Action Research: A Community Provider Reflection on a Decade of Changes and Ongoing Barriers to Health Care for Transgender and Gender Variant People

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February 27 2017
RHI Opportunity Conference: Advancing LGBT Health

Outline of Presentation

- Definitions
- Background and purpose of the study
- Theory and Methodology
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- Research Recommendations

Define Transgender

Transgender is a modern term, an umbrella term, used to describe a broad range of individuals with atypical gender characteristics or gender identities discordant from their anatomic sex, including transsexuals, cross-dressers, drag performers, androgynists, etc. (APA, 2015).

Transsexual: Transgender individuals who desire or have had hormone therapy and/or surgery to feminize or masculinize their body and may live full time in the cross-gender role (IOM, 2013). Often only a medical term and often avoided otherwise.

Define Transgender

- *Gender Binary*: The classification of gender into two discrete categories of boy/man and girl/woman (IOM, 2013).

- *Non-binary gender (Gender Variant)*: describes any gender identity which does not fit within the *binary* of male and female - a neutral or *non-existant* gender identity. Can include genderfluid, genderqueer and any term that signified those who do not identify with the gender binary but somewhere between or outside it. Some use neutral pronouns, such as “they” and “them”.

Sexual Orientation

- *Sexual orientation* and *gender identity* have been confused as a single entity, though it is important to understand each is a distinct identity (APA, 2015; IOM, 2015; Mayer, et. al., 2008).

- Sexual orientation: refers to an enduring pattern of emotional, romantic, and/or sexual attraction to men, women, both sexes, trans* and gender variant people, etc.

- Research has documented stigmatizing attitudes and discrimination toward transgender and gender variant individuals (TGV) in health care settings, which has been linked to barriers to health care and health disparities.

- The purpose of this study was to identify
  - advancements in care for TGV people in the last decade as well as ongoing barriers to health care
  - additional changes needed to continue to reduce health care barriers

Background & Purpose of Study

TGV people are the among the most socially stigmatized population in the US, facing discrimination in:

- family homes
- school systems
- the work place
- legal institutions
- housing

The stress associated with social stigmatization has been linked to elevated rates of

- cardiovascular disease,
- cigarette smoking,
- depression,
- anxiety,
- trauma exposure, and
- suicidal ideation (Blosnich, et. al., 2013; Bockting, et. al., 2014; Lutwak, et. al., 2014).

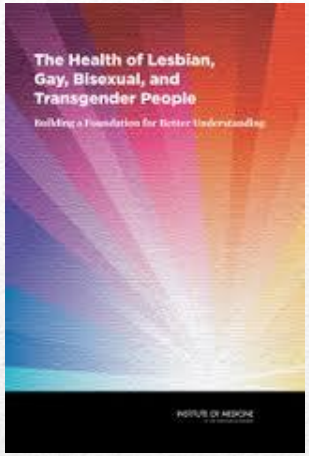
Background- Societal Stigmatized

Background – Stigma in Health Care

Stigmatizing attitudes & discrimination toward TGV individuals in health care settings, resulting in significant barriers to care and poor health outcomes (Bockting et al.,, 2004; Daulaire, 2013; Grant, et. al., 2011; IOM, 2011; Lombardi, et al., 2001)

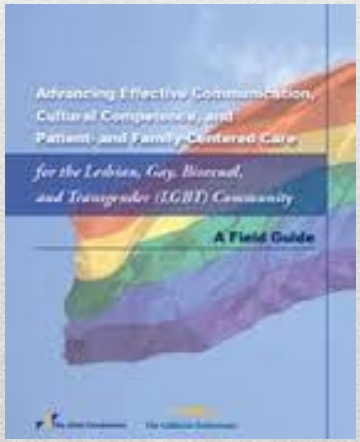
- Insensitive providers (Lambda Legal, 2010)
- Refusal of care (Lambda Legal, 2010)
- Health care providers blaming TGV people for their health issues (Lambda Legal, 2010)
- Medical providers refuse to touch them (Lambda Legal, 2010)
- Provider's lack of knowledge in cross-sex hormone treatments, surgeries, and other treatments for transitioning (Cruz, 2014; Snelgove, et al., 2012).

These negative experiences often lead to avoidance of care, delay of care, decreased preventive services, continuity of care, and life expectancy (IOM, 2011; Sabin, Riskind, & Nosek, 2015; Sherman, Kauth, Shipherd, & Street, 2014).



Reports announcing the importance of addressing health care needs of lesbian, gay, bisexual, and transgender (LGBT) people (IOM, 2011; The Joint Commission, 2011)

- The Joint Commission
- Institute of Medicine (IOM)
- Affordable Care Act (ACA)
- US Department of Health and Human Services, Healthy People 2020 (DHHS) (2014)
- The Obama Administration (Daulaire, 2013).
- The American Psychological Association (APA) (2015) mental health professionals who have limited training and expertise in transgender affirmative care may *cause harm*



Background

Theory & Methodology

Action Research using Qualitative Method

Appreciative Inquiry Approach:

- Purposive and snowball sampling
- Triangulation: individual interviews, focus group, field journal, member checking

Minority Stress Model (Meyer, 2003):

Minority stress underscores stress processes (experience of prejudice, expectations of rejection, internalized homophobia) and ameliorative coping processes and a greater likelihood for psychological distress and physical health problems.

9 practiced community health care providers serving transgender people participated.

- Medical Provider 4
- Mental Health Provider 5

Gender Identity

- Female 4
- Male 2
- Genderqueer 3
- Transgender 3
- Gender fluid 3
- Bi-gender 1, Two-spirited 1

9 Research Participants

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Years experience ranged from 2.5 to 44 years (median = 23.25)

- Age range of participants:
- 1 – 18 to 34 age range
- 4 – 31 to 45 age range
- 3 – 46 to 60 age range
- 1 – 60+ age range

Employment Settings

- 2 hospital
- 3 college/university
- 5 outpatient clinic
- 2 non-profit
- 3 private practice
- 1 residential treatment program

Individual Interview Questions

1. What are significant advancements in transgender health care in the past decade (consider nationally, regionally and locally; can include changes in policy, advocacy work, knowledge regarding health care for this specialized population, medical care, mental health care, and family care)?
2. What *medical health care* barriers continue to exist within Minnesota for the transgender population?
3. What *mental health care* barriers continue to exist within Minnesota for the transgender population?

4. What changes are needed to continue to enhance the health care of transgender people in Minnesota?
5. What training services are available to health care providers serving transgender people (consider national, regional, local, video, online, and print resources)?
6. What supports and resources are available to health care providers serving transgender people (consider national, regional, local, online, community referrals, employers)?
7. What role do you see yourself or people in your professional role playing in making changes to continue to enhance health care of the transgender population?

Individual Interview Questions

1. Are there any other missing significant advancements in transgender health in the past decade?
2. Are there any additional *medical health care* barriers that continue to exist for transgender people within Minnesota not captured in this data?
3. Are there any additional *mental health care* barriers that continue to exist within Minnesota for transgender people not captured in this data?
4. Does this data adequately cover the changes needed to continue to enhance the health care of transgender people in Minnesota?
5. Are there additional services available to health care providers serving transgender people (consider national, regional, local, video, online, and print resources) not represented in this data?
6. Are there additional supports available to health care providers serving transgender people (consider national, regional, local, online, community referrals, employers) not represented in this data?
7. Does this data adequately describe the roles you see yourself or people in your professions playing to make changes to continue to enhance health care of transgender people?

Group Interview Questions

Data Collection & Analysis

- Saturation was established and enough data to sufficiently answer the research questions
- Via Dedoose and review of transcriptions found consistent topics by words and content
- Started out with multiple and diverse topics – narrowed based on similarities
- Themes and sub-themes were established

Research Results

Three main themes with subthemes emerged:

1. Access to Medical and Mental Health Care
   a. Insurance and medical coverage
   b. Trained health care providers
2. Standardization of Health Care in the Midwest Region of United States
   a. Coalition building
   b. Fragmented medical and mental health care services
   c. Training and education in the community and in academic settings
   d. Development of an LGBT Community Center Versus Inter-Professional Provider Teams
3. Advocacy for Change at Local, State, and National Levels Through Advocacy and Coalition Building
   a. Existing pathology
   b. Discrimination in health care settings, and systemic and institutional change

1. Access to Medical and Mental Health Care

A. Insurance and Medical Coverage

"We should have been a single payer 50 years ago. Insurance in this country is a travesty. It sucks up so much productivity – it is useless."

"Insurance is still a huge barrier, especially for low income folks – which are many. And in fact, the majority of the trans community are living at or below poverty level or they are very underemployed."

B. Trained Health Care Providers

Well, then the other issue is that even though we have a huge trans community, we actually do not have that many medical providers – and providers have long waiting lists. Especially for our minors it can be months if not a year wait, which is really long if you are a minor and your body is changing. Especially with minors, there are few providers who are willing to provide support letters and who can provide medical interventions. So, from finding a provider, to then having services covered by your insurance, if you have insurance . . . remains problematic.

1. Access to Medical and Mental Health Care

1. Access to Medical and Mental Health Care

B. Trained Health Care Providers

- *That's one of the biggest complaints I hear from my clients is that, "I have this therapist who was perfectly nice though had no awareness and I have to do trans 101 every time… I just can't do that anymore, I don't want to do it"*
- *I have patients that will come in and say, "I've been seeing this therapist for a long time and she doesn't know anything about gender - she just thinks it's time for me to transition because I'm unhappy a lot, but that's not really what I'm looking for."*

A. Coalition Building

- *There really needs to be more coordination, trust building, and some real governance effort. Like, I do not know what is stopping the city of Minneapolis from saying we will create a center, or create a space; a partnership between political leaders and community organizations and something like a state university. It could be a really powerful partnership. But partnership has not been the name of the game locally or there are a lot of things that get in the way.*
- *Because there hasn't been a good trusting relationship between the gender nonconforming community and the medical community* --- *and the only way we're going to get it is if we actually engage them in conversations about "what does health mean to you".*

2. Standardization of Health Care in the Midwest Region of US

B. Fragmented Medical and Mental Health Care Services

- *You do not need to be a mental health provider to do a mental health evaluation for CSHT. So, I do my own with rare exception where I need somebody else's opinion.*
- *But what we found was that in that process [of conducting a global assessment], … they really looked at it [process of transitioning], most people were in deliberation for 6 months to a year. They would say, "Oh my gosh I don't have any money" and "I'm actually not sure what my insurance does or doesn't cover," and "I haven't talked with my family members ". . . I hear consistently from people that they usually get maybe a 15 to 20-minute medical appointment. Clients say, "I was shocked how readily I was given a prescription [CSHT] given that I had never spoken with this person before - - and how little they knew about me or my health history".*

2. Standardization of Health Care in the Midwest Region of US

B. Fragmented Medical and Mental Health Care Services

- "*They give them testosterone like 200 mg a week. Sure, they transition quickly, but that's levels that you see in the doping world. The testosterone levels are off the wall. And, I've seen some patients get really decompensated with that amount."*
- *They're [medical providers who prescribe CSHT] not even measuring them [CSHT]. They're not even measuring hormones in the trans female population. They don't check on the estrogen levels. They do check on the testosterone levels. They check on the prolactin. . . to me, if you're running estrogen levels at 700, 800, 900, it could be dangerous. You could be increasing the risk of breast cancer, strokes, heart attacks, thrombotic issues, and any cisgender female or bio-female that has undergone fertility treatment and run estrogen levels that high will tell you they feel freeking nuts. So why - why do that? You may get some more breast growth but it's not sustainable.*

2. Standardization of Health Care in the Midwest Region of US

B. Fragmented Medical and Mental Health Care Services

- *Now whether I agree or disagree with that (conservative practice) is sort of irrelevant because I know what I do and what I'm willing to do for a patient. But every provider is different. So, some people picked up on trends, where certain practices are known to be more conservative. So, there is this concern out there, and mine too, that when trans people go to conservative clinics, they get their spiel, and the patient says I don't like that, so I am going to a different clinic instead.*

2. Standardization of Health Care in the Midwest Region of US

C. **Training and Education in the Community and Academic settings**

- *Trans folks felt that most providers were friendly and accepting, but not necessarily competent. And it is always worrying when you know more about your health than your provider, which is not an unusual tale in terms of Trans communities. So, I think one of the areas that really needs to improve is some serious level of training that goes beyond trans 101. And where there is some real kind of comprehensive and inclusive training especially in the larger system.*

2. Standardization of Health Care in the Midwest Region of US

C. Training and Education in the Community and Academic Settings

- *The feedback that I have gotten from our psychologists and clinical social workers is that they do not feel adequately equipped necessarily to work with trans patients. I have forwarded some resources to them – electronically. But frankly, it's kind of parallel to my own feeling that this isn't specialty education – you need education but you don't need special expertise. These are human beings, they've got anxiety, depression and chemical dependency - that's the same for any human being. The gender stuff doesn't really change how you work*
- *Unfortunately, the model of care with gender nonconforming patients has been to go to specialty service. I don't think that we need a specialty area. But I'm biased because I'm a family medical provider and don't believe always in specialists. Why would I send someone to a facility where they can't get their flu shot, they can't get their colonoscopy, they can't get their x-rays and I can literally do all that in my clinic.*

2. Standardization of Health Care in the Midwest Region of US

D. Development of an LGBT Community Center Versus Inter-Professional Provider Teams

- *I have never lived in a community that's had something like that [LGBT Community Center]. Nor have I ever visited a place like a Howard Brown, but they seem like incredible resources to their community. So, I can only imagine it would be amazing here too. Clearly, we have problems with cohesion and our ability to work together – it is too fragmented. There are a lot of gaps.*

2. Standardization of Health Care in the Midwest Region of US

D. Development of an LGBT Community Center Versus Inter-Professional Provider Teams

- Some of our colleagues are very adamant about having transgender clinics…and I absolutely see it the other way. My approach with transgender care is to normalize it - to mainstream it, and we do not need to make it a separate entity. ... We don't need Gay health centers. We need health centers that are culturally competent to take care of gay people. Whenever you ghettoize people, we see it with economic ghettoization in the United States in many cases that has followed racial lines and new immigrant lines, there is stigmatization that innately happens. I think whenever we invite people into the mainstream of the culture, but respecting their cultural heritage as well - you just get much richer happier interaction then, here's my silo - here's my silo. … Let's continue to normalize and mainstream and routinize just being who you are.

2. Standardization of Health Care in the Midwest Region of US

A. **Existing Pathology and Discrimination in TGV Health Care Settings**

- *Trans people I work with still occasionally run into providers who really have poor bedside manner or don't know what to do, or just flat out say, "I don't know anything about that, go see someone else." But it seems like bigger systems are starting to pay attention to that more.*

3. Advocacy for Change at Local, State, & National Levels Through Advocacy & Coalition Building

B. Systemic and Institutional Change

- *What we need to do is to change conversations. While health disparities are horrible, we need to change the conversation to something that is more almost civil rights oriented. For example, health care access is a right and gender is what you make it. We do not have gender training in medical school for example and the average number of hours around LGBT issues for sexual health is less than five. We are not even talking about the things that impact people's day-to-day lives. But we do learn about rare cancers and tumors. So, I feel like we have to change the conversation from the get-go, which is a real pie in the sky.*

3. Advocacy for Change at Local, State, & National Levels Through Advocacy & Coalition Building

B. Systemic and Institutional Change

- *One thing that makes a difference that needs to be named explicitly is paperwork and forms - - do they reflect the possibility that someone could be transgender? Does the language reflect that not every person who does not have a penis is not male? - and things like that? And electronic healthcare systems don't generally have the flexibility to put a preferred name prominently or working with different gender markers that you would refer to patients by - - and the gender that the insurance company has. Our record systems are just not able to handle that.*

Advocacy for Change at Local, State, & National Levels Through Advocacy & Coalition Building

Recommendations

1. The development of a Midwest Region Collaborative to coordinate efforts to conduct more research, standardize Trans health care, and develop a strategies for advocacy
2. Coalition Building to formalize a more collaborative approach to Trans health care in the Midwest
3. Establish standards of health care in the Midwest
4. More training opportunities for providers with advanced topics
5. Alliance building to ensure coalition and trust among providers, leaders, and the trans community – to advocate for needed changes in health care institutions
6. More research in Trans* care to guide providers' work and support advocacy efforts

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