



Patient Safety and Patient Centered Care &

The Transgender Patient

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This is part of a series from the PULSE of NY Patient Safety Advisory Council.

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Patient Safety / Patient Centered Care and the Transgender Patient Contact Ilene Corina (516) 579-4711 August 2011

A Patient Safety Advisory Council was developed in Long Island, New York as part of a fellowship with the American Hospital Association and National Patient Safety Foundation for the Patient Safety Leadership Training program in 2009-10. The council consisted of community leaders from many diverse populations residing on Long Island, reflecting grassroots organizations up to major organizations. The primary objective of this council was to learn, from these leaders what information would be needed to address patient safety. The program included several components: (1) council meetings to educate each other on the communities and organizations they represented; (2) brainstorming to develop a list of needs; and (3) to acquire knowledge and tools to pass on to their constituents. These various formats were designed to fulfill the following goals: 1) patients will be better prepared to advocate for themselves and their family members with the improvement of health literacy; 2) communication between the community and local health systems will be improved: and 3) lessons learned will be passed on to improve patient safety in local healthcare settings.

Group Addressed: One of the council members, Donna Riley, LMSW, the executive director of the Trans-Solidarity Project, highlighted the needs and concerns of the Transgender Community.

Objective: Learning the needs of the transgender / transsexual patient during their medical care and hospitalization.

Discovery: The needs of the transgender/transsexual patient during medical care and hospitalization whether for their transition or other health care needs have both similar concerns and unique distinctions from, the general population.

A brief review of one community member's experience:

William (all names have been changed) left his position at a Long Island Hospital where he was employed for almost 16 years. He worked almost all of that time as Gwen and as he began his transition to William, he informed his superiors appropriately. Still, William told me repeatedly, even with hair growing on his face from the use of hormones, and his deepening voice, many of the nurses and doctors continued to refer to him as õsheö. Staff continued to use his previous





name, and William felt it was confusing to the patients and embarrassing and distracting to him. How could people who are supposed to be the most caring individuals to patients be so disrespectful of a colleague¢s transition?

Methodology:

After co-facilitating numerous focus groups and attending many transgender support group meetings; I have learned that there is not much mystery about someone who is transgender. A person born with a missing limb, cleft palate, poor eyesight or crooked teeth are urged to make changes to make them feel better about themselves and live what society calls a õnormalö life. But, a woman born with a penis or a man born with a vagina and breasts are often ridiculed or shunned by their friends, colleagues and sadly their own family when they õcome outö about their need to make changes or transition. Although the American Medical Association recognizes the medical necessity of medical procedures for transgender individuals, the majority of cases health insurance companies donøt recognize the necessity of medical interventions. Thus leaving a community of human beings to pay out of pocket, often spending life savings, retirement funds or foregoing due to the lack of financial resource, these changes so they can live normal, healthy lives.

I learned about this emerging group of individuals at a social event and then was drawn to the larger group through my work in the AHA Patient Safety Leadership Training. I had an opportunity to educate a group of transgender people about patient safety, and found myself drawn to learning about their experiences in doctor¢s offices and with medical professionals. Some people had stories of being treated with sensitivity and professionalism. Others had very specific stories that kept them from seeking medical treatment and /or being honest with their medical provider this endangering their future medical treatment. Some of the comments I heard were:

- All wanted their chosen name to be used even though their birth name was on the medical chart. It is embarrassing to be called a womenøs name when you present as a man.
- A receptionist questioned one transitioning female to male going for GYN tests in an open waiting room. He left the waiting room in embarrassment, not planning to return for the test. When he finally went for the test, pressured by the transgender community, he had a female friend sign in for him.
- A man was asked to remove his shirt for an EKG and was not offered a gown. He had to ask for a gown to cover up. Many felt modesty is generally not respected.





• A woman was asked in the emergency room when her last menstrual cycle was, instead of explaining that she is a pre-op transsexual (she has had no surgeries) she gave a date.

These kinds of experiences distracted transgender patients from being able to gather their thoughts and questions and being able to focus on and be active in their own care. Transgender people are understandably sensitive to gender identity issues, and when it comes to medical care and how they are treated, they are on guardo about how they are or will be treated.

Other experiences were:

- One woman said she was told by a hospital worker (possibly trying to be funny) that she was the ugliest woman he ever saw.
- One transgender woman visiting family in the hospital was followed by medical residents as a curiosity. All felt that if they werenot blending well, or if they were perceived as transitioning, they were a curiosity to professional hospital staff.

As of this writing, I have been the bedside Patient Safety Care Partner for four transgender patients, on six different occasions with a total of 245 bedside hours. Each hospitalization was very different. The patients were all residents of Long Island; the surgeries were done in three nonaffiliated hospitals in three different states.

The rule to bring someone with you to the hospital takes a very different turn with transgender patients. They are often estranged from family. Betty was married for almost thirty years. The relationship was rocky for many of those years and when she came out to her spouse about her thoughts of transitioning, the marriage, and relationship with her daughters dissolved.

William, from the opening story, had a troubled childhood and was bullied by his older brother. Spending most of his life as a lesbian, many of Williamøs family members, not unlike his colleagues at work, would not use his new name or refer to him as õheö. Finding this hurtful and disrespectful, William became, like many transgender people, distant from his family, seeking to find new family through the close knit support groups of the transgender community.

Much of my role, besides the checking of medication, making sure the patient understood the care plan, checking on cleanliness and the usual Patient Safety Care Partner Role, was to be sure the chosen names and pronouns were used and the patient was treated respectfully.

Many of these patients waited their whole life for this chance to begin a new life as the gender they felt they were. Whether it was a hysterectomy to start the female to male transition, surgery





on the sexual organs, or facial reconstruction, these patients have already, in most cases, lived for a year or more as their newly defined gender, and have waited eagerly for the day they could

begin the surgical procedures that would make them feel more complete. They search the internet and research doctors, procedures and support groups.

In two of the hospitals where transition related surgeries are done and where I supported a transitioning patient, there clearly had been some diversity and sensitivity training for some staff. Nurses were very comfortable with the patient surgery and seemed to have no curious questions. In contrast, at a third hospital, support staff seemed more curious. A male nurse asked the patient owhy the change? In this same hospital employees with no reason to be in the patient room tried to come in. When I requested that hospital staff introduce themselves and state their reason for being there, most were stopped from entering.

In one hospital, where nurses were trained in working with transgender patients, the volunteers distributing newspapers and books would avoid entering the room with a transgendered patient in it. When I questioned the nurse about this practice, the nurse explained that the volunteers, usually senior citizens, are õafraidö of transgender patients. She used the word õafraidö more than twice. It was acceptable, in this hospital, where nurses had a few hours of sensitivity training, to allow the volunteers to pass a patient on out of fear.

In one hospital, there were four rooms set aside for the transgendered patient. This hospital, where surgeries are done regularly is a small 130-bed facility. I was given a sleeping chair and patients had private rooms. Each nurse had 5 patients to care for with no aides or assistants. Dora had full top (breast implants) and bottom (male to female) reconstructive surgery. Immediate after care orders are that there is no standing, sitting, rolling over or moving for almost three days. Completely opposite of what most instructions are following surgery ó to walk around and keep moving. Surgery was done on Monday and there was no movement permitted until Wednesday. When Wednesday arrived, the patient was anxious to move. Nurses seemed frazzled, overworked and because three nurses were needed to move the patient, getting everyone together seemed a chore.

On one occasion, after long periods of lying down, the patient fainted. A fall would have devastated this surgery. She was in a sitting position when she collapsed. This caused one additional night in the hospital.

As mentioned earlier health insurance, in most cases does not pay for these surgeries. Considered cosmetic, patients save their money and must pay out of pocket for all hospitalization, doctors and often hotel rooms before and after if the surgery is done out of state. An additional nightøs stay can devastate a patient paying for their surgery.





Before discharge of the patient who got male to female SRS (sex reassignment surgery) I asked the surgeon that if the patient was to experience any problems, to the surgery itself or infection,

should she call 911 or go the nearest hospital. The surgeon said, õNo, any doctor looking at this procedure would not know what to doö. The surgeon wanted to be called. Again, contradicting years of patient safety procedures.

The recuperation time can be longer because of the lack of general support. Patients often receiving SRS or sex reassignment surgery, will get most of their support from others in the transgender community who have had the same or similar surgery. Because of the privacy of transitioning surgery, which can include SRS, or facial surgery, the support system to the patient will vary.

Transgender patients also have a history of not sharing their needs and / or feelings and can often not tell others what they need. They seek other transgender patients to share their concerns with.

Finally, it is my belief that transgender patients have many of the same needs as any other patient. They need to be talked to and questioned privately about their needs and experiences. Training in communication between hospital staff and all patients is crucial for patient centered care and the best quality outcomes.

Recommendations:

- Advocacy Training / buddy system for transgender patients and their friends / family.
- Intake forms should have a place to mark off transgender (preferred) ó male, female or other (M to F, F to M)
- All patients need to be offered gowns to cover up. Male or female.
- Develop a website and/or brochure to empower transgender people with their rights and responsibilities as a patient.

Training

- Should be done and include transgender people using films, testimonials or in person.
- Staff needs to be taught to stay on topic and not ask or comment on matters not relevant to the transgender patient medical condition.





• Staff needs to be able to pull patient aside and quietly ask information in a consultation area.

As of this writing, PULSE of NY, in partnership with the Trans Solidarity Project:

- Developed a glossary of terms that transgender patients may distribute to their healthcare provider or others who do not feel comfortable with the language or terms.
- Developed films of testimonials.
- Has speakers available to talk to medical professionals about their experience.
- Prepared a client intake sheet using appropriate language.
- Developed information to inform a transgender person what they might expect from the doctor when beginning their transition.





Empowering Transsexuals to Partner with Their Doctor

The survey was conducted over the Fall of 2010 and Spring of 2011

Purpose:

To empower transsexuals with information on what to expect when they visit their endocrinologist when beginning their medical transition.

Currently, the use of estrogen or testosterone (cross gender hormone replacement) for hormone replacement therapy for transgender individuals is considered off label use. As such, there does not seem to be any known standards of care. We looked to gather empirical evidence to determine if a standards set in the treatment of transsexual patients by the endocrinologist should be developed. This information was gathered to empower transitioning transgender patients with information on what to expect when seeing an endocrinologist. Additionally, this document could provide a primer for new medical providers who are looking to serve the transgender community.

Background:

The need for the study was discovered through transgender / transsexual focus groups held at the support group of the Trans Solidarity Project, Long Island New York which is a member of the PULSE, LI Patient Safety Advisory Council. Participants voiced concerns over not knowing how to proceed or what to expect when seeking HRT (Hormone Replacement Therapy).

Transgendered individuals from this group and around the country were asked to provide information regarding their experiences with seeking out hormone therapy and their dealing with endocrinologists, their treatment experiences, and their dealing with office staff. This was accomplished utilizing an anonymous online survey. Participants were chosen based upon their association with online social groups and are self - identified as being transgendered.

Forty-four people responded to the survey.

The respondents were asked to complete an eight question qualitative survey designed to describe their personal experiences with a licensed Endocrinologist who provide them with hormone therapy to assist in their transition from one gender to the other.

Results/Findings:

It was discovered that:





- 1. 39% of the respondents self-identified as male to female transsexuals followed by 24.4% self-identified as Female to Male.
- 2. 67.5 % of those questioned also have a General Practitioner they see in addition to an Endocrinologist.
- 3. 77% see only one endocrinologist at each visit and do not see any other practitioners in their Endocrinologists office.
- 4. 86.4% do not receive similar exams when they do see other practitioners from the same office.
- 5. 38.6% of those surveyed have been seeing their Endocrinologist less than one year or less followed by 25% at 2-4 years.
- 6. Between 94.9% and 76.9% of the 39 of those choosing to describe their experiences with the office staff described their experiences as pleasant. The staff treated them with respect, called them by their preferred name, and seemed to be trained to be sensitive to their needs.

Of the 44 patients who responded, all described the following components of the exam;

- 42 (95.5%) have their blood pressure checked.
- 31 (70.5%) have their heart and lungs checked.
- 41 (93.2%) have their blood work reviewed
- 11 (25%) have their sexual organs viewed and examined
- 1 (2.3%) stated that they have their sexual organs measured
- 8 (18.2%) are examined for body hair
- 40 (90.9%) have their weight checked
- 28 (63.6%) have their height recorded
- 10 (22.7%) discuss personal relationships with their endocrinologist.

Conclusion:

The results show that most respondents do not receive the same care. From our sample group we concluded that each Endocrinologist has their own idea as to what that *Standard of Care* should be.





Therefore it is necessary to clearly define exactly what the *Standard of Care* should be regarding the treating of Transsexual patients. As the transgender community consists of a wide diversity of expression, it seems the absence of *Standard of Care* would not bode well for the transgender individuals as well as the medical provider.

Limitations:

While our sample size was somewhat limited, the findings suggest further work in this field is important. It also should be noted that we attempted to contact Endocrinologists, however they declined to be interviewed or respond to our study findings.

About PULSE:

PULSE is a nonprofit 501 (c)3 grassroots organization dedicated to raising awareness about patient safety and reducing medical errors through advocacy, education, and support. We work to empower the public to make informed decisions, increase effective communication and respect between healthcare providers and the public, and create community partnerships that will foster and ultimately lead to safer healthcare environments. www.pulseofny.org

About The Trans Solidarity Project

The Trans Solidarity Project is an organization dedicated to the engagement of effective advocacy for Transgender/Gender Variant people. The Trans-Solidarity Project brings scholars and advocates together to engage in research, education and policy initiatives designed to advance transgender equality, understanding and community. To that end, we strive to remove barriers that might inhibit these goals and promote the education of all people and governing bodies. http://transsolidarity.org

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