get away with doing that. (PGY-3: 11)"</p>		<p>burner...[some of the attendings taught me that] through greater medical understanding your opinion can kind of creep into the room and be helpful adjunct. You should come in with a mind-set like what you think is your recommendation from a medical standpoint. So that's definitely changed. (PGY-2: 13)"</p> <p>"I feel like I have embraced the idea of a physician as somebody who makes recommendations and offers alternatives based on assessment of best interest, that if I'm going to make an informed assent, it's with the understanding of what the patient or their loved ones framework of best interest is and trying to match those goals. (PGY-3:10)"</p>	<p>say this is what I think, would you like to have some input, what are your ideas? You know do my recommendations align with your thoughts? That's often a better way to approach the discussion. (SpR: 14)"</p>
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Trainees did not feel comfortable recommending that resuscitation be withheld even if the chance of successful resuscitation were negligible (See Table 5.4 above, columns 3 and 4). One resident at Hospital A felt it was inappropriate to, "inject your own personal opinions of life and death." To another resident, respecting autonomy meant providing information without biasing the patient with a recommendation and that "it's my responsibility...to do everything as they say (Hopkins, PGY-2: 15)." Less experienced physicians at autonomy-focused hospitals expressed to a degree their responsibility for decision-making, but they appeared to be more hesitant to take on that responsibility.

In contrast, trainees at hospitals that had policies that encouraged a best interest decision-making approach (UW and Addenbrooke's) felt more comfortable expressing clinical judgement against resuscitation when appropriate. Many of the trainees at UW were

willing to utilise informed assent and strongly recommend against or not offer resuscitation if it was very unlikely not to work. One resident said:

“I can think of a few times per rotation where informed assent was done. I did it at least a few times in the ICU, where if things head towards CPR then I’d say, ‘It wouldn’t be something that we think would be appropriate for you and here is why (UW, PGY-3: C12).’”

This chart below (Figure 5.1) presents a summary of the patterns that emerged amongst respondents, which appeared to vary based upon institutional prioritisation of autonomy and level of experience.

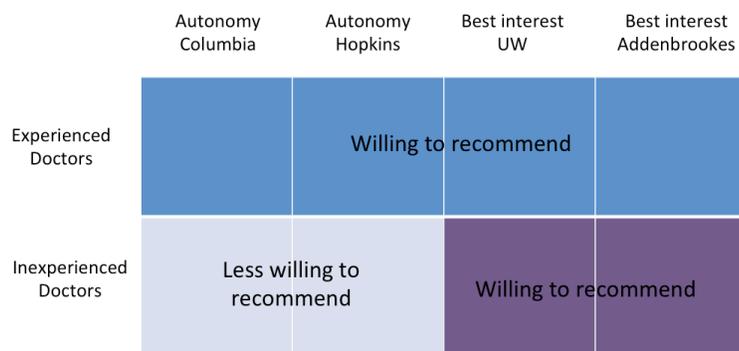


Figure 5.1: Differences in physicians’ willingness to make recommendations regarding the decision to pursue a DNR order amongst institutions focused on autonomy versus best interest decision-making

Section 5.6: Perceived Conflict Between Physicians and Patients

One study noted conflict regarding the decision to limit life sustaining therapies in the ICU perceived by staff in 78% of the cases, 48% between the staff and family members (Breen et al. 2001). Families also acknowledge conflict; 46% of families perceived conflicts regarding withholding life-sustaining support, the majority of which were between themselves and the medical staff (Abbott et al. 2001). There was much variation in the degree of perceived conflict between doctors and patients regarding resuscitation

preference. Most often, this involved scenarios where the physician believed it would not be medically appropriate to resuscitate and the patient/surrogate wishes to be resuscitated.

Despite this variation, there were also striking patterns between institutions, especially amongst less experienced trainees. In my interviews, conflicts between patients and/or surrogates and physicians regarding decisions to institute a DNR order seemed to be more common amongst physicians at autonomy focused than beneficence focused institutions. These respondents at autonomy focused institutions described instances where they felt patients were demanding and difficult:

“I’m thinking of a particular case of a gentleman who had cancer that had spread, completely wiped out his liver and he came here because they told him nothing else was to be done at Penn, and we felt there was nothing to be done. He and his family didn’t want to hear it, they insisted, they brought us the patients’ Bill of Rights and said we should see the Liver and Oncology specialists (Hopkins, PGY-3: 14).”

“We’ve certainly had patients that families that were asking for things that just don’t exist. A colleague of mine had someone asking for a brain transplant (Hopkins, Attending: 9).”

Table 5.5 below further illustrates the contrast between autonomy-focused and best interest-focused institutions in the perceived degree of discordance between physicians and patients regarding resuscitation decisions.

Table 5.5: Selective Illustrative Quotations Describing Degree of Discordance Between Physicians and Patients Regarding DNR Decisions

Columbia – Autonomy focused approach	Hopkins – Autonomy focused approach	UW – Best Interest focused approach	Addenbrooke’s– Best Interest focused approach
<p>“It’s not uncommon. I would say 30% to 40%. But that maybe more. The patients where I thought by the parameters that I mentioned earlier -- age, illness, and all that. I think of those patients, I think there are about 30% that we could, that they chose things that I felt fairly confident were things that I would not recommend. (Attending: 6)”</p> <p>“It depends...on whether they’ve talked about it...how sick the person...but what percentage actually want to continue to get everything done, I would say anywhere from 25% to 50%. (PGY-2: 13)”</p>	<p>“I think about half/half. I would say, about equal...I would say about half of the time, that they agree with the recommendation or they insist on being full...despite having conversations the family still insists on doing everything. (PGY-4: 12)”</p> <p>“After those discussions? Probably 2/3 to 3/4.”(PGY-3: 13)</p> <p>“I think that a surprising number of people want a full resuscitation. (PGY-1: 16)</p>	<p>I’ve never had a family argue with me or the team because normally it’s such a relief that someone else is making that decision and that they don’t have to make any decision.” (PGY-6: 7)</p> <p>In a situation where I don’t think doing CPR would achieve the goals of the family or the patient then I would say in this situation it’s very unlikely that your mom or dad or whatever will survive this. I would not recommend that if he were to have a cardiac arrest we would perform a CPR. Most people, once you’ve gone through all that, we’re all usually all on the same page. I don’t find that, fortunately the over conflicts don’t happen to me that frequently. (PGY-6: 6)</p>	<p>“Less than 1%, you know point something percent, a very small proportion.” (SpR: 14)</p> <p>“I’ve never been in this exact situation myself.” (Consultant: 5)</p> <p>“I will often say at the tail end of that, and if in the unlikely event that your heart was to stop, our plan at the moment is that we wouldn’t be active at that stage to try and re-start your heart and many of them say well thank goodness for that.” (Consultant: 2)</p>

I was not very surprised to see less conflict amongst British doctors and patients in comparison to the US given the cultural and social differences between the US and UK. Americans are known for being more vocal and demanding about their wishes and are stereotyped for their willingness to voice individual preferences. In contrast, the British are often perceived as being more reserved and less willing to overtly admit disagreement, especially to authority. Lack of conflict might then reflect these cultural differences with respect to questioning authority. Given that UK physicians had unilateral authority to institute a DNR order at the time of my study, there is likely a tendency to

communicate medical realities in a more directive and authoritative manner making it more difficult to question in general.

General Medical Council (GMC) best practices at the time of my study, stated that not only did physicians not have to provide treatments that would not be clinically appropriate, but that they:

“Must carefully consider whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made... While some patients may want to be told, others may find discussion about interventions that would not be clinically appropriate burdensome and of little or no value (GMC, 2010)”

Given this, there are likely situations where there is little conflict because the physician simply did not have a conversation with patients about DNR decisions. During my observations and informal conversations with patients at Addenbrookes, it was not uncommon to see DNACPR orders in the chart with documentation that the ward team had discussed with the patient. However, the patient was neither aware that a DNACPR had been instituted nor could they recall that they had a conversation about resuscitation with the doctor. This policy has changed in light of the Tracey court case as patients now need to be involved and informed in the DNR decision-making process if so desired.

It was thus especially striking to me when interviewing at UW in the US, that they appeared to also rarely experience conflict in ways more similar to the UK physicians than the US physicians. I could not attribute this as easily to cross cultural differences. My research suggests that an important determinant of conflict might include the ways in which physicians offer choices, frame conversations, and make recommendations. I hypothesize this is a major reason why the doctors at UW and Addenbrooke's both seemed to encounter less conflict with patients regarding resuscitation preferences.

Conflict between physician and patient/surrogate seemed to be greater at hospitals that prioritized autonomy in comparison to hospitals that prioritized beneficence in part due to

the differences in their willingness to make recommendations (trainees at Columbia and Hopkins less willing to make recommendations than UW and Addenbrooke's). These patterns of conflict that emerged, while striking, also demonstrated significant within institution variation amongst respondents. This likely reflects the degree to which communication skills, framing, and even personality of the physician influences interactions and degree of conflict. These physicians at UW appeared to understand the importance of communication and presentation of facts:

“You offer somebody something, they say what they want, they say I don't really like that answer...that seems adversarial. But in the UK it seems that they just don't offer something and take it away but simply go with the decision and says that's what's appropriate. That makes more sense.” (UW, PGY-3: 11)

“Usually its an easy sell, it's easy to get the family on the same page as long as it's presented in the right way. There've been times where I could tell that the family appreciated having the decision taken off their shoulders and that's one of the things I think about a lot is this idea that we don't force a family to choose antibiotics for their loved one. It seems strange that we force them to choose whether or not to do this one procedure. I have never had somebody seem offended that I propose it this way [informed assent]” (UW, PGY -3: 10)

Section 5.7: Conclusion

A hospital's culture and policies' prioritisation of autonomy versus best interest appears to influence the way that physician trainees conceptualise patient autonomy. This may subsequently influence the degree of choice and recommendations they are willing to offer regarding DNR decision-making. While experienced physicians in this study acknowledge institutional culture and policies, it appears they do not exclusively allow their actions to be prescribed by policies, and were willing to make recommendations against resuscitation if they believed it would be futile. While variation existed amongst respondents, in general, experienced doctors at all sites understood and acted upon their

ethical obligations to recommend and offer treatments responsibly. This may subsequently influence the degree of conflict regarding patients and physicians' preference of whether resuscitation should be pursued.

Although hospital policies, even at the most patient autonomy-focused institutions, do not require doctors to offer futile resuscitation nor to withhold recommendations, I found that less experienced doctors at autonomy-focused hospitals tend to over-interpret hospital policies and embrace a reductionist, limited understanding of autonomy. Ethics and communications at the end of life are generally present in the medical school and residency didactic curricula, but lack of time and space on the wards for reflection might promote an excessive, un-reflexive deference to patient autonomy that risks placing unwanted and unreasonable responsibility for medical decision-making onto the patient or surrogate (Billings and Krakauer 2011; Quill and Brody 1996; Salmon and Hall 2003).”

It seemed that as physicians become more experienced, they develop a professional confidence that allows them to feel empowered to act according to their own moral compass, despite policies or cultures that incentivised not doing so. This would for example entail strongly recommending against resuscitation that would have a negligible benefit for the patient. They have learned through experiences with patients – what worked and what didn't – that the idea of autonomy as merely giving choices is overly simplistic.

Unlike more senior physicians, trainees have not yet developed the experience or professional confidence to advocate for their patient's best interest by making explicit recommendations regardless of their institution's policy or cultural constraints. Trainees at autonomy-focused hospitals appear compelled to offer the choice of resuscitation neutrally without a specific recommendation in all situations regardless of whether they believed it to be clinically appropriate. Their attitudes might reflect perceived constraints due to policies and expectations, which focus on patient autonomy. It suggests that the ethical principles embraced by experienced physicians were not transmitted to learners at

autonomy-focused institutions.

The culture and policies at UW and Addenbrooke's actively encourage best interest decision-making. Although some of the physicians at UW had never heard the term informed assent, the cultural norm at that institution, similar to the hospital in the UK, was not only that it was appropriate to discourage ineffective CPR, but also that it would be ethically suspect to offer CPR in futile situations. These trainees appeared to have the time and space within their workflow and culture to develop similar attitudes to experienced physicians. Interns and residents come from medical schools across the country, and yet seemed to adapt similar attitudes to their peers in residency training.

Studies have shown that in practice, physicians and residents do not provide adequate information during conversations regarding resuscitation (Anderson et al. 2011; Tulskey, Chesney, and Lo 1995). The majority omit critical information on prognosis, goals of care, or explanations of the processes involved in various interventions. Although medical residents generally have a great respect for autonomy, omission of these critical elements may deprive patients of the very autonomy that physicians seek to respect (Billings and Krakauer 2011; Salmon and Hall 2003).

Interventions to improve end of life communication skills have focused on formal curricula and increasing opportunities for house staff to practise these skills (Curtis et al. 2013). Few studies have explored the effects of a hidden curriculum on the development of medical trainees and its effect on their ethical beliefs and communication strategies (Cribb and Bignold 1999; Goldie 2000; Hafferty and Franks 1994; Hundert 1996). This hidden curriculum describes the inadvertent transmission of attitudes and behaviors to trainees through everyday interactions during their training that are in conflict with the normative ideals and official policies of the medical profession (Hafferty 1998). Because so much of residency training involves an apprenticeship-based peer learning, the influence of the cultural milieu cannot be overemphasised.

It is often perceived that the US and the UK are on opposite ends of the autonomy-best

interest spectrum, where the focus in the US is more on individual choice and patient rights, and the culture in the UK reflecting a greater acceptance of more paternalistic practices (Iserson 2010). This study suggests that there may be important differences in approaches not only between the US and UK, but within the US itself. Trainees at the American hospital that encouraged best interest decision-making had attitudes and beliefs about DNR decision-making that appeared more similar to British doctors than doctors at the other American sites. In contrast to trainees at the autonomy-focused hospitals, they seemed more willing to not offer resuscitation if they did not think that it was indicated.

There are inadequacies in physician communication at the end of life, especially amongst medical trainees (Chi and Verghese 2013). Prior studies have shown that advanced care norms impact end of life ICU use, but to my knowledge, this is the first study that explores the influence of a hospital's policy or culture on physicians' understanding of autonomy and willingness to recommend resuscitation decisions (Barnato et al. 2012, 2014). This thesis hypothesises that culture and policies oriented towards autonomy may have unintended consequences of constraining a physician's willingness to make recommendations, especially that of trainees.

It is ironic that the very policies that seek to empower patients might inadvertently deprive them of their autonomy through an overemphasis on a reductionist, checklist approach to autonomy. Perhaps policies more oriented towards best interest decision-making, might allow physicians the space to shift their focus from a discourse of choice to one of care and compassion.

In the next chapter, I will elaborate upon the ethical issue introduced in this chapter and position my findings within current ethical debates on principlism and whether autonomy should be the principle that rises to the top. Subsequent chapters will further demonstrate how the way these ethical conceptualisations harm physician trainees, patients and surrogates. Chapter 7 will link this powerlessness with moral distress regarding futile treatments at the end of life, while Chapter 8 will focus on how this failure to recommend encourages physician trainees to revert to pathologic forms of communication to try to

convince patients and surrogates to reject futile resuscitation.

Chapter 6: Principlism in Practice: Moving Beyond an Ethics of Choice

In this chapter I discuss principlism - the dominant framework for ethics in the US - in practice on the wards, followed by a discussion of the problems with the ideology of choice in this quest to honour patient autonomy. I critique the reductionist thinking that equates autonomy as choice in autonomy focused institutions and suggest that we should instead shift the focus from the beneficence of outcome towards beneficence in the process of decision-making. I further critique the current neoliberal discourse of choice in decision-making at the end of life and argue that it both disempowers and allows the physician to absolve himself of responsibility. I conclude with an enquiry into why best interest decision-making seems to align itself more with a more nuanced understanding of choice, and what we can do in practice to improve that.

Section 6.1: Introduction

This chapter contributes empirical evidence to debates surrounding principlism and the manner in which its theory inadequately translates to clinical practice. Again, because the focus of the thesis is on local institutional practices predominantly in the US, with the UK serving as an additional “control” site, my ethical analysis in this chapter will be focused on ethics in the US. Ethical principles are established in the clinical setting by institutional policies and culture through the hidden curriculum and influence how medical trainees conceptualise ethical conflicts surrounding the decision to pursue a DNR order at the end of life. The contrasts between policies and cultures that prioritise autonomy versus beneficence describe the practical manifestations of theoretical debates surrounding autonomy and beneficence. It is worth reviewing relevant background from Chapters 2 and 3 in light of the specific ethical quandaries that I discuss in this chapter.

Based on Hippocratic principles, medicine was traditionally governed by a beneficence model, where the physician’s primary obligation was to provide medical benefit (Faden

and Beauchamp 1986). Popular trust that physicians acting on behalf of patients in their best interest reflected the dominance and authority of physicians. In part because physicians possessed control over the esoteric knowledge of medicine and a professional aura of altruism, physicians were able to command a paternalistic authority over patients and indeed act in a patient's best interest (or at least the physician's perception of what was in the patient's best interest) (Katz 2002). The social transformation of American medicine that began decades ago shifted power from the doctor to the patient, and younger physicians are now predominantly indoctrinated in an ideology of autonomy (Starr 1982). The question that remains now is whether society's move away from best interest towards autonomy is ultimately in patients' best interest.

Section 6.2: Sociological Trends in Patient Autonomy and Decision-Making

Section 6.2.1: The Shift Towards Autonomy as a Consequence of the Social Transformation of Physicians

These changes in the dominance of physicians and the consumerisation of medicine outlined in Chapter 2 shifted the power dynamic within the clinical interaction. No longer were people willing to accept the "doctor knows best" attitude (Rhem 2012). Changes in the physician-patient relationship resulted in a new emphasis on patient autonomy and participation. The emergence of patients rights as a societal demand reflect the more general trend of empowering individuals against authority (Truog 2012). Practitioners find themselves offering and discussing decisions in ways they would have never imagined in the past. Consumer-based health care models have enshrined this primacy of choice into policy. Americans increasingly see health care as a commodity that they, rather than their physician, should have the right to decide. Some physicians questioned whether offering this a la carte menu of choices was a clinically appropriate response to this culture of consumerism (Billings and Krakauer 2011; Quill and Brody 1996).

The increasing bureaucratisation and corporatisation of health care has also threatened the autonomy of physicians not only from an administrative and economic standpoint, but

also within the clinical setting (Mckinlay and Marceau 2002). Physicians lament that they are now being told how to practice medicine (Hejafred 2014). The encroachment of prior approval requirements and limited choice of therapies dictated by insurance companies result in clinical decisions that are not made at the bedside, but instead by a non-medically qualified administrator miles away from the actual patient. In the quest for autonomy, patients may have exchanged paternalism by doctors with paternalism by non-physician administrators who are more concerned about cost savings than care. Increased use of information technologies also closely monitor physician performance and scrutinise based on conformity, efficiency and cost savings, further decreasing physician autonomy and self-regulation.

This move away from paternalism is a positive step, as it prevents undue influence of power and authority, where a paternalistic physician prescribes therapies that might not be the best fit for the patient. However, what I argue in the remainder of this chapter is that patient choice alone does not guarantee better outcomes or patient empowerment, and that we must be more nuanced about the way that we fulfill this autonomy.

Section 6.2.2: The Rise of Autonomy and its Challenges to Beneficence

Medical ethics established its prominence within the practice of modern medicine with the Nuremberg Code, established as a response to the atrocities of World War II and specifically the role of Nazi physicians in holocaust and eugenics experiments (Katz 1996; Kaufman 2006). The Nuremberg Code comprised of ten principles that outlined basic medical ethical standards, including voluntary consent. Despite this, for several more decades researchers in the US paid relatively little attention to these principles and especially that of informed consent (Katz 1996). It was not until the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research's Belmont Report was created by Congress in 1979, that patient rights and autonomy became a priority in the US (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). Involvement of lawyers and academic philosophers in these sorts of commissions led to the dominant principles

of patient autonomy, first in the research realm, and subsequently in the clinical setting. It is important to note that this evolution away from paternalism and physician authority was primarily led by those outside of the medical profession (Kaufman 2006: 73).

The dominant ethical framework in clinical practice today in the United States is principlism, based on the four principles of autonomy, beneficence, nonmaleficence, and justice, as outlined by Beauchamp and Childress in “Principles of Biomedical Ethics” (PBE) (Beauchamp and Childress 2013). Beneficence dictates that a physician should act in the best interest of the patient, which oftentimes also means making efforts to help secure their well being. Justice focuses on conceptions of equality and fairness. Non-maleficence is the concept of first doing no harm (*Primum non nocere*), an ancient moral standard enshrined by the Hippocratic Oath. The importance and weight of each of these elements have shifted significantly through the decades, most importantly with shifts from acting with beneficence to an emphasis on autonomy. Autonomy can be broadly defined as the liberty and agency to act freely and ownership over one’s own body.

Contemporary origins of the ideas of individual autonomy hark back to Immanuel Kant, who believed that autonomy reflected the capacity of a person guide one’s actions based upon their free and flexible use of their own reasoning, not the person’s liberty to do whatever they want (Halpern 2001). In the nineteenth century, in his essay *On Liberty*, John Stuart Mill noted that individuality and autonomy are not fulfilled merely by the ability to choose, but that one must take charge of their own desires and choices:

“A person whose desires and impulses are his own – are the expression of his own nature, as it has been developed and modified by his own culture – is said to have a character. One whose desires and impulses are not his own, has no character, no more than a steam engine has a character (Mill 1974)”

More recently, bioethicist Ruth Faden defines autonomy as requiring intentionality, non-control, and patient understanding (Faden and Beauchamp 1986). Contemporary definitions of autonomy were in part shaped by the Belmont Report, which includes a

respect for persons where the focus is on treating people with courtesy and respect. This means acknowledging autonomy, but also a requirement to protect those with diminished autonomy (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). For those who are capable of self-deliberation about personal goals, weight should be given to the autonomous person's opinions and choices, and the freedom to act on these considered judgements. It also means respecting and protecting those who are incapable of self-determination.

The challenge facing physicians as a result of this shift creates a potential conflict between autonomy and beneficence, especially the commitment not to provide non-effective treatments where the risks outweigh the potential benefits of treatment. To what extent does autonomy cover the right to demand treatments? How can autonomy be respected in a way that preserves the ultimate goals of the physician-patient encounter, which is to initiate treatments that are mutually agreed upon as in the best interest of the patient?

Section 6.2.3: Models of Decision-making

An autonomy focused model of decision-making (independent choice model) describes a strategy where the physician “objectively present patients with options and odds but withholds their own experience and recommendations to avoid overly influencing patients” (Quill and Brody 1996). Within the patient encounter, there is increasing recognition that “excessive or reflexive deference to an unreflective concept of patient autonomy...places unwarranted and unreasonable responsibility for technical medical decisions on patients...[thereby] harming patients [and] depriving them of expert, professional advice” (Billings and Krakauer 2011). An ideal balance of roles and responsibilities might assume that the patient is the expert on his or her values, goals, and preferences, while the physician is the expert on the medical means for honouring the patient's perspective.

One critique of the independent choice model states that it, “confuses the concepts of independence and autonomy and assumes that the physician’s exercise of power and influence inevitably diminishes the patient’s ability to choose...it sacrifices competence for control” (Quill and Brody 1996). In a recent lecture, Joseph Nye, a preeminent international relations scholar, urged countries influential in the geopolitical arena not to think of “power *over* others, which is a zero sum game, but power *with* others, which is not a zero sum game” (Nye, 2012). Perhaps the medical profession should approach issues of power and authority similarly. One should not think of power as a zero sum game that must be wrestled from the physician to the patient, but as a cooperative interaction that reimagines the concept of power in a more sophisticated manner.

An alternative is the shared decision-making model, which recognises that autonomy does not merely equate to an unqualified right to choose. Decisions that prioritise autonomy should not go against clinical judgement and evidence based reason. The physician should not be passively following patient requests but instead providing “coherent deliberation” (Brett and McCullough 2012). The shared decision-making model is an alternative, which encourages patients and physicians to share their power and actively exchange ideas in order to create a plan that best fits that particular patient. Shared decision-making is an attractive option for both people who feel that there is too much physician paternalism, as well as those who believe that the pendulum has swung too far towards autonomy.

The evidence for whether patients want to be the ones making the decisions is not entirely clear. One study found that 97% of patients wanted to be told what was going on, but 67% wanted the doctor to make the decision (Chung et al. 2012). It is also not apparent that patient satisfaction is the best mechanism for determining quality of care and costs. One study highlighting the “cost of satisfaction,” showed that patient satisfaction was associated with greater inpatient use, higher overall health care and prescription drug expenditures, and increased mortality (Fenton et al. 2012).

Section 6.2.4: Debates Surrounding the Principlist Approach

There has been much debate as to whether the principlist approach can adequately and universally capture the whole scope of ethical dilemmas in medicine (Campbell 2003). Raanan Gillon has been a major advocate of principlism, championing its applicability across the majority of clinical contexts. He recognises its limitations with respect to addressing conflicts between principles and the overall scope of individual principles, but also argues that the approach provides a basic moral language and analytical framework for doctors that is practical and simple for use in the clinical setting (Gillon 2015).

Although principlism when understood properly and appreciated in its entirety, provides a useful and universalisable framework for understanding applied medical ethics, most doctors have not had the opportunity to read PBE nor reflected upon them beyond its chapter headings. The challenge of principlism thus lies not only in its content, but also its overly simplified and frequently misconstrued interpretation in the clinical setting. Criticisms of the four principles often centre around the reductionist, unreflective checklist approach of principlism seen in clinical practice that is “reduced to a flowchart approach denuded of nuanced reasoning” (Kong 2015).

A related debate centres around autonomy as the principle that rises “first amongst equals” (Gillon 2003). American medicine, and increasingly British medicine, reflects an ideology of autonomy and choice. Both ethicists and physicians have raised questions as to whether there has been too much emphasis on autonomy as a principle that supersedes the others (Billings and Krakauer 2011; Dawson 2010; Quill and Brody 1996). These attitudes lead to dogmatic and unreflective understandings of autonomy that do not question the nature and grounds for this moral claim (Dawson 2010). As a result, autonomy is frequently the trump card in the majority of ethical dilemmas, automatically taking precedence over beneficence, nonmaleficance, and justice, without due introspection on how autonomy is meant to be fulfilled beyond giving the patient choice.

Section 6.3: An Ethics of Choice?

These ethical challenges are common at the end of life; the uncertainty of prognosis and the ethically permissible boundaries of treatment create confusion and conflict about balance of benefits and burdens experienced by patients. Embedded in end of life care are ethical dilemmas that are punctuated by conflicts between two conflicting ethical obligations such as respecting a patient's autonomy and the duty to do not harm.

Section 6.3.1: Respect for Autonomy Misconstrued as Giving Choice

Overall survival to discharge after in hospital CPR is around 18.3% in elderly patients over the age of 65 in the US (Ehlenbach et al. 2009). Studies have shown that likelihood of survival is highly unlikely in certain conditions such as sepsis or metastatic cancer, and is near zero when irreversible death is imminent (Ebell et al. 1998; Taylor et al. 2010). Despite these odds, as I explicated in the previous chapter, doctors at autonomy-focused hospitals often felt compelled to offer choice in situations even when the likelihood of meaningful success from resuscitation was negligible (Dzeng, Colaianni, Roland, Smith, et al. 2015).

Some trainee respondents' interpretation of autonomy had strayed quite a bit from the definitions of autonomy proposed in the ethical literature. Rather than autonomy focused on understanding and the ability for self-reasoning, they had been taught that autonomy meant giving choice of therapies in a "neutral" manner. Medical trainees at autonomy-focused hospitals frequently misinterpreted autonomy to mean the freedom to make one's own choice:

“For patients I think have a chance of dying on this hospitalisation, I'd say explicitly. 'One of the things we always ask people when they come to the hospital is, in case of extremis where your heart stops beating, what would you want us to do? There are many things that we can do these days in medical practice.’” (Hopkins, PGY-3: 13)

They felt that offering choice justified treatment decisions regardless of whether it might cause harm or benefit. Amongst some interviewees, there was a degree of self-reflexivity about the pressure at their institution to offer a menu of choices:

“I feel there’s no room for clinical judgement. We have to put the entire menu out there” (Hopkins, PGY-2: 15)

“One thing I have noticed is this kind of grab bag of things offered. It’s almost like a buffet. ‘Well, we can do this, this and this. We can offer chest compressions and intubation.’ And a family will say, ‘Maybe I’ll take the compressions but I won’t take the intubation.’ I really don’t understand how we’ve gotten to that point.” (Columbia, PGY-2: 12)

Erich Loewy argues that presenting a laundry list of choices and insisting the patient chooses “is not only abandoning patients to their autonomy but is, in fact, a crass form of violating the patient’s autonomy (Loewy 2005).” He instead champions a shared decision-making approach (though he does not use the term himself), where the patient states his or her goals and values, and the physician in turn informs the patient whether the goal is attainable and if so, how that goal can be reached.

In contrast to autonomy-focused hospitals, the cultural and policy milieu at beneficence-oriented hospitals appeared to cultivate an understanding that it was the clinician’s responsibility to guide patients with their expert opinion, and that it was not always appropriate to give a menu of choices. These trainees employed shared decision-making approaches in their communication with patients. This resident at UW said:

“We don’t necessarily need them to pick from a list of options. It’s within the bounds of our responsibility to offer what our expert opinion is. I think it’s totally reasonable.” (UW, PGY-3: 10)

Experienced physicians at all hospitals also understood that autonomy did not just mean giving a list of things to choose from. In the interviews, experienced physicians at autonomy-focused institutions frequently lamented the way that house staff believed that giving choice was the way to fulfill autonomy:

“House staff are thoroughly inculcated in the concept of patient autonomy. DNR decisions are just the tip of the iceberg. I often see them taking overwhelmed families and giving them a long list of therapies to approve or disapprove.”
(Hopkins, Attending of Pulmonary and Critical Care Medicine: 4)

Section 6.3.2: Autonomy or False Choice?

Physicians at beneficence-oriented hospitals were at times critical of this reductionist approach to autonomy. This sort of introspection and critique of autonomy in practice was less frequently seen in trainees at autonomy dominant hospitals. An English registrar at Addenbrooke's suggested:

“I think the issue in my mind is calling it autonomy...you can't choose whether to be resuscitated or not, only whether someone *tries*. But the way we phrase it is to make it sound like you're choosing. Most of the people in whom I fill out resuscitation forms it just will not work. So actually you haven't really got any autonomy...because there isn't a decision to be made.” (Addenbrooke's, Consultant in Geriatrics: 9)

This resident at UW recognised the contradictions in the way that doctors sometimes give choice to patients, and how this can be overly burdensome in some cases:

“There's been times where I could tell that the family appreciated having the decision taken off of their shoulders and that's one of the things I thought about a lot is this idea of we don't force a family to choose antibiotics for their loved ones. It seems strange that we force them to choose whether or not to do this one

procedure. I've never had somebody seem offended that I proposed it this way.”
(UW, PGY-3: 10)

Critique of this idealised discourse of choice highlights that some of the choices surrogates are asked to make are physiologically false choices (Drought and Koenig 2002). Families are often asked whether they want to resuscitate a loved when the likelihood of meaningful survival is negligible. Even in situations where the patient has a negligible chance of surviving CPR, surrogates may still be asked to make this exceedingly difficult decision, which is often framed as a decision between life and death rather than a decision whether CPR will be attempted before death most certainly occurs.

Section 6.3.3: Ethical Challenges in Surrogate's Substituted Judgement

In Chapter 3 I described differences in decision-making following the patients' loss of capacity. In the US, surrogate substituted judgement, though controversial, is the accepted practice. Many respondents acknowledged that surrogates were often more aggressive than patients, and that it was not uncommon to feel that the patient's wishes were being trumped by the family's emotionally motivated decisions. Even when emotions are not a factor, studies have shown that surrogates are quite poor at choosing treatments that were the same as what the patient would have chosen for himself (Hare, Pratt, and Nelson 1992). Many surrogates are concerned about guilt and are not ready to let go and allow their loved one to die. Others may have secondary gain interests in keeping their family member alive, such as disability payments. As such, the emphasis on substituted judgement might contribute to the general culture of overly aggressive care. For example, these residents at Hopkins said:

“The patient has lost capacity. When they still had capacity, you've had conversations with them and they've said they didn't want this. But when the patient lost capacity [the family] says the patient would want to continue fighting.” (Hopkins, PGY-3: 13)

“He says he is suffering. He says he is in pain, but the family is really moving for continued aggressive resuscitation and everything else. What does the patient really want and what’s coming from the family?” (Hopkins, PGY-4: 12)

Doctors provide patients and surrogates with choice, but are more often willing to take away this autonomy to err on the side of aggressive care than towards less. Physicians in my study sometimes questioned the ethics of the not uncommon scenario where a patient had previously expressed the wish not to receive extraordinary life sustaining treatments, but once capacity was lost, their surrogates wanted them be full code and for aggressive measure. Respondents alluded to avoidance of conflict and potential for litigation as reasons that the surrogate’s wishes were more often honoured. Several trainees voiced moral distress and discomfort over having to treat patients in ways that were overly aggressive.

One trainee at the autonomy-focused hospital recalled a situation where a severely burned boy’s mother wanted to continue aggressive treatments but the father wanted comfort care. She questioned why the team sided with the father and continued aggressive treatments, despite the fact that the father’s views were more clinically reasonable:

“It was horrible taking care of him because he seemed to be in so much pain... There’s actually a discordance between the parents because dad didn't have any guilt feelings cause he was not involved in the house fire. Dad wanted care withdrawn and mom didn't and I though ethically: Why do we have to go with mom, why do we have to go with the parent that's going to be more aggressive? Dad was having his wishes not honoured. And that was hard, partially cause I agree with him...Everyday we'd round to him and just I felt horrible continuing to do everything to this kid rather than withdraw care and let him die.” (Hopkins, PGY-2: 15)

In these interviews, the hierarchical constraints where trainees who had to perform treatments, but were not able to make decisions about them, in combination with this default of aggressive care, contributed to moral distress in trainees. This moral distress

will be discussed in detail in Chapter 7. Some trainees at the beneficence focused hospital further pointed out that at times the way in which doctors frame these choices beg a decision that is inherently biased towards aggressive care:

But I think that it all starts with getting everybody on the same pathway before you just dive right into what do you want. Because then they're like 'what do you mean, what do we want?' Of course you want your family member to live forever. We don't want them to die. Because if you say 'what do you want' then that implies that their thought is we want them to live, so do everything. (UW, PGY-6: 6)

"They might know that they're not going to recover or they might have a very bad outcome, but they're almost certainly going to say yes anyway because otherwise they would be the ones who say, "No, don't resuscitate her." Can you imagine living with that? But then if they're thinking, "Oh, I don't want her to suffer either or I don't want her to be in a coma or have hypoxic brain injury" or all these things, they don't want that either. But it's still probably, they might feel that they're giving them a death sentence by, even if you explain it and say, "No, they've already died, technically they've already died," they probably would feel that they were the ones who said no, don't resuscitate. I think that's too much guilt for a family member to have to deal with." (Addenbrooke's, F2: 16)

Furthermore, surrogates are frequently unaware that there may be a physiologically false choice that resuscitation for example, would likely not work. Even if surrogates wish to de-escalate aggressive care at the end of life, they may find it very difficult to decline treatments offered, as it might be perceived as "killing" their loved one. This places an unfair and unnecessary burden and guilt on families, as it is not true. Respondents at beneficence-oriented hospitals mentioned the burden and guilt that these decisions placed on surrogates more frequently than respondents at autonomy-focused hospitals. These physicians at UW said:

“I feel that to give a family member a choice is a remarkable burden and for them to say don’t do anything more would be really hard. It seems at times more respectful rather than making them say those words but simply to say it’s time for your loved one to pass and we’ve done everything we can and we’re going to let him or she pass peacefully rather than forcing a family member to make that choice.” (UW, PGY-3: 11)

“I generally make a point never to ask a family what do you want to do. I think it puts the family in a very uncomfortable position and implies that it’s their decision alone to terminate support, which I think is an enormous burden for a family to say. It makes you seem like a neutral party like, ‘what do you want? We’ll do whatever you want. Just tell us.’ That’s really unfair to family members. Most people, once you’ve gone through all that, we’re all usually on the same page. Fortunately overt conflicts don’t happen to me that frequently.” (UW, PGY-6: 6)

There were several mentions from physicians that when the medical team made decisions, family members were relieved to have the burden of decision-making lifted:

“I’ve never had a family argue with me or the team because normally it’s such a relief that someone else is making that decision and that they don’t have to make any decision.” (UW, PGY-6: 7)

“I certainly have had really meaningful conversations with families after their loved one has died and haven’t been coded where they were just incredibly thankful that decision was taken off their shoulders and that we were there talking to them the whole way.” (UW, PGY-3: 10)

This British house officer said that taking on the responsibility of decision-making absolved surrogates from having to make these seemingly cruel decisions:

“I usually say I want to make it clear that it’s my decision to make. And I spin that positively and say it’s my decision to make, the responsibility lies with me, its not that you're having to make this decision, it’s my decision, I just want you to help me to get a feel of a few things that will help me make that decision. So that they're not, they're not feeling gosh I’ve just condemned my mother to death.”
(Addenbrooke's, ST5 in Geriatrics: 10)

Physicians often acknowledged treating the family rather than the patient. Treatments may be administered that do not benefit and potentially even harm patients, in order to help the family feel like they were “doing everything”. There are major problems with this term, “do everything,” which drives overly aggressive care by the failure to place reasonable parameters on the limitations of care based on physiology and patient preference. It also often reflects a false promise (on the part of the physicians) and false request (on the part of the surrogates) as modern medical technologies allow us an almost endless array of possible interventions and saying that everything will be done is an unreasonable and untenable promise. It then confounds communications and expectations on what actually can be accomplished.

Furthermore, there are often disparate understandings of what “doing everything” entails, potentially meaning very different things to the patient/surrogate than the physician. For example, one interview study described the following, “One woman said that her grandson would definitely want everything done, but in the next breath said that when it was his time, though, they should just let him go, let him have some dignity (Drought and Koenig 2002).” This highlights the importance of avoiding terms such as “doing everything” and clarifying what is exactly meant by those terms rather than leaving it at that.

There was much ethical uncertainty amongst respondents as to whether to respect the patient’s prior wishes or the surrogate’s wishes when they conflict:

“We felt this shouldn't be done anymore because it didn't feel like it was the patient who really wanted this. I think at the end of life for a lot of these people, they might be doing this to treat their family members. I guess there is somewhere a role for that, but I'm not sure. I think it depends on how much you think you're hurting the person in order to treat the family.” (Hopkins, PGY-1: 16)

“It's a real challenge because you want to first do no harm and you don't feel like that's what you're doing, but sometimes the patient is not your only patient, the parents are your patient too. This little boy is going to die and Mom has to live with it to the rest of her life. So I think we will remind ourselves that this is an illness episode that we participate in briefly, whereas for the patient and the family this is everything - forever.” (Hopkins, PGY-2: 15)

“I think that as a resident it's almost cruel to us to resuscitate people when there's no chance of bringing them back or it's going to lead to a long ICU admission that they probably won't survive. But some families take comfort in knowing they did everything. So it's hard to say.” (Hopkins, PGY-3: 13)

This fellow discusses his ethical reasoning for treating the family by performing resuscitation that would not work:

“I don't see the harm in trying. You could argue that yes, you are wasting resources but I really think in the big scheme of things if that's what the family needs, then I would see more harm in not giving the family what they need because they are the ones who are going to be alive. The patient is going to be dead and probably not aware of what's going on. So you're not really harming the patient, right? But the family could go away with a lot of harm if the outcome of their death is not what they need it to be.” (UW, PGY-6: 7)

Section 6.3.4: Why Having Choice Isn't Always Better

A relatively unquestioned assumption of this discourse of choice amongst doctors is that choice is always better than no choice and that individuals are the best judges of their own interests. However, there are also significant burdens and costs to increased choice. I have already previously discussed the psychic cost of responsibility of deciding whether to “kill” their loved one, a decision that can cause significant harm. Social and legal sanctions on the choice maker, such as family discord and pressures to conform to certain choices potentially leave the surrogates worse off for having to make the decision.

Gerald Dworkin provides many examples where expanding choices actually limits freedom and diminishes welfare in ways that are irreversible once the choice has been offered (Dworkin 1982a). For example, if blood is permitted to be sold rather than donated, the gift relationship is inherently threatened; altruism becomes unnecessary once blood is a commodity. Offering a choice can have inherent implications. For example, offering the option for remedial tutoring informs a pupil they are falling behind. These more general examples illustrate that the assumption that choice is always preferred to not having choice, as is the case in our individualistic societies, is not always the case.

One could say that patients have the right to refuse to make a decision, but this is especially difficult given the inherent power differential between doctors and patients and something that patients may not think they are able to do. As Dworkin emphasises, it is already morally significant that the patient has been given the choice. The option to decline having a choice is already different than never having had a choice at all. The evidence for whether patients want to be the ones making the decisions is not entirely clear. One US study found that 97% of patients wanted to be told what was going on, but 67% wanted the doctor to make the decision (Chung et al. 2012). Another study showed that 66% of patients thought that resuscitation decisions should be a joint decision between the patient and physician and 40% believed the decision should be made by the physician (Stolman et al. 1990).

In a meta-analysis of surrogates' experiences with decision-making, most surrogates wanted to make life support decisions (55%) and 40% wanted to share the decision-making with physicians (Wendler and Rid 2011). 29 of the 40 articles reported that a "substantial minority of surrogates experienced stress, anxiety, or other emotional burden as the result of making or helping to make treatment decisions for an incapacitated adult" and at least 1/3 of surrogates overall experienced a negative emotional burden.

Another study of parents dealing with "tragic choices" in Neonatal Intensive Care Units in France and America is particularly noteworthy (Botti et al. 2009). In contrast to the US, where parents are given the choice of whether to remove their terminally ill babies off life support, French doctors generally make this decision on behalf of families. Qualitative interviews of these parents demonstrated that American parents struggled more to cope, have difficulty reaching closure, and experience a greater duration of psychological pain. They had greater guilt and self-blame and had a significant perception of a personal causal link to the negative decision and the death of their child, despite the inevitable terminal nature of their child's condition. Parents are not able to blame it on bad luck or fate, but feel that they've had a hand in their child's death.

Section 6.3.5: Issues of Time

Time is a structural constraint that hinders trainees' capability to reflect and consider ethical principles. Issues of time arose frequently in interviews, both from the perspective of the patient and surrogate needing time to make decisions, but also the way that time and physicians' schedules restricted the ability to have in-depth, focused conversations about resuscitation. Oftentimes the difficulty of translating theory to practise in medical ethics lies with the challenges that occur in the practice environment which challenge our abilities to achieve best practices. The following quotes emphasise the difficulties balancing daily workflow and necessarily time intensive end of life conversations. These quotes are in some ways concerning as the tone of these quotes imply a resignation to the inability to do the right thing due to structural constraints.

“There were several pressures to not have that conversation in as much depth. One was a time pressure. With increased demands to discharge patients more quickly and to pick up higher patients, you have less time than you had before. So when it comes down to having these kinds of conversations that require time. It's harder and harder to have them. I do try to at least briefly let the family and the patient know that I think this would do more harm than good. But I also let them know that it's their decision. In the past, I had been more aggressive about getting the ethics consults. Now, I've given up on that, again because of time constraints. If they've already made their mind about it, then I just respect their decision and if the patient suffers, then the patient suffers.” (Hopkins, *Attending in Hospital Medicine*: 7)

“It always made me uncomfortable because if I had a senior resident that said, ‘I need to know the code status on you patient’, I can remember a few times thinking you’ve got to be kidding me, a code status conversation is a forty five minute discussion with this patient and you expect me to do that between now and five pm? Where are we going to make some time to actually do this? I remember feeling what I was being asked to do when I was learning was not consistent with where I knew I needed to end up. So there's a recognition that we were as a group doing it badly and I didn't want to be a part of that, but I needed to pick my battles.” (Hopkins, *Attending in Hospital Medicine*: 6)

“It's difficult. Obviously it's a nuanced, long conversation. Intern year on your fifth admission at two o'clock in the morning, you have to present in like five hours and you still have to write three notes. It becomes very, very difficult. So it just becomes, ‘Oh have you guys talked about it, you know do you want everything done, do you want shocks, do you want chest compressions, do you want tube breathing machine? Yes, no, okay.’” (Hopkins, *PGY-3*: 13)

These quotes highlight the importance of considering how theory is translated to practise in clinical ethics. Physicians that are overwhelmed by patient care are less likely to have

the capacity within the structure of everyday clinical practice to focus on ethical considerations.

Section 6.3.6: Time to Shift the Focus From the Outcome to the Process?

Patient centred care and personalised medicine are buzzwords in medicine today, but more thought should be given to how one achieves personalisation. Perhaps the best way to realise patient centred care in this particular context is to think about individualizing *approaches* to choice rather than the ultimate choice itself. Shifting the focus to the process would allow patients and surrogates the choice of how much choice they want in decision-making, rather than forcing a choice or giving false choices.

The approach more frequently employed at beneficence-oriented institutions was a flexible, tailored approach towards decision-making. These physicians noted that some patients and surrogates were more interested in making decisions than others, and that a key facet of the ideal decision-making approach required understanding how much autonomy the patient or surrogate wanted in the decision-making process:

“It’s hard to have a blanket approach to that. I think it’s really dependent on the dynamic of the family. If it’s a family that I feel like they need some guidance or direction or they’re having difficulty making that decision themselves, then I would give a stronger recommendation. If I get a sense that the family has thought about this and considered it, they understand it, and depending on their view and what their relationship is with the ICU team, I would be more inclined to let them come to that decision on their own.” (UW, Attending in Critical Care: 5)

Beauchamps and Childress discuss the “triumph of autonomy” in American bioethics, and the fallacy of its critiques by pointing out that importantly “the duty of respect for autonomy has a correlative *right* to choose, but there is not correlative *duty* to choose (Beauchamp and Childress 2013).” They further emphasise that “health professionals should almost always enquire about their patients’ wishes to receive information and to

make decisions.” While more experienced physicians and trainees at beneficence-oriented hospitals more frequently recognised this, trainees at autonomy-dominant hospitals less often recognised that autonomy requires in essence, a choice of choice. As Daniel Sulmasy states in his support for a model of “substituted interests and best judgements”, decision-making should honour the diversity of patient beliefs about how decisions should be made, whether that be a desire for greater autonomy or deferral of decisional authority to loved ones due to their relationship or cultural norms (Sulmasy and Snyder 2014).

Perhaps the ethical foci of autonomy and beneficence itself should shift from outcomes to the process that leads to the best decision. Beneficence and autonomy of choice would encourage physicians to identify cases where it would be in the patient’s best interest to have a choice in consultation with the patient. To give choice due respect, practitioners would need to carefully consider with beneficence how choice is enacted. Physicians can act with beneficence in structuring choice, which should begin by assessing and asking how much choice patients/surrogates want to make. It allows surrogates to make not just the best decision, but allowing the best decisions to be made, in order to have the best outcome. Autonomy of choice allows patients the autonomy to choose how they want decisions to be made. The emphasis would be on their freedom to make decisions on the spectrum from accepting responsibility for decision-making, to allowing the physician to make a best interest decision based on his medical expertise.

From this perspective, beneficence becomes aligned with shared decision-making. Shared decision-making holds a certain appeal to people who are wary of both extremes of the spectrum. Shared decision-making was conceived as a response to paternalistic practices, as a way to equalise the physician patient relationship and give patients and surrogates a voice. But as the pendulum has swung towards autonomy, physicians who felt that the focus has shifted too much towards autonomy began to also see shared decision-making as an opportunity to bring medical expertise back into the decision-making process (Billings and Krakauer 2011; Quill and Brody 1996). Focusing autonomy and beneficence on the choice itself allows us to embrace shared decision-making as part of

this process, where first patients and surrogates are asked their preferences in the actual decision-making process.

It is important to note that this beneficence of choice lies closer to the UW model of best interest and differs from the UK's traditional best interest oriented model. Although practices and policies are changing in the UK to ensure that families are informed and involved in end of life conversations, in reality, the degree to which doctors communicate treatment plans with patients needs to be improved (Parliamentary and Health Service Ombudsman 2014). UK physicians are mandated to act in the patient's best interest, but this does not reflect the beneficence of choice that I described in this section. The UW appears to incorporate a beneficence of choice strategy into their DNR practices by focusing on a tailored approach to decision-making.

This framework also implores trainees to pay closer attention to the intentional and unintentional effects of framing in their conversations. One could make a case for libertarian paternalism, where framing is deliberately used to act with beneficence. Framing is inevitable regardless of what is said, as choices are necessarily conveyed with a default one way or another. Defaults have been shown to significantly affect one's choices in health care decisions (Halpern, 2007).

Even when a physician attempts to remain neutral and say, "In the event that your heart were to stop, would you want us to restart it?" there is still a positive frame on the statement. As such, doctors' attempts to frame neutrally are in actually framed with a positive default. Rather than make these choices haphazardly, why not recognise the inevitability of framing and appropriately use deliberate framing to act with beneficence. These issues of framing and persuasion will be explored further in Chapter 8.

Section 6.4: Understandings of Autonomy

Section 6.4.1: Patient Understanding of Illness as a Challenge to Fulfilling Autonomy

The attitudes of trainees at autonomy-focused hospitals reflect a commitment to a simplified dogma of autonomy rather than a nuanced understanding of what is required to truly respect autonomy. These trainees believed that autonomy was fulfilled as long as choice was given, regardless of whether the patient or surrogate had the information necessary to make the decision. In particular, the requirement of understanding and the preconditions necessary to fulfil it were often ignored. For example, they rarely considered the potential for illness, psychological duress, and emotions to hinder patients' or surrogates' ability to understand and act rationally and autonomously beyond that of mental capacity from a medical sense (Loewy 2005).

While many trainees stressed the importance of autonomy, they simultaneously acknowledged that they did not think their patients necessarily understood neither the choices they were making nor its prognostic implications. This resident said:

Interviewer: What is your understanding of the definition of autonomy?

Respondent: I guess it would be the ability of the individual to determine their own destiny. To be autonomous, you have to have capacity to use medical terms and you have to be making an informed decision knowing all the options. Having all available information is what you need to be autonomous.

Interviewer: Do you think you give patients that? Do they know the information to make a decision?

Respondent: I think often times they don't.

Interviewer: Do you think they understand what the severity is and what the prognosis is?

Respondent: I think a lot of people don't understand.

(Columbia, PGY-4: 9)

Yet it was common for trainees at autonomy-focused hospitals to say that giving choice was the way in which they respected autonomy. In their minds, their role was to provide information about resuscitation, including the risks and benefits, but refrain from providing a recommendation since that was potentially seen as unduly influencing the patient with their medical “opinion”. This corroborates with criticism in the ethical and biomedical literature that practitioners “confuse the concepts of independence and autonomy and assumes that the physician’s exercise of power and influence inevitably diminishes the patient’s ability to choose...it sacrifices competence for control (Quill and Brody 1996).”

Section 6.4.2: Prognostication and Truth Telling in Autonomy

This discomfort stems in part from the difficulty of prognostication. It is frequently difficult to extrapolate population based prognostic indicators onto individual patients and physicians resist the attempt to do so. Although there are several epidemiological studies describing comorbidities and factors associated with low likelihood of survival following resuscitation (Larkin et al. 2010), most physicians are not aware of these statistics and tend to be overly optimistic about likelihood of success. One study showed that while 95% of physician survey respondents believed that there are some medical conditions where in-hospital resuscitation would be futile, these respondents overestimated the likelihood of survival to discharge following in-hospital CPR by as much as 300% for some clinical scenarios (Miller et al. 1993). Other studies on prognostic accuracy have shown that only 29% of physician predictions were accurate, with 63% of physicians being overly optimistic about prognosis (Christakis and Lamont 2000).

Many experts in palliative care recommend that physicians need to change what they tell patients about prognosis and ensure understanding, using the “Ask-Tell-Ask” approach

(Christakis 2001; Weeks et al. 1998). In practice, one study demonstrated that in only 14% of family conferences did physicians check to verify that families understood the prognostic information (White et al. 2011). Another study showed that 69% of patients with incurable lung cancer and 81% with colorectal cancer did not understand that their chemotherapy treatments were palliative rather than curative (Weeks et al. 2012). This is likely due to a combination of factors including optimism bias regarding bad news, choosing not to believe bad news, lack of understanding of the message, or physicians not telling them or not adequately conveying the message (Smith and Longo 2012). This same study also demonstrated that these inaccurate beliefs were most prevalent amongst patients who rated their communication with their physician very favorably.

In another sense, the willingness to tell the truth (i.e. accurate prognostication) might reflect courage shunned behind the façade of autonomy. It is difficult to tell the truth about a patient's prognosis, especially given both the allure and frustration of prognostic uncertainty. Prognostic uncertainty gives some the justification to say that they can not tell the truth at all as it might be possible to beat the odds:

“I have a very hard time saying there is no hope. Can I say with 100% certainty that we can't bring you back if you were to code? I can't say that. I'm not going to say it wouldn't probably be better if I said, 'definitely there's no chance that you would be able to come back to any kind of meaningful quality of life,' but I have a hard time saying that.” (Hopkins, PGY-3: 13)

The SUPPORT study showed that physicians often choose not to engage patients in discussions surrounding DNR (SUPPORT Principal Investigators 1995). Newer studies have continued to show that physicians delay discussions about DNR status and other end of life decisions (Keating et al. 2010). Others have shown that during direct observation, while two thirds of doctors tell patients that they have an incurable disease in an initial visit, only one third explain the prognosis (Kiely, Stockler, and Tattersall 2011). In practice, physicians and residents do not provide adequate information during conversations regarding resuscitation (Anderson et al. 2011; Tulsky et al. 1995). Doctors

are as prone as the general public to societal taboos against talking about death and do not enjoy having to give patients such bad news (Wise 2012). They are fearful of destroying hope and causing depression, but some studies have shown that that does not always happen (Mack and Smith 2012; Von Roenn 2003). Recommended ways to tell the truth include emphasizing that the patient will not be abandoned and that the doctor will help them live as long and as comfortably as possible (Smith and Swisher 1998).

Being a physician necessitates actions that are unpleasant and in other contexts, taboo. Part of the goals of medical training are not only to learn the knowledge and skills of medicine, but also to establish the professionalism that allows them to cause physical pain and discomfort for the patient's long-term benefit. Learning how to for example, insert a central venous catheter is as much about as the confident but compassionate willingness to put the patient through discomfort, as it is identifying the right vessel and insertion point.

Similarly, physicians should take as seriously their professional duty to practise necessary emotional harm when required and develop a willingness to breaking bad news and convey truthful prognoses with skill. Learning the most sensitive way to break this bad news is similarly analogous to learning how to insert a central line in the most comfortable way possible. This is not to say that there aren't barriers and challenges to do this. A recent study showed that patients found doctors who were less optimistic in delivering bad news were perceived to be less compassionate and less trustworthy (Tanco et al. 2015). More research and dialogue is clearly needed to explore the best ways to communicate in these conversations.

Section 6.4.3: Balancing Principles

Section 6.4.3.1: Conflicts or Harmony Between Autonomy and Beneficence

The tension between autonomy and beneficence can be described as balancing an ethic of choice at the cost of doing what is good for the patient versus the "ethical obligation to

persuade patients from making a poor choice (Gillon 2015; Kong 2015).” In the medical ethics literature, beneficence is not defined as an imposition against an autonomous person’s wishes, but rather a responsibility of the physician to *persuade* and *reason* with patients. Faden further states that “professionals would be morally blameworthy if they did not attempt to persuade their patients to consent to interventions that are medically necessitated.” (Faden and Beauchamp 1986). If one accepts a definition of beneficence, which permits persuasion (rather than conflating it with paternalism), then the possibility remains open to simultaneously honour beneficence and autonomy.

In contrast to this definition, trainees at autonomy-focused hospitals felt that autonomy prevented them from acting with beneficence, because their understanding of autonomy required them to withhold influencing recommendations. In essence, these trainees conflated beneficence with paternalism. When asked whether they would feel comfortable recommending against resuscitation if it would be in the patient’s best interest, they responded:

“I think it’s not a very common practice. I feel like the standard is that it’s the patient’s decision. It would be great if there were some type of standard where you could make medical recommendations and then it may not be such a heartless thing to decide to do.” (Columbia, PGY-2: 13)

“I have thought about that and I have wanted to say [my recommendation], but I never do because I feel that it is wrong, that it goes against ethics in terms of autonomy. You want to say it but at the same time but you doubt yourself. It is the family’s decision, not ours.” (Columbia, PGY-2: 12)

These trainees more frequently perceived internal personal conflict between honouring autonomy and acting with beneficence. There was no space for persuasion and recommendation in these trainees’ understanding of beneficence, and thus there was no way to balance the two. These residents at the autonomy focused hospital said:

“If they say yes I want everything to be done, I do probably subscribe to autonomy over beneficence in the sense that...I don't know, maybe I'm jaded too much in the sense that in this hospital I've seen people do so much to themselves. You know hopefully not in the hospital, it's like I can't force you to do the right thing.” (Hopkins, PGY-3: 13)

“In terms of DNR discussions, it's definitely more because of autonomy. Often we'll think it's not in their best interest. I think it would be extremely painful and uncomfortable and have very little benefit. But we err on the side of autonomy.” (Columbia, PGY-3: 10)

These physicians frequently felt moral distress over providing treatments that they did not feel was in the best interest of the patient. However, by internalizing a discourse of choice, some respondents were able to absolve themselves of the moral distress of providing futile care. It is in part a coping mechanism as they must act within the system and subject themselves to the rhetoric of autonomy in order to make their lives easier. They were able to justify these behaviours by saying that it was what the patient wanted:

“Because you know you are presumably doing something which someone would want, whether or not they were informed enough to know what it is they were asking for, but you are doing everything (Hopkins, PGY-3: 13).”

Some physician trainees reflected upon the challenges between honouring patient autonomy at the expense of acting in a patient's best interest. One resident from Columbia said:

“I think it's really tough. It's this American value that patients get to dictate. I do think you should have some say in how you end your life, that's the right of the patient. But it's difficult when the decision is to have everything done. And you're wondering, what are we doing? We're spending all of these resources, all

of this money on somebody that is clearly not going to benefit from it. So it's tough...you see so often how poorly it turns out." (Columbia, PGY-2: 13)

It is concerning that physicians believe that some of the treatments they are being asked to perform are harmful to patients and potentially unethical. At best interest focused institutions, respondents felt that they were able to act in a way where autonomy and beneficence could be balanced, rather than stand in conflict. This fellow at UW said:

"Oftentimes we're prioritizing autonomy because autonomy in the best case scenario should be best interest patient autonomy, they should not be mutually exclusive but it should be the same thing." (UW, PGY-6: 7)

Unlike Columbia in New York where resuscitation must be performed if a patient or surrogate desires, UW encourages "informed assent," whereby the clinician does not insist that the decision ultimately be made by the patient or family member, and explicitly recommends against CPR when clearly not indicated (Curtis and Burt 2007a):

"Many of us will take that approach where we make sure that the family understands why CPR is not indicated but don't give them the option, just say we're not going to do it. If the family objects despite that than I often would not write DNR order because I feel like that just puts a barrier between me and the family. Most of the time the family doesn't object. They will just let me make that decision." (UW, Attending in Critical Care and Palliative Care Medicine: 2)

"My belief is that the goal, this idea that this informed assent conversation what this does, it does align the best interest with the autonomy of the patient and lets the patient dictate what their goals are, and then finds the solution that best achieves those goals." (UW, PGY-3: 10)

This permission to withhold futile treatments gave physicians the space to act with beneficence:

“I think it’s easier to do here because there is an acceptance of not offering interventions that aren’t going to have clear benefit. I think just having that acceptance makes it easier to have the discussion... Ideally I like for patient best interest and patient autonomy to line up. To get to a place where if the patient understands that what we’re recommending is probably best interest. I don’t think they are completely mutually exclusive. If it’s not in the patient’s best interest, we shouldn’t be offering it.” (UW, PGY-6: 8)

“I feel that when I watch the way they did it here and when I felt like I was doing it myself, it felt both morally and philosophically like I was being consistent with what I consider the rules of the game. I feel like I have embraced the idea of a physician as somebody who makes recommendations and offers alternatives based on assessment of best interest.” (UW, PGY-3: 10)

Section 6.4.3.2: Balancing Justice

To recapitulate what I described in Chapter 2, in contrast to US practices, UK intensivists are empowered to triage and refuse ICU admission to those unlikely to survive. For example, if a patient arrests, is resuscitated, regains a heartbeat but is unlikely to survive, in the US the patient would automatically go to the ICU. In the UK, the intensivist would likely refuse the patient, notify family, and withdraw life support. Therefore, there is less scope in the UK to accept futile treatments regardless of surrogate wishes. Physicians would for example say this to the patient:

“You know [the ICU] won’t just say ‘well okay we’ve got a patient and now we’ll ventilate them just because they’re handed a patient’... I often say to them, ‘Even if you would like to be considered for intensive care there’s absolutely no guarantee that intensive care physicians would offer you a place on the unit’. And if [the intensivist] were to ask my advice I would say that that wouldn’t be appropriate. Given that, I think it’s very unlikely that you would get an

opportunity for intensive care treatment and mechanical ventilation.”
(Addenbrooke's, Consultant in Critical Care Medicine: 7)

Many UK respondents noted that they were able to place limits on ineffective treatments by invoking institutional limitations such as NICE and NHS regulations. In the UK, physicians have the authority to unilaterally institute a DNR order (Bishop et al. 2010b; NHS 2011). As such, the burden does not fall to the doctor to say, deny fourth line chemotherapy to a forty year old mother with young children – a situation where giving the drug is easier to do than deny the drug. Instead, the doctor can instead say that it is not he who is denying the drug, but simply that the NHS will not pay for the drug, as it is not covered based on NICE guidelines. When asked whether justice factored into treatment decisions, and how the ethical principle of justice fit into their ethical thinking, many of the British physicians stated that consideration of limited resources rarely played a part on an individual level:

“As an individual doctor treating an individual patient, I don’t think resources should come into it. I think you may have to have the discussion in a country or in a hospital about what resources are valuable that you can spend on patients, but I don’t think when you're treating an individual patient. It is a wider discussion to decide whether people over the age of X or Y or people with this condition get this drug. So that’s why things like NICE that decide that certain drugs are appropriate. The funding decisions need to be taken out of an acute clinical situation.” (Addenbrooke's, Consultant in Critical Care Medicine: 4)

It was evident in interviews that although doctors believed that they did not allow distribution of limited resources to factor into decisions at the individual patient level, that societal and institutional prioritisations of justice subconsciously influenced their attitudes and behaviours towards individual decision-making. For example, the scenario described above regarding withdraw of life support following resuscitation during an ICU triage decision was deemed acceptable to UK physicians, but would likely be completely inappropriate to most US doctors. US doctors were also cognizant of justice concerns and

mentioned but did not act upon them. This difference reflects the relative positioning of justice amongst ethical principles, and the manner in which that influenced treatment decisions for the individual patient.

One British physician's perspective was particularly interesting. He believed that a doctor's verbal limit was a way for families to still feel like they had "done everything," rather than in the US where "doing everything" was a physiologic limit:

"If they've protested to me and I've still said that I don't think we should do it, then they have tried everything they can try. So actually they even got the mentality well. In the end was we had the intensive care doctor comes along and said they wouldn't ventilate him again. I said, 'Well, there's no point trying to restart his heart again because he'd be exactly the same, you can't go back to intensive care, we would just putting him through unpleasant experience we'd have to watch the heart stop again.' But, they had the ability to feel that they've protested as much as possible and then they've all sit with me saying, 'We're just not meant to do it'. Whereas if you said to the family, 'He's very frail and he's old, his heart might stop, what would you like us to do if it stops?' Then they're not trying their hardest and so they say, 'Let's try'." (Addenbrooke's, Consultant in Critical Care Medicine: 4)

Section 6.4.4: Self-Surveillance Magnifies the Effect of Policies and Litigation

This reductionist interpretation of autonomy appeared to be more prevalent in hospitals whose policies prioritise autonomy, but were less often seen in hospitals whose policies prioritise beneficence, suggesting that trainees feel constrained by these policies which shackled them to a dogmatic conceptualisation of autonomy, enforced by laws and policies rather than their own moral compass. One senior attending at Columbia said this as an example of common house staff thinking:

"I have to do it because I cannot break the law. There are things in medicine that are ethical but not legal and there are things that are unethical but legal. I can be a

martyr to the cause and say, I refuse to resuscitate your loved one, but what is that going to accomplish? All that does really is it is going to push off to somebody else the unpleasant task of attempting resuscitation. So I can feel very holy about it but I don't think it fair to my colleague who is going to carry out the resuscitation because they will go to patient services.” (Columbia, Attending in Pulmonary: 1)

In New York, laws are most restrictively in favour of patient autonomy, stating that physicians must obtain consent from patient or surrogate before entering a DNR order “even if the physician concludes that administration of CPR would be ‘medically futile’” but even here, the policy does not advise against making a medical recommendation (Spitzer 2003). Indeed, Johns Hopkins’ policy states that it is a “physician’s responsibility to engage the patient/surrogate in discussion and advise him/her if it is consistent with expert medical opinion, that resuscitation may be futile or produce an undesirable outcome for the patient.”

Policies favoring patient autonomy were put in place in order to prevent biased decision-making partially based on unconscious factors (i.e. patient race, age, socioeconomic status), but the unintended consequences of these policies may have even more harmful effects. No hospital’s policy states that physicians should refrain from making recommendations, and does not require that physicians offer treatments that won’t work, but trainees at autonomy-focused institutions often over-interpreted policies in that way. This reflects not only their personal ethical beliefs shaped by their learning environment, but for some respondents, it seemed constrained by a fear of litigation – be it real or imagined:

“I just think the idea of imposing [a DNR order], to me, all sorts of badness comes as a consequence of that mode of arrival at a code decision. Lots of patient dissatisfaction, well, the patient’s dead, but the patient’s family’s dissatisfaction, and the litigious nature of our society, like, I think badness comes from that (Hopkins, PGY-4: 12).”

This respondent reflected upon how legal concerns can become intertwined with what individuals might believe is normatively ethical:

“...the fact that ethical principles get stacked to protect the institution, that’s definitely coming out of the ethics committee. There are hospital lawyers on the ethics committee. You know, I’ve had ethical decisions come down, obviously came out of the concern that the husband was going to sue us, therefore we should do what he says (Hopkins, Attending: 3).”

However, the case for litigation being a major driving factor in decisions is not so straight forward. Several other respondents described feeling that litigation was not a significant concern nor contributor to their resuscitation decision-making practices:

“Depending on how you weigh those [ethical] principles, I think you can make an ethical argument to say I’m implementing a DNR/DNI. I also, I don’t know for sure, but I think legally you’d be well supported to say that because you are a physician and you are allowed to impose these sorts of judgement...(Hopkins, PGY-4: 12)”

“No, I don’t feel that drives most people in this system. I think we’re a huge system that’s self-insured and pretty protected from mal-practise insurance rates and things like that. So I don’t see much decision-making driven by fears of malpractise and try to discourage them whenever I see it (UW, Attending: 2).”

These quotes demonstrate that fears of litigation are intertwined and perhaps conflated by fears of difficulties that may occur with families and discomfort with conflict:

“I mean there's a legalistic aspect of it too. The ideal thing in that situation would be saying to the family, he probably would not want this. The right thing for the patient would be to let them pass. But if they insist on it, I don’t think you can

defend insisting. It would be a huge fight and you would probably be fighting it in court and all that kind of stuff because I'm sure they would be pissed off enough to sue you and all that kind of stuff. They would say, 'how dare you make that judgement, we're his family, we know the patient, and that's right.' (Hopkins, PGY-3: 13)

“We still escalate care. I think you still just push straight ahead...I have been told this by many people before that the idea that the hospital does not want to create a scene. They never say lawsuit or anything like that. You do not want to upset the remaining family members for even patients who are in all senses dead already. And so you just if the family still pushes for it you go ahead and do it as much as you do, not necessarily [because you] want to (Columbia, PGY-3: 11’.

As these quotes demonstrate, while litigation is an oft cited reason for overly cautious or overly aggressive practices in the US, there is much disagreement and uncertainty as to the actual extent of real or imagined worries about litigation. Notably, none of the three hospitals in the US have recently been subjected to legal issues due to the withholding of aggressive treatments or inappropriate resuscitation, but Addenbrooke's has recently been embroiled in a legal battle over improperly placed DNR orders in the Janet Tracey case¹⁸ (Davies 2014). Although the doctors at the UK hospital were very cognisant of the case and had thought about its implication on their decision-making at the end of life, they nonetheless still appeared less concerned about litigation than the US respondents:

“Not particularly, no...Generally what I'm being told from the senior clinicians is that you're making the right decision for the patient. It's the right decision legally as long as you inform the patient. You're making clear your reasoning for that decision-making. That will usually stand up in terms of people getting sued when they do things wrong, not for doing the right thing (Addenbrookes, CT3: 13).”

¹⁸ Please refer back to Chapter 3 for details on the Janet Tracey case

This fear of litigation in the US reflects a self-surveillance that seemed to be a more powerful mechanism for societal control than the actual policies themselves. As Michel Foucault writes in *Discipline and Punish*, the invisible and all-encompassing nature of this surveillance, where the source of surveillance can come from any direction, be it a colleague, superior, patient or family:

“The more numerous those anonymous and temporary observers are, the greater the risk for the inmate of being surprised and the greater his anxious awareness of being observed...He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection (Foucault 1977).”

This response in some ways demonstrates the social nature of concerns over litigation, and that that beliefs and behaviours play off of each others’ real or imagined fears of litigation:

“I don’t [worry about litigation] but I’m a resident and that may change next year. I don’t want to say that my attendings do fear being sued, but if nothing else it’s developed a culture where some doctor was scared of being sued and they instilled a behaviour and the person became the next attending and they instilled the behaviour in the person below them so it could be a domino effect (UW, PGY-3: 11).”

Section 6.4.5: The Importance of the Hidden Curriculum in Moulding Local Normative Ethical Beliefs

An interesting finding in my study was what American physicians believed was ethically normative, how universal they believed them to be, and how local these understandings in actuality were. There was a belief that what was ethically normative at their institution

was ethically normative universally in the US. When I interviewed doctors at Hopkins and Columbia on the East Coast the US, many physicians stated as a universal fact that no American physician or patient would likely accept an approach where physicians made explicit recommendations against a treatment that were unlikely to work.

“If I bring in my 85 year old mother with Alzheimer’s disease who is non-verbal and has a feeding tube and pneumonia, and I say in the US, I want her intubated and in the ICU and I want you to keep her alive as long as possible. You might get an argument from the doctor, you are sure you want this? But when push comes to shove she will go, she will be intubated and she will go into the ICU. In England I suspect it would be, well your mum has had a good life, it is really time now and I suspect they will not be given the choice. Over here ultimately it is the choice of the family.” (Columbia, Attending in Pulmonary Medicine: 1)

It was thus especially interesting subsequently interviewing at UW in the Pacific Northwest, where ethical norms appeared to favor beneficence or in many cases, aim for balance between autonomy and beneficence. Many physicians at this hospital practised and accepted the concept of informed assent. Although UW’s policies did not endorse unilateral decision-making in the way that the UK does, there was a distinct understanding that unrestricted choice of resuscitation was not always appropriate. In essence, UW’s doctors had attitudes and beliefs about DNR decision-making that were more similar to British doctors than doctors at the other American sites.

There is likely no significant difference in the formal ethical training in medical school received by house staff at these four hospitals, since trainees come from medical schools around the country before beginning residency at these respective institutions. It speaks to the power of the hidden curriculum of these hospitals in modulating not only their understanding of ethics, but also their beliefs about what is ethically normative. It reflects the *is/ought* distinction in ethics that I described briefly in the beginning of my methods chapter, which emphasises that because something *is* done in a certain way, does not mean that it *should* be done in that way (Hedgecoe 2004; Ives and Draper 2009). In

practice, physicians' understanding of what ought to be done appeared to be influenced by what people were already doing. Values that were seen as distinctly and universally American are not necessarily universal, and can be moulded by the institution's cultures and policies.

Section 6.4.6: Critiques of Autonomy in Practice

Reductionist interpretations of autonomy and choice are riddled with contradictions (Dworkin 1982b). If informed consent and choice are so ethically imperative to the practice of medicine, why is choice not offered in every possible circumstance? Doctors still often choose when they decide to allow patients to make decisions. Although studies have shown that some patients would like to make decisions as routine as antibiotic choices (12% in one study), doctors generally do not offer this option to patients (Johnson et al. 2011). So why are these unattainable standards taken so seriously and how can we morally justify applying them only in select circumstances? Doctors make countless unilateral decisions throughout the course of a hospital stay, but subsequently present patients with a choice of whether they want resuscitation at the end of life. Is this as paternalistic as the paternalism that medicine has sought to distance itself from? As one interviewee stated:

“You offer somebody something, then ask them what they want, then say I don't really like the answer, that seems adversarial. In the UK it seems that they just don't offer something and simply go with the decision that's appropriate and makes more sense. It doesn't make sense for me for us to do as we do in the US to offer a choice, not like the choice, and then say it's not the right choice. You either offer it with respect saying this is going to be the decision, or not.” (UW, PGY-3: 11)

Far from actually challenging medical authority, this right to refuse or accept treatment choices is merely a small concession that physicians have given to patients to provide the illusion of challenging medical authority without actually securing truly meaningful

independence (O'Neill 2002). Although patients have the right to refuse treatments, their choices may be false choices. In the case of futile resuscitation, there is merely an illusion of choice between life and death, and yet, when given the choice, it is difficult to say no. In informed consent more generally, treatment may be the only option, and so consent becomes a hollow gesture. In practice, physicians have tremendous power to sway patients into agreeing to procedures in ways that may be inconsistent with autonomy, regardless of whether an informed consent form was signed. I will discuss this in detail in relation to manipulation and framing in DNR conversations in Chapter 8. These choices can also become a burdensome forced choice, if the patient or surrogate does not want to make decisions and would prefer to defer choice to the physician.

Although there has been a shift of power from the physician to patient over the past several decades, physicians are still dominant in the relationship. As discussed above, the manners in which choice is given still places power distinctly in the physician's hands. And yet, the language in the interviews, particularly in trainees who operate at the bottom of a structured hierarchical system, was often one of powerlessness to provide care in the patient's best interest:

“The family wanted to do everything and it didn't seem like the patient's wishes. I wish I could have just said, I think it's not really medically indicated and we'll make sure that she's comfortable.” (Hopkins, PGY-2: 15)

In this current system, neither party feels satisfied nor in control. The choices given to patients have not actually helped secure patient autonomy, but have succeeded in changing physician's perceived authority in ways that potentially harm the patient and contribute to practitioner moral distress.

This foisting of responsibility onto the patient reflects a neoliberal conception of autonomy where positive freedoms and empowerment exaggerates an individual's actual power, thus implying that people are only to blame themselves when they fall ill (Crawford 1977).” It also reflect an ethical thinking that ignores the inherent power differences between the doctor patient relationship, where autonomy might be

experienced instead as abandonment (Hedgecoe 2004). In the case of surrogate decision-making in resuscitation, this responsibility results in surrogates feeling guilt and blaming themselves for their decisions. On the other side, this “discourse of the patient as agent has been used in clinical consultations to constrain doctor’s responsibility for patient suffering (Salmon and Hall 2003).” This discourse of choice inadvertently teaches young physicians to escape the responsibility of delivering potentially harmful care, absolves them of risk of litigation, and permits physicians to manage their time more efficiently:

“it’s what makes the decision-making easier. In the old days, paternalism made it easier. You didn’t talk about things with patients, but today you can’t do that anymore. You still want to make the decision-making easy. You’re still under the gun as an intern. You still have too many things to do and too few minutes to do it in. And so they’re going to find the next easiest way. They can’t get away with paternalism anymore, so they just go in they say, ‘yes, no we’ll do whatever you want’, and they don’t spend a lot of time on the decision-making.” (Hopkins, *Attending in Oncology*: 2)

Section 6.5: Conclusion

While the initial ethical foundations of principlism were grounded in moral reasoning, due to time constraints as well as policies and cultures that simply prioritise autonomy, reductionist¹⁹ notions of autonomy have been canonised to mean unlimited patient choice, encouraging trainees to employ checklist thinking. There is a certain allure to principlism in applied medical ethics primarily because it can be easily simplified and understood by practitioners with little ethics training. There is simply not enough time or space in their busy schedules to contemplate moral philosophy. The great dilemma in medical ethics is how to translate the rigorous, nuanced thinking that theoretical ethics affords, into clinical practice where practitioners are often deluged with competing demands and too little time.

¹⁹ What I mean by reductionist is that the original concept has been reduced down to a level that distorts its original meaning.

An interesting relationship emerged in the interviews between autonomy and checklist thinking, and beneficence and more reflective thinking. Why was it that there was a correlation between beneficence-focused cultures and more reflective, nuanced understandings of autonomy, and between autonomy-focused cultures and checklist thinking? One possibility is that if autonomy is believed to merely equal choice, the “correct” action is straightforward and can be easily simplified to a checklist. This mentality is easily operationalised in a busy resident schedule. It is similar to the notion of “Getting the DNR” which is much lamented in the palliative care world as a checklist strategy for end of life care conversations, which should instead focused on a discussion of the patient’s goals and values (Billings 2012). In contrast, if one employs a beneficence-based approach, there is no single easy action that allows a physician to act ethically with beneficence. It is an inherently nuanced concept, requiring a tailored approach to each individual scenario taking into considering the medical situation, patient’s values, culture, etc.

Furthermore, it appeared that there was more “give” in the system regarding end of life decision-making at beneficence-focused institutions, as compared to autonomy-focused institutions. Trainees felt more constrained by policies that seemed to demand a specific action. By this, I mean that there was more leeway and space for doctors to make medical decisions that were not strictly rules-based. This concept is similar to that of the previous paragraph on an institutional level. Because policies in autonomy-focused hospitals prioritised autonomy above all others, there tended to be less space for trainees to develop their own moral confidence about what was ethically right and wrong beyond the giving autonomy. In contrast, at beneficence-focused institutions, best interest decision-making necessarily gave physicians the freedom and flexibility to be reflective and act ethically based on the specific situation at hand.

These findings highlight the importance of the hidden curriculum and the unintended consequences of policies that encourage an unreflective black and white depiction of autonomy. My research suggests that policies that orient institutions towards a focus on autonomy rather than beneficence affects the ways practitioners conceptualise autonomy,

give recommendations, and understand their relationship with and responsibilities towards their patients. Trainees at autonomy-focused institutions often felt shackled by demands for autonomy and developed a perceived powerlessness where they felt constrained and sometime unable to act with beneficence, causing in some cases significant moral dilemmas between conflicting principles. Although this was a qualitative study that will need to be further validated, there are promising suggestions that policies and cultures oriented towards beneficence have the potential to ameliorate these reductionist tendencies.

While principlism might be the most practical ethical framework for physicians, perhaps ethics curricula should also broaden its scope to also include other frameworks, which might challenge medical trainees to think about ethics beyond a checklist manner. Perhaps for example, as Annemarie Mol suggests in her book, *Logic of Care*, the focus should shift from a discourse of choice, to a logic of care where we can return to medicine's original values of compassion and relief of suffering that were lost with medicine's shift to consumerisation (Mol 2008).

Ethical approaches that might help the profession reclaim their original call to healing might include expanding medical education to also include a virtue ethics approach. On a more individual level, virtue ethics focuses on the character of the moral agent as the basis of moral decisions rather than the rightness of the action (Gardiner 2003). Beauchamps and Childress discuss the five virtues applicable to medical practitioners to be: trustworthiness, integrity, discernment, compassion and conscientiousness (Beauchamp and Childress 2013). A virtue ethics approach would allow the medical establishment to emphasise internal sources of moral good, rather than externally enforced approaches that are rule based and thus easily circumvented or enacted without reflection. It encourages the physician to "take responsibility as moral agents and to fully acknowledge the humanity of others (de Zulueta 2015)."

Another alternative to the justice-based approach is care ethics, which focuses on relationships rather than the individual. Similar to virtue ethics, it focuses on the practices

and values that a caring person has in order to care for others. It focuses on the moral importance of meeting the needs of others whom we take responsibility for. By placing care in the context of social relations, care ethics helps create communities that foster healthy social interactions rather than individual self interest (Gilligan 1990). Ethics of care also places great value in emotions, rather than rejecting them, as is often done in rationalistic moral theories (Held 2007). It recognises that emotions such as sympathy, empathy, responsiveness and sensitivity are moral emotions that should be cultivated to help us become moral beings. Given the degree of moral distress experienced by trainees, recognizing rather than suppressing emotions would allow house staff to better care for themselves, and by doing so, enhance their ability to care for others.

Some might argue that a care or virtue ethics approach might be too abstract for the clinical setting, where discrete situations arise necessitating an actionable approach (Allmark 1995). That after all explains the appeal of the checklist approach to principlism. I agree that neither virtue nor care ethics can practically replace principlism. However, as my research suggests, the effects of the cultural milieu and hidden curriculum cannot be ignored. More needs to be done to foster cultures of ethics that allow trainees to internalise moral goodness, rather than policies and checklist ethics that lies extrinsic to the individual's identity.

There has been a growing realisation in medical education of the need to foster greater humanism, empathy and compassion in medical trainees. Expanding ethics curricula to include awareness and understanding of other ethical frameworks would expose young doctors to the broader frameworks that guide ethical behaviour and influence the overall culture of the institution. The justice-based approaches of principlism will appeal to the need for a basic ethical standard and a simple, practical way of conceptualizing complex ethical dilemmas. Care and virtue ethics could then complement this by influencing the cultural milieu within which trainees learn and practice, allowing them to internalise moral character and embrace the roles of emotions, compassion, and suffering in moral decision-making.

In this chapter, I described a need to shift from beneficence of the outcome, to a beneficence of process. Questioning the inherent power differences between doctors and patients, I discussed how this focus on autonomy as merely choice disempowers rather than empowers patients. Yet, I also described the ethical tensions felt by physician trainees who felt unable to balance beneficence and autonomy leading them to feel morally compromised. I expand upon these concepts in the next chapters by exploring further the alienating and empathy decreasing effects of this perceived powerless and inability to act in what physicians believe are in a patients' best interest.

Chapter 7: Moral Distress and Alienation in US Physician Trainees Regarding Futile End of Life Care²⁰

In this chapter, I describe how physician trainees associate their obligation to offer choice with a perception of powerlessness over their ability to guide patients towards treatments that would be in the patient's best interest. Feeling forced to provide treatments that they believe are harmful threatens their moral personhood and professional self-identity. These physicians experience significant moral distress and emotional angst over seeing patient suffering, and they in turn suffer.

Section 7.1: Introduction

Earlier in this thesis, I described how physician trainees at autonomy-focused hospitals appeared to equate autonomy with choice and as a consequence, did not feel comfortable constraining choices by making clinical recommendations regarding resuscitation decisions even if they felt that resuscitation would be inappropriate. In the preceding chapter, I discussed how this emphasis on choice betrayed a simplistic understanding of autonomy and principlism as a whole. Young physicians have fully embraced the necessary shift towards patient autonomy described in chapter 2, but an unreflective focus on choice and hesitation to provide recommendations provides a distorted illusion of autonomy. Unfortunately, this autonomy in practice may be more harmful than helpful, as it places the burden of decision-making onto patients and surrogates without giving them the tools and guidance necessary to make informed decisions. Offering treatments that violate good medical practice not only results in false hope and false choice, but may also compromise the physician's professional integrity (American Thoracic Society 2015).

²⁰ A paper based on this chapter has been published in the *Journal of General Internal Medicine* entitled "Moral Distress Amongst Physician Trainees Regarding Perceived Futile Treatments at the End of Life: A Qualitative Inquiry" (Dzeng, Colaianni, Roland, Levine, et al. 2015).

Another harmful consequence of equating autonomy with choice is its effects on moral distress and empathy in American physician trainees, which arose as a major theme in my interviews. Themes that emerged amongst American trainee respondents relating to moral distress included language of torture and suffering, practitioner suffering, powerlessness, hierarchy, and dehumanisation. Physician trainees at UW also discussed institutionally organised coping mechanisms such as conversations about patients who died.

In this chapter, I will describe how physician trainees associate their obligation to offer choice with a perception of powerlessness over their ability to guide patients towards treatments that would be in the patient's best interest. More insidiously, feeling forced to provide treatments that they believe are harmful threatens their moral personhood and professional self-identity. Their over-interpretation of policies and reductionist interpretation of autonomy create institutionally influenced, self-imposed constraints that are distressing. These physicians experience significant moral distress and emotional angst over seeing patient suffering, and they in turn suffer.

I argue that this has significant implications for the health of the medical profession and for individual physicians. Firstly, in order to care for others, one must first be able to care for themselves. The moral distress they experience, and coping mechanisms of dehumanisation and detachment contribute to decreased empathy and burnout. Their perceived powerlessness to act in a patient's best interest results in a withdrawal of responsibility for the negative consequences of care. They reason that harming the patient was acceptable, as it was the patient's choice.

These feelings of powerlessness and performing of meaningless events (i.e. futile treatments) that are out of their control contributes to an alienation that has significant implications for both the individual as well as for medical care. Marx's theory of alienation focuses on the alienating aspects of the social and economic conditions of capitalism; the social processes affecting the medical profession described in chapter 2

are analogous, with alienation occurring as a consequence of this process (Sayers 2011). In this chapter, I primarily rely upon Rahel Jaeggi's interpretation of alienation, which draws upon the philosophical traditions of Hegel, Marx, Heidegger and others. In her book, *Alienation*, she characterises alienation as the “absence of meaningful relationships to oneself and others, which manifests in feelings of helplessness and the despondent acceptance of ossified social roles and expectations (Jaeggi 2014).”

There is a growing crisis in medicine where physician burnout, mental illness, thoughts of quitting, and suicide are an intrinsic problem (Dyrbye et al. 2008; Dyrbye, Thomas, et al. 2010; Shannon 2013). This is a deadly problem; two medical interns in New York committed suicide months after starting residency last year (Sinha 2014). Patients complain that physicians are unempathetic and uncaring, and yet medical culture dismisses demonstrations of emotion and empathy as weak and unprofessional and encourage physicians instead to display *aequanimitas*, or unperturbability (Dzeng 2013a; Johns Hopkins Osler Medical Residency 2014)

Medical educators in the United States have struggled to counteract problems with humanism and compassion in several ways including selecting for more empathetic students or implementing courses designed to foster empathy. However, these interventions frequently focus on individual responsibility for problems associated with burnout and seek to remediate unempathetic trainees, rather than recognising the systemic challenges that may also be at the root of the problem (Hughes 2002; Paice and Hamilton-Fairley 2013). For example, residents struggling with burnout are asked to take responsibility by sleeping more and pursuing wellness activities – something impossible in the face of 80 hour per week of a physically and emotionally exhausting job (Krasner et al. 2009; Peteet 2015).

Section 7.2: Futility

Physicians experience moral angst regarding overly aggressive or “futile” care (Schneiderman 1993). The definition of futility is controversial and no one definition is

universally accepted. One definition describes futility as an “effort to provide a benefit to a patient that is highly likely to fail and whose rare exceptions cannot be systematically produced (Schneiderman and Jecker 2011).” In one study, nearly 70% of house staff reported acting against their conscience in the care they provided at the end of life, with four times as many respondents concerned about overtreatment than undertreatment (Solomon et al. 1993). Surveys have shown that clinicians sometimes perceive care in the Intensive Care Unit (ICU) to be inappropriate or futile, which result in high costs and resource utilization (Huynh et al. 2013; Piers et al. 2011). Practitioners can also experience a high level of moral distress regarding treatments they perceive to be overly aggressive but are unable to conscientiously object to, creating feelings of powerlessness (Hefferman and Heilig 1999; Murphy and Finucane 1993).

It is important to note that I was interested in trainee physicians’ attitudes towards treatments that they perceived to be futile, thus reflecting a broader typification of respondents’ understanding of futility. This is because I was primarily interested in their perceptions and reactions to clinical situations that they personally felt were futile and distressing. When respondents were asked to describe relevant cases specifically in the context of a decision to pursue resuscitation, the majority of these cases appeared to fulfill the standard definitions of futility described earlier in the thesis. Some examples include these patients:

“This person with advanced dementia had been in and out of the ICU multiple times that month at baseline, and had very poor cognitive functioning. She had no quality of life. She was septic. I forget how many other comorbidities on board. Just kind of a remote family member was making the decisions, and had spent a week in the ICU remaining full code despite everybody’s efforts and ultimately coded again and didn’t survive. But I think that’s a pretty common scenario especially in the ICUs and everything.” (Columbia, PGY-2: 13)

“This ICU patient was in severe sepsis and septic shock. There were multiple rounds in this. The family said absolutely we are going to do everything and he was on four pressers. Was on every antibiotic and had all of these MDR bugs. He had peritoneal signs but was not a surgical candidate. The family was just very

upset and it had been going on for quite a while so it's like a lot of ICU resources even though we think that there is nothing further to be gained by it. This guy was on CVVH. He was intubated.” (Columbia, PGY-2: 11)

Section 7.3: Site-Specific Variations in Futility Policies and Practices

Johns Hopkins has a futility policy. UW has a futility clause that is incorporated into their DNR policy. Columbia does not have a futility policy at all. Given that New York state law requires physicians to perform resuscitation even if the physician believes that it would be medically futile (Spitzer 2003), one key informant and respondent at Columbia said, “I could never see that happening any time soon, honestly.” Similar to their awareness of resuscitation policies, trainees were generally not aware of futility policies nor DNR policies but appeared more aware of the culture of their institution regarding these policies rather than the policies themselves.

While most hospital policies and state laws, do not require physicians to provide futile treatments, the privilege to act according to one's moral beliefs is primarily held by the attending physician. Even so, attendings may find it difficult to act in accord with their moral convictions. While ethical objections against futile treatments in theory allow them to transfer patients to the care of another physician or institution, this is in practice challenging. Few hospitals are willing to accept patient for futile care and the patient may be too unstable to survive a hospital transfer.

Hopkins' policy for example, allows members of the health care team to request not to participate in patient care that “conflict with their strongly held personal cultural values, ethics, or religious beliefs (Johns Hopkins Hospital 2013).” In practice, this is also rarely seen. Many are unwilling to do so because they do not think they would not be institutionally supported in the decision despite the policy. Furthermore, given the tremendous residency workload, most house staff also refrains from choices, which would further burden their colleagues.

It is notable that these themes of moral distress did not frequently arise in interviews with UK respondents nor with experienced physicians. I suspect that this might be in part due to UK physicians being more empowered to make resuscitation decisions. This is especially relevant in situations where a patient has a cardiac arrest whilst being “full code,” and the hospital team is unable to discuss prognosis and treatment options with the family. Physicians of ST3 level or higher in the UK have the authority to halt an ineffective resuscitation. In contrast, in the US, only an attending physician with the consent of a family member if possible, are permitted to halt a futile resuscitation.

Because attending physicians are not in hospital at all hours of the day, there are frequently situations where the code team is called to a futile resuscitation but must carry on resuscitating the patient until the code is “called²¹.” Notably, the code team leader, who is usually a second or third year resident, does not have the authority to discontinue a futile resuscitation unless ACLS has been fully attempted and there is no physiologically realistic possibility of establishing a viable heart rhythm. As such, there are systematically mandated situations where futile resuscitation must be performed in the US but less so in the UK. This likely contributed to a greater propensity for moral distress in American physician trainees due to perceived futile treatments.

Interestingly, these themes of moral distress that I will describe in this chapter appeared both amongst trainees at Columbia, Hopkins, *and* UW. Given my findings regarding the differences in ethical thinking, willingness to recommend, and communication strategies between trainees at autonomy focused and best interest focused institutions, I would have expected trainees at the UW to demonstrate less moral distress than trainees at Hopkins and Columbia. This was indeed the case amongst fellows (approximately PGY 4-6) at UW, but residents at UW (PGY 1-3) appeared to have similar levels of moral distress to residents at other American institutions. Perhaps the effect of hierarchy and inexperience

²¹ American term for when the code team leader decides there is no physiologic possibility of re-establishing a viable heart rhythm (i.e. when there is no shockable rhythm or after prolonged periods of aystole despite all possible ACLS interventions). The code team leader at the hospitals in this study are usually junior or senior residents (PGY 2 or 3).

is still stronger than that of best interest oriented policies and cultures. Further research will be needed to explore possible reasons for these findings.

Section 7.4: Themes of “Torture” and “Suffering”

While definitions of futility are controversial, what is perhaps more relevant in this chapter are trainees’ *perceptions* of treatments and the effects these treatments have on practitioner suffering and moral distress. As such, it was particularly notable that the words “torture” and “suffering” were frequently used to describe therapies that physicians felt obligated to inflict upon their patients. Several residents and fellows believe that some of the things they have had to do to patients at the end of life were not in a patient’s best interest.

“It felt horrible. I felt like I was torturing him. Absolutely torturing him. He was telling us we were torturing him. I did not think we were necessarily doing things for the patient. I think that a lot of times when we go aggressive care all the way.” (Columbia, PGY-3: 11)

“I think that as a resident it’s almost cruel to us to resuscitate people when there’s no chance of bringing them back or it’s going to lead to a long ICU admission that they probably won’t survive.” (Columbia, PGY-2: 13)

“We spend a lot of time at the end of life in the ICU torturing our patients and so, I can’t in good conscience say that our current system really seems to serve the best interests of the patient because, we torture them before they die, even though we know that they are going to die.” (Hopkins, PGY-4: 12)

“There are scenarios in people with metastatic disease that family members have a tough time being able to give up and that you know they’re in DIC or something and they have this really gruesome bloody codes that feel wrong and feels like this is just not the way we should be doing it.” (UW, PGY-3: 12)

A common source of moral angst among respondents appeared to relate to situations where surrogate decisions appeared to go against prior patient wishes. Physicians questioned whether the families made decisions in the patient's best interest. For example, one said:

“It is just infuriating I think when the family is not there and they cannot see and that makes me feel like it's morally wrong. I think when people see their family members suffering and they are there suffering with them I have more of an understanding of what they are feeling...I agree within giving choice when it's the patient giving the choice, but oftentimes it's the family member who is not the patient. Sure, if the patient says, “Torture me, I want everything done.” Okay fine. The family member is doing it for other reasons. Guilt, they can't let go.”

(Columbia, PGY-3: 11)

Section 7.5: Perceived Powerlessness

One theme that frequently emerged from these interviews was a perceived powerlessness over physicians' ability to prevent harmful and futile treatments:

“You know there's no good outcome. You just continue to code them and at some point they're going to die. You've wasted time and resources and you've just provided futile care and tortured somebody for however much more time. Then there's the whole disassociation where you want what's best, but what you can do? And what do you have ability to affect? You just do your job.” (Hopkins, PGY-3)

Another physician remarked:

“We do a lot of terrible things to critically ill patients and at the end of life. It's routine care and I feel pretty numb to having done those things...it seems like there is no benefit and only risk. Yet I am accepting the patient to have these

procedures done to them. I'm in that situation all the time. I'm pretty powerless to do anything about it." (Hopkins, PGY-4: 12)

Some residents remarked specifically on ethical conflicts that occurred between patient autonomy and acting in the best interest of the patient or not harming the patient. They felt powerless to do what they thought was the right thing to do:

"...and if they still say, yes, I want everything to be done, I do probably subscribe to autonomy over beneficence in the sense that...I don't know, maybe I'm jaded too much in the sense that, in this hospital I've seen people do so much to themselves. I can't force you to do the right thing." (Hopkins, PGY-3: 13)

"I think it's really tough. It's this American value that patients get to dictate. I do think you should have some say in how you end your life, that's the right of the patient. But it's difficult when the decision is to have everything done. And you're wondering, what are we doing? We're spending all of these resources, all of this money on somebody that is clearly not going to benefit from it. So it's tough...you see so often how poorly it turns out." (Columbia, PGY-2: 13)

One senior attending and director of the ethics committee at one hospital site remarked that this was not an uncommon concern:

"As I say, I often say, there are things in medicine that are ethical but not legal and there are things that are unethical but legal. I think the house staff...agree with me and are loath to carry out resuscitations on people who are hopelessly ill. They're human beings. They feel that there is something wrong with this picture. It is not a mannequin. I think they are very sympathetic to it and they really find themselves in very uncomfortable positions. Some people are more sensitive than others, some will really recoil but do it, and others will say, 'look, it's part of the job.' It is a lousy law but you have got to do what you have got to do." (Columbia, Attending in Pulmonary Medicine: 1)

Section 7.6: Dehumanisation and Rationalisation

This resident appeared to employ a process of dehumanisation to detach himself as a coping mechanism:

“We’re abusing a body and I get that, but as long as I remember I’m only abusing a body and not a person, it’s okay. Frequently when it’s an inappropriate code, that’s what’s happening.” (UW, PGY-3: 10)

One fellow (Columbia, PGY-5: 8) remarked that she had become “numb to it” and that to not reflect upon these ethical dilemmas was the only way to make it through training. Another resident worried that his cynicism would affect his behavior and attitudes towards patient care:

“I have grown increasingly cynical about what medicine has the capacity to do. That has shaped how I converse with patients. I think cynically through residency I started to wish this person would be DNR/DNI because they are totally unfixable. The danger is that you get a bit sloppy and you’re looking for DNR as a way to off-burden your work and labor and not be meticulous.” (Hopkins, PGY-4: 12)

Section 7.7 : Moral Distress

Moral distress occurs when individuals believe they are unable to act in accordance with their ethical beliefs due to hierarchical or institutional constraints (Jameton 1984). It is an affective response rather than a cognitive one, where the individual’s integrity becomes threatened due to actions and situations they feel are ethically wrong. Practitioners can experience a high level of moral distress regarding treatments they perceive might be overly aggressive and contributes to a feeling of powerlessness regarding treatment decisions (Hefferman and Heilig 1999; Murphy and Finucane 1993). Mobley *et al.*

hypothesised that the intensity and frequency of moral distress increased with exposure time to futile care, resulting in burnout and emotional exhaustion (Mobley et al. 2007). This can have significant negative effects on job satisfaction, psychological and physical well being, and self-image, resulting in burnout and thoughts of quitting (Dyrbye, Thomas, et al. 2010; Elpern, Covert, and Kleinpell 2005; Piers et al. 2011; Sanchez-Reilly et al. 2013).

While both doctors and nurses experience moral distress regarding end of life decision-making, the vast majority of the literature on moral distress derives from the nursing profession (Hefferman and Heilig 1999; Oberle and Hughes 2001). Several qualitative studies on nurses have demonstrated that moral distress is associated with provision of treatments perceived to be overly aggressive and non-beneficial to patients (Austin et al. 2009; Elpern et al. 2005; Ferrell 2006). A small number of studies have demonstrated moral distress in physicians but there is overall a paucity of research on moral distress in American physicians and even fewer specifically on physician trainees (Abbasi et al. 2014; Houston et al. 2013).

Many of the American trainees in my study expressed practitioner suffering and emotional angst over treatments they or their colleagues provided at the end of life:

“Usually at this point the staff has felt so much moral distress caring for this person. It’s been some time where they just feel like they’ve been prolonging suffering as opposed to providing care.” (UW, PGY-6: 7)

“I thought maybe we should involve ethics here because the house staff team were very, very demoralised by this gentleman’s care.” (Hopkins, PGY-4: 12)

Trainees felt particularly distressed providing what they believed to be overly aggressive treatments such as resuscitation that was unlikely to work:

“A lot of things happen when you're a resident, traumatic things you know. There was this tiny 90 something year old lady, she was so thin you could count her every rib. I remember we had to code her and it was one of the worst experiences in my life...I had a lot of moral distress when I kept coding her for an hour.” (Hopkins, PGY-6: 10)

“The person who was on call that night that he died, who gave him the bag of blood is still really upset about having done that, cause she feels she's prolonged his suffering...” (Hopkins, PGY-1: 16)

“A lot of the paediatrics residents who coded her, from talking to them, it sounds like some of them felt somewhat violated by being in the situation where that sort of had to do, against any judgement that they have.” (Hopkins, PGY-2: 15)

“I felt plenty of emotional distress from just a very human way about what we do to others and how I would never want that for myself or a loved one. And then also from a kind of societal and medical system vein, distress of just how much resources there were and energy we're putting in to things that are practices that I don't necessarily agree with.” (UW, PGY-2: 13)

Section 7.8: Can Moral Distress Lead to Declines in Empathy and Burnout?

Studies have shown progressive declines in empathy throughout medical training (Neumann et al. 2011). While empathy remains intact during the first two years of medical school, empathy decreases significantly in the third year of medical school as well as through medicine residency training (Bellini and Shea 2005; Hojat et al. 2004, 2009). Empathy is defined as defined an emotional attunement and sympathy with the patient's experiences and perspectives, as well as the ability to communicate this understanding in a therapeutic manner (Halpern 2003; Neumann et al. 2011).

Lack of empathy hinders communication with patients, while good communication has been shown to have a positive effect on patients' quality of life, anxiety, depression, and outcomes, as well as lower incidence of malpractice lawsuits (Levinson et al. 2014; Stewart 1995; Stewart et al. 2000). Physician empathy has been shown to improve clinical outcomes, medication adherence, and patient satisfaction (Hojat et al. 2011; Kim, Kaplowitz, and Johnston 2004), while declines in empathy have been associated with physician mood disturbances and depression (Bellini and Shea 2005; Thomas et al. 2007). These therapeutic effects demonstrate the importance of empathy in the quality and effectiveness of care delivered. The Institute of Medicine recognised the key role that empathy plays in professionalism and in the delivery of patient centred care, which they have listed as one of six main goals for quality health care in the 21st century (Institute of Medicine 2001).

Increasing or maintaining empathy has been the focus of interventions which have primarily centred around time limited, discrete interventions such as patient narratives, communication skills training, and empathy focused training (Batt-Rawden et al. 2013). Understanding the root cause of empathy declines might help us design more effective, long lasting interventions. Trainee distress may be one root cause of empathy decline and cynicism (Dyrbye, Thomas, and Shanafelt 2005; Hojat et al. 2004, 2011; Lomis, Carpenter, and Miller 2009; Neumann et al. 2011; Patenaude, Niyonsenga, and Fafard 2003; Sheehan et al. 2014; Thomas et al. 2007). This distress may result in burnout, low sense of well being, depression and poor quality of life (Dyrbye et al. 2008; Dyrbye, Thomas, et al. 2010). It can be attributed to experiences such as mistreatment by superiors, high work load, perceived ethical and professional dilemmas, as well as exposures to death and human suffering (Dyrbye et al. 2005; Neumann et al. 2011).

Contradictions between the ethics taught in medical school and practices on the wards teach trainees that acts of "torture" and "suffering" are not only acceptable, but inevitable (Hafferty and Franks 1994). This might contribute to ethical erosion that occurs during medical training, which can be a result of an inability to address the moral distress and ethically unjustified treatments they are asked to provide (Feudtner, Christakis, and

Christakis 1994). Ethical erosion and empathy decline may reflect self-preservation through detachment and dehumanization (Jennings 2009).

These experiences have significant impacts on a physicians' professional identity and moral personhood during their most formative years and can contribute to empathy declines through justification of "torture" and "abuse" in the name of medicine (Epstein and Hamric 2009; Jennings 2009; Lemonidou et al. 2004). This professional dispensation to inflict pain is a necessary professional duty, but also engenders moral vulnerabilities (Colaizzi 2012). Stepping over the fine line between inflicting necessary and unnecessary pain may contribute to the undesirable declines in empathy during medical training demonstrated by many previous studies in the United States (Bellini and Shea 2005; Hojat et al. 2004, 2009; Neumann et al. 2011).

This detachment threatens a trainee's professional and personal sense of self and leads to burnout, which then further contributes to decreased empathy (Walocha et al. 2013). Characterised by exhaustion, depersonalisation and a diminished sense of accomplishment, burnout impairs medical trainee well-being and has been associated with self-reported unprofessional conduct and decreased altruism (Dyrbye, Massie, et al. 2010). Burnout has also been associated with increased depression, suicidal ideations, and serious thoughts of dropping out (Dyrbye et al. 2008; Dyrbye, Thomas, et al. 2010). One study showed that burnout in the Hopkins Osler residency programme was found in 76% of respondents (Block et al. 2013).

Section 7.9: A Crisis of Alienation in Medical Education

The medical literature on burnout tends to focus on the physical aspects of burnout such as stress, long work hours, and physical and emotional exhaustion (Block et al. 2013; Paice and Hamilton-Fairley 2013). A less acknowledged source of burnout are the existential threats to personhood associated with moral distress and alienation. The destructive potential of moral distress due to their obligation to provide perceived futile

treatments on the trainee physician can be elucidated by a closer analysis of trainee alienation.

Alienated labor occurs when individuals have an inability to identify with what one is doing, an inability to exert control over what one does, and a feeling that the work that she has produced does not belong to her (Jaeggi 2014). It turns labor into meaningless events that the individual has no power to determine – the laborer is rendered powerless and impotent. Alienated labor has no intrinsic purpose, and is performed for its own sake not as an end, but only as a means to itself.

These descriptions highlight the challenges of futile care and its role in alienation, where the object of labor is futile treatment itself. Providing futile care has no intrinsic purpose, for it will not achieve its purpose of successful resuscitation nor fulfil the patient's goals and values. Futile treatments are provided for its for its own sake rather than for a health promoting end in order to achieve an external requirement set by structural constraints imposed by the system in part through a twisted logic of choice. The physician trainee feels powerless to negotiate these choices and feels no control over whether she can agree or refuse to provide futile care. The act of torture in the name of medicine alienates the young physician from meaningful labor and her ideals that led her to pursue a career in medicine. Her own self-identity, which is intertwined with her professional identity, becomes alien to herself.

Notably, Jaeggi emphasises that alienation describes a relationship beyond that of dominance, but rather that of a more self-inflicted nature:

“What we are alienated from is always *at once alien and our own*. In alienated relations we appear to be, in a complicated manner, both victims and perpetrators. Someone who has become alienated in or through a role at the same time plays this role *herself*; someone who is led by alien desires at the same time *has* those desires...Social institutions that confront us as rigid and alien are at the same time created by us. In such as case we are not – and this is what is specific to the

diagnosis of alienation – masters over what we (collectively) do (Jaeggi 2014: 24).”

As I argued in chapter 5, physician trainees, especially at autonomy-focused institutions, felt compelled to offer choice and withhold recommendations regarding resuscitation regardless of clinical scenario. Their failure to communicate contributes to conflicts with patients and families, and drives care towards the futile treatments that they feel powerless to control. These trainees, influenced by the structure of their institutions, are unable to realise how their own failure to recommend reproduces the very moral distress and conflict that alienates them.

Section 7.10: Academic Medical Centre Hierarchy

Physician trainees attributed some of their powerlessness to a clear hierarchy in academic institutions. This is supported by the fact that themes and patterns that emerged relating to moral distress appeared primarily amongst trainees and more rarely amongst more experienced physicians. Trainees felt unable to question the decisions of their attending even when their decisions seemed contrary to what they believed was right. As this resident noted, the trend was often towards more aggressive care:

“I was taken aback. I had multiple patients where the patient and families were on board with comfort care. They had the goal of decreasing suffering and pain, but the attending was not on board with comfort care and DNR/DNI. That can be very difficult as a resident.” (Hopkins, PGY-2: 15)

Another reflected on the overall hierarchy with less moral distress the more removed one is from patient care:

“It’s very significant moral distress. There are definitely patients that disturb the nursing staff because they are the ones who have to carry out the doctor’s orders and who are at bedside seeing the effects of our treatment - seeing patients suffer.

That translates to the interns who are seeing the patients suffer, then the residents, fellows, and sometimes even attendings. So it goes up the chain, but I feel that each step is slightly further removed from the patient so they're seeing less."

(UW, PGY-6: 7)

Hospital hierarchies are important for patient safety and physician training, but ethical issues such as the extent to which aggressive therapies should be offered at the end of life are subject to significant personal variation with no precise right answer. They have not yet developed the experience or confidence to cope with these ethical conflicts.

Among physicians, trainees are particularly vulnerable to moral distress because they are subordinate but on the front line (Winkenwerder 1985). This reinforces a sense of perceived powerlessness to act as independent moral agents against treatments that they believe may do more harm than good. Because trainee physicians are licensed to practise medicine, but do not have the experience or autonomy to make independent decisions, they may be particularly prone to moral distress arising from these situations in ways more similar to nurses than attending physicians. One study noted that decreased autonomy was associated with increased frequency and intensity of moral distress amongst nurses (Papathanassoglou et al. 2012). My findings highlight the need for more nuance and attention to the differences between trainees and attending physicians, rather than defining moral distress monochromatically across the entire range of experience.

Section 7.11: Coping Mechanisms Against Moral Distress

The most common coping strategies described involved formal and informal open forum discussions. Notably, UW had a culture that actively promoted such conversation:

"When I was a med student, a patient I was taking care of died. I didn't find out for two days because I had left. I felt hurt by that. I have noticed that whenever a patient dies here, whoever is taking care of them is notified, whether it's by a quick text message or whatever. The first time an intern has a patient who dies, I

talk about it with them before, how to approach the family and talk about with them afterwards about how they felt it went to the family. I feel like there is a lot of space for emotions here.” (UW, PGY-3: 10)

“I got feedback from the ethics team that there were some people that were severely still morally distressed about what happened. Some of the providers actually reflected afterwards in mass emails and I think that also helped dispel some of the residual distress that remained. So yes, I definitely rely a lot on my colleagues and particularly ethics consult if there is something that I feel isn’t right.” (UW, PGY-6: 7)

The medicine/paediatrics resident at Hopkins also described the culture being more open to discussing deaths in the paediatrics department:

“I wrote it up actually in debrief at the end of my PICU but I just got all the sympathetic nods. ‘Yep, that’s hard. Yeah, that is hard, yeah.’ As a department and we had a lot of chronically ill kids a lot of the house staff was taking care of... send the chief resident to all send death notices. FYI, everyone who took care of, you know, baby girl Smith, she passed away on Thursday.” (Hopkins, PGY-2: 15)

The culture at UW seemed to be influenced in part by a palliative care-friendly environment, especially a programme called “death rounds.” This weekly session facilitated open discussion and normalisation of emotional issues, providing time and space for reflection within a busy resident schedule:

“We have death rounds once a week and talk about our emotions around making these decisions. It gives us time to slow down and everybody can say their story about a patient that touched them, or a concern that they had, or that made them feel a little uncomfortable. It usually ends with people crying. The programme, the staff, and the residents tend to talk about emotions a lot. I think death rounds helps facilitate that.” (UW, PGY-3: 12)

“We have death rounds because the interns see a lot of things that I think they find rather disturbing. Often times when you start death rounds, every single death rounds that I have facilitated everybody’s dead silent. It takes one of the attendings or one of the senior residents to be like ‘wasn’t there that Mr. So-and-So?’ Then once you bring up a case everybody starts talking or you’ll have somebody who starts talking and sometimes starts crying. I mean it’s really fascinating to see how they are very much at the beginning and then as soon as you bring one of the cases up that has been really challenging, then people all start talking.” (UW, PGY-6: 7)

“I think just giving permission to talk about death and to talk about end of life issues normalises it for us and then makes it easier to talk about it with patients, because nobody wants to talk about death.” (UW, PGY-6: 8)

Interventions that remind physicians of the humanity of their patients and reconnect them to their own humanity and purpose for their work can help counteract this process. Programmes such as Schwartz Rounds²² and Death Rounds, held at UW, serve as important coping strategies for dealing with these difficult issues (Hough et al. 2005; Penson et al. 2010). Providing a safe space where emotions and compassion are encouraged counteracts medicine’s culture of stoicism. In the harried life of a resident, encouraging opportunities to stand back and reflect, even as simple as a text message or a short time-out, gives permission to acknowledge the inherently challenging emotional and humanistic aspects of patient care. These conversations also promote the importance of physician self-care, which is an important first step in the ability to care for others (Rushton et al. 2009; Sanchez-Reilly et al. 2013). This in turn may help foster the empathy needed to remain a compassionate physician.

²² Schwartz Rounds are meetings for health care practitioners to reflect on the emotional aspects of their work. Originally developed by the Schwartz Center for Compassionate Healthcare in Boston USA, this program has been implemented by more than 375 healthcare facilities in the US and over 115 in the UK (The Schwartz Center Rounds 2015).

A crucial component of fostering open dialogue and awareness of issues surrounding death and dying are establishing palliative care friendly environments through palliative care and ethics services and consultations. While all three hospitals had palliative care and ethics consult services, some were more established than others. UW has had a long tradition of palliative care and is known to be exceptionally palliative care friendly. Hopkins had just established a palliative care service the year before interviews commenced. At all three sites, palliative care services are not only a source of clinical palliative care services, but serve an educational and supportive role for trainees. It is likely that the degree of ethics and palliative care presence may have a distinct influence on how well trainees cope with moral distress surrounding end of life issues (Olthuis and Dekkers 2003). Utilizing the existing infrastructure of palliative care and ethics consults may be a potential area for interventions seeking to decrease moral distress and foster empathy and compassion amongst physician trainees.

Strategies to address moral distress have been explored in the literature including recalibration of emotional response and individual perception through “hedonistic adaption (Mobley et al. 2007)” or through “principled moral outrage”, where the “energy-draining frustration, anger, disgust and powerlessness” is balanced by principled compassion, integrity and wisdom that re-establishes the person’s moral value (Rushton 2013). Other strategies include increasing resilience, mindfulness, and developing methods for the promotion of inquiry and reflection (Back et al. 2015; Krasner et al. 2009; Rushton, Kaszniak, and Halifax 2013). Medical education should recognise the continuing importance of addressing these issues through focus groups, didactic sessions, and awareness of the training environment and culture regarding these issues. Root cause analyses and other systematic methods to understand structural and organisational factors can also help recognise and address sources of moral distress (Rushton 2006). Policy oriented interventions include a statement by the American Thoracic Society on situations that a clinician might morally object to, that seeks to establish institutional norms that allow for practitioners to personally excuse themselves from morally problematic situations (Lewis-Newby et al. 2015).

Section 7.12: Conclusion

Ethical challenges are common at the end of life; the uncertainty of prognosis and the ethically permissible boundaries of treatment create confusion and conflict about balance of benefits and burdens experienced by patients. This chapter sheds light on a significant cause of moral distress amongst physician trainees when they feel obligated to provide treatments at the end of life that they believe to be futile or harmful. Their words - “torture”, “gruesome”, “abuse”, “mutilate”, and “cruel” evoke images more fitting of penal regimes than hospitals. The moral toll exacted upon these physicians is evident in their descriptions of feeling “violated”, “traumatised”, and “morally sick to my stomach.”

In light of this perceived helplessness, physician trainees can become emotionally detached, and may dehumanise their patients in order to protect themselves. Respondents in my interviews described coping by becoming “cynical”, “numb”, “powerless”, and “jaded.” Prior reports have highlighted the negative effects of cynicism on empathy, care of patients, and the culture of medicine (Dyrbye et al. 2005). Cynicism alienates young physicians from their profession, as they begin to wonder whether their efforts are meaningless or harmful.

One physician trainees once described to me feeling that “nothing you do matters”, “residency destroyed me as a person” and like a “cog in a wheel”. A feeling that one is engaged in meaningful work is as important, if not more important, than the physical challenges of long hours. Many are willing to endure long hours if they feel that work is meaningful, but without meaningful work, stressful hours are much more difficult to tolerate. This is particularly important amongst the millennial generation who currently comprise the youngest cohort of physicians. Millennials tend to prioritise having a career that matters and making a difference over more material concerns such as money (Smith and Aaker 2013). Contrary to stereotypes of the millennial generation that claim that

Millennials²³ are self centred and narcissistic, research has shown that they seek out meaningful lives rather than merely personal happiness.

It is this clash of Millennial ideals with the changes that occurred in the physician profession described earlier in this thesis that have created a crisis in the medical profession's collective search for meaning. For without meaning, one becomes jaded to the ideals of compassion and empathy, which should at its heart be the central mission of the healing arts. Shifts from paternalism to autonomy resulted in a rush to honour choice in lieu of a beneficence-oriented partnership, alienating physicians from their ability to meaningfully engage with patients and to identify with the goals of treatments they are providing.

Seeking a life of meaning, Millennials entered the medical profession with the same ideals of healing that inspired previous generations of doctors, but this time with a tour de force of a generational cultural movement. The clash of these two trends has magnified the consequences of alienation, which in essence concerns itself with the question of the good society. Alienation describes the ways individuals' lives go wrong when apathy and indifference towards life undermines the good life (Jaeggi 2014).

Addressing issues of moral distress must include strategies to counter alienation by helping individuals regain power over and find meaning in what they do. Finding meaning in the good life requires a self-realisation of a more appropriate relationship between oneself and the world. Understanding that alienation harms self-identity, meaning and control, which then affects the way physicians are able to care for others, is the first step. Through this realisation and self-empowerment, the physician profession can seek ways to change it through gaining power to find meaning. The goal in all of this is not to shift power back to the doctor, but understand ingrained problems in the system and *recalibrate* it so that doctors can find meaning in what they are doing.

²³ Millennials are a demographic generational cohort characterised by those born somewhere roughly between 1980 to the early 2000s. Other American generations include the baby boomers (those born after World War II up to the 1960s) and Generation X (early 1960s to early 1980s) (Wallop 2014).

This may involve changes to the system that give doctors more freedom to act in a patient's best interest and move the focus from that of impersonal choice to one of care and compassion. In order to fully develop this argument, I need to first position these decisions and communication practices in relation to Habermas' concepts of the system and the lifeworld. Once I have explicated the links between alienation and colonisation of the physician's lifeworld in the next chapter, I will then be able to propose strategies to foster unalienated labor in the conclusion of this thesis.

Chapter 8: Communication Pathologies in End of Life Care

In this chapter, I first position my interview data on the spectrum that Ruth Faden delineates between coercion, manipulation, and persuasion, and in particular the differences between manipulation and persuasion. I then focus on how communication pathologies from the perspective of Jürgen Habermas' Theory of Communicative Action challenge autonomous decision-making. I then relate these micro-sociological communicative interactions between doctor and patient to the greater macro-sociological shifts in the physician profession described in Chapter 2, and how this reflects the unintended consequences of action influencing social patterns as described by Antony Giddens' Structuration Theory. Throughout this chapter, I also bring in discussions of the system versus lifeworld. Finally, I tie this sociological argument to that of language, framing and heuristics.

Section 8.1: Manipulation versus Persuasion

In Faden and Beauchamp's book²⁴, *A History and Theory of Informed Consent*, they describe three conditions necessary for an act to be autonomous: intentionality, understanding, and non-control by others. Coercion occurs when a person is compelled by someone else to do something she does not want to do, or is prevented from doing something she wants to do. The coerced person's "choice" is not her own, but instead the coercer's choice. This occurs when the coercer is able to present "a credible threat of unwanted and unavoidable harm so severe that the person is unable to resist acting to avoid it (Faden & Beauchamp, 1986: 339)."

In this analysis, I focus primarily on persuasion versus manipulation. Faden defines persuasion as an attempt to influence through appeals to *reason*, and are an accepted and unconcealed form of interpersonal influence (Faden & Beauchamp, 1986: 261-2). Decisions made by patients are autonomous because the physician openly explains to

²⁴ To be referred to as Faden for the remainder of the chapter

promote understanding and puts forward reasons for accepting or adopting a particular decision, which the patient can freely accept or decline as his or her own. These decisions are based on the person's beliefs, values, intentions, attitudes, and actions as advocated by the persuader.

In contrast, manipulation is characterised by any intention to influence a person through altering the actual choices available or the person's perception of these choices in order to get the person to do what the manipulator intends²⁵ (Faden & Beauchamp, 1986: 261). In particular, manipulation of information alters a person's understanding of the situation and perception of the options available. One particularly notable form of informational manipulation is the exploitation of framing effects by presenting information in a way that leads to predictable inferences.

These controlling influences lie on a continuum from controlling influences (coercion) to non-controlling influences (persuasion). Notably, manipulation lies on the spectrum and can encompass varying forms of control or non-control, with no definitive threshold for distinguishing influence. It is also possible for manipulative influences to be compatible with autonomous decision-making. The degree to which a manipulative act is deemed to be controlling versus non-controlling is also inherently subjective and can depend on the individuals' reaction to the particular controlling influence.

These definitional subtleties illustrate the complexity of these nuances in applying them to real life scenarios. One cannot just assume that a particular act is universally manipulative if it appears that autonomy is not granted or whether an act is manipulative may differ between one person to the next depending on the person's health literacy, prior experiences, etc. For example, as I argue later in this chapter, framing should not be universally perceived as either manipulative or persuasive, but rather the *way* in which framing is used will determine whether it has been used positively or negatively. Faden describes debate in the literature on informed consent regarding the role of persuasion.

²⁵ It is important to note that Faden's use of the word "manipulation" is not meant to imply immorality or fault in moral character where a person actively tricks a person into doing something he would not otherwise do through a deceptive act.

She disagrees with those who equate informed consent with non-influence, where the physicians, “presents the information in a way that is ‘neutral’ – that reflects as little personal bias as possible for one alternative as opposed to another.” This was the perspective that some house staff at the autonomy-focused sites held:

“I have thought about that and I have wanted to say it and I never [make recommendations in the patient’s best interest] because I feel that it is wrong, that it goes against the ethics that we are talking about in terms of autonomy and you want to say it but at the same time I think you doubt yourself. You can never fully say what will happen to somebody and again it is the family’s decision, it is not ours.” (Columbia, PGY-2: 12)

“I personally don’t feel that that’s a problem, but I see where people might feel like that might be injecting your own personal opinions about life and death upon someone. I think somebody might say, I think you should just stick to facts and known things. Just give them a picture of what’s going on, versus injecting your own personal opinions of life and death.” (Columbia, PGY-3: 10)

This viewpoint is the very strategy that shared decision-making²⁶ opposes, as it deprives the decision-maker (patient) of the guidance and clinical expertise that is the responsibility of the physician. Faden argues against the conflation of persuasion and coercion, which misconstrues the physician’s proper role in the consent process:

“Professionals would be morally blameworthy if they did not attempt to persuade their patients to consent to interventions that are medically necessitated...It would be a mistake to infer...that persuasion is incompatible with autonomous choice and absence of control by others or that bias or undue or non-rational influence is somehow at work...In persuasion, the influence agent must bring to the persuadee’s attention *reasons* for acceptance of the desired perspective (Faden & Beauchamp, 1986: 348).”

²⁶ As previously discussed in Chapter 6

Others argue that the opposite is necessary; absence of manipulation is believed by some to be essential for informed consent to be truly informed and autonomous. For example, Jeffrie Murphy highlights the need to prevent informational manipulation, “whereby the structure or perception of choices available to a patient is altered by managing information so that the person does what the physician intends (Faden & Beauchamp, 1986: 261).” The remainder of the chapter seeks to further dissect these nuances and determine the point at which manipulation ends and persuasion begins.

Section 8.2: Empirical Findings Demonstrating Manipulative Communications

In earlier chapters, I described the influence of hospital policies on trainees’ conceptualisation of autonomy and how that affected their willingness to make recommendations. House staff at institutions where autonomy was prioritised, tended to interpret autonomy as merely giving choice. As described above, they felt that there was no role for reasoned persuasion and that options must be presented as neutrally as possible. They felt constrained to refrain from giving a recommendation on whether resuscitation would benefit the patient. In this chapter I will outline how this understanding might affect the way trainees communicate with patients regarding discussions surrounding DNR orders and end of life discussions in general (Steps 3 to 4 in the framework (Figure 1.1) I outlined in the Introduction on page 24).

Due to a need to honour their version of autonomy, these trainees felt compelled to offer a menu of choices, but because they still had a clear sense of their particular medical treatment preference, conversations were potentially framed in different ways depending on the circumstance:

“One thing I have noticed is this grab bag of things people can now offer, almost like a buffet. We can do this, this and this. We can do chest compressions, we can intubate. A family will maybe say, maybe I will take the compressions but I won’t take intubation. I really don’t understand how we have gotten to that point and I

think physicians don't really present that the same way each time. I think we present code status differently, we may use different language and we can make things very graphic if we want to or make them very un-graphic if we want to. I get pretty disturbed with how I see it presented (Columbia, PGY-2: 12)."

A common strategy by trainees at autonomy focused institutions to address code status in patients where the trainee believed resuscitation would likely not work, was to use graphic descriptions of resuscitation to convince surrogates (by this stage, frequently the surrogate is the decision-maker) to not choose resuscitation. These respondents emphasised giving patient/surrogate choice and the need to not inject their "opinion" into this decision by making a clinical recommendation. However, their recommendations took on this form:

"For patients that I think should be DNR, I go into graphic detail pretty aggressively that we can do chest compressions which can break ribs and puncture lungs, which can be very painful, and we can put them indefinitely on a machine that could prolong their life without improving their quality of life. Then I usually say, 'but of course it is your decision and it should be what you think they would want.'" (Columbia, PGY-3: 11)

"By default we'll do everything which includes chest compressions, which means someone on top of you compressing your chest and breaking your ribs. Trying to be as non-judgmental as possible in the sense that, but then saying, 'Especially in an elderly individual who is frail, it will entail breaking your ribs and potentially causing a lot of distress.' And then electrical shocks and medications to try to get your heart to beat back again. Then intubation by putting a tube down your throat and hooking you up to a breathing machine. I will try to describe the mechanics of what that will entail. We do chest compressions, which involves someone standing over you and doing something really serious. They're not just pushing on your chest - they're *really* pushing down. The bed bounces. If they're doing it right you break ribs. There are electric shocks, which people have described as being

kicked by a horse, potentially many times. There's the breathing tube, which you can imagine the tube going down into your throat and breathing for you. I try to be descriptive about it. If they still say yes I want everything to be done, I do probably subscribe to autonomy over beneficence in the sense that...I don't know, maybe I'm jaded too much in the sense that in this hospital I've seen people do so much to themselves. You know hopefully not in the hospital, it's like I can't force you to do the right thing." (Hopkins, PGY-3: 13)

"This is kind of paternalistic, but if I'm feeling strongly that the patient would not really benefit from resuscitation, I'll be pretty graphic. So if her heart were to stop, you'll see on TV that's when people are pounding on somebody's chest. 'Do you want the doctors to go in and press on the chest to pump the blood through the heart?' I want you to know we have to press really hard and break ribs. If we're not breaking ribs, we're not pumping the blood enough. Sometimes it doesn't work anyway, you know. So it's pretty physical and can be kind of violent. If you want us to do that, we'll do anything that you want for your grandmother. But some people decide that if their heart were to stop and that means that it's their time, then they just want their family there, without the doctors on their chests." (Hopkins, PGY-2: 15)

Rather than persuading the surrogate that resuscitation would not be consistent with the patient's goals of care, the physician trainee attempts to manipulate the surrogates' *perception* of the actual choice. While honest descriptions of the resuscitation process are important for understanding and interventions have focused on improving understanding through videos and other decision aid modalities (Vollandes et al. 2013), these descriptions should be presented to improve understanding, rather than as the specific means to dissuade.

It is interesting to note the tension within these quotations between neutrally offering choice ("Trying to be as non-judgmental as possible (Hopkins, PGY-3: 13)"), but still having the desire to persuade the decision-maker to pursue the "right" treatment. The

emphasis on freedom of choice is clear: “but of course it is your decision and it should be what you think they would want.” (Columbia, PGY-3: 11) The fact that they employ this strategy more in their frail, elderly patients or in general people whom they think should not be full code, demonstrates that even though they feel compelled not to offer a recommendation and are potentially uncomfortable prognosticating, in their minds they know who they think should and should not be resuscitated and they try to convey that through alternative means.

They emphasise that they’ll “do everything,” (Hopkins, PGY-3: 13 and Hopkins, PGY-2: 15) offering the menu of choices, but the message that they convey is that to choose “everything” involves pain, violence, and bodily harm. Also notable is the perception of these strategies in relation to autonomy, beneficence and paternalism. Hopkins, PGY-3: 13 notes after his description that he still subscribed to autonomy over beneficence, while Hopkins, PGY-2: 15 recognised that these descriptions were potentially paternalistic.

Attending physicians at these hospitals sometimes alluded to these graphic strategies that house staff employed in code status conversations. This one in particular summarises some of the concerns with this particular strategy:

“I think that it’s really been unfortunately bastardised to a large extent. I won’t get into representing how sick you are, but instead say, ‘would you like us to pound on your chest and break your ribs.’ They are infusing it with such aggressive language that there is a right answer...and it’s potentially not an accurate way to frame it... I’m picking again on house staff here I think that this was something that, this is something that I think is ubiquitous. The verbiage that’s being chosen to express these choices is so laden with bias that you’re taking away the patient’s autonomy but still has the illusion of giving full autonomy to them.... There’s been an unhealthy over-emphasis on leaving it so much in the patient’s court that it has left to crafty work arounds with how the discussion is framed. Using such negative language that the patients bristle at the notion of being resuscitated.

I mean could you imagine getting consent for Whipple procedure by saying yes I'm going to take this sharp knife and I'm going to slice you open, and there'll be lots of bleeding and yes there'll be lots of bleeding and it's a huge amount of trauma to your tissues. I mean we'll be mutilating your insides and removing organs that are helpful but not needed to sustain life. Yes well that's not how we describe things that we want to do to people we use nomenclature when we're describing CPR efforts that imply an inhumanity to it. We use nomenclature when we describe surgical procedures that imply we're trying to help the person. And you know words matter.” (Hopkins, *Attending in Hospital Medicine*: 6)

Experienced physicians and palliative care experts never described themselves utilizing this strategy of graphic descriptions in resuscitation conversations. Although there was some variation amongst institutions, with attendings at autonomy-focused hospitals palpably more concerned about autonomy than attendings at best interest oriented hospitals and best interest physicians more willing to be directive when they felt necessary, overall they had an approach to these conversations that were more focused on the patient's understanding and overall goals of care:

“I think it's an inherent part of decision-making. You have to discern what's best for the patient. It's not just about what the patient believes is best for him or herself. More importantly, the values that they have, the goals that they have in respect to healthcare. For me, it's about trying to first and foremost, understand that. Make recommendations that are in tune with those values and those goals. I find that doing that, I'm less likely to find this conflict, between patient autonomy and physician paternalism or physician beliefs.” (Columbia, *Attending in Palliative Care*: 6)

House staff at best interest oriented institutions appeared to straddle the continuum between the more goals of care oriented conversations that experts and more experienced physicians used and the graphic descriptions of autonomy focused house staff. Many inexperienced physicians at these institutions were similar to experienced physicians and

understood the importance of placing these conversations in the overall context of goals of care:

“A totally reasonable thing to do is just to have a conversation about goals. The true ideal of this is to sit down with the family and the patient and have a conversation about what life means to them and what goals mean to them and be able to run the numbers and say ‘all right, for somebody like you having CPR means you’ll have no chance of ever leaving a skilled nursing facility’ and you hear somebody say ‘that’s not life.’ Based on that, I think it’s the right thing for you.” (UW, PGY-3: 10)

“I usually start off with, what are your goals in all of this? What do you want most? If you can have whatever you wanted and short of live forever, what would you want? Then usually it’s much easier to get people to understand what you’re asking of them once you frame it in that context.” (UW, PGY-6: 6)

Two of the residents at UW described conversations focused on medical recommendations, which at times included allusions to these graphic descriptions:

“Phrasing it in the context of, ‘do you think you're loved one wants to pass peacefully or go through aggressive measures including fractured ribs and invasive procedures would be consistent with their wishes?’ It’s so much in the phrasing in so far as helping the family member to say yes or no to that question.” (UW, PGY-3: 11)

“I said, this means she wouldn’t want people pounding on her chest and breathing tubes down her throat and often bloody and gruesome measures at the end of her life. Instead, we can offer her things to make her more comfortable through comfort care that we offer people at the end of their lives.” (UW, PGY-3: 12)

These quotations reflect these UW residents' understanding of the importance of goals of care conversations; placing treatment options in the context of the patients' wishes. However, the use of graphic descriptions in these two quotations illustrates the fine (and debatable) line between manipulation and persuasion. As I mentioned earlier, these graphic descriptions in itself are not problematic. Indeed, it is sometimes important to describe the process of resuscitation in order to guide understanding. These descriptions move from persuasion to manipulation when these graphic descriptions are used to achieve a set purpose rather than using communication to achieve understanding. The resident in the first quotation appears more successful in using these descriptions for understanding rather than to achieve a goal of discouraging resuscitation than the second resident.

Section 8.3: Communication Pathologies from the Perspective of Habermas' Theory of Communicative Action

Jürgen Habermas' critical theory provides insights into why the graphic descriptions used manipulatively described in the previous section are problematic and helps us critique this model of autonomy's dubious claims to patient empowerment. Habermas builds upon Max Weber's work on bureaucratisation and critiques bureaucracy's orientation towards reasoning for the purpose of efficiency and control. He describes this rationalisation as a means to *instrumentalism*, which seeks to homogenise and formalise human activities, leading to the dehumanising aspects of bureaucracy (Blaug 1995).

The instrumental rationality of these bureaucratic social organisations threatens to overpower, or *colonise*, the *lifeworld*²⁷, the contextually derived lived experiences of everyday life that naturally embraces the person's biography. It consists of interactions and relationships established through shared cultural understanding and meanings.

²⁷ This concept of lifeworld was popularised by Alfred Schutz who described it as "socially approved systems of typification and relevances (Schutz 1970)." The lifeworld constitutes the "stocks of knowledge" shared by social actors (Schutz 1962). It comprises the emergent product of cognition, decisions, and actions of individuals who operate within a wholly familiar and subjectively meaningful world (Wacquant, 1992: 9).

Through these shared meanings derived from the lifeworld, people are able to interact and interpret each other based on a mutually understandable set of assumptions.

Lifeworld interactions occur on a more equal footing where *communicative action* prevails (Barry, *et al*, 2001). Communicative action is oriented towards understanding, where all speakers engage in speech actions at a mutually open level to reach “an agreement that will provide the basis for a consensual coordination of individually pursued plans of action (Habermas, 1984: 289).” In communicative action, definitions of the situation are jointly constructed, negotiated, and agreed upon: “participants pursue their plans cooperatively on the basis of a shared definition of the situation...the attainment of consensus can itself become an end...Participants cannot attain their goals if they cannot meet the need for mutual understanding (Habermas 1987).”

The *system* lies in opposition to the lifeworld and is epitomised by markets and bureaucracies. Communication strategies in the *system* are characterised by strategic action that orients speech actions towards success, where the ends are defined by technical success rather than moral objectives. This strategic action “instrumentalises speech acts for purposes that are contingently related to the meaning of what is said (Habermas, 1984: 289).” The system’s use of strategic action is used to maintain its dominance, by using speech not just to say something, but also to achieve a purpose through acting in saying something. To summarise, strategic action is used when an actor uses communication to achieve his goals whereas in communicative action the actor uses communication to achieve understanding.

Strategic action can be further partitioned into *open strategic action*, where speakers openly pursue the aim of influencing and *concealed strategic action*, where this attempt at manipulation is hidden. When this strategic action is concealed, the other party does not have the opportunity to participate in the conversation at an equal level. In contrast, in communicative action, both speakers can dialectically engage in the conversation by raising criticisable *validity claims*, which allow both parties to judge whether the communicated facts are truthful, appropriate, justifiable, and/or sincere (Habermas, 1984:

Ch 1). Rationality and reason by both parties are used to accept or stand up against the speech acts and in the process, establish a dialogue to co-create consensus.

Habermas further partitions concealed strategic action into *conscious deception*, which he describes as *manipulation*, and *unconscious deception*, which he describes as *systematically distorted communications*. This systematically distorted communication is described as a pathology where the speaker manipulates and exerts their influence through concealed means such as through use of technical jargon. Of note, this deception can be conscious or unconscious, as neither the doctor nor patient are aware that strategic action is being used. The doctor uses systematically distorted communication to act “with an orientation towards success, not understanding, but yet sincerely and in good faith (Scambler and Britten 2001).”

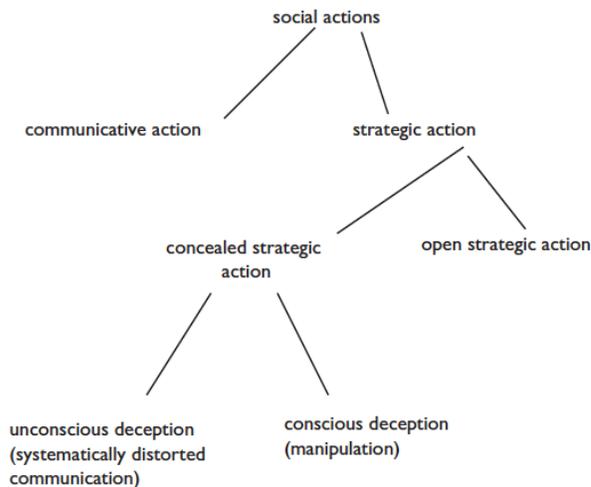


Figure 8.1: Communicative and Strategic Action (Habermas 1984; Scambler and Britten 2001)

Here again, we see parallels to Faden’s conception of manipulation, where the boundaries between intentional and unintentional action, as well as persuasion and manipulation blur. For both, the difference appears to lie with the capacity of the patient to openly engage and reason at an equal level with the physician, rather than in conscious deception or manipulation where a doctor uses “technical jargon to browbeat, subdue or gain assent from a resistant patient (Scambler and Britten 2001).” For Habermas, both unconscious

deception (systematically distorted communication) and conscious deception (manipulation) are considered pathologic.

In *The Discourse of Medicine: Dialectics of Medical Interviews*, Elliot Mishler adapts this concept of system/lifeworld and the dialectical tension between these two forms of rationality to medicine (Mishler 1984). He describes the medical equivalent to the system as the “voice of medicine”, which uses strategies like jargon, medicalisation of daily life, and decontextualised interactions to maintain dominance and control. This voice of medicine encompasses technical and scientific interests that strip away the context of the “voice of the lifeworld.” He describes his analysis of a series of outpatient medical consultations, where physicians use the voice of medicine to strategically carry out his own agenda during the consultation, thus suppressing the patient’s accounts and purpose. This pattern is similar to the colonisation of the lifeworld, where doctors use distorted communication in a success-oriented manner.

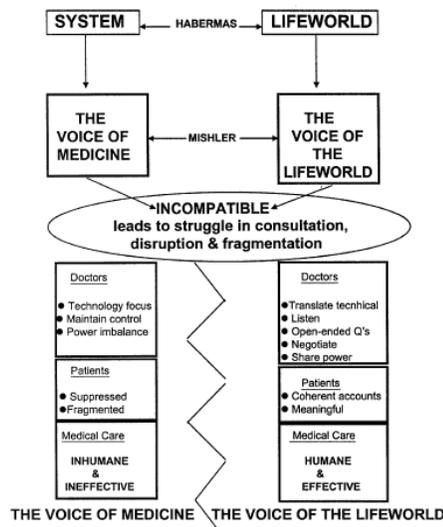


Figure 8.2: Mishler’s Voices of Medicine and the Lifeworld (Barry et al. 2001)

Christine Barry, *et al.* further elucidated the tensions between the voice of the lifeworld and the voice of medicine in a 2001 paper where they described four communication patterns across 35 outpatient consultations (Barry et al. 2001). *Strictly medicine*

communications occurred when both doctor and patient used the voice of medicine exclusively, such as in a simple single acute physical concern. *Mutually lifeworld* situations occurred when the patient's agenda was voiced and recognised and both the doctor and patient used the voice of the lifeworld, where the patient was "recognised as a unique human being (Barry et al. 2001)." The poorest outcomes occurred where the patient's voice of the lifeworld was ignored (*lifeworld ignored*) or blocked (*lifeworld blocked*).

Consultations that were *mutually lifeworld* were most similar to Habermas' *ideal speech type*, where communicative action predominated and speech is "contextually grounded in everyday events where there is an emphasis on working together to reach understanding through negotiation (Barry et al. 2001)." It is in these situations where the patients are most truly empowered at an equal level with the physician to approach the conversation on an equal footing. This is also the situation which appears to most closely align with the American Sociological Association's definition of humane healthcare, where there is the necessary "empathy, equality and view of the whole situated person (Barry et al. 2001)."

Section 8.3.1: Communication Pathologies in End of Life Conversations – Relating Back to the Interview Data

Applying this to the resuscitation conversation examples described earlier in this chapter by American physician trainees at autonomy focused institutions, we see that their conversations employ strategic action, where action is oriented to success rather than to understanding. They use the voice of medicine to distort communications to lead patients towards a particular desired goal. Those graphic descriptions are entirely true and important for the surrogate and patients to be aware of as a part of an overall conversation that informs and engages the patient in a dialogue to determine the best course of action to achieve the patient's goals of care. However, these physicians' intent in using these graphic descriptions were not to foster understanding, but instead to manipulate through distortion of information and to viscerally repel them from choosing resuscitation. This

manipulative communication appeared to occur more frequently in autonomy focused institutions.

Respondents in my interviews appeared to have little insight into how these forms of communication might potentially be manipulative or pathologic. I also recall that this was the way I was taught to have these conversations by my senior resident at Columbia. As such, I do not believe that these physicians are deliberately attempting to deceive, and are thus participating in unconscious deception. They are not fully aware that the reason they frame resuscitation in this manner is for the purpose of strategic action, but more likely they have learned these behaviours from role models as the way DNR conversations should occur. However, house staff have likely learned from experience that this form of communication might potentially yield the desired outcome so there may be an element of conscious deception which encourages them to act in this way. Future studies can help elucidate physicians' motivations and insights into these behaviours.

Ironically, this act of dominance stemmed in part from the current discourse of patient autonomy and choice in decision-making. This is supported by the fact that trainees at autonomy-dominant hospitals described these graphic conversations more frequently. Because medical trainees at autonomy dominant hospitals feel uncomfortable not giving choice, but frequently feel that patients choose the wrong intervention resulting in harmful overly aggressive treatment measures and futile resuscitation, they instead frame conversations in deceptive ways in order to manipulate patients and surrogates into choosing the "correct" treatment. They did not feel at liberty to engage in open communicative action, and as such felt compelled to act strategically.

The graphic descriptions described earlier in the chapter all reflect a *strictly medicine* communication strategy. The way conversation is initiated and framed from the start cuts off the possibility of engaging in the voice of the lifeworld. The question is framed as a medical question, "In the event your heart were to stop would you want us to restart it." Given the inherent power imbalances towards the physician, patients and families frequently are unwilling or unable to redirect the conversation towards the voice of the

lifeworld. Furthermore, colonisation of the lifeworld has turned death, one of the most human of experiences, into a medical choice. The system has essentially also colonised death. Death in this instance has been completely decontextualised and removed from the personal and social context (Scambler & Britten, 2001: 55).

In contrast, the focus of conversations by experienced physicians as well as established best practices by palliative care experts is on goals of care conversations rather than “getting the DNR.” This was also more frequently seen to a degree, amongst house staff at best interest-focused institutions. This resident noted that learning to incorporate the lifeworld in these discussions was something that she improved upon with experience:

“I tend to think not just about the getting the DNR itself but what that looks like after CPR and putting that more in the context of who they were as a person more often now than I did as an intern or resident.” (UW, PGY-6: 8)

Because there was not a cultural perception of the need to adhere to a strict notion of autonomy, they had greater leeway to pursue conversations that were more broadly focused. These conversations begin with questions about the patient – the kind of person he was, the relationship he had with the surrogate decision maker, what his values and beliefs were, and what his goals were. This focus clearly employs a *mutually lifeworld* perspective, which acknowledges the patient as a person situated in a particular lifeworld and allows that biography to be the driving force in the discussion and decision. Also inherent in best interest focused communities, are increased trust founded on a mutual understanding of lifeworld perspective. This resident at UW demonstrates how the lifeworld perspective can be incorporated into these conversations:

“For some people it is based on other things. We have our experience based on our clinical gestalt and our knowledge base of disease...but for some people there is a grey zone that lies outside of clinical medicine, which is religious practices or their social and cultural beliefs that do kind of supersede the medicine. It doesn't matter what you tell them in terms of this is what I know to be true, they're still

going to tell you that this would not be in line with their goals and so, and honestly it's hard to really argue with that. Because I'm not obtuse enough to think that I know more than their belief system, their cultural system. So I usually won't try to disregard that, I'll usually gauge with it and kind of tease out a little bit more than just what I'm getting at face value which is this would be against our practice to understand why to make sure that there's not some disconnect between understanding of what CPR entails and what their belief is." (UW, PGY-2: 13)

By focusing on goals of care (i.e. lifeworld), the physician and patient and/or surrogate both agree they are on the same side, and are able to proceed with a deliberative process that allows for a dialogical interaction. This junior faculty member at Hopkins demonstrates communicative rationality:

"Ask them about their insight into their illness is what they understand about their disease and try and eventually lead them to talk about what they think the short term and what the long term outcomes of the disease is. And in situations where the ultimate decision that's made is not very discordant with the medical decision-making, that process itself gives you the answer." (Hopkins, Attending in Hospital Medicine: 8)

In this quotation, this respondent focuses on the importance of the process of decision-making, and the importance of hearing the patients' voice and their own understanding of the situation.

Section 8.3.2: Micro-Actions Reflecting Macro-Sociological Changes

We can draw further insight into how these communication patterns developed by reflecting the effects of macro-sociological shifts from paternalism to autonomy described in Chapter 2, onto the micro-interactions between individual actors and between actors and the larger system described in this chapter. Decades ago, it was

perfectly acceptable and even expected for the doctor to have a “doctor knows best” attitude. These paternalistic norms allowed for open strategic action. Changes towards autonomous decision-making made this no longer acceptable. But rather than fostering true autonomous decision-making, communication instead shifted towards concealed strategic action, where doctors unconsciously manipulated in order to achieve his goals.

While these shifts towards autonomy were meant to improve the patient experience and provide a more ethical decision-making framework, this strategic concealment of communicative purpose has undermined the original intentions of increased autonomy. Rather than truly empowering patients, this concealed action merely drove the acts of domination underground. This might perhaps explain why institutions that had less of a focus on autonomy and more on beneficence may in fact allow for a more empowered patient experience by providing the space for open communicative action.

However, this discourse of autonomy constrains a doctor’s responsibility for patient suffering (Salmon and Hall 2003):

“Sometimes with these end of life decisions, it becomes like [doctors] don't want to take responsibility to make a decision. But now there's a family and so instead of saying: ‘This is what we recommend and this is what we will do and if you don't agree, let's talk about it’, they instead say, ‘What would you like?’”
(Hopkins, PGY-1: 16)

“An alternative system which I got to make the decisions would put a lot more responsibility on me and I think that’s one thing that is a relief about our system. You don’t ever know who is going to pop right back out.” (Hopkins, PGY-3: 14)

The unintended negative consequence of patient autonomy is that it allowed the doctor to withdraw from the responsibility of choice while still maintaining dominance in other ways. Doctors still choose when to give this choice; they do not ask patients whether they

want to have a blood test ordered or what antibiotic they would prefer despite the fact that some patients would actually prefer to choose their own antibiotics (Johnson, *et al.* 2011). As I will explain later in this chapter, physicians are still able to exert considerable control through framing and manipulation of language and conversations. Despite doctors' relative power, as I discussed in the previous chapter some doctors feel powerless to act in the patient's best interest – neither party feels satisfied or in control.

Section 8.3.3: Critique of the Literature on the Applications of Habermas to Medicine and a Proposed New Direction

The literature on applications of Habermas' concept of system/lifeworld in medicine reflects the traditional theories of professional dominance described in Chapter 2. For example, Gemma Edwards states that, “the interaction that takes place between the doctor and patient in a consultation should at least strive to be ‘communicative’ in this manner. The definition of illness and course of treatment should, for example, be negotiated through an open dialogue that is not influenced by the power of medical expertise (Edwards, 2012: 36)”

This view, I believe is too simplistic and does not reflect the changing nature of physician power. This monochromatic representation of physicians and their dominance does not reflect the variations that occur institutionally, geographically, and amongst physicians of varying experience within the same hospital. If we revisit Mishler's concept of the voice of the lifeworld versus the voice of medicine, the assumption at the time (which was likely more accurate in the 1980s when Mishler was writing) was that the physician was the agent of the voice of medicine. He in fact uses the provocative term, “inhumane,” to describe the care that results from these distorted communication patterns.

Modern day prioritisation of patient autonomy has shifted the power balance towards the patient in a disjointed manner where the physician maintains control of many elements of the interaction but is lacking in others. However, younger physicians have been fully

inculcated in a dogmatic understanding of autonomy feel dominated by the *system*²⁸, enacted through institutional culture and policies. The young doctor is caught between two roles. He acts as the system/voice of medicine agent upon the patient, but is also acted upon by the greater system. His own lifeworld becomes colonised by the system during the process of medical education, which slowly removes his recognition of the lifeworld perspective during the professionalisation process and inculcates him into the system.

Simon Sinclair describes in his ethnography of UK medical students, the nature of medical school as a “total institution,²⁹” where the lay world (lifeworld) is completely offstage - not even in the arena of day to day consciousness and completely distinct from the front stage and back stage of daily medical school activities³⁰ (Sinclair 1997). During the process of acculturation into the profession of medicine, students learn from the start that their familiar lay world is to remain off stage; their private lives become fully inundated by the institutional system.

Perhaps this might be why in Howard Becker, *et al.*'s *Boys in White*, the authors noted the “tremendous homogeneity of the student body” in terms of their attitudes and actions regarding the medical school experience (Becker, Geer, Hughes, & Strauss, 1961: 22). They have all been through a homogenising process where their former lifeworld experiences are no longer relevant. Indeed, the goals of the system are to maximise efficiency through control rather than understanding and consensus. We have seen the transition from medicine as a cottage industry to the rise of the medical industrial

²⁸ I define system here in the way that Habermas originally defines it – the economy with its capitalist market and its focus on profit, and the nation state, with its bureaucratic and legal forms of power (Edwards, 2012: 38).

²⁹ Howard Becker, et al. in *Boys in White* described medical schools to be “total institutions” in the way first described by Erving Goffman in *Asylums (1961)* such as prisons, hospitals and asylums (Becker et al. 1961; Goffman 1961).

³⁰ He is referring to Erving Goffman's concept of the dramaturgic everyday social stage proposed in *The Presentation of Self in Everyday Life*, where Goffman describes the importance of the presentation of self on the front stage where impressions are played (Goffman 1959). This is distinct from the back stage, which is the true self constructs and contradicts the impressions played on the front stage. In medical school, the front stage comprises clinical teaching, lectures, etc. whereas the back stage is in libraries, at home, on the hospital wards (outside of the sight of patients), and informal and mutually supportive socialisation amongst students.

complex dominated by bureaucratic managers whom themselves are not physicians. The creation of a *system* that controls the controller is in some ways the most efficient means of establishing the bureaucratic efficiency necessary for the overall system to control patients.

In the previous chapter, I described how perceived futile treatments hinder trainees' ability to find meaning in their work, its effect on self-identity, and the alienation that results from this moral distress. Indeed, a word referenced in both Mishler's description of the voice of medicine, and Jaeggi's description of alienation is "inhumane/inhuman". Mishler uses the emotive and judgmental term to emphasise the importance of humanely respecting the patient as a whole person (Barry et al. 2001). Jaeggi similarly uses the word "inhuman" to forcefully describe the problematic aspects of alienated labour, where the worker feels that her work is meaningless, one that she does not identify with, and one that she has no control over (Jaeggi 2014). The use of the same emotive term, inhumane/inhuman to describe both the inhumane voice of medicine that the doctor imposes upon the patient, but the doctor herself feels inhuman due to alienated work, highlights the dual tensions converging upon the doctor.

Alienation's fundamental critique is that of relationlessness with respect to both the world and oneself. Jaeggi states, "a distinctive feature of the concept of alienation is that it refers not only to powerlessness and a lack of freedom but also to a characteristic impoverishment of the relation self and the world (Jaeggi 2014)." Highlighting the importance of relations from the perspective of alienation to this discussion allows us to realise the dangers that occur when the system colonises the doctor's lifeworld. The institutions of medical training and their ability as a total institution to drive out the doctor's lifeworld, replacing it with the voice of medicine serves its purpose in the professional capacity, but at the expense of nurturing a whole physician who is able to maintain her lifeworld experiences throughout her professional career. The lifeworld-impoverished physician may be able to competently practice as a physician, but her relationlessness to both her lifeworld and herself prevent her from engaging with the

patient's lifeworld and challenge her ability to practise with compassion, empathy, and with open communicative action.

One can look to how the medical profession seeks to better itself and the ideals it aspires to as further evidence that critique of the physician profession around DNR decision-making cannot simply be cast as a physician's quest for domination. Best practices and experts in palliative care, as well as experienced physicians practice and advocate a patient-centered approach that focuses on a goals of care approach that employs open communicative rationalities. One study demonstrated that palliative care experts were less verbally dominant in conversations, allowing more time for the patient to speak and fostered more of a partnership in the dialogue (Roter, *et al*, 2012). Most importantly, they gave less biomedical information and focused more on psychosocial and lifestyle discussions. In essence, these experts acknowledged the lifeworld and utilised open communicative patterns.

The intentions of individual physicians are rarely to dominate or control, but rather structural factors such as time pressure, lack of space to be reflective about issues of autonomy, interpretations of policies, and policies themselves contribute to this drive towards more strategic action and consequent "inhumane" care. The hidden curriculum and the physician trainee socialisation I described earlier also contribute. Thus, to fully dissect and ameliorate these communication pathologies, we must recognise the way the lifeworld of young physicians are themselves colonised by the system.

Recognizing too the role of the system in reproducing a medical culture that is now focused more on choice than care and humanity, also helps shed light on how we came to where we are today. The "professionalisation" process from a layperson to a physician during medical school is an indoctrination that changes the student's lifeworld perspective to that of medicine³¹. The ways in which patients have become customers and

³¹ The physician becomes colonised as they go through the transition to become a professional. In many ways, this is a necessary process but perhaps in other ways, educational institutions should strive to make doctors who have lost too much of their own lifeworld perspective. The institutional policies and cultures, which influence trainees through both didactic lectures as well as the hidden

doctors providing a service rather than embarking on a professional calling, draws into question how the system itself has infiltrated the voice of medicine and the doctor's own lifeworld.

Section 8.3.4: The Unintended Consequences of Individual Actions Producing the Structure of Wayward Autonomy

Much of the literature on the social transformation of the American physician suggested that physicians were either unaware of or resistant to the necessary power shifts in medicine. For example, in McKinlay and Arches' 1985 paper on the proletarianisation of physicians, they described that physicians at that time were unable to fully comprehend the proletarianisation that was occurring in their profession. McKinlay and Arches emphasise in subsequent papers, that physicians have been increasingly subject to this process, but that it was masked by an "elitist conception of their role, so that even if the process is recognised, doctors are quite reluctant to admit it (McKinlay and Stoeckle 1988)." Wolinsky cautioned the medical profession that if they remain unchanged in behaviour and attitude despite these capitalistic forces, then "its privileged status and professional dominance may well go the way of the dinosaur" (Wolinsky 1988).

These claims might either reflect physicians' relative lack of awareness in the 1980-90s, but they may also reflect their functionalist stance, of which Antony Giddens is critical. He instead believes that "human agents or actors...have, as an inherent aspect of what they do, the capacity to understand what they do while they are doing it...actors know tacitly about how to 'go on' in the context of social life without being able to give them direct discursive expression (Giddens 1984)." Actors are generally able to explain most of what they do, if asked. The issue is that they ordinarily are not asked.

My interviews generally demonstrated that physicians are both aware of this change, as well as "thoroughly inculcated in the concept of patient autonomy (Hopkins, Senior

curriculum, encourage a systems-oriented focus that may be harmful not only for the doctor's own personhood, but also for patient care.

Attending: 4).” When asked, both formally in interviews as well as in informal conversations about my project, the majority of physicians were able to generally draw links between the changing nature of the physician profession and the culture of choice and autonomy within which they practice. More experienced physicians were entirely aware of the changes in the medical profession over their years of practice, and how it affected their practice. For example, this experienced physician said:

“I think that factor of experience or inexperience is overlaid on a historical shift. I was in training when the Karen Ann Quinlan case was decided. Then the Belmont report came out. That was really the origin of the whole field of medical ethics and discussions of end of life care. So this field has grown up around my career. I’ve seen things change from a very physician centered, paternalistic approach to one which stresses patient involvement (Hopkins, Attending in Pulmonary and Critical Care Medicine: 4).”

During a recent session on end of life conversations that I led with fourth (final) year medical students at Johns Hopkins, I was struck by the nuanced reflexivity these students possessed when one remarked that while the medical profession has swung over time toward a focus on autonomy, had had noticed Hopkins subtly shifting back towards desiring a more shared decision-making approach.

These insights in combination with the macro/micro sociological changes discussed throughout this thesis, reflect the unintended consequences of social action, best summarised by Giddens in his Theory of Structuration (Giddens, 1984). In Structuration Theory, Giddens brings together structure and agency by emphasizing the recursive nature of social life via the *duality of structure*, whereby structure is constantly recreated out of the resources that constitute them. Human social activities are “not brought into being by social actors but continually recreated by them via the very means whereby they express themselves *as* actors. In and through these activities, agents reproduce the conditions that make these activities possible. He brings in interpretative sociologies by

further stating that human agents display knowledgeability about their surroundings which feeds back into the recursive ordering of social practices.

In other words, human actors are purposeful agents who have a reflexive knowledge of the structures within which they operate and make choices based on this interpretative understanding. However, aggregated social patterns emerge out of these individual human actions. These unintended consequences then constrain choices, imposing a structure onto human behaviour. A major part of Structuration Theory involves the routinisation of day to day social activity, which reflect “the psychological mechanism whereby a sense of trust or ontological security is sustained in the daily activities of social life (Giddens, 1984).”

Physicians are fully aware of the social changes in their profession and the resulting prioritisation of autonomy, which they have accepted as a necessary and important component of physician professionalism. The problem is that the pre-existing structural constraints of the hospital such as workflow, limited time, and the hidden curriculum hinder trainees’ abilities to develop a nuanced, mature understanding of autonomy. Their interpretation of policies promoting autonomy then become warped into a simplistic notion of choice, sometimes even reflecting a false or forced choice.

While the original intentions of autonomy were positive, the unintended consequences of this autonomy interpreted through individual physicians feed back onto the overall structure to create the pathologic systems of communications I describe in this thesis. Power transferred from the doctor to the patient during this professional evolution occurred in a piecemeal manner, resulting in perceived lack of power by physicians but without the commensurate improvements in patient empowerment that American society desires.

Section 8.3.5: Problems with Applying Habermas' Theory of Communicative Action to End of Life Conversations

One critique of Habermas' Theory of Communicative Action that must be addressed in this context is the patient or surrogate's ability to participate in this dialogical interaction (Baert, 1998: 149). His theories are predicated on the patient and surrogate having the ability to make reasoned choices. Particularly for the elderly and those at the end of life, cognitive impairment, delirium and critical illness make it challenging for patients to fully engage in this co-creation of consensus. Perhaps as relevant, but less frequently recognised, is the emotional toll of critical illness on decision-making capacity and judgment.

These life threatening circumstances can lead to intense fear, demoralisation and catastrophic thinking which leads to poor judgment and “emotionally grounded beliefs that are systematically unresponsive to evidence, [which]...can block the ability to deliberate about alternatives (Halpern, 2012).” Surrogate decision makers too may be especially vulnerable to emotional catastrophic thinking. However, the autonomy discourse is as fallible if not more to this critique, as choice can also be thrust upon those who neither have the capacity nor will to make informed decisions.

I described in Chapter 6 the ethical fallacy of forced choice and the need to consider a tailored approach to decision-making. Habermas' theories applied to this context presuppose that patients and surrogates *want* to engage with decision-making if they are able to. Attaining understanding and participating in a reasoned decision-making process is both mentally and psychologically taxing and may not be what the patient or surrogate want to do. It is thus imperative that in applying these theories, that we do not also forget the importance of first asking patients/surrogates what role they want to play in the decision-making process and tailoring approaches to their desires. As described in earlier chapters, I propose not just focusing on best interest outcomes, but beneficence of process. This focus on the *process* of consensus is consistent with the spirit of Habermas's self-emancipatory theories.

Health illiteracy remains another major challenge in health care today and those who lack monetary resources and education are particularly prone to being subordinated by the medical system. These communicative practices require a certain level of cultural and educational capital, which many patients and surrogates may not have. In almost any medical situation, the physician will always have the upper hand in an effort to convince via “the force of the better argument.” This recognition though, only convinces us further of the need for a more communicative rationality, as poor health literacy compounds problems in situations where autonomy is thrust upon the patient without support from the physician.

It also must be noted that cultural differences may influence the patient or surrogate’s willingness to act at an equal level and debate with the physician, even if the physician is willing, given certain cultures’ respect and subservience to authority figures. It is especially important in these situations, that the physician make it very clear that communicative rationality should prevail, but also allow for more directive, paternalistic interactions if the patient wishes. This would be consistent with the need to give the patient a “choice of choice” described in the last chapter. It is again essential to first determine or get a sense of whether the patient has the ability or desire to participate in communicative rationality. Of course, regardless of health literacy or cultural predisposition, there would never be a case where the use of manipulative language such as the graphic descriptions described earlier would be appropriate.

Section 8.4: Language and Framing

Language is a powerful tool that can either facilitate end of life conversations or contribute to misunderstandings and create additional emotional distress and conflict. According to Habermas, language is “the medium for domination and social power; it serves to legitimate relations of organised force. In so far as the legitimations do not articulate the power relations whose institutionalisation they make possible, in so far as these relations manifest themselves in the legitimations, language is also ideological

(Held, 1980: 316).” Beyond the ways in which language situates communicative or strategic rationality as described above, the physician’s framing and use of language is powerful in other ways.

Defaults can be interpreted as the suggested option. Particularly in situations where resuscitation is unlikely to succeed, offering choice with a default of resuscitation potentially misguides a patient towards the non-beneficial option. The act itself of offering the decision to pursue full code can create false hope. Offering the decision, but then discouraging it when they ask for it, demonstrates that “preferences are elicited but not respected, decreasing trust when it is most needed (Workman 2011).” The effort to obtain consent for CPR often changes the physician’s focus to obtaining a DNR order rather than on goals of care (Billings 2012).

Indeed, the importance of language is being increasingly recognised amongst the palliative care research community. The effort to obtain consent for CPR often changes the physician’s focus to “getting the DNR” rather than focusing on shared decision-making and the larger conversations of goals of care (Billings 2012). There have been attempts to change the language of this decision in the US to “Allow Natural Death” (AND) in order to more accurately reflect the realities of this decision. Even the difference in language between the US and UK is informative; most American hospitals use “Do Not Resuscitate” and the British and UW use “Do Not Attempt Resuscitation.” This single additional word helpfully emphasises that this is an attempt and not actually an expected outcome.

Although there has undoubtedly been a shift of power from the physician to patient over the past several decades, physicians are still dominant in the relationship. By definition, there will always be an inevitable power imbalance between physicians and patients. Failure to acknowledge this confers a risk of ignoring the ways in which communication can be used to either foster or sabotage good medical care. The main consideration is rather how this dominance is utilised; physician power can be used positively to persuade or negatively to manipulate or coerce. As Trisha Greenhalgh, *et al.* assert, “a ‘good

consultation' does not require silencing the voice of medicine. What is required for communicative action is that medicine's validity claim be open to challenge, not that they necessarily *be* challenged (Greenhalgh, Robb, and Scambler 2006)."

As I explained earlier in the chapter, inexperienced physicians sometimes felt powerless to provide best interest oriented care due to perceived constraints of autonomy, and instead reverted to manipulative ways to shape decisions rather than achieving reasoned consensus. This is counter-productive, as it creates additional conflict between doctor and patient. Doctors perceive patients as being "demanding" and "difficult" without realizing their own role in creating situations where consensus is strained."

Framing is inevitable, as even the most neutral of questions can have a positive or negative default, which are known to influence decisions (Halpern, Ubel, and Asch 2007). Framing occurs when two statements are both true, but meaning differ based on the associations implied by the way the statements are phrased. For example, if a physician tells a patient that the surgery has a 90% one month survival rate, people are more likely to choose surgery than if the physician says there is a 10% mortality in the first month (McNeill, *et al.*, 1982). These two statements are both truthful statements of the exact same situation, but the associations evoked by framing mean very different things to the patient.

Daniel Kahneman and Amos Tversky, who were pioneers in the field of decision sciences, described the mind as having two systems that drive the way we think³². System 1 is automatic, instinctive and emotional; System 2 is deliberate, reflective, and more

³² The epistemological links between the interpretivist approaches in the previous chapters, Habermas, and the behavioural economics approaches in this section are not as distant as one might think. Symbolic interactionists had previously emphasised that humans are not simply rational users of a cost benefit calculus. This is the very idea that that has lately been "discovered" in behavioural economics. Symbolic interactionists and phenomenologists argued that humans construct their lifeworlds using typifications and their social actions are determined by these taken for granted ideas (Kelly 2015). Those who study heuristics, such as Kahneman provide us with interesting and compelling empirical evidence of the ways these typifications work. Although sociology traditionally concerns itself with relationships and psychology (which influences behavioural economics) is concerned with the individual, it is legitimate to epistemologically link the two, as both heuristics and Habermas' concepts of the lifeworld deal with our taken for granted understandings of the lifeworld, and the ways we respond automatically from them.

logical (Kahneman 2011). Framing betrays the rational choice side of us, and occurs when System 1 preferentially reacts to these choices. In one of their experiments, they allowed participants many trials where they encountered different frames, and thus had the opportunity to recognise this distracting effect of framing and “translate” the two statements to a common frame. While most people succumb to framing because they do not suspect that framing was influencing their choices, these participants had the opportunity to neutralise the frame. Despite this, few participants were able to do so: “reframing is effortful and System 1 is normally lazy. Unless there is an obvious reason to do otherwise, most of us passively accept decision problems as they are framed and therefore rarely have the opportunity to discover the extent to which our preferences are *frame-bound* rather than *reality-bound* (Kahneman, 2011: 367).”

Faden finds biases in informed consent by framing troublesome (Faden & Beauchamp, 1986: 319). She asserts that this gives professionals the power to manipulate decisions without resorting to deception. She wonders what the implications of this framing is when neither the physician nor patient are aware of the impact of framing on decisions. She believes that framing potentially diminishes autonomy by compromising understanding, as in the person fails to understand the material description of their choices. However, experiments have shown that experts are just as susceptible to framing as those without expert knowledge, making it unlikely that lack of understanding is the cause of our cognitive vulnerabilities towards bias.

Researchers at Harvard gave the scenario above (90% survival versus a 10% mortality for surgery) to three groups: ambulatory patients with chronic diseases, graduate students, and physicians (McNeill, *et al.*, 1982). The preferences of all three groups, including that of physicians (“experts”), were significantly affected by whether the choice was framed by the probability of survival or death. Similarly, when a framing problem outlining a choice of public health measures for a disease outbreak, known as the “Asian disease problem³³” was given to public health experts, they too were susceptible to the problem’s

³³ The “Asian disease problem” is as follows (Kahneman, 2011: 368):
Imagine that the US is preparing for the outbreak of an unusual Asian disease, which is expected to kill 600 people. Two alternative programmes to combat the disease have been proposed. Assume that the exact scientific estimates of the consequences of the programmes are as follows:

framing effects. Neither expert knowledge nor professional experience protects from the effect of framing. Given this evidence, it is difficult to claim that framing is deceptive due to lack of understanding.

Indeed, framing is possibly less likely due to problems in understanding, than biologically determined flaws in rationality. fMRI studies have shown differences in brain region activation when study participants are given framing questions under fMRI (Kahneman, 2011: 366). When participants' choices conformed to the frame, the amygdala, the region of the brain associated with emotional stimuli (i.e. System 1), lit up. In contrast, when participants resisted the temptation of System 1 and chose in spite of the frame, the anterior cingulate, the area associated with conflict and self-control, lit up. Finally, in the most "rational" subjects – those who were least susceptible to framing - demonstrated enhanced activity in the frontal area, the part of the brain that combines reasoning and emotions.

Given that framing does not necessarily imply deception and cannot be attributed to a lack of understanding, what are the ethical principles that surround a physician's ability to use framing in conversations? Earlier in this chapter, I discussed how persuasion was not only an acceptable, but necessary duty of the physician. How different is framing from persuading a patient to make a decision in their best interest? It is a fine line indeed.

The typical "neutral" way in which residents ask about resuscitation decisions tends to be, "In the event that your heart were to stop, would you want us to restart it." Many assume that this is as unbiased a way of asking the question as possible, but this statement is framed positively such that the default is for the treatment to be done. To

If programme A is adopted, 200 people will be saved.

If programme B is adopted there are a one third probability that 600 people will be saved and a two-thirds probability that no one will be saved.

If the outcomes of the programmes are framed differently in a second version:

If programme A' is adopted, 400 people will die.

If programme B' is adopted, there is a one third probability that nobody will die and a two-thirds probability that 600 people will die.

Although the consequences of programmes A and A' are identical as are B and B', but in the first version, a substantial majority choose programme A because they preferred the certain option over the gamble, but in the second frame, a large majority choose the gamble.

further illustrate, this same question asked with a negative default is encapsulated in the informed assent strategy: “Your father is very ill and there is not much more that medicine can do to give him a quality of life which would be acceptable to him. When his heart stops, would you want us to allow him to die a natural death?” Both these statements ask the same thing with a positive or negative default, and can have a great influence on the decision ultimately made:

“I think there is, anybody who has been part of a conversation will tell you that there is words you can choose, just how you describe CPR, how you describe intubation, how you phrase the odds. Do you say that 10% of people walk out of the hospital, or do you say that 90% of people don’t? And so I think that’s where physician emotion regarding both their own perspectives or end of life and individual patient prospects and prognosis come in because there are very different terms used on a twenty two year old who is here with a drug overdose, versus somebody who has a chronic disease and is ninety-five.” (Hopkins, PGY-3: 14)

This situation is similar to that of food placement in a school cafeteria in that framing is inevitable (Thaler and Sunstein 2008). People are more likely to choose healthier options if healthier options are put first in the queue than if unhealthy foods are placed at the beginning. Richard Thaler and Cass Sunstein describe this choice architecture as a “nudge”, which is defined as “any aspect of the choice architecture that alters people’s behaviour in a predictable way without forbidding any options or significantly changing their economic incentives.” Since the food has to be placed somewhere, a choice has to be made. Since we know that placement affects food choices, is it ethical to leave it to 50/50 chance that we inadvertently harm people by placing unhealthier options first (Sunstein 2015)?

Similarly, since framing is inevitable, should physicians harness this power of defaults and frames for the good of patients and/or surrogates? Would it be unethical not to? Would it be more or less ethical to understand and use inevitable framing in describing end of life choices?

Moreover, the framing of this positive default may also be interpreted as asking someone to volitionally give up something (would you want us to *withhold* CPR, and essentially *let* them die), in contrast to the alternative system where the meaning is not focused on loss by allowing a natural death and transitioning to comfort care. In Kahneman's book *Thinking, Fast and Slow*, he describes an experiment where a decision to play the lottery is framed as either \$5 for the cost of the lottery ticket or \$5 as the loss of a gamble (Kahneman, 2011: 364). More people choose to play when the decision was framed as \$5 for the cost of a ticket because "*losses* evoked a stronger negative feeling than *costs*." The inevitable frame thus makes resuscitation something that must be taken away or refused, which goes counter to our propensity towards loss aversion.

This resident's acknowledgement and acceptance of framing reflected her institution's prioritisations of autonomy versus best interest. Her focus on providing autonomy by portraying choices neutrally and free of bias did not allow her to see the inevitability of framing. This quote illustrates the controversy between distinguishing the need to frame in a way that helps persuade a patient towards the best treatment versus framing in a manipulative manner:

"If you have a 50 year-old guy who has pneumonia in hospital who you are expecting to make a full recovery, but you need the doctor to get a code status, he would say, 'if your heart were to stop would you want us to press on your chest?' And [the patient will] say, 'Sure, do everything, Doc.' And then we go into an 85 year-old lady's room whose osteoporotic and we will say, 'If your heart were to stop would you want us to do chest compressions? When we do these compressions we will do them so hard that we will break your ribs and you will be in severe pain.' It's very different to say that, which I don't think we necessarily say to everyone. It is inconsistent...I think something more standardised, structured and uniform way to get a code status would be better because what is very disturbing is watching your resident or the attending present the code status to different patients very differently and you can tell by the way they are presenting it that it has an intention and your words are very impactful

and they can really persuade so, even though as doctors we don't, patients have the autonomy, we have a lot of power. (Columbia, PGY-2: 12)

Her discomfort with the situation is not in the manipulative nature of graphic descriptions, but in the fact that there are differences in the way that these scenarios are framed. Given that providing recommendations are considered best practices as well as that framing is inevitable, shouldn't practitioners use framing as another tool of persuasion? The challenge of course is again the fine line between persuasion and manipulation. Problems occur in the way that many of these conversations are framed not because framing occurs, but that the framing is done in the context of strategic rationality:

“Often if they are very ill and I really think a DNR is in the best interests, I will describe a resuscitation in more detail than I would if it was just somebody who was coming in who wasn't so severely sick and I find my descriptions will vary depending on the situation. Definitely the motivation in doing the description is to encourage people to consider how maybe painful or how much suffering could be gained from that type of intervention and I definitely choose my words sometimes specifically to communicate that because I generally think that people don't know what a resuscitation involves.” (Columbia, PGY-2: 12)

“Yes I always say it can break your ribs. It can be very uncomfortable. You can even puncture a lung. You can have adverse outcomes from it. I think from that a lot of my very frail patients who are very elderly who I'd recommend being DNR/DNI to and that kind of helps them to imagine it for themselves.”
(Columbia, PGY-2: 13)

As I alluded to earlier, while some of the residents at UW still inappropriately used manipulative graphic descriptions, they acknowledged and recognised the power of framing:

“Phrasing it in the context of do you think you're loved one wants to pass peacefully or if going through aggressive measures including fractured ribs and invasive procedures would be consistent with their wishes. Its so much in the phrasing in so far as helping the family member to say yes or no to that question.” (UW, PGY-3: 11)

“...so repeating that back to her, I said I take this to mean she wouldn't want people pounding on her chest and breathing tubes down her throat and often bloody and gruesome measures at the end of her life. Instead we have these, we can offer her things to make her more comfortable and kind of comfort care that we offer people at the end of their lives. If it's somebody with like multiple comorbidities and you know probably cancer or end stage heart disease or something, and in my mind it's like this person is nearing their death and we should probably allow death without these gruesome measures. And then I would recommend it, then I would frame it, I would first still again see if they'd had that conversation, have you ever had, have you ever talked about what you would want at the end of your life?” (UW, PGY-3: 12)

These responses reveal similar desires as house staff at autonomy-focused hospitals to dissuade patients from resuscitation through graphic descriptions, but because they did not feel strictly constrained to offer choice, they were willing to use framing as a part of recommendations.

In this thesis, I have moved from description towards a normative stance where I critique the communication practices of trainee physicians at autonomy-focused institutions. However, I have also emphasised the role of the system and the social forces that influence these physicians' ethical thinking that steer them towards manipulative forms of communication. The preponderance of these behaviours in trainees at autonomy-focused institutions in contrast to experienced physicians and those at best interest-focused institutions speaks to the importance of institutional cultures and policies.

Many of the thinkers I cite, such as Faden and Habermas, clearly take a normative position, implicitly or explicitly stating that systematically distorted communications, coercion, and manipulation (but not persuasion) are unethical. However, the view I wish to advance, is that physicians are not consciously behaving unethically, but that the systems and structures at the societal level function sub-optimally. As I described earlier in the chapter, a fundamental element of this systematically distorted communication is its unconscious and unintentional nature. Based upon my auto-ethnographic experiences, physician trainees learn these behaviours and communication practices through peer learning and modelling.

Section 8.5: Conclusion: Autonomy, Ideology and Emancipation

Habermas' theories have always had an emancipatory goal, employing these insights into distorted communication as a means for securing freedom by highlighting people's capacity to reason and make rational decisions (Held, 1980: 317). His interest in knowledge stemmed from his belief that self-reflection, self-understanding, and awareness of forces that influence them, could achieve autonomy and emancipation. He draws inspiration from Sigmund Freud's psychoanalytic therapy where the goals are to change behaviour by shifting "what happens to the individual into what the individual makes happen (Giddens, 1985: 126)."

Habermas believes that the goals of critical theory should be the same, where individuals actively control their own lives through an enhanced understanding of the forces that influence it. With reason and understanding as a central tenant of autonomy, neither the doctor nor patient can withdraw from the responsibility of decision-making, as these acts are not passive and require the dialogical engagement of both parties. By conceptualising challenges in end of life communications through this emancipatory lens, we can focus on the ability of individual actors to truly empower themselves rather than through paying mere lip service to the idea of individual choice and autonomy.

When the *lifeworld* rather than the *system* is engaged, ends are defined by moral considerations rather than by technical ones. Awareness and critique of these distorted communication practices allows us to unmask the contradictions of the current rhetoric of patient empowerment which continues to dominate through an illusion of patient autonomy and encourages us to seek a more effective way to transform the doctor patient relationship. Habermas critiques the use of ideology as a controlling mechanism by the system, as a technocratic justification for the current social order. However, this dogmatic adherence to ideology can be delegitimised if they cannot be validated when subjected to rational discourse.

In contrast, Giddens believes that ideology reflects the “capability of the dominant groups or classes to make their own sectional interests appear to others as universal ones. Such capacity is therefore one type of resource involved in domination (Giddens, 1979: p5).” While Habermas emphasises the role of the *system* in using ideology as a controlling mechanism, Giddens attributes ideological dominance to that of the dominant class (i.e. physicians themselves). Giddens’ Structuration Theory allows us to reconcile and unite these two contrasting theories. The interpreted knowledge and actions of individual physicians feeds back onto the overall system. This recursive social pattern in turn has the unintended effect of constraining both physicians’ and patients’ choices. As such, both the dominant class of physicians and the system recursively act upon each other to produce a controlling effect.

In previous chapters, I focused on the problems associated with the tendency towards an un-reflective ideology of autonomy and choice, especially at autonomy-focused institutions. Critical theory’s critiques of ideology shed light onto the problems associated with this dogmatic way of thinking; “Their ideology is what prevents agents in the society from correctly perceiving their true situation and real interests; if they are to free themselves from social repression, the agents must rid themselves of ideological illusion (Geuss, 1981: 3).”

The problem with the ideology of autonomy is that it supports, legitimises and stabilises certain kinds of social practices. Physician trainees' over-interpretation of policies that encourage patient autonomy constrains them to act in ways that cause moral distress, but they feel powerless to act otherwise. Ideology is also something that "masks social contradictions" as seems to be the case in medicine's ideology of autonomy and patient empowerment (Geuss, 1981: 18). The focus on patient empowerment in modern medicine as a means of honouring autonomy is contradicted by the disempowering elements of systematically distorted communications and lack of understanding of the medical circumstance to make a reasoned decision.

Rather than focusing on autonomy for autonomy's sake, Habermas' Theory of Communicative Action can be used to empower patients by emphasizing the need to co-create consensus through an open discussion. This concept has familiar echoes to the ethical discussions on informed consent discussed at the beginning of the chapter. Providing the space for patients to exercise reason is a key component of both Faden's concept of persuasion and Habermas' communicative action. Further extending Habermas' theories onto more contemporary fields of heuristics and framing allow us to further understand the ways human actors react and respond to communication cues.

In previous decades when physician paternalism was permitted, physicians were able to engage in open strategic action. When norms shifted towards patient autonomy, rather than transitioning to open communicative action, the act of domination was driven underground with concealed strategic action, thus disempowering rather than empowering patients. Despite this, the loss of physician power still resulted in a perceived powerlessness by physician trainees.

I then related these discussions of communication practices to behavioural economics and heuristics and discuss how framing might relate to and potentially aid decision-making. There is controversy over whether framing should be used by physicians, but I argue that framing is inevitable. As such, by not using it, we not only fail to use a valuable communication tool, but might even harm patients. Because there is no way to neutrally

frame, that framing must occur either positively or negatively, by refusing to frame positively to help enforce a recommendation, the physician inevitably frames negatively which may sway the patient towards an undesired result.

In the last chapter of my thesis, I conclude by bringing together these various strands to propose ways that we can move forward to simultaneously empower physicians, patients and surrogates while also truly respecting patient autonomy.

Chapter 9: Conclusion

This final chapter concludes the thesis by first summarising the thesis and reiterating its contributions to understanding how institutional policies and culture influence how physician trainees understand and operationalise the ethical principles of autonomy and best interest. I follow this with policy and practice implications. Based upon the findings of this thesis, I believe that the medical profession needs to recalibrate the way that physicians understand and process autonomy in practice and reform medical education such that we continue to keep medical trainees engaged with the lay world as they go through the medical education process. Policies that focus more on best interest decision-making rather than solely autonomy appear to give physicians the space to consider autonomy more carefully while also encouraging trust and open communicative practices. I then follow with a discussion of the limitations of this study and potential future directions.

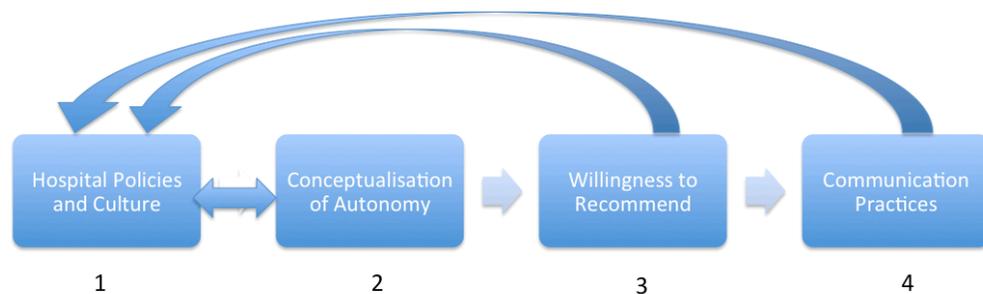
Section 9.1: Summary of the Thesis

Americans are not dying well, but little attention has been paid to the effect of hospital culture and policy and social structure on the way we experience death and dying. In this thesis, I argued that local institutional cultures and policies might influence how physicians conceptualise ethical principles relating to patient autonomy. I described how this might ultimately influence their willingness to make recommendations and how they communicate with patients regarding DNR and end of life decisions.

This thesis was based on a limited sample of 58 physicians at four hospitals in the US and UK. As is usually the nature of qualitative inquiry, it was never the intention to claim that the findings can be generalisable to all US or UK settings or the medical profession more broadly. The study throws a spotlight on four hospitals and draws out some important differences between them and the role of some of the doctors working in those hospitals. However, these findings are still instructive. The dilemmas posed by the systems for the

physicians practicing medicine in them are sociologically interesting in themselves and may well occur in similar or different configurations in other institutions. These findings describe a set of physician attitudes and behaviours that potentially arise from institutional cultures and policies. However, my sample is limited and these findings need to be read against that.

This conceptual framework below, which I first introduced in the Introduction, outlines the pathway by which hospital cultures might ultimately influence how physicians communicate end of life decisions with patients:



Although there was significant within-institution variation with a diversity of responses amongst respondents, there were general patterns that emerged throughout the interviews. In this interview study, there appeared to be a dichotomy between autonomy focused institutions and best interest focused institutions where trainee physicians at autonomy dominant institutions developed a more simplistic notion of autonomy that defined autonomy to merely mean giving choice. Ironically, a simplified ideology of autonomy to mean offering unlimited choice without ensuring understanding or providing guidance, actually runs counter to the goals of respect for autonomy.

This might result in harm by overwhelming the patient and lead to poor decision-making inconsistent with the patients' goals and values. Because trainees at autonomy dominant institutions felt that the way in which autonomy is honoured is by giving "unbiased" choice without influence, these trainees felt less willing to provide recommendations against resuscitation in clinical situations where the likelihood of survival was negligible. In contrast, at hospitals where the focus remained on the patients' best interest, there

appeared to be more freedom and flexibility to focus on a discourse of care rather than that of just choice.

It appeared that the trainee physicians in my study experience significant moral distress over treatments at the end of life that they believe to be overly aggressive, including resuscitation that believe to be futile. Although not sufficiently experienced to feel comfortable prognosticating, these trainees still recognised cases where survival would be unlikely. They would then either consciously or subconsciously change the way they communicate resuscitation options with patients depending on their assessment of the patients' prognosis. While framing and persuasion are appropriate and important tools in medical communication, because these trainees did not feel comfortable making recommendations, they instead reverted to more manipulative means of communications.

In patients whom they believed survival would be unlikely, trainee physicians at the autonomy dominant institutions in my study described resuscitation in a graphic manner, emphasizing the bodily harm that would be committed. They did this not to provide information but rather to discourage the patient or surrogate from choosing resuscitation by viscerally repelling them from it. I explored this from a Habermasian perspective, drawing upon his Theory of Communicative Action to demonstrate how these strategic forms of communication disempowers patients. Trainees who used graphic descriptions to discourage demonstrate systematically distorted communications rather than open communicative action, which prevented the patient from engaging with the physician at an equal level.

These trainee physicians felt powerless on an individual and, but they had also been manipulated by the system (in the Habermasian sense) to act with power over the patient. As a result of the sociological shifts in the physician profession over the past several decades, the traditional sociological interpretations of physicians' powerful imposition of the voice of medicine onto the patient may be somewhat imprecise. One must also recognise the way in which the physician herself has been colonised by the voice of medicine which then drives the physician to then act as the system that colonises the

patient's lifeworld. The influence of the system on physicians encourage them to revert to unconscious systematically distorted communications which then drives the act of domination underground. This piecemeal fulfillment of autonomy in a disjointed manner gives the illusion of autonomy in the most detrimental of ways by disempowering doctors to do what's best for patients while not transferring this power over to patients by giving them true autonomy.

Interestingly, none of these four institutions required that physicians refrain from giving recommendations. In fact, all four institutions' policies state in their DNR policy that the physician must consider the patient's prognosis and make a recommendation. New York State policy, the policy that is the most stringently focused on autonomy, does require that a physician perform resuscitation if the patient or surrogate requests it, but even that policy does not require that a physician refrain from making a recommendation. These trainee physicians were generally not aware of the policy, but due to the cultural milieu of their institution, they had an overall sense of how things were done, which they assumed reflected the policies they had never read. Trainees at hospitals that prioritised autonomy, essentially over-interpreted policies and felt shackled to an exaggerated form of autonomy in ways that did not occur at best interest focused institutions.

Although trainee physicians appeared to be influenced by local cultures and policies, experienced physicians at all four sites appeared to be willing to make recommendations against resuscitation where appropriate and did not have an oversimplified conceptualisation of autonomy. They understood that a key facet of respecting autonomy included guiding the patient or surrogate by providing their clinical expertise. It seemed that as physicians become more experienced, they develop a professional confidence that allows them to feel empowered to act according to their own moral compass, despite policies or cultures that incentivised not doing so. They have learned through experiences with patients – what worked and what didn't – that the idea of autonomy as merely giving choices is overly simplistic and potentially harmful.

While the initial intentions of autonomy derived from the moral philosophy of Kant and Mill, and adapted into principlism were rigourously thought out and may contribute to

patient empowerment, the theory of autonomy has been poorly translated into clinical practice. The current forms of autonomy practiced at autonomy focused institutions in the United States merely play lip service to the original ideas of autonomy, resulting in an alienated physician patient interaction where the physician is able to use autonomy as a way to distance oneself from the responsibility for the consequences of treatment decisions. While autonomy was intended to empower patients, thrusting potentially unwanted decisions onto patients without giving them the tools to make informed decisions only disempowers. The use of systematic strategies to manipulate patients into making particular decisions drives acts of domination underground so that power is still exercised, but in a covert manner.

It is of course important to acknowledge that the processes and systems described in this thesis, which were the main focus of this investigation, take place in a broader socio-cultural context. Factors that have not been explored in depth here, such as health care financing structures and incentives, the technological development of new technologies that sustain life, and legal discourse at the state and national level, provide a broader context and interact in various ways with the processes described.

For example, insurance systems might have some influence on clinical decision-making interaction. However this is not a simple matter. Insurance based versus state-based health systems may influence individual physicians' ethical thinking and practices surrounding DNR decision-making. In sections 6.4.3.2. and 9.3 above I considered how a state-based system (UK) versus insurance-based system (US) affected physicians' understanding of justice in their ethical consideration.

However my auto-ethnographic experiences in American academic medical centres, suggest that finances and insurance status plays a surprisingly small explicit role in DNR and treatment decisions overall. The ethos and rhetoric in American academic centres has always appeared to be one where money should never be an issue. For house staff and attendings, day to day clinical decisions for individual patients in the hospital is to a significant degree sheltered from considerations of the ability to pay. Financial pressures

appear to be reflected in less direct ways such as pressures from the administration such as efforts to decrease length of stay. These kinds of complexities remain to be described in detail. It will therefore be an important in the future to explore the extent to which financial incentives might drive hospitals towards more aggressive care for profit generating purposes for example. The other broader issues too deserve further consideration and are rich areas for further research.

Section 9.2: Policy Implications

While we should never look back at and over-sentimentalise the medical paternalism of days past, I believe that the pendulum has swung too far towards a focus on patient autonomy in the US at the expense of other important principles such as acting in a patient's best interest and respect for person. Ethical norms in American medicine today reflect an ideology of autonomy, which leads trainees towards an unreflective simplistic interpretation of autonomy narrowly focused on choice. Rather than offering a menu of choices, a more satisfying strategy would include shared responsibility to develop a treatment plan that balances clinical risks and benefits in ways that are most likely to honour the patient's goals and values. Autonomy should mean more engagement, not less.

This feedback between macro-sociological patterns and the micro-sociological interactions reflect Giddens' Structuration Theory. Here, we see that the original positive intentions of mitigating physician paternalism inadvertently became warped into a system that eventually became constrained by a distorted interpretation of autonomy.

Recognition of this problem allows us to determine ways to recalibrate the way we operationalise autonomy by focussing on the way social structures, policies, and cultural norms influence the way that physicians interpret and act upon the ethical principles of autonomy and beneficence. I will now outline two areas of focus for potential policy implications:

1) Change policies to focus more on best interest decision-making rather than solely autonomy. This gives physicians the space to consider the patients' best interest, as well as encourage trusting relationships and compassionate care.

I believe that policies focused more on best interest decision-making would allow physicians the space and liberty to reflect upon ethical principles and align them with their own moral compass. Physician trainees at best interest focused institutions appeared more able to balance and honour both autonomy and beneficence whereas physician trainees at autonomy focused hospitals often felt conflict between the two principles that required them to prioritise autonomy at the expense of beneficence.

Here we must also note the powerful influence of the hidden curriculum and cultural norms in shaping beliefs and behaviours. Physician trainees in the US come from medical schools across the country, and yet even after a short period of residency training, they appeared to have embraced the cultural norms of their residency institution. These trainees were often aware of the differences between their medical schools' culture and their residency training institution's cultures and were generally able to reflect upon them cogently.

Autonomy in the US tends to be simplified to a principle of choice, especially in a busy hospital setting when doctors do not have the time and space in their busy work flow to deliberate on ethical principles. Autonomy can be interpreted as the right to have "everything done." In contrast, best interest decision-making inherently focuses on care, as the ethical focus is on what is best for the patient. In contrast to prior conceptions of paternalism, modern interpretations of best interest require physicians to acknowledge and account for the patients' goals of care and values to determine this best interest. Furthermore, I argue that best interest decision-making should focus on beneficence of process rather than merely of outcome, as I described in Chapter 6.

By focusing on these more humanistic values through best interest decision-making, rather than a detached systems-oriented prioritisation of autonomy, the medical establishment might be able to focus on care and compassion rather than a discourse of choice. A best interest focused approach also necessitates a degree of trust between the doctor and patient, as well as trust of the society in the medical profession. Whether the medical profession has earned the trust of society is a point of contention and something the medical profession needs to continue to improve.

However, important first steps include establishing a mutual trust and belief among patients and the general public that physicians generally are genuinely concerned about providing the best care to their patients, rather than interested in their own incentives. We must recognise that frequently it is lack of time, stress, and bureaucracy that prevent optimal care rather than physician malevolence. Physicians must in turn empathise with patients and understand the emotional, mental and physical toll of illness and compassionately and patiently guide them towards treatments that fulfil their goals and values. Rather than attributing problems of overly aggressive care and barriers to end of life care on demanding or difficult patients, physicians should reflect upon and understand their own role through poor communications and structural incentives within the health care system that encourage overly aggressive care (You et al. 2015).

2) Reforming medical education such that medical students and physician trainees maintain their engagement with their own lay experiences outside of the world of medicine. Theoretically speaking, medical trainees need to stay engaged with their lifeworld and resist colonisation by the system.

In chapters 7, I discussed the moral distress experienced when the physician trainees interviewed felt powerless to withhold perceived futile treatments, which lead to alienation and meaninglessness in their labour. I subsequently elaborated in Chapter 8 that this alienation and lack of meaning in part stemmed from as well as contributed to the colonisation of the physician trainee's own lifeworld. The inability to recognise herself in her activities and find a meaningful relationship between the physician and her own activities encourages both self-alienation and professional alienation.

Jaeggi emphasises that unalienated work requires that the individual produces and realises herself in her work (Jaeggi 2014). This sentiment emphasises the importance of caring for the physician's self before the physician can care for others, as the two are inherently intertwined. As such, interventions to improve compassionate care and humanism must begin by caring for the physician herself. This is not a selfish goal, but rather addresses a root cause of the problems we see in health care today of unempathetic doctors, bureaucratic medicine, physician burnout, and much more. As I described in

Chapter 8, the colonisation of the physicians' lifeworld is what ultimately leads to the colonisation of the patient by the system and voice of medicine.

During the course of my PhD research, several senior American physicians had remarked to me that addressing moral distress in physician trainees was unimportant because it is a temporary event in a physician's life marked by a distinct ending. What they have failed to acknowledge is the lasting impact of moral distress on individual physicians and the culture of medicine as a whole. Moral residue is a lasting and powerful consequence of unaddressed moral distress which has been defined as "that which each of us carries with us from those times in our lives when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised (Epstein and Hamric 2009)." Individual acts of alienation, detachment and empathy loss further aggregate to reproduce a culture of dispassionate care and stoicism in the medical profession.

I hypothesised earlier that experienced physicians felt comfortable making recommendations because they had both the professional confidence and experience to act according to their moral compass and not be swayed by ideologies that blindly pursue an ethics of choice. Perhaps these physicians maintained the empathy and compassion to continue guiding patients even when the easier choice may have been to give them whatever they wanted. Much of this can be attributed to improved communication skills that come with experience and having more time to talk to patients than physician trainees. This trainee reflects on her time as an intern and offers her regarding the challenges inherent in DNR conversations as an inexperienced physician:

"I think when you first start out when you're an intern, you don't really know what you're doing. It's really hard to have a conversation with a family member about the prognosis when you've only taken care of X number of patients and maybe none with that particular disease. You don't want to overstep. Then I think that ratio of certainty to uncertainty goes into the other direction. You really don't know because you just don't have the experience. You get that by seeing hundreds and hundreds of patients. If you really don't know that's usually when

you can focus more broadly on their goals, which is what I think I used to do.”
(UW, PGY-6: C6)

As a trainee at UW, she does describe how this lack of prognostic uncertainty encourages her to focus more broadly on the patients’ goals and values, which is actually the strategy more often taken by experienced experts rather than trainees. This emphasises the fact that using a goals of care approach does not require experience and can be successfully accomplished by inexperienced trainees, particularly when they feel uncomfortable prognosticating.

However, another factor might be that experienced physicians have re-learned how to engage with the lay human world and reconcile the professional jargon and mentality of medicine with that of real world interactions. Studies have demonstrated how end of life care communications or ethics experts in end of life care conversations “practise what they preach,” and spend more time compassionately listening than talking in comparison to primary care physicians who did not specialise in end of life care (Roter et al. 2012). They engaged more with the lifeworld than with the voice of medicine, talking more about psychosocial and lifestyle issues than biomedical treatments. The manipulative graphic descriptions that physician trainees used blocked the lifeworld and engaged in strategic rather than open communication patterns. They exert medical power over patients by using strictly medicine jargon, which blocks opportunities for the doctor and patient to engage mutually in the familiar language of the lay world.

While educational training modules are undoubtedly important, perhaps prevention can be more effective than treatment. Rather than intervening late after colonisation of the physician’s lifeworld has already occurred, we should find ways to reform medical education to continue engaging the lay world during medical training so that trainees never lose their engagement with their personal experiences. Medical students often cite their desire to help people in their motivation to pursue medicine. This is oftentimes motivated by human compassion and empathy, but the indoctrination process of medicine replaces this humanism with a jaded detachment (99 2015).

This year at the American Society of Bioethics and Humanities, a session leader on using theatre improvisation techniques to teach medical students how to communicate with patients joked, “Medical students all know how to be human beings but as soon as they put on the white coat, they become awkward.” Perhaps the medical profession needs to look past the idea of *Aequanimtas*³⁴ and consider that it might be better for both the medical profession and for patients that physicians not lose themselves and thus their sense of humanity and compassion during medical training.

Section 9.3: Limitations

This study has several limitations. I have broadly divided this section into issues surrounding limitations related to myself as a researcher, limitations in methodology, and limitations related to the hospital sampling. The limitations section is naturally the stepping-stone for the next section on future directions.

Section 9.3.1: Self-reflexivity as a Researcher

Given my position as an insider, and especially as a former resident at Columbia, a PhD candidate at the University of Cambridge, and a former medical student and current general internal medicine fellow at Johns Hopkins, social desirability bias may have influenced answers. I have had prior interactions with several of the respondents at both Johns Hopkins and Columbia, some as resident colleagues and some as superiors (attendings). Regardless of whether I had past interactions with respondents, I noticed distinct differences in the ways I interacted with physicians of differing age and seniority.

I could not help the fact that interactions with residents and fellows were more collegial and relaxed, whereas interactions with the more senior physicians were more formal and reflected a clear hierarchy. This was inevitable given my age and rank. I found it especially notable when speaking with a former attending physician at Columbia, who

³⁴ Unperturbability, coolness under fire (Johns Hopkins Osler Medical Residency 2014)

brought out his iPad and started drawing survival curves and charts to describe some of the evidence he brought to support his statements – something I recalled him doing frequently during ICU rounds when I was a resident.

I also noticed that some physicians who had some academic interest in this area had difficulty engaging their own personal understandings rather than evidence from the academic literature. For example, if I asked them for their impression on a particular trend, rather than describing their own experience or thoughts, they would instead cite evidence in the literature regarding that trend. In these situations, I attempted to redirect them towards a more personal reflection with varying levels of success. It was interesting to see how immersion in academic research distances oneself from reflecting upon the more personal aspects of these issues. Perhaps this in some ways reflects the colonisation of these physicians' lifeworlds. It was easier to cite scientific studies of their experiences rather than reflect upon their own narratives and their years of training educated them in the way to detach themselves from this personal inquiry in an evidence-based manner.

A related limitation was differences in sampling protocol amongst institutions. Because I had a history and established network at Johns Hopkins and Columbia, it was significantly easier to recruit physicians for the study. For example, because I knew the house staff schedule, and the login information to access their call schedules, I was able to search call schedules for residents who were on easy electives, access the intranet to find the resident's e-mail addresses and directly e-mail house staff who were likely to have more time for interviews. I also had institutional knowledge of the faculty so could specifically recruit physicians to provide for a diverse array of opinions.

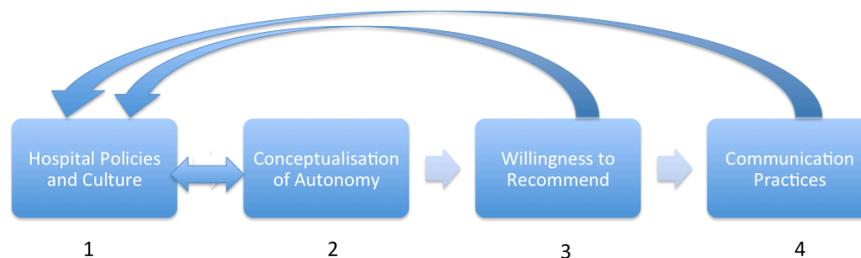
My knowledge of Addenbrooke's and the British medical education system was much more limited. As such, I did not have easy access to insiders' knowledge that made recruitment easier. Similarly, at the University of Washington, I was dependent upon the help of Randy Curtis and Jimmy Hoard for recruitment. I only had two days to interview at UW and am indebted to them for helping to make this study possible at UW. Dr. Curtis is a pioneer in palliative care and is the section head of Harborview's Centre for

Palliative Care Excellence. As such, recruitment of physicians was remarkably easy for him as he had more clout at his institution than I did at mine. I had significantly less control though, over whether the physicians he recruited were different from those not recruited.

I discussed earlier that as an insider, it was inevitable that I came into this project with my own preconceptions and views. It was important to maintain stringent self-reflexivity and recognise how my own biases could effect the way I conducted interviews and interpreted data. I was very cognisant of the need to ask questions in as neutral a manner as possible, without biasing by framing the question in a certain way. The evolution of my own thinking I believe reflects the rigour of my attempts at minimising bias and preventing my preconceived biases from influencing my data. The fact that I initially came to this project intending to pursue a comparative analysis of the US and UK, but later realising after my UW interviews that local cultures play a dominant role illustrates my willingness to let the data guide my direction and focus.

Section 9.3.2: Limitations on the Methodology

Interviews with physicians do not reflect actual practices but instead reflect physician's opinions, attitudes, and their perceptions of clinical practice. As the first portion of this thesis primarily concerned about how physicians conceptualise ethical principles, this is less relevant of a limitation, but rather a purposeful intent of the project (boxes 1 and 2 below).



This limitation becomes more relevant in the relationships detailed in boxes 3 and 4 of this thesis, their willingness to recommend and their communication practices. I was only able to determine what they believed they communicated in end of life conversations rather than what they actually said. Further validation for what is actually done in practice rather than what respondents state they do will be an important future step.

Although the difference between more and less experienced physicians' willingness to offer clinical recommendation could reflect more traditional paternalistic attitudes among older respondents, my study suggests a different explanation as trainees at the best interest focused hospital had similar attitudes to experienced physicians in those hospitals. It was also beyond the scope of my study to interview nurses or other health care practitioners, as well as patients or surrogates. The lack of these alternative voices is a significant limitation and an area of potential future study.

The research methods employed in this study did not allow for a determination of the exact interaction between policies and culture. My informal observations lead me to hypothesise that the cultures of the hospitals in New England and the UK are strongly influenced by policies. In the UK, national policies govern practices at local hospitals, although local variations are still known to exist. In New York, state laws very strongly defend patient autonomy and hospitals are required to be adherent. As such, policies have a greater effect on these hospitals' cultures than vice versa. In contrast, from informal conversations with key informants at the hospital in the Pacific North-West, it appears that their policies were developed to reflect their existing hospital culture. This heterogeneity illustrates the complexity of the interactions between cultures and policies at different institutions. Alternative methodologies such as ethnographic work would allow for further determination of the relationships between institutional cultures and policies.

Section 9.3.3: Limitations Related to Hospital Sampling

The research objectives and hypotheses generated in this study evolved organically through the interviews based on the themes and patterns that emerged from initial

interviews which had a profound influence on the subsequent course of the project. As described in the methods section, this project began as a cross-cultural comparison of the US and UK through two sites, Johns Hopkins and Addenbrooke's Hospital in Cambridge. My initial research question was to understand and explore how US and UK physicians differed in their prioritisation of best interest and autonomy in DNR decision-making. It was only after interviews at Hopkins revealed to me differences in perception between my own experiences at Columbia and Hopkins that I decided to expand my interviews to Columbia. Subsequently, we decided that it would be important to have a third site in the US whose practices might be more similar to the UK (i.e. University of Washington).

Several limitations emerge as a result of this organic hospital sampling strategy. Although my study highlights the importance of institutional cultures, there may be other internal and external factors that influence physician attitudes and communication practices regarding end of life decision-making. For example, it is possible that the backgrounds of patients and the cultural milieu around which these hospitals are located influence aggressiveness of care, attitudes towards death, and degree of deference to authority.

For example, I highlighted the distrust prevalent in African Americans communities due to the medical establishment's unfortunate history of unethical experimentation and inequitable care in this population. Given that Johns Hopkins serves a predominantly low income, inner city, African American population, mistrust runs high and may influence physicians' behavior regarding choice and resolving conflict. In contrast, UW's location in the Pacific Northwest results in a higher prevalence of Asian American patients, who may harbour more traditionally Asian views that are deferential to authority and who prioritise family-centered decision making. Columbia's patient population is predominantly Dominican Republican and Catholic. Columbia is also near predominantly Orthodox Jewish neighborhoods. Jewish beliefs focus on the sanctity of life and that every second of life matters. Both of these populations tend towards religious view of life and death, which tend towards more aggressive care. Addenbrookes Hospital is located in the highly educated and affluent city of Cambridge, although there are areas of East

Cambridge that are economically depressed.

There are cultural differences and stereotypes between the US and UK which have also influenced my results. These have not been legitimated through academic research, but are nonetheless present and influential. In informal conversations with British physicians who had clinical experience in the States, they believed from their experiences that UK patients were indeed less pushy, less demanding, and more grateful. Many physicians saw this behaviour as reflective of a more collective ethos in the UK, which can be contrasted with the more entitled behaviour of Americans.

More generally, I have noticed striking differences between the US and UK during my own experiences living in the UK for six years. The cultural stereotypes of loud Americans who feel entitled to choice and are much more willing to demand them stands in contrast to the more reserved and politely tolerant nature of the British. While both may feel just as dissatisfied with a particular issue, the American is more likely to complain whereas the British person would be more likely to grumble internally but say that everything is fine (Anon 2012). These cultural factors may contribute to less overt conflict between doctors and patients for reasons unrelated to medical communication or practices. Future studies comparing hospitals within the same geographic location that prioritise autonomy and best interest would help mitigate this confounding factor.

Institutional culture is also a very broad concept. There are many factors, which contribute to an institution's cultural milieu. I've chosen to focus on the ethical dichotomy between autonomy and best interest. As I discussed previously, this can be influenced by other factors such as receptiveness to palliative care, ethics consultation practices, degree of shared decision-making, leadership, national culture, educational curricula, and many other things.

For example, is UW more similar to British hospitals because they also prioritise best interest? Or is it because UW has a very palliative care friendly environment, with significant commitment within senior leadership to palliative care? Britain is far ahead of

the US in uptake and integration of palliative care into the health system. Perhaps the overarching philosophy of palliative care may be a contributing factor. Although I believe palliative care friendliness may be a factor, the reason I focused more on ethical principles rather than palliative care friendliness in this study is because the specific responses demonstrated a link between their willingness to recommend and their understandings of autonomy.

Similarly, institutions might differ by the way they think about care on a spectrum of aggressiveness of care. For example, Barnato *et al.* studied two institutions within the same hospital system that were of high intensity and low intensity with regards to norms surrounding use of life sustaining therapies (Barnato et al. 2012). Future studies are needed to more fully dissect the potential interactions between palliative care environment, aggressiveness of care, ethical thinking, and communication practices.

Other sampling limitations include the fact that I have only interviewed physicians at academic medical centres. I have not included community hospitals or for profit hospitals in this study. As I described above, I believe the exclusion of for profit and community hospitals have helped focus my attention towards the sociological interactions without the potential confounding factor of economic incentives.

Section 9.4: Changes in Institutional Culture and Policy During the Study

Time does not stand still during the course of a PhD; cultures, attitudes, and policies are ever evolving. As I remarked in Chapter 4, there were many changes that occurred at a national and institutional level, which may have influenced results. Most notably, UK policies on DNR decision-making changed following the completion of my interviews as a result of the Janet Tracey court decision, which required that physicians consult with patients regarding these decisions. The unilateral physician decision-making previously permitted was no longer possible. This does not substantively affect my study or outdate it, as I was interested in the UK as a site that offered a greater extreme of physician authority than permitted in the US, rather than a comparative analysis. Indeed, it was a

good thing that I conducted my study prior to this policy change. The Janet Tracey did occur during my study and thus did raise awareness of issues of DNR decision-making at Addenbrooke's Hospital and may have possibly influenced respondents' answers.

Institutional level changes such as the UFTO project at Addenbrooke's, Tom Smith's arrival to Hopkins and the establishment of the Palliative Care Program, as well as many of the interventions research occurring at Randy Curtis's group at UW may have also affected respondents' attitudes and awareness of palliative care issues. As I emphasised earlier, society and culture is constantly evolving and its aggregate effects influence and mould the very institutional cultures that I sought to examine. As such, rather than limitations, I saw these instead as influencing factors that dynamically contributed to my respondents' understanding and response to these issues.

This relates to another influential factor, which is the presence of individuals whom through their leadership had profound influences on their hospital's culture. I was struck during my interviews at UW, the degree to which respondents referred to Randy Curtis's leadership and research in palliative care and how that influenced their thinking on the issues discussed. The University of Washington's Palliative Care Centre of Excellence recently received a \$10 million endowment from the Cambia Health Foundation to advance palliative care leadership and research (University of Washington 2014). This award reflects UW and Randy Curtis's excellence in this field, which may make UW an exceptional institution that is not necessarily representative of a more typical institution that is best interest focused. Similarly, in the methods section (Chapter 3), I described the changes and palliative care initiatives that occurred at Johns Hopkins and Addenbrooke's that may have affected the culture and evolution of palliative care at these institutions.

Section 9.5: Future Directions

I have accepted an Assistant Professor faculty position as a clinician investigator in the Division of Hospital Medicine at the University of California, San Francisco (UCSF)

starting 1 October 2015. During this next phase of my academic career, I will build upon this PhD thesis to further validate the hypotheses generated in this qualitative inquiry.

Naturally, my observations of the limitations of my study have been a jumping off point for potential future studies, which will help to further elucidate the influence of hospital cultures and policies on physicians' ethical thinking, clinical reasoning, and communications practices. I have divided this section on potential future steps into two strands: generalizability of results and culture change, communications, and framing.

Section 9.5.1: Further Descriptive Studies Needed to Determine Generalisability of Results

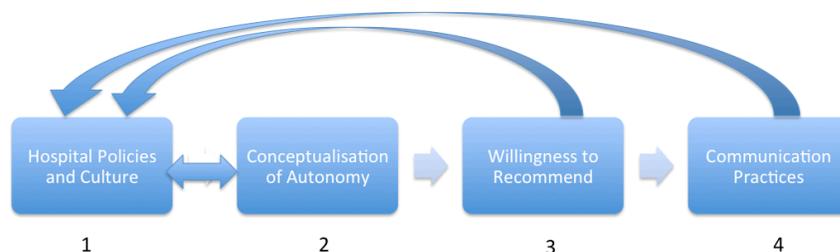
Qualitative studies are helpful in generating hypotheses, which can be later be tested for generalizability through mixed methods approaches. A limitation of the study was the potential confounding factor of cultural diversity between different geographic regions. The cultures between the US and UK are most obvious, but there are also cultural differences between New York, Baltimore, and Seattle. Different demographics such as a prevalence of Asian-Americans versus Hispanics versus African-American populations also influence doctor patient relationships, especially in relation to trust and norms of patient autonomy. Further descriptive studies are also needed to obtain other voices such as that of nurses, patients, and surrogates.

As such, I hope to conduct a future mixed methods study between hospitals with expected differences in institutional culture but in similar geographic regions. As I will be working in California, I will focus on institutions within the same state of California. I have already established links between key faculty members at UCLA (Neil Wenger) and Stanford (several faculty members in the ethics and palliative care departments) for future collaborations. Barnato, *et al.* previously established variations in end of life ICU use between hospitals with different advanced care planning norms (Barnato et al. 2014). The two hospitals used in this study were UCSF (low intensity) and UCLA (high intensity). From informal conversations with colleagues at both institutions, it seems that there are

differences in approaches to futility and possibly autonomy as well, with UCLA possibly being more aggressive (Huynh et al. 2013).

More pilot studies would obviously be necessary, but this remains a practical and promising possibility. As I mentioned earlier in this conclusion, I believe that a good nexus to establish culture change can be ethics and palliative care consults. In addition to selecting hospitals based on policy differences, I am also aware of very different usages of ethics consultations between Stanford and UCSF. Stanford has a very busy ethics consultation service whereas UCSF's appears underutilised. Some combination of these three institutions might be a good foundation for a future study examining institutional variations within a similar geographic region.

Future studies to further validate my findings regarding the influence of institutional culture and policies on DNR decision-making could more closely examine each step of the framework I described earlier:



To further validate steps 1 through 3, I could conduct surveys of a greater number of trainees within the institution of choice on their attitudes towards autonomy and other ethical principles and their understanding of their hospital's policies and cultures, as well as their willingness to recommend using clinical vignettes. I could also do a combination of a smaller number of semi-structured in-depth interviews and ethnography to get an understanding of the hospital's culture with respect to these issues.

My study focused on physicians' reports of what they would say during end of life conversations, rather than what they actually said. My hypotheses on graphic descriptions and manipulative language will need to further exploration in order to determine actual

practices. As such, to further explore steps 3 to 4, I could audiotape end of life conversations between physician trainees and patients/surrogates to examine actual communication strategies used and the degree of conflict experienced.

Section 9.5.2: Potential Future Interventions: Communication Pathologies and Culture Change

More descriptive studies are needed before interventions can be designed. I must first emphasise the inherent tensions between sociology, which often seeks to identify and describe social interactions, and clinical medical sciences, which is more focused on designing interventions to improve medical care. This will be a tension I will need to come to terms with and balance as my career moves forward. One major challenge is how one can change culture, and whether changing policies can potentially influence culture.

How can we use insights from Habermas's theories to improve how physicians communicate with patients? Habermas believed that "theory and practice are intimately connected in the process of self-reflection. Through self-reflection, individuals can become aware of forces, which have exerted a hitherto unacknowledged influence over them. Thus, the act of knowing coincides with the act which achieves the goal of the interest, namely emancipation from hypostatic forces (Held 1980: p 318)." From this self-emancipatory perspective, better understandings of these communication pathologies and the sociological forces that drive these attitudes and behaviours have the potential to change behaviour.

One important finding in Barry *et al.*'s analysis was that some doctors switched communication strategies between patients, suggesting that their behaviour might be amenable to change. They suggest that if doctors could be sensitised to these communication patterns and develop an understanding of the importance of dealing with lifeworld concerns, especially in conditions such as chronic physical conditions, this might enable doctors to better utilise *mutually lifeworld* communication strategies.

There is a need to better educate medical trainees, especially at autonomy dominant hospitals of the fallacies of this communication strategy and help them understand how this does not achieve the goals of autonomy and medicine in an honest and trustworthy way. Physician trainees are easily influenced at this stage of training and absorb behaviours and attitudes that are reflective of the culture and role models they experience. Simply an understanding of ineffective communication behaviours that were either subconsciously enacted or incorrectly taught might go far as a first step in improving end of life care outcomes and satisfaction.

What is as important though, is ensuring that structural constraints such as lack of time and space to reflect upon these issues are simultaneously addressed. Without addressing the hidden curriculum and structural constraints, interventions focused on the individual are unlikely to promote long-standing change. Another potential area for future interventions might be in the realm of language, heuristics and framing, although more ethical inquiry needs to be pursued prior to this given the controversial nature of libertarian paternalism and its uses more generally as well as at the end of life.

Section 9.6: Closing Thoughts

This experienced attending summarises his interpretation of how changes in the medical profession changed the way autonomy was fulfilled and its unintended consequences:

“It’s what makes the decision-making easier. In the old days, paternalism made it easier. You didn’t talk about things with patients, but today you can’t do that anymore. You still want to make the decision-making easy. You’re still under the gun as an intern. You still have too many things to do and too few minutes to do it in. And so they’re going to find the next easiest way. They can’t get away with paternalism anymore, so they just go in they say, ‘yes, no we’ll do whatever you want’, and they don’t spend a lot of time on the decision-making.” (Hopkins, Attending of Oncology: A2)

This quotation demonstrates how individuals oftentimes learn how to take the path of least resistance to produce unintended consequences of policies and actions. While policies prioritising autonomy were intended to empower patients, by equating autonomy to unlimited choice, patients risk again being unempowered by having responsibility for decisions they do not have the understanding to make, thrust upon them. This thesis focuses on how these sociological shifts resulted in these unintended consequences of social action, which subsequently form social constraints that encourage reductionist ethical thinking, physician moral distress and alienation, and manipulative communication pathologies.

In recent years, the medical profession has embarked in a degree of soul searching as it increasingly recognises the degree and impact of decreased empathy, compassion and humanism. While the Accreditation Council for Graduate Medical Education's (ACGME) requirements for professionalism reflect an ideal of compassion and care, the hidden curriculum of medical training encourages something very different. On the wards, these "soft" characteristics of care and compassion take the back burner to medical knowledge and expertise. While of course medical knowledge and expertise is of critical importance, what I argue is that the medical profession needs to recalibrate medical education so that physicians and students are able to maintain their connect with their own lifeworld throughout their medical training.

An important aspect of this is addressing moral distress and the alienation that results from perceived meaningless work (i.e. provision of futile treatments). As I described earlier, this alienation and the relationlessness have similarities to Habermas's concept of the system and lifeworld. Alienated physician trainees are deprived of connections between themselves, the work they produce, and the world. The lasting effects of moral distress in the form of moral residue can subconsciously affect them during the remainder of their professional careers. The emotional detachment that physician trainees learn as a coping mechanism may affect their ability to empathise with patients and on a larger scale, influence the physician profession's ability to deliver compassionate, humanistic care. In order to address the problems in the medical profession of lack of empathy and

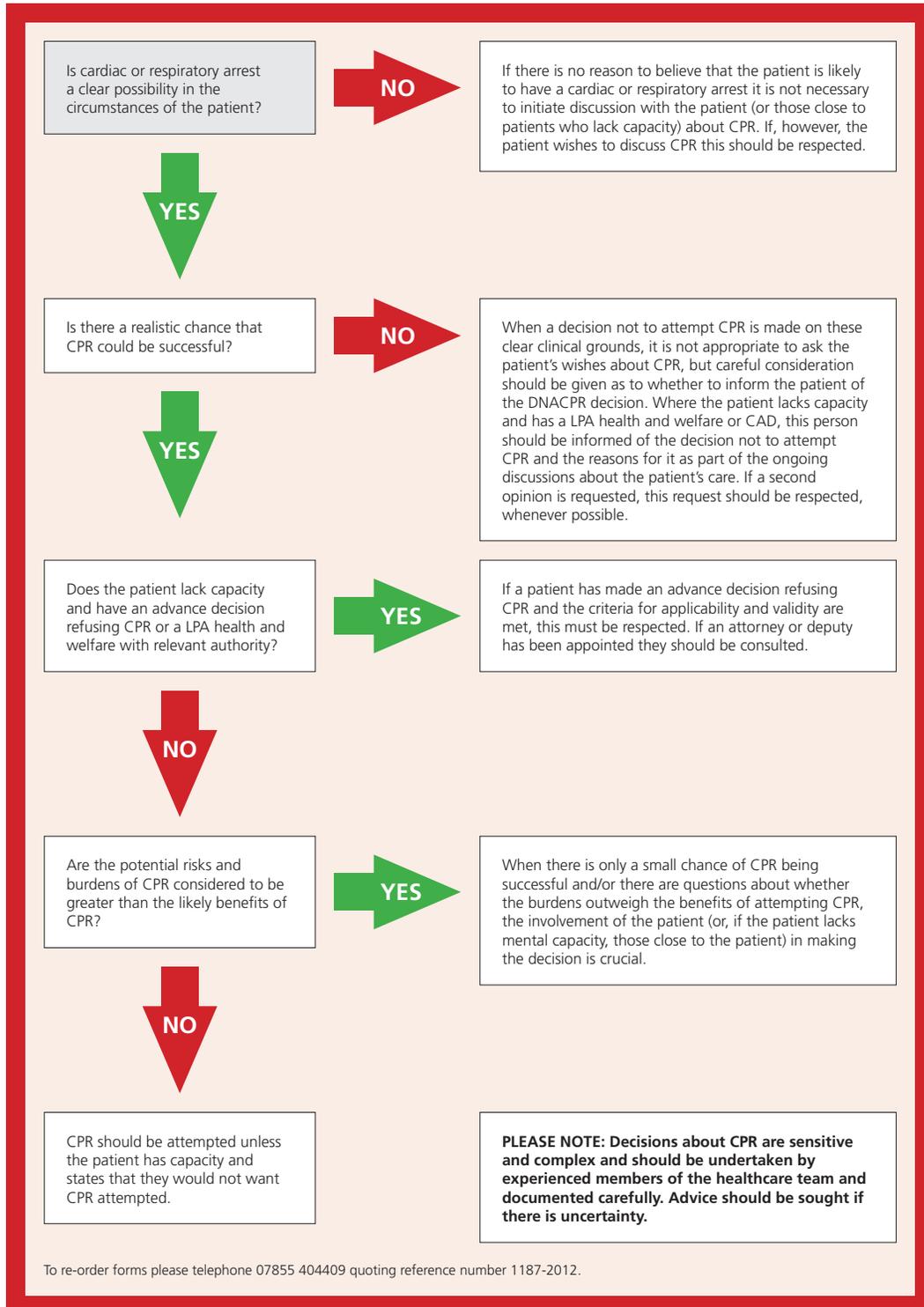
compassion, we must look beyond the superficial and address root causes and influences by institutional cultures and policies.

In the tradition of Habermas and critical theory, an essential component of this project was its self-emancipatory nature. This PhD journey was a very personal one, inspired and motivated by my own moral distress and ethical dilemmas that arose during my medical residency training. I recognised my experiences as a house staff as one without power and control over one's actions. I recognised a physician's power in society and yet, like some of the other respondents in the study, I felt powerless always to do what I thought was in my patients' best interest. It was challenging and painful to realise "that the decision has been made (by a more senior physician or by the team's failure to determine resuscitative status) to 'flog' a hopeless patient and that [I] would be the one doing the flogging (Winkenwerder 1985)."

Through this emancipatory self-reflection, I became aware of the greater sociological forces, which had an unacknowledged influence on the ways that physicians (i.e. myself) practice and communicate. It elucidated some of the root causes of the tensions and conflicts which we grapple with on a daily basis. Understanding how domination is inadvertently realised despite the best of intentions through the use of systematically distorted communication, might allow us to conceive strategies for self-emancipation and consequently foster mutual emancipation for both physicians and patients.

Appendices

Appendix A. NHS East of England's DNACPR Flowsheet for DNACPR Decision-Making



Appendix B. DNR Forms for Columbia New York Presbyterian Hospital

<p>NewYork-Presbyterian The University Hospital of Columbia and Cornell</p>  <p style="text-align: center;">50232</p> <p style="text-align: center;">DNR DOCUMENTATION SHEET #5 ADULT PATIENT WITHOUT CAPACITY AND WITH A SURROGATE</p>	<p style="text-align: right; font-size: small;">IF NO PLATE, PRINT NAME, SEX AND MEDICAL RECORD NO.</p>								
<p><i>Directions:</i> This Documentation Sheet sets forth in consecutive order the steps that must be taken prior to writing a DNR ORDER for an ADULT patient without CAPACITY who does not have a health care agent (see sheet #4) but who has a SURROGATE. Words that appear in all capital letters are defined in the DNR Policy. When completed, this Sheet must be placed in the patient's record.</p> <p><u>Step One</u> The ATTENDING PHYSICIAN must determine that the patient lacks CAPACITY.</p> <p style="text-align: center;">DETERMINATION OF CAPACITY</p> <p>I have examined the patient and have determined to a reasonable degree of medical certainty that he/she lacks the ability to understand and appreciate the nature and consequences of a DNR ORDER, including the benefits and disadvantages, and to reach an informed decision. In my opinion, the cause and nature of the patient's incapacity are:</p> <p>_____</p> <p>and its extent and probable duration are:</p> <p>_____</p> <p>_____</p> <table style="width: 100%; border: none;"> <tr> <td style="border: none;">Signature of Attending Physician</td> <td style="border: none;">Date</td> <td style="border: none;">Print Name</td> <td style="border: none;">M.D. Code</td> </tr> </table> <p><u>Step Two</u> A CONCURRING PHYSICIAN must agree with the determination that the patient lacks capacity. (If the patient's incapacity is due to MENTAL ILLNESS, the concurring opinion must be provided by a physician who is certified or eligible to be certified by the American Board of Psychiatry and Neurology. If the patient's incapacity is due to a DEVELOPMENTAL DISABILITY, the concurring opinion must be provided by a physician or psychologist with special credentials who has been designated by the Director of the Department of Psychiatry.)</p> <p style="text-align: center;">CONCURRING PHYSICIAN'S STATEMENT</p> <p>I have personally examined the patient and have determined to a reasonable degree of medical certainty that he/she lacks the ability to understand and appreciate the nature and consequences of a DNR Order, including the benefits and disadvantages, and to reach an informed decision. In my opinion, the cause and nature of the patient's incapacity are:</p> <p>_____</p> <p>and its extent and probable duration are:</p> <p>_____</p> <table style="width: 100%; border: none;"> <tr> <td style="border: none;">Signature of Concurring Physician</td> <td style="border: none;">Date</td> <td style="border: none;">Print Name</td> <td style="border: none;">M.D. Code</td> </tr> </table> <p><u>Step Three</u> The ATTENDING PHYSICIAN must determine who is the proper SURROGATE. The SURROGATE must be selected from the following list in the order of priority listed. (If there is no qualified SURROGATE and if resuscitation would be MEDICALLY FUTILE, use Documentation Sheet #6).</p> <ul style="list-style-type: none"> a. Court-appointed guardian authorized to make health care decisions; b. a HEALTH CARE AGENT who is available and would be authorized to make a decision regarding CPR if the patient had not previously consented to DNR (Use Sheet #4); c. the spouse; d. a son or daughter, aged 18 or older; e. a parent; f. a brother or sister, aged 18 or older; or g. a CLOSE FRIEND; <p>Name of Surrogate: _____</p> <p>Relationship to Patient: _____</p>		Signature of Attending Physician	Date	Print Name	M.D. Code	Signature of Concurring Physician	Date	Print Name	M.D. Code
Signature of Attending Physician	Date	Print Name	M.D. Code						
Signature of Concurring Physician	Date	Print Name	M.D. Code						
<p>50236 (3/00) 1</p>									

DNR DOCUMENTATION SHEET #5
ADULT PATIENT WITHOUT CAPACITY AND WITH A SURROGATE *

IF NO PLATE, PRINT NAME, SEX AND MEDICAL RECORD NO.

Step Four

The ATTENDING PHYSICIAN must notify the SURROGATE of the determination that the patient lacks CAPACITY. In addition, if there is any indication of the patient's ability to understand, notice must be given to the patient, together with a copy of the Department of Health's pamphlet "Do Not Resuscitate Orders - A Guide for Patients and Families." If the patient is in or is transferred from a MENTAL HYGIENE FACILITY, notice must be given to the facility director.

* If the patient has previously consented to a DNR ORDER, use Documentation Sheet #3.

NOTICE TO PATIENT AND SURROGATE OF LACK OF CAPACITY

a) I have given notice of the determination of the patient's lack of capacity to the surrogate; and
 b) (Check one)

_____ 1. There is no indication of the patient's ability to comprehend such notice and I am therefore not giving notice to the patient; or

_____ 2. I have given the patient notice of the determination.

c) (check if applicable)

_____ I have given notice to the mental hygiene facility director.

 Signature of Attending Physician

Date _____

 Print Name

 M.D. Code

Step Five

The ATTENDING PHYSICIAN must determine that the patient is suitable for the issuance of a DNR ORDER. A CONCURRING PHYSICIAN must agree with the determination.

DETERMINATION OF SUITABILITY FOR DNR ORDER

I have personally examined the patient and I have determined to a reasonable degree of medical certainty that:
 (check as applicable)

_____ a. the patient has a terminal condition; or

_____ b. the patient is permanently unconscious;

_____ c. resuscitation would be medically futile; or

_____ d. resuscitation would impose an extraordinary burden on the patient in light of the patient's medical condition and the expected outcome of resuscitation for the patient.

 Signature of Attending Physician

Date _____

 Print Name

 M.D. Code

 Signature of Concurring Physician

Date _____

 Print Name

 M.D. Code

DNR DOCUMENTATION SHEET #5
ADULT PATIENT - WITHOUT CAPACITY AND WITH A SURROGATE *

IF NO PLATE, PRINT NAME, SEX AND MEDICAL RECORD NO.

Step Six

The ATTENDING PHYSICIAN must obtain consent to the DNR ORDER from the SURROGATE. The consent may be oral or written. Oral consent must be expressed to two WITNESSES, one of whom must be a physician on staff at the Hospital.

WITNESSES' STATEMENT/DECLARACIÓN DEL LOS TESTIGOS

The surrogate has expressed orally in my presence the decision to consent to a DNR Order, subject to the following conditions or limitations (if any): / El Apoderado ha expresado verbalmente en mi presencia la decisión de autorizar una ORDEN DNR, sujeta a las siguientes condiciones o limitaciones (si existen algunas):

Signature of Witness/Firma del Testigo _____

Signature of Physician Witness/Firma del Médico _____

Print Name/Nombre en Imprenta _____

Print Name/Nombre en Imprenta M.D. Code _____

Title/Relationship to Patient/Título/Relación con el Paciente _____

Date/Fecha _____

Date/Fecha _____

Instead of oral consent, the SURROGATE may choose to consent in writing to the DNR ORDER. Such consent must be documented on the form entitled "Consent by Surrogate to DNR Order" attached to this Documentation Sheet. A WITNESS must also sign this form on page 5 or 6.

Step Seven

If there is any indication of the patient's ability to comprehend, and the ATTENDING PHYSICIAN has not determined that the patient would suffer immediate and severe injury from a discussion of CPR, notice of the SURROGATE's decision must be provided to the patient.

NOTICE TO PATIENT OF DNR ORDER

Check one:

- a. There is no indication of the patient's ability to comprehend, and I am therefore not providing notice of the surrogate's decision to the patient; or
- b. I have determined that the patient would suffer immediate and severe injury from a discussion of CPR, and I am therefore not providing notice of the surrogate's decision to the patient; or
- c. Neither a. nor b. apply and I have given notice of the surrogate's decision to the patient.

Signature of Attending Physician _____

Date _____

Print Name _____ M.D. Code _____

DNR DOCUMENTATION SHEET #5
ADULT PATIENT - WITHOUT CAPACITY AND WITH A SURROGATE *

IF NO PLATE, PRINT NAME, SEX AND MEDICAL RECORD NO.

IF THE PATIENT OBJECTS, A DNR ORDER MUST NOT BE WRITTEN.

* If the patient is in or is transferred from a MENTAL HYGIENE FACILITY, notice of a surrogate's consent to a DNR ORDER shall be given to the facility director prior to issuance of a DNR ORDER. Notification to the facility director shall not delay issuance of a DNR Order. If the facility director concludes that the patient has capacity or that issuance of a DNR ORDER is otherwise inappropriate, the facility director shall submit the matter to the DISPUTE MEDIATION SYSTEM.

Step Eight

THE ATTENDING PHYSICIAN must promptly do one of the following:

- a. issue the DNR Order and either write the order himself or herself or direct the house staff to do so; or
- b. if he/she has actual notice that someone on the SURROGATE list objects to the DNR ORDER, submit the matter to the DISPUTE MEDIATION SYSTEM; or
- c. object to issuance of the DNR ORDER and either transfer the patient to another ATTENDING PHYSICIAN or submit the matter to the DISPUTE MEDIATION SYSTEM.

Indicate action taken:

- DNR Order issued
- Patient transferred to another ATTENDING PHYSICIAN
- Matter submitted to DISPUTE MEDIATION SYSTEM

REMINDER: For inpatients, other than alternate level of care ("ALC") patients, the DNR ORDER must be reviewed every seven days, or sooner if the patient's condition changes, and the review must be documented in the medical record. For ALC patients and outpatients, such review must be done each time the ATTENDING PHYSICIAN examines the patient, except that such review need not occur more than once every seven days. In addition, for ALC patients, the review must occur at least once every sixty days.

DNR DOCUMENTATION SHEET #5
ADULT PATIENT - WITHOUT CAPACITY AND WITH A SURROGATE *

IF NO PLATE, PRINT NAME, SEX AND MEDICAL RECORD NO.

AUTORIZACIÓN PROVISTA POR UN APODERADO PARA UNA ORDEN DNR

1. Por medio de la presente, Yo autorizo al Dr. _____ para emitir una ORDEN DNR para el paciente _____
Yo entiendo que no se ejecutará una resucitación cardiopulmonar en el caso de que su corazón deje de palpar o que él/ella deje de respirar.
2. El Dr. _____ me ha explicado el diagnóstico y el pronóstico, las medidas de resucitación disponibles, los eventuales y posibles riesgos y beneficios para él o ella, de una resucitación cardiopulmonar; y las consecuencias de una orden de no resucitar al paciente.
3. Yo estoy tomando esta decisión basado/a en: (marque uno)
 a. los deseos que se conocen del paciente; o
 b. los mejores intereses del paciente, ya que no se conocen los del paciente y no se pueden predecir.
4. Mi relación con el paciente es la siguiente: (marque uno)
 a. comité o apoderado nombrado por la corte (adjunte documentación adecuada)
 b. persona designada por el paciente (adjunte la documentación adecuada)
 c. esposo/a
 d. hijo o hija de dieciocho años o más
 e. padre/madre
 f. hermano o hermana de dieciocho años o más
 g. amigo cercano (tiene que llenar el nombramiento de Amigo Cercano)
5. De acuerdo a mi criterio, no hay una persona de más alto rango en la lista del punto número 4 que este disponible para dar una autorización por el paciente.
6. Yo confirmo que he leído y he entendido todo lo anterior y que se han llenado todos los espacios antes de firmar.

Firma del Apoderado

Nombre en Imprenta

Fecha:

CERTIFICACIÓN DEL TESTIGO

Yo, por medio de la presente certifico que el apoderado firmó y fechó esta autorización en mi presencia.

Firma del Testigo

Firma del Médico

Nombre en Imprenta

Nombre en Imprenta

M.D. Code

Título/Relación con el Paciente

Fecha

Fecha

Appendix C. DNACPR Form for NHS East of England and Addenbrooke's Hospital

<p>DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION Adults aged 16 years and over. In the event of cardiac or respiratory arrest do not attempt cardiopulmonary resuscitation (CPR). All other appropriate treatment and care will be provided.</p>					
<p>Name: _____ (OR USE ADDRESSOGRAPH)</p> <p>Address: _____</p> <p>_____</p> <p>Postcode: _____ Date of birth: <input type="text"/> <input type="text"/> <input type="text"/></p> <p>NHS number: _____</p>	<div style="background-color: #0070c0; color: white; padding: 5px; text-align: center; font-weight: bold;"> ORIGINAL PATIENT COPY TO STAY WITH PATIENT </div> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>Date of DNACPR order:</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> </table> </div>				
<p>Reason for DNACPR decision (tick one or more boxes and provide further information)</p> <p><input type="checkbox"/> CPR is unlikely to be successful [i.e. medically futile] because:</p> <p>_____</p> <p><input type="checkbox"/> Successful CPR is likely to result in a length and quality of life not in the best interests of the patient because:</p> <p>_____</p> <p><input type="checkbox"/> Patient does not want to be resuscitated as evidenced by:</p> <p>_____</p>					
<p>Record of discussion of decision (tick one or more boxes and provide further information)</p> <p>Discussed with the patient / Lasting Power of Attorney [welfare]? Yes <input type="checkbox"/> No <input type="checkbox"/> If 'yes' record content of discussion. If 'no' say why not discussed.</p> <p>_____</p> <p>Discussed with relatives/carers/others? Yes <input type="checkbox"/> No <input type="checkbox"/> If 'yes' record name, relationship to patient and content of discussion. If 'no' say why not discussed.</p> <p>_____</p> <p>Discussed with other members of the health care team? Yes <input type="checkbox"/> No <input type="checkbox"/> If 'yes' record name, role and content of discussion. If 'no' say why not discussed.</p>					
<p>Is DNACPR decision indefinite? Yes <input type="checkbox"/> No <input type="checkbox"/> If 'no' specify review date: _____</p>					
<p>Healthcare professional completing this DNACPR order</p> <p>Name: _____ Signature: _____</p> <p>Position: _____ Date: <input type="text"/> <input type="text"/> <input type="text"/> Time: _____</p>					
<p>Review and endorsement by responsible senior clinician</p> <p>Name: _____ Signature: _____</p> <p>Position: _____ Date: <input type="text"/> <input type="text"/> <input type="text"/> Time: _____</p>					

Appendix D. Sample DNACPR Form from Addenbrooke's Hospital

ward:/...../.....

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

This form should be inserted behind the alert sheet inside the front cover of the patient's current medical records.

Reasons for initiation of DNACPR order:

fatality recurrent falls + osteoporosis

This decision has been discussed with the following: (if patient/parents not involved please state why)

ward staff

Plan for Review: (either insert review dates or state review is not appropriate)

/

Name of SpR (ST3 and above) initiating DNACPR (please print):
.....

SpR signature:

Bleep:

Date:/...../..... Time::..... (24hr)

If an SpR initiated the DNACPR order an appropriate consultant must complete this section *within 72 hours* of the time of commencement otherwise this proforma is considered to be invalid.

Appendix E. Consent Forms for the US and UK

US Version:

<small>Patient ID Data</small>

RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM

Protocol Title: Understanding the Do Not Resuscitate (DNR) Decision Making
Process:

A Comparative Analysis of the United States and England

Application No.: NA_00080529

Principal Investigator: David Levine, MD. 2024 E. Monument Street, Suite 2-600;
Baltimore, MD 21205. Phone: (410) 614-4577. Fax: (410)
614-5593

1. What you should know about this study:

- You are being asked to join a research study.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can quit at any time. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.
- When the Johns Hopkins University School of Medicine IRB reviews a study that includes participants from Anne Arundel Medical Center, Greater Baltimore Medical Center, Inova Health System and/or Peninsula Regional Medical Center then the term “Johns Hopkins” when used in this consent form also refers to Anne Arundel Medical Center, Greater Baltimore Medical Center, Inova Health System and Peninsula Regional Medical Center.

Why is this research being done?

The purpose of this research is to compare the practices of DNR in the United States and the United Kingdom. In England, it is not required that the physician

seek permission for the patient or family to institute DNR orders. We will enquire into how doctors understand the DNR process, as well as their attitudes and satisfaction with it.

How many people will be in this study?

This study will interview approximately twenty physicians in the Johns Hopkins Health Care System. In addition twenty physicians from the Addenbrookes Hospital in Cambridge, England will be interviewed in a separate arm of the study.

2. What will happen if you join this study?

If you agree to be in this study, we will ask you to do the following things:

- The study doctor will explain to you the purpose of the interview and obtain your informed consent
- The study doctor will ask you questions about your thoughts and beliefs about the research topic

How long will you be in the study?

You will be in this study for the duration of this one time interview, which will last approximately one hour. We will not contact you after the interview unless you give us permission to do so.

3. What are the risks or discomforts of the study?

The risks to the physician volunteers in the study should be minimal. Discussing the topic of resuscitation might raise some emotional concern with a given physician. However, this if anything should be transient because this is a topic that all physicians are aware of and are required to deal with in their profession.

4. Are there benefits to being in the study?

There is no direct benefit to you from being in this study. If you take part in this study, you may help others in the future.

5. What are your options if you do not want to be in the study?

Your participation is completely voluntary and you do not have to join this study.

6. Will it cost you anything to be in this study?

No, there are no costs associated with participation in this study.

7. Will you be paid if you join this study?

No, this study is voluntary and you will not be compensated monetarily for the study.

8. Can you leave the study early?

You can agree to be in the study now and change your mind later. Any part of the interview that you do not wish to respond to does not need to be answered.

9. How will your privacy be protected?

Johns Hopkins has rules to protect information about you. Federal and state laws also protect your privacy.

The research team working on the study will collect information about you. This includes things learned from the procedures described in this consent form. We may also collect other information including your name, address, date of birth, and other details, which will be stored in a separate location from the interview data. Any information collected about you will have identifying information removed.

Generally, only people on the research team will know your identity and that you are in the research study. We cannot do this study without your permission to use and give out your information. Once collected, any identifying information will be removed. Your responses will only be seen by study personnel, all of whom have been fully trained in privacy.

10. What does a conflict of interest mean to you as a participant in this study?

None of the research staff have any financial conflicts of interest or other interest in this study which might affect their judgment.

11. What other things should you know about this research study?

a. What is the Institutional Review Board (IRB) and how does it protect you?

The Johns Hopkins Medicine IRB is made up of:

- Doctors
- Nurses
- Ethicists
- Non-scientists
- and people from the local community.

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your rights as a participant or if you think you have not been

treated fairly. The IRB office number is 410-955-3008. You may also call this number for other questions, concerns or complaints about the research.

If you are a participant at Greater Baltimore Medical Center, you may contact James Mersey, M.D. (Chairman of the GBMC IRB) at 410-828-7417.

b. What do you do if you have questions about the study?

Call the principal investigator, Dr. David Levine at (410) 614-4577. If you wish, you may contact the principal investigator by letter or by fax. The address and fax number are on page one of this consent form. If you cannot reach the principal investigator or wish to talk to someone else, call the IRB office at 410-955-3008.

c. What are the Organizations that are part of Johns Hopkins?

Johns Hopkins includes the following:

- The Johns Hopkins University
- The Johns Hopkins Hospital
- Johns Hopkins Bayview Medical Center
- Howard County General Hospital
- Johns Hopkins Community Physicians.
- Suburban Hospital
- Sibley Memorial Hospital

Anne Arundel Medical Center, Greater Baltimore Medical Center, Inova Health System, Peninsula Regional Medical Center and Johns Hopkins University are separate organizations that work together on research studies. When the Johns Hopkins University School of Medicine IRB reviews a study that includes participants from Anne Arundel Medical Center, Greater Baltimore Medical Center, Inova Health System and/or Peninsula Regional Medical Center, then the term “Johns Hopkins” when used in this consent form also refers to Anne Arundel Medical Center, Greater Baltimore Medical Center, Inova Health System and/or Peninsula Regional Medical Center.

12. What does your signature on this consent form mean?

Your signature on this form means that:

- You understand the information given to you in this form
- You accept the provisions in the form
- You agree to join the study

You will not give up any legal rights by signing this consent form.

Please let me know if you have any questions about this form. I will be happy to clarify whatever is not clear

May we contact you by phone, mail, or email in the next year for further interviews or group meetings related to the study?

- Yes**
- No**

WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED CONSENT FORM

Signature of Participant
Date/Time

Signature of Person Obtaining Consent
Date/Time

NOTE: A COPY OF THE SIGNED, DATED CONSENT FORM MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND, IF APPROPRIATE A COPY OF THE CONSENT FORM MUST BE PLACED IN THE PARTICIPANT'S MEDICAL RECORD.

Patient I.D. Data

UK Version:

Title of Project: Understanding the Do Not Resuscitate (DNR) Decision Making Process: A Comparative Analysis of the United States and England

Lead Investigator: Dr Elizabeth Dzung

Consent by Physician

ID number: _____

Please
initial
box

1. I confirm that I have read and understood the information leaflet dated 21/2/13 version 3.0 for this research study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my legal rights being affected.

3. I give my consent for audio-recording of interviews and for transcriptions of the audio-recordings to be made.

4. I understand that any information I provide will be treated as confidential. Anonymization will occur at the point of audio recording prior to transcription. I confirm that anonymous quotations from audio recordings may be used in research publications.

5. I would be willing to be contacted after the interview once more briefly, if there are additional questions that the study coordinator wants to clarify.

6. I agree to take part in the above study.

Name of Physician	Date	Signature
----------------------	------	-----------

Name of researcher	Date	Signature
-----------------------	------	-----------

Please write your name and contact information below:

Name: _____

Mobile Number:

E-mail Address:

One copy for the participant, one copy for the researcher

Appendix F. Participant Information Sheets for the US and UK

US Version:

Understanding the Do Not Resuscitate (DNR) Decision Making Process: A Comparative Analysis of the United States and England

Information about the Research

I am writing to request your participation in a research study. Please read this information sheet, which might answer questions you might have about the study. If you have any additional questions, please feel free to ask me. Thank you for considering participating in this study.

Who am I?

This study is led by Liz Dzung, MD, who will be doing the interviewing and analysis. The principle investigator of the study is David Levine, MD. Both are in the department of General Internal Medicine

What is the purpose of the study?

I am interested in the medical decisions surrounding institution of Do Not Resuscitate (DNR) orders at the end of life. I am especially interested in physician attitudes and beliefs about the decision making process, and their satisfaction with the process

Why have I been invited?

I am requesting your participation in the study because you have been suggested as a good person to talk to about this subject, by one of your colleagues.

Do I have to take part?

The decision to take part is entirely up to you. You are free to stop at any time and without giving a reason. You should feel free not to answer any questions you do not want to answer.

What do I do if I want to take part?

Please reply to my e-mail or verbally expressing your interest in the study. We will then arrange a time that is mutually suitable to meet.

What will happen if I take part?

The interviews will take place at a pre-arranged location that is private. This can be at your office, or at another location convenient to you on campus. I will first ask you to fill out the informed consent form. This will also be an opportunity for you to ask any questions you might have about the study. With your permission, the interview will be audio recorded and transcribed.

I will also ask you if you are willing to be contacted after the interview with additional questions I may have. You are free to accept or refuse this. If you do, I will not contact you again after the interview.

What will happen to the study findings?

Results of this study will be published in peer-reviewed journals and at conferences. In addition, the information will be used to write my doctoral thesis. If you are interested in receiving information about the results of the study, please let me know.

Will my taking part in this study be kept confidential?

All information relating to you as a result of this research will be kept strictly confidential, any contribution you make will not be identifiable in any reports, presentations or papers.

Who has reviewed the study?

This study has been approved by the Hopkins IRB committee

How do I contact the researchers?

If you have any questions about the study or taking part please call me at (410) 207-9923 or e-mail me at edzeng1@jhmi.edu

UK Version:

Cambridge University Hospitals 
NHS Foundation Trust

Title of Project: Understanding the Do Not Resuscitate (DNR) Decision Making Process: A Comparative Analysis of the United States and England

Lead Investigator: Dr Elizabeth Dzeng

Information about the Research for Physicians

I am writing to request your participation in a research study. Please read this information sheet, which answers questions you might have about the study. If you have any additional questions, please feel free to ask me. Thank you for thinking about participating in this study.

Who am I?

I am a doctoral research student at the University of Cambridge. I am doing this research as part of my studies.

What is the purpose of the study?

I am interested in the medical decisions surrounding institution of Do Not Resuscitate (DNR) orders at the end of life. I am especially interested in whether or not physicians act in the best interest of patients and the balance between autonomy and non-maleficance.

Why have I been invited?

I am requesting your participation in the study because you have been suggested as a good person to talk to about this subject, by one of your colleagues.

Do I have to take part?

The decision to take part is entirely up to you. You are free to stop at any time and without giving a reason. You should feel free not to answer any questions you do not want to answer.

What do I do if I want to take part?

Please reply to my e-mail or verbally expressing your interest in the study. We will then arrange a time that is mutually suitable to meet.

What will happen if I take part?

The interviews will take place at a pre-arranged location that is private. This will most likely be a meeting room within the Addenbrookes Institute of Public Health. I will first ask you to fill out the informed consent form. This will also be an opportunity for you to ask any questions you might have about the study. With your permission, the interview will be audio recorded and outsourced for transcription.

I will also ask you if you are willing to be contacted after the interview with additional questions I may have. You are free to accept or refuse this. If you do, I will not contact you again after the interview.

What will happen to the study findings?

Results of this study will be published in peer-reviewed journals and at conferences. In addition, the information will be used to write my doctoral thesis. If you are interested in receiving information about the results of the study, please let me know.

Are there any risks to participation?

Participants are at liberty to give as much or as little information as they wish. I will not be asking about bad practices and you will not be asked to reveal identities of your colleagues. If any practices giving rise to concerns are disclosed by the participant, I will discuss the situation on a case by case basis with my supervisor. Given my position as a PhD student, it is highly unlikely that I would have the capacity or authority to pursue any legal action. Instead, any concerns would only be explored from the perspective of promoting ethical and professional patient care.

Who is involved with the study?

This study is led by Dr Liz Dzeng, a PhD Student at Cambridge. Her supervisors are Professor Martin Roland and Dr Stephen Barclay, both based at the Institute of Public Health and the General Practice and Primary Care Research Unit of the University of Cambridge.

Will my taking part in this study be kept confidential?

All information relating to you as a result of this research will be kept strictly confidential. Your information will be anonymized from the very start before transcription, as I will not identify your name in any of the recordings. Direct quotes will be used in publications in an anonymized manner. Any contribution you make will not be identifiable in any reports, presentations or papers.

Who is organizing and funding the research?

The research has been organized by myself and my supervisors at the University of Cambridge as part of my doctoral studies. My doctoral studies are funded by a Gates Cambridge Scholarship.

Who has reviewed the study?

The NHS Research Ethics Committee (Norfolk) has reviewed this study and has approved its procedures.

How do I contact the researchers?

If you have any questions about the study or taking part please call me at 07890 622577 or e-mail me at ed263@cam.ac.uk

Appendix G. Recruitment Email for the US and UK

US Version

Dear Dr. _____,

My name is Liz Dzung and I am a General Internal Medicine Fellow at Johns Hopkins. I am conducting a qualitative research study investigating experiences of US and UK doctors regarding autonomy and satisfaction in DNR decision-making at the end of life. It hopes to explore the prioritization of autonomy versus non-maleficence in decisions surrounding the “Do Not Resuscitate” (DNR) status.

I am writing to ask you if you would be interested in participating in an interview asking about your experiences with patients at the end of their life and how you and the patient came to decisions whether or not to pursue a DNR order. This interview will take approximately 45 minutes.

I would be very much appreciative if you would be interested in participating in this interview. We can schedule it in a way that best fits your schedule. Please reply to this e-mail if you are interested in the study.

Sincerely,

Elizabeth Dzung, MD, MPH

UK Version

Dear Dr. _____,

My name is Liz Dzung and I am a PhD student at the University of Cambridge. I am conducting a qualitative research study investigating experiences of US and UK doctors regarding autonomy and satisfaction in DNR decision-making at the end of life. It hopes to explore the prioritization of autonomy versus non-maleficence in decisions surrounding the “Do Not Resuscitate” (DNR) status.

I am writing to ask you if you would be interested in participating in an interview asking about your experiences with patients at the end of their life and how you and the patient came to decisions whether or not to pursue a DNR order.

In order to participate in this study, you must be a registered doctor practicing through the NHS in internal medicine or a medicine subspecialty. You should also regularly encounter patients at the end of life and discuss resuscitation status with patients.

I would be very much appreciative if you would be interested in participating in this interview. This interview will take approximately 45 minutes. We can schedule it in a way that best fits your schedule. Interviews will take place in a private location, either in your office or in a room at the Institute of Public Health at Addenbrooke’s, whichever you prefer. I have attached the participant information sheet to this e-mail which provides more details on the study. Please reply to this e-mail if you are interested in the study.

Sincerely,

Elizabeth Dzung, MD, MPH

Appendix H. Initial Interview Guide

Thank you for taking the time to talk with me today. I know that your time is very valuable and I appreciate you taking the time out of your busy schedule to speak with me. I am interested in decision-making concerning DNR orders and how these decisions reflect broader issues concerning the doctor patient relationship.

End of life questions

How frequently are you involved with patients at the EOL?

What has been your typical involvement in DNR decision making. Please describe your role.

Could you please describe your hospital's policy regarding DNR?

What is your hospital's culture when it comes to DNR decisions, i.e. what do people usually do?

Describe your usual process of reaching a decision to pursue a DNR order. Please think about recent experiences that you've had with patients. If it helps your thinking, you can think about one particular patient.

Usual clinical context

How are decisions normally reached regarding a DNR order and by whom?

Who was this decision discussed with?

Was there any disagreement and how was that dealt with?

How do you feel about the current approach that you take to DNR orders?

How satisfied are you with the way decisions are reached?

How satisfied are you about the way decisions are discussed with patients/family?

Do you think the current system of DNR practice serves the best interest of the patient?

If yes, why? If no, why not?

Are there any situations where you think the current system for DNR does not serve the best interest of the patient?

Can you tell me why that is?

What might be a better approach in these cases?

Have you ever felt emotional distress in relation to issues around DNR status.

Autonomy

I'd like to move on to talk about your views of who should have priority in making DNR decisions and how patient autonomy fits within this.

What do you feel is the role of the patient or family in making DNR decisions?

How much priority do you think their preferences have in the decision made?

To what extent do you feel this is a clinical decision?

What is your reasoning behind that position?

How much do you feel patients generally want to know about their situation?

If legally permitted, would you feel comfortable making a decision to pursue a DNR order without consulting the patient or family?

If yes, what are your reasons for answering yes.

If permitted at your institution, would you feel comfortable making a decision to pursue a DNR order against the patient or family's wishes?

If yes, what are your reasons for answering yes.

What might your thoughts be about making a DNR decision against the patient/family's wishes?

What is your reasoning behind that position?

General questions

I'd like to finish with some background information about yourself

What is your medical specialty?

Do you see patients with all types of medical problems or mostly those with a particular disease?

Are you based primarily in an ICU, inpatient or outpatient?

How long have you been practicing medicine?

What stage of your training are you in or what is your title?

How long have you been working at this hospital

Appendix I. Final Working Interview Guide

This was my final working interview guide, which I have left in its original unedited form to show the actual printed document I carried with me to my interviews. It includes my original interview guide as well as notes generated from subsequent interviews and analyses that reminded me of other questions and/or themes I wanted to address.

Understanding the Do Not Attempt Resuscitate (DNAR) Decision Making Process: A Comparative Analysis of the United States and England In-Depth Interview Guide – Doctors/US Updated 21 September, 2013

What is your understanding of rules/laws/hospital policy on DNR

Thinking of a patient where DNR would be appropriate, how would you go about with that conversation. You can pretend I'm the patient/family

How often is there a conflict when you say this (again a patient who you think should be DNR)

Where did your ideas of what should be done regarding DNR/Autonomy come from? Were there any particular role models for this? Any particularly memorable experiences which shaped your views about this issue and informs you of what needs to be done in certain situations?

Have you ever had to do a procedure or CPR that you thought to be against your moral/ethical beliefs

Depending on your views (i.e. choice v "autonomy) – do you feel like this option respects a patient's autonomy OR works in the best interest of the patient. Do you think the opposite scenario – disrespects or respects autonomy/best interest?

-what role models, mentors, experiences informed your understanding of DNR policies, of how to approach patients, on how to think about and give these conversations?

-has that changed at all over the course of your training?

-have you noticed any differences in the way your thinking is with other clinicians (i.e. junior and senior doctors). What is your reaction to that?

-what is your definition of autonomy?

-what experiences/factors/training made you think of that particular definition ?

-do you think families have the information they need to know to make these decisions?
Are we giving them autonomy

-do you think you're in a privileged position of having more knowledge. what do you think is your professional obligation to do what is best for the patient, what would be inappropriate?

-what is your moral obligation? To the patient? where do your ethical principles arise from? Do you think about it? Is it consistent with what you think your institution's practices are?

-would you be supported by your institution to do what you think is right?

-do you think that these issues are opinion or fact (obviously said in a different way)

So just sort of looking through your evolution as you've gone from just starting out after med school to now, how have you seen your process of talking to a patient as a family about this evolve?

Docs are often portrayed as having power. Do you think dr or pt has power in this situation

Why do you think we have a society that prioritized best interest or autonomy?

Do you feel like you have a choice in what choices to offer patients.

In your ideal world how would you do things differently (or stay the same)

in interviews, is there a way to distinguish between differences of age, vs experience, vs change in perception of role of doctor in society (profession)?

How well do you think we communicate with patients

Think back to when you started medical school and/or internship. Was there anything in particular that you thought went against your personal beliefs in terms of what was right or wrong, or appropriate, that people in medicine do, that you later found commonplace?

describe your understanding of this hospital's official policy regarding DNR decisions that end in conflict (i.e. whether 2 physician consent is permitted, who has to make the decision, who signs of, etc.)

What is your hospital's culture when it comes to DNR decisions, i.e. what do people usually do?

Think of a case where there was conflict

How are decisions normally reached regarding a DNR order and by whom?

Who was this decision discussed with?

Was there any disagreement and how was that dealt with?

Do you think that patients/families understand what is being asked of them regarding

DNR? Before convo? After convo?

Do you think they know all the information needed to make the decision?

How do you feel about the current approach that you take to DNR orders?

How satisfied are you with the way decisions are reached?

How satisfied are you about the way decisions are discussed with patients/family?

Have you ever performed a slow code?

2 physician consent? Have you ever done it or seen it?

Emotional conflict/moral distress?

Have you ever had a patient refuse DNR? Have you ever had a patient who instituted a DNR that you felt was inappropriate?

Do you think the current system of DNR practice serves the best interest of the patient?

If yes, why? If no, why not?

Why do you think patients full code even if doctors think it's futile?

Are there any situations where you think the current system for DNR does not serve the best interest of the patient?

Can you tell me why that is?

What might be a better approach in these cases?

Do you think hospital/doctor culture has anything to do with driving patients in one direction vs other?

How much do you think patients trust doctors?

Have you had situations where you felt that your clinical and personal beliefs were in conflict with what a patient wanted?

Have you ever felt emotional or moral distress in relation to issues around DNR status. Can you describe a situation that resulted in moral distress. How did others in the team react to this situation, do you feel that they may have experienced moral distress as well? Are there opportunities to talk about these situations? Did that help?

Autonomy

What is your definition of autonomy?

Do we give patient autonomy according to this definition?

What is your definition of best interest?

What is prioritized in your system? Do you think this is the appropriate prioritization based on your moral belief system?

Is DNR a clinical or other decision (legal, personal, opinion?)

Would you feel comfortable making decisions unilaterally? (i.e. UK system)

What do you feel is the role of the patient or family in making DNR decisions? What do you think it should be based on your beliefs? What is it in reality?

How much priority do you think their preferences should have in the decision made? What do you think it should be based on your beliefs? What is it in reality?

To what extent do you feel that a DNR order is a clinical decision?

What is your reasoning behind that position?

How much do you feel patients generally want to know about their situation?

If legally permitted, would you feel comfortable making a decision to pursue a DNR order without consulting the patient or family? (i.e. would you do it if you were allowed to? Would you do it in the system that you are in now?)

If yes, what are your reasons for answering yes.

If permitted at your institution, would you feel comfortable making a decision to pursue a DNR order against the patient or family's wishes? (i.e. would you do it if you were allowed to? Would you do it in the system that you are in now?)

If yes, what are your reasons for answering yes.

Would you feel comfortable making a DNR decision against the patient/family's wishes? Why?

General questions

How long have you been practicing medicine?

How long have you been working at this hospital

What is your religion?

What is your family cultural background?

Have you had any personal experiences that have informed your views on the EOL?

Appendix J. Initial Codebook

These were initial themes that I developed for my initial codebook developed prior to initiation of coding but following completion of all interviews

Conversations (examples of what they'd say)
What doctors/interviewee would want for himself/herself/loved one/family
Families "seeing" patient suffering (i.e. the "California" daughter)
Would you feel comfortable with the UK system - for US doctors, not telling patients or deciding unilaterally
Aggressive care/technology/expectations of technology/ethics of technology
Appropriate/inappropriate resuscitation
Autonomy
Best interest
Burden on family
Burden of doctor/fear of responsibility
Burnout/emotional strain
Capacity (of patient)
Choice/decision of patient/what patient wants/false choice/offering choice
Class/race/SES/education of patient
Confidence (of house staff v experienced doctors)/"comfortable"
Communicative action/Habermas/manipulation/graphic descriptions
Communication/phrasing of conversation/biasing
Compassion
Conflict/agreement (doctor/patient)/discordance
Conflict within family
Consent/informed consent
Consumerisation
Continuity of care (i.e. outpatient/floor/ER/ICU)
Conversation/discussion/family meeting
CPR
Culture/ethnicity death (thinking about it/fear of)
Decision-making
Defaults (choice architecture)
Discussing DNR status/telling a patient their DNR status
DNR forms (anything to do with it)
Doctor's personality
Dying/EOL/death
Emotions of patient/family
Empathy
Patient empowerment
DNR status and quality/escalation of care
Ethics committee
Ethics/morals, experience (house staff)/experienced doctors/evolution of professional development
Family member/surrogate/surrogate decision making/proxy

Fighting
Futility
"Getting the DNR"
Goals of care
Good death
Grief
Guardian
Guilt
Harm/do no harm/nonmaleficence
Health literacy
Hospice
Hospital culture
House staff/junior trainee behaviour/younger doctor
Humanism
ICU (setting)
Inappropriate resuscitation (either before convo too late, or done appropriately by pt choice)
Information/education of patient/family/understanding/knowledge
Informed assent
Informed consent
Lay impressions of CPR
Legal/litigation
Letting go
Lifeworld of doctor
Setting limits (by doctor)/withholding care
Limits of medicine/iatrogenesis
Living will
Miracle/hope
Moral distress/emotions of doctor/personal views/personal conflict
Nurses
Oncology
Opinion vs clinical decision of CPR
Palliative care
Patient case examples
Policy/law
Politics of DNR
Power
Prognostication/certainty
Quality of life
Recommendation against
Religion
Resources(limited)/rationing
Respecting patient's wishes/respect
Responsibility (as a doctor)
Rights (of patient) to CPR
Shared decision-making

Slow code/limited codes
Sociological transformation of doctors
Societal norms
Suffering
Surveillance/panopticon (Foucault)
Teaching of doctors/training
Television
Terminal/end stage
Time for patients to make decision
Time/workflow/structure of doctor routine
Torture/painful, etc.
Trust/truth
Two physician consent
US/UK impressions
Variation
"Want everything"

Appendix K. Sample Transcript with Hand Coding

(Cont'd)
 - clinical decision
 - best interest

order in when a 90 year old is like no. But I think approaching it again if somebody is full code should be a medical decision where we can predict if somebody is going to benefit or not from a resuscitation. And obviously people can refuse it based on their values but we should pursue it based on clinical.

Page | 10

73 Interviewer: Okay. And then what do you feel is the balance that our system has between patient autonomy and doing what you think is in the best interest of the patient?

74 Respondent: It's tough. I think that's really tough. I don't know what to answer really. Because I think it's almost this American value that you get to dictate this. I do think you should have some say in how you end your life. I think that's the right of the patient. But it's difficult in the setting where that decision is to have everything done then as a doctor you're like what are we doing? We're spending all of these resources, all of this money on somebody that is clearly not going to benefit from it. So it's tough to a certain extent up to a point you should be able to have a say, but you see so often how poorly it turns out. But I think that in some sense there should almost be a required documentation or required action to actually have the discussion across the board if it's clinically warranted. Whereas I think it really varies now how that discussion goes or if that discussion even takes place.

- autonomy priority
 - cultural norm
 - autonomy
 - justice
 - ethics balance
 - harm
 - documentation
 - conversation

75 Interviewer: Do you think that we are acting in the best interest of the patient in this current system that we have?

76 Respondent: I really think it varies on the doctor. Just as patients are different I think doctor's approaches to these things are so different. You can discuss this with a lot of people on the same page but I'm always surprised at attendings comments or other doctors you hear. You wouldn't even have the same conversation that I would have. So it's definitely not standardised and I think it's such an emotional decision, both for the doctor and the patient that it's not happening across the board in a standardised way. There's even, we watched some video in geriatrics. It was made at Mount Sinai I think and it was on facing death. It was this documentary and I think they go through their ICU and oncology service and the spectrum of opinions amongst their attendings was just so amazing to see.

- variation
 emotion
 D
 control

Appendix L. Sample Excel Spreadsheet

PhD quotes RESIDENT ☆ ■

File Edit View Insert Format Data Tools Add-ons Help Last edit was on March 18

Code			
A	B	C	D
Code		<p>I've seen a code that was limited by the parent's desires. I've seen a chemical code but it wasn't physician driven chemical code, I mean there was a doctor running it...But one of my PICU patients, this little kid with 80% total body surface area burns and he was in a horrible condition and on adult setting ??? 22:14 oscillator and, you know, was dying and mom had a lot of guilt couldn't let him go and was a very religious person et cetera et cetera. He was full code for a long time and he was one of those kids that we were hoping not to have to code. And finally over the weekend one of the doctors talked to her and she decided on no chest compressions. And then he coded 2 day later and was a chemical code and... I thought it was really great actually in a way, because he didn't have a lot of skin left from all these burns, but what skin he had left was on his chest. And because we weren't on his chest mom was rubbing him and kissing him and we were pushing ACLS drugs and, you know, not that anyone thought we were gonna save his life but you know, the medical personnel never thought we were gonna save his life and I didn't feel like I was hurting him giving epi.</p>	A15/46
	Code status delay	<p>What is more interesting for me is the ones who have many chronic diseases who are completely surprised they haven't thought about it all. You're looking at their past record at the hospital admission and they've been here six times the last twelve months or six hospitals or something like that. It depends, you know pneumonia, heart failure exacerbations. To them no one ever broached the subject. And that is surprising to me.</p> <p>Also you know you say last record looks like it's there, but no one ever sat them down and said so here's why we're asking these questions because once you're here three times in a year you're two year mortality is X and we would like to know how you would like that to go.</p>	A14/12
		<p>Yes, I think it has a lot to do with maintaining hope and it all depends on what is the disease process. The people who are, like the COPD-ers who are on home oxygen, you know they're always like what. You have to carry supplemental oxygen with you. People see themselves in the small end of the statistics and all these things. It's a phenomenon of the human mind.</p>	A14/14
	Code status neutral	<p>Some people have thought about it beforehand, other people haven't. It's really once you get more information about what disease process is going on that the clinical prognosis part of it comes in. And usually at that point patients and their families are asking. I try not to bring in my own personal feelings, I don't, I try not to talk about what I would want done or what I would do for my family member if they were my family member. But patients often want to know that. That's something that they ask you. If I were your mom, or if this were you mom, an intubated patient. At that point that's more of an emotional reaction. As far as the clinical prognosis it all depends how familiar I am with the disease.</p>	A14/6
		<p>Yes where patients have said that they want CPR done and they needed it, yes I've been part of that. And it's hard, that situation that you hear people talk about where they code softly. The ninety-five year old and the soft code, which I think some people will</p>	

+ [Menu] A Housestaff ▾ B Housestaff ▾ C Housestaff ▾ D Housestaff ▾

Appendix M. Final Codebook

AD: Advanced directive. Any conversation about institution of an advanced directive, or having a DNR form coming in, etc.

Administration: Any supportive administrative staff, such as patient services or administrator-on-duty. Usually called if there are problematic patient situations or conflicts.

Advanced planning: Also patient's own wishes. (even if not advanced) Any discussion of whether a person has previously thought about their wishes, or not thought about their wishes. Does not have to include actually having an AD. Also can be allusions to starting the conversation earlier, or needing to start these conversations as an outpatient.

Aggressive care: Care that is aggressive, care that involves excessive use of technology, care that would not benefit the patient. Use of technology.

Appropriate care: care that is appropriate

Autonomy: autonomy of the patient, rights of the patient

Autonomy definition: direct answer to question of defining autonomy

Autonomy priority: prioritization of autonomy (especially US)

Bad healthcare experience: usually in reference to lack of trust or more difficulty convincing them to do what the doctor wants.

Bad news: discussion of learning how to give, or giving bad news. As distinct from discussing death.

Bad news rosy: delivering bad news in too optimistic a way, painting a rosy picture

Best Interest: Actions that are determined by a doctor to be in the best interests of the patient. Also when people discuss whether something is a benefit.

Best practice: or guidelines

Bull's ring: Not really knowing what you're going to do or the full situation until you're actually in that situation yourself.

Burden: Burden upon the family for having to make a decision about the patient. Burden of responsibility onto family

Burnout

"California daughter": reference to far away relative who swoops in and wants everything

CAM: complementary and alternative medicines

Can't demand: in the UK referring to not being able to demand therapies.

Capacity: whether doctors deem someone to have the capacity to make decisions

Caring:

Capitulate: when doctor sides with family because they feel like they have to.

Case Example: When an interviewee gives a specific case.

Choice:

Choice false: also refers to when docs say of course a family would say no don't kill my loved one I want everything

Choice of choice: ability to decide how much choice one wants to make

Choice offering: offering a choice. Giving patients or family a choice to make between different treatment options (e.g. DNR/no DNR)

Choice public perception: how UK (usually) public understands how much choice they have in EOL decisions. or patients themselves thinking they have more choice than they do.

Chronic disease: disease such as COPD, CHF where decline is slower and more insidious so EOL more difficult to accept or determine

Clinical Decision: Also clinical judgment. Physician's personal opinion versus clinical opinion.

Clinical Decision Accuracy: discussion of whether doctor is making right decision or not. Sensitivity and specificity.

Code:

Code discussion: any discussion of code status or need to have convo

Code Limited: With the patient or family's knowledge and permission, performing some aspects of a code but not others. E.g. chemical code only, compressions but not intubation, etc. Also called a tailored code.

Code Slow: Without patient's/family's knowledge. Intentionally ineffective CPR performed by providers. This can be a "short code" (e.g. "We only do one round of epi"), a sham code (e.g. injecting the mattress instead of the patient).

Code Status

Code status delay: not having asked about code status when it should have been addressed ages ago. sometimes causing inappropriate resuscitation

Code status neutral: being sure not to inject any personal opinion into code status discussion

Code Stop: when you decide not to resuscitate when called to a code and the person is obviously not appropriate. pretty much same as limited code actually...but I guess not necessarily with family's understanding.

Code teaching: Resuscitation on “futile” patients as a teaching experience for residents.

Comfort care: when goals at the end of life change so that patient comfort is the priority.

Comfortable: whether the doctor is comfortable making decisions or having conversations. Also confidence.

Communication: Communication in the broad sense - talking about “we are bad at communication” generally, or having “communication” seminars.

Communication F/P: communication between the family and the patient

Lack of communication: can be any sort of lack of communication, including when services are not speaking to each other and giving conflicting information to the family. mixed messages

Compassion: also includes “caring” for people

Complication: iatrogenesis, side effects

Conflict: Discordance or disagreement.

Conflict bt F: inter-family conflict (e.g. sister disagrees with mother)

Conflict D: internal conflicts that the doctor herself perceives i.e. between what she thinks is best and what she has to do, or conflict about what is best. Ethical conflicts/problems/reservations.

Conflict D/D: Conflicts between team members or doctors.

Conflict F/D: conflicts of opinion on best course of action between family and doctor

Conflict P/D: conflict of opinion between patient and doctor

Conflict P/F: conflict of opinion between patient and family. when family does not do what patient wanted

Conflict rare: when doctors say conflicts are rare. Started coding this halfway through so some of these may be under conflict %

Conflict secrecy: primarily in the UK, when a DNR written without the patient/family’s permission creates conflict, or there is a complaint about it

Conflict %: specific answer to my question of how frequently do you see discordance in your preferences for patient code status and their wishes

consensus: consensus between everyone

Consumer: consumerization

Control: patient/family maintaining control

Conversation: discussion

Conversation E: Examples of dialogue or imagined dialogue between physician and patient. (e.g. “I would probably approach them and say, ‘We’re at the end of the road...’”)

Conversations F: anytime a conversation comes up with the family, having a conversation with the family. Family meeting

Conversation fear D: Doctor afraid to broach subject of DNR, death, etc. not wanting to hurt patient.

Conversations P: anytime a conversation comes up with the patient, having a conversation with the patient

Cost: cost of care, health care costs, end of life costs

CPR:

CPR Appropriate: may also refer to medical interventions generally

CPR Different: Any discussion of CPR as being somehow different from other treatment options in the way that we treat it.

CPR Inappropriate:

CPR Patient Aware: discussion that the patient is dead and won't feel the code anyways. That the patient can't feel when CPR is being done, so things are okay to do. (i.e. teaching case, treating the family)

CPR Reality: what actually happens in CPR, reality chance of survival, worse than when you started. realistic views on CPR, history of CPR.

CPR request: or request treatments. more in the UK, when patients specifically request to be full code.

CPR won't work

Culture:

Culture background: Patient or family's religious, cultural, ethnic, or socioeconomic background. Also may refer to things that prevent good communication/understanding such as language barriers, etc.

Culture change: general changes occurring in societal mindsets. social transformation

Culture change profession: discussion of Social transformation: discussion of change in profession, swing from paternalism to autonomy, etc.

Culture comparisons: comparing two systems, i.e. US, UK

Cultural Disparities: Referring to a particular racial or ethnic group as having a particular characteristic.

Culture Hospital: Referring to a particular hospital's specific culture around a particular practice. Differences in VA hospitals as well most notably. Can also refer to variation in hospitals

Culture medicine: culture of the medical profession, medicine in general

Culture Mistrust: not trusting doctor because of race/culture issues

Culture Norms: Cultural assumptions. For example views on youth. Attitudes towards death.

Culture SES: culture and behaviour of people who have higher SES, etc. (late category, may have missed some wrt knowledge self, trust, etc.) May tend to feel more entitled.

Curriculum: also refers to teaching/training

Curriculum Formal: Didactic training, role-play, any mention of medical school.

Curriculum Hidden: Unintentional or unspoken lessons learned. Often in conflict with formal curriculum.

Curriculum Informal: Learning on the wards; training on the wards.

Death:

Death accepting: accepting death

Death border - discussion of border between life and death

Death CPR: discussion that CPR is occurring after the patient is already dead.

Death Denial: The patient, doctor or society being in “denial” about death being imminent or about death in general. also can be unrealistic expectations

Death Delay D: Doctor not talking about death in conversations

Death Fearing: society or individuals not comfortable with death

Death inevitable: that despite anything we do the patient will die.

Death Natural: discussion of dying a natural death or “allowing natural death”

Death Talking: Talking explicitly about death. Can be feeling uncomfortable about talking about death or illness. Could be things done in program which help facilitate talking about death.

Death unexpected: where illness and death are rather sudden, rather than chronic, which usually means that families/patients have not had time to accept death and tend to be more aggressive.

Good death: dying the “good death”.

Decision Making: Any discussion of a patient weighing the options, family weighing the options.

SDM: Shared decision-making. Also any situation where interviewee alludes to doctor’s role being giving information and/or patient’s role giving goals and values

Wrong decision: doctor alluding to there being a right or wrong decision, and the wrong one was made by the patient. Or a bad decision made. When it’s the doctor making the wrong decision, that would go under “clinical decision accuracy”

Default: the default option of CPR. Erring towards aggressive treatment when there is disagreement.

Default Aggressive: when the default is aggressive. Situations where there are conflicting views and the default goes with the most aggressive treatment.

Demanding: demanding patient or family. May also mean that the patient requests something that won’t work. Or any allusion to doing what they ask.

Did everything: the medical team and/or family tried everything. For many of these interviews, these are under “want everything”.

Difficult:

Difficult F: difficult family

Difficult P: difficult patient

Dignity: dying with dignity

Distress: withholding information or discussion of DNR from a patient (usually in the UK) due to concern that it would be too emotionally distressing for the patient/family.

DNR: includes the process

DNR Form: form

DNR ask everyone: anything pertaining to the norm of always asking anyone on admission what their code status is

DNR change mind: when doctor has a unilateral decision but changes mind after speaking with the family. (different from capitulate, as he actually changes mind and not capitulates)

DNR omission: Primarily in the UK, when a DNR form is signed unilaterally, with intention to discuss with the family or patient, but doesn't get around to doing so. Or when they are unable to discuss with the family because they are not there, etc. logistical difficulties. Not making sure that the family is aware of what is going on, aware of care plan, etc.

DNR not informing: instituted w/o discussion w family or patient

DNR wrong reason: unilateral DNR instituted in UK for wrong reasons, i.e. prejudice, time, etc.

DNR worse care: when a patient is DNR, physician impressions that the patient receives worse care overall.

Doctor personal: Personal experiences of doctor which informs or influences practice. also personal qualities/personality. Respondent's own EOL wishes

Dying: patient is just dying

Emotion: Talking about specific emotions (e.g sad, frustrated, relieved)

Emotion D: Physician Emotion (crossover with Moral Distress)

Emotion F: Family emotion, usually surrounding CPR

Emotions P: Patient emotions, usually surrounding CPR

Empathy: on the part of the doctor for the patient/family/situation

Empowerment: patient empowerment. Control of patient

Entitled: patient feeling entitled to certain things.

Environment: the environment with which we operate within hospitals. location, environment of hospital/discussions that may or may not be conducive to good conversation/comfort

EOL: end of life

Ethics:

Ethics balance: any discussion of balancing the four principles of ethics

Ethics consult: when ethics is called

Ethics D: ethical beliefs of doctor. when doctor talks about the "right thing" to do

Euthanasia

Evolution: Or evolution of experience through training? Development

Experience: Experience of doctor. Any mention of the doctor's level of training as being a factor in their decision-making (e.g. "I've only seen a few cases..."). also refers to house staff

Expertise: IN CLINICAL JUDGEMENT

False hope: when doctors waffle or suggest treatments that will not work

Family dynamic:

Family informed: also can mean patient. Includes anytime doctors talk about explaining the situation, not using jargon. educating the patient

Family involved: Making sure the family/surrogates/patient are involved in discussions.

Family not informed:

Feedback: any occasion where a learner is observed by attending and gets feedback. or any opportunity where doctors see other doctors doing things and can get feedback. also includes "observation"

Fighter: references to the EOL or battling terminal disease as a battle, war. The person is a fighter, or she is fighting. Or going on because family wants you to go on

Fixer: doctors being types of people who want to fix things, and be aggressive

Framing: use of graphic descriptions of CPR. (i.e. breaking ribs, etc.) any discussion of phrasing that influences, bias, attempts not to bias. Discussions of manipulation v persuasion.

Front line: discussion of the people doing the code, usually referring to residents or people running the code.

Futility: something is futile, not going to work

Geriatrics: any discussion of the elderly, including frailty, etc.

Getting the DNR: house staff attitudes to conversations with the goal being getting a DNR, and associated comments around why getting a DNR is important in workflow/house staff issues (i.e. so that cross cover knows what to do). Also refers to checklists of getting code status. How it is a check box

GOC: Goals of care. discussion of this being more than just DNR, but addressing goals of care. Also means being on active treatment, or treatment decisions apart from DNR. Also means big picture.

Got better last time: when families want everything because it worked last time, or because docs said he'd die but he lived last time

Grey area: where it's not clear clinically whether CPR would be in the patient's best interest.

Grey hair: reference to having grey hair or other signs of age as a reason people tend to trust them more because they are old/experienced.

Guardian: when there is no surrogate available and patient has no capacity. May generally refer to a situation where a guardian would be appropriate

Guilt: can be about giving up, letting go. Inability to make decision due to guilt or issues of letting go. May hinder decision making. Could also be "giving up" when a patient's family or the patient or the physician uses the term "giving up" on a patient, abandoning patient. "Letting" someone die. guilt also to mean inability to say no to aggressive treatment. afraid of blame, family dynamics, etc

Harm: Do no harm, non-maleficence. Causing a patient to suffer; avoiding patient suffering. Words used by interviewee such as trauma, etc. Torture is also a separate sub-category. This is also a count of how many times words such as trauma, horrible, etc. are used

Health literacy: any discussion of patient's educational background, especially wrt how they are able to understand the medical situation

Healthcare System: discussion of how the healthcare system influences behavior or thinking, broader structural constraints. This might also include the business of medicine or economics. Cost of care, economic incentives that are skewed, etc.

Hierarchy: "attending level discussion", going up the hierarchy in discussions

Holistic: thinking about the whole person, the art of medicine, well being, etc. discussion about healing relationship, etc. rather than just fixing the person. Also humanism (I know that's not a precise fit). Humane

Honest: giving honest answers, being upfront with them, being open with them etc.

Hope: either absence or presence of it. optimism.

IA: Informed assent. When you inform the patient and don't ask them to make a decision, but say "this is what we are going to do" and they don't object.

IA Changed: when doctor goes in with an informed assent approach, but then the patient/family wants differently so doctor goes with patient's wishes.

ICU: Intensive care unit. A setting of care.

ICU Triage: decisions not to (or to) take patients to the ICU, esp in UK if that means stopping code.

Inappropriate CPR: Instance where there are requests for CPR which the doctor believes is inappropriate. Similar to *want everything* but specifically for CPR.

Informed consent: any use of this word, or discussion of this process.

Interdisciplinary team: involvement of interdisciplinary team, ancillary staff, i.e. clergy, social work

Internet: Under “knowledge self”

Intervention: when the respondent suggests interventions that could be done to improve the process of EOL care

Jargon: Medical language, overly medical language.

Junior: changed to EXPERIENCE

Keeping from patient: family requesting informatino about prognosis not be told to patient

Kill loved one: Similar to false choice, but situation where families are asked impossible question of whether they want loved one to live or not. and reference to killing that said loved one. Or doctors saying of course loved ones will say yes to resuscitation because of course they would want them to live. (similar to false choice)

Knowledge self: patient able to find their own information by looking on the internet, support groups, etc. Anything to do with the internet including social media

LCP: Liverpool care pathway

Leadership: discussion of someone being able to do something more because he’s in a leadership position. Stories about a leader in the hospital influencing.

Legal/Litigation: Any situation where legal services or consultations are called or when people practice defensive medicine. also could be fear of losing job

Limits: limits of medicine

Listen: hearing the patient out, why they want certian things, listening to them. (added late)

Managing expectations

MD refusing: Revised, now under “Setting Limits”

Mechanic: Use of a mechanic to defend not giving patients choice

Media: Television/movie influence on understanding of CPR

Media news: press coverage of CPR, also includes public understandings/perception of CPR. Includes the Tracey case

Medical team: discussion of team, medical personnel, references to staff, etc. reference to colleagues

Mental Capacity Act

Miracle: Family (or doctor) expecting things that are very unlikely to be possible. or that their loved one will be the exception where things will work.

MOLST

Moral distress: Does not have to be so strong as to encompass actual moral distress, but a general feeling of negativity such as discomfort felt by a caregiver (nurse or physician) over some aspect of a patient’s care. For example, “feeling bad” about being required to give CPR to a patient who is terminally ill. Use of words such as “frustrating” “uncomfortable”

Multiple admissions: reference to frequent flyers or multiple admissions, etc.

NHS: referring to NHS or NICE.

Non beneficial treatments: treatments docs don't think will help

Nurses

Obviously dying: Gestalt - terminal patient.

Oncology: Any mention of oncologists or oncology wards specifically.

Open mind - not being judgemental, open to other ideas, not going in with an agenda

Opinion: Doctors’ opinion. Also bias as distinct from framing, as this is not bias that comes up in conversation, but acknowledgement of bias. Also anything “subjective”

Opt out: option for practitioner uncomfortable with situation to opt out of care

Other specialties: any reference to other subspecialties or medical disciplines, such as surgery, neurology, etc.

Outpatient: previously in relationship, advanced planning, or others.

Past Experiences: Family's prior experiences with hospitals, end-of-life care, hospice, etc., with other family members.

Paternalism: or reference to decisions that doctor make about what autonomy to grant, etc. (paternalistic autonomy)

PC (Palliative Care): Talking about calling a PC consult, PC practices, etc. Also includes hospice.

Politics: when politics gets mentioned, i.e. Death Panels, Obama Care.

Preferences P/F: changed to "choice of choice"

Professional: professionalism, any comment pertaining to being a doctor, or the experience of being a doctor. anything referring to the act of being a doctor. Doesn't necessarily need to be professionalism in the traditional physician sense

Prognostication: Physician giving an opinion about what will happen to the patient. Terminal, outcome. Prognosis. also means uncertainty

Proletarianization: any discussion of doctors being reduced to workers, or the bureaucrats above.

Policies: Policies/law - any description of what their impression of what hospital requirements are

Power: of doctor, discussion of doctor having power in the relationship. Sense of authority

Powerless: any description of feeling powerless to do the right thing, learned helplessness, feeling "numb" to it, cynicism about what medicine can accomplish, etc. giving up on thinking about something, not bothering because of time, etc. Feeling of helplessness. Resignation. Could also be feeling numb

QOL: Quality of Life: The state of a patient's general well-being. Discussion of life worth living

Rapport: discussion of establishing one in patient doctor relationship. Distinct from relationship

Rationing: of limited resources

Recommendation: Physician making a recommendation

Reflection: Physician reflecting on end-of-life issues or ethical issues.

Relationship: Physician-patient relationship, mention of having prior relationship with patient, etc. Continuity of care. Or having face to face contact with the patient. Also refers to primary care.

Relief: when doctors make decision and family relieved to have decision taken away.

Religion: influence of religion or mention of religion. Also includes discussion on the sanctity of life

Resource: resource use, societal distribution of justice. May also include rationing.

Respect: also includes respect for persons (from an autonomy standpoint)

Respect F: Respecting family's wishes (or health care proxy's wishes) - not written advanced directive or what the patient has previously expressed, but what the family has chosen.

Respect P: Respecting patient's wishes - not written advanced directive but what the patient had previously expressed as what they wanted to do. Or respect for patient

Responsibility: Physician's responsibility to make a decision in the patient's best interest. Or could be patient's as well. Burden of decision making. Also Duty .

Role Models: observation

Role Models Peers: fellow residents, etc. If you are an intern, learning from resident.

Role Models Superior: i.e. attendings

RR: situations describing what would be a rapid response. (This was a late addition, may be previously in other categories)

Sanctity of life: every minute of life is precious

Satisfaction: of doctor or family/patient

Scientific: where doctors have scientific mindset, either EBM or etc.

Second opinion: referring to a second opinion (i.e. if the doc cant provide said aggressive treatment)

Setting limits: i.e. surgeons can say surgery not an option, but not CPR, harder to do with medicine. setting limits on things. Not offering things

Social media: Under "knowledge self"

Skills: discussion of skills involved to have these conversations, to be able to convey these things.

Spectrum: using the spectrum of decision making from autonomy to paternalism where appropriate. Similar to tailored approach.

Stalling: Doctors not making decisions, being indecisive, kicking the stone down the road, not wanting to make decisions or feeling that they should be offering treatments (i.e. he can have surgery if he gets stronger)

Substituted judgement

Subversive: acts by doctors to defy policy in the best interest of the patient.

Success unlikely: discussion of intervention unlikely to succeed. Less extreme than futility.

Suffering: use of word suffering

Surrogate: Speaking to a surrogate-decision maker for the patient. This can be a family member or a healthcare proxy.

Surrogate secondary gain: if surrogates make decisions with other incentives influencing

Surrogate worse: Reference to the surrogate being more difficult than patients and oftentimes more aggressive. Differences between decisions of patient vs. family (i.e. families often want more than the patient”). Situations where the default goes to more aggressive care (specific situation of a surrogate) will go under “default”

Tailored approach: the idea that you have to approach convos differently with different people. Similar to spectrum.

Technology: Description of specific life-sustaining technologies, the role of technology, etc.

Tertiary Care: When very sick patients transfer to a tertiary care hospital perceived as “really good” as a hail-mary pass. Or discussion of tertiary care vs community hospital.

Theory versus practice: Any mention of teaching versus “real life experience”

Time:

Time earlier: Discussion of need to approach conversations about DNR or GOC earlier

Time F: Time for family to make the decision regarding DNR.

Time P: Time for the patient to make the decision regarding DNR.

Time W: Time - Anything about workflow of doctor. As in, is there time during the working day/clinic visit for physicians to have conversations about DNR with their patients.

Time trial: willingness to do a time limited trial of aggressive care.

Torture: Anytime an interviewee independently uses the word “torture.” Should also put in “Harm”

Transfer: when a patient is transferred because hospital won't provide futile care.

Treating the Family: Mention of CPR as a treatment for the family as opposed to for the patient.

Trust: Patients trusting doctors, believing doctor is telling the truth, etc. Also includes mistrust that is not cultural

Truth: Doctor telling the truth about the prognosis, being honest.

Two physician consent: mythical two physician consent

UFTO: Universal form of Treatment Options. RCT at Addenbrookes on Advanced Care Planning

UK mindset less: the trend that UK docs tend to think the default or what people want is less rather than US assumption that patients usually want more.

Understanding: (Also: information, education, knowledge)

Understanding CPR: Patient/family's understanding of what CPR is.

Understanding F: Family understanding/comprehension of patient's medical situation or options for treatment.

Understanding P: Patient understanding/comprehension of their medical situation or options for treatment.

Unilateral:

Unilateral DNR: when a unilateral DNR is instituted. Opposite sort of, of choice offering. But could also be a situation where a UK doctor describes not having to have the conversation before instituting a DNR, or saying they'll talk to the family after instituting, but never get to it, etc. And could be about conversation that occurs.

Unilateral US? : answer to question to US docs as to whether they'd be comfortable with UK system of unilateral DNRs

Unrealistic expectation: when family wants things that medicine can't achieve or hearing an overly optimistic version of what the doctor says

Values:

Values D: values of the doctor. What doctors would want for themselves

Values F: Values of Family

Values P: Values Patient: Discussion of patients' values, morals, etc. wrt EOL. Also can be values surrounding what it is to have a “meaningful life”

Variation: Whether there is variation in institutions or within opinions of doctors. Or alternatively, interviewee alluding to the fact that their views are mainstream or not uncommon. Generally speaking - this is distinct from overt conflicts with doctors (which would belong in Conflict D/D)

WWYD: what would you do - when patients ask doctors what they would do if it were they're loved one. Or more simply, patient asking, what should I do?

Waiting for family: keeping someone alive so that family members can come to see them one last time.

Want everything: Patient/family wants everything done. Doctor giving everything would go under "choice offering". Could also be variation on "do everything" → wanting to do everything

Want less: situation where patient wanted less intervention than what doctors thought should be right. i.e. DNR in a healthy patient

Whim: things that don't make sense medically that families or patients request, given to make them feel better. Psychologically therapeutic. Tailored treatments that don't make sense. Like full code but DNI.

Withdrawal: Withdrawal of care - Removing care from a patient, e.g. turning off a ventilator.

Won't work: not giving treatments that wont work (primarily UK)

Young: when talking about young people and how that makes a difference in this situation.

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