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**Sedation Practices, Tragic Dying and Palliative Care:  
An Ethical Inquiry**

by  
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A dissertation submitted to the  
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# **Sedation Practices, Tragic Dying, and Palliative Care: An Ethical Inquiry**

## **Abstract**

With the increased ability of medical technology to manipulate or prolong the end of a patient's life, and with the increased dependency of patients on technology for survival and comfort, health care professionals who manipulate these "end of life" technologies seem to more directly manipulate the life and death of the patient. The end of life is the focus of the health care discipline of palliative care. It has been promoted as a holistic approach addressing the needs of dying patients which, if not addressed, give rise to requests for physician assisted suicide. Yet, concerns regarding the direct killing of patients also arise in palliative care through sedation practices. Discussion of this apparent contradiction is especially poignant given the value palliative care places on the dying process as a time of potential growth and self-actualization.

Two traditional and foundational criteria within the principle of double effect (PDE) which are often cited as identifying significant ethical differences between killing and letting die are: 1) The psychological intention of the agent, 2) the direct/indirect action distinction. The problem is that the meaning and pertinence of these criteria have been argued as being both inadequate and adequate in demonstrating a moral difference between killing and letting die within healthcare debates. The question for palliative care clinicians is, "What is the ethically significant difference between killing and letting die in palliative care where death is not only foreseen through the treatment but, part of the complex act of doing good through the treatment, such as relieving pain and suffering?".

A consistent goal of this inquiry has been to understand the one-sided nature of the principles, moralities and strategies implicit within palliative approaches to sedation

practices. The moral reasoning implicit within the interpretation and application of PDE in palliative sedation literature was discovered to focus on the physical, causal or psychological intent of action and not integrate other elements signifying the moral intent or destiny of the action. Dialectics explored within the work of Paul Ricoeur offered insight into the complex operations within the process of interpretation and helped to frame and explore palliative sedation dilemmas as a complex problem of decision in situation.

With novel palliative sedation dilemmas arising which betray convention, palliative care is engaged in a new moral frontier. The complexity and rawness of tragic suffering and dying, which accompanies the transition of identity and meaning of the patient, were discovered not as unexpected among palliative care professionals but interpreted as uncontrolled pathology and as the symbols of failure for palliative care. The humanization of dying, the ethical aim spawning the birth and genesis of palliative care, involved introducing a renewed vulnerability and mutuality within this clinical encounter. The challenge of re-establishing, continuing, and creating interpersonal meaning within the context of new and more dramatic forms of tragic suffering and fragmentation is the key challenge now facing the discipline of palliative care. Confronted by unique and tragic forms of dying, the resources of ethical deliberation, *practical wisdom*, vulnerability and mutuality between the self and the other, are approaches which palliative care professionals seek and yet feel ill prepared for by their own present health care formation.

**Sedation Practices, Tragic Dying and Palliative Care:  
An Ethical Inquiry**

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## **Sedation Practices, Tragic Dying and Palliative Care: An Ethical Inquiry**

### **INTRODUCTION**

#### **Palliative Care: Moral Ambiguity and Irony**

Death and dying have many faces. There are images of peace and of tragedy, of fragmentation and of wholeness, of human transcendence and of human degradation. The images paint a picture that is complex not simple. Its texture draws both our continued attention and repulsion. More complex still is the ever present struggle to agree and foster a shared interpretation, hope and meaning of this diverse, important and inevitable human experience. How do we share and participate together in the dying process of a person in a manner that is humanizing?

The struggle deepens as we enter the tangible, concrete moments of decision regarding how we wish to shape our own dying process, those we love, or those we serve as healthcare professionals. Even before we speak, before clinicians, patients and family members begin to discuss ethically difficult care dilemmas at the end of life, concern can easily arise about the potential for conflict and coercion.<sup>1</sup> Will I be forced to change my perceptions, coerced into doing something I do not want to do? Will discussion only be more divisive

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<sup>1</sup> See, Haavi E. MORRIEIM, "Profoundly Diminished Life: The Casualties of Coercion" in *Hastings Center Report* 24: 1 (1994), pp. 33-42. Amy GUTMANN and Dennis THOMPSON, "Deliberating About Bioethics," in *Hastings Center Report*, 27:3 (1997), pp. 38-41.

leaving participants more embedded in their positions and less likely to continue the discussion? These questions arise because cherished personal and professional values, concerns and identities are at the heart of these discussions. Given the uniqueness, complexity and tragedy implicated within these dilemmas, their layers of meaning deserve to be unraveled.

This inquiry began with my clinical involvement in the complexity of ethically difficult care dilemmas in hospitals. Healthcare professionals were and are concerned about how their actions might implicate their participation in the death of their patient. An action such as withdrawing ventilation or offering doses of sedation can have both positive and negative effects. In the case of sedation it might relieve the patient's physical pain but may also suppress the patient's respiratory system and hasten their death.

Two perspectives can be depicted as arising regarding this type of issue either in clinical healthcare literature, philosophical literature, or national public debates on end of life issues. One perspective proposes that the principle of double effect (PDE)<sup>2</sup> distinguishes and justifies decisions, regarding the use of sedation in tragic palliative care dilemmas, strictly on the psychological intent of the agent. This perspective understands PDE, as interpreted above, as offering the necessary distinctions justifying present sedation practices. Palliative care is believed to have the clinical and ethical resources needed to adequately

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<sup>2</sup> The principle of double effect, also identified as "PDE" within this inquiry, is a moral principle assisting to identify when it is permissible to cause evil in conjunction with good.

**address issues of pain and suffering for terminally ill patients. If there is a problem within palliative care, this perspective presents it as a lack of financial resources, commitment to disseminate and receive current and successful palliative care approaches, or incorrect application of those approaches. Regarding this perspective, I was suspicious whether their response of inadequate education appreciated and appropriated the complexity, tragedy and experiences of limit that clinicians were voicing.**

**The second perspective believed that the principle of double effect did not address the complexity of participation that clinicians and family members felt in their decisions and actions to offer potentially life-threatening sedation to palliative patients when intending to address their pain and suffering. To this perspective I was suspicious of characterization of the principle of double effect as inadequate moral reasoning not offering any relevant distinction or guidance to these types of dilemmas.**

**Palliative sedation dilemmas are often framed as a problem regarding the interpretation and application of the principle of double effect, a principle whose genesis is rooted in the heritage of Catholic moral theology. This principle, now as in its birth, was attempting to address practical decisions in conflictual situations. Its relevance has been debated in theological, philosophical, and clinical forums. Given this history and the public nature of this dilemma, this inquiry seeks to engage in a genuine public discourse by engaging and**

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addressing the three principal publics<sup>3</sup> involved: the wider society, the academy and the church. Insight will be gained not only from debate within each public but discovered in the debate among them.

The first chapter of this inquiry begins with the suffering experience of terminally ill patients and palliative care professionals articulated in four narratives. Implicitly and explicitly within these narratives are traditional questions raised in the voices of palliative care clinicians such as, "What is the ethically significant difference between killing and letting die in palliative care, where death is not only foreseen through the treatment but, part of the complex act of doing good such as relieving pain and suffering?". Yet, does such a traditional question properly frame the nature of the problem of palliative sedation practices? This inquiry will necessitate the exploration of key limit experiences which clinicians point to as responsible for creating the complexity of these tragic dilemmas. These limit experiences included the context of interdisciplinary decision making, the experience of tragic ethical dilemmas as an unpredictable trauma without obvious meaning, the limitations experienced in addressing difficult pain and suffering, the debate and expressed confusion

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<sup>3</sup> I use the term "public" in the manner used by David Tracy when speaking of the commitment of theologians to genuine public discourse. He states, "I have suggested that there are three principal "publics" for a contemporary theologian: the wider society, the academy and the church. ...The assumption of this analysis is straightforward: However personally committed to a single public (society, academy or church) a particular theologian may be, each strives, in principle and in fact, for a genuine publicness and thereby implicitly addresses all three publics." David TRACY, *The Analogical Imagination: Christian Theology and the Culture of Pluralism*. (New York: Crossroad, 1986), p. 5-6. This inquiry also strives for a genuine publicness and therefore implicitly addresses all three publics.

**on whether PDE offered adequate and authentic guidance regarding these tragic palliative sedation dilemmas.**

**The second chapter of this inquiry explores the theological and philosophical debates on the interpretation, application and adequacy of PDE to distinguish morally relevant features of actions with multiple effects. The origins of PDE are reviewed as well as key elements in the philosophical and theological debates. The goal is to identify key areas of conflict offering clues to deeper understandings on the interpretation and application of PDE as a type of moral reasoning. Insights are also gained from comparing how these two autonomous debates approached and critiqued this same principle.**

**Chapter three explores the practice of palliative care and the prior socially constructed meanings and goods of its history which both create and shape its understanding of how dying is humanized and how tragedy is experienced within difficult palliative sedation dilemmas. The inquiry reflects first on the traditions of medicine from which palliative care was formed. The chapter fundamentally attempts to gain insight on the environment, path and place palliative care seeks to bring its patients. This occurs through an exploration of two foundational goods of palliative care: the management of pain and suffering as well as the orchestration of a good dying process. This reflection demonstrates a diversity of approaches as opposed to what one might assume is one homogeneous approach.**

The focus of chapter four will be to delve more into some of the problematics of the ethical and moral conflicts within tragic palliative sedation dilemmas. First reflection on the nature of tragedy will provide instruction on the structure, vulnerability and limitations of our moral reasonings within healthcare ethics and specifically, tragic palliative sedation dilemmas. Second, this inquiry will explore how Paul Ricoeur's dialectics between universalism and contextualism, the self and the other, tradition and innovation, the ethical aim and the moral norm are fruitful resources to understanding the narrow approaches creating ethical conflicts within palliative sedation narratives. Finally, this inquiry will explore how such analysis of the social goods of palliative care and its ethical reasonings would appropriate less reductive approaches to the ethical aim of humanizing dying.

A general theme found throughout this inquiry are the limitations palliative care is discovering within its own self-understanding. Limitations not only in the sense of *finiteness*, of coming up against walls and borders, but also in the sense of *fragility*, the fragility of its own self-identity and ideology. Also, limitations regarding its implicit telos or the "good death" it wishes to foster for its patients. The fundamental challenge will be for the discipline of palliative care to integrate, in the midst of dynamic and diverse social goods, approaches to dying which are less reductive and more humanizing for both terminally ill patients and palliative care professionals.

## CHAPTER ONE

### Ethically Difficult Palliative Sedation Dilemmas: Complexities and Limitations

#### Introduction

A foundational goal of palliative care is to assist the dying process of the terminally ill patient such that the last days of the patient's life are experienced as meaningful and with as little pain as possible. In pursuit of that goal, palliative care clinicians are confronted with complexities and limitations. Each palliative care patient is unique not only in their life story but in how they physically respond to palliative care treatments. In attempting to manage the pain or suffering that a terminally ill patient may experience, patients are often given doses of analgesics to offer relief. These doses are usually offered in a titrated and rotated manner to offset the effects of the analgesics on the patient's central nervous system. These effects include potential unconsciousness and the suppression of the patient's respiratory system, therefore hastening the patient's death. The dilemma confronting palliative care professionals is, while clinicians have the intention of relieving a patient's pain with sedation, the same sedation may hasten the death of the patient. What moral reasoning will help healthcare professionals to differentiate their participation with palliative sedation practices as helping or harming patients? Given the pain and suffering that a patient may experience in the dying process, how might the palliative care clinician respond to foster this experience as meaningful to both the patient and

**themselves?**

**The focus of this chapter will be to begin to unravel the clinical limitations palliative care professionals experience within palliative sedation practices when all other methods of excellent palliative care fail to adequately address the pain and suffering of the dying patient. What concerns or questions will such limitations foster? Delving into the complexities of this type of dilemma will highlight how our current moral norms and pain management resources seem to fall short from satisfying our desire to respond to the pain and suffering of some terminally ill patients. Palliative care professionals will ask what is the ethically significant difference between killing and letting die in palliative cases, where death is not only foreseen through sedation practices, but part of the complex act of doing good, such as relieving pain and suffering? What is the ethical role, the responsibility, the most appropriate response as a healthcare professional when I experience limitations faced in such unique and tragic palliative care stories?**

**Such questions will demand an exploration of the layers of ethical complexity inherent in such a specific clinical encounter. This will be achieved by first reviewing four palliative sedation stories which have arisen to disrupt a perceived consensus on how the principle of double effect is practically applied to responsibly respond to these situations. Second, we will review some types of the conflicts shaping the interdisciplinary decision making context of healthcare professionals. Third, we will review the debate and concerns**

clinicians have voiced concerning their abilities to address refractory pain and suffering within types of unique palliative sedation cases. Fourth, we will review the ethical reasonings which have been employed by clinicians to offer direction and respond to these tragic stories. I will conclude with a clearer view of the felt limitations and challenges facing palliative care professionals. This inquiry will uncover clues and point to new areas of exploration for offering a more satisfactory response to these unique palliative care situations.

#### **A) Stories Disrupting Consensus**

The debate evoked by contrary interpretations of palliative sedation practices is a conflict rooted not so much in clinical techniques and dosage but, in the social meaning created through networks of relationships, roles and interactions. It is a debate rooted in a complex challenge; what types of cooperative action must we embrace if tragic human dying is to be humanized? Such a challenge will require nothing less than a dynamic integration of the traditions of palliative care with its present experience of limitation. To begin to explore and humanize this network of cooperative action, it will be helpful to root ourselves in four current clinical case stories where clinicians implicitly or explicitly express their experiences of limitation.

These narratives offer windows into a unique landscape in which palliative care clinicians and patients find themselves. The narratives are written by palliative care clinicians and are a form of knowing, telling and reflecting which is complementary to logico-scientific, or formalist, means of interpreting

events and information. They are a recognition of types of palliative sedation problems, a formulation of that problem, an interpretation, and perhaps a validation of the chosen interpretation of the case as the most reasonable or relevant.<sup>4</sup> They offer insight into the complexity, coherence, resonance and singular meaning of these particular human events. These narratives invite us to explore and discover the challenges, loyalties, biases, relationships and the moral worlds of their narrators. Recent published works<sup>5</sup> offer such narratives in an attempt to portray the layered range of psychological, spiritual and social issues and meanings arising in palliative care and as a complement to the scientific and clinical aspects of palliative care.

The first story offered is articulated in a very technical style, intended for a clinical, medical audience with the requisite knowledge to understand the terminology. I have included it in this inquiry as a contrast to the other narratives. The technical language and format highlights the agency of the author in composing such a narrative and conveying a meaning to the reader. The story was found in the second edition, 1998, of the *Oxford Textbook of Palliative Medicine* within the chapter entitled, "Difficult Pain Problems". The

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<sup>4</sup> Rita CHARON, "Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation, and Validation in the Practice of the Ethicist," in Edwin R. DUBOSE, Ron HAMEL and Lawrence J. O'CONNELL, eds., *A Matter of Principles? Ferment in U.S. Bioethics*. (Valley Forge, Pennsylvania: Trinity Press International, 1994), p. 261.

<sup>5</sup> David BARNARD, Anna TOWERS, Patricia BOSTON, Yanna LAMBRINIDOU, *Crossing Over: Narratives of Palliative Care*. (New York: Oxford University Press, 2000); Timothy E. QUILL, *A Midwife Through the Dying Process: Stories of Healing and Hard Choices*. (Baltimore: John Hopkins University Press, 1996); Michael KEARNEY, *Mortality Wounded:*

story is at the end of that chapter, under the heading *Pain in the Delirious Patient*. The story is introduced, as it will also be in this text, with the following introduction.

*When sorrows come they come not single spies, but in battalions*.<sup>6</sup> So it seems to family and staff alike when faced with the vexing problem of a delirious patient, often on high doses of medication for management of severe pain, who is restless, moaning, and yet unable to pin-point the root of his distress. Nerves become frayed, families are angry, and each therapeutic approach appears to move one into checkmate.<sup>7</sup>

Such an introduction conveys insight into the experience of the story which the following more technical description of the story does not offer. Now the story,

A 32-year-old woman presented with recurrent carcinoma of the ovary with widespread metastases throughout the abdomen. Since diagnosis 18 months prior to admission, she had received repeated courses of chemotherapy and two surgical interventions for relief of small bowel obstruction. Six months prior to admission she developed an inoperable small bowel obstruction. Subsequently, she was maintained at home on parenteral nutrition together with a venting percutaneous gastrostomy.

Prior to her final admission to hospital, in addition to chronic intermittent abdominal pain, the patient had developed increasing pain in the left back and hip secondary to lumbar nerve root involvement. At home the patient was receiving subcutaneous hydromorphone delivered via an Edmonton injector. She was admitted to hospital for pain control.

In hospital, the dose of hydromorphone required to control pain increased until she was receiving 65 mg/h. Nevertheless, the patient remained in poor pain control and she became agitated, confused, developed paranoid ideation, and myoclonus. Her cries and moans were thought to be caused by pain, which

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*Stories of Soul Pain, Death, and Healing*. (New York: Scribner, 1996)

<sup>6</sup> The reference for this sentence is offered by the authors of "Difficult Pain Problems" in a footnote as, William Shakespeare, *Tragedy of Hamlet, Prince of Denmark*, Act IV, Scene V. See Geoffrey HANKS, Russell K. PORTENOY, Neil MACDONALD, and Karen FORBES, "Difficult Pain Problems," in Derek DOYLE, Geoffrey W. C. HANKS, Neil MACDONALD, (eds.) *Oxford Textbook of Palliative Medicine*, (New York: Oxford University Press, 1998), p. 471.

<sup>7</sup> Geoffrey HANKS, Russell K. PORTENOY, Neil MACDONALD, and Karen FORBES, "Difficult Pain Problems," in *Oxford Textbook of Palliative Medicine*, (New York: Oxford University Press, 1998), p. 471.

stimulated further increases in the dose of hydromorphone. The patient had modest alteration in liver function tests but her renal function was normal and there was no obvious metabolic reason for her agitation.

The patient was switched to morphine by continuous intravenous infusion at a rate of 75 mg/h (23 percent of the equivalent dose of hydromorphone). Within 24 hours the myoclonus and agitation cleared and the patient was lucid and her pain was well controlled. Three days after switching to morphine, it was decided that the patient was over sedated and the rate of morphine infusion was decreased to 60 mg/h and subsequently, on the same day, to 50 mg/h. At this dose her pain was controlled and she was alert but sleepy. Three days later a secondary infection was thought to be present. The patient remained comfortable but the morphine infusion was increased to 65 and then 90 mg/h. The patient died within the following 24 hours.<sup>8</sup>

This second story,<sup>9</sup> written by Dr. Timothy Quill, reflects on "Mrs. B.",

Mrs. B had had breast cancer for over ten years. For the first five years of her illness she lived fully, continuing her job as a school researcher, being minimally bothered by her disease. But she unfortunately had an aggressive form of breast cancer, and the last five years of her life were mired by repeated hospitalizations, surgeries, hormonal therapies, chemotherapy, and radiation. At age sixty, she was nearing the end of a long ordeal – exhausted, weary, and losing hope of finding any solution that would have meaning for her. Her illness had forced her to give up teaching prematurely, and she was becoming more dependent on her three children and the healthcare system. She had found the last six months completely empty, since she was bedbound from repeated fractures and forced to move to a nursing facility that also served as a hospice. There she made a few new friends and had some moments with her family that she viewed as tolerable. Yet, she became weaker and could no longer read or even care for her basic bodily functions, she found her continued existence unbearable.

Mrs B. clearly wanted to die. Her life had been stripped of all that was important to her. Death was the only thing she looked forward to. She no longer feared death, but was terrified about continuing to live under the current circumstances. She had nothing left to give.

As occurs all too often, death did not come in a timely way. Feeling trapped and desperate, Mrs B. asked her personal physician for help. Her doctor cared deeply about Mrs .B. She knew from their shared, grueling experience, and from in-depth exploration of her reasoning, the Mrs. B. request was rational,

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<sup>8</sup> HANKS, PORTENOY, MACDONALD, and FORBES, in *Oxford Textbook of Palliative Care*, p. 471.

<sup>9</sup> Timothy E. QUILL, *Death and Dignity: Making Choices and Taking Charge*, (New York: W.W. Norton & Company, 1993), pp. 111-112.

and not distorted by depression. The doctor wanted to be helpful, but feared the potential professional and legal effects of providing active assistance. After getting permission from Mrs B., the doctor decided to present the dilemma to the hospital ethics committee for guidance.

I am not privy to the deliberations of the ethics committee, but I do know their recommendations. They suggested that the physician could actively treat Mrs. B.'s suffering by giving her enough morphine and sedation so that she became unconscious (therefore unaware of her suffering) and then letting her die by dehydration. This method, they felt, would be within the acceptable limits of comfort care, using the double effect to treat her suffering aggressively without intending death. Death would come passively, they presumably reasoned, through a more natural process. The committee suggested that providing active assistance by more forthrightly helping the patient to die would be outside of current professional and legal restraints, and therefore inadvisable.

The doctor was very ambivalent and somewhat disturbed by the plan, but she reported the option to Mrs B., who knew of the consultation. The doctor felt it was the only way she could respond to Mrs. B.'s request without taking a very large personal risk. (In fact the risk of providing more "active" assistance had become even greater now that the patient's dilemma had been discussed in a relatively public forum.) Mrs B. accepted the only option she had that would eventually ensure death. She subsequently said goodbye to her family and closest friends, and was put on an intravenous drip that contained morphine and sedative, until she was unarousable. She remained in this state for ten days before dying, periodically attended by friends and family who found the experience deeply disturbing. Mrs. B.'s family had accepted her wish to die, but forcing her into a medically induced twilight zone so that she could then die of "natural causes" seemed macabre.

The third story<sup>10</sup> is written by Dr. Balfour M. Mount and Pat Hamilton regarding a patient known as "Mr. G."

Mr. G, a 59 year old right handed French Canadian businessman with an attentive family, was admitted to the Royal Victoria palliative care unit (PCU) with a 10 day history of decreasing mobility, increasing expressive dysphasia, lability of affect with crying and agitation, and focal seizures. This occurred 14 months following the diagnosis of a left parietal glioblastoma multiforme which had been treated with protocol radiosurgery and external beam radiotherapy. Physical examination revealed an apparently alert, well-nourished man, looking somewhat younger than his stated age, who was oriented to person but not to time or place. He was grossly dysphasic, answering apparently unreliably to questioning. Enquiries as to whether he had headaches were inconclusive, although he did not appear to be in any physical distress during the intervals of

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<sup>10</sup> Balfour M. MOUNT and Pat HAMILTON, "When Palliative Care Fails to Control Suffering," in *Journal of Palliative Care*, 10 (2) (1994), pp. 24-26.

calm between bursts of aggressive agitation. He had a dense right hemiparesis and agitation. He had a dense right hemiparesis and his left arm was heavily bruised as a result of injuries sustained while striking out during his periods of agitation. A CT scan showed disease progression with massive edema.

Initial symptom control was obtained using parenteral dexamethasone, midazolam, and haloperidol at doses of 16 mg, 30 mg, and 3mg per 24 hours respectively. Three days following admission the patient was more calm and alert but remained extremely frustrated by his expressive dysphasia. The addition of chlorpromazine 100 mg q8h rectally to replace haloperidol appeared to allay much of this residual frustrated agitation without further sedation. Pharmacologic symptom control strategies were complemented by an intensive investment by the palliative care team. The nursing staff, admitting physician, music therapist, pastoral care worker, and occupational therapist were particularly involved in establishing an atmosphere of trust and understanding in this period of intense emotional distress for family and patient.

Ten days following PCU admission (D10), the patient's speech was noted to be significantly clearer. Over the ensuing 48 hours his mood and general status improved, particularly with respect to his ability to transfer from bed to chair and his ability and desire to communicate. This improvement was thought to be due to the parenteral steroids and possible tumor necrosis and involution with resultant decrease in intracranial pressure. His previous agitation gone, he related warmly to his delighted family and his daily routine became punctuated by favorite meals with wine brought in by his wife, attendance at ward musical events, and warm interactions with the palliative care team, including meetings with the team psychologist. On D21 antibiotics were started when cough and congestion were thought to be due to aspiration pneumonia.

On D24, while still lucid, conversant, actively involved with his family, and symptom-free, Mr G expressed to a nurse that he was ready to die and hoped that the end would come soon. Chart notes document the increasingly evident anguish that marked the following days.

- D26: "Patient expressed the wish to die. Says he no longer wants to go on like this. Wife at bedside, tearful." OT
- D27: "Appears sad." RN
- D29: "Not happy today. Quiet. Not smiling. Looks depressed... Answers appropriately but becomes easily agitated now." RN
- D31: "Physically comfortable but anguished. Reassured that eating will increase quality but not the length of his life." MD
- D32: "Appears depressed. Not initiating conversation as he used to." RN
- D34: "Remains alert and oriented... Saying very little." RN
- D36: "Patient expresses some feelings regarding his eventual death. He is waiting for this and finds it too long. He hopes that he will not be alive for Christmas but states that his family will be heartbroken when he is gone. Some tears then. Support given." RN
- D38: "Had a meeting with both patient and wife. He asked for euthanasia. Cried a lot. We explored the lack of sense for him to be living in such a condition. A very open and rich exchange between the three of us. At the end he asked if I, together with the team, could pray sincerely and

- ask God to come and get him. I said that we would." Psychologist
- D40: "I just want to die. Do you have any idea what it is like to wake up and realize you're still alive when that's exactly what you don't want? I am suffering greatly." Mr G.

Commencing on D38 several steps were taken to better equip patient, family and staff to reconsider treatment options. A repeat CT scan of the brain showed further progression of tumor. A team meeting heard reports from all disciplines and included a discussion of the concept of therapeutic "double effect". The team ethicist was consulted. Following a detailed analysis of the issues involved in this specific case he observed: "Pharmacological sedation as a palliative modality for emotional/spiritual suffering is an ethically acceptable option in these circumstances." The team psychiatrist was consulted and concluded that the patient was competent and not depressed. "

On D41 the palliative care physician discussed Mr G's severe mental anguish at length with the patient and family. Sedation was offered as an option in the form of diminishing dexamethasone doses and individually optimized doses of morphine and midazolam to ensure comfort. The patient responded, "That would be more humane."

The syringe driver dose of midazolam was then increase from 30 mg to 50 mg per 24 hours and a schedule of diminishing doses of dexamethasone was ordered that would lead to its discontinuation over six days. Morphine 2-4 mg q4h SC p.r.n. was ordered for pain.

On D42 , the midazolam dose was increased to 90 mg per 24 hours SC and later to 120 mg because of significant persistent anguish and a decreased ability to communicate. Morphine 40 mg per 24 hours was added to the syringe driver to cover any headaches that might arise. Valproic acid 250 mg t.i.d. rectally was added as a precautionary antiseizure medication.

- D43: "Took breakfast... Back pain – given morphine 4 mg SC with good relief. Slept soundly." RN
- D43: "Sleepy but responds by nodding. No verbal answers." RN
- D44: "Moaning at times but settled easily. No response to care. Mouth care and backrub given." RN
- D45: Chest congestion. Seizure activity controlled by midazolam 5 mg IM and dexamethasone 10 mg IM. Continuing seizures treated with two doses of midazolam 5 mg IM. "Irregular respirations. Patient very comfortable. Hyoscine given... Family present." RN

Mr. G died peacefully on D45 with family and team members in attendance in an atmosphere of trust and calm.

In the post-death admission review meeting, the team voiced general approval for all aspects of the treatment care plan. During bereavement follow-up contacts the wife described a sense of great peace associated with her husband's final hours. The family adjusted to their loss with expected sadness and considerable mutual support.

The authors narrating this latter story above found their involvement unsettling because sedating an alert, physically comfortable man for psychological distress seemed to be a shift from past directions of sedation usage to relieve neuropathic pain or dyspnea.<sup>11</sup> They presented this case story wondering if this shift opened the door to new type of slippery slope. One reviewer of this case story believed it did open such a door and claimed that the experience was a case of euthanasia.<sup>12</sup>

The fourth palliative sedation story<sup>13</sup>, written by Dr. Michael Kearney, is of a patient named "Jackie",

Jackie was in her early fifties, a music teacher in a girls' school, described by a friend as someone who was always "bright, brusque, and breezy". Her family doctor had referred her to the hospice for control of a long-standing and severe pain in her right leg. Two years previously she had had a hysterectomy because of cancer and had subsequently remained well until the pain had started. A scan showed that the tumor had recurred and was invading the muscles and nerves on the back wall of her abdomen. Despite treatment with radiotherapy and painkillers, both the tumor and the pain had worsened.

By the time Jackie was admitted to the hospice, she was confined to bed because of pain. The nurses caring for her described her as a woman who was terrified of even the slightest movement in case it should worsen her pain. When I asked her how she saw her situation at that time, she replied, "I honestly believe its all due to a fall I had from my bike last September." I felt that she was denying the seriousness of her situation and that this was probably contributing to her difficulties. This was confirmed when her close friend, Jean, spoke of how she had confronted Jackie some weeks previously with the fact that the cancer had recurred. Apparently, while this had initially triggered an outburst of tears,

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<sup>11</sup> MOUNT and HAMILTON, "When Palliative Care Fails to Control Suffering," p. 26.

<sup>12</sup> Margaret SCOTT, "Commentaries: When Palliative Care Fails to Control Suffering," in *Journal of Palliative Care*, 10 (2) (1994), p. 30.

<sup>13</sup> Michael KEARNEY, *Mortally Wounded: Stories of Soul Pain, Death, and Healing* (New York: Scribner, 1996), pp. 25-27.

Jackie had then been much better for days afterward. Even though it became increasingly evident to all caring for Jackie that her pain was due as much to her fear and denial as to the cancer invading the nerves of her leg, she herself was adamant that it was simply a mechanical and physical problem. Looking me straight in the eye she would ask, "And what are you going to do about it?" Over the next two weeks we tried a variety of usually successful medications. Simultaneously, different members of the ward team attempted to approach the psychological aspects of her pain both directly (by asking her how she was feeling and whether or not she had any questions or worries) and indirectly (through massage). However, all these efforts were to no avail. Her pain worsened and was now exacerbated by a rising sense of disappointment and desperation, feelings which I and other members of the team were also beginning to experience.

At around this time I met Jean again. We discussed Jackie's situation and decided that we should meet her the following morning. We could see no way forward other than to confront her, as gently as possible, with the hard truth of her situation. Although we had serious reservations about this plan, our hypothesis was that her denial was not longer working as a helpful psychological defense but rather was exacerbating her distress by isolating her in a prison of fear which, in turn, was making her pain worse.

That afternoon, before any such confrontation, Jackie's defenses cracked in an eruption of uncontrollable fear, paranoia, and pain. She writhed about in her bed as she groaned, hyperventilated, and cried out, wide-eyed, for someone to help. When the nurses came, she became even more terrified, accusing them of trying to kill her and refusing their offers of additional pain and tranquilizing medication. When, with her friend's persuasion, she eventually agreed to take the medication, it appeared to have little or no effect. Jackie's panic and agitation worsened, as did our sense of utter impotence.

Jean and the nurses stayed with Jackie throughout that evening. They held her in their arms and spoke soothingly in an attempt to calm and comfort her, but to no avail. Eventually we took a decision to give her medication to sedate her. She soon drifted off into a fitful and uneasy sleep.

Jackie was still sedated and sleeping deeply when I visited her the following morning. I called her name, and her eyes flickered open in momentary panic but then shut again. I asked her how she was. In words that were slurred and barely audible she replied that she was "climbing in the mountains with Jean."

Over the next few days we tried, on a number of occasions, to lighten the sedation. However, each time Jackie began to waken she was terrified and cried out, and although we sat and held her she remained agitated and would not settle until we had given her further medication. The nurses and I met her family and Jean. We agreed that the only way we could treat this anguish and pain was to keep her asleep. Over the following weekend Jackie developed pneumonia and died.

While my training in palliative care had introduced me to a holistic model

of pain which acknowledged that the "total pain" of the dying individual was a multifaceted and dynamic experience with social, emotional, and spiritual as well as physical dimensions, I still felt utterly ill equipped to deal with Jackie's overwhelming fear and suffering. I simply did not have the means to describe, let alone respond to, what was happening in her situation.

Jackie left me with feelings of disappointment and failure and a number of unanswered questions. When confronted with anguish like hers, did I have to accept that there was nothing I, nor indeed anyone else, could do to make it better? When I attempted to help someone like Jackie, whose pain was I ultimately trying to alleviate, mine or hers? And what precisely was the nature of this particular form of suffering? I felt sure that if I had a better understanding of this it would point me toward another way, a more appropriate way, of responding to someone in such distress.

These narratives offer the reader a broader insight and context of the types of unique palliative sedation dilemmas that have emerged for palliative care professionals. Our next step in this exploration is to understand the context and complexity of collaborative clinical decision making of ethically difficult end of life care dilemmas.

#### **B) Ethical Complexity and "End of Life" Decision Making**

What kind of challenge or complexity is ethical decision making in an interdisciplinary palliative care team when faced with such tragic palliative sedation dilemmas? Healthcare teams, including palliative care teams, have value conflicts over ethically difficult "end of life" care dilemmas. It is one of the fundamental experiences of limit which healthcare professionals experience. Essential to this inquiry is to discover what interdependent elements create the complexity of these unique dilemmas in order to better understand the decision-making context.

First, healthcare professionals often experience ethically difficult care

dilemmas, especially those that implicate whether a patient will live or die, as a type of trauma. The American Psychiatric Association defines trauma as a psychologically distressing event outside the range of normal human experience which typically overwhelms ones coping mechanisms.<sup>14</sup> The DSM-IV of the American Psychiatric Association denotes a traumatic event as "...directly experiencing or witnessing actual or threatened death or serious injury or experiencing a threat to one's own physical integrity or the physical integrity of someone else."<sup>15</sup> Most often these events are characterized as unpredictable and without obvious meaning. The DSM-IV also mandates that the individual's response must be characterized by fear, helplessness or horror. These types of tragic deaths and their sedation dilemmas are not the normative experiencing of the dying process for palliative care professionals. These deaths are experienced by clinicians as "worst case" scenarios, the antithesis of dying peacefully or dying well. As they unfold, whether over a period of hours or weeks, they are an incredibly stressful experience for all involved. The cognitive effects of this type of trauma include confusion in thinking, difficulty making decisions, and lowered concentration while the behavioral effects can include

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<sup>14</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, Second Edition (Washington DC: American Psychiatric Association, 1987), p. 247.

<sup>15</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (Washington D.C.: American Psychiatric Association, 1994) Cited in, John P. WILSON, "The Historical Evolution of PTSD Diagnostic Criteria: From Freud to DSM-IV." In *Psychotraumatology*. George S. EVERLY, Jr., and Jeffrey M LATING (eds) (New York: Plenum Press, 1995), p. 24.

changes in ordinary eating habits, withdrawal from others, and prolonged silences.<sup>16</sup> Tragic palliative sedation dilemmas can be experienced as trauma which has the potential to create further challenges to interdisciplinary decision making, such as post traumatic stress disorder, if not recognized and addressed as trauma.

How healthcare clinicians interpret the meaning of these events is entwined with their professional moral identity. The moral identity of healthcare clinicians has long been characterised by the moral principles of beneficence (duty to help) and nonmaleficence (duty not to harm). In the Western Christian world<sup>17</sup> these principles have come to mean "clinicians must not directly kill patients"<sup>18</sup>. It is no secret that powerful abilities were gained through the development of modern medicine to assess and intervene, limit or even stop what once were life threatening pathologies. With the increased ability of medical technology to prolong biological life, and the increased dependency of patients on such technology for survival, those clinicians who manipulate these "end of life technologies" seem to more directly manipulate the life and death of the patient.

The influence of clinicians on the dying process and the death of their

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<sup>16</sup> Jeffrey T. MITCHELL and George S. EVERLY, *Critical Incident Stress Debriefing*. (Ellicott City, MD: Chevron Publishing, 1995), p. 24.

<sup>17</sup> In greek antiquity the killing of the handicapped was supported.

<sup>18</sup> See, Willard GAYLIN, et al, "Doctors Must not Kill," in *Journal of the American Medical Association*, 259 (14) (1988), pp. 2139-2140.

patient through decisions to use or not use cardiopulmonary respiration, respirators or ventilators, have a more immediate effect on whether and when the patient will die. The more immediate life and death effect of such decisions seems to bring greater feelings of responsibility on the shoulders of clinicians. On the one hand they want to help and not harm. They do not want to participate in the hastening of death or the killing of patients through their decisions or actions. On the other hand they feel that their manipulation of technologies has such an immediate life or death effect on their patients that they bear the responsibility in a concrete way in the ensuing death of a patient. For example, when palliative care clinicians offer analgesics in various titrations and rotations to address intractable pain in terminally ill patients, they attempt to reach a balance between the two effects of the drugs: 1) giving relief to the patient from the intractable pain and, 2) that higher doses of the drug will breach the patient's tolerance for the drug and it will suppress their respiratory system. Palliative care clinicians question how their use of higher doses of pain management treatments such as analgesics may hasten or "tip the scale" to cause the death of their patients. Clinicians ask whether their use of sedation helps or harms or effects both results in such edge of life scenarios. When is participation with the death of a dying patient wrong? How would one participate in a manner that would be wrong?

The discussion of these questions and such ethically difficult treatment decisions usually occurs within the context of some combination of team

members (physicians, nurses, social workers, pastoral care, administration, ethicists, lawyers, etc.), the patient, and others whom the patient wishes to involve. It is important to note that each healthcare professional group comes to the discussion with a unique and implicit value perspective. These different value perspectives are not intentionally "hidden" but are an unconscious part of each professional moral identity. Inherent within the training and experience of these professional groups is a different priority of values and therefore, differing perceptions of what is an "ethics problem."<sup>19</sup> These values will help to shape the context, the potential and the limits, the very meaning of ethically difficult "end of life" care dilemmas. The input from such diverse perspectives is also a positive factor fostering responsible analysis of an ethically difficult care dilemma. The experience and work of each of these specialized professionals often focuses on different aspects or "snapshots" within the life of their patient or aspects of the healthcare issue. A diversity of participants can bring a broader range of information into focus in the discussion and the ethical dilemma then also becomes subject to multi-professional scrutiny.

Power imbalances within the interdisciplinary team are also evident in these treatment discussions and can have a negative impact on the issue being

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<sup>19</sup> See, R.M. WALKER, S.H. MILES, C.B. STOCKING and M. SIEGLER, "Physicians and Nurses Perceptions of Ethics Problems on General Medicine Services," in *Journal of General Internal Medicine*, 6 (5) (1991), pp. 424-429. Laura BLICKENSDEFER, "Nurses and Physicians: Creating a Collaborative Environment," in *Journal of Intravenous Nursing*, 19 (3) (1996), pp. 127-131. Deborah CASWELL and H. Gill CRYER, "Case Study: When the Nurse and Physician Don't Agree," in *Journal of Cardiovascular Nursing*, 9 (3) (1995), pp. 30-42.

analysed. It should be pointed out that this influence is not always intentional on the part of participants but, is implicit in the professional relationship between healthcare professionals. As an example, leadership in care plan discussions can often be implicitly given to the physicians or nurses who offer specifically "medical information".<sup>20</sup> The effect is that these implicit value concerns can monopolize the discussion rather than the other types of patient information, such as psycho-social, cultural or spiritual, which is integral to the patient's life plans. The prioritization of "medical" information in the discussion is a values priority within healthcare culture that can affect the insights and discernment of the ethically difficult care dilemma.

Consensus can sometimes intentionally camouflage or non-intentionally overlook types of uncertainty, doubt, division, or disagreement.<sup>21</sup> The linking of science and the concept of progress creates a formidable force behind the voices of modern medicine. This force is so strong that at times we can automatically link the human good to modern medicine and become deaf to critiques that one person's medical progress might be another person's loss of human dignity or their degradation. While the positive influence of medical science is undeniable, reminders are also evident among types of horrible

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<sup>20</sup> *Research Report on Ethical Deliberation in the Field of Pediatric Chronic Illness. Stage Three: Discussion of the Results of the Research.* Centre for Techno Ethics, Saint Paul University, Ottawa (April, 1996), pp. 3-4.

<sup>21</sup> George WEBSTER and Pat MURPHY, "Frank Medical Discussion a Must," in *Winnipeg Free Press*, November 18, 1998. George WEBSTER and Pat MURPHY, "Life After Mr. Sawatzky," in *Steps in Healthcare Ethics*, 2 (2) (March, 2000), p. 2.

human experimentation and social degradation in the name of the progress of medical science.<sup>22</sup> Our positive and negative experiences in the advancement of medical technologies have led to both a fear of the dynamism of science and technology and a fear of being tied to an out of date moralism no longer appropriate to this time, culture and place.<sup>23</sup>

Conflicts within decision making can also occur on other levels. One type of conflict can be communication problems between clinicians, patients and family members. It has long been recognized that many clinician/patient disagreements were due to inadequate and insensitive communication problems. Studies identified that clinicians may not describe alternative plans in

<sup>22</sup> See, John Howard JONES, *Bad Blood: The Tuskegee Syphilis Experiment: A Tragedy of Race and Medicine* (New York: The Free Press, 1981). Between 1966-67, two notable, published works authored by medical doctors together recounted over two hundred cases considered as unethical experimentation involving human subjects. Henry K. BEECHER, "Ethics and Clinical Research," in *New England Journal of Medicine*, 247 (1966), pp. 1354-1360. Maurice PAPPWORTH, *Human Guinea Pigs*. (London: Routledge & KeganPaul, 1976). Also, a 1990 California court decision gave property rights to a patient's tissue to a physician researcher and a biotechnology company rather than the patient. The concern of the court was that giving the patient a property right to his tissue would destroy the economic incentive to conduct important, leading edge, medical research. Dorothy NELKIN and Lori ANDREWS, "Homo Economicus: Commercialization of Body Tissue in the Age of Biotechnology," in *Hastings Center Report*, (September-October, 1998), pp. 32-33. See also, *Moore vs Regents of the University of California*, 793 P.2d 479 (Cal.1990), p. 495.

<sup>23</sup> "...tomorrow's world will be different from that of today. And in this coming world man will be the one who, both as an individual and as a society, plans, controls and manipulates himself to a degree which was previously both undreamed-of and impracticable. He *must* do so; he can do no other if he wishes to exist on the Earth side by side with many thousand millions of other human beings. He *want* to be "operable" man, even though the extent and the right way of carrying out this self-manipulation are still largely obscure..." and "One ought to complain that (as opposed to the official Church, which as such has no task here) Christians contribute so little courage and creative imagination to an ideology of the future for this self-manipulation, but are generally content to provide conservative admonitions and obstructions." See Karl RAHNER, "The Experiment with Man: Theological Observations on Man's Self-Manipulation," in *Theological Investigations*, (9) (New York: Herder and Herder, 1972-1973), p. 211 and p. 224.

terms patients can understand, do not give quantitative prognostic estimates and commonly do not take advantage of opportunities to address patient's concerns and values.<sup>24</sup> When these elements were addressed, many unrealistic expectations of patients were found to dissolve. A second type of conflict at the root of seemingly unreasonable demands of the clinician or patient can be due to coping problems. One psychological theory of autonomy proposes three basic elements at the root of inner conflict: life plans, anticipation and preparedness to adjust or adapt.<sup>25</sup> It identifies that an unreasonable demand to use or not use treatment with no medical benefit may not be a decision regarding limiting treatment but an attempt to cope and make sense of a crisis of life and identity. Once recognized as an attempt to cope, as opposed to a treatment demand, the most important response is a healing relationship where the necessary conditions for the individual to integrate the meaning of this illness event into their life are provided.<sup>26</sup>

The third type of conflict concerns foundational value conflicts. In this

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<sup>24</sup> Lo TULSKY, "Do Not Resuscitate Discussions: Are Doctors and Patients Speaking the Same Language?" in *Clinical Research*, 41 (1993). Lo TULSKY, "See One, Do One, Teach One" Fails in Discussions About Resuscitation," in *Journal of General Internal Medicine*, 9 (1994). Rita A. LAYSON, Harold M. ADELMAN, Paul M. WALLACH, "Discussions About the Use of Life Sustaining Treatments: A Literature Review of Physicians and Patients Attitudes and Practices," in *Journal of Clinical Ethics*, 5 (3) (1993), pp. 195-203.

<sup>25</sup> M. SEEMAN and T. E. SEEMAN, "Health Behavior and Personal Autonomy," in *Journal of Health and Social Behavior*, 24 (1993), pp. 144-160.

<sup>26</sup> David C. THOMASMA, "Beyond Autonomy to the Person Coping With Illness," in *Cambridge Quarterly of Healthcare Ethics*, 4 (1) (1995), pp.12-22.

type of situation the issue is not communication or coping but of fundamentally valuing treatments and the meaning of the illness event differently. One 1988 study claimed that there was little correlation between individual patients and clinicians when assessing the value of receiving aggressive medical intensive care.<sup>27</sup> Patients wanted the aggressive treatments that clinicians said they would not want for themselves if they had to make the same decision confronting the patient. The argument supporting clinicians making unilateral futility judgements has rested on the assumption that the clinicians' judgements are more objective and less based on judgements of value or quality of life. Yet, it has been demonstrated that clinical practice and judgement are not only science but also art.<sup>28</sup> There are idiosyncratic elements, tacit knowledge and intuitive insights which play an important role in clinical knowing and decision making.<sup>29</sup> Variance has been noted in the prognostic predictions among intensive care unit (ICU) physicians on patient survival and found to be strongly influenced if not rooted in the different backgrounds and experiences of

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<sup>27</sup> M. DANIS, M.S. GERRITY, L.I. SOUTHERLAND, and D.L. PATRICK, "A Comparison of Patient, Family, and Physician Assessments of the Value of Medical Intensive Care," in *Critical Care Medicine*, 16 (1988), pp. 594-600. M. DANIS, D.L. PATRICK, L.I. SOUTHERLAND, and M.L. GREEN, "Patients and Families' Preferences for Medical Intensive Care," in *Journal of the American Medical Association*, 260 (1988), pp. 797- 800.

<sup>28</sup> Nuala P. KENNY, "Does Good Science Make Good Medicine: Incorporating Evidence into Practice is Complicated by the Fact that Clinical Practice is as Much Art as Science," in *Canadian Medical Association Journal*, 157 (1) (1997), pp. 33-36.

<sup>29</sup> G.M. GOLDMAN, "The Tacit Dimension of Clinical Judgement," in *The Yale Journal of Biology and Medicine*, 63 (1990), pp. 47-61.

clinicians.<sup>30</sup> Studies have shown that not only were clinicians' willingness to withdraw life support influenced by personal characteristics such as age, religion and clinical experience,<sup>31</sup> but personal preferences also impacted *when* they chose to withdraw life support.<sup>32</sup> One 1985 study identified a "chagrin factor", where clinicians who faced differing degrees of opposition for differing types of potential wrong results within a clinical decision, a customary clinical strategy was to choose the option which would result in the least opposition or "chagrin".<sup>33</sup>

Finally, studies also show that some clinicians will misperceive their patients preferences and substitute their own preferences for those of their patient.<sup>34</sup> Due to such value judgements within clinical decision making, it is considered unethical for clinicians to make unilateral determinations of the

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<sup>30</sup> R.M. POSES, C. BEKES, F.J. COPARE, and W.E. SCOTT, "The Answer to "What Are My Chances Doctor?" Depends on Whom is Asked: Prognostic Disagreement and Inaccuracy for Critically Ill Patients," in *Critical Care Medicine*, 17 (1989), pp. 827-833.

<sup>31</sup> N.A. CHRISTAKIS and D.A. ASCH, "Physician Characteristics Associated with Decisions to Withdraw Life Support," in *American Journal of Public Health*, 85 (1995), pp. 367-372.

<sup>32</sup> N.A. CHRISTAKIS, "Biases in How Physicians Choose to Withdraw Life Support," in *Lancet*, 342 (1993), pp. 642-646.

<sup>33</sup> A.R. FEINSTEIN, "The Chagrin Factor and Qualitative Decision Analysis," in *Archives of Internal Medicine*, 145 (1985), pp.1257-1259.

<sup>34</sup> L.J. SCHNEIDERMAN, R.A. PEARLMAN, R.M. KAPLAN, et al "Do Physicians' Own Preferences for Life Sustaining Treatment Influence Their Perceptions Upon Patient Preferences?" in *Journal of Clinical Ethics*, 4 (1993), pp. 23-33. L.J. SCHNEIDERMAN, R.M. KAPLAN, E. ROSENBERG, and H. TEETZEL, "Do Physicians Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences? A Second Look," in *Cambridge Quarterly of Health Care Ethics*, 6 (2) (1997), pp. 131-137.

futility<sup>35</sup> of clinical treatments based on their own individual or professional criteria of futility.<sup>36</sup> It has been proposed that clinicians could have the authority to limit perceived inappropriate treatments, but that criteria for such limitations be based on standards of practice outlined by governmental agencies, professional associations and other public forums.<sup>37</sup> The difficulty is the present criteria from such social dialogue and policy statements do not offer clear direction to clinicians in unique care situations.

Several North American professional healthcare associations have attempted to provide their guiding policy definition of *medical futility*. The difficulty is that such policy statements can potentially incorporate as many as eight different, and sometimes conflicting, approaches to defining futility within the same policy statement.<sup>38</sup> Confusion ensues within the moral reasoning of the clinician, as they attempt to identify which definition best applies to the unique ethically difficult "end of life" care dilemma they are challenged with.

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<sup>35</sup> The issue of medical futility evolved by the increase of patient autonomy and involvement in decisions concerning medical treatments that affected their life. The issue concerns the struggle to the futility of treatments according to biological, physiological, or medical effectiveness criteria or according to the values and life goals of the patient.

<sup>36</sup> Robert M. VEATCH, "Why Physicians Cannot Determine if Care is Futile?" in *Journal of American Geriatrics Society*, 42 (1994), pp. 871-874.

<sup>37</sup> L.J. SCHNEIDERMAN and N.S. JECKER, "Futility in Practice," in *Archives of Internal Medicine*, 153 (1993), pp. 437-441. L.J. SCHNEIDERMAN, N.S. JECKER, and A.R. JONSEN, "Medical Futility: Responses to Critiques," in *Annals of Internal Medicine*, 125 (1996), pp. 669-674. Tom TOMLINSON and Howard BRODY, "Futility and the Ethics of Resuscitation," in *Journal of the American Medical Association*, 264 (10)(1990), p. 1280.

<sup>38</sup> Baruch A. BRODY and Amir HALEVY, "Is Futility a Futile Concept?" in *Journal of Medicine and Philosophy*, 20 (2) (1995), pp. 123-144.

An example of this application and moral reasoning dilemma can be found within the *1995 Joint Statement on Resuscitative Measures*. This collaborative statement of the Canadian Medical Association, Canadian Nurses Association, Canadian Hospital Association and the Catholic Health Association of Canada offers five different approaches to defining futility within the same policy statement.

**In some situations a physician can determine that a treatment is medically futile or non beneficial because it (1) offers no reasonable hope of recovery or improvement, or because (2) the person is permanently unable to experience any benefit. In other cases the utility of and benefit of a treatment (3) can only be determined with reference to the person's subjective judgement about his or her overall well-being. (4) As a general rule a person should be involved in determining futility in his or her case. In exceptional circumstances (5) such discussion may not be in the person's best interests.**<sup>39</sup>

The policy statement does not advocate any one approach on the various options or directions proposed within the "futility" debate as much as make the reader aware of the different available options as parameters for action. It is most likely written in that manner because the authors recognize both the diversity of definitions and that no one approach can apply to the diversity of situations which arise to challenge clinicians and patients. The first two approaches, identified by numbers one and two in the preceding quoted paragraph, seem to be giving unilateral decision-making authority to the clinician and the decision seems to be based on physiological criteria. The third

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<sup>39</sup> Canadian Medical Association, Canadian Nurses Association, Catholic Health Association of Canada, Canadian Bar Association, "Joint Statement on Resuscitative Measures", *Canadian Medical Association Journal* 153 (11) (1995), p. 1652B.

and fourth approaches support the decision making authority of the patient, basing the decision on criteria valued from the patient's perspective. The fifth approach proposes that the clinician might not involve or inform the patient of the decision at all. What is not offered to the reader in these types of policy statements are guiding parameters in determining when it might be more appropriate to follow a particular approach. The clinician is left to complete the most difficult part of ethical reasoning in unique situations; deliberating between the norms offered and the particularity of their practical situation until arriving at the point of conviction on the most appropriate way to proceed. The policy does not take a stand on two of the early and key questions clinicians had and continue to have in the "futility" debate: 1) Do I need to involve the patient in this decision? 2) Can I make this decision solely on physiological criteria? What the policy tends not to address, and perhaps correctly due to the inherent limitations of norms and policy statements is more specific parameters that would assist in discerning when a particular approach would be more appropriate for a particular situation. The reader is left unassisted in the most formidable part of the ethical discernment; choosing which option most appropriately applies to the unique context of the ethically difficult care dilemma that confronts them – not an easy task. It is this process of ethical reasoning, this developed practical wisdom, that healthcare professionals are perhaps least prepared for and find most difficult.

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The difficulty and complexity inherent in collaborative "end of life" decision making unique situations is clearly evident. Given that discernment of these care plans are a shared decision among a clinical team, patients and family members, how is the decision to weave its way through intractable conflicts of value to the "most appropriate decision" for the patient? In what ways are our past and present abilities to achieve a tenuous consensus being disrupted within unique palliative sedation dilemmas?

### **C) Limitations with Pain Management**

Pain is a subject elusive to definition. One reason offered for this difficulty is that pain is considered a subjective experience and therefore difficult to evaluate.<sup>40</sup> Perhaps one "benchmark" can be found in the definition of pain proposed by the International Association for the Study of Pain. The Association defines pain as, "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage".<sup>41</sup> Within definitions are often found implicit debates. With the term *pain* the debates have included, 1) Is pain caused by physical tissue damage, emotional and psychological damage to a person's worldview, or both, 2) Is *pain* the best term to use to define emotional, spiritual and psychological dissonance or is the better term *suffering*? 3) How might clinicians distinguish between and respond

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<sup>40</sup> Kathleen M. FOLEY, "The Treatment of Cancer Pain," in *New England Journal of Medicine*, 313 (2) (July, 1985), p. 85.

<sup>41</sup> International Association for the Study of Pain Subcommittee on Taxonomy, "Pain Terms: A List With Definitions and Notes on Usage," in *Pain*, 82 (1979), pp. 815-818.

differently to *pain* as opposed to *suffering*? These questions are key reasons why the term pain has been difficult to define. *Total pain* is another term that has been used to describe and capture not only the etiologic components but also to include the emotional, social, bureaucratic, financial and spiritual components of our experience.<sup>42</sup>

Bodies are said to endure pain while persons endure suffering. Such dichotomies are an attempt to include the role of the subject in the experiences of pain and suffering. The dichotomy seems to provide insight by recognizing that the meaning is broader than physicality but, at the same time, seems to create a relationship between pain and suffering that is perhaps too separated, therefore no light is shed on their complex interdependency. The interrelation and interdependence of pain and suffering still seems an elusive struggle to identify. As a consequence, the potential to manage or control pain and suffering as an established goal within palliative care continues to be an elusive struggle to identify.

Relieving the pain incurred by a terminally ill patient can involve a very complex, multidimensional assessment and treatment plan. This is because each of the components of *total pain* have been considered as becoming more

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<sup>42</sup> Cicely SAUNDERS, *The Management of Terminal Illness* (London: Edward Arnold, 1967), cited in Geoffrey HANKS, Russell K. PORTENOY, Neil MACDONALD, AND Karen FORBES, "Difficult Pain Problems," in *Oxford Textbook of Palliative Medicine*, (New York: Oxford university Press, 1998), p. 257.

prominent in patients dying with pain.<sup>43</sup> Pain can destroy a patient's quality of life. The sense of hopelessness and fear of impending death may exaggerate pain.<sup>44</sup> Physically, pain can foster the impairing of sleep, producing fatigue and poor appetite, thus reducing the availability of nutrients to be absorbed and heal the organs. Clinical pain management techniques use a combination of opioid and non-opioid drugs enabling the physician to both improve physical pain relief and limit the patient's tolerance to such drugs without escalation of the narcotic dose. Calculations are based more on clinical experience rather than controlled studies, because of the inability to predict an ideal maintenance infusion rate and the need to accommodate differences among patients.<sup>45</sup> The majority of the difficulty with respect to using these techniques is attributed to the differences in the responses of individual patients to the same dose of drug.

There are two types of limitations creating unrelieved pain and suffering of palliative care patients. The first limitation is the need for wider education of healthcare professionals on current palliative care knowledge and pain management techniques. Such lack of education is considered a cause of healthcare professionals ill-founded concerns that patients will become addicted

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<sup>43</sup> FOLEY, "The Treatment of Cancer Pain," p. 86.

<sup>44</sup> FOLEY, "The Treatment of Cancer Pain," p. 85. Kathleen M. FOLEY, "The Relationship of Pain and Symptom Management to Patient Requests for Physician-Assisted Suicide," in *Journal of Pain and Symptom Management*, 6 (5) (1991), p. 293.

<sup>45</sup> FOLEY, "The Treatment of Cancer Pain," p. 91.

to analgesics such as morphine,<sup>46</sup> or simply poor pain assessment.

In a recent survey of physicians providing care for patients with cancer, 76 % stated that the single most important barrier to adequate pain management was poor pain assessment. In another survey, fewer than one half of patients with pain had a staff member ask about pain or note pain in the record during the 72 hour period after their admission to hospital.<sup>47</sup>

The second limitation is experienced within the ability of current pain management techniques and knowledge to satisfactorily address difficult pain management problems and dilemmas. This second type of limitation is often described as patients having *refractory symptoms*.

### 1) Refractory Symptoms

While some suggest that 80% of patients in specialist palliative care units respond well to pharmacological management,<sup>48</sup> others suggest that between 10% and 50 % of patients in programs devoted to palliative care still report significant pain one week before death.<sup>49</sup> There are some types of pain in terminal illness that are not so easily relieved and are difficult to manage. With

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<sup>46</sup> Ronald MELZACK, "The Tragedy of Needless Pain," in *Scientific American*, 262 (2) (February, 1990), p. 27.

<sup>47</sup> Jane INGHAM and Russell K. PORTENOY, "The Measurement of Pain and Other Symptoms," in *Oxford Textbook of Palliative Care* (New York: Oxford University Press, 1998), p. 214.

<sup>48</sup> HANKS, PORTENOY, MACDONALD, and FORBES, "Difficult Pain Problems," in *Oxford Textbook of Palliative Medicine*, p. 454.

<sup>49</sup> Timothy E. QUILL, Bernard LO and Dan W. BROCK, "Palliative Options of Last Resort: A Comparison of Voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia," in *Journal of the American Medical Association*, 278, (23) (December 17, 1997), p. 2099.

respect to cancer pain these types include:<sup>50</sup> 1) Opioid poorly-responsive pain regarding patients with chronic neuropathic pain. 2) Opioid irrelevant pain concerns social, psychological, or spiritual turmoil rather than a result of physical injury or damage. 3) Breakthrough pain which refers to a transitory increase in pain with a patient who has a relatively stable and controlled baseline pain. 4) Pain in the delirious patient is perhaps the most frustrating since it concerns pain where there are no apparent causes for the delirium.

There is a distinction made between *difficult* and *refractory symptoms* in pain management. *Difficult symptoms* have the potential to respond within a tolerable time frame to noninvasive or invasive interventions and achieve adequate relief and preserved consciousness without excessive adverse effects.<sup>51</sup> *Refractory symptoms*, on the other hand, are those not adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.<sup>52</sup> Different reasons are suggested for the existence of refractory symptoms. They exist due to intensity of the apparent distress experienced by the patient or due to the fact that clinicians may be unfamiliar

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<sup>50</sup> The following four categories are presented as the most challenges situations to pain management in HANKS, PORTENOY, MACDONALD, and FORBES, "Difficult Pain Problems," in *Oxford Textbook of Palliative Medicine*, pp. 454-474.

<sup>51</sup> Nathan I. CHERNY and Russell K. PORTENOY, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," in *Journal of Palliative Care*, 10 (2) (1994), p. 32.

<sup>52</sup> CHERNY and PORTENOY, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," p. 31.

with therapeutic strategies.<sup>53</sup> Some suggest that assistance with such symptoms is available through cognitive restructuring, through life review techniques, and through assisting patients to distinguish between remediable and non-remediable issues.<sup>54</sup>

*Terminal anguish* is another term denoting a type of refractory symptom but the term denotes this pain and suffering as emotional, psychological, and spiritual rather than physical. *Terminal anguish* is defined as,

A tormented mental state, characterized by extreme restlessness, thrashing about, and moaning or groaning. If these symptoms are not relieved, profoundly distressing memories of this agony may remain with the family forever. For staff, stress levels rise and they are left with a sense of futility and failure.<sup>55</sup>

A tormented state of mind which relates to longstanding unresolved emotional problems and/or interpersonal conflicts, or to long-hidden unhappy memories often with guilty content. These problems have festered in the mind but have never been brought out into the open.<sup>56</sup>

Terminal anguish or "hidden thoughts" are felt to present themselves when the patient's repressed guilt or unpleasant thoughts are expressed *due* to their increasing weakness and drowsiness due to sedating drugs. At this point it is considered too late for psychological therapy and "meaningful

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<sup>53</sup> Nathan I. CHERNY, Nessa COYLE, Kathleen M. FOLEY, "The Treatment of Suffering When Patients Request Elective Death," in *Journal of Palliative Care*, 10 (2) (1994), p. 75.

<sup>54</sup> CHERNY, COYLE AND FOLEY "The Treatment of Suffering When Patients Request Elective Death," p. 75.

<sup>55</sup> Marion D. COOPER, "Commentaries: When Palliative Care Fails to Control Suffering," in *Journal of Palliative Care*, 10 (2) (1994), p 27.

<sup>56</sup> R.G. TWYLCROSS and I. LICHTER, "The Terminal Phase," in DOYLE Derek, HANKS, Geoffrey, MACDONALD N. eds., *Oxford Textbook of Palliative Medicine*. (Oxford: Oxford

communication" with clinicians, family or friends. Analgesics are increased at this point because it is difficult to exclude the presence of pain when the symptoms of terminal anguish appear and nothing short of lapse into coma or deep sedation is believed to provide relief. "Enormous doses of analgesics and sedatives may be needed to obliterate the mental anguish".<sup>57</sup> Evident in the use of this term is the attempt to distinguish pain from suffering through the term *terminal anguish*. Also evident in all description and debate surrounding refractory symptoms are some foundational shifts and struggles within the identity of palliative care professionals. Implicit in the description and debate is a theme of failure, a questioning of whether the existence of refractory symptoms is due to their inability to deal with psychological issues earlier in the dying process. With this experience of limitation is a shift of focus from the meaning of the terminal illness from the patient to a focus on the meanings interpreted and lived by clinicians, the patient's family members and friends.

The information regarding the incidence of refractory symptoms (pain, cognitive impairment through delirium, nausea, vomiting or dyspnea) and the palliative sedation practices used to address them is inconsistent.<sup>58</sup> One study defines refractory symptoms as those that, "could not be adequately controlled

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University Press, 1995), p. 659.

<sup>57</sup> COOPER, "Commentaries: When Palliative Care Fails to Control Suffering," p. 27.

<sup>58</sup> Robin FAINSINGER, Melvin MILLER, Eduardo BRUERA, J. HANSON, and T. MACEACHERM, "Symptom Control During the Last Week of Life on a Palliative Care Unit," in *Journal of Palliative Care*, 7 (1) (1991), p. 6.

despite aggressive efforts to identify a tolerable therapy that did not compromise consciousness", and reported the incidence of refractory symptoms in palliative care patients range between 16-52%.<sup>59</sup> Ventafridda<sup>60</sup> noted 63 of 120 patients or 52%, Fainsinger<sup>61</sup> in a retrospective study noted 16 of 100 or 6%, Lichter<sup>62</sup> prospectively evaluated 22% of 200 patients, while Higginson<sup>63</sup> noted 18 of 86 patients or less than 5%. The results of various studies are diverse ranging anywhere from 5% to 52%.<sup>64</sup> Balfour M. Mount feels one of the major reasons for the discrepancy in the experience of terminal distress concerns patient selection factors. He claims that patient populations more relevant to the Milan data of Ventifrida may be found in hospice programs admitting patients whose symptoms have been found difficult to control elsewhere.<sup>65</sup> Others also question the etiology, whether the semi-consciousness is due to the cancer and its

<sup>59</sup> CHERNY and PORTNOY, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," p. 31.

<sup>60</sup> V. VENTAFRIDDA, C. RIPAMONTI, F. DECONNO, M. TAMBURINI and B.R. CASSILETH, "Symptom Prevalence and Control During Cancer Patients' Last Days of Life," in *Journal of Palliative Care*, 6 (1990), p. 9.

<sup>61</sup> FAINSINGER, MILLER, BRUERA, HANSON and MACEACHERM, "Symptom Control During the Last Week of Life on a Palliative Care Unit," p. 7.

<sup>62</sup> I. LICHTER and E. HUNT, "The Last 48 Hours of Life," in *Journal of Palliative Care*, 6 (1990), p. 14-15.

<sup>63</sup> I. HIGGINSON and M. MCCARTHY, "Measuring Symptoms in Terminal Cancer: Are Pain and Dyspnoea Controlled?", in *Journal of Social Medicine*, 82 (1989), pp. 266-267.

<sup>64</sup> Paul ROUSSEAU, "Terminal Sedation in the Care of Dying Patients," in *Archives of Internal Medicine*, 156 (September 9, 1996), pp. 1785-1786.

<sup>65</sup> Balfour M. MOUNT, "A Final Crescendo of Pain?" in *Journal of Palliative Care*, 6 (3)

progression, the concomitant physiological and neurological events, or to pain management treatments.<sup>66</sup>

## 2) Sedation

Sedation is considered an appropriate response for some palliative care patients with refractory symptoms because of the assumption that suffering is a perceptual experience requiring consciousness; therefore, an unconscious patient does not suffer.<sup>67</sup> Such an assumption is challenged by other palliative care professionals who point to controversy<sup>68</sup> in the anesthesia literature regarding whether heavily sedated persons are actually free of suffering or simply unable to report or remember it.<sup>69</sup> Concerns are also expressed that once consciousness is compromised by drug therapy, any downward titration of drugs to reestablish lucidity may not be promptly restored, or death may be ensured as doses are again escalated.<sup>70</sup> This tension between lucidity and

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(1990), p. 5.

<sup>66</sup> ROY, "Need They Sleep Before They Die?" p.3.

<sup>67</sup> CHERNY and PORTNOY, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," p. 76.

<sup>68</sup> The literature being referred to is, N. MOERMAN, B. BONKE, and J. OOSTING, "Awareness and Recall During General Anesthesia: Facts and Feelings," in *Anesthesiology*, 79 (1993) pp. 454-464. J.E. UTTING, "Awareness: Clinical Aspects: Consciousness, Awareness, and Pain," in M. ROSEN and J.N. LINN, eds., *General Anesthesia*, (London: Butterworths, 1987), pp.171-179. J.M. EVANS, "Patient's Experience of Awareness During General Anesthesia: Consciousness, Awareness and Pain," in ROSEN and LINN, *General Anesthesia*, pp. 184-192.

<sup>69</sup> QUILL, LO and BROCK, "Palliative Options of Last Resort: A Comparison of Voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia", p. 2100.

<sup>70</sup> CHERNY and PORTNOY, "Sedation in the Management of Refractory Symptoms:

**treatment of refractory symptoms with sedation is a key value conflict. It is a concern for some palliative care professionals and patients that compromising the lucidity of the patient in the name of pain management is actually a dehumanization of the dying process for patients, families and clinicians.<sup>71</sup> Others claim that such action is justified through the principle of double effect which is interpreted as focusing on "primary intent" and a distinction regarding foreseeing and intending the effects of sedation.<sup>72</sup>**

**Improvements are being achieved in sedation practices through switching opioids more frequently and at a much earlier stage when confronted with the development of opioid-related side effects (delirium, myoclonus, seizures, or respiratory complications such as narcotic induced pulmonary edema<sup>73</sup>) or rapidly escalating doses.<sup>74</sup> These improvements were noted to be a result of, "increased vigilance in noting opioid side effects and switching opioids to take advantage of incomplete cross-tolerance".<sup>75</sup> The results confirmed a decrease in**

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**Guidelines for Evaluation and Treatment," p. 36.**

<sup>71</sup> **QUILL, *Death and Dignity: Making Choices and Taking Charge*, p. 106.**

<sup>72</sup> **CHERNY and PORTNOY, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," p. 36.**

<sup>73</sup> **There is some debate regarding whether pulmonary edema can be induced by narcotics. One study claiming this event is, Eduardo BRUERA, "Narcotic-Induced Pulmonary Edema," in *Journal of Pain and Symptom Management*, 5 (1) (1990), p. 57.**

<sup>74</sup> **Robin FAINSINGER, Karen LOUIE, Michelle BELZILE, Eduardo BRUERA, John HANSON, "Decreased Opioid Doses used on a Palliative Care Unit," in *Journal of Palliative Care*, 12 (4) (1996), p. 6.**

<sup>75</sup> **FAINSINGER, et al, "Decreased Opioid Doses Used on a Palliative Care Unit," p. 8.**

the range of opioids used, as well as statistically significant decrease in the daily opioid dose in the last week of life. The difference was attributed to the use of methadone in patients showing either, "a poor response to other opioids or a rapid development of tolerance, as well as switching opioids more frequently to take advantage of incomplete cross-tolerance".<sup>76</sup>

*Terminal sedation* is a term used to describe a palliative sedation practice addressing the refractory symptoms of terminally ill patients. In one of the few studies completed attempting to understand this practice, the term *terminal sedation* was defined as,

...the intention of deliberately inducing and maintaining deep sleep, but not deliberately causing death in very specific circumstances. These are: 1) for the relief of more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death, or 2) for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological, or other interventions, and the patient is perceived to be close to death. This does not include the management of delirium or the use of anxiolytic/psychotropic drugs for the management of symptoms such as hallucinations, paranoia, myoclonus, etc. Nor does it include planned temporary sedation that is reversed.<sup>77</sup>

With respect to that study, it is interesting to note that the least prominent reasons for clinician participants to use terminal sedation was seizures, twitching, nausea, vomiting, and retching. The most prominent were pain, anguish, respiratory distress, agitation, delirium, confusion and hallucinations.

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<sup>76</sup> FAINSINGER, et al, "Decreased Opioid Doses Used on a Palliative Care Unit," p. 6.

<sup>77</sup> Susan CHATER, Raymond VIOLA, Judi PATERSON, Virginia JARVIS, "Sedation for Intractable Distress in the Dying – a Survey of Experts," in *Palliative Medicine*, 12 (1999), p. 257-258.

While no definition was given regarding a consistent understanding of the term *anguish* in the study, 7% of the respondents did not agree with using terminal sedation to address anguish.<sup>78</sup> While other study authors advise deep or terminal sedation for the management of refractory symptoms, and one third of the reasons for sedation reported in that study were for psychological reasons, the use of sedation for such reasons or symptoms raises controversy. Other studies have shown there is no significant difference in survival time between sedated and non-sedated patients which raises the foundational question of whether terminal sedation does in fact hasten death.<sup>79</sup>

Nevertheless, concerns on the part of palliative care professionals remain regarding intractable suffering, patients living as tragedies, and sedation technologies delivering a dehumanizing death. Since a high proportion of patients report in studies with psychic distress, studies searching for better indicators of psychic distress would be advocated to lessen the use of sedation by allowing for earlier symptom recognition and earlier depth psycho/social/spiritual intervention. It is evident that clinicians are still not completely comfortable with sedation as either a last option or a solution of

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<sup>78</sup> CHATER et al, "Sedation for Intractable Distress in the Dying – a Survey of Experts," p. 258-259.

<sup>79</sup> CHATER et al, "Sedation for Intractable Distress in the Dying – a Survey of Experts," p. 262. See also, VENTAFRIDDA, RIPAMONTI, DECONNO, TAMBURINI and CASSILETH, "Symptom Prevalence and Control During Cancer Patients' Last Days of Life," pp. 7-11. P. STONE and C. PHILLIPS, "A Comparison of the Use of Sedatives in a Hospital Support Team and in a Hospice," in *Palliative Medicine*, 11 (1997), p.143.

choice.<sup>80</sup>

#### **D) Trends and Limitations with Ethical Norms**

**Just as limitations are experienced when attempting to relieve the symptoms of pain and suffering, limitations are experienced by clinicians when attempting to appropriately respond and accompany the dying patient at the end stage of their life. Ambiguity is even more pronounced when challenged with the tragedy of patients with refractory symptoms. Palliative care professionals have been offered the principle of double effect (PDE) as a guide offering parameters in complex end of life dilemmas. Yet the dilemmas, such as those found within the four tragic narratives presented at the beginning of this chapter, are disrupting agreement that PDE adequately addresses the ethical complexity of such tragic cases. It is claimed that cases such as these highlight weaknesses inherent in PDE. There is a struggle underway for a new synthesis of meaning, better able to appreciate, evaluate and integrate the evolution of palliative illnesses; the evolution of the socially constructed meaning of dying, the *telos* or ethical aim of the tradition of palliative care and the relational skill sets believed necessary to appropriately respond to diverse dying patients. This section will explore the clinical debate questioning whether PDE continues to be an adequate approach to addressing such tragic palliative sedation cases.**

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<sup>80</sup> CHATER et al, "Sedation for Intractable Distress in the Dying – a Survey of Experts," p. 263.

## 1) The Context of Consensus

Current Canadian debate on physician assisted suicide and euthanasia, as highlighted in Canadian Supreme Court hearings<sup>81</sup> (S.C.R., 3, 1993) and the *Report of the Special Canadian Senate Committee on Euthanasia and Assisted Suicide* (June, 1995) focus on the causality of a patient's death in health care by asking: which type of harm (pain, suffering, meaninglessness, death) caused by giving, withdrawing, or withholding a medical treatment should be permitted?

This question was in part answered in the 1995 Senate Report when they explored the types of support which should be offered to dying patients.<sup>82</sup>

Palliative care medicine,<sup>83</sup> officially recognized as a medical speciality in Britain

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<sup>81</sup> Rodriguez vs B.C. Supreme Court (S.C.R., 3, 1993)

<sup>82</sup> Senate Committee hearings in 1999 and 2000 reviewing progress on the recommendations of the Senate Committee Report On Life and Death heard Senator Sharon Carstairs say, "Just to refresh the memories of our witnesses and senators, it was never the intention of the committee to study anything other than euthanasia and assisted suicide. It was only when all these other issues came forward in our debate on euthanasia and assisted suicide that we found ourselves in a real dilemma. We felt it was only fair to report all those things because that is what Canadians seemed to be far more concerned about, quite frankly, than the issue of euthanasia and assisted suicide. They were concerned about palliative care, advanced directives, the withholding and withdrawing of life support treatment, and adequate pain medication. That is how the report came out." Proceedings of the Senate Subcommittee to Update "Of Life and Death". Monday, February 28, 2000, Ottawa.

<sup>83</sup> Palliative medicine is distinguished from palliative care according to its interdisciplinary nature. Palliative medicine is considered a medical specialty practiced by doctors concerning, "the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life." Derek DOYLE, Geoffrey HANKS, Neil MACDONALD, "Introduction" in *Oxford Textbook of Palliative Medicine* (1998), p. 3. Palliative care describes interdisciplinary care offered by a team of doctors, nurses, therapists, social workers, clergy, and volunteers. A useful definition offered by the World Health Organization is, "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment." World Health Organization,

in 1987, was explicitly advocated within the Report as an important healthcare resource holistically addressing the medical, psychological, social and spiritual needs of patients whose disease was not responsive to curative treatment.<sup>64</sup> The Senate Report explicitly recommended that the federal and provincial governments make palliative care a top priority as the Canadian health care system was being restructured. Reading between the lines, the Senate Report seemed to implicitly propose that, if palliative care was adequately supported, Canadians would experience a decrease in desire and requests for euthanasia and assisted suicide. The public's fears of the dying process would be allayed if they knew the dying process was understood, that they would be supported through it and not considered a burden on loved ones or the healthcare system. Good palliative care was proposed as a remedy, addressing not just the symptoms, but the root causes of why healthcare clinicians are asked by dying patients to participate in hastening their death. Within the Senate Report, the discipline of palliative care was proposed as a public moral good and as a product of medical progress without a differentiated understanding of what type of implicit common good approach it offers nor what type of implicit understanding of progress.

**Ironically the Senate Report also went on to explore the concerns of**

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**Cancer Pain Relief and Palliative Care. Technical Report Series 804. (Geneva: World Health Organization, 1990)**

<sup>64</sup> Senate of Canada. *On Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide*. June 1995. p. 18.

palliative care clinicians<sup>85</sup> regarding their own morally ambiguous dilemmas within the dying process – namely how they might be participating in hastening the death of dying patients through palliative sedation practices. For example, as noted previously, palliative care clinicians give higher doses of analgesics, such as morphine, to address the pain of their patients, the analgesic also suppresses the respiratory system. Because of this latter effect clinicians feel uncomfortable and struggle within their own professional integrity. Clinicians in such circumstances try to distinguish between how they address a patient's suffering through sedation and how they are participating in hastening the death, or killing, the dying patient. The Senate Report noted that Mr. Justice Sopinka, writing for the majority decision in the Supreme Court of Canada decision on the Rodriguez case,

"drew a legal distinction based on intention, between the administration of drugs that are likely to hasten death on the one hand and assistance in suicide on the other. Without deciding on the issue, by implication he seems to have suggested that if the intention is to alleviate suffering, it is legally permissible to provide treatment notwithstanding that this may hasten death."<sup>86</sup>

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<sup>85</sup> Various articles have been written articulating the struggle of palliative care clinicians to address their ethical difficulty over discerning adequate sedation practices and their uncertainty with participating in hastening the death of their patient. See case studies: MOUNT and HAMILTON, "When Palliative Care Fails to Control Suffering," pp. 24-30. Robert D. TRUOG, Charles B. BERDE, Christine MITCHELL and Holcombe E. GRIER "Barbituates in the Care of the Terminally Ill," in *New England Journal of Medicine* 327 (23) (1992), pp. 1678-1679. Howard BRODY, "Causing, Intending, and Assisting Death," in *Journal of Clinical Ethics*, 4 (3) (1993), pp.112-117. See also: David J. ROY, "Need They Sleep Before They Die?" in *Journal of Palliative Care*, 6 (3) (1990), p. 4. BRUERA, "Narcotic-Induced Pulmonary Edema," pp. 55-58. L.R. SCHWARZ, "Morphine for Pain Control, Not Death," in *American Journal of Health Systems Pharmacology*, 52 (6) (March 15, 1995), p. 654. B.M. KINZBRUNNER, "Ethical Dilemmas in Hospice and Palliative Care," in *Supportive Care and Cancers*, 3 (1) (January, 1995), pp. 28-36.

<sup>86</sup> Senate of Canada. *On Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide*. June 1995 p.27. The original comment of Mr. Justice Sopinka which the Report refers to can be found in *R. v. Rodriguez*, (1993) 3 S.C.R. 519, p. 607. "The

**This legal decision and those like it are claimed to be part of a tenuous evolving consensus regarding forgoing and discontinuing medical procedures. However, this legal and ethical consensus does not equal unanimity. The consensus is better characterized as a trend built from life situations debated in legal or ethical forums and then adopted as part of legal or clinical practice.**

**This consensus is built around the following features.<sup>67</sup> 1) Competent patients have the right to refuse treatment, 2) Incompetent patients have the same rights as competent patients, 3) Limitations are placed on the right to refuse treatment by societal interests such as the preservation of life, the prevention of suicide or the protection of the ethical integrity of healthcare professionals. 4) The clinical setting is deemed as the appropriate place for the decision making process to occur rather than the courts. 5) When discerning an incompetent patient's preferences, surrogate decision makers and the patient's advance directive may be relied upon, 6) Artificial nutrition and hydration is a medical treatment and may be withheld or withdrawn as any other form of medical treatment and 7) Active euthanasia is regarded as killing and distinct**

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**administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active contribution to death by any standard. However, the distinction drawn here is one based upon intention – in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death...In my view, distinctions based upon intent are important, and in fact, form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear."**

<sup>67</sup> These features are found in both of the following articles: Alan MEISEL, "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects," in *Kennedy Institute of Ethics Journal*, 2 (4) (1993), p. 315. David ROY and Neil MACDONALD, "Ethical Issues in Palliative Care," in *Oxford Textbook of Palliative Care* (1998), pp. 112-120.

from forgoing life sustaining treatment which is regarded as allowing the patient to die.

The principle of double effect (PDE) was used to justify the difference between killing and letting die. It became accepted clinical practice that treatments were withheld or withdrawn, either when they were not deemed to have any medical benefit, were harmful to the patient, or did not serve the life plans of the patient. The intention of the withdrawing or withholding treatment could never be to directly kill, or bring about the death of the patient. If death occurred shortly after the withdrawing or withholding of treatments, death was deemed to be caused by the underlying pathology, and not the action or inaction of the physician. The distinction between killing and letting die has consistently been upheld in high profile cases such as Karen Ann Quinlan and Nancy Cruzan cases in the United States, the Nancy B case in province of Quebec (Canada), the Sue Rodriguez case in Canada<sup>88</sup>, and the Anthony Bland case in the United Kingdom.<sup>89</sup>

## 2) Points Disrupting Consensus

Within the 1995 Senate report, palliative sedation practices seemed to be less characterized by consensus and more by moral ambiguity. Alan Rock, the Canadian Minister of Justice in 1995, suggested that there is confusion within

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<sup>88</sup> R. v. Rodriguez, (1993) 3 *Supreme Court Reports*. 519, p. 607.

<sup>89</sup> David ROY and Neil MACDONALD, "Ethical Issues in Palliative Care," in *Oxford Textbook of Palliative Care* (1998), p. 113.

the medical profession as to what is legally permitted and medically appropriate. "When is it permissible to keep prescribing morphine when you know within the next six hours it will cause death? The underlying disease will not kill the person, however the treatment of pain will. At present, that is shrouded in obscurity."<sup>90</sup> Within the statements of the witnesses at the public hearings of the Committee, together with the written submissions, old moral debates seemed to arise. Was there a significant moral difference between killing and letting die? Was the principle of double effect, and more specific the criteria of intention, an adequate resource to pertinently distinguish between a clinician appropriately or inappropriately participating in the death of a patient? When physicians are treating dying patients with refractory symptoms, physicians are claimed to have a multiplicity of intentions that are often complex, ambiguous and often contradictory. Pointing to a physician's primary psychological intention as the key to distinguishing between addressing suffering and an illicit hastening of death with the intention to kill is proposed as naïve and not practically helpful.<sup>91</sup> The symptoms of pain in some dying patients are addressed by dosages of sedation that pose no threat of respiratory depression. Other patients with lung or oral cancer who are dying of respiratory failure are found to be at greater risk

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<sup>90</sup> Senate of Canada. *On Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide*. June 1995. p. 27.

<sup>91</sup> Timothy E. QUILL, "The Ambiguity of Clinical Intentions," in *New England Journal of Medicine*, 329(14) (1993), pp. 1039-1040.

for developing respiratory depression through the use of morphine to address their pain and thus hasten their death.<sup>92</sup> Finally there are those patients with symptoms so intractable that the dosage of sedation needed to alleviate pain will certainly and more immediately suppress the respiratory system and hasten the patient's death. In these cases it is claimed to be difficult to distinguish intentions when the intent is to relieve the pain and suffering of the patient yet the dosage required to do so is a dosage which will certainly cause death. The focus on the physical causality of the agent's action or physician intention seem limited indicators to assess the meaning of the event. What collaborative role do the combined disease pathologies, the refractory symptoms, and the social meanings implicit within the experience of tragedy and hastening death in the practice of palliative care play in this assessment of moral meaning?

These focal questions were not explored in the Senate Report but were implicitly stated in the presentations of the witnesses. It is extremely important to note that the Senate Report did recommend that government divisions develop both guidelines for treatment, aimed at alleviating suffering even where it may shorten life, and research into palliative pain control and symptom relief.<sup>93</sup>

In November of 1999 to June of 2000, a Senate Committee was created to review and update progress on the unanimous recommendations offered in

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<sup>92</sup> QUILL, *Death and Dignity: Making Choices and Taking Charge*, p. 106.

<sup>93</sup> *On Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide*, (June, 1995), p. 24.

the Senate Report "On Life and Death." Many lamented the shortfall or non-existent funding for education and research in the area of palliative care.<sup>94</sup>

Some presented that the second recommendation of the Committee that a set of guidelines for the provision of treatment for the purpose of alleviating suffering, where that may shorten life, had not been established in the past five years.<sup>95</sup> Others mentioned that some criteria had been made available through the Office of the Chief Coroner of Ontario but in fact these guidelines simply reflect distinctions already present within PDE which is critiqued as ineffective.<sup>96</sup>

In the course of deliberations, there was reference made to a consensus existing on the validity of distinguishing between cases where no longer continuing with treatment due a competent patient's wishes is legally acceptable and appropriate.<sup>97</sup> Concerns were raised that the trend developed over the past

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<sup>94</sup> Dr. Neil MacDonald stated, "Approximately five years ago, I presented information in which I pointed out that the training of doctors in palliative medicine was clearly unsatisfactory. Five years and five months later I am back, and I would like to be able to tell you that the situation has changed positively and dramatically, but it has not." Tuesday, March 28, 2000, Ottawa, Proceedings of the Subcommittee to Update "Of Life and Death". p. 2.

<sup>95</sup> Ms. Virginia Jarvis, Tuesday, April 4, 2000, Ottawa, Proceedings of the Subcommittee to Update "Of Life and Death". p. 2.

<sup>96</sup> Peter Singer from the University of Toronto's Centre for Bioethics mentioned the guidelines from the Office of the Chief Coroner which state; "There is nothing to prevent a qualified medical practitioner from commencing or continuing to administer palliative care that does or may reduce the patient's life expectancy provided the palliative care meets the following criteria: 1) It is intended solely to relieve the person's suffering. 2) It is administered in response to symptoms or signs of the patient's suffering and is commensurate with that suffering. 3) It is not the deliberate infliction of death. ...It is important for physicians to make sufficient documentation on the patient's chart to show that the above criteria have been followed." Monday, February 28, 2000, Ottawa, Proceedings of the Subcommittee to Update "Of Life and Death". p. 2.

<sup>97</sup> Clearly the Canadian case of Nancy B. in Quebec seemed to be such a consensus

two decades away from an ethics of prolonging life at all costs is beginning to break down or unravel over the past couple of years.<sup>98</sup> Although this concern was raised without offering specific cases of "unraveling", such concerns are supported. Efforts oriented toward the legalization of mercy killing or increasing the decision making authority of physicians are claimed to be "unraveling" consensus by attempting to extend the trend away from prolonging life at all costs.<sup>99</sup> Novel cases themselves, new twists on old problems, are arising to which the consensus on principles cannot be applied directly nor offer clear conclusions.<sup>100</sup> Given the complexity and elusive nature of these novel cases, others were concerned that premature forgoing of life saving treatments, such as nutrition and hydration for incompetent patients, by act or omission, would not be evaluated or understood as non-voluntary euthanasia.<sup>101</sup>

From a causality viewpoint, cases of forgoing life-sustaining treatments differ from sedation cases and the difference does not concern the desire to prolong life. Withdrawing or withholding treatments, "letting die" through

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case. *Nancy B. v. Hotel-Dieu de Quebec et al.* 86 D.L.R. (4<sup>th</sup>), p. 385.

<sup>98</sup> This concern was voiced by Dr. David ROY, Tuesday, April 4, 2000, Ottawa, Proceedings of the Subcommittee to Update "Of Life and Death", p.11.

<sup>99</sup> Alan MEISEL, "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects," *Kennedy Institute of Ethics Journal*, 2 (4) (1992): p. 329.

<sup>100</sup> Robert M. VEATCH, "Forgoing Life Sustaining Treatment: Limits to the Consensus," *Kennedy Institute of Ethics Journal*, 3 (1) (1993) pp. 18-19.

<sup>101</sup> Peter RYAN, Monday, March 20, 2000, Ottawa, Proceedings of the Subcommittee to Update "Of Life and Death", p. 22.

omission, seemed to place the control and therefore the responsibility of death back into the hands of the patient's pathology. If death was hastened it was hastened by giving death back to the illness.<sup>102</sup> Death was no longer prolonged or slowed down by preserving life functions. With sedation cases the participation of the health care professional seems to have changed. The treatment of sedation does not accelerate death by delivering death to the pathology but accelerates death by collaborating with the pathology (especially patients with lung cancers or respiratory problems). Both seem to be causal collaborations.

### 3) Themes of Common Ground and Concern

In the course of deliberation there exist both themes of common ground and continuing concerns in the debate concerning sedation practices in palliative care. There is agreement that hospice care is the standard of care for the dying, that it is very effective when applied with skill and caring, that physician-assisted death is adamantly opposed as an alternative to adequate palliative care for the terminally ill.<sup>103</sup> There is agreement on the importance of the process of caring, intensive symptom relief, and mutual decision making that precedes the decision. So when the best of palliative care pain management techniques fail, what then?

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<sup>102</sup> Daniel CALLAHAN, *The Troubled Dream of Life: Living with Mortality* (New York: Simon and Schuster, 1993), p. 77.

<sup>103</sup> Timothy E. QUILL, "When All Else Fails," in *Pain Forum*, 4 (3) (1995), p. 189.

In the past decade foundational concerns have arisen with palliative sedation practices such as those engaged within the four narratives found at the beginning of this chapter. The story of Mr G. expressed concern that palliative care's present understanding of the determinants of psychological and spiritual suffering are far more primitive than physical suffering. Since physicians are less prepared and perhaps uncomfortable in dealing with the psychological and spiritual aspects of suffering, could they revert to sedation as a reaction due to the lack of education? There was concern over the potential harm and confusion created by linking how we address emotional suffering in the dying with terminal sedation and immanent death, since emotional suffering may not be linked to an advanced state of physiological deterioration and therefore immanent death may not be implicated. Finally, there was concern that a focus upon bodily integrity may be misplaced and that quality of life in terminal illness may depend more on the integrity of the web of relationships with self and others experienced by the sufferer. Quite practically, while sedation in addition to anti-anxiety and antidepressant drugs is agreed to be part of the proper management of end-stage symptoms, sedation used to produce continuous sleep or twilight sleep is considered by some as the euthanasia.<sup>104</sup> In the case of Mr. G. found at the beginning of this chapter, critiques arose over the medical or ethical authority that would allow for such a shift.

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<sup>104</sup> SCOTT, "Commentaries: When Palliative Care Fails to Control Suffering," p. 30.

Did the staff ethicist cite further authority for his position that pharmacological sedation as a palliative modality for emotional/spiritual suffering is an ethically acceptable option under these circumstances? I do not find confirmation for this in the literature or in my experience.<sup>105</sup>

This shift was described by others as *slow euthanasia*, with the definition being articulated as, "the clinical practice of treating a terminally ill patient in a fashion that will assuredly lead to a comfortable death, but not too quickly".<sup>106</sup> A *comfortable death* is claimed to be the aim of *slow euthanasia* but clinicians seem to diverge in what cooperative action constitutes a comfortable death and what practices are appropriate and harmful to achieving it.

In slow euthanasia with a morphine drip, regardless of how well the patient's pain or other physical distress is controlled, the dosage is maintained or adjusted upward gradually to assure at least somnolence, often to produce obtundation, coma, and even apparent respiratory depression. Similarly, other agents initiated to control symptoms of anxiety, agitation, or dyspnea may be adjusted upwards in spite of the patient having achieved adequate symptom control. A stuporous patient can no longer drink or eat. Since the patient is generally not receiving significant amounts of fluids or nutrition, dehydration and further mental clouding progress. An easeful death is assured within a few days or weeks.<sup>107</sup>

What is described in the above quotation is a description of an easeful death in a situation of refractory pain and suffering. Although it is not clear from the description that the author is distinguishing between pain and suffering, it is clear that easeful death in these situations is somnolence, obtundation, or coma. The intention claimed not to be to control the patients pain, physical

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<sup>105</sup> SCOTT, "Commentaries: When Palliative Care Fails to Control Suffering," p. 30.

<sup>106</sup> J. Andrew BILLINGS, Susan D. BLOCK, "Slow Euthanasia," *Journal of Palliative Care* 12 (4) (1996), p. 21.

<sup>107</sup> BILLINGS, "Slow Euthanasia," p. 21.

distress or other symptoms but to produce an *easeful death* implicitly defined as unconsciousness. The author claims that this goal of bringing about unconsciousness in extreme circumstances of pain and suffering is interpreted by some physicians as providing euthanasia, while other physicians interpret that they are not overtly causing death but merely keeping the patient comfortable.<sup>108</sup> The authors support the former interpretation of euthanasia rather than the latter and feel the slowness of the process – the series of small increases in sedation that gradually leads to death – softens the sense of the physician's agency. Physicians are discovered to, "ethically justify the practice of slow euthanasia by the principle of double effect: the fundamental goal of treatment is to alleviate suffering, and death is foreseen as a possible or even likely consequence of the treatment, but is not the intended outcome".<sup>109</sup> The authors believe PDE to be an ethical rationalization and cite the work of James Rachels as a place where its moral unimportance has been adequately proven. The practice of *slow euthanasia* is proposed by the authors to be humane, to be in fact euthanasia, and not revealing it as such fosters dishonesty and potential harm. The question posed to the above proposal is do such distinctions or definitions of *easeful death* adequately address the concerns of clinicians regarding their participation and feelings of responsibility in hastening the death

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<sup>108</sup> BILLINGS, "Slow Euthanasia," p. 22.

<sup>109</sup> BILLINGS, "Slow Euthanasia," p. 22.

of their patients evident in the long philosophical and theological debates regarding these issues?

In the face of such limit and suffering, it is proposed that the patient's personal autonomy is the distinction of primary importance. What is needed is to allow patients to determine the time of death and to decide how much suffering is enough.<sup>110</sup> The assumption is that respect for patient autonomy and compassion places the initiative in the patient's hands yet in current physician assisted suicide legislation and practice, so much control is in the physicians' hands who are given the status of gatekeepers.

The physician controls the availability and timing of the means whereby the patient kills himself. Physicians also judge whether the patients are clinically depressed, their suffering really unbearable, and their psychological and spiritual crises resolvable. Finally, the physician's assessment determines whether the patient is in the "extreme" category that, per se, justifies suicide assistance. The opportunities for conscious or unconscious abuse of this power are easy to obscure, even for the best-intentioned physician...the decision to respond to a request for assistance in suicide can be as much a danger to, as a safeguard of, the patient's right to self-determination. If it is known to be a viable option at the outset, it cannot fail to influence the patient, the physician, and everyone else involved in the patient's care.<sup>111</sup>

Such concerns seem reasonable and perhaps evident within the recent Oregon *Death with Dignity Act*, which requires physicians to point out to terminally ill patients requesting assisted suicide that palliative care is a feasible alternative. However, physicians are not required to be knowledgeable about

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<sup>110</sup> QUILL, "The Ambiguity of Clinical Intentions," p. 1040.

<sup>111</sup> Edmund D. PELLEGRINO, "Commentary: Compassion Needs Reason Too," in *Journal of the American Medical Association*, 270 (7) (1993), pp. 874-875.

how to relieve either physical or emotional suffering in terminally ill patients. Without such knowledge, how can physicians provide feasible alternatives credibly to the patient?<sup>112</sup> Concern is also raised regarding both physician's underestimation of the pain patients experience<sup>113</sup> and the patients' focus on using their time with their physician to discuss treatments rather than pain relief<sup>114</sup> create barriers to addressing the needs of terminally ill patients.<sup>115</sup>

While some concerns divide, other concerns seem to be the place of agreement and common ground. Such common ground is demonstrated in a number of common concerns. First, there is agreement that clinicians are believed not to be speaking of situations occurring in their practice because of lack of knowledge, discomfort and perhaps a resultant lack of honesty. Second, our current ability to discern that the patient truly has intractable suffering before we hasten death through using sedation is agreed to be weak. A third common concern arises with the practice of offering solace to dying patients by guaranteeing patients that healthcare professionals have the ability to control

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<sup>112</sup> Kathleen M. FOLEY and Herbert HENDIN, "The Oregon Report: Don't Ask, Don't Tell," in *Hastings Center Report*, 29 (3) (1999), p. 38.

<sup>113</sup> Stuart GROSSMAN, Vivian R. SHEIDLER, Karen SWEDEEN et al, "Correlation of Patient and Caregiver Ratings of Cancer Pain," in *Journal of Pain and Symptom Management*, 6 (1991), pp. 53.

<sup>114</sup> Sandra E. WARD, Nancy GOLDBERG, Vivian MILLER-MCCAULEY et al "Patient Related Barriers to Management of Cancer Pain," in *Journal of Pain*, 52 (1993), pp. 323-4.

<sup>115</sup> FOLEY and HENDIN, "The Oregon Report: Don't Ask, Don't Tell," p. 38.

the pain and suffering of the patient.<sup>116</sup> The reasons for the necessity of this assurance are not made clear, though one might assume it is linked to the need of healthcare professionals to build hope and trust with patients, in the face of the challenge of dying. Is such assurance an honest expression of our ability? The desire to be able to provide such assurance seems to contradict a previous claim that palliative care's present understanding of the determinants of psychological and spiritual suffering are far more primitive than physical pain.

The fourth concern is that the practice may foster a misunderstanding on the "appropriate" use of opioids.

Clinicians who only learn how a morphine drip can hasten death for terminally ill patients may not appreciate that a similar regimen, when carefully managed, can produce excellent pain control and a good quality of life in other patients.<sup>117</sup>

This latter concern demonstrates a desire and need for ethical distinctions adequately identifying the difference between appropriate and inappropriate use of sedation. It asks for knowledge of how two types of patient situations are different not just with regard to sedation dosage but with respect to human meaning and needed human response.

#### **Conclusion: Clues to Deeper Meanings**

Palliative care clinicians, lawyers, legislators and patients are struggling for a new synthesis of the moral meaning of these tragic palliative sedation

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<sup>116</sup> BILLINGS, "Slow Euthanasia," p. 22.

<sup>117</sup> BILLINGS, "Slow Euthanasia," p. 24.

**treatment dilemmas. The four narratives offer a window into the multifaceted landscape, the complexities and limitations, that palliative care is attempting to navigate. Essentially the limitation is the ability of current pain management techniques and knowledge to satisfactorily address difficult pain management symptoms and dilemmas. Yet the limitations are not focused on technical ability of sedation treatments but also with the moral principles used to assess these types of dilemmas. Present approaches based on the principle of double effect, used to distinguish appropriate participation of the clinician in ethically difficult palliative sedation cases, are argued to be incomplete or false "solutions. That the clinician's participation is justified because they are addressing pain and not intending to kill, that the patient "really" dies of their underlying disease or pathology, is claimed inadequate to articulate the layers of ethical meaning and conflict within these human tragedies. In essence, critiques claim that current clinical and ethical approaches do not integrate the singular complexity that is uniquely present in these tragic palliative sedation dilemmas.**

**Both the clinical and public policy debate seem to be asking if these palliative care narratives demonstrate that we are in a new type of moral frontier and whether we are justifying our actions appropriately. While the use of ethical distinctions was claimed to have an approving consensus regarding previous "end of life" dilemmas involving withholding or withdrawal of treatments, this consensus might be more adequately described as a trend of practice rather than a proven solution. From the exploration of the limitations identified within**

**this chapter there seem to be central questions surfacing that focus not only on ethical principles such as the principle of double effect but also the ethical aim of palliative care. Is there a significant difference between killing and letting die in palliative care, where death is not only foreseen through the treatment but, part of the complex act of doing good such as relieving pain and suffering? Are responses to extreme emotional suffering and anguish through the use of sedation appropriate? What type of human response in the face of tragic suffering and the experience of limitation will humanize dying? These questions will be explored in turn. But, since the adequacy of the principle of double effect is consistently pointed to as central to these dilemmas and debates, this inquiry will turn now to theological and philosophical debate over the interpretation and application of PDE to adequately explore the ethical meaning of these tragic palliative sedation dilemmas.**

## CHAPTER TWO

### Struggling for Clues Among Multiple Effects

#### Introduction

Physicians such as Robert D. Truog, Timothy Quill and Balfour M. Mount have presented clinical cases implicitly demonstrating the difficulty and even the inadequacy of the principle of double effect in assessing sedation practices.<sup>118</sup> Yet physicians such as Kathleen Foley have proposed that the effect of respiratory suppression is not a significant issue in the management of palliative pain because first, PDE justifies the use of morphine and second, the patient develops a type of tolerance<sup>119</sup>. In this regard, the second condition of PDE, the intention of the agent, is pointed to as the key when making a distinction possible between direct participation (killing) and indirect participation (letting die while addressing pain and suffering).<sup>120</sup> However, attempting to identify a singular intention of the clinician to kill the patient seems an inadequate

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<sup>118</sup> TRUOG, BERDE, MITCHELL and GRIER, "Barbituates in the Care of the Terminally Ill," pp. 1678-1679. MOUNT and HAMILTON, "When Palliative Care Fails to Control Suffering," pp. 24-26. SCOTT claims that the type of case recounted by Balfour M. Mount is considered by her as equivalent to euthanasia. SCOTT, "Commentaries: When Palliative Care Fails to Control Suffering", p. 30.

<sup>119</sup> Kathleen M. FOLEY, "The Relationship of Pain and Symptom Management to Patient Requests for Physician-Assisted Suicide," in *Journal of Pain and Symptom Management*, 6 (5) (1991), p. 292.

<sup>120</sup> Nathan I. CHERNY and Russel K. PORTENOY, "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," in *Journal of Palliative Care*, 10 (2) (1994), p. 36. See also, R. Rodriguez, (1993) 3 Supreme Court Reports 519, p. 607. E. J. LATIMER, "Ethical Decision-Making in the Care of the Dying and its Applications to Clinical Practice," in *Journal of Pain and Symptom Management*, 6 (1991), pp. 329-336.

simplification of the moral reasoning process needed in the types of tragic palliative cases presented earlier. Identifying the single intention of a physician in these types of palliative cases has been proposed as difficult, if not impossible, since a physician often has a multiplicity of intentions within these ethically difficult care dilemmas.<sup>121</sup> Not only the criteria of the *intention of the agent* (i.e. the physician) has been critiqued as inadequate, but also the *direct/indirect* distinction has been debated as both inadequate<sup>122</sup> and adequate<sup>123</sup> in demonstrating a moral difference between killing and letting die. As we begin to explore the relevance of PDE for palliative care, some questions arise. First, PDE was developed as an answer to what question? Second, if PDE was once considered a relevant distinction and moral reasoning in palliative care, but is no longer, what were the conditions shaping such change?

Various thinkers have engaged in this debate over PDE within the

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<sup>121</sup> Timothy E. QUILL, "The Ambiguity of Clinical Intentions," in *New England Journal of Medicine*, 329 (14) (1993), pp. 1039-1040. Howard BRODY, "Causing, Intending, and Assisting Death," in *Journal of Clinical Ethics*, 4 (3) (1993), p. 117.

<sup>122</sup> Examples include: Jonathan GLOVER, *Causing Death and Saving Lives* (Harmondsworth: Penguin Books, 1977). Michael TOOLEY, *Abortion and Infanticide* (Oxford: Clarendon Press, 1983). John HARRIS, *The Value of Life* (London: Routledge, 1985). James RACHELS, *The End of Life: Euthanasia and Morality* (Oxford: Oxford University Press, 1986). Helga KUHSE, *The Sanctity of Life Doctrine in Medicine: A Critique* (Oxford: Clarendon Press, 1987). E. Peter SINGER, *Practical Ethics*. 2nd ed., (Cambridge: Cambridge University Press, 1993). E. Peter SINGER, *Rethinking Life and Death: The Collapse of Our Traditional Ethics* (Oxford: Oxford University Press, 1995). Roy W. PERRETT, "Killing, Letting Die and the Bare Difference Argument," in *Bioethics*, 10 (2) (1996), pp. 131-139.

<sup>123</sup> Tom L. BEAUCHAMP, "A Reply to Rachels on Active and Passive Euthanasia," in BEAUCHAMP, Tom L. and PERLIN, Seymour, eds. in *Ethical Issues in Death and Dying* (Englewood Cliffs: Prentice-Hall, 1978). Daniel CALLAHAN, *What Kind of Life: The Limits of Medical Progress* (New York: Simon and Schuster, 1990), p.232. Winston NESBITT, "Is Killing

context of philosophical and theological debates. The discourse has unraveled past assumptions of consensus and produced new insights and directions to follow. The inquiry within this chapter will focus on debate regarding where the principle of double effect originated, the theological debate on the interpretation and application of PDE, the analytic philosophy debate on the adequacy of PDE to offer relevant distinctions, as well as the identification of common issues among the theological and philosophical debates. I will begin with the theological debate which casts a broader net in attempting to understand the historical development and interpretation of the principle of double effect.

#### A) New Questions from Double Effect Reasonings

The principle of double effect (PDE) has its own genesis and history of development as a form of moral reasoning.<sup>124</sup> Traditionally, this principle was believed to have emerged or was first expressed by the moral theologian Thomas Aquinas (b. 1227- d. 1274) within the context of debating the issue of defence against unjust aggression in *Summa Theologica*, IIa IIae, q. 64, art. 7.<sup>125</sup> The validity of Aquinas's authorship has been critiqued, as the genesis of the present principle is also believed to have emerged between the thirteenth and sixteenth centuries. This historical theory of PDE proposes that four

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No Worse Than Letting Die?" in *Journal of Applied Philosophy*, 12 (1995), pp. 101-106.

<sup>124</sup> Christopher KACZOR, "Double Effect Reasoning from Jean Pierre Gury to Peter Knauer," in *Theological Studies*, 59 (1998), p. 315.

<sup>125</sup> Joseph T. MANGAN, "An Historical Analysis of the Principle of Double Effect," in *Theological Studies*, 10 (1949), p. 42.

conditions of PDE emerged as common factors among paradigm moral cases, which were articulated into their present form by John of St. Thomas (1589 - 1644).<sup>126</sup> The authorship of Aquinas has also been questioned because the third condition of PDE, within traditional formulations, is claimed not to be found within the writings of Aquinas.<sup>127</sup> Diverse opinion exists on how the present day formulation of the PDE historically developed, and whether it is appropriately articulated, interpreted and applied to concrete healthcare dilemmas.<sup>128</sup> Such diversity highlights the perception that the meaning of the four conditions of PDE might not be self-evident nor their interpretation "common sense". Therefore, the meaning of PDE may in fact not be as readily available as might be assumed. Simply stated the four conditions of PDE are as follows<sup>129</sup>:

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<sup>126</sup> James F. KEENAN, "The Function of the Principle of Double Effect," in *Theological Studies*, 54 (1993), p. 299. It is interesting that Peter Knauer states, "There is substantial foundation for criticism of Mangan's conclusions by J. Ghos." KNAUER, *The Principle of Double Effect*, p. 36, footnote 2. See also, Josef GHOOS, "L'Acte a Double Effet: Étude de Théologie Positive," in *Ephemerides Theologicae Lovanienses*, 27 (1951), pp. 30-52.

<sup>127</sup> Charles CURRAN, "The Principle of Double Effect: Some Historical and Contemporary Observations," in *Congresso Internazionale Tommaso D'Aquino Nel Suo Settimo Centenario*, Roma - Napoli, 1974. *L'agire Morale*. (Napoli, Edizioni Domenicane Italiane, 1977), p. 428.

<sup>128</sup> See Donald B. MARQUIS, "Four Versions of Double Effect," in *Journal of Medicine and Philosophy*, 16 (1991), pp. 515-544. The author claims there are currently four versions of the doctrine being used in debates: two formulations of the traditional Catholic doctrine, Joseph M. Boyle's revision of that doctrine, and Warren Quinn's version of PDE.

<sup>129</sup> The *New Catholic Encyclopedia* (1967), articulates the four conditions of the principle of double effect as follows: "1) the act itself must be morally good or at least indifferent. 2) The agent may not positively will the bad effect but may merely permit it. If he could obtain the good effect without the bad effect, he should do so. The bad effect is sometimes said to be indirectly voluntary. 3) The good effect must be produced directly by the action, not by the bad effect. Otherwise, the agent would be using a bad means to a good end, which is never allowed. 4) The good effect must be sufficiently desirable to compensate for the allowing of the bad effect." *New Catholic Encyclopedia*, Vol. 4, (New York: McGraw-Hill, 1967), p. 1020. The version used within

- 1) That the **action in itself from its very object** be good or at least indifferent;
- 2) That the **good effect and not the evil effect be intended**;
- 3) That the **good effect be not produced by means of the evil effect**; and
- 4) That there be a **proportionately grave reason for permitting the evil effect**.

If we apply PDE in an algorithmic or "check list" approach, the four conditions could be interpreted to focus on physical causality and to be independently answered rather than interdependently discerned. Such an approach would seem to support offering high doses of sedation, with the intention to address the pain of the patient, even if it is known to hasten the death of the patient. Such action is supported because it seems differentiated through a type of PDE moral reasoning from the prohibition against the intentional killing innocent human life. First, the **action** of giving sedation to address pain is considered good palliative care. Second, the **intention** of offering the sedation to relieve the pain of the patient is good. Third, when using high doses of analgesics to address more severe levels of pain, although the hastening of the death of the patient is foreseen, such hastening of death is an **indirect** outcome of the giving of sedation because the intention is to offer relief from pain. Fourth, the **reason** for the evil effect of hastening, perhaps causing, the death of the patient is **proportionate or commensurate** since the sedation

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the main text above is articulated more simply and is similar if not identical to versions used by: Joseph T. MANGAN, "An Historical Analysis of the Principle of Double Effect." *Theological Studies*, 10 (1949), p. 43.; Germaine GRISEZ, *Abortion* (New York: Corpus Books, 1970), p. 329.; Charles CURRAN, "The Principle of Double Effect: Some Historical and Contemporary Observations." In *Congresso Internazionale Tommaso D'Aquino Nel Suo Settimo Centenario*,

used is in accordance with the standard of practice of what is needed to address the intractable pain experienced by such terminally ill patients.

In 1967<sup>130</sup> Peter Knauer attempted to recover Aquinas's original meaning of PDE and in the process began a debate on the function, interpretation and application of PDE as well as on exceptionless moral norms within the Christian moral heritage. In some ways Knauer was trying to determine what the four conditions of PDE were answers to. What he proposed was that Thomas Aquinas's double effect reasoning and the interpretation of key words such as *act*, *intention*, *effect* and *commensurate reason*, were commonly misinterpreted. Therefore the present use of the PDE was commonly misunderstood and misused.

Knauer made a unique claim that the concept of and the use of the term *intention* means something quite different in ethics and the PDE. In other words, *intention* means more than a psychological interpretation inferring the desires of the actor.<sup>131</sup> If we are to follow Knauer, then how do we interpret or define Aquinas's understanding of intention if it is not defined through psychological parameters? *Intention* is defined as, "the end of an act, the *finis operis* and, eventually more broadly, the *finis operantis*, the ordering of the act to the *finis*

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Roma – Napoli, (1974). *Liagire Morale*. Napoli, Edizioni Domenicane Italiane, (1977), p. 426.

<sup>130</sup> Peter KNAUER, "The Hermeneutic Function of the Principle of Double Effect," in *Natural Law Forum*, 12 (1967). Also in *Moral Norms and Catholic Tradition*, Charles E. CURRAN and Richard A. MCCORMICK, eds. (New York: Paulist Press, 1979), pp.1-39.

<sup>131</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p. 4.

*operis* of a more comprehensive act".<sup>132</sup> Knauer would suggest that one discerns intention by reviewing the three sources of the morality of an act: 1) the ***finis operis*** - the act which is willed and intended by the actor (i.e. The clinician giving the patient analgesics has as *finis operis* the relief of the patient's pain). This is not merely a physical act but becomes a moral act through the intention of the physician. 2) the ***finis operantis***: is not merely identified with the moral intention of the person acting. It is the act towards which the person acting relates his first action (i.e. Helping the patient achieve a good dying process and death). 3) ***Circumstances***: their only function is to determine the act quantitatively (how much sedation, had the patient signed over their bank account, etc). Knauer suggests that you must determine whether there is **correspondence or contradiction** between these three sources of morality. "Neither the external happening nor the psychological intention is morally understandable alone."<sup>133</sup> This understanding of intention is obviously different from psychological intention.

"In ethics an injury can be "intended" even if the person acting would have preferred its absence or was not thinking much about it. Conversely, as in the killing of an aggressor, an effect can be beyond moral intention, although the person acting was psychologically concentrated on it."<sup>134</sup>

Knauer was critiquing current interpretations of the principle of double

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<sup>132</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p. 15.

<sup>133</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p. 5.

<sup>134</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p. 4.

effect that defined the term *intention* as psychological intention<sup>135</sup> and defined the terms *direct* and *indirect effect* in terms of indirect or direct physical causality. These were two key misinterpretations he saw as being currently made. The third key misinterpretation according to Knauer's analysis is that each of the four conditions and the terms *act*, *effect*, *intention* and *commensurate reason* are not to be defined and assessed independently of one another but their very definition and use in assessing moral action are interdependent.

*Commensurate reason* is another term that Knauer approaches in a different manner. I will use his definition of *commensurate reason* as an example of how its definition and assessment is interdependent on the other four conditions. *Commensurate reason* has also been called proportionate reason and its ordinary usage conveys a definition of either having 1) a "really good" or "serious reason in the circumstances"<sup>136</sup> or 2) attempting a quantitative comparison between the good achieved and the evil accepted such that the good outweighs the evil. Such a comparison between qualitatively different

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<sup>135</sup> Richard McCormick states, "Knauer rightly rejects the use of moral evil to describe actions independently of the reasons for which they are done, hence independently of their context and intention. However, in interpreting the direct/indirect distinction in an exclusively moral way (that is, with no relation to psychological intentionality), he underestimates the real differences in the meaning of our conduct that could be generated by psychological intentionality. In Richard MCCORMICK, "Ambiguity in Moral Choice," in Paul RAMSEY AND Richard MCCORMICK, eds., *Doing Evil to Achieve Good: Moral Choice in Conflict Situations* (Chicago: Loyola University Press, 1978), p. 34.

<sup>136</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p.6.

values cannot be achieved and the values are indeed incommensurable.<sup>137</sup>

Again, Knauer interprets *commensurate reason* as a proportionality of the act to its proper objective. The notion of proportion denotes a comparison of values between the value sought and the way of achieving that value in order to identify if there is any contradiction. In other words, there is commensurate reason if in the last analysis there is no contradiction between the act and its objective. "Unintelligent and therefore immoral acts are in the last analysis self-contradictions and consist in unmeasured desire taking the fruit from the tree before it is ripe."<sup>138</sup>

I will adapt a scenario of Knauer's, where he alludes to the issue of palliative sedation practices, for the purposes of demonstrating how his critique of double effect reasoning influences the ethical exploration of palliative sedation practices.<sup>139</sup> In the giving of sedation the physician does not think of anything other than the skillful use of analgesics to control and hopefully remove the pain the terminally ill patient experiences. The control of the removal of this pain is the concrete thing willed by the physician. However, the morality of the act is not determined on this level. Whether the removal of pain through sedation is a health measure or a hastening of the death of the patient cannot be recognized in the concrete actuality that might be photographed. The reason

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<sup>137</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," pp. 11-12.

<sup>138</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p.13.

<sup>139</sup> KNAUER, "The Hermeneutic Function of the Principle of Double Effect," p.22.

why the surgeon removes the pain must be looked at. What value does the act seek to serve? It is done because of the health of the patient, in fact for the integrity of the dying process, to allow the patient to experience a good death according to the implicit values of palliative care. A purely good intention in the psychological sense does not determine the moral goodness of an act. It must be established that this reason is a commensurate one. If, in the given circumstances, the act is the best possible solution of the problem in terms of the horizon given by the whole reality, it may be said that the act is morally good. In a moral sense, what is then intended is not the removal of the pain, but the provision of the conditions of possibility for the meaning of this dying event to be integrated within the narrative life of the patient. The issue which then follows focuses on whether the patient needs to be aware of his or her surroundings for such meaning to be constructed or whether the patient's consciousness is just one element of the totality of event of dying.

The evaluation of an act becomes an evaluation for contradiction between the various elements of an act. Knauer was proposing a shift from an analysis of physical causality to an analysis of the human moral meaning of an event, within the totality of its context. Proposing that moral analysis requires more than an analysis of physicality or physical causality understands that other features of an act may have a greater influence on the moral interpretation of an event than do the features of plain physicality. Knauer essentially proposed that

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the PDE recognizes a more interdependent approach and integrates a broader analysis of the moral meaning of an event or act. Such a proposal would move away from an interpretation of PDE as a checklist of independent questions to be answered through an assessment focusing only on the causality of physical action. To do this, Knauer proposed that Thomas Aquinas understood the word "act" not in terms of physical causality, but as a more complex event – the sum of the total network of relations envisioned by the actors within the structure and context of this event. In other words,

All those things pertain to the object of the act that constitute its substance, viewed not physically but morally; furthermore, all those things constitute the substance of an act which are so essential and necessary to it that if something is lacking or added, the act is different. Thus, the object of theft is someone's property taken against his reasonable will; for if the thing is not someone else's, or is taken with the owner's consent or not against his reasonable opposition, it is not theft.<sup>140</sup>

Upon Knauer's lead, other revisionist theologians<sup>141</sup> have supported this critique of the interpretation of the criteria of PDE although there is diversity among their double effect reasonings. Louis Janssens<sup>142</sup> proposes that the

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<sup>140</sup> Hieronymus NOLDIN, in *De Principiis Theologiae Moralis* (Oeniponte: F. Rauch, 1906), cited in Richard MCCORMICK, "Killing the Patient" in John WILKINS, ed., *Considering Veritatis Splendor*, (Cleveland, Ohio: Pilgrim Press, 1994), p. 16.

<sup>141</sup> Perhaps the first theologian to coin the term revisionist was David Tracy in an attempt to explain the role of contemporary theologians who shares a morality of scientific knowledge with contemporaries, that being – assuming a critical posture and "a fidelity to open-ended inquiry, a loyalty to defended methodological canons, a willingness to follow the evidence wherever it may lead." David TRACY, *Blessed Rage for Order: The New Pluralism in Theology*, (New York: Seabury Press, 1975), p. 7

<sup>142</sup> Louis JANSSENS, "Ontic Evil and Moral Evil," in *Louvain Studies* 4 (1972). Also in CURRAN and MCCORMICK, eds., *Moral Norms and the Catholic Tradition*, p. 43.

moral character of an act is a unity and cannot be determined independently of the intentionality and reasoning activity of a moral subject. Joseph Fuchs<sup>143</sup> also claims that we cannot make moral judgements without knowing all the relevant circumstances and the intentions of the agent. This is an important point of agreement among these revisionist theologians and one to keep in mind since it might seem to be in complete disagreement with philosopher James Rachels who, as will be discussed in this chapter, claims that the intentions of an agent do not have any bearing on physical acts. There seems to be a consensus among these theologians that PDE is a more dynamic as opposed to static principle. This would seem to correspond with the analysis of Bruno Schuller who identified two types of contexts where PDE would need to be applied differently, according to the paradigm with which it was involved.<sup>144</sup> The first context concerns an action which could be seen in advance as morally evil (the example he offers is leading another to sin). Schuller defines the meaning of "direct", in the direct/indirect distinction, as that where the evil effect is not only foreseen, but also intended. The second context concerns an action, such as contraception, where he claims it is questionable whether we are dealing with a moral or premoral evil. The central insight useful for this proposal is not the

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<sup>143</sup> Joseph FUCHS, "The Absoluteness of Moral Terms," in *Gregorianum*, 52 (1971). Also in CURRAN and MCCORMICK, eds., *Moral Norms and Catholic Tradition*, p. 120.

<sup>144</sup> Bruno SCHULLER, "Direct Killing/Indirect Killing," in *Theologie und Philosophie*, 47 (1972). Also in CURRAN and MCCORMICK, eds., *Moral Norms and Catholic Tradition*, p. 140.

specific paradigms identified by Schuller but that within PDE the direct/indirect criteria may function differently according to the paradigm it is addressing. Clearly, one needs to distinguish how double effect reasoning would need to be carefully discerned to adequately integrate the particularity of different conflict situations such as killing, self-defence, war, cooperation, or euthanasia.<sup>145</sup>

Within this debate, there seems to be a perceptible shift between authors attempting to establish the traditional understanding of PDE within Aquinas and the development of different double effect reasonings and applications among authors over time.<sup>146</sup> Types of double effect reasoning were being identified, sometimes distinguished by one of two approaches; either between *positively willing* an effect versus *permitting* an effect, or based on intending an effect versus merely foreseeing an effect.<sup>147</sup> With a diversity of double effect reasonings questions arose as to the conditions that gave a particular interpretation an authoritative status. Given the diversity of double effect reasonings, what would help us to limit the subjectivism and relativism of these interpretations? Was it the physical nature of acts? Was it a continuity with the historicity and tradition of double effect reasoning? The ability of the reasoning

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<sup>145</sup>CURRAN, "The Principle of Double Effect: Some Historical and Contemporary Observations," p. 439.

<sup>146</sup> Analysis of such types of differing interpretations include MARQUIS, "Four Versions of Double Effect," pp. 515-544. KEENAN, "The Function of the Principle of Double Effect," pp. 295-315. KACZOR, "Double Effect Reasoning from Jean Pierre Gury to Peter Knauer," pp. 296-316.

<sup>147</sup> MARQUIS, "Four Versions of Double Effect," p. 541.

to integrate and differentiate greater complexities of moral meaning? One danger, demonstrated through the use of conflicting interpretations of PDE by moral theologians T. Lincoln Bouscaren, John C. Ford and Paul Ramsey, would be to interpret the texts of influential authors such as Thomas Aquinas to support one's own position, rather than fully engaging the moral meaning evident in the particular conflict situation studied.<sup>148</sup> Another such critique was against the use of PDE as a justifying principle used simply to justify or legitimate the morality of a particular course of action.<sup>149</sup> Examples of this concern were found not only within deontologist authors engaged in theological debate on moral norms but influential biomedical authors speaking to healthcare professionals in bioethics textbooks such as Tom L. Beauchamp and James Childress's *Principles of Biomedical Ethics*. Examples pointed to where PDE is used as a justifying principle within *Principles of Biomedical Ethics* include the case where using fetal craniotomy in order to save a woman in labor "is **disqualified** by the principle of double effect"<sup>150</sup>. In the case of administering pain killers, "If the four conditions of the principle of double effect **are met**,...the

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<sup>148</sup> CURRAN, "The Principle of Double Effect: Some Historical and Contemporary Observations," p. 428.

<sup>149</sup> KEENAN, "The Function of the Principle of Double Effect," p. 294.

<sup>150</sup> Tom BEAUCHAMP and James CHILDRESS, *Principles of Biomedical Ethics*, 3<sup>rd</sup> ed. (New York: Oxford University Press, 1989), p. 129.

patient's death ***does not qualify*** as homicide and ***is justified***.<sup>151</sup> Such instances demonstrate the assumption that the principle of double effect is a justifying principle or legitimates moral activity. Is such authority properly vested in the principle? Or does the principle simply demonstrate from its origins in case comparison or casuistry that, "one case is congruent with a paradigm case and that the rightness of the solution is already internal to the case"<sup>152</sup>

If the historicity of double effect reasonings and continuity of moral development are criteria of adequacy for PDE, then one has to ask how did we and how will we integrate that history into our present and future in order to make it practically our own? Such diversity in interpretation and debate which continues today led to questions of whether Knauer's or others formulation of PDE was a change in character from Aquinas's initial formulations. While changes or developments are certainly evident, the revisions are not completely divorced from the tradition of double effect reasoning but rather demonstrate a continuity of development in the tradition of PDE reasoning.<sup>153</sup> Why the importance of continuity and historical tradition? First, it is important to recognize that the human person is a social being, shaped but not determined by, the social structures of their historical culture. Given that social character, a

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<sup>151</sup> *Ibid*, p. 130.

<sup>152</sup> KEENAN, "The Function of the Principle of Double Effect," p. 295.

<sup>153</sup> KACZOR, "Double Effect Reasoning from Jean Pierre Gury to Peter Knauer," p. 314-15.

theory of development in double effect reasonings attempts to respond to both taking our social/historical context seriously and, the concern that the reasoning is not simply a projection of the subjective needs and desires of that historical time. It has been proposed that the development of double effect reasonings which occurred was a transition from act/end proportion utilized by Aquinas to effect/effect proportion utilized by both Gury and the Scholastics who followed him, as well as Knauer and the proportionalists who follow him.<sup>154</sup> Of course, the question remains unanswered today as to whose double effect reasoning is to be preferred. The first point of common ground might be those double effect reasonings that take historicity and continuity of development seriously. The next point of common ground might be those reasonings that best integrate and differentiate the complex moral meaning occurring within the particular context of action being explored. For the purposes of this inquiry, it is enough to recognize: a) a development within double-effect reasoning, b) the shift to integrate the constitutive function of human meaning in the object of an act, c) the necessity to face the challenge of identifying criteria suitable for application in spheres of double effect reasoning such as palliative sedation practices.

With these shifts to integrate historicity and the constitutive function of human meaning within double effect reasonings, concerns became evident in

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<sup>154</sup> KACZOR, "Double Effect Reasoning from Jean Pierre Gury to Peter Knauer," p. 313. Kaczor also cites as the original source for this analysis Brian V. JOHNSTONE, "The Meaning of Proportionate Reason in Contemporary Theology," in *Thomist*, 49 (1985), pp. 244-245.

the deliberations. What is the ability of members of the general public to responsibly discern moral action in increasingly diverse and complex spheres of human meaning? Is there still a role for any public moral authority? What objects should be characterized as morally wrong and on what criteria? What is to count as pertaining to the object? These are questions that pertain to such issues as moral certainty, moral order and concern for moral vulnerability of the human community in the enterprise of cooperative living. Does such an interpretation of PDE allow too much individual autonomy in determining when a proportionate reason exists within PDE for choosing to engage in any particular action?<sup>155</sup> Deontologists such as Germain Grisez, William E. May, and Paul Ramsey offer an understanding of PDE as a justifying moral norm which prohibits our ever acting in a manner that is directly destructive of "basic goods", such as respect for human life.<sup>156</sup> They maintain that there are some human acts that are intrinsically or inherently evil in a moral sense. Revisionists agree but only in a manner where moral evil is not used to describe acts independent of their particular context of historicity and social meaning. The concern of the deontologists is how this historically conscious double effect reasoning offer

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<sup>155</sup> William E. MAY, "The Moral Meaning of Human Acts," in *Homiletic and Pastoral Review*, (79) October 1978, p. 13.

<sup>156</sup> See, Paul RAMSEY, "Incommensurability and Indeterminacy in Moral Choice," in RAMSEY and MCCORMICK, eds. *Doing Evil to Achieve Good*, p. 88. Germain GRISEZ, *Abortion*. (New York: Corpus Books, 1970), p. 321. Bernard HOOSE, *Proportionalism: The American Debate and Its European Roots* (Washington, D.C.: Georgetown University Press, 1987), p. 139.

objective criteria for decision making and a place for any type of moral authority, which is foundational if community living is to be possible. Theologians such as Richard A. McCormick claim there are kinds of actions for which the community can claim there is no proportionate reason<sup>157</sup> but he does not describe how such community claims or norms may be objectively justified. However, McCormick does challenge Ramsey's and Grisez's proposal of never turning against basic human goods. McCormick claims that if these basic goods cannot be compared or ever turned against, then when Ramsey or Grisez argue that it is morally permissible to tolerate an indirect violation of a basic good, is this not an appeal to a form of "lesser evil", and hence some form of proportionate reason?<sup>158</sup>

Ramsey seems to deny proportionality and use incommensurability because he feels commensurability is always used in a quantitative sense; that the revisionist analysis is a utilitarian analysis. McCormick maintains that he is not using proportionate reason in that sense.<sup>159</sup> Ramsey fears that to appeal to the principle of lesser evil is to begin our way down a "slippery slope" of relativism and subjectivism where unconcern for human life and acts against commonly held convictions and goods could be validated. The control element which McCormick points to is the essential link and relevant impact between the

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<sup>157</sup> Richard MCCORMICK, "Notes on Moral Theology," in *Theological Studies*, 39 (1) (1978), p. 85.

<sup>158</sup> Richard MCCORMICK, "A Commentary on the Commentaries," in RAMSEY and MCCORMICK, eds., *Doing Evil To Achieve Good*, pp. 213-214.

<sup>159</sup> MCCORMICK, "A Commentary on the Commentaries," p. 202.

means and the ends found in proportionate reason and attention to circumstances. As opposed to non-systematic or random linkage, one action or meaning must be a condition of possibility for the other action or meaning; it has to be systematic. McCormick indicates that proportionate reason has the tools to deal precisely with this fear of "slippery slope".<sup>160</sup> While the "control element" of systematic linkage has been pointed to, deontologists have rightly critiqued that revisionists such as McCormick have not adequately specified the criteria for appropriate data selection, classification, and generalization in that realm.<sup>161</sup> If such criteria cannot be attained then we have excluded any possible role for public moral authorities and norms; an unacceptable situation. Such a fundamental concern provides a key point of tension and an avenue for insight into this exploration of palliative sedation practices.

Revisionist theologians point to a need to recognize both the constitutive function of meaning in human relations and the redefinition of the proper object of ethics in terms of human meaning. This type of revision in ethics is occurring not only in the arena of healthcare ethics but also contemporary authors in sexual ethics attempt to offer renewed ethical theories in line with the contemporary human experience of sexuality. The difficulty of such a shift has been commented upon by revisionist theologians. Theological ethicist Andre

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<sup>160</sup> MCCORMICK, "A Commentary on the Commentaries," p. 239.

<sup>161</sup> Kenneth R. MELCHIN, "Revisionists, Deontologists, and the Structure of Moral Understanding," in *Theological Studies*, 51 (1990), pp. 397-398.

Guindon questioned the depth of revision as he noted that revisionist theologians had focused their exploration on the same list of acts as earlier moral manuals: masturbation, homosexual acts, premarital, extramarital or postmarital acts.<sup>162</sup> In other words, while contemporary revisionist theologians offer criticism to an act-centred approach within sexual ethics, they fall short in pursuing the broader moral meaning found in their proposed person-centred approaches.<sup>163</sup> Could an exploration of revisionist approaches within bioethics generally, or palliative care sedation practices specifically, fall prey to the same trap of making only a partial shift from an act-centered approach of moral reasoning?

This theological debate offers unique insight into the different types of double effect reasonings employed and the attempts to understand our participation with, and the human meaning of, our complex moral acts. The key points of contention or consensus are: 1) Understanding PDE as having a hermeneutic function and the redefinition of the proper object of ethics in terms of human meaning. 2) The challenge of adequately specifying the criteria for appropriate data selection, classification, and generalization in the realm of human meaning. These two key challenges will need to be incorporated in any

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<sup>162</sup> André GUINDON, "Sexual Acts or Sexual Lifestyles?: A Methodological Problem in Sexual Ethics," in *Eglise et Théologie*, 18 (1987), p. 315.

<sup>163</sup> GUINDON, "Sexual Acts or Sexual Lifestyles?: A Methodological Problem in Sexual Ethics," p. 316.

attempt to identify significant ethical differences between types of ambiguous clinical cases involving palliative sedation practices and the distinction between killing and letting die.

### **B) Holding Moral Weight: The Killing/Letting Die Distinction**

A moment of consensus disruption occurred in 1975<sup>164</sup> when philosopher James Rachels<sup>165</sup> challenged the "active versus passive" euthanasia distinction, which he claimed was at the basis of a statement adopted by the House of Delegates of the American Medical Association (AMA) on December 4, 1973. The AMA statement claimed "it is permissible, at least in some cases, to withhold treatment and allow a patient to die, but it is never permissible to take any direct action designed to kill the patient." Rachels claimed that, all other circumstances being equal, both the actions of killing and letting die may involve the deliberate and intentional termination of a life. In effect, he was charging there was no significant moral difference between killing and letting die in the AMA statement. Rachels leaves open the possibility that there may be reasons for preferring one over the other but claims the reason does not lie in the

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<sup>164</sup> James RACHELS claims he did not invent his argument but that it had been previously advanced by both: 1) Michael TOOLEY, "Abortion and Infanticide," in *Philosophy and Public Affairs*, 2 (1972), pp. 59-60; also see Michael TOOLEY'S "An Irrelevant Consideration: Killing Versus Letting Die," in Bonnie STEINBOCK, Alastair NORCROSS, eds., *Killing and Letting Die* (New York: Fordham University Press, 1995), pp. 56-62. 2) Judith Jarvis THOMSON, "Rights and Deaths," in *Philosophy and Public Affairs*, 2 (1973), pp. 146-159. Thomson later changed her mind and rejected her earlier position in, Judith Jarvis THOMSON, "Killing, Letting Die, and the Trolley Problem," in *The Monist*, 59 (1976), p. 204.

<sup>165</sup> James RACHELS, "Active and Passive Euthanasia," in *New England Journal of Medicine*, 292 (2) (January 9, 1975), pp. 78-80.

**intrinsic difference between active, direct physical actions (killing) and passive, indirect omissions (letting die). Through this challenge Rachels felt he placed the "burden of proof" on those who claim that there is a morally significant difference between killing and letting die.**

**Beneath Rachels position were some foundational concerns or beliefs. First, Rachels felt there were times when the protection of life served no point and the western tradition placed an inordinately high value on human life which it had difficulty acknowledging.<sup>166</sup> Ultimately he felt the protection of life and the principle of the sanctity of life should be interpreted to protect lives in the biographical sense and not merely biological sense.<sup>167</sup> Second, he believed that having life, a biography, is linked with the ability to contemplate futures and have memories. Rachels linked the two criteria of consciousness and cognitive ability with humanness, with these two criteria therefore serving as important conditions for a worthwhile life. Proposing consciousness and cognitive ability as criteria for a worthwhile life would be strongly critiqued as arising from a "hypercognitive culture" and, neglecting the emotional, relational, aesthetic and spiritual aspects of humanness and well being that are open to persons in an advanced stage of Alzheimers disease.<sup>168</sup> While Rachel's link of humanness**

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<sup>166</sup> James RACHELS, *The End of Life: Euthanasia and Morality*, (New York: Oxford University Press, 1986), p. 24.

<sup>167</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 26.

<sup>168</sup> Stephen G. POST, "The Fear of Forgetfulness: A Grassroots Approach to an Ethics of Alzheimer's Disease," in *Journal of Clinical Ethics*, 9 (1) (Spring, 1998), p. 72. See also,

with cognitive ability may be weak, his interest seemed to have been to differentiate between the types of responsibilities and obligations we should have towards types of human life. A third concern was, in making distinctions between active, direct physical actions (killing) and passive, indirect omissions (letting die), Rachels claimed the use of the intention of an actor was not helpful. Intention is claimed not to be relevant to deciding whether an act of omission is right or wrong, but is only relevant for assessing the character of the person who does it, which is considered another thing entirely.<sup>169</sup> Fourth, Rachels mistrusts intuitions as a form of moral knowing, due to their ability to be produced by prejudice, selfishness or cultural conditioning, he admits that no moral view can escape reliance on intuition at some point. His orientation is that one must "avoid any reliance on intuition until it becomes absolutely necessary".<sup>170</sup> Fifth, and fundamentally, Rachels believed, letting die is much worse than we normally admit, and that letting die is much closer to killing than is normally assumed.<sup>171</sup> In other words, "we overestimate how bad it is to kill

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Stephen G. POST, *The Moral Challenge of Alzheimer Disease* (Baltimore, Md.: John Hopkins University Press, 1995). Tom KITWOOD, "Toward a Theory of Dementia Care: Ethics and Interaction," in *Journal of Clinical Ethics*, 9 (1) (Spring, 1998), p. 32; Tom KITWOOD, *Dementia Reconsidered: The Person Comes First* (Philadelphia, Penn.: Open University Press, 1997). Steven R. SABAT, "Voices of Alzheimer's Disease Sufferers: A Call for Treatment Based on Personhood," in *Journal of Clinical Ethics*, 9 (1) (Spring 1998), p. 47.

<sup>169</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 94.

<sup>170</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 148.

<sup>171</sup> James RACHELS, "Killing and Starving to Death," in *Philosophy*, 54 (1979), p. 163.

and we underestimate how bad it is to let people die."<sup>172</sup> This inquiry engages these underlying concerns of Rachels because they inform us of a deeper level of reasoning at play not immediately accessible from the positions Rachels takes through his argument.

Essentially, Rachels focuses his argument on what he names as the *Equivalence Thesis* which proposes there is no intrinsic moral difference between killing and letting die, between an action and an omission. To demonstrate his point he offers two imaginary cases for comparison. These two cases are created by eliminating the unique characteristics or circumstances between them except for the bare difference between active, direct physical actions (killing) and passive, indirect omissions (letting die). With this single variable isolated he claims the difference between the two cases is not morally significant.<sup>173</sup>

Smith stands to gain a large inheritance if anything should happen to his six-year-old cousin. One evening while the child is taking his bath, Smith sneaks into the bathroom and drowns the child, and then arranges things so that it will look like an accident. No one is the wiser, and Smith gets his inheritance.

Jones also stand to gain if anything should happen to his six-year-old cousin. Like Smith, Jones sneaks in planning to drown the child in his bath. However, just as he enters the bathroom Jones sees the child slip, hit his head, and fall face-down in the water. Jones is delighted; he stands by, ready to push the child's head back under if necessary, but it is not necessary. With only a little thrashing about, the child drowns all by himself, "accidentally", as Jones watches and does nothing. No one is the wiser, and Jones gets his inheritance.

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<sup>172</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 134.

Rachels claims that, "if the difference between killing and letting die were itself a morally important matter, then we should say that Jones's behavior was less reprehensible than Smith's."<sup>174</sup> However, both cases seem as reprehensible which leads Rachels to claim that there is no morally relevant difference between active, direct physical actions (killing) and passive, indirect omissions (letting die). He later does qualify his argument by stating that in some cases it may be permissible to let die and not kill, or to kill but not let die, but it is *some other feature* of the case that makes the difference.<sup>175</sup> In essence Rachels is arguing against a moral assessment claiming that a moral distinction could be found within the physical causality of acts.

It is perhaps Rachels's definition or use of the terms "killing" and "letting die" where confusion may be present. Rachels seems to define and limit the terms "killing" or "letting die" to the physical actions of a moral agent. It is clear that others, such as the theological revisionists we explored, define "the act" of killing or letting die as a broader event which includes the intention of the agent and other contextual features of the case as internal to their definition of "the act". While Rachels does not include the intentions of the actor in his definition of the act of killing/action or letting die/omission, he does not seem to preclude

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<sup>173</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 112.

<sup>174</sup> James RACHELS, "Euthanasia, Killing and Letting Die," in John LADD, ed., *Ethical Issues Relating to Life and Death*, (New York: Oxford University Press, 1979), p. 154.

<sup>175</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 127.

intentions of the actor from being morally significant in interpreting the moral meaning of the wider event.

Let us turn to another case comparison more related to the healthcare context; the dilemmas of Dr.'s Black and White:<sup>176</sup>

A massively necrotic bowel condition in a neonate is out of control. Dr. White realizes that further treatment offers little hope of reversing the dying process and will only increase the suffering; so, he does not submit the infant to the further treatment – even though he knows that this decision will hasten death. However, Dr. White does not seek, choose, or plan that death, so it is not part of his intention that the baby dies.

Dr Black is faced with a similar case. A massively necrotic bowel condition in a neonate is out of control. He realizes that further treatment offers little hope of saving the baby and will only increase its suffering. He decides that it is better for the baby to die a bit sooner than to go on suffering pointlessly; so, with the intention of letting the baby die, he ceases treatment.

In Rachels view each doctor did *the very same thing*. Each doctor ceased treatment knowing the patient would die sooner, and each did so due to the realization that continued treatment would be pointless.<sup>177</sup> He claims that if a doctor allows a patient to die for humane reasons, the doctor is in the same moral position as if s/he had given the patient a lethal injection for humane reasons.<sup>178</sup> He states that it may be permissible in some cases to let die (omission) but not to kill (action), and vice versa. However, Rachels emphasizes

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<sup>176</sup> James RACHELS, "Impertinent Distinctions and a Defense of Active Euthanasia," in STEINBOCK, *Killing and Letting Die*, p. 142.

<sup>177</sup> RACHELS, in STEINBOCK, *Killing and Letting Die*, p. 142.

<sup>178</sup> RACHELS, *The End of Life: Euthanasia and Morality*, p. 155.

that in such cases, it is some feature other than the difference between a physical action and an omission that will make that moral difference.<sup>179</sup>

Rachels limits the meaning of the terms *killing* and *letting die* to physical actions of doing and allowing, positive actions and omissions. They are no longer terms describing, as they do for others, broader events of human moral meaning making. Two questions arise from his approach: First, do the terms *killing* and *letting die* describe for Rachels something different than they do for the authors of the AMA statement<sup>180</sup> – physical action or broader events of contextual meaning? Second, is Rachels approach of "bare difference" case comparison the best approach for eliciting significant moral differences between killing and letting die in the healthcare context?

In the struggle to understand our participation in the deaths of patients, it is clear our inquiry is leading us away from relying solely on the criteria of physical causality. Our assumptions are becoming clearer. Rachels takes issue<sup>181</sup> with those who locate the moral difference between killing and letting

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<sup>179</sup> James RACHELS, "Reasoning About Killing and Letting Die," in *The Southern Journal of Philosophy*, 19 (1981), pp. 471-472.

<sup>180</sup> Bonnie Steinbock claims that the AMA statement does not imply support of the active/passive euthanasia distinction. She claims that both Rachels and Tooley understand the AMA position to prohibit active euthanasia, while allowing, under certain conditions, passive euthanasia. She claims the mistake of Rachels and Tooley is "in identifying the cessation of life-prolonging treatment with passive euthanasia, or intentionally letting die." Bonnie STEINBOCK, "The Intentional Termination of Life" in Bonnie STEINBOCK, Alastair NORCROSS, eds., *Killing and Letting Die* (New York: Fordham University Press, 1995), p. 121. Thomas SULLIVAN, "Active and Passive Euthanasia: An Impertinent Distinction?", in Bonnie STEINBOCK, Alastair NORCROSS, eds., *Killing and Letting Die* p. 135.

<sup>181</sup> RACHELS, in LADD, *Ethical Issues Relating to Life and Death*, p. 152.

die in the causality of the agent's action;<sup>182</sup> that killing is doing something (a positive action) to bring about the death of another, whereas letting die is doing nothing or allowing (an omission). Omissions, therefore, do not seem subject to the same kind of moral standards used to judge and critically evaluate positive actions. It is retorted that inaction cannot be equated to freedom from moral blame just as action is not equated with culpability.<sup>183</sup> Consider the physician and patient who decide to no longer continue with kidney dialysis treatment will not longer help the patient medically given the progression of their disease and the complications related to that progression. What shapes such as decision as appropriate or inappropriate?

What about locating the moral difference between killing and letting die in the intention of the agent? In that circumstance, Rachels claims that such a proposal has been undermined since both of his case comparisons intend the death of the patient.<sup>184</sup> It is his undifferentiated use of the term *intention* that others take issue with. Both Drs Black and White participated in the death of the patient but, was their participation morally different? Death may have been foreseen or anticipated on the part of Dr. White but, was it intended as was the case with Dr. Black? In these circumstances, the moral difference is located in

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<sup>182</sup> Paul RAMSEY, *Patient as Person* (New Haven: Yale University Press, 1970), p.151.

<sup>183</sup> Bruce R. REICHENBACH, "Euthanasia and the Active-Passive Distinction," in *Bioethics*, 1 (1) (1987), p. 56.

<sup>184</sup> Also see QUILL, "The Ambiguity of Clinical Intentions," pp. 1039-1040.

the deliberate resolve of the agent between the relation of the act to the certainty of the outcome.<sup>185</sup> This difference is considered by some as morally significant because letting die is considered not as deliberate and forceful an intervention.<sup>186</sup> Letting die is considered safer because it leaves open the possibility for alternative outcomes that may be significantly beneficial. However, why should the less deliberate action be considered safer and therefore morally better?<sup>187</sup> Rachels adds to this critique by claiming the intentions of the agent never affect the moral status of actions, but rather only the character of agents. Such a claim requires more substantial support because if the motivating intention is withdrawn from an act, the residue seems not to be the same act.<sup>188</sup>

Often our ordinary usage of the distinction between the terms killing and letting die has us link responsibility for a result with the term "making" but not with the term "allowing". The example of throwing a ball at a window reveals some of these common sense (ie false) assumptions.<sup>189</sup> Imagine two actors, one throwing the ball, one with a mitt able to catch the ball, and the last possible point that the ball could be caught without the window being broken, is identified

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<sup>185</sup> Douglas WALTON, "Splitting the Difference: Killing and Letting Die," in *Dialogue*, 20 (1981), p. 72.

<sup>186</sup> WALTON, "Splitting the Difference: Killing and Letting Die," p. 75.

<sup>187</sup> REICHENBACH, "Euthanasia and the Active-Passive Distinction," p. 61.

<sup>188</sup> SULLIVAN in STEINBOCK, *Killing and Letting Die* p. 156.

<sup>189</sup> Alastair NORCROSS, "Introduction to the Second Edition" in STEINBOCK, *Killing and Letting Die*, p. 11-12.

as T1. If the ball is thrown and the other actor could catch the ball at T1 but decides not to, a question arises as to who is responsible for the broken window? Although the person throwing the ball causes the window break by throwing the ball, the other person just as clearly allowed the window to break. The implicit claim is that an agent causes an upshot to come about if his behavior is positively relevant to it. It is a valid insight that clearly underscores that the moral significance of contextual features such as circumstances, the intention, or the social inter-relations of that particular context. Have we been led astray by too much attention to the ordinary usage of the term "allow" where every case of immobility or passivity leading to a harmful upshot will be a case of "allowing" and misleadingly understood as always morally permissible? Have our intuitions become conditioned through common language usage to assess even positive cases of immobility as cases of *allowing*?

Could the psychological intention of the actor be too fragile to bear the moral weight required to affect the permissibility of actions?<sup>190</sup> Although intention shapes a physical act, does the difference in intention infer a relevant difference in moral status or only a difference in the narrative identity of the act? What is unclear in this question is the nature of fragility and the expectation placed upon intention. Such a question would seem to be implicitly concerned

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<sup>190</sup> Alastair NORCROSS. "Introduction to the Second Edition," in STEINBOCK, *Killing and Letting Die*, p. 7.

with the tension between the subjectivity of psychological intention and the evaluative requirements for universality, justice and community living.

Another claim arising in the philosophical debate is the distinction between intention and foresight does not play the moral role it is given in the moral difference view because the distinction fails to take into account other more important causal considerations.<sup>191</sup> By pointing to a distinction between permissibility and responsibility, this claim challenges the suggestion that one is not responsible for foreseen but unwanted consequences. Three senses of responsibility are distinguished: to be guilty, to be the cause, to be answerable. In the example of a fetal craniotomy case

...suppose that the doctor opposes abortion, "permits " the mother and fetus to die, yet has powerful evidence that the delivered child will die shortly after birth in any event. This piece of information about the fetus seems obviously morally relevant to the decision whether to operate.<sup>192</sup>

Essentially the key question arises, "For what is the doctor answerable?".<sup>193</sup> Does not a theory of causation need to cast a "broader net" to understand the other partial causes leading to a patient's death. The intention/foresight distinction fails to pick out the important causal concerns

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<sup>191</sup> Raymond G. FREY, "Intention, Foresight, and Killing," in Tom L. BEAUCHAMP ed., *Intending Death: The Ethics of Assisted Suicide and Euthanasia* (New Jersey: Prentice Hall, 1996), p. 67.

<sup>192</sup> FREY, "Intention, Foresight, and Killing," in BEAUCHAMP, *Intending Death: The Ethics of Assisted Suicide and Euthanasia*, p. 72.

<sup>193</sup> FREY, in BEAUCHAMP, *Intending Death: The Ethics of Assisted Suicide and Euthanasia*, p. 72.

which lie outside the distinction because of its narrow causal focus. This produces the counterintuitive result of thinking that failures to act or passivity are, because they are noninterventions, causally inert.

In the continuing exploration of morally relevant distinctions, one critique of the Equivalence Thesis proposes that those deeds making a difference in the *course of nature* are interventions and, bear greater moral weight than abstentions which leave the course of nature unchanged.<sup>194</sup> However, in a technological, interventionist environment such as modern healthcare, the "course of nature" becomes hard to define. The intuition pointed to is that the events of illness emerge from factors and determinants not in the control and often not within the awareness of clinicians or patients. This does offer a broader understanding of acts, defining them as, a deed done in a particular situation or set of circumstances and which consist partly of the agent's own bodily and mental states.<sup>195</sup> The discernment of moral meaning therefore does not focus only on the physical action alone but other determinants, including intentions, which are also understood to shape acts.

Bennett contends that the making/allowing distinction does not equip healthcare professionals to deal with the odd cases where only one of those

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<sup>194</sup> BENNETT, in STEINBOCK, *Killing and Letting Die*, p. 231.

<sup>195</sup> Alan DONAGAN, *The Theory of Morality* (Chicago: The University of Chicago Press, 1977), p. 42.

thoughts is available.<sup>196</sup> However he struggles to see how either can carry "moral weight". Bennett's conclusion echos Rachels challenge that the burden of proof that there is a morally significant difference between killing and letting die remains with those who make that claim. This begs the question of what kind of moral weight are Bennett and others looking for? Their search seems to be for a moral norm applicable to all cases or permutations.

Can a morally relevant distinction be drawn between originating or sustaining a fatal sequence on the one hand, and allowing such a sequence to run its course on the other, the latter being more permissible than the former? Philippa Foot proposes that the moral difference is derived from how types of agency receive their moral significance through their connection with different types of "right".<sup>197</sup> Originating or sustaining a harmful sequence is claimed by Foot to usually involve the violation of a right to noninterference, whereas allowing such a sequence to run its course is considered a lesser violation of a right to goods and services. Therefore the former type of agency of interference is considered to be less permissible than the latter.<sup>198</sup> This type of distinction does not seem to address the distinction of bare difference as much as redirect

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<sup>196</sup> BENNETT in STEINBOCK, *Killing and Letting Die*, pp. 249-50.

<sup>197</sup> Philippa FOOT, "Killing and Letting Die," in STEINBOCK, *Killing and Letting Die*, pp. 284-5.

<sup>198</sup> Philippa FOOT, "Killing and Letting Die," in STEINBOCK, *Killing and Letting Die*, p. 284.

the debate to an explanation of positive and negative rights. Warren Quinn<sup>199</sup> criticizes both Bennett's *immobility objection* and Foot's *already existing fatal sequences* accounts of the doing/allowing distinction. In addressing the distinction between making/allowing Quinn claims the significant element to be that "an agent's most direct contribution to a harmful upshot of his agency is the contribution that most directly explains the harm".<sup>200</sup>

Both Quinn's notion of more and less direction explanation and Bennett's proposal stressing the weakest fact necessary to explain a harmful upshot are attempts to identify the missing distinction which our intuitions whisper is there. One might wonder if our focus is too narrow – pursuing and limiting the search to one distinction, one element within the dilemma as opposed to say the interrelation of insight among multiple elements assessed within an event that shapes the moral meaning of an event. We must question whether the search for the "bare difference" is a futile search given its narrow approach. Such intuition seems voiced by Bennett who proposes that our intuitions are shaped by so many factors that there is not a single clear distinction to explain them all.<sup>201</sup> If Bennett is not attempting to give an account of a distinction between making and allowing that fits all our intuitions, is he perhaps betting that

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<sup>199</sup> Warren S. QUINN, "Actions, Intentions, and Consequences: The Doctrine of Doing and Allowing," in STEINBOCK, *Killing and Letting Die* (New York: Fordham University Press, 1994) pp. 355-382.

<sup>200</sup> QUINN, in STEINBOCK, *Killing and Letting Die*, p. 366.

<sup>201</sup> BENNETT, in STEINBOCK, *Killing and Letting Die*, p. 241.

**distinctions will operate differently depending on the type of dilemma, paradigm or sphere of human meaning we are engaged with? Is this perhaps a realization that since our intuitions are shaped by so many factors that our approach needs to integrate this network of relations in its complexity?**

**Such a proposal would seem to be in concert with the work of Jeff McMahan.<sup>202</sup> He claims that the concepts of killing and letting die are not evaluatively neutral, that their use while reflecting certain moral beliefs is nonetheless governed primarily by empirical criteria, and that the focal task is to uncover the empirical criteria.<sup>203</sup> Upon focusing on problem cases involving the removal or withdrawal of life-supporting aid or protection, McMahan argues that, "whether or not life-supporting aid or protection is self-sustaining is only one of a number of factors that may determine whether an instance of withdrawing aid counts as killing or letting die"<sup>204</sup>. Other factors might include: 1) whether the person who withdraws the aid is the person who initially provided it, 2) whether the aid is operative or inoperative when it is withdrawn, 3) whether the aid is self-sustaining or requires further intervention from the agent. McMahan concludes that,**

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<sup>202</sup> Jeff MCMAHAN, "Killing, Letting Die, and Withdrawing Aid," in STEINBOCK, *Killing and Letting Die*, pp.383-420.

<sup>203</sup> Jeff MCMAHAN, "Killing, Letting Die, and Withdrawing Aid," in STEINBOCK, *Killing and Letting Die*, p. 383.

<sup>204</sup> Jeff MCMAHAN, "Killing, Letting Die, and Withdrawing Aid," in STEINBOCK, *Killing and Letting Die*, p. 401.

If I am right that all of these factors have to be taken into account, then the full analysis of the distinction between killing and letting die (which I will not endeavor to give here) will be complicated, messy, and seemingly ad hoc. Moreover, since there may be vagueness or uncertainty about certain relevant factors, and since the various factors may present in different combinations and to different degrees in different cases, we should expect that there will be numerous cases that we are uncertain how to classify or that we disagree about how to classify.<sup>205</sup>

### **C) Conclusion: Conflicting Answers to More Fundamental Questions**

Within our exploration of these two debates, patterns of common ground and divergence have emerged which will be carried forward and explored further. These patterns help to shape our own directions that would seem to offer promise. They are as follows: 1) Usage of Terms: Our ordinary usage of terms such as "allowing", "making" and "acts" has been misleading, not only because as in the case of "allowing" it has been inappropriately linked to passivity and inaction but, within the debates, authors have often used the terms differently without recognizing these various interpretations. The terms "killing" and "letting die" have been intended to express morally neutral actions while others have used them in a morally evaluative manner (i.e. the term *killing* being automatically equated with the term *murder*). The meaning of terms are often not explicitly stated when used and could explain some preventable divergence and conflict. Linking the terms "killing" and "letting die" with the terms "active" and "passive" euthanasia has often been misleading. Such a linkage seems to join moral evaluation with the activeness or passiveness of

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physical action and could therefore portray inaction as freeing one from moral culpability or blame. What seems to be missing is an understanding of how the moral culture of healthcare, more specifically the culture of palliative care, shapes the human meaning of such terms as *killing* and *letting die*. 2) Moral object of an Act: Differing usages of the terms also signifies differing approaches in ethical assessment. The term "act" is understood both as narrowly as a physical act and also as an event (ie. The inclusion of interrelations of actions, intentions and actors within a sphere of human meaning which together shape meaning). The former approach was an attempt to discover the relevance of a distinction by creating situations where the meaning of the terms conveyed seem to no longer be true. The bare difference approach in its attempt to pare down differing circumstances to a "Bare Difference" excluded as unimportant those intentions and circumstances that other theologians and philosophers believed were relevant in understanding the meaning of *killing* and *letting die* within their moral contexts.

The different theological and philosophical mindsets and approaches to double effect reasoning are also responses to more implicit and fundamental questions. What issues are at the root of such differences? Do they concern worldview, orientations of moral psychology, abilities of individuals to integrate and adapt to change, differing tolerance for living with risk? Each of these

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<sup>205</sup> Jeff MCMAHAN, "Killing, Letting Die, and Withdrawing Aid," in STEINBOCK, *Killing and Letting Die*, p. 402-3.

elements are probably implicated within this experience of diversity.

However, the polarizing conflict in these approaches might also be linked to how theologians, philosophers and clinicians approach and integrate the past and the future. There are mindsets that are more tradition oriented and mindsets that are more future oriented. These differences of approach might be set in motion or explained either through an accident of nature (biological, neural, psychic) or of history (parental influence, education, reading, friendships).<sup>206</sup> It is proposed that one of the great cultural changes in our time is a turning from a domination of the past to a freedom for the future.<sup>207</sup> For the traditionalists the question remains, is the tradition of the past enough to create a home of meaning in our present. To those oriented toward the future and creative innovation the questions could include:

What attitude, I would ask them, would you have us take to the past? Given the historicity of our race, given the historicity of all our expression of faith, be they scripture, creed or conciliar definition, what are we to do with these expressions now? Do they come forward in any way into our time? Do they relate to us? Are they part of our faith in any way? If not, how justify the repudiation? But if they are, other questions press upon us. How do we deal with them? How do we bring the past forward and make it our own?<sup>208</sup>

Essentially we are speaking of how ethics attempts not to be duped by

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<sup>206</sup> Fred CROWE, "The Janus Problematic: Tradition Versus Innovation," in Michael VERTIN, ed., *Appropriating the Lonergan Idea* (Washington: Catholic University of America Press, 1989) p. 287.

<sup>207</sup> CROWE, "The Janus Problematic: Tradition Versus Innovation," in VERTIN, *Approaching the Lonergan Idea*, p. 280.

<sup>208</sup> CROWE, "The Janus Problematic: Tradition Versus Innovation," in VERTIN, *Approaching the Lonergan Idea*, pp. 294-295.

inadequate moralities. Such inquiry seeks to understand how moral teachings, tools and evaluations develop to integrate changes in human social living in various spheres of human living. How would one conceive of and articulate the development of moral doctrine or ethical parameters? Key historical examples include killing in self-defence or ectopic pregnancies. Killing in self-defence was differentiated from the intentional killing of innocent human life. Ectopic pregnancies were argued as differentiated from intentional abortions. Other examples of moral differentiation and development within the Roman Catholic moral tradition have also occurred in areas such as usury, marriage, slavery and religious freedom. Within such an analysis of moral development, the goal is to identify and understand what the conditions of change were, to observe the extent of the change that was possible and to construct a provisional theory as to the limits of change.<sup>209</sup> For example, as noted by John Noonan,

Even at the height of the prohibition of usury not every form of credit transaction was classified as a loan from which no profit might be sought. The idea of legitimate interest was also not absent. Formally it can be argued that the old usury rule, narrowly construed, still stands: namely, that no profit on a loan may be taken without a just title to that profit. But in terms *of emphasis, of perspective, of practice*, the old usury rule has disappeared: the just title to profit is assumed to exist.<sup>210</sup>

This present inquiry focuses on the clinician's experience of limit when using PDE as a moral reasoning within tragic palliative care encounters. When a

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<sup>209</sup> John T. NOONAN, "Development in Moral Doctrine," in *Theological Studies*, 54 (1993), p. 669.

<sup>210</sup> NOONAN, "Development in Moral Doctrine," p. 663.

**type of moral reasoning or morality confronts limits in concrete situations, it seeks a type of practical wisdom. It is a practical wisdom having no recourse other than to, "return to the initial intuition of ethics, in the framework of moral judgement in situation and the conviction that dwells in it".<sup>211</sup>**

**The health care discipline of palliative care is a sphere of human meaning that can be argued as produced and reproduced, a sphere of social relations that is a skilled performance on the part of its members and not merely a mechanical series of processes.<sup>212</sup> Yet this skilled performance also has boundaries of human agency. This performance occurs through historically located actors and not under conditions of their own choosing. Such a duality of structure both constrains and enables human agency where the processes of production and reproduction involve the interplay of meanings, norms and power.<sup>213</sup>**

**It is the explication of the production and reproduction of the sphere of palliative care that is the purpose of the following two chapters. Chapter three will involve a foundational exploration of the birth, development and shifts within the self-identity of palliative care. An inquiry into its production and reproduction.**

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<sup>211</sup> Paul RICOEUR, *Oneself as Another* (Chicago: University of Chicago Press, 1992), p. 240.

<sup>212</sup> Anthony GIDDENS, *New Rules of Sociological Method: A Positive Critique of Interpretative Sociologies*, (London: Hutchinson & Co. 1976), pp. 126-127.

<sup>213</sup> GIDDENS, *New Rules of Sociological Method: A Positive Critique of Interpretative Sociologies*, p. 159.

**This is an exploration and appreciation of human valuing and choosing which takes account of the social determination of the social self, but it also has to take account of the active, creative determination of social process by the self. It attempts to understand and adequately formulate the problem between the creative self and the social self<sup>214</sup> before offering a perspective on the type of resource PDE is within the tragic stories of palliative care and the encounter between clinician and patient.**

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<sup>214</sup> Gibson WINTER, *Elements for a Social Ethics: Scientific and Ethical Perspectives on Social Process* (New York: The MacMillan Company, 1966), p. 32.

## CHAPTER THREE

### Palliative Care: A Sphere of Moral Meaning

#### Introduction

The previous two chapters have demonstrated debate and a diversity of approach regarding palliative sedation practices and the interpretation and application of the principle of double effect. Confronted with the challenges and limitations of these sedation treatment dilemmas and engaged in a search for a new synthesis of the moral meaning of these events, reflection turns to the foundations and genesis of the discipline palliative care itself. What are the goods which the health care discipline of palliative care seeks to create and offer society? What are the moral meanings of those goods and how were they created? Do these socially created goods now foster or undermine the humanization of the patient in the singular situations of dying which present palliative sedation practices attempt to address? This chapter will attempt to identify and understand that prior account of social and moral life that is palliative care and how it informs the meaning of palliative sedation procedures. **First**, attention is focused on gaining an understanding of "goods" which will offer frameworks for understanding palliative care as a medical practice with socially constructed goods. The distinctions made regarding goods internal to a practice will assist in framing the fragility and vulnerabilities of a practice like

palliative care and how goods are transformed in a manner that can either foster the flourishing or decline of goods and practices. The goal would be that the elements within a theory of goods would expose any one-sided conception of the telos of palliative care that might leave it vulnerable in responding to the complexities of ethically difficult, even tragic, treatment situations. We know that there is an experience of limit within these tragic situations. The question is whether this limit is due to how these goods are socially constructed and whether they adequately appreciate rather than manipulate or dominate other human values present in these particular end of life situations? **Second**, the influential social factors, traditions and elements both creating the emergence of palliative care and continuing to shape its development will be explored. Identification of these elements will help to assess how they shape the problem of palliative sedation practices. **Third**, and finally, two foundational goods of palliative care will be explored to understand their evolution, their socially constructed meanings, and how their approaches or meanings have shaped the practice of palliative care. These two goods are the management of pain and preparation of the patient for dying well. Through the inquiry into these two goods, the question will arise as to which aspects of the dying process are technical problems to be settled and which are intractable mysteries which are not subject to future resolution but serve rather as the horizon within which we live, move and have our being.<sup>215</sup> From this inquiry, our present approaches to

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<sup>215</sup> Walter J. LOWE, "Introduction", in Paul Ricoeur, *Fallible Man* (New York: Fordham

these palliative goals or "goods" will not be evaluated as wrong as much as one-sided. It will be suggested that a more adequate understanding of the implicit moral meanings of the culture of palliative care will offer insight into the limitations of our approaches which tragic palliative care sedation dilemmas make evident. Evident will be insights which the discipline of palliative care might address and integrate to broaden and deepen its ethical self-understanding.

#### **A) Palliative Care's Social Goods**

The first question to be faced is how might a theory of social goods created and offered through palliative care be defined or characterized? Alasdair MacIntyre's work within After Virtue<sup>216</sup>, provides valuable distinctions between types of social goods within a medical discipline such as palliative care. According to MacIntyre, the current climate of moral debate regarding needs and goods is within the grip of the doctrine of Emotivism which claims that evaluative judgements and more specifically all moral judgements are only expressions of preference, of attitude or feeling, insofar as they are moral or evaluative in nature.<sup>217</sup> He suggests that what has arisen in contemporary moral debate is a disquieting private arbitrariness which becomes a matter of pure

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University Press, 1986), p. xi.

<sup>216</sup> Alasdair MACINTYRE, *After Virtue: A Study in Moral Theory* (Notre Dame, Indiana: University of Notre Dame Press, 1984)

<sup>217</sup> Alasdair MACINTYRE, *After Virtue: A Study in Moral Theory* (Notre Dame, Indiana: University of Notre Dame Press, 1984), p. 12.

assertion. Two key social outcomes from the existence and pervasiveness of this doctrine are: 1) The destruction of any genuine distinction between manipulative and non-manipulative social relations.<sup>218</sup> 2) The loss of, "any widespread understanding of or allegiance to a particular concept of authority".<sup>219</sup> The moral arbitrariness and pluralism characterizing our modern culture creates a fundamental challenge since the flourishing of any tradition of authority requires a high degree of moral consensus and the ability to settle moral difference.<sup>220</sup> When the traditional authority of a practice, such as the practice of medicine, is lost sight of due to the presence of emotivism, MacIntyre suggests that the vacuum is filled by a notion of authority defined in terms of regulation<sup>221</sup> and organizational hierarchy.<sup>222</sup>

When there is continuous resort to the law, it is generally a sign that moral relations have to some large degree broken down. It is a sign that the motives which make us invoke the law are those of fear and self-interest. And when fear and self-interest have to be brought into play, law itself tends to be morally discredited.<sup>223</sup>

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<sup>218</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 23.

<sup>219</sup> Alasdair MACINTYRE, "Patients as Agents," in Stuart F. Spicker and H. Tristram Engelhardt, eds., *Philosophical Medical Ethics: Its Nature and Significance*: proceedings of the third trans-disciplinary symposium on philosophy and medicine held at Farmington, Connecticut, December 11-13 (Dordrecht, Holland: D. Reidel, 1977), p. 199.

<sup>220</sup> MACINTYRE, "Patients as Agents," p. 204.

<sup>221</sup> Alasdair MACINTYRE, "Regulation: A Substitute for Morality," in *Hastings Center Report* (February, 1980), pp. 31-33.

<sup>222</sup> MACINTYRE, "Patients as Agents," p. 202.

<sup>223</sup> MACINTYRE, "Regulation: A Substitute for Morality," p. 32.

With such a current moral culture, it is not surprising that challenging dilemmas and debate arise over justifying which goods and techniques, such as sedation, within the practice of palliative care are most appropriate.

Within his argument engaging pluralism and equality, Michael Walzer<sup>224</sup> proposes a theory of goods describing how goods are socially constructed. Walzer's "theory of goods", which honors historical and cultural particularism, can be summed up in the following statements,

All the goods with which distributive justice is concerned are social goods.<sup>225</sup> Men and women take on concrete identities because of the way they conceive and create, and then possess and employ social goods.<sup>226</sup> There is no single set of primary or basic goods conceivable across all moral and material worlds.<sup>227</sup> But it is the meaning of goods that determines their movement.<sup>228</sup> Social meanings are historical in character; and so distributions, and just and unjust distributions change over time.<sup>229</sup> When meanings are distinct, distributions must be autonomous.<sup>230</sup> But there are standards (roughly knowable even when they are controversial) for every social good and every distributive sphere in every particular society; and these standards are often violated, goods taken, and spheres invaded by men and women in power.<sup>231</sup>

In essence, understanding the particularity of a social good lessens the

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<sup>224</sup> Michael WALZER, *Spheres of Justice: A Defence of Pluralism and Equality* (New York: Basic Books, 1983)

<sup>225</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 7.

<sup>226</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 8.

<sup>227</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 8.

<sup>228</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 8.

<sup>229</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 9.

<sup>230</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 10.

<sup>231</sup> WALZER, *Spheres of Justice: A Defence of Pluralism and Equality*, p. 10.

**potential for manipulative social relations and for not being deceived by one-sided moralities.**

**In *After Virtue*, MacIntyre addresses the challenge of moral relativism in our modern culture by searching for a single core conception of the virtues which might make a claim for a universal allegiance. After surveying the seemingly different if not incompatible accounts of Homer, Aristotle, Aquinas and Benjamin Franklin, MacIntyre claims that every account of a virtue, "always requires for its application the acceptance of some prior account of certain features of social and moral life in terms of which it has to be defined and explained".<sup>232</sup> Each account addressing the virtues may list different virtues or differing kinds of features of virtues , but fundamentally each of these lists "embodies, is the expression of a different theory about what a virtue is".<sup>233</sup> MacIntyre claims that what is universal among these various accounts of virtue are three stages in the logical development of the core concept of virtue,<sup>234</sup> each with their own conceptual background. The stages are: 1) a practice, 2) the narrative order of a single human life, 3) a moral tradition. Each earlier stage provides a foundation for, but is also reinterpreted by, the later stage.**

**The goal of this present inquiry is not to create an understanding of virtue for palliative care. The goal is to understand that prior account of social and**

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<sup>232</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 186.

<sup>233</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 183.

<sup>234</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 186.

moral life that is palliative care, those vulnerabilities of goods internal to a practice, that would inform the meaning of sedation techniques. The distinctions MacIntyre has developed within his theory will assist in understanding the nature and vulnerabilities of the socially constructed goods that have evolved within the practice of palliative care. As each of these stages are here examined, suggestions will be offered as to what insight these states offer for a more adequate understanding of the foundational "goods" within the practice of palliative care.

The first stage of MacIntyre's core concept of virtue is a *practice*. For MacIntyre, a *practice* is,

...any form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended.<sup>235</sup>

Architecture, farming and medicine<sup>236</sup> are each offered by MacIntyre as examples of a *practice*. To further characterize *practices*, they are not to be confused with technical skills,

What is distinctive in a practice is in part the way in which conceptions of the relevant goods and ends which the technical skills serve - and every practice

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<sup>235</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 187.

<sup>236</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 194. It is important to note that this type of definition of medicine as a practice is a revision of a narrower and more traditional understanding of the practice of medicine as the work of physicians. It offers a more relevant understanding of the practice of medicine as the schemes or patterns of relationships and professions which attempt to address the pain and suffering of patients.

does require the exercise of technical skills - are transformed and enriched by these extensions of human powers and by that regard for its own internal goods which are partially definitive of each particular practice or type of practice. It therefore turns out not to be accidental that every practice has its own history and a history which is more and other than that of the improvement of the relevant technical skills. This historical dimension is crucial in relation to the virtues.<sup>237</sup>

He further develops his notion of a *practice* by distinguishing it from *institutions*. *Institutions* are the social bearers and sustainers of *practices*<sup>238</sup> and are primarily concerned with what MacIntyre considers as external goods - money, power, status.<sup>239</sup> They are external goods precisely because they are goods that can also be achieved through the exercise of alternative practices. **Internal goods** can only be recognized in relation to specific and individual practices. Furthermore these internal goods, specific to a practice, can only be identified and achieved through the experience of participating in the practice in question.<sup>240</sup> It is for this reason that MacIntyre claims that those who lack the relevant experience through participating in the practice are incompetent as judges of the internal goods of the practice.<sup>241</sup>

MacIntyre makes a second clarifying distinction between internal and external goods. External goods, when attained, are always the property or

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<sup>237</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, pp. 193-194.

<sup>238</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 195.

<sup>239</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 194.

<sup>240</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 189.

<sup>241</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 189.

possession of some individual; the more someone has of them, the less there is for other people. Internal goods, when achieved, are goods which not only benefit the individual but also enrich the whole community who participate in the practice. As an example, the humanization of the dying process within a scientific and technological delivery of medicine would be a particular internal good of palliative care. It is this key distinction between internal and external goods which first points to the more complex context of relationships and dynamics which are inherent in the structure of the moral life of a practice.

MacIntyre further identifies two kinds of internal goods with respect to a practice. The first is the excellence of products: both in the performance and in the finished product. Examples of such internal goods within the practice of medicine could include: surgery, diagnosis, relating to patients, deliberation of ethically difficult care dilemmas, or pain management. The second type of internal good is what the person discovers that is meaningful, rewarding and formative through the very pursuit of excellence within a practice. "...it is the good of a certain kind of life...It is the painter living out a greater or lesser part of his or her life as a *painter* that is the second kind of good internal to painting".<sup>242</sup> Palliative care examples of this type of internal good could include: gaining insight into how the dying process of terminally ill patients might be humanized, or a sense of self discovery regarding how they desire to live their life

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<sup>242</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 190.

**intentionally and with wonder due to being present as dying patients reflect and recount those elements and lessons most important to them in their own life.**

**Given these distinctions between these types of internal and external goods, MacIntyre then moves on to offering his understanding of a *virtue* within a practice.**

**A virtue is an acquired human quality the possession and exercise of which tends to enable us to achieve those goods which are internal to practices and the lack of which effectively prevents us from achieving any such goods.<sup>243</sup>**

**These distinctions between internal and external goods demonstrate an insight into the diverse goods required for a practice to flourish. They demonstrate the fragile socially and historically determined construction of these goods and suggest how such goods both self define a practice and also inform or shape that practice. They are goods or orientations that do not simply involve excellence in skills but concern other human qualities or resources needing to be developed by professionals if the practice is to flourish. Such an understanding of the flourishing of goods demonstrates the limited nature of regulative or compliance attempts to shape the moral authority of a practice. Clearly, there is also a need to learn and recognize the character and orientation of the relationships within a practice if the internal goods of a practice, and humanization, are to be achieved.<sup>244</sup>**

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<sup>243</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 191.

<sup>244</sup> MACINTYRE proposes that moral philosophy and sociology should not be conceived of a separate disciplines. Alasdair MACINTYRE, "How Virtues Become Vices: Values, Medicine

Every practice requires a certain kind of relationship between those who participate in it. Now the virtues are those goods by reference to which, whether we like it or not, we define our relationships to those other people with whom we share the kind of purposes and standards which inform practices... It belongs to the concept of a practice that its goods can only be achieved by subordinating ourselves within the practice in our relationship to other practitioners. We have to learn to recognize what is due to whom; we have to be prepared to take whatever self-endangering risks are demanded along the way; and we have to listen carefully to what we are told about our own inadequacies and to reply with the same carefulness for the facts.<sup>245</sup>

It is precisely this quest of recognizing "what is due to whom" that is being asked in palliative care regarding its internal goods of preparing patients for death and pain management. It is the socially constructed character and meaning of these goods that shape our perceptions and meanings regarding tragic palliative care situations and the use of sedation.

What becomes evident with this understanding of internal and external goods is that a practice spanning diverse historical times may need to shape different goods for that practice to flourish in another particular social and historical era. What was a virtue in one era of a practice could become a vice in another era. An internal good could also become a vice by how it is employed as part of a technique.<sup>246</sup> An example could be a health care provider becoming "friends" with their patient in order to gain their confidence and thus enabling the

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and Social Context," in H. Tristram ENGELHARDT and Stuart F. SPICKER, eds., *Evaluation and Explanation in the Biomedical Sciences: Proceedings of the first Transdisciplinary Symposium on Philosophy and Medicine held at Gavelston, May 9-11, 1974.* (Dordrecht, Holland: D. Reidel, 1975) p. 103.

<sup>245</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 191.

<sup>246</sup> MACINTYRE, "How Virtues Become Vices: Values, Medicine and Social Context." pp. 105-107.

provider to manipulate the patient more effectively. MacIntyre believes that without the virtues there could be a recognition of only external goods and not of internal goods in the context of practices. In any society that recognizes only external goods, competitiveness would be the dominant and even exclusive feature.<sup>247</sup> An unawareness of the types of internal goods in the practice of palliative care could lead to manipulative social relations and socially constructed meanings of goods. How might the practice of palliative care be vulnerable to such manipulations and thus reductions of human being? How might internal goods within palliative care be either "out of date" or used in a manner that is manipulative or reductive rather than helping the practice to flourish? Given the present historical and social conditions of dying, how might the flourishing of palliative care look?

As an example, let us explore moral authority within the physician-patient relationship. Physicians and the practice of medicine have claimed a kind of authority having a moral component,<sup>248</sup> since its medical research, technological developments and decision making have an enormous influence on our individual and collective self understandings. If the role of the patient is defined through incapacity, and the patient in certain respects invites the physician to take some type of responsibility for him or her, then the doctor in fact can be,

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<sup>247</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 196.

<sup>248</sup> MACINTYRE, "Patients as Agents," p. 204.

and has been, understood as *telling* the patient what care plan is necessary. While the relationship can be understood to have contractual elements, this relationship is also much more than contractual. Both the contractual and the more than contractual relationship of the physician with the patient has to do less with the possession of technical skills on the part of the physician and more with the history of how the two came to be co-joined.<sup>249</sup> Partly it is a trust in the tradition of the physician - patient relationship which has been passed on and in which we are socialized.

Yet within our modern, plural moral culture the patient approaches the physician as stranger to stranger. Each do not know the individual expectations and moral orientations they expect from each other and therefore the encounter, one of a certain degree of vulnerability and intimacy, is treated by both with a certain amount of suspicion, defensiveness and fear. Professional codes of ethics, institutional mission statements and organizational guarantees attempt to infuse a foundation of trust that, given the same conditions, each patient - physician encounter or treatment will produce the same outcomes.

So in handing over authority to the traditional family doctor, we conferred on him a personal right of interpretation in virtue of his moral status. But bureaucracy aspires to remove rules from contexts of interpretation as far as possible; for it want to substitute uniformity of expectation and predictive reliability for trust in persons. The outcome is imposed interpretation.<sup>250</sup>

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<sup>249</sup> MACINTYRE, "Patients as Agents," p. 205.

<sup>250</sup> MACINTYRE, "Patients as Agents," p. 208.

The evolution of the physician – patient relationship from trust in persons and replaced by trust in norms, the development of “imposed interpretation” on the patient, is one example of evolution within a practice which is claimed to undermine the physician – patient relationship.

The instance of physician error provides a second example of the shift from trust in persons to trust in bureaucratic authority with the outcome of the physician - patient relationship being reduced to a purely contractual one. Sanctions are given by bureaucratic organizations, as authorities within the practice of medicine, to the physician if the physician abuses the trust conferred on him or her. What has developed is a shift from traditional social authority to bureaucratic authority where the rules of a practice govern functions and not persons. The question is whether the shift from trust in persons to trust in bureaucratic authority causes the flourishing of trust and a flourishing of the physician - patient relationship. MacIntyre’s response to that question is,

When there is continuous resort to the law, it is generally a sign that moral relations have to some large degree broken down. It is a sign that the motives which make us invoke the law are those of fear and self-interest. And when fear and self-interest have to be brought into play, law itself tends to be morally discredited.<sup>251</sup>

It would seem evident that as the physician – patient relationship evolves in a manner where moral relations have broken down and the contractual nature of the relationship is primary, the relationship will be more dependent on legal or

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<sup>251</sup> Alasdair MACINTYRE, “Regulation: A Substitute for Morality,” *Hastings Center Report* February (1980), p. 32.

**ethical guidelines used in a manner to justify treatment decision making. Such a dependence has obviously faced limitations in the tragic palliative care dilemmas recounted earlier.**

**The second stage in MacIntyre's concept of a virtue is the narrative order or unity of a human life. This concept speaks to the search for order, unity and meaning in the particular and random life events of the individual. It is through the setting, history, the narrative of a life that the changes and challenges of life become intelligible. The concept of narrative is appropriate for understanding the actions of others because we understand our own life in terms of the narratives we live.<sup>252</sup> Each act becomes intelligible by finding its place in the narrative.**

**MacIntyre then suggests that the unity of the moral life of an individual occurs through a type of deliberation between two questions. To ask the first question, "what is the good for me ?", is to ask how best I might live out that unity and bring it to completion. To ask the second question, "what is the good for humanity?" is to ask what all answers to the former question must have in common. He emphasizes that it is the systematic asking of these two questions, the good for me and for humanity, and the attempt to answer them in human living which provide the moral life of the individual with its unity. This deliberation takes on the nature of a narrative quest.**

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<sup>252</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 212.

Quests sometimes fail, are frustrated, abandoned or dissipated into distractions; and human lives may in all these ways also fail. But the only criteria for success or failure in a human life as a whole are the criteria of success or failure in a narrated or to be narrated quest.<sup>253</sup>

It is the continuous quest itself, the asking of the good for myself and humanity, which provides the moral life with its unity.

The virtues are therefore to be understood as those dispositions which will not only sustain practices and enable us to achieve the goods internal to practices, but which will also sustain us in the relevant kind of quest for the good, by enabling us to overcome the harms, dangers, temptations and distraction which we encounter and which will furnish us with increasing self-knowledge and increasing knowledge of the good.<sup>254</sup>

The third stage in MacIntyre's concept of a virtue is the moral tradition. The highlighting of the importance of tradition is founded on the narrative view of the self, that the story of the self is always embedded in the story of those communities from where it has derived its identity. The self does not have to accept the limitations of the moral particularity of those communities, but it is in moving from such particularities that the search for the good consists.<sup>255</sup> A vital tradition then embodies continuities of conflicts. It is an argument in part about the goods that constitute that tradition.<sup>256</sup> What then sustains and strengthens traditions is claimed to be the exercise of relevant virtues. Such relevant virtues include having an adequate sense of the traditions to which one belongs or

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<sup>253</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 219.

<sup>254</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 219.

<sup>255</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 221.

<sup>256</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 222.

which confront one. Another includes a practical reasoning manifested not so much in knowledge of norms but in, "a capacity for judgement which the agent possesses in knowing how to select among the relevant stack of maxims and how to apply them in particular situations".<sup>257</sup>

MacIntyre suggests that there are those traditions which are living and vibrant and there are traditions that decay, disintegrate and disappear. The challenge is how the traditions will address the changes in its techniques or abilities, identify its external and internal goods, foster institutions which will maintain the necessary internal goods and foster the necessary virtues which will engender the practice and tradition to flourish.

These are indeed the challenges being witnessed within palliative care and being recognized in tragic treatment dilemmas such as those regarding palliative sedation. Next we will explore the particularity of the traditions of palliative care in its birth, its history, identity and two consistent goods pursued within its evolution: pain management and preparing patients to die well.

#### **B) The Emergence of Palliative Care**

The genesis of palliative care occurred within the broader context of evolutions and conflicting values within the traditions of medicine. Medicine has always struggled to incorporate two conflicting traditions, each having shaped

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<sup>257</sup> MACINTYRE, *After Virtue: A Study in Moral Theory*, p. 223.

the provision of healthcare.<sup>258</sup> First, there is a scientific tradition, initiated with the Age of Enlightenment and the scientific revolution through humanists such as Francis Bacon.<sup>259</sup> This tradition takes an instrumental approach to nature and approaches human illness with the technological focus of conquering or mastering disease within the body and the prolongation of life.<sup>260</sup> The focus of biomedical inquiry was not the patient as person but the eradication of disease. Such an approach has a presumption in favor of technological treatment without defined limits. This tradition led to significant discoveries such as the cardiopulmonary system or the discovery of ether, but at the expense of the significance of how illness was experienced and given meaning, to and by the patient. The modern struggle with this instrumental and technological tradition is clearly evident in the following reflection on the medical approach to cancer treatment in the early 1960's.

Insidiously, imperceptibly, doctors saw themselves primarily as diagnosticians and therapists (whether surgical, pharmacological, or radiation). Hospitals were seen as being for investigative treatment, and early discharge home. Those who could not be cured, or at least not put into remission state, were often made to feel less welcome and less deserving of expensive, highly educated medical input. Those who were dying were given the lowest medical priority, and death itself became not the fact of life it had always been but a medical defeat or, worse still, a statistical embarrassment.<sup>261</sup>

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<sup>258</sup> Nancy S. JECKER, "Knowing When to Stop: The Limits of Medicine," in *Hastings Center Report* (May/June, 1991), p. 6.

<sup>259</sup> Hubert DOUCET, "Taming the Suffering Associated With Dying: Palliative Care's Ethical Challenge," in *Grail* 11 (3) (1996), pp. 42-43.

<sup>260</sup> Francis BACON, *Works of Lord Bacon*, edited by Joseph Devey (London: George Bell and Sons, 1894), p. 163.

<sup>261</sup> Derek DOYLE, Geoffrey HANKS, Neil MACDONALD, "Introduction" in Derek Doyle, Geoffrey Hanks, Neil MacDonald (eds.) *Oxford Textbook of Palliative Medicine 2<sup>nd</sup> Edition*

This technological approach has implications for approaches to suffering as well. If the goal of medicine within this tradition is the preservation and enhancement of human life through technological labor, then suffering from natural causes is no longer inevitable but capable of being controlled and an object of human responsibility.<sup>262</sup> This tradition offers a moral authority requiring the elimination of human suffering.

The second and earlier tradition within medicine, although perhaps with less contemporary impact, is the Hippocratic tradition. While its authorship is unknown, its origin is placed anywhere from the sixth century B.C. to the first century A.D..<sup>263</sup> The goal of this tradition is claimed to be a holistic healing of the patient. Here, medicine is understood as a cooperative rather than a transforming art, that the body itself is a healer, and that the physician is an assistant to nature through corrective and preventative measures.<sup>264</sup> Evident is an orientation of cooperation with nature rather than domination over nature which might therefore approach human suffering in a different manner. These two traditions of medicine are also both at play and in conflict within the self-

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(Oxford: Oxford University Press, 1998), p. 4.

<sup>262</sup> Gerald P. MCKENNY, *To Relieve the Human Condition: Bioethics, Technology and the Body*. (New York: State University of New York Press, 1997), p. 19.

<sup>263</sup> Leon R. KASS, *Toward a More Natural Science: Biology and Human Affairs*. (New York: Free Press, 1985), p. 227.

<sup>264</sup> Leon R. KASS, *Toward a More Natural Science: Biology and Human Affairs*. (New

**understanding of palliative care and its dilemmas with sedation practices.**

**Between these two traditions lies an ambivalence about whether death should be fought or accepted. The scientific, technological approach seemed to instil an Enlightenment hope that humanity could overcome nature and in fact could overcome death. While many modern scientists would not confess to believe that death can be overcome they might at the same time harbour a more subtle variation of that belief. The claim would be that medicine can, "in its conquest of disease, remove the unpleasant, distressing causes of death, thus transmuting it from a condition to be feared to one that can be managed, domesticated, camouflaged by modern technology and therefore more tolerable."<sup>265</sup> Yet this is not how death has turned out at all. Many fear the prospect of a dying process where they are stripped of dignity, tied to technologies and impersonal medical bureaucracies. Perhaps more feared than the technologies is being hostage to a moral logic of medical progress. This moral logic refers to a concept of progress where scientific possibility and a moral imperative become one: what can be known should be known, or what can be done should be done. Such an imperative believes that if we do not pursue the conquest of disease, than clinicians or family decision makers are open to moral blame. What emerges through this marriage of scientific**

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York: Free Press, 1985), p. 233.

<sup>265</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 32.

possibility and moral imperative is the tendency to attribute everything that happens to the patient to the human agency of clinicians or loved ones. What is erased is, "the difference between human action as a cause of what happens in the world, and independent, natural biological processes, those old-fashioned causes of disease and death."<sup>286</sup> The influence of the scientific approach to medicine cannot be underestimated in how it shapes the way we think about modern approaches to dying.

Within the history of medicine, modern palliative care is a relatively young discipline, struggling for definition and self-understanding. It was recognized as a medical specialty in Great Britain in 1987<sup>287</sup> but its modern genesis is often noted as beginning in the late 1960's with the pioneering work of Dr. Cicely Saunders and the establishment of St. Christopher's Hospice in London. The birth of palliative care is described by some<sup>288</sup> as a recognition of poorly addressed pain management needs of cancer patients and by others<sup>289</sup> as a protest against the evolution and practice of a scientific, technologically and cure oriented medicine which offered little to terminally ill cancer patients. Palliative care was born with a corrective vision claiming, in the words of Cicely

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<sup>286</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 67.

<sup>287</sup> DOYLE, HANKS and MACDONALD, "Introduction", p. 3.

<sup>288</sup> DOYLE, HANKS and MACDONALD, "Introduction", p. 4.

<sup>289</sup> DOUCET, "Taming the Suffering Associated With Dying: Palliative Care's Dying Challenge," p. 44.

Saunders, that an agitated and restless patient can do little to prepare self or family for the *final parting*.<sup>270</sup> The goal was to create that container, that space, where the patient makes, integrates, and most importantly lives the meaning of that final illness event in relationship with others. Initially it was a space created where technological medicine was thought to be antithetical<sup>271</sup>. Palliative care still struggles with its understanding of the role of technology, but also recognizes the positive influences technological advances have had in the lives of palliative care patients.<sup>272</sup> Such advances have contributed a legitimate development to pain management techniques in an attempt to,

spare no scientific or clinical effort to free dying persons from twisting and racking pain that invades, dominates and shrivels their consciousness, that leaves them no psychic or mental space for the things they want to think and say and do before they die.<sup>273</sup>

### **C) The Evolving Definition of Palliative Care**

Several attempts have been made to define the nature and goals of palliative care. In fact, such definitions have undergone an evolution over the past forty years along with the evolution of medicine and the appearance of new diseases such as the human immunodeficiency virus (HIV). First was the

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<sup>270</sup> ROY, "Need They Sleep Before They Die?" p. 4.

<sup>271</sup> D.M. DUSH, "High-Tech, Aggressive Palliative Care: in the Service of Quality of Life," in *Journal of Palliative Care*, 9 (1993), pp. 37-41. J.C. HARYS, "High-Technology and Hospice Home Care," in *Nurs Clin North Am* 23 (1988), pp. 329-340. D. THORNE, "Adding Technology to Care – Is this Progress?" in *Prog Palliative Care*, 7 (1999), pp. 53-54.

<sup>272</sup> John F. SEELY and Balfour M. MOUNT, "Palliative Medicine and Modern Technology," in *Canadian Medical Association Journal*, 161 (9) (1999), p. 1121.

<sup>273</sup> ROY, "Need They Sleep Before They Die?", p. 3

**palliative care model rooted in the work of Cicely Saunders, focused on cancer care and suggesting that palliative care begins when anti-disease therapy fails to cure the illness. This palliative care approach focuses on pain management and creating a pain free environment allowing the patient to prepare for their death. Such an approach can be found in one of the first definitions of palliative care in Canada, the 1981 definition by the Palliative Care Foundation of Toronto.**

**Palliative care is active compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms – physical and emotional – is paramount. It is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope.<sup>274</sup>**

**The key defining reference points of a patient requiring palliative care were they were terminally ill and aggressive, curative therapy was no longer beneficial. Yet two realities began emerging making it difficult to determine when to stop the use of technology and thus signalling the beginning and need for palliative therapies.<sup>275</sup> The first was the vanishing line between life and death. To determine well in advance that an illness is terminal has become increasingly difficult as well as being able to predict that death is "immanent",**

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<sup>274</sup> CANADIAN PALLIATIVE CARE ASSOCIATION, *Palliative Care: Towards a Consensus in Standardized Principles of Practice*, Frank D. FERRIS and Ina CUMMINGS (eds.) (Ottawa: Palliative Care Association, 1995), p. 10.

<sup>275</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 42.

defined as within a few hours or days.<sup>276</sup> The second reality is the growing public and medical ambivalence about what is wanted and valued in coping with illness and dying.

Given the above difficulties it is understandable to note the changes within another definition proposed in 1989 by Health and Welfare Canada.

**Palliative Care is a program of active compassionate care primarily directed towards improving the quality of life for the dying. It is delivered by an interdisciplinary team that provides sensitive and skilled care to meet the physical, psycho-social and spiritual needs of both the patient and the family. The philosophy and principles of palliative care may apply to the patient populations other than the dying and the palliative care program may have a secondary role in addressing the needs of these groups.<sup>277</sup>**

This definition suggests that the palliative care program would have a secondary role in addressing the needs of patients who are not dying. It is a broader definition perhaps addressing evolving challenges in the areas of diagnosis and new diseases. Distinctions regarding the role of palliative care are also present within the 1990 definition of palliative care offered by the World Health Organization.

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment. Palliative care:

- Affirms life and regards dying as a normal process.
- Neither hastens nor postpones death.
- Provides relief from pain and other distressing symptoms.

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<sup>276</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 44.

<sup>277</sup> CANADIAN PALLIATIVE CARE ASSOCIATION, "Palliative Care: Towards a Consensus in Standardized Principles of Practice", p. 10.

- Integrates the psychological and the spiritual aspects of care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.<sup>278</sup>

This definition suggests that palliative care is exclusively oriented to patients not receiving active anti-disease therapy, and suggests that if there is another role, it includes only those receiving anti-cancer therapy.<sup>279</sup> It also speaks of neither hastening not postponing death which is puzzling given the legal and ethical justifications used by palliative care clinicians to legitimize sedation practices because they are known to hasten death. Also if palliative care is offered in conjunction with anti disease or anti illness therapy, such active therapy is life prolonging.

In 1995, with the absence of an accepted definition of palliative care by the Canadian Palliative Care Association, that association's Standards Committee proposed the following working definition,

Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time

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<sup>278</sup> CANADIAN PALLIATIVE CARE ASSOCIATION, "Palliative Care: Towards a Consensus in Standardized Principles of Practice", p. 11.

<sup>279</sup> CANADIAN PALLIATIVE CARE ASSOCIATION, "Palliative Care: Towards a Consensus in Standardized Principles of Practice", p. 11.

during the illness trajectory and bereavement.

While many service providers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized palliative care program may be required as the degree of distress, discomfort and dysfunction increases.

Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.<sup>280</sup>

This definition is interesting in its broad view of the role of palliative care.

It is oriented to patients not simply with a terminal illness and preparing to die but to patients living with a life threatening illness. Also that palliative care is no longer linked with those preparing to die but with therapies aimed at reducing or curing the illness.

Such a diversity of definition is most likely linked to the differing needs of patient needs due to their specific illness. Palliative care began in the 1950s and 1960s with a focus on needs of terminally ill cancer patients, and was shaped by available treatments as well as the characteristics and trajectory of that type of disease. The identity of palliative care changed with differing needs of new types of patients, such as HIV patients, with the available treatments and the characteristics and trajectory of that type of disease. For example, some HIV patients may require complex and active treatments, such as the treatment of the visual problem *cytomegalovirus retinitis*, until the last days of their life.<sup>281</sup>

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<sup>280</sup>CANADIAN PALLIATIVE CARE ASSOCIATION, "Palliative Care: Towards a Consensus in Standardized Principles of Practice", p. 12.

<sup>281</sup> Philip D. WELSBY, Alison RICHARDSON, R.P. BRETTLE, "AIDS: Aspects in Adults,"

**Social dynamics of patients' lives have also presented challenges to clinicians in how to understand and respond to the complex social dynamics and prejudice involved in a disease transmitted sexually or through intravenous drug use. With such changes and challenges, questions arise as to the approach and identity of palliative care: 1) the place of active treatments, 2) the time or indicator specifying when to engage palliative care, 3) can palliative care be engaged in collaboration with active curative treatments?, 4) at what stage of a life threatening illness do we help people to prepare to die?**

**Even though there has been an evolution among the above definitions of palliative care, two central goods of palliative care remain consistent among this evolution: 1) the relief of pain and suffering, 2) preparing patients for dying well. Given the recognition that the character of illness is socially constructed, what has been the evolution in meaning that has occurred with these two essential palliative goods?**

**D) Interpreting the Relief of Pain and Suffering**

**The goal of Cicely Saunders, arguably the foundress of modern palliative care, to alter the experience of dying for terminally ill cancer patients had its genesis before she became a physician. It emerged from her experience of witnessing the fragile pain, meaninglessness, and hope of loved ones as they were dying. Her professional experience, first becoming a social worker, then a**

nurse and finally a physician, was perhaps also formative in her choice to focus on the terminally ill as well as instilling an interdisciplinary approach to palliative care. Through her experience of volunteering at St. Luke's home for the Dying Poor in London, England, she gained her first insight into the value and importance of pain management techniques.<sup>282</sup> From Dr. Howard Barrett she learned the value of giving pain killing drugs at regular dosages before the pain might reassert itself or of giving medication by mouth whenever possible.<sup>283</sup> From these nascent beginnings, a concern for pain relief was central to the identity of palliative care.

However, adequate interpretations of what pain and suffering are, how they might be distinguished, as well as the quest for abilities to lessen their effect have provided both valuable benefit and elusive gain. The pain or suffering portrayed in the four palliative sedation narratives noted earlier are gripping. The existence of such pain which grips a patient seems to thwart the essential goal of palliative care: to facilitate with those suffering from a terminal illness the belief and goal that the process of dying may actually be a time of self-actualization and optimal growth in one's lifetime. A patient gripped with pain is not found to be able to participate in such self-actualization. Palliative care strives to understand and create better approaches for addressing such

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<sup>282</sup> Shirley DE BOULAY, *Cicely Saunders*, (London: Hodder & Stoughton: 1984), p. 61.

<sup>283</sup> DE BOULAY, *Cicely Saunders*, p. 71.

refractory pain symptoms and yet both interpreting and addressing pain and suffering is difficult and complex.

### 1) Pain as Biology

Historical explorations of the cultural construction of pain offer critique of a biomedical, scientific approach which biases our current approaches toward understanding pain. Such a western, biomedical and technological approach is critiqued for understanding pain entirely as a medical puzzle of biochemistry, nerves and neurotransmitters.<sup>284</sup> Critiques of this approach claim that it integrates no distinction between illness and disease. Illness narratives speak to us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life story. Illness is understood to refer to how the sick person and members of the family or wider social network perceive, live with, and respond to symptoms of disability. Disease on the other hand is understood to refer to what the practitioner creates in the recasting of illness in terms of theories of disorder.<sup>285</sup> Within a biomedical and technological approach to understanding pain, inquiries into such cultural construction of illness or pain do not routinely occur. In fact the priority structure of medical training and of health care delivery, with its pursuit of the biological mechanism

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<sup>284</sup> David B. MORRIS, *The Culture of Pain* (Berkeley: University of California Press, 1991), p. 2.

<sup>285</sup> Arthur KLEINMAN, *The Illness Narratives*, (New York; Basic Books, 1988), p. 5.

of disease precludes such inquiry.<sup>286</sup> Yet, more integrated approaches to pain are attempting to integrate both concepts of disease and illness into definitions of pain. As an example, in 1979 pain was defined by the International Association for the Study of Pain as, "as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."<sup>287</sup>

Historians exploring the interpretation of pain point to the scientific discovery of asilicylic acid in 1899 and the use of ether in surgery in 1846 as turning points toward the emergence of our modern period of the medicalization of pain.<sup>288</sup> The positive impact of such discoveries to relieve bodily pain cannot be denied. But their success seemed to create a hope for the eradication of pain and suffering much like the scientific movement of the Enlightenment hoped for the eradication of disease. Historical critiques of this scientific and technological approach claim that pain is never simply "a matter of nerves and neurotransmitters but always requires a personal and cultural encounter with meaning."<sup>289</sup> Such a medicalized interpretation of pain so strips an understanding of pain from social meaning, that it has almost no meaning or

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<sup>286</sup> KLEINMAN, *The Illness Narratives*, p. 9.

<sup>287</sup> "Pain Terms: A List with Definitions and Notes on Usage," in *Pain* 6 (1979), p. 249.

<sup>288</sup> MORRIS, *The Culture of Pain*, p. 61.

<sup>289</sup> MORRIS, *The Culture of Pain*, p. 267.

social value at all.<sup>290</sup> Given the one-sided nature of defining pain as a biological and organic event, and the strength and pervasiveness of this understanding in our scientific and technological health care culture, it is difficult to remove ourselves from this narrow focus. The concern is whether such medicalized understandings of pain will in the future be ample and sustaining for the human community or thin and sterile, whether these meanings which we discover as well as shape will help us or merely increase our feeling of affliction.<sup>291</sup> The response needed to humanize this reduction in human meaning is to recognize and consciously employ our power to create and to reshape the meanings of pain and suffering. Such a re-engagement with a personal and cultural encounter with meaning, will occur only when the official scientific and biological explanations have been found to experience limitations or simply fail. Tragic ethical dilemmas regarding palliative sedation techniques seem to point to such limitations although other examples have also been expressed. How is the biological concept of pain being presented in a manner that eclipses other meanings expressed through the concept of suffering?

## 2) Pain Versus Suffering

Palliative care professionals are questioning whether their discipline is failing to accept, overlooking or placing at a lower priority two focal challenges

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<sup>290</sup> MORRIS, *The Culture of Pain*, p. 274.

<sup>291</sup> MORRIS, *The Culture of Pain*, p. 267.

or limitations. The first challenge is the ability to adequately distinguish and uniquely address physical pain versus the suffering experienced by the patient. The second challenge, perhaps rooted in a scientific and technological approach to medicine, is perception within the palliative care discipline that it has the ability to control all pain and suffering either through pharmacological therapies or psychological/spiritual therapies. To state this in another manner, some palliative care professionals are concerned that a singular focus on pain management does not adequately distinguish pain from suffering and is rooted in an unreasonable promise and attempt to control the suffering of patients.<sup>292</sup> Attempts at clinical control of a suffering not amenable to control are perceived as a response affording the clinician distance from the suffering of the patient and the tragedy of the illness story. Behind this critique of a palliative care claim to control pain and suffering is a desire to better understand the uniqueness and relationship shared between pain and suffering to better meet the needs of dying patients. The complexity of the relationship between pain and suffering is underscored by research identifying that the will to live of dying patients fluctuates substantially and is correlated with depression, anxiety, shortness of breath and a sense of well being.<sup>293</sup> The concern is that by not adequately

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<sup>292</sup> GREGORY and ENGLISH, "The Myth of Control: Suffering in Palliative Care," p. 19.

<sup>293</sup> Harvey M. CHOCHINOV, Douglas TATARYN, Jennifer J. CLINCH and Deborah DUDGEON, "Will to Live in the Terminally Ill," *The Lancet* Vol. 354 (September 4, 1999), p. 816. Also Harvey M. CHOCHINOV, Keith G. WILSON, Murray ENNS, Neil MOWCHUN, Sheila LANDER, Martin LEVITT and Jennifer J. CLINCH, "Desire for Death in the Terminally Ill," *American Journal of Psychiatry* 152:8 (August, 1995), p. 1187.

recognizing these challenges palliative care clinicians are perhaps increasing the suffering of patients, distancing themselves from their patients, and fooling themselves with a false sense of control.

The problematic understanding of pain versus suffering is claimed to have begun with the Cartesian dualism between mind and body, delivered to allow science escape from church control in the 17<sup>th</sup> century.<sup>294</sup> *Person*, synonymous with *mind* was off limits to science which dealt with *the body*. This narrow and seemingly artificial dualism is proposed as allowing clinicians to concentrate solely on curing bodily disease, without regard to how their efforts might cause the patient to suffer as a person.<sup>295</sup> Given this initial focus on the body, presently found inadequate and yet still ingrained in the training of the medical sciences, what are potential distinctions and relationships discovered between pain and suffering?

Three significant elements are identified when suffering was found to occur during either the course of disease or its treatment:<sup>296</sup> 1) suffering is not confined to physical symptoms 2) suffering occurs from the disease but also from its treatment, 3) one cannot anticipate what a patient would describe as a source of suffering; the patient had to be asked.

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<sup>294</sup> CASSELL, "The Nature of Suffering and the Goals of Medicine," p. 640.

<sup>295</sup> CASSELL, "The Nature of Suffering and the Goals of Medicine," p. 640.

<sup>296</sup> CASSELL, "The Nature of Suffering and the Goals of Medicine," pp. 639-640.

The relationship between pain and suffering is also distinguished through its unique structure or makeup. First, people in physical pain frequently report *suffering from pain* when they feel out of control, when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is chronic.<sup>297</sup> This is often because the physical pain has been inextricably linked with the patient's perception of future events, and the physical pain disrupts their future from their present and their past.<sup>298</sup> Suffering can occur when patients perceive their physical disease, or its effects such as physical pain, as a threat to their continued existence.

Second, suffering has a social dimension that pain does not have. While basic human needs and desires are considered a part of human biology, they are not reduced to biology. The physical pain or disease experienced may not simply be a threat to their life but to their integrity and self-understanding as a human being. For example, a father with cancer who is no longer able to work and financially provide for his children, as he believes a father should, experiences the disease as a threat to his integrity defined by his self-perception. But illness is also defined not just by the self but by a community. When illness happens to an individual in the community, it does so because the community has set the social framework for what illness is, and yet nothing in

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<sup>297</sup> CASSELL, "The Nature of Suffering and the Goals of Medicine," p. 641.

<sup>298</sup> LOEWY, "The Role of Suffering and Community in Clinical Ethics," p. 84.

**the social framework determines the biological basis for the illness.<sup>299</sup> Suffering is claimed to have a social structure which a strictly biological understanding of pain does not have. As such, the capacity to suffer is also the condition of possibility of relationships in health care.<sup>300</sup> As an example, suffering can occur when a patient's pain is not validated, when a patient's pain is labeled by another as "psychological" or "faking it". Such an experience engenders both social isolation and the person learns to distrust their own perceptions. Essentially, this is an understanding of suffering as the relation of meaning to the way in which illness is experienced.<sup>301</sup>**

**Patients suffer from losses of themselves , their identity, in relation to their world of objects, events and relationships. Such losses could include memory, past life experiences, deep ties to family or loved ones, cultural background, social roles, even identifying their own body within illness as the enemy. The processes and human contact of diagnosis and treatment can either reduce the impact or increase the disruption of such loss if it is not attentive to such meanings?<sup>302</sup>**

**At times suffering is relieved. The challenge did not become a threat, the person was able to transcend their earlier self identity and social identity to**

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<sup>299</sup> THOMASMA, "Commentary: Response to Erich Loewy," p. 90.

<sup>300</sup> THOMASMA, "Commentary: Response to Erich Loewy," p. 91.

<sup>301</sup> CASSELL, "The Nature of Suffering and the Goals of Medicine," p. 641.

<sup>302</sup> CASSELL, "The Nature of Suffering and the Goals of Medicine," p. 642.

integrate the illness event within a redefined framework of personal and social meaning. Perhaps the patient is able to integrate the illness experience into a larger life narrative where the illness experience does not eclipse threads of meaning found throughout the life narrative but only plays a chapter in the larger story. But if suffering is not relieved, if it does begin to direct the narrative in a way that eclipses other important meanings, what then? What if the future perceived without hope of medical recovery or personal integration looms large with all other life meanings eclipsed by the illness experience? How does one transcend such suffering into the future? What does the identity of the suffering palliative patient require? Some palliative care professionals feel ill equipped to respond to these questions and believe this palliative exploration is as essential as research on physical pain management strategies.

The lack of "mentoring" and support to health care workers dealing with suffering and death is identified as a serious problem.<sup>303</sup> Being inexperienced or unprepared for the unique demands of living this embodied dying process of patients can create added suffering for either clinician or patient and eventually to distance or abandonment. First, there needs to be a recognition of the interdependent nature and the various types of pain and suffering which require different types of responses. Second, there needs to exist an invitation or a request to participate in the experience of suffering from the patient who

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<sup>303</sup> GREGORY and ENGLISH, "The Myth of Control: Suffering in Palliative Care," p. 21.

embodies illness. The opening of such a relationship seems to require mutual demands on healthcare professionals and clinicians but it is proposed that in this relationship and among the mutual demands, embodied sufferers lead and caregivers follow.<sup>304</sup> Such an approach looking for patient's to lead would seem to contradict the concerns of healthcare professionals and palliative care specialists who believe suffering disables the autonomy of the patient and an active role needs to be taken by the clinician to enable the patient. In fact the function of medicine is proposed as enabling sick persons, within the constraints of their illness, to continue to live true to themselves.<sup>305</sup> Successful patient self-expression and self-representation needs the support of clinicians because, "suffering persons, alone and unaided, cannot articulate their best interest beyond seeking the relief of their suffering or its source".<sup>306</sup> Clarity seems to be needed concerning the collaborative relationship or how and when patients might lead caregivers as well as how and when caregivers might lead patients.

As palliative care professionals seek to learn how they might best contribute to preparing a space for patients dying with a terminal illness, it is interesting to recognize that only 5% of terminally ill patients express a desire for a *good death* while most desire dying in *ordinary life*, defined as life

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<sup>304</sup> FRANK, *The Wounded Storyteller*, p. 33.

<sup>305</sup> CASSELL, "The Importance of Understanding Suffering for Clinical Ethics," p. 82.

<sup>306</sup> CASSELL, "The Importance of Understanding Suffering for Clinical Ethics," p. 81.

continuing to resemble familiar routine until the end.<sup>307</sup> One has to wonder whether the uniform "good death" defined by the values and discipline of palliative care is the same as diverse types of "ordinary life" individually defined by terminally ill patients? Such a question raises the possibility that the very *telos* of palliative care, that passage being prepared for terminal patients, may not be what is needed and given the social character of dying, may even be harmful. When expectations of a *good death* are not realized (ie tragic suffering, lack of personal integration or closure with loved ones) then the reasons for such discordance are sometimes misplaced by either stigmatizing the patient as a bad patient or laying blame with healthcare professionals.<sup>308</sup> Stigmatization of patients raises the awareness of confusing whose suffering, whose identity, we are attempting to heal; the patient's, the family's, or our own.<sup>309</sup> Such stigmatization reveals how patients and clinicians are part of the fabric of the social meaning of illness and how personal identities are wrapped up in pre-designed conceptions of a good death, success and failure in palliative care.

### 3) Corrective Vision

Is pain and suffering the enemy within palliative care or also a voice

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<sup>307</sup> DUNLOP, "Commentaries: When Palliative Care Fails to Control Suffering," pp. 28-29.

<sup>308</sup> Susan SONTAG wrote her work *Illness as Metaphor* because of the many ways she found cancer patients were stigmatized by clinicians and caregivers because of the social images and meanings created in the social psyche about cancer. See *AIDS and Its Metaphors*. (New York: Farrar, Straus and Giroux, 1989). pp. 11-12.

<sup>309</sup> DUNLOP, "Commentaries: When Palliative Care Fails to Control Suffering," p. 29.

needing something essentially different than have been offered in traditional palliative treatments or therapies? Given the complexities and limitations experienced within one-sided approaches to pain and suffering, what are some insights pointing to corrective vision? Certainly the corrective vision of palliative care needs further exploration and differentiation to inform its current approaches to dilemmas such as palliative sedation practices. Distinctions and separations which once helped to clarify are perhaps now not integrating or differentiating the complexity of our experience.<sup>310</sup>

Separations of cure from care, of dying patient from family, of clinical objectivity from human compassion, of hard from soft data, of a dying patient's body from that person's biography. These separations disfavored, when they did not outrightly exclude, scientific, clinical, and compassionate attention to a sick and dying person's pain, discomfort, distress, insomnia, anxiety, joys, sorrows, guilts and other manifestations of complexity at work in every human life.<sup>311</sup>

In our effort to establish meaningfulness we realize that causal explanations, such as those that try to place culpability if not guilt, do not establish meaning, if only because causal explanation and interpersonal understanding are radically different activities.<sup>312</sup> So if the task of reestablishing, continuing and creating

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<sup>310</sup> "The moral experience of human life are more varied and complex than the theories we use to try to grasp them conceptually. Moral practice continues to outrun and elude total theoretical encapsulation." In, Larry R. CHURCHILL, "Why We Need a Theory of Suffering, and Lots of Other Theories as Well," in *Journal of Clinical Ethics* 2 (2) (1991), p. 96.

<sup>311</sup> David ROY, "Ethics and Complexity in Palliative Care," in *Journal of Palliative Care* 11 (4) (1995), p. 3. See also David ROY, "A Handful of Sugar Onto the Fire?" in *Journal of Palliative Care* 9 (1) (1993), pp. 3-4.

<sup>312</sup> Georg GADOW, "Suffering and Interpersonal Meaning," in *Journal of Clinical Ethics* 2 (2) (1991), p. 105.

interpersonal meaning within the context of tragic suffering and fragmentation is accepted, the challenge becomes understanding the social meaning structure that is palliative care; the structures of meaning, power, and interdependence.<sup>313</sup>

Might the tragic suffering seen and expressed within palliative sedation dilemmas be the most embodied and intimate gestural expression of the self who is ill? Is it this intimacy and vulnerable expression of the self that would potentially cause another to turn away from such "nakedness" because it is too intimate, too vulnerable, too revealing? Such experiences of self-expression seem to necessitate the establishment of meaningful patterns in the face of disruption that bind human beings together as opposed to creating separation and distance. In order to create such meaningful patterns it will be necessary to analyze what palliative care social meaning structures are foundational to its traditions and presently in place.

Perhaps a place to begin is to understand the vulnerabilities and preferences of the social encounter between the patient and palliative care professionals. To be a patient is to deal with illness, to deal with pain, suffering, vulnerability, and an intensity of living. Incapacity is what qualifies the patient to be a patient.<sup>314</sup> Illness represents a threat to self, a challenge, to which a response will be given through how the illness is lived, is addressed. It is

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<sup>313</sup> GADOW, "Suffering and Interpersonal Meaning," p. 106.

<sup>314</sup> MACINTYRE, "Patients as Agents," p. 205.

individual, something happening to me, until others are asked to play a role. It is often during serious illness when the most profound life questions and emotional issues arise in a person.<sup>315</sup> Within the relationship between healthcare professionals and the patient, the role of the patient has been to be acted upon; to submit, accept, cooperate. It is due to this vulnerability that Pellegrino claims that patients are condemned to a relationship of inequality with the professed healer.<sup>316</sup> Susan Sontag suggests that there is a connection between this expected role of submitting and cooperating without complaint and our concepts of where illness originates and what it represents. She suggests that illness has always been used as a metaphor for judgement, an indication of sin and a test of moral character.<sup>317</sup> Patients with illnesses such as tuberculosis, cancer and AIDS have been treated by societies in an isolating and punitive manner. Since patients with these diseases have represented death, the possibility of any treatment was expected to be received by patients with gratefulness and without complaint.

It would seem that some illnesses or tragic illness narratives become or are shaped into a social meaning where the patient embodies the most intimate

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<sup>315</sup> Karen LEBACQZ, "The Virtuous Patient" in Earl E. SHELP, ed., *Virtue and Medicine: Explorations in the Character of Medicine* (Dordrecht, Holland: D. Reidel, 1985), p. 278.

<sup>316</sup> Edmund D. PELLEGRINO, "Moral Agency and Professional Ethics" in Stuart F. SPICKER and H. Tristram ENGELHARDT, eds., *Philosophical Medical Ethics: Its Nature and Significance: Proceedings of the third Trans-Disciplinary Symposium on Philosophy and Medicine held at Farmington, Connecticut, December 11-13, 1975.* (Dordrecht, Holland: D. Reidel, 1977), pp. 218-219.

and vulnerable expression of tragedy. We wish to turn away because these embodied metaphors offer an interpreted image that is too intimate, too vulnerable, too revealing. Given this context how does the patient interpret and communicate the illness experience with their body and with others? Three possible approaches are those of restitution, quest or chaos.

The quest narrative meets suffering head on, where the ill has a voice and the future is not closed but open with possibility. The restitution narrative, is a self-story only by default because the main actor is the remedy and the remedy steals the focus and the show. The chaos narrative, remains the sufferer's own story, but the suffering is too great for a self to be told. "The voice of the teller has been lost as a result of the chaos, and this loss then perpetuates that chaos."<sup>318</sup> It is the quest narrative which the ethos of palliative care has the closest correlation and the chaos narrative which for healthcare and certainly palliative care has the most difficulty in approaching and accepting. Perhaps these illness stories are each experienced by the patient, each rising to the foreground at particular moments while the others play background roles. Within the quest narrative, the author compares illness to the journey of mythic heroes where the narrative structure of the journey is divided into the stages of departure, initiation and return.<sup>319</sup> Heroism in the quest

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<sup>317</sup> SONTAG, *Illness as Metaphor*, p.7.

<sup>318</sup> FRANK, *The Wounded Storyteller: Body, Illness, and Ethics*, p. 115.

<sup>319</sup> FRANK, *The Wounded Storyteller: Body, Illness, and Ethics*, p. 117. Frank cites the

narrative is evidenced not by physical strength but in perseverance, the one who vows to return and share their enlightenment with others.

The hero's moral status derives from being initiated through agony to atonement; the realization of oneness of himself with the world, and oneness of the world with its principle of creation. Suffering is integral to this principle, and learning the integrity of suffering is central to the boon. The problem of return is to convince others that this atonement is a boon...The return thus sets in place the ill person's responsibility, and problem, of being a witness.<sup>320</sup>

The hero has traveled to a world beyond our own and has access to different experiences and a different knowledge. It is this knowledge that is the treasure that is communicated perhaps either vocally, bodily, or through sheer presence. Such metaphors and narratives open our eyes to different questions in facing the challenge of intractable pain and/or suffering. Should the *telos* of palliative care be oriented towards leading the patient to the quest narrative? In the process of dying, where does palliative care's vision of success want the patient, clinicians and families to arrive?

#### E) Preparation for Dying Well

From its birth, palliative care has desired to understand the process of dying in order to support the meaning of this experience for patients. First, was the goal to not increase the pain and limitation experienced by patients, through the care that was offered to them. More fundamentally, palliative care also desires to guide patients in a particular

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narrative structure he uses as identified by Joseph CAMPBELL in *The Hero with a Thousand Faces* (New Jersey: Princeton University Press, 1949).

environment, on a path, to a place. After Cicely Saunders decided to pursue the medical profession, then gained seven years clinical experience at St. Joseph's Hospital in London, she established St. Christopher's Hospice in London. There where she developed new pain management techniques she also brought an understanding of dying as a time of potential fulfillment,

To talk of accepting death when its approach has become inevitable is not mere resignation on the part of the patient nor defeatism or neglect on the part of the doctor. Certainly they will take no steps to hasten its coming, but for both of them it is the very opposite of doing nothing. The patient may well achieve more in this part of his life than in any other, making of it a real reconciliation and fulfillment. This will do more than anything else to comfort the relatives and help them on to the road to normal living again.<sup>321</sup>

Within this understanding, dying is embraced as a natural process rather than defeat, as an encounter to be engaged rather than hastened, and as a final stage of growth or human fulfillment. Within this understanding is also an implicit view of what it means to "die well".

"Dying well" or the "good death" have also be depicted through the use of the terms "tame" and "wild". Both historians and ethicists have used these terms to "tame" and "wild" to characterize way people of different cultures and historical periods approached death. Philippe Aries, in his historical review of death, claimed that the "tame death" was the

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<sup>320</sup> FRANK, *The Wounded Storyteller: Body, Illness, and Ethics*, p. 119.

<sup>321</sup> DE BOULAY, *Cicely Saunders*, p. 84.

oldest type of death there was.<sup>322</sup> This tame death was characterized as familiar, simple and public. The ordinary "tame death" of the Middle Ages is a death known to be coming, then prepared for, and takes place calmly amid a circle of friends and acquaintances. This is contrasted with the "vile and ugly" death of the Middle Ages characterized as,

...the secret death that is without witness or ceremony: the death of the traveler on the road, or the man who drowns in the river, or the stranger whose body is found at the edge of a field, or even the neighbor who is struck down for no reason.<sup>323</sup>

An important historical fact is helpful here. For the most part people in earlier times died of infectious disease of rapid onset and quick crisis; they did in fact die over a relatively short period of time.<sup>324</sup> Quite uncommon was the long and lingering death we can experience in our current day. The "tame death" Aries depicts as occurring in the Middle Ages as tolerable and familiar, affirmative of the bonds of community and solidarity, expected with certainty and without a crippling fear, begins to change at the beginning of the 18<sup>th</sup> century. To gain some perspective on modern implicit and socially constructed meanings of dying and death, it will be helpful to explore further shifts in socially constructed meanings for the process of dying from another historical vantage point.

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<sup>322</sup> Philippe ARIES, *The Hour of Our Death*, (New York: Alfred A. Knopf, 1981), p. 28

<sup>323</sup> ARIES, *The Hour of Our Death*, p. 11.

<sup>324</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 28.

### **1) Social and Historical Contexts for Death**

**The meanings of death are shaped within historical and social contexts. Between the thirteenth and sixteenth centuries in Western Europe, the interpretation and meaning of death underwent significant change. Two significant shifts concerned the emergence of judgement at the moment of death and the macabre. What meaning did these shifts offer in the turmoil of western medieval Europe, a period characterized by strong challenges to religious and state structures as well as the seemingly random visitations of famine and the Black plague?**

**Eleventh and twelfth century Europe was politically stable for the first time since the Carolingian period in the eighth century.<sup>325</sup> The stability put an end to two hundred years of invasion. During this time of peace, Europe was remarkably disease free allowing for a steady, unabated population growth from 25 million in 950 to 75 million in 1250.<sup>326</sup> A food surplus was fostered through agricultural innovations such as crop rotation and technological innovations such as the shoulder harness for animals. The combination of a food surplus and a population growth liberated people from having to live directly off the land and allowed their attention to develop other skills and specializations. Such**

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<sup>325</sup> Thomas Sherrer Ross BOASE, *Death in the Middle Ages: Mortality, Judgement, and Remembrance* (New York: McGraw-Hill, 1972), p. 15.

<sup>326</sup> Robert S. GOTTFRIED, *The Black Death* (New York: Free Press, 1983), p. 17.

changes in Europe's rural economy spurred the development of an efficient economic organization which, among other things, provided incentive for personal material gain. By the 1180's Europe had developed a market economy.<sup>327</sup>

Urbanization provided a new environment for economy and culture but also overcrowding fostered unhygienic conditions breeding disease. Due to unhygienic conditions food easily turned bad and its consumption was a frequent cause of death.<sup>328</sup> Contact with death was common not because of some special attraction to the cadaver but because the hospitals were simply hostels for the sick desititute. Medicine had nothing to offer that could not be done at home, morbidity and mortality were high, and the concept of the spread of infectious diseases was rudimentary.<sup>329</sup>

Conditions deteriorated between 1300 and 1347. In 1304 - 1305 famine struck northern France and persisted until 1310. From 1316-1322 a series of livestock epidemics devastated what remained of Europe's cattle population.<sup>330</sup> A succession of very wet seasons caused a series of

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<sup>327</sup> GOTTFRIED, *The Black Death*, p. 20.

<sup>328</sup> BOASE, *Death in the Middle Ages*, p. 11.

<sup>329</sup> Plinio PRIORESCHI, *A History of Human Responses to Death: Mythologies, Rituals and Ethics*, (Lewiston, New York: Edwin Mellen Press, 1990), p. 256.

<sup>330</sup> GOTTFRIED, *The Black Death*, p. 27.

crop failures and food shortages, which would not come entirely to an end until after the Black Plague. The Black Plague, or "black death", was a combination of bubonic, pneumonic, and septicaemic plague strains. It devastated the Western world from 1347 to 1351, killing 25%-50% of Europe's population and causing or accelerating marked political, economic, social and cultural changes.<sup>331</sup>

## 2) Meanings of the Moment of Death

Given the environmental factors shaping the physical reality of death in a historical time, meaning was also bestowed on death in belief and ritual. Before the thirteenth century the fate of the dead was represented within Christianity by the resurrection of the dead at the second coming of Christ. Christians believed they rested after death until this time when Christ returned in glory, similar to the image described in Revelation 4:2.<sup>332</sup> The focus of such a physical resurrection is clear since questions arose concerning the fate of bodies, which had been mutilated from warfare or eaten and digested by animals.<sup>333</sup> Responses found in thirteenth century handbooks for the laity, such as *La Lumiere as Lais*, claimed that the blessed would enjoy the use of all the senses. Their body would enjoy full vigor with the Resurrection of the Dead, regardless

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<sup>331</sup> GOTTFRIED, *The Black Death*, p. xiii.

<sup>332</sup> ARIES, *The Hour of Our Death*, p. 97.

<sup>333</sup> BOASE, *Death in the Middle Ages*, p. 36-37.

of the age at which they died. These meanings surrounding death at that time certainly express concerns and beliefs focusing on both the physical fate of death and the individuality of death.

Another key shift in the meaning of death and the fate of the dead can be found within twelfth century iconography. The shift in meaning moves from a focus on the theme of resurrection at the second coming of Christ, to a focus on the judgement of lives on the day of the second coming. This shift continues to develop until the moment of judgement is believed to occur not at the second coming of Christ but at the moment of individual death.<sup>334</sup> With this evolution the traditional interval of time between physical death and judgement disappeared.<sup>335</sup> Such a focus on judgement in the fate of the dead is also found in Dante's influential *Divina Commedia*. From the fourteenth century onwards, popular ideas of hell, purgatory and paradise were largely conditioned by Dante's vivid narrative.<sup>336</sup>

With the moment of judgement occurring at the moment of an individual's death, the bedroom chamber becomes the arena of a drama in which the fate of the dying person was decided for the last time and

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<sup>334</sup> ARIES, *The Hour of Our Death*, p. 101.

<sup>335</sup> ARIES, *The Hour of Our Death*, p. 107.

<sup>336</sup> BOASE, *Death in the Middle Ages*, p. 54.

where one's whole life, passions and attachments were called into question. The scene of this type of drama is depicted in illustrations found in treatises of the fifteenth and sixteenth centuries on the art of dying known as the *Artes Moriendi*. These treatises were to prepare individuals for death suggest that death is no respecter of person, their stress not upon hell but hope for heaven.<sup>337</sup> The development of the theme of judgement continues with the depictions of God no longer as judge but as arbiter or observer. The bedroom is full of adults and children for one always dies in public, never alone. The dying person is depicted as oblivious to these people and focusing on the battle in the room between angels and devils for possession of her soul; a battle which only the dying person can see.

How does the judge know of the events? The history of an individual's evil and good deeds are recorded in a book (Rev.12:1) known as the *Book of Life* or the *liber vitae*. Depictions in the *Artes Moriendi* of the fourteenth and fifteenth centuries show the accounts being kept by the devils who are confident that the evil deeds will outnumber the good.<sup>338</sup> It is an intimidating depiction of a triumphant devil if it were not for the gracious intervention of divine mercy. God and the court are there

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<sup>337</sup> Mary O'CONNOR, *The Art of Dying Well: The Development of the Ars Moriendi* (New York: AMS Press, 1966), p. 5.

<sup>338</sup> ARIES, *The Hour of Our Death*, p. 105.

to observe how the one dying conducts himself during this trial or test. Will the person display deathbed repentance or despair over their sins, display vanity over their deeds, display passionate love of things and persons? Such was the importance ascribed to the moment of death as the defining moment of one's life. In this stage the lead role was that of the dying individual with the role being so important that it was considered necessary to provide manuals for preparation. Each page of the text was illustrated so that those who could not read could discern the meaning. These depictions, such as the *Rohan Book of Hours* (1418-25), stressed the importance of deathbed repentance such that, even at the last moment, the life lived and the afterlife expected might not be lost.<sup>339</sup>

The focus of judgement at the moment of death with the possibility of repentance did give rise to the popular belief that regardless of how one lived, one could still redeem themselves by conducting themselves in a repentant manner.<sup>340</sup> Repentance and redemption were key definers of a "good death". A more extreme belief was that death might itself be postponed by good intentions. This was exemplified by the story of the Empress Matilda who was grievously ill after the difficult birth

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<sup>339</sup> BOASE, *Death in the Middle Ages*, p. 119.

<sup>340</sup> Philippe ARIES, *Western Attitudes Toward Death: From the Middle Ages to the Present* (Maryland: John Hopkins University Press, 1974), p. 38.

of her son, the future Henry II.<sup>341</sup> The story relates how she distributed her treasures to widows, orphans and the poor and so escaped death.

The resemblance of this deathbed court to that experienced in daily life in the middle ages is striking. Life in the Middle Ages is described as a long legal process in which every act is sanctioned by a legal transaction or at least by members of the legal profession. Government is modeled on the court of justice and every judicial Department or treasury is organized like a court with a president councilors prosecutor and court clerk.<sup>342</sup>

Another image and meaning of death that appears in literature and iconography around the same time as the *Artes Moriendi* is the *macabre*. The word *macabre* is often used to refer to realistic representations of the human body in the process of decomposition. The half-decomposed corpse, or *transi*, is the most common representation of death and an important minor character in the macabre iconography of the fourteenth to sixteenth centuries.<sup>343</sup> The horror of physical death and decomposition is also a familiar theme in poetry such as the thirteenth century, "Le Dit des trois morts et destrois vifs."<sup>344</sup> But this feeling of horror with

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<sup>341</sup> BOASE, *Death in the Middle Ages* p. 124.

<sup>342</sup> ARIES, *The Hour of Our Death*. p. 102.

<sup>343</sup> ARIES, *The Hour of Our Death*. pp. 110-114.

<sup>344</sup> BOASE, *Death in the Middle Ages*, p. 104.

decomposition was not limited to post-mortum decomposition. It included as well the mutilation, disfigurement and decomposition of the body in illness and in old age.<sup>345</sup> There are different reasons, interpretations, offered for the rise of the images of the *macabre*. One reason offered is that the *macabre* represented an expression of humanity's failure; that the struggle against the turmoil and death of the era produced such a strong love for life that the eventual triumph of death produced a discouragement in humanity's "failure to overcome death."<sup>346</sup> Another implies that the *macabre* was an exhortation of the Church to convert the lay populations and maintain orthodoxy in the midst of heresy and the medieval inquisition.<sup>347</sup> Could the expressions of the macabre be a search for realistic resemblances not reproduced in order to frighten but used as a presence of the person, as a photograph would be used today?<sup>348</sup> Perhaps the middle ages tired of the horrors of damnation from judgement, but afraid to question orthodox teaching due to the practice of the medieval inquisition, simply focused on the realism of the physical

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<sup>345</sup> ARIES, *Western Attitudes Toward Death from the Middle Ages to the Present*, p. 41.

<sup>346</sup> Johan HUIZINGA, *The Waning of the Middle Ages: a study of the forms of life, thought, and art in France and the Netherlands in the fourteenth and fifteenth centuries*. (New York: Doubleday, 1954) p. 141, cited in ARIES, *The Hour of Our Death*, p. 137.

<sup>347</sup> ARIES, *The Hour of Our Death*, p. 123.

<sup>348</sup> ARIES, *The Hour of Our Death*, p. 127.

corruption of their body.<sup>349</sup> Still others propose that the images of the macabre represented the equality of death; that death has no favorites – even among the class layered society of the middle ages.<sup>350</sup> It is this latter notion of the equality of death and its inherent justice that seems to resonate with the social and political environment of the European middle ages.

The tumultuous shifts and changes that occurred during the Middle Ages with respect to economy, government, religion, and disease shifted and revised the societal structures and self-understandings of the culture. The two shifts in the representations of death, a more immediate judgement at the moment of death and the corruption of the body represented in the *macabre*, seem to share a concern for equality and justice. A more immediate judgement could perhaps offer a greater sense of justice in direct proportion to the injustice and disorder being experienced in living. A focus on the corruption of the body before and after death would seem to place each individual on equal footing regardless of their status in society. These shifts in the representation of death in western, medieval Europe provided structures of justice that more immediate, individual and equal in a society whose experience of

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<sup>349</sup> BOASE, *Death in the Middle Ages*, p. 106.

<sup>350</sup> PRIORESCHI, *A History of Human Responses to Death*, p. 402

**unexplainable disease and corrupt justice in governmental, religious and social structures was prominent and turbulent.**

### **3) Patterns and Themes**

**Has such incapacity always existed in the narratives of patients? Before the Middle Ages, it was taken for granted that the person dying was the one who knew they were dying before anyone else had that knowledge. It is often the case in the modern practice of medicine that physicians, nurses, healthcare professionals or family are the first to have that knowledge and assume the responsibility to tell the person of their illness and potential or immanent death. Beginning with the fifteenth century, the moment of death was a public occasion where the death bed was surrounded with family and friends. Within this public occasion the physician and the priest had their place but the person dying, the patient held the primary role of presiding over the event because this was understood as an exceptional moment which gave his individuality its definitive form. The dying person spoke to friends and family in these final conversations where forgiveness was asked, blessing was given and goodbyes were completed. Today the good death for many patients and healthcare professionals consists of dying as discreetly and with as much dignity as possible.<sup>351</sup> Often the courage needed on the part of patients is to endure the efficiency of schedules, treatment with techniques. What is significant is the**

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<sup>351</sup> Philippe ARIES, "Death Inside Out," in Peter STEINFELS and Robert M. VEATCH, eds., *Death Inside Out: The Hastings Center Report* (New York: Hastings Center: 1975), p. 45.

recognition that there has been a shift over time in the role of a patient with their physician concerning illness and death. The shift concerns the social frameworks at the disposal of the patient which offer them a participatory and responsible role in how their illness, treatment and the event of death are given meaning and integrated within their life. Such historical shifts in the narrative quest of patient participation demonstrate changes in when and how is the patient to comply, to inform, decide, listen, act, and wait?

In a modern, scientific and technological approach to dying an ethical dilemma is often focused on from the perspective of making treatment decisions rather than the creation of meaning. In these contexts treatment decisions become the framework and focus for defining whether a death is a tragedy or meaningful, professional and personal success or failure. Prioritizing the autonomous treatment decisions of patients as *the* priority or "good" within a clinical dilemma could be faulty.<sup>362</sup> The coping skills of patients include variations based upon their ability to clearly picture their future life plans and the risks and opportunities most likely to be encountered. It is suggested that clinical practice needs to be sensitised to the narrative of the patient's life and how this medical event needs to be oriented within the context of their life history before attempting to come to conclusions with respect to moral

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<sup>362</sup> David C. THOMASMA, "Beyond Autonomy to the Person Coping With Illness, " in *Cambridge Quarterly of Healthcare Ethics* 4 (1) (1995), p. 12.

clinical dilemmas. Within the physician - patient relationship, it may not be as important to respect a patient's autonomy by respecting their decisions as much as "the necessity to provide in a healing relationship the necessary conditions for patients to develop their own reintegrating techniques".<sup>353</sup>

#### **4) Modern Dying as Preparation for Growth**

Upon reflecting on the work of Philippe Aries, Daniel Callahan argues that two illusions mark the change in our perceptions of death.<sup>354</sup> The first illusion is the naïve belief that the watchful self, aided by the right laws and medical practices, can master the body by means of carefully controlled medical technology. The second illusion is the belief that we can know ourselves and our own wishes well enough to manage ourselves with the same precision with which we would control the technology. Callahan attempts to recover a modern understanding of the tame death through his concept called a peaceful death. This peaceful death is defined as 1) an acceptance of death where control over fate will pass from its hands, 2) a self awareness that one is dying, that the end has come, 3) a belief that death should be public, a time when family and

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<sup>353</sup> THOMASMA, "Beyond Autonomy to the Person Coping with Illness," p. 17.

<sup>354</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 37.

friends draw near, where goodbyes and closure are created.<sup>355</sup> The key barriers precluding this peaceful death are,

1) the increasing difficulty of finding any clear line between living and dying, 2) the ambivalence, exacerbated by medical science, that many feel about whether death should be fought or accepted, 3) by medical science focusing on the causes of death the illusion has been fostered that mortality can be eliminated by eradicating lethal disease, 4) death is no longer the fault of nature; it has become an exclusively human responsibility, 5) in the conflation of respect for the sanctity of life and the technological imperative, medicine and morality have combined to create a powerful pressure against the acceptance of death.<sup>356</sup>

Aries, Becker<sup>357</sup> and Gorer<sup>358</sup> each speak of an extreme attempt to tame death, to make death less feared through a cultural denial of death. In spite of any attempt to make the dying process and death less feared, many still experience dying in a manner that is feared. Modern palliative care attempts to tame death but the four tragic palliative care dilemmas offered at the beginning of this inquiry seem to highlight a lack of success. What is the particular environment, path or place which palliative care seeks to create to tame death and guide patients, the antithesis of which would describe tragedy or defeat for palliative care?

It would be incorrect to state that there is one modern way of dying. It is perhaps more appropriate to say there are dominant trends

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<sup>355</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality*, p. 54.

<sup>356</sup> CALLAHAN, *The Troubled Dream of Life: Living with Mortality* p. 89.

<sup>357</sup> Ernest BECKER, *The Denial of Death*. (New York: Free Press, 1973)

<sup>358</sup> Geoffrey GORER, *Death, Grief and Mourning in Contemporary Britain*. (London: The Cresset Press, 1965)

shaping current experience and goals for "dying well". Within the practice of palliative care there are two dominant beliefs or goals at work. The first goal as we have discussed is that of pain management and the belief that the pain and suffering can be managed or controlled. The second goal is to help prepare the patient for dying as the final stage of growth and the belief that death has an order or telos towards integration, disrupted only by the patient's psycho-social or spiritual inability to achieve integration through acceptance. Two women physicians in the 1960's, one in England and the other in the United States, have been foundational in pioneering these two trends as they attempted to understand and create the best environment for dying patients. Drs. Cicely Saunders and Elisabeth Kubler-Ross are arguably the founders of modern palliative care. Each were shaped by the limitations they experienced in caring for incurable, terminally ill patients. Each with their own focus attempted to tame the potentially chaotic and confusing character of dying for both patients and clinicians. They sought knowledge that could foster dying well, a beautiful dying, a dying accepted and integrated within the identity of the patient. In attempting to shape dying, they had in mind a process they would like dying patients to travel and a destination they hoped patients would arrive. Of the two, Dr. Kubler-Ross is perhaps most well known for proposing that dying is

perhaps the last stage of growth. It is an exploration of her goal, particular understanding and implicit *telos* that will now be characterized.

Dr. Kubler Ross was born in Switzerland and moved to New York in the late 1950's. Soon after arriving at Billings hospital, New York, in 1966 she became involved with educational seminars aimed at teaching chaplains how to prepare patients to receive the news they were dying and how to comfort them through the remaining days of their lives.<sup>359</sup> From these interviews over the next couple of years came the material for her widely disseminated and influential 1969 published work, *On Death and Dying*. This work offered a five stage theory on the process of dying. Kubler-Ross proposed that the dying person passes through five stages. They are depicted as normal responses to a person with illness learning of their impending death. The first stage is *denial*, which is in effect the person saying "no!" to death. The second stage is *anger* where the person is asking the question of why me? The third stage is *bargaining* where the person attempts to pragmatically bargain for an extension to life. *Depression* is the fourth stage and begins when the person can no longer deny his illness and experiences loss. The fifth and final stage is *acceptance*. It is interesting to note that Kubler-Ross remarks that this stage of *acceptance* should not be mistaken for a happy

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<sup>359</sup> Heather ROBERTSON, "Dead Wrong," in *Elm Street* (September, 1998), p. 74.

**stage. "It is almost void of feelings. It is as if the pain had gone, the struggle is over, and there comes a time for the final rest before the long journey as one patient phrased it."<sup>360</sup>**

**Stage theory in general is found to have certain parameters. Change is characterized as occurring through qualitative differences. With Kubler-Ross's stages, individuals are found not to move through the stages at the same rate. Some do not reach the final stage at all. A person can be "caught" in a certain stage, unable to progress. There can be some regression between stages and two stages can be found to coexist.<sup>361</sup>**

**Because of its wide dissemination and exposure, this stage theory of Kubler-Ross became the primary approach for understanding and interpreting the experience of dying. It offered the healthcare professional and the layperson something to look for, even a *telos* or a direction. It was intended, "to summarize what we have learned from our dying patients in terms of coping mechanisms at the time of terminal illness".<sup>362</sup> It contributed a language to an experience often treated as taboo or**

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<sup>360</sup> Elizabeth KUBLER-ROSS, *On Death and Dying* (New York: Macmillan, 1969), p. 100.

<sup>361</sup> Robert KASTENBAUM, "Do We Die in Stages?" in Sandra Galdieri WILCOX and Marilyn SUTTON, eds., *Understanding Death and Dying: An Interdisciplinary Approach*, (London: Mayfield Publishing Company: 1977), p. 124.

<sup>362</sup> KUBLER-ROSS, *On Death and Dying*, p. 33.

found confusing to those caring for terminally ill patients. Anxiety and lack of cognitive structure were replaced by the security of a knowledge. The debate that has arisen is whether this theory of dying is the most accurate or the most useful. There is acknowledgement that the stage theory of dying is an empirically valid formulation of human experience during the dying process but little effort has been given to study the relationship between theory and fact.<sup>363</sup> The most common critique is that this stage theory of dying assumes a single primary path of movement.

Variations are acknowledged, but are seen as deviations from a central mode of progression. This approach is objectionable in the stage theory of dying as well as other forms of developmental theory – objectionable because the uncritical perpetuation of the one-path conception (a) impedes the appreciation and discovery of alternate approaches and (b) has the effect of stereotyping uncommon or idiosyncratic patterns as deviant.<sup>364</sup>

Healthcare professionals have used the path of this five-stage theory as a measure or thermometer of success in their work for patients. This has been demonstrated in how some healthcare professionals pressure, manipulate and perhaps stigmatize as uncooperative those angry or depressed dying patients who are not "moving on" in the five stage process to the stage of acceptance.<sup>365</sup> Success would seem to be

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<sup>363</sup> KASTENBAUM in WILCOX and SUTTON, *Understanding Death and Dying: An Interdisciplinary Approach*, p. 128.

<sup>364</sup> KASTENBAUM in WILCOX and SUTTON, *Understanding Death and Dying: An Interdisciplinary Approach*, p. 131.

<sup>365</sup> Robert FITCHETT, "Its Time to Bury the Stage Theory of Death and Dying," *Oncology Nurse Exchange* Vol II, Issue 3 (1980), p. 1. See also, Robert P. HUDSON, "Death, Dying and the Zealous Phase." *Annals of Internal Medicine*, Vol. 88 (1978), pp. 700-1.

understood in these terms as the ability of professionals to guide patients through the process to acceptance. A patient not reaching the last stage of acceptance before death might be evaluated by professionals as failure and the result of either an uncooperative, deviant patient or ineffective healthcare professional. Such stages theory offers little to understand the variance that may occur in the dying experience according to the nature of the disease<sup>366</sup> or other differences related to gender, ethnicity, or sociophysical environment.<sup>367</sup> What this stage theory offered to those caring for terminally ill patients was an understanding of dying, a telos, a direction to manage and perhaps an element of control within a frightening experience. As the theory became widely used it perhaps became the predominant cultural meaning in healthcare for a socially acceptable death.

Other models which have been offered include a three stage model claimed to be based on two central principles.<sup>368</sup> The first principle is that patients facing death exhibit a mixture of reactions and responses

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<sup>366</sup> There are those who maintain that a patient's dying is strongly influenced by the pathology and meaning that characterizes their disease. See Sherwin B. NULAND, *How We Die: Reflections on Life's Final Chapter* (New York: Vintage Books, 1995), pp. xvii-xviii.

<sup>367</sup> The research interviews with patients conducted by Barney G. GLASER and Anselm L. STRAUSS preceded the work of Elizabeth Kubler-Ross and focuses more on the social environment shapes the experience of dying for the patient. See *Awareness of Dying* (1965) or *Time for Dying* (Chicago: Aldine, 1968).

<sup>368</sup> Robert BUCKMAN, "Communication in Palliative Care," in *Oxford Textbook of Palliative Care* (1998), p. 145.

which are characteristic of the patient rather than the diagnosis or the stage of the dying process. Second, progress through the dying process is marked, not by a change in the type or nature of emotions, but by resolution of the resolvable elements of those emotions. The three stages offered by Therese A. Rando<sup>369</sup> are the avoidance phase, the confrontation phase and the accommodation phase. The accommodation phase is described as a gradual decline of grief and a reentry into the everyday world. Implicit within this final stage is perhaps not an element of completion but an element of integration - of a new type of lived meaning through the integration of this experience in the life of the grieving person. The three stages offered by Robert Buckman include an initial stage where the patient first faces the possibility of dying. The second stage is the process where the patient encounters and resolves those elements of their initial reactions that are resolvable. The third stage is an acceptance stage. While it is noted that "acceptance is helpful but not an absolute necessity",<sup>370</sup> arrival at the stage of acceptance continues to be the end point of a process where movement is characterized as progress, growth, integration, self-actualization or

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<sup>369</sup> Therese A. RANDO, *Grieving: How to go on When Someone You Love Dies*, (Lexington, Mass: Lexington Books, 1988), pp. 20-24. See also, *Grief, Dying and Death: Clinical Interventions for Caregivers*, (Chicago: Research Press Company, 1984), p. 199-223.

<sup>370</sup> Robert BUCKMAN, "Communication in Palliative Care," in *Oxford Textbook of Palliative Care* (1998), p. 146.

**wholeness. There is still a culturally constructed goal or good implicit within this movement through the process of dying and the experience of grief.**

**Stage theories of dying seem to be caught in a tension between the attempt to strike a balance between the particularity and individuality of dying and the universal stages of development or progression. Critiques seem aimed less at the stage theory itself and more with how their rigid use in practice leads to the stigmatization and blaming of patients. A final challenge of its universal claims is the particularity of tragic palliative sedation dilemmas. In the next chapter an exploration of how tragedy might serve to instruct ethics would be helpful.**

### **Conclusion**

**This chapter sought to identify the goods the discipline of palliative care seeks to offer society, their particularity, their orientation and their vulnerability. The two goods focused upon were the relief of pain and suffering as well as preparation for dying well. Concerns were identified about a scientific and technological approach to pain and suffering, which would narrowly focus on neurotransmitters and strip pain and suffering from any personal or cultural encounter with meaning. The concern is whether such medicalized understandings of pain will in the future be ample and sustaining for the human community or thin and sterile, will these meanings which we discover as well as**

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shape, help us or merely increase our feeling of affliction? Palliative care professionals are concerned that a singular focus on the good of a technological pain management does not adequately distinguish pain from suffering and is rooted in an unreasonable promise and attempt to control the suffering of patients. What is interesting is this particular manner which palliative care seeks to tame the dying process of patients. Its attempts to understand the needs of patients through interviews with dying patients seem to become caught between universal stages of dying such as that developed by Kubler-Ross and the particularity and individuality of dying. The challenge of palliative care is the integration of tragic and fragmented forms of dying which are beyond their ability to tame or control. To that end, the shift may concern a better understanding of the type of problem tragic dying is for palliative care, of how professionals might foster interpersonal meaning with the context of tragic suffering and fragmentation. Clarity seems to be needed concerning the type collaborative relationship the palliative care encounter is, how and when patients might lead caregivers as well as how and when caregivers might lead patients. To this aim, how might the experience of the palliative sedation dilemmas as tragedies offer instruction in the pursuit of the humanization of dying? It is this question that we will explore in the following chapter.

## CHAPTER FOUR

### Decision in Situation: Avoidance and Conviction Within Palliative Sedation Practices

#### A) Introduction: Decision in Situation

This inquiry began with the suffering experience of dying patients articulated in four narratives and a question raised in the voices of palliative care clinicians. What is the ethically significant difference between killing and letting die in palliative care, where death is not only foreseen through the treatment but, part of the complex act of doing good such as relieving pain and suffering? Implicit within the narratives and this question are themes such as the interpretation of action, evil, suffering, as well as the limitations confronted within particular tragedies.

As this inquiry moved to incorporate reflection on tragedy and moral reasoning in particular situations, the work of philosopher Paul Ricoeur, self described as a "philosophical anthropology", offered insightful analysis and integration of these themes. The earlier work of Paul Ricoeur such as *Fallible Man and the Symbolism of Evil* focused on themes of evil and the human experience of limit. Within his more recent work, *Oneself as Another*, he reflects on "practical wisdom", a dialectic between ethics and morality played out in moral reasoning and judgement in difficult particular cases, which does not fall into a kind of arbitrary situationism. At the center of this reflection is a nine page

interlude entitled "Tragic Action", dedicated to his late son, Olivier, who died from suicide at the age of thirty nine only days after Ricoeur finished the Gifford lectures in Edinburgh.<sup>371</sup> It is Ricoeur's use of tragedy as an instructor to ethical reasoning that was found insightful and particularly appropriate to the palliative sedation practices being questioned by palliative care professionals.

Chapter One explored the clinical context of palliative care sedation dilemmas, the types of palliative sedation stories which disrupted consensus on the adequacy of the principle of double effect, and the limit experiences clinicians point to creating the complexity of these tragic dilemmas. These limit experiences included the context of interdisciplinary decision making, the experience of these dilemmas as a trauma that is unpredictable and without obvious meaning, the limitations experienced in addressing difficult pain and suffering, the debate and expressed confusion on whether PDE offered adequate and authentic guidance regarding these tragic palliative sedation dilemmas.

Chapter Two explored the theological and philosophical debates on the interpretation, application and adequacy of PDE to distinguish morally relevant features of actions with multiple effects. The focus of the theological debate concerned the criteria of adequacy for allowing exceptions to what are considered by some as exceptionless moral norms. The conflict of the debate

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<sup>371</sup> Charles E. REAGAN, *Paul Ricoeur: His Life and His Work*. (Chicago: University of Chicago Press, 1996), p. 92.

seemed focused on two underlying concerns. On one hand, deontologists argue for exceptionless moral norms and privilege universalism and respect for the norm which provides support for the role of public moral authorities and community living. On the other hand, revisionists privilege the importance of circumstances and the singularity of unique situations not appropriated by the moral norm traditionally interpreted, thus requiring exceptions to the moral norm. The philosophical debate initiated by Rachels proposed that there is not a significant morally relevant difference between killing and letting die when comparing the internal physical causality between a positive action described as "killing" and an omission described as "letting die". Others who debate Rachels attempt to show the relevance of such a distinction by demonstrating the importance of factors not limited to a focus on physical causality.

Chapter Three explored the practice of palliative care and the socially constructed meanings of its history which both creates and shapes its understanding of how dying is humanized and the tragedy of some types of difficult palliative sedation dilemmas. Operative in palliative care was discovered a struggle between a healthcare tradition focused on scientific and technological approaches to eradicate disease seemingly in conflict with a person centered healthcare tradition focused on wholistic care and healing approaches with the patient as person. This struggle has demonstrated the existence of heterogeneous approaches within palliative care as opposed to one

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homogeneous approach. Nonetheless these heterogeneous approaches do share a common struggle between utopia and dead traditionality as they attempt to manage the pain and suffering of patients as well as orchestrate a dying that is self-actualizing and a death that is peaceful.

This exploration has highlighted the experience palliative sedation dilemmas as experiences of tragedy. Questions arising from this experience concern the adequacy to approaches of interpretation of action, the recognition of the type of violence palliative approaches may have on dying patients or palliative care professionals, as well as the process of ethical deliberation and decision making which integrates the particularity of unique situations.

Palliative care is discovering limitations. Limitations not only in the sense of *finiteness*, of coming up against walls and borders, but also in the sense of *fragility*, the fragility of its own self-identity and ideology. It faces such limitations with respect to the ethical reasonings it utilizes when challenged with tragic palliative sedation dilemmas. It faces such limitations regarding its implicit telos or the "good death" it wishes to foster for its patients. Explicitly these goals are spoken of as pain management and that the stage of dying would be a time of fulfilment, acceptance, as well as personal integration and meaning.

A consistent goal within each of the chapters in this inquiry has been to understand moralities and strategies avoiding the one-sidedness of their arguments and thus fooling or duping the reader. How we may have been fooled or duped by the moralities created within and shaping the context of

**palliative care. The tragedy within these stories has caused the exploration to shift its gaze from the formal and analytical exploration and application of the principle of double effect to understanding how not only these moral reasonings and the principles themselves are not so much wrong but one-sided. Our inquiry has supported that certain approaches have perhaps indeed been one-sided. Theological debate on the principle of double effect demonstrated different double effect reasonings regarding: a) its origin, genesis and whether PDE is being currently interpreted in a manner true to its original intent and origin, b) to what extent its universalizing use as a moral norm can appreciate and integrate the particularity of various moral contexts, c) whether PDE is a justifying principle or has a hermeneutic function, d) whether these various moral reasonings have followed a valid development of PDE as a moral norm. Problematics are also found with the philosophical debate over PDE and whether the criticism of interpreters such as James Rachels follow a narrow, physical and causal interpretation which does not integrate the particularity or circumstances or the singularity of the intentions of actors.**

**Two of the most prominent goods of palliative care, the management of pain and the preparation for dying, were also discovered to have the potential for one-sided orientations. The reductive threat created by a medicalized interpretation of pain is that pain would no longer be understood as involving a personal and cultural encounter with meaning. Such an approach would wish to eradicate pain and suffering in much the same way that the scientific approach**

to medicine wishes to eradicate disease from the human body. Either approach seems to reduce the social meaning of illness and objectifies the physicality of the human body in a manner that reduces human meaning and the human person. Also, palliative approaches preparing the patient for the dying process favored understanding the process of dying as a time of self-actualization where mortality and death are accepted as a stage of human living. Yet a sense of failure can linger in tragic situations where patients do not reach a stage of acceptance or personal integration of dying and mortality in their life story. There is a feeling that a "natural" or "conventional" process of self-actualized dying, as defined by the patterns experienced within palliative care, was not realized. Most palliative care clinicians would not claim that they expect all dying to be peaceful or a time of self-actualization. Yet the telos, the achievement and satisfaction, of palliative care is to orchestrate the experience of death according to these types of parameters. The complexity and rawness of tragic suffering which accompanies the transition of identity and meaning of the patient are not so much unexpected as interpreted as uncontrolled "pathos" and as the symbols of failure for palliative care. In essence the patient becomes reduced to being understood as pathos and an anomaly.

The avoidance within each of these one-sided approaches is a struggle between convention and the particular meaning of other dying narratives. Is the particularity and importance of these particular types of dilemmas being ignored? Questions arise from tragic palliative care stories which disrupt

**consensus not simply concerning clinical/technical ability but our moral and ethical reasonings.**

**The focus of this chapter will be to highlight the characteristics of the ethical and moral conflicts within tragic palliative sedation dilemmas. This focus will be attained through first identifying how the genre of tragedy is instructive to the limits we experience in healthcare ethics and specifically in tragic palliative sedation dilemmas. Second, this inquiry will explore how Paul Ricoeur's dialectics between universalism and contextualism, the self and the other, the past and the future, the ethical aim and the moral norm are fruitful resources to understanding the ethical conflicts within palliative sedation narratives. Third, These insights will be applied to instances of limitation and avoidance within current palliative sedation practices. Fourth, and finally, this inquiry will explore how a such a critical evaluation of the social goods of palliative care and its ethical reasonings would effect a different use of PDE and less reductive approaches to the ethical aim of humanizing dying.**

#### **B) Tragedy and Vulnerability**

**Exploring the palliative care goods of pain management and preparation for dying offer perspective on the diversity and complexity of dying. Complex palliative sedation narratives, such as those offered earlier, heighten our awareness of limitations, loss of control, and vulnerability as we attempt to responsibly respond to patients with profound suffering. Such palliative care experiences witness suffering and terror not only on the part of patients but also**

on the part of healthcare professionals and family members. The accounts seem tragic not only due to the presence of intense suffering and terror but also due to the manner in which the events unfold. Suffering and death in these narratives seem to have a character of inevitability, a relentless sequence of events seemingly already set in motion. It proceeds almost like the adding up of a sum or like the losing chessplayer, who sees options disappear and finds herself backed into a corner, visualizing checkmate unfolding before her. The suffering and death are not perceived as proceeding accidentally, nor even as preventable, but almost mathematically.<sup>372</sup> There is a "pathos" in place that seems larger than disease and biological pathology. This losing struggle and loss of control throw our attention on the vulnerability of both the human body and our ability to explain the meaning of that extreme vulnerability or absurd suffering.<sup>373</sup> If we can indeed call these narratives tragedies, does tragedy equate with failure? How might one recognize and appropriately respond to tragedy in healthcare? Does tragedy simply offer the experience of meaninglessness or the opportunity for development, instruction or meaning within this struggle? To better understand an appropriate response to our experience of these sedation narratives as tragedies, it is important to understand what tragedy, as a narrative genre emerging from ancient Greek

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<sup>372</sup> David B. MORRIS, *The Culture of Pain*, (Berkeley: University of California, 1991), p. 261.

<sup>373</sup> MORRIS, *The Culture of Pain*, p. 258.

civilization, seeks to express or instruct.

### 1) Recognition of Tragedy

At the beginning of this inquiry, four narratives were presented which might be described as tragic. How might a narrative or an action be characterized or recognized as tragic? Two definitions of "tragedy" offered by Webster's Third New International Dictionary are,

a drama in verse or prose and of serious or dignified character that typically describes the development of a conflict between the protagonist and a superior for (as destiny, circumstance, society) and reaches a sorrowful or disastrous conclusion that excites pity or terror.<sup>374</sup>

The second definition offered is, "a disastrous often fatal event or series of events."<sup>375</sup> The etymology of the term *tragedy* (*tragoidia*) has a couple of explanations. One is that *tragoidia* comes from *tragon oide* meaning goat song and it is believed that the original chorus within Greek tragedies consisted of satyrs who were in some respects goat like.<sup>376</sup> Another explanation is that before the year 506 or 502 BC, *tragoidoi* was the official title of the contestants in tragedy competing for a prize which was a goat.<sup>377</sup>

Aristotle also offered a celebrated definition of *tragedy* found in his *Poetics*.

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<sup>374</sup> Webster's Third New International Dictionary of the English Language Unabridged. (Springfield, Mass.: G. & C. Merriam Company, 1969): 2423.

<sup>375</sup> Webster's Third New International Dictionary of the English Language Unabridged. (Springfield, Mass.: G. & C. Merriam Company, 1969): 2423.

<sup>376</sup> Walter KAUFMANN, *Tragedy and Philosophy*, (New York:Doubleday, 1968), p. 34.

<sup>377</sup> Gerald F. ELSE, *The Origin and Early Form of Greek Tragedy*, (Harvard: Harvard University Press, 1965), p. 56.

Tragedy, then is the imitation of good action, which is complete and of a certain length, by means of language made pleasing for each part separately; it relies in its various elements not on narrative but on acting; through pity and fear it achieves the purgation of such emotions. <sup>378</sup>

Strong and continued debate has occurred regarding the english translation of key terms within Aristotle's description of tragedy. These key greek terms debates, with their traditional translations in brackets, are: *mimesis* (imitation or representation); *eleos and phobos* – (pity and fear or ruth); and *catharsis* (purgation). Aristotle actually distinguished four types of tragedy. The fourth is described as a person who is "neither outstanding in virtue and righteousness, nor is it through wickedness and vice that he falls into misfortune, but through some *hamartia*. Various translations are offered for *hamartia*: 1) a moral failing or fault of some kind, 2) an error due to inadequate knowledge of particular circumstances, 3) an act that is conscious and intentional, but not deliberate, 4) a defect of character, distinct on the one hand from an isolated error or fault, and, on the other, from the vice which has its seat in a depraved will, 5) a tragic flaw.<sup>379</sup> The conflict arising within tragedy is characterized by a hero or heroine choosing an approach that is correct, given the situation, but in this particular situation requires the violation of an important claim that, under ordinary circumstances, would also be justified.<sup>380</sup>

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<sup>378</sup> Aristotle, *Poetics* 6:49b.

<sup>379</sup> KAUFMANN, *Tragedy and Philosophy*, (New York: Doubleday, 1968), p. 61.

<sup>380</sup> KAUFMANN, *Tragedy and Philosophy*, (New York: Doubleday, 1968), p. 216.

## 2) Tragedy and Civilizing Power

The broader context of Greek tragedy begins with understanding the Greek conception of civilization as the confrontation between savage and civilized spaces. The center of the Greek world was the *polis*, the city. The *polis* was the safe, formed world as opposed to the *agros*, the dangerous, formless, territory outside the *polis* from which the adjective *agrios* is derived meaning "wild" or "savage".<sup>381</sup> At stake within the confrontation between these two spaces was civilization and civilizing power of the Greek world. Civilization was considered the fruit of humanity's struggle to discover and assert humanness in the face of the impersonal forces of nature and its own potential violence on the one hand and the remote powers of the gods on the other.<sup>382</sup> With the Peloponnesian War (431-404 BC) and its atrocities regarding the Athenian treatment of the Mytileneans and the Melians, the paradox was revealed that Greek civilization could hold within itself all the savagery of the beast world.<sup>383</sup> That human works are vulnerable to relapse into savagery in a manner that is swift and sudden grips the imagination of the classic Greek writers of tragedy, Euripedes, Thucydides and Sophocles.

What is the tragic genre an answer to? It is proposed that tragedy

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<sup>381</sup> Charles SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles* (Norman: University of Oklahoma Press, 1999), p. 1.

<sup>382</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 2.

<sup>383</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 5.

promotes a sacralizing and ritualizing of violence as a means of keeping the person human and civilized. This violence is experienced as a numinous power that is both a part of ourselves and a mysterious visitation of something beyond ourselves. This force is approached with awe, respect and dread, and it is tragedy that helps us to recognize, acknowledge and expel it.<sup>364</sup> Given the suffering exposed and the pity and fear evoked the question arises why Greek audiences found tragic plays enjoyable? What is the experience of tragedy for the reader or viewer? One proposal is that tragedy involves the spectator who recognizes their sorrow on the stage. Suffering shared is sometimes suffering halved. Terror which may have been suffered unknowingly and silently is perhaps now articulated and liberated. If the grief and terror I see before me exceeds my own, the spectator feels lucky that their fate is lucky.<sup>365</sup>

The major point is that not all suffering is held to be truly tragic. The suffering hero must be great or noble; he must fail but be more admirable in catastrophe than ever before; the unhappy end must be inevitable and issue from the hero's own decision in a moral conflict in which disaster was inescapable whatever choice he made. Some writers stress that there must be a moral conflict; others, the importance of the belief that failure is compatible with greatness, that greatness and the universe remain mysterious, and that failure must be final and inevitable.<sup>366</sup>

Sophoclean tragedies exhibit a number of tensions and paradoxes within their narratives. These ironies or paradoxes are man's self knowledge and self-

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<sup>364</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 7.

<sup>365</sup> KAUFMANN, *Tragedy and Philosophy*, p. 270.

<sup>366</sup> KAUFMANN, *Tragedy and Philosophy*, p. 311.

ignorance, the drive of the hero's life toward pattern and coherent meaning, the interlocking and divergence of divine and human intention are illuminated from multiple perspectives. The meaning of events are hidden and the characters cannot seem to penetrate them with any degree of certainty. "In tragedy truth has many voices. The time that reveals truth moves in many rhythms...but always the total meaning of events grows to fulfillment only slowly, partially, darkly."<sup>397</sup> The hero's confrontation with the extreme polarities of the human condition unleashes the safety net which holds together our logical, ordered world, and delivers the hero to the "inconclusive, compromised middle" where much of human life is lived.<sup>398</sup> The tragic hero lives in a type of moral frontier, a living at the limits of human experience. Places that should give shelter or safety become destructive, savage ...the tragic situation inverts or collapses the relation between civilization and the wild. The tragic hero belongs to both the "raw" or "savage" world outside the polis and by virtue of his loyalty and love, a place of honor within the polis. The hero lacks that stability of place and identity which others possess as a given of their humanness. The hero must reconstruct his humanness on new terms. For all his dangerous potential, the hero possesses some qualities indispensable to civilization. His selfhood loses its simplicity and his ambiguous identity threatens the logical categories which

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<sup>397</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 10.

<sup>398</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 11.

**civilization needs to safeguard against.**

**Greek tragedy, I have suggested, operates both within and beyond the limits of the polis, at the borders where polarities merge, definitions become unclear, the orderly composition of human institutions become ambiguous. Here, through the suffering of the tragic hero, man discovers and experiences anew the preciousness and the fragility of this most distinctively human, and therefore most ambiguous attributes.<sup>300</sup>**

**The tragic hero enacts what anthropologists have called "liminality", the boundary situations of human life, the experience of nothingness in moving between or beyond the familiar categories into the irregular, the interstitial, the ambiguous, the unique and the unclassifiable.<sup>300</sup> Tragedy seems to suspend the normal coherence of logical, manipulative relation to reality. It is this experience, the tragic confrontation with the negation of civilization which is a profoundly civilizing experience, where our potential for violence is recognized and the violence is potentially expelled.**

### **3) Tragedy Instructing Ethics**

**What might tragedies have to teach us about human living? Reflections on Greek tragedy characterize these experiences as "a conflict of value with two actors coming from very narrow perspectives".<sup>301</sup> The two main protagonists in a conflict seem to be locked in "a strategy of avoidance with regard to the conflicts**

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<sup>300</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 43.

<sup>300</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 47.

<sup>301</sup> Martha C. NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy* (Cambridge: Cambridge University Press, 1986), p. 56.

internal to their respective causes".<sup>302</sup> It is a limit experience capable of instructing ethics through its potential to produce "aporia". Such conflict requires a, "renunciation of the partiality of their views and this has the value of a pardon in which each is truly recognized by the other".<sup>303</sup> But what makes tragic conflicts inevitable and what solution is action capable of bringing to these conflicts?

...the source of conflict lies not only in the one-sidedness of the characters but also in the one-sidedness of the moral principles which themselves are confronted with the complexity of life...in the conflicts to which morality gives rise, only a recourse to the ethical ground against which morality stands out can give rise to the wisdom of judgement in situation. From tragic *phronesis* to practical *phronesis*; this will be the maxim that can shelter moral conviction from the ruinous alternatives of univocity or arbitrariness.<sup>304</sup>

Due to the narrow and one-sided approaches of two actors, the conflict reveals important values that each of the actors has failed or refused to take into account. From such tragic conflict we learn not to attempt to eliminate conflict by an exclusive attachment to one value, a false certainty and disregard the rest. We are taught to attempt an appreciation and an appropriation of the plurality of human values involved.

Tragedy is the limit experience leading to the need for a reconciliation of the narrow one-sidedness of the moral principles of the protagonists. Tragedy exposes assumptions and sheds light on the vulnerability within a moral

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<sup>302</sup> RICOEUR, *Oneself as Another*, p. 243.

<sup>303</sup> RICOEUR, *Oneself as Another*, p. 248.

<sup>304</sup> RICOEUR, *Oneself as Another*, p. 249.

approach or a naïve expectation of progress. It reveals something about the plurality of human values and casts doubt on attempts to create harmony through synthesis.<sup>395</sup> Within the genuinely conflictual situation, when digging under the rule of procedure or convention, the diversity of the goods distributed is unearthed which convention or the moral norm tend to obliterate.<sup>396</sup> It is the particularity of these goods that is of interest to us because we are interested in the human values which are being lost or trampled upon. As a result the moral norm of sedation practices in palliative care are found to not only be limited but perhaps not up to the task of adequately recognizing the inherent conflict within its sedation practices nor offering a more humanizing approach to this social conflict.

Within a genuinely conflictual situation, the alternatives are not to respond either with violence against the external nor helpless passivity but a responsiveness open to the claims and pulls of the external, a finer more supple sort of responsiveness, balancing control and vulnerability.<sup>397</sup> In contrast are two types of deliberation. One type, a Platonic scientific deductive understanding proposing progress and aspiring universality, precision and stable control. The

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<sup>395</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 74.

<sup>396</sup> RICOEUR, *Oneself as Another*, p. 251.

<sup>397</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 81.

other, an Aristotelian non-deductive but practical deliberation aspiring to a yielding conception of responsive perception and proposing that, "the best life is more vulnerable to ungoverned *tuche* (luck), essentially more open and less ambitious for control".<sup>398</sup> Nussbaum points to three features outlined by Aristotle which demonstrate that practical choices cannot be captured in a system of universal rules.<sup>399</sup> These three features are mutability, indeterminacy, and particularity. Mutability points to the constant change evolving in ever new configurations. Indeterminacy refers to the situation-relativity of appropriate choice. Aristotle's example of joke telling is offered to demonstrate how what is funny to some is not to others. Particularity refers to the contingencies within contexts and situations. This Aristotelian understanding of practical wisdom is identified as in opposition to, "...a well-established tradition in moral philosophy, both ancient and modern, according to which moral goodness, that which is an appropriate object of ethical praise and blame, cannot be harmed or affected by external circumstances".<sup>400</sup>

What is considered a reduction or impoverishment in a knowing or discovery of scientific deliberation which prioritizes universality, self-sufficiency

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<sup>398</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 290-291.

<sup>399</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 302.

<sup>400</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 329.

and control is the vulnerability of the good human life and its potential to be disrupted by catastrophe, by forces external to the actor. Vulnerability allows for the possibility of *aporia*; a discovery beyond the narrowness of the actor's approach, an attentiveness to discovering the particular in a singular situation.

At risk with this vulnerability are the virtues that require openness or guilelessness rather than self-defensiveness, trust in the other people and in the world rather than self-protecting suspiciousness. This openness or vulnerability indeed creates the risk that the actor, "is more easily betrayed than the self-enclosed person, and it is the experience of betrayal that slowly erodes the foundation of the virtues. Virtue contains in this way the seeds of its own disaster."<sup>401</sup> What is interesting is with the experience of tragedy and without the recognition of the narrowness of the actors moral claims, the actor may feel betrayal in the experience of limit and project the reason for betrayal on either their own moral understanding or the moral understanding of the opposing actor. Without recognition of tragedy and the inherent contradiction in their own moral claims, the actor may seek vengeance. What might that vengeance be or how might it take shape? How does it take shape in the ethos of palliative care? Is it part of the burned out syndrome of turning within? How do these palliative medical tragedies offer havoc, contingency and risk in the lives of those trained in scientific positivism?

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<sup>401</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 339.

**We see too, how each virtue subtly shifts its nature when it is no longer based on trust and association...Prudence or moderation becomes a solitary cunning which has no respect for any decency and trusts no man's respect for hers. Justice becomes an instrument of personal punishment and personal safety. Wisdom is simply the clever plotting that will put everything in good order.<sup>402</sup>**

**This reflection on tragedy and the human vulnerability that is recognized within it will be key to this inquiry. The identification of strategies of avoidance, one-sided approaches, the refusal to offer solution in the boundary situations of human life, the experience of betrayal and the potential for vengeance, all offer insight to the dynamics within decision in situation such as tragic palliative sedation dilemmas.**

### **C) Interpreting Action**

**Exploring the type of problem tragedy is has provided insight into the type of problem palliative sedation dilemmas are and how they might be more adequately explored, interpreted and understood. This reflection has brought attention to the potential one-sidedness of interpretation, the problematics and vulnerabilities, the diversity of goods which if appropriated might offer a more complete interpretation. This inquiry will continue on the theme of interpretation by exploring the problematics of the interpretation of action and the "middle way" offered through the hermeneutical inquiry of Paul Ricoeur.**

**Paul Ricoeur is a philosopher in the hermeneutic tradition whose project**

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<sup>402</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 415.

has focused on the connection between language and action. Fundamental to this project is his concern with the perils of objectification of the human being, a reductionism, limiting the fullness of human freedom. Ricoeur's method is to search for dialectics between seemingly opposing poles, to mediate the partial view of these poles through a "middle way" which seeks to preserve or create a productive dialectic which appropriates a less one-sided orientation. He does not content himself with simply opposing a reductive interpretation since this would simply advocate for the neglected part and foster a reductionism of another sort. The goal is to begin from within the fullness of experience, begin within the multiplicity, not to proceed from the simple to the complex, but to allow various dimensions to unfold as aspects of a single fullness. It is because of its fullness we must recognize and be constantly aware of a reality which constantly transcends us. The tendency can be to avoid this risk of openness and transcendence by seeking a refuge within what is known, what is within the known of the self. Ricoeur's struggle is to prevent us from slipping into such conventional and reductive modes of thought.

Key dialectics within Ricoeur's theory of interpretation, applied initially to the interpretation of texts, are also found to apply to the interpretation of action. Just as Ricoeur identifies a kind of distance between the intention of the speaker and the verbal meaning of the text, a similar distance is found between

the agent and his works.<sup>403</sup>

In the same way that a text is detached from its author, an action is detached from its agent and develops consequences of its own. This automatization of human action constitutes the social dimension of action.<sup>404</sup>

These dialectics and the insights gained from them provide valuable resources for understanding the theoretical problematics of action within healthcare ethics dilemmas such as those encountered within palliative sedation practices. The first dialectic that will be helpful are the operations between *explanation* and *understanding*.

### 1) Explanation and Understanding

Ricoeur notes a methodological dualism present in the work of Wilhelm Dilthey between *explanation* and *understanding*. For Dilthey, the distinctions constituted an alternative wherein the terms *explanation* and *understanding* excluded the other. A person is considered to either "explain" in the manner of a natural scientist, or one "interprets" in the manner of the historian.<sup>405</sup> It is Ricoeur's desire to replace this dualism which sets *explanation* and *understanding* as mutually exclusive poles with an approach which would consider them as "relative moments in a complex process that could be termed

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<sup>403</sup> Ted KLEIN, "The Idea of Hermeneutical Ethics" in *The Philosophy of Paul Ricoeur*, (Illinois: Open Court, 1995), p. 356.

<sup>404</sup> Paul RICOEUR, cited in Ted KLEIN's work on "The Idea of Hermeneutical Ethics", p. 356.

<sup>405</sup> Paul RICOEUR, "What is a Text? Explanation and Understanding" in *From Text to Action: Essays in Hermeneutics II* (Illinois: Northwestern University Press, 1986), p. 110.

interpretation".<sup>406</sup> Ricoeur's goal is to search for a complementarity and reciprocity between *explanation* and *understanding*. He maintains that the distinction offered by Dilthey breaks down at the very heart of interpretation. The breakdown is asserted to occur between the intuitive and unverifiable character of the psychologizing concept of understanding on the one hand, and the demand for objectivity that belongs to the very notion of human science.<sup>407</sup>

Using the structural explanation of texts as an example, Ricoeur notes the type of meaning structural analysis offers as it identifies the logic of action which consists in an "interconnected series of action kernels that together constitute the structural continuity of the narrative".<sup>408</sup> Here the text is closed in upon itself for meaning. This understanding of "reading a text" is contrasted with Ricoeur's understanding of the term of *appropriation* and its three features. The first feature is the fusing of textual interpretation with self-interpretation where, "the interpretation of a text culminates in the self-interpretation of a subject who henceforth understands himself better, understands himself differently, or simply begins to understand himself".<sup>409</sup> The second feature is to overcome the cultural distance of the text, the struggle against estrangement from the meaning or the

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<sup>406</sup> Paul RICOEUR, "Explanation and Understanding: On Some Remarkable Connections Between the Theory of Texts, Action Theory, and the Theory of History," in *From Text to Action: Essays in Hermeneutics II* (Illinois: Northwestern University Press, 1986), p. 126.

<sup>407</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 111

<sup>408</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 116.

<sup>409</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 118.

system of values upon which the text is based.<sup>410</sup> The third feature is like the execution of a musical score where it marks the realization, the enactment, the semantic possibilities of the text".<sup>411</sup> This final feature is considered by Ricoeur as the most important because it is the condition of the other two.

Using the example of myth Ricoeur then points out how in the background of the myth are questions of life and death that are highly significant. These questions point toward limit situations, toward the meaning of origins and ends, toward death and suffering. In his new concept of interpretation Ricoeur defines explanation as "to bring out the structure, that is the internal relations of dependence that constitute the statics of the text", and understanding as "to follow the path of thought opened up by the text, to place oneself en route toward the *orient* of the text."<sup>412</sup> Reading is understood as the act in which the *destiny* of the text is fulfilled. The relationship between tradition and interpretation is proposed as a relation within the text since the exegete interprets by placing himself in the meaning indicated by the relation of interpretation that the text itself supports. The subjective experience of interpretation is considered as an act on the text but the objective process of

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<sup>410</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 119.

<sup>411</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 119.

<sup>412</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 121.

interpretation would be an act of the text.<sup>413</sup> Therefore, to interpret is to place oneself "within the sense indicated by the relation of interpretation supported by the text".<sup>414</sup> "Appropriation loses its arbitrariness insofar as it is the recovery of that which is at work, in labor, within the text."<sup>415</sup>

This description of the dialectic of explanation and interpretation is instructive when considering the earlier debates and approaches concerning the interpretation of the principle of double effect. Both within the theological and philosophical debates there was an orientation to interpret PDE in a strictly physical and causal manner. This interpretation of PDE seems to be within the approach of "explanation", of closing the action in upon itself to understand the internal operations of the action. Yet Ricoeur also calls attention to "follow the path of thought opened up by the text, to place oneself en route toward the *orient* of the text."<sup>416</sup> Consideration of the orient of this type of act opens interpretation to consider the broader context of human meaning that the causal action is engaged within without rendering such interpretations as arbitrary. Such a description highlights potentially reductive approaches to interpreting PDE.

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<sup>413</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 122.

<sup>414</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p.124.

<sup>415</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 124.

<sup>416</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics II*, p. 121.

## 2) Mimesis as "Creative Imitation"

The second dialectic implicating the operations of interpretation, the act of composing, bringing together, and arranging incidents into a unique and complete action, are explored within Ricoeur's understanding of the operations of the Greek term *mimesis*. As we have mentioned earlier, the Greek term *mimesis* had often been interpreted to mean *imitation*, in the sense of a weakened copy. Within the tradition of Aristotle and contrasted from Plato, Ricoeur interprets *mimesis* not in terms of a weakened copy but as a creative imitation. The operations of this creative imitation are described by Ricoeur as Mimesis1, Mimesis2, and Mimesis3. Mimesis1 is the pre-understanding shared by author and reader of what human action is (motive, intention circumstance, obstacle), of semantics and symbolism (how it is articulated by signs, rules and norms), its temporality (the time in which we live and act, the time for doing this or that, the time that can be won or lost).<sup>417</sup> Mimesis2 is the configuration of action, the *emplotment*, the act of grasping together the details or what we have called the incidents of the story.<sup>418</sup> *Emplotment* brings together factors such as circumstances, agents, interactions, ends, means and unintended results. It is the framing of the story where a new surprise counts as recognition or a pitiable incident counts as a complication of the plot. Mimesis3 is the reception and

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<sup>417</sup> Paul RICOEUR, "Mimesis and Representation", in Mario J. VALDES, ed., *A Ricoeur Reader: Reflection and Imagination* (Toronto: University of Toronto Press, 1991), p. 142

<sup>418</sup> RICOEUR, in VALDES, *A Ricoeur Reader: Reflection and Imagination*, p. 146.

application of the *emplotment* of the story. Through Mimesis<sup>3</sup> occurs the revelation, learning and transformation of reality into a world in which the spectator, or reader, can live after having his or her emotions "purified" by the catharsis of the entire process.<sup>419</sup> When Aristotle refers to tragedy arousing pity and fear, or to the pleasure we take in seeing frightening or pitiable incidents, Ricoeur proposes that this is an indication that it is in the audience or the reader that the process of mimesis ends.<sup>420</sup> In summary, these three stages of mimesis are designated by Ricoeur as a *prefiguration* of the field of practice, a *configuration* of the text, and a *refiguration* of the world of the living, acting and suffering through the appropriation of the text.<sup>421</sup>

The question arises, how does this three-stage process of *mimesis*, of creative imitation, link with the dialectic of explanation and understanding? Its meeting point is interpretation and the insight each offers into the operations of interpretation. Each demonstrates the link between objectivity, the objective analysis of texts and actions, and subjectivity, the appropriation of meaning by subjects.

In composing a fable, a plot, a *muthos*, the poet offers a *mimesis*, a creative imitation of human action. In the same way, a logic of possible narratives, to which a formal analysis of narrative codes may aspire, finds its completion only in the mimetic function by which the narrative remakes the human world of action. It is, therefore, no longer a question of denying the subjective character

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<sup>419</sup> Peter KEMP, "Ethics and Narrativity," Lewis E. Hahn (ed.), in *The Philosophy of Paul Ricoeur* (Illinois: Open Court, 1996), p. 373.

<sup>420</sup> RICOEUR, in VALDES, *A Ricoeur Reader: Reflection and Imagination* p. 148.

<sup>421</sup> KEMP, "Ethics and Narrativity", p. 373.

of the understanding in which explanation reaches its completion. For it is always someone who receives, makes her own, appropriates the meaning for herself. But there is no sudden short circuit between the entirely objective analysis of narrative structures and the appropriation of meaning by subjects. Between the two unfolds the world of the text, the work signified – namely, in the case of the narrative text, the world of the possible paths open to real action. If the subject is called upon to understand himself in light of the text, this is to the extent that the text is not closed in upon itself but open onto the world, which it re-describes and remakes.<sup>422</sup>

This use of threefold mimesis offers insight into the problematic of maintaining objectivity and integrating subjectivity of the world of the agent within the meaning of the agent's action. The operations of mimesis demonstrate how action is constituted by a multidimensional meaning, the fullness of which is not described simply in terms of physical causality nor the intention of the agent.

### 3) Initiative

It is through continuing the exploration of Ricoeur's understanding of interpretation as a dynamic revitalizing of tradition that we are brought to his use of the concept of *initiative* to speak of the relation of action to the present. Ricoeur defines initiative as, "the living, active, operative present answering to the present that is gazed upon, considered, contemplated, reflected"<sup>423</sup>. Initiative is the moment, "when the weight of history that has already been made is deposited, suspended and interrupted and when the dream of history yet to be

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<sup>422</sup> Paul RICOEUR, "Explanation and Understanding: On Some Remarkable Connections Between the Theory of Texts, Action Theory, and the Theory of History," in *From Text to Action: Essays in Hermeneutics. II* (Illinois: Northwestern University Press, 1986), p. 132.

<sup>423</sup> Paul RICOEUR, "Initiative," in *From Text to Action: Essays in Hermeneutics, II*, (Illinois: Northwestern University Press, 1986), p. 208.

made is transposed into a responsible decision".<sup>424</sup> To set up his dialectic, Ricoeur categorizes the future as "the horizon of expectation" and the past as the "space of experience" and argues that the tension between these two categories has to be preserved, "if there is to be any history at all".<sup>425</sup> Responsible commitment is found in preventing the tension between the two poles of degenerating into a crisis of the present either through expectation taking refuge in utopia or by traditionality becoming understood as only a dead deposit of the past.<sup>426</sup> Initiative, the response of practice to speculation and its difficulties, if it is to confront this crisis, is proposed as consisting of an incessant transaction between these two tasks. More specifically, initiative is defined as, "the living, active, operative present answering to the present that is gazed upon, considered, contemplated, reflected".<sup>427</sup> But this description of initiative is tempered through the claim that humanity is not the sole agent of its own history. The awareness integrated into this understanding of initiative, as contrasted to the thought of Rachels appearing earlier, is that, "in addition to the unintended results that action brings about, action itself takes place only in

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<sup>424</sup> Paul RICOEUR, *Time and Narrative: Volume III* (Chicago: University of Chicago Press, 1984), p. 208.

<sup>425</sup> RICOEUR, *Time and Narrative: Volume III*, p. 215.

<sup>426</sup> RICOEUR, *Time and Narrative: Volume III*, p. 235.

<sup>427</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics, II*, p. 208.

circumstances that it has not produced".<sup>428</sup> What is key about this assertion is its claim that we are both affected by the history that we did not make as well as the history that we ourselves do make.<sup>429</sup> In order to clearly situate the challenges both the *space of experience* and the *horizon of expectation* offer to initiative, Ricoeur offers the following advice,

On the one hand, we must resist being seduced by purely utopian expectations: they can only bring us to despair of action, since, for lack of any grounds in current experience, they are incapable of formulating a practical path directed to ideals that have been situated "elsewhere." Expectations must be determinant, hence finite and relatively modest, if they are to lead to responsible commitments. Yes, we must keep the horizon of expectation from running away from us and bring it closer to the present by means of a series of intermediary projects within the scope of action.<sup>430</sup>

This initiative, this "force of the present" as Ricoeur alternately names it elsewhere<sup>431</sup>, is the force that gives, "to our ethical and political aims in the future the strength to reactivate the unfulfilled potentialities of the past transmitted to us".<sup>432</sup> The importance of this insight is evident not only for the tradition of palliative care in the humanization of dying but also for the tradition of interpretation of PDE in singular concrete situations.

These operations, the dialectic of explanation and understanding, the threefold mimesis, the space of experience and the horizon of expectation, offer

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<sup>428</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics, II*, p. 220.

<sup>429</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics, II* p. 220.

<sup>430</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics, II*, p. 221.

<sup>431</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics, II* p. 222.

<sup>432</sup> RICOEUR, *From Text to Action: Essays in Hermeneutics, II*, p. 222.

descriptions and insight into interpretation. In order to further develop the theoretical foundations that will help guide our inquiry into palliative sedation practices, I will turn to Ricoeur's development of the operations involved in the concept of practical wisdom, of decision in situation. From the broader operations located within the concept of "initiative" we move, perhaps more specifically, to the operations within the concept of "deliberation". It is an inquiry into the ability and limitation of the moral norm in the face of the particularity or singularity of case situations, such as the palliative sedation stories presented within the first chapter of this inquiry.

#### D) Practical Wisdom

Within his work *Oneself as Another*,<sup>433</sup> Paul Ricoeur offers insight into the problematic when there is an impasse between respect for the moral norm and respect for persons in the particularity and singularity of their situation. Through the previous chapters in this inquiry, we have discovered definite points of impasse in palliative sedation stories. Such impasse seems to be experienced in situations where intolerable suffering eclipses peaceful dying, where increasing sedation to address pain also hastens death, where scientific and technological orientations in palliative medicine seem reductive to the palliative aim of humanizing dying, where sedating to unconsciousness undermines conscious self-actualization, where moral conflicts between respect for the

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<sup>433</sup> RICOEUR, *Oneself as Another* (Chicago: University of Chicago Press, 1992)

moral norm and the respect for persons seem inevitable. When we reach that point, what resources are available to provide direction or guidance in decision making and the dynamic practice of palliative care? How might one respond to such situations in a manner where both the legitimacy of the moral norm and the multiplicity or singularity of the situation are both recognized?

The operations that Ricoeur proposes as a response to this impasse involves three propositions: 1) the primacy of ethics over morality, 2) the necessity of the ethical aim to pass through the sieve of the moral norm, 3) the legitimacy of following a return movement from the moral norm to the ethical aim in unusual singular situations.<sup>434</sup> As an entry into this discussion, I will begin with a distinction that Ricoeur makes between the terms "ethics" and "morality". The term "ethics" signifies for Ricoeur, "the aim of an accomplished life" while the term "morality" signifies, "the articulation of this aim in norms characterized at once by the claim to universality and by an effect of constraint".<sup>435</sup> Moreover, Ricoeur claims that ethics has a primacy over morality, that morality is a limited though legitimate and indispensable actualization of the ethical aim which encompasses it.<sup>436</sup> To better understand this relation between the moral norm and the ethical aim, we will first delve further into the meaning of the ethical aim.

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<sup>434</sup> RICOEUR, *Oneself as Another*, p. 170.

<sup>435</sup> RICOEUR, *Oneself as Another*, p. 170.

<sup>436</sup> RICOEUR, *Oneself as Another*, p. 170.

The ethical aim for Ricoeur is expressed as "aiming at the good life with and for others, in just institutions"<sup>437</sup>. The "good life", "living well", "a full life", "an accomplished life" all represent that object of the ethical aim. First to be sought is the fundamental aim of the good life in praxis. With respect to this present inquiry into palliative care, I suggest the object of the ethical aim within palliative care is the humanization of dying. Ricoeur uses a dialectic found within MacIntyre's notion of "a practice", described earlier in chapter three, to speak of how ethical aim of the good life in praxis is discerned. The dialectic is between "standards of excellence" and the internal goods of a practice. The dialectic between the two demonstrates a moving back and forth between far-off ideals, which have to be made more precise, and the weighing of the advantages and disadvantages of the choice of a given internal good on the level of practice.<sup>438</sup>

With respect to its content, the "good life" is, for each of us, the nebula of ideals and dreams of achievements with regard to which a life is held to be more or less fulfilled or unfulfilled. It is the plane of "time lost" and "time regained". In this sense, the "good life" is "that in view of which" all these actions are directed, actions which were nevertheless said to have their ends in themselves.<sup>439</sup>

"Internal goods" within a practice are used as a way to characterize as "good" - a doctor, an architect, or a musician.<sup>440</sup> Standards of excellence offer a sense of internal goods immanent to a practice and constitute the teleology

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<sup>437</sup> RICOEUR, *Oneself as Another*, p. 172.

<sup>438</sup> RICOEUR, *Oneself as Another*, p. 177.

<sup>439</sup> RICOEUR, *Oneself as Another*, p. 179.

<sup>440</sup> RICOEUR, *Oneself as Another*, p. 176.

immanent to the action as expressed with phenomenological notions such as *satisfaction*.<sup>441</sup> The search for adequacy or verification between our life ideals (the internal goods of a practice) and our decisions is not the same sort of verification expected in the sciences of observation. The criteria of adequacy for interpretation involves an exercise of judgement which, at best, aspires to plausibility in the eyes of others.<sup>442</sup> With this review of the first component, the object of the ethical aim, we turn to the second component of the ethical aim.

### 1) The Encounter Between the Self and the Other

The second component of the ethical aim, articulated earlier as "with and for others", is expressed for Ricoeur through the term "solicitude". This term signifies Ricoeur's attempt to establish a relationship between the Self, conscious ego, and the Other in a manner which does not entail the dissolution of either. The question at stake is the ability of consciousness to encounter something other than itself, something that is truly alien to itself and that is not a product of its own activity. But who is this other? Ricoeur speaks of the face of the other as an epiphany and uses the analyses of Emmanuel Levinas to contrast his own understanding of the "face of the other".<sup>443</sup>

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<sup>441</sup> RICOEUR, *Oneself as Another*, pp. 176-177.

<sup>442</sup> RICOEUR, *Oneself as Another*, p. 180.

<sup>443</sup> RICOEUR, *Oneself as Another*, p. 189.

Levinas's work has critiqued philosophy for its failure to think of the Other as Other. His work has attempted to describe encounters between the self and the other which do not annul the otherness or strangeness of the Other. Levinas distinguishes himself from previous philosophical points of view by critiquing that the self pre-exists the encounter with others and instead asserts that the self, the subject is constituted by and as its exposure to the Other. Secondly, Levinas critiques basing the encounter between the self and the other on knowledge of the other or self and instead privileges ethics as the foundation of the relationship. Essentially Levinas rejects both the notion of the subject's sovereignty and the dissolution of the subject.<sup>444</sup> The self is hostage to the other because the self's existence as an individuated subject is entirely bound up with my relationship to the other. To attempt to escape this dominance of the Other over me would be to relinquish my subjectivity. Metaphors of comprehension and possession are replaced by metaphors which emphasize approach, proximity, caress and fecundity. The self's existing in proximity, its approach is essentially "a risky uncovering of oneself, in sincerity, in the breaking up of inwardness and the abandon of all shelter, in exposure to traumas, in vulnerability".<sup>445</sup>

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<sup>444</sup> Colin DAVIS, *Levinas: An Introduction* (Cambridge: Polity Press, 1996), p. 78.

<sup>445</sup> DAVIS, *Levinas: An Introduction*, p. 78.

Ricoeur joins Levinas in underscoring the mediating role of others between capacities within the self and the realization of those capacities. Ricoeur uses Aristotle's notion of friendship to develop elements in this notion of solicitude. First, this understanding of friendship is not defined in terms of psychological feelings of affection but as an ethics, a virtue or an excellence.<sup>446</sup> Second, Ricoeur desires to retain an ethics of reciprocity, of sharing, an exchange of giving and receiving.<sup>447</sup> It is precisely concerning reciprocity between the self and the other that Ricoeur separates from Emmanuel Levinas's understanding of the radical Other, the other who is a master of justice, a master who instructs and who "forbids murder and commands justice".<sup>448</sup> This summons to responsibility and instruction by this radically other needed to be integrated into the dialectic of giving and receiving for Ricoeur. The resources for giving and receiving are a notion of *goodness* considered as acting, "on behalf of other, out of regard for others"<sup>449</sup>. It is this notion of regard for others that Ricoeur chooses to focus on next.

Yet Ricoeur finds Levinas's "radically Other", who summons the self to responsibility in an accusative mode as master of justice and persecutor, to be too much within the sphere of the imperative or of the norm. This "radically

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<sup>446</sup> RICOEUR, *Oneself as Another*, p. 181.

<sup>447</sup> RICOEUR, *Oneself as Another*, p. 188.

<sup>448</sup> RICOEUR, *Oneself as Another* p. 189.

<sup>449</sup> RICOEUR, *Oneself as Another*, p. 189.

**Other** is in conflict with the original hypothesis of Ricoeur's study; the primacy of the ethical over the moral. The more fundamental status of solicitude is *benevolent spontaneity*. The self compensates the initial primacy of the other experienced as injunction through a reverse movement of the self's recognition of the other's suffering. Suffering is not defined solely by physical or mental pain but by "the reduction, even the destruction, of the capacity for acting, of being-able-to-act, experienced as a violation of self-integrity".<sup>450</sup> It is the giving inherent in this "suffering-with" that becomes the opposite, the equalizing, the reciprocity, of the assignment of responsibility by the face or the voice of the other. Ricoeur questions if the response was not spontaneous would not solicitude be reduced to a dreary duty?

In true sympathy, the self, whose power of acting is at the start greater than that of its other, finds itself affected by all that the suffering other offers to it in return. For from the suffering other there comes a giving that is not longer drawn from the power of acting and existing but precisely from weakness itself. This is perhaps the supreme test of solicitude, when unequal power finds compensation in an authentic reciprocity in exchange, which, in the hour of agony, finds refuge in the shared whisper of voices or the feeble embrace of clasped hands.<sup>451</sup>

Equality is re-established between the ability to act of the self and the command to responsibility of the other through a shared admission of fragility and mortality.

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<sup>450</sup> RICOEUR, *Oneself as Another*, p. 190.

<sup>451</sup> RICOEUR, *Oneself as Another*, p. 191.

The third part of the ethical aim is "...in just institutions". This element points to the justice extending beyond face to face encounters to institutions. The term "institution" is understood as, the structure of living together as this belongs to a historical community such as a people, nation, or region and is characterized more by "the bond of common mores and not that of constraining rules".<sup>452</sup> A reflection on the distributive interpretation of the institution contributes a cohesion between the individual, the interpersonal and the societal within Ricoeur's concept of the ethical aim. Equality is identified as the name of the ethical core common to distributive justice. Equality is,

...to life in institutions what solicitude is to interpersonal relations. Solicitude provides to the self another who is a face, in the strong sense that Emmanuel Levinas has taught us to recognize. Equality provides to the self another who is an *each*.<sup>453</sup>

## 2) The Moral Norm

If the first proposition was the primacy of the ethical aim over the moral norm, the second proposition is the necessity to, "subject the ethical aim to the test of the norm".<sup>454</sup> The goal is to express the strength and place of the moral norm, rather than criticize the weaknesses of the morality of duty. Morality is a reply to violence, a rejection and indignation to indignities inflicted on others.<sup>455</sup>

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<sup>452</sup> RICOEUR, *Oneself as Another*, p. 194.

<sup>453</sup> RICOEUR, *Oneself as Another*, p. 202.

<sup>454</sup> RICOEUR, *Oneself as Another*, p. 203.

<sup>455</sup> RICOEUR, *Oneself as Another*, p. 221.

While the aim of these imperatives is to establish reciprocity wherever a lack of reciprocity is experienced, the difficulty arising within universalization is that the moral norm must annihilate the effects of contingency, to neutralize the diversity of goods to the benefit of the rule of distribution.

On the one hand, one can show in what sense an attempt to provide a strictly procedural foundation for justice applied to the basic institutions of society carries to its heights the ambition to free the deontological viewpoint of morality from the teleological perspective of ethics. On the other hand, it appears that his attempt also best illustrates the limits of this ambition.<sup>456</sup>

A confrontation seems erected between the globalizing idea of humanity and the demand that the plurality of persons and their otherness not be obliterated.<sup>457</sup>

### 3) Practical Wisdom and Conviction

What mediates the general maxims of moral norms and the particularity of singular situations requiring moral judgement? This role, Ricoeur asserts is filled by the Greek concept of *phronesis* or *practical wisdom*. In the words of Aristotle, *practical wisdom* is concerned with,

...things human and things about which it is possible to deliberate; for we say this is above all the work of the man of practical wisdom, to deliberate well, but no one deliberates about things invariable, nor about things which have not an end, and that a good can be brought about by action. The man who is without qualification good at deliberating is the man who is capable of aiming in accordance with calculation at the best for man of things attainable by action.<sup>458</sup>

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<sup>456</sup> RICOEUR, *Oneself as Another* pp. 237-238.

<sup>457</sup> RICOEUR, *Oneself as Another*, p. 227.

<sup>458</sup> Citing Aristotle's *Nicomachean Ethics*, 6.7.1141b 8-14 in footnote 4 of RICOEUR's, *Oneself as Another*, p. 175.

Essentially we are speaking of a type of deliberation concerning practical actions. Ricoeur uses the notion of tragedy to reflect on this type of deliberation which is also a reflection on the inevitability of conflict in moral life. Within tragedy one discovers a strategy of avoidance on the part of the protagonists with respect to the conflicts internal to their respective causes. By refusing to offer a solution or direct counsel, the genre of tragedy both disorients our initial path and necessitates a reorientation of action at the protagonist's risk.<sup>450</sup> This reorientation takes place both in the form of catharsis and in the moment of conviction. On this path which catharsis opens to the moment of conviction, two questions surface: 1) What makes ethical conflicts inevitable?, 2) What solution is action capable of bringing to these conflicts?<sup>460</sup> Ricoeur responds to these questions by saying,

To the first question, the response proposed will be this: the source of conflict lies not only in the one-sidedness of the characters but also in the one-sidedness of the moral principles which themselves are confronted with the complexity of life. To the second question, the response we shall sketch out is this: in the conflicts to which morality gives rise, only a recourse to the ethical ground against which morality stands out can give rise to the wisdom of judgement in situation. From tragic *phronēin* to practical *phronēsis*: This will be the maxim that can shelter moral conviction from the ruinous alternatives of univocity or arbitrariness.<sup>461</sup>

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<sup>450</sup> RICOEUR, *Oneself as Another* p. 247.

<sup>460</sup> RICOEUR, *Oneself as Another*, p. 249.

<sup>461</sup> RICOEUR, *Oneself as Another*, p. 249.

Essentially one finds conflictual situations when digging under the universality of moral norms. It is here that one discovers the real diversity of the goods to be shared which the formulation of moral norms tends to obliterate. It is within the application of the norm to a concrete situation where the otherness of persons in their irreplaceable singularity can be reduced and where conflicts can arise. Here the rule is tested through circumstances and consequences.<sup>462</sup> It is the dialogic structure within the application of norms to the concrete situation that is key. Fundamental is the desire to respond to an expectation, a commitment which is a faithful response to the other, an availability to the other.<sup>463</sup> In this dialogic structure within respect understood as promising, as availability, as "counting on", one becomes aware of the tear between respect for the rule and respect for the person. Conflicts between respect for the norm and the respect of persons is "inscribed in the structure of reciprocity belonging to the promise. If fidelity consists in responding to the expectation of the other who is counting on me, I must take this expectation as the measure for applying the rule."<sup>464</sup> In asking what is the nature of this promising in relation to bioethics cases, three common features are proposed to stand out.<sup>465</sup> First, the conflicting positions call upon the same principle of respect and differ in the degree of the

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<sup>462</sup> RICOEUR, *Oneself as Another*, p. 265.

<sup>463</sup> RICOEUR, *Oneself as Another*, pp. 267-268.

<sup>464</sup> RICOEUR, *Oneself as Another*, p. 268.

<sup>465</sup> RICOEUR, *Oneself as Another*, p. 273.

field of application. Second, the most serious moral decisions consist in drawing the dividing line between what is permitted and what is forbidden in zones which themselves are "median" and resistant to familiar dichotomies. Third, moral judgement in situation is all the less arbitrary as the decision maker has taken the counsel of men and women reputed to be the most competent and the wisest. Practical wisdom is here concluded to be "inventing conduct that will best satisfy the exception required by solicitude, by betraying the rule to the smallest extent possible."<sup>466</sup> It is a critical solicitude that, "has passed through the double test of the moral conditions of respect and the conflicts generated by the latter".<sup>467</sup> It is this *critical solicitude* in which practical wisdom takes its form in the context of interpersonal relations.

Ricoeur then speaks of "additional" or "specificatory" premises whose role it is "to extend the class of actions to which the formal imperative applies. The principle of double effect is an example of such a specificatory principle in the principle of killing in self-defence. "The apparent exception to the imperative "Thou shall not kill" is then placed under the rule made more precise by the specificatory premise."<sup>468</sup> What is demonstrated here is that formalism does not imply vacuity, that duties do not generate situations such that in order to obey

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<sup>466</sup> RICOEUR, *Oneself as Another* p. 269.

<sup>467</sup> RICOEUR, *Oneself as Another*, p. 273.

<sup>468</sup> RICOEUR, *Oneself as Another*, pp. 278-279.

one rule, one must disobey another, and that the content of derivative rules must be in agreement with the immediately superior rule.

It is clear that the plea for universality gives full weight to the problems encountered within the concrete morality of decision in situation. Furthermore, the concern for justification of norms tends to conceal "the conflicts that lead morality back toward a practical wisdom whose place is that of moral judgement in situation".<sup>469</sup> In effect, these conflictual situations as found within palliative sedation practices would not have their dramatic character if they did not stand in the shadow of a demand for universality.

This ethics of argumentation in Ricoeur's thought seeks an integration of the objections of contextualism while at the same time taking the demand for universality seriously in order to focus on the conditions for placing this requirement in context. Ricoeur seeks to substitute the antagonism between argumentation and convention for a dialectic between argumentation and conviction. Key is that argumentation is considered not simply as an antagonist of tradition and convention but as the "critical agency operating at the heart of convictions, argumentation assuming the task not of eliminating but of carrying them to the level of *considered convictions*".<sup>470</sup> Practical wisdom does not offer the same sort of verification expected within sciences of observation. Its criteria

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<sup>469</sup> RICOEUR, *Oneself as Another*, p. 280.

<sup>470</sup> RICOEUR, *Oneself as Another* p., 288.

of adequacy for interpretation "involves an exercise of judgement which, at best, can aspire to plausibility in the eyes of others".<sup>471</sup> Citing Book Six of Aristotle's *Nichomachean Ethics*, Ricoeur asserts the key lesson is the close tie established by Aristotle between phronesis (practical wisdom) and phronimos (the path that the man of phronesis follows to guide his life), a tie that becomes meaningful only if the man of wise judgement determines at the same time the rule and the case, by grasping the situation in its singularity.<sup>472</sup>

#### E) The Palliative Care Encounter: Avoidance and Conviction

##### 1) Introduction

This inquiry began with four narratives with palliative care clinicians describing what they believe to be a new moral frontier for the dying process of patients. The stories seemed to disrupt a perceived consensus that the principle of double effect drew an adequate distinction between treatments that inappropriately "killed" patients as opposed to appropriately "allowed or permitted" patients to die. Clinicians who wrote these narratives portrayed the tragedy of the patients predicament as well as their concerns as clinicians about whether their own participation through treatments were influencing and hastening the death of their patients through palliative sedation practices. Clinicians were either implicitly or explicitly questioning what the ethically

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<sup>471</sup> RICOEUR, *Oneself as Another* p. 180.

<sup>472</sup> RICOEUR, *Oneself as Another* p. 175.

significant difference is between "killing" and "letting die" in palliative care. This distinction seemed subtle and perhaps not morally significant especially in those situations where death is not only foreseen through the treatment but part of the complex act of doing good through the palliative sedation treatments, such as relieving the pain and suffering experienced by their patients. Palliative care clinicians also seemed to be asking whether their actions of sedating someone to the point of unconsciousness to address extreme types of emotional suffering was justified. There was the perception that such actions were heading into a new moral frontier. To quote again the questions of one clinician,

Jackie left me with feelings of disappointment and failure and a number of unanswered questions. When confronted with anguish like hers, did I have to accept that there was nothing I, nor indeed anyone else, could do to make it better? When attempting to help someone like Jackie, whose pain was I ultimately trying to alleviate, mine or hers? And what precisely was the nature of this particular form of suffering? I felt sure that if I had a better understanding of this it would point me toward another way, a more appropriate way, of responding to someone in such distress.<sup>473</sup>

As this new moral frontier has been explored, certain unique characteristics have arisen. First, the responsibility of making decisions on behalf of others is felt more keenly by clinicians since the patient is often incapable of articulating their autonomous wishes at this stage of the dying process. Second, suffering is often interpreted as a sign of psychological or spiritual "pathology" to be addressed within palliative care either on the part of the patient or the clinician. Not knowing how to address types of extreme

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<sup>473</sup> Michael KEARNEY, *Mortally Wounded: Stories of Soul Pain, Death, and Healing*.

suffering such as anguish through conventional palliative treatment approaches is often interpreted and experienced as failure or the betrayal of convention on the part of either the patient or clinicians. Third, the action of giving sedation treatments may be interpreted by the clinician that they are participating or collaborating with the biological pathology to create a pathology which will suppress the respiratory system and hasten death. Here it might seem that the clinician has become part of the biological pathology. Withdrawal of ventilation on the other hand may signify acceptance of defeat to the biological pathology at work and no longer able to work effectively against it. Fourth, withdrawal of treatments like ventilation may seem like a single event. The titration and dosage of sedation is much harder to know what to expect and to know and control the variables regarding the unique tolerance of the individual patient and the ability to get the right combination of titration and dosage. Fifth, the discomfort of the patient is visually striking. The patient's gasping for breath with dyspnea, the moaning that accompanies delirium, the anguish dramatically demonstrates the patient's bodily and psychic vulnerability as well as the vulnerability or impotence of clinical treatments. Such suffering and anguish seems disproportionate to any conventional explanation. In fact, any explanation which attempts to justify this suffering seems banal. The experience does strike fear and pity within clinicians and family members. Sixth, clinicians

seem more comfortable with the distinction of double effect if the time gap is a matter of days or hours as opposed to minutes. They feel their action is more influential in the latter as opposed to the former.

In addition to this seemingly unique terrain and moral frontier of palliative sedation practices, a certain uncomfortable familiarity is also implicitly present. Also discovered within the reflection on tragedy is the confrontation between the spaces of the civilizing power of the safe and formed world of the city and the savage, wild and formless territory outside the city. The civilizing power was considered the fruit of humanity's struggle to discover and assert humanness in the face of the impersonal forces of nature and its own potential violence.<sup>474</sup> That human works considered civilizing are vulnerable to relapse into savagery in a manner that is swift and sudden is what grips the imagination of the classic Greek writers of tragedy. This type of relapse is a key insight to understanding the underlying concern of palliative care clinicians and sedation practices. In the attempts of palliative care to humanize dying in these tragic dilemmas, have the techniques and principles utilized within palliative sedation practices, due to their potential one-sided nature, relapsed into a type of savagery or violence which are manipulating or reductive of the dying patient and of palliative care professionals?

As was mentioned earlier, palliative care was born as a protest against

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<sup>474</sup> SEGAL, *Tragedy and Civilization: An Interpretation of Sophocles*, p. 2.

**the abandonment of cancer patients by a healthcare delivery system focused on the cure and eradication of diseases. It was a protest against an approach which considered the work of the medical profession completed when all curative approaches had been exhausted. This curative medical approach constructed a valid but narrow search for a very particular biological pathology of disease which it sought to eradicate. When this curative medical approach exhausted its ability and found itself unable to match that "pathos", an incurable cancer, not able in some ways to engage or recognize the tragedy of the patient as person when terminally and incurably ill, instead turned away feeling impotence and failure. Palliative care emerged to fill a gap, to understand what it identified as the continuing medical needs of terminally ill patients which were not being addressed by this curative approach to healthcare. As palliative care developed it established an approach similar to curative medicine; the search and eradication of pathology. It constructed its own distinct search for pathology regarding pain and suffering by developing its own pain management techniques as well as borrowing and developing techniques of psychological, social and spiritual integration. The pathology sought had changed from biological disease to biological pain and fragmented personal meaning which inhibited integration and self-actualization.**

**When palliative care now exhausts its ability and finds itself unable to control or address the pathologies of pain and personal integration which it had identified, it wonders whether it is now abandoning patients in a manner similar**

to which it once protested against curative healthcare delivery. It is this feeling of abandonment, of a lack of fidelity, that palliative care clinicians point to when debating the appropriateness of whether the discipline of palliative care should embrace or appropriate the practices of euthanasia or physician assisted suicide. It is this same issue, feeling and question of abandonment that arises among some palliative care clinicians when the practice of terminal sedation is used to address refractory symptoms or when sedation is used to address the emotional suffering of patients with the knowledge that it may also affect the respiratory system and hasten the death of the patient. They question whether they are following the same pattern with terminally ill patients which they once protested against curative medical approaches.

This "pattern" seems to begin with the experience of limit to control or address the identified and sought pathology. Second, through that experience of limit one experiences the vulnerability of their approach and perhaps labels and internalizes the experience as failure. Finally, one might recognize the experience as vulnerability and tragedy allowing a reconnection to the terminally ill patient as a person, an other, and witness or continue to be available to the otherness of this experience. Alternatively types of vengeance might be exacted upon the patient or upon clinicians in response to this betrayal. Perhaps the most subtle vengeance is to distance oneself from the patient when techniques or treatments are not "working" and turn to the next patient where the satisfaction of the efficacy of techniques and treatments can be experienced. In

**this last step of the pattern some clinicians seem to be implicitly questioning whether the use of sedation to create somnolence as a response to extreme unresolvable emotional suffering of the patient humanizes the dying of that patient? Would there be a use of sedation to create somnolence as a response to extreme unresolvable suffering that would dehumanize dying? Is it a solution because it is the best solution or because it is the only solution we have at present in these situations? What resources, learning and corrective vision does such experiences of vulnerability, limit, and tragedy offer to the humanization of dying?**

**At the beginning of this chapter we have summarized the one-sided strategies identified within this dilemma. We have learned there was more than one interpretation of the principle of double effect, as well as divergent approaches to the humanization of dying within the practice of palliative care. Reflection on the operations and problematics of both the nature of conflict within *tragedy* and the concept of *interpretation* have offered insight and the potential for a corrective vision which might be appropriated within the practice of palliative care. It is towards this corrective vision and positive critique of the practice of palliative care as well as the interpretation and application of the principle of double effect that this inquiry now turns.**

## **2) Humanizing vs Orchestrating Dying**

**As one reads the palliative care narratives, it is unclear at times who the "hero" or the protagonist of the narrative might be. At times it seems to be the**

patient. Within this intense struggle with pain and suffering, the reader wonders if this anguish will be mastered or tamed by the patient. Will the patient achieve some sort of self-actualization or meaning through this process? At other times the potential "hero" seems to be the palliative care physician or the interdisciplinary team. The reader wonders if the palliative care team will master or tame the anguish the patient experiences or how the dying process and the patient's anguish will be humanized? In essence these narratives are framed in a manner that seeks solution.

The focus of these narratives is often the humanization of dying but this humanization is interpreted as a technical knowledge regarding the management and control of pain or a psychological or spiritual pathology considered as destructive to the process to a good dying process. The focus is really on the formula for the correct manipulation or orchestration of elements to co-create with the patient a peaceful death. Often the narratives maintain a narrow focus on physical actions or interventions regarding the dosage of sedation delivered, whether options for titrations and rotations were exhausted to offset the negative effects of the analgesics such as hastening the patient's death through suppression of the patient's respiratory system. It is this focus on pathology and the ability to actively manage, master or control its effects, to change or eradicate the experience of anguish that seem key to characterizing the orchestration of dying.

The structure of the conflict and the questions which seek to understand

the conflict seem focused on how increases in sedation seem to either suppress the respiratory system or lose the lucidity of the patient and create somnolence. In suppressing the respiratory system the clinician seems caught in the conflict between respecting the moral norms of not killing or hastening the death of the patient and respecting the norm and the person of the patient by attempting to control the pain and suffering which the patient experiences. In losing the lucidity of the patient due to sedation, the clinician seems caught in the conflict between respecting the moral norm within palliative care to address the pain and suffering of the patient and the moral norms to orchestrate the dying of the patient such that it can be experienced as peaceful, as a time of conscious self-actualization not only for the patient but also for their family members or loved ones. These are the two situations, likened to tragedy, where the clinician feels "caught" and forced to compromise by honoring one moral norm to the exclusion of the other valid norm.

The reflection on Greek tragedy characterized these experiences as a conflict of value with two actors coming from very narrow perspectives.<sup>475</sup> These two main protagonists were identified as in a conflict, with each locked in a strategy of avoidance with regard to the conflicts internal to their respective causes.<sup>476</sup> Further, the conflict was identified as stemming not only from the

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<sup>475</sup> NUSSBAUM, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*, p. 56.

<sup>476</sup> RICOEUR, *Oneself as Another*, p. 243.

**one-sidedness of the characters choices and approach but in the one-sidedness of the moral principles which are also confronted with the complexity of life.<sup>477</sup>**

**How might these strategies of avoidance or one-sided approaches already identified in palliative care be offered a corrective vision concerning the humanization of dying?**

### **3) Deliberating Unique Palliative Care Encounters**

**The context of the humanization of dying as the ethical aim of palliative care offers a necessary background to understand how the principle of double effect (PDE) could be adequately applied to tragic palliative sedation cases. It is this aim which offers a telos to the deliberation that is inherent within the principle of double effect.**

**In two of the narratives at the beginning of this inquiry, PDE was mentioned as principle used to justify the giving of sedation to produce unconsciousness to address the suffering of the patient even though the amounts given to adequately address the suffering may suppress the patient's respiratory system and hasten the patient's death. Within the story of Mrs B., this line of action was supported through the deliberations of the hospital ethics committee. Within the story of Mr. G., the team ethicist was consulted with the resultant suggestion that, "Pharmacological sedation as a palliative modality for emotional/spiritual suffering is an ethically acceptable option in these**

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<sup>477</sup> RICOEUR, *Oneself as Another*, p. 249.

circumstances". In both cases it is clear that ethical deliberation did take place, the deliberation does not strike the reader as straightforward, but none of the key elements that assisted either the ethics committee or the ethicist to arrive at those two conclusions in those two specific cases is forthcoming. Three questions arise implicitly within the text of the two stories and at the end of this inquiry. What is the path of deliberation within these types of cases? What is the type of verification and risk that must be expected from this type of ethical deliberation? What parameters or insights might assist deliberation in these specific palliative sedation stories?

#### 4) The Path of Deliberation

When this inquiry reviewed the 1995 *Joint Statement on Resuscitative Measures*<sup>478</sup> regarding decisions of futility and the foregoing of medical treatments within that policy statement, it was identified that the clinician was left to complete the most difficult part of ethical reasoning in unique situations. This was the deliberation between the norms offered and the particularity of their practical situation. It was this process of ethical reasoning, this developed practical wisdom, that healthcare professionals are perhaps least prepared for and find most difficult. The challenge through the deliberation is how the decision can be shown not to be arbitrary or a choice of simple personal

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<sup>478</sup> Canadian Medical Association, Canadian Nurses Association, Catholic Health Association of Canada, Canadian Bar Association, "Joint Statement on Resuscitative Measures", *Canadian Medical Association Journal* 153 (11) (1995), pp. 1652A -1652C.

preference. It is important that the decision appropriates a continuity with past ethical orientations regarding double effect reasonings and palliative care ethical decision making, the singular uniqueness of our present experience, the expectation of where we believe our future is oriented.

The starting point for this path is to articulate again the four conditions of the principle of double effect: 1) The act must be good in itself, 2) The intention must be good, 3) The evil effect must be indirect, 4) There must be a commensurate reason for any evil effect. From our exploration of PDE in Chapter Two it is clear that in debate concerning the operations of interpretation and deliberation, key underlying concerns arose. First, interpreting the principle in a strictly physical and causal manner without considering the importance of the circumstances of the event, the intention of the agent, or other elements which contribute to constructing the *orient* of the action event and the appropriation of this meaning by the subject. Second, the potential for arbitrariness and subjectivism in privileging the importance of the singular circumstances in situations and the concern that this would undermine the potential for exceptionless moral norms and a role for moral authorities within community living. The third concern focused on the valuing of human life and contrasted the seeming devaluing of vibrant human life due to the starvation of populations in developing countries as opposed to an overvaluing of severely limited, biological human life within the technologically oriented healthcare system in developed countries. Essentially the assertion was there are times

when the protection of human life served no point. The necessity was therefore to develop the ability to differentiate between the differing types of responsibilities and obligations towards differing types of human life. The claim was that we should be able to distinguish a higher value on human life which had the ability of biography, cognitive ability and consciousness, rather than only the most limited and vital biological capacities such as respiratory or heart function.

The path of deliberation is first identifying how this decision in situation is unique from those situations where there is a great degree of consensus. Typically in some withdrawal of treatment situations the principle of double effect is used. Ventilator support is withdrawn from a patient with advanced *Amyotrophic Lateral Sclerosis (ALS)*, or Lou Gehrig's disease, because it is the patient's expressed wish. The treatment which will not cure is withdrawn even though the clinician is aware that the patient will die. The difference between a case like this and one in palliative sedation practices is that: it seems less tragic, the weight of the decision is on the shoulders of the patient, because the decision is made by the patient it is an appropriation of meaning on the patient's terms (the patient is the author) whereas with the palliative patient the evidence of extreme suffering is interpreted by clinicians as evidence that the work of the patient is not complete and is in fact failure, the pain and suffering of the patient is not as extreme, the time that passes between withdrawal and death may be longer, the clinician is taking away technology that more understood as artificial,

it is a single event whereas the titration and dosage of sedation is much harder to know what to expect and to know and control the variables regarding the bodies tolerance and the ability to get the right combination, giving sedation treatments may seem to the clinician that they are participating with and constructing the pathos of suppression of the respiratory system and hastening death where withdrawal is resignation to the pathos and allowing it to take its course, ventilation can be framed easier as a burdensome or alien or unnatural technology whereas sedation and nutrition and hydration are less easily framed in that manner, the vision of the vulnerability of the patient is much more extreme – the reaction to their pain is "to do something". The commonalities include that both could be experienced as failure, inability to control or help the patient, the treatment involves a type of brinkmanship and failure at brinkmanship right up to the end of life.

##### **5) Deliberation Specific to Palliative Sedation Practices**

The experience of limitation in the current approaches in palliative care gives rise to challenges regarding how dying might be humanized in such tragic sedation dilemmas. These challenges are actually dialectics of deliberation more specific to the singular situations of tragic palliative sedation dilemmas.

The first dialectic for deliberation is between **the approach of searching for pathology and the approach of availability**. What developed first in palliative care was the ability to recognize the tragedy and needs of terminally patients. Palliative care developed through a witnessing of their dying and

fostering an availability that was more passive and less active in the sense that their role was to allow the story of the patient, the otherness of the patient, to unfold before them. Patients were leading and clinicians were following. As more of a science of palliative care developed and the pathology to a humanized dying was constructed, clinicians were more active in the search for conventional pathologies and perhaps more willing to name deviations from convention as pathology. The approach is critiqued not so much as wrong but as one-sided and perhaps needs to navigate a "middle way" in between the search for pathos and its ability to witness tragedy not as failure but as insight into a greater diversity of experience in the humanization of dying.

The second theme regards deliberation between the experience of convention as betrayal and a turning to the other, who is the patient. The experience of tragedy can in some ways be experienced as a violent power that is both part of ourselves and a force beyond ourselves. The experience of this entwined force claimed to be tragedy is approached with awe and dread. It is the experience of pity and fear evoked by tragedy that allowing us to recognize, acknowledge and expel this force. The catharsis involves not only an experience of vulnerability, pity and fear, there is also a learning involved. As mentioned above there is a revealing of one-sided approaches, but the infinite meaning grows to fulfillment only slowly, partially and darkly. The confrontation between civilized or ordered and wild or unordered spaces is an experience of living in a type of moral frontier, at the limits of human experience. This is the

**lived meaning of tragedy. The Greek hero, like the palliative care hero, like the dying patient, all experience the nothingness of moving between or beyond the familiar categories into the irregular, the interstitial, the ambiguous, the unique and the unclassifiable. The negation of convention, or civilization to keep with the metaphor, becomes in fact a civilizing experience where our potential for violence is recognized, our gaze is turned, and the violence has the potential to be expelled.**

**Openness and vulnerability are traits needed by the hero to discover the "other" of the patient or the humanization of dying not described by their present one-sided approach. If these virtues create the risk that the hero is more easily betrayed by convention than the self-enclosed person, and the experience of betrayal erodes these foundations of openness and vulnerability, how might palliative care recognize and respond to such seeds of destruction? How might this continued experience of betrayal shape an experience of vengeance within the ethos of palliative care? A type of subtle vengeance is precisely what some might describe sedation practices such as terminal sedation to be when the suffering of the patient persists in spite of the fact that all forms of excellent palliative care have been exhausted. Finally, there is discomfort because this resort to a drug oriented technique perpetuates the notion that suffering is an issue that can be addressed through medication. The pervasive belief within palliative care that this suffering is constructed not due to a biological or neurological "pathos" but due to another type of "pathos", the inability on the**

part of the patient to address and integrate the fragmentation of their identity and this dying process into the narrative of their life story. Because it is the "option of last resort", is the pressure that is moving us to resort to it a type of vengeance camouflaged as addressing the suffering of the patient? Our inability to diagnose and understand the type of suffering the patient is experiencing inhibits our ability to evaluate the healing ability of terminal sedation. Due to its description as an option of last resort, there is a degree of uncomfortability whether this option resolves or heals the issue of pain and suffering as much as camouflages or tames them for palliative care clinicians and the loved ones of the patient.

The final theme of struggle within palliative care is its own tension between solution vs conviction. Our reflection on Greek tragedy demonstrated the reluctance of tragedy to offer solution. Certainty, safety and an absence of risk are what "solution" desires to limit if not eradicate. Having travelled the path of deliberation, our knowledge has passed through problematics of conflict between the respect for persons and the respect for the moral norm. Our knowledge is understood as partial, as still appropriating a diversity of values, as inconclusive and still fragile. The total meaning of these palliative sedation events grows to fulfillment only slowly and partially. But this path of deliberation has tested and revealed narrower, one-sided approaches to this issue. The knowledge cannot be claimed to be arbitrary or simply subjective. There is a vulnerability and fragility to conviction that has attempted

**to balance utopic expectations and the continuation of convention or dead traditionality in unique situations. The moral norm has sought universality and the eradication of mutability, indeterminacy, and the particularity of singular situations. Palliative care clinicians who allow their present approaches to take refuge in either utopic expectation or dead traditionality risk the inevitability of betrayal.**

#### **F) Conclusion**

**It would seem that palliative care is engaged within a new moral frontier regarding sedation practices. What is the ethically significant difference between killing and letting die in palliative care where death is not only foreseen through the treatment but, part of the complex act of doing good such as relieving pain and suffering? Is sedating a terminally ill patient to the point of unconsciousness to address extreme types of suffering justified through the principle of double effect? These are foundational challenges of palliative care shaping their approach to the humanization of dying. Perhaps these questions might be framed in a different manner. Would the use of sedation to create unconsciousness as a response to extreme unresolvable emotional suffering of the patient humanize the dying of that patient? Would there be a use of sedation to create unconsciousness as a response to extreme unresolvable suffering that would dehumanize dying. Is this an inadequate taming of the "wild" frontier of dying? Is it a solution because it is the best solution or because it is the only solution we have in these situations? Is our search for justification**

in the principle of double effect an attempt to hide our vulnerability behind a moral norm of justification? Does this approach allow us not to recognize the tragedy of the situation, provide a "solution" and distance ourselves from the real experience of vulnerability? Is this the best assertion of humanness into these tragic situations with the patient, "the other", who is dying and with colleagues who are also suffering?

The use of sedation is ultimately an attempt to tame or civilize the "wild" experiences of dying that are encountered in narratives describing tragic palliative sedation practices. It is a response to a type of extreme anguish and suffering to which any explanation or justification seems banal.<sup>479</sup> Sedation may indeed be the most appropriate response to situations involving dyspnea or racking pain where the body needs physical rest. For emotional suffering it is less clear. The necessity to respond to these situations in a manner that asserts humanness, that prioritizes the inter-human understood as a non-indifference of one to another or a responsibility of one for another.<sup>480</sup> Such a responsibility asks what resources of the self will this demand from palliative care professionals to humanize absurd suffering? Such resources have been mentioned and include an understanding of the type of problem decision in situation is, vulnerability and openness to be present with a dying patient

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<sup>479</sup> Emmanuel LEVINAS, "Useless Suffering," in *The Provocation of Levinas: Rethinking the Other*. (New York: Routledge, 1988), p. 163.

<sup>480</sup> LEVINAS, in *The Provocation of Levinas: Rethinking the Other*, p. 165.

**experiencing absurd suffering, an ability to deal with the inevitability of betrayal of convention.**

## CONCLUSION

### **A) A Stance of Suspicion**

**This inquiry began from an experience of suspicion. The origin of that suspicion was the subtle claims of manageability if not the ability to master profound and complex types of pain and suffering experienced by palliative care patients and witnessed by the healthcare professionals who care for them. Four narratives involving tragic palliative sedation treatment dilemmas were articulated above which served to heighten our awareness of limitations, loss of control, and vulnerability as palliative care professionals attempt to responsibly respond to the tragic suffering of patients. These narratives acknowledge the complex influence of a range of medical data, psychological influences, spiritual and social dynamics and existential suffering as well as the opportunities for growth or healing that a tragic form of dying presents. The experience of clinical limitation and moral ambiguity gave rise to questions framed in a manner reminiscent of old moral debates thought settled. Was there a significant moral difference between killing and letting die? Was the principle of double effect, and more specifically the criteria of psychological intention, an adequate resource to pertinently distinguish between a clinician appropriately or inappropriately participating in the death of a patient? When is it permissible to keep prescribing morphine when you know it will cause death within hours or minutes?**

**Essentially these questions and clinical narratives articulate an experience of limit and question whether conventional modes of responding are adequate. These limitations not only regard the sense of finiteness of professional and technical skills but also the fragility of the self-identity and ideology of palliative care itself. The fundamental suspicion was that of mastery, that palliative care professionals can master the body through carefully controlled technology or that the orchestration of a good death can be mastered with the same precision.**

**B) Moral Reasoning and Deliberation: A Narrow Framing of the Problem**

**A consistent theme within this inquiry has been to understand the one-sided nature of the principles, moralities and strategies within the ethos of palliative care and implicit within palliative sedation practices. Essentially, this inquiry was questioning whether the approaches palliative care has constructed to tame and civilize dying, especially tragic dying, are in fact humanizing. A focal area of analysis was the interpretation and application of the principle of double effect as a form of moral reasoning and deliberation in particular case situations.**

**My clinical experience of working with healthcare professionals to address ethically difficult care dilemmas has made me aware of expectations or perhaps orientations these professionals can have of moral principles such as PDE. The first expectation is that a moral principle will confront healthcare professionals as prohibition or constraint rather than having a creative or innovative function in addressing unique and particular situations. The second**

expectation is that, to be effective, moral norms will offer a similar type of certainty as a law of physics, requiring simple application rather than complex deliberation. If the principle does not offer that type of certainty then it might be evaluated as weak or arbitrary. The third expectation regards whether distinctions between what clinicians do and what patients suffer is even possible. Palliative care is a healthcare discipline still struggling with the ghosts of a scientific and technological approach to medicine. Within this approach, an implicit concept of progress and moral imperative become one where if we do not pursue the conquest of pathology, then clinicians are open to moral blame. What emerges is a tendency to attribute everything that happens to the patient to the human agency of clinicians. It is this cultural belief and burden of responsibility, that all clinician actions affect patients, which confronts PDE as it attempts to make relevant distinctions regarding the moral intent of actions. These types of expectations can shape how healthcare professionals begin to interpret and apply PDE in tragic palliative sedation practices.

Second, there is a specific character or context the healthcare professional finds themselves in when a moral reasoning such as PDE encounters tragic palliative sedation dilemmas. The context is that of a moral frontier, of living at the limits of human experience where conventional practices expected to offer shelter and safety seem to invert in tragic situations to become destructive or savage. This is the landscape of tragedy often experienced as a type of trauma. As mentioned before, this is the experience of the tragic hero

described as "liminality", the experience of the boundary situations of human life. It is the experience of nothingness in moving between or beyond the familiar categories into the irregular, the interstitial, the ambiguous, the unique and the unclassifiable. This place where convention no longer addresses the new and tragic experience, is the home of deliberation in the context of decision in situation.

Third, PDE is a principle attempting to deliberate and distinguish the intent of action, but will be interpreted and applied according to how one defines the features that constitute both "an act" and "intent". It is this deliberation and interpretation which appropriates the ethical complexity of decision within these types of unique situations. When it is proposed to address unique palliative sedation dilemmas through legislating moral norms, the argument is offered that these decisions are best left to those healthcare professionals and decision makers closest to the problem. Yet it is this understanding of the operations of deliberation, an understanding of the interpretation and application of the principle of double effect which incorporates the physical and psychological intent of action within moral intent, that is absent from clinical healthcare reflection on PDE and palliative sedation practices.

The foundational insight is the necessity of integrating both the internal, physical operations of action, as the tradition of analytic philosophy has offered, as well as the orient, the moral intent, the destiny of the action. This is an insight inspired by Ricoeur in his understanding of interpretation as a dialectic

between the operations of *explanation* and *understanding*. In this light, the function of PDE is not so much a justifying principle as hermeneutical, offering lines of inquiry for deliberation. Its ability for justification comes through a path of deliberation and is more aptly called "conviction". Demonstrated is the limited or perhaps incomplete nature of a causal and physicalist interpretation of the principle of double effect.

### **C) Challenges within the Dialectic of Tradition and Innovation**

The operative interpretation of PDE was potentially reductive if its orientation focused solely on the physical, causal or psychological intent of action rather than a broader understanding of the moral intent of the action. The operations of deliberation, or practical wisdom, understood as the ethical aim passing through the moral norm and reverting back to the ethical aim in dialectic leading to conviction offers insight and direction to the operations of decision in situation. This type of deliberation is complementary to the operations of PDE interpreted as a hermeneutical principle attempting to identify the moral intent of potential modes of action seeking to innovatively fulfil the ethical aim of a tradition in singular situations.

Second, is the challenge to integrate the dialectic of tradition and innovation with the challenges and vulnerabilities confronting the socially constructed palliative goods of pain management and preparation for dying well. Recognized is palliative care's struggles within its "ethos", its struggle with the medicalized orientation of dying, its struggle between activity and passivity. The

orientation to eradicate pathology either biological or psycho-spiritual is critiqued for inadequately appreciating the relationship between pain and suffering, reducing suffering to a pathology with no meaning or social value at all. The tragedy of palliative sedation practices reveals a plurality of human values and casts doubt on attempts to create harmony through synthesis. Within the genuine and inevitable conflict, the diversity of goods is unearthed which convention and the moral norm tend to obliterate. Within the palliative sedation narratives presented, the conventional process of self-actualized dying, as defined by the patterns experienced within palliative care, was not realized. Most palliative care clinicians would not claim that they expect all dying to be peaceful or a time of self-actualization. Yet the *telos*, the achievement and satisfaction of palliative care is to orchestrate the experience of death according to these types of parameters. The complexity and rawness of tragic suffering which accompanies the transition of identity and meaning of the patient are not so much unexpected as interpreted as uncontrolled pathology and as the symbols of failure for palliative care.

To heed Ricoeur, the place to begin is in the fullness of this experience, the multiplicity, not to proceed from the simple to the complex, but to allow various dimensions to unfold as aspects of a single fullness. The fullness of this experience awakens us to the fact that we must be constantly aware of a reality constantly transcending us. The tendency is to avoid this risk of openness and transcendence by seeking a refuge within convention or what is known. Have

**the conventions used by palliative care to humanize dying in tragic palliative sedation dilemmas, due to their one-sided nature, serve only to manipulate or reduce the dying patient and palliative care professionals?**

**This humanization of dying addresses a particular type of encounter within palliative care. This is an encounter shaped by a particular experience of limitation: a diversity of goods and values as well as an elusive pursuit in understanding of the other as well as the totality of the dying process and experience. The humanization of dying attempts to apply a corrective vision, as palliative care was in its genesis, of introducing a renewed vulnerability and mutuality within this clinical encounter. It is this encounter of the self with the other, this ethics of solicitude that is foundational. The challenge of re-establishing, continuing and creating interpersonal meaning within the context of tragic suffering and fragmentation needs to be accepted within palliative care. Responding to this challenge requires understanding the mutuality and vulnerability of the encounter between the patient and palliative care professionals, the reductive moralities, the conceptions of tragedy as failure, if dying is to be foundationally humanized.**

**One of the conclusions of this inquiry is not that the sedating of a terminally ill patient with refractory physical pain is wrong. It does question if addressing profound emotional suffering of terminally ill patients with a physical focus on consciousness is perhaps a narrow approach. Is our responsibility to the other that we will guarantee they will not experience profound emotional suffering at**

**the end of life or that my presence will not seek distance from it, reduce it, but witness it? It is a witnessing characterized by Ricoeur's notion of solicitude, as availability, mutuality, vulnerability, that the profound suffering does not reduce the other to an enemy, a monster. Human presence as solicitude, engaged with the patient as other, is what humanizes and transcends.**

**It would seem to be this path of deliberation, practical wisdom, vulnerability and mutuality that palliative care professionals feel less prepared for but are confronted in tragic forms of dying that may not be able to be eradicated. The genesis and ethos of palliative care had rested on identification of the terminally ill patient and the humanization of that particular dying experience. Now, with the definition of the terminally ill patient becoming more problematic, a new defining moment for palliative care is discovered in the humanization of tragic forms of dying. The ethical resources needing development are the resources of the self of palliative care professionals on the inter-human level to adequately humanize the absurd suffering confronted in narratives describing palliative sedation dilemmas. Its course is open before it whether it accepts to understand its one-sided approaches in light of the fullness, the diversity of dying, that requires different, perhaps more personally and professionally demanding approaches for its humanization.**

**Sedation Practices, Tragic Dying and Palliative Care:  
An Ethical Inquiry**

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