From Compliance to Alliance: How Education and Peer Support Help to Heal Mood Disorders

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…"No pill can help me deal with the problem of not wanting to take pills"…

- Moving from compliance to alliance involves considering person's :
  - **Understanding and acceptance of the mood disorder**
  - **Motivation for self-care**
  - **Hope**

- Two areas that revolutionized the alliance movement:

  - **Psychoeducation about living with a mood disorder**
  - **Peer involvement in the support, treatment, and advocacy**

K. Jamison, "An Unquiet Mind"

Aims of Psychoeducation

1. Informs patients, caregivers, and communities about symptoms, triggers, and course of mood disorders →insight and acceptance of the illness
2. Clarifies how medications act and their side effects →adherence
3. Emphasizes stress management and healthy lifestyle (e.g., diet, use of substances such as nicotine and drugs, regularity in sleep, and activities) → to stabilize the episodes
4. Teaches patients early recognition of symptoms leading to episodes → prevent relapses; and
5. Provides problem- solving → assist with work and relationship issues.

Casamassima, F. (2011). Prophylactic efficacy of psychoeducation for mood disrorders: eview or the evidence and future directions. *Medicographia*, *33*, 195-201.

Examples of Psychoeducation

- Brochures (printed and web-delivered), lectures, podcasts, interactive/experiential workshops, films/videos

- These are addressed to the individual and/or caregivers/family members

Education

The path to mental health begins with knowledge.

People who have mood disorders can more readily achieve wellness when they recognize the symptoms and understand the issues related to this spectrum of conditions. Written in plain English and crafted in consultation with both peers and leading clinicians, DBSA educational materials help people with diagnoses and their loved ones to know what mood disorders are, and what can be done for treatment and management.

Mood Disorders

Depression and bipolar disorder, once known as depression and manic depression, are two of the best-known conditions within the spectrum of mood disorders. But mood disorders can take other forms, too, including anxiety. And co-occurring mental and physical health concerns often go hand in hand with mood disorders. Read more...

Educational Materials

Brochures and publications on a variety of topics related to depression and bipolar disorder provide detailed information, balanced perspective, and hopeful insights on how people can and do get better with treatment. Read more...

Training & Events

DBSA's Peer Specialist Training and educational events for the public, including Chapter Leadership Forums and National Conferences, bring people together to learn skills and access tools that aim to improve the lives of people who have mood disorders. Read more about DBSA Training and Consulting. Read more about DBSA events.

EDUCATION

Mood Disorders
- Depression
- Bipolar Disorder
- Anxiety
- Screening Center
- Co-occurring Illnesses/Disorders

Educational Materials
- Brochures
- Podcasts
- Publications
- Videos
- Living Successfully Course
- Ask the Doc
- Outside Resources
- Store

Brief Psychoeducation

- Improvement in attitudes towards treatment (individual and family)
- Improvement in knowledge and adherence to medication
- In the one study that assessed clinical status (Hogin et al., 1997), brief psychoeducation was not as effective

Goodwin, F. K., Jamison, K. R. (1990). Manic-Depressive Illness. New York, NY: Oxford University Press.

Longer psychoeducation

- Longer psychoeducation (group) is effective in improving symptoms and functioning

Colom, et al., 2003	Group CBT psychoed for relapse prevention (21 sessions, 8-12 pts in each group).	BDI and II to group psychoed (N=60) or nonstructured groups (N=60).
Colom, et al., 2003	Group CBT psychoed for relapse prevention in adherent patients.	BD I , adherent to meds, randomly assigned to psychoed plus TAU (N=25) or TAU groups only (N=25).

Psychoeducation is part of every EBT for mood disorders

- One example: Family Psychoeducation in Family Focused Therapy
- 7-9 sessions that aim to:
  - Create a shared understanding of bipolar disorder in the family
  - Go over signs and symptoms of mood disorders
  - Discuss the patient's **unique** ways to manifest mood episodes
  - Separate the person from the illness
  - Identify precipitating life events and keep the family environment low-key

FFT Psychoeducation (continued):

- Conduct a relapse prevention drill
  - Discuss the emerging signs and symptoms of an episode (*"how do you know you are getting depressed/ manic?"*)
  - Develop an action plan:
    - Have a plan to reduce risky behaviors (e.g., use of credit cards, cell phone, driving fast, etc…)
    - Have a plan to help with decisions when to contact therapeutic team *("if you can't sleep for 3 days, contact me on the fourth")*.
- Encourage medication adherence
  - Normalize skipping medication doses

Peer involvement in Psychoeducation

- Recent increase in the participation of persons with mood disorders and families in the design and the delivery of the material
- Alvidrez et al. 2010: The team interviewed 34 Black consumers from the San Francisco County mental health treatment system
- Generate content for psychoeducational booklet about stigma for Black mental health clients

Alvidrez, J., Snowden, L. R., & Kaiser, D. M. (2010). Involving consumers in the development of a psychoeducational booklet about stigma for Black mental health clients. Health Promotion Practice, 11, 249–258. doi: 10.1177/1524839908318286.

TABLE 2
Themes Emerging From Consumer Interviews

Theme	*Number of Consumers Expressing*	*% of Consumers*	*Number of Passages*
I. Things I Wished I'd Known About Mental Health Treatment			
What outpatient treatment involves[a]	19	50	27
The benefits of treatment[a]	8	21	9
The rules about confidentiality or involuntary treatment[a]	7	18	8
That it's okay to seek or receive treatment	6	16	7
How to make treatment work for me	3	8	6
II. Challenges I Faced around Getting Treatment			
I didn't want to admit I had a problem[a]	26	68	76
I was afraid of what other people might think[a]	25	66	71
My family and friends didn't want me to get treatment[a]	16	42	29
Negative treatment experiences	16	42	78
Mistrust of mental health treatment and/or providers	14	37	27
Concerns about involuntary or coercive treatment	7	18	13
III. Advice to Make Treatment Work for Others			
Don't feel bad that you need help[a]	17	45	26
Do it before it's too late[a]	13	34	17
Be active and ask for what you need[a]	12	32	22
Just give it a try[a]	12	32	12
Keep at it and do it for real[a]	11	29	16
Learn to recognize and accept your problems	8	21	9
You need to take the first step yourself	5	13	6

a. Included as a topic in booklet

Peer Support (Campbell, 2010)

- Organized movement in the 1970s by:
  - Those who felt their rights were violated by the mental health system
  - Those who were discharged and had no follow-up care and community resources
- Offered individuals 'mutual aid, housing support, advocacy and human rights' (Harp & Zinman, 1987; Chamberlin, 1979)
- In the 1990s: Consumer-Operated Service Programs (COSPs) operated by consumers with mental illness

Campbell, J. (2010). Peer support and peer providers: Redefining mental health recovery.

Primary COSP Models

- Today, a proliferation of COSP service delivery models:
  - Self-help groups
  - Drop-in centers
  - Specialized peer services (crisis, unemployment, homelessness)
  - Multi-service agencies
  - Peer educator and advocacy programs
  - Peer phone services (warmlines)

Campbell, J. (2010). Peer support and peer providers: Redefining mental health recovery.

Benefits of Peer Support

- Does not use a “problem” orientation, but rather offers a community of trust and openness
- Utilizes mutual responsibility and communication to express **needs** instead of assessments and evaluations
- Does not use a medical framework, instead focus is on developing relationships that support learning and growth

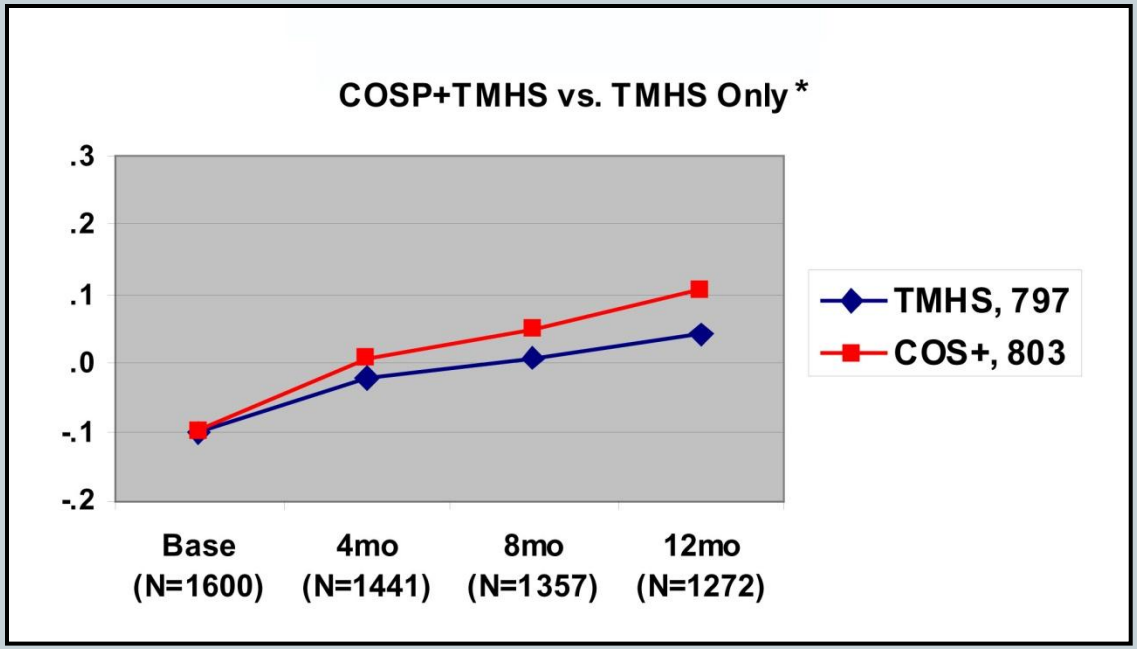
Principles of Peer Support

- Adopts a recovery-based model
- Assumes full reciprocity (no static roles of “helper” and “helpee”)
- Inspires hope; empowerment; encouragement
- Strengthens self-management, problem-solving, and informed choice
- Emphasizes advocacy

Does peer support help with functioning and quality of life?

- COSP Multi-site Research Initiative (1998–2008)
- 1,800 participants in a randomized controlled trial comparing traditional mental health services (TMHS) vs. consumer-operated services (COSP) as an adjunct to their traditional mental health services

Change in Well-being Over Time



*COSP = Consumer-Operated Service Programs
TMHS = Traditional Mental Health Services

Results

- The study showed that, as an adjunct to TMHS, participation in COSPs by adults with mental illness had positive effects on participants' well-being and empowerment
- There was also a modest effect on clinical outcomes (number of hospitalizations, etc)
- The participants who used the peer support services the most had the greatest gains in well-being

Recent vast expansion of COSPs

- Increase in both volunteer and paid peer support services
- A DBSA example: Contracts for training and certification of peer support staff employed by VA facilities (within 2013 training and certification for 160 veterans)
  - Rigorous training in 34 competency areas through distance learning and face to face training courses
  - Have to pass written exam and in-person skills observation

Advocacy

- In the USA but also around the world (even in resource-poor regions) persons with mood and other psychiatric conditions and families play a central role in advocacy
- Advocacy areas lead by consumers include:
  - Raising awareness in communities and government
  - Disseminating information about mental illness and treatment
  - Counseling
  - Mutual help
  - Mediating
  - Defending
  - Denouncing