



# Ecstasy Experts Want Realistic Messages

Brian Vastag

BETHESDA—As the popularity of the drug ecstasy (MDMA) continues to climb—11% of high school seniors have tried it, according to a National Institute on Drug Abuse (NIDA) survey—behavioral researchers are recommending control strategies that may seem antithetical to ever-expanding law enforcement efforts. Instead of focusing on eradication and punishment, these social scientists take another tack: they encourage harm reduction that acknowledges the realities of ecstasy.

At a recent NIDA conference, a half-dozen speakers advocated this immediate action approach. Providing plenty of water at rave parties to prevent dehydration (a common adverse effect), offering purity testing to help users avoid ubiquitous adulterants, and developing peer-led programs will go a long way toward reducing dangers, they said.

Ecstasy pills sold in the United States generally contain 100 mg or less of MDMA. According to the social scientists, typical users take no more than one pill at a time during a “session” and most limit their use to once or twice per week.

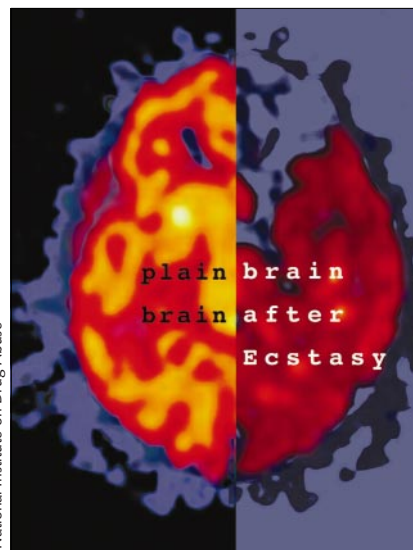
“Ecstasy is seen as relatively benign,” said Robert Carlson, PhD, an addiction researcher at Wright State University of Medicine in Dayton, Ohio. “[Prevention] messages are not getting across, and something needs to be done.”

Skepticism about government studies, perception that ecstasy is safer than other drugs (including alcohol and tobacco), and willingness to take calculated risks all factor into the ecstasy equation, said Patricia Case, ScD, director of the program in urban health at Harvard University. “A lot of [ecstasy users] make clear decisions, despite the known or unknown risks, that the benefits outweigh those risks,” she said.

With considerations like these, Carlson and his colleagues are emphatic that

one-size-fits-all campaigns hyping the dangers of ecstasy fail to sway users. Instead, they want messages that reflect reality: the effects of ecstasy feel good, different groups use it for various reasons in a range of settings, and evidence of addiction remains scant.

Claire Sterk, PhD, professor of behavioral sciences at Emory University’s



Social science researchers say that blunt prevention messages like this one fail to reduce ecstasy use. They advocate less extreme campaigns that users can identify with.

Rollins School of Public Health, Atlanta, Ga, would drive proponents of “Just Say No”-style campaigns crazy. “We’ll be better off having a campaign [poster] that says, ‘Ecstasy can . . . make you feel really good. It increases your sensory awareness, it makes you feel music.’ It’s okay to acknowledge that,” she said. “And then have a big comma and say, ‘But there are consequences.’”

In contrast, NIDA’s prevention campaign uses scare tactics. The oft-seen image of a brain before and after ecstasy provides a prime example. Split in half, a brain scan displays a lurid orange hemisphere on the left—the “plain

brain.” On the “brain after ecstasy” side, muted tones and a missing chunk of cortex offer vivid testimony of the drug’s propensity for destroying serotonin neurons, according to NIDA, which has distributed thousands of postcards and handouts displaying the graphic.

What the materials don’t say is that the “after” scan comes from someone who abused multiple drugs and took several hundred doses of ecstasy, a huge amount the average user will never approach (*Lancet*. 1998;352:1433-1437). “We need to stop exaggerating the negative consequences and stop using extreme cases,” said Sterk. “I’m not saying there aren’t consequences, I’m saying we don’t know what they are.”

Sterk and colleagues say that effective campaigns will take shape only after researchers come to grips with why people take ecstasy. This application of ethnography teaches that understanding springs from getting to know users. It’s a social, not clinical, approach.

Case and her team spent hundreds of hours in New York City bars and clubs, gauging drug habits in the gay community. Carlson explored the lives of young adults who took ecstasy in Ohio. And Jean Schensul, PhD, executive director of the Institute for Community Research in Hartford, Conn, tracked networks of ecstasy-involved urban teenagers.

Their conclusion: each group is driven by unique motivations. Whereas older New York City gay men may use ecstasy “as part of a posttraumatic stress response” to having “lived through the ‘death years’ of AIDS,” midwestern youth may simply be rebelling, and Hartford’s poor teens may be yearning for an escape. Targeting all of them with the same message doesn’t make sense. “We know people will continue to use,” said Sterk. “What we can do right away is come up with appropriate, targeted messages to reduce the risk.” □



# NCI to Lead Palliative Care Improvements

Brian Vastag

WASHINGTON—Saying that more patients deserve appropriate palliative care for pain, nausea, fatigue, and other debilitating symptoms, the National Cancer Policy Board is asking the federal government to lead the medical community toward a place where physicians and patients do not have to choose between “treatments with curative intents or comfort care.”

Too often, cancer research and treatment focus exclusively on trying to cure patients, with little attention paid to improving quality of life, according to *Improving Palliative Care for Cancer*, a report prepared by the board under the auspices of the Institute of Medicine and the National Research Council (available online at <http://www.nap.edu/catalog/10149.html>).

At a press conference announcing the report, which the board wants to stimulate a broad public discussion of better distress relief, the authors reeled off a litany of oversights: just 1% of the National Cancer Institute’s (NCI) \$3 billion annual budget goes to palliative care research and training; reimbursers quick to pay for chemotherapy and radiation deny palliative care items such as pain relievers and walkers; and the separation between palliative care and hospice artificially puts patients into groups that receive or do not receive appropriate symptom control based solely on life expectancy.

“Without federal leadership, we’ve been unsuccessful in convincing medical schools and care providers to take this on,” said Kathleen Foley, MD, a cancer pain specialist at Memorial Sloan-Kettering Cancer Center, New York, director of the Project on Death in America, and an editor of the report.

While the National Comprehensive Cancer Network and other groups provide guidelines for palliative care, they are rarely followed, added Foley. She gave one example from a recent survey of oncologists. Chemotherapy patients

## Patient Education Resources for Managing Cancer Pain



The National Cancer Institute, in collaborations with the Johns Hopkins Oncology Center and the American Cancer Society, has developed new patient education resources designed to teach patients with cancer as well as their families and friends about cancer pain. The materials, many of which are also available in Spanish, focus on how to evaluate and communicate about pain symptoms and provide basic information on treatment options for the management of pain.

The following new materials are available:

- *Controlling Cancer Pain* (order #V814): A 12-minute videotape that reviews causes, treatment options, and the importance of having patients discuss pain symptoms with health care professionals.
- *Understanding Cancer Pain* (#P817): A booklet, written at 2nd- to 3rd-grade reading level, that helps patients understand, assess, and communicate about pain. It includes a pain scale and a diary for monitoring and recording pain.
- *El dolor relacionado con el cáncer* (#P696): Spanish version of the above.
- *Pain Control: A Guide for People with Cancer and their Families* (#P258): A booklet, written at an 8th-grade reading level, that includes more detailed information than *Understanding Cancer Pain*.
- *Control del dolor: guía para las personas con cáncer y sus familias* (#P821): Spanish version of the above.
- Hand-held pain scale (#G818): A clinical tool to measure pain on an ongoing basis.

Additional resources include:

- *Young People with Cancer* (P#130): A booklet that discusses the most common types of childhood cancer, treatments, adverse effects, and other relevant issues when a child is diagnosed with cancer.
- NCI PDQ Cancer Information Database: The latest information on pain management is available online at [http://cancer.net.nci.nih.gov/pdq/pdq\\_supportive\\_care.shtml](http://cancer.net.nci.nih.gov/pdq/pdq_supportive_care.shtml).

The educational materials may be ordered by telephone from the NCI Cancer Information Service at (800)-4-CANCER ([800] 422-6237) or online at <http://cancer.gov/publications>. The first 20 copies are free; more information is available at (800)-4-CANCER.

—Marsha F. Goldsmith



often receive nausea-control medication during the first few days of treatment, but their chances for continuing relief drop off dramatically as the days and weeks go by. Proposed solutions include the creation of a dedicated palliative care program at the NCI, the designation of some NCI-funded cancer centers as “centers of excellence” in palliative care, new NCI-sponsored scientific meetings on the topic, and improved reimbursement—from both the public and private sectors—for symptom relief and end-of-life care.

As cancer caregivers begin to provide better palliative care, the improvements will spill over to other chronic, life-threatening illnesses, said Joanne Lynn, MD, director of the RAND Center to Improve Care of the Dying, Arlington, Va.

She added that every patient with cancer should be enrolled in a quality-of-life clinical trial. “Eventually everyone is going to have to face this” for themselves or for a loved one, said Lynn. “People are going to make palliative care a political issue.” □

## Racial Barriers May Hamper Diagnosis, Care of Patients With Alzheimer Disease

Joan Stephenson, PhD

CHICAGO—Alzheimer disease (AD) may present something of a double whammy to black Americans. Evidence suggests that elderly African Americans may be more likely than white people to receive a misdiagnosis because of racial bias inherent in at least some of the available screening tools, and even those who are given correct diagnoses face barriers that discourage them and their caregivers from obtaining needed services.

“Barriers exist to early detection of Alzheimer’s disease and acquisition of services for African Americans,” said geriatrician Vicki T. Lampley-Dallas, MD, MPH, of the University of Oklahoma Health Sciences Center in Oklahoma City, speaking here at the 10th National Alzheimer’s Disease Education Conference. Based on her analysis of published studies, she said that “African Americans stand a greater chance of being misdiagnosed and mistreated by the very people who are supposed to help them, including physicians, nursing homes, and community service providers.”

Experts agree that early recognition of AD has become increasingly impor-

tant for several reasons. Currently available drugs are useful only in the early stages of the disease, and new agents being developed are considered far more likely to arrest or slow disease progression than to reverse damage that has already occurred. Other interventions, such as adult day care programs that help support caregivers and stimulate patients, also are aimed at those with early disease.

### BIAS IN SCREENING TESTS?

Neuropsychological tests used to screen for AD often fail to detect early dementia, so pursuing the lengthy investigation that may lead to early diagnosis often depends on investigating red flags raised by the patient, a family member, or an astute primary care physician, Lampley-Dallas pointed out. The limitations of screening tests may be compounded by racial bias in some standard neuropsychological tests, such as the Mini-Mental Status Examination (MMSE), that too often result in misdiagnosis of black patients, she added.

Some researchers have found that these brief screening tests result in a disproportionate number of false-positive results in blacks, incorrectly classifying as many as 42% of black

Americans without dementia as being demented vs 6% of whites. And while some studies have found that such racial bias is eliminated when education and socioeconomic conditions are taken into account, others have found it persists even after controlling for these elements.

This situation suggests that other, unknown factors are involved, resulting in higher false-positive rates of cognitive impairment in African Americans compared with whites, noted Lampley-Dallas.

Whatever the reason, misdiagnosis can be traumatic for the patient and family, can lead to unnecessary and costly testing and inappropriate treatment, and may further undermine an already tenuous sense of trust that many blacks have in the health care system.

“The literature does seem to suggest diagnostic disparities across populations with respect to Alzheimer’s disease and that blacks tend to be overdiagnosed, particularly when the MMSE is part of the screening process,” agreed Jennie Ward Robinson, PhD, director of Medical and Scientific Affairs at the Alzheimer’s Association. “But it’s not clear where the bias lies.”

According to Lampley-Dallas, more intensive screening tools, such as the Cambridge Cognitive Examination (*Br J Psychiatry*. 1986;149:698-709), which takes 20 minutes to administer compared with the 10 minutes needed for the MMSE, may be more successful in detecting early dementia and have the potential to be less biased in their application. In the CamCog, as this “mini-neuropsychological test” is called, values range from 0 to 106 rather than 0 to 30, as in the MMSE, thus allowing for the detection of smaller differences in cognitive abilities.

The Alzheimer Association’s Robinson said she was unfamiliar with the CamCog, which was developed in Great Britain, but that she is interested in learning more about the examination and its application—particularly about whether it is useful in minority groups—because better evaluation tools are needed that are culturally sensitive and



can account for cultural, ethnic, and racial differences among individuals. “We really need to have more tests and to have more African Americans and other minorities included in large-scale population studies that will tease out small nuances and will allow us to get accurate prevalence figures,” she said.

Given the limitations of current screening tools, physicians “should consider culture and experiential differences, along with age and education, when administering these tests to any minority groups,” said Lampley-Dallas. “The good news is that there’s a lot of interest in this area and studies are being planned.”

#### UNANSWERED QUESTIONS

Getting a better handle on how AD plays out in different populations is more than an academic question. There’s a pressing need to determine whether there are differences in disease risk, incidence, and prevalence among various racial and ethnic groups, according to the National Institute on Aging’s *Progress Report on Alzheimer’s Disease, 2000*. For one thing, the proportion of older nonwhites in the US population is growing rapidly and is expected to rise from 16% to 34% between now and 2050.

In addition, differences in prevalence among racial and ethnic groups

could help researchers zero in on the roles particular genetic and environmental factors play in the development of AD. Although some studies have found evidence that the overall risk of developing the disorder is higher among African Americans and Hispanic Americans than whites, others have turned up conflicting results.

“Clearly, further careful investigation is needed to examine the role that ethnic and racial differences may play in determining the risk of [AD], and studies now ongoing should begin to provide the answers,” the report notes.

#### OTHER BARRIERS

In addition to screening tests that too often misdiagnose black patients, such factors as caregivers’ perception of covert racism or cultural insensitivity by some health care professionals and support staff has kept patients and family members from seeking needed services, explained Lampley-Dallas.

For example, participants in two focus group sessions involving 13 black caregivers of people with AD said they were insulted by automatic assumptions that they would not be able to pay for services. “This may not be so much racism as cultural ignorance or insensitivity, so cultural sensitivity training may help change this,” said Lampley-Dallas.

Some focus group participants also noted that many blacks care for a loved one through the extended family, and because they consider it a private matter, they are reluctant to share their “business” with others, particularly in an integrated setting. This reticence, and the lack of local support groups for caregivers within many minority communities, tends to reinforce the isolation of blacks caring for family members with AD.

Lampley-Dallas noted that the Alzheimer’s Association of Oklahoma is taking steps to address this situation by developing support groups in minority communities. The Oklahoma chapter also has formed a multicultural committee to ensure inclusion of multicultural issues in all new and existing programs.

In other areas of the country—Detroit, St Louis, and Los Angeles, for example—Alzheimer’s Association chapters have developed outreach efforts and are finding creative ways to address the lack of resources targeting minorities in the community and to include minorities in research efforts, said Robinson. “There is really a need for recruitment, retention, and inclusion in general of minorities in population-based studies that get at not only detection but also diagnosis and clinical trials,” said Robinson, “This is an urgent matter.” □

### MISCELLANEA MEDICA

• **Robert Hales, MD**, professor and chair of psychiatry at University of California, Davis, School of Medicine, has been appointed editor-in-chief of the books division of American Psychiatric Publishing, Inc, an adjunct of the American Psychiatric Association.

• **Richard D. deShazo, MD**, chair of the Department of Medicine at University of Mississippi School of Medicine in Jackson, is the new president of the Association of Professors of Medicine. He succeeds **D. Craig Brater, MD**, who is dean of Indiana University School of Medicine in Indianapolis. President-

elect of the APM is John B. O’Connell, MD, chair of the Department of Internal Medicine at Wayne State University School of Medicine in Detroit, Mich.

• **H. Dirk Sostman, MD**, professor and chair of radiology at Weill Medical College of Cornell University and radiologist-in-chief at New York Weill Medical Center, New York city, has been elected president of the Association of University Radiologists.

• **Mark Blum, MD**, an assistant clinical professor of medicine at the College of Medicine and Dentistry of New Jersey in Newark and a cardiologist affiliated

with several hospitals in the area, has been elected president of Mid-Atlantic Cardiology, a group practice in New Jersey.

• **Edmund C. Tramont, MD**, has been named director of the Division of AIDS in the National Institute of Allergy and Infectious Diseases, Bethesda, Md. He replaces **John Y. Killen, Jr, MD**, who has become associate director for research ethics at the same institute.

**Editor’s Note:** Miscellanea Medica appears in the Medical News & Perspectives section occasionally. Items submitted for consideration should be directed to the attention of Marsha F. Goldsmith, Editor, Medical News & Perspectives.