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Preserving Dignity

In the Long-Term Care of Actively Dying Residents



An All College Thesis

For Distinction in the Department of Philosophy

Academic Year 2016-2017

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Preface: To the Nurses

I began this research with the intent to learn more about the care process in long-term care facilities, primarily with regard to actively dying residents. Through my own experience as a nursing aide, I saw how being over worked, underpaid and underappreciated took its toll on how well I could authentically care for my patients. This problem became glaringly obvious to me when, as a nurse's aide at 19, I watched one of my residents die while feeling "completely and utterly alone... as if no one even cares. No one listens." Broken hearted, a fire began to burn in me. I needed to learn and grow in ways that would allow me to give back to two communities I have grown to love and where I have found my closest friends: the elderly and their caretakers.

The results of my research are intended to help instruct the long-term care nurse and nurse's aide on how to better care for the spirit and overall well-being of their geriatric patients. However, my aims go deeper than this. I also worked with nurses and nurse educators to determine ways in which the nurses themselves can feel appreciated and cared for. Nearly all fields in nursing gain merit in providing lifesaving care to their patients. A typical result of attributed merit is the lifesaving nurse gaining a just wage and a lowered patient load. This is not the case for long-term care nurses. Their focus is not to extend life but to bring comfort and companionship to the elderly and dying. What often results are long-term care nurses finding themselves overworked, underappreciated, facing low wages and finding no upward mobility in their career. Perhaps by reading this thesis and knowing that there is a bright eyed undergraduate researcher out there who thinks that their work is vital and that these nurses deserve good care will offer a brief moment of affirmation and encouragement to all nurses. Since this is an undergraduate research project, I do not have the financial or temporal resources to formalize my work into a project with which I can collect objectifiable results. It is my hope that one day I will

be able to do this. For now, let this short work be used as a starting point for greater dialogue among nurses, aides, managers, educators and policy makers on what can be done to improve the way residents die in what are often underfunded and understaffed long term care facilities.

I have spent a year and a half formally researching dignity and its role in end of life care. This project blends philosophical concepts of dignity, care ethics and nursing practice in long term care to determine how aging and end of life care can be improved. The improvements and suggestions I make here are meant to provide the nurse with tools which can assist them in safeguarding against the some of the harms patients are vulnerable to. While approaching end of life through old age or physical illness, many patients go through a series of mental, physical and social losses. These losses leave patients vulnerable to harm by others or even themselves. Simple actions or words provided by a caretaker or nurse can either safeguard these individuals from harm or contribute to further harm.

I begin my thesis with a chapter called ‘An Overview of Dignity in Health Care’. This chapter begins with the words of my participants, to whom I owe my greatest gratitude. From there, I write about how the process of aging causes a series of losses that leaves the aging individual vulnerable to harm from others, themselves, and their underlying terminal illness. I then point towards the role of the nurse and how they are often the ones who are best situated to safeguard residents against such harms. One way in which the nurse’s practice of care can become specialized to prevent harms is through supporting the patient’s dignity. The original notion of dignity in medical ethics has been credited to Immanuel Kant’s notion of dignity and his definition of autonomy. Both have helped to drive health care law and practices to become what they are today.

In chapter two, called ‘Interpreting Dignity’, I draw out and critique Kant’s notion of dignity and autonomy. I make the point that Kant’s definition of autonomy is too narrow and is not inclusive of all human beings and their abilities. To begin responding to this major critique, I turn to care ethics and relational autonomy as proposed by feminist philosophers, connecting it to dignity. Dignity should encompass and protect more of our humanness. I point out that we live in a multicultural world with a wide variety of human experiences and understandings. It should come as no surprise, then, that dignity should be broadened to consider this diversity, especially with regards to informing one’s practice of care. Because of this, I turn to the writings of Lennart Nordenfelt, a Swedish medical ethicist and philosopher, who works to broaden dignity in ways that encompasses and protects humans in all stages of life. To do this, Nordenfelt breaks the overarching concept of dignity down into several different notions. Such notions of dignity will include: dignity as rights, dignity as merit, and dignity as identity. In my analysis, I look closely at how well these different understandings of dignity best inform the nurse in her care practice towards the elderly and the dying.

In chapter three called “Identity, Dignity and the Process of Care” I narrow my focus to the dignity of identity and feminist philosophers’ concepts of care. Intertwining these two concepts, I extrapolate four aims of care in the end of life that can be used to affirm and support the patient’s shifting sense of identity. These four aims are: caring for bodily needs; caring for security needs; respecting the resident’s dignity of identity; and affirming the resident’s shifting sense of autonomy. In many facilities, the first two aims are nearly always fulfilled without the nurse giving the patient a second thought. Therefore, I spend most of my time talking about how the dignity of identity can be promoted as well as the resident’s shifting sense of autonomy. In being bound to the fulfillment of these last two aims to ensure good nursing practice, the nurse

can adapt to the patient's shifting sense of autonomy and help the patient to socially and mentally prepare for death while administering the proper medications which keep the patient comfortable. I argue that supporting the patient's identity also supports and upholds their dignity as it is affirming an intimate part of their humanness while allowing the nurse to uphold the rights the patient has.

Chapter four is called 'Nursing and its Challenges'. Affirming another's identity or part of their identity has powerful benefits. Therefore, this chapter is designed to address two common factors which can prevent the nurse from realizing or working towards the four aims of care in the end of life: compassion burn out and depersonalization. These persistent burn out side effects are common in long-term care and are correlated with the nurse's inability to grow professionally, being underpaid or overworked, and being forced to work in a poorly kept facility. I will propose a solution and test study that I hope to one day pursue within a Master's or a PhD program. For now, this solution is meant to acknowledge that the nurse is not expected to be a miracle worker. Long-term care nurses themselves are in need of being affirmed with respect to their profession. My proposed solution and study is meant to promote better self-care practices for the nurse. This will allow her to continue with her self-emptying care practice within long term care.

In my conclusion, I give a brief overview of what has been covered. I restate my broadened sense of Kantian dignity and autonomy. I trace these concepts directly to the four aims of care the nurse must acknowledge in order to have a good care practice. Finally, I re-emphasize the importance of self-care within the work place to help prevent two common symptoms of nurse burn-out in long term care facilities.

Chapter One: An Overview of Dignity in Health Care

1.1 Varying Views of Dignity in Long-term and End of Life Care

“...dignity is living. I would say that living is a privilege. I mean, I’ve enjoyed the good times and put up with the bad times cause I knew the good times were around the corner.”

~Resident 5, ‘Sharon’

“Dignity for my patients, for me, is not about rights. It is about keeping them comfortable and being honest with them. I am trying to comfort them and their ailing bodies.”

~Nurse A, ‘Jaimie’

“Personally, dignity for my patients means preserving themselves as a unit and all that they stand for and all that makes up them.”

~Nurse C, ‘Glenn’

After spending two years working in various long term facilities, I took a step back from working directly in the field to studying it and what makes care work in order to determine simple strategies for improving end of life care. It began with a three-month long research internship at one of the best long-term care facilities in the Midwest. This internship involved spending time each week building relationships with and interviewing various nursing staff and long-term residents about their lives and experiences. We covered a wide range of topics from proper patient care to dignity to life stories or simply thoughts about the day. I collected a lot of qualitative data from my time at ‘Country Acres’ as well as my own personal experience. I use that in my ongoing research. Before diving into this, here are several important qualitative research findings I discovered.

As one ages or nears death, the individual goes through a series of physical, mental and social losses. Some lose their hearing or grow weak and lose the ability to walk or bathe. Others lose their ability to remember if they took their medications, how to pay the bills or feed themselves. With these losses come dramatic changes for the aging or dying individual. They

become less and less of the fully independent person they once were. They reach out and rely on others to take care of simple tasks they were once able to do such as driving, cooking, feeding themselves, toileting, etc. As they rely on others to fulfill their care needs, most continue to decline and do not regain full health. This loss of health and dwindling sense of independence leads the individual to demand more and more from their caregivers. As their physical health continues to decline, more is lost and more is demanded of their caretakers. Eventually, the caretaker is unable to fulfill all of these demands on their own, resulting in the individual being hospitalized or placed in assisted living, nursing homes or hospice care. In this transition, the individual faces one final loss before death: the loss of the social network that surrounded them in their homes (Cronican 2016).

The self-defeating, dramatic process of loss in aging and end of life leaves the individual vulnerable to harms. Moving to new environments means that the individual must reassert their needs to new faces and make new friends. This is hard for some as they may not have interacted with strangers on such intimate levels for years. In some cases, the individual may have already lost their ability to speak or coherently communicate their needs by the time they arrive in a new environment of direct and skilled care. This leads to yet more vulnerabilities.

Vulnerability is not bad in and of itself because it illuminates to us how all humans are in need of care and are dependent upon one another (Mackenzie, Rogers, and Dodds 2014, 4). Instead it is what others who surround the aging or dying individual do which can result in harm or in good. The life of the dying individual has been shattered due to a variety of factors such as the realization of imminent death, the loss of independence, suddenly becoming socially isolated from friends and loved ones for long periods of the day or any other physical or mental loss (Tong 2014, 298). Having an altered ability for self-care leaves the person deeply compromised on

both an emotional and physical level. In my interviews and observations, the only way the dying person can reconcile themselves to such losses and dramatic changes is by being surrounded by a network of supportive and caring individuals. This, ultimately, helps the individual feel as if they are held by others in emotionally and physically comforting ways which encourages them in the process of dying a good death. (Nussbaum, 1995). Supportive individuals are one important factor in bringing about a peaceful death. It is the main result I found through all of my interviews with both residents and nurses in addition to the time I spent shadowing nurses who care for the aging and the dying. Yet, support and care are tricky to do with individuals whose health and ability is in constant flux and is declining. Being supported or cared for in the wrong ways can lead to a harmful outcome for the patient in many ways such as feeling stressed or unable to express needs through spoken or body language. To address this, there needs to be a set of principles that those who surround and care for aging or dying persons can use to minimize physical, mental or social harm done to the resident.

The underlying principle that can be used in order to promote good aging and end of life care lies within a word that is commonly used but very obscure. That word is dignity. In the following chapters, I will slowly unfold how dignity can be used to improve end of life care particularly in the realm of nursing. First, however, we must define what dignity is and determine its past and present use in shaping how medical professionals approach health care and the care of the dying.

1.2 A Brief History of Dignity

The word ‘dignity’ originates from the Latin word *dignitatem* which means ‘worth’ or worthiness. The word was then adapted into the French language as *dignite* before being adapted

into Middle English in the 13th century as the word it is today (Harper 2017). Dignity as a concept was written about during the Renaissance by Pico della Mirandola, a known philosopher of the time (Mirandola 15th ce) . However, the concept of dignity was not popularized until philosophers of the Modern era in the 17th and 18th centuries made common use of it within the realm of metaphysics and ethics (Baird 2011, 552-4).

The concept of dignity didn't enter the legal or medical literature until the early 20th century when medicine was transformed as a result of the rapid advancement of technology. Due to technology, new medical advancements were discovered at a rapid pace. With the rise of medical technology came the rise of paternalism in the health care field. Rather than being upfront with patients or research subjects about the status of their physical ailment or the side-effects of certain treatments, many doctors and nurses felt that it was in the patient's best interest to withhold this information (Arneson 1989, 410). Tied into this mentality is the image of a patient as passive. Using the metaphor of medical advancement being a well-tuned machine, the doctor is seen as the main engineer who learns about the mechanics of the body and researches how to keep it running smoothly. The nurse is the assistant who waits to see if the proposed solution (AKA: treatment) works. This leaves the patient being the machine, a passive object that has no say in how the engineer works on their body. This image and the overall ideal of paternalism on health care fails as the thing being worked on is not a thing at all. Rather, it is a living, thinking, feeling human being who deserves to be treated in a dignified manner.

The dignity of the patient wasn't acknowledged until nurses began to advocate for the just and proper treatment of patients. This involved informing patients about their medical condition and the treatment options available to them. Thanks to wonderful nursing advocates, currently many in long-term care facilities see dignity playing a central role in the facility itself

(2013). Now, marketing slogans such as ‘Dignity in Life’ for long-term care facilities or campaign mottos for legislative changes such as ‘Death with Dignity’ and ‘Dignity in Dying’ enter the consciousness of aging Americans, their relatives, terminally ill individuals, nurses, doctors, chaplains, journalists, lawyers and academics. Say one of those slogans and most in the room will admit to having heard it. Yet, if one were to ask the listener just what the word “dignity” means, many would give unique answers that don’t fit the exact definition of dignity in the dictionary or in the legislation. There is no one set definition of dignity. In 2008, the President’s Council on Bioethics joined together to discuss dignity and its role in American bioethics. Many essays were written during the council about dignity and how it is driving health care and its culture. Yet, at the end of the conference, the council was still unable to settle on one particular definition for the word dignity and reported this to the President of the United States in their letter of transmittal (Pellegrino 2008).

Having no set definition of dignity should not be alarming so long as the general concept behind the word is known. At its conceptual core, dignity is meant to shine light on our value as human beings. It is supposed to articulate and acknowledge a value inherent to being human. This inherent value is given to humans, in Kantian terms, through one’s ability to rationalize and make ethical decisions without the assistance of others. However, I argue that our inherent humanness and our embodied experiences are unique in themselves. What Sally experiences and chooses for her life as an aging gay white woman in Sweden will be different from the lived experiences and choices of Amhal, a heterosexual Muslim black American who is dying of metastasized testicular cancer. The subtle differences between the lives of Sally and Amhal alters their rationality and sense of autonomy in ways that affects their moral judgements. Thus, what we define dignity to be should be broad enough to encompass humans at all stages of life to

ensure that all humans receive a just amount of care to live full, robust lives. In the following chapter I cover several senses of dignity which carry different weight in one's practice of long-term care and discuss their usefulness.

1.3 Kantian Influences in Health Care and Medical Ethics

In American health care today, patient autonomy and patient rights are common concepts and language used when considering how to care for a patient properly. This language stems from the need to ensure that medicine progresses ethically and in ways that respect the people medical intervention is designed for. These concepts were primarily seeded by Immanuel Kant, an 18th century philosopher who investigated the foundation of morality. Kant's writings define ethics using terms like dignity, autonomy and reason. Others - such as the United Nations General Assembly of 1948, the African Union, and the Organization of American States - built upon Kantian concepts to justify how individuals are afforded certain universal rights (Griffin 2008, 33-34, Martin and Nickel 1978, 395-413). This ethical foundation was drawn on by the health care field when medical ethics took root in the 1980's to protect the well-being and dignity of the patient (Schachter 1983, 852). In order to understand how a patient care model centered on dignity, one needs to take a close look at the writings of Immanuel Kant and the definitions he provides.

Kant writes about autonomy, dignity, and duty in *Groundwork of the Metaphysics of Morals*. The piece of writing was intended as one of two preludes to a greater work Kant wrote known as *The Metaphysics of Morals*. In *Groundwork*, Kant states that dignity is "that which constitutes the condition under which alone something can be an end in itself has not merely a relative worth, that is, a price, but an inner worth" (Kant 1996, 84, 4:35). This inner worth is "raised above all price and therefore admits of no equivalent" (Kant 1996, 84, 4:434). This

definition of dignity appears to closely mirror the meaning of the Latin word for dignity, meaning worthiness. In this definition, Kant sets a worth to humans through the word dignity. He sets human existence beyond price saying that each rational being is unique and cannot be replaced. The irreplaceable value of human beings was set due to Kant's basis of morality. To Kant, morality is related to the process of ends and means. Certain objects, those that have a set price, can be a means to another end. Other objects, such as humans, who have dignity, can only be ends. Human being's ability to have rational, logical thought and the power to determine for themselves what is right or wrong places humans closer to the ideal of being a god, for Kant. Human's god-like attributes of rational thought, autonomy and Kant's notion of dignity leads Kant to conclude that humans should never be treated as a means to an end. Rather, humans always ought to be respected as ends in themselves(Kant 1996, 85, 4:436).

One aspect of human dignity is their capacity for autonomy (Kant 1996, 85, 4:436). Autonomy, to Kant, is the principle of self-determination (Kant 1996, 96, 4:448). In other words, all humans who have the capacity to be rational are free to use their own judgement pertaining to choices of right and wrong. Kant provides a tool for making rational, moral decisions which he labels the categorical imperative. The categorical imperative is an ethical tool which states that ethical actions are those that can be universalized without contradiction (Shafer-Landau 2010, 87-88). Using the categorical imperative, one is bound ethically by certain moral duties, which he labels: duties of justice and duties of beneficence. Duties of justice correlates to logical contradictions in one's moral thought (O'Neill 2000, 45). If universalizing a proposed course of action would result in a logical, then the action is not moral and doing the opposite of one's proposed action would be one's moral duty. Duties of justice are the most important duties for Kant. With them, we are ethically bound to never treat a human being as means to an end. For

example, if a disgruntled mom with two screaming children is stuck in a long line at the grocery store checkout, she may feel that it is in her best interest to kill everyone in front of her so she can get her children home sooner for their nap. However, if the mother were to universalize this ideal by using the categorical imperative to say, “it is in everyone’s best interest to kill anyone who keeps them waiting”, this would be a logical contradiction as killing people for one’s own personal convenience would be destructive to human beings everywhere.

On the other hand, duties of beneficence arise when universalizing a proposed course of action results, not in logical contradiction, but in a world in which one would not want to live. The reason for this being, one would not want to live in a world where beneficent actions never occurred. Duties of beneficence are not as important to Kant as duties of justice are and are only used at the user’s discretion (O’Neill 2000, 45). However, duties of beneficence have moral implications and should be included in our moral judgments. For example, it may not be in my best interest to transfer Bethany, a resident on my unit who is a full assist, from her chair to her bed because I am too busy. However, transferring Bethany as many times as she wants is a duty of beneficence, as I would be creating a world where one day I will be able to ask another to transfer me as much or as little as I want. Without this duty of beneficence, the world of long-term care would be a grim place where residents wouldn’t be moved often causing a myriad of health problems for the residents such as bed sores and infections.

Kantian notions of dignity and autonomy were used when the need for medical ethics arose in the 1970’s. However, Kant’s language was interpreted in two distinctive ways. One organization which used Kantian dignity and autonomy was the American Medical Association in 1980 during its revision of the Physician’s Code of Ethics (Riddick 2003, 6-7). In this revision, the AMA adapted Kant’s notions of dignity and autonomy into legal language which gave

patients certain rights which the physician was ethically and legally bound to uphold. This outlook is still found in health care today. For example, it is Lupita's legal and ethical right, as a patient living in Minnesota, to refuse treatment after receiving adequate information (Statutes 2016). In this interpretation of the Kantian notion of dignity and autonomy, physicians and lawyers maintain the viewpoint that all patients are humans and ought to be treated with equal amounts of respect towards specified legal rights. Failing to respect these rights would have legal consequences for the physician.

Unlike the American Medical Association, the American Nurses Association used Kantian's notion of dignity and autonomy to help move nursing care away from being a science and towards an art that respected the patient's autonomy and dignity out of the desire to maintain good caring practices. Unlike the AMA, the ANA revised the language in their code of ethics to reflect that the entirety of the nursing practice would shift to see the individual as a unique human who ought to receive proper care (Epstein and Turner 2015, 4-5). This subtle difference in approach may seem trivial; however, the ANA's additions to their code of ethics advanced nursing care to its current practice of caring for a specific individual with a specific set of medical needs. This directly contrasts the medical doctor's approach to medicine where all patients ought to be treated by the same means with the same expected results. In their practice, physicians still continue to ignore the emotional and spiritual aspects of the patient being treated whereas the nurse, in his practice, attempts to promote individualized care and healing to the patient on all levels: spiritual, emotional and physical.

In both the medical and nursing practice, Kant's concepts of dignity and autonomy opened up dialogue about what was and wasn't ethical in healthcare. It led to creating certain legal rights of patients such as informed consent, the right to refuse treatment and the creation of

advance directives as a means to record and thus respect patient rights which have safeguarded the dignity and well-being of patients from the 1960's through today (2013). Kantian ethics has done a lot of good for the health care field. However, sticking to this one narrow focus of what dignity is and what autonomy means limits the amount of good doctors, nurses, lawmakers and patients can do to improve the overall well-being of the patient. This is especially true when thinking about the unique care process for aging or terminally ill individuals. In the next chapter, I explore these limitations further and introduce other concepts that may help both the resident and the nurse in adjusting to the losses experienced at the end of life. I'll introduce differing notions of dignity and autonomy in ways that improve patient care.

Chapter Two: Interpreting Dignity

2.1 A Critique of Kant's Conception of Dignity

The Kantian notion of autonomy has been interpreted to be characteristic of a patient who is “wholly and even necessarily self-sufficient, self-determined, self-guided – in a term *atomistic*, - who is entirely free to make his or her own choices” (Beever and Morar 2016, 3). In other words, the patient is a free standing being who is able to make their own unique choices pertaining to their personal health regardless of any outside factors. However, such an individual who makes such choices pertaining to their health has not been found. In fact, when looking at the wording of laws protecting patient rights and autonomy, specific language is used to include outside factors that must be present for the patient to make a decision that is considered autonomous in the eyes of the court. For example, most of the legal language states that a patient has the right to refuse treatment as long as they have been properly educated by a health care professional about all available treatment options (Statutes 2016). Laws establishing advance care directives were created spelling out that a person has to be of a sound, rational mind to write an advance directive that health care professionals then have to honor (Sabatino 2007).

With a strict interpretation of Kantian autonomy, patients would not be viewed as fully autonomous when making important medical decisions because many often look towards their family or close friends for guidance and support when making important choices that pertain to their health. For Kant, seeking the guidance and support of others when making an important decision would be considered heteronomy rather than autonomy: other's reason informing one's decision regarding the moral law versus making that decision through the use of one's own

reason. By acting heteronomously, the patient is not making fully self-determined choices. Yet, one typically seeks more social support when they are faced with making choices about the end of their life.

This observation does not imply that Kant's concept of autonomy is useless. If one were to do away with autonomy, Kant's justification of dignity would go straight out the window too. Without autonomy, humans would not have much to point to that gives them an internal worth or value that is unique and irreplaceable. To me, Kant was a pretty important philosopher who had good insight into determining philosophical truths that fit well with his audience and the time period he lived in. If we consider that Kant grew up and was educated in an age when slavery was legal and supported and where women were considered property and had limited access to education, we can get a look at who Kant for: other well educated men. This doesn't mean that Kant was a bad person. Given the times, he was in an environment where certain ideas about morality and self-worth were different than what we know today. For example, a woman's right to education wasn't well accepted during the time Kant was alive. On the other hand, many of Kant's writings on reason, autonomy, and dignity laid the moral foundations for movements today as they give us a platform and a specific discourse that many oppressed people can and have used to argue for their rights as human beings.

Therefore, Kant's notions shouldn't be thrown out. Rather, dignity and autonomy need to be broadened to become more inclusive of all human beings, regardless of their rational ability or their sense of independence. Although Kantians would claim that to 'flourish' is simply to become fully autonomous, many philosophers have critiqued this in order to better advocate for the flourishing of all humans. For example, out of the classic notion of autonomy, a new definition was created to take into account that human beings are not totally free, unencumbered

beings. They are bound to and created by their relationships. These relationships help to inform humans on how to make decisions pertaining to their health. This new form of autonomy is known as relational autonomy and has been developed by many different feminist philosophers.

In the early 2000's, a feminist philosopher named Anne Donchin began to write about the relational aspect of autonomy. In her article, "Understanding Autonomy Relationally: Toward a Reconfiguration of Bioethical Principles", Donchin talks about the value of relationships, especially those pertaining to the physician and the patient that can be related to the relationship between the nurse and the resident in long-term care. The nurse holds a wealth of medical knowledge that the resident does not and typically shares information to help preserve the health of the resident and to help assist the resident in making informed decisions pertaining to their health (Donchin 2001, 368). This relational process illustrates how the resident is not a free being who can make decisions about their health completely on their own. They need the help and guidance of health care practitioners including the nurse. The way in which the nurse relates and relays medical information to the resident should be done from a basis of care by promoting an environment for open dialogue between the nurse, the patient and their family (White et al. 2007, 461).

Although Donchin was not the first philosopher to write about relational autonomy and its role in health care, she makes good points about why the standard form of autonomy is not inclusive or caring enough to ensure that the patient is able to make a good informed choice pertaining to their health. Patients' health decisions are informed by the relationships they hold with both their family and their health care professional (Beever and Morar 2016, 5). It seems that feminist philosophers are suggesting the way in which nurses and nursing aides communicate medical information to their elderly or dying patient should be done in a relational manner where

the nurse focuses not only on the information being relayed but how well the patient or their loved one understands the information. The nurse should ensure that the patient knows all the options they have available. In addition, the patient's or guardian's values for how to live the rest of their lives should be acknowledged and the patient should feel listened and understood. More will be said on this in the following chapter.

In addition to disregarding the importance of relationships in the decision-making process, the classic form of autonomy has been used in conjunction with dignity to exclude marginalized groups of people, which can harm these individuals' well-being. For example, many Kantians would agree a woman who grew up in a poor family, got her PhD in philosophy and raised three children is autonomous. However, due to her dwindling cognitive abilities and poor eyesight, that same woman does not possess the capacity to take the medications prescribed to her on her own nor is she able to manage her checkbook or live on her own. In the eyes of her caretakers, she is not autonomous because of her lack of cognitive and physical abilities. Likewise, a real-estate manager is very knowledgeable in their field but wouldn't be able to write a dissertation on the role carcinogens play in the spiking rates of cancer and heart disease within the United States or what caused his own lung cancer. Yet, his autonomy is not respected because the nurse who is caring for him refuses to tell him that his cancer is terminal. In the eyes of the nurse, telling him he is terminal will cause him to give up on life and die. Regardless of if the patient is able to fully understand their medical diagnosis to the degree of the nurse or is able to care for themselves, many would agree that they are still human beings who possess dignity and should be treated as an invaluable individual worthy of respect and care. In addition, their varying degrees of autonomy ought to be respected.

As usual, the law can step in to help the health care professional determine when the patient is autonomous enough to make big decisions like creating an advance directive, choosing to take a life ending medication, or refusing lifesaving treatment (Sabatino 2007) (Oregon 1997). Yet within everyday interactions with patients, while assisting them with activities of daily living such as choosing what food to eat, the long-term care nurse or nurse's aide is left without much guidance into what determines if the patient is autonomous enough to choose ice cream over a salad. This critical thinking, decision making process that the nurse or aide is making in order to properly care for this particular patient can become even more complex when considering this patient's recent medical history of poorly regulated diabetes. When over-worked and underpaid, the nurse or aide may not even think about the patient's autonomy in such a simple decision. Perhaps, within the mind of the nurse or nurse's aide, there isn't even a decision offered to the patient at all. Being overworked causes the nurse to see the resident less as a human and more like a laundry list of care tasks that need to be fulfilled. Promoting life sustaining care becomes her outlook. If the resident has type two diabetes, the over worked, underpaid, and burnt out nurse may not see the resident as having a choice. Rather, there is only one choice which will prolong his life. That choice is the salad.

It is in this conflict that I noticed that the concept of dignity, let alone promoting it in long-term care, is not considered by nurses in the facilities I worked in. Yet, philosophers, policy writers and some managers see how the process of care can be improved simply by acknowledging and upholding key concepts like patient dignity and autonomy. The question now lies in how a long-term care nurse or aide can support the dignity of an age group who is so large and so diverse that one care method which works for one individual fails when applied to another individual. To answer this, one needs to change the way in which they conceive dignity.

2.2 Introduction to Three Notions of Dignity

Lennart Nordenfelt is a Swedish philosopher who has been studying the philosophy of medicine for years. Working collaboratively with his peers, Nordenfelt released a recent book called *Dignity in Care for Older People*. In it, Nordenfelt writes about the different interpretations of the concept of dignity and how it can assist one in considering how to respect the dignity of the elderly. He does this by writing in depth about five different notions of dignity that have been written about in the philosophical and bioethical literature. Three notions he writes about are worth exploring here, when thinking about how to properly uphold the aging or dying individual's dignity. They are: *Menschenwürde* (translated from German to mean: Inherent Human Worth), the Dignity of Merit, and the Dignity of Identity.

Many philosophers would agree with what Nordenfelt writes about *Menschenwürde*. It is deeply related to what Kantians have said about Kant's notion of dignity. *Menschenwürde* is the type of dignity that is inherent. It is something that everyone possesses because they are human. It cannot be taken away and binds others to respect humans relating to their rights (Nordenfelt 2004, 78-79). *Menschenwürde* closely mirrors the way in which Kant thinks about dignity except instead of being irreplaceable and justified through the human's capacity for reason and autonomy, contemporary philosophers see *Menschenwürde* as something is grounded in personhood. It is in personhood that all humans are afforded rights (Nordenfelt 2003, 103). The notion of dignity as *Menschenwürde* is seen in modern policy. The Universal Declaration of Human Rights, first approved and promoted by the General Meeting of the United Nations in 1948 begins with these words:

“All human beings are born free, equal in dignity and human rights. They are endowed with reason and conscience and should act towards one another in the spirit of brotherhood.”

Later in the document, in article 25, the Declaration goes on to state that:

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family... and the right to security in the event of... old age or other lack of livelihood in circumstances beyond his control.”

All of this ties back into the philosophical notion of *Menschenwürde*. Yet, there is much debate about *Menschenwürde* itself and how it should be interpreted. Nordenfelt writes that critics claim that *Menschenwürde* should be tied to something more limited outside of being human (Nordenfelt 2003, 104). Nordenfelt does not elaborate on this point and I believe that he is merely mentioning the history of dignity before discussing other notions of dignity. However, several important points need to be made about the ideal set forth by *Menschenwürde*.

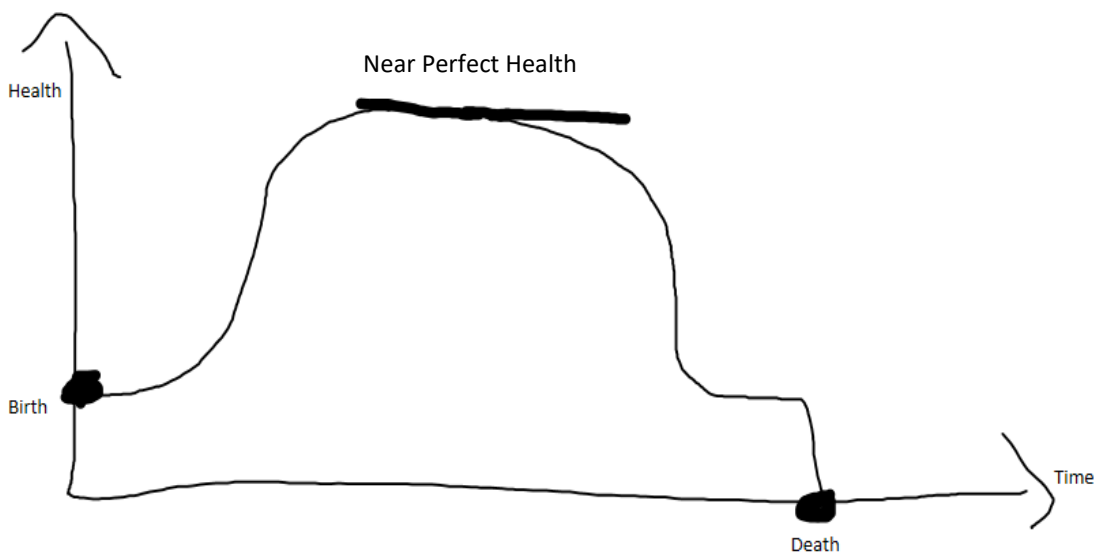
In *Menschenwürde*, people are seen as having the same value with equal rights. This is something which is constantly addressed within the nursing home. Objective interventions and care plans are created to ensure that the resident is well-fed, physically treated well and feels secure. Because of this, nurses and aides attempt to treat residents according to this standard, making the fulfillment of the residents' rights second nature to them. Therefore, using the notion of *Menschenwürde* to determine how nurses and aides can better care for their patients would fail because it already does a good job at protecting the resident's autonomy and their right to proper care. Though *Menschenwürde* assists the nurse in providing for the resident's basic needs while respecting the resident's basic autonomy, something more needs to be added to their practice of care which addresses the resident's social and mental needs.

This moves us to look at the dignity of merit. Nordenfelt writes that the dignity of merit is the oldest notion of dignity. It was first used in its Latin context to refer to a distinction that gave a particular person in the Roman culture a high rank within the government or society (Nordenfelt et al. 2009, 31). Today, the dignity of merit is still used in the same way the Romans used it. A person gains prestige and dignity as they do more and more in terms of their career, education or often times, merely aging. Gaining merit dignity means that the person deserves or is granted a certain form of respect. Most are treated with some form of reverence. A good example of the reverence merit dignity can afford people resides in a commonly used phrase parents tell their children as they are in the car on their way to visit their grandparents. It was one that I heard time and again by my own parents as a young girl, “Respect your elders.” Examples of what this respect afforded to elders consists in actions including: responding politely when addressed, or saying please and thank you when asking for or receiving something. In my case, it meant not asking to watch television and not shifting around in your seat too much as it sent the message that you were impatient to leave.

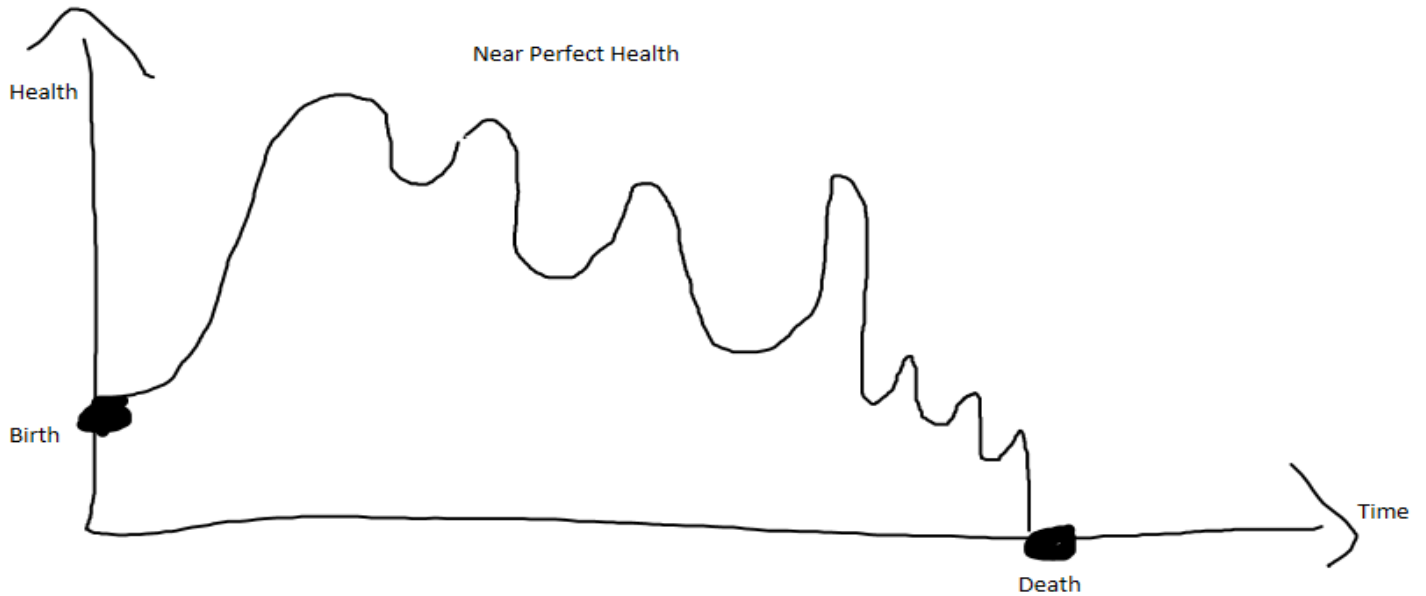
One interesting difference between merit dignity and *Menschenwürde* is that *Menschenwürde* is a value that ought never to be taken away. It is something that a human possesses merely for being human. Other humans ought to treat the human with enough respect to assist in providing for their basic needs of survival. This is not the case for merit dignity. As an individual progresses through life, they gain and lose merit dignity to differing degrees. For example, using the perspective of health: a child is born and grows into a healthy Olympic athlete. She gains a lot of merit dignity which leads to gaining respect for being at the height of her physical ability. This means that, for the most part, she is at the peak of physical health. This health remains towards the top as the athlete ages, making her what has been dubbed by

admiring gerontologists and health care professionals alike as “a super-ager.” She cannot be beat. The Olympic athlete has optimum health. Then the process of aging begins to take its toll. The athlete loses her balance, becomes hard of hearing and goes blind in one eye due to a faulty cataract surgery.

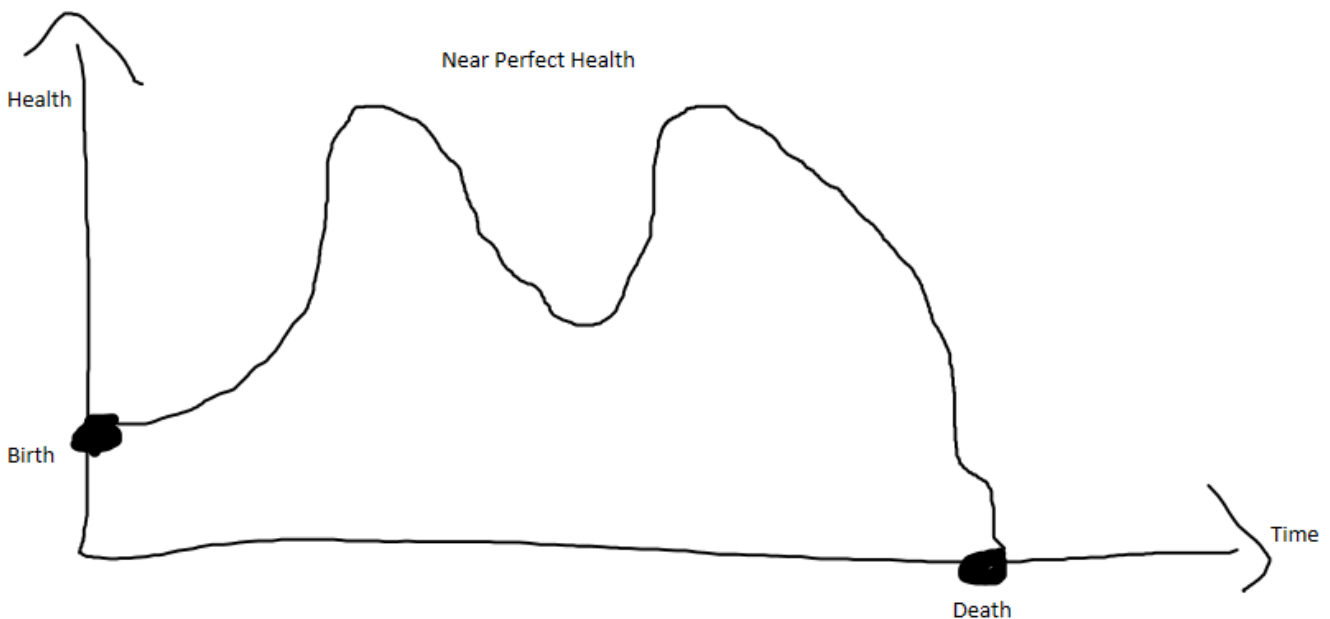
One day, she realizes that she’s too weak to cook for herself properly or walk without the assistance of a cane. Suddenly, this athlete who was once considered one of the healthiest people on earth is trying to figure out what happened or what caused her health to slide downhill. Sitting in a nursing home, she may feel all but forgotten. People no longer respect and idolize her in large numbers the way they used to when she was a star athlete at the top of her game. This is just one example of how a person, throughout their life time can gain merit dignity in health and lose it. To help envision how the dignity of merit pertaining to health would look over the lifespan of an individual of this sort, here is a graph that a medical doctor and gerontologist, Dr. Atul Gawande, drew to include in his book about the aging and dying process (Gawande 2014, 28-32):



There are countless other paths towards death an individual could take within their life time. Think of someone who develops a chronic illness early in life. Their dignity of merit related to health is a gradual period of ups and downs; gaining them respect sometime and losing it during times within their illness where they are not in what others perceive as perfect health:



Another example would be a cancer survivor. Most survivors were healthy or felt healthy until their diagnosis. Then, for a year to maybe even fifteen years, they underwent treatment that made them feel very ill with the assurance and promise that it would extend their life.



In short, the dignity of merit can be gained and lost all throughout a person's life. It is a notion that is very applicable to the health care process as the nurse can recognize past merits to show respect for the patient. Despite its usefulness in helping the long-term care nurse provide better authentic care to their dying patients, it is not significant enough to build a better model of care out of. What can help the dignity of merit become part of a model of care is the last notion of dignity which Nordenfelt writes about. This final notion of dignity can be used to help improve the care process in significant ways and is known as dignity of identity.

Like merit dignity, the dignity of identity is dynamic. It can be built up over a lifetime but also can be shattered quickly. The dignity of identity is the process of building a lens by which the individual sees themselves and others. It shapes how well they know themselves and can articulate their needs to others. In order to communicate their needs and address the needs of others well, one must build into their self-knowledge respect for the self (Nordenfelt et al. 2009, 33). This self-respect is developed as the individual grows and matures both socially and emotionally (Nussbaum 2001, 32). The process of building the self closely mirrors that of gaining merit dignity. Over time, the individual builds up and claims certain traits about their lives as their own. For example, one could say that they are a parent who is gay and values hard work. Their behavior will mirror this, especially in how they relate to others. However, unlike merit dignity, the dignity of identity can be shattered by others in a single sentence.

Going back to the gay parent who values hard work, they enter a skilled nursing facility and tell the nurse's aide who they are. The aide scoffs in their face and remarks, "Gay people can't be parents! Kids need a mother and a father." This remark may seem extreme to some. However, it can inflict lasting damage on the individual's emotional and social well-being. This harm hinders how well the elderly gay parent will communicate with the aide after hearing her

views on gay parenting. This will directly affect how well the elderly gay parent is cared for and their overall quality of life in the nursing home.

A direct distinction between the dignity of merit and the dignity of identity is time. The dignity of merit is something one gains and losses throughout life. By the time an individual enters into a long-term care facility, all of the merit they have gained in their life relates to their past. Resident A was a steel welder. Resident G fought in the Vietnam war as a soldier in the army. These labels create in the resident's mind a certain expectation as to how they ought to be treated regarding these merits, some of which have been integrated into the resident's identity. For example, a professor at my college, who is now deceased, grew up in a poor community and was the only person in her family to get a college degree. This was a major point of pride to her as she not only went to college but attained her PhD. Having a PhD was so important to who she was and how she saw herself that even as she moved into a long-term care facility, she insisted that everyone call her Dr. Rose. Even close to death, this was an important merit translated into her identity which, when recognized by the nursing staff, assisted her in being able to properly receive the care given by them.

By contrast, the dignity of identity is timeless. The dignity of identity accounts for the resident's past, present and future by creating overarching themes in the resident's life which they lay claim to as their own. The dignity of identity is unique to each individual, leading them to treating others and expecting others to treat them in specific ways. Even after death, the resident's identity lives on through the stories carried by friends and loved ones which displays traits of who they were. In the case of Dr. Rose, Dr. Rose made her educational experience into a facet of her identity; thus, making it timeless. Many still remember her by as Dr. Rose and how proud she was that she had been educated. Dr. Rose would cease to be Dr. Rose in her mind and

the minds of others had she not been called by this name. Her name recognized not only her merit but also her identity. Without this aspect of her identity being respected, Dr. Rose would have been left to communicate with the world as someone else, hindering her ability to communicate her needs to others.

The process of creating and respecting the dignity of identity is a complex process similar to that of creating a magnificent painting or writing a novel. In creating the portrait of our unique lives which reflects our specific identity and demands others to respect it, we begin by choosing our color pallet and our paint brushes. In choosing and differentiating what parts of ourselves we claim as our core self and what we pin on the outside world, it is assumed that we have a measure of power. Therefore, at the start of the process of knowing our self, we have to have some sense of autonomy to choose what colors and to put certain brush strokes where we deem best (Nordenfelt et al. 2009, 34). Yet, this process of painting a portrait or coming to know the self is completed relationally and socially. Friends and families help tell us what looks good on the canvas and maybe even teaches us a few specific brush strokes. Society and the culture around us provides us with the colors we'll use, deeming some beautiful and others ugly.

In addition to autonomy, we must have a canvas on which to paint ourselves. This canvas is time. In time, we find that we have a history and a future ahead of us. We use the previous strokes we and others have laid down in our past to determine where we will place the next strokes of paint in our self-portrait. With time, we and those who we encounter step back and look at the portrait in its totality, providing feedback. This is where the heart of the dignity of identity lies. By receiving affirmations from others about who we are, we are able to see ourselves in a positive light. In looking at the whole portrait, we have confirmed for ourselves that we are a person of value worthy of receiving and giving care. We are worthy of respect and

proper treatment. We see ourselves worthy of being in relationships and surrounding ourselves in an environment that is caring. Out of a positive self-image and self-respect, we are more likely to seek medical care when our health declines because we feel worthy of receiving that care. In turn, our worthiness for our own self-care allows us to give care to others and to treat them well. A positive sense of self allows one to notice and use their sense of rationality and autonomy to care for their own dignity and the dignity of others with ease.

The opposite is true when we encounter others who deny our self-understanding or who speak of and to us in a self-deprecating way. This can come from being belittled or humiliated to simply ignored or not heard. These failures of recognition cause one to lose their sense of self-worth and self-respect. What results is an individual who is unable to maintain a positive sense of self and who may cope with negative thoughts of self-worth in ways that damage them and their bodies. Yet, due to the relational side of our humanity, this damage stretches far beyond the person who holds a negative sense of self. When one becomes unable to see themselves as worthy, they subconsciously communicate this message to others they relate to which can damage overall relationships.

One harm that occurs with the loss of dignity in one's identity was noted by Hilde Lindemann-Nelson in her book *Damaged Identities: Narrative Repair*. She explains how the negative conceptions of the individual being communicated implicitly and explicitly by those in power can damage that person's sense of self. This can lead to pain and an inability to view oneself as a person with moral worth, autonomy and reason (Lindemann Nelson 2001, 107). In the sense of the dignity of identity, having fundamental parts of the self ignored or put down by others eventually disempowers the individual. They begin to feel as if they are doing something wrong which contributes to the other treating them in a devaluing way. Eventually, the person

may blame themselves and begin to self-hate. In the cycle of self-hate, the individual may feel that it is not in their power or self-confidence to choose right from wrong. These choices are left for those in power. Thus, the individual's sense of autonomy and moral worth may be lost as well as their faith in reason.

Let's apply this to the context of long-term care and the relationship between the nurse and the dying, elderly resident. Most long-term care facilities are underfunded and understaffed. This means that the nurse is expected to care for a large number of patients for long periods of time with minimal help. The same occurs for the nurse's aide who is assigned to the same unit. Due to the overwhelming load of residents who have a high need for care, many nurses and aides are exposed to high levels of stress. This can lead to care burn-out, a phenomenon in nursing where the nurse begins to depersonalize her patients in order to fulfill all the necessary care tasks of each resident in a timely manner (Pereira, Fonseca, and Carvalho 2011).

This is where Kantian ethics can lend a hand. Suddenly, the long-term care nurse has stopped seeing her task of care as a means to the end (her resident). Instead, the nurse uses her resident as a means to an end (of fulfilling her assigned care tasks). This subtle shift usually goes undetected but has negative effects on the resident's sense of self-worth and their sense of dignity in their identity. The patient is left to see and affirm that they are a burden and are useless due to these factors: profound alterations in and the loss of their physical and mental capabilities; a shrinking pool of close relationships; and being treated as an object by those who care for them on intimate levels.

In my research, I often listened to residents whose sense of self-worth was damaged due to harmful comments and interactions inflicted on them by their family or the nursing staff. These interactions were subtle and reflected how each resident coped with the dramatic change

of moving into long-term care. Because these interactions were small, they seemed similar to microaggressions: small covert interactions which are meant to belittle or offend a person's sense of self. Except, in these instances, these subtle interactions were more like micro-harms to one's dignity of identity (Cronican 2016). For example, one resident I interviewed often during my research, Mike, believed he was a burden to the nursing staff and his family. Seeing himself in this light did not occur individually, it happened relationally. As he lost the ability to care for himself, his children immediately moved him into a long-term care facility, saying that they were unable to care for them. Mike didn't feel like he was listened to or respected during this transition.

Eventually, Mike concluded that his children put him in long-term care because they were too busy for him. Once in the nursing home, he found himself confined alone in his room with the exception of meal times or when he pushed his call light for assistance. Because he had no one to interact with most of the day, he decided that even the nursing staff was too busy to care. What resulted was Mike communicating his needs to his family and the nursing staff less and less. It took him two full weeks before mentioning to the nursing staff that he was experiencing chest pains. He only commented on this when the nurse came in one day to ask why he was eating less. The same reaction occurred when he woke up one day to realize that his hearing aids stopped working, even though the batteries had been replaced last night. He didn't feel worthy or respected enough to mention this to the staff until a week later.

The damage inflicted onto the resident's sense of self and dignity of identity in the long-term care facility is what is causing a chronic lack of social and emotional care for these individuals. The profession of nursing was founded on not only caring for the resident's physical needs but their social and emotional needs as well. Because the resident's dignity of identity is

not being respected, the nurse or aide is practicing bad care. The lack of affirming the resident's identity by the failure to build authentic relationships illuminates the vulnerability of the elderly in long-term care facilities and the lack of appropriate care that exists within long-term care facilities. This is particularly true when we consider a resident whose care needs have changed as they approach their death. Within the realm of the dignity of identity and one's end-of-life, dying residents are finishing up their self-portrait. They are adding the last strokes of color to their life before they lay their paint brush down for good. The role of the long-term care nurse and nurse's aide should be to help provide the tools and insight necessary to assist the resident in coming to terms with the changes to their lives and their altered sense of identity. It is in this act of respecting and affirming the patient's dignity of identity that long-term care for the elderly and the dying can be improved. How nurses can go about doing this is what we'll turn to next.

Chapter Three: Identity, Dignity and the Process of Care

So far, we have explored several different notions of dignity: *Menschenwürde*, the dignity of merit and the dignity of identity. Each of these notions helps the nurse or aide to properly care for their residents. Though the least developed notion of the three, *Menschenwürde* leads a nurse to recognize that each of her residents has equal claim to their right to food, clothing, shelter and safety. The ideal of patient rights is often mentioned in one's nursing practice and is regulated using objective medical interventions and care plans. The dignity of merit refers to the resident's past life where they gained respect for certain accomplishments they achieved. Such accomplishments allow the resident to be seen and treated with a measure of respect. This notion of dignity is closely tied in with the notion of the dignity of identity as certain merits, like that of Dr. Rose's PhD, are often incorporated into the resident's sense of self. However, the dignity of merit relates only to a resident's past while the dignity of identity is timeless. The dignity of identity is defined as a dynamic process of building self-respect which one uses to communicate their needs and be in relationship with others. This directly relates to long-term care as micro-harms to a resident's dignity of identity can shatter their sense of self, leaving them unable to communicate their needs either at all or in a timely manner.

In this analysis, we discovered that respecting and sustaining the patient's dignity of identity was the notion of dignity that could improve a nurse's practice of care in the long-term care setting the most. However, due to being overworked, underappreciated and underpaid, it may be hard for the nurse or aide to fully support this notion of dignity. These factors may lead the nurse to interact with the resident using micro-harms which communicates their lack of respect and support for the resident's dignity of identity. In this chapter, let's take a closer look at

the evolution of care in ethics and how it is used to inform the judgements of care a nurse uses when dealing with a dying, elderly resident. From there, we can extrapolate four aims of care - caring for the resident's bodily needs; caring for the resident's security needs; respecting the resident's dignity of identity; and affirming the resident's shifting sense of autonomy - which is important to improve care for the dying, elderly individual in a long-term care facility.

Understanding that the first two aims of care are fulfilled in nearly all long-term care facilities as it respects the resident's *Menschenwürde* due to patient care plans and nursing assessment, I spend most of my time here writing about how and why these last two aims of care are necessary for a good care practice. Finally, let's see how a broadened sense of the dignity of identity can work to transform common ethical concepts used by nurses to care for residents in order to determine some simple strategies the nurses can utilize to uphold these four aims of care.

3.1 An Introduction to Care Ethics

Because the profession of nursing was created to promote better patient care within the health care field, it seems only natural to begin with a brief overview of how care can be turned into an ethical and professional practice. Nel Noddings and Carol Gilligan were the first philosophers to suggest ethics was more than a measure of justice. They proposed, in their own unique philosophies, that ethics involved caring as well. In her book, *Caring*, Noddings proposes that care can be used to help inform ethical decision making. She makes this point by starting from the ground up by looking at how care exists naturally. For example, when a child cries or someone trips and falls on some ice, most people naturally gravitate towards these people, looking for ways to soothe their hurts or address their needs. In addition to this, everyone has experiences of being cared for by someone else when they were the person who was injured

tripping on ice or being comforted by an adult when they were scared as a child. These two factors of care, which exist naturally, are what Noddings uses to help build a theoretical ethic of care. Our experiences of care and our unconscious tendency to gravitate towards caring for others in need help us to go from determining if “I should care” to “I must care” (Noddings 1984, 7).

In order for us to make the proper ethical judgement to care or even determine when and how to care, we must figure out a practice of care which can guide us in making such ethical decisions. Shortly after Noddings wrote about using care for ethical decision making, Sara Ruddick published her book on how maternal thinking can be made into a practice that promotes and supports a peace politics. The philosophical work that she does to determine how to make maternal caring into an ethical practice is useful in determining how care can be professionalized and turned into an ethical platform that can assist in guiding long-term care nurses and aides when making proper caring decisions for their residents. In Ruddick’s writings, caring acts constitute a practice when these acts are informed and consistent with a goal or aim that guides or justifies that particular act of care (Ruddick 1989, 15).

To better guide the nurse in providing proper care for their dying, elderly residents, several more factors are necessary to create an environment where the nurse is able to provide good, authentic care to her patients. One factor comes from literature written by feminist philosophers, such as Kari Waerness and Clare Ungerson, in the 1980’s. Along with the philosophical concepts presented by Ruddick and Noddings on creating a practice of care, these philosophers began to talk about two sides of care that would one day be described as a community of care (Ungerson 1987, 23, Waerness 1987, 133-134). In community care, the practice of care is not unidirectional as Nodding speaks of care. Rather, community care is bidirectional

in that a nurse or aide gives care and receives care from the resident (Abel et al. 2009, 4). In the model of community care, it was noted that the care is more than just an ethical practice; it can also be considered a process that takes place between two beings who have the ability to act in morally caring ways towards one another. In order for the caregiver to give proper care, they must care for and about the other being while also having their own care needs fulfilled (Ungerson 1983, Engster 2007, 25). In other words, the practice of care has a measure of reciprocity to it. In order for the caregiver to give care to another, they must first feel cared for and receive care by others.

With this framework of how to form a reciprocating practice of care, let us create a model of care that long-term care nurses ought to use as the best caring practice for their dying, elderly residents. To create a good practice of care, one must begin by recognizing its goals. Spending so much space writing about dignity and its use in improving care, it would seem natural to set respecting the patient's dignity of identity as the first, primary aim of the nurse's end of life care they provide to the resident. From there, I would propose an additional goal that can be set towards this care practice: affirming the patient's shifting sense of autonomy. However, this second goal I only mention tentatively as I can see it becoming absorbed into the first with further research. In addition to these, caring for the resident's bodily and security needs are also necessary for a good care practice. As mentioned before, these last two aims of care are practiced by all long-term care nurses through respecting a resident's *Menschenwürde* and is measured in written care plans and nursing interventions. Therefore, my primary focus will be on the first two aims of care: respecting the dignity of identity and affirming the patient's shifting sense of autonomy.

Out of these first two goals of care for the dying, elderly resident, the process of determining strategies to achieve these aims can begin. Although I will turn to several strategies that were taught to me by the participants in my study and my philosophical research, I understand that the process of dying is complex. As one nurse shared with me during a conversation, “I never use the exact same strategy for my patients. How I care for them shifts as I recognize a shift in them” (Cronican 2016). Because of this unique process, the strategies I cover below could be interpreted as specific strategies in upholding the overarching goals of care for dying, elderly residents. However, I would suggest that these strategies become tools for the nurse and nurse’s aide in determining what actions of care are proper for their specific resident who is approaching death. The intent of these tools are to encourage better relationships between the nurse or aide and the dying, aging resident. It is in this deepened, authentic relationship that I think care for the dying can be improved.

3.2 A Shifting Sense of Autonomy in Individuals Nearing Death

Anne Donchin and other feminist philosophers who have written on the use of relational autonomy in health care typically focus on relational autonomy with regard to relationships alone and their usefulness in helping one make decisions (Baier 1981, Nedelsky 1989, MacKenzie and Stoljar 2000 , Christman 2004). This works within the realm of care ethics well. However, when thinking about health care, I think the concept of relational autonomy needs to be widened to encompass other factors that also feed into a resident’s decision making process and inform how the nurse or aide views and relates to the resident. Such factors are known as social determinants and are discussed in Paul Farmer’s introduction to his book, *Reimagining Global Health: An Introduction*. Farmer and his peers write about how societal structures influence the individual’s

understanding of health care. This understanding informs the individual's illness experience and shapes the decisions the individual makes with regard to those they relate to (Farmer et al. 2013, 8).

The term "social determinant" is commonly used in anthropology to talk about the different factors that create the cultural context which surrounds a specific individual and informs their experience. These factors are numerous: one's status within realms of religion, socioeconomic status, education, sex, and gender are just a few of them (Mikkonen and Raphael 2010, 7). Many medical anthropologists find that health is an experience partly informed by the way culture and one's social position have shaped the individual and their understanding. Thus, what is deemed healthy by white Americans may be seen as unhealthy to Americans of color or Eastern European immigrants. Because of this, when thinking about the resident's autonomy in long-term care, the nurse or aide should take the time to learn about the resident's cultural background and their self-defining relationships with others. This will help them in understanding how the resident makes and communicates decisions related to their overall health and their daily choices which feed into the resident's sense of health. Understanding the social and relational factors which surround the resident and their understanding of health is not meant to minimize the importance of the medical knowledge the nurse and aide know. Instead, this broadened sense of cultural and relational understanding about the resident can assist the nurse or aide in communicating medical concerns with the resident and properly educating the resident about certain medical interventions the resident may have the option of receiving.

One major social determinant that plays into how well the elderly and dying are cared for is the negative stigma American culture holds against the aging and those with weakening mental faculties (Levy et al. 2002, Link, Mirotznik, and Cullen 1991). In my research study, this stigma had

a profound effect on the mental and social well-being of aging residents as well as the pride the nursing staff took in their practice of care. Because the elderly are part of the marginalized in society, the value of caring for and relating to the elderly is overlooked by the majority. Instead, the majority focuses on the financial burden aging and dying has on their families or institutional welfare programs. The fact that many are diagnosed with chronic conditions or not worth caring for at all is perpetuated through the mass media, which perpetuates stereotypes of the elderly. The result of such stereotypes is sometimes hate crime. Hate crimes against the elderly, women especially, are popularized via news sources and Facebook posts with hardly any protective measures and laws being created (2017). Therefore, the elderly resident may already have thoughts and doubts of their usefulness in general. This alters the way in which they make decisions pertaining to their health and overall well-being (Lindemann 2001, 23). Often, decisions are made with another person in mind, like a relative or the nursing staff themselves. I have sat in on doctor's appointments where a new medication was to be prescribed just to hear the patient respond, "I don't know. Will the girls (nurses) be put through too much trouble with this new medication" (Cronican 2016).

Additionally, this stigma against the elderly's usefulness to society leaves the nurse or aide in long-term care to be underappreciated and underpaid for the important and valuable work they do. Since the greater society and other health care practitioners often do not see the hard work long-term care nurses and aides accomplish, the overall prestige and merit credited to the long-term care nurse by others in the nursing field is quite low. Therefore, we can add underappreciation to the list of challenges long-term care nurses and aides have to overcome in order to even begin thinking of ways in which to fulfill the two aims of care for dying, elderly residents. This challenge sheds light on the unique constraints of the caregiver's autonomy in the

long-term care nursing practice. Being too worried about their own self-preservation and need for care, nurses become emptied or slowly burn out and are left unable to see the care needs of their patients.

Out of this example of the greater society's impact on long-term care and the views of the elderly, it can be seen that autonomy is not just relational or individualistic. Rather, the definition of autonomy ought to be broadened in ways that gives all individuals some decision-making power relating to their health and well-being. No matter the age or mental capacity, people still have the ability to make choices relating to themselves set within a specific cultural context, informed by their relations and their personal values. Such choices that are made with reference to the self have moral worth. I choose to eat lunch to keep the processes in my body working so that I may continue my research. Eating in order to maintain my physical strength also allows me to remain in relationship with my younger sister, with whom aspects of my identity are closely related. These relationships help to inform me on how to act within my world in ways which promote good care for all people. This good is produced and rendered in part because I chose to eat today; thus, making the choice to eat a decision with moral and relational implications.

In the realm of long-term care, no matter the mental ability or the age of the resident, they still have the ability to make a choice pertaining to their life in some way. Whether that be something as big as refusing treatment, to merely choosing what they would like to eat, to communicating that the way in which they are being transferred is leading to physical pain, the ability to choose and to verbally or non-verbally communicate that choice is always there. The moral obligation to recognize this choice and honor it resides in those who surround the resident and who provide that resident with care. Even if the patient suffers from Alzheimer's Disease or dementia, they still have the ability to make some form of choice, such as choosing to sleep or

clutch onto a little baby. In order to have a good care practice in long-term care, a resident's sense of dignity in identity should be fulfilled by the nurse making the choice to honor the resident's wishes. This new interpretation of autonomy allows the elderly, dying patient to express their right to making a decision related to their bodies and their care.

Although I think this concept deserves more research before being considered an ethical concept or theory on its own, I will propose a tentative name for it just to ensure clarity when I refer to this notion of autonomy later on in this article: the shifting sense of autonomy. This form of autonomy requires that the individual is seen as an agent worthy of making decisions based off of their sense of identity, cultural understandings and relational background. The shifting sense of autonomy allows the nurse or aide to meet the resident where they are at with regards to the resident's physical or mental ability while morally tying the nurse or aide to affirming the resident's power to make some form of choice related to that resident's specific well-being. Within this affirmation and respect of the patient's wishes, the nurse or aide is recognizing the resident's dignity of identity and helping to positively build on it by giving the resident the right to self-determine on at least a rudimentary level.

I did not create the concept of the shifting sense of autonomy on my own. My thoughts on how autonomy needs to be altered to help fulfill two of the four goals of care for dying, elderly long-term care residents - respecting the resident's dignity of identity and affirming the resident's shifting sense of autonomy - came from my conversations with my participants and through the works of Eva Feder Kittay (Cronican 2016, Kittay 1999, Kittay and Feder 2002).

3.3 Vulnerability

The need to be more attentive to a patient's cultural values and values of their identity in order to recognize the resident's shifting sense of autonomy should not be the only area a nurse or aide focuses on when determining how to care for their residents. Special attention needs to be given to the reality that, in the face of physical and social loss along with the attendant emotional distress, residents are rendered vulnerable to harms by those who hold primary power in their immediate environment. The status of higher power falls on the nurses and aides, even if they themselves do not recognize this. Many nurses or aides would point to doctors and family members as having the most power over their residents. Although this may be true with regard to the major decisions a resident makes pertaining to their overall health, the everyday tasks which constitute the way in which the elderly see and experience their identity rests within the power of the nurse or the nurse's aide. In other words, choices such as deciding whether to eat what they want or what is healthy for them, to take a bath, use the restroom, when to have meals, when and how to walk and many other small tasks that come before the resident in their day to day life are suddenly taken from their control and given to someone who is supposed to assist them with these tasks in a loving and caring way.

Yet, due to the caretaker being overworked, underpaid and underappreciated, he begins to treat the resident as a means to the end of fulfilling the long list of tasks required of him. By caring in a way that is unethical, micro-harms to the resident's dignity of identity begin to accumulate, which can shatter the resident's identity. For example, imagine a scenario where the caregiver is too stressed or burned out, leaving them unable to see the resident as a human being worthy of authentic care and love. Suddenly, the choice the resident was led to believe they had between eating an ice cream cone or mashed peas is ripped from them by someone in power who

is too stressed to hear and honor the resident's choice. To make matters worse, the harm within the refusal of the right to make such a simple choice about food is worsened when the resident is in a way force fed by the powerful caretaker who offers those unwanted peas to the resident spoonful by spoonful with vacant eyes and silence or words of coercion meant to convince the aging and dying resident that they have to eat those peas. The resident is told by this powerful person that their refusal to eat those mashed, tasteless peas is just inconveniencing the person further by wasting their time when they could be caring for someone elsewhere.

In all, this inflicted micro-harm introduces an idea into the mind of the resident that the care they are receiving from the nurse is something that needs to be earned. Slowly, with reinforced experiences such as these, the idea that the resident is not worthy of the nurse's care or is a bother even to the people the resident and their family is paying hard earned money to. What eventually results is a human robbed of their sense of self-worth, and eventually the resident is left having no self-respect at all, let alone the will to live or to face the adversity of dwindling mental or physical ability in ways that guides their hands toward creating the final strokes of their life's painting that are strong and display value, self-worth or peace.

This brief example is one that powerfully displays how nurses and aides in many long-term care facilities fail to uphold the last two aims of care: respecting the resident's dignity of identity and affirming the resident's shifting sense of autonomy. Thus, the nurse or aide is failing to practice good care which creates real moral harm to the resident being cared for. The example given was not an imagined occurrence. It was a lived experience that I myself had as a young, overwhelmed nurse's aide in a long-term care facility that cared for a high patient load with a small staff. I was the one who inflicted harm on a dying individual by forcing them to eat bad smelling food when, in actuality, that resident needed someone there to hold their hand as they

prepared their mind and spirit for the death that would come three days after I expressed my anger and used my subtle words of coercion to get them to eat food that I was taught was ‘healthy’ and would prolong their life. It was then that I realized a dying resident’s focus slowly transforms. What is most important to them in these times is not that they’re eating the right food or taking proper medications to continue to lengthen their life. At some point, within themselves, they made a choice that it was time to stop focusing on the quantity of their life but focus on the quality of it. They made the choice and have the luxury to prepare for their death.

During my time as a volunteer in Hospice and through my research of the hospice care model, focusing on the quality of one’s remaining days is a value that is held very dear and written on by philosophers and nurses alike (Himmel, S., and Smith 2013). Even with their diminishing sense of autonomy, residents still have the ability to make the choice to prepare for death and let go in ways which are expressions of themselves, such as choosing to treat themselves every night with an ice cream for dinner and not eating pureed, tasteless carrots. Nurses and aides should be able to see and honor these final choices the resident is making. However, most in long-term care aren’t trained in seeing the signs of this or are too stressed to notice these signs. Unless some major medical change occurs in which the resident is put on hospice while remaining in a long-term care facility, most end up dying in their rooms alone or with a curtain drawn to separate them from their roommates, without loving support, proper care and affirmation. Dying alone feeling useless and undervalued are common concerns for dying individuals as no one wishes to die alone thinking or feeling this way. In fact, it has been reported in a 2013 study that companionship and comfort are two major needs many dying patients long for (Oosterveld-Vlug et al. 2013).

This is why knowing about vulnerability and the heightened power a nurse or aide holds over their resident within their care practice is important. With this heightened sense of awareness and understanding, the nurse or aide will be able to use their power in ways that display good authentic care towards their aging and dying residents and properly fulfill the four aims of care for long-term, dying residents which are caring for the resident's bodily needs; caring for the resident's security needs; respecting the resident's dignity of identity; and affirming the resident's shifting sense of autonomy. In the book, *Vulnerability: New Essays in Ethics and Feminist Philosophy*, Rosemarie Tong writes a wonderful article covering the different vulnerabilities the elderly and their caretakers in America face and makes suggestions regarding how these vulnerabilities can be protected. In a line, she shares a common truth about humanity that when read through a compassionate lens can help the nurse or aide begin to see their patients in a new light. This new light will help them to make caring decisions that can help to uphold the two latter aims of care for dying, elderly residents. Tong writes, "... we human beings are all subject to decay, disintegrations, disorder, and death, and our only real recourse is to hang onto each other" (Tong 2014, 289). In other words, relationships matter. The relationship a nurse holds with her resident matters as it is foundational in respecting the resident's dignity of identity while recognizing their shifting sense of autonomy. Therefore, we need to find tools and strategies the nurse can use to promote a sustaining relationship which can help drive care and uphold the two aims of care listed here.

3.4 Strategies to Promote the Aims of Long-Term Care for Elderly and Dying Residents

We have already determined that the long-term care nurse or aide is stretched quite thin. Asking them to make dramatic changes in the way they provide care to their patients in addition

to the normal number of assessments they have to administer in their practice would be akin to asking a three-year-old to run a half marathon. In other words, the likelihood of any real change occurring will reside within minute changes rather than proposing big ones. The good news for nurses and aides is that most of the small alterations in the way they provide care in order to reach all four aims have already been taught to them through work experience or in their schooling. Many nurse educators encourage traits such as listening, respect for the individual and compassionate honesty to be used by their students in their eventual practice. These traits become solidified as the nurse or aide gathers experience through the jobs they hold.

In nursing schools, educators mention these broad skills rather briefly. No in depth instruction is provided to the student on when and how to listen or where to be honest and in what ways patients deserve the nurse's respect versus when patients need to be giving respect. I believe that the intention for this is both unconscious and serves a purpose. How a nurse listens, responds and shows respect to their patient is largely dependent on how the nurse develops as a professional within nursing practice. When thinking about long-term care, there are specific ways in which the nurse can use these three skills properly to assist them in determining how to properly care for a specific resident. These skills were the three most common skills nurses mentioned to me when asked about what helps them practice good care in my research (Cronican 2016).

Listening, respect for the individual and compassionate honesty. These three values seem to be simple enough. When thinking about how to care for the dying or aging resident, these three values seem to go hand in hand. Together, they create the foundation a long-term care nurse or aide needs in order to determine their actions of care towards a resident. Without the trait of listening, the nurse will be unable to find, honor or respect the resident's shifting sense of

autonomy. This deafens the nurse's ability to hear the resident's self mandated care needs. In addition, the nurse will be unable to see how the resident's cultural understanding of health and the relationships which surround the resident aid in the resident's responsiveness or assent to treatments.

A common argument from long-term care nurses is they do listen to the resident all the time. They hear the resident's complaint of aches and pains, worries and confusions. However, based off of my experience as a nurse's aide myself in addition to the interactions I observed between long-term care nurses and residents, the nurse is taught to listen by her profession to try and fit the resident's experience into a monolithic experience of health. This is taught by using the "compassionate listening" ideal in many nursing schools. A nurse hears what the patient is complaining about and translates it into objectifiable codes which can be used in nursing interventions which suggest the same treatment for all patients. Since it has been previously argued that the resident's understanding of health is culturally formed and informed through relationships outside the nurse-resident relationship, the nurse is failing to provide good individualized care.

Sometimes medical interventions are not needed to help address the concern, worry or distress of a dying patient. Instead hand holding, ice creams, cups of hot cocoa, warm blankets or a back rub are the proper cure. When and how to use these 'interventions' depend upon the relationship the nurse establishes with the resident. It should not need to be mandated through objectified medical interventions. Therefore, the nurse should stop listening and looking solely for words or non-verbal expressions which fit a resident into a specific medical intervention category that can be objectified in paperwork. Rather, more attention should be given to the resident's cultural background, their relationships and their understanding of health care.

Likewise, a nurse must respect the individual. At times, it can be hard to offer respect and guidance to a resident who is, for example, physically combative or belligerent and refuses to take medications due to paranoia. It is in these cases that a nurse may develop a prejudice towards this specific resident and may begin discriminating against the resident by refusing to care for them as well as the nurse cares for others. It is in these situations where the nurse should hold back from doing this as these residents are especially vulnerable to harm such as neglect and even physical abuse. Instead, the nurse needs ensuring that the resident is not a harm to themselves or others. The nurse should give the resident time to calm down and assistance with medication if need be. She ought to treat this individual with extra respect and compassion by recognizing that the resident is facing many confusing, complex changes to their physical, mental and social self. Once the resident is calm, the nurse should continue to practice caring well towards the resident by affirming that the resident is still loved and still valuable regardless of their outbursts or violent actions. In doing this, the nurse is respecting the individual rather than viewing the resident as an individual who ought to earn the nurse's respect.

A special note should be added to the nurse respecting the individual. Respect is a relational value. It does not travel one way. Therefore, there may be times in one's practice where a resident does not deserve the nurse's respect or relational care due to the resident's repeated abuses towards her. In other words, the resident is also morally tied to respect the nurse as an individual within the relationship of care the two hold with each other. However, this moral obligation may weaken overtime as the resident's mental or emotional capacity is altered via persisting illness or fluctuating confusion. Should this happen, the nurse needs to turn towards good self-care measures which are elaborated in chapter four. For now, know that respecting the

individual allows the nurse to listen and give care in authentic ways which help to uphold the patient's shifting sense of autonomy and their dignity of identity.

Compassionate honesty also helps to promote the resident's dignity of identity. Unlike the normal notion of honesty which binds the individual to release any and all pertinent information without regard to the individual's well-being, compassionate honesty does just this. For example, one of the residents living in the hall I conducted research at had developing Alzheimer's disease. She no longer remembered the death of her husband. Instead, every time a certain aide worked with her, she grew convinced that he was her husband and demanded that he sit down and chat with her for a while. Normal honesty and its moral connotations would require that the aide inform the resident that her husband was dead and that he was someone else. However, doing this would inflict trauma onto the resident. She would experience grief for three to five days after hearing of her husband's death again, refusing treatments and meals. She would experience all over again the feeling of an integral part of her identity being ripped from her in the loss of her husband until three to five days later, she would forget her husband ever died and go back to being her normal cheerful self. In this instance, the aide is being more caring by pretending he is his resident's long lost husband who has come back to visit during the war. In this example, this aide is using compassionate honesty by refusing to disclose to the resident the fact that her husband is dead. This choice is most caring as it keeps the resident content and happy to be alive.

Another example can have the opposite effect on the resident. In a recent visit to my research site, I was catching up with one of the floor nurses about the well-being of my old participants. She sadly informed me that one had taken a turn for the worse and would likely die soon. She informed me that the doctor had not disclosed this information to the resident and that

she didn't feel it was her position to share this information with the resident even though he had been expressing his exhaustion and had inquired several times if he was going to die soon. The nurse reported that the resident was becoming more and more depressed and unresponsive to anti-depressant medications. Still, the nurse refused to disclose the information that the resident's health status had changed for the worse to him, even though in the resident's charts, the doctor had written that the resident only had a short while left to live with a 'grim' prognosis. This is an example where withholding medical information from the patient is not using compassionate honesty. By withholding this pertinent information about the resident's overall health, the nurse is preventing the resident from facing and adjusting to their new health status. This robs the resident of the time necessary to have meaningful conversations with those whom they love most. It also keeps the resident's loved ones from physically and emotionally saying good bye before they pass away. In this case, without the use of compassionate honesty, the nurse fails in creating a good practice of care. Instead, she is letting her preconceived notions of how dying individuals ought to be treated by nurses and doctors prevent her from practicing good care.

With these two examples, it can be inferred that compassionate honesty is highly contextual, calling upon the nurse or aide to disclose information which promotes a resident's positive sense of self and gives the resident a contextual form of power to choose how to mandate their care needs. In the case of the Alzheimer's resident, this power was to interact with a ghost of the past in order to communicate how she liked the care she was receiving and express worries or fears about the future. In the case of the dying participant, the power to handle one's mortality and relate it to others ought to have been given to the resident, not the nurse. Compassionate honesty relies heavily on the nurse's respect for the individual resident and how well they authentically listen to the resident and their experiences.

In all, authentic listening, respecting the individual and compassionate honesty helps the nurse not only to address the resident's bodily and security needs, these three tools help the nurse promote the resident's dignity of identity and their shifting sense of autonomy. By not properly using these three tools, the nurse fails in giving proper care to his resident because the resident's dignity of identity is damaged or they are robbed of their shifting autonomy through neglect, being coerced into eating or taking medications that are not in their best interest or seeing themselves as a burden to all which moves them to self-harm. The reason such harms stem from the nurse's failure to care is that the nurse is the one in power. Ultimately, the nurse has the ability to change the physical or emotional situation the resident dwells in in ways that are productive towards fostering the patient's dignity of identity and their shifting sense of autonomy.

Therefore, the nurse needs to determine how to authentically listen and respect their residents again while being compassionately honest. All three of those traits are marks of a healthy relationship set within the context of care and will help to address the care crisis most long-term care residents face. In order to develop such a deep and profound relationship, though, the nurse needs to learn how to properly relate to the self and perform self-care. If the nurse has a positive self-image, it makes it easier to determine how to better care for their residents. It does not make logical sense to try to care for another's dignity of identity or shifting autonomy when the nurse does not have a sense of their own self-worth and value. Just as it takes a group of others relating to and affirming the dignity of identity and shifting autonomy of the dying resident, so too does this process need to occur for the nurse. The marked difference between the situation of the nurse and the situation of the resident is who provides this care to each of them. We already know who provides acts of care to fulfill the four aims of care for the dying resident.

Let's shift our focus to who cares for the nurse's dignity of identity and shifting autonomy before ending our discussion on dignity in long-term, end of life care.

4. Nursing and Its Challenges

4.1 A Call for Intervention by Nurse Managers and Leaders

In chapter three, we were able to set four aims of care with specific regard to the dying, elderly residents in long-term care: sustaining bodily and security needs, affirming the resident's shifting sense of autonomy and respecting the resident's dignity of identity. To accomplish this the notion of autonomy was broadened to include the individuals cultural understanding of health and the relationships they hold with others. This altered form of autonomy is tentatively called shifting autonomy. In addition, we found that authentic listening, compassionate honesty and respect for the individual can be used to help the nurse determine what the resident's care needs are to uphold the four aims of long-term care for elderly dying residents. Out of this, it was noted that in order for the long-term care nurse to improve end of life care in subtle ways so as to fulfill the four aims of care for their residents, they also need to feel valued and cared for. The practice of care which can do just this is closely tied to the practice of care the nurse uses when caring for their patient. Although, when it comes to fulfilling these four aims of care for the nurse, the difference between the nurse and the resident - aside from physical and mental ability, social networks, and education levels pertaining to health - is who is providing the care. In the case of the resident, it is the nurse. In the case of the nurse, these care task fall on many different groups of people encouraging the nurse to partake is self-filling care to address what is lost in the nurse's self-emptying care practice.

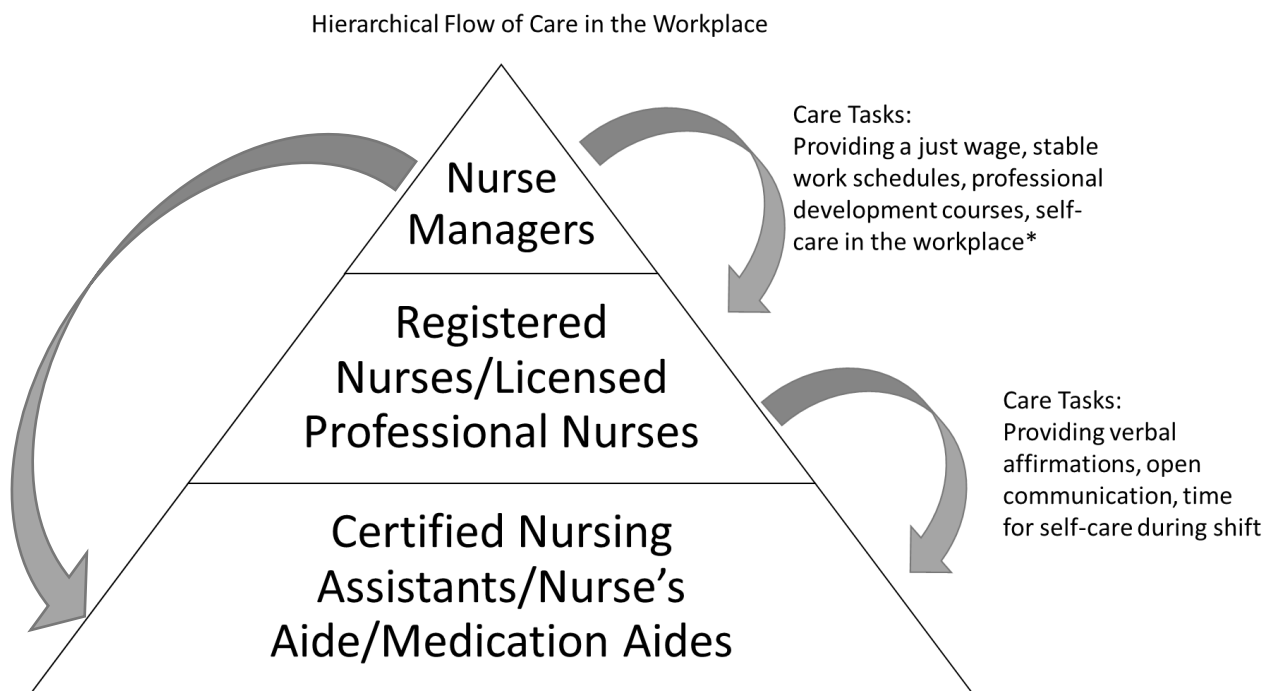
The group I focus my attention on are the nursing management or nurse leaders who run the business side of the long-term care facility or directly manage how nurses care for their

residents. It is commonly accepted by many that the role of a general manager or leader is to market and find new admits to the facility. Should they be running a facility that receives state or federal funding such as Medicaid or Medicare, they also may work to ensure that the facility is being kept up to code which ensures this funding. Other tasks that the manager may do is manage the facility's finances and the payroll of its employees. They may also be involved in the hiring of new employees as well as continuing education for their current employees. Employee evaluations are typically overseen by a manager, director of nursing, or nurse educator as well.

These latter tasks show that the nursing leaders and management have direct ties to their nursing staff. Not only this, such individuals in power have a better understanding of what nurses are experiencing while caring for residents within the facility than any other friend or relative the nurse may have. Ultimately, nurse leaders and managers are the ones responsible for ensuring that the nurses and the residents are well cared for. Because of this, the same four aims - sustaining bodily and security needs, affirming the resident's shifting sense of autonomy and respecting the resident's dignity of identity - found in the long-term care nurse's care practice apply to the management. This specific practice of care morally binds the nursing management and nurse leaders to care for nurses and aides in ways which allows them to properly care for their residents. This includes but is not limited to: a just wage, continued professional development, affirmations which add prestige to the long-term care nurse's position and the promotion and implementation of self-care practices within the work place.

Put more specifically, in long-term care, there exists a hierarchy in the nursing culture, as illustrated below. Each individual in the nursing hierarchy has the ability to fulfill the four aims of long-term nursing care for the individuals below them. The continuance of this chapter will elaborate on a specific way the managers of nurses and aides can do this. However, nurses can

have this impact on the aides who work alongside them which can help the aides provide better, authentic care to their residents. The only difference between the hall with the most amount of resident falls at Caring Acres, one of the long-term care facilities I conducted research in, and the hall with the least amount of falls was how self-care was implemented. In the hall with the least number of falls, a nurse began each shift by leading her aides in stretches. Each aide cared for the same number of residents with similar needs as aides in other hallways. Therefore, implementing self-care was the only distinguishable difference I found between them. This is just one example of how small interactions to communicate the dignity of the aides' identities helped them to partake in a better practice of care towards their residents. The same effect can be created by actions the nursing management implements towards nurses.



*Note: Management are bound to providing these items to CNA's as well

In addition to being morally bound to the nursing staff and the resident's care, the nursing management is also financially bound to those working and living in the long-term care facility.

As the manager of finances, admissions and hiring, the manager is often times the one who is disciplined when a resident is poorly cared for or a nurse is treated unjustly. An underpaid, overworked or underappreciated nurse cannot begin to recognize the ways in which their residents need to be cared for in order to fulfill all four necessary aims of long-term care. This results in a lack of care that can lead to many potential negatives for the facility which could result in a loss of funding or new patients due to poor patient reviews or many documented falls. Additionally, the cost of a high turnover rate is much more than many would think. The hidden cost of orienting a new hire on average falls between \$20,000 and \$60,000 depending on the new hire's credentials, the position and the long-term care setting (Tollefson 2017).

An easy intervention which may support the long-term care nurse in fulfilling the four aims of care - sustaining bodily and security needs, affirming the resident's shifting sense of autonomy and respecting the resident's dignity of identity - is by encouraging and implementing that each nurse and aide take 15-30 minutes each week during their time at work to practice a self-care strategy. By encouraging and partaking in this act of self-care with the nursing staff, the manager communicates to their nursing staff that they are important. Implementing self-care in the work place may also be the starting point for the manager to see their nursing staff in a new light. It may provide them the opportunity to communicate with their nursing staff that the staff has someone who is working hard to provide them with a just wage, job benefits, time in the work place to partake in self-care and the option for professional growth. By using a plan to promote and implement self-care practices in the workplace, the manager can begin to promote a nursing culture that is positive and better equipped to care for their residents in authentic ways.

Most managements also play a vital role in providing continuing education for their nursing staff. To begin the process of promoting and implementing self-care in the work place,

the management can increase a nurse's education by beginning with a training on good self-care practices and how it creates a positive and supportive nursing culture. The manager can do this by bringing in speakers or massage therapists to talk about the importance of self-care; lead a training promoted to teaching about the importance of self-care; offering a subsidized YMCA membership; or offering yoga classes during one's lunch break or after work. The practice and social reinforcement of self-care for nurses is what can be the beginning steps to providing an environment where the nurse is able to create a good practice of care by recognizing and working towards the four aims of care for dying long-term residents.

Certain managers think that their role within a facility is to find new residents while ensuring that care standards are being held up to code in order to receive government aid. Perhaps as the manager, due to financial constraints and a small staff size, one is not able to increase pay or decrease hours. This does not mean a manager is completely unable to further support their nursing staff. Simply taking 15 or even 30 minutes out of their week to work towards ensuring that the nursing staff feels appreciated and cared for can begin creating a nursing culture within the facility which can work to fulfill the two aims of care for dying, elderly residents. In addition to this, having a concrete work schedule that does not often change can help make all the difference when thinking about the nurse's ability to care for themselves. Having a concrete schedule with other nurses who can be on-call when a family emergency arises allows nurses to have a sustaining family and social life outside of work without the added stress of finding someone to cover their shift in the event of illness or an emergency.

It is the mindset of empowering managers to actively seek ways to appreciate and support their nursing staff that I will address through the rest of this chapter. In it, I will discuss the value and importance of good self-care for nurses. Without it, the nurse will begin suffering from burn-

out which can compromise the way in which she cares for her residents. The improper or below par standard of care given by a culture of burnt out nurses and aides can lead to low patient satisfaction and a low admittance rate, a higher fall rate, a higher rate of dispensed narcotics and psychotropic meds or other factors that can put the facility's state and federal funding and their staff retention in jeopardy. With this in mind, let us take a moment to ponder the usefulness of self-care and determine ways in which appreciation for the nursing staff can be communicated which leaves the nurse or aide feeling cared for. It is in this care and properly relating to themselves that the nurse will be able to use the strategies mentioned in chapter three to fulfill all four aims of care. This process all begins with a healthy relationship to the self, brought out through proper self-care practices.

4.2 The Value of Self-Care in Long-term Care Nursing

The concept and reality of nurse burn out has been studied by nursing researchers for quite some time. The term burn out refers to a condition experienced by nurses in which the nurse becomes emotionally exhausted, is moved to depersonalize their resident, or develops feelings of low accomplishment and professional worth due to a variety of stressors (Pereira, Fonseca, and Carvalho 2011). Although I have mentioned several broad stressors which may lead to burn out for long-term care nurses, several specific stressors have been identified in a recent study called "Stress, Social Support, and Burnout Among Long-Term Care Nursing Staff". Researchers of this study used the job-demands resources model to determine stressors associated with burnout. This model considers personal and occupational stressors to be job demands (Demerouti et al. 2001). Within the research study, it was determined that not only do long-term care nurses experience a high level of occupational stress, they also experience a high

level of personal stress. The level of personal stress a long-term care nurse experiences is much higher compared to their counterparts in acute care (Woodhead, Northrop, and Edelstein 2014).

Though the research study does not test the factors which increase personal stress, the known fact that long-term care nurses are underpaid and often underappreciated by their residents and nurses or doctors in acute care may be part of the cause for increased personal stress. In addition, all of the stress identified by this study shows that the job demands of long-term care nurses are much higher than that of other nursing positions, such as being an acute care nurse. With this in mind, nurses ought to be compensated with a just wage for the high demands and stress they are subjected to while working in long-term care. With a just wage comes a just schedule that does not change from week to week but remains the same over the course of the year. Creating a concrete working schedule will help to reduce the amount of personal stress a long-term care nurse experiences by taking away from the strain of attempting to partake in one's social life in addition to accommodating a work schedule that is constantly in flux.

Facing high levels of both occupational and personal stress leads to high rates of nurse burn-out in long term care (Woodhead, Northrop, and Edelstein 2014). Heightened burn out rates correlates with high rates of turnover (Leiter and Maslach 2009). In long-term care, high turnover rates disrupt the continuity of care for residents. This disruption leads to a lower quality of care as the resident is forced to voice their care needs to different nurses with whom they do not have a relationship (Cohen-Mansfield 1997). When looking at this issue through the lens of a resident's ever changing health status, their ability to properly voice their needs may be inadequate enough for the long-term care nurse to make a proper care decision which supports the four aims of care for dying, elderly residents: sustaining bodily and security needs, affirming the resident's shifting sense of autonomy and respecting the resident's dignity of identity. An inauthentic relationship

between the new or constantly changing nurse contributes to bad care practice. One way in which this failure to care properly can be avoided is merely by getting the nurse to practice coping strategies through self-care which allows them to handle stress in positive ways. In turn, good self-care and the work benefits that ought to be afforded to long-term care nurses will allow the nurse to establish a good caring practice and authentically relate to and care for their residents.

The results of promoting self-care as a coping strategy for long-term care nurses and the stress they face has been reported in several studies conducted by researchers Kravits, Shapiro, Brown and Biegel. In these studies, self-care practices substantially lowered burnout and turnover rates (Kravits et al. 2010, Shapiro, Brown, and Biegel 2007). It has also been determined that the frequent use of self-care assists the nurse in coping with work related stress in ways that improves how they care for their residents (Alkema, Linton, and Davies 2008). Compassion exhaustion, depersonalization and the perception of low professional worth associated with burnout are detrimental coping mechanisms for nurses in long-term care as they detract from the nurse's ability to fulfill the four aims of care.

Self-care is defined as a practice which one does to maintain and promote their overall health (Yamashita 1998). The concept of one's health extends beyond that of one's physical well-being and includes their overall mental, emotional and spiritual well-being also (Nordenfelt et al. 2009, 15). In knowing this, most forms of self-care that have been studied in nursing include practices such as exercise, mindfulness based stress relief (MBSR), journaling and massage (Blum 2014). In consideration of the already busy life of a long-term care nurse, most of these practices listed take about 15-30 minutes a day to complete. Spending fifteen minutes doing a task to promote the nurse's own physical or mental well-being can directly improve the care they

give to their residents. However, initiating and practicing good self-care doesn't usually start with the individual. These practices begin and are kept up or created through a supportive social environment (Woodhead, Northrop, and Edelstein 2014). Encouraging the implementation of self-care within the workplace becomes a manager's financial and moral obligation to their nurses and residents. Through the social support offered by managers, nurses and aides will begin to feel that they have enough self-worth to seek out relationships within and beyond the workplace to sustain their own well-being.

4.3 Implementing Self-Care in the Workplace to Fulfill Aims of Care: A Proposal

Daily, short practices of self-care can be implemented into long-term care facilities to ensure that nurses are being filled with care in order to give good care and achieve the four aims of care for dying, elderly residents: sustaining bodily and security needs, affirming the resident's shifting sense of autonomy and respecting the resident's dignity of identity. The importance of altering the long-term care nursing practice to address the resident's dignity of identity and shifting sense of autonomy as well as the nurse's self-care, though not yet tested, is that these aims could possibly heighten patient satisfaction, potentially lowering the use of expensive, life extending drugs among aging and dying residents as caregivers are more attentive to a resident's needs or reduce nurse turn-over rate. However, the benefits beyond morality are all merely hypotheses.

When I continue this research in a Master's or PhD program, I would track the fall rate among residents and their use of narcotics as well as take surveys among the nursing staff to test overall job satisfaction and perceived stress. I would measure these rates before promoting and implementing the long-term use of one or two self-care interventions among nurses connecting

these self-care tasks to the four aims of care for both the nurse and the resident. For now, it is useful to brainstorm ways in which long-term care nurses and their aides can partake in self-care during their shift. This self-care will allow the nurse to practice good care by fulfilling the four aims of care.

The use and practice of mindfulness based stress relief (MBSR) has become popularized within the nursing field due to its ease of use and the benefits it creates. MBSR encourages the nurse to be present to each moment which assists the nursing staff in being present to their residents (Tollefson 2017). Taking 5 to 10 minutes each day to practice MBSR by journaling about something that one did well can be self-filling in ways which reassure the nurse that their practice of care is important. It also allows them to seek and form authentic relationships with their residents. Because of this, the intervention I propose below is a three-phase process which introduces, promotes and implements the long-term use of journaling in the work place to promote good self-care among nurses and nurse's aides.

Phase One: Mindfulness Journaling.

The use of mindfulness journaling is to provide a creative outlet for nursing staff to put their experiences of care into words or pictures. By doing this, the staff member's awareness of their place within the care team for an aging, dying individual is heightened. Slowly, the staff member's perspective on the usefulness of their job and the personal rewards associated with caring for others becomes heightened.

As a nurse manager, encourage the staff each day/week/biweekly to take 5 to 10 minutes during their shift to write or draw a picture about specific prompts which encourage the staff to see their work in a positive light. Some journal prompts could be as follows:

“Write a story about how you were most compassionate this week/month.”

“Describe how you provided family centered care.”

“Put down one frustration you have when caring for a resident.”

“What are you an expert at?”

“Why did you become a nurse? How do you live this out now in your profession?”

Here is an example of what a journaling sheet passed out may look like when filled out by a nurse. Again note that nurses can have the option to draw a picture if that assists them in creatively expressing their experiences as a long-term care nurse:

Date: 11/15	How do you feel when there is a new admit? (Please take 5-10 minutes to think about and write a response)
	<p>When there is a new admit, I often feel overwhelmed. A lot of paper work goes into a new admit as well as contacting the doctors, looking over charts, completing assessments, making the new resident and family feel welcome as well as answering all of their questions or concerns.</p> <p>I try to see new admits in a positive light. Here is a new person who I will get to know well over the course of their time here. I wonder what their life has been like.</p> <p>Then, I look down at my long list of care tasks and easily get pulled away from the new admit and towards other call lights. It makes me feel like I am not doing enough.</p>

To make it easy for staff to complete these mindful journaling exercises, provide paper with the prompt already written on it or a small notebook and a writing utensil. Hand these out personally, if possible, which will allow the nurse manager to explain the usefulness of the journaling exercises. Afterwards, place signs within staff break rooms and at nursing stations that encourage the staff to take this activity seriously and to complete the activity within a deadline. This will create a sort of accountability with the staff which can assist in creating a habit for the Preserving Dignity in the Long-term Care of Actively Dying Residents

staff to continue practicing self-care. In addition, as a nurse manager, tell the staff how valuable they are in promoting the mission of the facility. Likewise, mentioning via e-mail or face to face how valuable the staff's work is in caring for the residents and their families allows the nurse to feel supported and appreciated, relieving stress. Just as the nursing staff must develop authentic relationships with their residents to drive the ethical process of care forward, so too does the manager have an obligation to authentically be in relationship with the nursing staff when encouraging and promoting a self-care activity or affirming the nurse's work.

In addition to promoting the nursing staff to write or draw about their experiences once or twice a week, begin encouraging the staff to care for themselves in other ways. This may involve some work on the manager's part by bringing in speakers to run workshops on physical care such as stretching before work; offering yoga during or after a shift; partaking in MBSR; or offering massages during the lunch hour to show that staff are appreciated. Additionally, a subsidized gym or YMCA membership can be offered.

Phase two: Promoting a Sustaining Nursing Culture.

At the end of each week or every two weeks, have the staff tape one journal entry or the journal entry of the week to a wall within the staff break room, if willing. Be sure to encourage the staff to omit their names or any factors which may link them back to the posted entry. This will ensure confidentiality. Confidentiality is important as the focus of the second phase is to foster conversation among staff about their working experiences. This will increase feelings of community support. As one of my nursing participants (Nurse C: Jeanine) once told me when our interview was interrupted by another nurse, "What makes this place great is the fact that we have each other. I know I can walk over to Glenn's station and cry or fume about a resident on a

bad day. I can also go over and tell her a joke a resident shared or a silly thing they did. Here at Caring Acres, I know I have my girls, no matter what kind of day I am having” (Cronican 2016).

Phase two within this self-care model is meant to support open dialogue and camaraderie among nurses and aides who work in facilities where each hall is cloistered or the feeling of community is lacking. By having tangible journal entries posted to a wall in the break room, staff looking for something to do during their breaks can read entries from other co-workers and use them as conversation starters among staff. For example, if another nurse were to read the sample journal entry above while on his break, he may be able to identify with some of these feelings and seek support through the co-workers surrounding him. In this theoretical context, the nurse has the opportunity to open up with other nurses and share his vulnerability, allowing him and his peers to work together in overcoming their sense of inadequacy or underappreciation. In addition to this, managers will be able to see what needs to be done to further support the nursing staff while promoting self-care. This phase assists the manager in discovering ways to promote a more honest and open nursing culture such as, offering a caring snack in the break room; creating a public recognition wall where staff, administration, and families can post thank you’s to staff, residents and family for going above and beyond; or encouraging better communication between the administration and the nursing staff via a comments and suggestions box.

Incentives to continue self-care may also be created at this phase. Once workshops, trainings, staff appreciation days, and a gym membership have been offered to the staff, the administration or managers may seek to hold a contest to see who continues self-care at work. One way such a contest can be created is by having the staff keep and hand-in a short self-care log. Rewards can be set based on an individual or unit or hall fulfilling a suggested amount of self-care. Rewards could be free massages, movie tickets, a free lunch or a day at the spa.

Here is an example of what a submission sheet could look like,

created by Bethany Tollefson, PhD:

	Date	Mindfulness Exercise	Minutes of Practice	I'm grateful for...
Monday				1. 2.
Tuesday				1. 2.
Wednesday				1. 2.
Thursday				1. 2.
Friday (Add Sat/Sunday if needed)				1. 2.

Phase Three: Fulfilling the Four Aims of Care for Dying, Elderly Residents

After proper self-care practices have been implemented and nurses begin to feel sufficiently supported and adequate in fulfilling their role in the care process, the time then comes to promote better end of life care for residents. It would not be surprising if, past phase one and two, this step was not necessary due to noted improvements of authentic care and relationships between the nursing staff and their residents. However, should this turn into a formalized research study, a researcher can work with each individual nursing staff member of a

long-term care facility to determine one or two personal goals the nurse or aide can make to better improve care both to the self and to the resident. For example, sitting in each resident's room for five minutes a day to promote authentic listening or being honest with residents and their family about the nurse's interpretation of their changes in health. The fulfillment of these goals can be determined by using quantitative tests to determine the nurse's perception and experience of stress before, during and after the study as well as noting if the level of falls or pain medications dispensed to residents changed during the course of the study.

It is good to note that at the end of this process, phases one, two and three should be practiced concurrently and feed into and off of one another. For example, a future journal prompt could be "How are you fulfilling your goal of care well?/How can you improve?" or "How are you caring for yourself/your residents well? How can you, with the help of the rest of the staff, improve this?" Additionally, the manager could ask this question of their staff while spending 20-30 minutes a week speaking with staff.

Conclusion: Self-Care leads to Good Nursing Practice

We began this inquiry into improving the care for the dying, elderly in long-term care facilities by looking at how the word dignity has informed health care practitioners and nurses on how to properly care for their residents. After this, we critically looked at how the common notion of dignity and the definition of autonomy used to justify it fall short of including the human experiences of marginalized individuals due to the requirement that one must have reason to receive respect. Because of this, we moved towards broadening this notion of dignity to encompass a human's identity and the relationships which affirm it. This sense of dignity has been discussed by Lennart Nordenfelt; he calls it the dignity of identity. In turn, the concept of autonomy needed to be broadened to give power to individuals of differing mental abilities in order to allow them to make moral decisions pertaining to everyday life choices. This new concept is tentatively called the shifting sense of autonomy.

Out of these two broadened ethical concepts, we looked at care and feminist ethics to determine how the care practice of nursing for the elderly, dying resident could be shaped to improve care. Seeking such an improvement required us to create an ethical practice of care with four explicit aims: fulfilling the resident's bodily and security needs, respecting the resident's dignity of identity and honoring the resident's shifting sense of autonomy. The nurse is bound morally by care to care for the resident and fulfill these four aims. If these four aims are not fulfilled, the nurse fails to practice her care well. The failure to fulfill the four aims of care for the dying, elderly in long-term care results in real physical, mental and relational harm to the resident as it hinders their ability to face their impending death.

There are a lot of external factors which prevent the nurse or aide from properly fulfilling the four aims of care listed above. A few that were discussed were care burn-out, low pay, a high

patient volume and being underappreciated for the work the long-term nurse or aide does. To help overcome some of these obstacles and minimize stress, a simple solution in promoting self-care through MBSR, workshops, fair pay, massage, journaling, subsidized gym memberships, verbal affirmations or public recognition boards. The administration and management team are morally and financially obligated to provide some of these outlets for self-care and support their continual use as these self-care practices have a high potential for improving resident care, lowering the nurse turn-out rate and lowering the rate of falls within their facility.

The main intent of this research was to search for ways in which the nursing practice in long-term care facilities could be improved to once again recognize and care for the humanity dwelling inside each resident regardless of mental or physical ability. I hope I have done that well. Throughout my research, I began to learn that in order to treat others well, you must learn how to treat yourself well. My journey in learning how to do and practice the art of self-care is what ultimately led me towards recognizing and affirming the dignity and autonomy of my residents as I continued to care for the elderly in long-term care. My dying residents suddenly transformed from being burdens to jewels where my moments and experiences with them in their last days were fulfilling. I was able to laugh when they laughed and cry with their families and my co-workers when they finally passed away.

By researching and articulating improvements in nursing care, I was finally able to be there with others, whole heartedly, as they decided when and where to put their final brush strokes of vibrant color on the canvas of their life. I sighed their sighs of relief, grief, contentment and loss with them as they laid the pallet and their brushes down for the final time. Though I was only able to see specific parts of their portraits, I loved each one. In this love, I

was able to recognize the dignity of identity each held and affirm their shifting sense of autonomy. In this recognition, I was able to care for them in the ways they required.

In all, learning how to love myself allowed me to fully love and care for another in their moments of aging and death. In my care, I felt grateful and that my job as a nursing assistant was important. By engaging in self-care, I was able to return to the present moment and share it with my dying patients. I hope other nurses and aides in long-term care learn these lessons too. I hope that one day, each and every one of them wakes up with pride and joy for who they are and the care they give. For now, though, more research and promotion is needed to improve the treatment of nurses as well as address the cost and quality of care at the end of life. With that, I leave you with these words: take care.

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