Unveiled

After 9/11, as Arab Americans with AIDS retreat deeper into the closet, a band of brave advocates battles to strip its community of a denial as deadly as the virus

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When Nabil was injecting drugs as a teenager in Syria, he didn't know that dirty needles could infect him with a deadly virus. But, years later, when a prospective Miami employer made him take a battery of medical tests, he says on an AIDS awareness video, "The doctor informed me I was HIV positive." Shocked and depressed, Nabil found neither sympathy nor support from his family, who now live in Amman, Jordan. His sisters were forbidden from uttering his name; his father considered him already dead. Ignorance, shame and denial about HIV were still so powerful, Nabil says, "I felt no one would propose to my sisters if they knew their older brother had AIDS." Slowly, through the help of a New York City organization called MENTORS -- Middle East Natives Testing, Orientation and Referral Service -- Nabil was eventually able to come to terms with both the virus and his shame. Eventually he volunteered, educating other Arab Americans and Muslims and fighting the notion that AIDS is not their disease.

Meanwhile, Nabil's health deteriorated. As he lay in a coma before he died in February 2001, Wahba Ghaly, a fellow Arab emigré and the founder of MENTORS, called Nabil's family. One of Nabil's sisters answered. "Please let Nabil read the Koran so that he doesn't die away from religion," was her response.

Ghaly was furious. "If anyone brought the Koran into the MENTORS office, it was Nabil," he says. He knew Nabil wanted to be remembered in a service at a mosque. So the MENTORS founder, an Egyptian Christian, approached the imam of the mosque where Nabil used to pray, asking him to include the young man in the following Friday service. But he made no mention of Nabil's cause of death because, he says, "I was afraid he might not do it if he knew," he says.

But Nabil's AIDS legacy did not vanish with his death. He had courageously agreed to share his story for the MENTORS' educational video. He was joined by three other Arabs for whom AIDS is indeed their disease: a woman infected by her husband, a daughter who watched her mother die after a bad blood transfusion and a man who cared for a dying gay Muslim couple.

As far as "putting a face on AIDS," the video presents itself as standard fare. But in fact, it is utterly exceptional. Before the closing credits, a disclaimer appears, explaining that while the four stories are based on interviews with real people, those pictured on camera are actors. This veil-of-illusion effect only intensifies when Ghaly tells me later that Nabil's story was purposely altered:

Nabil never injected drugs. He got HIV through sex with men. His real name was Fawzi, and he was a Palestinian -- not a Syrian -- run out of his hometown because of his homosexuality. “That’s why he was shunned by his family, to the end,” Ghaly says. As for full disclosure, try this: Despite weeks of inquiries nationwide, even bartering on my own background as an Arab and son of a Muslim father, the closest I get to an Arab or native-born Muslim with HIV is this single, singular video.

Arab Americans are hesitant to talk not only because I am asking about HIV, of course, but because of September 11. Pinned in the beam of U.S. mass media, lost in a vortex of visual clichés, cultural distortions and incriminating stereotypes, many American Muslims are, in a sense, terrorized. “Now more than ever, Muslims in the United States are trying to cultivate a cohesive community and a positive public image to outsiders,” Faisal Alam, who heads up Al-Fatiha, a national gay Muslim group based in Washington, DC, says. “Even under the best of circumstances, we were in denial and didn’t talk openly about AIDS. Now it’s the worst of circumstances for Muslims in America. You can’t expect AIDS to even be on the radar screen.”

According to the Arab American Institute in Washington, DC, there are approximately 3 million in America. Most are Lebanese, Palestinian, Egyptian, Iraqi or Syrian, and live in Los Angeles, New York and north New Jersey, or metropolitan Detroit. Slightly more than half, contrary to popular belief, are Christian. HIV education targeting this diverse population has to be not only in Arabic and English but sensitive to traditionally conservative cultural and religious norms. The difficulties are multiplied by the fact that prevention must also take care to reach Arab youth, who are at greatest risk for HIV and, while more assimilated than many adults, are making life decisions amid conflicting cultural values and messages.

Although awareness about HIV in the Arab-American community is low, social service workers and peer educators acknowledge, so is the level of HIV infection. Arab-American AIDS activists would, of course, like to keep it that way -- by making more educational videos, say, and more sophisticated prevention. But all that requires money, money requires a proven need, and a proven need requires numbers, but funders don’t see any. This Catch-22 remains a source of endless frustration, and no one abhors the numbers game more -- or understands its dangers better -- than Wahba Ghaly, MENTORS’ executive director.

Ghaly is a pioneer of HIV education in the Arab world. He first began talking publicly about AIDS in Cairo in 1993, when there was still official denial that HIV even existed in Egypt. He won grants to travel to the U.S. to learn how to set up an AIDS outreach program. Predictably, establishing what is now the Center for HIV and AIDS Prevention in Cairo took immense effort. “If I tried to address HIV the same way American agencies do -- if I said, ’My message is condoms and safer sex,’ anywhere I went -- I’d be told, ’Get out!’” he says. Such a direct approach would have alienated just about anyone in Arab society, with its staunchly conservative rules on drugs and sex. Still, he says, he found people “hungry for information.” Today, the center’s staff of 13 psychologists and psychiatrists has documented some 350 cases of HIV, which, Ghaly notes humorously, is the now the government’s official tally (UN estimates put Egypt’s total caseload at 8,100 in 1999.)

Moving to New York City in 1998, Ghaly was struck by a different brand of denial among American AIDS experts. "In my training sessions, whenever the word *minority* was used, it would mean only blacks or Latinos," he says. "I repeatedly asked about AIDS in the Muslim and Arab communities [in the U.S.], and every time, I was told the same thing: 'It's insignificant.'"

That Arabs constitute a specific risk group with specific needs is an argument Ghaly has labored hard to justify. It also led him to establish MENTORS. Last year in metropolitan Detroit, home of the second-largest Arab community in the U.S., the Arab Community Center for Economic and Social Services (ACCESS) applied for state money to fund HIV prevention and counseling. But ACCESS was unable to provide the required statistical data. Because Arabs have been classified as, alternately, whites, blacks or "other," statistics on Arabs, much less Arabs with HIV, are as elusive here as in Egypt. But as Asyah Ali, the HIV prevention coordinator at ACCESS, says, "I know there are Arabs with AIDS because I've held their hands and watched them die at hospitals."

The only statistical data Ali can point to is a review of names that "sound Arabic," conducted by Detroit's AIDS surveillance department. At Ali's prodding, the city agreed to a confidential search of its database, which yielded 32 cases -- nine HIV positive, 23 with an official AIDS diagnosis. "Those numbers are low," Ali says. "It's a paradox. Our goal is to keep the numbers low. But we can't get the money we need to ensure they stay that way until the numbers rise."

While ACCESS didn't get the AIDS education money it needed last year, it did win a smaller grant to conduct a study. But again, the need for knowledge was pre-empted by the funder's priorities: In spite of rising HIV stats among youth and women, the study had to target the population the state deemed at highest risk: men who have sex with men. With no expertise or contacts in the gay community, ACCESS approached the Midwest AIDS Prevention Project (MAPP) for help. MAPP volunteers hit the bars, called up friends and passed out fliers at Detroit's Pride celebration, says MAPP Executive Director Craig Covey.

Eight men, all Middle Easterners, attended a focus group. They ranged in age from 19 to 52. Seven said they had been tested for HIV, all negative. Four reported using condoms, three "on occasion," and one never because he was in a monogamous relationship with a negative partner. Seven out of the eight men thought their personal risk of HIV infection was "very low or nonexistent." Not surprisingly, most of the men were "out" only to a select group of friends -- but not to their families or on their jobs. Some told horror stories about being rejected by their families for being gay. But only one -- the youngest -- felt his religion as a Muslim was a personal burden. "I'm going against God and I know I'm going to hell," he said in anguish.

While emphasizing that it is difficult to draw conclusions from such a small sample, Covey said the experience clarified that the men were "definitely a neglected group. They're neglected by the gay community, they're neglected by the traditional AIDS agencies and they're neglected by other Muslims."

At MENTORS, considerable measures are taken to tailor HIV education to suit Muslim sensitivities. Ghaly and his team of three employees -- all women, one each from Morocco, Palestine and Yemen

-- comb local mosques, approaching imams for permission to conduct their seminars for congregation members. In deference to Islam's traditional separation of the sexes, men talk to men about sex and HIV, and women to women. The male workshops are held at the mosques, while women prefer smaller groups in private settings, usually someone's home, says Najat Dahbi, a 32-year-old Casablanca-born outreach worker with a law degree from Hassan II University. Though Dahbi doesn't normally cover her head, she does don a scarf, or *hijab*, when she goes to a mosque. "Initially, I find there is big denial," Dahbi says. "The response is, 'We are *Muslim* women -- we behave well, so we don't need to address this.' But then I tell them that HIV doesn't discriminate. I talk about their children growing up in American culture. That grabs their attention." Dahbi won't single out Islam for head-in-the-sand attitudes. "Sometimes I think there's even worse denial among Arab Christians."

The cornerstone of the MENTORS program is an AIDS information book that cites specific Koran verses promoting good health and personal responsibility. The geometric patterns and fanciful arches that define Islamic architecture cover the book's front and back jacket. Inside, the 148 pages of Arabic touch on everything from male and female anatomy to instructions for a self-examination of the breast. There are also graphic diagrams, such as one detailing how to put a condom on an erect penis -- ho-hum for a typical AIDS agency, but brave, bordering on shocking, for a conservative Arab and Muslim audience. "I've had imams ask me why I'm trying to poison the brains of Muslim people," Ghaly says without smiling. "Others try to censor parts of our presentation."

Still, even the intrepid Ghaly yields to certain limits, such as sex outside of marriage. "I'm forced to give the message in a way that is palatable," he says. "So we talk about protection within marriage." But he points to an old adage in Arabic that, roughly translated, says: "Anyone with two ears can listen." He clings to this motto, hoping that his listeners apply the knowledge he provides as needed.

The same strategy of pushing and yielding is ingrained among staff at suburban Detroit's Arab-American and Chaldean Council (ACC), which has launched an after-school HIV education pilot program for Arab-American youth, ages 9 to 17. Severe restrictions prevail. For example, the program not only can't give out condoms, but it "has to market the abstinence approach," says Amani Younis, ACC's director of health services. "If we were seen as promoting sexual activity, the parents wouldn't allow their children to participate at all. At least this way, we're giving them the basic information." But the topics of drug use and homosexuality remain unspoken.

"We know we have IV-drug users and gay men in the community," says Monther Fakhouri, an ACC health consultant. "But the culture of shame and family honor is fierce. It keeps everyone who is positive in the closet. We really need someone with the virus to come forward and talk openly to shatter the notion that this doesn't happen here. But I'm afraid we're 10 years away from that. Right now, we have to take baby steps."

If prevention activists in Arab and Muslim communities have always needed sensitivity and delicacy, in the wake of 9/11 they need greater reserves of patience than ever. The aftershocks

have cast a pall over HIV-prevention efforts. At ACCESS, for example, Asyah Ali called off a meeting with local imams to strategize over her hard-won HIV data. “Muslim leaders had other more pressing things on their minds,” she says.

In New York City, MENTORS’ Ghaly has suspended new outreach, although he continues to serve current clients. “Some of our clients have been questioned by the FBI,” he says. Worried that in its vast “national security” sweep of Arabs and Muslims, the U.S. government may try to seize the MENTORS’ files as a way to locate suspects to interview, Ghaly has hidden confidential files, downloaded HIV information on individuals onto disks and safeguarded them. Though he can’t predict when he will be able to resume outreach, Ghaly is sure of one thing: Muslims with HIV as well as those at risk are going to be harder to reach than ever. “September 11 has added new layers of fear and isolation for them,” he says.
