

## Special Issue Focuses on the LGBT Health

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## From the Editor

Sue Wintz

#### **LGBT** Issues in Health Care

Twenty years ago, in the hospital where I worked at the time, part of my responsibilities included working in partnership with the county health department to provide spiritual care to persons living with HIV and AIDS. I ran a support group, functioned as the lead in providing chaplaincy care to persons when they were hospitalized, and was involved in community outreach and education programs.

I remember how the LGBT community met me tentatively at first. Many revealed to me that due to past experiences they were fearful about how I would interact with them. Story after story was shared with me about encounters that had been disrespectful, judgmental, and dismissive, especially when they interacted with the health care system. Before long, I was being called when someone was on the way to being admitted to the hospital. I was viewed as the "safe person, the guardian who will stand up for us."

There were several occasions when I confronted less-than-respectful care from the hospital staff. I'll never forget the afternoon when one of the AIDS patients was admitted to the hospital directly from his doctor's office. As sick as he was, he called me as soon as he got to his room. When I went up, I found that the nurse hadn't entered the room. She stood at the door asking his admission questions. She tossed a gown towards the bed, telling him to change. When I asked her why she wasn't helping him, she said that she didn't want to get close to him: "I think he deserved what he got."

I wish I could say that we've come a long way in healthcare in the ways that we treat LGBT persons – and in some ways we have. But there is still much to be done. I can recall not too long ago when I ran across staff in a trauma room making comments and laughing about a patient's transgender dress as well as the family waiting anxiously outside for information.

June is nationally proclaimed as Lesbian, Gay, Bisexual, and Transgender Pride Month. It is a time for each one of us to eliminate prejudice everywhere it exists, and to celebrate the great diversity of those we encounter not only personally, but as part of our professional work.

Each of us as professionals can contribute to improving the care of LGBT patients, encouraging a LGBT workforce, and supporting LGBT chaplain colleagues. Because of the importance of these topics, this issue of PlainViews has been designated as Open Access with the hope that it will bring information, resources, and dialogue to a wide audience. Share this issue with others and help raise the bar.

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#### Some of the topics being sought for upcoming issues of *PlainViews*:

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My *PlainViews* colleagues and I hope that you find this special sample issue of interest and encourage you to subscribe at this link: http://plainviews.healthcarechaplaincy.org/.

Sue Wintz, MDiv, BCC Managing Editor

Susan K. Wintz. BCC



## Offering Pastoral Care to LGBT Patients and Families

Last year, NYU Langone Medical Center decided to pursue <u>Leadership Status in the Healthcare Equality Index (HEI)</u> administered by the Human Rights Campaign. A key component to the HEI is comprehensive staff education. We took a variety of paths toward this goal, including bringing an expert (<u>Shane Snowden</u>) to speak around the campus. We also designed smaller in-services for various workgroups. The following is adapted from one such in-service.

So here's the scenario: you walk into a room in pediatrics where you know there is a critically ill infant. The nurses have told you that the family could use some support. Wishing only to support this family, you knock and enter the room to find two young men leaning by the side of the crib. Both are teary and red-faced. Introducing yourself, you try to identify who is in the room. One of the men says, "I'm Michael, and this is Andrew. We're Mia's parents." Your brain misses a step.

Comprehension dawning, you hear your mouth saying, "You're...? Ooooooh..." Your face turns red, your anxiety starts to rise, and you start planning your exit strategy.

Unfortunately, your reaction is probably very familiar to Michael and Andrew, the fictional parents in that story. But consider this: because of your discomfort, your visit shifted from being an opportunity for you to offer support to a family in crisis to being about their sexual orientation.

And this is not an insignificant point because most of the LGBT patients and families you will encounter will not be seeking your support because of their sexual orientation or gender identity. The vast majority of LGBT patients and families will be, like Michael and Andrew, seeking your support because their family is experiencing a medical crisis. That is not to suggest that a person's sexual orientation or gender identity is immaterial to the pastoral encounter. On the contrary, an LGBT patient or family member likely has a certain amount of anxiety upon meeting a chaplain: will he accept me? Will she be willing to pray with me? Will I find support in this encounter, or condemnation? Can I talk about the grief I'm experiencing, or will we have to talk about my sexuality?

So, if like most chaplains, you want to provide hospitality and good care to LGBT patients and families, what can you do to gain cultural competency?

#### Learn the Language.

People are often intimidated by the "Alphabet Soup" of sexuality and gender identity. L, G, B, T, Q, I, A...do you know what those stand for? Know your resources; know who you can ask when you hear a word that confuses you. (See my article, Alphabet Soup: Learning the Language, elsewhere in this issue.)

#### Listen for Self-Identification.

There are countless words that LGBT people use to self-identify, and they have deeply-held

reasons for choosing the words they do. The point is not to argue or insist upon the most accurate term. If the woman you meet describes herself as "gay," do not argue that she should refer to herself as a "lesbian." Likewise, if the couple you meet refer to one another as "housemates," do not push them to use any other word. Respect their use of the title "housemates," and use it in your conversations.

### Look for Invisible People.

Perhaps you've been called to support the family of an elderly man who has just died. In the room, you find children and grandchildren, all grieving and supporting one another. On your way in, however, you noticed another young woman halfway down the hall, sitting alone, weeping. You ask her if she'd like to go into the room with the rest of her family. "Oh, I'm not really family," she replies. "That's my partner's grandfather." Your compassion to that woman, your attention to her experience of grief – disenfranchised grief – is a critical pastoral care intervention. It may not be your place to force that family to allow this woman in, but through your actions, your presence, the words of your prayers, you can acknowledge her grief, and validate her experience rather than adding to her sense of exclusion.

#### **Use Open Language.**

Rather than asking the 86-year-old man if his wife will be able to visit, ask him about his loved ones. Rather than asking the seven-year-old girl about her mom and dad, ask her about her parents, or her family. General terms such as "loved one," "significant other," "spouse," "family," or "parents" allow people to provide their own details, and self-disclose as they feel comfortable.

So what about Michael, Andrew, and little Mia? How do you provide culturally-competent pastoral care to their family? Imagine that you encounter them shortly after having read this issue of PlainViews. You're painfully aware of the challenges facing LGBT families in the healthcare world. Though surprised to encounter two dads in Mia's room, you don't let your anxiety overwhelm you. With a moment to recover, you remind yourself that Michael and Andrew, like all the other parents on your peds unit, are worried about their child. You listen to their fears and their hopes. In your prayers, you express gratitude for the love you see in their family. As you build rapport, you ask Michael and Andrew whether they've been treated with compassion within the hospital, and are pleased to hear that they have felt nothing but acceptance. As a matter of fact, they tell you, when a chaplain knocked on their door, they were a little afraid, having both experienced painful rejection by their faith communities. Your presence with them was a gift – a moment of comfort in the midst of a devastating crisis. And that, after all, is what we strive do with every patient, and for every family.



Holly Gaudette is the staff chaplain at NYU Langone Medical Center, where she serves as a member of the LGBT Advisory Council, an interdisciplinary workgroup devoted to advancing institutional cultural competency for LGBT patients, families, and staff members, throughout the institution.

# Healthcare Equality Index: A Road Map Toward Equity and Inclusion

LGBT inclusion is a key element of the Diversity and Inclusion strategy for Christiana Care Health System. We have used the Healthcare Equality Index (HEI) published by the Human Rights Campaign Foundation as our "road map" in our journey. Shane Snowden, HEI National Advisory Council and Director of the University of California at San Francisco Center for LGBT Health and Equity, says "at UCSF, we've found the HEI invaluable in extending a knowledgeable, sensitive welcome to our LGBT patients. It's functioned as kind of road map, pointing us to where we need to go." The HEI is an annual survey of policies and practices related to lesbian, gay, bisexual and transgender patients, their families and the healthcare workforce. Healthcare systems are rated on four key policy areas: patient non-discrimination, visitation, employment non-discrimination, and cultural competency training (the "core four").

As Tom Sullivan, Human Rights Campaign Foundation Deputy Director says, "The HEI was specially designed to give facilities reality-tested tools for increasing LGBT equity and inclusion. The "Core Four" criteria for "Leader" status on the HEI incorporate the LGBT-related requirements of the Center for Medicaid and Medicare Services (CMS) and The Joint Commission and supplement them to ensure LGBT patient-centered care."

#### The HEI Core Four

- 1. Same-sex partner visitation policy: yes for CMS, TJC, and HEI
- 2. Patient non-discrimination policy: yes for TJC and HEI
- 3. Employee non-discrimination policy: yes for HEI only
- 4. LGBT patient-family centered care training: yes for HEI only

One of the reasons why it has been helpful for Christiana Care to use the HEI as a tool is because some of the primary researchers/writers of the HEI were key advisors to The Joint Commission in the excellent resource they published in the fall of 2011, <u>Advancing Effective Communication</u>, <u>Cultural Competence</u>, and <u>Patient- and Family-Centered Care for the Lesbian</u>, <u>Gay</u>, <u>Bisexual</u>, and <u>Transgender (LGBT) Community</u>.

Utilizing the HEI allowed Christiana Care to "get ahead of the curve" in preparation for key changes that came about with the Joint Commission and the regulations on visitation rights that the CMS instituted last year. As part of my involvement in the Diversity and Inclusion Council I volunteered to help guide our system to review, revise/rewrite, institute new policies, and develop education/training in a proactive approach to providing the most culturally competent patient-centered care to LGBT patients and families as possible. This involved calling together key stakeholders from accreditation, legal, nursing, human resources, patient relations, registration/admitting, organizational development, and senior leadership to work on the various components of the HEI. I found willing partners in Human Resources, Patient Relations, Accreditation, Nursing and System Learning to help steer the broader process.

Having LGBT inclusive policies in place is necessary and is a basic stepping stone to the provision of best care. The second tier of the approach was to simultaneously incorporate education on LGBT healthcare concerns in a variety of venues already in place and to create new opportunities for learning to occur. Examples include:

- Incorporating information about best practices and rights of non-married couples in advance directive planning during nurse orientation so that nurses can be patient advocates for couples (same sex and different sex) lacking this legal protection;
- Incorporating role based examples utilizing LGBT scenarios in a comprehensive interactive emodule education on cultural competency;
- Developing targeted role based training focused on particular diversity dimensions in 60-minute experiential "cultural labs" concentrating on culture/religion, language and LGBT based scenarios. The labs have allowed small groups time to explore instances of inclusion within their department from a patient/customer frame of reference. Participants have been able to explore the resources they already possess within their team while learning about other system resources available. These labs have been facilitated by chaplains and educators from our system learning department.
- An hour-long interactive and multi-media curriculum titled LGBT Considerations in Healthcare was developed utilizing resources from the <u>National LGBT Cancer Network</u>, the <u>Healthcare Equality Index</u>, <u>USCF Center for LGBT Health and Equity</u>, <u>The Fenway Institute</u> among others. A version of this curriculum with transgender issues highlighted has also been developed because of an assessed need to increase understanding of the particular barriers to healthcare that transgender people face.
- In 2011 Delaware passed Civil Union legislation which changed the healthcare legal landscape for same-sex couples with a civil union. Beginning on January 1, 2012 a same sex couple with a civil union in Delaware has the same legal healthcare surrogacy decision making rights as a married heterosexual spouse. Along with our corporate counsel and patient relations manager, we developed the education plan for employees and medical-dental staff so that they were prepared for this change in surrogacy healthcare decision making in Delaware.

In all of the these efforts I have only encountered people from every level of the healthcare system eager to learn and understand more so that we can provide the best care possible to a culturally diverse patient population that includes LGBT patients and families.

What is called for is someone able to pull together system stakeholders ready to take a hospital/system to the next level of inclusion and cultural competency. Board Certified Chaplains are ideally qualified to carry out this endeavor. I would be very happy to share resources, ideas, and examples of polices we have developed and discovered to assist as you work in your own healthcare system to provide LGBT patient and family centered care and inclusion.

#### **Selected Resources:**

Human Rights Campaign (Healthcare Equality Index) www.hrc.org (Issues drop down menu, Health)

The Joint Commission's Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide <a href="https://www.jointcommission.org/lgbt/">www.jointcommission.org/lgbt/</a>

National LGBT Cancer Network

UCSF's Center for LGBT Health & Equity

<u>The Fenway Institute</u> (Learning Modules under Training drop down menu)



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Katy Allen and Vera O'Brien

## **Touching Lives: The Voices of Two Chaplains**

The experience of supporting LBGT patients and families is in some ways universal for all chaplains, and in some ways differs for those of us who also self-identify as LGBT. Some of the questions that go through our minds are the same, but the answers may be different. Other questions may be different. Here are the voices of two chaplains – one lesbian and one straight – at the Brigham and Women's Hospital in Boston, an acute care institution.

**Katy asks:** As we go through the CPE process, one of the topics of discussion is self-revelation in our encounters with patients. How much do we tell about ourselves? When do we say something personal? How do we answer personal questions?

In the case of a chaplain with an LGBT sexual orientation, the question holds a special level of acuity. Identifying our sexual orientation could, with some patients, suddenly change the tone of the visit and make it impossible to provide quality spiritual care. But there is another side to this question, as well, which came home to me after a series of visits with a gay couple.

The patients were newborn twins, born to a surrogate mother here in the United States. The parents-to-be were gay Israelis, part of a community with a large population of children under the age of three, the result of the booming use of surrogate mothers outside the country. An unexpected early delivery brought these tiny babies into the Newborn ICU while the two new dads were still on a plane flying across the Atlantic.

I became involved with the parents after a referral from the NICU chaplain. The babies were far enough along that there was little worry about their ability to survive, and the two new dads were like kids in a candy shop, filled with smiles and delight and sheer joy. After more than a decade of being together, they were incredibly happy to have children. I immediately loved them both.

The love and joy the two men expressed spread to anyone who came into contact with them, including this Jewish chaplain. One of the dads enjoyed speaking Hebrew with me. Both were delighted when I said a traditional prayer of healing for the babies in Hebrew. Both expressed genuine pleasure at seeing me each time I returned.

These two men had a tenuous connection with a liberal synagogue in Israel, of which there are a small but slowly growing number as secular Israelis in search of a spiritual life seek out a place of comfort religiously. Here in the United States, where liberal Judaism is more firmly entrenched, these two new dads received the unexpected added dimension of comfortable spiritual care, in addition to the first-rate medical care the babies were receiving.

On my last visit only one of the fathers was present. He was preparing to take the second baby, who was about to be discharged, to their hotel. At the end of our time together, as I turned away, I saw a tear slip from the father's eye. I was so glad that I had never told them that my life partner is of the same sex! I was so glad that they just knew the rabbi as someone who welcomed them as human beings and fathers and Jews and treated them with love and caring without asking questions, and with no other agenda than to provide the best possible spiritual and religious care. I was so glad I had just provided spiritual care, and not a personal agenda.

Before leaving the country, the grateful new parents presented the NICU team with a framed thank-you and pictures of themselves and the babies: "Thank you for taking care of us, helping us to accomplish our development. Now that we are mature, healthy, and strong enough for life, we are ready to go home to Israel."

These babies received first-class care, and so did their dads.

**Vera asks additional questions**: How does a straight chaplain best serve LGBT patients? When is it appropriate to ask about or acknowledge sexual orientation?

At 6 A.M., on my pre-op rounds, I was asked to see a patient whose anxiety level was leading her to try to rip her IV's out of her arms. She was terrified of going into the OR. I introduced myself to her and to the woman who accompanied her. She described her faith tradition as pagan and I could see her watching carefully for my reaction. I told her I was a Unitarian Universalist and that nature was central to my own spirituality. She was delighted to find that the hospital had a Unitarian Universalist chaplain, and it distracted her from tearing out her

IV's--at least temporarily. When the anesthesiologist arrived, her anxiety increased dramatically again. When he left, I felt as though we were back to square one.

During the initial part of the visit I had a growing sense that they were more than friends and debated whether to acknowledge their relationship. What if I was wrong? How would my question be received? For whose benefit would I be asking the question? A multitude of questions went through my mind. Finally, I let go of the debate in my head, trusted my intuition, and took a risk that changed everything. I simply asked how long they had been together. It turned out that they had been one of the first same gender couples legally married in Massachusetts and had been married by a Unitarian Universalist minister. She needed to have this surgery so they could go on their honeymoon in Europe. Hiking together in Europe was a dream they had shared for a long time. Her anxiety had led her to cancel the surgery and the honeymoon once already. As they spoke about their relationship, and as I named the love I saw between them, she relaxed and reconnected with her wife and the reasons to go ahead with this surgery. I offered a blessing for healing and in celebration of their relationship and she proceeded to have the surgery.

When I dropped by after the surgery to check in on her, she told me how shocked she was that the hospital was so supportive of both her paganism and her marriage. I told her what a privilege it had been to meet them, to hear their story, and to be their chaplain that morning.

On another occasion, I had the privilege of performing a wedding ceremony for two young women in our chapel. One was the daughter of a patient who was awaiting a heart transplant. The efforts of the staff at the hospital to make this wedding special for this family made me so proud to work at the Brigham. Most often the weddings at which we officiate are for seriously ill or dying patients. It was a great joy to marry these two young women who had met in college, had been devoted to each other for several years, and had life not death immediately ahead of them. They had cancelled a large wedding in another state that they had been planning for over a year because it was more important to them that our patient be there than to have a big wedding. As patient's nurses heard about their plans, the wedding went from a simple ceremony in the patient's room to a service in the chapel with medical staff to support the patient, flowers, and a photographer. A lovely reception attended by the wedding guests, and hospital staff followed back on the patient's floor.

While there have been many same sex weddings at the Brigham, this was the first such wedding in our chapel and it was featured in our in-house publications and there were video clips on our internal website. I lost count of how many people contacted me because they heard or read about the wedding. I am pleased to report that 100% of the people who contacted me were delighted that the hospital had supported these young women and this patient on such a special day.

Katy and Vera conclude: We don't always get it right. We have a long way to go in our efforts to honor the inherent worth and dignity of each and every patient and employee. But as Richard Gilbert says, at least sometimes we feel that "We meet on holy ground, for that place is holy where lives touch, love moves, hope stirs." (Richard Gilbert, In the Holy Quiet of this Hour, Boston: Skinner House Books, p. 16.)



Rev. Vera O'Brien is a Staff Chaplain at Brigham and Women's Hospital in Boston. She is a Board Certified Chaplain through the Association of Professional Chaplains and is a Unitarian Universalist Minister. She is an Affiliated Minister at the Arlington Street Church in Boston where she was ordained.



Rabbi Katy Z. Allen is a staff chaplain at the Brigham and Women's Hospital in Boston where she is currently switching from a general medical floor to an oncology floor. She is a Board Certified Chaplain through the National Association of Jewish Chaplains and received her ordination from the Academy for Jewish Religion. In her spare time she serves as the rabbi if Ma'yan Tikvah - A Wellspring of Hope in Wayland, MA, where she is building a Nature Chaplaincy program.

Cindi Knox

## When a Transgender Person Is in the Hospital

Transgender persons face unique challenges in health care: they may be concerned about discrimination, and they have medical histories that include pharmacological and surgical treatments with which caregivers may be unfamiliar. Chaplains have a unique opportunity for ministry that mediates these issues.

The umbrella term "transgender" refers to people who self-identify many ways. People whose sex assigned at birth was male, but who identify as women, may identify as transgender women, transsexual women, or transwomen, though some (especially after having sex reassignment surgery) may identify as women, or as women of transsexual experience or history. The reverse is true for transgender and transsexual men, or transmen. Persons who wear clothing usually associated with the opposite sex may call themselves crossdressers or (less frequently) transgenderists.

In addition, there are people who might appear to be transgender but do not identify themselves that way. Women who identify as butch or butch Lesbian may wear clothing and use mannerisms often associated with men, but identify as women. People who feel they have two genders may call themselves bi-gendered or co-gendered. Others who don't identify as male or female may consider themselves androgynous or agendered. These people are sometimes considered under the broader term "gender variant".

In all cases, chaplains should see people – beloved creations of God – first. Each person deserves respect and dignity, and access to appropriate care.

Transgender and gender variant people can have special needs in healthcare settings. One such need is treatment specific to their bodies and medical histories.

There are differences between the bodies of persons born male and born female. For example, persons born male generally have greater lung capacity, which can affect peak flow readings taken for asthma and COPD patients to the degree that a serious problem may be mistaken as a minor one.

In cases where treatment for men and women is the same, the patient's birth sex may not be an issue. If, however, the patient does not report all medications, interactions may occur. Hormone replacement therapy is used to develop secondary sexual characteristics such as voice changes, facial hair and musculature in transgender men, and breasts in transgender women. These hormones can increase susceptibility to various conditions, as well as interact with medications. Transgender women may take a testosterone suppressant such as spironolactone, which lowers blood pressure, spares potassium, and is a diuretic.

Finally, transgender persons may have had surgeries to masculinize or feminize their appearance. A physician may need this information to determine how to treat the patient. These are merely illustrations, and not intended to be definitive medical implications. It is sufficient for chaplains to recognize that there are health issues associated with gender transition.

It may seem obvious that doctors need to know what medications patients are taking, and what surgeries they have had. But for transgender people, disclosing medical history is not simple. There are cases where they have been denied health care because they were transgender.

Tyra Hunter was seriously injured in an automobile collision in which she was a passenger. When the EMTs cut away her clothing in determining the extent of her injuries, they discovered she had male genitals and stopped treating her. They made fun of her, while she gasped for breath on the pavement, until a supervisor arrived and ordered them to resume care. Tyra died in the hospital. (Feinberg, 2001)

Robert Eads transitioned to living as male late in life. When he went to the emergency department complaining of abdominal pain, he was diagnosed with ovarian cancer. In his search for treatment, he was rejected over 20 times before finding gynecological care for his cancer, which was by then end stage. (Davis, 2001)

After Erin Vaught coughed up a cup of blood, she and her wife went to the emergency department. The nurse asked Erin's wife, "Is it a he, a she, or a he-she?" After the nurse decided "it is a he", she informed them that they couldn't treat Erin because of her condition – that condition being transsexual. (Kinsey, 2010)

The space between disclosure for proper care and anxiety over discrimination presents an opportunity for ministry: chaplains can be advocates for the proper recognition and treatment of transgender and gender-variant people. There are several obstacles, however, to such ministry.

First, identification of transgender people is difficult. Not all people who at first appear to be transgender are, and many transgender people do not appear to be transgender. Asking a person "Are you transgender?" will likely offend both transgender and non-transgender persons. Second, because some clergy condemn transgender persons, there may be some hesitance to trust a chaplain.

In cases where a transgender patient confides in a chaplain who understands issues of transgender persons, the chaplain can offer support for the patient. Using appropriate pronouns (and asking the patient if the chaplain is unsure what the patient prefers) and respecting the gender and sexual identity of the patient's significant other help to testify to the sensitivity of the chaplain. If the patient trusts the chaplain to be an advocate, the patient is more likely to disclose full medical history, increasing the likelihood of a positive outcome.

Another issue in treatment of transgender people is in communication with the patient's family, friends, and place of employment. A transgender person early in the process of transitioning may still be known by birth name and sex to some people. If transition was completed long ago, many contacts may not be aware that the person is transgender. When possible, chaplains should ask how the patient would like to be identified to their contacts.

A hospital that develops a reputation for respecting patients may find an increase in transgender and gender-variant patients: an opportunity to serve people in need. A chaplain who ministers to transgender and gender-variant people testifies to God's love for all people.

For more information on care for transgender people, and a glossary of terms, see <u>Gender Variance 101 for Hospital Chaplains</u>, which is found <u>here</u>.

Footnotes: Davis, K., Director. Southern Comfort [Documentary]. 2001, New Video Group. Feinberg, L. "Trans health crisis: For us it's life or death" in American Journal of Public Health, 91(6), 897–900, 2001.

Kinsey, M. "Transsexual woman claims she was mistreated by BMH staff" in The Star Press, July 20, 2010



Cindi Knox is a woman of transsexual history; a member in Discernment in the Fox Valley Association, Illinois Conference, United Church of Christ; an MDiv student at Chicago Theological Seminary; and a CPE student at Advocate Good Samaritan Hospital in Downer's Grove, IL.

## Concerns and Resources for Ministering to LGBT Patients and Families

It was a typical spring night. Just warm enough for bikers to get their motorcycles out of winter storage and go for a ride. So it wasn't much of a surprise when a motorcycle accident was brought by helicopter to my hospital, a level one trauma center. The gentleman did not have many injuries; so the trip was more precautionary than necessary.

As he was wheeled into the room, I saw a middle-aged man with a grizzly beard, and a Harley Davidson jacket and t-shirt, including the beer gut, a typical biker wearing his leathers. Yet as he was moved from the gurney to the hospital bed, the helicopter nurse turned to me and said, "He's wearing panty hose. Sorry, I just had to tell someone." Under his jeans, which had been torn open to treat him, he was indeed wearing pantyhose. The trauma surgeon noticed and clarified that the helicopter crew had not placed them on him.

As he was further undressed, it turned out he was wearing a bra and a feminine hygiene product. There was much laughing and joking over this man's choice of attire. Whether or not he was LGBT I will never know (I didn't ask) but whatever his sexuality, his choice of dress caused much laughter and derision amongst the staff.

Lesbian, gay, bisexual, and transgender patients (LGBT) come into our hospitals and nursing homes each and every day. We may not know it, they may not say, they may not want us to know, but they are our patients, whether we want them or not. Whether we understand their needs or not, they present themselves to us, as patients, parents, loved ones, and friends.

A woman in her 40s was dying in the oncology ward. Present were her roommate, who had the Durable Power of Attorney for Healthcare, and her family. Nursing staff was nice to the roommate but deferred to the family, giving them the space and privacy desired. As I met with the family and the roommate, it turned out the roommate was really the partner of 15 years. They had never told their families they were together and now it was too late. The roommate did not tell the staff for fear of the treatment she or the patient might receive and fear they may tell the family. So the partner was left behind, labeled just a roommate, not given the time or space she desired.

#### **Fear of Bias**

Unfortunately many patients and families do not tell staff of their relationships for fear of the negative treatment they may receive. Or, if there are other family members present, partners may not disclose their relationship status in order to avoid fights and disagreements.

These fears are valid. Numerous studies have documented both fears and experiences of LGBT patients. These include refusal of treatment, laughter, joking and embarrassment of providers, as well as detachment and shock. Some patients have endured lectures on morality and the non-natural behavior of being LGBT. Another study reported that LGBT patients experienced infliction of pain, unconcern, neglect, and exams that are "rough," "brutal," or "violent." LGBT patients are more likely to be scolded, treated hostilely, patronized, categorized as "difficult," and provided fewer explanations.

A study in 1994 showed 91 percent of physicians and medical student members of the American Association of Physicians for Human Rights reported knowledge of anti-gay bias directed toward patients. Sixty-seven percent reported knowledge of LGBT patients who have received substandard care or been denied care due to their sexuality. Even The Joint Commission in its recent publication Advancing Effective Communication, Cultural Competence, and Patient and Family Centered Care found that LGBT patients are subject to health disparities, as well as "refusal of care, delayed or substandard care, mistreatment ... little or no inclusion in health outreach or education, and inappropriate restrictions or limits on visitation."

Why do LGBT patients receive substandard care as well as brutal or rough treatment? It can be said to be a combination of ignorance, being uncomfortable with the unknown, sexism, homophobia, and a religious or cultural bias. As was the case with the unfortunate gentlemen on the motorcycle, when faced with different expressions of sexuality some folks turn to laughter and derision. Others turn to their faith or cultural understandings, which can condemn those who are homosexual or transgender.

So how do we as chaplains minister to these "friends" and "roommates"? What motivates a chaplain to provide care? As chaplains we come from religious traditions that have a basis in believing human life is sacred, and all individuals' possess dignity and worth. Also, most religions have a basis in hospitality, offering help to the stranger. In addition to our religious mandate to care for others the standards of the Association of Professional Chaplains (APC) affirm the dignity and worth of individuals, and inclusivity and diversity are foundational values in pastoral service. The APC standards state that "members shall treat all persons with dignity and respect" as well as stating that members "shall serve all persons" without discriminating based on religion, faith, group, race, ethnicity, sexual orientation, gender, age, or disability. Finally, chaplains subscribe to the idea of holistic care, providing care for the whole body, the mind, soul and physical. Within that idea of holistic care is care that is patient and family centered.

#### **Called to Support and Advocate**

Thus, chaplains are called to support and advocate for all patients. With LGBT patients and families this may include being aware of concerns, fears about treatments, providing support for patient and "family of choice" as well as biological family, being aware of stereotypes, jokes, derogatory statements, being aware of non traditional families and having a wider definition of family, and being willing to educate staff and call out staff for inappropriate statements.

Chaplains should make sure, when addressing patients, to use the chosen or preferred name and/or gender. Finally, because there is a higher percentage of criminal behavior, drug abuse, sex work, and homelessness among LGBT patients, especially patients who identify as transgender, chaplains should be willing to support without judgment, and meet the patient where the patient is, despite our possible discomfort with their situation or choices.

Chaplains can also advocate for increased information on and use of Durable Power of Attorney for Healthcare, for information and education to and for staff on issues of sexual orientation and gender identity, for a wider definition of family, for non-discrimination statements that would protect patients and families who identify as LGBT, and for issues

related to transgender patients and the use of the name and gender preferred by the patient.

Before addressing resources that can be of use for chaplains, as well as other health care professionals, other issues of concern for LGBT patients need to be addressed. These include lack of respect for LGBT families, such as refusal to allow partners to visit, and preference for biological families despite valid DPOA's being presented at time of admission. Also, there can be stronger requirements to prove the legitimacy of families, such as a request for birth certificates or adoption papers, request for DPOA's, living wills, or marriage/commitment/civil union certificates. Heterosexual couples are usually not asked or required to show proof of marriage or proof of parenthood when visiting hospitalized spouses or children. Yet, same sex families may be asked to produce such evidence in order to be part of the care for their loved ones.

The Joint Commission, in its newly published Advancing Effective Communication, advocates for partners, if married, to be given the same rights as other married couples even if the state does not recognize same sex marriage, noting the importance of including same sex partners as part of the patient's care. The Joint Commission also advocates for both same sex parents be involved in the care of their child, even if both do not have legal custody. Finally, it is worth mentioning that in April of 2010, President Obama issued a memorandum that ensures hospitals respect all Advanced Directive and DPOA's and proxies are honored for all patients.

Three resources that can help educate and inform chaplains and other medical staff are:

- The Institute of Medicine's (IOM) <u>The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding</u>, published in 2011
- The previously referenced The Joint Commission's <u>Advancing Effective Communication</u>, <u>Cultural Competence</u>, and <u>Patient- and Family-Centered Care</u>: A <u>Roadmap for Hospitals</u>, published in 2010, and
- The Joint Commission's <u>Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide published in 2011.</u>

The Health of Lesbian, Gay, Bisexual, and Transgender People is a compilation of information about health issues and specific concerns for LGBT patients and includes information focusing on differing ages and specific concerns in those stages of life. It gives a good general foundation of the issues and concerns facing LGBT patients and families.

The Joint Commission's <u>Roadmap</u> uses concepts from the fields of communication, cultural competency, and patient- and family-centered care to improve performance, train staff, inform policy, and evaluate compliance with relevant laws, regulations, and standards. It is a good resource for addressing cultural competency, and effective communication for all patients.

<u>The Field Guide</u> looks at specific issues of concern for LGBT patients set forth in the Road Map and compiles strategies, practice examples, resources, and testimonials designed to assist hospital staff in improving quality of care by enhancing their efforts to provide care that is more welcoming, safe and inclusive of LGBT patients and families.

Looking back on that spring night, I wish I had not gotten caught up in the laughter, and had spoken out. The unfortunate gentlemen riding his motorcycle had not planned on ending up in

a hospital, had not planned for anyone to know his secret, yet there he was undressed for the world to see and laugh. As his chaplain, I failed him. But with the knowledge now available to chaplains from The Joint Commission and the IOM, may we not fail any other patients, families or staff.

Rev Tanya J Denley, BCC is an ordained Minister of Word and Sacrament for the PC(USA) and until recently worked at Advocate Lutheran General Hospital in Park Ridge, IL. She has a MA in Bioethics from Loyola University Chicago and wrote her Masters Thesis on LGBT Health. She can be contacted at tjdenley@gmail.com

Holly Gaudette

## **Alphabet Soup: Learning the Language**

Providing culturally competent care to LGBT patients and families is not just about learning a bunch of new words. That said, language is powerful. As chaplains, we know the power of words, and you can be sure that our LGBT patients and families are paying careful attention to ours. When you encounter a LGBT patient or family member in your role as a hospital chaplain, one thing is for certain: they are experiencing a stressful and tumultuous moment in their lives. Whether they are grieving the impending death of a loved one or celebrating the birth of a new baby, you are encountering them at a very vulnerable and critical time. Knowing what words to use (and not use), and having some familiarity with the words when you hear them, can be an offering of hospitality – a way of quickly communicating that your presence can be a safe and supportive one.

#### The "Technical" Terms

(Note: these are words of self-identification, so you should never quarrel with someone's choice of terms to define themselves. There is no right or wrong. Always follow their lead and mirror their language choices.)

**Bisexual**: or "bi," is an adjective used to describe a person who may be attracted to a man or a woman

**Gay**: an adjective sometimes used broadly ("gay folks," "the gay community") to describe anyone whose primary sexual and emotional attraction is toward those of the same gender; alternatively, used as an adjective ("a gay man") to describe a man whose primary sexual attraction is toward men

**Gender**: a culturally-defined set of attitudes, feelings, and behaviors associated with a person's biological sex

Gender Expression: external characteristics (behavior, appearance, personality) that are

culturally defined as either masculine or feminine

**Gender Identity**: a person's own innate sense of being male or female

**Heterosexual**: a term for people whose primary sexual and emotional attraction is toward those of the opposite gender

**Intersex**: a broad term used to describe a person whose biological characteristics do not fit typical definitions of male or female

**Lesbian**: a woman whose primary sexual and emotional attraction is toward women

**LGBT:** An acronym for the terms Lesbian, Gay, Bisexual, and Transgender. It's often used as an adjective ("the LGBT community") to serve as an umbrella term for a group of people that is diverse in respect to gender identity and/or sexual orientation. Sometimes you will see other letters added to the acronym such as Q (Queer/Questioning), I (Intersex), or A (Ally).

**Queer**: when used to self-identify, this is a broad, non-specific adjective for people who do not conform to gender or sexual norms

**Questioning**: a person (typically an adolescent) who is wondering about his or her sexual orientation or gender identity

**Sexual Orientation**: the term for a person's physical and emotional attraction (gay, lesbian, and bisexual are all terms that refer to a person's sexual orientation)

**Transgender**: an adjective used to indicate that a person's gender identity or expression differs from their sex assigned at birth

**Transsexual**: a somewhat clinical term used to describe a person who seeks therapies (hormones, surgery, etc.) in order to live as a member of the gender with which they identify

## **Grammar/Usage**

- Many of the terms above are adjectives, not nouns, and it is important that they are used appropriately. For instance, you should say "a gay man," not "a gay." And you should say, "a transgender person," not "a transgender." Remember, these words describe something about a person, they do not categorize.
- Use of these terms varies widely generationally, geographically, and culturally. Not everyone in a same-gender relationship would identify themselves as gay. Not everyone whose innate sense of gender differs from their sex assigned at birth identifies as transgender. Some embrace words like queer, while others feel they are derogatory. Never argue a person's self-identification.
- You will note the absence of the term homosexual from the list above. Most gay people today do not use this term to self-identify. Gay is preferable, if you need a broad term.
- There are many derogatory terms that hopefully you do not need to be told not to use. You

should be aware also that some seemingly benign terms carry negative connotations, and you should therefore not use them. For instance, you should use sexual orientation, rather than sexual preference, or lifestyle choice (as these phrases suggest that being gay is a simple matter of choice or preference). Similarly, you should use gender affirmation surgery rather than sex change (as the process is one of aligning external characteristics with internal identification, not deciding to be something different).

#### **Important Words and Concepts**

Research has shown that LGBT families "scan" new environments to assess whether they are likely to be accepted, and gauge how much personal information to reveal. Upon arriving at your hospital, and with each new staff encounter, LGBT patients and families will be listening for key words that will indicate the person's acceptance and cultural competence. Knowing these concepts, and being able to use these terms comfortably will send a clear message that you are willing to offer care.

**Ally:** Allies are non-LGBT people who support, accept, affirm, and advocate on behalf of LGBT people. If your hospital is affiliated with a university, it may have a specific training program for how to be a good ally (often called Safe Zone training – see below for more).

**Closet(ed):** When an LGBT person intentionally hides their sexual orientation or gender identity, they are said to be "in the closet." This dynamic of hiding and revealing is a constant part of life. A person may be "closeted" at work, but not with friends. A person might be closeted with certain friends of family members, but not others. This is a dynamic that members of the healthcare team must be sensitive to, as it may be critically important for a patient's physician to know his or her sexual orientation or gender identity, but it is not your place to share that information.

Coming out: the process of claiming and revealing one's sexual orientation or gender identity. It is important to note that this is not a one-time event. LGBT people may speak of "coming out to myself" (the internal process of self-realization), which is often a very tumultuous and difficult time. However, every new encounter is an opportunity to come out or not. And every time a person chooses to come out, there is risk involved. Consider how many staff people enter a patient's room in your hospital. Consider how many times a day a partner at the bedside is asked, "and you are...?" This can be exhausting and stressful for a family in the midst of an already stressful situation. Remember that there are many, many valid reasons a person may choose not to come out to you, despite your hospitality and acceptance. Respect their choice.

**Domestic Partnership**: a legal option available to same-sex couples in some states where marriage is not an option. In some states, domestic partners have the same decision-making abilities as spouses, in medical circumstances . You can be sure that LGBT patients and families in your hospital will be anxious about their right to visit and (if need be) make decisions on behalf of their partners. You can extend hospitality by familiarizing yourself with the laws of your state.

**Family:** for many LGBT families, this is a deeply important and many-faceted concept.

1. Using the word "family" to describe your patient and his partner or the lesbian moms of your peds patient communicates that you understand that they are one another's support system.

Use it in your conversations ("tell me about your family,"), in your prayers ("be with this family,"), and in your reports to the rest of the healthcare team ("I met with him and his family this morning,") as a way of extending hospitality.

- 2. In a hospital setting, remember that "family" is patient-defined, and may not be based on biological relationships. LGBT patients may have strained relationships with some biological family members, but close friends who are their primary support system. In a health crisis, it may be these non-biological family members who the patient wants at his or her bedside. (Sometimes people will distinguish between their Family of Origin and Family of Choice).
- 3. "Family" is also sometimes used as a subtle way for someone to identify themselves as LGBT, particularly to another LGBT person. For instance, a gay man and his partner found themselves in the emergency room one night. Hesitant about the reaction they would receive, his partner initially introduced himself as the patient's "friend." He reached for his partner's hand when they were alone in the room, but at that moment, the nurse returned. He quickly withdrew his hand, but the nurse stopped him saying, "Don't worry, I'm family." The patient and his partner understood that the nurse was also gay, and felt comfortable being out with her.

**Healthcare Proxy**: a critical document for LGBT families. In states where domestic partnerships, civil unions, or gay marriage is not an option, Healthcare Proxy forms may be the only way partners have of assuring access to their loved one when they are hospitalized. You can be an important advocate for your LGBT patients by ensuring their healthcare proxy forms are placed in their chart.

**Partner**: one of dozens of terms an LGBT couple may use to refer to one another. It is also a generic, non-specific term, similar to "significant other," so a patient who indicates that he has a partner may not be referring to a man. Using this word rather than "husband or wife" in language, on forms, and signs is an important gesture of inclusion and hospitality. For instance, on the door of the Labor and Delivery unit, the visiting hours sign at our hospital say, "Partners, 24 hours. Grandparents, siblings, and friends, 9am-9pm."

**Safe**: whether a setting or person will be accepting of an LGBT person/family. If an LGBT patient of family feels comfortable with you, they may ask you whether the hospital or a particular staff person is "safe." They're trying to decide if they should come out to that person, or if it's okay for them to be out in that place. Inclusive language, signs, and images all help send a message that a place is safe. Also, if your hospital is associated with a university, there may be a formal program where spaces can be designated as Safe Zones.

Is learning these terms all you need to do to provide culturally competent care to LGBT patients and families? No, and it's probably not even the most important step you should take, but it is an important step nonetheless. Know that language changes as people and times change, so terms that are commonly used now may be out of date in a few years. Have some good sources at your disposal where you can check things out: Lambda Legal, the Human Rights Campaign, and The Joint Commission Field Guide are excellent starting points. And know who you have in your life that's safe for you to ask questions so that when you hear a word you're unfamiliar with, you can learn. You're always welcome to call me.

Thank you to Chaplain Cindi Knox for her contributions to this article.

# When It Comes to LGBT Health, I'm Putting My Database Where My Mouth Is

This column was originally published on <u>Advocate.com</u> and is reprinted with the permission of the author.



As the founder and executive director of the National LGBT Cancer Network, it would be very easy for me to sit in an office and dictate the tenets of good health. I deeply care about improving the health of my community, and constantly read new

findings about exercise, nutrition, and, most important for my work, cancer. It would be too easy to espouse a "just do it" approach in advising LGBT patients to get mammograms, anal Paps, or the deeply dreaded colonoscopies. Easy, but not tempting to me.

For when the day ends and I get up from the computer to head for bed, I would be unable to sleep. I would be worried sick about those who took my advice at face value and headed off to whatever medical provider was most conveniently located. Health provider bias against LGBT people is declining, but it is still absolutely present today. I might have sent my people into yet another lion's den of discrimination, even as I meant to improve their health.

A large Harris Interactive Poll found that 75 percent of lesbians surveyed avoid or delay medical care. After cost, the most common reasons were "feared negative experiences" and "previous discrimination." If I can't guarantee my sisters and brothers a decent and respectful experience when they get screened for cancer, I have no right to push for it. Research already confirms that nearly one out of five transgender patients is turned away by a health care provider.

Still, I remain upset about the increased cancer risks and lower screening rates of LGBT people. I aim to lower our burden of this disease to at least that of our heterosexual counterparts. Our task was clear: make it safe to get

#### **Some Improvements Made**

The National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk by:

- EDUCATING the LGBT community about our increased cancer risks and the importance of screening and early detection;
- TRAINING health care providers to offer more culturally-competent, safe and welcoming care; and
- ADVOCATING for LGBT survivors in mainstream cancer organizations, the media and research.

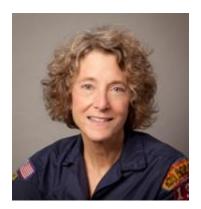
The Network has launched a pioneering online cancer-education and screening program. Visitors to its website can create a personalized cancer risk report, find LGBT-friendly free/low cost cancer screening providers and sign up for electronic (text or email) screening reminders.

In 2010, the Network was hired by the New York City Health and Hospitals Corporation to create their first LGBT cultural competence training, now mandatory for all 38,000 HHC employees. The Network markets its own training materials, "Reexamining LGBT Healthcare," to healthcare providers, social service organizations, LGBT community groups and universities across the country.

screened for cancer and then spread the news about it far and wide.

With a generous grant from the Palette Fund and the fierce determination of my staff, we scoured the country and found over 400 LGBT-friendly, safe, welcoming, free or low-cost facilities that offer cancer screenings. They are all uploaded in a simple state-by-state <u>directory</u> on our <u>website</u>. In most, we have a designated individual who will personally shepherd LGBT people through the process, ensuring, for example, that transgender men who come for a mammogram will not be given a pink robe and expected to sit in a waiting room with women. If there is no individual name and email listed, it is because everyone in that facility has been trained in the issues faced by LGBT people and will welcome you in, providing a safe and nonjudgmental setting for your screening.

Our goal is to have every person in this country be within driving distance of a safe and affordable place to be screened for cancer. If we missed a place in your part of the country, write to us at info@cancer-network.org or call us at 212.675.2633 and we will update the directory. More broadly, we aim to eliminate the undue burden of cancer among LGBT people. Take care of that body. Get screened for cancer. When the results come back negative, we will both sleep better that night.



Liz Margolies, LCSW, is the founder and executive director of the National LGBT Cancer Network, the first organization in the country that addresses the needs of LGBT people with cancer and those at risk. In addition to her public work on LGBT health disparities, Liz is a psychotherapist in private practice in New York City, specializing in trauma, loss and sexuality.

### Eronica King

## A Dance Where the Steps Keep Changing

As a kid, I always approached the first day of school with much angst. Not so much the fear of a new teacher or classmates, but rather knowing that this new teacher is going to mess up my name. I knew that we were going to engage in a dialogue of me pronouncing my name, then the teacher mispronouncing my name, and finally me settling on the mispronunciation that most closely resembled my name always created a high level of anxiety and shame for me. Fast forward to today. I still have much angst when meeting people and trying to make friends. It's no longer my name, well at least not initially, but rather my sexuality and gender identity. The conversation usually goes:

Person: What do you do? Me: I work in a hospital. Person: Doing what? Me: I'm a chaplain.

Person: Chaplain? What's that?

Me: It's a minister or priest that works in a hospital instead of a church.

Person: You are a minister? But I thought you were....

Me: I am

Person: How does THAT work?

The answer I would like to give is slowly, painfully, full of anxiety and fear, and sometimes not at all. But, I usually say, "It just does." However, "It just does" rarely suffices and what follows is a conversation that makes me uncomfortable and frustrated. This is mostly because these are questions that I am currently struggling to answer. It is also frustrating because of the dynamics of chaplaincy and working in a hospital setting. At some point in the conversation, the question "Are you out?" will arise. This is such a simple question that has such a complicated answer.

In my personal life, it's all rainbows and skittles. Well, that's not entirely true. My LGBT friends wonder how I can not only embrace Christianity but also be a purveyor of it. They want me to be an out gay, but a closeted Christian. At work, I am out to my supervisor and department, but not outside of that. Were you to ask any nurse in my clinical areas, I'm sure they would venture to take a guess, but could not speak with any certainty. At work, it's okay to be an out Christian, but I must be a closeted gay.

I understand the value of the closet. I do. Even in 2012, there are myths and misconceptions about what it means to be gay or lesbian. Being a gay or lesbian chaplain or minister in some denominations is career or vocation suicide. Just as some people hide being Jewish, Muslim, Wiccan, or Mormon, we hide our sexuality or face personal and professional persecution. The closet provides a means of protection. It is a way for us to have a sense of safety, despite the pain of denying who we are.

As I strive to be my authentic self, I have come to understand that I don't have to be all out, all the time. Yes, I am a lesbian, but I am also so many other things. I am more than my sexuality and I am striving to not let my sexuality become more than me. Yet, more often than I care to admit, my sexuality becomes bigger than me. Do I use the women's bathroom or the unisex one? When a patient comes out to me, should I in turn come out to them? Do I out myself to a patient when I know they need an LGBT advocate? Do I introduce myself as Eronica or Roni?

This often feels like a dance where the steps keep changing and any misstep could be a landmine. Just because a person identifies as LGBT, doesn't mean that a person is comfortable with an LGBT chaplain. The patient may not be out to family and may fear that my presence will "out" them. The implications of the LGBT label are far and wide. People have lost friends and family after coming out. There are companies that can, and will, fire LGBT persons. Protection for LGBT persons varies by state and often falls short of the needs of the community.

I struggle with my attire. As a masculine of center woman, can I wear ties to work? Should I

even ask if that is an option for me? How do I explain to my LGBT friends the importance of my religion to me when it's people in my line of work telling them that they are damned? Long gone are the days of trying to get a teacher to say my name properly. They have been replaced with days of me trying to balance the rainbow and the cross.

CPE has helped me to understand my questions and to ask more questions. What does it mean to form a pastoral role that is congruent with my personhood when my personhood is under so much scrutiny? I have learned that at the end of the day it's up to me to decide. I can either offer the best pastoral care I can or get hung up on my own stuff. Self-supervision is so important because I have found myself getting excited when I see LGBT couples. CPE has encouraged me to ask myself the "why" question and to stop and wait for an answer.

I don't think my issues will soon be resolved. I have to be confident enough in myself as a pastoral care provider to know that I am doing good work and nothing else matters. As I form a deeper understanding within myself, I find that I am forming deeper connections with my patients.

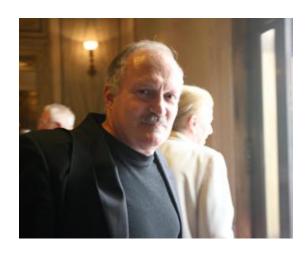


Eronica is a Georgia native living in New Orleans, Louisiana but Georgia is always on her mind, especially during football season! When she isn't roaming the halls of the hospital, Eronica can be found roaming the French Quarter looking for great art. She is doing her best to make New Orleans home with her girlfriend (Kay), cat (Wednesday), and dog (Eros).

Marian Betancourt

## **Helping Those With Long-Term AIDS Find Meaning**





"Both men and women in their 50s say they didn't expect to live this long and now they are faced with how to live," says Dan Shenk about the AIDS patients he works with at St. Mary's Center in Harlem, an area with the highest infection rate in Manhattan. "They contacted the virus before the new drugs were available," he points out, "and it is difficult for them to find jobs." There are an equal number of men and women at the center, most in their 30s through 70s.

St. Mary's has two programs. The nursing home has 40 beds and patients must abstain from

PlainViews hopes that you find interest on this special issue focuses on the LGBT health care. If you'd like to subscribe, please visit <a href="https://secure.healthcarechaplaincy.org/cart/ProductDetailsPv.aspx">https://secure.healthcarechaplaincy.org/cart/ProductDetailsPv.aspx</a>.

alcohol and drugs. The day program has no stipulation about using drugs or alcohol and currently serves 70 people. This program provides two nutritious meals a day, assistance in finding housing, and medical checkups and monitoring. Most people in the day program have many health problems, Shenk explains. Some are on dialysis; some have hepatitis C, cirrhosis of the liver, and other side effects of drug use. Group activities and gatherings at the center focus on mental health and faith and addiction, as well as outings to sporting events, and museums, help them stabilize their lives. They will also participate in the city-wide <a href="Gay Pride Parade">Gay Pride Parade</a> on June 24.

#### **Born to a Missionary Family**

Shenk grew up in Tanzania in East Africa, the youngest of five children of a Mennonite missionary family that went there in 1936. When his mother was killed in an air crash there in 1969, more than 1800 people attended her funeral. Tanzania remains important to Shenk and his siblings, some of whom still live there. At 16 Shenk came to the United States to acculturate into the Mennonite community here, although he has since become a Baptist. He studied at Eastern Mennonite University in Harrisonburg, Virginia; then earned his Master's in Divinity at Union Theological Seminary in New York. In the 1970s he acquired his CPE credits at HealthCare Chaplaincy.

Shenk's first job was as prison farm chaplain in Virginia and for the next 11 years he was chaplain in state prisons in Virginia and New York City. In 1983 he helped found <a href="Bailey House">Bailey House</a> in New York City, the nation's first response to homelessness among men living with AIDS. The house is named in honor of Mead Bailey "who was a good friend of mine and a chaplain at Bellevue Hospital at the beginning of the AIDS epidemic," says Shenk. (Mead died of a heart attack the following year.) With the aid of the state and city governments, Bailey House began with a few apartments and evolved into an AIDS resource center. It was first time any agency publicly acknowledged and funded a program that addressed poverty and homelessness among people with AIDS. In the early 1990s Shenk helped organize the Bronx-Harlem needle exchange, known as <a href="New York Harm Reduction Educators">New York Harm Reduction Educators</a>.

Now 63, Shenk is in his tenth year at St. Mary's. He is an unimposing man, with a graying mustache, receding hairline and friendly eyes. Shenk says an important influence in his work was Gerald May's book, <u>Addiction and Grace: Love and Spirituality in the Healing of Addictions</u> (Harper & Row, 1988; Harper One, 2007). "Everyone is addicted to something, whether it's a behavior or substance," Shenk says. He talks of the sense of isolation and fear some feel when they think about giving up drugs or alcohol. They don't want to face that empty space, "which only God can fill. The opposite of love is fear," and Shenk takes his motto from the first book of John: *Perfect love casts out fear*.

### **Encouraging Others to Heal**

"St. Mary's is like a family; people share a lot," Shenk says. "It is interesting to see change take place. New clients are defensive until they gradually realize it is safe to talk about their inner feelings. It's amazing to see how the defenses decrease. If not absolutely cured," he explains, they are gaining some control when they eat well and stick to their medications. "It's miraculous," he says, "when they regain their health."

Shenk tells of a single mom in her mid-40s with several grown children and an addiction to

crack cocaine and marijuana, who is trying to stop her addictive behavior. She has had several months of sobriety, but talks of her sense of loneliness and fear of not getting high. As she learns this is not unusual in early sobriety, she has found resources with other people, such as phone numbers from those who are successful. She has learned how to share feelings with a group. Some use the 12-step program, or some form of it," Shenk adds.

For the day program Shenk runs or co-runs several groups such as the role of spirituality in healing of addictions or about empowerment. His "Faith and Addiction" is a popular group. A mind, body, spirit program is the only group available on Saturdays and is attended by most of the clients.

The patients in the nursing home have fewer resources. "Most are estranged from family," Shenk says. "It's a priority to see them. I tell them I represent St. Mary's--the caring spirit of St. Mary's--and want them to get well soon." He tells of a man in his late forties diagnosed 20 years ago, before the anti-retro viral medications, who was very much bed ridden. "He had dementia and would not talk." The staff asked Shenk to visit him. "The first time, I helped him put on his shoes to get him to the dining room," says Shenk. "With gradual steps, he gained the capacity to talk and become independent." This man now lives in his own studio apartment with assistance from <a href="HASA (HIV/AIDS Services Administration">HASA (HIV/AIDS Services Administration</a>) the city's program to provide housing, food, and disability coverage.

Holly Argent Tariq, St. Mary's CEO and Administrator, credits Shenk with being "able to reach residents and their families when some of the rest of us cannot." She describes him as "a humble man who embodies the strength of his faith and willingly shares his gifts with residents, clients and staff. He does not scoff at some of the stories he hears in St. Mary's, and there are many of them," she notes.

## **Spirituality Needs to be Evoked**

"Spirituality is already at St. Mary's," says Shenk. "It needs to be evoked. That's what I do. If one of the group breaks down, I try not to jump up with a box of Kleenex. I know they'll do it for each other. I don't do what they can do. I help them. I see myself in a relationship to a community and I try to see where patients are connecting with one another. I see it in positive ways; how people are dealing with their lives and doubts; people helping each other without bringing it to a conscious level."

If someone in the group is in the hospital, Shenk leads the group in offering prayers and he will go see the person in the hospital. He tells me about a woman and a younger man who met at St. Mary's and formed a loving relationship. The woman, recently hospitalized for abdominal surgery, faces a long recovery. The man, Shenk says, now has a strong purpose in his life to help her maintain sobriety, and he is always by her side. Shenk shows me a paper he is bringing to them on his visit, a copy of Elizabeth Barrett Browning's poem from *Sonnets from the Portuguese*, "How do I Love Thee, Let Me Count the Ways." Shenk wants them to share those words together so he had a Spanish translation printed.

#### Sonnet 43

#### **How Do I Love Thee?**

by Elizabeth Barrett Browning

How do I love thee? Let me count the ways. I love thee to the depth and breadth and height My soul can reach, when feeling out of sight For the ends of being and ideal grace. I love thee to the level of every day's Most quiet need, by sun and candle-light. I love thee freely, as men strive for right. I love thee purely, as they turn from praise. I love thee with the passion put to use In my old griefs, and with my childhood's faith. I love thee with a love I seemed to lose With my lost saints. I love thee with the breath, Smiles, tears, of all my life; and, if God choose, I shall but love thee better after death.

#### ¿Cómo Love Thee? (Soneto 43)

por Elizabeth Barrett Browning

¿Cómo love thee? Permítanme recuento de las formas.
TI amo a la profundidad y la amplitud y la altura
Mi alma puede alcanzar, al sentirse fuera de la vista
Para los extremos de ser y ideal gracia.
TI amo al nivel de cada día
La mayoría de necesidad de tranquila, por el sol y la luz de velas.
Me encanta TI libremente, como hombres luchan por el derecho.
Me encanta TI puramente, como resultan de alabanza.
TI amo con la pasión que puso para utilizar
En mis viejos duelos y con la fe de mi infancia.
TI amo con un amor que parecía perder
Con mis Santos pierde. TI amo con el aliento,
Sonrisas, lágrimas, de toda mi vida; y, si Dios decide,
Deberán, pero love thee mejor después de la muerte.



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## Talk Back

**TalkBack** is a regular feature of *PlainViews*. It is a unique forum where readers are provided with a specific question to engage in dialogue.

PlainViews Staff

## **LGBT Bereavement Groups**

More and more organizations are providing bereavement groups for LGBT grievers. Just a few include:

- Massachusetts Department of Public Health
- Hospice Care of Boulder and Broomfield Counties (Colorado)
- Hospice of the Valley (Arizona)
- The Pride Center at Equality Park (Florida)

The two facilitators of the Boulder group, Phyllis Kline and Susan Palmquist, are both HospiceCare chaplains. They believe that there is a great need for a grief support group of this kind. According to Susan, "Even with the incredible strides that have been made in society towards accepting us, there is still a lot of stigma and prejudice out there. This results in 'layers of stigma'—being gay—our relationships not being honored, and then another layer is added because grief is something that people don't want to deal with in general."

Yet there are many institutions that provide grief services that, while offering support groups for other unique grievers – parents, siblings, widows/widowers, trauma - the LGBT bereavement population is not included.

Perhaps it is because they organizations have not had sufficient and realistic trainings about the unique needs of LGBT mourners.

If you are involved in leading or planning a bereavement support group for the LGBT population, what are the unique spiritual and psychosocial issues that are addressed? What wisdom would you share with professional colleagues who wish to start such a group?

## News & Journal Watch

**News and Journal Watch** is a regular feature that provides information about and links to current articles with questions to consider.

PlainViews Staff

## Sources of Information For and About the LGBT Community

1. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding

<u>The National Institute of Medicine of the National Academies</u> published a consensus report in 2011 to identify research gaps and opportunities; and to outline a research agenda to help NIH focus its research in this area.

The PDF can be accessed here.

2. Lesbian, Gay, Bisexual, and Transgender Populations in the 2011 National Healthcare Disparities Report (NHDR)

The Agency for HealthCare Research and Quality is charged with tracking healthcare disparities related to "racial factors and socioeconomic factors in priority populations." The 2011 NHDR begins tracking of lesbian, gay, bisexual, and transgender (LGBT) populations as one of these priority populations.

The full report can be accessed here.

The 2011 NHDR includes an excerpt from the National Transgender Discrimination Survey Report, which is available <a href="here">here</a>.

3. The Aging and Health Report – Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults

<u>Caring and Aging With Pride</u> released the results of a national study of LGBT older adults and caregivers which identified key aging and health disparities.

The report can be found <u>here</u>.

4. Inclusive Services for LGBT Older Adults: A Practical Guide to Creating Welcoming Agencies

<u>The National Resource Center On LGBT Aging</u> provides numerous resources, articles and information on a variety of issues that impact older LGBT adults.

*Inclusive Services for LGBT Older Adults* is written for service providers "to understand the unique barriers that LGBT older adults face, as well as the many ways to improve and expand

the continuum of care and services available." It includes suggestions, tips and practical ideas from mainstream aging providers in the field.

The guide can be downloaded here.

Other resources on the National Resource Center on LGBT Aging website can be found here.

#### 5. Fenway Institute Learning Modules on LGBT Health

<u>The Fenway Institute's National LGBT Health Education Center</u> offers online modules of LGBT topics to health professionals and students. The information includes PDF files and PowerPoint presentations.

The modules can be accessed <u>here</u>.

# 6. Advancing Effective Communication, Cultural Competence, and Patient-and Family-Centered Care for the Lesbian, Gay, Bisexual and Transgender (LGBT) Community: A Field Guide

<u>The Joint Commission</u> released this field guide in 2011, which includes a compilation of strategies, and practice examples.

The field guide can be downloaded here.

## 7. A Provider's Handbook on Culturally Competent Care: Lesbian, Gay, Bisexual and Transgendered Population

<u>Kaiser Permanente</u> published this guide in 2000 as part of their series on culturally competent care.

The second edition can be found here.

The other guides in the series, including information on the African American population, the Asian and Pacific Islander populations, Individuals with Disabilities, the Latino population, People with Hearing Loss, and Womens Health can be found here.

#### 8. Best Practice Resources For Suicide Prevention For LGBT Youth

Researchers at the <u>Family Acceptance Project</u> have produced a new series of resources aimed at identifying best practices for preventing LGBT young people from committing suicide. The first of the multi-lingual guides, "Supportive Families, Healthy Children," helps families understand how reactions to their children's LGBT identity can have a big impact on increasing or minimizing suicide risk and other health problems.

The guides, available in English, Spanish, or Chinese, are here.

## 9. A Provider's Introduction to Substance Abuse Treatment for Lesbian, Gay, Bisexual, and Transgender Individuals

The Association of Lesbian, Gay, Bisexual, Transgender Addiction Professionals and Their Allies (NALGAP) provides on their website the PDF file of *A Provider's Introduction to Substance Abuse Treatment for Lesbian, Gay, Bisexual, and Transgender Individuals*, which is a comprehensive curriculum.

The training curriculum can be found <u>here</u>.

The 2012 NALGAP Webinar Series is free to attend and features monthly events throughout the summer. Offerings include:

- June 20, 1:00 pm Eastern Time: Epidemics in Our Youth Culture: Bullying, Violence and Suicide: Public Health Prevention Resources for At Risk Youth
- July 25, 1:00 pm Eastern Time: Recovery and Spiritual Abuse
- August 29, 1:00 pm Eastern Time: Don't Ask, Don't Tell LGBT Veterans and Addiction

To register, go here.

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