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Breaking the Silence: Examining Personal Preparedness for Supporting Students Living with HIV/AIDS

Christopher Purcell

Often, when an article is written, it implies a certain level of expertise on the part of the author. I do not know if one can ever be an expert on supporting friends, family members, and students living with or affected by HIV/AIDS. This article is not a declaration of finite practices of being an ally to these individuals. Rather, it draws from personal reflection, public health research, and student affairs theory to make sense of a personal journey where HIV/AIDS has touched nearly every aspect of my life: family, friends, colleagues, and students. This article asks the reader to examine their personal connections, experiences, perceptions and biases of students living with HIV/AIDS, particularly those who are newly diagnosed, in order to be better prepared and informed friends, colleagues, and student affairs practitioners to those living with the disease.

When my friend told me he was HIV-positive, I could see fear dripping from his shaking lips. His eyes were wide and subdued, and in them I could see a reluctant acceptance of a destiny he could no longer control. The unspoken fear of every gay man's mother had turned into a reality. I couldn't even imagine what he must be holding in his heart. He knew what I was thinking immediately when he saw my face. He always knows exactly what I'm thinking. "I used a condom, I always use a condom," he said. I felt guilty and ashamed immediately. So conditioned to hearing the stories of men who "do not like the feeling" of condoms, I was quick to push upon him this narrative of irresponsibility. But this did not fit that narrative. This was one man, putting his fate in his partner's hands. While it had been the condom that broke, I could not help but think what had really broken was the promise of being "disease free" they had made before their encounter. I hugged him closer than I ever had before to let him know that I was not afraid, but as this was happening a selfish moment was revealing itself in my mind. It could have been me. What if it was? Would I tell my friends or partners? Or would I just bide in silence, shame, and guilt? Would I tell my mother and hope that any sign of acceptance would

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escape her lips while disappointment lingered in her eyes and heart? I released my hug and sat down to begin what would be a long conversation.

If such conversations regarding the HIV are difficult amongst friends, imagine how difficult it could be to have conversations regarding HIV status with students. Are student affairs professionals truly ready for the challenge of responding to a student who discloses they are HIV-positive? Typically the testing social support services for students with HIV, assuming they have them, would be situated in the health services offices on college campuses. However, the challenges of living with HIV affect many other aspects of students' lives. The premise of this article is not that student affairs practitioners should take the place of or interfere with the jobs of healthcare workers. Rather, drawing upon public health research, limited student affairs research on HIV-positive students, and personal reflection, this article seeks to better prepare student affairs professionals for working with students affected by HIV. Student affairs professionals must not only have adequate knowledge of the disease and its implications but must also be prepared for status disclosure from students. By working through our fears and biases, we can strive to be more compassionate, understanding, and supportive professionals and more compassionate, understanding beings.

Knowing More

HIV is the virus that causes AIDS. HIV-disease (encompassing all HIV infection regardless of AIDS diagnosis) is a disease of the immune system, which progressively weakens the body's ability to fend off infections. Though there is no cure for the virus currently, there are treatments for both HIV infection and for many of the opportunistic infections that may arise from complications resulting from a compromised immune system. As of 2007, 33 million people in the world were estimated to be living with HIV/AIDS (UNAIDS Report [Joint United Nations Programme on HIV/AIDS]/World Health Organization, 2009). In the United States, there are an estimated 1.2 million individuals living with HIV/AIDS (Centers for Disease Control and Prevention, 2009).

Of the individuals infected with HIV, the Centers for Disease Control and Prevention (CDC) report that men who have sex with men (MSM) represent the largest proportion (45%). However, MSM are not the only ones affected by the disease. Those infected through heterosexual sexual activity make up 27% of infections in the United States. Additionally, individuals infected through injection drug use make up 22% of those living with HIV and those who are both MSM and use injection drugs make up approximately 5% of reported new infections in 2007 (Centers for Disease Control and Prevention, 2009).

A closer look at statistics revealed that the rates of women, people of color,

and young people contracting HIV are increasing at an alarming pace. In 1992, women accounted for 14% of people living with AIDS; in 2004, that percentage had increased to over 23%. In 2004, the rate of new AIDS diagnoses for African American adults and adolescents was 10 times the rate for White individuals. Latinos comprise only 14% of the nation's population (including Puerto Ricans) but 19% of all AIDS cases. In addition, it is estimated that half of all new HIV infections are believed to occur in people under the age of 25 (Centers for Disease Control and Prevention, 2009).

Given this data, the discrepancy between actual and perceived risk is shocking. Among a traditional student population (18-24 years old, full-time enrollment), respondents said they believe AIDS is a "very serious" or "serious" problem for college students. However, only about half of these students expressed personal concern about becoming infected with HIV (Opt, Loffredo, Knowles, & Fletcher, 2000). Such a discrepancy regarding personal risk should be alarming to us as educators as we seek to inform students about the prevalence and seriousness of HIV/AIDS.

Student Development Theory and the HIV-positive Student Experience

He walked into my office and looked exhausted. "Out late last night?" I asked. "Yes," he said. He closed my door and sat down. "Actually...I'm having trouble... dealing... I'm [HIV] positive, and it is all so new... I do not know what to think or how to act." I knew this student was working through many things in his life: racial identity, sexual orientation, his life goals and ambitions, drugs, and relationships. After all he had told me in his frequent visits to my office, I did not think a new story or life plot twist could phase me. This time I was stunned. I just listened for a while as he told me about being diagnosed, having to contact his past partners (and not remembering some). He told me about his initial appointments with the doctor and how he was going to attend support groups.

He had clearly done quite a bit of life reflection since his diagnosis. He did not even want to think about telling family yet. He was open to telling friends, but knew that "people talk." He acknowledged he used drugs to escape his problems, but was afraid of what he might do when under the influence. He knew he would have to tell every partner, and wondered aloud if it was even worth it "just to have a hook up." "And I will have to use condoms now," a statement which jolted me further into disbelief. After he talked for a while he paused and waited for my response. "You know I am here for you, no matter what, and I will do all I can to help, but it sounds like you know you are going to need a network of support here, so what are your next steps?"

In a qualitative study of HIV-positive college students, students reported feelings of intense loneliness, isolation, anger, anxiety, and fear (Bower & Collins, 2000). An examination of these results in the context of transition theory (Evans, For-

ney, & Guido-DiBrito, 1998) provides insight into the complexity of the newly diagnosed student's transition. Schlossberg (1995) named four factors that determine an individual's effectiveness in coping with any transitional period: situation, self, support, and strategies (as cited in Evans et al.). Consider, for instance, the first two indicators of ability to cope with transition: *situation* and *self*. The permanence, timing, and life changes make the situation of being HIV-positive seem daunting. The factors related to *self* revolve around perceptions, outlook, and optimism about life. Students may report having little optimism or positive outlook on their situation (Bower & Collins, 2000).

Students with HIV struggle daily. They suffer from the physical and emotional burden of dealing with HIV. Coping with a diagnosis and the changes this disease precipitates is both physically and mentally exhausting. The students interviewed complained that they have little energy to grow intellectually or to interact with students outside the classroom. (Bower & Collins, p.441)

Support is the third determinant to a student's ability to cope with transition. Specifically, family units, networks of friends, institutions, and communities are mentioned as four systems of (social) support (Evans et al., 1998). In order to receive social support, individuals must make the difficult choice to disclose their status. "Unfortunately, the potential for rejection, abandonment, physical and emotional abuse, and other adverse consequences creates substantial barriers to disclosing HIV status" (Kalichman, Kalichman, O'Connell, Freedman, Eaton, & Cain, 2007, p. 260).

Our job is to help students find networks of *support* that will help the whole student: physically, emotionally, and spiritually. Assisting students to develop *strategies* (the fourth determinant) that "aid in managing the stress in the aftermath" may be particularly helpful for coping with transition (Evans et al., 1998, p. 115). Strategies should include: focusing on the student's physical, mental, and spiritual well-being, and should channel on-campus and community resources.

While transition theory is one way to examine the HIV-positive college experience, Bower and Collins (2000) explained this experience in the context of Kohlberg's moral development theory:

Because they must deal with a life threatening illness, these students are forced to confront a number of emotional, physical, and moral issues that do not challenge other students their age. They had developed a clearer appreciation for individual rights and responsibilities, personal standards, justice, and reciprocity. (p. 434)

Although students with HIV may develop an increased capacity to examine seri-

ous moral issues as defined by Kohlberg's (1976) theory, students with HIV were found to struggle with *managing emotions* and *finding purpose*, two of Chickering's (1979) development tasks, or vectors (as cited in Bower & Collins, 2000). Models of racial and sexual identity are also of important consideration. Developmental models for lesbian, gay, bisexual, or transgender (LGBT) students and students of color typically involve a stage of exploration and immersion in their community, such as identity pride in the model of homosexual development (Evans et al., 1998). Such progression through particular stages might be contingent upon the perception of how accepting a community is of people living with HIV, and whether or not they feel comfortable being honest about their status within identity-based support systems. Continuing to understand the complexities of the HIV-positive student experience will serve us well as a profession, but it must be coupled with a better self-understanding of our relationship with HIV/AIDS and how it affects us personally.

Examining Personal Bias and HIV-Negative Privilege

When my uncle's partner (who at the time I thought was just his friend) passed away, I did not know why. It was never explained to me until I watched the television program "The Real World: San Francisco." Pedro Zamora was a cast member, and he had AIDS. Pedro was young, gay, and dying. He lived every day like it was his last. Pedro's presence on television had a profound effect on me: he humanized the disease. In another way, he also helped to perpetuate the thought that as a gay man I was almost certainly doomed to get AIDS and meet a similar fate. It was just another reason to remain closeted (and fearful). It took me a long time to move past the fear. Every new experience talking with someone or reading something about HIV peels away a small layer of fear and anxiety about the disease and the people who have it. My uncle is now in a relationship with his second long-term partner—both were HIV-positive when he met them. If this is not inspiration to overcome fear for the sake of love, I do not know what is.

There are potentially many influences on our individual perceptions and views of HIV/AIDS and society. Portrayals of HIV-positive individuals in movies, media, and popular culture, as well as having a friend or family member living with the disease may impact our view. In addition to external influences, our individual perceptions may also be linked to misinformation, fear, and misconceptions. Furthermore, any particular experiences with but one or two individuals living with HIV will fail to represent the diversity of experiences of HIV-positive persons.

Student affairs professionals could very well be members of communities that experience a greater burden of HIV (not to mention, may be HIV-positive themselves). This could affect how they may engage with this issue. For some, their experiences with HIV will be inseparable from their identity. In addition, disclosure of HIV status from a student could lead to personal reflection on the part of the

professional. They may consider their own HIV status, their last testing date, and how they might cope with an HIV-positive diagnosis. Professionals who are HIV-negative must also examine the privileges they have that an HIV-positive student may not, and remember that they may be working with HIV-positive students on a daily basis—and may never know it.

Consider the following lists of privileges that are enjoyed by an HIV-negative individual that are not afforded to HIV-positive persons. HIV-negative individuals can engage in sexual intimacy without thinking about potentially infecting their partner. They do not have to negotiate when the right time is to disclose their status to potential intimate partners. They do not have to worry that they could be “outed” (i.e. having others learn about their HIV status through means other than the student disclosing), which could affect friendships, social perceptions, and realities, family relationships, and dating. Professionally, HIV-negative individuals may pursue careers or personal interests without having to think about disclosure to coworkers and supervisors. They will not have to talk about their HIV status with their employers as it concerns taking time off for proper care and in cases of emergency. They also may not have to consider being rejected by loved ones or stigma from mental or medical health professionals.

In essence, there may be goals that will be difficult for HIV-positive individuals to achieve, and others that will be possible only through encouragement and reassurance from support systems. As is the case in all instances of privilege and power, awareness of these differences is essential to understanding the HIV-positive student’s experience. As we examine our personal relationship with the disease and help students understand their own experiences and biases, we can begin to have the crucial conversations that can promote understanding and encourage acceptance.

Understanding Your Capabilities and Limitations

I still do not think there is any sort of “skill” to master when it comes to supporting HIV-positive students. I do, however, know what I cannot do: position myself as an expert or as someone that could ever fully understand what that student is going through. I see myself going back to the foundational principles of student affairs: challenge and support. I try to be prepared to talk about whatever the student has going on that day. Most of the time it is schoolwork, friendships, relationships, and life ambitions. Most times their concerns may not be HIV-related, though sometimes it is more directly about their HIV status. When it is, I am always open to listening. I ask where the student is finding support. When they are not fully utilizing campus or community resources, I challenge them to be self-advocates. We look together for alternative support resources. Sometimes I can see I said the right thing by the look on a student’s face—sometimes I do not know what to say.

After each conversation, I think about what I have just told the student. I ask myself, did I make assumptions? Did privilege affect how I spoke with the student? Sometimes I make mistakes. There are times I have cried. There are days where I have had to find my own networks of support. I often call my colleagues in health promotions, student health, and counseling and psychological services for advice, as I know they are the real experts and the primary caregivers. No, I am not perfect. But I know that I am looking internally at myself as well as externally at the student's needs. As I continue to do both, I know I am doing good work.

Student affairs practitioners must do more than serve as distributors of safe sex supplies and co-sponsors of awareness days, although both activities are helpful in raising awareness about HIV and may serve as a necessary first step toward prevention. Student affairs professionals have to be equal partners with campus health services by serving as educators about the prevalence and implications of HIV. In addition to providing proactive education, professionals must understand the many challenges of being HIV-positive in the college environment in order to respond to those students living with HIV. While it may not be possible for us to know and fully understand all of the support services available for students, we must be insatiable seekers of knowledge for our students and ourselves. Acquiring HIV may be the manifestation of larger underlying issues. Therefore, we must be prepared to find our students the resources and strength to tackle these related issues. We have to get past our own fear and judgment, and be present with the students in their struggles.

The institutional battles in supporting HIV-positive students will be daunting. They will need physical, emotional, and spiritual support from administrative units and individuals across campus and some will be uninformed or reluctant to engage. We must prepare ourselves first, and we will be ready for the long road ahead. Our students are finding the strength to confide in us; we in turn must find the strength within ourselves to assist them.

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