



11. Relief of Patients' Suffering: An Ethical Overview of a Practical Responsibility

Charge and Scope

The charge to write this report includes addressing the following questions:

- A. What should count as suffering?
- B. Who should make the determination that a patient is suffering?
- C. Are health care providers ethically required to attempt to relieve the sufferings of patients?
- D. Are there limits to these obligations?
- E. Is there ethical justification for providing relief of suffering that might produce harmful, unintended consequences including loss of life (i.e., double effect reasoning)?
- F. What is the institutional responsibility to relieve suffering?

The arguments and conclusions of this report are drawn from lengthy discussions among committee members and a sample of other clinicians, and from reviews of VA policy and relevant literature, particularly Eric Cassell's book, *The Nature of Suffering and the Goals of Medicine*. This report separately addresses each of the specific questions outlined above. We have included three case stories to illustrate examples of suffering as experienced by different veterans and the responses of health care providers. We hope that this report will be a catalyst for future discussion, education, clinical practice, and



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policymaking within the VA. We also hope that this report inspires providers to accept relief of suffering as a compelling and central goal in the care of patients.

Discussion

A. What experiences of patients should count as suffering?

Cassell writes that “most generally suffering can be described as the state of severe distress associated with events that threaten the intactness of the person (p. 33)... in everyday life and function . . . compared to the person’s or culture’s ideal (p. 50).” Cassell identifies suffering as disruptions of personhood, that is, disruptions of a patient’s estimation of his or her individual health, identity, interpersonal abilities, and social standing. For the purposes of this report, the committee defines suffering as the subjective perception of physical and personal disruption, caused or exacerbated by disease and illness. This definition is intentionally broad: it captures obvious and obscure aspects of suffering.

Disease and illness can assault patients’ wholeness, distort their sense of meaning, affect their relationships and social standings, and seize control of their lives. They can elicit mental aberrations and psychological and spiritual extremes of anger, fear, shame, and despair. Providers must understand that these disturbances can coexist and overlap and manifest themselves in behaviors and conditions including denial, depression, abuse, and violence. Finally, suffering that results from disease and illness can be episodic and/or progressive and/or cumulative.

Suffering has both somatic and nonsomatic dimensions. Physical ailments, as well as non-physical illness, might cause physical suffering. Bodily disturbances are usually felt in physical symptoms, and these are often identified in the course of work-ups by health care providers. The best evidence of the link between non-physical illness and somatic suffering is seen in relief of somatic symptoms with successful treatment of depression, panic, anxiety, or stress.



Non-somatic suffering includes psychological, spiritual, relational, social, functional, and communicative disturbances. Examples of this kind of suffering include a sense of diminished capacity for experiencing love, friendship, and daily functioning. Sick persons might express feeling burdensome, isolated, vulnerable, stigmatized, and endangered. Also, sickness can be more intensely suffered in unsettling contexts such as divorce, unemployment, poverty, and homelessness.

We specifically differentiate between suffering and pain because a failure to do so could impede relief of either. Pain and pain relief have been addressed elsewhere by VA. For the purposes of this report, we regard pain in a literal, perhaps reductionistic sense, as aching or stabbing or burning physical discomfort. Pain can cause suffering and suffering can increase pain. But not all suffering includes pain, and not all pain causes suffering.

B. Who should make the determination that a patient is suffering?

Cassell writes, “Ultimately, to know whether a patient is suffering, you must ask the patient (p. 245); ... to know in what ways others are suffering requires an exhaustive understanding of what makes them the individuals they are (p. 212); and, ... there is much to be seen that can only be seen by those who care (p. 155).” Health care providers and patients (or surrogates) together should make determinations of suffering. Patients define their own suffering, but they typically define it in response to questions and inferences from providers to whom they report symptoms and worries. Providers can come to know patients’ suffering only by asking them about it. Asking is a professional responsibility.

Obstacles for Health Care Providers

There must be a concerted effort by all health care providers who care for patients to ask about suffering, because suffering is easy to overlook and not asking could cause additional suffering. There are obstacles to asking that providers should recognize and try to overcome. Different health care disciplines are trained to pay attention to different aspects of disease and illness. For example, physicians are



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trained to treat pathology and associated physical symptoms. Social workers are trained to address patients' psychosocial needs; chaplains attend to individuals' spiritual needs. We acknowledge that these examples take a narrow view of what providers are trained to do, but we include them to make the point that different training could lead an individual provider to overlook a critical component of a patient's suffering simply because asking didn't occur to him or her.

Some health care providers may choose not to ask because it makes them vulnerable to suffering as well. Because of their own fear or avoidance of suffering, they may respond to patients with impatience, disapproval, excessive reasoning, challenging, and labeling. Or, providers may avoid asking about a patient's suffering because they lack the requisite skills or disposition. Asking takes time and time might be limited for either party. Asking can elicit a depth of revelation and relationship to which one or both provider or patient might not want to go. Individual patients might feel fearful, or intruded upon, or invaded in communicating about their suffering, and so disposed to silence. These feelings might be shared by providers as well.

Systemic barriers can sabotage relief of suffering. The skills and practice of relief are not prioritized in providers' professional education and training. Additional barriers include poor communication among providers, fragmentation of care, excessively restricted funding, inefficiently utilized resources, and eligibility criteria that limit access to necessary care.

Suggested Guidelines for Health Care Providers

We offer the following as suggested guidelines that providers should carefully consider and implement:

- First, relief of suffering begins with empathetic and compassionate practitioners who care enough to ask, and who, in asking, elicit trust, rapport, confidence, hope, and cooperation of their patients. In other words, health care providers who attempt to relieve suffering need to take a real interest, establish an inspiring connection, and risk experiencing some of their patients' suffering that seeks relief.



- Second, relief of suffering requires respect for the person. Suffering persons often need an invitation to communicate their feelings, because suffering can involve negative personal matters that the sufferer feels uncomfortable in sharing or at risk in exposing. Respect gets expressed by answering questions and continuing inquiries begun by patients, correcting misunderstandings, and relieving fears. In addition, respect is shown by preserving confidentiality and privacy, and eliciting consent.
- Third, in order to relieve suffering, health care providers need to connect with the whole person, the individual who is embodied, subjective, relational, communicative, and socially and culturally influenced. Providers should attempt to elicit the patient's understanding of disease, illness, and the suffering that arise from them. They should ask about suffering across the range of possible personal disturbances. Possible physical and non-physical suffering should be directly addressed.
- Fourth, health care providers need to nurture the person when they attempt to relieve suffering. This can occur by establishing a reassuring presence with friendly facial expression and relaxed body language. It requires patience and active listening, which may mean being there without necessarily doing anything. This can happen by asking open-ended questions, acknowledging what the person is saying, and accepting his/her reactions.
- Fifth, relief of suffering can very importantly include validating patients' individual feelings and perceptions of suffering as being normal and expected.
- Sixth, health care providers responsible for relief of physical suffering should listen carefully to the patient's account of bodily suffering. This stance requires careful observations, competent examinations, and accurate diagnoses. Physical symptoms need to be treated and evaluated with conscientious follow-up.
- Seventh, relief of personal, relational, and social suffering can occur when health care providers identify factors that seem out of control. This approach might require trial-and-error problem



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solving and other strategies, including those suggested by patients. Providers can propose alternative outlooks and outcomes if the suffering has induced rigidity and fatalism. In some situations, the provider may encourage the restoration of impaired relations, invite renewed or expanded communication, and assist the patient in recovering autonomy, a sense of control, a role in a story, a place in the big picture.

- Eighth, in the present system of providing medicine and health care, the primary care provider should initiate and coordinate relief of suffering. Primary care providers need to practice within the parameters of their expertise, abilities, and limits and refer to others (such as social workers) for services that exceed these parameters. It is also very important for health care providers to keep informed of a patient's ongoing experience, such that one can talk meaningfully with the patient and other caregivers about how things are going.
- Ninth, the patient's primary care provider should foster coordinated care among the involved services. Documentation in the patient's medical record should be sufficiently detailed to assure meaningful communication between providers, especially if providers change.

C. Are health care providers ethically required to attempt to relieve the sufferings of patients?

The positive ethical duty to relieve suffering is one that providers accept in choosing and learning their professions. They are generally obliged, upon the consent of patients, to take measures to relieve experiences that patients and they have identified as suffering.

There are several sources of this ethical responsibility. One exists in the virtues of the professions of medicine and health care. In this context, "virtues" are standards of excellence that guide providers in their practices. Providers should exhibit intellectual ability to learn professional virtues, personal inclination to practice them, and prudential wisdom to realize them. Relief of suffering, combined with



professional competency, respect for persons, effective communication, compassion, and mercy are a group of virtues that providers should strive to realize.

Relief of suffering is a traditional professional duty of providers: it is explicitly identified as such in historically influential and currently governing canons of medicine, nursing, allied health, and corporate health care practices. Relief of suffering is also part of health care providers' fiduciary responsibility for patients. Fiduciaries accept professional and legal responsibility for matters such as loyalty, truth-telling, informed consent, and putting patients' interests first. Thus, since fiduciaries are responsible for securing the best interests of their clients, and suffering that is not voluntarily borne detracts from patients' interests, providers are responsible to attempt to relieve that suffering.

Relief of suffering is also required by ethical principles to which providers subscribe, including respect for persons, beneficence, and nonmaleficence. Respect for persons includes attempting to relieve suffering primarily because successful relief restores or assists patient self-determination. Beneficence elicits attempted relief of suffering because successful relief contributes to patients' well-being, for example, enabling patients to better assess their own best interests. Nonmaleficence compels attempting to relieve involuntary suffering caused by disease and illness because such suffering can constitute harm to patients.

D. Are there limits to these obligations?

Limits on this positive ethical duty originate in society, in patients, and in providers themselves. Society's limits stem from specific cultural interpretations of health and medicine, disease and illness, and associated suffering. Our society defines health, disease, illness, and suffering more broadly than it does the responsibilities of health care givers. Our society holds that many factors contribute to understanding health, disease, illness, and suffering. These factors include, but are not limited to, science, technology, medicine, nursing



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and allied health, education, age, class, race, gender, genetics, diet, fitness, the environment, psychology, religion, faith, hope, spirituality, and law. Our society obliges health care givers to attempt to relieve sufferings that fall under their competencies, and to refer appropriately either within health care or beyond it for relief that exceeds their responsibilities. Our society does not expect health care providers to redress all causes of diseases and illness and to relieve all human suffering.

Patient-originated limits on the duty to relieve suffering are found in patients' bodies and particular conditions, in patients' knowledge, attitudes, and dispositions, and in their preferences, rights, choices, and actions. The body has a life of its own, and certain advanced physical conditions impose limits on the duty to relieve suffering. Patients primarily determine whether they are suffering or not. A patient's repeated determination that he or she is not suffering, appearances and providers' beliefs to the contrary, usually sets a limit on providers' responsibilities. So does a patient's persistent non-compliance with consensual therapies. So do states of being that patients define as suffering, but for which they do not seek or for which they refuse relief. Examples can include sufferings that the sufferers feel are voluntary, justified, maturing, purging, sacrificial, atoning, mourning, and defeatist. These limitations should not discourage providers from continuing to attend to patients' suffering. This is particularly true for patients in denial or refusing treatment for severe depression.

For individual health care providers, the duty to relieve suffering extends only to patients within their care. Additional limits are encountered in providers' specific education and training, their expertise and competence, their finite knowledge and abilities, their work situations, and their personalities.

E. Is there ethical justification for providing relief of suffering that might produce harmful, unintended consequences including loss of life (i.e., double effect reasoning)?

Many clinical responses to relieving suffering could have



unintended negative consequences. An example is sedating a patient who is anxious and afraid of an imminent surgical procedure, such that one cannot talk with or be comforted by one's family. Another example is treating a patient's advanced dyspnea with drugs that could also hasten the patient's death. Some clinicians argue against aggressive treatment because they fear that this could cause death. Clinicians often voice the same reasoning about aggressive treatment for pain.

The ethical justification for giving helpful treatments that produce harmful consequences follows from the principle of double effect. This principle stems from the common human experience that morally right or good actions sometimes have unintended wrong or bad consequences. In health care these actions are justified if the following five conditions are met:

1. the intervention is indicated and appropriate,
2. informed patients or surrogates consent to risking the side effects,
3. the negative side effects are truly consequences of the intervention, not means of achieving it,
4. providers do not intend or directly cause the negative side effects, and
5. the benefits of the intervention outweigh the harms of the side effects.

Double Effect Reasoning and Pain Control: Objections and Replies

In spite of this ethical justification, undertreatment of acute and end-of-life pain continues, due to some health care providers' objections to the addictive and/or depressant effects of narcotics. This reservation is influenced by the traditional professional rule against fostering dependency, and the perceived ethical and professional prohibitions and legal risks of causing death by overdosing. Indeed, several objections have been raised to the principle of double effect, however, they are not sufficiently convincing to undermine its guiding value.

For example, some individuals object to double effect reasoning



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because they consider it to be a religious principle rooted in Roman Catholicism and not appropriate for a pluralistic secular society. We hold that double effect reasoning is primarily rational, not religious. The reasoning is embraced beyond Roman Catholicism, and it is an ethical staple of hospice.

Another objection is that pain control often directly, not indirectly, causes death. After reviewing the literature on pain management and discussing this with clinical experts, we believe that the multiple effects of available pain medications are much misunderstood. Although clinicians often worry that pain medications may cause death, this is rarely the case. A third objection to double effect reasoning is that it focuses too exclusively on the intentions of the involved parties. As intentions are impossible to verify, considerable causing of death, disguised as pain control, could occur. This objection is really one to an abuse of double effect reasoning. We hold that possible abuse does not undermine the value of double effect reasoning. It does, however, raise a concern about deception, but deception is morally another matter that stands apart from the principle *per se*.

Some individuals object to double effect reasoning because they view it as being too restrictive in its consideration of consequences of beneficial therapies. For example, one can hold that the beneficial consequence of adequate pain control justifies other outcomes (e.g., death) regardless of the intentions of the involved parties and the causal efficacy of the utilized substances or methods (i.e., even if the providers intend death, and even if the substances or methods cause death). This objection merely suggests that double effect reasoning is unnecessary. Thus, we do not believe that a rebuttal is necessary.

A fifth objection is that directly causing the deaths of patients is not always wrong. Double-effect reasoning is again, albeit differently, unnecessary in justifying pain control that also effects death.

Lastly, some individuals object to double effect reasoning because they consider the law as being intolerant of this justification for unintentionally causing death. This view holds that foreseen consequences of medical acts are likely to be held as both caused and



intended. Several states' laws (e.g., Ohio, Minnesota), however, explicitly adopt double effect reasoning in permitting adequate pain control for dying patients while still prohibiting killing or causing death. In addition, all prior case law supports the non-culpability of unintentionally causing death while trying to treat pain and alleviate suffering.

Treatment of Pain

We recognize that challenges exist to the recommendation that health care providers alleviate or minimize the suffering associated with pain. Failure to ask about pain is the initial challenge. Not asking sends a signal to some patients that it is best not to report or to understate their pain. Some providers' unfamiliarity with opioids, analgesics, and other modalities of pain control exacerbate the problem. Medical and nursing students are not sufficiently schooled in pain's physiology and control. Unacknowledged attitudes that pain must be borne present another challenge. Especially noteworthy is the lack of institutional (facility) policy and protocol requiring effective diagnosis and relief of pain-driven suffering. The harmful consequence implicit in all these observations is that providers routinely do not relieve suffering from pain that they could relieve.

We adhere to the principle that inadequate pain control is bad for patients. Poor pain control might reinforce the belief that pain necessarily accompanies dying. Acute pain can be so debilitating that it sabotages patients' attempts to seek relief from other kinds of suffering. Chronic pain may cause patients to consider suicide.

Treatment of chronic pain is often more complicated than that of acute pain or pain experienced while dying. Attention to pain-related behavior and suffering is often minimized in patient-provider discussions. In the treatment of chronic pain, providers and patients need to develop a plan of care that allows the patient to function as normally as possible. In some situations, providers need to share both uncertainty and authority with patients by clarifying that further medication interventions are probably futile for eliminating the pain.



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We urge providers to alleviate or minimize the suffering associated with acute pain, end-of-life pain, and behavior and suffering associated with chronic pain. Any patient (and especially dying patients) suffering from acute pain should be offered pain control. Pain control consists of an informed, coordinated, consensual, documented, and revisited regimen of medication and other therapeutic interventions that eliminate or reduce the pain. Providers should encourage patients to report pain and inform them that acute pain need not be borne. Providers should administer sufficient pain control to relieve it. The measure of success is the patient's report that he or she is no longer suffering from pain.

E. What is the institutional responsibility to relieve suffering?

We suggest the institutional responsibility to relieve suffering lies in four domains:

1. Patient care should be scheduled and coordinated to allow more time for health care providers to elicit patients' perceptions of suffering;
2. Educational programs should be designed and implemented to ensure that providers are adequately skilled to address patients' suffering;
3. Research should be conducted to better understand what contributes to suffering and to evaluate interventions designed to relieve it; and
4. VHA should advocate changes in eligibility, access, and scope of services that contribute to more effective relief of suffering of sick veterans. We elaborate on these responsibilities below.

Schedule Adequate Time and Coordinate Patient Care

Institutions can facilitate opportunities for clinicians to ask about patients' suffering by scheduling more time for listening during outpatient visits, and restructuring traditional care teams so that interdisciplinary communication is maximized. Special consultative



clinical teams promoting the use of palliative care could be staffed. These special teams might include a psychologist, social worker, nurse, chaplain, and physician with expertise in palliative care. Any of these individuals could serve as the facility's palliative care case manager. Palliative care is widely understood as pain control and other comfort measures extended to dying patients. VHA's hospice consultative teams have expertise in palliative care and are currently available to assist with or provide end-of-life care. We advocate expanding the meaning of palliative care and the role of palliative care teams or case managers to include special interventions that would attempt to relieve any patient's suffering when routine measures fail.

Education

Because suffering does not fit within one discipline, educational programs need to be developed for students, trainees, and experienced clinicians in many of the clinical disciplines, including social work, nursing, medicine, psychology, chaplaincy, and other health care professions. Providers should learn the most recent recommendations of drugs, dosage, administration, and frequency for pain management. Educational programs should be case-based, clinically relevant to the learner, and interactive. Particular attention should be focused on the importance of listening to patients, asking them open-ended questions, and fostering trust in the relationship. In other formats, educational programs will need to foster sufficient self-awareness on the part of clinical trainees and clinicians to ensure that they do not impose their own projections and interpretations on the experiences that the patients report. In clinical settings, role modeling can help clinical trainees develop favorable attitudes about exploring suffering and learn practical skills such as talking to patients, listening to their stories, respecting their experiences, and knowing when to recognize the need for outside resources to help in the relief of the patients suffering. Educational objectives that promote desirable attitudes and skills are as important as those that target points of knowledge.



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Research

Research needs to follow several paths to advance knowledge in this area. First, it should be patient-centered and characterize the nuances of suffering such as how it feels, and what makes it better or worse, and how the patients respond to the clinicians' attempts at trying to relate to and relieve it. Research studies should also characterize secondary suffering on the part of family members and care providers. Second, research needs to identify the most efficacious strategies for eliciting and relieving suffering. This research will also need to identify those strategies that might work as part of institutional programs. Third, research needs to evaluate the effectiveness of educational interventions. Finally, research should evaluate quality improvement mechanisms to ensure that standards of practice with regard to relief of suffering are maintained and improved over time.

Eligibility, Access, and Scope of Service

VHA and each individual facility need to consider how policy decisions about the delivery and scope of health care effect the health, well-being, and suffering of veterans. Reduction of suffering related to disease and illness should be a desired outcome of comprehensive service and quality of care. Performance measures such as those developed for hospice care should be developed and employed to monitor this dimension of care.



Stories of Suffering

The Story of John: Suffering from Pain

John, a 66 year-old Korean War veteran, was admitted with excruciating pain in his right hip. He had suffered the pain for seven days and was unable to walk. For the past three months his private physician had prescribed 50 mg of Demerol prn and that plan had achieved very little relief. His wife, Marilyn, was at his bedside. John's facial expression suggested pain and fear. Marilyn was anxious. Both John and Marilyn looked fatigued and appeared depressed.

History and physical examination revealed that John had been diagnosed with prostate cancer several years ago. There was clinical evidence of severe bony pain over the upper lateral aspect of his right femur. No other sites of bone pain could be elicited. Aggressive pain control was immediately instituted with nonsteroidal anti-inflammatory drugs (NSAIDs), oral morphine, and a night time sedative. Later that day on evening rounds, John's pain had reduced from 10 of 10 to 4 of 10 on the visual analogue pain scale. He was much more relaxed. Marilyn, asleep in the bedside chair, awakened easily and expressed her thanks for the almost miraculous relief of John's pain. The next morning John said he had his first good night's rest in several weeks. His pain was well-controlled except on movement. He consented to additional diagnostic studies and received an extra dose of morphine. A bone scan revealed a single metastatic area in his right femur. After consultation with the radiotherapist, John agreed to a single hypo-fractionated dose of radiotherapy to his femur. He was discharged to home two days later on oral medications. He was assisted in entering his community's hospice program after a full discussion with him and his wife about his prognosis. Two weeks later John was able to walk and enjoy outings with his grandson. He died seven months later at home with support from the local community hospice.

John: What to Ask About

John's suffering is primarily physical. He is additionally suffering relationally and socially because of the physical suffering. What should



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providers ask in attempting to relieve John's suffering?

The lack of pain control at home is the primary source of the current suffering. In the story, adequate pain control reduces the suffering. The VAMC pain regimen is informed, effective, and appropriate. Why was it not provided at home? Did John not report his pain? Did he understate it? Was he fearful that the pain meant spread of his original cancer? Were John and his family too accepting of pain-based suffering? Did they not know that they could ask for pain control? Were they not informed about pain control? Did they think they should not ask (e.g., they believed they should keep a stiff upper lip, or, they were too intimidated to ask)?

Did the home town physician not hear John's pain? Not observe or infer its effects in his life? Not know how to redress it (i.e., pharmaceutical ignorance)? Not want to address it (e.g., John is a whiner, or pain is inevitable, or pain is good for the soul, or John will not become a bothersome addict while under my care)? Did the physician fear addressing it (e.g., prescribing opiates and analgesics invites trouble)? Or, simply, did the physician not ask about pain?

The story's descriptions of the characters give hints about what else to ask. John's physical suffering is also non-physical because effective relief began not with simply observance of symptoms, but with him telling his story to the VAMC physicians. Those physicians initiated relief of suffering by eliciting a complete medical, family, and social history. Also, John's suffering disturbed many aspects of his personhood. His body and bodily functions, mobility, overall functioning, sleep, feelings, spirit, and life plan are disrupted. Additionally, John's suffering was relational and contagious. His wife and grandson (and probably others back home) had caught it. Each person had come to suffer uniquely. Their sufferings combined to strongly disturb the quality of family life. Family disruption was next in the downward spiral. The family's psychological and spiritual suffering manifested in their fear, frustration, isolation, maladjustment, powerlessness, sorrow, and dread that they brought to the VAMC. Finally, the suffering in this story was acute, progressive, and



overwhelming. John and his family sought reassurance that they would survive these sufferings. The VAMC staff provided that reassurance, in large part by effectively communicating about the causes of the suffering and addressing them.

The Story of Paul: Suffering from Morbidity of Treatment

Paul, a 54 year-old veteran, was evaluated for liver transplant at the local VAMC and admitted to a VHA transplant center for more comprehensive evaluation. The patient and referring hospital staff had been hopeful that he would be accepted for transplant. Paul had been an alcoholic, but had stopped drinking many years before. He received consistent support from the VA Ambulatory Care Clinic's substance abuse team in sustaining sobriety during the wait for transplant.

After several weeks of evaluation at the transplant center, Paul was denied the liver transplant. At that time he was offered treatment for cancer that had been discovered during the transplant evaluation workup. The determination of the specific oncology protocol would be communicated following discharge. Paul was discharged to the referring VAMC to receive outpatient dental work prior to chemotherapy. He had to travel 200 miles round trip several times for the dental work. He suffered excruciating pain and loss of teeth. Morphine made him ill. During this time, communication about the oncology protocol proved futile. Repeated requests from the tertiary VAMC were answered by "doctors are still considering the options."

Paul was generally depressed, fearful, anxious, and lonely. Contributing factors were disease and disabilities, rejection for treatment, system inefficiency, family abandonment, marginalization, and impending death. Abandonment and rejection were shaping themes of Paul's life. A parent had abandoned him when he was a child. His wife had divorced him and left him with two children to raise. He had adapted in part by drinking excessively. Family violence, alienation, and loss followed.

At the time of admission to the local VAMC, family relations were strained. Some family said "he brought it on himself," and most of the



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family denied his plight or displayed minimal concern. He was greatly afraid that the family would further abandon him. Paul was also newly disturbed by the tertiary center's delay in prescribing his cancer therapy and the burdensome travel for dental treatment. He had felt a surge of desperate urgency about his liver transplant, and the health care system had responded slowly, indifferently, and bureaucratically. Paul had lost faith in VHA.

Health care providers from the local VA hospital and outpatient clinic finally came to grips with Paul's estrangement and suffering. His social worker and addiction therapist helped him overcome his resistance to talking with family members about his feelings regarding illness and prognosis. A brother-in-law was the first to grasp the seriousness of the situation, and he rallied other family. Paul's elderly mother came from another state and provided the 200-mile round trip transport for dental treatments. Two brothers, two sisters, a son, and a daughter communicated among themselves about their concerns, then pulled together to be with Paul in this critical time in his life. Everyone's quality of life improved.

Paul: What to Ask About

Paul's physical sufferings include bodily disabilities, discomforts and pain stemming from liver disease, cancer, dental extractions, and opioid therapy. A primary source of suffering was the combined failure of Paul's local and tertiary caregivers to organize and implement a plan of care that would provide comprehensive relief of these somatic morbidities. Why did the tertiary caregivers respond inconclusively for several weeks regarding an oncology protocol that they themselves had promised the patient? Why did local caregivers tolerate the delay? Why did morphine make Paul ill? What non-opioid pain control did the local health care providers offer for his pervasive pain?

This story alerts us about other sources of Paul's suffering. Paul's social worker, addiction therapist, and primary care physician from the local VA made a good start on relieving his suffering by asking about his social and family histories. Paul's relational and social sufferings were



acute, chronic, progressive, and cumulative. His life plan and his overall sense of meaning had dwindled. Alcoholism had severely strained family relations. Loss of family, indeed active rejection and negligence by the family, were hastening his death. Isolation, maladjustment, powerlessness, sorrow, and awareness of death built up. Yet, Paul was sufficiently hopeful about life and health that he sought life-sustaining and palliative medical treatments for his terminal and chronic conditions. VHA's slow response to meet Paul's needs triggered an old feeling of abandonment and a new one of despair.

Most of the relief of Paul's suffering came from his family. Family members forgave old offenses. They attended to Paul's spectrum of needs. The family convened and assured Paul that he would survive his immediate dire circumstances. Paul's family could not eliminate all suffering secondary to his lethal diseases. But they would soften suffering's final sting in their solidarity with Paul in his dying.

The Story of Michelle: Suffering from Mental Illness

Michelle, a 35 year-old single woman, had been in therapy with a dozen different therapists over many years. Michelle was brought to the local VAMC for treatment by a friend who had observed persistent suicidal thoughts and uncontrolled self-abusive behavior. Michelle was living in a tent in a public park. She was regularly abusing alcohol and prescription drugs. Her history included setting fires and cutting her forearms with a razor blade. The cuts were many and deep. She kept them hidden with bandages and long sleeves, even in the summer. The concerned friend had brought her to receive treatment and relief.

Michelle was estranged from her family. As a child, she had been sexually abused by brothers and neighbors. The family had neither believed nor prevented the abuse, effectively turning a blind eye to the situation. The family remained in denial that anything was wrong, despite Michelle's aberrant and self-destructive behavior. They professed embarrassment and would not visit Michelle. In their small town, their shared guilt would bring down the house should things be exposed. In addition, Michelle was torn by society's conflicted ideals.



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On the one hand, she was a bright and intellectual individual who had amassed many college credits without completing a course of study. Also, she served competently and honorably in the military for four years. On the other hand, she was morbidly obese. She was shunned and ridiculed because of her size. This rejection and ridicule caused her great discomfort and deflated any esteem she might have gained because she was smart, schooled, and a veteran.

Michelle was hospitalized at the local VA. The treatment plan was to address the life-threatening, self-destructive behavior, followed by outpatient therapy. In this hospitalization, a team of three individuals combined to relieve an element of Michelle's suffering. The team included an out-patient psychologist, an in-patient psychiatrist, and a social worker. A first breakthrough occurred in an in-patient group therapy session with the social worker. Michelle said that for the first time in her life, as best she could remember, she felt that she wanted to die. It was her first reported perceived feeling of the admission. Albeit depressed and wanting to die, she was happy that she was having a real feeling. Lasting only a few minutes, it was the beginning of something real. It seemed like a light at the end of the tunnel.

Unfortunately, other caregivers at the local VA added to Michelle's suffering. Some ward staff believed that self-abusive behavior was attention-seeking and manipulative. They actively alienated Michelle by treating her as if she were inferior. They completely discounted Michelle's self-destructive behavior, the message it was sending, and her as a person. Their response to her behavior intensified her suffering.

Michelle: What to Ask About

Michelle was desperately suffering. Her current suffering was manifestly expressed: self-medication, substance abuse, self-abuse, arson, and suicidal ideation. Her personhood was so disturbed that she welcomed her own death.

The three caregivers attempted to help Michelle by inviting her to tell her story about her estrangement from her family. Michelle's



relational and social suffering was rooted here. Michelle's mental illness was not named, nor pharmacological treatment of it discussed, and these were essential factors to ask about in considering relief of her suffering.

Michelle's medical and social history showed that she was disconnected from her personhood, indeed, displaced as the teller of her story. Except for the current three therapists, no one had asked about her suffering. Notably, the patient, her family, and the ward staff were all suffering in ways that prevented any of them from asking about any of the others. It is not surprising that therapeutic interventions to date had been ineffective.

Michelle's suffering exceeded the singular competencies of any of the medical and health care disciplines. Team care was needed to achieve partial relief of her suffering. Continued relief of suffering will require long-term therapeutic interventions. This may require challenging decisions to allocate limited resources.

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