

Social Support Experiences for Psychiatric Survivors



Preliminary Findings

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Background: Social Support



- **Social Support:** “support accessible to an individual through social ties to other individuals, groups, and the larger community” (Lin et al., 1979)
- **Social Support Network:** “set of people from whom an individual can reasonably expect to receive help in a time of need” (Cunningham & Barbee, 2000)
- **4 types of social support** (House, 1981):
 - Emotional (empathy, love, trust)
 - Instrumental (money, time)
 - Informational (advice, suggestions)
 - Appraisal (affirmation, feedback)



Health Benefits of Social Support



- For decades, social support has been linked to well-being, especially for individuals experiencing life transitions, stress, and crises
- Research on social support and mental illness:
 - Facilitate coping with mental illness (Letvak, 2002)
 - Linked to residential stability, lower depression, and higher rates of mental health recovery (Chronister, Chou & Liao, 2013)
 - Associated with lower levels of psychological distress (Lepore, 1992)

Sources of Social Support



- Social support in one domain (e.g. friend) can help buffer negative effects of social conflict within another domain (e.g. family) (Lepore, 1992)
- Marriage Support: Particularly helpful in lowering stress and depression (quality of relationship is important) (Holt-Lunstad & Birmingham, 2008)
- Peer Support: Helpful to make people feel like part of a community, accepted, not alone (Mead, Hilton & Curtis, 2001)

Caveat



- Presence of people in one's life does not necessarily equal supportive relationships
- Some relationships add to rejection and stigma, undermining the potential positive effects of true support
 - Family members may try to conceal an individuals' mental illness (Phelan, Bromet & Link, 1998; Leff & Warner, 2006)
 - Adolescents report rejection and stigmatization from friends and peers (Moses, 2010)



Purpose of Study



- Examine how psychiatric survivors experience social support networks, including sources of support, barriers and facilitators to maintaining social support networks
- Additional analysis will examine how perceptions of social support relate to stigma experiences for psychiatric survivors

Methodology



Primary Research Program

- Community-University Research Alliance (CURA)
- 4-year, mixed method participatory-action research

Current Project

- Secondary analysis
- Based on data from year 1 focus groups with psychiatric survivors
- Additional analysis of year 1 quantitative data underway

Methodology



Sample

- 7 focus groups held in year 1
- 46 focus group participants
 - 20 male
 - 26 female
- No specific demographic data collected for participants during focus groups
- Recruited from quantitative interview sample

Methodology



Focus Group Questions

- What are challenges associated with your social situation?
- What are some of the resources/people that have made you feel included in society?
- How does poverty influence your relationship with others?

Data Analysis

- Audio-recordings transcribed verbatim and integrated with field notes
- Transcripts were coded according to the topics discussed (Leininger, 1990)
- Coding was then reviewed to identify thematic patterns

Results



1. Sources of Social Support
2. Barriers to Finding and Maintaining Support
3. Components of Positive Support Relationships



Sources of Social Support



Informal Social Support

- **Family**

- *“My family was very supportive of me and help out quite a bit, because my life would be very different if I didn’t have them”*
- *“I am unlucky that I have this [illness] but I am lucky that I got the support of my family”*

- **Friends**

- *“I got good support in friends, I’ve been very picky and choosey in who I hang around with in my life”*
- *“I have some pretty understanding friends”*

- **Partners/Spouses**

- *“If it wasn’t for my spouse ... I would have lost the job three years ago ... cause she takes over for me when I’m not well”*

Sources of Social Support



Formal Social Support

- Peer Support

- *“Being able ... to be around other people that are living similar experiences that I am really helps”*
- *“No one judged me and I felt safe there. I was able to build healthy relationships, I had never built a healthy relationship before”*

- Support through Volunteer Work

- *“I have made friends in these place and I have gained successes”*

- Health Care Support

- *“I see a psychologist ... and that has been just an absolute lifeline because I can just bounce things off of him”*
- *“My psychiatrist ... has been hugely supportive”*

Barriers to Finding/Maintaining Support



Lack of Understanding/Education in Mental Health

- *“I am not connected with my family; [they] do not understand my mental health at all ... they think I’m a wing ding”*
- *“Even my adopted family to this day doesn’t seek out any information on bipolar so you become isolated within your own family because nobody understands”*
- *“My diagnosis affects me from having good relationships with people because they don’t understand why I might have to cancel ... I have actually found people feel resentful of me”*

Barriers to Finding/Maintaining Support



- Experience of Stigmatization
 - *“I’m labeled, [my daughter’s] been programmed that daddy’s a mental fruit loop, don’t bother with him at all”*
 - *“I would much rather stay home ... I don’t have to worry about people labeling me or judging me for who I am”*
 - *I found I was stigmatizing myself and I ... perceived myself the way other people were perceiving mental health people ... I have a tendency to think I’m so different”*
 - *“I’ve been left out of a lot of stuff ... [family] wont come visit, they’re ashamed of you”*
 - *“If somebody just thinks that for whatever reason, that you’re a little different ... suddenly you’re not welcome anymore”*

Barriers to Finding/Maintaining Support



Issues of Poverty

- Financial Limitations

- *“My friends say ‘hey let’s go out’ ... I can’t really afford it right now, sometimes I just ignore it, I don’t even answer the phone ... I just don’t bother”*
- *“I personally find I hide a lot of it [financial situation]. I just don’t want to share it with people ... but that limits you from developing close relationships with people too cause it’s such a huge thing in my life”*

- Housing Situation

- *“It’s not the greatest of areas or the best place to live, and I automatically get ‘oh you live there? We don’t wanna talk to you, we don’t wanna bother with you”*

Barriers to Finding/Maintaining Support



- **Choosing Isolation over the Risk of Getting Hurt**
 - *“I don’t want to be included. Sometimes I just want to stay to myself ... ‘cause the world is harsh and people are judgmental”*
 - *“I stay alone ... I am more comfortable. I don’t have to deal with anything”*
 - *“Live your life and look after yourself ... because nobody else is going to do it for you”*
- **Not Knowing Where or How to Find Support**
 - *“I only have three friends ... I know thousands of people but I only have three friends ... meeting new people is always really a challenge”*
 - *“I walked away from my friends due to addiction, where do you find new ones?”*

Barriers to Finding/Maintaining Support



Limitations of Peer Support

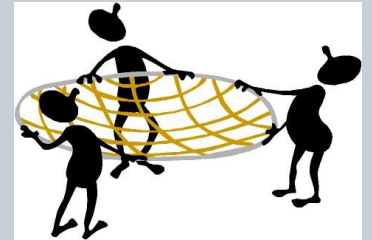
- **Being forced to self-identify**
 - *“I would have to identify myself as belonging to that demographic ... I’m forced to identify again”*
- **Burden of similar issues**
 - *“When you make friends with people who have mental illness, you’ve gotta accept their baggage too and sometimes they want you to carry theirs and yours is really heavy, and it’s hard”*
- **No other similarities**
 - *“We don’t have the same interests so I still do feel isolated”*
 - *“It’s better than having no friends”*

Components of Positive Support Relationships



- **Acceptance**

- *“They simply care about me, they don’t have any real knowledge, but they do care, those people are very rare”*
- *“I know a few people who [think] people are people ... it all comes down to the person’s perspective”*
- *“The more acceptance I get, then the better I get”*



- **Understanding**

- *“My family has been very supportive – very protective, in terms of ‘don’t take on too much’”*
- *What’s been really working good for me is just talking with people in a safe environment where I know I’ll be respected and not ridiculed”*

Components of Positive Support Relationships



- **Self Assurance**

- *“I decided to take some chances, to quit worrying about whether I say the right things at the right time to the right people in the right way ... I started getting help and I started trusting people. 95% of the time, the people that you meet are really good people, you just remember the 5%”*
- *“As I’ve grown older I’ve come to realize people like me for me, that’s fine if they don’t like what I’m doing, then they don’t have to like me, they don’t have to like what I’m doing, like I’m gonna do for me what I feel is best for me”*

Components of Positive Support Relationships



- **Realistic Expectations**

- *“What you put into [relationships] is what you get”*
- *“I could be included if I were to reach out”*
- *“There is always at least one person in an organization ... that is willing to help and is actually caring. You need to be proactive”*
- *“Some of the challenges are how we feel about ourselves, because if we are not feeling good about ourselves or about the situation we are in, that is going to come across as very negative to other people and other people are gonna think [we are] negative and not want to be around us”*

Take Away Messages



- Sources of support vary from person to person and are less important than the quality of support
- While support relationships have many benefits, there are a number of barriers that psychiatric survivors face when developing and maintaining them
- Individuals can benefit from finding support networks that suit their needs, level of comfort, and desire for inclusion
- Realistic expectations are important



Next Steps



- Quantitative analysis to supplement qualitative results
 - Personal Resource Questionnaire (measures perceived social support)
 - The Stigma Scale (measures stigma experiences)

Questions?



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