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## ENGAGEMENT AND SUFFERING IN RESPONSIBLE CAREGIVING: ON OVERCOMING MALEFICIENCE IN HEALTH CARE

**ABSTRACT.** The thesis of this article is that engagement and suffering are essential aspects of responsible caregiving. The sense of medical responsibility engendered by engaged caregiving is referred to herein as 'clinical *phronesis*,' i.e. practical wisdom in health care, or, simply, practical health care wisdom. The idea of clinical *phronesis* calls to mind a *relational* or *communicative* sense of medical responsibility which can best be understood as a kind of 'virtue ethics,' yet one that is informed by the exigencies of moral discourse and dialogue, as well as by the technical rigors of formal reasoning. The ideal of clinical *phronesis* is not (necessarily) contrary to the more common understandings of medical responsibility as either *beneficence* or *patient autonomy* – except, of course, when these notions are taken in their "disengaged" form (reflecting the malaise of "modern medicine"). Clinical *phronesis*, which gives rise to a deeper, broader, and richer, yet also to a more complex, sense than these other notions connote, holds the promise both of expanding, correcting, and perhaps completing what it currently means to be a fully responsible health care provider. In engaged caregiving, providers appropriately suffer *with* the patient, that is, they suffer the exigencies of the patient's affliction (though not his or her actual loss) by consenting to its inescapability. In disengaged caregiving – that ruse Katz has described as the 'silent world of doctor and patient' – providers may deny or refuse any 'given' connection with the patient, especially the inevitability of the patient's affliction and suffering (and, by parody of reasoning, the inevitability of *their own*. When, however, responsibility is construed *qualitatively* as an evaluative feature of medical rationality, rather than *quantitatively* as a form of 'calculative reasoning' only, responsibility can be viewed more broadly as not only a matter of science and will, but of language and communication as well – in particular, as the task of responsibly narrating and interpreting the patient's story of illness. In summary, the question is not whether *phronesis* can 'save the life of medical ethics' – only responsible humans can do that! Instead, the question should be whether *phronesis*, as an ethical requirement of health care delivery, can 'prevent the death of medical ethics.'

**KEY WORDS:** hermeneutics, virtue ethics, *phronesis*, practical, wisdom, engagement, responsibility, modern medicine, beneficence, patient autonomy, relationship, language, Charles Taylor, Max Scheler, Richard Zaner

### INTRODUCTION

It can only be expected that modern man will be a difficult patient because the sickbed dictates to him the task for which he is least prepared: confrontation with (or suffering) the vulnerability of his body and the transience of his life . . .

The really healthy person . . . is aware of this vulnerability. This (however) results in a certain responsibility . . .

J. H. van den Berg, *The Psychology of The Sickbed*<sup>1</sup>

Is there a sense in which engagement and suffering are essential to responsible caregiving? While some providers engage with their patients, many of whom are suffering, the ideology of medicine opposes such connection. Medicine has adopted the stance that responsible care requires objectivity and therefore distance from the patient and his or her experience. One of the functions of the patient professional relationship within modern medicine is to create and maintain a “safe distance” between the professional and his or her patient. Such distance is supposed to serve at least two purposes. First, it is supposed to preserve the objectivity of clinical judgment, thereby assuring “impartial” or “unbiased” and “correct” clinical decision-making. And second, it is supposed to protect the professional’s self-identity at the personal level from being emotionally and psychologically threatened by the affliction of his or her patient.

We will argue that this distant, objectivist and rationalist stance has contributed to what Robert Veatch and others call the crisis of modern medicine – a crisis in which care is often disengaged and in which interminable bioethical problems are endemic. We will argue that disengaged and distant care promote bioethical problems because caregivers fail to understand their patients’ experiences, meanings and choices, and as such are hindered in their ability to responsibly engage in the process of respectful bioethical dialogue. We will develop a model of “clinical phronesis,” which requires caregivers to develop the skills of engaged interpretation with patients towards the end of responsible clinical decision-making, and we will illustrate how engaged caregiving promotes this process of responsible clinical decision-making with an illness narrative, “Jimmy’s Story.” In the course of our work, we will also argue that disengaged care represents an attempt by caregivers to deny what we assert is a fundamental existential connection. The issue is thus, not whether caregiver and patient will be connected or “engaged” in some way, but how they will be engaged. How will caregivers choose to respond to their given connection with patients, many of whom are suffering?

#### TO HELP OR TO HURT?: MODERN VERSUS POSTMODERN MEDICINE

Robert Veatch has advanced the observation that medicine today is in a state of crisis. The crux of the problem involves a growing perception that

caregiving, which is supposed to “help,” all too often needlessly “hurts” instead.<sup>2</sup>

Although this sense of malaise is evident in clinical ethical problems, the difficulty is not simply that increasingly there are more disagreements over what should be done. Rather, as Alasdair MacIntyre has suggested, the problem is that the disagreement in moral debate seems to be “interminable.” The type of disagreement that arises suggests that the differences in perspective, which are manifest in moral debate, often reflect an incommensurability of the underlying differences in the “universe of discourse” in which the debate is conducted.

In our view, the interminability of moral debate is not simply a problem in ranking the height of ethical principles or rules, but rather is symptomatic of an erosion in the *applicability* of medicine’s standards. Medicine is increasingly confronted by the following bitter irony: ethical guideposts or guidelines involving standards that are supposed to reduce or eliminate moral uncertainty and ambiguity in clinical decision-making are helpful to caregivers mainly in the straightforward cases in which they are least needed; while in the tough cases – the very type in which guidance is most badly needed – the guideposts seem to offer little or not help at all. Veatch suggests that we are currently in the midst of a “paradigm shift” from modern medicine to a new form which he describes as “postmodern medicine.” This paradigm shift results, he says, when medicine is conceptualized “*as essentially an evaluative enterprise in the most routine, day-to-day decisions. Postmodern medicine calls for a radical shift in paradigm to one where every move of the health professional as well as the lay person in the medical sphere is an evaluative act.*”<sup>3</sup>

This analysis contains several important clues for understanding what has gone wrong with medicine as we have known it in the twentieth century. The paradigm on which modern medicine rests, according to Veatch, is one in which medical knowledge is viewed as essentially factual in nature. Even more sophisticated accounts that acknowledge the “occasional need” here and there for certain discriminations in the process of clinical judgment nevertheless represent the essential epistemological status of medical knowledge as “factually-based.” Medical professionals become “experts not only on a set of facts and a scientific method, but also on a set of values, sometimes called medical values.”<sup>4</sup> The medical values involved in professional evaluation, such as quantifiability, predictability, efficiency, etc., however, are those which are geared to certain uses of science, rather than for use in responsible physician–patient relationships.

It is, of course, true that the more sophisticated accounts of medical knowledge recognize the importance of both facts and values. Veatch

correctly suggests, however, that the recognition which these accounts give to the occasional need for professional evaluation fails to recognize the essentially evaluative nature of such knowledge, since such evaluation commonly involves little more than a mere "adjustment" of medical, factual judgments.

In our view, most standard accounts of medical knowledge fail in three ways. First, they do not recognize that the significance of facts *per se*, even of the "brute" variety, is inherently evaluative. Second, they do not recognize that the cognitive processes in terms of which matters of fact are determined are already imbued, through and through, with value. And third, they misconstrue and distort the nature of value in health care by objectifying its significance as "medical value." This objectification truncates or reduces the significance of values in both health care and medicine to the status of yet another species of fact (e.g. "facts about values"). This narrow and distorted understanding of clinical reality is a source of moral problems in medicine.

#### DISENGAGED CARE: THE MALAISE OF MODERN MEDICINE

Mainstream bioethics, too, tends to be overly rationalistic. It has not yet fully incorporated the importance of relational knowledge into the process of ethical decision-making. Many of the efforts in applied biomedical ethics have attempted to construct more powerful and more precise formal decisional schemes for correctly identifying the "highest" principle or value, from among a set of competing principles or values, as that which would give force to morally valid clinical decisions. The problem with this formalistic process is that it excludes certain aspects of awareness which are essential in fully moral comportment, i.e., aspects such as moral imagining, perceiving, recollecting, and, especially, feeling. When clinical activity is construed only or mainly in functional terms, driven by values like efficiency of operation, caregiving is denigrated into the kind of technical process which excludes much of the richness and complexity that is inherent in practical moral experience. Little or no attention has been given to the type of hermeneutic of understanding which is involved in understanding clinical realities (on which clinical decision-making rests). In clinical work it sometimes matters little whether autonomy or beneficence or justice is the "highest" principle or value, unless members of the health care team fully and correctly understand "what is going on" in the patient's situation of illness.

Charles Taylor has recently performed a hermeneutical analysis of rationality that can provide a helpful model for understanding the nature of

the problem with the ethical process in modern caregiving. According to Taylor's analysis, the form of rationality which structures the social and behavioral sciences is a process that "tries to reconstruct social reality as consisting of brute data alone." This process has led to the creation of an overly narrow, abstract, distorted picture of "social reality."<sup>5</sup> The distortion results from the way in which the predominant knowledge-process *excludes* a "consideration of social reality as characterized by inter-subjective and common meanings."<sup>6</sup>

He goes on to show how this distorted sense of social reality is related to or is a particular "expression" of the modern self's "disengaged" way of being in the world. Applying Taylor's analysis to the malaise of medicine, it is possible to see that modernist forms of caregiving not only involve but require "disengagement" of the caregiver as human person or self from the patient's situation of illness. We describe the type of care that results from this approach as "*disengaged care*," a type which on reflection appears to be less than fully responsible.<sup>7</sup>

The forms of disengaged care that dominate modern medicine transform the nature of much of what caregivers "do" from an authentic form of *human action or praxis* into a form of mere technical production. The structure of caregiving has been changed from the kind of activity that exemplifies what Aristotle understood as practical wisdom or *phronesis* – a process in which the agent exercises deliberation on and interpretation of all the morally relevant particulars of the situation to determine the goals or directions, as well as the means, of action – into the kind that exemplifies what he understood as "applied science" or *technè*.

## RESPONSIBILITY AS CLINICAL PHRONÈSIS

In contrast to the disengaged approach, engaged caregiving reflects a different understanding of responsibility in medicine. In this approach, the caregiving process is structured around a sympathetic understanding of the patient's suffering.

Clinical responsibility compels caregivers to sincerely strive to help their patients in a way that fits the circumstances of the situation at hand. The full and proper realization of this sense of responsibility in caregiving activity, however, often involves more than simply the desire to help the patient. It also involves a sense of "working through" the medical narrative with the guidance of a sense of practical health care wisdom – "clinical *phronesis*".

Clinical *phronesis* is a type of rationality, which is broader, richer, and more complex than instrumentalist rationality, a sense of rationality

that respects, preserves, and makes creative use of “difference” rather than simply neutralizing it. The different facets of phronesis disclose a variety of different aspects of moral experience, which are mostly excluded by instrumentalist rationality. These facets include the “moral imagination,” feeling, recollecting, and various modalities of perceiving, especially “expert clinical observation.” When the agent is alert to the full range of meanings that are disclosed through all of these aspects of moral experience, he or she can better appreciate the intersubjective or common meanings of illness which often have relevance to therapeutic choice.

We agree that there is a sense in which distance and objectivity are unquestionably necessary elements of professional responsibility. The approach of phronesis is not anti-scientific, although, as Richard J. Bernstein has suggested, it commonly is opposed to objectivism both in natural science and in medicine.<sup>8</sup>

In fact, clinical phronesis includes many of the elements and values of Enlightenment medicine. In this discussion, however, we have mentioned only one, namely, the necessity and importance of clinical distance and objectivity as a tool or instrument – rather than as a guiding ideal – of responsible caregiving. This is to say that objectivity and distance, like other values including quantifiability, prediction, and efficaciousness, should *serve rather than dominate* selection of the purposes and goals of medicine both in specific cases and in public policy as well.

What do we mean by “clinical phronesis” and how is it practised in the clinical setting? Clinical phronesis involves incorporating knowledge of the patient as person into the best ethical and clinical decision to be made in continuing dialogue with the person as patient. It necessitates a certain level of involvement with the patient, what we call engaged-sympathetic care. How does a physician, or indeed, anyone, develop a “knowledge” of another? What type of knowledge is knowledge of other people?

Clinical phronesis is the process in which caregivers search out the middle course of action, the mean which lies somewhere between the excess involved in “doing everything possible,” and the deficiencies entailed by resignation, indifference, or “doing nothing at all.” The operative term is “somewhere,” since the purposes and goals of medical intervention indicated by clinical phronesis in specific instances will often vary from case to case, depending on the circumstances at hand. Clinical phronesis thus requires informed, thoughtful mediation between the “received” tradition including general concepts, principles, and rules, on the one hand, and the particular circumstances of “this” patient’s situation of illness, on the other. In short, the process of application involving mediation between universals and particulars in clinical encounters – the process that comprises clinical

understanding – is clinical phronesis. Consequently, clinical application is, itself, neither a technical production nor a formal procedure that is subordinate to understanding. It is rather a *knowledge process* characterized mainly by narrative and dialogue that makes selective use of technique in various ways. As the dynamic process of speech and language that drives (and is driven by) narration and interpretation of “what is going” on in the patient’s situation of illness, application, as clinical phronesis, *is* understanding. Hans-Georg Gadamer suggests this line of thought in *Truth and Method* when he indicates that application is an integral aspect or moment of understanding and interpretation, rather than a mere technical machination. Was it not something very close to this hermeneutical concept of “the mean” that functioned as the conceptual basis of Aristotle’s ethics?<sup>9</sup>

Clinical phronesis signals the agent’s alertness, receptivity, and acquiescence to an engaged approach to clinical decision-making. The process is dialogical, in the sense that it can be realized only through respectful, truthful conversation and dialogue. In this respect, it is fundamentally different from the intellectualist process in which many transactions of modern medicine and bioethics are conducted. In the phronesis approach, responsibility requires that clinical decision cannot normally be made in advance of, or apart from, the caregiver’s full participation in the patient’s situation of illness. It is dedicated to the discovery or creation of strategies and techniques (whichever works best) that will be helpful in facilitating renewal in ways that diminish the burden of suffering. Clinical phronesis requires not only *calculations* of the mean between extremes, but also interpretation concerning the significance of the “lived” experience of time and space whose exigencies, practically speaking, constitute the world of sick existence – the aegis of the clinical lifeworld.

### RESPONSIBILITY OF SUFFERING CLINICAL PRESENCE

Clinical phronesis also requires what can be described as “suffering clinical presence.” This presence is the felt *reciprocity* that exists between the affliction suffered by the patient, and its reflection mirrored in our own experience by the images, metaphors, and symbols that comprise clinical discourse.

Max Scheler’s phenomenological description of interactions is illuminating as a starting point for our consideration of the necessity of “suffering clinical presence” for clinical phronesis. Scheler argues that humans are fundamentally and existentially related. Feeling is not, in a Cartesian sense, a “private mental entity” to which the subject, alone, has privileged access. Rather it is an essentially intersubjective event which is experienced in

different ways by the self and his or her fellow other. Fellow feeling is the intersubjective form in which feeling occurs.

In *The Nature of Sympathy*, Scheler sharply distinguishes between true “fellow feeling” and mere “emotional infection.” Fellow feeling involves a genuine reciprocity between self and other, as well as between the different complex facets or sides of the self. In a sense, therefore, both self and other share intersubjectively in what is essentially one and the same feeling. Although each person “feels” one and the same emotion, each normally does so in quite different ways which are appropriate to his or her respective standpoint and life experience.

While I sense your sorrow by being brought into your expression of sadness, still I may never know the magnitude, complexity, or the full significance of what you feel. But, Scheler would add, the same may also be true of myself as well! In other words, the relationship that exists between your own *self-understanding* of “what is going on” inside and its *expression* is as equally complex as the relationship that exists between my understanding of your feelings and your expression of them. In some cases, e.g. self-deception, I may even have a clearer idea of what your feelings mean than you yourself do because of certain complexities involved in your particular situation. *The significance of the emotional experience of both self and other remains essentially incomplete apart from a work of interpretation, a project that requires the joint participation involving a dialogue or conversation between both parties.*

Mere emotional infection, by contrast, which, according to Scheler, is a distortion of fellow-feeling that “occurs in its most elementary form in the behavior of herds and crowds,” involves either one of two things. The infection involves either the miraculous feat of “empathic projection” of self – via imagination – into the other’s feeling or experience (which Wittgenstein, among others, has shown to be quite fanciful), or else an “imitation” based on a crude machination wherein self supposedly draws a mental analogy with the other’s “external behavior.”<sup>10</sup>

Simply stated, both empathic projection and imitation, in Scheler’s view, go wrong by presupposing what, today, we understand as the Cartesian dichotomy between subject and object, fact and value, self and other, doctor and patient. In contrast, Scheler’s phenomenological perspective holds that in fellow-feeling, *I and Thou* are *already* intersubjectively joined in a common (although non-reflective) experience of relationality. This experience occurs *prior* to these intellectualist divisions.

Fellow-feeling pervades the world of clinical medicine as the phenomenon of *affliction*. Affliction occurs in the patient – physician relation in a way that implicates both caregiver and patient alike. The caregiver’s



receptivity to, as opposed to his or her or denial of, the inevitability of affliction and suffering engenders an experience of responsibility, but one that remains inchoate without interpretation of “what is going on.” Such interpretation is necessary to complete and sometimes correct the understanding of the experience. Whereas the force of fellow-feeling activates the caregiver’s responsiveness to the other, its *right or proper* exercise, clinical phronesis, moves the caregiver in a “fitting” therapeutic direction in the care of “this” patient. Given the necessity of interpretation for completing and sometimes correcting the inchoate significance of what is going on in fellow-feeling, medicine therefore has an unavoidably hermeneutical component.

Engagement and suffering the patient’s affliction is most appropriately achieved, therefore, through active involvement in a dialogical process of *interpreting the illness*. This interpretive process, “suffering the patient’s affliction,” opens the caregiver to “sources of the self,” which are already implicated in moral experience. For example, at the level of “clinical existence” – the existential level that lies beneath or prior to cognition and volition – interpretation shows that caregivers and patients are *already* intersubjectively related through the phenomenon of “fellow-feeling.”<sup>11</sup>

To truly “be with” the afflicted other – to be fully engaged in the other’s situation of illness, and, hence, to be faithful to what he or she suffers – is to suffer the presence of the other’s affliction. Although to suffer such presence does not mean, of course, that we undergo the actual loss suffered by the other, it nevertheless involves facing, without recoil, the presence of our own affliction – the sense that foreshadows our own fragility and fatality. Suffering clinical presence thus requires both openness to the patient’s suffering and openness to that in us which the patient’s suffering evokes: our own fragility and mortality.

In the experience of clinical phronesis, responsibility thus requires the caregiver to appropriately participate or share in the patient’s affliction by remaining vulnerable to his or her own suffering. Suffering with the patient in a manner that fits the situation at hand is an inescapable part of becoming engaged in the patient’s situation of illness. The ideal of responsibility implicit in clinical phronesis is not *escape from loss*, but rather *renewal in loss*, in which the experience of healing is an important element.

What we have described as suffering clinical presence and its role in clinical phronesis requires that suffering be acknowledged in the clinical relationship. This acknowledgement is anomalous in the modern paradigm of medicine which recoils from the notion of suffering affliction with the patient. Many of the practices and assumptions of medicine seek to escape

the reality of suffering and of involvement with suffering, usually through denying it, objectifying it (as a therapeutic “skill”), or sentimentalizing it.

We have argued that, existentially, the reality of suffering cannot be denied. We cannot escape our relational nature. That such escape is possible is one of the great illusions of modernity. Affliction by its very nature is essentially a relational event in which both self and other are already implicated. The thought of “escaping” such presence actually constitutes one possible response to the reality of our relational nature. Contrary to the order of modern medicine, the question of responsible patient care in clinical encounters, as well as in encounters of other kinds, is, therefore, not whether it is possible both to fully care for the patient and, at the same time, to refuse, deny, or else remain indifferent to the patient’s suffering. Rather, the question of responsible clinical care concerns whether the professional’s relation with the patient will be a sympathetic engaged relation – whether his or her manner of dwelling in the “jaws” of suffering clinical presence will be engaged – or disengaged. The hermeneutical significance of sympathetic-engaged caregiving is hinted at by Elliot Mishler in *The Discourse of Medicine*. Truly humane care, Mishler suggests, concerns the “primary accorded to patients’ lifeworld contexts of meaning as the basis for understanding, diagnosing, and treating their problems.”<sup>12</sup>

Engaged care is the kind that engenders and evokes the sense of practical health care wisdom that guides truly responsible health care practice. Disengaged care – instrumentalized care in which professionals either objectify or else sentimentalize the fellow-feeling that already exists between themselves and their patients by refusal, denial or indifference to suffering presence – is fundamentally unconscionable. It is unconscionable not only because these responses endanger the quality of patient care (because the caregiver does not know the patient), but because they negate and destroy the life and character of the professional as person as well, as evidenced by the euphemism of “burnout syndrome.” It engenders and evokes the kind of health care practice which can be less than fully responsible or even irresponsible – the source of medical maleficence.

The approach involving “engaged care” is a potential “corrective” to the malaise of medicine. This practice, when conceived in Aristotelian terms, cannot be understood simply as a technical process of production or *technè*. Rather, as mentioned earlier, it involves a distinctive form of human action or *praxis* in which caregivers join together with their patients in a sympathetic therapeutic alliance. In this sympathetic relationship, the caregiver appropriately suffers the patient’s affliction, rather than refusing or denying its inescapability.<sup>13</sup> The engaged approach to caregiving,

as earlier suggested, leads to the reconceptualization of medicine along Aristotelian lines as *clinical phronesis and praxis*.<sup>14</sup> We offer the following example of engaged caregiving involving clinical phronesis and praxis.

#### “JIMMY’S STORY”: A NARRATIVE OF ENGAGED, SYMPATHIC CARE

In this section only, we will depart from the usual “third person voice” in order to let the patient’s primary care nurse (the second author of this paper) tell Jimmy’s story and comment on its significance from *his* standpoint of practice.

The case presentation draws on the narrative methods described by Patricia Benner as a process of reporting clinical experience.<sup>15</sup> Benner suggests that these stories can help to uncover meanings and feelings in ways that illuminate the contextual and relational dimensions of a clinical encounter.

Jimmy is a 14-year-old Inuit boy who lives in the Canadian Arctic. One winter morning, he was working with a gas stove and it exploded into flames. His clothes ignited. He ran for several minutes with all of his clothes flaming until some neighbors helped him roll in the snow to extinguish the flames. He was rushed to the local hospital for initial burn care. Within a day, his overall status became unstable. So he was flown, with his father, for six hours to Montreal and was admitted to our Pediatric Intensive Care Unit.

Jimmy arrived around 10:00 in the morning. Sixty percent of his body surface was burned (second and third degree). This involved all of his legs, buttocks, groin and lower abdomen, as well as most of his arms and back. His face had superficial (first degree) burns. His burns were extremely swollen. He was continuously expressing intense pain through loud moans and screams, and sharp facial grimacing. In order to ensure good circulation to his legs and arms, the surgeons had to perform escharotomies. This involves slitting open the skin and underlying tissue in order to relieve pressure on the circulation. This was done in his room in order to avoid the risks associated with receiving a general anesthetic. This procedure required two to three hours, during which he received sedatives and analgesics (principally Fentanyl) intravenously. Every few minutes he squirmed, moaned, and sometimes sat up screaming in pain. On occasion the surgeons would stop to allow time for more analgesic to be given. This surgical intervention was followed by extensive management of his burns by surgeons and nurses. This involved the excision of dead tissue, cleaning of the burns and the application of dressings. This continued into the evening, without rest.

By the evening, he had received so much medication that his breathing became shallow. He had to be intubated and receive assisted ventilation with a respirator.

After this first day, Jimmy's burn care required extensive cleaning and dressing application twice a day, for three to four hours at a time. Over the following two weeks, although he was receiving large amounts of analgesics, he expressed feelings of sharp pain throughout most of the day, and always throughout the course of burn care. On several occasions, he became wildly panicky and told nurses that he saw "fire everywhere."

In the course of searching for an effective pain control drug regimen, Jimmy's care team invited me to provide some form of counselling for his "mental pain." This was an unusual circumstance for counselling. Jimmy was unable to speak because of the respirator, and almost all of his day was consumed by burn care, physiotherapy to ensure function of his joints, and sleep. As well, Jimmy was severely isolated and withdrawn. Visits by his family were sparse, as a result of the significant costs involved with travelling such a long distance.

In an attempt to ensure "therapeutic outcomes" in working with Jimmy, I engaged in regular consultations with a child psychologist and a child psychiatrist to review the evolution of Jimmy's condition. My aim was to establish a non-threatening relationship with Jimmy wherein he could feel free to express anything that was significant to him. I also examined his response to relaxation and guided imagery exercises for managing his pain and distress. I spent time with Jimmy (1 to 2 times a day) during quiet periods when no interventions were being performed. I presented myself simply as a nurse who would visit Jimmy regularly, try to find ways to help him feel better, and find ways of arranging some pleasant things for him to experience. I stated clearly that I would not do any painful procedures on Jimmy, but instead would try to help establish a "safe space" in which he could dwell.

My first three encounters with Jimmy were discouraging. I was not able to engage any eye contact or to get Jimmy's attention. On the third day, however, I used a different approach. I offered to read a couple of Inuit stories to him. At that point, his entire face lit up with approval. These were short folk tales of children successfully overcoming adversity. Jimmy focused attentively on the illustrations in the books and seemed fully engaged in the stories. The stories seemed to enable him to escape to a more familiar, more comfortable place. After the stories, Jimmy and I "spoke" for several minutes about his home life. We established a method of discourse whereby I could easily read Jimmy's facial expressions. I quickly learned that he enjoyed traditional ice fishing and hunting. He was

terrified of most doctors and nurses, especially those who did things to him quickly without first checking to see how he was feeling. Jimmy missed home deeply and was very scared that he would never be able to go back.

After a story and some conversation, Jimmy actively participated in a relaxation exercise that he and I created together. I played a calming “new age” cassette recording while engaging Jimmy in an imagery exercise. With closed eyes, Jimmy imagined himself back in the outdoors, quietly fishing, as I repeatedly instilled suggestions of feeling calm relaxation all over. We did this a few minutes at a time, a couple of times a day. After a few days, Jimmy required minimal prompting from me. I would put on the tape and he would close his eyes for several minutes on his own. At this point, I encouraged him to use these relaxation exercises during his dressing changes to assist with pain control.

I “accompanied” Jimmy on two to three dressing changes per week for three weeks. Together we participated in the relaxation exercises, I provided messages of encouragement regarding his progress. During the painful dressing changes, I positioned myself close to Jimmy – my face being only a few inches away; my arms around Jimmy’s neck. When Jimmy’s face expressed pain, I would “call it out” to the other nurses who would then stop and give more analgesics.

Over time, most of the ICU staff (nurses, physicians and physiotherapists) remarked that Jimmy exhibited less distress and participated more willingly during dressing changes when I was able to accompany him. Indeed, in reviewing the nurses’ notes over a two-week period, the dressing changes in which I participated were described more favorably, although they showed no obvious relationship with the amount of analgesics administered during the dressing changes. Sometimes Jimmy received less than the usual amounts of analgesics and sometimes more, during the times I was present.

Three of the staff nurses involved with Jimmy’s usual care also established a strong relationship with him. It became common knowledge on the unit that someone who “knew him” should be around for dressing change in order for the experience to be comfortable. On the many occasions when no such people were around, Jimmy’s dressing changes were typically described as a “horror show,” wherein he exhibited extreme pain and suffering, regardless of the extraordinary amounts of analgesics that were administered. Many of the staff felt intimidated by being assigned to Jimmy’s care.

It became apparent to me that a principal therapeutic factor in caring for Jimmy was “knowing him.” Four of us “knew him” well. Although each of us approached Jimmy in different ways, using different strategies,

we all attained comparable outcomes of comfort. Despite our different techniques, each of us not only knew how to interpret Jimmy's nonverbal communication, but we gave him significant control over his own care as well.

These relationships felt highly sympathetic. We each experienced a profound bond with Jimmy. We sensed cringes inside ourselves whenever he suffered and felt very deep pleasure when we were able to assist him in finding some measure of comfort. Our relationship with Jimmy felt intimate. Our work with him stayed with us for hours after the end of the work day. We each thought of him while we were at home, trying to think of ways to help him better. We each described this relationship as a fragile balance between being gratifying and consuming.

This early phase of Jimmy's affliction was followed by several months of skin grafting and strenuous physical rehabilitation. Six months following his admission, arrangements were made for Jimmy to finally return home. Around this time, Jimmy revealed that the fire had not been an accident. He wanted to kill himself. Tearfully, he described that his father had been beating his mother for some time. This made Jimmy hurt inside so much that he "couldn't take it anymore."

### NARRATIVES OF "ENGAGED CARE"

The narrative of Jimmy's care by his primary care nurse raises some probing questions. What can (and should) be said about the nature of the care that Jimmy received in the Paediatric Intensive Care Unit? What kind of patient – professional relation is portrayed between Jimmy and his caregivers?

After the explosion, and for many weeks and months thereafter, Jimmy was afflicted with what we describe as the insult of "fiery existence." He endured pain and suffering – continuously, intensely, and to a degree that we, the unburned, can hardly begin to imagine. During this time Jimmy's existence – a veritable metaphor of pain and suffering – was marked primarily by the intrusion of events: the surgical "slitting" of his skin; the subsequent repeated excision of dead tissue; the repeated cleaning of burns, and the application of fresh dressings (twice a day, for three to four hours at a time); massive doses of Fentanyl and other analgesics, which, although partly successful in alleviating pain-related suffering, brought on suffering of a different kind related to the terror of ventilator dependency; and the repeated "sightings" of fire.

The "state-of-the-art" biomedical technologies employed in his care were quite efficacious in helping to facilitate the healing processes that

eventually enabled his body to mend and regenerate. Furthermore the “cognitive-behavioral” psychosocial interventions carried out by the nurses and other professionals – interventions which aimed to achieve certain “behavioral adjustments” designed to maximize his potential for “stress reduction” and to optimize the efficiency of his “coping mechanisms” – appear to have been efficacious as well. Jimmy was fortunate to benefit from the high quality of medical and nursing care that he received in this Paediatric ICU. But what was significant in this case, what marks it as exemplary, is the care-givers’ willingness to “suffer clinical presence” with Jimmy.

The nurses did not understand their participation in Jimmy’s affliction simply as an “instrument of care.” That is, the care he received was not simply the result of techniques of various kinds, but a combination of the nurses’ technical skillfulness and deep emotions and sentiments for him. The nurses’ suffering Jimmy’s affliction was not simply another technique, but rather an application of their whole being and identity in the project of caring for Jimmy. This is suggested in the narrative by the allusion to their work as the “existential dimension” of the case. The whole approach to his care was conducted in terms of a dialogic process which involved the kind of “back and forth” movement through which everyone concerned sympathetically attempted to understand Jimmy’s pain and suffering by appropriately participating in it.

By establishing a non-threatening relationship with Jimmy; by guiding him in relaxation and imagery exercises for managing his pain and distress; by visiting him regularly; by trying to arrange some pleasant things for him to experience; by playing some calming music while Jimmy was undergoing the tortuous daily experience of having his burns cleaned, and his dressings replaced; by positioning himself literally near Jimmy’s face and body during these painful maneuvers – Jimmy’s primary care nurse (and several other nurses) came to “know” him well. His manner involved putting his face “close to Jimmy’s” (only “a few inches away”), placing his arms “around Jimmy’s neck,” and providing a voice for Jimmy – “calling out his pain” – when Jimmy himself could not verbally express it.

The primary care nurse, together with these other nurses, allowed himself to be with Jimmy in such a way that he entered into Jimmy’s “world.” He became involved in the meaning-structures or meaning-horizons that comprised Jimmy’s fiery existence, even though entering this world meant becoming open to the sense of affliction that appeared through Jimmy’s suffering presence.

The narrative states that the nature of the empathic relationship involved the kind of closeness in which the nurses sensed “cringes” inside them-

selves whenever Jimmy suffered. The nurses' work with Jimmy "stayed with them" for hours after the end of the work day. They thought of him after they were at home. Perhaps some of these thoughts were dreadful.

The nurses also say, however, that they felt "very deep pleasure" when they were able to assist Jimmy in ways that made him feel better. In short, they participated or shared in Jimmy's affliction – both in the suffering of his loss, and in the joy of his renewal. Although they suffered Jimmy's affliction, there is no evidence that their participation in his affliction either devastated them personally, or impaired or diminished the quality of their clinical judgment. What the narrative shows is that several of the nurses involved in Jimmy's care went beyond "doing," which involved various psychosocial interventions, to "be with" him in his affliction of fiery existence.

This event – the relation of closeness or togetherness that developed between Jimmy and his nurse – marks an anomalous aspect to the case. By allowing himself to enter the world of Jimmy's affliction, his nurse opened himself to a sense of relatedness that is characteristic of an approach to care whose order and norms are different from those of modern medicine. That Jimmy's care portends a different order of medicine is not only suggested by the content of the narrative, but by its form as well. According to the narrative, the nurses' "knowledge" of Jimmy was a principal therapeutic aspect of the care that precipitated his process of healing. This knowledge, however, is not described as a cognitivity that involved correspondence between the nurse's idea or statements about Jimmy and some bodily state of affairs (it was not knowledge based on the "correspondence" theory of truth). Rather such knowledge was described as having occurred in the context – and reflected the significance – of the nurses' relationship with Jimmy.

### DISENGAGED OR ENGAGED CARE?

Medicine has been dominated by an instrumentalist, technical form of rationality that has fundamentally altered the structure of health care activity, transforming it from a form of engaged practice, into a form of technical production of disengaged care. In our view, the abstractness and narrowness of this understanding of good or responsible medical care falls short of the phronesis approach involving clinical praxis.

The sense of responsibility involved in clinical phronesis or practical health care wisdom cuts against one of the main assumptions of medicine, namely that all suffering is harmful – to patients and caregivers alike, and therefore, that it should be avoided or eliminated. In light of the harm osten-



sibly caused by suffering, it is commonly believed that caregivers should strictly maintain “distance and objectivity” when relating to patients, even to the exclusion of subjective experiences involving human relationships (or relationality). Subjectivity is unwelcome in the patient–physician relation, so the logic of this assumption goes, because its allowance might put caregivers at risk for suffering the patient’s affliction. Furthermore, the refusal or denial of subjectivity, like that of suffering itself, is understood as partly constitutive of professional responsibility.

The assumption that all suffering is harmful fails to adequately take account of the fact that there are different kinds of suffering, not all of which can be eradicated or neutralized by the innovations of biomedical technology.<sup>16</sup> Although some forms of suffering of course can – and properly should – be eliminated whenever and wherever possible, still others not only cannot be eliminated, but responsibility requires that we should not even attempt to try. In the latter type of case, the attempt to eliminate the burden of suffering, the scourge of existence, can itself sometimes increase the burden instead.<sup>17</sup>

\* \* \*

In summary, our thesis has been that caregiving practice *per se* brings the caregiver into the *immediate* presence of the patient’s affliction in a way that involves an inescapable element of suffering. Fully responsible caregiving requires the caregiver to sympathetically participate in the patient’s suffering by becoming engaged in his or her situation of illness. The *form of suffering* which satisfies the requirements of clinical pronesis is neither a sentimental “*groveling* in affliction,” nor a cerebral, intellectual feat of “empathic projection.” Responsibility in medicine involves sympathetic-engaged caregiving, the approach that requires a dialogical process of interpreting the patient’s illness through respectful, truthful *clinical conversation*. “Ethical dialogue” or “ethical conversation,” however, is the kind in which the caregiver remains open, vulnerable, and responsive to the questions evoked by his or her sympathetic participation in “clinical presence” – the appearing of the patient’s loss suffered in affliction. Being and doing from within the jaws of clinical presence means that the caregiver will suffer not only the patient’s affliction, but his or her own affliction as well. Providers who are unwilling or unable to risk themselves by appropriately suffering clinical presence increase the chance of inflicting harm upon their patients and upon themselves as well.

In conclusion, to those who persist in the belief that a sympathetic-engaged response to suffering clinical presence is bad – that it either devastates the caregiver personally, rather than renewing and enabling him

or her, or else compromises the objectivity of clinical judgment and therefore denigrates the quality of patient care, rather than engendering practical health care wisdom and thereby increasing responsibility – we point only to the experience of Jimmy’s nurse. At the conclusion of the narrative concerning Jimmy’s care, the author shared an observation regarding both his empathic relation with Jimmy, and that of his staff’s, which suggested the possibility of renewal “in” loss. He characterized their relation with Jimmy as a “fragile balance” between “being gratifying and consuming.” We are reminded that the achievement of such a fragile balance is what Plato meant by the notion of “justice.”

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### NOTES

<sup>1</sup> van den Berg JH. *The Psychology of The Sickbed*. New York: Humanities Press, 1980: 50 and 74 (my emphasis).

<sup>2</sup> The type of caregiving referred to herein is illustrated and documented in a series of about 40 pediatric case-narratives and commentaries written by the first author while acting as a Clinical Ethics Consultant at The Montreal Children’s Hospital between 1985 and 1990. In many of these cases, the ethical issue or problem that prompted the request for an ethics consultation was the perception of a potential or actual harm associated with the child’s treatment, either by members of the health care team or the sick child’s parents (or both). Time and time again, this ethicist’s consultative experience displayed the irony that seemed to plague pediatric care, namely, that attempts to help the sick children all too often seemed to harm them instead. See Schultz, D. S. ‘Canadian Pediatric Narrative: Stories of Loss and Renewal Among Sick Children and Infants’ [in preparation for publication, 1998].

<sup>3</sup> Veatch R. *The Patient–Physician Relation: The Patient as Partner*, Part 2, Bloomington, IN: Indiana University Press, 1991: 278.

<sup>4</sup> Ibid: 56.

<sup>5</sup> Taylor C. *Human Agency and Language: Philosophical Papers II*. Cambridge: Cambridge University Press, 1985: 40.

<sup>6</sup> Ibid: 41.

<sup>7</sup> The sense of “engagement” and “disengagement” to which we refer is suggested by Charles Taylor’s analysis of responsibility in relation to the self. Taylor regards disengagement to be an important characteristic of the very being and identity of the “modern self.”

Drawing on this distinction, we view "sympathetic" care as an essential element of engaged care, in contrast to the disengaged nature of various sentimentalist and cognitive forms of care that are given primacy in modern medicine (of which "empathic" care is a variation). See Taylor C. *Human Agency and Language: Philosophical Papers I*. Cambridge: Cambridge University Press, 1985: 4–5; Taylor C. *Human Agency and Language*, 15–57; and Taylor C. Responsibility for self. In: Rorty AO, ed. *The Identities of Persons*. Berkeley: University of California Press, 1976: 289.

<sup>8</sup> According to Bernstein, objectivism refers to "the basic conviction that there is or must be some permanent, ahistorical matrix or framework to which we can ultimately appeal in determining the nature of rationality, knowledge, truth, reality, goodness, or rightness . . . The objectivist maintains (wrongly) that unless we can ground philosophy, knowledge, or language in a rigorous manner we cannot avoid radical skepticism." See Bernstein J. *Beyond Objectivism and Relativism*. Philadelphia: University of Pennsylvania Press, 1985: 8.

<sup>9</sup> Gadamer HG. *Truth and Method*, Part II, Sect. II (2a–b).

<sup>10</sup> Scheler M. *The Nature of Sympathy*: 8–19.

<sup>11</sup> Although Scheler's description of the structure of sympathy remains the most perspicuous phenomenology of fellow-feeling to date, other phenomenologists have since helped to expand our knowledge of what is involved in this phenomenon. For example, Zaner R.'s recent account of the "dyad of trust and care" has placed the phenomenon of fellow-feeling at the center of clinical understanding, which, in his view, actually guides responsible clinical decision making. See Scheler M. *The Nature of Sympathy*: 8–36 and 238–264; and Zaner R. *Ethics and The Clinical Encounter*.

<sup>12</sup> Mishler E. *The Discourse of Medicine*: 192.

<sup>13</sup> Aristotle. *Nicomachean Ethics*: 151–155 and 167–173.

<sup>14</sup> This reconceptualization of medicine can be understood as an expansion of Veatch's notion of post-modern medicine mentioned earlier (although it is different in some respects). See Veatch RM. *The Patient–Physician Relation: The Patient as Partner, Part 2*: 264–265; and Aristotle. *Nicomachean Ethics*, Books II and VI.

<sup>15</sup> Benner P. The role of experience, narrative, and community in skilled ethical comportment. *Advances in Nursing Science* 14(2): 1–21.

<sup>16</sup> Hauerwas differentiates between different kinds of suffering. Although he acknowledges that we bring some kinds of suffering upon ourselves, he clarifies the sense in which there are other kinds which are necessary by virtue of being the mortal creatures that we are. See Hauerwas S. *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church*. (Notre Dame, Indiana: University of Notre Dame Press, 1986.

<sup>17</sup> *Ibid.* Stanley Hauerwas makes a very similar point about suffering.

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