

**Phenomenology of Pain and Suffering at the End of Life:  
An Ethical Perspective in Gerontological Social Work**

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## **Abstract**

This paper examines the phenomenology of pain and suffering and the fundamentally social nature of dying for persons at life's end. The paper focuses on three concerns for practice with older adults in gerontological social work: to develop a phenomenological account of pain and suffering; to determine what phenomenology can tell us about the ethics of end-of-life decisions; and to determine whether phenomenology can provide an account of the essence of the experiences of pain and suffering that is pragmatic for social work practice with older adults. Particular attention is given to understanding the relationship between pain and suffering in the phenomenological account. Oral history data from interviews with an older adult suffering from advanced chronic illness are analyzed. Levinas's ethical philosophy and conceptualizations of the non-totalizing relation of self to other, infinity and radical passivity, are employed in this paper to help reframe an approach to the ethical relation and the nature of obligation in end-of-life care, specifically with reference to the phenomenology of pain and suffering and their meanings in an intersubjectively experienced world. Differences in Husserl's account of the other and alterity in Levinas's ethics are explored and explained in the context of phenomenology as a descriptive science that respond directly to the concerns of the paper.

## **Introduction**

A central concern for social workers, psychologists, physicians, nurses, chaplains and other members of the health care team practicing in interdisciplinary hospice and palliative end-of-life care is the pain and suffering of persons facing advanced, life-limiting and terminal illness. This is especially a concern for older adults, many of whom may face declining health, disabilities and dementia as they age and who may be unable to communicate about their illness experiences and end-of-life wishes. There is increasing interest among policymakers, practitioners and researchers in broadening understanding of the meaning of lived through pain and suffering experiences of persons for whom death looms on the horizon, whether imminently or in an indeterminate future (Kramer & Bern-Klug, 2004). Recent research evidence suggests that pain and suffering, while recognized as distinct phenomena (Cassell, 1982), are both multidimensional in nature and may include biological, cognitive, emotional, spiritual and cultural experiences, not only for the solitary subject who may be dying, but for significant others in that person's life including family, caregivers and members of the health care team (Altilio et al., 2006; Kramer & Bern-Klug, 2004). This paper examines questions of pain and suffering for older adults from an interdisciplinary perspective at the intersections of health law and policy, and social work research and practice.

The prevalence of pain and suffering among older adults and other vulnerable populations calls for a stronger focus by social workers on a palliative ethic of care (Fins, 2006) that responds to the burden of pain and suffering for individuals, their families and communities consistent with principles of justice across cultures (Sulmasy, 2003). Social workers have not had a long history of involvement with palliative care as a discipline and lack formal training in the discipline (Altilio et al., 2006). An ethic of care that is palliative is by definition, person- and

family-centered, interdisciplinary, and aimed at encouraging conversations with loved ones about end-of-life care choices, values and treatment preferences, empowering individuals to exercise their right to refuse excessively burdensome and invasive medical interventions that may provide little or no benefit or comfort to the patient. The National Consensus Project for Quality

Palliative Care defines the goal of palliative care as follows:

...to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. (NCP, 2004, p. 6).

These goals are consistent with the goals of the social work profession, the profession's code of ethics (NASW Code of Ethics, 2000) and standards for professional practice. Affirming the dignity or worth of the person is a core principle of the NASW Code of Ethics. The NASW Standards for Social Work Practice in Palliative and End of Life Care (2004) call for an understanding of the ethical principles of justice, beneficence, nonmaleficence, respect for the person, and autonomy or an individual's right to make his or her own decisions.

Theories of health care justice and therapeutic jurisprudence acknowledge the fundamentally social nature of human beings, the social force of the law, and the conditions of our human finitude and equal intrinsic worth that make a claim upon other persons (Sulmasy, 2003; Kapp, 2003). The unexamined ethics of relationality in end-of-life decision making and the impact of such an ethical perspective upon outcomes for older adults and other intended beneficiaries of law and policy have been considered in the health law literature (Morrissey & Jennings, 2006). In the excessive rationalism, excessive individualism and middle class cultural bias of the current legal and ethical autonomy framework that have emerged from both judicial

and federal policymaking (*Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 1990; Patient Self-Determination Act of 1990, Public Law No. 101-508.), no space has been made for social and family relationships (Morrissey & Jennings, 2006). Pain and suffering experiences for older adults are outcomes or consequences of the law as lived, the law as social practice, to which we are called to make socially responsible ethical responses as members of family and social ecological systems.

Improving care at the end of life for older adults who are suffering by increasing access to meaningful palliative care services is an important public health mandate. Recent legislation has been introduced in the New York State Legislature to amend the New York State Public Health Law to require a patient's attending health care practitioner to inform the patient about information regarding palliative care and end-of-life care options appropriate to the patient consistent with the patient's prognosis and the patient's legal rights to pain and symptom management at the end of life (Palliative Care Information Act, S.4498, A.7617 ). This bill defines "palliative care" as health care treatment, including interdisciplinary end-of-life care and consultation with patients and family members to prevent or relieve pain and suffering and to enhance the patient's quality of life including hospice care.

### **Developing A Phenomenological Account of Pain and Suffering**

Phenomenology may help illuminate the structure of lived experiences of pain and suffering in end-of-life illness and their fundamentally social nature. This tradition is founded upon the work of philosophers, Immanuel Kant (1785/1966) and Edmund Husserl (Husserl, 1913/1989), and later evidenced in the work of philosophers, Maurice Merleau-Ponty (1945/1962; 1964) and Emmanuel Levinas (1961; 1981; 1987). Amedeo Giorgi (1970) and Frederick J. Wertz (1993; 2005; 2006; 2008) have advanced the phenomenological method in

psychology. The tradition is characterized by a fidelity to lived experience; a focus on subjectivity; a recognition of the primacy of sociality and relationality in the structure and meaning of psychic life; and an account of motivation or desire for ethical and moral action through responsible agency (Wertz, 1993; 2005; 2006; 2008; Drummond, 2005; 2006; 2008). This paper seeks to give a phenomenological description of the experiences of pain and suffering in end-of-life illness and their structure based primarily upon the phenomenological philosophies of Husserl (Husserl, 1913/1989) and Levinas (Levinas, 1961; 1981; 1987). The social work literature does not satisfactorily deal with the problem of pain and suffering for older adults. The paper focuses on three concerns for practice with older adults in gerontological social work: to develop a phenomenological account of pain and suffering; to determine what phenomenology can tell us about the ethics of end-of-life decision making; and to determine whether phenomenology can provide an account of the essence of the experiences of pain and suffering that is pragmatic for social work practice with older adults. The nature of the ethical demand or moral claim made by persons at the end of life upon others with whom they stand in social relation will be examined in the context of the cognitive, emotional and affective dimensions thereof; motivation; normativity; and the ground of obligation. The insights provided by a phenomenological investigation of the structure of pain and suffering experiences at the end of life and their significance in the intersubjectively experienced world for the subject will help to inform ethical approaches to both research and praxis in social work and palliative end-of-life care with older adults.

### *Defining pain and suffering*

The principal focus of this paper is the dimensions of pain and suffering in illness for older adults who are approaching the end of life. While there is no clear consensus supporting a

single definition of end of life (Lorenz et al., 2004; Bern-Klug, 2004), the concern in this paper is with the frail elderly who are struggling with life-limiting or life-threatening illness. However, as the social work literature documents, the conceptualizations of dying under our current dominant biomedical models need reframing to permit conversations about dying and transitions to social roles of dying for persons who are in stages of advanced chronic illness for whom any certainty about death eludes them (Bern-Klug, 2004).

The current thinking on pain and suffering is a conceptual swamp that presents numerous difficulties by attempting to demarcate perhaps too clearly the margins of pain and suffering on the ground in both medical and non-medical settings. Cassell (1991) defines pain physically and in a cause and effect relationship with suffering: “While pain and suffering are not synonymous, physical pain remains a major cause of human suffering and is the primary image formed by people when they think about suffering. However, no one disputes that pain is only one among many sources of suffering” (p. 31). Implicit in Cassell’s definition is the mind-body problem of Cartesian dualism. Cassell may be defining pain as a bodily form of suffering and in that sense as a species or type of suffering. Cassell acknowledges, however, that suffering is not limited to physical pain and is “experienced by persons, not merely by bodies” (Cassell, 1982, p. 639). While Cassell (1991) explicitly rejects Cartesian mind-body dualism in his writing about suffering and places emphasis on the person as the center of all suffering (p. 33), it is clear that suffering has forms of unexplained etiologies that concern things other than the lived body, even though they are in their own way related to the lived body. In the social work literature, citing the International Association for the Study of Pain, Altilio and colleagues (2006) provide the following definition of pain: “an unpleasant sensory and emotional experience associated with actual tissues damage, or described in terms of such damage. While it is unquestionably a

sensation in part or parts of the body, it is always unpleasant and therefore an emotional experience” (p. 637). This definition of pain suggests too that there are elements of Cartesian philosophy at play, on the one hand, in relating pain to pure physicality, and on the other hand, a sensation located in parts of the body. Altilio (2004) explains that an assessment of pain extends beyond the physical and the sensory to “total pain” (p. 387), which encompasses the social, psychological and the spiritual. According to Altilio (2004) , both pain and suffering are subjective experiences and are not measurable either for the patient or the patient’s family members or caregivers with traditional objective measures used in health care settings.

Like Altilio, Chapman and Gavrin (1993) acknowledge the “imperfect” relationship of pain and suffering in that there can be pain without suffering, and suffering in the absence of pain. Thus, pain is neither a necessary nor a sufficient condition for suffering. The problem of suffering has been written about extensively in the literature of medical anthropology, psychology and psychoanalysis, sociology, social work and other disciplines (Cassell, 1991; Doka, 2006; Frank, 1995; 2001; Frankl, 2006; Freud, 1965; Kleinman, 1988; Kugelman, 1999; 2000). Cassell’s definition of suffering has been widely accepted in the literature on suffering and acknowledges that pain and suffering, while phenomenologically distinct, may be present at once:

Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner. It follows, then, that although it often occurs in the presence of acute pain, shortness of breath, or other bodily symptoms, suffering extends beyond the physical. Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person. (Cassell, 1991, p. 32).

As suggested by the foregoing definition, it is evident that the seriousness or magnitude of suffering stems from the threat to bodily integrity *and* the integrity of the whole person. The

perspective offered by Frank (2001) in his inquiry about whether we can research suffering provides an important context for the knowledge objectives sought in this phenomenological investigation. While Frank (2001) captures suffering as central in illness experience, he expresses reservations about whether suffering can legitimately be made the subject of study in the social sciences. Frank (2001) acknowledges the limits of discourse in studying the experience of suffering that oftentimes involves that which cannot be spoken, that which is unknowable, and that which cannot be translated into what he calls the extralocal texts of the social sciences. According to Frank, the experience of suffering is local, yet sometimes cannot be located. One appropriate role for research that Frank (2001) recognizes is giving voice to suffering individuals and the meaning they make in their stories. The human sciences, particularly phenomenological investigation, may be particularly well suited to the study of suffering for this reason among others.

Many of the obscurities and difficulties with the pain and suffering conceptual swamp arise from Cartesian philosophy and the medical model that either dichotomize pain and suffering into body- mind dualisms or impose scientific paradigms on understandings of pain and suffering. Instead, pain and suffering are lived experiences and therefore, require phenomenological investigation. As part of such investigation, bracketing natural scientific constructions like the medical model and the physical world is required. Altilio (2004), who practices in palliative care social work, suggests that suffering may be concerned with a search for meaning. A movement away from explanatory scientific investigation of suffering rooted in the biomedical model and diagnosis may thus be indicated, restoring the centrality of ethics and the moral content of interpersonal relationships to the study of taken-for-granted experiences of suffering in everyday life (Miller, 2004). For the purposes of this phenomenological

description, pain and suffering will be examined as part of the end-of-life continuum of illness experiences for older adults with or without capacity who may face pain and suffering in myriad forms. Consistent with the palliative ethic of care, the goal of care planning is to control pain and relieve suffering, although a legitimate question is raised as to whether a claim can be made at all that suffering may be controlled (Chapman & Gavrin, 1993). Such a claim may suggest authority and power that rests only with the person who is the sufferer.

*Phenomenology as a human science: study of pain and suffering*

It is reported that qualitative methods have been used increasingly in health and medicine in studies of relational meaning (Breitbart, 2003; 2004 ). Consistent with this evidence, Wertz's (2006) history of the qualitative revolution in the human sciences illuminates the primacy of ethics in the emerging qualitative movement. Phenomenology as a human science is poised to capture the voices, perspectives and subjective experiences of human persons in their suffering at the end of life because in Husserl's own words, it goes directly to the "things themselves," to the world disclosed by the subject's consciousness (Giorgi, 1970; Wertz, 2005; Kugelman, 2000). Wertz (1993) finds certain parallels between Husserl's approach to phenomenology and Freud's psychoanalytic methods in the study of psychic phenomena, perhaps most importantly their conceptualizations of an emotive body and its relation to a disclosive "horizon-structure" of the psychic that taps Freud's notion of the unconscious (p. 124). Freud's concern with melancholia, loss, libido and coping have been well charted in the psychological and pain and suffering literature (Frank, 1991; Hooyman & Kramer, 2006). This phenomenological investigation will be disclosive of the voices of the suffering in describing lived experiences, acts and subjective performances of pain and suffering for older adults. Pain is significant because it is so prevalent among older adults who have illnesses, especially among the frail elderly whose

bodily structures and capabilities are declining, and who may have to surrender personal autonomy in seeking care and support through formal and informal systems. One of the contributions of this investigation will be to examine the relationship among various forms of pain and suffering, access a unified and general conceptualization of “the structure of suffering” in severe illness and at the end of life for the frail elderly, and explore whether the experience of suffering is so radically different from the experience of pain that such differences need to be accounted for in human science investigation.

*Account of suffering older adult with life-limiting pain and illness*

The prevalence of pain and suffering among older adults is well supported in the social work and gerontological health care literature, although understudied (Altilio, 2006; Gibson & Helme, 1999; 2001; Gold & Roberto, 2000; Teno et al., 2004). Pain interference with older adults’ functioning and activities of daily living is well documented and recognized as a public health issue (Peat et al., 2004). Chronic pain may significantly influence older adults’ quality of life and intimacy in relationships (Roberto, 2001). While studies have addressed the assessment and treatment aspects of the pain problem for older adults, very few studies have undertaken good descriptions of pain and suffering in their full panoply of physical and psychosocial manifestations (Lorenz, 2004; Roberto & Reynolds, 2002). Decisions about pain and suffering for older adults are also not without complexity. Values and treatment preferences may not have stability over time and may be influenced by individual differences, culture, attitudes toward the health systems and family decision making, social context and other factors (Karel et al., 2007; Lockhart et al., 2001). Communication between older adults and their health care professionals, health care agents and even within their own families has become a critical concern in improving end-of-life care (Pantilat, 2009; Gutheil & Heyman, 2006; 2005).

In order to facilitate a phenomenological description of the structure of pain and suffering experiences in late life illness, I am sharing an account of chronic pain and suffering involving my 81-year old mother who returned home after the completion of her stay in a rehabilitation facility. As the researcher for this project, I am in a privileged position to document my mother's experiences from the perspective of a daughter who participated in her lived through experiences of pain and suffering. Approaching research through the lens of the family is not new in illness and dying narratives. In 1965, Simone de Beauvoir recorded a very personal account of her mother's illness and death in a slim volume entitled, *A Very Easy Death*. More recently, Freeman (2008) has used narrative methods to explore his mother's experiences with dementia in "Life without narrative" and "Beyond narrative."

The value of studying one's mother is the phenomenological givenness of the mother-child relationship, deeply rooted not only in narrative tradition, but in history, myth, psychology, philosophy, religion, and social work. The mother-child relationship has powerful resonance with, and provides a firm foundation for research concerning the palliative ethic of care, sociality and relationality. The contractarian, rights-based framework in end-of-life care planning and decision making that has evolved in law and policy has been challenged on many fronts as inadequate (Fins, 2006; Rogers, 2008; Shabahangi et al, 2009). Perhaps Robert Burt (2005) puts it best in foreshadowing the demise of pure rational choice, individual autonomy frameworks in favor of shared decision making schemes. An ethic of care that is based upon the pre-cognitive mother-child unity and the syncretic "me-other" sociability system described by Merleau-Ponty (1964) may be useful in exploring the relational context of social relationships and their meaning for older adults at the end of life. The foundation of syncretic sociability is the identity of the self with others and what others live and experience (Merleau-Ponty, 1964). In *Otherwise Than*

*Being*, Levinas (1981) develops his thinking more fully about sensibility and signification in relation to maternity as a metaphor for the other-in-the-same, the radical passivity and vulnerability of the self who is exposed to the “Other” (Bevis, 2007). Mary Rogers (2008) draws upon the work of Alfred Schutz, Carol Gilligan and Jane Addams, one of the founders of social work, in offering a new understanding about the feminist ethics of care that is shaped more by social context and care for the whole person in the Schutzian sphere of the “We” than by an ethics of rights.

With the mother-child relationship and the ethics of care in mind, I am honored to present the account of my mother, a graduate school dean and educator for 50 years, who was diagnosed with shingles in the fall of 2005 and subsequently suffered a fracture of the pelvis the following winter while at work. In two separate interviews for her oral history, she describes her lived experiences of pain and suffering in encountering unexpected illness:

Q (March 10<sup>th</sup>): ... Well, I've been very fortunate in my life in regard to my physical stamina and physical health throughout all the decades. It was very traumatic to be felled by this disease, the shingles... The shingles was very devastating. I am a very independent person. It was difficult to be dependent. But one thing I haven't mentioned is drive – I have tremendous drive to be independent to be productive as I can be, not to sit back. Some of my colleagues and friends want to retire, play bridge. My aspiration is to be a contributing member of society for as long as my health ... Illness devastated me temporarily... I bounded back. Drive is extremely important. I have this great drive to ..participate. I'm not into that. I want to be a contributing member of society until my time comes to expire.

Q (April 1<sup>st</sup>): The shingles was a devastating experience for me. It seemed so benign. It was a band of sores around my middle. I thought it would pass – that it was an infection. It was shingles. It was so debilitating. It's hard to find words to describe how debilitating it was. Speaking metaphorically – it was like someone stuck a needle into my system and took all my life away. I was so exhausted all the time. I lacked my usual energy. It went on for a very long time. There was pain on my right side. It wasn't the pain as much as the sense that your energy was being sapped and taken from you. It got so bad I had to give up my work and try to survive it. There was no medical cure, no medicines or no interventions. You just had to survive it if you could. It was not life threatening but threatening to living the kind of life to which I was accustomed. I did return to work.

My university was very supportive and helpful. I had a limited schedule because I didn't have energy to have a full schedule. I was able to do a great deal from home. I required a great deal of rest. I lost my appetite and lost a considerable amount of weight. I was back at work. About a year after shingles I had on a new pair of shoes and they had a rubber sole and they didn't interact well with the carpet. I didn't know the rubber ... I fell and I was unable to recover the balance that I would normally have been able to do but I was so debilitated from shingles. I attribute the accident to shingles. I attribute a great deal to shingles. Actually shingles were very attached to my right side, right hip – I did have a lot of pain on my right side. Side was very weakened. So I had the hip fracture. I was operated on. They had to put pins in my hip. I spent several weeks in a rehab center. They tried to help me recover .... I went back to work I'm gradually regaining my strength. It was an incredibly debilitating experience. I attribute bodily loss of energy to shingles.

In this account, my mother who is struggling with life-limiting illness describes in rich language her lived experiences of bodily pain and her personal suffering in encountering what she herself calls “devastating” illness and trauma. In the first interview (March 10<sup>th</sup>), while assuming the voice of a professional at times, she speaks of being “felled” by the “disease” of shingles and relying on her family, friends and neighborhood for support. Her expressions of devastation about the loss of her independence and productivity and their meaning for her selfhood begin to break through her professional persona. In speaking of her social support systems and social networks, she is also revealing the double loss she experiences in being isolated from her familiar social context of work and collegiality at the university, a lifeworld that she clearly holds dear. Toward the end of this excerpt, she actually contemplates in explicit terms her finitude and mortality, “...until my time comes to expire.” With these expressions, there is a third level of loss with which she is struggling, the anticipated loss of life and her concomitant anxieties and fears in facing death. Her pain and suffering are expressed very clearly in her language and stand as evidence of the experiences she has undergone and is undergoing.

Punctuating these expressions of loss and trauma, however, are her allusions to “drive” and “recovery.” This dimension of experience points to evidence of my mother's resilience from her trauma. It seems, however, that the first meaning is that of loss, how the loss of energy and the

overall experience of being ill interrupts her “drive life.” She still is the person “with drive” but she cannot embody and act it out as she once did. It is this fracturing of her experience from which she attempts to recover, which is not merely a return to the previous “drive life” but a new structure of “recovery”. Resilience is a phenomenon that has been observed in older adults who are chronically and terminally ill (Hooyman & Kramer, 2006; Nelson-Becker, 2006; Greene & Cohen, 2005). My mother is engaged in a performance of her pain and suffering through her discourse, her active and passive acts, her creative responses to her situation, her valuing and relating (Kugelman, 1999; 2000; Shabahangi et al., 2009). She is at work, but it is now a different kind of work.

#### *Formation of identity as suffering person*

Consistent with Cassell’s definition of suffering as a threat to the intactness of the whole person, we begin to see the formation of my mother’s identity in the account given as a suffering person (Cassell, 1991; Kugelman, 2000). In the account itself, my mother as subject directs her reflective consciousness to the loss of independence and productivity, loss of self (Charmaz, 1983; 1999), the loss of sociality and communicative relations in her lifeworld, loss of meaning, and her pain and suffering. In describing the social context in which she places herself in her “sick” role as belonging to multiple communities, the intentional objects of her consciousness (i.e., full correlate of consciousness) are multiple and also include the emotional objectivities connected with her social roles as mother, grandmother, colleague and friend; her love of family and friends; family members, friends and colleagues themselves who are meaningful to her; her anxiety and fear of death; as well as her drive, recovery and resilience. Embree (1992) explains how in this fashion doxic, pathic and praxic characteristics such as a mother’s love and the

emotional objectivities associated with it can be objectivated in an objectifying turn, but “without seizing upon them” (Embree, 1992, p.170).

In the second interview given (April 1<sup>st</sup>), my mother’s expressions of her real pain and suffering in life-limiting illness become more explicit. She describes what she endures with the shingles – loss of appetite, loss of weight, loss of energy. As explained above, her discursive about her experiences takes an objectifying turn. The pain itself becomes an object of her intentional consciousness. She speaks of the pain as if it is embodied as a thing with thingly qualities that is “attached to her right hip, right side,” a needle in her side that has withdrawn all her life and energy. She directs her consciousness to the illness itself in the same fashion. The objectifying turn surpasses the positing of pain as bodily or physicalistic and extends to emotional objectivities. In describing the pain of her illness as devastating and debilitating, she is pointing to the emotional responses that she has to the pain and suffering that afflict her. She does not greet this pain and suffering with welcomeness; they are hostile, like an intruder that comes from the outside like a foreign object, and to which she responds with a range of emotions – depression, anxiety, and ultimately fear.

Using Cassel’s (1991) conceptualization of suffering as a frame of reference, the sense of distress which my mother describes in a number of ways both expressly and implicitly, is disruptive of her well being, assaultive to her sense of self and integrity, and a threat not only to her personal intactness, as Cassell (1991) says, but to the intactness of her very lifeworld. The needle my mother speaks of in her account is certainly a metaphor for more than her bodily pain – my mother is speaking directly to her loss of self and personhood, her experience of suffering: ***“It wasn’t the pain*** as much as the sense that your energy was being sapped and taken from you. It got so bad I had to give up my work and try to survive it. There was no medical cure, no

medicines or no interventions. You just had to survive it if you could. It was not life threatening but threatening to living the kind of life to which I was accustomed.” In these words, we see her dislocation and her marginalization, the element of the tragic so close to what Ferreira (2006) speaks about in drawing certain parallels between Kierkegaard’s and Levinas’s paradox of thought, i.e., the passion of desire willing its own downfall. There is an anticipation of death embedded in the structure of my mother’s suffering; there may even be a desire for the infinite, or that which cannot be thought in contemplation of death and dying. Levinas (1987) uses the language of tragedy in *Time and the Other*: “In pain, sorrow and suffering, we once again find, in a state of purity, the finality that constitutes the tragedy of solitude... The content of suffering merges with the impossibility of detaching oneself from suffering. And this is not to define suffering by suffering but to insist on the *sui generis* implication that constitutes its essence. In suffering there is an absence of all refuge” (p. 69).

My mother’s suffering may involve the pain of living more than pain and threat specifically associated with actual illness or disease (Barbato, 2006; Kleinman, 1988). This notion is echoed by Strang et al. (2004) in their study of existential pain in which many participants described suffering in the absence of any physical pain as more closely allied with annihilation and separation. The thread of suffering’s surpassing the boundaries of illness and fundamentally concerning the burdens of living is interwoven into my mother’s account with her attribution of “a great deal” in her everyday living to the shingles, and her multiple allusions to survival.

There is no doubt that my mother’s suffering is essentially a struggle for meaning, making meaning of her dying in her living at the end of life (Breitbart et al., 2003; 2004; Chochinov, 2004). In this way, suffering is radically different from pain. It would certainly seem that from all the research evidence that has been amassed on pain, pain and symptom management and the

development of clinical practice guidelines on pain (Lorenz, 2004; Altilio, 2004; Altilio et al., 2006), we can state with some comfort that pain, even psychosocial pain, can to some extent be assessed, located, treated, and when pain medications are made available as appropriate, controlled. However, we have not reached this level of understanding about suffering. Suffering evades definition, review, location. Suffering necessarily involves the identity of the sufferer in his or her social, cultural and life history context. How do we assess suffering in the Other, understand suffering and respond to suffering with an ethic of care? These questions of suffering in living and dying as death draws near are some of the very questions that have long been the subject of moral phenomenology to which we now turn for illumination.

### **What can phenomenology tell us about the ethics of end-of-life decisions?**

#### *Suffering and the “Other”*

End-of-life decision making ethics has traditionally focused on principles of autonomy, beneficence, non-maleficence and justice (Gerbino & Henderson, 2004). However, the problems of suffering at the end of life, especially for frail older adults, may involve complexities that go beyond principled ethical analysis. The work of Emmanuel Levinas (1961; 1981) and his concepts of infinity, alterity and exteriority, may be helpful in coming to grips with the ethical and moral aspects of the problem of suffering. In concrete terms, Levinas’s “Other” can be applied to the case of a frail older adult who voluntarily stops eating and drinking. There is an ethical dilemma as to whether the older adult is appropriate for a feeding tube. Will the insertion of a feeding tube relieve the older adult’s suffering or heighten suffering for that older adult? Let’s return to the case of my mother who now has progressive dementia, does not wish to eat, and does not wish to engage in advance care planning. Rational choice theory and the autonomy framework fail us to a large extent in such a case. If an older adult has limited or no decision

making capacity and has left no clear expressions of her wishes, a surrogate may be guided by what the older adult would have wanted, what Brudney (2009) calls an authenticity question – how she would have lived her life, not an autonomy question. The real problem in this case is one of suffering, a problem that has not been adequately explored in law, health or social work, and is ripe for phenomenological investigation. What we do know in the law is that we have seen too many egregious cases of feeding tubes for patients for whom there was no surrogate who had legal authority to refuse life sustaining treatment. How can phenomenology help us understand the problem of suffering for older adults who are faced with unwelcome life-sustaining treatments such as feeding tubes that unnecessarily prolong their lives or make the quality of their lives unbearable?

In *Totality and Infinity*, Levinas (1961) describes the relation between the “Other” and “me” in the encounter with the face: “The Other remains infinitely transcendent, infinitely foreign; his face in which his epiphany is produced and which appeals to me breaks with the world that can be common to us” (p. 194). Levinas gives primacy to ethics over ontology, or commanded love in explicating this pre-ontological and pre-theoretical moral claim (Ferreira, 2008). The dyadic self-other relation has the character of an obsession or persecution through which the self, “me,” is accused and assigned a responsibility for the “Other” through substitution for the “Other.”

Levinas extends this notion of being “hostage” to the “Other” by making clear that the responsibility to the “Other” cannot be declined. Ethical responsibility is motivated by metaphysical desire, both the appetite for infinity and a non-complacent happiness in sociality (Ferreira, 2006), and consists in responding to the call or summons of the “Other.” Metaphysical desire is distinguished from and springs up only after the need of the “I” is satisfied by “living from” good soup in the totality of the world (Levinas, 1961). Levinas recognizes that a well

developed ego is a condition precedent to the ethical relation. Only a capable and nourished ego can take care of another. The “I” welcomes the trauma of the encounter with the “Other” so as to achieve intersubjective relationality and transcendence. Westphal (2008) takes the position that the trauma of transcendence in Levinas is inextricably linked with heteronomous intersubjectivity, “in which the “Other” is the law of the same” (p. 82):

As trauma of identity, transcendence means that the Other is internally related to me. We find ourselves back at Hegel’s notion of a relation ‘more like an identity than even the relation of faith or trust.’ I am who We are. Except that by virtue of the asymmetry of the relation we do not form a totality based on reciprocity. When in reflection I turn my intentional arrows back toward myself in order to recognize myself, to define myself and to choose myself in short, to say I, I discover the Other already there between me and myself. ... This notion of being taken hostage, along with the notions of election and persecution, calls to our attention a second dimension of trauma. Along with my Identity, my Authority is decentered. I am called and questioned by the saying of the Other, assigned and accused, judged and found guilty. But none of these require my consent for their validity. Nor do I have any right of veto and deep down I recognize this. ... Finally..., the trauma of transcendence is heteronomous intersubjectivity because the Other, to whom and for whom I find myself responsible, is not just a law that comes to me from outside (formal heteronomy) but a command that contradicts my *conatus essendi* (material heteronomy). (pp. 82-83).

In the feeding tube case example, my mother is the “Other” who makes a moral claim upon me in her suffering state, to whom I am held hostage. I am commanded to take responsibility for her, to take up her suffering. As totally “Other” to me in her exteriority, my mother’s suffering is unknowable to me. Her suffering is present to me in my encounter with her and I bear witness to it. Using Levinas’s maternity metaphor, I receive her suffering and am hospitable to her “Otherness.” In substituting myself for her, I have an ethical and moral obligation to make a decision about whether the insertion of a feeding tube will be burdensome to her, and will increase her suffering by unnecessarily prolonging her life. It would be inherently immoral and unethical and a violation of her personhood to make any decisions that would cause her suffering to increase.

*Levinas and Husserl: Exteriority and intersubjectivity*

While Levinas's thinking is consistent with Husserl's with respect to the irreducibility of the "Other," there are significant differences in their philosophies that have bearing on the concerns in this paper with respect to understanding the nature of suffering and the obligation to suffering persons. Levinas's account of the ethical relation gives meaningful insight into the appeal made by the suffering "Other" in the face of imminent dying or death. However, his description of suffering, while adequate in the context of rescue from death, may not fully explain intersubjectivity and the motivation for ethical action in other end-of-life care contexts such as chronic progressive illness (Drummond, 2005).

In the example of my mother's situation, we may be assured that her family members are motivated by a desire to prevent her premature and painful death and to relieve her pain and suffering. Their taking up of pain and suffering is not a departure from Husserl. In fact, we see very clearly in Husserlian terms how intersubjectivity works in this account. In later segments of the interview given by my mother as part of her oral history project, she speaks directly to the question of intersubjectivity in suffering. In describing her experiences interacting with her grandchildren during her illness and how these shared experiences influenced her recovery, it is evident that her suffering is intersubjectively experienced by her meaningful others in her lifeworld. My mother's family members access her pain and suffering in a number of ways, through pairing in seeing that she is like them and has pain and suffering like them, through cognitive empathy, and through her expressivity. There is a meaningful social exchange in which my mother participates with her family members. However, as we have acknowledged, for Levinas there is no reciprocity for answering the "Other's" call. It is possible that Levinas's description of suffering may fall short of giving a sufficiently rich understanding of the complex

structure of experience for persons at the end of life to the extent that an authentically intersubjective world motivated by intentional consciousness, explicitly rejected by Levinas as the ground of the ethical relation, remains in question (Levinas 1981; Davenport, 2008). Despite this possible deficit in Levinas's account, his explication of an ethical relation through which the subject undergoes a responsible submission to the burden of suffering of the "Other" is fully embraceable. Within this ethical framework, the suffering of my mother is made meaningful in specifically ethical terms as imposing an agapeistic and asymmetrical obligation on neighbor. In giving primacy to ethics over ontology, Levinas helps us understand the central importance of ethics in our lived experiences and the original responsibility we have to others in their suffering. We are left still, however, with aspects of suffering, that as Levinas (1987) himself acknowledges, are refractory to light.

*Valuing experiences of pain and suffering:*

Husserl's description of the role of passive and active associations as an extension of time consciousness in the development of motivation sheds light on the situation of the seriously ill patient and the meaning of her suffering. In the account given by my mother, the most difficult challenge for the researcher is understanding the issue of motivation in suffering, and in recovery. Practical interests and ethical concerns in not violating the subject may limit the researcher to bearing witness to the subject's pain and suffering. In my mother's case, it is fairly clear from her expressiveness that her pre-reflective drive and reflective self-awareness motivate her recovery. In her interviews, she speaks repeatedly of her drive to recover, to be independent and to continue to be a contributing member of society for as long as her health or her living with pain and suffering will allow. This motivation is well grounded in syntheses of associations that arise from her habitualities and convictions as a dedicated professional, and caring and loving

human being in all her social roles. The horizon of perceiving, acts, thoughts, feelings and valuing in her illness experience may include a taking or appropriation as ordinary and meaningful as accepting care from her caregivers. While this act may seem everyday and ordinary, it may involve certain transformational or epiphanic experiences that reorient her in her living with suffering. Her suffering motivates her recovery, and is retained in the process of recovering, just as her relatively happy life as a fulfilled professional is retained (as no longer) in her suffering..

Husserl's theory of valuing is important to understanding the axiological complexity of my mother's pain and suffering experiences. Drummond (2005; 2006; 2008) has explicated Husserl's theory of valuing in moral intentionality and phenomenology as involving a foundational order. In applying this order to the example under consideration, we may see how Husserl's theory works and understand its implications for the phenomenology of pain and suffering. The founding or presentational level of my mother's valuing is the descriptive objective sense that belongs to the pain and suffering experiences. How does she describe her experiences of pain and suffering? She indicates that she has intentional feelings of dislike or displeasure directed to the bodily pain and suffering. With such affective moments as the foundation, my mother experiences another affective moment or emotional condition in response to the objects of her experiences to which she will attach value attributes. As her pain and suffering become unbearable and intolerable and she finds no comfort or palliation for her needs, her emotional condition grows into fear and depression. Therefore, she intends and attaches other value attributes to her situation such as burdensome, meaningless, or harmful that correlate to the emotional condition. In the alternate, if her emotional condition were happiness

or acceptance, she may attach positive value attributes to her situation such as beneficence or redemption.

This axiological valuing process founds my mother's practical reasoning as she makes decisions between choices that she may recognize as ethically competing. As a virtuous agent, she may without any deliberation accept her pain and suffering experiences as spiritually transforming and opening horizons to her in her lifeworld to which she did not have access before. An ethically competing choice may be to seek curative medical interventions that will not alter the course of her pain and suffering, exhausting scarce resources that could be allocated to others who have a real medical need for such services. Such insights may be epiphanic in nature, as Levinas describes the encounter with the face of the "Other" as an epiphany. If my mother deliberates about her choices, she may recognize after deliberation that while her pain and suffering are burdensome and not welcome, she will appropriate them in a way to bring positive meanings into the lifeworld she shares with her family members and choose not to opt for unnecessary medical procedures. In their ethical relation, she takes the standpoint of receiving their care.

But what about the ethical relation from the standpoint of the "Other" - my mother - who stands in relation to the caregiving family members who are called by the Levinasian "Other?" It is they who are called to serve, to be held hostage, to be responsible for and to my mother. The family members sit by my mother's bedside, massage her feet, tell her stories, take up her pain and suffering – they are present to her and she is present to them. In these intersubjective experiences, she has a renewed sense of their psychic beings and how they have substituted themselves *for* her in her living and dying with pain and suffering as a subject in the world, of

the world and for the world. She understands they expect no return for their caring in keeping with Levinas's notion of metaphysical desire.

*Nature of obligation:*

Husserl and Levinas take divergent paths with respect to the important question of the nature of moral obligation. This question has priority for Levinas in his exposition of the primacy of ethics as first philosophy. He turns to ethics as pre-ontological and pre-theoretical. While Husserl may not give the question of obligation priority in his philosophy, his description of intentionality in experience may provide a much firmer ground for normativity in obligation for the transcendental subject than Levinas's noumenal "Other."

The limitations of Levinas's grounding of obligation may be explained to some extent by drawing certain parallels between Levinas and Kant. Both philosophers have highly formal structures which obligate the subject to action. In Kant, the moral law is a categorical imperative that I give to myself; similarly, in Levinas, the imperative arises from exteriority or the call of the "Other," also formal and noumenal in character. In each instance, it can be argued that universal normativity stems from an absolute necessity for moral action. In Kant, the sense structure of obligation is reason over/against the inclinations, whereas in Levinas, it is absolutely "Other" over/against the self (Drummond, 2005). For Kant, freedom is autonomously determined, while in Levinas, freedom is heteronomous in its constitution. In other words, freedom is called into question by the "Other." In Kant, the unity of transcendental consciousness is the source of motivation where a non-empirical practical wisdom gives itself the moral law and thereby obligates itself. Absent from Levinas's description of the nature of obligation is the centrality of intentional consciousness as the source of motivation. Levinas's disinterestedness is without intentionality (Levinas, 1981; Gaston, 2003).

Husserl succeeds in laying out an account of full intention that arises from the intentional consciousness of the subject. Normativity for Husserl is evidential in nature based upon full intention, an intention that is based upon an originary intuitive experience (Husserl, 1989). The moral agent is striving for fulfillment of intentionalities in the pursuit of vocational or moral goods. In the case of my mother, her vocations are many and are the impetus for her striving for goodness and truth in her intentional acts. Beyond the pursuit of moral goods by the moral agent is the transcendental good of moral agency itself (Drummond, 2005). Drummond (2005) frames this as a non-manifest good that is universal (Drummond, 2005). In some ways, this transcendental good bears resemblance to the transcendent “Other” of Levinas in that they are not prescriptive universals like the categorical imperative of Kant. It is in the taking up of the transcendental for Levinas and Husserl that the subject becomes fully ethical and moral. In some sense, this notion of the transcendental good of moral agency is at work for my suffering mother facing life-limiting pain and illness. While voluntarily choosing to pursue the vocational goods of social work professional and educator, mother, and now care recipient in the time she spends with her family, she is at the same time seeking what Husserl calls evidential truth about having appropriate responses to things, namely, her relational pain and suffering experiences. In these experiences of pain and suffering, she retains the happiness of her past experiences that are no longer. In taking responsibility for her pain and suffering, she strives for a meaningful life in her social world even as death draws near (Husserl, 1989; Drummond, 2005).

### **What can phenomenology tell us about pragmatic social work practice with older adults?**

We may entertain the thought, given the analysis of suffering conducted in this paper using my mother’s account as a basis, that the experience of suffering of older adults with life-limiting illness may be celebratory, liberating. We hear my mother’s voice: “I want to be a contributing

member of society until my time comes to expire.” Freeman (2008) hints at these possibilities in his exploration of the lifeworlds of those suffering from dementia, describing a process he calls “unselfing.” Can the suffering older adult who is decentered experience change, transformation, personal growth, epiphany even in the midst of overwhelming loss, dislocation and tragedy? My mother’s account is testimony to such possibilities. I quote from Arthur Frank’s phenomenological inquiry into anxiety aroused by dying in his discussion of Simone de Beauvoir’s account of her mother’s dying:

The implications of the explication proposed above suggest the possibility of a phenomenology of the givenness of the experience of dying, for both the dying person and those around him. ... The applied conclusion is that another argument has been advanced implying that the ongoing institutional reorganization of the settings in which most people die ought to aim at minimizing the bureaucratic rationalization in the Weberian sense of the experiences of both the dying and those who are with them. Insofar as the experiences of both involve a sort of shock, the settings ought to make this shock a possible occasion for personal reinterpretation – to be capitalized on or avoided as the individual chooses - rather than compounding the inherent distresses by forcing individuals to increased levels of the sort of recipe conduct implicit in bureaucratic regulation. (Frank, 1978, p. 110).

My mother has found new pathways to meaningful work, but it is the work of suffering. Suffering is radically different in nature from other illness experiences in the trajectory of death and dying, even experiences of pain, for the very reason that in suffering there is a horizon of meaning that is inextricably tied to a person’s life history. The social work literature on resilience in older adults offers hope that even those older adults who may be burdened with intolerable suffering in living and dying may find a promise for recovery and generativity in meaning-driven therapies that give comfort and care to the whole person (Breitbart, 2000; 2003; 2004; Hooyman & Kramer, 2006; Nelson-Becker, 2006; Greene & Cohen, 2005). Further research is needed on these important questions to strengthen pragmatic social work practice with older adults in palliative end-of-life care.

## **Conclusion**

This paper posed three challenges critical to an understanding of the phenomenology of pain and suffering at the end of life: to develop a phenomenological account of pain and suffering for the frail elderly; to determine what phenomenology can tell us about ethics in end-of-life decision making; and to determine if the phenomenological account is pragmatic for social work practice with older adults. In summary, we can make certain findings. The palliative ethic of care that seeks to relieve pain and suffering for the individual and family and her loved ones is by its very structure ethical. Palliative care has emerged from a strong foundation of commitment to person- and family-centered decision making that honors the wishes of the patient, supports the family and encourages conversations among loved ones and in the community that will maximize benefit and comfort for all beneficiaries of care. Husserl and Levinas enrich our understanding of suffering and relational decision making for older adults in ways that go beyond rigid application of legislating principles or ruling frameworks. Moral phenomenology permits us to view moral agency in terms that give primacy to personhood and authenticity.

Phenomenological description of lived experiences of pain and suffering and their structure gives us access to the lifeworlds of subjects. The tradition of phenomenology that is characterized by fidelity to lived experience is well suited to the study of pain and suffering and its fully moral dimensions. An account of illness examined in this paper concerning my mother, a frail elderly woman, helps to illuminate the complexity of the bodily, cognitive, emotive, and axiological dimensions of pain and suffering. In a brief analysis of oral history data, the catastrophic, tragic nature to suffering that unmakes the sufferer and her remarkable world leaves the suffering subject homeless and without any real relief to her suffering. The subject

cannot return or be returned home and faces an unknown horizon, in living with chronic progressive illness and in approaching the trajectory of death and dying. By making person- and family-centered care the goal of assessment and treatment, the palliative ethic of care may be helpful in situating the suffering person within a broader social and relational context, and encouraging acceptance of personal history and pathways to moral agency and resilience at life's end. Making sense of suffering involves the horizon structure of a person's full life in social relation to meaningful others. Social workers are uniquely equipped by virtue of their training and ethical commitment to self-determination and social justice values to work with the frail elderly, their families and the other members of the health care team with the processes of conversation and active listening that are so central to the palliative ethic of care.

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