“It would be nice if …” LGBTQ people talk about supportive places and spaces

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Overview

• Research Team
• Background
• Research Design & Methods
• Findings
• Concluding Thoughts
Research Team

• Taryn Tang, Schizophrenia Society of Ontario

• Alisa de Bie, Community Researcher

• Andrea Daley, School of Social Work, York University

• Lori Ross, Dalla Lana School of Public Health, University of Toronto

• Sean Kidd, Centre for Addiction and Mental Health

• Loralee Gillis, Rainbow Health Ontario
Background

• Little known about the experiences of LGBTQ persons living with schizophrenia or psychosis

• General mental health of sexual & gender minorities, and the relationship between stigma & depression and anxiety (Meyer, 2003)

• Health care use (Van Dam, Koh & Dibble, 2001)

• Lesbian/queer women & mental health system (Daley, 2010, 2012)

• Experience of community participation (Kidd et al., 2016)
Purpose

• Respond to the literature gap re: experiences of LGBTQ people living with psychosis
  • Most literature on psychosis doesn’t attend to LGBTQ-specific experiences
  • Most literature on LGBTQ mental health focuses on depression/anxiety/stress

• Emphasize access to supportive community places and spaces
  • vs. reducing focus to only healthcare/medical systems

• Look for resistance and strengths
  • vs. pathology

• Bring a consumer/survivor/Mad and LGBTQ analysis to this area.
Research Design

LGBTQ People Labelled or Living with Psychosis

Experiences Navigating Communities & Relationships

• How are multiple identities negotiated in systems, communities & relationships?
• What are the strengths/resilience and barriers to finding supportive communities & relationships?
• What are the characteristics of supportive communities & relationships?

N = 16
Recruitment & Data Collection

- Purposive sampling: Toronto, London, Ottawa
- Identify as lesbian, gay, bisexual, transgender, queer
- Past or present lived experience with schizophrenia or psychosis
- Informed consent
- Honorarium received
- Individual in-depth interviews

Process:
- All interviews conducted by consumer/survivors;
- Most interviews conducted by LGBTQ-identifying interviewers.
Data Analysis

- Interviews recorded & transcribed verbatim
- Becoming familiar with the data
- Generating initial codes
- Searching for themes
- Reviewing the themes
- Defining and naming themes
- Producing the report
- Nvivo

(Braun and Clarke, 2006)
Who we spoke with...

- Total = 16 (demographic data for 15)

- Age
  - 19-39: 7
  - 40-56: 8

- Gender
  - Male: 5
  - Female: 6
  - 2-Spirit: 1
  - Questioning: 1
  - Genderqueer: 1
  - Trans: 1

- Sexual Orientation
  - Gay: 5
  - Lesbian: 3
  - Bisexual: 4
  - Queer: 1
  - Asexual: 1
  - Pansexual: 1
  - Unsure: 1

- Race/Indigenous
  - White: 10
  - Indigenous: 2
  - South East Asian: 1
  - Black Caribbean: 1
  - African/European: 1
Who we spoke with ...

- Over half of the participants were single at the time of the interview
- Highest levels of completed education ranged from completed primary school to completed post-secondary education
- Most living on low incomes & received government disability benefits
- Bipolar, schizophrenia & schizoaffective ‘disorders’
- Many experienced substance use concerns (cocaine, crack-cocaine, alcohol)
- 13 interviews in large urban centres & 3 in smaller urban centre two hours away
Attributes of Supportive Places & Spaces

- Affirmation of Intersecting Identities
- Complex Narratives
- "Just Listen"
- Shared Experiences
- Community: Identity
- Community: Geography
- Service Providers
Reading Through a Queer Lens

• Historical context of severe discrimination of LGBTQ persons within mainstream psychiatry (Cochran, 2001)

• Within the context of health equity frameworks ongoing access barriers due to the legacy of psychiatric pathologizing and regulating of sexuality and gender

• Ongoing pathologizing & regulating of sexuality & gender:
  • Women’s sexuality implicated in psychiatric disorders that are embedded in white, middle class, heteronormativity and cisnormativity
  • ‘gender dysphoria’ among children, youth & adults
Intersecting Identities ...

“If I came out to a bunch of people about gender stuff, I wouldn’t feel comfortable with my mental stuff ... like, heaping that on them. And if I came out to people with my mental stuff, I wouldn’t want to heap my gender stuff on them. So ... I don’t know if they could co-exist, ‘cuz I’m just worried about how ... what people think. *It’s hard to find people tolerant with both, you know?*”

“It’s hard to find a place that’s fully accepting of my sexual orientation like um that was, that place was pretty accepting, and they knew that I had mental health issue and it was good. . . . they were accepting of that too.”
“I’ve been to a lot of mental health organizations. Right now I’m a volunteer at [name of agency] where I’ve just come from. I find that [name of mental health agency], it’s a safe inclusive space for people with mental health diagnosis as well as LGBTQ where they support you and you feel supported.”

“I don’t know all the programs that they’re offering at [name of agency]. I know that it’s definitely a safe space for people of color I can tell you that much but I really don’t know a lot about all the programs.”
Intersecting Identities ... 

“I feel supported at the [name] community food bank because *I am a poor person and it’s a place for poor people and I feel like I belong there* and my needs are being met with food and I that I can support people in the community and it makes me feel good about myself ... *its highly populated by consumer survivors that’s one reason why I feel like I belong here but also, and poor people.*”
Service Provider Interactions

“When I bring up like ‘oh so I’ve been diagnosed with schizophrenia’, like he, he’s like ‘no I work more from like a different approach, like I don’t want to just be like here’s your label and it’s because of this biology, and let’s talk more about your feelings around it, and maybe like these hallucinations or like delusions are actually related to your own like feelings of insecurity that then relate to your gender identity ... because I wanted to transition dealing with queer, trans therapy was more of a priority for me, so this psychologist worked out fine.”
Family & Relationships ...

“I think they’ve [family members] been pretty good ... my mom, is always concerned, like, how I’m doing in both aspects [mental health and trans identity], right? Like, *is medication doing o.k.*, like am I still taking it, all that kind of stuff, and then you know, *how is my personal like feelings, as I transition*, like helping me feel better. And *how the two kind of go together*.”

“I’d say I have a number of sexual relationships, and in those relationships the people I’m seeing are *accepting of my sexual orientation and my mental health status*.”
Complex Narratives

• Intersecting aspects of self: sexual identity, gender identity, mental health, race & poverty:

"She wasn’t, you know, as soon as I would say something, she wouldn’t shut me down, and even if she didn’t have like all the answers, or a lot of knowledge let’s say like about trans things, like she herself, I feel like kind of like went out of the way to educate herself, which was nice because then she was able to support me better, and like listen to me better."
“Just Listen”   “Don’t Judge

“... *just to listen*. It’s a big start eh? *Don’t judge me*. *Let me tell my story* ... Let me just tell my story. Don’t be judge, or quick to judge me or jump in. You know? Just... yeah, *just listen*.

“... it’s like *they don’t judge*, they give you support if you want, or they give you feedback if you want it, but if you don’t want it, *they don’t just say anything to say, you know, it’s good ... I’m being heard*.”
Service Provider Interactions

“It has a lot of effect, I know for a fact. Because... I never went to [name of support service] before, until I found out XYZ worked there, and when I found out XYZ worked there, and I felt safer just going in knowing that XYZ was there, somebody I knew was going to be there, to say you know say ‘hey, what’s going on?’, ‘what do you need?’”
“I just felt that it [Mad Pride] was space where there was other people like me ... weren’t labeled and tossed aside by the system instead of like, you know, just pretty much treated like shit and that they understand what the frustration that I have with the system, and I find that in standard medical systems that it’s [sexual identity] not really as appreciative as in the Mad Pride movement.”
“My drag mother, as she would call herself, she lives in Toronto. And when I go down to see her, I have no fear when I’m down there. I’m happy, you know, I’m proud to be who I am. And I feel like I’m in the best place in the world. But when I’m at home, in my own home town, it’s like, ‘I don’t want to be here’. That’s what bothers me. I feel like I’m the happiest person in the world. I come home, and it’s like ‘oh, what am I doing here’. I don’t think that’s right. I see that we’re equal, it’s like everybody else, just because our sexual orientation’s different than a straight person’s ... it shouldn’t matter.”
Community: Identity & Geography

“I’m better in, what do you call it ... the gay community more than I am in the straight community right? Like I, I feel more at home, comfortable ... whatever you call it.”
Concluding … but not final thoughts …

• How does your agency/practice recognize and affirm intersecting identities & associated complex narratives?

• How do you facilitate and honour the self-directed telling of complex narratives?

• Are you able to hear complex narratives through a queer lens (recognition of past and ongoing psychiatric pathologizing & regulating of sexuality and gender)?

• Do you seek out narratives of community participation and activism – LGBTQ community, consumer/survivor/Mad community as these may be places and spaces of support?
References


• Kidd, S., et al., [http://grantome.com/grant/NIH/R03-MH100542-01](http://grantome.com/grant/NIH/R03-MH100542-01)


Thank you
Questions? Comments?

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