

Issues in Trans Eldercare

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There is an invisible minority in the United States and elsewhere, a minority based not on religion or ideology but on biological composition. If this comes as a surprise, it is perhaps even more surprising that that minority is the transsexual, transgender, intergender (or trans for short) population. Many people believe they can tell if a person is trans and/or do not know the difference between points on the trans spectrum or between the trans spectrum and the fetish transvestism, in which typically heterosexual men dress in women's clothing for sexual pleasure, or the performance art of drag, in which typically gay men dress in women's clothing as entertainers. Garrity & Ansara (frth) explain the potentially invisible status of transsexual, transgender, and intergender people below.

Actually, you have probably interacted with someone who was trans this week without knowing it. Trans people are nurses, attorneys, professors, authors, athletes, teachers, artists, mothers, fathers, and students within your school. They ride buses, fly on airplanes, walk down the street, sit in coffee shops, shop in stores, and carry on with life like everyone else. Yet if you had known that the lady you chat with at the bus stop or the new boy in your class were trans, you might have judged them for not feeling connected to the bodies they had at birth or for stepping out of their birth gender assignments and living in different genders. If interacting with a trans person makes you uncomfortable or if you hold negative attitudes, you are not alone. Anti-trans sentiments are pervasive in the US, and they are fiercest among those who have never had personal contact with a trans person. Personal contact, however, is unlikely for most people, as many trans people choose to be invisible for multiple reasons (some of which we will

explain in the next section). Thus, many of us never get to know anyone with trans life experience or don't know if we do know someone who is trans.

Trans people who “pass” as the gender in which they are comfortable may be invisible, as can trans people who have not yet affirmed their gender. It was mentioned earlier (p. 1) that being trans is different from transvestism and drag. Despite them being very different concepts, there is some overlap for some individuals. Trans people can be drag performers, because it fun or exciting or because it is the only job a person can get due to not passing (Lifelines Rhode Island, personal communication, 2007). Trans people who have not yet affirmed their gender may resort to cross-dressing as a sexual aid (transvestism), because they have no other outlet for dressing and behaving in their identified gender. This may be particularly true for elders, who may have had to live for many years playing a part to which they do not fully relate. Brian Kovacs, a sociologist and board member of Lifelines Rhode Island, relates, “... phenomena like transvestism, genderqueering, and drag may align more closely with trans. These social roles evolved long before modern understandings of trans. An awful lot of research in the area is hopelessly out of date ... How many trans people ended up in marginal communities defined by the dominant culture because that was their only ‘safe harbor’ (mentally, emotionally, socially, etc.)? We’re still learning. The elderly are the most likely to be excluded from modern standards of care, as they have been all their lives. They are the most vulnerable population. And because they spent most of their lives on the margins, they will be invisible to most care-givers.”

One issue in discussing trans eldercare is terminology as variations exist in different geographic areas and fields. Additionally, lay language often imposes terms from the outside or even terms that are offensive; it is best to inquire and to use the terms the person prefers. Extrinsic labeling of TGI people has contributed to discrimination, reifying a view that some

people's narratives are real or 'sincere' and that others' are less authentic or valid, based on DSM IV 'gender identity disorder' and stereotyped gender roles. These clinical paradigms are inconsistent with the lived experiences actually reported in in-group environments (Y. G. Ansara, personal communication, October 5, 2008, regarding a forthcoming publication) and many trans people consider themselves in multiple categories along the spectrum. Individuals whose gender identity, brain sex (including neurological "hard-wiring" and body concept), primary sexual attributes (genital sex), and/or biochemical attributes differ from the standard male/female dichotomy include transsexual, transgender, and intergender (trans) individuals. For the purposes of this paper, *trans* will be used throughout. There is a demonstrated deficiency in the quality and quantity of treatment that they receive. Many resort to self-medication or denial of illness, because they are abused, neglected, or simply misunderstood by healthcare providers. Access to quality medical care is associated with longer life expectancy (Bunker, Frazier, & Mosteller, 1994) and greater quality of life (Kobau et al, 2004).

People who are beginning affirmation or who have seen years of the wrong hormones deciding the structure of their bodies may not pass as their stated gender and have the potential to receive the worst mistreatment and embarrassment in social, healthcare, employment, and other situations. In most US states, trans people are still fighting for the right to access these institutions. In some countries (e.g. the United Kingdom) and US states (e.g. Rhode Island) or cities (e.g. Boston, Massachusetts), "gender identity or expression" is a protected status and is afforded the same protection as religion, national origin, marital status, and sexual/affectional orientation. In these places, the law obliges healthcare providers to provide equal access to care and treatment to trans patients, regardless of whether a person passes. This is not possible, though, if providers are not aware of basic background information on trans issues or if their

staff is ignorant of how or are unwilling to treat these patients with dignity. There is a growing interest in providing safe and appropriate care in hospitals, clinics, and private practices to clients and patients who are trans. However, there has been very little work in eldercare, possibly because of age and trans stereotypes. In this paper, a number of challenges that face elders and trans people, and most importantly the compounded challenges for trans elders, will be discussed. Actions that can be taken to help meet the needs of trans elders as well as some of the people and organizations that offer these services will then be covered. Healthcare issues reported for trans people will be mainly from professional experience, because there is a lack of published research in this area. Citations will be given where appropriate and available.

Recent estimates put the prevalence of individuals across the trans spectrum at approximately 1:100 (e.g. Conway, 2002; Kelly, 2001; c.f. Olyslager & Conway, 2007). The US Census estimated that the percent of people over 65 years of age in the US was 12.6%, which would give more than 380,000 trans elders in the United States. Estimates, however, tend to show low prevalence because many trans people do not identify themselves as trans to surveyors. Garrity and Ansara (forth) explain:

One reason why statistics on trans people are believed to be underreported is that fact that many people of trans experience are stealth, a word that is often used among people in trans social networks to describe people who do not disclose their trans status or history to others. People may chose to be stealth for many reason: social stigma; fear of violence, inability to have a legal marriage with the partner of choosing; loss of health insurance coverage; loss of family or friends; or simply the desire to live in the gender that feels comfortable and right

for them without having to answer invasive questions or face inaccurate assumptions about their past.

Disparities and Challenges Facing Elders

Elder abuse, ranging from verbal to physical and/or sexual assault, is perhaps the most appalling challenge facing elders, but it is not the only one by far. Socioeconomic challenges that many elders face can contribute to higher rates of disease and lower treatment rates. Many elders are additionally faced with living alone or in an institutional setting, and loneliness and inactivity may result in a decreased life expectancy, particularly for widows and widowers. Sensory changes, loss of taste and smell, can also lead elders to eat less and thereby slowly and unintentionally starve themselves. Finding a physician as well as staff who understand – whether primary care, hospital, or residential – is a major challenge that elders must face.

Healthcare providers do not always take complaints seriously. They may attribute hearing, sight, or memory loss or even pains to ageing rather than rule out other causes. Alzheimer's disease was originally only diagnosed in patients 45-65 (Boller & Forbes, 1998), because it was expected that elders would inevitably become "senile." This attitude can lead to undiscovered diseases taking their toll without the person being treated. All possibilities should be ruled out before an unspecified diagnosis is given. Unfortunately, in the case of Alzheimer's disease, treatment is currently limited. Thanks to the growing awareness, research is ongoing in finding better treatments and a potential cure.

Disparities and Challenges Facing Trans People

Trans people need providers who understand and take seriously their ailments just like anyone. Unfortunately, trans people in particular are often prejudged by physicians to be mentally ill and consequently their health concerns unfairly regarded as psychosomatic or

hypochondriatic. Trans people may be diagnosed as clinically depressed by providers who are not qualified to diagnose mental illness (i.e. primary care physicians) rather than suffering from a legitimate illness, particularly those who have not yet affirmed their gender or are in the process of affirming their gender.

In addition to being misdiagnosed, trans people often fear the medical establishment in general due to rampant patient abuse, particularly in emergency wards. Harassment and gawking is typical, and while this is troubling and can cause psychological damage, there is also far greater abuse of trans people. The abuse that is perpetrated against trans people in medical establishments typically is sexual assault ranging from inappropriate comments or touching to blatant torture. An example of the latter is a horrific tale of something that happened to a deaf trans woman at an emergency ward in the last few years. Her female partner took her to a local emergency ward for an ailment completely unrelated to her torso or genital area. Once she was taken back, she was strapped to a hospital bed with the door open as staff would come by to gawk and fondle her genitals. This went on for several hours. Her partner was not allowed to see her, and she was denied a sign language interpreter. She had no idea what was going on, when she would be treated, who was saying what to whom, or when she would be released. (Lifelines case, personal communication, 2007)

Unfortunately, similar situations are all too common. A caring and sensitive primary care physician can help a patient recover from trauma or fear of being traumatized at the hands of medical personnel. Primary care physicians with whom I am acquainted administer urgent care whenever possible, sometimes through a trusted nurse or colleague, rather than relying on emergency wards for similar treatment.

Trans patients who have insurance face a particularly troublesome prospect with providers who are not versed in trans healthcare issues. Insurance companies in the United States do not cover gender affirmation-related healthcare, and many trans people have found themselves without health insurance entirely after their trans status is disclosed to their insurance companies. The San Francisco Department of Public Health found that 51% of trans people in San Francisco, a relatively trans-friendly city, did not have health insurance (1999). It is common practice for insurance companies to claim that non-affirmation related procedures (such as having a broken bone set) are “Sex Reassignment Surgery-related.” One online forum poster was seeking health insurance coverage for a woman of trans experience and her two children following a divorce:

User Becoming EHEALTHy (May 2, 2006):

Am assisting in seeking coverage for 39 year old central florida female (mtf srs in october 2005) and two daughters asap. If anyone has suggestions as to what health insurers will underwrite, please post reply. Have been refused blue cross and humana. Need coverage asap...Divorce will be final and will lose benefits. Thank you.

If the folks in colorado need to ask that question they 1) probably don't cover folks in florida and, 2) they probably don't cover folks having had that that type of surgery. Fyi mtf srs is male to female, sex reassignment surgery. There is a wonderful hospital in colorado (marci bowers). This individual, however, went to bangkok, thailand for the best and least expensive surgery. If, on the outside chance, this company in colorado will underwrite a woman and her two kids in

florida ...Post reply and we'll get going on an application. Divorce was final today and need coverage to start asap. Thank you for the reply.

From (<http://ehealthforum.com/health/topic62129.html>)

The above excerpt illustrates very well the kind of discrimination that trans people face when seeking and maintaining health insurance. Should a provider write the reason for a hormone prescription, for example, as transsexualism, gender affirmation, transition, etc., in many cases the insurance company will discontinue coverage, not only of visits to that physician and for that medication but also for other medical expenses. If the physician instead writes the reason for the prescription as endocrine disorder not otherwise specified or as hypogonadism, both legitimate reasons for trans patients, the patient is much less likely to be scrutinized and have their coverage revoked. Similarly, medical staff must be sensitive to issues of gender markers in paperwork. Most insurance companies will not cover, for example, gynecological treatments for people whose gender marker is male, and this can be another tip off that the patient is trans. Many trans patients choose to self-pay for treatment that could potentially cause problems for insurance coverage. Some even choose to be treated anonymously at clinics such as Planned Parenthood.

Disparities and Challenges Facing Trans Elders

One can easily see how the combined inaccurate perception of elders as incompetent complainers and trans people as mentally ill can lead to double discrimination. The potential for abuse is also greater. Trans elders have the additional problem of, should their status be disclosed, potentially having a much harder time integrating with peers. This is especially problematic in residential settings, where most social interaction is with other residents rather than friends or family who live elsewhere.

Many trans elders have not transitioned and never will. However, there are some who after “doing their duty” of raising a family and working a lifetime, finally feel able to dedicate their energy to themselves. It is not uncommon for people to affirm their gender after their children have moved out or when they retire. They then must go through puberty and experience being a teenager in the right body (Y. G. Ansara, personal communication, November 24, 2006). In addition to these adjustments, one must deal with family and friends and their reactions. Imagine if your father suddenly disclosed to you that he had decided to affirm his gender as a woman. Would you automatically start referring to her as Mother, as Catherine, as she? Would you believe her or think it a whim? Didn't Dad go by Pete and join the army at 18? But he was so macho! How would family gatherings be? Would there be tension between family members who accept her and family members who don't? Would she be allowed to see the grandchildren? These are some of the many questions people who affirm their gender as older adult face. Trans adults, especially trans women, may hold on to very stereotypical gender roles, such as being a Marine and working on cars, in order to suppress their feelings of discontent. Often this translates into an extreme on the other end when they affirm their gender, with people who portray themselves as macho policemen now portraying themselves as dainty ladies in an attempt to wash away the “old life” and the mask they used for so many years. This is something to which that family members and friends may have difficulty adjusting, and both reactions are normal. Family therapy may be able to help with these adjustment issues, but it is ultimately the responsibility of the person who has the issue to overcome it and love and respect their trans family member or friend how she now presents.

The issues facing trans elders are mainly combinations of issues facing trans people in general and elders in general as well as with the additional social challenges such as described

above. It is therefore important to address both social and professional factors in making plans to meet the needs of trans elders in an elder care or medical establishment.

Ways to Accommodate

A few simple ways in which providers can provide quality care to trans patients or residents are:

- If you are unsure of a client's *preferred name or pronoun*, ask.
- Allow trans clients access to changing rooms, bathrooms, segregated halls, etc. according to their *stated* gender.
- Ask, do not assume, what gender person the client wishes to bathe, toilet, etc. them.
- Ask what style bedpan/urinal the client would be most comfortable using.
- Avoid using gendered language to refer to trans people's genitals; ask for the client's terminology and use it.
- Do not make remarks such as "It's so big!" or "Wow, are those real?" in reference to trans people's body parts.
- Use gender-neutral and trans status-neutral language for insurance billing and inter-office communication as well as any communication that those who do not need to know may overhear.
- Do not disclose a client's trans status, former (or sometimes currently legal) name, genital configuration, etc. without proper cause.
- Ensure that anyone who will see the client undressed knows their stated gender and preferred name/pronoun (and will respect them!)
- Do not tolerate trans jokes or any behavior that you would not tolerate regarding other underprivileged populations.

Conclusion

The challenges facing elders and trans people are many, and the challenges are compounded for trans elders. However, steps can be taken to lessen the burden with which this population is faced. Some steps were discussed, mainly with regard to direct care, and some steps, such as legal action and advocacy were not. A more thorough discussion of steps not mentioned here can be found in a previous paper (Malotte-Berger, 2008). Additionally, the Transgender Aging Network (<http://www.forge-forward.org/tan/>) is “devoted solely to researching, supporting, advocating for, and providing services to transgender elders.”

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