

**I'LL BE A WINDOW IN YOUR HOME.
THE ART OF BEING FULLY PRESENT TO THE DYING PATIENT
IN PALLIATIVE CARE.**

by
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A dissertation submitted to the
Faculty of Theology, Saint Paul University
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

Ottawa, Canada

2012

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ABSTRACT

“I’ll be a window in your home:

The art of being fully present to the dying patient in palliative care.”

Dying is an embodied and relational process. It is also a mutually enriching process, not only for the dying patient in palliative care, but also for all involved in his dying. Unfortunately, due to the lack of attention and subsequent understanding of these mutually enriching human experiences, the caring process strictly focuses on medical, psychological, and social needs rather than on the caring presence within a more comprehensive holistic caring practice.

The dissertation is a response to this lack of attention in dealing with the human experiences of dying patients in palliative care, and in being open to care and being fully present to them. I have set out to focus on the role of the self-understanding of all involved in a dying patient’s care, as themselves embodied and relational persons, and how their bodily and relational self-understanding enhances and contributes to better outcomes in palliative care practice. I have critically analyzed the anthropological foundations of embodiment and relationality, and from these foundations, developed a new framework for a more comprehensive approach towards a caring presence to the dying in palliative care.

This dissertation is divided into five chapters. In Chapter One, I provide a historical, societal, cultural, and bioethical analysis of the challenges that have been affecting palliative care since the 1960s. In Chapter Two, I introduce the concept of embodiment as presented by philosophers Gail Weiss and John F. Kavanaugh. In

Chapter Three, I introduce the discourse of feminist scholars Lisa S. Cahill and Eva F. Kittay and their development of the notion of relationality. In Chapter Four, I deepen my analyses and integrate them into my new framework that is comprehensive in its approach to the caring presence to the dying in palliative care. In Chapter Five, I continue with the implications of incorporating an embodied and relational foundation into the training program and practice of all involved in the dying patient's care. Finally, I also identify some limitations of my research and suggest possible further research in the area of end-of-life palliative care.

DEDICATION

I dedicate this doctoral dissertation to my family. I have always believed that education begins in the home and my home was the best school in which I have had the pleasure to learn. I especially wish to thank my parents Francis and Anna, my brother Francis and his wife Jane, all – without a doubt, my favourite mentors and teachers!

ACKNOWLEDGMENTS

First, I would like to thank Almighty God for the gift of my priesthood, and for giving me the strength and wisdom to accomplish this “challenging” task.

Second, my heartfelt appreciation goes to Dr. Carolyn Sharp, my thesis advisor. Her guidance has been timely, encouraging, and enriching. Her support and constructive feedback, along with her guidance toward the completion of this thesis was enormous. I can say proudly: “Yes, Dr. Sharp, I did this thesis for your mom!”

Third, special recognition goes to Dr. Kenneth Melchin and Dr. Manal Giurgis-Younger of the departments of Theology and Human Sciences, who reviewed my drafts and my final manuscript. Your help and constructive criticism have been very helpful.

Fourth, another special recognition goes to Dr. Noël Simard, Faculty of Theology, now His Grace Msgr. Simard, for his guidance prior to my doctoral studies.

Fifth, to the director of Graduate Studies at Saint Paul University, Dr. Gregory L. Bloomquist, whose feedback was very helpful and insightful.

Sixth, to my classmates in the doctoral program who showed a keen interest in my dissertation and for assisting me with the PhD formatting guidelines.

Seventh, to all of the health care professionals at the Élisabeth Bruyère Hospital, Saint-Vincent Hospital and Saint-Louis Residence in Ottawa, for their generous guidance in instructing and teaching me more about the palliative and hospice care programs.

Eighth, special thanks goes to Ms. Frances Kremarik and Ms. Theresa Ann Keogh for their proofreading and language corrections. Their time and effort has been of tremendous help to me.

Ninth, to St. Patrick's Basilica, in particular to Msgr. Robert Martineau, Fr. Richard Siok, and Fr. Larry McCormick for their assistance and giving me a home during my thesis project; also to the German Bishops and the Taylor family who granted me a scholarship for my studies at Saint Paul University.

Tenth, and finally, to my family and friends I thank you for your patience, moral and financial support and understanding.

To all I express my thanks!

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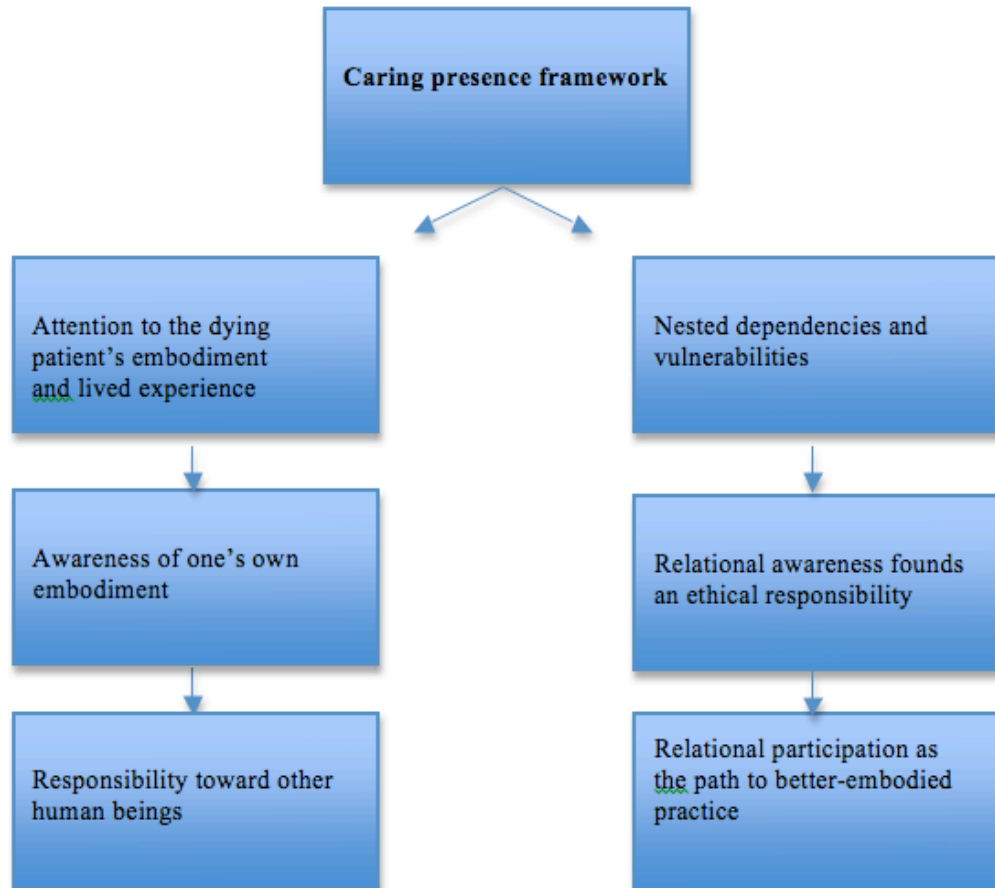
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Figure 1.1 A new framework that is comprehensive in its approach to the caring presence to the dying in palliative care.



ABBREVIATIONS

The following abbreviations are used through the text and footnotes of this research.

BMJ	The Bioethical Medical Journal
Cf.	Confer/compare
diss.	Dissertation
ed.	Single editor
eds.	Multiple editors
EU	The European Union
HAPM	The Hospice and Palliative Movement
CHPCA	Canadian Hospice Palliative Care Association
JAMA	The Journal of the American Medical Association
MFMER	Mayo Foundation for Medical Education and Research
NIH	The National Institute of Health
NJB	New Jerusalem Bible
no. (nn.)	Number (numbers)
p. (pp.)	Page (pages)
rev.	Revised
U.S.	United States
vol. (vols.)	Volume (volumes)
WHO	The World Health Organization

INTRODUCTION

Honouring and responding to the human experiences of dying patients is a major challenge of our time. Hence, the human experience of dying is at the heart of this dissertation. The lack of attention to these human experiences and the challenge of being fully present to dying persons remain. In order to correct this oversight, I will examine the notion of embodiment and relationality, and its link to the body-subject and relation to others in the social world, and then propose a new caring presence framework that is comprehensive in its approach to the caring for the dying, and leads to actual practice in end-of-life palliative care.

With this lack of attention to the human experiences of dying patients, I began my research in end-of-life palliative care. It was within the context of the current discourse in bioethics that I embarked upon discovering better practices in palliative care for the future as my contribution to this area of research. My new framework is comprehensive in its approach to the caring presence to the dying in palliative care, and lies in our bodily understanding, connectedness and commitment to be “a window in your home”¹ in the words of hospice pioneer, Dame Cicely Saunders, founder of St. Christopher’s Hospice in London, England.

Dame Saunders tells the story of David Tasma, a patient she met in 1967 at her hospice in London. Tasma was a Jewish patient rescued from the Warsaw ghetto who felt isolated in his hospital bed. Saunders shared with him the story of her life and faith, and offered her support and encouragement until his death. She pointed out that

¹ Cicely SAUNDERS, “Some Challenges that Face Us” in *Palliative Medicine* 7 (1993), (suppl.): 77-83.

² Dr. Cicely Saunders founded *St. Christopher’s Hospice* in the late 1960s in Sydenham, a district of London. As described by Jesus C. HERRANZ in his article “Palliative Care: Origins, Precedents

“discussions about a setting that could have helped him find not only symptom relief but also time and space to make his own terms with an apparently unfulfilled and meaningless life, led not only to an initial inspiration but also to his own quiet place.” Saunders’ openness helped Tasma complete his life with dignity and respect. She became for him a “window into his home”. Throughout their exchanges, Tasma provided Saunders some insights from his life about caring for the palliative patients.

In another more personal exchange, he said: “I only want what is in your mind and in your heart”. This later thought led to a commitment to continually developing skills, understanding and research in conjunction with a readiness for personal concern. “When he died, having made a quiet and personal peace with the God of his forefathers, he left me with the assurance that he had found his answers and that all our caring must give total freedom to others to make their own way into meaning”.²

Saunders’ story invites us to ask if we are truly attentive to the phenomenon of the lived experiences of dying patients. It also suggests the need to discover the art of being fully present to a dying patient in palliative care. My research seeks to contribute to this question. When caring for dying patients in palliative care, be it in regards to themselves, or to the responsibility of family members, healthcare professionals, and community volunteers, we all as human beings must be fully present to other human beings and be open to care for them. I believe that this art of being fully present opens for us possibilities for personal growth and maturation.

² Dr. Cicely Saunders founded *St. Christopher’s Hospice* in the late 1960s in Sydenham, a district of London. As described by Jesus C. HERRANZ in his article “Palliative Care: Origins, Precedents and the History of a Christian Approach,” in *Dolentium Hominum* 58 (2005): 58-59, “In the statutes of *St. Christopher’s Hospice* we read: The hospice aim is to express the love of God in everything it touches and in every possible way: with efficiency of medical and nursing care, the use of all scientific knowledge to alleviate suffering and discomfort, sympathy and personal common sense, with respect for the dignity of every person just as he or she is appreciated by God and men, without race, colour, class or creed.”

Maurice Merleau-Ponty's work³ is arguably the most rigorous and comprehensive examination of subjectivity as an embodied engagement with the world. Philosophers John F. Kavanaugh and Gail Weiss drawn on this importance of subjectivity and develop the notion of embodiment even further. Furthermore, philosophers Lisa S. Cahill and Eva F. Kittay also draw on the work of Merleau-Ponty and develop the relational dimension of embodiment. I have turned to these scholars to develop my thinking about embodiment and relationality.

Through their work, I have been able to articulate a framework for my own thoughts regarding a caring presence to the dying in palliative care. The insights of these authors are the following: 1) personal existence is both embodied and relational; 2) the connection between two individuals in an ethical and social relationship not only facilitates, but becomes the experience; and 3) a caring presence is one way of being open and available to another human being. Moreover, based upon my chosen authors' anthropological foundation of embodiment and relationality, I argue that the emphasis must be placed upon the importance of being fully present. I believe that this will address the gap in palliative care and contribute toward better daily practices for dying patients by health care professionals, families, and communities, and also offer a new way on how to understand and examine an embodied relational person in end-of-life bioethics.⁴

³ Maurice MERLEAU-PONTY, *Phenomenology of Perception* (London: Routledge Classics, 2002).

⁴ To narrow my research, my focus is neither 'quandary ethics' nor a case study nor specific topics in applied bioethics, as there are already volumes of studies devoted to them. My intention is to enrich the anthropological foundations in end-of life bioethics specific to the notions of embodiment and relationality.

This research is of interest to numerous groups. Much of this research assists medical and health care professionals, as well as theological ethics students who investigate the anthropological/philosophical foundations and the implications of embodiment and relationality. As well, it is of interest to any ethics reader exploring what it means to be an embodied and relational person at the terminal stage of life.

While carrying out my research, I committed myself to visiting dying patients in Élisabeth Bruyère Hospital and other hospitals and hospices in Ottawa. Because of these experiences, I have developed my passion for exploring the practical as well as the theoretical aspects of being present with, and helping, dying patients in palliative care.

Research Hypothesis

My hypothesis is that caring for the dying patient in palliative care requires attention and answers the following question: how can one be attentive to an embodied relational person in palliative care, and how can an embodied relational person be present in an embodied relationship with another relational person? In other words, how can we rediscover the art of being fully present to another human being when that person is dying?

In order to propose a new awareness in the practice of palliative care, a clear and consistent anthropology is needed that takes into account the phenomenon of embodiment and relationality. Such anthropology seeks to provide the basis for a better understanding in addressing the challenges affecting palliative care today. This anthropology can then provide insight into personal existence, which is both embodied and relational. A clear understanding of what is meant by “embodied” and “relational” provides the foundation for understanding person-centered care and relationship-

centered care. I believe that the anthropological foundation based on embodiment and relationality presented by Gail Weiss, John F. Kavanaugh, Lisa S. Cahill, and Eva F. Kittay provides the basis for understanding the importance of a fully caring presence in an embodied ethical practice today; a practice where mutual trust, sharing, power of narrative, listening and witnessing play an important part. A new path to better practices in palliative care will then be proposed.

Method and Overview

Due to the nature of this project and its questions, choosing a methodology required careful choices. I have chosen to focus on the recent literature⁵ on embodiment by Weiss and Kavanaugh, and on relationality by Cahill and Kittay. I will use the dialectical method to evaluate these authors and propose a new framework for a caring presence as an embodied practice to dying patients in palliative care. The reason I have chosen such a method is as follows: 1) it provides a conceptual framework for a phenomenological understanding of embodiment and relationality that are broadly constructed and related to others and to the world as expounded upon in Merleau-Ponty's work and by my chosen authors; and 2) it helps me to develop the new framework of caring presence based upon previous accounts of embodiment and relationality.

In my research, I intend to take the following steps:

In Chapter One, I will review the challenges affecting end-of-life palliative care which have shaped palliative care since the mid-1960s and outline my definition of

⁵ My research only takes account of the literature on embodiment and relationality within the North American context published between 1995 and 2008.

operative terms like palliative, hospice care, and dying. From there, I will present the best content of the palliative care practices today relying upon a more holistic approach. This presentation will broadly outline the palliative care practices offered on a daily basis by health care professionals, as well as volunteers, while specifically focusing on the personal and professional involvement that is predominantly designed to relieve suffering and improving the quality of life for the living as well as for the dying. Finally, I will argue that there is still a gap in ethical, philosophical and medical theory and practice today because it is excessively relativistic and individualistic, and not concerned with the implications of embodied ethics and caring presence as embodied practice.

In Chapter Two, I will present the anthropological foundation based on embodiment. Merleau-Ponty's work presents the most comprehensive examination on body-subject in the world. Weiss and Kavanaugh have used his approach to theorize that the body of a concrete person-patient is the basis of experience. Through their phenomenological method and approach, based on Merleau-Ponty's work, I have been able to find a framework for my own thoughts.

This concept of embodiment, which Weiss and Kavanaugh have developed, brings both the past and future together, and opens the door to a deeper understanding of the human person while offering a continuous dialectical exchange with the world and other embodied subjects. This also helps us to be fully present, and is not just an ethical set of principles for patient-centred care; it also addresses our relational responsibility for dying patients in palliative care. I will argue that when we are speaking about a dying patient, the body must be our point of departure for understanding the ambiguities of meaningful existence.

According to Kavanaugh, for instance, “My being human, my embodied-self-consciousness, is the arena of and condition of ethics.”⁶ Therefore, from a phenomenological perspective, the embodied body of a dying patient is composed of both a habitual and present body-subject, and is the meeting place of the past, present, and future; it is carrying forward the past, outlining the future, and is in the present living in this bodily momentum. Most importantly, dying patients cannot detach themselves from their bodies. The lived body of an embodied dying patient does not consist as a totality of its functioning physical parts, nor exist apart from its materiality altogether. Their bodies are permanently present for them without ever being able to observe them like objects. Yet the permanent presence of the body is what enables them to observe objects.

Further, Weiss also argues for the multiplicity of body images as they are co-present in any given individual and are themselves constructed through a series of corporeal exchanges that take place both within and outside of specific bodies. As Weiss writes, “To say that the body does not impose any sort of pregiven structure upon the world, but is itself structured by its world, which in turn implies that the body image reflects from the start the particularities and generalities of a given situation, not merely the idiosyncrasies of its own physiological or genetic makeup and physical constitution”⁷ What Weiss refers to is that our body and body images are also situated culturally and historically, and tell us of our social and cultural situation that continually shape us as human beings.

⁶ John F. KAVANAUGH, *Who Counts as Persons? Human Identity and the Ethics of Killing* (Washington, D.C: Georgetown University Press, 2001), p. 34.

⁷ Gail WEISS, *Body Images: Embodiment as Intercorporeality* (London: Routledge Press, 1999), p. 11.

Importantly, bodily spatiality, bodily unity and communion, and bodily intentionality, all inherently dynamic, are the very conditions for coming into ‘being-in-the-world’. Thus, they underline the embodied person’s entire existence as a human being. The dying patient experiences themselves as being constantly open to the world and made available to space and history. The only way to find his body is to locate it in time, or to spot his body in the here and now. The world and space-time is also available for a dying patient. The ambiguous phenomenon of the body is precisely the occasion of historical limitation and liberation at the same time. An embodied, dying patient is unleashed and freed to history. Thus, Weiss adds to this description of the dying patient by outlining how race, gender, class, technology, place, space, and time structure affects his ways of being.

Finally, embodiment is the experience of one’s body with others in the world. A dying patient, or for that matter any of us, already has an internal relationship to the natural world by virtue of our possessing sensory functions. Weiss speaks about these “bodily imperatives” as being vital to palliative care because especially in human relations, the body is very often not just the object around which ethical discussions are made, but a central element in those very discussions.

In Chapter Three, I will present the relational dimension of embodiment, and draw on the work of Cahill and Kittay. In reference to the notion of relationality, my exploration must begin with the human experience as a starting point for us into the meaning and significance of suffering and death. It opens up for us the perspective that to be a human person is to be essentially directed toward others.

How we experience the world and especially other people is more than our physiological functioning even though the nature of our experience cannot be ultimately separated from the way in which our bodies function. In the palliative context, our experience with suffering and death, along with the person's lived experience are connected and represent the gateway toward dependency on one another.

As previously stated, the dying patient is situated within the context of a larger community, and it is important to emphasize that as relational human beings, all human beings are dependent on the care of others from birth until death. Kittay argues convincingly that dependence, a pre-condition of relationality, begins with our birth.⁸ It is also our ethical responsibility to provide loving and quality care for terminally ill patients. We must provide them appropriate treatment and medical procedures, as well as to pay attention to their religious, social, and psychological dimensions.

Cahill further develops this notion of dependency when she highlights the social dimension of responsibility and theorizes that all individuals embody social relations, including relationships based upon gender, race, ethnicity, age, class status, as well as philosophical faith commitments. All of us share a common ground for moral action, and important values like freedom and equality stand in dialectical relation with community solidarity and compassion for each other.⁹ Relational participation is essential for human existence and sharing the good life.

Finally, responsibility requires publicly shared norms and a moral community to listen and respond to the actions of each individual. In essence, when speaking about

⁸ See Eva F. KITTAY, *Love's Labor: Essays on Women, Equality and Dependency* (London, Routledge: J. A. Parks, 2003), p. 17.

⁹ See Lisa S. CAHILL, *Sex, Gender, and Christian Ethics. New Studies in Christian Ethics* (Cambridge: Cambridge University Press, 1996), p. 63.

personal involvement and social relations, the question and emphasis should not be on what *I am capable of doing*, but more about whom *I regard as an embodied being*. In other words, being a responsible relational being means more than just occupying a social position that is based on self-interest or only to respond to a select constituency. One must attempt to address the needs of the many, not of the few.

In Chapter Four, I will implement the insights from previous conversations into my analysis of caring presence and explore the theological/spiritual dimension of caring presence. I will propose that a new framework based upon the notion of embodiment and relationality, and developed from my chosen authors, must incorporate not only the medical, psychological, social, and religious needs of the dying patient in palliative care, but also a bodily and relational understanding of all interested in dying care; if accepted, it may represent one pathway toward better practice in palliative care and toward self-realization/understanding of one's own embodiment. In other words, there is a strong inner connection, or an awakening of human-to-human consciousness when a health care professional, family member or community volunteer meets and cares for a dying patient instead of simply dealing with the dying patient's physical needs.

Importantly, there is also a theological implication in my proposed framework that grasps the interrelationship of embodiment and relationship in a caring presence, and provides the context within which God's presence can be expressed in the intercorporeal space in which one person is dying; connections can be made not only with oneself, but also with others who are caring and grieving.

Furthermore, I will stress in my framework that the importance of a caring presence can only begin with personal awareness, mutual trust and sharing in a patient's

relationships, be it with a health care professional, a family member, or a community volunteer. The formation of a caring presence framework fully and completely within the palliative care context requires all involved in palliative care to learn the strategies of narrative, listening and witnessing as a part of the comprehensive holistic care for the dying patient.

In Chapter Five, I will conclude my dissertation by advising various communities to be present and to participate more in end-of-life palliative care, and finally, I will also suggest other possible paths to better practices in end-of-life palliative care. Before the conclusion of this chapter, I will present the implications for incorporating embodied ethics into the training of health care professionals or volunteers. I will also identify some of the limitations of my research, and suggest possible further discussion in the area of end-of-life palliative care.

Finally, my dissertation is in response to the lack of attention to the human experience of dying and being fully present to them. It is my belief, based on the anthropological foundation of embodiment and relationality in the work of my chosen authors, that there is an urgent need for a new awareness and dynamic framework in the practice of palliative care. Having been personally inspired by numerous stories, and witnessing dying patients and their families in palliative care, I claim that dying patients need more than just to have their medical and psychological needs taken care of. No technological means can fully replace us as human beings. As embodied and relational human beings, dying patients need our attention to their lived experiences, our bodily presence, and the ability to bear witness to them.

*“Our most important foundation for St Christopher's
is the hope that in watching, we should learn not only
how to free patients from pain and distress,
how to understand them and never let them down,
but also how to be silent, how to listen and how to just be there.
As we learn this we will also learn that the real work is not ours at all.
We are building for so much more than ourselves.
I think if we will remember this, we will see that
the work is truly to the greater glory of God.”*

Dame Cicely Saunders¹⁰

Chapter 1: Challenges Affecting Palliative Care Since 1960

1.0 Introduction

How does an embodied and relational ethics contribute to new ways of thinking about a dying patient today? Would an embodied ethics, grounded in the body, affect and challenge dying patients and those interested in their care? Providing a sufficient answer requires an exploration of the challenges in the field of bioethics in the West (primarily in Canada and the U.S., but also in Europe) since the 1960s. This exploration, however, requires focus on an understanding of the embodied experiences of an embodied relational person in hospice and palliative care.

After conducting a review of the bioethics literature with a focus on end-of-life care, terminal care, palliative care, hospice care, and dying, I will argue, along with phenomenology philosopher John Kavanaugh (2001) and feminist scholars Gail Weiss (1999), Lisa Sowle Cahill (1996), and Eva Feder Kittay (2002), that there is still a lack of attention towards the human experiences of dying patients in palliative care, in as far as being open to caring and being fully present for them.

¹⁰ Dame Cicely SAUNDERS, “Watch with Me,” in *Nursing Times*, 26 Nov. 1965, pp. 16-17.

1.1. Historical, Cultural, Biomedical, Philosophical and Ethical Challenges

1.1.1 Historical Challenges: Palliative Care Since 1960

Since 1960, the importance of ethical responsibility for a dying patient in palliative care has risen to great prominence. Fox (1990) outlined this development into three distinct phases: 1) from the 1960s through the mid-1970s, bioethicists and medical professionals began to turn their attention to ethical dilemmas as a result of scientific and technological developments in biomedicine, and to the medical and psychological care provided to a dying patient (Saunders, 1959, 1965; Feifel, 1963); 2) from the mid-1970s to the mid-1980s, bioethicists and medical professionals became increasingly involved in defining life, death and personhood (Rachel, 1975; Ramsey, 1978); and 3) from the mid-1980s to the present, bioethicists and medical professionals remained concerned with issues such as autonomy, individualism in ethical reasoning, and issues surrounding the concepts of communities, justice, embodiment and relational ethics (Curran, 1984; Kittay, 1987; Hauerwas, 1990; Schweiker, 1999; Kavanaugh, 2002).¹¹

In the West, the topics of death and dying were not freely talked about and sometimes simply avoided (Feifel, 1963); care about the emotional aspects of dying patients and their suffering was insufficient (Saunders, 1959).

Many health care professionals, often with relatively little or no training in how to interact with or care for dying patients, left their patients abandoned and alone without any interaction with them. A patient commonly went through various stages of hospitalization, surgery, chemotherapy, radiation, and even experimental treatment, as

¹¹ See more in Patricia A. MARSHALL, "Anthropology of Bioethics," in *Medical Anthropology Quarterly* 6/1 (1992): 50-4. Another way to outline the development of palliative care would be to present three historical periods: 1) Before hospice; 2) Advent of hospice care; 3) Present palliative care. For the purpose of this research, Fox's (1990) outline is more relevant, because Fox's outline appears to be more reflective of palliative care literature.

there was little or no attention paid to informed consent, advanced directives or similar protocols.

Furthermore, physicians or health care professionals did not adequately discuss the burdens, risks or benefits of different treatment options, or patient/family preferences as a part of the patient's care. In addition, family members were not empowered to participate in the care of their loved ones or in the decision-making process; on some occasions they were overwhelmed, and even withdrew their presence. In sum, many dying patients in the mid-1960s suffered not just from their terminal conditions but also from the loneliness of abandonment (Saunders, 1959; Fox, 1990).

From the mid-1970s to the mid-1980s, many medical and health care professionals began applying non-normative ethics, which according to Marshall “involves inquiry into moral dilemmas created by the theoretical and practical application of technological developments associated with the Western biomedical sciences.”¹² This application and inquiry was a result of what bio-ethicists and health care professionals witnessed since the mid-1960s when looking into the experience of dying patients: a silent emotional suffering, the social discomfort of ostracism and unnecessary physical pain as a result of the limited number of pain-relief medications available at the time, and restrictions on others like morphine. Many were also unaware of their future, as physicians commonly withheld information of terminal diagnoses from patients (Kalish, 1969; Saunders, 1969). However, these combined experiences led a number of medical and health care professionals open to listening to the dying patients themselves.

¹² MARSHALL, “Anthropology of Bioethics,” p. 50.

In 1969, psychiatrist Elisabeth Kübler-Ross pioneered a new approach toward dying patients and their families in her publication, *On Death and Dying*.¹³ Her ideas and work have since dominated the field. The stages of dying which she theorized – denial, anger, bargaining, depression, and acceptance – have become well known in the medical field. While Kübler-Ross' work has been criticized in different medical and ethical studies for not accurately describing the experience of a dying person (Kastenbaum, 1981; Kalish, 1978; Pattison, 1977), her pioneering work is valued and widely recognized. Kübler-Ross' achievement and contribution can be summarized as follows: she appealed to society, medical professionals, and family members of dying patients to speak about dying and death in both the public arena and at the 'kitchen table'. By emphasizing the attention that needs to be given to the experience of dying, to the point of an earlier or even lifelong preparation for death, Kübler-Ross' writings marked a departure from the existing body of medical literature dealing with death, and initiated a new approach in caring for dying patients.

Kübler-Ross has been criticized for her methodological approach towards dying patients (Carter, 1989; Corr, 1993; Klass, 1981). Many contemporary experts in palliative care like Corr or Klass criticize her for a lack of data and reliance on subjective observations and intuition, which she interpreted in her own unique way. They further argue that Kübler-Ross' five stages of the dying process were based on observations and interviews with dying patients and lack medical history observations, which also need to be taken into consideration when evaluating a specific dying process. Some other palliative care experts like Carter (1989) argued that Kübler-Ross' five

¹³ Elisabeth KÜBLER-ROSS, *On Death and Dying* (New York, NY: Simon & Schuster, 1969). See also Elisabeth KÜBLER-ROSS, *Living with Death and Dying* (New York, NY: Macmillan, 1981).

stages of dying do not take into account that there is a non-uniform sequence of dying for every human being. We all experience the dying process differently in spite of some commonalities or similarities. However, despite all these and similar methodological criticisms, many healthcare professionals of her era, and even today, consider Kübler-Ross an early pioneer in palliative care and a great admirer of human life (Young & Cullen, 1996).

In 1969 another pioneering work with a new hospice¹⁴ approach towards dying patients was offered by Cicely Saunders in London. Saunders entered nursing school at the Nightingale Training School of London's St. Thomas Hospital in 1940; she then qualified as a physician in 1957 at the medical school of the same hospital. What was so significant about Saunders was that her combined background in nursing and medicine, coupled with a strong personal religious faith, provided the basis for her goal of easing the pain and suffering of dying patients. Seeing dying patients in pain being denied the full benefits of the practice of modern medicine (Pollard, 1997), she realized the importance of continuity in developing holistic hospice and palliative care. It is important to note that from the very beginning, she had no support from many of her colleagues for her holistic vision of care.

Moreover in 1957 (Realizing a vision section: 1959–1967) Saunders wrote her first paper on the care of the dying where she introduced her concept of total pain (Clark, 1999). 1957 was a time when resources for the care of patients dying with advanced cancer were minimal and care was only limited and formal. What Saunders introduced

¹⁴ 'Hospice', from the Latin root 'host' or 'hospitality', can be traced back to medieval times and originally referred to a shelter/place of rest for weary or ill travelers on a long journey (Koff, 1980). I will define this and similar terms later in the chapter.

in her paper and then in practice can be summarized as follows: attention to the individual patient, and the need to use drugs according to strict pharmacological principles, ideas that now provide the basis for rational clinical practice. Unfortunately, not all of her medical colleagues accepted this paper at the time. Nevertheless, her vision of holistic care was later (1967) introduced and realized. It is also good to observe how vision, strategy and personal energy are closely linked in the life of Saunders and present a new development in palliative care.¹⁵

In 1967, Saunders carefully drafted a 10-page document called ‘The Scheme’, and generated enough medical and financial support for her new concept of care to open fifty five beds at St. Christopher’s Hospice in Sydenham, London (James & Field, 1992; Spooner, 1986).

St. Christopher’s Hospice became a source of inspiration for a holistic approach towards care for dying patients not only in Great Britain (London, 1967) but also in the U.S. (New York, 1978) and in Canada (Montreal, 1979). This new approach to care introduced by Saunders helped found the Hospice and Palliative Movement [henceforth HAPM] whose aim is to give patients with painful and terminal diseases the best possible quality of life (McNamara et al., 1994; Clark, 1998). However, as rightly pointed out by many experts in hospice and palliative care, while HAPM has made many positive advances in the 20th and 21st centuries, the movement has shortcomings, especially due to the following problems: lack of service planning, lack of objective evaluation, and vision (Bradbury, 2001; Katz, Komaromy, 2004; Andersen, 2005).

¹⁵ See more in David CLARK, *Cicely Saunders—Founder of the Hospice Movement: Selected Letters 1959–1999* (Oxford: Oxford University Press, 2002); Shirley DU BOULAY, *Cicely Saunders: Founder of the Modern Hospice Movement* (London: Hodder and Stoughton, 1984).

This holistic approach towards care for dying patients, as conceived by Saunders, was later developed into a home-care service, an outpatient department, a family and bereavement service, and even a day-care centre; research programs were also set up, as well as a teaching centre, and hospice information services. However, despite these achievements in palliative care, there was still reluctance in the medical arena to recognize palliative care as a specialty, something that had been urged by Saunders for a period of time. Formal accreditation by the Royal College of Physicians and the Royal College of General Practitioners was finally granted in 1987.¹⁶ Shortly after this formal accreditation, it was internationally accepted that the hospice was a successful model of care for dying patients (Kane, Wales, Bernstein, Leibowitz, & Kaplan, 1984; Morris et al., 1986; Teno et al., 2004).

One of the significant pioneers influenced by the work of Kübler-Ross and Saunders was Dr. Balfour Mount, a medical graduate of Queen's University who in 1974/75 began one of the first palliative care wards in Canada called 'care that relieves'; this ward later developed into the Royal Victoria Hospital Palliative Care Services. He also initiated McGill's biennial International Congress for Care of the Dying in 1976, and internationally promoted through his research the importance of quality of life and whole person care models.

Today, there are over 2600 palliative care beds in 140 hospices and units in Great Britain (Bruera, 1994; McNamara, 1994, 2000); in the U.S. and Canada there are

¹⁶ This date and accreditation is important not only from a historical point of view, but also for the whole development of palliative and hospice care. See more in Henk TEN HAVE, David, CLARK, *The Ethics of Palliative Care: European Perspectives* (London: Open University Press, 2002); Beverley, MCNAMARA, *Fragile Lives: Death, Dying and Care* (Philadelphia: Open University Press, 2001).

over 1800 hospice programs (Gurfolino and Dumas, 1994, 1999) with almost 700,000 residents. For example, in Canada, Ontario's hospices are “community-based volunteer organizations dedicated to helping people who are living with a life-threatening or terminal illness.”¹⁷ Traditionally, the medical community concentrates on investigation, diagnosis, and cure, so that often the dying are lonely, frightened, and in pain. The mission of Ontario's Hospices is to help these people live at home – wherever that may be – or in a home-like setting as comfortably and fully as possible. They provide support to families and friends, with a range of services focusing on quality of life until the end of life, as well as bereavement support for loved ones.

In the mid-1980s, improvements in technology and developments in the field of death and dying brought many changes in medical treatment and care for dying patients and their families. The presence of interdisciplinary palliative care teams providing care for dying patients was increasingly ensured, not only in hospices and hospitals but also in home-based palliative care. The palliative team would meet with the patient and his family, and after a full bio-psycho-social-spiritual assessment of the dying patient, would not only facilitate but also discuss the goals of care.

Furthermore, in the mid-1980s proper pain management was also established; emotional and social support for dying patients was provided by health care professionals, family, and volunteers, as a part of the curing and caring process. Lastly, the transition from palliative care to hospice (usually lasting 6 months or less) was slow, but definitely established. A number of research studies were done on topics like open awareness (Kastenbaum, 1981), and volunteer engagement (Veatch & Byock, 2006)

¹⁷ See HOSPICE ASSOCIATION OF ONTARIO (Toronto, Ontario, Canada, 2009), available at: <http://www.hospice.on.ca/faq.php>, accessed, April 17, 2009.

1.1.2 Cultural Challenges: Palliative Care Across Different Cultures

Culture¹⁸ plays an important role in palliative care today. Palliative care scholar Mary Pickett reminds us of the need to be attentive to how palliative care could vary across different cultures, and what problems may be encountered or how religious beliefs may alter views on end-of-life and palliative care (Pickett, 1998). To properly tailor palliative care to a dying patient, today's interdisciplinary palliative teams must take into consideration a patient's specific culture, faith, and worldview.

The study by Barbara Koenig & Jan Gates-Williams (1995) stresses the importance of cultural variations.

Our study suggest a way to assess cultural variation in end-of-life care, arguing that culture is only meaningful when interpreted in the context of a patient's unique history, family constellation, and socioeconomic status. Efforts to use racial or ethnic background as simplistic, straightforward predictors of beliefs or behavior will lead to harmful stereotyping of patients and culturally insensitive care for the dying.”¹⁹

Koenig & Gates-Williams remind us is that instead of focusing only on medical-psychological priorities, medical and healthcare professionals also need to pay attention to the social-religious needs of dying patients in defined cultural settings. They conclude that by omitting a dying patient's culture, they can make his dying very harmful and non-beneficent.

Moreover, different socio-economic and demographic concepts of illness and dying may influence the type of palliative care that will be provided. For example, some western cultures place a high value on individualism, personal happiness, and self-

¹⁸ “Culture” here is defined as the values, norms, beliefs, and practices of a particular community that are learned, shared and guide decisions and actions in daily life.

¹⁹ Barbara A. KOENIG, Jan GATES-WILLIAMS, “Understanding Cultural Difference in Caring for Dying Patients”, in *Caring for Patients at the End of Life* [Special Issue] *The Western Journal of Medicine* 163 (1995): 244.

determination, while some non-western cultures place a higher value on emotional dependence or family closeness. The intention here is to understand that illness and death are social events and the entire community or family must share any grief (Cassell, 2004). With constant migration, increasing rural to urban movement, and the search for better life opportunities, social services, health care and global palliative care, the palliative care teams that usually make first contact with a patient and his family must in the admitting process carefully discuss with the patient and his family their cultural values and priorities, and draft corresponding palliative protocols (Ashley & O'Rourke, 1989).

Another palliative challenge connected with culture, deals with the problem of misinformation regarding the adequacy and importance of palliative care and hospices (Leininger, 1977). For example, immigrants (especially from Latin American and Eastern countries) as well as domestic citizens may consider home care as sufficient care for dying patients. Palliative or hospice settings are usually considered by them to be expensive and/or extraordinary options. Careful discussion and adequate information helps address these concerns.

Furthermore, another palliative challenge connected with culture deals with the various forms of alternative therapy. In many cultures traditional healers are more common than palliative care. Once again, careful communication and presentation offer alternatives to the western medical palliative model.

Lastly, religious beliefs, which can be included in these cultural dilemmas, may provide a person in palliative care with meaning and an understanding of his suffering and dying, whereas a non-religious person may find meaning in art, or a meaningful

work, or philosophy (Wright et al., 1997). Attentiveness to religious beliefs may improve not only the curative process, but also the caring approach to dying patients. Again, palliative care teams ideally comprised of a physician, nurse, social worker, and chaplain, need to be attentive, respectful and non-offensive to the religious needs of patients when investigating and establishing a palliative protocol or advanced directives.

In sum, society is becoming increasingly multicultural, with diverse socio-cultural problems and cultural variations affecting palliative care. Medical and health care professionals have come to the consensus that a new framework for application in palliative care is needed: a framework that will take into account not only medical data and quality of care, but also take into consideration a diverse multicultural context.

1.1.3 Bioethical Challenges: New Bioethical Dilemmas in Palliative Care

Despite all of these developments, medical professionals along with ethics scholars continue to face new bioethical dilemmas concerning dying patients: allocation of resources, insufficient financial sources for palliative care, cultural differences in palliative practice, confidentiality in medical encounters, truth telling, informed consent in medical treatment and human experimentation, definitions of personhood, and the manipulation of life by withdrawing life-sustaining treatments. Famous medical cases like those of Karen A. Quinlan (1975), Nancy B. Cruzan (1983), and Terry S. Schiavo (2005), point toward the need for an expanded theoretical and conceptual framing of medical and ethical problems (Callahan, 1973; Beauchamp, 1978; Pellegrino, 1986; Jonsen, 2003). Unfortunately, because of the extensive media and political involvement, the anthropological framework for improving the quality of life of dying patients in

health care facilities has been forgotten.

Bioethicist David Thomasma warns us about this forgotten anthropological framework and recommends integrating four features into our compassionate approach: First, when we are approaching patients, we must adopt an interdisciplinary ethical stand which is based on the whole as well as on the individual parts of the individual person, because patients are more than the sum of their parts and they possess a certain wholeness that often transcends reason. Second, we must always take into account a patient's emotional, spiritual, embodied and relational dimensions. Third, decisions must be made on the basis of helping persons complete their lives. Fourth, going beyond the standards of practice, we must ask: What is the purpose of life? Thomasma (1996) also point to the importance of an interdisciplinary approach, with an emphasis on effectiveness and efficiency, forming a part of the professional education and training in medical schools today.

Alongside secular bioethicists, Catholic bioethicists like McCormick (1984), Curran (1968), Dedek (1975), Shannon (1980), Grisez (1979), and Cahill (1980), working from within the Catholic tradition and often in cooperation with Catholic health care institutions,²⁰ have addressed many bioethical end-of-life dilemmas. When offering their views on death and dying, they have often drawn upon natural law approaches and personalist theories.

Finally, as Catholic or broader bioethics today is more interdisciplinary than ever, there is new attention being paid to the person (Ashley, 2006), to virtues (Keenan, 1996, 1999; Vogt, 2004), suffering (Callahan, 1993; Kavanaugh, 2001), and death and

²⁰ Charles E. CURRAN, *Catholic Moral Theology in the United States: A History* (Washington, D.C: Georgetown University Press, 2008), p. 220.

dying, in light of the common good and anthropological principles (Cahill, 2006) such as embodiment and relationality, which I will explore in my research.

1.1.4 Philosophical Challenges: Phenomenology and Theories of Embodiment

Before going into philosophical challenges, let me present one story from my volunteering experience, which I would like to call my ‘encounter with Paul’. This personal story will set the stage for a more comprehensive understanding of phenomenology as a method and study of human experiences based on theories of embodiment and relationality.

It was 5:45 pm on October 27, 1997, and I had just finished my class in physiology. Although the class was interesting, it was also very difficult. For the following week, the class had been assigned a significant amount of material to read. However, while my classmates were heading back to their residence rooms, it was time for me to go to Košice General Hospital, where I volunteered to spend some time every Tuesday and Thursday with patients, especially in the palliative unit where many of the patients were alone and dying.

Among these, I was assigned to a patient named Paul. He was in his 60s and had been diagnosed with a brain tumor. According to the medical reports, although Paul had already received all of the necessary radiation and chemical procedures, his brain tumor was still growing and there was an abnormal mass of tissue present in other parts of his brain. I already knew from my medical training that a tumor takes up space within the skull and interferes with normal brain activity, and the prognosis for brain tumor patients is as individual as the patients themselves. As different parts of the brain control

different functions, symptoms vary depending on the tumor's location. The nurse told me that Paul was having another headache, and that he was vomiting. After greeting him and pulling up an empty chair, I also noticed that he had difficulty speaking or finding words, and that his body was weak. What I also observed from his pre-entry information was that even though his cognitive functions were weak, his body language was significant.

It seemed to me that Paul had a sense of being in control in the midst of his diagnosis, and that the whole health-care team and all of us volunteers were invited not just to focus on Paul's assessed needs and pain/symptoms, but that Paul was inviting us to care for him as his friends or family; in doing so, he strengthened and taught us to be aware of our own embodiment and dependency. With this insight in mind, I spent more time with Paul. Sometimes I read him a story or told him the daily news; we prayed together, held hands, and often times until he died, I was just bodily present for him. Paul taught me more than I could understand. He taught me that while providing appropriate medical care and focusing on assessing needs and symptoms is important, the key to understanding a human person is to be aware of your own embodiment and dependency.

This story concerning Paul invites us to ask if we are truly attentive to the phenomenon of the human experience of dying patients. It also suggests the need to rediscover the phenomenological embodied and relational approach to dying patients in palliative care. But what is phenomenology? Who are the proponents of the embodied and relational phenomenological framework and how we can pay attention to and be open to human experiences in the lives of ordinary people?

The term phenomenology²¹ was first employed in the 18th century before being developed into a significant field by Edmund Husserl (1859-1938). For Husserl, one's own body was what orients us and allows us to relate to the phenomenal field. Embodiment, according to Husserl, is what makes possible the very ascription of thoughts and sensations to subjects in the world. Husserl further offered phenomenological reduction as a method of looking past the cultural or constructed world and focusing instead on one's immediate experience. Because of this approach, Husserl came to view the reduction of phenomenology as the foundation of both science and philosophy. After Husserl, many other philosophers, like Martin Heidegger (1927), Jean-Paul Sartre (1946), and Maurice Merleau-Ponty (1962), developed and addressed this theory in their seminal works.

Each of these philosophers in their own way began to recognize the lack of attention paid to the bodily experiences of ordinary people. This same observation was made at the same time by many social scientists (Good, 1977; Good and Good, 1981; Kleinman, 1980) who investigated the role of the body and described the body's role in knowledge creation, maintenance, and expression through habits.

In addition, aside from the bodily connection and experiences, each one of these philosophers also recognized the significance of the relational aspect of our bodies. We are not only related to the world, but we are essentially directed toward others. When we meet other persons our body incorporates them into our own bodies, so there is a

²¹ See Jan PATOČKA, "Qu'est-ce que la phénoménologie?" in: *Qu'est-ce que la phénoménologie?*, eds., trans. E. ABRAMS (Grenoble: J. Millon, 1988), p. 263–302; Dermot MORAN, *Introduction to Phenomenology* (Oxford, UK: Routledge Press, 2000); Christopher MACANN, *Four Phenomenological Philosophers: Husserl, Heidegger, Sartre, Merleau-Ponty* (New York: Routledge, 1993); Pierre THÉVENAZ, *What is Phenomenology?* (Chicago: Quadrangle Books, 1962); Robert SOKOLOWSKI, *Introduction to Phenomenology* (Cambridge: Cambridge University Press, 2000).

merging of subjectivity and intersubjectivity of inner personal field perspectives in our lives that provides us a greater awareness of human-to-human consciousness, and strengthens our relationships and our responsibility.

In this dissertation I use phenomenology as a philosophical framework, “designed to explore human experiences from the standpoint of the everyday meaning ascribed to the lived experience by the individuals who experience them rather than theoretical meaning ascribed by an observer” (Streubert & Carpenter, 1999; Van Manne, 1990).

Moreover, phenomenology takes as its domain of inquiry both natural and cultural objects as well as modes of being. These are generally known by examining the conditions under which they appear to a subject. This is done in order to shed light on the transcendental constitution of what appears, and the subject for whom it appears. Every phenomenological inquiry involves undertaking a detailed description and analysis of the appearances being studied. Such descriptions are taken to be phenomenological evidence.

Furthermore, phenomenology takes as its primary claim the idea that the study of how things appear or present themselves can tell us about these things and the subject to whom they are presented. Phenomenology can do this because as persons, we are caught up in the world and appearances could be considered as consciousness rather than as a property of consciousness. However, because this understanding of appearances is in opposition to the realist or objectivist view of the world, there are many critics of phenomenology. For example, Merleau-Ponty rejected the idea that appearance is an element of consciousness that is locked into the mind and independent of the world.

Rather, he argued for appearance as an object of consciousness, as it tells us more about the subject and the object.²²

Phenomenology utilizes descriptions to capture how things appear, because the structure of how they show themselves always has an implicit reference to the subjectivity to which they are shown. In other words, it is this basic relationship between the appearance of things and the subject to whom they appear that constitutes the phenomenological inquiry, which is at its basis a method of approaching phenomenality. In other words, phenomenology allows individuals to give voice to actual lived experiences as well as their own beliefs and ideas to another individual with the intent of understanding the meaning of that lived experience.

Finally, phenomenology understands consciousness as the subjective structure of the lived experience, and is always attached to a perceiving and situated subject. Also, there are two kinds of consciousness: reflective (as our sense of the world is the product of thematising, but also focal, explicit and conceptual) and pre-reflective (as our sense of the world prior to the act of thematising, but also general, implicit, and non-conceptual). Importantly, the pre-reflective is usually considered as the primary type of consciousness, as it motivates reflective consciousness, which is therefore secondary, and also retains a part of reflective consciousness.

Let us note that what the phenomenological method requires, however, is an alteration of consciousness, namely the taking of a reflective relation to our pre-reflective experiences. To put it more simply, the boundary between the matter and sense of not yet thematised consciousness and thematised consciousness is modulated in

²² See MERLEAU-PONTY, *The Phenomenology of Perception*, p. 143.

the development of theoretical knowledge. Phenomenology considers consciousness as intrinsically open (beyond itself) to the world of which it is considered a part.²³ For this reason, consciousness is easily related to the transcendental and open to any disclosure, appearance or encounter.

To sum up, phenomenology considers the subjective structure of consciousness as a structural feature. Intentionality here can be defined as an involuntary mode of being open to and directed at the world rather than as a state of openness to the world modulated by our voluntary efforts. Philosophers like Merleau-Ponty sometimes spoke about intentionality as a kind of self-transcendence²⁴ with respect to the world. In other words, intentionality is a complex phenomenon, understood as being object-directed (correlational) or as an operative (unthematized openness to the world that makes possible object-directed intentionality) intentionality, as they are both constitutive elements of the subjective and objective sides of our human experience.

Frequently, the writings of Merleau-Ponty,²⁵ who has been described as one of the most prominent proponents of the phenomenological method, focused on the body-subject and provided the underlying philosophical anthropological foundation of embodiment and relationality for phenomenological research. He addressed the lack of attention towards dealing with the human experiences of dying patients in palliative care, and towards being open to care and being fully present for them. Let me briefly describe Merleau-Ponty's life, work, and research.

²³ It is also opposite to the Cartesian understanding of consciousness as being self-contained and separated from the world of objects it seeks to understand.

²⁴ See MERLEAU-PONTY, *The Phenomenology of Perception*, p. 143.

²⁵ Ibid., p. 143; Maurice MERLEAU-PONTY, *La Structure du Comportement* (Paris: Presses Universitaires de France, 1942).

Maurice Merleau-Ponty was born on March 14, 1908, in Rochefort-sur-Mer, France. Like many of his generation, he lost his father in the First World War. He attended the Lycée Janson-de-Sailly and Lycée Louis-le-Grande, and then received his accreditation in philosophy at the École Normale Supérieure in 1930. Merleau-Ponty attended the lectures of Kojève on Hegel, and also worked with the Catholic Journal *Ésprit* for a brief period. After he completed his studies at the École Normale Supérieure, he then began teaching philosophy at high schools in Beauvais, Chartres, and Paris. He completed his Docteur des Lettres based on two dissertations, *La Structure du Comportement (the Structure of Behaviour)* in 1942 and the *Phénoménologie de la Perception (the Phenomenology of Perception)* in 1945. He became the Chair of Child Psychology at the Sorbonne in 1949, and in 1952 was elected to the Chair of Philosophy at the Collège de France, the youngest ever appointed to the position, which he held until his death in May 1961.

Merleau-Ponty served in the infantry during World War II. He collaborated with his friend Jean-Paul Sartre and co-founded *Les Temps Modernes* in 1945. However, in 1952 he became disillusioned with the war and Sartrean politics, and resigned from the editorial board.²⁶ Merleau-Ponty died in 1961 while working on an unfinished manuscript, *The Visible and the Invisible* (later published in 1964).

From reading Husserl's works, Merleau-Ponty drew a phenomenological analysis of the body subject and its relation to other subjects and the world, and captured some important tendencies in Husserl's thinking. As revealed in his book, *The Phenomenology of Perception*, he surpassed the dualisms between the subject and object, and the self and

²⁶ The nature of Merleau-Ponty's disagreements with Sartre is formulated in the *Adventures of the Dialectic*, published in 1955.

the world, through the lived experience of the existential body. He argued that the 'body subject' was frequently underestimated in philosophy, which tended to view the body as something to be transcended by the power of the mind. For this reason, he was interested in the 'primacy of perception' as a place of embodied inherence in the world, while admitting that perception itself is primarily cognitive. He confirmed the primacy of the lived experience by stating, "the perceiving mind is an incarnate mind."²⁷

He saw the body in continuity with the world, arguing that considering the body as external yet in the world was inconsistent with the concept of the primacy of the lived experience. This is a difficult mode of thinking, where the consideration of perception in the world itself delivers the subject into the state of perception. Therefore, there is no perception in general; there is only perception in the world. For Merleau-Ponty, the 'lived' perception is fundamental to phenomenology; it is what makes it possible and necessary. As the perceiving subject changes, the relation of the subject to the world also changes, thus beginning things anew. Consciousness for Merleau-Ponty was also perceptual, in a state of flux, and never autonomous from what it perceived of the world. The certainty of an idea is based on the certainty of perception, which, contrary to the thinking of Descartes, always remains to be established by phenomenological investigation; there is no universal or ideal certainty at the level of ideas. One cannot say that 'I perceive' is equivalent to 'I think', nor is the concept of 'being' strictly a universalism.

Many philosophers and ethicists have drawn on Merleau-Ponty's examination of the embodied 'body-subject' as being the focus in the lived experience, albeit with

²⁷ Maurice MERLEAU-PONTY, *The Primacy of Perception: And Other Essays on Phenomenological Psychology*, ed. James M. EDIE (Evanston: Northwestern University Press, 1964), p. 3.

limitations; an embodied capacity that develops in response to the needs called for by his environment, and refers to those skills which are relevant to one's social, cultural and political context. The philosophers I have chosen to focus on are John F. Kavanaugh, Gail Weiss, Lisa S. Cahill and Eva F. Kittay, who have drawn on Merleau-Ponty's method and approach to theorize the 'body-subject' of a concrete person-patient as the basis of experience.

The foundation for my choice of these four selected authors is this: 1) in their writings, every human person is for them both embodied and relational; 2) when they present a connection between two embodied persons in an ethical and social relation, they do not describe this connection as an ordinary one, but rather as an intersubjective experience; and 3) the embodied presence is for them one way of being open and available to another human being. All these insights have helped me to develop my framework of caring presence and its implications for palliative care.

To be more specific, let me briefly present first Kavanaugh's and Weiss's ideas on the concept of embodiment, and then Cahill and Kittay's ideas on the concept of relationality.

Weiss and Kavanaugh draw on Merleau-Ponty's approach to theorize the body of a concrete person as the embodiment and the basis of experience, and claims that to speak about a particular human embodied person means always to speak about that person as a subject, or as an embodied subject with a certain degree of autonomy, rights, freedom and knowledge. More specifically, for Weiss (1999, 2008), the "body is always responded to in a particular fashion, that is, as a woman's body, a Latina's body, a mother's body, a daughter's body, a friend's body, an attractive body, an aging body, a

Jewish body.”²⁸ For Kavanaugh (2006, 2008, 2011), the “openness and closeness, unity and separateness, revelation and concealment, freedom and determinateness are the ambiguities or paradoxes of embodiment.”²⁹

Furthermore, for Weiss and Kavanaugh, our body plays an important role in our own existence. This understanding lies in our own ability to continuously find meaning in the world through our previous learning and future intentions, both of which are found in expressions of the present moment in our individual perceptions. However, we can go so far as to say that our body makes these moments meaningful by reorienting, redeveloping and projecting them toward the future. Importantly, this amazing embodied process of reorientation, redevelopment, and reconstruction helps us to continually connect with our past experiences and future expectations, while remaining open to new experiences without totally obscuring the continuity of “our style of being-in-the-world,”³⁰ to use Merleau-Ponty’s expression. Notably, this process of ongoing construction and reconstruction of our body image is never complete, insofar as our life experiences lead us back to the past or toward the future. The only way to stop these possibilities is through death.

Weiss and Kavanaugh further claim that as embodied persons we are part of the material world and our self-embodied-somatic knowing helps us act on this understanding and knowledge toward others. We are united with everything around us, through our bodies, and the way they appear to us as historically and factually situated

²⁸ WEISS, *Body Images*, p. 1.

²⁹ KAVANAUGH, *Who Counts as Persons*, p. 39.

³⁰ MERLEAU-PONTY, *The Phenomenology of Perception*, p. 98.

beings. “I enter into relation to the world, question it, interpret it. I do this because I am capable of a consciousness that relates to itself in being conscious of the world,”³¹ says Kavanaugh. Our bodies are in a constant dynamic state of overlapping and complementing each other as each is inscribed in the other. Thus, the bond between the world and others’ existence and essence comes to us through experience. This holistic bodily experience that precedes our cognition is our style of being.

Moreover, our embodied existence constitutes our human relationships and plays a role in our relationships with one another. This connection occurs at the level of our bodily existence and serves also as the foundation for our moral obligation and motivation. Weiss further develops this notion of connection at the level of our basic embodiment and argues that others affect us not just when they are in good health, but also when they are terminally ill or dying. In her own words: “An embodied ethics, one that works from bodily as opposed to categorical imperatives and which arrives at a noncognivist resolution that lacks formal universality but which can nonetheless serve as a model for how we live, rather than (merely) think about, morality.”³²

In sum, these ideas by Kavanaugh and Weiss point toward contemporary approaches to embodiment and relationality. It is good to note that a number of other feminist scholars have developed and proposed these ideas (Farley, 1975) in addition to defining what embodiment is and developing the ethical implications for taking care of embodied relational persons in end-of-life care today; unfortunately, it seems that their voices are still being ignored (Young, 1990).

³¹ KAVANAUGH, *Who Counts as Persons*, p. 44.

³² WEISS, *Body Images*, p. 146, italic in original.

Let us now turn to the concept of relationality. Lisa S. Cahill and Eva F. Kittay draw on Merleau-Ponty's approach to relationality and argue that we are all connected and dependent people. Similarly, Margaret Farley and Lisa S. Cahill, leading Catholic feminists in bioethics, remind us in their book *Embodiment, Morality and Medicine*, that we are all connected at the level of our human existence and that we are all relational human beings.

Farley and Cahill also emphasized that our exploration must begin with the human experience as a starting point for us into the meaning and significance of suffering and death. It opens up for us the perspective that to be a human person is to be essentially directed toward others. In the end-of-life context, our experience with suffering and death is connected to our lived experience and represents a gateway toward dependency upon one another (Noddings, 1984; Kavanaugh, 2006; Veatch & Byock, 2006).

Moreover, Kittay argues in convincing fashion that we are all dependent beginning with our birth. It is also the start of feeling an ethical responsibility to provide loving and qualified care for terminally ill patients. We must provide them with all appropriate treatment and medical procedures, and to be compassionate with them. Kittay explicitly explained dependency, the fundamental experience of humanness, as the following: "interdependence begins with dependence. It begins with the dependency of an infant, continues with the life-dependency on others and ends with the dependency of a very ill or frail person close to dying. The infant may develop into a person who can reciprocate an individual upon whom another can be dependent and whose continuing needs make her interdependent with others. The frail elderly person... may herself have

been involved in a series of interdependent relations. But at some point there is a dependency that is not yet, nor longer interdependency”.³³

This dependence, which is a pre-condition of relationality, also provides the foundation for social responsibility. As pointed out by Cahill, all individuals embody social relations, including relationships pertaining to our gender, race, ethnicity, age, class status and communities. All of us share a common ground for moral action, and important values like freedom and equality stand in dialectical relation with community solidarity and compassion for each other.³⁴ Relational participation in the community is essential for human existence and sharing a vision of the good life. Unfortunately, there is still ignorance within the societal community regarding people’s experiences, embodiment, relationality, and dependency (Asch, 2005; Berger et al., 2000).

Further based upon the notion of relationality, Kittay and Feder in their book, *The Subject of Care*, suggest, “that a new moral primacy should be placed upon care and a caring presence”.³⁵ In other words, there has to be a primacy of caring over curing, not the reverse that we experience in medical practice today (Paterson & Zderad, 1978; Gilligan, 1982; Jennings, Kaebnick, Murray, 2005). Joan Tronto and Bernice Fisher (1990) suggest that care is more than just theory: it is a cornerstone of our morality that is rooted in our body and our bodily practices. This concept is also shared by many

³³ See KITTAY, *Love's Labor*, Introduction, p. xii; Drew CHRISTIANSEN, “The Elderly and Their Families: The Problems of Dependence,” in *New Catholic World* 223 (1980): 102.

³⁴ See CAHILL, *Sex, Gender, and Christian Ethics*.

³⁵ See Eva F. KITTAY, Ellen K. FEDER, eds., *The Subject of Care: Feminist Perspectives on Dependency* (Lanham: Rowman & Littlefield Publishers, 2002). For a theoretical and conceptual understanding of caring presence in holistic nursing, see the work by Holly COVINGTON, “Caring Presence. Delineation of a Concept for Holistic Nursing,” in *Journal of Holistic Nursing* 21/3 (2003): 301-17.

medical scholars who have elaborated upon the major impacts on the nurse-patient relationship (Swanson-Kauffman, 1983; Fredriksson, 1999; Gilje, 1993; Ray, 1991; Fareed, 1996; Zerwekh, 1997; Walsh, 1999). Caring, therefore, should be accepted as a primary task in medical practice and the cooperation of volunteers should be welcomed (Guirguis-Younger, Kelley, McKee, 2005).

Finally, in this sub-section I will explore the historical, cultural, bioethical, and philosophical challenges with a focus on understanding the embodied experiences of embodied relational persons in order to set the stage for my further discussions.

I have also chosen the phenomenological method in my discussion because: 1) it provides a conceptual framework for understanding the human experience as a starting point for any exploration into the meaning and significance of suffering and death; and 2) it provides a conceptual framework for understanding embodiment and relationality that is broadly constructed, and relates to others and to the world, as expanded in Merleau-Ponty's work.

Importantly, for the purpose of my research, I would define *embodiment* in the context of palliative care as an existential and bodily condition, in which 'the body' is the subjective source of lived experience and plays an active and intersubjective role in palliative care; *relationality* as an existential and the intersubjective bodily condition based on a strong inner connection and responsibility to one another in palliative care; *dependence* as the embodied and relational phenomenon, when one dependent person who is dying, is inevitably dependent on others.

Lastly, despite this exploration of human experiences and the notions of embodiment, relationality and dependency, I argue that there is a lack in definition and

legitimacy in hospice and palliative care today. In order to continue in my research, I need to present and clarify these terms and define my working definitions.

1.2 Lack of Consensus in Definition, Visibility and Legitimacy of Palliative Care

From the onset of my research, I have been using various healthcare terms without clarifying their meaning. In this section, I will define the following terms, which are related to my research project: *end-of-life care*, *terminal care*, *hospice care*, *palliative care*, *dying*, and *active dying*, according to medical, nursing, palliative and other related definitions as presented in books and resources along with my own operative definitions.

Although there is a lack of consensus regarding the definition, visibility, and legitimacy of palliative care, I argue that we need to develop a framework for the better delivery of palliative care, and that this framework should be based on the theory of personal embodiment and relationality.

1.2.1 Definition of Operative Terms

End-of-life Care

End-of-life care, according to the *Oxford Handbook of Palliative Care*, refers to “the care of a person during the last part of their life, beginning from the point at which it has become clear that the person is in a progressive state of decline.”³⁶ In other words, end-of-life care is the active, embodied care that treats, comforts, and supports persons approaching the end of their life, either as the result of chronic or progressive life threatening conditions. Usually, it continues in hospice care.

³⁶ Max S. WATSON, et al., *Oxford Handbook of Palliative Care* (London: Oxford University Press, 2005), p. 56.

The National Institute of Health [henceforth NIH] in their 2004 State-of-the-Science Conference Statement defined *end-of-life care* in the following way: “End of life care aims to support people approaching the end of their life to live as well as possible until they die. Specialist palliative care is an aspect of end of life care delivered by health and social care staff with specific training in the management of pain and other symptoms and the provision of psychological, social and spiritual support.”³⁷

For the purpose of my research, as my operative definition, I define *end-of-life care* as the active, intersubjective, bodily, compassionate, dependency-oriented approach that treats, comforts, and supports persons who are living with, or dying from, a progressive or chronic life threatening condition(s). It focuses on preparing for an anticipated death and managing the end stages of a fatal medical condition. It usually lasts for a longer period than the time during which someone is considered to be ‘dying’. However, the time at the end of life is different for each person, and each person has unique needs for information, for support and for care.

Terminal Care

In contrast to *end-of-life care*, terminal care usually refers to a shorter period of time when a patient is facing impending death and his anticipated life expectancy is measured in days or weeks, and quality of life has become the primary goal.

Terminal care is the care provided to a patient in the terminal or end phase of his life. It emphasizes quality of life as a goal of care, as well as pain alleviation to the extent possible. Terminal care is, in other words, an extension of continual caring for the

³⁷ NATIONAL INSTITUTES OF HEALTH STATE-OF-THE-SCIENCE, *Improving the End-of-Life Care*, 2004, available at: <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>, accessed, April 20, 2009.

whole person (physical body, emotional and spiritual concerns, and complex relationships) while that person is facing a chronic mortal illness that is progressive and will eventually kill the patient. Usually the patient and family are aware at either the conscious or subconscious level of the final result.

According to Buchholz, “Terminal Care is not a subspecialty but the logical extension of caring for the whole person throughout a chronic mortal illness. Quality of life rather than length of life becomes the goal... Terminal is a process that occurs over a time measured in days, weeks or months and awareness may be delayed until after the biological events have become obvious.”³⁸

Furthermore, according to *The Westminster Dictionary of Christian Ethics*, a person becomes “terminally ill when they have reached a certain medical condition, which is usually specific to the disease that they have.”³⁹ Ethicists Lum and Radbruch in their article, “Cultural Issues in End-of-Life Sedation” published in the *European Association for Palliative Care*, define a person as “being terminally ill when it is expected that there is only a short period of time, perhaps a few days or weeks, or at the most a month or two, before the person is expected to die.”⁴⁰

For the purpose of my research, as my operative definition, I define *terminal care* as the difficult, time-consuming and demanding care for a patient in the terminal, or final phase of their life. It encompasses the collective attitudes and actions of doctors,

³⁸ William M. BUCHHOLZ, “Terminal Care. Treating the Whole Person,” in *New England Journal of Medicine* 6 (1993): 203, 204.

³⁹ James F. CHILDRESS, John MACQUARRIE, eds., *The Westminster Dictionary of Christian Ethics* (Philadelphia: Westminster Press, 1986), p. 250, index: terminal care.

⁴⁰ See LUM K., RADBRUCH L., “Cultural Issues in End-of-Life Sedation,” in *European Association for Palliative Care*, available at: [http://www.eapcnet.org/forum/Cultural Issues in End-of-Life Sedation](http://www.eapcnet.org/forum/Cultural%20Issues%20in%20End-of-Life%20Sedation), accessed, May 14, 2010.

nurses, health professionals and social workers towards improving the quality of the patient's life. To sum up, let us visually summarize the main relevant distinctions between end-of-life care and terminal care:

Table 1. End-of-Life Care and Terminal Care

End-of-Life Care	Terminal Care
Care is focused on preparing for an anticipated death and managing the end stages of a fatal medical condition.	Demanding care provided for a patient in the terminal stage of life.
In conjunction with curative therapies	In lieu of curative therapies
Can last a few weeks or months or for many years	Shorter period of life, usually weeks or days

Palliative Care

Palliative care is both a method of care and a system for delivering care for adult patients that emphasizes relief from pain and suffering, and is a complement to traditional medical care that focuses on curing disease and prolonging life. Palliative care is appropriate at any point in a serious or life-threatening illness; it is not dependent upon a prognosis and can be provided at the same time as curative and life-prolonging treatment.

Moreover, the World Health Organization [henceforth WHO] defines *palliative care* as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and

treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”⁴¹ This definition is today widely accepted by many healthcare leaders, policymakers and key stakeholders. However, I would argue with respect to all medical professionals, policymakers and key stakeholders, we need to develop a better framework for the delivery of palliative care in order to increase accountability and embodied awareness.

For the purpose of my research, as my operative definition, I would define *palliative care* as an embodied caring practice that prevents and relieves suffering and continues to support the best possible quality of life for patients, regardless of the stage of the disease or the need for other therapies (death may not be imminent), and which

⁴¹ WORLD HEALTH ORGANIZATION, “Cancer Pain Relief and Palliative Care,” in *Geneva WHO* (1990): 11 - WHO technical report series 804. See also THE SECRETARIAT ON PALLIATIVE AND END-OF-LIFE CARE (Ottawa, Ontario, Canada), “Palliative care,” 2009, available at: <http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php>, accessed, April 12, 2009; NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION AND THE CENTER TO ADVANCE PALLIATIVE CARE, *Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Service* (New York: Center to Advance Palliative Care, 2001).

also supports the needs of family members. The goal is to provide relief of symptoms that interfere with the quality of life when treatments won't change the time course of the illness, and to prevent and ease suffering.

Hospice Care

Hospice care is active, compassionate care directed towards improving the quality of life of those with a life-threatening illness; patients “whose own preferences must be taken into account in all decision making, along with family members and other caregivers whose legitimate needs and interests must be also taken into consideration.”⁴² Hospices are also called a “caring community” or “a place to stop and rest before one’s death.”⁴³

Moreover, Schuster and Kabcenell in their medical textbook, *Glossary, Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*, define hospice care as “centralized palliative care and supportive services to dying patients and their families, in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings.”⁴⁴ The Mayo Foundation offers a similar definition: “Hospice is available for people with any terminal illness, such as heart disease, dementia, chronic obstructive pulmonary disease

⁴² PALLIATIVE AND END-OF-LIFE CARE TASK FORCE, *Hospice Care* (New York, 1975), p. 1-2.

⁴³ Marianne MATZO; Deborah Witt SHERMAN, *Palliative Care Nursing: Quality Care to the End-of-Life* (New York: Springer Publishers, 2005), p. 32.

⁴⁴ Lynn J. SCHUSTER and Anne KABCENELL, *Glossary. Improving Care for the End-of-Life: A Sourcebook for Health Care Managers and Clinicians* (NIH, 2004), p. 124. See also NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION, “What is Hospice,” 2010, available at: <http://www.nhpco.org/i4a/pages/index.cfm?pageid=4648>, accessed, March 24, 2010.

or any other condition. In general, hospice care is reserved for those who've been evaluated by a doctor and have six months or less to live and it is provided at special facilities or family homes or at nursing homes or assisted living residences.”⁴⁵

For the purpose of my research, as my operative definition, I would define *hospice care* as a holistic service to relieve or decrease pain or other symptoms, and to provide as much quality time as possible for the patient with family and friends. The caregivers/palliative teams (consisting of physicians, nurses, health aides, social workers, spiritual caregivers, counselors, therapists and volunteers from the community) try to control pain and other symptoms so a person can remain as alert and comfortable as possible.

Unlike other medical care, the focus of hospice care is not to cure or treat the underlying disease. The goal of hospice care is to provide the highest quality of life, comfort, and dignity to dying patients for whatever time remains. Finally, hospice programs also provide bereavement support to a patient's family after the patient's death.

To sum up, let us visually summarize the ‘main’ distinctions⁴⁶ relevant in this research between palliative care and hospice care:

⁴⁵ MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH [henceforth MFMER], *Hospice Care: An Option when Confronting Terminal Illness* (MFMER, 2008): *Introduction*.

⁴⁶ It is important to note that there will be exceptions to the general precepts outlined as many hospice or palliative programs may vary in their services. For example see: NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION & THE CENTER TO ADVANCE PALLIATIVE CARE, *Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Service* (New York, December, 2001).

Table 2. Palliative Care and Hospice Care

Palliative Care	Hospice Care
Care is provided in hospitals and other settings, such as conventional care hospitals or programs, nursing homes	Care is provided in the home or private “freestanding” hospices such as day care units, community based care hospices, hospital based hospices
In conjunction with curative therapies	In lieu of curative therapies
No time restrictions, uncertain prognosis	6 months or less

Dying

Dying is often referred to as the terminal phase of illness, and is a part of our entire life experience, as our life culminates in death. The body begins to shut down as major organs cease to continue functioning. Medical professionals like Corr et al. define *dying* as “the active process of or associated with the process of ceasing to be or passing from life. Drawing to an end or declining.”⁴⁷ Medical ethicists Lynn et al. suggest that rather than label patients as dying and not dying, we should ask clinicians this ‘surprise’ question: would you be surprised if this patient died in the next six months or so?”⁴⁸ This approach would according to Lynn help us to better define the patients for whom appropriate services are needed to help them live well while dying.

For the purpose of my research, as my operative definition, *death* is an event and not the same as *dying* - an active process. Dying is a personal journey, a normal process

⁴⁷ See Charles A. CORR, Clyde M. NABE, and Dona M. CORR, *Death and Dying Life and Living*, 4th ed. (Belmont: Wadsworth, Thomson Learning Publishing, 2003).

⁴⁸ Joanne LYNN, Janice L. SCHUSTER, and Andrea KABCENELL, *Improving Care for the End-of-Life: A Sourcebook for Health Care Managers and Clinicians* (New York: Oxford University Press, 2000), p. 5.

that each individual approaches in his own unique way at the end of his life. People who are dying are living human beings; they continue to be living persons as long as they are dying. I also claim that dying is a deeply personal experience and a part of living; it is not just a medical event and the opportunity for personal growth does not stop with a diagnosis.

Active Dying

Active dying is characterized by a series of changes that affect the dying patient, the family, and clinicians. There are usually specific symptoms of approaching death that may be observed, depending on the type of terminal illness and the metabolic condition of the patient.

Medical theorists Long, Phipps, and Cassmeyer define active dying as the time when a person is facing impending death. Once a person has entered the actively dying phase, the focus of his care shifts from aggressively treating his medical problems, to providing comfort care.⁴⁹

Moreover, there are two phases, which arise prior to the actual time of death: the 'pre-active phase of dying' and the 'active phase of dying'. Typically, the pre-active phase of dying may last approximately two weeks, while the active phase of dying lasts about three days. Signs of pre-active dying are usually the following: withdrawal from social activities; increased sleep; seeing others who have already passed; self-awareness of the dying process; delayed healing of wounds and infections; and rallying, where there will be a short period of good appetite and energy level. Signs of the active phase

⁴⁹ Barbara C. LONG, Wilma J. PHIPPS, and Virginia L. CASSMEYER, *Adult Nursing: A Nursing Process Approach* (Philadelphia: Elsevier Health Sciences, 1995), p. 183.

of dying are the following: inability to rouse; sometimes, severe agitation/hallucinations; periods of apnea; respiratory congestion; eyes open or semi-open but unaware of the environment; darkening of urine; decrease in body pressure; and extremities that are cold and mottled. However, everyone dies differently, and each person's signs are unique at this terminal stage.⁵⁰

For the purpose of my research, as my operative definition, I would define *active dying* as the time when the patient is in the terminal phase and death is imminent (from two weeks to three days), even if life support therapy is being utilized; the focus of care shifts from treating medical problems to providing comfort or care. I would also claim that this is a special time not only for volunteers or family members, but for all involved in the dying patient's care to bring forth something that comes from deep within us - our ability to be bodily present.

1.2.2 Visibility and Legitimacy of Palliative Care

There are present day struggles with the visibility and legitimacy of palliative care. Although there have been many articles and papers devoted to the definition of common terms in palliative care,⁵¹ those focusing on the visibility and legitimacy of palliative care have been absent in the literature (Hanson, Henderson, Menon, 2002; Herbert, Schulz, Copeland, Arnold, 2008; Johnston, Holt 2006; Miller, Weitzen,

⁵⁰ BEERS, M. H., ed., "At the Bedside of a Dying Person in Palliative and End-of-Life Care," in *The Merck Manual of Health & Aging* (Whitehouse Station, NJ: Merck & Co., 2005). Here it is good to note that when referring to the numbers of days or weeks it may differ for every patient and for every stage of the dying process.

⁵¹ See Eric J. CASSELL, "Recognizing Suffering: A Perspective," in *Hasting Center Report* (May – June, 1991): 24-31; Thomas PASTRANA, et al., "A Matter of Definition - Key Elements Identified in a Discourse Analysis of Definitions of Palliative Care," in *Journal of Palliative Medicine* 22/3 (2008): 222-32.

Kinzbrunner, 2003; Pastrana, Jünger, Ostgathe, Elsner, Radbruch, 2008). This struggle however has long historical roots. As noted previously, from the early 1960s, hospice care and palliative medicine were not accepted as a part of routine medical care and many practicing physicians and nurses were not trained in hospice and palliative medicine. The focus of medical and health care training was on curing rather than caring for palliative patients: such training focused on formal and highly professional medical and health care practices rather than patient-centered care.

Fortunately, in recent years there has been substantive improvement in medical, nursing and public education concerning palliative medicine. There are a number of palliative organizations, like the Canadian Palliative Care Association or the National Hospice and Palliative Care Organization, which are presenting and educating the general public about consent, structures, legal and medical dilemmas in palliative care.

Nonetheless, health care education still needs significant educational curriculum changes. Even if the creation of palliative centres and hospices seem positive for society, another problem is defining the following: who will educate and serve in these palliative centers and hospices when many health care professionals have never worked outside of hospitals? This problem with training and experience in palliative care is not just a current gap in palliative care: the education of health care personnel has been a problem since the creation of palliative care (Pellegrino & Thomasma, 1997; Sulmasy, 1997).

However, I claim that although there is a good prognosis for future palliative care, our present emphasis needs to be more based on embodiment and relationality. I believe that a better anthropological understanding may improve not only the practice of palliative care, but also our understanding of our own embodiment.

1.3 Embodied Relational Practices in Palliative Care Today

In this sub-section, I will broadly outline the palliative care practices offered on a daily basis by health care professionals as well as volunteers; I will focus specifically on the kind of personal and professional involvement that is predominantly designed to relieve suffering and improve the quality of life for living as well as dying patients.

Moreover, I would like to present the best practices in the field of palliative care today, which rely upon a more holistic approach. In the next sub-section (1.4), I will respectfully argue that there are still gaps in palliative care today.

I have encountered the best practices of palliative care, which rely upon a more holistic approach not only in my research, but also in my experience as a volunteer and chaplain in palliative care. I became a hospice volunteer in 1990 while at the Secondary Nursing School in Humenné, Slovakia, and spent a lot of time in different hospital departments, especially in Palliative Units across the city of Humenné. While continuing my education at the School of Medicine in Košice, Slovakia, I once again had mandatory practical classes in Košice General Hospital, and spent time as a volunteer in different hospital departments. I discontinued my studies at the School of Medicine to enter the priesthood and after completing my seminary preparation; I was ordained as a priest in 2002. During my first assignment, I served as a hospital chaplain in two private hospices. After coming to Ottawa to pursue my studies, I had many occasions as a priest to visit dying patients in Élisabeth Bruyère Hospital, as well as other hospitals and hospices, and to provide patients with spiritual care. It is because of these experiences, and my continuous study of human suffering (M.A. and L.Th. research paper), that I have developed a passion for exploring the theoretical as well as practical aspects of

being present with and helping dying patients in palliative care. During my time as a volunteer, I was able to observe different practices in palliative care.

Today, medical professionals along with palliative care teams provide good medical treatment, by alleviating pain, treating symptoms, communicating with patients and their families, allowing volunteers to help and really try to individualize the care provided according to the patient's needs. But in spite of my deep respect for the work of these professionals, there are still barriers and gaps in palliative care, which on occasion pit the dying patient on one side and teams of professionals on the other side. Some refer to these divisions as the "team of the living" versus the "team of the dying". When a separation like this occurs, one must wonder what has happened to the vision of a holistic, palliative, patient-centered approach that was espoused by pioneers in palliative care like Saunders or Kübler-Ross.

Why do family members, professional caregivers, and faith-based communities literally "give up" on a dying patient and underestimate the power of their bodily presence or the power of narrative, of listening, and mutual trust? Why are we not focusing on embodied personal care, and instead focus only on autonomy, beneficence, non-maleficence and justice, as suggested by Childress and Beauchamp?⁵² Consequently, all these and similar questions lead many scholars, health care professionals, and indeed myself, to study, evaluate and present a better framework

⁵² See more in Thomas L. BEAUCHAMP, James F. CHILDRESS, *Principles of Biomedical Ethics*, 4th rev. ed. (New York: Oxford University Press, 1994). The four principles of autonomy, beneficence, non-maleficence and justice are considered today as the 'mantra' in medical and clinical ethics, especially in the Western world.

based on embodiment and relationality in an effort to establish embodied relational practice in palliative care today.

Moreover, best practices today focus on the human dignity and quality of life of the dying patient. Human dignity and the quality of life of the dying patient are therefore the foundation of any health care practice. The dying patient determines what constitutes a good quality of life for him. Physicians, health-care professionals, and volunteers should help a dying patient assess his quality of life by reviewing the patient's world on different levels. They have to have a “clear picture” of the well being of the dying patient that goes beyond his diagnosis. According to Fins, to see a “clear picture is possible only when a compassionate and knowledgeable palliative team is committed to provide and ensure the best comfort and care for dying patient, and ensure that loved ones have access to the support and information they need to cope with life changes.”⁵³ Fortunately today, many hospices in North America and in Europe offer palliative programs where the individual dying patient and his family work together with a personal care team and create an individualized plan of care that ensures their human dignity and quality of life.⁵⁴ These individualized plans of care ensure that care for the dying patient is continual, coordinated, and comprehensive, and that the patient and his family are prepared for everything that is likely to happen during the course of his illness.

⁵³ See Joseph J. FINS, *A Palliative Ethic of Care* (Sudbury: Jones and Bartlett Publishers, 2006), p. 15.

⁵⁴ This is very important fact comparing to palliative care prior to 1960. See more in Beverley McNAMARA, *Fragile Lives: Death, Dying and Care* (Philadelphia: Open University Press, 2001).

Another common practice in palliative care today is care delivery with a focus on assessing the needs of the dying patient and his family as well as appropriate care. Many palliative programs today provide excellent qualitative holistic care through the presence of compassionate and knowledgeable interdisciplinary teams. There are physicians and medical directors who are aware of the patient's medical history and symptoms and who are available for patient consultations when requested; there are skilled nurses who provide expertise in managing the patient's physical symptoms and support patients whenever care is needed; there are social workers who provide emotional support and assist patients and their families in obtaining community and financial resources; there are certified nursing assistants who provide care for patients in a variety of ways, including personal care and bath assistance, depending on the patient's individualized plan of care; there are trained volunteers who support various patient needs, including companion-sitting, light meal preparation, light housekeeping, transportation, delivery of supplies, and assistance with personal care, spiritual support and bereavement support; there are chaplains who provide spiritual care to patients and families as they work through end-of-life feelings and concerns, and who can act as a liaison to the patient's chosen faith community; there are grief counselors who offer bereavement support to the patient's loved ones after death and are trained to talk about issues of grief and loss; and finally, and perhaps most importantly, there are the volunteers who offer their time, effort, and their bodily presence to dying patients and accompany them on their journey, helping them to face suffering and to find meaning in it. Before being admitted to palliative or hospices facilities today, all volunteers are required to complete extensive orientation and training sessions, as well as to submit to a background check. Their

contribution may vary from providing transportation, deliveries, hair and/or bath care, and meal preparation to providing spiritual support, bereavement care or grief support. The work of all members of these interdisciplinary teams is integral to the delivery of comprehensive palliative care today.⁵⁵

This delivery of care is realized 24 hours a day on a one-to-one basis in palliative units, in hospices or in private homes, in community-based residential facilities or in residential care apartment complexes. A good delivery of care is ensured by palliative protocols,⁵⁶ which are based on best practices and standing orders to ensure that a dying patient's right and wishes are respected, realized and that he is receiving appropriate medical attention and care.⁵⁷

Further, another common practice today in palliative care is good communication between the dying patient, family members, and medical professionals. Effective communication usually begins at the moment of admission into the palliative program or hospice, and is ensured for the duration of the patient's stay. Palliative teams are aware today that open communication is necessary in creating an advanced care plan, protocols, or health care directives. Open communication also helps palliative teams to

⁵⁵ Even if this list and description seems extensive, for the purpose of my thesis and in general for good care delivery, it is important to itemize the members of an interdisciplinary team and describe their work, contributions and relational engagement.

⁵⁶ These protocols are sometimes called 'advance directives', and usually reflect cultural, spiritual, practical needs and specific instructions about treatments like: ventilator withdrawal, DNR, and pain and symptom management, or just recommendations when death does not occur after the cessation of life-extending interventions and necessary ongoing staff support. In palliative practice these protocols/advance directives not only have an informative value, but also a legal value.

⁵⁷ See Ira BYOCK, *Dying Well: The Prospect for Growth at the End of Life* (New York: Riverhead Books, 1997). Dr. Ira Byock, a long time palliative care physician and advocate for improved end-of-life care, is internationally known for his framework, which is based on four simple statements: *Please forgive me, I forgive you, thank you, and I love you*. See also www.dyingwell.org or www.choices.org.

determine the physical, psychosocial and spiritual needs, and expectations of the dying patient and his family.⁵⁸

Finally, along with the continuous delivery of medical care, there is another common practice in palliative care today and that is post-death bereavement care. In many Canadian and European palliative care units, there is a policy, which requires deceased residents to be removed through the “back door”. While many medical professionals see this as a very important policy to “help” the grieving family, many others like the Canadian Hospice Palliative Care Association [henceforth CHPCA] see the practice as cold and impersonal. They instead suggest providing a special covering for gurneys, and using the front door rather than using the ‘back door’, placing a memorial wreath on the deceased resident’s door, and posting the deceased resident’s name on the common board with the resident’s name, date of death and a photograph. Debriefing for staff is also a part of the CHPCA suggestion.

1.4 Gaps in Palliative Care

As stated previously (sub-section 1.3), there are many gaps in palliative care delivery today because it is excessively relativistic and individualistic. What is common to many gaps in the delivery of palliative care is the lack of attention to the human experience of dying patients, whose normative behaviours and values, skills, abilities, recourses, cost reductions and most importantly, with attitudes, awareness and the implications of embodied ethics and caring presence as embodied practice.

⁵⁸ See Maggie CALLAHAN, Patricia KELLEY, *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* (Simon & Shuster, New York, 1992).

1.4.1 Gaps Dealing with Relativistic and Individualistic Behaviour and Values

First of all, with due respect to professional caregivers and faith-based communities, I recognize that the development of a strong interest in normative behaviours and the practice of examining values and value orientation has shaped the last 40 years. For example, in the past, the presence of family members, neighbours, clergy, and sometimes even a family doctor at the bedside of the dying was commonplace. This was especially true in rural societies that were more reliant on traditions.

Today, based on empirical evidence provided by Callahan (1990) and Kavanaugh (2006) I argue that our individualist, relativist-centered and technological culture has gradually transformed into an urban society and is no longer interested in “traditional care”.⁵⁹ In other words, there is a present-day struggle between the genuine freedom we all enjoy as human beings, and the call we have to live as one human family. Consequently, with the development of an increasingly technologically dependent environment in hospitals, this has led many patients in the last 40 years to feel more like an object in a hospital than as a subject in a healthcare environment. These experiences of loneliness, in conjunction with the systematic discrimination that can occur because of class status, gender, or other factors, has helped spur the creation of palliative centres and hospices (Butler, 1990; Irigaray, 1993; Stawarska, 2006).

Elaborating further, the technological environment in hospital or hospice settings seems to be one of the biggest gaps in palliative care or end-of-life care in general, and

⁵⁹ By ‘traditional care’ I refer here to the practice of medical care known from ancient Greece to the middle of the 20th century, based upon medical beneficence, concern for the quality of life, and respect for the sanctity of life. Today’s care is enhanced by life-prolonging technologies and present more ethical and practical conflicts between quality of life considerations and respect for the sanctity of life.

ethicist Daniel Callahan argues that many people today are obsessed with trying to control and defeat the chaotic forces of nature. This has resulted in the unconscious belief that medical technology will, with enough miraculous breakthroughs, overturn the domination of death. Unfortunately, this has resulted in a loss of the meaning and value of life through a misguided correlation between the length of life and its meaning or sanctity. Depending on the age of the dying person and possibility of prevention, it becomes something that should eventually be overcome with enough technological research or technological breakthroughs (Cahill, 2005; Kavanaugh, 2006; Veatch & Byock, 2006). I argue however, along with Robert Veatch and Ira Byock, that the technological imperative in conjunction with our individualist and technological culture has painted us into a corner: any acceptance of death and dying has been avoided or rejected, and death is even a mark of shame for our society.

Kavanaugh (2001) elaborates upon Veatch and Byock's remarks even further. He argues that "within our consumerist culture it is easy for us to depersonalize our existence and thus to open the way to treating ourselves and others as nonpersons. We hide in fear from the deepest questions about ourselves, becoming willfully forgetful of our own dignity as human beings and losing ourselves in the many distractions made available by modern technological sophistication."⁶⁰ Kavanaugh charges that not only medicine but even philosophy has forgotten the quest for meaning and wisdom about who we are as human beings, and what it means to be embodied and dependent persons who are seeking self-understanding. In sum, this presented socio-cultural outlook in today's society is reflected in the 'simple' question, "Whose life or body is it anyway?"

⁶⁰ See KAVANAUGH, *Who Counts As Persons, Introduction*, p. 1.

Palliative care programs are complex and holistic programs of care, and without appropriate education and practice, holistic care cannot be provided. These programs need more visibility and legitimacy, and must change from a hostile environment into a new pathway of caring. Their reliability depends on factors that may be beyond their control: adequate staff and economic viability. These factors also affect the attitudes of medical personnel who may not be willing to participate in training; this creates a division between management and staff approaches to dying, and finally, they lead to an acceptance that ‘patients as persons matter’, not just ‘paying clients matter’.⁶¹

1.4.2 Gaps Dealing with the Lack of Resources and Cost Control

In recent decades, the above-presented factors revealed other gaps that can be addressed in the Canadian, as well as the US context: 1) dealing with the lack of resources for palliative care or hospice settings; and 2) the problem of cost control.

First, there is a lack of funding, a shortage of nurses, and time restrictions as well as competing demands on time. This shortage of resources affects both the cure and the care provided to the dying patient in many ways.

Second, there is another problem dealing with uninsured patients and the problem of cost control. According to Callahan, “there are at bottom only three ways to deal with the high cost of health care. One of them is to increase revenues for the system. With government programs such as Medicare, this means raising taxes sharply; with private insurance it means raising premiums. Another approach is to cut benefits

⁶¹ I am aware that research can be done on each of these factors. For my purposes I only want to name and label them, and to present the bigger picture when dealing with improvements in palliative care practices today.

drastically, giving people less care. Still another way is to force individuals to pay more out of pocket for their care.”⁶²

Is there a way to solve this economic gap or problem? Again, according to Callahan, “a huge economic gap and an equally huge cultural gap must be closed. We have become accustomed to living (and dying) with an expensive and disorganized system that serves many ends other than health. It is a system designed for reckless affluence. It builds upon a model of health and medical progress that is open-ended and infinite in its aspirations. Suffering, aging and death are enemies to be conquered, at whatever the cost to other social needs... Medicine should rather seek a good quality of life within a finite life span.”⁶³ I agree with Callahan that the goal of medicine must be devoted to caring, or caring communities, and require social priorities and limits be set on the use of health care resources. However, even if Callahan’s idea or proposal seems valid, I would argue that the whole problem of effective cost control or resources is a larger and national societal, economical, and legal problem, which is not easily resolved without cultural, social and anthropological understanding: who is the human person, what are his rights and what does it mean to care for him until death comes?

Another gap according to Eric Cassell (2007) has to do with “the task to develop an understanding of persons and their relationships”⁶⁴ in clinical and palliative care. Cassell argues that “we have to ask ourselves: what are human relationships, why do

⁶² Daniel CALLAHAN, “Curbing Medical Costs,” in *America* 198/8 (2008): 12.

⁶³ *Ibid.*, p. 13. See also Daniel CALLAHAN, *Setting Limits: Medical Goals in an Aging Society* (Washington, D.C: Georgetown University Press, 1987).

⁶⁴ Eric J. CASSELL, “Unanswered Questions: Bioethics and Human Relationships,” in *Hasting Center Report* 37/5 (2007): 21.

they have an impact on us, how do they work, what are their limits?”⁶⁵ I agree with Cassell and would add to his questions the necessity to clarify the doctor-patient relationship; the family relationship and responsibility; and what is the community’s responsibility and relationship toward the dying patient? I suggest that we as a society, and in particular ethicists and medical professionals, have to avoid the futile debates into which we have fallen and refocus on the clarification of our duties and responsibilities toward the human beings who are dependent on us. However, another solution dealing with problem of communication would be to improve the internal communication among the staff, the palliative care resident, and his family. Other good solutions would include adequate debriefings between shifts with attention to the individual’s needs and possible feedbacks by the palliative care coordinator, and more consultation sessions or palliative courses.

Yet another gap deals with the full and explicit disclosure of personal advance care plans or palliative advance directives. Part of the problem is the absence of information or an unwillingness to sit down with the patient and his proxy or surrogate, and to communicate in ways that the laws of our Western society reinforce; in part, this has to do with the involvement of his family and the limits of their involvement. Experience has shown us that sometimes families want to change advance plans and ignore a dying person’s needs and requests. It must be made clear to both the medical staff and families that such plans are here to protect and respect the patient, not to harm him/her.

⁶⁵ Ibid., p. 22.

In summary, specific gaps include a better understanding of human values, knowledge transfer, continuous quality improvement, and transformational leadership. Overall, these include challenges in accreditation and licensing, public disclosure, and the importance of more funding resources and community involvement.

Finally, is there a common factor in all of these presented gaps in palliative care today? What is really lacking, both implicitly and explicitly in today's palliative practices? I would argue that the main problem has to do with a lack of awareness and attention regarding the human experiences of dying patients in palliative care today, and a lack of being open to care and to being fully present to them.

To better describe and understand this key problem, let us ask the following question: if medical professionals, special medical teams or palliative teams cannot cure a dying patient, does it mean that their job is over? I claim that it is not, because when a cure is not possible for a dying patient, the continual caring presence of these persons, along with an emphasis on comfort care, is just beginning. Unfortunately, the previously described historical, cultural, and biomedical challenges and practices in palliative care have created a praxis that teaches something different. With respect to all healthcare professionals, there is a tendency by some physicians, specialists and some palliative team members to forget that their professional and human duty is to actively participate in a palliative role with an understanding that this role cannot be mandated.

So, is there a way to solve this problem? Drawing upon Kavanaugh, Weiss, Cahill and Kittay, I would claim that one way to correct this failure and improve the present practices for dying patients in palliative care is to propose a new framework that is comprehensive in its approach to the caring presence. There is a need for a new

framework based upon the notion of embodiment and relationality, which incorporates self-understanding of all interested in dying care as themselves bodily and relational persons and contribute toward better daily practices for dying patients.

1.5 Conclusion

In this chapter, I have reviewed the challenges affecting end-of-life palliative care which have shaped the field since the mid-1960s, and then outlined my definition of operative terms like palliative, hospice care, and dying.

Furthermore, I have presented the content of the best embodied and relational palliative care practices today, practices that rely upon a more holistic approach. This presentation broadly outlined the palliative care practices offered daily by health care professionals as well as volunteers, while specifically focusing on the personal and professional involvement that is predominantly designed to relieve suffering and improve the quality of life for the living as well as for the dying.

Finally, I have presented some important gaps in ethical, philosophical, and medical practices today, because at present, palliative care is excessively relativistic and individualistic, and lacks an anthropological foundation and an adequate comprehensive framework for attending to dying patients in palliative care.

Chapter 2: Embodiment in the Work of Gail Weiss and John F. Kavanaugh

2.0 Introduction

In this chapter, I will carefully analyze philosophers Gail Weiss and John F. Kavanaugh's concept of embodiment, as well as how this concept opens the door to a deeper understanding of the human person and his continuous relationship to the socio-physical environment and other embodied subjects.

In terms of the philosophy of embodiment studies, Weiss and Kavanaugh have both drawn on Merleau-Ponty's comprehensive examination of subjectivity as an embodied engagement with the world. Their work further explores the philosophical post-Cartesian ideas of the human embodied person not as a body with a mind or a mind in a body, but rather as a whole embodied being never isolated in its activity, and always actively involved through interaction with the world and other embodied beings.

Moreover, through a critical reading of Weiss and Kavanaugh's approach to embodiment, I have been able to find a new framework for my own thoughts and suggestions for improving palliative care.

2.1 Body as Object vs. Body as Subject

Before conducting an analysis of the anthropological foundation based on embodiment, let me focus my research with some brief remarks on 'embodiment' and 'embodied object-subject understanding' in the phenomenological tradition. A clear understanding of these concepts provides insight into one's personal existence and the basis for a better understanding of Weiss and Kavanaugh's work.

In the phenomenological tradition, the concept of embodiment is “regarded as experienced body sensation, whereby the body is understood as the scene of the immediate, of the pre-reflexive or the life’s taking place, in the context of individual actions, perceptions and experiences in their role for human self-understanding.”⁶⁶

Richard M. Zaner describes *embodiment* as the following:

“From the earliest stirrings of human fetal life through old age, individuals are embodied. Whether their bodies are more or less healthy, or are sick, injured, compromised by congenital or genetic defects, or are such that they arouse social prejudice, individuals experience the surrounding world by means of a particular body... Individuals experience their own bodies in different ways, depending on initial biological endowments, native and cultivated abilities, activities that are available and/or encouraged, and others. Embodiment is thus fundamentally connected with various levels and modalities of bodily actions, attitudes, stances, and movements, personal striving or willing, and perceptual awareness of things.”⁶⁷

Zaner also summarizes these experiences as follows: “In sum, regardless of the state of health, skin coloration, sexuality, or sociopolitical usage, one body is uniquely singled out for a person’s experience as ‘mine’, as that sole body through which anything else is experienced.”⁶⁸ What Zaner observes here is that the body is always regarded as a carrier of, or vehicle for, the preferences, wishes or interests of a person. As embodied human beings we do not occupy our bodies, rather we are bodies.

Furthermore, many body theory scholars like Zaner or Fielding draw on Merleau-Ponty, who probably more than any other philosopher presented an insightful comprehensive examination of subjectivity as embodied engagement with the world.

⁶⁶ FIELDING, H. A., “Body Measures: Phenomenological Considerations of Corporeal Ethics,” in *Journal of Medicine and Philosophy* 23/5 (1998): 533-5.

⁶⁷ Richard M. ZANER, “Embodiment: The Phenomenological Tradition,” in *Encyclopedia of Bioethics* 1 (New York: Georgetown University Press, 1996), p. 293-6.

⁶⁸ *Ibid.*, p. 300. See also Julie CHEVILLE, “Confronting the Problem of Embodiment,” in *International Journal of Qualitative Studies in Education* 18/1 (2005): 85-107.

What makes Merleau-Ponty's account of embodied engagement both important and attractive is that as a living 'body-subject', both skills and bodily movements are incorporated into the body-subject. Therefore, we are not objects but rather physical subjects, shaped and formed within a particular cultural, social, and political context via our embodied engagement. We are also not spirits imprisoned in our bodies.⁶⁹ Further to this, Elisabeth Moltman-Wendel in her book, *I am My Body: a Theology of Embodiment*, elaborates upon the expression "we are body-subject" this way:

We have a body for working, for running, for carrying, for loving, for eating, for dancing, in short for doing all the things that we have to do and like to do. Our predominant experience is also that the body functions, that it does what we want it to. When it no longer does so, we become insecure. If the body no longer functions, we no longer function. If the body begins to stop functioning, we make those around us insecure. And in such crises we have another experience, namely that we are bodies. The instrument of our pleasure gives us another experience: that it is our prison. The body takes over our will, our understanding. Now it no longer begins below the head, but is the whole of us. We are bodies...without this body I do not exist, and I am myself as my body.⁷⁰

What Moltman-Wendel points out in this example is that we always perceive the world and others through our physical and biological body. We are embodied subjects.

Another good example that reveals the elements of this embodied "subject-object" understanding can be observed in the case of a dying patient in palliative care. The first aspect is his innate biological structure; he experiences himself/herself and the world around him/her through his/her physical body quite differently from one who is healthy, or even one who is taking care of him/her. The second aspect is the dying

⁶⁹ These ideas on the body-subject in the world express Merleau-Ponty's effort to avoid the materialists' and the idealists' concept of 'being-in-the-world' in phenomenological philosophy.

⁷⁰ Elisabeth MOLTMAN-WENDEL, *I am My Body: A Theology of Embodiment* (New York: Continuum, 1995), p. 1.

patient's physical body, which experiences sensations and embodies wishes and movements. It is the means by which she/he perceives and through which other things are experienced. Finally, the dying patient's bodily experiences refer also to a particular cultural and social context unique to the dying patient.

Importantly, this embodied "subject-object" understanding has a tremendous impact on how we see our bodies and how we should be attentive to an embodied relational person in palliative care. When we approach someone's body, we are not just opening our world to him, but rather we are entering into his world of experiences and movements.

Furthermore, as I choose the phenomenological approach based on the human experiences of a dying person in palliative care, let us define *embodiment* as an human being in its own right: giving one's immediacy and materiality to the world around her and being constitutive of one's own self-understanding. Choosing phenomenology here reflects not only upon the importance of the body as the subject of medical treatments, but also to the physical body as it encompasses everyday concerns and care. In a broader perspective, this phenomenological approach presents an important insight into a personal existence that is both embodied and relational.

This brings us to my chosen authors, Weiss and Kavanaugh, who describe embodiment not only as the bodily existence, but also as the bodily experience: that is, to emphasize the fact that the experience of being embodied is never a private affair, but is always shared through our continued interactions with other human and nonhuman bodies. Acknowledging and addressing the multiple corporeal exchanges that

continually take place in our everyday lives⁷¹ demands a corresponding recognition of the ongoing construction and reconstruction of our bodies and our body images. These processes of construction and reconstruction in turn alter the very nature of these intercorporeal exchanges, and in so doing; offer the possibility of expanding our social, political and ethical horizons. What is especially evident in Weiss' and Kavanaugh's approaches is that they open up for us a new, or perhaps an 'old forgotten' perceptive and holistic anthropological understanding of human beings as an integral union of consciousness, soul, and body.

At this point, let me propose a more detailed context within which the notion of embodiment has been developed and defined using Merleau-Ponty's account of the lived body-subject. Weiss and Kavanaugh drew on Merleau-Ponty's approach and phenomenological method of inquiry, and described the anthropological foundation of the human being with two important observations: 1) subjectivity is embodied; and 2) all subjectivity is intersubjectivity. As Weiss writes, "For Merleau-Ponty, the danger of viewing the body as a singular entity is that we may lose sight of the fact that the body is never isolated in its activity but always already engaged with the world".⁷² Or, as Kavanaugh puts it, "I am more influenced with the approach and style of Merleau-Ponty, a philosopher who provides us the idea that the body is the basis for the self."⁷³

In order to situate my chosen authors, it should be noted that attention to subjectivity as embodied has been developed by philosophers like Olkowski (2006),

⁷¹ These multiple corporeal exchanges will be explained later in this chapter.

⁷² WEISS, *Body Images*, p. 1.

⁷³ KAVANAUGH, *Who Count as Persons*, p. 33.

Brubaker (2006) and Dreyfus (2002, 2005). However, these scholars do not elaborate on anthropological foundations beyond the notion of subjectivity. More comprehensive attention to subjectivity as intersubjectivity has been developed by philosophers Weiss (2006), Kavanaugh (2006), Kittay (1999) and Cahill (1996, 2006), who emphasize that we are always related to the world and to others through our embodied bodies.

2.1.1 Gail Weiss

Gail Weiss⁷⁴ is an Associate Professor of Philosophy and Anthropology as well as the Director of the Human Sciences Graduate Program at George Washington University in Washington, D.C. She works in the field of phenomenology and existentialism, specialising in the areas of embodiment, gender, personal identity and variation. Weiss actively participates in co-operative research between the United States and Europe, especially in the International Merleau-Ponty's Circle and in two networks of feminist phenomenology: The Society for Interdisciplinary Feminist Phenomenology⁷⁵ and the European Network for Feminist Phenomenology.

Weiss' approach to the lived body seeks to promote a philosophical discussion of the relationship between bodies and body images with, crucial corporeal, social, ethical and political implications. She argues that embodiment is central to our social identity as

⁷⁴ See more of Weiss' work: Gail WEISS, *Body Images: Embodiment as Intercorporeality* (London: Routledge, 1999); Gail WEISS, *Refiguring the Ordinary* (Bloomington: Indiana University Press, 2008); Gail WEISS, Jeffrey J. COHEN, eds., *Thinking the Limits of the Body* (SUNY Press, 2003); Gail WEISS, H. HABER, eds., *Perspectives on Embodiment: The Intersections of Nature and Culture* (London: Routledge, 1999); Gail WEISS, ed., *Intertwinings: Interdisciplinary Encounters with Merleau-Ponty* (SUNY Press, 2008); Gail WEISS, Dorothea OLKOWSKI, eds., *Feminist Interpretations of Maurice Merleau-Ponty* (University Park, PA: Pennsylvania State University Press, 2006).

⁷⁵ See SOCIETY FOR INTERDISCIPLINARY FEMINIST PHENOMENOLOGY at the University of Oregon, available online at <http://sifp.uoregon.edu/>, accessed January 3, 2011.

well as to our practical physical existence. Throughout her writings, every discussion of the lived embodied body acknowledges the body as the basis of experience.

Moreover, Weiss' exploration of what it means to be an embodied subject involves a critical appraisal of the phenomenology of embodiment as an embodied engagement with the world and others, as found in the works of Merleau-Ponty and Paul Schilder, and in dialogue with feminist authors like Susan Bordo, Judith Butler, Elizabeth Grosz, Donna Haraway, Luce Irigaray, and Julia Kristeva and their analyses of the socio-historical basis of embodied body/ body images with all its social, ethical and political implications.

Furthermore, Weiss draws on Merleau-Ponty's understanding of embodiment as a form of knowledge gained from our bodily experience, or as a non-conscious way of knowing the common physical skills and everyday activities that have been repeated and learned over time. Throughout her writings, she expounds this definition of embodiment into both corporeal and intercorporeal conditions of human life formed by a series of overlapping identities and body images, leading the way to a new embodied ethics instead of traditional theories which do not observe the ambiguities of embodiment, nor pay attention to the human experiences of relational persons. The phenomenon of the body is the basis of the human experience and begins from the concrete situatedness in the world. Thus, the body of a concrete person is the basis of experience.

Moreover, according to Weiss, the unity of the human being is given as a non-negotiable point: it is the touchstone that serves to break apart single aspect or dualistic theories of human nature. Consequently, any philosophical anthropology that would deny the integral unity of a human being is not sufficiently attentive to the basic

perception that is foundational to any philosophy, because this perception can only occur if a human being is already an integral union of body, soul, and consciousness.

In her book, *Perspectives on Embodiment: The Intersections of Nature and Culture* (1999), Weiss explores this concept even further and claims that the lived body not only serves as the medium through which the body, mind, and environment emerge, but also that our lived body, from its inception, is related and plays a role in our relationships with one another. Because of our shared embodiment, she argues, we have something that connects us and makes dialogue possible. Thus, we need not necessarily rely on language or reason: our connection with others occurs at a much more basic level – our bodily existence.

Moreover, Weiss in her development of embodiment also indicates the importance of attentiveness to basic perceptions that must be understood not as global perceptions, but rather as the richness of perception through which the human being is opened up to the world. Weiss, drawing on Merleau-Ponty's work on perception, suggests that perception refers to awareness achieved through all of the senses and includes our emotional grasp of the world and the value of things. Thus, perception also includes the basic sense not only of the things themselves, but also of our relationship to them. Perception reveals that the human mind is incarnated in a body, and therefore, we as human beings are an integral union of body and consciousness.

Lastly, Weiss reminds us that our embodied union is not the result of any experience: it is a fact - too often forgotten by many philosophers, theologians and ethicists - that our thinking is inherently grounded in our bodies. Therefore, it is important to note here, especially in our Western culture, that our minds are shaped by

different scientific ways of thinking about ourselves and when we try to detach ourselves from our bodies, we often forget that we are our bodies; we reflect the world and other human beings around us only through our material bodies. We are truly lived bodies and our consciousness infuses our bodies; we are an integral union of body and consciousness.

Building upon these initial insights and remarks concerning the understanding and development of embodiment, Weiss continued in her exploration on the lived embodied body in her monograph, *Body Images: Embodiment as Intercorporeality* (1999). There, she used the phenomenological approach to better understand embodiment as intercorporeality, and argued for a multiplicity of body images that are co-present in any given individual, and are constructed through a series of corporeal exchanges that take place both within and outside of specific bodies. In other words, Weiss explored how to approach and address the multiple corporeal exchanges that demand a corresponding recognition of the ongoing construction and reconstruction of our bodies and our body images.

At this point, it is good to note that many other feminist critics like Luce Irigaray or Elisabeth Grosz presented and analyzed the importance of the embodied body and the formation of one's own body image. Weiss believes, however, and herein lies her essential contribution to embodied theory, that more substantial and specific exploration and examination is needed of the body image and its influence in forming our identity in relation to our physiological, social, and psychological bodily dimension.

Moreover, Weiss' understanding of body image and its influence in personal identity formation also differs from the writings of Iris Marion Young and her concept

of the female-lived body, distinguished by the idea of the “socially referred character” of bodily existence. Weiss resists this distinction and points out that the embodied body presents a unified subject around which ethical and social discussion reasoning is made.

Weiss’ contribution and understanding of body image(s) offers a new and important foundational ground for better articulating embodied ethics with an emphasis on a more comprehensive ethics of care. In seeking to approach the embodied body/body image, Weiss argues that the body image is multi-faceted in how one sees oneself and how it relates to others. Weiss, however, suggests that the embodied body or body image is never isolated in activity, but always related to the world, as similarly suggested by Merleau-Ponty:

I experience my own body as the power of adopting certain forms of behaviour and a certain world, and I am given to myself merely as a certain hold upon the world; now, it is precisely my body which perceives the body of another and discovers in that other body a miraculous prolongation of my own intentions, a familiar way of dealing with world.⁷⁶

Moreover, body image is not for Weiss a cohesive, coherent phenomenon that operates in a relatively uniform way in our daily existence; rather the body image/body schema is the result of a series of overlapping identities, and one or more of these images may be especially salient at any given point in time.⁷⁷ The body image in Weiss’ analysis presents an innovative definition or understanding of the embodied person as a dynamic unit that is not only the locus of a social or central identity and existence, but

⁷⁶ MERLEAU-PONTY, *Phenomenology of the Perception*, p. 412.

⁷⁷ Weiss’ observations are very significant here for medical or bioethical ethics, as they define human beings with medical, cultural or spiritual needs. See also VOGEL, *Body Theology*, pp. 148-60.

rather as a body not yet finished but still engaged with the world around it. The body is presented here as being open to transformation towards many possibilities for existence.

In addition, one may notice that Weiss uses two terms: body image and body schema. As a result of mixing these two terms, one may ask if body image refers only to the manifold manner in which one views oneself and one's relation to others, and the body schema as the manner in which one organizes the world for motor action that can engage with the world, or if the body image is only part of the body schema or not. As Weiss is sympathetic to the theory of embodiment, one is led to believe that the body schema is also seriously affected by the body image. There is at present a dispute regarding whether Merleau-Ponty recognized a clear distinction between these two terms. Weiss suggests that Merleau-Ponty used the terms body image and body schema interchangeably (as she also does), but philosophers like Gallagher and Meltzoff contend that he did not make an explicit conceptual distinction.⁷⁸

As Weiss further argues for the multiplicity of body images, she removes the account of body as 'the' body, and also challenges us by adding the socially and historically specific dimensions of corporeality. These various body images also emphasize the importance of social relations in our daily life. She also suggests the following: "To emphasize the moral agency of particular bodies at once involves paying attention to how gender, race, ethnicity, age, and class status are embodied and to how

⁷⁸ See more in Shaun GALLAGHER and Andrew MELTZOFF, "The Earliest Sense of Self and Others: Merleau-Ponty and Recent Developmental Studies" in *Philosophical Psychology* 9 (1996): 213-36.

these (differentially) affect the nature of the interactions between individuals as well as the obligations that arise out of those interactions.”⁷⁹

These analyses and syntheses demonstrate Weiss' argument about how complex and interdependent these aspects of our existence truly are, and what a central role body images play in our everyday experience.

Weiss also proposes a very important observation when she suggests that by paying continuous attention to gender, race, ethnicity, age, and class status, all of which are subject to historical context, one cannot (especially philosophers, moralists or sociologists) voluntarily refrain from making judgements and state that these things happen only in moral theory. Weiss says that it is in and through our bodies that we feel the effects of our moral judgments and practices. Hence, the importance of moral theory or ethics cannot be fully embodied and relational without taking into account the role of the material body.

Moreover, Weiss further seeks and critically analyzes the best available accounts of the body and body images by Merleau-Ponty and Schilder. In the works of Merleau-Ponty and Schilder, she finds the most helpful philosophical discussions regarding the relationship between bodies and body images: a relationship, which has crucial corporeal, social, ethical and political implications. Thus, when she introduces Merleau-Ponty and Schilder's account of the body, based on their own understanding of the human image as found in the research findings of Sir Henry Head, she notes that both Merleau-Ponty and Schilder expanded the understanding of the centrality of the body image in many aspects of experience. She stresses “the body image changes not only in

⁷⁹ WEISS, *Body Images*, p. 140.

response to actual, physiological changes in the body and/or physical changes in the situation, but is greatly (and often lastingly) affected by psychological and social changes in the body/situation that need not be grounded in or tied to a current state of affairs.”⁸⁰

At this point, it is good to note the importance of insights from cognitive sciences like neurology, clinical medicine, and psychology on the body/body image, with their definition of the body as an organized whole, rather than as an abstract perceptual organ structure. However, both Merleau-Ponty’s and Schilder’s account of the lived body/body image as an integral union of consciousness and as an organic unity, lack these insights from this comprehensive and interdisciplinary account that includes both neuroscience and medical research.

Weiss claimed that both Merleau-Ponty and Schilder were significant in expanding the understanding of the centrality of the body image as ‘Gestalt’: “developing from a fragmented set of experience to a more or less coherent phenomenon through the mirror stage; already emerging narcissistically prior to the mirror stage; consistently seeking to establish an always temporary equilibrium; generating its own body image ideal; and lastly, as revealing its own constitutive otherness or alterity from one moment to the next.”⁸¹ However, she rightly points out that even if Merleau-Ponty and Schilder in their account of the body image do justice to the kinesthetic aspects of the bodily experience, it is really feminists philosophers who do justice to the foundational accounts of body images as the site of cultural clashes through their analyses of the socio-historical basis of the human body and its experience. What Weiss

⁸⁰ WEISS, *Body Images*, p. 9.

⁸¹ *Ibid.*, p. 10.

seeks is a more expanded discussion on the materiality of corporeal existence from different life perspectives.

Weiss, therefore, critically examines the implication of what Butler calls ‘the morphological imaginary’, that is, what constitutive roles body images play in imagination and fantasy. She also investigates the concept of ‘abjection’ and ‘the abject’ as introduced by Kristeva and presented by Grosz in order to understand the common social practices, which demand that we exclude certain aspects of our corporeal existence from our body images.

Weiss argues that these processes of abjection lead to a distortion in our body image that differs in the extreme rather than in degrees, from the distortions produced from gender associated diseases such as anorexia. In Weiss’ words, “...the deadly distortions in the anorexic’s body image stem from its excessive coherence, a coherence that can only be maintained through her disidentification with and repudiation of her own multiple body images.”⁸² In this claim, Weiss points out how distortion, contradictions, or some pathological and non-pathological site of oppression that can easily arise in our body image, brings about consequences as a result of necessary corporeal flexibility in response to our daily encounters in the world and with others around us. In other words, one’s openness to others and to the world around us, as well as awareness of one’s condition as being human, does not eliminate alterity.⁸³

⁸² Ibid., p. 99. See also essay by WEISS, HABER, “The Abject Borders of the Body Image,” in *Perspectives on Embodiment*, pp. 41-61.

⁸³ See also similarity with Merleau-Ponty’s account of intercorporeality in MERLEAU-PONTY, *Phenomenology of Perception*, p. 56 and 120 respectively.

Later in the chapter, “The Durée of the Techno-Body”, Weiss critically examines the interrelationship between bodies and technology, used both by and for them. In Weiss’ words, “I focus not only on your growing dependence on technologies to inform us about our bodies and to alter our bodily capabilities, but just as crucially on how the interdependent relationship between bodies and technologies retemporalizes and respatializes our embodied existence.”⁸⁴

Furthermore, Weiss also presents the moral agency of the body when she examines feminist theorists Friedman and Card, who view “moral agency as embodied phenomenon and the role that body plays in our moral interactions, bodily demands, needs, desires, and how appropriate is to pay attention to the gender, race, age or class statement who are embodied and affect the nature of the interaction between individuals as well as the obligations that arise out of those interaction.”⁸⁵

She argues, however, against the goal of Marilyn Friedman and Claudia Card’s project to go beyond a “nongendered moral framework.”⁸⁶ She explains, that going beyond a ‘nongendered moral framework’ means to be “disassociating morality from its source, namely, the bodies of moral agents, and this leaves her (especially Friedman) in an unlikely (and unintended) alliance with some of the very accounts she is rejecting (Kant or Rawls).”⁸⁷

⁸⁴ WEISS, *Body Images*, p. 4.

⁸⁵ See WEISS, *Body Images*, p. 140.

⁸⁶ Ibid., pp. 140-1. See also Marilyn FRIEDMAN, “Beyond Caring: The De-Moralization of Gender,” in *Justice and Care: Essential Readings in Feminist Ethics*, ed. by Virginia HELD (Boulder: Westview Press, 1995), pp. 70-1.

⁸⁷ WEISS, *Body Images*, p. 141, emphasis added.

The significance of Weiss' critique is that by using different theorists' examples from contemporary moral philosophy, she problematizes their transition from embodied differences toward a universal moral framework that is supposed to present the problem of justice within ethical reasoning. Weiss' critique, heavily based on Merleau-Ponty's account of embodiment, suggests more focus on the body as an open-ended, historically and socially contingent embodied agent.

Overall, Weiss seeks to promote the continued philosophical discussion of the relationship between embodied bodies and body images with their corporeal, social, ethical and political implications.⁸⁸ Therefore, her successful and concise critical examination leads to the importance of the embodied body as intercorporeality; that is to say that the experience of being embodied is always mediated by our continued interactions with other human bodies. This is far more important in its theory and implication than previously assumed by embodied studies in postmodern feminist body theory, embodied ethics or the ethics of care.

Furthermore, in order to strengthen her argument for the multiplicity of body images and bodily demands that bodies place on other bodies in the course of our daily existence, Weiss outlines the concept of bodily imperatives. In other words, I dismiss my bodily impulses and inclinations as irrelevant to my ethical projects by attending to reason alone. She also suggests that paying attention to the moral significance of our actions is not merely intellectual, but is also a concomitant physical and emotional response that arises out of our complex, concrete relationships with other bodies.

⁸⁸ See for instance, how Weiss in her essay "Urban Flesh", *Feminist Interpretations of Maurice Merleau-Ponty*, eds. with Dorothea OLKOWSKI, p. 157, encourages us to rethink the urban flesh relationship to its environment.

Finally, Weiss proposes that we make our bodies central to our moral theorizing. It is good to note that bodily imperatives present an excellent prolegomena to an embodied ethics and provide a comprehensive point of departure for our understanding of the entire phenomenon of embodiment.

The question arises as to how Weiss came to such a conclusion and also why bodily imperatives present an excellent prolegomena to an embodied ethics and to embodiment as intercorporeality. For this task, according to Weiss, one needs to look at the human experience in real living conditions, like dying in palliative care or in a hospital. As a thoughtful phenomenologist, Weiss carefully outlines the situation from Beauvoir's memoir of her mother's death from cancer, *A Very Easy Death*.⁸⁹ This story presents the fundamental relationship between people in their embodied existence, and their association with each other's demands.

Moreover, Beauvoir's memoir acknowledges her complicity in deceiving her mother, as she lay in a hospital bed, weak and dying of cancer. Her mother had a fall while in hospital and was unaware that she was diagnosed with terminal cancer without a prognosis for a full recovery. Of course, the doctors discussed if it would be wise to share such news with her mother. However, Beauvoir finally complies with the doctors' deception knowing her mother's deteriorating condition while wondering whether the deception is correct.⁹⁰ She identifies with her mother's suffering and understands that

⁸⁹ Simone DE BEAUVOIR, *A Very Easy Death* (New York: GP Putnam's Sons, 1966). See also the essay by Gail WEISS, "Review of Penelope Deutscher, *The Philosophy of Simone De Beauvoir: Ambiguity, Conversion, Resistance*," in *Notre Dame Philosophical Reviews* 2 (2009), where Weiss offers more detailed and developed reading of Beauvoir's insights regarding embodied existence and bodily demands.

⁹⁰ As this story was written in 1966, neither the ethical problem of not disclosing information to the patient nor that of medical paternalism was evident.

what is good for her mother is to give her false hope, even if it contradicts Beauvoir's personal philosophy. Here are the 'bodily imperatives' that Weiss describes; Beauvoir's responsiveness to her mother's suffering body is a reaction to something in her mother, which demands a response from her. These bodily demands are grounded in the intercorporeality of being.

Weiss' bodily imperatives remind us once again that we are embodied and relational human beings and that throughout our lives we empathize with the suffering of others, and share their joy, sadness, peace and hurt. It must be said that Weiss' concept of bodily imperatives provides important insight into embodiment and relationality, and reminds us that we are all corporally interrelated and dependent on one another (more in Chapter 3).

Weiss says that Beauvoir "definitely moves out from under Sartre's philosophical shadow", and provides a hitherto unrecognized anticipation of, and contribution to, the development of an ethics of care. It expands the moral domain so that it can no longer be understood through the limiting dichotomies of intentions versus actions on the one hand, and feelings versus principles on the other, but rather, incorporates and contextualizes all of these moral dimensions in the wider, embodied realm that Virginia Held calls "moral experience".⁹¹

Beauvoir's memoir recognizes a terminally ill patient not as an object, but as a subject, or as a person with specific needs and wishes. Weiss emphasizes this concept when she says, "Beauvoir herself is compelled to grant the moral legitimacy of these bodily imperatives, despite the fact that her mother's interests, needs and desires are so

⁹¹ WEISS, *Body Images*, p. 146.

very much in conflict with her own.”⁹² Weiss goes even further by saying that while Beauvoir and the doctors tried to decide how to care for Beauvoir’s dying mother, “the imperatives themselves arise out of the unique moral demands relationships place upon us, demands that are too complex to be understood through the confines of a master/slave battle in which each seeks the death of the other subjectivity.”⁹³ Later, Weiss also adds that Beauvoir’s dying mother, “set the terms for relationships the other parties all come to sustain with her and with one another.”⁹⁴

Another important insight from Beauvoir’s story is the ‘disturbance’ of the daughter over her mother’s naked body. One may detect the daughter’s resistance when she must see her mother’s body not as a beautiful being that can move and stand up or run, or as a competitive, attractive, dynamic body, but instead sees her mother’s body as tormented and adds that “the sight of my mother’s nakedness had jarred me. No body existed less for me: none existed more.”⁹⁵ She can hardly understand that her mother’s body is a fundamental aspect of that mode of relating with her mother.⁹⁶

Moreover, one of the most significant moments in Beauvoir’s story is the embodied presence of her mother to which Beauvoir is attentive. Even if her mother is alone in her pain and must die, Beauvoir comforts her mother with her bodily presence and in doing so, also comforts herself. Herein also lies the part of my new caring

⁹² Ibid., p. 150.

⁹³ Ibid., p. 149. It is good to point out here how moral dilemmas, and certainly interpersonal relationships, are more complex and difficult than any battle of subjectivities.

⁹⁴ Ibid., p. 149.

⁹⁵ See Simone DE BEAUVOIR, *A Very Easy Death*, p. 19.

⁹⁶ Here I suggest that for our ethical reasoning and also for medical practice today, we must return to this bodily understanding (head-trunk-two arms-two legs) as a mode of relating. Moral attention must be directed to the ambiguities of the body and bodily demands that are placed upon us.

presence framework, as Beauvoir's attentiveness and openness lie in their bodily demands and commitment to be "a window in your home".

This attentiveness and openness in Beauvoir's body, as well as her thoughts, are not without internal conflicts at her mother's passing in front of her eyes, despite her awareness of her mother's terminal prognosis. The scenario surrounding her mother's deathbed is like a sacred place where a sacrifice is burning and all involved are participating in the sacrifice. Beauvoir's mother wants to live, and to live both longer and fully. What is evident is that the value of life is stronger than death itself. In addition, Beauvoir's mother's body tells us about the lived human experience and about our embodied and relational existence.

This personal story chosen by Weiss points not only to the circumstances, relationships, and a good and peaceful way of dying when surrounded by family members and doctors, but also to the ambiguities of human bodies and to the moral legitimacy of bodily imperatives. Beauvoir's story also points to the importance of a person's wishes, desires, and specific needs, and to the importance of telling the truth about medical conditions to the dying patient, in addition to the importance of personal corporeal responsiveness toward dying. In other words, it is no longer just an embodied relational person who is dying, not just person's body, but also our own. In Weiss' words, "to act as a daughter, a mother, a sister, is not to deny my individuality or to diminish my moral agency; it is to affirm my own embodiment as well as the embodiment of others."⁹⁷

⁹⁷ WEISS, *Body Images*, p. 158.

Finally, what one finds interesting about Weiss' bodily imperatives, as part of our own embodiment is the body's demands on a moral subject's attention to the specific and changing needs of others. As Weiss says at the end of Beauvoir's story, "while the need to practice the deception may reflect a 'character flaw' in Françoise de Beauvoir, to affirm that desire that gives rise to it is to affirm the person from whom it issues as a living body who, in the act of dying, silently demands to be heard."⁹⁸

In sum, one of the most essential contributions by Weiss to embodied ethics, for the purposes of this thesis, is that our bodies are not static objects about which differing claims can be argued, but that they are actively involved in changing and shifting the discussion at hand. In Weiss' words, "to be embodied is to be capable of being affected by the bodies of others and, therefore, to be embodied is both necessary and a sufficient condition for generation of a bodily imperative."⁹⁹

Weiss draws on existing literature on the physiological, social and psychological dimension of body images and helps us to focus and acknowledge the lived body as the basis of experience. Moreover, her emphasis and development of Merleau-Ponty's examination of subjectivity as embodied engagement with the world expounds into both the corporeal and intercorporeal condition of human life, formed by a series of overlapping identities and body images, and brings a novel and important dimension into embodied ethics, specifically as it points to the body of the embodied person as the unity and basis of experience.

⁹⁸ Ibid., p. 157.

⁹⁹ Ibid., p. 162.

Weiss also explains some of her very important ideas that deal with our embodiment as intercorporeality. For example, through a reading of Merleau-Ponty's comprehensive examination of embodied subjectivity as an embodied engagement with the world, she articulates the link between things and our relationships to them. As embodied human beings we are in the world, and we perceive the things around us and have a relationship with them through our bodies. Weiss also overrides the subject/object dichotomy and articulates the union of our mind and body as the "body-subject". Our body is always responded to in a particular fashion.

In her writings, Weiss claims that our body image/body schema is not a cohesive, coherent phenomenon that operates in only one uniform way, but rather that our body image is formed by a series of overlapping identities. However, she did not truly clarify the distinction between body image and body schema.

Weiss also argues for the sociality and historicity of our body images. First she develops an insight from Merleau-Ponty and Schilder's theses about the corporeality and intercorporeality of human embodiment, which then evolves into the body image as subject of corporeal and contextual changes. Second, drawing on feminist scholars Bordo, Beauvoir, Butler, Irigaray, Kristeva, and Young and their analyses of the socio-historical basis of human embodiment, she points to body images as sites of cultural contestation. In this way, she shows how the body image is marked by assumptions about gender, race, ethnicity, class, or natural abilities and what a central role the body plays in our everyday experience.

Moreover, Weiss also promotes a philosophical discussion about the relationship between our bodies and body images with their corporeal, social, ethical, and political

implications. She argues that specific influences on body images in our society have not received sufficient attention to date.

Finally, in her most personal chapter, Weiss articulates the bodily demands or imperatives that our bodies place on other bodies in the course of our everyday existence. Drawing on Beauvoir's memories on her mother's death in *A Very Easy Death*, Weiss shows how concomitant physical and emotional responses arise out of our complex and concrete relationships with other bodies. In other words, she shows how our bodies and other bodies invade all aspects of our ethical discussion and debates.

Overall, Weiss' ideas provide a constructive and phenomenological understanding of how corporeal as well as intercorporeal bodies and body images are in our daily life, and what a central role they play.

2.1.2 John F. Kavanaugh

John F. Kavanaugh,¹⁰⁰ also drew on Merleau-Ponty's thoughts and on his embodied approach to the human body, seeking to promote the philosophical discussion of an embodied view of our human nature and of the intrinsic value of an embodied and relational person. For Kavanaugh, this is essential to our sense of self as an individual and as a social being, in whom cultural processes and societal ideals play out.

¹⁰⁰ See more of Kavanaugh's work: John F. KAVANAUGH, "The Quaker Approach to Contemporary Problems," in *The Western Political Quarterly* 7/3 (1954): 490-2; John F. KAVANAUGH, *Human Realization: An Introduction to the Philosophy of Man* (New York: Corpus Books, 1970); John F. KAVANAUGH, *Following Christ in a Consumer Society: The Spirituality of Cultural Resistance* (Washington, DC: Georgetown University Press, 1981, 1991, 2006); John F. KAVANAUGH, *Faces of Poverty, Faces of Christ* (Washington, DC: Georgetown University Press, 1991); John F. KAVANAUGH, *The World Embodied: Meditations on the Sunday Scriptures - Cycle A, Cycle B, Cycle C* (New York: Orbis Books, 1996-98); John F. KAVANAUGH, *Who Count as Persons? Human Identity and the Ethics of Killing* (Washington, DC: Georgetown University Press, 2001).

Kavanaugh is a professor of Philosophy and Ethics at St. Louis University in St. Louis, MO, where he is also a Director of the Ethics Across the Curriculum Program. He is well known not just among philosophers but also among theologians as an analyst and expert on topics at the intersection of ethics and philosophy, including embodiment, phenomenology, moral philosophy, and philosophical anthropology. He is also well known as a frequent contributor to *America*, the national Jesuit weekly magazine in the U.S.

Kavanaugh's aims and his essential contribution to the philosophy of embodiment and body theory has been to develop a philosophical anthropology or anthropological account of what it means to be 'an embodied human person' based on human experience as the starting point for moral inquiry. Therefore, his exploration and analysis of the 'embodied human person' has been the subject of his reflection since his Ph.D. dissertation, subsequently published as *Human Realization: An Introduction to the Philosophy of Man* (1970), and then later in his major works: *Following Christ in a Consumer Society* (1981), *Faces of Poverty, Faces of Christ* (1991), and *Who Counts as Persons: Human Identity and the Ethics of Killing* (2001).

Since 1980 in his weekly column "Ethics Notebook" in *America* magazine, he has also reflected on different philosophical and anthropological topics like war and terrorism, capital punishment, the killing of undeveloped human persons such as embryos, fetuses, and infants, and the killing of those who are dying in end-of-life care. Moreover, in reference to Kavanaugh's academic work and publications, the questions he asks and explores in philosophy come from his personal experience (as indicated in

his reflections and articles on Mother Theresa's work in Calcutta and elsewhere)¹⁰¹ and his concern for society today.

Kavanaugh is known not only for his phenomenological approach to personality, but also for his straightforward and non-didactic approach, never afraid to ask disturbing questions in reference to the Gospel or to society in general. In his writings, he not only critically evaluates society today, but also points out that every examination of today's ethics must use human experience as a starting point for us into the meaning and significance of suffering and death.

Let us outline Kavanaugh's account of the embodied human person along with an analysis and synthesis of his exploration. In his book, *Human Realization: An Introduction to the Philosophy of Man* (1970), he begins with this question: what does it mean that human beings are persons? He responds that it means that we are embodied persons. What Kavanaugh is referring to is the concrete living body-subject in the real world as draws on Merleau-Ponty's account of the body-subject, which is not just a union of body and soul, but also something else: an embodied and relational body-subject that perceives the world while engaging in the habits of interiority, intimacy and respect.

Kavanaugh also favoured Merleau-Ponty's insight on the embodied body-subject and used it as a foundation for his further arguments when speaking about the 'embodied self-conscious unity', which will be explained later in this chapter. In Kavanaugh's words, "Merleau-Ponty reminds us of our beginning. He gives us a map of reality that does not exclude the insights of a Hume or a Descartes or the challenges of a Derek

¹⁰¹ See Berry CLAYTON, "SLU Jesuit Philosopher Recounts Transforming Time Spent with Mother Teresa," in *Saint Louis University Newsletter*, 4 Sept. 2007, p. 2.

Parfit—but also does not repress the flesh-and-blood self-conscious reality of these men...Our immediate experience of ourselves in the world is a unity prior to brokenness, prior to a delusion that we must be either of two isolated substances, soul and body, that somehow must now, by philosophical conjuring, be brought together.”¹⁰² Kavanaugh furthermore emphasized that we are all embodied persons who are constituted as persons by our ability to be ‘aware of our awareness’.¹⁰³ Kavanaugh’s expression of ‘aware of our awareness’ is important here as it brings in a novel and important embodied dimension of our life, namely the awareness of oneself as a lived body. Kavanaugh is not referring here to some idea or philosophical notion, but rather to our personal experience of embodiment as the foundation of our personhood in relationality with other human beings. We discover the nature of beings by looking at what they are capable of. For Kavanaugh, we are embodied self-conscious units and autonomous centers of rationality and individuality.

This development and interest in embodied self-conscious unity can be clearly seen in Kavanaugh’s subsequent books, *Following Christ in a Consumer Society* (1981) and *Faces of Poverty, Faces of Christ* (1991), where he analyses the relationship between the body and society. In these books, Kavanaugh critically analyses the modern consumerist society and argues that such a capitalist society (US, 1981, 1991), with its framework of competitive and acquisitive values, leads to the idolizing of the nation, success and self-interest: it leaves its citizens with “empty interiors”, “broken

¹⁰² KAVANAUGH, *Who Count as Persons*, p. 32.

¹⁰³ Kavanaugh’s insight reflects the intense academic interest and activity of many other body theory scholars in philosophy since the 1970s like Bourdieu (1977), Foucault (1979), and Mauss (1973), who were concerned with social theory and equality issues, and redefined the body as a socio-cultural and historical phenomenon.

relationships”, and a “craving for things”, as well as “injustice” and a culture that is “disgraced and inhuman”¹⁰⁴. He describes the situation at that time as dangerous and poisonous, and leading man away from his human personhood and changing them into commodities and things. “Once self-worth is defined in terms of appropriation, the cultural myth will relentlessly be one of materialism, property, consumption, buy-power, competition, and great economic exploitation”,¹⁰⁵ says Kavanaugh. He rejects such a “commodity form” of life and rather proposes the search for a “personal form” that presents the human person as irreplaceable and of intrinsic worth, and whose role in the embodied body is to be an active participant or agent in the social world.

Moreover, in *Following Christ in a Consumer Society* (1981), Kavanaugh claims that this personal form has been greatly revealed in Jesus and his Gospels with its values and vision as a way of life. The human embodied person, as an active participant and agent in the consumerists’ culture, must find himself in a position of resistance. Jesus, according to Kavanaugh, shows us in his way of life and Gospel what it means to be dependent on God and one another. “It should not come as a surprise, that a follower of Jesus might find himself or herself to be an outsider in a culture dominated by the commodity. It should be no shame to be different, even to feel a bit disjointed and out of place, in a civilization which divinizes the thing,”¹⁰⁶ says Kavanaugh. To put it differently, Kavanaugh offers us here an insight into what it means to enter into Christ

¹⁰⁴ KAVANAUGH, *Following Christ in a Consumer Society*, pp. 3-19, pp. 25-37.

¹⁰⁵ *Ibid.*, p. 35; KAVANAUGH, *Faces of Poverty, Faces of Christ*, pp. 12-45.

¹⁰⁶ KAVANAUGH, *Following Christ in a Consumer Society*, p. 99. See also John F. KAVANAUGH, “Wounded Humanity and Catholic Health Care. Some Contemporary Thinkers Have Forgotten What ‘Healing’ Really Means,” in *Health Progress* 81/5 (Sept.-Oct., 2000): 12-18.

and to meet him in one another. He further encourages Christians in the midst of the consumerist culture to be alert, and to live in a personal form through prayer.¹⁰⁷ At the same time, he advises all Christians to cooperate with one another, educating and working for social justice.

Moreover, from the point of body theory, Kavanaugh provides a sense of understanding about our embodied body as an active agent in the social world, although always mediating our relationship to the world around us. As such, he favours Merleau-Ponty's insight that "the body is our general medium for having a world"¹⁰⁸, and therefore, not only constitutive of subjectivity, but also of intersubjectivity, that is, the ongoing interplay and partnering among embodied agents that take place in daily life and in our relationships.

In his book, *Who Counts as Persons: Human Identity and the Ethics of Killing* (2001), Kavanaugh follows these preliminary remarks and developments using a personality-oriented approach, and offers a compelling critique of Western contemporary society in regards to every embodied person. He sets out to "formulate a view of the human person that embraces our animal existence as well as our personal endowments; establish a theory of intrinsic value, not only of every species but preeminently of the personalized human species; integrate an objective ethical system with our identity as ethical animals, and defend the extremely controversial position that intentionally killing a human person is never ethically permissible."¹⁰⁹

¹⁰⁷ One may find here an association with Christian humanism/personalism as seen in the lives of Peter Maurier or Dorothy Day, or in the writings of John Courtney Murray.

¹⁰⁸ MERLEAU-PONTY, *The Phenomenology of Perception*, p. 146.

¹⁰⁹ KAVANAUGH, *Who Count as Persons*, p. 4.

As such, Kavanaugh rejects both the utilitarian and deontological methods exemplified by philosophers like Mill and Kant, and regards his thesis as a personal recovery from the reintegration of the human person: “my being human, my embodied-self-consciousness, is the arena of and condition of ethics. Therefore to understand ethics, I must first understand the personal ground from which it grows, the soil of my own space-history aware of itself, the soil of embodiment.”¹¹⁰

He then develops his definition of an ‘embodied self-conscious unity’, in contrast to the existing norms and understanding of the human person in recent contemporary philosophy and in the media, which tries to continually detach from the human person and separate his own interior world from the interpersonal world. According to Kavanaugh, this contemporary view is seen in the writings of Derek Parfit in his book, *Reasons and Persons*,¹¹¹ where he argues (with similarity to Merleau-Ponty’s rejection of mechanistic theories of perception) that “personal identity is not what matters”. Parfit’s book focuses only on the “mechanical brain and disembodied Cartesian ego”, and points to what has been discussed in the writings of many philosophers, specifically, that “persons are either airy, insubstantial selves that can be literally ‘nowhere,’ or highly localizable bio-computers, either reluctantly or eagerly identified as brains. The ‘self’ is either ghost or a machine.”¹¹²

In my view, Kavanaugh has chosen Parfit’s book and critiques it because he sees in Parfit’s argument one of the core issues that Western society is struggling with: the

¹¹⁰ Ibid., p. 23.

¹¹¹ See Derek PARFIT, *Reasons and Persons* (Oxford: Clarendon Press, 1984).

¹¹² KAVANAUGH, *Who Count as Persons*, p. 12.

inability to come to a consensus regarding who and what is a human person. Within the broader consumer-driven contemporary liberal democracy, the focus is on dominant values like individual autonomy, independence, economic prosperity, or enjoying the pleasures of a hedonistic lifestyle.

Later, Kavanaugh posits that behind the recent theorists' talk of the end of the self or the end of humanism, there is "the disenfranchisement of the human person".¹¹³ He further states that "we experience ourselves as driven to seek out our truth, yet so often we repress and dampen the drive itself...The conflict between the repression and liberation of our personhood ranges throughout our personal, social, and theoretical worlds. To find and accept the true self or to flee it."¹¹⁴ The society in which we live, as presented by Kavanaugh, is constantly trying to separate our interior world from our interpersonal world. In other words, we will never find the truth about ourselves as long as we do not understand that personal, social, and theoretical worlds penetrate our embodied being.

Kavanaugh argues that even philosophy today is not searching for wisdom, but is itself almost detached from any context that focuses on the human person. A philosopher forgets that when he observes a human person's values, moral principles or theories, he is first of all an embodied, relational and dependent person who is seeking self-understanding. In his own words, "we just don't determine the meaning of our own

¹¹³ Ibid., p. 21.

¹¹⁴ Ibid., p. 14.

lives, but rather write our own autobiographies within a rich context of meaning that is already set in place by the sort of embodied animals we are.”¹¹⁵

Note, how Kavanaugh’s description of the embodied, relational and self-conscious person supports Merleau-Ponty’s idea of the embodied body and consciousness as not disconnected, but rather as integral parts of one another.

Later in his book, Kavanaugh continues in his attempt to explore, clarify and propose a more comprehensive anthropological account. He poses questions for his readers to allow them to ask the same questions that he did: “what is it about myself that makes me so? What is it about our longings that they so easily deplete us? What abiding truth is there to our loves that soars and aspires to permanence? Why do you threaten me in a way I have never experienced in the presence of even the loveliest of animals? Why is there so much at stake for myself in my own actions? And why am I offended when my actions are taken away from me?”¹¹⁶

In my view, Kavanaugh’s questions represent not only an excellent description of human existence as embedded in the human person, but they also remind us of the continuous separation of one human embodied person from another. This lack of attention to our self and to one another is a continual threat, and may be the cause of the malaise¹¹⁷ of Western society today.

Thus, to emphasize the present depersonalization, Kavanaugh also looks at social, political, and cultural agendas, and points out that we are a society that is

¹¹⁵ Ibid., p. 62.

¹¹⁶ Ibid., p. 16.

¹¹⁷ For more, see Charles TAYLOR, *Sources of the Self: The Making of Modern Identity* (Cambridge: Harvard University Press, 1989), especially “The Malaise of Modernity”.

becoming willfully forgetful of our own dignity and is easily distracted with modern technological sophistications. A troubling problem is that this forgetfulness also extends to others in regards to respect for human life and dignity. The powerful rhetoric of concern and compassion is refuted with the reality of the starvation and death of 15 million people every day, notes Kavanaugh, and today, society is constantly forgetful of the disciplines of interiority, community, labouring for justice, simplicity of life, and even openness to the marginalized.¹¹⁸

In addition, drawing on phenomenologist Calvin Schrag's book, *Experience and Being*, Kavanaugh argues for the importance of human experience as the foundation of ethics. He claims that the experience of our private world is mirrored in our interpersonal lives. This claim in the phenomenological tradition is not just a reference to Merleau-Ponty's account of human experience as essential for the understanding of the totality of the human embodied person, but is also essential for any investigation into human ethics. According to Kavanaugh, "A human ethics must be open to consideration of anything that is human: open to the demands that human questioning makes of us, and open to an understanding of what makes questioning possible in the first place. That experiential openness is not only what makes ethics possible; it is what makes mature human experience possible."¹¹⁹ In other words, this self-questioning allows us to search for an understanding of who we are as flesh, incarnated in space and time.

Finally, after all these previous insights and analyses, which form a 'map of

¹¹⁸ For more on social, cultural and political issues, see Kavanaugh's book, *Following Christ in a Consumer Society: The Spirituality of Cultural Resistance*, where Kavanaugh speaks about capitalism and consumerism, and also about contemporary society's biggest threat: the "fetishism of commodities".

¹¹⁹ KAVANAUGH, *Who Count as Persons*, p. 25.

present reality’, Kavanaugh formulates his understanding of embodiment in the following statement: “We are in the world as self-conscious bodies. We find ourselves in the middle of lives that are urgent to us, lives that are morally and existentially significant...The words we use, the texts we write, even the way we approach words and texts is set in coordinates of space and time, mediated to us by culture and intersubjective discourse.”¹²⁰ The phenomenological emphasis on the body in Kavanaugh’s definition is neither disembodied ethics nor the ethics of disembodied minds, but rather an expression of the lived body as an ‘embodied self-conscious unity’ or an ‘entire individual career’. Also, this exploration of the human body occurs not only when the body is fully functioning, but rather, it is a presentation of the embodied self-conscious unity of each of us from the moment that our individual lives begin until the moment we die. The body is the arena and the condition for ethics and any ethical explorations. Even if the body is fragile, it is still an amalgamation of the body and soul.

Therefore, for Kavanaugh embodiment is also union. The embodied body expresses and reveals self-consciousness; sensations and other feelings are expressed through our bodies. The embodied body is a locus and where one experiences one’s body as oneself. My body is mine. Your body is yours. Kavanaugh stated: “My body always reveals more than itself as an object. As embodiment, it reveals me as a subject of life. It is my primary and first expression to the world. My body is a revealing, an utterance... My body is my self-conscious revelation, expressing me, unveiling me in space and time. My body is the very personalization of this reality I know as me – the

¹²⁰ Ibid., p. 33.

condition for my possibility as a person in the world of nature, things and memory.”¹²¹

At this point, one may notice that when Kavanaugh or Weiss speaks about the “lived body” or “embodiment”, they both refer to the body not as a machine, but rather as a living organism which brings forth multiple possibilities to the world. In my view, we must understand the human person as a living body or an embodied body, as it is through our bodies that our personal intentional existence is lived. Thus, our intentional consciousness is experienced in and through our bodies. Our consciousness is not just locked up inside our heads.

It is important to acknowledge that both authors recognize the importance of the body’s ambivalences. It has been said that “our bodies are in the world as self-conscious bodies” and that belonging makes us both open and closed to the world. We belong to the world, to space and to history. In Kavanaugh’s words: “the only way to find me is to locate me in time, to spot my body, in the here and now...I experience myself as apart from the world, even though we are part of it. Although our bodies make us available to the world, as bodied, our availability is also held in check.”¹²² In this passage, Kavanaugh comprehensively explores how our experiences of space, time, and motility depend upon our embodiment. He elaborates not only who we are now, but also who we were, and how we continue to be a self-reporting narrative. Kavanaugh summarizes all these paradoxes of embodiment in the following way: “Openness and closedness, unity and separatedness, revelation and concealment, freedom and determination are the

¹²¹ Ibid., p. 36.

¹²² Ibid., p. 37.

ambiguities, then, of finding ourselves as embodied self-consciousnesses.”¹²³

Then, Kavanaugh further uncovers how our bodily comportment is infused with our mind and how our body needs to be understood as a whole, in both unity and communion rather than as a machine. Here Kavanaugh not only overcomes physiological reductionism, of which some may accuse him, but shows how it is impossible to speak about embodiment as a sum of the parts, beginning with the reductive approach. His strong emphasis on unity and communion presents another part of our bodily experience, and that is our relationship toward an experienced world, other people, other things and the environment.

More specifically, the lived body helps us to understand the world as experienced. To put it differently, we cannot understand the objects in the world or their meaning without reference to the bodily powers (senses, motility, language, desires) through which we have engaged them. Thus, as embodied and united, we are not just one part of the world, but rather a way of how the world comes to be.

This last statement also points to another dimension of embodiment: self-revelation. Embodiment, according to Kavanaugh, is the revelation of one's personhood. Our lived bodies not only open to us who we are and make us transparent, but also hide who we are: our self-revelation hides us. As Kavanaugh says, “Embodiment is expression, interpretation, communication, and language – all at once and primarily. Yet embodiment is concealment.”¹²⁴

Hence, the lived embodied body is also the “embodied awareness of awareness.”

¹²³ Ibid., p. 39.

¹²⁴ Ibid., p. 38.

In other words, what Kavanaugh means here is that our awareness of being aware is immaterial as it cannot be fully located in terms of space and time. This reflexive awareness makes us personalized animals. Kavanaugh says, “We are personal animals because among our endowments is the capacity for awareness of our own act of awareness that makes us animals who are not living a life but having a moral life.”¹²⁵ Therefore, the embodied person is an integrated, embodied life, inseparable from the facility of the body, abiding in time and history. In Kavanaugh’s words: “The human person is an embodied, self-conscious drama. We are life stories, narratives that start with endowments that make possible our becoming aware of our own stories and eventually writing our own autobiographies within the limits of our diverse histories.”¹²⁶

Kavanaugh then continues his exploration of the concept of embodiment and places the human person at the center of his ethical discourse. He claims that even the Universal Declaration of Human Rights announces that human beings are endowed with capacities that make them a person, but that the specific as to what really constitutes a person is missing. Kavanaugh wants to correct this definition and adds, “a human person is spread out in space and history; subject to development; formed by information of environment, genetic code, molecular chemistry, and historical accident. The personal self is the whole career-generated, elaborated, and realized over a finite and individual time frame. For embodied persons, these determinants are the necessary conditions of historical actuality – from which we, as embodied, have never been separated.”¹²⁷

¹²⁵ Ibid., p. 47.

¹²⁶ Ibid., p. 62.

¹²⁷ Ibid., p. 56.

Moreover, Kavanaugh also argues against the philosophical construction of a moral agent by theorists like Kant or Mill, and suggests a more “intrinsic approach to the anthropological ethics”¹²⁸ which does not eliminate or disembodify the human being, but rather points to the living body with its embodied emotions, value, experience, dignity and vulnerability as part of its existence. However, when Kavanaugh speaks in his intrinsic approach about the living embodied body as an agency, he refers to the body primarily as being intersubjective rather than as intercorporeal. What Kavanaugh wants to emphasize is the importance of intersubjectivity, and then explains the inner connection to intercorporeality. This structure also avoids the problem of subjective idealism, which is usually questioned when speaking about the embodied body per se.

In sum, one of Kavanaugh's most essential contributions toward embodied ethics for the purposes of my thesis is his claim that our embodied self-conscious bodies are inseparable from the “facticity of the body, abiding in time and history” with the capacity for freedom and the capacity for a relational affirmation of love. Moreover, our embodied body helps us to understand the world as experienced; therefore, our embodiment is a revelation of our personhood, or an “embodied awareness of awareness” of who we are.

Kavanaugh's interest in embodied ethics is inspired by a question arising from philosophical anthropology and the embodied ethics of what it means to be ‘an embodied human person’ based on human experiences as the starting point for moral inquiry. Kavanaugh develops his exploration through a broad philosophical, social, and cultural representation of the embodied body in philosophical and ethical literature and

¹²⁸ See KAVANAUGH, *Who Count as Persons*, pp. 75-7.

specifically favours Merleau-Ponty's insight about an embodied and relational body-subject that perceives the world while engaging in self-respect along with intimacy and the habits of interiority. He further develops this embodied approach to the human body and points out that our embodied body is not only constitutive of subjectivity, but also of intersubjectivity as an ongoing interplay and partnering with other embodied bodies.

Later, Kavanaugh offers a critique of Western society with its own social, political, and cultural agenda of depersonalization in regards to the embodied body as an embodied self-conscious unity, with a personal, social, and theoretical world that has an intrinsic value, self-identity, and untouchable human dignity. Kavanaugh argues against such a depersonalization and claims that we are active agents in the social world, which mediates our relationship to the world and others around us.

Finally, drawing on various philosophers like Parfit or Scharg, Kavanaugh also argues for the importance of human experiences as the foundation of an embodied ethics. In Kavanaugh's words, "My being human, my embodied-self-consciousness, is the arena of and condition of ethics."¹²⁹ This exploration is, according to Kavanaugh, essential for any investigation in human ethics as its emphasize on who we are as flesh, unity and communion, as "a map of present reality" or as the arena and the condition for ethics.

In the next sub-section (2.2), I will present a more critical reflection on the findings of selected authors in a comprehensive formulation of one's own body.

¹²⁹ KAVANAUGH, *Who Count as Persons*, p. 34.

2.2 Synthesis of One's Own Body

In this sub-section, I will synthesize Weiss and Kavanaugh's ideas on the concept of embodiment. Drawing on their responses to the concept of embodiment, I intend to refine their various positions into my own framework that is comprehensive in its approach to the caring presence.

Weiss and Kavanaugh wrote extensively about the concept of embodiment, drawing on the work of Merleau-Ponty and other notable accounts of the body in the recent philosophy literature. When they refer to the lived body of a human person, they identify him as an embodied human being. In other words, they both agree that to call someone a person means to give him a certain status, and they do not reduce him to the law of mechanistic or kinesthetic physiology.¹³⁰

Moreover, according to Weiss and Kavanaugh, there are three significant conclusions regarding the spatial and temporal existence of the embodied body: 1) a lived embodied body is always relating spatially to other beings; 2) a lived embodied body is always engaged with the world; and 3) a lived embodied body is always an expressive unity.

First, both authors explore the philosophical post-Cartesian ideas about a lived embodied body as always relating spatially to other beings. For Weiss and Kavanaugh in their core texts, *Body Images*, and *Who Count as Persons*, the lived body of an embodied person reaches beyond itself to meet and relate to others. In contrast to all

¹³⁰ Here I want to emphasize that to show respect by naming someone and not something is not just an act of respect by one person towards another, but is also an act of recognition, of acknowledgement and awareness of her/his personal presence. It is good to point out that this is an act of recognition, and our acknowledgement of personal awareness is part of our own embodiment.

other living beings, a person relates according to what they are, not for who they are. However, a more central revelation about this relatedness is based on the corporeal and intercorporeal condition of human life that is, from its inception, related and plays a role in our relationship with others. Weiss claims that our corporeal existence is always formed from a series of overlapping identities (that take place both within and outside of specific bodies).¹³¹ In other words, our life is not reducible to features of corporeality, but rather has an incorporeal quality: it is the ongoing construction and reconstruction of our bodies. Kavanaugh claims that as an embodied being we are not only constitutive of subjectivity or endowed with reflexive consciousness, but we are also constitutive of an intersubjectivity that allows us to connect to and help one another.¹³²

Moreover, when referring spatially to others, both authors point to the lived body as the base-line point for spatial orientation. Our bodies are always, and at every moment, living as spatial beings and relating spatially to other beings.¹³³ To put it differently, every word that we hear comes from somewhere in space, as does every colour or smell. All of the interactions of our bodies require that we live as spatial beings. Weiss further claims that our body is also always responded to in a particular fashion. Therefore, it is always a specific body, like mom's body, sister's body, etc.

Furthermore, Weiss and Kavanaugh's insight on bodily spatial orientation challenges the prevalent view on care for dying patients. Dying patients are living as spatial beings, and relating spatially to the palliative teams and also to their beds and to

¹³¹ WEISS, *Body Images*, pp. 66-7.

¹³² See KAVANAUGH, *Who Count as Persons*, pp. 152-3.

¹³³ WEISS, *Body Images*, p. 140.

their rooms. Through all of the different procedures or treatments, through all of the care, dying patients are always relating to all persons involved in their care. Dying patients' bodies occupy space and associates with human perceptions or actions in the world. In other words, the embodied human body is intercorporeally bound to other beings, and thus, is called to bear certain responsibilities beyond itself. Weiss, drawing on the human experiences in the real embodied existence of Simone de Beauvoir's memoir of her mother's death from cancer, calls these responsibilities "bodily imperatives", that is, demands that bodies place on other bodies.

Secondly, for Weiss and Kavanaugh the embodied body is also engaged with the world. Moreover, the embodied body is the meeting place of the past, present, and future: therefore it is carrying forward the past, outlining the future, and is in the present living in this bodily momentum.

Weiss draws on Merleau-Ponty's account of embodiment and observes that the embodied person cannot detach himself from own body. The embodied person body is permanently present for her without ever being able to observe itself as an object. Yet, the permanent presence and openness of her body is what enables her to observe objects and the world. "I experience myself as apart from the world, even though I am part of it. Although my body is my availability to the world, as bodied, my availability is held in check,"¹³⁴ claims Kavanaugh.

Most importantly, Weiss and Kavanaugh's insight about the body as engaged with the world also challenges the prevalent view on care for the dying patient. The dying patient's embodied body is situated in a dynamic envelopment of his limbs and

¹³⁴ KAVANAUGH, *Who Count as Persons*, p. 37.

organs into an organic whole or synthesized organism. Kavanaugh, here would go as far as saying that “our bodies are our invitation to life...My body is my self-conscious revelation, expressing me, unveiling me in space and time. My body is the very personalization of this reality I know as me – the condition for my possibility as a person in the world of nature, things and memory.”¹³⁵ In healthcare practice this means that the dying patient's embodied body is not only a subject to care for, but also an “invitation” for all involved in his care to enter into his personal existence or personal world. In *Body Images*, Weiss emphasizes this experience of being embodied as never a private affair, but rather as an open invitation to the world and to others that “calls us to respond ethically to one another and make our bodies as central to our moral theorizing as they are in our moral actions/practices”.¹³⁶

Furthermore, Kavanaugh also speaks about how “the dignity of an embodied person” or the “dignity of subjectivity” has to do with affirming the lived body as the expression of a unique perspective, not to be confused with an objective body understood as being only a collection of bones and tissue. In Kavanaugh's words, “the dignity of the human person resides in the capacities with which such personhood is endowed: the capacity for self-consciousness, the capacity for freedom, and the capacity for the affirmation of love.”¹³⁷

Overall, the recognition of the embodied body as engaged with other beings and with the world links *Body Images* and *Who Count as Persons*, because both Weiss and

¹³⁵ Ibid., p. 36.

¹³⁶ See WEISS, *Body Images*, pp. 134-6.

¹³⁷ KAVANAUGH, *Who Count as Persons*, p. 70.

Kavanaugh, through a critical appropriation of the phenomenology of embodiment in dialogue with a wide range of sources, through theoretical and narrative analysis, seek to show how complex our embodied bodies are in our everyday experience.

Thirdly, for Weiss and Kavanaugh, the embodied body is an ‘expressive unity’ which is experienced regardless of any of its parts, functions, or materiality. *Body Images* and *Who Count as Persons* complement each other by describing bodily spatiality, bodily intentionality, and expressive bodily unity, all inherently dynamic, and the very conditions for coming into ‘being-in-the-world’.

Weiss further claims that when we refer to the “body schema”,¹³⁸ it does not limit itself to the contents of the actual lived experience or nature, or even the global awareness of the existing parts of the body. Each human body is unique, and this uniqueness brings forth the field of perception. In other words, the expressive bodily existence that is singular to human beings is an ontological source of the establishment of fields of perception. Our bodily involvement in these fields of perception is also part of this expressive bodily existence. According to Kavanaugh, a body “as a way of unity and communion”¹³⁹ must incarnate itself, and in so doing bring about an incarnate meaning. We are truly not an uneasy alliance of matter and mind, but are really a ‘third kind’ of being.

Weiss in *Body Images* claims that the embodied human body is a participant in the field of perception that a person recognizes and is involved in, and constitutes a major component of each of his fields of perception. In other words, the person’s body is

¹³⁸ WEISS, *Body Images*, p. 27.

¹³⁹ KAVANAUGH, *Who Count as Persons*, p. 37, also pp. 15-16, pp. 150-3.

intimately and firmly involved and engaged in the field of perception that the person perceives. Kavanaugh also claims in *Who Count as Persons* that a person's body shares its being with every one of his fields of perception.¹⁴⁰ Therefore, they both contend that our personal embodied body breathes life into the system and sustains the fields of perception in which we are all involved.

Moreover, Weiss and Kavanaugh's analysis of an expressive body unity is also crucial for medical theory and healthcare practice. In my judgment, the fundamental challenge for medical theory and practice is to not regard the objective body as the object of medical interventions and medical, clinical, and palliative practice, but rather to focus on the subjective embodied body of the patient as a living body/personal body. With this focus, comprehensive care for the dying person in palliative care can change its character and practice as it incorporates an embodied and relational understanding and strong inner connection into the medical, psychological, and social need of the dying patient.

Finally, in agreement with Weiss' and Kavanaugh's analyses of embodiment, I would argue that the following insights are fundamental for my new framework, which is comprehensive in its caring approach towards a caring presence for the dying in palliative care: 1) human subjectivity or embodiment, understood as the self-consciousness and awareness of one's condition as human, is a corporeal as well as an intercorporeal condition of human life. Therefore, understanding our own life as intercorporeal beings helps us to understand our responsibility toward other human embodied beings and life itself; 2) we must bring both the past and the future together,

¹⁴⁰ See KAVANAUGH, *Who Count as Persons*, pp. 39-42.

and in so doing, open the door to a deeper understanding of the human person while offering a continuous dialectical exchange with the world; and 3) we must understand that our expressive unity is an integral union of body, soul, and consciousness, and points to our uniqueness as human embodied and relational beings.

This leads us to the next sub-section (2.3) where I agree with Weiss and Kavanaugh that the concept of embodiment is not only personal, but also has social aspects, never isolated in activity, but always engaged with the world and others.

2.3 Cultural and Social Dimensions of Embodiment

Both Weiss' and Kavanaugh's analyses of the phenomenon of embodiment highlight the need to be attentive to cultural and social dimensions. This sub-section will focus on these two dimensions and elaborate upon them. The reason for this elaboration lies in our embodied bodies situated in a specific culture, related to a public world, and striving always to make ethical decisions.

Weiss and Kavanaugh claim that the embodied person is never hermetically sealed. Our body's insertion into the world is a fundamental condition for our interacting with other people. Essentially, "embodied subjectivity is grounded in social, sensual and energetic interactions between embodied beings that exist within social relations of power."¹⁴¹ However, it cannot be forgotten that an embodied person is a social being by nature. The person perfects himself in society when realizing his generous and fraternal commitment towards improving the condition of the members of the community: person-family-society, in that order, gives realism to human sociability.

¹⁴¹ Jean S. JONES, *Narrating Multiple Selves and Embodying Subjectivity: Female Academics From the Working Class* (Ph.D. diss., Boston College, 1998), p. 43.

To be more specific, when arguing for personal and social embodiment, we must enhance our understanding of our exposedness to others. Consequently, one of the main descriptions of subjectivity is that it is not only intersubjective, but also intercorporeal. In other words, we inhabit the space between the body and the world, and similarly between subjects. For example, when my gestures play off of the gestures of others, they are also an expression of the world. Note that if our bodies are themselves meaningful through gestures, and if it is the case that subjectivity is present to some degree in the body itself, then indeed the perception of other subjects is not a problem.

At this point it is good to bring to our attention to one of the most important quotes from Merleau-Ponty's *Phenomenology of Perception*:

It is precisely my body, which perceives the body of another and discovers in that other body a miraculous prolongation of my own intentions, a familiar way of dealing with the world. Henceforth, as the parts of my body together compromise a system, so my body and the other's are on whole, two sides of the same phenomena, and the anonymous existence of which my body is the ever-renewed trace henceforth inhabits both bodies simultaneously.¹⁴²

What Merleau-Ponty is emphasizing here is that both “I” and “the other” belong to the world – in fact, we inhabit the same world – and because it is our world, and the only world we live in, it is as such only to the extent that it is expressed by us. In fact, we are only to the extent that we are expressed, and it is legitimate to reverse the description of the intentionality of the action. In other words, we are co-subjects of the world; the world returns to itself – “coiling over” on itself – through us.¹⁴³

¹⁴² MERLEAU-PONTY, *The Phenomenology of Perception*, p. 412.

¹⁴³ See also how different historical-social events in the world changed our understanding of embodiment, of who we are, and our identities, in MOLTSMANN-WENDEL, *I am My Body*, pp. 4-9.

Weiss and Kavanaugh in their respective works also situate the human person or the embodied person in a specific socio-cultural context. Although they both extend a total understanding of embodiment as not being limited to the physiological or technological influences on the human mind, they also incorporate the experiences of the social and cultural body and its impact. For example, when Weiss presents her perspective on cultural and social dimensions, she focuses on the importance of gender and race as sites of cultural contestation. She further points to the pathologies of today's society as always focusing on a socially acceptable identity and the negativity associated with the impossibility of maintaining a coherent identity. Weiss further argues that because foundational theories of body image are found to be deficient in their neglect of the social dimensions of corporal existence, some feminist scholars err when they reduce body images only to the social dimension. According to Weiss, individual perspectives on particular situations are connected to other perspectives through the interdependency of multiple horizons that reflect networks of social relationships and systems of meaning. Since the horizons of a situation are presupposed by an individual's perceptions and responses, we tend to overlook the "broader contexts of significance within which human beings give meaning to their lives."¹⁴⁴ She further adds that describing ordinary experiences thus requires "recourse to the horizons that contextualize them."¹⁴⁵ Such recourse can shed light on the horizons we share as well as

¹⁴⁴ For more about the multiple horizons that influence our bodies and habits, see WEISS, *Refiguring the Ordinary*, p. 24.

¹⁴⁵ *Ibid.*, p. 25.

the “fluidity of the intersubjective experiences out of which they are composed”¹⁴⁶ and so suggest alternative configurations of the ordinary.

Note how Weiss also claims the importance of the physiological dimension rather than focusing on the “discursive effects of historical power relationships”¹⁴⁷, which play a crucial and continuous role in the construction of body images. This reinstallation of the materiality of corporeal existence in Weiss’ work is of great significance also for embodied ethics. However, Weiss does not make an exact distinction between the material body (the physiological body as a style of being) and the social body image (the style of being with its social identity and practical existence), so one may refer to them as two separate layers of corporeal existence, with which I would personally disagree, as I consider both layers to be part of the corporeal existence of the whole embodied person. For example, in end-of-life palliative care, this understanding of the materiality of corporeal existence as the unity of the material body and social body image is very important, because the body of the dying person is not an object around which ethical decisions are made, but the dying person is a living subject that is actively involved in the changing physiological, social and practical realities of caring for the whole person.

Moreover, Kavanaugh looks at the shaping of contemporary culture by economic forces. The materiality of our corporeal existence, according to Kavanaugh, is continually shaping our self-identities within the particular culture that we live in, through acts of conscious introspection and deliberate reflection on the lived structures

¹⁴⁶ Ibid., p. 25.

¹⁴⁷ WEISS, *Body Images*, p. 2.

of our experience.¹⁴⁸ He also states that not only do our own lived experiences of our body shape us, but so does the way in which our experience of other animate bodies moving differs from our experiences of other moving objects in the physical world.

Furthermore, Kavanaugh, in contrast to Weiss, presents another view on the social and cultural dimension of embodiment, namely two modes for the perceiving, valuing, and living of life: the commodity form and the personal form. These two forms are totalizing perspectives from which the whole of social and personal life may be viewed. Under the commodity form, human embodied persons come to be regarded as marketable and replaceable commodities:

The Commodity Form, in effect, represses those qualities, which are most intimately and most specifically human... Persons relate to things as if they were persons; they relate to persons—including themselves—as if they were things. Having patterned ourselves after the image of our commodities, we become disenfranchised of our very every humaneness. Reduced to commodities, we lose the intimacy of personal touch. We cannot truly see or listen as vibrant men and women... We do not walk in freedom, since we are paralyzed by what is. Such is the result of idolatry. Those who make idols and put their trust in them become like them.¹⁴⁹

Under the personal form, a human embodied person is an embodied life-statement, a self-saying, which is uttered out of each one's finiteness. According to Kavanaugh, the personal form is a meeting point between the human and the divine and each one of us should live this form. He further argues that the fullness of personhood is only possible when each and every one of us adopts the necessary spirituality of resistance to the commodity form. In other words, true personhood is constituted in the

¹⁴⁸ See also how our bodies are shaped daily in bioethics: Silke SCHICKTANZ, "Why the Way We Consider the Body Matters – Reflections on Four Bioethical Perspectives on the Human Body," in *Philosophy, Ethics, and Humanities in Medicine* 2 (2007): 30.

¹⁴⁹ KAVANAUGH, *Following Christ*, p. 68.

acceptance of our own poverty rather than in trust in power, or escape, or in the acquisition of possessions.

Why is Kavanaugh's view on the form of cultural and social embodiment so important for this thesis project? I believe it is for two reasons: 1) for his emphasis on the importance of the body in defining personal identity; and 2) for his emphasis on the role of the social and cultural context in shaping the experience of the body. To be more specific, the body as a materiality of corporeal existence plays a significant role in defining personal identity. It defines who the person is not only as a physical being, but also as a distinct social and cultural personality with temperamental, behavioural, emotional and mental attributes. Moreover, the cultural and social context also constantly and dynamically shapes the body. The body is part of the culture and society, and vice-versa. Therefore, Kavanaugh's view on the form of cultural and social embodiment helps us to be aware when caring for dying persons. It is not just the dying person who needs our help, but also his distinct bodily, social, and cultural personality.

Thus, my only critique of Kavanaugh's proposal is in his narrowness in describing the commodity and the personal form. To explain briefly, for Kavanaugh, persons only count in the personal form. In commodity form, only "certain kinds of persons" count. I critique this part of Kavanaugh's proposal because our society usually doesn't degrade anyone, but rather looks into the circumstances that result in the inherent inequality of a person's life. Also, Kavanaugh's narrow definition of the personal form focuses on the virtues of faith, hope, and love. Even if these virtues are counter cultural, I would also add that along with them, the personal form must embody

social justice, missionary compassion, and care for one another, especially for those who suffer.

Moreover, it may have been sufficient in 1981, but today, in both end-of-care ethics and anthropological philosophy, we need new forms and categories to define and describe precisely our life-facing realities. In other words, we lack new forms and categories that would help us, in end-of-care ethics and anthropological philosophy, to appreciate what forms/categories we already have and then to propose new ones that will lead us to change the life-facing realities we deal with everyday. What I suggest here is that the one way we can create new forms is to apply the phenomenological method, with an emphasis on our embodied understanding of being as being-in-the-world, and to describe and define our relationship with the world we live in as intertwined, not only as the mere spatial locations of embodied subjects. By creating these forms we can better understand, connect, and care for persons who suffer and die in palliative and hospice care.

In sum, Weiss and Kavanaugh present different yet complementary perspectives on the cultural and social dimensions. They both recognize persons as a materiality of corporeal existence with certain types of biological capacities that allow certain forms of social interactions. However, for Weiss, one's 'status' of person is inseparable from one's interconnectedness with other persons. For Kavanaugh, while that interconnectedness is mediated through the body, it involves more than the simple possession of a certain type of body. It involves attitude and the practice of Christian values and virtues. Overall, the practices of nurturing, education, and socialization formed through social relations are important as well.

2.4 Vulnerability, Agency and Human Dignity

When I speak about the embodied body as a frame of reference, I cannot avoid the concepts of embodied vulnerability, agency, and human dignity. This sub-section will focus on these three aspects that emerge from reading both Weiss and Kavanaugh.

The works of Weiss and Kavanaugh suggest that vulnerability, agency, and human dignity can only be taken seriously when embodied realities and bodily needs are incorporated and developed. Their suggestion confirms what Wainwright and Turner argued: “bodies make themselves present at the very core of a range of different embodied phenomena, such as emotions, desires, identity, and agency.”¹⁵⁰ In other words, the lived body grounds the possibility of all experience, and bodies are also sites of vulnerability, agency and dignity.

Furthermore, vulnerability, agency, and human dignity are, according to Kavanaugh, best understood as a contemporary reformulation of a question of politics and spirituality: how should power be exercised, in which venues, by whom, and above all, according to which understandings of the human condition and the human good? I agree with Kavanaugh that the presented terms are in part a question of philosophical and political speculation, but I argue that we must ask what these terms mean for marginalized persons who are often dispossessed by the realities of racism, homophobia, and poverty.

¹⁵⁰ See more in S. P. WAINWRIGHT, B. S. TURNER, “Reflection on Embodiment and Vulnerability,” in *Journal of Medical Ethics: Medical Humanities* 29 (2003): 4-7.

Moreover, while Kavanaugh and Weiss identified the body as an active and vulnerable agent¹⁵¹ in the social world which deserves appropriate dignity¹⁵² and respect, they also observed that bodies also mediate the relationship between persons and the world. In other words, we meet through our bodies, and therefore our bodies participate in the agency of ourselves. This brings us to an important premise: one is an embodied self that acts on the world through his body. Note how this premise can influence our relationship to our own embodiment and also to other embodied beings. Importantly, the emphases here are not on subjectivity per se, but rather on the living embodied body as a vulnerable agent, as being constitutive of subjectivity and mediating the relationship between the person and the world.¹⁵³

Furthermore, many feminist scholars have tried not only to emphasize the importance of awareness when speaking and theorizing about the embodied living body, but have also pointed out how our lived bodies are sites of oppression. This significant feminist phenomenological approach to the embodied living body represents for me the social and ethical embodied realities in a globalized world, as well as in healthcare

¹⁵¹ To be a vulnerable agent is to possess a structure of being, sensing, thinking, and acting by which we can reflect upon and steer a passage through the social world. Vulnerability is also the concrete reality of our embodied lives, and of our inner connection or presence to be “a window in someone’s life.”

¹⁵² Some anthropological theorists like COMAROFF (1985) and CSORDAS (1990) use here a new category: “dignitary vulnerability.” Dignity is also the concrete reality of who we are as embodied beings, and situates us as a ‘being-in-the-world’, always in interrelation with others and the world around us.

¹⁵³ Here I would like to suggest that in palliative practice when dealing with dying patients, all involved in their care should not only seek to fulfill their psychological, medical or religious needs, but in focusing on the bodily experience should also seek to create meaning through the intersubjectivity between patients and the dependency workers. This embodied approach, heavily focused on the body, may enable us to redefine our relationship to the human experiences of perception, intuition, vulnerability and human dignity.

practice; only when all of these realities are taken into account, can we improve gaps at the national or local level concerning the human body.¹⁵⁴

To be more specific, the body has a social nature, as it is an expression of one's self as an active and vulnerable agent who plays a significant role in society, culture, and politics. Not only in the past but also today, the body is an active and vulnerable agent that is not just a symbol of gender, race, age, or class, but is also a site for resistance to the transformation of dominant values and conceptions. However, as a result of that transformation and resistance, it is appropriate to refer to our bodies as conceptualized and vulnerable embodied bodies.

Finally, let us look briefly at the concept of human dignity. This concept or principle is very well known as a universal affirmation that human beings have the highest value, and is the basis upon which human rights are understood to rest; it is inherent in each and every person, and is also inalienable.

More importantly, since the Universal Declaration of Human Rights in 1948, this principle has become widely presented in many official and non-official documents, statements, and policies defining the innate and cultural needs of every human person, including her medical, social, and religious needs as a member of the world community. Today we use many different concepts or frameworks for expressing and defining human dignity: the cosmo-centric framework of Antiquity, which defines human dignity

¹⁵⁴ For more on *Ethics of Embodiment*, see a special group of predominantly feminist scholars (like Gail Weiss and Habers among others) interested in Embodied studies as a theoretical framework, and who want to engage in “transgressive understandings of the body and embodiment; they resist rigid dichotomies and categories, and search for a radical theorizing of the materiality of bodies and their singularities, which question the very possibility of retaining stability in generalizing notions and frameworks of thinking.” CENTRE FOR GENDER RESEARCH, Uppsala University, “Mission statement of The Body/Embodiment Group”, available online at <http://www.embodimentstudies.com>, accessed May 20, 2010.

on the basis of nature; the Christo-centric framework, which defines human dignity in relation to Jesus Christ; the logo-centric framework, which defines human dignity as a tribute to reason; and finally, the polis-centered framework, which defines human dignity in relation to social acceptability.

However, given this general understanding of human dignity, along with Weiss and Kavanaugh, I would argue that when speaking about human dignity, one needs to take into consideration, along with vulnerability and agency, not only what is proper to a person as a person (for example humanness or earthliness), but also her living embodiedness. It is only when we are aware of our subjectivity that we can identify from the depth of our being, the fundamental value of other human persons and give them the respect they deserve. In other words, human dignity as self-actualization in relation to others is always embedded and relational, and is marked by a bodily understanding, and a sense of connectedness, respect and commitment.

Finally, all of these presented analyses of vulnerability, agency, and human dignity show how important these concepts are when embodied realities and bodily needs are incorporated and developed. They also suggest how the body is a vehicle for political, social, and economic forces, and a vehicle for resistance to these forces.

2.5 Conclusion

In this chapter I have described the anthropological foundation based on embodiment through the dialectical reading of my authors, Weiss and Kavanaugh, who have theorized the body of the concrete person-patient as the basis of experience.

Weiss and Kavanaugh have brought to the ethics forum a brilliantly fruitful way of thinking about one's embodiment as trans-agentic, and a neutral ensemble of corporal practices and demands that produce and give 'a body' its place in everyday life.

Moreover, in a more precise analysis of the embodied body, Weiss and Kavanaugh point out how our "self-conscious body" or "body image" is implicated in current individual, social, and political inequalities as an ongoing site of cultural oppression, and how our embodied body is also open to potential re-inscription and transformation. They both explicitly suggest that we must create a new image of the body; a dynamic image of the non-docile body that resists the human reality today.

Finally, based upon my dialectical reading of Weiss and Kavanaugh, I outlined three final elements for my new comprehensive caring presence framework: a) embodiment is a subjective condition of every human life and the source of lived experience; b) our self-awareness and self-understanding as embodied beings helps us to evaluate our own bodies and to act on this understanding towards others; c) our body is not reducible to its features of a corporeal quality, but also has an intercorporeal quality that helps us to understand our responsibility toward other human beings and life itself.

To complete my new framework for a comprehensive approach to the caring presence to the dying in palliative care, I will now focus on the notion of relationality.

Chapter 3: Relationality in the Work of Lisa S. Cahill and Eva F. Kittay

3.0 Introduction

Merleau-Ponty, in his *Phenomenology of Perception*, observes the way that beings are dynamically interconnected: “[I] discover in that other body is a miraculous prolongation of my own intentions...Henceforth, as the parts of my body together comprise one system, so my body and the other’s are one whole.”¹⁵⁵ What Merleau-Ponty calls to our attention is the embodied and relational way that we are related to others and the world around us.

Based upon Merleau-Ponty’s observation of the relational dimension of embodiment, let us now reflect on the concept of relationality, which I would argue, along with Cahill and Kittay, is one of the most important anthropological principles for a better-embodied care in palliative care today. In terms of the philosophy of embodiment and relationality studies, Cahill and Kittay are both adherents of a feminist body theory based on Merleau-Ponty’s comprehensive examination of subjectivity as an embodied engagement with others and the human world. In reference to the notion of relationality, both authors put an emphasis on relational responsibility – the immediacy of being with and dependent on one another. Therefore, their main argument is compelling and relevant to this dissertation: to be an embodied person means not to live in isolation, but rather to be essentially directed toward others and to be formed within a socio-cultural context.

Moreover, through a critical reading of Cahill and Kittay, I would argue that how we experience the world, and especially other people, is more than our physiological

¹⁵⁵ See MERLEAU-PONTY, *The Phenomenology of Perception*, p. 412, emphasis added.

functioning, even though the nature of our experience cannot be ultimately separated from the way in which our bodies function. In an end-of-life context, our experience with suffering and death is connected with a person's lived experience, and together represent these the gateway toward responsibility for each other.

Finally, our relational responsibility requires publicly shared norms and a moral community to listen and respond to the actions of each individual.

3.1 Human Experience as Starting Point of Moral Inquiry

Lisa S. Cahill and Margaret A. Farley remind us in *Embodiment, Morality, and Medicine* (1995), that we are all connected on the level of our human existence and that we are all relational human beings. However, Cahill and Farley also emphasize that our exploration must begin with the human experience mediated with both the body and mind as a starting point for us into the meaning and significance of suffering and death. It opens up for us the perspective that to be a human person is to be essentially directed toward others.

I agree with Cahill and Farley that our human experience is mediated through both body and mind and that we relate to one another as embodied human beings. However, I would also add that as relational human beings, we not only relate to one another, but because of our interdependence, we bear mutual responsibility. But how can we know what other human beings want? What are our mutual responsibilities?

To find possible answers, I suggest that we go back to the concept of embodiment as articulated by Merleau-Ponty, who defines embodiment as how we live and experience the world and human beings around us through our perception, emotion,

language, time, movement in time, and sexuality. He does not state that perceptions fill the core of our persons and then slowly define the world and others around us. In other words, there is a relational link between our bodies and the world of meaning, as we experience and relate to others through the operation of our embodied selves. We must note that because of our human relationality, we have the ability to go beyond our physical embodiment and to understand love, pain, the value of suffering, and even our embodied selves. All these are human experiences at the level of our embodiment, as they shape who we are and how we see others.

Moreover, the most significant quality that determines our relationship and mutual responsibility is communication. In fact, communication with others determines our social responsibility to one another. Perhaps a simple example of the importance of dialogue and embodied intersubjectivity is that between the dying patient and nurse, a part of the necessary process of knowing one another and making meaning of the world and mutual experiences. The interaction between the dying patient and nurse allows for the mutual process of knowing one another, and their embodied responses provide insight into themselves, as well as immediate knowledge of their bodies, finally revealing the necessary needs and characteristics.

In other words, in order to know someone and to know her needs, any exploration must first of all focus on her human experience of himself and the world around him. This requires attention to the particular and contextual structural forms of a person's bodily dimensions. Let me note however, that there are interchangeable body images in a person's life. Thus, this multiple bodily dimension can vary individually,

like corrective experiences¹⁵⁶, social or religious experiences. Some dimensions are more important than others, but they all point to a person's needs and his understanding of the world around him.

As part of this intercorporeal participation and exploration, an inner or intimate space is created where the subjectivities of one person (e.g. the dying patient) and another person (e.g. healthcare professional or community volunteer) meet, and where relationality is at the centre of their attention. This inner intercorporeal space is created and maintained via embodied relationality, and I would suggest, should be part of any practice when dealing with the human experiences and needs of an embodied human person. Such an exchange of one's subjective (embodied and relational) self can enable someone to experience "being" with another, and can reach towards the knowledge of the potential space of the other. At the same time, during such an exchange with others the subjective self creates, co-creates, and even re-discovers himself. Thus, both actors in such an exchange are not "foreigners" but rather "active" contributors in their mutual development.

In short, attention to human experiences, particularly to the significance of bodily relationality to the self, to others, and to the world, reveals that our self, our world and others are intertwined together in important ways. The world and others are capable of altering us, just as we are capable of altering them. This mutual process and influence attests to the relational, moral or ethical responsibility that we bear, whether we like it, are aware of it, or even realize it; a responsibility for ourselves first of all, but also for others and for the world. Becoming more aware of this responsibility increases our

¹⁵⁶ Corrective experiences are the foundation for a new way to relate, one that enables mutual recognition, respect and intimate exchange.

sensitivity to others and therefore our ability to respond to others. Likewise, our relational responsibility to and for others is a manifestation of our relationship to a relational God.

Up to this point, I have spoken of our human experience as being fundamentally intercorporeal. However, this bodily approach to our human experience has been advanced and developed thanks to contemporary feminist scholarship. Thanks to feminist scholarship today, we are better able to understand the experiences and struggle of persons under oppressive social and economic systems; the experience of disabled children or adults; the experience of the elderly, or of those who are suffering or who are dying. Why? Because the people who meet the needs of these groups, and who are caring for them, are usually women. This “work of love” or “care/labour” is also connected to various hidden dependencies and impediments, of which I will build upon this scholarship and draw on the work of feminist scholars Cahill and Kittay.

Moreover, let me suggest some brief notes¹⁵⁷ regarding the importance of feminist scholarship and the feminist appeal to human experience as the source of relationality. Many feminist scholars have observed that women’s experiences have been ignored, silenced, or not even taken into consideration when presenting or speaking about the human person, or even about God.

Fortunately, this has started to change and feminist scholars like Kittay, Cahill, Nussbaum and Carr, among others, have begun to explore the various ways that women’s experiences are situated, concrete or historical, and might transform

¹⁵⁷ Let me note that these brief considerations and insights are very important for my dissertation, not only because I have used the women’s experiences of Cahill and Kittay and their writings, but also because I use women’s experiences as the norm for the critical evolution of palliative care today.

theological, philosophical or medical scholarship and lead to new traditions or to more specific theoretical and practical notions. However, this reconstruction of human experience orients our thoughts particularly to those who are vulnerable, recognizing at the same time our own vulnerability, and also that of those who are suffering or are under various (e.g. patriarchal or kinship) oppression. Thus, a feminist approach to human experience is the shared experience of loving, serving or compassionate caring and being “there” with others. It also can be situated in its own praxis and makes the social and community context both more specific and structured.

Let me suggest here that by being more attentive to the human experiences of dying that emerge from critical consciousness regarding, for example, palliative care or hospice care, we will be able to not only identify the present problems and flaws in such care, but also to be more attentive to the dying patient needs and desires.

Moreover, feminist theological and ethical scholarship by being more attentive to experiences of women is also unmasking the hidden caring responsibilities and dependencies in our society. Many feminist scholars (e.g. Nussbaum, 2000, 2002; Ruddick, 2002; Tong, 2002) critique the typical gender-assigned responsibilities of caregiving for children, the disabled, dying patients, or the elderly, handing these tasks to women as “normal” labour, usually as unpaid and often not respected work. As this work is many times assigned to women within their own families, this care or dependency work is not even considered to be work. To these caring women, to whom we all deserve our apologies and a change in our approach, their pursuit of life activities, careers, political participation and love was, and is, often impeded.

What is needed today, therefore, is not only a better articulation of the principles, conditions, and values of caring work, but also on a societal level, new proposals for improvement and better care for dependency workers. Fortunately, both of my chosen authors Cahill and Kittay have greatly contributed to investigating this problem, especially by the theoretical-social critiques of John Rawls' liberal theory and the ideal of equality.

Finally, when feminist scholars speak about the human experience, they don't romanticize bodily experiences or the body itself, nor do they appeal to biological determinism, but rather some of them¹⁵⁸ articulate the embodied and relational dimension of the human body as a whole.

Women's experiences of relationality, often described as interconnectedness and interrelatedness, go back to Merleau-Ponty's approach of intercorporeality, where the self is essential, relational and inseparable from the human body, relationships, perceptions, others or even the world. What is so powerful about this notion of relationality is the fundamental understanding that we are embodied, relational, communal human beings, dependent on one another from our birth and responsible for one another. Therefore, by being open to relationships and going beyond ourselves to reach and serve others, we may discover the meaning of life, and I would also suggest, a better embodied and relational care.

¹⁵⁸ Some other feminist scholars have used various approaches in defining women's experiences. For instance see Joan W. CONN and Walter E. CONN, *Horizons on Catholic Feminist Theology* (Washington, D.C: Georgetown University Press, 1992); Catherine M. LACUGNA, *Freeing Theology: The Essentials of Theology in Feminist Perspective* (New York: Harper Collins, 1993).

3.2 Relationality as Intersubjectivity – “Am I my Brother’s Keeper?” (Gn 4:9)

In the previous section, I argued that our exploration must begin with the human experience, as it opens up for us the perspective that to be a human person is to be essentially directed to each other. At the same time, using the phenomenological method and approach, I further argued that we must extend embodiment beyond the individual focus on subjectivity, and explore our understanding of the vital, intrinsic and relational nature of persons as intersubjectivity through an immediacy or ability to be with or to respond to others.

Prior to a more detailed understanding of our human relationality and intersubjectivity, let me quote from the book of Genesis, as it aptly describes the notion I am exploring: “The Lord asked Cain: “Where is your brother Abel?” He answered, “I do not know. Am I my brother's keeper?” (Gn 4:9 NJB) This biblical quote, so provocative and in many ways existential according to some bible scholars (Brown, 1997; Fitzmayer, 2002), requires watchfulness and responsibility for protecting everyone, not just certain individuals or friends.

For the purposes of my dissertation, however, this biblical quote narrows my research to the following questions: What does it mean to be a relational human being? Do we have a responsibility to watch out for and care for one another? The answers to these questions may reveal how well, or how poorly, we are fulfilling our responsibility to be our brother's keeper, and how well we are living up to the one responsibility we have that includes others and the world around us.

There have been many philosophical attempts to address the various aspects of relationality, but I have found my thinking continually challenged by the work of Lisa S.

Cahill, especially by her comprehensive treatment of relationality in her book *Sex, Gender, and Christian Ethics. New Studies in Christian Ethics* (1996)¹⁵⁹, and by the work of Eva F. Kittay and her book, *Love's Labor: Essays on Women, Equality and Dependency* (1999)¹⁶⁰.

Importantly, I will not only analyze how Cahill and Kittay have been influenced by Merleau-Ponty's method and approach to relationality, but I will also point out their weaknesses and propose how their oversights can be addressed. In conclusion, I will present an assessment of their thoughts that will lead into the construction of my new framework, based on embodiment and relationality, which can be utilised in providing a caring presence for the dying patient in palliative care today.

3.2.1 Lisa Sowle Cahill

Lisa S. Cahill's¹⁶¹ approach to relationality seeks to expand the philosophical and theological discussion of "the relationship of a theoretical anthropology of relationality to social practices that realize relationality in a practical and challenging way."¹⁶² In

¹⁵⁹ Lisa S. CAHILL, *Sex, Gender, and Christian Ethics. New Studies in Christian Ethics*. (Cambridge: Cambridge University Press, 1996).

¹⁶⁰ Eva F. KITTAY, *Love's Labor: Essays on Women, Equality and Dependency* (London: Routledge: J.A. Parks, 1999).

¹⁶¹ See more of Cahill's work: Lisa S. CAHILL, *Between the Sexes: Toward a Christian Ethics of Sexuality* (Minneapolis, MN: Fortress and Paulist Presses, 1985); Lisa S. CAHILL, Thomas A. SHANNON, eds., *Religion and Artificial Reproduction: An Inquiry Into the Vatican Instruction on Human Life* (Fort Collins, CO: Crossroad Press, 1988); Lisa S. CAHILL, *Women and Sexuality* (Mahwah, NJ: Paulist, 1992); Lisa S. CAHILL, *'Love Your Enemies': Discipleship, Pacifism, and Just War Theory* (Minneapolis, MN: Fortress, 1994); Lisa Sowle CAHILL and Margaret A. FARLEY, ed., *Embodiment, Morality and Medicine* (Dordrecht, Netherlands: Kluwer Academic, 1995); James CHILDRESS, Lisa S. CAHILL, eds., *Christian Ethics: Problems and Prospects* (Cleveland, OH: Pilgrim Press, 1996); Lisa S. CAHILL, *A Christian Social Perspective* (Minneapolis, MN: Fortress, 2000).

¹⁶² Lisa S. CAHILL, "Bioethics, Relationships, and Participation in the Common Good," p. 209, in Carol TAYLOR, Roberto DELL'ORO, eds., *Health and Human Flourishing: Religion, Medicine and Moral Anthropology* (Washington, D.C.: Georgetown University Press, 2006).

other words, what Cahill identifies is that our subject-body is inseparable from the social world and other persons. This indissolubility is expressed in Cahill's claim that "movement back and forth between the body and its social world seems to be intrinsic to the meaning of body itself."¹⁶³ This means that to be a human person is to be in a relationship and essentially directed toward others in a community. What is important here, from the end-of-life palliative care context, is the realization that our relationality, grounded in our human bodily experiences, influences our self-understanding and calls us to act and to be bodily present to those who are suffering and dying. Moreover, our human experience and a dying person's lived experience are connected and represent a mutual dependence on one another.

Lisa S. Cahill is the J. Donald Monan, S.J. Professor at Boston College, where she has taught theology since 1976. She is a past president of both the Catholic Theological Society of America (1992-93) and the Society of Christian Ethics (1997-98). She was a visiting scholar at the Kennedy Institute of Ethics, Georgetown University, in 1986, and a visiting Professor of Catholic Theology at Yale University in 1997. Cahill's special interests are ethical methods in theological ethics, especially the Catholic natural-law tradition and phenomenology, Scripture in ethics, gender, medical ethics and the history of Christian ethics.

Cahill is also one of the Christian feminist ethicists who underlines and supports the importance of the empirical sciences of psychology, biology, sociology and anthropology, all of which provide valuable insights into what constitutes human action.

¹⁶³ CAHILL, *Sex, Gender, and Christian Ethics*, p. 76.

This is especially important in the cooperation between Christian ethics and the empirical sciences, which she sees as the future of theology and ethics/bioethics.

What characterizes Cahill's methodology in discerning and applying moral norms is the four-source method: scriptures, tradition, natural law and human experience, which in her writings are well balanced and dialectic. Moreover, what characterizes Cahill's methodological approach is her reflection and arguments on the human experience (the primacy of the experience of women) as descriptive and normative; gender inequality; embodiment as relationality and intersubjectivity; the application of virtues which do not manifest differently in men and women; the importance of gender; and the notion of the common good and justice. Her focus and research on the value of human community and the proper social relationships that exist within it is also significant.

Another significant characteristic in Cahill's work is her reconfiguration of notions like love, relationship, mutuality and dependency by removing them from the context of the public/private split. In many of her writings she claims that a moral rift has been created by the public/private dichotomy by limiting class and gender roles to particular spheres, and in general, individuals are not allowed to achieve their full humanity. As a solution, Cahill suggests focusing on the importance of mutuality within the total web of social relations, where everybody in society has access to power and resources, but also where everybody, based on our common relationality, has a responsibility for one another.

In contrast to Cahill, many feminist authors like Christine Gudorf (1993) or Margaret Farley (1993) have described and approached different theological or

philosophical meanings to the body, though Cahill's reflections, critique and insights can be found in two important publications.¹⁶⁴ In both these publications, Cahill's emphasis lies on the importance of: 1) the body as embodied and as intrinsically relational and social; 2) the body as enclosed in time and space; 3) the bodily experience as regulated by cultural institutions; 3) the bodily experience as engaged with a "critical and normative stance"¹⁶⁵; and 4) the foundation to any moral or medical discourse as a comprehensively embodied and relational holistic view of the person per se.

In relation to the above, in her book, *Between the Sexes: Toward a Christian Ethics of Sexuality*, Cahill is very critical of the Christian tradition and Scriptures, stating that it is marked by literal and uncritical flawed interpretations, and an acceptance of dated cultural norms. For instance, she analyses and critiques these inconsistencies in regards to gender relations and current science vis-a-vis the book of Genesis.

According to Cahill, there is no evidence or objective reference from empirical research to prove that men and women are divided into two hierarchical, essential or cultural human embodied natures, or that women are more suited to domestic roles than men.¹⁶⁶ A reader of the Scripture must be reflective when he approaches such a text to discern the internal claims and intentions of the writer. Cahill then continues with a review of the anthropological literature that has attributed certain roles to men and women and has influenced many different societies in history. But it is difficult to find,

¹⁶⁴ CAHILL, *Between the Sexes: Toward a Christian Ethics of Sexuality* (1985) and CAHILL, *Sex, Gender, and Christian Ethics* (1996).

¹⁶⁵ CAHILL, *Sex, Gender, and Christian Ethics*, p. 80.

¹⁶⁶ CAHILL, *Between the Sexes*, pp. 87-9.

according to Cahill, “why a disparity in power comes into being between the delineated social spheres.”¹⁶⁷

What Cahill proposes here are two important claims regarding gender and biology roles. First, gender has an essential and historical effect on the nature and interpretation of women's or men's experiences. Therefore, human sexual differences always need to be understood within the framework of human freedom and potential, not strictly within a biological context. Any attribution or separation of human natures was, and is, a contradiction of the notion of the active historical process and the notion of human relationality. Second, distinctive women's embodied experiences are infused with gender meaning and therefore contribute to a woman's self and her social relations. The importance of women's embodied experiences still needs to be recognized.

Moreover, from a theological point of view, what Cahill calls to our attention is the understanding that gender differences and gender equality were God's intentions for human social structure from the onset, and that our sinfulness has made this equality difficult to maintain. Therefore, by emphasizing a return to the equality created by God in the beginning, Cahill's account of moral development places the individual more readily within the original order of creation described in Genesis. She further suggest that our gender differences should serve the whole community in communicating and caring for one another.

Cahill continued in her research on these issues of body, gender and sexuality, and along with Margaret Farley, edited the book, *Embodiment, Morality and Medicine*

¹⁶⁷ Ibid., p. 93.

(1995), where they reminded us how our embodiment and relationality influence our moral relationships and particularly how they affect us in the end-of-life care settings.¹⁶⁸

Moreover, Cahill in her essay, “Embodiment and Moral Critique: A Christian Social Perspective”, contends that “the body enters into the subjectivity of the person, mediates that subjectivity to the world and other person interact with the subject as embodied self.”¹⁶⁹ Clearly, Cahill's observation and insight goes back to her understanding of the human bodily experience, and recognizes the body's ability to understand not only its own subjectivity, but also the subjectivity that lies outside of one's body and its relations. Therefore, Cahill's focus on the subjectivity of the person outlines the role our body plays in determining what kind of relation we are able to, can or want to enter into; it helps us to understand how we can organize our community life and our dependence on one another. She is also convinced that as embodied and relational beings, “we are dependent on our meaningful interpersonal relationships and social living.”¹⁷⁰ Our nature, which is both interrelated and interdependent, allows us to go beyond ourselves to reach and connect with others, and carries with it a enriching potential.

In 1996, right after Cahill edited, with James Childress, the book *Christian Ethics: Problems and Prospects: A Collection in Honor of James M. Gustafson* (1996), she presented her most comprehensive treatment on the human body and sexuality in *Sex, Gender, and Christian Ethics. New Studies in Christian Ethics* (1996), where she

¹⁶⁸ CAHILL, FARLEY, *Embodiment, Morality and Medicine*, p. viii.

¹⁶⁹ Ibid., p. 199. See also Stephen E. LAMMERS, Allen VERHEY, *On Moral Medicine: Theological Perspectives in Medical Ethics*, 2nd ed., (Grand Rapids, MI: W.B. Eerdmans, 1998), pp. 401-12.

¹⁷⁰ CAHILL, FARLEY, *Embodiment, Morality and Medicine*, p. 201.

addressed and critically analysed: 1) the body as a locus determining moral meaning; 2) the reality of sex and gender ethics as a construct of the human moral project (Aristotelian-Thomistic tradition) regarding the concrete condition of human flourishing; and 3) the retrieval of the social importance of sex based on our basic good and embodied, relational/intersubjective and social experiences. In other words, Cahill explains that this book was “written from a feminist perspective, by which is meant simply a commitment to equal personal respect and equal social status for women and for men.”¹⁷¹

Therefore, due to the “centrality of human action to the focus of moral theory”¹⁷² and the body as a locus determining moral meaning, ethics must always be based on the human embodied and relational body. In particular, Cahill proposes that one's body is incapable of experiencing the reality around him apart from one's body; this includes not only thinking, but also speech and movement. In other words, our body is immediately present to us, because we are our body. Our bodies are not separated from the world we experience, because our embodiment and incarnate intentionality already implies the pole of that global bodily purpose. Cahill's account of the body/embodiment will not leave the world out of account, as our bodies are being-in-the-world; she argues that bodies cannot be seen as the product of discourse, as they can also interact in social space. Cahill describes this in the following way: “Not only do bodies open out to

¹⁷¹ CAHILL, *Sex, Gender, and Christian Ethics*, p. 1.

¹⁷² *Ibid.*, pp. 73-6.

worlds beyond, but movements back and forth between the body and its social world seem to be intrinsic to the meaning of the body itself.¹⁷³

Cahill has drawn on various sources, like Merleau-Ponty's approach on embodiment, where embodiment is seen not only as the spatial and temporal qualities of ourselves, but also as a holistic unity of self and body situated in the personal and social world where human experiences and perceptions occur.

Cahill maintains that the body potentially affects the moral meaning of the action. According to Cahill, "they interact in social space"¹⁷⁴. This is why there is a need for phenomenological research in order to determine our actions and our social involvement in such a space. Once again, human experience, which plays a central role in evaluating these actions, is filtered through our bodies. Cahill's project is very clear here: to achieve a theory of morality in which the body and culture are in reasonable balance. Using her descriptive style of expression, Cahill situates her project in the following way:

Hence to speak of the body means, on the one side, to stand up against moralities which take for granted a physical body which can "determine" social roles as norm and rule preceding them; and, on the other, to take up the question of social relationships (especially gender relationships) from the standpoint of human concreteness and presence.¹⁷⁵

Later she adds: "Fundamental to our embodiment is the fact that each person in his or her individuality is both body and the "more" which selfhood entails (intellect, will, emotions, "spirit," and relationality, especially to other embodied individuals).

¹⁷³ CAHILL, *Sex, Gender, and Christian Ethics*, p. 76.

¹⁷⁴ *Ibid.*, p. 76.

¹⁷⁵ *Ibid.*

Similarly, society consists both in material conditions and in the cultural institutionalizations of materiality which give the society of members of our species its human quality.”¹⁷⁶

What Cahill suggest is an integrated view of the body as the unity of the self as embodied and intrinsically social, which does not require a rejection of the body and its relation to the values of an encompassing social order.¹⁷⁷ Thus, society influences the body and experiences of the self, not only repressively, but also expressively. This means that our subjectivity and active bodily expression are linked to society and influence each other.

Furthermore, Cahill’s work on “The Body – in Context,” deals with the realities of sex and gender as a construct of the human moral project, or more simply, with gender differences and gender equality. She draws on the Aristotelian-Thomistic vision of humans flourishing, as well as on her four-source method, particularly Scripture, and argues against the postmodern deconstructionism and theological sectarianism that contributes to relativism. She points out that Christian discipleship is able to transform cultural interpretations of sex and gender toward values like compassion and solidarity. According to Cahill: “the self as embodied is strongly influences by social significance of gender as an elaboration of maleness or femaleness.”¹⁷⁸ In other words, gender has a profound effect on the nature and interpretation of one’s social experience. Thus, “the

¹⁷⁶ Ibid., p. 77.

¹⁷⁷ Cahill’s thesis is very different here from that of many Catholic ethicists, who usually use embodiment to counteract a dualism about the body and mind, and whose analyses the body is presented as the inferior partner in an uneasy relationship.

¹⁷⁸ CAHILL, *Sex, Gender, and Christian Ethics*, pp. 82-90. See also, CAHILL, FARLEY, *Embodiment, Morality and Medicine*, pp. 199-217.

issue for contemporary feminists is whether, in a nondualist perspective, the differential embodiment of men and women must be assumed to make difference in their way of being in the world, even if not a difference which implies hierarchy, or even very extensive or firmly demarcated role allocation.”¹⁷⁹

In contrast to contemporary feminists, the key for Cahill to any discourse on gender differences is monogamy and kinship. She points out that sex and reproduction are not only biological functions, but also social ones. There are survival advantages for raising children in kinship units. Also, monogamy meets not only the human need for lasting relationships, but also offers protection and security for infants of heterosexual unions. Kinship, Cahill claims, is better understood today as “the organization of labor, good exchange, and property rights, and lineage of children” and sometimes more as “emotional fulfillment”.¹⁸⁰

In summary, gender and sex are central to human social engagements and existence, which can and have limited the flourishing of women. She suggests, however, that a constant critique of heterosexual, reproductive and patriarchal marriages will help achieve a better recognition for women, contingent on gender equality.

Moreover, when speaking about gender differences and critical approaches, Cahill used the terms “justice” and “care”. However, her engagement of justice is not a classic definition founded in virtue theory or social theory, but an approach towards the equality of men and women and the defining of the quality of their relationships.¹⁸¹

¹⁷⁹ Ibid., p. 84, and “Women and Sexuality”, pp. 61-2.

¹⁸⁰ Ibid., p. 105.

¹⁸¹ Ibid., p. 36.

Let me note that it is difficult to say precisely whether Cahill is more sympathetic towards an essentialist account of gender differences, which offers a set of characteristics that defines “normal” differently for men and women, or to a constructionist account of gender (a social construct and thus not really constitutive of one’s identity) which states that being female and male would have no effect on what constitutes the “normal” qualities for the individual.

Overall, Cahill’s approach to gender differences and her suggestions for correcting gender equalities are, in my opinion, not wholly sympathetic to many of the strands of feminist thought; for the purpose of my dissertation, however, it is not necessary to examine this here. However, what is necessary is Cahill’s emphasis on the biological, social and intersubjective importance of human relationships, and the insights through which gender differences enrich the (Christian) community by equitable communication and support for one another.¹⁸²

Later, when Cahill re-examines the social importance of sex based on our basic good and embodied, relational/intersubjective and social experiences, she refers to the basic good of the individual as being intimately connected to the good of the whole society.¹⁸³ This suggests an analogy for presenting the human embodied person not only as an individual, but also as the intersection of relationships.¹⁸⁴ In that context, our relationality extends both to interpersonal relationships and the relationships of individuals to groups as well as to the whole society. Therefore, human embodied beings

¹⁸² See CAHILL, *Sex, Gender, and Christian Ethics*, p. 121, pp. 162-4.

¹⁸³ There are four different philosophy and theology scholars to whom Cahill is attuned: Maurice Merleau-Ponty, Michael Foucault, Richard H. Niebuhr and Mary Douglas.

¹⁸⁴ Most likely, this analogy happens at the most basic level of human nature as an unfolding series of connections and relationships.

are intrinsically relational and find their identity and meaning only through the mutuality of personal relationships. In this manner, to be relational, can be seen as intersubjective and evolving dynamically by nature: intersubjective because attention must always be paid to the relational nexus within which the embodied human being exists; and dynamic, because it evolves through the interaction and communication that takes place between persons.

Cahill's emphasis on intersubjectivity involves a corporeal engagement with others where subjectivity is constantly transforming. Cahill takes embodied subjectivity seriously when speaking about the embodied body within the context of unity, but also by referring to the body as connected to others in intercorporeal relationality or interchangeably as intercorporeal responsibility. In other words, Cahill pairs relationality with responsibility. According to Cahill: "Relationality is the basic dimension of being human, of which response is the moral heart and responsibility is the moral call."¹⁸⁵ Cahill presents her argument on the basis of how human experience and human nature as individuals and as social beings.

Therefore, using not only Merleau-Ponty's notion of intersubjectivity, but also H. R. Niebuhr's and then Gustafson's moral language and understanding, Cahill argues that human relationality/responsibility is historical, dynamic, interactive and communal.¹⁸⁶ It is historical because it begins with our birth, a response to actions visited upon us to which we continually reply; it is dynamic because of the active participation between agent to agent; it is interactive as we act in anticipation of a reply; and it is communal as

¹⁸⁵ CAHILL, "Bioethics, Relationships, and Participation in the Common Good," p. 219.

¹⁸⁶ See Lisa S. CAHILL, "Consent in Time of Affliction: The Ethics of a Circumspect Theist," in *Journal of Religious Ethics* 13/1 (1985): 22-6.

we always act accountably and socially (social solidarity), and interact with our fellow human beings and environment constantly.

The ideal of responsibility/relationality is for Cahill not only a language for discourse in Christian bioethics, but also the basis for “response,” “moral call” and “social solidarity,” and an anchor for the future in philosophical and theological anthropology, grounded in human experience and embodiment, and shared by different traditions (religious and nonreligious) and other cultures.

Cahill’s emphases and considerations of our relationality remind us not only of its social dimension, social interdependence, and social obligation, but also the fact that we become less human through our degradation of others, be it because of their class status, race, ethnicity, gender or illness. Therefore, her insights point to specific priorities: an embodied and relational human person seeks equal opportunities for all in the community and would not accept an oppressive social structure built on minimizing the value of others. Within the palliative care context, health care professional, family member or community volunteer aware of his own embodiment and relationality/responsibility would always pay attention to the human experiences of the dying patient and always be there and care for him.

In conclusion, Cahill’s proportionalist and often realistic approach toward embodiment and social relationality, based on one’s experience, can be used as a solid foundation for understanding our embodied and relational human nature, in concordance with the concern for social equality and the role of the community today. Moreover, Cahill’s anthropological understanding of relationality as responsibility is also very essential for human existence and for sharing a good moral life.

Three of Cahill's principal insights are important for my new caring-presence framework: a) our exploration must always begin with the human experience as the starting point for moral inquiry and meaning; b) the nature of our human experience cannot be ultimately separated from the way in which our bodies function; and c) we are relational human beings and relational participation is essential for human existence and for sharing a good life.

3.3 The Importance of Dependency – “We are All Some Mother's Child.”¹⁸⁷

After outlining Cahill's approach and understanding of our relationality, let me present another theoretical viewpoint, that of feminist scholar Eva F. Kittay, whose vision relies on our nested dependency as a pre-condition of our relationality.

3.3.1 Eva Feder Kittay

Eva F. Kittay¹⁸⁸ utilizes a feminist approach to the ethics of care that regards the importance of nested human dependency as one of the central features of human relationality, and as an opportunity for human flourishing.

In contrast to Cahill's normative references to the human experience, Kittay's references to the human experience are more descriptive than normative, and help to minimize and to shed light on the problems and biases contained in any sort of social or ontological objectivity. Kittay's perspective is different from that of Cahill's: her

¹⁸⁷ KITTAY, *Love's Labor*, p. 25.

¹⁸⁸ For more of Kittay's work see: Eva F. KITTAY, *Metaphor: Its Linguistic Structure and Its Cognitive Force* (Oxford: Oxford University Press, 1987); Eva F. KITTAY, Diana MEYERS, eds., *Women and Moral Theory* (New Jersey: Rowman and Littlefield, 1987); Eva F. KITTAY, A. LEHRER, eds., *Frames, Fields and Contrasts: New Essays in Semantics and Lexical Organization* (New Jersey: Lawrence Erlbaum Associates, 1992); Eva F. KITTAY, Ellen K. FEDER, eds., *The Subject of Care: Feminist Perspectives on Dependency* (Totowa, NJ: Rowman and Littlefield, 2003); Eva F. KITTAY, *Blackwell Guide to Feminist Philosophy* (New York: Blackwell, 2006).

primary focus is on the inevitable account of the nested dependency of human life, with the many interdependent relations that all human beings experience being of secondary concern. What she is concerned with is to re-centre human vulnerability at the core of the debate surrounding social welfare and the social value of care work. Thus, her tasks are heavily person-centered or citizen-centered, and are always fully embodied and relational.

Eva F. Kittay has been a Professor of Philosophy and Ethics at Stony Brook University, New York, Department of Philosophy since 1993. She has also been Senior Fellow at the Center for Medical Humanities, Compassionate Care, and Bioethics, SUNY - Stony Brook since 2008. From 1979-86, she was an Assistant Professor at Stony Brook, Department of Philosophy, and then an Associate Professor from 1986-1993. Before coming to SUNY- Stony Brook, she was an adjunct lecturer at the John Jay College of Criminal Justice, CUNY - Department of Philosophy in 1975, and at Lehman College, CUNY - Department of Philosophy in 1974-75.

Kittay's research interests focus on the ethics of care and on issues of disability as a new agenda of moral and political philosophy. However, her originality comes from the incorporation of her personal experience with her paralyzed daughter, Sesha - whose life is integral to many of Kittay's books and articles - as a way to describe and elaborate upon the idea of inevitable human dependency and dependency relations.

Importantly, for Kittay, the idea of an inevitable human dependency is not only embodied and relational, but also lies on an inevitable nested dependency, usually alleviated by cultural and social practices that require a sustaining relationship between the dependency worker and the dependent. Moreover, Kittay regards the "dependency

relationship” as a complex relationship, where the “caregiver acquires a dependence on others to supply the resources needed to sustain herself and the dependents who are in her charge. The dependency relationship is a cooperative arrangement sustained by these resources, the labor of the dependency worker, and the responsiveness to care on the part of the cared-for.”¹⁸⁹

In her most significant publication, *Love’s Labor: Essays on Women, Equality and Dependency* (1999), Kittay presents the issues of disability as part of the agenda of moral and political philosophy; she articulates some very persuasive and powerful criticisms of Rawls’ contractarian theories of justice. She suggests that if we are to make adequate proposals for the just treatment of people who need care and for those who care for them, we must move beyond the image of citizenship embedded in the dominant social contract tradition that has been at the heart of much Western theorizing about society.

Furthermore, in her work Kittay identifies the following theoretical viewpoints:

1) all embodied human beings are in nested dependencies which require a sustaining relationship with one who needs care, and with another who provides care. Nevertheless, these nested dependencies form a network of social and personal interdependencies that are the essential bonds of social human life, and; 2) that once we understand the implications of dependency, and see how political, social and medical-caring concepts need to reflect them in their daily practices and care, we will be better able to embrace a

¹⁸⁹ Eva F. KITTAY, “Taking Dependency Seriously: The Family and Medical Leave Act Considered in Light of the Social Organization of Dependency Work and Gender Equality,” in *Hypatia* 10/1 (1995): 12.

vast proportion of human interaction and will also better understand our relational responsibilities and interdependencies.

Her principal statement is this: “We are all some mother’s child.”¹⁹⁰ This principal statement goes back to Kittay’s family experience, where she observed her mother serving her and her father at the dinner table, which led Kittay to justify her own actions by saying: “after all, I’m also a mother’s child.”¹⁹¹ Hence, we are all connected and dependent people, not just the dying, but also children, people with mental and physical disabilities, frail elderly people, and even individuals who have lost their way.

Moreover, this alternative to the concept forwarded by liberal political theory begins not with an “individual whose characteristics that pertain him as an individual and entitle him to equal status,”¹⁹² but rather with an understanding of equality as invoking a property that a person has only by virtue of a property that another person has. Going back to her mother, she says: “she is the child of a mother only because another person is (or was) someone who mothered her.”¹⁹³

Kittay’s understanding of nested dependency is as unavoidable as birth and death for all living organisms and “has a crucial bearing on the ordering of social institutions

¹⁹⁰ KITTAY, *Love’s Labor*, p. 25.

¹⁹¹ *Ibid.*, p. 25.

¹⁹² *Ibid.*, p. 25.

¹⁹³ *Ibid.*, p. 25. Here the objection can be raised concerning that some children are abandoned by their mother and not raised by them, rather by someone else. To this objection Kittay reply, “by mothering person I do not necessary mean a biological, or even an adoptive mother. I mean a woman (or man) who devotes herself (or himself) to, or take responsibility for, the care of a dependent and vulnerable other, and who sees that other’s well-being as central and enmeshed with her or his own.” Eva F. KITTAY, *Equality, Dignity and Disability*, in Mary Ann LYONS and Fionnuala WALDRON, eds., *Perspectives on Equality: The Second Seamus Heaney Lectures* (Dublin, Ireland: The Liffey Press, 2005), p. 114.

and on the moral intuitions that serve to guarantee adherence to just institutions.”¹⁹⁴ It is also the start of feeling an ethical and social responsibility to maintain the quality of life, to provide loving and qualified care for terminally ill patients and their families: to provide them with all appropriate therapy and treatment, medical procedures and information, and to be compassionate and respectful towards them.¹⁹⁵

Kittay further explains dependency as the fundamental human experience of humanness, which according to her, many social and political positions fail to acknowledge:

My point is that this interdependence begins with dependence. It begins with the dependency of an infant, and often ends with the dependency of a very ill or frail person close to dying. The infant may develop into a person who can reciprocate, an individual upon whom another can be dependent and whose continuing needs make her interdependent with others... But at some point there is a dependency that is not yet, nor longer interdependency. By excluding *this* dependency from social and political concerns, we have been able to fashion the pretense that we are *independent*—that the cooperation between persons that some insist is *interdependence* is simply the mutual (often voluntary) cooperation between essentially independent persons.”¹⁹⁶

These observations, according to Kittay, lead us to see our human world, or the world around us, as full of dependent and relational persons who are “unable to reciprocate”¹⁹⁷: children, older people, infirm people, homeless people, indigent people, people of different race or class status, and ethnic groups.

¹⁹⁴ KITTAY, *Love's Labor*, p. 28.

¹⁹⁵ The philosopher and ethicist Levinas, who examined these ideas more broadly, also suggested that with an openness to care and to having a “face-to face relationship”. See Emmanuel LEVINAS, *Otherwise Than Being or Beyond Essence* (Pittsburg, PA: Duquesne University Press, 1998), p. 15.

¹⁹⁶ KITTAY, *Love's Labor*, xii, italic in original. For more about “dependency” see KITTAY, FEDER, eds., *The Subject of Care*, Part 2, pp. 88-160, Part 5, pp. 322-69.

¹⁹⁷ KITTAY, *Love's Labor*, p. xiii.

Kittay defines persons who care for dependent persons as dependency workers: formal and informal caregivers, usually women, who care but whose dependency work is many times not recognized by society itself, and their work is often “chosen” for them by a society that seems all too willing to exploit them.¹⁹⁸ Elsewhere, Kittay also defines care for dependents as “dependency work”¹⁹⁹ to emphasize the care as real work, not just unpaid work usually performed at home, but also in hospitals and nursing homes. Above all, it is often nurturing assigned by gender and usually assigned to women as part of their familial duty.

In order to eliminate this inequality, Kittay offers a new “theory of equality” based on the assumption that we are all dependent people and we are all dedicated to the cause of empowering dependency workers (caregivers). This dependency critique of equality is in Kittay’s words defined this way:

“While we are dependent, we are not well positioned to enter a competition for the goods of social cooperation on equal terms. And those who care for dependents, who must put their own interests aside to care for one who is entirely vulnerable to their actions, enter the competition for social goods with a handicap...Yes, equality has been elusive for women and will continue to be unless and until better institutional supports are put in place to enable women who wish to leave the exclusive domain of home without jeopardizing the well-being of those they love.”²⁰⁰

However, to understand Kittay’s “theory of equality” based on dependency critique and empowering dependency workers, it is good to start with a few clarifications going back to Kittay’s analyses of other feminist critiques of equality in regard to interdependencies of caring relations namely, that they are not as unique as

¹⁹⁸ Dependency workers direct their attention to an intended beneficiary, a charge (a person committed to the care, custody, management or support of another. See KITTAY, *Love’s Labor*, pp. 30-1.

¹⁹⁹ See KITTAY, *Love’s Labor*, p. 30.

²⁰⁰ *Ibid.*, p. xi.

presented in today's society. Kittay argues that they are common and care may be reciprocated simultaneously.

Firstly, Kittay argues that while there is no inherent reason why dependency work cannot be shared, it may be necessary that at least some responsibility is assigned, if not to one individual, then to a few. Secondly, dependency work can be distributed and shared among people, but often it is assigned to only one individual – the “dependency worker”. Thirdly, dependency work needs to be situated within a specific practice.

Furthermore, using Sara Ruddick's understanding of *maternal practice* as a paradigmatic instance of dependency work, Kittay suggests three desired dependency practices for the caring of the elderly and severely disabled: preservative love, fostering growth, and training for social acceptance.²⁰¹ All these practices, according to Kittay, must, however, always focus on fostering self-sufficiency, self-esteem, and social acceptability.

Thus, within the palliative and hospice care context, all of the above-presented constructions by Kittay point to the best desired embodied and relational care. This embodied and relational caring presence and care requires good moral character: the dependency relationship is always determined not by domination as the exercise of power, but rather with a relation of trust and affection, and the understanding that the dependency worker will not abuse his power or the authority entrusted to him when encountering vulnerable persons.

²⁰¹ See Sara RUDDICK, “An Appreciation of Love's Labor,” in *Hypatia* 17/3 (2002): 214-23, especially Part II, “Eva Kittay's Dependency Approach to Equality,” pp. 203-6.

Kittay's focus on the inevitable dependency of embodied human life and on the dependency relationship points to the importance of re-centring our inherent human vulnerability, as a means for better recognizing the social contingency of dependency. In other words, once the inevitable dependency of embodied human life is recognized as the ground from which the relationship of the dependency worker and the dependent emerge, it leads to interdependent as opposed to independent relations between the carer and the one cared for, where dependency work is not considered as a selfless act directed toward someone who is lacking human personhood or life quality, but rather as dependent meaningful work on which we are all likely to be dependent at different points in our lives, and which also deserves social value and recognition.

This presented perspective, so unique in itself, allows for reclaiming the language of dependence without the negation of autonomy, still requires an explanation concerning personal autonomy and individual rights, and plays an especially important role in the dominant liberal conception. To such an objection, Kittay replied that personal autonomy is not seen as a matter of rational choice and self-realized values, but rather as relational. Thus, the relational approach to autonomy does not pose autonomy and dependency in opposition, but rather provides the structure and limits of our lives and actions.

Importantly, any exploration of the relationship of a dependent to a dependency worker, according to Kittay, requires sensitivity in intervention or power and the exertion of domination in a relation of inequality. Kittay further explains: "The inequality of power is endemic to dependency relations. But not every such inequality amounts to domination. Domination involves the exercise of power over another against

her best interests and for purposes that have no moral legitimacy...Domination is an illegitimate exercise of power.”²⁰² Correct and legitimate dependency relations have always determined how the parties in a dependency relationship respond to one another, with respect to the vulnerability of the dependent and the vulnerabilities created for the dependency worker.

Finally, one more thought regarding the dependency worker in Kittay’s work deserves our attention here. Kittay stresses that “unlike the subject of traditional justice theory, a dependency worker is not a self-interested self but rather a transparent self: that is a self through whom the needs of the another are discerned, a self that, when it looks to its own needs, it first sees the needs of another.”²⁰³ This transparent sense of self of a dependency worker, in contrast to the autonomous sense of self in the Rawlsian original position, is not self-interested or disinterested, but rather focused on caring for another or the well being of another. In other words, this often times “passionate” transparent sense of self doesn’t look or focus on her/his own perceptions or needs, but rather acknowledges one’s own dependency and vulnerability as the opportunity for flourishing.

Furthermore, let us look at Kittay’s justification for her “theory of equality”. Kittay builds her argument and moral grounds on American philosopher Robert Goodin’s work, *Protecting the Vulnerable* (1985)²⁰⁴, and his “moral basis of special relations between individuals which arises from the vulnerability of one party to the

²⁰² KITTAY, *Love’s Labor*, p. 34.

²⁰³ *Ibid.*, p. 51; pp. 52-3 respectively.

²⁰⁴ See Robert E. GOODIN, *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities* (Chicago: University of Chicago Press, 1985).

action of another”²⁰⁵. More specifically, Kittay, being aware of the present voluntary model of ethical obligation used in the ethics of care today, one that is based on individuals choosing their moral obligations towards one another, instead chooses and applauds Goodin’s model is claim for relationality as situated in the vulnerability of another person to our actions.

Even if Goodin’s concern is not specifically the ethics of caring, his vulnerability model of special relations, which also influences Kittay, arises from the vulnerability of one person to the actions of another person. In other words, a special obligation to care is claimed upon me as a dependency worker, and only then if I am so situated as to be able to answer the needs of the dependent. It is a special claim upon me only if the other person is vulnerable to my actions.

Thus, this theory is important for palliative care today because it focuses not on the virtue of the properties of the individual, but rather on the relational responsibility between the dying patient in need and her/his palliative care worker who is situated to meet the need.

Kittay agrees with Goodin’s work about the non-contractual nature of most human relations and the mutuality of interpersonal relationships as the dynamic constitutive of human embodiment and relationality; however, she disagrees with him about the scope of the dependency worker’s obligations to dependents.

Moreover, Kittay raises some objections to Goodin’s model: 1) it is too open to the charge of making our obligations too general; and 2) it limits us in our responsibility to meet the needs of dependents and avoid the needs of anyone else. It seems, that “the

²⁰⁵ GOODIN, *Protecting the Vulnerable*. Cf. KITTAY, *Love’s Labor*, p. 55.

principles are meant to delimit the sphere and scope of vulnerability-responsive obligations,”²⁰⁶ says Kittay. She then responds to her objections as follows: 1) it is important to define who is responsible for whom as a matter of absolute judgment; 2) one has to accept that our relational responsibility arises in multiple ways; and 3) one needs to recognize that our relational obligation arises within a set of cultural and social practices.

Therefore, given all these insights on vulnerability relations and obligations, as well as responsibility actions, Kittay presents her own *connection-based equality theory* from the relationship of dependency.

First of all, the *connection-based theory of equality* derives, according to Kittay, from the intersubjective connections that we have with those with whom we have had relations of care and dependency. In other words, Kittay’s theory is based here on “entitlements to a relationship, in which one can be cared for if and when appropriate; and then on a socially supported situation, in which one can give care without the care giving becoming a liability to one’s own well-being.”²⁰⁷ Moreover, this *connection-based theory of equality* could be well structured within any palliative care policies, health-care norms, or family-policy models, as it is concerned first and foremost with the embodiment and well-being of the dependent.

Secondly, the *connection-based theory of equality* is not equivalent per se to reciprocity theory, as there is no immediate reciprocation here in care; it is rather set on a nested set of obligations, and on the “reciprocity of those who see their equality in

²⁰⁶ KITTAY, *Love’s Labor*, p. 56.

²⁰⁷ *Ibid.*, p. 66.

their connections with, and obligation towards, others.”²⁰⁸ It calls for social cooperation, which depends on this nested set of social relations and obligations, and which is henceforth called “doulia”²⁰⁹, and refers to those who care, namely dependency workers who act as a mother to a child, or as Kittay claims, “Just as the *doula* gives care to the one who cares for the dependent infant, the direction of the obligation in connection-based reciprocity goes from those in position to discharge the obligations to those to whom they are relevantly connected.”²¹⁰ Kittay's emphasis here is on defending the social recognition of dependency work, and on pointing out the present failings in our society. Her approach to human dependency and dependency relations is a strong appeal to theorists, health care professionals and various volunteers in our society to never discount those dependent on us in our communities, and to take care of those who are dependent on them.

However, I would like to take Kittay's arguments further and suggest that the attention of all of us, society or community, should always be focused on human embodiment, vulnerability, inevitable dependency, and the caring relational presence, in order to not only help those who require our help (dependents), but to do so with a proper understanding and without the abusive power of domination. This may challenge the dominant liberal conception of the self and our “body image” as being inherently vulnerable, dependent and open to the importance and social significance of work care.

²⁰⁸ Ibid., p. 68.

²⁰⁹ “Doulia” comes from the Greek word *a doula*, which means a slave who provides care to a woman while she is caring for a newborn. In Kittay's terminology, it is the material support needed by and owing to the caretaker who provides for a dependent. See Kittay, *Love's Labor*, pp. 107-9.

²¹⁰ KITTAY, *Love's Labor*, p. 68, italics in original.

Thirdly, Kittay argues that her *connection-based theory of equality* calls upon those who, “within the nested set of social relations to support dependency workers, those involved in daily care, fulfill not just the needs of the dependent, but also the ones who are recognized for the contribution of her/his work, skills, compassion, care and presence, and as having a long relationship of mutual respect with the dependent.”²¹¹ What Kittay calls for here is the “*doulia* right” for dependency workers.²¹² However, what needs to be added is that for such protection specific laws must be passed by legislatures, as we cannot rely solely upon court rulings in specific extraordinary cases.

In conclusion, Kittay presents her arguments for “*doulia*” using the example of her severely developmentally - disabled daughter Sesha. Very briefly, Sesha is 30 years old and dependent on paid and unpaid dependency workers for meeting her daily life sustaining needs, and for interpreting her needs and desires.²¹³ In response to Sesha’s dependency, Kittay’s goal is not independent living, but rather to create an environment where Sesha can flourish within the limits imposed by Sesha’s incapacity. This

²¹¹ Here Kittay critiques the Rawlsian *theory of justice* for not acknowledging or taking into account the inevitable human dependency in a democratic society. According to Kittay, “A justice which does not incorporate the need to respond to vulnerability with care is incomplete, and the social order which ignores care will itself fail to be just.” In KITTAY, *Love’s Labor*, p. 102. Rawls’ position could remain viable, but it must expand as Kittay claims to “the good both to be cared for in a responsive dependency relation if and when one is unable to care for oneself, and to meet the dependency needs of others without incurring undue sacrifices oneself.” In KITTAY, *Love’s Labor*, p. 103. However, her attempt, according to some scholars failed, as she didn’t fully understand the objective of Rawls’ “circumstances of justice”. See more in Martha NUSSBAUM, “Introduction to the Symposium on Eva Kittay’s *Love’s Labor: Essays on Women, Equality and Dependency*,” in *Hypatia* 17/3 (2002): 194-9. Note, that as Kittay’s critique of the Rawlsian theory of justice is not relevant to my research, I will not further elaborate here.

²¹² KITTAY, *Love’s Labor*, pp. 143-6.

²¹³ Kittay introduces here an example of a dependency worker, namely Peggy, the woman who is taking care of her daughter Sesha. She admits that without Peggy, who has been taking care for Sesha, she and her husband would not have been able to achieve successful academic careers. KITTAY, *Love’s Labor*, p. 38.

“challenging and substantial challenge”²¹⁴ must, according to Kittay, focus on Sesha’s bodily sensations and Sesha’s engagement within the world around her. Herein lies the reason for proper recognition of paid care demands, recognition of the need for carers and those cared for to have mechanisms for negotiating those aspects of their relationship that may be important and salient for both parties, but cannot be fully regulated contractually. Dependency workers need to be protected against exploitation by those they care for; those cared for also need to be protected against manipulation by dependency workers. This mutual protection requires negotiation within the frame of a particular set of relationships, which reflect the tension between work and life or work and care.

Lastly, let us not underestimate Kittay’s attentiveness and caring relationship to Sesha’s. This embodied and relational bond between parent and child is Kittay’s point of departure for any ethics of care. Kittay’s remarks regarding her daughter’s life also reveal our human inter-subjective and embodied orientation as relationally constituted human beings. They also provide an important challenge to the way society constructs meaning and care for the life-long disabled, or those that are dependent on the care of dependency workers. I would also argue that this new challenge in approach towards all dependents is an issue of community concern, which must be more precisely addressed and requires a new framework based on a better understanding of embodiment and relationality. This is not to suggest that care and attention must be given only to dependents, but also, as expressed in Kittay’s theory, to the dependency worker.

²¹⁴ Ibid., p. 155.

In summary, Kittay's original contribution lies in her successful attempt to protect inevitable dependents at the same time as dependency workers. She also successfully points to the role of society and its obligation for all citizens, who are vulnerable, dependable and equal.

Two of Kittay's principal insights are important for palliative care practice, as well as for my caring-presence framework: 1) based on our nested dependencies, we are all relational human persons, who through care and attention to the vulnerabilities of dependent persons and communal trust create a network of multiple interdependencies important for our personal and social life; 2) our dependency care and work requires the adoption of a transparent sense of self that puts aside our agenda and needs, and completely focuses on the needs of dependent persons.

3.4 The Imperative of Social Responsibility for Actions

The task to which I turn now is to present a critical analysis, common agreements, differences or flaws in Cahill or Kittay's work, and then, to extend all of these related insights into a three-level imperative of social responsibility for actions.

First, both Cahill and Kittay theorized, each in her own way, about the embodied and relational body of a concrete person, and recognized that the way we experience the world and others around us cannot ultimately be separated from the way our bodies function. More importantly, the human body is for Cahill and Kittay not only a frame of reference, but also the social-identity-forming bearer of value in society, and is in continuous dialectical exchange with the world and others.

Second, they further recognized that our mutuality of interpersonal relationships is the dynamic constitutive of our personhood. They both agree that we are responsible for the constitution of our personhood in a given field of inter-relational or intersubjective exchange.

Third, Cahill and Kittay have argued that we do not live inferior lives, but rather embodied – relational lives, in conjunction with the whole world, where we are all dependent, one way or another, on the participation or assistance of others; and where we construct our understanding of the world through our embodied engagement of the different practices and habits of our bodies.

Fourth, even if both chosen authors begin and present their exploration from human experience, as a starting point into the meaning and significance of human life and suffering and eventually death, they both express their understanding of human dependency relations in different ways. Let me elaborate each approach individually.

Cahill's experiences are strongly motivated by community relations, with the obligations and responsibility of individual members. Her focus and emphasis on personal autonomy and then on individual rights and obligations is on the one hand compatible with the ideas of liberal democratic society, on the other hand, using feminist methods and approaches to the ethics of care, she admits that human dependencies are bonds that are life forming and important for society. As pointed out by Cahill, all individuals embody social relations, including relationships pertaining to our gender, race, ethnicity, age, class status and communities. All of us share a common ground for moral action, and important values like freedom and equality stand in dialectical relation

with community solidarity and compassion for each other.²¹⁵ Relational participation in the community, according to Cahill, is essential for human existence and sharing a vision of the good life. Unfortunately, there is still ignorance within the societal community regarding people's experiences, hopes, compassion, trust, embodiment, relationality, and dependency.

Critically speaking, however, even if Cahill referred to the gender relations and re-conceptualization of traditional family structures and responsibilities, her arguments are sometimes very descriptive, and offer no specific theory or model for this re-conceptualization.

Another critique of Cahill's experiences of human dependency relations is her reduction of terms like the human person ("independent subject") and community as purely functional, which leaves out a consideration of the persons involved. It is good to note that even when Cahill, for example, offers her analysis on the decision for a child's adoption based upon her personal experiences, she still refers to a person as an autonomous individual rather than as a personal-embodied and relational person. This flaw in Cahill's terms is unfortunately common to many Catholic ethicists and philosophers. Nonetheless, the relationship between the human person and the community must be always taken in its profound existential significance, as it shapes our lives.

In contrast to Cahill, Kittay's world and human experiences are more personal-social-theoretical: she sees a world full of dependent people. As a mother whose daughter requires care around the clock, and whose life is engaged through her

²¹⁵ See CAHILL, *Sex, Gender, and Christian Ethics*, pp. 76-7.

dependency worker Peggy, Kittay is not afraid to present and reflect not only upon her life experiences, but also upon the social equality, dependency, relationality and the unequal attitude of society toward women today. Like Cahill, Kittay criticizes the egalitarian ideal of society, where there is no place for the disabled, for dependency concerns, or just for the recognition of those who care for dependents. In contrast to Cahill, however, Kittay suggests a new theory, namely a *connection – based theory of equality*, based on a nested set of dependencies and the *doulia* practice.

Following the belief that “what goes around comes around,” Kittay’s human experiences, arguments and dependency critiques link nested dependencies with social cooperation and suggest, without attacking personal autonomy or immediate reciprocity, that as relational and dependent persons based on our own vulnerability, we all have the same responsibility and that: 1) every dependent has a caretaker; 2) the dependency relation is respected; and 3) the caretaker or dependency worker is adequately provided for his work for the dependent, which does not in turn deplete him. Moreover, let me note here that even if Kittay is not attacking personal autonomy or immediate reciprocity in her approach to the dependency of loving relations, she still lacks in her relational approach the importance of values like freedom, self-respect and human dignity.

Furthermore Kittay, in contrast to Cahill, also calls for the “caring presence”. Along with Ellen K. Feder, in their book, *The Subject of Care*, they suggest, “that a new moral primacy should be placed upon care and a caring presence.”²¹⁶ In other words, there has to be a dominance of caring over curing, not the reverse that we experience in medical practice today. Here I completely agree with Kittay and Feder who suggests that

²¹⁶ See KITTAY, FEDER, *The Subject of Care*, p. 257, p. 277.

care is more than just a theory: it is the very foundation of morality that is rooted in our body and our bodily practices. Lastly, caring should be accepted as a primary task in medical practice, with the openness and cooperation of volunteers.

Both scholars have pointed to the isolation of today's individualism as contrary to commitment, care and compassion. Indeed, compassion and care are only conceivable where there exists interdependence between people. A community or society wishing to be strong can only do so with the bonds of interdependence, where mutual relationships are lived as interpersonal, where there is a reciprocity of communication, and where those who are in power (but still vulnerable) are taking care of those who are more vulnerable.

Finally, after pointing to the commonalities, differences and flaws in Cahill and Kittay's work, at this point, I would like to implement all of these insights and suggestions into three moral implications for the imperative of social responsibility for actions: 1) social responsibility at the individual level; 2) social responsibility at the community level; and 3) social responsibility as an ethical imperative.²¹⁷

Let me start here with these simple questions: what is the imperative of social responsibility for actions? What responsibility do we have? I would define social responsibility as the responsibility of all equal citizens in a democratic society without the exploitation of anyone based upon gender, race, ethnicity, age, or class status; it is

²¹⁷ Let us note that this "three-folded structure" of social responsibility is very common, especially in the human sciences, but also more recently in ethics or bioethics. I do not follow the Hans Jonas or Emmanuel Levinas structure, but rather propose the three-folded synthesis of the imperative of social responsibility, as considered by my related authors. Let me also note that all of these moral implications for social responsibility envision a world where embodiment and relationality are understood and lived. However, I am aware that many readers will not agree with me.

based upon nested dependencies for a common good, and goes beyond legal and economic responsibility.

First, let us elaborate upon social responsibility at the individual level. At the individual level, every human person is an embodied and relational self-conscious human being; at the same time the meeting place of the past, present and future, and through one's own embodiment related to others and the world around him.

In other words, at the individual level every embodied and relational person based on his nested dependency has a responsibility to society and the world beyond the boundaries of his own body. Social responsibility under this percept suggests that every individual person has a moral obligation to contribute to the common good of a democratic society and is dependent upon others.²¹⁸ Indeed, this responsibility and moral obligation is also an excellent opportunity for personal flourishing and an occasion for forming deep bonds of love and friendship.

Second, social responsibility at the community level means that our community, generally speaking, has a moral obligation for the common good in a society of equals, which goes beyond legal and economic interests. It should protect all of its citizens and members, and should never exploit the disabled, children, the old, or anyone based upon their gender, race, ethnicity, age, or class status. At the same time, it must always offer adequate support to dependents and those who care for them in relations of dependency. Some scholars²¹⁹ have pointed out that at the community level, as well as at the

²¹⁸ See KITTAY, FEDER, *The Subject of Care*, p. 330.

²¹⁹ Bonnie MANN, "Dependence on Place, Dependence in Place," in KITTAY, FEDER, eds., *The Subject of Care*, pp. 348-68.

individual level, we have the same moral obligation for the environment and to become attuned to the affective energies that sustain us.

In summary, I would also suggest that at the community level, one of our most important social responsibilities is to be attuned to dying persons in palliative care centres or hospices, and to the dependency workers who provide care within the framework of connection-based equality for all. I further suggest that this social responsibility can only be realized when the wider community pays attention to the human experiences of dying persons in palliative care, and when a caring approach includes embodied understanding, shared humanity as relationality, and commitment to be present as “a window in a person's home”.

Third, social responsibility as an ethical imperative requires that we promote human life as dependent upon interdependencies and responsiveness as an ethical responsibility of one to another. Insofar as we are all relational and dependent upon each other for survival, we also have the ethical obligation to sustain each other. Moreover, we have ethical obligations to care and to be more attentive, especially to those who are unable to care for themselves, and who are dependent upon our caring work, and to provide them not only with care but also caring relationships and a caring presence.

In other words, this imperative of social responsibility as an ethical imperative implies that we acknowledge our fundamental relationality as dependence on others, and understand that as a member of human society, we occupy more than just a social position based on our own self-interest or selective personal intentions. We must always promote and realize the best embodied and relational care for all in society, not just for the few. Reformulating Cahill's understanding of relationality as responsibility, a subject

who refuses responsibility for another subject absolves himself of the most important fundamental obligation – to be cared for and to care for others.

Overall, all three levels of this imperative of social responsibility for action suggest not only our personal involvement and social relations, but rather outline our own theoretical bodily and relational understanding as human beings, dependent on others and serving one another through loving work/labour of care. They also demand a necessary challenge in our philosophical and anthropological understanding of human nature as embodied and relational, and then remind us of our identity and virtue-forming responsibility.

3.5 Conclusion

I have demonstrated that both Cahill's and Kittay's work is relevant to the concept of relationality, as they both outline our priorities for our relational world. Their related insights, however, differ in the way they highlight the importance of human experience, intersubjectivity, dependency and relationality.

Cahill's interest in relationality is inspired by her examination of the subject-body as inseparable from its bodiliness and is always related to others in the world. She rejects the notion of biological determinism by relying on an analysis of historicity and freedom. She suggests that our experience of the body influences our self-understanding and the action we must take.

Moreover, Cahill also presents gender as a continuous moral project, and discusses its critical gender-role interpretations. She also exposes the need for a realistic integration of the material world into the social relations of men and women.

In contrast to Cahill, Kittay's interest in the relationship between our bodies and others is inspired by the concept of our nested dependencies and interdependencies on one another. She develops her argument for dependency and interdependency through a broad feminist and social construct of care, and presents a connection-based equality theory that calls upon those within the nested set of social relations to care not only for those who are dependent, but also for those who are dependency workers. In other words, Kittay in her work reminded us how attention to others, and to the world around us, reveals that our self, our world and others are always intertwined together.

Overall, both of my chosen authors are not blindly idealistic about the world in which do we live. They both express not only their suggestions and theories, but also critique the present power of relations, which according to them deform society, communities and individuals. Cahill identified the body as a subject of experience, so that the way we experience the world and especially other people in it is more than just our physiological functioning, even though the nature of our experience cannot be ultimately separated from the way in which our bodies function. Similarly, Kittay also developed the notion of human relationality, and added the further insight that a person's lived experience is connected and represents the gateway toward dependency on one another.

Most importantly, in relation to dying patients in palliative care, Cahill and Kittay suggests that our attention to the vulnerabilities of dependent dying persons must take into account our own mortality, dependency and vulnerability. Medicine, ethics, or bioethics, must direct those who cure and care (doctors, nurses, palliative teams, family

members or communities volunteers) in their preparation process, to focus on the flourishing of the person and not just on the treatment of particular pathologies.

Finally, based on Cahill's and Kittay's analysis of relationality, as the final outcome, I am implementing for my new caring presence framework these following elements:

1) we are all relational human persons, based on our nested dependencies. The care and attention to the vulnerabilities of dependent persons by the dependency worker, and communal trust, create a network of multiple interdependencies that form the central bonds of human social life;

2) our embodied and relational existence finds its full meaning in human relationships. Human relationship is the foundation of our ethical responsibility;

3) relational or community participation is essential for human existence and sharing the good life. One way to do so is to become personally engaged to care or to pay attention to those who need us and are dependent on us.

In the next chapter, I will propose my new comprehensive caring presence framework based on the notion of embodiment and relationality and its two sets of elements. I will also claim that a new caring presence framework must incorporate not only the medical, psychological, social and religious needs of the dying patient in palliative care, but also integrate the self-understanding of all interested in dying care as themselves bodily and relational persons.

*“You matter because you are. You matter the last moment of your life.
We will do all we can, not only do to help you die peacefully,
but to live until you die.”*

Dame Cecily Saunders²²⁰

Chapter 4: Caring Presence as an Embodied Relational Practice

4.0 Introduction

Prior to this chapter, I examined the notion of embodiment and the notion of relationality with its two sets of elements for better identification and organization of palliative care practice. In this chapter, I will incorporate embodied and relational elements into my analysis of caring presence²²¹, and I will propose a new comprehensive caring presence framework for attending to the lived experiences of dying patients based on the self-understanding of all health care professionals, family members and community volunteers as themselves embodied and relational persons in the provision of care. I believe that there is a strong inner connection, an awakening of human-to-human consciousness when any caregiver is bodily present to dying patients instead of simply dealing with the patients' physical needs.

Then, I will claim that there is also a spiritual implication in my caring presence framework that grasps the connectivity of embodiment and relationship in the caring presence, and provides the context within which God's presence can be expressed in the intercorporeal space in which one person is dying.

²²⁰ Maggie CALLANAN and Patricia KELLY, *Final Gifts: Understanding the Special Awareness, Needs, and Communication of the Dying* (New York: Bantam, 1992), p. 25.

²²¹ In order to clarify the importance of “caring presence,” I propose from an epistemological point of view that both “caring” and “presence” need to be merged into one phenomenon and practice. By merging them into one, they provide a richer and more descriptive phenomenon of what happens in the nurse-patient relationship and for which I am arguing through my new caring presence framework.

Later, I will address the challenges facing those who provide care for dying patients in the context of my caring presence framework, and the strategies of mutual trust and sharing, narrative, listening, and witnessing in meeting these challenges.

Finally, I will provide my personal insight into how this personal awareness of a strong inner connection within the context of my caring presence framework reframes and refocuses the caregiver's understanding of their caring work.

4.1 Caring Presence Framework for Attending to Dying in Palliative Care

In this sub-section, I will briefly propose how care/caring²²² has been defined in recent palliative literature with its own approaches, and how there is not an adequate comprehensive framework for attending to the lived experiences of dying patients in palliative care. Then, I will propose my caring presence framework for palliative care practice based on the self-attention and self-understanding of all involved in dying patients care as themselves embodied and relational persons, and their ability to relate bodily to the lived experiences of dying patients.

Physician and ethicist Fins defines care/caring within the context of palliative nursing care as the “specific activity that includes delivery of all the medical, psychological and social needs of dying patients in palliative care.”²²³ This care also includes the work of all palliative care personnel (doctors, nurses, health aides, social workers, spiritual caregivers, counselors, therapists, the patient's own family, as well as

²²² I am using the terms *care* and *caring* here interchangeably, as the two terms in my thesis refer to the same goal: the caring activity for a patient and his needs, as well as the care for all interested in his care. I am aware that these activities and needs are dependent upon the medical, social, and cultural context in which they are embedded. For more detail, see both the Introduction and Chapter 1.

²²³ See Joseph J. FINS, *A Palliative Ethics of Care* (Sudbury: Jones and Bartlett, 2006), pp. 228-29.

various volunteers), who try to alleviate the dying patients' pain and other symptoms and provide the highest quality of life for them.

With this formulation, one may see the resonance of the definition of care/caring within the context of palliative care, defined by the World Health Organization (henceforth WHO) as a curative, rehabilitative, and palliative approach to improve the quality of life for patients and their families:

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.²²⁴

This articulation by the WHO concerning the goal of care is helpful for the purposes of palliative care processes through its utilization of the best approaches to make the patient comfortable. It is by itself or in combination with similar approaches, however, neither sufficient nor effective, as it lacks attention to the human experiences of dying patients in palliative care and in being open to both caring and being fully present to them.

I would endorse care/caring as an embodied caring practice that provides both reliefs of symptoms that interfere with the quality of life when treatment will not change

²²⁴ WORLD HEALTH ORGANIZATION, "Cancer Pain Relief and Palliative Care," in Geneva WHO (1990): 11, *The WHO technical report series* 804. See also THE SECRETARIAT ON PALLIATIVE AND END-OF-LIFE CARE (Ottawa, Ontario, Canada), <http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php>, accessed April 12, 2009.

the time course of the illness, and eases suffering. The goal is to relieve suffering, as well as to continue to support the best possible quality of life for dying patients, regardless of the stage of the disease or the need for other therapies, and as death may not be imminent, to also support the needs of family members.

What I am proposing here is the necessity for a new framework for palliative care that must incorporate the embodied and relational understanding of all those interested in dying care. If accepted, it may represent one pathway towards better care for dying patients and a better self-understanding of one's own embodiment and relationality. I also claim that my proposed framework can contribute toward better daily practices, including better communication, policies and procedures for dying patients by health care professionals, families and community volunteers, and also offer another way to understand and examine an embodied relational person in end-of-life palliative care.

My new caring presence framework based on a subjective bodily self-understanding, connectedness, and caring-commitment to dying patients and their lived experiences in palliative care can be described as follows:

1. Attention to dying patients embodiment and lived experiences. Who are dying patients in palliative care and what are their lived experiences? The intent here is to pay attention to and to be aware of dying patients' embodiment and lived experiences, by all interested in their care. In other words, dying patients' embodiment and lived experiences always play an important role in understanding their own existence. Dying patients' bodies not only refers to the capacities of their general or cultural skills or

habits as presented in numerous relevant medical, ethical or sociological studies²²⁵, but also refers to the bodies as the subjects, as the mediums, as the source of consciousness, and as the points of departure through which dying patients are able to understand the ambiguities of their existence and enter into the subjectivity of others; it allows us to communicate and care for them.

Moreover, dying patients perceive the world around them as if the world is already there for them. Dying patients do not create the world around them; rather they explore and discover the world. To put it more clearly, the dying patients' bodies and world are deeply intertwined. The objects in their palliative room, like their beds, tables, chairs, and machines all mold into meaning through the context of their bodies. Also, their fingers, eyes, legs, internal organs, are all part of their subjectivity. Thus, everything about dying patients' bodies is part of their subjectivity, and, in that sense, dying patients are a being-in-the-world as embodied and relational subjects.

Therefore, what I propose here is the importance of paying attention to the embodied and subjective world of dying patients as the point of departure for all interested in their care. In other words, the bodies in front of them are no longer objects, but rather the subjective embodied bodies of dying patients entrusted to their care. This leads us to the second step.

2. Awareness of one's own embodiment. Who am I as an embodied and relational being? Who do I see in the mirror? This second step lies in self-conscious bodily

²²⁵ See for example Bruce JENNINGS, Gregory E. KAEBNICK, and Thomas H. MURRAY, "Improving End Of Life Care: Why Has It Been So Difficult," in *The Hastings Center Report* 35/6 (2005): S2-S4.

awareness of all those involved in dying patients care, be it a health care professional, family member or community volunteer.

Our embodied-somatic knowing helps us not only to evaluate our own bodies, but also helps us to act on this understanding and knowledge towards others.²²⁶ Therefore, a health care professional, family member, or community volunteer's own embodiment and subjectivity plays a significant role, as their bodies facilitates caring activities; through their own bodily embodiment, they recognize the embodiment of dying patients.

Consequently, when a health care professional, family member or community volunteer cares for dying patients, through their own bodily perception they can incorporate dying patients into their own bodies and vice-versa. Their human bodies record this embodied practice and can help them to become better socially and medically suited in their roles and may improve their caring practices in the future.

I further propose that the connection between two individuals in an ethical and social relation not only facilitates the experience, but also becomes the experience. However, this human experience is always embodied and corporeally constituted and it provides a very specific context for being with another in their shared humanity that allows for a deep, intersubjective experience and understanding.

Meanwhile, it can also be understood as a therapeutic tool that gives the dependent person a sense of comfort, as well as the ability to be open and cared for. For a dependency worker (the person who gives care to someone) it can be the opportunity

²²⁶ Regarding this point, see WEISS, *Body Images*, p. 1; KAVANAUGH, *Who Count as Persons*, p. 34; Chapter 2.1 of my dissertation, pp. 66-105.

for personal growth and self-embodied understanding.²²⁷

Lastly, awareness has to be reciprocal, as the human-to-human experience of being there is an intersubjective aspect of the caring presence that involves the deepest connection between dying patients and those involved in their care. I am aware that this experience of being there can be presented in many different ways and can occur on many different levels, be they personal, psychological or transcendental. However, what I am arguing for is mainly an awareness of these experiences as part of better practice in palliative care and as self-realization of one's own embodiment and relationality, which represents an important element of my framework of caring presence.

3. Responsibility toward other human beings. Because of our personal bodily experience we are able to understand and relate to others. In other words, our own life is not reducible to its features of a subjective/corporeal quality, but also has an intersubjective/intercorporeal quality that helps us to understand our responsibility toward other human beings. The bond between the world and others' existence and essence comes to us through our personal bodily experience.

For instance, palliative care nurses simply cannot regard themselves as objects from which subjectivity and intersubjectivity are essentially divided, but must regard themselves as subjects who are unable to leave their bodies, and who perceive and are related to dying patients through their bodies. Because of this embodied self-awareness and relationality, palliative care nurses, as well as all involved in dying patients' care, have an ethical responsibility to provide loving and high quality care for dying patients.

²²⁷ Regarding this point, see K. DOKA, B. JENNINGS, and C. CORR, eds., *Ethical Dilemmas in End of Life Care* (Washington, D.C: Hospice Foundation of America, 2004), pp. 81-175.

Moreover because of their personal bodily experiences, dying patients are always related to health care professionals, family members, or community volunteers, as well as to their beds and rooms. Through all of the different treatments, through all of the care, they are always relating to them and to all of the persons involved in their care. Dying patients' embodied bodies are intercorporeally bound to other beings, and thus, are called to bear certain responsibilities beyond itself. In other words, dying patients' embodied bodies yield to demands that their bodies place on other bodies, to what Weiss calls "bodily imperatives".

4. *Nested dependencies and vulnerabilities.* Based on our nested dependencies and vulnerabilities, through care and attention to the vulnerabilities of dependent persons and communal trust, we create a network of multiple interdependencies that form the central bonds of human social life. In other words, when health care professionals, family members, or community volunteers approach dying patients, they must take into account their own dependency and vulnerability, and then, through holistic care and attention to the needs of dying patients, create a network of multiple interdependencies, communal trust and sharing in helping to move together towards a mutual goal.

Notably, this emphasis on nested dependencies takes into account not only our own dependency, but also our own mortality and vulnerability. From this perspective, attention to the vulnerabilities of dependent dying persons not only represents dying persons as being dependent and vulnerable, but also shows how all involved in dying persons' care are equally vulnerable and dependent persons.²²⁸ As this relational concept is based on trust and personal sharing and creates a network of multiple

²²⁸ See KITTAY, *Love's Labor*, pp. 49-75; CAHILL, *Sex, Gender, and Christian Ethics*, p. 11. See also Chapter 3.3 of my dissertation, pp. 145-159.

interdependencies that form the central bonds of human social life. This network of multiple interdependencies of mutual trust and personal sharing must focus on the bodily presence, the power of narrative, the good listening and witnessing skills of a dependent person and of everyone involved in his care.

Ultimately, despite embodied connectedness and commonality, a health care professional, family member, or community volunteer must always be careful not to project himself and his own intentions too far when considering others. In other words, all involved in dying patients' care must be careful about their own egoistic and personal projections, as shaped by their own sets of experiences, being projected onto dying patients. The best way to avoid that is to respect and to be willing to listen to a dying patient's wishes, needs and interpretations as part of her daily care. Communication with the patient's family is crucial here; a patient's families and friends are significant in the patient's world and they impact her world as a dying patient brings her lived experiences into her world.

5. Relational awareness founds an ethical responsibility. One must open the door to a deeper understanding of the human person while offering a continuous exchange with other embodied persons. From this foundation, one understands own life and responsibility towards others.

Therefore, the embodied existence finds its full meaning only in human relationships. Moreover, this human relationship is the foundation of an ethical responsibility which demands that we be attentive to one another: in particular, our ability to respond to others increases as we become more aware of our own embodied and relational structure and connectedness with others. In other words, we not only

influence each other, but others also influence us. We learn about ourselves through the observations of others, like a child who learns by imitating others.

This deep conceptualization of our embodiment leads us to see ourselves as embodied and relational beings, who through our bodies, are simultaneously open to other bodies and are also engaged in a phenomenal field. To put it more simply, our bodies are neither subjects nor objects, but rather a means of interaction offering a continuous dialectical exchange with the world and others.²²⁹

Within the caring presence framework, the dialogical exchange between dying patients and health care professionals and the world around them is part of a larger communication and relationship; specifically, it is constant embodied and relational engagement with the world and others.

6. Relational participation as the path to better-embodied practice. One way to enhance and participate in better-embodied practice is to become bodily and relationally engaged to care and pay attention to those who are dependent on us. For example, within the caring presence context, a health care professional, family member or community volunteer's participation must always involve the body, mind, and spirit. This will establish profound relationships of caring presence that will eventually transform our societal or community values of commitment or responsibility for others, as well as an understanding of our own-shared humanity. Therefore, the more we understand our shared humanity, the more we contribute to a common good and to society itself.

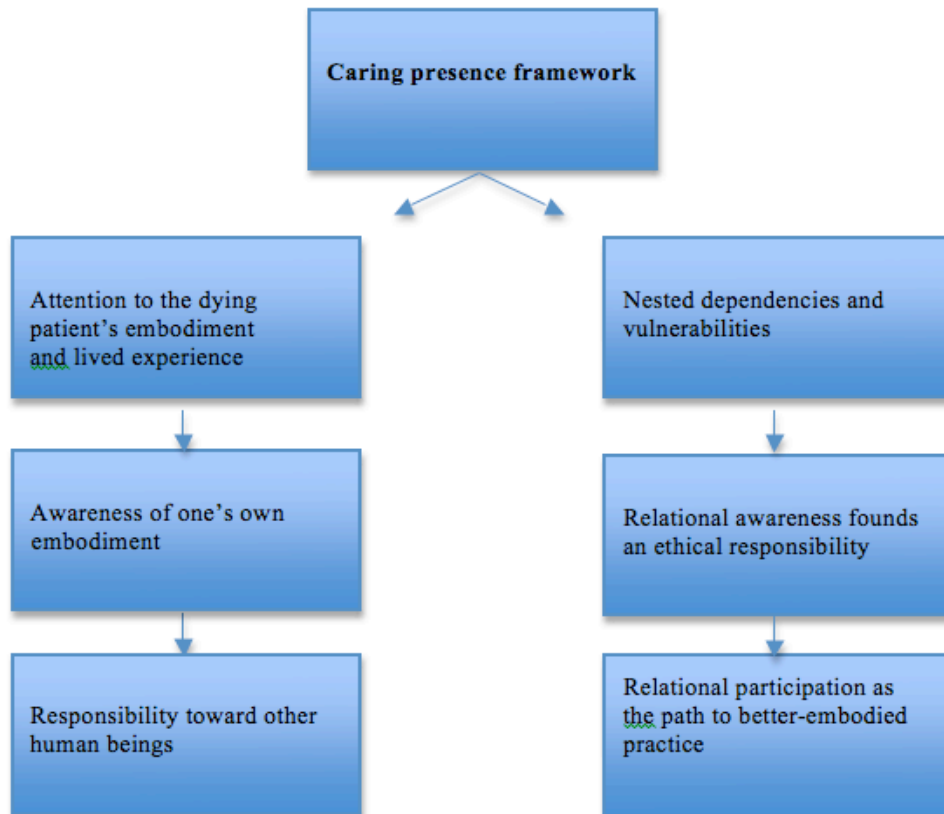
Overall, the emphasis in caring-presence should not be on what we are capable of doing, but rather about whom we regard as an embodied being. In other words, being a

²²⁹ See WEISS, *Body Images*, p. 146; KAVANAUGH, *Who Count as Persons*, p. 34.

responsible relational being means more than just occupying a social position that is based on self-interest or only being responsible for a select constituency. We must attempt to address the needs of the many, not of the few. Also, being open to one another within a relationship provides an important bond of dependency and communal trust, which, as an outcome, may provide a better understanding of the human experience of health and suffering.

Finally, for a better visual presentation of my new comprehensive caring presence framework, see Figure 1.

Figure 1: A new framework that is comprehensive in its approach to the caring presence of dying patients in palliative care.



In summary, all these six elements of embodiment and relationality come together in what I am calling the caring presence framework. Each of these elements is of equal importance. There is no primacy among them and they are all inter-related. In addition, they are all dependent on a self-embodied and relational understanding and on engagement with others.

My framework shows that the actual caring presence is an embodied and intersubjective moment, when all interested in dying patients' care, self-consciously aware of their own embodiment, enter into the embodied and subjective world of dying patients. Recognizing dying patients' lived experiences results in a merging of the subjectivity and intersubjectivity of inner, personal field perspectives at the present moment, and this provides better awareness of human-to-human consciousness for a better and more efficient holistic care, while at the same time, strengthening the bonds of human relationships and responsibility. I believe that the six elements in my caring presence framework show not only how we could attend to dying patients and their lived experiences in palliative care, but also how we could change our caring behaviours and attitudes toward them.

4.2 Spiritual Dimension in Caring Presence Framework

In this sub-section, I will present the spiritual/theological dimension in my caring presence framework that grasps the connectivity of embodiment and relationship in the caring presence and provides the context within which God's presence can be expressed in the inter-corporeal space in which someone is dying. In the first step, I will briefly discuss the spiritual dimensions of caring presence in recent palliative care literature.

Then, in the second step, I will describe how all the main elements in the context of my caring presence framework have a spiritual dimension.

There have been many attempts in palliative care literature to address spirituality and its role in caring presence practice. For instance, Wesorick (1995) suggests that spiritual care is the one of the therapeutic strategies in caring presence practice for dying patients: according to Wesorick, spiritual care is one way to focus attention. The nurse should promote spiritual care in the relationship with dying patients by focusing on her spiritual needs and by creating an environment for spiritual practice. Palliative scholar Hines (1992) found that there is always a spiritual dimension in a caring presence practice when nurses are connected to their client in a mutually explorative presence. However, Hines argued that this process of connecting with patients requires only good communication skills and a certain level of compassion. Parse (1998), for example, speaks about the spirituality of a caring presence practice as the art of becoming human. Such a presence, according to Parse, requires an active opening, talking, fulfilling the medical, social and spiritual needs, without a whole-person exchange or any intersubjectivity between nurses and dying patients. What is important is to provide the best quality of life for dying patients; something that could be also interpreted as spiritual well-being.²³⁰

With regards to the spiritual implication in a caring presence practice as described in the palliative care literature, I claim that my new caring presence

²³⁰ See also Daniel P. SULMASY, *A Balm for Gilead: Meditations on Spirituality and the Healing Arts* (Washington, D.C: Georgetown University Press, 2006); Lisa TRAFECANTY, "Biblical Caring Comes Full Circle: Identifying What Constitutes Caring in the 21st Century Remains Imperative to Defining Nursing," in *Journal of Christian Nursing* 23/3 (2006): 6-11.

framework provides the context within which God's presence can be expressed in the inter-corporeal space in which someone is dying; connections can be made not only with oneself, but also with others who are caring and grieving. This also provides new possibilities for entering into communion with God, and with each other, through an awareness of our embodied and relational dimensions with an emphasis on our suffering and our hope. I suggest that we have to rediscover what it means to love God through each other, as God abides in us all. Moreover, within the palliative care context, as intercorporeal human beings, as caregivers/actors of provision of care, we must help dying patients to connect to us, to other people, to God and to the world around them. By not providing caring presence to the dying, we not only fail them, but also God.²³¹

Furthermore, within my caring presence framework, each of my embodied and relational elements also has a spiritual dimension. As previously noted in my caring presence framework, our human subjectivity/embodiment is not simply a collection of organs and bodily actions, but rather an awareness of our functionality as a bodily unity that allows us to act and relate to the world and others through God who abides in us. In other words, when we as bodily beings open to the world and to others, we are relating and entering into communion with God through them.

I also claim that we are united with God and to everything and everyone around us through our body, and this in turn influences the way it appears to us as historically, spiritually, and factually situated beings. Also, as we are not only corporeal but also intercorporeal beings, we understand our bodily and ethical responsibility toward other human beings. This responsibility helps us to pay attention to those suffering and dying,

²³¹ For more specific personal involvement of Christian communities in palliative care see Chapter V, sub-section 5.3.

and to serve God through them. I propose that being responsible is not just a matter of occupying a social position that places demands on the caregivers as agents when providing care for a dying patient in palliative care, but it is also a privilege to become an agent of care and to spiritually transcend and connect both time and space in a caring moment.

Moreover, I also claim in my framework that through care and attention to the vulnerabilities of dependent persons and through the development of communal trust, we as embodied and relational persons create a network of multiple interdependencies that form the central bonds of our personal and social lives. Therefore, every time we, as persons, care or pay attention to a vulnerable person, we are also providing the love of God to him. Such care expresses not only the personal and social bonds of our life, but our spiritual bonds as well. Thus, the relational connection between two individuals is not only a personal or bodily experience, but also a spiritual experience that binds all of us together.

Finally, by caring for those who are suffering and dying, we are expressing our love of God and God constant presence to them. Our interconnection and witness to dying patients suffering and dying, is therefore, very vital and important.

4.3 The Strategies of Mutual Trust and Sharing

In this sub-section, I want to focus on the question: how can health care professionals, family members and community volunteers live out their personal ethical responsibility when taking care of dying patients within my caring presence framework based on embodiment and relationality? I suggest that one of the strategies to live out

their personal ethical responsibility according to the high ethical demands of palliative care is to focus on the strategies of mutual trust and sharing.

Moreover, this sub-section is structured as a conversation with alternative approaches and frameworks, showing the merits of my comprehensive framework in relation to the achievements and limitations of other frameworks found in palliative literature. I will then identify how the strategies of mutual trust and sharing between health care professionals and dying patients can improve such ethical demands of care.

There are many stories of health care professionals and community volunteers providing attention to the caring presence in their daily work that illustrate the importance of the caring presence framework, and illustrate how the relationship of mutual trust and sharing opens for them a new perspective toward enhancing the quality of life for dying patients and entrenches their commitment to be their caring companions. Examples of these stories can be found in the literature of many holistic nursing authors like Cody (1999), Jonas-Simpson (1997), Rasmusson (1999), and Bernardo (1998),²³² where they argue that a “caring presence allows the nurse to bear witness to and understand the patient’s experiences of an overwhelmingly technological health care environment”.²³³ However, others like Jones & Churchill (1994) and Younger (1995) suggest examining caring presence with its focus on trust, sharing, and connection as a “method of meeting a patient’s needs and facilitating healing during a time of suffering.”²³⁴

²³² See also Ira BYOCK, *Dying Well* (New York: Riverhead Books, 1997).

²³³ See COVINGTON, “Caring Presence: Delineation of a Concept for Holistic Nursing,” p. 307.

²³⁴ Holly COVINGTON, “Caring Presence: Journey Toward a Mutual Goal” (Ph.D. diss., University of Colorado, 2002), p. 307.

Moreover, Morse et al. (1990), as well as Morse et al. (1991) look into the whole spectrum of literature dealing with caring presence with its focus on trust, sharing, and connection and point out five different categories of conceptualization of this care: a) a human trait; b) a moral imperative; c) an effect; d) an interpersonal interaction; and e) an intervention.²³⁵

Boykn & Schoenhofer (1990) relate the caring presence with its focus on trust and sharing as an “authentic presence”; Gaut (1993) speaks about “a way of being-with the patient in genuine concern”; Montgomery (1992) refers to “authenticity and availability”; Ray (1994) regards this care as “love and co-presence”; and finally Watson (1979, 1988, 1999, 2000) regards this as “holding reverence for the person and human life. The goal of Watson’s caring presence is to help people gain a higher degree of harmony within the mind-body-spirit, achieved through the caring transaction.”²³⁶

I have noted these various authors in holistic palliative care in an attempt to better situate the already known theory or intervention of the caring presence as an attitudinal and behavioural phenomenon with its focus on the importance of mutual trust and sharing. It is evident through these studies, that the caring presence framework requires trust, genuineness, and sharing, and that these all have an effect not only on patient outcomes, but also on the palliative team members involved in dying patients' care. However, conceptualization of the caring presence framework with its focus on mutual trust and sharing is, in my judgment, still lacking an awareness and attentiveness

²³⁵ See J. M. MORSE, et al., “Concepts of Caring and Caring as a Concept,” in *Advances in Nursing Science* 13/1 (1990): 1-14.

²³⁶ For more see COVINGTON, “Caring Presence: Delineation of a Concept for Holistic Nursing,” pp. 309-10.

to a personal, embodied, and relational presence. I further argue that this lack of attentiveness needs to be addressed not only in palliative and hospice practice, but first of all, it needs to be incorporated into the nursing and medical curriculum and preparation in nursing and medical schools.

To correct this lack of awareness and attentiveness to an embodied, and relational presence in palliative care, I propose through my new caring presence framework a clear understanding of embodiment and relationality as the anthropological foundations for caring presence.²³⁷ Both notions are part of human nature, which nonetheless form an ontological unity in the human person. Thus, the human person as the whole interactive, consists of embodied being and it relates to others.

Moreover, embodiment and relationality are the means through which we relate to others and through which we are dependent on one another. Paying attention to these means may not only improve palliative care practice, but also offer a better theoretical perspective for the ethics of care in general.

Hence, in caring presence this anthropological understanding of the human person with personal awareness plays a very important part, as it focuses on an embodied-relational existence and the formation of meaningful relationships. However, this meaningful human relationship presents us with an ethical and social responsibility, which demands that we be responsive to one another.

Meanwhile, our ability to respond or to be responsive to one another increases only when we take into consideration our own embodiment and relationality and transform them into the caring practice, where personal awareness, mutual trust, and

²³⁷ Regarding this point, see Chapters 2 and 3 of my dissertation.

sharing form a meaningful friendship. As a result, this mutual friendship between the health care professional, family member, or community volunteer and dying patients will allow all of the contextual, personal, medical, psychological, spiritual, and social needs to be considered in palliative holistic care.

Following these remarks, let us turn to the importance of trust as one of the practical elements of my caring presence framework. Trust, in general, allows patients to be more open and less isolated, and it facilitates decision-making. This process is usually built on good communication that is both honest and open.

The health care professional, family member, or community volunteer must take into consideration that mutual and meaningful relationships of trust can only be established when the health care professional, family member, or community volunteer, as well as the patient, perceive each other as unique individuals. It is expected that each will come with different perceptions and perspectives of what the needs might be, how to meet them, or how they have already been met.

Different authors in holistic palliative care posit different opinions on those needs and how they can be met. For instance, McKinnon (1991) believed that patients cannot be solely responsible for setting their health-care goals and if they were, then a nurse or health care professional would be relieved from their accountability for the quality of the patient's life. Some others, like Mulholland (1994), argued even further that a patient's choices are always subjective and not objective, and cannot validate the nursing process or care. Adding to this conversation, Emanuel et al. (2000) asserted that different

perceptions can only be met in open and mutual relationships between the nurse and patient, and that the patient's autonomy and wishes must always be respected.²³⁸

Furthermore, along with trust, sharing is another practical element of my caring-presence framework. Through trust and sharing, we are able to better understand the commonalities and better able to meet the needs of both parties in the relationship. An open atmosphere of sharing cannot be established when people are in an inferior position of power in a relationship, but rather when they recognize each other's vulnerability.

Kittay described this problem of vulnerability when she explained a dependency relationship as always determined and how the parties in a dependency relationship respond to one another, with respect to the vulnerability of the dependant and to the vulnerabilities created for the dependency worker. What she argued for was the societal awareness of the vulnerability of patients and the health care professional in a dependency relationship as part of better caring and societal responsibility for them.²³⁹

Finally, how can we be attentive to embodied and relational dying patients in palliative care? I suggest that we can effectively do this by paying more attention to the human experiences of dying patients in palliative care, by being open to care and by being fully present to them. Moreover, based upon my caring presence framework, I would argue that this attention must be built not only on a personal, embodied, and relational understanding, but also on practical elements such as mutual trust and sharing between the one who cares and dying patients.

²³⁸ See L. L. EMANUEL, et al., "What Terminally Ill Patients Care About: Toward a Validated Construct of Patients' Perspectives," in *Journal of Palliative Medicine* 3/4 (2000): 419-32.

²³⁹ See KITTAY, *Love's Labor*, p. 53; Michael FINE, "Dependency Work: A Critical Exploration of Kittay's Perspective on Care as a Relationship of Power," in *Health Sociology Review* 14/2 (2005): 146-60.

I also claim that, in the caring presence, the actual merging of subjectivity and intersubjectivity between the health care professional, family member, or volunteer may occur, only when each party is consciously aware of and guided by that personal and subjective aspect of self within the circle of sharing and mutual trust. Importantly, the outcome of this caring presence framework is not only an understanding of both parties' needs, but also an awakening of human-to-human consciousness.

4.4 The Strategy of Learning the Power of Narrative

In this sub-section, I would like to focus on the challenges facing all involved in a dying patient's care in the context of my caring presence framework, and the strategy of learning the power of narrative in meeting this challenge. My question related to my comprehensive caring presence framework is this: How can caregivers live out their personal ethical responsibility when taking care of dying patients? How can caregivers live out their personal ethical responsibility when taking care of dying patients? I will propose that one of the strategies to live out their personal ethical responsibility in palliative care is to focus on the power of narrative in the health care professional – dying patient relationship.

I will discuss various approaches, showing the outcomes of my caring presence framework in relation to the achievements and limitations of other approaches in recent palliative literature. Moreover, the role of narrative is closely related to two of my elements: attention to dying patients embodiment and lived experiences, and to an awareness of one's own embodiment. I suggest that these two elements need to be recognized and applied before any narrative approach is realized.

In *A Palliative Ethic of Care*, Fins argues that it is the “common responsibility of medicine to communicate to the patients and their families.”²⁴⁰ Fins is referring to the importance of the power of narrative within the comprehensive, holistic palliative care context that requires all involved in palliative care to learn the power of narrative.

Why should health care professionals need to learn the power of narrative today?²⁴¹ Based on my caring presence framework, situated within the palliative care context for a dying person today, my hypothesis is that by learning and implementing the power of narrative within the caring presence framework, a health care professional, family member or community volunteer can honour and witness a dying patient’s suffering and dying and be, at the same time, nourished by them. I further argue that through narrative, one can explore and find the meaning in a dying patient’s lived experience and also find meaning in the events for the patient’s own life. All of these arguments however, require some necessary definitions, analysis and applications, to which I now turn.

What is narrative? Is there any structure or method to such an approach? Firstly, narrative refers to the stories organized around important events and it provides a temporal structure for considering the fundamental aspects of human life. Within the narrative structure, a human person thinks, perceives, imagines, and makes moral choices and it thus provides context to the meaning of events in one’s life. Secondly, narrative is always co-constructed and given as a result of cultural beliefs and

²⁴⁰ FINS, *A Palliative Ethic of Care*, p. 73.

²⁴¹ See Kathryn MONTGOMERY, *How Doctors Think: Clinical Judgment and Practice of Medicine* (New York: Oxford University Press, 2005), p. 216, especially Montgomery question: “Do we need health care professionals as medical-storytellers?”

influences. Thirdly, through narrative or personal stories, one constructs one's sense of self, the meaning of life and how to adapt to life's situations. Therefore, narrative not only interprets one's life and personal experiences, but also becomes the experience, as self-narratives are embodied in culture and belief and fundamentally influence them. Fourthly, narrative is a personal undertaking and also a part of social interaction.²⁴²

Moreover, narrative, either descriptive or explanatory, provides valuable insight into the patient's perceptual experience helps to track and organize his memories and explains why such a phenomenon occurred in a particular time and the context. It also encourages a holistic approach to care and promotes an understanding and reflection between health care professionals, family, volunteers and the patient.

Narrative also fulfills several functions: it integrates past and present experiences into a coherent picture and comprehensive structure; makes sense of personal experiences, especially suffering and traumatic events; provides an answer to existential questions; and categorizes the role of others in our lives. Importantly, as the teller reveals his past as it happened, or how they remember it happening, the story has narrative truth and can be understood through interpretation. Through different narrative analyses, the listener helps to comprehend the whole picture of narrative truth and to pay attention to the subtlety and nuance of the telling. All this information is valuable and must be carefully drafted and recorded for future communication in the caring process as it create new material about the patient. It validates his experience and enhances communication between the patient and those who are involved into his care.

Now, using the power of narrative or storytelling as a technique in order to form

²⁴² See Trisha GREENHALGH, "Narrative Based Medicine in an Evidence Based World," in *British Medical Journal* [henceforth BMJ] 318 (1999): 323-5.

an effective caring presence framework within the palliative care context, I would define narrative as the personal, embodied, intersubjective form of communicating the meaning of a person's life and history and expressing his own identity. It allows dying patients and the health care professionals, family members or community volunteers to open up to one another through the narrative, linking their identity to the story. This mutual sharing and listening also creates a network of multiple interdependencies that form the central bonds of human life. It further provides a deeper analysis into the person's life and history and offers a method for approaching a patient's medical problems holistically with the possibility of discovering new therapeutic medical options. In other words, the narrative provides the meaning, context and perspective for the patient's predicament. It offers the how, why and what the patient experiences and wants.

The importance of the power of narrative and the related narrative competencies in medical care today is, however, not a new invention, rather a forgotten one. Since the late 1990s, according to medical professionals like Charon (1997, 1999) or Greenhalgh (1999), many health care professionals have begun to recognize narrative approaches and methods as valuable and important in caring practice. Through the narrative analysis method, they have been able to explore the meaning and the understanding of a patient's experiences of suffering and dying. However, attempts to incorporate the power of narrative into the embodied, holistic caring presence are not apparent in any of the narrative analyses.²⁴³

²⁴³ For example: Rita CHARON, *Honoring the Stories of Illness* (Oxford & New York: Oxford University Press, 2006); Kate HUNTER, *Doctors' Stories: The Narrative Structure of Medical Knowledge* (Princeton, NJ: Princeton University Press, 1991); Rita CHARON, "Narrative Medicine: Form, Function, and Ethics," in *Annals of Internal Medicine* 134/1 (2001): 83-7.

For instance, the medical protagonists of narrative medicine, Greehalgh and Hurwitz, define *narrative* as an approach to treatment based upon the following propositions:

The processes of getting ill, being ill, getting better (or getting worse), and coping (or failing to cope) with illness, can all be thought of as enacted narratives within the wider narratives (stories) of people's life; narratives of illness provide a framework for approaching a patient's problem holistically, and may uncover diagnostic and therapeutic options; taking a history is an interpretative act, interpretation (the discernment of meaning) is central to the analysis of narratives; narratives offers a method for addressing existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses.²⁴⁴

Based upon Greehalgh and Hurwitz's research, *narrative* in medicine and nursing takes into account the importance of telling stories about others and ourselves, not as a passive literal documentation of some previous or present events, but rather as a dynamic, and contextual, one that provides meaning and perspective about a patient and our lives. Meanwhile, these stories provide a framework for approaching a patient's problems and his life in a more holistic fashion, along with revealing diagnostic and therapeutic options. More importantly, as suggested by Nelson (2002) or Frank (1991), these patients' histories and storied psychologies are part of medical intervention.

Analyzing Greehalgh and Hurwitz's insight, I argue that even if narrative in medicine and nursing is based upon attentiveness and the importance of a patient's stories, recognition of the patient's embodiment and relationality play a crucial role to be recognized and applied before any narrative approach is realized. This, however, requires all involved in palliative care to be aware of their embodiment, relationality, connection, and connectedness and then to be more engaged and perceptive listeners,

²⁴⁴ Trisha GREEHALGH; Brian HURWITZ, "Why to Study Narrative?" in *BMJ* 318 (1999): 48.

caregivers, speakers, and witnesses to a patient's suffering.

Another good example of attempting to implement narrative into the embodied holistic care and similar to my caring presence framework, comes from the research of Charon (2001), who stated: "Physicians need the ability to listen to the narratives of the patient, grasp and honour their meanings, and be moved to act on the patient's behalf. This is narrative competence, that is, the competence that human beings use to absorb, interpret, and respond to stories."²⁴⁵ Charon also suggests three more explanations:

Narrative [in] medicine 1) simultaneously offers physicians the means to improve the effectiveness of their work with patients, themselves, their colleagues, and the public; 2) provides access to a large body of theory and practice that examines and illuminates narrative acts; 3) can give physicians and surgeons the skills, methods, and texts to learn how to imbue the facts and objects of health and illness with their consequences and meanings for individual patients and physicians.²⁴⁶

What Charon suggests, is her attempt to learn the "narrative competence"²⁴⁷ by all involved in medical and nursing (palliative) care through a series of interpretative practices such as listening to the stories of others, especially dying patients. What is so insightful in Charon's approach, and similar to my caring presence framework, is the ability to listen to and learn the power of the narrative and of the realization of awareness and attention through which the physician and patient encounter one another, thus enabling them to see each other not as 'strangers', but rather as two human beings in a mutual relationship.

²⁴⁵ Rita CHARON, "Narrative Medicine. A Model for Empathy, Reflection, Profession, and Trust" in *Journal of American Medical Association* [henceforth *JAMA*] 286/15 (2001): 1897.

²⁴⁶ *Ibid.*, p. 1897, my edition [in], numbers and emphasis added.

²⁴⁷ The term "narrative competence" is defined according to Charon as "the ability to acknowledge, absorb, interpret, and act on the stories and plights of others." CHARON, "Narrative Medicine," p. 1897.

I contend, however, that even if Charon's approach²⁴⁸ and insights are valuable for holistic palliative or hospice care today, the ability to listen to a patient's narratives as their lived experiences must be based, before any initial healthcare professional-patient encounter, on embodied self-awareness of all interested in dying patients care and then on the recognition of dying patients embodiment and common relationality. This better awareness of human-to-human embodied and relational consciousness provides a more specific formation of the caring presence framework for comprehensive holistic care and space for mutual witnessing and reconciliation.

Thus, what does it truly mean within the caring presence framework for all involved in a dying person's care to learn the power of narrative? I propose that learning the power of narrative within the caring presence framework will allow: evaluation of human experiences of sickness and suffering as complex as a patient's past and present state; promotion of better embodied and relational pathways towards holistic care; to enable rediscovery of meaning, history, dependence, and perspective of a patient's personal life; encouragement of awakening of human-to-human consciousness and to possible diagnostic and therapeutic procedures. To be more specific, let me briefly outline these outcomes in detail.

Firstly, through narrative competence within the caring presence framework, a health care professional, family member or community volunteer may better evaluate the patient's human experience of sickness and suffering by being attentive to the content of

²⁴⁸ For the purpose of this project, it is not necessary to present a detailed structure of Charon's narrative practice, known as the reader-response critical approach, but to note that the most important aspect of listening draws upon three crucial components: attention, representation and affiliation. Though such a technique Charon believes the patient opens up for his medical professionals complex, multifaceted, and therapeutic care. See more in GOTLIB, "Stories From the Margins: Immigrant Patients, Health Care, and Narrative Medicine," p. 67-8; Rita CHARON, "Narrative and Medicine," in *The New England Journal of Medicine* [henceforth NEJM] 350/9 (2004): 862-64.

the patient's narrative and its form. If there are complete or incomplete stories, pauses, images, silence, gestures, breathing, body movements and positions, tones of voice, a health care professional or a community volunteer may better understand the human experience of the patient's sickness and suffering and even the complexities of the world in which he is living right now.

Moreover, some narrative tools may also offer a specific framework for approaching a patient's illness as a part of his whole life and provide a medium for mutual physician-patient education, as well as uncovering assumptions of hidden medical or personal problems.

Secondly, Charon claims that, "Without the patient's robust narrative world the physician cannot enter into the patient's suffering world, cannot offer comfort, and cannot accompany the patient through the illness experience. Only doctors who have developed narrative competence will recognize their patients' motives and desires, will allow patients to tell their full stories of illness, and will offer themselves as therapeutic instruments."²⁴⁹ What Charon observes here is the "multifaceted and complex" reality of lived experience and the special significance of suffering and dying within.

In other words, if a health care professional, family member or a community volunteer wants to understand and interpret dying patients lived experiences, they must, as Weiss previously proposed, take into consideration their own embodiment. The body of a dying person in front of them is a person that cannot detach itself from its body, as the body enables the dying person to observe objects. Similarly, Kavanaugh claims, "the

²⁴⁹ Rita CHARON, "The Narrative Road to Empathy," in *Empathy and the Practice of Medicine: Beyond Pills and the Scalpel*, ed. by Howard SPIRO et al., (New Haven: Yale University Press, 1993), p. 150.

human person is an embodied, self-conscious drama. We are life stories, narratives that start with endowments that make possible our becoming aware of our own stories and eventually writing our own autobiographies within the limits of our diverse histories [...] To be a person is to be an expressive animal, a self-creating drama, a center of action, a narrative becoming conscious of itself, revealing and yet concealed through the embodiment of mask.”²⁵⁰

What Weiss and Kavanaugh bring to our attention is that dying patients' bodies always reveal themselves as more than objects. It reveals an utterance and a personalization of a dying patient's reality and who they are. However, at the same time, the body is a vehicle for interaction with other people. Therefore, dying persons' relations with others is an attempt to influence others while others are simultaneously seeking to influence them.

Overall, better narrative competence by a health care professional encourages an awakening of human-to-human consciousness. There is a strong, inner connection, when a health care professional, family member or community volunteer meets and cares for a dying patient instead of simply dealing with the patient's physical needs. This strong, inner connection or awakening of human-to-human consciousness lies in our bodily understanding, connectedness and commitment to be “a window in someone's home”. Therefore, by accompanying each other in the time of suffering and dying, we truly become aware of who we are, how deeply we are connected, and how dependent we are on one another. This special time is also a time for reconciliation and thanksgiving.

Thirdly, through narrative competence within the caring presence framework, a

²⁵⁰ KAVANAUGH, *Who Count as Persons*, p. 62.

health care professional, family member or a community volunteer may rediscover the meaning, dependence and perspective of dying patients' personal lives. Kittay argues in convincing fashion that dependence, which is a pre-condition of relationality, begins with our birth. Therefore, we are all connected and dependent people and the quest for relational meaning is an essential part of human life. By listening to the patient's stories as expressed through their narratives, a health care professional, family member or community volunteer encounters not only the patient's dependence on them, but, moreover, their own dependence on someone else.

Fourthly, good, narrative competence within the caring presence framework suggests possible diagnostic and therapeutic procedures and helps to determine the best such procedures. Through a careful set of narrative skills, be it textual, creative or affective,²⁵¹ a health care professional or a community volunteer is able to explain and apply all appropriate treatment and medical procedures to dying patients in palliative care and to help them understand their suffering as dying takes hold of their flesh, affecting their gestures, movements, and all their senses.²⁵²

In summary, what I propose in this sub-section is the importance of the power of narrative within my caring presence framework for comprehensive palliative care today. I have argued that the formation of a good narrative skills within the caring presence framework by all involved in dying persons' care may improve the persons experiences of dying and may also contribute to a better care for dying patients in palliative care.

²⁵¹ See more in CHARON, "Narrative and Medicine," p. 862.

²⁵² Some studies have been done on using communication as a method for diagnostic and therapeutic procedures. See for example Nikki JARRETT, et al., "Someone to Talk to and Pain Control: What People Expect From a Specialist Palliative Care Team," in *Palliative Medicine* 13 (1999): 139-44.

4.5 The Strategies of Listening and Witnessing

In this sub-section, I will continue to focus on the question: how can caregivers involved in a dying patient's care live out their personal ethical responsibility within my caring presence framework based on embodiment and relationality? I suggest that one of the strategies for enabling caregivers involved in dying patients' care to live up to the high ethical demands of palliative care within my caring presence framework is to focus on the strategies of active listening and witnessing.

As in the previous sub-sections, I will discuss the literature related to palliative care practice with these specific goals: illustrate how to implement the strategies of active listening and witnessing; then, examine the effectiveness of active listening and witnessing; and finally, discuss the outcomes of these strategies within my caring presence framework in relation to other approaches.

4.5.1 The Strategy of Active Listening

In this sub-section, I will focus on how the strategy of active listening can improve the health care professional and dying patient relationship within my caring presence framework based on embodiment and relationality, and provide better outcomes in such care.

Active listening is a very specific and demanding task, as it requires from the listener intense attention and concentration towards the person talking and to his non-verbal movement. Every word, every action, and every movement counts and enhances the mutual relationship. Active listening also explores the illness and its experiences, and helps in understanding the whole person. In addition, it fosters trust, sharing, and the

patient's sense of feeling that he is heard and understood. The outcome is a better understanding of the patient's needs and concerns by a health care professional, family member, or community volunteer, and how these needs may be appropriately met.

From my caring presence framework perspective, active listening is a specific and inter-subjective moment when one person, self-consciously aware of his own embodiment, places his whole attention and awareness at the disposal of another person; he enters into the embodied and subjective world of such a person, listens and explores with interest his train of thought, and then tries to understand, relate, focus, and assist such a person. This process, however, requires from the listener intense concentration, focus, and the ability to empty oneself from prejudices, frame of references, and patterns of responding in a way to better understand, help, and respect another person's embodied and subjective world, feelings, and different needs.

In contrast to this specific and demanding act of listening, the acts to avoid in active listening are disembodied and paternalistic acts. Paternalism in this context assumes that the health care professional knows what is best for the patient. By not listening to the patient's experiences and not letting his voice be heard, the final outcome is the following: an unhappy, unsatisfied, and un-cooperative patient, who often feels betrayed and alone. This unfortunate practice has been known for some time in palliative care, along with the bad habit of "labeling people's experiences"²⁵³ by their disease and illness experiences. For example, when a patient is labeled with one illness like liver cancer, all the rest of her experiences like feelings of loss or powerlessness are denied. Dying patients' lived experiences were neither a point of care nor of interest.

²⁵³ See Chapter 1.1 of my dissertation, pp. 12-40.

To correct this oversight, and to implement a more positive and successful caring outcome and to ensure a better quality of life for dying patients, I propose that we pay more attention to all five elements of my caring presence framework, with a special focus on active listening and witnessing. When we actively listen to dying patients not only do our words count, but also our bodily presence, openness, and trust, and it gives patients a sense of safety as they shares their personal information with us. In other words, when we listen to dying patients, we listen not only with our ears, but also with our mind, heart, and imagination. If we want to know and explore dying patients' subjective world, we cannot detach ourselves from them.

We must actively listen and try to understand everything that is happening in front of us, like appearance, body movements, body language, gestures, facial expressions, eye contact, crying and depression. Therapeutic and inter-subjective active listening must go beyond simply paying attention to dying patients.

Moreover, being attuned to dying patients and to their embodied and subjective world requires us to be open to our own bodily understanding and nested dependency, “self-exploration, personal connections and significant emotional experiences”²⁵⁴. In other words, a health care professional, family member, or community volunteer must first face his own subjectivity, which lies in his embodied, bodily understanding, relational engagement with the world and others and it lies, moreover, in one's own awareness and understanding of his own dependency and vulnerability. This awareness is the moment of existential and ethical self-conscious reflection, vital for our realization of self-understanding, limitation, vulnerability, dignity and our ethical obligation to care,

²⁵⁴ See Manal GUIRGUIS-YOUNGER, Soti GRAFANAKI, “Narrative Accounts of Volunteers in Palliative Care Settings,” in *American Journal of Hospice and Medicine* 25/1 (2008): 16-23.

to listen, and to be with others. Having a sense of oneself as a subject, and at the same time as an agent, allows a caring person to understand, listen and relate to others. In retrospect, it allows one to relate to oneself.

As Oliver observed in Kittay's work on relational responsibility and dependency, "One can only address oneself to oneself, or respond to oneself, if one has first addressed or been addressed by and responded to others. At its core, subjectivity is relational and formed and sustained by addressability (the ability to address others and be addressed by them) and response-ability (the ability to respond to others and oneself)."²⁵⁵

Oliver is right in his assessment, because by conceiving ourselves as bodily subjects who are vulnerable, dependent, and connected to others, we are able to address, listen, and respond to others. Oliver further describes "subjectivity as the ability to respond is linked in its connection to ethical responsibility. Responsibility, then, has a double sense of opening up the ability to response—response-ability—and ethically obligating subjects to respond by virtue of their very subjectivity itself. Response-ability is the founding possibility of subjectivity and its most fundamental obligation."²⁵⁶ In other words, Oliver's observations of Kittay's work lay down for us and for all involved in palliative care, solid phenomenological foundations, which are also part of my caring presence framework, based on our embodied and relational foundations.²⁵⁷

²⁵⁵ Kelly OLIVER, "Subjectivity as Responsivity," in *The Subject of Care: Feminist Perspectives on Dependency*, eds. by Eva F. KITTAY, Ellen K. FEDER (Oxford: Rowman & Littlefield Publishers Press, 2002), p. 326.

²⁵⁶ *Ibid.*, p. 327.

Furthermore, for the comprehensive, holistic care for dying patients, the ability or skill to focus on the therapeutic aspect of active listening, along with witnessing, is seminal. It must involve the whole person, truly present and attentive in reaching out to dying patients and their families, to hear them and to then respond to them in an appropriate fashion. It requires extensive training. Listening contributes to a deeper and richer interpersonal dialogue, opens our deepest generosity and fosters an active suspension of bias. In this sense, this deeper health care professional-dying person relationship creates a new understanding and meaning.

Moreover, health care professionals or community volunteers must facilitate not only interactive listening with dying patients, but at the same time facilitate this communication with patients' families. By actively listening to them, informed choices and priorities in regard to the diagnosis and prognosis consistent with dying patients' values and preferences can be specified and realized. Palliative health care professional Haase summarizes this practice as follows: "It is important, then, for us to listen, to ask, to be creative and to remember to always focus our attention on the needs of the person and family to whom we are ministering."²⁵⁸

To even better illustrate the importance of active listening within the caring presence framework that leads to better comprehensive, holistic care, let me quote from

²⁵⁷ This "comeback" to the notion of subjectivity and response-ability is important here, as it presents and narrows the human person as the subject and agent who is always embodied and relational when entering into the subjectivity of another person.

²⁵⁸ Elizabeth Turner HAASE, "Pastoral Care of the Dying: The Art of Being Present," in *New Theology Review* 17/2 (May 2004): 40. See also a qualitative study of hospice volunteering in the rural communities of northwestern Ontario. Margaret MCKEE, Mary Lou KELLEY, and Manal GURIGUIS-YOUNGER, "So No One Dies Alone: a Study of Hospice Volunteering With Rural Seniors," in *Journal of Palliative Care* 23/3 (2007): 163-72.

one of the experiences of palliative care volunteer Mr. Yoko Tsuyuki, a St. Joseph's Palliative Care Volunteer in Toronto, who describes his role in palliative care the following way: "Sometimes, palliative patients have families who can be here for them, but some are totally alone. Our role is to sit with them and listen and hold their hand if they need it, to let them know someone is there for them."²⁵⁹ This wonderful and personal experience of one of the volunteers is not a rare one; there are many others like this one. Many palliative and hospice care services through ongoing communication make every attempt to provide full presence and listen to the personal narratives of dying patients and their families and, at the same time, try to address their various needs.

Yet some recent studies in palliative care and holistic nursing show that active listening is not an easy task.²⁶⁰ For example, palliative care volunteers often describe this experience as one of their most difficult duties, as they visit and stay with dying patients, usually for short periods. To bring yourself to be the person who will sit, be able to listen rather than speak, to hear the experiences of patients with whom we are engaged, to pray with those who want to, is not always easy.

There is yet another area that can be problematic in regard to active listening and that is avoiding the other's person concerns. This avoidance can be conscious or unconscious and can be problematic to dying patients or even to the health care professional, family member or community volunteer. No one can force dying patients

²⁵⁹ Michelle TADIQUE, "Palliative Care Volunteers Provide a Caring Presence and a Listening Heart for Patients and Their Families," in *Hospital News* (September 2009). See also EMANUEL et al., "What Terminally Ill Patients Care About: Toward a Validated Construct of Patients' Perspectives," in *Journal of Palliative Medicine* 3/4 (2000): 419-32.

²⁶⁰ Here I present only some of the more recent studies, but in my bibliography I will list more of them for further research. See for example Anne H. BISHOP, John R. SCUDDER, *Nursing Ethics: Holistic Caring Practice*, 2nd ed. (Boston: Jones & Bartlett Publishing Company, 2000).

to speak. Sometimes, the topic of discussion is too challenging, emotional, stressful, and full of bad memories or just too demanding on dying patients. Also, there can be legitimate reasons why dying patients don't want to speak with anyone. Again, respect and different settings are usually a good solution for such a situation.

In conclusion, listening is a truly important element in the caring presence framework and all involved in dying patients' care must master it. For that reason, one way to alleviate such a fear and to prepare for better, comprehensive holistic care is further ongoing education of health care personnel and community volunteers.

This preparation must, however, involve not only an embodied and relational understanding, but also ongoing training on listening practice and in examining their own fears and feelings about death and grief to avoid panic in the face of what is a difficult but final process in human life. In addition, other necessary skills for holistic care like questioning, explaining and interpretation are also necessary. I will speak more in detail about these future directions for caring practice in Chapter Five.

4.5.2 The Strategy of Witnessing

In this sub-section, I will focus on how the strategy of witnessing can improve the health care professional and dying patients relationship within my caring presence framework based on embodiment and relationality, and provide better outcomes from such care.

Active listening leads to another important practical element within my caring-

presence framework, that is, the aspect of witnessing.²⁶¹ What, though, does it mean to bear witness for dying patients? Based upon my caring presence framework, I propose that to bear witness means to be present with and for dying patients within a network of complete trust and sharing, and then to reflect back to him what you have seen and to act accordingly with what you have perceived.

This dynamic, interactive and therapeutic aspect of witnessing differs from other types of relationships, like social or intimate relationships, and attempts to be caring, genuine, available, attentive, non-judgmental, willing to listen, maintaining hope, supportive, and willing to share with dying patients; at the same time, one is aware of one's own embodiment, mutual vulnerability and relational commitment. In other words, to be a witness to dying patients in palliative care means to grasp one's own, as well as dying patients embodiment and relationality, and to be open to actively listen and stay with them, however futile that action might appear.

Moreover, in health care palliative practice, as a result of improving technology, internal insurance policies, and societal and cultural changes, the idea of witnessing is more important than ever.²⁶² Drawing on my caring presence framework and with respect to the palliative practice as a defined enterprise whose goal is to prevent and relieve suffering and to support the best quality of life for dying patients, I propose that a health care professional, family member, or community volunteer needs to always focus

²⁶¹ It is good to note that terms such as testimony, or bearing witness are closely related in this dissertation. They all present in the goal of nursing: a way of being with dying patients and to focus on their personal experiences and their interpretations.

²⁶² For more studies done on this aspect of witnessing see Chana ULLMAN, "Bearing Witness Across the Barriers in Society and in the Clinic," in *Psychoanalytic Dialogues* 16/2 (2006): 181-98; Rahel NAEF, "Bearing Witness: a Moral Way of Engaging in the Nurse-Person Relationship," in *Nursing Philosophy* 7 (2006): 146-56; William K. CODY, "Bearing Witness-Not Bearing Witness as Synergistic Individual-Community Becoming," in *Nursing Science Quarterly* 14/2 (2001): 94-100.

on the act of witnessing as a part of comprehensive, holistic care for dying patients. In doing so, this focus on witnessing will offer them not only the ability to be a bridge for understanding life in the face of the suffering and death of dying patients, but it will become for them, a self-transformation process that enriches their life with shared meaning for all interested in care of the dying.

To be more specific, within the health care professional-dying patients relationship, this aspect of witnessing must be an embodied and relational mode of coexistence, based upon nested dependencies, to protect, respect, honour, and care for other human persons and not to leave patients alone in their suffering and dying. Moreover, witnessing and caring presence are inherently linked: to witness means to be present and to be open to another's experience and then to demonstrate this experience toward others. In short, if there are no witnesses, there is no human sharing and caring.

Witnessing, however, from the point of human suffering and dying, is also a good therapeutic tool for knowing a dying patient's psychological, spiritual, or social needs and ideas and it provides the necessary information for those involved in dying patients care to be more effective in their medical and caring approaches. Well-trained health care personnel know how important this time is with dying patients; not just to know their decision or way of thinking, but also as a way of relating to them and to their living experience. It is both an honour and a commitment, to be present and close to dying patients, to be able to enter into their embodied and subjective world and to know their priorities, dreams, and hopes.

In addition, witnessing also involves revering and remembering dying patients' lived experience. Therefore, every aspect of witnessing should be a very respectful and

honest expression or testimony of one vulnerable-dependent person toward another vulnerable-dependent person in suffering or who is dying. By realizing our own vulnerability and dependence, all involved in dying patients' care should be able to understand dying patients' vulnerability and not only grasp the questions and needs of dying patients, but also to create a network of multiple interdependencies that form the central bonds of the patients' personal and social life.

In other words, the aspect of witnessing is not just a way of fulfilling the physical, medical, psychological, social, and religious needs of dying patients in palliative care, but also “staying with” or “being with” him through the whole journey of their suffering and dying. Nor is it just a practice or gesture of solidarity, concern, or obligation, but rather a day-to-day, personal presence with dying patients as a mutual shared connection and interconnection, assurance, reconciliation, thanksgiving and shared common humanity.²⁶³ Witnessing is, then, an embodied and intersubjective moment, when a dying patient's and a health care professional's world interconnect, based on communal trust and sharing humanity and where reconciliation and thankfulness has its place and full realization.

Meanwhile, dependency workers also experience their own needs, expectations, and struggles. Thus, caring and witnessing form a mutually enriching process, complex yet essential for comprehensive, holistic care today. It must be based, as previously suggested, on an embodied, relational commitment to respect, care, and stay with dying patients, who needs help and a bodily presence. This, however, presupposes a specific

²⁶³ See also J. WATSON, “Love and Caring: Ethics of Face and Hand: An Invitation to Return to the Heart and Soul of Nursing and our Deep Humanity,” in *Nursing Administration Quarterly* 27/3 (2003): 197–202; Per NORTVEDT, “Needs, Closeness and Responsibility. An Inquiry Into Some Rival Moral Considerations in Nursing Care,” in *Nursing Philosophy* 2/2 (2001): 112–21.

and sufficient anthropological and phenomenological knowledge of all interested in dying patients' care, along with personal awareness and social commitment to share and care for others.

Furthermore, this specific aspect of witnessing involves not only those who are responsible for them, but of the whole community. We are all part of a living community, so we bear witness to people, their ideas and their thoughts. In Bunker's words, "We must realize that we are in community with those who suffer. We must bear witness."²⁶⁴ In Chapter Five, I will speak more about the importance of creating and energizing caring communities. For now, it is sufficient to note that dying patients are members of a living community where all the members bear witness to them.

Lastly, how can a health care professional, family member, or community volunteer engage and bear witness to dying patients in palliative care within the health care-socio-political context of care, when present health care practices are too often preoccupied with technology and budgetary constraints in their approach to health and health care? How, too, are health care professionals, who because of their hard work are usually too busy or are too preoccupied with their healing work, able to engage, witness, and enter into caring- presence relationships with dying patients?

Firstly, opinions on these questions vary in the health care literature. For instance, Cody (2001) argues that "it is quite possible to be near another person, to be aware of her or his situation, to have a verbal exchange, and to feel affection for the

²⁶⁴ S. S. BUNKERS, "Reflection on Suffering," in *Nursing Science Quarterly* 14/3 (2001): 199-204.

person while not witnessing to the lived reality of the person; indeed, it is common.”²⁶⁵ He even further argues that within current palliative practice, nurses should pay attention to the empirical science and technology, and only when there is time, to bear witness and be the caring presence.

Secondly, some others, like Malone (2003) or Callahan (1993, 1997), argue that there is ignorance within the medical community regarding people’s experiences, hopes, compassion, trust, embodiment, relationality, and dependency. As a result, both authors see the solution within a societal and healthcare theoretical level, rather than acknowledging the importance of knowledge and implementing practices of caring by health care professionals, family members or community volunteers.

Finally, there is validity in these opinions and analyses and many others similar to them, but I contend, along with Cahill and Kittay, that a new moral primacy of caring should be focused on active listening and witnessing²⁶⁶ as part of the comprehensive, holistic care for dying patients. In other words, caring presence with a focus on listening and witnessing should be accepted as the primary task in health care practice along with the openness and cooperation of community volunteers.

There has to be a primacy of caring over curing. This, however, presupposes the following premises: 1) a whole caring framework with a focus on active listening and witnessing needs to be rooted in embodied and relational knowledge, based on and arising from a personal living experience and then oriented toward others who suffer and those who are dying; 2) an embodied and relational knowledge needs to be implemented

²⁶⁵ William K. CODY, “The Ethics of Bearing Witness in Healthcare: A Beginning Exploration,” in *Nursing Science Quarterly* 14/4 (2001): 289.

²⁶⁶ See Cahill, *Sex, Gender, and Christian Ethics*, p. 63; KITTAY, *Love’s Labor*, p. 53.

within health care educational process and programs; 3) the caring presence framework with a focus on active listening and witnessing needs to form the foundation of daily palliative practice as the way to caring for and being fully present to them, listening to them, bearing witness, respecting their human dignity, honouring them, and providing them with the best quality care at the end of their lives; to be for them “a window in their home”, in Dr. Saunders’s words.

4.6 Care as Bodily Labour: A Way of Understanding the Work of Care

Bodily labour, which caring in palliative care requires, is rightly called “the labour of love”. In this sub-section, I will again continue to focus on question: how can caregivers live out their personal ethical responsibility when taking care of a dying patient within the context of my caring presence framework based on embodiment and relationality? I will suggest that the formation of the caring presence, fully and completely within the context of caring presence framework, requires all involved in palliative care to not just implement the strategies of trust, sharing, listening or witnessing; they must also embrace a new understanding of the work of care that reframes and refocuses the healthcare professional's understanding of the work of care as active and demanding labour, because dying is a labour.²⁶⁷

This sub-section is based on my insights and appeals to my dialogue partner Kittay and her understanding of “dependency labour” that enhances the healthcare professional's ability to live up to the high ethical demands of care as presented in my caring presence framework.

²⁶⁷ A similar study was conducted by Susan HIMMELWEIT, “Caring Labor,” in *Annals of the American Academy of Political and Social Science* 561 (1999): 52-63.

First, I would define “care as bodily labour”²⁶⁸ as a physical, emotional, spiritual, embodied and relational carrying task for an extrinsic reward. To be more specific, it is first of all a challenging, physical task that is often endless and exhausting. Health care professionals or community volunteers must not only take care of the well-being of the patient, but they must also deal with dying patients' growing weakness and fatigue as they near death; they have to take care of all of dying patients' needs. For example, they may have to administer oxygen or morphine or change a dying person's position in bed almost every two hours, as they are unable to do it themselves. They may have to gently massage dry skin areas on the patient's body to stimulate blood flow, or to place pillows under the body. All of these heavy, physical tasks are provided not only as routine care duties, but also as part of comprehensive holistic-centred care for the patient: “We do everything, what we can”.

Then, there is also emotional work or labour (Hochschild, 1983) that deals not only with a dying person's emotions, but also with the emotions of the one who provides care. More specifically, according to Hochschild, it deals with: “The social representations of nurses and the constant management and suppression of real feelings.”²⁶⁹ This emotional labour impacts the work of health care professionals or community volunteers, as it provides stress, depression, and many somatic health problems and also affects the performance of their work. Even if there are some solutions, like prevention or empowerment, as suggested by some sociologists, it still

²⁶⁸ See also the distinction between “caring as a work” and “caring as a labor”, where work contains always “a noncommodified element” and labor is a fully “commodified element”. Margaret J. ADIN, *Contested Commodities* (Cambridge: Harvard University Press, 1996), p. 105.

²⁶⁹ Arlie R. HOCHSCHILD, *The Managed Heart: Commercialization of Human Feelings* (Berkeley: University of California Press, 1983).

remains the task of many academic and medical institutions to help unmask the emotional labour as soon as possible and to help dependency workers and volunteers to better manage their emotions towards more effective comprehensive care.

As a spiritual work or labour, care as bodily labour for dying patients is considered as the rewarding act of love, not only for dying patients and their families, but again, also for the one who provides that care. This labour relies upon a solid spiritual formation and the ability to listen and witness, as well as bodily self-awareness and presence. It offers a unique, but also very challenging, opportunity for a more direct experience and spiritual assistance, and serves as a rewarding spiritual education founded in actual human experience around dying patients and their families. Moreover, it is an act that is usually reserved for hospital or hospice chaplains, or Christian community volunteers, who are members of the palliative team.

Finally, based upon my framework that is comprehensive in its approach to the caring presence to dying patients in palliative care, care as bodily labour is also an important, intersubjective, embodied, relational labour, as one embodied, relational person is attentive to another embodied relational person, who is dependent on her care. This process, however, requires that the one who provides care be self-aware of her own embodiment and relationality/dependency in a way that allows her to be attentive to the vulnerabilities and needs of the dependent person.

Moreover, to better understand this last process as it relates to my caring-presence framework, I would suggest going back to Kittay's *Love's Labor*, and to briefly elaborate her theory of dependency work that in my judgment, provides a solid

foundation for understanding ‘care as bodily labour’²⁷⁰ for not only dying patients, but also for those who are involved in their care and dying.

Kittay in her theory suggests that dependency work is an inherently embodied and social task done through the relationships between one dependent person and another person who is dependent on him. Kittay then argues that this dependency work should not only remain as a private, emotional or cultural endeavour, but that it should be a part of everyone’s life.

It is good to note how Kittay’s theory of dependency work changes our attitudes toward caring as labour. Seen only as a bodily, emotional and spiritual task, through the embodied dependency relations, it changes into inter-subjective reality and personal care as the labouring presence. However, this change only occurs when embodied dependency relations are recognized as central and foundational aspects of human life. In Kittay’s words, “In truth we know that no one is independent. We are all dependent—the fates of each of us hang on those of others.”²⁷¹ Kittay’s observations of embodied dependency work and relations are of great significance here, as they emphasize an ordinary and unavoidable condition in our human life: our dependency on others.

Dying patients in palliative care are also dependent persons whose needs should be met. In order to meet and satisfy their needs, the relationship and trust between a dependency worker (a health care professional or community volunteer) and a dependent person (dying patients) must be established. However, seen from a multiple, social

²⁷⁰ In subchapter 3.3, pp. 157-9 I presented Kittay’s theory of ‘nested dependencies’, through the personal story of her daughter, Sessa. In this sub-section 4.6, I will briefly refer to the theory of dependency work, which relates to the embodied and relational work in my caring presence framework.

²⁷¹ KITTAY, *Love’s Labor*, p. 184.

perspective, both the dependency worker and dependent person rely on persons who provide for them.

As such, care as bodily labour for dying patients in palliative care as realized through a dependency worker is truly derived from their inter-subjective connection or awakening of human-to-human consciousness, which lies in their bodily understanding and connectedness. Importantly, even if this inter-subjective connection becomes “unequal”, to use Kittay’s word, it still remains a connection, because no one can separate us from these relationships and our dependencies.

One more remark needs to be made regarding the role of a dependency worker who is a health care professional or community volunteer. Most of them provide magnificent, demanding labour and truly do the best they can. However, as embodied and relational human beings paying attention to their own embodiment and relationality, they must identify dying patients interests as their own. Kittay calls this aspect the “transparent self”, the ability to identify someone’s interest as his own. This identification of interest by Kittay is of great importance for palliative care as it provides the capacity to understand a dying patient’s needs and it attempts to fulfill them.

Finally, I would suggest that “care as bodily labour” is also a labour of love, not the love as described in fairytales, but rather as a given reality. A reality that is rewarding and seen as a requirement in someone’s care: a love that will not seek to serve one’s own interest, but rather to enhance dying patients well-being.

A good example would be a health care professional or community volunteer who spends a good portion of his time being bodily present to dying patients in palliative care by offering a variety of soft foods or liquids while dying patients are awake or

moistening patients mouth with a few drops of water, when they are no longer conscious. This labour of love is not only rewarding for the dependent persons, but also for one who provides care, as it strengthens their connection through recognition and respect.

4.7 Conclusion

In Chapter Four, I have incorporated the two fold elements of embodiment and relationality from previous conversations into my analyses of caring presence and explored the various dimensions of caring presence today.

In sub-section 4.1, I have proposed a new caring presence framework that incorporates not only the medical, psychological, social, and religious needs of dying patients in palliative care, but also focuses on the self-attention and self-understanding of all involved in dying patients care as embodied and relational persons engaged in the provision of palliative care.

Moreover, what I have observed in my caring presence framework that may serve as a point of departure for further research in palliative care is the following: 1) No framework can cover all possible palliative care cases, much less touch the critical ambiguities in palliative care that distinguish any one case from another. My effort was to examine only the situation of dying patients and one way of improving palliative care today. However, in around-the-clock palliative and hospice practice, the caring presence framework must always be done in conjunction with other caring frameworks; 2) In caring practice, there is always a place for principles, virtues, and theories. Principles, in general, serve a critical function while theories allow us to understand the principles.

Both, however, are important in the practice of palliative care. With respect to the practice of palliative care today and with respect to the ethical principles on which it operates, we will not be able to avoid the conflict among some of these theories and their viewpoints.

In sub-section 4.2, I presented the spiritual implication in my caring presence framework. I claimed that all of the main elements of my framework have a spiritual dimension. I suggested rediscovering what it means to love and serve God in others, and how we all as human beings have a responsibility to provide caring presence to others, and not to abandon them.

In sub-section 4.3, I proposed that in order for caregivers to fully realize and to live out their personal ethical responsibility in a dying patient's care within the context of my caring presence framework based on embodiment and relationality, caregivers must focus on the strategies of mutual trust and sharing within the caregiver - dying patients relationship.

In sub-section 4.4, I proposed that in order for caregivers to live out their personal ethical responsibility within the context of my caring presence framework, caregivers must focus on the strategy of learning the power of narrative, with an emphasis on the narrative skills and competence required for enhancing the caregiver - dying patient relationship. This strategy can contribute to a better self-understanding of the human experiences of sickness and suffering; it promotes a better-embodied and relational pathway toward comprehensive holistic care; and it encourages an awakening of human-to-human consciousness.

In sub-section 4.5, I proposed that in order for caregivers to live out their personal ethical responsibility within the context of my caring presence framework, they must focus on the strategies of active listening and witnessing. I claimed that the aspects of active listening and witnessing should be accepted as a primary task in palliative care practice with the openness and cooperation of volunteers.

In the final sub-section, 4.6, I concluded with a new understanding of the work of care that reframes and refocuses the health care professional's understanding of the work of care as active and demanding labour. Going back to Kittay's theory of "dependency labor", I argued that caring for dying patients in palliative care within the caring presence framework is not only a physical, emotional, and a spiritual task, but it is also an embodied and relational labour that relies on the bodily awareness of all involved in dying patients care, as well as on the ability of the dependency worker to identify with dying patients experiences and needs. In conclusion, I argue that such a labour of love is also rewarding and mutually enriching.

*“I once asked a man who knew he was dying
what he needed above all in those who were caring for him.
He said, “For someone to look as if they are trying to understand me.”*

Dame Cicely Saunders²⁷²

Chapter 5: The Path to Better-Embodied Practices in Palliative Care

5.0 Introduction

In this final chapter, I would like to offer some directions for palliative care practice. First, I will begin by exploring some advantages that could be gained by incorporating existing models of individual and social care into my caring presence framework based on embodiment and relationality and rooted in the method of bodily self-understanding for more comprehensive, holistic, palliative care practice.

I will then continue with the implications of incorporating my caring presence framework into the palliative training programs and practices of all involved in dying patients' care. Particularly, I will focus on the role of bodily self-understanding and its implications for palliative care practices by various (Christian) community volunteers, families, healthcare professionals, medical students and palliative care doctors.

Moreover, I will argue that there exists not only the necessity of educating, and energizing various communities and specialized palliative teams, but also the need to inspire a personal witness and personal commitment that would help the relational exchange remain alive in its fullest sense.

In the end, I identify some limitations of my research and suggest possible future research in the area of palliative care in the light of my caring presence framework.

²⁷² CALLANAN & KELLY, *Final Gifts: Understanding the Special Awareness, Needs, and Communication of the Dying*, p. 25.

5.1 The Incorporation of Existing Models of Individual and Social Care into My Proposed Framework for an Embodied and Relational Palliative Practice.

In this sub-section, I will underline the importance of incorporating an individual and social model of care into a more holistic, embodied, and relational palliative practice, and emphasize why such a palliative practice must always begin with a personal and social commitment.

As previously noted in Chapter 1 (1.1, p.12), since the 1960s, new models and frameworks of palliative care for dying patients have emerged. Frameworks directed towards palliative care practice were formal and curative, with the sole intent to relieve symptoms and to cure the patient's medical problems: attention to the human experiences of dying patients and attentiveness to their embodiment and relationality were generally non-existent.

Fortunately, during the last 40 years, developments in medical, philosophical, and ethical scholarship in palliative care²⁷³ have led to a deeper understanding of the human body as a subject, rather than as an object, with the body being open to the world and interacting within the world. This embodied and relational focus on the body has resulted in greater attention being paid to the human experiences of dying patients and has consequently changed palliative care curriculums and practices for all involved in dying patients' care.

Since the 1960s, two different caring models of palliative care have generally formed the basis for palliative care practice: a) *The biomedical, individual curative*

²⁷³ See the following reports: TASK FORCE ON PALLIATIVE CARE, *Last Acts: Care and Caring at the End of Life* (December 1997); THE SUPPORT, "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)," in *JAMA* 274 (1995): 1591-98.

model, which focuses on the cure within its own framework, based on medical evidence, physical causes, and physical treatments. However, this model is predominantly scientific, rationalistic, and analytical, and discounts any subjective data. It still dominates medical curriculums around the world and has many supporters, especially in the U.S; b) *The hospice/palliative care social model* focuses on care and on understanding the human experiences of suffering and dying patients with an emphasis on relationship building. In this model, the human patient's body is seen as an embodied body that exists within a web of social relationships. One of the major advocates of the hospice/palliative care social model and 'care philosophy' was Dame Cicely Saunders, who implemented this in her work at St. Christopher Hospice, London, England, and which was later used in many hospices by devoted medical and health care professionals around the world. In Canada, the extraordinary work of Dr. Balfour Mount and the Royal Victoria Hospital Palliative Care Services was, and is still, recognized as pioneering work. Indeed, Canada is considered today as one of the most important advocates of palliative care services.

Both models of care have their own representatives and champions from the point of administration to caring practices, and each model advocates how 'their' model, with its own structure and goals, is more important than the other.²⁷⁴ My caring presence framework is more situated within *the hospice/palliative care social model*, because it focuses on dying patients as the locus of human subjectivity and palliative care practice. Moreover, my caring presence framework is not a radical departure from either of these

²⁷⁴ Harvey M. CHOCHINOV, "Dignity-Conserving Care—A New Model for Palliative Care. Helping the Patient Feel Valued," in *JAMA* 287/17 (2002): 2253-60; DIANE E. et al., "Improving Palliative Care," in *Annals of Internal Medicine* 127 (1997): 225-30.

models; it instead emphasizes the importance of the bodily self-understanding and its implementation into daily, palliative practice, and calls for more personal and social community involvement and commitment. My task however, is not to further compare or contrast these models, but rather to ask: what direction should comprehensive, embodied and relational palliative care take now, when present palliative care practices are driven more by technology and are trying to prolong the dying process? The medical evidence²⁷⁵ suggests that an answer lies in dignity-conserving care, providing a better quality of life, better palliative education, and in enacting financial and structural reforms.

Based upon my assessment of the present gaps and practices in end-of-life palliative care (Chapter 1, 1.3, p. 51, 1.4, p. 57), I argue that the best way to fill the present gaps and to improve palliative care practices must be rooted in personal conversion and in socially responsible action. In other words, I claim that unless health care professionals, doctors or any palliative care team members act ethically and see themselves as being accountable for their responsibility toward other human beings, any palliative care framework or model can be subverted and corrupted, however noble its purpose.

How then can we change current palliative care practices and make every human being accountable for his responsibility toward other human beings, especially toward those who are the most dependent, such as dying patients and their families? Going back to my caring presence framework, I suggest that we begin by focusing on the role our physical bodies play as themselves embodied and relational and on the implementation

²⁷⁵ See Gillian FORD, "The Development of Palliative Care Services," in DOYLE D., et al., eds., *Oxford Textbook of Palliative Medicine* (Oxford: Oxford Medical Publications, 1993), pp. 43-5.

of our embodied and relational understanding into the provision of comprehensive, holistic, palliative care for dying patients.

To illustrate my suggestion within the palliative care context, if health care professionals, family members, or community volunteers first pay attention to their own embodiment, this will enhance their ability to better relate bodily to the lived experiences and needs of the dying and also will enhance strong personal relationships between them. By doing that, a health care professional, family member, or community volunteer can truly become for dying patients a willing companion and, through the strategies of mutual communication, trust and sharing, can create a network of multiple interdependencies that form the central bonds of human social life.

In addition, in order to make every individual human being accountable for his or her responsibility toward others, we all as human beings need to be aware of our embodiment and relationality as central to our well being. By an understanding of who we are as embodied beings, with a complex history of relationships, values, habits, nested dependencies, responsibilities, and commitments, we can understand the unique and irreplaceable position we occupy in this world. Indeed, our subjective and intersubjective human existence, in an ethical and social relationship with others, always becomes an enriching, mutual and social experience.

Our mutual responsibility and accountability to care for and to be fully present to dying patients in palliative care is not grounded in an “out-of-body-experience”, but in the pre-reflective dynamics of an embodied being in a shared, social world. Therefore, *the biomedical, individual curative model* and *the hospice/palliative social model* need

to incorporate into embodied and relational palliative care practices the cooperation of multidisciplinary teams²⁷⁶, community volunteers, and the dying patient's family.

Finally, to improve the palliative care practice we must always begin with questions such as those proposed in my comprehensive framework: Who are dying patients? Who am I as a caregiver in palliative care? How can I relate to dying patients' lived experiences? What do the dying patients' experiences tell us, and what do they want us to know and do? Searching for an answer might challenge each of us to consider whether our efforts are correct or not, and how they can be improved.

In order to get health care professionals and community volunteers to pay attention to the dying patient's lived experiences and to respond to the patient's needs, as well as to be fully present to him or her throughout the whole journey of dying, we must return to our embodiment and relational self-understanding as the core of our foundation as human beings, and to incorporate that into present palliative care practice. This framework, however, requires a change in core educational objectives, and greater personal and social community involvement of all involved in dying patients' care.

5.2 The Necessity of Creating and Energizing Community Involvement

In this sub-section I am going to discuss a larger community involvement in caring for dying patients in palliative care, and to explain why family members and various community volunteers need to be fully present and to bear witness to them.²⁷⁷ I

²⁷⁶ See more about the role of multidisciplinary teams in Pat MCNEES, *Dying: A Book of Comfort* (New York: Grand Central Publishing, 1998), pp. 15-57.

²⁷⁷ I am aware that there are many issues and problems to be discussed when addressing the involvement of various communities in palliative care, like that of burnout, professionalization, low-wage work, and privacy issues. For the purpose of my dissertation, I will only focus on the necessity of creating and energizing larger social community involvement.

consider this to be vital because as embodied and relational beings, we can all embrace the dying patient's journey as an expression of our own humanity and become for the dying patient caring companions. This is based on three arguments: 1) our human existence is always embodied and relational; 2) as human beings, "we are all some mother's child"²⁷⁸ and we form a community of dependent people that are always dependent on one another; and 3) caring presence is always mutually enriching and transformative.

In regards to being bodily present and actively participating in palliative care, Farley suggests that we must "bear with the sufferer, in love and respect."²⁷⁹ This is an important insight from Farley, because it points to our bodily engagement and attention to the caring presence with a person who is suffering or dying, and enables us to transform our love into care and respect. Similarly, Remen adds to this inherent reciprocity in caring relations by claiming: "In attending to our own capacity to suffer, we can uncover a simple and profound connection between our own vulnerability and the vulnerability in all others. Experiencing this allows us to find an instinctive kindness toward life, which is the foundation of all compassion and genuine service."²⁸⁰

Furthermore, our caring presence and active participation in palliative care must always extend to the whole community, as every human being in society is part of an embodied-social relationship, including relationships pertaining to our gender, race, ethnicity, age, class status and community.²⁸¹

²⁷⁸ KITTAY, *Love's Labor*, p. 50, pp. 23-6.

²⁷⁹ FARLEY, *Compassionate Respect*, p. 10.

²⁸⁰ See Rachel REMEN, *My Grandfather's Blessings* (New York: Riverhead Books, 2000), p. 12.

In addition to our personal commitment, legal policies and rules should support and encourage this societal engagement to be fully present and to care for the dying patient entrusted to our care. The basis for such a statement lies in our intercorporeal understanding: we are all embodied and relational creatures, dependent and called upon to bear a certain responsibility for one another.

Moreover, our caring presence cannot be understood apart from its societal aspect. Cahill expresses this permanent body-subject disposition when claiming, “Movements back and forth between the body and its social world seem to be intrinsic to the meaning of the body itself.”²⁸² This means that our bodies are related to their social aspects, or as Kavanaugh critically remarks, “The lives we build together in friendship, community, or family are much more than personal needs or interpersonal comforts. They are strategic choices we make as social and political beings.”²⁸³ What is important then, is that we extend as a larger community beyond ourselves to support our members in suffering and dying.

More specifically, if we speak about a larger community and its actors’ involvement, we must include not only volunteers, families, or various health care professionals, but also our neighbours, co-workers and various members of religious communities and non-profit organizations. This community involvement should last as long as the dying patient’s journey towards death and even after she dies. More importantly, as a larger community we need to be aware that we are truly not

²⁸¹ See also the excellent essay by Marie J. GIBLIN, “Care of the Dying: A Kairos Moment,” in *Second Opinion* 4 (2001): 49–72; WEISS, *Body Images*, p. 1.

²⁸² CAHILL, *Sex, Gender and Christian Ethics*, p. 73.

²⁸³ KAVANAUGH, *Who Counts as Persons*, p. 153.

autonomous islands, but rather dependent and responsible to “open up to the other and to take that other in charge – for the sake of the other.”²⁸⁴ Or as Kavanaugh puts it, “We must ask ourselves – whether student, philosopher, or citizen – how the experience of the marginal, the wounded, the dying, might lead us to love them, rather than to fear or destroy them.”²⁸⁵ Ignorance and non-participation would be a failure not only to society, but also of humanity itself.

Based on all these embodied relational remarks and a larger community involvement in the dying patient’s care, I would suggest that more than ever before, an awakening of human-to-human consciousness is needed today: to participate and to enable more collective action to transform the present state of hierarchical and formal palliative care into interdependent, embodied, and relational practice for those who are most vulnerable and dependent on us in their suffering and dying.²⁸⁶

This suggestion leads us to ask: what needs to be done to make our embodied and relational palliative practice to dying patients more meaningful? Based on my comprehensive caring presence framework, I suggest that it must begin with a self-understanding by caregivers as themselves embodied and relational persons: to come to the bedside of dying patients with the ability to respect their suffering and dying, expressing personal care, and the communication skills to fulfill a particular dying patient's needs with the ability to adjust as her needs change. The focus of such

²⁸⁴ Enrique DUSSEL, *Ethics & Community* (Maryknoll, NY: Orbis Press, 1989), p. 39.

²⁸⁵ KAVANAUGH, *Who Counts as Persons*, p. 155. See also the book by Arthur W. FRANK, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago, IL: University of Chicago, 1995).

²⁸⁶ See also the excellent book by Kenneth J. DOKA and Joyce D. DAVIDSON, eds., *Caregiving and Loss: Family Needs, Professional Responses* (Washington, D.C: Hospice Foundation of America, 2001).

caring must involve a commitment to establish trust and to bear witness to dying patients rather than to focus on their treatment. It can begin with keeping dying patients comfortable, and with open communication, by asking what are their needs and what they expect from us. It can continue with simple gestures like holding their hands, brushing their hair, or reading to them from a book or newspaper, singing a song, or praying with them. We can encourage them to drink fluids or to eat food if they want, help them change their position, and keep them clean. Finally, we have to be honest with them, not lead them into despair or confusion, but rather tell them the truth, tell them how much they are loved and appreciated, what they mean to us, and how rewarding it is for us to be with them.

There are some limitations within the embodied and relational caring presence framework and practice, which should be noted.

First, the caring presence as an embodied and relational framework and practice may differ in its scope and application when it is experienced and realized by men rather than women. At present, the responsibility of primary care and caring presence is borne predominantly by women.²⁸⁷ Communities should encourage more men to care and support the dying. Both women and men are equally responsible for sharing this care and for facing the burden of such work.

Secondly, the caring presence as an embodied and relational framework and practice may change with different health care professional or volunteer/community members, or even from dying patient to dying patient. With respect to many specialized

²⁸⁷ See also Kittay's remark: "Most men assume their responsibilities, but so many abandon them." KITTAY, *Love's Labor*, p. 26.

palliative care and hospice facilities, some recent medical studies²⁸⁸ show that not all care is truly compassionate, grace-filled, or friendly, even when performed as holistically as possible. However, dying patients and their families should always remain the subject, rather than the object of care.

Thirdly, the caring presence as an embodied and relational framework and practice realized through community volunteers needs to be applied with respect and sensitivity, especially when dealing with different ethnic and cultural groups. Both health care professionals and community volunteers need to ask direct questions, so as to determine what is meaningful to each dying patient and his family. Without such respect and sensitivity, caring embodied and relational practice may not be as effective and respectful, in regards to cultural differences, as desired.

In summary, the caring presence framework, based on embodiment and relationality practice and realized through family or various community volunteers is not just the responsibility of a particular religious or societal group. It is the social responsibility of all of us as members of a larger social community. For that reason, there is the necessity of creating more and more energizing communities willing to care for the most vulnerable, dependent, and voiceless patients. By caring and being fully present to them, we can show them our love and support and become aware of our own dependency and embodiment. In return, dying patients can provide us with their lived experience, as we care and comfort them during their dying journey.

In addition, when we comfort the dying, we also comfort ourselves. Our death also belongs to others; in a way it will have an impact on those around us. Because of

²⁸⁸ See for example LAST ACTS FINANCING TASK FORCE, *The Challenge of End-of-Life Care: Moving Toward Metanoia?* (Washington, D.C: Last Acts, 1997).

our intercorporeality, when the dying patient dies, he shows us, his caregivers, how to die. By caring for the dying patient, we are living our caring engagement with others.²⁸⁹ Therefore, as a way of strengthening dying patients, let us offer them our full caring presence, our feelings of personal grief and sadness on losing and missing them in our life, and assist them in settling unfinished business. By comforting the dying patient, we learn how interconnected we are as human beings, and what it is that makes our life worth living.

5.3 Christian Community Volunteers Involvement in Palliative Care

Up to this point, I have suggested that in the present state of palliative care there is a need for a larger community involvement. In this sub-section I will emphasize how, in particular, Christian community volunteer involvement is important and vital for palliative care practice. This is based on interrelationship of embodiment and relationality that provide, in my caring presence framework, the context within which God's care and love is revealed through people who are dependent on each other and help each other to grow into the fullness of life.

Through my research I have been challenged by Vogt's suggestion that "adding care for the terminally ill and dying to the social ministry of parishes is one possible way to mainstream such care to see it as a part of life. Everyone should play a role as a member of the community in supporting and caring for those who are dying."²⁹⁰

²⁸⁹ See WEISS, *Body Images*, p. 157.

²⁹⁰ Christopher VOGT, *Patience, Compassion, Hope, and the Christian Art of Dying Well* (Lanham, Maryland: Rowman & Littlefield Publishers, 2004), p. 150.

Vogt's suggestion in his dissertation and later book, *Patience, Compassion, Hope, and the Christian Art of Dying Well*, is very relevant to this dissertation, as it reminds all Christian communities not only to look to the paradigm of the Jesus community as a prototype for friendship and liturgical worship, but also as a prototype for caring presence with an emphasis on mutual dependency and connectedness within the total web of social relations. Therefore, to be a "Jesus community" means to stand with Him and everyone else united by a common vision of mutuality, communal caring, and justice. It further means to yearn inherently for a relationship with dying patients and to be open to them in the community of caring friends, to not only care and support them, but more importantly, to be bodily present for them. To put it simply, Christian community volunteers need to be aware of the role their bodies play in the provision of care. By being aware of their bodily self-understanding, they can better bodily relate and minister to dying patients and their families.²⁹¹

In regards to such a bodily self-understanding based on my caring presence framework, Christian community volunteers can minister to the dying by visiting them and their families, listening and talking to them, strengthening them, praying with them, laughing with them, reading and sharing news or pictures with them, as well as being a constant bodily presence and comfort to them and to their families. Christian community volunteers should never leave a dying patient's room saying "goodbye" to them, but rather "I will be back" or "I am always here for you". This kind of personal example of

²⁹¹ Health care professionals Cassell and Gillespie are critical of Vogt's work, and contend that this individual or community engagement in "embodied and relational ethic of care" can be also constructed as negative when regarding the self-sacrifice needed in caring for others. I disagree with this critique, and argue that being aware of our own dependency and bodily self-understanding, always calls for a personal and immediate response and action when a dying patient needs our care, support, and more than anything else, our bodily presence. Eric J. CASSELL, "The Body of the Future," in *The Body in Medical Thought and Practice*, ed. by Drew LEDER (Boston, MA: Kluwer Academic, 1992), p. 237.

caring presence can set a good example for other volunteers, family members and health care professionals.

It is also true that sometimes even Christian community volunteers do not know what to say or what to do for the dying patient. However, as human beings dependent on one another, we must pay attention to our bodily self-understanding and be willing to commit ourselves to the dying patient, to bear witness to the dying patient's suffering and dying, and to promote such a caring practice as our priority.

Moreover, Christian communities can, through their own pastoral channels, educate, counsel, and organize sensible discussion about personhood, death, dying, palliative care and bereavement for their own members, as well as for future patients and caregivers. As Kavanaugh suggests, "We must know what being a human person means, who counts as a person, and what the implications of personhood are."²⁹² Through this community education, and counselling, and also through debates, they may not only help their own members to think about "how to live more deeply now,"²⁹³ but also how to serve and to be companions to others, never leaving anyone to suffer and die alone.

Christian community volunteers play a crucial role in the end-of-life palliative care. It is a time when life is reviewed from different angles and when existential and spiritual questions are asked. Addressing particular spiritual questions can give a sense of meaning and purpose to the dying patient and his family. The Christian community volunteer, aware of his embodiment, can provide the caring presence framework as the

²⁹² KAVANAUGH, *Who Counts as Persons*, pp. 139-140.

²⁹³ See Bill MOYERS, "On Our Own Terms: Moyers on Dying," (Thirteen/WNET, NY, 2000), available at <http://www.pbs.org/wnet/onourown/terms/index.html>, accessed November 21, 2010.

context within which these spiritual and existential questions are expressed and answered and connections can be made with one another and with God.

Moreover, through this deep connection within the caring presence framework, Christian community volunteers can provide the space for verbalizing the dying patient's suffering and dying, helping him to interpret it in a meaningful and spiritual way that may bring healing and peace. A transformative experience along with personal witnessing may be the outcomes of such care and bodily presence.

Finally, the involvement of Christian community volunteers in caring for dying patients is not about denying death, but about caring for dying patients as embodied, relational, spiritual persons. It is about the presence of God that is mediated to dying patients in and through their caring presence. By relating to dying, Christian community volunteers, as well as all involved in dying patients' care, can experience and reflect the presence of God.²⁹⁴ However, by neglecting to provide care or to be bodily present for them in their suffering and dying, we not only abandon the dying, but also ourselves.

5.4 The Implications for Health Care Professionals

I will now discuss the implications of incorporating embodied and relational ethics into the training and practice of palliative care nurses, nursing students, and nursing professionals.²⁹⁵ These health care professionals provide good medical treatment

²⁹⁴ See also Arthur A. VOGEL, *Body Theology: God's Presence in Man's World* (New York: Harper & Row, 1973), pp. 36-8.

²⁹⁵ There are many different levels of nursing. For the purpose of this research, I want to make a distinction between palliative care nurses, who cooperate with other members of the palliative team and provide support, care, and safety for their dying patients and their families, and palliative nursing professionals who are more specialized in specific areas of medical, clinical, and palliative care, and mentor younger/newer nurses or students.

by managing dying patients' medications, their comfort and cleanliness, and by communicating with them and their families. But to be able to better care and connect with dying patients, it is important that these health care professionals incorporate the anthropological foundation of embodiment and relationality into their core educational objectives, and then implement them into their palliative care practices. Moreover, this formation and subsequent incorporation of embodied and relational practices must begin with embodied self-understanding, honesty and sharing, good communication and listening skills, and the ability to bear witness to dying patients.

It should be noted that my suggestion to incorporate the phenomenon of embodiment and relationality into palliative care nursing and practice is not a radical departure from academic palliative nursing: it instead involves the anthropological, philosophical, and ethical arguments as to why embodied and relational understanding is necessary in palliative education, and it emphasizes the importance of its implementation into daily palliative care practice for dying patients.

I also claim that even when the notion of embodiment and relationality is incorporated into the formal palliative curriculum and practice, it cannot be adequately addressed merely through better educational practices. It requires from all involved in dying patients' care, self-attention and self-understanding as embodied and relational persons. Through this understanding they can better relate, bodily, to the lived experiences of dying patients, and can give dying patients, "a sense of being in control"²⁹⁶ in their dying.

²⁹⁶ WEISS, *Body Images*, p. 151.

5.4.1 The Implications for Palliative Care Nurses and Nursing Students

Recent studies in palliative nursing show that there exists the need to further improve palliative nursing education and training for palliative care nurses and nursing students in order to provide more comprehensive, holistic care for dying patients in palliative care.²⁹⁷ My personal experience at the Nursing School in Humenné, Slovakia, underlines this deficiency in palliative nursing education, and points to the urgent need for improvement.

In 1990, I was a student at the Nursing School in Humenné, Slovakia, and was taught by medical and nursing instructors about different dilemmas and ambiguities in daily medical and nursing care. However, the topic of palliative and hospice care was presented as a discrete element within the necessarily professional and formal way of taking care of dying patients and their families. It was evident that the notion of embodiment (briefly taught along with some other approaches in ethics) was different from other approaches in ethics and needed to be isolated from other areas of theoretical knowledge and medical schemas and frameworks. The focus of the school, however, was to teach young nursing students to distance themselves from dying patients and to not become personally involved with them, but to maintain professional boundaries.

With respect to the present state of nursing palliative care, in the fifteen years since my nursing education and my subsequent nursing practice, and later as a hospital chaplain conducting numerous pastoral visits to dying patients, I have observed a number of gaps in palliative care as a result of not utilizing the latest ethical, philosophical, and theological knowledge. These gaps suggest some common omissions:

²⁹⁷ Marilyn J. FIELD, Christine K. CASSEL, eds., *Approaching Death: Improving Care at the End of Life* (Washington, D.C: National Academy Press, 1997).

the lack of an adequate comprehensive framework for attending to dying patients; the result of inadequate self-understanding of healthcare professionals as themselves bodily persons in the provision of care, and the lack of access to educational programs that teach how to prevent death anxiety and to identify the barriers that make caring for the dying patient difficult. For example, I can recall from my nursing education and subsequent nursing practice that no one ever explained the role our body plays in the provision of care for the dying, or how to deal with our own fear, sadness, and other emotions when dealing with dying and death.

Moreover, not only do my observations, but also numerous recent research nursing studies by Ferrell, Virani and Grant (1999, 2005), Dunn, Otten and Stephens (2005), and Fins (2006, 2009), indicate deficiencies in palliative nursing education, as well as in present palliative care practice. Their studies' findings, however, can be summarized into specific areas that need urgent improvement, such as truth-telling to dying patients and their families; personal assessment of dying persons and their families; and insufficient education in emergency, oncology, paediatrics, pharmacology, and palliative care. All these major and urgent areas call for further research, investigation, and proper implementation into palliative nursing education and palliative practice. Some, such as relief of pain and other symptoms, and ongoing education in critical palliative care,²⁹⁸ have already been investigated and implemented, while others still need to be addressed. It is not my intention to present further research directions and

²⁹⁸ See also reports with specific recommendations, for instance, INTERNATIONAL COUNCIL OF NURSES, *Basic Principles of Nursing Care* (Washington, D.C: American Nurses Publishing, 1997) or NATIONAL INSTITUTES OF HEALTH, *Approaching Death: Improving End of Life Care* (Bethesda, Maryland, 1997).

recommendations in all of these areas, but rather to emphasize the need for incorporating an embodied and relational foundation into the core palliative didactic and training nursing curriculums, in an effort to provide better comprehensive holistic care for dying patients.

In regards to palliative nursing education, some care-based models have already been implemented into nursing education. For illustration purposes, let me mention three of them: 1) *The Nursing Care Delivery Model* is a multidisciplinary team oriented approach based on Jean Watson's Theory on Human Caring, providing palliative care with a focus on the quality of life and a humanistic care approach; 2) *The Patient Centred Care Model* assigns control to nursing palliative care experts and the patient's care managers with a focus on the patient's dying process and on alleviating pain; 3) *The Value Based Model of Care* is a multidisciplinary palliative team oriented approach with a focus on the individual patient's values, and on effective communication with the dying patient and his family.²⁹⁹

What all of these and many similar models or frameworks of care have in common in palliative nursing education is their focus on an understanding of the dying patient's health report, the illness, relieving suffering, and improving the quality of the patient's life. I claim, however, that along with symptom assessment and management, narrative communication, mutual support and bereavement management, it is also important that a palliative nursing education be based on the embodied and relational self-understanding through didactic and practicum curricula focusing on more comprehensive palliative practice. For example, such an embodied and relational self-

²⁹⁹ See Jennifer JOYNT, Bobbi KIMBALL, "Innovative Care Delivery Models: Identifying New Models that Effectively Leverage Nurses," in *White Paper* (Human Capital Team, January 2008): 1-12.

understanding can help the nursing students establish better mutual connection and deeper knowledge or understanding of the patient's suffering experience. Also, as revealed by Webster and Kristjanson,³⁰⁰ theoretical and practical lessons learned through palliative nursing work add meaning to the personal and professional lives of those who care for dying patients.

Furthermore, my proposed caring presence framework based on embodiment and relationality goes to the very core of palliative care education and centers on dying patients as present bodies-subject: concrete, live bodies in the real world that are embodied and relational and perceive the world and others around them. In fact, dying patients' bodies reveal more than themselves as objects. It reveals an utterance and is a personalization of their reality and identity.

Nursing students, as well as all involved in dying patients' care need to be aware of their own embodiment when dealing with the dying patient. It enhances their ability to relate bodily to dying patients subjectivity and lived experiences, and to be aware of their own dependency on and interdependencies with one another.

There are many different responsibilities and needs that palliative care nurses must attend to on a daily basis: administer treatment and medications, perform diagnostic tests and analyses, provide advice and emotional support to patients and their families, and consult other health care professionals.

Palliative care literature on nursing shows that actual embodied and relational practices are primarily focused on the needs, and on the human dignity and quality of

³⁰⁰ J. WEBSTER, L. J. KRISTJANSON, "But isn't it Depressing? The Vitality of Palliative Care," in *Journal of Palliative Care* 18 (2002): 15-24.

life of dying patients, rather than on bodily presence.³⁰¹ Fins (2006) stresses that even if palliative caring lies within the nursing profession and practice, many times nurses and nursing students need to be encouraged by their employers or nursing professionals/mentors to spend some time with dying patients and to be attentive to and available for them.³⁰² Some other studies by Fagerberg and Kihlgren (2001) show that in general, the palliative care nursing experience is positive for many palliative nurses once they realize that caring for the dying patient is also a rewarding experience. The study also shows that those who did not commit themselves to such an approach and care became more frustrated and tired. Finally, Field and Cassel (2007) point out that there is a shift in palliative nursing today from actual palliative caring practice into a more comprehensive, embodied and relational practice.

I would consider my caring presence framework a valuable addition to daily palliative care practice. I propose that this shift from actual practice into more comprehensive, embodied and relational practice be rooted in the method of bodily self-understanding as emphasized in my caring presence framework, and, in so doing, it will represent a better pathway towards more comprehensive care for the dying patient.

In other words, if the palliative care nurse involved in a dying patient's care, being aware of her embodiment, enters into the embodied and subjective world of the dying patient, there is a merging of subjectivities and intersubjectivities that consequently leads to better care for the dying patient and towards a better relationship

³⁰¹ See David K. SHEEHAN, B. FERRELL, "Nursing Education," in B. FERRELL, N. COYLE, eds., *Textbook of Palliative Nursing* (Oxford: Oxford University Press, 2001).

³⁰² See Marianne MATZO, Deborah W. SHERMAN, *Palliative Care Nursing: Quality Care to the End of Life* (New York: Springer Publishing, 2005).

and communication between them. By self-attention and bodily self-understanding as embodied and attentive to dying patients lived experiences and needs, such as feeding, dressing or simply listening to them, the palliative care nurse can become for dying patients a truly caring companion and a witness in their suffering and dying. To recall Weiss' words: "[...] the experience of being embodied is never a private affair, but it is always already mediated by our continual interactions with other human and nonhuman bodies."³⁰³

In regards to dying patient's families, the palliative care nurse often has a very challenging opportunity to share the dying patient's thoughts, feelings, medical, physical and spiritual condition. Many times, the palliative care nurse is also the only channel between health care professionals and patient's families. Therefore, as an embodied person, through careful listening and mutual communication, the palliative nurse can better relate bodily to the family and to dying patient's experiences and needs, and is able to establish a trusting relationship with them.

In summary, by building a didactic and practical framework of care with a focus on bodily self-understanding as embodied and relational, and to relate bodily to the dying patient's lived experiences and needs, palliative care nurses and nursing students can establish better communication and relationship with dying patients and provide better care for them.

³⁰³ WEISS, *Body Images*, p. 5.

5.4.2 The Implications for Nursing Professionals

Similar to the implications for palliative nursing education and training, a study by Sheehan and Ferrell (2006) not only identified the urgent educational and practical gaps in palliative care nursing, but also recognized the importance of embodied and relational ethics for nursing professionals/mentors: people who already have experience and knowledge in caring for dying patients in palliative and hospice care settings, and who are “specialist” to inexperienced young nurses or community volunteers.³⁰⁴

In fact, these nursing professionals can help and support young nurses gain expertise and the necessary confidence to be able to contend with the holistic complexities of their profession and service, and it may help them to avoid the burnout they might be facing. However, their educational and guide-based approach must lead to a personal awareness to be always close at the bedside to dying patients, and to be able to establish a relationship that is at the same time both mutually enriching and transforming.

Moreover, according to James and MacLeod (1993), to enhance the quality of palliative nursing education and practice, any tutoring or successful relationship between the mentor/educator and her students must be based on trust, respectful mutual criticism, and sharing.³⁰⁵ To put it more simply, without communal trust, respectful, mutual criticism, and sharing, there is no place for caring presence and there is no personal, professional, or ethical growth.

³⁰⁴ See SHEEHAN, FERRELL, “Nursing Education,” pp. 647-62.

³⁰⁵ Christopher R. JAMES, Roderick D. MACLEOD, “The Problematic Nature of Education in Palliative Care,” in *Journal of Palliative Care* 9/4 (1993): 5-10.

Positive role modeling³⁰⁶ with good mentoring and guidance can provide a better supportive environment for the practice of caring presence and better quality of care. It can encourage cooperation and promote conflict resolution. At the same time, this reciprocal modeling may benefit all involved in a dying patient's care; it means that they would all remain aware of what is happening with dying patients, and would thereby gain insight into the dying patient's experiences and needs.

In addition, while mentoring inexperienced nurses, mentors can in turn mutually nurture one another. The teaching of the holistic complexities of palliative and hospice care requires the continual involvement of all nursing professional educators. Mentors/nursing professional educators themselves should and must practice a caring presence and then assist students and the palliative care nurses in dealing with different situations in palliative and hospice care.³⁰⁷

Another area in which to enhance the provision of didactic and practicum courses by nursing professionals involves special situations and cases in palliative care, for example, where a nursing professional is unable to provide a peaceful death for dying patients.³⁰⁸ The ability to cope with such suffering and dying, and the personal impact on the nursing professional needs to be further explored, investigated, and implemented into palliative education. Also, the articulation of a nursing professional's feelings and emotions, as well as the centrality of a moral agency in the nursing professional in

³⁰⁶ See JEAN J. GEORGES, et al. "Being a Palliative Care Nurse in an Academic Hospital: A Qualitative Study about Nurses' Perceptions of Palliative Care Nursing," in *Journal of Clinical Nursing* 11 (2002): 785–93.

³⁰⁷ See CALMAN, K. C., "Education and Training in Palliative Medicine," in DOYLE, D. et al., eds., *Oxford Textbook of Palliative Medicine*, 3rded., (Oxford: Oxford University Press, 2004).

³⁰⁸ See Derek DOYLE, "Education in Palliative Medicine," in *Palliative Medicine* 10 (1996): 91-2.

relation to aggressive palliative care needs to be addressed here. Permanent, continuing education, seminars, and presentations should be oriented toward the identification and improvement of these feelings and emotions and their importance.

Along with many health care professionals, I would agree overall that palliative care in today's social and challenging economic context can not provide unlimited resources for meeting every health-related need of the dying patient. Yet as Cahill reminds us in *Sex, Gender and Christian Ethics*: "The human body provides the specific nexus around which social relations are built."³⁰⁹ Therefore, embodied and relational self-understanding can lay the foundation for enabling all health care professionals to change their attitude towards the care of dying patients and their families; to practice holistic nursing ethically and responsibly; and to actively contribute to the social context that supports caring and committed human relationships.

5.5 The Implication for Medical Students and Doctors

In the previous sub-section I presented the implications of embodied and relational ethics for the education and training of health care professionals. Now, I am going to discuss the implications for medical students and palliative care doctors who are involved in palliative care, and who are members of a palliative care team. I claim that medical students and palliative care doctors must also be aware of the role that bodily self-understanding plays in their professional practice, when they approach dying patients in order to better understand, connect, and communicate with patients and their families as well as with other members of the palliative care team.

Callahan (1993, 1999), Fins (2006), and Doka et al. (2005, 2007, 2010) in their

³⁰⁹ CAHILL, *Sex, Gender and Christian Ethics*, p. 76.

studies identified that both medical education and practice today focus predominantly on issues such as neurological and respiratory issues, prognosis, and pain control, and are usually associated with technical skills, and, therefore, require some important changes.³¹⁰ In fact, even if current didactic and practical medical preparation tries to represent itself today as interdisciplinary and personalistic, it unfortunately lacks in many respects the comprehensive framework for such care based on subjective and intersubjective foundations, rather than on formal care practices, science and technical skills.³¹¹

What the above-mentioned studies identify is the lack of a solid, anthropological framework of care that may help medical students and doctors to define the subject before them, generate questions, create more specific palliative models, and evaluate outcomes. In order to correct this oversight, I propose the integration of my caring presence framework with its method of bodily self-understanding into the present medical palliative care education, along with other anthropological foundations such as the notion of autonomy and vulnerability, to help medical students and doctors to better relate bodily to the lived experiences of dying patients and provide a more holistic care for dying patients. For example, by integrating bodily self-understanding into the present medical palliative care education and practice a medical student or doctor will be able to enter into a relationship with the dying patient more intensively and with more specific

³¹⁰ See also Kathryn MONTGOMERY, *How Doctors Think: Clinical Judgment and Practice of Medicine* (New York: Oxford University Press, 2005); MEEKIN, S. A. et al., "Development of a Palliative Education Assessment Tool for Medical Student Education," in *Academic Medicine* 75/10 (2000): 986-92.

³¹¹ See also the conclusion of THE ASSOCIATION OF FACULTIES OF MEDICINE OF CANADA, "The Future of Medical Education in Canada: A Collective Vision for MD Education," January 2010, available at <http://www.afmc.ca/future-of-medial-education-in-canada/medical-doctor-project/index.php>, accessed, November 3, 2010.

attention to his/her needs and medical symptoms.

Moreover, training and rotations in the residency programme could begin with educational opportunities highlighting an awareness of attitudes towards death and reflections on personal lived experiences, as well as on suffering and dying.³¹²

Furthermore, it is also vital that an awareness of the dying patient's lived experiences and vulnerability is one of the main parts of such a medical palliative education, as the dying patient is exposed to harm when a doctor, medical student, or any other health care professional lacks the correct skills in embodied practices.

Indeed, it is necessary that any educational component must provide not only a balance of theoretical content and practical experience, but also the framework for implementation. Therefore, any educational plan for medical professionals must focus on how to effectively train and educate medical professionals in their caring abilities; the identification of potential problems and barriers that medical professionals may encounter in their future practice; determining whether they understand the outcomes and their impact in palliative practice; and, finally, ensuring their continuing formation through educational sessions, case/model studies, and various lectures.³¹³

Another important goal of integrating the role of embodied and relational self-understanding into medical education and practice is to encourage medical students and doctors to spend quality time with their patients, to focus on their patients' lived

³¹² See SULMASY, *The Healer's Calling. A Spirituality for Physicians and Other Health Care Professionals*, pp. 91-109; See also WEISS, *Body Images*, pp. 153-63.

³¹³ See R. SEBAG-LANOE, "Les Perspectives Essentielles pour le Développement de la Formation en Soins Palliatifs, les Défis en Clinique et dans la Formation," in *Les Annales de Soins Palliatifs, les Défis* (Montréal: Amaryllis, 1992): 79.

experiences, and to listen to their stories and needs. Some recent studies³¹⁴ noted that dying patients did not cooperate with their doctors and medical students when sufficient time was not spent with them, or when there was no one to listen to them. Better bodily self-understanding, connectedness and commitment can provide for doctors and medical students the context for creating a connection in a mutually rewarding and relaxing atmosphere. It is, however, the responsibility of palliative care executives to create an environment that facilitates better patient experiences and a caring presence atmosphere.

Overall, I claim that the focus and emphasis of medical education and practices should not be built only on diagnostic instruments and detached conclusions to form a professional opinion of dying patients, but rather to relate bodily to the lived experiences of dying patients, to their needs and concerns. In order to do that, it is essential for medical professionals to learn in their educational didactic and practical process how to be self-consciously aware of their embodiment, as well as what it means to be bodily present to their patients and to their families.

Again, as previously proposed, the method of bodily self-understanding as part of my caring presence framework can provide us with the ability to relate bodily to the lived experiences of dying patients and can be the main component for improvement of the palliative curriculum and practice for medical students and doctors. However, it is clear that even if medical professionals were to learn all of these embodied and relational practices, this would not automatically change palliative practice itself unless it also inspired a personal commitment and responsibility.

³¹⁴ See Stein KAASA, Jon Håvard LOGE, "Quality of Life in Palliative Care: Principles and Practice," in *Palliative Medicine* 17 (2003): 11-20; F. D. FERRIS, I. CUMMINGS, *Palliative Care: Towards a Consensus in Standardized Principles of Practice* (Canadian Palliative Care Association, Ottawa, 1995).

5.6 Recommendations for Further Research in the Area of Palliative Care

My research in end-of-life palliative care leads me to the conclusion that there are many gaps and ambiguities that call for further research in palliative care today. Based upon the work of Gail Weiss, John Kavanaugh, Lisa Cahill, and Eva Kittay and their insights into human subjectivity and intersubjectivity, I have been able to examine the anthropological foundation of embodiment and relationality, and to address only one gap in palliative care today: the role of a more comprehensive framework and the self-understanding of all involved in dying patients' care, who are themselves embodied and relational persons, and their ethical responsibility to relate bodily to the human experiences of dying patients. In this last section, my task is to outline and explain why further research is needed in end-of-life palliative care. Before I turn to the further research, let me first identify some of the limitations of my own research.

Through my research and discussions with palliative health care professionals, I have come to the realization that palliative and hospice care are not only complex and challenging, but also rewarding, with their understanding of embodied and relational experiences of dying patients. It has also changed since the 1960s, and I have found, for example, that since then more effort has been devoted to the comprehensive care for dying patients in palliative care by way of eliminating their pain, stress, and loneliness, and in meeting other needs through interdisciplinary care teams and dedicated community volunteers, providing emotional and practical support to them. Also, many policymakers, and even society itself today, devote more attention to palliative care, creating better organizational structures and better regulations.

However, one of the main problems remains: an inadequate framework for attending to dying patients in palliative care and the role of inadequate bodily self-understanding of all involved in the dying patient's care, as themselves bodily persons. My chosen methodology has allowed me to identify and to address this gap, and I have suggested that this lack of attention can be corrected when the notion of embodiment and relationality is examined and then incorporated through my caring presence framework and its six elements.

My new caring presence framework consists of these six elements: 1) attention to the dying patient's embodied and lived experience; 2) self-awareness of one's embodiment and relationality; 3) responsibility toward other human beings; 4) nested dependencies and vulnerabilities; 5) relational awareness founds an ethical responsibility; and 6) relational participation as the path to better-embodied practice. Each of these elements is of equal importance and all are interrelated.

I have argued that if this caring presence framework is accepted correctly, it represents one possible pathway towards better caring practice in palliative care and could be a source of mutual satisfaction for dying patients and all involved in their care. However, if this practice is not accepted or even rejected, then it is a source of disconnection and dissatisfaction for dying patients, their families, and all involved in their care. I also suggest that caring presence should begin first with bodily self-awareness, and then, develop with strategies of the narrative, mutual trust, listening, and sharing. In addition, there are also some other notable aspects of comprehensive palliative care such as human empathy, compassion, and solidarity. These are, however, behavioural and social rather than anthropological aspects.

Based upon my research, what are the priorities in end-of-life palliative care education and practice that call for further research today?

First, the focus of this research was to provide a caring presence framework for a better comprehensive caring practice for dying patients in palliative care. In further research, an examination of values like compassion, solidarity or social values in light of my caring presence framework could identify how these values can further improve the present, palliative care practice. Further research may also identify, the best values, in light of my caring presence framework, for urban, suburban, or rural communities and their palliative care practices.

Secondly, my research focuses on the anthropological foundations of embodiment and relationality as the two groups of elements in my caring presence framework. Further research could identify how autonomy and vulnerability in light of my caring presence framework contrast and affect palliative care practices today. How can healthcare professionals, community volunteers, and family members be fully present to dying patients and still preserve the freedom and autonomy of dying patients?

Thirdly, I set out to address the lack of an adequate framework for attending to dying patients in palliative care and the role of inadequate self-understanding of all involved in dying patient's care as themselves bodily person in the provision of care. In further research, an examination of the lack of an adequate framework for the emotions and behaviour of the dying in light of my caring presence framework could identify why a dying patient's emotions and specific caring behaviours require more specific caring attention, and what role they play in the caring process.

Fourthly, my research focuses on self-understanding of caregivers as embodied human beings and their ability to relate bodily to dying patients within the caring presence relationships that occur over three months or less within the hospital-based palliative care centers. Further research can provide insight, in light of my caring presence framework, as to whether there is a difference in perception in regards to the caring and being fully present in a home-based hospice program.

Fifthly, as previously noted, there are many ambiguities and gaps in palliative care education, training and practice today: individual rather than collaborative models of care; the lack of personal/professional accountability and responsibility for dying patients; insufficient mutual communication; broken mutual trust within the dying patient-healthcare professional relationship. Further research could identify all these individual gaps and present a more complex and holistic formation of a caring presence fully and completely within the palliative care framework, and could suggest changes to present educational models, training and palliative care practices.

Sixthly, due to the rapid improvement of science and development in medical technology, healthcare professionals are better able to manage pain and to provide better care for dying patients and their well being. While this medical, technological development seems to be a great improvement, it creates less professional-personal interest in suffering and the dying process. Further research could identify how to restore a corporeally present connection with others in light of my caring presence framework based on anthropological embodied and relational foundations, rather than through a 'virtual' connection and technology. How does one raise the level of human-to-human consciousness in a medically, technologically reliant society, where healthcare

professionals and their focus on a caring presence connection with dying patients is replaceable by technological means?

Seventhly, my caring presence framework and its challenge of being fully present to the dying cannot be understood as separate from its cultural and socio-economic context and the approach to life (quality of life), and the suffering and death (quality of suffering and death) that may vary across different cultures and nations. Further research could focus on how my caring presence framework might be applied and realized in nations outside of the US, Canada and Europe. How do cultural or social differences vary and affect caring presence in other countries? What does it mean to be aware of generalizations based on ethnic identity, as well as cross-cultural misunderstandings or ineptness when being bodily present to dying? In addition, more qualitative research is needed today to help provide a more universal insight in the approach to the dying patient's lived experiences, and the challenge of being fully present to them.

5.7 Conclusion

The last chapter of this dissertation underlines the specific implications toward better-embodied, relational palliative care practices for dying patients in end-of-life palliative care. In the beginning, I suggested that one direction was to incorporate an individual and social model into embodied and relational palliative care practice that must begin with a personal and social commitment, and to pay attention not only to the physical, psychological, social and religious needs of dying patients, but also to the self-

understanding of bodily and relational experiences of all involved in the dying persons' care.

I then advised family members, various communities and particularly Christian communities, based on their self-embodied and relational experience, to be bodily present, to witness and to participate more fully in palliative care. I have argued that it is vital to inspire a personal and social commitment that helps keep our social exchange alive in its fullest sense. In other words, we are in communion with those who suffer and die.

Another direction, perhaps the most important direction towards better holistic caring practices for dying patients in palliative care, is the incorporation of embodied and relational foundations into the education, training and practice of all health care professionals. I believe that the notion of embodiment and relationality can provide specifically the foundation for enabling all of these health care professionals to participate in their life-learning endeavour; it can change their attitudes towards the bodily care for dying patients and their families; it will help focus on ethical and responsible, holistic nursing, and it will actively contribute to the social context that supports caring presence and committed human relations.

In conclusion, I identified some of the limitations of my research and suggested seven topic discussion for that would call for further research in the area of end-of-life palliative care. All seven suggested research directions are proposed in light of my caring presence framework for attending to dying in palliative care.

Lastly, my intention in this chapter was to propose a path towards better holistic, palliative care practice and to enrich the anthropological foundation in end-of-life

palliative care through the notions of embodiment and relationality. I have suggested that we must acknowledge that our bodies play a vital role in our life and connect us to each and every other human being. Our body embeds us with one another. Moreover, we must be aware of our own embodiment and relationality and then care for and be bodily present to one another. In other words, others need us just as we need others!

CONCLUSION

Dying is an embodied and relational process. It is also a mutually enriching process, not only for dying patients in palliative care, but also for all involved in their dying. Unfortunately, due to the lack of attention and subsequent understanding of these mutually enriching human experiences, the caring process strictly focuses on medical, psychological, and social needs rather than on the caring presence within a more comprehensive holistic caring practice. In this dissertation, I have set out to focus on the role of self-understanding of all involved in a dying patient's care as themselves embodied and relational persons, and how their bodily and relational self-understanding enhance their ability to relate bodily to the lived experiences of dying patients and contribute to better outcomes in palliative care practice.

This inquiry into dealing with the emerging need for awareness to the phenomenon of the lived experience of dying patients, and the need to rediscover the art of being fully present to them began from my previous experiences. It goes back to my nursing and medical experiences prior to my philosophical and theological education. It continued when I was ordained as a priest in 2002 and served as a hospital chaplain in two private hospices in Slovakia. Finally, after coming to Ottawa to pursue my studies, I had many occasions as a Roman Catholic priest to visit dying patients in Elisabeth Bruyère Hospital, as well as other hospitals and hospices, and to provide them spiritual care. It is through these kinds of experiences and the continuous study of human suffering, that I came to think about the theoretical as well as practical aspects of being open to care and being bodily present for dying patients in palliative care.

Throughout my dissertation, I continued this inquiry and decided to explore the

challenges in the field of bioethics/end-of-life care in the west (primarily in Canada and the US but also in Europe), especially its understanding of embodied experiences of an embodied and relational person in palliative care. This led me to my research hypothesis where I proposed that caring for dying patients at the terminal stage of palliative care requires one to be attentive and to be able to respond to the following question: How can one be attentive to an embodied and relational person in palliative care, and how can an embodied and relational person be present in an embodied relationship with another relational person? The answer, as my findings indicate, can only be found in our self-attention and self-understanding of caregivers as embodied and relational persons, which provides the basis for understanding the importance of a fully caring presence in an embodied and ethical practice today, as well as a practice where mutual trust, sharing, power of narrative, listening, and witnessing play an important part.

Addressing the lack of attention dealing with the human experiences of dying in palliative care, being open to care and being bodily present for them, and offering an original solution was not an easy task. I was continually challenged in my thinking by Merleau-Ponty's examination of human subjectivity as an embodied and relational engagement with the world and others, and by philosophers Weiss and Kavanaugh who have drawn on his work and developed the notion of embodiment, and by Cahill and Kittay, who have also drawn on Merleau-Ponty's work and developed the notion of relationality.

Using the dialectical method, I was able to evaluate these chosen authors and their unique phenomenological inquiry with a focus on embodiment and relationality, and to propose a caring presence framework as an embodied and relational practice to

dying patients in palliative care. My new caring presence framework consists of these six elements: 1) attention to dying patients embodied and lived experiences; 2) self-awareness of one's embodiment and relationality; 3) responsibility toward other human beings; 4) nested dependencies and vulnerabilities; 5) relational awareness founds an ethical responsibility; and 6) relational participation as the path to better-embodied practice. All these six elements come together to what I call caring presence framework. I suggest that this caring presence framework needs to be implemented into the daily caring practice for dying patients in palliative care by all involved in their care, with a special emphasis on being bodily present to them, as well as to their families.

On a personal note, there were times when the research process became very frustrating in regards to the exploration of human experiences and the present practices and gaps in palliative care. However, I have experienced throughout the whole research process a sense of personal gratitude and satisfaction when I grasped the notion of embodiment and relationality and incorporated them into the caring presence framework. Later on, I was able to incorporate this framework into my Élisabeth Bruyère Hospital visits to dying patients as a chaplain-on-call, and to be there for them as a window in someone's home.

This dissertation addresses current gaps and focuses on the role of a more comprehensive framework and self-understanding of all involved in the care of dying patients, who are themselves embodied and relational persons, and their ethical responsibility to relate bodily to the human experiences of dying patients. It also offers health care professionals as well as medical and theological ethics students a solid foundational anthropology within the context of ethical life and death issues on how to

relate, understand, and examine an embodied relational person in end-of-life palliative care.

However, there is still a great deal to be investigated as indicated in the present state of the literature on palliative care, and as I outlined in Chapter Five, particularly in addressing other paths toward better-embodied practices in palliative care.

Finally, let me summarize my research steps in this dissertation.

In Chapter One, I outlined the challenges affecting palliative care since the mid-1960s, and then outlined the definition of operative terms used in my dissertation like “palliative”, “hospice care”, “dying”, “embodiment”, “relationality” and “dependence”. Clarification of these terms helped me to narrow my research and focus on palliative care practices based on the notions of embodiment and relationality, as opposed to other end-of-life care practices that are related to the care of dying patients in palliative/hospice care.

Then, I presented the most needed of palliative care practices today relying upon a more holistic approach. My brief presentation broadly outlined the present practices in palliative care offered daily by palliative teams composed of health care professionals, including medical specialists, and community volunteers, whose professional focus is to relieve suffering and improve the quality of life for dying patients, as well as for their families and relatives. However, this brief presentation helped me to uncover many gaps and ambiguities in current ethical, philosophical, and medical practice as a result of excessively relativistic and individualistic practices. I decided in my research to address one of these gaps, namely an inadequate framework for attending to dying patients, and the role of inadequate self-understanding by caregivers as themselves bodily persons in

the provision of care. Other issues and ambiguities that require further research were then outlined in Chapter Five.

In Chapter Two, I described the anthropological foundation based on embodiment that is comprehensive in its approach to the caring presence to the dying in palliative care. Challenged by Merleau-Ponty's work in his book, *Phenomenology of Perception*, where he theorized the body of the concrete person-patient as the basis and subject of experience, I used the dialectical method to evaluate Weiss and Kavanaugh's notion of embodiment, and presented their analysis of the embodied body as an ensemble of corporeal practices and demands, with its place in everyday life.

In a more precise analysis of the embodied body, Weiss and Kavanaugh offered not only a remarkable description of how our self-conscious body or body image is imprinted in an individual as well as social and political inequalities as the ongoing site of cultural oppression, but also how our embodied bodies are open to re-inscription and daily transformation.

I also noted how both authors chose for their description of embodiment two similar, but different models of the embodied subject. Kavanaugh spoke about himself in the first person as "I am my body", the embodied subject that always has a unique point of view by simply being a lived dynamic body in interaction with the world and others or as the source of existence. Weiss, in contrast, presents her description of embodiment as intercorporeality, or as the body never isolated in its activity, but always engaged with the world: body image(s) that co-exist in any person and are dynamically formed through a series of corporeal exchanges that take place within and outside of specific bodies. Weiss builds on models not only from Merleau-Ponty's *Phenomenology of*

Perception, but also on Lacan and Schilder, and then later, on Simone de Beauvoir's writing on her mother's death in the book, *A Very Easy Death*.

More importantly, even if the authors chose for their inquiry two different models for the embodied subject, they both suggested that being an embodied person is never a private affair: it is always mediated by our continued interaction with other human bodies and the world, and is spatially grounded. To this debate, I have added the importance of embodied understanding for medical theory and practice. I have also argued that without the lived embodied person there is not a subject to be taken care of, and principles like beneficence or autonomy or justice cannot be applied. By this I mean that embodiment is not solely a philosophical or ethical concept, but also a social, political, and medical phenomenon, never isolated in activity, but always engaged with the world and others.

Then, based upon my dialectical reading of Weiss and Kavanaugh, I outlined three final elements that I later implemented into my caring presence framework: a) embodiment, understood as self-consciousness and awareness of one's condition as being human, is a corporeal as well as an intercorporeal condition of human life; b) our subjective human existence is always formed by a series of overlapping identities; and c) to understand our own life as intercorporeal beings helps us to understand our responsibility toward other human embodied beings and life itself.

In Chapter Three, I used the dialectical reading of Cahill and Kittay, who drew on Merleau-Ponty's notion of relationality, to examine and analyze the notion of relationality and develop a new perspective for understanding our relationality to other people. The purpose of this exercise was to bring forward our human priorities for our

relational world. My dialectical reading explored Cahill and Kittay's assumptions and ideas that highlight the importance of dialogue, embodied experiences, intersubjectivity, dependency, and finally our common relationality.

However, in order to better understand these authors and their notion of relationality, I chose to begin my exploration of the human experience as a starting point into the meaning and significance of suffering and death. It opened up for me the perspective that to be a human person is to be essentially directed toward others. In particular I explored how attention to the bodily relationality to one's self, to others, and to the world, reveals that our self, our world and others are intertwined. It is this mutual process of intercorporeal human experience that Merleau-Ponty observed, and Cahill and Kittay built upon, when referring to our relational and ethical responsibility for one another and for the world.

My exploration also revealed the importance and analysis of human experience by feminist scholars, to which Cahill and Kittay both contributed. Thanks to this feminist scholarship, we are better able to understand the social experience and struggles of persons under oppressive social, political, and economic systems, and to hear the voices of those who are marginalized, dying, disabled, and in special need, and to those caregivers who care for them.

Moreover, I further noticed how neither author is blindly idealistic to the world we live in, and how both women/mothers/scholars express their distinct theories and suggestions: they critique present power relations which according to them, as well as according to the feminist movement, and also in my opinion, deform society, communities, and even individuals.

Cahill further argued that our human bodies couldn't be understood apart from their social aspects. In other words, the way we experience the world and other people is more than just our physiological functioning, even though the nature of our experience cannot be separated from the way in which our bodies function. There is indissolubility between our bodies and consciousness. What is problematic, as Cahill pointed out, is the realization that the one who defines and forms the experience, may be only remotely acquainted with it. For that reason, Cahill suggested the need for a critical stance to re-address this imbalance between the physical and the social spheres. Cahill's critical approach, even if it tries to extract a predominantly female embodied experience distinct from men's embodied experiences, has a social meaning that is inseparable from its material existence.

Similarly, Kittay also adds to this social aspect. She accepts the embodiment of the person and adds with a further precision that the person's lived experience is connected and represents the gateway toward dependency on one another. As relational human beings, all human beings are by nature dependent on the care of others from birth until death. The more relationality and dependency we have in our life, the more independent we are.

However, both Cahill and Kittay recognized that relationships could be limiting and alienating. Even if they did not draw an explicit connection between their ethical and philosophical proposals and palliative care, a number of applications still come to mind.

Finally, based upon my dialectical reading of Cahill and Kittay I outlined three final elements that I later implemented into my caring presence framework: a) we are all

relational human persons based on our nested dependencies and vulnerabilities; b) the connection between two individuals in an ethical and social relationship not only facilitates, but becomes, the experience; and c) relational or community participation is essential for human existence and sharing a good life.

In Chapter Four, I proposed my new caring presence framework based on the notion of embodiment and relationality and its six elements that must incorporate not only the medical, psychological, and social needs of dying patients in palliative care, but also the self-understanding of all interested in the dying patients' care who are themselves bodily and relational persons involved in the provision of care. My new caring presence framework comprises these six elements:

1) *Attention to dying patients embodied and lived experiences.* The intent of all those interested and involved in the care of dying persons, be it a health care professional, family member, or community volunteer, is to be aware of dying persons' embodied and lived experiences. It must begin with the question: who are dying persons in palliative care and what are their lived experiences?

2) *Self-awareness of one's own embodiment and relationality.* The intent of all health care professionals, family members, or community volunteers interested and involved in the care of dying persons must always be based on self-conscious bodily awareness. It must begin with the following question: Who am I as an embodied and relational being?

3) *Responsibility toward other human beings.* To understand our own life as intercorporeal beings helps us to understand our responsibility toward other human embodied beings and life itself. One way to do so is to bring both the past and future

together and in so doing, open the door to a deeper understanding of the human person while offering a continuous dialectical exchange with the world and other embodied subjects;

4) *Nested dependencies and vulnerabilities*. The intent of all health care professionals interested and involved in a dying person's care should then focus on the best comprehensive and holistic care and attention to the vulnerabilities of the dependent persons;

5) *Relational awareness founds an ethical responsibility*. There is a rewarding, strong, inner connection or awakening of human-to-human consciousness when a health care professional, family member, or community volunteer meets and cares for a dying patient instead of simply dealing with the patient's physical needs. This rewarding, strong, inner connection or awakening of human-to-human consciousness lies in our bodily understanding, connectedness, and commitment to be as Dr. Saunders says, "a window in your/someone's home";

6) *Relational participation as the path to better-embodied practice*. One way to enhance and participate in better-embodied practice is to get personally engaged to care and pay attention to those who are dependent on us.

Furthermore, from a theological or spiritual perspective, caring presence provides possibilities for entering into communion with God and with each other through an awareness of our embodied and relational dimensions with an emphasis on our suffering and our hope.

Later in this chapter I also emphasized that caring presence framework must always begin with personal awareness, ability to trust, listen, and bear witness to dying

patients. Therefore, formation of caring presence framework requires from all involved in dying patients care to learn all of these strategies and incorporate them into their comprehensive daily palliative care.

In summary, I claim that the emphasis in better daily practices for dying patients by health care professionals, families, and various volunteers must be placed upon the importance of being fully present. I also claim that being a responsible relational being means more than just occupying a social position that is based on being responsible to respond to a select constituency. It means to be more aware and connected and to participate with those who are dependent on us.

In Chapter Five, I concluded by advising patients' families and various communities to be present and to participate more in palliative care. I also suggested some possible implications for incorporating the embodied ethics into the caring presence framework within the context of a relationship between a health care professionals and dying patients, and more generally, within the context of the current discourse in medical curricula and in palliative care ethics.

Then, I suggested some other possible paths to better practices in palliative care, like paying attention to cultural sensitivities, or studying dying patients' emotions and behaviour. By being attentive to the cultural sensitivity of dying patients, we may improve current practices in palliative care and provide better quality of life for dying patients and their families. Similarly, other studies and research may analyse the emotions or behaviour of dying patients, and then open up for us other avenues to better communicate dying patients needs, and possibly improve our embodied practices for them.

Finally, the aim of this dissertation was both modest and radical. It was modest, because the practices of caring for dying patients in hospices or palliative care settings is an old one, although many gaps still remain and need to be solved. It was radical because my proposition calls for the implementation of embodiment and relationality into daily practice and care, and asks us to attend to an aspect of philosophy and morality that has been largely ignored: the body.

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APPENDIX I: Resources for Palliative Care Today in North America

www.palliative.org	<p>Edmonton Palliative Care Group</p> <p>(Informs and educates about the Regional Palliative Care Program for the general public and health care professionals)</p>
www.pallcare.org	<p>University of Ottawa Institute of Palliative Care</p> <p>(Informs and educates about the Palliative Care for the general public and health care professionals. Also participates in many Health Canada Palliative Research Programs)</p>
www.utoronto.ca/jcb	<p>University of Toronto Joint Centre for Bioethics</p> <p>(Seeks to promote public debate about various bioethics issues and educates about various medical programs for the public and health care professionals)</p>
www.nhpco.org	<p>National Hospice and Palliative Care Organization</p> <p>(The world's largest organization promoting access to hospice and palliative care and issues related to the end of life)</p>
www.chpca.net	<p>Canadian Palliative Care Association</p> <p>(Association promoting an access to quality end-of-life care for every Canadian)</p>
www.hospicefoundation.org	<p>Hospice Foundation of America</p> <p>(Seeks to enhance the idea and platform of hospice and its care for end-of-life patients.)</p>
http://www.hpna.org/	<p>Hospice and Palliative Nurses Association</p> <p>(Promotes the best quality of life for end-of-life patients and is considered the oldest</p>

	national organization of palliative care in US)
http://www.swhpn.org/	<p>Social Work Hospice and Palliative Care Network</p> <p>(Bridges the gaps between social issues and palliative care)</p>
http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php	<p>The Secretariat on Palliative and End-of-Life Care (Ottawa, Ontario, Canada).</p> <p>(Official headquarters of the organization known for mapping comprehensive activities of palliative care in Canada)</p>
http://www.ohpcn.ca/	<p>The Ottawa Hospice Palliative Care Network</p> <p>(Provides a forum for discussion and access to hospice care for residents in Ottawa and elsewhere in Canada)</p>
http://www.oulton.com/chpca	<p>Directory of Hospice Palliative Care Services</p> <p>(National directory of all Canadian Hospice and Palliative Care Services)</p>
http://pallium.ca/	<p>The Pallium Project</p> <p>(Provides clinical, educational and legacy resources across Canada)</p>
http://www.aahpm.org/	<p>The American Academy of Hospice and Palliative Medicine (AAHPM)</p> <p>(The professional organization for almost 4000 physicians with a specialty in hospice and palliative medicine. In order to facilitate better communication with palliative patients and their families, the organization created the website http://www.palliativedoctors.org/)</p>

APPENDIX II: Resources for Palliative Care Today in Europe

www.hospicecare.com	<p>International Association for Hospice and Palliative Care</p> <p>(International Association promoting access to hospice and palliative care and issues related to the end of life)</p>
www.oncology.am.poznan.pl/ecept/	<p>Eastern European Task Force</p> <p>(Eastern European Association promoting the research and importance of palliative care)</p>
www.nci.sk	<p>Department of Palliative care, National Cancer Institute Slovakia</p> <p>(Slovak National Institute promoting access and better quality of life for end-of-life patients and their families)</p>
www.fedcp.org	<p>Federazione Cure Palliative Onlus</p> <p>(Italian Association promoting palliative care through research, education, and written publications)</p>
www.stchristophers.org.uk	<p>St. Christopher's Hospice, London UK</p> <p>(Founded by Dr. Cicely Saunders in 1967. Still considered a pioneer in the modern hospice movement)</p>
http://www.eapcnet.eu/	<p>European Association for Palliative Care</p> <p>(Promoting palliative care in Europe through information, education and research using multi-professional collaboration. It provides connections to many individual national associations)</p>