

May 2017

Volume 19, Number 5: 411-513

Ethics in Mental Health and Oncology

From the Editor

- Unexplored Ethical Issues at the Intersection of Mental Health and Oncology** **413**
Weisheng Renee Mao

Ethics Cases

- Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal** **416**
Commentary by Joshua M. Baruth and Maria I. Lapid
- Do Pediatric Patients Have a Right to Know?** **426**
Commentary by Philip M. Rosoff
- How Should Clinicians Respond to Transference Reactions with Cancer Patients?** **436**
Commentary by Fatima Noorani and Allen R. Dyer
- Ethical Management of Patients with Cancer and Mental Illness** **444**
Case and Commentary by Laurel J. Lyckholm and Arwa K. Aburizik

Podcast

- The Importance of Spiritual Care Referrals for Cancer Patients: An Interview with Dr. Tarris Rosell**

In the Literature

- How Situational Diagnosis Helps Disentangle Ethical and Psychological Features of Complex Cases** **454**
Jerry Joseph Ignatius and Walter Baile

State of the Art and Science

- Assessing Psychological Toxicity and Patient-Reported Distress as the Sixth Vital Sign in Cancer Care and Clinical Trials** **460**
Thomas W. LeBlanc and Arif H. Kamal

**When and Why Should Mental Health Professionals Offer
Traditional Psychodynamic Therapy to Cancer Patients?** 467
David P. Yuppa and Fremonta Meyer

Medicine and Society

**Decreasing Smoking but Increasing Stigma? Anti-tobacco
Campaigns, Public Health, and Cancer Care** 475
Kristen E. Riley, Michael R. Ulrich, Heidi A. Hamann, and Jamie
S. Ostroff

**Prioritizing Mental Health Research in Cancer Patients
and Survivors** 486
Monica R. Martinez and Amirala Pasha

**Should Clinicians Intervene If They Suspect That a Caregiver
Whose Child Has Cancer Is at Risk of Psychological Harm?** 493
Amy E. Caruso Brown

Images of Healing and Learning

**From Silence into Language: Questioning the Power of
Physician Illness Narratives** 501
Amy E. Caruso Brown and Rebecca Garden

They Are People First, Then Patients 508
Monica Lalanda, Eva Gracia-Peligero, and Maria Teresa
Delgado-Marroquín

About the Contributors 510

FROM THE EDITOR

Unexplored Ethical Issues at the Intersection of Mental Health and Oncology

Perhaps no diagnosis is as universally feared as that of cancer. It is intuitively and empirically evident that fundamental uncertainties of a cancer diagnosis, such as prognosis and morbidity, can engender significant distress and dominate a patient's cancer experience. For instance, reported rates of depression range from 22 percent to 57 percent and from 33 percent to 50 percent for oropharyngeal and pancreatic cancers, respectively [1], which are significantly higher than the 6.7 percent 12-month prevalence of a major depressive episode among US adults [2]. In addition, there are not only psychological mechanisms at play in cancer patients' experiences but also biological ones, with bidirectional relationships between mental and physical outcomes in oncological settings that are not entirely understood at this time but which might have significant clinical implications [3, 4].

Despite the importance of the relationship between mental health and oncology, psycho-oncology did not formally develop as a field until the mid-1970s due to stigma related to cancer and mental health issues [5]. Although stigma from both sources still exists, multiple disciplines have made contributions to both research and clinical care that seek to minimize its impact on patients' illness experiences. Research and clinical care innovations include but are not limited to behavioral interventions to decrease cancer risk and increase early detection; management of psychological issues before, during, and after treatment; and discovery of connections between psychological and physiological domains that relate to cancer risk and survival [5]. This issue of the *AMA Journal of Ethics*® aims to contribute to the developing model of integrative cancer care by examining several currently unexplored sources of ethical complexity in cancer illness experiences.

One ethical concern is the relative lack of distress screening and interventions in cancer research and care settings. Mónica R. Martínez and Amirala Pasha assess the landscape of contemporary cancer research and argue that more attention and [funding](#) should be devoted to mental health research. Considering that many cancer centers have added distress as the "sixth vital sign" as the psychological impact of patients' cancer experiences and treatment have gained attention [5, 6], Thomas W. LeBlanc and Arif H. Kamal look specifically at whether [clinical trials](#) adequately incorporate assessments of distress and how this information might guide treatment decisions within routine clinical care.

Decision making is a focus of several other contributors to this issue. Responding to a case in which a patient with a potential mood disorder has rejected further cancer treatment, Joshua M. Baruth and Maria I. Lapid discuss a conceptual model of informed consent and [decision-making capacity assessment](#) and examine how clinicians' conversations with family members or surrogates is key to understanding a patient's best interests and values. A patient's role is emphasized in Philip M. Rosoff's commentary on a case in which parents do not wish to inform their child of likely [infertility following chemotherapy](#) or to delay his treatment for the purpose of sperm cryopreservation. Rosoff considers potential mental health consequences from the child's exclusion from this decision and ultimately suggests what might constitute an appropriate clinical, ethical, and legal response in light of possible future harms to the patient. And Jerry Joseph Ignatius and Walter Baile discuss several [factors that can obscure an ethical dilemma](#) and consider their influence in psycho-oncological settings.

Two articles consider the ethics of treatment. Focusing on psychiatric treatment for oncological patients, David P. Yuppa and Fremonta Meyer [compare treatment modalities](#) and argue that while time-limited "manualized" (e.g., behavioral) therapies are prominent in recent studies and potentially easier—emotionally and clinically—to conduct than traditional psychodynamic psychotherapy, they might not have superior efficacy depending on the treatment goals and thus might not represent a more appropriate treatment approach. Focusing on cancer treatment, Laurel J. Lyckholm and Arwa K. Aburizik argue that clinicians must give those with [preexisting mental illness](#) special attention due to their vulnerability and exercise empathy and imagination in delivering just, compassionate care.

Medical decision making and treatment, however, cannot ignore the context in which care is delivered. In their commentary on a case of a young cancer patient who terminates all treatment after her psychiatrist responds professionally to her confession of a romantic attachment to him, Fatima Noorani and Allen R. Dyer discuss the ethics of [maintaining boundaries](#) and how to manage patients' and physicians' emotional responses and transference reactions to each other in settings in which patients might feel particularly vulnerable and in need of support. Amy E. Caruso Brown considers how to [support caregivers](#) in an article examining the ethical obligations of clinicians who have concerns about the mental health of a pediatric patient's caretaker.

Last, this issue of the *AMA Journal of Ethics* considers factors outside the clinical setting and how they might impact a patient's experience of cancer. Kristen E. Riley, Michael R. Ulrich, Heidi A. Hamman, and Jamie S. Ostroff question whether stigma generated by hard-hitting [anti-tobacco public health campaigns](#) is a justifiable cost of efficacious public health benefits; they also consider how clinicians might diminish their potential roles in perpetuating stigma among patients with lung cancer. Amy E. Caruso Brown and Rebecca Garden analyze how [physicians' literary memoirs](#) about their own cancer

experiences help them bridge the divide between clinicians and patients and examine ethical issues that arise in clinicians' writing about patients. Finally, in the podcast, Tarris Rosell discusses the role that [religion or spirituality](#) can play in an oncological patient's health, particularly his or her mental health, and considers what constitutes an appropriate response to a patient's spirituality concerns.

The relationship between mental health and oncology is nuanced, and it can be approached from multiple directions—for instance, by considering the biological and psychological impact of cancer treatment on a patient's mental health, the oncological care afforded to those with mental illness, and the ways that mental illness can affect oncological treatment and vice versa. This theme issue aims to probe issues of clinical and ethical importance, with the hope of focusing more attention and research on exciting and essential intersections of cancer and mental health care.

References

1. Massie MJ. Prevalence of depression in patients with cancer. *J Natl Cancer Inst Monogr.* 2004;(32):57-71.
2. National Institute of Mental Health. Major depression among adults. <https://www.nimh.nih.gov/health/statistics/prevalence/major-depression-among-adults.shtml>. Accessed March 13, 2017.
3. Bortolato B, Hyphantis TN, Valpione S, et al. Depression in cancer: the many biobehavioral pathways driving tumor progression. *Cancer Treat Rev.* 2017;52:58-70.
4. Mayr M, Schmid RM. Pancreatic cancer and depression: myth and truth. *BMC Cancer.* 2010;10:569. <http://bmccancer.biomedcentral.com/articles/10.1186/1471-2407-10-569>. Accessed March 28, 2017.
5. Holland JC. History of psycho-oncology: overcoming attitudinal and conceptual barriers. *Psychosom Med.* 2002;64(2):206-221.
6. Bultz BD, Carlson LE. Emotional distress: the sixth vital sign—future directions in cancer care. *Psychooncology.* 2006;15(2):93-95.

Weisheng Renee Mao

MS-3

*The George Washington University School of Medicine and Health Sciences
Washington, DC*

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

ETHICS CASE

Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal

Commentary by Joshua M. Baruth, MD, PhD, and Maria I. Lapid, MD

Abstract

How psychiatric symptoms affect patients' decision making in practice can inform how we think—theoretically and conceptually—about what it means for those patients to have decision-making capacity. Assessment of a patient's decisional capacity allows those with adequate capacity to make choices regarding treatment and protects those who lack capacity from potential harm caused by impaired decision making. In analyzing a case in which a patient with stage II breast cancer refuses further treatment, we review the conceptual model of informed consent and approaches to assessing decision-making capacity that are in accordance with the American Medical Association *Code of Medical Ethics* as well as tools to assess decisional capacity.

Case

Dr. A is the oncologist for Catherine, a 55-year-old woman with newly diagnosed stage II breast cancer. When Dr. A asks about Catherine's past medical history during her initial consultation, Catherine mentions that she has often felt so tired over the past two years that she could barely get out of bed. "It just didn't seem worth it to wake up," she explains. "So I'd just sleep all day because I didn't want to do anything. It's not like anyone would really miss me, anyway." Dr. A asks if Catherine feels that way now, and she shrugs, "Sometimes. It comes and goes. It was bad after my husband died two years ago, but I guess I feel okay now." Dr. A also notices in Catherine's health record that her weight has fluctuated up to thirty pounds in both directions. When asked about this, Catherine says, "I don't really remember why—probably different diets." Catherine reports that she has never talked about her mood with a clinician. She adds, "Everybody used to say I was just moody."

During treatment, Catherine experiences side effects so severe that she cannot go to work and reports difficulty with activities of daily living, as she lives alone and lacks immediate family or close friends. As Dr. A evaluates her initial response to treatment, he sees that her tumor burden has actually increased slightly, and he informs Catherine that she might have to undergo more aggressive therapy. At this, Catherine shakes her head and says, "I won't do it." When pressed further, Catherine says, "It isn't worth it to me. I've thought a lot about my life over the past weeks, and there just isn't any reason to

keep going, especially since my husband died." Dr. A asks Catherine to consider people or activities she still enjoys, to which Catherine retorts, "That's exactly what I did. I couldn't think of any." Dr. A then asks about her struggling to come to terms with her cancer and suffering during treatment. Catherine says sarcastically, "Well, it's no picnic. But honestly, Dr. A, I'm okay with things ending here. I've lived my life, and, at this point, I'm tired of suffering. I just want to be with my husband. I miss him all the time."

Uncertain about Catherine's mental health, particularly given her history, Dr. A consults Catherine's primary care physician, Dr. B. Dr. B recalls, "There were times over the years when she seemed a little withdrawn, but nothing ever jumped out at me." He confirms that her husband, who was her main social support, died two years ago and says that he has not seen her since then. "She and I had a pretty good relationship, though," Dr. B adds. "I'm sure I can convince her to consent to further treatment. I can't imagine having *nothing* to live for."

Wanting additional and more up-to-date information, Dr. A refers Catherine to a psychiatrist, Dr. C, who diagnoses Catherine with complicated grief and prescribes antidepressants. However, Catherine does not fill the prescription. When Dr. A calls to ask her about this, Catherine says, "Look, I understand what's at stake here, and I've made up my mind. Please don't make this harder for me." She expresses understanding of the risks and benefits of refusing further treatment for her cancer.

Dr. A wonders if Catherine's grief has compromised her capacity to give an informed refusal. He also wonders just how far her current feelings are from her baseline mood, how much distress her cancer experience has caused her, and the degree to which this could be influencing her decision making. Lastly, Dr. A considers Dr. B's offer to try to "convince" her and wonders whether further attempts at persuading her might not be respectful of her decision and values. What should Dr. A do?

Commentary

Determinations of medical decision-making capacity are intended to uphold patients' rights to make their own medical decisions but at the same time protect them from their decisions when their capacity is compromised. It should be noted that capacity is attached to a particular medical decision (e.g., consent to treatment, participation in research) at a particular time [1]. A person lacking capacity for one medical decision may have capacity for other decisions [2]. Assessing capacity can be subjective and confusing for clinicians, particularly when patients refuse a recommended treatment or the treatment involves substantial risk.

The presence of adequate decision-making capacity is a mandatory criterion of the informed consent process. For informed consent to be valid, three elements must be present: *provision of information*, *voluntariness*, and *competence* [3]. Provision of

information requires that a patient receive adequate information regarding the nature and purpose of a treatment or procedure as well as the risks, benefits, and alternatives of each option, including no treatment. Voluntariness requires a decision to be made voluntarily and free from coercion. Competence is a legal determination of mental capacity that includes those abilities evaluated by clinicians in assessing decisional capacity. The legal standards for evaluating capacity are generally based on patients' ability to: (1) understand the relevant information about their condition and proposed treatment; (2) appreciate the nature of their situation, including their underlying values and the potential consequences of their choice; (3) reason about the potential risks and benefits of their choices; and (4) express their choice [4, 5]. This assessment process is in accordance with the American Medical Association *Code of Medical Ethics*' "Opinions on Consent, Communication & Decision Making" [6]. In this article, we discuss the case in the context of this guidance and the conceptual model for informed consent and approaches to assessing decision-making capacity.

Influence of Psychiatric History and Current Diagnosis

As we see in this vignette, Catherine is experiencing complicated grief following the death of her husband two years prior as well as a recent diagnosis of stage II breast cancer. Complicated grief is an older term for grief in which significant incapacitation persists for over six months following a loss [7]. In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, it is now included in a proposed psychiatric syndrome called persistent complex bereavement disorder (PCBD), although the emphasis remains on distress or functional impairment so severe that is outside of sociocultural norms of [bereavement](#) [8].

Catherine presents a clinical picture consistent with depressive symptomatology occurring initially in the context of grief, since her husband died almost two years prior to her cancer diagnosis. After her husband's death she experienced fatigue, inability to get out of bed, feeling it was not worthwhile to wake up, excessive sleepiness, lack of motivation, severe weight fluctuations, and moodiness. Although Catherine reports these symptoms are now intermittent, they clearly are in excess of normal grief given their duration (two years) and severity. Her depressive symptoms have worsened during the progression of her cancer, to the extent that she now expresses increasing feelings of worthlessness, finding no reason to live, anhedonia, and desire for death suggestive of passive suicidality. It is important in this case to recognize the presence of major depression, the serious risk of suicide, and the need to treat appropriately.

Depression can impair medical decision making, and Catherine's severe depression, significant functional impairment, and possible passive suicidality put her at risk of making treatment decisions that she would not otherwise make if she were not depressed. One important ethical consideration, then, is whether it is ever justifiable to consider a patient's refusal of treatment to be indicative of lack of decisional capacity

based on a patient's symptoms of mental illness. What is the relationship between psychiatric symptoms and medical decision-making capacity, and is it ever appropriate to take into consideration a patient's psychiatric diagnosis when determining capacity? And what if the patient is refusing treatment? Historically, it has been a common perception that people with mental illness have a reduced ability to provide informed consent [9]. Severe depression can manifest as impairment of information processing and reasoning that can significantly affect decision making [10]. Compromised ability for decision-making capacity has also been associated with disorders like dementia and delirium [11], intellectual disability [12, 13], psychosis [14, 15], and bipolar disorder [16-18]. Additionally, reduced decision-making capacity has been associated with patients admitted involuntarily or patients refusing treatment [15]. Not surprisingly, there has been controversy regarding the appropriateness of including people with mental illness in medical research [19, 20].

Yet, studies have shown that decision-making capacity is preserved in the majority of psychiatric patients [15], including those with mild to moderate depression [21-23]. Diagnostic categories alone (i.e., Alzheimer's, depression, schizophrenia) do not equate with presence or absence of decision-making capacity [1]. For example, in schizophrenia, capacity is correlated only modestly with psychotic symptoms but more strongly with cognitive dysfunction [24].

Therefore, based on the bioethical literature, it would be inappropriate to let a prior or current psychiatric diagnosis determine Catherine's medical decision-making capacity. Accordingly, her capacity should be determined in the context of her current decision and underlying values. Determining that she has some understanding and ability to communicate her decision may be straightforward. In the vignette, Catherine says: "Look, I understand what's at stake here, and I've made up my mind." However, it may be a bit more difficult to adequately assess her ability to reason and appreciate her underlying values. Is Catherine able to use reason in the context of a psychiatric diagnosis for complicated grief? Is she able to identify her underlying values while experiencing significant distress related to her husband's death and her own cancer diagnosis?

One instrument to assist clinicians in evaluating decisional capacity is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), a semistructured interview that requires the clinician to provide patients relevant information about the medical condition; the proposed treatment options; and the risks, benefits, and alternatives of each treatment option. After [provision of information](#), the clinician is further guided by a set of questions to test patients' understanding and appreciation of the information presented to them, their reasoning ability in going through the different treatment options and making a selection, and their ability to communicate a choice [25]. The MacCAT-T has been used to measure decisional capacity in people who are severely depressed [26], so use of this instrument in Catherine's case would provide valuable

information regarding her unique situation and decision. Importantly, it has been shown that physicians often fail to correctly recognize incapacity, sometimes as much as 58 percent of the time [2], which further highlights the importance of using formal assessments like the MacCAT-T as well as consulting relatives and other members of the health care team.

Determination of Best Interest and Capacity

Another important ethical question highlighted by this vignette is who is best positioned to [assess decisional capacity](#) and the patient's best interest. A psychiatrist is most commonly consulted to assess decisional capacity, but any licensed physician can make the determination [27]. It is important for physicians to consider that their determination is not just clinical, but ethical [28, 29], and should not be based solely on objective measures [29]. The belief system and morals of physicians should not unjustly influence their decisions about capacity. It has been proposed that the influence of these factors can potentially be reduced by physicians' recognizing their own biases, seeking second and contrasting opinions, and reporting the results of different conclusions [29].

Discussions with family and the multidisciplinary health care team are key in determining patient values that inform medical decision making. For example, including physicians previously involved in the patient's care and the hospital ethics service can be important in understanding a patient's belief system and decision-making history, which information can support conclusions regarding capacity if prior medical decisions are in agreement with the decision being made currently. Not only can information from family and other health care professionals be used to support conclusions when determining capacity, but it can be useful to a surrogate or proxy decision maker when a patient is deemed to lack decisional capacity. Through substituted judgment based on knowledge of the patient's wishes or preferences, a surrogate decision maker upholds the ethical principle of respect for autonomy [30]. If the patient's wishes are unknown, or when necessary to prevent suffering, the surrogate makes decisions based on what he or she thinks is in the best interest of the patient [30]. For example, a surrogate may rely on knowledge of a patient's spiritual commitment and its role in past medical decisions in judging what is in the best interest of the patient.

Influencing a Patient's Decision

Another important ethical consideration for this vignette is whether it is ever appropriate for a physician to attempt to influence the patient's decision. One of the essential elements of informed consent is a lack of coercion, assuming the patient has capacity to make a decision independently. In cases in which the patient's decision may not appear to some to be in his or her best interest, despite seeming to have adequate decisional capacity, there are approaches physicians can use to assist the patient in an unbiased way without disrespecting his or her autonomy. First, if the patient does not recognize the importance of a capacity assessment, the physician should encourage the patient to

perform to the best of his or her ability on the evaluation [2]. Furthermore, a patient's capacity can be restored by treating reversible disorders that affect cognition (e.g., metabolic delirium, mania) and reassessing capacity later.

For those who require assistance with decision making due to impairments in decisional capacity, information provided to the patient can be simplified with alternate forms of communication (e.g., visual aids) [31]. In a prior study, one of the authors (MIL) and colleagues found that implementing an educational intervention improved decisional capacity in severely depressed patients [26]. Similarly, Carpenter and colleagues [24] showed that patients with schizophrenia improved understanding and capacity as measured by a study-specific version of the MacCAT-T following education. Other investigations also showed that education can assist psychiatric patients in achieving capacity to consent [32, 33].

Additionally, the impact of a decision should be considered. For example, vastly different outcomes result from refusing a life-saving treatment that could result in death and refusing a low-risk treatment that may or may not have negative consequences. Accordingly, with decisions involving greater risk, a physician should consider more than a single, objective assessment of capacity and incorporate more information based on prior decisions or what others consider a reasonable decision [34]. When grief, guilt, or personal loss distorts cognition, a psychiatrist would have the necessary expertise to assess how a patient's decision might be different when these emotions are not present [29]. However, when deviating from assessing capacity purely objectively, there is always the potential for paternalism. An approach to assessing capacity should be adopted that best fits the patient's needs, respects the patient's autonomy and values, and limits unnecessary physician influence [35].

In Catherine's case, it is imperative to communicate the importance of the capacity assessment and encourage her to optimize the process by treating her depression. Additionally, an approach to decision making that considers her established values and past decisions, without the undue influence of her current grief and personal loss, would be respectful of her best interest and autonomy.

Conclusion

When evaluating decisional capacity, it is essential for physicians to obtain a mental status examination and formal assessment of cognitive function. This procedure should be followed by assessment of the patient's: (1) understanding; (2) appreciation of his or her situation, including underlying values and potential consequences; (3) reasoning about the potential risks and benefits; and (4) ability to communicate a choice. Using a structured capacity assessment tool may provide valuable information concerning the patient's situation and decision. It is not appropriate to let a prior or current psychiatric diagnosis solely determine decisional capacity. However, if a patient is currently suffering

from a mood disorder, is potentially suicidal, or has any another condition that could potentially compromise his or her capacity, the patient should be referred to a psychiatrist for a formal consultation.

Decisional capacity can be optimized by treating reversible disorders that affect cognition. Information provided to patients can be simplified and educational efforts or alternative forms of communication should be implemented when needed. When patients have impaired decisional capacity, information from relatives, friends, or other physicians about their underlying values or spiritual beliefs, as well as their prior medical preferences and decisions, can be used to help assess whether medical decisions being made on their behalf are in alignment with what they value and what is important to them. Finally, a formal ethics consultation is an option, especially in more uncertain cases. For those with adequate decisional capacity, it is ethically acceptable to refuse treatment and, accordingly, for physicians to respect patients' autonomy.

References

1. Candia PC, Barba AC. Mental capacity and consent to treatment in psychiatric patients: the state of the research. *Curr Opin Psychiatry*. 2011;24(5):442-446.
2. Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? *JAMA*. 2011;306(4):420-427.
3. Meisel A, Roth LH, Lidz CW. Toward a model of the legal doctrine of informed consent. *Am J Psychiatry*. 1977;134(3):285-289.
4. Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment. *N Engl J Med*. 1988;319(25):1635-1638.
5. Appelbaum BC, Appelbaum PS, Grisso T. Competence to consent to voluntary psychiatric hospitalization: a test of a standard proposed by APA. *Psychiatr Serv*. 1998;49(9):1193-1196.
6. American Medical Association. Opinions on consent, communication & decision making. *Code of Medical Ethics*. <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-2.pdf>. Published 2016:chap 2. Accessed March 8, 2017.
7. Shear MK, Simon N, Wall M, et al. Complicated grief and related bereavement issues for *DSM 5*. *Depress Anxiety*. 2011;28(2):103-117.
8. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. 5th ed. Arlington, VA: American Psychiatric Association Publishing; 2013.
9. Pescosolido BA, Monahan J, Link BG, Stueve A, Kikuzawa S. The public's view of the competence, dangerousness, and need for legal coercion of persons with mental health problems. *Am J Public Health*. 1999;89(9):1339-1345.
10. Sullivan MD, Youngner SJ. Depression, competence, and the right to refuse lifesaving medical treatment. *Am J Psychiatry*. 1994;151(7):971-978.
11. Katz B. Detecting Alzheimer's disease. *Science*. 1995;267(5204):1578-1579.

12. Cea CD, Fisher CB. Health care decision-making by adults with mental retardation. *Ment Retard*. 2003;41(2):78-87.
13. Wong JG, Clare CH, Holland AJ, Watson PC, Gunn M. The capacity of people with a "mental disability" to make a health care decision. *Psychol Med*. 2000;30(2):295-306.
14. Dunn LB, Palmer BW, Keehan M, Jeste DV, Appelbaum PS. Assessment of therapeutic misconception in older schizophrenia patients with a brief instrument. *Am J Psychiatry*. 2006;163(3):500-506.
15. Okai D, Owen G, McGuire H, Singh S, Churchill R, Hotopf M. Mental capacity in psychiatric patients: systematic review. *Br J Psychiatry*. 2007;191(4):291-297.
16. Clark L, Iversen SD, Goodwin GM. Sustained attention deficit in bipolar disorder. *Br J Psychiatry*. 2002;180(4):313-319.
17. Clark L, Sarna A, Goodwin GM. Impairment of executive function but not memory in first-degree relatives of patients with bipolar I disorder and in euthymic patients with unipolar depression. *Am J Psychiatry*. 2005;162(10):1980-1982.
18. Adida M, Clark L, Pomietto P, et al. Lack of insight may predict impaired decision making in manic patients. *Bipolar Disord*. 2008;10(7):829-837.
19. Roth LH, Meisel A, Lidz CW. Tests of competency to consent to treatment. *Am J Psychiatry*. 1977;134(3):279-284.
20. Grisso T, Appelbaum PS. Comparison of standards for assessing patients' capacities to make treatment decisions. *Am J Psychiatry*. 1995;152(7):1033-1037.
21. Appelbaum PS, Grisso T, Frank E, O'Donnell S, Kupfer DJ. Competence of depressed patients for consent to research. *Am J Psychiatry*. 1999;156(9):1380-1384.
22. Appelbaum PS. Psychiatric research and the incompetent subject. *Psychiatr Serv*. 1997;48(7):873-874.
23. Vollmann J, Bauer A, Danke-Hopfe H, Helmchen H. Competence of mentally ill patients: a comparative empirical study. *Psychol Med*. 2003;33(8):1463-1471.
24. Carpenter WT Jr, Gold JM, Lahti AC, et al. Decisional capacity for informed consent in schizophrenia research. *Arch Gen Psychiatry*. 2000;57(6):533-538.
25. Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatr Serv*. 1997;48(11):1415-1419.
26. Lapid MI, Rummans TA, Poole KL, et al. Decisional capacity of severely depressed patients requiring electroconvulsive therapy. *J ECT*. 2003;19(2):67-72.
27. Huffman JC, Stern TA. Capacity decisions in the general hospital: when can you refuse to follow a person's wishes? *Prim Care Companion J Clin Psychiatry*. 2003;5(4):177-181.
28. Buchanan A. Commentary: facts and values in competency assessment. *J Am Acad Psychiatry Law*. 2008;36(3):352-353.

29. Howe E. Ethical aspects of evaluating a patient's mental capacity. *Psychiatry (Edgmont)*. 2009;6(7):15-23.
30. Perry CL, Lapid MI, Richardson JW. Ethical dilemmas with an elderly Christian Scientist. *Ann Longterm Care*. 2007;15(3):29-34.
31. Tymchuk AJ, Andron L, Rahbar B. Effective decision-making/problem-solving training with mothers who have mental retardation. *Am J Ment Retard*. 1988;92(6):510-516.
32. Palmer CR. Ethics, data-dependent designs, and the strategy of clinical trials: time to start learning-as-we-go? *Stat Methods Med Res*. 2002;11(5):381-402.
33. Roth LH, Appelbaum PS, Sallee R, Reynolds CF, Huber G. The dilemma of denial in the assessment of competency to refuse treatment. *Am J Psychiatry*. 1982;139(7):910-913.
34. Charland LC. Mental competence and value: the problem of normativity in the assessment of decision-making capacity. *Psychiatry Psychol Law*. 2001;8(2):135-145.
35. Moberg PJ, Rick JH. Decision-making capacity and competency in the elderly: a clinical and neuropsychological perspective. *NeuroRehabilitation*. 2008;23(5):403-413.

Joshua M. Baruth, MD, PhD, is a resident in the Department of Psychiatry & Psychology at the Mayo Clinic in Rochester, Minnesota. He obtained his MD and PhD from the University of Louisville and completed a postdoctoral research fellowship in psychiatry at the Mayo Clinic in Rochester. He has an ongoing interest in medical education and ethics.

Maria I. Lapid, MD, is a geriatric psychiatrist and palliative care specialist at the Mayo Clinic in Rochester, Minnesota. After college and medical school in her native Philippines, Dr. Lapid completed her residency and fellowship training in the United States, gaining clinical expertise through formal training programs in psychiatry, geriatric psychiatry, and hospice and palliative medicine and through practice in inpatient and outpatient geriatric psychiatry settings and in the inpatient palliative care consultation service and hospice program. At the Mayo Clinic, she has led research projects on investigations of various clinical issues relevant to electroconvulsive therapy, palliative care, and quality of life in elderly patients.

Related in the *AMA Journal of Ethics*

[Deciding for Others: Limitations of Advance Directives, Substituted Judgment, and Best Interest](#), August 2009

[How Reliable is the Competency Assessment Process?](#), August 2008

[Informed Consent: What Must a Physician Disclose to a Patient?](#), July 2012

[The Legal Boundaries of Informed Consent](#), August 2008

[The Limits of Informed Consent for an Overwhelmed Patient: Clinicians' Role in Protecting Patients and Preventing Overwhelm](#), September 2016

[The Patient's Piece of the Informed Consent Pie](#), August 2008
[Treating Bereavement](#), June 2012

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

ETHICS CASE

Do Pediatric Patients Have a Right to Know?

Commentary by Philip M. Rosoff, MD, MA

Abstract

In Western medicine, a central component of respecting a person's ability to make decisions governing what happens to herself is ensuring that she is provided with sufficient relevant information to make a rational choice. For patients who lack the cognitive capacity to do so because of either inborn or acquired deficits or because of youth, the extent to which they can participate in medical decisions is variable. Minors present a unique challenge, as their ability to understand and process information usually increases with age. The case presented here poses special problems because of the parents' desire to shield their child from certain information deemed important by his physicians. I consider whether minors, particularly older ones, have a right to know that supersedes their parents' wishes.

Case

Jenny is a medical student following the care of Adam, a 13-year-old boy who has just been diagnosed with Ewing's sarcoma of the left distal femur. The attending physician, Dr. K, explains to Adam and his parents that the treatment has a very high cure rate and should be started immediately. Dr. K also explains to Adam's parents that Adam will likely be infertile after treatment and that he might not have time to bank sperm. Adam's parents say that they are not interested in sperm banking and request that Dr. K not mention the possibility of infertility to Adam. Adam's father states, "He's too young to understand." Later, Jenny is talking with Adam about his hobbies and aspirations and Adam says, "I can't wait to have a big family one day." Jenny relates this to Dr. K, and he and Jenny discuss Adam's future views about family at length with no mention of the infertility risk posed by Adam's treatment. They also discuss Adam's anger, which often stems from his feeling a lack of control over his life, commonly seen in adolescents with cancer.

Later, Jenny asks Dr. K about whether to inform Adam about the virtual certainty of his infertility due to the chemotherapy he needs. Dr. K says, "His parents understand that Adam needs to be treated immediately and they've clearly stated that they don't want him to know about the infertility risk. We must respect their wishes." Jenny wonders whether Adam could suffer psychologically if he survives his cancer and later realizes he

was uninformed about the treatment's infertility risk. She also wonders whether Adam, who clearly is interested in his future with respect to being a father, has a right to know about this side effect. What, if anything, should Jenny do?

Commentary

Our general understanding of informed consent, based upon the conviction that moral agents have an (almost) unfettered right to control what happens to their bodies, demands that for patients to exercise this power they must have adequate relevant information to make choices they deem appropriate [1]. In order to perform this function adequately, persons must have sufficient cognitive function to both understand and appreciate the potential benefits and harms associated with the proposed intervention and to incorporate this knowledge and their values into a decision. The kind and quantity of information provided can vary, but broadly speaking it must be both satisfactory and materially pertinent such that patients can make an informed choice. For children, the capacity to engage in informed decision making is a gradually acquired capability, and different young people exhibit varying degrees of ability to make informed decisions as they age. The acquisition of the intellectual aptitude to engage in acceptable decision making of this sort correlates with the development of those areas of the brain associated with complex reasoning and forethought, a process that is not complete until the early twenties [2, 3]. Older teenagers and young adults appear to have similar abilities in this domain [4].

At least 14 states recognize the idiosyncratic nature of health care decision making by having so-called "mature minor" laws that can empower certain children, with demonstrable evidence of pertinent faculties (e.g., an understanding of their medical condition and the potential benefits and harms of the proposed treatment) to exercise this authority for themselves [5]. Different professionals—for example, judges or social workers, depending upon the jurisdiction—may be authorized to determine whether a child meets the standard to qualify as an autonomous medical decision maker. In those states in which they are mandated by law to ascertain the case-specific ability of the child, the statutes often specify that the patient must simply meet the "informed consent standard" [5]. In the absence of a court-ordered declaration of emancipation or other mechanism to warrant decisional autonomy—and therefore to be entitled to know all clinically pertinent information associated with the recommended treatment—minors must bend to the wishes of their authorized surrogates, usually their parent(s). While adolescents may be arguably unable to appreciate all of the benefits and burdens of a proposed course of action, they certainly have some appreciation, and engaging them in the decision-making process may be beneficial, although the data to support this are scant [6, 7]. Nevertheless, physicians faced with the situation illustrated by this case can be torn between their beliefs that the child has a "right" to know about a probable side effect that could profoundly affect him in his adult life—and that could be mitigated by an anticipatory intervention such as sperm [cryopreservation](#)—and the desire of his

parents to “protect” him. While the need for initiating treatment may be pressing, as in this case, it is likely that the patient could be offered the opportunity to produce a semen sample if his parents were willing to seriously consider this as an option.

Making Decisions for Children

The sort of problem raised by this case is pervasive throughout the world of [surrogate decision making](#) on behalf of patients who lack capacity, either because of age (children) or cognitive dysfunction, such as that associated with dementia, mental illness, and the like. While few would argue against the reasonableness of respecting surrogates’ discretion in withholding potentially distracting, frightening, or distressing information from those whose intellectual impairment or immaturity is profound (for example, people with advanced Alzheimer’s or five-year-old children), the issue becomes more complicated when the patients clearly have the capability to at least partially understand and appreciate what they have been told and hence should be able to participate to a limited extent in the decision-making (i.e., consent) process. It is often stated by surrogates that they wish to spare their charges the anguish or worry that they might experience when faced with potentially (or imagined-to-be) frightening information [8-11], but it is unclear if these concerns are truly warranted (meaning that children may not be harmed by knowledge of the illness). Unfortunately, many encounters of this type take place with specialists who might not know the patient or her parents all that well and hence may be unable to effectively argue against parents’ refusal to permit the child to participate in discussions about medical care. Nevertheless, it is widely understood and accepted that the preferred model for effective and ethically justifiable medical decision making for both adults and children is one that embraces shared responsibility, involving the parents and child (to the extent she can or wishes to be involved) in a two-way conversation, which can be challenging at times given the differences in family dynamics, the emotional tension of the situation, and so on [7, 12, 13].

Of course, if Adam and his parents lived in a state that permitted adolescents judged to be sufficiently mature to make their own health care decisions (either some or all), then this could complicate matters, especially if he and his parents and his physician were at odds about the appropriate content of and mechanism for delivering important information. If his oncologist believed that it was vital for Adam to know about the potential for infertility and his parents remained adamantly opposed to his knowing, *and* he met the standards for informed consent (however they might be applied and interpreted in his case and jurisdiction), then he could presumably override his parents’ objections. The potential repercussions of doing so could (at a minimum) erode or even rupture trust in this nascent patient-clinician relationship that could ultimately be fatal.

It is also worth noting that many seemingly irrational decisions made by surrogates and patients can stem from misinformation or simply lack of knowledge when a calm, informed discussion could allay their fears and set to rest misconceptions or

misunderstanding [14]. This approach might not always work, however. As the ongoing challenge of parents who refuse to vaccinate their children attests, some people might be immune to this form of rational argument [15, 16]. Moreover, the increasing availability and accessibility of unfiltered and unvetted information obtained from sources on the internet—including websites, blogs, social media networks, and the like—can radically affect the ability of physicians to counter preformed and deeply held beliefs with more reliable and trustworthy data [17-19].

Nevertheless, it is the physician's ethical (and legal) duty to ensure that the responsible consent-granting parties have all the relevant and true information—to the extent possible—needed to make an informed decision [1]. In this case, this would be the parents; the degree to which Adam would be involved and the power granted him to determine what he knows and what happens would be dependent upon his parents' discretionary authority or the state, if they live in a state with a mature minor statute. One final detail is worth noting with respect to legally recognized mature minors. Like other authorized decision makers, minors have a legal right to delegate this prerogative to others (such as their family) if they do not wish to take part in all or some of the decisions that might need to be made [1]. Indeed, if personal autonomy is to have true meaning, autonomous individuals (including mature minors) must be able to grant to others the power to make decisions for them as one instance of an informed choice, although this choice might perhaps be better labelled as a form of shared decision making [20].

A recent report by the Committee on Bioethics of the American Academy of Pediatrics discusses the goals of surrogate decision making:

Surrogate decision-making by parents or guardians for pediatric patients should seek to maximize benefits for the child by balancing health care needs with social and emotional needs within the context of overall family goals, religious and cultural beliefs, and values.... Physicians have both a moral obligation and a legal responsibility to question and, if necessary, to contest both the surrogate's and the patient's medical decisions if they put the patient at significant risk of serious harm [21].

This guidance acknowledges that, in practice, standards of surrogate decision making, whether they are for adults with diminished capacity or for children, involve a complex integration of best interests, family input, and minimizing risk of harm. This is especially the case for pediatric patients who exist, developmentally and cognitively, on a continuum and whose place and role in their family can be constantly changing with time and situation. Some have suggested that a plausible litmus test for the adequacy of a surrogate decision—the bare minimum for what physicians should respect and accept—is what has been termed the “not unreasonable standard,” based in large part on the

kinds of reasons given by the surrogates in support of their choices [22]. Reasons for decisions that could lead to significant harm to the person for whom the decisions are being made must be judged to be sufficiently rational, such that others could not reasonably object [23].

Who is Right in This Case?

Are the parents correct in this case or in others in which parents wish to shield their child from certain information that they believe will be harmful? In my clinical experience caring for children with cancer, it's not unusual for parents to wish for or ask physicians to refrain from telling the patient her diagnosis. In my and others' views, this tendency arises from parents' perhaps mistaken belief that a cancer diagnosis means their child will die and from a belief that their child should be spared the trauma of having the news of a fatal diagnosis revealed [24-26]. In the case, Adam's parents are, probably, similarly motivated by a desire to protect their child from information they believe could be psychologically damaging. However, if Adam's parents' motivation to protect him comes from their belief that he will die, this belief is not based in fact. Indeed, for Ewing sarcoma—Adam's diagnosis—the five-year event-free survival is up to 73 percent [27]. Generally speaking, pediatric clinicians, others caring for those lacking [decision-making capacity](#), and courts have traditionally given great deference to the expressed will of the surrogates unless there is good reason to believe that their decisions could place the patient at risk of imminent harm [28]. However, the meaning of harm has usually been interpreted as "physical," especially in cases such as Adam's [28]. For example, if his parents had refused to give consent for his treatment, it is likely Adam's physicians would have pursued legal action to compel his therapy, and they likely would have been successful due to the risk of significant, life-altering—and, in Adam's case, probably life-ending—harm. But it is doubtful they could make a plausibly compelling argument that, based upon his current statements about his wishes to have a large family, Adam might suffer psychological harm of an incalculable degree sometime in the future, such that this harm would be sufficiently credible to override the parents' authority [29].

There are at least three kinds of potential—and avoidable—related harms that could occur in this case, and while they might be identifiable, their future impact is difficult to quantify. The first is the possibility that Adam would suffer from knowing that he could have had the opportunity to take steps to cryopreserve semen and hence retain a chance (importantly, not a guarantee) to be the biological father of children at some unspecified later time. The second is damage that could be caused by the knowledge that his views and beliefs about what was important to him (the nascent desire to have a number of children as an adult) were ignored or considered insignificant by both his parents and his physician (assuming the latter abided by the demands of the parents to conceal pertinent information from Adam). Finally, Adam will be rendered infertile from physical destruction of spermatogonia due to alkylating agents [30], and, while the biological effects will be anatomic, any negative aftermath will almost undoubtedly be

psychological.

Deliberations about this case depend on how we view and attempt to answer two fundamental questions, assuming that Adam does not live in a state where mature minors may be empowered to make their own health care decisions (and that he would be considered capable of doing so). First, is the physician required to obey the wishes of Adam's parents concerning what happens to their son *no matter what*? Of course that cannot be true, as I have indicated above. However, distinguishing between permissible deviations from medical advice on behalf of others and impermissible deviations is difficult. Technically, Adam's parents' duty within the framework of medical decision making is to act in his best interests—which can be construed as those interests that all children share, such as continued life, and those that may be unique to him, such that only they can define, express, and act upon those interests to protect him from harm. Second, are the putative psychological harms that could occur should Adam not know about his probable infertility and the means to avoid it (sperm-banking) both sufficiently determinable (perhaps as a quantifiable risk) and predictively severe for the physician to attempt to refuse to accept Adam's parents' decision? There are good reasons to believe that effective therapy for Adam's disease will render him infertile. However, future iatrogenic harms that could result from treatments' toxicity are considerably less determinable and hence hypothetical. While it is true that his physician believes he should know about his future infertility, the subjective assessment of hypothetical information on which this belief is based would seem to weigh in favor of the parents' authority. It is also likely that the law would defer to Adam's parents' discretionary authority to keep information from Adam that would seem to fall within their purview to guide and control many aspects of his life.

Conclusion

While I agree that it would be better if Adam knew about this side effect that could affect his life in profound, yet unknown ways, it seems that in this case Dr. K must defer—albeit reluctantly—to Adam's parents' wishes [31]. Nevertheless, it is important that Dr. K convey the reasons why he believes it's important for Adam to know that the treatment almost certainly causes infertility, although I am pessimistic about his chances of altering the parents' views (based upon my personal and my colleagues' clinical experience as well as the lack of consensus on how to alter parental views on childhood vaccinations [32]). The question of whether Adam has a right to know about his condition and the question of how to consider, from a moral point of view, the iatrogenic harms of its treatment are complex ones. Legally, the answer to the question of whether Adam has a right to know is "no." Due to his status as a minor, he is not legally authorized to consent (although many institutions require assent of minors, especially for research participation [33]), and hence he is not entitled to be informed of the benefits and burdens of the proposed therapy as his surrogates (i.e., his parents) are. And it would be unwise to cast his right—legal or moral—in terms of a multitude of

elaborated human rights, only some of which inhere in persons who lack decision-making capacity (such as Adam) [34], as that would potentially distort or even trivialize the moral power that we have accorded rights by amplifying their breadth and scope. We are thus left with a situation that, like so much in health care, is messy and not entirely satisfactory, at least as Adam's physician might view it. It is conceivable that his parents might later regret their decision to withhold information from him, but that, too, like our projections about potential harm to his psychological state, must remain speculative. The bottom line is that, in this situation, the parents' wishes must prevail.

As unsettling to her as it undoubtedly would be, this conclusion also addresses the problem of what the student, Jenny, should do. As torn as she might be, an ethical and legal analysis of this case supports that she should not disclose anything further to Adam. That being said, it would also be incumbent upon the attending physician to discuss the troubling features of this situation and the reasons why he decided to defer to the wishes of the parents despite his (and her) misgivings. It is not uncommon that the most disturbing cases present the best opportunities for learning that clinical practice can be decidedly messy.

References

1. Faden RR, Beauchamp TL. *A History and Theory of Informed Consent*. New York, NY: Oxford University Press; 1986.
2. Arshagouni P. "But I'm an adult now ... sort of": adolescent consent in health care decision-making and the adolescent brain. *J Health Care Law Policy*. 2006;9(2):315-364.
3. Cohen AO, Casey BJ. Rewiring juvenile justice: the intersection of developmental neuroscience and legal policy. *Trends Cogn Sci*. 2014;18(2):63-65.
4. Steinberg L. Should the science of adolescent brain development inform public policy? *Am Psychol*. 2009;64(8):739-750.
5. Coleman DL, Rosoff PM. The legal authority of mature minors to consent to general medical treatment. *Pediatrics*. 2013;131(4):786-793.
6. Kon AA, Davidson JE, Morrison W, Danis M, White DB; American College of Critical Care Medicine; American Thoracic Society. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med*. 2016;44(1):188-201.
7. Wyatt KD, List B, Brinkman WB, et al. Shared decision making in pediatrics: a systematic review and meta-analysis. *Acad Pediatr*. 2015;15(6):573-583.
8. Higgs R, Ingram L, Atkin M, Dare J, Neuberger J. A father says, "Don't tell my son the truth." *J Med Ethics*. 1985;11(3):153-158.
9. Sigman GS, Kraut J, La Puma J. Disclosure of a diagnosis to children and adolescents when parents object: a clinical ethics analysis. *Am J Dis Child*. 1993;147(7):764-768.

10. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med*. 2006;166(5):493-497.
11. Gentry J. "Don't tell her she's on hospice": ethics and pastoral care for families who withhold medical information. *J Pastoral Care Counsel*. 2007;62(suppl 5):421-426.
12. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *New Engl J Med*. 2012;366(9):780-781.
13. Moulton B, King JS. Aligning ethics with medical decision-making: the quest for informed patient choice. *J Law Med Ethics*. 2010;38(1):85-97.
14. Grady C. Enduring and emerging challenges of informed consent. *N Engl J Med*. 2015;372(9):855-862.
15. Dredze M, Broniatowski DA, Smith MC, Hilyard KM. Understanding vaccine refusal: why we need social media now. *Am J Prev Med*. 2016;50(4):550-552.
16. Dubé E, Vivion M, MacDonald NE. Vaccine hesitancy, vaccine refusal and the anti-vaccine movement: influence, impact and implications. *Expert Rev Vaccines*. 2015;14(1):99-117.
17. Fisher JH, O'Connor D, Flexman AM, Shapera S, Ryerson CJ. Accuracy and reliability of internet resources for information on idiopathic pulmonary fibrosis. *Am J Respir Crit Care Med*. 2016;194(2):218-225.
18. Ogah I, Wassersug RJ. How reliable are "reputable sources" for medical information on the internet? The case of hormonal therapy to treat prostate cancer. *Urol Oncol*. 2013;31(8):1546-1552.
19. Winship B, Grisell M, Yang CB, Chen RX, Bauer AS. The quality of pediatric orthopaedic information on the internet. *J Pediatr Orthop*. 2014;34(4):474-477.
20. Coyne I, Amory A, Kiernan G, Gibson F. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs*. 2014;18(3):273-280.
21. American Academy of Pediatrics Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics*. 2016;138(2):e20161484. <http://pediatrics.aappublications.org/content/138/2/e20161484.long>. Accessed March 27, 2017.
22. Rhodes R, Holzman IR. The not unreasonable standard for assessment of surrogates and surrogate decisions. *Theor Med Bioeth*. 2004;25(4):367-385.
23. Scanlon TM. *What We Owe to Each Other*. Cambridge, MA: Belknap Press; 1998.
24. Parsons SK, Saiki-Craighill S, Mayer DK, et al. Telling children and adolescents about their cancer diagnosis: cross-cultural comparisons between pediatric oncologists in the US and Japan. *Psychooncology*. 2007;16(1):60-68.
25. Badarau DO, Wangmo T, Ruhe KM, et al. Parents' challenges and physicians' tasks in disclosing cancer to children. A qualitative interview study and reflections on professional duties in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(12):2177-2182.

26. Sisk BA, Bluebond-Langner M, Wiener L, Mack J, Wolfe J. Prognostic disclosures to children: a historical perspective. *Pediatrics*. 2016;138(3): e20161278. <http://pediatrics.aappublications.org/content/138/3/e20161278.long>. Accessed April 3, 2017.
27. Womer RB, West DC, Krailo MD, et al. Randomized controlled trial of interval-compressed chemotherapy for the treatment of localized Ewing sarcoma: a report from the Children's Oncology Group. *J Clin Oncol*. 2012;30(33):4148-4154.
28. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004;25(4):243-264.
29. On emotional harms to patients, see Sokol-Hessner L, Folcarelli PH, Sands KE. Emotional harm from disrespect: the neglected preventable harm. *BMJ Qual Saf*. 2015;24(9):550-553.
30. Meistrich ML. Effects of chemotherapy and radiotherapy on spermatogenesis in humans. *Fertil Steril*. 2013;100(5):1180-1186.
31. Clayman ML, Galvin KM, Arntson P. Shared decision making: fertility and pediatric cancers. In: Woodruff TK, Snyder KA, eds. *Oncofertility: Fertility Preservation for Cancer Survivors*. Boston, MA: Springer; 2007:149-160.
32. Eskola J, Duclos P, Schuster M, MacDonald NE; SAGE Working Group on Vaccine Hesitancy. How to deal with vaccine hesitancy? *Vaccine*. 2015;33(34):4215-4217.
33. Grady C, Wiener L, Abdoler E, et al. Assent in research: the voices of adolescents. *J Adolesc Health*. 2014;54(5):515-520.
34. Fortin J. *Children's Rights and the Developing Law*. 2nd ed. Cambridge, UK: Cambridge University Press; 2003.

Philip M. Rosoff, MD, MA, is a professor of pediatrics (oncology) and medicine at Duke University Medical Center and Duke University School of Medicine in Durham, North Carolina, where he is also a member scholar in the Trent Center for Bioethics, Humanities & History of Medicine and chair of Duke Hospital's ethics committee. His latest book is *Drawing the Line: Healthcare Rationing and the Cutoff Problem* (Oxford University Press, 2017). His scholarly interest is in the area of the equitable distribution of scarce resources (rationing).

Related in the *AMA Journal of Ethics and Code of Medical Ethics*

[AMA Code of Medical Ethics' Opinion 2.1.2 Decisions for Adult Patients Who Lack Capacity](#), June 2016

[Can a Minor Refuse Assent for Emergency Care?](#), October 2012

[Deciding for Others: Limitations of Advance Directives, Substituted Judgment, and Best Interest](#), August 2009

[Ethical Management of Patients with Cancer and Mental Illness](#), May 2017

[Oncofertility for Adolescents: When Parents and Physicians Disagree about Egg Cryopreservation for a Mature Minor](#), September 2016

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

ETHICS CASE

How Should Clinicians Respond to Transference Reactions with Cancer Patients?

Commentary by Fatima Noorani, MD, and Allen R. Dyer, MD, PhD

Abstract

Patients with cancer can feel particularly vulnerable and need special attention and support, so clinicians' attention to transference reactions—theirs and their patients—is especially important. Mismanaged transference reactions can undermine the therapeutic alliance in the patient-clinician relationship and negatively influence treatment outcomes. In oncology settings, real and perceived needs of patients in serious distress can occasion modification of usual outpatient protocols, particularly when flexible scheduling or home or hospital visits are warranted. Here, we comment on a case in which transference reactions of a young woman with cancer prompt her to terminate treatment. We discuss the importance of clinicians' recognizing and managing transference and countertransference, maintaining boundaries, and responding with empathy and integrity to cancer patients' concerns.

Case

Amy is a 25-year-old woman who has recently been diagnosed with lymphoma, but her prognosis seems to be good. She has a history of drug use and abusive relationships. Amy's father abandoned her mother when she was a child, and Amy spent most of her adolescence caring for her mother, who was also addicted to drugs, before having an argument and moving away. She has weekly meetings with the cancer center's psychiatrist, Dr. T, to discuss her well-being and her adjustment to cancer and cancer treatment.

Over the course of treatment, Amy opens up to Dr. T and begins to confide in him. She admits that her last boyfriend recently cheated on her and that she has not told any of her friends about her illness because she is afraid that they might desert her. "Everybody always leaves me," she says on multiple occasions. "I've never been able to open up to someone without them running away."

Dr. T notices that Amy seems to put a lot of effort into her personal appearance when she comes to appointments, sometimes asking him what he thinks of a particular outfit.

She also asks him about his personal life despite his efforts to keep the conversation focused on her and wonders if she is his favorite patient. Dr. T remembers his psychodynamic training and worries that Amy is developing an eroticized transference, unconsciously transposing her past and ongoing feelings of abandonment onto him and experiencing them now as a fantasy that he might be the attachment figure she longs for and have similar feelings for her. He is uncertain whether he should comment on this or try to focus on the more immediate concerns of the cancer treatment.

Amy becomes agitated as her treatment progresses. She confesses that she is afraid of losing her relationship with Dr. T if she gets better and that she has grown deeply attached to him. She asks to see him outside the hospital. "You're the only one who understands me," Amy says. Dr. T explains that he must maintain professional boundaries and that it is his job to be understanding. At this point, Amy accuses him of only pretending to care about her. She leaves angrily and does not answer any of Dr. T's subsequent phone calls.

Amy does not come in for her subsequent oncology appointment. When the oncologist, Dr. Y, finally reaches her, she says that she doesn't need more treatment and that he cannot force her to come in. Dr. Y discusses this exchange with the rest of the care team, including Dr. T, who explains what happened during his last meeting with Amy. Dr. Y groans in frustration, "Say whatever you need to say to her to get her back here for treatment." What should Dr. T do?

Commentary

Cancer is a complex illness with biological, psychosocial, and spiritual aspects. While oncology treatments focus on biological aspects, it is important to address all aspects of the patient's treatment. The value of providing psychosocial support to patients with cancer is widely known [1]. The George Washington University's psycho-oncology clinic [2], for example, is a multidisciplinary clinic involving psychiatry and social work as well as psychotherapy, art therapy, nurse navigators, and chaplains when available. It offers five to eight sessions of (brief) psychotherapy conducted by third-year psychiatry residents under supervision, at no cost to the patient. Patients may be continued or referred for ongoing therapy if indicated.

A new cancer diagnosis is an adjustment under the best of circumstances, if not a potential source of an adjustment disorder. Elisabeth Kübler-Ross has described five "stages of grief" that provide words to express feelings that otherwise might be difficult to bear and process, such as denial or disbelief, anger or outrage, sadness or even depression, guilt, blame or self-blame, and acceptance or at least acknowledgement of loss [3]. Additionally, people diagnosed with cancer may be experiencing relationship conflicts, have suffered from early adverse experiences, or be facing [stigma](#) related to the illness that makes it difficult for them to receive support or to cope with the

additional challenges that cancer diagnosis and cancer treatment entail. Susan Sontag noted that when she became a cancer patient, “What particularly enraged me—and distracted me from my own terror and despair at my doctors’ gloomy prognosis—was seeing how much the very reputation of this illness added to the suffering of those who have it” [4].

Dr. T thought he was providing support to a patient whose major concerns had to do with a new cancer diagnosis. However, over the course of the treatment it became clear that Amy’s past abandonment issues were being played out in the present—in the relationship between her and Dr. T—and became the central issue of their work together. As we will show, understanding transference, its influence on the patient-clinician relationship, and its impact on treatment is key in addressing Amy’s abandonment of treatment.

What Is Transference?

The relationship between patient and clinician is central to any type of therapy. Thus, both the patient’s and the clinician’s awareness and recognition of the feelings that they have about each other is vital to the treatment. In psychodynamic psychotherapy, patients’ reactions to clinicians are often referred to as transference and clinicians’ reactions to patients, as countertransference [5]. More specifically, transference can be understood as *repetition* of feelings, attitudes, and behaviors attached to early formative relationships in the context of a therapy relationship [6]. The clinician’s unconsciously motivated response to a patient is known as countertransference [7]. Utilizing transference (and countertransference) in understanding patients, the ethical complexities of interacting with seriously ill patients [6], and promoting healing is at the heart of the psychotherapeutic process.

Although transference reactions can occur in any emotionally meaningful human relationship, the nature of the patient-clinician relationship can inherently evoke strong feelings. The power imbalance in this relationship between a patient in need and a clinician looked to for help can revive patients’ memories of relationships with earliest caregivers and elicit powerful feelings of love, hate, longing, and dependency. This is especially important in the oncology setting, where illness and disability can threaten patients’ autonomy, self-esteem, and self-control, leaving them feeling especially vulnerable. Such a situation can stir up powerful desires and fears from unresolved childhood conflicts that can then be directed toward the clinician [8]. Moreover, under the stress of illness patients can often regress, leading them to use less mature coping mechanisms such as denial of illness or nonadherence to treatment recommendations [6]. In the above case, Amy is the victim of neglect and abuse. Based on what she tells Dr. T, she fantasizes a savior—someone she can open up to, who cares about her, and who will not abandon her. Early in the therapy, she idealizes Dr. T as this savior. But

when he draws firmer boundaries, she feels betrayed and abandoned, re-enacting the roles of victim and abuser.

Types of Transference

Transference can manifest itself in therapy in many ways. Positive, negative, and sexualized transference are some common types of transference. When the patient views the clinician as a loving, caring, attentive, trusting figure, he or she may develop a *positive* transference in therapy. However, the patient can also experience the clinician as a distrustful, distant, adversarial figure, possibly leading him or her to develop *negative* transference [8]. *Sexualized* transference refers to transference in which the patient's fantasies contain elements that are primarily reverential, romantic, intimate, sensual, or sexual. It can be further differentiated into erotic and eroticized transference. *Erotic* transference is generally positive transference, which is egodystonic (i.e., recognized as unrealistic by the patient) and does not interfere with work in therapy. *Eroticized* transference, on the other hand, is a type of negative transference that involves a more intense, irrational preoccupation with erotic fantasies with the hope and expectation of reciprocation by the clinician [9]. Positive transference can facilitate a working alliance and willingness to come to sessions and talk about feelings, whereas negative transference can become resistance to treatment or simply put up barriers to treatment. In the above case, Amy initially develops a positive transference to Dr. T but later, as recognized correctly by Dr. T, develops an eroticized transference towards him.

Understanding Transference

A collaborative working relationship between patient and clinician is essential for transference to be explored in therapy. Some techniques that can help in establishing a strong therapeutic relationship include the clinician's taking a comprehensive developmental history, which facilitates understanding of the patient's early life experiences. It also enables patients to put forth a narrative of their life story and feel listened to with curiosity and interest [6]. In the case of Dr. T's patient, Amy, the history of "having an argument [with her mother] and moving away" might alert him to a pattern that might be repeated. Although her departure from therapy seemed an abrupt surprise, it was not a new behavior.

Most importantly, encouraging patients to talk freely about their emotional responses to the clinician allows them to bring up difficult feelings that they would not have done otherwise. It is important to maintain a nonjudgmental, open, and curious attitude to create a safe and trusting space for the patient [6]. Such an attitude allows patients to make connections between what they are feeling in the room with their clinician and their early life experiences, which enables development and growth [9].

Countertransference

In the same way that patients develop a variety of emotions toward the physician based on their past experiences, physicians bring their past to the room as well, and these memories—along with the patient's transference—may unconsciously influence their reactions to a patient [7]. While it is normal to have all kinds of feelings towards the patient, it is important to recognize and manage these emotional responses.

Countertransference, when utilized correctly, can help the physician to understand how patients relate to others and experience the world around them. The key is to recognize, accept, and discuss these feelings, in supervision or consultation, if necessary [5]. For example, in the above case, while Dr. T was aware of Amy's desire for more contact, and even for extra-therapeutic contact, he may have been less attentive to his own reaction to her demands. He may have felt that Amy's cancer warranted extra attention and support from him and acted on these feelings, which might have added to Amy's emotional misunderstanding and frustration.

Managing Negative Transference

When a patient expresses or harbors aggressive or sexual feelings towards the clinician, as in the above case of eroticized transference, it might not be easy for a clinician to maintain an open and accepting attitude. The challenge is to maintain [therapeutic boundaries](#) while empathically responding to the patient to prevent him or her from feeling rejected or abandoned, thereby risking premature termination. The clinician's first task is to identify the transference and *not* avoid its existence. Encouraging patients to talk comfortably about transference is often helpful, although this may not happen right away or may not be possible for all patients [9]. One way to do this is to explain to patients that a lot can be learned about them and their relationships with others by discussing their thoughts and feelings about the clinician. It is important for the patient to know that these feelings are not taboo and that the clinician is comfortable discussing and trying to understand them in order to prevent him or her from feeling embarrassed, rejected, or negatively judged [10]. For example, a clinician might say, "Thank you for sharing how you feel about me. Those feelings can often be very hard to talk about." Equally important, the therapist should clearly explain that there are boundaries of the psychotherapeutic relationship that must be respected for effective and safe treatment [9-11]. The clinician might say something like "This is the place where we can discuss feelings, so you can better cope with things that are going on elsewhere, such as your cancer treatment." While Dr. T identified the transference reaction, he was not able to help Amy explore the meaning or significance of this reaction.

In order to explore the patient's sexual fantasies, the clinician must first work through his or her own countertransference [11]. It is important to understand that the patient's sexual or romantic fantasies are not directly caused by personal attributes of the clinician but, as stated above, are closely tied to the setting and structure of therapy in which the patient's dependence on the clinician can arouse powerful feelings from past conflicts.

This realization prevents the clinician from feeling shame or guilt about the situation as well as from gaining narcissistic gratification associated with it [12]. If the clinician experiences sexual feelings toward the patient, he or she may become either overly involved with the patient or distance him- or herself from the patient, both of which are detrimental to effective and safe treatment. It is important to seek consultation if the clinician's own sexual feelings are compromising patient care [8].

The nature and strength of the therapeutic relationship is another variable in management of negative transference. Interpreting the transference or making any connections between early childhood experiences and transference without adequate therapeutic alliance can be premature and risk being misinterpreted or rejected by the patient [8]. Working with sexualized transference is challenging and may pose a threat to treatment if mismanaged. However, it is often a window into the internal world of patients—their unconscious conflicts, narcissistic wounds, and past trauma—and, when worked through, can be highly therapeutic [13].

Ethical Considerations in Psychotherapeutic Technique

Ethical traditions dating back at least to the Hippocratic Oath have recognized the importance of maintaining professional boundaries [14], and Freud specifically cautioned against ignoring erotic feelings in psychoanalytic treatment [15]. Dr. T may well have respected the principle to “do no harm,” but he didn't seem to appreciate that even if a patient is not in psychodynamic therapy, it is important to attend to transference reactions that may interfere with the treatment—specifically, the psychotherapy, but even the cancer treatment. While there may be instances when it becomes important to alter protocol by scheduling a hospital or a home visit or a telephone or Skype session, one always needs to be mindful of what is going on with the patient, what is going on with one's own feelings, and what is going on in the relationship, and then decide what needs attention and when is it appropriate and necessary to comment on these feelings to further the patient's best interest and the goals of the therapy.

What could Dr. T have done differently and what could be done at this point to salvage the treatment—the psychotherapy and, more importantly, the oncological treatment? Retrospectively, it might have been useful had Dr. T explicitly reviewed the treatment goals at each stage of the treatment, identifying issues related to the cancer and cancer treatment that needed attention and how issues from the patient's past would be addressed. Also, when Dr. T recognized Amy's eroticized transference and was uncertain how to respond to it, seeking out supervision might have been helpful. Is there anything Dr. T can do to get Amy back into therapy, or is it too late? Since she is not responding to his telephone calls, it might be useful to draft a letter explaining that the treatment is important, that he is available to continue with her if she should choose or that she could work with someone else. Another member of the team might reach out to her if she doesn't respond.

In sum, this case is a cautionary tale of the importance of being vigilant of transference reactions, even when they may not appear to be the immediate focus of therapeutic concern. Transference may help foster a therapeutic alliance, but it needs to be addressed if it becomes a source of resistance. Moreover, it is important for the clinician to be aware of his or her own feelings in face of a cancer diagnosis and to realize that cancer may not be the only issue a patient is dealing with.

References

1. Adler NE, Page AEK, eds; Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press; 2008.
2. GW (George Washington) Medical Faculty Associates. Cancer Survivorship Clinic. <http://www.gwdocs.com/cancer-survivorship-clinic/clinic-services>. Accessed March 18, 2017.
3. Kübler-Ross E. *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*. London, UK: Routledge; 2009.
4. Sontag S. *Illness as Metaphor and AIDS and Its Metaphors*. New York, NY: Picador; 1989:100.
5. Cabaniss DL, Cherry S, Douglas CJ, Schwartz AR. *Psychodynamic Psychotherapy: A Clinical Manual*. Chichester, UK: Wiley-Blackwell; 2011.
6. Corradi RB. A conceptual model of transference and its psychotherapeutic application. *J Am Acad Psychoanal Dyn Psychiatry*. 2006;34(3):415-439.
7. Rentmeester CA, George C. Legalism, countertransference, and clinical moral perception. *Am J Bioeth*. 2009;9(10):20-28.
8. Shedler J. That was then and this is now: an introduction to psychodynamic therapy. [http://www.jonathanshedler.com/PDFs/Shedler%20\(2006\)%20That%20was%20then,%20this%20is%20now%20R9.pdf](http://www.jonathanshedler.com/PDFs/Shedler%20(2006)%20That%20was%20then,%20this%20is%20now%20R9.pdf). Published 2006. Accessed December 6, 2016.
9. Ladson D, Welton R. Recognizing and managing erotic and eroticized transferences. *Psychiatry (Edgmont)*. 2007;4(4):47-50.
10. Golden GA, Brennan M. Managing erotic feelings in the physician-patient relationship. *CMAJ*. 1995;153(9):1241-1245.
11. Yeomans F, Clarkin J. Erotic transfer in borderline personality patients. *Psychiatric News*. January 15, 2015. <http://psychnews.psychiatryonline.org/doi/full/10.1176/appi.pn.2015.1a1>. Accessed December 6, 2016.
12. Celenza A. Analytic love and power: responsiveness and responsibility. *Psychoanal Inq*. 2007;27(3):287-301.

13. Gabbard G. Identifying and working with countertransference. *Long-Term Psychodynamic Psychotherapy: A Basic Text*. 3rd ed. Arlington, VA: American Psychiatric Association Publishing; 2017:chap 8.
14. Dyer AR. *Ethics and Psychiatry: Toward Professional Definition*. Washington, DC: American Psychiatric Press; 1988.
15. Freud S. Psycho-analytic notes on an autobiographical account of a case of paranoia (dementia paranoides). In: Strachey J, trans-ed. *The Standard Edition of the Complete Psychological Works of Sigmund Freud*. London, England: Hogarth Press; 1958:1-82. *The Case of Schreber, Papers on Technique, and Other Works*; vol 12.

Fatima Noorani, MD, is a clinical assistant professor in the Department of Psychiatry and Behavioral Sciences at the George Washington University in Washington, DC, and she is also the medical director of the McClendon Center.

Allen R. Dyer, MD, PhD, is a professor of psychiatry and behavioral sciences and the vice-chair for education at the George Washington University (GW) in Washington, DC, where he is also the director of the GW Psycho-oncology Clinic.

Related in the *AMA Journal of Ethics*

[Decreasing Smoking but Increasing Stigma? Anti-tobacco Campaigns, Public Health, and Cancer Care](#), May 2017

[Necessary Boundary Crossings in Pediatrics](#), May 2015

[Negotiating Professional Boundaries in the Patient-Physician Relationship](#), May 2015

[Observing Boundaries in Conversations with Patients](#), April 2007

[When the Patient-Physician Relationship Is Broken](#), September 2008

[Where the Rubber Meets the Road: The Challenge of Reporting Colleagues' Boundary Violations](#), May 2015

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

ETHICS CASE

Ethical Management of Patients with Cancer and Mental Illness

Case and Commentary by Laurel J. Lyckholm, MD, and Arwa K. Aburizik, MD, MS

Abstract

Patients with co-existing cancer and mental illness must be given special attention due to the vulnerability that is created by their compromised psychological ability to comprehend the meaning of their cancer diagnosis, treatment, and prognosis. They are at increased risk for mortality due to many factors arising from their mental illness. To provide them with care that is just and compassionate, clinicians must be empathic and imaginative. Using a case and brief application of theories of justice involving vulnerable populations, we explore practical and ethical issues surrounding the care of patients with mental illness and cancer, arguing that society must provide the resources needed to provide comparable cancer care to those who are more vulnerable.

Case

TM, a 56-year-old man with schizophrenia, presented to his primary care physician with intermittent difficulty swallowing. He did not elaborate on exacerbating or alleviating features or associated symptoms. His review of systems was negative.

TM lived locally in an adult home. He was unwilling to consistently perform activities of daily living, such as bathing and dressing. The nursing staff of the adult home provided his medications. TM's younger sister was his next of kin and had health care power of attorney. She attended appointments with him and assisted him in making decisions regarding his health care. Specifically, she aided in explaining clinical information to him in a manner that he seemed to better understand. She would not consent to procedures or therapies to which he was opposed.

Physical exam revealed a thin and disheveled man. He was alert and oriented. He had no outward signs of perceptual disturbances such as delusions or hallucinations. The remainder of the exam was unremarkable. A chest radiograph revealed a 3.8-cm lung mass. The patient was referred for a CT-guided biopsy of the lesion. Although he was initially reluctant, he ultimately agreed to the procedure after further counseling and discussion, and his sister supported his decision and provided consent. The biopsy confirmed the diagnosis of squamous cell carcinoma. Further staging did not reveal locally extensive or metastatic disease. Therefore the cancer was considered to be Stage

Ib (T2aNOMO). He was referred to the surgical oncology service for possible resection of the mass.

During the initial surgical consultation, the patient stated that he did not believe he had cancer and would not consent to any surgical procedures. However, during a subsequent visit, the patient acknowledged the diagnosis and stated that he would consider surgery. After lengthy deliberation about the case, the members of the surgical oncology team opted against surgical intervention based on their feeling that the patient did not reliably demonstrate a good understanding of the diagnosis and might therefore have a higher risk of complications postoperatively. They stated that they did not feel it was safe to operate but offered no further explanation. TM completed radiation therapy, and a six-week post-treatment CT scan revealed stable disease, although with possible residual tumor.

Commentary

People with mental illness face significant health challenges that extend beyond the obvious effects of their psychiatric symptoms, adversely influencing their physical health and access to medical care [1, 2]. The Centers for Disease Control and Prevention (CDC) [3] reports a lower use of medical care and lower adherence to treatment for chronic disease among patients with mental illness. A variety of affective, psychological, and cognitive symptoms can interfere with healthy lifestyle decisions, motivation to seek care for physical complaints, and the ability to trust and effectively engage with health care clinicians. Depression, fatigue, asthenia, despair, hopelessness, and distorted perceptions of reality, such as hallucinations and delusions, are among symptoms that can increase the challenge of accessing health care [4].

People with mental illness also face multiple challenges as they navigate relationships within the health care system, make clinical decisions, and otherwise participate in their medical and psychiatric care. Studies show that clinicians can have negative attitudes toward or biases against people with mental illness [5-7], making it difficult for those patients to identify clinicians who will understand their specific needs, advocate for them, and assist them in navigating the system. Clinicians might lack training and skill in detecting somatic signs and symptoms in the context of psychiatric illness. In addition to the factors mentioned, time and resource constraints render this group of patients vulnerable to disparities of health care uptake and reception [8-10].

Mental illness complicates care for patients with cancer. Several studies report a significantly higher rate of mortality in psychiatric patients overall compared to the general population [11-13], and one study has shown a higher rate of mortality for psychiatric patients with cancer even though the incidence of cancer in psychiatric patients is no greater than in the general population [11]. One possible explanation includes reduced access to screening [14, 15], leading to delayed diagnosis and a more

advanced stage at presentation. In addition, people with mental illness have more limited access to cancer care and a lower likelihood of receiving specialized interventions [11].

What might explain these [treatment disparities](#)? They might be attributable to clinicians' concerns about patients' ability to physically, emotionally, or mentally tolerate procedures or comply with complex care instructions. For example, one study found that Medicare patients with coexisting mental illness who received elective surgical procedures had longer length-of-stay and worse postoperative outcomes, including higher risk of 30-day and 1-year mortality, than those without mental illness [16]. Or treatment disparities might result from the presence of contraindications to specialized interventions due to cognitive, psychological, or social factors. For example, patients taking chemotherapy for cancer might understand that the chemotherapy will help the tumor shrink and enable them to live longer and also that chemotherapy is toxic, but they can have limited ability to connect side effects with the treatment or to access resources if they are experiencing serious toxicity, which could be life-threatening [17]. The oncologist might feel that certain chemotherapy or other cancer treatments, while superior in their survival or palliative benefits, present too much risk in a patient who may have waxing and waning insight. While family members and others may assist the patient in making medical decisions, they might not always be present to assist the patient in managing the side effects and toxicity of treatment. Another example might be of a patient who becomes ill from the side effects of therapy and stops taking his or her psychiatric medications or who errs in dosing oral chemotherapy and other supportive medications, such as anti-emetics and analgesics, which could be harmful or dangerous.

In what follows, we describe decision making in mental illness and in patients with co-existing mental illness and cancer. We then discuss how and why provision of cancer care can be different and challenging for people with mental illness and offer recommendations for ethical care in light of the case.

Decision Making in Mental Illness

Autonomy can be seen as empowering in that it can strengthen one's self-respect and control over one's life [18]. One way in which autonomy can be diminished is through mental illness, which is an example of a controlling influence occurring internally [19]. Mental illness can cloud one's judgment, making it difficult to reach decisions about one's cancer care that are in harmony with one's beliefs and values.

If a person's autonomy is truly compromised, then a surrogate decision maker should decide for the patient on the basis of substituted judgment or the best interest standard. Substituted judgment involves knowing what the patient would want if he or she were able to make a decision, based on his or her known values [20]. The best interest standard is based on what most people in a similar situation would want and what would be in their best interest assuming there is no information about the patient's wishes

[20]. Ideally, application of both standards involves significant investment by people who both know and care about the patient. This includes family members, treating psychiatrists, and other health care professionals who have been involved in the patient's care. It also involves understanding the patient's goals and values, even if he or she is not able to fully articulate them. In that case, friends and family can provide narratives that include life choices and previous health care and other significant decisions that the person has made [21].

[Decision-making capacity](#) involves three essential components: comprehending, evaluating, and choosing among realistic options. People with mental illness facing medical decisions should be presumed to have decision-making capacity unless there is evidence to the contrary that warrants further assessment, as in TM's case. Patients with mental illness should not be deemed to lack decision-making capacity until they have been formally evaluated [22]. Discussion between mental health and cancer clinicians should be mandatory.

Patients with psychiatric illness can retain their decision-making capacity or at least be able to participate in assisted decision making. Jonsen, Siegler, and Winslade write:

Psychiatric diagnoses such as schizophrenia, depression, or dementia do not, in themselves, rule out the possibility that a patient has mental capacity to make particular decisions. Many persons with mental disease retain the ability to make reasonable decisions about particular medical choices that face them [23].

Decision making is on a spectrum as wide as that of mental illness. Some patients retain the ability to understand the information provided to them and are able to communicate choices, appreciate the situation and its consequences, and manipulate information rationally in order to make decisions. In addition, since capacity is a clinical standard that applies to a particular decision at a given moment, the evaluation of capacity must be assessed in the context of the decision at hand [22, 24]. For example, a patient may be able to decide that he does not want aggressive life support, but he might not be able to understand the concept of radiation and chemotherapy or the purpose of a cancer-directed surgery.

Decision Making and Treatment Disparities in Cancer Patients with Mental Illness

Decision making. Patients with psychoses such as manic or major depressive episodes may have significant challenges in making informed decisions due to indifference, ambivalence, or indecisiveness [25]. Furthermore, psychotic illness may prevent patients from understanding the nature and purpose of a medical intervention. They may be unable to choose or communicate their consent. Much like TM, some patients with mental illness do not understand or accept that they are ill or need treatment [25].

Some cancer-related conditions, especially those that affect the central nervous system (CNS)—such as lymphoma, primary brain tumors, and metastatic cancer—may also impair judgment, understanding, and communication [26]. For example, a patient with CNS lymphoma and significant cerebral edema may be unable to understand his or her condition, the reason for it, the goals of therapy, or the therapy itself, which is often quite intricate. The decisions involved in undergoing toxic or high-risk treatment—including chemotherapy, radiation, and surgery—are complex and challenging to understand even when a person is unencumbered by mental illness.

Treatment disparities. The case of TM is also illustrative of potential disparities in cancer care for patients with mental illness; based on the foregoing discussion of decision making, we offer steps that might be taken in caring for such a patient with mental illness and cancer (see table 1). One might ask if there was a justifiable basis for the decision made by the surgical service to forego primary resection, which would be the standard of care for this patient with stage I squamous cell lung cancer [27]. One might also ask if enough care was taken to explain as well as possible to the patient and his sister the patient's situation, the diagnosis, the staging, and standard treatment for stage I squamous cell lung cancer, as well as the prognosis of the cancer and how veering from standard treatment might negatively affect the prognosis. While the surgeons did not demonstrate any specific evidence of personal bias against the patient, they did not seem to demonstrate significant rigor in their consideration of his case. They met with the patient and his sister once regarding their recommendation, but they did not perform further psychological testing or contact his psychiatrist or anyone else who might aid further in decision making.

Table 1. Considerations for providing ethical care to mentally ill patients with cancer

Decision Making
Patients should be presumed to have decision-making capacity unless evidence suggests otherwise. Patients with mental illness may be able to make appropriate, independent decisions. Caretakers must be involved in the care and decision making at all levels.
Treatment
Mental illness does not rule out aggressive treatments. Treatment must be even more carefully considered and the patient more carefully monitored. Antipsychotic and other medications should be reviewed for side effects, toxicity, and interactions with chemotherapy and palliative medicines such as anti-emetics.
Care Team
The patient’s mental health team should be involved, and treatment of the mental illness should be optimized. Comorbidities Depression commonly accompanies the diagnosis of cancer.

How can such disparities in cancer care be rectified? Health literacy is an important aspect of cancer care. Patients with mental illness have variable levels of health literacy [28]. They may be unable to comprehend their diagnosis, its impact on their life, what various treatments entail, and their prognosis. For patients with limited ability to understand their diagnosis and prognosis, it is especially important to ensure that they are provided information in a way that is more comprehensible to them [29] as well as to critically evaluate their candidacy for treatment. More specifically, those providing care for such vulnerable patients must be extraordinarily thoughtful and empathic in order to provide equivalent and compassionate care [30], which are primary goals of medicine and a just society in general.

The standard of care, simply stated, would be that which provides the patient with the highest quality, patient-centered care that benefits him most from the standpoint of what is known of his individual preferences and values or what is in his best interest if these preferences and values are unknown. Well-known ethical theories of [justice](#) complement this idea, including liberation theology [31], of which a central thesis is the “preferential option for the poor”—to prioritize service to poor people in order to ensure that those with the least resources are provided a standard of care at the very least

equivalent to that of those with more resources—which Paul Farmer and others have applied specifically to the provision of medical care [32]. John Rawls’s theory of justice proposes that persons living under a “veil of ignorance” of their place in society should be the decision makers for others [33]. He writes that “this ensures that no one is advantaged or disadvantaged in the choice of principles by the outcome of natural chance or the contingency of social circumstances” [34]. He advocates distributing social and economic inequalities “to the greatest benefit of the least advantaged” members of society [35]. Both of these theories seek to provide advantages to the most disadvantaged in order to provide care that is equivalent to that provided to others less disadvantaged.

Conclusion

In summary, patients with co-existing cancer and mental illness must be given special attention due to the vulnerability that arises from their possible inability to fully comprehend the meaning of their cancer diagnosis, treatment, and prognosis. They are at increased risk for mortality due to many factors arising from their disability [11-13]. To deliver care that is just and compassionate, clinicians must be empathic, imaginative, and nonjudgmental. The principle of “equivalence of care,” which refers to approximating the quality of care given to non-prisoners and prisoners can be applied in a similar way to the care of the mentally ill [36]. Society as a whole and the health care system must provide the extra resources needed to approximate the cancer care provided to those less vulnerable.

References

1. Lin WC, Zhang J, Leung GY, Clark RE. Chronic physical conditions in older adults with mental illness and/or substance use disorders. *J Am Geriatr Soc*. 2011;59(10):1913-1921.
2. Ostrow L, Manderscheid R, Mojtabai R. Stigma and difficulty accessing medical care in a sample of adults with serious mental illness. *J Health Care Poor Underserved*. 2014;25(4):1956-1965.
3. Reeves WC, Strine TW, Pratt LA, et al; Centers for Disease Control and Prevention. Mental illness surveillance among adults in the United States. *MMWR Suppl*. 2011;60(3):1-29.
4. Gerson LD, Rose LE. Needs of persons with serious mental illness following discharge from inpatient treatment: patient and family views. *Arch Psychiatr Nurs*. 2012;26(4):261-271.
5. Giandinoto JA, Edward KL. Challenges in acute care of people with co-morbid mental illness. *Br J Nurs*. 2014;23(13):728-732.
6. Kopera M, Suszek H, Bonar E, et al. Evaluating explicit and implicit stigma of mental illness in mental health professionals and medical students. *Community Ment Health J*. 2015;51(5):628-634.

7. Stull LG, McGrew JH, Salyers MP, Ashburn-Nardo L. Implicit and explicit stigma of mental illness: attitudes in an evidence-based practice. *J Nerv Ment Dis.* 2013;201(12):1072-1079.
8. Kisely S, Ehrlich C, Kendall E, Lawrence D. Using avoidable admissions to measure quality of care for cardiometabolic and other physical comorbidities of psychiatric disorders: a population-based, record-linkage analysis. *Can J Psychiatry.* 2015;60(11):497-506.
9. Roberts L, Roalfe A, Wilson S, Lester H. Physical health care of patients with schizophrenia in primary care: a comparative study. *Fam Pract.* 2007;24(1):34-40.
10. Zolnierek CD. Non-psychiatric hospitalization of people with mental illness: systematic review. *J Adv Nurs.* 2009;65(8):1570-1583.
11. Kisely S, Crowe E, Lawrence D. Cancer-related mortality in people with mental illness. *JAMA Psychiatry.* 2013;70(2):209-217.
12. Parks J, Svendsen D, Singer P, Foti ME, eds. Morbidity and mortality in people with serious mental illness. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council; October 2006. <http://www.nasmhpd.org/sites/default/files/Mortality%20and%20Morbidity%20Final%20Report%208.18.08.pdf>. Accessed December 7, 2016.
13. Piatt EE, Munetz MR, Ritter C. An examination of premature mortality among decedents with serious mental illness and those in the general population. *Psychiatr Serv.* 2010;61(7):663-668.
14. Carney CP, Jones LE. The influence of type and severity of mental illness on receipt of screening mammography. *J Gen Intern Med.* 2006;21(10):1097-1104.
15. Xiong GL, Bermudes RA, Torres SN, Hales RE. Use of cancer-screening services among persons with serious mental illness in Sacramento County. *Psychiatr Serv.* 2008;59(8):929-932.
16. Li Y, Cai X, Du H, et al. Mentally ill Medicare patients are less likely than others to receive certain types of surgery. *Health Aff (Millwood).* 2011;30(7):1307-1315.
17. Puisset F, Alexandre J, Treluyer J-M, et al. Clinical pharmacodynamic factors in docetaxel toxicity. *Br J Cancer.* 2007;97(3):290-296.
18. Blackhall LJ, Frank G, Murphy S, Michel V. Bioethics in a different tongue: the case of truth-telling. *J Urban Health.* 2001;78(1):59-71.
19. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 7th ed. New York, NY: Oxford University Press; 2013.
20. Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. *J Gen Intern Med.* 2008;23(9):1514-1517.
21. Scheunemann LP, Arnold RM, White DB. The facilitated values history: helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care Med.* 2012;186(6):480-486.
22. Neilson G, Chaimowitz G. Informed consent to treatment in psychiatry. *Can J Psychiatry.* 2015;60(4):1-11.

23. Jonsen AR, Siegler M, Winslade WJ. Preferences of patients. In: Jonsen AR, Siegler M, Winslade WJ, eds. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 8th ed. New York, NY: McGraw-Hill Education; 2015:70.
24. Ganzini L, Volicer L, Nelson WA, Fox E, Derse AR. Ten myths about decision-making capacity. *J Am Med Dir Assoc*. 2004;5(4):263-267.
25. Van Staden CW, Krüger C. Incapacity to give informed consent owing to mental disorder. *J Med Ethics*. 2003;29(1):41-43.
26. Martin RC, Gerstenecker A, Nabors LB, Marson DC, Triebel KL. Impairment of medical decisional capacity in relation to Karnofsky Performance Status in adults with malignant brain tumor. *Neurooncol Pract*. 2015;2(1):13-19.
27. Detterbeck FC, Lewis SZ, Diekemper R, Addrizzo-Harris D, Alberts WM. Executive summary: diagnosis and management of lung cancer, 3rd ed: American College of Chest Physicians evidence-based clinical practice guidelines. *Chest*. 2013;143(suppl 5):7S-37S.
28. Clausen W, Watanabe-Galloway S, Bill Baerentzen M, Britigan DH. Health literacy among people with serious mental illness. *Community Ment Health J*. 2016;52(4):399-405.
29. Killian L, Coletti M. The role of Universal Health Literacy Precautions in minimizing "medspeak" and promoting shared decision making. *AMA J Ethics*. 2017;19(3):296-303.
30. Green CA, Wisdom JP, Wolfe L, Firemark A. Engaging youths with serious mental illnesses in treatment: STARS Study Consumer Recommendations. *Psychiatr Rehabil J*. 2012;35(5):360-368.
31. Gutierrez G. The task and content of liberation theology. In: Rowland C, ed. Condor J, trans. *The Cambridge Companion to Liberation Theology*. New York, NY: Cambridge University Press; 1999:19-38.
32. Kidder T. *Mountains Beyond Mountains: The Quest of Dr. Paul Farmer, a Man Who Would Cure the World*. New York, NY: Random House; 2009.
33. Rawls J. *A Theory of Justice*. Cambridge, MA: Harvard University Press; 1971.
34. Rawls, 12.
35. Rawls, 83.
36. Niveau G. Relevance and limits of the principle of "equivalence of care" in prison medicine. *J Med Ethics* 2007;33(10):610-613.

Laurel J. Lyckholm, MD, is a clinical professor of hematology, oncology, and blood and marrow transplantation at the University of Iowa Carver College of Medicine in Iowa City, where she is also a primary faculty member in the Program in Bioethics and Humanities and a consultant on the University of Iowa Hospitals and Clinics Ethics Consult Service. Dr. Lyckholm's research and clinical interests are directed toward improving cancer and palliative care for the most vulnerable of our citizens.

Arwa K. Aburizik, MD, MS, is a clinical assistant professor of hematology, oncology, and blood and marrow transplantation, and psychiatry at the University of Iowa Carver College of Medicine in Iowa City. She specializes in caring for medically ill patients with psychiatric comorbidity and has a special focus on psycho-oncology.

Acknowledgements

We would like to thank Laura Shinkunas, MS, for her expertise and contribution to the development of the manuscript.

Related in the *AMA Journal of Ethics* and the *Code of Medical Ethics*

[AMA Code of Medical Ethics' Opinion 8.5 Disparities in Health Care](#), June 2016

[AMA Code of Medical Ethics' Opinion 2.1.2 Decisions for Adult Patients Who Lack Capacity](#), June 2016

[Beyond Charity—Social Justice and Health Care](#), August 2011

[Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal](#), May 2017

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

IN THE LITERATURE

How Situational Diagnosis Helps Disentangle Ethical and Psychological Features of Complex Cases

Jerry Joseph Ignatius, DO, and Walter Baile, MD

Lederberg MS. Disentangling ethical and psychological issues—a guide for oncologists. *Acta Oncol.* 1999;38(6):771-779.

Abstract

We review Marguerite S. Lederberg's 1999 *Acta Oncologica* article entitled "Disentangling Ethical and Psychological Issues: A Guide for Oncologists," in which she introduces a method of analysis that facilitates clarification of ethical and psychological aspects of complex cases. Based on her understanding of the dynamics at play in patients', family members', and physicians' experiences, Lederberg formulated what she calls "situational diagnosis," a guide on how to distinguish ethical from psychological issues at the bedside or when an ethics consultation is requested. Here, we apply situational diagnosis to a case and consider whether and how Lederberg's guidance relates to current literature on how clinicians communicate with patients about serious illnesses.

Introduction

In a 1999 article in *Acta Oncologica* entitled "Disentangling Ethical and Psychological Issues: A Guide for Oncologists," Marguerite S. Lederberg describes dilemmas that patients, their family members, and physicians experience in cancer medicine [1]. Cancer patients can sometimes see autonomy as a burden when struggling to make decisions fraught with uncertainty. Such decisions can generate anxiety about both survival and managing side effects from treatments. Families suffer with increased financial burdens of medical expenses, and their careers might falter or their jobs disappear. They also struggle psychologically, as they tend to be critical resources for the patient's care. In this role, they collaborate with the patient on treatment decisions, make decisions when the patient lacks capacity, and often suffer from guilt and depression when the patient experiences unfavorable outcomes. Physicians struggle with their personal feelings, patient load, time constraints, and political and financial constraints in delivery of care. Finally, there can be dilemmas in the patient-physician relationship, such as those over appropriate professional boundaries. An example of such a dilemma would be whether to accept a gift from or dine with a patient, which could lead to expectations of special treatment.

These dilemmas motivated Lederberg to develop a method for separating out ethical issues from issues pertaining to the relational dynamics represented by four factors: “patient/family factors,” “staff factors,” “staff/family interface,” and “legal/regulatory constraints.” In her method, which she calls “situational diagnosis,” each of these factors can be systematically analyzed to clarify a dilemma and decide whether a true ethical issue exists or not [1]. In this paper, we will discuss Lederberg’s method of situational diagnosis and apply it to a case. We will then discuss the contemporary relevance of components of situational diagnosis and offer possible strategies for resolving stressful clinical situations involving these components.

The Method of Situational Diagnosis

Based on her understanding of the dilemmas at play in the patient’s, the families’, and the physician’s experiences of cancer, Lederberg formulated the method of situational diagnosis, which is a guide on how to elucidate an ethical issue—either at the bedside or when an ethics consultation is requested—and identify possible interventions. As mentioned above, she described four components that that can be analyzed systematically to clarify an ethical dilemma: patient/family factors, staff factors, the staff/family interface, and legal/regulatory constraints [1].

Questions and issues arising from the first four components need to be addressed for an ethical dilemma—if there is one—to be unmasked. It is not uncommon for patients and families to have a distorted understanding of the patient’s disease and prognosis. First, there can be cultural and religious issues, psychiatric problems, or a history of family conflict. Second, staff members can have differing opinions on [medical management](#), or there might be inter-staff conflict. Third, relationships among staff and family members can be fraught, so those need to be analyzed as well, particularly when one party has strong negative or positive perceptions of the other or when there is poor communication. Fourth, laws or institutional constraints can be at play in a case. What remains after each of these factors has been clarified is a clearer picture of the actual ethical dilemma. Situational diagnosis thus facilitates clearer deliberation about what might constitute an appropriate response to the ethical issues and questions.

Situational Diagnosis Applied to a Case

Here we provide an example of how situational diagnosis can be applied to a case seen by one of the authors (JJJ).

A 17-year-old Venezuelan woman had been diagnosed as a child with metastatic NUT midline carcinoma—a rare, aggressive, genetically defined, poorly differentiated cancer. The patient did not respond to several lines of chemotherapy. She was eligible for a clinical trial, which posed risk of harm from the experimental agent’s side effects. However, the patient refused to allow any discussion of risks and didn’t want to hear

anything “negative.” When she was a child, she would defer to her parents, who would receive information and sign consent forms, but after she turned 18, she still declined to review risks and benefits. In fact, when the clinical team would discuss risks posed by the clinical trial or attempt to discuss her poor prognosis, she would cry to the point of nausea and, on occasion, vomit.

Using situational diagnosis to review this case, the apparent ethical issue (the patient’s refusal to consider risks and benefits of clinical trial participation or to sign a consent form) was more complicated than it seemed. The patient’s parents explained that, in their culture, children weren’t “truly” considered adults until age 25, and when it came to illnesses and decision making, they would defer to parents. Because of the patient’s emotional reactions to attempts to discuss risks and benefits of clinical trial participation, a psychiatric-psychological consultation was requested; consultants evaluated the patient and concluded that she was also suffering from an anxiety disorder that stemmed from asthma attacks when she was younger. (According to the situational diagnosis method, this would be a patient/family factor.) The staff had inadvertently increased the patient’s anxiety by explaining risks and benefits of participating in the clinical trial when it was culturally inappropriate for her to consent for herself. (According to the situational diagnosis method, this would be a staff/family interface factor.) The apparent ethical dilemma was created by a hospital and government policy requiring adult patients to hear risks and benefits of clinical trial participation before giving consent. (According to the situational diagnosis method, this would be a legal/regulatory constraint.)

Is Situational Diagnosis Still Relevant?

The current literature seems to support the value of applying Lederberg’s method of situational diagnosis for stressful clinical situations. A number of patient factors must be clarified before ethical issues can be framed and analyzed. Patients might demand what clinicians consider to be futile treatment because they misunderstand their disease status or prognosis [2]. In one study, 25 percent of cancer patients misunderstood the goal of their chemotherapy treatment, with age and language ability being significant predictors of misunderstanding of goals of care [3]. Some patients might be in a psychological state of denial about their illness, inhibiting discussion and understanding of care goals [4]. Others might refuse to “give up” because of religious beliefs, such as “putting everything in God’s hands.” Chevaux et al., for example, found that religious patients tend to desire aggressive measures to extend life [5]. However, one must be careful about making generalizations about specific religious groups; Chevaux et al. also found that Protestants tended to desire do-not-resuscitate orders by cardiopulmonary resuscitation [5].

Awareness and treatment of psychopathology is also of utmost importance before ethical issues can be analyzed, specifically when considering informed consent. Severe

mental illness, such as major depression, bipolar disorder, or schizophrenia, has been found to be associated with poor decision making [6]. And decision-making capacity can fluctuate in patients with bipolar disorder, being impaired when the patient is in a manic episode but returning with the patient's recuperation [7].

Sometimes communication problems between staff and family and patients can appear as ethical issues about treatment choices. For example, a clinician who tells a family member of an ICU patient with a poor prognosis that "his numbers look good" might mislead the family into believing that the patient is rallying. This could cause a patient and family to desire continuation of chemotherapy when it would be futile and could create a [conflict of values](#) between them and the staff. Primary care physicians can be overly optimistic about a prognosis with patients and families out of a desire not to destroy hope or because of the psychological stress of being bearers of bad news. For example, in one study, the primary physician was found to be the only significant factor in patients' continuation of chemotherapy during the last four weeks of life [8]. On the other hand, when physicians do deliver bad news, patients tend to view them with cynicism or mistrust [9].

It is important that interventions address these factors once they have been identified. These might include providing chaplains or mental health consultation. Good communication can also help clarify patient/family factors. For example, promoting effective communication can prevent conflict in discussions of prognosis and [end-of-life care](#) [10]. Part of effective communication is to ensure that the patient and family have correct information about the disease prognosis and interventions. This can be done by continually assessing patients' and family members' understandings about goals of care and trying to clarify discrepancies, thereby preventing the previously described issues [11].

Sometimes interactions between staff members can mask a possible ethical issue. For example, when a nurse perceives that a patient with advanced disease was not given an opportunity to discuss a desire to forego aggressive treatment, she might experience [moral distress](#) if she refrains from speaking up [12]. This situation raises the issue of whether it would be unethical for a physician to proceed with aggressive treatment in such a case. One solution might be for the nurse to request an ethics consultation. Another would be for the nurse to discuss the patient's wishes with the physician. One of the authors (WFB) and colleagues have described a six-step protocol called SPIKES for disclosing unfavorable information [13], which can help guide nurses to accomplish this communication task.

Finally, being aware of institutional and legal policy can be important to clarify if there truly is an ethical issue. The Texas Advance Directives Act of 1999 allows physicians to

remove a medically inappropriate intervention after giving the family and patient time to find an alternative facility that might administer the intervention [14].

Conclusion

In addition to the method of situational diagnosis, several methods have been discussed in the literature on how to approach an ethics consultation, including the “four quadrants” approach [15], the Montefiore model [16], and the CASES approach [17]. However, we believe that situational diagnosis provides an organized and systematic way to approach a stressful clinical situation by creating awareness of patient/family factors, staff factors, the staff/family interface, and legal/regulatory constraints. A clinician faced with such a situation can use the method of situational diagnosis as an algorithm to rule out and resolve issues related to the four (non-ethical) factors, possibly preventing the need for an ethics consultation. Ethicists, however, are usually trained to identify factors affecting patient care that are not true ethical dilemmas and to recommend other solutions.

References

1. Lederberg MS. Disentangling ethical and psychological issues—a guide for oncologists. *Acta Oncol.* 1999;38(6):771-779.
2. Badger JM. Factors that enable or complicate end-of-life transitions in critical care. *Am J Crit Care.* 2005;14(6):513-521.
3. Lennes IT, Temel JS, Hoedt C, Meilleuer A, Lamont EB. Predictors of newly diagnosed cancer patients’ understanding of the goals of their care at initiation of chemotherapy. *Cancer.* 2013;119(3):691-699.
4. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med.* 2014;174(12):1994-2003.
5. Chevaux F, Gagliano M, Waeber G, Marques-Vidal P, Schwab M. Patients’ characteristics associated with the decision of “do not attempt cardiopulmonary resuscitation” order in a Swiss hospital. *Eur J Intern Med.* 2015;26(5):311-316.
6. Cáceda R, Nemeroff CB, Harvey PD. Toward an understanding of decision making in severe mental illness. *J Neuropsychiatry Clin Neurosci.* 2014;26(3):196-213.
7. Gergel T, Owen GS. Fluctuating capacity and advance decision-making in bipolar affective disorder—self-binding directives and self-determination. *Int J Law Psychiatry.* 2015;40:92-101.
8. Kao S, Shafiq J, Vardy J, Adams D. Use of chemotherapy at end of life in oncology patients. *Ann Oncol.* 2009;20(9):1555-1559.
9. Communication: what do patients want and need? *J Oncol Pract.* 2008;4(5):249-253.
10. Back A, Arnold RM, Tulsky JA. *Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope.* New York, NY: Cambridge University Press; 2009.

11. Dintzis S. Improving pathologists' communication skills. *AMA J Ethics*. 2016;18(8):802-808.
12. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs*. 2001;33(6):707-715.
13. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-311.
14. Gallagher CM, Holmes RF. Handling cases of “medical futility.” *HEC Forum*. 2012;24(2):91-98.
15. Sokol DK. The “four quadrants” approach to clinical ethics case analysis; an application and review. *J Med Ethics*. 2008;34(7):513-516.
16. Post LF, Blustein J, Dubler NN. *Handbook for Health Care Ethics Committees*. Baltimore, MD: Johns Hopkins University Press; 2007.
17. CASES is the acronym for the five-step approach: “clarify,” “assemble the relevant information,” “synthesize the information,” “explain the synthesis,” “support the consultation process.” See Berkowitz KA, Chanko BL, Foglia MB, Fox E, Powell T. *Ethics consultation: responding to ethics questions in health care*. 2nd ed. Washington, DC: National Center for Ethics in Health Care; 2015. https://www.ethics.va.gov/docs/integratedethics/ec_primer_2nd_ed_080515.pdf. Accessed March 28, 2017.

Jerry Joseph Ignatius, DO, is an assistant professor in the Department of Psychiatry at the University of Texas MD Anderson Cancer Center in Houston. He has a special interest in demoralization and spirituality in cancer patients.

Walter Baile, MD, is a distinguished teaching professor in the departments of psychiatry and behavioral science at the University of Texas MD Anderson Cancer Center in Houston. He is also director of the Interpersonal Communication and Relationship Enhancement (I*Care) program at MD Anderson Cancer Center, where he develops and oversees teaching in the area of clinician-patient communication.

Related in the *AMA Journal of Ethics*

[Ethical Management of Patients with Cancer and Mental Illness](#), May 2017

[Moral Distress and Nurse-Physician Relationships](#), January 2010

[When Patient and Physician Disagree on Patient's “Best Interest”](#), March 2009

[When Physicians and Surrogates Disagree about Futility](#), December 2013

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

STATE OF THE ART AND SCIENCE

Assessing Psychological Toxicity and Patient-Reported Distress as the Sixth Vital Sign in Cancer Care and Clinical Trials

Thomas W. LeBlanc, MD, MA, MHS, and Arif H. Kamal, MD, MBA, MHS

Abstract

As the number of available cancer therapies continues to grow, there is increasing interest in their impact on cancer patients' lived experiences. Screening for distress is one way to measure psychological dimensions of cancer patients' experiences, and doing so is increasingly part of standard operations at major cancer centers across the US. To date, however, most clinical trials have not adequately captured patients' experiences as part of their outcome assessments, so clinicians lack data needed to guide their responses to psychological features of patients' illness experiences. As distress becomes the "sixth vital sign" in routine cancer care, we argue that clinical trials should assess patients' experiences in the same way that they robustly screen for adverse events and toxicities. New interventions are needed to address distress.

Introduction

After many years of exclusive emphasis on physical symptoms and clinical outcomes, the twenty-first century has ushered in heightened attention to psychological issues in cancer care. In 1999, the Institute of Medicine (IOM) (now the National Academy of Medicine) published a report, *Ensuring Quality Cancer Care*, which outlined psychological distress assessment and management as a core component of quality cancer care [1]. Then in its landmark 2008 report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, the IOM more strongly recommended that psychological assessments be integrated into routine cancer care [2]. Shortly thereafter, the International Psycho-Oncology Society (IPOS) recommended a revision to cancer care standards and clinical practice guidelines, ranking distress as the "6th vital sign" in cancer care [3, 4]. These recommendations have since been translated into cancer center accreditation requirements [5].

While these recommendations are quite clear, their justification and evidence base until recently have been a bit murkier. Ensuing discussions have raised important questions about the concept of "distress," the reliability of measurements thereof, and the implications of these recommendations for clinical practice and research [6-9]. We argue that the evidence supporting the guidelines is now clear and that there is ultimately an

ethical imperative to follow the IOM and IPOS recommendations in routine clinical care. Taken to its logical conclusion, this argument also suggests that we should incorporate assessments of distress into oncology clinical trials as well. We will discuss and defend this viewpoint here.

Distress is Measurable and Actionable

While the notion of distress may sound vague or confusing to some, it actually has a rather specific definition. The National Comprehensive Cancer Network® (NCCN®) defines distress as “an unpleasant emotional experience associated with the psychosocial complications of cancer that may interfere with quality of life” [10]. As such, distress encompasses more than just anxiety or depression, although it does include these experiences within its broader scope. For example, evidence demonstrates the close relationships between physical symptoms, like pain and constipation, and emotional distress [11]. In other words, various experiences can cause distress among patients with cancer: physical symptoms can be distressing, but so are financial hardships as well as emotional challenges like anxiety or depression.

Distress has also been the topic of a great deal of research in oncology in the last decade. For example, evidence suggests that distress is quite prevalent among patients with cancer; one study estimates its prevalence is as high as 35 percent [12]. Yet it is frequently overlooked or inadequately addressed in practice [13]. Patients who are facing a serious illness like cancer deserve to have their distress assessed and addressed, and we are not alone in this view; our perspective aligns with recommendations from the most recent IOM report in this area, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* [14], which emphasizes the need to collect more data directly from patients to better understand their needs and experiences [15]. As such, we argue that personalized cancer care must include the systematic assessment of, and attention to, patients’ experiences, including but not limited to distress.

As a defined construct, distress is readily measurable. Several standardized, short scales are available to measure distress, including the NCCN’s “Distress Thermometer” (DT), one of the most widely-used validated scales with people affected by cancer [16, 17]. The DT is a simple 0 to 10 ordinal scale that looks like a thermometer; it allows patients to quickly rate their overall level of distress. In addition, its accompanying “problem list” includes a set of 39 items in 5 domains of well-being, allowing patients to quickly mark “yes” or “no” to any issues that may be contributing to their distress in physical, family, practical, emotional, and spiritual/religious domains [18].

In 2015, the American College of Surgeons Commission on Cancer® (CoC) instituted an accreditation requirement for comprehensive cancer centers regarding distress screening [5]. Meeting this guideline requires a program to integrate psychosocial

experts into the cancer center to vet and select a distress screening instrument, determine timing and frequency of screening, develop a referral management plan, and document the entire process. Given the number of cancer centers accredited through the CoC [19], it is likely that this new mandate has significantly increased the use of distress screening in clinical practice. What has not followed as quickly, however, is the development of more systematic, rigorously tested and implemented interventions to actually address this distress in routine clinical care and in clinical trials.

Amid this gap, we often hear our colleagues complain that distress scores are not particularly actionable in daily practice. In other words, many clinicians are unsure of how to interpret the results of distress screening or what to do about abnormal results. They might expect that distress is occurring due to side effects of treatment and perhaps believe these side effects cannot be mitigated and will improve on their own with time. Or they might feel ill equipped to “fix” problems related to anxiety or depressed mood. Similar critiques have been levied against systematic quality of life assessments in routine practice [20].

To the contrary, emerging data now suggest there are distinct benefits conferred by regular distress screening and symptom or quality of life assessment among patients with cancer. For example, in a study comparing patients who received care either before ($n = 740$) or after ($n = 534$) implementation of routine distress screening and appropriate interventions, patients in the post-implementation cohort showed significant improvements in psychological and physical symptoms as well as psychosocial well-being [21]. Follow-up analyses in this study assessed clinician confidence in managing distress and demonstrated significant improvements therein [22]. Similarly, in a large randomized controlled trial conducted by Basch et al., investigators found that patients who participated in weekly symptom monitoring via tablet computers actually had improved overall quality of life over time [23]. Furthermore, recent work by our group in specialty palliative care demonstrates that more comprehensive and frequent assessments of distress are associated with higher quality of life among cancer patients living in the community [24].

We contend that these findings, among others, substantiate the decision by IPOS to recommend distress assessment as the sixth vital sign and provide compelling data to reinforce the National Academy of Medicine’s recommendation from over a decade ago. Not only are these kinds of “softer” patient-reported data readily collectable in a reliable manner, but they are also amenable to intervention. Most importantly, the systematic inclusion of distress screening and management into routine cancer care practices appears to improve patient-centered outcomes, as discussed above.

Clinical Trials' Emphasis on Physical Toxicities over Psychological Ones

While distress screening is increasingly common since the CoC issued its accreditation mandate, distress data remain relatively scarce in oncology clinical trials. Standard outcome assessments in drug trials include expected measures of disease response to treatment, such as response rate or progression-free survival. They also include standard toxicity assessments such as the Common Terminology Criteria for Adverse Events (CTCAE), a standardized clinical trials toxicity-reporting instrument for assessing adverse events that allows comparison across trials and may include other patient-reported outcome measures of overall quality of life. Measures of distress, or "psychological toxicity" as one might call it, have not generally been collected as part of drug trials, despite the fact that distress is indeed a predictable "toxicity" of cancer treatment and that distress screening tools have existed for at least 20 years. As such, we have a very limited understanding of the degree of distress seen in different diseases or across different treatment regimens, even within randomized controlled trials, which provide the most rigorous level of evidence in medicine. The same is true for quality of life, which is not measured in many oncology drug trials or often not reported in landmark publications of initial results [25].

We therefore argue that, beyond its inclusion in standard care assessments as the sixth vital sign, more systematic, regular assessment of psychological well-being should be part of clinical trials and other [research efforts](#) in oncology, in part to help remedy this knowledge gap. Such assessments can be implemented easily alongside other patient-reported outcome assessments of demographics and medical history (e.g., routine intake forms prior to appointments) or toxicity and efficacy assessments (e.g., symptoms) during routine clinical care that also serves to support research [26]. Calls have been made for drug trials to assess adverse symptom events, including distress as a toxicity measure [27] (i.e., psychological toxicity), and we suggest that novel interventions to address distress must be developed and rigorously tested, just as clinical trials test novel cancer therapeutics.

Ethical Considerations and Future Directions

In light of the growing data about psychological toxicity and distress as presented above, we therefore argue that there is an ethical imperative to measure and address distress as part of clinical care and research endeavors, including clinical trials. Survival and progression-free survival, two of the most common clinical trial endpoints, are not the only important endpoints for patients. Indeed, for patients and patient advocates, the patient experience itself matters, and it matters a lot [28]. It can matter even more than the estimated increases in overall survival seen with many approved novel oncology drugs, which are sometimes only in the order of 12 weeks or less [29, 30]. We envision a future in which patients will report their symptoms, [quality of life](#), and distress on electronic devices as part of routine care, and that these data will serve as actionable items in their care, helping us to better understand and meet the needs of those who are

facing serious illness. This will enable us to further test, refine, and disseminate interventions that improve patients' experiences. Such is truly "personalized medicine," in its most personal sense, as it addresses those things that matter most to an individual, in an effort to improve his or her life. Patients and families deserve the best care we can provide, and that includes assessing and addressing distress as a core component of comprehensive cancer care and clinical trials.

References

1. Hewitt ME, Simone JV, eds; National Cancer Policy Board; Institute of Medicine and Commission on Life Sciences; National Research Council. *Ensuring Quality Cancer Care*. Washington, DC: National Academy Press; 1999.
2. Adler NE, Page AEK; Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington DC: National Academies Press; 2008.
3. Watson M, Bultz BD. Distress, the 6th vital sign in cancer care. *Psycho-Oncology*. 2010;4(3):159-163.
4. International Psycho-Oncology Society (IPOS). IPOS standard of quality cancer care. <http://ipos-society.org/about-ipos/ipos-standard-of-quality-cancer-care/>. Accessed March 29, 2017.
5. Commission on Cancer®. *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. V1.2.1. Chicago, IL: American College of Surgeons; 2012. https://www.facs.org/~media/files/quality%20programs/cancer/coc/programs_tandards2012.ashx. Accessed March 29, 2017.
6. Coyne JC. Benefits of screening cancer patients for distress still not demonstrated. *Br J Cancer*. 2013;108(3):736-737.
7. Carlson LE, Waller A, Groff SL, Zhong L, Bultz BD. Reply: benefits of screening cancer patients for distress still not demonstrated. *Br J Cancer*. 2013;108(3):738-739.
8. Fielding R, Lam WW. Unresolved problems with distress screening. *Br J Cancer*. 2013;108(9):1922-1923.
9. Feldstain A, Tomei C, Bélanger M, Lebel S. Screening for distress in patients with cancer: methodologic considerations. *Curr Oncol*. 2014;21(2):e330-e333.
10. Troy JD, DeCastro C, Pupa MR, Samsa GP, Abernethy AP, LeBlanc TW. Patient-reported distress in adults with myelodysplastic syndromes (MDS) [Palliative Care in Oncology Symposium abstract]. *J Clin Oncol*. 2016;34(26)(suppl):80.
11. Ong CK, Forbes D. Embracing Cicely Saunders's concept of total pain. *BMJ*. 2005;331(7516):576-577.
12. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psychooncology*. 2001;10(1):19-28.
13. Carlson LE, Angen M, Cullum J, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer*. 2004;90(12):2297-2304.

14. Institute of Medicine. *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. Washington, DC: National Academies Press; 2013.
15. Ganz PA, Hassett MJ, Miller DC. Challenges and opportunities in delivering high-quality cancer care: a 2016 update. *Am Soc Clin Oncol Educ Book*. 2016;35:e294-e300.
16. Mitchell AJ. Short screening tools for cancer-related distress: a review and diagnostic validity meta-analysis. *J Natl Compr Canc Netw*. 2010;8(4):487-494.
17. Stewart-Knight K, Parry R, Abey A, Seymour J. Does the distress thermometer work? A systematic review of the evidence for its use and validity [Palliative Care Congress abstract 44]. *BMJ Support Palliat Care*. 2012;2(suppl 1):A30.
18. National Comprehensive Cancer Network®. NCCN Distress Thermometer and problem list for patients.
https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf. Published July 25, 2016. Accessed March 27, 2017.
19. Merkow RP, Chung JW, Paruch JL, Bentrem DJ, Bilimoria KY. Relationship between cancer center accreditation and performance on publicly reported quality measures. *Ann Surg*. 2014;259(6):1091-1097.
20. Grumann M, Schlag PM. Assessment of quality of life in cancer patients: complexity, criticism, challenges. *Onkologie*. 2001;24(1):10-15.
21. Watson L, Groff S, Tamagawa R, et al. Evaluating the impact of provincial implementation of screening for distress on quality of life, symptom reports, and psychosocial well-being in patients with cancer. *J Natl Compr Canc Netw*. 2016;14(2):164-172.
22. Tamagawa R, Groff S, Anderson J, et al. Effects of a provincial-wide implementation of screening for distress on healthcare professionals' confidence and understanding of person-centered care in oncology. *J Natl Compr Canc Netw*. 2016;14(10):1259-1266.
23. Basch E, Deal AM, Kris MG, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. *J Clin Oncol*. 2016;34(6):557-565.
24. Kamal AH, Bull J, Stinson CS, Blue DL, Abernethy AP. Conformance with supportive care quality measures is associated with better quality of life in patients with cancer receiving palliative care. *J Oncol Pract*. 2013;9(3):e73-e76.
25. LeBlanc TW, Abernethy AP. Quality of life in higher resolution: the next generation of comparative effectiveness research in malignant hematology. *Haematologica*. 2013;98(6):823-824.
26. Abernethy AP, Ahmad A, Zafar SY, Wheeler JL, Reese JB, Lyerly HK. Electronic patient-reported data capture as a foundation of rapid learning cancer care. *Med Care*. 2010;48(suppl 6):S32-S38.
27. Basch E. The missing voice of patients in drug-safety reporting. *N Engl J Med*. 2010;362(10):865-869.

28. Kamal AH, LeBlanc TW, Meier DE. Better palliative care for all: improving the lived experience with cancer. *JAMA*. 2016;316(1):29-30.
29. Salas-Vega S, Iliopoulos O, Mossialos E. Assessment of overall survival, quality of life, and safety benefits associated with new cancer medicines. *JAMA Oncol*. 2017;3(3):382-390.
30. Garg PK, Jain BK. New cancer drugs at the cost of bankruptcy: will the oncologist tell the patients the benefit in terms of days/weeks added to life? *Oncologist*. 2014;19(12):1291.

Thomas W. LeBlanc, MD, MA, MHS, is a medical oncologist and palliative medicine physician at Duke University School of Medicine in Durham, North Carolina, where he is also a patient experience researcher at the Duke Cancer Institute.

Arif H. Kamal, MD, MBA, MHS, is a medical oncologist and palliative medicine physician at Duke University School of Medicine in Durham, North Carolina, where he is also the physician quality and outcomes officer for the Duke Cancer Institute.

Related in the *AMA Journal of Ethics*

[Ethical Management of Patients with Cancer and Mental Illness](#), May 2017

[Emotional Harms to Patients: An Interview with Dr. Kenneth Sands](#), April 2015

[How Situational Diagnosis Helps Disentangle Ethical and Psychological Features of Complex Cases](#), May 2017

[The Importance of Quality of Life to Patient Decision Making in Breast Cancer Care](#), February 2014

[Prioritizing Mental Health Research in Cancer Patients and Survivors](#), May 2017

[When and Why Should Mental Health Professionals Offer Traditional Psychodynamic Therapy to Cancer Patients?](#), May 2017

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

STATE OF THE ART AND SCIENCE

When and Why Should Mental Health Professionals Offer Traditional Psychodynamic Therapy to Cancer Patients?

David P. Yuppa, MD, and Fremonta Meyer, MD

Abstract

Given the recent studies promoting time-limited manualized therapies in the oncology setting, clinicians may be reluctant to offer traditional psychodynamic therapy to cancer patients. However, there are no studies directly comparing psychodynamic therapy and other therapy modalities in this patient population and no data suggesting harm from psychodynamic approaches. Therefore, it is inappropriate to draw the conclusion that psychodynamic therapy is inferior to manualized therapy from existing evidence. Manualized treatment, such as cognitive behavioral therapy, is generally short term and therefore may reduce the practitioner's own anxiety stemming from exposure to patients facing grave disability and death. However, manualized treatment is not fully effective in specific clinical scenarios. We present a case reflecting these limitations and advocate for a flexible treatment approach incorporating elements of psychodynamic therapy.

Introduction

The field of psycho-oncology has moved away from psychodynamic psychotherapy toward discrete methods of measuring psychological distress and monitoring treatment response using self-report symptom assessment scales, as recommended by clinical practice guidelines [1]. Psychodynamic psychotherapy is understood to be based upon the principles of psychoanalysis and encourages patients to speak openly and freely without any agendas or "goals" on the part of the therapist. Treatment frequency ranges from one to three times per week and lasts for a few weeks to a few years. The method involves analyzing and interpreting conflicts and other psychic forces outside of the patient's awareness. It is the resolution of these conflicts that leads to symptom improvement [2]. By contrast, manualized therapies, such as cognitive behavioral therapy (CBT), involve the use of standardized treatment guidebooks that prescribe specific techniques to be applied and goals to be attained in a designated number of therapy sessions, measuring responses with validated symptom rating scales. CBT is a time-limited intervention (with weekly sessions lasting 45-60 minutes for approximately 8-12 weeks) that emphasizes the patient's ability to change his or her emotions by modulating thoughts and behaviors [3].

To our knowledge, there are no studies directly comparing CBT or other manualized therapies to psychodynamic therapy in cancer patients. In this paper, we first discuss the general debate about the comparative efficacy of manualized treatments, such as CBT and psychodynamic psychotherapies, and then discuss the potential applicability of these therapies to oncology patients specifically. We will then present clinical scenarios that reveal the potential limitations of manualized treatment and propose a more flexible approach incorporating psychodynamic elements.

CBT versus Psychodynamic Psychotherapy: A Brief Review

Shedler notes that the push for “evidence-based” therapy, which started in the 1990s, has in the realm of psychotherapy “been appropriated to promote a particular ideology and agenda” [4]. Indeed, evidence-based therapy has become synonymous for manualized treatments, specifically CBT; this is possibly because the endpoints proposed for CBT studies (whether emotions such as anxiety or depression, or behaviors such as smoking or binge eating) are quantifiable and therefore easier to study than postulated psychodynamic therapy endpoints such as life satisfaction and quality of relationships. However, psychodynamic psychotherapy is also well established as an efficacious treatment for “harder” endpoints such as anxiety and depression, and its effects not only endure but also increase over time, in contrast to non-psychodynamic therapies whose benefits tend to decay after treatment completion [5]. Moreover, a recent meta-analysis of CBT for unipolar depression found that the efficacy of CBT has declined in a linear fashion between 1977, when it was introduced, and 2014, as measured by patient self-reports, clinician ratings, and rates of remission [6].

Psychodynamic Therapy in the Medically Ill

Because people are living longer after a cancer diagnosis than they were in the early 1970s [7], they may be more suitable candidates for, and gain lasting benefits from, a more intensive and longer-term treatment such as psychodynamic psychotherapy, even though psychodynamic therapy was regarded as beneficial then. In 1972, Wahl [8] noted that medically ill patients were in a unique position to benefit from brief psychotherapeutic interventions due to fears of death, abandonment, and physical incapacity, as well as being placed in a foreign and depersonalized setting (the hospital). Wahl noted that “this state of affairs, distressing as it so often is to the patient, can, however, be highly conducive to effective psychotherapeutic work” [9] and hypothesized that the regression—a return to a previous state of emotional development—caused by medical illness paralleled the regression that occurred in medically healthy people after long periods of time in psychotherapy. He noted of positive [transference](#)—the unconscious “transfer” of positive/loving feelings from the patient’s past onto someone in the present—that “in no other category of patients is the positive transference developed so quickly and to such a degree of intensity,” and added, “It is this strongly positive and trusting transference that is the sine qua non of brief, rapid psychotherapy”

[10]. We can attest to the aptness of Wahl's observation on the basis of our clinical experience. However, this result is not universal; regression may result in either positive or negative transference depending on the nature of a patient's early childhood experiences.

More recently, Postone [11] specifically addressed psychotherapeutic treatment of cancer patients, noting that "psychotherapy is particularly useful for patients whose illness has triggered an intensification of intrapsychic conflict" and that "the unconscious meaning that patients attribute to their illness and treatment becomes an important part of their illness, and frequently intensifies their suffering." An oft-encountered clinical scenario is that of survivors of childhood sexual abuse, who can experience re-activation of previously forgotten emotions in the setting of exposure to new caregivers (e.g., cancer treatment clinicians) because the perpetrators of childhood sexual abuse are often early caregivers (e.g., family members, babysitters, coaches). In our clinical experience, additional themes that arise in the psychotherapy of cancer patients include basic threats to narcissistic integrity, loss of control, dependency, fear of abandonment, loss of identity, treatment-related issues (e.g., loss of privacy during hospitalization, needle phobias), specific meaning of illness (e.g., patient's guilt about life decisions or behaviors that may have led to illness), and death anxiety.

Insight-oriented psychodynamic psychotherapy may alleviate cancer patients' reactions of mourning, rage, and aggression. For example, a patient whose father abandoned her early in life may experience anxiety after completing cancer treatment as she begins to receive less attention from her clinicians. In psychodynamic therapy, the practitioner would explore the emotional state underlying the anxiety, which might actually be a mixture of anger or sadness augmented by her childhood emotions toward her father (i.e., transference). Recognizing these core emotions while expressing, containing, and working through them in a safe professional relationship often greatly reduces the overlying anxiety. These methods do not preclude the concurrent use of problem-solving strategies to manage crises; experienced therapists have advocated for clinicians' flexibility in their work with cancer patients [12].

An additional clinical scenario seen in the cancer setting is that of requests for [physician-assisted suicide](#). As noted by Nash, Kent, and Muskin [13], "consideration of the psychodynamic motivation for the request to die can reveal a perspective that can lead to a deeper understanding of the patient's experience and preconscious intentions" [14]. Requests to die can be expressions of patients' wishes to control their own death, maintain control over their lives, or a call for help to the clinician to find a reason to live [15]. Alternately, they may be the final enactment of a masochistic character organization or an attempt at revenge towards their family or their doctors [15]. Requests for hastened death are not well-suited to intervention via CBT or other manualized therapies except perhaps in the relatively rare instances in which a clinical

depression is the sole driver of the request. This is because patients often are not experiencing the distorted thought patterns that CBT may be best suited to address. For example, a medically healthy person with panic disorder may report feeling so anxious that he thinks he is going to die. In this case, CBT would be very beneficial to address catastrophization regarding the meaning of physical symptoms. By contrast, a patient with terminal lung cancer who is experiencing worsening dyspnea, resulting in severe anxiety, and requesting hastened death has a very realistic interpretation of the meaning of her symptoms and would not be likely to benefit from CBT.

Manualized Therapy versus Psychodynamic Therapy: A Case Study

Meaning-centered psychotherapy, a brief (seven-session) intervention offered to critically ill patients that aims to increase a sense of meaning and decrease emotional distress [16], has been shown to benefit cancer patients [16, 17]. We know of no comparable randomized studies of psychodynamic psychotherapy in the cancer setting. Hence, the claim can be made that this form of manualized therapy is a reasonably efficacious and better studied approach to treating cancer-related distress than psychodynamic psychotherapy and thus a more “ethical” strategy. To counter that postulate, we pose the following clinical scenario.

Case. Ms. A is a 38-year-old mother of two who is being treated for advanced breast cancer. She experienced treatment-related menopause and had attempted mastectomy with reconstruction but could not tolerate the constant pain from tissue expanders. She presented for mental health treatment with reports of anxiety about leaving her children and intense despair at the abrupt loss of her femininity and disruption in the intimate relationship with her partner. She also reported a history of childhood sexual assault by a family member, with a recent emergence of extremely disturbing incestuous nightmares during her cancer treatment.

Ms. A confided in her mental health clinician that she had begun to have sexual fantasies about her male oncologist and experienced their interactions as overly erotic, triggering intrusive memories of her past sexual trauma. Ms. A’s clinician attempted to manage her distress with a manualized CBT approach. Ms. A’s distress continued unabated, and she began to engage in splitting behaviors (which are seen in certain personality types, resulting in the patient’s conflicts being enacted among others). Specifically, she praised certain members of her care team and spoke pejoratively about her oncologist, presenting variable information about her symptoms and their severity. Attempts to contain the patient’s anxiety with guided imagery, problem solving, deep breathing, and challenging cognitive distortions were ineffective, because she experienced these attempts as failing to address the underlying causes of her emotional distress (which was deeply rooted in her sense of loss and her personal history of trauma). She ultimately accused her oncologist of being inappropriate during a routine exam. Ms. A’s mental health clinician began to feel increasingly anxious with each visit and confided in

a colleague that she “dreaded” her scheduled visits with Ms. A. The therapist found some solace in the routine of the manualized therapy, as she was “doing something” to help the patient, and this intervention was an “evidence-based” approach. However, Ms. A became more emotionally unstable and eventually noncompliant with her oncology treatment, and she was lost to follow-up.

Commentary. The purpose of the above vignette is not to suggest that a psychodynamic approach would have necessarily led to a more favorable outcome. However, Mrs. A’s history of childhood sexual abuse illustrates the significant shortcomings of an overly manualized approach for a patient with significant trauma history. A psychodynamic approach would have prioritized the shared understanding of the patient’s history and the possibility that a pathological enactment (i.e., a maladaptive relational interaction based upon unresolved unconscious conflicts) could take place. A dynamic therapist would have encouraged the patient to speak about her dreams and fantasies so as to modulate the associated distress, whereas CBT would have focused more on eliminating the symptom of anxiety that was aroused by these memories, perhaps inadvertently stripping them of their meaning. While Ms. A might have experienced ongoing distress regardless of the specific intervention, a dynamic approach might have assigned the most meaning to her experience, thereby strengthening therapeutic rapport and potentially improving treatment compliance.

Other Considerations

Countertransference. While a detailed discussion of countertransference, which can be understood as the clinician’s emotional reaction towards the patient, is beyond the scope of this paper, it is worthwhile to call attention to the anxiolytic effect that a manualized, time-limited treatment can have on the *clinician*. As Mendelson and Meyer have explained [18], the countertransference reaction of the clinician working with chronically or severely ill patients has the potential to lead to “pessimism, hopelessness, and despair,” and exposure to patients facing imminent death can trigger significant anxiety in the clinician. Clinician anxiety often leads to avoidance, which can increase the allure of short-term therapy that offers a clearly defined end of treatment. The prospect of a time-limited approach further benefits the clinician for if, at the conclusion of the intervention, the patient continued to be significantly distressed, the clinician would—perhaps unconsciously so—regard it as the patient’s “fault” for not “getting better” despite following the recommended techniques and surely not blame herself or the intervention. By contrast, a dynamic approach stipulates that the treatment may continue for a more flexibly determined period of time so that the patient can receive the most person-centered intervention for psychological distress.

Flexible approach. When evaluating if a psychodynamic approach to the mental health treatment of a cancer patient is ethical, it is imperative to determine the goals of treatment. For a patient with limited ability to tolerate affect and a pre-existing personality disorder, a manualized approach to helping the patient manage affect and tolerate anxiety so that he or she can receive necessary medical treatment is a more beneficent approach than reliance on interpretation of the patient's behavior to promote insight. For a patient with a lifelong history of depressive neurosis who seeks to gain insight and derive meaning from this experience in the waning period of life, it may be unethical to offer manualized, time-limited therapy when it would be unlikely to have lasting benefit.

Conclusion

Each patient presents with his or her own life experiences and unresolved conflicts, which in the setting of cancer diagnosis and treatment are often amplified in intensity; for many, the treatment setting is uniquely suited for psychotherapeutic intervention and rapid development of a strong therapeutic alliance (through the transference). Rather than overly standardizing their therapeutic armamentarium, psycho-oncology clinicians should carefully consider which treatments might be best suited for which patient at a given point in the medical trajectory. We are ultimately in agreement with Nash, Kent, and Muskin, who note that "the use and understanding of psychodynamics and psychodynamic theory allows [clinicians] the opportunity to interpret the life narratives of medically ill patients in a meaningful way that contributes importantly to treatment" [19].

References

1. Andersen BL, DeRubeis RJ, Berman BS, et al; American Society of Clinical Oncology. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *J Clin Oncol.* 2014;32(15):1605-1619.
2. Cabaniss DL. *Psychodynamic Psychotherapy: A Clinical Manual.* 2nd ed. Hoboken, NJ: John Wiley and Sons; 2016.
3. Beck JS. *Cognitive Behavior Therapy: Basics and Beyond.* 2nd ed. New York, NY: Guilford Press; 2011.
4. Shedler J. Where is the evidence for "evidence-based" therapy? *J Psychol Ther Prim Care.* 2015;4(1):47.
5. Shedler J. The efficacy of psychodynamic psychotherapy. *Am Psychol.* 2010;65(2):98-109.
6. Johnsen TJ, Friborg O. The effects of cognitive behavioral therapy as an anti-depressive treatment is falling: a meta-analysis. *Psychol Bull.* 2015;141(4):747-768.
7. Thousands of cancer sufferers surviving decades after diagnosis. *Guardian.* August 1, 2016. <https://www.theguardian.com/society/2016/aug/01/long->

term-cancer-suvivors-nhs-macmillan-cancer-support-report. Accessed March 17, 2017.

8. Wahl CW. The technique of brief psychotherapy with hospitalized psychosomatic patients. *Int J Psychoanal Psychother*. 1972;1(4):69-82.
9. Wahl, 71.
10. Wahl, 74.
11. Postone N. Psychotherapy with cancer patients. *Am J Psychother*. 1998;52(4):415-416.
12. Straker N. Psychodynamic psychotherapy for cancer patients. *J Psychother Pract Res*. 1998;7(1):1-9.
13. Nash SS, Kent LK, Muskin PR. Psychodynamics in medically ill patients. *Harv Rev Psychiatry*. 2009;17(6):389-397.
14. Nash, Kent, Muskin, 394.
15. Muskin PR. The request to die: role for a psychodynamic perspective on physician-assisted suicide. *JAMA*. 1998;279(4):323-328.
16. Breitbart W, Poppito S, Rosenfeld B, et al. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *J Clin Oncol*. 2012;30(12):1304-1309.
17. Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psychooncology*. 2010;19(1):21-28.
18. Mendelson M, Meyer E. Countertransference problems of the liaison psychiatrist. *Psychosom Med*. 1961;23(2):121.
19. Nash, Kent, Muskin, 389.

David P. Yuppa, MD, is an attending psychiatrist at the Dana-Farber Cancer Institute and Brigham and Women's Hospital and an instructor in psychiatry at Harvard Medical School in Boston. He is a former fellow of the American Psychoanalytic Association and a candidate in adult psychoanalysis at the Boston Psychoanalytic Society and Institute.

Fremonta Meyer, MD, is an assistant professor of psychiatry at Harvard Medical School in Boston, where she is also an attending psychiatrist at the Dana-Farber Cancer Institute and Brigham and Women's Hospital.

Related in the *AMA Journal of Ethics and Code of Medical Ethics*

[AMA Code of Medical Ethics' Opinion 5.7 Physician-Assisted Suicide](#), November 2016

[Assessing Psychological Toxicity and Patient-Reported Distress as the Sixth Vital Sign in Cancer Care and Clinical Trials](#), May 2017

[Ethical Management of Patients with Cancer and Mental Illness](#), May 2017

[How Should Clinicians Respond to Transference Reactions with Cancer Patients?](#), May 2017

[Prioritizing Mental Health Research in Cancer Patients and Survivors](#), May 2017

[When Is Depression a Terminal Illness? Deliberative Suicide in Chronic Mental Illness,](#)
June 2016

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980

MEDICINE AND SOCIETY

Decreasing Smoking but Increasing Stigma? Anti-tobacco Campaigns, Public Health, and Cancer Care

Kristen E. Riley, PhD, Michael R. Ulrich, JD, MPH, Heidi A. Hamann, PhD, and Jamie S. Ostroff, PhD

Abstract

Public health researchers, mental health clinicians, philosophers, and medical ethicists have questioned whether the public health benefits of large-scale anti-tobacco campaigns are justified in light of the potential for exacerbating stigma toward patients diagnosed with lung cancer. Although there is strong evidence for the public health benefits of anti-tobacco campaigns, there is a growing appreciation for the need to better attend to the unintended consequence of lung cancer stigma. We argue that there is an ethical burden for creators of public health campaigns to consider lung cancer stigma in the development and dissemination of hard-hitting anti-tobacco campaigns. We also contend that health care professionals have an ethical responsibility to try to mitigate stigmatizing messages of public health campaigns with empathic patient-clinician communication during clinical encounters.

Introduction

Tobacco use remains the leading cause of preventable death in the United States, with cigarette smoking killing more than 480,000 Americans every year [1]. An estimated 41,000 of these deaths among adults are attributable to secondhand smoke exposure [1]. Every day in the US more than 3,800 youths under the age of 18 smoke their first cigarette; an estimated 26 percent of these will become adult smokers [2].

Given the well-established health [consequences of smoking](#), the public health community has established and maintained a comprehensive tobacco control effort, including restrictions on smoking in worksites and other public places, increased tobacco taxation, increased access to evidence-based tobacco treatment, and public health national media campaigns [3]. Collectively, this comprehensive tobacco control effort represents one of the leading public health success stories. In the 50 years since the 1964 Surgeon General's report, *Smoking and Health*, US adult smoking rates have fallen from 43 percent to 18 percent [4].

Although what we'll call "hard-hitting" anti-tobacco public health campaigns—those with fear-arousing messages—have been shown to be the most effective type of anti-tobacco mass-reach health communication interventions, they might have the unintended consequence of stigmatizing those with smoking-related illnesses [5, 6]. In this paper, we explore the ethical dilemma whereby these campaigns are seen as helpful for public health in promoting smoking prevention and cessation but also potentially harmful for persons suffering from tobacco-related illnesses, including lung cancer. We discuss types of stigma and ethical implications, drawing upon concepts such as *respect for persons*. We then make recommendations for public health campaigns to incorporate counter-stigmatizing themes and for health care professionals to use empathic communication to mitigate the effects of stigma on patients with tobacco-related diseases. Finally, we provide direction for future research.

Hard-Hitting Anti-tobacco Public Health Campaigns Are Effective in Reducing Smoking Prevalence

Hard-hitting media anti-smoking campaigns often focus on both raising awareness about the health consequences of smoking and denormalizing smoking behavior, thereby motivating prevention among the general public and motivating smokers specifically toward cessation [7-9]. The term "hard-hitting" has been used to describe ad campaigns that are uncompromisingly direct, often with strong fear-arousing messages and personal stories about negative health consequences of smoking. These types of ads are supported by well-established theories of health behavior change (e.g., the Health Belief Model [10], the theory of planned behavior [11, 12]) that focus broadly on cognitive, emotional, and social processes (e.g., perceived susceptibility to disease, health beliefs regarding the consequences of behavior change, self-efficacy, and social norms) that predict behavior change.

Hard-hitting ads have been shown to be more effective than humorous or neutral educational communication messages at reducing smoking [13]. Most recently, the Tips From Former Smokers™ campaign [14], featuring real people suffering from serious medical conditions as a result of smoking and exposure to secondhand smoke, has been credited with an estimated 1.64 million American smokers making a quit attempt; 100,000 of these smokers are expected to maintain smoking abstinence [8]. Public health leaders assert that the hard-hitting ads are justified by the benefits observed in reducing smoking and related health consequences [5, 15-17]. Although some hard-hitting anti-tobacco campaigns (e.g., graphic warnings on cigarette packs) have been challenged by the tobacco industry [18, 19], the Family Smoking Prevention and Tobacco Control Act of 2009 gives the FDA authority to regulate the tobacco industry [20]. Regardless of these legal challenges, hard-hitting anti-tobacco public health campaigns remain best practice for mass-reach public health communications.

Do Hard-Hitting Anti-tobacco Ad Campaigns Contribute to Stigma?

There are several types of stigma that might be experienced by patients diagnosed with lung cancer: (1) anticipated stigma, or the expectation of discrimination, stereotyping, or prejudice; (2) enacted stigma, which involves actually experiencing discrimination, stereotyping, or prejudice; and (3) internalized stigma, which refers to people's self-endorsing negative feelings and beliefs about themselves [21]. While effective in decreasing smoking rates, hard-hitting anti-tobacco public health campaigns might increase the third kind of stigma. That is, internalization of stigma can result in negative self-appraisal and self-devaluation among persons diagnosed with lung cancer and other tobacco-related diseases [5, 6]. The majority of persons diagnosed with lung cancer report experiencing stigma, often related to guilt, regret, perceived blame, and other negative beliefs about smoking history [16, 22-24].

Stigma is associated with a number of deleterious psychosocial and medical outcomes in lung cancer patients, including delayed diagnoses [25-27], poor quality of life [26], and poor patient-clinician communication [28]. Although there has been limited investigation of stigma and long-term outcomes, stigma may have clear downstream effects, such as reduced treatment adherence and heightened psychosocial distress [24, 28]. One survey found that physicians were more likely to refer breast cancer patients than lung cancer patients for further therapy [29], which could be due to lung cancer stigma—the ubiquitous and damaging nature of which is well established [24, 28, 29].

Previous research has additionally pointed to differential rates of stigma experienced by lung cancer patients who used to or who currently smoke and those who have never smoked. Namely, lung cancer patients who have smoked and those who currently smoke report higher levels of stigma than those who have never smoked [26], although lung cancer patients who have never smoked also report experiencing stigma [26]. Given the epidemiology of lung cancer, health care professionals might assume that a patient's lung disease is acquired "firsthand" as opposed to "secondhand" or without smoking exposure at all. As stigma is experienced by patients across this continuum of smoking exposures, the salience of this ethical debate is relevant for current, former, and never smokers—all those suffering from illnesses associated with smoking.

An Ethical Dilemma

While recognizing that the public health goals of tobacco prevention and cessation remain paramount, an ethical question arises as to whether these ads should continue to be hard-hitting or whether public health communication messages should be reframed to try to reduce stigma and blame that could be experienced by the 16 million Americans living with smoking-related diseases [30]. Looking at denormalization of smoking through a purely utilitarian lens renders a favorable assessment, as evidenced by a 12 percent drop in the smoking rate of 18- to 29-year-olds in the US from 2005 to 2015 [31]. However, when viewing hard-hitting anti-tobacco public health campaigns as

sanctioned social stigmatization in the context of people suffering from nicotine addiction and related medical illnesses, the “benefits” of these anti-tobacco ads should be tempered [32]. Internalized stigma (e.g., self-blame, shame, or guilt) could result in low self-esteem as people question their identity and self-worth. In its extreme form, stigma can be thought to “turn the individual into his own jailor, his own chorus of denunciation” [33].

Mental health clinicians caring for the psychosocial needs of cancer patients and health care ethicists have questioned whether the public health benefits are worth the “incidental” costs of stigma for individual patients [16, 34, 35]. Some health scientists have labeled anti-tobacco public health campaigns “demoralizing” [22] and “victim blaming” [6]. Additionally, hard-hitting campaigns could extend lung cancer stigma to any person who suffers from any smoking-related illness, regardless of the patient’s actual smoking history [24]. This “guilt by association” can be especially difficult for those with secondhand or even no prior tobacco exposure who perceive others’ negative attitudes as based on false assumptions about the nature and scope of their disease culpability. Given the current demographics of tobacco use, these campaigns might further stigmatize low-income and other vulnerable populations of smokers, who currently represent the majority of tobacco users [22]. And people who already feel disempowered tend to feel even more resentful, defensive, and demoralized after exposure to anti-tobacco campaigns [17, 36]. As a result, hard-hitting anti-tobacco ads could exacerbate health disparities and discourage access to high-quality health care.

An important ethical question is how much iatrogenic stigma should matter if hard-hitting campaigns are successful in preventing tobacco use and motivating smoking cessation as public health goals. Stigma and associated distress certainly matter at a level of clinicians interacting with individual patients diagnosed with lung cancer or other tobacco-related diseases. How much should an individual’s experience of stigma matter at a macro- and public health level of disease prevention? If the overarching goal is to reduce the negative health effects of tobacco use and smoking, whether the result of firsthand or secondhand use, the potential stigmatizing impact of anti-tobacco ads on those who are already suffering from tobacco-related illnesses such as lung cancer cannot be ignored.

Stigma is not benign and has been shown to be associated with lung cancer patients’ avoidance or delay of seeking medical care [25], resulting in downstream risk of worsening lung cancer morbidity and mortality. While public health principles often emphasize prevention, stigma does not exclude those populations that prevention efforts have failed to reach. Meanwhile, the ethical principle of respect for persons and appreciating the intrinsic value of each individual requires that those who are suffering from tobacco-related illnesses, such as lung cancer, be treated with equity and justice. Health care professionals taking their ethical obligation of nonmaleficence seriously

should certainly be concerned about their roles in whether and how their individual patients experience stigma as a result of their specific actions or communications.

What Should Be Done?

Because anti-tobacco public health campaigns have been effective in reducing population smoking rates, banning hard-hitting ads completely would be shortsighted. Our attempt to raise awareness about the impact of lung cancer stigma is not to suggest that public health campaigns refrain from educating the public about the unquestionable, far-reaching health hazards of smoking. Rather, we offer several recommendations for addressing the iatrogenic consequences of hard-hitting anti-tobacco campaigns.

First, public health campaigns could highlight counter-stigma themes. One such theme is the unscrupulous, predatory nature of big tobacco as an industry. Emphasizing how much money is spent annually by the tobacco industry on tobacco advertising and social marketing has been a compelling theme for prior anti-tobacco campaigns, particularly those targeting prevention of youth smoking [37-39]. The Lung Cancer Alliance's campaign, "No One Deserves to Die of Lung Cancer," serves as an excellent example of an effective public health campaign that acknowledges the dangerous nature of cigarette smoking while also emphasizing compassion and a nonjudgmental stance by using the ironic message that certain segments of the population (e.g., cat ladies, hipsters) deserve to die [40]. Ads that provide self-affirming messages (e.g., the value of raising a family or maintaining health) might buffer against defensive processing—dismissal of a health message perceived as personally threatening—because it has been shown that self-affirmation prior to exposure to graphic images on cigarette pack warnings reduces such defensive processing [41]. Recent research shows that gain-framed messages—those that highlight benefits of quitting rather than costs of smoking—might be more effective for smokers who feel helpless and demoralized in their quitting efforts [42]. We also recommend ads that encourage the use of evidence-based smoking behavior change strategies and promote self-efficacy in quitting. Finally, given that lung cancer stigma can intersect with social and structural hierarchies such as power, culture, and privilege [43], it would seem important for public health campaigns to target all tobacco users, not just ethnic minorities and tobacco users of low socioeconomic status [32].

Second, health care professionals treating patients with lung cancer can communicate empathically to build patients' resilience and try to help inoculate them to the stigmatizing effects of anti-tobacco health campaigns [6, 24, 26, 28]. One study found that physicians miss 90 percent of opportunities for demonstrating empathy in lung cancer care [44]. Physicians have noted the challenge of advising their patients to quit smoking while concurrently managing patients' emotional distress following cancer diagnosis and treatment [6]. Good patient-clinician communication has been associated with lower levels of stigma in the health care setting [28]. Building resilience in lung cancer patients and those with tobacco-related illnesses through empathic responses

and problem-focused strategies may mitigate the negative consequences of stigma resulting from hard-hitting anti-tobacco campaigns [45]. We currently are working to develop and evaluate an empathic, nonjudgmental communication skills training module for health care professionals treating patients with lung cancer that focuses on taking a detailed tobacco history, advising current smokers to quit, and making a reliable referral for tobacco treatment services.

Additional research is needed to determine how anti-tobacco campaigns can minimize the internalized stigma of patients living with tobacco-related diseases without compromising the campaigns' strong public health effectiveness. For example, public health campaigns are often pretested using focus groups; new candidate ads could be assessed for whether and to what extent they generate stigma and unintended consequences such as shame and guilt. To our knowledge, the Tips campaign has not examined whether patients with lung and other tobacco-related conditions experience heightened stigma and regret. We recommend eliciting patient perspectives early in the development of anti-tobacco campaigns. There is much to be learned from other public health campaigns grappling with similar concerns (e.g., risky sexual and drug use behaviors and HIV/AIDS, alcohol and driving, obesity, and sun exposure). The Joint United Nations Programme on HIV/AIDS (UNAIDS) has suggested that negative views of [people living with HIV](#) can be attributed largely to stigma and ignorance about the harm of stigma and moral judgment, which is likely germane to those suffering from tobacco-related diseases [46]. Accordingly, the HIV/AIDS public health community has made a concerted effort to examine the impact of stigma and embark on multipronged efforts to counter stigma with educational programs targeting specific vulnerable populations, in addition to addressing the role of health care professionals in exacerbating the effects of stigma [47].

Conclusion

Overall, hard-hitting anti-tobacco public health campaigns work, although they might also inadvertently increase stigma among lung cancer patients, leading to deleterious downstream psychosocial and medical outcomes for this vulnerable population. Specific recommendations include shifting the focus of public health campaigns away from patient blaming and emphasizing clinician-level empathic communication interventions. Further research and attention are needed to ensure that hard-hitting anti-tobacco campaigns find the "sweet spot" for maximizing tobacco control while minimizing stigma experienced by lung cancer patients and those suffering from tobacco-related illnesses. Researchers, leaders of nonprofit organizations, government, hospital systems, health care professionals, and patient advocates can all be involved and accountable for decreasing stigma directed towards lung cancer patients.

References

1. Centers for Disease Control and Prevention. Tobacco-related mortality. https://www.cdc.gov/tobacco/data_statistics/fact_sheets/health_effects/tobacco_related_mortality/. Updated December 1, 2016. Accessed March 10, 2017.
2. US Department of Health and Human Services. *Preventing Tobacco Use Among Youth and Young Adults: A Report of the Surgeon General*. Rockville, MD: US Department of Health and Human Services; 2012. <https://www.surgeongeneral.gov/library/reports/preventing-youth-tobacco-use/full-report.pdf>. Accessed March 31, 2017.
3. Centers for Disease Control and Prevention. *Best Practices for Comprehensive Tobacco Control Programs—2014*. Atlanta, GA: Centers for Disease Control and Prevention; 2014. https://www.cdc.gov/tobacco/stateandcommunity/best_practices/pdfs/2014/comprehensive.pdf. Accessed March 10, 2017.
4. US Department of Health and Human Services. *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*. Atlanta, GA: Centers for Disease Control and Prevention; 2014. <http://www.surgeongeneral.gov/library/reports/50-years-of-progress/full-report.pdf>. Accessed September 15, 2016.
5. Bayer R. Stigma and the ethics of public health: not can we but should we. *Soc Sci Med*. 2008;67(3):463-472.
6. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *BMJ*. 2004;328(7454):1470. <http://www.bmj.com/content/328/7454/1470>. Accessed March 30, 2017.
7. Duke JC, Hansen H, Kim AE, Curry L, Allen J. The use of social media by state tobacco control programs to promote smoking cessation: a cross-sectional study. *J Med Internet Res*. 2014;16(7):e169.
8. McAfee T, Babb S, McNabb S, Fiore MC. Helping smokers quit—opportunities created by the Affordable Care Act. *N Engl J Med*. 2015;372(1):5-7.
9. Johnson KA, Stewart S, Rosenfield D, Steeves D, Zvolensky MJ. Prospective evaluation of the effects of anxiety sensitivity and state anxiety in predicting acute nicotine withdrawal symptoms during smoking cessation. *Psychol Addict Behav*. 2012;26(2):289-297.
10. Rosenstock IM. The health belief model and preventive health behavior. *Health Educ Behav*. 1974;2(4):354-386.
11. Ajzen I. From intentions to actions: a theory of planned behavior. In: Kuhl J, Beckmann J. *Action Control: From Cognition to Behavior*. Berlin, Germany: Springer Berlin-Heidelberg; 1985:11-39.
12. Fishbein M, Ajzen I. *Belief, Attitude, Intention, and Behavior: An Introduction to Theory and Research*. Reading, MA: Addison-Wesley; 1975:6.

13. Durkin SJ, Biener L, Wakefield MA. Effects of different types of antismoking ads on reducing disparities in smoking cessation among socioeconomic subgroups. *Am J Public Health*. 2009;99(12):2217-2223.
14. Centers for Disease Control and Prevention. TIPS From Former Smokers™. <https://www.cdc.gov/tobacco/campaign/tips/>. Updated January 19, 2017. Accessed March 13, 2017.
15. Alderman J, Dollar KM, Kozlowski LT. Commentary: understanding the origins of anger, contempt, and disgust in public health policy disputes: applying moral psychology to harm reduction debates. *J Public Health Policy*. 2010;31(1):1-16.
16. Bayer R, Stuber J. Tobacco control, stigma, and public health: rethinking the relations. *Am J Public Health*. 2006;96(1):47-50.
17. Lupton D. The pedagogy of disgust: the ethical, moral and political implications of using disgust in public health campaigns. *Crit Public Health*. 2015;25(1):4-14.
18. Bayer R, Johns D, Colgrove J. The FDA and graphic cigarette-pack warnings—thwarted by the courts. *New Engl J Med*. 2013;369(3):206-208.
19. Mickle T. Antitobacco groups sue FDA to require graphic warning labels on cigarette packs. *Wall Street Journal*. October 4, 2016. <https://www.wsj.com/articles/antitobacco-groups-sue-fda-to-require-graphic-warning-labels-on-cigarette-packs-1475599261>. Accessed March 30, 2017.
20. Family Smoking Prevention and Tobacco Control Act of 2009, Pub L No. 111-31, 123 Stat 1776. <https://www.gpo.gov/fdsys/pkg/PLAW-111publ31/html/PLAW-111publ31.htm>. Accessed March 30, 2017.
21. Sweeney SM, Venable PA. The association of HIV-related stigma to HIV medication adherence: a systematic review and synthesis of the literature. *AIDS Behav*. 2016;20(1):29-50.
22. Bell K, Salmon A, Bowers M, Bell J, McCullough L. Smoking, stigma and tobacco “denormalization”: further reflections on the use of stigma as a public health tool. A commentary on *Social Science & Medicine's* stigma, prejudice, discrimination and health special issue (67:3). *Soc Sci Med*. 2010;70(6):795-799.
23. Gritz ER, Vidrine DJ, Fingeret MC. Smoking cessation: a critical component of medical management in chronic disease populations. *Am J Prev Med*. 2007;33(suppl 6):S414-S422.
24. Hamann HA, Ostroff JS, Marks EG, Gerber DE, Schiller JH, Lee SJ. Stigma among patients with lung cancer: a patient reported measurement model. *Psychooncology*. 2014;23(1):81-92.
25. Carter-Harris L, Hermann CP, Schreiber J, Weaver MT, Rawl SM. Lung cancer stigma predicts timing of medical help-seeking behavior. *Oncol Nurs Forum*. 2014;41(3):e203-e210.
26. Cataldo JK, Jahan TM, Pongquan VL. Lung cancer stigma, depression, and quality of life among ever and never smokers. *Eur J Oncol Nurs*. 2012;16(3):264-269.
27. Chambers SK, Dunn J, Occhipinti S, et al. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer*. 2012;12:184.

<https://bmccancer.biomedcentral.com/articles/10.1186/1471-2407-12-184>. Accessed March 30, 2017.

28. Shen MJ, Hamann HA, Thomas AJ, Ostroff JS. Association between patient-provider communication and lung cancer stigma. *Support Care Cancer*. 2016;24(5):2093-2099.
29. Wassenaar TR, Eickhoff JC, Jarzemsky DR, Smith SS, Larson ML, Schiller JH. Differences in primary care clinicians' approach to non-small cell lung cancer patients compared with breast cancer. *J Thorac Oncol*. 2007;2(8):722-728.
30. Centers for Disease Control and Prevention. Fast facts: diseases and death. https://www.cdc.gov/tobacco/data_statistics/fact_sheets/fast_facts/. Updated December 20, 2016. Accessed March 12, 2017.
31. Nader N, Liu D. In US, young adults' cigarette use is down sharply. *Gallup*. December 10, 2015. <http://www.gallup.com/poll/187592/young-adults-cigarette-down-sharply.aspx>. Accessed March 12, 2017.
32. Burris S. Disease stigma in public health law. *J Law Med Ethics*. 2002;30(2):179-190.
33. Burris S. Stigma, ethics and policy: a commentary on Bayer's "Stigma and the ethics of public health: not can we but should we." *Soc Sci Med*. 2008;67(3):476.
34. Guttman N, Salmon CT. Guilt, fear, stigma and knowledge gaps: ethical issues in public health communication interventions. *Bioethics*. 2004;18(6):531-552.
35. Fairchild AL, Bayer R, Colgrove J. The renormalization of smoking? E-cigarettes and the tobacco "endgame." *N Engl J Med*. 2014;370(4):293-295.
36. Hastings G, Stead M, Webb J. Fear appeals in social marketing: strategic and ethical reasons for concern. *Psychol Mark*. 2004;21(11):961-986.
37. Farrelly MC, Davis KC, Duke J, Messeri P. Sustaining "truth": changes in youth tobacco attitudes and smoking intentions after 3 years of a national antismoking campaign. *Health Educ Res*. 2009;24(1):42-48.
38. Farrelly MC, Davis KC, Haviland ML, Messeri P, Healton CG. Evidence of a dose-response relationship between "truth" antismoking ads and youth smoking prevalence. *Am J Public Health*. 2005;95(3):425-431.
39. Malone RE, Grundy Q, Bero LA. Tobacco industry denormalisation as a tobacco control intervention: a review. *Tob Control*. 2012;21(2):162-170.
40. Lung Cancer Alliance. No one deserves to die of lung cancer. <http://www.noonedeservestodie.org/>. Accessed March 12, 2017.
41. Harris PR, Mayle K, Mabbott L, Napper L. Self-affirmation reduces smokers' defensiveness to graphic on-pack cigarette warning labels. *Health Psychol*. 2007;26(4):437-446.
42. Mead EL. *Moving Beyond Fear: Exploring Perceptions of Theory-Based Graphic Warning Labels Among Low-Income, Urban Smokers* [dissertation]. Baltimore, MD: Johns Hopkins University; 2014. <https://jscholarship.library.jhu.edu/bitstream/handle/1774.2/39316/MEAD-DISSERTATION-2014.pdf?sequence=1&isAllowed=y>. Accessed March 31, 2017.

43. Knight J. Updated definition of internationalization. *Int High Educ.* 2015;(33):2-3.
44. Morse DS, Edwardsen EA, Gordon HS. Missed opportunities for interval empathy in lung cancer communication. *Arch Intern Med.* 2008;168(17):1853-1858.
45. Thompson L, Barnett JR, Pearce JR. Scared straight? Fear-appeal anti-smoking campaigns, risk, self-efficacy and addiction. *Health Risk Soc.* 2009;11(2):181-196.
46. Brent RJ. The value of reducing HIV stigma. *Soc Sci Med.* 2016;151:233-240.
47. Pellowski JA, Kalichman SC, Matthews KA, Adler N. A pandemic of the poor: social disadvantage and the US HIV epidemic. *Am Psychol.* 2013;68(4):197-209.

Kristen E. Riley, PhD, is a postdoctoral research fellow at Memorial Sloan Kettering Cancer Center in New York City, where she studies health behavior decision making and tobacco cessation for cancer prevention.

Michael R. Ulrich, JD, MPH, is an assistant professor in the Center for Health Law, Ethics & Human Rights and the Department of Health, Law, and Policy Management at Boston University School of Public Health. He studies public health, ethics, and law.

Heidi A. Hamann, PhD, is an associate professor in the Departments of Psychology and Family and Community Medicine at the University of Arizona in Tucson. Her primary research focuses on psychosocial and behavioral concerns, including stigma of lung cancer patients and survivors.

Jamie S. Ostroff, PhD, is the chief of the behavioral sciences service in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center and a professor of psychology in the Department of Healthcare Policy and Research at Weill Cornell Medical College, both in New York City. Her cancer prevention and control research focuses on tobacco cessation and stigma experienced by patients with lung cancer.

Acknowledgements

This work was supported in part through a cancer center support grant (P30CA0087748) from the National Cancer Institute to the Memorial Sloan Kettering Cancer Center, a training grant from the National Cancer Institute (T32CA009461) (KER), the National Cancer Institute (R03CA154016) and the National Lung Cancer Partnership and its North Carolina Chapter (Young Investigator Award, HAH), and the Lung Cancer Research Foundation (JSO). We would like to thank Jack Burkhalter, PhD, Lisa Carter-Harris, PhD, Maureen Rigney, LCSW, and Christine Sheffer, PhD, for their constructive feedback on an earlier version of this paper.

Related in the *AMA Journal of Ethics*

[The Ethics of Requiring Employees To Quit Smoking](#), January 2007

[Health Effects of Smoking and the Benefits of Quitting](#), January 2011

[HIV Stigma and Discrimination Persist, Even in Health Care](#), December 2009
[Teaching Smoking Cessation in U.S. Medical Schools: A Long Way to Go](#), January 2007
[Use of Images in Public Health Campaigns](#), August 2007

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

MEDICINE AND SOCIETY

Prioritizing Mental Health Research in Cancer Patients and Survivors

Monica R. Martinez and Amirala Pasha, DO, MS

Abstract

The United States spends billions of dollars annually on cancer research. Historically, compared to other areas of cancer research, very little funding has been dedicated to mental health research in cancer patients and survivors. Previous studies have indicated that psychological disorders are common in patients with cancer and might have significant influence on overall morbidity and mortality. However, adequate data are lacking to better assess this influence and the potential benefits of interventions. As the number of cancer survivors is projected to grow dramatically in the coming years, we review the importance of dedicating additional funding to mental health research in cancer patients and survivors.

Introduction

In recent years, there has been a shift from viewing cancer as an acute medical problem to viewing it as a chronic condition that starts with a diagnosis and ends with a patient's death, commonly many years after initial diagnosis [1]. The National Cancer Institute spent over \$3.5 billion on cancer research in 2015 [2]. Yet, if history is any indication, very little of that funding will be spent on assessing potential psychological disorders—from initial diagnosis through treatment and post-treatment surveillance—in cancer patients and survivors [3]. In an era of improved mortality rates—by 2026 it is estimated that more than 20 million people in the US will be considered cancer survivors [4, 5]—[research priorities](#) will likely need to be realigned to include more funding to assess and treat potential short-term and long-term mental health disorders in cancer patients and survivors. In order to better understand the need for additional funding and research in this field, we review the prevalence and clinical effects of psychological disorders in cancer patients, some goals for future studies, potential benefits of such studies, and potential funding sources.

Prevalence and Clinical Effects of Psychological Disorders in Cancer Patients

The following review of pertinent statistics provides support for developing a body of research that would serve to inform the understanding and treatment of mental health issues specific to cancer patients and long-term survivors. To begin, for adults diagnosed with cancer and other chronic illnesses, the “risk of psychological disability” is nearly six

times higher than for adults not living with cancer [6]. Moreover, population-based data indicate that adult cancer survivors are more than twice as likely to have “disabling psychological problems” as adults without cancer [6]. Among long-term cancer survivors, depression and anxiety are the most commonly diagnosed psychological disorders [7]. However, mental health care [disparities](#) exist between rural and urban cancer survivors with respect to transportation, practitioner availability, and insurance access [8].

In addition to being more prevalent in cancer patients, mental health disorders, if untreated, have been shown to negatively influence the underlying cellular and molecular processes that facilitate the progression of cancer [9]. Moreover, there is clear evidence that depression, which might be undiagnosed, is associated with poor adherence to medical therapies [10]. These statistics only begin to demonstrate the heightened risk of overall health deterioration for cancer patients who simultaneously suffer from common psychological disorders [10].

Why Addressing Mental Health in Cancer Patients Is Important

Given the prevalence of psychological disorders in cancer patients and their potential negative effects on outcomes, in the absence of adequate data, neither physicians nor patients can accurately predict the mental health impact of cancer diagnosis and treatment, thereby potentially limiting a patient’s autonomy. Particularly when alternative therapies exist or in cases in which aggressive treatment has not been definitively shown to improve outcomes, such as in cases of early stage ductal carcinoma in situ [11], patients should be informed, to the extent possible, of potential mental health side effects of available options. This would allow the physician and patient to make informed decisions regarding treatment by encouraging the patient to be vigilant about any mental health issues that develop and increasing the physician’s and patient’s ability to assess overall costs and benefits of all available options. Thus, mental health effects should be evaluated at diagnosis, throughout treatment and the post-treatment phase, and in [survivorship](#) [12]. Given that untreated mental health disorders negatively affect treatment and cancer progression [10], the question naturally arises as to whether treatment of such disorders has any positive effect on overall morbidity and mortality. This relation is yet to be conclusively established.

In our opinion, some important questions that remain unanswered and that should be addressed include: (1) whether certain cancer types place patients at more risk of developing psychological disorders, (2) the extent to which cancer diagnosis causes psychological disorders, (3) whether iatrogenesis contributes to psychological disorders, (4) whether treatment of psychological disorders has any effect on overall morbidity and mortality, and (5) whether psychological sequelae are experienced by cancer survivors. In order for these questions to be answered, prevention, detection, and treatment of psychological disorders must be prioritized within the cancer research funding agenda.

Potential Funding Sources for Mental Health Research

Although many funding venues might be available, in this section we explore three potential sources, including federal grants, public-private partnerships (PPPs), and private funding from the pharmaceutical industry. These venues were chosen based on their past successes in supporting oncological research.

Federal grants. Allocating federal funding for assessment, prevention, and treatment of potential side effects of cancer therapy is not unprecedented. For instance, in the late 1990s, the National Institutes of Health (NIH) made grants available specifically to address “uncomfortable, disabling, or even life-threatening secondary clinical problems” caused by oncological treatment modalities [13]. Other examples include the National Institute of Mental Health’s (NIMH) support for research on mental disorders in “people with other physical disorders,” such as cancer, in 2010 [14]. That year, the NIMH solicited studies on preventing depression in patients undergoing cancer treatment and on promoting behavioral changes in people with underlying mental disorders and with high-risk behaviors such as smoking, poor nutrition, and sedentary lifestyles to reduce their risk factors for developing cancer [14]. Therefore, if there is sufficient political will, similar federal grants can be developed to more broadly assess mental health care in cancer patients and survivors.

Strategic partnerships. Alternatively, strategic partnerships have the potential to help researchers achieve necessary funding levels. For example, PPPs hold enormous potential for increasing translational—from bench to clinic—research investments [15]. These partnerships are already found in other areas of oncological research and can therefore be developed to enhance mental health research [15]. Such partnerships can be developed through existing frameworks if priorities are aligned. The Foundation for the National Institutes of Health (FNIH), which was established by Congress in 1990, operates as an independent organization that in part facilitates PPPs [16]. In this capacity, it procures funding for, and supports alliances between, programs and institutions that work to advance the mission of the NIH [16]. The FNIH could implement mental health research within oncology research by helping to form new PPPs targeting this specific aspect of cancer research. Various other partnerships could help researchers to overcome resource limitations, including those incorporating nontraditional disciplines such as engineering, behavioral sciences, and social sciences, which could be tied into mental health.

Private funding. It is worth examining previous efforts to treat cancer therapy side effects as a model for how private funding might flow to mental health research. Consider the pharmaceutical industry’s response to the side effects associated with administration of chemotherapy and radiation. Chemotherapy-induced nausea and vomiting (CINV) was once reported as a top concern of patients undergoing cancer treatment. In fact, this particular side effect of chemotherapy in the not-too-distant past led to prolonged

hospitalizations that could result in premature termination of chemotherapy [17]. CINV became a major barrier to care especially after the development of highly emetogenic platinum-based therapies in the 1970s [17]. Once studies established that available antiemetic agents were insufficient to address this problem, CINV became a major area of pharmaceutical research with dedicated funding and studies [17]. Consequently, a number of new antiemetic agents were developed in the 1980s and 1990s [17]. With the development of national and international guidelines, the focus shifted from treatment to prevention through antiemetic prophylaxis [18]. Although CINV remains a concern, studies have shown that whereas the overall incidence of CINV was 83 percent in 1979 [19], the incidence of acute nausea was 35 percent just 25 years later [20]. The pharmaceutical industry's successful efforts had a profound impact on patients' quality of life and allowed many patients to complete chemotherapy regimens who previously would not have been able to do so [17]. In fact, the progress in prevention and treatment of CINV was voted as one of the "Top 5 Advances in 50 Years of Modern Oncology" [21]. This achievement was a result of the pharmaceutical industry's response to studies demonstrating the debilitating effects of CINV [17]. Sufficient preliminary research demonstrating short-term and long-term psychological side effects of cancer diagnosis, care, and survivorship may lead to a similar response from the pharmaceutical industry in terms of funding and dedicating resources to treatment of psychological harms associated with cancer.

Conclusion

As the foregoing makes clear, psychological disorders are a commonly found comorbidity in cancer patients and survivors, and, if untreated, they potentially can have a negative impact on their care. Correcting for the lack of research at the intersection of cancer and mental health requires a fundamental shift in research interests and reprioritization of resources. We believe that advancing the cancer research agenda to adequately address mental health outcomes requires the successful interplay of several factors. First, it requires attention from medical researchers and cancer patients, policymakers, the pharmaceutical industry, and funders alike. Second, it requires the reframing of cancer research to encompass both short-term and long-term cancer patient and survivor mental health. Third, it requires cancer patients to take an active role in monitoring and reporting perceived mental health reactions to cancer therapy and to make informed decisions with regard to the costs and benefits of that therapy. Fourth, it requires strategic partnerships and creative collaborations across multiple fields of study. Finally, it would benefit from the review of previously employed models that proved successful—such as those pertaining to CINV. With oncology-related medical visits expected to increase from 38 million in 2005 to 57 million in 2020 [22], continuing to overlook the mental health of cancer patients will render incomplete any emerging and imperative cancer research.

References

1. Markman M. Commentary: implications of cancer managed as a "chronic illness." *Curr Oncol Rep.* 2011;13(2):90-91.
2. National Cancer Institute. Funding allocated to major NCI program areas: program structure: fiscal year 2015. <https://www.cancer.gov/about-nci/budget/fact-book/data/program-structure>. Published December 16, 2016. Accessed April 3, 2017.
3. National Institutes of Health. Estimates of funding for various research, condition, and disease categories (RCDC). https://report.nih.gov/categorical_spending.aspx. Updated July 22, 2016. Accessed April 3, 2017.
4. American Cancer Society. Survivorship and quality of life research. <http://www.cancer.org/research/survivaltreatmentresearch/cancer-survivorship-grants>. Accessed December 4, 2016.
5. National Cancer Institute. Building on opportunities in cancer research: an annual plan and budget proposal for fiscal year 2016. <https://www.cancer.gov/about-nci/budget/annual-plan/nci-plan-2016.pdf>. NIH publication 15-7957. Published December 2014. Accessed December 4, 2016.
6. Hewitt M, Rowland JH, Yancik R. Cancer survivors in the United States: age, health, and disability. *J Gerontol A Biol Sci Med Sci.* 2003;58(1):82-91. Cited by: Naughton MJ, Weaver KE. Physical and mental health among cancer survivors: considerations for long-term care and quality of life. *N C Med J.* 2014;75(4):283.
7. Mitchell AJ, Ferguson DW, Gill J, Paul J, Symonds P. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol.* 2013;14(8):721-732.
8. Burris JL, Andrykowski M. Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psychooncology.* 2010;19(6):637-645.
9. Adler NE, Page AEK, eds; Institute of Medicine. Consequences of unmet psychosocial needs. In: *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press; 2008:51-80.
10. Grenard JL, Munjas BA, Adams JL, et al. Depression and medication adherence in the treatment of chronic diseases in the United States: a meta-analysis. *J Gen Intern Med.* 2011;26(10):1175-1182.
11. Merrill A. Ductal carcinoma in situ. *N Engl J Med.* 2016;374(4):390-392.
12. Stanton AL, Rowland JH, Ganz PA. Life after diagnosis and treatment of cancer in adulthood: contributions from psychosocial oncology research. *Am Psychol.* 2015;70(2):159-74.
13. National Institutes of Health. Management of symptoms secondary to treatment. *NIH Guide.* 1997;26(24). <https://grants.nih.gov/grants/guide/pa-files/PA-97-082.html>. Accessed December 4, 2016.

14. US Department of Health and Human Services. National Institute of Mental Health FY 2010 Budget.
15. President's Cancer Panel. *The Future of Cancer Research: Accelerating Scientific Innovation*. Washington, DC: US Department of Health and Human Services; November 2012.
<http://deainfo.nci.nih.gov/advisory/pcp/annualReports/pcp10-11rpt/FullReport.pdf>. Accessed December 4, 2016.
16. Foundation for the National Institutes of Health. About us.
<http://fnih.org/about>. Accessed December 4, 2016.
17. Navari RM, Aapro M. Antiemetic prophylaxis for chemotherapy-induced nausea and vomiting. *N Engl J Med*. 2016;374(14):1356-1367.
18. Vidall C, Dielenseger P, Farrell C, et al. Evidence-based management of chemotherapy-induced nausea and vomiting: a position statement from a European cancer nursing forum. *Ecancermedicalscience*. 2011;5:211.
<http://ecancer.org/journal/5/211-evidence-based-management-of-chemotherapy-induced-nausea-and-vomiting-a-position-statement-from-a-european-cancer-nursing-forum.php>. Accessed April 3, 2017.
19. Morran C, Smith DC, Anderson DA, McArdle CS. Incidence of nausea and vomiting with cytotoxic chemotherapy: a prospective randomised trial of antiemetics. *Br Med J*. 1979;1(6174):1323-1324.
20. Grunberg SM, Deuson RR, Mavros P, et al. Incidence of chemotherapy-induced nausea and emesis after modern antiemetics. *Cancer*. 2004;100(10):2261-2268.
21. ASCO 50th anniversary poll names the top 5 advances from the past 50 years [news release]. Alexandria, VA: American Society of Clinical Oncology; September 17, 2014. <http://www.asco.org/about-asco/press-center/news-releases/asco-50th-anniversary-poll-names-top-5-advances-past-50-years>. Accessed April 3, 2017.
22. Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists: challenges to assuring access to oncology services. *J Oncol Pract*. 2007;3(2):79-86. Cited by: Dulko D, Pace CM, Dittus KL, et al. Barriers and facilitators to implementing cancer survivorship care plans. *Oncol Nurs Forum*. 2013;40(6):575-580.

Monica R. Martinez will complete her JD at the George Mason University School of Law in Arlington, Virginia, in 2017. Her research interests include administrative law, disability law, and food and drug law.

Amirala Pasha, DO, MS, is an assistant professor of medicine at the George Washington University School of Medicine and Health Sciences in Washington, DC. He is also completing his JD at the George Washington University Law School. He has a strong interest in health law and policy as well as bioethics.

Related in the *AMA Journal of Ethics*

[Assessing Psychological Toxicity and Patient-Reported Distress as the Sixth Vital Sign in Cancer Care and Clinical Trials](#), May 2017

[Defining Quality, Disseminating Evidence, and Enforcing Guidelines for Cancer Treatment](#), August 2013

[Ethical Management of Patients with Cancer and Mental Illness](#), May 2017

[Inequality of Care and Cancer Survival](#), January 2007

[Overcoming Inequalities: The Affordable Care Act and Cancer Treatment](#), August 2013

[What Cancer Survivorship Means](#), August 2013

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

MEDICINE AND SOCIETY

Should Clinicians Intervene If They Suspect That a Caregiver Whose Child Has Cancer Is at Risk of Psychological Harm?

Amy E. Caruso Brown, MD, MSc, MSCS

Abstract

Compelling arguments suggest that pediatric oncologists who have concerns about the mental health and well-being of a child's caregiver have a duty to intervene. These arguments are rooted in fundamental principles of beneficence, nonmaleficence, and justice. Not only do patients benefit when their parents and others caregivers are happy and healthy, but when the psychological distress of a caregiver is a consequence of the experience of illness and treatment, some of the responsibility for mitigating the harm falls to those who have an active role in directing treatment—the clinicians. However, systems to support clinicians in meeting this obligation are inadequate.

Introduction

Every year, some 300,000 children and adolescents are diagnosed with cancer globally [1], with over 15,000 cases occurring in the US [2]. Despite excellent outcomes in high-income countries, with more than 80 percent of children and adolescents diagnosed with cancer in the US surviving at least five years [3], the experience of diagnosis, treatment, and recovery is still physically, psychologically, spiritually, and financially challenging [4, 5].

Nearly all of these children will share their cancer journey with a parent, grandparent, or other caregiver. Studies have shown that while many caregivers demonstrate impressive resilience in the face of a cancer diagnosis, some are at increased risk for post-traumatic stress, depression, anxiety, and somatic illness [6-8]. The additional financial burden of treatment may contribute significantly to caregivers' psychological distress [8].

Every pediatric encounter involves, minimally, a triad: the young patient, the physician or other health care professionals, and the patient's parent or guardian. Children are, by definition, not fully autonomous beings and require a parent or legal guardian to make decisions on their behalf. Although the historical standard in pediatric ethics has been for parents and other surrogate decision makers to act in children's "best interests" [9], in practice, these decision makers are often weighing competing demands and struggling

to do what is best for the entire family, and recent discussions of pediatric decision making take this into account [10, 11].

The provision of ethically optimal care to children, therefore, requires considering such care in the context of the family [11]. For many children, the family environment is the most important single influence on their emotional and psychological well-being [12]. I argue that clinicians who have concerns about the mental health and well-being of a child's caregiver have a duty to intervene in order to promote the patient's welfare and to prevent harm—the classical ethical principles of beneficence and nonmaleficence. This duty will be further explored through two clinical case studies.

Case Studies

Case 1. A two-year-old girl is diagnosed with acute lymphoblastic leukemia. She experiences several complications during induction chemotherapy and requires a prolonged hospitalization. During this time, her 23-year-old mother drops out of college, citing the stress of caring for her daughter while working two part-time jobs to support the family, which includes the patient's three-year-old brother. The mother's outburst directed at her manager results in the loss of one of her two jobs. Violent altercations with other family members have resulted in hospital security being called, and the family has been referred by hospital staff to Child Protective Services (CPS) for investigation.

Commentary. While the mother does not have an obvious or known psychiatric diagnosis, she appears to be suffering considerable stress related to her daughter's illness—expected for parents of children with cancer [13, 14]—possibly exacerbated by previous life stressors, such as financial instability, young motherhood, and a lack of support from her children's father or other family members. Her distress has already resulted in the loss of income to the family, and it may have a more direct negative impact on her daughter's physical and mental well-being in a variety of ways. She may be more likely to administer medications incorrectly at home, or she may be distracted, less attentive, and less responsive to her daughter's needs.

In this context, it is easy to appreciate the rationale for immediately addressing this mother's psychological needs: without intervention, her daughter is potentially at imminent risk of physical harm if she fails to provide necessary care. It is also important, however, to consider the potential long-term sequelae. This mother might in fact be capable of meeting her daughter's needs during the acute period of illness, but both of her children are at greater risk for poorer health in adult life. Studies have identified associations between adverse childhood experiences and poor health outcomes in adult life. Such adverse experiences include not only serious illnesses, such as cancer in childhood, but also growing up with a parent with a mental illness or substance use

disorder [15, 16]. Other studies have shown a relationship between parental stress and the likelihood of both post-traumatic stress and long-term functional impairment after childhood cancer [17, 18]. Thus the potential risks to a child with cancer, especially one whose parent is suffering psychological distress, are both immediate and lifelong.

Case 2. A 13-year-old boy with metastatic osteosarcoma responds poorly to chemotherapy. His disease progresses despite his trying second- and third-line options, including experimental therapies, and his divorced parents frequently argue about treatment options. His father has a prior history of depression and alcohol abuse. He is an only child, and the nurses caring for him have expressed concern that his father may attempt suicide if the patient dies.

Commentary. Because the patient is not expected to survive, his father's psychological distress is not likely to affect his immediate or long-term physical and mental health, although it could impede the achievement of palliative care goals and his overall quality of life. However, it would be incorrect to conclude that health care professionals have fewer obligations to the father of this child than to the mother of the first patient. When the [psychological distress of a caregiver](#) is in part a consequence of the experience of illness and treatment, some of the responsibility for mitigating the harm falls to those who have an active role in directing treatment: the clinicians [19].

What Can Clinicians Do To Help?

Implement and adhere to the psychosocial standards of care for children with cancer. Evidence- and consensus-based guidelines for providing comprehensive psychosocial care to children with cancer and their families were published in 2015 by *Pediatric Blood & Cancer*, the official journal of the American Society of Pediatric Hematology/Oncology and the International Society of Paediatric Oncology [20, 21]. Among the adopted standards included recommendations for routine assessment of psychosocial needs of patients and families and access to psychosocial support and interventions, including psychiatric or other [mental health treatment](#) as appropriate [20]. Notably, the standards specifically reference the need to ensure that parents or other caregivers have access to mental health care [21, 22]. In the above cases, adoption of these standards would mean that both families would be identified as having psychosocial risk factors early, during routine psychosocial assessments, and offered appropriate services and interventions—perhaps preventing deterioration of the first patient's situation to the point at which referral to CPS was legally mandated.

Recognize the financial impact of a childhood cancer diagnosis and help families access resources within the community. As noted previously, families of children

with cancer are at heightened risk for significant financial burden, which may negatively impact parental coping and mental health [4, 20, 22, 23]. Some evidence has even suggested a relationship between financial insecurity and risk of relapse in childhood cancer [24]. Clinicians can work with other members of the health care team, such as social workers, to ensure that all families are assessed for [financial hardship](#) at the time of diagnosis, are reassessed regularly throughout treatment, and are referred appropriately. Referrals might be made to the hospital's financial counseling office, community organizations, and governmental programs [25]. Families may also require assistance navigating state and federal safety-net programs. Regular reassessment is crucial because families who seem financially secure at the time of diagnosis may not be so six months later. For example, in the second scenario, the parents may have expended significant personal resources obtaining second opinions and pursuing clinical trials at other health care institutions, perhaps involving frequent travel and loss of income from missed work.

Explore the use of interventions to promote resilience. Resilience, the capacity to recover from adversity, is difficult to define and measure reliably [26]. It is therefore even more difficult to intentionally promote [26]. However, some pediatric oncology researchers have begun to test interventions to encourage the development of resilience in parents and caregivers (as well as patients) and have suggested a role for health care professionals in promoting resilience by offering psychosocial supportive care and optimizing communication and decision-making support [27, 28]. Resilience is associated with several positive psychosocial outcomes, including post-traumatic growth, benefit-finding, and lack of psychological distress [27]. In the first case study, greater resilience might have helped the mother to cope with her anger more constructively, rather than with an "outburst" that resulted in the loss of one of her jobs. In the second case, resilience might serve to ameliorate the father's risk of suicide after his child's death.

Promoting Systemic Change to Meet Families' Needs

Unfortunately, these obligations to meet families' psychosocial needs intersect with two historic weaknesses of the US health care system: mental health care and preventive care. Health care professionals, however, can [advocate for change](#) on multiple levels.

At the institutional level, practice guidelines and standards of care like those discussed above can be implemented to ensure that all families receive appropriate psychosocial care, rather than relying solely on the accountability of individual clinicians. As there is significant variation in psychosocial resources among institutions, clinicians may also need to advocate for the hiring of qualified individuals—including psychologists, social workers, and child life specialists—and for productive collaboration with psychiatry

departments [20]. Clinician-educators in pediatric oncology—including physician- and nurse-educators—must also support the development and implementation of training standards so that new graduates enter the specialty prepared to integrate psychosocial care into their practice [29].

Finally, the health care profession has a collective responsibility to support and advocate for the financing of research in the area of psychosocial support [30]—which receives substantially fewer federal dollars compared to cure-directed biomedical research [31]—and to support and advocate for the integration of this research into oncology care [32]. In addition, the profession has a collective responsibility to support state and federal legislation that might ameliorate the financial impact of illness and attenuate stress for parents and caregivers. Examples of the latter might include more generous family and medical leave policies and subsidized respite care programs [33].

Conclusion

Compelling arguments suggest that pediatric oncology professionals who have concerns about the mental health and well-being of a child's caregiver have a duty to intervene. These arguments are rooted not only in the basic principles of beneficence and nonmaleficence but also in justice and a broad vision of health and health care. By addressing psychological distress and mental illness affecting caregivers, clinicians can promote positive outcomes and prevent or ameliorate both short- and long-term negative outcomes. As I've argued here, because those who have already experienced other types of adversity—such as single-parent families, families with a history of mental illness or substance abuse, and low-income families—are more likely to be negatively impacted by a diagnosis of cancer, addressing psychological distress is fundamentally an issue of justice. By integrating psychosocial care of the whole family into pediatric oncology practice, pediatric oncologists and other health care professionals can achieve better outcomes for all children—particularly those at greatest risk.

References

1. International Childhood Cancer Day: much remains to be done to fight childhood cancer [news release]. Lyons, France: International Agency for Research on Cancer; February 15, 2016. http://www.acco.org/wp-content/uploads/2016/02/pr241_E.pdf. Accessed March 30, 2017.
2. Ward E, DeSantis C, Robbins A, Kohler B, Jemal A. Childhood and adolescent cancer statistics, 2014. *CA Cancer J Clin*. 2014;64(2):83-103.
3. Howlader N, Noone AM, Krapcho M, et al, eds. SEER Cancer Statistics Review (CSR), 1975-2011: 5-year survival rates. Bethesda, MD: National Cancer Institute; April 2016. https://seer.cancer.gov/csr/1975_2013/sections.html. Accessed September 9, 2016.

4. Bona K, London WB, Guo D, Frank DA, Wolfe J. Trajectory of material hardship and income poverty in families of children undergoing chemotherapy: a prospective cohort study. *Pediatr Blood Cancer*. 2016;63(1):105-111.
5. Askins MA, Moore BD 3rd. Psychosocial support of the pediatric cancer patient: lessons learned over the past 50 years. *Curr Oncol Rep*. 2008;10(6):469-476.
6. Creswell PD, Wisk LE, Litzelman K, Allchin A, Witt WP. Parental depressive symptoms and childhood cancer: the importance of financial difficulties. *Support Care Cancer*. 2014;22(2):503-511.
7. Phipps S, Long A, Willard VW, et al. Parents of children with cancer: at-risk or resilient? *J Pediatr Psychol*. 2015;40(9):914-925.
8. Pollock EA, Litzelman K, Wisk LE, Witt WP. Correlates of physiological and psychological stress among parents of childhood cancer and brain tumor survivors. *Acad Pediatr*. 2013;13(2):105-112.
9. Kopelman LM. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos*. 1997;22(3):271-289.
10. Salter EK. Deciding for a child: a comprehensive analysis of the best interest standard. *Theor Med Bioeth*. 2012;33(3):179-198.
11. Groll D. Four models of family interests. *Pediatrics*. 2014;134(suppl 2):S81-S86.
12. Verkerk MA, Lindemann H, McLaughlin J, et al. Where families and healthcare meet. *J Med Ethics*. 2015;41(2):183-185.
13. Barrera M, D'Agostino NM, Gibson J, Gilbert T, Weksberg R, Malkin D. Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. *Psychooncology*. 2004;13(9):630-641.
14. Pai AL, Greenley RN, Lewandowski A, Drotar D, Youngstrom E, Peterson CC. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *J Fam Psychol*. 2007;21(3):407-415.
15. Edwards VJ, Anda RF, Dube SR, Dong M, Chapman DF, Felitti VJ. The wide-ranging health consequences of adverse childhood experiences. In: Kendall-Tackett KA, Giacomoni SM, eds. *Child Victimization: Maltreatment, Bullying and Dating Violence, Prevention and Intervention*. Kingston, NJ: Civic Research Institute; 2005:chap 8.
16. Felitti VJ. Adverse childhood experiences and adult health. *Acad Pediatr*. 2009;9(3):131-132.
17. Hile S, Erickson SJ, Agee B, Annett RD. Parental stress predicts functional outcome in pediatric cancer survivors. *Psychooncology*. 2014;23(10):1157-1164.
18. Howard Sharp KM, Willard VW, Barnes S, Tillery R, Long A, Phipps S. Emotion socialization in the context of childhood cancer: perceptions of parental support promotes posttraumatic growth *J Pediatr Psychol*. 2017;42(1):95-103.
19. Shapiro J, Perez M, Warden MJ. The importance of family functioning to caregiver adaptation in mothers of child cancer patients: testing a social ecological model. *J Pediatr Oncol Nurs*. 1998;15(1):47-54.

20. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatr Blood Cancer*. 2015;62(suppl 5):S419-S424.
21. Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015;62(suppl 5):S632-S683.
22. Bona K, Dussel V, Orellana L, et al. Economic impact of advanced pediatric cancer on families. *J Pain Symptom Manage*. 2014;47(3):594-603.
23. Dussel V, Bona K, Heath JA, Hilden JM, Weeks JC, Wolfe J. Unmeasured costs of a child's death: perceived financial burden, work disruptions, and economic coping strategies used by American and Australian families who lost children to cancer. *J Clin Oncol*. 2011;29(8):1007-1013.
24. Bona K, Blonquist TM, Neuberg DS, Silverman LB, Wolfe J. Impact of socioeconomic status on timing of relapse and overall survival for children treated on Dana-Farber Cancer Institute ALL Consortium Protocols (2000-2010). *Pediatr Blood Cancer*. 2016;63(6):1012-1018.
25. Pelletier W, Bona K. Assessment of financial burden as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S619-S631.
26. Rosenberg AR, Starks H, Jones B. "I know it when I see it." The complexities of measuring resilience among parents of children with cancer. *Support Care Cancer*. 2014;22(10):2661-2668.
27. Rosenberg AR, Wolfe J, Bradford MC, et al. Resilience and psychosocial outcomes in parents of children with cancer. *Pediatr Blood Cancer*. 2014;61(3):552-557.
28. Rosenberg AR, Yi-Frazier JP, Eaton L, et al. Promoting resilience in stress management: a pilot study of a novel resilience-promoting intervention for adolescents and young adults with serious illness. *J Pediatr Psychol*. 2015;40(9):992-999.
29. Patenaude AF, Pelletier W, Bingen K. Communication, documentation, and training standards in pediatric psychosocial oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S870-S895.
30. Phipps S. Commentary: contexts and challenges in pediatric psychosocial oncology research: chasing moving targets and embracing "good news" outcomes. *J Pediatr Psychol*. 2005;30(1):41-45.
31. McGeary M, Hanna KE, eds; Institute of Medicine. Sources of funding for biomedical research. *Strategies to Leverage Research Funding: Guiding DOD's Peer Reviewed Medical Research Programs*. Washington, DC: National Academies Press; 2004:37-54.
32. Mehnert A, Koch U. Psychosocial care of cancer patients—international differences in definition, healthcare structures, and therapeutic approaches. *Support Care Cancer*. 2005;13(8):579-588.
33. Weaver MS, Heinze KE, Bell CJ, et al. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: an integrative review. *Palliative Med*. 2016;30(3):212-223.

Amy E. Caruso Brown, MD, MSc, MSCS, is an assistant professor in the Center for Bioethics and Humanities and the Department of Pediatrics at Upstate Medical University in Syracuse, New York, where she also co-directs Foundations of Reasoning in Medicine, a required course for preclinical medical students. She earned a medical degree from Emory University, a master's degree in medical anthropology from the University of Oxford, and a master's degree in clinical science from the University of Colorado. She completed residency and fellowship training in pediatrics and pediatric oncology at the Children's Hospital of Philadelphia and the Children's Hospital Colorado.

Related in the *AMA Journal of Ethics*

[Assessing Psychological Toxicity and Patient-Reported Distress as the Sixth Vital Sign in Cancer Care and Clinical Trials](#), May 2017

[Physicians' Role in Protecting Patients' Financial Well-Being](#), February 2013

[What Is the Physician's Responsibility to a Patient's Family Caregiver?](#), May 2014

[When and Why Should Mental Health Professionals Offer Traditional Psychodynamic Therapy to Cancer Patients?](#), May 2017

[Who Should Assess the Needs of and Care for a Dementia Patient's Caregiver?](#), December 2016

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

IMAGES OF HEALING AND LEARNING

From Silence into Language: Questioning the Power of Physician Illness Narratives

Amy E. Caruso Brown, MD, MSc, MSCS, and Rebecca Garden, PhD

Abstract

Physicians' narratives of their own experiences of illness can be a kind of empathic bridge across the divide between a professional healer and a sick patient. This essay considers ways in which physicians' narratives of their own and family members' experiences of cancer shape encounters with patients and patients' experiences of illness. It analyzes ethical dimensions of physicians' narratives (such as those by Atul Gawande, Siddhartha Mukherjee, and Paul Kalanithi) and of reflective writing in medical education. It also compares illness narratives written by physicians-turned-patients to those written by patients without medical training in order to explore questions of who ultimately benefits from these narratives and whether these narratives can engender greater empathy between clinicians and patients.

Introduction

Binary thinking has been characteristic of Western culture since the time of Plato and Socrates [1], and the same holds true in today's scientific and medical cultures. These dichotomies range from the body and mind and the normal and the pathological to—most importantly in health care—the patient's subjectivity and the physician's presumed objectivity (based in scientific observation and analysis) and the perceived power of the physician and the patient's relative powerlessness and vulnerability. This paper examines ways in which this kind of dualistic thinking can create distance between physicians and patients. This distance, which can develop into a chasm of incomprehension and miscommunication, often derives from fundamental differences in ways of thinking and knowing, beginning with a healthy physician's difficulty imagining an experience of illness.

Physicians are assumed and expected to be healthy in order to care for sick patients, an ironic conception given their high rates of mental illness and suicide [2-4]. The notion of "self-care," a topic of increasing interest in medical culture [5-7], derives from the tendency of physicians to neglect their own health and deny their susceptibility to illness, a tendency driven by a culture that perpetuates the myth of the impervious physician [8, 9]. Popular narratives like the 1991 movie *The Doctor* reflect our culture's struggle with

the effects of binary thinking in health care. The title character, an arrogant surgeon, echoes the popular view that empathy and expertise are incompatible when he tells his residents, “I’d rather you cut straight and cared less.” When he develops throat cancer, his own encounter with illness transforms him into a professional who deeply values empathy [10]. The protagonist in *The Doctor* provides a popular representation of the personal transformation that enables some physicians to both embody the stoic—and, at times, super-heroic—physician and embody, or at least empathize with, the vulnerable patient. Bridging this gap requires a change in thinking, in action, and, importantly, in one’s sense of identity. This essay explores the role that illness experiences and illness narratives can play by promoting humility and engendering a radical shift in perspective.

Bridging the Chasm

The physician who becomes ill and learns empathy from it is a compelling cultural figure who can break down the binary, drawing on her subjective experience of illness to guide her objective thinking—with compassion. Suzanne Fiala, a physician with bipolar disorder, has eloquently observed that “being personally intimate with pain and suffering has been translated into an ability to reach out to my patients at a deep level of connection and caring” [11].

Arthur W. Frank, a medical sociologist who survived a heart attack and then cancer, wrote *At the Will of the Body: Reflections on Illness*, a memoir [12], and *The Wounded Storyteller: Body, Illness, and Ethics* [13], which analyzes others’ illness narratives. In Frank’s work, illness narratives effect the translation that Fiala describes; stories of sickness build connections among those who share the condition of [vulnerability](#). The premise of *The Wounded Storyteller* is that the experience of illness is a form of suffering that engenders empathy: “The wounded storyteller is anyone who has suffered and lived to tell the tale... a fragile human body and a witness to what endures” [14]. The story of illness breaches a chasm that may otherwise exist between the well and the sick and the physician and patient; the illness narrative forms “the common bond of suffering that joins bodies in their shared vulnerability” [15].

Patients—and readers in general—yearn for literary experiences that bridge the chasm between experience and expertise, subjective suffering and objective knowledge. In Atul Gawande’s best-selling book, *Being Mortal: Medicine and What Matters in the End* [16], the physician-author writes about his father’s experience of cancer. This account and the stories of other family members and patients structure Gawande’s exploration of approaches to aging, illness, and the end of life. Here the physician-author’s role as listener and witness to stories forges a connection with his readers. Pulitzer-Prize-winning author and oncologist Siddhartha Mukherjee reinforces story as a bond with patients when he tells journalists that his bestselling book, *The Emperor of All Maladies: A Biography of Cancer* [17], is written for a patient with stomach cancer who told him, “I

need to know what it is that I'm battling" in order to fight [18]. Mukherjee's commitment to bridging the divide involves listening to his patients' stories and collaborating in telling them as a means of healing: "A patient, long before he becomes the subject of medical scrutiny, is, at first, simply a storyteller, a narrator of suffering.... To relieve an illness, one must begin, then, by unburdening its story" [19]. Mukherjee sees medicine as "a narrative form, in which patients tell stories to doctors, and doctors digest and deconstruct and offer a new story to the patient" [20]. This act, creating a bond with patients through storytelling, is fundamental to the discipline of the health humanities and to narrative medicine [21, 22], which view the ability to understand and respond with sensitivity and insight to patients' stories as fundamental to healing.

The Sick Healer

One might conclude, then, that the ideal healer would be the physician who has personal experience with illness and thus the ability to tell the story from the patient's perspective, like Gawande. One possible exemplar is found in the widely acclaimed and posthumously published memoir *When Breath Becomes Air* by physician Paul Kalanithi [23], who wrote of the transformation of power and position wrought by the discovery that he had inoperable cancer. "Instead of being the pastoral figure aiding a life transition," Kalanithi recalls, "I found myself the sheep, lost and confused" [24]. Best-selling physician illness narratives capture the popular imagination with the specter of the heroic physician, the "pastoral figure," as Kalanithi puts it, rendered even more mythically powerful because of being wounded by illness and thus possessing genuine empathy. The fact of Kalanithi's mortality—that he writes fully aware that he will not survive his cancer—serves as an antidote to a traditional barrier to physician empathy, namely, the deeply embedded belief that the role of the physician is to cure and that anything else implies loss of control and failure [25].

Yet Kalanithi, not unlike other nonmedical writers facing unexpected suffering, seeks to situate his intimate viewpoint within a greater tradition of literature and storytelling [26, 27]. In this sense, Kalanithi writes not to share his insights as a physician dying of cancer but to make sense of his life. He is, to paraphrase narrative ethicist Martha Montello, telling a story he can live with [28]. However, Kalanithi's story also provides an important counterpoint to the narratives in Gawande's *Being Mortal*. Gawande and other physicians who have written about encounters with patients and family members at the end of life tend to idealize a certain type of death and a certain type of patient—one who courageously but passively submits to mortality [29, 30]. While it is no doubt true that American medicine has historically failed to help patients set realistic goals when cure is unlikely, Kalanithi's writing creates a space for patients who do not believe that fighting until the end (with the hope of a miraculous cure) and hoping for a peaceful death are mutually exclusive. This is the double-edged sword of physician-as-patient illness narratives—that these narratives may be exalted as the "right" way to approach illness.

The Role of Narrative in Medical Education

Physician [illness narratives](#) align with the increasingly popular practice in all levels of medical education to encourage empathy through reflective writing in journals, portfolios, “critical incident reports,” and the imagined autobiographies of patients [31-33]. Some health care educators encourage students to write narratives of their own illness experiences in part as a means of counteracting the myth of the impossibly healthy physician [34] and to better recognize the complex embodiment of trainees in terms of not only illness but also race, ethnicity, and gender [34-36], which, along with ability, may be bound up in the myth of the physician or physician-in-training as healthy and otherwise normative. Writing about experiences of illness—their patients’ and their own—can help health care professionals develop the moral imagination necessary to understand and be moved to action by patients’ suffering. Physicians who write about their own illness may develop their capacity not only to empathize with patients but also to cope with personal suffering.

However, writing that focuses on personal experience, whether as a physician or patient, risks becoming an end in itself. Physician illness narratives may also inadvertently promote the ideal of the heroic physician, adding poignancy and courageous empathy to the archetypal characteristics of knowledge, expertise, and strength. Furthermore, physician writers may lack the humility necessary to recognize the limits of their own experiences when trying to understand and empathize with their patients. Physicians will always have more power than their patients in clinical settings, and they wield a significant amount of social capital outside those settings. Their writing, therefore, always holds the potential to pull the focus away from patients rather than to deepen their understanding of them [37]. Writing and publishing about patients should involve an ethical analysis that begins with questions such as who benefits the most and whether the publication comes at a cost to patients [38].

Conclusion

A fundamental question to ask of this genre is whether physician authors will always expand their own authority, even when writing to empower patients. For those whose social standing and role in the clinical setting grant them influence and control, writing about themselves could, at the very least, distract from the needed focus on patients. Thus it is critical to foreground illness narratives written by nonphysicians, particularly those who frame their experiences, and the writing itself, in explicitly political terms. A famous example of this is Audre Lorde’s *Cancer Journals* [39], which begins with a chapter called “The Transformation of Silence into Language and Action,” an analysis of the harms and benefits, to the author and others, of writing about her experience of cancer. Lorde observes that “I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking profits me, beyond any other effect” [40]. She goes on to say that, once she received her cancer diagnosis, she regretted her

former “silences.” She says, “My silences had not protected me. Your silence will not protect you. But for every . . . attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all believed, bridging our differences” [40]. Lorde reminds us that, while we must weigh the risks of telling our stories—including who tells the stories and how—the greatest harm is silence and the greatest benefit is solidarity. By placing physician illness narratives alongside those of patients without professional medical training, we build bridges across differences through solidarity.

References

1. Elbow P. The uses of binary thinking. *J Adv Comp*. 2009;13(1):51-78.
2. Aggarwal AK, Thompson M, Falik R, Shaw A, O’Sullivan P, Lowenstein DH. Mental illness among us: a new curriculum to reduce mental illness stigma among medical students. *Acad Psychiatry*. 2013;37(6): 385-391.
3. Eckleberry-Hunt J, Lick D. Physician depression and suicide: a shared responsibility. *Teach Learn Med*. 2015;27(3):341-345.
4. Dobson R. Suicide rate of women doctors in US is twice that of other working women. *BMJ*. 2007;335(7627):961.
5. Sanchez-Reilly S, Morrison LJ, Carey E, et al. Caring for oneself to care for others: physicians and their self-care. *J Support Oncol*. 2013;11(2):75-81.
6. Kuhn CM, Flanagan EM. Self-care as a professional imperative: physician burnout, depression, and suicide. *Can J Anaesth*. 2017;64(2):158-168.
7. West CP, Dyrbye LN, Erwin PJ, Shanafelt TD. Interventions to prevent and reduce physician burnout: a systematic review and meta-analysis. *Lancet*. 2016;388(10057):2272-2281.
8. Edney D. The myth of the invincible doctor. *J Miss State Med Assoc*. 2016;57(1):17.
9. McCredie J. Exploding the super-doctor myth. *Australian Doctor*. October 16, 2007.
10. Haines R. *The Doctor* [film]. Los Angeles, CA: Touchstone Pictures; 1991.
11. Fiala SJ. Normal is a place I visit. *JAMA*. 2004;291(24):2925.
12. Frank AW. *At the Will of the Body: Reflections on Illness*. Boston, MA: Houghton Mifflin; 2002.
13. Frank AW. *The Wounded Storyteller: Body, Illness and Ethics*. 2nd ed. Chicago, IL: University Of Chicago Press; 2013.
14. Frank, *The Wounded Storyteller*, xi-xii.
15. Frank, *The Wounded Storyteller*, xix.
16. Gawande A. *Being Mortal: Medicine and What Matters in the End*. New York, NY: Metropolitan Books; 2014.
17. Mukherjee S. *The Emperor of All Maladies: A Biography of Cancer*. New York, NY: Scribner; 2010.
18. McGrath C. How cancer acquired its own biographer. *New York Times*. November 8, 2010.

http://www.nytimes.com/2010/11/09/books/09mukherjee.html?_r=1&ref=review&. Accessed November 27, 2016.

19. Mukherjee, 46.
20. Telling the story of cancer. *Zocalo*. January 12, 2011. <http://www.zocalopublicsquare.org/2011/01/12/telling-the-story-of-cancer/events/the-takeaway/>. Accessed December 7, 2016.
21. Jones T, Wear D, Friedman L, Pachucki K, eds. *Health and Humanities Reader*. New Brunswick, NJ: Rutgers University Press; 2014.
22. Charon R. *Narrative Medicine: Honoring the Stories of Illness*. New York, NY: Oxford University Press; 2006.
23. Kalanithi P. *When Breath Becomes Air*. New York, NY: Random House; 2016.
24. Kalanithi, 120.
25. Shapiro J. Walking a mile in their patients' shoes: empathy and othering in medical students' education. *Philos Ethics Humanit Med*. 2008;3:10. <https://peh-med.biomedcentral.com/articles/10.1186/1747-5341-3-10>. Accessed April 3, 2017.
26. Rapp E. *The Still Point of a Turning World: A Mother's Story*. New York, NY: Penguin Press; 2013.
27. Gerson S. *Disaster Falls: A Family Story*. New York, NY: Crown; 2017.
28. Montello M. Narrative ethics. *Hastings Cent Rep*. 2014;44(suppl 1):S2-S6.
29. Hirni K, Carter B. White flag. *Ann Intern Med*. 2015;162(6):453-454.
30. Sacks O. *Gratitude*. New York, NY: Knopf; 2015.
31. Branch WT Jr. Use of critical incident reports in medical education: a perspective. *J Gen Intern Med*. 2005;20(11):1063-1067.
32. Kirkpatrick JN, Nash K, Duffy TP. Well rounded. *Arch Intern Med*. 2005;165(6):613-616.
33. Marshall PA, O'Keefe JP. Medical students' first-person narratives of a patient's story of AIDS. *Soc Sci Med*. 1995;40(1):67-76.
34. DasGupta S, Charon R. Personal illness narratives: using reflective writing to teach empathy. *Acad Med*. 2004;79(4):351-356.
35. Kumagai AK. A conceptual framework for the use of illness narratives in medical education. *Acad Med*. 2008;83(7):653-658.
36. Wear D, Aultman JM. The limits of narrative: medical student resistance to confronting inequality and oppression in literature and beyond. *Med Educ*. 2005;39(10):1056-1065.
37. Garden R. Expanding clinical empathy: an activist perspective. *J Gen Intern Med*. 2009;24(1):122-125.
38. Peterkin A. Primum non nocere: on accountability in narrative-based medicine. *Lit Med*. 2011;29(2):396-411.
39. Lorde A. *The Cancer Journals*. San Francisco, CA: Aunt Lute Books; 1997.
40. Lorde, 17.

Amy E. Caruso Brown, MD, MSc, MScS, is an assistant professor in the Center for Bioethics and Humanities and the Department of Pediatrics at Upstate Medical University in Syracuse, New York, where she also co-directs Foundations of Reasoning in Medicine, a required course for preclinical medical students. She earned a medical degree from Emory University, a master's degree in medical anthropology from the University of Oxford, and a master's degree in clinical science from the University of Colorado. She completed residency and fellowship training in pediatrics and pediatric oncology at the Children's Hospital of Philadelphia and the Children's Hospital Colorado.

Rebecca Garden, PhD, is an associate professor in the Center for Bioethics and Humanities at Upstate Medical University in Syracuse, New York. She earned her doctorate in English literature at Columbia University and has published in a range of journals including *New Literary History*, the *Journal of General Internal Medicine*, and the *Journal of Clinical Ethics*. She is executive director of the inter-institutional Consortium for Culture and Medicine and president of the Medical Humanities and Health Studies Forum executive committee for the Modern Language Association.

Acknowledgements

With thanks to Lauren Zahn for her editorial assistance.

Related in the *AMA Journal of Ethics*

[The Ethical Force of Stories: Narrative Ethics and Beyond](#), August 2014

[From *Doctors' Stories* to *Doctors' Stories*, and Back Again](#), March 2017

[From Particularities to Context: Refining Our Thinking on Illness Narratives](#), March 2017

[The House of God—Is It Pertinent 30 Years Later?](#), July 2011

["Sickness Is a Place": The Foreign Culture of Illness](#), April 2012

[Tangles: An Illness Narrative in Graphic Form](#), August 2014

[Vulnerability in Physicians' Narratives](#), July 2011

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

IMAGES OF HEALING AND LEARNING

They Are People First, Then Patients

Mónica Lalanda, MD, MSc, Eva Gracia-Peligero, MD, and Maria Teresa Delgado-Marroquín, MD, PhD

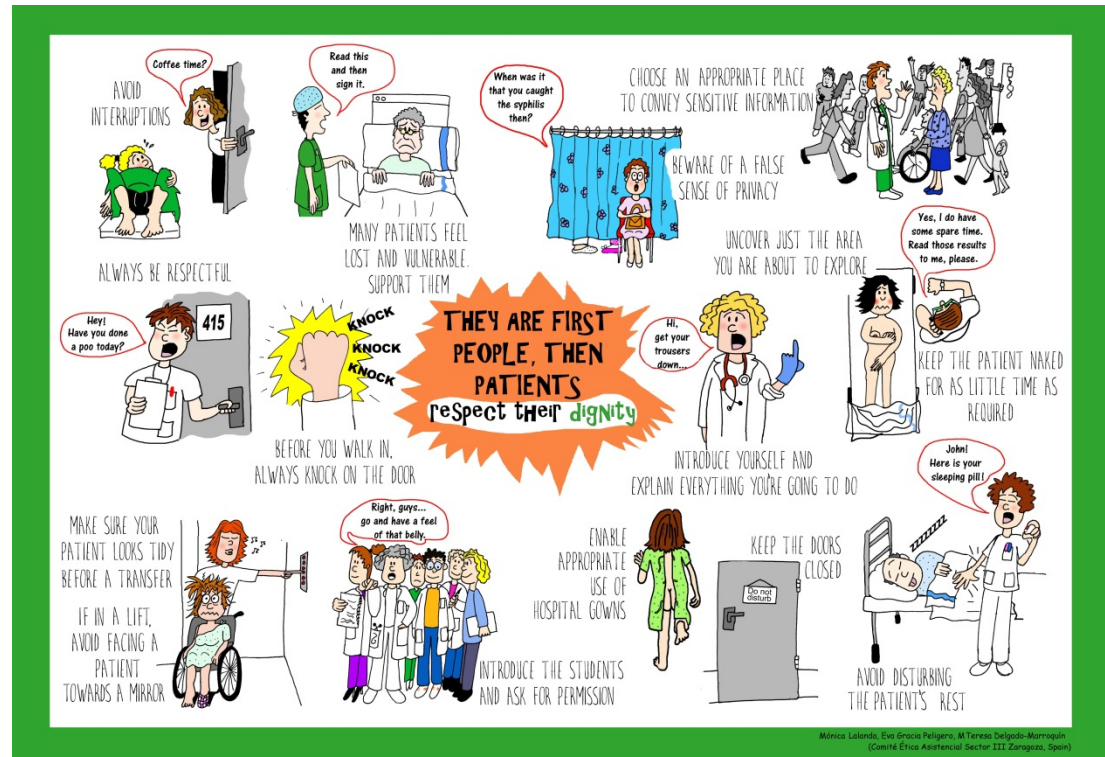


Figure 1. *They Are People First, Then Patients*, by Mónica Lalanda, Eva Gracia-Peligero, and Maria Teresa Delgado-Marroquín

Caption

Working in a health care environment, it's easy to forget that patients are not just patients but people who have become ill. When we are short of time, tired or just careless, we may fail to care for patients' dignity. This is a poster that uses humor and simple cartoons to convey powerful messages to anyone who deals with patients, from porters to doctors. Everyone needs to be involved to make the experience more humane. This poster is based on a document created by the Medical Ethics Committee in Sector III, Zaragoza (Spain).

Mónica Lalanda, MD, MSc, is an emergency medicine physician and holds master of science degrees in medical ethics and bioethics. She is also a comic artist.

Eva Gracia-Peligero, MD, is a psychiatrist at University Clinical Hospital Lozano Blesa in Zaragoza, Spain, and chair of the medical ethics committee in sector III Zaragoza.

Maria Teresa Delgado-Marroquín, MD, PhD, is a general practitioner at Delicias Norte Health Center in Zaragoza, Spain, and an assistant professor of ethics at the University of Zaragoza Medical School. She has a PhD in medical ethics.

Acknowledgements

Members of the *Comité de Ética Asistencial del Sector Zaragoza III (CEA ZSIII)*: M Yolanda Ariza Martín; M Jesús Ballestín Miguel; Carlota Canet Fajas; Ángeles Echave Esteban; M Teresa Delgado-Marroquín; Sandra Freire Díaz; Miguel Angel Fuertes Palacio; Nieves Galán Cerrato; Olga Gasca Andreu; Rafael González de Agüero Laborda; Eva Gracia Peligero; Trinidad Hermosilla Cabreirzo; Jesús Labar Alcubierre; Eva Lamote de Grignon Alfonso; Miguel Lorente López; Bárbara Marco Gómez; Andrés Martín Gracia; Julián Mozota Duarte; M Isabel Ocón Andrés; Visitación Palormero Llovera; Miguel Angel Quintanilla López; Yolanda Ruiz Borau Sanz; Cristina Sarasa Bellosta; Alejandro Tres Sánchez; Pablo Vela Condón; José Manuel Vitoria Ágreda.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**

AMA Journal of Ethics®

May 2017, Volume 19, Number 5: 510-513

ABOUT THE CONTRIBUTORS

Theme Issue Editor

Weisheng Renee Mao is a third-year medical student at the George Washington University School of Medicine and Health Sciences in Washington, DC. She is interested in psychiatry, medical ethics, and medical humanities.

Contributors

Arwa K. Aburizik, MD, MS, is a clinical assistant professor of hematology, oncology and blood and marrow transplantation, and psychiatry at the University of Iowa Carver College of Medicine in Iowa City. She specializes in caring for medically ill patients with psychiatric comorbidity and has a special focus on psycho-oncology.

Walter Baile, MD, is a distinguished teaching professor in the departments of psychiatry and behavioral science at the University of Texas MD Anderson Cancer Center in Houston. He is also director of the Interpersonal Communication and Relationship Enhancement (I*Care) program at MD Anderson Cancer Center, where he develops and oversees teaching in the area of clinician-patient communication.

Joshua M. Baruth, MD, PhD, is a resident in the Department of Psychiatry & Psychology at the Mayo Clinic in Rochester, Minnesota. He obtained his MD and PhD from the University of Louisville and completed a postdoctoral research fellowship in psychiatry at the Mayo Clinic in Rochester. He has an ongoing interest in medical education and ethics.

Amy E. Caruso Brown, MD, MSc, MSCS, is an assistant professor in the Center for Bioethics and Humanities and the Department of Pediatrics at Upstate Medical University in Syracuse, New York, where she also co-directs Foundations of Reasoning in Medicine, a required course for preclinical medical students. She earned a medical degree from Emory University, a master's degree in medical anthropology from the University of Oxford, and a master's degree in clinical science from the University of Colorado. She completed residency and fellowship training in pediatrics and pediatric oncology at the Children's Hospital of Philadelphia and the Children's Hospital Colorado.

Maria Teresa Delgado-Marroquín, MD, PhD, is a general practitioner at Delicias Norte Health Center in Zaragoza, Spain, and an assistant professor of ethics at the University of Zaragoza Medical School. She has a PhD in medical ethics.

Allen R. Dyer, MD, PhD, is a professor of psychiatry and behavioral sciences and the vice-chair for education at the George Washington University (GW) in Washington, DC, where he is also director of the GW Psycho-oncology Clinic.

Rebecca Garden, PhD, is an associate professor in the Center for Bioethics and Humanities at Upstate Medical University in Syracuse, New York. She earned her doctorate in English literature at Columbia University and has published in a range of journals including *New Literary History*, the *Journal of General Internal Medicine*, and the *Journal of Clinical Ethics*. She is executive director of the inter-institutional Consortium for Culture and Medicine and president of the Medical Humanities and Health Studies Forum executive committee for the Modern Language Association.

Eva Gracia-Peligero, MD, is a psychiatrist at University Clinical Hospital Lozano Blesa in Zaragoza, Spain, and chair of the medical ethics committee in sector III Zaragoza.

Heidi A. Hamann, PhD, is an associate professor in the Departments of Psychology and Family and Community Medicine at the University of Arizona in Tucson. Her primary research focuses on psychosocial and behavioral concerns, including stigma of lung cancer patients and survivors.

Jerry Joseph Ignatius, DO, is an assistant professor in the Department of Psychiatry at the University of Texas MD Anderson Cancer Center in Houston. He has a special interest in demoralization and spirituality in cancer patients.

Arif H. Kamal, MD, MBA, MHS, is a medical oncologist and palliative medicine physician at Duke University School of Medicine in Durham, North Carolina, where he is also the physician quality and outcomes officer for the Duke Cancer Institute.

Mónica Lalanda, MD, MSc, is an emergency medicine physician and holds master of science degrees in medical ethics and bioethics. She is also a comic artist.

Maria I. Lapid, MD, is a geriatric psychiatrist and palliative care specialist at the Mayo Clinic in Rochester, Minnesota. After college and medical school in her native Philippines, Dr. Lapid completed her residency and fellowship training in the United States, gaining clinical expertise through formal training programs in psychiatry, geriatric psychiatry, and hospice and palliative medicine, and through practice in inpatient and outpatient geriatric psychiatry settings and in the inpatient palliative care consultation service and hospice program. At the Mayo Clinic, she has led research projects on investigations of various clinical issues relevant to electroconvulsive therapy, palliative care, and quality of life in elderly patients.

Thomas W. LeBlanc, MD, MA, MHS, is a medical oncologist and palliative medicine physician at Duke University School of Medicine in Durham, North Carolina, where he is also a patient experience researcher at the Duke Cancer Institute.

Laurel J. Lyckholm, MD, is a clinical professor of hematology, oncology and blood and marrow transplantation at the University of Iowa Carver College of Medicine in Iowa City, where she is also a primary faculty member in the Program in Bioethics and Humanities and a consultant on the University of Iowa Hospitals and Clinics Ethics Consult Service. Dr. Lyckholm's research and clinical interests are directed toward improving cancer and palliative care for the most vulnerable of our citizens.

Monica R. Martinez will complete her JD at the George Mason University School of Law in Arlington, Virginia, in 2017. Her research interests include administrative law, disability law, and food and drug law.

Fremonta Meyer, MD, is an assistant professor of psychiatry at Harvard Medical School in Boston, where she is also an attending psychiatrist at the Dana-Farber Cancer Institute and Brigham and Women's Hospital.

Fatima Noorani, MD, is a clinical assistant professor in the Department of Psychiatry and Behavioral Sciences at the George Washington University in Washington, DC, and she is also the medical director of the McClendon Center.

Jamie S. Ostroff, PhD, is the chief of the behavioral sciences service in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center and a professor of psychology in the Department of Healthcare Policy and Research at Weill Cornell Medical College, both in New York City. Her cancer prevention and control research focuses on tobacco cessation and stigma experienced by patients with lung cancer.

Amirala Pasha, DO, MS, is an assistant professor of medicine at the George Washington University School of Medicine and Health Sciences in Washington, DC. He is also completing his JD at the George Washington University Law School. He has a strong interest in health law and policy as well as bioethics.

Kristen E. Riley, PhD, is a postdoctoral research fellow at Memorial Sloan Kettering Cancer Center in New York City, where she studies health behavior decision making and tobacco cessation for cancer prevention.

Philip M. Rosoff, MD, MA, is a professor of pediatrics (oncology) and medicine at Duke University Medical Center and Duke University School of Medicine in Durham, North Carolina, where he is also a member scholar in the Trent Center for Bioethics, Humanities

& History of Medicine and chair of Duke Hospital's ethics committee. His latest book is *Drawing the Line: Healthcare Rationing and the Cutoff Problem* (Oxford University Press, 2017). His scholarly interest is in the area of the equitable distribution of scarce resources (rationing).

Michael R. Ulrich, JD, MPH, is an assistant professor in the Center for Health Law, Ethics & Human Rights and the Department of Health, Law, and Policy Management at Boston University School of Public Health. He studies public health, ethics, and law.

David P. Yuppa, MD, is an attending psychiatrist at the Dana-Farber Cancer Institute and Brigham and Women's Hospital and an instructor in psychiatry at Harvard Medical School in Boston. He is a former fellow of the American Psychoanalytic Association and a candidate in adult psychoanalysis at the Boston Psychoanalytic Society and Institute.