

Health Communication Ethics and CDC Quality-Control Guidelines for Information

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In their article, “Apply Federal Research Rules on Deception to Misleading Health Information: An Example on Smokeless Tobacco and Cigarettes,” Kozlowski and O’Connor argue for holding government health communication efforts to the highest standards of scientific and ethical integrity. We at the Centers for Disease Control and Prevention (CDC) agree with that position. However, we disagree with the authors in their characterization of certain CDC information as “deception” and “disinformation” and their insistence on rigidly applying clinical medicine’s informed consent standards for research to population-based, mass media health communication. We believe the ethics of such communications are more appropriately guided by broader public health principles and practices to which CDC firmly adheres.

Kozlowski and O’Connor cite as deceptive a specific posting on CDC’s website—a 150-word article for young people originally titled, “Is Smokeless Tobacco Safer Than Cigarettes?” The article appears on the website under the Surgeon General’s Report for Kids About Smoking (SGR4Kids). SGR4Kids was a 12-page, easy-to-understand magazine version of the 1994 Surgeon General’s Report (SGR) on preventing tobacco use, written for and pretested among young people (aged 10 through 13).¹ It was originally published as a four-color printed piece; in 1996 it was reformatted and loaded onto the Web. In the original magazine, the smokeless tobacco (SLT) article was printed as a sidebar alongside an interview with then-Surgeon General Dr. Joycelyn Elders.

In our effort to communicate complex information from the SGR to high-risk middle-school students, we made a great effort to simplify language and concepts while being as accurate as possible. The text was reviewed and cleared under standard CDC procedures, which include review for editorial style and scientific content. Crafting of the title, “Is Smokeless Tobacco Safer Than Cigarettes?” was our attempt to simplify for a young audience the more complicated question, is smokeless tobacco a safe alternative to (or substitute for) cigarettes?

The SGR4Kids article emphasizing SLT hazards was particularly salient in 1994, when SLT use was rising among young people and perception of harm

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was low.¹ The SGR noted that SLT use among young males had “become markedly more prevalent in the past two decades” and that “some research indicates an average age of onset of 10 years.” The report underscored SLT’s high addictive potential and concluded “adolescent smokeless tobacco users are more likely than nonusers to become cigarette smokers.” Moreover, the SGR stated that tobacco industry advertising and promotional activities contributed to the growing perception that SLT was a safe alternative to cigarette smoking. An earlier report from the Advisory Committee to the Surgeon General concluded that “the oral use of smokeless tobacco represents a significant health risk,” prompting then-Surgeon General C. Everett Koop to write, “It is critical that our society prevent the use of this health hazard and avoid the tragic mistake of replacing the ashtray with the spittoon.”²

The SGR4Kids article attempted to summarize many SLT-related emerging health and behavioral issues in an accurate, straightforward, and engaging manner for the vulnerable adolescent population. In retrospect, especially with the benefit of another decade of research on the comparative dangers of cigarettes and SLT, the headline’s “safer than cigarettes” phrase should have been changed to “safe” during the CDC clearance process. As the authors in the accompanying article acknowledge, in June 2002 we made that change on the website to read, “Is Smokeless Tobacco Safe?”

Given the state of SLT-use science in the late 1980s and early 1990s, it is inaccurate to label the SGR4Kids article an attempt to deceive the public. It would be fairer to criticize the agency for failing to keep our website information as up-to-date as possible. But it is clearly erroneous to judge the behavior or motives of CDC communicators and scientists who prepared and reviewed the information.

The CDC has issued no current public pronouncements about the relative dangers of SLT and cigarettes, given the lack of scientific consensus about this and other harm-reduction issues in tobacco control. In general, most public health authorities agree that SLT is less hazardous than cigarette use in terms of overall mortality when evaluated in the context of lifetime exclusive use.³ There are insufficient data, however, to evaluate the reduced risk of switching from cigarettes to SLT. We therefore lack the data to assess the degree to which a cigarette smoker’s risk might be reduced to that of an exclusive SLT user. Thus, for a current cigarette smoker, SLT would be characterized in Institute of Medicine (IOM) terminology as a “potential reduced-exposure product” whose potential to

reduce risk according to criteria in the IOM report should be evaluated.³ Unfortunately, no agency has the authority to monitor SLT products to determine whether they truly reduce harm or are being manipulated in a way that could even increase risk.

Even if some smokers who switch to SLT do reduce their individual risk, it is plausible that overall population risk would increase if SLT were promoted as a potential reduced-exposure product. This conclusion assumes that (*a*) some smokers who would have otherwise quit using tobacco would switch to SLT or continue to smoke and use SLT; (*b*) the number of lifetime SLT users would rise as a result of increased youth SLT initiation; (*c*) the number of smokers would rise as a result of increased youth SLT initiation with subsequent switching to cigarette use; and/or (*d*) some former smokers would relapse, believing SLT a less hazardous way to consume tobacco.³

The CDC therefore concludes that it is not currently possible to make a nondeceptive claim regarding the risk-reduction potential of switching to SLT from cigarettes. In fact, no major public health organization or public health scientific body has endorsed a recommendation that smokers switch to SLT products. Even if such a claim were valid, it is plausible that such a claim would result in significant and negative overall public health consequences.

Regarding Kozlowski and O’Connor’s discussion of health communication ethics, the CDC and other scientific agencies have in place the checks and balances needed to ensure the accurate communication of science-based information. The CDC’s health communication efforts are guided by its core value of integrity: “We are honest and ethical in all we do. We will do what we say. We prize scientific integrity and professional excellence.”⁴ Adherence to this value is critical because health communications by their nature are a purposeful attempt to influence personal behaviors and social environments; they are inherently value-laden.⁵ As one medical ethicist observed, “It can be tempting to think that work for health is value-free, that some endeavors are simply good and desirable by all, and have no effects that can be described as bad or undesirable. . . . It is an inescapable truth that all work for health, every last bit of it, is at some point inspired by a human value that has been chosen from alternatives.”⁶

While acknowledging that selecting among alternatives in the communication process—e.g., who to reach, what to say, what strategies and techniques to use, how to evaluate these efforts—poses ethical challenges, we assert that applying to health communication the informed consent protocols developed for human sub-

jects research is fraught with ethical peril. Practically, this proposed model is flawed with regard to youth-focused communication because adolescents do not generally complete informed consent documents. The very process of informed consent—presenting scripted disclaimers about possible health effects irrespective of these probabilities occurring—could mislead people, especially adolescents who typically struggle to make considered judgments about health risks, including those related to tobacco use. An extensive body of evidence shows that large proportions of people, especially adolescents, do not understand statements about relative risk.⁷ Over the past decade, the CDC has spent considerable time and effort developing media literacy and other educational interventions for adolescents,⁸ and standards of practice for communicating tobacco-prevention messages to young people.⁹

We disagree with the authors' assertion that "health communication frequently represents a large-scale uncontrolled research study. . . ." In fact, health communication as practiced by the CDC is based on rigorous consumer and market research aimed at getting the message right and controlling as much as possible for unintended negative effects.¹⁰ At that point, as set forth in the Public Health Code of Ethics, "there is a moral obligation in some cases to share what is known," by inference, *before* obtaining informed consent.¹¹ This code further stresses that knowledge is not morally neutral and that information, even when incomplete, should be translated into timely action.

As taught and practiced by the CDC, health communication must be responsive and ultimately accountable to the public, respecting individual self-determination and freedom of choice. As a key part of its mission, the CDC provides credible information to enhance health decisions: "We recognize that the best, most up-to-date health information is meaningless unless it is meaningful and accessible to the people it is meant to serve. By working with public health and grassroots partners, and by leveraging the voices of the internet, and communication media, we ensure the best health and safety information is accessible to the communities and people who need it every day."¹² Every step of the health communication process—from formative consumer research to message development to evaluation and feedback—is guided by the end-user's perspective. This viewpoint is consistent with health communication ethics, which emphasizes promoting, and using a community standard to determine, the common good.^{13–15}

More recently, a new statutory requirement became effective in October 2002 that requires federal agencies to ensure and maximize the quality, objectivity,

utility, and integrity (collectively referred to as quality) of information disseminated by federal agencies.¹⁶ In response, the CDC developed agency-specific guidelines and procedures to ensure the quality of its disseminated information, and an administrative process by which affected persons may seek and obtain correction of information that does not comply with the guidelines.¹⁷ Because information quality is critical to the CDC's public health mission, the agency insists that all employees promote and ensure quality throughout the information life cycle, including data and information collection, analysis, management, and dissemination.

CDC information guidelines codify the agency's longstanding approach to maximizing the quality of its information with regard to utility, objectivity, and integrity:

- The CDC addresses utility, a measure of information product usefulness, by staying informed of user needs through information product research, user needs assessment, user feedback, consultation with advisory committees, and conference participation.
- The CDC assures that information is accurate, reliable, and unbiased. Objectivity is achieved through review and clearance procedures and, in many cases, peer review of disseminated information.
- The CDC assures the integrity of its data and information products by enforcing rigorous controls that protect against unauthorized access, revision, or corruption. These include access control, user authentication, encryption, access monitoring, provision of unalterable electronic content, and audit trails.

Together, consumer-focused discipline, health communication ethics, and CDC quality-control guidelines for information ensure information quality and provide the best possible opportunity for consumer "debriefing" that Kozlowski and O'Connor advocate. We believe this process provides a rigorous yet practical safeguard against communications the authors might characterize as, at best, well-intended and paternalistic or, at worst, ill-intended and deceptive.

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