

Looking Back, Looking Forward: The Ethical Framing of Complementary and Alternative Medicine in Oncology Over the Last 20 Years

BRITTANY C. KIMBALL¹,^{a,b} GAIL GELLER,^{2,h} RAHMA WARSAME,³ ASHOK KUMBAMU,⁴ AMINAH JATOI,⁵ BARBARA KOENIG,⁶ JON C. TILBURT^{2,d,f}

¹Mayo Clinic School of Medicine, Rochester, Minnesota, USA; ²Biomedical Ethics Research Program, ³Division of Hematology, ⁴Division of Health Care Policy and Research, ⁵Division of Medical Oncology, ⁶Division of General Internal Medicine, Mayo Clinic, Rochester, Minnesota, USA; ⁷Division of General Internal Medicine, Johns Hopkins School of Medicine, Baltimore, Maryland, USA, ⁸Berman Institute for Bioethics, Johns Hopkins University, Baltimore, Maryland, USA; ⁹Institute for Health & Aging, University of California, San Francisco, San Francisco, California, USA

Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Complementary medicine • Ethical issues

2017 marked the 20th anniversary of the statement adopted by the American Society of Clinical Oncology (ASCO) titled “The Physician and Unorthodox Cancer Therapies,” which outlined the physician’s role in navigating “unorthodox or questionable methods of care” with oncology patients [1]. The ASCO statement signaled a watershed moment in which oncology began to address complementary and alternative medicine (CAM). Although many traditional practices for healing encompassed by CAM are very old, our engagement with them in modern Western medicine is relatively new. That newness, along with major studies disproving some specific and publicly hyped CAM modalities for cancer treatment, prompted this early commentary from oncology leaders about CAM [2, 3].

A lot has happened in the science and language surrounding CAM in the last two decades. A look back at the original ASCO statement reflects the tone and mentality of the era in which it was written, providing an opportunity to consider where we have been and where we are going. Here, we reflect on that statement and trace how the language around CAM therapies in oncology has evolved since. Although medicine’s approach to CAM has progressed significantly over the past two decades, we argue that the conversation around CAM in cancer care can become yet more nuanced, patient centered, and respectful in order to better meet the needs of patients in the coming decades.

CONTEXT OF CAM IN CANCER CARE IN THE 1990S

The 1990s brought broad awareness in medicine about patient practices of CAM [4–6]. The ASCO statement reflected a safety-oriented skepticism toward CAM during an era in which strong public enthusiasm for CAM had little corresponding scientific evidence. Many oncologists still remembered cases of patients forgoing chemotherapy for Laetrile, a much-touted but toxic compound patented in the 1960s and tested over the next 20 years with no evidence of benefit against cancer [7]. Simultaneously at the NIH, institutional efforts were stirring to shift the

conversation scientifically with the goal of understanding both benefits and harms of CAM therapies from a biomedical perspective. Despite criticism, national investments in centers and offices through the NIH and National Cancer Institute increased research dollars, and public pressure resulted in studies using scientific methodology to investigate CAM modalities [8–11].

ETHICAL FRAMING OF CAM IN “THE PHYSICIAN AND UNORTHODOX CANCER THERAPIES”: A SNAPSHOT OF PROFESSIONAL THOUGHT IN THE 1990S

“The Physician and Unorthodox Cancer Therapies” attempted to reconcile what oncologists perceived as the major risks of CAM with the desire of patients with cancer to be viewed in “physical and spiritual totality” [1]. Like a protective parent, the tone of the statement was decidedly precautionary. It focused on the “reliability” of information, thus casting CAM as inherently unreliable. It instructed oncologists to discuss “unproven ‘alternative treatments’” in order to “preempt later confrontation with an absolutely committed patient” [1]. In addition to paternalistic overtones, it seemed to conflate “unproven” and “disproven,” thus shutting the door to even the possibility of future investigation that might prove a therapy’s benefit. Although understandable for its time, given lingering paternalism and historical context, the ethical framing reads to contemporary ears as unduly focused on nonmaleficence, without the same consideration paid to autonomy and respect. In hindsight, that language might have acknowledged that CAM—a broad umbrella term for a diverse assortment of therapies—could complement conventional medicine if adequately studied.

A patient’s desire to be proactive in his or her health and to be treated as a whole person, although acknowledged in the 1997 statement, were quickly dismissed. Missing from the discourse was a fundamental acknowledgment of alternate worldviews about healing [12]. These worldviews, stemming from geography or locality, culture, and spirituality, influence our

Correspondence: Brittany C. Kimball, B.S., Mayo Clinic, 200 First Street SW, Rochester, Minnesota 55905, USA. Telephone: 507-266-1105; e-mail: kimball.brittany@mayo.edu Received October 8, 2017; accepted for publication December 19, 2017; published Online First on March 9, 2018. <http://dx.doi.org/10.1634/theoncologist.2017-0518>

own and our patients' values and decisions about health care and are worth acknowledging and understanding. Terms in the statement such as "unsubstantiated claims" and "questionable methods of care" placed healing practices outside of conventional oncology as other, inaccurately implying that if patients want care, they must conform to one particular worldview: the biomedical one. Although most oncologists would not stop conventional treatment if CAM were used, framing CAM in this way potentiates a common misinterpretation that in cancer care it's "the oncologist's way or the highway," thus closing the door to discussion topics and psychosocial concerns that might not fit neatly into typical oncologic care. Furthermore, this implication creates binary opposition between perspectives on healing—scientific versus unscientific, modern versus traditional, and rational versus irrational. Arguably, patient-centered care requires clinicians to at least acknowledge and furthermore, be willing to accommodate lay forms of wisdom within some bounds of safety [13]. By emphasizing lack of scientific evidence and creating cautionary alarm, the statement missed a crucial dimension of whole person care—remaining open to CAM approaches to healing as a matter of respect, even if the data are inconclusive [14].

LOOKING BACK: CHANGES IN LANGUAGE, VALUES, AND UNDERSTANDING

The discourse around CAM in oncology has evolved since that statement was written. As part of the shift away from medical paternalism and toward more patient-centered models of participatory medicine, patients began playing an increasingly active role in shaping the environment of medicine [15–17]. Furthermore, as cancer survivorship has become a reality for more and more people, these survivors identify needs beyond mere life extension—needs related to thriving with and after cancer [18–22]. Many cancer survivors use CAM therapies to address unmet needs after cancer treatment, and indeed, CAM modalities may be useful for common symptoms both during and after treatment [23–29]. As we start recognizing the holistic needs of patients, and as patients become more empowered to voice their needs and values, conversations about CAM become increasingly relevant as a quality-of-life topic.

Oncology literature has shifted away from distinct paternalism when it comes to CAM and into a more contemporary benign tolerance of CAM as unavoidable risk behavior. A 2001 article in the *Journal of Clinical Oncology* argued that academic oncology has no choice but to confront CAM [30]. Yet the tone remained precautionary. Recent commentary has advocated for oncologists to broach the subject of CAM with patients primarily as a means for enhancing disclosure of those therapies so that doctors can address risk [31]. CAM modalities can pose risks, and ethical analysis of their role cannot avoid considering nonmaleficence. However, we must also acknowledge our own biases in this harm-avoidant framing. There is a tendency to apply strict scrutiny to CAM in terms of dollars spent, time expended, and possible side effects experienced that are not as rigorously and frequently applied to medical cancer therapy, itself costly and time consuming and often laden with severe and potentially irreversible side effects. This tendency exposes a natural human inclination: doctors scrutinize more what they do not know [32, 33]. This seeming double standard is difficult but important to own in how we address CAM.

Furthermore, talking about CAM simply for disclosure and consistently couching CAM as a risk behavior threaten to alienate patients. By not acknowledging the biases of the biomedical worldview, we create a barrier to better understanding our patients' perspectives.

The current state of how CAM conversations fit in conventional oncology is informed by research. Those conversations are scant. In a large NIH-funded observational study, we found that although CAM is discussed in a relative minority of medical oncology visits (11%), and the discussions were brief (<4 minutes total in a visit), those discussions were also characterized by greater patient engagement in dialogue and less physician verbal dominance [34]. Furthermore, conversations that include CAM are rated as better by both patient and clinician. We also found that in those conversations, more psychosocial topics get discussed on the whole. We suspect that the essence of benefit in discussing CAM was less about the content of those conversations and more about the way clinicians remained open to discussing life outside of the biomedical realm.

LOOKING FORWARD: WHERE DO WE GO FROM HERE?

Language around CAM in oncology deserves further reframing. The historical evolution from paternalistic caution to contemporary benign tolerance should now take a further step toward a fundamentally respect-based, person-centered approach. Medicine need not fully integrate alternative practices in order to be patient-centered, nor must doctors know everything about every CAM modality patients would like to discuss. Rather, we advocate for meeting people where they are, understanding what they identify as critical elements of healing, and navigating that interpersonal relationship with curiosity and openness. These conversations can be hard. If physicians do not think they are equipped to discuss CAM with patients, perhaps the most ethical approach is to refer patients to colleagues with the experience to have that conversation.

We posit that clinicians ought to talk about CAM with their patients, but not for mere disclosure or solely to do no harm. Rather, if we discuss with patients what is important to them and are open to the answers they give us in an effort to come to know them as people embedded in a particular social, cultural, and historical context, we will have a better ability to connect and discover their values. This understanding can help us offer more person-centered care. It is plausible that physician receptivity to patient use of CAM could have a positive effect on the therapeutic alliance. If so, it is possible that being open to CAM could have numerous positive therapeutic benefits associated with that alliance, including making patients more willing to fully participate in treatment, thus improving the efficacy of those treatments and making patients' experiences of cancer more tolerable [35, 36].

A person-centered approach to CAM in contemporary oncology would incorporate both self-awareness and acknowledgment of the diversity of worldviews held by patients who might experience healing differently. It would employ nonjudgment, involve physicians talking less and patients talking more, and focus on partnership with patients throughout their cancer journey, even when their perspectives and choices differ from our own. Protecting patients and expressing medical viewpoints or concerns about CAM treatments may be indicated, but this should be predicated on first understanding and

respecting the cultural, spiritual, and personal positioning of the patient. Patients need guidance, but they also need a doctor who understands and respects them. We can do both. If we shift our framing of CAM from one that is directly oppositional or solely focused on risk behavior to a more nuanced, respect-based approach that seeks understanding through probing questions, self-awareness, and basic understanding of diverse worldviews, we can help each person navigate his or her cancer journey in a way that is not only safe and effective but authentic, whole, and healing.

REFERENCES

- American Society of Clinical Oncology. The physician and unorthodox cancer therapies. *J Clin Oncol* 1997;15:401–406.
- Creagan ET, Moertel CG, O'Fallon JR et al. Failure of high-dose vitamin C (ascorbic acid) therapy to benefit patients with advanced cancer. A controlled trial. *N Engl J Med* 1979;301:687–690.
- Moertel CG, Fleming TR, Rubin J et al. A clinical trial of amygdalin (Laetrile) in the treatment of human cancer. *N Engl J Med* 1982;306:201–206.
- Eisenberg DM, Kessler RC, Foster C et al. Unconventional medicine in the United States. Prevalence, costs, and patterns of use. *N Engl J Med* 1993;328:246–252.
- Murray RH, Rubel AJ. Physicians and healers—unwitting partners in health care. *N Engl J Med* 1992;326:61–64.
- Campion EW. Why unconventional medicine? *N Engl J Med* 1993;328:282–283.
- Rosen GM, Shorr RI. Laetrile: End play around the FDA. A review of legal developments. *Ann Intern Med* 1979;90:418–423.
- Offit PA. *Do You Believe in Magic? The Sense and Nonsense of Alternative Medicine*. New York: HarperCollins; 2013.
- Marcus DM, Grollman AP. Science and government. Review for NCCAM is overdue. *Science* 2006;313:301–302.
- NCCIH funding: Appropriations history. National Center for Complementary and Integrative Health (NCCIH) Web site. Available at <https://nccih.nih.gov/about/budget/appropriations.htm>. Updated June 15, 2017. Accessed July 26, 2016.
- Jia L. Cancer complementary and alternative medicine research at the US National Cancer Institute. *Chin J Integr Med* 2012;18:325–332.
- Tilburt J, Geller G. Viewpoint: The importance of worldviews for medical education. *Acad Med* 2007;82:819–822.
- Tilburt JC, Miller FG. Responding to medical pluralism in practice: A principled ethical approach. *J Am Board Fam Med* 2007;20:489–494.
- Institute of Medicine of the National Academies. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, D.C.: National Academies Press; 2008.
- Cloninger CR. Person-centred integrative care. *J Eval Clin Pract* 2011;17:371–372.
- Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med* 2012;366:780–781.
- Swan M. Emerging patient-driven health care models: An examination of health social networks, consumer personalized medicine and quantified self-tracking. *Int J Environ Res Public Health* 2009;6:492–525.
- Institute of Medicine and National Research Council of the National Academies. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: National Academies Press; 2006.
- Cancer survivors—United States, 2007. *JAMA* 2011;305:2281–2282.
- Mao JJ, Armstrong K, Bowman MA et al. Symptom burden among cancer survivors: Impact of age and comorbidity. *J Am Board Fam Med* 2007;20:434–443.
- Wu HS, Harden JK. Symptom burden and quality of life in survivorship: A review of the literature. *Cancer Nurs* 2015;38:E29–E54.
- Shi Q, Smith TG, Michonski JD et al. Symptom burden in cancer survivors 1 year after diagnosis: A report from the American Cancer Society's studies of cancer survivors. *Cancer* 2011;117:2779–2790.
- Mao JJ, Palmer SC, Straton JB et al. Cancer survivors with unmet needs were more likely to use complementary and alternative medicine. *J Cancer Surviv* 2008;2:116–124.
- Alimi D, Rubino C, Pichard-Léandri E et al. Analgesic effect of auricular acupuncture for cancer pain: A randomized, blinded, controlled trial. *J Clin Oncol* 2003;21:4120–4126.
- Garcia MK, McQuade J, Haddad R et al. Systematic review of acupuncture in cancer care: A synthesis of the evidence. *J Clin Oncol* 2013;31:952–960.
- Kwekkeboom KL, Cherwin CH, Lee JW et al. Mind-body treatments for the pain-fatigue-sleep disturbance symptom cluster in persons with cancer. *J Pain Symptom Manage* 2010;39:126–138.
- Wilkinson SM, Love SB, Westcombe AM et al. Effectiveness of aromatherapy massage in the management of anxiety and depression in patients with cancer: A multicenter randomized controlled trial. *J Clin Oncol* 2007;25:532–539.
- Bower JE, Garet D, Sternlieb B et al. Yoga for persistent fatigue in breast cancer survivors: A randomized controlled trial. *Cancer* 2012;118:3766–3775.
- Marx W, Kiss N, Iсенring L. Is ginger beneficial for nausea and vomiting? An update of the literature. *Curr Opin Support Palliat Care* 2015;9:189–195.
- Markman M. Interactions between academic oncology and alternative/complementary/integrative medicine: Complex but necessary. *J Clin Oncol* 2001;19(suppl 18):52S–53S.
- Zachariae R. Complementary and alternative medicine use among patients with cancer: A challenge in the oncologist-patient relationship. *JAMA Oncol* 2016;2:1177–1178.
- Kaptchuk TJ. Effect of interpretive bias on research evidence. *BMJ* 2003;326:1453–1455.
- Tilburt JC, Miller FG, Jenkins S et al. Factors that influence practitioners' interpretations of evidence from alternative medicine trials: A factorial vignette experiment embedded in a national survey. *Med Care* 2010;48:341–348.
- Roter DL, Yost KJ, O'Byrne T et al. Communication predictors and consequences of Complementary and Alternative Medicine (CAM) discussions in oncology visits. *Patient Educ Couns* 2016;99:1519–1525.
- Trevino KM, Abbott CH, Fisch MJ et al. Patient-oncologist alliance as protection against suicidal ideation in young adults with advanced cancer. *Cancer* 2014;120:2272–2281.
- Hillen MA, de Haes HC, Smets EM. Cancer patients' trust in their physician—a review. *Psychooncology* 2011;20:227–241.

ACKNOWLEDGMENTS

This work was partially supported by Grant R01 AT006515 from the National Center for Complementary and Integrative Health.

DISCLOSURES

Barbara Koenig: Illumina Corporation (other—travel). The other authors indicated no financial relationships.

(C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board