

**REASSESSING THE 'BURDEN OF LIFE':  
THE MORAL JUDGMENT OF TERMINALLY ILL PATIENTS  
REGARDING THE VALUE OF THEIR LIVES  
AND WHAT THE REST OF US CAN DO ABOUT IT**

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Submitted to the Graduate Faculty of  
Arts and Sciences in partial fulfillment  
of the requirements for the degree of  
Masters in Bioethics

University of Pittsburgh

2002

UNIVERSITY OF PITTSBURGH  
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FIGHTING THE 'BURDEN OF LIFE':  
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AND WHAT THE REST OF US CAN DO ABOUT IT

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ABSTRACT

In a highly influential piece supporting a patient's right to choose euthanasia, Dan Brock uses an incomplete notion of autonomy in one of the key premises to his argument. He defines autonomy as the individual's ability to pass judgment on the value of his/her own life, using his/her established set of values, and then to act accordingly. The respect that others should have for the patient's autonomy is then seen as primarily the negative 'letting alone' of the patient. Brock identifies autonomy, in this sense, to be a necessary element in a person's 'dignity.' In other words, suffering, terminally ill patients who do not have the freedom to determine the amount of suffering they experience before death, or to decide the timing and manner of their death, are seen to be 'undignified.' What this view leaves out is the necessary analysis of how patients go through the process of their life assessments, the intrinsic relational nature of this process, and how respect for autonomy and dignity understood in a broader sense can be seen to entail obligations to foster positive opportunities and beneficial circumstances for terminally ill persons, rather than acquiescence to their demands.

One of the most biting criticisms of this account of autonomy comes from a type of feminist bioethical thinking called 'the ethics of care.' The ethics of care aims to replace the false moral ideal of the masculine, atomistic, emotionless individual who seeks control with a feminine, interdependent, emotional individual who seeks positive relationships. However, the ethics of care goes too far in its opposition to the importance of autonomy in the moral life of the individual. There is a better concept of autonomy that simultaneously defends the individuality of the person deciding (free from coercion) and the interdependence of that person on others in that person's: 1) formation of values, 2) deliberation or assessment of how to decide based on those values, and 3) following

through with the action decided upon. This ‘redefined’ autonomy requires, not only the negative allowing of decision and action on the part of others emphasized by Brock, but also and primarily the positive support of others and their input into those three steps of autonomous decision-making, as Grace Clement speaks of. It is this concept of autonomy as intrinsically relational that allows us to focus, not on obeying or allowing a patient’s wishes at all costs (such as euthanasia), but in fact commits us to respond to and to attempt to influence the process by which the patient arrives at his/her judgments. We see that the circumstances and opportunities open to a person are a significant part of the persons’ life assessment, and that these circumstances and opportunities depend to a large extent on the social structures surrounding the patient and the messages coming from society, and most directly from one’s caregivers. The best thing for caregivers to do is to focus on the intrinsic dignity of each patient and to help identify an array of opportunities available to each patient to exercise his/her autonomy and to grow in virtue.

The feeling or sense that patients have over their own dignity relates more to how they perceive their losses and circumstances than to what those losses are. The patient’s self-worth is not completely invulnerable to the loss of health. Both external goods, such as health and wealth, and relational goods influence the value judgment of a person and can, in fact, influence the very character of the person- positively or negatively. The ancient philosopher, Aristotle, says that ‘eudemonia’ or happiness is vulnerable to the great loss of external goods, such as in the case of a patient who has lost health to the point of being terminally ill. Yet, he also says that even in great loss, the “fineness shines through” in the person who is noble and magnanimous. Within the hierarchy of goods, Aristotle places the goods of the soul as higher than the goods of the body. Relational goods play an especially important role, and are also higher than the goods of the body. From this perspective, a terminally ill patient and his/her caregivers may be encouraged to place greater weight on relationships and virtue than on physiological limitations. In fact, the loss of health and function can be re-evaluated as precisely the needed opportunity to grow in certain context-dependent relational virtues. Within the appropriate circumstances, the patient will be more easily able to live more of ‘the good life’, and become, not less human through external loss, but rather more human through relational virtues. The new moral ideal becomes, not the atomistic-autonomous

individual, but the interdependent-autonomous individual. Politically, socially, and personally, we would do better to promote this latter moral ideal by creating circumstances and opportunities for caregivers to respect the patients' autonomy and dignity in the positive sense.

*Dedicated to my Father,  
Dominick E. Fortunato, who recently told me,  
“I was viewing life as a burden; then I realized that ultimately life is a gift.”*

*And in loving memory of my mother,  
Loreta G. Fortunato  
(1940-2000)*

## PREFACE

*“It is by learning how to die that we learn how to live.”*

-Tuesdays with Morrie by Mitch Albom

Physician-assisted suicide and euthanasia are complex biomedical ethical issues for individuals, and even more so for our society. Although I am adamantly opposed to both practices, I recognize that many do not share my point of view. It is my hope that this thesis will help to broaden the dialogue to include theoretical and practical ways of addressing the concerns and fears of the terminally ill in ways I deem much more ‘human’ than euthanasia and assisted suicide. In a survey reported on the progress of Oregon’s Death with Dignity Act,<sup>1</sup> the twenty-one patients who chose physician-assisted suicide in 2001 said that their top two motives for the choice were the loss of autonomy and the decreased ability to participate in activities that make life enjoyable. It is my stance that both autonomy and life enjoyment can and should be maintained and encouraged throughout the entire dying process.

In his article entitled “Voluntary Active Euthanasia,” Dan W. Brock says the following:

Many (terminally ill) people adjust to these disabilities and find meaning and value in new activities and ways. Others find the impairments and burdens in the last stage of their lives at some point sufficiently great to make life no longer worth living.<sup>2</sup>

This thesis is a hopeful move in the direction of increasing the size of the former group described by Brock, and thus decreasing the size of the latter.

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<sup>1</sup> <http://www.ohd.hr.state.or.us/chs/pas/ar-tbl-3.htm>

<sup>2</sup> Brock, Dan W.. “Voluntary Active Euthanasia,” *Hastings Center Report* 22, No. 2 (March/ April 1992), pg. 10-22. as reprinted in Beachamp and Walters’ *Contemporary Issues in Bioethics* fifth ed. pg. 297.

It is my impression from the literature that many terminally ill patients focus excessively on what they can no longer decide and do. Many patients are not encouraged or at times not even allowed to choose to do and to do things that they can do. In practice, other people such as caregivers and family do not always put enough emphasis on the value of the small choices and actions that are so important for the validation of the patient's autonomy and dignity. It would be beneficial to increase our emphasis on encouraging patients (and all of us) to see their un-chosen, limited circumstances as opportunities to voluntarily live virtue, and thus to become 'more human.' In this way, I think that more people will find their lives, not only bearable, but also indeed invaluable. As way of providing a concrete example, I include a passage below telling the story of my mother, and how she taught me how to live well while dying.

I would like to thank my thesis committee: David Kelly, Alex London, and Mark Wicclair, and especially David Barnard, my thesis advisor. David has been incredibly patient and supportive through my many thesis ideas, drafts, re-drafts, and ethical inquiry journeys. I would also like to thank Heda Segvic and Lisa Parker for their help and input.

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"One day in late August, 1999, I received a phone call from my youngest brother. My mother was in the hospital and in bad condition. She had reacted badly to prednisone, a drug upon which her hope for a lung transplant rested. The drug had created a false energy in her, and an impression in all of us that she was healthier than she actually was. A week prior she had been running her household, just as she had done for the previous three decades. But now it was clear that she was dying.

I had the great honor of being her primary caregiver for about one and a half weeks when she came home from the hospital. She was confused, experiencing short-term memory loss, and incredibly stubborn. One of my brothers soon joined me to set up a long-term care system since my full-time care giving prevented me from having time to make such arrangements myself. On his first night home, after we had put my mother to bed (at least for the time being), he and I sat on the couch and talked. I told him the highlights of the previous days. First there was my mother's talking as if she was having a conversation with someone who wasn't there. Then there was my finding her crying in the middle of the night frustrated as she tried to work the microwave, a simple task that she had now forgotten. More troubling was the "help" she gave me in the kitchen, filling the fried chicken pan to the brim with water and insisting that she knew how to cook better than I did. Finally there was the fact that she had managed to hide her medication, even though I had had her in my sight for all but the two minutes during the day.

My brother took out a piece of paper and a pen, and wrote the words: "*Things that we can't let Mom do anymore.*" Partially out of physical exhaustion, I yelled at him: "You can't take everything that Mom *is* away from her! What about her functional independence?"

Together, my brother and I created a new list, entitled "*Things that Mom can do.*" During those days, my mother and I completed several projects. They were of little import to the world, but of the most pressing importance to her (and therefore to me). I knew that she would not be able to go to my nephew's second birthday party in her condition (although at that time she still insisted that she would get totally better and go), so we made him a birthday card. I cut out the photo, and passed it to her to glue onto the

piece of paper. She told me what to write, and I wrote the many small words. She topped it off with a big “I love you! Love Lola (the Filipino word for grandmother).” These last words she could write herself, making the letters big enough that she could correct the jagged lines of her previously beautiful handwriting. She also guided me to choose photos for a photograph tree that had collected dust in our dresser for several years. I did the delicate work of the cutting and arranging, but we were equally proud to show it off to my father. One day we changed the bed linens. And then the next day we changed the bed linens. On the third day we changed them again. At first I tried to tell her that they were clean. Then I learned. In her mind, they needed to be changed, so that was good enough for me. Another very important project was teaching me a new Filipino “dance.” My mother was always a dancer, and spoke about wanting only to be able to dance again so she could teach dances to my nephew and his classmates (even though he was only two and not in school at that time). Every day, she turned on some Filipino music, sat down, and with her legs still, waved her arms with the grace of a swan. She taught me a new song, arm movements and all. It is called ‘Clean little hands.’

By December, my mother had regained her short-term memory and had fully accepted the fact that her illness was terminal. The doctors said that she could live up to another nine months. At Christmas, I asked her if she wanted to do anything special, such as visit the gardens nearby. She responded with a smile: “Angela, I have a lot of work to do.” This came from a woman who hadn’t worked as a nurse in a year and a half. This came from a woman who no longer shopped for the family, and no longer did all the laundry. In many senses, she no longer worked at all. She kept on smiling and

continued: “I need to pray more and write more letters.” In those few months, she wrote hundreds and hundreds of letters to friends and family. She also wrote her autobiography up until 1995, passing her handwritten notes to my father who then typed them out. She also kept in touch with all of her children often, writing me many more letters than before. In several of them, she complained of her failing handwriting. In one, she made the resolution to start printing since she could no longer write in script well.

I was thoroughly impressed by how professionally she did her “work.” Her prayer book was neatly organized, and her day was divided into various times of prayer. She looked after her vitamins and medications with the diligence of someone working in a laboratory of infectious diseases. Her home health care aide had taken over doing the laundry, but she proudly helped with the folding. For a time, she even went on food shopping trips in her wheelchair, picking out the items herself. Her rest time was similarly adjusted to her illness. She and my father taped their pre-selected television programs, and watched them together at a time that they planned. My father only watched the programs that my mother liked, and the majority of their time was spent together.

However, as time went on, and her limitations increased, her daily occupations became quite few in number. On my last visit, in late April, 2000, I observed her taking many naps. She spent the weekend talking with me, and letting me massage her hands and legs. It was the last time I saw her alive.

On May 20, she died, with my sister and one brother by her bedside. I arrived twenty minutes later from the airport. When I arrived home, I read through her prayer book. The most recent additions came under the heading “Resolutions.” She had

written: “Sit up straight in bed to make the morning prayer-offering.” “Remember to look at the three statues” (of the Virgin Mary in the house). And finally the last entry, written just days before her passing: “Work with cheerfulness. Be a prayer.”

My family unanimously decided to place these last words on her funeral card. At the funeral, I spoke about my mother. I mentioned what one friend of my mother’s had commented to me on the phone, that she would always remember my mother dancing. That friend had not known her in the circumstances of her terminal illness, only in her healthy years. It is that Loreta G. Fortunato that I decided to speak of at the funeral- the terminally ill one. I wanted to pass on to the people at the funeral the lessons that my mother had shared with me, lessons that she couldn’t have taught outside of those circumstances. I told them how well she accepted her limitations, and how much virtue she exercised in the many little things she could do. I told them about how happy she was during her final months. Then I taught them ‘Clean little hands’:

‘These are my hands, my left and my right.  
Hold them up high, so clean and bright.  
Clap them slowly, 1, 2, 3,  
Clean little hands are good to see.’

Angela T.  
Fortunato,  
May 20, 2002

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## Down the Logical Road to Euthanasia?

Recently, there has been much discussion concerning the practices of physician-assisted suicide and euthanasia. Among the proponents of allowing both practices, Dan W. Brock stands out as a highly influential bioethicist. His article entitled, “Voluntary Active Euthanasia,” first published in the Hastings Center Report in March/April 1992, provides many readers with a logical argument as to why we as a society should endorse this type of euthanasia. His major argument brings the reader from a certain understanding of the right to refuse life sustaining treatment, and links that generally accepted right to the right to euthanasia via the fundamental ethical values of patient autonomy and individual well-being. In his many published works, Brock also explains what he means by the concepts of autonomy, dignity, and the quality of life, and the relationships between the three. After defending his view against the two most common opposing claims that the deliberate killing of an innocent person is always wrong and that the bad consequences of euthanasia outweigh the good, Brock concludes that voluntary active euthanasia should be permitted for patients who reach that point when “continued life is worse than no further life at all.”<sup>3</sup> In this chapter, I will summarize his argument as a springboard for the remainder of the thesis.

“It is the very same two fundamental ethical values supporting the consensus on patients’ rights to decide about life-sustaining treatment that also support the ethical permissibility of euthanasia.”<sup>4</sup> Although there is consensus that the patient has a right to

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<sup>3</sup> Brock, Dan W. “Quality of Life Measures in Health Care and Medical Ethics,” in *The Quality of Life*. Nussbaum, Martha and Sen, Amartya eds. Oxford: Clarendon Press. 1993, pg. 103.

<sup>4</sup> Brock, Dan W. “Voluntary Active Euthanasia,” *Hastings Center Report* 22, No. 2 (March/ April 1992), pg. 10-22. as reprinted in Beachamp and Walters’ *Contemporary Issues in Bioethics* fifth ed., pg. 297.

decide about life-sustaining treatment, Brock's conception of that right is rather particular.<sup>5</sup> In the patient's assessment, he includes not only the benefits and burdens of the treatment itself, but also of "the life it sustains."<sup>6</sup> Thus, he identifies the threshold question for the patient to decide whether or not to accept life-sustaining treatment as: "Is the quality of the patient's life so poor that for that person continued life is worse than no further life at all?"<sup>7</sup> He says that the deliberation concerning treatment will involve an assessment of the patient's own quality of life, unless the patient is some sort of vitalist who wants to hang onto life no matter at what cost.<sup>8</sup>

Quality of life is defined by Brock as "how the conditions of the patient's life affect the value of that life *to that patient*,"<sup>9</sup> and specifically not the value of that life as judged by other people. In this way, Brock promises to prevent people from passing judgment on the value of the patient's life based on the cost and effort needed to sustain them. This, he asserts, is only a danger of the quality of life concept misunderstood. In other words, when he defines the quality of life precisely as the value of the life of a person to that person him/herself, then he purports to forego the risk for people to treat other people unjustly as lacking value. He claims that he also does not take away from the intrinsic value of each human person; he is speaking only of the value of a life so conditioned by illness, pain, and impairment to that person. At a certain point, then, the conditions of the illness may make the patient deem his/her life as "no longer a benefit."<sup>10</sup>

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<sup>5</sup> Many people, including myself, would view the right to refuse life-sustaining treatment as an assessment of the value of the treatment itself, not of the life that is always invaluable.

<sup>6</sup> Brock 1993, Quality of Life Measures, pg. 102.

<sup>7</sup> Brock 1993, Quality of Life Measures, pg. 103.

<sup>8</sup> Brock 1993, Quality of Life Measures, pg. 102.

<sup>9</sup> Brock 1993, Quality of Life Measures, pg. 103

<sup>10</sup> Brock 1993, Quality of Life Measures, pg. 103.

When the patients deem their lives as burdens, they have the right to forego life-sustaining treatment and so to choose to die.

Patients have the choice to die because they are autonomous, or self-determining, persons. Brock defines autonomy in the following way: “By self-determination as it bears on euthanasia, I mean people’s interest in making important decisions about their lives for themselves according to their own values or conceptions of a good life, and in being left free to act on those decisions.”<sup>11</sup> Autonomy thus has two components: to decide and to act. To respect patient autonomy is to allow them to follow their own values and conceptions of the ‘good life’ and not force or coerce according to the values of others. It can be seen, as Justice Brandeis defined it, as the “right to be let alone.”<sup>12</sup>

Autonomy involves the rational capacity to form and revise one’s conception of one’s own good.<sup>13</sup> Brock admits that a person’s biological nature limits a person’s conception of the good, providing the example of a person not being able to choose not to desire food. Yet, within those natural limitations, a person does have the ability to choose, such as which food to desire. These decisions shape whom a person is on an ongoing manner, often receiving influence from surroundings including from other people.<sup>14</sup> However, it is the person him/herself who develops the values, and thus creates his/her own “unique self.”<sup>15</sup>

Since these decisions come from that unique self, it is very important for other people to respect them. To oppose a patient’s decisions is to oppose his/her values, and

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<sup>11</sup> Brock 1992, pg. 297.

<sup>12</sup> Justice Brandeis, “The Right to Privacy,” *Harvard Law Review*. Vol. 4, no. 5. December 1890.

<sup>13</sup> Brock, Dan W. *Life and Death: Philosophical Essays in Biomedical Ethics*. New York: Cambridge University Press. 1993, pg. 28.

<sup>14</sup> Brock 1993, *Life and Death*, pg. 29.

<sup>15</sup> Brock 1993, *Life and Death*, pg. 29.

supplant them with one's own. This would be disrespectful to that patient as a dignified, autonomous human being. Brock says that: "A central aspect of human dignity lies in people's capacity to direct their lives..."<sup>16</sup> Each human being's rational decision-making capacity is part of what makes him/her special within the animal kingdom, and unique from other human beings who use their own rational decision-making capacity, often to reach different conclusions. Patients exercise their dignity when they use that rational capacity to develop their own conception of the 'good life,' when they make choices according to those conceptions, and when they act according to those conceptions. For clinicians and others to respect the dignity of patients is to allow them to make their own decisions, and then to allow them to act upon those decisions. "Respecting self-determination consequently involves avoiding both these interferences, with decision and with action."<sup>17</sup> Furthermore, respecting autonomy is non-interference, even when the patient chooses in a manner sharply contrary to his/her own well being.<sup>18</sup>

The desire of people to determine the time and manner of their own death, whether by refusing life-sustaining treatment or by euthanasia, reflects their desire to retain dignity and control.<sup>19</sup> In Brock's view, when someone is terminally ill, he/she has lost so much dignity and control already. The patient did not autonomously decide to get ill, nor have the circumstantial list of physical and mental limitations, nor the list of circumstantial conditions they may deem 'beneath them'.<sup>20</sup> One of the only exercises of the patient's dignity and control at this point will be to determine how and when he/she

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<sup>16</sup> Brock 1992, pg. 297.

<sup>17</sup> Brock 1993, Life and Death, pg. 30.

<sup>18</sup> Brock 1993, Quality of Life Measures, pg. 108.

<sup>19</sup> Brock 1992, pg. 297.

<sup>20</sup> Such as wearing a diaper due to bowel incontinence, having someone feed them, etc.

will die. To take that choice away from the patient, in this view, would be to take even more dignity and control away from them.

Brock argues that since the same principle of autonomy guides both the right to refuse life-sustaining treatment and the right to euthanasia here endorsed, it is unjust to allow people to exercise the former and not the latter. Some medical conditions require life-sustaining treatment such as ventilators and feeding tubes, but some do not. One of the arguments made in *Vacco vs. Quill*<sup>21</sup> stated that allowing the patients in the former group to choose to die, while prohibiting the patients in the latter group from choosing to die violates the equal protection clause of the fourteenth amendment of our nation's constitution.<sup>22</sup> With this understanding of the right to refuse treatment as the patient choosing when and how to die, then it would seem unfair to exclude such choices to other autonomous beings who had no life-sustaining treatment to refuse. In effect, some patients seem to be 'trapped' by their disease; they cannot choose to live because their disease is killing them, but they cannot choose to die by forgoing life-sustaining treatment because their disease does not require life-sustaining treatment.

Currently, a right to refuse life-sustaining treatment is recognized, while a right to euthanasia is not. Brock rejects the distinction between the two, at least in many instances, where either is an act of deliberate killing. He sees the term "allowing to die" as merely a useful euphemism for those of us who are uncomfortable with the act of killing; he seems to think that we should become more comfortable with killing, at least in certain medical circumstances. "Some killings are ethically justified, including many

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<sup>21</sup> The 'right to die' case from New York State. The U.S. Supreme Court rejected this argument in 1997.

<sup>22</sup> Furrow, Barry R. et al *Health Law: Cases, Materials and Problems*. St. Paul, MN: WestGroup. 2001., pg. 1435.

instances of stopping life support.”<sup>23</sup> Brock states that we understand unlawful killing as that which “denies the victim something that he or she values greatly- continued life or a future.”<sup>24</sup> However, if the life is no longer valued by the patient, but is instead rejected as a burden and the person prefers to die, then he sees killing to be the ethical thing to do to that person.

The second major opposing argument that Brock addresses is that the bad consequences of permitting active euthanasia outweigh the good consequences. He identifies four potential good consequences, and six potential bad consequences, and concludes that the good actually outweigh the bad. The good consequences of permitting euthanasia are:

- 1) respect for patient self-determination,
- 2) reassurance for the majority of Americans who think the right to euthanasia exists that they could obtain it if they wanted to,
- 3) a means to be released from prolonged suffering and pain, especially when there is no other means to do so, and
- 4) the benefit of being remembered well, rather than as undignified in prolonged dying.

The bad consequences are:

- 1) its incompatibility with the medical goal of healing,
- 2) it would weaken society’s commitment to provide good care for dying patients,

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<sup>23</sup> Brock 1992, pg. 299.

<sup>24</sup> Brock 1992, pg. 299.

- 3) as a threat to the progress made in securing the individual's right to refuse life-sustaining treatment,
- 4) the arising of subtle pressure to request euthanasia if in an impaired state,
- 5) a weakening of the prohibition against homicide, and
- 6) the 'slippery slope' worry that active euthanasia will lead to non-voluntary and involuntary euthanasia, and other abuses against humanity.

Brock concludes that the more important moral distinction be between the voluntary and non-voluntary performance of either cessation of life-sustaining treatment or euthanasia, but not between the two practices since in many cases the two amount to the same thing: deliberately killing someone who deems their own life to be a burden.

In conclusion, the arguments made in favor of permitting active euthanasia are logical extensions of particular understandings of the right to refuse life-sustaining treatment. If we are indeed deliberately killing human persons in many cases of stopping life support, then it is inconsistent to argue that we should not allow euthanasia because we do not want to allow killing. Furthermore, if the right to refuse life-sustaining treatment is equivalent to the right to choose the time, place, and conditions of one's own death, then to prohibit such choices from those who do not require life sustaining treatment is to unjustly discriminate between groups of patients.

Although I would like to challenge Brock on his particular conception of the right to refuse life-sustaining treatment, I will currently leave that task to others.<sup>25</sup> My major concern for this thesis is the broader cultural ethos surrounding a discussion of euthanasia and physician-assisted suicide that obscures the possibility of helping the dying. It is an

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<sup>25</sup> Callahan, Daniel. "When Self-Determination Runs Amok," in *Ethical Issues in Modern Medicine 4<sup>th</sup> ed.* John Arras and Bonnie Steinbock eds. Toronto: Mayfield Publishing Company, 1995. pg. 311.

ethos that focuses on the legal rather than the person, and on the ‘letting alone’ side of autonomy to the detriment of the positive, fostering side of autonomy.

Although I read Brock as following after this ethos, I do not accuse him of being at all responsible for it. Rather, I believe that his explanation of why as a society we should endorse a right of dying patients to commit euthanasia introduces certain terms and ideas that I want to analyze in the remainder of this thesis. The first of these terms is autonomy and the second is dignity.

Autonomy is self-determination, and as Brock explains, is the key ethical principle to a right to forgo life-sustaining treatment, and the proposed rights to physician-assisted suicide and euthanasia. As I will argue in the next chapter of this thesis, autonomy can be misunderstood, particularly in the law. In law, one is concerned with boundaries of where to make oneself and others stop, so it makes sense that laws concerning life sustaining treatment would open the doors to proposals for laws approving physician-assisted suicide and euthanasia. Yet this legal way of viewing autonomy can be misleading if we do not identify it as just that: the legal way of looking at autonomy. While the courts debate limits to patient and physician autonomy and states’ interests regarding suicide etc., there are people in our society who continue to live along the arduous path of dying. As Brock accurately describes, there are those who “adjust to these disabilities and find meaning and value in new activities and ways” and there are “others (who) find the impairments and burdens in the last stage of their lives at some point sufficiently great to make life no longer worth living.”<sup>26</sup> By stepping aside from the strictly legal discussion, we are able to step closer to the real people involved

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<sup>26</sup> Brock, Dan W.. “Voluntary Active Euthanasia,” *Hastings Center Report* 22, No. 2 (March/ April 1992), pg. 10-22. as reprinted in Beachamp and Walters’ *Contemporary Issues in Bioethics* fifth ed. pg. 297.

and ask: “Why do these people find their lives no longer worth living?” and “How do they come to that conclusion, and is there not something that we can do so that they find their lives to be meaningful?”

The discussion focused on the personal automatically brings us to look more closely at the concept of dignity. Brock speaks of dignity when he says that certain patients feel they lack dignity. He argues that it is then that patients deem their lives solely as burdens. Clearly then, dignity and one’s sense or feeling of one’s dignity is wrapped up with the personal assessment of one’s worth and the worth of one’s life. At the close of chapter two, I will differentiate between what I call “intrinsic” dignity and what I call “subjective” dignity. I hope that the distinction sheds light on how caregivers can and should better respect the autonomy of their patients, by not just giving the patient his/her own way in all things, but by fostering opportunities for the patient to live self-determination.

The great arena of virtues in the life of the dying patient, the topic of the final chapter, is one way to look at those opportunities to live autonomy when possible. Since the life of virtue is simultaneously unfathomable, in that it can never fully be attained, and yet practical, in that it is within our grasp in the array of circumstances of life, the discussion of virtue is perhaps a fitting conclusion to a topic that is both idealistic and readily practicable, that of helping the dying to live well.

## Autonomy ‘Re’-defined

Dan Brock’s argument in favor of allowing euthanasia described in chapter one relies on a particular conception of autonomy. He defines autonomy as the individual’s ability to pass value judgment on one’s own life, using one’s established set of values, and then to act accordingly. I find this definition to be incomplete, and argue that it leads to inappropriate conclusions. Within the many sources of criticisms of autonomy, several feminist thinkers have accused autonomy of being an outright sexist term, pertaining mostly to men and being an unfair moral goal to set for women.<sup>27</sup> However, I believe that autonomy does have a key role in the moral life of the human person, and should not be outright opposed, but rather should be redefined. This chapter will look at two lines of feminist thinking concerning autonomy. The first is the above-mentioned critique of autonomy altogether, and then its replacement with a parallel term for the feminine. The second is an understanding of autonomy that reconciles itself with the concerns of the former and with a broader agenda of feminist thinking. I will then join the latter of the groups, providing first my own account of autonomy, and then showing how this account better completes the analysis of euthanasia summarized in chapter one.

### **The Ethics of Care VERSUS Autonomy**

The most common definition of autonomy seems to be “self-determination” with emphasis on one’s rationality. In *The Virtues of Medical Practice*, Edmund D. Pellegrino defines autonomy as: “the capacity of humans to make self-determining choices based

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<sup>27</sup> Carol Gilligan and Margaret Urban Walker, among others, especially those who hold to the ‘ethics of care.’

on their rational nature.”<sup>28</sup> Autonomy is said to be fundamental in a person’s moral decision-making, such that one’s autonomous decisions should be respected.<sup>29</sup>

According to Immanuel Kant, this respect for a person’s autonomy is also linked to that person’s intrinsic value.<sup>30</sup> In other words, to respect a person’s self-determined decision regarding his/her own person is to respect that person’s dignity. Pellegrino explains the link in terms of one’s “integrity” in this way: “Autonomy thus is grounded ultimately in the fact that to usurp the patient’s human capacity for self-governance is to violate the integrity of her person. To ignore, override, repudiate, or ridicule the patient’s values is to assault the patient’s very humanity.”<sup>31</sup> In practice, and particularly in law, the respect for a patient’s autonomy is mostly viewed as a negative right of the patient to be *free from* external coercion, in their decision-making concerning their own medical care or refusal of care for example.<sup>32</sup>

Although few would argue against the idea that a patient’s values and beliefs should be respected, there are several writers on ethics that appeal to feminism to critique the importance placed on autonomy in moral decision-making. By definition, autonomy requires the critical use of reason, to decide for oneself. The critiques seem to be two-fold, that autonomy denies the importance of the human person’s nature (and particularly the female human) that is 1) emotional and 2) interdependent. Rosemarie Tong, in her book *Feminist Approaches to Bioethics*, says that: “Many theoreticians are dissatisfied with a moral decision-making process that relies too much on reason and critical analysis

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<sup>28</sup> Pellegrino, Edmund D. and Thomasma, David C. *The Virtues in Medical Practice*. New York: Oxford University Press. 1993. pg. 131.

<sup>29</sup> Beachamp, Tom L. and Walter, LeRoy. *Contemporary Issues in Bioethics fifth ed.* Albany, NY: Wadsworth Publishing Company. pg. 19.

<sup>30</sup> Ibid

<sup>31</sup> Pellegrino and Thomasma. Pg. 130.

<sup>32</sup> Furrow, Barry R. et al *Health Law: Cases, Materials and Problems*. St. Paul, MN: WestGroup. 2001, pgs. 1305.

and too little on emotion and sympathetic interpretation.”<sup>33</sup> Carol Gilligan is one such theoretician. In her book *In A Different Voice*, Gilligan traces out a wholly different process of moral progression and development from that which places abstract, rational thinking at the summit, for example that of Lawrence Kohlberg.<sup>34</sup> In the place of individual self-governance, the author focuses on relationships.<sup>35</sup> Rather than following what Gilligan describes as an ascent towards independence and human separateness in the predominant ‘ethics of justice’, this feminine ‘ethics of care’ brings one towards human connectedness.<sup>36</sup> According to Gilligan, the moral development that emphasizes abstract autonomy and justice pertains mostly to men, and her model explains the situation of most women. Therefore, to say that a person morally progresses as that person closes in upon independent, autonomous determinations is gendered and unfair. Although that may describe most men’s progression, it necessarily puts down the valid moral progression of most women, who instead find themselves ascending towards interdependence and the maintenance of relationships with other people, with emotions playing a key role in those relationships. To continue to equate moral decision-making with rational autonomy is to reinforce patterns of oppression, namely of women, based on a false idea that females are somehow less human or less valuable than males.<sup>37</sup> In contrast, placing the ethic of care at the center of morality is “thought to reveal that the prevailing ethic of justice and its emphasis on autonomy are often dangerous and

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<sup>33</sup> Tong, Rosemarie. *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications*. Boulder, CO: Westview Press. 1997. pg. 243.

<sup>34</sup> Kohlberg, Lawrence. *The Philosophy of Moral Development*. San Francisco: Harper and Row Publishers. 1981.

<sup>35</sup> Gilligan, Carol. “Moral Orientation and Moral Development,” in *Women and Moral Theory*. Kittay and Meyers eds. Stony Brook, NY: Rowman and Littlefield Publishers. 1987. Pg. 24

<sup>36</sup> Clement, Grace. *Care, Autonomy, and Justice: Feminism and the Ethic of Care*. Boulder, CO: Westview Press. 1996. pg. 11-12.

<sup>37</sup> Hill, Jr., Thomas E. “The Importance of Autonomy,” in *Women and Moral Theory*. Kittay and Meyers eds. Stony Brook, NY: Rowman and Littlefield Publishers. 1987. pg. 130.

illusory.”<sup>38</sup> It is seen as dangerous especially for women who are deemed less moral for not following the ethics of justice, and indeed for all people because such autonomy misses out on a major component of moral human living, namely the social component. By identifying an alternative model for the moral development of women, Gilligan hopes to validate the moral experience of women.

Gilligan finds the quest for autonomy and independence as not only inapplicable to women, but also quite impossible for all people. She points to the limits of autonomy, saying: “Since the reality of interconnection as experienced by women is given rather than freely contracted, they arrive at an understanding of life that reflects the limits of autonomy and control.”<sup>39</sup> Similarly, Margaret Urban Walker has written: “Autonomy cannot encompass the realities of human interdependence and community nor explain the concrete conditions of responsibility, the commitments, and the attachments to others that move us to action.”<sup>40</sup> These authors view autonomy itself as limited in its role in the moral life because it neglects the social dimension of the person.

Since we are social beings, we will never be fully independent. We not only need each other to live, but we also need each other to be moral. If the autonomous, independent person is not the ideal of self, then the autonomous, independent person is not the ideal of the moral self. Rather, the ideal of the moral self is precisely an interdependent person who maintains good and fulfilling relationships.

To many, the concept of autonomy also includes one of control. The authors of *Health Law* define the principle of autonomy as a declaration “that each person is in

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<sup>38</sup> Clement, pg. 2. ref. Gilligan 1986a. pg. 48.

<sup>39</sup> Gilligan, Carol. *In A Different Voice: Psychological Theory and Women's Development*. Cambridge, MA: Harvard University Press. 1986a. pg. 172.

<sup>40</sup> Walker, Margaret Urban ed. “Getting Out of Line: Alternatives to Life as a Career,” *Mother Time: Women, Aging, and Ethics*. New York: Rowman & Littlefield Publishers, Inc. 1999. pg. 99.

control of his own person, including his body and mind.”<sup>41</sup> Yet, Gilligan has just been quoted as saying that the reality of life shows us that there are limits to control.<sup>42</sup> Tong also writes that the recent focus on autonomy by the so-called ‘deductivists’ has created the “new assumption...that patients have the right to control their own destiny.”<sup>43</sup> If Gilligan is correct about reality, then such a promise of control is very misleading because it can never be fulfilled. Based on her studies, Gilligan says that women understand this reality of life that lacks total control, and that they, in fact, are after an ideal of self that is different, more realistic, and perhaps better. This self-realization will include compassion and give proper importance to the emotions.

Four years after the publication of her original *Different Voice*, Gilligan published her article, “In a Different Voice: Women’s’ Conceptions of Self and of Morality.”<sup>44</sup> In this article, she proposes her progressive three stages of the ethics of care: 1) self survival 2) self sacrifice by deferring to others’ wishes, with a realization that in the first stage one was selfish and 3) responsibility for one’s own choices, with a realization that the self in stage two put down one’s desires for one’s own needs.<sup>45</sup> In stage three, one places one’s self worth on equal footing to the worth of the other person. Women, therefore, are after a realization of self that is in relation to others, and that at the same time does not endanger their own individual well being. One may see this as an exercise of autonomy, as we will see later in the thoughts of Grace Clement. However, others see

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<sup>41</sup> Furrow et al. pg. 1305.

<sup>42</sup> Gilligan 1986a. pg. 172.

<sup>43</sup> Tong, pg. 3.

<sup>44</sup> Gilligan, Carol. “In a different voice: Womens’ conceptions of self and morality.” In *Women and Values*. Ed. Pearsall, pg. 309-339. Belmont, CA: Wadsworth Publishing Company. 1986b.

<sup>45</sup> Gilligan 1986a. pg 318.

this exposition of personal choices as intrinsically relational, and therefore altogether different than autonomy.

Sarah Lucia Hoagland furthers some of these criticisms against autonomy (self-rule), and replaces the concept with “autokoonomy” (self-community), saying that the self cannot be defined outside of relationships.<sup>46</sup> Rather than an ontology of separateness, Hoagland’s metaphysical view of the person is one of connectedness. Tong summarizes Hoagland thus:

Unlike the autonomous man who thinks that his self is entirely separable from others, the autokoonomous woman realizes that she is a self inextricably related to other selves. Since she views herself as largely the product of her relationships with other selves, the autokoonomous woman, when she chooses to do something for someone else, perceives her actions as self-directed as well as other-directed. In other words, the autokoonomous woman realizes that in choosing a ‘good’ for other, she is simultaneously choosing a ‘good’ for herself. Her actions will cause a reaction in the other who, in turn, will exert their will upon her.<sup>47</sup>

### **Autonomy AND the Ethics of Care**

Yet, has Hoagland perhaps gone too far in opposing autonomy? Or is there room in the concept of autonomy for the woman who finds herself in her relationships? Are we not autonomous beings at all? Or can we conceive of an autonomy that does not necessarily include the independence and lack of relationships nor exclude the emotions as Gilligan and others critique? In a female psychological text originally published prior to Gilligan’s *Different Voice*, Jean Baker Miller talks about self-determination as having acquired a certain connotation that is not intrinsic to its definition,<sup>48</sup> and that has in fact

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<sup>46</sup> Hoagland, Sarah Lucia. *Lesbian Ethics*. Palo Alto, CA: Institute for Lesbian Studies. 1989. pg. 12.

<sup>47</sup> Tong, pg. 94-95.

<sup>48</sup> Miller, Jean Baker. *Toward a New Psychology of Women*. Boston: Beacon Press. 1986. pg. 115-116.

caused some women to “fear” self-determination unnecessarily.<sup>49</sup> She then redefines self-determination as including aspects of interdependence, namely “feeling effective and free along with feeling intense connections with other people.”<sup>50</sup> Thus, we see a view of autonomy that itself includes interdependence.

One of Gilligan’s articles referred to above<sup>51</sup> appears in an anthology, *Women and Moral Theory*, that also contains two articles defending the concept of autonomy, at least in part. Both Thomas E Hill, Jr. and Diana T. Meyers attempt to reconcile parts of the ethics of care and its concern for compassion with a concept of autonomy. Hill sees Gilligan as offering an “exaggerated reaction to extravagant praise of autonomy,” and fears that she has overlooked some of the more basic parts of the concept of autonomy that are valuable to one’s morality.<sup>52</sup> One of the valuable uses of autonomy that Hill identifies is autonomy as a goal for personal development recognized by many people. As one goes to make a decision, one tries to meet that ideal of making it as an autonomous person. Hill deems autonomy as not in conflict with, but rather of encompassing, the compassion sought after by the ethics of care. To that end, Hill states: “Without compassion, one can never really become aware of the morally relevant facts in the situation one faces. The inner needs and the feelings of others are virtually always relevant, and without compassion one can perhaps never fully know what these are- or give them their appropriate weight.”<sup>53</sup> Therefore, Hill believes that autonomy usually requires the feeling of emotions for other people.

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<sup>49</sup> Miller, pg. 119.

<sup>50</sup> Miller, pg. 119.

<sup>51</sup> “Moral Orientation and Moral Development”

<sup>52</sup> Hill, pg. 130.

<sup>53</sup> Hill, pg. 137.

Diana Meyers takes a very different approach in her article regarding socialization and autonomy, but she too reconciles aspects of the ethics of care with the important role of autonomy in morality. She returns to behavioral psychological studies such as those analyzed by Gilligan and Kohlberg, and concludes that socialization affects each person's ethics and that there is quite a variety among persons as to how they reach moral decisions. She then goes on to develop a concept of moral autonomy that is non-Kantian, in other words, a self-determination without the creation of and adherence to universal, impartial rules rationally derived. It is this non-Kantian autonomy that Meyers deems compatible with the ethics of care, because this autonomy does not deny human connectedness.<sup>54</sup> The "responsibility reasoning" of the care ethicist is indeed a reasoning, just one that takes emotions and relationships into account. Finally, this autonomy complements the ethics of care properly understood as desiring a curb of self-interest within relationships, not a total abnegation of self-interest for the sake of the relationship.

Another feminist ethicist, Grace Clement picks up this last point in her book, *Care, Autonomy and Justice*. She says that the ethics of care version of autonomy is only autonomy if it allows people to critically reflect and decide to leave relationships that are bad for their own well being.<sup>55</sup> Clement considers Gilligan's third stage of the ethics of care to be autonomy, rather than a call for a different term such as autokoenomy. Clement emphasizes the important possibility for a woman to leave a relationship where her self worth is not on equal footing with the other, or where the woman has to put down her desires for her own needs. She therefore highlights the third stage of the ethics of

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<sup>54</sup> Meyers, Diana T. "The Socialized Individual and Individual Autonomy: An Intersection between Philosophy and Psychology," in *Women and Moral Theory*. Kittay and Meyers eds. Stony Brook, NY: Rowman and Littlefield Publishers. 1987. pg. 152.

<sup>55</sup> Clement, pg. 39-41.

care as a good description of the moral life. She differentiates the extremes or “ideal” ethics of care and justice that are irreconcilable with each other, from the two more proper ethics of care and justice that can be reconciled with one another. Clement compares the ethics of justice and the ethics of care and concludes that the correctly understood concept of justice encompasses care.<sup>56</sup> Within this combined ethic, then, autonomy is not individualistic and exclusively rational, but rather recognizes the social and emotional nature of the human person.

Clement’s redefined autonomy is a capacity for self-determination that creates and promotes healthy relationships, while maintaining one’s reflective and critical stance towards those relationships.<sup>57</sup> She says that autonomy requires two things: 1) the more commonly spoken of negative right to be *free from* others’ coercion in decision-making and 2) the positive aspect of thinking reflectively and critically about one’s choices.<sup>58</sup> She thinks that autonomy is incomplete if it is only the former, and lacks the necessary reflection. Furthermore, Clement includes here critical reflection not only about one’s choices, but also about the process of how one makes those choices. The influences from both internal and external sources, from the non-rational parts of one’s soul and from others, are to be acknowledged and critically analyzed. As Meyers pointed out, we are all socialized into behavior and beliefs, at least to a partial extent. “In some ways psychological autonomy depends on social conditions that are usually unacknowledged.”<sup>59</sup> Therefore, in order for one to be truly autonomous, one needs to ruminate about those influences.

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<sup>56</sup> Clement, pg. 4.

<sup>57</sup> Clement, pg. 43.

<sup>58</sup> Clement, pg. 22-23.

<sup>59</sup> Clement, pg. 26.

Clement's concept of autonomy is one that recognizes the influence of psychological and social conditions, whether positive or negative. It is only in positive or, one could say, human conditions that one develops the capacity for proper reflection and decision-making. Community, interdependence, and feelings like compassion are all important components of that environment that allows for true autonomy. Clement says that isolation from others may allow autonomy in the negative sense, but never in the positive sense because we need guidance and education from other people in order to determine how we want to make decisions and thus how we want to live. "There are degrees of critical capacity, and thus degrees of autonomy, but it is clear that our critical capacities are maximized in social conditions that permit or encourage us to critically assess and influence the social ideals that in turn shape our lives."<sup>60</sup>

These redefined concepts of autonomy complement important aspects of the ethics of care, such as compassion and the importance of relationships. They also engage the broader agenda of feminism. Clement voices a concern that the ethics of care may be used to reinforce the gendered power struggle of men over women.<sup>61</sup> At times the ethics of care seems to inappropriately generalize the experience of some women who are caring biological mothers and wives, for example, to all women. In addition, if a woman were to follow the ethics of care, but never reach the third level of responsible autonomy, then she might stay at a level where her own needs were not looked after in her attempt to care for another. A woman might remain in a bad relationship in the name of focusing on the importance of relationships for her moral life. By critically reflecting on one's decisions and the health of one's relationships, a woman may set out on her own

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<sup>60</sup> Clement, pg. 25.

<sup>61</sup> Clement, pg. 5.

individual moral path where she is of equal worth as others, even if she does not fit the stereotype of the caring biological mother and housewife. In this way, she may build a vision of women that is broader and more valued in her society.

### **Autonomy “Re”-Defined**

As we have seen with the ideas of control and independence apart from relationships, there are certain connotations of autonomy that are not intrinsic to its definition. For my definition of autonomy, I will stick to the definition quoted above from Edmund Pellegrino: “the capacity of humans to make self-determining choices based on their rational nature.”<sup>62</sup> In a sense, then, it is not a ‘re’-definition at all, but rather a clarification of what autonomy is and was all along. Similar to the authors who attempted to reconcile the ethics of care with autonomy, I think that the feminine opposition to the ascent towards independence and the lack of emotions is a valid opposition, and thus points us to an autonomy rightly conceived. Like Clement, I argue that: “the ethics of care reveals important problems with the concept of autonomy, but that these problems are not present in all versions of autonomy.”<sup>63</sup> In the version I hold to, autonomy is self-determination that involves one’s reason. It is a negative right to prevent other people from acting upon patients contrary to their wishes, but primarily it is those patients’ positive ability to choose what they will do or not do within the possibilities of their limited circumstances, an ability that can be facilitated by others. I think this definition leaves room for the human being’s social nature, as well as reason’s interplay with the emotions, and in fact demands both. It focuses a person on what one can control from within oneself i.e. what one can choose to do within one’s own

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<sup>62</sup> Pellegrino and Thomasma. pg. 131.

<sup>63</sup> Clement, pg. 7.

possibilities. What I see it leave out is that false promise of control of things external to the person him/herself, which I will now examine more closely.

Above, I quoted one definition of autonomy as: “that each person is in control of his own person, including his body and mind.”<sup>64</sup> However, this definition attaches too much to the concept of autonomy. Since such control is hardly possible, it is dangerous for us to promote this “ideology of control.”<sup>65</sup> As Daniel Callahan has written, it gives us a false presumption that we can control even life and death.<sup>66</sup> We are hardly ever in full control of our person, both because we all have limitations to our body and mind, and because we are interdependent with other people, including in our decision-making.

We can all think of many instances in which we are not in control of our body or mind, and yet consider ourselves autonomous. I often may have the capacity to choose to do something, but if it is simply not possible in my circumstances, then I lack the capacity to act upon that decision. Autonomy does not guarantee me the capacity to do anything I may choose to do. For example, I may choose to walk, but be limited by my broken legs. Similarly, I may choose to remember something but my mind is simply unable to carry out that decision. The range of possibilities open to persons is often out of their control. Many times, such fully controlled “autonomy” is impossible, but it does not mean that the agent is not autonomous. If I have broken legs, and lack the ability to walk today, I am still an autonomous being capable of choosing among my possibilities at a given time. I may choose to stand or sit up straight, or even to slouch. These are real, autonomous decisions. It is part of our humanity that we are all limited in our

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<sup>64</sup> Furrow et al, pg. 1305.

<sup>65</sup> Callahan, Daniel. *The Troubled Dream of Life: Living with Mortality*. New York: Simon and Schuster. 1993. pg. 93.

<sup>66</sup> Ibid

control of our bodily person in some ways. If it is also part of humanity that we are autonomous beings, then autonomy cannot presume to include control over externals because we could not be limited in control and simultaneously controlling in all things. Some of these conditions are limited by physiological health, but other people determine many of the other conditions, as we shall see later on.

With mental limitations caused by illness, the question of whether or not the person in question is still an autonomous agent is more complicated. By definition autonomy requires the use of one's reason. At what point an individual becomes unable to make a particular autonomous decision is debatable. As Clement has said, autonomy has degrees.<sup>67</sup> What is clear, however, is that while one is able to use one's reason at all, one is able to make at least some autonomous decisions for oneself. A dementia patient may, for example, be able to make daily living choices such as which shirt to wear on a given day, but on the same day no longer be able to determine where he/she lives. In the case of mental limitations, it may be precisely the action of choosing that is precluded. In this case, autonomy is diminished, but is not altogether gone as long as there is some rational capacity.

In addition to the lack of control due to one's physical and mental limitations, I have also said that autonomy does not include the full control of oneself because we are interdependent with others. The human being is social by nature. It is, therefore, not surprising that we need other people in order to be fulfilled as human beings.<sup>68</sup> This is especially true when we are speaking of morality, as we are here. Key moral aspects,

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<sup>67</sup> Clement, pg. 25.

<sup>68</sup> Aristotle, *The Nicomachean Ethics*. Translated by Terence Irwin. Indianapolis: Hackett Publishing Company, Inc. 1999. and Niebuhr, H. Richard. *The Responsible Self: An Essay in Christian Moral Philosophy*. New York: Harper & Row Publishers. 1963.

such as justice and beneficence, are intrinsically relational. These virtues<sup>69</sup> or principles<sup>70</sup> pertain to interactions between persons (including within a single person in the case of justice to oneself). The moral life is lived with and for other people, in addition to ourselves. As feminine ethicists such as Gilligan point out, people often make moral decisions precisely with other people in mind; we are seldom if ever exclusively self-interested in our decisions we deem to be moral. Autonomy, too, has a relational component; it cannot be lived as an atomistic, isolated individual.

Autonomy does not necessarily include the notion of independence as Gilligan surmises, but it does necessarily include the notion of the social nature of the human person. As Clement explains, autonomy requires that second level of reflection, including a consideration about how and from what sources one has derived one's own very way of reflecting. This, in turn, requires education and continued input from other people. We are all, to a great degree, educated into our belief systems and understandings of life and the world and ourselves. Historically, much of one's education comes from one's parents, and then from the school chosen by one's parents. Regardless of their source, we are inculcated with certain ideas and judgments regarding morality, such as "do not kill innocent human persons" or "it is better to use your talents to do good than to waste them, or to use them to do evil." Furthermore, this influence from others does not end with the completion of our formal education, but continues throughout the deliberations through which we each proceed in prudent decision-making throughout our lives, and even to our deaths.

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<sup>69</sup> Pellegrino, Edmund D. and Thomasma, David C. *The Virtues in Medical Practice*. New York: Oxford University Press. 1993.

<sup>70</sup> Beachamp, Tom L. and Childress, James F. *Principles of Biomedical Ethics*. New York: Oxford University Press. 1989.

Therefore, we are to critically analyze the influences from others. This does not mean that we are to reject those influences. On the contrary, we are to see how we ourselves as relational beings are positively supported by external inputs, as well as seeing when neglectful and abusive influence should lead us to terminate certain relationships. This emphasis on the importance of relationships for the moral life encourages us to work to maintain healthy relationships, and to work to make our current relationships healthy. Relationships that help us to value ourselves equally to others can be seen as positive because they help us to live in the third stage of the ethics of care. If the third stage of responsibility of one's decisions is understood to be autonomous responsibility, then we see that autonomy is incredibly important in the moral life. This autonomy that depends upon others would never allow women to suppress their own needs in favor of another's needs because it would never allow people to value themselves as less than other people.

As Clement has written, when one lacks the social conditions needed to develop one's vision of life and morality, one is not truly autonomous. The fulfillment of the first negative right to absence of external coercion is simply not enough. Autonomy requires one to critically reflect, and one needs a continuing education from others to do so. Dan Brock would have us understand autonomy as including the formation of one's own conception of the good life.<sup>71</sup> However, this formation of our own conception requires input from other people. It does not come solely from our selves, as he himself admits.<sup>72</sup>

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<sup>71</sup> Brock, Dan W. "Voluntary Active Euthanasia," *Hastings Center Report* 22, No. 2 (March/April 1992), pp. 10-22. As reprinted in Beachamp and Walters' *Contemporary Issues in Bioethics* Fifth ed. Pg. 297.

<sup>72</sup> Brock, Dan W. *Life and Death: Philosophical Essays in Biomedical Ethics*. New York: Cambridge University Press. 1993. Pg. 29.

It is important to note that autonomy does not exclude the importance of emotions, but does necessarily include the use of reason. Emotions and passions are part of who we are as human beings, and to deny that is to ignore reality. Yet, it is also part of human existence that human beings have a special rational capacity that sets us apart from the other animals, by which we can guide our non-rational faculties to their proper place.<sup>73</sup> At times, reason will guide an emotion to be expressed appropriately, to the proper degree and for an appropriate period of time. Most of the time, our reason will get input from the emotions and passions, such as in the responsibility reasoning that Meyers has developed. Appeals to compassion will often be part of our deliberation, as Hill pointed out. Therefore, reason always plays a role in autonomous decision-making, including the many cases when emotions play an important role as well.

In summary, in my view, autonomy is self-determination that entails the use of reason, with reason's directive role of the emotions. This definition assumes a social nature of the human person, whose capacity for self-determination has been educated and influenced by other people in relationships. Autonomy does not denote control either of body, mind, or circumstances of life because such control is often impossible for autonomous persons. Furthermore, autonomy does not denote the formation of one's vision of the good life as an isolated being, but rather assumes that such formation has occurred and continues to occur within relationships. This ideal of autonomy is admittedly often unobtainable, but serves the important function of "a goal of self-fulfillment" to which to strive, as Hill has suggested.

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<sup>73</sup> Aristotle, *The Nicomachean Ethics*. Translated by Terence Irwin. Indianapolis: Hackett Publishing Company, Inc. 1999. 1098a2-3 and Book III on virtues of thought.

## **Autonomy and The Case of the Terminally Ill Patient**

In his discussions regarding the terminally ill and “death with dignity,” Dan W. Brock says that the circumstances of terminal illness are often undignified and lacking autonomy. He concludes that others should respect the autonomy and dignity of the terminally ill patient by allowing the patients to follow their wishes, and therefore by respecting the ‘unique self’ of each patient. If we leave the discussion of autonomy at this point, we neglect the positive sides of autonomy and dignity, as conditions that can be fostered and increased. Let us now continue the discussion to see some ways for those around the patient to truly respect the patient’s autonomy and dignity.

The cases of terminally ill patients are particularly instructive to our analysis of autonomy and control because these people increasingly experience losses of control. They are, at the same time, good cases to look to for examples of how patients can live autonomously without full control, and how caregivers can help them to do so.

As we have seen, the external circumstances are often out of control of the patient, and so should not be part of the patients’ assessment of the value of their own lives. The lack of control intrinsic to the particular physiological or mental illness comes from the illness itself, and it has to be recognized as such. The patients have no reason to blame themselves for having these limitations<sup>74</sup> but rather have all the reason to seek help to ameliorate or overcome the limitations, and when that is not possible, to accept them. It is important to remember that autonomy comes into play only in those areas where the patient has some volition.

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<sup>74</sup> There are many cases in which the patients themselves are at least partially responsible for an illness. This is not to say that they should not face their responsibility, but rather that they should look forward to what they can do about their illness.

However, those circumstances and opportunities depend directly on other people, both in societal structures and in individual actions by caregivers. For example, a patient with muscular deficiency may be encouraged to walk to combat the effects of his/her illness, and also be provided with safe and easy places to walk within their own residential area. Besides physical set up, financial arrangements can allow a patient to have, for example, a qualified nurse available for more hours of the day if needed.

On a personal level, individual caregivers can foster patient autonomy by helping patients to identify activities that they can do, and thus do well. Caregivers should also, therefore, provide the circumstances and conditions needed to facilitate these activities. Many elderly citizens of our country are enjoying facilities where various activities are offered. It is not only the number of activities offered that matters, but also the content, fitted to each individual as much as possible. For people who could be helped to tell their stories about starting their own business, for example, someone would need to set up both an appropriate audience and a physical forum. For another patient whose activities are limited to their bed, the activities of listening to poetry or news require a speaker to be present. Whatever the illness, the identification and facilitation of worthwhile activities takes time and effort and forethought on the part of those around the patient, as well as the patient him/herself. When the execution of patients' decisions seem inefficient to the caregiver, the caregiver should remember that he/she is working, not only to get things done, but also to build the autonomy of one's patient. Since we are talking about activities and opportunities fitted to the individual, the best situations for people to live while dying is with those who can best treat them as individuals, with known histories and personalities, such as within their natural families.

The assessment of the value and meaningfulness of life itself can be greatly influenced by caregivers who focus on the patient's dignity, on facilitating that the patient do what he/she can do, and on providing positive advice in the patient's deliberation. Human beings are emotional beings, as we have seen. Often times, a terminally ill patient will need someone to talk through emotions with, and will need help to have their reason guide their emotions. A particular patient may feel valueless and undignified the first time he/she needs to wear a diaper, for example. The caregiver can remind the patient that the illness is the cause of the diaper, that the patient is still dignified, and help the patient focus on what he/she can do by offering an appropriate activity. Furthermore, emotions are reactions to stimuli, including personal stimuli. The patient may have emotions in response, not only to physical limitations, but also to relationships. The positive relationships that caregivers can foster can help the patient to have positive emotions.

Although certain activities may be precluded due to illness, autonomy itself is present in a person in some degree for as long as the patient can use his/her reason at all. The respect owed to those patients by the others is respect for their autonomy, both in the negative AND positive sense. Others will respect the patient's autonomy by facilitating the patient to determine what he/she can determine, and by not imposing one's own determination for that person, but by providing advice for their critical reflection. Small decisions and actions that may be made or done more efficiently by another from an objective point of view should be left to the patient whenever possible in order to respect his/her autonomy. The patient's autonomy will also be respected by facilitating the

understanding, intent, and ability of that person to use one's reason and not be swayed solely by emotions.

Finally, much has been written concerning the limits to patient autonomy,<sup>75</sup> both in its role in bioethical decision-making and in terms of the fact that many patients lack autonomy altogether or for certain decisions. In decisions that require the action of another person, such as a physician, that other person's autonomy needs to be taken into account also.<sup>76</sup> In the cases where patients lack autonomy, since neither understanding of human dignity is exclusively dependent on autonomy (even though the concepts are related), the patient's dignity should still be respected. However, these cases are not the matter for this paper. I am rather speaking about people who can decide many things for themselves, and that others should protect and facilitate their autonomy and dignity. I admit that there will still be some patients who come to the conclusion that they want to commit suicide, and want help from the medical community to do so, but I strongly believe that the numbers will be greatly decreased if we as a society focus on both autonomy and dignity as the positive concepts that they are, even for the dying patient.

### **Conclusion: 'Death with Dignity'**

The view that dignity is linked to autonomy is not new. Immanuel Kant viewed autonomy as the foundation of human dignity.<sup>77</sup> In his defense of voluntary active euthanasia, Dan Brock has called autonomy "a central aspect of human dignity."<sup>78</sup> Respect for one's autonomy is seen as a respect for one's dignity. Much of our society's discussion of the dying focuses on the legality of physician-assisted suicide and

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<sup>75</sup> Pellegrino and Thomasma; and Brock, Dan W. and Buchanan, Allen E. *Deciding For Others: The Ethics of Surrogate Decision-making*. New York: Cambridge University Press. 1990.

<sup>76</sup> Pellegrino, pg. 47-68.

<sup>77</sup> Hill, pg. 129.

<sup>78</sup> Brock, pg. 297.

euthanasia and so views this respect in a predominantly negative and limited sense. For example, Brock sees euthanasia as respecting the patient's dignity, and sees the opposition of the patient's wishes as a disrespect of the patient's failing dignity. I wish to show that by respecting a patient's autonomy in the positive sense, others can help the patient focus on their 'intrinsic' dignity and also actually increase their 'subjective' dignity through virtue.

In order to continue, I need to define and distinguish between these two related forms of dignity. 'Intrinsic' dignity is the invaluable worth of every human person because that being is a human person. It is the dignity of the human being qua human. 'Subjective' dignity is the feeling or judgment or sense an individual person has for his/her own worth or for the worth of another's life, be it invaluable or not valuable or somewhere in the middle. This latter dignity can change according to how each person chooses to live and according to how each person chooses to pass judgment on a human life.

In my view, human dignity is founded on autonomy only in so far as dignity is intrinsic to beings that have autonomy. Human beings are recognizable as different than the rest of the animal world by our capacity to reason and make autonomous decisions. In this way, like Kant, we are able to conclude that a human being has an intrinsic value, as an end in him/herself based on the reasoning capacity.<sup>79</sup> This is the dignity of the human being qua human or 'intrinsic' dignity. As Pellegrino states: "This principle (autonomy) is fundamental in the sense that it is grounded in the fact of being human, a

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<sup>79</sup> Beachamp and Walters, pg. 19.

species of being that is essentially defined in part by its capacity to reason, to plan for the future, and thus to provide self-direction.<sup>80</sup>

In this sense of the word dignity, it is important to respect a person's autonomy because that autonomy *points to* the fact that they have dignity, that they are a being with dignity. However, I would argue that autonomy here does not *make* one dignified; there are human beings who lack autonomous decision-making capacity who do have dignity of a human person qua human by right of their inclusion in the species. Their capacity to exercise that autonomy has been hindered by some illness, but they are still human beings with intrinsic dignity.

I have also identified a 'subjective' dignity or the feeling of an individual concerning the worth of his/her life or the life of another. It is often said that certain conditions of poverty are 'undignified' for people to be allowed to live in by others, for example. Or someone may lack the table etiquette to eat in a 'dignified' manner. Dignity in this sense seems to pertain to a judgment about whether or not a person is living in a worthy manner. To say someone is behaving undignified, then, means that he/she still has intrinsic dignity, but is not living up to that dignity at the subjective level.

This living up to one's dignity in turn requires some voluntariness, either by the person him/herself or the others to allow the person to live under the said conditions. Therefore, this subjective dignity can be increased or decreased by how a patient voluntarily chooses to act and react under given circumstances, and how others choose to treat the patient.

To further distinguish between the two senses of dignity, let us examine the example of an older woman who reluctantly moves into a nursing home, when she would

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<sup>80</sup> Pellegrino and Thomasma, pg. 21.

have preferred to continue living alone in her own house. The possibility of living alone in her own home is now cut off from her. She may not recognize the vast possibilities now open for her, and may feel undignified in the subjective sense of the word because she deems her current situation as unworthy of her. To her, the dignified thing to do would be to move back to her own house. Yet, she is still an autonomous being, with the ability to choose within her realm of reality, that now excludes the possibility to return to her own house. The patient can choose to stay in her room or chose to come out for this activity or that one, or all of the activities listed above. The patient can make friends with this resident or that one, or none at all. To leave the resident there with no viable options and/or with no information about the possibilities is not to respect her autonomy.

Leaving the patient alone is not good enough. The nursing home staff and family have to take a more proactive stance of informing, advising, and supporting the patient in her new choices if they want to support her dignity.

Much of the discussion surrounding autonomy and dignity has centered on the need to show respect to the patient's dignity by non-interference with a patient's decision-making and action. *Yet, there is also the component of the other person fostering the patient's autonomy in a positive sense, by creating possibilities or pointing out possibilities that are within the patient's reality to choose.* In this way, the person's intrinsic dignity is respected and the person's subjective dignity is increased. As people get more ill, many possibilities are cut off from them, often leaving them feeling trapped by their circumstances. If the family members and medical staff surrounding that patient can figure out what the patient can do, and therefore can do well, then they can help that patient regain their sense of autonomy and dignity.

One thing that caregivers and all of us can do is to constantly place our attention onto the more complete sense of the term ‘dignity,’ that of the ‘intrinsic’ dignity of each patient. If people are reminded of their underlying, intrinsic dignity as a human being, they will feel more wanted and more empowered. If the staff and family surrounding a patient remind themselves that the patient is intrinsically dignified, then they will be more wont to treat the patient accordingly. It is due to this intrinsic human dignity that we try to find, promote, and support autonomous decisions of our loved ones and patients.

Furthermore, this emphasis on the first sense of ‘dignity’ will potentially enhance dignity in the second subjective sense. The more a person focuses on his/her intrinsic dignity, the more that person will feel dignified in a subjective sense. This is still, and especially, the case in the situations where patients find themselves in physical and/or mental conditions they deem somehow degrading. Perhaps a particular patient thinks that wearing an adult diaper is an embarrassing condition. He/she feels less human and burdened by the life with the diaper. If the medical staff and family focuses on the patient’s intrinsic dignity and on what that patient can decide and do, and supports the patient in those matters, then perhaps the diaper issue will change for the patient. The goal is for the patient to recognize that the external condition of bowel incontinence is not itself undignified because it is a natural part of the disease or physical ailment, and that the incontinence does not thereby detract from the person’s ‘intrinsic’ dignity. In fact, the incontinence in this case can be itself seen as dignified because it is tied to a human person, a person with ‘intrinsic’ dignity. The person becomes primary, and the limitation is seen in correspondence to the person, rather than the reverse. To judge the value of the

person according to the limitation(s), as some people in fact do, is an expression of a neglect of the ‘intrinsic’ dignity of each human qua human.

What determines the dignity of the patient is, first, his/her humanity which is constant, and secondly, his/her internal reaction to the external conditions. What a patient chooses to do, as a patient with incontinence is what matters in terms of dignity. By choosing to deal with the situation well, the person’s subjective dignity increases. Many of the possibilities for the patient’s use of autonomy will be in small matters. However, these small matters now become big matters. They are very important to the patient, and therefore should be very important to their caregivers. If a particular patient wants to wear the same shirt two days in a row or have his/her blind drawn a certain way or paint the walls green (and then change their mind on the color half way through the job), then the care-givers should try to do their best to see those decisions to fruition. This is still the case when the decisions require more work or *apparently* inefficient labor for either the patient or the caregivers or both. It does not matter that the walls could be finished off green and look splendid; what matters is that the patient is exercising his/her autonomy. Part of the “work” being performed is the respect and promotion of the patient’s autonomy and dignity, so the effectiveness of the other work is not the complete picture. Part of the ‘building’ has nothing to do with the walls, and everything to do with the patient.

I argue that a terminally ill patient is dignified. He/she is certainly dignified as a human being, and such intrinsic worth should always be remembered. By focusing on this ‘intrinsic’ dignity of each individual patient, the people around the patient will more readily facilitate and support the patient’s autonomy decisions. Yet, patients can also feel

themselves to be dignified depending on how they individually decide to deal with their present circumstances. To maintain one's dignity, one should continue to decide in a way proper to a human being: as one with equal value to the others, with interdependence, and using one's autonomy in what one can for as long as one can. Involuntary conditions, such as loss of physiological functioning, are in fact dignified in that they are states proper to a human person with that illness. If patients were to choose to live as if they were more ill and limited than they actually are, that alone would be an undignified condition. I will now continue the discussion about dignity, but in respect to the virtues in chapter three: "The Virtuous Life of the Terminally Ill Patient."

## The Virtuous Life of the Terminally Ill Patient

Dan Brock has argued that the life of the terminally ill person may be considered to be undignified by the patients themselves, and that dying persons should be allowed to make their autonomous decisions to embrace euthanasia as a last grasp at failing dignity and autonomy once they deem their lives as burdens. I have argued that the patients' judgments of the value of their own lives is greatly influenced by the people around them, with emphasis on how those other people can foster the autonomy of the patients in a positive sense. To look through the lens of Aristotelian virtues at the possibilities of facilitating that the terminally ill patient grow in a subjective sense of dignity, I branch out from my discussion of autonomy and dignity in this final chapter. My previous description of dignity and Aristotle's analysis of the virtues and nobility coincide and so provide a bridge into questions regarding the 'good life' of the life nearing its end.

### **Aristotle and Eudemonia**

In book one of the *Nicomachean Ethics*, Aristotle puts forth his general thesis regarding virtue and happiness. He defends his claim that happiness or 'eudemonia' is the ultimate good or 'telos'<sup>81</sup>. He then argues that the function or 'ergon' of the human person is to live well,<sup>82</sup> and therefore that happiness consists in activities done with virtue. He defines neither happiness nor virtue in terms of only particular activities; however he says that both are context-dependent so that virtue can only be exercised in the activities available to a person at his/her available time and place. At the same time, Aristotle is clear that the activities of the soul are higher than those of the body. The

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<sup>81</sup> Telos means end as in 'for the sake of' or 'to hou heneka' in Greek.

<sup>82</sup> Aristotle, *Nicomachean Ethics*. Translated by Terence Irwin. Indianapolis: Hackett Publishing Company, Inc. 1999. I.7. (EN)

good of the soul is the more important of the two because the soul is that which makes you live. More specifically, the most properly human activity of the soul is that “in accord with reason or requiring reason.”<sup>83</sup> Therefore, for a human person to live well, he/she is to live the activities of the soul well<sup>84</sup>, i.e. with the proper use of and/or guidance from reason.

In the second book of the *Nicomachean Ethics*, Aristotle goes further into his discussion regarding virtue itself. Virtue is an excellence that is most often the mean between deficiency and excess. It is acquired only in *voluntary* activity that exemplifies that specific virtue, i.e. one becomes patient by acting patiently. The two types of virtues are the intellectual, stemming from the rational part of the soul, and the virtues of character, stemming from the non-rational part of the soul. Reason plays a part in every exercise of virtue in two ways: first through the necessary intellectual virtue of prudence<sup>85</sup> involved in virtuous activity, and secondly through reason’s directive role in both intellectual and appetitive virtues. As we have seen in the previous chapter regarding autonomy, pointing to the importance of reason in the moral life does not by necessity entail the neglect of the role of the emotions in the moral life.

### **The Vulnerability of the Good Life**

To Aristotle, virtue is the controlling element of happiness. Yet, one should be sufficiently equipped with external goods<sup>86</sup> in the life of Eudemonia. In book one, chapter ten of the *Nicomachean Ethics*, Aristotle explains that the happy person- the ‘Eudemon’- has a good character that is not affected by minor differences in good or bad

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<sup>83</sup> EN I.7 1098a. 7

<sup>84</sup> meaning virtuously

<sup>85</sup> The Greek is ‘phronesis.’

<sup>86</sup> External goods are those goods that come from outside of the person, such as wealth, health, and beauty.

fortune. In the *Eudemian Ethics*, he says: “For if the good life consists in what is due to fortune or nature, it would be something that many cannot hope for, since its acquisition is not in their power, nor attainable by their care of activity, but if it depends on the individual and his personal acts being of a certain character, then the supreme good would be both more general and more divine.”<sup>87</sup> When a person lives the good life of virtue, he/she is said to have the virtue of character, which is described as something more or less stable.

However, Aristotle also says that great changes in fortune or ‘tuche’<sup>88</sup> can affect one’s happiness. Martha C. Nussbaum is a renowned philosopher who often writes on the role of resources in ‘the good life.’ In a book dedicated to the vulnerability of ‘eudemonia’ to external loss in the thought of Plato and Aristotle, she greatly supports the work of Aristotle. In chapter eleven of *The Fragility of Goodness* concerning external disasters, Nussbaum explains that the virtue of character can be damaged by great loss of fortune<sup>89</sup>, although it does not necessarily do so. Before considering Aristotle’s extreme example of Priam,<sup>90</sup> Nussbaum considers several instances in which “uncontrolled circumstances may interfere with excellent activity.”<sup>91</sup> She says that if the external loss means that either the instrumental means for the activity or the recipient of the activity are gone then the activity itself is impeded. As Aristotle wrote, “It is impossible or not easy to do fine things without resources.”<sup>92</sup>

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<sup>87</sup> Aristotle, Eudemian Ethics (EE) in *The Complete Works of Aristotle* edited by Jonathan Barnes. Princeton, NJ: Princeton University Press. 1984. 1215a11-19.

<sup>88</sup> Also translated as luck. I will use fortune.

<sup>89</sup> Nussbaum, Martha C. *The Fragility of Goodness 2<sup>nd</sup> edition*, New York: Cambridge University Press. 2001. pg. 327.

<sup>90</sup> Priam is mentioned several times in the EN. I will return to him later.

<sup>91</sup> Nussbaum, pg. 327.

<sup>92</sup> EN 1099a31-33.

The question then arises: How are happiness and virtue affected by the great losses associated with terminal illness? Some may say that it would be more effective to look to Plato for a virtuous life of the terminally ill patient due to his belief that the virtuous life is invulnerable to the loss of external goods such as health, and even life itself. Plato said that death should not be feared and that the goods of the body play an indifferent role in the true good- the good of the soul.<sup>93</sup> As we have seen, Aristotle on the other hand has said that there is a certain vulnerability to the good life if the losses are great enough. For example, the loss of life itself negates any possibility of virtuous activity, and as such is something undesirable. However, like Nussbaum, I deem Aristotle's assessment more realistic and more fruitful in our understanding of the situation of the terminally ill patient who tries to live virtuously than that of Plato. Plato would have the patient's character be totally unaffected by the approach of death; experience shows us otherwise.

Nussbaum says that Aristotle values the life that is vulnerable to loss- loss of relational goods like love and friendship, and loss of external goods like wealth and health. "We want life which includes what makes us us"<sup>94</sup> are words she places on Aristotle's lips. The life of the human being, as opposed to the animal and the god, is the life where many important goods can be lost, especially the relational goods. In a life in which one can lose a friend, one will value that friend more, for example. To Aristotle, the best life is more vulnerable to fortune and "more open and less ambitious for

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<sup>93</sup> Nussbaum, chapter 5 on Plato's Republic.

<sup>94</sup> Nussbaum, 293.

control.”<sup>95</sup> Perhaps this realistic vision of life points to the fact that we simply cannot control everything. It definitely points to a particular hierarchy of goods.

### **The Hierarchy of Goods**

In *The Rhetoric*, Aristotle differentiates between external goods of fortune and those goods that affect one’s character: “And herein of necessity lies the difference between good fortune and happiness; for external goods come of themselves, and chance is the author of them, but no one is just or temperate by or through chance.”<sup>96</sup> The key appears to be volition, or authorship, on the part of the individual. The goods associated with virtue and those involving meaningful relationships with other people are much more important than external goods that entail no voluntariness. In the *Eudemonian Ethics*,<sup>97</sup> Aristotle seems to say that no combination of bad luck would make life not worth living. If virtue is exercised and acquired only in voluntary action, then the involuntary loss of external goods associated with terminal illness does not in and of itself necessarily take away happiness.<sup>98</sup> Only if the virtue of character is impeded greatly by the loss is happiness diminished. Rather than asking which activities are impeded by a terminal illness, the focus now becomes how an individual reacts to the loss, i.e. how is their virtue of character affected, and how can the person exercise virtues in the activities available to him/her. Furthermore, this view leads us to ask whether or not it is possible for the virtue of character to actually be strengthened by the loss if the reaction by the person is one of great virtue.

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<sup>95</sup> Nussbaum, 291.

<sup>96</sup> Aristotle, *The Rhetoric* in *The Complete Works of Aristotle* edited by Jonathan Barnes. Princeton, NJ: Princeton University Press. 1984. 1323b 15-19.

<sup>97</sup> EE 1215b27-31.

<sup>98</sup> Certainly much of illness can be affected by voluntary action. However, we are dealing with the case where the illness is already terminal, and where the patient cannot choose to behave in a way to improve health in any major way. At the same time, the virtuous patient will certainly do what he/she can to take care of one’s body while he/she can.

The fact that certain external goods are lost in terminal illness is not in question. However, there are more important goods in the assessment of ‘eudemonia’ or, in our case, the value of one’s life. Aristotle specifically identifies relational goods such as friendship as being important for the good life.<sup>99</sup> These relational goods are inherently linked to other people. The other people in society, and specifically those immediately around the terminally ill patient, therefore, can either increase or decrease the relational goods that a person has. The caregivers and friends (including family and professional relations)<sup>100</sup> can affirm the patient’s life by acknowledging its intrinsic value, and by being good friends to the patient. Aristotle himself identifies the importance of friendship, and the effects of friendship, within situations of great loss.<sup>101</sup> These relational goods are particularly important because they are so linked to the relational virtues, or virtues that entail the exercise of excellence in relation to others. The virtue of character, then, seems especially vulnerable to these relational goods, and not especially vulnerable to the external goods that entail no volition. This leads one to conclude that if the patient grows closer to his/her friends in the circumstances of terminal illness, then the patient may live more virtuously, despite the loss of external goods.

In addition, the reactions and actions of other people have a great impact on the patient’s emotions. In an article about Aristotle and affections, L.A. Kosman says that the emotions point to a “subject being acted upon” or an “agent... as patient.”<sup>102</sup>

Therefore, the terminally ill patient is a ‘patient’ in more than one sense. He/she not

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<sup>99</sup> EN 1155a 5-10.

<sup>100</sup> Cooper, John M. “Aristotle on Friendship” in *Essays on Aristotle’s Ethics* ed. Amelie Oksenberg Rorty, LA: University of California Press, 1980. pg. 302-304.

<sup>101</sup> EN 1171a 22-30.

<sup>102</sup> Kosman, L.A. “Being Properly Affected: Virtues and Feelings in Aristotle’s Ethics,” in *Essays on Aristotle’s Ethics* ed. Amelie Oksenberg Rorty, LA: University of California Press, 1980. pg. 104.

only is a receiver of the illness and the limitations entailed therein, but also is a receiver of the reactions and actions from other people. The reception is taken in as the feeling of emotions. These can be negative or positive, directed towards viewing life as either of positive value or as excessively burdensome. The emotions, as we have said, are not negligible in human life, but are an intrinsic part of the human person.

In fact, Aristotle posits that the emotions are part of the person's process of judgment, saying: "the emotions are all those feelings that so change men as to affect their judgments, and that are also attended by pain or pleasure."<sup>103</sup> The emotions are often reactions to other people, and so other people can in effect "change men as to affect their judgments," including their judgment regarding the value of one's own life with severe illness. The people surrounding the terminally ill patient can affect the patient to experience good emotions, and also can help the patient to place those emotions under the guidance of his/her reason. This input can help the patient live the virtue of prudence better, since the deliberative process of prudence often includes the acquisition of advice. All of these interactions require time and effort on the part of the caregivers and friends, but it is specifically these interactions that increase the relational goods to the patient. They do more than compensate for the wealth and health lost in other ways; they can help strengthen the very character of the person.

### **Nobility and Dignity**

In the tenth chapter of book one of *Nicomachean Ethics*, Aristotle says the following:

...if he suffers many major misfortunes, they oppress and spoil his blessedness, since they involve pain and impede many activities. And yet, even here what is

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<sup>103</sup> The Rhetoric, 1371a 20-21.

fine shines through, whenever someone bears many severe misfortunes with good temper, not because he feels no distress, but because he is noble and magnanimous.<sup>104</sup>

Clearly, Aristotle believes that a person who has suffered great external loss may still retain the virtue of character. However, it would seem that Aristotle is setting up a distinction between ‘Eudemonia’ and ‘Makariotes’, i.e. between living well and being blessed. ‘Makariotes’ or blessedness denotes a relationship to the god(s) in which the mortal human is gratuitously given blessings of good fortune. This explanation put forth by Sir David Ross<sup>105</sup> and H.H. Joachim<sup>106</sup> would explain why Aristotle seems to believe that someone could still be ‘Eudemon’ while losing some external goods, while at the same time not being considered ‘blessed.’ However, this reading is not without its critics, including Nussbaum.<sup>107</sup> She points to passages in Aristotle’s ethics where he clearly believes that ‘Eudemonia’ itself can be lost through external losses. Again, she provides Aristotle’s example of Priam.<sup>108</sup> Priam lost all his wealth and fortune, his children and his country, and according to Aristotle, would never be considered happy in his extreme sense of loss.

However, I think that the example of Priam points to how we can take pieces of both interpretations and still remain faithful to the text. Aristotle clearly states that virtue is the controlling element in the life of ‘Eudemonia’.<sup>109</sup> He has said that the loss of some external goods should not damage a truly virtuous life. At the same time, he seems to say, as in Nussbaum’s reading, that ‘Eudemonia’ is vulnerable to great external loss, i.e.

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<sup>104</sup> EN 1100b27-33.

<sup>105</sup> W.D. Ross, *The Works of Aristotle* (London 1923) 192.

<sup>106</sup> H.H. Joachim, *The Nicomachean Ethics* (Oxford 1951) *al loc.*

<sup>107</sup> Nussbaum, pg. 329-330.

<sup>108</sup> EN 1100a9-10.

<sup>109</sup> EN 1102a5-8 as elsewhere.

it *may* be lost if the loss is so great as to affect the virtue of character. Therefore, let us conclude that a virtuous person who has experienced some loss of health is not ‘blessed,’ but is probably still ‘Eudemon.’ At a certain point, however, the loss of health may be so great as to negatively affect one’s very character and therefore take away happiness. Furthermore, if the loss of health is accompanied by great relational losses, as is the case with poor Priam, then the chances of that person’s character being unaffected are increasingly diminished.

If on the other hand, the person’s response to the loss of the external good of health is to improve his/her virtue of character by growing in particularly important relational goods and virtues, then the ‘eudemonia’ is retained and perhaps even strengthened. Aristotle says that ‘the fine shines through’ in the person who is magnanimous and noble. The circumstances of terminal illness, that include not only physiological loss, but often times opportunities to grow in relational goods, may be precisely those needed to exercise and so grow in the paramount virtue of magnanimity, and so to attain what Aristotle calls ‘nobility.’

Aristotle defines nobility as the characteristic of possessing noble goods and practicing the virtues for their own sake<sup>110</sup>. He defines the magnanimous person as “characterized by a certain greatness of soul and faculty; and so he seems like the dignified and magnificent man, since magnanimity seems to accompany all the excellences.”<sup>111</sup> I read the state of nobility as the culmination of all virtues, and pertaining to our concept of subjective dignity. He/she who is noble is the dignified person. In the previous chapter, I differentiated between intrinsic dignity that is proper to

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<sup>110</sup> EE 1248b 34-36.

<sup>111</sup> EE 1232a 29-33.

the human qua human, and subjective dignity that entails choices to live in a manner proper to that intrinsic worth. Since subjective dignity can be increased by choices to live more in accord with that intrinsic dignity, then nobility can also be increased by those same choices. They are, in fact, precisely choices to live virtue, because it is most proper to the intrinsic worth of the human being to be virtuous. By living more of the relational virtues, a terminally ill patient lives that part of their humanity that is interdependent and social to a greater degree. He/she lives better friendships, and has more relational goods. In this way, the patient can be said to be ‘more human’ through virtue, rather than ‘less human’ through physiological loss.

### **Virtues in Terminal Illness**

In her article on virtues in old age, Sara Ruddick critiques our cultural view that older people should be “healthy, sexually active, engaged, productive, and self-reliant,” the supposed virtues for all Americans.<sup>112</sup> Instead, she proposes virtues more appropriate to the reality of older people’s lives, namely: curiosity, capacity for delight, concern for others, capacity to forgive, capacity to accept, adjust, and appreciate, and ‘wise independence.’<sup>113</sup> These are not merely virtues that the elderly can live as if we have lowered the ‘bar of virtue’ to fit the limited capacities of older people. We are not trying to make them feel all right with themselves for *at least* being able to be virtuous about *something*, as if we are giving up on their ability for virtue.

Nor are we imposing great burdens on them to have to live virtuously. Virtue is only exercised in activity, and is context-dependent to the opportunities available to a particular person at a particular time and place. Those opportunities are highly dependent

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<sup>112</sup> Ruddick, Sara. “Virtues and Age,” in *Mother Time: Women, Aging, and Ethics*. Margaret Urban Walker ed. New York: Rowman & Littlefield Publishers, Inc. 1999. p. 45.

<sup>113</sup> Ruddick, pg. 50.

on other people, most notably on the caregivers of the patient and on the social structures that allow the caregiver to serve the patient well. Ruddick says: “Social policies shape the conditions and the experiences of loss and decline. Political, not individual, will determine the availability to some or all people of respectful medical care, varieties of home service, elderly-friendly public transportation and home furnishing...”<sup>114</sup>

We can apply what Ruddick says regarding the elderly to the terminally ill patient, although the circumstances, and therefore pertinent virtues, may differ. The terminally ill patient is a complete human person with intrinsic dignity. He/she is similar to any other person in that he/she will find great meaning in a personal struggle for virtue. This struggle for virtue, particularly the relational virtues,<sup>115</sup> will yield a greater dignity in the subjective sense. However, the patient cannot struggle for virtue in the absence of others. He/she needs other people to relate with in order to exercise those relational virtues. The input into the patient’s judgments in the forms of deliberative and emotional support is an important component of the moral life of the patient. The terminally ill patient, just like any human person, is therefore unable to be truly moral without other people. The patient is, by nature, interdependent.

The interdependence of human persons is not limited to patient-caregiver interactions. Caregivers, too, act and react within a system of social beings. There are many things that we can do in our society to better avail caregivers to be able to provide the type of positive care that I have expounded here. Their struggles for virtue, too, depend on the opportunities provided by others. The economic, political, and social changes needed to support more positive caregiver-patient interactions are not the content

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<sup>114</sup> Ruddick, pg. 49.

<sup>115</sup> Relational virtues that are particularly important for the terminally ill patient may include: friendship, prudence, the virtue of contemplation, wit, mildness, and Ruddick’s wise independence.

of this paper. However, I will briefly mention some ideas sponsored by the Center to Improve Care of the Dying, as published in the book: *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*.<sup>116</sup>

In the chapter on relationships, the authors provide examples of institutions that have implemented the following ideas for positive change: 1) better communication with physicians regarding what the patient and family can expect in the course of the illness and death 2) institutional resources for activities on meaningfulness and spirituality for patients and 3) support for families and loved ones, particularly in terms of bereavement. In the chapter on helping caregivers, the authors suggest the following: 1) making the caregiver part of an interdisciplinary team 2) providing opportunities for career advancement for caregivers and 3) bereavement and counseling for staff. What is increasingly clear as one reads through the ideas, many of which have still not been instituted, is that much more can be done within our system to help those who want to help patients live well while dying. What is also apparent is that the primary organization within society is the family, and thus in most cases much of the care giving in question will be provided by the patient's family. Although there is no bureaucratic means of strengthening families in our society, there are ways for civil society to support the family as they attempt to care for their dying members.<sup>117</sup>

### **The New Moral Ideal**

By supporting the moral ideal of an atomistic-autonomous individual, our society promotes an individualism that places the patient's choices as paramount in the terminal illness. Perhaps it is that ethos of individualism that leads Brock to believe that we

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<sup>116</sup> Lynn, Joanne; Schuster, Janice Lynch; and Kabcenell, Andrea. *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*. New York: Oxford University Press. 2000

<sup>117</sup> such as financial support for home health care

should permit terminally ill patients both to choose euthanasia and to act on that choice. However, as several feminist thinkers have pointed out,<sup>118</sup> this ideal is both unrealistic and unfair.

The human person is, by nature, social and interdependent. Relationships are extremely important in all of the following: the formation of one's values, the deliberation or assessment of one's life value based on those values, and the action based on those values. Other people, especially those immediately surrounding the patient, positively influence how the patient assesses his/her life value by making the circumstances of that life meaningful and as full of autonomy as possible. We would be better off fostering an image of the ideal moral individual that recognizes this interpersonal nature of the human person, including the dying human person. It is an interdependent-autonomous individual that one becomes through relational virtues and the weighing of relational goods as superior than external goods such as health. Perhaps this is the greatest lesson that we all can learn from those who live well while dying.

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<sup>118</sup> Carol Gilligan and other proponents of the 'ethics of care' for example

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