Barriers to Receiving Behavioral Treatment for OCD in a Community Mental Health Center

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Background

- Exposure-based treatments are most effective psychosocial treatments available for anxiety disorders
  - 65-85% of treatment completers are very much or much improved
  - effective for SRI nonresponders or partial responders
- Ex/RP is underutilized outside of specialty centers
  - 25% of patients in OP mental health settings receive min dose
  - 5% of patients with disabling symptoms
  - Low-income individuals cannot access Ex/RP
- Clients with OCD receiving services at CMHCs usually have severe, disabling sympotms

Research Questions

- What are barriers to receiving Ex/RP for low-income individuals receiving care in a CMHC?
- What modifications to standard Ex/RP treatment protocols are need to effectively deliver tx?

Methods: Recruitment

- Gateway Healthcare – largest non-profit mental health care agency in RI
- Focus groups at two sites
  - 2 groups with Gateway CMHC clients (n=9)
  - 2 groups with direct care providers (n=)
  - 1 group with agency administrators and team leaders
- Staff referred clients with prominent OCD sxs (n=17)
  - Incl: ages 18-65, low-income, at least moderate OCD sxs
  - Excl: Past-month psychosis or sub dep.; sign cognitive imp
- Clients paid $25 for time. Transportation and refreshments provided
- 15 screened: 9 enrolled and participated
  - 1 not eligible, 5 did not attend (2 no-shows, 3 last minute cancellations)

Methods: Continued

- Moderator used semi-structured Interview (1 hour)
  - Cognitive testing used to identify question understanding and responses
- Groups videotaped and later transcribed
- Coded by hand by PI to identify broad themes

Focus Group Questions

- Opening Question for clients:
  - "Please tell me your story about OCD and experiences with treatments"
    - How did you learn about it?
    - What went well? What could have gone better?
- Opening question for staff:
  - "Please tell me about your experiences with clients and treatments for OCD"
    - What has worked well? What could have gone better?
- Described proposed Ex/RP intervention and asked for feedback:
  - "What do you think about this treatment?"
    - Do you think you might wish to try it?
    - What are some things that you like about it?
    - What are some things that could get in the way?

Results: Client Perceptions

- Two groups (n=9) of clients
- Five main themes
  1. Symptom severity and impact
  2. Impact of treatments
  3. Beliefs about OCD and treatment
  4. Overlap with co-occurring illnesses
  5. Barriers and attitudes towards T-ERP

Theme 1: Symptoms

- Severe and disabling symptoms
- Therapy-interfering symptoms (attending, talking)

Theme 1: Symptoms

"Michael" 29 yo single, male, disabled living in group residence

> "I'm not lying about this but a.. If I don't wash my hands a perfect way, I have to start over again. Sometimes I bump into the base of the sink and I start all over again….Everything in my life has to be perfect…my speech has to be perfect or I start over again…washing my hands…walking…being at certain places in the floor. Everything has to be perfect or I feel guilty like I'm not doing very well…It seems like every time I have to something, I (pause) Each time I got to do everything (pause) I got to wash my hands."

> "My turn again? [Go ahead, Michael] Ah.Ah.well my talking, no (pause)…when, when I(pause) hold on (long pause). I get distracted easily. Like with someone coughing, you know (long pause)…..[Michael, Can I give you some time to think about what you want to say and come back to you?] Yeah."

Theme 2: Impact of Treatments

- Types
  - Medications
  - Self-help books
  - Neurosurgery – cingulotomy, deep brain stimulation
- Response to Medications
  - Reduced symptoms to a “manageable” level
  - Helps mood symptoms (depression, energy)
  - No change in symptoms
  - Not sure if change in symptoms has anything to do with meds
  - AEs: tachycardia
- Response to self-help
  - “Helps to understand why I have to do these things”

Theme 2: Impact of Treatments

- Symptoms reduced to manageable level:

  “Anafranil helped a lot. Yeah,definitely…Every morning when I got up, the first thing I did was scrub the bathroom. Every single morning. Ceiling to floor. Walls. I washed the walls. Everything….It’s nowhere near that now. I let things go now… [So how often do you clean your bathroom now?] Just once a week. It’s a big difference, I’m telling you. Big difference”

Treatments

- “Now with Anafranil, with me… I don’t clean my house up as much as I used to. To me it looks like a pigsty; to other people it’s normal. I have my spaces, and she has her junk spot…I said you can have your lazy junky spot and the rest of our house has to be perfect…[So you can tolerate that then? And before you could not?] Oh God no. I couldn’t tolerate a pit on the floor.”

Theme 3: Beliefs

- About OCD
  - Compulsions are necessary “I have to do it”
  - Symptom replacement (if you eliminate one sx, it will only be replaced by another)

- About Behavioral Therapy
  - Have/have not heard of behavioral therapy
  - It won’t work for me
  - It may work for me but can’t access a provider

Beliefs About Illness

- 36 year old, single, female, disabled.

  “Yea, when my girlfriend cooks, I have to redo the whole kitchen after she cleans it up because I can’t take that……It’s got to be rubbed clean, right. So now, I don’t say nothin to her; I just do it my own way. Cause it gets her upset, but I can’t help it…that’s my OCD. I can’t help it”.

Beliefs About Illness

- 36 year old, single, female, disabled.

  “You would not believe all the (different kinds of) obsessions I’ve had. You just switch one obsession for another….I’m sorry, but you can never get rid of it. And it just…it just drives you crazy, and I’ve tried so hard….”

Beliefs about Treatment

- “Deconditiong. That’s a behavioral type of thing. I never thought much of it because, to me, OCD has always been an anxiety disease. I don’t see how you’re going to get rid of anxiety somehow by deconditioning…behavioral. [So you’ve heard of it but never tried it b/c it didn’t make sense?] It didn’t appeal to me one damn bit!

Beliefs about Treatment

- “I’ve seen those behavioral specials on tv…They got the behaviorist and the clinical psychiatrist that comes to your house and that goes out with the people in the community. This one guy, couldn’t be around people cause of germs…some lady took him to a jail, and that’s how she cured him…But I never had anything like that…Because I don’t have the money or the means to do anything like that. That would be something I would mind doing, trying.”
- “She [therapist] wasn’t trained in that area…She said, ‘Ana, I support you, I know something about OCD, but I’m not trained professionally in that area’”

Theme 4: Co-occurring Illness

- Bipolar
  - Hypomania is preferable to anxiety
- Schizoaffective or schizophrenia
- Medical conditions

Theme 5: Lack of Access

Theme 6: Attitudes toward T-ERP

- Like idea of learning to change bx
- All but 2 willing to try it
- Like group with similar people
- Like one-to-one: “private symptoms”
- Prefer to work with own case manager
- “Relieved to see study about OCD”
- Anxious in groups
- Hard to “get your nerve” and participate
- Lack of transporation
- Health problems may result in missed appts

Results: Staff Perceptions

- Two groups of direct care providers (n=11)
- One group of administrators (n=9)
- Six main themes
  1. *Symptom severity and impact on services
  2. *Treatment interventions and impact
  3. Perceptions of OCD clients
  4. *Overlap with co-occurring illnesses
  5. Lack of training in OCD and ERP
  6. *Barriers and Attitudes towards T-ERP

*Similar to client themes

Theme 1: Symptom Severity/Impact

- Classic OCD symptoms
- Extreme, debilitating symptoms
- Although not listed as “primary” often the most problematic psychiatric issue
- Symptoms interfere with providing services

OCD Symptoms

"Although clients have other comorbid diagnoses, we see that their OCD is their primary struggle".

"If the OCD was resolved, I could really see these people leaving and living pretty good lives".

"I cannot get any of my clients to go to the (OCD support) group at night…..I can arrange for transportation but they will never actually get on the van. And because of cleanliness issues, they may not want to go on the van or take public transportation. I've offered to accompany someone, but …morning is difficult for them because of their rituals, and for others nighttime is difficult."

Theme 2: Interventions Used for OCD

- Medications, neurosurgery
- Talk therapy
- CBT- “changing thoughts”, raising awareness
- Limit-setting regarding time spent on rituals
- Support through daily tasks and crises
  - Shopping, moving, opening mail
- Educate roommates and family members
- Refer to OCD Specialty programs

Theme 2: Perceived Impact of Treatment

- Limit-setting and medications helpful in short-term for some
- Clients don't practice behavioral techniques after they attend intensive programs
- Providers feel frustrated
  - "We're not touching those OCD sxs"

Theme 3: Perceptions of Clients

- Don’t recognize or acknowledge OCD sxs
- OCD is adaptive (“better than doing drugs”)
- Clients don’t want to change behavior
  - “Invested in their illness”
  - “Sabotage their treatment”
- Interpersonally challenging

Perceptions of clients

- Interpersonally challenging
  - “Urges are so strong, you can’t penetrate it”
  - Rigid regarding scheduling appointments
  - Call frequently or don’t answer the phone
  - Angry, aggressive, “need for control”

Theme 4: Overlap with Comorbid Illnesses

- Schizophrenia
- Substance Use Disorders
- Personality Disorders
- Tourette's
- Eating Disorders*
- Body Dysmorphic Disorder*
- Pedophilia*

*Unclear if comorbid or misdiagnosed –
Staff described some of these symptoms as "OCD"

Theme 6: Perceived Barriers

- Effects on staff productivity counts
- High staff turnover (esp. case managers)
- Groups
  - Scheduling and transportation
  - Staff accustomed to two co-leaders
  - Less efficient way to earn productivity
- Communication between team members
- Perceptions that ERP is difficult to implement

Perceived Barriers

- “I think my biggest concern is..how to fit something that seems like such a great plan into the environment that we work in and I think that’s gonna be the area of stress for me…I think this sounds great and ..would really benefit our clients. The weekly supervision…(sounds fabulous) but that is also an hour of productivity that I would lose every week and that feels frustrating when it’s something that I want so badly to do (others agree).
- “And you’re not going to get a lot of volunteers from staff to do this, I guarantee that’s going to be an issue”.

Theme 5: Lack of Training

- Staff struggle to gain more knowledge
  - “Ask him (client), what would Dr. R say?”
  - “Ask Dr. X lots of questions”
  - Apply knowledge from personal experiences
  - Fears re: encouraging exposure “It could go totallly wrong”
  - Read about it and watch shows on tv
  - Trainings expensive and usually not local

Theme 6: Attitudes towards TERP

- Useful, clients will benefit
- Could service more clients, increase appointment attendance
- Interested in training and supervision
- Similar to DBT model already in place
- ERP difficult to implement
- Will negatively impact productivity

Conclusions

- Clients and staff perceive similar barriers
- Modifications to standard group E/RP needed
  - More sessions needed?
  - Therapy-interfering behaviors may need to be addressed first to engage clients
  - Need to address overlap with comorbid illnesses
- Staff training needed but must not interfere with productivity and be “portable” to address high turnover
- Cognitive component to address client and staff beliefs regarding treatment

- “Meds do help to a certain point, to bring them down to a baseline, but the hard part is after that the meds, what more can we do? We kind of have our hands tied.”