Transcending the Functional Self

A Discourse on the Continuity of Personhood in Degenerative Dementia

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For Ethel Jessie Hurley-White,
who, in the last stages of Alzheimer's disease,
taught me that *other*-consciousness, not *self*-consciousness,
is a true mark of personhood.

Abstract

My interest in studying neurodegenerative models of illness lies primarily in the need to define human personhood over the progressive and often irreversible experience of dementia. Here, I analyze, challenge, and ultimately move beyond purely functional theories of personhood, which are necessarily exclusive in their reduction of the human person to a mere demonstration of capacity (for rationality, self-consciousness, suffering, or otherwise) that is inversely proportional to neuropathology. Bringing to the fore important contributions from both secular philosophical thought and the Abrahamic faith traditions, I argue that functional perspectives neglect the psychosocial, spiritual, and biographical dimensions of personhood, which must be described in reference to both historical and concurrent life experiences. Accounting for these features requires the promotion of social environments that are ideal for the maintenance or preservation of this sense of "person" and calls for the treatment of patients with dementia based on personhood and inherent dignity.

My thesis, as an analysis of this debate in the interdisciplinary field of bioethics, brings together philosophy, medicine, law, and the Abrahamic faith traditions to establish guidelines *toward* a more integrative definition of personhood in the context of the evolving and interactive experiences of degenerative dementia.

Sommaire

Mon intérêt en étudiant les modèles de maladie neurodégénérative se situe principalement dans le besoin de définir “la personne” dans l'expérience progressive et souvent irréversible de la démence. Ici, j'analyse, je défie, et je me place finalement au delà des théories purement fonctionnelles de “la personne” qui sont nécessairement exclusives dans leur réduction de la personne humaine à une simple démonstration de capacité (pour la rationalité, la conscience de soi, la souffrance, ou autres) qui est inversement proportionnelle à la neuropathologie. En apportant les contributions importantes de la pensée philosophique séculière et celles des religions abrahamiques, je démontre le fait que les perspectives fonctionnelles négligent les dimensions psychosociales, spirituelles, et biographiques de “la personne” qui doivent être décrites en se référant à des expériences historiques et concourantes de la vie. La reconnaissance de ces caractéristiques sus-mentionnées exige la création d'environnements sociaux favorables à l'entretien ou à la préservation de ce sens de "la personne" et réclame un traitement pour les patients présentant de la démence basé sur le respect de la personne et une dignité inhérente.

Ma thèse, en tant qu'une analyse de ce débat dans le domaine interdisciplinaire de la bio-éthique, réunit la philosophie, la médecine, la loi, et les religions abrahamiques pour établir des directives *vers* une définition plus intégrative de “la personne” dans le contexte des expériences évolutives et interactives de la démence.

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Acknowledgments

I was rather concerned over the course of research and writing that my unbridled passion for the subject matter would necessarily result in a jumbled mess of too many ideas and too little cohesion. Any thesis that proposes to redefine a concept as complex and fundamental as personhood, regardless of the author's particular context or incentive, will inevitably overlook many themes that deserve a more detailed analysis. I am grateful, as such, to the many *persons* whose capacities for rationality, control, communication, coherence, and right judgment have guided my thoughts to proper articulation.

First, I acknowledge the invaluable counsel, direction, patience, and wisdom of my thesis supervisors, Dr. Leigh Turner and Dr. Gregory Baum, whose criticisms never ceased to be constructive and judicious.

I would also like to thank Drs. Edward Keyserlingk, Wael B. Hallaq, Michael E. Marmura, Robert Atchley, and Linda MacDonald Glenn who endured a battery of questions, inquiries, and meetings for the mere pursuit of my own clarity.

I am appreciative of the insightful works of the scholars studied herein and of all those with advanced dementia who continue to challenge functional definitions of personhood, pushing for full-fledged membership within the community of persons.

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Exordium

Consider the morally upstanding Job of the Biblical work of wisdom literature that bears the same name. A man of great wealth and happiness, Job finds favour with God who attests to the unconvinced Satan that "there is none like him on the earth, a blameless and upright man, one who fears God and shuns evil" (Job 1.8). Satan, the adversary, challenges this claim to advance his perpetual quest to upset the covenantal relationship that exists between God and humankind. With God's permission, Job is tested: death falls upon his animals, servants, and children, all marks of wealth are stripped of him, and he is inflicted with loathsome sores "from the sole of his foot to the crown of his head" (Job 2.7). Three friends, upon hearing of these troubles, come together to offer Job counsel, consolation, and clarity. Approaching from a distance, they see that, in the conundrum that is Job's suffering, he has been reduced beyond recognition; this is not the person they once knew. Job has become dis-eased in the sense described by George L. Engel: "marked by changes in physical appearance that frighten, puzzle, or awe, and by alterations in functioning, in feelings, in performance, in behavior, or in relationships that are experienced or perceived as threatening, harmful, unpleasant, deviant, undesirable, or unwanted" (130). It is in the face of this metamorphosis that Job's friends raise their voices, weep aloud, tear their robes, and throw dust upon their heads in mourning for the one who is as if dead (Job 2.12-13).

In his unbearable suffering and misery, Job cries out to God, "What is man, that You should exalt him, that You should set Your heart on him, that You should visit him every morning, and test him every moment?" (Job 7.17-18). This ontological and aetiological inquiry, which is never resolved in the exchange between Job and his friends, resurfaces time and again to challenge thinkers of every kind. The question posed here is not so much about what it means to be human, the subspecies *Homo sapiens sapiens* to which we belong, but is more the concern for understanding human personhood. This fundamental moral quandary incites the incessant pursuit of naturalistic, theistic, and rationalistic theorists to determine that which constitutes moral truth; indeed, this has become a collaborative project of many disciplines.[1] Although the venture in defining human personhood in the context of abortion, euthanasia, environmental ethics, and the progressive field of the new genetics is intriguing and the literature rather extensive, interest here lies in a particular interpretation of what Walter Glannon and Linda MacDonald Glenn call "the margins of personhood."[2] The margins, in this regard, refer to the elusive experience of patients with neurodegenerative dementia who fall short of meeting the standards of mainstream functional assessments of personhood, prevalent in bioethical literature, which focus primarily on consciousness, memory, sentience, reason, and language as requisite constituents of any satisfactory definition. The experience of the dementia patient is likened to that of the disfigured Job: how are we to make sense of the person who has markedly changed under the strains of disease? Is personhood a state of being that can dissolve over time, trial, and circumstance? If we answer the latter affirmatively in the context of progressive, irreversible dementia, then perhaps we should not be speaking of the *margins* of personhood, but, rather, *marginal* personhood.

As the most common cause of dementia in our increasingly ageing population, I shall focus largely on Alzheimer's disease (AD). Statistics Canada reports that 12.8% of the Canadian population is aged 65 and over; a proportion that is expected to reach 21.4% by 2026.[3] Age is a major risk factor of the disease and the prevalence of AD rises dramatically with each decade of life (Coffey 512). The Canadian Study of Health and Aging Working Group estimates, from a representative sample of more than 10,000 research participants, that 1 in 20 Canadians over the age of 65 meet the criteria for AD; the age-standardized rate ranges from 1 in 100, for those aged 65 to 74 years, to 1 in 4, for those aged 85 years and over (899). The alarming prevalence of degenerative disease, alongside greater risk for cancer, congestive cardiac failure, coronary artery disease, osteoarthritis, osteoporosis, cerebrovascular disease, and chronic lung disease, in a rapidly growing and increasingly susceptible elderly population may indeed lead to the erroneous presumption that ageing is, in and of itself, pathological (Fisher 1).

Shakespeare describes this seventh age as "second childishness and mere oblivion, / Sans teeth, sans eyes, sans taste, sans everything" (2.7.165-166). The stage is set for ageism: a systematic form of discrimination against the elderly as a homogeneous group of physical and mental incompetents (Fisher 1). This sweeping generalization and negative cultural interpretation of advanced age as a time of decline, regression, pathology, and immaturity inevitably leads to stigma, social isolation, infantilization, and dehumanization (Lyman 1998, 51). The intergenerational tensions revealed in this passage are certainly not foreign to the aged population and any theory that purports loss of personhood in the elderly due to mental and/or physical deterioration may inexorably justify ageism.

There is more to Shakespeare's famous, or perhaps infamous, passage on the seven ages of man than its ageist undertones; it provides the classic literary and popular proverbial idea of antiquity that describes human life as a predictable, unfolding drama in which each has numerous parts to play. In this light, George Lyman Kittredge calls to mind Augustus, who, at the moment of death, asked friends "whether they thought he had performed the farce of life becomingly" (qtd. in Shakespeare xviii). Shakespeare enumerates, rather ironically, the successive acts of the human drama in a monologue delivered by the melancholy and world-weary Jaques:

> All the world's a stage,
> And all the men and women merely players.
> They have their exits and their entrances,
> And one man in his time plays many parts,
> His acts being seven ages. At first, the infant,
> Mewling and puking in the nurse's arms.
> Then the whining schoolboy, with his satchel
> And shining morning face, creeping like snail
> Unwillingly to school. And then the lover,
> Sighing like furnace, with a woful ballad
> Made to his mistress' eyebrow. Then a soldier,
> Full of strange oaths and bearded like the pard,
> Jealous in honour, sudden and quick in quarrel,
> Seeking the bubble reputation
> Even in the cannon's mouth. And then the justice,
> In fair round belly with good capon lin'd,
> With eyes severe and beard of formal cut,
> Full of wise saws and modern instances;
> And so he plays his part. The sixth age shifts
> Into the lean and slipper'd pantaloon,
> With spectacles on nose and pouch on side;
> His youthful hose, well sav'd, a world too wide
> For his shrunk shank, and his big manly voice,
> Turning again toward childish treble, pipes
> And whistles in his sound. Last scene of all,
> That ends this strange eventful history,
> Is second childishness and mere oblivion,
> Sans teeth, sans eyes, sans taste, sans everything. (2.7.139-166)

The renowned metaphor of *totus mundus agit histrionem* draws our attention to the peculiar etymology of "person" that looms under the surface of this passage. Interestingly, both the Latin *persona* and the Greek *Πρόσωπον* disclose an original use of the word as "mask," such as that worn by a player who sets upon a stage. While the Greek term focuses on what the spectator sees, the Latin is concerned about what the player speaks through. Regardless of the emphasis, this image of person as that which is projected for the public eye and of human life as a dramatic performance is indeed a compelling one. This is especially true for advanced dementia patients whose subjective experience of memory, suffering, and consciousness (often elements required for functional definitions of personhood) is, largely, a mystery to the "spectator." Nevertheless, it is the spectator who is charged *per se* with assessing the patient's quality of life and evaluating his or her status as person. Due to a limited or deficient capacity for verbalization, questions about the actual player who wears the recognizable mask of dementia remain rather unanswerable. The mask is objectifiable; the actor is not. Nancy Harding and Colin Palfrey remind us, in The Social Construction of Dementia, that "[f]or many older people their ageing face resembles nothing more than a mask which disguises the 'them' they always were; they feel no different 'inside'" (134).

It follows, by this manner of thinking, that not all human beings are considered persons, especially in light of the person-as-agent/actor motif. I shall only entertain this distinction when the context of each chapter demands it. In this case, "human being" shall connote the biological identity of the subspecies *Homo sapiens sapiens*, while "person" shall additionally account for the biographical, spiritual, and psychosocial dimensions of human life; features, as we shall see, that are entirely overlooked by proponents of functional personhood theories.

Jaques' attestation that "one man in his time plays many parts" is reminiscent of an intriguing debate in bioethics. The discernable change of the human person under the progressive course of disease, illustrated rather explicitly in the passage from Job, often leads to a discussion of the 'then self' (pre-onset) and the 'now self' (post-onset); the two rarely described by hyper-rationalists along the same personhood continuum. Here, however, Shakespeare reveals life as a series of stages; a natural and gradual transition from one phase into the next. Although the stages are distinguished by unique features, they nevertheless constitute the acts of a single, continuous play that unfolds with relative predictability. Shakespeare, of course, uses this analogy to generalize the whole of human existence. For all his fame, little attention has been given to the ramifications of the playwright's need to address, partly in jest and partly genuine, the drama (or comedy, as Shakespeare might have it) that is human life. The concept of personhood and its biographical continuity is essential to bioethical debate. As such, bioethicists cannot sidestep this foundational question by insisting on neutrality or neglecting its significance altogether. One cannot proceed with analyses of end-of-life care, advance directives, and euthanasia without considering the centrality of the human person.

The task of defining concepts as complex, and yet so fundamental, as personhood, suffering, rationality, and consciousness becomes rather arduous in the multifaceted and multifarious context of degenerative dementia. However, it is over the course of my study concerning the perception and treatment of patients suffering from Alzheimer's disease that I have become acutely aware of the need to broaden our understanding of these basic concepts as to appreciate and account for the diversity of dementing illness experience. My interest in studying and analyzing neurodegenerative models of illness lies primarily in the challenge of defining, and redefining, personhood over the progressive, dynamic, and often irreversible experience of dementia. If, and when, such a challenge is met, contemplating and fostering a social environment that is ideal for the recovery, maintenance, or preservation of this sense of "person" takes precedence as the patient's struggle for meaning becomes a race against the dwindling capacity for articulation and rationality.

This challenge continues to intrigue philosophers, ethicists, theologians, and physicians alike who strain to capture a meaningful, accessible, suitable, and accurate definition of human personhood, consciousness, suffering, memory, and autonomy in the context of the evolving and interactive experience of degenerative dementia. The five major chapters of this thesis shall provide an analysis and interpretation of this existing debate in the interdisciplinary field of bioethics with particular interest in the contributions of religious studies.

The first section champions the biopsychosocial model for the conceptualization of health and illness as it recognizes the dynamic interplay and interrelation of biological (genetics and physiology), psychological (experience and behaviour), and sociocultural (community and family) systems in the experience of dementia. Developments in our understanding of neurodegenerative illness, its diagnosis, and treatment have come about through the integrative approach of this model, which has become an indispensable tool for culture to shape illness experience.

The second section of the thesis provides an analysis of the contributions and commentaries of leading figures in bioethics, such as Helga Kuhse, Allen Buchanan, James W. Walters, Michael Tooley, and Peter Singer, who are convinced that patients with advanced dementia are not persons. An organism's moral claim to life, they argue, is fundamentally dependent on the individual's capacity for higher mental function. To be a person of full moral status, that is, one must possess self-consciousness, rationality, a sense of the future, a sense of continuity over time, and the ability to suffer. Functional perceptions of personhood, which operate on an "all-or-none" or hierarchical (to the extent that one's degree of function, utility, and performance determines human worth) principle, not only impose conditionality on human dignity, but also neglect the biographical, spiritual, and psychosocial dimensions of human personhood; thus failing to appreciate the complexity of the experience of dementia. They cannot, therefore, offer a satisfactory definition that would advance a positive health care ethic for dementia patients.

The third section of the thesis is a discussion of scholars who defend abiding personal dignity in the absence of the functional requisites of personhood put forth by those in the previous chapter. The trend here is to move beyond a purely functional understanding and invest the human person with transcendence without arguing the metaphysical. I refer to Karen Lyman, Steven Sabat, and Stephen G. Post who adopt a more holistic and contextual approach to patients with dementia and call for treatment based on this particular conception of personhood.

The fourth section draws on the recent works of atheist German philosopher Jürgen Habermas. The religions, Habermas once argued, exhausted their creativity and social relevance; as such, they no longer had anything pertinent to say or contribute to a world grappling with contemporary issues. Now, he argues, alongside Daniel Callahan, Stanley Hauerwas, Lisa Sowle Cahill, Laurie Zoloth, and James Gustafson, that the secular world must listen to religious wisdom, particularly to the religious understanding of the human person. Since Habermas fears that scientific rationalism is unable to protect human dignity, he looks for allies in the religious communities and calls for "a post-secular society." Habermas' recent proposal is an appropriate prologue to a discussion of what the Abrahamic faiths have to offer to the ongoing debate on personhood in bioethics.

In the final section of the thesis, I shall consider religious notions of personhood from the Abrahamic faith traditions and focus on the extensive body of Roman Catholic teaching on biomedical and health care ethics. In Judaism and Christianity, with intriguing parallels drawn from the Sufi tradition, the human being (that is, human *person*), by virtue of being created in the image of God for covenantal existence, has inherent dignity and incalculable worth regardless of his or her capacity for higher mental function and independent of human society's recognition (Cataldo 2). This teaching has significant implications for the perception and care of patients suffering from neurodegenerative disease and is compatible with the patterns of dementia care reported by the Canadian Study of Health and Aging.

Over the course of these five principal chapters, my interpretation and analysis of the continuing debate on personhood shall bring to light the drama of value-pluralism in post-modern (or, as Habermas would argue, post-secular) society. The voices of philosophy and religion shall be brought into conversation to beget a more holistic understanding of the human person that considers the biographical, spiritual, and psychosocial dimensions of being.

I. The Patient as Person in the Conceptualization of Illness

Somatic Culture

Prior to a constructive critique of certain personhood criteria, it is essential that the reader be given some clarity regarding the use of such fundamental concepts as culture, disease, and illness. Although integral to biomedical and social scientific discourse, their meanings are not always transparent. The working definitions provided here shall set the scene for a more elaborate discussion of how particular understandings of culture, disease, and illness shape the way we think about persons with dementia.

In a rather rudimentary way, one might define culture as a concept based on symbol and ritual; it is shared, learned (socially inherited), and adaptive (Bodley 1). However, for our purpose, it would be wise to offer here the more explicit definition of culture as championed by Peter J. Brown. Rightly coining it as "the single most important 'orienting concept' in anthropology," Brown refers to culture as:

> the learned patterns of thought and behavior characteristic of a social group [. . .] [that] incorporates material factors–like economic systems and patterns of socioeconomic organization–as well as important non-material factors in human activities–like ideas, beliefs, and values. To a large extent, culture provides the behavioral and interpretive 'software' that people use to organize their experiences and make them meaningful. Culture provides both the habitual behaviors and common sense ideas and values that people use on a daily basis; as such, cultural knowledge and expectations are 'taken for granted' from the actor's point of view. (1997, 122-123)

Brown's working definition appreciates varied and complex manifestations of culture as a human construct evolving in the interactive community of persons. Thus, the concept of culture can only be defined in its "ecological" context. Marcia Inhorn and Peter Brown turn to the model of ecology, as the study of the interaction, interconnection, and interrelation of organisms and their environments (as well as hierarchies implied within such a model), as a basis for analyzing disease (38-39). It is within this interactive context, then, that human behaviour, ideology, and belief are observed and understood to affect pathogenesis.

Anthropologists are all too familiar with the illness/disease dichotomy that ostensibly separates medicine and its professionals from the culture in which they live (Janzen 150). The manner by which scholars approach and frame matters of health, either in terms of disease or illness, is indicative of how they will articulate personhood. My preferential use of the term "illness" over "disease" merits some elaboration. Here, disease is "a bio-physiological medical condition diagnosed by healthcare professionals," whereas illness is "a subjective experience perceived by the individual, which can exist in the absence of disease, or which may not occur despite the presence of disease" (Lyman 1998, 50). Engel has rightly found fault with this dichotomy: "Medicine's crisis stems from the logical inference that since 'disease' is defined in terms of somatic parameters, physicians need not be concerned with psychosocial issues which lie outside of medicine's responsibility and authority" (129). A culture preoccupied with such a narrow understanding of disease, as that which is experienced exclusively through the *soma*, inevitably neglects the psychosocial reality of illness.

The phenomenological perspective on dementia, championed by Karen Lyman, is grounded on the concern to contextualize the standing cultural interpretation of dementia within the "'lived experience' of those who have the condition" (1998, 49). This suggests that "quality of life or 'essential being' is only meaningful in the subjective definitions of [the] individuals" experiencing illness (Lyman 1998, 49). Arthur W. Frank, in At the Will of the Body, emphasizes this distinction:

> Illness is the experience of living through the disease. If disease talk measures the body, illness talk tells of the fear and frustration of being inside a body that is breaking down. Illness begins where medicine leaves off, where I recognize that what is happening to my body is not some set of measures. What happens to my body happens to my life. My life consists of temperature and circulation, but also of hopes and disappointments, joys and sorrows, none of which can be measured. In illness talk there is no such thing as *the* body, only *my* body as I experience it. (13)

This model offers a particular conceptual framework for ethical analysis that recognizes the social environment and the subjective experience of the patient as central themes in the neurodegenerative illness narrative; as such, it welcomes a pertinent discussion on the ethics of context. Contextualization is fundamental to discourse on personhood, consciousness, meaning, suffering, and quality of life. Lyman reports that:

> in both research and clinical practice, the interpretation and lived experience of persons with dementia most often are filtered through the lenses worn by observers. The voices of people with dementia are seldom heard, and when they are heard, they are muted by the interpretations of those thought to be more articulate and credible spokespersons and decision makers. (1998, 51)

This pursuit, then, of approaching the experience of neurodegeneration contextually and ecologically, in the sense we have discussed, demands an interdisciplinary effort.

Charles Rosenberg introduces the concept of disease in his monograph, Framing Disease: Studies in Cultural History, as "irrevocably a social actor, that is, a factor in a structured configuration of social interactions. The perception of disease," he continues, "is at once context-specific and context-determining" (Rosenberg and Golden xx). That is, one must understand disease: (1) in the context in which it is lived, (2) in the context within which it is shaped, and (3) in the context that is shaped by it. Arthur Kleinman makes it clear from the beginning of The Illness Narratives: Suffering, Illness, and the Human Condition that illness indeed has meaning; a meaning that is fundamentally different from disease. His discourse on illness reflects, in large part, the dichotomy noted at the start of this treatment of terminology. Illness, Kleinman attests, is polysemic; human experiences of suffering and symptoms "usually radiate (or conceal) more than one meaning" (8). Like Rosenberg, he focuses his study on the interactive nature of the experience of illness suffering between the afflicted patient and his or her family, or broader social network, and examines how each struggle with, experience, and respond to illness (Kleinman 3). In addition, Kleinman explains how "local cultural orientations (the patterned ways that we have learned to think about and act in our life worlds and that replicate the social structure of those worlds) organize our conventional common sense about how to understand and treat illness; thus we can say of illness experience that is always culturally shaped" (5). He notes that "illness idioms crystallize out of the dynamic dialectic between bodily processes and cultural categories, between experience and meaning" (Kleinman 14). Such idioms are shaped, and reshaped, by the interaction between biology and culture, as well as between experience and meaning.

This integrative understanding of disease and illness requires a new model for conceptualizing health. A culture that shapes disease and illness experience from an exclusively somatic perspective, as the biomedical model has encouraged for centuries, concerns itself only with the body and its processes, and invests only in those treatments which are bodily-oriented. Such a model fails to advance an adequate health care ethic for patients with dementia. While neuropsychopharmacology continues to search for the means to reverse degenerative pathology, we must not submit, as some have, to the hopeless perception of the person with dementia as a progressively dysfunctional machine whose brain cannot be fixed. A passivity of this sort implies that current efforts in dementia care and research by the various disciplines, including the "hard" sciences, are futile.

In this spirit, Z. J. Lipowski appreciates the biological dimension of the human person, but acknowledges the significance of biography and relationality. Being a person, he opines, also entails:

> feeling and symbolic activities in thought and language. Furthermore, he is a member of a social group with which he interacts. A concept of disease is incomplete unless it takes cognizance of these facts. How a person experiences the pathological process, what it means to him, and how this meaning influences his behavior and interaction with others are all integral components of disease as viewed as a total human response [. . .] The response of the family and other meaningful people to the patient's illness or disability, to his communication of distress, and to his inability to perform the usual social roles may spell the difference between optimal recovery or psychological invalidism. (Lipowski 1198-1200)

Nevertheless, the patient as a unique, relational, and biographical human person is not included in the biomedical model (Engel 132; Sarafino 9).

On the Sociology of the Ageing Body with Dementia

Harding and Palfrey argue that in the biomedicalization of dementia, the search for a cure for neurodegeneration is nothing more than a pursuit to repel ageing and, ultimately, death (126). This, I suppose, is expected from a society which, with an endemic fear of ageing and death, ploughs forward in the quest to immortalize the self, at least genetically, through the increasingly accessible technology of stem cells and their power for infinite renewal, or of recombinant DNA technology, for instance. Indeed, transhumanists, who are preoccupied with physical immortality and, thus, are active champions of such technologies, describe ageing not as a natural chapter of life, but as a deficit model of existence that must be avoided at all costs. Hence, one of the primary objectives of transhumanism is to make death a voluntary decision.

Although relatively little research has been conducted on the sociology of the ageing body, Harding and Palfrey argue that the major premise of this discipline is that the body is inextricably intertwined with identity (127). Here, though, we must discard the simplistic notion of the body as a biological machine and, instead, appreciate it as "an unfinished biological and social phenomenon which is transformed, within certain limits, as a result of its entry into, and participation in, society" (Shilling 12). If we are to argue that self-identity is bound up with the body, which in itself is amenable to change through social relations, then the community and the family play invaluable roles in preserving the personhood of the dementia patient through his or her body.

Accordingly, the social isolation of a dementia patient, who fails to conform to societal standards of rationality and whose body contests the ideal of a "quintessentially modern individual [who] is young and never dies," poses as much a threat to personhood as the neurological deterioration that causes impairment (Shilling 196). "The ageing body is feared, for it shows that all humankind's investment in the body is ultimately useless; deterioration and death cannot be avoided [. . .] dementia, in which the body becomes an empty, mind-free tomb and thus symbolic of death, has, through its medicalisation, come to serve as a proxy for death" and, as such, prompts the separation of the aged from the rest of society (Harding and Palfrey 138-139). Indeed, social derision of the (demented) elderly is not simply a ban from the community of persons; it is more a disqualification from the community of the *living*. As the mask of dementia and the face of old age expose the elderly to stigma and arouse in society fear and anxiety about inevitable death, the body becomes "alien territory" from which one must retreat; "with this retreat comes a loss of sense of self" (Harding and Palfrey 140).

The Biopsychosocial Model: An Integrative Paradigm for Personhood Theory

The mind-body relationship has been an issue in psychology, medicine, and philosophy since Plato (or even as early as Hippocrates and his humoural theory) who contended that the mind is distinct from the body and that both exist as independent entities. This mind/body split was preserved in the writings of Galen, was later challenged by Thomas Aquinas, and subsequently elaborated and defended by René Descartes whose influence on scientific thought has led to the formulation of the biomedical model for the conceptualization of health and illness (Sarafino 7-9).

Although Aquinas argued the interrelation between mind and body, and Descartes, still holding the entities to be separate, proposed communication (perhaps via the pineal gland) between the two, the mind/body split would become a hallmark of the biomedical model that has informed medical practice and theory since the 19th century (Sarafino 8-9). This model explains that disease manifests as a result of disturbance to physiological processes of the body as separate from psychosocial processes of the mind. While the biomedical model has, undoubtedly, led to great advancement in medicine, particularly in infectious disease, it is necessarily reductionistic, exclusionary, and atomistic (Engel 130). "Here the reductionistic primary principle," Engel argues, "is physicalistic; that is, it assumes that the language of chemistry and physics will ultimately suffice to explain biological phenomena" and that which cannot be explained away by such thinking is categorized as uncertainty or is assumed to have a bodily cause that is yet to be proven or disproved (130).

This is not to say that the likes of molecular biology, microbiology, immunology, physiology, pathology, biochemistry, and neuroendocrinology have not contributed to the conceptualization of health and illness. The biomedical model has served its purpose. Engel, though, insists that we refrain from resorting "to a model of disease no longer adequate for the scientific tasks and social responsibilities of either medicine or psychiatry" (129). Furthermore, the person as a unique individual is not part of the biomedical model (Engel 132; Sarafino 9). Consequently, in 1977, Engel called for a new approach and proposed the biopsychosocial model to conceptualize and *contextualize* health and illness in a broadened understanding of the human person, which recognized the dynamic interplay and interrelation of biological (genetics and physiology), psychological (experience and behaviour), and sociocultural (community and family) systems. This paradigm is essential for understanding the experience of dementia.

It is clear that the presence of neurofibrillary tangles and senile plaques, hippocampal damage, and cerebral atrophy which neurophysiology and neuropathology commonly associate with Alzheimer's disease, cannot capture the variety, in degree and kind, of symptoms and cognitive deficits in speech, motricity, memory, and perception. The diagnosis of Alzheimer's disease over the course of life has been, for the most part, exclusionary. That is, AD, lacking truly distinct diagnostic features, was identified upon exclusion of other treatable disorders (Coffey 514). The limitations of the biomedical model are clear in this regard. A definite diagnosis of the disease can only be given on the basis of histopathological evidence collected post-mortem or through biopsy (Sabat 2001, 7-8; Dawbarn 294). At this point in time, there exists no effective *in vivo* markers for diagnosis except for patients suffering from familial AD, which accounts for 5-10% of reported cases, where genetic factors linked to a mutation on chromosome 14 or the expression of the ϵ4 allele of apoprotein E play a role (Kumar 739). Studies have shown, however, that a considerable proportion of AD patients do not carry the allele, while some elderly individuals without AD do; as such, we are left sceptical of the contribution of ϵ4 allelic expression to AD pathogenesis (Kumar 739). Further, Steven Sabat records a list of studies from biomedicine that have been rather inconclusive: Blessed et al. and Tomlinson et al. have concluded that while 40% of patients suffering from dementia showed no cerebral atrophy, only 46% of the normal control group produced similar findings; Collerton and Fairbairn reported no hippocampal change in patients who undeniably showed signs of dementia; and Rothschild and Sharp have shown only mild neuropathology in three severely demented patients upon postmortem study, while observing severe neuropathology in two patients whose cognitive functions were intact (2001, 8-9).

Currently, the diagnosis of "possible" or "probable" Alzheimer's disease results from the collaborative work of somatic and psychosocial specialists. The biopsychosocial model of approaching disease in a more holistic way has been of marked use to the study of neurodegeneration. The development of geriatric neuropsychiatry as an integrative discipline bridging fields as diverse as sociology, neurology, psychiatry, radiology, pharmacology, neuroscience, medicine, and psychology demonstrates the need to integrate streams of subspecialized knowledge to ultimately improve the care of an increasingly elderly population (Coffey 4). Faced with the problem of differential diagnosis and nosological fusion, the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA) have joined forces to establish both somatic and psychosocial criteria for the diagnosis of AD.[4] In addition, a study conducted by Loewenstein et al. endorses the NINCDS-ADRDA's cooperative diagnostic system over and above single-factor models of AD assessment, arguing that multi-factor models are better suited to assess diseases whose aetiology and pathogenesis are multidimensional and the result of complex interactions (274). As a result, Engel has responded to the need for a new medical model that accounts for the social, psychological, and behavioural dimensions of illness (135). The evolution in our understanding of neurodegenerative illness, its diagnosis, and treatment has come about through the integrative contribution of the biopsychosocial model, which has become an indispensable tool for culture to shape illness experience.

Engel argues, "The historical fact we have to face is that in modern Western society biomedicine not only has provided a basis for the scientific study of disease, it has also become our own culturally specific perspective about disease" (130). The biomedical model has become somewhat dogmatic and there is need to revise the formistic and mechanistic ideology of defining disease, and mental illness in particular, "in terms of derangement of underlying physical mechanisms" (Engel 130). Ignoring the psychosocial dimension of disease and illness interferes with patient care. The move to include the patient as person will necessarily require an interdisciplinary, contextual, and organistic model that brings together both somatic and psychosocial elements of disease and illness experience.[5]

II. Functional Definitions of Personhood

The Human Person as Category

Cogito ergo sum or *Sum ergo cogito?* Chauvinism in Hypercognitive Culture

With the rapid advance of recombinant DNA technology and cloning throughout the 1970s and 1980s, geneticists became enthusiastic at the imminent possibility of sequencing all 3 x 10^9 nucleotide pairs in the human genome (Snustad 518-519). The Human Genome Project was launched in 1990 with James Watson, co-discoverer of the double helical structure of DNA, at its helm. In mapping the human genome in its entirety, Watson expected that we would finally come to know what it means to be human (Holstein 1998, 15). This "geneticization" called for a rethinking of traditional views of personhood. Here, not only disease, but also "humanness," is located exclusively within our DNA; thus, the divorce of human experience from its social context (Holstein 1998, 15). It is no wonder that, in this spirit, geneticists have gone so far as to suggest a genetic basis for belief and religiousness, and have set out in search for what has since been called the "God gene" (Highfield A14).

This reductionistic and atomistic perspective of human experience as a phenomenon that can be explained away by genetic principles is an excellent prologue to an analysis of functional definitions of personhood. R.C. Lewontin describes the method of the Human Genome Project as reducing the organism to "bits that cause it" and then analyzing "the properties of these individual bits. It breaks the world down into independent autonomous domains, the internal and the external. Causes are either internal or external, and there is no mutual dependency between them" (13). Holstein has rightly argued that applying this model, which inevitably neglects interconnectedness and interrelatedness, and reduces the whole to a mere sum of its parts, is completely inadequate for, in particular, the experience of advanced dementia where internal and external domains are highly interactive (1998, 15-16). Functional perspectives of the human person ignore these significant interactions.

Stephen G. Post is convinced that ours is a hypercognitive culture with tendencies to "exclude the deeply forgetful by reducing their moral status or by neglecting the emotional, relational, aesthetic, and spiritual aspects of well-being that are open to them, even in the advanced stage of the disease" (1998, 72). This hypercognitive culture finds its roots in René Descartes' notorious axiom, "I think, therefore I am." Whether accepted at face value or analyzed in the reverse, "I am, therefore I think," the message is explicit: thinking is being. Or, is it being is thinking? The equation here of being and cognitive function is of significance as it underlies many contemporary functional theories of personhood that fall short of including the dementia patient as person. Hypercognitive hubris has led to the definition of human personhood as a category of rationality and utility to which those of questionable or incomparable function cannot belong (Post 1998, 72). Any attempt to explain away the complexity of human personhood by appealing exclusively to function (or to the value of one's function in a culture driven by productivity) is necessarily reductionistic, atomistic, and mechanistic. Although worthy for a biomedical model that sets the exemplary course for prediction and experiment, such accounts of human personhood ignore the psychosocial dimension of existence altogether and cannot advance a satisfactory understanding that accentuates the complexity of persons, especially persons with dementia.

Further, functional perspectives, which require self-consciousness (and, therefore, consciousness in general), for instance, struggle to explain how it is that you or I remain persons during lapses of consciousness such as at sleep, in coma, or under temporary anaesthetic. Other functional perspectives, such as those that require the characteristic number of chromosomes in human diploid cells (44 autosomes, 2 sex cells) for personhood (this seems to make the concepts of "person" and "human being" synonymous), may be useful in pro-life argumentation, but fail to account for the numerous cases of aneuploidy; that is, chromosome abnormality described as a numerical change in part of the human genome. The chromosomal functional perspective, then, necessarily excludes all patients diagnosed with the clinical syndromes commonly known as Down, Patau, Edward, Turner, Klinefelter, and Triplo-X (Snustad 113). The shortcomings of functional theories of personhood and the implications of their neglect are clearly problematic for various expressions of human personhood. By this definition, only a select group of human beings are persons.

Reactions to the quandary of defining "person" have been shaped, in large part, by arrogance; they are either preposterously simplistic or dangerously absurd. While the U.S. Supreme Court ruled in 1857 that black people were not persons (*Dred Scott v. Sanford*) and decided in 1973 that unborn people were not persons (*Roe v. Wade*), the law did recognize entities such as corporations (the 1886 case of *Santa Clara County v. Southern Pacific Railroad Company)*, partnerships, or, at times, the collection of property as "persons" entitled to the legal rights and protections that the Constitution afforded any white American male. The principle of corporate personhood slipped into history rather quietly and unattested, elevating the corporation to a status once judged unworthy of black Americans. It was only in the last century, in 1929, that Canadian women were legally declared persons (the term, up until then, was synonymous with "human male") under the British North America Act, thereby becoming eligible to appointment in the Senate. Beforehand, British Common Law claimed that women were "persons in the matter of pains and penalties, but not in the matter of rights and privileges;" hence, they had not been full-fledged members of the community of persons (Heritage, par. 2). History exposes the selective bestowal of personhood on those whose function (or utility) in society was judged valuable. We are left with a most pressing question: who judges and by what standards?

The tools of hypercognitive culture used to measure the neurological function of persons with dementia are unsatisfactory and denigrate those capacities which remain intact: the capacity for experiencing shame, embarrassment, pride and maintaining dignity, for feeling concern for the well-being of others, to use non-linguistic forms of communication, as well as to manifest personhood and spiritual awareness in a variety of ways, to name only a few (Sabat 2001, 321-322; McCurdy 81-90). These enduring capacities, which Sabat rightly identifies as valuable to the human community, are neglected altogether by the *omni-competent* who inevitably judge quality of life based on a preoccupation with functions that characteristically diminish with progressive neurodegeneration (2001, 322). When caregivers foster these capacities and when the person with dementia is enabled to use them, the social sense of person is revived and a more stable social order is made manifest (Kitwood 1998, 32-33).

In his Respect for Persons, Immanuel Kant argues that human beings are of unconditional worth and that our inherent dignity, by virtue of our autonomy and rationality, demands respect for all persons (46-54). Although Kant does not address the idea of personhood in the context of neurodegeneration, it is clear that his perspective is not an all-inclusive one: "Beings whose existence does not depend on our will but on nature, if they are not rational beings, have only a relative worth as means and are therefore called 'things'; on the other hand, rational beings are designated 'persons'" (46). Only "rational nature," Kant argues, "exists as an end in itself;" it is rationality, then, that bestows unconditional worth (47). While I cannot predict what Kant would have argued in the context of our study, it would seem that dementia does not fit the latter interpretation. Rationality, glorified by the likes of Kant, Aristotle, Plato, and Locke, as *the* distinct feature that separates humankind from the rest of the non-human world, is crucial to contemporary functional definitions of personhood. Rudman is entirely right to conclude that "[w]hat Kant said of rational persons is now claimed by or for all persons [. . .] 'persons' have come to occupy a position of unparalleled regard in the competing value-systems of pluralist societies;" a category, no doubt, that fails to include patients with dementia (3).

Joseph Fletcher, the Episcopalian priest who penned such seminal texts as Situation Ethics and Humanhood, is testimony to the influence of such thinkers. It is clear to Fletcher that:

> [h]umans without some minimum of intelligence or mental capacity are not persons, no matter how many of their organs are active, no matter how spontaneous their living processes are. If the cerebrum is gone, due to disease or accident, and only the mid-brain or brainstem is keeping autonomic functions going, they are only objects, not subjects–they are *its*, not *thous*. Just because heart, lungs, and the neurological and vascular systems persist, we cannot say a *person* exists. Noncerebral organisms are not personal. (1979, 135)

Thus, only *cerebral* organisms are persons. Although I am led to believe that the category of "cerebral organisms" for Fletcher refers exclusively to humans (not only in light of the fact that his manuscript dwells on the question of humanhood and humanness, but also because cerebration and neocortical function constitute the fifteenth criterion in his "profile of man"), others might also include here non-human organisms, such as primates, which exhibit higher brain function. Whatever the case may be, I am convinced that such organisms would fail to meet Fletcher's criteria (perhaps not all, though), as we shall see. That said, a definition of personhood drawn primarily from the (proper) functioning of the cerebrum and its associated anatomical structures is prototypical. References to the human person are made solely in connection to the neurological status and cognitive capacity of the organism.

Human persons, in this regard, are properly functioning machines that operate on par with, or above, the minimal standards delineated by Fletcher in his fifteen positive criteria that constitute "a profile of man": minimal intelligence (any human whose I.Q. score is less than 40 on a standard Stanford-Binet test is questionably a person; an I.Q. less than 20 is certainly not a person), self-awareness, self-control, a sense of time, a sense of futurity, a sense of the past, the capacity to relate to others, concern for others, communication, control of existence, curiosity, change and changeability, balance of rationality and feeling, idiosyncrasy, and neocortical function (1979, 12-16). Although we are left guessing as to which features are necessary and which are sufficient for personhood, as is often the problem with functional theorists, Fletcher seems to offer here, as Keyserlingk rightly concludes, indicators of the "good," the "mature," or the "optimal" life (Keyserlingk 98). Nevertheless, these criteria brought to the fore for analysis are problematic as it is evident that any "indisputably" functional human organism ceases to be a person by these standards throughout the course of daily living; not just in temperament and perspective, but also in the natural periodic suspension of consciousness such as in the regularity of sleep and in the occasional experiences of fainting, coma, and anaesthetization, for instance. More problematic, I think, is the dangerous connection Fletcher forges between disease and nonpersonhood. He argues that lack of self-awareness is pathological, that lack of concern for others is a "clinical indication of psychopathology," and that lack of control of existence characteristically applies to "severe cases of toxic and degenerative psychosis" (1979, 12, 14-15). Failure to meet any one of these criteria not only risks one's status as person, but also indicates underlying disease.

Theorists who argue for functional definitions of personhood, such as Joseph Fletcher and Mary Anne Warren, often circumvent the venture of identifying which criteria are necessary and/or sufficient.[6] A speculative listing of possible (or probable) conditions is not at all helpful and is far from providing an actual definition. Further, the criteria may be presented in a hierarchical fashion as to suggest a personhood scale whereby an individual is graded along a continuum, according to number and quality of capacity and function, of nonpersons, quasi-persons, and fully human persons; the latter, of course, being the superior. This would suggest the gradual acquisition of personhood over the course of life and the subsequent possibility of its gradual loss due to neurodegeneration or other such assaults to any of the aforementioned features characteristic of the functional person. James W. Walters' proposal of proximate personhood is an excellent example of this dynamic. As a hypercognitivist, he accords or refuses personhood depending on how close or how distant one is to mirroring the "normal" self-conscious and rational adult human person:

> I argue that an entity's unique moral claim to life is primarily dependent on that individual's higher mental capacities. The individual being that will never possess–or is forever beyond possession of–neocortical functioning does not have a special moral claim to life. Thus, for example, I view an anencephalic infant or a permanently comatose patient as lacking the special claim to existence that you or I possess [. . .] *the more nearly an individual human or animal approximates a life of self-consciousness (such as yours or mine), the greater the claim of that individual to maximal moral status.* (Walters 4)

Following this, unless a person's capacity for rationality and consciousness resembles that of Walters or of his readers, we should be suspicious of conferring personhood status. The human person as category becomes increasingly elitist in functional theory. It is also worth noting that it is the "highly rational" and self-conscious person who decides which individuals will be inducted into the prestigious community of morally valuable persons. The margins, then, are defined by those who are "unarguably" persons. In other words, the more closely one's life approximates that of one who is undeniably a person by all functional standards of higher mental capacity and self-consciousness, the greater one's moral claim to life (Walters 156). "[T]he further beyond the threshold of incontestably personal life an adult individual is (such as a patient with advanced Alzheimer's disease)," Walters argues, "the less clear is that individual's moral status and claim to morally valuable and legally protectable life" (63).

Excluded from the community of persons, the advanced dementia patient is no longer entitled to basic protection, nor is he or she viewed as a valuable *someone*.

The possibility for stigmatization in a hierarchy of personhood-by-matter-of-degree or personhood-by-matter-of-proximity needs no elaboration. Definitions forged out of the experience of "rational," self-conscious, and overall "properly" functioning individuals fail, as we have seen, to capture the interactive nature of personhood even for those who are "undeniably" persons. Nevertheless, such definitions are mainstream in bioethical, legal, medical, and philosophical literature, as we shall see in our discussion of the personhood theories advanced by Singer, Tooley, Kuhse, and Buchanan. I intend to show that while these scholars propose certain criteria required for admission to the community of persons, the individual criterion themselves are inadequately defined. We are left, then, with functional theories of personhood that (1) avoid establishing which conditions, once and for all, are both necessary and sufficient for personhood, and (2) exclude large groups of individuals on account of an ambiguous definition of "person."

Unconscious *automata*

John Nolte is right in saying that "[w]e all have an intuitive understanding of what consciousness means, but no satisfactory definition for it has yet been devised" (385). Definitions of consciousness ordinarily rely on factors that are present when consciousness is present, such as self-awareness, access to memories, the ability to manipulate abstract ideas, and to direct one's attention (Nolte 385). Although a multitude of definitions of consciousness has emerged through diverse scholarship, including neuroanatomy, philosophy, law, and religion, what Nolte offers here shall be utilized in regard to its prototypically functionalist breed. Drawing from the study of neuroanatomy, it would seem that consciousness in itself is not located in a particular region of the brain, but, rather, arises from complex interactions involving many neural structures (Nolte 386). It is important that we analyze this notion of consciousness in the context of the neuropathology of dementia, particularly of the Alzheimer's type, where neuronal interaction and morphological integrity are considerably compromised.

To begin our study of consciousness, I allude to an ancient description of the human brain given by Hippocrates:

> The brain, and the brain alone, is the source of our pleasures, joys, laughter, and amusement, as well as our sorrow, pain, grief, and tears. It is especially the organ we use to think and learn, see and hear, to distinguish the ugly from the beautiful, the bad from the good, and the pleasant from the unpleasant. The brain is also the seat of madness and delirium, of the fears and terrors which assail by night or by day, of sleeplessness, awkward mistakes and thoughts that will not come, of pointless anxieties, forgetfulness and eccentricities. (qtd. in Nolte ii)

Twenty-four centuries later, one may still find agreement with Hippocrates' interpretation of the human brain as having particular jurisdiction over everything from physical movement to cognition to emotion. Hence, it has been argued that the brain is the seat of personhood; a description that has obvious ramifications for neurodegeneration as well as for brain tissue transplantation (Northoff 174-180).[7] One will note that lacking from this brief excerpt is the inescapable influence of the external (including social) environment on brain activity and processing. This organ, we know, does not function in isolation.

Evidently, neurodegenerative disease weakens, if not obliterates, the functional integrity and central control of the brain. The neuropathology of dementia of the Alzheimer's type includes the presence of neurofibrillary tangles (filamentary aggregates in the neuronal cytoplasm of the neocortex, hippocampus, basal forebrain, and brainstem), senile plaques (composed of beta-amyloid tissue found in neuronal cell processes), neuronal degeneration affecting information processing and behaviour, as well as a significant reduction in neurotransmitters resulting in decreased or interrupted interneuronal communication (Sabat 2001, 5). Further, atrophy of the frontal, temporal, and parietal lobes (often all cortical areas are affected to some degree) and enlargement of the cerebrospinal fluid-filled ventricles are marked indications of neuronal apoptosis. With the progression of neurodegeneration, the cortex may be atrophied to the extent of losing *a third* of its volume (Sabat 2001, 5). We are left wondering how an Alzheimer's patient can ever be considered a *conscious* being while sustaining such gross pathological detriment to brain structure, function, and integrity. Nolte, however, notes that "remarkably large cortical areas can be destroyed without abolishing consciousness, and no single cortical area appears to be crucial for maintaining it" (386). How is it, then, that a patient in the late stages of dementia, who is ostensibly lacking all of the aforementioned features listed for consciousness and has a severely compromised neuromorphology, be considered a *conscious* being?

Permit the author to offer here the speculative case of eighty-seven year old Ms. W. Ms. W. was diagnosed with AD over ten years ago and is in the advanced stages of the disease. She is incontinent, bedridden, has great difficulty using simple tools (such as utensils), apparently cannot recognize or identify even close relatives or friends, has limited linguistic capacity restricted to a vocabulary of three or four words and, for the most part, communicates in "gibberish." Ostensibly, Ms. W. cannot access any memory, be it long or short term, nor can she remember anything from her history or from the very recent past (as was determined when she was capable of more coherent speech). Similarly, her capacity for abstract thought, self-awareness, and attention direction is remote, if at all existent. She has no concept of time or space. As a result, one might conclude that Ms. W. is not conscious in any sense that Nolte described at the beginning of this discussion. Yet, when a visitor enters Ms. W.'s room in the long-term care unit, he or she may be unconvinced of this patient's unconsciousness. Indeed, Ms. W. is alert; she is sitting up, looking around, and, oftentimes, there is eye contact and an exchange of "words" to acknowledge and engage the visitor. Although mere alertness is far from being conscious in the sense that you and I are, Ms. W., in the same vein, is not unconscious in the sense that a coma patient is unconscious. If Ms. W. is neither unconscious nor conscious, then what is she? Should we simplify the concept of consciousness to mere alertness? Quite clearly, the working definition is inadequate, especially when applied to the context of neurodegenerative illness. Can one redefine consciousness in such a way as to accurately capture the various stages of neurodegenerative progression?

Jeff McMahan's "Brain Death, Cortical Death and Persistent Vegetative State" brings to the fore the whole-brain criterion of defining death which may enlighten this debate. Interestingly, defenders of the whole-brain criterion argue that "while loss of the capacity for consciousness does involve the loss of all that gives life its *value*, it is not the same as the loss of life itself" (McMahan 252). It is undeniable that McMahan would argue alongside whole-brain criterion scholars in their perception of consciousness. He makes the comparable, and perhaps overly generalized, statement: "To imagine oneself irreversibly losing all capacity for consciousness or mental activity is, for most of us, to envisage oneself ceasing to be" (McMahan 250). Has Ms. W., accordingly, lost "all that gives life its value" or has she ceased to be? The patterns of dementia care in Canada, as we shall see, indicate otherwise and affirm the need for an alternative definition of consciousness that can account for the complexity of conscious experience and that will, *a fortiori*, lead to a less biased perception of human value, quality of life, and personhood.

Our exercise in assessing Ms. W.'s consciousness, or lack thereof, is only superficial as it is grounded on the patient's ability, or inability, to make plain the aforementioned factors indicative of consciousness. The capacity for consciousness of an *avoce* (voiceless) late stage dementia patient cannot be evaluated or determined to any acceptable degree through mere observation. We *assume* that an advanced stage patient cannot access or process memory, for instance, merely because he or she cannot clearly articulate the experience in a way that is apparent to an observer. Importantly, a patient's ability to communicate the illness experience changes with neurodegenerative progression. In the early stages of development, a patient is capable of expressing him or herself both verbally and nonverbally, such as through body language for example. With progression of the disease, the verbal component of articulation is gradually lost and the patient relies exclusively on non-verbal cues. Further deterioration poses yet another challenge to caregivers who must decipher the patient's emotions, perceptions, or general well-being by way of more subtle modes of communication, such as eye contact and facial expression. Nolte's elements of consciousness, including self-awareness and access to memories, must be reinterpreted in this important context of a diminishing capacity for verbalization and more complete dependence on nonverbal means of expression, which may confound the untrained observer or baffle the caregiver who is unfamiliar with the patient's biography.

It remains unclear as to how functional particular neural interactions are in the dementia patient's brain. As previously mentioned, a large volume of cortical tissue can be destroyed without abolishing consciousness (Nolte 386). Functional theorists who refer to consciousness and self-consciousness as requisites of personhood cannot overlook the inadequacy of current working definitions of these experiences. Before suggesting criteria for personhood that will necessarily be exclusionary, each criterion must be scrutinized and described in an unambiguous manner if there is to be any validation to condemning a human being to nonpersonhood status. If clarity cannot be achieved to this end, I cannot fathom the toleration of an exclusivist and elitist understanding of the community of persons. Indeed, as Nolte suggests, the human person may even transcend the powers (and limits) of his or her own cerebral cortex.

Equal Consideration of Sentient Nonpersons

The linguistic facility characteristic of Peter Singer's writings can be both appealing and frustrating. An applied ethicist working within preference utilitarianism, Singer's advocacy for animal rights has, in many respects, left certain groups of humans out of the category of person. However controversial, Singer is probably the most influential moral philosopher of our time and he certainly does engage readers of his Practical Ethics and Animal Liberation, to which I refer here, to think about the concept of personhood in a nonhierarchical and nonanthropocentric way. I am not convinced, however, that he successfully escapes either of these confines.

In his attempt to disrupt the links of the Great Chain of Being, which has traditionally placed humans just under the divine, but far above animals, Singer advances his personhood theory without due caution. The controversy surrounding Singer concerns his categorization of some nonhuman animals as persons and some humans as nonpersons based on the demonstrable capacity for rationality and self-consciousness. As human nonpersons, Singer includes the "hopelessly senile," the "human vegetable," the "severely retarded," and the "human imbecile," to borrow his particular language (1995, 18-19; qtd. in Pojman 39). If the argument is that nonhuman animals should be considered persons because they exhibit, to some acceptable degree, a capacity for rationality and self-consciousness similar or comparable to that of human beings who belong to the category of undisputed persons, then it is an anthropocentric one. Further, much of Singer's argument drips of hypercognitive hubris in its selective bestowal of personhood on those organisms, human or otherwise, who prove capable of rationality; a capacity Singer finds wanting in his homogeneous category of the senile and mentally challenged. "The fact that a being is a human being, in the sense of a member of the species Homo sapiens, is not relevant to the wrongness of killing it;" Singer argues, "it is, rather, characteristics like rationality, autonomy, and self-consciousness that make a difference" (1993, 182). The claim to life is embedded in one's capacity for satisfactory cognitive function. What then of the wrongness of killing the advanced dementia patient who, according to Singer, lacks these latter features? Singer argues that killing a being in want of these capacities cannot be equated with killing "normal" self-conscious organisms (1993, 182). Whatever the case may be, in decentralizing the place of humans and deconstructing the hierarchy that is the Great Chain of Being, Singer introduces a new social order that elevates the interests of the indisputably rational and sentient before all others.

Singer advances equal consideration for humans and animals alike based on sentience:

> If a being suffers, there can be no moral justification for refusing to take that suffering into consideration. No matter what the nature of the being, the principle of equality requires that the suffering be counted equally with the like suffering–in so far as rough comparisons can be made–of any other being. If a being is not capable of suffering, or of experiencing enjoyment or happiness, there is nothing to be taken into account. (1993, 57-58)

Sentience, as the capacity for suffering, enjoyment, and happiness, he argues, is not only "a prerequisite for having interests at all," but "is the only defensible boundary of concern for the interests of others" (Singer 1995, 7, 9). Here, Singer draws from Jeremy Bentham, who, in his Introduction to the Principles of Morals and Legislation, contends that "the question is not, Can they *reason*? nor, Can they *talk*? but, Can they *suffer*?" (236). Consequently, rationality has nothing to do with suffering. Should we, then, completely discard the analysis of person, in Practical Ethics, as a rational and self-conscious being (87)? In this regard, Singer asserts that:

> [w]e should make it quite clear that the claim to equality does not depend on intelligence, moral capacity, physical strength, or similar matters of fact. Equality is a moral idea, not an assertion of fact. There is no logically compelling reason for assuming that a factual difference in ability between two people justifies any difference in the amount of consideration we give to their needs and interests. The principle of the equality of human beings is not a description of an alleged actual equality

> among humans: it is a prescription of how we should treat human beings. (1995, 4-5)

Further, Singer argues that self-awareness, futurity, and relationality are irrelevant when it comes to the infliction of pain (1995, 20). What, then, would Singer prescribe as the proper treatment of sentient nonpersons such as of the advanced dementia type?

If we equally consider interests, and not the agents of those interests, then what is our obligation to the interests of say the advanced dementia nonperson in his or her avoidance of suffering? That is, as Ronald Dworkin asks, should we, in the community of persons, recognize the right of this (non)person not to suffer indignity even when it seems clear that he or she has lost the capacity to recognize, appreciate, or even suffer from it (233-234)? Perhaps Singer might conclude that the "hopelessly senile," which I presume to be a collective term that includes advanced dementia, have no capacity for sentience and are, to employ Cartesian language, unconscious *automata* "possessing neither thought nor feeling nor a mental life of any kind" (1995, 10). Accordingly, we would have no reason to account for their interest in avoiding suffering or preserving dignity.

Singer's discourse on the feeling of pain in humans and animals is significant here. "Pain," he indicates, "is something that we feel, and we can only infer that others are feeling it from various external indications" (Singer 1995, 10). What of the advanced dementia patient who cannot verbally express the experience of pain? Should we assume that nonverbalization amounts to nonsentience or should we recognize, with Ajay Verma, that the issue might not be one of "no pain," but of "no complain" (13)? "Language may be necessary for abstract thought, at some level anyway," Singer argues, "but states like pain are more primitive, and have nothing to do with language" (1995, 14).

The problem of language raised in Singer's petition for the humane treatment of animals can easily be applied to the experience of advanced dementia where non-linguistic modes of communication become the only means for expression. The biomedical literature on pain and suffering in Alzheimer's disease is not extensive, but is gradually emerging. One important finding is the reportedly low use of analgesics in AD which can be attributed to the dwindling capacity of dementia patients to verbalize their experience of pain (Verma 13-15). Verma advises dementia caregivers to pay special attention to the Darwinian account of emotional expression of pain in humans and animals as to become more attentive to non-linguistic indications of pain and suffering.[8] Agitation, combativeness, and resistance to care (frequently passed off as the direct result of advancing neuropathology), as well as secondary symptoms related to disturbances in sleep, weight loss, and depression, may serve as clinical non-verbal expressions of discomfort and untreated underlying pain (Verma 14).[9] Indeed, bizarre behaviours are often indicative of the patient's effort to retain his or her sense of self amid the inexorable progression of disease (Tobin 66-67).

Singer's argument becomes rather contradictory, or at least cognizant of the complexity of these issues, when he claims that "there are many matters in which the superior mental powers of normal adult humans make a difference [in suffering]: anticipation, more detailed memory, greater knowledge of what is happening, and so on" (1995, 16). The impression here is that rationality, to some degree, *does* have a bearing on suffering; a significant departure from the reference made to Bentham earlier. "Yet these differences," Singer justifies, "do not at all point to greater suffering on the part of the moral human being. Sometimes animals may suffer more because of their more limited understanding" (1995, 16). Rationality in excess or in deficit, it would seem, increases suffering. While Singer elevates the reality of animal suffering to be on par, or at times greater than, human suffering, he is necessarily (and perhaps unintentionally) doing the same for advanced dementia patients whose understanding of, and memory for, pain experience diminishes with pathological progression.

After all this, we must question what Singer means by "considering" the interests of sentient beings and how he expects his principle to be prescriptive in terms of moral agency in the community of persons. Does "consider" insinuate the passive acknowledgment that others have interests in avoiding suffering? Or, does the consideration of interests imply a more active and engaged responsibility on part of the rational, self-conscious human person to prevent the suffering of sentient beings or *less capable* sentient beings? Further, when Singer argues that equality of consideration may indeed lead to different treatment for different beings, what "treatment" has he in mind for the likes of advanced dementia patients?

When we attend to Singer's functional discourse on rationality, self-consciousness, and then sentience (over and above rationality) in the context of the advanced dementia patient, we are left with a rather deficient assessment of human personhood. Singer argues that a human in the final stages of Alzheimer's disease is not a person. However, as a nonperson, who may indeed demonstrate sentience in a nonlinguistic way, he or she does have interests in avoiding suffering. Is there, or should there be, a difference in treatment between the sentient person and the sentient nonperson with advanced dementia? If there are grounds to answer affirmatively to differential treatment, I suspect in favour of the former, then Singer will need to reconsider the prejudicial undertones of his discourse.

A Sense of Discontinuity: The Interests of Different Selves

In his Abortion and Infanticide, Michael Tooley infers that while there are certain properties sufficient, but not necessary, for personhood, such as non-momentary interests and agency, others, such as self-consciousness (in the absence of interests) and rationality (unless defined in the weak sense of having thoughts or temporal judgment) are neither sufficient nor necessary (123-146). Nevertheless, he goes on to entertain the allegation that a human being is not a person unless he or she is capable of consciousness (90). As a personalist, Tooley is convinced that most people would agree that:

> anything that has, and has exercised, all of the following capacities is a person, and that anything that has never had any of them is not a person: the capacity for self-consciousness; the capacity to think; the capacity for rational thought; the capacity to arrive at decisions by deliberation; the capacity to envisage a future for oneself; the capacity to remember a past involving oneself; the capacity for being a subject of non-momentary interests; the capacity to use language. (349)

Whatever the case may be, Tooley admits that, in spite of his extensive discussion of person-making characteristics, he cannot determine the precise moment at which a human being becomes a person given that neither contemporary science nor our working definitions of properties supposed vital for personhood are adequate to this end (421). Tooley does make clear, however, that one cannot be deprived of the right to life if he or she lacks consciousness because one who lacks consciousness has no desire for continued existence (107-108). An organism "possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity" (Cohen, Nagel, and Scanlon 57). A person does not forfeit this right, once acquired, if he or she temporarily loses these capacities as long as it is certain, in principle, that they will be restored. A person does lose his or her right to life, though, if the relevant capacities can never again be regained (Tooley 146-157).

Singer reads Tooley in this way: "Continued existence cannot be in the interests of a being who *never* has had the concept of a continuing self–that is, never has been able to conceive of itself as existing over time. [. . .] To have a right to life, one must have, or at least at one time have had, the concept of having a continued existence" (1993, 97-98). Does this imply that a patient with dementia, who once had a sense of existence over time, has a right to life and an interest in continued existence? Or, is this right forfeit because the disease is progressive and, thus, there can be no anticipation of restored rationality, self-consciousness, or sense of continuity? Surely, this discourse on the right to life merits heightened attention in bioethical literature.

Singer brings the concept of a continued self into the context of our analysis, even if perhaps unintentionally. "[W]hen we go to sleep," he argues, "our desires for the future have not ceased to exist. They will still be there, when we wake" (1993, 98-99). Had Singer ended here, the reader would have to address the recurrent argument concerning potentiality, which is raised typically in the context of abortion and the foetus as a potential person.[10] That is, desires and interests (which Singer and Dworkin argue as crucial for personhood) do not cease to exist in periodic unconsciousness because it is certain that consciousness will soon be restored along with the whole experience of "conscious" living. Singer, though, takes the argument further: "[M]y desire to continue living–or to complete the book I am writing, or to travel around the world next year–does not cease whenever I am not consciously thinking about these things [. . .] As the desires are still part of us, so, too, our interest in continued life remains part of us while we are asleep or unconscious" (1993, 98-99). This raises an important question: where do these desires and interests reside in unconscious experience? Can we say that our desires and interests rest deep inside the brain matter and show themselves only upon conscious reactivation?

This idea of a continued self, or of the psychological continuity of self that is perpetuated by a series of psychological connections, has been made rather popular in the philosophical literature of Derek Parfit.[11] McMahan brings to the fore the influential view that:

> we are essentially psychological beings whose continued existence consists in psychological continuity, or the holding of certain continuities of mental life over time. A person twenty years ago and a person today are the same person if and only if the latter is related to the former by an overlapping series of psychological connections, involving memory and the persistence or gradual evolution of a particular set of desires, beliefs, intentions, dispositions of character and so on. (256)

Buchanan and Kuhse argue that no such continuity exists between the person before onset of the disease and the person after onset. Kuhse is convinced that "severely demented patients, in distinction from persons, no longer have an interest in their own continued existence" (1999, 361). The "then" self is completely destroyed by dementia and, therefore, one can only speak of the surviving *being* as a terminally ill nonperson that no longer has connection to the "then" self (Buchanan 285). As such, honouring precedent autonomy, perhaps via an advance directive instructing the refusal of medical treatment, would never just be an option; it would be an obligation. This brings to our attention the curious pursuit of certain scholars who, in this matter, argue adamantly for the stewardship function of the "then" self and the moral authority of advance directives in spite of being convinced that the dementia patient in question is completely disconnected from the person who authored the directive prior to disease.

McMahan's association of memory with meaning of life, in the above passage, assumes that with the loss of memory, considered typical of dementia, the search for meaning becomes irrelevant. However, although episodic, semantic, and working memory are gradually impaired with the progression of Alzheimer's disease, every patient's experience of memory loss is different and, indeed, impairment is not complete (Sabat 2001, 42-43). Sabat brings to light an array of case studies which have demonstrated, over and again, what cognitive psychologists call "implicit" memory: "change in a person's behavior as a result of prior experience even though the person many not be able to tell you, in words, what he or she has learned or even *that* he or she has learned" (2001, 42-43, 290). The access and expression of memory takes on new meaning as the patient moves from early to late stage dementia. This concept of implicit memory indicates, contrary to Kuhse and Buchanan, that psychological continuity is maintained, at least to some degree, throughout neurodegeneration.

Functional Theory in Praxis

For Singer, "[t]he lives of those who are not in a coma and are conscious but not self-conscious have value if such beings experience more pleasure than pain, or have preferences that can be satisfied; but it is difficult to see the point of keeping such human beings alive if their life is, on the whole, miserable" (1993, 192). Singer's controversial claim that a better case can be made, at times, for killing human nonpersons rather than nonhuman persons is expectedly utilitarian, accounting for the amount of pain and suffering involved. He argues that "killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all" (Singer 1993, 191). I am convinced that Singer would not make a grave distinction between a severely disabled infant and an irreversibly demented person, particularly in reference to consent.

Singer's justification for nonvoluntary euthanasia, in this regard, has often led to a charge of hypocrisy against him. In spite of the fact that his mother incidentally suffered from Alzheimer's disease, thus categorizing her as a nonperson by Singer's standards, he spent tens of thousands of dollars on her private care in lieu of resorting to nonvoluntary euthanasia as a justifiable end to a life considered not worth living (Specter 16). But this nonperson *is* still Singer's mother, or is she not?[12] His concern and investment in her critical and existential interests reveal an inherent clash between praxis and a utilitarian theory of ethics, while at once confirming the underlying problem of functional definitions: they may provide certain conditions sufficient for personhood (yet even these are varied and there is considerable debate as to which is more important), but they are not adequate in revealing *all* conditions necessary for personhood. I am alluding here, in particular, to the interaction of the personal and social dimensions of the human person.

Singer, perhaps inadvertently, makes known the importance of this social sense in an interview with Michael Specter for The New Yorker. Specter records the "dangerous" philosopher's comments on his mother's illness: "I think this has made me see how the issues of someone with these kinds of problems are really very difficult [. . .] Perhaps it is more difficult than I thought before, because it is different when it's your mother" (17). Although the biomedical model of conceptualizing illness in an atomistic way might be reasonable in theory, it is clearly inconsistent with the moral intuitions we make plain in our social interactions with ill persons (particularly ill persons who happen to be dear to us).

This rift between theory and praxis has major implications for dementia care. In terms of resource allocation, should patients suffering from advanced dementia be treated differently according to their capacity for rationality or their verbal/behavioural expression of pain, suffering, and happiness? If personhood is a matter of degree, should not treatment be as well? If we answer these in the affirmative, then what of the "hopelessly senile" whom Singer refers to as conscious (but not self-conscious) nonpersons with limited (if not non-existent) capacities to articulate pain experiences? Can a non-self-conscious, non-rational nonperson actually suffer? Does such an elusive experience merit equal consideration and, therefore, treatment of any kind?

Applying the criteria of functional personhood becomes increasingly difficult with an increasingly sophisticated array of instruments (medical, philosophical, legal) at our disposal to measure rationality, memory, and consciousness. The more intelligent our technology, it seems, the more exclusive our category of human person. The lived experience of the person with dementia is filtered through lenses worn by the *omni-competent* and tainted by hypercognitive culture. Ultimately, condemning certain groups of human beings as nonpersons, who do not meet the running elitist standard of being rational and self-conscious to some comparable degree that you and I are, becomes a simple formula to escape ethico-legal situations. Harris, in The Value of Life, reveals this ever so clearly:

> Personhood, as we have seen, involves the capacity to want to exist and the sort of self-consciousness that makes the possession of such a want possible. When these are present it is clear that the being in whom they are present is a person. Once they are lost, the being has ceased to be a person and then, even if their body is still technically alive, it has lost its moral significance and can either be killed or allowed to die or preserved alive as we choose. Where its organs or tissue can be used to save the lives of other people who have not lost personhood but who may be in danger of losing their personhood through death or some other cause, then

> we have a motive for keeping alive the body of the former person so that the tissue and organs remain alive and usable. (242)

Perhaps we should throw up our arms to the general futility of functional theories of personhood, which leave us with more questions than answers, and, like Singer in the face of uncertainty, give those at the margins "the benefit of the doubt" (1993, 119). I propose, instead, that we broaden our understanding of personhood beyond the merely functional and account for the psychosocial, biographical, and spiritual dimensions of human existence. The intention here is to appreciate an evolving understanding of the human person that recognizes the dynamic and evolving character of *being* (as opposed to *functioning* as) a person over the entire course and complexity of life experience. The call is for a more holistic perception of dementing illness shaped by a culture free from hypercognitive hubris. I suggest that this is neither idealistic nor unfathomable. That said, a change in consciousness *per se* must be consistent, as we have seen with Singer, with the moral intuitions we make plain in our relationship with others.

III. Transcendence Without Metaphysics

Beyond the Functional Person

A Sense of Continuity: An Interest in Relationality

To stem the tide of a dominant trend in philosophical bioethics to maintain functional theories of personhood, I intend to explore here the works of Karen Lyman, Steven Sabat, and Stephen G. Post who have found fault with such theories and recognize, in general, the many limitations of biomedical conceptions of disease and illness. Investing the human person with transcendence without arguing the metaphysical, these scholars describe patients with dementia as persons in the context of the plurality of progressive neurodegenerative experience, relationships, and abiding dignity. Such theorists advocate the treatment of patients with dementia based on this particular understanding of personhood.

I am reminded of Ronald Dworkin who considers two ways in which we might reflect on the experience of neurodegeneration. We might identify the "*demented person*" and emphasize his or her current capacities and context, or, instead, we might identity the "*person who has become demented*" and underscore the often overlooked fact that decades of life without neurodegeneration preceded the current experience (Dworkin 221). To define personhood exclusively by an individual's functioning during one particular chapter of the biographical narrative (of which disease is the major theme) completely devalues life prior to the onset of pathology. It is as if personhood can be described as a series of disconnected snapshots as opposed to a continuous array of diverse experiences which shape the human person over time.[13] Robert Atchley's writings on continuity theory indicate that people prefer to adapt to different circumstances over the course of existence by using the coping structures they have developed over a lifetime of learning and decision-making. These structures include habits of thinking and responding to environmental cues (1999, 4-12). Although his Continuity and Adaptation in Aging does not directly address dementing illness, Atchley has observed similar continuity of behaviour patterns and typical responses in persons with dementia (e-mail to the author).

Of the many proponents of functional personhood theories, H. Tristram Engelhardt, Jr. is, in many respects, the most inclusive. Like his contemporaries, he maintains that individuals with Alzheimer's disease are no longer persons in the strict sense of moral agency (Engelhardt 1986, 116). Engelhardt argues, however, that we must give admission to more than just one sense of person and, accordingly, appreciate the different senses of moral rights, obligations, and duties (1986, 120, 202). In this spirit, he bestows a certain *social* sense of personhood on, among others, advanced dementia patients. Engelhardt justifies the social role of advanced dementia persons in terms of "(1) the role's supporting important virtues such as sympathy and care for human life, especially when that life is fragile and defenseless, and (2) the role's offering a protection against the uncertainties as to when exactly humans become persons strictly, as well as protecting persons during various vicissitudes of competence and incompetence," for instance (1986, 117). Importantly, there is a move here beyond the particularistic and reductionistic perspective of functional personhood; one that recognizes the human person as complex and ecological in the sense that he or she not only interacts with the social environment, but is also identified within its context.

In this regard, Steven Sabat applies a social constructionist point of view concerning the person who has become demented: "Social identity cannot come into existence without the cooperation of others in the social sphere" (1998, 42). Holstein calls this "embodied personhood expressed within a context, and through relationships" (1998, 13). Thus, the experience of neurodegenerative illness cannot be isolated or secluded from the social environment, but must be understood contextually *within* it. Scholars have begun to focus their attention on the influence of the social and personal world of the patient on his or her behaviour (Sabat 1998, 36). Sabat describes this behaviour as a function of "(1) the organic disease process, (2) the ways in which others in the social world interact with and react to the AD sufferer, and (3) the AD sufferer's reaction to others and to the effects of the disease" (1998, 38). An ample discussion of the impact of social environment and social interaction on maintaining (or undermining) personhood in the neurodegenerative experience of illness will be brought to the fore in the following subsection on the ethics of context. It is sufficient, for the time being, for Sabat to offer us a brief glimpse in this regard:

> Specifically, the reduction of excess disability [. . .] requires the reduction of instances of malignant social psychology in the social world of the afflicted. Yet this requires making a decision about the way in which we understand the afflicted–we must decide to see him or her as one whose behavior can be affected by others, who has a valid experiential world, whose behavior can be driven by meaning, who may be tormented by his or her disabilities and what they mean, and as one whose sense of pride, dignity, and the need to avoid humiliation can remain alive long after the ability to sign his or her name has vanished. (1998, 40)

It is in this context of social interaction between healthy and afflicted persons that we recall Ronald Dworkin's notion of experiential interests.

In Life's Dominion, Dworkin suggests that life is guided by the desire to advance two types of interests: experiential (momentary) interests, although significant, are not as important as critical interests (hopes and aims that give coherence to the life narrative) (201-202). The dementia patient does indeed have experiential interests, through the power of the senses, and retains critical interests because "what happens to him then affects the value or success of his life as a whole. That he remains a person, and that the overall value of his life continues to be intrinsically important, are decisive truths in favor of his right to dignity [...] it would be inconsistent to deny dignity while recognizing the critical interests that it confirms" (Dworkin 229-230, 237). It is in this argument that Dworkin asserts the dementia patient's right to dignity and that "[w]e mark his continued moral standing, and we affirm the importance of the life he has lived, by insisting that nothing be done to or for him that, in our community's vocabulary of respect, denies him dignity;" proof, Dworkin is convinced, of the intrinsic and personal importance that human beings accord life (237). Here, we note a consideration of the biographical dimension of the human person where both historical and concurrent contexts of life are significant. That is, we cannot neglect "the importance of the life he has lived." Can we, though, overlook the critical interests of life before illness?

First, one must not blindly cast experiential interests, however momentary, so quickly to the sidelines. Whereas Dworkin raises the objection that experiential interests become more important and critical interests less so in dementia, he is quick to warn against ignoring the sense of one's own critical interests at a time before neuropathology (232). It seems, though, that the fine line which distinguishes experiential interests from critical ones can become blurred in the experience of dementia. Here, momentary interests indeed become critical to the extent that they, too, give the life narrative coherence, particularly in its concluding chapters.[14] I am rather reluctant, however, to pay critical interests, forged and possessed before the onset of disease, the same attention that Dworkin suggests they deserve; this is not to say that I neglect such interests altogether, on the contrary. Instead, I recognize that certain conditions must be in place in order to determine, especially in the case of an *avoce* patient, whether these interests should be honoured or dismissed. Permit me to substantiate this claim.

Considering the life narrative as analogous to a drama of interconnected acts and scenes performed by a single player assuming many parts reminds us that, over the course of existence, human personhood is marked, but not disrupted, by moments of change that add to biography without compromising continuity. I am not convinced that biographical continuity necessarily amounts to maintaining the same interests throughout life. While there is some incongruity between the interests (critical and existential) I harbour today and those which concerned me as a small child, I continue to live a single life narrative, a unique biography, that is not upset by even considerable revisions to my interests, ambitions, anxieties, opinions, education, and lifestyle. In fact, human development is very much a study of how the psychological and physical dimensions of being change over a single person's lifetime.

Whether suffering from dementia or not, individuals maintain certain interests, while overriding others and creating new ones in the context of circumstance without disrupting the continuity of personhood. Thus, like Rebecca Dresser, I am sceptical about advancing interests that were once critical to the person prior to the onset of dementia (say as articulated in an advance directive) when they are clearly no longer of interest to the patient currently experiencing illness; this would risk the withholding of certain basic and effective treatments, or, as Singer has suggested, nonvoluntary (or involuntary if we consider the life narrative as a whole) euthanasia (Dresser 36; Singer 1993, 179-193).[15]

In this vein, Rudman agrees with L. W. Sumner that "rationality as the determining criterion [. . .] is too severe, allowing if not requiring the deaths of many individuals who may, in fact, continue to enjoy simple pleasures despite their lack of rationality (e.g. mongoloids, psychotics, the autistic, the senile, the profoundly retarded)" (Rudman 57). Indeed, every dementia patient knows a different experience of illness within which interests are created, reinterpreted, or abandoned accordingly; as Atchley has found, there exists some continuity of behaviour patterns and typical responses in persons with dementia in terms of adaptation. To act on critical interests which may have preoccupied a person before neuropathological onset, but are clearly no longer a concern to the person now living (perhaps even "enjoyably") with the disease, is not preserving continuity of the life narrative, but is, rather, denying that patients with dementia can (or should), like other persons, formulate new interests (critical or existential) while maintaining others in the context of changing circumstances. One must be attentive, in this regard, to the distinction between continuity, which connects different chapters of a single life narrative and lends it coherence, and permanence, which resists change, multiplicity, and diversity.

At the same time, Sabat identifies, in his "Voices of Alzheimer's Disease Sufferers: A Call for Treatment Based on Personhood," certain critical interests that transcend the onset and progression of dementia, such as the pursuit of positive relationships and the constant struggle to maintain personhood. Sabat provides several cases, of moderate to severe stages of the disease, which clearly illustrate "the possibility that there can exist intelligible, meaning-driven intentions behind the AD sufferer's behavior;" as such, he or she possesses a personal identity that is intact and shaped within the scope of the social environment (1998, 45). Holstein accentuates the caregiver, specifically, as one who can assist in situating the patient within the whole life narrative and support his or her initiatives in maintaining meaning, social connectedness, coherence, self-respect, and dignity, to any possible degree (1998, 18). It is imperative, as we shall see, that in order to understand the experience of neurodegenerative illness, one must enter into relationship with the patient; "a relationship not defined solely on the basis of his present illness, but on the basis of the sum total of his life's inclinations and dispositions" (Sabat 1998, 41). The challenge, as proposed earlier, is to create a coherent, biographical narrative structure; a narrative, as Sabat suggests, that is neither partial nor intermittent, but whole, including the entire evolution of personhood pre-disease, through the experience of illness, and beyond. "[W]hen we consider how the fate of a demented person can affect the character of his life," Dworkin reminds, "we consider the patient's whole life, not just its sad final stages, and we consider his future in terms of how it affects the character of the whole" (230).

Agnieszka Jaworska, in "Respecting the Margins of Agency," discusses how a patient's capacity, or lack thereof, for articulation does not simply indicate a complete absence of critical interests. Jaworska writes in this way:

> The fact that the demented patient no longer affirms critical interests in no way implies that he does not have critical interests. Since such interests are not inherently time-specific, the prudential importance of satisfying them may survive the person's unawareness of their satisfaction, whether due to unconsciousness, dementia, or even death. Thus, a demented person who cannot generate contemporaneous critical interests may still have some of the same critical interests he professed when he was healthy. (111)

The view here is one of an intact personhood where the patient experiencing illness is not a new or completely different person than he or she was prior to illness. As we have seen, the patient not only develops new interests in changing circumstances, but can actually draw upon earlier interests (that are not expired with disease progression) to create, recreate, and maintain the coherence of his or her life narrative.

An ethic of context develops in response to the unsatisfactory care practice for dementia patients which acts on decisions that are reached "very rapidly and intuitively, implemented without clear conceptualization in the stream of life" (Kitwood 1998, 27). Recognizing meaning in the behaviour (however absurd or self-threatening) and utterances (however incoherent) of the dementia patient in the context of an unfolding narrative (consisting of historical and concurrent experiences) is what Kitwood has called "the mode of hermeneutics" (1998, 27). If we are fixated on universalizing some moral judgment, then Kitwood proposes the "universalization of the particular," possibly outside the resolve of moral principles, where meaning is defined in the context of the person's whole and unique life experience (1998, 27).

Similarly, Karen Lyman challenges the so-called standing biomedical truism that "dementia results in the 'loss of self'" (1998, 52). Instead, Lyman argues that the phenomenological perspective, as introduced earlier, offers a holistic view of the patient struggling through the experience of illness or, rather, counter-reacting to the disease.

She brings to the fore Oliver Sacks' esteemed The Man Who Mistook His Wife for a Hat to illustrate this point with further clarity. According to Sacks, "it must be said from the outset that a disease is never a mere loss or excess–that there is always a reaction, on the part of the affected organism or individual, to restore, to replace, to compensate for and to preserve its identity, however strange the means may be [. . .]" (6). Sacks envisages "the physician [as] concerned [. . .] with a single organism, the human subject, striving to preserve its identity in adverse circumstances;" this, he asserts, is central to the art and practice of medicine (6). The challenge to maintain personhood is embedded in the struggle to re-create meaning in the different, and most trying, phases of human life. Lyman reminds that the narrative epic that is human life can only be considered complete when chapters composed after onset of dementia are regarded as equally significant as those preceding the disease (1998, 53). This process, appropriately termed "reconstitution," involves the incorporation of the experience of illness into the ongoing life narrative of a truly *dynamic* person who is constantly, throughout the course of dementia, re-evaluating and redefining what is "normal" in the context of his or her own person (Lyman 1998, 53).

What is important for this discussion is a more developed understanding of the "then" self and "now" self, and how they are contextually related. It is within this particular conceptual framework that the principle of autonomy in dementia can be brought to light. Stephen G. Post argues that such a distinction is misleading because "the severely demented individual generally retains some continuity with the "then" self despite the loss of communicative capacities" (1995, 307). Post acknowledges that the "now" self is continuous with the "then" self (the degree of continuity required to argue for the existence of *one* person over the course of life is debatable) and he champions, as does Dworkin, the stewardship responsibility of the "then" self for personhood preservation as the patient progresses more deeply into dementia (1995, 319). Thus, while the exercise of precedent autonomy, that is honouring the decision-making capacity of the competent "then" self, demands extensive deliberation (especially concerning its temporal jurisdiction and the question as to when to exercise precedent autonomy over the course of neurodegenerative progression), both Dworkin and Post agree that it is a viable solution to the threat of overtreatment (Post 1995, 319; Dworkin 226-229, 231).

Others argue differently. Rebecca Dresser stresses that the moral significance of the "now" self's interests and well-being override those of the "then" self which never experienced the neurodegenerative illness (Dresser 35-36; Post 1995, 314). Instead of precedent autonomy, a term which in itself indicates a particular bias, she speaks of a future-oriented autonomy. Michael Quante rightly notes that Dresser, as well as her colleague Whitehouse, is convinced that "the orientation toward the value of respect for autonomy, which underlies advance directives, should not render the lives of nonautonomous patients valueless" (372). Future-oriented autonomy, then, does not necessarily take precedence in Dresser's argument, which emphasizes a concern for the patient's current welfare and a holistic approach that encompasses both the competent and incompetent phases of the patient's experience (35-36). Further, she is firm in the understanding that "we do not advance people's autonomy by giving effect to choices that originate in insufficient or mistaken information" (Dresser 35). The patient must be informed of the general and expected course of the disease, including its various stages of progression, and have the opportunity to discuss potential options with physicians, caregivers, and Alzheimer's patients before authorizing an advance directive. The emphasis here is on the recognition of changing *circumstances* and *interests*, not changing *persons*. Dresser and Holstein attempt to redefine autonomy in the context of community, where the individual does not have to make such choices in isolation (Dresser 36; Holstein 1998, 17).

The Ethics of Context and Dementia Care

Certain ethicists see no need to formulate a dementia care approach. Engelhardt reassures that "nothing but basic nursing care need morally be provided" for "hopelessly severely senile individuals" and "severely defective newborns" (1986, 119). In fact, he is convinced that "[f]etuses, infants, the profoundly mentally retarded, and the hopelessly comatose provide examples of human nonpersons [. . .] since they are not persons, they cannot require that they be respected" (Engelhardt 1986, 107, 112). In any case, Engelhardt, Kuhse, and Buchanan agree that standard pain relief and palliative medical care, for the most part, would be considered sufficient for these nonpersons. Dresser, on the other hand, calls for community reflection on dementia to dispel the common perception of the illness experience as "tragic, horrible, degrading, humiliating, to be avoided at all costs;" an assessment which is satisfied with only minimal care (37). Kitwood and Bredin discuss this somewhat unavowed perception of the dementia patient as burdensome to the community of persons and argue instead that such persons:

> are rather less of a problem than *we*. *They* are generally more authentic about what they are feeling and doing; many of the polite veneers of earlier life have been stripped away. *They* are clearly dependent on others, and usually come to accept that dependence; whereas many "normal" people, living under an ideology of extreme individualism, strenuously deny their dependency needs. *They* live largely in the present, because certain parts of their memory function have failed. *We* often find it very difficult to live in the present, suffering constant distraction; the sense of the present is often contaminated by regrets about the past and fears about the future. (273-274)

The image here is hardly compatible with that of the hypercognitivist. Although at first glance this description may seem far too romantic a conception of dementia, it is reflective of the cross-cultural discussion of neurodegeneration known to medical anthropology. Lyman has correctly observed that "what is missing from most of the current social and behavioral science research on dementia and caregiver strain is an analysis of the impact of cultural definitions, care settings, and the caregiving relationship on the experience of dementing illness" (1989, 604). In this spirit, Charlotte Ikels has conducted a longitudinal study in urban China, analyzing various factors which shape cultural perceptions of dementia (257, 271). At the risk of overgeneralization, she pulls together research findings from other medical anthropologists and concludes that beliefs about dementia, values, and situational variables specific to contemporary China "make this experience a generally less terrifying and devastating one than in the United States where dementia seemingly casts its shadow over everyone" (Ikels 257). In addition, Ikels reports that "the cognitive domain is not taken to be the total sum of the person" and, unlike the West where autonomy and independence are fêted, "the self in Chinese culture is perceived more as a relational entity whose potential perfectability is realized through the process of social interaction and the practice of proper role relationships" (274). The value, hence, is interdependence and emphasis shifts to filial obligation, family caregiving, and responsibility for others (Ikels 260-261, 275). She reminds that:

> throughout the life course one lives in intimate relationships with others, and as an infant and a child relies on these others to meet one's needs. In early and mid-adulthood one meets the needs of others, and in old age is fully entitled to have one's needs met again by others. This approach to life means that, unlike many Americans, most Chinese elderly do not feel they are somehow stigmatized by having to rely on others. (Ikels 275)

Interpersonal communication through emotional expression becomes a substitute for diminished verbalization. As such, the patient becomes increasingly dependent, both physiologically and psychologically, on others (McCurdy 84, Kitwood 1998, 23). David McCurdy argues, in stark opposition to Fletcher, that the loss of control associated with this increased dependency is actually a mark of personhood, especially at the very margins of human existence (84, 87). McCurdy cites Gilbert Meilaender in this regard: "Dependence is part of the story of a person's life" (87). The fundamental concern is not an individual's fall from personhood, but, rather, how we ourselves might alter our perception of dementia so that dementia patients may not have to find life in the community of persons so terrifying and be spared the various forms of mental anguish: confusion, frustration, fear, anger, helplessness, and hopelessness (Dresser 37; Kitwood 1998, 23; McCurdy 83).

Here, focus is on a more engaged responsibility in dementia care that fosters relationality and interaction; it is a shift from the familiar description of care as *burden* to a more interactive and responsible care approach. Fostering a positive interaction between the patient and his or her social environment can no longer be deemed a futile, unnecessary, or even idealistic endeavour; a position drawn from Kuhse and Buchanan's understanding of the demented person as reduced to nothing more than the simple remnants of a terminally ill organism. Buchanan, in this regard, suggests that "our obligations to such a being are at best quite limited because of the radically truncated character of its interests" and because the being's "existence will probably be brief no matter what we do and whose mental capacities are much less sophisticated than those of a small child or of a nonhuman animal such as a dog" (285, 286). On the contrary, proponents of a dementia care ethic perceive obligations to such "beings" as essential to the preservation of his or her personhood and sense of spirituality, as McCurdy discusses, while preventing the patient from falling into the oblivion of isolated existence. The intent is to move beyond functional definitions of personhood and to redefine the human person as an individual who transcends individualism and is deeply embedded in the social fabric of human existence.

In this light, Kitwood proposes that we attend to a person-centred care approach drawn particularly out of the ethic of context. Since discourse on context and contextualization has been, rather extensively, explored throughout this document, a concise reflection on Kitwood's ethic will be discussed here. As we have seen, it is an unattested truism that the deterioration of the person experiencing neurodegenerative illness is not a simple consequence of neuropathology, but is a dialectical interplay between neurological impairment and a combination of social and interpersonal factors (Kitwood 23). Kitwood provides three vignettes of the everyday life experience of persons with dementia, from mild to severe, and applies his ethic of context to facilitate debate.[16] In each scenario, the reader is presented with a case which describes a patient engaged in particularly "abnormal" conduct. For instance, one vignette recounts the story of a woman who, despite easy access to a washroom, urinates on the floor beside her bed every night. A hasty assessment, decision, and course of action conducted by a caregiver without reference to the patient's biography may have compromised the patient's dignity by restricting her to incontinence pads regardless of the fact that she is not incontinent (Kitwood 27). One must recognize here the important distinction between treating a real condition and accommodating, or adjusting, behaviour unusual to the current setting, but in congruity with the patient's former environment.

The ethic of context is particularistic as "it is inseparable from the unique experience and life history of each individual" (Kitwood 27). Therefore, in the given scenario, a staff member on the patient's ward investigates the situation by communicating to the patient's son and discovers that the patient had, in her former apartment, a commode beside her bed. The behaviour becomes less unusual in the context of the patient's life narrative. In light of this hermeneutical approach, the caregiver might accommodate the patient by placing a commode by her bed at night. Clearly, this does not require any great effort. Person-centred care requires that the patient's comfort and accommodation take precedence over those approaches which make "caregiving" more convenient or less time-consuming for the caregiver at the expense of the patient's well-being.

According to Kitwood, an ethic of dementia care includes the fostering of positive social interactions that would maintain the patient's personhood while discouraging negative social interactions that would undermine it. Positive interactions, which may or may not include verbal articulation, are conducive to personhood and well-being even into severe dementia (Kitwood 27). These interactions include recognition (of the patient by name), negotiation, collaboration (on a shared task), play (for self-expression), timalation (aromatherapy or massage), celebration, relaxation (in solitude or in community), validation (empathy), holding (to provide a safe psychological space), and facilitation (Kitwood 27-29). The patient may, in turn, offer something back to the social setting or he or she may express concern, or affection, for the caregiver. These particular interactions initiated by the patient have been respectively coined "creation" and "giving" (Kitwood 29). The fostering of social interactions between the caregiver and the person with dementia (and even between patients) nurture sustaining relationships; recall that relationships are constituent of Dworkin's critical interest paradigm which, in turn, is essential for personhood (Kitwood 29). Negative interactions, including disempowerment, infantilization, stigmatization, labelling, ignoring, and objectification, among several others, are examples of malignant practices that caregivers must identify and eliminate (Kitwood 29-30). Delineating both positive and negative interactions which may foster or undermine personhood provides some form of good to respond to the standing ethical inquiry: "What ought we to do?"

Toward a Spiritual Sense of Personhood

The authors discussed in this section have advanced positive perspectives of persons with dementia without having made reference to either metaphysics or the religions. It is interesting to note, however, that the major themes brought to the fore here, such as the significance of relationality and the continuity of personhood, are analogous to those accentuated in Abrahamic discourse on this subject. I end here with a scholar who attempts to bridge the gap between the secular models of personhood that we have explored thus far and the sacred notion of the human person advanced by Christians, Jews, and Muslims. Although his thesis emphasizes the capacity of AD patients for spiritual awareness and expression as significant for a broadened understanding of personhood, David McCurdy attempts to make his argument accessible to all by describing spirituality in, as well as apart from, the context of religion.

McCurdy works on the premise that all humans are spiritual beings. He employs the term "spirituality," to this end, in reference to "our need and capacity for relationship to whatever or whoever gives meaning, purpose, and direction to our lives [. . .] [and] engages human capacities for self-transcendence and meaning-making" (82). McCurdy argues that the experience of meaning, especially in relationship, is possible for those even in the advanced stages of dementia, claiming that rationality and self-consciousness are "not all there is to a person's meaning-seeking spirituality–and thus to one's humanity" (84). This concept can only be discussed within the social context of the illness experience, which requires moral solidarity; one cannot speak of the spirituality of persons with dementia without including those who are in relationship with them (McCurdy 82). Recognizing that human spirituality is universal (though manifest in different forms and not necessarily connected to established religion) should affect our approach to persons with dementia as "semiotic subjects whose behavior is driven by meaning and is quite rational, given who they are and who they have been" (Sabat 1998, 47). This sense of spirituality, McCurdy claims, is integral to personhood and the dignity of the human person with dementia is rooted in this social connectedness (83). Holstein propounds that this dignity "should rest on the fundamental knowledge that intimates, caregivers, and even strangers think well of me and recognize [. . .] me to be as fully human as they are" (1997, 850). It is no wonder, then, that there is an increasing interest in the clinical relevance of patient spirituality (Post, Puchalski, and Larson 578).

In McCurdy's attempt to provide an understanding of spirituality that is not necessarily religious, he is nevertheless compelled to locate his discussion of human helplessness and hopelessness within, and as a central concern of, the world religions and engages the person with dementia in conversation with God, the soul, and the *imago Dei* (83-89). The dynamic of his argument is an important one and I am, in many respects, appreciative of his attempt to treat spirituality in both religious and secular humanist terms. In this endeavour, McCurdy recognizes that, although different, religionists and non-religionists might, in appreciation for each other's distinctive approaches, come to similar conclusions, especially regarding relationality and social cohesion: the caregiver and patient are united in their need and capacity for relationship (82). Perhaps this is indication that "as a culture we still have not fully faced the implications of generating a genuine secular morality" and that there exists a "continued necessity of religious attitudes for the maintenance of our culture" (Hauerwas 1985, 23-24).

As McCurdy illustrates, perhaps unintentionally, there is something lacking in the secularization of religious terminology and concepts. When Singer and Kuhse advocate the dismissal of the Sanctity-of-Life "doctrine" in medicine and insist instead on the secular language of Quality-of-Life while still maintaining, to some degree, a discussion of sacredness without alluding to the Sacred, or when covenant is reduced to the simple terms of contract, the intended meaning of these words, known by the world to be born within religious ideology and yet deliberately transformed for this very reason, leaves much to be desired in the new secularized context. Paul Ramsey, for one, makes note of this, in his Patient as Person, when he refers to discourse on the dignity or quality of human life as "a sliver of a shield in comparison with the awesome respect required of men in all their dealings with men if man has a touch of sanctity in this his fetal, mortal, bodily, living and dying life" (xiii). One may recognize in McCurdy's recurrent association of spirituality with Spirit and in the centrality of major religious principles to his discourse, that religious understandings of the human person not only help theists and atheists alike identify the serious limitations of functional theories of personhood, but are also, as we shall see, harmonious with patterns of dementia care in Canada.

This raises an interesting battery of questions that requires our attention. Why search the religions for answers? Why borrow religiously laden terms and translate them into the *lingua franca* of secularism? Why turn to religious wisdom when medicine, law, and philosophy already have much to say about these bioethical concerns? "After all," H. Tristram Engelhardt, Jr. remarks, "philosophical bioethics analyzes issues, clarifies arguments, and assesses justification for claims. What more could one want? What more would one need and why?" (Davis and Zoloth 113).

IV. An Appeal to Religious Wisdom

On Transdisciplinarity, Language, and Religion in Bioethics

Denaturing Religion in the *Lingua Franca*

It is clear, Dena S. Davis attests, that in the late 1960s and early 1970s, no one would have fathomed asking these questions put forth by Engelhardt. Indeed, it is no secret that contemporary bioethics finds its origin in the works of certain theologians (such as Ramsey, McCormick, Gustafson, Hauerwas, Veatch, and Fletcher) who did not perceive their endeavour in "bioethics" as one involving purely secular moral principles and modes of reasoning (Davis and Zoloth 2; Brody 41). The ongoing secularization of society, and especially of bioethics which finds itself increasingly at the centre of public interest, has markedly suppressed the once dominant religious voice in bioethics while allowing philosophy and law to develop a certain *lingua franca* in the field (Callahan 3). "The consequence," Daniel Callahan reports, "has been a mode of public discourse that emphasizes secular themes: universal rights, individual self-direction, procedural justice, and a systematic denial of either a common good or a transcendent individual good" (2).

The pluralism that is celebrated by contemporary society can indeed, although somewhat ironically, become exclusive, if not oppressive, when the voices of other disciplines, traditions, and communities are silenced (Callahan 4). Further, it is deceptive when scholars, like Engelhardt in his Foundations of Bioethics, attempt to equate "secular" with "reason" and "religious" with "revelation" implying, no doubt, that the religions are bound to the interpretation of the mystical, the metaphysical, the transcendent, and other-worldly themes that, as noumena, lie outside the scope of human reasoning and, as such, cannot possibly be intelligible. It is in this sort of division between secular and religious thinking and motivation that some have opted for neutrality. Engelhardt suggests, however, that this neutrality be situated in a particular mode and style of thinking. His bias for a secular bioethics is plain to see:

> [A secular bioethics] promises the possibility of providing a context for health care that can encompass in toleration health care givers and receivers with diverse moral perspectives. Believers should also recognize that a secular bioethics can provide the peaceable neutral framework through which they can reach out to others beyond their own particular

> religious tradition and convert through witness and example, even if not through force [. . .] [i]t recalls one to the reality of modern medical practice in a pluralist context. (Engelhardt 1986, 12-13)

Engelhardt's suggestion that the religions' primary motivation for securing a place in bioethics and engaging in bioethical discourse is to proselytize and convert the masses is not only flawed, but highly offensive. Religions have, for millennia, participated in social life, contemplating the realities of birth, life, suffering, death, and the social justice dimension of health care, long before the advent of bioethics as a discipline in its own right. It is true, though, that reflections on such matters have never been isolated from their beliefs and convictions. Vital to the religious traditions is their role as advocates for the protection, and promotion of dignity, of the (ageing) human person, of whatever capacity for rationality, self-consciousness, or economic productivity, in bioethical debate. Religious participation in bioethics reflects a special concern for those at the margins and a particular commitment to social justice. Policy and bioethical decision-making cannot be conducted if we are to adopt a neutral posture toward bioethical issues, especially concerning the foundational question of human personhood which finds itself at the root of many, if not all, of these issues. As advocates for the poor, social outcast, suffering, and marginalized, the Abrahamic faith traditions seek to extend the moral boundaries of human personhood and adamantly defend those marked by neurodegenerative pathology, who dwell outside exclusive and conditional definitions of "person." Hence, the role and place of the religious traditions in informing bioethical issues and shaping policy, particularly in regard to the status and treatment of patients with dementia, is of paramount importance to the 1 in 13 Canadians over the age of 65 who are affected by AD and related dementias, to their families, and to those who care for them (CSHA Working Group 899).

Philosophy, law, religion, and medicine continuously find themselves engaged in situations of common practical interest. We must celebrate the transdisciplinarity of bioethics and seek, as Somerville counsels, integrated knowledge (284-286). A bioethicist educated in both secular and religious theory is much more beneficial, compatible, and suitable to both caregivers and patients with whom he or she can communicate the intersections of various streams of knowledge. A bioethics that is neutral, to the extent that it strives, above all things, to appease and tolerate all persons for the good of the peaceable community, is passive and refuses to actively engage in conversation with traditions, secular or religious, with which it is either unfamiliar or hesitant lest it stir up controversy. I am not equating neutrality to ignorance in this regard, but am implying a sort of perfidy: neutrality condemns the bioethicist, even the most thoroughly learned in the various disciplines, to silence.

It may very well be true that "[p]erhaps for the sake of getting a broader hearing, perhaps not to profane sacred teachings or to preserve a separation between the things of Caesar and the things of God, most religious ethicists entering the public practice of ethics leave their special religious insights at the door and talk about 'deontological vs. consequentialist,' 'autonomy vs. paternalism,' 'justice vs. utility,' just like everybody else" (Kass 7). At the same time, I think it rather ludicrous to expect ethicists, of whatever expertise, to conduct deliberation in such a way that is completely disconnected from a particular religious or philosophical perspective. When summoned to comment on any particular bioethical issue, Gilbert Meilaender rightly emphasizes that:

> [t]hese topics are not driven simply by concern for public policy regulations; rather, they involve some of the most important aspects of our humanity and raise some of the deepest questions about what it means to be human. There is no neutral ground from which to discuss such questions. They are inevitably normative, value-laden, metaphysical in character. [. . .] We are not philosopher-kings who can adjudicate disputes between conflicting views without ourselves being parties to the argument. We are human beings, invited to reflect upon what that humanity means and requires in the field of bioethics. (1)

My objective here is to formulate a convincing argument for transdisciplinarity which, as a mark of the integrative biopsychosocial model, has been instrumental in advancing our understanding of neurodegenerative illness and its diagnosis while bringing to the fore ethical implications for patient-centred care. While bioethicists cannot be expected to suppress the religious and philosophical dimensions of their person, the value of their contributions will be measured according to demonstrable competency and skill in analysis, interpretation, reasoning, and contextualization, as well as by eloquence and convincing argumentation. The greatest challenge for the bioethicist, then, is one that we have already described in the context of progressive dementia: preserving his or her whole person in the midst of trial. Creating a forum to foster the conversation of this particular expertise, and to operate constructively within it, should be sought above all else not only for the peaceable community as a collective, but also for the diversity of individual persons who constitute it.

That said, I agree with Robert Merrihew Adams who, admitting that "there is no realistic chance of general agreement on even a secular ethical theory," asserts that "common morality does not depend on agreement in ethical theory" and that the participation of religious traditions in no way undermines, or is subversive to, common morality (Outka and Reeder 98). Indeed, as Laurie Zoloth suggests, "to acknowledge the particular voice of religion's claims is to acknowledge the multiple voices of the moral horizon" (Davis and Zoloth 256).

James M. Gustafson remarks, in his "Theology Confronts Technology and the Life Sciences," that it is not just that the audience is uninterested in what the religions have to say, but that the problems are specifically shaped by non-theologians in such a way that contributions to moral critique from the religious traditions become rather arduous, if not completely unapproachable (1978, 387). Among the unfortunate consequences of the secularization that Callahan addresses are: an encouraged "form of moral philosophy for use in the marketplace that aspires simultaneously to a kind of detached neutrality (what Thomas Nagel has called the 'view from nowhere'), and a culture-free rationalistic universalism (which is suspicious of the emotions and the particularities of actual human communities)," as well as intimidation of the religious traditions from engaging in public discourse with its "own voice" and, subsequently, a confinement of religious discourse to its respective communities (Callahan 4). The inquiry, however, is not so much about *what place* theology and the religious traditions have in increasingly secularized bioethics. The concern is more rudimentary than this: *can* theology and the religious traditions have a role in the plurality that is "public" bioethical discourse? (Cahill 10). Further, if this role can be elucidated, the religions will be "talking of God–but with whom?" (Verhey 21).

At first glance, a thesis which posits both the secular and religious perceptions of a singular bioethical concern might precariously, perhaps even inevitably, be an invitation to the impossible enterprise of "comparing apples and oranges." Ostensibly, the approaches of these two worlds, each of such very different inner logic, may lead us to sterile polemics. There is, though, as atheist German philosopher Jürgen Habermas argues, a problem with this reasoning. Writing in the shadow of September 11th and in the context of the current debate over genetic engineering and human cloning, Habermas' discourse offers us an invaluable synopsis of the complementary, as opposed to competitive, contributions of secular and religious ethical theory. He contends that new deliberation on the secularization of society is imperative if we are to avoid what Samuel Huntington calls "the clash of civilizations."

Habermas recounts the development and original usage of the term "secularization" in Europe, recalling its juridical connotation as the involuntary transfer of ecclesial property to the secular state (2003, 103). Since then, Habermas observes that secularization has been:

> subject to contrasting evaluations, depending on whether its main feature is seen as the successful *taming* of clerical authority, or as the act of unlawful *appropriation*. According to the first reading–"taming"–religious ways of thinking and forms of life are *replaced* by rational, in any case superior, equivalents; whereas in the second reading–"stealing"–these modern ways of thinking and forms of life are *discredited* as illegitimately appropriated goods. The replacement model suggests a progressivist interpretation in terms of disenchanted modernity, while the expropriation model leads to an interpretation in terms of a theory of decline [. . .]. (2003, 103-104)

The argument here is that both of these readings make the mistake of interpreting secularization as an all-or-nothing conflict "between the capitalistically unbridled productivity of science and technology on the one hand, and the conservative forces of religion and the church on the other hand" where the gain and victory of one side necessarily implies the loss and defeat of the other (Habermas 2003, 104). As such, it is interesting to note that Habermas, an atheist philosopher, advocates that we move beyond the secular society and proposes, instead, a "postsecular" society that recognizes the continuing significance and ability of the religious traditions to contribute to, or perhaps even shape, public discourse (Simon 14). In a lecture delivered on the occasion of receiving the German Book Trade Peace Award in October of 2001, Habermas' positive revision of the role and place of religious traditions cautioned against a dialectic bound up in the "zero-sum game" between the secular and the religious; secularization can no longer equate to the compartmentalization of science as purely secular and the religious as purely sectarian. Clearly, this is reflective of how deeply interconnected the arguments of different scholars from various backgrounds have been in our study thus far. Although Stanley Hauerwas forewarns the religions not to be surprised to discover their particular beliefs and convictions "confirmed by the best humanistic alternatives," it is the interplay of secular and religious practical interests in theories of personhood that offer us, as a society informed by both, a more comprehensive understanding of the complexity of dementia (1985, 24).

Amid the seemingly competitive voices of religious versus secular/scientific lurks a third party, with which Habermas himself associates, of "a democratically shaped and enlightened common sense" that has adapted to the fact that religious traditions and communities have survived the ongoing secularization of society as a whole (2003, 104). This enlightened common sense is willing to be taught by both the sciences and the religions, without acknowledging that one or the other is an exclusive source of knowledge, and that the divisive screen between secular and religious reasoning is indeed porous (Habermas 2003, 105, 109). Such common sense is critical of the scientific endeavour to objectify nature (humanity included) as that which can be explained away in terms of the depersonalizing and extensional concepts of utility or captured by a language that is reductionistic, atomistic, and mechanistic. Indeed, Habermas argues, the sciences cannot account for the drama of human existence nor, for that matter, for moral agency or human autonomy (2003, 106-107). "The scientistic belief in a science which will one day not only supplement, but *replace* the self-understanding of actors as persons by an objectivating self-description is not science, but bad philosophy" (Habermas 2003, 108). Indeed, we have seen how the biomedical model, which inspires an understanding of the "loss of personhood" as the simple consequence of neuropathology, fails to appreciate the psychosocial, biographical, and spiritual dimensions of the person with dementia. Enlightened common sense, which informs the biopsychosocial model of conceptualizing health and illness, compels us to rely on integrative knowledge to produce a more holistic perception of the human person. It is in this spirit that I will proceed.

The religions, to this end, have a certain capacity for the articulation of this self-understanding and human meaning. One can remain open to listening to and interpreting religious insight without necessarily becoming a disciple of any one tradition (Habermas 2003, 113). To the question, "[c]an those of us who share [a] lack of belief still make use of at least some of the insights and perspectives of religions, even as we reject its roots?" both Callahan and Habermas, who proclaim estrangement from established religion, respond resoundingly in the affirmative (Callahan 2). The objective, in this regard, is "to discover a form of argumentation that permits religious insights to be valid as religious" (Lalonde 85). Enlightened common sense, as Gregory Baum indicates, "is the hermeneutic intelligence that allows us to interpret other people's communications and arrive at an understanding of who we are ourselves. [. . .] [It] is operative in the experience of daily living, 'the lifeworld,' where we presuppose that we are interdependent subjects, acting freely with intention and holding ourselves and others responsible for the choices made" (2). It is within this very framework that we have studied Lyman, Post, Sabat, and McCurdy's social perspectives of personhood. The proposal, then, is not so much the avoidance of a "clash of civilizations," but the promotion of effective dialogue between secular and religious theorists: a bridging of the two worlds.

Margaret Somerville addresses this issue in her description of *doing* ethics:

> Transdisciplinarity is based on a belief that the learning or methodologies of any one discipline are too confining to enable us to deal with the complexity of many of the most important and urgent societal issues, in particular, to do ethics properly in relation to these issues. Transdisciplinarity recognizes the major impact that our choice of methodology can have on the decisions we make, especially concerning ethics. This approach, which is still in the process of development, has an aim of embedding various streams of knowledge in one another and seeks to re-create integrated knowledge through doing this. [. . .] Transdisciplinarity will compel us to find a common vocabulary between the disciplines. But we also need integrated and integrating language that goes beyond the disciplines [. . .]. (285-286)

This *conversation* between medicine, ethics, law, and religion is at the heart of Somerville's Ethical Canary; it is the interplay of these faculties that becomes integral to the acknowledgment of, concern for, and preservation of human identity. Indeed, as we have seen, only an ecological approach to defining personhood, in the sense that it recognizes the interaction of biological, psychosocial, and spiritual dimensions, would be capable of appreciating the complexity of the human narrative.

Emile Durkheim proposes the beginnings of such a shared story in his reference to "the belief in the inherent dignity and worth of human life as 'the religion of humanity' and concludes that it is the only cohesive bond in a diverse and secular world [. . .] the last one that 'unites us as a human community and serves as the essential basis of our social and moral order'" (qtd. in Somerville 62). Indeed, the first chapters of this thesis indicate that questions regarding the inherent dignity and worth of human life are far less unifying than Durkheim suggests. To speak of the dignity of human *nonpersons* would be nothing less than absurd for several of the authors discussed herein. As we shall see, however, the general practice of dementia care in the cultural mosaic that is Canada is a common one that exposes a strong communitarian concern for the worth of human life, even in its most vulnerable and dependent state.

Lisa Sowle Cahill is convinced that there exists no neutral, impartial, or universal language into which theology can be translated. "To speak of distinctly secular language and arguments also implies that to be intelligible, religious or theological language must undergo some sort of 'translation' into the lingua franca–into some different vocabulary universally understood" is both a distorted understanding of the religious traditions and a rather impossible undertaking (Cahill 1990, 11). The challenge is to communicate religious and theological input in a clear, genuine, and concise language that neither underestimates nor overplays the complexity and wealth of religious dialogue, its history, and its place in bioethical discourse, while simultaneously being accessible to an interdisciplinary audience. The risk that surfaces here is a realistic one that concerns the religious traditions whenever they engage in public discourse: "[I]f what is said theologically is but a confirmation of what we can know on other grounds or can be said more clearly in nontheological language, then why bother saying it theologically at all?" (Hauerwas 1985, 25). To this, Theodor W. Adorno, to whom Jürgen Habermas was both student and assistant, adds, "Nothing of theological content will persist without being transformed; every content will have to put itself to the test of migrating into the realm of the secular, the profane" (qtd. in Habermas 2003, 112). Habermas, Cahill, and Callahan argue to the contrary. Any claim which implies that the only way the religions are to be heard is through translation of religious conviction (and experience) into secular discourse is not how we are to understand the pluralism that contemporary society celebrates. The need, then, is not necessarily to secularize the arguments, but, rather, make them intelligible for persons of different backgrounds. This, Stanley Hauerwas proposes, can best be done through the community of faith, which embodies narratives, traditions, rituals, and commitments to both God and humankind (1985, 42-44). Perhaps our concern should not rest on how to go about secularizing religious language to accommodate the masses, but how to effectively translate religious social and moral teaching into practice. It will be the cogency of this faith-in-action that will show nonreligious persons the difference such commitments to God and *ecclesia* make. However, theologians, Gustafson warns, must be prepared "to make a [. . .] theological case if challenged to do so" (qtd. in Hauerwas 1985, 38).

There was a time when Habermas argued for a secular society emancipated from dependence on (or interest in) religious traditions. Previously, he was convinced that the religions had exhausted their creativity and could no longer contribute, in a significant way, to an increasingly secularized society grappling with contemporary issues (Baum 3; Simon 14). Further, Habermas once argued, the only thing unique to religious language rested in its particular truth claims about God. In turn, as Marc P. Lalonde comments, "it is precisely this claim that eliminates the real possibility of discursively justifying the truth claims of theological discourse within a pluriform setting capable of accommodating diverse perspectives" (28). Thus, Habermas contended, that which made religious language unique necessarily made it inaccessible to public debate.

However, in his Postmetaphysical Thinking, composed over a decade ago, Habermas began articulating a rather different analysis of the role of religion in public debate. He advises that:

> it is better to speak, for the sake of clarity, of metaphysical *and* religious questions. Thus, I do not believe that we, as Europeans, can seriously understand concepts like morality and ethical life, person and individuality, or freedom and emancipation, without appropriating the substance of the Judeo-Christian understanding of history in terms of salvation [. . .] But without the transmission through socialization and the transformation through philosophy of *any one* of the great world religions,

> this semantic potential could one day become inaccessible. If the remnant of the intersubjectively shared self-understanding that makes human(e) intercourse with one another possible is not to disintegrate, this potential must be mastered anew by every generation. Each must be able to recognize him- or herself in all that wears a human face. To keep this sense of humanity alive and to clarify it–not, to be sure, through direct intervention, but through unceasing, indirect theoretical efforts–is certainly a task from which philosophers should not feel themselves wholly excused [. . .]. (Habermas 1992, 15)

To speak here of a "semantic potential" of the religious traditions and appealing to Judeo-Christian soteriological language presents a Habermas who is concerned about, compelled, and convinced by the fecundity and ability of the religions to articulate meaning in a manner that is both significant and worthwhile. It is the issue here of "transmission" and "transformation" of religious "substance" that is addressed more fully in his Religion and Rationality and The Future of Human Nature where he speaks of the validity of *untranslated* religious language. More importantly, however, is Habermas' appeal to the agapaic notion of love-for-neighbour, a central principle professed by the religions in various forms, made plain in the above passage: "each must be able to recognize him- or herself in all that wears a human face." Habermas binds both religionists and secularists to this mandate, which, in essence, grants protection, promotion, and care to patients with dementia.

Habermas' discourse on enlightened common sense suggests that the exclusion of religious traditions from the public forum is undemocratic and will result in serious ethical consequences (Baum 2). The issue becomes one not only of full inclusion, but also of full participation where the unique language of the religions is not diluted, distorted, or transformed into some idealistic notion of a universal dialect, a *lingua franca*. "For religious discourses would lose their identity if they were to open themselves up to a type of interpretation which no longer allows the religious experiences to be valid *as* religious" (Habermas 2002, 76). Indeed, bargaining for a *neutral* mode of reasoning and a *neutral* language will necessarily obliterate or, at least, dilute that which makes religious wisdom characteristically *religious*. Religious language, Habermas argues, can be effective, deliberative, and constructive in itself without its insights being translated into the language of another discipline: "Secular languages which only eliminate the substance once intended leave irritations. When sin was converted to culpability, and the breaking of divine commands to an offense against human laws, something was lost" (2003, 110). Callahan refers to this development as the "denaturing of religion," which leaves us "too heavily dependent upon the law as the working source of morality," "bereft of the accumulated wisdom and knowledge that are the fruit of long-established religious traditions," and "forced to pretend that we are not creatures both of particular moral communities and the more sprawling, inchoate general community that we celebrate as an expression of our pluralism" (4). Indeed, Stanley Hauerwas has argued that Christian ethicists, in particular, "should have been among the first to criticize the attempt to model the moral life primarily on the analogy of the law" (1985, 41).

Religion and Things of Ultimate Significance

As a preface to any discussion of the contributions of the religious traditions to bioethical discourse, I should provide a more lucid understanding of what the term "religion" actually entails throughout this analysis of transdisciplinary and postsecular thinking. The limited scope of this thesis cannot address the existing dispute over the word origin of "religion" nor offer an adequate synopsis of the complexity and multiplicity of definitions given by the traditions themselves. However, bioethicists writing from, for, or within, the religions will often justify the place and role of religious discourse in public life by appealing to its antiquity and uniqueness when dealing with things of "ultimate significance."

Indeed, students of theology will at once recognize in this phrase the familiar language of Paul Tillich. Tillich argued that "the object of theology is what concerns us ultimately" and "what concerns us ultimately determines our being or non-being" (12, 14). These things of "ultimate significance" are not wholly transcendental, but are very much a concern in ordinary life and in everyday human experience. So universal are these concerns, that we may, without hesitation, call humans "religious beings" (Catechism #28). To this understanding, James M. Gustafson would add the sense of relationship with an ultimate power that is experienced, if at the very least, indirectly and perhaps not even consciously (1975, 5). "Theology," Gustafson explains rather simply, "is a reflection upon human experience with reference to a particular dimension of the human experience denoted 'religious,'" where "religious" entails this sense of relationality with a higher power (1975, 4-5). Religion, as such, seeks "to broaden our moral vision by raising issues of existential interest that are not typically addressed in contemporary bioethics" such as the nature, meaning, and purpose of life; suffering, health, medicine, and death in the context of envisioning a broader sense of human existence that includes eschatology, soteriology, and non-linear thinking; as well as the ministry to the ill and dying, the covenantal nature of relationships, and the community of care, which far too often find themselves at the periphery of bioethical concern (Campbell 1990, 8). Indeed, this sense of relationship to which Gustafson alludes is crucial to our discussion of personhood in advanced dementia. The social connection between the patient and caregiver, as discussed previously, as well as the covenant between the patient, God, and the community of faith, to be discussed in the following chapter, are central tenets of this thesis.

Gustafson argues that:

> one's theological convictions and their articulation in principles about the character of ultimate reality and about human life have a fundamental bearing on one's attitude toward the life sciences and technology. This bearing, in fact, might be more significant in determining one's particular moral preferences than the specific principles chosen to justify a particular decision. It might turn out that passionate ethical debates about technology and the life sciences are missing the crucial point where the real differences lie, and (my goodness!) "ethicists" might have to become theologians! (1978, 389)

Both religion and the secular realm of science share practical interests, engage in questions of uncertainty, and are concerned with things of ultimate significance experienced both in ordinary life and in the transcendent as illustrated in the linguistics of symbol, story, and praxis. Perhaps, then, it is more suitable to speak of a shared worldview as opposed to the rivalry of two competing, and irreconcilable, realities that we far too often separate to the extent that discussion, time and again, between religion and science or between religious and secular communities ends in a stalemate.

Worldviews are revealed and communicated through the changing and reflective network of culture. Although in constant relationship, the terms "worldview" and "culture" are not synonymous. Glenn Smith reminds that the former can be studied with regard to four features: characteristic stories, fundamental symbols, habitual praxis, and a system of questions and answers (2). It is in studying the intersection of these four features in religion and science that one will undeniably unearth a shared worldview, ultimately illuminating commonality in the endeavours of both to comprehend and apprehend the world. A shared worldview, more importantly, does not require the need for a *lingua franca* to be communicated through culture; it does, however, demand that the disciplines-in-dialogue recognize the complexity of apprehending the world, confess the restraints of their own language, appreciate the contributions of their partners, and communicate through ideology-in-praxis. Habermas alludes to this cooperative relationship:

> But only if the secular side, too, remains sensitive to the force of articulation inherent in religious languages will the search for reasons that aim at universal acceptability not lead to an unfair exclusion of religions from the public sphere, nor sever secular society from important resources of meaning. In any event, the boundaries between secular and religious reasons are fluid. Determining these disputed boundaries should therefore be seen as a cooperative task which requires *both* sides to take on the perspective of the other one. (2003, 109)

Extending Religious Communities of Moral Discourse

"[T]heology might not provide answers you like to accept," Gustafson admits, "but it can force questions you ought to be aware of" (1978, 389). As such, religious communities can serve as "contrast models" to the mainstream, which, according to James P. Wind, "can contribute to a more variegated or motley view of humanity, helping us see more of the full marvel present in each human being" (19). However meaningful and insightful the religions very well may be, the concern remains: any faith tradition that professes God as "the sole warrant for moral conclusions" will be persuasive only to members of that particular faith community (Cahill 1990, 11). That is, the religions, in this light, are confined to exclusive communities of moral discourse which are selectively attuned to God-talk.

This returns us to our understanding of religion as that which orients human experience in the context of universal concern for things of ultimate significance. Religion, which emphasizes community, relationality (especially through the concept of covenant), and history, is, as such, embedded in the human condition. It is in this vein that Campbell situates the religious traditions within public life and discourse. "Religion," he writes, "offers an interpretation or revelation of reality that responds to what Max Weber referred to as the 'metaphysical needs of the human mind' to seek order, coherence, and meaning in our lives, to understand ultimate questions about our nature, purpose, and destiny" (Campbell 1990, 5). Religion, then, does not merely contribute to public discourse; it actually *responds* to a human need. If this human need is indeed universal, then one might want to consider how it is that religion has become "privatized" or "confined" to select forums of discussion.

Stanley Hauerwas suggests that in lieu of theologians invoking God in public discourse, they begin with a discussion of the *ecclesia*, the community of faith, in which God is experienced (1985, 43). The Abrahamic faith traditions will agree that "a community of a particular kind [is needed] to live well morally" (Hauerwas 1985, 43). Hauerwas advises that:

> [o]ur task as theologians remains what it has always been–namely, to exploit the considerable resources embodied in particular Christian convictions which sustain our ability to be a community faithful to our belief that we are creatures of a graceful God. If we do that we may well discover that we are speaking to more than just our fellow Christians, for others as a result may well find we have something interesting to say. (1985, 44)

For instance, the religious traditions, Campbell argues, "can enhance recognition" primarily under the preferential option and regard for the poor who "are not to be excluded from the community of moral concern" (1990, 9). It must be made very clear that "the poor," as described by the religions, is a much broader community than that which is defined by the language of the market; a more expansive understanding of the term does not necessarily imply that it is no longer of any use. The religions not only address material poverty in this regard, but also cultural and religious poverty as well. Who, then, are "the poor?" Inasmuch as feminist theologian Sallie McFague has proclaimed nature as the new poor, we must recognize in this neglected community those patients suffering from degenerative dementia who risk losing their status as persons (and, hence, their value and dignity) to a society which measures human worth against function and utility. The poor, as an oppressed and excluded group of persons, remain special subjects of the religions' commitment to social justice. This special concern, taken up by both religionists and secularists, is apparent in Canadian patterns of dementia care as well as in the establishment of charitable organizations, such as the King's Fund and the Alzheimer Society of Canada, charged with the protection and promotion of persons with dementia.

Beyond the Biomedicalization of Dementia: Patterns of Care in Canada

John Harris claims that "a person is a creature capable of valuing its own existence [. . .] if eventually she loses this capacity, she will have ceased to be a person" (1992, 68-69). Similarly, Dworkin has argued that "[v]alue cannot be poured into a life from the outside; it must be generated by the person whose life it is, and [for a dementia patient] this is no longer possible for him" (230). Herein lies a primary difference between functional and religious theories of personhood.

The process of becoming human, Jean Vanier writes, occurs in communion, in belonging, in the move to include the excluded; that is, in the development of the capacity to relate with others. It is within a community of men and women with intellectual disabilities, "people who are not very capable on the intellectual or practical level but who are very gifted in relationships," where Vanier learns what it means to be human. In this particular community, he shapes the vision of "a more human" society at the heart of which is compassion, trust, and renewed understanding (1-2, 97). Contrary to functional personhood theories, this requires that the human person, and the value of human life as a whole, not only be measured in isolation, but also in reference to relationships. Christians, Jews, and Muslims, whose existence as a people is marked by covenant, emphasize both the purpose and the need of human beings to live with others in community. The Canadian Study of Health and Aging (CSHA) Working Group's report on the patterns of dementia care in Canada reveals that caregiving trends in the general population are more congruent with a definition of personhood that includes reference to the notions of covenant, community, inclusion, and biography espoused by the religions. Functional personhood theories neglect these elements and, thus, require only basic treatment of persons with dementia; this, the CSHA finds, is counterintuitive.

In 1994, approximately $5.5 billion was spent annually in Canada on persons with Alzheimer's disease and related dementias (Ostbye and Crosse 1457). In addition, the study concluded that Canadians implicated in dementia care do so at the expense of their own health.[17] The Canadian Study of Health and Aging Working Group reports that about half of all people with dementia in Canada live in the community and over 98% of these persons have a caregiver (of which 94% are unpaid family members) regardless of the fact that providing care for loved ones with dementia results in chronic health conditions, anticipatory grief, distress, feelings of burden, and depression (471, 481-482). Ian Norman and Sally Redfern note that the move of Western societies from providing institutional care for persons with dementia to provisional care within the community, while acknowledging the toll of dementia care on the health of caregivers, emphasizes the importance of community and the family's responsibility in caregiving (184). Alongside the increasing multidisciplinarity of caregivers and emerging critiques of the biomedicalization of dementia, "developed against a background of suspicion against science and medicine," the move of dementia care into the community of persons, Norman and Redfern further argue, marks the recent resurgence of interest in psychosocial models of dementia (184).

In light of all this, dementia care has shifted from the individual treatment of one patient's pathology to concern and care for persons in relationship; that is, for patients and their caregiving families. Accordingly, the King Edward's Fund, a charitable foundation charged with the improvement of health in London by challenging health inequalities, has established principles for dementia care which have led to the development of practice guidelines for health care professionals who work with dementia patients and their families. The principles and objectives of the King's Fund draw together much of what we have discussed in the previous and current chapters and, as such, I shall enumerate them in detail: (1) "[p]eople with dementia have the same human value as anyone else, irrespective of their degree of disability or dependence. Recognising the status and worth of people with dementia"; (2) "[p]eople with dementia have the same varied human needs as anyone else. Responding to a full range of needs within the mainstream of society"; (3) "[p]eople with dementia have the same rights as other citizens. Promoting the rights of people with dementia who use services"; (4)

"[e]very person with dementia is an individual. Creating individual centred care"; and (5) "[p]eople with dementia have the right to forms of support which do not exploit family and friends. Safeguarding the quality of life of families and other caregivers" (Norman and Redfern 194). Similarly, the Alzheimer Society of Canada, with local chapters throughout the country, has published as many documents outlining guidelines for the care and support of caregivers as they have for patients, particularly in response to the CSHA findings of elevated stress and chronic health problems in the caregiving population.[18]

The simple fact that we have a King Edward's Fund and an Alzheimer Society of Canada, with thirty chapter offices in Québec alone, indicates a genuine effort to defend and promote the dignity and personhood of patients with Alzheimer's disease and those who care for them, while attesting to the value and meaning of life with dementia through support and education for patients, caregivers, and health care professionals. This is reflective of the religions' preferential option and special care for the poor, silenced, marginalized, and suffering. No such charitable initiatives would exist if large sectors of the public were convinced of the nonpersonhood status of dementia patients advanced by many of the functional theorists previously discussed.

Although the Canadian Study of Health and Aging Working Group fails to explicitly address the reasons and motivations for which caregivers risk their own health to expend great energy and material resources on the care of a loved one with dementia (in-depth research is lacking on this matter), it is evident that the patient as person, defined in a particular relationship with the caregiver, is somehow maintained through the very act of caregiving. Stanley Hauerwas reminds that the patient, even in his or her dementing illness, "is still my Uncle Charlie" (1987, 278-281). The preservation of his or her personhood becomes guaranteed, or is sustained, by the presence of the other and is, hence, linked to the intersubjectivity of patient and caregiver (Kitwood and Bredin 175). It seems quite clear, from the data collected by the CSHA, that there are at least three distinct, yet inseparable, motivations for dementia care: (1) caregiving as a means for personhood preservation, (2) caregiving as a responsibility of persons in relationship, and (3) caregiving as attestation to the inviolability and sanctity of human life, especially in its most vulnerable and dependent state. It is no wonder, then, that caregivers sacrifice health and time. The cause is a worthy one.

Theists will take note of the covenantal character of the caregiving relationship: a mutual bond between God, who loves infinitely, and human creation, which repeatedly falls short in its love for the Creator. The covenant not only binds humankind to God, but is also a special mandate for relationships between human persons. Jews, Christians, and Muslims are reminded, especially in the context of dementia care, that love for one's neighbour is an expression of love for one's self and for God. Atheists who assume the role of caregiver for a family member with dementia act more closely in the spirit of this covenantal relationship than simple obedience to contractual responsibility. It is unlikely that the pattern of care reported by the CSHA is motivated by contract, under which a particular family member is legally bound to care for a loved one with dementia at the expense of his or her own health. I presume here that the 98% of dementia patients who are cared for within the community (that is, at home and not in an institution) have caregivers, whether adherent to a particular religious tradition or not, who genuinely love them and wish to honour a relationship that has somehow survived the strains of disease. It seems that while adherents to the religions seek counsel from their communities and traditions in moral matters, many secularists accept, or at least appeal to, the anthropology and social theory of the religions without finding it necessary to accept their presuppositions (Hauerwas 1985, 31).

This understanding is reflective of Dworkin's concept of the process of becoming sacred. He suggests that something may become sacred through its history; that is, "how it came to be" (74). Dworkin illustrates this point in his usual reference to art:

> In the case of art, for example, inviolability is not associational but genetic: it is not what a painting symbolizes or is associated with but how it came to be that makes it valuable. We protect even a painting we do not much like, just as we try to preserve cultures we do not especially admire, because they embody processes of human creation we consider important and admirable. (74-75)

We may very well assume that the ultimate human creation of one's own life narrative and his or her co-creation of the biography of others is as, if not more, admirable as an artistic masterpiece. The patterns of dementia care recorded by the CSHA imply that a certain value, or worth, is attributed to patients with dementia; perhaps this is in the recognition of the lifelong creativity of such persons and gratitude for their contributions to the lives of those who assume the role of caregiver. The person is valuable, not simply in his or her current form, but, in the very process of becoming.

Dena S. Davis warns that "philosophy, by sheer numbers, threatens to overwhelm the contribution of religious studies to bioethics" (Davis and Zoloth 2). Yet, it would seem that religion, "because it is particular, culturally bound, and relationally based," will continue to inspire public praxis in spite of how vigorous pluralistic societies challenge the value of its contributions (Davis and Zoloth 256). For as long as the very stuff of religion (that is, the meaning of life, mortality, suffering, and natural diversity, for instance) provokes thought, elicits uncertainty, addresses questions of ultimate significance, and delights the human imagination, religious wisdom will remain a constant and invaluable resource for guiding human ideology and praxis.

Imagining the Image of God

The following section of the thesis will introduce perspectives of personhood drawn from the Abrahamic faith traditions of Christianity, Islam, and Judaism. Although such a discussion will inevitably be sweeping, I shall identify major religious premises which have shaped, and continue to shape, the moral attitudes and practices of society vis-à-vis persons with dementia and the care accorded to such persons.

Beforehand, though, in these final words regarding the place and role of the religions in public bioethical discourse, it is interesting, and pertinent to this study, to note how Habermas has employed religious language in his commentary on genetic engineering. His remarks on the doctrine of the image of God, central to both Christian and Judaic conceptions of personhood, are worth citing in full:

> In order to understand what *Gottesebenbildlichkeit* – "in the likeness of God" – means, one need not believe that the God who is love creates, with Adam and Eve, free creatures who are like him. One knows that there can be no love without recognition of the self in the other, nor freedom without mutual recognition. So, the other who has human form must himself be free in order to be able to return God's affection. In spite of his likeness to God, however, this other is also imagined as being God's creature. Regarding his origin, he cannot be of equal birth with God. This *creatural nature* of the image expresses an intuition which in the present

> context may even speak to those who are tone-deaf to religious connotations. (Habermas 2003, 114)

The Future of Human Nature is replete with such images of the social bond, interconnectivity, and community that assume centre stage in our analysis of persons with dementia. Habermas' discussion of the human person is never separate from the context of relationality. In this light, he argues that the language of science and the market cannot, by any stretch of the imagination, fully capture, as we have seen, the notion of social bond (or the moral feelings expressed in social bonding) that is integral to religious understandings of personhood. He appeals, it seems, to the religious conception of *covenant* (although without addressing this theological idea directly) as a more complete understanding of the mutuality, inclusiveness, and accountability existent in relationships. Habermas' insight regarding the *imago Dei*, as a concept immersed in covenant, shall guide our final chapter on the Abrahamic faith traditions.

Important to this study is how the scholars discussed herein have shown that one need not be part of a community of faith in order to appreciate the existential meaning and purpose articulated by the religions and to recognize a loss when such language is secularized. Perhaps, then, there is no need to make linguistic compromises, which would necessarily risk depriving the communicative fecundity unique to religious language. The contributions of the religions to public discourse shall be evaluated, as Gustafson has argued, in light of their "[c]ompetence in argumentation" (1978, 391). Accordingly, the argumentative competence of the religious traditions can, at the very least, match that of philosophy, law, and medicine. To some degree, Habermas argues, there are even occasions when the religions have proved superior in articulation, such as in their perspectives on personhood:

> [I]ndispensable potentials for meaning are preserved in religious language, potentials that philosophy has not yet fully exhausted, has not yet translated into the language of public, that is, of presumptively generally convincing, reasons. Taking the example of the concept of the individual person, which the religious language of monotheistic doctrine has indeed articulated from the very beginning with all the precision one could wish for, I have attempted to point out this deficit, or at least the clumsiness of philosophical attempts at translation. For me, the basic concepts of philosophical ethics, as they have developed up to this point, also fail to

> capture all the intuitions that have already found a more nuanced expression in the language of the Bible [. . .]. (2002, 162)

I cannot be certain as to how much of religious influence on the secular world should be attributed to preaching, accessible language, and public discourse rather than an effective translation of ideology and conviction into praxis. Indeed, the most telling means the religions can use to communicate their convictions to a pluralistic society such as ours is by *doing* ethics. That is, they must demonstrate how fruitful and beneficial such convictions are to the world through the practice of a faith which is living, conscious, and active.

In view of this developing analysis of personhood and in the context of his discourse on genetic engineering, Habermas welcomes the perspectives of the religious traditions with particular interest in the doctrine of the *imago Dei* and the concept of covenant. Note, in the passage above, the use of rather scientifically laden terms such as "precision," "convincing," and "reason" (elements often argued to be lacking in religious discourse) in his appeal to religious, specifically Biblical, language. Campbell, in full agreement with Habermas in this regard, suggests that "the biblical concept of the 'image of God' expresses a transcendent and relational understanding of the self that may de diminished by proposed equivalents of 'personhood' or 'autonomy,' while both the motivational and substantive elements of 'covenant' seem only minimally conveyed by the language of 'contract'" (1990, 5). As we shall see, the social commitment of agapaic love, as it is described in the New Testament, but practiced by religionists and non-religionists of various persuasions, is much more consistent with the social praxis of dementia care than it is with contractual obligation.

It is interesting to note, as we have, the many different ways religious traditions and communities might inform and shape bioethical debate in pluralistic society. The call by each of the authors mentioned here is for a serious consideration of the clarity, contextualization, and articulation of meaning that religious wisdom can offer as a significant partner (with law, medicine, philosophy, and perhaps others) in bioethics. The reader will detect a noticeable shift in voice, in the final chapter, as we move from philosophical analysis into theological discourse. I advocate here a dialogue between secular and religious ethics, each communicating in its own voice a shared interest in ontological and aetiological questions concerning the human person especially in light of recent trends in biotechnology, as to dismantle the existing Tower of Babel phenomenon of confounded intercommunication between the two worlds. Underlying this, is the intention of engaging religious cultures, which have growing political importance, with secular society in more effective, productive, and affable conversation.

V. The *Imago Dei* and Covenantal Ethics

Abrahamic Faith Discourse on Personhood

The Major Cornerstones of Judaic, Islamic, and Christian Bioethics

Interpretations of personhood by the Abrahamic faith traditions of Christianity, Islam, and Judaism, forged over a long and fascinating history, continue to shape mainstream cultural ideology. I must admit that a manuscript of this length can explore only a minute fraction of religious wisdom. Although I am suspicious of arguments advanced as representative of any one of these traditions, a general analysis of important themes relevant for personhood will reveal a certain commonality within and between the Abrahamic faith communities which, in this thesis, are brought into conversation with one another. I begin with a brief exploration of the major cornerstones of Judaic, Islamic, and Christian bioethics.

To speak of *a* Jewish perspective on personhood is rather misleading. There is no formal hierarchical structure to the various rabbinic authorities and the courts currently in function. As such, for certain opinions to become dominant, one relies on collegial review, community acceptance, and local authority. There is, as a result, an interesting interaction and debate within the Jewish academic community. There is significant rabbinic disagreement on many, if not all, of the concepts to be discussed here at some length.

Elliot Dorff instructs that:

> moral issues *can* be profitably treated by using Jewish law, but only if the law is applied intelligently–that is, with attention to the difference between principles and policies, the nuances of specific cases, the historical development in the meaning of legal texts, and the impact of the reader in discerning their meaning and applicability–as well as with constant and full recognition of Judaism's moral and religious purposes. (8)

Although Dorff does not claim to speak for the whole of Judaism (this would be impossible for the reasons aforementioned), nor even for the Conservative community, the implication here is that there exists a diversity of opinion in Judaism. Regardless of the challenge that Dorff brings to Jewish bioethical discourse and aside from the reality that, unlike Roman Catholicism, for instance, *halakhic* rulings on current issues cannot be promulgated by any central authority, there do exist some fundamental truths which inform Jewish moral theory and praxis.

Dorff, in his Matters of Life and Death, offers a synopsis of beliefs which underlie Jewish medico-ethical discourse. First, one cannot speak of being the owner of the body, but, rather, its tenant. As the body belongs to God, it is potentially good. Secondly, humans are created as integrated wholes in the image and likeness of God; human worth and dignity flow from this truth. Thirdly, Jewish Scripture and tradition stress the duty to heal. Miryam Wahrman adds to this list a few other principles that are, she suggests, distinctly Judaic since their source can be traced to the Written and Oral Torah: do not destroy (*ba'al tak-khit*), the concern for the suffering of animals (*tza'ar baalei khayim*), the preservation of life (*pikuakh nefesh*), and repairing the world (*tikkum olam*) (14-23). Permit me to include in this list of cornerstones a genuine concern for relationships within the family, within the community, within the natural world, and with God. How these fundamental beliefs and central tenets of Judaism play out in ethical discourse vary across rabbinic opinion, but shall be discussed here as to introduce their place and influence in a particularly Judaic understanding of the human person.

Here we identify similar themes and concerns in Islamic bioethics: the sovereignty and transcendence of God, the respect for and duty to protect life, the sanctity (*ḥurma*) and dignity (*karāma*) of the human body, and the concern for community welfare (Brockopp 12, 60, 194). Likewise, Christian discourse on the image of God, the respect for human and community life, the ideal of stewardship in creation (that is, acknowledging that both the body and the earth are God's), and the concern for healing find parallels in the ethical deliberations of Islam and Judaism. It is important to note that while there will always exist discrepancy among Christian scholars, as with every religious tradition, the Roman Catholic Church does have a central teaching authority in the Magisterium, the papal office, the councils, and the college of cardinals and bishops.

Considerable overlap and shared concerns between the religions, as we have seen, will allow for a constructive exchange that will bring to the fore of our study the major themes in personhood considered central to all three faith traditions.

Inclusiveness in Religious Perspectives of the Community of Persons

Singer proposes that we think outside of the "Christian moral framework that has, for so long, prevented any fundamental re-assessment" of issues such as infanticide, against which the Church has adamantly contested (1993, 173). Thinking outside this moral framework, however, has meant, at least for Singer, the disqualification of the "hopelessly senile," the "human vegetable," the "severely retarded," the "human imbecile," the foetus and, in some circumstances, the infant from the community of persons through no fault of their own. Singer argues that Christian teaching on the equal dignity of all human beings as persons (an inclusive rather than exclusive use of the term) is unjustified speciesism that inevitably leads to the blatant mistreatment of nonhuman animals. It is in this context that Singer attempts to unsanctify human life.[19] "[I]t is clear," Stanley Rudman warns, "that the emphasis on rationality easily leads to diminished concern for certain human beings such as infants, idiots, and the senile, groups of people who have, under the influence of both Christian and humanistic considerations, been given special protection" (47).

Rudman's study lends some support to Christians who argue that nonhuman animals should be included in the moral community and valued "in [their] own right and as part of God's creation, like humanity," without necessarily being defined as persons (339). In fact, at first glance, the emphasis of the religions on the social dimension of personhood and "being in relationship," therefore, includes the foetus (whose moral status varies considerably across the traditions) and the patient with advanced dementia, and cannot neglect, in this sense, the rest of creation (Rudman 171). Indeed, the Noahide covenant extends God's promise of indefinite preservation to *all* forms of life; a binding relationship between Creator and creation. Although the application of personhood theories to the context of the nonhuman world is intriguing and insightful in regards to many aspects of this study, I shall focus here on the dignity, value, and sanctity that the Abrahamic religions attribute to human life, even that which is marked by dementia. As a result, those, whom functional theorists banish to the margins of life, find themselves elevated by these faith traditions to equal ground with "incontestably" worthy members of the community of persons. Particular interest in Roman Catholic teaching on persons with dementia, with reflections from Islamic and Judaic ideology, will necessitate our treatment of the *imago Dei*, the sanctity and dignity of human life, the soul (and its relationship to the body), covenantal existence, and the continuity of personhood in the hereafter.

Human Dignity: A Gift of the Divine

The Book of Psalms reiterates the question posed by Job in the first pages of this manuscript, but then offers the reader, albeit rather covertly, a hint at some resolve to this standing moral quandary: "What is man that you are mindful of him, the son of man that you care for him? You made him a little lower than the heavenly beings and crowned him with glory and honor" (8.4-5). Less than God, but *created in his image*, the Catechism of the Catholic Church teaches that all human beings from conception to death enjoy the Creator's gift of an immortal soul and equal dignity as persons with the same nature and origin (#1934). "As a consequence of the special gift–the spiritual soul–each person has an inherent dignity and sacredness which is independent of human society's recognition. That dignity transcends the individual's age, condition, sex, socioeconomic status, religion, health, or stage of development" (Cataldo 1/2).

Further, as emphasized in the Second Vatican Council's Pastoral Constitution of the Church in the Modern World, called *Gaudium et Spes*, the sublime dignity of every human being (which, in the Judeo-Christian context, is synonymous with human *person*) principally rests on the fact that he or she is called to intimate communion with God; an invitation addressed to the human person at the first moment of existence (#19). Relationality with God and with other human beings is in the very nature of human persons. In this respect, McCurdy reminds that both Jewish and Christian (here, we can also include Islamic) traditions perceive the human person as one created for communal existence and as one with whom God continues to relate (83). He argues that "[e]ven those who are severely affected by dementia may experience deep meaning in relationships with caregivers and with other persons with dementia" (McCurdy 84).

Through the doctrine of the incarnation, the Roman Catholic Church teaches that Christ has united himself in some way with every human being to reveal God's ultimate love for all persons; hence, the incalculable worth of each human life regardless of function or capacity (Paul VI, *Gaudium* #22; John Paul II 1995, #2). Indeed, Thomas Groome affirms, "two great strains of Christian Story give unqualified affirmation to the human condition: the accounts of *creation* and *incarnation*. The first reflects that *human life shares in the very life of God;* the second, that *God shares our very human life* in Jesus" (49). Respect, then, for the whole human person and for all people is grounded in a shared createdness and is fostered in a certain "reverence for man; everyone must consider his every neighbor without exception as another self, taking into account first of all his life and the means necessary to living it with dignity" (Paul VI, *Gaudium* #27). This respect for the other, immersed in the idea of communion with God, is not limited to the Christian community of "capable" persons. All of humanity is implicated in the commandment to love (and to be loved by) one's neighbour (Lev. 19.18; Matt. 7.12, 22.36-40; Forty Hadīth of an-Nawawi 13; Talmud, Shabbat 31a).

The Roman Catholic Church's proclamation of the inestimable value and dignity of all human persons is especially timely in regard to the threat to the person and life of individuals and peoples, particularly where life is weak and defenceless. The promotion of human life at all stages and in all circumstances, with particular concern for the most vulnerable and fragile, demands the protection and accompaniment of persons with advanced dementia whose experience becomes one of increasing powerlessness, limitation, and dependency. Whereas these latter characteristics justify the exclusion of the dementia patient from the community of persons by functional theorists, Christians, Jews, and Muslims agree that it is precisely these features that give reason for their inclusion as persons who, as beings of worth and value, merit our enhanced attention. Although mind and body change under the strains of disease, human dignity remains an unchanging mark of being.

While the ageing body with dementia arouses fear and anxiety about human finitude, thus instigating the scientific pursuit of physical immortality, the religions are far less troubled by the inevitability of death. The Abrahamic faith traditions, in this regard, teach that death is a significant part of the life narrative in which the human person only momentarily ceases to exist in the separation of body and soul; God resurrects the dead by granting incorruptibility to human life with the restoration of composite existence (Catechism #997; Jacobs 231; Rahman 126; Brockopp 181). The religions do not perceive the patient with dementia as an "empty, mind-free tomb" who, because he or she lingers in society as an excruciating reminder of human finitude, must be excluded from the community of persons. Instead, the Abrahamic faith traditions compel, in the experience of this progressive illness, the finest expression of imitating the holiness of God by more fully attending to and accompanying the human person to the very moment of his or her transition from this life into the next. That the human *body* is both fleeting and corruptible, by dementia or some other force, is a truism accepted by the religions; it is the human *person*, however, who continues in some fashion after death. In this regard, the resurrection accounts of Jesus in the New Testament, for instance, strongly allude to the biographical continuity of personhood in eternity (John 20.12-18; Luke 24.13-35). That is, while human mortal life ceases at death, the human person survives the passage to immortality with the bonds forged in life unbroken. This natural continuity between life, death, and life eternal is shared by the traditions and has obvious ramifications for their perceptions of personhood in patients with dementia (Order #4, #272; Rahman 126; Dorff 339).

Hence, the Abrahamic religions' adamant defence of human life is not a clinging to that which is fleeting or the fear of that which is inevitable; instead it is gratitude and reverence for that which is considered a special gift from God. Indeed, most strains of Christianity, Islam, and Judaism discourage the aversion of imminent death (this, I must clarify, is not the same as purposely hastening death) by use of extraordinary medical means, which may be burdensome, dangerous, or disproportionate to the expected outcome (Catechism #2278; Rahman 109; Dorff 185-186, 209). At the same time, Christians are called to model Christ's preferential love for the poor and carry out his healing ministry to the sick and social outcast; thus, according special attention to all those who suffer. Similarly, Jews (who are permitted to violate the commandments if preservation of life and health requires it) and Muslims emphasize the mandate and duty to heal. There is no justification for the interruption of ordinary care for the incurably ill or dying. This solidarity with the suffering of others indicates that the religions remain alert to threats to the human dignity of patients with dementia; indeed, the increasingly vulnerable are assured certain consolation and protection within the community of faith.

Paul, in his first letter to the Church at Corinth, writes, "if one part suffers, every part suffers with it" (1 Cor. 12.26).

Comfort and accompaniment with those who suffer is not an exclusive privilege of persons in the faith community. *Gaudium et Spes* opens with a preface on the solidarity of the Church with the whole human family: "The joys and hopes, the grief and anguish of the people of our time, especially of those who are poor or afflicted, are the joys and hopes, the grief and anguish of the followers of Christ as well" (#1). The suffering of the human community, apart from those who look to Christ, is, by no stretch of the imagination, forgotten by God. Although the experience of human suffering is personal, it is, at the same time, universally shared. In this regard, the religions attend to the whole of humanity. To make this very clear, note that obligations to strangers is central to all three faith traditions. In Judaism, for instance, "the stranger's call is that which wakes us in the night, the obligation from which we cannot turn" (Davis and Zoloth 268). Likewise, the Qu'ran commands believers to "[b]e kind to parents, and the near kinsman, and to orphans, and to the needy, and to the neighbor who is of kin, and to the neighbor who is a stranger [. . .]" (4.36). Of further interest is the understanding of the duty of care and love for neighbour as the ultimate expression of love for God:

> On the day of judgment God Most High will say, "Son of Adam, I was sick and you did not visit Me." He will reply, "My Lord, how could I visit Thee when Thou art the Lord of the Universe!" He will say, "Did you not know that My servant so-and-so was ill and yet you did not visit him? Did you not know that if you had visited him you soon would have found Me with him?" (Hadīth of Muslim)

Following this, the value of human life is contingent on God, who abides by humanity even in its weakest and most vulnerable state. In the above passage, the believer is admonished so that he or she may take heed and respond accordingly by imitating the merciful presence of God to those who suffer. In this spirit, the elderly acquire a special status in Islam and "[t]he strain of caring for one's parents in this most difficult time of their lives is considered an honour and blessing;" indeed, the Australian Federation of Islamic Councils regards it a rarity for Muslims to institutionalize their elderly relatives (Australian, par. 6). Honour and special regard for aged persons is also an important feature of Judaism (Jacobs 205).

The equal dignity of each human person dispels any possibility of categorizing or elevating certain groups of human beings whether by degree or kind or capacity. Whereas functional definitions reserve personhood for the rational and self-conscious, this discussion on the universal createdness of humans in (or as) the *imago Dei*, the covenant, the soul, and suffering not only maintains the personhood of patients with dementia regardless of diminishing cognitive function, but also emphasizes the inherent value of human life and its inviolability, which demands respect especially for the weakest among us. "The sanctity of human life," Keyserlingk distils in his commissioned paper, "is not the result of the 'worth' a human being may attribute to it–either to one's own life or that of others. Considerations such as 'degrees of relative worth', 'functional proficiency', or 'pragmatic utility' which humans may acquire or have are in no sense appropriate yardsticks for determining or measuring sanctity of life" (13). In this regard, the sanctity of human life is neither quantifiable nor attributable to the passing judgment of any "indisputable" person; it is a virtue of being. This, as we have seen, is evident in the CSHA report on caregivers who are "affirming and protecting [. . .] the absolute value of human *personal* life" (Keyserlingk 187).

The papal Encyclical Letter on the Value and Inviolability of Human Life, called _Evangelium Vitae_, reminds that postmodern emphasis on secular humanism construes a society whose mentality "tends to equate personal dignity with the capacity for verbal and explicit, or at least perceptible, communication" in stark contrast with the equal and inestimable dignity of the human person who, regardless of function or capacity, never ceases to be in the image of God (John Paul II 1995, #19). William E. May makes this clear:

> Each human being is a living word, spoken by God himself and addressed by him to other human beings. Each human being, moreover, precisely because he or she is a living word spoken by God, is irreplaceable, precious, priceless. To be a human being, accordingly, is to be a *being of moral worth*. This means that every human being is the subject of inalienable rights that are to be recognized by others and that demand legal protection by society. It means that every human being has a dignity that is a created participation in the infinite dignity, indeed sanctity, of God himself. It means that every human being, precisely in virtue of being a human being, transcends or surpasses the society in which he or she lives and, as a consequence, can never rightly be considered simply a part

> related to some larger whole. It means, in other words, that membership in the human species is of transcendent moral significance. (4)

Although May is quick to follow this passage with a discussion on the corporate, or covenantal, character of human existence, which describes the human person as one who is meant to exist *with*, and *needs* to exist in, community, it stands that every human being, including the patient with dementia, has a dignity which participates in the infinite dignity of God himself (4-5). Unconditionally, each human person shares in God's transcendence. This is not to say that human beings escape the moral framework of this world, but, rather, the moral worth of all humans is elevated by virtue of a relationship with God.

I will give Paul Ramsey the last word here. He recapitulates our discussion in his preface to Patient as Person:

> Just as man is a *sacredness in the social and political order*, so he is a *sacredness in the natural, biological order.* He is a sacredness in bodily life. He is a person who within the ambience of the flesh claims our care. He is an embodied soul or ensouled body. He is therefore a sacredness in illness and in his dying. [. . .] The sanctity of human life prevents ultimate trespass upon him even for the sake of treating his bodily life, or for the sake of others who are also only a sacredness in their bodily lives. Only a being who is a sacredness in the social order can withstand complete dominion by "society." (xiii)

The pattern of dementia care reported by the CSHA and the establishment of charitable organizations charged with the protection, care, and promotion of persons with dementia reveal this social order, which recognizes the inherent value of the suffering person and the sacred process of becoming.

As the Image of God He Created Him, Male and Female He Created Them

"Being in the image of God," the Catechism of the Catholic Church teaches, "the human individual possesses the dignity of a *person*, who is not just something, but someone" (#357). To this, the Church adds a rather functional understanding of the *imago Dei*: "he is capable of self-knowledge, of self-possession and of freely giving himself and entering into communion with other persons. And he is called by grace to a covenant with his Creator, to offer him a response of faith and love that no other creature can give in his stead" (Catechism #357). Does this imply that those without such capacities imperfectly image God, or are completely lacking in this regard?

David Novak argues that the exclusivity of a theology which associates the *imago Dei* with reason and, as such, denies humanness to those at the margins of life, is "inconsistent with the whole thrust of the Jewish tradition on the issue of human personhood" (1998, 169). Novak reminds that "[h]uman dignity, which is sufficient to ground the minimal right to life and safety of every descendant of the first humans, means that human beings *are* more than they can ever *do* or *make* of themselves" (1998, 168). Human createdness in the *imago Dei* in Jewish and Christian thought is of paramount importance here and serves as the basis of these religions' perceptions of the human person with dementia.

Jonathan R. Cohen argues that "[p]erhaps no idea in history has done as much to protect and elevate the status of humans as the biblical view that humans were created by God 'in God's image'" (par. 11). The concept of the *imago Dei*, abbreviated as the *zelem elohim* in Hebrew, is fundamental to both a Biblical and theological understanding of the human person. Created in God's image, every human (whether a foetus is considered a human being/human person is the subject of another debate) merits respect. In rabbinic, this is called *kevod ha-beriot* ("respect for [God's] creatures"), where *beriot* includes all humans, Jews and Gentiles alike (Jacobs 204). The *zelem* is not only integral as a Jewish (and Christian) theological conception; its *halakhic* implications are significant and, as Yair Lorberbaum warns, "any account of Judaism that overlooks its *Halakhic* dimension misses what is probably its most essential characteristic" (Koslowski 58).

The *zelem* theosophy emerges as a central theme in early rabbinic literature, in the writings of the Tanna'im, the Jewish sages whose teachings are recorded in the Mishnah from mid-1st century to about 220 C.E., in Medieval Jewish philosophy, and Kabbalah (Koslowski 58). First, it is important to mention that in Tannaitic literature, particularly from the school of Rabbi Aqiva and from the Kabbalah of Nahmanides, the *zelem* includes and integrates all aspects of human experience: personality (in terms of feelings, intellect, and consciousness, for instance) and bodily (Koslowski 59). All human beings are born, therefore, wholly in the image of God. In fact, Lorberbaum discusses how the Rabbis' assumption of personality as an "ingredient" of the body necessarily implied that as long as the body remained intact, even after death, it retained emotions, feelings, and consciousness (Koslowski 60). In this regard, the Tanna'im dispel the mind-body problem (Koslowski 59). The seemingly dualistic nature of the Western religions by manner of pairing two seemingly opposite concepts and then raising one as superior to the other (such as heaven and earth, man and woman) has long been a barrier to an ecological, interconnected, and interrelational understanding of the cosmos and its living constituents. This interpretation of the *imago Dei* by the Tanna'im obliterates these dualistic patterns, particularly concerning the body-soul dichotomy. The human person is considered *one* in essence, where the soul is not a separate entity from the human body, but rather "its vital and animating principle" (Koslowski 59). Accordingly, we cannot speak in the atomistic manner characteristic of functional personhood theorists who disconnect consciousness, emotion, rationality, and the human body, and treat them as distinct entities. We may very well identify, in this centuries-old perspective of the *zelem*, an early attempt at a biopsychosocial model of conceptualizing the human person in health and illness. The patient with dementia, regardless of his or her dwindling capacities for rationality and self-consciousness, then, is perceived not as a collection of separate dysfunctional parts, but as a whole, whose essence as a body-soul composite survives the deterioration of these constituent parts.

In addition, Talmudic literature discusses the *zelem* in the context of relationality between the image (humankind) and its prototype (God), where the demarcation between the two is blurred (Koslowski 60). That is, the human person does not merely resemble God, but God is present in the image (Koslowski 61). A God who is present in the image is also a God who suffers with the image (Koslowski 64). In this context, God not only relates to each human person, particularly to each *suffering* human person, but is also indwelling. I am reminded here of the Christian concept of the incarnation, not only in the sense of God becoming human, but, more importantly, in the understanding of *Immanuel*, God with us (Isa. 7.14; Matt. 1.23). It is in this spirit that Chief Rabbi Jakobovits of the British Commonwealth of Nations wrote, "disease forges an especially close link between God and man; the Divine Presence Itself, as it were, 'rests on the head of the sickbed'" (2). On this note, in Tannaitic theosophy, the *zelem* reveals a God who desires to extend himself by creating humankind in his image. Lorberbaum conceives the *imago Dei* as “founded upon a theomorphic conception of man” (Koslowski 60). It is in identifying God present in the image that elevates the person with dementia as one, regardless of the observable deterioration of body and mind, to whom God extends himself.

The development of the *imago* doctrine is one that mimics the struggle between biomedical/functionalist/rationalist and holistic/biopsychosocial approaches to the human person. Maimonides, for instance, rejected the Tannaitic treatment of the *zelem* altogether, arguing that only an individual whose intellect is ‘in his most perfect and excellent state’ is in the image of God (Koslowski 70). That is, createdness in the divine image is restricted to “only those who reach the highest levels of philosophical apprehension” (Koslowski 70). Accordingly, very few of us would be considered in God’s likeness. This reasoning is comparable to the Alexandrian, Cappadocian, and Augustinian traditions which contended that the *imago Dei* “be sought only in the highest ‘reaches’ of the rational soul” (Tilley and Ross 27). Here we include the works of Philo, Origen, Cyril of Alexandria, Gregory of Nyssa, and Augustine who restrict the *imago* to the human soul. Certain capacity, either for rationality, volition, virtue, dominion, authority, or mystic contemplation, is associated with the *imago* in this regard. The distinction, to which the Biblical texts allude, of humankind *as* the image of God rather than *in* it lends to a rather functional perspective of the human person. The *imago Dei* is, in this sense, an indication of something we *do* rather something we *have*. This something-to-do motif emphasizes a theocentric order where humankind, by virtue of its nature as image of the Creator, is commanded to serve and, more particularly, watch over creation. This idea of stewardship is rooted in the perception of humanity as an extension, or model, of God’s function on the earth (as Swartz’s analysis of *avad* and *shamar* demonstrates) (Gottlieb 101).

A more holistic teaching on the *imago Dei*, which characterizes contemporary Christian doctrine on the subject, emerged first from the acknowledgment of *corpus et anima unus* in the Antiochene tradition and then was elaborated in the Edessene tradition of the fifth century. The latter community produced such thinkers as Narsai, who described the *imago* as a dignity of the whole human person, and Išoʿdad of Merv, who rejected the view that the *imago* be associated exclusively with the capacity for rationality (Tilley and Ross 32-43). Frederick McLeod brings to light the many ways in which Išoʿdad fathomed humans in the image God. As the "synthesis of the world," human beings "unite in themselves the entire creation of spiritual and corporeal beings" (Tilley and Ross 43). Further, human beings symbolize the unity and persons of the triune God by comparing "the soul to God the Father, the mental word engendered by the soul to the Son, and its spirituality to the Holy Spirit" (Tilley and Ross 43). The Trinitarian model of imaging God is an interesting one that merits further exploration.

Human beings are created in and for relationships with God, with other human persons, and with the rest of creation. Rudman is correct in saying that "[i]f God is a Trinity, and conformity with Christ is the goal of Christian personhood, this means that relational being, reflected in human nature, is central to what it means to be in the image and likeness of God" (177). Further, the Catechism teaches that "the divine image is present in every man. It shines forth in the communion of persons, in the likeness of the union of the divine persons among themselves" (#1702). The doctrine of the Trinity describes the reality of a God who "is one but not solitary" as Father, Son, and Holy Spirit (Catechism #254). God, as a community of persons, models the threefold relationality characteristic of human experience between self, other, and the divine.

In Roman Catholic literature, the term "person" is most often reserved for the three distinct members of the Trinity: the person of God the Father, the person of God the Son, and the person of God the Holy Spirit. Accordingly, the word "relation" is used to indicate that this distinction can only be understood in the relationship of each to the others (Catechism #252). As such, the Church can speak of one God in three consubstantial, indivisible, yet distinct persons (Catechism #689). "The divine persons do not share the one divinity among themselves but each of them is God whole and entire: 'The Father is that which the Son is, the Son that which the Father is, the Father and the Son that which the Holy Spirit is, i.e. by nature one God'" (Catechism #253). The Trinitarian communion models the fraternity that humans are called to establish among themselves as an attestation that love for neighbour is inseparable from love for self or love for God. Further, as the divine persons are relative to one another, the human person too is relative to the human community (Catechism #255). "The human person needs to live in society. Society is not for him an extraneous addition but a requirement of his nature" (Catechism #1879). Although I am reluctant to fully equate the triune relationship with human relationality, there is something to be learned from the communion of divine persons which is characterized by non-hierarchy, total equality, and mutual giving and receiving of love while preserving the self-differentiation that is necessary for distinct personhood (Rudman 181, 184).

Whether interpreting the *imago Dei* in the context of a rational soul, as the dignity of the whole human person, or as indication of the indwelling presence and extension of God, the Mishnah reveals a common implication:

> For this reason Adam was created as a single person, to teach you that anyone who destroys one soul is described in Scripture as if he destroyed an entire world, and anyone who sustains one soul is described in Scripture as if he sustained an entire world . . . . And to declare the greatness of the Holy One, praised be He, for a person uses a mold to cast a number of coins, and they are all similar to each other, while the Sovereign of all sovereigns, the Holy One, praised be He, cast each person in the mold of the first human being and none of them is similar to any other. Therefore each and every person must say: "For me the world was created." (Dorff 19)

We have traced the evolution of the *imago* doctrine noting an interesting shift from a purely biomedical/functionalist/rationalist perspective of imaging God and human personhood to a more holistic/biopsychosocial understanding that appreciates the complexity of being human. A contemporary reading of the *imago Dei*, in both Christian and Jewish traditions, appreciates human diversity and exalts every individual human being to infinite worth. The human person with advanced dementia, animated at creation by the very breath of God and cast in his image, is no exception. Not only are all humans considered worthy to image the divine, Christians are confident in proclaiming that we are loved enough to be called "children of God" (1 John 3.1). It is here that we may see how the antiquity of religion serves a particular benefit to pluralistic society. Meticulous contemplation and reflective development of the *imago Dei* by the various Judeo-Christian denominations over the course of many centuries has produced a record of ideological evolution that marks the transition from a highly exclusive understanding of the doctrine to an all-inclusive one. Secular theorists of personhood should question the motivation(s) behind this shift that has since engaged the Judeo-Christian traditions in bioethical deliberation and policy-making to vigorously promote and defend the inherent value of individual human beings, particularly the marginalized, as persons of unconditional dignity and with an inviolable right for care. This theology is easily identifiable in the CSHA report where selfless, altruistic, and self-sacrificing care of patients with dementia endures in spite of chronic health problems and depression.

Corpus et Anima Unus

The theology of the *imago Dei* looks beyond mere mental acuity and considers the full potential of the immortal soul as "the central locus of our relationship with God and of God's interaction with us" (McCurdy 85). As such, David Keck can indeed speak of the "passive-voice soul" of persons with dementia, which he describes "less as actor than as 'acted upon'" (qtd. in McCurdy 85).

The idea of the indwelling Spirit of God in the human person is common to all three faith traditions. The Qu'ran proclaims, "I have breathed into man of My spirit" (15.29). The Talmud counsels, "Let a man always consider himself as if the Holy One dwells within him" (Taanit 11b). The Hebrew Bible reminds that "the Lord God formed man from the dust of the ground, and breathed into his nostrils the breath of life" (Gen. 2.7). The New Testament professes, "I have been crucified with Christ; it is no longer I who live, but Christ who lives in me" (Gal. 2.20) and "do you not know that you are God's temple and that God's Spirit dwells in you? [. . .] For God's temple is holy, and that temple you are" (1 Cor 3.16-17). The Abrahamic traditions recognize that within the human body resides the living breath of God. In spite of the biological and psychological deterioration associated with neurodegenerative pathology, the soul remains bound to the body as its animating principle and serves as the centre of communication with the divine. Herein lies the sanctity of human life.

Gaudium et Spes discusses the human person as the union of body and soul that forms a single nature:

> Though made of body and soul, man is one. Through his bodily composition he gathers to himself the elements of the material world; thus they reach their crown through him, and through him raise their voice in free praise of the Creator. For this reason man is not allowed to despise his bodily life, rather he is obliged to regard his body as good and honorable since God has created it and will raise it up on the last day. (#14)

Created from the dust of the ground to image God and vested with the divine life breath, the human person is at once corporeal and spiritual. Endowed with an immortal soul created immediately by God, the human being "whole and entire is therefore willed by God" for its own sake and forged for eternity (Catechism #362, 366, 1703). It is important that separate attention be given here to the notions of body and soul in the context of the *imago Dei*. Although the Scriptures, at times, equate the "soul" to human life in general or to the entire human person, emphasis is on the soul as "the innermost aspect of man, that which is of greatest value in him, that by which he is most especially in God's image: 'soul' signifies the spiritual principle in man" (Catechism #363). The human body is raised to the dignity of "the image of God" because it is animated by a spiritual soul and "it is the whole human person that is intended to become, in the body of Christ, a temple of the Spirit" (Catechism #364).

John Paul II recognizes the body-soul nature of the human person as a central reality of existence which, incidentally, traverses the Abrahamic faith traditions. He describes this composite as follows:

> The biological nature of every human is untouchable, in the sense that it is constituent of the personal identity of the individual throughout the course of history. Each human person–in his or her absolutely unique singularity, is not constituted only by the spirit, but also by the body. Thus, in the body and through the body, one touches the person itself, in its concrete reality. Respecting the dignity of man consequently comes down to safeguarding this identity of man *corpus et anima unus* [. . .]. (Cataldo 22/3-22/4)

This non-dualistic understanding of the body-soul nature of the human person in Roman Catholicism, that at once resounds the Tannaitic teachings alluded to beforehand, may indeed be foreign to those scholars who have argued against the ostensibly dualistic reasoning of the Western religions. Further, it is "in the body and through the body," vested with the spiritual principle, that "one touches the person itself." This is reminiscent of our discussion on the sociology of the body, the ethics of context, and dementia care which identified a more holistic sense of the human person as the complex interaction of biological, biographical, psychosocial, and spiritual being. It is in and through the ageing body with dementia, as Kitwood has previously argued, that we might find ways to preserve personhood. Far from the narrow understanding of the body as an exclusively biological entity, the religions approach personhood through the body-soul composite that is unique to the human condition.

Cupio Ergo Sum

David Novak offers an interesting alternative to the Cartesian equation of being with thinking:

> Ultimately, we affirm the worth of every human person because we believe somehow or other that we are all the objects of God's concern. To apprehend that concern and Who is so concerned for us is the desire of all desires. That desire is so powerful, so urgent, that we cannot suppress it to wait for confirmation of the reality of its goal, to wait for the truth of the Subject of that concern to be revealed to us. It is, indeed, the greatest proof of our own unique existence as humans. (1998, 172-173)

Novak advocates a different axiom: *cupio ergo sum* ("I desire, therefore I am") (1998, 173). We are left, however, to deliberate how applicable this alternative is to the context of dementia. Just *what* is it that desires? Is it the rational human mind? Is it the human soul? Is it some combination of these that together desire God and apprehend his concern for creation? Can only a rational being desire? Where does this exchange between our desire and God's concern play out?

The emphasis here is on a God who relates both communally and individually. "[O]ur desire to apprehend this concern is the epitome of our existence as communal beings," Novak admits, "[o]ur desire can only be answered in the company of those whose desire is for it with us. Only in human community can we properly wait for God" (1998, 173). Is it enough that the patient with advanced dementia belongs to a community that waits *with* and desires *for* those who cannot articulate this desire? Or, is the desire to apprehend God's concern for humankind intrinsic to the souls of his creation? Does the Spirit, or breath, of God given at creation long for reunion with its source? If we answer these in the affirmative, then we are confident that the level of human functioning and rationality is irrelevant to this discussion.

David Keck defines the soul as "the central locus of our relationship with God and of God's interaction with us" and as that which is "less as actor than as 'acted upon'" (qtd. in McCurdy 85). Neither diminished rationality, nor reduced capacity for speech, nor death, "nor life, nor angels, nor rulers, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation, will be able to separate us from the love of God" (Rom. 8.38-39). In the paradigm of advanced dementia, the soul, as that which is acted upon, is significant. McCurdy brings forth the mystery of how God, through the means of community, sacraments, prayer, and grace, for instance, often (but not exclusively) works "in our unconscious or affective life without our self-conscious or rational awareness of their presence or effects" (85).

Indeed, Novak correctly argues that "to regard any human person as anything less than the object of God's concern is to fundamentally deny the true intention of his or her existence [. . .]" (1998, 173). In light of this argument and in retrospect of our discourse on dignity, createdness, and communion, it seems fitting to properly reinterpret Novak's claim in the context of McCurdy and Keck's analyses as, "I am the *subject* of God's concern, therefore I am." In accordance with the common religious attitude of love-for-neighbour, the person with dementia, who in essence is the subject of God's concern, is also, by extension, the subject of human concern. In this, we see, yet again, motivation to recognize in the dementia patient as person an inherent dignity and worth; he or she is a subject, as opposed to object, of biographical life and of ultimate, even divine, interest.

"Am I My Brother's Keeper?" The Social Commitment of Agapaic Love

The prophet Jeremiah proclaims the covenantal relationship that is central to Judaism: "They shall be My people, and I will be their God" (Jer. 32.38). Although covenant can be understood as a contractual agreement between two parties having mutual obligations, the notion of covenant in Jewish law is more accurately described as a loving relationship between Yahweh, the Lawgiver, and his chosen people (Deut. 7.6-11). The covenant relationship focuses on the reciprocity of agreements and promises in this mortal life and, hence, there is less emphasis on the life to come:

> This day the Lord your God commands you to observe these statutes and judgments; therefore you shall be careful to observe them with all your heart and with all your soul. Today you have proclaimed the Lord to be your God, and that you will walk in His ways and keep His statutes, His commandments, and His judgments, and that you will obey His voice. Also today the Lord has proclaimed you to be His special people, just as He promised you, that you should keep all His commandments, and that He will set you high above all nations which He has made, in praise, in

> name, and in honor, and that you may be a holy people to the Lord your God, just as He has spoken. (Deut. 26.16-19)

Ramsey, Barth, and Novak confirm covenant-fidelity as "the inner meaning and purpose of our creation as human beings" (Ramsey xii). As such, both Jewish and Christian perspectives on personhood must be articulated in the context of communal and covenantal ethics.

Halakha, as the collective of Jewish tradition, law and custom, is rooted in the fundamental concept of *berit*, or "covenant." Dorff, in his discourse on covenant as "the transcendent thrust in Jewish law," brings to the fore a well-balanced argument defending and questioning the Covenant model (Dorff and Newman 59-78). Although Dorff discusses covenant in the context of legal theory, using to some extent the language of contract, he makes it very clear that this model stresses a central tenet unique to *halakha*: the relationship between God and the Jewish people. I will dwell here, albeit briefly, on the notion of reciprocity in this covenantal relationship, which Dorff, too, deliberates to some end.

Reciprocity and mutuality are significant to a discussion of a people bound by covenant; secular theorists will recognize these as familiar markers of legal contracts. It is plain to me that both the Ancestral (through Abraham) and Sinai (through Moses) covenants require some commitment on part of the people (circumcision and observance of *Shabbat*, for instance, respectively). However, the Noahide covenant, also called the Primeval covenant, is peculiar in that it (1) establishes a binding relationship between God and the whole earth (not just humans), and (2) places exclusive responsibility on God who promises never again to destroy creation by deluge. There is no indication of reciprocal loyalty and the totality of the created world (as the second party of the covenant) is, thus, described as a collective, passive recipient of God's pledged unconditional preservation (Bandstra 43). It is important to note that the Noahide covenant binds all living creatures, regardless of capacity for rationality or self-consciousness; *all* life is the passive subject of God's concern. This unilateral feature, as we shall see, is relevant to our study of relationships, which include a person with advanced dementia who often seems inert or unresponsive to this end.

The Primeval covenant, although lacking in reciprocity, builds the foundation of relationships: between a God who loves and a people who stumble in returning this love, between a God who loves and the animals who "know and follow the rules that God has set for them," as well as between humanity and the rest of the created world (Dorff and Newman 64). It is in the forging of these relationships prior to, and in the framework of, the first covenant that we are introduced to the notion of stewardship. Daniel Swartz describes this "moral category" as a covenantal trust in which humans function in the context of particular relationships: as tenants with the earth, as children of God, and as kin with all humankind (Gottlieb 100-101). It is God's unilateral and unconditional promise, without direct command for particular conduct, that brings about an obedience of the people out of love for God, strengthened in the subsequent covenants, which finds itself at the heart of *halakha.* It is within this context that we see the confluence of the major cornerstones of Christian and Jewish bioethics (dignity of humankind by virtue of createdness in the image of God, duty to heal and preserve life, and the importance of relationships, in particular) to elevate the person with advanced dementia to a being worthy of dignity and care.

The Primeval covenant as described here is far from congruent with legal notions of contract where both signing parties have obligations that must be upheld lest one party be reprimanded, in some way, for not having complied with the promise. Accordingly, it is appropriate to introduce here the Christian notion of *agape*, a selfless form of love whose expression demands no response. The altruistic, unreciprocated, unconditional, sacrificial, and transcendental love of *agape* is distinct from the physical love of *eros*, or the platonic love of *philia*, or even the instinctual and familial affection of *storge*. Here, the New Testament suggests concern for the well-being of another (even a stranger) at the expense of, if it so demands, one's own well-being. The patterns of dementia care identified by the CSHA are a clear manifestation of the social commitment of agapaic love.

St. Paul exalts agapaic love as highest of the divine virtues:

> If I speak in the tongues of men and of angels, but have not love, I am only a resounding gong or a clanging cymbal. If I have the gift of prophecy and can fathom all mysteries and all knowledge, and if I have a faith that can move mountains, but have not love, I am nothing. If I give

> all I possess to the poor and surrender my body to the flames, but have not love, I gain nothing. Love is patient, love is kind. It does not envy, it does not boast, it is not proud. It is not rude, it is not self-seeking, it is not easily angered, it keeps no record of wrongs. Love does not delight in evil but rejoices with the truth. It always protects, always trusts, always hopes, always perseveres. Love never fails. [. . .] And now these three remain: faith, hope and love. But the greatest of these is love. (1 Cor 13.1-8, 13)

Agape demands that Christians image their God's munificent, endurant, and unconditional love by extending this love without return; it is a one way love that is "not contingent on response or results" and is at the heart of the Christian commitment to social justice (Groome 222). It is clear, from this particular perspective, that relationships between persons do not exist pending mutual responsibility, concern, and love. Dissolution of the social bond does not occur if mutuality ceases to be characteristic of the relationship. Indeed, *agape* requires active caregiving (a form of this selfless, sacrificial, unreciprocated love) especially when a patient seems passive in his or her reception of this care. It is this form of love that motivates the caregiver whose concern for the dementia patient necessitates, as the CSHA and numerous other studies show, self-sacrifice in spite of the fact that the recipient of such care may not possess the capacity to express appreciation or gratitude. In this, we may also find the notion of the *imago Dei* and the inherent dignity, value, and worth of all human persons without distinction (Lev. 19.34; Rom. 10.12; Luke 10.33; Matt. 5.23; Matt. 5.44).

We have already discussed how human persons, by their innermost nature, are social beings who must enter into relationship with others to live (Paul VI, Gaudium #12). The first Christians practiced communal ethics with a primary concern for "relationships, both vertical and horizontal, that is, with God and with one another" (Bohr 53). Evangelium Vitae gives context to this discussion on dignity, relationality, and the dynamic of human life:

> Man is called to a fullness of life which far exceeds the dimensions of his earthly existence, because it consists in sharing the very life of God. The loftiness of this supernatural vocation reveals the greatness and the inestimable value of human life even in its temporal phase. Life in time, in fact, is the fundamental condition, the initial stage and an integral part of the entire unified process of human existence. It is a process which, unexpectedly and undeservedly, is enlightened by the promise and renewed by the gift of divine life, which will reach its full realization in

> eternity (cf. 1 Jn 3:1-2). At the same time, it is precisely this supernatural calling which highlights the relative character of each individual's earthly life. After all, life on earth is not an "ultimate" but a "penultimate" reality; even so, it remains a sacred reality entrusted to us, to be preserved with a sense of responsibility and brought to perfection in love and in the gift of ourselves to God and to our brothers and sisters. (John Paul II 1995, #2)

The gift of life, then, transcends time and space: "For God created man for incorruption, and made him in the image of his own eternity" (Wisd. 2.23). The concept of human personhood, Keyserlingk concludes, "is more than capacities or qualities limited by time and space; it is a transcendent concept and not merely an empirical one" (103). Minimally, he looks to the notion of "being in relationship" with others (and with God) as that which gives life its meaning and purpose (Keyserlingk 103).

"Am I my brother's keeper?" (Gen. 4.9). In theory, people of the covenant, as beings in relationship, must *answer* resoundingly and unconditionally in the affirmative. In praxis, hundreds of thousands of dementia caregivers in Canada, in spite of risks to health, *act* in the affirmative.

Sanctity of the Human Soul

It is clear that, like Judaism, no one voice speaks for Islam. Islamic ethics are casuistical and paradigmatic cases are as significant as principles (Brockopp 218). Regardless, one cannot disregard application of certain basic principles that guide deliberation and action. While concerned for community welfare and for the respect and dignity of human life, tenets of Islam principally rest on the sovereignty, omniscience, and transcendence of God to whom none can be likened. First and foremost, "Muslims acknowledge the hand of God in all their doings" (Brockopp 60-61). To make this very clear, the Qu'ran insists that God is involved, as Creator, at *every* stage of human development (not just after the being is vested with a soul) (80.16-23). In the *Kitāb al-durra al-fākhira*, al-Ghazali affirms the value of potential human life by claiming that "even when the soul is lifeless, the divine nature of the soul keeps the body from decomposing until God breathes his spirit into it" (Brockopp 63). Although concern here is for the potential of *foetal* life, it is plain to see that the divine nature of the soul and the indwelling Spirit of God are what accord human life its value. That is, in Islam, it is incorrect to speak of the inherent worth of persons or for us to question the worth of another's life. The value of human life is contingent on God alone and it is "valuable because it is a trust (*amāna*) from God" (Brockopp 179). This, of course, speaks true of the person with advanced dementia who, though lacking in rationality and self-consciousness and, hence, is reduced in legal capacity, is never devoid of his or her soul; the human person continues to be animated by the divine breath regardless of how inanimate he or she has been made by illness and suffering. Birgit Krawietz reminds that the majority of Islamic scholars uphold "the underlying traditional *concept* of death as the departure of the soul (*rūh*)" (Brockopp 194-195). The duty to respect and preserve human life in Islam, then, is rooted in its divine authorship (Brockopp 16). Created by God and animated by his divine breath, human life is dependent upon the Creator and is, in its entirety, "a right shared between the Creator and His creature so that it cannot be disposed of by the consent of the creature" (Brockopp 197).

An Islamic discussion of personhood must account for juridical perspectives. Personhood discourse in Judaism and Christianity that emphasizes the createdness of humankind as (or in) the image of God would constitute *shirk* in mainstream Islam: the denial of the oneness of God. Instead, the legal dimension of Islam stresses the sanctity of the human soul as integral to any discussion of the human person. Indeed, it is important to note that Islamic law recognizes the human being as endowed with a soul, and thus with the legal capacity of a person, at 120 days following conception (Musallam 57-59). The equation here of ensoulment, or possession of a soul, with human personhood is significant. Of equal importance is the inseparability of this soul from the body, which itself is vested with sanctity (*ḥurma*) and dignity (*karāma*) in light of the anticipation of corporeal resurrection (Brockopp 196, Cahill and Farley 38). As a result, the human person with dementia, as a body-soul composite, must be tenderly cared for until the moment *after* death when the body is interred.

In Islamic intellectual thought, the capacity for reason distinguishes humankind from the rest of the created world; it is through use of this faculty, considered a gift of the divine, that humankind may come to know God (Koslowski 107-108). Accordingly, Rahman reminds that with loss of mind comes loss of honour and that "once a person's reason is lost his or her humanness is lost" as well (101). As a result, great attention in

Islamic law is paid to those who suffer mental disorders and cognitive impairment (Rahman 70, 101). This rather Aristotelian regard for the human person as a rational animal is in need of some clarification. Indeed, I can only guess that Rahman's incentive to equate the loss of reason with the loss of humanness is inspired by the timeless argument, which remains a central theme in the Peripatetics of the Islamic philosophical tradition, that identifies rationality as *the* feature which distinguishes humankind from the rest of the created world (Koslowski 108). In this regard, the concern is not about questionable personhood, but is more the disassociation of the non-rational from the species altogether. Juridically, the matter is whether the person with dementia is capable to consciously intend the observance of Islamic law.

Ibn Sina, known in the West as Avicenna, whose prominent influence on Islamic philosophy is likened to none other than that of al-Fārābī and Aristotle, discusses this issue in a more elaborate fashion and I turn to his Métaphysique du Shifā' for counsel to this end. In the ninth book, Avicenna deliberates the fate of the souls of the non-rational (which he calls "les âmes sottes" or "imbeciles") in the hereafter: "Quant aux âmes sottes qui n'ont pas acquis le désir [de leur perfection], quand elles se séparent du corps, et qu'elles n'ont pas acquis les dispositions mauvaises, elles se trouvent au large devant la miséricorde de Dieu et dans une sorte de repos" (164). We are left, from this passage, with the impression of a wideness or boundlessness of God's mercy that will certainly accommodate even those marked by cognitive incapacity. I agree with Michael Marmura who interprets Avicenna, in this regard, as recognizing that while some human beings lack certain capacities, particularly concerning rationality, they remain persons worthy of standing in judgment before a merciful God (e-mail to the author). As a result, the absence of the mental faculty is clearly not a measure of the sanctity of the soul, which, in turn, is indicative of human personhood.

Further, in the tenth book, Avicenna puts forth the correction of a popular stream of thought which threatened those whose likelihood of restored health was dismal: "Certains ont pensé qu'il fallait tuer ceux qu'on désespérait de guérir. Cela est mal. Car leur subsistance ne porte pas préjudice à la cité. Si des hommes semblables ont des proches qui ont du superflu, on leur imposera de les prendre en charge" (182). Avicenna rebukes the community for having identified persons with incurable illnesses as burdens on society, as some would have it, in need of prompt removal and isolation. Instead, he charges the people to care for and attend to those whose lives *seem* superfluous under the strains of disease; this is in accordance with the teaching of the value of life as contingent on God, not on humankind. Illness, in this context, is a communal experience in much the same way that it is in both Jewish and Christian traditions. "Implicit here," Marmura correctly argues, "is an indication of the value of life, that is the life of a human, of a person" (e-mail to the author).

The concern for ill persons and the fascination with illness experience, alluded to by Rahman and Avicenna, requires further attention here. Valerie J. Hoffman discusses how, according to Ḥadīth proper, Muhammad declared that death due to certain diseases, such as the plague or stomach troubles, was akin to martyrdom (Cahill and Farley 42; Rahman 46). This redemptive effect of illness is accentuated in the genre of prophetic medicine literature in Islam, primarily regarding the works of al-Dhahabī, which has generalized this Ḥadīth to suggest that death by *any* illness confers the status of martyr (Rahman 46). Muhammad is recorded to have commented in this way: "I find strange on the part of a man of faith that he should grieve at his ailment; if he knew what [goodness] is in his illness, he would love to be ill until he meets His Lord" (Rahman 46). Although we are left questioning whether or not an *advanced* dementia patient can actually grieve his or her illness (it is clear that persons in early and intermediate stages of neurodegeneration do), there is some consolation here to AD sufferers in the belief that current illness (regardless of one's ability to "grieve at his ailment"), and the experience of declining rationality to come, are not had in vain. In fact, these experiences are not only considered meaningful, but may indeed be elevated, as Rahman alludes, to the sacred domains of martyrdom, righteousness, and spiritual encounter. However, it must be said that the fruits of illness discussed here do not imply the abandonment of medical practice. Indeed, Rahman warns that we must be careful not to read such Ḥadīths outside of their historical contexts and neglect others which may seem contradictory (47). Good health, the Islamic tradition maintains, is considered God's blessing; one must strive for its preservation and attend to treatment in ill-health (Rahman 47-49). Either way, the experiences of health and well-being, as well as illness and suffering, are all vested with meaning.

I would like to conclude here with an alternative perspective of personhood which departs, on many fundamental levels, from orthodox Islam. Aminrazavi reminds that in Sufism, the mystical dimension of Islam which embraces the Qur'an and the bulk of Shi'a and Sunni beliefs, humans are considered extensions of God much in the same way as taught by the Tanna'im (Koslowski 109). "Metaphysically," Aminrazavi writes, "man is a theophany, who carries the divine gift or collateral (*al-amanah*) and through whom divine names and qualities manifest themselves" (Koslowski 109). The Sufi interpretation of *tawhid* describes the human person, "who comes from God," as "divine in some sense of the word, and divinity participates in him" (Koslowski 109). Aminrazavi discusses the Sufi understanding of the human being in this way: "God is the sun, from whom all light and love emanates, and man is the moon, within which divine light is reflected" (Koslowski 109). It is in the context of this receptivity of the human person to God that we can speak of the Sufi understanding of human beings, particularly in regard to the Sufi gnostic interpretation of *rūh*, as the images of a God (*khalaqa-llahu adama ala suratihi*) with whom they are in constant relationship.

Sufis strive for the ultimate state of selflessness (*fana'*) "in which the ego has vanished and has been replaced by God" (Koslowski 110). The human purpose is for unitive life in God, which can best be explained as the intentional loss of one's sense of a self that is separate from God, and to be absorbed into his knowledge to the extent that no distinction remains between the consciousness of God and the human person. Here, the desire to shed one's self is completely contrary to the efforts of Western academics who strive to preserve this sense in dementia. Instead, the patient with dementia, who is nearing the end of life and, hence, drawing closer to full equation with the Sacred, is to be cared for with a certain degree of reverence in light of this mystical union. Although many of these tenets in Sufism are unacceptable, even heretical, to orthodox Islam, which would undoubtedly claim this hermeneutic to constitute *shirk*, the notion of giving human existence a transcendent dimension reveals yet another common element with Judaism and Christianity. The intent here is to move the human person beyond functional and materialist ideologies.

The Religious Maintenance of Culture

Laurie Zoloth concludes her text on the role, place, and contribution of religion to bioethics with the very same question that motivated its compilation: "Of what *use* is religion?" (Davis and Zoloth 278). What are these religious attitudes of which Hauerwas speaks as necessary for maintaining our culture? Zoloth brings our discussion neatly to a close by offering a modern response to this rather modern question:

> Possible candidates for utility include the need for cultural coherency; the need for obligation beyond the frailty of romantic love; the regard for the stranger; the strength of communities of resistance; and the notion, first carried by science–but now, ironically, far more profoundly carried by faith-of deep skepticism in the givenness of modernity. There is more. There is the way that religion, because of the resistance community, not only resists triviality and the ugly, mundane banality that surrounds us, but offers a serious challenge to evil in the [world]; religion is not ashamed of seeing evil, naming it, and struggling to oppose it. And, not every time, but very many times in the last 2,000 years, it has been named as evil to oppress the vulnerable, to harm the widow and the orphan and the stranger. (Davis and Zoloth 278-279)

Indeed, we have discussed the religious teaching and practice of selfless agapaic love and of recognizing, and bringing to the public forum, the social injustice of stigmatizing patients with dementia as nonpersons and marginalizing them from the community of "capable" persons. We have explored how the religions strive to protect, defend, and promote patients with dementia as beings of moral worth, dignity, and value. As we have seen, Canadian caregivers join the religions in arguing that we must no longer tolerate the ageist categorization of patients with dementia as the "hopelessly senile," the "human vegetable," the "living dead," the "severely retarded," or the "human imbecile," but, instead, acknowledge them as living human persons who have authored, and continue to author, life narratives replete with biographical, psychosocial, and spiritual dimensions. We have the opportunity in the closing chapters of these life narratives to serve as co-authors. The question we must ask, then, is not how or why religion contributes to bioethical discourse, but, on a more personal note: how shall we live? (Davis and Zoloth 279).

Epilogue

The transdisciplinarity of bioethics offers wonderful opportunity and resource for contextual deliberation. Indeed, policy and bioethical decision-making cannot be conducted if we adhere to a neutral posture toward the question of personhood. Sidestepping the issue and neglecting to address the centrality of the human person, who is the principle and subject of bioethics, necessarily risks the protection of certain categories of human beings whose full-fledged membership in the community of persons is under dispute. That is, if we are to preserve a person-centred morality, we must be judicious in our unauthorized power to award, sequester, and abolish personhood according to ambiguous standards of what is judged necessary and sufficient for its definition. As we have seen, functional theories of personhood operate on an all-or-none principle that fails to account for the complexity and diversity of human experience. Hypercognitive hubris has led to the reduction of human personhood to a mere category, defined by *omni-competent* persons in terms of rationality and productivity, to which those of questionable or incomparable function cannot belong. There is a growing trend in bioethics, however, to move from exclusive reliance on the body, its genetics, functions, and processes to the appreciation of the biographical, psychological, social, and spiritual dimensions of human life as essential features of personhood. Here, we observe a shift from the biomedical model, which has dominated the art and science of medicine for centuries, to the more holistic and integrative biopsychosocial model of conceptualizing health and illness, which compels recognition of complexity and interaction.

In this brief account marking only few of the challenges posed by the experience of neurodegenerative illness, contextualization becomes integral for personhood, which can be preserved in advanced dementia through relationality. The secular arguments of Lyman, Kitwood, Sabat, and McCurdy, for instance, defend the abiding dignity of patients with advanced dementia regardless of the presence or absence of certain capacities otherwise deemed vital to functional theorists. The tendency here is to move beyond a purely functional understanding, to invest the human person with transcendence without arguing the metaphysical, and to call for treatment of advanced dementia based on personhood.

Habermas, the atheist philosopher, ushers in a "postsecular" society that recognizes the continuing significance and ability of the religious traditions to contribute to, or perhaps even shape, public discourse. The religions, he argues, have an incomparable capacity, forged over centuries of practice, for the articulation of self-understanding and human meaning. Religious wisdom addresses issues of existential interest such as the nature, meaning, and purpose of life; suffering, health, medicine, and death in the context of a broadened sense of human existence that includes eschatology, soteriology, and non-linear thinking; as well as the ministry to the ill and dying, the covenantal nature of relationships, and the community of care, which far too often occupy only the fringes of bioethical discourse.

The Abrahamic faith traditions, as we have seen, raise human beings with dementia, by virtue of their createdness, the indwelling breath of the divine, and the soul, to the status of persons with an incalculable worth contingent on God. Further, William E. May reminds that "we achieve such elevation with the help of the human community, the community of our fellow words, which, first of all, *lets us be* and then *enables* us to be ourselves. Thus, our existence as human beings is meant to be not only a being *with* others, a coexistence, but, more importantly, a being *for* others, a 'for-existence.'" (6). Christianity, Islam, and Judaism compel the protection and accompaniment of persons with advanced dementia whose experience becomes one of increasing powerlessness, limitation, marginalization, and stigmatization.

It is not only the accessibility and appeal of the language of religious social and moral teaching that influences postsecular ideology, but also the effective translation of faith into action by, and within, religious communities that informs general praxis. Patterns of dementia care and the self-sacrifice of caregivers, reported by the CSHA, strongly suggest that patients with dementia are valued as persons who are identified, at least in part, in terms of relationality. The relationship between a patient with dementia and his or her caregiver need not be characterized by the mutuality or the anticipatory reciprocal gain typical of contract. Rather, the unconditional and selfless love of *agape* is evident in the sizeable caregiving population which suffers depression and other chronic health conditions as a result of maintaining this relationship modelled after the Primeval covenant. In addition, the mandate of charitable organizations, such as the Alzheimer Society of Canada, to defend and promote persons with dementia and attend to the caregiver-patient bond, is more compatible with religious understandings of the human person rather than the perspectives of functional theory. While functional theorists would judge such patterns of dementia care to be supererogatory, religious ideology and popular praxis suggest that the respect, concern, and efforts accorded to patients with dementia through self-sacrifice and enduring care is nothing more than an expected human response to human persons in need.

As such, the biopsychosocial model of interaction is a contextual one that invites discourse from the various disciplines (law, gender study, philosophy, medicine, religion, and culture studies, to name a few) and provides a narrative framework that draws our attention, sharpens our moral sensibilities, brings us to analogy and participation in the story, invokes our analytical power, and summons an interest in careful application.

With these final words, we are left with multiple challenges. First, there is a need to redefine certain moral principles, such as autonomy, within the context of the community of persons. Instead of heteronomy, the Kantian term describing the source of determination of value being outside of the self, I propose "koinonomy," drawn from the Greek κοινωνία for community, close relationship, and participation, as to raise the decision-making process out of isolation. That is, moral calculus must derive from the cooperative effort of both the subject (or proxy if so appointed) and his or her immediate community. There are, of course, other matters that require our prompt attention: exploring new means of communicating the subjective experience of non-verbal dementia, extending dignity and a sense of meaning to those unduly categorized outside the moral realm, and appreciating that the complexity of personhood and the experiences of consciousness, sentience, memory, and spirituality cannot adequately be captured by functional definitions which disregard the psychosocial, biographical, and spiritual dimensions of life altogether. Furthermore, we are called to include an ethic of context, not simply in our records of bioethical theory *per se*, but, rather, embraced within each ethical framework for the creation of a *shared* narrative in which even persons with advanced dementia will have a significant part. Fostering effective dialogue between secular and religious ethics is fundamental to such a narrative; if we are to meet a challenge as critical as deciphering the very meaning of *person*, we must move beyond their surface tensions to access the depths of human wisdom.

We must be satisfied, for the time being, with guidelines *toward* a more integrative definition of personhood rather than a definition itself. Until we have contentedly explained the complexity and mystery of unconscious experience, pain and suffering, memory access, and rationality in "indisputable" persons, and subsequently understood these experiences in the multidimensional context of non-verbal advanced dementia, only then can we even begin to fathom a satisfactory definition of person that will indeed account for the evolution and diversity of *being*.

Notes

[1] Kenneth L. Vaux, in his Death Ethics, argues that inasmuch as moral *situations* are complex and polyfactoral, so, too, is moral *reality* as "that normative bedrock that yields knowledge of right and wrong" (ix). Vaux defines nine dimensions of this reality and categorizes them into three groups: naturalistic (ecologic, biologic), rationalistic, (psychologic, politic, philosophic, historic), and theistic (theologic, apocalyptic, eschatologic) (ix).

[2] In "Biotechnology at the Margins of Personhood: An Evolving Legal Paradigm" in the March 2003 issue of the Journal of Evolution and Technology 13.1, Linda MacDonald Glenn searches for evolving ethico-legal notions of personhood in the context of rapid technological progression (with special attention given to transgenics, chimeras, and artificial intelligence) and lagging legal perspectives of personhood. In "Tracing the Soul: Medical Decisions at the Margins of Life," in Christian Bioethics 6.1 (2000): 49-69, Walter Glannon identifies the soul with the capacity for consciousness and mental activity. He argues that while patients "at the margins" (that is, those who either never have had or have lost the capacity for consciousness and mental life) do not have moral status, they do have moral value as forms of God-given biological life.

[3] See Statistics Canada <http://www.statcan.ca>.

[4] Differential diagnosis refers to the systematic method of diagnosing a disorder that lacks *unique* signs or symptoms. There is significant overlap of signs and symptoms between the different dementias; neurological and histopathological features characteristic of AD are by no means pathognomonic of the disorder (Morris 29). Coffey and Cummings, in their Textbook of Geriatric Neuropsychiatry, argue that it is difficult to determine the exact prevalence of the disease because: (1) death certificates of patients suffering from end-stage AD record *infection* as cause of death, and (2) there is marked misdiagnosis of AD especially with patients actually suffering from frontotemporal disease, Lewy body disease, Parkinson's disease, and vascular dementia (512, 514).

Nosological fusion (or nosological *con*fusion) refers to the phenomenon of bringing together diagnostic categories that would otherwise be seen as distinct.

[5] The terms "formistic," "mechanistic," "contextual," and "organistic" are used here according to Gary E. Schwartz's appropriation of S. C. Pepper's four ways of looking at nature (as outlined in World Hypotheses, Berkeley: U of California P, 1942). Schwartz applies these categories to health and illness in his "Testing the Biopsychosocial Model: The Ultimate Challenge Facing Behavioral Medicine?" in the Journal of Consulting and Clinical Psychology (1982) 50.6. In brief, Schwartz explains that: (1) "things and processes," in formistic thinking, "are presumed to be part of certain categories and not part of other categories;" (2) "things and events," in mechanistic thinking, "are presumed to occur as a result of specific, single causes or as chains of single causes;" (3) contextual thinking is relational and appreciates that phenomena in nature "always depend on the context in which they exist as well as the context of the observer;" and (4) organistic

thinking is interactive and presumes that unique events "emerge as a result of the interaction of multiple causes" (1041-1043).

[6] See Mary Anne Warren's discussion "On the Moral and Legal Status of Abortion" in volume 57 of The Monist (1973): 43-61.

[7] Georg Northoff raises the question of whether personal identity might be altered through brain tissue transplantation. Refer to his article in the Journal of Medical Ethics 22 (1996): 174-180.

[8] Reference here is made to Charles Darwin's description of non-verbal pain communication in The Expression of the Emotions in Man and Animals:

> When animals suffer from an agony of pain, they generally writhe about with frightful contortions; and those which habitually use their voices utter piercing cries or groans. Almost every muscle of the body is brought into strong action. With man the mouth may be closely compressed, or more commonly the lips are retracted, with the teeth clenched or ground together. There is said to be "gnashing of teeth" in hell; and I have plainly heard the grinding of the molar teeth of a cow which was suffering acutely from inflammation of the bowels. The female hippopotamus in the Zoological Gardens, when she produced her young, suffered greatly; she incessantly walked about, or rolled on her sides, opening and closing her jaws, and clattering her teeth together. With man the eyes stare widely as in horrified astonishment, or the brows are heavily contracted. Perspiration bathes the body, and drops trickle down the face. The circulation and respiration are much affected. Hence the nostrils are generally dilated and often quiver; or the breath may be held until the blood stagnates in the purple face. If the agony be severe and prolonged, these signs all change; utter prostration follows, with fainting or convulsion. (69-70)

[9] See Feldt, Warne, and Ryden's article, in the Journal of Gerontological Nursing 24.11 (1998): 14-22, for an interesting discussion of aggression in advanced dementia as non-verbal means to communicate pain and discomfort.

[10] This debate concerning personhood at the margins often brings to the fore similar points of argumentation in the context of abortion, permanent unconsciousness, PVS, and advanced dementia. The notion of potentiality is typically applied to beginning-of-life issues or to cases where functional restoration is possible. Whereas one can claim the potential personhood of a foetus (or even of the zygote) because normal development includes the acquisition of self-consciousness, rationality, memory, and other functions thought essential to personhood, the experience of neurodegeneration is irreversible and, as such, involves the gradual loss of these capacities along with personhood. There is extensive writing concerning the notion of potentiality. Refer to H. Tristram Engelhardt, Jr.'s Foundations of Bioethics (110-123) and James W. Walters' What Is a Person? (62-68) for good synopses.

[11] Refer to Parfit's discourse on psychological continuity in his influential Reasons and Persons (204-209).

[12] Although Singer attempts to make plain the relationship between person and nonperson in the ethic he advances, actual praxis (as brought to the fore by Michael Specter) conflicts with his ideology. See Stanley Hauerwas' "Must a Patient Be a Person to Be a Patient? Or, My Uncle Charlie is Not Much of a Person But He is Still My Uncle Charlie" in Lammers and Verhey's On Moral Medicine (278-281).

[13] Engelhardt provides a good discussion of sleep, potentiality, and embodiment in the context of this sense of person, unifying continuous and discontinuous experiences into *one* life. Refer to his Foundations of Bioethics (121-123).

[14] See, for instance, Andrew D. Firlik's description of 55 year-old Margo (a patient with Alzheimer's disease who delights in the moment) in his brief write-up in the Journal of the American Medical Association 265.2 (1991): 201.

[15] Singer gives separate philosophical treatment to voluntary, nonvoluntary, and involuntary euthanasia in his Practical Ethics (176-181) and explains why he thinks the first two forms are justified while the last is not (181-213).

[16] See Kitwood's article in the Journal of Clinical Ethics 9.1 (1998): 23-34.

[17] Refer, in particular, to the studies conducted by M. Baumgarten et al., A. Jackson et al., J. K. Kiecolt-Glaser et al., M. M. Neundorfer, S. H. Parks and M. Pilisuk, as well as R. Schulz and G. M. Williamson.

[18] Refer to the Caring for Someone With Alzheimer Disease? Take Care of Yourself Too! pamphlet produced by the Alzheimer Society of Canada.

[19] See Singer's article in John Ladd's Ethical Issues Relating to Death (41-61).

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