An Approach to Helping Families of Treatment Refusers with Obsessive Compulsive Related Symptoms

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Disclosure:

- OC Foundation (currently IOCDF)
  - Funded pilot study
Treatment Refusal

- Major healthcare problem
- Little is known
- How do you treat someone who isn’t there?
- Families are the forgotten victims
Impact: Disorder ---> Family

- 75% of family members report feeling distress dealing with OCD or experience disruption to their lives*
- 1/4 of primary caregivers: “severely burdened”**
- Impact includes: 1) direct interference with life; and 2) secondary emotional responses (e.g., guilt, anger, anxiety)
- With recovery avoidance, the added burden of hopelessness and helplessness

*Calvacòressi et al., 1999; Cooper (1993); **Laidlaw et al., 1999
Impact: Disorder ---> Family

- Family accommodation, distress related to OCD severity, especially at post-tx
- Expressed emotion may be high as well, though evidence more equivocal
- Impact may be direct, but also indirect (e.g., motivation for change)

True or False?

Family members saddled with the burden of dealing with a treatment-refuser are flocking to psychotherapists’ offices to get the help they need.
False
Why?
External Obstacles to Families Getting Help

- Lack of resources available
- Financial limitations
- Healthcare system focused on the sufferer
- Even many clinicians underestimate family needs or don’t know what to do
Internal Obstacles to Families Getting Help: *The Myths*

*For example:*

1. The only way for my life to improve is if the person with the disorder gets better.
2. It’s selfish to try to help myself.
3. Getting help for me will jeopardize my efforts to help the person with the disorder.
4. The person with the disorder will get upset if I seek help.
5. I shouldn’t have to be the one to change.
6. I should be able to cope without help.
What are the options?

- Waiting
- Education
- The “Family Intervention” (e.g., substance abuse)
- Strategic Pressure (Grayson & Fitzgibbons)
- Brief Family Consultation (Pollard et al.)
Pilot Study of Brief Family Consultation

20 Families of OCD Treatment–Refusers

Brief Family Consultation (n = 10)

Education Placebo Condition (n = 10)
Pilot Study of Brief Family Consultation

- Goal: Normalize the family by creating a Family Recovery Plan with consultant
  1) Reduced family accommodation
     \( t (16) = 2.61; p = .02 \)
  2) Didn’t impact quality of life of family
     \( t (10) = 1.15; p = .28 \)
  3) Didn’t impact treatment-seeking

- Lessons learned
  - 5 sessions deemed insufficient
  - Long history of severe symptoms
Consultation to Families of Treatment–Refusers (CFTR)
The Family Intervention Team
Center for OCD & Anxiety-Related Disorders
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Basic Features of the Approach

- Family seen without the OCD sufferer
- Those who are motivated participate
- Initial focus on family recovery (“normalizing” the family)
- Strategic attempts to directly modify OCD sufferer’s behavior delayed till family is ready to do so successfully
Some Key Terms/Concepts

• Recovery avoidance
• Accommodation
• Minimizing
• Emotional vs Strategic Interactions
• Family Recovery Plan
• Sabotage Plan
Recovery Avoidance

- Pattern of behavior incompatible with the pursuit of recovery & well-being
- Does not seek help or information
- If in treatment: pressured by others, does not fully participate
- Others working harder than the OCD sufferer
2 problematic ways families respond to OCD
Accommodating (Enabling)

- **Examples**: helping avoid contact with obsessive triggers, assisting with compulsions, reassurance, unconditional financial support

- **Message**: “You will not recover, so I must protect you from life’s challenges.”

- **Expectations**: Too low

- **Effect**: Reduces incentive to seek recovery
Minimizing

- **Examples**: Lecturing, prodding, nagging, yelling, criticizing, threatening, name calling, shaming

- **Message**: “You can recover now if you’d just listen to me.”

- **Expectations**: Too high

- **Effect**: Increases disincentives (fear & defensiveness)
Components of the Approach

1. Education & Commitment
2. Family Self-Assessment
3. Setting Attainable Goals
4. Developing a Family Recovery Plan
5. Implementing the Family Recovery Plan
6. Refocusing on the TR: Shaping Treatment–Seeking Behavior
Case Illustration of the Treatment Components

The Barkley Family
The Barkley Family Situation

- **PARENTS:**
  Married, semi-retired couple in their 60s. Large home in middle class STL suburb. Non-OCD son & daughter successful & on their own.

- **OCD SUFFERER:**
  30-yr-old unemployed son (Don) living at home. Disabling OCD since adolescence: contamination, “just right” obsessions. Denies problem, refuses to seek treatment. Stays up late, sleeps late, plays video games. Limited social life, 1 friend.

- **COMPLAINT:**
  “We’re concerned about his future.” “He disrupts the rest of the family.” He doesn’t work. He won’t get help.”
Step 1

Education and Commitment
Assessed Barkley’s knowledge of OCD and provided targeted education
Defined key tx concepts: recovery avoidance, accommodation, minimizing.
Described tx approach (e.g., family recovery focus)
Obtained Barkley’s commitment to approach
Step 2
Family Self-Assessment
Family Self-Assessment

- Family Accommodation Scale
- Impact analysis (of OCD)
Step 3

Setting Attainable Goals
Setting Attainable Goals

- Mr. Barkley
  “...be less frustrated and angry.”
  “...start playing golf again.”

- Ms. Barkley
  “...spend less time worrying, feeling resentful.”
  “...eat out more often with my family.”
  “...spend more time with friends.”
Step 4

Develop a Recovery Plan
<table>
<thead>
<tr>
<th>The Situation</th>
<th>What I used to do</th>
<th>What I will do</th>
<th>The date I will start</th>
</tr>
</thead>
<tbody>
<tr>
<td>The family is waiting to leave the house. Don is still in his room engaged in checking rituals.</td>
<td>Get angry and yell at him to hurry up. Wait until he was ready and then feel frustrated the rest of the evening.</td>
<td>Inform Don of departure time &amp; give him a 10-min warning. Leave at departure time whether Don is ready or not. No more yelling.</td>
<td>June 1</td>
</tr>
<tr>
<td>Don asks me for money, often in a crisis.</td>
<td>Get frustrated, lecture Don. Then give him the money.</td>
<td>Stop lecturing. Give Don a monthly allowance. No other $ will be provided. Don will need to save $ to deal with crises.</td>
<td>July 1</td>
</tr>
<tr>
<td>The situation</td>
<td>What I used to do</td>
<td>What I will do</td>
<td>The date I will start</td>
</tr>
<tr>
<td>---------------</td>
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</tr>
<tr>
<td>The family is waiting to leave the house. Don is still in his room engaged in checking rituals.</td>
<td>Get frustrated. Go to his room and help him check. Try to prod him along.</td>
<td>Inform Don of departure time &amp; give him a 10-min warning. Leave at departure time whether Don is ready or not. No more checking or prodding.</td>
<td>June 1</td>
</tr>
<tr>
<td>Don refuses to do his laundry and insists that I do it his way.</td>
<td>Do Don’s laundry for him and follow his instructions or supervise him and argue. Complain.</td>
<td>Stop doing Don’s laundry. Designate time periods when Don has access to the laundry room. One box of detergent a month. Otherwise, allow Don to do it his way. No more complaining/arguing.</td>
<td>June 15</td>
</tr>
</tbody>
</table>
## Plan for Dealing with Sabotage Behavior

<table>
<thead>
<tr>
<th>Potential Behavior</th>
<th>Our Response</th>
<th>Start Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don talks about or hints at killing himself or makes an attempt to do so.</td>
<td>Any behavior of this kind will be taken very seriously. We will call 911 immediately and make sure that Don is taken to a hospital where he can be safe and get help.</td>
<td>Effective immediately</td>
</tr>
<tr>
<td>Don destroys property that does not belong to him.</td>
<td>Don will be treated the same as any other person who engages in this behavior in our home. We will call the police.</td>
<td>Effective immediately</td>
</tr>
</tbody>
</table>
Step 5

Implementing the Plan
Helping the Barkleys Implement their Plan

- Setting up the meeting with Don
- Rehearsing the meeting
- The meeting
- Supporting follow through
- Trouble shooting
- Monitoring family progress
Step 6

Shaping Treatment—Seeking Behavior
Reviewing Options

1. Creating incentives for treatment-seeking behavior
2. Creating disincentives for treatment-avoidant behavior
3. Planning for long-term disability
Targeting Incentives to Modify Don’s Behavior

- Target Behavior: seek and participate in treatment
- Incentive: “Recovery Allowance”
  - Point system for recovery behavior (meds, attend tx, homework)
  - Weekly reports from therapist’s office
  - Points = $, deposited in checking account
Final Note on Outcome

- Barkley’s report improved quality of life, less resentment/distress, maintained initial goals (e.g., going out more)
- Don is in therapy, earning most of his points each week
- Don’s prognosis...?
Coming Soon!

Consultation to Families of Treatment–Refusers

A Therapist Guide to Helping the Forgotten Victims of OCD

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