Providing ethical care:

Cardiopulmonary Resuscitation (CPR) for Chronic Obstructive Pulmonary Disease (COPD) Exacerbations in Patients with End Stage Lung Disease (ESLD)

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ABSTRACT

Cardiopulmonary resuscitation should generally not be offered to patients who suffer from a chronic obstructive pulmonary disease (COPD) exacerbation in the setting of end-stage lung disease (ESLD). Requests for CPR in this context may sometimes be uninformed, misguided, and the result of an unresolved grieving process by familial surrogates. While understandable, these requests rarely represent a truly autonomous patient perspective that is grounded in a competent, informed, and enlightened deliberation.

Alternatively, life-support technology and resuscitation is used appropriately when it is offered to patients with reversible disease, a disease for which functional recovery is possible, or to maintain a patient in an acceptable quality of life. It was never intended as, nor should it become, a treatment to delay the inevitable trajectory of a conscious or permanently unconscious and imminently dying patient.

When juxtaposed against perspectives of professional integrity, non-maleficence, distributive justice and basic human dignity, requests for CPR in this context rarely seem to be ethically persuasive or in the patient's best interests.

Pour les gens souffrant d'exacerbation en stade final des maladies respiratoires (SFMR) causée par une maladie pulmonaire obstructive chronique (MPOC), la réanimation cardio-pulmonaire est généralement à proscrire. Dans un tel contexte, la demande de réanimation peut être le résultant de mauvais renseignements, d'un choix malavisé ou même etre l'expression du refus des members de la famille face au deuil qu'ils auront à faire. Quoiqu'il est compréhensible de faire une telle demande, il est rare qu'elle soit bien fondée et représentative d'un choix éclairé et autonome de la part du patient ou de la patiente.

D'autre part, les technologies maintenant la vie ainsi que la réanimation sont utilisées de facon appropriée et juste lorsqu'elles sont offertes aux patient(e)s

chez qui la maladie est réversible, où le rétablissent fonctionnel est possible ou afin de maintenir une qualité de vie acceptable. En aucun temps devrait-on considérer la reanimation afin de prolonger l'inévitable parcours du patient inconscient ou conscient et du patient pour qui la mort est imminente.

Lorsque juxtaposée aux notions d'intégrité professionnelle, la bienfaisance, une justice distributive et de celle de la dignité humaine, la demande de réanimation cardio-pulmonaire dans ce contexte semble rarement être éthiquement persuasive ou être dans les meilleurs intérêts du patient.

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I am indebted to those who have gone before and shown me the path.

Gaol, Dilseachd.

Clinical Vignette

Mr. D. is a 71 year-old man, who has a past medical history of high blood pressure (hypertension), high cholesterol (hypercholesterolemia), and a longstanding history of smoking (one package/day for 55 years). He is a married, retired civil engineer who spends his time caring for his three grandchildren (ages 5, 9 and 11) two days per week, as well as golfing in the summer and curling in the winter. He volunteers at the Humane Society, leads his grandson's Scout troupe, assistant coaches his granddaughter's hockey team, and plays cards once every two weeks with his other retired engineer friends. He and his wife live in their own home and he looks after the yard work, snow clearance, and general maintenance duties. He is very proud to state he has only had a tradesperson in his home twice over the course of his lifetime.

Over the last two years, he has noticed that his energy level has significantly decreased and he is often short of breath (SOB). He used to be able to skate the entire duration of his granddaughter's hockey practice (two hours), and golf eighteen holes at a reasonable speed without resting. He now finds that he is often very winded and has to rest frequently for more than ten minutes at a time. He also has been concerned about his frequent lung infections over the last two and a half years. At first he thought the frequent infections were simply due to being in contact with his grandchildren and all their friends through their activities. He visited his family physician after the third "cold" in two months. He was concerned about the frequency and the duration of the illnesses. His physician, who could appreciate that Mr. D. rarely complained, ordered a chest x-ray (CXR), sputum cultures, blood, and lung function tests (LFTs). When Mr. D. asked his physician why so many tests were ordered, it was explained to him that due to his smoking history, it was important to ensure proper treatment for his infection and rule out any possible lung cancer. He was treated for pneumonia with antibiotics as well as bronchodilators.

Mr. D. attended a follow-up visit with his family physician. He was feeling generally better, but was still SOB with exertion. He was informed by his *physician that a lung specialist (respirologist) had reviewed his LFTs and CXR, and diagnosed him with a severe case of chronic obstructive pulmonary disease (COPD). The respirologist stated he had severe lung disease which would be progressive in nature. It was at this time that Mr. D.'s family physician began a discussion with him regarding an advance directive.*

Mr. D. was taken aback by the tone of the conversation. Mr. D. felt himself to be a reasonable person, and had not thought about advance directives. He always thought he would die in his sleep as he had been so healthy and active all his life. Mr. D. told his physician that he did not believe in CPR. He relayed a story about an unsuccessful attempt his neighbour's husband had sustained on their front lawn and how he would never want that for himself. He was not sure about a ventilator should that be considered medically necessary. Mr. D. enjoyed his life, but stated that unless he could return to a relative level of activity, he would not want to be "a vegetable, drooling in a home." He stated that it would "kill him" to not be able to at least see his granddaughter play hockey, and that he wouldn't go to his grandson's Scout troupe in a wheelchair with supplemental oxygen. Mr. D. told his physician that he would think about their discussion but when "…your number's up, it's up. That's it."

Eight months after the last visit to his physician, Mr. D. was feeling very unwell. He was so SOB he could not curl, go to the Scout troupe or coach hockey. He was having significant difficulty sleeping at night due to breathlessness, and his daytime activities had changed dramatically. He would tire walking around the inside of his house, and he had to hire someone to clear the least little bit of snow. He had supplemental oxygen for the last six months, but he noticed that the initial improvement had now plateaued. He also noticed that his spirits were waning. He could no longer care for his grandchildren or be active in their activities. He could no longer sleep with his wife as he was too SOB and restless. His appetite had withered and he always felt tired.

One day he was so SOB his wife called the ambulance and he was taken to the emergency department. He was in hypercapneic respiratory failure secondary *to his COPD. His wife consented to intubation and ventilation, as Mr. D. was unable to decide in his current state, and he was transferred to the ICU.*

After seven days in the ICU, Mr. D. had made no improvements. He remained on the ventilator with the same amount of support and oxygen as he had on his arrival. He had had a trial of lowering the support on day five of his admission but failed miserably. He and his family were spoken to at length about his poor progress and prognosis. He wanted his treatment to continue in spite of his previous comments to his family physician. At day twelve, he had still made no improvements, despite maximum medical management. His family attended to him everyday, interacting with him by telling him the latest news, bringing him flowers and family pictures and encouraging him to get well. Although it seemed he understood his family most times, there were many times when he was clearly too tired to even nod or shake his head "yes" or "no."

After fifteen days in the ICU with no improvements, the physician asked for a family meeting to discuss Mr. D.'s options. At this point, it was most likely that Mr. D. would never be able to live without a ventilator due to the extent of his disease, despite the tracheostomy that was performed three days earlier. The physician suggested that the kindest option for him would to be withdraw treatment, as he would never be able to live the life he enjoyed. He and his family were beside themselves with grief. The consent to withdraw treatment was denied. They were all devastated at the very suggestion of withdrawal of care.

The ICU physician asked Mr. D.'s family physician to come and discuss matters with Mr. D.'s family. Despite the earlier comments the family physician had recorded in Mr. D's chart about "not wanting to be a vegetable," "when your number's up," and "no CPR," the family was not convinced this was a true depiction of his wishes given his comments now. They believed it was his "engineering bravado," that led to such flippant comments about life and death. Mr. D. and the family could not come to grips with the fact that only three years earlier, he had been a robust, active, healthy man, coaching hockey, shoveling snow, caring for grandchildren and maintaining a house. Unfortunately, they were just too distraught to lose such an integral person in their family dynamic.

Neither Mr. D. nor his family could cope with his impending death. Mr. D. did not want the treatment stopped. They felt that if more time were given he would be able to rebound back to his usual self or at least not need the ventilator.

When discussing Mr. D. again at the three-week point (with still no improvement), it was clear to the physicians that he would never recover. Although Mr. D. had periods of lucidity during this time and wrote "want to live" on occasion, he was inconsistent in the nature of his responses due to the severe nature of his respiratory failure. A psychiatric assessment however, did not deem him incompetent. Mr. D. and his family wanted to continue treatment and often when they were at his bedside, they would encourage him to try and "get well." The physician could not convince them that a reasonable person would not want to continue with treatment given that the burdens outweighed the benefits.

Chapter 1

Introduction

The goal of this thesis is to integrate theoretical and clinical perspectives in addressing some of the complex ethical issues that I face as an intensive care physician in a hospital setting. I have attempted to research academic and professional positions on the withholding and withdrawing of life-support in the scenario of end-stage lung disease (ESLD), referring to literature from several disciplines such as medicine, law, and philosophy. My hope is to derive insights and potential answers from this literature so that I may be able to transfer and integrate these in a meaningful way to the clinical world in which I work. Specifically, I would hope to provide a more considered and ethical approach to the care of patients like the one described in the clinical vignette.

I am writing this thesis from the perspective of an intensive care unit (ICU) physician studying bioethics, rather than as a philosophy student. My goal is not to attempt a comprehensive or sophisticated philosophical, theological or legal analysis, but rather to understand the basic elements of an applied, clinical ethics analysis. While I am keenly aware of the extensive, rich and diverse literature on this subject, I have focused my analysis primarily on the works of Beauchamp and Childress, and McCollough, as well as to some of the legislation and jurisprudence related to my socio-cultural and clinical context. I have then tried to integrate this analysis with argumentation that is grounded in the clinical realities I encounter every day in the ICU setting.

Other limitations to the scope of this thesis are discussions that pertain to lung transplantation, (simple or heart-lung combination transplant). Individuals who suffer from congenital or metabolic lung disorders, cancer, asthma, tuberculosis or HIV/AIDS will also not be discussed. These conditions can be reversible or treatable diseases, and do not necessarily suggest an inevitable and imminent end-of-life trajectory. This thesis will be limited to some of the basic ethical dilemmas faced when considering whether or not to resuscitate patients during their COPD exacerbation who have end stage lung disease, as this represents non-curative, non-reversible pathology.

Within these restrictions, the ethics of considering life-support for ESLD patients will be discussed from a variety of perspectives. Fundamentally, I am interested in the following clinical questions. Should a patient with a chronic obstructive pulmonary disease (COPD) exacerbation in the setting of end-stage lung disease (ESLD) be resuscitated, and therefore mechanically ventilated? Should a patient have a trial of life-sustaining treatment in the form of respiratory support, when she knows the likelihood of being weaned successfully from the ventilator is extremely small and the burden for painful medical complications as a result of mechanical ventilation is very high? Furthermore, should she have a trial of life-support knowing that an unsuccessful weaning process will result in her demise without the ability to verbally communicate with her loved ones? Should a trial of life-support be offered by a physician when the very need for a ventilator signals a life expectancy that approximates one year? Alternatively, should she receive comfort care without the support of a ventilator, in order to control her symptoms and not prolong the dying process?

Patients, families and clinicians struggle with corollary questions. Who should have the final say in these complex decisions? While all parties have integral roles to play in the decision-making process, occasionally tensions and conflicts develop that appear irreconcilable. The permutations and combinations of such conflicts are numerous and each one presents a unique set of ethical dilemmas. The nature of the stated preferences may be morally relevant. However, to what extent should the moral agency of any one party be held hostage to irrational or idiosyncratic preferences of others?

These are difficult questions to answer. When medical paternalism flourished, the attending physician decided which patients received a resuscitation attempt. There was little discussion with the patient, the patient’s family or other healthcare members. As resuscitation technology evolved over time however, so too did the practice of medicine. In so doing, the practice has embraced the perspectives of scholars from many other disciplines with an interest in end-of-life issues and resuscitation.

This thesis will start with a review of the important historical points regarding the development of CPR and resuscitation (Chapter 2). This review aims to draw attention to the original use for this technology and how it has evolved. In Chapter 3, I will review the current definition, etiology, risk factors, natural history and medical recommendations for resuscitation of patients suffering from COPD.

In Chapter 4, I will consider position statements from some relevant constituencies in the medical profession. The analysis will demonstrate that the benefits of modern medical technology are very often lifesaving to those patients suffering from a critical illness. Cardiopulmonary resuscitation (CPR) is one modern medical treatment for such illnesses. It is a complex collective of medical procedures including, but not limited to, external chest compressions, invasive and non-invasive means of securing artificial airways, electrical shock treatment, sedation procedures, internal organ monitoring, temperature altering procedures, resuscitative medications and nutritional support. The frequency of fatalities of individuals from illnesses such as pneumonia, heart failure, cardiac arrest, and severe infection have been decreased as a result of aggressive intervention with resuscitation procedures and modern medical technologies.[1, 2, 3, 4]

One cohort of individuals in particular who have benefited from resuscitation measures are those with chronic obstructive pulmonary disease (COPD). They have benefited from the ability to have a machine help them breathe while they recuperate from their respiratory illness. Despite medical technology however, patients with chronic lung disease reach a point in time when the technology is unlikely to be helpful or life-sustaining. It is at this point that one must ask whether or not they should be resuscitated.

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[1] Jaber WA, Holms DR. "Outcome and Quality of Care of Patients who have Acute Myocardial Infarction." Medical Clinics of North America. 2007 Vol 91:4;751.

[2] Patel D et al. "Catheter ablation for atrial fibrillation: a promising therapy for congestive heart failure." Expert Reversible Cardiovascular Therapies. 2009 July 7:7;779.

[3] Fung, HB, Monteagudo-Chu MO. "Community-acquired pneumonia in the elderly." The American Journal of Geriatric Pharmacotherapy. 2010 Vol 8:1;47

[4] Nguyen HB, Rivers EP et al. "Severe Sepsis and septic shock: review of the literature and emergency department management guidelines." Annals of Emergency Medicine. 2006;48(1):28

In Chapter 5, I will examine some of the major legal cases that influenced a change in society's perception of resuscitation. I will focus on the Canadian, American, and Australian experiences, as these are three jurisdictions that have similar socio-cultural contexts, and arguably have the greatest influence on my clinical practice. Additionally, I have included the Israeli position on life-sustaining treatment, as it is the *only* country currently to have specific legislation regarding withholding and withdrawing life-sustaining treatment.

In Chapter 6, I will review basic deontological and teleological approaches to the clinical questions raised in the introduction, focusing on both Kantian and pluralistic notions of individual autonomy, as well as on principle-based theory as elaborated by Beauchamp and Childress in their seminal work *The Principles of Bioethics.* These will be complemented by utilitarian considerations, especially as they relate to notions of distributive justice in the allocation of scarce resources. I will consider additional philosophical contributions from McCollough's "appropriation model" of bioethics theory, some of the literature on futility and "futilitarianism," as well as feminist perspectives on how these issues relate to moral considerations with respect to human relationships and family dynamics. "Dignity ethics" will be discussed in the context of an alternative, palliative option to resuscitation in the setting of ESLD.

All of these ethical perspectives will be considered in the question of how a "reasonable person" standard could be appreciated and applied to the notions of a competent, informed, enlightened, and ultimately meaningful informed decision by a patient facing this clinical reality.

In the conclusion, I will argue that offering and providing a patient a resuscitation attempt for an end stage respiratory system is equivalent to inappropriately prolonging the imminent and inevitable trajectory of this chronic illness. Resuscitating a patient with ESLD adds a burden of pain and suffering to the patient with no appreciable benefit. Patients with ESLD who suffer from a COPD exacerbation should not be resuscitated with life-supporting technology. These patients should be offered appropriate and timely comfort care with the goal of palliation. In addition to these considerations of the patient's medical "best interests," I will argue that probable violations of patient autonomy through misguided surrogate representation, as well as significant threats to professional integrity fundamentally undermine any theoretical constructs in favour of providing resuscitation in this context.

Chapter 2

Cardiopulmonary Resuscitation

2.1 History of Cardiopulmonary Resuscitation

> *Thou takest away their breath, they die, and return to their dust.*
>
> *Psalms 104,29.*

Cardiopulmonary resuscitation (CPR) was a landmark medical development that had evolved over thousands of years, but had only come to fruition approximately forty years ago. All the experiments and theories that led to this discovery were based on a desire to preserve a sudden and unexpected death. A physician's ability to revive a person in this manner was nothing short of miraculous. The excitement of achieving this success however, overshadowed other societal constructs. Moral and ethical considerations lagged behind the science of CPR, and this created discord early on between physician groups and between physicians and society at large. Born from this discord were the lay scholars that emerged to assist decision-making within the medical community. Ethicists, legal experts, philosophers and religious leaders played an increasingly active role within the realm of medicine. For the first time, the "healing," as the ultimate medical goal, was re-evaluated, and with it the view of dying. Despite the early excitement around CPR, the last forty years have shown no appreciable improvement in patient outcomes. Instead, a revisionist would state that the technology spawned a new view of death. It meant the old medical demand of extending life at all costs was replaced with a new concept of maximizing quality rather than quantity of life.

Modern cardiopulmonary resuscitation (CPR) is credited to Kouwenhoven, Jude and Knickerbocker in 1960, although the origins of CPR date back to antiquity. Prior to the Egyptian papyri, which were the earliest written medical documents dating back 2000 years B.C., pictorial evidence found in

Spain depicted even earlier resuscitation attempts.[5] Hundreds of years later, Egyptian mythology depicts the healing goddess Isis reviving her husband Osiris with an artificial respiration technique,[6] "…she stirred up from his state of inactivity him whose heart was still."[7] There are biblical stories from the Old Testament in the books of Kings I and Kings II, describing two incidents of restored life, not from overt miracles or God's hands working through prophets, but by using very primitive CPR techniques.[8] The techniques of CPR and artificial respiration at this time relied on an individual person rhythmically inflating and deflating the lungs through direct insufflation through either the patient's nose or mouth. One technique involved moving the supine patient's arms back and forth over their head in an attempt to draw air into their lungs. Another technique described an upward thrusting and releasing motion on the patient's abdomen. This was also thought to draw air into a person's lungs. It was believed that if lung function returned, it could also stimulate cardiac function to return. The story in the book of Kings II describes the revival of an apparently dead child,[9] using the latter technique. Hebrew midwives were also known to use "resuscitation techniques" for newborn babies as early as 1300 B.C.[10]

It was not until some time between 200 B.C. and 400 A.D. that a procedure to secure an airway, bypassing the nose and mouth, was discovered. The earliest description of such an airway was recorded in the Babylonian Talmud, and the patient was in fact not human, but a lamb.[11] The Talmud describes the first successful tracheostomy.

In 177 A.D., Galen, the Greek physician, began experimenting with artificial respiration techniques, predominantly with the use of bellows. Using a dead animal, he would inflate the lungs and observe the change in the animals'

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[5] Varon J., Sternbach G.L. "Cardiopulmonary Resuscitation: Lessons From the Past." The Journal of Emergency Medicine. 1991; 9:503.
[6] Baker, A.B. "Artificial Respiration, the History of an Idea." Medical History. 1971;15:336.
[7] Ibid 336.
[8] Kings I, 17:17-22 (KJV), Kings II, 4:34-35 (KJV).
[9] Kings II, 4:34-35 (KJV).
[10] Varon and Sternbach 1991, 504.
[11] Weil M.H., Tang W. "Cardiopulmonary Resuscitation: A Promise As Yet Largely Unfulfilled." Disease-a-Month. 1997;43(7):441.

pulmonary physiology. Although many of his conclusions were incorrect, (he believed the right and left chambers of the heart communicated with each other) his view on physiology was not challenged for hundreds of years.[12, 13]

The16th century marked the beginning of the modern era of medicine. This was the time when Galen's ideas were starting to be questioned. He was no longer the undisputed authority on medicine and physiology, and his earlier idea regarding communicating heart chambers was proven false. In 1543, Vesalius, a Belgian anatomist published the first comprehensive anatomy textbook and documented the first experiments of successful tracheostomy on animals.[14] He inserted a hollow reed into the tracheae of live pigs and dogs, and demonstrated a functioning airway that bypassed the nose and mouth. Vesalius furthered his experiment by attaching these reeds to a bellows mechanism that Galen had described much earlier which would artificially inflate the animals' lungs,[15, 16] thus producing a very primitive ventilator.

At the same time, Paracelsus, a Swiss scientist who mixed medicine, chemistry, astrology and the mysticism of the cabala, described using the bellows technique for people who had suffered a cardiac arrest.[17, 18] Due to his dabbling in mysticism as well as his unusual writings, he was not taken as seriously as Vesalius. Hundreds of years later, he was still criticized.[19] In 1856, Renouard called Paracelsus "…a barbarian, an ignorant, who despised all the sciences, for the sole reason that he was ignorant of them all…." [20] Although many may have agreed with Renouard, there were others who did not. In 1871, less than twenty years after Renouard's harsh criticism, Friedrich Trendelenburg invented the first cuffed tracheotomy tube, based on Paracelsus's earlier concepts.[21, 22]

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[12] Varon and Sternbach 1991, 504.
[13] Baker, A.B. 1971, 336.
[14] Weil and Tang 1997, 442.
[15] Baker A.B. 1971, 337.
[16] Weil and Tang 1997, 442.
[17] Hemrock A.S. "The History of Cardiopulmonary Resuscitation." American Journal of Surgery. 1988;156:432.
[18] Liss H.P. "A History of Resuscitation." Annals of Emergency Medicine. 1986;15:65-72.
[19] Varon and Sternbach 1991, 504.
[20] Ibid 504.
[21] Weil and Tang 1997, 444.

The concepts of modern medicine continued to evolve quickly in the 17th century, and approaches to medicine changed from speculative to quantitative and experimental. In 1628, William Harvey provided the first accurate description of the circulation of blood, and postulated that a victim of cardiac arrest could be revived if the circulation of blood could be re-established.[23] In 1667, Robert Hooke demonstrated that the heart's movement and the lungs' movement were independent of each other.[24]

In the eighteenth century, the victims of drowning received increased attention both from the public and the medical community. In the later half of the century, societies were formed to promote the active revival of people who had apparently drowned.[25, 26] The first of such societies was the Academie des Sciences (Paris), which had stated that an attempt at artificial respiration should be made for anyone who had apparently drowned.[27] In 1744, Tossach was the first to have successfully resuscitated a human[28] and although the patient was a coal miner overcome with fumes, and not a drowning victim, the procedure resulted in the first documented successful resuscitation.[29, 30]

Following this success, other societies began to appear. In 1767, the Dutch founded a society in Amsterdam in 1767 for the purpose of reviving the apparently drowned, and in four years stated that they had successfully saved 150 drowning victims.[31] Other societies formed in Venice and Milan in 1768, Paris in 1771, London in 1774 and Philadelphia in 1780.[32] The British Society formed the "Society for the Recovery of Persons Apparently Drowned", and then renamed it the "Royal Humane Society for the Apparently Dead" in 1776. In the first 19

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[22] Varon and Sternbach 1991, 504.
[23] Ibid 504.
[24] Lee R.V. "Cardiopulmonary Resuscitation in the Eighteenth Century – A Historical Perspective on Present Practice." Journal of the History of Medicine. 1972;419.
[25] Baker A.B. 1971, 341.
[26] Varon J., Marik P.E., Fromm R.E. "Cardiopulmonary Resuscitation : A Review for Clinicians." Resuscitation. 1998;36:133.
[27] Baker A.B. 1971, 341.
[28] Ibid 341.
[29] Varon and Sternbach 1991, 505.
[30] Baker A.B. 1971, 341.
[31] Timmermans S. Sudden Death and the Myth of CPR. Philadelphia: Temple University Press, 1999; 33.
[32] Lee R.V. 1972, 421.

years of its existence, this society claimed it had revived 747 persons out of a total of 1 706 cases - a 43.7% success rate.[33] This high rate of success needs to be appreciated within the content of the definition of revival at the time. The successes not only included the apparently drowned, but those persons who were subjected to smoke inhalation, as well as those who had fallen into the sea from their crafts, yet were still conscious at the time of recovery. At the time, there were other techniques thought to resuscitate people, such as the "ice method," developed by the Russians, whereby the person's body would be encased in ice and snow in the hope of slowing the body's metabolism.[34] Unfortunately, they did not realise it was the head that also needed to be cooled for this to be successful.

In the mid 1700s, the double-chambered bellows was developed by the Scottish physician John Hunter. The bellows was the preferred mechanism of respiration from the time of Hunter to the early 1900s, when orotracheal tubes also became a tool in the resuscitation armamentarium. Some still believed however, that the mouth-to mouth method of artificial respiration was safer and much easier for the average man to perform.[35]

In 1775, Squires of London documented the first use of electricity to restart a three-year old girl's heart. She had suffered a cardiac arrest after falling from a height of one storey.[36] In 1783, DeHaen gave a description of a manual, external cardiac resuscitation. It was a technique that required not only chest pressure but the motion of arm lifting.[37] Members of the Royal Humane Society had made many contributions regarding revival, but perhaps none so foreshadowing of what was to come than the contribution of John Sherwin in 1786. He stated that one should "…go on inflating the lungs and alternately compressing the sternum."[38]

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[33] Timmermans S. 1999, 37.

[34] Bass, Madeline. Palliative Care Resuscitation. 2006. West Sussex, England: John Wiley And Sons Ltd.:3

[35] Lee 1972, 426.

[36] Debard, M.L. "The history of cardiopulmonary resuscitation." Annals of Emergency Medicine. 1980;9(5):274.

[37] Ibid 274.

[38] Julian D.G. "Cardiac Resuscitation in the Eighteenth Century." Heart and Lung. 1975;4(1):47.

Not long after this in 1809, the Scottish physician Allan Burns made two formidable conclusions that were well ahead of his time. The first was that death should not be assumed until there were unequivocal signs of death, and the second, that an electric shock and the use of artificial respiration needed to be linked together to have a successful resuscitation.[39] In his textbook on *Observations on Diseases of the Heart* in 1809, he states that "…we ought to inflate the lungs, and pass electric shocks through the chest; the practitioner ought never, if the death has been sudden, and the person not very far advanced in life, to despair of success till he has unequivocal signs of real death."

Perhaps the single, most noteworthy event to drive resuscitation experiments even further was the invention of anaesthesia in 1842. The advent of anaesthesia enabled physicians to perform more invasive surgeries and procedures on relatively well individuals. The introduction of chloroform as an anaesthetic produced the first well documented cardiac arrest in a young girl, which was completely iatrogenic in nature. Experimentation in closed and open heart massage techniques began to flourish.[40] In 1889, John MacWilliam from Aberdeen, Scotland had a brilliant hypothesis. He suggested that a cardiac arrest may not be the result of a poor heart due to a circulatory problem, but rather due to an electrical problem. He postulated that sudden cardiac death was a result of ventricular fibrillation.[41]

In 1898, Tuffier and Hallion performed a successful open chest cardiac massage, which was the basis for the 1950s version of the technique. In 1899, Provost and Batelli used alternating electrical current on dogs, which successfully induced ventricular fibrillation.[42] A dog was successfully internally defibrillated for the first time that same year.

A human was internally defibrillated successfully in 1947 for the first time. This was accomplished by Claude Beck, who was a cardiothoracic surgeon. He believed that the electrical circuitry in one's heart could cause a cardiac arrest.

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[39] Lamont 2001, 195.
[40] Debard 1980, 274.
[41] Weil and Tang 1997, 447.
[42] Bass 2006, 3.

He stated that there were “hearts too good to die.”[43] Zoll performed the first successful external defibrillation on a human in 1956.[44, 45] In 1960, Kouvenhoven, Jude, and Knickerbocker stunned the world with the first successful closed-chest cardiac resuscitation, and gave the medical world the current concept of cardiopulmonary resuscitation.

It was in 1966 that the Ad Hoc Committee on Cardiopulmonary Resuscitation of the National Academy of Sciences and National Research Council published their first statement on the procedure of CPR.[46] The knowledge of the history of the events and experiments leading up to the development of the current CPR techniques is paramount in understanding how this procedure has changed our perspective on death and dying. Until this point in history, and for approximately ten years afterwards, (1960-1968/69), the goal of understanding medical physiology and the mechanism of resuscitation was to prevent *sudden death* in the previously well person. It was to prevent sudden death by drowning, electrocution, toxic inhalation, and reversible physiological disasters in a patient with an otherwise good heart. The advancement of CPR from the earliest stages in 1842 through to the 1950s was also to enable physicians to reverse the effects of anaesthetic complications on the previously well person; primarily a cardiac arrest in a person with a healthy heart. It was well known in the 1950s that cardiac rhythm disorders and sudden drops in blood pressure due to anesthetic agents could cause cardiac tissue to fibrillate or die. Halothane was the latest of anaesthetics at the time, and it caused marked myocardial depression. The advent of successful CPR techniques led physicians to use halothane more widely and for longer surgical procedures, without as many concerns for myocardial depression and iatrogenic death.[47]

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[43] Weil and Tang 1997, 448.
[44] DeBard 1980, 275.
[45] Safar 1996, S7.
[46] Liss 1986, 69.
[47] Timmermans 1999, 51-52.

2.2 Medical and Social Evolution of Resuscitation Technology

The boundaries which divide Life and Death are, at best, shadowy and vague.
Who shall say where the one ends, and where the other begins? [48]

Until this point in medical history, the definition of death was based on cardiac death, or more specifically a total cessation of cardiac activity. Regardless of what disease a person suffers, or the extent of that disease, the cause of death in every person is an eventual failure of cardiac and pulmonary function. The ultimate mechanism of death is always a lethal arrhythmia,[49] regardless of what may have prompted that arrhythmia.

In 1960, the culmination of artificial respiration techniques, closed cardiac compression, successful external and internal defibrillation, coupled with the advance of instruments and tools to support an artificial cardio pulmonary system, created a situation in which the definition of death would soon be irrevocably changed. By 1968, after many discussions, an ad hoc committee of the Harvard Medical Faculty that included scholars and clinicians, redefined death, as "brain death." [50, 51] Brain death is defined as a "condition characterized by irreversible cessation of life-supporting function in the central nervous system."[52] No longer was a pulseless and apnoeic person qualified as "dead," as these functions could be temporarily overridden with ventilators, medicines, and defibrillation techniques. Kouvenhoven et al's discovery had pushed research forward to create an artificial system to regain cardiac function after it had been previously lost. Cardiac death could no longer adequately define death, as this could now be a "reversible" state.

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[48] Poe 1844, 532.

[49] Kumar V., Contran R.S., Robbins S.L. Basic Pathology. 5th Edition.1992 Philadelphia: W. B. Saunders Company, 314.

[50] JAMA. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death A definition of irreversible coma: report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. Journal of the American Medical Association. 1968;205:85.

[51] Giacomini, M. "A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968." Social Science and Medicine. 1997;44(10):1465.

[52] Marino, P.L. The ICU Book. 2nd Edition. 1998. Baltimore: Williams and Wilkins.

There were many accounts of *why* this change in the definition of death occurred, but they all fell into one of two categories – a "change in technical progress of medicine," and a "defensive response of medicine to public skepticism about the ethics of heart transplant research."[53] Giacomini argues that of these two categories, the technical progress of medicine was the more altruistic category and the more common explanation of why "brain death" developed. The fact that diagnostic techniques such as electroencephalograms (EEG) were being developed led to more information on brain waves and what it meant to be "alive."

Giacomini argues however, that evolving public skepticism provided a more critical analysis of the changes in the definition of death, and was perhaps the true scientific force behind the redefinition. These accounts consider transplantation as the key event that spurred the Ad Hoc Committee to redefine death. If a person was dead by cardiac criteria, their heart would have to cease to beat, and the opportunity for organ harvesting could be lost. If a person was dead by cerebral criteria, their heart might continue to beat, the supply of blood and oxygen to their organs would continue, and organ harvesting would be more feasible. One would be left with a corpse containing a complete set of viable, healthy organs (with the exception of the brain).

Regardless of the reasoning for the redefining of death, this new definition solidified the need for artificial "heart and lung" machines. It took the physiological advances of cardiopulmonary resuscitation out of the realm of medical science and foisted them into ethical and social arenas. The advance of CPR and the subsequent redefining of death changed the way people perceived death.

The excitement of medical science continued well beyond Kouvenhoven, Jude and Knickerbocker's landmark article in 1960 describing the success of CPR and closed cardiac compression. The world's first heart transplant was successfully performed in December of 1967 in South Africa by a team of physicians led by Dr. Christian Barnard. Although the patient lived for only 18

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[53] Giacomini 1997, 1465.

days after the transplant, the news of the success garnered expected worldwide attention.[54]

The perception of death had irrevocably changed with this landmark achievement of medical science. On one hand, the world was shocked and amazed that cardiac transplantation was feasible. This would naturally lead the lay public to believe that in time, other organs could eventually be transplanted. One could safely extrapolate that with continued research into transplantation, previously fatal diseases would not remain as such, and life expectancies would therefore increase.

It is no surprise that this era was marked by an explosion of non-medical scholars becoming very interested in the perception and meaning of death. It was the first time in modern history that the decision regarding who lived and who died was not the sole purview of the medical community. Ethicists, lawyers, philosophers, and theologians were now intimately involved in decisions about who was to be "saved" and resuscitated and who was not. Medical staff alone no longer had absolute authority regarding decisions about the use of life-saving, resuscitative techniques.

In the early 1960s, advocates of cardiopulmonary resuscitation rallied for more research funding as well as for more training of physicians and hospital staff in CPR. The hospitals were responsible for forming resuscitation teams, and medical schools were responsible for teaching CPR to its students.[55] The method of CPR was trialed over a nine-month period at John Hopkins Hospital and twenty patients aged 2 to 80 were all successfully resuscitated. Fourteen of these lived to the time when the publication of the article describing this trial was released 10 months later.[56] At the time, CPR was considered to be "the restoration of life after death."[57] It was the ultimate success story. But was this a success story?

To the public, CPR was an enormous success. Now no one was dead without first having a trial of CPR. The miraculous aspect of this procedure

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[54] Giacomini 1997, 1473.

[55] Bains, J. "From Reviving the Living to Raising the Dead: The Making of Cardiac Resuscitation." <u>Social Science and Medicine.</u> 1998;47(9):1344.

[56] Bass 2006, 4.

[57] Bains 1998, 1346.

changed the way in which people thought of death. Kouvenhoven's lectures and papers all espoused that CPR could be done by anyone, anywhere, with only two hands. Firefighters, police, ambulance attendants, and first aid personnel were all taught how to perform this technique. No longer was it merely a hospital procedure performed by experts. Early successes were reported with pride. A firefighter in Baltimore successfully revived a person only four days after being taught the technique. This story was reported in the *Baltimore New Post* on May 24, 1960.[58] CPR was thought to be such a success story that despite some concerns of safety with lay-person CPR, it began to be taught to the general public in 1973.

Success rates were variable. In a study by Sandoval in 1965, there was a 30% success rate for cardiac resuscitations at a community hospital.[59] These results were high when compared to other facilities. When eight facilities were compared, survival rates ranged from 3% to 30%, with five of eight facilities showing less than 10% survival rates. Those that survived were more likely to have suffered a witnessed, ventricular fibrillation arrest.[60] These studies and other studies since have shown that cardiopulmonary resuscitation was a success story for the people for whom it was originally designed. It was intended for those patients who were otherwise well; who did not suffer from a major underlying chronic disease. CPR was successful for those who had a singular cardiac event. Data from 1998 concur with the statistics of 1965 with respect to successful outcomes.[61] Varon quotes a success rate of approximately 15% of cardiac resuscitations performed in hospitals.

CPR was not a success story for those people who were already dying from an underlying chronic disease. It was not a "success" when the patient was perpetually maintained in a "living" state on machines, with no hope of recovery from the initial non- reversible disease. Death is inevitable, but the trauma and pain of resuscitative measures is not. It was not widely disseminated that

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[58] Bains 1998, 1344.

[59] Sandoval, R.G. "Survival Rate After Cardiac Arrest in a Community Hospital." Journal of the American Medical Association. 1965;194(6):206.

[60] Varon, Marik and Fromm 1998, 134.

[61] Ibid 134.

effective CPR could fracture ribs, puncture lungs, or lacerate spleens and livers. CPR is not a benign technique. Initially (as reported in the Globe and Mail in both 1962 and 1973) medical staff thought it too risky for the lay-person to apply.[62, 63] This concern diminished over the years as education and training programs developed for first responders and the general public. At the same time, the success rate did not significantly increase. Even after forty years of CPR experience, the success rates have remained virtually unchanged.

What did change was how people started to perceive death. At first there was a shift in thought within the medical community. Physicians started to ask themselves whether it was ethical to attempt to keep people alive at all cost. Which came first, the patient's best interests or the pursuit of science? Prior to the introduction of CPR and life support machines, medical resuscitative technology was very limited. Now with the development of new technology, the boundaries of ethical decision-making left the realm of medicine and now included the disciplines of morality, philosophy, and religion. What did it mean for a person to die? Was the manner in which people died important?

The advent of this technology spawned a new age of thinking about the nature of dying. The age-old paradigm of preserving life at all costs started to wane. There was a shift in importance from preserving *quantity* of life to promoting *quality* of life. As early as October of 1967, physicians were questioning at what point was treatment enough. In 1967, *The Lancet* received a letter addressed to the editor regarding concerns over resuscitation, a mere year after the Ad Hoc Committee stated that CPR was indeed the standard of care. The author was striving to make a clear distinction between the words "resuscitation" and "resurrection." He defined resuscitation as an intervention to help keep a living person alive, and resurrection as bringing a dead person back to life. He further discussed that the resurrected person was "no better than a vegetable – unable to speak, unable to do anything for himself, unable to express any emotion. Anyone who has seen such a resurrected man would agree that he would have

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[62] Globe and Mail. 1962. (December 1) Warn Heart Pumping by Layman Perilous. 11.
[63] Globe and Mail. 1973. (August 13) Doctors fear injury if public is trained in heart massage. 5.

been better left dead."[64] He continued with the notion that a physician should not think twice about *resuscitating* a person. However, she should think very carefully before attempting *to resurrect* someone.[65] *The British Medical Journal* (BMJ) published a letter to the editor in 1968 entitled "Not Allowed to Die." The physician described a case of a 68 year-old man with a gastric carcinoma who had received maximal medical, surgical, and palliative care. Following his surgery, he had expressly requested no further intervention to sustain his life. However, when his heart stopped, he was resuscitated 5 times on 5 separate occasions, within a twenty-four hour period, only to be left in a decerebrate neurological state, and to die in that state 3 weeks later.[66] The prima facie physician tenant of "do no harm," had been clearly neglected. The patient's right to autonomy and self-determination had been violated. His wishes were not violated from a sense of ignorance or simply unknown instruction. His right to self-determination was superceded by a sense of medical paternalism and an ability to implement an array of resuscitation techniques.

Similarly in 1969, another letter to the editor was published in the BMJ. It described the situation of an 84 year-old gentleman with metastatic carcinoma, who was resuscitated following a massive gastro-intestinal bleed secondary to the effects of the radiotherapy that he was receiving. The letter sums up the new and changing attitude regarding death:

> "Death, it seems, must be prevented whenever possible, whatever the ultimate costs, no matter how painful the period of repayment by the patient and his relatives. If one discounts the inhumanly human situation of deliberate torture the fear of death is normally divisible into two parts: the fear of death itself and the fear of the suffering that may have to be endured before death. Have we now to add a further dimension, the fear of resuscitation?

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[64] Perkins G. "Resuscitation." The Lancet. 1967;October 21:888.
[65] Ibid 888.
[66] Symmers W.St.C. "Not Allowed to Die." British Medical Journal. 1968;February 17 442.

> Many doctors used to feel that the greatest of our professional hazards was the mistake that kills. Has it now been usurped by that which keeps the patient alive?" [67]

CPR may have created a death-defying society that would fight death at all costs, attempting not only to resuscitate a terminally ill patient but to resurrect one in misguided attempts to stave off death. The earlier question regarding the use of CPR ("Because we can, should we?"), was partly answered by these letters. However, the ethics of this question remain controversial today. "It is available, therefore it must be done," still seems a prevailing thought. A campaign to deny and control death is being waged with technological machines and technological medicine.[68]

Conflict arose in the early 1970s between the growing number of physicians who believed CPR and life-support inappropriate for many patients, and the public's perception of its effectiveness. This public perception was only endorsed by the growing number of CPR training programs, the educational push by the media that "anyone could save a life" and the rapid emergence of intensive care units all over the country. The very public successes of resuscitation gave the public a very false view that CPR was appropriate for everyone. The belief that everyone could be saved with CPR was propagated by the media with falsely elevated success rates. The worst media source for inaccurate rates was television. A study completed by *Diem et al,* reviewed the success rates of CPR and resuscitation techniques for fictional medical television dramas, and found that there was a significantly higher success rate. The television rate was two to three times more successful than the documented results of the *most optimistic* medical literature.[69] With a distorted view of the reality of CPR, and the abundance of medical technology, how could the public have anything but an inappropriate optimistic understanding of resuscitation?

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[67] Emrys-Roberts M. "Death and Resuscitation." British Medical Journal. 1969;November 8, 364-365.

[68] Moller D. W. On Death Without Dignity – The Human Impact of Technical Dying. 1990 New York: Baywood Publishing Company.

[69] Diem S. J., Lantos J.D., Tulsky J.A. "Cardiopulmonary Resuscitation on Television." New England Journal of Medicine. 1996;334:1579.

During the paternalistic era of the 1970s, physicians would categorise a patient as a DNR candidate based on their medical expertise, as well as their own sense of medical futility. Conflict arose when families or patients found out that these decisions were often made without their knowledge and against their wishes. Many patients and families wanted full resuscitation attempts, regardless of the physicians' assessment of futility. In June of 1974, the Canadian Medical Association issued a statement, which was later published on the front page of the Globe and Mail, that a DNR order is an ethical decision,[70] based on the assessment of medical futility.

One can only wonder why DNR orders ever became necessary? Physicians' teachings, in the broadest of terms, were to administer to the sick and to relieve suffering. Preserving life is one of medicine's fundamental goals, but it is not the only goal. No historical document ever gave instruction to physicians to try to resurrect the dead. In earlier times, this notion of resurrection would have been fraught with danger for both the patient and the physician. Discussions of resuscitations would have invoked accusations of sinister medicine, occult mysticism, or outright devil worship.

Death, although the final stage of life, is a very natural part of it, one to which every person succumbs, regardless of any one factor or characteristic. Somehow, with the invention of artificial respiration and resuscitation techniques, the inevitability of death seemed lost in the quagmire of new and rapidly expanding medical science. Resuscitation was originally devised to only alleviate iatrogenic problems from medications and invasive procedures. It was never plausible to use this procedure as a tool to aid those that had died.

One of the early outmoded paternalistic assumptions in medicine was that a reasonable person would always consent to resuscitation efforts. But how could one consent to a procedure without knowing its risks and benefits? And if no consent was given, CPR could constitute a form of assault – an unauthorized

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[70] Globe and Mail. 1974. (June 25) 'No resuscitation' order for dying patient is ethical, doctors decide. 1.

touching.[71] The assumption that everyone would consent to CPR is inherently flawed. This was, in fact, how resuscitative medical procedures were changing society's views on life and death. For some, quantity of life was no longer paramount. Quality of life became an important criterion for consideration.

As the medical community's impression of the value of CPR changed over the years, there was increased discourse between patients and physicians regarding treatment plans. This change in the role of both caregiver and care receiver came about as a direct result of the advent of CPR. The advent of CPR created a new social convention and inadvertently gave birth to the advance directive. CPR, a technological landmark in medical history, changed the way society looked not at a resuscitated life, but at a planned death.

Advance directives are documents that outline a patient's wishes regarding medical care, in anticipation of the time when the patient is unable to communicate. It is a "formal document written by a competent person that is designed to guide medical treatment in the event of future mental incapacity."[72] (There is also an option for a surrogate decision maker, in the event that one does not have an advance directive.)

The first 'Living Will' was proposed by the Euthanasia Society of America in 1967.[73] This proposal was the first of its kind and was a document in which a person could specify whether they would like to forgo life-sustaining treatment. Interestingly, it came into existence merely *one year* after CPR was sanctioned. In 1976, as a result of the Karen Ann Quinlan case, the *Natural Death Act* was legislated in California. It remained in effect until 1991 when the *Federal Patient Self Determination Act* supplanted it.[74]

The Karen Ann Quinlan case was the first to put a human face on the notion of medical science overstepping its bounds in the context of resuscitation. This young woman was resuscitated after a tragic and deadly ingestion of alcohol

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[71] Veatch 2003, 1594.

[72] Quill. T.E. Death and Dignity – Making Choices and Taking Charge. 1993. NewYork, N.Y.: W.W.Norton and Company. 189

[73] Sanchez-Gonzalez M.A. "Advance Directives Outside the USA: Are They the Best Solution Everywhere?" Theoretical Medicine. 1997;18:284.

[74] Ibid 285.

and medications. She remained on life-support machines, despite the family's wishes to have them removed. Physicians at the time would not remove her life-supporting apparatus, even though she was declared dead by brain death criteria. They feared legal reprisal and punitive consequence

Since then, advance directives have been implemented in many jurisdictions, and have taken many forms over the years, including interestingly, tattoos. Instead of having paper documents, which can be inaccessible at a critical moment, some individuals have resorted to tattooing a symbol representing DNR, or the actual letters 'DNR' on their chest.[75] Perhaps this speaks to the extent to which the pendulum has swung to present society's fear of inappropriate use of resuscitative technology.

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[75] Iserson K.V. "The 'No Code' Tattoo – An Ethical Dilemma." Western Journal of Medicine. 1992; 156:310.

Chapter 3

Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is the most prevalent of all end stage lung diseases and accounts for the majority of end stage lung related ICU admissions. Therefore, for the purpose of this paper, end stage lung disease will constitute the final stages of COPD. Other end-stage lung diseases such as alpha anti-trypsin deficiency syndrome, tuberculosis, adult respiratory distress syndrome and the other fatal lung diseases will not be discussed.

3.1 Definition of Chronic Obstructive Pulmonary Disease (COPD)

Chronic obstructive pulmonary disease is characterized as one of the most important causes of morbidity and mortality worldwide,[76] and is responsible for the largest number of fatalities of all respiratory diseases.[77] The American Thoracic Society (ATS) and the European Respiratory Society (ERS) both define COPD as "a preventable and treatable disease state characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with abnormal inflammatory response of the lungs to noxious particles or gases, primarily caused by cigarette smoking. Although COPD affects the lungs, it also produces significant systemic consequences."[78] When stating that the airflow limitation is not fully reversible, it is in the context that some patients have partial reversibility of the limitation secondary to corticosteroid or bronchodilator use.[79]

COPD is a combination of two main processes - chronic bronchitis and emphysema, of which there is usually an uneven distribution of the two occurring

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[76] Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJ. "Global and regional burden of disease and risk factors, 2001: systematic analysis of population health data." Lancet. 2006;367:1747.

[77] Ibid 1747.

[78] Celli BR, MacNee W, ATS/ERS Task Force. "Standards for the diagnosis and treatment of patients with COPD: a summary of the ATS/ERS position paper." European Respiratory Journal. 2004;23:934.

[79] Mannino D. "Chronic Obstructive Pulmonary Disease: Definition and Epidemiology." Respiratory Care. 2003;48:1186.

in any given patient. Chronic bronchitis is defined as the “presence of chronic or recurrent increase in bronchial secretions to cause expectoration. The secretions are present on most days for a minimum of three months per year for at least two successive years and cannot be attributed to other pulmonary or cardiac limitation.”[80] Emphysema is defined anatomically as “ permanent, destructive enlargement of airspaces distal to the terminal bronchioles without obvious fibrosis.”[81] More simply, the lungs are no longer able to expand and recoil, therefore, unable to move air smoothly. Of note, asthma is not considered to be COPD.

3.2 Definition and Prognosis of End Stage Lung Disease (ESLD)

End stage lung disease (from COPD) can evolve into a complex constellation of clinical features such as “very severe airflow limitation measured as a forced expiratory volume in 1 second (FEV1) of less than 30% of predicted values, (the FEV1 is defined as the amount of air a person can breathe out as quickly as possible in one second, and measuring the volume of air that is exhaled; the predicted value is based on the parameters of the patients, such as height, weight, gender etc.), severely limited and declining performance status, presence of multiple co-morbidities, and severe systemic manifestations or complications, (such as body compositions alterations, peripheral muscle dysfunction, respiratory muscle dysfunction, osteoporosis, pulmonary hypertension, cardiac impairment and fluid retention/oedema).”[82]

3.3 Risk Factors for COPD

There are two main categories of risk factors for COPD, endogenous (host specific) and environmental. There is a genetic susceptibility to the disease, but most of the risk factors are environmental. Tobacco smoke is the pre-eminent risk

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[80] Viegi G, Pistelli F, Sherrill DL, Malo S, Baldacci S, and Carrozzi L. “Definition, epidemiology and natural history of COPD.” European Respiratory Journal. 2007;30:994.

[81] Ibid 994.

[82] Ibid 996.

factor for developing COPD.[83] Age at the time of starting to smoke, total years of smoking combined with number of packs per day, (total pack-years smoked), and current smoking status all figure heavily into the risk of COPD mortality.[84] Furthermore, active smoking in an adult causes a "premature onset of an accelerated age-related decline in lung function."[85] Nevertheless, smoking cessation, barring any underlying permanent damage, is associated with a "return of the rate of decline in pulmonary function to that of 'never-smokers',"[86] and slowing the decline in FEV1.[87] There is a higher risk for developing COPD by those individuals that have a higher level of dependence on nicotine or other addictive behaviours.

Air pollution and occupational exposure increase one's chances of developing COPD. Reducing air pollution and exposure to it have a positive effect on reducing not only the development of COPD, but its severity as well.

3.4 Natural History and Complications of COPD and ESLD

Dyspnoea (shortness of breath) is the most significant symptom of people who suffer from COPD. Early on in a person's lung health trajectory, this breathlessness can be modified with medical treatments as well as behavioural changes. Once a person progresses to severe COPD with a FEV1 of less than 30% predicted, the person becomes breathless even with very minimal exertion.

The amount of airflow limitation is related to symptom severity, and management is mostly symptom driven. A grading system to predict mortality has been used in recent years using "body mass index, airflow obstruction, dyspnoea, and exercise capacity."[88]

Unfortunately, COPD exacerbations can be not only repetitive, but severe in nature. An exacerbation is defined as an increase in baseline symptoms (such as dyspnoea, cough, or sputum production), or the prevalence of new symptoms such

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[83] Pauwels Romain A, Rabe Klaus F. "Burden and clinical features of chronic obstructive pulmonary diease (COPD)." The Lancet. 2004;364:616.
[84] Viegi et al. 2007, 999.
[85] Ibid 1000.
[86] Ibid 1000.
[87] Pauwels and Rabe 2004, 616.
[88] Pauwels and Rabe 2004, 619.

as infection, fever, diaphoresis or all-out respiratory failure. An exacerbation of COPD can result in death from respiratory failure unless ventilatory support is provided.[89]

3.5 Mechanical Ventilation

Ventilatory support can be invasive. A tube (endotracheal tube) is placed in a person's windpipe (trachea) and attached to a breathing machine (ventilator). The ventilator can then operate in two general forms to assist the patient in their breathing. It can act like an external pair of lungs, initiating and triggering the breathing cycle. Alternatively, it can offer support for the patient, in the sense that once a person initiates a breath, the machine will blow air into the lungs. Given the invasive nature of this device, patients often require sedation and pain relieving medications.

A non-invasive respiratory support system, bi-level positive airway pressure (BIPAP), consists of an airway mask that a patient wears on her face that forces air into her lungs when she triggers a breath. Although this is less invasive than an endotracheal tube, the patient has to be able to trigger a breath independently. If a patient is in acute respiratory failure, often she is not mentally alert enough or physically strong enough to trigger a breath independently.

Often patients with the need for ventilatory support can get back to their previous baseline of respiratory function. However, the need for mechanical ventilation itself implies a life expectancy on average of one year,[90] with accompanying in-hospital mortality of 25% and a one-year mortality rate of 40% with the first requirement for mechanical ventilation.[91]

3.6 Complications of Mechanical Ventilation

Unfortunately, there are potential complications with this invasive procedure, including, but not limited to, the rupture of a patient's lungs

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[89] Dales RE, O'Connor A, Hebert P, Sullivan K, McKim D, Llewellyn-Thomas H. "Intubation and Mechanical Ventilation for COPD." Chest. 1999;116:792.

[90] Ibid 792.

[91] MacIntyre N, Huang YC. "Acute Exacerbation and Respiratory Failure in Chronic Obstructive Pulmonary Disease." Proceedings of the American Thoracic Society, 2008;Vol.5:534.

(pneumothorax), temporary or permanent voice changes (partial or complete vocal cord paralysis), bleeding, and airway tube bleeding or puncture (haemoptysis or bronchial rupture). There are also risks of ventilator-acquired pneumonia, intravenous or intra-arterial line sepsis, pressure related skin breakdown, failure to wean from the ventilator requiring withdrawal or tracheostomy (surgical hole made into the airway), heart rhythm disturbances, and multi-system organ failure or sudden cardiac death.

3.7 Resuscitation for COPD Exacerbation in ESLD

Modern cardiopulmonary resuscitation comprises a system of treatment that includes an algorithm of procedures and medications based on the presumed underlying cause of cessation of cardiac or pulmonary drive. The most successful outcomes occur in witnessed, in-hospital events. Survival is related inversely to onset of treatment, and each minute that a person remains either pulseless or without respirations, "decreases their survival by 7-10 percent."[92] The purpose is to temporarily provide effective oxygenation of vital organs through artificial circulation of oxygenated blood until such time as a natural restoration of normal cardiac and pulmonary function occurs.[93] This occurs through the use of chest compressions and artificial respiration techniques as well as medications, electrical therapy, and advance resuscitative techniques with resuscitative machines.

Complications of cardiopulmonary resuscitation can be many and may be severe or even fatal. Ventilation (artificial respiration) can cause insufflation of the stomach rather than the lungs, which could lead to regurgitation of the stomach contents causing aspiration pneumonia or possible stomach rupture (gastric rupture). Chest compressions can cause rib fractures, which can complicate physiological function further by having the potential to puncture lungs or solid organs (organs that are not hollow) such as a spleen or liver. One could die from lungs not being able to function normally due to puncture or

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[92] Tintinalli Judith, Kelen Gabor D., Stapczynski J. Stephan. (Editors). Emergency Medicine - A Comprehensive Study Guide 5th Edition 2000;42.
[93] Ibid 44.

bleeding, or from massive haemorrhage into the lungs, secondary to bleeding from solid organ damage. Puncture of non-solid organs (organs that are hollow) such as a gall bladder or small or large intestine, is also a risk and although not usually an immediate cause of death, can cause overwhelming abdominal infection leading to death. Compressions can contuse heart tissue and fractured ribs can pierce the heart, both further limiting a successful outcome. Late complications can include a permanent brain injury from lack of oxygen, (anoxic brain injury), which leaves a person alive but with limited or no higher cognitive function. Ventilatory support has the potential to produce lung ruptures, and often the medications required for this procedure require large intravenous lines. These lines have the potential to rupture veins and arteries, cause clots in the vessels, which can travel to the lungs, (deep vein thrombosis/pulmonary emboli) and can act as a source for a full body infection, (sepsis).

While these risks of resuscitation are relevant for many categories of patients, they are particularly heightened for patients in ESLD. This condition represents a baseline state which already places the patient at a much higher risk of complications than the otherwise healthy individual experiencing a sudden cardiac arrest. Seneff described an in-hospital mortality of 24% for ESLD with the first admission to an ICU.[94] Another large study described one-year mortality as 40% for ESLD patients requiring intubation,[95] and patients that are aged 65 or older, their mortality increases substantially to 59%.[96] Five-year mortality rates are greater than 70%.[97]

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[94] Seneff MG et al. "Hospital and 1-Year Survival of Patients Admitted to Intensive Care Units with Acute Exacerbation of Chronic Obstructive Pulmonary Disease." JAMA. 1995;Vol 274 No 23: 1852.

[95] Ai-Ping C, Lee KH, Lim TK. "In-hospital and 5 year mortality of patients treated in the ICU for acute exacerbations of COPD: a retrospective study." Chest. 2005;128:518.

[96] Seneff MG et al. 1995, 1852.

[97] Ai-Ping C, Lee KH, Lim TK. 2005, 518.

Chapter 4

Medical Profession's Positions on Resuscitation

One must appreciate a working definition of life-support to understand the rationale of the prevalent medical positions regarding resuscitation. Often there is confusion in the lay public, as it sees withdrawal of medical care as withdrawal of *all* medical care, including comfort medications, hydration, nutrition and supplemental oxygen. There is an understandable, though unintended lay understanding that when a physician says there is "nothing we can do," that this is meant to be interpreted literally. The fault for this assumption must be placed on those physicians, who may unfortunately feel that brutal honesty is the best manner in which to discuss end-of-life issues. This manner of conversation is misguided, as there is always an option for comfort care treatment, even when a resuscitation attempt is not offered. *Latimer* states, "this bluntness [in discussing end of life issues] is mistakenly believed to be the best form of honesty."[98] It should be explained to patients and their families that "life-support" refers only to "the provision of any or all of ventilatory support, inotropic support for the cardiovascular system, and hemodialysis to intensive care unit patients."[99] It does not preclude the use of pain medications, hydration, dyspnoea relieving medications, and a comfort care treatment plan. There is often a misconception that discontinuation of life-supportive treatment includes discontinuation of all treatment, which is not the case.

4.1 College of Physicians and Surgeons of Manitoba

Fortunately, the initiative of medical associations to put forth statements on withdrawal and withholding of medical treatment has improved. In 1991, only four provinces (Manitoba, Ontario, Quebec, and Nova Scotia) had policies and

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[98] Latimer E. "Caring for seriously ill and dying patients: the philosophy and ethics." Canadian Medical Association Journal. 1991;144(7):860.

[99] Rocker Graeme, Dunbar Scott. "Withholding or Withdrawal of Life Support: the Canadian Critical Care Society Position Paper." Journal of Palliative Care. 2000;16 Supplement: S53.

passed legislation on advance directives.[100] The policies regarding theses two topics were not uniform across the country. Fortunately, there have been improvements with these policies. At the present time, The College of Physicians and Surgeons of Manitoba has been the first province to issue a statement on the process for withholding and withdrawing life-sustaining treatment. The Statement was made public on January 30, 2008, despite early autumn deliberations on the subject, and became policy on February 1, 2008. The statement's purpose (no.1602), "is to assist physicians, their patients and others involved with decisions to withhold or withdraw life-sustaining treatment by establishing a process for physicians to follow when withholding or withdrawing life-sustaining treatment is being considered. It stipulates the ethical obligations of physicians, emphasizes open communication aimed at achieving consensus and provides for conflict resolution in circumstances where consensus cannot be reached."[101]

The statement was created because there are specific aspects of current provincial law which are ambiguous, despite the province affirming the right of the physician to be an authority on deciding when to withhold and withdraw treatment. There are certain legalities in the province of Manitoba on which the statement is based:

> "1. Neither legislation nor common law recognize a right to demand life- sustaining treatment.
>
> 2. No one, including the patient's next of kin, has the legal authority to consent to or refuse medical treatment, including life-sustaining treatment, on behalf of an adult patient, unless that person has been granted that authority by the patient in a valid health care proxy or by Court appointment pursuant to legislation.
>
> 3. The Manitoba Courts have recognized that physicians have the authority to make medical decisions to withhold or withdraw life-

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[100] Rasooly Iris, Lavery James V., Urowitz Sara, Choudhry Sujit, Seeman Neil, Meslin Eric, Lowy Frederick H., Singer Peter A. "Hospital policies on life sustaining treatments and advance directives in Canada." Canadian Medical Association Journal. 1994;150:8.

[101] The College of Physicians and Surgeons of Manitoba – Statement 1602, (2008) 15-S1.

> sustaining treatment from a patient without the consent of the patient or the patient's family.
>
> 4. Physicians' legal authority to make such decisions is subject to significant corresponding legal duties and ethical obligations.
>
> 5. Legislation provides that the death of a person takes place at the time at which irreversible cessation of all that person's brain function occurs."[102]

From a clinical point of view, there are numerous requirements that need to be met in order to decide if one is to withhold or withdraw life-sustaining treatment. Each of these requirements is attributable to four main components, which are clinical assessment, communication, implementation and documentation. These components can be reviewed in full from Statement No.1602, which is available on the College's website at www.cpsm.mb.ca.

The clinical assessment component is noteworthy. It maintains that feasibility of life-sustaining treatment options in the context of the minimum goal of life-sustaining treatment is paramount. The minimum goal is clinically defined as: "maintenance of or recovery to a level of cerebral function that enables the patient to:

- achieve awareness of self; and
- achieve awareness of environment; and
- experience his/her own existence."[103]

When there is no consensus among physicians concerning the feasibility to provide resuscitation care, or disagreement between physicians and family wishes, mechanisms have been established to help reconcile these differences. On occasion however, the only mechanism to resolve conflict is through judicial review.

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[102] The College of Physicians and Surgeons of Manitoba – Statement 1602, (2008) 15-S1.
[103] The College of Physicians and Surgeons of Manitoba – Statement 1602, (2008) 15-S1.

4.2 Critical Care Society of North America

The Critical Care Society holds the four principles of medical ethics in high regard as outlined in their paper discussing the withholding and withdrawal of life-sustaining treatment. The Society is concerned with the events which precede the initiation of life-support, and whether there is an appropriate decision made to offer life-support in the first place. An assessment should determine "whether or not provision of life-support, in seemingly hopeless circumstances, would merely artificially prevent the natural death of the patient."[104] The question that must be addressed when deciding about withholding or withdrawing life-sustaining treatment is: "Will this intervention prolong their life or will it prolong their death?" Life-support was designed to support patients' physiology in a time of critical illness until the healing process was complete. It was not meant to merely sustain a body (tissue) without some opportunity for meaningful recovery in the form of an awareness of self or environment. If the intervention prolongs life with the goal of achieving personal awareness, then it is a correct treatment and an appropriate investment of resources. If the treatment, however, prolongs the dying process in a manner in which there will be no sense of self or awareness despite intensive medical treatment, the treatment is inappropriate, and should not be offered.

Physicians however, are autonomous professionals, with their own personal, cultural, ethnic, religious and professional perspectives. The set values that a physician holds is a combination of these perspectives, as well as her education and experience in treating patients. Medicine is not a "cookbook" science in which all the "ingredients" are uniform (patients, diseases, physiology, etc.), and all the combinations yield the same product, (physician's assimilation of the information). Every patient is unique and every physician has a unique method to practice medicine, within the boundaries of accepted, professional standards of care.

It is also very clear that physicians do not have to practice medicine in a manner that is morally unacceptable to them, provided this does not challenge an

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[104] Rocker and Dunbar 2000, S54.

accepted standard of care. This situation is clearly understood with respect to withdrawal or withholding of life-sustaining treatment, not only by the Canadian Medical Association, but the Canadian judicial system as well. Although physicians do not have to treat patients in a manner that they find morally unacceptable, physicians are obliged to treat patients in a morally acceptable manner. While the Canadian Medical Protection Association (CMPA) had delineated circumstances under which a physician can terminate a professional relationship with a patient, these do not include perceived differences in moral value systems or frameworks. Fundamentally, regardless of the morality inherent in a procedure or treatment, physicians have a duty to ensure that patients have access to safe medical treatment and care.[105]

4.3 Canadian Medical Association

The Canadian Medical Association (CMA) stands by the declaration that states: "health care providers should not be expected or required to participate in procedures that are contrary to their professional judgment or personal moral values or that are contrary to the values or mission of their facility or agency."[106] This statement is relevant not only to notions of futility, but also to moral values inherent to the medical profession. A further discussion about "futilitarianism" and the differing definitions of futility is presented in a subsequent chapter of this thesis.

Unfortunately, despite the best intentions of medical associations to give clear guidelines regarding the withdrawal and withholding of life-sustaining treatment, more work needs to be done to prevent conflict. "There is a need to work towards more consistent care, both before and during admission, for the protection of the individual patient and to allow rational assessment of intensive care need."[107]

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[105] Birchard K. "Irish Doctors Surveyed on Treatment Refusal." The Lancet. 1997;350:872.

[106] "Joint Statement of Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care." Canadian Medical Association Website (www.cma.ca) 1998.

[107] Ravenscroft Andrew J., Bell M.D. Dominic. " 'End-of-life' decision making within intensive care – objective, consistent, defensible?" Journal of Medical Ethics. 2000;26:435.

> The Canadian Medical Association's statement on resuscitation states: "…efficacy of CPR in restoring cardiac and respiratory functioning varies from nil to very high, depending on a number of factors. On the basis of research studies for such outcomes four general categories can be distinguished:
>
> 1. people who are likely to benefit from CPR
> 2. people for whom benefit is uncertain
> 3. people whom benefit is unlikely
> 4. people who almost certainly will not benefit
>
> **Implementation**
>
> People likely to benefit from CPR should be given this treatment if the need arises, unless they have specifically rejected it. People for whom the benefit of CPR is uncertain or unlikely should be given this treatment if the need arises, unless they have specifically rejected it. CPR should be initiated until the person's condition has been assessed." (CMA)[108]

While there is considerable consensus within the medical and legal communities regarding the appropriateness of offering and providing advanced resuscitation techniques to those patients who are reasonably likely to benefit from them, there is also a considerable challenge to this consensus. Many individuals challenge the relatively authoritative monopoly of the medical professional who evaluate the efficacy of resuscitative measures, as well as the normative framework on which such decisions are based.

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[108] Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care." <u>Canadian Medical Association Website</u> (www.cma.ca) 1998.

Chapter 5

Legal Positions on Resuscitation – Withholding and Withdrawal of Treatment

5.1 Canadian Position

There is a paucity of specific Canadian legal precedent regarding conflicts in choices between giving a person suffering from a COPD exacerbation with end stage lung disease a trial of ventilation or not. There is more information on whether or not to withdraw treatment once it has been initiated. The decision to withhold initiation of treatment is much less clear in the law.

This discussion will not focus on the issue of withdrawing treatment. Instead it will consider the legalities of initiating treatment. The corollary question is whether there is a duty to offer treatment when it is considered a futile endeavour by physicians. Some concepts that are common to both areas (not initiating treatment and withdrawal of treatment) will be discussed. Some of the discussion will also be based on extrapolating from the literature regarding the withdrawal of treatment.

There is little legal precedent in Canada for the withdrawal of life-support treatment when this is proposed by physicians. There are a few court decisions that support a physician's perception that there is no requirement to provide treatment in the face of physiological futility. *Futility* itself is a controversial notion. There are subtle but important differences in the meaning of futility when used in a medical or legal contexts. For the sake of clarity, futility in the medical context will be understood in terms of probabilities in the clinical context, rather than in terms of categorical certainty. Many physicians understand futility as meaning a highly improbably outcome which will nevertheless fail to produce a clinically meaningful result for the patient. A categorical definition can be attained from the Oxford English Dictionary, in which the definition is "incapable of producing any result; failing utterly of the desired end through intrinsic defect;

useless, ineffectual, vain."[109] The problem with the notion of "physiological futility" is that it cannot be meaningfully construed in absolute terms. Further discussions of futility will follow. Clinically, futility is best appreciated in the context of the goals of care. Thus, futility can mean very different things depending on whether the goals of care are curative, restorative, maintenance, or palliative.

Despite the legal void regarding the understanding of medical futility in relations to initiation of treatment, there is some jurisprudence that states that physicians are not required to act against their moral conscience in the performance of their duties. They cannot be compelled to provide care that they professionally judge to be harmful to the patient. They also cannot abandon patients. In section 215 of the Criminal Code, there is a duty of care to the patient: "…everyone is under a legal duty to provide the necessities of life to a person under his charge if that person is unable, by reason of illness…."[110]

The courts must also decide what is just and convenient. Justice Shulman (Manitoba) stated that, "the issue of what is just or convenient is rooted in the laws of England going back centuries, long before the invention of ventilators….It is a concept that has evolved over the years."[111] As the notion of "just and convenient" evolved however, differing opinions and legal outcomes evolved as well.

Although physicians have a professional duty to care, the Criminal Code of Canada presently makes reference only to consent or refusal of treatment.[112] In Chapter 1, *Integrity of the Person,* Section 1, Care, Article 11, where it states that "no person may be made to undergo care of any nature, whether for examination, specimen taking, removal of tissue, treatment of any other act, except with his consent…."[113]

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[109] Soanes Catherine. (Ed.) Oxford Dictionary of Current English 3rd Edition New York: The Oxford University Press, Inc., 2001, 368.

[110] Criminal Code of Canada Section 215, 2003.

[111] *Golubchuk v. Salvation Army Grace General Hospital et al.* 2008 MBQB 49.

[112] Criminal Code of Canada 2003.

[113] Ibid Section 1, Article 1, 2003.

There are two Manitoba court decisions that support physicians who withdraw treatment without the consent of either the individual or the individual's family. These two decisions are *Child and Family Services of Central Manitoba v. L.(R.) &H.(L.) (1997)* [114] and *Sawatzky v. Riverview Health Centre (1998).*[115]

In *Child and Family Services of Central Manitoba v. L.(R.) &H.(L.)*, a three month-old infant was admitted to *The Children's Hospital of Winnipeg* after he was injured by family members. Since the battery left the child in a permanent vegetative state, the physicians recommended a DNR (do not resuscitate) order, to which the child agency agreed. (The agency assumed care of the child after the child was apprehended from the parents). The family disagreed with this recommendation. Justice Twaddle (Manitoba) made the distinction between how treatment was defined and how consent was derived. "Treatment" was determined to be a positive act, and therefore consent needed so as to not inflict assault. However not treating was not a positive act and therefore required no consent. Further,

> "neither consent nor a court order in lieu is required for a medical doctor to issue a non-resuscitative direction where, in his or her judgment, the patient is in an irreversible vegetative state. Whether or not such a direction should be issued is a judgment call for the doctor to make having regard to the patient's history and condition and the doctor's evaluation of the hopelessness of the case. The wishes of the patient's family or guardians should be taken into account, but neither their consent nor the approval of the court is required."[116]

In *Sawatzky v. Riverview Health Centre*, a man with Parkinson's disease deteriorated and the physicians placed a DNR order in his medical chart without contacting the family for consent. Justice Beard (Manitoba) stated:

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[114] *Child and Family Services of Central Manitoba v. L.(R.) & H.(L.)* (1997), 154 D.L.R. (4th) 409 (Man. C.A.)

[115] *Sawatzky v. Riverveiw Health Centre Inc*., (1998) 167 D.L.R. (4th) 359 (Man.Q.B.)

[116] *Golubchuk v. Salvation Army Grace General Hospital et al.* 2008 MBQB 49:12-13.

> "Based on the case law to date, the courts have stated that a decision not to provide treatment is exclusively within the purview of the doctor and is not a decision to be made by the courts."[117]

In 2002, a Manitoba Law Reform Commission was appointed with a mandate to make recommendations regarding withholding and withdrawing life-sustaining treatment. The Commission made a distinction between the right to refuse treatment and the right to demand life-sustaining treatment which was deemed to be medically inappropriate. At the time of the Commission, neither right was recognized by the medical profession or by the law.[118] Professor B. Sneiderman (University Manitoba Law Faculty), commented on the Commission's recommendations, stating that:

> "if there is no touching, then consent is not required, [and yet] illustrates the peculiar nature of a ruling that takes the overall treatment plan for a patient and bisects it into treatment, which requires consent, and refraining from treatment, which does not."[119]

Despite the Commission's recommendations (and a law professor's opinion), the Commission was forthcoming and honest as it concluded that even if the recommendations were accepted and legally applied, there is no certainty for the clinical outcome of cases. Therefore, each case is at the mercy of its own specific merits and circumstances, as well as the need to fit legal precedents to each aspect of the case when making a court ruling.

The Quebec *Civil Code* also does not have any statute that could pertain directly to the withdrawal of medical care secondary to physiological futility. Article 12 however, attempts to include a more ethical viewpoint. It has been understood, at least in part, with respect to an appreciation of burdens and benefits. Article 12 of the Quebec *Civil Code* states that when a person "…gives his consent, he shall ensure that the care is beneficial notwithstanding the gravity and permanence of certain of its effects, that it is advisable in the circumstances

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[117] Ibid 13.

[118] *Golubchuk v. Salvation Army Grace General Hospital et al.* 2008 MBQB 49:14.

[119] Ibid 15.

and that the risks incurred are not disproportionate to the anticipated benefit."[120] Although this does not speak absolutely to the withholding of care, it does demonstrate some thought with respect to the contextualization of treatment. It does this by requiring a risk/benefit ratio for specific treatment. These considerations can be extrapolated to both the futility argument and the demand for care argument.

Although there is not a great deal of Canadian legal literature on the withdrawal of life support when requested by the patient, there is some relevant jurisprudence. There are very strict guidelines for care, and a request for withdrawal of care by a competent adult is supported by respect for the ethical principle of autonomy. This principle is upheld in both medical and legal spheres. The law is consistent in requiring consent for treatment (in the competent adult). There is no treatment (a positive act) without consent, except in cases of emergency when there is no opportunity to obtain consent.

This principle of consent to treatment was upheld in the Quebec case of *Nancy B. vs. Hotel-Dieu de Quebec et al.* The plaintiff, Nancy B., was a quadriplegic patient requiring long-term ventilation. Although she asked that the ventilator be removed, her physician denied her this request.[121] A psychiatrist evaluated her to be competent to make health care decisions in her own best interests. The Quebec Superior Court ruled in her favour, and she died painlessly after having the ventilation withdrawn.[122]

Although Nancy B. was a competent adult, most of the legal cases deal with patients who are unable to speak or act on their own behalf. There is no duty for physicians to provide care against their professional judgment, and no court has categorically required a physician to provide life-supporting care that is judged medically unwarranted.

A recent Manitoba court case however, temporarily forced physicians to treat a patient with life-sustaining treatment against their best professional

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[120] Quebec *Civil Code* Article 12, 2003.

[121] Eschun GM, Jacobsohn E, Roberts D, Sneiderman B. "Ethical and practical considerations of withdrawal of treatment in the Intensive Care Unit." Canadian Journal of Anesthesia. 1999;46(5):498.

[122] Ibid 498.

judgment. In *Golubchuk v. Salvation Army Grace General Hospital et al.*, a court injunction forced physicians to treat a patient with life-sustaining treatment against their best professional judgment while awaiting a trial. The case revolved around an 84 year-old man who was in end-stage respiratory failure and remained in a barely conscious state following a traumatic, closed-brain injury in 2003. He suffered from a significant intracranial bleed that required a partial resection of his brain (temporal lobe) in 2005. Since that time, he had required a ventilator to enable him to breathe, and a permanent feeding tube for nutrition. He did not walk, speak or have any meaningful awareness of his environment. After being admitted to the Intensive Care Unit (ICU) at the Salvation Army Grace General Hospital for pneumonia and pulmonary hypertension, he had steadily declined from his baseline state, despite maximal medical management. He slipped into renal failure that required dialysis and was in a sub-clinical state of sepsis secondary to wounds that would not heal. The family contested that he should die a “natural death” based on their notion of his religious beliefs, and therefore, be ventilated until he died. The physicians believed that in doing so, they were inflicting harm to a man who could not speak on his own behalf and who had no advance directive. Physicians felt that at best, they were delaying the dying process, and at worst, harming a dying man with futile procedures. An injunction sought by the family to maintain all level of treatment was granted by the Court of Queen’s Bench of Manitoba on February 13, 2008[123] until a trial date was to be set to hear arguments for and against withdrawing life-support. The case was not heard, as the patient died prior to the court date, despite the medical team following the directions of the legal injunction.

5.2 Australian Position

Similarly to Canada, Australia currently has no specific guidelines with respect to the withdrawal of life-support. The law “largely places responsibilities for the decision to withdraw therapy on the doctor in charge of the patient’s

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[123] *Golubchuk v. Salvation Army Grace General Hospital et al.* 2008 MBQB, 49.

care."[124] The physician bases decisions on the wishes of the patient, the probability of survival, a subjective assessment of the patient's quality of life and the degree of discomfort to support that quality.[125] The autonomy of the person is understood to be paramount, and medical staff cannot provide treatment to a patient who does not consent to treatment. There are also stipulations for cessation of treatment when the treatment is deemed physiologically futile, in which case a physician is under no obligation to provide treatment. Given these legal parameters, the patient with ESLD suffering from a COPD exacerbation would most likely not be offered a resuscitation attempt or life-supportive treatment.

5.3 American Position

American legal jurisprudence seems to portray a more complex legal landscape. The New Jersey Supreme Court ruled in the *Karen Ann Quinlan* case in 1975, that "medical technology had obfuscated the use of the traditional definition of death, and that she could be removed from life-support."[126] Despite what had happened in the *Quinlan* case, the *Nancy Cruzan* case in Missouri (1990), still required legislative direction when decisions arose regarding her treatment. There had to be a burden of proof that Nancy Cruzan would not have wanted artificial feeding. The argument was not whether or not to discontinue treatment on the basis of futility, but rather whether there was a valid consent to treat her during her PVS state.[127]

Interestingly, in recent years, Texas produced a protocol to decide how to resolve difficult decisions within the health care context of withholding and withdrawing treatment. This protocol is an attempt to address conflicts between physicians, patients and families regarding the notion of medical futility. The protocol however, does not preclude challenges through the legal system. Given

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[124] Young R. J. and King A. "Legal Aspects of Withdrawal of Therapy," Anaesthesia and Intensive Care. 2003;31:501.

[125] Ibid 502.

[126] Ibid 503.

[127] Schneider Carl E. "Cruzan and the Constitutionalization of American Life," The Journal of Medicine and Philosophy. 1992;17:594.

its development and characteristics, this protocol will be discussed in the chapter dealing with the subject of medical futility.

5.4 Israeli Position

Israel is the only country to have set policies in legislation with respect to the dying person. In 2005, Israel enacted the "Dying Patient Act,"[128] which is a law that "attempts to respect the cultural reluctance to withdraw treatment while offering a practical solution that respects the wishes of patients and families and allows patients to end their lives with dignity."[129] The fundamental assumption of the law is that the majority of people do not want to die, but that they do not want to suffer at the end of life and do not want their lives prolonged artificially.[130] The most defined principles of the Act are 1) "that a dying patient is defined as one who will die within six months despite medical therapy, whereas the last weeks are defined as the final stage,"[131] 2) "when patients wish to prolong their lives, this wish should be respected, even if it seems futile," [132] and 3) "decisions concerning dying patients should be based solely on their medical condition, wishes and degree of suffering. No other factors should be considered."[133]

In this regard, Israel is also unique in having legally clarified a patient's right to full resuscitative measures, even in the face of a physician's objections on the grounds of futility. They are the only country to have accepted this tenet.

5.5 Human Rights Act 1998 (United Kingdom) on Resuscitation[134]

The Human Rights Act of 1998 (UK) generated from the European Convention on Human Rights (1950), states the following regarding CPR, outlining that every patient should be entitled to a trial of CPR, except in the case

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[128] Steinberg A, Sprung CL. "The Dying Patient Act, 2005: Israeli innovative legislation," Israel Medical Association Journal. 2007;9:550.

[129] Bentur N. "The Attitudes of Physicians Toward the New "Dying Patient Act" Enacted in Israel." Americal Journal of Hospice and Pallliative Medicine. 2008;20(10)June:2.

[130] Ibid 1.

[131] Ibid 2.

[132] Ibid 2.

[133] Ibid 2.

[134] Committee on Medical Ethics, British Medical Association. "The impact of the Human Rights Act 1998 on medical decision making." London: British Medical Association, 2000.

of informed refusal. When an informed and competent patient refuses CPR, providing it against her wishes is seen as a degrading and inhumane treatment.

- The Right to Life (Article 2(1) states: ‘Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction for which this penalty is provided by law.’
- The Right Not to be Subjected to Inhuman or Degrading Treatment (Article 3) states: ‘No one shall be subjected to torture or to inhuman or degrading treatment or punishment.’[135]

The Human Rights Act on Resuscitation is broad and inclusive in the sense that every life is equally protected (barring court sanctions), and that no assault should come to any person if they refuse medical treatment. It makes decisions regarding resuscitation difficult however, as it does not offer any specific protocols, guidelines or rules. It does not suggest the use of surrogates or any other means of conflict resolution, if necessary. Furthermore, it does not comment on any ethical or moral obligations of patients, legal experts, physicians, or philosophers. In that regard, it provides little additional clarity on the issue at hand.

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[135] Bass 2006, 107.

Chapter 6

Ethical Considerations for Resuscitation in End-Stage Lung Disease

6.1 Deontological Perspectives on Resuscitation in ESLD

A principle-based approach must "hold that some general moral norms or action guides are central in moral reasoning."[136] Despite a similarity in a number of principle-based approaches to bioethics, the differences can usually be attributed to how the obligations are determined. *Beauchamp and Childress's* four foundational principles of bioethics are autonomy, beneficence, non-maleficence, and justice. Autonomy is understood as the right of the individual to choose a plan for her life, or the right of any person to determine for herself what is in her best interests based on her particular values, concerns and goals.[137] Beneficence is the principle of acting to benefit those one serves, and non-maleficence is the principle of acting to not impose unnecessary harm to those one serves. Justice is an ethical principle which emphasizes values of fairness, equity and equal respect for individuals.[138]

There are numerous criticisms of this principle-based theory, predominantly they are concerned that this theory ignores "history, convention, community, tradition and the like."[139] There is however, little specific convention or tradition when deciding the best course of action for patients in need of resuscitation for end-stage lung disease. It is arguably more pertinent that the wishes of the patient are forefront in the decision-making process (autonomy) and the decision is pursued in the patient's best interest, while avoiding additional harm. Among the difficulties with the principle-based method of medical decision-making is that the patient's best interests are difficult to fully appreciate.

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[136] Childress, James F. "A principle-based approach." In: A Companion to Bioethics. Helga Kuhse and Peter Singer eds. (Oxford, UK: Blackwell Publishers Limited, 2001), 61.

[137] Young Robert. "Informed Consent and Patient Autonomy." In: A Companion to Bioethics. Helga Kuhse and Peter Singer eds. (Oxford, UK: Blackwell Publishers Limited, 2001), 442.

[138] Crosthwaite Jan, "Gender and Bioethics," In: A Companion to Bioethics. Helga Kuhse and Peter Singer eds. (Oxford, UK: Blackwell Publishers Limited, 2001), 36.

[139] Childress 2001, 63.

Patients' best interests are highly individualistic and often unique. Furthermore, when there are disagreements or conflicts between two parties, these principles can support two different conflicting views, leading to a perceived stalemate in decision-making. Justice is often brought to bear when issues of resources are involved, however this reflects a more utilitarian approach, (trying to provide the most care for the most people on limited resources, or an adequate sense of utility).

Determining whether to resuscitate a person with an end stage disease state is a difficult decision to make, and although the principle-based approach to medical ethics provides a framework, it has its limitations. One has to come to a consensus on the best interest of the patient, taking into consideration the minimization of harm, and the autonomy and justice concerns of all those involved. The balancing of these principles can be very difficult, particularly in such a highly charged area as medicine, and when dealing with potentially end-of-life situations. The principles need to be prioritized in such a way as to maximize the moral good, and to minimize the harm. Autonomous choice must be valued, but not at the expense of disproportionate harm to the individual. For many physicians, the avoidance of harm (non-maleficence) to an individual is often perceived as a higher moral priority than respect for patient autonomy. Providing resuscitation and life-support technology to a patient with ESLD is arguably too harmful, as it artificially prolongs the patient's dying trajectory without adding any realistic improvement in quality or quantity of meaningful life.

6.1.1 Personal Autonomy

When discussing the concept "autonomy of the person," there is often a distinction made in a principle-based framework between a bioethical principle and a bioethical rule. Generally, "rules" are derived from principles which are thought to lend a framework for decision-making. *Beauchamp and Childress* identify four primary principles – "respect for autonomy, non-maleficence, beneficence and justice."[140] From these principles, they also derive certain rules, such as being honest with patients about information ("truth-telling"), respecting the decisions of others and maintaining professional courtesy with respect to privacy issues. Autonomy is one of the key principles when discussing bioethics, as it is imperative for every decision-making process. Individuals have the right to decide the course their lives will take, regardless of whether that choice possesses a universal or a mainstream consensus, (barring of course egregious behaviour towards others). Once a person possesses the information that is required to make an informed decision, and has weighed the options and alternatives, she must make the decision for herself based on her own experiences and her own expectations. In making this decision, she must also be prepared for the results or consequences of those decisions. *Beauchamp and Childress's* principles "appeal to the 'common morality' … to principles discerned in a society's laws, policies and practices."[141] It seems the common morality allows individuals the right to make their own decisions in the course of their life, regardless of the possible benefits or detriments.

In the case of a patient with end-stage lung disease who requires resuscitation, the autonomy of that individual should be maintained, unless the respect for autonomy overrides another's autonomy or a higher prioritized principle. When implementing a principle-based model of medical access, the patient in need of advanced medical technology and who understands the technology's potential hazards and benefits, should be allowed to access this treatment. The "common morality" would allow for the best possible treatment available to that individual, including life-saving treatment. The moral good would be to help those who are least able to care for themselves. The people who need the technology to breathe are among the most fragile groups in society, and as such deserve medical support. Furthermore, these individuals are in the process of dying from a chronic and terminal disease. End-stage lung disease, in the

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[140] Childress, James. "A Principle Based Approach" In A Companion to Bioethics. Helga Kuhse and Peter Singer eds. (Oxford, UK: Blackwell Publishers Limited, 2001) 2001; 62.
[141] Ibid 63.

spectrum of diseases, is no different in its chronic debilitation than terminal lung cancer. The slow erosion of the essential lung tissue and the inability to halt the process categorises ESLD as a terminal illness. The dying patient is one of the most fragile and needy in society. The patients who have ESLD fall into two categories of fragility – the chronically ill and the actively dying. The common morality would insist on providing these individuals with adequate care. The question remains, what constitutes adequate care?

The definition of "adequate" care may vary, from patient to patient and from physician to physician. There are of course, particular standards of care which are stipulated by the professional medical associations. These patients are fragile due to their illness, however they remain competent adults who require treatment in an honest and professional manner. They also require protection from untoward medical procedures that offer more burdens than benefits. The principles of care need to be prioritized with these patients and one of my key arguments in this thesis is that patient autonomy should not over-ride a physician's respect for the principle of non-maleficence. Adequate care needs to include the idea of "honest care" for the patient. A resuscitation attempt for a patient with ESLD will only prolong the dying trajectory without significant or meaningful benefits to the patient.

The clinical vignette describes a man who is faced with his own mortality. He was healthy and active until three years ago but now is critically ill. At this point, he cannot speak for himself due to his illness. He made some health care comments to his physician before his acute illness and subsequent ICU admission. I would categorise his view of the world as that of a "reasonable person" prior to his hospitalization. He has made comments to his family physician regarding the nature in which he views resuscitation and dying. He has made his own choices in the world with respect to caring for his family and his home, and does not expect special treatment. There have been no complaints of his ill health, nor episodes of blaming others for his troubles. He has set certain standards for himself that he is not willing to change, such as not going to the Scout troupe in a wheelchair with oxygen. He has stated that "it would kill him" not to be able to at least watch his granddaughter play hockey. These events are now upon him for he can no longer go to the hockey arena, nor to the Scout troupe. He has however changed his wishes regarding his healthcare at a dire point in his end stage lung disease trajectory. It seems that he has now rejected a "reasonable person standard."

The "reasonable person standard" or the "prudent patient standard" focuses on the patient's "informational needs and so affords… a greater respect to patient autonomy."[142] This standard is not a "medical or physician standard" but rather a "reasonable patient standard"[143] as a means of protecting a patient's autonomy and needs. The standard assesses the amount of risk when proposing to go ahead with medical treatment, and the decisions for the risk may be subject to "cultural bias, psychological makeup, and values."[144] Furthermore, the significance of the reasonable person standard is based on risk of treatment, and that risk is "material when a reasonable person…would be likely to attach significance to the risk or cluster of risks in deciding whether or not to forgo the proposed therapy."[145]

In this case, Mr. D. witnessed an unsuccessful resuscitation attempt of his neighbour's husband, and has a clear event on which to base his refusal for CPR and resuscitation. The decision seems to be based on a "reasonable standard." He has however succumbed to his fears of loss at the end of his life and the wishes and desires of his family. He has lived his life in such a way that it would be unreasonable for a man with his experiences and his prognosis to want to undergo further treatment. He himself recognizes his significant limitations due to his disease and yet he is not able to adequately grasp the next phase of life, in so much as his death. His "reasonableness" has eluded him in the context of severe illness, hypoxia and impending death.

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[142] Maclean Alasdair. "Giving the reasonable patient a voice: information disclosure and the relevance of empirical evidence." Medical Law International. 2005;7:3.

[143] Cassidy PS. "Cooper v. Roberts: A "Reasonable Patient" Test For Informed Consent." University of Pittsburgh Law Review. 1973;34(3):501.

[144] Maclean 2005, 5.

[145] Ibid 7.

6.1.1.1 Kant's Autonomy

Individual autonomy seems to garner the highest level of respect in modern bioethics, and is often perceived as the "trump card" of moral principles. This has in part been inspired by Kant's moral philosophy, which was constructed from his idea of "freedom and causal determination."[146] He declared that the laws of freedom and morality applied to the intelligible world and causality and knowledge applied to the natural world.[147] He adhered to a state of rationalism, and professed that the choices made from the ability to reason are universal. Therefore, the autonomy of the will was the main focus of Kant's moral philosophy,[148] and as such a person was "bound to act in accordance with his own will…."[149] Furthermore, he believed one must act on the basis of intelligent thought and not emotional reasoning or compulsive behaviour, or forms of manipulation or coercion.[150] Kant's notion of rationality was derived primarily from reason and rationality and not from life experiences, emotions or consideration of unique, irrational circumstances. In his work *Groundwork of the Metaphysic of Morals,* he "held that consequences of action were irrelevant."[151] He stated that rationality has universal truths and that these truths hold for all time, regardless of people, circumstances and situations, and that an action would be good if it satisfied the "categorical imperative."[152] The imperative relates to the fact that there are no exceptions to the rule of rationality and therefore no exceptions with regard to the action. He believed that practical reason would subvert the need to have a differential decision-making body between groups of people with different circumstances. If one were to act autonomously, one "must

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[146] Secker, Barbara. "The Appearance of Kant's Deontology in Contemporary Kantianism: Concept of Patient Autonomy in Bioethics." Journal of Medicine and Philosophy. 1999;24 (1):45.
[147] Ibid 45.
[148] Ibid 45.
[149] Ibid 45.
[150] Ibid 47.
[151] Edge Raymond S., Groves John Randall. Ethics of Health Care – A Guide for Clinical Practice 3rd Edition 2006 Thomas Delmar Learning, NY:38.
[152] Ibid 38.

act according to the rules which could be autonomously chosen by any rational agent, … thereby the moral laws are universal."[153]

Kantian autonomy is criticized considerably when applied to modern bioethics for several reasons. The most significant criticism is with respect to his statement that "rational decision-making is devoid of emotion." Bioethics and health care decisions, by contrast, are not devoid of emotion. There are layers of emotion in the decision-making processes regarding healthcare. These layers of emotion are not only the individual patient's emotions but often the emotions of the people with whom the person is in contact. Despite an individual's attempts to make an autonomous decision, there are often outside factors that persuade or dissuade decisions. In terms of absoluteness, a "purely autonomous" decision is rare. There are relevant emotions related to the individual who is providing the information, the person receiving the information and those who care for the individual, as well as the myriad of other people who provide treatment, book appointments, perform follow-up care, etc. Given a holistic appreciation of the human condition, it is hardly persuasive to claim that a decision regarding medical treatment should be one devoid of emotion. It can potentially be one of the most deeply personal and thus significantly emotional decisions one makes.

There is a large emphasis placed on independence throughout Kant's writings on autonomy. Ideally, independence is a positive trait required to make an informed decision, as this decreases outside and potentially undue influence in the decision-making process. However, with such a premium on independence, there is a potential to "devalue dependence." In the sphere of medical decision-making, there is often emotional behaviour as well as *dependent* behaviour due to the essential nature of close relationships, especially when a patient is confronted with the fear of the unknown. "Fear, mourning, compassion, anger, relief – all have de facto immediate effects or perceptions and assessments of situations and

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[153] Hayry M. "The tension between self governance and absolute inner worth in Kant's moral philosophy." Journal of Medical Ethics. 2005; 31:646.

on actions."[154] Therefore, the notion that a patient with end-stage lung disease can act completely rationally and free of family involvement when deciding about a resuscitation attempt is extremely unlikely and possibly unwarranted.

Moreover, fear and anxiety often cloud the nature in which information is received when discussing life-limiting treatment. This "clouding of understanding" has a devaluing effect on the doctrine of informed consent. Life-limiting treatment discussions are then the most emotionally charged conversations in medical practice. A patient's ability to manifest completely independent behaviour at this stage in the trajectory of her chronic illness is highly suspect. Kant's autonomy however, suggests that these people are somehow less morally adequate by virtue of their dependence on others, as well as their emotional reality.

Secker further criticizes Kantian autonomy by suggesting that it paradoxically promotes paternalism, something quite opposite to what an autonomous person would aspire.[155] As she states, and *Heubel* reiterates', if a patient was not to measure up to Kantian autonomy, then medical staff may in fact resort to "justify paternalism"[156, 157] as the only viable rational option. The paternalism may become a default measure when difficult decisions are required, therefore denying a certain amount of control or self-determination for the patient.

Resuscitative medicine is an area that is highly sophisticated and often intimidating for patients, particularly ones who are gravely ill. Many patients could fall into Kant's description of being irrational or emotional or simply "not measuring up," when faced with a resuscitation decision. The paternalistic nature of physicians is often heightened at this time due to the direness and urgency of a patient's medical condition. The timeline in making decisions also adds another layer of complexity to an already highly emotionally charged environment. All of

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[154] Heubel Friedrich and Biller-Andorno Nikola. "The contribution of Kantian moral theory to contemporary medical ethics: A critical analysis." Medicine, Health Care and Philosophy. 2005;8:11.

[155] Secker 1999, 51.

[156] Ibid 51.

[157] Huebel 2005, 13.

these factors can be seen to lend themselves to justify a paternalistic decision-making process.

Lastly, Kant's theory deliberately ignores consequences of actions. As such, his theory has significant limitations in medical bioethics, as consequences are important factors in the process of informed consent for medical treatment. Every person is unique, with specific life experiences and backgrounds, and the consequences of their choices can be as polarized as life and death when deciding on a resuscitation attempt in ESLD. These decisions have consequences for a host of people involved in the patient's care, including the patient's family members and caregivers. Disregard for the potential consequences of one's action could have terrible and unpredictable results for all the parties involved.

6.1.1.2 Pluralistic Constructs of Autonomy

A pluralistic view of autonomy considers more aspects of human nature than Kant's version. This form of autonomy seems much more appropriate toward medical and bioethical decision-making as it includes a wider breadth of not only moral context but social interaction and the emotional well being of the person. Despite the duty-oriented nature of John Rawls' *Theory of Justice*, his theory of autonomy is more applicable to health care than Kant's autonomy, as it possesses a "blinded" decision- maker. Rawls proposed that if the decision maker were aware of the situation, but unaware as to which role was to be played, the moral individual would choose an inherent good. He called this the "Original Position." The construct includes a "blinded" decision maker, but it does not require an absence of emotion. Given my earlier arguments describing the complex and holistic nature of decision-making in the clinical context of resuscitation in ESLD, this theory is a much more robust and applicable theory. It is "a restatement of the Golden Rule," wherein an individual's choice would be reciprocated by another in an identical situation."[158] Rawls states his original position as:

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[158] Edge and Groves 2006, 41.

> “ a hypothetical situation characterized so as to lead to a certain conception of justice. Among the essential features of this situation is that no one knows his place in society, his class position of social status, nor does any one know his fortune in the distribution of natural assets….”[159]
> “This ensures that no one is advantaged or disadvantaged in the choice of principles by the outcome of natural chance or the contingency of social circumstance.”[160]

This is a valued theory as it would inherently protect the people in society who can least care and protect themselves, such as those who are chronically ill or those who are in the process of dying. This theory has a blinded sense of morality in that the decisions are determined equitably and are free from skewed political structures. It accepts the premise that emotion is an essential part of being a human, and therefore parlays itself into human decision-making. It also appreciates a sense of consequence, which differs greatly from Kant’s autonomy, by acknowledging that all actions have consequences that have moral implications. Acknowledging that actions have consequences and that the world is not an emotionless void, further demonstrates the importance of the “original position.” The inherent good chosen by the “blinded” decision-maker benefits not only the individual patient, but society as well.

Rawls’ theory is limited in the clinical context in that it maintains a duty-bound perspective and as such, despite its ability to allow for emotion and consequences, it can be interpreted as relatively inflexible. If one intuitively believed in a moral position or an “original position” as “right,” there could be great difficulty making individual decisions in health care that reflected unique aspects of a patient’s circumstances, despite expert advice and experience to the contrary. Health care is a complex and dynamic field and does not easily conform to “black and white” situations, but rather exists in a “gray” environment. Conflict

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[159] Rawls John. A Theory of Justice – Revised Edition 1999 Cambridge, Massachusetts: Harvard University Press :11.
[160] Ibid 11.

in medical decision-making would arise for those individuals who base their original position in a “black and white” or polarized moral context.

Feminist theory also supports a more pluralistic notion of autonomy. It includes a style of autonomy more tailored toward the individual, with less emphasis on the exclusionary rationalization that is key to Kant’s work. Feminist theory considers emotions as well as the environment from which people originate, so as not to exclude those experiences and events that appreciates the uniqueness of individuals.[161]

Feminist theory’s strongest attribute when discussing autonomy is the acceptance that no one exists without the presence of external influences. These influences can be tangible, such as family members, health care professionals, or the society in which one lives. The influences can also be less tangible such as experience, culture, religion and background. Feminist ethicists acknowledge patients’ ties and relationships to the world, stating that patients’ medical decisions often directly affect their caregivers and family members. Despite the need for autonomous decision-making patients’, decisions do not occur in a vacuum. These decisions influence and affect others. There will be more discussion on feminist theory and resuscitation in chapter 6.4.

6.1.2 Beneficence & Non-maleficence

If the treatment administered has more potential benefit (beneficence) than potential risk, the physician in most instances will offer to treat the patient. Although a patient may have no right to demand treatment that has no beneficial outcome, the patient does have a right for treatment when there are benefits, even if those benefits are small.[162] A common example is the notion of a gaming lottery. The chances of winning are infinitely small, and this is widely known. Yet despite knowing the odds, people continue to play the lottery in hopes of the “big win.” The occasional, positive reinforcement by the winners encourages people to

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[161] Donchin A. “Reworking autonomy: toward a feminist perspective.” Cambridge Quarterly of Healthcare Ethics. 1995;4:46.

[162] Tomlinson T, Brody H. “Futility and the Ethics of Resuscitation.” Journal of American Medical Association (JAMA). 1990;264:1277.

continue to play. The same can be true for the benefits of resuscitation. The rates of successful resuscitation are small (depending on the status of the patient) and yet the desire for the procedure is often present, hoping for the "big win." Unfortunately the "big win" with resuscitation is not the same as for the lottery. The lottery represents a potential for a clear cut financial improvement to a person's life. Resuscitation does not necessarily improve a person's life. Often the person who survives a resuscitation is more functionally impaired after the resuscitation than before it.

Beneficence and non-maleficence can be described in terms of a risk and benefit ratio when discussing healthcare. Providing a "beneficial" treatment is beneficence and providing "no harm" treatment is non-maleficence. The discussions on what entails "beneficial" and "no harm" treatment however, are often based on a particular individual's standard or perspective. There are four recognized standards of risk/benefit assessment - the subjective patient standard, the subjective doctor standard, the reasonable patient standard and the reasonable doctor standard.[163] Arguments against the subjective standards are that these standards are open to abuse and may lead to patient harm as well as offering no protection to other medical staff in questionable procedures.[164] Although the "reasonable standard" (both physician and patient) also has pitfalls, it is reflected in practice guidelines that can be relied on for some basic tenants of risk and benefits in choosing healthcare treatments. The reasonable patient standard needs to be thought of as what most people in the same position would choose. Or rather, if one was using Rawls original position, looking in from behind Rawls' "veil of ignorance," what would the majority of people feel to be the appropriate risk to benefit ratio?

In the case of Mr. D. it is very likely that participants in Rawls' original position would agree that they love Mr. D. and do not want him to die, however that is not the question being asked. The question that is proposed is what is the benefit and the harm that will be imposed on him with further treatment? His

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[163] Ross Isobel A. "Practice Guidelines, patient interests, and risky procedures." Bioethics. 1996;10(4):313.
[164] Ibid 317.

benefit with further treatment is outweighed by his risk for further pain and delaying his inevitable death. He will no longer be able to partake in those activities that he cared for, and with his current state of health, this fact will not change. At this point, any further life-supporting treatment would be adding considerable burden over any appreciable benefit.

6.1.3 Distributive Justice

Distributive justice is the notion of fairness amongst a group and must be considered for the good of society. Resources should be allocated equitably and all patients should have equal access to appropriate care. Justice as a moral framework can be discussed referring to John Rawls' *Theory of Justice*. In a diverse society with differing viewpoints, there is bound to be conflict. The principles of justice are intended to form a basis for adjudicating the conflicts that invariably arise.[165] Rawls argues that these principles can be decided by using "the original position" idea quoted earlier.

Rawls simply states that had everyone gathered together, before the world was established and before everyone knew what social and economic station they would possess, that their ideas of fairness would constitute the "principles of justice." This would be achieved only by not knowing how those principles might affect them later. To a lay person, these principles would be the inherent "goods" that everyone "just knows." A straightforward example would be the case of a drowning person. Discounting extraneous details, it would be an inherent "good" to help a person not to drown and it would be very difficult to reasonably argue that it would be an inherent good to let a person drown.

When discussing health care, justice also encompasses economic considerations. The difficult question to answer is where does justice fit when trying to allocate medical funds? Is justice served spending an equal proportion of resources on one patient with a poor prognosis versus the same proportion of resources on more people who have better prognoses?

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[165] Swenson, M.D. "Scarcity in the Intensive Care Unit: Principles of Justice for Rationing ICU Beds." The American Journal of Medicine. 1992; 92:552.

It is helpful when trying to understand economic justice, to know that there are four types of economic evaluations. They are “cost minimization, cost benefit, cost effectiveness and cost utility analysis.”[166] The cost effective analysis evaluates the incremental cost-effectiveness, which can be more simply stated as the cost of switching one treatment to another.[167] This can then be determined by dividing the cost for treatment one minus total costs for treatment two divided by the incremental change in health outcome. Interestingly, there has been no change in costs of hospitilisations for patients with advance stages of diseases from the late eighties until the early nineties, and the SUPPORT study (**S**tudy to **U**nderstand **P**rognoses and **P**references for **O**utcomes and **R**isks of **T**reatment) showed the use of advance directives has (surprisingly) not been associated with a reduction in hospital resource use.[168] If advance directives have not decreased hospital costs, and patients are living to older ages with increased illness burden, there is going to be a negative balance of costs to expenditures. This means that decisions must be made as to who receives care and to what extent. “It is important to understand that the provision of ICU care to some patients is at the cost of denying that care to others.”[169] This is a very tenuous position in which to administer care, however high the costs. Ebell and Kruse state that an in-hospital arrest approximates $110 270.00 (USD) per survivor.[170] Marco furthers with the fact that $58 million (USD) is the estimated cost resulting from unsuccessful resuscitation annually in the USA[171] and typical costs for a ventilated patient in the ICU is $1500 (USD) per day.[172, 173]

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[166] Pronovost P.,Angus D.C., “Economics of end-of-life care in the intensive care unit.” Critical Care Medicine. 2001:29(2Supplement);N46.

[167] Pronovost and Angus 2001, N46.

[168] Ibid N46-47.

[169] Scheinkestel CD. “The evolution of the intensivist: from health care provided to economic rationalist and ethicist.” Medical Journal of Australia. 1996;164:310.

[170] Ebell M.H., Kruse J.A. “A Proposed Model for the Cost of Cardiopulmonary Resuscitation.” Medical Care. 1994;32:643.

[171] Marco CA. “Ethical issues of resuscitation: an American perspective.” Postgraduate Medical Journal. 2005;81:608.

[172] Dasta et al. “Daily cost of an intensive care unit day: The contribution of mechanical ventilation.” Critical Care Medicine. 2005;33(6)1266.

[173] Zilberberg MD, Luippold RS, Sulsky S, Shorr AF. “Prolonged acute mechanical ventilation, hospital resource utilization and mortality in the United States.” Critical Care Medicine. 2008; 36(3):724.

In what just manner is it right to offer one patient treatment and another no treatment? At this point let's look back at *Rawls* theory, and in so doing, try to eliminate any biasing information. The theory states that everyone would be equal, and that treatment would be based on what the majority of people thought was fair. This excludes basing treatment on social, economic, or financial status. Everyone would agree that need is the just method to determine priority with respect to treatment. This seems to make sense – the most ill person is first to receive aid. But what if that person is not going to benefit from that aid, the treatment is wasted, and as a result resources are wasted? At this juncture no one receives the treatment. Therefore, there must be two criteria to prioritize patients. The first is need, and the second is benefit. It does not seem just to spend countless resources on the most dire of patients when there is no reasonable expectation for a positive outcome, (life). This would then penalise all those remaining in the pool of needy. It seems more just that resources are allocated to those who have the most potential for a positive outcome, and those who are in the greatest need. These decisions however must be made at macro and meso levels of health policy, and not at the bedside. The criteria for such decisions must be known and abided to uniformly in order to fulfill the requirements of justice. Unfortunately, the criteria are often in place, and yet the decisions are determined based on the subjective perspectives of the attending physician in charge.[174]

Mr. D. has an irreversible pathology from which he will not recover. He has been treated with maximum medical therapy with no response for weeks, which strongly suggests that this is not a case where treatment will change the outcome. Continuing with this treatment with no appreciable benefit shifts resource dollars away from others in need who are more likely to benefit.

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[174] Elo G. et al. "Ethical considerations behind the limitation of cardiopulmonary resuscitation in Hungary – the role of education and training." Resuscitation. 2005;64:76.

6.2 Teleological Perspectives on Resuscitation in ESLD

6.2.1 Utilitarianism, Distributive Justice and Resuscitation in ESLD

Utilitarianism (or consequence-oriented) theory considers the moral value of decisions based on the consequences resulting from the actions. The maximization of good is the goal, and therefore based on the consequences of the action, one tries to amass the greatest good. Jeremy Bentham and John Stuart Mill are considered the originators of utilitarianism. They state it "is the most common form of consequence-based reasoning."[175] The goal is to promote happiness over pain but to ensure that happiness has a more cognitive function over simply sensory input, and as Mill states, includes intellectual, aesthetic and social enjoyments rather than mere sensual pleasures.[176]

The sensation of pleasure can be complex. Therefore, Bentham offered seven categories and questions as a method of determining utility, which were: 1) intensity (how intense was the pleasure?); 2) duration (how long does the pleasure last?); 3)certainty (how certain are you that the pleasure will occur?); 4) proximity (how soon will the pleasure be experienced?); 5)fecundity (how many more pleasures will happen as a result of this one?); 6) purity (how free from pain is this pleasure?); and 7) extent (how many will experience the pleasure?).[177] The pleasure versus pain equation has major flaws, as it could imply enhancing one individual's pleasure at the cost of another person's pain (including infringements of rights). The modern consequentialists enlist a principle of "equal consideration of interest"[178] to ensure that one person's pleasure is not at the expense of another person's pain. Another aspect of consequentialism is "welfarism," which can be described as the choosing of options that maximize the welfare of all those involved. The choices will either increase or decrease the welfare of those affected,[179] and those who are affected should be considered equally and impartially. "Welfare" to a utilitarian is defined as "the obtaining to a high or at

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[175] Edge and Groves 2006, 33.
[176] Ibid 33.
[177] Ibid 34.
[178] Ibid 34.
[179] Hare R.M. "A Utilitarian approach." In: A Companion to Bioethics. Helga Kuhse and Peter Singer eds. (Oxford, UK: Blackwell Publishers Limited, 2001)80.

least reasonable degree of a quality of life which on the whole a person wants, or prefers to have."[180] Furthermore, the utilitarian uses the aggregate notion, which is "all in sum."[181] It is a concept designed to maximize the welfare for the most people when there is a conflict between two groups. When healthcare decisions are made regarding people's respective welfare, the aggregate is the maximization for the greatest good for the greatest number of people. There are criticisms of aggregationism with respect to its distribution, and the special relationship with respect to duty-boundness of patient and physician relationships. These criticisms will be discussed later.

The utilitarian approach to health care choices has some very favourable attributes when discussing resuscitation in end-stage lung disease. Consequence-based theory is attractive as every decision in medicine has an inherent consequence of a practical nature. If one were to not resuscitate a patient with ESLD, the consequence of that action is the death of the patient. If one were to attempt to resuscitate a patient with ESLD, it may or may not be successful but there would be definitive consequences of the action regardless of its success. The "purest" utilitarian, who understands both the life expectancy for a patient with ESLD and the high demand for ICU support, would state that the most utility is achieved by not resuscitating the patient. The welfare of the majority would be jeopardized by attempting to save a person who is at the end of her life, and in fact is in the natural progression of her disease. ESLD patients have a *very* small chance of surviving a resuscitation attempt, and the success does not ensure the patient will ultimately live. It only suggests a remote possibility of a successful return of cardiac and respiratory circulation. Those who do survive usually have a quality of life which is further impaired and their death is merely delayed through medical technology. A patient's quality of life almost never returns to her previous baseline,[182] and those who survive often have a prolonged course in hospital that does not generally prolong the natural history of their disease by more than a few weeks to months. A strict utilitarian would state that the

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[180] Ibid 81.
[181] Ibid 82.
[182] Dales et al. 1999, 792.

resources required to prolong an inevitable death comes with a financial burden that a medical system should not bear. Such is the case with Mr.D. Agreeing to support him with technology for another few weeks is not going to change the outcome of his care. It will merely exhaust resources that could be funneled into other areas of care. Furthermore, the resources that are required to delay an inevitable death (ICU technology) could be allocated elsewhere to maximize the greatest good for the greatest number of people. This is a "reasonable person standard."

Critics of this theory state that ensuring the best interests of the many over the interests of the few is not simple. There could be gross injustices based on this very dichotomous decision-making policy. *Hare* argues that based on this theory, one could legitimately kill a person and use each human organ for transplant, thereby creating the greatest good for the greatest number of people.[183] Aggregationism ensures that this kind of distribution of the utility is ignored, and that it is simply a "maximum utility" for the situation that matters. The distribution of the welfare is an ideal situation. It is an equal division of the social good for all the people involved and this would prevent the non-volunteer organ donour situation. Unfortunately, as *Hare* states, because the distribution is often ignored, utilitarianism is often dismissed as a practical theory.[184] If one were to embrace the distribution ideal, one could not overrule a first person over a second person in the pursuit of utility. It would not only be morally wrong to kill one person in an attempt to have greater utility for organ transplantation, but the distribution of welfarism would be ignored as well.

The maximization of welfarism, without a just distribution ideal, is but one criticism of utilitarianism in the medical sphere. Another criticism is the idea of impartiality. The opponents of utilitarianism state that impartiality needs to be forefront when deciding medical (and moral) decisions. It is difficult to remain impartial when making medical decisions. The physicians who decide on medical treatment often have developed a relationship with those people for whom they

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[183] Hare 2001, 84.
[184] Ibid 82.

are caring. Impartiality would be best used as a policy dictum, to ensure a minimum relationship between caregiver and patient. The policy would provide a framework to avoid conflicts. Unfortunately, each person is unique and a single policy does not fit each individual despite the best interests of the policy makers. There are many variances and subtleties between seemingly similar situations. Medical decisions are a dynamic area where the “one shoe fits all policy” does not apply.

Lastly, a consequence-based theory such as utilitarianism has flaws with respect to medical decisions, for it has an inability to respond to the infinite amount of possible consequences that such a decision would dictate. Consequences are infinite in scope and number, and only some consequences are immediately apparent while others do not manifest for weeks, months or years. The consequences can have a rippling or cumulative effect derived from both action and inaction. In the case of a resuscitation attempt for a person with ESLD, one can never be absolutely certain if the statistics that are presently accepted will apply to the person who requires treatment. The individual person will not necessarily have a specific outcome despite the presumed outcomes based on large databases of results. The individual person may be an outlier. The ability to predict the future and know the consequences of every action or inaction “appears impossible.”[185]

A resuscitation attempt for a person with ESLD from a strict utilitarian theorist perspective would be considered an unjust use of resources. The resources of labour, finances, and time could be better spent making a positive difference for a large number of people rather than for the very few who may or may not survive. Resuscitating someone from a COPD exacerbation with ESLD is merely using technology to interrupt the natural history of a life-limiting disease and to prolong the dying process of the individual. This therapy is not a bridge for a patient to recover from a reversible disease. It will not reverse any loss of function to a pre-illness state. The best possible outcome would be to achieve a lesser quality of baseline function. The purpose of this technology is very different for a

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[185] Edge and Groves 2006, 35.

patient who has a life-limiting disease and is at the end of that trajectory, as opposed to someone who has pneumonia and needs temporary respiratory support during the recovery period.

6.3 Other Perspectives on Resuscitation in ESLD

6.3.1 Feminist Bioethics and Resuscitation in ESLD

Feminist bioethics refers to bioethics from a feminist theory viewpoint, and not simply as a study of issues about women's health or about women speaking about women's health. Feminist bioethicists have argued that medical decision-making impact not only the individual but others as well. Resuscitation has far-reaching consequences to many parties other than the patient, and this consideration is a prime example where feminist bioethics plays a significant role. The premise of feminist bioethics is that gender differences may influence and distort people's view of the world. These distortions need to be addressed so that society can appreciate how these distortions are hurtful to everyone.[186] Furthermore, women play an increasingly important role in health care ethics, as they form the majority of both the caregivers and the aged in today's society.[187] A number of feminist theorists [188, 189] believe that gender inequity in health care exists, and that poverty is a risk factor for ill health. As a result, those individuals who are most disadvantaged in society or are least able to care for themselves require protection, and special attention towards "those historically least served and most harmed."[190]

Feminist bioethics has a number of central themes, the most obvious of which is the notion of androcentrism, or male centeredness. This concept states

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[186] Little Margaret Olivia "Why a Feminist Approach to Bioethics?" Kennedy Institute of Ethics Journal. 1996;1.

[187] Rogers W.A. "Feminism and public health ethics." Journal of Medical Ethics. 2006;32:351.

[188] Sherwin S. "Feminism and Bioethics." In: Wolf SM, ed. Feminism and bioethics: Beyond reproduction. 1996 New York: Oxford University Press 52

[189] Wolf SM. "Introduction: gender and feminism in bioethics. Feminism and bioethics: Beyond Reproduction. 1996 New York: Oxford University Press 23

[190] Ibid 23.

that man is “the tacit standard for human,”[191] and as such is in a “privileged position” as he alone represents humankind. The male human as the reference point for medical studies is well known, however androcentrism goes further in subtle and not so subtle ways. Feminist bioethics elaborates on this concept. If man is the standard, then everything else must revolve around this standard, therefore creating a subconscious idea that the “revolvers” are secondary players to the central being. This is illustrated in the now famous trial of aspirin and cardiac health. A 1990 trial studying only men (22 000 in total) concluded that an aspirin a day might decrease ischaemic heart disease (plaque formation in the coronary arteries causing poor blood supply and oxygen deprivation to the cardiac muscle fibres). The standard of care for those at risk for ischaemic heart disease was therefore one aspirin a day. Blatantly absent from this study was the inclusion of any women, which leads one to wonder whether this treatment is beneficial to women as well, or only men.

Furthermore, how could a scientist suggest there is physiological gender equality and simply translate data and medical guidelines from one gender to another? This may not be a scientifically valid assumption. The exclusion of women subjects is another example of androcentrism, and raises concerns regarding the ability of women to advocate for their own group with their own unique characteristics. Assuming the two genders are equal in every way is erroneous, and yet subtle (and not so subtle) societal events continue to portray this inequity.

This inequity is illustrated in the ICU, and studies[192, 193, 194] show that men are more likely to be admitted to an ICU than women, and once admitted, are

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[191] Little 1996, 2.

[192] Raine R., Goldfrad C, Rowen K et al. “Influence of patient gender on admission to intensive care.” Journal of Epidemiology and Community Health. 2002; 56;419.

[193] Valentin A, Jorndan B, Lang T, et al. “Gender related differences in intensive care: a multiple center cohort study of therapeutic interventions and outcome in critically ill patients.” Critical Care Medicine. 2003; 31:1903.

[194] Fowler Robert A, Sabur Natasha, Li Ping, Juurlink David N, Pinto Ruxandra, Hladunewich Michelle A, Adhikari Neill K.J, Sibbald William J, Martin Claudio M. “Sex- and age-based differences in the delivery and outcomes of critical care.” Canadian Medical Association Journal. 2007;177(12):1513.

more likely to be treated more aggressively than their female counterparts.[195] This has implications when deciding on resuscitation candidacy. Men are believed to have significantly worse symptoms when rated by physicians, and are perceived to require more aggressive medical treatment. Not only are men more often admitted to the ICU, they receive mechanical ventilation more often than women once they are admitted.[196] These perceptions are examples of androcentrism that are adopted into the practice of physicians.

Little argues that the distortion between men and women lies in the fact that men traditionally live in the public sphere of work, politics, and culture, while women live in a private sphere of domestic, caregiver and nurturer.[197] When the devaluation of work associated with women occurred, women's private sphere was devalued. The public sphere of men's work retained its high regard. This split between private and public spheres has an implication on the choice of patients for ICU admission and the candidacy for resuscitation. Men are believed to require the most aggressive care, so that they can "get back to work." Work in the public sphere is deemed more important when compared to domestic work. This is directly opposite to what actually occurs with the patient population and its caregivers. Women constitute not only the most aged group of the population but also the largest proportion of caregivers.[198] They should be entitled to the same aggressive nature of care in a critical incident to avoid the androcentrism that *Little* discusses. Women also deserve equal care as they continue to provide private sphere work to the population who are least able to care for themselves.

Since women constitute the bulk of the caregivers in society[199], it would be a disproportionate burden for them if patients with ESLD were to be resuscitated successfully. Once again, the definition of a successful resuscitation needs to be repeated. A successful resuscitation is one in which a patient recovers to their baseline function with respect to health. Unfortunately, there are many "unsuccessful" resuscitation attempts in which patients live in a very

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[195] Ibid 1517.
[196] Ibid 1517.
[197] Little 1996, 6.
[198] Rogers 2006, 351.
[199] Ibid 351.

compromised condition. These patients place an undue burden on women caregivers due to their numbers and the intensity and longevity of their care. A patient may live for years, requiring twenty-four hour nursing care, in a semi-comatose state, unaware of themselves or their environment. The inappropriate resuscitation attempt for a patient with ESLD does not simply place a burden on the patient and the family, but encourages an androcentric society which burdens women preferentially.

In the case of Mr. D., despite his previous comments to his family physician about “no CPR” and “when your number’s up, it’s up. That’s it.”, Mr. D. was intubated and ventilated. This was done at the behest of Mr. D.’s wife, as Mr. D. was unable to speak on his own behalf. This situation seems to fit with the androcentric society that feminist bioethicists describe, as he was treated very aggressively for an end-stage irreversible disease the minute he entered the emergency room and through ICU doors. Again, their view of society is accurate, for if Mr. D. were to live, he would need long term care for the rest of his life. His wife and family would likely try to provide this for him. The caregivers (mostly women) in society would be burdened by his level of care, and his family would also maintain a burden of care. The is exactly the type of inequality that feminist bioethicists argue against, in particular the unnecessary strain on the family unit and the women caregivers, to prolong an inevitable death, by aggressively treating a disease process that is a natural and irreversible one.

6.4 Futility and “Futilitarianism” in Bioethics

The Oxford English Dictionary defines the notion of futility as “incapable of producing any result; failing utterly of the desired end through intrinsic defect; useless, ineffectual, vain.”[200] For the purpose of this thesis however, the simplest definition of futility shall be “medical interventions that are unlikely to benefit the patient.”

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[200] Soanes Catherine, (Ed.) Oxford Dictionary of Current English 3rd Edition New York: The Oxford University Press, Inc., 2001, 368.

Futility describes an inability to produce a result, however in daily usage there are numerous interpretations of "producing a result" with significant variations in meaning. Unfortunately, when dealing with life and death decision-making, the notion of futility can mean different things to different people at different times. What one person feels is "futile" in one instance another may feel is "somewhat hopeful" in the same scenario. This disagreement over the definition of futility has never been more apparent than when discussing resuscitation attempts. *Brody* "notes that 'futility' had been taken to mean at least three things: (a) that resuscitation will fail to restore the heartbeat; (b) that resuscitation will restore the heartbeat but leave the patient in permanent unconsciousness; (c) that resuscitation will restore the heartbeat and consciousness, but the patient will not survive long enough to leave hospital." [201] *Dunphy* echoes *Brody's* ideas in his article insomuch as one must be cautious in defining a "successful resuscitation," for it can describe very different results.[202]

Futility, however can be related to moral judgments and value systems. Often, conflict arises in medical cases when there are differences between varying value systems. Hoping to mitigate some of the potential conflict, some have reduced the complex notion of medical futility to "physiological futility." "…[P]hysicians should not offer treatments that are physiologically futile….beyond that, they run the risk of 'giving opinions disguised as data.'"[203] The same thoughts are echoed in the *Hastings Centre Task Force on Guidelines for the Termination of Life- Sustaining Treatment*:

> "…in the event that the patient or surrogate requests a treatment that the responsible health care professional regards as clearly futile in achieving its physiological benefit to the patient, the professional has no obligation to provide it."[204]

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[201] Brody H. Appleton International Conference, "Developing guidelines for decisions to forgo life-prolonging medical treatment." Journal of Medical Ethics. 1992;18:6.

[202] Dunphy Kilian. "Futilitarianism:knowing how much is enough in end-of-life health care." Palliative Medicine. 2000;4:314.

[203] Tomlinson and Brody 1990, 1277.

[204] Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying: A Report of the Hastings Centre. Briarcliff Manor, NY: Hastings Centre, 1987, 32.

6.4.1 Physiological Futility

Physiological futility is a relatively simple version of futility in the sense that the physiological outcome which is desired is unattainable despite maximum medical treatment. Physiological futility conveys the least contentious definition in discussions. One cannot change a patient's pulmonary function with respect to metabolic parameters when the patient has a diseased lung, despite offering the maximum medical treatment. Treating a diseased lung at the cellular level is futile when the physiological function cannot be changed.

Physiological futility is a more accepted diagnosis or definition of futility than qualitative (or medical futility) in the area of resuscitation medicine. One argument for escalating intensive care is that often one cannot know absolutely that a treatment will not produce a desired outcome. Family members may agree to withhold or withdraw care if they could be assured *without a doubt* that the treatment for a particular type of disease *never* produced an improvement to the patient's baseline function. Despite the best clinical judgment, expertise and statistics, there are those who state, "in real life, there is no such thing as never, and the most unlikely outcomes imaginable can happen if given enough chances."[205] Given that the definition of physiological futility is not infallible, a quantitative approach to the definition of futility has been proposed. *Schneiderman* states that if "in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile."[206] The question remains however, at what level does the benefit outweigh the harm? This is a more qualitative question, as it pertains to percentages or ratios of benefits and burdens, which are discussed in the next section.

6.4.2 Medical or Qualitative Futility

The medical or qualitative definition of futility is most often used in end-of-life or near end-of-life decision scenarios, despite recommendations for reference to physiological futility. It is often invoked in a situation when no

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[205] Truog R.D. "Beyond Futility." Journal of Clinical Ethics. 1992;3:144.

[206] Schneiderman LJ, Jecker NS, Jonsen AR. "Medical futility: its meaning and ethical implications." Annals of Internal Medicine. 1990; 112:951.

further intervention will assist to bring about the desired outcome when looking toward a more global outcome rather than mere cellular improvement. There is a judgment concerning the benefit of the outcome, for although the treatment may have been partially successful, the effect is not worth achieving,[207] or when “the desirability of the goal is being brought into question.”[208]

The difference between medical and physiological futility can be appreciated as a difference between a “macro” and “micro” world of medicine. Physiological futility describes a situation where there is no improvement with treatment when evaluating the biochemical or functional effects of the patient’s organs. Medical futility describes the situation on a larger scale and evaluates the entire being rather than the parts. Despite perhaps some cellular improvement, or even organ improvement, the improvement is not enough to make a difference in the patient as a whole, or the difference is not enough to be a “good” difference. When one thinks of pulmonary function in this manner, there could be physiological improvement in the performance of the lung with different treatments, however it may never be enough to sustain a patient without the use of a ventilator. A patient *may* recover some lung function with the use of a ventilator. If however, one cannot live without a ventilator despite this improvement, the “macro” burden likely outweighs the “micro” benefit.

Many times the interventions at this stage of life cause harm (maleficence), manifested as unnecessary pain, suffering and the prevention of a peaceful death. *Nelson and Danis* reported that despite a belief there is adequate pain control at the end of life, more than “70% of patients reported to have pain in the ICU, with 63% of these patients rating their pain as moderate to severe in intensity.”[209] The **S**tudy to **U**nderstand **P**rognoses and **P**references for **O**utcomes and **R**isks of **T**reatment (SUPPORT) also reported that 50% of conscious patients who subsequently died, had experienced moderate to severe pain in their last few

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[207] Dunphy 2000, 315.
[208] Griener, Glenn G. “The Physicians Authority to Withhold Futile Treatment.” The Journal of Medicine and Philosophy. 1995;20:209.
[209] Nelson Judith E., Davis Marion. “End-of-life care in the intensive care unit: Where are we now?” Critical Care Medicine. 2001;(29)2 Supplement:N2.

days.[210] It is disturbing to realize that patients are often under-treated with respect to their pain control, and how "comfortable" deaths are not as frequent as one would believe.

The unavoidable pain and discomfort from *beneficial* treatment is often a burden a patient will accept. Take the example of the lumbar puncture (LP) to diagnose meningitis. The LP is not a comfortable procedure, but it is the key investigation required to adequately treat a potentially fatal disease. The temporary pain from the procedure is tolerated for the benefit of appropriate treatment and therefore, the avoidance of the associated morbidity and mortality of meningitis.

Pain and suffering for no perceivable benefit however, seems medically (and morally) wrong. There is little benefit (beneficence) to a patient by prolonging an inevitable death. Perpetuating harm and ignoring benefit is in direct violation to fundamental ethical principles.[211] The concept of futility (medical or physiological) is accepted by both the medical and legal professions, and physicians are not required to treat patients who they deem to be medically futile. Most physicians who work in intensive care units, emergency rooms, or on the palliative care wards, agree that certain medical acts are physiologically futile.[212,213,214,215,216,217] The Canadian Medical Association agrees with this statement, as does the Critical Care Society of North America, and the Court of Queen's Bench of Manitoba. This consensus may appear to leave much of the "when to withdraw or when to withhold treatment" question very much in the hands of physicians, for they are the professionals who are not only responding to the guidelines, but also to their own professional ethics and clinical judgment.

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[210] Pronovost and Angus 2001, N46.

[211] Tomlinson and Brody 1990, 1278.

[212] Eschun et al. 1999, 498.

[213] Scheinkestel C.D. "The evolution of the intensivist: from health care provider to economic rationalist and ethicist." Medical Journal of Australia. 1996;164:312.

[214] Farber S.J. "Ethics of life support and resuscitation." New England Journal of Medicine.1988;318:1757.

[215] Bedell S.E., Delbanco T.L., Cook E.F., Epstein F.H. "Survival after cardiopulmonary resuscitation in the hospital." New England Journal of Medicine. 1983;309:570.

[216] Tomlinson and Brody 1990, 1276.

[217] Simonds A.K. "Ethics and decision making in end stage lung disease." Thorax. 2003;58:273.

The decision that a treatment is futile is determined most often by a physician, but can in theory be determined by another individual (the patient or patient's proxy). Regardless who decides a patient is medically futile, the *implementation* of the decision to not treat the patient has defaulted to the role of the physician. It seems as if a societal expectation has developed, (without a formal acceptance by the medical profession), that physicians are obligated to implement the physical act of withdrawal of treatment. Few would suggest that a family member, clergy, ethicist or other person take on the act (with medical guidance) of withdrawing medical treatment. Currently, there is no professional or non-professional association that has made a formal legal application to be the administrators of this final act. It would be more appropriate perhaps for family or clergy to be responsible for the implementation of withdrawing life-sustaining treatment, as these two groups could be (potentially) the most emotionally invested in the outcome.

Texas has recently developed a document (*Texas Advance Directives Act*) to resolve disputes when there is a conflicting view regarding resuscitation and futility between physicians, patients and family. They have devised a due process protocol to aid in conflict and to have decisions made in a timely fashion. Texas was the first state to develop a law on futility in 1999, which "provided a legislatively sanctioned, extrajudicial, due process mechanism for resolving medical futility disputes and other end of life ethical disagreements."[218] The document has seven rules: 1) the patient or the patient's family/proxy must be given information on the requested ethics consultation; 2) the patient or the family/proxy must be given 48 hours notice to participate in the ethics consultation; 3) the consultation must provide the patient or the family/proxy with a written report; 4) if discussions break down between the physician and the patient or the family/proxy, the hospital must attempt to arrange transfer to another physician and another facility; 5) if after 10 days no alternative provider can be found, treatment may be withheld or withdrawn; 6) the patient, or

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[218] Fine Robert L., Mayo Thomas William. "Resolution of Futility by Due Process: Early Experience with the Texas Advance Directive Act." Annals of Internal Medicine. 2003;138:743.

family/proxy may apply to a judge for a time extension; 7) if no extension is applied for or granted, treatment can be withheld or withdrawn.[219]

Fine and *Mayo* found that no one sought a judge's order after the dispute had involved an ethics committee. The document also operationalized the definition of futility more clearly for if there was another physician and facility willing to treat a "futile" case, then the law would not allow the withholding or withdrawing of life-support on the basis of futility.[220]

Mr. D. has an end stage respiratory system due to his COPD. His pathology is such that he will not recover as his tissue is damaged beyond repair. He is a man who is being treated for a medically futile condition. Despite his treatment, he will not be able to live without a ventilator.

6.5 Appropriation Model

There has always been controversy when trying to meld the disciplines of philosophy and medicine. The philosophical and moral theories are sometimes construed as pursuits of lofty thought, of point and counterpoint, while medical choices are often perceived as very concrete and more of a practical and applied nature. The two disciplines do share an "interactive discourse" in the sense that neither is limited to a simplistic, self-evident categorical framework. They both possess multiple shades of nuance, and even those individuals who expressly consider themselves in one discipline or the other often have complementary ideas. It was not until the late 1960s and early 1970s that there was a *significant* meeting of the two groups, when the issue of resuscitation and life-support came into vogue. It is not easy however, to create a system whereby philosophy and science interact on an equal footing.

Baker and McCullough discuss why an attempt to meld these two areas failed: they claim that philosophy texts "treat bioethics as a form of applied

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[219] Ibid 744.
[220] Ibid 746.

ethics," or "an attempt to apply a moral theory."[221] When attempting to artificially apply a moral theory, there is often little that appears directly relevant to the practical or concrete nature of medical choices. This "applied ethics" has little to offer when trying to support difficult medical decisions, and as such "historians can find virtually no cases in which applied philosophical moral theory influenced ethical practice in biology or medicine."[222]

Baker and McCullough suggest a different relationship between philosophy and medical ethics. They have named the relationship the "appropriation model," and it attempts to appropriate philosophical concepts and theoretical fragments for use in practical contexts.[223] This is an adaptation technique in an attempt to meld philosophical concepts into a more practical method for dealing with medical decision-making. They state that the appropriated method "illuminates issues and provides conceptual resources useful in resolving practical difficulties." [224] They go on to state that this framework will eventually be embedded in everyday life and everyday practice to support medical decision-making, and eventually will be accepted as conventional.[225] The only manner in which the philosophy is revisited is if controversy erupts, and the theory is re-examined to support the opposing side to the conventional decision-making. They use the example of *John Gregory*, who was a physician-philosopher at the University of Edinburgh in the 1700s. He felt that morality was based on the ability to feel the suffering of another and not grounded in reasoning or intellect, and unlike other important "intellectual reflection, it could motivate action."[226] *Gregory* taught his medical students the character of a good physician, and although he used the language of Scottish moral philosophy, he did "not apply principles of Scottish moral philosophy to medicine, he appropriated concepts, adapting them to medical contexts, transforming them into a

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[221] Baker Robert and McCullough Laurence. "Medical Ethics' Appropriation of Moral Philosophy: The Case of the Sympathetic and the Unsympathetic Physician." Kennedy Institute of Ethics Journal. 2007;17:3.
[222] Ibid 3.
[223] Baker and McCullough 2007, 4.
[224] Ibid 3.
[225] Ibid 7.
[226] Ibid 10.

medicalised morality directly comprehensible and practically useful to medical students.[227]

Childress has described Kant as “a philosopher who has influenced the contemporary interpretation of autonomy.”[228] Kant’s moral philosophy was appropriated to further the legitimacy of the notion of autonomy. *Childress* continues that autonomy flows from Kant’s recognition that “all person have unconditional worth, each having the capacity to determine his or her own destiny. To violate a person’s autonomy is to treat that person merely as a means, that is, in accordance with others’ goals without regard to that person’s own goals.”[229] This interpretation is a change of the original idea to support the newer concept of autonomy. The appropriation model offers an account of moral change and how it can promote moral innovation in medical ethics.[230]

The appropriation model may be the most indicated model for decision-making in the medical field for practical decision-making. Difficult decisions are usually argued on the basis of what is presumed to be a moral theory or on the basis of a set of principles from a philosophical theory. The truth is that *Baker* and *McCullough* are correct in stating that the status quo decision-making that was perhaps loosely based on philosophy is now based on the common perception of what morality entails. These prevailing notions are taught to medical students from medical attending physicians (or medical bioethicists) and not from philosophers. Those students become attending physicians and continue to teach what they learned to the next generation of students. The convention becomes the norm, and the “new norm” is believed (erroneously) to be directly linked to the moral theory. This is clearly not the case. One has to only examine the idea of resuscitation to determine that the theoretical vocabulary and “principles” have evolved. They were changed by society as changes in medical care evolved. By contrast, philosophical theories have in effect remained rather static.

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[227] Ibid 10.

[228] Miyasaka Michio. “Resourcifying human bodies – Kant and bioethics.” Medicine, Health Care and Philosophy. 2005; 8:20.

[229] Miyasaka 2005, 19.

[230] Baker Robert B. and McCullough Laurence. “The Relationship Between Moral Philosophy and Medical Ethics Reconsidered.” Kennedy Institute of Ethics Journal. 2007;17(3):273.

In the early 1960s, resuscitation was believed to represent the peak of medical science. A dying heart could be revived with the appropriate technological care. Resuscitation in the 1980-1990s changed significantly, not in the treatment protocols per se but in the manner in which it was offered and the manner in which it was thought to be appropriate. The “do not resuscitate” (DNR) concept became more prevalent and the appropriateness of resuscitation was challenged. In the 21st century, the evolution of resuscitation technology continued. It changed from an accepted procedure to one embroiled in restrictions by patients, families, and physicians. The prevailing norm in the medical community is that not all patients should have a resuscitation attempt, which is a complete contradiction of the ideology of the early 1960s.

The changing ideas regarding the value and need for resuscitation attempts between the 1960s and the present have mainly been based on the progress of medical ethics. However, the core philosophies on which these difficult decisions were originally based has not changed. The prevailing convention regarding resuscitation has appropriated the ideas of what is morally sound, and has applied them to the current mores of society. In the 1960s, the fundamental medical goal was to preserve life, and the procedure for resuscitation added to that goal. There was little question as to whether the attempt to preserve life through resuscitation was moral. In the 21st century, there is significant question regarding the morality of the very same procedure. Currently, the moral imperative is to decide if the procedure is *reasonable* and does the attempt underscore the patient’s wishes. At one time, the goal in medicine was to save a life by any means, including a resuscitation attempt, *regardless* of the patient’s wishes. This action was believed to be the most moral and reasonable act, based in large part on the philosophical theories regarding duties and obligations of moral “rightness.” The theories were appropriated to reflect the ideas of the time.

At one time, patients and families would have been universally outraged if a physician suggested that aggressive treatment for a patient’s condition was unwarranted. Presently, the opposite is often true. Patients and families would be outraged to have aggressive medical care foisted upon them without their consent.

One has only to examine the *Nancy B.* case to appreciate the change in medical and societal attitudes toward life-support. The family's request to discontinue treatment was denied by the physician, for fear of legal reprisal. The family had to petition the courts (on *Nancy B's* behalf) to discontinue her aggressive care.

6.6 Dignity and Palliative Care Ethics

> ***But, Oh for the touch of a vanished hand, and the sound of a voice that is still.***
>
> ***-Alfred, Lord Tennyson***

Hippocratic writings suggested "three goals for medicine: cure, relief of suffering, and refus[al] to treat those who are overmastered by their diseases."[231] Dignity for end-of-life patients with terminal disease such as ESLD, has come to the forefront with the "do not resuscitate" controversy. "Dignity ethics"[232] have not reached the same level of awareness that other bioethical approaches have achieved. It is important to consider dignity ethics as another option when discussing the merits of resuscitation. Human dignity currently has two main ideas, dignity as "intrinsic worth" and dignity as "worth judged according to extrinsic social constructs."[233] Human dignity is the characteristic that all humans possess as a function of their humanity. Dignity as an extrinsic social construct is the more usual notion of what dignity entails. Dignity is a broad concept however, and despite its enormity, only a small aspect of it is discussed here. (Further discussion of it is beyond the scope of this paper.)

Over the last number of decades, *quality* of life for many people has become more important than *quantity* of life. Some people opt for aggressive comfort care measures rather than aggressive acute care medical treatment upon discovering that they have a life-limiting disease. They prefer a comfort care plan instead of subjecting themselves to medical procedures that may or may not extend their life. This care plan aims at improving the *quality* of a person's life

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[231] Fine and Mayo 2003, 743.

[232] Chochinov Harvey Max, Hack Thomas, Hassard Thomas, Kristjanson Linda J., McClement Susan, and Harlos Mike. "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life." Journal of Clinical Oncology. 2005;23:5520.

[233] Hawryluck L. "Lost in Translation: Dignity Dialogues at the End of Life." Journal of Palliative Care. 2004;20(3):150.

over the *quantity* of time left, thereby maximizing the "good days." These patients attempt to have more "good days" filled with comfort care, symptom control, sociability, lucidity and emotional support rather than simply an increased number of days. The palliative care and hospice phenomena arose from people choosing a less medicalised death insofar as they opted for fewer medical interventions in the days prior to death.

Palliative care is not merely the administration of morphine to dull pain and the senses but rather an *approach* focusing on "symptom management, maintenance of a reasonable quality of life, good communication, increasing physical activities to maintain independence, and practical support of emotional, spiritual and psychosocial support for patients and caregivers."[234] When speaking about end-of-life issues, palliative care and "dignity ethics" have become slowly interconnected and now complement each other. Dignity for a patient is generally more prevalent in a palliative care environment as opposed to a general medical ward due to the acceptance of the life-limiting outcome and goals of treatment by patients, families and medical staff. Due to this rather recent change in focus within the medical community, *dignity therapy or dignity ethics* for palliative care patients has emerged.

Human dignity is characterised in this paper as something that "signifies a general presumption of equal moral worthiness in spite of differences of individual merit, giving every human being basic rights that preclude their being treated only as means to others' ends rather than ends-in-themselves."[235] This notion of dignity is extremely important in the area of palliative care, for an ongoing value is placed on dying individuals and their *total care* (medical, spiritual, cultural, and physical care). This relates to the protection of society's weakest members who are those individuals in the active stage of dying, or those who are too frail or weak to speak adequately for themselves.

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[234] Yohannes, Abebaw Mengistu "Palliative care provision for patients with chronic obstructive pulmonary disease." Health and Quality of Life Outcomes. 200;5:2.

[235] Simpson Evan "Harms to Dignity, Bioethics, and the Scope of Biolaw." Journal of Palliative Care. 2004;(20)3:186.

Dignified, humane care seems like inherent characteristics of any good medical system. Yet there are inequities in the health care system which appear to undermine the dignity of some patients more than others. It is presumed that human dignity signifies an equal moral worthiness between all people, and yet the treatment of patients with COPD exacerbations in the setting of ESLD is not equal to others with a similar life-limiting terminal lung disease. It is surprising to know that patients with ESLD from COPD receive worse treatment than those who are dying from ESLD due to lung cancer.[236] The patients with ESLD from COPD have a worse quality of life than those with lung cancer.[237, 238] Patients with ESLD from COPD have a *longer duration* of symptoms and those symptoms are *more intense* than lung cancer patients, and yet they are less likely to be offered palliative care treatment and support.[239]

The "dignity ethics" frame would require an accounting for the different treatments offered to patients with similar needs. The philosophical and practical approaches to ethics, whether they are duty-oriented, consequence-oriented or principle-based, adhere to a consistent treatment of patients with similar needs in similar circumstances. Despite a case-by-case basis in making medical decisions, even Kant and his duty-based theory noted that treatment is to be decided with rationality and lack of emotion. This would imply that those with similar medical needs would receive similar medical care, and there would not be discrepancies between similar groups. Rawls and his "original position theory" supports similar treatment for similar situations, as his action of "goodness" is understood in the context of what everyone values. The utilitarians and consequentialists would agree that comparable or equal groups require equal treatment, without overriding others needs or wishes. This level of fairness satisfies both a sense of utility and justice. Rawls states that "each person possesses an inviolability founded on justice that even the welfare of the society as a whole cannot override. For this reason justice denies that the loss of freedom for some is made right by a greater

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[236] Yohannes 2007, 2.
[237] Ibid 2.
[238] Neerkin J and Riley J. "Ethical aspects of palliative care in lung cancer and end stage lung disease." Chronic Respiratory Disease. 2006;3:93.
[239] Neerkin J and Riley J. 2006, 97.

good shared by others… the rights secured by justice are not subject to political bargaining or to the calculus of social interest."[240] Furthermore, the principle-based approaches support this sense of equality. The principle of autonomy demands availability to access treatment, regardless of disease process. The principles of beneficence and non-maleficence also support equal access to treatment. Patients with ESLD or lung cancer should have their best interests recognized and their autonomous choices for care should be respected as much as other patients.

"Dignity care" describes those measures that preserve or enhance the dignity a person feels at the end of her life. Often patients suffering from ESLD have to choose between aggressive care and comfort care at the end of their lives. If they choose to follow a comfort care path, there are many methods to ensure a dignified approach to their care. The methods relate to respecting the autonomy of the person, for a patient should participate in the trajectory of her life, regardless of how limited it may be due to a terminal disease. Existential angst, feelings of being a burden to family and friends, depression, and anxiety are often prevalent and may be more stressful than physical pain.[241, 242] "Dignity therapy" focuses on discussion therapy and highlights issues that matter most or issues that the patient would most want remembered.[243] This therapy mitigates suffering at the end of life by building on methods to engender a sense of meaning and purpose in patients' lives.[244]

Dignity is an important moral concept when considering a resuscitation attempt. There is significant trauma that is inherent in a resuscitation attempt, as well various forms of bodily indignities. If this attempt is unlikely to be successful, patients should be offered and counseled about the option for comfort/palliative care. This counseling should also include such measures as teaching patients that palliative care is an active form of treatment. Patients are

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[240] Rawls 1999, 3.
[241] Chochinov et al. 2005, 5520.
[242] Chochinov Harvey Max "Dignity-Conserving Care- A New Model for Palliative Care." JAMA. 2002; 287(17):2254.
[243] Chochinov et al. 2005, 5520.
[244] Ibid 5521.

treated holistically with attention to all of the emotional, spiritual, social and physiological concerns. The notion that palliation is a "closed door at the end of the hall" is false. It is a disservice to palliative physicians to suggest their role is simply the administration of morphine. Patients need to be informed regarding medical choices and access to life-affirming decisions about their medical care. They must actively consent to treatment plans so they may plot their own life course.

It is morally wrong to not offer palliative care to a dying patient as it continues to encourage a system of paternalism and belittles the principles elucidated by *Beauchamp* and *Childress.* The caring community-approach to healthcare that feminist bioethicists embrace is belittled also by not offering all forms of available treatment. The "two tiered system" of offering some a care plan and not others contravenes Kant's rationalism and Mill's and Bentham's utility bound approach. Dignity and palliative care ethics are currently not a mainstream theoretical approach in medical ethics. Given the importance of these two concepts and how they cross into other approaches, it is important they are mentioned.

Mr. D. has led a dignified life in the sense of his accomplishments and his interests. He notes those things most important to him are his family and work ethic. He is very proud of his home and his ability to maintain it as well as to be able to be a valued contributor to his wife, children and society at large. Given his level of activity and interest, the reasonable person would likely find his current status very undignified. He prided himself on being able to do practically everything for himself. Now he can do none of it, not even breathe. He prided himself on being active with his grandchildren, now he can no longer speak to them, participate in their activities or hold them when he chooses to, due to the constraints of his illness and his environment. At this point in his care, it would be kinder to allow him the gentle and dignified death that he had wished for in so much as "dying in my sleep," with an adequate comfort care approach.

6.7 Informed Consent

Consent is a "contract based on a special relationship of trust."[245] Informed consent is a contract that stipulates a critical core of knowledge given by an expert in the field. Informed consent is one of the fundamental hallmarks of medical decision-making. It is paramount in importance. Patients must be safe from undue harm and an informed consent is but one mechanism to decrease the potential for a paternalistic style of medicine. The process of informed consent must be informative and voluntary. It should consist of details about the procedure or treatment, the expected benefits, the expected side effects, any possible alternatives (if available) and the right to change one's mind about the treatment offered.[246] Informed consent should also encourage the opportunity to ask questions and receive answers, and to be free from misrepresentation of material with information.[247] The patient must have a clear understanding in language that is appropriate to the person to truly make an informed decision regarding medical care. The consent should be voluntary "not only technically, but also in spirit."[248] Physicians must endorse and subscribe to the concept of informed consent to ensure patients' rights to autonomy.

A fundamental premise of my thesis is that no "reasonable person" would consent to resuscitation in the context of ESLD, if they were truly providing an informed, enlightened and uncoerced consent . So why do some ESLD patients seemingly consent to such care? In my clinical experience, I am convinced that these patients have not received all the relevant information, especially with respect to the risks and potential burdens of resuscitation. In the absence of clinical education and support, they fear the suffering associated with the dying process and hold on to a misguided belief in the grossly inflated rates of

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[245] Rozovsky Lorne E. The Canadian Law of Consent to Treatment -Third Edition 2003 LexisNexis: Canada, 4.

[246] Ibid 1825.

[247] Rozovsky 2003, 6.

[248] Edwards Sarah J.L., Lilford Richard J., Thorton Jim, Hewison Jenny. "Informed Consent for Clinical trials: In Search of the "Best" Method." Social Science & Medicine. 1998;47(11):1825.

resuscitation promoted in the media.[249] At other times, it is the patient's family members who are engulfed in fear and grief who appear to pressure or coerce the patients to agree to accepting such care. All of these factors can have a significant impact on the patient's clinical competence to provide an enlightened consent. Furthermore, in my clinical experience, I am convinced that a competent, un-coerced, informed patient with ESLD would choose a comfort care treatment plan over a resuscitative treatment plan, if presented with the two options. I believe Mr. D. would be in this category.

6.7.1 Competency

The law presumes competency once one reaches the age of majority. Under common law, "adults are presumed to be competent to make decision for themselves." This has been codified in many laws, including Manitoba's *"The Health Care Directives Act"* and the "*New Mental Health Act."*[250] Furthermore, a physician is "required to assume capacity"[251] unless there is a belief or question regarding that patient's capacity. Incompetence however, needs to be proven and no one has a right to deny or question competence based on pure speculation.[252]

There are some situations however, where there is no presumption of competence (*The Human Tissue Act, The Family Maintenance Act* and *The Heath Care Directives Act).* Competence is not presumed from those people who have not reached sixteen years of age. These individuals are not deemed to be incompetent, but instead the presumption of competence needs to be fulfilled with other evidence. Competence is not necessarily a static descriptor. Individuals with mental health issues can have a fluctuating level of competence, and the level of competence may need to be addressed as necessary.

In the past, one was deemed either competent or incompetent. One was either able to manage all financial, social, legal and medical decisions, or one was

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[249] Diem et al. 1996, 1578.

[250] Manitoba Law Reform Commission – Informal Assessment of Competence (1999 September), 4.

[251] Manitoba Law Reform Commission – Informal Assessment of Competence (1999 September), 5.

[252] Ibid 5.

not. The situation has since evolved so that competence is now "recognized as being specific to certain types of problems, tasks or decisions."[253] If a patient is deemed competent, that person is entitled to certain rights and freedoms, but in particular, she is entitled to autonomy and self-determination.[254] The ability to exert one's will and to be independent from the decisions of others is the basis for an autonomous person.

After considering her best interests, an autonomous person has the right to choose a resuscitation attempt, if it is offered by a physician. A person may choose to be intubated and resuscitated, once she understands and appreciates the risks and benefits of the procedures. Some individuals may have had a previous admission to an intensive care unit and may benefit from the experience again. Another person may decide that she is not interested in any form of artificial life-support, regardless of her needs and potential outcome.

"There is a broad ethical, legal, and medical consensus that competent adult patients have the right to determine the course of their medical care. In particular, patients have a fundamental ethical and legal right to refuse all proposed treatments including life-sustaining medical treatments. In ethics, this right is based on the principle of individual autonomy. In law, it is based on the common law right to be free from unconsented bodily invasions…."[255] Regardless of the individual's decision, the person has a presumption of competency to make such decisions unless proven otherwise.

6.7.2 Knowledge and Communication

Knowledge and an ability to choose one's path in medical decision-making are intertwined. An informed consent is the basis on which medical decisions are determined. A person's knowledge however, regarding complex and other emotionally charged medical situations can be sparse. The physician must adequately inform a patient and pass on all necessary information so a person can

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[253] Ibid 6.
[254] Ibid 10.
[255] Singer PA, Siegler M. "Elective Use of Life Sustaining Treatments in Internal Medicine." Advances in Internal Medicine. 1991;36.

make an informed choice. Disseminating the knowledge appropriately and communicating the information accurately have often been significant roadblocks to a truly informed consent by patients.[256] Despite even the best intentions on behalf of the physician, there are individuals who lack the mental capacity to grasp what can be medical complex issues. At other times, unfortunately these conversations sometimes do not happen regardless of specific hospital guidelines to mandate them.[257]

Furthermore, physicians can provide the information but it can be meaningless to patients if it is not somehow contextualised to their unique situation and have some guidance or recommendation attached to it. In the past, physicians were criticized for treating patients without providing for an open dialogue. The physician's experience however, is invaluable with respect to providing guidance and recommendations, regardless of the information that is passed along. "…Presenting them (patients) with information is one thing, but assisting them in the decision-making is another thing. I should have made stronger recommendations."[258]

Tulsky suggests ideas to improve communication thereby improving the patient's ability to provide an informed consent. He counsels physicians thus: "…encourage patients and families to talk, do not contradict or put down other health care providers, yet recognise patients concerns, acknowledge errors, be humble, demonstrate respect and do not force decisions."[259] Despite the very grim prognosis for patients with ESLD, the patients' and families' hopefulness is usually still present. The physician must discuss medical options honestly, however there is a humanitarian duty to avoid undermining the patient's hope for a better outcome. Hope is a powerful emotion which often helps patients cope with their predicament, as well as "construct their future."[260] Physicians and other

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[256] Rady Mohamed Y., Johnson Daniel J. "Admission to intensive care unit at the end-of-life: is it an informed decision?" Palliative Medicine. 2004;18:709.

[257] Wilson J. "To what extent should older patients be included in decisions regarding their resuscitation status?" Journal of Medical Ethics. 2008; 34:353.

[258] Tulsky J.A. "Beyond Advance Directives – Importance of Communication Skills at the End of Life." JAMA. 2005;362.

[259] Ibid 362.

[260] Ibid 363.

health care providers have often been guilty of sheltering a patient from truthful information regarding her condition in an attempt to maintain the patient's hope for a better outcome. Physicians often believe that undermining a patient's hope is cruel, for it would inadvertently remove a patient's remaining desire to live. However, this sheltering of information does not lend itself to good communication regarding the prognosis nor does it provide an adequate knowledge about the disease process in the context of seeking a duly informed consent.

Sheltering patients from the truth to soften the appreciation of the prognosis is to remove a person's ability to fully recognize the gravity of her situation. It belittles her ability to make an adult, autonomous and competent decision. It would be better to be truthful in a kindly and supportive manner and then "acknowledge the emotion(s), identify loss, legitimize the feelings, and offer support."[261]

Framing is a key element for good communication skills. A patient may have a very different outlook on her choices, depending on how one states the information and recommendations. If one were to say "you will never wean from a ventilator – you will never be able to eat or speak normally to your loved ones," many people would not be willing to undertake this treatment option. This is not an ethical way of framing the conversation. There is never an *absolute* certainty in the field of medicine. This overtly negative framing of information virtually removes the patient's ability to make a weighted decision on the benefits and burdens of ventilation. Patients "tend to avoid risky or negatively framed choices,"[262] and 93% of the physicians in *Sullivan's* study admitted that the information presented to patients "was modified in order to influence the patient's choice."[263] Furthermore, "information was usually framed according to the

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[261] Ibid 363.

[262] Sullivan K., Hebert P., Logan J., O'Connor A., and McNeely PD. "What Do Physicians Tell Patients with End Stage COPD About Intubation and Mechanical Ventilation?" Ethics in Cardiopulmonary Medicine. 1996;109:262.

[263] Ibid 261.

physician's clinical judgment about the potential for a successful mechanical ventilation outcome, and return to a suitable quality of life."[264]

Clearly, many conversations are morally suspect when there is an ability to frame the conversation in such a manner as to achieve the physician's desired answer, or to achieve the "consent" that the *physician* wanted. In an effort to avoid this scenario, the American Thoracic Society outlines physicians' responsibilities to assess the competence of the patient, to inform the patient regarding the diagnosis, prognosis, risks, benefits, and consequences of the full range of available medical interventions, and to provide a professional recommendation.[265]

Another significant barrier to an informed consent and to good communication between physicians and patients with ESLD, are the patients who do not want to discuss outcomes. The three most common barriers to an informed consent from the patient's perspective are: 1) patients would rather concentrate on staying alive than talk about impending death; 2) there is uncertainty as to a who will be the specific attending physician at the time when patients become very sick; and 3) many patients state they do not know what kind of treatment they would like if they were very ill.[266] *Knauft's* study showed that only one third of patients with oxygen dependent end-stage lung disease discuss with their physicians the type of care that they would request if they required ventilation and resuscitation. The patients that do have a discussion with their physician rate these discussions on a satisfaction scale as 8.9 out of 10, (with 1 being the lowest rating and 10 being the highest rating)[267] Despite the paucity of discussions which occur, the ones that do occur are highly rated. Sadly, informed decisions regarding treatment options seem to be stymied by the *barriers* to these conversations, and not the conversations themselves.

Mr. D. was aware of the seriousness of his condition long before he was intubated. He recognized his limitations and how they were becoming more and

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[264] Ibid 261.

[265] Ibid 263.

[266] Knauft E., Nielsen EL., Engelberg RA., Patrick DL., Curtis JR. "Barriers and Facilitators to End of Life Care Communication for Patients with COPD." Chest. 2005;127: 2190.

[267] Ibid 2193.

more severe and burdensome on himself and those around him. He was approached by his family physician about an advance care directive early on in his ESLD trajectory, and his respirologist also commented on his severe disease. Mr. D did not shy away from these conversations, and was an active participant in the discussions and treatment modalities up until the time he was intubated.

6.7.3 Understanding

Some studies demonstrate a very low level of conversation and discussion between physicians and patients with ESLD regarding resuscitation. A further problem however, is the *understanding* of the conversation. *Knauft's* study demonstrated a high satisfaction rating of the conversation, but this is not necessarily the standard of care.[268] There are other studies which clearly show that even with appropriate conversations, the understanding of those conversations is insufficient upon admission to an intensive care unit (ICU).[269, 270] A 2005 study by *Thorevska et al.,* illustrated several interesting facts when speaking to patients about resuscitation and ventilation. They demonstrated in their study that most patients with "living wills" created them with friends or a lawyer, only 7% consulted a physician, and only 19% of those creating a "living will" had any information as to what resuscitation entailed.[271] More importantly, after they were informed of the procedure, 37% of those with "living wills" did not want the procedure and if it was already started, 39% stated they would not want it if chances of recovery were less than 10%.[272] The percentage of people who had an accurate understanding of the success rate was also poor. As far as understanding the success rate of CPR, 79% of patients thought that resuscitation was successful in 50-90% of cases.[273] This statistic was similar to the *New England Journal of Medicine's* study on the perception of successful resuscitation

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[268] Ibid 2190.
[269] Rady and Johnson 2004, 705.
[270] Thorevska Natalya, Tilluckdharry Lisa, Tickoo Sumit, Havasi Andrea, Amoateng-Adjepong Yaw, Manthous Constantine A. "Patients' understanding of advance directives and cardiopulmonary resuscitation." Journal of Critical Care. 2005;20:26.
[271] Thorevska et al 2005, 26.
[272] Ibid 28.
[273] Ibid 26.

as viewed in the media. It is plausible that the patients who provide a "living will" wish for a more individualised treatment plan, and yet their knowledge regarding the treatment is ill informed or simply lacking. Significantly, once the resuscitation process is explained by the appropriate health care professional, people choose this option much less frequently.[274]

Again, in reviewing the clinical vignette, it is clear that Mr. D understood the process of his COPD and ESLD. He did not shirk away from being involved in getting the supplemental oxygen at home, and taking his medications.

6.7.4 Self-Determination and Medical Decision-Making

The right to self-determination is the right to make decisions about the path one seeks, whereas the right to autonomy is the right to act toward the world in general in accordance with one's worldview. Self-determination and autonomy are often used interchangeably in the medical world, despite having different meanings. As stated before, autonomy is held in high regard, in so far as patients are expected to choose their own paths for health care based on their particular background and experience. Some of the difficulties patients have in the process of decision-making such as informed consent, competency and autonomy were discussed previously. Despite one's best intentions for an ethical decision based on these fundamental concepts, there are patients who *do not want to make their own decisions.* They wish to relinquish their responsibility for their treatment options and have others make decisions on their behalf. Despite physicians' attempts to encourage patients to make informed decisions, *Levinson et al.* found that many patients simply do not want to participate in their own health care choices.[275] This was a population-based study with a 70% response rate of 2750 respondents (with participants of mixed heritage, gender, and education levels). Significantly, 52% of respondents preferred to leave final decisions regarding

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[274] Ibid 28.

[275] Levinson Wendy, Kao Audley, Kuby Alma, Thisted Ronald A. "Not all Patients Want to Participate in Decision Making – A Notional Study of Public Preferences." <u>Journal of General Internal Medicine.</u> 2005; 20:531.

health care up to their physicians.[276] Forty-four percent preferred to rely solely on their physician for medical knowledge, rather than seeking alternative or complimentary sources of information.[277]

Patients have the right to decide where they receive medical attention. They also have the right to seek information and alternative therapies at their own discretion. In an environment that values autonomy and self-determination however, the studies regarding the numbers of individuals who would leave these decisions solely to their physician is surprising. Leaving medical decisions solely to the medical professionals could be construed as a form of self-determination, however it is possible that some individuals may be happy (or resigned) to a paternalistic delivery system of medical treatment.

The higher level of sophisticated understanding that may be needed for medical decision-making may partially explain the high number of patients who leave final decisions to their physicians. The survey by *Levinson et al.* was for general medical choices and not specifically for life-saving or palliative care decisions. It would be reasonable to speculate that one may find an even greater number of individuals relying on physicians when the complexity of the decision-making increases. This decreased participation limits the ethical nature of self-determination and decision-making by allowing a continued paternalistic approach to medical practice.

Mr. D. made some medical decisions on his own by the comments that he made to his family physician. He stated contradictory decisions at the point when withdrawal of treatment was proposed. These decisions were not made with lawyers and documents, but the verbal decisions are to be respected as steadfastly as written ones. Furthermore, his way of life gives one ample examples of his nature and character and one can derive some semblance of preferences for choice that he would have in this situation had he been provided options prior to intubation. If he had been asked on the cusp of intubation, he may not have consented to the procedure.

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[276] Ibid 532.

[277] Ibid 532.

6.7.5 Problems with Surrogate Representation of Patient's Informed Consent

Patients with longstanding, debilitating diseases often appoint a person to represent their medical wishes in the event that the patient themselves are unable to speak on their own behalf. This appointment can occur before a critical illness or during an illness. The appointed person's role is to inform the physician of the wishes of the patient, and is known as a "surrogate representative." The surrogate representative's role is to be the "voice" of the patient, and relay *only* the patient's wishes and not to impart their own personal wishes on the direction of medical care. This does not necessarily mean the patient's competency is at issue, but rather they are too ill to consistently and meaningfully voice their wishes. Often these surrogates are spouses or other family members, but close friends can also fulfill this role.

The Patient Self-Determination Act (1990 USA) allows patients to choose a representative to act on their behalf for medical decisions if the patient themselves is unable to do so and if no surrogate is appointed, there are often statutes to facilitate a next-of-kin surrogate on their behalf.[278] The surrogate representatives are to provide direction for medical care in the role as a substitute decision maker, making the "treatment decision that the patient would have made,"[279] and reflect the "values and preferences of the patient in light of the patient's clinical status and prognosis."[280] The representative is not to superimpose their own wishes for the patient they are representing.

There are many difficulties with the use of surrogate representation and substitute decision-making. The surrogates are often unreliable in accurately representing the patient's wishes.[281, 282, 283, 284, 285, 286] Numerous studies have

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[278] Shalowitz DI, Garrett-Mayer E, Wendler D. "The Accuracy of Surrogate Decision Makers – A Systematic Review." Archives of Internal Medicine. 2006; 166:493.

[279] Shalowitz et al. 2006, 493.

[280] Bramstedt KA. "Questioning the decision-making capacity of surrogates." Internal Medicine Journal. 2003;33:257.

[281] Fried TR, Bradley EH, Towle VR. "Valuing the Outcomes of Treatment – Do Patients and Their Caregivers Agree?" Archives of Internal Medicine. 2003;163:2076.

recorded the inaccuracy of patient and surrogate concordance in choosing specific medical interventions. A surrogates' accuracy in deciding on patient preferences has been rated as poor to moderate,[287] or poor[288] and often described as being no more accurate than chance.[289, 290] The same studies determined that if prior conversations had occurred between the patient and the surrogate, there was accurate representation in only certain treatment options but not accurate representation with all treatment options. If the patient had discussed that they did not want resuscitation, there was a higher level of accurate representation with this request. If there was no discussion however, there was a high level of inaccurate representation whether or not to perform a resuscitation attempt. The studies on substitute decision-making generally demonstrated an accuracy rate of 59-69%, [291, 292, 293] however as the seriousness of medical decisions increased (such as intubation or resuscitation) the accuracy rate of representation dropped. The highest level of accurate representation were those choices that involved scenarios regarding the patient's current health[294] and were of a low acuity such as whether or not to have antibiotics.

The surrogates often make inaccurate substitute decisions as they base their decisions from their own experiences and desires and fail to advocate for decisions based on the patient's perspective. They often agree to more aggressive treatment than what the patients would have wanted, and it has been suggested

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[282] Layde PM et al. "Surrogates' Predictions of Seriously Ill Patients' Resuscitation Preferences." Archives of Family Medicine. 1995;4:518.

[283] Shalowitz et al. 2006, 495.

[284] Suhl J, Simons P, Reedy T, Garrick T. "Myth of Substituted Judgment – Surrogate Decision Making Regarding Life Support Is Unreliable." Archives of Internal Medicine. 1994;154:93.

[285] Sulmasy DP et al. "The Accuracy of Substituted Judgments in patients with Terminal Diagnoses." Annals of Internal Medicine. 1998;128(8):624.

[286] Bramstedt 2003, 258.

[287] Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K. "Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making." Journal of American Geriatric Society. 2006;54:1688.

[288] Fried et al. 2003, 2077.

[289] Shalowitz et al. 2006, 493.

[290] Sulmasy et al. 1998, 627.

[291] Ibid 493.

[292] Suhl et al. 1994, 90.

[293] Sulmasy et al. 1998, 621.

[294] Shalowitz et al. 2006, 495.

that the surrogates' own values colour the decisions they make for others.[295] Discussions by patients with surrogates regarding their CPR choice did not improve the accuracy of the substituted decision,[296] and variables such as length of relationship between the patient and surrogate, educational level and age of patient and surrogate did not improve accuracy of decision-making.[297] Furthermore, surrogates consistently rate physical and cognitive impairment as less debilitating than the patients themselves, and as such would continue care in a state that the patients would not want.[298] Lastly, the decisions that patient-appointed surrogates make on behalf of the patient are no more accurate than decisions made by a court appointed next–of–kin surrogate.[299]

The lack of accurate representation by a substitute decision maker (surrogate) with respect to treatment choice in critically ill patients is concerning. Conflict between a family and a physician regarding the treatment options for a debilitated patient can be further escalated when the family's treatment choice is challenged as a valid substitute decision for a patient. When such a conflict arises, an attempt to gain further evidence of specific treatment choices from another source such as a family physician is warranted. The family physician often will have a[300] longstanding, confidential relationship with a patient and has the potential to be an unbiased source of information with respect to treatment preferences. Family physicians often have an opportunity to discuss "end-of-life care preferences before patients are terminally ill and uncommunicative."[301]

Mr. D. had a longstanding history with his family physician and had on several previous occasions discussed preferences about end-of-life issues. These preferences were recorded by his physician in his medical chart (file). Despite his documented preferences, such as "when your number's up, it's up. That's it," and "no CPR," conflict arose at a critical juncture. He and his family wanted to continue care. It is clear from a "reasonable person" vantage point that they are

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[295] Ibid 495.
[296] Layde et al. 1995, 523.
[297] Suhl et al. 1994, 94.
[298] Fried et al. 2003, 2076.
[299] Shalowitz et al. 2006, 493.
[300] Suhl et al. 1994, 94.
[301] Layde et al. 1995, 523.

failing in their duty, as he does not need a surrogate decision maker. The family wishes are in fact obfuscating Mr. D's wishes, as they are adding another layer of emotion on to an already emotionally charged scenario. For them to act as a surrogate decision maker, they in fact should step back from the situation and evaluate his statements to his family physician, and reflect on the type of man he was when he was well. They are negating his family physician's relationship with him as well as that physician's documentation on Mr.D.'s wishes. The family's choice for his care is based on their own desires and they are clearly "overestimating patient desires for life-support."

In Mr. D.'s case, there is a problem with decision-making and the surrogate representation. Clearly, his family is too distraught at his impending death to come to act more "reasonable," when evaluating the burdens and benefits of continuing life supportive care. Conflict has arisen in this clinical vignette between the family, patient and the physician as to what is the best interest of Mr.D. At one time, the model of medical decision-making was paternalism, and the decisions were left to the hands of the physician. This evolved to a shared decision making model which has its benefits and perils. Some scholars advocate an extension of shared decision making.[302] Whitney et al. suggest that there are reasonable medical decisions to be made often when there is only one reasonable choice for medical treatment. They argue that the physician's role is "not to offer alternatives but to explain why there is only one viable choice and move the decision-making process forward. The physician does not thereby undermine the patient's autonomy; rather, the disease process itself constrains both patient and physician."[303] Of course, the patients can choose unwisely,[304] and not choose the reasonable choice.

It is often the case however, and is such with Mr. D. that the person herself is not against the reasonable choice but the substitute decision maker or family member have either convinced the patient otherwise and cannot choose the same

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[302] Whitney SN, Holmes-Rovner M, Brody H, Schneider C, McCullough LB, Volk RJ, McGuire AL. "Beyond Shared Decision Making: An Expanded Typology of Medical Decisions." Medical Decision Making. 2008;28:699.
[303] Ibid 699.
[304] Ibid 700.

reasonable choice. It seems clear in this vignette that Mr. D.'s choices have been initially clear but the family at this point in time cannot come to grips with their grief reaction, and as such are providing encouragement and a new voice to continue treatment.

Chapter 7

Conclusions

The goal of this thesis is to integrate theoretical and clinical perspectives in addressing some of the complex ethical issues that I face as an intensive care physician in a hospital setting. My hope is to consider many of the thoughts and ideas of the main literature in the areas of medicine, philosophy and law when discussing end-of-life care issues such as resuscitation for ESLD. Good patient care is the priority in a clinical setting, and to review different theories to improve on that care is always the primary goal. My clinical vignette describes a patient whose situation is a very common occurrence in the ICU setting, and being able to transfer some insight with respect to care in a meaningful way is important to me in the work that I do as an intensive care physician.

I would like to re-emphasize that I am writing this thesis from the perspective of an intensive care unit (ICU) physician studying bioethics, rather than as a philosophy student. I am acutely aware that this is not a complete philosophical, or legal analysis. I have tried to structure the knowledge that I have gained from the literature and translate it into a more ethical approach for the patients for whom I care in the ICU setting.

The clinical setting is restricted to the patient with a COPD exacerbation requiring resuscitation and ventilation. Patients with other lung diseases that are by definition reversible or treatable, which have been previously mentioned, are excluded from this thesis.

The ethics of considering life-supportive technology was discussed with an emphasis on the historical points regarding the natural development and implementation of CPR, and the current definitions, etiology, risk factors, natural history and medical recommendation for resuscitation for patients suffering from COPD. I continued by describing the current legal positions as they pertain to my clinical practice, and the current medical opinions, again as they pertain to my practice.

The basic deontological and teleological approaches were discussed with attention of both Kantian and pluralistic notions of autonomy, principle based theory as well as utilitarian considerations, and McCollough’s “appropriation model” of bioethics. I continued with a discussion on futility and “futilitarianism,” as well as feminist bioethics, “dignity ethics,” and palliative care. Throughout the thesis, there were discussions on the “reasonable person standard” as it pertains to the patient in the clinical vignette.

Offering and providing a patient a resuscitation attempt for an end stage respiratory system is equivalent to inappropriately prolonging the imminent and inevitable trajectory of this chronic illness. There is a level of burden that is imposed on these patients that is not worth the benefit when one contemplates the natural process of dying and the dying trajectory of a patient with such an end-stage disease. These patients should be allowed to die peacefully with the least medical interference as possible. It is completely acceptable to die at the end of one’s life. It is one manifestation of the natural order. It is not in the best interests of patients to suggest that death is an unacceptable conclusion. Resuscitating a patient with ESLD adds a burden of pain and suffering to the patient with no appreciable benefit, and they should not be resuscitated with life-supporting technology. This resuscitation also burdens the resources of the health care system and places undue strain on the caregivers of these patients. Instead, the patients and their families should be offered (and treated) with dignity, complete comfort care, an opportunity to grieve, a means for acceptance of life’s natural order, and most of all compassion, understanding, and Godspeed.

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