

PRAYER | Minister lives as exception to AIDS community's mantra — 'Every dose, every day'

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impaired my judgment, I had sleep problems, I was always tired."

He was tired of feeling sick. Lawary's choice is at the center of a scientific controversy in research labs and medical clinics across America over the effectiveness of these so-called "drug holidays" that AIDS patients are embarking on for days, weeks, even months at a time.

The idea is to give people a chance to allow their minds and bodies to recover from the toxic side effects of the three- and four-drug "cocktails" that target the enzymes HIV needs to invade the immune system and replicate.

These drug cocktails can result in a long list of side effects, forcing AIDS patients to take dozens more pills a day to control depression, liver damage, nausea and other symptoms.

People who take these drug holidays almost always return to their medications, though, when their immune systems grow too weak.

So far, Lawary hasn't gone back. How long he can stay off the drugs is anyone's guess.

Either way, he was committed to making the most of the days ahead.

"We are all given a certain amount of time," he said. "I'm just going to ride it until the wheels fall off."

Life of contradictions

Lawary is a walking contradiction.

He is an AIDS educator and co-chairman of the Ryan White Title 1 Planning Council for St. Louis — the group that serves as the main pipeline of federal dollars for AIDS support and treatment in the 12-county area that includes Madison and St. Clair counties. In this position, Lawary is the face of the AIDS establishment.

But he also is violating the mantra of the AIDS community, which is "every dose, every day," by quitting the drugs that suppress the spread of HIV inside him.

"So I have broken every rule," said Lawary, who also serves as program director of the Harambee Youth Empowerment Center in St. Louis, which counsels young people on how to deal with AIDS.

Lawary has been upfront about disclosing his medical condition. It has often been the centerpiece of his sermons.

Perhaps most strikingly, Lawary is a living rebuke of the standard model of how AIDS affects the immune system.

Usually people with AIDS grow sicker the longer they stay



ZIA NIZAMI/News-Democrat

Harold Lawary holds on to his older sister, Lula Dorsey, after he admitted himself to Barnes-Jewish Hospital in St. Louis after feeling chest pains. Later, Lawary finds out he has diabetes.

off the medications that suppress the virus. That's because the virus, in the absence of anti-retroviral drugs, can multiply rampantly — in the process killing off more and more of the crucial CD4 cells that alert the white blood cells and the cells that make antibodies to repel foreign invaders.

But the opposite has been true for Lawary. It's no mystery to him.

"I'm strong in my faith," he said. "I'm strong in the fact that if my system takes a turn for the worse, so be it."

Lawary said he doesn't push his way on others.

"I tell them it's a personal choice," he said. "What works for me maybe doesn't work for you. I don't encourage them, nor do I discourage them."

Lawary has always been open about his decision to quit his drugs, said Monica McDaniel-Collins, an AIDS educator in St. Louis who serves with Lawary on the Ryan White planning council.

McDaniel-Collins described Lawary as "energetic and stubborn" and called him an advocate for people with HIV and AIDS.

"He believes in what he believes in," she said, "and he stands for it."

The Rev. O.V. Carter, pastor of New Macedonia Missionary Baptist Church, where Lawary

serves as an associate pastor, has little doubt what motivates Lawary.

"The need, the need, the need," Carter said. "He don't want people to get caught like he did."

'A competent witness for Christ'

On a Sunday afternoon in August, in a small church in East St. Louis, Lawary rose from his seat beside five other ministers and walked to the lectern of the Ira Grove Free Will Baptist Church, 1701 Belmont Ave.

He wore a white shirt, tan jacket and tan trousers; a white gardenia jutted through a buttonhole in his left lapel.

Ceiling fans whirred above him while worshippers used folded sheets of paper to fan themselves in the heat.

Lawary paged through his Bible, then set it down and looked outward upon narrow white pews where about 80 people had gathered in the cramped church for an event billed as the sixth annual Gospel Explosion.

"In order for one to become a competent witness for Christ, a couple things must happen," Lawary said. "One is, is that they have to be called, or have to have an experience with Christ. Another is they have to know that only Christ took them through that situation."

Lawary began reading from

the Gospel of St. Matthew.

He stopped. "You see, Matthew was a tax collector for the Roman government. His job was not to only collect the taxes that was due, but to get a little bit on the side, too," he said. "Matthew had a scam going on. He deceived the people time and time and time again."

"All right!" a man shouted. "All right!"

A woman applauded, then two others, then more. The applause grew louder, more fevered, along with the cheers. A young man played a guitar while another pounded at a drum set.

"You see, it was 21 years ago that my own situation, that I had to go through my experience with Christ. And that experience led me to today," Lawary said.

"There was a time when I thought I was being a witness for Satan, when all I was doing was becoming a competent witness for Christ."

His shoulders trembled, like a man pulling against a great weight.

"A competent witness for Christ!"

Fists tightened at his sides, he narrowed his eyes into slits and hunched his body over.

"A competent witness for Christ!"

"A competent witness for Christ!"

Divine intervention

Lawary gives credit for his continued good health to his large extended family of brothers and sisters.

"They've embraced me," he said.

Two decades ago, his family accepted the news that Lawary was HIV positive with some misgiving, said Lula Dorsey, his older sister by three years.

"You know, it was this new disease that came about and it was quoted as a 'gay disease,'" Dorsey said. "And then it was like there was no cure. My sisters had a thing about using the same glasses and using the same utensils and things like that, and so did I."

Dorsey got over her fears through an exercise of "mind over matter," she said. As for her brother's survival, Dorsey called it a matter of divine intervention.

"The AIDS that he has, I don't believe that was put on him to take him away. I truly believe that was put on him as testimony, to show the world you can beat this."

'He was going to live'

Lawary is also quick to credit his physician, Dr. Darren Wethers, an internist with an office in Clayton, Mo.

"There are people who, once they hear they have HIV, start to train themselves to die, instead

of trying to live," Wethers said. "He was going to live."

Although Wethers today supports Lawary's decision to quit his medications, that wasn't always the case.

"It's not like he hasn't ever recommended a med regimen for me," Lawary said. "It's not like he never warned me of the dangers of not taking the meds. No, it's like he has painted a pretty cold picture. But by the same token, that the choice is mine."

Wethers cautioned that Lawary's choice might not be the right one for others living with AIDS.

"HIV is an interesting illness in that no two people respond the same way to the same challenge," Wethers said. "We don't entirely understand all the parameters that govern who does well and who does poorly with respect to HIV."

One of the mysteries surrounding AIDS concerns a class of patients known as "long-term nonprogressors," who, for unknown reasons, never show the symptoms of full-blown AIDS. Former NBA superstar Magic Johnson is among them. Lawary may be, too.

"A good healthy lifestyle, no alcohol or drug use, a good diet, a strong faith life, support of family — these things are invaluable," Wethers said. "That's not to say that everyone will have that experience. But for these individuals it has been enough."

A hard life

A few hours after the Gospel Explosion ended, Lawary drove his car from the church to a quiet street on the northwest corner of East St. Louis, a few blocks from the boundary line with Washington Park.

He parked along the gravel shoulder, stepped out and started walking.

Most of the neighborhood where he grew up has long since vanished. Vacant, grass-covered lots have, over the past three decades, replaced the houses that once surrounded Lawary's childhood home.

"This was a peaceful street," Lawary said. "This street had so much laughter and playing. Every house in this neighborhood had kids."

The seventh child of 13, Lawary is the son of an East St. Louis man who never acknowledged him as his own.

He and his many siblings were raised by their mother, Carol Jean Lawary, who provided them with all the basics, plus lots of love and laughter.

But it was a hard life. Lawary remembers how his mother's

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AIDS patients take holidays to get relief from drugs

By MIKE FITZGERALD
mfitzgerald@bnd.com

Drug holidays are all the rage in the AIDS community.

These structured treatment interruptions, as researchers call them, are designed to cut costs and help people with AIDS handle the toxic side effects of their anti-AIDS drugs.

The controversial practice has doctors and researchers stymied.

Scientists presented 20 research papers on structured treatment interruptions in July during the World AIDS Conference in Bangkok, Thailand.

In one yearlong study in Boston, 23 HIV-positive men took their meds for five days, then took weekends off. The result was that they all kept the virus under control, according to Dr. Calvin Cohen, director of research, Community Research Initiative of New England.

Another study found it feasible to treat HIV-infected patients with a different regimen of anti-HIV drugs. The drugs were given in cycles of seven days on, seven days off.

But a study of long-term

drug holidays, in which a handful of patients took part in anti-retroviral therapy for eight weeks, followed by four weeks off, led to an unacceptable rate of viral resistance.

Still, drug holidays are gaining momentum, said Monica McDaniel-Collins, who lives with AIDS and who recently finished a drug holiday of her own.

"In the last couple years it's been a big trend," she said.

The benefits of such breaks are both psychological and physical, said McDaniel-Collins, an AIDS educator

and a member of the St. Louis Ryan White Title 1 Planning Council.

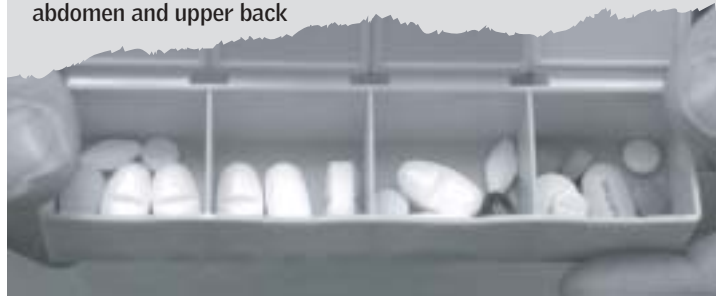
"It helped me mentally," she said, "because taking meds every single day is a reminder every single day that you're HIV positive. It's in your face all the time, and that's part of the psychosocial issues of HIV."

The growing trend of patients rejecting their AIDS medications stands in contrast to the euphoric mood of 1996. That's when AIDS researchers unveiled some of the first successes they had achieved with a new class of drugs called protease inhibitors.

Toxic side effects of AIDS drug cocktails

Side effects can include:

- Severe diarrhea, nausea and vomiting
- High cholesterol counts resulting in heart disease
- Liver failure
- Severe pancreatitis
- Muscle spasms, back and joint pain, fatigue, difficulty sleeping and bizarre nightmares
- Lipid dystrophy — a vexing condition that plays havoc with the distribution of fat in the patient's body; wasting occurs in the face, arms and legs, but big deposits of fat build up in the abdomen and upper back



ZIA NIZAMI/JIM MOELLER/News-Democrat

These drugs, taken in combination with drugs already on the market, worked by disrupting the life cycle of the AIDS virus. Their impact was stunning.

In 1995, AIDS killed 50,000 Americans. By 1999, however, the death toll fell to about 16,000.

But the side effects of these three- and four-drug "cocktails" can include severe diarrhea and nausea, high cholesterol counts resulting in heart disease, bizarre nightmares and a vexing condition known as lipid dystrophy, which plays havoc with the distribution of fat in the patient's body. Wasting oc-

curs in the face, arms and legs, but big deposits of fat build up in the abdomen and upper back.

As a result, many AIDS patients take dozens more pills every day just to try to offset the side effects.

The side effects have led to a common syndrome known as "treatment fatigue," in which patients quit their medications on their own because of drug-related toxicity.

But such a step is risky because doing so could enable the AIDS virus inside their cells to develop a resistance to future drugs, said Dr. Elizabeth Laffey, a physician in Belleville whose

practice handles more than 70 people with HIV and AIDS.

Antiretroviral drugs work by attacking the life cycle of the AIDS virus by zapping the enzymes the virus needs to attach to CD4 cells and to reproduce, Laffey explained.

"So the problem with the medications is that they have to get into your cells and affect only those enzymes that only HIV has attacked exclusively," she said. "While the medications are certainly hard to take, the alternative is continuing to get sicker and sicker."

Until now, doctors have preached that the long-term consequences of not taking the AIDS drugs outweigh any discomfort today.

But, the benefits of treatment interruptions for carefully selected patients continues to be closely monitored, said Dr. Jeff Kirchner, a family practice physician in Lancaster, Pa., who who recommends drug holidays for some of his AIDS patients.

For starters, their CD4 counts — the measure of critical sentry cells within a patient's immune system — must be at least 400 to take part. That's twice the number for a diagnosis of full-blown AIDS.

"We recite, 'Every dose, every day; every dose, every day,' to our patients, and then coming back in the next room saying, 'Hey, do you want to stop for a month?'" he said. "I'm sure the patients are scratching their heads, saying, 'What the hell is he talking about?'"

HIV life cycle

How the virus reproduces

Binding
Virus attaches to a CD4 cell (binds to it and injects its genes into it)

CD4 cell
The CD4 cells are the sentry cells that help the immune system counterattack invaders

Fusion
Viral and cell membranes fuse. To reproduce, the cell uses the

viral DNA like a template. Genes and proteins are copied using the cell's own machinery and raw materials.

Assembly and spread
Once the bacterium is assembled, the cell wall ruptures allowing new viral particles to spread and infect other cells.

Drug cocktails combine medications to interrupt the HIV life cycle
Antiretroviral drugs attack the life cycle of the AIDS virus by zapping the enzymes the virus needs, stopping the virus from attaching to CD4 cells.

Source: U.S. Centers for Disease Control and Prevention

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