

Edmund G. Howe, "Comment on the CEJA Guidelines: Treating Patients Who Deny Reality," *The Journal of Clinical Ethics* 17, no. 4 (Winter 2006): 317-22.

Comment on the CEJA Guidelines: Treating Patients Who Deny Reality

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The guidelines regarding therapeutic privilege that were recently issued by the American Medical Association Council on Ethical and Judicial Affairs (CEJA) direct doctors to exercise their best clinical judgment. The guidelines state, "physicians should assess the amount of information a patient is capable of receiving at a given time. . . ." In doing this, the CEJA has affirmed physicians' traditional approach, which remains open to ethical challenge.

When a careprovider doesn't disclose information, patients may undergo many losses, the greatest of which may be to lose the opportunity to state what they want.¹ If careproviders disclose all information to all patients, however, this might cause some patients inordinate harm. If a patient is in a situation such that he or she must deny reality, and a careprovider provides too much information, it may overwhelm the patient's psychological defenses. In response, the patient may have a catastrophic and psychotic reaction, commit suicide, or leave treatment, as it appears Ms. E did in the case described by Nicole Sirotin and Bernard Lo in "The End of Therapeutic Privilege?" in this issue of *JCE*.²

The CEJA guidelines may, then, represent an optimal ethical compromise between extremes, but this still leaves careproviders with an extremely difficult clinical question: *When should we use this therapeutic privilege?* Ideally, to answer this question, careproviders should understand as much about denial as possible.³ This is particularly important now, because the clinical significance of denial has recently changed radically. It had been viewed as being always pathological. Now, denial is viewed — in some cases — as being highly adaptive.⁴ In some instances, for example, it may reflect that a patient is not allowing illness, even when it is fatal, to dictate the remaining quality of the patient's life. This "fighting spirit" may help the patient emotionally and socially.⁵ It may also, in some cases, help a patient to live longer.⁶

This newly recognized difference in denial may be examined in considering scenes from two plays, Maxim Gorky's *The Lower Depths* and Eugene O'Neill's *The Iceman Cometh*. (In fact, O'Neill based his play on Gorky's). The main characters in the plays use denial to a great degree and rely on another character to help them in this — in a way as the characters in Samuel Beckett's play, *Waiting for Godot*, wait for Godot.⁷ In Gorky's play, the character Satine (a Godot-like character from whom others derive hope and faith) says:

I'm a convict, a murderer . . . granted. . . [Roars with laughter]. . . Man stands above hunger. . . What's a man to be afraid of?⁸

In O'Neill's play, *Hickey*, a Godot-like character, says:

It's always fair weather, when good fellows get together. . . And another little drink won't do us any harm. . . Bring on the rat poison.⁹

We might assume that these leading characters — and the characters who depend on them — are essentially the same in the two plays, especially as O'Neill based his play on Gorky's; in context, however, they are quite opposite. The character Satine in Gorky's play may offer the other characters a crucially important reason to "go on." As Gorky said of his own life,

[Why do] I try to recall those vile abominations of that barbarous life in Russia. . . [The] human power of goodness . . . awakens our indestructible hope that a brighter . . . life will be reborn.¹⁰

However, Stephen A. Black, in his biography of Eugene O'Neill, noted that writing *The Iceman Cometh*

took O'Neill deep into his mother's . . . addiction, which had made it impossible for her to care for him during his childhood.¹¹

While this inference regarding O'Neill is open to question, this possible contrast illustrates how denial may be beneficial in one context and harmful in another.

It appears that denial may be brought about consciously or unconsciously. Some patients report, for example, that denial is an active process, and that they produce it more or less intentionally to give themselves some more "time" (meaning time to absorb and adjust to highly distressing information).¹²

Other phenomena associated with denial seem to be "automatic and unmotivated."¹³ How might this be explained? In an article, "The Management of Denial in Cancer Patients," H. Steven Greer, MD, FRC, offers an explanation regarding patients who have anorexia nervosa (AN): "Conditioning history and selective information processing can perpetuate symptoms independently of anorexics' will or intent."¹⁴ Fortunately, whether denial is consciously or unconsciously motivated — or both — clinically, it doesn't make a difference. In either case, the approach is the same.

Sirotnin and Lo present the basic guidelines in their commentary in this issue of *JCE*. As they point out, the core consideration is that confrontation may "increase resistance in most people."¹⁵ Consequently, they urge careproviders who treat patients with denial to disclose new information slowly, to "titrate" it, if possible, to patients' apparent capacity to accept the information, and when necessary to disclose information only partially.

In addition, there are steps we can use to insure that patients' denial doesn't have a biological cause; for example, patients' denial may be caused by a brain tumor.¹⁶ Careproviders should have accurate information on what other careproviders have told patients, to be sure that patients are actually denying information.¹⁷ We can also discern whether a patient's denial interferes with obtaining optimal care. If it isn't, perhaps it may allow the patient to do better.¹⁸

Finally, careproviders should probably always consult with someone who has special expertise in mental health.¹⁹ One reason that patients may acquire denial is that they unconsciously associate new, potentially threatening information with a previous painful experience that they — or someone they know — has had. If this is the case, a careprovider skilled in psychotherapy may be able to help patients see this connection. If patients can see the connection, they may also be able, as a result, to overcome their denial.²⁰

Beyond these more-general principles, there are some additional approaches that careproviders may find useful, especially in more difficult cases.

"I'M NOT SURE I COULD LET YOU DIE"

As I suggested above, in some cases when patients' denial doesn't cause them to refuse treatment, it may be best to not intervene. Some patients report that they consciously deny to give themselves more time, as stated earlier. This suggests that in some cases patients may need additional time to give up their denial on their own. In a Japanese study just published, the careproviders on an in-patient service did not tell all of their patients that they had cancer. The authors explain that the patients went through stages of grief much like those Elizabeth Kubler-Ross described in her well-known research; however, the authors state that the patients who were not informed did better in their last days than the patients Kubler-Ross described, and they did better than the patients the authors used as a "control" group, who were informed.²¹ While these are the findings of only one study, and its findings are extremely limited, it nonetheless may suggest a very important aspect of patients' reality: that they can "do best" if they can accept stressful new information at their own pace.

Notwithstanding this, however, it may be that, in all cases that may involve denial, careproviders should determine whether they may ultimately try to override a patient's wishes and treat them. If this might happen, careproviders should inform the patient ahead of time. The best example of this may be when a patient has AN and may deny that she or he is greatly underweight, which may ultimately result in the death of the patient. This type of denial is, in fact, pathognomonic of AN. As one careprovider states, these patients' "fiercely egosyntonic pursuit of symptoms distinguishes anorexics even from drug abusers who rival their reputation as unmotivated clients."²² A critical difference between AN and many other medical conditions, such as cancer, is that AN is regarded as a psychiatric illness that legally may deprive patients of their capacity for competency. As this is the case, careproviders can try to hospitalize these patients against their will, and, when necessary, force-feed them.²³ Patients with other illnesses, such as cancer, may also deny that they are seriously ill and refuse treatment. Their careproviders may have no choice, however, but accept this.

When careproviders see a patient (such as a patient with AN) with whom they may intervene in this way, they should warn the patient, because that may be the only way to preserve the patient's trust. As K. Vitousek and S. Watson, leading experts on treating patients with AN noted, "Any hints of insincerity or duplicity can cause irreparable harm to the fragile alliance bridging the separate interests of therapist and client."²⁴ Such "fragile alliances" may be the only way that some patients may be able to overcome their denial. By telling the truth from the start, careproviders may have a hope of being able to help patients. One strategy for patients with AN may be to say, "I must tell you something before we proceed. You can die from not eating. I'm not sure if I could bear that emotionally. If you chose not to eat, I don't know what I would feel. I might feel that I must do whatever I can, legally, to try to prevent you from dying. Since you know this now, you might want to try to find another doctor."

When careproviders say this, based on what they feel — not on the law — it may increase their credibility with a patient, particularly because it is honest. It is true that none of us can predict with 100 percent accuracy how we will react in the future. By stating that they are uncertain, careproviders may avoid triggering oppositional tendencies in patients who are "primed" to resist: careproviders who tell a patient something like this are not saying *what they will* do; they have only said what they *could* do.

In my own practice, I took an approach somewhat like this with a patient who had chosen the day on which he would take his own life. The psychiatrist whom the patient had been seeing — for years — was to move overseas in a short time. The patient told his psychiatrist about his decision, and the day he chose. The patient had been hospitalized and received electroconvulsive therapy (ECT) for severe and intractable depression many times. The psychiatrist believed she could try to hospitalize him involuntarily, and administer ECT against his will, but that this would make his prognosis worse in the long run. The patient indicated this was absolutely what he didn't want, and would regard this as a complete betrayal. He indicated that if the psychiatrist did this he would "get out" sooner or later, and then would certainly not see a careprovider, but would end his life.

The patient said he wanted to stop seeing the psychiatrist immediately, so that when the day came weeks later, he could end his life without hurting her quite as much. She knew she didn't want to hospitalize him against his will, but beyond this she didn't know what to do. She consulted me, and I met with the patient. I said that I would be willing to continue to meet with him, to see if he could feel better and/or better accept his life as it was. I said that he had to know that I couldn't guarantee that, as the date came nearer, I wouldn't try to do everything I could to try to save his life. I said, "I can't imagine seeing you one morning, knowing that you will go and kill yourself later on the same day." He agreed to continue to meet with me, and I have to admit that I became "unraveled" as the date came nearer; especially after a meeting less than a week before the date, when he called to tell me he lied when he said that he no longer planned to kill himself. Fortunately — in my view — the date passed and he still hasn't ended his life. He is trying, instead, to see if he can feel better.²⁵

HOW WOULD YOU FEEL IF SOMEONE SAID, "I THINK YOU SHOULD GIVE UP YOUR CHILD"?

In many instances, careproviders will already have a relationship with a patient before a difficult diagnosis is made. In these cases, careproviders may ask the patient how much he or she would want to know once the diagnosis has been made. As Sirotin and Lo note, some patients may specifically say they don't want any information.

But when careproviders already know a patient's diagnosis, the dilemma is exponentially greater. Perhaps careproviders should not ask the patient what she or he thinks a hypothetical patient in the same situation might want (even though this is often advised). Asking this question in this way risks destroying the patient's trust — the patient may see through this and realize that the careprovider is asking the patient about himself or herself in a disguised way. The patient may conclude that if the careprovider is unwilling to be forthright, the careprovider may be less than honest with the patient and may not be able to work with the patient effectively.

To reach patients with denial, careproviders must first be able to truly empathize with them. As Vitousek and Watson suggest, "Clinicians need to acquire a frame of reference that helps them 'get' this condition before they can make effective use of . . . techniques for validating the experience of difficult clients."²⁶

"Getting" a patient's frame of reference may not be as easy as it would seem. To imagine how a patient feels when her or his denial is challenged, Vitousek and Watson suggest trying to imagine how we would respond if a careprovider said to us, "After careful assessment of your family, I am convinced that it was a terrible mistake for you to have had your daughter. . . . Therefore, I have decided to take your daughter away."²⁷

Once we have tried to imagine this, then we may be able to elicit patients' reasons for having and maintaining their denial — as well as they are able to provide a reason.

Once a patient provides reasons, careproviders can continue to help them by "validating" the reasons. In most cases this is not difficult. As Vitousek and Watson point out regarding patients with AN, for example, "After all, they do feel better when they lose weight, and they do feel worse when they gain."²⁸ Careproviders can acknowledge other reasons that patients may have for denial, including the desperation that patients may feel about changing when they don't want to change, or patients' fear of losing control in front of others whom they don't trust.²⁹

Careproviders could consider praising patients for having courage — the courage to maintain their denial, notwithstanding the extreme pressure they may face from others. One might say, for instance, "It must be extraordinarily difficult for you to maintain this belief when you are under such pressure from others to give it up. What courage you must have. . . . I am not sure I could do this at all."³⁰

If a careprovider can acknowledge a patient's reason for denial, they might be able to ask a patient if he or she would be willing to discuss the "pros and cons" of making a decision that would be consistent with the patient's denial. If the patient gives permission to do this, the careprovider can take the lead in asking helpful

questions. For example, for a patient with AN, a careprovider could ask, "Would the significance of your body's shape change for you if you were stranded on a desert island?"³¹

Finally, careproviders might invite patients to consider changing their behavior on a wager, like Pascal. For example, patients may still choose to believe within themselves that they don't have a disease like cancer, but, at the same time, accept treatment regardless.³² Careproviders can also introduce other reasons that patients might accept treatment; for example, if patients accept treatment — regardless of their own beliefs about illness — this may provide profound emotional relief for their family members and other loved ones.

In time, patients may decide, consciously or unconsciously, in response to these questions, that their denial — or at least the consequences of refusing treatment due to denial — isn't "worth it." If they don't make this decision, however, it is unlikely that they will ever give up their denial.

Given all of these considerations, patients' interpersonal interactions with their careprovider may be the best — perhaps only — way that they have to overcome denial. As their denial may have begun in response to interpersonal pressures, it may be through interpersonal relationships that their denial is best undone.³³

Such "undoing" may occur as it did in this case. At 3 a.m., a patient, who was unable to sleep, began to talk with the nurse who was sitting by her side. After weeks in the hospital, still showing denial, the patient suddenly asked the nurse, "Do you think there's any chance that what all my doctors have been telling me might be true?"

NOTES

1. As D. Pirakitikulr and H.J. Bursztajn state, in "The Grand Inquisitor's Choice: Comment on the CEJA Report on Withholding Information from Patients," in this issue of *JCE*, the CEJA guidelines could be used by physicians as a Trojan horse to excuse failure to obtain informed consent. As Norman Quist noted, to give careproviders discretion keeps the door open for "backdoor paternalism." Communication with the author, November 2006.

2. M. Marzanski, "Would You like to Know What is Wrong with You? On Telling the Truth to Patients with Dementia," *Journal of Medical Ethics* 26, no. 2 (April 2000): 108-13.

3. See, generally, M.S. Vos and J.C. Haes, "Denial in Cancer Patients, an Exploratory Review," *Psych-Oncology* (25 July 2006), www.interscience.wiley.com DOI: 10.1002/pon.1051.

This piece distinguishes four different kinds of denial and reviews all of the studies regarding each.

4. The concept of denial originated in psychoanalytic theory.

5. R. Goldbeck, "Denial in Physical Illness," *Journal of Psychosomatic Research* 43, no. 6 (1997): 575-93. For a provocative discussion of how information may make decision-making worse, see also R. De Vries and C. Elliot, "Why Disclosure?" *Journal of General Internal Medicine* 21, no. 9 (2006): 1003-4.

6. S. Greer, "The Management of Denial in Cancer Patients," *Oncology* 6, no. 12 (December 1992): 33-6, and D. Dudley et al., "Long-Term Adjustment, Prognosis and Death in Irreversible Diffuse Obstructive Pulmonary Syndrome," *Psychosomatic Medicine* 31 (1969): 310-25.

7. S. Beckett, *Waiting for Godot* (New York: Grove Press, 1982).

8. M. Gorky, *The Lower Depths*, trans. J. Covan (Mineola, N.Y.: Dover Publications, 2000), 61-2.

9. E. O'Neill, *The Iceman Cometh* (New York: Vintage Books, 1957), 76.

10. M. Gorky, *My Childhood*, trans. R. Wilks (London: Penguin Books, 1966), 217.

11. S.A. Black, *Eugene O'Neill* (Yale University Press, 1999), 424.

12. C. O'Callaghan, T. Powell, and J. Oyebo, "An Exploration of the Experience of Gaining Awareness of Deficit in People Who Have Suffered a Traumatic Brain Injury," *Neuropsychological Rehabilitation* 16, no. 5 (2006): 579-93, 591.

13. Greer, see note 6 above.

14. *Ibid.*

15. *Ibid.*

16. Goldbeck, see note 5 above, p. 586.

17. *Ibid.*, 585-6.

18. *Ibid.*

19. Greer, see note 6 above.

20. *Ibid.*, 36.

21. Y. Maeda et al., "Psychological Process from Hospitalization to Death among Uniformed Terminal Liver Cancer Patients in Japan," *BMC Palliative Care* 5, no. 6 (2006), www.biomedcentral.com/1472-684X/5/6 doi: 10.1186/1472-684X-5-6. "The informed patients of Kubler-Ross were not happy and were almost devoid of feelings at the 'acceptance' stage, . . . the uninformed patients in this study had peaceful feelings about accepting death," (p. 19).

22. K. Vitousek and S. Watson, "Enhancing Motivation for Change in Treatment-Resistant Eating Disorders," *Clinical Psychology Review* 18, no. 4 (1998): 391-420, at 393. See also C. MacDonald, "Treatment Resistance in Anorexia Nervosa and the Pervasiveness of Ethics in Clinical Decision Making," *Canadian Journal of Psychiatry* 47, no. 3 (1 April 2002): 267-70; Work Group on Eating Disorders, "Treatment of Patients with Eating Disorders," *American Journal of Psychiatry* 163, no. 7 (2 July 2006, supp.): 1-54.

23. M. Gans and W.B. Gunn, Jr., "End Stage Anorexia: Criteria for Competence to Refuse Treatment," *International Journal of Law and Psychiatry* 26 (2003): 677-95.

24. Vitousek and Watson, see note 22 above.

25. In light of this patient's profound, unremitting emotional suffering, others may feel that it is not fortunate that he survived past this date.

26. Vitousek and Watson, see note 22 above, p. 398.

27. *Ibid.*, 394.

28. Vitousek and Watson, see note 22 above.

29. *Ibid.*

30. An example of the success of this approach is offered by psychiatrist Leston Havens. In regard to a patient with schizophrenia who had denial, Havens states, "[When I] admired him for clinging to [his ideals], . . . the bridge back to his mature self was put in place." L. Haven, *A Safe Place* (New York: Ballantine, 1989), 113.

31. Vitousek and Watson, see note 22 above.

32. J.A. Connor, *Pascal's Wager* (San Francisco: Harper, 2006), 200.

33. This is suggested by studies that report that persons may be more likely to show denial if they are married, and that they may be more likely to have denial if they have lung cancer. J. Levine and E. Zigler, "Denial and Self-Image in Stroke, Lung Cancer, and Heart Disease," *Journal of Consulting and Clinical Psychology* 43, no.6 (1975): 751-7. See also Vos and Haes, see note 3 above.

The finding regarding marital state may result from a need or desire to protect others; if patients' loved ones know the truth, they may experience extraordinarily emotional pain, and patients may experience pain each time they see others' pain in response to them. A.A. Reinders et al., "Detecting Fearful and Neutral Faces: Latency Differences in Amygdale-Hippocampal Junction," *Neuroimage* 33, no. 2 (1 November 2006): 805-14. Each time patients' pain is cued by discussion of their illness, it may make the pain more intense. More generally, talking about painful realities can increase patients' trauma. See R. Mayou, A. Ehlers, and M. Hobbs, "Psychological Debriefing for Road Traffic Accident Victims: Three-Year Follow-Up of a Randomized Controlled Trial," *British Journal of Psychiatry* 176 (2000): 589-93. This repeated stress may result in the pain becoming ever-present, rather than transient. J. Debiek and J. LeDoux, "Noradrenergic Signaling in the Amygdala Contributes to the Reconsolidation of Fear Memory," *Annals of the New York Academy of Sciences* 1071 (2006): 521-4; G.M. Morris et al., "Memory Reconsolidation: Sensitivity of Spatial Memory to Inhibition of Protein Synthesis in Dorsal Hippocampus during Encoding and Retrieval," *Neuron* 50 (4 May 2006): 479-89.

The latter finding (regarding lung cancer, smoking, and guilt), some suggest, may be caused by patients' feelings that contributed to acquiring cancer by smoking; and so they deny their illness, consciously or unconsciously, to assuage feelings of guilt.